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THE HIDDEN HAND

**BIG PHARMA'S INFLUENCE ON  
PATIENT ADVOCACY GROUPS**

PATIENTS FOR AFFORDABLE DRUGS<sup>™</sup>

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## INTRODUCTION

Patient advocacy groups and charities are not always what they appear to be. Although most well-known patient organizations have important missions and provide invaluable services to patients, many appear unable or unwilling to take positions on consumer issues such as lowering prescription drug prices that might anger their drug corporation funders. Other groups that claim to represent patients are actually tools of the pharmaceutical industry created and operated to serve the interests of their corporate supporters. In some cases, it is not easy to tell the difference.

**To examine the influence of pharma on patient advocacy groups – and specifically the impact on their drug price policy positions and activities – we examined a sample of three different types of groups:**

- 1. Fifteen prominent and respected patient groups that generally focus on specific diseases or conditions.** These organizations provide support and services that patients need and rely on, such as disease education, community networking, advice on accessing benefits, helplines, and nurse hotlines. We found, however, that virtually all of these organizations are deeply intertwined with the pharmaceutical industry. Most rely on pharma funding that is often not fully and clearly disclosed.<sup>1</sup> They frequently have drug industry representation on their boards, and some have leadership that comes from pharmaceutical corporations. These financial ties and other relationships create potential conflicts of interest and constrain their ability to take positions and act in opposition to the pharmaceutical industry on the issue of lowering drug prices.
- 2. Four groups that news media investigations have identified as pharma-funded front groups.** Our research findings support news reports that these types of groups are controlled by the industry. They are commonly referred to as “astroturf” groups because they are not actually authentic grassroots organizations. They have

wonderful sounding names like Patients Rising and Alliance for Patient Access. But these astroturf groups serve the purposes of their drug industry funders and act on their behalf.

- 3. Four so-called “patient assistance charities.”** In the United States today, 10 of the 20 largest charities are affiliated with drug corporations.<sup>2</sup> They, too, have attractive names like Patient Access Network Foundation and Patient Advocate Foundation. As congressional investigations and legal settlements have revealed, these “charities” are tools of drug companies designed to ensure they can sell more drugs at ever-higher prices.<sup>3,4</sup> According to a report from Citi Research, “each \$1 million industry donation to a charitable foundation to enable Medicare patients’ access to high-priced drugs has the potential to generate up to \$21 million for the sponsor company, funded by the U.S. government.”<sup>5</sup>

Every one of the 23 groups we investigated has one thing in common: They are linked to the pharmaceutical industry financially, structurally, or both. But the role and influence of Big Pharma on these groups are rarely fully divulged and, in fact, are sometimes even camouflaged.

This report seeks to pull back the curtain to reveal the truth about Big Pharma’s influence on all three types of patient groups. It is based on hundreds of pages of documentation compiled over months of research examining tax disclosures; annual reports; news coverage; court proceedings; congressional hearings and investigations; lobbying disclosures; and other publicly available sources. We examined the groups’ funding; transparency and disclosure of funding; board representation; leadership; and the positions they have or have not taken on drug pricing policies.

### Here are summary findings:

- All but one of the 15 major patient groups we examined fail to fully and clearly disclose the total amount of funding they receive from the pharmaceutical industry. Some disclose

1 McCoy, M. S., Carniol, M., Chockley, K., Urwin, J. W., Emanuel, E. J., & Schmidt, H. (2017). Conflicts of Interest for Patient-Advocacy Organizations. *New England Journal of Medicine*, 376(9), 880-885. <http://dx.doi.org/10.1056/NEJMs1610625>

2 Why America’s biggest charities are owned by pharmaceutical companies. (2019, August 17). *The Economist*. <https://www.economist.com/united-states/2019/08/15/why-americas-biggest-charities-are-owned-by-pharmaceutical-companies>

3 Silverman, E. (2020, January 24). Another patient charity settles charges it helped drug makers pay Medicare kickbacks. *STAT*. <https://www.statnews.com/pharmalot/2020/01/24/patient-charity-medicare-kickbacks-free-speech/>

4 House Committee on Oversight and Reform. (2020). Drug pricing investigation: Novartis—Gleevec. <https://oversight.house.gov/sites/democrats.oversight.house.gov/files/Novartis%20Staff%20Report%2010-1-2020.pdf>

5 Baum, A., Verdult, P., Li, Y., & Nieland, N. (2017, May 16). The Straw That Could Break The Camel’s Back. *Citi Research*. [https://drive.google.com/file/d/1iiQUwfs-Pa\\_8TUn431w0RCffPsFnt0kB/view](https://drive.google.com/file/d/1iiQUwfs-Pa_8TUn431w0RCffPsFnt0kB/view)

no information; some provide only partial information.

- Of the pharma funding that is disclosed by the mainstream patient groups reviewed, it is clear that many take in millions of dollars from drug corporations and pharmaceutical trade associations each year. One of the groups, the International Myeloma Foundation, disclosed in a 2019 audited financial report that just two pharmaceutical companies accounted for 57 percent of its total revenue — nearly \$11.5 million of \$20 million.<sup>6</sup>
- Among the 15 major patient organizations examined, 12 have representation from the pharmaceutical industry on their boards.
- Among the 15 major groups we examined, more than half work with lobbyists who also represent Big Pharma.
- Many of the 15 major groups supported elements of H.R. 3 (the Elijah E. Cummings Lower Drug Costs Now Act) in the 116th Congress that were also supported by the pharmaceutical industry, such as lowering out-of-pocket costs under Medicare Part D. Not one, however, took a position in support of lower prices for drug companies through Medicare negotiation, which was the centerpiece of the bill but was opposed by the pharmaceutical industry.
- Of the patient assistance charities we looked at, all four appear to rely heavily on funding from drug corporations. None reveals the full extent of drug industry funding. Two of the four were founded by private companies in the pharmaceutical industry, and two have recently entered into settlements with the government for illegal coordination with their drug company funders.
- According to their websites and/or news reports, all four “astroturf” groups we examined receive funding from the pharmaceutical industry. None of the four groups transparently discloses the details of its funding. Three of the four astroturf groups are actually housed in or staffed by for-profit lobbying and public relations firms that advocate for pharmaceutical companies, or have been staffed directly by PhRMA employees in the past.

It is important to note that all but one of the 23 organizations we researched have some kind of policy to govern potential conflicts of interest. These policies can go by other names, such as “Ethics Policy,” “Corporate Support Policy,” or “Guidelines for Corporate Relationships.” We refer to them collectively below as “COI Policies.”

Several of the organizations have policies or statements asserting their independence from donor influence. The Leukemia and Lymphoma Society, for example, has a specific “Pharmaceutical Funding Statement” that acknowledges its receipt of funding from the drug industry, but asserts that those donations do not influence the Society’s public policy positions.<sup>7</sup> Notwithstanding these COI policies, our research into the actual behavior of the organizations on drug pricing betrays the influence of pharma’s hidden hand in most cases.

The money flowing from pharma to these groups and the interlocking relationships appear to leave even the most well-intentioned among them with a potential conflict of interest on drug pricing reforms. Our research raises serious questions as to whether they are constrained from advocating for patients on issues that would hurt the profits of their industry funders for fear of losing millions of dollars in revenue.

*The impact of drug corporations on mainstream patient groups was documented in The New York Times in 2016. When the CEO of the National Multiple Sclerosis Society spoke out for lower drug prices and offered a modest proposal, she said she encountered resistance. The Times reported: “Other patient groups would not join her, and she said she was told by members of Congress, as well as some of the pharmaceutical companies that donate to her group, to tread carefully. ‘We were warned, you know, in a number of ways, just sort of to be careful about this,’” the CEO said.<sup>8</sup>*

**Patients and the public need to know that the pharmaceutical industry’s financial power may influence the public policies for which these organizations advocate, especially on the issue of drug pricing. Policymakers, elected officials, and the news media must be made aware that when these**

<sup>6</sup> International Myeloma Foundation. (2019, September 30). Financial Statements. <https://s3.us-west-1.wasabisys.com/imf-d8-prod/IMF%20FS%209-30-2019.pdf>

<sup>7</sup> Leukemia and Lymphoma Society. (n.d.). LLS Statement on Financial Support from the Biopharmaceutical Industry. <https://www.lls.org/sites/default/files/National/USA/Pdf/LLS-POSITION-ON-FINANCIAL-SUPPORT-FROM-BIOPHARM-INDUSTRY.pdf>

<sup>8</sup> Thomas, K. (2016, September 27). Furor over drug prices puts patient advocacy groups in bind. The New York Times. <https://www.nytimes.com/2016/09/28/business/furor-over-drug-prices-puts-patient-advocacy-groups-in-bind.html>

**groups act and speak, the influence of Big Pharma money may actually be at work behind the scenes.**

To better understand pharma’s influence, we suggest patients, elected officials, policymakers, and the news media ask each patient group advocating on drug pricing issues four key questions:

- How much money do you receive from the drug industry and what proportion of your budget does that represent?
- Is drug industry funding fully and clearly disclosed on your website?
- Do you have drug industry representation on your board?

- Do you ever take positions opposed by your drug industry funders?

## KEY FINDINGS

### Part 1: Leading National Patient Advocacy Organizations

The nation’s leading patient advocacy groups do very important work for the people they represent. They are an expert source of information on specific conditions, and some organizations run helplines and offer nurse hotlines. They advocate for adequate coverage in private and government insurance design

**Table 1: Leading National Patient Advocacy Organizations**

Table 1 below summarizes how the 15 major patient groups we looked at interact with the pharmaceutical industry, the lack of transparency about their financial relationships with drug companies, and the groups’ positions on key drug pricing proposals opposed by the pharma industry.

Organization	Accepts funding from pharma industry	Fails to fully disclose pharma contributions	Has board members with financial ties to pharma industry	Shares lobbyist and/or lobby firm with pharma	Fails to support Medicare negotiation for lower list prices in 2021
American Cancer Society (ACS)	X	X	X	X	X
American Diabetes Association (ADA)	X	X	X	X	X*
American Heart Association (AHA)	X	X	X	X	X
American Lung Association (ALA)	X	X	X	X	X
Arthritis Foundation	X	X	X		X
Cancer Support Community (CSC)	X	X	X		X
International Myeloma Foundation (IMF)	X	X		X	X
JDRF	X	X	X		X
Leukemia and Lymphoma Society (LLS)	X	X	X	X	X
Lupus Foundation of America (LFA)	X	X		X	X
National Alliance on Mental Illness (NAMI)	X				X
National Health Council (NHC)	X	X	X		X
National Organization for Rare Disorders (NORD)	X	X	X		X
National Psoriasis Foundation (NPF)	X	X	X	X	X
Sickle Cell Disease Association of America (SCDAA)	X	X	X		X

\*ADA did support Medicare negotiation in 2016, but did not in 2019 or 2020 in the case of H.R. 3.

and work to ensure that funds continue to flow to those who are researching their respective diseases. But, on the issue of drug prices, most appear to have a conflict of interest and to be constrained by their intertwined relationships and reliance on funding from drug companies. Here are key findings on each of the 15 individual patient advocacy groups we examined.

### American Cancer Society

The American Cancer Society (ACS) fails to disclose how much revenue it receives from the pharmaceutical industry, is led by a former pharma executive, and refuses to back policy provisions that would allow Medicare to negotiate lower drug prices.

- While ACS does not share how much of its \$728 million budget comes from pharmaceutical corporations, its 2019 annual report lists \$146 million in revenue from Relay for Life, including corporate sponsorships; \$83 million from community-based events, including corporate sponsorships; and \$26 million from corporate and cause-related campaigns.<sup>9</sup>
- Three drug companies (Abbott, Amgen, and Merck) were recognized in 2019 for contributions of more than \$1 million each, but ACS does not disclose how much it specifically received from the companies.<sup>9</sup>
- Former CEO Gary Reedy had a 37-year career in pharma before joining ACS in 2015, including senior leadership positions at Johnson & Johnson, SmithKline Beecham, and Centocor.<sup>10</sup>
- At least three of the 22 members of the ACS board of directors are pharmaceutical executives.
- ACS' advocacy arm, the Cancer Action Network (ACS CAN), uses lobbying firms that also lobby for some of the world's largest pharmaceutical

companies, and several of those lobbyists have experience working directly in the pharmaceutical industry.<sup>11</sup>

- In 2019, ACS CAN actively supported federal legislation to cap out-of-pocket costs and supported patient assistance programs, but did not specifically support allowing Medicare to negotiate lower drug prices under H.R. 3 in the 116th Congress.<sup>12,13</sup>
- ACS CAN cautioned against tying prescription drug prices in the United States to prices overseas because of “the need to incentivize innovation and development of new cancer drugs” — one of the pharma industry's favorite false arguments against reforms.<sup>14,15</sup>

### American Diabetes Association

The American Diabetes Association (ADA) receives millions of dollars from pharmaceutical companies but does not disclose exactly how much those corporate funders contribute. One-third of the members of the ADA board of directors have financial ties to the pharmaceutical industry and, despite growing outrage over the high price of insulin, the group has failed to support recent policy proposals that would allow Medicare to negotiate prices for drugs, including insulin.

- While the ADA lists pharmaceutical corporations that contribute and ranges of those contributions, it does not share specific dollar amounts or totals for drug industry funding.<sup>16</sup>
- The ADA board of directors includes at least five executives with ties to the pharmaceutical industry.<sup>17,18</sup>
- The group uses Venn Strategies and

9 American Cancer Society. (n.d.). 2019 Annual Report.

<https://www.cancer.org/content/dam/cancer-org/online-documents/en/pdf/reports/American%20Cancer%20Society%202019%20Annual%20Report.pdf>

10 American Cancer Society. (n.d.) Executive Leadership Team. Retrieved June 8, 2021, from <https://www.cancer.org/about-us/who-we-are/executive-leadership.html>

11 Compiled from U.S. Senate Lobbying Disclosure Database. Retrieved January 25, 2021, from <https://lda.senate.gov/system/public/>

12 Medicare Access for Patients Rx. (2019, October 16). [Letter to Reps. Pallone, Neal, and Scott].

<https://go2foundation.org/wp-content/uploads/Final-MAPRx-Coalition-Letter-on-HR-3.pdf>

13 American Cancer Society Cancer Action Network. (2019, December 12). House to Vote on Comprehensive Drug Pricing Legislation, Provisions Include Capping Medicare Patients' Out-Of-Pocket Prescription Drug Costs.

<https://www.fightcancer.org/releases/house-vote-comprehensive-drug-pricing-legislation-provisions-include-capping-medicare>

14 American Cancer Society Cancer Action Network. (2019, September 19). House Leadership Proposes Broad Legislation to Reduce Patient Out-Of-Pocket Drug Costs.

<https://www.fightcancer.org/releases/house-leadership-proposes-broad-legislation-reduce-patient-out-pocket-drug-costs>

15 Patients For Affordable Drugs. (2021, February 3). Big Pharma's Big Lie: The Truth About Innovation and Drug Prices.

<https://patientsforaffordabledrugs.org/2021/02/03/innovation-report/>

16 American Diabetes Association. (n.d.). 2019 Annual Report. <https://www.diabetes.org/sites/default/files/2021-01/ADA-2019-AnnualReport.pdf>

17 Compiled from American Diabetes Association, LinkedIn, U.S. Senate Lobbying Disclosure Database, and OpenPaymentsData.CMS.gov. See Detailed Findings.

18 American Diabetes Association. (n.d.). Board of Directors. Retrieved June 8, 2021, from <https://www.diabetes.org/about-us/who-we-are/board-of-directors>

McDermott+Consulting, lobbying firms also used by pharmaceutical companies and trade associations.<sup>19,20</sup>

- The ADA has endorsed legislation that would reduce insulin costs and supported Medicare price negotiation in 2016.<sup>21</sup> But in the 116th Congress, the ADA did not take a position on H.R. 3, which would have allowed Medicare price negotiation and lowered prices for drugs, including insulin.
- In 2018, Kaiser Health News reported that the ADA had decried rising insulin prices but refused to call out a single drug maker that had increased their prices and avoided taking a position on state legislation that would require transparency from drug companies.<sup>22</sup>

### American Heart Association

The American Heart Association (AHA) highlights millions of dollars in pledges from pharmaceutical corporations but discloses neither its total revenue from the drug industry nor specific amounts from individual companies. Based on our research, the AHA has been silent on policy proposals that would allow Medicare to negotiate lower drug prices, as well as other drug pricing reforms opposed by the pharmaceutical industry.

- It is impossible to determine the total amount of money the AHA receives from individual drug corporations or trade associations, as AHA does not disclose that information.<sup>23</sup>
- While three pharmaceutical corporations collectively pledged at least \$11.1 million to the AHA's annual \$795 million budget in 2019, the actual amounts given were not revealed.<sup>23</sup>
- The AHA's 2019 annual report said that its \$85 million program, One Brave Idea, "received significant support from AstraZeneca and pillar support from Quest."<sup>24</sup>

- More than 20 percent — four of 18 members — of AHA's board of directors have direct financial ties to the pharmaceutical industry, including payments from drug makers for research and other compensation ranging from a total of \$225,000 to more than \$697,000 between 2013 and 2019.<sup>25,26</sup>
- The AHA shares a lobbying firm, the Capitol Hill Consulting Group, with pharmaceutical companies.<sup>11</sup>

### American Lung Association

The American Lung Association (ALA) does not disclose exactly how much support it receives from pharmaceutical companies. The group's Health Industry Council is comprised exclusively of pharmaceutical company executives. ALA has not taken a stance on policy proposals that would allow Medicare to negotiate drug prices or other reforms opposed by the pharmaceutical industry that would lower drug prices.

- Based on partial disclosures, the ALA received more than \$18 million in corporate and foundation support in 2019, about 14.4 percent of its more than \$125 million revenue. It acknowledged that major drug companies, including Bristol Myers Squibb, Sanofi Pasteur, Merck, Pfizer, AstraZeneca, GlaxoSmithKline, Mallinckrodt Pharmaceuticals, and Mylan, were financial supporters of the association.<sup>27</sup> ALA did not disclose how much each company donated or what share of donations came from the pharmaceutical industry.<sup>28</sup>
- All nine members of the ALA Health Industry Council are pharmaceutical company executives. The council "meets to allow members to gain meaningful and relevant information on policy, research and patient education, and support efforts at twice yearly meetings that also serve

19 Venn Strategies. (n.d.). Current and Recent Clients. Retrieved June 8, 2021 from <https://vennstrategies.com/clients/>

20 McDermott+Consulting. (n.d.). Pharmaceuticals and Biologicals. Retrieved June 8, 2021, from <https://www.mcdermottplus.com/industries/pharmaceuticals-and-biologicals/>

21 American Diabetes Association. (2016, February 23). Statement on Accessibility and Affordability of Diabetes Medications. Internet Archive. Retrieved June 3, 2021, from: <https://web.archive.org/web/20190228104649/http://www.diabetes.org/newsroom/press-releases/2016/statement-on-accessibility-and-affordability-of-diabetes-medications.html?referrer=https://www.google.com/>

22 Kopp, E., Lupkin, S., & Lucas, E. (2018, April 6). Patient Advocacy Groups Take In Millions From Drugmakers. Is There A Payback?. Kaiser Health News. <https://khn.org/news/patient-advocacy-groups-take-in-millions-from-drugmakers-is-there-a-payback/>

23 American Heart Association. (n.d.). 2019-20 Annual Report — Working Together for Healthier Communities.

24 American Heart Association. (n.d.). 2019-20 Annual Report — Leading Breakthroughs in Science & Technology. <https://www.heart.org/en/about-us/annual-report/raising-money-to-save-lives/working-together-for-healthier-communities>

25 Centers for Medicare and Medicaid Services. (n.d.). Regina M Benjamin. Open Payments. Retrieved February 18, 2021, from <https://openpaymentsdata.cms.gov/physician/677715>

26 Centers for Medicare and Medicaid Services. (n.d.). Joseph Loscalzo. Open Payments. Retrieved February 18, 2021, from <https://openpaymentsdata.cms.gov/physician/668125>

27 American Lung Association. (n.d.). FY19 Annual Report. <https://www.lung.org/getmedia/3023be30-9482-4e6e-a30a-ab980d27a9c8/fy19-annual-report.pdf>

28 Sikich. (n.d.). American Lung Association: Financial Statements and Independent Auditor's Report For the Years Ended June 30, 2019 and 2018. <https://www.lung.org/getmedia/ffaf83fd-86e3-4bf5-9e24-5a8155fb1cec/2019-audited-financials.pdf.pdf>

as exclusive networking opportunities among corporate leaders.”<sup>27</sup>

- In the 116th Congress, the ALA supported legislation to cap out-of-pocket costs, increase subsidies, and eliminate cost-sharing on generics for low-income patients, but did not support provisions of H.R. 3 that would allow Medicare to negotiate lower drug prices.<sup>12</sup>
- Mark Johnson serves on the board of directors for ALA and is currently a Vice President of Acadia Pharmaceuticals. He has a long career working at pharma companies — prior to Acadia, he was the Senior Director of Investor Relations for aTyr Pharma and he started his career at pharma company MediciNova.<sup>29</sup>
- The ALA shares the lobby firm Health and Medicine Counsel of Washington with Prolong Pharmaceuticals and pharma-funded foundation Patient Services, Inc.<sup>11</sup>

## Arthritis Foundation

The Arthritis Foundation partially discloses information about the revenue it receives from pharmaceutical corporations but does not provide clear details. Four members of the group’s board of directors have significant financial ties to the pharmaceutical industry. The Arthritis Foundation has failed to support policy proposals that would allow Medicare to negotiate lower drug prices or other drug pricing reforms opposed by the pharmaceutical industry.

- In 2019, the Arthritis Foundation reported receiving between 12.5 and 19 percent of its more than \$90 million revenue from pharmaceutical, biotechnology, and medical device corporations.<sup>30</sup>
- The Arthritis Foundation does not disclose exact amounts of industry funding, either in total or from specific companies.
- Four of the 15 members of the Arthritis Foundation’s board of directors have significant financial ties to the pharmaceutical industry,

including three members who received research funding and other payments from drug companies and medical device manufacturers totaling more than \$306,000 to almost \$3 million between 2013 and 2019.

- In the 116th Congress, the Arthritis Foundation supported legislation to cap out-of-pocket costs, increase subsidies, and eliminate cost-sharing on generics for low-income patients, but did not support provisions of H.R. 3 that would allow Medicare to negotiate lower drug prices.<sup>12</sup>

## Cancer Support Community

The Cancer Support Community (CSC) does not fully disclose the total amount of funding it receives from pharmaceutical companies. CSC instead lists pharmaceutical industry support by company in ranges, revealing that between 40 percent and almost 70 percent of its \$11.8 million revenue in 2019 came from drug companies.<sup>31</sup> Nearly one-third of CSC’s board of directors are individuals with ties to the pharmaceutical industry, and CSC has waffled on support of legislation that would lower prices paid to drug companies.

- CSC does not disclose the precise amounts of gifts from drug companies. Instead, the list of donors in CSC’s 2019 annual report provides ranges of contributions. The donors in its largest contribution bracket, a donation of at least \$500,000, consist of four major drug corporations: Amgen, Bristol Myers Squibb, Genentech, and Pfizer.<sup>31</sup>
- Eight of the 25 members of CSC’s board of directors are current or former leaders of pharmaceutical companies. This includes Robert DeFrantz, current Senior Director for Immunology in Global Market Access and Pricing at pharma giant AbbVie and former Senior Director for Oncology in Global Pricing, Reimbursement, and Market Access at Eli Lilly. Stuart Arbuckle, Chief Commercial Officer of Vertex Pharmaceuticals, also sits on the board.<sup>32</sup>

29 American Lung Association. (n.d.). Mark C. Johnson, CFA, MBA. Retrieved June 8, 2021, from <https://www.lung.org/about-us/our-leadership/mark-c-johnson>

30 Arthritis Foundation. (2020, July 29). Victories & Vision: 2019 Annual Report.

[https://www.arthritis.org/getmedia/c960ca8e-1fd7-424a-b404-439ab9bf4685/Annual-Report-2019-Web-Final\\_7-29-20.pdf](https://www.arthritis.org/getmedia/c960ca8e-1fd7-424a-b404-439ab9bf4685/Annual-Report-2019-Web-Final_7-29-20.pdf)

31 Cancer Support Community. (n.d.). Annual Report 2019-2020.

[https://annualreport.cancersupportcommunity.org/a-community-connected?\\_ga=2.94259226.680202413.1598280643-1290600329.1598038466](https://annualreport.cancersupportcommunity.org/a-community-connected?_ga=2.94259226.680202413.1598280643-1290600329.1598038466)

32 Cancer Support Community. (n.d.). Board of Directors. Retrieved November 27, 2020, from <https://www.cancersupportcommunity.org/about-us/leadership/board-directors>



- CEO Linda Bohannon spent 12 years at Eli Lilly before joining CSC, rising to a leadership position as senior director of advocacy and professional relations for Lilly Oncology.<sup>33</sup>
- In 2020, CSC stated that it “fully supported the intent” behind Title I of H.R. 3, highlighting “the need to ensure fair drug prices and lower out-of-pocket expenses for patients.” However, the organization did not explicitly endorse direct Medicare drug price negotiation and never took a position supporting the legislation.<sup>34</sup>

## International Myeloma Foundation

In 2019, the International Myeloma Foundation (IMF) reported receiving over half of its funding from just two drug companies. It does not disclose information on its donors or the total amount of contributions it receives from the pharmaceutical industry. Although multiple myeloma drugs are among the most expensive in the world, IMF has not explicitly backed policy proposals that would lower list prices of drugs or allow Medicare to negotiate lower drug prices. Instead, its policy positions align with its industry funders.

- IMF does not disclose how much funding it receives from pharmaceutical industry sponsors individually or in total.
- Although IMF does not disclose the identities of its corporate donors, the organization revealed in an audited financial report that 57 percent of its \$20.2 million revenue in 2019 came from just two pharmaceutical companies.<sup>35</sup> Given that IMF acknowledges “support of educational grants from more than a dozen different industry sponsors,” it is reasonable to assume that its total corporate support from the drug industry exceeds 57 percent.
- IMF has supported out-of-pocket caps on drug costs but, despite the fact that drugs for multiple myeloma are among the most costly cancer medications in the world, it has not advocated for

lower prices set by drug companies.<sup>36</sup>

- Consistent with the positions of its pharma industry funders, it failed to support provisions in H.R. 3 that would allow Medicare to negotiate directly with drug companies.
- The Global Myeloma Action Network, an IMF advocacy coalition, published a patient bill of rights that called for “equitable and timely access” to treatments and for governments to collect data on costs associated with myeloma, but does not call for drug companies to lower prices.<sup>37</sup>
- IMF states that its advocacy activities are sponsored by Bristol Myers Squibb.<sup>38</sup>

## JDRF

JDRF does not clearly disclose its funding from the pharmaceutical industry. Several members of its board of directors have ties to the drug industry. JDRF has never advocated for lowering drug prices and explicitly told its advocates not to take a position on drug pricing legislation.

- JDRF only reports its donors in contribution brackets, making it difficult to determine the total amount of donations it receives from the pharmaceutical industry. Companies in the largest contribution bracket, a donation of at least \$1 million, included Lilly Diabetes and Novo Nordisk, two of the three insulin manufacturers that comprise an oligopoly in the insulin market. Trade group PhRMA and its CEO, Steve Ubl, also made donations of at least \$100,000 and \$25,000, respectively.<sup>39</sup>
- JDRF is the parent company of the JDRF T1D Fund, which invests directly in 25 biopharma companies developing type 1 diabetes treatments, potentially putting JDRF at odds with the goal of lowering drug prices.<sup>40</sup>
- JDRF trumpets its alliances and alignment with the pharmaceutical industry. In its 2019 Annual Report, it said: “We collaborate with hundreds

33 Linda B. (n.d.). LinkedIn. Retrieved January 25, 2021, from <https://www.linkedin.com/in/lindabohannon/>

34 Solomon, R. (2020, June 29). The Affordable Care Act: An Update. Cancer Support Community. <https://www.cancersupportcommunity.org/blog/2020/06/affordable-health-care-act-update>

35 International Myeloma Foundation. (2019, September 30). Financial Statements. <https://s3.us-west-1.amazonaws.com/imf-d8-prod/IMF%20FS%209-30-2019.pdf>

36 Medicare Access for Patients Rx. (2019, July 25). [Letter to Sens. Grassley and Wyden].

<https://www.kidneyfund.org/assets/pdf/advocacy/maprx-coalition-letter-on-the-prescription-drug-pricing-reduction-act-of-2019.pdf>

37 International Myeloma Foundation. (n.d.). Multiple Myeloma: International Bill of Rights. Retrieved June 8, 2021, from <https://www.myeloma.org/patient-bill-of-rights>

38 International Myeloma Foundation. (2021, June 7). May 2021: Advocacy Update. Scribd. <https://www.scribd.com/document/510915319/IMF-Advocacy-Update-June-2021>

39 JDRF. (n.d.). Donor Honor Roll 2019. <https://1x5o5mujiug388ttap1p8s17-wpengine.netdna-ssl.com/wp-content/uploads/2020/08/STEW-2019DonorHonorRoll.pdf>

40 JDRF T1D Fund. (n.d.). Our Portfolio. Retrieved December 20, 2020, from <https://t1dfund.org/our-portfolio/>

of industry partners — including pharmaceutical and technology companies — that also invest in T1D research. Together, we have become a strong network, funding and supporting T1D advances.”<sup>41</sup>

- Two of the 13 members of JDRF’s board of directors have held senior positions in drug companies. Another member, Christopher Turner, is the managing director of a private equity firm that has invested in or founded numerous pharmaceutical companies.<sup>42</sup>
- JDRF supports insurance and pharmacy benefit manager (PBM) reforms that would lower out-of-pocket costs for insulin, but the organization has not backed policies that would specifically reduce list prices of insulin.<sup>43</sup>
- In an email to attendees of the 2020 State of the Union, JDRF told diabetes advocates to avoid speaking about drug pricing legislation, and to “stick to the messaging.” In the email, there were also suggested talking points that acknowledged the importance of insulin affordability but emphasized the need for research funding.<sup>44</sup>

### Leukemia and Lymphoma Society

The Leukemia and Lymphoma Society (LLS) fails to clearly disclose its funding from drug corporations and pharmaceutical trade associations. Members of the organization’s leadership have ties to the pharmaceutical industry, and the group has failed to advocate for lower list prices for prescription drugs.

- LLS only reports its donors in contribution brackets, making it difficult to determine the total amount of donations it receives from the pharmaceutical industry. However, the list of donors in its annual report allows us to estimate that, on the low end, the organization received at least \$10.2 million from drug corporations in 2019. Among the 12 corporate partners in its top contribution bracket (a donation of at least \$1 million), half are pharmaceutical companies.<sup>45</sup>
- CEO Louis DeGennaro served in leadership roles

in drug companies Wyeth and Synex prior to joining LLS.<sup>46</sup>

- Six out of 20 members of LLS’ board of directors have financial ties to the drug industry. This includes Rich Bagger, a former Executive Vice President of Corporate Affairs and Market Access for Celgene who also spent over 16 years at Pfizer, and Casey Cunningham, the Chief Medical Officer of a health care and biotechnology venture capital fund that is directly invested in at least six drug companies.<sup>47</sup>
- LLS has commissioned studies examining the impact of high out-of-pocket drug costs and has advocated for out-of-pocket spending caps, but our research did not uncover any calls from LLS for drug companies to lower list prices through any methods, including Medicare negotiation.<sup>8</sup>
- LLS retains the services of lobby firm Kountoupes Denham Carr & Reid, LLC, which also represents pharma client Glenmark Pharmaceuticals.<sup>11</sup>
- In 2016, The New York Times observed: “The Leukemia and Lymphoma Society, for instance, one of the largest charities in the United States, has frequently criticized insurers for exposing patients to high out-of-pocket costs for patients, commissioning two studies that looked at the impact of these high costs. But it has not been as outspoken about the decision by drug companies to set those prices. Some blood cancer drugs that the society’s members need cost tens of thousands of dollars.”<sup>8</sup>

### Lupus Foundation of America

The Lupus Foundation of America (LFA) does not disclose the identities of its donors or the contribution amounts from individual pharmaceutical companies. LFA employed a lobbying firm that has also lobbied on behalf of drug companies. While it has supported out-of-pocket caps on drug costs, the LFA has not advocated for reforms that would lower prices set by drug corporations.

41 JDRF. (n.d.). Fiscal Year 2019 Annual Report. [https://www.jdrf.org/wp-content/uploads/2020/06/JDRF\\_AR\\_2019.pdf](https://www.jdrf.org/wp-content/uploads/2020/06/JDRF_AR_2019.pdf)

42 JDRF. (n.d.). JDRF Leadership. Retrieved December 6, 2020, from <https://www.jdrf.org/about/leadership/>

43 JDRF. (n.d.). Insulin Access and Innovation. Retrieved June 4, 2021, from <https://www.jdrf.org/impact/advocacy/insulin-access/>

44 JDRF. (n.d.). Scribd. [https://www.scribd.com/document/510484865/JDRF?secret\\_password=WuhCPYcZIULVmaxQZT2M](https://www.scribd.com/document/510484865/JDRF?secret_password=WuhCPYcZIULVmaxQZT2M)

45 Leukemia and Lymphoma Society. (2020, January). Generations of Impact: Annual Report 2019.

[https://www.lls.org/sites/default/files/National/USA/Image/Landing\\_Pages/AnnualReport/2019\\_LLS\\_Annual\\_Report\\_1\\_20.pdf](https://www.lls.org/sites/default/files/National/USA/Image/Landing_Pages/AnnualReport/2019_LLS_Annual_Report_1_20.pdf)

46 Leukemia and Lymphoma Society. (n.d.). Executive Team. Retrieved June 8, 2021, from <https://www.lls.org/leadership/executive-team?src1=22681&src2=>

47 Leukemia and Lymphoma Society. (n.d.). Board of Directors. Retrieved December 2, 2020, from <https://www.lls.org/leadership/board-of-directors?src1=22681&src2=>

- Though LFA does not reveal the identities of its donors, it states in its corporate partners disclosure that 14 percent of its revenue came from “pharmaceutical, biotechnology, and medical device companies” in its 2018 fiscal year.<sup>48</sup>
- LFA CEO Stevan Gibson has ties to the drug industry, having served as a consultant to the trade group PhRMA.<sup>49</sup>
- In 2020, LFA employed lobbying firm NVG, whose list of clients also includes Novo Nordisk, Pfizer, and PhRMA.<sup>11</sup>
- LFA has signed on to multiple letters supporting out-of-pocket cost caps, including those proposed in H.R. 3. However, LFA has not commented on the core drug pricing reform component of H.R. 3, which would allow Medicare to negotiate directly with drug manufacturers for lower prices.<sup>12,50</sup>

### National Alliance on Mental Illness

The National Alliance on Mental Illness (NAMI) stands out among the 15 national disease groups reviewed for its transparent and complete quarterly disclosure of corporate and major foundation sponsorships and donations. NAMI does not aggregate donations by industry, making it difficult to easily determine the pharmaceutical industry’s contribution to its budget. The detailed disclosure enabled us to estimate that in 2019, the organization received more than \$2.3 million from the drug industry, comprising 8.8 percent of its total revenue, including \$130,000 from the two major lobby groups BIO and PhRMA.<sup>51</sup>

NAMI does not appear to engage in advocacy relating to drug pricing. But when the organization has weighed in, it endorses solutions that align with those supported by the pharmaceutical industry, such as lowering out-of-pocket expenses for Medicare beneficiaries. When commenting on H.R. 3, NAMI

failed to endorse the centerpiece of the bill — Medicare price negotiation — or inflation caps on annual price increases, both of which are strongly opposed by its industry funders.<sup>12</sup>

### National Health Council

The National Health Council (NHC) has deep financial and leadership ties to the pharmaceutical industry but does not disclose specific contributions. The group has not taken a stance on policy proposals that would allow Medicare to negotiate lower drug prices or other drug pricing reforms.

- Although the NHC does not make complete disclosures, it reported in 2019 that more than \$2.2 million of its greater than \$4 million budget came from sponsorships and grants, while 21 of NHC’s 24 sponsors came from the pharmaceutical industry.<sup>52</sup>
- In addition, \$982,000 of NHC’s budget came from business and industry membership dues, and 32 of the 38 business and industry members are in the pharmaceutical industry.<sup>52</sup>
- In 2015, the CEO of NHC said that 62 percent of the organization’s budget was made up of pharmaceutical industry contributions.<sup>8</sup>
- NHC’s long-time Vice President (who recently served as interim CEO), Eleanor M. Perfetto, previously held the position of Senior Director of Federal Government Relations for Pfizer.<sup>53</sup>
- The National Health Council’s board of directors includes the CEOs of the two industry associations (PhRMA and BIO), and representatives from Pfizer and Alexion Pharmaceuticals.<sup>54,55,56,57</sup>
- The council did not take a position on H.R. 3 in the 116th Congress, but, in a statement, downplayed the likelihood of the legislation passing out

48 Lupus Foundation of America. (n.d.). Corporate Partners. Retrieved January 27, 2021, from <https://www.lupus.org/financials/corporate-partners>

49 Lupus Foundation of America. (n.d.). Stevan W. Gibson, President & CEO. Retrieved January 25, 2021, from <https://www.lupus.org/leadership/stevan-w-gibson>

50 Alliance for Aging Research. (2020, July 21). Patient Advocacy Groups Call for Bipartisan Action to Alleviate Older Americans’ Undue Medicare Part D Cost Burden. <https://www.agingresearch.org/press-release/patient-advocacy-groups-call-for-bipartisan-action-to-alleviate-older-americans-undue-medicare-part-d-cost-burden/>

51 Compiled from NAMI. Retrieved January 27, 2021. See Detailed Findings.

52 National Health Council. (n.d.). Our Support. Retrieved January 27, 2021, from <https://nationalhealthcouncil.org/our-support/>

53 National Health Council. (n.d.). Eleanor M. Perfetto, PhD, MS, Executive Vice President of Strategic Initiatives. Retrieved January 25, 2021, from <https://nationalhealthcouncil.org/staff/eleanor-perfetto/>

54 National Health Council. (n.d.). Stephen J. Ubl. Retrieved December 8, 2020, from <https://nationalhealthcouncil.org/staff/stephen-j-ubl-2/>

55 National Health Council. (n.d.). Michelle McMurry-Heath, MD. Retrieved December 8, 2020, from <https://nationalhealthcouncil.org/staff/michell-mcmurry-heath-md/>

56 National Health Council. (n.d.). Rod Mackenzie, PhD. Retrieved December 8, 2020, from <https://nationalhealthcouncil.org/staff/rod-mackenzie-phd/>

57 National Health Council. (n.d.). Tanisha Carino, PhD. Retrieved December 8, 2020, from <https://nationalhealthcouncil.org/staff/tanisha-carino-phd/>

of Congress. Instead, NHC emphasized the Congressional Budget Office finding that H.R. 3 would reduce the number of new drugs coming to market – one of pharma’s misleading talking points.<sup>58</sup>

- NHC declared public support for capping out-of-pocket costs for Medicare beneficiaries. It also has called for increased transparency into drug pricing and passing manufacturer rebates from PBMs through to the consumer. This position is consistent with the pharmaceutical industry’s.<sup>58</sup>
- NHC has expressed caution about applying inflationary caps on drug companies that increase prices, but supports addressing arbitrary price increases year over year.<sup>58</sup>
- Consistent with the pharmaceutical industry position, NHC expressed concern over using international reference pricing used in the “most-favored nation” rule favored by the Trump administration.<sup>59</sup>

### National Organization for Rare Disorders

The National Organization for Rare Disorders (NORD) does not disclose how much of its revenue comes from pharmaceutical companies. The group has not taken a stance on policy proposals that would allow Medicare to negotiate lower drug prices.

- It is unclear how much drug companies contribute to NORD’s \$12 million annual revenue, as the information is not disclosed.
- Dozens of pharmaceutical companies and trade association companies serve on four different NORD corporate councils that require a range of financial contributions, according to NORD’s 2019 Annual Report. NORD does not disclose how much each company contributes.<sup>60</sup>
- Three of the 11 members of NORD’s board of

directors have strong ties to the pharmaceutical industry.<sup>61</sup>

- NORD did not support H.R. 3 in the 116th Congress, which would have allowed Medicare to negotiate lower drug prices. It took a nuanced approach to the Prescription Drug Pricing Reduction Act of 2019, cautioning that inflation caps on price increases could affect new drug development. This is consistent with NORD’s primary focus, which is to help bring to market new drugs for rare diseases. It is also consistent with claims from the pharmaceutical industry that any steps to curb its pricing power will hurt innovation.<sup>62</sup>
- In 2019, NORD released principles for assessing proposals to lower drug prices without offering suggestions for reform. One of those principles is that “the policy must not place an undue burden on innovation of new therapies,” which is a key talking point of the pharma industry.<sup>60</sup>

### National Psoriasis Foundation

The National Psoriasis Foundation (NPF) fails to disclose how much of its revenue comes from pharmaceutical companies. The foundation’s lobbyists also work for drug companies, and NPF has not taken a stance on policy proposals that would allow Medicare to negotiate lower drug prices.

- NPF only discloses contribution amounts from corporate donors as ranges. Based on those disclosures, in 2019, the foundation received between \$6.7 million (48 percent) and \$9.4 million (67 percent) of its more than \$14 million budget from the pharmaceutical industry.<sup>63</sup>
- Three of the foundation’s 18 members of the board of directors have ties to the pharmaceutical industry.<sup>64</sup>

58 Mason, M. (2019, December 18). Updates on Congressional Efforts to Lower the Costs of Prescription Drugs. National Health Council. <https://nationalhealthcouncil.org/blog/updates-on-congressional-efforts-to-lower-the-costs-of-prescription-drugs/>

59 National Health Council. (2020, November 20). Statement on “Most-Favored Nation” Drug Pricing Rule By Eleanor M. Perfetto, PhD, MS, Interim Chief Executive Officer and Executive Vice President of Strategic Initiatives. <https://nationalhealthcouncil.org/most-favored-nation-drug-pricing-rule/>

60 National Organization for Rare Disorders. (n.d.). NORD 2019 Annual Report. [https://rarediseases.org/wp-content/uploads/2020/03/NRD-1198-2019\\_Annual-Report\\_FNL\\_WebSize.pdf](https://rarediseases.org/wp-content/uploads/2020/03/NRD-1198-2019_Annual-Report_FNL_WebSize.pdf)

61 National Organization for Rare Disorders. (n.d.). Board of Directors. Retrieved January 25, 2021. <https://rarediseases.org/about/leadership/board-directors/>

62 National Organization for Rare Disorders. (2019, July 24). [Letter to Sens. Grassley and Wyden]. [https://www.finance.senate.gov/imo/media/doc/2019-07-24%20NORD%20to%20CEG,%20RW%20\(PDPRA\).pdf](https://www.finance.senate.gov/imo/media/doc/2019-07-24%20NORD%20to%20CEG,%20RW%20(PDPRA).pdf)

63 Compiled from National Psoriasis Foundation 2019 Annual Report. See Detailed Findings. [https://npf-website.cdn.prismic.io/npf-website/7ca0f5d8-99dd-445c-a1db-1bf682175c21\\_NPF\\_2019\\_Annual-Report\\_Digital.pdf](https://npf-website.cdn.prismic.io/npf-website/7ca0f5d8-99dd-445c-a1db-1bf682175c21_NPF_2019_Annual-Report_Digital.pdf)

64 National Psoriasis Foundation. (n.d.). Board of Directors. Retrieved January 25, 2021, from <https://www.psoriasis.org/leadership/board-of-directors/>

- The lobbying firm NPF employs also works for the pharmaceutical industry.<sup>65</sup>
- The foundation has advocated for fixes to the structure of Medicare Part D, including caps on out-of-pocket expenses and offering the option to distribute out-of-pocket payments evenly over a year.<sup>66,67</sup> Consistent with the position of the pharmaceutical industry, it explicitly opposes international reference pricing.<sup>50</sup> NPF did not take a position on allowing Medicare to negotiate lower drug prices.

## Sickle Cell Disease Association of America

The Sickle Cell Disease Association of America (SCDAA) does not disclose how much of its \$4.3 million annual revenue comes from pharmaceutical companies. Based on our review, the organization has not supported any efforts to address drug prices.

- SCDAA discloses total revenue in broad categories only.<sup>68</sup>
- SCDAA partners with many pharmaceutical companies, including Pfizer, Novartis, Emmaus Life Science, and Arivant Sciences, on a variety of advocacy campaigns and strategic work but does not disclose amounts of revenue from these companies.<sup>69,70,71,72,73</sup>
- The group works with pharmaceutical companies to “address legislation that impacts the sickle cell community” in state legislatures but does not share details of the work it undertakes jointly with industry.<sup>69</sup>
- Five of the 15 members of SCDAA’s board of directors have financial ties to the pharmaceutical industry.<sup>74</sup>

65 Faegre Drinker Biddle & Reath. (n.d.). Related Services and Industries. Retrieved February 19, 2021, from <https://www.faegredrinker.com/en/services/services/health-care/research#!#tab-Overview>

66 National Psoriasis Foundation. (n.d.). Medicare Part D Reform: Pathways for Reducing Out-of-Pocket Costs in Medicare. Retrieved October 16, 2020, from <https://www.psoriasis.org/watch-and-listen/medicare-part-d-reform-pathways-reducing-opc-in-medicare/>

67 National Psoriasis Foundation. (n.d.). Action Alert Center: Ask Congress to Cap Medicare Part D Costs. Retrieved December 28, 2020, from <https://www.psoriasis.org/action-alert-center/?vsrc=%2fcampaigns%2f77785%2frespond%3fTrackingID%3dAdv>

68 Sickle Cell Disease Association of America. (n.d.). 2019 Annual Report. [https://www.sicklecelldisease.org/files/sites/181/2021/03/SCDAA\\_2019-Annual-Report-002-2.pdf](https://www.sicklecelldisease.org/files/sites/181/2021/03/SCDAA_2019-Annual-Report-002-2.pdf)

69 Sickle Cell Disease Association of America. (n.d.). Pfizer. Retrieved December 12, 2020, from <https://www.sicklecelldisease.org/strategic-partners/pfizer/>

70 Sickle Cell Disease Association of America. (n.d.). Generation S Campaign. Retrieved December 12, 202, from <https://www.sicklecelldisease.org/strategic-partners/generation-s-campaign/>

71 Sickle Cell Disease Association of America. (n.d.). Emmaus Life Science. Retrieved December 12, 2020, from <https://www.sicklecelldisease.org/emmaus-life-science/>

72 Sickle Cell Disease Association of America. (2020, October 13). Sickle Cell Disease Association of America and Arivant Sciences Forge New Partnership to Educate Around Gene Therapy.

<https://www.sicklecelldisease.org/2020/10/13/sickle-cell-disease-association-of-america-and-arivant-sciences-forge-new-partnership-to-educate-around-gene-therapy/>

73 Sickle Cell Disease Association of America. (2020, May 6). Sickle Cell Disease Association of America, Inc. and Hemanext, Inc. Form New Strategic Partnership.

<https://www.sicklecelldisease.org/project/sickle-cell-disease-association-of-america-inc-and-hemanext-inc-form-new-strategic-partnership/>

74 Sickle Cell Disease Association of America. (n.d.). Board of Directors. Retrieved January 25, 2021, from <https://www.sicklecelldisease.org/about-us/board-members/>

## Part 2: Pharma-Funded and Allied Groups and Astroturf Organizations

Some organizations are called astroturf groups because they don't represent real grassroots efforts. They talk like patients and may even have some positions that are good for patients, but they were created and/or are funded by the pharmaceutical industry to press its point of view. These groups lead the effort to distract attention from the power of the drug companies to set prices and to focus attention on other players in the drug supply chain. They don't disclose their funding or the relationships they have with their drug company supporters and attempt to be seen as honest brokers, which they are not. A look at the following highlights from our research demonstrates why.

### Alliance for Patient Access (AfPA) and Sister Organizations IfPA and GfPA

The Associated Press encapsulated the Alliance For Patient Access (AfPA) in 2019 quite neatly with this

headline: "Group with consumer-friendly vibe pushes drugmakers' message."<sup>75</sup>

Here are the key facts about this pharma-funded group:

- AfPA is funded by three dozen drug corporations and pharmaceutical trade associations.<sup>76</sup>
- AfPA does not clearly disclose the amount of money it receives from each pharma industry entity or total industry contributions, but its annual reported revenue is often in the millions. In 2018, its revenue was \$13.6 million, the lion's share of which appears to have gone to advertising.<sup>77</sup>
- The Associated Press reported in 2019 that AfPA is housed in and run by a lobbying firm named Woodberry Associates.<sup>75</sup>
- Josie Cooper is Executive Director of AfPA and leads the health care advocacy division at Woodberry Associates. She formerly worked in communications for an industry trade association.<sup>78</sup>

**Table 2: Pharma-Funded and Allied Groups and Astroturf Organizations**

Organization	Fails to fully and clearly disclose individual or total pharma contributions	Funded by pharmaceutical industry, according to disclosures or news reports	Has been housed in or staffed by public relations firms, lobbyists, or pharma trade groups	Failed to support Medicare negotiation for lower list prices in 2019/2020
Alliance for Patient Access (AfPA)	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Partnership for Safe Medicines (PSM)	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Partnership to Improve Patient Care (PIPC)	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Patients Rising	<b>X</b>	<b>X</b>		<b>X</b>

<sup>75</sup> Lardner, R. (2019, March 18). Group with consumer-friendly vibe pushes drugmakers' message. Associated Press.

<sup>76</sup> <https://apnews.com/article/7c8d0728c38345cd8dfc0fe1abd456ae>

<sup>76</sup> Alliance for Patient Access and Institute for Patient Access. (2020, December). Associate Members and Financial Supporters.

<sup>77</sup> <https://admin.allianceforpatientaccess.org/wp-content/uploads/2020/12/AfPADonorsDecember2020.pdf>

<sup>77</sup> Alliance for Patient Access. (2019, November 14). IRS Form 990.

<sup>77</sup> [https://projects.propublica.org/nonprofits/display\\_990/205130312/02\\_2020\\_prefixes\\_20-22%2F205130312\\_201812\\_990O\\_2020021217140360](https://projects.propublica.org/nonprofits/display_990/205130312/02_2020_prefixes_20-22%2F205130312_201812_990O_2020021217140360)

<sup>78</sup> Alliance for Patient Access. (n.d.). About AfPA. Retrieved December 14, 2020, from <https://allianceforpatientaccess.org/about/#leadership>

- The former Executive Director of AfPA was Brian Kennedy, who is Founder and President of Woodberry Associates.<sup>79,80</sup>
- Seven other staff of AfPA are employees of Woodberry Associates:
  - Gavin Clingham<sup>81</sup>
  - Amanda Conschafter<sup>82</sup>
  - Jasmine Patel<sup>83</sup>
  - John Bates<sup>84</sup>
  - Alexa DeVantier<sup>85</sup>
  - Lauren Carter-Early<sup>86</sup>
- The AfPA board and the boards of its sister organizations are composed of individuals, many of whom have been paid hundreds of thousands of dollars by drug corporations over the years.<sup>87</sup>
- Like the pharmaceutical industry, AfPA advocates for lower out-of-pocket costs for drugs but does not support legislation that would lower drug corporations' prices.<sup>50</sup> It opposes solutions such as international reference pricing that would reduce drug prices in the United States.<sup>88</sup> Like its industry funders, it supports reforms that would affect insurers and PBMs, but does not take positions in opposition to its industry funders.<sup>88</sup>
- Consistent with its pharma partners, AfPA lobbied Congress in support of the out-of-pocket caps in H.R. 3 but failed to endorse the key component of the bill, allowing Medicare to negotiate lower drug prices.<sup>89,90</sup>

## Partnership for Safe Medicines

Partnership for Safe Medicines (PSM) touts itself as a coalition of non-profit organizations fighting the importation of unsafe medicines.<sup>91</sup> PSM says

it's entirely funded by member dues, but refused to say how much each member, including PhRMA, contributed.<sup>92</sup> Numerous media reports reveal details about PSM's close relationship with the pharmaceutical industry:

Bloomberg reported: "In 2017, the nonprofit's annual budget jumped twentyfold, to \$7.3 million. The group says it's entirely funded by dues from its 49 member organizations, including PhRMA, but it doesn't disclose how much each member pays."<sup>92</sup>

Many of PSM's members pay little or no dues. According to a Bloomberg News report, "Fourteen of the group's non-PhRMA members shared detailed information about their payments, all of which were either \$0 or \$100 in 2017."<sup>92</sup> This suggests that industry contributions comprise the lion's share of PSM's budget.

That same Bloomberg report noted: "Headquartered in a San Francisco high-rise, the nonprofit has had deep ties to PhRMA for most of its existence. From 2005 to 2017, it was run by executives who simultaneously worked for PhRMA."<sup>92</sup>

PhRMA Senior Vice President Scott LaGanga was executive director of PSM for 10 years. According to Kaiser Health News: "A PhRMA senior vice president, Scott LaGanga, for 10 years led the Partnership for Safe Medicines, a nonprofit that has recently emerged as a leading voice against Senate bills that would allow drug importation from Canada. LaGanga was responsible for PhRMA alliances with patient advocacy groups and served until recently as the nonprofit's principal officer, according to the Partnership's tax forms."<sup>93</sup>

James Class was Executive Director of PSM from 2005 to 2007 while he was working for PhRMA

79 Brian Kennedy. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/bmfkennedy/>

80 Woodberry Associates. (n.d.). Brian Kennedy, J.D. Retrieved December 14, 2020, from <https://www.woodberryassociates.com/brian-kennedy>

81 Gavin Clingham. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/gavinclingham/>

82 Amanda Conschafter. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/amanda-conschafter-0936ab78/>

83 Woodberry Associates. (n.d.). Jasmine Patel. Retrieved December 14, 2020, from <https://www.woodberryassociates.com/jasmine-patel>

84 John Bates. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/johnbates2/>

85 Alexa DeVantier. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/alexa-devantier-3a051b53/>

86 Lauren Carter-Early. (n.d.). LinkedIn. Retrieved December 14, 2020, from <https://www.linkedin.com/in/lauren-carter-early-989708158/>

87 Compiled from Alliance for Patient Access, Vanderbilt University Medical Center, PubMed.gov, Institute for Patient Access, OpenPaymentsData.CMS.gov, and LinkedIn. See detailed findings.

88 Alliance for Patient Access and Institute for Patient Access. (2018). 2018 Annual Report.

[https://admin.allianceforpatientaccess.org/wp-content/uploads/2020/02/AfPA\\_IFPA\\_Annual-Report\\_2018.pdf](https://admin.allianceforpatientaccess.org/wp-content/uploads/2020/02/AfPA_IFPA_Annual-Report_2018.pdf)

89 Alliance for Patient Access. (2020, April 20). LD-2 Disclosure Form.

<https://soprweb.senate.gov/index.cfm?event=getFilingDetails&filingID=C6BD0046-1140-4023-835C-2EA4F19C3943&filingTypeID=51>

90 Alliance for Patient Access. (2020, July 20). LD-2 Disclosure Form.

<https://soprweb.senate.gov/index.cfm?event=getFilingDetails&filingID=AB89462B-55BB-452A-B28B-0BA32048237A&filingTypeID=60>

91 Partnership For Safe Medicines. (n.d.). About The Partnership For Safe Medicines. Retrieved June 8, 2021, from <https://www.safemedicines.org/about-us>

92 Elgin, B. (2019, October 23). Sheriffs' Ads Slammed Drug Imports, and Big Pharma Helped Pay the Tab. Bloomberg.

<https://www.bloomberg.com/news/features/2019-10-23/big-pharma-helped-fund-sheriffs-ad-blitz-against-drug-imports>

93 Kopp, E., & Bluth, R. (2017, April 19). Nonprofit Linked to PhRMA Rolls Out Campaign to Block Drug Imports. Kaiser Health News. <https://khn.org/news/non-profit-linked-to-pharma-rolls-out-campaign-to-block-drug-imports/>

conducting “Policy, Government Affairs, Alliance Development.”<sup>94</sup> Class held various leadership positions at PhRMA from 2001 to 2010.<sup>95</sup>

Former employees and consultants who worked for PhRMA and PSM told Bloomberg that PhRMA ran PSM.

- “Four former employees and consultants who worked with PhRMA and the Partnership for Safe Medicines say the industry group largely ran the nonprofit. For example, Justin Kenderes worked for the partnership as a consultant from 2007 to 2016, and for the first several years, he says, his paychecks came directly from PhRMA.”<sup>92</sup>
- “In 2017, the nonprofit’s annual budget jumped twentyfold, to \$7.3 million. The group says it’s entirely funded by dues from its 49 member organizations, including PhRMA, but it doesn’t disclose how much each member pays. Its executive director, Shabbir J. Safdar, declined to comment.”<sup>92</sup>

PhRMA acknowledged funding PSM but refused to answer specific questions from Bloomberg.

- “Holly Campbell, a spokeswoman for the pharmaceutical-industry’s main trade group, didn’t respond to specific questions for this story. In a written statement, she confirmed that her group, Pharmaceutical Research and Manufacturers of America, or PhRMA, gives money to the Partnership for Safe Medicines.”<sup>92</sup>

In 2019, Bloomberg reported that PSM secretly funded a \$900,000 TV ad blitz in Washington, D.C., by the National Sheriffs’ Association opposing plans to import prescription drugs from other countries.<sup>92</sup> PSM has touted pharma’s talking points on drug pricing by calling drug importation from Canada “not a viable option,” directing patients to shop around for lower drug prices, and placing blame on pharmacy benefit managers for high drug costs to consumers.<sup>96</sup> PSM has

not endorsed Medicare negotiation or other reforms that would force its pharma funders to lower drug prices.

## Partnership to Improve Patient Care

The Partnership to Improve Patient Care (PIPC) was created by PhRMA, advocates for the pharmaceutical industry, and refuses to discuss its funding from the pharmaceutical industry.

- The Wall Street Journal reported that PIPC is “a pharmaceutical industry-funded advocacy group ... founded by the drug industry’s principal lobby in Washington, the Pharmaceutical Research and Manufacturers of America.”<sup>97</sup>
- A Reuters investigation found that “groups including PIPC are parroting the industry arguments while claiming to represent patients — without disclosing their industry ties, according to a Reuters review of the groups’ press releases, blogs, webcasts, and letters.”<sup>98</sup>
- USA Today reported: “While many industries fund purported grass-roots groups in what’s known as astroturfing, critics say it’s especially troubling at a time when research shows Americans want Congress and the White House to do something about high drug prices. The most notable of these when it comes to drug prices is the Partnership to Improve Patient Care, which is chaired by former representative Tony Coelho, D-Calif. PIPC’s steering committee includes PhRMA, Easter Seals, and several industry groups.”<sup>99</sup>
- Uber D.C.-insider Tony Coelho runs PIPC.
  - According to The New York Times: “Drug lobbyists have enlisted the help of Tony Coelho, a former Democratic congressman who cites his battle with epilepsy to make their case. Mr. Coelho is ‘the chairman of an industry-backed group called the Partnership to Improve Patient Care.’”<sup>100</sup>

94 Partnership for Safe Medicines. (2014, September 18). INTERCHANGE 2014 Program.

[https://www.safemedicines.org/wp-content/uploads/Interchange2014\\_Program.pdf](https://www.safemedicines.org/wp-content/uploads/Interchange2014_Program.pdf)

95 James N. Class, Ph.D. (n.d.). LinkedIn. Retrieved June 8, 2021, from <https://www.linkedin.com/in/jamesclass/>

96 Partnership for Safe Medicines. (n.d.). Importation 101 for 2021. Retrieved December 21, 2020, from <https://www.safemedicines.org/2020/12/importation-101.html>

97 Mundy, A. (2009, May 19). To Get Bigger Say in Research, Drug Makers Enlist Democrats. The Wall Street Journal. <https://www.wsj.com/articles/BL-WB-10290>

98 Humer, C. (2020, September 11). Special Report: Big Pharma wages stealth war on drug price watchdog. Reuters.

<https://www.reuters.com/article/us-usa-drugpricing-lobbying-special-repo/special-report-big-pharma-wages-stealth-war-on-drug-price-watchdog-idUSKBN26211Q>

99 O'Donnell, J., & Crescente, F. (2016, July 11). Pharma trade group helps fund patient fight against Medicare project. USA Today. <https://www.usatoday.com/story/news/politics/2016/07/11/pharma-trade-group-helps-fund-patient-fight-against-medicare-project/86592800/>

100 Kirkpatrick, D. (2009, September 11). Groups Back Health Reform, but Seek Cover. The New York Times. <https://www.nytimes.com/2009/09/12/health/policy/12lobby.html>



- The pharmaceutical industry trade associations PhRMA and BIO sit on the PIPC Steering Committee.<sup>101</sup>
- Although news reports have stated PIPC is supported by contributions from the pharmaceutical industry, PIPC refuses to discuss its funding.
  - There is no information on funding available on its website.
- Although PIPC lists a number of affiliated patient organizations on its website, it is neither a non-profit nor a separate legal entity from the lobbying firm in which it is housed.<sup>99</sup>
  - PIPC is actually a division of the lobbying firm Thorn Run Partners. They share the same address and staff.
  - Reuters found that “the Partnership to Improve Patient Care (PIPC) and Value our Health are led by employees of Thorn Run Partners, a Washington-based lobbying and public relations firm that counts nearly a dozen drugmakers as clients.”<sup>98</sup>
  - “Sara van Geertruyden, PIPC’s executive director, is also a partner in Thorn Run Partners, a lobbying and public affairs firm that counts PIPC and many drug companies as clients and hires other firms to lobby on comparative effectiveness research. Unlike most groups that say they represent patients, PIPC is neither a non-profit nor a separate legal entity from the lobbying firm,” a USA Today investigation found.<sup>99</sup> Deputy Director Thayer Surette Roberts is a Senior Vice President at Thorn Run Partners.<sup>102,103</sup>
- Consistent with the pharma industry’s talking points, PIPC opposes international reference pricing, as used in H.R. 3, which would reduce drug prices in the United States.<sup>104</sup> PIPC has actively organized against policies that include international reference pricing.<sup>105</sup>

## Patients Rising/Patients Rising Now

It is clear that Patients Rising is funded by and works for drug companies. Here are facts about the organization:

- Patients Rising and Patients Rising Now are funded by Amgen, Pfizer, Takeda, BMS/Celgene, Janssen, Alexion, AbbVie, and Boehringer Ingelheim.<sup>106,107</sup> Total funding and exact amounts of funding from each company are not disclosed.
- Patients Rising Now frankly acknowledges that the perspectives of corporate funders “inform our advocacy” and corporate funders participate in joint lobbying.<sup>108</sup>
- Patients Rising Now shared a public relations firm with PhRMA called 720 Strategies.<sup>109</sup>
- Patients Rising Now employs a lobbying firm, Winning Strategies Washington, which also represents drug corporations including Kaleo, Phlow, and Circassia Pharmaceuticals.<sup>11</sup>
- Patients Rising trains individuals to advocate before Congress with instructors who have deep ties to the pharmaceutical industry. Those instructors include:<sup>110</sup>
  - Brooke Abbott, who has served on advisory boards for Pfizer, Janssen, and Abbvie.<sup>11</sup>
  - Stephanie Fischer, who worked as communications director for trade associations PhRMA and BIO.<sup>111</sup>
  - Chelsey Hickman was a lobbyist for drug companies Kaleo and Phlow.<sup>11</sup>
  - Jenn McNary has served as a consultant to Marathon Pharmaceuticals, Fulcrum Therapeutics, and Centogene.<sup>112</sup>

101 Partnership to Improve Patient Care. (n.d.). Steering Committee Members. Retrieved June 8, 2021, from <http://www.pipcpatients.org/steering-committee.html>

102 Partnership to Improve Patient Care. (n.d.). About Us. Retrieved December 17, 2020, from <http://www.pipcpatients.org/mission-and-priorities.html>

103 Thorn Run Partners. (n.d.). Thayer Surette Roberts. Retrieved December 17, 2020, from <http://thornrun.com/team/thayer-surette/>

104 Partnership to Improve Patient Care. (2021, February 8). PIPC Weekly Update. Retrieved June 4, 2021, from

<http://www.pipcpatients.org/blog/pipc-weekly-update-february-8-2020>

105 American Association of People with Disabilities. (n.d.). Reject Health Policies That Discriminate. <https://www.aapd.com/wp-content/uploads/2021/04/Updated-Open-Letter-Reject-Health-Policies-That-Discriminate.pdf>

106 Patients Rising. (n.d.). Partners and Supporters. Retrieved January 27, 2021, from <https://www.patientsrising.org/about/partners-and-supporters/>

107 Patients Rising Now. (n.d.). Current Corporate Members. Retrieved June 8, 2021, from <https://patientsrisingnow.org/current-corporate-members/>

108 Patients Rising Now. (n.d.). Corporate Membership. Retrieved December 11, 2020, from <https://patientsrisingnow.org/corporate-membership/>

109 720Strategies. (n.d.). Pharmaceutical Research and Manufacturers of America: We Work For Health. Retrieved December 9, 2020, from

<https://www.720strategies.com/work/phrma-we-work-for-health/>

110 Compiled from multiple sources. See Detailed Findings.

111 Patients Rising Now. (n.d.). Advocacy Master Class. Retrieved December 10, 2020, from <https://patientsrisingnow.org/advocacy-master-class/>

112 Jennifer McNary. (n.d.). LinkedIn. Retrieved June 8, 2021, from <https://www.linkedin.com/in/jennifer-mcnary-a2723669/>

- Charla Penn was a lobbyist for Kaleo.<sup>113</sup>
- Patients Rising advocates for the pharmaceutical industry’s position virtually point-for-point:
  - It opposed H.R. 3 in the 116th Congress.<sup>113</sup>
  - It opposed the CREATES Act.<sup>114</sup>
  - It opposes drug importation.<sup>115</sup>
  - It puts the blame for high prices on pharmacy benefit managers and insurers.<sup>116</sup>

that cover the premiums, copays, and sometimes even travel costs of patients who encounter financial barriers to medications and care. Drug companies can translate these donations into profits – especially for Medicare patients – by contributing money to charities that focus on the specific patient populations who take their drug. Since anti-kickback statutes prohibit drug companies from directly assisting Medicare beneficiaries, investigational reports from the media and Congress have shown that drug companies use these charities as a conduit to facilitate the patient’s adherence – and the drug company’s reimbursement by the taxpayer-funded program. The schemes have led to settlements with the Department of Justice after allegations of violating anti-kickback statutes.

### Part 3: Pharma-Funded “Charity” Foundations/Independent Assistance Groups

The pharmaceutical industry donates large sums of money each year to independent charity foundations

**Table 3: Pharma-Funded “Charity” Foundations/Independent Assistance Groups**

Organization	Founded by pharma	Fails to fully disclose pharma contributions	Has confirmed that primary funding comes from pharma	Settled charges of illegal kickback schemes with pharma companies
HealthWell Foundation	<b>X</b>	<b>X</b>	<b>X</b>	
Patient Access Network (PAN) Foundation	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Patient Advocate Foundation (PAF)		<b>X</b>		
Patient Services, Inc. (PSI)		<b>X</b>	<b>X</b>	<b>X</b>

113 Wilcox, T. (2019, November 25). Prescription Drug Bill Overlooks Cost of Foregone Innovation. RealClearPolicy. [https://www.realclearpolicy.com/articles/2019/11/25/prescription\\_drug\\_bill\\_overlooks\\_cost\\_of\\_foregone\\_innovation\\_111316.html](https://www.realclearpolicy.com/articles/2019/11/25/prescription_drug_bill_overlooks_cost_of_foregone_innovation_111316.html)

114 Rowland, C. (2018, March 19). Everyone wants to kill generic drug loophole -- except drug makers and some GOP leaders. The Boston Globe. <https://www.bostonglobe.com/news/nation/2018/03/19/congress-won-stop-drug-companies-who-use-shenanigans-block-generics/SOnAziaeVlhlvGvyX5BYkN/story.html>

115 Wilcox, T. (2019, April 18). States’ Quixotic Efforts to Import Prescription Drugs From Canada. Inside Sources. <https://insidesources.com/states-quixotic-efforts-to-import-prescription-drugs-from-canada/>

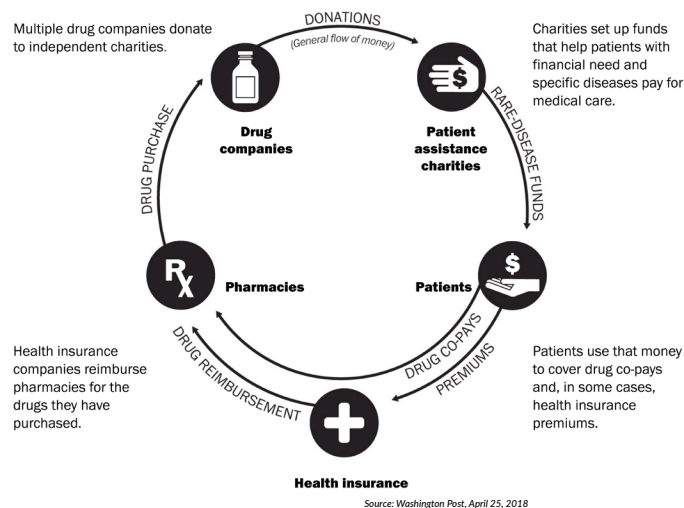
116 Patients Rising Now. (2019, July 23). This one reform could immediately lower patient drug costs. Insurance companies and pharmacy benefit managers just blocked it. <https://patientsrisingnow.org/drug-rebate-rule/>

## Summary findings for all four foundations:

- Three of the four groups we examined (HealthWell, PAN Foundation, and PSI) disclose that they're funded by donations primarily from the pharmaceutical industry.
- These patient charities provide enormous benefits to the companies that fund them. Independent foundations provide drug companies with up to \$21 million in sales for every \$1 million donated; the lion's share of this return on investment is derived from the U.S. government, according to a Citi Research memo written to warn of increasing scrutiny of independent foundations.<sup>5</sup>
- The same memo alluded to how dependent pharma is on these charities for revenue, warning that scrutiny could have "the potential to severely limit future revenues for several high-priced blockbuster Medicare Part D drugs."<sup>5</sup>
- The Washington Post detailed these relationships and used this graphic to illustrate that a hefty share of the tax-deductible money given by drug corporations to the charities often finds its way back to the donor companies.<sup>117</sup>

### The flow of money

Drug company donations to independent charities help financially needy patients with rare diseases afford treatment, but also increase sales and help maintain high drug prices.



- Two of the four groups have recently settled allegations of participating in illegal kickback schemes with pharma companies (PSI, \$3 million;

PAN, \$4 million)<sup>118,119</sup>

- For these four groups, 90 percent to 100 percent of contributions are "donor-restricted" — the type of earmarks used to direct donations to specific disease funds, and therefore, specific drugs. The precision with which drug companies direct these contributions can be seen in a list from a Pfizer charitable donations report, denoting which foundations get money for which diseases<sup>5</sup>:

Figure 6. Notable Charitable Funding by Pfizer from 1Q 2016 to 3Q 2016.

Organisations	Contributions (\$)
American Academy of Pediatrics (Immunisation, ADHD)	2,110,000
American College of Physicians (Immunisation)	1,171,068
Assistance Fund Inc (RCC)	2,000,000
Avon Products Foundation Inc (Breast Cancer)	750,000
Conquer Cancer Foundation ASCO	1,000,000
Healthwell Foundation (NSCLC, CML)	750,000
Immunization Action Coalition (Immunisation)	1,000,000
PAN Foundation (Acromegaly, RCC, Arrhythmia)	10,950,000
Patient Advocate Foundation (Breast Cancer)	3,025,000
Task Force for Global Health Inc (Trachoma)	5,300,000
Assistance Fund Inc (RCC, RA)	1,500,000
<b>Sub-Total</b>	<b>\$29.6m</b>
Total Charitable Donations	\$82.2m

Source: Citi Research, Company Report

## HealthWell Foundation

HealthWell Foundation was founded in 2004 by Covance, a life sciences research company that works closely with the pharmaceutical and biotech industries.<sup>120</sup> In 2006, all HealthWell employees also worked for Covance; 15 years later, the close ties with the pharmaceutical industry persist:<sup>120</sup>

- HealthWell's chief development officer, Alan Klein, who is tasked with soliciting donations for the organization, has worked at four different biopharma companies since the early 1990s.
- Stephen Weiner, the head of HealthWell's board of directors, is a founding chair of Mintz Levin's Health Law Practice.<sup>121</sup> Mintz's website boasts that they've "breathed life into the life sciences industry," in part by providing assistance to pharma mergers and acquisitions.<sup>122</sup>

Like other patient assistance foundations, HealthWell's donor base is overwhelmingly concentrated; according to 2019 financial disclosures,

117 Johnson, C. (2018, April 25). Wife, mother, million-dollar patient. The Washington Post. <https://www.washingtonpost.com/graphics/2018/business/million-dollar-patient/>

118 U.S. Department of Justice. (2020, January 21). Patient Services Inc. Agrees to Pay \$3 Million for Allegedly Serving as a Conduit for Pharmaceutical Companies to Illegally Pay Patient Copayments. <https://www.justice.gov/opa/pr/patient-services-inc-agrees-pay-3-million-allegedly-serving-conduit-pharmaceutical-companies>

119 U.S. Department of Justice. (2019, October 25). Foundations Resolve Allegations of Enabling Pharmaceutical Companies to Pay Kickbacks to Medicare Patients. <https://www.justice.gov/usao-ma/pr/foundations-resolve-allegations-enabling-pharmaceutical-companies-pay-kickbacks-medicare>

120 Berenson, A. (2006, April 8). In Drug-Aid Foundations, a Web of Corporate Interests. The New York Times. <https://www.nytimes.com/2006/04/08/business/in-drugaid-foundations-a-web-of-corporate-interests.html>

121 HealthWell Foundation. (n.d.). Board of Directors. Retrieved December 10, 2020, from <https://www.healthwellfoundation.org/about/who-we-are/>

122 Mintz. (n.d.). Life Sciences. Retrieved December 10, 2020, from <https://www.mintz.com/industries-practices/life-sciences>

the organization received 84 percent of its total revenue from just four donors.<sup>123</sup> Despite repeatedly claiming a commitment to transparency in disclosures, HealthWell does not list these major donors — citing compliance with the Office of the Inspector General (OIG) guidance; however, its leadership admits HealthWell is funded “in majority by donations from the pharmaceutical industry.”<sup>124</sup>

Despite repeatedly claiming to prioritize access and affordability, HealthWell has not gone on the record advocating for any of the numerous federal proposals to lower drug prices for patients.

### Patient Access Network Foundation

The Patient Access Network (PAN) Foundation was “created and is staffed by” the Lash Group, a subsidiary of the pharmaceutical wholesale distribution company AmerisourceBergen, The New York Times reports.<sup>120</sup> The Lash Group operates over 100 “patient support programs.” The Lash Group’s stated goals include improving access, affordability, and adherence — but they promote no legislative or regulatory solutions to lower drug prices.<sup>125</sup> PAN’s advocacy matches its parent company and pharma interests:

- In 2019 and 2020, the foundation’s lobbying focused almost exclusively on policies that limited out-of-pocket costs and protected the patient assistance programs — neglecting all legislative proposals aimed at actually lowering drug prices.<sup>12,36</sup>
- PAN employs lobbyist Jeremy Scott, whose clients include pharmaceutical companies.<sup>11,126</sup>

PAN’s donor base is concentrated — financial statements maintain that “approximately 99 percent of the Foundation’s contributions receivable were provided by two donors,” but they fail to list which donors. Since the same disclosures also say that contributions derive from donors “primarily within the pharmaceutical drug industry,” it’s easy to deduce from

which sector the two main donors likely originate.<sup>127</sup>

Details of a 2018 settlement illustrate how closely drug companies work with foundations to fend off public backlash from their pricing practices. According to Kaiser Health News, “Planning a price increase, Pfizer worked with the PAN Foundation to ‘create and finance a fund’ for Medicare patients with a specific irregular heartbeat, the settlement says. ‘For the next nine months, Tikosyn patients accounted for virtually all of the beneficiaries of PAN’s fund.’”<sup>128</sup>

A year later — in October 2019 — PAN paid \$4 million to settle allegations that four drug companies used the organization “as a conduit to pay kickbacks to Medicare patients taking their drugs.” The FBI added that the PAN Foundation used its charitable status “to shield the illegal activities of pharmaceutical companies seeking to maximize profits.”<sup>119</sup>

### Patient Advocate Foundation

According to a recent Patient Advocate Foundation (PAF) financial report, “During the years ended June 30, 2020 and 2019, four donors accounted for approximately 85 percent and 96 percent of donations received for the Co-Pay Relief Program, respectively.” Out of PAF’s \$278 million in grant revenue in 2020, 98.6 percent of contributions came with donor restrictions, the type of earmarks often used to direct donations to specific disease programs and, consequently, certain drugs.<sup>129</sup>

PAF’s comprehensive donor list through the years has included major drug companies like AbbVie, Allergan, Amgen, AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Celgene, EMD Serono, Genentech, Gilead Sciences, GlaxoSmithKline, Merck, Novartis, Pfizer, Sanofi US, Takeda Oncology, and ViiV Healthcare.<sup>130</sup>

National Patient Advocate Foundation (NPAF), the foundation’s advocacy arm, spent more than \$6 million on lobbying between 1999 and 2020.<sup>11</sup> NPAF

123 HealthWell Foundation. (2019, December 31). Consolidated Financial Statements.

<https://www.healthwellfoundation.org/wp-content/uploads/2020/07/2019-Audited-Financials.pdf>

124 HealthWell Foundation. (n.d.). 2019 Annual Report.

<https://www.healthwellfoundation.org/wp-content/uploads/2020/11/HealthWell-Foundation-2019-Annual-Report.pdf>

125 AmerisourceBergen Lash Group. (n.d.). Who We Are. Retrieved June 4, 2021, from <https://www.lashgroup.com/who-we-are>

126 Jeremy Scott. (n.d.). LinkedIn. Retrieved December 1, 2020, from <https://www.linkedin.com/in/jerrscott/>

127 Cherry Bekaert. (2020, May 19). Patient Access Network Foundation: Financial Statements and Accompanying Information.

<https://www.panfoundation.org/app/uploads/2020/05/PAN-Audited-Financial-Statement-2019.pdf>

128 Lupkin, S. (2018, May 24). Pfizer Settles Kickback Case Related to Copay Assistance For \$24M. Kaiser Health News.

<https://khn.org/news/pfizer-settles-kickback-case-related-to-copay-assistance-for-24m/>

129 Brown Edwards. (n.d.). Patient Advocate Foundation Financial Report, June 30, 2020 and 2019.

<https://www.patientadvocate.org/wp-content/uploads/Patient-Advocate-Foundation-2020-FINAL.pdf>

130 Patient Advocate Foundation. (2020, May 28). 2019 Annual Impact Report. <https://www.patientadvocate.org/wp-content/uploads/2019-Impact-Infographic.pdf>

has publicly advocated and lobbied for limiting cost-sharing on medications and establishing an out-of-pocket cap in Medicare Part D, but has not spoken out in favor of the numerous proposals that would actually lower prices of prescription drugs.<sup>12,36</sup>

### Patient Services, Inc.

Patient Services, Inc. (PSI) is a patient assistance organization that provides help to patients with 15 rare diseases and 11 chronic illnesses.<sup>117</sup> PSI does not reveal contribution amounts from specific donors, but financial disclosures have indicated that the organization relies overwhelmingly on donations from the drug industry.

- Although PSI claims to have “thousands of donors,” financial disclosures reveal how concentrated their funding sources are; <sup>131</sup> in 2018, it reported that “contributions from four donors comprised approximately 76 percent of total contributions.”<sup>132</sup>
- This aligns with what the organization told The Washington Post the same year, when it said that 97 percent of their funding came from drug companies in 2016.<sup>117</sup>

PSI’s model matches that of other charity foundations. The organization acts as a conduit — covering copays and premiums that might otherwise pose a barrier to accessing expensive medications sold by their drug company donors:

- PSI agreed to pay \$3 million in 2020 to settle allegations it served as an illegal conduit between drug companies and patients.<sup>118</sup>
- The settlements alleged that PSI coordinated with three drug companies in order to facilitate sales of their pricey drugs.<sup>118</sup>
- PSI’s lobbying revolves around protecting this model. According to annual reports, their advocacy team focused on advancing “legislation to protect access to nonprofit patient assistance programs,” and neglects to mention any advocacy to lower the actual price of prescription drugs.<sup>131</sup>
- PSI shared a lobbying firm, Thorn Run Partners, with the pharma industry.<sup>11</sup>

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<sup>131</sup> Patient Services, Inc. (n.d.). Annual Report 2019 [https://www.patientservicesinc.org/wp-content/uploads/2020/10/PSI\\_Annual\\_Report\\_2019\\_FINAL.pdf](https://www.patientservicesinc.org/wp-content/uploads/2020/10/PSI_Annual_Report_2019_FINAL.pdf)

<sup>132</sup> Keiter. (2018 and 2019, December 31). Patient Services: Consolidated Financial Statements. <https://www.patientservicesinc.org/wp-content/uploads/2021/01/2019-AFS.pdf>

## METHODOLOGY

To develop this report, the P4AD staff and researcher James Lynch, J.D., reviewed the organizations' websites, annual reports, tax filings, audited financial statements, media coverage, social media and other publicly available data. Other databases and websites used include [PubMed.gov](https://pubmed.ncbi.nlm.nih.gov/), a project of the National Center for Biotechnology Information; [OpenPaymentsData.CMS.gov](https://openpaymentsdata.cms.gov/), which is managed by the Centers for Medicare and Medicaid Services; "[Dollars for Docs](https://dollarsfordocs.org/)," a project of ProPublica; [OpenSecrets.org](https://www.opensecrets.org/), a project of the nonprofit Center for Responsive Politics; and the [U.S. Senate Lobbying Disclosure website](https://www.senate.gov/legislative/lobbydisclosure/), which publishes reports filed pursuant to the Lobbying Disclosure Act.

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## PART 1: LEADING NATIONAL PATIENT ADVOCACY ORGANIZATIONS

The nation's leading patient advocacy groups do very important work for the people they represent. They are an expert source of information on specific diseases. Some organizations run helplines and offer nurse hotlines. They advocate for adequate coverage in private and government insurance design and work to ensure research dollars are flowing to their diseases. But on the issue of drug prices, most have a clear conflict of interest and are constrained by their intertwined relationships and reliance on funding from drug companies.

The chart below summarizes how the 15 major patient groups we looked at interact with the pharmaceutical industry that provides much of their funding, and the lack of transparency about their financial relationships.

### AMERICAN CANCER SOCIETY (ACS)

Website: <https://www.cancer.org/>

Website: <https://www.fightcancer.org/>

Documents: [Conflict of Interest Policy](#)  
[Code of Ethics](#)  
[Contributions Policy](#)

### Financials

#### AMERICAN CANCER SOCIETY OFFERS SOME DISCLOSURE OF CONTRIBUTIONS FROM PHARMACEUTICAL COMPANIES, BUT ISN'T CLEAR ABOUT HOW MUCH EACH HAS GIVEN

**2019: The American Cancer Society's annual report thanked corporations that gave it more than \$1 million, including Abbott Laboratories, Amgen, and Merck.**

"The American Cancer Society is grateful to the following corporations that gave more than \$1 million to help us attack cancer from every angle. Abbott Laboratories, Amgen Inc., Baylor Scott & White Health, Centene Corporation, Chevrolet, CVS Health, Delta Air Lines, Extended Stay America, Houston Methodist Hospital, IBM, The Kroger Company, Merck & Co., Inc., New Avon Company, NFL, Nissan North America Inc., Nucor Paul Ferrante, Inc. Presbyterian Health Foundation, The Proctor & Gamble Company, Sanford Health, UnitedHealth Group, Inc., The University of Texas MD Anderson Cancer Center, Walmart, Wells Fargo, World Wide Technology, Inc." [American Cancer Society, 2019 Annual Report, accessed [12/2/20](#)]

The American Cancer Society discloses corporate "Partners Against Cancer" on several different levels but doesn't appear to disclose what levels of contributions are required to become a "partner" at any level. [American Cancer Society, [1/27/21](#)]

- **November 2020: Abbvie was listed as a "Groundbreaker" among the American Cancer Society's "Partners Against Cancer."** [American Cancer Society, accessed [11/17/20](#)]

- **2018: AbbVie provided at least \$1 million to the American Cancer Society.**

"We are incredibly grateful for these corporations who provided \$1 million or more to support our mission in 2018. AbbVie" [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]

- **2017: AbbVie gave at least \$1 million to the American Cancer Society.**

- "We gratefully acknowledge the many corporations who actively support our mission. The following organizations each provided \$1 million or more in 2017 to support our mission to save lives, celebrate lives, and lead the fight for a world

without cancer. AbbVie” [American Cancer Society, 2017 Annual Report, accessed [11/17/20](#)]

- **November 2020: Abbott was listed as a “Pioneer” among the American Cancer Society’s “Partners Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Merck was listed as a “Pioneer” among the American Cancer Society’s “Partners Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Amgen was listed as a “Pioneer” among the American Cancer Society’s “Partners Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Perrigo was listed as a “Champion” among the American Cancer Society’s “Partners Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
  - **Perrigo is a generic prescription drug manufacturer.**

“Perrigo is a leading generic pharmaceutical manufacturer offering the largest portfolio of dermatological products in the United States.” [Perrigo, accessed [11/17/20](#)]

**October 2020-January 2021: Perrigo partnered with the American Cancer Society by donating at least \$350,000 to ACS, when customers bought Perrigo’s nicotine replacement therapy products at participating retailers.**

“ACS and Perrigo are joining forces again this year to help people quit smoking. Perrigo’s store-branded line of nicotine replacement products will be featured across retail partners including Walmart, Walgreens, Sam’s Club, Amazon, and many other participating retailers. Program Active: Oct 1, 2020 -Jan 31, 2021 Guaranteed Contribution: \$350,000” [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Wamberg Genomic Advisors was listed as a “Guardian” in the American Cancer Society’s list of “Partners Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Lilly Oncology was listed as a partner organization in the American Cancer Society’s list of “Partners Against Cancer” for Employee Events Engagement.** [American Cancer Society, accessed [11/17/20](#)]
- **November 2020: Pfizer was listed as a partner organization for the American Cancer Society’s list of “Partners Against Cancer” for Employee Events Engagement.** [American Cancer Society, accessed [11/17/20](#)]

## AMERICAN CANCER SOCIETY MAY HAVE RECEIVED AS MUCH AS \$255 MILLION IN CORPORATE DONATIONS OR 36 PERCENT OF THEIR REVENUE

**The American Cancer Society doesn’t report corporate contributions as a separate revenue category but divides the category into multiple revenue streams.**

The American Cancer Society breaks down its public financial support into the following categories: Relay For Life (including corporate sponsorships); planned gifts (legacies and bequests); other community-based events (including corporate sponsorships); direct response (direct mail, telemarketing, online); major gifts and campaigns; contributed services and in-kind contributions; distinguished events (galas and golf); corporate and cause-related giving; employer-based strategies United Way/Combined Federal Campaign, and other. [American Cancer Society, 2019 Annual Report, accessed [12/2/20](#)]

**2019: American Cancer Society reported a total revenue of \$728 million in contributions.**

“In 2019 the American Cancer Society raised \$728 million in contributions from the public:

- 21 percent of these funds came from Relay For Life events held in the United States and US territories.
- 22 percent was raised through various planned gifts, including gifts from estates and charitable trusts.
- 12 percent was from community-based events, including Making Strides Against Breast Cancer, Real Men Wear Pink, and our newest fundraising platform, ResearchHERS.

- 13 percent came through our direct-to-consumer channels, including direct mail, telemarketing, giving through cancer.org, and social media platforms, including Facebook.
- The remainder of our funds were raised through a combination of corporate gifts, major gifts, and employee giving. We also raised more than \$34 million in contributed services and in-kind items to support our lifesaving mission.” [American Cancer Society, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: 21 percent (\$146 million) of ACS’ revenue came from the “Relay For Life (including corporate sponsorships).”** [American Cancer Society, 2019 Annual Report, [12/2/20](#)]
- **2019: 12 percent (\$83 million) of ACS’s revenue came from “Other community-based events (including corporate sponsorships).”** [American Cancer Society, 2019 Annual Report, [12/2/20](#)]
- **2019: 4 percent (\$26 million) of ACS’s revenue came from “corporate and cause-related giving.”** [American Cancer Society, 2019 Annual Report, [12/2/20](#)]

## ADDITIONAL FINANCIAL INFORMATION

**2018: The American Cancer Society had more than \$724 million in total revenue.** [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]

- **2018: 11 percent (\$78 million) of the American Cancer Society’s revenue came from community-based events “including corporate sponsorships.”** [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]
- **2018: 9 percent (\$66 million) of the American Cancer Society’s revenue came from “major gifts and campaigns.”** [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]
- **2018: 8 percent (\$58 million) of the American Cancer Society’s revenue came from “contributed services and in-kind contributions.”** [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]
- **2018: 2018: 3 percent (\$25 million) of the American Cancer Society’s revenue came from “corporate and cause-related giving.”** [American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]

**2018: The American Cancer Society Cancer Action Network had more than \$37 million in revenue.**

According to their 2018 IRS Form 990, ACS CAN took in \$37,948,021 in total revenue. Most of the revenue, \$37,801,356, came from “contributions and grants.” [American Cancer Society Cancer Action Network, IRS Form 990, [11/15/19](#)]

- **November 2020: CVS Health was an American Cancer Society “Partner Against Cancer.”** [American Cancer Society, accessed [11/17/20](#)]
- **2020: CVS Health customers could “support” the American Cancer Society by purchasing nicotine replacement therapy products made by GlaxoSmithKline.** “This year, CVS Pharmacy customers can also support the American Cancer Society (ACS) by purchasing GlaxoSmithKline’s Nicorette or NicoDerm nicotine replacement therapy (NRT) products. For every product purchased from August 30- September 19th, 2020, \$1 will go to the American Cancer Society, up to \$100,000.” [American Cancer Society, accessed [11/17/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Reportable compensation from related organizations	Estimated amount of other compensation from the organization and related organizations	Total
GARY M REEDY	CHIEF EXECUTIVE OFFICER	\$937,478.00	\$85,225.00	\$68,326.00	\$1,091,029.00
SUSAN G HERRINGTON	EVP, ENTERPRISE GOV. & CORP. SVCS	\$446,314.00	\$-	\$625,756.00	\$1,072,070.00
SHARON BYERS	CHIEF DEVELOPMENT & MARKETING OFCR	\$720,953.00	\$-	\$45,821.00	\$766,774.00
CATHERINE E. MICKLE	CHIEF ADMINISTRATIVE OFFICER	\$545,602.00	\$8,945.00	\$273,297.00	\$827,844.00
JUNG H. KIM	EVP, NORTHEAST REGION	\$441,672.00	\$-	\$277,461.00	\$719,133.00
MICHAEL L. NEAL	SENIOR EVP, FIELD OPERATIONS	\$489,932.00	\$-	\$214,909.00	\$704,841.00
RICHARD C. WENDER	CHIEF CANCER CONTROL OFFICER	\$551,206.00	\$-	\$55,400.00	\$606,606.00
ROBERT L CRUTCHFIELD	MANAGING DIR., BRIGHTEDGE VENTURES	\$567,662.00	\$-	\$31,657.00	\$599,319.00
ROBERT M. KING	CFO, OUTGOING	\$379,899.00	\$48,350.00	\$81,331.00	\$509,580.00
LEONARD LICHTENFELD	DEPUTY CHIEF MEDICAL OFFICER	\$388,577.00	\$-	\$53,188.00	\$441,765.00
JEFF D KLAAS	EVP, WEST REGION	\$386,035.00	\$-	\$21,371.00	\$407,406.00

[American Cancer Society, IRS Form 990, accessed. [11/12/20](#)]

**AMERICAN CANCER SOCIETY AND AMERICAN CANCER SOCIETY ACTION NETWORK CEO, GARY M. REEDY, SPENT 37 YEARS WORKING IN THE PHARMACEUTICAL INDUSTRY.**

**April 2015: Reedy became CEO of the American Cancer Society and American Cancer Society Action Network**

“Gary M. Reedy has dedicated his life to improving the health of people around the globe. He took that vision to the American Cancer Society, Inc., when he became chief executive officer in April 2015, but his work with the organization began more than 15 years ago, when he first became a volunteer leader with the organization.”

[American Cancer Society, accessed [11/17/20](#)]

**Prior to joining the American Cancer Society, Reedy had a 37-year career in the pharmaceutical industry, including senior leadership positions at Johnson & Johnson, SmithKline Beecham, and Centocor.**

“Prior to taking the helm of the American Cancer Society, Gary had a distinguished 37-year career as a healthcare business and advocacy leader, most recently as worldwide vice president, government affairs and policy, at Johnson & Johnson, where he spearheaded initiatives to influence global health policy. He previously devoted more than 25 years of his career to the business side of the industry, including senior leadership positions with SmithKline Beecham, Centocor, and Johnson & Johnson. During his tenure at Johnson & Johnson, Gary served as president of Ortho Biotech, a Johnson & Johnson company with annual revenues of more than \$3 billion.” [American Cancer Society, accessed [11/17/20](#)]

- **“Reedy was worldwide vice president, government affairs and policy, at Johnson & Johnson.”**

“Before taking the helm of ACS CAN and the Society, Reedy was worldwide vice president, government affairs and policy at Johnson & Johnson, where he spearheaded initiatives to influence global health policy and interacted with government officials around the globe.” [American Cancer Society Cancer Action Network, accessed [11/17/20](#)]

**Reedy is on the board of directors of Research America.**

“Gary’s nonprofit experience includes current board appointments for the Campaign for Tobacco-Free Kids, the Tobacco-Free Kids Action Fund, the National Health Council, Research America, and Emory & Henry College. He is an active member of the Georgia Tech Advisory Board and the Atlanta Rotary Club, previously served on the C-Change board of directors, and was a charter member of the CEO Roundtable on Cancer.” [American Cancer Society, accessed [11/17/20](#)]

**BRUCE N. BARRON, BOARD OF DIRECTORS, AMERICAN CANCER SOCIETY**

**Barron “has been involved with the management” of Applied NeuroSolutions, Inc.**

“Bruce Barron is a partner and co-founder of Origin Ventures, an early-stage technology focused venture capital firm. Bruce is a member of the Boards of Directors of DialogTech, the Chicago Baseball Cancer Charities, and the Chicago Chapter Board and the International Board of the Israel Cancer Research Fund. Bruce has been involved with the management of several start-up medical technology companies, including Applied NeuroSolutions, Inc. Bruce has served on the American Cancer Society Board of Directors since 2018 and is a member of the finance committee.” [American Cancer Society, accessed [11/17/20](#)]

**Applied NeuroSolutions is a biopharmaceutical company focused on Alzheimer’s treatment.**

“Applied NeuroSolutions, Inc. (APNS) is a development stage biopharmaceutical company focused on diagnostics and therapeutics for the treatment of Alzheimer’s Disease (AD).” [Applied NeuroSolutions, accessed [11/17/20](#)]

**Barron has served in executive roles for several pharmaceutical companies.**

“Bruce has served as President/Chairman CEO and/or CFO, from time to time, of the following companies: Gynex Pharmaceuticals, Inc. (sold to what is now known as Savient Pharmaceuticals in 1993), Pharmatec Inc. (merged with Pharmos Corp. in 1992) and Xtramedics, Inc. (merged with Athena Medical Corp. in 1994). Bruce assisted in guiding these entrepreneurial, public companies through their early stages to their ultimate sales or mergers with larger companies.” [BrightEdge Fund, accessed [11/20/20](#)]

**MARK A. GOLDBERG, MD, BOARD OF DIRECTORS, AMERICAN CANCER SOCIETY**

**Goldberg is a “veteran biotech executive” who also serves on the boards of directors of several pharmaceutical companies.**

“Mark Goldberg, MD, is a medical oncologist and hematologist on the faculty of Brigham & Women’s Hospital and Harvard Medical School, a veteran biotech executive, and long-time American Cancer Society (ACS) and ACS Cancer Action Network (CAN) volunteer. Dr. Goldberg currently serves on the boards of directors of ImmunoGen, Idera Pharmaceuticals, GlycoMimetics, Audentes Therapeutics, and Blueprint Medicines. Dr. Goldberg previously served on the executive management team of Synageva Biopharma from 2011-2014 and



before that served in various management capacities of increasing responsibility at Genzyme Corporation from 1996-2011, most recently as senior vice president of clinical development. Dr. Goldberg is the chair of the Eastern New England Area Board and was a member of the former New England Division Board. Dr. Goldberg is chair of the Mission Outcomes Committee and a member of the Governance Committee.”

[American Cancer Society, accessed [11/18/20](#)]

### **AMIT KUMAR, PHD, BOARD OF DIRECTORS AMERICAN CANCER SOCIETY**

**Kumar is the President and CEO of Anixa Biosciences and has served on the boards of directors of other biotechnology firms.**

“Amit Kumar, PhD, is the President and Chief Executive Officer of Anixa Biosciences and sits on the Boards of other public and private biotechnology companies. Dr. Kumar is an experienced research scientist, executive, and investor. Over the last 20 years, Dr. Kumar has performed and managed research programs in both cancer diagnostics and therapeutics. Dr. Kumar has also built strong relationships with venture capital firms and other investors in the biotechnology space and has a strong understanding and experience in structuring financial and business transactions. Dr. Kumar has served on the American Cancer Society Board of Directors since 2017 and serves as a member of the Compensation, Mission Outcomes, and Revenue and Marketing committees.”

[American Cancer Society, accessed [11/18/20](#)]

- **Anixa Biosciences is developing “a number of programs addressing cancer and infectious diseases.”**

“Anixa is a biotechnology company developing a number of programs addressing cancer and infectious disease. Anixa’s therapeutic portfolio includes a cancer immunotherapy program which uses a novel type of CAR-T, known as chimeric endocrine receptor T-cell (CER-T) technology, and a COVID-19 therapeutics program focused on inhibiting certain viral protein function. Anixa’s vaccine portfolio consists of a technology focused on the immunization against a “retired” protein,  $\beta$ -Lactalbumin, to prevent triple negative breast cancer (TNBC), the most lethal form of breast cancer. Anixa continually examines emerging technologies in complementary fields for further development and commercialization.” [Anixa Biosciences, accessed [11/18/20](#)]

### **2000-2007: Kumar was Vice President of Life Sciences at Acacia Research Corporation.**

“Dr. Amit Kumar, 55, Chairman of the Board, President and Chief Executive Officer. Dr. Kumar has served as our President and Chief Executive Officer since July 2017, as a director of the Company since November 2012 and as Chairman of the Board since August 2016. From June 2015 until August 2016, he served as Vice Chairman of the Board. Dr. Kumar served as a strategic advisor to the Company from September 2012 until July 2017. He has been Executive Chairman of the board of directors of Anixa Diagnostics Corporation, a wholly-owned subsidiary of the Company, since June 2015. Upon his appointment as Executive Chairman of Anixa Diagnostics, Dr. Kumar resigned from his position as the CEO of Geo Fossil Fuels LLC, an energy company, which he had held since December 2010. From September 2001 to June 2010, he was President and CEO of CombiMatrix Corporation, a NASDAQ listed biotechnology company and also served as director from September 2000 to June 2012. He was Vice President of Life Sciences of Acacia Research Corporation, a publicly traded investment company, from July 2000 to August 2007 and also served as a director from January 2003 to August 2007. Dr. Kumar has served as Chairman of the board of directors of Ascent Solar Technologies, Inc., a publicly held solar energy company, since June 2007. He served as a director of Aeolus Pharmaceuticals, Inc., a publicly traded biotechnology company, from June 2004 to June 2018. Dr. Kumar is Chairman of Actym Therapeutics, a private biotechnology company. Dr. Kumar has served on the board of the American Cancer Society since 2016. Dr. Kumar holds an A.B. in Chemistry from Occidental College. After graduate studies at Stanford University and Caltech, he received his Ph.D. from Caltech and completed his postdoctoral training at Harvard University. He has experience in technology driven start-ups, both at the board of directors and operating levels, in a broad variety of areas including finance, acquisitions, research and development, and marketing, and, as described above, has served as a director and/or officer of various

publicly traded companies.” [Anixa Biosciences, SEC Form 10-K, accessed [1/10/20](#)]

- **Acacia Research Corporation invests in intellectual property in the life sciences.**

“Founded in 1993, Acacia Research Corporation (NASDAQ: ACTG) invests in absolute return assets of intellectual property, life sciences, and other developed technologies. In 2020, Acacia embarked on a strategic partnership with Starboard Value, L.P. to build a platform to pursue opportunities that leverage Acacia’s governance experience and significant capital resources.” [Acacia Research Corporation, accessed [11/18/20](#)]

#### **2004-2018: Kumar was a Director of Aeolus Pharmaceuticals.**

“Dr. Amit Kumar, 55, Chairman of the Board, President and Chief Executive Officer. Dr. Kumar has served as our President and Chief Executive Officer since July 2017, as a director of the Company since November 2012 and as Chairman of the Board since August 2016. From June 2015 until August 2016, he served as Vice Chairman of the Board. Dr. Kumar served as a strategic advisor to the Company from September 2012 until July 2017. He has been Executive Chairman of the board of directors of Anixa Diagnostics Corporation, a wholly owned subsidiary of the Company, since June 2015. Upon his appointment as Executive Chairman of Anixa Diagnostics, Dr. Kumar resigned from his position as the CEO of Geo Fossil Fuels LLC, an energy company, which he had held since December 2010. From September 2001 to June 2010, he was President and CEO of CombiMatrix Corporation, a NASDAQ listed biotechnology company and also served as director from September 2000 to June 2012. He was Vice President of Life Sciences of Acacia Research Corporation, a publicly traded investment company, from July 2000 to August 2007 and also served as a director from January 2003 to August 2007. Dr. Kumar has served as Chairman of the board of directors of Ascent Solar Technologies, Inc., a publicly held solar energy company, since June 2007. He served as a director of Aeolus Pharmaceuticals, Inc., a publicly traded biotechnology company, from June 2004 to June 2018. Dr. Kumar is Chairman of Actym Therapeutics, a private biotechnology company. Dr. Kumar has served on the board of the American Cancer Society since 2016. Dr. Kumar holds an A.B. in Chemistry from Occidental College. After graduate studies at Stanford University and Caltech, he received his Ph.D. from Caltech and completed his postdoctoral training at Harvard University. He has experience in technology-driven start-ups, both at the board of directors and operating levels, in a broad variety of areas including finance, acquisitions, research and development, and marketing, and, as described above, has served as a director and/or officer of various publicly traded companies.” [Anixa Biosciences, SEC Form 10-K, accessed [1/10/20](#)]

- **Aeolus Pharmaceuticals was a biopharmaceutical company.**

“Aeolus Pharmaceuticals, Inc. is a biopharmaceutical company. The Company develops catalytic antioxidants for use in oncology, as well as in treating central nervous system, respiratory, and autoimmune disorders.” [Bloomberg, accessed [11/18/20](#)]

#### **Kumar is co-founder and director of Actym Therapeutics.**

“Amit Kumar, Ph.D. Cofounder Dr. Kumar is an experienced scientist, executive and board director, who has founded, built, and operated a number of technology enterprises. Dr. Kumar is currently the Chairman, CEO and President of Anixa Biosciences Corp., (NASDAQ:ANIX) a cancer diagnostic and therapy company. Dr. Kumar is currently a member of the Board of Directors of the American Cancer Society.” [Actym Therapeutics, accessed [11/18/20](#)]

- **Actym Therapeutics developed an immunotherapy platform to treat cancerous tumors.**

Actym Therapeutics is based in Berkeley, California and was founded in 2017 by Christopher Thanos, Ph.D., Laura Hix Glickman, Ph.D., and Amit Kumar, Ph.D. The company has developed a microbial-based immunotherapy platform called STACT (S. Typhimurium Attenuated Cancer Therapy). In preclinical studies, STACT specifically entrenches in many types of solid tumors and not in healthy tissue. Once there, STACT delivers multiplexed immuno-modulatory payloads directly to tumor-resident immune cells. Many of these payloads are of significant interest to the biopharmaceutical community but are intractable

using conventional approaches due to systemic toxicities after IV dosing. Furthermore, STACT has been engineered to deliver payload combinations, which facilitates engagement of multiple biological pathways from a single therapy.” [Actym Therapeutics press release, accessed [4/27/20](#)]

- **Kumar held a position at Signature BioScience.**

“Amit Kumar, Ph.D. Cofounder Dr. Kumar is an experienced scientist, executive and board director, who has founded, built, and operated a number of technology enterprises. Dr. Kumar is currently the Chairman, CEO and President of Anixa Biosciences Corp., (NASDAQ:ANIX) a cancer diagnostic and therapy company. Dr. Kumar is currently a member of the Board of Directors of the American Cancer Society. Previously, Dr. Kumar was CEO of GFF, a privately held biotech company. Before that, he was President and CEO of CombiMatrix Corporation from 2001 to 2010 (NASDAQ:CBMX), where he took the company public. Dr. Kumar sits on the Boards of two public companies and two private companies. Dr. Kumar has held positions at Venture Capital Firms (Oak Investment Partners, Acacia Research Corporation) and Biotech firms, IDEXX Laboratories (NASDAQ:IDXX), Signature Biosciences (acquired), Idetek Corporation (acquired), Tacere Therapeutics (acquired) and others.” [Actym Therapeutics, accessed [11/18/20](#)]

- **Signature BioScience was developing an anti-cancer compound when it was dissolved.**

“Signature BioScience Inc. was the first biotechnology company based in San Francisco. It was formed in 1998 but closed in 2003 due to lack of funding. Before Signature was dissolved, it had just completed Phase II trials on Digitoxin, which the company was pursuing as an anti-cancer compound. However, the company’s core competency was developing biotechnology tools that would be used to identify highly qualified pre-clinical leads.” [CrunchBase.com, accessed [11/18/20](#)]

- **Kumar was a founder of Signature BioScience.** [CrunchBase.com, accessed [11/18/20](#)]

#### **Kumar held a position at Tacere Therapeutics.**

“Amit Kumar, Ph.D. Cofounder Dr. Kumar is an experienced scientist, executive and board director, who has founded, built, and operated a number of technology enterprises. Dr. Kumar is currently the Chairman, CEO and President of Anixa Biosciences Corp., (NASDAQ:ANIX) a cancer diagnostic and therapy company. Dr. Kumar is currently a member of the Board of Directors of the American Cancer Society. Previously, Dr. Kumar was CEO of GFF, a privately held biotech company. Before that, he was President and CEO of CombiMatrix Corporation from 2001 to 2010 (NASDAQ:CBMX), where he took the company public. Dr. Kumar sits on the Boards of two public companies and two private companies. Dr. Kumar has held positions at Venture Capital Firms (Oak Investment Partners, Acacia Research Corporation) and Biotech firms, IDEXX Laboratories (NASDAQ:IDXX), Signature Biosciences (acquired), Idetek Corporation (acquired), Tacere Therapeutics (acquired) and others.” [Actym Therapeutics, accessed [11/18/20](#)]

- **Tacere was a “privately-held drug development company” working on hepatitis C treatments.**

“Benitec Biopharma (ASX: BLT) today announced the acquisition of US-based RNA interference (RNAi) therapeutics company Tacere Therapeutics, Inc. (Tacere). Tacere is a privately-held drug development company with a Phase I/II ready program in hepatitis C (HCV) that utilises Benitec Biopharma’s novel gene silencing technology called DNA-directed RNA interference (ddRNAi).”

[GlobalNewswire, accessed [10/11/12](#)]

#### **ALICE L. POMPONIO, BOARD OF DIRECTORS, AMERICAN CANCER SOCIETY CANCER ACTION NETWORK**

##### **Pomponio is an advisor at Red Sky Partners LLC.**

“Ms. Pomponio serves as Advisor at Red Sky Partners LLC and is the founder and managing director of Accendo, an independent social innovation platform aimed at accelerating innovative solutions to patient access, affordability, and adherence through enterprise formation, impact investment, and nonprofit strategic planning.” [American Cancer Society Cancer Action Network, accessed [11/19/20](#)]

- **Red Sky Partners LLC's clients include many pharmaceutical and biotechnology firms, including Acetylon Pharmaceuticals, Cadurion Pharmaceuticals, and Mosaic Biosciences.** [Red Sky Partners, accessed [11/19/20](#)]

**Pomponio was VP of Corporate Affairs at Radius Health.**

“For over 20 years, Alice has held strategy and functional leadership roles in biotech and pharmaceutical companies. Previously, she was VP of Corporate Affairs at Radius Health, where she built public affairs and patient assistance capabilities and transformed the company’s image for its first commercial launch.”

[Red Sky Partners, accessed [11/19/20](#)]

**Pomponio was head of science affairs at AstraZeneca Pharmaceuticals.**

“For over 20 years, Alice has held strategy and functional leadership roles in biotech and pharmaceutical companies. Previously, she was VP of Corporate Affairs at Radius Health, where she built public affairs and patient assistance capabilities and transformed company image for its first commercial launch. As Head of Science Affairs at AstraZeneca Pharmaceuticals, she led collaborations with patient associations and policymakers on alternative clinical trial design, drug repurposing, and biomarker qualification to streamline drug development.” [Red Sky Partners, accessed [11/19/20](#)]

**Pomponio worked at Genzyme where she “drove novel pricing and reimbursement approaches to secure patient access.”**

“At Genzyme Corporation, Alice expanded international markets through passage of orphan drug policy and drove novel pricing and reimbursement approaches to secure patient access.” [Red Sky Partners, accessed [11/19/20](#)]

**Pomponio is a director of the Massachusetts Biotechnology Council.**

“Alice currently serves as a Director of the Massachusetts Biotechnology Council (MassBio) and the American Cancer Society of Eastern New England.” [Red Sky Partners, accessed [11/19/20](#)]

- **The Massachusetts Biotechnology Council counts dozens of drug development companies among their members, including Abbott, AbbVie, Amgen, AstraZeneca, Bristol Myers Squibb, Eli Lilly, Genentech, Gilead, GlaxoSmithKline, Johnson & Johnson, and Pfizer.** [Massachusetts Biotechnology Council, accessed [11/19/20](#)]

**Lobbying Activities**

*Through the American Cancer Society Cancer Action Network, ACS spends more than \$1 million per year on lobbying firms that also lobby for some of the world’s largest pharmaceutical companies; several of those lobbyists have experience working directly for pharmaceutical companies and special interest groups.*

**THE AMERICAN CANCER SOCIETY EMPLOYS LOBBYING FIRMS THAT ALSO REPRESENT THE PHARMACEUTICAL INDUSTRY**

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
American Cancer Society	Cornerstone Government Affairs	Genentech; American Pharmaceutical Services, Inc; Baxter; Elusys Therapeutics; Johnson & Johnson; Pfizer
	Tarplin, Downs & Young (TDY)	Abbott; AbbVie; Aimmune Therapeutics; Amgen; AstraZeneca; Baxter; Biotechnology Innovation Organization; Boehringer Ingelheim; Eli Lilly; Genentech; Gilead Sciences; Jazz Pharmaceuticals; Mallinckrodt Pharmaceuticals; Merck; Novo Nordisk; Otsuka America Pharmaceutical; Pfizer; PhRMA; Sanofi; Sarepta Therapeutics; Takeda Pharmaceuticals America; Vertex Pharmaceuticals

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

## 2020: ACS CAN EMPLOYED TWO PROFESSIONAL LOBBYING FIRMS FOR FEDERAL LOBBYING.

### *Cornerstone Government Affairs and Erik Fatemi*

**Q1-Q3 2020:** According to federal lobbying disclosure records, ACS CAN paid at least \$320,000 to lobbying firms Cornerstone Government Affairs, Inc. and Tarplin, Downs & Young, LLC. [U.S. Senate Lobbying Disclosure Database, accessed [11/23/20](#)]

**Q1-Q3 2020:** ACS CAN employed Erik Fatemi of Cornerstone Government Affairs to lobby Congress on Health and Human Services appropriations for cancer research and prevention.

According to federal lobbying disclosure filings, Erik Fatemi of Cornerstone Government Affairs, Inc., lobbied on behalf of ACS CAN related to “HHS Appropriations for cancer research and prevention.” [Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/18/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/19/20](#)]

**8/3/20:** Fatemi registered as a lobbyist for the American Chemistry Council.

According to federal lobbying disclosures, Fatemi registered as a lobbyist for “American Chemistry Council OBO its Center for Biocide Chemistries” on August 3, 2020. [Cornerstone Government Affairs, Lobbying Registration, [8/3/20](#)]

- **The American Chemistry Council counts major pharmaceutical companies among its members, including Bayer, Eli Lilly, and Merck.** [American Chemistry Council, accessed [11/23/20](#)]

**2020:** Fatemi lobbied for drug maker Genentech.

According to federal lobbying disclosures, Fatemi lobbied for Genentech in the first three quarters of 2020. [Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/18/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/19/20](#)]

**2020:** Cornerstone Government Affairs registered to lobby on behalf of American Pharmaceutical Services, Inc.

According to federal lobbying registration filings, on August 10, 2020, Cornerstone Government Affairs registered to lobby for American Pharmaceutical Services, Inc.

[Cornerstone Government Affairs, Lobbying Registration, [8/10/20](#)]

- **According to federal lobbying disclosure records, American Pharmaceutical Services “Manufacture[s] Active Pharmaceutical Ingredients.”** [Cornerstone Government Affairs, Lobbying Registration, [8/10/20](#)]

**Q1-Q3 2020: Cornerstone Government Affairs lobbied on behalf of pharmaceutical company Baxter.**

According to federal lobbying disclosure reports, Cornerstone Government Affairs lobbied on behalf of Baxter Healthcare Corporation in the first three quarters of 2020.

[Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/19/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/20/20](#)]

**Q1-Q3 2020: Cornerstone Government Affairs lobbied on behalf of pharmaceutical company Elusys Therapeutics.**

According to federal lobbying disclosure reports, Cornerstone Government Affairs lobbied on behalf of Elusys Therapeutics in the first three quarters of 2020. [Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/19/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/20/20](#)]

- **Elusys Therapeutics is developing treatments for infectious diseases.**

“Elusys Therapeutics is a private company focused on the development of antibody therapeutics for the treatment of infectious disease. For over 10 years, Elusys has been engaged in development of new therapies for the treatment of anthrax exposure following a natural or intentional release of anthrax spores.” [Elusys Therapeutics, accessed [11/23/20](#)]

**Q1-Q3 2020: Cornerstone Government Affairs lobbied on behalf of pharmaceutical company Johnson & Johnson.**

According to federal lobbying disclosure reports, Cornerstone Government Affairs lobbied on behalf of Johnson & Johnson in the first three quarters of 2020. [Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/19/20](#)]

**Q1-Q3 2020: Cornerstone Government Affairs lobbied on behalf of pharmaceutical company Pfizer.**

According to federal lobbying disclosure reports, Cornerstone Government Affairs lobbied on behalf of Pfizer in the first three quarters of 2020. [Cornerstone Government Affairs, Lobbying Disclosure Report, Q1 2020, [4/18/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/19/20](#)]

***Tarplin, Downs & Young (TDY)***

**Q1-Q3 2020: ACS CAN paid at least \$200,000 to Tarplin, Downs & Young.**

[U.S. Senate Lobbying Disclosure Database, accessed [11/23/20](#)]

**2020: At least seven Tarplin, Downs & Young lobbyists worked on behalf of ACS CAN.**

According to federal lobbying disclosures, seven Tarplin, Downs & Young lobbyists worked on behalf of ACS CAN. Those lobbyists were: Raissa Downs, Jennifer Young, Michelle Easton, Elizabeth Murray, Charlotte Ivancic, Pamela Smith, and Emily Murry. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/14/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/17/20](#)]

- **Tarplin, Downs & Young specializes in health care issues and serves global corporations and trade associations.**

“Tarplin, Downs & Young, LLC (TDY) opened its doors in 2006, as a firm specializing in strategic consulting and policy development with a particular focus on health care. The firm combines the broad political experience and policy expertise of Washington veterans on both sides of the aisle to offer the highest level of service to global corporations, trade associations, patient groups and provider organizations on their legislative and regulatory priorities.” [Tarplin, Downs & Young, accessed [11/24/20](#)]

**Tarplin, Downs & Young lobbyist Michelle Easton was a Vice President at PhRMA.**

“Michelle P. Easton joined the firm in 2008, bringing over 14 years of health care experience on Capitol Hill. She most recently served as the Chief Health Counsel to the United States Senate Committee on Finance

Chairman Max Baucus (D-MT). Prior to joining the Finance Committee team, she served in several capacities for former Senator John Breaux (D-LA), including as Legislative Director and Staff Director for the Senate Special Committee on Aging. Michelle worked extensively on the Medicare and Medicaid programs while working in the Congress, including instrumental work on the Modernization Act (MMA). She also was a Vice President at PhRMA during the critical MMA enrollment process and coordinated efforts with third-party allied groups to maximize enrollment in the Medicare prescription drug benefit. Easton comes to the firm uniquely positioned to help the firm's clients prepare for the opportunities and challenges of major Medicare legislation and health care reform." [Tarplin, Downs & Young, accessed [11/24/20](#)]

**Tarplin, Downs & Young lobbyist Pamela Smith was a Vice President of Federal Advocacy at PhRMA.**

"Prior to joining TDY, Smith served as Vice President of Federal Advocacy at the Pharmaceutical Research and Manufacturers of America (PhRMA), where she directed PhRMA's advocacy work with Senate and House Democrats." [Tarplin, Downs & Young, [11/24/20](#)]

**Q1 2020: TDY lobbied Congress on behalf of ACS CAN on drug pricing issues.**

According to federal lobbying disclosure reports, TDY lobbied Congress on behalf of ACS CAN on "Prescription drug pricing and access S. 1895 - Lower Health Care Costs Act H.R. 3 - Lower Drug Costs Now Act S. 2543 - Prescription Drug Pricing Reduction Act" during the first quarter of 2020 [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/14/20](#)]

**Q2 2020: TDY lobbied Congress on behalf of ACS CAN on drug pricing issues**

According to federal lobbying disclosure reports, TDY lobbied Congress on behalf of ACS CAN on "Prescription drug pricing and access S. 1895 - Lower Health Care Costs Act H.R. 3 - Lower Drug Costs Now Act S. 2543 - Prescription Drug Pricing Reduction Act" during the second quarter of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q2 2020, [7/15/20](#); Q3 2020, [10/17/20](#)]

**Q3 2020: TDY lobbied Congress on behalf of ACS CAN on drug pricing issues.**

According to federal lobbying disclosure reports, TDY lobbied Congress on behalf of ACS CAN on "Prescription drug pricing and access S. 1895 - Lower Health Care Costs Act H.R. 3 - Lower Drug Costs Now Act S. 2543 - Prescription Drug Pricing Reduction Act" during the third quarter of 2020.

[Tarplin, Downs & Young, Lobbying Disclosure Report, Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Abbott.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Abbott in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/14/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/19/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, AbbVie.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of AbbVie in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/16/20](#); Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Aimmune Therapeutics.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Aimmune Therapeutics in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/14/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Amgen.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Amgen in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/20/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/19/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, AstraZeneca.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of AstraZeneca in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/14/20](#); Q2 2020, [7/16/20](#); Q3 2020, [10/14/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Baxter.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Baxter in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/16/20](#); Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the Biotechnology Industry Organization.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of the Biotechnology Industry Organization in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/14/20](#)]

**2016: The Biotechnology Industry Organization changed its name to Biotechnology Innovation Organization, also known as BIO.**

“To better reflect the remarkable progress and groundbreaking innovations its members achieve in healing, fueling and feeding the world, BIO – the world’s largest biotechnology trade association – is changing its name to Biotechnology Innovation Organization. The organization will continue to use the shortened, ‘BIO’ name.” [Businesswire, [1/4/16](#)]

**Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Boehringer Ingelheim.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Boehringer Ingelheim in the third quarter of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Eli Lilly.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Eli Lilly in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/17/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Genentech.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Genentech in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/16/20](#); Q3 2020, [10/14/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Gilead Sciences.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Gilead Sciences in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/19/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/14/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Jazz Pharmaceuticals.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Jazz Pharmaceuticals in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/16/20](#); Q3 2020, [10/18/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Mallinckrodt Pharmaceuticals.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Mallinckrodt Pharmaceuticals in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/16/20](#)]



**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Merck.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Merck in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/19/20](#)]

**Q2-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Novo Nordisk.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Novo Nordisk in the second and third quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q2 2020, [7/17/20](#); Q3 2020, [10/19/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Otsuka America Pharmaceutical.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Otsuka America Pharmaceutical in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/15/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/18/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Pfizer.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Pfizer in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/18/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of PhRMA.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of PhRMA in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/15/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Sanofi.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Sanofi in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/15/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Sarepta Therapeutics.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Sarepta Therapeutics in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/16/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of the pharmaceutical company, Takeda Pharmaceuticals America.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Takeda Pharmaceuticals America in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/14/20](#)]

**Q1-Q3 2020: TDY lobbied Congress on behalf of “Thorn Run Partners (on behalf of the Partnership to Improve Patient Care).”**

According to federal lobbying disclosure reports, TDY lobbied on behalf of “Thorn Run Partners (on behalf of the Partnership to Improve Patient Care)” in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/15/20](#)]

- **Q1-Q3 2020: TDY lobbied Congress on behalf of “Thorn Run Partners (on behalf of the Partnership to Improve Patient Care)” for “alternative payment models” and Medicare Part B.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of “Thorn Run Partners (on behalf of the Partnership to Improve Patient Care)” for “alternative payment models” and Medicare Part B in the

first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/15/20](#)]

### **Q1-Q3 2020: TDY lobbied Congress on behalf of pharmaceutical company Vertex Pharmaceuticals.**

According to federal lobbying disclosure reports, TDY lobbied on behalf of Vertex Pharmaceuticals in the first three quarters of 2020. [Tarplin, Downs & Young, Lobbying Disclosure Report, Q1 2020, [4/16/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/15/20](#)]

### **THE AMERICAN CANCER SOCIETY HAS PUBLICLY TOUTED ITS FEDERAL LOBBYING EFFORTS**

#### **2018: The American Cancer Society touted its lobbying of Congress in favor of bills that increased funding for the NIH by \$5 billion.**

“American Cancer Society Cancer Action Network (ACS CAN) In 2018 ACS CAN successfully continued urging lawmakers to make cancer a top priority. Congress passed two bills that together increased funding for the National Institutes of Health (NIH) by \$5 billion.”

[American Cancer Society, 2018 Annual Report, accessed [11/17/20](#)]

#### **2017: The American Cancer Society touted its lobbying of Congress in favor of increased medical research funding for the NIH and National Cancer Institute in the FY 2018 budget.**

“ACS CAN ADVOCATED FOR AND CONGRESS APPROVED A \$2 BILLION INCREASE in medical research funding for the National Institutes of Health, including \$475 million for the National Cancer Institute in the FY18 budget” [American Cancer Society, 2017 Annual Report, accessed [11/17/20](#)]

#### **ACS CAN “advocates for robust federal funding for cancer research, as well as research and drug approval policies that accelerate the development of new treatments.”**

“Improvements in outcomes for cancer patients require continued research and innovation. ACS CAN advocates for robust federal funding for cancer research, as well as research and drug approval policies that accelerate the development of new treatments while still ensuring patient safety.” [American Cancer Society Cancer Action Network, accessed [11/27/20](#)]

#### **1998-2019: The American Cancer Society and associated entities spent \$84,798,026 on federal lobbying.**

[Center for Responsive Politics, accessed [11/19/20](#)]

#### **2018: According to their 2018 IRS Form 990, the American Cancer Society spent just \$1,748 on lobbying.**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

#### **2018: According to their 2018 IRS Form 990, the American Cancer Society gave \$17,237,753 to other organizations “for lobbying purposes.”**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

#### **2018: According to their 2018 IRS Form 990, the American Cancer Society spent \$107,639 on “direct contact with legislators, their staffs, government officials, or a legislative body.”**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

### **THE AMERICAN CANCER SOCIETY CANCER ACTION NETWORK (ACS CAN)**

ACS CAN is the advocacy wing of the American Cancer Society that encourages “lawmakers, candidates and government officials to support laws and policies that make cancer a top national priority.”

“The American Cancer Society Cancer Action Network, Inc. (ACS CAN) is the nonprofit, nonpartisan advocacy

affiliate of the American Cancer Society inc. Dedicated to eliminating cancer as a major health problem, ACS CAN works to encourage lawmakers, candidates and government officials to support laws and policies that will make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer.”

[American Cancer Society Cancer Action Network, IRS Form 990, [11/15/19](#)]

- **2018: According to their 2018 IRS Form 990, ACS CAN spent \$1,581,343 on lobbying.** [American Cancer Society Cancer Action Network, IRS Form 990, [11/15/19](#)]

## Prescription Drug Cost Legislation

### HR 3, THE ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

**Seven Tarplin, Downs & Young lobbyists reported lobbying on HR 3 more than any other lobbyist, as measured by the number of lobbying disclosure reports on which the bill appeared.**

According to data from the Center for Responsive Politics, TDY lobbyists Jennifer Young, Michelle Easton, Pam Smith, Raissa Downs, Elizabeth Murray, Charlotte Ivancic, and Emily Murry appeared on 82 separate federal lobbying disclosure reports indicating they lobbied on H.R. 3, the Elijah E. Cummings Lower Drug Costs Now Act.

[Center for Responsive Politics, accessed [12/4/20](#)]

### OCTOBER 2019: AMERICAN CANCER SOCIETY CANCER ACTION NETWORK, SIGNED ON TO THE MAPRX LETTER COMMENTING ON HR 3 AND ENDORSING OUT-OF-POCKET CAPS FOR MEDICARE PART D.

[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

**12/12/19: ACS CAN issued a statement in support of House passage of the Elijah E. Cummings Lower Drug Costs Now Act, without ever mentioning the name of the bill.**

“The U.S. House of Representatives will vote today on a bill intended to bring down patient prescription drug costs. Several of the bill’s numerous provisions are important to cancer care, including establishing an annual cap on Medicare enrollees’ out-of-pocket expenses, allowing some Medicare beneficiaries to spread out high-cost prescription cost-sharing over the course of the year, and expanding Medicare eligibility for low-income subsidies under the program. A portion of the bill’s estimated savings would be directed to increasing federal investment in medical research at the National Institutes of Health (NIH) and extending funding for the Cancer Moonshot Initiative at the National Cancer Institute (NCI). The following is a statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN): ‘Today’s vote in the House is an important step towards Congress addressing prescription drug costs for patients, especially for those enrolled in Medicare. Cancer is a disease more common with age and can be very expensive to treat. For Medicare enrollees who currently face unlimited cost-sharing for some of their prescription drugs, the financial burden can be overwhelming. Establishing an annual cap for outpatient prescription drug costs would enable patients to plan for their expenses and provide some financial relief for a population often on fixed incomes. Additionally, more than one in three Medicare enrollees taking a cancer drug in 2017 hit the catastrophic cap in just the first two months of the year, according to research done for ACS CAN by Avalere Health. Rather than requiring full payment upfront, we support allowing those patients with high-cost drugs to space out their prescription drug copays in installments. This change could further alleviate some cancer patients’ economic stress. Of course, the ability to afford prescription drugs at all — no matter the payment plan — is critical, which is why we are pleased the bill includes improvements to allow more low-income beneficiaries to qualify for financial assistance with their Medicare benefits. Directing projected savings from this bill to medical research, specifically extending the Cancer Moonshot Initiative at NCI, is a welcome inclusion. Sustainable federal funding increases for NIH and NCI are essential for the continued development of new

tools to prevent, detect and treat this disease and we greatly appreciate lawmakers' continued commitment to medical research investment. We also appreciate their recognition of prevention as an essential component to quality health care and strongly support the inclusion of a provision to eliminate cost sharing for seniors on Medicare who are hit with a surprise bill during a routine screening colonoscopy when a polyp is discovered and removed during the same procedure. ACS CAN has long advocated for the passage of this proposal to close a loophole that was already fixed in private insurance and is deterring a population at higher risk for disease from getting a potentially lifesaving screening. Cancer patients and survivors depend on access to quality, affordable medical care including prescription drug therapies and preventive screenings. On behalf of the more than 1.7 million Americans estimated to be diagnosed with cancer this year, ACS CAN is encouraged by the House action to address these pressing issues and urges lawmakers to work in a bipartisan way to make provisions that will impact the cancer burden a reality."

[American Cancer Society Cancer Action Network press release, [12/12/19](#)]

- **12/12/19: ACS CAN said "Today's vote in the House is an important step towards Congress addressing prescription drug costs for patients, especially for those enrolled in Medicare. Cancer is a disease more common with age and can be very expensive to treat."**

"The following is a statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN): 'Today's vote in the House is an important step towards Congress addressing prescription drug costs for patients, especially for those enrolled in Medicare. Cancer is a disease more common with age and can be very expensive to treat. For Medicare enrollees who currently face unlimited cost-sharing for some of their prescription drugs, the financial burden can be overwhelming. Establishing an annual cap for outpatient prescription drug costs would enable patients to plan for their expenses and provide some financial relief for a population often on fixed incomes. Additionally, more than one in three Medicare enrollees taking a cancer drug in 2017 hit the catastrophic cap in just the first two months of the year, according to research done for ACS CAN by Avalere Health. Rather than requiring full payment upfront, we support allowing those patients with high-cost drugs to space out their prescription drug copays in installments. This change could further alleviate some cancer patients' economic stress.'" [American Cancer Society Cancer Action Network press release, [12/12/19](#)]

- **12/12/19: The House of Representatives passed the Elijah E. Cummings Lower Drug Costs Now Act.**  
[House Roll Call vote #682, [12/12/19](#)]

**12/9/19: ACS CAN issued a statement in support of the Removing Barriers to Colorectal Cancer Screening Act, included in the Elijah E. Cummings Lower Drug Costs Now Act, which would eliminate cost-sharing for some Medicare recipients who undergo colonoscopies.**

"Bipartisan legislation that would ensure surprise out-of-pocket expenses are not a barrier to lifesaving colorectal cancer screenings for seniors on Medicare is expected to be taken up by the House of Representatives this week. The Removing Barriers to Colorectal Cancer Screening Act will be considered as part of HR 3, the Elijah E. Cummings Lower Drug Costs Now Act, and is also included in HR 19, the Lower Costs More Cures Act. The Removing Barriers to Colorectal Cancer Screening Act would eliminate cost-sharing for seniors on Medicare who are hit with a surprise bill during a routine screening colonoscopy when a polyp is discovered and removed during the same procedure. Under current law, Medicare covers the full costs of a preventive screening colonoscopy. However, if a polyp is found and removed during that preventive procedure, patients wake up to a pricey cost-sharing bill often totalling several hundred dollars. Evidence shows that any cost-sharing can deter people from getting a preventive, and potentially life-saving, screening. Following is a statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN): 'We know colorectal cancer can be prevented with regularly-scheduled screenings. Yet too many seniors on Medicare choose to forego this simple procedure because of cost. We applaud House lawmakers for taking the opportunity to help reduce the burden and suffering of colorectal cancer on senior citizens by advancing legislation to remove financial barriers to screenings. 'Closing this loophole for seniors on Medicare has been a longtime priority for

ACS CAN and legislation our volunteers in congressional districts across the country have tirelessly advocated for. The bill has unwavering bipartisan support with 335 sponsors in the House of Representatives and 60 sponsors in the US Senate. We thank Reps. Donald Payne, Rodney Davis, Donald McEachin and David McKinley for their work to move this important policy forward. The Removing Barriers to Colorectal Cancer Screening Act would ensure everyone on Medicare has access to life-saving cancer screenings by eliminating unexpected out-of-pocket expenses. More than 145,000 Americans will be diagnosed with colorectal cancer this year and over 51,000 of them will die from the disease. ACS CAN is committed to increasing colorectal cancer screening rates, and removing financial barriers to screening would help increase screening rates and save more lives from this preventable disease.”

[American Cancer Society Cancer Action Network press release, [12/9/19](#)]

- **ACS CAN’s statement didn’t address lowering prescription drug costs, but only focused on surprise bills resulting from colonoscopies.**

“Bipartisan legislation that would ensure surprise out-of-pocket expenses are not a barrier to lifesaving colorectal cancer screenings for seniors on Medicare is expected to be taken up by the House of Representatives this week. The Removing Barriers to Colorectal Cancer Screening Act will be considered as part of HR 3, the Elijah E. Cummings Lower Drug Costs Now Act and is also included in HR 19, the Lower Costs More Cures Act. The Removing Barriers to Colorectal Cancer Screening Act would eliminate cost-sharing for seniors on Medicare who are hit with a surprise bill during a routine screening colonoscopy when a polyp is discovered and removed during the same procedure. Under current law, Medicare covers the full costs of a preventive screening colonoscopy. However, if a polyp is found and removed during that preventive procedure, patients wake up to a pricey cost-sharing bill often totalling several hundred dollars. Evidence shows that any cost-sharing can deter people from getting a preventive, and potentially life-saving, screening. Following is a statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN): ‘We know colorectal cancer can be prevented with regularly-scheduled screenings. Yet too many seniors on Medicare choose to forego this simple procedure because of cost. We applaud House lawmakers for taking the opportunity to help reduce the burden and suffering of colorectal cancer on senior citizens by advancing legislation to remove financial barriers to screenings. ‘Closing this loophole for seniors on Medicare has been a longtime priority for ACS CAN and legislation our volunteers in congressional districts across the country have tirelessly advocated for. The bill has unwavering bipartisan support with 335 sponsors in the House of Representatives and 60 sponsors in the US Senate. We thank Reps. Donald Payne, Rodney Davis, Donald McEachin and David McKinley for their work to move this important policy forward. ‘The Removing Barriers to Colorectal Cancer Screening Act would ensure everyone on Medicare has access to life-saving cancer screenings by eliminating unexpected out-of-pocket expenses. More than 145,000 Americans will be diagnosed with colorectal cancer this year and over 51,000 of them will die from the disease. ACS CAN is committed to increasing colorectal cancer screening rates, and removing financial barriers to screening would help increase screening rates and save more lives from this preventable disease.’” [American Cancer Society Cancer Action Network press release, [12/9/19](#)]

### **HR 19/S. 3129, THE LOWER COSTS MORE CURES ACT**

#### **12/9/19: ACS CAN issued a statement in support of the Removing Barriers to Colorectal Cancer Screening Act, included in the Lower Costs More Cures Act, which would eliminate cost-sharing for some Medicare recipients who undergo colonoscopies.**

“Bipartisan legislation that would ensure surprise out-of-pocket expenses are not a barrier to lifesaving colorectal cancer screenings for seniors on Medicare is expected to be taken up by the House of Representatives this week. The Removing Barriers to Colorectal Cancer Screening Act will be considered as part of HR 3, the Elijah E. Cummings Lower Drug Costs Now Act and is also included in HR 19, the Lower Costs More Cures Act. The Removing Barriers to Colorectal Cancer Screening Act would eliminate cost-

sharing for seniors on Medicare who are hit with a surprise bill during a routine screening colonoscopy when a polyp is discovered and removed during the same procedure. Under current law, Medicare covers the full costs of a preventive screening colonoscopy. However, if a polyp is found and removed during that preventive procedure, patients wake up to a pricey cost-sharing bill often totalling several hundred dollars. Evidence shows that any cost-sharing can deter people from getting a preventive, and potentially life-saving, screening. Following is a statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN): ‘We know colorectal cancer can be prevented with regularly-scheduled screenings. Yet too many seniors on Medicare choose to forego this simple procedure because of cost. We applaud House lawmakers for taking the opportunity to help reduce the burden and suffering of colorectal cancer on senior citizens by advancing legislation to remove financial barriers to screenings. Closing this loophole for seniors on Medicare has been a longtime priority for ACS CAN and legislation our volunteers in congressional districts across the country have tirelessly advocated for. The bill has unwavering bipartisan support with 335 sponsors in the House of Representatives and 60 sponsors in the US Senate. We thank Reps. Donald Payne, Rodney Davis, Donald McEachin and David McKinley for their work to move this important policy forward. ‘The Removing Barriers to Colorectal Cancer Screening Act would ensure everyone on Medicare has access to life-saving cancer screenings by eliminating unexpected out-of-pocket expenses. More than 145,000 Americans will be diagnosed with colorectal cancer this year and over 51,000 of them will die from the disease. ACS CAN is committed to increasing colorectal cancer screening rates, and removing financial barriers to screening would help increase screening rates and save more lives from this preventable disease.’” [American Cancer Society Cancer Action Network press release, [12/9/19](#)]

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## S. 2543, THE SENATE PRESCRIPTION DRUG PRICING REDUCTION ACT

**Seven Tarplin, Downs & Young lobbyists reported lobbying on S. 2543 more than any other lobbyist, as measured by the number of lobbying disclosure reports the bill appeared on.**

According to data from the Center for Responsive Politics, TDY lobbyists Jennifer Young, Michelle Easton, Pam Smith, Raissa Downs, Elizabeth Murray, Charlotte Ivancic, and Emily Murry appeared on 79 separate federal lobbying disclosure reports indicating they lobbied on S. 2543, the Prescription Drug Pricing Reduction Act of 2019. [Center for Responsive Politics, accessed [12/4/20](#)]

**July 2019: ACS CAN issued a statement in support of reducing out-of-pocket costs for cancer patients when the Senate Finance Committee marked up the Prescription Drug Pricing Reduction Act.**

- “Today the Senate Finance Committee is marking up the Prescription Drug Pricing Reduction Act (PDPRA) of 2019, which includes a provision to cap Medicare beneficiaries’ out-of-pocket prescription drug costs in Medicare Part D, among several other proposed changes intended to bring down patient costs. ACS CAN will continue to evaluate proposed provisions in the package to determine potential impact on cancer patients and survivors. A statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN) follows: ‘We’re pleased the Committee is taking bipartisan action to address the high out-of-pocket costs for prescription drugs. For cancer patients, in particular, expensive drug therapies are their only option to treat their disease. The proposed cap for Medicare Part D enrollees has the potential to provide some important financial relief to these patients. However, we have concerns that the \$3,100 threshold may still be too high of a cost burden for those patients on a fixed income. We urge the Committee to consider those that are most impacted by these costs and adjust the cap accordingly. We would also ask lawmakers to consider ways to address those sometimes overwhelming upfront costs Medicare patients face when it comes to reaching the catastrophic coverage phase of the current drug benefit. Patients taking high-cost drugs can face several thousand dollars in cost-sharing simply trying to fill their first prescription. These costs have been shown to prompt some cancer patients to never fill their prescriptions and abandon treatment. We welcome the opportunity to work with the Committee as they examine ways to address these significant upfront costs and make it more financially feasible for a patient to access often life-saving therapy. Medicare provides essential health coverage to millions of Americans with a history of cancer. These patients need to have access to the best available therapies at costs they can afford. ACS CAN looks forward to continuing to review the package and working with the Finance Committee to address changes to Part D as well as other proposals that would directly affect cancer patients.’” [American Cancer Society Cancer Action Network press release, [7/25/19](#)]
- **ACS CAN called for lowering the proposed out-of-pocket cap on prescription drug costs for cancer patients because a “\$3,100 threshold may still be too high of a cost burden for those patients on a fixed income.”**

“The proposed cap for Medicare Part D enrollees has the potential to provide some important financial relief to these patients. However, we have concerns that the \$3,100 threshold may still be too high of a cost burden for those patients on a fixed income. We urge the Committee to consider those that are most impacted by these costs and adjust the cap accordingly.” [American Cancer Society Cancer Action Network press release, [7/25/19](#)]

**7/25/19: As part of the MAPRx Coalition, ACS CAN signed on to a letter commenting on the Medicare Part D Benefit Redesign provisions in the Senate Prescription Drug Pricing Act, thanking the senators for the out-of-pocket cap and calling on them to strengthen it.**

“Dear Chairman Grassley and Ranking Member Wyden: We are writing to comment on the Medicare Part D Benefit Redesign provisions in your legislation, The Prescription Drug Pricing Reduction Act of 2019. Our group, MAPRx Coalition (MAPRx), is a national coalition of beneficiary, caregiver and health care professional organizations committed to improving access to prescription medications in Medicare Part D and safeguarding

the well-being of Medicare beneficiaries with chronic diseases and disabilities. We greatly appreciate your leadership in improving access to prescription drugs for Medicare beneficiaries with Part D coverage. First and foremost, thank you for including a Part D out-of-pocket (OOP) cap in your legislation. Over the years, Part D has been viewed as a success due to its broad popularity among enrollees and lower-than-expected government expenditures. Nevertheless, serious challenges remain and the lack of an OOP cap is a hurdle for some of the most vulnerable Medicare beneficiaries. An OOP cap would be an important new patient protection for some of the most vulnerable enrollees in the Medicare program—drastically reducing costs for hundreds of thousands of beneficiaries who rely on prescription drugs to treat chronic and life-threatening conditions. Currently, many beneficiaries often cannot access the most clinically appropriate medication because, financially, it is out of reach. We urge you to strengthen the OOP cap in your legislation. To ensure an OOP cap is meaningful to as many beneficiaries as possible, MAPRx recommends a monthly cap (or other ‘smoothing’ mechanism) that would allow total OOP costs to be distributed more evenly throughout the year. Such a mechanism would ease the financial strain for Medicare beneficiaries who currently are faced with paying a significant percentage of their total OOP financial burden at the beginning of each benefit year. In addition, we would like to see beneficiaries benefit from the cap sooner than your proposed start date of 2022. As you know, currently, the average Medicare beneficiary will pay approximately \$2,750 in OOP costs by the time they reach the catastrophic threshold. As such, MAPRx strongly urges the Committee to consider an OOP cap below this amount. [...] As more Americans become eligible for Medicare, the Part D program will play an increasingly integral role in maintaining beneficiaries’ health and reducing overall health care costs. The undersigned members of MAPRx appreciate your work on Medicare Part D, and we look forward to working with you as your bill moves through the legislative process. For questions related to MAPRx or the above comments, please contact Bonnie Hogue Duffy, Convener, MAPRx Coalition, at (202) 540-1070 or [bduffy@nvgllc.com](mailto:bduffy@nvgllc.com). Sincerely, [...] American Cancer Society Cancer Action Network”

[KidneyFund.org, accessed [7/25/19](#)]

## **OTHER STATEMENTS ON PRESCRIPTION DRUG COSTS**

### **5/11/18: ACS CAN said it supported “proposals that balance innovation with affordability including those that cap out-of-pocket drug costs for patients.”**

A statement from Chris Hansen, President of the American Cancer Society Cancer Action Network (ACS CAN) is as follows: “Cancer patients rely on prescription drugs to treat, survive and recover from their disease. Promising new therapies have improved cancer patients’ survival, yet increasingly, patients are struggling with unaffordable out-of-pocket costs. Because cancer risk increases with age, the proposed Medicare changes anticipated today have the potential to impact many cancer patients and survivors. Limiting catastrophic out-of-pocket costs, sharing rebates with patients and improving formulary transparency could collectively reduce financial vulnerability that too often forces seniors to choose between lifesaving care and their life savings. However, providing benefit design flexibility – while potentially leading to lower up-front costs— could result in long-term financial challenges for patients with serious conditions like cancer, who could end up footing the bill if their particular cancer drug is not included on the plan’s formulary. With more than 200 different cancers with a tremendous range of therapies to address the heterogeneous nature of the various types of the disease, it is imperative that those facing a cancer diagnosis have access to evidence-based therapies. ‘ACS CAN supports proposals that balance innovation with affordability including those that cap out-of-pocket drug costs for patients, and improve the transparency and patient understanding of prescription drug coverage including the list of drugs covered under a medical benefit, the cost sharing, and any utilization management tools.’” [American Cancer Society Cancer Action Network press release, [5/11/18](#)]

### **7/16/18: ACS CAN said it supported lowering Medicare “beneficiaries’ cost sharing for high-cost drugs,” as long as it didn’t limit access to life-saving medications for cancer patients.**



“Currently, Medicare Part D prescription drug plans are required to cover nearly all drugs in what are known as the ‘six protected classes.’ This policy is intended to ensure the most vulnerable Medicare enrollees, including cancer patients, are able to access the drugs required to treat their disease. If these classes are changed or eliminated, Part D plans could exclude or restrict access to certain drugs as a means to reduce costs. Prescription drug indications vary widely and increasingly in cancer — with the development of precision medicine — drugs target specific mutations. Restricting formularies would leave out many unique drugs that have no alternative to treat distinct cancers. Part D plans already have flexibility in how they cover drugs in the six protected classes and can use formulary tiers to negotiate better prices without jeopardizing patient access. While ACS CAN supports efforts to reduce beneficiaries’ cost sharing for high-cost drugs, limiting access to potentially life-saving medications could significantly harm cancer patients.”

[American Cancer Society Cancer Action Network press release, [7/16/18](#)]

**ACS CAN said it opposed moving some prescription drug coverage from Medicare Part B to Part D because it could increase out-of-pocket costs for consumers.**

“The administration is also proposing to shift some drug coverage from Medicare Part B to Part D. Currently some drugs, including cancer drugs, are covered under Part B because they need to be administered by a physician. It is unclear how these drugs would be managed in Part D without potentially risking patient safety. Moreover, moving some drug coverage to Part D is likely to significantly increase out-of-pocket costs for most cancer patients in Medicare. Supplemental Medicare plans — like Medigap — cover some or all of enrollees’ co-insurance under Part B, but do not cover Part D expenses. Part D plans can also charge higher co-insurance for some drugs — up to 33 percent instead of the flat 20 percent under Part B. Moving prescription drug coverage from Part B to Part D may likewise increase Part D premiums as plans pass on the cost of covering more expensive drugs to consumers.” [American Cancer Society Cancer Action Network press release, [7/16/18](#)]

**ACS CAN said it supported including out-of-pocket caps for Medicare Part D.**

“ACS CAN is pleased to see the administration is considering some important cost-saving measures proposed in the RFI and the blueprint that have the potential to reduce out-of-pocket costs for patients. ACS CAN supports including out-of-pocket caps on expenses in Part D. Right now, enrollees have no limit on the amount they may spend annually on prescription drugs, a situation that is especially challenging since the average Medicare enrollee lives on less than \$30,000 a year. Capping out-of-pocket costs in Part D is an issue of equity, as those under 65 with private insurance already have a limit on out-of-pocket costs they pay for drugs included on plan formularies. ACS CAN is calling on HHS Secretary Azar and Congress to work together to cap costs in the program in new national ads launched this week.” [American Cancer Society Cancer Action Network press release, [7/16/18](#)]

**ACS CAN suggested proposals that could reduce consumer costs for prescription drugs, like allowing the use of copay discount cards when generics are unavailable, allowing pharmacists to advise patients that their medications could be cheaper without using their insurance, and eliminating some cost-sharing for low-income Medicare beneficiaries.**

“Other proposals that could help patients include allowing Medicare enrollees to use copay discount cards when generics or biosimilar drugs are unavailable, allowing pharmacists to tell patients when they could buy a drug for less without using their insurance, and eliminating cost sharing for generic drugs for certain low-income Medicare beneficiaries. Drug therapies play an integral role in cancer treatment. Providing access to affordable prescription drug therapies to all Americans, including those on Medicare, will be key to improving cancer outcomes and decreasing death and suffering from this disease.” [American Cancer Society Cancer Action Network press release, [7/16/18](#)]

**7/16/18: ACS CAN submitted a 23-page letter with comments on the HHS Blueprint to Lower Drug Prices and Reduce Out-of-Pocket Costs.**

[Christopher W. Hansen, President, American Cancer Society Cancer Action Network, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**September 2019: ACS CAN said it welcomes Speaker Pelosi's efforts to reduce prescription drug prices, especially for Medicare beneficiaries.**

"Today House Speaker, Nancy Pelosi (D-Calif.), introduced legislation intended to bring down patient drug costs. The bill includes a provision to cap Medicare beneficiaries' out-of-pocket prescription drug costs in Medicare Part D, allow the Health and Human Services (HHS) Secretary to negotiate prices for some drugs, and link select drug prices to the rates paid by other industrialized countries, among several other proposed changes. ACS CAN will continue to evaluate proposed provisions in the package to determine potential impact on cancer patients and survivors. A statement from Lisa Lacasse, president of the American Cancer Society Cancer Action Network (ACS CAN) follows: 'We welcome Speaker Pelosi and House leadership's action to address the rising costs of prescription drugs for patients, especially those enrolled in Medicare. Cancer patients often need some of the most expensive drugs on the market to treat their disease and mitigate side effects; implementing a cap on Medicare Part D out-of-pocket costs would provide some financial relief for these patients. We are pleased to see the House legislation sets the out-of-pocket cap at \$2,000 and welcome the opportunity to work with the committee as they address policy proposals to keep the cap low and spread out those costs throughout the year. Medicare provides essential health coverage to millions of Americans with a history of cancer. These patients need to have access to the best available therapies at costs they can afford.'" [American Cancer Society Cancer Action Network press release, [9/19/20](#)]

- **ACS CAN cautioned tying prescription drug prices in the US to prices overseas because of "the need to incentivize innovation and development of new cancer drugs."**

"Preserving uninterrupted access should also be paramount when considering tying U.S. drug prices to those in other industrialized countries including, Australia, Canada, France, Germany, Japan and the United Kingdom. The inherent challenge would be balancing the need to incentivize continued innovation and development of new cancer drugs with greater affordability of these therapies." [American Cancer Society Cancer Action Network press release, [9/19/20](#)]

**Headline: "ACS CAN: Efforts to Reduce Drug Prices Must Balance Affordability with Access to Innovation and Safety"**

[American Cancer Society Cancer Action Network press release, [7/24/20](#)]

**7/24/20: ACS CAN cautioned that President Trump's Executive Order on pharmaceutical rebates could cause Medicare Part D premiums to increase.**

"Today President Trump signed executive orders on pharmaceutical rebates, prescription drug importation and an International Pricing Index (IPI) or "Most Favored Nation" Model. The following is a response to the executive orders from the American Cancer Society Cancer Action Network (ACS CAN). 'While we acknowledge the administration's attempt to further examine new ways to tackle prescription drug costs, this must be done in a manner which balances affordability with access to innovation and maintaining safety. The executive order would direct HHS to complete its rulemaking on prescription drug rebates. We believe that the proposed rule holds promise, but more details are needed as noted in our previous comments. The proposed rule issued last year encouraged discounts at the point of sale where discounts can be shared with consumers. This would particularly benefit individuals who take high-cost drugs, like cancer patients and survivors, and those with total drug spending in the coverage gap (Medicare Part D). However, we noted that the proposal could cause Part D premiums to rise. We look forward to more details on how this plan can work to make prescription drugs more affordable for individuals on Medicare.'" [American Cancer Society Cancer Action Network press release, [7/24/20](#)]

**ACS CAN warned that there must be a balance between low-cost prescription drugs and the need to incentivize innovation and new drug development.**

“Today President Trump signed executive orders on pharmaceutical rebates, prescription drug importation and an International Pricing Index (IPI) or ‘Most Favored Nation’ Model. The following is a response to the executive orders from the American Cancer Society Cancer Action Network (ACS CAN). ‘While we acknowledge the administration’s attempt to further examine new ways to tackle prescription drug costs, this must be done in a manner which balances affordability with access to innovation and maintaining safety. [...] Unfortunately, we are concerned that the prescription drug importation plan outlined in the executive order does not strike the critical balance between affordability and access to innovation and maintaining safety. The prescription drug importation plan does not include details on the robust safeguards necessary to ensure the safety of the prescription drugs imported into the U.S. In our comments on the proposed rule in March, we noted that the proposal as outlined raises a number of serious questions about the administrative feasibility, safety and actual savings for consumers. Not only does this plan create significant safety concerns for patients, the prescription drug importation plan is unlikely to lead to cost savings, as establishing a program to provide for prescription drug importation would negate savings provided under the importation program.’” [American Constitution Society Cancer Action Network press release, [7/24/20](#)]

**ACS CAN said that International Pricing Index plans must ensure patients can maintain access to needed prescription drugs.**

“While the executive order on the International Pricing Index (IPI) or ‘Most Favored Nation’ Model is being held until August 24, we had serious concerns with the administration’s previously proposed IPI model. As noted in our comments on the IPI advance notice of proposed rulemaking, the IPI model failed to provide sufficient details to ensure that beneficiaries — particularly those in active cancer treatment — will have access to the medications needed for their cancer care. Unfortunately, this model, as proposed in the advance notice of proposed rulemaking, could make it harder for cancer patients, especially those living in rural areas, to find the right provider to treat their cancer with the right drug. Preserving uninterrupted access should also be paramount when considering tying U.S. drug prices to those in other industrialized countries.” [American Constitution Society Cancer Action Network press release, [7/24/20](#)]

**ACS CAN said it supported capping out-of-pocket expenses for Medicare beneficiaries.**

“ACS CAN strongly supports efforts to cap patient out-of-pocket spending in Medicare. Several recent federal bills proposed such a cap in Medicare Part D, which would help many enrollees with cancer who have high and ongoing costs for prescription drugs — ensuring that they are able to take their drugs as needed, improving their cancer outcomes. ACS CAN encourages policymakers to enact this Part D cap and continue finding ways to limit total out-of-pocket spending for Medicare enrollees by considering caps in other parts of Medicare (e.g., Parts A and B). This is especially important for those Medicare enrollees who do not have supplemental or Medigap coverage that protects them from high out-of-pocket expenses in Part B. Capping out-of-pocket spending in Medicare will reduce the financial toxicity of cancer for Medicare enrollees, and will give these enrollees more predictability in their annual expenses, which is especially helpful to those on fixed incomes.” [American Cancer Society Cancer Action Network, *The Costs of Cancer: 2020 Edition*, [October 2020](#)]

**ACS CAN said it supported increasing patient access to generic drugs and biosimilars to help reduce costs for cancer patients.**

“While it is important to continue to incentivize innovation through research that leads to development of new drug therapies, diagnostics and screenings; it is also important that patients have access to and are prescribed lower cost drug alternatives when they are available and medically appropriate for the individual. ACS CAN supports policy efforts to ensure that biosimilar and generic drugs are available to patients either through direct prescription or appropriate pharmacy substitution of interchangeable products. Further, ACS CAN encourages policymakers to explore policies that would increase access through reducing or eliminating cost-sharing for patients taking a biosimilar and incentivize biosimilar utilization through payment policies. Lastly, we support efforts that remove artificial barriers to the development and approval of generics and

biosimilars.”

[American Cancer Society Cancer Action Network, The Costs of Cancer: 2020 Edition, [October 2020](#)]

**ACS CAN said that Medicare enrollees should be allowed to use patient assistance programs or co-pay programs to reduce their out-of-pocket costs.**

“Ensure Patients Can Use Co-pay Coupons and Discounts In our patient scenarios, Franklin had to take a drug that did not have a lower cost generic or biosimilar alternative and used a co-pay coupon to help him pay the cost of the drug. These coupons, often distributed through patient assistance programs, can give patients access to a life-saving drug that they otherwise could not afford. Despite these benefits, because of federal anti-kickback rules, Medicare enrollees are not allowed to use these programs or coupons – leaving them vulnerable to high drug costs. Additionally, some pharmacy benefit managers, insurers and/or employers are implementing ‘accumulator adjustment programs,’ which prevent the costs that are covered by a patient assistance program or co-pay coupon from applying towards the patient’s deductible or out-of-pocket maximum. A decision regarding oncology treatment should be a medical decision between a doctor and patient. Patient assistance programs help enrollees to have access to the most appropriate prescription drugs. Prohibiting the use of these programs or not counting their support toward out-of-pocket spending requirements could deny cancer patients access to medically necessary prescription drugs. At the same time, these programs should not be used to steer patients toward a higher-cost medication when a less expensive alternative is available, covered and medically appropriate for an enrollee. ACS CAN supports policies that ensure patients can use these coupons to help afford their drugs in situations where there is no clinically appropriate alternative.’

[American Cancer Society Cancer Action Network, The Costs of Cancer: 2020 Edition, [October 2020](#)]

**ACS CAN said it supported limiting the out-of-pocket expenses for prescription drugs.**

“Other priorities to ensuring access to care: [...] Limiting the amount that patients must pay out-of-pocket for their drugs, including policies that encourage plans to use only co-pays on their formularies (which are more transparent and predictable than co-insurance), policies that cap cost-sharing amounts for drugs and policies that cap all out-of-pocket drug spending for the year.”

[American Cancer Society Cancer Action Network, The Costs of Cancer: 2020 Edition, [October 2020](#)]

**ACS CAN said it supported “Requiring plans to cover oral anti-cancer drugs with cost-sharing amounts that are comparable to their coverage of physician-administered anti-cancer drugs.”**

“Other priorities to ensuring access to care: [...] Requiring plans to cover oral anti-cancer drugs with cost-sharing amounts that are comparable to their coverage of physician-administered anti-cancer drugs.” [American Cancer Society Cancer Action Network, The Costs of Cancer: 2020 Edition, [October 2020](#)]

**ACS CAN said it supported patient assistance programs because limiting their use could deny cancer patients necessary prescription drugs, despite acknowledging that the programs may work to keep drug list prices high.**

“Manufacturer programs and charitable patient assistance programs help many cancer patients afford their medications. In many cases a cancer patient needs a drug that does not yet have a modestly-priced generic or other alternative to drug treatment. A patient assistance program’s financial support can give patients access to a life-saving drug that they otherwise could not afford. Some policymakers argue that these programs potentially increase prescription drug costs by allowing the manufacturers to keep the “list price” of their drugs high, but without these programs, many cancer patients are left with few options to pay for their therapies. Additionally, some argue that these programs cause patients and doctors to choose more expensive drugs, where generic or cheaper alternatives exist. This reduces a plan’s ability to steer patients towards more cost-effective drugs and may increase premiums. However, many of the programs exist for drugs without generic alternatives. [...] A decision regarding oncology treatment should be a medical decision between a doctor and patient. Patient assistance programs help enrollees to have access to the most appropriate prescription drugs. Prohibiting the use of these programs could deny cancer patients access to medically necessary prescription drugs. At the

same time, these programs should not be used to steer patients toward a higher-cost medication when a less expensive alternative is available, covered, and medically appropriate for an enrollee.” [American Cancer Society Cancer Action Network, [5/28/20](#)]

### **ACS CAN supported the Creating and Restoring Equal Access to Equivalent Samples – CREATES Act.**

“Today the Senate Health, Education, Labor and Pensions Committee will markup legislation aimed at helping reduce patients’ out-of-pocket health care costs and improving public health. The Lower Health Care Costs Act would exempt patients from having to pay surprise medical bills in most circumstances. Surprise medical bills are often large bills that result from a patient unknowingly receiving care or a service from an out-of-network provider, often during an urgent or emergency situation. The bill also includes a measure to encourage generic competition (the Creating and Restoring Equal Access to Equivalent Samples – CREATES Act) so generic drugs can more quickly enter the market, raises the federal age for tobacco sales from 18 to 21, and extends funding for Federally Qualified Health Centers (FQHC) through 2024. [...] Reducing out-of-pocket prescription drug costs is another top priority for cancer patients and we’re encouraged that the CREATES Act is included in this bill. CREATES has the potential to incentivize even more generic drug competition, giving patients cheaper access to lifesaving drug therapies.”

[American Cancer Society Cancer Action Network press release, [6/26/20](#)]

### **Investments: ACS BrightEdge Venture LLC**

*The American Cancer Society created a venture capital fund called BrightEdge Venture LLC that directly invests in companies that are developing oncology therapeutics—but its investments aren’t exclusive to oncology drugs. ACS says that it expects BrightEdge to accelerate development of cancer drugs and that the revenue will help fund ACS’ general mission. This suggests that it has a financial stake in not reducing drug prices on the manufacturer side of the pricing equation.*

**According to their 2018 IRS tax filings, the American Cancer Society is a “direct controlling entity” in “ACS BRIGHTEDGE VENTURE LLC,” which has a “primary activity” of investing.**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

**ACS BrightEdge is a venture capital fund designed to invest in companies that are “developing novel cancer-focused treatments.”**

“Launched in 2019, BrightEdge is the American Cancer Society’s mission-driven venture capital fund. The fund invests in for-profit companies developing novel cancer-focused treatments.”

[BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge is trading on ACS’ access to scientific experts and investment experts.**

“While the American Cancer Society focuses on discovering tomorrow’s treatments, BrightEdge focuses on accelerating market adoption to innovations today. BrightEdge leverages the extensive scientific expertise of the American Cancer Society and other investment experts to diligence potential investments and offer support to portfolio companies.” [BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge’s goal is to “accelerate market delivery” for cancer treatments through “capital investment.”**

“BrightEdge’s goal is to accelerate market delivery of innovative oncology treatments through capital investment, market awareness, and a shared commitment to eradicate cancer.” [BrightEdge Fund, accessed [11/20/20](#)]

**A portion of contributions made to the American Cancer Society are dedicated to BrightEdge.**

“A portion of donations to the ACS are dedicated to BrightEdge annually to invest in companies poised to

have real impact on lives. By supporting innovation that is nearing market-readiness, we strive to reach a world without cancer sooner.” [BrightEdge Fund, accessed [11/20/20](#)]

**Profits generated by BrightEdge are reinvested in “with the goal of ultimately creating a sustainable stream of capital to fund other critical ACS initiatives.”**

“BrightEdge returns are reinvested with the goal of ultimately creating a sustainable stream of capital to fund other critical ACS initiatives that dramatically improve the lives of cancer patients and their loved ones.”

[BrightEdge Fund, accessed [11/20/20](#)]

**While BrightEdge investments are primarily focused on oncology applications, they may invest in non-oncology treatments.**

“BrightEdge portfolio companies must have a substantial focus on oncology. We may invest in companies that have non-oncology applications, but the primary value proposition must be overwhelmingly in oncology.”

[BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge invests alongside traditional venture capitalists.**

“BrightEdge invests alongside the industry’s top VC funds to accelerate the most innovative companies that are raising capital through equity or convertible debt.” [BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge does not provide grant funding like ACS does.**

“BrightEdge invests alongside the industry’s top VC funds to accelerate the most innovative companies that are raising capital through equity or convertible debt. (Note that while ACS Research distributes over one hundred million dollars of translational grants per year, the BrightEdge fund does not provide grant funding.)” [BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge is soliciting donors.**

“Contact us at [BrightEdgeInfo@cancer.org](mailto:BrightEdgeInfo@cancer.org) to donate or learn more. Become a part of BrightEdge by becoming a donor. You will make a transformational impact in joining us as we invest directly into the companies and entrepreneurs that are changing the landscape of cancer care while simultaneously helping us to create a long-term, sustainable revenue stream for the ACS.” [BrightEdge Fund, accessed [11/20/20](#)]

**BrightEdge lists at least seven companies among its investment portfolio, including Interius, Checkmate Pharmaceuticals, GreatPoint, Freenome, Tmunity, Navigating Cancer, and Castle Biosciences.**

[BrightEdge Fund, accessed [11/20/20](#)]

- **Interius Biotherapeutics is developing gene therapies.**

“Interius Biotherapeutics is at the nexus of gene and cell therapy. Using next-generation lentiviral pseudotyping, we aim to enable the efficiency and specificity required for direct patient administration of gene therapies.” [Interius, accessed [11/20/20](#)]

- **Checkmate Pharmaceuticals is a biotechnology company whose “goal is to leverage its proprietary technology to discover, develop and commercialize transformative treatments to fight cancer.”**

“Checkmate Pharmaceuticals is a clinical stage biotechnology company focused on developing proprietary technology to harness the power of the immune system to combat cancer. Checkmate’s product candidate, CMP-001, is a differentiated TLR9 agonist delivered as a biologic virus-like particle designed to trigger the body’s innate immune system to attack tumors in combination with other therapies. Checkmate’s goal is to leverage its proprietary technology to discover, develop and commercialize transformative treatments to fight cancer.” [Checkmate Pharmaceuticals, accessed [11/20/20](#)]

- **GreatPoint is a venture capital firm.**

“We’re GreatPoint, a venture capital firm founded by entrepreneurs and company-builders [...] As

entrepreneurs, we were grateful to have amazing investors and board members who helped us succeed. These dedicated individuals flew around the world with us to raise 100-million-dollar funding rounds, opened doors to our biggest customers, and recruited veteran executives. We founded GreatPoint to be this kind of partner to every team we back.” [GreatPoint, accessed [11/20/20](#)]

- **GreatPoint has invested in pharmaceutical companies, such as Glympse Bio, Guide Therapeutics, and OncoResponse.** [GreatPoint, accessed [11/20/20](#)]

- **Freenome is working to “reinvent disease management through early detection and precision intervention.”**

“Since our beginning in 2014, Freenome has had a clear vision – building a multi-disciplinary team with expertise in computational biology and machine learning techniques to reinvent disease management through early detection and precision intervention. In this way, we seek to radically transform the way patients with cancer are managed, equipping people everywhere with the knowledge and tools they need to maintain a healthier life, and one day, prevent cancer altogether.” [Freenome, accessed [11/20/20](#)]

- **Tmunity Therapeutics “is developing personalized immunotherapies.”**

“Tmunity Therapeutics is a private biotherapeutics company focused on saving and improving lives by delivering the full potential of next-generation T cell immunotherapy to more patients with devastating diseases. Integrating broad collaborations with the University of Pennsylvania (UPenn) with the groundbreaking scientific, clinical and manufacturing expertise and demonstrated track record of its founders, Tmunity is developing personalized immunotherapies for cancer that are advancing rapidly toward the clinic. With headquarters in Philadelphia, Tmunity utilizes laboratories and production facilities at UPenn and its own dedicated cGMP manufacturing facility in Norristown, PA, to pursue process improvement and production scale-up in support of clinical development of T cell therapies.” [Tmunity, accessed [11/20/20](#)]

- **Navigating Cancer’s mission is to improve the cancer patient experience.**

“Navigating Cancer was founded in 2008 with the goal of filling a critical gap in oncology care: a better patient experience. That’s why we created the first patient-centered platform for oncology. Today, our Navigating Care platform supports over one million patients and thousands of cancer care providers nationwide to lower costs, improve patient satisfaction, and drive better outcomes.” [Navigating Cancer, accessed [11/20/20](#)]

- **Navigating Cancer serves pharmaceutical companies by driving brand awareness.**

“At Navigating Cancer, we support pharmaceutical companies and other partners in driving brand awareness and medication adherence through our information and data solutions. Succeeding in value-based cancer care requires coordination and shared mission to put the patient at the center of their care.” [Navigating Cancer, accessed [11/20/20](#)]

- **Castle Biosciences develops tests for dermatological cancers.**

“Castle Biosciences develops and commercializes diagnostic and prognostic tests for dermatologic cancers. Our tests provide clinically actionable, tumor-specific genomic information to enable more accurate treatment plan decisions. We believe that the traditional approach to developing a treatment plan for dermatologic cancers using clinical and pathology factors alone is inadequate, and can be improved by incorporating personalized genomic information.” [Castle Biosciences, accessed [11/20/20](#)]

### **The American Cancer Society lists BrightEdge on its IRS Form 990 as a “Disregarded Entity.”**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

- **According to the IRS, a tax-exempt entity may be the sole owner of a limited liability company, which can benefit from the owner’s tax-exempt status.**

“This part addresses general federal tax issues that may arise regarding an LLC that is associated with a tax-exempt organization. A tax-exempt entity may choose to become a member or owner of an LLC with

other members or owners, or to establish an LLC of which it is the sole owner or member for a variety of legitimate business reasons. The terms ‘owner’ and ‘member’ are used interchangeably throughout these instructions. An LLC with two or more owners may elect to be treated either as a partnership or as an association that is taxable as a corporation. A domestic LLC with a single owner is disregarded for federal tax purposes unless it elects to be regarded separately from its member, in which case it is treated as an association that is taxable as a corporation. A disregarded LLC whose sole owner is exempt from federal income tax under section 501(a) of the Code is not required to pay federal taxes or file a federal tax or information return; that is the responsibility of its sole owner. See Announcement 99-102. 1999-43 I.R.B. 545. The disregarded entity receives the benefit of its owner’s tax-exempt status, including exemption from federal income tax, federal unemployment tax, and other federal taxes where applicable. A disregarded entity may also choose to report and pay employment tax for its employees. See Notice 99-6, 1999-3 I.R.B. 12. Nevertheless, the sole owner is generally protected against potential liabilities that may arise, under state law, from the activities of its disregarded entity.” [IRS, Instructions for Limited Liability Company Reference Guide Sheet, accessed [11/20/20](#)]

- **An LLC whose sole owner is a tax-exempt entity is “disregarded” by the IRS for tax purposes and not required to pay taxes, a liability which accrues to the otherwise tax-exempt entity.**

“This part addresses general federal tax issues that may arise regarding an LLC that is associated with a tax-exempt organization. A tax-exempt entity may choose to become a member or owner of an LLC with other members or owners, or to establish an LLC of which it is the sole owner or member for a variety of legitimate business reasons. The terms ‘owner’ and ‘member’ are used interchangeably throughout these instructions. An LLC with two or more owners may elect to be treated either as a partnership or as an association that is taxable as a corporation. A domestic LLC with a single owner is disregarded for federal tax purposes unless it elects to be regarded separately from its member, in which case it is treated as an association that is taxable as a corporation. A disregarded LLC whose sole owner is exempt from federal income tax under section 501(a) of the Code is not required to pay federal taxes or file a federal tax or information return; that is the responsibility of its sole owner. See Announcement 99-102. 1999-43 I.R.B. 545. The disregarded entity receives the benefit of its owner’s tax-exempt status, including exemption from federal income tax, federal unemployment tax, and other federal taxes where applicable. A disregarded entity may also choose to report and pay employment tax for its employees. See Notice 99-6, 1999-3 I.R.B. 12. Nevertheless, the sole owner is generally protected against potential liabilities that may arise, under state law, from the activities of its disregarded entity.” [IRS, Instructions for Limited Liability Company Reference Guide Sheet, accessed [11/20/20](#)]

## **BRIGHTEDGE’S LEADERSHIP INCLUDES INDIVIDUALS WITH BACKGROUNDS IN THE PHARMACEUTICAL INDUSTRY**

**Michael Krepps, the principal investor at BrightEdge, was a co-founder of a biosciences company.**

“Prior to joining the BrightEdge Fund, Michael was an Associate Principal in the Life Sciences practice at Charles River Associates. While at CRA, Michael led engagements in asset/portfolio strategy, mergers and acquisitions, pipeline optimization, BD/investment strategy, and pricing & market access (primarily in oncology, rare disease, and immunology). Prior to his role at CRA, he co-founded SynActive Biosciences, which focused on stem cell-derived neuron technologies. Previously, he was a Program Manager in the Biosciences Division at the Department of Defense where he researched emerging pathogens and bio-terrorism threat agents. He has written numerous publications on genomics, immunology, infectious disease, and competitive dynamics in the biopharma marketplace, and has presented his research at leading academic conferences.”

[BrightEdge Fund, accessed [11/20/20](#)]

- Before joining BridgeEdge, **Krepps “led engagements” with “pharma and biotech clients” for Charles River Associates.**



“Mike Krepps, Principal, BrightEdge Ventures Prior to joining BrightEdge, Mike worked as a strategy consultant for Charles River Associates. As an Associate Principal in the Life Sciences practice, Mike led engagements for CRA’s pharma and biotech clients (primarily focusing on oncology, immunology, and gene therapy). Previous experience includes working as a scientist for the US Department of Defense and co-founding a neurological discovery startup called SynActive Biosciences. He received his MBA from the University of Chicago Booth and his BS & PhD (Genetics) from the University of Wisconsin-Madison.” [RESI Conference, accessed [11/20/20](#)]

**Bruce Barron, an advisor to BrightEdge, has served in executive roles for several pharmaceutical companies.**

“Bruce has served as President/Chairman CEO and/or CFO, from time to time, of the following companies: Gynex Pharmaceuticals, Inc. (sold to what is now known as Savient Pharmaceuticals in 1993), Pharmatec Inc. (merged with Pharmos Corp. in 1992) and Xtramedics, Inc. (merged with Athena Medical Corp. in 1994). Bruce assisted in guiding these entrepreneurial, public companies through their early stages to their ultimate sales or mergers with larger companies.” [BrightEdge Fund, accessed [11/20/20](#)]

**John Lazo, an advisor to BrightEdge, was a “corporate associate” at Johnson & Johnson and co-founded three biopharmaceutical companies.**

“John is the Associate Director for Basic Science at the University of Virginia Health System and Harrison Distinguished Teaching Professor in the Department of Pharmacology at the University of Virginia John is the Associate Dean for Basic Research at the University of Virginia School of Medicine. He also holds a secondary appointment in the Department of Chemistry and is the current President of the American Society for Pharmacology and Experimental Therapeutics (ASPET). [...] After receiving postdoctoral training at Yale University with Alan Sartorelli, John joined the faculty in the Department of Pharmacology at Yale. He moved to the University of Pittsburgh in 1987, where he served as the Allegheny Foundation Professor and Chair of Pharmacology until 2004. From 2004 until 2010, John was the founding Director of the University of Pittsburgh Drug Discovery Institute. His primary research interests are in molecular pharmacology and drug discovery with a special interest in drugs for cancer. John was a Corporate Associate of Johnson & Johnson between 2002-2005. He has authored 11 books, published more than 300 scientific articles and reviews, invented eight U.S. issued patents, and has been the principal investigator on numerous research grants. John has co-founded three biopharmaceutical companies.” [BrightEdge Fund, accessed [11/20/20](#)]

**Mark Goldberg, an advisor to BrightEdge, has served on boards of directors and in executive management roles for several pharmaceutical companies.**

“Dr. Mark Goldberg, MD, is a medical oncologist and hematologist on the faculty of Brigham & Women’s Hospital and Harvard Medical School, a veteran biotech executive, and long-time American Cancer Society (ACS) and ACS Cancer Action Network (CAN) volunteer. Dr. Goldberg currently serves on the boards of directors of ImmunoGen, Idera Pharmaceuticals, GlycoMimetics, Audentes Therapeutics, and Blueprint Medicines. Dr. Goldberg previously served on the executive management team of Synageva Biopharma from 2011-2014 and, before that, served in various management capacities of increasing responsibility at Genzyme Corporation from 1996-2011, most recently as senior vice president of clinical development.” [BrightEdge Fund, accessed [11/20/20](#)]

**Lita Nelson, an advisor to BrightEdge, has a professional background in the biotechnology services industry.**

“Lita is an advisor to the BrightEdge Fund and former Director of the Technology Licensing Office at the Massachusetts Institute of Technology, where she had been since 1986. [...] Prior to joining the M.I.T. Technology Licensing Office, Ms. Nelsen spent 20 years in industry, primarily in the fields of membrane separations, medical devices, and biotechnology, at such companies as Amicon, Millipore, Arthur D. Little, Inc., and Applied Biotechnology.” [BrightEdge Fund, accessed [11/20/20](#)]

**Alice Pomponio is an advisor to BrightEdge.**

[BrightEdge Fund, accessed [11/20/20](#)]

“Ms. Pomponio serves as Advisor at Red Sky Partners LLC and is the founder and managing director of Accendo, an independent social innovation platform aimed at accelerating innovative solutions to patient access, affordability, and adherence through enterprise formation, impact investment, and nonprofit strategic planning.”

[American Cancer Society Cancer Action Network, accessed [11/19/20](#)]

- **Red Sky Partners LLC’s clients include many pharmaceutical and biotechnology firms, including Acetylon Pharmaceuticals, Cadurion Pharmaceuticals, and Mosaic Biosciences.**

[Red Sky Partners, accessed [11/19/20](#)]

- **Pomponio was VP of Corporate Affairs at Radius Health.**

[Red Sky Partners, accessed [11/19/20](#)]

- **Pomponio was head of science affairs at AstraZeneca Pharmaceuticals.**

[Red Sky Partners, accessed [11/19/20](#)]

- **Pomponio worked at Genzyme where she “drove novel pricing and reimbursement approaches to secure patient access.”**

[Red Sky Partners, accessed [11/19/20](#)]

- **Pomponio is a director of the Massachusetts Biotechnology Council.**

[Red Sky Partners, accessed [11/19/20](#)]

- **The Massachusetts Biotechnology Council counts dozens of drug development companies among their members, including Abbott, AbbVie, Amgen, AstraZeneca, Bristol Myers Squibb, Eli Lilly, Genentech, Gilead, GlaxoSmithKline, Johnson & Johnson, and Pfizer.** [Massachusetts Biotechnology Council, accessed [11/19/20](#)]

**Amit Kumar is an advisor to BrightEdge.**

[BrightEdge Fund, accessed [11/20/20](#)]

- **Kumar is the President and CEO of Anixa Biosciences and has served on the boards of directors of other biotechnology firms.**

[American Cancer Society, accessed [11/18/20](#)]

- **2000-2007: Kumar was Vice President of Life Sciences at Acacia Research Corporation.**

[Anixa Biosciences, SEC Form 10-K, [1/10/20](#)]

- **2004-2018: Kumar was a Director of Aeolus Pharmaceuticals.**

[Anixa Biosciences, SEC Form 10-K, [1/10/20](#)]

- **Kumar is cofounder and director of Actym Therapeutics.**

[Actym Therapeutics, accessed [11/18/20](#)]

- **Kumar was a founder of Signature BioScience.**

[CrunchBase.com, accessed [11/18/20](#)]

- **Kumar held a position at Tacere Therapeutics.**

[Actym Therapeutics, accessed [11/18/20](#)]

## GRANT-MAKING

**2018: The American Cancer Society gave a \$500,000 grant to the Patient Advocate Foundation.**

[American Cancer Society, IRS Form 990, [11/14/19](#)]

- **The Patient Advocate Foundation operates a “co-pay relief” program for certain insured patients who need additional help paying for their prescription medications.**

“The PAF Co-Pay Relief Program, one of the self-contained divisions of PAF, provides direct financial assistance to insured patients who meet certain qualifications to help them pay for the prescriptions and/or treatments they need. This assistance helps patients afford the out-of-pocket costs for these items that their insurance companies require.” [Patient Advocate Foundation, accessed [11/20/20](#)]

- **The Patient Advocate Foundation co-pay relief program includes a disclaimer saying it will not “recommend or refer” a patient to “any fund donor, provider, supplier or product.”**

“PAF will not consider the identity of any physician, provider, supplier of items or services, donor, drug therapy, services or supplies being utilized or the referral source when assessing whether an applicant is qualified for financial assistance from a PAF CPR disease-specific fund. Under no circumstances will PAF recommend or refer an applicant or enrollee to any fund donor, provider, supplier or product.”

[Patient Advocate Foundation, accessed [11/20/20](#)]

- **Dr. Deborah Morosini, VP of Clinical Affairs & Patent Engagement at Loxo Oncology, is a member of the scientific committee for the Patient Advocate Foundation.**

[Patient Advocate Foundation, accessed [11/20/20](#)]

- **Loxo Oncology is a subsidiary of Eli Lilly.**

“Loxo Oncology at Lilly was created in December 2019, combining the Lilly Research Laboratories oncology organization and Loxo Oncology, which was acquired by Lilly in early 2019. Loxo Oncology at Lilly brings together the focus and spirit of a biotech with the scale and resources of large pharma, with the goal of rapidly delivering impactful new medicines for people with cancer.” [Loxo Oncology, accessed [11/20/20](#)]

- **Bill McGivney is an honorary board member of the Patient Advocate Foundation.**

[Patient Advocate Foundation, accessed [11/20/20](#)]

- **McGivney is the founder of McGivney Global Advisors, a consultancy for the biopharmaceutical market.**

“McGivney Global Advisors was founded by Bill McGivney, PhD, former CEO of National Comprehensive Cancer Network (NCCN) and former Vice President, Clinical and Coverage Policy for Aetna Health Plans. McGA differentiates itself from other consultancies by focusing on real-world impact and expertise-driven strategic approaches for the oncology and specialty biopharmaceutical market. The firm brings together experts in health policy, managed care and market access, clinical science, and health care delivery to provide strategies that bridge clinical, economic, and policy issues end-to-end in an increasingly competitive biopharma market.” [McGivney Global Advisors, accessed [11/20/20](#)]

**The Patient Advocate Foundation’s executive Vice President for business development and operations for the co-pay relief program, Alan Wood, previously worked in the pharmaceutical industry.**

“As the EVP of Business Development and Operations for the Co-Pay Relief Program (CPR), Alan plays a key role in managing the creation and promotion of compliant Co-Pay Relief funds, as well as designing and implementing competitive market strategies supporting the continual expansion and evolution of the program. He facilitates continual internal and external analysis of the patient support needs and the broader environment to ensure that PAF’s Co-Pay Relief program remains at the forefront of patient assistance programming, providing an efficient, reliable, and compliant resource for those in need. Alan joined Patient Advocate Foundation in 2013 as Development Director, Industry Relations. In this role, he secured grants and donations to maintain and expand support for the PAF Co-Pay Relief program. Additionally, he leveraged these donor relationships to introduce and, with fellow members of the development team, negotiate customized case management and novel patient support partnerships. Prior to Patient Advocate Foundation, Alan worked in the pharmaceutical industry with a focus on managed care markets.” [Patient Advocate Foundation, accessed [11/20/20](#)]

- **The Patient Advocate Foundation receives support from pharmaceutical companies like Allergan, Bristol**

- Myers Squibb, Boehringer Ingelheim, Genentech, Gilead Sciences, Pfizer, and PhRMA.

[Patient Advocate Foundation, 2019 Annual Impact Report, [2019](#)]

## AMERICAN DIABETES ASSOCIATION (ADA)

Website: <https://www.diabetes.org/>

Documents: [Conflict of Interest Policy](#)  
[Whistleblower Program](#)  
[Scientific Ethics and Integrity in Research Grants Policy](#)

### Financials

#### AMERICAN DIABETES ASSOCIATION DISCLOSED CORPORATIONS THAT GAVE MORE THAN \$150,000

**2019: The American Diabetes Association disclosed corporate donors who gave more than \$150,000 in a single year in their annual report.**

[American Diabetes Association, 2019 Annual Report, accessed [1/27/21](#)]

#### 2019: AMERICAN DIABETES ASSOCIATION RECEIVED AT LEAST \$9.9 MILLION AND POSSIBLY MORE THAN \$11.9 MILLION FROM PHARMACEUTICAL COMPANIES—BETWEEN 6 AND 7.6 PERCENT OF THEIR TOTAL REVENUES

**2019: ADA received at least a \$1 million from Abbott Diabetes Care, AstraZeneca Pharmaceuticals LP, Bayer Healthcare, Boehringer-Ingelheim Pharmaceuticals, Inc., Eli Lilly and Company, Merck, Novo Nordisk, Inc., Regeneron Pharmaceuticals, Inc., Sanofi S.A.**

“Banting Circle Supporters Companies that make medicines and devices to help people live with diabetes are recognized for their cumulative annual support. Our highest level of recognition, Banting Circle Elite, honors companies that have given \$1 million or more. Banting Circle Elite Companies(\$1 million+) • Abbott Diabetes Care • AstraZeneca Pharmaceuticals LP • Bayer Healthcare • Boehringer-Ingelheim Pharmaceuticals, Inc. • Eli Lilly and Company • Merck • Novo Nordisk, Inc. • Regeneron Pharmaceuticals, Inc. • Sanofi S.A.”

[American Diabetes Association, 2019 Annual Report, accessed [1/27/21](#)]

**2019: ADA received between \$150,000 and \$499,999 from Amarin, Amgen, Genentech, Janssen, MannKind Corporation, and Pfizer, totaling between \$900,000 and \$2,999,994**

“National Sponsors (\$150,000–\$499,999) Our National Sponsors support the ADA with an annual financial commitment of at least \$150,000 and conduct promotional activities to help raise awareness about the seriousness of diabetes. • Amarin Corporation • Amgen • BD Diabetes Care • Catherines • Cintas Corporation • Genentech Pharmaceuticals • Healogics, Inc. • Insulet Corporation • Janssen Pharmaceuticals, Inc. • MannKind Corporation • Medtronic Diabetes • Organogenesis, Inc. • Pfizer Inc. • Sun Life”

[American Diabetes Association, 2019 Annual Report, accessed [1/27/21](#)]

**2019: ADA’s total revenue was just under \$156 million.**

[American Diabetes Association, 2019 Annual Report, accessed [1/27/21](#)]

#### 2017: 12 PERCENT OF ADA’S REVENUE CAME FROM THE PHARMACEUTICAL INDUSTRY.

**2017: The American Diabetes Association received \$18.3 million from the pharmaceutical industry, accounting for more than 12 percent of its revenue.**

“The American Diabetes Association said in an email to KHN that it received \$18.3 million in pharmaceutical funding in 2017, accounting for 12.3 percent of its revenue; that was down from \$26.7 million in 2015. The

money flowed in as insulin makers continued to hike prices in those years – up to four times per product – leading to hardships for patients.” [Kaiser Health News, 4/6/18]

- **2017: Eli Lilly gave ADA \$2.9 million.**  
“The only ‘Big Three’ insulin maker in the database, Eli Lilly, gave \$2.9 million to the American Diabetes Association in 2015, according to disclosures from the company and its foundation. [...] Over the past 20 years, Eli Lilly has repeatedly raised prices on its bestselling insulins, Humalog and Humulin, even though the medicines have been around for decades. The drugmaker faced protests – by people demanding to know the cost of manufacturing a vial of insulin – at its Indianapolis headquarters last fall.” [Kaiser Health News, 4/6/18]
- **Eli Lilly said that it gave money to ADA because they share the same goals.**  
“Eli Lilly said it contributes money to the American Diabetes Association because the two share a ‘common goal’ of helping diabetes patients. ‘We provide funding for a wide variety of educational programs and opportunities at ADA, and they design and implement those programs in ways that are aligned with their goals,’ Eli Lilly said in a statement. ‘We’re proud to support the ADA on important work that helps millions of people living with diabetes.’” [Kaiser Health News, 4/6/18]

### 2015: 14.5 PERCENT OF ADA'S BUDGET CAME FROM THE PHARMACEUTICAL INDUSTRY

**2015: ADA received \$26.7 million from the pharmaceutical industry, accounting for 14.5 percent of its budget.**

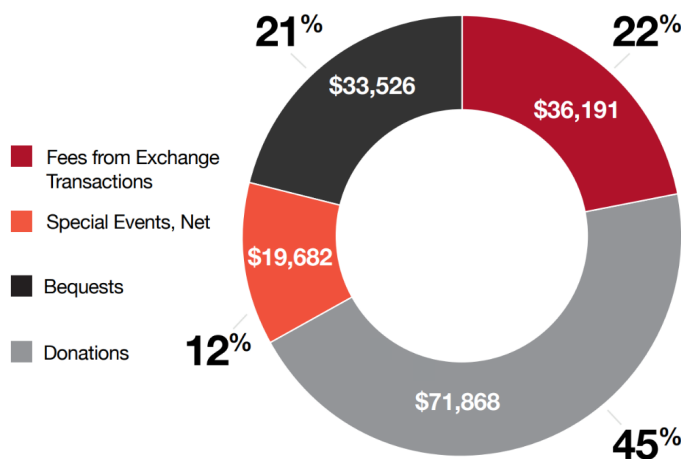
“Some patient groups have directly challenged the industry. The American Diabetes Association, for example, this year called on drug companies to be more open about their prices and to allow the federal government to negotiate over Medicare drug pricing. The association said it received \$26.7 million from the pharmaceutical industry in 2015, accounting for 14.5 percent of its budget.” [New York Times, 9/27/16]

### OTHER FINANCIAL INFORMATION

**2018: The ADA had more than \$161 million in total revenue.**

[ADA, 2018 Annual Report, accessed 12/1/20]

**Public Support and Other Revenue\***  
(in thousands)



**Total Revenue: \$161,267**

[ADA, 2018 Annual Report, accessed 12/1/20]

- **2018: 45 percent (\$71 million) of the ADA's revenue came from “Donations.”**  
[ADA, 2018 Annual Report, accessed 12/1/20]

- **2018: 22 percent (\$36 million) of the ADA’s revenue came from “Fees from Exchange Transactions.”**  
[ADA, 2018 Annual Report, accessed [12/1/20](#)]
- **2018: 21 percent (\$33 million) of the ADA’s revenue came from “Bequests.”**  
[ADA, 2018 Annual Report, accessed [12/1/20](#)]

## **\$75.5M** Individual donations in 2018

More than  
**\$19.6M**  
raised through our  
**Tour de Cure,  
Step Out, and  
Signature Events**



[ADA, 2018 Annual Report, accessed [12/1/20](#)]

- **2018: 12 percent (\$19 million) of the ADA’s revenue came from “Special Events, Net.”**  
[ADA, 2018 Annual Report, accessed [12/1/20](#)]  
**2018: \$75.5 million of the ADA’s revenue came from “individual donations.”**  
[ADA, 2018 Annual Report, accessed [12/1/20](#)]
- **2018: \$19.6 million “were raised through our “tour de Cure, Step Out, and Signature Events.”**  
[ADA, 2018 Annual Report, accessed [12/1/20](#)]

**2018: ADA Partnered with Abbott, AstraZeneca, Merck, Novo Nordisk and Sanofi, plus Strategic Sponsors Dexcom, Janssen, Lilly Diabetes and Medtronic on phase one of the “Overcoming Therapeutic Inertia Initiative.”**

“In November 2018, the ADA partnered with industry leaders on Phase One of the Overcoming Therapeutic Inertia Initiative to address and provide solutions for this long-standing problem. The initiative is supported by Founding Sponsors Abbott, AstraZeneca, Merck, Novo Nordisk and Sanofi, plus Strategic Sponsors Dexcom, Janssen, Lilly Diabetes and Medtronic.”

[ADA, 2018 Annual Report, accessed [12/1/20](#)]

### **BANTING CIRCLE ELITE**

**Banting Circle Elite was included in the ADA’s “Highest Level Of Recognition For Companies” that have given at least \$1 million.**

“The Banting Circle Elite is the American Diabetes Association’s highest level of recognition for companies that develop medicines and devices to help individuals living with diabetes. It is named for Sir Frederick Grant Banting, a Canadian medical scientist, doctor, Nobel Laureate and co-discoverer of insulin. The annual total support for companies reaching the Banting Circle Elite level is at least \$1,000,000.” [ADA, accessed [12/1/20](#)]

**Dec. 2020: Regeneron was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**[ADA, accessed [12/1/20](#)]

- **May 2020: “American Diabetes Association Welcomes Regeneron to Initiative to Help Prevent Vision Loss in People with Diabetes.”**

“Multi-year public health campaign will raise awareness of the need for understanding and early detection of diabetes-related eye disease The American Diabetes Association (ADA) today announced Regeneron Pharmaceuticals, Inc., has joined VSP® Vision Care as a Visionary Partner to focus on an often overlooked

but costly and devastating complication of diabetes: vision loss. This eye health initiative, “Focus on Diabetes,” will highlight the crucial role annual comprehensive eye exams play in the early detection, intervention and possible prevention of eye disease and vision loss caused by diabetes.” [ADA, Press Release, [5/6/20](#)]

**Dec. 2020: Abbot was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

- **Nov. 2018: Abbot contributed \$5 million over three years to ADA “to help close the health disparities gap for underserved diabetes communities.”**

“Abbott is committing \$5 million over three years to the American Diabetes Association (ADA) to help close the health disparities gap for underserved diabetes communities, especially people of color and lower-income Americans. Today, Abbott and the American Diabetes Association (ADA) announced that Abbott has become the first anchor sponsor of the Health Equity Now (HEN) platform to address health disparities for people with diabetes. Abbott’s sponsorship includes a three-year, \$5 million commitment to support the ADA’s advocacy and community-driven projects aimed at removing barriers to care and providing greater access to the latest medical technologies and health resources for underserved diabetes populations.” [ADA, Press Release, [11/18/20](#)]

**Dec. 2020: AstraZeneca was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

**Dec. 2020: Eli Lilly was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

**Dec. 2020: Merck was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

**Dec. 2020: Novo Nordisk was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

- **May 2020: “The American Diabetes Association® Celebrates Milestone of Novo Nordisk’s Support for the 5K@ADA: 15 Years Running.”**

“The American Diabetes Association (ADA) and Novo Nordisk, one of the world’s leading companies in diabetes management and long-time supporter of the ADA, announce the transition of their 15-year signature 5K@ADA Run/Walk event to a virtual challenge. The 5K@ADA has been an official event during the Scientific Sessions for 15 years and has brought together over 13,400 participants. Through the continued support of Novo Nordisk, the 5K@ADA Virtual Challenge is free of charge to all participants.” [ADA, Press Release, [5/7/20](#)]

**Dec. 2020: Sanofi was listed in the “Banting Circle Elite Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

## **BANTING CIRCLE**

**The ADA’s Banting Circle recognizes companies whose support is at least \$500,000.**

“Companies whose support total is at least \$500,000 are recognized at the Banting Circle level.” [ADA, accessed [12/1/20](#)]

**Dec. 2020: Dexcom was listed in the “Banting Circle Support” group as part of the ADA’s “Corporate Support.”**

[ADA, accessed [12/1/20](#)]

- **Dexcom is a medical device company that develops blood glucose monitoring systems.**

“Founded in 1999, Dexcom, Inc. (NASDAQ: DXCM), is developing and marketing Continuous Glucose Monitoring (CGM) systems for ambulatory use by people with diabetes and by healthcare providers for the treatment of people with diabetes.” [LinkedIn, accessed [12/1/20](#)]

## **NATIONAL STRATEGIC PARTNERS**

**Dec. 2020: CVS Pharmacy was listed as one of the ADA’s “National Strategic Partners.”**

“CVS and the ADA are coordinating efforts to work toward common goals of preventing diabetes and improving the lives of people impacted by the disease. Together, CVS and the ADA will raise awareness by encouraging people to learn their risk for type 2 diabetes through ADA resources made available to CVS’ Project Health and HealthHUBs and online ADA Risk Test screenings.” [ADA, accessed [12/1/20](#)]



## LEADERSHIP

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
Tracey D. Brown	Chief Executive Officer	\$740,424.00	\$297,583.00	\$1,038,007.00
Eloise Scavella	Chief Operating and Strategy Officer	\$351,489.00	\$34,838.00	\$386,327.00
John Agos	Chief Strategic Development Officer	\$299,585.00	\$42,037.00	\$341,622.00
William Cefalu (ended 8/15/19)	Chief Scientific, Medical & Mission Officer	\$290,418.00	\$28,732.00	\$319,150.00
Vignesh Clingam (effective 2/28/19 ended 11/1)	Chief Marketing & Digital Officer	\$304,518.00	\$11,087.00	\$315,605.00
Charlotte M. Carter	Chief Financial Officer	\$279,844.00	\$26,353.00	\$306,197.00
Linda Cann	Sr Vice President, Professional Services	\$211,011.00	\$48,286.00	\$259,297.00
Paul Nalbandian	Assoc. Publisher, Advertising Sales & Sponsor	\$223,979.00	\$29,908.00	\$253,887.00
Sean McDonough	Vice President & General Counsel	\$214,573.00	\$14,744.00	\$229,317.00
Anthony Webster (ended 9/10/19)	Chief Human Resources Officer	\$200,403.00	\$21,436.00	\$221,839.00
LaShawn Mclver	SVP, Government Affairs, Advocacy & Community	\$187,644.00	\$32,873.00	\$220,517.00
Tricia Cedotal	VP Corporate Alliances	\$187,611.00	\$20,086.00	\$207,697.00
Roy Furman	Medical Director, Quality Improvement	\$192,292.00	\$12,084.00	\$204,376.00
Tony Chiles (ended 9/20/19)	Chief Information Officer	\$172,278.00	\$29,585.00	\$201,863.00
Jeanine Jones	VP, HR Operations	\$178,382.00	\$20,028.00	\$198,410.00
Elaine Curran	VP Development	\$175,357.00	\$19,033.00	\$194,390.00
Christa Wilson	VP, Information Technology	\$156,327.00	\$18,258.00	\$174,585.00

[American Diabetes Association, IRS Form 990, [10/11/19](#)]

## AMERICAN DIABETES ASSOCIATION BOARD OF DIRECTORS INCLUDES CURRENT AND FORMER JOHNSON & JOHNSON LEADERS AND A BIG PHARMA LOBBYIST.

### MARY DE GROOT: ADA BOARD OF DIRECTORS PRESIDENT-ELECT, HEALTH CARE AND EDUCATION

**2017 – Present: de Groot served as a member of the ADA National Board of Directors.**

“Since 2017, Dr. de Groot has been a member of the American Diabetes Association National Board of Directors.” [ADA, accessed [12/1/20](#)]

**Jan. 2019 – Present: de Groot serves as the ADA’s President Elect, Health Care and Education.**

According to her LinkedIn profile, de Groot has served as the “President Elect, Health Care and Education” at American Diabetes Association since Jan. 2019. [LinkedIn, [accessed 12/1/20](#)]

**2007 – Present: de Groot is a consultant at the Johnson & Johnson Diabetes Institute.**

According to her LinkedIn profile, de Groot has been a “Consultant” for the Johnson & Johnson Diabetes Institute since 2007. [LinkedIn, [accessed 12/1/20](#)]

### ROBERT M. CUDDIHY: ADA BOARD OF DIRECTORS MEMBER

**May 2020 – Present: Cuddihy served as CEO at Capsida Biotherapeutics.**

According to his LinkedIn profile, Cuddihy has served as “Chief Executive Officer” of Capsida Biotherapeutics since May 2020. [LinkedIn, accessed [12/1/20](#)]

- **Capsida Pharmaceuticals States it is “engineering novel AAVs and developing the next generation of gene therapies.”**

According to the company’s LinkedIn profile, it is “Engineering novel AAVs and developing the next generation of gene therapies.” Their website does not appear to be live. [LinkedIn, accessed [12/1/20](#)]

**Apr. 2018 – May 2020: Cuddihy served as Vice President, US Medical Affairs, at Amgen.**

According to his LinkedIn profile, Cuddihy served as “VP US Medical Affairs” at Amgen from April 2018 through May 2020. He described the job as: “Leading US Medical Affairs across all therapeutic areas, Immunology, Oncology, Neuroscience, Cardiovascular, Metabolism/Bone, and Biosimilars.” [LinkedIn, accessed [12/1/20](#)]

- **“Robert M. Cuddihy is the CEO, Biotech Gene Therapy and former Vice President, US Medical Affairs, at AMGEN.”** [ADA, accessed [12/1/20](#)]

### AMPARO GONZALEZ: ADA BOARD OF DIRECTORS MEMBER

**Oct. 2018 – Present: Gonzalez serves as the “Global Head” for LifeScan.**

According to her LinkedIn profile, Gonzal has served as the Global Head of Life Scan since Oct. 2018. [LinkedIn, accessed [12/1/20](#)]

- **“Amparo Gonzalez is the Head Global for the LifeScan Diabetes Institute. In her role, Amparo has strategic oversight for all initiatives related to diabetes professional education activities globally, including the direction of the Institute.”** [ADA, accessed [12/1/20](#)]

- **LifeScan is a medical device company that develops blood glucose monitoring products, including the OneTouch line of blood glucose monitors.**

“LifeScan is a global leader in blood glucose monitoring innovation and digital health technology and has a vision to create a world without limits for people with diabetes and related conditions. More than 20 million people and their caregivers around the world count on LifeScan’s OneTouch brand products to manage their diabetes. Together, LifeScan and OneTouch improve the quality of life for people with diabetes with products and digital platforms defined by simplicity, accuracy, and trust.”

[LinkedIn, accessed [12/1/20](#)]

**Jul. 2013 – Oct. 2018: Gonzalez served as the “Head Global” at the Johnson & Johnson Diabetes Institute. According to her LinkedIn profile, Gonzalez served as the “Head Global” at the Johnson & Johnson Diabetes Institute from Jul. 2013 through Oct. 2013.**

[LinkedIn, accessed [12/1/20](#)]

**Jun. 2012 – Oct. 2018: Gonzalez served as the Director of Johnson & Johnson Diabetes Institute.**

According to her LinkedIn profile, Gonzalez was the Director of Johnson & Johnson’s Diabetes Institute from Jun. 2012 through Oct. 2018. She described the work as “Create and implement strategy for Professional Education for the USA and Canada. Run the operation of the Johnson & Johnson Diabetes Institute in California.”

[LinkedIn, accessed [12/1/20](#)]

**STEPHANIE SILVERMAN, ADA BOARD OF DIRECTORS MEMBER**

**2020 – Present: Silverman served as an ADA board member.**

According to her LinkedIn profile, Silverman is a new member of ADA’s board, joining it in 2020. [LinkedIn, accessed [12/1/20](#)]

**Q1-Q3 2020: Stephanie E. Silverman was a registered lobbyist for Eli Lilly and Company, Pacira Pharmaceuticals, Inc., and Regeneron Pharmaceuticals Inc.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/1/20](#)]

**RUTH WEINSTOCK, ADA BOARD OF DIRECTORS, PRESIDENT, MEDICINE & SCIENCE**

**2013-2019: Ruth Weinstock received 322 payments totaling \$588,992.22 from drug makers and medical device companies in associated research funding, research payments, and general payments.**

[OpenPaymentsData.CMS.gov, accessed [2/18/21](#)]

**GUILLERMO UMPIERREZ, ADA BOARD OF DIRECTORS, PRESIDENT-ELECT, MEDICINE & SCIENCE**

**2013-2019: Guillermo Umpierrez received 888 payments totaling \$9,784,650.10 from drug makers and medical device companies in associated research funding, research payments, and general payments.**

[OpenPaymentsData.CMS.gov, accessed [2/18/21](#)]

*Guillermo Umpierrez’s name in the Open Payments database operated by CMS appears to be misspelled as “Gulliermo”; however, based on the descriptions both on the Open Payments page and the American Diabetes Association website, they appear to be the same person.*

**LOBBYING ACTIVITIES**

**2020: ADA EMPLOYED TWO PROFESSIONAL LOBBYING FIRMS THAT ALSO LOBBIED FOR THE PHARMACEUTICAL INDUSTRY**

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
American Diabetes Association	McDermott+Consulting	Abbott; AIS Healthcare; Baxter International; Roche Diagnostics
	VENN STRATEGIES	Civica Inc.; Eli Lilly; Pacira Pharmaceuticals; Regeneron Pharmaceuticals
	Crowell & Moring	No pharmaceutical clients

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

## **Q1-Q3 2020: Venn Strategies, LLC lobbied on behalf of pharmaceutical companies Civic Inc., Eli Lilly, Pacira Pharmaceuticals, Regeneron Pharmaceuticals.**

According to federal lobbying disclosure records Venn Strategies, LLC lobbied on behalf of Civica Inc., Eli Lilly and Company, Pacira Pharmaceuticals, and Regeneron Pharmaceuticals. [U.S. Senate Lobbying Disclosure Database, accessed [12/1/20](#)]

- **Venn Strategies' website touted many clients related to the pharmaceutical and biotechnology industry, including Baxter and Eli Lilly.**

According to its website, Venn Strategies' clients included: Amerisource Bergen Corporation, Baxter, BioMarin, Biotechnology Industry Organization, Eli Lilly, Mallinckrodt Pharmaceuticals, PACIRA Biosciences, PhRMA, Regeneron, Pharmaceuticals, Sanofi, Sanofi Foundation North America, TriNetX. [Venn Strategies, accessed [12/1/20](#)]

- **2020: McDermott+Consulting lobbied the federal government on behalf of pharmaceutical companies Abbott, AIS Healthcare, Baxter International, and Roche Diagnostics.**

[U.S. Senate Lobbying Disclosure Database, 2/18/21]

- **McDermott+Consulting's website indicates that they advise pharmaceutical manufacturers.**

"McDermottPlus advises some of the world's largest and most innovative pharmaceutical and biological developers and manufacturers."

[McDermott+Consulting, accessed [2/18/21](#)]

## **ADDITIONAL LOBBYING INFORMATION**

**1998 – 2019: The ADA spent \$12,344,290 on federal lobbying.**

[Center for Responsive Politics, accessed [12/1/20](#)]

- **2018: ADA spent \$65,520 on "mailings to members, legislators or the public."**  
[ADA, IRS Form 990, [11/15/19](#)]
- **2018: ADA spent \$601,067 on "direct contact with legislators, their staffs, government officials, or a legislative body."**  
[ADA, IRS Form 990, [11/15/19](#)]
- **2018: ADA spent \$63,141 on "rallies, demonstrations, seminars, conventions, speeches, lectures or any similar means."**  
[ADA, IRS Form 990, [11/15/19](#)]

## **Prescription Drug Cost Legislation**

### **H.R. 3: ELIJAH E. CUMMING LOWER DRUG COSTS NOW ACT**

*No relevant information*

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information*

## **OTHER STATEMENTS ON PRESCRIPTION DRUG COSTS**

Kaiser Health News: ADA has decried rising insulin prices, but refused to name a single drug maker for increasing their prices, and it avoided taking a position on legislation targeting drug companies for increased transparency.

“The ADA launched a campaign decrying ‘skyrocketing’ insulin in late 2016 but did not call out any drugmaker in its literature. When legislators in Nevada passed a bill last year requiring insulin makers to disclose their profits to the public, the ADA did not take a public stance. The American Diabetes Association said it doesn’t confront individual companies because it is seeking action from ‘all entities in the supply chain’ – manufacturers, wholesalers, pharmacy benefit managers and insurers.” [Kaiser Health News, [4/6/18](#)]

**2016: ADA called for increased pricing transparency for insulin, in a statement no longer available on their website.**

“We recognize that many parties, including pharmacy benefit managers, insurers and retailers are involved in the path of medications from manufacturer to patient. As an advocate for all people affected by diabetes, we strongly encourage transparency by all parties in their pricing policies as well as a continued dialogue across the diabetes marketplace, in public policy and in the private sector, to develop lasting, affordable solutions.” [ADA, 2/23/16, via Internet Archive, accessed [2/28/19](#)]

**2020: ADA endorsed three bills they said were aimed at reducing insulin prices.**

“The American Diabetes Association (ADA) announced formal endorsement of three bills aiming to reduce the high cost of insulin and prescription drugs: the Insulin Price Reduction Act, the Safe Step Act, and the Chronic Condition Copay Elimination Act. The three bills were analyzed using ADA’s newly launched Engagement Platform. The Insulin Price Reduction Act (H.R.4906/S.2199) will reduce the skyrocketing cost of insulin by providing incentives for manufacturers to revert to the 2006 list price of all insulin products. The Safe Step Act (H.R.2279/S.2546) will remove barriers to good diabetes management and prevent the delay of treatment for people with diabetes due to ‘step therapy,’ in which a health plan can require patients to try a drug before they pay for one prescribed by the patient’s health care provider. The Chronic Condition Copay Elimination Act (H.R. 4457) will remove copays for certain items and services to treat chronic conditions.” [ADA press release, [1/15/20](#)]

**2020: ADA lauded Nancy Pelosi for calling for zero-dollar co-pays for medications for Medicare recipients.**

“The American Diabetes Association (ADA) applauds Speaker of the House Nancy Pelosi for calling for zero-dollar copays for medication for seniors on Medicare as a response to the coronavirus (COVID-19). Tracey D. Brown, Chief Executive Officer of the ADA, issued the following statement: ‘The cost of insulin for those living with diabetes can be debilitating as people are facing reduced paychecks and unemployment as a result of the coronavirus (COVID-19), making it that much harder for them to stay healthy. With 1 in 3 Medicare beneficiaries living with diabetes, and over three million of them relying on insulin, this is a critical step to help older adults stay healthy.’” [ADA, [4/1/20](#)]

**2020: ADA supported the Affordable Insulin for the COVID-19 Emergency Act by Maxine Waters.**

“The American Diabetes Association (ADA) announced its strong support today for the Affordable Insulin for the COVID-19 Emergency Act, introduced by Representative Maxine Waters (D-CA-43). The ADA called on all Members of Congress to join the measure’s 25 original co-sponsors. The bill ensures that insulin-dependent Medicare beneficiaries are able to obtain their prescriptions for insulin and associated medical supplies with no copayments, coinsurance, deductibles or other cost-sharing for the duration of the COVID-19 emergency. The bill will also ensure that Medicare beneficiaries are able to obtain a 90-day supply of insulin by mail without the additional risk of going to a pharmacy.” [ADA, [5/28/20](#)]

## AMERICAN HEART ASSOCIATION (AHA)

Website: <https://www.heart.org/>

Documents: [Policy on Corporate Relationships](#)  
[Ethics Policy](#)  
[Conflict of Interest Policy](#)

### Financials

#### AMERICAN HEART ASSOCIATION PROVIDED ONLY SELECTIVE DISCLOSURE ABOUT CORPORATE CONTRIBUTIONS

**AHA only disclosed select corporate donors, including Alexion Pharmaceuticals, MyoKardia, and Amgen, which collectively gave AHA at least \$11.1 million, though it's unclear when those pledges were made.**

"Alexion Pharmaceuticals: With the support of a three-year, \$4 million commitment by Alexion Pharmaceuticals, the American Heart Association is expanding its Get With The Guidelines® – Stroke quality improvement program to enhance hemorrhagic stroke care. This type of stroke – caused when a weakened blood vessel ruptures – makes up roughly 13percent of the nearly 800,000 strokes annually. While less common than strokes caused by a blockage, hemorrhagic strokes have higher mortality rates. Alexion Pharmaceuticals will provide funding for the initiative's education efforts for physicians along the stroke system of care. 'The initiative will enable health care providers to deliver the highest-quality process of care and evidence-based treatment strategies,' said Rajiv Patni, M.D., chief medical officer. MyoKardia MyoKardia is a national supporter of the American Heart Association's hypertrophic cardiomyopathy initiative. HCM is the most common form of genetic heart disease and can affect people of any age, yet it often goes undiagnosed. It's usually caused by abnormal genes that make the septum (the wall of the heart's main pumping chamber) thicken and stiffen, which can reduce the heart's blood flow. MyoKardia invested \$3.1 million in an AHA initiative to spotlight HCM among clinicians and patients to improve its early detection, diagnosis and management. At the same time, the goal is to increase the understanding of the disease, its pathophysiology, progressive nature, the residual burden on patient quality of life and the need for diagnosis and ongoing monitoring. Amgen Chairman and CEO Robert A. Bradway is a member of the AHA's CEO Roundtable. Under his leadership, Amgen committed \$3 million over three years to support Check. Change. Control. Cholesterol, which launched in 2016 to reduce the number of Americans who have heart attacks and strokes due to high cholesterol. The initiative urges medical practices, health service organizations and patients to prioritize cholesterol control through adoption of the latest treatment guidelines. In addition, Amgen donated \$1 million to support the AHA's response to the COVID-19 pandemic." [American Heart Association, accessed [1/27/21](#)]

**The American Heart Association only discloses funding amounts by broad categories.**

In a "Financial Highlights" document, the AHA only indicated how much of their revenue came from "Contributions: 26.9 percent. Net Special Events: 31.0 percent. Bequests: 10.1 percent. Other: Public Support: 1.0 percent. CPR Training Revenue: 20.5 percent. Other Revenue: 10.5 percent." [American Heart Association, Financial Highlights, accessed [11/5/20](#)]

#### 2019: AMERICAN HEART ASSOCIATION MAY HAVE RECEIVED AT LEAST \$12.6 MILLION FROM THE PHARMACEUTICAL INDUSTRY AND RELATED FOUNDATIONS, ABOUT 1.5 PERCENT OF ITS TOTAL REVENUE.

**AHA only disclosed select corporate donors, including Alexion Pharmaceuticals, MyoKardia, and Amgen, which collectively gave AHA at least \$11.1 million, although it's unclear when those pledges were made.**

“Alexion Pharmaceuticals: With the support of a three-year, \$4 million commitment by Alexion Pharmaceuticals, the American Heart Association is expanding its Get With The Guidelines® – Stroke quality improvement program to enhance hemorrhagic stroke care. [...] MyoKardia invested \$3.1 million in an AHA initiative to spotlight HCM among clinicians and patients to improve its early detection, diagnosis and management. [...] Amgen Chairman and CEO Robert A. Bradway is a member of the AHA’s CEO Roundtable. Under his leadership, Amgen committed \$3 million over three years to support Check. Change. Control. Cholesterol, which launched in 2016 to reduce the number of Americans who have heart attacks and strokes due to high cholesterol. The initiative urges medical practices, health service organizations and patients to prioritize cholesterol control through adoption of the latest treatment guidelines. In addition, Amgen donated \$1 million to support the AHA’s response to the COVID-19 pandemic.” [American Heart Association, accessed [1/27/21](#)]

**2019: AHA had total revenues of \$795 million.**

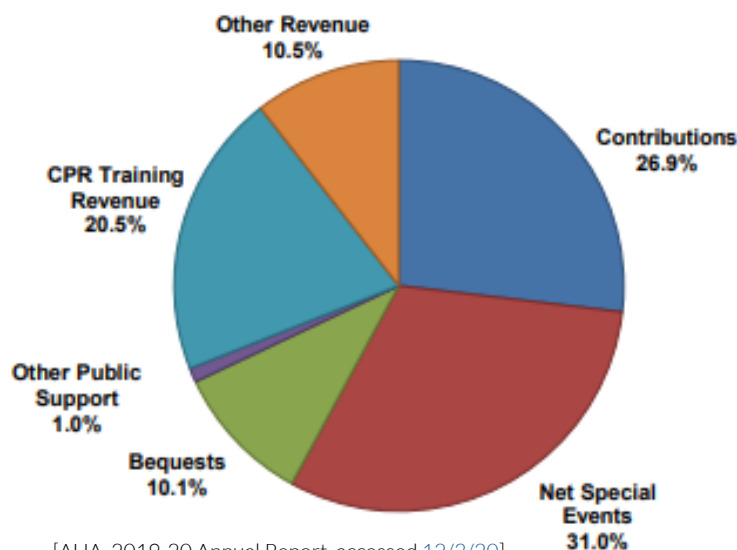
[American Heart Association, Financial Highlights, accessed [11/5/20](#)]

**ADDITIONAL FINANCIAL INFORMATION**

**2019: The American Heart Association had more than \$795 million in revenue.**

[American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]

- **2019: 26.9 percent (\$213 million) of the American Heart Association’s revenue came from “Contributions.”** [American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]
- **2019: 31.0 percent (\$246 million) of the American Heart Association’s revenue came from “Net Special Events.”** [American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]
- **2019: 10.1 percent (\$80 million) of the American Heart Association’s revenue came from “Bequests.”** [American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]
- **2019: 1.0 percent (\$7.9 million) of the American Heart Association’s revenue came from “Other Public Support.”** [American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]
- **2019: 20.5 percent (\$162 million) of the American Heart Association’s revenue came from “CPR Training Revenue.”** [American Heart Association, 2019-20 Annual Report, accessed [12/3/20](#)]
- **2019: 10.5 percent (\$83 million) of the American Heart Association’s revenue came from “Other Revenue.”** [AHA, 2019-20 Annual Report, accessed [12/3/20](#)]



**2019-2020: The AHA’s \$85 million “One Brave Idea” program received “significant support from AstraZeneca and pillar support from Quest.”**

“One Brave Idea, our \$85 million quest co-founded by AHA and Verily with significant support from AstraZeneca and pillar support from Quest, has worked to use nimble and novel scientific approaches to prevent or reverse coronary heart disease and its consequences. Three core projects have focused on deep phenotyping through wet and digital approaches, data science, machine learning and software engineering. The team has created an interactive educational platform to engage scientists, entrepreneurs and clinicians from across the country to advance innovation in health care. OBI2, our next generation enterprise, will pioneer scientific breakthroughs and revolutionize how discoveries get to the bedside.” [AHA, 2019-20 Annual Report Annual Report, accessed [12/3/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
NANCY BROWN	CEO	\$3,408,415.00	\$66,020.00	\$3,474,435.00
LARRY CANNON	CAO/CORP SEC	\$520,033.00	\$7,743.00	\$527,776.00
CYNTHIA ROBERTS	CFO	\$363,749.00	\$55,944.00	\$419,693.00
LESLIE UPTON	COO	\$731,770.00	\$74,781.00	\$806,551.00
ROSE MARIE ROBERTSON	CHF SC/MED	\$719,805.00	\$49,498.00	\$769,303.00
JOHN J MEINERS	CHIEF - MISS	\$457,585.00	\$52,695.00	\$510,280.00
DAVID MARKIEWICZ	EVP SOUTHEAST	\$438,825.00	\$68,167.00	\$506,992.00
MIDGE EPSTEIN	EVP SOUTHWEST	\$523,861.00	\$58,727.00	\$582,588.00
KATHLEEN ROGERS	EVP WESTERN	\$546,982.00	\$80,551.00	\$627,533.00
KEVIN HARKER	EVP MIDWEST	\$416,570.00	\$74,340.00	\$490,910.00
MEIGHAN VAFA	CHIEF MKTG/P	\$513,417.00	\$78,327.00	\$591,744.00
LYNNE DARROUZET	CORP SEC THR	\$278,319.00	\$56,013.00	\$334,332.00
JEREMY BEAUCHAMP	EVP MIDATLAN	\$354,622.00	\$64,569.00	\$419,191.00
NICOLE SAPIO	EVP GREAT RI	\$352,686.00	\$62,797.00	\$415,483.00

[American Heart Association, IRS Form 990, 3/6/20]



## AHA DIRECTOR, DR. CHERYL PEGUS, PREVIOUSLY WORKED FOR PFIZER.

Dr. Cheryl Pegus is on the American Heart Association board of directors.

[American Heart Association, accessed [1/25/21](#)]

- **1996-2001: Pegus previously worked for pharmaceutical giant, Pfizer.**

“Medical Director, Cardiovascular Risk Factor Group, Company Name Pfizer, Dates Employed 1996 – 2001, Employment Duration 5 yrs. Developed clinical research protocols and CMEs for product categories in cardiovascular and diabetes for a Fortune 100 pharmaceutical company. Recruited Principal Investigators, delivered FDA presentations and developed early disease management programs.”

[Cheryl Pegus LinkedIn profile, accessed [1/25/21](#)]

## MITCHELL S. ELKIND, AHA BOARD OF DIRECTORS PRESIDENT

2020: Mitchell S Elkind served as the president of the AHA's board of directors.

[AHA, accessed [12/16/20](#)]

2013-2019: Mitchell Elkind received 140 payments totaling \$270,258.43 from drug makers and medical device manufacturers in associated research funding, research payments, and general payments.

[OpenPayments.CMS.gov, accessed [2/18/21](#)]

## LEE SCHWAMM, AHA BOARD OF DIRECTORS MEMBER

2020: Lee Schwamm is a member of AHA's Board of Directors. [AHA, accessed [12/16/20](#)]

2013-2019: Schwamm received 108 payments totaling \$584,390.35 from drug makers and medical device manufacturers in associated research funding, research payments, and general payments.

[OpenPayments.CMS.gov, accessed [2/18/21](#)]

## REGINA M. BENJAMIN, AHA BOARD OF DIRECTOR'S MEMBER

2020: Regina M. Benjamin a member of AHA's Board of Directors. [AHA, accessed [12/16/20](#)]

2014-2019: Benjamin received 63 payments totaling \$225,345.02 in general payments from drug makers and medical device manufacturers. [OpenPayments.CMS.gov, accessed [2/18/21](#)]

## JOSEPH LOSCALZO, AHA BOARD OF DIRECTOR'S MEMBER

2020: Joseph Loscalzo a member of AHA's Board of Directors. [AHA, accessed [12/16/20](#)]

2014-2018: Dr. Loscalzo received 50 payments totaling \$ 697,543.53 in associated research funding and general payments from drug makers and medical device manufacturers.

[OpenPayments.CMS.gov, accessed [2/18/21](#)]

## Lobbying Activities

### THE AMERICAN HEART ASSOCIATION EMPLOYS A LOBBYING FIRM THAT ALSO REPRESENTS THE PHARMACEUTICAL INDUSTRY

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
American Heart Association	Capitol Hill Consulting Group	Association for Accessible Medicines; Coherus Bioscience; Purdue Pharma; Teva Pharmaceuticals
	Rubin Health Policy Consulting	No pharmaceutical clients
	UNCORKED ADVOCATES	No pharmaceutical clients

## 2020: THE AMERICAN HEART ASSOCIATION EMPLOYED 3 PROFESSIONAL LOBBYING FIRMS FOR FEDERAL LOBBYING

Q1-Q3 2020: According to federal lobbying disclosure records, AHA spent at least \$108,000 on lobbying firms Rubin Health Policy Consulting, Uncorked Advocated and Capitol Hill Consulting Group (CHCG).

[U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]

Q1-Q3 2020: CHCG lobbied on behalf of pharmaceutical and related companies Allied Bioscience, Association for Accessible Medicines, Coherus Biosciences, Purdue Pharma, and Teva Pharmaceuticals.

[U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]

- Q1-Q3 2020: Emily Wilkinson was a registered lobbyist for pharmaceutical and related companies that included the Association for Accessible Medicines, Coherus Biosciences, Purdue Pharma, and Teva Pharmaceuticals, in addition to lobbying for AHA. [U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]
- Q1-Q3 2020: Thomas Wharton was a registered lobbyist for pharmaceutical and related companies that included the Association for Accessible Medicines, Coherus Biosciences, Purdue Pharma, and Teva Pharmaceuticals, in addition to lobbying for AHA. [U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]
- Q1-Q3 2020: Brian Sutter lobbied on behalf of pharmaceutical and related companies that included the Association for Accessible Medicines, Coherus Biosciences, Purdue Pharma, and Teva Pharmaceuticals, in addition to lobbying for AHA. [U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]

## ADDITIONAL LOBBYING INFORMATION

1998-2019: The American Heart Association spent \$19,075,048 on federal lobbying.

[Center for Responsive Politics, accessed [12/3/20](#)]

- 2018: The American Heart Association spent \$413,196 on “media advertisements.” [American Heart Association, IRS Form 990, [3/11/20](#)]
- 2018: The American Heart Association spent \$119,413 on “mailings to members legislators or the public.” [American Heart Association, IRS Form 990, [3/11/20](#)]
- 2018: The American Heart Association spent \$149,587 on “publications, or published or broadcast statements.” [American Heart Association, IRS Form 990, [3/11/20](#)]
- 2018: The American Heart Association spent \$3,834,459 on “grants to other organizations for lobbying purposes.” [American Heart Association, IRS Form 990, [3/11/20](#)]
- 2018: The American Heart Association spent \$332,045 on “direct contact with legislators, their staffs, government officials, or a legislative body.” [American Heart Association, IRS Form 990, [3/11/20](#)]
- 2018: The American Heart Association spent \$128,744 on “rallies, demonstrations, seminars conventions, speeches, lectures or any similar means.” [American Heart Association, IRS Form 990, [3/11/20](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMING LOWER DRUG COSTS NOW ACT

*No relevant information*

### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information*

### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information*

## AMERICAN LUNG ASSOCIATION (ALA)

Website: <https://www.lung.org/>

Documents: [Ethics Policy](#)  
[Donor Bill of Rights](#)

### Financials

#### **THE AMERICAN LUNG ASSOCIATION DISCLOSED A LIST OF CORPORATE AND FOUNDATION SUPPORTERS, BUT DIDN'T INDICATE HOW MUCH EACH HAD DONATED.**

**2019: The American Lung Association disclosed a list of corporate and foundation supporters, including pharmaceutical companies, but didn't disclose how much those companies gave.**

"The American Lung Association gratefully acknowledges the businesses and foundations that have supported our lifesaving mission through their financial support in fiscal year 2019. Their support not only helps fuel our mission, but also demonstrates their trust in the American Lung Association to make a real difference in the health of Americans. [...] Bristol-Myers Squibb Foundation [...] Sanofi Pasteur [...] Merck, Pfizer, [...] AstraZeneca, Bristol-Myers Squibb [...] GSK [...] Mallinckrodt Pharmaceuticals, Mylan, PhRMA [...] Sanofi Genzyme Regeneron." [American Lung Association, FY19 Annual Report, accessed [1/27/21](#)]

**2019: ALA disclosed their "Health Industry Council", members of which were all pharmaceutical companies.**

"Health Industry Council Fellow champions of lung health, American Lung Association Health Industry Council members gain meaningful and relevant information on policy, research and patient education and support efforts at twice yearly meetings that also serve as exclusive networking opportunities among corporate leaders. AstraZeneca, Boehringer Ingelheim, Bristol-Myers Squibb, GSK, Mallinckrodt Pharmaceuticals, Merck, Mylan, Sanofi Genzyme Regeneron, Sunovion." [American Lung Association, FY19 Annual Report, accessed [1/27/21](#)]

#### **2019: THE AMERICAN LUNG ASSOCIATION RECEIVED MORE THAN \$18 MILLION IN CORPORATE AND FOUNDATION SUPPORT – ABOUT 14.4 PERCENT OF TOTAL REVENUE – THOUGH IT IS UNKNOWN HOW MUCH CAME FROM THE PHARMACEUTICAL INDUSTRY.**

**2019: The American Lung Association disclosed total dollars received from "corporate support" and "foundation support" but didn't disclose how much each donor gave.**

According to their audited financial statements for the year that ended June 30, 2019, ALA received \$13,977,277 in "Corporate support." ALA also received a total of \$5,024,126 in "Foundation support." [American Lung Association, FINANCIAL STATEMENTS AND INDEPENDENT AUDITOR'S REPORT, [11/25/19](#)]

**2019: ALA's total revenue was more than \$125 million.**

[American Lung Association, FINANCIAL STATEMENTS AND INDEPENDENT AUDITOR'S REPORT, [11/25/19](#)]

### **ADDITIONAL FINANCIAL INFORMATION**

**FY 2019: The ALA had \$125,262,032 in total revenue.**

[ALA, 2019 Statements, accessed [12/4/20](#)]

- **FY 2019: \$75.1 million of ALA's revenue came from "public support."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
  - **FY 2019: \$16.4 million of the ALA's revenue came from "direct mail."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
  - **FY 2019: \$7.5 million of the ALA's revenue came from "contributions."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]

- **FY 2019: \$19.1 million of the ALA's revenue came from "contributed media services and materials."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$16.7 million of the ALA's revenue came from "bequests and trust income."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$18.9 million of the ALA's revenue came from "special events."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$50.1 million of the ALA's revenue came from "other revenue."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$13.9 million of the ALA's revenue came from "corporate support."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$5 million of the ALA's revenue came from "foundation support."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$24.1 million of the ALA's revenue came from "government grants."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$3.3 million of the ALA's revenue came from "interest and dividends."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$408,500 of the ALA's revenue came from "research co-funding."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$2.2 million of the ALA's revenue came from "program service fees."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]
- **FY 2019: \$968,626 of the ALA's revenue came from "other."**  
[ALA, 2019 Statements, accessed [12/4/20](#)]

**2019: The American Lung Association disclosed a list of corporate and foundation supporters, including pharmaceutical companies, but didn't disclose how much those companies gave.**

"The American Lung Association gratefully acknowledges the businesses and foundations that have supported our lifesaving mission through their financial support in fiscal year 2019. Their support not only helps fuel our mission, but also demonstrates their trust in the American Lung Association to make a real difference in the health of Americans. [...] Bristol-Myers Squibb Foundation [...] Sanofi Pasteur [...] Merck, Pfizer, [...] AstraZeneca, Bristol-Myers Squibb [...] GSK [...] Mallinckrodt Pharmaceuticals, Mylan, PhRMA [...] Sanofi Genzyme Regeneron." [American Lung Association, FY19 Annual Report, accessed [1/27/21](#)]

- **2020: CVS Health, Bristol-Myers Squibb Foundation, Sanofi Pasteur, Merck, Pfizer, Amgen, AstraZeneca, GlaxoSmithKline, Intuitive, Mallinckrodt Pharmaceuticals, Mylan, PhRMA, Sanofi Genzyme Regeneron, and Tesoro were listed as ALA supporters.** [ALA, accessed [12/4/20](#)]

**2019: ALA disclosed their "Health Industry Council" that was totally comprised of pharmaceutical companies.**

"Health Industry Council Fellow champions of lung health, American Lung Association Health Industry Council members gain meaningful and relevant information on policy, research and patient education and support efforts at twice yearly meetings that also serve as exclusive networking opportunities among corporate leaders. AstraZeneca, Boehringer Ingelheim, Bristol-Myers Squibb, GSK, Mallinckrodt Pharmaceuticals, Merck, Mylan, Sanofi Genzyme Regeneron, Sunovion." [American Lung Association, FY19 Annual Report, accessed [1/27/21](#)]

- **The Health Industry Council members "gain meaningful and relevant information on policy, research and patient education and support efforts at twice yearly meetings that also serve as exclusive networking opportunities among corporate leaders."**

"Fellow champions of lung health, American Lung Association Health Industry Council members gain meaningful and relevant information on policy, research and patient education and support efforts at twice yearly meetings that also serve as exclusive networking opportunities among corporate leaders."

[ALA, FY 2019 Annual Report, accessed [12/4/20](#)]

- **2020: AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Genentech, GlaxoSmithKline, Mallinckrodt, Merck, Mylan, Novartis, Pfizer Oncology, Sanofi Genzyme Regeneron, and Sunovion were listed as members of ALA's "Health Industry Council."** [ALA, accessed [12/4/20](#)]

**Apr. 2019: ALA awards CVS Health its first "Outstanding Corporate Partner Award"**

"In April 2019, the American Lung Association presented CVS Health with our first Outstanding Corporate Partner Award recognizing them for five years of support as our LUNG FORCE National Presenting Sponsor. Generous funding from CVS Health has helped to expand research, offer cessation services, increase awareness and support lung cancer patients and their families — all in an effort to defeat lung cancer. CVS Health began partnering with the Lung Association when they made the bold decision to remove tobacco from CVS Pharmacy shelves. Together, we are working toward the first tobacco-free generation. The CVS Pharmacy in-store fundraising campaign encouraged customers to join us in making this goal a reality. CVS Health is one of many generous LUNG FORCE partners who have joined us to make a positive impact for people with lung cancer." [ALA, FY 2019 Annual Report, accessed [12/4/20](#)]

**ALA touted the commercial benefits of its "Proud Partner" program to "create consumer preference" and "increase brand recognition and strength positioning."**

"By using the Create Consumer Preference Through our Proud Partner program, cause marketing, and other corporate sponsorships, the American Lung Association's logo can help increase consumer preference over other competing brands. According to the 2015 Cone Communications/Ubiquity Global CSR Study, 90 percent of global consumers would switch brands to one that is associated with a good cause, given similar price or quality. By aligning with our trusted and respected national organization, your product or service will stand out from the pack and can help increase consumer preference toward your organization and drive purchase behavior. Increase Brand Recognition & Strengthen Positioning: Your partnership with a highly-regarded non-profit organization that advocates for the millions of Americans living with a lung disease — and the millions more who love them — can help open avenues with new customers and increase reach. Your brand will also be seen as a change leader in health education, research, and advocacy, which will set your company apart as a positive corporate citizen within your stakeholder group." [ALA, accessed [12/4/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
HAROLD WIMMER	PRESIDENT & CEO	\$500,373.00	\$54,339.00	\$554,712.00
LAURA SCOTT	CHIEF FINANCIAL OFFICER	\$254,351.00	\$19,552.00	\$273,903.00
SUE SWAN	CHIEF DEVELOPMENT OFFICER	\$221,660.00	\$27,327.00	\$248,987.00
DEBORAH BROWN	CHIEF MISSION OFFICER	\$226,023.00	\$25,615.00	\$251,638.00
LEWIS BARTFIELD	CHIEF DIVISION OFFICER, WEST	\$272,086.00	\$21,273.00	\$293,359.00
JEFF SEYLER	CHIEF DIVISION OFFICER, EAST	\$247,350.00	\$34,318.00	\$281,668.00
JULIA FITZGERALD	CMO (BEGINNING DEC 2018)	\$10,000.00	\$41.00	\$10,041.00
PAUL BILLINGS	SVP, ADVOCACY	\$204,641.00	\$22,283.00	\$226,924.00
SUSAN RAPPAPORT	VP, RESEARCH & SCIENTIFIC AFFAIRS	\$192,955.00	\$30,788.00	\$223,743.00
MARTHA BOGDAN	EXE VP, SOUTHEAST REGION	\$238,414.00	\$44,394.00	\$282,808.00
BARRY GOTTSCHALK	EXE VP, MIDLAND STATES REGION	\$205,177.00	\$43,657.00	\$248,834.00
ALLISON HICKEY	EXE VP, MOUNTAIN PACIFIC	\$193,390.00	\$19,105.00	\$212,495.00
WILLIAM PFEIFER	VP, GOVERNANCE	\$236,695.00	\$56,269.00	\$292,964.00
SALLY DRAPER	VP, DEVELOPMENT	\$190,430.00	\$23,806.00	\$214,236.00
EMILY MURPHY	DIVISION SENIOR VP, DEV	\$160,993.00	\$20,346.00	\$181,339.00
NEIL BALLENTINE	VP, DIGITAL STRATEGY/INFO TECH	\$148,820.00	\$21,890.00	\$170,710.00
CRAIG FINSTAD	AVP, DIRECT RESPONSE OPS	\$145,666.00	\$16,378.00	\$162,044.00
RITA REDAELLI	EXEC DIRECTOR, SAN DIEGO	\$145,845.00	\$7,078.00	\$152,923.00

[American Lung Association IRS Form 990, 2/13/20]

## MARK C. JOHNSON, ALA BOARD OF DIRECTORS MEMBER

### **Mark Johnson is VP of Investor Relations at ACADIA Pharmaceuticals.**

“Mark Johnson currently serves as Vice President, Investor Relations for ACADIA Pharmaceuticals Inc., a publicly traded biopharmaceutical company in San Diego focused on the development and commercialization of innovative medicines to address unmet medical needs in central nervous system disorders. In Johnson’s role, he is charged with communicating the ACADIA story to Wall Street investors, analysts and bankers. In addition, he works directly with executive management and the board of directors on strategic and corporate finance initiatives.” [ALA, accessed [12/4/20](#)]

### **Johnson previously served as a senior director of investor relations for aTyr Pharma.**

“Previously, Johnson worked as senior director of Investor Relations for aTyr Pharma, a publicly traded biopharmaceutical company focused on immune-mediated diseases, including a clinical-stage program for the treatment of interstitial lung disease.” [ALA, accessed [12/4/20](#)]

### **Johnson started his career at the biopharmaceutical company MediciNova.**

“Johnson started his career in San Diego at another biopharmaceutical company, MediciNova, which is developing new treatments for patients with multiple sclerosis, idiopathic pulmonary fibrosis and acute exacerbations from asthma and COPD.” [ALA, accessed [12/4/20](#)]

## Lobbying Activities

### THE AMERICAN LUNG ASSOCIATION EMPLOYS A LOBBYING FIRM THAT REPRESENTS THE PHARMACEUTICAL INDUSTRY

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
American Lung Association	Health and Medicine Counsel of Washington	Patient Services Inc.; Prolong Pharmaceuticals

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**Q1-Q3 2020: The ALA spent at least \$40,000 on the lobbying firm Health & Medicine Counsel of Washington.** [U.S. Senate Lobbying Disclosure Database, accessed [12/3/20](#)]

**2020: The Health and Medicine Counsel of Washington lobbied on behalf of Prolong Pharmaceuticals and Patient Services Inc.** [U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

### ADDITIONAL LOBBYING INFORMATION

**The American Lung Association spent more than \$5.3 million on federal lobbying.**

[Center for Responsive Politics, [12/4/20](#)]

**2018: The ALA spent \$213 on “mailings to members, legislators, or the public.”** [ALA, IRS Form 990, [2/24/20](#)]

**2018: The ALA spent \$1,436 on “publications, or published or broadcast statements.”**  
[ALA, IRS Form 990, [2/24/20](#)]

**2018: The ALA Spent \$21,850 on “grants to other organizations for lobbying purposes.”**  
[ALA, IRS Form 990, [2/24/20](#)]

**2018: The ALA spent \$788,327 on “direct contact with legislators, their staffs, government officials, or a legislative body.”** [ALA, IRS Form 990, [2/24/20](#)]

**2018: The ALA spent \$1,943 on “rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means.”** [ALA, IRS Form 990, [2/24/20](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

**October 2019: The American Lung Association joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including: • Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135 percent to 150 percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15 percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.”

[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information*

### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information*

## ARTHRITIS FOUNDATION

Website: <https://www.arthritis.org/>

Documents: [Code of Ethics](#)  
[Conflict of Interest Policy](#)

## Financials

### THE ARTHRITIS FOUNDATION DISCLOSED DONORS WHO GAVE AT LEAST \$10,000, AND PROVIDED RANGES OF CONTRIBUTIONS GIVEN.

**2019: The Arthritis Foundation disclosed it received over \$10,000 in contributions from corporations and individuals.** [Arthritis Foundation, 2019 Annual Report, [7/30/20](#)]

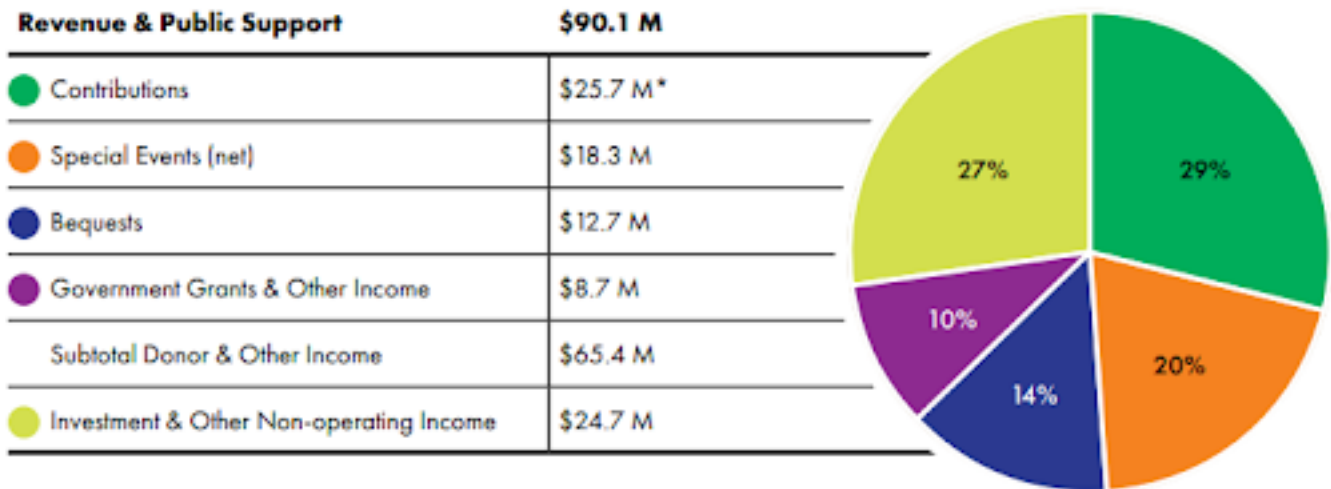
**2019: THE ARTHRITIS FOUNDATION DISCLOSED CONTRIBUTIONS FROM THE PHARMACEUTICAL INDUSTRY TOTALING BETWEEN \$11.2 MILLION AND NEARLY \$17 MILLION – OR BETWEEN 12.4 AND 18.7 PERCENT OF THEIR TOTAL REVENUE.**



2019: The Arthritis Foundation had more than \$90 million in revenue.

[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

- 2019: 29 percent (\$25.7 million) of the Arthritis Foundation’s revenue came from “Contributions.”  
[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]
- 2019: 12 percent of the Arthritis Foundation’s revenue came from “pharmaceutical, biotechnology and medical device corporate support.”  
“Includes \$10.5 M in pharmaceutical, biotechnology and medical device corporate support, representing 12 percent of total organization revenue.” [Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]



**Net Assets End-of-Year: \$155.2 M**

**Complete audited financial statements are available online at [arthritis.org/financials](https://www.arthritis.org/financials).**

\*Includes \$10.5 M in pharmaceutical, biotechnology and medical device corporate support, representing 12% of total organization revenue.

[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

2019: The Arthritis Foundation disclosed at least 25 contributions from the pharmaceutical industry totaling between \$11.2 million and \$16.9 million.

Donor	Minimum Contribution	Maximum Contribution
AbbVie	\$2,000,000.00	>\$2,000,000.00
Amgen	\$2,000,000.00	>\$2,000,000.00
Sanofi Genzyme Regeneron	\$1,500,000.00	\$1,999,999.00
Novartis	\$1,000,000.00	\$1,499,999.00
Pfizer	\$1,000,000.00	\$1,499,999.00
Bristol Myers Squibb	\$500,000.00	\$999,999.00
Eli Lilly & Company	\$500,000.00	\$999,999.00
GlaxoSmithKline	\$500,000.00	\$999,999.00
Janssen, a Johnson & Johnson Company	\$500,000.00	\$999,999.00
Celgene	\$250,000.00	\$499,999.00
Flexion Therapeutics	\$250,000.00	\$499,999.00
Genentech	\$250,000.00	\$499,999.00
Move Free	\$250,000.00	\$499,999.00
Bayer Health Care LLC	\$100,000.00	\$249,999.00
Horizon Therapeutic	\$100,000.00	\$249,999.00
Mallinckrodt LLC	\$100,000.00	\$249,999.00
Sandoz Inc.	\$100,000.00	\$249,999.00
Vizuri Health Sciences	\$100,000.00	\$249,999.00
AbbVie Foundation	\$100,000.00	\$499,999.00
Bioventus LLC	\$25,000.00	\$49,999.00
Coherus Biosciences Inc.	\$25,000.00	\$49,999.00
Gilead Sciences Inc.	\$25,000.00	\$49,999.00
Immunex Rhode Island Corp.	\$10,000.00	\$24,999.00
Medexus Pharma	\$10,000.00	\$24,999.00
PhRMA	\$10,000.00	\$24,999.00
<b>Totals</b>	<b>\$11,205,000.00</b>	<b>&gt;\$16,974,977.00</b>

[Arthritis Foundation, 2019 Annual Report, [7/30/20](#)]

2019: The Arthritis Foundation had total revenue of \$90.1 million.

[Arthritis Foundation, 2019 Annual Report, [7/30/20](#)]

### ADDITIONAL FINANCIAL INFORMATION

2019: The Arthritis Foundation had more than \$90 million in revenue.

[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

- 2019: 27 percent (\$24.7 million) of the Arthritis Foundation’s revenue came from “Investment & Other Non-operating Income.” [Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]
- 2019: 20 percent (\$18.3 million) of the Arthritis Foundation’s revenue came from “Special Events (net).” [Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]
- 2019: 14 percent (\$12.7 million) of the Arthritis Foundation’s revenue came from “Bequests.” [Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]
- 2019: 10 percent (\$8.7 million) of the Arthritis Foundation’s revenue came from “Government Grants & Other Income.” [Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

The Arthritis Foundation offered a “special thank you” to AbbVie, Genentech, Lilly, Vizuri Pain Bloc, Sanofi Genzyme, and Regeneron for their support of the organization’s “Live Yes!” programs:

A special **thank you** to our partners who supported **Live Yes! RA** educational events or who powered the Live Yes! Arthritis Network, which offers connections 24/7 for everyone impacted by arthritis. Join [arthritis.org/LiveYes](https://arthritis.org/LiveYes).



[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

The Arthritis Foundation thanked AbbVie, Bristol Myers Squibb, CVS, Genentech, and Novartis for sponsoring the organization’s “JA” programs.

Our partners who supported youth and families battling juvenile arthritis are life-changers. **Thank you** for sponsoring the **JA Conference**, **JA camps** and many more JA initiatives.



[Arthritis Foundation, 2019 Annual Report, accessed [12/5/20](#)]

## THE ARTHRITIS FOUNDATION PROVIDES FOR SEVERAL LEVELS OF CONTRIBUTIONS TO THE ORGANIZATION

**2019: An Arthritis Foundation “trailblazer” contributed between \$2 million to \$2.7 million to the organization.**

“Trailblazers are dedicated to the movement and ready to help us make the discovery that changes it all. Together, we will break ground on the next big thing that makes the difference in the lives of those who have arthritis. By contributing \$2,000,000 to \$2,749,999, you put us in the forefront of the fight against arthritis.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: AbbVie was listed as an Arthritis Foundation Trailblazer and has “contributed more than 10 years and \$10 million to support the Arthritis community.”**

“AbbVie has dedicated more than 10 years and \$10 million to support the arthritis community. AbbVie has demonstrated their aim of making an impact on people’s lives by partnering with us through our juvenile arthritis programs, Live Yes! Connect Groups and local community events, along with the CARRA Annual Scientific Meeting. To date, AbbVie has dedicated more than \$10 million to support the arthritis community so people can live the best life possible.” [Arthritis Foundation, accessed [12/5/20](#)]

**2019: An Arthritis Foundation “visionary” contributed between \$1.5 and nearly \$2 million to the organization.**

“Visionaries use their imagination and see the path to a future without arthritis. They partner with the Arthritis Foundation on original ideas for innovation that help further the fight against arthritis. By contributing \$1,500,000 to \$1,999,999, you are an inspiration.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Sanofi Genzyme and Regeneron were jointly listed as an Arthritis Foundation visionary.**

“Sanofi Genzyme and Regeneron companies joined forces to support the Arthritis Foundation and arthritis community in significant ways. In addition to being a national sponsor for both the annual Walk to Cure Arthritis and Jingle Bell Run events, they’re sponsoring the Foundation’s work to enhance patient engagement through the Live Yes! INSIGHTS program and Patients First: Expanding the Circle of Care programs. The Sanofi Genzyme/Regeneron alliance also supports by helping bring the patient voice to critical meetings, including the annual American College of Rheumatology (ACR) conference and Advocacy Summit.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Pfizer was listed as an Arthritis Foundation visionary.**

“A partner of the Arthritis Foundation for almost a decade, Pfizer supports our Advocacy pillar through our ‘State of Your Health’ initiative, annual Patient Summit event, and local community events.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Eli Lilly was listed as an Arthritis Foundation visionary.**

“Eli Lilly and Company unites caring with discovery to make life better for people around the world. As a partner of the Arthritis Foundation since 2012, Lilly continues to support several of our programs. Together with Lilly, we are focused on innovative and affordable treatments for people impacted by arthritis. To learn more about Lilly and its work in the field of immunology, please visit their website.”

[Arthritis Foundation, accessed [12/5/20](#)]

**2019: An Arthritis Foundation “pioneer” contributed between \$1 million and nearly \$1.5 million.**

“Pioneers are not afraid to enter new territory in the search for a cure for arthritis. They partner with the Arthritis Foundation to offer new programs, connect people to each other and search for new treatments. By contributing \$1,000,000 to \$1,499,999, you are showing others the way.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Amgen was listed as an Arthritis Foundation pioneer.**

“Amgen’s partnership with the Arthritis Foundation has spanned more than 13 years, during which they have been the National Presenting Sponsor of Walk to Cure Arthritis along with supporting additional educational programs around the juvenile arthritis community and the CARRA Annual Scientific Meeting. Amgen has invested several millions to support programs that impact the lives of people living.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Novartis was listed as an Arthritis Foundation pioneer.**

“In our collaborative partnership, Novartis supports the Arthritis Foundation’s National Juvenile Arthritis (JA) Conference, the CARRA Annual Scientific Meeting, the Live Yes! Conference of Champions and the State of Your Health program.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Arthritis Foundation “Pacesetters” contributed between \$500,000 and nearly \$1 million to the organization.**

“Pacesetters chart the course for all that follows, leading the way for discovery of new treatments and resources for people with arthritis. With their contribution of \$500,000 to \$999,000, the Arthritis Foundation is able to set the standard.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: CVS Health was listed as an Arthritis foundation pacesetter.**

- “CVS Health is sharing their commitment to those living with arthritis by serving as the National Presenting Sponsor of Let’s Get a Grip on Arthritis consumer cause campaign. CVS Health first joined forces with the Arthritis Foundation in 2014 and has since deepened their commitment by leading that inaugural campaign. Playing an active, supportive role in each person’s unique health experience, they work collaboratively with the Foundation to bring arthritis out of the shadows.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Bristol-Myers Squibb was listed as an Arthritis foundation pacesetter.**

- “Bristol-Myers Squibb (BMS) is a proud national site sponsor for both Jingle Bell Run and Walk to Cure Arthritis, two important ways of raising both donations and awareness for the arthritis community in cities across the U.S. Additionally, dedicated employees form their own national Jingle Bell Run and Walk to Cure Arthritis teams further emphasize their commitment to the cause. BMS co-sponsors the Arthritis Foundation’s Advocacy Summit, JA Power Pack program, the National JA Conference and the Annual Scientific Meeting of the Childhood Arthritis Rheumatology and Research Alliance (CARRA). BMS is also an inaugural supporter of the Foundation’s Live Yes! Arthritis Network.” [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Voltaren Arthritis Pain Gel was listed as an Arthritis foundation pacesetter.**

“Voltaren Arthritis Pain Gel is the first full prescription-strength, over-the-counter nonsteroidal anti-inflammatory gel that targets pain at the source to deliver arthritis pain relief. The approval of Voltaren Arthritis Pain Gel as an over-the-counter (OTC) option provides greater access to an effective topical for the temporary relief of osteoarthritis-related pain in the hand, wrist, elbow, foot, ankle or knee. Voltaren is proud to partner with the Arthritis Foundation in their efforts to champion the fight against arthritis.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: An Arthritis Foundation “signature partners” contributed between \$250,000 and \$499,999 to the organization.**

“Signature partners distinguish themselves by working with us to develop unique programming and resources. With their contributions of \$250,000 to \$499,999, they ensure that we put the patient at the forefront.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: UCB was listed as an Arthritis Foundation signature partner.**

“UCB provided funding for the Arthritis Foundation to develop Family Planning and Pregnancy program, which has given us the opportunity to develop new tools and resources for women of child-bearing age.”

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Janssen was listed as an Arthritis Foundation signature partner.**

“Janssen, a Johnson & Johnson Company, has been a long-standing sponsor of Walk to Cure Arthritis and

Jingle Bell Run events. Their teams are always ready to engage at the community level and advance the patient voice and awareness for the arthritis community. Janssen also supports the Arthritis Foundation's State of Your Health, Patients First: Expanding the Circle of Care, and Live Yes! Insights program." [Arthritis Foundation, accessed [12/5/20](#)]

**2019: An Arthritis Foundation "supporting partner" contributed between \$100,000 and \$249,999 to the organization.**

"Our Supporting partners display the spirit of true champions. They provide resources that support our core mission pillars of research, advocacy and community-based programs and services. They contribute \$100,000 to \$249,999 to make a difference for people with arthritis."

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: PainBloc24 was listed as an Arthritis Foundation supporting partner.**

"PainBloc24, a product developed by Vizuri Health Sciences, joined the Arthritis Foundation in the fight against arthritis in 2018. As a Supporting Partner of the Live Yes! Arthritis Network campaign, PainBloc24 is joining other consumer brands to bring arthritis out of the shadows and impact real change." [Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Mallinckrodt was listed as an Arthritis Foundation supporting partner.**

"Mallinckrodt supports the Arthritis Foundation's Advocacy Platform as we work to fight for and amplify the voice of the patient and their needs at the state and national levels. They also support the annual Live Yes! Conference of Champions meeting where we gather patient families, champions and other stakeholders to celebrate the strides we've made together while looking towards a new year of impact for the Arthritis Foundation and the community we serve."

[Arthritis Foundation, accessed [12/5/20](#)]

- **2019: Boehringer Ingelheim was listed as an Arthritis Foundation supporting partner.**

"In 2018, Boehringer Ingelheim became a Proud Partner and Ease of Use Sponsor. BI's exclusive Ease of Use Commendation for their Respimat COPD Inhaler/Cartridge raises the bar in treatment options. They provide generous help and support to further the Arthritis Foundation's mission."

[Arthritis Foundation, accessed [12/5/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
ANN PALMER	PRESIDENT/CEO	\$641,867.00	\$54,372.00	\$696,239.00
DAVID MCLOUGHLIN	COO/ASST SEC/ASST TREA	\$377,568.00	\$38,570.00	\$416,138.00
ANN MCNAMARA	SR. VP, REVENUE STRATEGY	\$262,220.00	\$11,758.00	\$273,978.00
JANE BASCLE	CHIEF FINANCIAL OFF/ASST TREA	\$238,179.00	\$31,831.00	\$270,010.00
RICHARD WILLIS	SR. VP, FIELD MANAGEMENT	\$237,267.00	\$31,028.00	\$268,295.00
GUY EAKIN	SR. VICE PRESIDENT, SCIENCE	\$240,600.00	\$20,298.00	\$260,898.00
CINDY MCDANIEL	SR. VP, CONSUMER AFFAIRS	\$214,516.00	\$35,009.00	\$249,525.00
ANDY GAMMUTO	CHIEF INFORMATION OFFICER	\$219,512.00	\$24,941.00	\$244,453.00
MARTINE DENIS-DIOULU	REGION VICE PRESIDENT	\$194,814.00	\$17,626.00	\$212,440.00
MELISSA HONABACH	SR. VP, MARKETING & COMM	\$189,429.00	\$22,642.00	\$212,071.00
NANCY STINSON HARRIS	REGION VICE PRESIDENT	\$194,385.00	\$17,318.00	\$211,703.00
CATHY HOOD	VP, HUMAN RESOURCES	\$185,715.00	\$23,590.00	\$209,305.00

[Arthritis Foundation, IRS Form 990, [10/16/20](#)]

### TONY BIHL, ARTHRITIS FOUNDATION BOARD OF DIRECTORS TREASURER

**2020: Tony Bihl served as a treasurer for the Arthritis Foundation's board of directors.**

[Arthritis Foundation, accessed [12/5/20](#)]

**2020: Bihl joined the board of Meridian Bioscience.**

"Meridian Bioscience, Inc. (NASDAQ: VIVO) announces the appointment of Anthony Bihl III to its Board of Directors, effective immediately. 'We welcome Tony to the board as a new independent director and look forward to the leadership he will bring,' said David Phillips, Chairman of Meridian Bioscience. 'We were looking to add diagnostics expertise to the board and Tony additionally brings the breadth of leading both large and small public organizations.'" [Meridian Bioscience, Press Release, [7/28/20](#)]

**2008- 2020: Bihl served on the Spectral Medical board of directors and is currently serving as chairman of the board.**

"Mr. Bihl has served on the Board since March 2008. He is an experienced executive with more than 30 years in leadership of global healthcare businesses, including a broad base of operational, financial, and senior executive positions. Mr. Bihl is currently the CEO of Bioventus LLC, a global provider of ortho biologic products, and has held this role since December 2013. He served on the Board of Directors of Greatbatch Inc., now Integer, from 2011 to December 2015, and joined the board of Nuvectra Inc., in February 2016, where he now serves as Chairman of the Board, and a member of the Audit Committee. He is also a member of the Board of Directors of the Arthritis Foundation." [Spectral Medical, accessed [12/5/20](#)]

### ROBIN DORE, ARTHRITIS FOUNDATION BOARD OF DIRECTORS MEMBER

2021: Robin Dore is on the Arthritis Foundation board of directors. [Arthritis Foundation, accessed [12/5/20](#)]

2013-2019: Robin Dore received 3,969 payments totaling \$2,981,622.22 in associated research funding, research payments, and general payments from drug makers and medical device manufacturers. [ProPublica, accessed [12/16/20](#)]

### MARK FROIMSON, ARTHRITIS FOUNDATION BOARD OF DIRECTORS MEMBER

2021: Mark Froimson is on the Arthritis Foundation board of directors.

[Arthritis Foundation, accessed [12/5/20](#)]

2013-2019: Fromison received 274 payments totaling \$902,039.61 in general payments from drug makers and medical device manufacturers. [OpenPayments.CMS.gov, accessed [2/18/21](#)]

### DIANA MILOJEVIC, ARTHRITIS FOUNDATION BOARD OF DIRECTORS MEMBER

2021: Diana Milojevic is on the Arthritis Foundation board of directors.

[Arthritis Foundation, accessed [12/5/20](#)]

2013-2019: Diana Milojevic received 77 payments totaling \$306,798.04 in associated research funding and general payments from drug makers and medical device manufacturers. [OpenPayments.CMS.gov, accessed [2/18/21](#)]

## Lobbying Activities

### 1999-2020: THE ARTHRITIS FOUNDATION SPENT MORE THAN \$12 MILLION ON FEDERAL LOBBYING

1999-2020: The Arthritis Foundation spent at least \$12,340,137.77 lobbying the federal government.

[U.S. Senate Lobbying Disclosure Database, accessed [2/18/21](#)]

2017-Present: The Arthritis Foundation has done all of their federal lobbying in-house, not employing an outside lobbying firm

[U.S. Senate Lobbying Disclosure Database, accessed [2/18/21](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMING LOWER DRUG COSTS NOW ACT

October 2019: The Arthritis Foundation joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including:

- Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits



through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135 percent to 150 percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15 percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.” [MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*

## **CANCER SUPPORT COMMUNITY (CSC)**

Website: <https://www.cancersupportcommunity.org/>

Documents: [Corporate Support Policy](#)

### **Financials**

#### **CANCER SUPPORT COMMUNITY DISCLOSED THE NAMES OF DONORS WHO GAVE AT LEAST \$500, AND OTHER DONORS AS WELL.**

**2019-2020: The Cancer Support Community disclosed donors who gave at least \$500 and provided ranges of contributions up to \$500,000.** [Cancer Support Community, Annual Report 2019-2020, accessed [1/27/20](#)]

#### **2019: THE ARTHRITIS FOUNDATION DISCLOSED CONTRIBUTIONS FROM THE PHARMACEUTICAL INDUSTRY TOTALING BETWEEN \$11.2 MILLION AND NEARLY \$17 MILLION – OR BETWEEN 12.4 AND 18.7 PERCENT OF THEIR TOTAL REVENUE.**

**2019-2020: The Cancer Support Community disclosed donors who gave at least \$500 and provided ranges of contributions up to \$500,000.**

[Cancer Support Community, Annual Report 2019-2020, accessed [1/27/20](#)]

#### **2019-2020: CANCER SUPPORT COMMUNITY RECEIVED AT LEAST \$4.8 MILLION AND POSSIBLY MORE THAN \$8.1 MILLION FROM PHARMACEUTICAL COMPANIES—BETWEEN 40.6 AND 68.6 PERCENT OF THEIR TOTAL REVENUE**

2019-2020: CSC disclosed at least 28 contributions from pharmaceutical companies totaling at least \$4.8 million and possibly more than \$8.1 million.

Donor	Minimum Contribution	Maximum Contribution
Amgen	\$500,000	>\$500,000
Bristol-Myers Squibb Company	\$500,000	>\$500,000
Genentech, Inc.	\$500,000	>\$500,000
Pfizer Inc.	\$500,000	>\$500,000
Athenex Inc.	\$250,000	\$499,999
Eisai Inc.	\$250,000	\$499,999
Gilead Sciences	\$250,000	\$499,999
Incyte Corporation	\$250,000	\$499,999
Merck & Co. Inc.	\$250,000	\$499,999
Novartis Pharmaceuticals Corporation	\$250,000	\$499,999
Takeda Oncology	\$250,000	\$499,999
Astellas Pharma US, Inc.	\$100,000	\$249,999
BeiGene	\$100,000	\$249,999
GlaxoSmithKline	\$100,000	\$249,999
Janssen	\$100,000	\$249,999
Jaxx Pharmaceuticals	\$100,000	\$249,999
Lilly Oncology	\$100,000	\$249,999
Pharmacyclics	\$100,000	\$249,999
Sanofi-Genzyme	\$100,000	\$249,999
AbbVie	\$50,000	\$99,999
Daiichi Sankyo	\$50,000	\$99,999
Celgene Corporation	\$50,000	\$99,999
Seattle Genetics	\$50,000	\$99,999
Taiho Oncology	\$50,000	\$99,999

AstraZeneca	\$25,000	\$49,999
Agios Pharmaceuticals, Inc.	\$10,000	\$24,999
Verastem Oncology	\$10,000	\$24,999
Vertex Pharmaceuticals Charity Trust	\$2,500	\$4,999
<b>Totals</b>	<b>\$4,847,500</b>	<b>\$8,104,976</b>

[Cancer Support Community, Annual Report 2019-2020, accessed [1/27/20](#)]

**2019-2020: CSC had total revenues of \$11.8 million.**

[Cancer Support Community, Annual Report 2019-2020, accessed [1/27/20](#)]

### ADDITIONAL FINANCIAL INFORMATION

**2019: The Cancer Support Community had more Than \$11.8 million in total revenue.**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$1 million of the Cancer Support Community’s revenue came from “development income.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$1.3 million of the Cancer Support Community’s revenue came from “Service delivery: Program”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$1.2 million of the Cancer Support Community’s revenue came from “Service delivery: Research and training.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$560,368 of the Cancer Support Community’s revenue came from “Service delivery: Events and special initiatives.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$2.2 million of the Cancer Support Community’s revenue came from “Service delivery: Education/Outreach.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$2.2 million of the Cancer Support Community’s revenue came from “Service delivery: Policy/Advocacy.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$75,019 of the Cancer Support Community’s revenue came from “Special purpose funds.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$520,310 of the Cancer Support Community’s revenue came from “Affiliate activities.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$9,443 of the Cancer Support Community’s Revenue came from “In-kind revenue.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: \$30,808 of the Cancer Support Community’s Revenue came from “Miscellaneous income.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed [12/8/20](#)]

- **2019: 220,531 of the Cancer Support Community’s revenue came from “PPS sales, net of direct costs of \$42,477.”**

[Cancer Support Community, 2019-2020 Annual Report, accessed ]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
KIM THIBOLDEAUX	CEO	\$361,452.00	\$19,687.00	\$381,139.00
LINDA BOHANNON	PRESIDENT	\$271,452.00	\$21,741.00	\$293,193.00
JEFFREY TRAVERS	COO	\$211,324.00	\$15,914.00	\$227,238.00
SALLY WERNER	ED, INSTITUTE FOR EXCELLENCE IN PSYCHOSOCIAL CARE	\$166,412.00	\$13,693.00	\$180,105.00
THEODORE MILLER	VP, DEVELOPMENT & EXTERNAL AFFAIRS	\$161,520.00	\$14,223.00	\$175,743.00
ELIZABETH FRANKLIN	ED, CANCER POLICY INSTITUTE	\$147,353.00	\$10,456.00	\$157,809.00
HILDY DILLON	SVP, PROGRAM & EDUCATION	\$144,372.00	\$21,542.00	\$165,914.00
MARCIA DONZIGER	VP, DIGITAL STRATEGY	\$133,591.00	\$14,003.00	\$147,594.00

[Cancer Support Community, IRS Form 990, [1/11/21](#)]

## LINDA BOHANNON, CSC'S CEO, PREVIOUSLY WAS IN LEADERSHIP POSITIONS AT ELI LILLY.

**Prior to joining the Cancer Support Community, Linda Bohannon was a senior director of advocacy and professional relations at drugmaker Eli Lilly.**

"Linda Bohannon has a long-standing history with the Cancer Support Community. First she served as a local, affiliate volunteer and now, serves as Chief Executive Officer of the global headquarters office. In her current role, Linda oversees all areas of CSC that directly touch the patient, including the Research and Training Institute, the Cancer Policy Institute, and the Institute for Excellence in Psychosocial Care. Linda also works closely across all aspects of CSC including strategic growth and development and marketing and communications. Linda joined CSC after many years working in the cancer care environment, including over a decade of direct patient care in the acute oncology and hospice care setting. Immediately prior to joining CSC, Linda served as Executive Director of St. Vincent Cancer Care in Indianapolis where she led a team of individuals to provide care across the full cancer continuum. Prior to that, Linda was Senior Director of Advocacy and Professional Relations for Lilly Oncology working with patient and professional organizations on programs and broad issues related to cancer care. Linda serves in a variety of advisory roles in the national cancer community and has also been an active volunteer with a number of organizations in her local community." [Cancer Support Community, accessed [2/18/21](#)]

- **Bohannon spent 12 years climbing the corporate ladder at Eli Lilly.**

"Eli Lilly and Company Total Duration: 12 yrs. Title: Multiple positions with growing accountability in and beyond oncology - please see below. Dates Employed: Aug 1998 – Jul 2010. Employment Duration: 12 yrs. Title: Senior Director, Advocacy & Professional Relations, U.S. Affiliate, Dates Employed: Jan 2008 – Jun 2010. Employment Duration: 2 yrs, 6 mos. Title: Director, Advocacy and Professional Relations, Specialty Business Units. Dates Employed: May 2006 – Jan 2008. Employment Duration: 1 yr, 9 mos. Title: Brand Manager, U.S. Lilly Oncology and Advocacy and Professional Relations. Dates Employed: Jul 2003 – May 2006. Employment Duration: 2 yrs, 11 mos. Title: Associate Manager, Lilly Oncology Dates. Employed: Jul 2000 – Jul 2003. Employment Duration: 3 yrs, 1 mo. Title: Relief Sales Specialist, GEMZAR, Manhattan Central. Dates Employed: Mar 2000 – Jul 2000. Employment Duration: 5 mos. Title: Senior Medical Information Associate. Dates Employed: Aug 1998 – Mar 2000, Employment Duration: 1 yr, 8 mos."

[Linda Bohannon LinkedIn profile, accessed [1/25/21](#)]

## CHUCK R. SCHEPER, CSC BOARD OF DIRECTORS MEMBER

**2020: Chuck Scheper was a member of CSC's board of directors.**

[CSC, accessed [12/8/20](#)]

**Scheper is the board chairman of Bexion Pharmaceuticals.**

"Chuck Scheper is the Chairman of the Board of Bexion Pharmaceuticals LLC, an emerging bio-tech company focused on the development and commercialization of innovative cures for cancer."

[CSC, accessed [12/8/20](#)]

## DON ELSEY, CSC BOARD OF DIRECTORS MEMBER

**2020: Don Elsey was a member of CSC's board of directors.**

[CSC, accessed [12/8/20](#)]

**Elsey was the CFO for Senseonics; he previously served as CFO of Regado Biosciences and LifeCell Inc. and Senior VP and CFO at Emergent BioSolutions Inc.**

"Don Elsey has served in executive finance positions for both privately and publicly held companies. He

is currently Chief Financial Officer of Senseonics, Incorporated. Senseonics is developing the first fully implantable continuous glucose sensor designed for highly accurate, long-term wear. Previously, he served as the CFO of Regado Biosciences, a public biopharmaceutical company. He was the CFO of LifeCell, Inc., a private regenerative medicine company, from 2013-2014 and a Senior VP and CFO at Emergent BioSolutions, Inc., a public biopharmaceutical company, from 2005-2012.”

[CSC, accessed [12/8/20](#)]

**Elsey is a member of Regene RX Biopharmaceuticals board of directors.**

“Mr. Elsey serves on the board of directors of RegeneRx Biopharmaceuticals, a public biopharmaceuticals company, as well as on the board of the Cancer Support Community.”

[CSC, accessed [12/8/20](#)]

**FAUZZA HUSSAIN, CSC BOARD OF DIRECTORS MEMBER**

**Fauzza Hussain is a Vice President for Public Policy at McKesson.**

“Fauzza Hussain currently serves as the Vice President, Public Policy for McKesson. In this role, Fauzza works across the enterprise to ensure McKesson’s public policy strategy meets the diverse needs of McKesson’s comprehensive suite of solutions across the care continuum, while meeting the company’s mission of creating a sustainable healthcare environment that drives better health for all patients. She works across the business on issues impacting distributors and wholesalers, community providers, health systems, pharmacies, and most importantly patients.”

[CSC, accessed [12/8/20](#)]

**Hussain had worked at Avalere, a “well-recognized leader in developing and implementing innovative integrated market access strategies for drugs, biologics, devices and technologies across payers and settings.”**

“Prior to joining McKesson, Fauzza led Avalere’s Reimbursement and Market Access team, a well-recognized leader in developing and implementing innovative integrated market access strategies for drugs, biologics, devices and technologies across payers and settings.”

[CSC, accessed [12/8/20](#)]

**JEFFREY A. GALVIN, CSC BOARD OF DIRECTORS MEMBER**

**Jeffrey A. Galvin is CEO and co-founder of American Gene Technologies.**

“Jeffrey A. Galvin is the CEO and Co-founder of American Gene Technologies™ (AGT). Mr. Galvin earned his BA degree in Economics from Harvard in 1981. Mr. Galvin has more than 30 years of business and entrepreneurial experience, including founder or executive positions at a variety of Silicon Valley startups. Several of his companies were taken public and/or sold to public companies, including one in the medical-technology arena that was sold to Varian, the leading maker of linear accelerators used in cancer therapy.”

[CSC, accessed [12/8/20](#)]

- **American Gene Technologies “is developing and commercializing genetic medicines targeting major diseases.”**

“Following his startup experience, he retired to become an Angel Investor in real estate and high tech. Mr. Galvin came out of retirement to found and fund AGT after meeting Roscoe Brady at NIH. AGT is developing and commercializing genetic medicines targeting major diseases, including HIV/AIDS, Phenylketonuria (PKU) and Hepatocellular carcinoma (liver cancer, or HCC). Its drug candidates have achieved initial proof of concept in preclinical studies and have potential to deliver cost-effective therapies that are better targeted and more potent with fewer side effects. AGT’s drugs will treat symptomatic disease, but are intended to provide durable cures that extend the length and improve the quality of patients’ lives.”

[CSC, accessed [12/8/20](#)]

## **LAUREN BARNES, CSC BOARD OF DIRECTORS MEMBER**

**Lauren Barnes is VP for Managed Markets at Vertex Pharmaceuticals.**

“Lauren Barnes is Vice President, Managed Markets at Vertex Pharmaceuticals, a global biotechnology company that aims to discover, develop and commercialize innovative medicines so people with serious diseases can lead better lives. In addition to its clinical development programs focused on cystic fibrosis, Vertex has more than a dozen”

[CSC, accessed [12/8/20](#)]

**Barnes previously worked as a Senior VP at Avalere Health where she worked with “clients in the pharmaceutical and biotechnology industries to assist in the successful commercialization of their products.”**

“Ms. Barnes was previously Senior Vice President, Avalere Health. At Avalere, she provided strategic payer planning and public policy expertise to clients in the pharmaceutical and biotechnology industries to assist in the successful commercialization of their products.”

[CSC, accessed [12/8/20](#)]

**Barnes worked as a Director of the Payment and Coverage Group at Amgen.**

“Prior to joining Avalere, Ms. Barnes was Director of the Payment and Coverage Group at Amgen. Immediately prior to her time with Amgen, she worked for the Centers for Medicare & Medicaid Services in the Coverage and Analysis Group and sat on the Healthcare Common Procedure Coding System panel.”

[CSC, accessed [12/8/20](#)]

## **LYNNE O'BRIEN, CSC BOARD OF DIRECTORS MEMBER**

**Lynn O'Brien was a director at the Washington Government Affairs Office of DuPont Merck and DuPont Pharmaceuticals where she worked with members of Congress and the FDA.**

“Previously, she worked as director of the Washington Government Affairs Office of DuPont Merck and DuPont Pharmaceuticals, working with members of Congress on issues involving the U.S. Food and Drug Administration, tax legislation, and health care reform.”

[CSC, accessed [12/8/20](#)]

## **RICH MUTELL, CSC BOARD OF DIRECTORS MEMBER**

**Rich Mutell worked in various positions at EPOGEN, one of the first commercially successful biologics.**

“Prior to starting Apex Health Innovations, Mr. Mutell served as Head of the Health Economic Modeling and Medical Informatics and Technology group at DaVita Clinical Research. In this role, he built a team of scientific, medical, and technology experts to create innovative, mobile platform solutions for real-world data from clinical, market access, and health economic studies. Prior to joining DaVita Clinical Research, Mr. Mutell spent more than ten years at Amgen, the world's largest biotechnology company. He served in different positions of increasing responsibilities, including as a health economist for EPOGEN, one of the first commercially successful biologics. He also served as the Operations Director for the Global Health Economics, Global Pricing and Payer Planning, and International Health Economics teams.”

[CSC, accessed [12/8/20](#)]

## **STUART A. ARBUCKLE, CSC BOARD OF DIRECTORS MEMBER**

**Stuart A. Arbuckle is an Executive VP and CCO at Vertex Pharmaceuticals and oversees the company's global commercial team.**

“Stuart A. Arbuckle joined Vertex in September 2012. As Vertex's Executive Vice President and Chief Commercial Officer, Mr. Arbuckle oversees Vertex's global commercial team, which is responsible for the company's sales, marketing, patient support, market research and other activities that support the approved use of Vertex's two medicines.”

[CSC, accessed [12/8/20](#)]

- **Arbuckle “has more than 25 years of experience in leading global sales and marketing efforts at biopharmaceutical companies” including positions at Amgen and GlaxoSmithKline**

“Mr. Arbuckle has more than 25 years of experience in leading global sales and marketing efforts at biopharmaceutical companies. Prior to joining Vertex, Mr. Arbuckle held multiple commercial leadership roles at Amgen, Inc., a 17,000-person biotechnology company. As Vice President and General Manager, Oncology Business Unit, he led sales, marketing, patient advocacy and access efforts for Amgen’s portfolio of cancer medicines. He was responsible for sales and marketing efforts for Aranesp®, Neulasta® and NEUPOGEN®, which accounted for more than \$5 billion in sales in 2011, and led the successful launches of XGEVA® and Nplate®. Most recently, he served as Vice President and Regional General Manager where he led efforts to expand Amgen’s presence in Japan and emerging markets in Asia, the Middle East and Africa. Prior to these roles, Mr. Arbuckle spent more than 15 years at GlaxoSmithKline (GSK) plc, where he held sales and marketing roles of increasing responsibility for medicines aimed at treating respiratory, metabolic, musculoskeletal, cardiovascular and other diseases.” [CSC, accessed [12/8/20](#)]

### **Lobbying Activities**

*The Cancer Support Community did not appear to engage in any registered federal lobbying activities directly or via a professional lobbying firm.*

**2019: The Cancer Support Community spent \$14,400 on “direct contact with legislators, their staffs, government officials, or a legislative body.”**

[Cancer Support Community, IRS Form 990, [11/12/20](#)]

### **Prescription Drug Cost Legislation**

#### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

**June 2020: CSC said it supported the “intent behind” H.R. 3, but cautioned that conversations about reducing prescription drug prices must center on the patient-provider relationship.**

“The legislation also aims to lower drug pricing through the inclusion of the drug price negotiation mechanism from Title 1 of the Elijah E. Cummings Lower Drug Costs Now Act. CSC fully supports the intent behind Title 1, especially the need to ensure fair drug prices and lower out-of-pocket expenses for patients; however, we firmly believe that the high cost of prescription drugs must be addressed and done so with patients at the center of the conversation. Any effort to reform drug pricing must include sufficient safeguards that honor the patient-provider relationship and respect the treatment plan chosen as best for that patient through the shared decision-making process. Learn more about the policy principles that CSC supports at Health Care Principles For Individuals Impacted by Cancer.”

[Cancer Support Community, [6/29/20](#)]

#### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

#### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*



Website: <https://www.myeloma.org/>

### Financials

#### **2019: THE INTERNATIONAL MYELOMA FOUNDATION DISCLOSED IN ITS AUDITED FINANCIAL REPORTS THAT JUST TWO PHARMACEUTICAL COMPANIES ACCOUNTED FOR 57 PERCENT OF TOTAL REVENUE – ABOUT \$11.5 MILLION.**

**2019: The International Myeloma Foundation disclosed in its audited financial reports that just two pharmaceutical companies accounted for 57 percent of total revenue.**

“Two pharmaceutical companies accounted for approximately 57 percent of total revenues during the year ended September 30, 2019.” [International Myeloma Foundation, Financial Statements, [9/30/19](#)]

**2019: IMF disclosed that two pharmaceutical companies accounted for 86 percent of “contributions receivable.”**

“Two pharmaceutical company donors accounted for approximately 86 percent of contributions receivable as of September 30, 2019.” [International Myeloma Foundation, Financial Statements, [9/30/19](#)]

**2019: IMF’s total revenue was more than \$20 million.**

According to their audited financial reports for the year that ended September 30, 2019, IMF’s total revenue was \$20,223,788. [International Myeloma Foundation, Financial Statements, [9/30/19](#)]

**2018: The International Myeloma Foundation had more than \$20 million in revenue.**

According to their IRS Form 990, the International Myeloma Foundation had \$20,025,618 in total revenue from “contributions and grants.” [International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**The International Myeloma Foundation doesn’t appear to disclose financial support from corporations, only indicating broad categories.**

IMF disclosed revenue received from “educational and program grants,” “general contributions,” “change in split interest agreements,” “fundraising programs,” “seminar fees and support group income,” “fundraising events, net of direct benefit to donors of \$376,704,” and “investment income, net.” [International Myeloma Foundation, 2019 GLOBAL ANNUAL REPORT, [4/13/20](#)]

#### **THE INTERNATIONAL MYELOMA FOUNDATION DISCLAIMS ANY INFLUENCE FROM CORPORATE PHARMACEUTICAL FUNDERS AND PUSHES PATIENTS TO THE INDUSTRIES FINANCIAL ASSISTANCE PROGRAMS.**

**2019: Pharmaceutical companies Takeda, Celgene, Sanofi, and Amgen participated in the annual Global Myeloma Action Network meeting, presenting on their treatment development progress.**

“The mission of the Global Myeloma Action Network (GMAN) is to improve the lives of myeloma patients around the world by raising awareness about myeloma, building the capacity of local myeloma organizations, and increasing access to medicine and treatment. Founded in 2013 by the International Myeloma Foundation, GMAN is a group of myeloma patient organizations that share best practices and a commitment to our shared mission. This year, the annual GMAN Summit was held in Amsterdam from June 7–9. The meeting was attended by 35 advocates representing 5 continents and 23 countries, and it was facilitated by Serdar Erdoğan (Director of GMAN, Europe & Middle East Patient Programs, and a myeloma advocate representing Turkey). Serdar presented a summary of the result of a GMAN survey of member advocates, which drove the development of this year’s Summit agenda and focused on caregivers, acknowledging caregivers as one of the key components of the patient ecosystem. [...] During the meeting, representatives from Takeda (future drug TAK 573 ADC), Celgene (iberdomide IMiD®), Sanofi (isatuximab CD38 mAb), and Amgen (AMG420 BCMA BiTE) presented updates on their myeloma product pipeline as well as other myeloma-related industry news.”

[International Myeloma Foundation, accessed [11/27/20](#)]

**The International Myeloma Foundation said it is “solely responsible for the criteria, objectives, content, quality, and scientific integrity of all research and educational programs,” regardless of corporate funding.**

“The IMF receives corporate support. How are those funds used? The IMF educates tens of thousands of myeloma patients, caregivers, and healthcare professionals around the world each year thanks in part to the support of educational grants from more than a dozen different industry sponsors. While we are grateful for support from corporate entities, the IMF is solely responsible for the criteria, objectives, content, quality, and scientific integrity of all research and educational programs.” [International Myeloma Foundation, accessed [11/27/20](#)]

**The International Myeloma Foundation does not provide direct financial assistance to myeloma patients, but refers people to “co-pay assistance programs.”**

“Does the IMF provide financial assistance to patients and their families[?] Unfortunately, the IMF is not able to provide direct monetary assistance to patients, but we do have information about financial resources that may be available to you. You can view a list of co-pay assistance programs here or contact our InfoLine at 1-800-452-CURE (2873) in the U.S./Canada, or globally at 1-818-487-7455. You may also email them with your inquiry at [InfoLine@myeloma.org](mailto:InfoLine@myeloma.org).”

[International Myeloma Foundation, accessed [11/27/20](#)]

- **IMF maintains a webpage directing myeloma patients to drug company financial assistance programs.**

[International Myeloma Foundation, accessed [11/30/20](#)]

- **IMF directs myeloma patients to Amgen’s “Assist 360” program for help “covering the costs of Amgen medicines.”**

“Drug Reimbursement Information and Assistance Amgen Assist 360: Help with covering the costs of Amgen medicines, including KYPROLIS® (carfilzomib).”

[International Myeloma Foundation, accessed [11/30/20](#)]

- **IMF directs myeloma patients to GlaxoSmithKline’s expanded access program.**

- “Expanded access program (EAP) for belantamab mafodotin, an investigational immunoconjugate against B-cell maturation antigen (anti-BCMA) being evaluated in several studies as a treatment for multiple myeloma. The EAP is available to eligible multiple myeloma patients in the U.S. who have undergone stem cell transplant or are considered transplant ineligible and are refractory to previous treatment with a proteasome inhibitor, immunomodulatory drug, and anti-CD38 therapy.” [International Myeloma Foundation, accessed [11/30/20](#)]

- **IMF directs myeloma patients to Celgene’s “Patient Support” program.**

- “Drug Reimbursement Information and Assistance [...] Celgene Patient Support®: Help with navigating the challenges of reimbursement, co-pay assistance, and questions about obtaining Bristol-Myers Squibb (BMS) products REVLIMID® (lenalidomide), POMALYST® (pomalidomide), and THALOMID® (thalidomide).” [International Myeloma Foundation, accessed [11/30/20](#)]

- **Celgene’s “Patient Support” program advertises that patients’ out-of-pocket co-pay may be limited to just \$25.**

“At Celgene Patient Support®, we care about making sure you get the answers you need. That’s why our Specialists are ready to help answer questions about the insurance approval process, and the financial help that may be available for your prescribed Celgene medicine. Celgene Patient Support® can help you and your loved ones understand the programs and services available to you. [...] If you have commercial insurance, you may qualify for the Celgene Commercial Co-pay Program. If you qualify, your out-of-pocket co-pay responsibility will be \$25 or less (subject to annual benefit limits) for your prescribed Celgene medicine.”

[Celgene Patient Support, accessed [11/30/20](#)]

- IMF directs myeloma patients to the Janssen Pharmaceutical financial assistance program for three different drugs.**

“Drug Reimbursement Information and Assistance [...] DARZALEX®: Reimbursement support, insurance coverage verification, and product-specific claims and appeals for DARZALEX®(daratumumab). Referrals to independent foundations that may have available funding to help minimize drug costs. DOXIL®: Reimbursement support, insurance coverage verification, and product-specific claims and appeals for DOXIL®(doxorubicin HCl liposome injection). Referrals to independent foundations that may have available funding to help minimize drug costs. [...] PROCRT®: Reimbursement support, insurance coverage verification, and product-specific claims and appeals for PROCRT®(epoetin alfa). Referrals to independent foundations that may have available funding to help minimize drug costs.” [International Myeloma Foundation, accessed [11/30/20](#)]

  - Janssen’s CarePath program “helps find financial assistance options for eligible patients.”**

“Janssen CarePath is your one source for access, affordability, and treatment support for your patients. Janssen CarePath helps verify insurance coverage for your patients, provides reimbursement information, helps find financial assistance options for eligible patients, and provides ongoing support to help patients start and stay on prescribed Janssen medications.”

[Janssen CarePath, accessed [11/30/20](#)]
- IMF directs myeloma patients to a co-payment assistance program for a Bristol-Myers Squibb drug.**

“Drug Reimbursement Information and Assistance [...] EMLICITI®: Assistance with co-payment or co-insurance requirements for eligible, commercially insured patients who have been prescribed Bristol-Myers Squibb oncology products, including EMLICITI® (elotuzumab).”

[International Myeloma Foundation, accessed [11/30/20](#)]
- MF directs myeloma patients to a co-pay assistance program by Secura Bio.**

“Drug Reimbursement Information and Assistance [...] FARYDAK®: Co-pay support for FARYDAK® (panobinostat) by Secura Bio.” [International Myeloma Foundation, accessed [11/30/20](#)]
- IMF directs myeloma patients to a co-pay assistance program by Takeda Pharmaceuticals for drug Ninlaro.**

“Drug Reimbursement Information and Assistance [...] NINLARO®: Assistance with costs and other day-to-day needs associated with NINLARO® (ixazomib) treatment.”

[International Myeloma Foundation, accessed [11/30/20](#)]
- IMF directs myeloma patients to a co-pay assistance program by Sanofi Genzyme for Sarclisa.**

“Drug Reimbursement Information and Assistance [...] SARCLISA®: Helping eligible patients with access and support for the treatment they’ve been prescribed.”

[International Myeloma Foundation, accessed [11/30/20](#)]

  - Sanofi Genzyme’s financial assistance program for Sarclisa tells patients their “out-of-pocket costs may be as little as \$0.”**

“CareASSIST by Sanofi Genzyme for SARCLISA® (isatuximab-irfc) Helping eligible patients with access and support for the treatment they’ve been prescribed. If you have commercial insurance, you may be eligible for the CareASSIST Copay Program. If you qualify, your out-of-pocket costs may be as little as \$0.”

[Sanofi CareAssist, accessed [11/30/20](#)]
- IMF directs myeloma patients to a Takeda Oncology financial assistance program.**

“Drug Reimbursement Information and Assistance [...] Takeda Oncology Here2Assist™ A comprehensive program committed to helping patients taking Takeda Oncology medicines navigate coverage requirements, identify available financial assistance and connect with helpful resources throughout their treatment. The Takeda Oncology Here2Assist™ Patient Support Program is ready to support the needs of patients. Any

customer questions should be directed to Takeda Oncology at 1-844-817-6468, Option 2.”  
 [International Myeloma Foundation, accessed [11/30/20](#)]

- **IMF directs myeloma patients to a Takeda financial assistance program for the drug Velcade.**  
 “Drug Reimbursement Information and Assistance [...] VELCADE®: Takeda’s program for patients, physicians, and caregivers to provide reimbursement assistance related to the use of VELCADE® (bortezomib).” [International Myeloma Foundation, accessed [11/30/20](#)]
- **IMF directs myeloma patients to a Karyopharm financial assistance program for the drug Xpovio.**  
 “Drug Reimbursement Information and Assistance [...] XPOVIO® The KaryForward patient support program by Karyopharm has Copay and Patient Assistance programs which can help you with the cost of and access to Xpovio.” [International Myeloma Foundation, accessed [11/30/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
SUSAN DURIE	PRESIDENT	\$243,242.00	\$36,845.00	\$280,087.00
JENNIFER SCARNE	CFO/C00	\$264,200.00	\$22,103.00	\$286,303.00
DIANE MORAN	STRATEGIC PLANNER	\$363,025.00	\$18,423.00	\$381,448.00
LISA PAIK	SENIOR VICE PRESIDENT	\$190,967.00	\$25,710.00	\$216,677.00
JOSEPH MIKHAEL	CHIEF MEDICAL OFFICER	\$450,000.00	\$24,989.00	\$474,989.00
PETER ANTON	VICEPRESIDENT, MARKETING	\$186,517.00	\$31,021.00	\$217,538.00
LYNN GREEN	SENIOR VICE PRESIDENT, PHILANTHROPY	\$109,731.00	\$4,130.00	\$113,861.00

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**2019: International Myeloma Foundation President Susan Durie received \$280,087 in total compensation.**  
 [International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

- **1990: Susie Durie co-founded the International Myeloma Foundation with her now-late husband, Brian Novis, and Dr. Brian Durie.**  
 “Susie Novis Durie has a specific vision for the future of the International Myeloma Foundation (IMF), a group she co-founded in 1990 after her late husband Brian Novis was initially diagnosed with multiple myeloma.” [Cure Today, [3/7/16](#)]
- **2019: International Myeloma Foundation Board Chairman Dr. Brian Durie received \$192,000 from his company for services rendered to the foundation.**  
 “Chairman, Dr. Brian Durie, was compensated \$192,000 from the Durie Group for services rendered to the organization.” [International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

- **Brian and Susie Durie are married.**

“Dr. Durie (center) and his wife, Susie Novis Durie, with one of his youngest patients, her parents, and her significant other.” [ASH Clinical News photo caption, [10/1/17](#)]

- **The Duries’ daughter works for the International Myeloma Foundation.**

“Did either of your children go into medicine?” “Indirectly, yes. My daughter works for the International Myeloma Foundation in the meeting planning division.” [ASH Clinical News, [10/1/17](#)]

- **Brian Durie established the International Myeloma Working Group, the research division of the International Myeloma Foundation.**

“What do you view as your greatest career accomplishment? It would be the establishment of the International Myeloma Working Group – the research division of the International Myeloma Foundation. A key research project of the group is the Black Swan Research Initiative, which seeks a cure for myeloma. This collaborative effort has brought together international experts in myeloma, and, from these efforts, we have launched joint research projects, developed guidelines, and furthered the discussion about myeloma research.”

[ASH Clinical News, [10/1/17](#)]

**2019: International Myeloma Foundation CFO/COO Jennifer Scarne received \$286,303 in total compensation.**

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**2019: International Myeloma Foundation strategic planner Diane Moran received \$381,448 in total compensation.**

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**2019: International Myeloma Foundation Senior Vice President Lisa Paik received \$216,667 in total compensation.**

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**2019: International Myeloma Foundation Chief Medical Officer Joseph Mikhael received \$474,989 in total compensation.**

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**2019: International Myeloma Foundation Vice President of marketing Peter Anton received \$217,538 in total compensation.**

[International Myeloma Foundation, IRS Form 990, [4/24/20](#)]

**MARTINE ELIAS, IMF BOARD OF DIRECTORS**

**International Myeloma Foundation board member and executive director of Myeloma Canada, Martine Elias began her career in the pharmaceutical industry.**

“Martine Elias is the Executive Director at Myeloma Canada, the only patient-driven, grassroots organization bringing the Canadian myeloma community together and promoting a strong, unified national voice for people living with multiple myeloma. In addition, Martine is Chair of the Collective Oncology Network for Exchange, Cancer Care Innovation, Treatment Access and Education (CONNECTed), a Canadian-based organization. Martine started her career in clinical research in the pharmaceutical industry and has since dedicated her professional life to patient advocacy, empowering the patient voice, and helping patients gain access to essential medical treatments. She is passionate about ensuring that the patient voice is included in all aspects of health policy decisions. Previously, Martine was Director Access, Advocacy, and Community Relations at Myeloma Canada where she developed, led, and executed all advocacy strategies and programs. Before that, Martine held roles as National Patient Engagement Strategy at Janssen as a member of an international working team to advance a global patient advocacy strategy, and as National Director of Community Relations, as well as a Market Access and Health Economics team leader.”

[International Myeloma Foundation, accessed [11/27/20](#)]

- **2002-2015: Martine Elias spent more than 13 years working for Janssen Pharmaceuticals.**  
[Martine Elias LinkedIn profile, accessed [11/27/20](#)]
- **2001-2002: Martine Elias worked nearly 2 years for Sanofi.**  
[Martine Elias LinkedIn profile, accessed [11/27/20](#)]
- **1987-2001: Martine Elias worked about 13 years for GlaxoSmithKline.**  
[Martine Elias LinkedIn profile, accessed [11/27/20](#)]

#### **MIMI CHOON-QUINONES, IMF SVP FOR GLOBAL ADVOCACY, ACCESS, POLICY & RESEARCH**

**International Myeloma Foundation Senior Vice President for Global Advocacy, Access, Policy & Research**  
**Mimi Choon-Quinones spent “more than 20 years” in the pharmaceutical industry.**

“Dr. Mimi Choon-Quinones joined the IMF in 2018, bringing with her more than 20 years of experience in the pharmaceutical industry, her strategic leadership in 88+ countries focusing on Medical and Clinical Operations.”  
[International Myeloma Foundation, accessed [11/27/20](#)]

- **2008-2018: Choon-Quinones was in leadership roles at international pharmaceutical company Roche.**  
[Mimi Choon-Quinones LinkedIn profile, accessed [11/27/20](#)]
- **2005-2008: Choon-Quinones worked for pharmaceutical company Novartis.**  
[Mimi Choon-Quinones LinkedIn profile, accessed [11/27/20](#)]
- **1995-2005: Choon-Quinones worked for pharmaceutical company Merck.**  
[Mimi Choon-Quinones LinkedIn profile, accessed [11/27/20](#)]

#### **STEPHEN HARDING, IMF BLACK SWAN RESEARCH TEAM**

**Stephen Harding is part of the IMF’s Black Swan Research Initiative team.**

[International Myeloma Foundation, accessed [11/28/20](#)]

- **2001-2002: Harding worked for BioFocus.**  
[Stephen Harding LinkedIn profile, accessed [11/28/20](#)]
- **BioFocus’ “services have supported the pipeline of several large pharmaceutical companies such as AstraZeneca.”**  
“Founded in 1997, BioFocus’s integrated drug and target discovery services have supported the pipeline of several large pharmaceutical companies such as AstraZeneca.”  
[Charles River Laboratories, accessed [11/28/20](#)]

- **2001-2006: Harding worked for Scancell.**  
[Stephen Harding LinkedIn profile, accessed [11/28/20](#)]
- **Scancell is a biopharmaceutical company focused on cancer vaccines.**  
“Scancell is a clinical-stage immuno-oncology company which was founded in 1997 on research led by Professor Lindy Durrant at the University of Nottingham. The Company is operating at the forefront of immuno-oncology, an exciting field of cancer research which involves the development of immunotherapies to harness the body’s ability to generate and sustain an effective immune response against cancer. The cancer immunotherapy market is one of the most rapidly growing markets within the biopharmaceutical industry, estimated to be worth USD100 billion by the year 2022.”  
[Scancell, accessed [11/28/20](#)]

#### **ÁSDÍS RÓSA ÞÓRÐARDÓTTIR, IMF BLACK SWAN RESEARCH TEAM**

**Ásdís Rósa Þórðardóttir is part of the IMF’s Black Swan Research Initiative team.**

[International Myeloma Foundation, accessed [11/28/20](#)]

- **2003-2016: Þórðardóttir worked for Actavis.**  
[Ásdís Rósa Þórðardóttir LinkedIn profile, accessed [11/28/20](#)]
- **2015: Actavis changed its name to Allergan.**

“Actavis PLC said Monday it has changed its name to Allergan PLC, three months after acquiring the maker of the antiwrinkle treatment Botox.” [Wall Street Journal, [6/15/15](#)]

## Grants

### **THE INTERNATIONAL MYELOMA FOUNDATION HAS FINANCIALLY SPONSORED CLINICAL TRIALS IN PARTNERSHIP WITH PHARMACEUTICAL CORPORATIONS.**

#### **2018: IMF sponsored the “ASCENT” clinical trial for cure for myeloma.**

“The U.S.-based ASCENT trial (Aggressive Smoldering Cure Evaluating Novel Therapies) is headed by Dr. Shaji Kumar of the Mayo Clinic (Rochester, MN). This trial uses a combination of carfilzomib, lenalidomide, dexamethasone, and daratumumab in high-risk smoldering multiple myeloma. Its goal: to learn whether starting treatment early substantially improves outcomes, leads to a higher level of undetected minimal residual disease (MRD), sustained remissions, and potential cure. All enrolled patients will receive a reduced dose of carfilzomib, lenalidomide, and daratumumab for one year of maintenance. At this point, it is anticipated that approximately 80 percent of patients will achieve MRD negativity (versus 62 percent already achieved with KRd in the CESAR trial), said Dr. Brian G.M. Durie. MRD testing will be done at diagnosis and during therapy, allowing intensive tracking of the disease in patients. The number of cycles of therapy will be determined by the individual patient’s response. The ASCENT trial will open for accrual in March 2018 at 12 IMF Consortium sites. Further information may be found here.”

[International Myeloma Foundation, accessed [11/28/20](#)]

- **IMF collaborators on the ASCENT clinical trial include pharmaceutical companies Amgen, Janssen, and Celgene.**

“Aggressive Smoldering Curative Approach Evaluating Novel Therapies and Transplant (ASCENT) [...] Sponsor: International Myeloma Foundation Collaborators: Amgen Janssen Scientific Affairs, LLC Celgene” [ClinicalTrials.gov, [8/12/20](#)]

#### **IMF funded the CESAR “cure” trial for treatment of smoldering myeloma.**

“Cure Trials: CESAR—Treating High-Risk Smoldering Myeloma with a Three-Drug Regimen Along with the ASCENT and iStopMM clinical trials, the CESAR trials is one of three BSRI-funded “Cure” trials. The CESAR trial is ongoing in Spain with Professor María Victoria Mateos as the Principal Investigator. CESAR uses the combination of Kyprolis, Revlimid, and dexamethasone (KRd) with autologous stem cell transplant in the same setting as ASCENT. With a median follow-up of 28 months, 94 percent of patients are in remission, with 62 percent having undetected MRD at the 10<sup>-6</sup> (zero out of a million cells). It is hoped that the addition of daratumumab in the U.S. ASCENT trial will enhance the undetected MRD level among patients to approximately 80 percent (at 10<sup>-6</sup> level). Because the CESAR trial has been well tolerated, there is great optimism moving forward. Although longer follow-up is required, this curative strategy for high-risk SMM is encouraging.”

[International Myeloma Foundation, accessed [11/28/20](#)]

- **Many of the lead investigators for the CESAR trial had deep ties to major pharmaceutical corporations.**

“Curative Strategy (GEM-CESAR) for High-Risk Smoldering Myeloma (SMM): Carfilzomib, Lenalidomide and Dexamethasone (KRd) As Induction Followed By HDT-ASCT, Consolidation with Krd and Maintenance with Rd [...] Disclosures Mateos:GSK: Membership on an entity’s Board of Directors or advisory committees; Celgene: Honoraria, Membership on an entity’s Board of Directors or advisory committees; Adaptive: Honoraria; Takeda: Honoraria, Membership on an entity’s Board of Directors or advisory committees; Janssen: Honoraria, Membership on an entity’s Board of Directors or advisory committees; Pharmamar: Membership on an entity’s Board of Directors or advisory committees; EDO: Membership on an entity’s Board of Directors or advisory committees; Abbvie: Membership on an entity’s Board of Directors or advisory committees; Amgen: Honoraria, Membership on an entity’s Board of Directors or advisory committees. Rodriguez Otero: Celgene Corporation: Consultancy, Honoraria,

Speakers Bureau; Janssen: Consultancy, Honoraria; Takeda: Consultancy; BMS: Honoraria; Kite Pharma: Consultancy. Oriol:Amgen: Consultancy, Speakers Bureau; Janssen: Consultancy; Takeda: Consultancy, Speakers Bureau; Celgene Corporation: Consultancy, Speakers Bureau. Paiva:Amgen, Bristol-Myers Squibb, Celgene, Janssen, Merck, Novartis, Roche, and Sanofi; unrestricted grants from Celgene, EngMab, Sanofi, and Takeda; and consultancy for Celgene, Janssen, and Sanofi: Consultancy, Honoraria, Research Funding, Speakers Bureau. Rosinol Dachs:Janssen, Celgene, Amgen and Takeda: Honoraria. Amor:Takeda: Membership on an entity’s Board of Directors or advisory committees; Amgen: Membership on an entity’s Board of Directors or advisory committees; Janssen: Membership on an entity’s Board of Directors or advisory committees; Celgene: Membership on an entity’s Board of Directors or advisory committees. Puig:Janssen: Consultancy, Honoraria, Research Funding; Amgen: Consultancy, Honoraria; Celgene: Consultancy, Honoraria, Membership on an entity’s Board of Directors or advisory committees, Research Funding, Speakers Bureau; Takeda: Consultancy, Honoraria; The Binding Site: Honoraria. De La Rubia:AMGEN: Consultancy; Celgene Corporation: Consultancy; Takeda: Consultancy; Janssen: Consultancy; AbbVie: Consultancy. De Arriba:Takeda: Honoraria; Amgen: Consultancy, Honoraria; Janssen: Consultancy, Honoraria; Celgene: Consultancy, Honoraria. Lopez Jimenez:GILEAD SCIENCES: Honoraria, Other: Education funding. Ocio:Celgene: Consultancy, Honoraria, Research Funding; BMS: Honoraria; Takeda: Consultancy, Honoraria; Janssen: Consultancy, Honoraria; Mundipharma: Research Funding; AbbVie: Consultancy; Sanofi: Research Funding; Seattle Genetics: Consultancy; Array Pharmaceuticals: Research Funding; Amgen: Consultancy, Honoraria, Research Funding; Novartis: Consultancy, Honoraria; Pharmamar: Consultancy. Bladé:Jansen, Celgene, Takeda, Amgen and Oncopeptides: Honoraria. San-Miguel:Amgen, Bristol-Myers Squibb, Celgene, Janssen, MSD, Novartis, Roche, Sanofi, and Takeda: Consultancy, Honoraria.” [Blood, [11/13/19](#)]

**Lobbying**

**1998-2020: The IMF spent \$2,329,576 on lobbying the federal government.**

According to the Center for Responsive Politics, the International Myeloma Foundation spent \$2,329,576 on lobbying the federal government from 1998 to 2020.

[Center for Responsive Politics, accessed [12/1/20](#)]

**THE INTERNATIONAL MYELOMA FOUNDATION EMPLOYS A LOBBYING FIRM THAT REPRESENTS PHARMACEUTICAL COMPANIES IN AN FDA REGULATORY PRACTICE.**

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
International Myeloma Foundation	Powers, Pyles, Sutter & Verville	Powers, Pyles, Sutter & Verville doesn't appear to lobby on behalf of pharmaceutical companies, though they have represented pharmaceutical companies through their legal practice, and they do maintain an FDA regulatory practice largely targeted at medical device manufacturers and a practice for pharmacies and pharmacy benefit managers.

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]



**2020: The International Myeloma Foundation spent at least \$120,000 on contract lobbying firm Powers, Pyles, Sutter & Verville.**

Powers, Pyles, Sutter & Verville doesn't appear to lobby on behalf of pharmaceutical companies, although they have represented pharmaceutical companies through their legal practice, and they do maintain a FDA regulatory practice largely targeted at medical device manufacturers and a practice for pharmacies and pharmacy benefit managers.

**Q1-Q3 2020: The IMF spent \$120,000 on lobbying firm Powers, Pyles, Sutter & Verville.**

According to federal lobbying disclosures, IMF spent at least \$120,000 on the lobbying firm Powers, Pyles, Sutter & Verville in the first three quarters of 2020.

[Powers, Pyles, Sutter & Verville, Lobbying Disclosure Reports, Q1 2020, [4/17/20](#); Q2 2020, [7/13/20](#); Q3 2020, [10/14/20](#)]

**Q1-Q3 2020: The IMF used Powers, Pyles, Sutter & Verville lobbyists Jeremy Scott and Joseph Nahra.**

According to federal lobbying disclosures, IMF used Powers, Pyles, Sutter & Verville lobbyists Jeremy Scott and Joseph Nahra in the first three quarters of 2020.

[Powers, Pyles, Sutter & Verville, Lobbying Disclosure Reports, Q1 2020, [4/17/20](#); Q2 2020, [7/13/20](#); Q3 2020, [10/14/20](#)]

- **Jeremy Scott advised biopharmaceutical companies on how to achieve “their federal legislative, regulatory, programmatic, policy, and grassroots advocacy goals.”**

“I have over 20 years of government relations experience – on Capitol Hill, in a nonprofit, and within a national law firm. I provide my clients with strategic counsel looking for both threats and opportunities to advance their legislative and regulatory goals, with a specific focus on oncology. • Advise biopharmaceutical/medical technology companies, patient advocacy organizations, national nursing and pharmacy associations, hospital and health systems, and other health related entities with respect to achieving their federal legislative, regulatory, programmatic, policy, and grassroots advocacy goals; • Counsel and represent clients with respect to legislative, regulatory, and grassroots advocacy efforts and proactively identify threats and opportunities, and design and implement response plans to protect and advance clients’ interests; • Represent clients before Congressional Members and staff, White House and federal agency staff, coalition partners, and other third-party stakeholders; • Develop advocacy materials including draft legislation, report language, Congressional testimony, fact sheets, issue briefs, position papers, Congressional and federal agency correspondence, bill and regulatory analyses, government relations strategic plans, policy agendas, advocacy action alerts, regulatory comments, speeches, articles, and newsletters; • Design grassroots and grassroots advocacy campaigns, devise branding and messaging for advocacy initiatives, and undertake strategic partnerships and coalitions in support of such campaigns; • Plan and execute client advocacy events including advocacy trainings and workshops, Congressional briefings, Capitol Hill lobby days, coalition meetings, policy summits, and strategic planning retreats; and • Deliver presentations, speeches, and webinar remarks on topics, such as the Supreme Court review of health care reform, election outlook and outcomes, Congressional trends and happenings, and use of social media in advocacy” [Jeremy Scott LinkedIn profile, accessed [12/1/20](#)]

- **Powers, Pyles, Sutter & Verville maintains a practice for the 340B drug pricing program and advises clients on how to access lower prices for prescription drugs.**

“Powers Pyles Sutter & Verville has represented safety net providers and pharmacies participating in the 340B drug pricing program since the program’s inception in 1992. The firm’s drug pricing and 340B Program practice is led by William von Oehsen, one of the primary architects of the 340B program who fought for the inclusion of safety net hospitals as covered entities eligible to access lower cost drugs. William von Oehsen and others within the practice continue to advocate for the interests of safety net hospitals, federally qualified health centers, Ryan White HIV/AIDS clinics, their pharmacies, and others. The firm represents a diverse group of clients on 340B matters, ranging from safety net hospitals to federally-funded clinics to retail pharmacies and pharmacy-related vendors. The firm serves as counsel to the 340B Health, formerly known as the Safety Net Hospitals for Pharmaceutical Access, which William von

Oehsen founded. Our hospital clients include disproportionate share hospitals, children's hospitals, cancer hospitals, and rural hospitals. Our clinic clients include federally qualified health centers and FQHC look-alikes, Ryan White clinics, hemophilia treatment centers, family planning clinics, etc. Our pharmacy-related clients include independent and chain pharmacies, contract pharmacy administrators, pharmaceutical distributors, pharmacy benefit managers, and related vendors. We also provide cutting-edge guidance on the Medicaid Drug Rebate Program, Medicare Part D, and other federal drug payment and acquisition mechanisms. State and local governments look to Powers when developing programs to help individuals, especially seniors and low-income patients, access affordable drugs. Accordingly, Powers' drug pricing client base includes a growing number of states and local government agencies that are seeking to lower drug costs for government-funded populations, such as Medicaid recipients, Medicaid expansion populations, prisoners, mental health, and other long-term care patients, and government employees. Powers is also at the forefront of developing prescription drug value-based purchasing solutions for Medicaid agencies. The firm brings decades of experience advocating for safety net providers and their allies. We testify and advocate before state legislatures, state and federal executive branch officials and Congress. Another area of collaboration with states and local government agencies relates to numerous ongoing investigations into potential violations by industry of federal and state drug discount laws and efforts to recover overpayments from industry. We also form and lead coalitions specific to the 340B program where our team uses our legal, policy, and advocacy skills to advance our clients' interests on Capitol Hill and within the agencies. Finally, as a result of the firm's extensive expertise in the drug pricing area, it has found itself serving a growing number of pharmacies, both freestanding and institutional, in various legal and regulatory matters. Our pharmacy-related projects have involved analysis of federal laws such as Robinson-Patman and the Non-Profit Institutions Act, food and drug law, DEA registration, the Prescription Drug Marketing Act, Medicare/Medicaid coverage and reimbursement of pharmaceutical care and federal fraud and abuse laws such as Stark and anti-kickback. At the state level, we have advised clients on the practice of pharmacy, mail-order regulation, wholesaler registration, and related state licensure laws. We also assist our pharmacy clients with their transactional and litigation needs."

[Powers, Pyles, Sutter & Verville, accessed [12/4/20](#)]

### **Powers, Pyles, Sutter & Verville maintains a regulatory practice directed at companies navigating interactions with the Food and Drug Administration.**

"The regulatory practice at Powers Pyles Sutter & Verville is backed by substantial experience representing clients in matters involving the Food and Drug Administration. Our attorneys have experience guiding companies through the FDA's premarket clearance process and assisting with product development and commercialization strategies to minimize FDA regulatory costs. Powers attorneys also have experience in providing advice on FDA labeling, advertising, and manufacturing requirements, as well as advice and guidance on other issues arising during the progression of a product from premarket clinical testing to postmarket commercial distribution. We assist clients with issues relating to medical devices, biologics, food, food additives, dietary supplements, nutritional products, cosmetics products, and veterinary products."

[Powers, Pyles, Sutter & Verville, accessed [12/4/20](#)]

- **Powers, Pyles, Sutter & Verville has represented a drug manufacturer during a product recall.**

"Another focus area includes representing clients on FDA enforcement and compliance matters. Among the members of the firm's litigation group is a former supervisory Assistant U.S. Attorney with substantial experience with FDA-related litigation. Our attorneys have undertaken compliance projects in numerous situations, including: Helping a manufacturer of over-the-counter drugs with a product recall." [Powers, Pyles, Sutter & Verville, accessed [12/4/20](#)]

- **Powers, Pyles, Sutter & Verville has defended "employees of a vaccine manufacturer against criminal charges of falsifying data and knowingly violating good manufacturer practices and drug export requirements."**

"Another focus area includes representing clients on FDA enforcement and compliance

matters. Among the members of the firm’s litigation group is a former supervisory Assistant U.S. Attorney with substantial experience with FDA-related litigation. Our attorneys have undertaken compliance projects in numerous situations, including:[...] Defending employees of a vaccine manufacturer against criminal charges of falsifying data and knowingly violating good manufacturer practices and drug export requirements.” [Powers, Pyles, Sutter & Verville, accessed [12/4/20](#)]

- **“Powers’ drug pricing and pharmacy practices intersect in numerous areas.”**

“Powers is especially active in helping pharmacies address coverage, billing and reimbursement issues. We have substantial experience advising pharmacies with respect to the Medicare Part B and Part D programs, as well as Medicaid fee-for-service and Medicaid managed care. Our attorneys have also navigated the requirements for pharmacy participation in the Federal Employees Health Benefit Program (FEHBP), TRICARE, and other federal health care programs, including those administered by the VA and the DOD. Powers’ drug pricing and pharmacy practices intersect in numerous areas, which means Powers regularly advises clients on pharmacy-related 340B issues, including the unique billing and reimbursement requirements applicable to 340B pharmacies.” [Powers, Pyles, Sutter & Verville, accessed [12/4/20](#)]

## Prescription Drug Cost Legislation

### HR 3, THE ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

*No statements found.*

### HR 19/S. 3129, THE LOWER COSTS MORE CURES ACT

*No statements found.*

### S. 2543, THE SENATE PRESCRIPTION DRUG PRICING REDUCTION ACT

**7/25/19: As part of the MAPRx Coalition, IMF signed on to a letter commenting on the Medicare Part D Benefit Redesign provisions in the Senate Prescription Drug Pricing Act, thanking the senators for the out-of-pocket cap and calling on them to strengthen it.**

“Dear Chairman Grassley and Ranking Member Wyden: We are writing to comment on the Medicare Part D Benefit Redesign provisions in your legislation, The Prescription Drug Pricing Reduction Act of 2019. Our group, MAPRx Coalition (MAPRx), is a national coalition of beneficiary, caregiver and health care professional organizations committed to improving access to prescription medications in Medicare Part D and safeguarding the well-being of Medicare beneficiaries with chronic diseases and disabilities. We greatly appreciate your leadership in improving access to prescription drugs for Medicare beneficiaries with Part D coverage. First and foremost, thank you for including a Part D out-of-pocket (OOP) cap in your legislation. Over the years, Part D has been viewed as a success due to its broad popularity among enrollees and lower-than-expected government expenditures. Nevertheless, serious challenges remain and the lack of an OOP cap is a hurdle for some of the most vulnerable Medicare beneficiaries. An OOP cap would be an important new patient protection for some of the most vulnerable enrollees in the Medicare program – drastically reducing costs for hundreds of thousands of beneficiaries who rely on prescription drugs to treat chronic and life-threatening conditions. Currently, many beneficiaries often cannot access the most clinically appropriate medication because, financially, it is out of reach. We urge you to strengthen the OOP cap in your legislation. To ensure an OOP cap is meaningful to as many beneficiaries as possible, MAPRx recommends a monthly cap (or other ‘smoothing’ mechanism) that would allow total OOP costs to be distributed more evenly throughout the year. Such a mechanism would ease the financial strain for Medicare beneficiaries who currently are faced with paying a significant percentage of their total OOP financial burden at the beginning of each benefit year. In addition, we would like to see beneficiaries benefit from the cap sooner than your proposed start date of 2022. As you know, currently, the average Medicare beneficiary will pay approximately \$2,750 in OOP costs by the time they reach the catastrophic threshold. As such, MAPRx strongly urges the Committee to consider an OOP cap below this amount. [...] As more Americans become eligible for Medicare, the Part D program will play an increasingly integral role in maintaining beneficiaries’ health and reducing overall health care costs. The undersigned members of MAPRx appreciate your work on Medicare Part D, and we look forward to working with you as your bill moves through the legislative process. For questions related to MAPRx or the above comments, please contact Bonnie Hogue Duffy, Convener, MAPRx Coalition, at (202) 540-1070 or [bduffy@nvgllc.com](mailto:bduffy@nvgllc.com). Sincerely, [...] International Myeloma Foundation.”  
[[KidneyFund.org](http://KidneyFund.org), [7/25/19](https://www.kidneyfund.org/news/2019/07/25/19)]

### OTHER STATEMENTS ON DRUG PRICING

**The Global Myeloma Action Network patient bill of rights says that patients have the right to “affordable access to medications.”**

“Global Myeloma Action Network (GMAN) developed a patient bill of rights, the International Myeloma Patient Charter, to ensure that, no matter where in the world a person lives, the following principles apply to people affected by multiple myeloma and those involved in their lives and treatments. We believe that all parties involved in a patient’s journey have a responsibility to meet the expectations expressed in this document. [...] People with Multiple Myeloma Have the Right to: [...] Affordable access to medications and high-quality care, regardless of a person’s income or where they live.” [International Myeloma Foundation, accessed [11/27/20](https://www.imf.org/2020/11/27/20)]

**The Global Myeloma Action Network patient bill of rights says that governments should “collect data on**

### **myeloma...costs” and “guarantee equitable and timely access to treatments.”**

“Global Myeloma Action Network (GMAN) developed a patient bill of rights, the International Myeloma Patient Charter, to ensure that, no matter where in the world a person lives, the following principles apply to people affected by multiple myeloma and those involved in their lives and treatments. We believe that all parties involved in a patient’s journey have a responsibility to meet the expectations expressed in this document. [...] There Is an expectation that governments will: [...] adopt comprehensive health policies and plans for the diagnosis, and treatment of multiple myeloma. Collect data on myeloma, such as: costs, incidence, survival, mortality and complications. Guarantee equitable and timely access to myeloma treatments, Provide access to treatment for all multiple myeloma patients. Provide a favorable research environment to promote discovery and access to clinical trials for innovative treatments.”

[International Myeloma Foundation, accessed [11/27/20](#)]

### **The Global Myeloma Action Network patient bill of rights says that the “pharmaceutical industry will... provide compassionate use programs.”**

“Global Myeloma Action Network (GMAN) developed a patient bill of rights, the International Myeloma Patient Charter, to ensure that, no matter where in the world a person lives, the following principles apply to people affected by multiple myeloma and those involved in their lives and treatments. We believe that all parties involved in a patient’s journey have a responsibility to meet the expectations expressed in this document. [...] There Is an expectation that the pharmaceutical industry will: Provide safe, effective, tested and approved medications. Provide compassionate use programs. Continue to work collaboratively, and partner with patient groups in a transparent and ethical manner.” [International Myeloma Foundation, accessed [11/27/20](#)]

- **The Global Myeloma Action Network patient bill of rights does not demand that the pharmaceutical industry provide affordable treatments for the disease.**

“Global Myeloma Action Network (GMAN) developed a patient bill of rights, the International Myeloma Patient Charter, to ensure that, no matter where in the world a person lives, the following principles apply to people affected by multiple myeloma and those involved in their lives and treatments. We believe that all parties involved in a patient’s journey have a responsibility to meet the expectations expressed in this document. [...] There Is an expectation that the pharmaceutical industry will: Provide safe, effective, tested and approved medications. Provide compassionate use programs. Continue to work collaboratively, and partner with patient groups in a transparent and ethical manner.” [International Myeloma Foundation, accessed [11/27/20](#)]

### **2018: The International Myeloma Foundation supported sharing drug rebates with patients at the pharmacy point-of-sale.**

“In the five-point plan, you propose requiring plans to share a portion of drug rebates with patients at the pharmacy counter. We are supportive of this idea and agree with the Administration; this will both ‘improve price transparency’and ‘allow beneficiaries to share directly in the savings from discounts.” [Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

### **2018: The International Myeloma Foundation supported eliminating cost-sharing on generic drugs for low-income patients.**

“We were pleased to see the Administration’s proposal to eliminate cost-sharing on generics for low-income subsidy beneficiaries. We are supportive of this idea and believe this will help generate greater access. In the same vein, we are also appreciative of the Administration’s efforts to encourage bringing new generics to market.” [Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

### **2018: The International Myeloma Foundation opposed “[e]xcluding manufacturer discounts from beneficiaries’ true out-of-pocket spending.”**

“Excluding manufacturer discounts from beneficiaries’ true out-of-pocket spending (TrOOP): We have deep concerns with the Administration’s proposal to exclude manufacturer discounts from a beneficiary’s true out-

of-pocket spending. This change would put patients with high cost drugs, such as myeloma patients, into the coverage gap for a much longer amount of time and increase how much patients pay out-of-pocket for their prescriptions. We believe the implementation of this portion of the proposal will cause additional financial difficulties for patients who are already struggling to make ends meet, with unforeseen consequences to the support community of older patients.”

[Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**2018: The International Myeloma Foundation opposed the Trump Administration’s efforts to move oncology drugs from Medicare Part B coverage to Medicare Part D coverage citing cost and safety concerns.**

“We also wish to express our reservations about the idea of moving oncology Part B drugs into Part D. Our organization has general preliminary concerns about this proposal in regard to beneficiary access to oncology drugs. These include concerns surrounding potential delays in treatment, reduction in adherence to medications, problems with dosing flexibility, increased cost-sharing to beneficiaries, and the possibility of premium increasing for all beneficiaries due to new stresses being put on the Part D program. Most importantly, safety issues stemming from the new operational challenges arise when moving some of these drugs into Part D for both patients and providers.” [Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**2018: IMF said that it was important not to allow drug manufacturer assistance to be counted against deductibles or out-of-pocket maximums.**

“We also wish to use this opportunity to make you aware of a new trend in benefits design we believe has the potential to hinder access to drugs for our patients. Copay accumulator/accumulator adjustment programs prohibit manufacturer assistance from being used by a patient to meet their deductible or out-of-pocket-maximum. We understand it is the goal of payers to reduce drug costs; however, our concerns surround the immediate impact of these programs on patients who are often caught off guard by these new policies. We also raise concern with these programs applying to oncology drugs without generic alternatives. We hope the impact these accumulator adjustment programs have on patient out-of-pocket spending and access will be examined and that steps will be taken to ensure patients are not being hindered when trying to access the most appropriate drugs for them. Until it is determined that these programs reduce costs, it is important for our patients to have co-pay and premium assistance included in their deductibles and out-of-pocket-maximums to help reduce their out-of-pocket costs.”

[Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**2018: IMF thanked the Trump Administration for addressing the issue of pharmacy gag clauses.**

“Lastly, on this topic, we would like to thank the Administration for addressing pharmacy gag clauses. We feel this is a helpful step for patients and we are happy pharmacists can now freely speak with patients about whether or not they can pay less out-of-pocket-by not using their insurance. We believe this is a positive change and we will educate our patient population on the implications of it.”

[Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**2018: IMF said that reducing out-of-pocket costs to patients they serve was very important.**

“Reducing out-of-pocket costs are very important to the patients we serve, and we hope you will keep the needs of cancer patients in mind as you continue this important work.”

[Robin Roland Levy, International Myeloma Foundation, letter to HHS Secretary Alex Azar, [7/16/18](#)]

**IMF state advocacy priorities include addressing drug costs and insurance coverage in Kentucky and Ohio and oral anti-cancer treatment parity in Idaho and North Carolina.**

“State Work Ban Copay Accumulators in Kentucky H72 would ban this practice and put money back into the pockets of patients. I ask that you support this bill. Urge your State Senator to help move H206 for a vote. Insured cancer patients are fighting for their lives, but being hit every single month with skyhigh out-of-pocket costs to get their life-saving cancer treatments, just because it comes in pill form. Move H206 for a vote this special session. Tell your state senator to support oral parity with SB 1034. Help SB 1034 pass the Idaho State

Senate by contacting your senator today! NC- We need your help! Move the Cancer Treatment Fairness Act (HB206). Please urge Senator Berger to move the Cancer Treatment Fairness Act (HB206) forward in January so that the out-of-pocket costs for oral and infusion chemotherapy are treated the same.”  
 [International Myeloma Foundation, accessed [11/28/20](#)]

## JDRF

Website: <https://www.jdrf.org/>  
<https://t1dfund.org/>

Documents: [Code of Ethics](#)

## Financials

### JDRF DISCLOSED A “DONOR HONOR ROLL” THAT INDICATED DONORS WHO CONTRIBUTED MORE THAN \$25,000.

2019: JDRF published a “donor honor roll” disclosing donors who gave at least \$25,000 and provided ranges of contributions up to \$1 million and above.

[JDRF, Donor Honor Roll, [8/4/20](#)]

### 2019: JDRF RECEIVED AT LEAST \$4.75 MILLION FROM THE PHARMACEUTICAL INDUSTRY, POSSIBLY MORE THAN \$5.9 MILLION – BETWEEN 2 TO 2.5 PERCENT OF JDRF’S TOTAL REVENUES.

Donor	Minimum Contribution	Maximum Contribution
Abbott Diabetes Care	\$1,000,000	>\$1,000,000
Just Therapeutics, Inc.	\$1,000,000	>\$1,000,000
Lilly Diabetes	\$1,000,000	>\$1,000,000
Novo Nordisk	\$1,000,000	>\$1,000,000
Xeris Pharmaceuticals	\$250,000	\$499,999
Lexicon Pharmaceuticals	\$100,000	\$249,999
Merck	\$100,000	\$249,999
Pfizer, Inc.	\$100,000	\$249,999
PhRMA	\$100,000	\$249,999
Genentech	\$25,000	\$99,999
Roche	\$25,000	\$99,999
Sanofi	\$25,000	\$99,999
Anne and Steve Ubl*	\$25,000	\$99,999
<b>Totals</b>	<b>\$4,750,000</b>	<b>\$5,899,991</b>

[JDRF, Donor Honor Roll, [8/4/20](#); \*Steve Ubl is president and CEO of PhRMA]

2019: JDRF's total revenue was more than \$231 million.

[JDRF, Consolidated Financial Statements June 30, 2019 and 2018, [10/16/19](#)]

## ADDITIONAL FINANCIAL INFORMATION

2019: JDRF had \$232 million in total revenue.

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

- 2019: \$132 million of JDRF's revenue came from "Events (galas, walks, rides, etc.)."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

- 2019: \$79 million of JDRF's revenue came from "Contributions."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

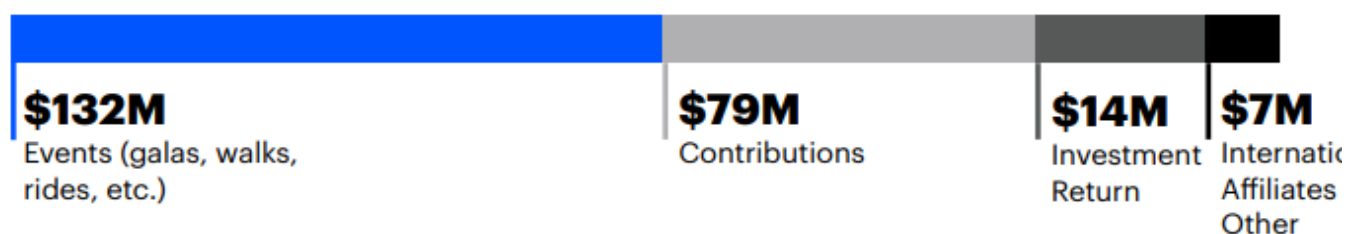
- 2019: \$14 million of JDRF's revenue came from "Investment return."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

- 2019: \$7 million of JDRF's revenue came from "International Affiliates/other."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

## **\$232M** in revenue



[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

2019: Lilly Diabetes and Novo Nordisk were listed among JDRF's "Principal Partners" for "Contributing between \$1,000,000 and \$1,999,999 annually."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

2019: Medtronic was listed as one of JDRF's "Champion Partners" for "Contributing between \$500,000 and \$999,999 annually."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

2019: Abbot and Dexcom were listed among JDRF's "Major Partners" for "Contributing between \$250,000 and \$499,999 annually."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

2019: Walgreens, MilliporeSigma, Xeris Pharmaceuticals, CVS Health, and Sanofi were listed among JDRF's "Supporting Partners" for "contributing between \$100,000 and \$249,999 annually."

[JDRF, 2019 Annual Report, accessed [12/1/20](#)]

2019: JDRF touted that it collaborated with industry partners, "including pharmaceutical and technology companies."

"Our advocacy, leadership and expertise in emerging research influences and attracts still more funding for cures research and advances to improve lives. This includes funding from the U.S. government and international governments. Other non-profit organizations and philanthropy foundations also either partner with us to invest



funding or do so on their own based on our leadership work. We collaborate with hundreds of industry partners – including pharmaceutical and technology companies – that also invest in T1D research. Together, we have become a strong network, funding and supporting T1D advances.” [JDRF, 2019 Annual Report, accessed [12/1/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
DEREK RAPP	PRESIDENT AND CEO	\$800,000.00	\$49,089.00	\$849,089.00
SANDRA HIJIKATA	CHIEF DEV OFFICER & ASST SECY	\$443,750.00	\$21,194.00	\$464,944.00
JILL CLARK	CHIEF OF STAFF & ASST SECY	\$353,603.00	\$19,251.00	\$372,854.00
JOANNE MARTZ BEGAN 1018	CFO	\$79,982.00	\$1,371.00	\$81,353.00
JONATHAN R BEHR	MANAGING DIRECTOR JDRF-T1D FND	\$499,333.00	\$51,654.00	\$550,987.00
AARON KOWALSKI	CHIEF MISSION OFFICER	\$502,667.00	\$48,716.00	\$551,383.00
ALISA NORRIS	CHIEF MARKETING OFFICER	\$403,200.00	\$53,539.00	\$456,739.00
JULIA GREENSTEIN	VP RESEARCH	\$319,567.00	\$14,996.00	\$334,563.00
SUSAN YUN	CHIEF PEOPLE OFFICER	\$353,333.00	\$18,647.00	\$371,980.00
CYNTHIA RICE	SVP ADVOCACY AND POLICY	\$342,405.00	\$49,089.00	\$391,494.00
MARK GREENE THRU 518	FORMER CFO & ASST PRES	\$351,877.00	\$4,694.00	\$356,571.00

### JDRF’S BOARD OF DIRECTORS INCLUDES TWO INDIVIDUALS WHO PREVIOUSLY WORKED FOR PHARMACEUTICAL COMPANIES, AND ONE PRIVATE EQUITY EXECUTIVE INVESTED IN SEVERAL NEW PHARMACEUTICAL COMPANIES.

JDRF director Claudia Graham previously worked at pharmaceutical company Parke-Davis.

[Claudia Graham LinkedIn profile, accessed [1/25/21](#)]

- **Parke-Davis, now a part of Pfizer, developed Dilantin and Lipitor.**

“In 2000, Pfizer acquired Warner-Lambert, bringing together two of the fastest-growing companies in the pharmaceutical industry and adding to Pfizer’s global strengths and rich heritage. With Warner-Lambert, Pfizer gained product lines ranging from Parke-Davis branded pharmaceuticals to Listerine mouthwash to Schick and Wilkinson Sword wet-shave products. [...] In the first half of the 20th Century, Parke-Davis introduced a number of breakthrough products, including the first bacterial vaccine, a pure form of adrenaline, and Dilantin® (phenytoin), the first widely available treatment for epilepsy and seizure. Dilantin® remains a valuable therapy against convulsions. [...] In 1993, Warner-Lambert acquired Wilkinson Sword, combining it with Schick® to create the world’s second largest wet-shave business. However, a far greater expansion of the company came in 1996, when Warner-Lambert entered into a co-marketing agreement with Pfizer on Lipitor® (atorvastatin calcium), a new entry into the statin class of lipid-lowering agents. Discovered by Parke-Davis Research and introduced in 1997, Lipitor® is the largest-selling pharmaceutical of any kind worldwide.” [Pfizer, accessed [1/25/21](#)]

JDRF director Drayton Virkler previously worked for pharmaceutical companies Grifols, Talecris, and GlaxoSmithKline.

[Drayton Virkler LinkedIn profile, accessed [1/25/21](#)]

**Christopher Turner is a Managing Director at Warburg Pincus.**

“Christopher H. Turner is a Managing Director, Chief Administrative Officer, Head of Capital Markets and member of the Executive Management Group. He manages the firm’s Investment Support Group comprising Capital Markets, Marketing and Communications, Public Policy/ESG, Digital Strategy and Innovation, Shared Services, and Leadership/Organizational Effectiveness. He also oversees the firm’s[1] Human Resources Management, internal IT services, and other staff functions. Prior to joining Warburg Pincus in 2005, Mr. Turner was a Managing Director at Goldman Sachs.”

[Warburg Pincus, accessed [12/6/20](#)]

**Warburg Pincus invested in and/or founded pharmaceutical companies, including:**

- **Warburg Pharma Formed Vertice Pharma In 2015.**

“Vertice Pharma is a specialty branded and generic pharmaceuticals platform focused on acquiring specialty pharmaceutical companies and products to create a durable specialty pharmaceutical platform of scale. Vertice Pharma was formed in 2015 by Warburg Pincus and senior pharmaceutical executive Don DeGolyer, former COO of Endo International plc and CEO of North America for Sandoz International GmbH. In late 2015, Warburg Pincus helped Vertice Pharma acquire VistaPharm, Inc., a Tampa, Florida-based specialty generics manufacturer of liquid and unit dosage medications focused on the hospital channel. Vertice Pharma has global headquarters in the United Kingdom and United States headquarters in New Providence, New Jersey.”

[Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus is invested In Apteki Gemini.**

“Apteki Gemini, headquartered in Gdansk, Poland was founded in 1990 and operates pharmacies in Northern Poland, as well as a nationwide online business. The company offers the broadest range and the lowest prices of drugs in the Polish market, which allows large groups of patients access to drugs which they would otherwise not purchase. Gemini currently operates predominantly in Northern Poland and plans to expand its operations across the country. The online business, Aptekagemini.pl, was established in 2012 and is the largest Polish e-pharmacy, selling a wide range of OTC and consumer products to patients and consumers nationwide. With the support of Warburg Pincus, the business is well placed for further growth and development.” [Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus invested in Haihe Pharmaceutical.**

“Haihe Pharmaceutical focuses on discovery, development and commercialization of innovative anti-tumor drugs. Led by an academician of the Chinese Academy of Engineering and a senior management team with extensive experience in drug research and development in China and abroad, Haihe Pharmaceutical has built a precision medical platform guided by biomarkers. The company has also built a fully integrated pre-clinical evaluation technical platform and clinical study system for innovative drugs, with advanced technology and operation in consistence with international standards and norms, covering subunits from compound synthesis, CMC study, biomarker discovery and validation, medical strategy and clinical study, etc. With a globally competitive innovative drug R&D system, the company has a robust product pipeline, including eight compounds in clinical and three compounds in preclinical studies.”

[Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus is invested in Helix.**

“Helix is the leading population genomics company working at the intersection of clinical care, research, and genomics. Its end-to-end platform enables health systems, life sciences companies, and payers to advance genomic research and accelerate the integration of genomic data into clinical care. Powered by one of the world’s largest CLIA / CAP next-generation sequencing labs and its proprietary Exome+® assay, Helix supports all aspects of population genomics, including recruitment and engagement, clinically actionable disease screening, return of results, and basic and translational research.” [Warburg Pincus, accessed

[12/6/20](#)]

- **Warburg Pincus is invested in HTDK.**  
“HTDK is a leading healthcare total solution provider focusing on medical devices, over-the-counter medication, consumer health, and pharmaceuticals, with a strong track record of more than 100 years. The company offers innovative, integrated and customized solutions in logistics (especially cold chain logistics), market entry, channel development, marketing and sales, and supply chain management to support the business growth in China.” [Warburg Pincus, accessed [12/6/20](#)]
- **Warburg Pincus is invested in Outset.**  
“Outset, based in San Jose, CA, is a pioneering medical technology company focused on commercializing a novel therapy for patients suffering from end stage renal disease, or kidney failure.” [Warburg Pincus, accessed [12/6/20](#)]
- **Warburg Pincus is invested in Polyplus-transfection.**  
“Founded in 2001 and based in Strasbourg, France, Polyplus is a leading global supplier of transfection reagents, which are critical inputs used in the manufacturing of cell and gene therapies. Polyplus’ reagents are embedded in the majority of clinical-stage and commercially approved drugs in the rapidly growing gene therapy market.” [Warburg Pincus, accessed [12/6/20](#)]
- **Warburg Pincus is invested in Sotera Health.**  
“Sotera Health LLC (fka Sterigenics), along with its business entities, is the world’s leading, fully integrated protector of global health. With over 500 years of combined scientific expertise, the company ensures the safety of healthcare by providing mission-critical services to the medical device, pharmaceutical, tissue and food industries. Sotera Health operates more than 62 facilities in 13 countries. The company has over 2,800 employees globally and touches the lives of more than 180 million people around the world each year. Sotera Health serves more than 6,000 customers worldwide including 75 of the top 100 medical device manufacturers. Sotera Health goes to market through its three best-in-class companies D Nelson Labs, Nordion and Sterigenics D with the mission of ensuring the safety of healthcare each and every day.” [Warburg Pincus, accessed [12/6/20](#)]

## Lobbying Activities

### 1999-2020: JDRF SPENT MORE THAN \$15 MILLION ON FEDERAL LOBBYING.

**1999-2020: JDRF spent \$15,788,342.00 lobbying the federal government.**

[U.S. Senate Lobbying Disclosure Database, accessed [2/18/21](#)]

**JDRF does not appear to have employed a lobbying firm since at least 1999.**

[U.S. Senate Lobbying Disclosure Database, accessed [2/18/21](#)]

- **Sep. 2018-Nov.2020: Aaron W Hunter served as a Director for Government Relations for JDRF.**  
[LinkedIn, accessed [12/1/20](#)]
  - **Nov. 2020: Hunter left JDRF to be a Director for Federal Government Affairs Policy at AstraZeneca.**  
[LinkedIn, accessed [12/1/20](#)]

## Investments: JDRF T1D Fund LLC

### 2016: JDRF CREATED A PHILANTHROPIC VENTURE CAPITAL TO INVEST IN TYPE-1 DIABETES THERAPIES AND MEDICAL DEVICES, USING THE RETURNS TO MAKE FURTHER INVESTMENTS.

**2016: JDRF created the JDRF T1D Fund as a “philanthropic vehicle run as a venture capital fund” to “create a new investment market” related to type-1 diabetes.**

“The JDRF T1D Fund: A philanthropic vehicle run as a venture capital fund. Launched in December 2016, the T1D Fund was established to create a new investment market aimed at delivering solutions to people living with or at risk of developing T1D. We are now one of the largest disease-focused venture philanthropy funds

in the world, with \$100m in assets, and our philanthropic dollars are spurring private investment to ultimately secure the billions we need to generate cures. Our portfolio consists of therapeutics, diagnostics, devices and vaccines. We invest with an emphasis on cure-oriented therapies.”

[JDRF T1D Fund, accessed [2/19/21](#)]

**The JDRF T1D Fund's management and donors do not receive distributions from returns, and returns are reinvested into the fund to support additional ventures.**

“The T1D Fund invests in products and therapies that enable people with T1D, or those at risk of developing it, to lead a more normal and longer life. We invest in opportunities that can generate returns. Potential for returns on investments is important to attract outside investors and create syndicates necessary to finance T1D opportunities. As a venture philanthropy fund, neither management nor donors to the T1D Fund receive distributions. Our returns are reinvested back into the Fund so that we can support the next generation of life-changing T1D treatments.” [JDRF T1D Fund, accessed [2/19/21](#)]

**JDRF T1D FUND'S MANAGING DIRECTOR STEVEN ST. PETER FOUNDED AND INVESTED IN PHARMACEUTICAL COMPANIES.**

**JDRF T1D Fund managing director Steve St. Peter “founded, invested in and/or been involved with pharmaceutical companies.”**

“Managing Director Steven St. Peter joined the T1D Fund in November 2019. From 2012 until 2019, Steven was Founder, President and Chief Executive Officer of Aratana Therapeutics, Inc. (NASDAQ: PETX), an animal health company focused on the licensing, development and commercialization of innovative therapeutics. Steven was previously a Managing Director at MPM Capital in Boston where his investment scope included both venture and buyout transactions across the pharmaceutical and medical technology industries. His investment experience also includes positions at Apex Partners and The Carlyle Group. Over the past decades, Steven has founded, invested in and/or been involved with several life sciences companies, including Align Technologies (NASDAQ: ALGN), Medpointe, ESP Pharma, SkinMedica, Omrix (NASDAQ: OMRI), Pharmathene (NYSE: PIP), Xanodyne, Syndax (NASDAQ: SNDX), EKR Therapeutics, Proteon (NASDAQ: PRTO), Rhythm (NASDAQ:RYTM) and others. Steven has served on the Executive Committee & Board of Directors of the New England Venture Capital Association and he has been active in a variety of other professional organizations.” [JDRF T1D Fund, accessed 2/19/21]

**AT LEAST TWO MEMBERS OF THE JDRF T1D FUND'S INVESTMENT COMMITTEE HAVE BACKGROUNDS IN THE PHARMACEUTICAL INDUSTRY.**

**T1D Fund investment committee member Stephen Newman was on the board of directors of Zavante Therapeutics.**

“Stephen Newman served as Chair of the JDRF Research Committee from 2016 to 2018 and a member of its International Board of Directors, serving as vice chair from 2014-2016. He has served as a board member of the T1D Fund and was the founding chair of the T1D Fund Investment Committee. Steve and his wife Debbie's daughter Emilie was diagnosed with T1D in 1983 at age 5. In his professional life, he is a Strategic Advisor at Gryphon Investors and recently served as a member of the board of directors of Zavante Therapeutics Inc. Newman presently serves as Executive Chairman of the board of directors of CentraForce, LLC. Previously, Steve served in a number of senior leadership roles at Tenet Healthcare Corporation, including Vice Chairman, C.O.O., Executive Vice President and C.E.O., Tenet California. Before joining Tenet, he held executive positions at HCA Holdings Kentucky Region and served as Senior Vice President and Chief Medical Officer of Touro Infirmary in New Orleans. Prior to 1990, he was an Associate Professor of Pediatrics and Medicine at Wright State University School of Medicine, and Director of Gastroenterology and Nutrition Support at Children's Medical Center in Dayton, Ohio.”

[JDRF T1D Fund, accessed [2/19/21](#)]

**T1D Fund investment committee member Jerry Wisler “spent over 30 years in the pharmaceutical industry,” including as the founder and CEO of Omthera Pharmaceuticals, as well as roles with Novartis and Merck.**

“Jerry Wisler and his wife Dee’s son Michael was diagnosed with T1D in 2004 at age 8. Jerry spent over 30 years in the pharmaceutical industry. He was the President, C.E.O., and Co-Founder of Omthera Pharmaceuticals, which was acquired by Astra Zeneca in July 2013. Throughout his career, Jerry has held multiple executive positions, serving as President and C.E.O. of Aegerion Pharmaceuticals, Vice President of Novartis Pharmaceuticals, and the Vice President of Merck and Co, Inc. Previously, he held leadership positions on the Board of Directors for Omthera Pharmaceuticals, Aegerion Pharmaceuticals, and Thermalin Diabetes, LLC. Jerry is a former member of the JDRF International Board of Directors.”  
[JDRF T1D Fund, accessed [2/19/21](#)]

## **THE JDRF T1D FUND HAS INVESTED IN A NUMBER OF PHARMACEUTICAL AND MEDICAL DEVICE COMPANIES.**

### **JDRF T1D Fund Invested in AnToIRx, Inc.**

“Approach: Developing antigen-specific immune tolerance therapies for autoimmune and allergic diseases  
Strategic Area: Immunotherapies T1D Funding Impact: Catalyzing company formation and T1D program, together with a pharmaceutical company partner.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Bigfoot Biomedical.**

“Approach: Developing a comprehensive diabetes management ecosystem to reduce the burden of diabetes for insulin-dependent individuals living with T1D and T2D  
Strategic Area: Improving Lives T1D Funding Impact: Accelerating the development of interoperable automated insulin delivery systems for people with T1D.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Biolinq.**

“Approach: Developing a wirelessly-enabled biosensor patch capable of continuously monitoring multiple biomarkers. Initially focused on a minimally-invasive continuous glucose monitor (CGM) for people with diabetes  
Strategic Area: Improving Lives T1D Funding Impact: Accelerating the development of a clinical-stage next gen sensing platform.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Capillary Biomedical.**

“Approach: Clinical-stage novel extended wear insulin infusion set technology to improve the lives of people with T1D on insulin pump therapy  
Strategic Area: Improving Lives T1D Funding Impact: Supporting the development and entry to the clinic of a novel long wear infusion set system for clinical benefit and comfort.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Diasome Pharmaceuticals.**

“Approach: Developing a clinical stage liver-targeted insulin for improved glycemic control  
Strategic Area: Improving Lives T1D Funding Impact: Catalyzing financing alongside VC lead to complete critical clinical studies”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in DiogenX.**

“Approach: Developing a regenerative agent to restore functional beta cell mass  
Strategic Area: Beta Cell Therapies T1D Funding Impact: Supporting a T1D-focused company founded on compelling science with transformational potential.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in eGenesis Bio.**

“Approach: Creating a renewable islet source from animal organs  
Strategic Area: Beta Cell Therapies T1D Funding Impact: Bringing T1D experience to a platform company.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Entera.**

“Approach: Developing antibodies that inhibit beta cell death  
Strategic Area: Beta Cell Therapies T1D Funding Impact: Bringing T1D focus and experience to a multi-indication drug.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in GluSense Medical.**

“Approach: Developing a long-term implantable continuous glucose monitor (CGM) for diabetes patients  
Strategic Area: Improving Lives T1D Funding Impact: Funding to critical value inflection points.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in i2o Therapeutics.**

“Approach: Developing a platform of ionic liquids to enable oral drug delivery of insulin and other therapies  
Strategic Area: Improving Lives T1D Funding Impact: Accelerate the development of a delivery platform enabling oral insulin dosing for more physiologic glucose control.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in ImmusanT.**

“Approach: Developing a peptide desensitization therapy for T1D Strategic Area: Immunotherapies T1D  
Funding Impact: Catalyzing the creation of a T1D-focused program using a powerful platform.” [JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Immunocore.**

“Approach: Soluble TCR bi-specific approach for safer, durable, tissue-specific immunomodulation to preserve beta cells  
Strategic Area: Immunotherapies T1D Funding Impact: Catalyzing the acceleration of a T1D-focused autoimmune program using a powerful platform.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in IM Therapeutics.**

“Approach: Precision medicine platform developing small molecules blockers of autoimmunity Strategic Area: Immunotherapies T1D  
Funding Impact: Advancing second generation of genetically targeted blockers.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Inversago Pharma.**

“Approach: Developing an oral drug to promote beta cell functional recovery Strategic Area: Beta Cell Therapies.  
T1D Funding Impact: Bringing T1D focus and experience to a multi-indication drug.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Kriya Therapeutics.**

“Approach: Using gene therapy to achieve insulin independence in established T1D Strategic Area: Beta Cell Therapies T1D  
Funding Impact: Bringing T1D expertise to a next-generation gene therapy platform company focused on prevalent and severe chronic diseases.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Pandion Therapeutics.**

“Approach: Islet-targeted immunotherapies for safer, durable treatments Strategic Area: Immunotherapies T1D  
Funding Impact: Catalyzing the creation of a T1D-focused program using a powerful platform.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Protomer Technologies.**

“Approach: Developing a highly-sensitive glucose-responsive insulin Strategic Area: Improving Lives T1D  
Funding Impact: Accelerating the development of a novel insulin formulation.”  
[JDRF T1D Fund, accessed [12/2/20](#)]

### **JDRF T1D Fund Invested in Prevention Bio.**

“Approach: Building and advancing a diversified portfolio of advanced clinical-stage and pre commercial-stage candidates that intercept, prevent or delay the progression of debilitating, life-impacting, and life-threatening diseases such as type 1 diabetes, celiac disease, and lupus (NASDAQ: PRVB) Strategic Area: Immunotherapies T1D  
Funding Impact: Facilitated the acquisition and clinical development of T1D-relevant assets” (IPO JULY

2018).

[JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in Repertoire Immune Medicines.**

“Approach: Decoding the targets of disease-causing T cells to develop immunotherapy treatments Strategic Area: Immunotherapies T1D Funding Impact: Catalyzing the creation of a T1D program using a powerful discovery platform.”

[JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in Semma Therapeutics.**

“Approach: Combining proprietary cells with state-of-the-art devices towards insulin independence Strategic Area: Beta Cell Therapies T1D Funding Impact: Funding development of beta cell replacement therapy with JDRF collaboration (ACQUIRED BY VERTEX SEPT. 2019).”

[JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in Sonoma Biotherapeutics.**

“Approach: Developing a promising immune modulator to preserve beta cell function Strategic Area: Immunotherapies T1D Funding Impact: Accelerating the development of targeted therapy for T1D.” [JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in SQZ Biotech.**

“Approach: Creating an off-the shelf cell therapy to retrain the immune system Strategic Area: Immunotherapies T1D Funding Impact: Catalyzing the creation of a T1D-focused program and a new tolerance effort on a compelling platform.”

[JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in TetraGenetics.**

“Approach: Engineering a first-in-class, disease modifying immune therapy to prevent beta cell destruction Strategic Area: Immunotherapies T1D Funding Impact: Aiding in securing a downstream strategic partner for asset development.”

[JDRF T1D Fund, accessed [12/2/20](#)]

#### **JDRF T1D Fund Invested in Veralox Therapeutics.**

“Approach: Developing a therapeutic to inhibit beta cell stress Strategic Area: Beta Cell Therapies T1D Funding Impact: Accelerating the development of early stage therapy for T1D, catalyzing matching participation from other investors.”

[JDRF T1D Fund, accessed [12/2/20](#)]

### **Prescription Drug Cost Legislation**

#### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

#### **2020: JDRF told advocates not to take positions on specific federal or state legislation and faced criticism for not advocating for H.R. 3 and S. 2543.**

“Among invited guests at the State of the Union Tuesday night were diabetes patients whom lawmakers brought to help highlight insulin affordability issues. But a large, politically well-connected diabetes group advised these advocates to avoid talking about prescription drug pricing policies. In an email obtained by CQ Roll Call, the advocacy group JDRF International told attendees with diabetes to ‘stick to the messaging.’ ‘Avoid any/all political or partisan discussion,’ the group wrote in an email to several advocates for patients with Type 1 diabetes attending the State of the Union. ‘Do not speak to any specific state or Federal legislation,’ the email reads. JDRF didn’t address the email directly in response to questions. ‘JDRF has called for real, tangible bipartisan action to make insulin more affordable, to pass a multi-year renewal of the Special Diabetes Program this year, and to protect people with preexisting conditions,’ said Rachel Katz, a public relations consultant for JDRF. ‘We’ve encouraged advocates to speak out about these priorities in any engagements

with their representatives.' Michelle Freedman, the mother of a 20-year-old daughter with Type 1 diabetes and an advocate with JDRF, was the guest of Rep. Earl Blumenauer. Freedman said she was not at the address on behalf of JDRF, but still worried that talking about drug pricing legislation would compromise the organization's status as a 501(c)3 charity, which is limited in its capacity to lobby. Elizabeth Pfister, founder of T1International, a smaller diabetes organization that has criticized JDRF for accepting drugmaker funding and not advocating for drug pricing bills (HR 3, S 2543) was critical of the email. 'More than ever for patients with diabetes, the personal is political. Asking advocates not to speak to legislators about politics and bills that will affect their lives is dangerous,' Pfister said." [Congressional Quarterly Health, 2/5/20]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

#### **2020: JDRF told advocates not to take positions on specific federal or state legislation and faced criticism for not advocating for H.R. 3 and S. 2543.**

"Among invited guests at the State of the Union Tuesday night were diabetes patients who lawmakers brought to help highlight insulin affordability issues. But a large, politically well-connected diabetes group advised these advocates to avoid talking about prescription drug pricing policies. In an email obtained by CQ Roll Call, the advocacy group JDRF International told attendees with diabetes to 'stick to the messaging.' 'Avoid any/all political or partisan discussion,' the group wrote in an email to several advocates for patients with Type 1 diabetes attending the State of the Union. 'Do not speak to any specific state or Federal legislation,' the email reads. JDRF didn't address the email directly in response to questions. 'JDRF has called for real, tangible bipartisan action to make insulin more affordable, to pass a multi-year renewal of the Special Diabetes Program this year, and to protect people with preexisting conditions,' said Rachel Katz, a public relations consultant for JDRF. 'We've encouraged advocates to speak out about these priorities in any engagements with their representatives.' Michelle Freedman, the mother of a 20-year-old daughter with Type 1 diabetes and an advocate with JDRF, was the guest of Rep. Earl Blumenauer. Freedman said she was not at the address on behalf of JDRF, but still worried that talking about drug pricing legislation would compromise the organization's status as a 501(c)3 charity, which is limited in its capacity to lobby. Elizabeth Pfister, founder of T1International, a smaller diabetes organization that has criticized JDRF for accepting drugmaker funding and not advocating for drug pricing bills (HR 3, S 2543) was critical of the email. 'More than ever for patients with diabetes, the personal is political. Asking advocates not to speak to legislators about politics and bills that will affect their lives is dangerous,' Pfister said." [Congressional Quarterly Health, 2/5/20]

## **LEUKEMIA LYMPHOMA SOCIETY (LLS)**

Website: <https://www.lls.org/>

Documents: [Conflict of Interest Policy](#)  
[Whistleblower Program](#)  
[Gift Policy](#)  
[Corporate Relations Policy](#)  
[Pharmaceutical Funding Statement](#)

### **Financials**

#### **LEUKEMIA & LYMPHOMA SOCIETY DISCLOSED DONORS WHO CONTRIBUTED MORE THAN \$10,000.**

**2019: LLS disclosed all donors who contributed more than \$10,000 to the organization and provided ranges of up to \$1 million and above.**

[LLS, Annual Report 2019, [2/6/20](#)]



**LLS stated it “does receive financial support from the pharmaceutical and Allied Health Industry” and discloses such contributions in their annual reports.**

“LLS response to Senator Charles E. Grassley’s letters of inquiry regarding public disclosure of industry support dated December 7, 2009 and May 4, 2011 The Leukemia & Lymphoma Society (LLS) is committed to maintaining the highest standards of compliance and transparency regarding the support we receive from Industry and Allied Health partners. LLS does receive financial support from the pharmaceutical and the Allied Health Industry. Accordingly, we identify these donations in our Annual Report, which is published annually. The LLS Annual Report is distributed to LLS individual, corporate and foundation donors. The Annual report is also available as a PDF document on the LLS website, as are all LLS educational programs and printed materials. LLS accepts funding from corporate donors, including pharmaceutical, medical device and insurance industries when it identifies companies that will provide support for LLS programs, research or fundraising/campaign events. LLS applies for industry funding through grant requests to individual companies. LLS will only accept industry funding that is free of influence as to the content, format or delivery of its educational, research, public policy and fundraising programs. This policy is directed by the National Office of LLS and is followed by all LLS chapter offices as well.”

[LLS, accessed [12/2/20](#)]

**2015: Half of LLS’ largest donors were pharmaceutical companies, each contributing more than \$1 million.**

“The group, which has an annual budget of about \$300 million, spends millions of dollars a year funding research at universities and pharmaceutical companies that it hopes will lead to new treatments for blood cancers. According to its annual report, of the group’s 16 largest donors, eight were pharmaceutical companies. All eight donated more than \$1 million to the society in 2015.”

[New York Times, [9/27/16](#)]

**2019: LEUKEMIA & LYMPHOMA SOCIETY RECEIVED AT LEAST \$10.2 MILLION FROM THE PHARMACEUTICAL INDUSTRY AND POSSIBLY MORE THAN \$14.6 MILLION – BETWEEN 2.4 AND 3.5 PERCENT OF THEIR TOTAL REVENUE.**

**2019: LLS received at least \$10.2 million and possibly more than \$14.6 million in contributions from the pharmaceutical industry.**

Donor	Minimum Contribution	Maximum Contribution
Celgene Corporation	\$1,000,000	>\$1,000,000
Genentech/Biogen	\$1,000,000	>\$1,000,000
Gilead Sciences, Inc.	\$1,000,000	>\$1,000,000
Jazz Pharmaceuticals, Inc.	\$1,000,000	>\$1,000,000
Pharmacyclics/Janssen	\$1,000,000	>\$1,000,000
Takeda Oncology	\$1,000,000	>\$1,000,000
AbbVie Inc.	\$500,000	\$999,999
Amgen Inc.	\$500,000	\$999,999
Astellas Pharma US, Inc.	\$500,000	\$999,999
Kite, A Gilead Company	\$500,000	\$999,999

Donor	Minimum Contribution	Maximum Contribution
Novartis Pharmaceuticals	\$500,000	\$999,999
AstraZeneca Pharmaceuticals	\$250,000	\$499,999
Bayer	\$250,000	\$499,999
Bristol-Myers Squibb	\$250,000	\$499,999
Pfizer, Inc.	\$250,000	\$499,999
Daiichi Sankyo	\$100,000	\$249,000
Incyte Corporation	\$100,000	\$249,000
Teva Pharmaceuticals	\$100,000	\$249,000
Janssen Biotech	\$50,000	\$99,999
Seattle Genetics	\$50,000	\$99,999
BeiGene, Ltd	\$25,000	\$49,999
Eli Lilly and Company	\$25,000	\$49,999
Merck & Company	\$25,000	\$49,999
Otsuka	\$25,000	\$49,999
Sanofi Genzyme	\$25,000	\$49,999
Tolero Pharmaceuticals, Inc.	\$25,000	\$49,999
Aptose Biosciences	\$10,000	\$24,999
Astellas	\$10,000	\$24,999
Biotechnology Innovation Organization	\$10,000	\$24,999
Boston Biomedical	\$10,000	\$24,999
Epizyme	\$10,000	\$24,999
Helsinn Therapeutics, Inc.	\$10,000	\$24,999
Horizon Pharma USA, Inc.	\$10,000	\$24,999
Immunogen	\$10,000	\$24,999
Incyte Corp	\$10,000	\$24,999
Mallinckrodt Pharmaceuticals	\$10,000	\$24,999
Merck	\$10,000	\$24,999

Donor	Minimum Contribution	Maximum Contribution
PhRMA	\$10,000	\$24,999
Servier Pharmaceuticals	\$10,000	\$24,999
Stemline Therapeutics	\$10,000	\$24,999
Vanda Pharmaceuticals Inc.	\$10,000	\$24,999
Verastem	\$10,000	\$24,999
<b>Totals</b>	<b>\$10,210,000</b>	<b>\$14,646,967</b>

[LLS, Annual Report 2019, [2/6/20](#)]

**2019: The Leukemia & Lymphoma Society's total revenue was more than \$414 million.**

[LLS, Annual Report 2019, [2/6/20](#)]

**2018-2019: The Leukemia & Lymphoma Society's copay assistance program was funded entirely by just six donors.**

"By contrast to the granularity of the general public donations, the Co Pay program in 2019 and 2018 was funded by six donors."

[LLS, Annual Report 2019, [2/6/20](#)]

- **2019: The LLS copay assistance program received contributions totaling more than \$90 million.**  
[LLS, Annual Report 2019, [2/6/20](#)]
- **2018: The LLS co-pay assistance program received contributions totaling more than \$159 million.**  
[LLS, Annual Report 2019, [2/6/20](#)]

## ADDITIONAL FINANCIAL INFORMATION

**2019: LLS had more than \$414.3 million in total operating revenue.**

[LLS, 2019 Annual Report, accessed [12/2/20](#)]

- **2019: \$264 million of LLS' revenue came from "net campaign contributions."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$90.9 million of LLS' revenue came from "co-pay contributions."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$4.4 million of LLS' revenue came from "Therapy Acceleration Program contractual return."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$14.9 million of LLS' revenue came from "service revenue."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$11.9 million of LLS' revenue came from "donated services, goods and media."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$19.9 million of LLS' revenue came from "legacies and other revenue."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]
- **2019: \$7.1 million of LLS' revenue came from "net interest and dividend income."**  
[LLS, 2019 Annual Report, accessed [12/2/20](#)]

Pharmacyclics and Janssen were each listed as a “National Presenting Sponsor of Survivorship & Hope” for the 2020 LLS Light the Night event. [LLS, accessed [12/2/20](#)]

Walgreens was listed as one of the “Leading Lights” of the 2020 LLS Light the Night event. [LLS, accessed [12/2/20](#)]

AbbVie, Amgen, AstraZeneca, Bristol Myers Squibb, Pfizer, and Genentech were each listed as a “Luminary” for the 2020 LLS Light the Night event. [LLS, accessed [12/2/20](#)]

2020: Bristol Myers Squibb, Genentech and Biogen, Gilead, Jazz Pharmaceuticals, Pharmacyclics and Janssen, Takeda and Walgreens were members of LLS’ President’s Circle for contributing \$1 million+. [LLS, accessed [12/2/20](#)]

2020: AbbVie, Amgen, Astellas, Kite and Gilead, and Novartis were members of LLS’ Leadership Circle for contributing between \$500,000 and \$999,999. [LLS, accessed [12/2/20](#)]

2020: AstraZeneca and Pfizer were members of LLS’ Innovation Circle for contributions of between \$250,000 and \$499,999. [LLS, accessed [12/2/20](#)]

**Leadership**

**MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION**

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
LOUIS J DEGENNARO	PRESIDENT &	\$781,916.00	\$41,686.00	\$823,602.00
ROSEMARIE A LOFFREDO - END 33119	EVP CHIEF FI	\$405,232.00	\$22,698.00	\$427,930.00
GORDON MILLER JR	EVP CHIEF FI	\$283,759.00	\$39,673.00	\$323,432.00
ROBERT BECK - END 7519	EVP CHIEF OP	\$256,730.00	\$835.00	\$257,565.00
GWEN NICHOLS	EVP CHIEF ME	\$481,501.00	\$38,386.00	\$519,887.00
ALICE O'ROURKE - END 81518	EVP CHIEF DE	\$387,674.00	\$31,477.00	\$419,151.00
KATHY GRIESENBECK	EVP CHIEF RE	\$377,786.00	\$36,695.00	\$414,481.00
LEE M GREENBERGER	SVP CHIEF SC	\$344,708.00	\$43,281.00	\$387,989.00
THOMAS OSGOOD	EVP CHIEF HU	\$312,125.00	\$24,807.00	\$336,932.00
MARCIE KLEIN	EVP COMMUNIC	\$292,249.00	\$35,199.00	\$327,448.00
ANDREW S COCCARI - END 7618	EVP CHIEF PR	\$191,345.00	\$26,623.00	\$217,968.00

[Leukemia & Lymphoma Society Inc., IRS Form 990, [2/4/20](#)]

## LEUKEMIA & LYMPHOMA SOCIETY PRESIDENT AND CEO LOUIS DEGENNARO PREVIOUSLY WORKED IN THE PHARMACEUTICAL INDUSTRY.

**Leukemia & Lymphoma Society President and CEO Louis DeGennaro previously worked at pharmaceutical companies Wyeth and Synex.**

“Louis J. DeGennaro, Ph.D., is president and chief executive officer of The Leukemia & Lymphoma Society (LLS), a global leader in the fight against cancer. Dr. DeGennaro leads the mission and operations of this \$400 million cancer patient advocacy agency with headquarters in Rye Brook, New York. [...] After receiving his doctorate in biochemistry from the University of California at San Francisco, Dr. DeGennaro did his post-doctoral research at the Yale University School of Medicine. His previous academic appointments include research group leader, Max Planck Institute in Munich, Germany and associate professor of neurology and cell biology, University of Massachusetts Medical School. His previous private sector appointments included Senior Director, Molecular Genetics, Wyeth Pharmaceuticals and Executive Vice President, Synex Pharmaceuticals.”

[Leukemia & Lymphoma Society, accessed [1/25/21](#)]

- **DeGennaro spent 8 years at Wyeth Pharmaceuticals as a senior director of molecular genetics, and a year as an executive vice president at SynX Pharma.**

“Executive Vice President, R&D Company Name SynX Pharma Inc. Dates Employed: 2003 – 2004.

Employment Duration: 1 yr. Wyeth Senior Director, Molecular Genetics Company, Name Wyeth. Dates Employed: 1993–2001. Employment Duration: 8 yrs.”

[Louis DeGennaro LinkedIn profile, accessed [1/25/21](#)]

## KATHLEEN MERIWEATHER, LLS BOARD OF DIRECTORS SECRETARY/TREASURER

**Kathleen Meriwether is an “America’s Life Sciences Leader” at Ernst & Young LLP where she specializes in “assisting health sciences companies.”**

“Kathleen Meriwether is the Americas Life Sciences Leader for Ernst & Young LLP’s Forensic and Integrity practice. She specializes in assisting health sciences companies with global risks and compliance assessments and regulatory compliance analysis. She works closely with management teams, compliance officers and counsel to identify compliance and enforcement risks, determine potential vulnerabilities and recommend solutions from business and operational perspectives.”

[LLS, accessed [12/2/20](#)]

**Meriwether worked at Bristol-Myers Squibb for more than 16 years.**

“She previously spent more than 16 years with Bristol-Myers Squibb Company in a number of legal, regulatory affairs and compliance positions, including division counsel for the Oncology and Immunology franchise.”

[LLS, accessed [12/2/20](#)]

## RICK BAGGER, LLS BOARD OF DIRECTORS MEMBER

**Rich Bagger was VP of Corporate Affairs and Market Access for Celgene from Jan. 2012 through Dec. 2019.**

“Rich Bagger served as executive vice president of corporate affairs and market access for Celgene from January 2012 through December 2019, where he oversaw communications, patient advocacy, government relations and policy, market access, global health and corporate responsibility.”

[LLS, accessed [12/2/20](#)]

## RENZO CANETTA, LLS BOARD OF DIRECTORS MEMBER

**2020: Renzo Canetta was an LLS board of directors member who had “more than 35 years of clinical and regulatory research experience at Bristol-Myers Squibb.”**

[LLS, accessed [12/2/20](#)]

## LYNNE O'BRIEN, LLS BOARD OF DIRECTORS MEMBER

**2020: Lynne O'Brien was an LLS board of directors member who had previously worked as the "director of the Washington government affairs office of DuPont Merck."**

"Previously, she worked as director of the Washington government affairs office of DuPont Merck, working with members of Congress on issues involving the U.S. Food and Drug Administration, tax legislation, and health care reform." [LLS, accessed [12/2/20](#)]

## MARLA PERSKY, LLS BOARD OF DIRECTORS MEMBER

**LLS board member Marla Persky was previously a senior vice president and general counsel at Boehringer Ingelheim.**

"Board Member Marla S. Persky retired as senior vice president and general counsel of Boehringer Ingelheim USA Corporation in 2013."

[Leukemia & Lymphoma Society, accessed [1/25/21](#)]

## CASEY CUNNINGHAM, LLS BOARD OF DIRECTORS MEMBER

**2020: Casey Cunningham was an LLS board member and the chief scientific officer at a venture capital fund focused on "companies in healthcare and life sciences."**

"Casey Cunningham, M.D. is the chief scientific officer of Santé Ventures, a venture capital fund focused on creating and investing in companies in healthcare and life sciences."

[LLS, accessed [12/2/20](#)]

- **Santé Ventures is invested in new pharmaceutical companies, Glyscend, Iterion Therapeutics, Libra Therapeutics, Lumos Pharma, Molecular Templates (MTem), and Nirogy Therapeutics.**

[Santé Ventures, accessed [1/25/21](#)]

## Lobbying Activities

### THE LEUKEMIA & LYMPHOMA SOCIETY EMPLOYS A LOBBYING FIRM THAT REPRESENTS THE PHARMACEUTICAL INDUSTRY.

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
Leukemia & Lymphoma Society	Kountopes Denham Carr & Reid	Association for Accessible Medicines; Glenmark Pharmaceuticals

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**Q1-Q3 2020: According to federal lobbying disclosure records, LLS spent at least \$150,000 on lobbying firm Kountopes Denham Carr & Reid, LLC (KCDR).**

[U.S. Senate Lobbying Disclosure Database, accessed [12/2/20](#)]

**Q1-Q3 2020: KCDR lobbied on behalf of pharmaceutical and related companies, including AHIP, CVS Health and Glenmark Pharmaceuticals.**

Association for Accessible Medicines (formerly – Generic Pharmaceutical Assn), AHIP, Consumer Healthcare Products Association, CVS Health, Dialysis Patient Citizens, and Glenmark Pharmaceuticals Inc. USA. [U.S. Senate Lobbying Disclosure Database, accessed [12/2/20](#)]

**Q1-Q3 2020: Julie Hershey Carr was a registered lobbyist for pharmaceutical and related companies, including AHIP, CVS Health and Glenmark Pharmaceuticals, while serving as a registered lobbyist for LLS.**

- According to federal lobbying disclosure records, Carr was a registered lobbyist in Q1-Q3 2020 for

pharmaceutical and related companies, AHIP, the Association for Accessible Medicines (formerly – Generic Pharmaceutical Assn.), the Consumer Healthcare Products Association, CVS Health, and Glenmark Pharmaceuticals. [U.S. Senate Lobbying Disclosure Database, accessed [12/2/20](#)]

- **Q1-Q3 2020: Lori Denham was a registered lobbyist for pharmaceutical and related companies, including AHIP and CVS Health, while serving as a registered lobbyist for LLS.**

According to Federal Lobbying disclosure records, Denham was a registered lobbyist in Q1-Q3 2020 for pharmaceutical and related companies AHIP, the Association for Accessible Medicines (formerly – Generic Pharmaceutical Assn), Consumer Healthcare Products Association, CVS Health, Dialysis Patient Citizens while serving as a registered lobbyist for LLS.

[U.S. Senate Lobbying Disclosure Database, accessed [12/2/20](#)]

## **ADDITIONAL LOBBYING INFORMATION**

**1998-2019: LLS spent \$6,743,955 on federal lobbying.**

[Center for Responsive Politics, accessed [12/2/20](#)]

**2018: LLS spent \$378,846 on “publications, or published broadcast statements.”**

[LLS, IRS Form 990, [2/4/20](#)]

**2018: LLS spent \$288,980 on “direct contact with legislators, their staffs, government officials, or a legislative body.”**

[LLS, IRS Form 990, [2/4/20](#)]

**2018: LLS spent \$292,721 on “rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means.”**

[LLS, IRS Form 990, [2/4/20](#)]

**2018: LLS spent \$709,983 on “other activities.”**

[LLS, IRS Form 990, [2/4/20](#)]

## **Grants**

**2018: LLS provided a \$250,000 therapy acceleration grant to Forty Seven Inc.**

[LLS, IRS Form 990, [2/4/20](#)]

- **Forty Seven Inc. was an “immune-oncology company” developing monoclonal antibodies to treat cancer.**

“Forty Seven, Inc. is a clinical-stage immuno-oncology company that is developing therapies targeting cancer immune evasion pathways and specific cell targeting approaches based on technology licensed from Stanford University. Forty Seven’s lead program, magrolimab, is a monoclonal antibody against the CD47 receptor, a “don’t eat me” signal that cancer cells commandeer to avoid being ingested by macrophages. This antibody is currently being evaluated in multiple clinical studies in patients with myelodysplastic syndrome, acute myeloid leukemia, non-Hodgkin lymphoma, and solid tumors.”

- **2020: Gilead acquired Forty Seven Inc.**

[Gilead, Press Release, [4/7/20](#)]

## **Prescription Drug Cost Legislation**

**H.R. 3: ELIJAH E. CUMMING LOWER DRUG COSTS NOW ACT**

*No relevant information.*

## H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

## S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information.*

## OTHER

### **LLS has commissioned studies finding fault with the drug pricing by insurers, but hasn't criticized drug companies for setting prices.**

"The Leukemia & Lymphoma Society, for instance, one of the largest charities in the United States, has frequently criticized insurers for exposing patients to high out-of-pocket costs for patients, commissioning two studies that looked at the impact of these high costs. But it has not been as outspoken about the decision by drug companies to set those prices. Some blood cancer drugs that the society's members need cost tens of thousands of dollars." [New York Times, [9/27/16](#)]

### **LLS has called for an out-of-pocket cap for Medicare Part D patients.**

"It's time for a real out-of-pocket cap on Medicare Part D drug costs that ensures patients aren't exposed to expensive, limitless drug costs. Importantly, we also need to ensure that the first pharmacy visit of the year isn't prohibitively expensive. When reforming Part D, policymakers should include a 'smoothing' mechanism that allows patients to pay what they owe towards the cap monthly, over the course of a year, instead of all at once." [LLS, accessed [12/28/20](#)]

## **LUPUS FOUNDATION OF AMERICA (LFA)**

Website: <https://www.lupus.org/>

Documents: [Corporate Partners Policy](#)  
[Whistleblower Protection Policy](#)  
[Conflict of Interest Policy](#)

## **Financials**

### **2018: THE LUPUS FOUNDATION RECEIVED 14 PERCENT OF ITS REVENUE FROM PHARMACEUTICAL COMPANIES – ABOUT \$2.3 MILLION.**

#### **FY 2018: The Lupus Foundation received 14 percent of its revenue "from pharmaceutical, biotechnology, and medical device companies."**

"Several corporations have provided educational grants and sponsorships for the Lupus Foundation of America's many programs and educational initiatives during the fiscal year ending September 30, 2018 (FY18). In FY18, 14 percent of the Foundation's overall revenue came from pharmaceutical, biotechnology, and medical device companies. The Foundation exercises independent judgement in its decision making, regardless of any financial support received from these organizations." [Lupus Foundation, accessed [1/27/21](#)]

#### **2018: The Lupus Foundation had total revenues of \$16.6 million.**

According to their audited financials for the fiscal year ending September 30, 2019, in FY 2018, the Lupus Foundation had total revenues of \$16,602,751. [Lupus Foundation, Financial Statements For the Years Ended September 30, 2019 and 2018, Lupus Foundation [5/4/20](#)]



**THE LUPUS FOUNDATION SAYS IT DISCLOSES CORPORATE DONORS, BUT THE ONLY CORPORATIONS THAT SEEM TO BE DISCLOSED ARE “NATIONAL LUPUS PARTNERS NETWORK,” WITH NO INDICATION OF WHETHER THESE CORPORATIONS CONTRIBUTED.**

**The Lupus Foundation said it disclosed its corporate donors on its website.**

“The Lupus Foundation of America routinely solicits donations from corporations to support its mission and programs that advance research into the causes of and cure for lupus, help raise awareness of lupus, improve the diagnosis and treatment of the disease, and support individuals and families affected by lupus. The Foundation’s board of directors has established a corporate relationships policy to ensure that all corporate support is appropriate and void of potential conflicts of interest. The policy includes a requirement to disclose information on the Foundation’s website about corporate support which meets minimum reporting criteria established by the National Health Council and other nonprofit oversight organizations. Several corporations have provided educational grants and sponsorships for the Lupus Foundation of America’s many programs and educational initiatives during the fiscal year ending September 30, 2018 (FY18). In FY18, 14 percent of the Foundation’s overall revenue came from pharmaceutical, biotechnology, and medical device companies. The Foundation exercises independent judgement in its decision making regardless of any financial support received from these organizations.” [Lupus Foundation, accessed [1/27/21](#)]

**The Lupus Foundation recognized a number of pharmaceutical companies as part of its “National Lupus Partners Network.”**

“We would like to thank all of our National Lupus Partners Network members for their ongoing guidance and support in the planning and execution of lupus education and awareness initiatives. [...] Industry leaders Aurinia Biogen Boehringer-Ingelheim EMD Serono Exagen GSK KPI Therapeutics Eli Lilly & Company Pfizer Progentec UCB.”

[Lupus Foundation, accessed [1/27/21](#)]

**ADDITIONAL FINANCIAL INFORMATION**

**FY 2020: LFA had more than \$17 million in “revenue and support” and did not provide a further breakdown of revenue sources.**

[LFA, 2019-2020 Annual Report, accessed [12/5/20](#)]

**2018: LFA’s 990 showed the organization had \$14,173,781 in revenue.**

[LFA, 2018 Form 990, [4/13/20](#)]

- **2018: LFA had \$119,989 in revenue from “Federated campaigns.”**  
[LFA, 2018 Form 990, [4/13/20](#)]
- **2018: LFA had \$343,624 in revenue from “Fundraising events.”**  
[LFA, 2018 Form 990, [4/13/20](#)]
- **2018: LFA had \$28,908 in revenue from “Related organizations.”**  
[LFA, 2018 Form 990, [4/13/20](#)]  
**2018: LFA had \$1,339,551 in revenue from “Government grants (contributions).”**  
[LFA, 2018 Form 990, [4/13/20](#)]
- **2018: LFA had \$12,341,709 in revenue from “All other contributions, gifts, grants and similar amounts not included above.”**  
[LFA, 2018 Form 990, [4/13/20](#)]
- **2018: LFA had \$2,087,933 in “Noncash contributions.”**  
[LFA, 2018 Form 990, [4/13/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
STEVAN W. GIBSON	PRESIDENT & CEO	\$275,513.00	\$15,700.00	\$291,213.00
SEUNG-AE CHUNG	CHIEF FINANCIAL OFFICER	\$208,641.00	\$24,107.00	\$232,748.00
SANDRA C. RAYMOND	SENIOR ADVISOR	\$295,640.00	\$35,863.00	\$331,503.00
LESLIE HANRAHAN	VP MARKETING & COMMUNICATIONS	\$209,456.00	\$25,630.00	\$235,086.00
MARY T. CRIMMINGS	VP, MARKETING C COMMUNICATIONS	\$205,573.00	\$24,127.00	\$229,700.00
DONNA GROGAN	VP, DEVELOPMENT AND FUNDRAISING	\$196,162.00	\$21,010.00	\$217,172.00
PATRICK WILDMAN	VP ADVOCACY & GOVERNMENT	\$183,239.00	\$16,210.00	\$199,449.00
JEANINE SMITH	VP, NETWORK DEVELOPMENT	\$182,036.00	\$17,782.00	\$199,818.00
PATRICIA DAVIDSON	SR. DIRECTOR OF EDUCATION & RESEARCH	\$127,119.00	\$17,783.00	\$144,902.00
SUSAN J. GLOOR	REGIONAL DIRECTOR, NE	\$120,045.00	\$15,943.00	\$135,988.00
MONICA SMITH	DIRECTOR OF DEVELOPMENT NE	\$120,045.00	\$12,371.00	\$132,416.00
DUANE PETERS	SR. DIRECTOR OF COMMUNICATIONS	\$118,910.00	\$21,753.00	\$140,663.00

[Lupus Foundation, IRS Form 990, [3/7/19](#)]

### LUPUS FOUNDATION PRESIDENT & CEO, STEVAN W. GIBSON, PREVIOUSLY WORKED FOR PHRMA.

#### **Lupus Foundation President & CEO Stevan W. Gibson worked for PhRMA before joining the organization.**

“Stevan W. Gibson joined the Lupus Foundation of America in August 2017 and was named president and CEO in October 2018. Gibson oversees the senior management of the organization and is responsible for carrying out the Foundation’s mission, organizational growth and strategic framework, including research, advocacy, care services, and development. [...] Prior to joining ALSA, Gibson worked in the White House Office of Intergovernmental Affairs in the George H.W. Bush Administration where he conducted outreach to the nation’s governors. He also has experience consulting with global corporations and serving other national and governmental organizations, including as Press Secretary for the Treasurer of the United States, and with Pharmaceutical Research and Manufacturers of America (PhRMA).”

[Lupus Foundation, accessed [1/25/21](#)]

- **2016-2017: Gibson was a consultant for alliance development at PhRMA.**

“Consultant, Alliance Development Company. Name: PhRMA. Dates Employed: Jul 2016 – Jun 2017. Employment Duration: 1 yr. Location: Washington D.C. Metro Area.”

[Stevan Gibson LinkedIn profile, accessed [1/25/21](#)]

## **DR. SUSAN MANZI, LFA BOARD OF DIRECTORS CHAIR**

**2020: Dr. Susan Manzi served as LFA's Board of Directors chair.**

"Dr. Susan Manzi is Chair of the Lupus Foundation of America Board of Directors and also serves as the Foundation's Acting Medical Director."

[LFA, accessed [12/16/20](#)]

- **2009: Manzi licensed a medical device she developed to Cypress Biosciences, a biopharmaceutical company.**

"Cypress Bioscience, Inc. (NASDAQ: CYPB) today announced it has completed a transaction to acquire Cellatope's technology platform that uses cell-bound complement activation products (CB-CAP) to diagnose and monitor debilitating autoimmune disorders, including systemic lupus erythematosus (SLE/Lupus). The acquisition is consistent with Cypress' strategy of providing innovative products and services that address unmet medical needs in the fields of rheumatology and pain. [...] The role of the complement system in autoimmune conditions, such as Lupus, has been studied for several years, and genetic defects in the complement system have been associated with the development of disease. In addition, it has been observed that activation of the complement pathway can result in inflammation and tissue damage once Lupus is established. The CB-CAP technology was developed by Dr. Joseph Ahearn and Dr. Susan Manzi at the Lupus Center for Excellence at the University of Pittsburgh, to evaluate cell bound fragments of activated complement proteins and their utility in improved diagnosis and monitoring of Lupus patients. In connection with this asset purchase, Cypress will be assuming a license from the University of Pittsburgh. Cypress plans to complete the development program and add these important Lupus personalized medicine services to the current Avise(SM) product line, which includes tests for diagnosis, prognosis and monitoring treatment of Rheumatoid Arthritis. [...] Cypress Bioscience, Inc. provides therapeutics and personalized medicine services, facilitating improved and individualized patient care. Cypress addresses the evolving needs of specialist physicians and their patients by identifying unmet medical needs in the areas of pain, rheumatology, and physical medicine and rehabilitation, including challenging disorders such as fibromyalgia and rheumatoid arthritis. This approach to improving patient care creates a unique partnership with physicians. Current products include Savella™ (milnacipran HCl) and the Avise PG(SM) and Avise MCV(SM) therapeutic monitoring, diagnostic and prognostic tests for rheumatoid arthritis."

[BioSpace, 2/24/09]

**2013-2019: Dr. Manzi received 126 payments totaling \$ 431,234.12 in associated research funding and general payments from drug makers and medical device manufacturers.**

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

## **STEPHEN RABINOWITZ, LFA BOARD OF DIRECTORS MEMBER**

**2020: Stephen Rabinowitz was a member of LFA's Board of Directors.**

[LFA, accessed [12/5/20](#)]

**Greenberg Traurig had a "Pharmaceutical, Medical Device & Health Care Practice" with more than 90 trial attorneys.**

"Greenberg Traurig's Pharmaceutical, Medical Device & Health Care Practice includes more than 90 trial attorneys representing clients in complex litigation in courts across the country. We regularly serve as national, regional, special trial, or science counsel - in both mass torts and individual cases - to leading global companies that produce innovative, life-saving products. We draw on the experience of our colleagues in related disciplines to provide strategic regulatory counsel to our pharmaceutical and medical device clients at every stage, from developing preventative measures to limit or minimize potential products liability exposure, to investigating claims, to settlement, mediation, or defending at trial. According to Chambers USA, our group is "trusted with the most difficult and sensitive matters" by our clients."

[Greenberg Traurig, accessed [12/5/20](#)]

## Lobbying Activities

### THE LUPUS FOUNDATION EMPLOYS TWO LOBBYING FIRMS THAT ALSO LOBBY FOR THE PHARMACEUTICAL INDUSTRY.

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
Lupus Foundation of America	Faegre Drinker Biddle & Reath	Alliance for Safe Online Pharmacies
	NVG, LLC (on behalf of MAPRx Coalition, an LFA initiative)	Alexion Pharmaceuticals; Astellas Pharma US; Global Blood Therapeutics; Novo Nordisk; Pfizer; PhRMA

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**Q1-Q3 2020: According to federal lobbying disclosure records, the LFA spent at least \$110,000 on lobbying firms Faegre, Drinker Biddle & Reath LLP and NVG, LLC.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/5/20](#)]

- **Faegre Drinker represents pharmaceutical companies.**

“Whether as an academic medical center, research institute, cutting-edge physician practice, pharmaceutical company, device manufacturer or clinical research organization, your focus is on medical breakthroughs and new treatment options that enhance patient care. We partner with you as you seek to ensure that your clinical research programs adhere to all accepted clinical trial guidelines, including clinical trial design and agreements, Food and Drug Administration approvals and commercialization. We help you navigate institutional review board requirements and human-subject protection rules at both the federal and state levels. We can serve as an extension of your team to help you write grants, draft budgets, develop contracts and manage data rights. We can help manage your clinical research compliance needs so that you can focus on scientific pursuits. Our attorneys, consultants and other professionals work with clinical research organizations across the industry in the U.S. and internationally.”

[Faegre Drinker Biddle & Reath, accessed [2/19/21](#)]

- **The Alliance for Safe Online Pharmacies board of directors includes a representative from pharmaceutical company Merck.**

[Alliance for Safe Online Pharmacies, accessed [2/19/21](#)]

**1999-2020: LFA spent more than \$2.3 million on federal lobbying.**

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

**October 2019: LFA joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP

cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including: • Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135 percent to 150 percent FPL in 2019), who also meet the program’s asset test, are exposed to premiums, deductibles, and high coinsurance rates (15 percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.” [MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

### **July 2020: LFA joined a letter praising the out-of-pocket caps in H.R. 3.**

“Current legislation from both the House of Representatives and the Senate has proposed putting a cap on OOP costs when Medicare Part D beneficiaries hit certain thresholds. The Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) would limit OOP spending to \$2,000 beginning in 2022 and the Prescription Drug Pricing Reduction Act of 2019 (S. 2543) would limit OOP spending to \$3,100 beginning in 2022, indexed to growth in Part D spending. The proposed cap in both bills would constitute significant progress in constraining the growth of OOP costs for Part D beneficiaries. We support a cap structure that minimizes financial exposure, as many Medicare beneficiaries live on fixed and limited incomes.”  
[InsuranceNewsNet.com, [7/21/20](#)]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*

## **OTHER**

### **November 2020: LFA issued a statement objecting to the Trump Administration’s “most favored nation” rule for prescription drug prices.**

“The Lupus Foundation of America supports efforts to lower patient out-of-pocket costs in Medicare Part B, which provides people with lupus access to critical medications, including the only drug approved to treat the disease. However, we are deeply concerned that the Administration’s Most Favored Nation rule may limit patient access to current and future therapies. Moreover, we are troubled that the Administration is rushing to implement such a significant and complex change without allowing for public comment and input from the patient communities most impacted by this rule. We strongly oppose this rule and believe that those living with lupus in the United States should have access to the full range of treatment options and not have those options limited by the decisions made in foreign countries.”

[LFA, [11/24/20](#)]

## NATIONAL ALLIANCE ON MENTAL ILLNESS (NAMI)

Website: <https://nami.org/Home>

Documents: [Donor Privacy Policy](#)  
[Board of Directors Operating Policies and Procedures](#)

### Financials

#### **NAMI DISCLOSED CORPORATE AND MAJOR FOUNDATION SPONSORSHIPS ON A QUARTERLY BASIS, PROVIDING AMOUNTS AS WELL AS DONATION PURPOSES.**

NAMI provides quarterly reports on corporate funding to the organization.

“NAMI forms strategic and innovative partnerships with foundations, corporations, federal agencies and individuals, that share our vision of a better world for people affected by mental illness. Through corporate sponsorship of signature events, we are able to raise the profile of mental illness in communities throughout the country. [...] Current and Past Corporate Sponsorships We are grateful to our corporate supporters that have helped NAMI advance our mission. The list reflects contributions only to the national organization. NAMI state organizations and affiliates are separate entities and where appropriate are established independently as non-profit 501c3 organizations.”

[NAMI, accessed [1/27/21](#)]

#### **2019: NAMI RECEIVED AT LEAST \$2.3 MILLION FROM PHARMACEUTICAL COMPANIES—ABOUT 8.8 PERCENT OF THEIR REVENUE.**

**2019: NAMI received at least \$2.3 million from pharmaceutical companies.**

Funder	Funding Purpose	Amount
Alkermes	National Walks Elite Sponsorship	\$500,000.00
Alkermes	Corporate Supporter Membership	\$75,000.00
Allergan	Corporate Supporter Membership	\$50,000.00
Allergan Foundation	NAMI Walks National Sponsorship	\$100,000.00
Boehringer Ingelheim	Corporate Supporter Membership	\$35,000.00
Lundbeck	Corporate Supporter Membership	\$35,000.00
Merck	Public Policy Initiatives	\$25,000.00
Myriad Genetics	Corporate Supporter Membership	\$50,000.00
Neurocrine	NAMI Convention	\$10,000.00
Neurocrine	Corporate Supporter Membership	\$50,000.00
Otsuka	Corporate Supporter Membership	\$50,000.00
Otsuka	NAMI Family-to-Family	\$250,000.00
Pfizer	Corporate Supporter Membership	\$35,000.00

Sage Therapeutics	Corporate Supporter Membership	\$50,000.00
Sage Therapeutics	Advancing Discovery	\$25,000.00
Sunovion	Corporate Supporter Membership	\$50,000.00
ACADIA	Corporate Supporter Membership	\$35,000.00
Alkermes	Advancing Discovery Summit	\$35,000.00
Allergan Foundation	NAMI Education Programs	\$50,000.00
Boehringer Ingelheim	Advancing Discovery Summit	\$35,000.00
Indivior	Corporate Supporter Membership	\$50,000.00
PhRMA	Inspiring Hope Through Research Event and Convention	\$125,000.00
Sunovion	Be Vocal 2019	\$25,000.00
Supernus Pharmaceuticals	Corporate Supporter Membership	\$15,000.00
Takeda	Advancing Discovery Summit	\$35,000.00
Alkermes	Inspiring Hope Through Research Event	\$25,000.00
Astellas	One Astellas Spirit Run	\$8,343.00
BIO	Inspiring Hope Through Research Event	\$5,000.00
Corcept Therapeutics	Inspiring Hope Through Research Event	\$15,000.00
Pfizer	Advocacy Efforts	\$75,000.00
Sunovion	Inspiring Hope Through Research Event	\$25,000.00
Teva	Corporate Supporter Membership	\$50,000.00
Teva	Inspiring Hope Through Research Event	\$10,000.00
Allergan	Inspiring Hope Through Research Event	\$15,000.00
Boehringer Ingelheim	Unrestricted	\$15,000.00
Genentech	Unrestricted	\$35,000.00
Janssen	Corporate Supporter Membership	\$60,000.00
Janssen	NAMI Helpline and CIT	\$150,000.00
Janssen	Inspiring Hope Through Research Event	\$15,000.00
Otsuka	Inspiring Hope Through Research Event	\$15,000.00
Sage Therapeutics	Inspiring Hope Through Research Event	\$5,000.00

Sunovion	Corporate Supporter Membership	\$50,000.00
Supernus Pharmaceuticals	Inspiring Hope Through Research Event	\$10,000.00
<b>TOTAL</b>		<b>\$2,378,343.00</b>

[Compiled from NAMI, [Q1 2019 Grants and Contributions](#); [Q2 2019 Grants and Contributions](#); [Q3 2019 Grants and Contributions](#); [Q4 2019 Grants and Contributions](#), accessed 1/27/21]

### 2019: NAMI had a total revenue of more than \$27 million.

According to their audited financials for the fiscal year ending December 31, 2019, NAMI had a total revenue of \$27,025,092.

[NAMI, Financial Statements and Independent Auditors' Report, [3/24/20](#)]

### ADDITIONAL FINANCIAL INFORMATION

#### 2019: NAMI had \$27 million in revenue.

[NAMI, 2019 Annual Report, accessed [12/9/20](#)]

- **2019: 62 percent (\$16.3 million) of NAMI's revenue came from "contributions."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 23 percent (\$6.4 million) of NAMI's revenue came from "in-kind."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 5 percent (\$1.5 million) of NAMI's revenue came from "investments."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 4 percent (\$1.1 million) of NAMI's revenue came from "walks."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 3 percent (\$0.7 million) of NAMI's revenue came from "government."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 1 percent (\$0.4 million) of NAMI's revenue came from "events."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 1 percent (\$0.3 million) of NAMI's revenue came from "dues."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]
- **2019: 1 percent (\$0.3 million) of NAMI's revenue came from "other."**  
[NAMI, 2019 Annual Report, accessed [12/9/20](#)]

#### 2019: Multiple pharmaceutical companies, including the Biotechnology Innovation Organization, Bristol-Myers Squibb and Genentech, were listed as "Corporate and Philanthropic Partners."

NAMI's 2019 annual report listed the follow organizations as "Corporate and Philanthropic Partners": Acadia Pharmaceuticals, Alkermes, Allergan, Allergan Foundation, Astellas US, Biotechnology Innovation Organization, Bristol-Myers Squibb, Boehringer Ingelheim, Genentech, Indivior, Intra-Cellular Therapies, Janssen Pharmaceuticals, Kaiser Permanente, Lundbeck US, Merck, Myriad Genetics, Neurocrine Biosciences, Merounetics, Otsuka Pharmaceutical, Pfizer, Sunovion Pharmaceuticals, Supernus Pharmaceuticals Takeda Pharmaceutical Company, Teva Pharmaceutical Industries.

[NAMI, 2019 Annual Report, accessed [12/9/20](#)]

#### 2020: Multiple pharmaceutical companies, including Bristol-Myers Squibb, Genentech, Pfizer, and PhRMA, were listed as "Corporate & Foundation Supporters."

NAMI's website listed the following companies as "Corporate & Foundation Supporters": Alkermes, Allergan, Allergan Foundation, Boehringer Ingelheim, Bristol-Myers Squibb, Corcept Therapeutics, Envolve, Genentech, Greenwich Biosciences, Intra-Cellular Therapies, Janssen, Kaiser Permanente, Lilly, Lundbeck, Myriad



Neuroscience, Neurocrine Biosciences, Neurostar, Novo Nordisk, Otsuka, Pfizer, PhRMA, Sage Therapeutics, Sunovion, Supernus, Takeda and TEVA.  
[NAMI, accessed [12/9/20](#)]

**2020: Boehringer Ingelheim, Janssen Neuroscience, Johnson & Johnson Foundation, LivaNova, Lundbeck, PhRMA, Sozosei Foundation Otsuka, and Takeda were supporters of NAMI's "COVI-19 Mental Health Support Fund."**  
[NAMI, accessed [12/9/20](#)]

**2020: Janssen Neuroscience and the Johnson & Johnson Foundation were listed as ALA "Frontline Wellness Partners."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Alkermes contributed \$75,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Allergan contributed \$50,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Allergan contributed \$15,000 to NAMI for "Inspiring Hope Through Research Event."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Boehringer Ingelheim contributed \$35,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Genentech contributed \$35,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Lundbeck contributed \$35,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Neurocrine contributed \$50,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Otsuka contributed \$250,000 to NAMI for "NAMI Family-to-Family."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Otsuka contributed \$50,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: PhRMA contributed \$125,000 to NAMI for "NAMI Convention and Inspiring Hope Through Research."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Supernus contributed \$35,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020 Sunovion contributed \$25,000 to NAMI for "Be Vocal."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Takeda contributed \$40,000 to NAMI for "corporate supporter membership."**  
[NAMI, accessed [12/9/20](#)]

**Q1 2020: Takeda/Lundbeck contributed \$50,000 to NAMI for “NAMI Smarts.”**

[NAMI, accessed [12/9/20](#)]

**Q1 2020: Takeda/Lundbeck contributed \$40,000 to NAMI for “NAMI Convention.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Alkermes contributed \$350,000 to NAMI for “NAMI Walks.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Eli Lilly contributed \$35,000 to NAMI for corporate supporter membership.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Janssen contributed \$75,000 to NAMI for “COVID-19 Relief Fund.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Johnson and Johnson Health Care Systems contributed \$75,000 to NAMI for “COVID-19 First Responders Response.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Merck contributed \$25,000 to NAMI for “General Advocacy Support 2020.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Myriad Genetics contributed \$50,000 to NAMI for “corporate supporter membership.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Livanova contributed \$15,000 to NAMI for “COVID-19 Relief Fund, NAMI HelpLine.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Neuronetics contributed \$25,000 to NAMI for “NAMI Convention / Inspiring Hope Through Research.”  
Event”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Sage Therapeutics contributed \$85,000 to NAMI for “Public Opinion Survey.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Sozosei Foundation contributed \$75,000 to NAMI for “COVID-19 Relief Fund.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Teva contributed \$50,000 to NAMI for “corporate supporter membership.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: Teva contributed \$25,000 to NAMI for “Disease Education.”**

[NAMI, accessed [12/9/20](#)]

**Q2 2020: The Allergan Foundation contributed \$100,000 to NAMI for “NAMI Homefront.”**

[NAMI, accessed [12/9/20](#)]

## **Leadership**

### **MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION**

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
Mary Gilbert'	CEO through 4/22/19	\$225,028.00	\$32,364.00	\$257,392.00
David Levy	Chief Financial Officer	\$134,507.00	\$36,304.00	\$170,811.00
Angela Kimball	Acting Chief Executive Officer	\$138,063.00	\$17,868.00	\$155,931.00
Cheri Villa	Chief Operating Officer	\$74,115.00		\$74,115.00
Charles Harman	Chief Development Officer	\$135,788.00	\$31,761.00	\$167,549.00
Andrew Sperling	Director, Legislative Affairs	\$150,232.00	\$36,439.00	\$186,671.00
Karen Gerndt	National Director, Education	\$130,420.00	\$19,222.00	\$149,642.00
Katrina Gay	Nat'l Dir , Strategic Partnerships	\$133,072.00	\$30,694.00	\$163,766.00
William Jarred	Nat'l Dir , Marketing/Communications	\$132,900.00	\$16,866.00	\$149,766.00

[NAMI, IRS Form 990, [6/16/20](#)]

## Lobbying Activities

### **1999-2020: NAMI SPENT MORE THAN \$1.7 MILLION ON FEDERAL LOBBYING.**

**1999-2020: NAMI spent \$1,718,123.98 on lobbying the federal government.**

[U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**2017-Present: NAMI has not employed a lobbying firm for federal lobbying.**

[U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

- **1996-Present: Andrew Sperling served as Director of Legislative Advocacy for NAMI.**

[LinkedIn, accessed [12/8/20](#)]

## Prescription Drug Cost Legislation

### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

**October 2019: NAMI joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching

the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including: • Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135 percent to 150 percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15 percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.”

[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*

## **NATIONAL HEALTH COUNCIL (NHC)**

Website: <https://nationalhealthcouncil.org/>

Documents: [Conflict of Interest Policy](#)  
[Code of Ethics](#)  
[Whistleblower Policy](#)

### **Financials**

#### **2019: THE NATIONAL HEALTH COUNCIL MAY HAVE RECEIVED AS MUCH AS \$2.7 MILLION FROM THE PHARMACEUTICAL INDUSTRY – OR 68.5 PERCENT OF ITS REVENUE – ASSUMING MEMBERS AND SPONSORSHIPS WERE ALL PROPORTIONAL.**

**2019: The National Health Council had total revenue of more than \$4 million.**

According to their audited financials for the fiscal year ending December 31, 2019, NHC had total revenue of \$4,033,511.

[National Health Council, DECEMBER 31, 2019 AND 2018, [3/10/20](#)]

**The National Health Council is funded through membership dues, sponsorships and grants.**

“The NHC is funded through a combination of member dues, sponsorships, and grants. All sponsors are disclosed on our website.”

[National Health Council, accessed [1/27/21](#)]

- **2019: NHC received \$1,573,600 from membership dues.**

[National Health Council, accessed [1/27/21](#)]

- **“Business & Industry” members of NHC paid 62.45 percent of membership dues – about \$982,000.**

[National Health Council, accessed [1/27/21](#)]

- **32 of NHC’s 38 Business & Industry members, or 84 percent, are in the pharmaceutical industry.**

[National Health Council, accessed [1/27/21](#)]

- **2019: NHC received \$2,212,276 from sponsorships and grants..** [National Health Council, accessed [1/27/21](#)]

- **21 of NHC’s 24 sponsors, or 87.5 percent, were in the pharmaceutical industry.**

[National Health Council, accessed [1/27/21](#)]

**2015: NHC received 62 percent of its budget from pharmaceutical companies.**

“We’re in an environment where all the stakeholders are blaming each other, and undermining each

other, because of escalating costs,' said Marc Boutin, chief executive of the National Health Council, the organization that represents patient groups. Pharmaceutical companies accounted for 62 percent of the council's \$3.5 million budget in 2015, a spokeswoman said, and representatives from drug companies and an insurer sit on its board." [New York Times, [9/27/16](#)]

The National Health Council only describes their revenue in broad categories of "Membership dues," "sponsorships & grants," "other contract services," "honoraria," and "other income."

[National Health Council, accessed [1/27/21](#)]

**2020: NHC's "Professional and Membership Associations" members included Biotechnology Innovation Organization, National Pharmaceutical Council, PhRMA, and Research America.**

[NHC, accessed [12/8/20](#)]

**2020: NHC's "Business and Industry" members included many major pharmaceutical companies, such as AbbVie, Bristol-Myers Squibb, Eli Lilly, GSK, and Pfizer, among others.**

NHC's "Business and Industry" members included: Abbot, AbbVie, Alexion Pharmaceuticals, Alkermes, Amgen, Astellas Pharma, AstraZeneca, Axovant Sciences, Biogen Idec, Bluebird Bio, Boehringer Ingelheim Pharmaceuticals, Bristol-Myers Squibb, Dermira, Edwards Lifesciences, Eli Lilly, Genentech, Gilead, GlaxoSmithKline, Horizon Pharma, Johnson & Johnson, Mallinckrodt Pharmaceuticals, Merck, Neurocrine Biosciences, Novartis, Pfizer, Regeneron, REGENXBIO, Sangamo Therapeutics, Sanofi, Servier Pharmaceuticals, Takeda Pharmaceuticals North America, and UCB.

[NHC, accessed [12/8/20](#)]

### **ADDITIONAL FINANCIAL INFORMATION**

**2019: NHC had \$4,033,511 in total revenue.**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$2.2 million of the NHC's revenue came from "sponsorship contributions and grants."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$1.5 million of the NHC's revenue came from "membership dues."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$180,040 of the NHC's revenue came from "other contract services."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$39,315 of the NHC's revenue came from "honoraria."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$24,859 of the NHC's revenue came from "investment gains, net."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

- **2019: \$3,421 of the NHC's revenue came from "other income."**

[NHC, FY2019 Audited Financial Statement, accessed [12/8/20](#)]

### **Leadership**

#### **MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION**

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
MARC BOUTIN	CHIEF EXECUTIVE OFFICER	\$448,876.00	\$46,345.00	\$495,221.00

ELEANOR PERFETTO	SENIOR VP, STRAT. INITIATIVES	\$268,770.00	\$31,741.00	\$300,511.00
ERIC GASCHO	VP, POLICY AND GOVT AFFAIRS	\$147,218.00	\$22,043.00	\$169,261.00
JENNIFER SCHLEMAN	SR DIRECTOR, MARKETING & PR	\$126,713.00	\$16,919.00	\$143,632.00
ELISABETH OEHRLEIN	SR DIRECTOR RESEARCH	\$128,260.00	\$11,440.00	\$139,700.00
BOBBIE ALEXANDER	SENIOR ADMIN MANAGER	\$121,465.00	\$12,470.00	\$133,935.00

[National Health Council, IRS Form 990, [11/7/19](#)]

### **ELEANOR PERFETTO, NHC EXECUTIVE VICE PRESIDENT (PREVIOUSLY INTERIM CEO)**

**National Health Council Executive Vice President of Strategic Initiatives, Eleanor M. Perfetto previously worked for eight years at Pfizer, most recently as senior director of federal government relations.**

“In October 2020, Eleanor M. Perfetto was named Interim CEO of the National Health Council (NHC). She has been Executive Vice President of Strategic Initiatives since January 2019 and joined the NHC in July 2015 as Senior Vice President. Dr. Perfetto also holds a part-time faculty appointment at the University of Maryland School of Pharmacy where she is Professor of Pharmaceutical Health Service Research. Her research and policy work primarily focuses on patient engagement in health care, including comparative effectiveness and patient centered-outcomes research (CER-PCOR); medical product development; patient-reported outcome selection and development; value assessment; and health care quality. Prior to joining the University faculty, Dr. Perfetto was with Pfizer Inc. for over almost eight years, most recently as Senior Director, Federal Government Relations; past positions were in Evidence-Based Strategies and Payment Policy Analysis. She served in the U.S. Public Health Service as senior pharmacoepidemiologist at the Agency for Health Care Policy & Research (now Agency for Healthcare Research & Quality) and began her government career by serving for six years as a pharmacist in the Indian Health Service in South Dakota and Oklahoma.” [National Health Council, accessed [1/25/21](#)]

### **THE NATIONAL HEALTH COUNCIL BOARD OF DIRECTORS INCLUDES THE PRESIDENTS AND CEOS OF PHRMA AND BIO, AS WELL AS OTHER PAST AND PRESENT PHARMACEUTICAL COMPANY EXECUTIVES.**

**2020: Tanisha Carino represented Alexion on the NHC’s board of directors.**

“Alexion is a global biopharmaceutical company focused on serving patients and families affected by rare diseases through the discovery, development and commercialization of life-changing therapies.” [NHC, accessed [12/8/20](#)]

- **Carino is chief corporate affairs officer at Alexion and previously was vice president of U.S. public policy at GlaxoSmithKline.**

[Tanisha Carino LinkedIn profile, accessed [1/25/21](#)]

**2020: Rod Mackenzie represented Pfizer on NHC’s board of directors.**

“Good health is vital to all of us, and finding sustainable solutions to the most pressing health care challenges of our world cannot wait. That’s why we at Pfizer are committed to applying science and our global resources to improve health and well-being at every stage of life. We strive to provide access to safe, effective and affordable medicines and related health care services to the people who need them. We have a leading portfolio of products and medicines that support wellness and prevention, as well as treatment and cures for diseases across a broad range of therapeutic areas; and we have an industry-leading pipeline of promising new products that have the potential to challenge some of the most feared diseases of our time, like Alzheimer’s disease and cancer.” [NHC, accessed [12/8/20](#)]

**Mackenzie is chief development officer and executive vice president at Pfizer.**

[Pfizer, accessed [1/26/21](#)]

**2020: Michelle McMurry-Heath represented BIO on NHC's board of directors.**

"BIO is the world's largest trade association representing biotechnology companies, academic institutions, state biotechnology centers and related organizations across the United States and in more than 30 other nations. BIO members are involved in the research and development of innovative healthcare, agricultural, industrial and environmental biotechnology products."

[NHC, accessed [12/8/20](#)]

- **McMurry-Heath is the president and CEO of the Biotechnology Innovation Organization.** [BIO, accessed [1/26/21](#)]

- **McMurry-Heath previously was an executive at Johnson & Johnson.**

"Michelle McMurry-Heath assumed the leadership of the Biotechnology Innovation Organization (BIO) as President and CEO on June 1, 2020. A medical doctor and molecular immunologist by training, Dr. McMurry-Heath becomes just the third chief executive to steward the world's largest biotechnology advocacy group since BIO's founding in 1993. [...] She comes to BIO from Johnson & Johnson where she served as Global Head of Evidence Generation for Medical Device Companies and then Vice President of Global External Innovation and Global Leader for Regulatory Sciences. She was also instrumental in bringing J&J's incubator, J Labs, to Washington, DC. She led a global team of 900 with responsibilities in 150 countries around the globe." [BIO, accessed [1/26/21](#)]

**National Health Council director Gary Reedy is the CEO of the American Cancer Society.**

[National Health Council, accessed [1/25/21](#)]

- **Prior to joining the American Cancer Society, Gary Reedy had a 37-year career in the pharmaceutical industry, including senior leadership positions at Johnson & Johnson, SmithKline Beecham, and Centocor.**

"Prior to taking the helm of the American Cancer Society, Gary had a distinguished 37-year career as a healthcare business and advocacy leader, most recently as worldwide vice president, government affairs and policy, at Johnson & Johnson, where he spearheaded initiatives to influence global health policy. He previously devoted more than 25 years of his career to the business side of the industry, including senior leadership positions with SmithKline Beecham, Centocor, and Johnson & Johnson. During his tenure at Johnson & Johnson, Gary served as president of Ortho Biotech, a Johnson & Johnson company with annual revenues of more than \$3 billion."

[American Cancer Society, accessed [11/17/20](#)]

**2020: Stephen J. Ubl represented PhRMA on NHC's board of directors.**

"The Pharmaceutical Manufacturers Association (PhRMA) was founded in 1958. Its name was changed to the Pharmaceutical Research and Manufacturers of America in 1994 to underscore the extraordinary commitment of member companies to research. Headquartered in Washington, D.C., PhRMA represents the country's leading pharmaceutical research and biotechnology companies, which are devoted to inventing medicines that allow patients to live longer, healthier and more productive lives."

[NHC, accessed [12/8/20](#)]

- **Ubl is president and CEO of PhRMA.**

[PhRMA, accessed [1/26/21](#)]

## Lobbying Activities

### 1999-2020: NHC SPENT MORE THAN \$650,000 ON FEDERAL LOBBYING.

**1999-2020: NHC spent \$650,611 on lobbying the federal government.**

[U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**2009-Present: NHC has not employed a lobbying firm for federal lobbying.**

[U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMING LOWER DRUG COSTS NOW ACT

**NHC didn't express a position on H.R. 3, except to downplay its chances of becoming law.**

"The Lower Drug Costs Now Act is the House version of drug pricing legislation, which is supported by House Democrats. This legislation passed through the House on December 12, largely along party lines, but is highly unlikely to make it through the Senate or receive support from the Administration. The Lower Drug Costs Now Act aims to give Medicare the authority to directly negotiate with drug companies, and these lower drug prices would not only be available to Medicare beneficiaries but also to Americans with private insurance if their company opted into the plan. The ceiling for the negotiated prices would be the average prices of the same drugs in different countries. Like PDPRA, this legislation makes changes to the benefit design of Medicare Part D and would impose an OOP cap of \$2,000 and has a limited allowance for patients to spread their costs throughout the year. H.R. 3 also contains requirements for manufacturers to pay inflation rebates. The CBO expects the bill to save \$500 billion, which would be invested in vision and dental care, the NIH, the FDA, and improving the low-income subsidy program. The legislation is, however, expected to reduce the number of treatments coming to market as well."

[NHC, [12/18/19](#)]

- **NHC said it supported not raising drug prices arbitrarily but cautioned against penalizing drug makers who raise their prices faster than inflation.**

"The NHC appreciates efforts to address rapidly increasing drug prices. In 2017, NHC developed recommendations to reduce health care costs. In these recommendations, we called for system-wide transparency, including requiring manufacturer justification of price increases. We also recommended transparency and pass through of manufacturer rebates, which is why we were pleased to see recent passage of legislation to require transparency of rebates. H.R. 3 and S. 1895 also require manufacturers to pay penalties if prices rise faster than inflation. The NHC agrees with the premise that the costs of medical products should not arbitrarily increase year-over-year and support the aim of these provisions. However, we also recognize this is a multi-faceted issue with perverse incentives created by the current rebating system. This should be considered when crafting policy to reduce price increases. Additionally, any savings realized by such policy should be passed directly to the patients most directly impacted."

[NHC, [12/17/19](#)]

### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

**NHC said it supported parts of the PDPRA providing for out-of-pocket caps and an option for monthly out-of-pocket caps, but didn't take a position on penalizing drug companies that raise their prices faster than inflation.**



“PDPRA is the bipartisan legislation that was developed in the Senate Finance Committee by Chairman Chuck Grassley (R-IA) and his counterpart, ranking member Ron Wyden (D-OR). The legislation passed through Committee July 2019 with a 19-9 vote. This legislation is designed to tackle many of the issues associated with prescription drug pricing, including modifying the benefit design of Medicare Part D, which would incorporate an out-of-pocket (OOP) cap of \$3,100 for patients reaching the catastrophic level. The NHC sent a letter of support to Senators Grassley and Wyden on OOP Costs for Medicare Part D. The current version also contains provisions that would allow beneficiaries to opt for a monthly out-of-pocket cap, a policy that the NHC strongly supports. Another key policy of PDPRA would require pharmaceutical manufacturers to pay a penalty if their prices rise faster than the rate of inflation, a provision that is supported by Democrats with split support among Republicans.”

[NHC, [12/18/19](#)]

## **OTHER STATEMENTS ON PRESCRIPTION DRUG COSTS**

**NHC said it agreed with the final “most-favored nation” rule but stated that it was “irresponsible to finalize” the rule without proper public comment and to leave it to the next administration to implement.**

“Today, the Centers for Medicare and Medicaid released a final “most-favored nation” rule, linking government payments to drug prices paid in foreign countries. The National Health Council agrees, people with chronic diseases and disabilities are poorly served by our current pharmaceutical pricing and coverage system. However, it is irresponsible to finalize this rule without an opportunity for public comment and to leave it for the next administration to implement. The NHC is a long-time supporter of appropriate value assessment that uses patient engagement and input to ensure value is evaluated from the patient perspective. We are concerned that, through this rule, the government could define value based on the needs, perceptions, and preferences of people in other countries, without considering the views of US patients.”

[NHC, Press Release, [11/20/20](#)]

**NHC praised the HEROES Act for prohibiting cost-sharing for COVID-19 treatment, testing and vaccines in any kind of coverage.**

“The Health and Economic Recovery Omnibus Emergency Solutions (HEROES) Act, passed today by the House of Representatives, includes many important patient-focused provisions as well as important improvements to help nonprofit patient organizations that serve people most at risk for COVID-19 while also dealing with the negative economic impact of the virus. By including provisions such as prohibiting cost-sharing for treatment, testing, and vaccines in any kind of coverage; increased federal spending for Medicaid programs; COBRA premium subsidies; a Special Enrollment Period for public health emergencies; and drug refill policy clarification, those with chronic diseases and disabilities can be assured of continued coverage for care during this unprecedented time.”

[NHC, Press Release, [5/15/20](#)]

## **NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)**

Website: <https://rarediseases.org/>

Documents: [Corporate Council Code of Conduct](#)

### **Financials**

**2019: NORD HAD FIVE DONORS THAT COLLECTIVELY ACCOUNTED FOR 67 PERCENT OF ITS “TOTAL REVENUE AND SUPPORT.”**

**2019: NORD had five donors that collectively accounted for 67 percent of its “total revenue and support.”**

[NORD, FINANCIAL STATEMENTS DECEMBER 31, 2019 AND 2018, accessed [6/30/20](#)]

## NORD PROVIDES LITTLE IN THE WAY OF DISCLOSURE OF CORPORATE SUPPORT TO THE ORGANIZATION.

**NORD describes their corporate revenue streams in several ways, but doesn't indicate how much any one individual corporation provides.**

"How is NORD funded? NORD's primary sources of funding are grants and contracts, contributions, and an annual fund-raising event. Specific sources of revenue include: administrative fees and grants for patient assistance programs, foundation and corporate grants, individual and organizational membership dues, conferences and events, philanthropic contributions from individuals, organizations, and companies."

[NORD, accessed [1/27/21](#)]

## NORD'S CORPORATE COUNCIL INCLUDES MANY PHARMACEUTICAL CORPORATIONS.

**NORD discloses members of their "corporate council," but does not indicate how much each member contributed.**

[NORD, 2019 Annual Report, [3/27/20](#)]

**NORD's Corporate Council was comprised of "pharmaceutical, biotech and medical device companies."**

"The NORD Corporate Council is composed of a select group of leading companies committed to helping people with rare diseases. Members include pharmaceutical, biotech and medical device companies that are developing or marketing therapeutic or diagnostic products, as well as companies that are engaged in other aspects of healthcare for the rare disease/orphan product community such as specialty pharmacies, distributors, contract research organizations, integrated healthcare systems and consulting firms."

[NORD, accessed [12/4/20](#)]

**2020: Cabaletta Bio, EdiGENE, Exicure, Neurogene, Orna Therapeutics, Shape Therapeutics, and Taysha Gene Therapies were part of NORD's Pre-Clinical Research Corporate Council.**

[NORD, accessed [12/4/20](#)]

**2020: Dozens of pharmaceutical and medical device companies were part of NORD's Clinical Development Corporate Council, including Acceleron Pharma, Harmony Biosciences, Moderna, and Pfizer.**

[NORD, accessed [12/4/20](#)]

**2020: Dozens of pharmaceutical and medical device companies were part of NORD's Approved Product Corporate Council, including AbbVie, Amgen, GlaxoSmithKline, and Pfizer.**

[NORD, accessed [12/4/20](#)]

**2020: 12 pharmaceutical and medical device companies were part of NORD's Business Member Corporate Council, including BIO, MassBio, and PhRMA.**

[NORD, accessed [12/4/20](#)]

**2019: EdiGENE, Exicure, Neurogene, and Passage Bio were part of NORD's Pre-Clinical Research Corporate Council.**

[NORD, 2019 Annual Report, accessed [12/4/20](#)]

**2019: Dozens of pharmaceutical and medical device companies were part of NORD's Clinical Development Corporate Council, including Acceleron Pharma, Harmony Biosciences, Moderna, and Pfizer.**

[NORD, 2019 Annual Report, accessed [12/4/20](#)]

**2019: 15 pharmaceutical and medical device companies were part of NORD's Business Member Corporate Council, including BIO, MassBio, and PhRMA.**

[NORD, 2019 Annual Report, accessed [12/4/20](#)]

## NATIONAL PARTNERS

**NORD said it worked with its national partners “to achieve its advocacy goals.”**

“NORD works with many partners to achieve its advocacy goals.”

[LinkedIn, accessed [12/4/20](#)]

**2020: Research America was a NORD national partner.**

[NORD, accessed [12/4/20](#)]

**2020: Partners for Better Care was a NORD national partner.**

[NORD, accessed [12/4/20](#)]

- **Partners for Better Care’s members included Genentech and Novo Nordisk.**

[Partners for Better Care, accessed [12/4/20](#)]

## ADDITIONAL FINANCIAL INFORMATION

**2019: NORD had more than \$12 million in “total other revenue and support.”**

[NORD, 2018 IRS Form 990, [11/4/19](#)]

- **2019: \$2.4 million of NORD’s revenue came from “special events revenue.”**  
[NORD, 2018 IRS Form 990 [11/4/19](#)]
- **2019: \$1.1 million of NORD’s revenue came from “grants, contributions and bequests.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$595,629 of NORD’s revenue came from “interest and dividend income.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$234,128 of NORD’s revenue came from “registry, web subscriptions and other related fees.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$174,162 of NORD’s revenue came from “drug, travel and lodging program administrative fees.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$4.4 million of NORD’s revenue came from “net assets released from purpose restriction – patient service administration fees.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$34,000 of NORD’s revenue came from “net assets release from purpose restrictions – research grant administrative fees.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$1.6 million of NORD’s revenue came from “net assets release from time restrictions – membership dues.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]
- **2019: \$1.7 million of NORD’s revenue came from “net assets release from purpose restrictions – contributions.”**  
[NORD, 2018 IRS Form 990, [11/4/19](#)]

## Leadership

## MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
PETER SALTONSTALL	PRESIDENT/CEO	\$385,121.00	\$40,931.00	\$426,052.00
PAMELA GAVIN	CHIEF OPERATING OFFICER	\$296,720.00	\$22,361.00	\$319,081.00
VINCENT J. MURPHY JR	VP FINANCE	\$128,606.00	\$30,930.00	\$159,536.00
TIM EHRHARD	DIRECTOR OF IT	\$164,800.00	\$32,815.00	\$197,615.00
MARY DUNKLE	VP OF EDUCATIONAL INITIATIVES	\$121,014.00	\$7,010.00	\$128,024.00
MARK LLOYD	SENIOR SOFTWARE ARCHITECT	\$117,734.00	\$27,302.00	\$145,036.00
ALEXA MOORE	VP OF DEVELOPMENT	\$205,192.00	\$34,209.00	\$239,401.00
JAMES BERG	PRINCIPAL SOFTWARE ARCHITECT	\$124,057.00	\$31,125.00	\$155,182.00

[National Organization for Rare Disorders, IRS Form 990, [11/4/19](#)]

## **KAY HOLCOMB, NORD BOARD OF DIRECTORS CHAIR**

**Kay Holcombe is on the NORD board of directors.**

[NORD, accessed [1/25/21](#)]

- **Holcombe was previously the senior vice president for science policy at BIO and vice president for government relations at Sanofi-Genzyme.**

“Kay Holcombe recently retired as Senior Vice President for Science Policy at BIO, the Biotechnology Innovation Organization. Prior to that, she was Vice President for Government Relations at Sanofi-Genzyme; Executive Vice President of Policy Directions Inc., a policy advisory and advocacy firm; professional health legislative staff and senior health policy advisor for the House of Representatives Committee on Energy and Commerce; professional health legislative staff for the Senate Committee on Labor and Human Resources; Deputy Associate Commissioner for Legislative Affairs, US Food and Drug Administration; Executive Vice President of the Foundation for Biomedical Research; Associate Director for Public Health Legislation, HHS Office of the Assistant Secretary for Legislation; Deputy Associate Administrator for Planning, Evaluation, and Legislation, Health Resources and Services Administration; Special Assistant to the Director, Division of Legislative Affairs, National Institutes of Health; Executive Secretary, National Heart, Lung, and Blood Institute National Advisory Council; and NHLBI researcher.” [Critical Path Institute, [3/19/18](#)]

## **STEVEN GROSSMAN, NORD BOARD OF DIRECTORS**

**Steven Grossman is on the NORD board of directors.**

[NORD, accessed [1/25/21](#)]

- **Grossman previously lobbied for Rare Disease Therapeutics.**

[HPS Group, Lobbying Disclosure Database, Lobbying Termination, [8/5/13](#)]

- **Rare Disease Therapeutics was founded as Orphan Pharmaceuticals and develops drugs.**
- “Rare Disease Therapeutics, Inc., is a well established company founded in 1991 as Orphan Pharmaceuticals, U.S.A., Inc., strategically located in Nashville, Tennessee. The company changed its name to Rare Disease Therapeutics, Inc., in March 2001 to better describe its mission. Rare Disease Therapeutics, Inc., has a solid track record with multiple

licensing agreements, a comprehensive global patient advocacy network, and significant success in drug development and approval.” [Rare Disease Therapeutics, accessed [1/26/21](#)]

- **2008-2009: Grossman lobbied for pharmaceutical company Allergan.**  
According to federal lobbying disclosures, Grossman registered as a lobbyist for Allergan in 2008 and filed his last lobbying disclosure report on behalf of Allergan in July 2009. [HPS Group, Lobbying Disclosure Database, Registration, filed [1/21/09](#); Lobbying Report, Q2 2009, [7/14/09](#)]
- **Grossman is deputy executive director of the Alliance for a Stronger FDA.**  
[Alliance for a Stronger FDA, accessed [1/26/21](#)]
  - **Alliance for a Stronger FDA’s members include BIO, PhRMA, and at least a dozen pharmaceutical companies.**  
[Alliance for a Stronger FDA, accessed [1/26/21](#)]
  - **Grossman is also the registered lobbyist for the Alliance for a Stronger FDA.** [HPS Group, Lobbying Disclosure Database, Lobbying Report, Q3 2020, [10/21/20](#)]

### SUSAN A. BERRY, NORD BOARD OF DIRECTORS MEMBER

**2020: Susan A. Berry was a member of NORD’s board of directors.**  
[NORD, accessed [12/4/20](#)]

**2013-2019: Susan Berry has received 39 payments totaling of \$ 66,121.37 in associated research funding and general payments from drug makers and medical device manufacturers.**  
[OpenPayments.CMS.gov, accessed [2/19/21](#)]

### Lobbying Activities

#### 2001-2020: THE NATIONAL ORGANIZATION FOR RARE DISORDERS SPENT \$890,000 ON FEDERAL LOBBYING.

**2001-2020: The National Organization for Rare Disorders spent \$890,000 on federal lobbying.**  
[U.S. Senate Lobbying Disclosure Database, accessed [2/19/21](#)]

**2001-Present: NORD has not employed a lobbying firm.**  
[U.S. Senate Lobbying Disclosure Database, accessed [2/19/21](#)]

### Prescription Drug Cost Legislation

**H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**  
*No relevant information.*

**H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**  
*No relevant information.*

**S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

**7/24/19: NORD expressed general support for the PDPRA, but shared that rare disease patients “depend on a vibrant pharmaceutical industry.”**

“NORD believes that all individuals with a rare disease should have access to quality and affordable health care that is best suited to their medical needs. NORD commends you for your hard work on this bipartisan Chairman’s mark of the Prescription Drug Pricing Reduction Act (PDPRA) of 2019 (Chairman’s mark) aimed at lowering costs for all patients. [...] As all levels of government and a variety of stakeholders look for legislative

and regulatory tools to ensure that medicines are affordable, NORD has compiled a set of drug pricing principles to help guide NORD's engagement with these issues in a deliberate and transparent manner.<sup>1</sup> As the principles convey, NORD believes that it is critical to assure that a balance is struck between preserving incentives to innovate in the rare disease space and access to such innovative new therapies. NORD urges the Committee to remain vigilant about the fact that over 90 percent of rare diseases continue to lack a treatment approved by the Food and Drug Administration (FDA). Thus, rare disease patients depend on a vibrant pharmaceutical industry. Any efforts to address the high cost of medicines should not inhibit the innovation that has led to the kinds of orphan therapies that have made it to market or restrict access to those same therapies."

[NORD letter to Sens. Grassley and Wyden, [7/24/19](#)]

#### **NORD expressed concern that PDPRA could inadvertently decrease patient access to treatments.**

"Like many other stakeholders, NORD is still evaluating the Chairman's mark with a particular focus on whether its policies adhere to the drug pricing principles described above. Based on our initial review, it appears that many of these principles are generally reflected in the Committee's proposal. However, we are concerned that some policies could inadvertently decrease patients' coverage and access, particularly for treatments for rare diseases. As this legislation moves forward, NORD urges the Committee to carefully consider the unique access and innovation issues impacting the rare disease community."

[NORD letter to Sens. Grassley and Wyden, [7/24/19](#)]

#### **NORD objected to the conflicts of interest section of PDPRA, saying it could disqualify an entire community of stakeholders from participating because of conflicts.**

"Pharmacy and therapeutics committees (P&T committees) and drug use review (DUR) boards play an important role in ensuring that coverage and payment decisions about covered outpatient drugs are based on sound science. These entities should make such decisions in an unbiased and conflict-free manner. NORD supports the intent of the Chairman's mark in addressing this goal. However, NORD is concerned that the conflict of interest provisions in the Chairman's mark may be too restrictive in the context of evaluations of therapies necessary for the rare disease community. Of particular concern are Sections 201 and 202, which would require the P&T committee or DUR to include at least one practicing physician and one practicing pharmacist who are independent and free of manufacturer, Medicaid plan, and PBM conflicts of interest. That same P&T committee member would also be required to have expertise in the care of at least one Medicaid-specific beneficiary population. This requirement may not be feasible within the rare disease community and may preclude medical experts with specific knowledge about a particular rare disease from participating in these important P&T committees. In many rare diseases, the pool of individuals who possess the requisite knowledge and experience about a particular rare disease is highly limited. Therefore, it is not unusual for an entire stakeholder community to be deemed "conflicted." The P&T committee and DUR are responsible for ensuring that Medicaid covered outpatient drugs prescriptions are appropriate, medically necessary, and unlikely to result in adverse reactions. We urge the Committee to consider the need for a more flexible conflict of interest provision when it comes to the rare disease community."

[NORD letter to Sens. Grassley and Wyden, [7/24/19](#)]

### **OTHER STATEMENTS ON PRESCRIPTION DRUG COSTS**

#### **2019: NORD announced the development of its key drug pricing principles created with the needs of the rare disease community in mind.**

"In 2019, NORD announced its development of key drug pricing principles, created with the needs of the rare disease community in mind. People living with rare diseases need to be able to afford the therapies that come to the market. The high cost of prescription drugs has a direct impact on the ability of patients to access lifesaving care. The small patient populations and medical complexities associated with rare diseases can lead to costly therapies, but it is vital that these therapies remain affordable and, therefore, accessible to rare disease patients. Throughout 2019, NORD advocated at the federal and state levels for policies that would foster access to affordable and innovative rare disease therapies."

[NORD, 2019 Annual Report, accessed [12/4/20](#)]

## NATIONAL PSORIASIS FOUNDATION (NPF)

Website: <https://www.psoriasis.org/>

Documents: [Conflict of Interest Policies](#)  
[Whistleblower Policy](#)

### Financials

**2019: NATIONAL PSORIASIS FOUNDATION RECEIVED AT LEAST \$6.7 MILLION FROM THE PHARMACEUTICAL INDUSTRY AND POSSIBLY MORE THAN \$9.4 MILLION – BETWEEN 47.2 PERCENT AND 66.4 PERCENT OF ITS REVENUE.**

2019: National Psoriasis Foundation received at least \$6.7 million and possibly more than \$9.4 million from the pharmaceutical industry.

Donor	Minimum Contribution	Maximum Contribution
Abbvie	\$1,000,000	>\$1,000,000
Amgen	\$1,000,000	>\$1,000,000
Lilly	\$1,000,000	>\$1,000,000
Pfizer	\$1,000,000	>\$1,000,000
Celgene	\$500,000	\$999,000
Janssen	\$500,000	\$999,000
Novartis	\$500,000	\$999,000
Bristol-Myers Squibb	\$250,000	\$499,999
Ortho Dermatologics	\$250,000	\$499,999
Sun Pharmaceuticals	\$250,000	\$499,999
UCB	\$250,000	\$499,999
Boehringer Ingelheim	50,000	99,999
Chattem	\$25,000	\$49,999
Dermavant Sciences	\$25,000	\$49,999
LEO Pharma	\$25,000	\$49,999
Mallinckrodt	\$25,000	\$49,999
Mayne Pharma	\$25,000	\$49,999
Promius Pharma	\$25,000	\$49,999

Biotechnology Innovation Organization	\$10,000	\$24,999
Sandoz	\$10,000	\$24,999
<b>Totals</b>	<b>\$6,720,000</b>	<b>\$9,446,987</b>

[Compiled from National Psoriasis Foundation, 2019 Annual Report, [7/15/20](#)]

**2019: National Psoriasis Foundation had total revenues of \$14,223,722.**

[National Psoriasis Foundation, 2019 Annual Report, [7/15/20](#)]

### ADDITIONAL FINANCIAL INFORMATION

**2019: The NPF had more than \$14 million in “total revenue, gains, and other support.”**

[NPF, 2019 Annual Report, accessed [12/6/20](#)]

- **2019: 76 percent (\$10.8 million) of the NPF’s revenue came from “contributions, legacies, and sponsorships.”** [NPF, 2019 Annual Report, accessed [12/6/20](#)]
- **2019: 14 percent (\$1.9 million) of the NPF’s revenue came from “net special events revenue.”** [NPF, 2019 Annual Report, accessed [12/6/20](#)]
- **2019: 14 percent (\$1.9 million) of the NPF’s revenue came from “net special events revenue.”** [NPF, 2019 Annual Report, accessed [12/6/20](#)]

#### **Support and Revenue**



Contributions, legacies, and sponsorships	\$10,842,850	76%
Net special events revenue	\$1,960,871	14%
Fees, advertising and other	\$1,420,001	10%
<b>Total revenue, gains, and other support</b>	<b>\$14,223,722</b>	

[NPF, 2019 Annual Report, accessed [12/6/20](#)]



## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
RANDY BERANEK	PRESIDENT AND CEO	\$316,006.00	\$28,420.00	\$344,426.00
LEAH HOWARD	CHIEF OPERATING OFFICER	\$196,800.00	\$20,149.00	\$216,949.00
EMILY BOYD	CHIEF REVENUE OFFICER	\$186,306.00	\$19,394.00	\$205,700.00
BRIDGET HART	DIRECTOR OF MAJOR GIFTS	\$145,428.00	\$24,950.00	\$170,378.00
BETTE DRAKE	VP FINANCE AND OPERATIONS	\$119,799.00	\$15,541.00	\$135,340.00
PATRICK STONE	VP ADVOCACY AND GOVERNMENT RELATIONS	\$116,615.00	\$6,759.00	\$123,374.00
KRISTINE BOCKMIER	DIRECTOR OF FIELD OPERATIONS	\$115,222.00	\$19,213.00	\$134,435.00

[National Psoriasis Foundation, IRS Form 990, [2/25/20](#)]

### CAROL OSTROW & MICHAEL GRAFF, NPF BOARD OF DIRECTORS

**Carol Ostrow is vice-chair of the National Psoriasis Foundation and is married to Michael Graff, managing director of Warburg Pincus.**

“Carol Ostrow was elected to the board of directors in November 2012 and currently serves as vice-chair. Ostrow is also a member of the executive committee and serves as chair of governance committees. Ostrow is the producing director of the award-winning Flea Theater, an off-off-Broadway theater located in Lower Manhattan. She has been an adjunct professor of theater at Vassar College, Chatham College and McGill University. Ostrow holds a B.A. from Vassar College and an MFA from the Yale School of Drama. Ostrow is a trustee of Vassar College and also serves on Yale Drama School board of advisors. She is married to Michael Graff (managing director at Warburg Pincus, LLC). They have four children: daughters Anabel, Emily and Candace and son, Jesse. She and her family count Pittsburgh, London, Montreal and, now, New York City once again as home.”

[National Psoriasis Foundation, accessed [1/25/21](#)]

**Michael Graff is on the National Psoriasis Foundation board of directors.**

“Michael Graff was elected to the board of directors in 2018. He has been an active member of NPF’s New York division and has a personal connection to psoriasis. For the past few years, Graff has supported and participated in the Team NPF Hamptons Cycle event. In 2016, Graff was the Cure Champion, having raised the most money to find a cure for psoriatic disease. Graff is a managing director of Warburg Pincus and is involved with the firm’s industrial and business services activities, focusing primarily on the industrial sector. He is chair of the U.S. Olympic Water Polo Committee and a member of the board of the Flea Theater. Graff received an A.B. in economics from Harvard College, and an M.S. from the Sloan School of Management at the Massachusetts Institute of Technology. Graff is a member of the finance committee, where he helps direct the organization by evaluating and approving long-term plans, determining goals and assisting with financial oversight. He also serves on the compensation committee.”

- **Warburg Pincus formed Vertice Pharma In 2015.**

“Vertice Pharma is a specialty branded and generic pharmaceuticals platform focused on acquiring

specialty pharmaceutical companies and products to create a durable specialty pharmaceutical platform of scale. Vertice Pharma was formed in 2015 by Warburg Pincus and senior pharmaceutical executive Don DeGolyer, former COO of Endo International plc and CEO of North America for Sandoz International GmbH. In late 2015, Warburg Pincus helped Vertice Pharma acquire VistaPharm, Inc., a Tampa, Florida-based specialty generics manufacturer of liquid and unit dosage medications focused on the hospital channel. Vertice Pharma has global headquarters in the United Kingdom and United States headquarters in New Providence, New Jersey.”

[Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus is invested in Haihe Pharmaceutical.**

“Haihe Pharmaceutical focuses on discovery, development and commercialization of innovative anti-tumor drugs. Led by an academician of the Chinese Academy of Engineering and a senior management team with extensive experience in drug research and development in China and abroad, Haihe Pharmaceutical has built a precision medical platform guided by biomarkers. The company has also built a fully integrated pre-clinical evaluation technical platform and clinical study system for innovative drugs, with advanced technology and operation in consistence with international standards and norms, covering subunits from compound synthesis, CMC study, biomarker discovery and validation, medical strategy and clinical study, etc. With a globally competitive innovative drug R&D system, the company has a robust product pipeline, including 8 compounds in clinical and 3 compounds in preclinical studies.”

[Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus is invested in Polyplus-transfection, which services pharmaceutical companies.**

“Founded in 2001 and based in Strasbourg, France, Polyplus is a leading global supplier of transfection reagents, which are critical inputs used in the manufacturing of cell and gene therapies. Polyplus’ reagents are embedded in the majority of clinical-stage and commercially approved drugs in the rapidly growing gene therapy market.” [Warburg Pincus, accessed [12/6/20](#)]

- **Warburg Pincus is invested in Sotera Health, which services pharmaceutical companies.**

“Sotera Health LLC (fka Sterigenics), along with its business entities, is the world’s leading, fully integrated protector of global health. With over 500 years of combined scientific expertise, the company ensures the safety of healthcare by providing mission-critical services to the medical device, pharmaceutical, tissue and food industries. Sotera Health operates more than 62 facilities in 13 countries. The company has over 2,800 employees globally and touches the lives of more than 180 million people around the world each year. Sotera Health serves more than 6,000 customers worldwide including 75 of the top 100 medical device manufacturers. Sotera Health goes to market through its three best-in-class companies D Nelson Labs, Nordion and Sterigenics D with the mission of ensuring the safety of healthcare each and every day.”

[Warburg Pincus, accessed [12/6/20](#)]

## **EYAL OFIR, NPF BOARD OF DIRECTORS TREASURER**

### **Eyal Ofir joined NPF’s board of directors in 2017 and is currently its treasurer.**

“Eyal Ofir was appointed to the board of directors in 2017 and currently serves as treasurer. Ofir is also a member of the executive and governance committees and serves as chair of the finance committee. As chair of the finance committee, he helps direct the organization by evaluating and approving long-term plans, determining goals and assisting with financial oversight. Ofir, who works in finance in New York City, has had psoriasis since he was a child. Wanting to give back in a meaningful way, Ofir became an active member of NPF’s New York Division in 2016, and has since worked to raise the profile of psoriatic disease through fundraising and advocacy efforts for NPF.” [National Psoriasis Foundation, accessed [12/6/20](#)]

### **Since Feb. 2019, Ofir has been President at Lazard after joining the company in July 2013**

According to his LinkedIn profile, Eyal Ofir has served as a “President” at Lazard since Feb. 2019. He has worked at Lazard since July 2013, previously serving as an “Associate, Investment Banking” and a “Vice President.” [LinkedIn, accessed [12/6/20](#)]

- Lazard is a major international financial advisory and asset management firm.**  
 “Lazard, one of the world’s preeminent financial advisory and asset management firms, operates from more than 40 cities across 25 countries in North America, Europe, Asia, Australia, Central and South America. With origins dating to 1848, the firm provides advice on mergers and acquisitions, strategic matters, restructuring and capital structure, capital raising and corporate finance, as well as asset management services to corporations, partnerships, institutions, governments and individuals.”  
 [LinkedIn, accessed [12/6/20](#)]
- 2020: A Lazard senior investment banker said “a sharp recovery in health-care deal making will quicken as large pharmaceutical companies chase new treatments through acquisitions.**  
 “A sharp recovery in health-care dealmaking will quicken as large pharmaceutical companies chase new treatments through acquisitions, according to one of Lazard Ltd.’s senior investment bankers covering the sector.” [Bloomberg, [9/22/20](#)]
- 2020: Lazard was the “No. 2 adviser globally on announced health-care deals” including one involving Gilead.**  
 “Lazard is the No. 2 adviser globally on announced health-care deals in 2020, according to data compiled by Bloomberg. The bank worked with Gilead on the Immunomedics purchase and Aimmune Therapeutics Inc. on its takeover by Nestle SA in August.” [Bloomberg, [9/22/20](#)]
- 2019: Lazard’s CEO Said, “It’s a ‘wild time’ in the healthcare industry” in regard to “advancement in medicine.”**  
 “It’s a ‘wild time’ in the health-care industry as new technology pressures companies to innovate while advancements in medicine hold the promise of cures for previously fatal diseases, investors said at CNBC’s Healthy Returns conference in New York Tuesday. ‘It’s a wild time to be in health care at large because business models are evolving rapidly,’ Lazard’s financial advisory CEO Peter Orszag said in an interview at the conference with CNBC’s David Faber.” [CNBC, [5/21/19](#)]

**Lobbying Activities**

**THE NATIONAL PSORIASIS FOUNDATION EMPLOYS A LOBBYING FIRM THAT ALSO REPRESENTS THE PHARMACEUTICAL INDUSTRY.**

ORGANIZATION	2020 LOBBY FIRMS	2020 PHARMA CLIENTS
National Psoriasis Foundation	Faegre Drinker Biddle & Reath	Alliance for Safe Online Pharmacies

[Compiled from U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

**Q1-Q3 2020: According to federal lobbying disclosure records, NPF spent at least \$170,000 on lobbying firms Faegre Baker Daniels Consulting and Faegre Drinker Biddle & Reath LLP.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/6/20](#)]

- Faegre Drinker represents pharmaceutical companies.**  
 “Whether as an academic medical center, research institute, cutting-edge physician practice, pharmaceutical company, device manufacturer or clinical research organization, your focus is on medical breakthroughs and new treatment options that enhance patient care. We partner with you as you seek to ensure that your clinical research programs adhere to all accepted clinical trial guidelines, including clinical trial design and agreements, Food and Drug Administration approvals and commercialization. We help you navigate institutional review board requirements and human-subject protection rules at both the federal and state levels. We can serve as an extension of your team to help you write grants, draft budgets, develop contracts and manage data rights. We can help manage your clinical research compliance needs so that you can focus on scientific pursuits. Our

attorneys, consultants and other professionals work with clinical research organizations across the industry in the U.S. and internationally.”

- **The Alliance for Safe Online Pharmacies board of directors includes a representative from pharmaceutical company Merck.** [Alliance for Safe Online Pharmacies, accessed [2/19/21](#)]

### **2006-2020: THE NATIONAL PSORIASIS FOUNDATION SPENT NEARLY \$6.7 MILLION ON FEDERAL LOBBYING.**

**2006-2020: The National Psoriasis Foundation spent \$6,698,858 on federal lobbying.**

[U.S. Senate Lobbying Disclosure Database, accessed 1/25/21]

### **2020: ONE OF THE NATIONAL PSORIASIS FOUNDATION'S IN-HOUSE LOBBYISTS PREVIOUSLY WORKED AT THE BIOTECHNOLOGY INNOVATION ORGANIZATION.**

**March 2020-Present: Hannah Lynch serves as Association Director of Federal Government Relations and Health Policy at the National Psoriasis Foundation.**

[LinkedIn, accessed [12/6/20](#)]

- **June 2019-Mar. 2020: Lynch served as a Manager for Healthcare Policy and Research at the Biotechnology Innovation Organization.** [LinkedIn, accessed [12/6/20](#)]
- **August 2016-Jun. 2019: Lynch served as a Coordinator for Healthcare Policy and Research at the Biotechnology Innovation Organization.** [LinkedIn, accessed [12/6/20](#)]

## **Prescription Drug Cost Legislation**

### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

**July 2020: NPF joined a letter praising the out-of-pocket caps in H.R. 3.**

“Current legislation from both the House of Representatives and the Senate has proposed putting a cap on OOP costs when Medicare Part D beneficiaries hit certain thresholds. The Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) would limit OOP spending to \$2,000 beginning in 2022 and the Prescription Drug Pricing Reduction Act of 2019 (S. 2543) would limit OOP spending to \$3,100 beginning in 2022, indexed to growth in Part D spending. The proposed cap in both bills would constitute significant progress in constraining the growth of OOP costs for Part D beneficiaries. We support a cap structure that minimizes financial exposure, as many Medicare beneficiaries live on fixed and limited incomes.”

[InsuranceNewsNet.com, [7/21/20](#)]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*

## **OTHER**

**NPF advocates for reducing Medicare out-of-pocket caps.**

“Current legislation from both the House of Representatives and the Senate has proposed putting a cap on OOP costs when Medicare Part D beneficiaries hit certain thresholds. The Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) would limit OOP spending to \$2,000 beginning in 2022 and the Prescription Drug Pricing Reduction Act of 2019 (S. 2543) would limit OOP spending to \$3,100 beginning in 2022, indexed to growth in Part D spending. The proposed cap in both bills would constitute significant progress in constraining the growth of OOP costs for Part D beneficiaries. We support a cap structure that minimizes financial exposure, as many Medicare beneficiaries live on fixed and limited incomes.” [InsuranceNewsNet.com, [7/21/20](#)]

## NPF calls on supporters to contact Congress in support of Medicare out-of-pocket caps and “smoothing” mechanisms.

“Medicare Part D, which provides prescription drug coverage for 45 million Americans, does not have an annual out-of-pocket cap. Ask your members of Congress to reduce the burden of out-of-pocket costs for America’s seniors by creating an annual maximum and spreading the costs across the year (called smoothing).” [NPF, accessed [12/28/20](#)]

## SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA) / NATIONAL SICKLE CELL ADVOCACY NETWORK (NSCAN)

Website: <https://www.sicklecelldisease.org/>

Documents: [Conflict of Interest Policy](#)  
[Guiding Principles](#)

### Financials

#### SCDAA DOES NOT DISCLOSE CORPORATE DONORS.

The Sickle Cell Disease Association of America does not appear explicitly to disclose corporate donors. [SCDAA, accessed [1/27/21](#)]

#### ADDITIONAL FINANCIAL INFORMATION

2016\*: SCDAA had \$2.8 million in revenue.

[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]

*\*Note: A more recent SCDAA annual report does not appear to be available.*

- **2016: \$2.8 million of SCDAA’s revenue came from “federal grant.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$468,660 of SCDAA’s revenue came from “convention and special events.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$279,443 of SCDAA’s revenue came from “contributions.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$34,028 of SCDAA’s revenue came from “other grant income.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$29,731 of SCDAA’s revenue came from “investment income.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$151,380 of SCDAA’s revenue came from “other income.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$20,066 of SCDAA’s revenue came from “membership dues.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]
- **2016: \$12,325 of SCDAA’s revenue came from “sales of educational materials.”**  
[SCDAA, 2017 Annual Report, accessed [12/12/20](#)]

### 2020: Pfizer was an SCDAA “strategic partner.”

“Pfizer has partnered with Sickle Cell Disease Association of America, Inc. on an advocacy campaign to develop OpEds to place in ten media markets across the country. The purpose of this advocacy initiative is to leverage awareness through media placement in key states to address legislation that impacts the sickle cell community.” [SCDAA, accessed [12/12/20](#)]

### 2020: Novartis was a partner with SCDAA on the “Generation S Campaign.”

“Novartis is teaming up with Grammy®-nominated singer, film and Broadway star Jordin Sparks and the Sickle Cell Disease Association of America, Inc. (SCDAA) to launch Generation S, a national sickle cell disease (SCD) storytelling project that will help rewrite the SCD story for generations to come. Generation S encourages anyone touched by SCD to help inspire the sickle cell community and educate the nation by sharing their story. The campaign was launched at SCDAA’s 46th Annual National Convention in Baltimore, MD in October 2018. Jordin Sparks attended the Annual Unity Soiree, a special gala, held at the Annual National Convention and spoke about the campaign and her commitment to increasing awareness about sickle cell disease.” [SCDAA, accessed [12/12/20](#)]

### 2020: Emmaus Life Science was a SCDAA “strategic partners.”

“Sickle Cell Disease Association of America, Inc. (SCDAA) and Emmaus Life Sciences, Inc. have announced a new partnership involving national awareness and patient education initiatives to address the complications of sickle cell disease (SCD). The collaboration will expand educational materials for individuals living with SCD and their families to ensure that patients better understand the disease, treatment options and the importance of having comprehensive, coordinated medical care. The partnership also enhances national awareness efforts that will increase the dissemination of information to a broad audience through online platforms.” [SCDAA, accessed [12/12/20](#)]

### Oct. 2020: SCDAA announced a new partnership with Aruvant Sciences.

“The Sickle Cell Disease Association of America (SCDAA) and Aruvant Sciences are proud to announce a new partnership to create educational programs to increase awareness of gene therapy as a potential curative treatment option for sickle cell disease patients. This collaboration will help SCDAA continue to deliver on its mission, while assisting Aruvant in learning more about the needs of sickle cell disease (SCD) patients. Under the agreement, Aruvant will collaborate with SCDAA to host local and national educational events and develop materials for a public-awareness campaign.” [SCDAA, Press Release, [10/13/20](#)]

### May 2020: SCDAA announced a new partnership with Hemanext.

“Sickle Cell Disease Association of America, Inc. (SCDAA) and Hemanext Inc., a privately held medical technology company dedicated to improving the quality, safety, efficacy and cost of red blood cell (RBC) transfusion therapy, are proud to announce a new partnership that will help SCDAA deliver on its mission and meet its goals. In 2020, Hemanext will collaborate with SCDAA on its educational programs, grassroots events and public-awareness campaigns.” [SCDAA, Press Release, [5/6/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization
Beverly Francis-Gibson	President/CEO	\$144,000

[Sickle Cell Disease Association of America, IRS Form 990, [6/24/20](#)]

**THE SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA) HAS A CURRENT PHARMACEUTICAL EXECUTIVE ON THEIR BOARD, AS WELL AS TWO MEMBERS WHO PREVIOUSLY WORKED FOR ELI LILLY.**

**JaKela Walker is chair of the board of directors of SCDAA.**

[Sickle Cell Disease Association of America, accessed [1/25/21](#)]

- **Walker worked at Eli Lilly for more than eight years.**

“Eli Lilly and Company: Total Duration: 8 yrs, 1 mo. Title: Consultant. Financial Dates Employed: Apr 2011 – Jul 2012. Employment Duration: 1 yr, 4 mos. Location: Indianapolis, IN. Title: Consultant. Financial Dates Employed: Sep 2008 – Apr 2011. Employment Duration: 2 yrs, 8 mos. Location: San Juan, PR. Title: Sr. HR Representative - Finance & Procurement. Dates Employed: Aug 2007 – Sep 2008. Employment Duration: 1 yr, 2 mos. Location: Indianapolis, Indiana. Title: Sales Representative - Diabetes Health. Dates Employed: Feb 2007 – Aug 2007. Employment Duration: 7 mos. Title: Sr. Financial Analyst - Audit. Dates Employed: Jul 2004 – Feb 2007. Employment Duration: 2 yrs, 8 mos. Location: Indianapolis, Indiana”

[JaKela Walker LinkedIn profile, accessed [1/25/21](#)]

**SCDAA director Dr. Crystal Riley is deputy director for government policy and reimbursement for pharmaceutical company Baxter International.**

“Crystal A. Riley, PharmD. MHA, MBA Deputy Director / Government Policy & Reimbursement Baxter International, Inc. Washington, DC.”

[Sickle Cell Disease Association Of America, accessed [1/25/21](#)]

**Bobby Staten III is on the SCDAA board of directors.**

[Sickle Cell Disease Association Of America, accessed [1/25/21](#)]

- **Staten worked for Eli Lilly for six years.**

“Senior Analyst/Design Lead. Company Name: Eli Lilly. Dates Employed: Feb 2005 – Feb 2011. Employment Duration: 6 yrs, 1 mo. Location: Indianapolis, Indiana. Responsible for leading the design, development, and implementation phases of various IT projects that align with Lilly’s Supply Chain Management strategy. Assisted in developing methodology aimed at automating testing efforts for global production support through use of SAP Solution Manager and Worksoft software solutions. Led small team through successful transition from Catalyst Warehouse Management System to the SAP Warehouse Management (WM) solution at Lilly Puerto Rico affiliate, which resulted in an annual cost savings of \$1.5M and a one time savings of \$1.2M. Had oversight of system design and development and worked with local and global development teams to bridge the gap and effectuate change across cultures. Designed and implemented a WM solution for the Puerto Rico affiliate, which allowed the warehouse to track drums of raw materials within the plant at the container level as opposed to pallet level. This solution resulted in \$150,000 in cost savings and 28 percent reduction in cycle time in the pick process. Developed a pilot Account Management model that reframed the way that change was managed and service was extended to internal global business partners. Adoption of this model resulted in a 63 percent reduction in trouble ticket backlog in 2007, increased throughput of change, and improved customer relationships. Model is currently a candidate for Six Sigma implementation. Managed development/fix releases for GBIP Supply Chain organization, delivering 150+ successful production support changes, which had a considerable impact on trouble ticket backlog and delivered valuable change to Lilly customer base. Led and executed global software upgrade from Business Objects, v5.0 to Business Objects, v6.5 for 1000+ users across Lilly enterprise; worked with application support team to resolve stabilization issues quickly.”

[Bobby Staten III LinkedIn profile, accessed [1/25/21](#)]

### LEWIS L. HSU, SCDAABOARD OF DIRECTORS MEMBER

2013- 2019: Lewis L Hsu received 115 payments totaling \$420,754.17 in associated research funding, research payments, and general payments from drug makers and medical device manufacturers.

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

### KIM SMITH-WHITLEY, SCDAABOARD OF DIRECTORS MEMBER

2013- 2019: Kim Smith-Whitely received 57 payments totaling \$767,412.39 in associated research funding, research payments, and general payments from drug makers and medical device manufacturers.

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

## Lobbying Activities

### SCDAABAS NOT REPORTED ANY FEDERAL LOBBYING SINCE 2015.

SCDDA hasn't reported any federal lobbying since the second quarter of 2015.

[U.S. Senate Lobbying Disclosure Database, accessed [2/19/21](#)]

### 2000-2015: SCDAASPENT \$700,000 ON FEDERAL LOBBYING.

2000-2015: SCDAAspent \$700,000 on federal lobbying.

[U.S. Senate Lobbying Disclosure Database, accessed [2/19/21](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

*No relevant information.*

### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information.*



## PART 2: PHARMA FUNDED ALLIED GROUPS AND ASTROTURF ORGANIZATIONS

Some are called astroturf groups because they don't represent real grassroots. They talk like patients and may even have some positions that are good for patients, but they were created by and/or are funded by the pharmaceutical industry to press its point of view. These groups lead the effort to distract attention from the power of the drug companies to set prices and to focus attention on other players in the drug supply chain. They hide their funding and the relationships they have with their drug company funders and try to make people see them as honest brokers, which they are not. A look at the following highlights from our research shows why.

### ALLIANCE FOR PATIENT ACCESS (AFPA) / GLOBAL ALLIANCE FOR PATIENT ACCESS (GAFPA) / INSTITUTE FOR PATIENT ACCESS (IFPA)

Website: <https://allianceforpatientaccess.org/>

Website: <https://gafpa.org/>

Website: <https://instituteforpatientaccess.org/>

#### ALLIANCE FOR PATIENT ACCESS IS PURPOSEFULLY OPAQUE.

**Groups like Patients Rising and the Alliance for Patient Access deliberately make it difficult to understand their ties to the pharmaceutical industry.**

“The political war over prescription drug practices is spawning a frenzy of activity by outside lobbying groups, some with names that mask their ties to industry and one that has gone to great lengths to disguise its origins. The increase in advertising, advocacy and pressure tactics is aimed at thwarting some efforts to control drug costs proposed in the Democratic-controlled House, such as allowing Medicare to negotiate drug prices, as well as ideas pursued by the Trump administration to curb prices. The operations of these groups often dovetail with work by corporate lobbying shops. Most, but not all, disclose industry funding sources on their websites. Some of the more active groups are the Alliance for Patient Access and Patients Rising. Those names make it hard for people to understand their ties to industry, consumer advocates say. The Alliance for Patient Access has launched digital and radio advertisements in recent weeks opposing the Trump administration’s plans to cut Medicare reimbursement for drugs administered in hospitals and doctor’s offices. Patients Rising has a strong presence on social media.” [Washington Post, [1/22/19](#)]

#### Financials

#### MOST OF AFPA'S CORPORATE ASSOCIATE MEMBERS AND FINANCIAL SUPPORTERS ARE PHARMACEUTICAL AND BIOTECHNOLOGY COMPANIES AND TRADE ORGANIZATIONS.

**December 2020: Most of AfPA's corporate associate members and financial supporters are pharmaceutical and biotechnology companies.**

“Associate Members and Financial Supporters, December 2020: Abbvie, Acadia Pharmaceuticals, Adamas, Akcea, Alnylam, Amarin, Amgen, Avanir, Becton, Dickinson and Company, Biogen, Boehringer Ingelheim Pharmaceuticals, Bristol-Myers Squibb, EMD Serono, Eli Lilly, Esperion Flexion Therapeutics, GSK, Heron Therapeutics, Horizon Therapeutics, Johnson & Johnson, Health Care Systems, Leo Pharma, Lundbeck, Mallinckrodt Pharmaceuticals, Momenta National Fisheries Institute, Neurocrine, Novo Nordisk, Pfizer, Prolacta Bioscience, PhRMA, Sanofi, Scipher, Shire, Sobi, Sunovion, Takeda, Teva, UCB, Vert.”

[Alliance for Patient Access, [December 2020](#)]

- **December 2020: Of the 10 “associate members and financial supporters” of the Global Alliance for Patient Access, seven were pharmaceutical companies, two were funded by pharmaceutical companies, and the last was PhRMA.**

“Associate Members and Financial Supporters, December 2020: Alliance for Patient Access, Alnylam, Amgen, EMD Serono, Merck, Janssen, Partnership to Advance Cardiovascular Health, Pfizer, PhRMA, Regeneron, and Sanofi,” [Global Alliance for Patient Access, [December 2020](#)]

**Alliance for Patient Access’ website lists “large drug companies among their supporters” and “lists PhRMA and BIO” among its “associate members and financial supporters.”**

“On their websites, the Alliance for Patient Access and Patients Rising list large drug companies among their supporters. The alliance does not disclose funding levels, while Patients Rising does list funding ranges. The Alliance for Patient Access (AfPA), which is led by physicians, lists PhRMA and BIO among its three dozen ‘associate members and financial supporters.’ ‘AfPA advocates in defense of the physician-patient relationship to ensure patients can access the medicines their health care providers prescribe,’ the group said in an email.” [Washington Post, [1/22/19](#)]

**The Alliance for Patient Access is funded by BIO, PhRMA, and at least 14 pharmaceutical companies, among others.**

“The Alliance for Patient Access is funded by AbbVie, Allergan, Amgen, AstraZeneca, the Biotechnology Innovation Organization, Bristol-Myers Squibb, Celgene, Eli Lilly, Genentech, GlaxoSmithKline, Johnson & Johnson Health Care, Novo Nordisk, Pfizer, PhRMA, Sanofi and Teva, among others.” [Inside Drug Pricing, 4/1/19]

**ALLIANCE FOR PATIENT ACCESS HAS RECEIVED SIGNIFICANT SUPPORT FROM INDUSTRY TRADE GROUPS PHRMA AND BIO, ACCOUNTING FOR AS MUCH AS NEARLY 20 PERCENT OF THEIR REVENUE SOME YEARS.**

**2018: AfPA had a total revenue of more than \$13.6 million.**

According to their IRS Form 990 tax filings, in 2018, AfPA had \$13,601,842 in total revenue: \$10,421,612 in “program service revenue” and \$3,180,230 in “contributions and grants.” [Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

**2017: AfPA’s total revenue was \$2,004,250, all from “contributions and grants.”**

According to their IRS Form 990 tax filings, in 2018, AfPA had \$2,004,250 in total revenue. Of that total, \$325,000 was from “membership dues” and \$1,679,250 was from “all other contributions, gifts, grants, and similar amounts not included above.” [Alliance for Patient Access, IRS Form 990, [7/3/18](#)]

- **2017: AbbVie gave the Alliance for Patient Access \$30,000 in “Corporate Sponsorships.”**  
[AbbVie, Grants Donation Report 2017, [4/30/18](#)]

**2016: AfPA had a total revenue of \$9,820,150.**

According to their IRS Form 990 tax filings, in 2016, AfPA had \$9,820,150 in total revenue, including \$950,000 from “membership dues;” \$974,100 from “other contributions, gifts, grants, and similar amounts not included above;” and \$7,896,050 in “program service revenue” from “PATIENT ACCESS RECOGNITION.” [Alliance for Patient Access, IRS Form 990, [11/14/17](#)]

- **2016: PhRMA gave at least \$1.425 million to AfPA.**  
According to their IRS Form 990 tax filings, in 2016, PhRMA gave \$1,425,000 to the Alliance for Patient Access, which was characterized as a “general contribution.” [PhRMA, IRS Form 990, [11/14/17](#)]

**2015: AfPA had a total revenue of \$7,485,900.**

According to their IRS Form 990 tax filings, in 2015, AfPA had \$7,485,900 in total revenues, including \$440,000 in “membership dues,” \$720,600 in “all other contributions, gifts, grants, and similar amounts not included above,” and \$6,325,300 in “program service revenue” from “patient access champion recognition” [Alliance for Patient Access, IRS Form 990, [11/10/16](#)]

- **2015: PhRMA gave at least \$50,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2015, PhRMA gave \$50,000 to the Alliance for Patient Access, which was characterized as a “general contribution.”  
[PhRMA, IRS Form 990, [11/15/16](#)]

- **2015: BIO gave at least \$30,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2015, BIO gave \$30,000 to Alliance for Patient Access, for “program activities.”  
[BIO, IRS Form 990, [11/4/16](#)]

**2014: AfPA had \$2,229,600 in total revenue.**

According to their IRS Form 990 tax filings, in 2014, AfPA had \$2,229,600 in total revenue, including \$329,600 in “membership dues,” \$400,000 in “all other contributions, gifts, grants, and similar amounts not included above,” and \$1,500,000 in “program service revenue” for “patient access champion recognition.”  
[Alliance for Patient Access, IRS Form 990, [5/12/15](#)]

- **2014: PhRMA gave at least \$55,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2014, PhRMA gave \$55,000 to the Alliance for Patient Access, which was characterized as a contribution-general.  
[PhRMA, IRS Form 990, [11/12/15](#)]

- **2014: PhRMA gave at least \$25,000 to the Coalition for Clinical Trials Awareness.**

According to their IRS Form 990 tax filings, in 2014, PhRMA gave \$55,000 to the Coalition for Clinical Trials Awareness, which was characterized as a contribution-general.  
[PhRMA, IRS Form 990, [11/12/15](#)]

- **2014: BIO gave at least \$30,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2014, BIO gave \$30,000 to Alliance for Patient Access, for “program activities.”  
[BIO, IRS Form 990, [11/13/15](#)]

**2013: AfPA had \$713,750 in total revenue.**

According to their IRS Form 990 tax filings, in 2013, AfPA had \$713,750 in total revenue, including \$322,500 from “membership dues” and \$391,250 from “all other contributions, gifts, grants, and similar amounts not included above.”  
[Alliance for Patient Access, IRS Form 990, [6/2/14](#)]

- **2013: PhRMA gave at least \$85,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2013, PhRMA gave \$85,000 to the Alliance for Patient Access, which was characterized as contributions-general.  
[PhRMA, IRS Form 990, [11/13/14](#)]

- **2013: BIO gave at least \$50,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2013, BIO gave \$30,000 to Alliance for Patient Access, for general support.  
[BIO, IRS Form 990, [11/13/14](#)]

**2012: AfPA had \$325,000 in total revenue.**

According to their IRS Form 990 tax filings, In 2012, AfPA had \$325,000 in total revenue, including \$110,000 from “membership dues” and \$215,000 from “all other contributions, gifts, grants, and similar amounts not included above.” [Alliance for Patient Access, IRS Form 990, [6/21/13](#)]

- **2012: PhRMA gave at least \$55,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2012, PhRMA gave \$55,000 to the Alliance for Patient Access, which was characterized as a contribution-general.

[PhRMA, IRS Form 990, [11/14/13](#)]

**2011: AfPA had \$420,000 in total revenue.**

According to their IRS Form 990 tax filings, in 2011, AfPA had \$420,000 in total revenue, all of it from “all other contributions, gifts, grants, and similar amounts not included above.”

[Alliance for Patient Access, IRS Form 990, [7/16/12](#)]

- **2011: PhRMA gave at least \$40,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2011, PhRMA gave \$40,000 to the Alliance for Patient Access, which was characterized as a general grant.

[PhRMA, IRS Form 990, [10/20/12](#)]

**2010: AfPA had \$375,000 in total revenue.**

According to their IRS Form 990 tax filings, in 2010, AfPA had \$375,000 in total revenue, all of it from “all other contributions, gifts, grants, and similar amounts not included above.”

[Alliance for Patient Access, IRS Form 990, [5/16/11](#)]

- **2010: PhRMA gave at least \$55,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2010, PhRMA gave \$55,000 to the Alliance for Patient Access, which was characterized as a general grant.

[PhRMA, IRS Form 990, [11/11/11](#)]

**2009: AfPA had \$454,400 in total revenue.**

According to their IRS Form 990 tax filings, in 2009, AfPA had \$454,400 in total revenue, all of it from “contributions, gifts, grants, and similar amounts received.”

[Alliance for Patient Access, IRS Form 990, [4/29/10](#)]

- **2009: PhRMA gave at least \$75,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2009, PhRMA gave \$75,000 to the Alliance for Patient Access, which was characterized as a general contribution.

[PhRMA, IRS Form 990, [11/11/10](#)]

**2008: AfPA had \$548,059 in total revenue.**

According to their IRS Form 990 tax filings, in 2008, AfPA had \$548,059 in total revenue, all of it from “contributions, gifts, grants, and similar amounts received.”

[Alliance for Patient Access, IRS Form 990, [7/20/09](#)]

- **2008: PhRMA gave at least \$95,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2008, PhRMA gave \$95,000 to the Alliance for Patient Access, in two contributions. The first contribution of \$70,000 was characterized as general contribution. The second contribution of \$25,000 was characterized as “grant-Educational Studies 2008 Trans-Atlantic Summer Institute.”

[PhRMA, IRS Form 990, [11/16/09](#)]

**AFPA AFFILIATES, GLOBAL ALLIANCE FOR PATIENT ACCESS AND THE INSTITUTE FOR PATIENT ACCESS, HAVE ALSO RECEIVED SIGNIFICANT FINANCIAL SUPPORT FROM PHRMA.**

**The Global Alliance for Patient Access receives funding from AfPA, PhRMA, and at least seven major pharmaceutical companies.**

“Associate Members and Financial Supporters, December 2020: Alliance for Patient Access, Alnylam, Amgen, EMD Serono, Merck Janssen Partnership to Advance Cardiovascular Health, Pfizer, PhRMA, Regeneron, Sanofi.”  
[Global Alliance for Patient Access, December 2020]

**2019: GAfPA had a revenue of \$489,965.**

[Global Alliance for Patient Access, IRS Form 990, undated; on file]

- **2019: GAfPA reported no revenue from membership dues.**

[Global Alliance for Patient Access, IRS Form 990, undated; on file]

**2018: GAfPA had a revenue of \$826,000.**

[Global Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

- **2018: GAfPA reported no revenue from membership dues.**

[Global Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

- **2018: PhRMA gave at least \$25,000 to GAfPA.**

According to their IRS Form 990 tax filings, in 2018, PhRMA gave \$25,000 to the Global Alliance for Patient Access, which was characterized as a general contribution.

[PhRMA, IRS Form 990, [11/12/19](#)]

**2018: IfPA had a revenue of \$1,017,100.**

According to their IRS Form 990, in 2018, IfPA had total revenue of \$1,017,100, including \$100,000 from “membership dues” and \$917,100 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Institute for Patient Access, IRS Form 990, [11/14/19](#)]

- **2018: 33.99 percent of IfPA’s revenue came from “public support.”**

“Public support percentage for 2018 [...] 33.990 percent.”

[Institute for Patient Access, IRS Form 990, [11/14/19](#)]

- **2018: AfPA gave \$58,000 to IfPA for “support for programming and summits.”**

According to their IRS Form 990 tax filings, in 2018, AfPA gave \$58,000 to IfPA for “support for programming and summits.”

[Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

- **2018: BIO gave at least \$30,000 to IfPA.**

According to their IRS Form 990 tax filings, in 2018, BIO gave \$30,000 to the Institute for Patient Access, characterized as a donation.

[BIO, IRS Form 990, [11/15/19](#)]

**2017: GAfPA had a revenue of \$711,520.**

[Global Alliance for Patient Access, IRS Form 990, [7/9/18](#)]

- **2017: GAfPA reported no revenue from membership dues.**

[Global Alliance for Patient Access, IRS Form 990, [7/9/18](#)]

- **2017: PhRMA gave at least \$40,000 to GAfPA.**

According to their IRS Form 990 tax filings, in 2017, PhRMA gave \$40,000 to the Global Alliance for Patient Access, which was characterized as a general contribution.

[PhRMA, IRS Form 990, [11/15/18](#)]

**2017: IfPA had a revenue of \$530,000.**

According to their IRS Form 990, in 2017, IfPA had total revenue of \$530,000, including \$175,000 from “membership dues” and \$355,000 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Institute for Patient Access, IRS Form 990, [8/22/18](#)]

- **2017: Just 24 percent of IfPA's financial support came from the general public, failing to achieve the goal of 33 1/3 percent generally required of “public charities.”**

“I am pleased to highlight that in 2017, IfPA made substantial progress in achieving the goal of at least 33 1/3 percent of its support coming from the general public and while doing so continued to operate as a public charity. For tax year 2017, 24 percent of IfPA's support was provided by the general public, which is an increase from previous years. Furthermore, achieving the required threshold of public support is amongst IfPA's top 2018 priorities, and substantial progress has been made in that regard through July 2018. To that end, this year IfPA has seen an increase in not only the number of donors but also a number of new supporters as well. [...] as mentioned above, 2017 represented a year of great progress in not only achieving IfPA's exempt purpose, but also in continuing to develop its capacity as a public charity. I am confident that in 2018 the goal of achieving the desired 33 1/3 percent threshold of public support will be met, which will serve to fuel even greater progress.”

[Institute for Patient Access, IRS Form 990, [8/22/18](#)]

- **IfPA asserted that based on the “facts-and-circumstances” test, they should be considered a public charity because the organization hosted policy summits, produced white papers, and maintained a public website and social media presence.**

“10 percent-facts-and-circumstances test—2017. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10 percent or more, and if the organization meets the ‘facts-and-circumstances’ test, check this box and stop here. Explain in Part VI how the organization meets the ‘facts-and-circumstances’ test. The organization qualifies as a publicly supported organization. [...] the application of the facts and circumstances test to IfPA's 2017 programming demonstrates that IfPA continued to operate as a public charity. Last year, IfPA produced three major policy summits, all widely attended and with no admission charge to the participants. The subject matter of these day-long conferences included addressing racial disparities in provision of health resources for at-risk infants, access to balanced pain management and integrative care for patient suffering from addiction, and the need to preserve physician-patient clinical decision making in the treatment of chronic diseases. Amongst those participating were patient advocates, healthcare providers, policymakers and members of the media. These events were promoted before, during and after on multiple social media platforms, and the enduring content (reports and videos) were similarly shared via social media and made available on IfPA's website. The other area of 2017 programming where IfPA continues to manifest its mission of public charitable service is in the production of educational materials provided to the general public at no cost. In 2017, IfPA produced a total of 16 policy white papers, health analytic briefs, health technology assessment guides, event reports and info-graphics. These resources covered public health concerns including: the costs of cancer treatment, access to treatment for prison populations suffering from infectious disease, the role of co-pay assistance in furthering patient care, and patient safety protections in the disbursement of medicines. All of these resources were posted to publicly accessible websites, promoted and widely disseminated via social media platforms and featured in free e-newsletters. These highly regarded resources explore issues impacting patient access to care, from both the patient and providers' perspectives, and are meant to inform the public's understanding of these topics.”

[Institute for Patient Access, IRS Form 990, [8/22/18](#)]

- **2017: AfPA gave \$25,000 to IfPA for “general operations.”**

According to their IRS Form 990 tax filings, in 2017, AfPA gave \$25,000 to IfPA for “general operations.” [Alliance for Patient Access, IRS Form 990, [7/3/18](#)]

- **2017: PhRMA gave at least \$50,000 to IfPA.**

According to their IRS Form 990 tax filings, in 2017, PhRMA gave \$50,000 to the Institute for Patient Access, which was characterized as a “general contribution.” [PhRMA, IRS Form 990, [11/15/18](#)]

**2016: GAfPA had revenue of \$655,000.**

[Global Alliance for Patient Access, IRS Form 990, [11/15/17](#)]

- **2016: GAfPA reported no revenue from membership dues.**

[Global Alliance for Patient Access, IRS Form 990, [11/15/17](#)]

- **2016: PhRMA gave at least \$25,000 to GAfPA.**

According to their IRS Form 990 tax filings, in 2016, PhRMA gave \$25,000 to the Global Alliance for Patient Access, which was characterized as a “general contribution.” [PhRMA, IRS Form 990, [11/14/17](#)]

**2016: IfPA had a revenue of \$390,000.**

According to their IRS Form 990, in 2016 IfPA had a total revenue of \$390,000, including \$200,000 from “membership dues” and \$190,000 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Institute for Patient Access, IRS Form 990, [11/14/17](#)]

- **2016: PhRMA gave at least \$100,000 to IfPA.**

According to their IRS Form 990 tax filings, in 2016, PhRMA gave \$100,000 to the Institute for Patient Access, which was characterized as a “general contribution.” [PhRMA, IRS Form 990, [11/14/17](#)]

**2015: GAfPA had a revenue of \$755,000.**

According to their IRS Form 990, in 2015, IfPA had total revenue of \$755,000, including \$400,000 from “membership dues” and \$355,000 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Global Alliance for Patient Access, IRS Form 990, [11/11/16](#)]

- **2015: AfPA gave \$25,000 to GAfPA for “General Support.”**

[Alliance for Patient Access, IRS Form 990, [11/10/16](#)]

**2015: IfPA had a revenue of \$385,000.**

According to their IRS Form 990, in 2015, IfPA had total revenue of \$385,000, including \$150,000 from “membership dues” and \$235,000 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Institute for Patient Access, IRS Form 990, [11/11/16](#)]

**2014: GAfPA had a total revenue of \$100,000, entirely from “membership dues and assessments.”**

[Global Alliance for Patient Access, IRS Form 990, [6/15/15](#)]

**2014: IfPA had revenue of \$180,010.**

According to their IRS Form 990, in 2014, IfPA had total revenue of \$180,010, including \$100,000 from “membership dues and assessments” and \$80,010 from “contributions, gifts, grants, and similar amounts received.” [Institute for Patient Access, IRS Form 990, [5/12/15](#)]

### **2013: AfPA had \$713,750 in total revenue.**

According to their IRS Form 990 tax filings, in 2013, AfPA had \$713,750 in total revenue, including \$322,500 from “membership dues” and \$391,250 from “all other contributions, gifts, grants, and similar amounts not included above.”

[Alliance for Patient Access, IRS Form 990, [6/2/14](#)]

- **2013: PhRMA gave at least \$85,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2013, PhRMA gave \$85,000 to the Alliance for Patient Access, which was characterized as a general contribution.

[PhRMA, IRS Form 990, [11/13/14](#)]

- **2013: BIO gave at least \$50,000 to AfPA.**

According to their IRS Form 990 tax filings, in 2013, BIO gave \$30,000 to Alliance for Patient Access, for general support.

[BIO, IRS Form 990, [11/13/14](#)]

### **2013: IfPA had a revenue of \$120,000.**

According to their IRS Form 990, in 2013, IfPA had a total revenue of \$180,010, all from “contributions, gifts, grants, and similar amounts received.”

[Institute for Patient Access, IRS Form 990, [5/29/14](#)]

- **2013: IfPA disclosed that zero percent of their revenue came from public support.**

“Public support percentage for 2013 [...] 0 percent.”

[Institute for Patient Access, IRS Form 990, [5/29/14](#)]

### **2012: IfPA had a revenue of \$35,000.**

According to their IRS Form 990, in 2012, IfPA had a total revenue of \$35,000, all from “contributions, gifts, grants, and similar amounts received.”

[Institute for Patient Access, IRS Form 990, [7/17/13](#)]

- **2012: IfPA disclosed that zero percent of their revenue came from public support.**

“Public support percentage for 2012 [...] 0 percent.”

[Institute for Patient Access, IRS Form 990, [7/17/13](#)]

- **2012: IfPA told the IRS that its mission was to sponsor “physicians discussing...patient access to approved therapeutics.”**

“The institute for patient access promotes a better understanding of the physician-patient relationship in the provision of quality healthcare by sponsoring programming designed to feature physicians discussing the need to preserve physician clinical decision making and patient access to approved therapeutics.”

[Institute for Patient Access, IRS Form 990, [7/17/13](#)]

## **Leadership & Lobbying**

*AfPA's executive leadership is indistinct from the staff of lobbying firm Woodberry Associates. AfPA's current and former executive directors are both in leadership positions at Woodberry Associates.*

*Additionally, the office address listed on AfPA's website is the same as Woodberry Associates' office address: 1275 Pennsylvania Ave. NW, Suite 1100A, Washington, D.C. 20004.*



[Woodberry Associates, accessed [2/22/21](#)]

## MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

According to their most recent tax filings, AfPA, GfPA, and IfPA appear to only provide direct compensation to treasurer Colleen Evans (significantly less than \$20,000 per entity per year). Evans appears to be a professional accountant in Bettendorf, IA. She doesn't seem to be otherwise involved in the organization's advocacy work.

AfPA appears to compensate its executive management team through payments made to Woodberry Associates, as discussed below, though Woodberry Associates founder Brian Kennedy and lobbyist Gavin Clingham appear to have been paid directly by the organization as well, for "consulting" services.

Others receiving payment from AfPA and its affiliates are discussed below.

## JOSIE COOPER, AFPA EXECUTIVE DIRECTOR / WOODBERRY ASSOCIATES HEALTH CARE ADVOCACY LEADER

### **Josie Cooper is Executive Director of AfPA.**

"Executive Director Josie Cooper WASHINGTON, DC. Josie Cooper serves as executive director of the Alliance for Patient Access. At AfPA, Ms. Cooper has worked in stakeholder and clinician mobilization, developing policy and educational strategies to improve patient access to care. Ms. Cooper has a background in communications, research, grassroots organization and campaign politics. Ms. Cooper has worked at the state and national level advising political campaigns and public affairs clients on supporter and stakeholder mobilization. She has worked on major races across the country, from presidential campaigns to Senate and congressional races. Prior to joining AfPA, Ms. Cooper worked for a DC-based consulting firm and for a trade association representing biotechnology companies."

[Alliance for Patient Access, accessed [12/14/20](#)]

- **April 2017-November 2017: Cooper was a communications manager for BIO.**  
[Josie (Peterson) Cooper LinkedIn profile, accessed [12/14/20](#)]
- **Cooper helped "develop effective communications strategies" for "BIO, the world's largest biotechnology trade association."**  
"Josie Cooper leads Woodberry Associates' health care advocacy division, managing stakeholder and clinician engagement and developing policy and educational strategies around health care issues. Josie Cooper has a background in communications, grassroots organization and campaign politics. Prior to joining Woodberry Associates, Ms. Cooper worked for a DC-based consulting firm, where she specialized in helping political and corporate clients run targeted, data driven campaigns across the country. She also worked for BIO, the world's largest biotechnology trade association, helping develop effective communications strategies."  
[Woodberry Associates, accessed [12/14/20](#)]
- **Cooper "leads Woodberry Associates' health care advocacy division, managing stakeholder and clinician engagement and developing policy and educational strategies around health care issues."**  
"Josie Cooper leads Woodberry Associates' health care advocacy division, managing stakeholder and clinician engagement and developing policy and educational strategies around health care issues. Josie Cooper has a background in communications, grassroots organization and campaign politics. Prior to joining Woodberry Associates, Ms. Cooper worked for a DC-based consulting firm, where she specialized in helping political and corporate clients run targeted, data driven campaigns across the country. She also worked for BIO, the world's largest biotechnology trade association, helping develop effective communications strategies."  
[Woodberry Associates, accessed [12/14/20](#)]

## **BRIAN KENNEDY, FORMER AFPA EXECUTIVE DIRECTOR & CONSULTANT / FOUNDER OF WOODBERRY ASSOCIATES.**

**2006-2019: Brian Kennedy was executive director of AfPA.**

[Brian Kennedy LinkedIn profile, accessed [12/14/20](#)]

**Kennedy is founder and president of Woodberry Associates.**

“Brian Kennedy is founder and president of Woodberry Associates, a Washington, DC-based public affairs consultancy with years of experience in stakeholder advocacy, government relations and coalition management. For over two decades, Brian’s professional career has spanned the practice of law, campaign politics and corporate public affairs. He has served as the organizer, manager and/or a strategic consultant to dozens of non-profit organizations, coalitions and associations, including the Alliance for Patient Access. He has served on the national political staff of two presidential campaigns and is a past Executive Director of the Republican Governors Association. Brian is an alumnus of Iowa State University and earned his J.D. from Drake University Law School. He is a long standing member of the Iowa State Bar Association.”

[Woodberry Associates, accessed [12/14/20](#)]

**2018: AfPA paid Woodberry Associates \$91,500 for “consulting services provided to the organization.”**

According to their IRS Form 990 tax filings, in 2018, AfPA paid Woodberry Associates \$91,500 for “consulting services provided to the organization.”

[Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

- **“BRIAN KENNEDY RECEIVED PAYMENT FOR EXECUTIVE DIRECTOR SERVICES FROM CONSULTING FEES PAID TO WOODBERRY ASSOCIATES.”**

[Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

**2017: AfPA paid Brian Kennedy \$75,000 for “consulting services” and received other compensation from Woodberry Associates for his role as executive director of AfPA.**

According to their IRS Form 990 tax filings, in 2017, AfPA paid \$75,000 to Brian Kennedy for “consulting services.” Kennedy is “president of woodberry associates and executive director of the AfPA.” Additionally, “brian kennedy received payment for executive director services from consulting fees paid to Woodberry Associates.”

[Alliance for Patient Access, IRS Form 990, [7/3/18](#)]

**2016: AfPA paid \$344,233 to Brian Kennedy for “consulting services” and reimbursements.**

According to their IRS Form 990 tax filings, in 2016, AfPA paid 344,233 to Brian Kennedy for “consulting services (\$67,008), as well as reimbursement of expenses (\$277,225) not included on Form 990, Part VII.” Kennedy is the “president of Woodberry Associates and executive director of the AfPA.”

[Alliance for Patient Access, IRS Form 990, [11/14/17](#)]

## **GAVIN CLINGHAM, AFPA DIRECTOR OF PUBLIC POLICY, CONSULTANT, LOBBYIST / WOODBERRY ASSOCIATES PRINCIPAL.**

**Gavin Clingham is principal at Woodberry Associates and director of public policy for AfPA.**

[Gavin Clingham LinkedIn profile, accessed [12/14/20](#)]

**2017: AfPA paid \$144,000 to Gavin Clingham for “consulting services.”**

According to their IRS Form 990 tax filings, in 2017, AfPA paid \$144,000 to Gavin Clingham for “consulting services.”

[Alliance for Patient Access, IRS Form 990, [7/3/18](#)]

- **Gavin Clingham is a partner and senior Vice President at Woodberry Associates.**

“Gavin Clingham, J.D., Partner / Senior Vice President | Client Services. Gavin Clingham leads Client Services at Woodberry Associates overseeing division leaders and directly servicing clients.”

[Woodberry Associates, accessed [12/16/20](#)]

**2016: AfPA paid \$130,000 to Gavin Clingham for “consulting services.”**

According to their IRS Form 990 tax filings, in 2016, AfPA paid \$130,000 to Gavin Clingham for “AfPA policy director and manager of biol.”

[Alliance for Patient Access, IRS Form 990, [11/14/17](#)]

- **Gavin Clingham is a partner and senior Vice President at Woodberry Associates.**

“Gavin Clingham, J.D., Partner / Senior Vice President | Client Services. Gavin Clingham leads Client Services at Woodberry Associates overseeing division leaders and directly servicing clients.”

[Woodberry Associates, accessed [12/16/20](#)]

**2015-2019: Woodberry Associates was the registered lobbyist for AfPA.**

According to federal lobbying reports, Woodberry Associates registered as the lobbying firm for AfPA on September 1, 2015 and filed a termination as their lobbyist April 19, 2019. Gavin Clingham of Woodberry Associates first registered as the lobbyist for AfPA. Clinham and Darby O’Donnell were listed as the lobbyists terminating representation of AfPA.

[Woodberry Associates, Lobbyist Registration, [9/1/15](#); Lobbyist Termination, [4/19/19](#)]

- **2015-2019: AfPA paid Woodberry Associates at least \$430,000 for federal lobbying.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/14/20](#)]

**OTHER AFPA STAFF WHO ALSO HOLD POSITIONS AT WOODBERRY ASSOCIATES.**

**Amanda Conschafter is a partner and senior Vice President at Woodberry Associates and communication director of AfPA.**

[Amanda Conschafter LinkedIn profile, accessed [12/14/20](#)]

- **2017: AfPA paid \$102,000 to Amanda Conschafter for “consulting services.”**

According to their IRS Form 990 tax filings, in 2017, AfPA paid \$102,000 to Amanda Conschafter for “consulting services.”

[Alliance for Patient Access, IRS Form 990, [7/3/18](#)]

- **Amanda Conschafter is a partner and senior Vice President at Woodberry Associates.**

“Amanda Conschafter Partner / Senior Vice President | Strategic Communications. Amanda Conschafter leads Woodberry Associates’ Strategic Communications division, which distills client messages into cohesive, compelling narratives that inform public policy. Amanda oversees the creation and dissemination of videos, policy papers, infographics, blog posts and other content that educates policymakers and empowers advocates.”

[Woodberry Associates, accessed [12/16/20](#)]

**Jasmine Patel, a senior director at Woodberry Associates, is director of global policy for the Global Alliance for Patient Access.**

“Jasmine Patel, MPH, Senior Director | Coalition & Non-Profit Management. Jasmine Patel is a senior director in Woodberry Associates’ coalition & non-profit management division. She currently serves as Director of Policy and Outreach for the Partnership to Advance Cardiovascular Health (PACH) and Director of Global Policy for the Global Alliance for Patient Access (GAfPA). Jasmine has extensive experience working in cardiovascular health, growing patient communities, advancing collaborative partnerships with multi-stakeholder groups, and driving public health and global advocacy initiatives.” [Woodberry Associates, accessed [12/14/20](#)]

**February 2019-Present John Bates is a director of both Woodberry Associates and AfPA.**

[John Bates LinkedIn profile, accessed [12/14/20](#)]

**Olivia Perry holds positions at both Woodberry Associates (senior associate) and AfPA (policy and advocacy program coordinator).**

[Olivia Perry LinkedIn profile, accessed [12/14/20](#)]

**Alexa DeVantier holds positions at both Woodberry Associates and AfPA.**

[Alexa DeVantier LinkedIn profile, accessed [12/14/20](#)]

**Lauren Carter-Early is an associate at both Woodberry Associates and AfPA.**

[Lauren Carter-Early LinkedIn profile, accessed [12/14/20](#)]

**2015-2020: AFPA HAS SPENT AT LEAST \$610,000 LOBBYING CONGRESS THROUGH WOODBERRY ASSOCIATES AND STAFF.**

**2015-2020: AfPA has spent at least \$610,000 lobbying Congress.**

[U.S. Senate Lobbying Disclosure Database, accessed 12/16/20]

REGISTRANT NAME	CLIENT NAME	FILING TYPE	AMOUNT REPORTED	DATE POSTED	FILING YEAR
Alliance for Patient Access	Alliance for Patient Access	THIRD QUARTER REPORT	\$30,000.00	10/20/20	2020
Alliance for Patient Access	Alliance for Patient Access	SECOND QUARTER REPORT	\$30,000.00	7/20/20	2020
Alliance for Patient Access	Alliance for Patient Access	FIRST QUARTER REPORT	\$30,000.00	4/20/20	2020
Alliance for Patient Access	Alliance for Patient Access	FOURTH QUARTER REPORT	\$30,000.00	1/20/20	2019
Alliance for Patient Access	Alliance for Patient Access	THIRD QUARTER REPORT	\$30,000.00	10/19/19	2019
Alliance for Patient Access	Alliance for Patient Access	SECOND QUARTER REPORT	\$30,000.00	7/21/19	2019
Alliance for Patient Access	Alliance for Patient Access	REGISTRATION		4/25/19	2019
Woodberry Associates	Alliance for Patient Access	FIRST QUARTER TERMINATION	\$30,000.00	4/19/19	2019
Woodberry Associates	Alliance for Patient Access	FOURTH QUARTER REPORT	\$30,000.00	1/20/19	2018
Woodberry Associates	Alliance for Patient Access	THIRD QUARTER REPORT	\$30,000.00	10/18/18	2018
Woodberry Associates	Alliance for Patient Access	SECOND QUARTER REPORT	\$30,000.00	7/20/18	2018
Woodberry Associates	Alliance for Patient Access	FIRST QUARTER REPORT	\$30,000.00	4/20/18	2018
Woodberry Associates	Alliance for Patient Access	FOURTH QUARTER REPORT	\$30,000.00	1/19/18	2017
Woodberry Associates	Alliance for Patient Access	THIRD QUARTER REPORT	\$30,000.00	10/20/17	2017
Woodberry Associates	Alliance for Patient Access	SECOND QUARTER REPORT	\$30,000.00	7/20/17	2017
Woodberry Associates	Alliance for Patient Access	FIRST QUARTER REPORT	\$30,000.00	4/20/17	2017
Woodberry Associates	Alliance for Patient Access	FOURTH QUARTER REPORT	\$30,000.00	1/23/17	2016
Woodberry Associates	Alliance for Patient Access	THIRD QUARTER REPORT	\$30,000.00	10/20/16	2016

Woodberry Associates	Alliance for Patient Access	SECOND QUARTER REPORT	\$30,000.00	7/20/16	2016
Woodberry Associates	Alliance for Patient Access	FIRST QUARTER REPORT	\$30,000.00	4/20/16	2016
Woodberry Associates	Alliance for Patient Access	FOURTH QUARTER REPORT	\$30,000.00	1/20/16	2015
Woodberry Associates	Alliance for Patient Access	THIRD QUARTER REPORT	\$10,000.00	10/20/15	2015
Woodberry Associates	Alliance for Patient Access	REGISTRATION		10/13/15	2015
<b>TOTAL</b>			<b>\$610,000.00</b>		

[U.S. Senate Lobbying Disclosure Database, accessed [12/16/20](#)]

## **Board of Directors and Other Consultants**

### **DR. DAVID CHARLES, AfPA FOUNDER**

**AfPA was founded by Dr. David Charles, who spent a year as a fellow on Sen. Bill Frist's staff.**

“David Charles, MD, Nashville, TN. AfPA is led by founding member David Charles, M.D., Professor and Vice-Chair of Neurology at Vanderbilt University Medical Center. He is a national leader in Movement Disorders research. Dr. Charles took leave from his practice in 1998 and spent a year on the staff of U.S. Senator Bill Frist, where he served as a health policy advisor. Following this experience in Washington, he conducted Parkinson's disease research in France as a Fulbright Senior Scholar.”

[Alliance for Patient Access, accessed [12/14/20](#)]

- **Charles' bio page on the Vanderbilt University website includes a disclaimer about the funding the university received from pharmaceutical companies.**

“Clinical Research Opportunities: We are accepting applications for undergraduate research roles within our team. Please send your résumé with an accompanying statement of interest to david.charles@vanderbilt.edu Vanderbilt University has received or currently receives income from grants or contracts with Allergan, Boehringer-Ingelheim, Pharma 2 B, Revance, USWorldMeds, Voyager, DuPont, Elan, Hoffman-LaRoche, Ipsen, Kyowa, Medtronic, Merz, Novartis, and Smith-Kline to support Dr. Charles research efforts. Dr. Charles has received or currently receives income from Allergan, Alliance for Patient Access, Boehringer-Ingelheim, Ipsen, Medtronic, Merz, Mylan-Bertek, Novartis, Ovation, Pfizer, Prestwick, Revance, Schwarz, UCB, USWorldMeds, and Vernalis for consulting services.”

[Vanderbilt University Medical Center, accessed [12/14/20](#)]

- **Other biographical pages for faculty leadership in the Neurology Department at the Vanderbilt University do not include the funding disclaimer that is included on Charles' biography page.**

[Vanderbilt University Medical Center, accessed [12/14/20](#)]

- **Charles has received income from pharmaceutical companies Allergan, Ipsen, Revance, and USA WorldMeds.**

“Vanderbilt University Medical Center receives income from Abbott, Allergan, Boston Scientific, Impax, Ipsen, Lundbeck, Merz, Medtronic, Pharma 2B, US World Meds, and Voyager for research or educational programs led by Charles. Charles has received income from Allergan, Alliance for Patient Access, Ipsen, Revance, and USA WorldMeds, for consulting services.”

[PubMed.gov, [4/22/20](#)]

- **Alliance for Patient Access was listed among pharmaceutical companies in Charles' conflict of interest statement on a published journal article.**

"Vanderbilt University Medical Center receives income from Abbott, Allergan, Boston Scientific, Impax, Ipsen, Lundbeck, Merz, Medtronic, Pharma 2B, US World Meds, and Voyager for research or educational programs led by Charles. Charles has received income from Allergan, Alliance for Patient Access, Ipsen, Revance, and USA WorldMeds, for consulting services."

[PubMed.gov, [4/22/20](#)]

- **Charles' research at Vanderbilt University has been funded by major pharmaceutical companies.**

"Vanderbilt University Medical Center receives income from Abbott, Allergan, Boston Scientific, Impax, Ipsen, Lundbeck, Merz, Medtronic, Pharma 2B, US World Meds, and Voyager for research or educational programs led by Charles. Charles has received income from Allergan, Alliance for Patient Access, Ipsen, Revance, and USA WorldMeds, for consulting services."

[PubMed.gov, [4/22/20](#)]

#### **Dr. David Charles leads the IfPA.**

"David Charles, M.D., Nashville, TN. IfPA is led by David Charles, M.D., who is the Chief Medical Officer of the Vanderbilt University Clinical Neurosciences Institute. Dr. Charles is a national leader in Movement Disorders research. He took leave from his practice in 1998 and spent a year on the staff of U.S. Senator Bill Frist, where he served as a health policy advisor. Following this experience in Washington, Dr. Charles conducted Parkinson's disease research in France as a Fulbright Senior Scholar."

[Institute for Patient Access, accessed [12/15/20](#)]

#### **DR. KEITH FERDINAND, AFPA BOARD OF DIRECTORS**

#### **Dr. Keith C. Ferdinand is on the board of directors of AfPA.**

"Keith C. Ferdinand, MD, New Orleans, LA. Keith C. Ferdinand, MD, is Professor of Medicine at the John W. Deming Department of Medicine, Tulane University School of Medicine and the Tulane Heart and Vascular Institute in New Orleans, Louisiana. He is board certified in internal medicine and cardiovascular disease, certified in the subspecialty of nuclear cardiology, and a specialist in clinical hypertension certified by the American Society of Hypertension."

[Alliance for Patient Access, accessed [12/14/20](#)]

- **Ferdinand has received grants and been a consultant for major pharmaceutical companies.**

"Conflict of interest: Dr Cryer serves as consultant for Esperion Therapeutics. Dr Ferdinand received a grant from Boehringer Ingelheim and serves as consultant for Amgen, Sanofi, Boehringer Ingelheim, Quantum Genomics, Novartis, and Eli Lilly. Drs. Senatore, Clayton-Jeter, Lewin, Nasser, and Yadav have nothing to disclose."

[PubMed.gov, [October 2017](#)]

- **2013-2019: Ferdinand received \$319,534.12 in "general payments" from pharmaceutical companies and medical device manufacturers.**

According to federal records, Ferdinand received a total of \$319,534.12 in 366 payments from pharmaceutical companies and medical device manufacturers. "General payments" are "payments that are not associated with a research study."

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Ferdinand received \$11,329.21 in "research payments" from pharmaceutical companies and medical device manufacturers.**

According to federal records, Ferdinand received a total of \$11,329.21 in 8 payments from pharmaceutical companies and medical device manufacturers. "Research payments" are "payments that are associated with a research study."

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Ferdinand received \$201,313.06 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Ferdinand received a total of \$201,313.06 in eight payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “Funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

## DR. BRUCE RUBIN, AFPA BOARD OF DIRECTORS

### **Dr. Bruce Rubin is on AfPA’s board of directors.**

“Bruce Rubin, MD, Miami, FL. Bruce Rubin, MD, is an Assistant Professor of Clinical Neurology at the University of Miami Miller School Of Medicine. Dr. Rubin received his Bachelor of Science degree from Hobart College and his Doctor of Medicine degree from State University of New York Health Science Center at Syracuse. He completed his neurological residency at the Neurologic Institute at Columbia Presbyterian Medical Center in New York and his post-doctoral fellowship at the University of Miami School of Medicine. Dr. Rubin has lectured nationally and published articles in several scientific journals. He is a member of the American Academy of Neurology, American Society of Neurorehabilitation and Brain Injury Association of Florida. He is chairman of the Florida Chapter of the Alliance for Patient Access.”

[Alliance for Patient Access, accessed [12/14/20](#)]

- **2018-2019: Rubin was senior director of U.S. medical affairs in neurology for pharmaceutical company Ipsen.**

[Bruce Rubin LinkedIn profile, accessed [12/14/20](#)]

- **2018: Rubin was “medical director, neuroscience” at pharmaceutical company Syneos Health.**

“Medical Director, Neuroscience Company Name Syneos Health (Previously INC Research/inVentiv Health). Dates Employed: 2018. Employment Duration: less than a year. Location: Raleigh-Durham, North Carolina Area Corporate profile: A Global Clinical Research Organization with ~23,000 employees. PHASE II, III, AND IV STUDIES. In this role, I was responsible for collaborating with multifunctional stakeholders in a large matrix environment to design and complete clinical research. Collaborated with cross-functional stakeholders in a large matrix environment to design and complete clinical research. This resulted in the successful development of numerous Phase II, III, and IV studies simultaneously for multiple pharmaceutical companies.”

[Bruce Rubin LinkedIn profile, accessed [12/14/20](#)]

- **2019: Rubin was an author on a journal article sponsored by Merz Pharmaceuticals.**

“IncobotulinumtoxinA Efficacy and Safety in Adults with Upper-Limb Spasticity Following Stroke: Results from the Open-Label Extension Period of a Phase 3 Study Christina Marciniak 1, Michael C Munin 2, Allison Brashear 3, Bruce S Rubin 4, Atul T Patel 5, Jarosław Sławek 6, Angelika Hanschmann 7, Reinhard Hiersemenzel 7, Elie P Elovic 8 [...] Conclusions: Repeated injections of incobotulinumtoxinA for the treatment of post-stroke upper-limb spasticity led to significant improvements in muscle tone and investigator’s global impression of change. Treatment was well tolerated, with no serious treatment-related AEs. Funding: Merz Pharmaceuticals GmbH.”

[PubMed.gov, [January 2019](#)]

- **2013-2019: Rubin received at least \$182,571.71 from pharmaceutical companies and medical device manufacturers.**

According to federal records, Rubin received a total of \$182,571.71 in 655 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Rubin received \$5,407.00 in “research payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Rubin received a total of \$5,407.00 in one payment from pharmaceutical companies and medical device manufacturers. “Research payments” are “payments that are associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Rubin received \$416,155.17 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Rubin received a total of \$416,155.17 in 104 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

#### **Dr. Bruce Rubin is on the IfPA board of directors.**

“Bruce Rubin, M.D., Miami, FL. Dr. Bruce Rubin is an Assistant Professor of Clinical Neurology at the University of Miami Miller School Of Medicine. He also currently serves as the Director of the Spasticity Clinic at Jackson Memorial Hospital. Dr. Rubin has lectured nationally and has published articles in scientific journals such as Stroke, Neurology and Archives of Family Medicine. He is a member of several professional organizations, such as the American Academy of Neurology, Dade County Medical association, American Society of Neurorehabilitation and Brain Injury Association of Florida. He also serves as the Chairman for the Florida Chapter of the Alliance for Patient Access. Dr. Rubin received his Bachelor’s of Science degree from Hobart College and his Doctor of Medicine degree from State University of New York Health Science Center at Syracuse. He completed his Neurological residency at the Neurologic Institute at Columbia Presbyterian Medical Center in New York and his post-doctoral fellowship in Neurological Rehabilitation at the University of Miami School of Medicine.”

[Institute for Patient Access, accessed [12/15/20](#)]

#### **DR. JACK SCHIM, AFPA BOARD OF DIRECTOR**

#### **Dr. Jack Schim is on the AfPA board of directors.**

“Jack Shim, [sic], MD, Oceanside, CA. Jack Schim, MD, is Voluntary Assistant Clinical Professor in the Neuroscience Department at University of California San Diego and is on staff at the VA Medical Center in La Jolla.”

[Alliance for Patient Access, accessed [12/14/20](#)]

- **Schim has received personal compensation and research support from major pharmaceutical companies.**

“Efficacy and safety of lasmiditan in patients using concomitant migraine preventive medications: findings from SAMURAI and SPARTAN, two randomized phase 3 trials. Li Shen Loo 1, Jessica Ailani 2, Jack Schim 3, Simin Baygani 1, Hans-Peter Hundemer 4, Martha Port 5, John H Krege 1 [...] Conflict of interest statement [...] JS received personal compensation from Acorda, Alder, Allergan, Amgen, Avanir, Depomed, electroCore, Eli Lilly, Novartis, Pernix, Promius, Supernus, Teva, and Upsher-Smith for consulting and speaking. He has received research support from Alder, Allergan, Amgen, electroCore, Eli Lilly, and Teva.”

[PubMed.gov, [7/24/19](#)]

- **2013-2019: Schim received at least \$1,152,418.55 from pharmaceutical companies and medical device manufacturers.**

According to federal records, Schim received a total of \$1,152,418.55 in 2,172 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]



- **2013-2019: Schim received \$1,142.00 in “research payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Schim received a total of \$1,142.00 in four payments from pharmaceutical companies and medical device manufacturers. “Research payments” are “payments that are associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Schim received \$113,549.97 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Schim received a total of \$113,549.97 in 28 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

#### **Dr. Jack Schim is on the IfPA board of directors.**

“Jack Shim (sic), M.D., Oceanside, CA. Dr. Schim is Voluntary Assistant Clinical Professor in the Neuroscience Department at University of California San Diego, and is on staff at the VA Medical Center in La Jolla. He has special interests in headache management, stroke prevention, acute stroke intervention, and neurologic rehabilitation. Dr. Schim earned his medical degree from University of California San Diego (UCSD) Medical School, served as a medical intern at Cedars Sinai Medical Center, Los Angeles, and completed his neurology residency at UCSD, with special emphasis on electromyography and neuromuscular disease. He is Past President of the Association of California Neurologists and an active member of the American Academy of Neurology, American Stroke Association, and American Headache Society. Dr. Schim is Chair of the Division of Neuroscience at Scripps Hospital, Encinitas. Dr. Schim is Board certified in Neurology, and has certification in Headache Medicine by the United Council of Neurologic Subspecialties. He has published articles in Experimental Neurology, Current Medical Research and Opinion, Pain Practice, Headache and Neurology.”

[Institute for Patient Access, accessed [12/15/20](#)]

#### **DR. WESLEY MIZUTANI, AFPA BOARD OF DIRECTORS**

#### **Dr. Wesley Mizutani is on the AfPA board of directors.**

“Wesley Mizutani, MD, Huntington Beach, CA. Wesley Mizutani, MD, is a practicing rheumatologist who also serves as Assistant Clinical Professor of Medicine at the University of California, San Diego School of Medicine. Dr. Mizutani received his undergraduate degree from the University of Southern California. He earned his medical degree from University of California Los Angeles, and he completed his internship and residency in internal medicine at Los Angeles County-USC Medical Center. Dr. Mizutani was also the recipient of a fellowship in rheumatology from the University of California, San Diego.”

[Alliance for Patient Access, accessed [12/15/20](#)]

- **2013-2019: Mizutani received at least \$175,306.40 from pharmaceutical companies and medical device manufacturers.**

According to federal records, Mizutani received a total of \$175,306.40 in 452 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Mizutani received \$14,033.47 in “research payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Mizutani received a total of \$14,033.47 in 13 payments from pharmaceutical companies and medical device manufacturers. “Research payments” are “payments that are associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Mizutani received \$1,490,257.79 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Mizutani received a total of \$1,490,257.79 in 364 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

## **DR. ROBERT YAPUNDICH, AFPA BOARD OF DIRECTORS**

### **Dr. Robert Yapundich is on the AfPA board of directors.**

“Robert Yapundich, MD, is a neurologist in private practice with Neurology Associates in Hickory, NC. Dr. Yapundich completed a neurology residency at the University of Alabama at Birmingham, followed by a fellowship in electromyography/neuromuscular diseases. He is a diplomat of The American Board of Psychiatry and Neurology with subspecialty certifications in Clinical Neurophysiology and Sleep Medicine, along with certification by the American Board of Electrodiagnostic Medicine. Dr. Yapundich has served as president of the North Carolina Neurological Society and is a board member of the North Carolina Medical Society. He has participated in clinical trials, many as primary investigator, and co-authored a variety of publications.”

[Alliance for Patient Access, accessed [12/15/20](#)]

- **2013-2019: Yapundich received at least \$447,582.03 in “general payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Yapundich received a total of \$447,582.03 in 1,112 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Yapundich received \$454,715.66 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Yapundich received a total of \$454,715.66 in 219 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

### **Dr. Robert Yapundich is on the IfPA board of directors.**

“Robert Yapundich, M.D., Hickory, NC. Dr. Robert Yapundich is a neurologist in private practice with Neurology Associates in Hickory, N.C. Dr. Yapundich completed a neurology residency at the University of Alabama at Birmingham, followed by a fellowship in electromyography/neuromuscular diseases. He is a diplomat of The American Board of Psychiatry and Neurology with subspecialty certifications in Clinical Neurophysiology and Sleep Medicine, along with certification by the American Board of Electrodiagnostic Medicine. Dr. Yapundich maintains an active outpatient practice that involves all aspects of Neurology, with a special interest in Electrodiagnostic Medicine. He has served as president of the North Carolina Neurological Society, and participates in various other local and statewide committees. Currently he is a board member of the North Carolina Medical Society and state liaison for the American Association of Neuromuscular and Electrodiagnostic Medicine. Healthcare advocacy at the state and national levels has also been an area of significant interest. He has participated in clinical trials, many as primary investigator, and has served as co-author on a variety of past publications.”

[Institute for Patient Access, accessed [12/15/20](#)]

## **DR. ROGER KOBAYASHI, IFPA BOARD OF DIRECTORS**

### **Dr. Roger Kobayashi is on the IfPA board of directors.**

“Roger Kobayashi, M.D., Omaha, NE. Dr. Roger H. Kobayashi is an immunologist-allergist and served on the full time faculty at the University of Nebraska [director immunology/allergy]” and UCLA [director Pediatric Allergy

Clinic] Schools of Medicine. He is currently in private practice in Omaha, Nebraska and Clinical Professor at UCLA. Dr. Kobayashi was born and raised in Honolulu, Hawaii and received his BA in Economics [senior thesis socialized medicine] and M.D. from the University of Nebraska as well as an M.S. in cardiovascular physiology from University of Hawaii-Manoa. He received his residency and fellowship training at USC and UCLA respectively. Of the 80 papers published, most have focused on Asthma and Recurrent infections in the Pediatric population. He has been visiting professor at a number of U.S. medical schools as well as at the Universities of Hanoi, Hue and the Military Medical School in Hanoi and an invited lecturer in Europe, Asia, the Middle East and Central America. He is an Expert Consultant for the Immune Deficiency Foundation and is a recipient of their Physician Volunteer Award and was founding member and first president of the Nebraska Allergy Society. He is a member of the Executive Committee, Negotiating Committee and Patient Advocacy Committee [Chair] of the Consortium of Independent Immunology Clinics.”  
[Institute for Patient Access, accessed [12/15/20](#)]

- **2013-2019: Kobayashi received at least \$66,524.07 in “general payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Kobayashi received a total of \$66,524.07 in 376 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Kobayashi received \$8,869.58 in “research payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Kobayashi received a total of \$8,869.58 in 6 payments from pharmaceutical companies and medical device manufacturers. “Research payments” are “payments that are associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Kobayashi received \$132,751.89 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Kobayashi received a total of \$132,751.89 in 37 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

## **DR. PAUL CHRISTO, IFPA BOARD OF DIRECTORS**

### **Dr. Paul Christo is on the IfPA board of directors.**

“Paul J. Christo, M.D., Baltimore, MD. Paul Christo, MD, MBA, is an Associate Professor in the Department of Anesthesiology and Critical Care Medicine at Johns Hopkins University School of Medicine in Baltimore, Maryland. Dr. Christo is a board certified, Harvard-trained anesthesiologist and Hopkins-trained pain medicine specialist. He directed the Multidisciplinary Pain Fellowship Program at The Johns Hopkins Hospital for eight years, and directed the Blaustein Pain Treatment Center at Hopkins for five years. Dr. Christo is an invited lecturer both nationally and internationally, serves on four journal editorial boards and reviews for several others, has published more than 90 articles and book chapters, co-edited three textbooks on pain, and actively teaches medical students, residents, and pain fellows. He has been a course director or coordinator for many CME (continuing medical education) programs that focus on educating both specialists and generalists on important aspects of pain diagnosis and treatment. He has served on Advisory Boards for the American Academy of Pain Medicine (AAPM), American Society of Anesthesiologists, International Association for the Study of Pain, and the American Pain Society (APS). He has also earned an MBA from the Johns Hopkins Carey Business School in Health Care Management.”

[Institute for Patient Access, accessed [12/15/20](#)]

- **2013-2019: Christo received at least \$130,517.05 in “general payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Christo received a total of \$130,517.05 in 96 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

#### DR. ARTURO LOAIZA-BONILLA, GAFPA PRESIDENT

**2019: Dr. Arturo Loaiza-Bonilla was president of GAFPA.**

[Global Alliance for Patient Access, IRS Form 990, undated; on file]

- **2013-2019: Loaiza-Bonilla received at least \$197,432.46 from pharmaceutical companies and medical device manufacturers.**

According to federal records, Loaiza-Bonilla received a total of \$197,432.46 in 271 payments from pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Loaiza-Bonilla received \$9,983.19 in “research payments” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Loaiza-Bonilla received a total of \$9,983.19 in five payments from pharmaceutical companies and medical device manufacturers. “Research payments” are “payments that are associated with a research study.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

- **2013-2019: Loaiza-Bonilla received \$291,744.81 in “associated research funding” from pharmaceutical companies and medical device manufacturers.**

According to federal records, Loaiza-Bonilla received a total of \$291,744.81 in 106 payments from pharmaceutical companies and medical device manufacturers. “Associated research funding” is “funding for a research project or study where the physician is named as a principal investigator.”

[OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

#### DR. ALAN MARKS, IFPA

**October 2015: Dr. Alan Marks wrote a policy brief for IfPA that acknowledged the high costs of immunology treatments and called on “manufacturers, insurers, physicians, and patients” to find a “mutually acceptable solution.”**

“Prior to immuno-oncology therapies, no cancer treatment had ever significantly extended life for patients with advanced melanoma, a particularly deadly form of skin cancer. Based on this and similar reports, immuno oncology therapy has been deemed a medical breakthrough that many believe will revolutionize cancer treatment. However, these therapies are costly and most patients cannot afford them—even with insurance. The lack of patient access to immuno-oncology therapies has stimulated debates about value in healthcare and how best to get these important therapies to patients who need them. [...] Immuno-oncology therapies are breakthrough treatments for a number of cancers, with the potential to benefit many more patients as their development proceeds. However, patient access to these high value treatments is limited because of their cost and the high co-pays required by insurers. It is imperative that manufacturers, insurers, physicians, and patients seek a mutually acceptable solution that allows patients to access treatments that meaningfully benefit them.”

[IfPA, The Physician’s Perspective: A Health Policy Brief, accessed October [2015](#)]

- **2013-2019: Dr. Alan Marks has received at least \$4,717.90 from pharmaceutical companies and medical device manufacturers.**

According to federal records, Marks has received a total of at least \$4,717.90 in 82 “general payments” from

pharmaceutical companies and medical device manufacturers. “General payments” are “payments that are not associated with a research study.” [OpenPaymentsData.CMS.gov, accessed [12/15/20](#)]

## **MICHAEL WALSH, CONSULTANT TO AFPA**

### **2017: AfPA paid \$122,500 to Michael Walsh for “Consulting Services.”**

According to their IRS Form 990 tax filings, in 2017, AfPA paid \$122,500 to Michael Walsh of Winchester, MA for “consulting services.”

[Alliance for Patient Access, IRS Form 990, accessed [7/3/18](#)]

- **Michael Walsh is president and CEO of Patient Advocacy Strategies and previously worked for Amgen, MedImmune, Biogen, InterMune, and Genentech.**

“Michael Walsh is the Principal/CEO of Patient Advocacy Strategies, overseeing all aspects of the company’s direction and client strategy. He has spent his 24-year career within the life science industry and calls upon this experience to offer strategic counsel and leadership to clients. Prior to establishing PAS, Michael served in advocacy and management leadership roles at Amgen, MedImmune, Biogen, InterMune, and Genentech. Michael currently serves on the Board of Directors for the Prescription Process Advocacy Network, the OA Action Alliance, Corporator for Eagle Bank, and previously served on the Board for the MA March Of Dimes, Co-Chair of the MassBio Marketing & Communications Committee and the MassBio Patient Advocacy Task Force.”

[Patient Advocacy Strategies, accessed [12/16/20](#)]

- **Patient Advocacy Strategies works with drug companies to build relationships with stakeholders and policymakers.**

“Patient Advocacy Strategies is a life science, patient-focused, strategic consulting organization providing patient advocacy relations, supporting industry’s novel research and clinical programs through targeted, innovative collaborations between patients, patient foundations, industry, regulatory, and other health stakeholder influencers. In the past two decades, the drug development landscape has transformed between the biopharmaceutical industry and patients. PAS recognizes the value of incorporating the patient voice early and into each stage of development with patients providing essential information on disease and treatments and have established themselves as respected expert leaders in fostering proactive, compliant two-way dialogue, delivering tangible results for all. What We Do Strategic and Tactical Advocacy Development Patient Advocacy Strategies is an authentic partner to healthcare innovators, forging strategic collaborations with targeted disease stakeholders, delivering a tailored approach to each client. Whether researching a therapeutic landscape analysis, creating patient journey maps, fostering relationships with key industry stakeholders through coalition-building, or developing unique disease awareness campaigns, PAS brings its vast industry experience, innovative spirit, and trusted relationships with patient stakeholders to craft a program that embraces your business goals to advance your mission.”

[Patient Advocacy Strategies, accessed [12/16/20](#)]

### **2018: AfPA paid \$150,000 to Patient Advocacy Strategies, LLC for “consulting services.”**

According to their IRS Form 990 tax filings, in 2018 AfPA paid \$150,000 to Patient Advocacy Strategies LLC., of 45 Wildwood Street Winchester, MA 01890 for “consulting services.”

[Alliance for Patient Access, IRS Form 990, accessed [11/14/19](#)]

### **AfPA encourages members to “advocate for patient-centered care” by sharing stories with policy makers.**

“AfPA members can participate in activities such as: joining a working group; engaging in advocacy initiatives; contributing to educational policy papers and videos; and sharing their perspective with policymakers about the benefits of patient-centered care. Every day, health policy decisions are made that impact patients and clinicians across the country. Have a say. Advocate for patient-centered care.”

[Alliance for Patient Access, accessed [12/14/20](#)]

## **AFPA HAS SPENT MILLIONS ON CONSULTANTS WHO WORK WITH OTHER ASTROTURF GROUPS AND PHARMACEUTICAL COMPANIES.**

### **2018: AfPA paid more than \$9.5 million to Strategic Consulting, Inc.**

According to their IRS Form 990 tax filings, in 2018, AfPA paid \$9,219,018 and \$332,594 to Strategic Consulting, Inc. of 2700 Woodley Road NW, Unit PH4, Washington, DC 20008, for a total of \$9,551,612. According to the filing, more than \$9.2 million of that was for digital, radio, print, and direct mail ad placement and mailings. “Strategic Consulting, LLC payment breakdown consulting services - \$332,595, including print ad design - \$93,845 digital production - \$58,000 direct mail design - \$77,750 patch through production - \$15,000 radio production - \$88,000 digital, radio, print, direct mail placement and mailings - \$9,219,018” [Alliance for Patient Access, IRS Form 990, accessed [11/14/19](#)]

- **Strategic Consulting Inc. is run by Kira Swencki (aka Kira Lieberman), who is a PR professional.**  
“Owner President Company Name Strategic Consulting / Issue Management Media Dates Employed 001 –; Present Employment Duration: 19 yrs. Kira is currently the owner of Issue Management Media / Strategic Consulting, where she works towards the execution of media, project management and advocacy initiatives. In all her capacities, Kira has focused her work on managing programs that foster better understanding and appreciation of issues through education and advocacy” [Kira Swencki LinkedIn profile, accessed [12/16/20](#)]
- **2018: Partnership for Safe Medicines paid \$3,738,748 to Strategic Consulting Inc., for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, accessed [11/13/19](#)]

### **2016: AfPA paid \$501,548 to SEVEN TWENTY STRATEGIES.**

According to their IRS Form 990 tax filings, in 2016 AfPA paid \$501,548 to 720 Strategies for “patient access recognition program.” [Alliance for Patient Access, IRS Form 990, accessed [11/14/17](#)]

- **720 Strategies did work for PhRMA and uses it as a case study on their website.**  
“Facing a climate of substantial health care policy change and reputational challenges, the biopharmaceutical industry’s national trade association, the Pharmaceutical Research and Manufacturers of America (PhRMA), and its member companies sought an advocacy solution to convey the industry’s value and commitment to positive change in health care policy through its member company employees. [...] To address these challenges, 720 Strategies developed and continues to implement an integrated advocacy and communications program called We Work For Health (WWFH) – a grassroots initiative that unites health consumers, pharmaceutical company employees and retirees, vendors, suppliers and other partners to demonstrate how these diverse groups work together to deliver life-saving, life-enhancing advancements in medicine, while also serving as a driving force for our nation’s economy. As the first initiative in PhRMA’s history to secure the approval of member companies to directly engage their employees in a cohesive, industry-sponsored grassroots program, WWFH aims to help advance policies that promote medical innovation in the U.S. What started as a pilot program in three states in 2008 has expanded to include 14 states in 2015. WWFH has flourished into an alliance of biopharmaceutical employees, retirees, vendors, suppliers and other local business groups, labor unions, concerned patients and academic and community partners who share the common goal of preserving medical innovation in the country.” [720 Strategies, accessed [12/9/20](#)]
- **720 Strategies designed and built a “Science Ambassadors” program for PhRMA specifically to lobby Congress, with a focus on communicating “PhRMA’s commitment to promote access to health care and prescription drugs.”**  
“Established to engage biopharmaceutical scientists and researchers across the country to join together to help advance the industry, the Science Ambassadors program is a multifaceted approach to communicating PhRMA’s medical innovation agenda within local communities and with Members of Congress. The program leverages ambassadors’ extensive research and development experience in helping to shape the dialogue

about the role and value of medical innovation in bettering health care in the U.S. and around the world – not only on the innovation of new medicines, but on the industry’s commitment and contribution to overall health and well-being. The program includes a dedicated website with congressional contact capability, as well as a speaker’s bureau of research scientists who carry the industry’s message in their local community. These communications reinforce PhRMA’s commitment to promote access to health care and prescription drugs, encourage prevention and healthier living, and innovations that help families live longer, healthier lives.” [720 Strategies, accessed [12/9/20](#)]

**2015: AfPA paid \$104,000 to Carolyn TenEyck for “consulting.”**

According to their IRS Form 990 tax filings, in 2015, AfPA paid \$104,000 to Carolyn TenEyck for “consulting.” [Alliance for Patient Access, IRS Form 990, accessed [11/10/16](#)]

- **TenEyck worked for AfPA at the same time she was working for Jazz Pharmaceuticals and Prolacta Bioscience.**

According to her LinkedIn profile, Carolyn TenEyck’s work for AfAP overlapped with her time working for Jazz Pharmaceuticals and Prolacta Biosciences. “Director of Advocacy Dates Employed: Sep 2014 – Present. Employment Duration: six yrs, four mos. Location: City of Industry, CA. Leads Advocacy relations with all external patient and professional organizations to ensure the highest standards for optimal nutrition throughout the US and Canada. Collaborates with internal c-suite, management, marketing & sales, health economics, legal, business development, clinical and government affairs, public relations and R&D. Mobilizes collective action to enhance access, education and empowerment for parents and families. Aligns mutually with the therapeutic “community” to bring innovative partnerships and programs to the marketplace. Manages grants and annual budget. Provides landscape analysis of new and potential markets. Amplifies the voice and experience of patients and families with internal programs that help enhance employee engagement.” “Oncology Therapy Access Working Group Director. Company Name: Alliance for Patient Access (AfPA); Dates Employed: Feb 2014 – May 2015; Employment Duration: one yr, four mos. Location: Washington D.C. Metro Area. Established the Oncology Therapy Access Physicians Working Group as home for oncologists interested in health policy issues relating to access to cancer therapies. Working Group members from throughout the nation collaborate in the development of educational resources such as white papers, policy briefs and videos to be utilized in encouraging informed policymaking, while ensuring the physician’s perspective is shared as policymakers consider how to balance access and costs. Particular challenges include step therapy, clinical pathways, 340B pricing, prior authorization and access to precision diagnostics and immunotherapy.” “Advocacy Consultant Company Name: Jazz Pharmaceuticals. Dates Employed: Mar 2014 – Jul 2014. Employment Duration: five mos. Location: Palo Alto, CA Developed a strategic plan to build a best-in-class, patient-focused Advocacy function and external engagement plan within Corporate Affairs. Conducted analysis of the structure, gaps, opportunities and resources needed across the pain, rare sleep disorder and oncology franchises. Aligned cross-functional business goals and objectives to meet the unique needs of Jazz. Provided counsel and construction of compliance guidelines. Built a master calendar of priority events across the varied stakeholder landscape.” [Carolyn TenEyck LinkedIn profile, accessed [12/16/20](#)]

## **Drug Pricing Legislation**

### **HR 3 AND S.2543**

**2020: AfPA spent \$60,000 lobbying Congress on HR 3 and S.2543, in “support for Part D out-of-pocket expense cap.”**

According to federal lobbying disclosure reports, in each the first and second quarters of 2020, AfPA spent \$30,000 lobbying Congress on “HR 3/S 2543 - Prescription Drug Pricing Reduction Act of 2019 (support for Part D out-of-pocket expense cap)” [Alliance for Patient Access, Lobbying Disclosure Reports, Q1 2020, [4/20/20](#); Q2 2020, [7/20/20](#)]

### **2019: AfPA spent at least \$120,000 lobbying Congress on Medicare Part D out-of-pocket caps.**

In the second quarter of 2019, AfPA spent \$30,000 lobbying Congress on “Part D out-of-pocket expense cap” and other legislation. In the third quarter of 2019, AfPA spent \$30,000 lobbying Congress on “S 2543 - Prescription Drug Pricing Reduction Act (PDPRA) of 2019 (support for Part D out-of-pocket expense cap) HR 3 (support for Part D out-of-pocket expense cap)” and other legislation. In the fourth quarter of 2019, AfPA spent \$30,000 lobbying Congress on “HR 3/S.2543 - Prescription Drug Pricing Reduction Act of 2019 (support for Part D out-of-pocket expense cap)” and other legislation.

[Alliance for Patient Access, Lobbying Disclosure Reports, Q2 2020, [7/21/19](#); Q3 2020, [10/19/19](#); Q4 2020, [1/20/20](#)]

### **July 2020: AfPA joined a letter praising the out-of-pocket caps in H.R. 3.**

“Current legislation from both the House of Representatives and the Senate has proposed putting a cap on OOP costs when Medicare Part D beneficiaries hit certain thresholds. The Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) would limit OOP spending to \$2,000 beginning in 2022 and the Prescription Drug Pricing Reduction Act of 2019 (S. 2543) would limit OOP spending to \$3,100 beginning in 2022, indexed to growth in Part D spending. The proposed cap in both bills would constitute significant progress in constraining the growth of OOP costs for Part D beneficiaries. We support a cap structure that minimizes financial exposure, as many Medicare beneficiaries live on fixed and limited incomes.”

[InsuranceNewsNet.com, [7/21/20](#)]

## **OTHER PROPOSED REGULATIONS**

### **2018: AfPA expressed concerns about the Trump Administration’s proposed changes to Medicare Part B and Medicare Part D.**

“When the Trump administration suggested shifting Medicare Part B drugs to Part D, AfPA responded with: A letter outlining concerns about how such a policy would impact patient care. An infographic depicting potential access challenges that could result. An Institute for Patient Access Policy Blog post explaining how the move could hurt cancer patients.”

[Alliance for Patient Access, 2018 Annual Report, [2018](#)]

### **2018: AfPA opposed a Trump Administration proposal to tie Medicare Part B drug prices to foreign prices.**

“When the administration suggested a Medicare experiment that would import foreign prices for Part B medicines and change the way these medicines are delivered in the United States, AfPA likewise responded with: A letter explaining why the proposed experiment could be disruptive for cancer care. An Institute for Patient Access Policy Blog post highlighting concerns about the experiment. An advertising campaign designed to raise public awareness on the issue.”

[Alliance for Patient Access, 2018 Annual Report, [2018](#)]

### **IfPA said that “reference pricing,” or tying the price of prescription drugs to their prices in other countries, “raised questions about future accessibility and medical innovation in the United States.”**

“Reference pricing is an approach to reduce U.S. prescription drug prices by aligning them with the lower prices paid by other countries. Reference pricing can take at least two different forms: the “most-favored nation” approach or the international pricing index approach. The most-favored nation approach would have the United States select a single country with the lowest prescription drug prices and then adjust domestic prices accordingly. President Donald Trump introduced the concept in August 2020. The “international pricing index,” introduced in 2018, would set a prescription drug’s price in the United States based on the average price of that same drug across selected developed countries. The maximum price of a prescription drug in the United States would be limited to that average. While most Americans support lower drug prices, reference pricing has raised questions about future accessibility and medical innovation in the United States.”

[Institute for Patient Access, September [2020](#)]



**IfPA said that reference pricing could lead to patients having only limited access to necessary treatments.**

“Reference pricing proposals apply to Medicare Part B medications, which are infused or injected in a doctor’s office or clinic. These may include treatments for diseases such as asthma, migraine, psoriasis or cancer. Reference pricing would impact patients and health care providers who use these drugs in several ways. An international pricing index would first directly impact patients and providers selected to participate in the Centers for Medicare and Medicaid Innovation demonstration model to test the approach. The demonstration would require participation by 50 percent of the patients and providers who use Medicare Part B drugs. Indirectly, the approach would also impact the other half of Medicare Part B patients and providers. Even health care providers outside of the demonstration are reimbursed by Medicare based on the average sales price of the Part B drugs they administer. The reimbursement policy is designed to cover the special handling, storage and oversight required for Part B drugs, many of which are complex biologics. If reference pricing drives down that average price, it may no longer be financially feasible for providers to continue administering certain drugs. The chain of events ultimately could limit access for patients who rely on these medications. In September 2020, President Donald Trump issued an executive order on reference pricing that also included Part D drugs. These are medications typically picked up by patients at the pharmacy and taken at home. The president directed the Centers for Medicare and Medicaid Services to initiate a demonstration model testing the impact of reference pricing for these drugs.”

[Institute for Patient Access, September [2020](#)]

**IfPA said that reference pricing “could weaken medical innovation.”**

“Reference pricing may lower some Americans’ prescription drug costs, but it also could weaken medical innovation. Lower prices mean lower return on investment for manufacturers, which could in turn deter investors from supporting medical research and development. The National Bureau of Economic Research reported that price control measures could lead to 50-60 percent fewer potential medications moving from the lab into clinical trials.”

[Institute for Patient Access, September [2020](#)]

**IfPA said that reference pricing could lead to “restrictions on access to new medicines” as happens in Europe and warned that “[w]hile lower prices for prescription drugs are appealing, it is unclear what the unintended consequences may be of adopting prices from a foreign country where access is based on an entirely different health care system.”**

“In some European countries, lower prescription drug prices come with trade-offs. The European nations that the United States would use for pricing reference have more restrictions on access to new medicines. Patients can experience longer wait times to receive care and may not have access to a new treatment when they need it most. In the United Kingdom, for example, it takes about 14 years for a new cancer treatment to become available to patients. And between 1986 and 2010, there were 46 new medicines introduced in the United States that were not made available in Europe because of price controls. While lower prices for prescription drugs are appealing, it is unclear what the unintended consequences may be of adopting prices from a foreign country where access is based on an entirely different health care system.”

[Institute for Patient Access, September [2020](#)]

**IfPA said that reference pricing could lead to discrimination against older and disabled patients through the adoption of QALY valuations.**

“U.S. disability and senior citizen advocates worry that reference pricing could open a back door to accepting discriminatory methods of assessing health care value. Specifically, European countries often determine prices using a controversial metric called the quality-adjusted life year. The QALY, as it’s called, measures a drug’s value based on how many years of “perfect” health it can provide. For people with disabilities, whose optimal health may not meet economists’ definition of perfection, or people who are older and have fewer years ahead of them, the metric falls short. Policymakers in the United States have been discouraged from using the QALY. In 2020, the National Council on Disability recommended a ban on QALY due to discrimination concerns.”

[Institute for Patient Access, September [2020](#)]

**IfPA said that reference pricing wouldn't be sufficient to bring down health care costs in the United States and any solution "must be far broader."**

"The United States does spend more money on health care than other developed countries. Prescription drugs are a factor in rising health care costs, but so are visits to doctors and specialists, as well as hospital spending. In 2019, hospital spending alone made up one-third of total health care spending. This was closely followed by physician and clinical services, which comprised 19 percent of spending. Prescription drugs represented 9 percent of health care spending. While no conversation about health care spending in the United States is complete without considering prescription drug costs, a long-term solution must be far broader than reference pricing."

[Institute for Patient Access, September [2020](#)]

**IfPA acknowledged that "prescription drugs are a factor in rising health care costs" and that "no conversation about health care spending in the United States is complete without considering prescription drug costs," but downplayed prescription prices as compared with hospital spending and physician and clinical spending.**

"The United States does spend more money on health care than other developed countries. Prescription drugs are a factor in rising health care costs, but so are visits to doctors and specialists, as well as hospital spending. In 2019, hospital spending alone made up one-third of total health care spending. This was closely followed by physician and clinical services, which comprised 19 percent of spending. Prescription drugs represented 9 percent of health care spending. While no conversation about health care spending in the United States is complete without considering prescription drug costs, a long-term solution must be far broader than reference pricing."

[Institute for Patient Access, September [2020](#)]

**IfPA acknowledged that reference pricing could lower prescription drug costs for some, but said that would come at the expense of limiting patient access and discouraging innovation.**

"Reference pricing could lower the price of prescription drugs for some, but it may also limit patient access and discourage innovation over the long term. Policymakers would do well to take a comprehensive look at the health care system rather than embrace short-term cost-cutting measures that may pursue savings at the expense of patient care."

[Institute for Patient Access, September [2020](#)]

### Other drug pricing statements

**AFPA EXPLICITLY ASSERTED THAT "SOCIETY" SHOULD BEAR THE BURDEN OF THE HIGH COSTS OF PRESCRIPTION DRUGS.**

**AfPA said that all health care stakeholders, including drug manufacturers, patients, payers and "broader society" should bear the "cost burden," of "advanced medicine."**

"Society shares both benefits and risks. All stakeholders – including manufacturers, payers, patients and broader society – should enjoy the benefits, and help shoulder the cost burden of advanced medicine."

[Alliance for Patient Access, accessed [12/14/20](#)]

**November 2018: AfPA said that drug manufacturers' pricing should include input from patients, physicians, and insurance companies.**

"Pricing should prioritize access. Manufacturers' pricing process should include input from all stakeholders, including physicians, patients and payers."

[Alliance for Patient Access, *Worth It? Value & Valuation in Today's Health Care System*, November [2018](#)]

**November 2018: AfPA said that drug makers, insurers, patients, and all of society should bear the cost burdens of "expensive advanced therapies."**

"Society shares both benefits and risks. Expensive advanced therapies, such as biologics, offer a societal benefit. All stakeholders – including manufacturers, payers, patients and broader society – should help shoulder the cost

burden.” [Alliance for Patient Access, *Worth It? Value & Valuation in Today’s Health Care System*, November [2018](#)]

**November 2018: AfPA said that “valuation” should consider the cost of drug development and the “burden of the disease it treats.”**

“Valuation is not a one-size-fits-all endeavor. Valuation should consider a medicine’s effectiveness, patient satisfaction and development costs, as well as the burden of the disease it treats.”

[Alliance for Patient Access, *Worth It? Value & Valuation in Today’s Health Care System*, November [2018](#)]

**AFPA HAS SAID THAT PATIENT “ACCESS” TO DRUGS SHOULD BE THE PRIORITY AND THAT PRICING DECISIONS SHOULD BE BASED ON INPUT FROM MANY STAKEHOLDERS.**

**AfPA said that drug pricing should “prioritize access” and pricing decisions should include input from “providers, patients and payers”**

“Pricing should prioritize access. Manufacturers’ pricing process should include input from all stakeholders, including health care providers, patients and payers.”

[Alliance for Patient Access, accessed [12/14/20](#)]

**AfPA said that all stakeholders, including payers and drug makers, should have a voice in the valuation process.**

“PRINCIPLE 2: Value. All stakeholders deserve a voice. Determining the value of a medication or medical intervention requires input from patients, health care providers, payers and manufacturers.” [Alliance for Patient Access, accessed [12/14/20](#)]

**AfPA said that value varies by patient and that valuation shouldn’t dictate “coverage.”**

“Valuation is not a one-size-fits-all endeavor. Value varies based on patients’ unique circumstances. Valuation should not dictate coverage. Findings should instead inform a patient-centered approach that’s driven by physician-patient decision making and professional society guidelines.”

[Alliance for Patient Access, accessed [12/14/20](#)]

**AfPA said that their oncology working group “advocated for an out-of-pocket spending cap for Medicare Part D” and “a smoothing mechanism to make out-of-pocket payments more predictable and manageable for seniors.”**

“In 2019, AfPA’s Oncology Therapy Access Working Group recognized this reality by advocating for protected drug classes, CAR-T coverage and policies to make Medicare out-of-pocket expenses more affordable. The working group: [...] advocated for an out-of-pocket cap for Medicare Part D; advocated for a smoothing mechanism to make out-of-pocket payments more predictable and manageable for seniors.”

[Alliance for Patient Access, 2019 Annual Report, accessed January [2020](#)]

**AfPA produced a video blaming PBMs, the “Middlemen,” for driving up the cost of insulin.**

“From advocacy training to educational content, the Diabetes Policy Collaborative and AfPA’s Diabetes Therapy Access Working Group strove this year to address a growing problem: people with diabetes’ inability to access appropriate medicine and supplies. Advocacy and education efforts included: [...] ‘The Middleman,’ an educational video from the Diabetes Policy Collaborative narrating the role of the pharmacy benefit manager in insulin unaffordability.”

[Alliance for Patient Access, 2018 Annual Report, [2018](#); [VIDEO](#)]

**AFPA HAS ARGUED AGAINST THE PBM “MIDDLEMEN” AND COPAY ACCUMULATORS.**

**2018: AfPA fought against the expansion of copay accumulators by insurance companies, which they blamed for “unmanageable and unexpected expenses.”**

“The ‘Co-Pay Surprise’ frustrated patients and physicians alike this year. In a sly cost-shifting move, health insurers introduced co-pay accumulator adjustment programs to discourage the use of manufacturer-provided co-pay cards for high-cost medicines. The results could mean unmanageable and unexpected expenses — even

medication abandonment – for patients. AfPA and IfPA tackled the issue head on, striving across working groups and coalitions to help providers and patients understand the phenomenon. The effort included: • A quick-draw explainer video detailing how accumulator programs work • A physician-authored policy brief • Infographics to raise online awareness • A fact sheet on potential policy solutions • A series of IfPA Policy Blog posts on the issue. Co-pay accumulators also served as the topic of a policy e-brief distributed by the National Council of Physician Legislators. The group consists of physicians who also serve as legislators in statehouses throughout the country.”

[Alliance for Patient Access, 2018 Annual Report, [2018](#)]

**November 2018: AfPA hosted a panel discussion on pharmaceutical pricing with a representative from the Pacific Research Institute and a representative from PhRMA who agreed that insurers and PBMs were driving up the costs of prescription drugs.**

“The Alliance for Patient Access’ Susan Hepworth moderated the panel, arguing that the high price of drugs suggests the current pricing system doesn’t work. Panelists Wayne Winegarden, PhD, of the Pacific Research Institute and Mike Ybarra, MD, of PhRMA agreed. Part of the problem is the convoluted nature of the rebate system. ‘The price you hear about in the news isn’t actually the price that’s being paid,’ Winegarden explained, noting, ‘How much do drugs cost? We should be able to answer that question, but we can’t.’ Pharmacy benefit managers, who consistently push for higher rebates, can create problems of their own, Dr. Ybarra noted. He alluded to rebates on insulin being as high as 70 percent of the drug’s price. The problem? Some patients’ out-of-pocket is based on the drug’s list price. Co-pay assistance from manufacturers can help, but co-pay accumulators are making even that process complicated. Part of the challenge may be the approach to drug pricing. Prescription drug spending is only part of the picture, Winegarden explained. What matters is ‘total health care spend,’ he argued, adding ‘If you spend more in one area but drive down costs overall, then it’s a win.’ What is working? ‘Competition,’ argued Dr. Ybarra. He added, ‘Negotiation does happen in the health care system,’ but noted that, ‘if the patient isn’t benefitting, then it isn’t worth it.’ Participants agreed that, as with valuation, pricing should be an exercise that welcomes input from diverse stakeholders.”

[Alliance for Patient Access, *Worth It? Value & Valuation in Today’s Health Care System*, November [2018](#)]

**February 2019: AfPA hailed the “era of lower out-of-pocket drug prices” when the Trump Administration proposed eliminating drug maker rebates to PBMs and insurers.**

“HELLO, LOWER OUT-OF-POCKET RX PRICES Has the era of lower out-of-pocket drug prices finally arrived? The Trump administration’s newest plan to reduce prescription drug costs targets a mainstay of the price negotiation process – rebates driven by health insurance middlemen known as pharmacy benefit managers. These rebates can equal 20, even 30 percent of a prescription drug’s list price. But the savings don’t necessarily benefit patients. Instead, at the pharmacy counter, patients often pay a percentage of the drug’s full list price. For some, the cost ‘sharing’ is unmanageable, leading them to ration or altogether abandon their medication. Meanwhile, rebates that average \$29 billion a year for Medicare Part D alone drive massive profits for pharmacy benefit managers. But that may all be about to change. Calling for the end of ‘backdoor deals,’ the Department of Health and Human Services has issued a proposed rule that would treat rebates as illegal kickbacks under federal law. Instead, the rule would allow for list price negotiations – straightforward price cuts that translate directly into lower out-of-pocket payments for patients. The rule would apply to Medicare and Medicaid managed care programs beginning in 2020.”

[Institute for Patient Access, February [2019](#)]

**AfPA has called for an end to copay accumulators and the institution of out-of-pocket caps for patients.**

“The Alliance for Patient Access presents the following principles for co-pay accumulator programs and the laws that govern insurers’ use of them: Limit the use of co-pay accumulators. Policymakers can limit co-pay accumulator programs’ negative impact on patients by mandating that co-pay cards’ value counts toward patients’ annual deductibles. Institute out-of-pocket caps. Creating out-of-pocket maximums for patients minimizes the impact of a co-pay accumulator program and ensures that patients can plan for modest, predictable out-of-pocket costs.”

[Alliance for Patient Access, April [2019](#)]

**AfPA called for out-of-pocket caps for patients and “co-pay only insurance options” that would make patient costs more predictable “regardless of fluctuation in the drug’s cost.”**

“The Alliance for Patient Access presents the following principles for out-of-pocket costs and the laws that govern them: 1. Patients need predictable out-of-pocket limits that keep spending manageable. Patients carefully select their insurance plan, and they expect predictability from it. Out-of-pocket caps allow patients to know their maximum out-of-pocket financial liability. Caps also make health care and medication more affordable and accessible for patients. 2. Co-pay only insurance options provide patients with predictable cost sharing. Patients should be able to obtain an insurance option that requires only co-pays as a way to increase out-of-pocket predictability. Unlike co-insurance, which asks patients to pay an unpredictable percentage of their medication’s cost, set amounts allow patients to know their cost sharing based on which tier their medication is on – regardless of fluctuation in the drug’s cost. With these safeguards in place, policymakers can make certain that high out-of-pocket costs do not harm patients.”

[Alliance for Patient Access, July [2019](#)]

**June 2018: IfPA acknowledged the skyrocketing prices for insulin, but their only policy prescriptions for lowering costs for diabetes patients address insurers and PBMs.**

“Insulin prices have skyrocketed in recent years, more than tripling between 2002 and 2013. [...] POLICY SOLUTIONS Policymakers at both the state and federal level are becoming more aware of the dangers of these tactics. Some are taking steps to protect patients. State Efforts One national advocacy group has crafted model state legislation addressing step therapy for patients with chronic diseases. The group emphasizes that health plan policies should rely on current clinical data, be transparent, and offer clear and concise exceptions to step therapy protocols based on medical necessity. As of early 2018, 18 states had adopted step therapy regulations crafted along those precepts. Efforts in support of similar bills were underway in at least 11 more states.<sup>19</sup> Legislation addressing non-medical switching has also received approval in multiple states. To date, 10 states have adopted regulations on nonmedical switching, and other state legislatures are considering their own plans to protect patients.<sup>20</sup> Federal Efforts At the federal level, the Affordable Care Act caps out-of-pocket expenses for covered services. Once the maximum payment limit on deductibles, copayments, and coinsurance is reached, the health plan pays 100 percent of the cost of covered benefits. For the 2018 plan year, the out-of-pocket limit for a plan purchased on the exchange is \$7,350 for an individual and \$14,700 for a family. Meanwhile, the White House has acknowledged the role pharmacy benefit managers and manufacturer rebates play in high drug prices. In a May 2018 address on prescription drug affordability, President Donald Trump specifically mentioned pharmacy benefit managers, calling them middlemen who increase out-of-pocket costs for patients. The Congressional Diabetes Caucus, which includes more than 300 senators and U.S. representatives is also exploring the challenges and access barriers posed by diabetes costs. The Senate Special Committee on Aging, chaired by Diabetes Caucus member Senator Susan Collins, heard testimony on insulin access and affordability from several witnesses in May 2018. In other federal policy efforts, the 115th Congress is considering legislation to address step therapy. With 44 Republican and Democratic cosponsors in the House of Representatives, The Restoring the Patient’s Voice Act of 2017 would require insurance companies to establish a clear protocol for exceptions to step therapy. Patients could request an exception by meeting one of five circumstances that make their situation unsuitable for a fail first process.”

[Institute for Patient Access, Protecting Access to Diabetes Care, accessed June [2018](#)]

**PARTNERSHIP FOR SAFE MEDICINES**

Website: <https://www.safemedicines.org/>

**PARTNERSHIP FOR SAFE MEDICINES PURPORTS TO HAVE A CONFLICT OF INTEREST POLICY, BUT IT DOES NOT APPEAR TO BE PUBLICLY AVAILABLE ON THEIR WEBSITE.**

**2017: The PSM board of directors approved a conflict of interest policy, and said it “self-polices” potential conflicts.**

“In 2017, at a regular board meeting, the board reviewed and approved the conflict of interest policy due to the

small board size, the board is well versed on the activities of others on the board and coupled with self-policing, monitors and enforces compliance with this policy.”

[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

**2016: Board members were required to sign a conflict of interest policy, and were verbally asked about any potential changes in work that would pose a potential conflict.**

“Biannually, during PSM’s in-person board meetings, board members are asked if there are any changes in their work that could be a conflict of interest. In 2007, all board members signed the conflict of interest policy. Due to the small board size, the board is well versed on the activities of others on the board and coupled with self-policing, monitors and enforces compliance with this policy.”

[Partnership for Safe Medicines, IRS Form 990, [6/20/17](#)]

## **Financials**

**ACCORDING TO TAX FILINGS, NONPROFIT ORGANIZATIONS THAT ARE MEMBERS OF THE PARTNERSHIP FOR SAFE MEDICINES PAY NOMINAL ANNUAL DUES, WHILE PSM AND BIG PHARMA REFUSE TO SAY HOW MUCH INDUSTRY FUNDING THEY GET.**

**PSM touts itself as a coalition of non-profit organizations.**

“Comprised of more than 70 non-profit organizations, the Partnership for Safe Medicines (PSM) is a public health group committed to the safety of prescription drugs and protecting consumers against counterfeit, substandard or otherwise unsafe medicines.”

[Partnership for Safe Medicines LinkedIn profile, accessed [12/20/20](#)]

**2009: Non-profit membership dues for PSM ranged from \$250 to \$1,500 per year.**

[Partnership for Safe Medicines, IRS Form 990, [4/29/10](#)]

- **PSM says it’s entirely funded by member dues, but refused to say how much each member, including PhRMA, contributed.**

“In 2017, the nonprofit’s annual budget jumped twentyfold, to \$7.3 million. The group says it’s entirely funded by dues from its 49 member organizations, including PhRMA, but it doesn’t disclose how much each member pays. Its executive director, Shabbir J. Safdar, declined to comment.”

[Bloomberg, [10/23/19](#)]

- **Many of PSM’s members pay little or no dues.**

“It’s hard to determine exactly how much PhRMA contributed to that dramatic 2017 cash infusion – but this much is clear: Many of the nonprofit’s other member groups pay no dues at all. Fourteen of the group’s non-PhRMA members shared detailed information about their payments, all of which were either \$0 or \$100 in 2017. For example, the National Association of Chain Drug Stores, which had a budget of \$44 million in 2017, said it paid just \$100 to be a member of the Partnership for Safe Medicines that year.”

[Bloomberg, [10/23/19](#)]

- **Members may apply for a “hardship waiver” to avoid paying dues to PSM.**

“All PSM members are expected to pay annual dues or submit a hardship waiver.” [Partnership for Safe Medicines, [1/27/20](#)]

**“Both PhRMA and the partnership have gone to great lengths to show that drugmakers are not driving what they describe as a grass-roots effort.”**

“Both PhRMA and the partnership have gone to great lengths to show that drugmakers are not driving what they describe as a grass-roots effort to fight imports including an expensive advertising blitz and an event last week that featured high-profile former FBI officers and a former Food and Drug Administration commissioner.”  
[Pharma & Healthcare Monitor Worldwide, 4/20/17]

### **2017: PSM and PhRMA refused to say how much PhRMA contributed to PSM.**

“The nonprofit describes PhRMA as a dues-paying member with no larger role in shaping the group’s activities. Partnership spokeswoman Clare Krusing would not say how much each member contributes. PhRMA spokeswoman Allyson Funk declined to say whether PhRMA funds the partnership.”  
[Healthcare Monitor Worldwide, 4/20/17]

- **PSM’s members include BIO and PhRMA.**

“The Partnership for Safe Medicines is a group of organizations and individuals that have policies, procedures, or programs to protect consumers from counterfeit or contraband medicines. To learn about how to support or join us, see our About Page. All PSM members are expected to pay annual dues or submit a hardship waiver. [...] Biotechnology Innovation Organization [...] Pharmaceutical Researchers and Manufacturers of America”  
[Partnership for Safe Medicines, accessed [12/20/20](#)]

### **2019: PhRMA acknowledged funding PSM, but refused to answer specific questions.**

“Holly Campbell, a spokeswoman for the pharmaceutical-industry’s main trade group, didn’t respond to specific questions for this story. In a written statement, she confirmed that her group, Pharmaceutical Research and Manufacturers of America, or PhRMA, gives money to the Partnership for Safe Medicines, the group that gave the sheriffs’ association the grant. PhRMA, which had a 2017 budget of \$456 million, donates to the much smaller nonprofit to support the fight against drug-importation plans, Campbell said. She called such plans ‘far too dangerous for American patients.’ A spokesman for the sheriffs’ association declined to comment.”  
[Bloomberg, [10/23/19](#)]

### **PhRMA and PSM have long ties, with executives from PhRMA operating PSM.**

“Headquartered in a San Francisco high-rise, the nonprofit has had deep ties to PhRMA for most of its existence. From 2005 to 2017, it was run by executives who simultaneously worked for PhRMA. And in its tax filing for 2017, the smaller group listed Shannon Monsif, PhRMA’s vice president of advocacy and strategic alliances, as its ‘principal officer’ and treasurer. (PhRMA’s Campbell called that listing a mistake. ‘Due to an error, Shannon’s name was mistakenly listed,’ she said in a statement. ‘Shannon has never been an officer of the organization.’)”  
[Bloomberg, [10/23/19](#)]

- **Former employees and consultants who worked for PhRMA and PSM say that PhRMA ran PSM and their paychecks came directly from PSM.**

“Four former employees and consultants who worked with PhRMA and the Partnership for Safe Medicines say the industry group largely ran the nonprofit. For example, Justin Kenderes worked for the partnership as a consultant from 2007 to 2016, and for the first several years, he says, his paychecks came directly from PhRMA. (Kenderes says importation plans are a poor solution for rising drug costs, but he believes PhRMA should be more transparent about how it’s trying to influence the debate.)”  
[Bloomberg, [10/23/19](#)]

**PharmacyChecker.com LLC alleged in a lawsuit that “PSM was a secret arm of PhRMA” and was “funded and controlled by PhRMA.”**

“PSM is funded and controlled by PhRMA (a lobbying group for the pharmaceutical industry) but calls itself a ‘consumer protection group.’ More than one third of PSM members have received PhRMA funding or are local chapters of groups that have received PhRMA funding, and until February 2017, PSM’s principal officer was Scott LaGanga, who concurrently served as deputy vice president of advocacy for PhRMA. He stepped down from PSM to ‘avoid the appearance of a conflict of interest,’ according to investigative reporting that revealed PSM was a secret arm of PhRMA.”

[PharmacyChecker.com LLC v. National Association of Boards of Pharmacy, et al., Case No. 7:19-cv-07577-KMK, Complaint, filed 8/13/19; on file]

- **2019: In a federal court case, PSM attorneys said that allegations that PSM was “funded and controlled by PhRMA” were “inflammatory” and “intended to cast PSM in a less than favorable light” but didn’t actually deny the allegations.**

“PharmacyChecker dedicates a paragraph in its Complaint to inflammatory, but irrelevant, allegations concerning PhRMA, including that ‘PSM is funded and controlled by PhRMA.’ D.E. 82 ¶ 76. These allegations are intended to cast PSM in a less than favorable light.”

[PharmacyChecker.com LLC v. National Association of Boards of Pharmacy, et al., Case No. 7:19-cv-07577-KMK, Defendant Partnership for Safe Medicines’ Memorandum of Law, Document 98, filed 3/13/20; on file]

*\*This federal lawsuit is ongoing.\*\**

**PSM HAS SEEN ITS REVENUE INCREASE FROM LOW FIVE-FIGURES TO MORE THAN \$6 MILLION, LARGELY FROM “MEMBERSHIP DUES.”**

**2018: PSM had a revenue of \$6,018,513, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

**2017: PSM had a revenue of \$7,250,962, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [7/20/18](#)]

- **2017: PSM’s focus changed from fighting counterfeit drugs to fighting prescription drug importation, and its budget “jumped twentyfold.”**

“For most of its life, the PhRMA-backed nonprofit focused on raising awareness about counterfeit prescription drugs and fly-by-night online pharmacies. That changed after the 2016 election, when both candidates, Donald Trump and Hillary Clinton, expressed support for importing cheaper medicines from foreign markets as a means of cutting drug prices. In 2017, the nonprofit’s annual budget jumped twentyfold, to \$7.3 million.”

[Bloomberg, [10/23/19](#)]

**2016: PSM had a revenue of \$329,600, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, accessed [6/20/17](#)]

**2015: PSM had a revenue of \$402,500, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [6/16/16](#)]

**2014: PSM had a revenue of \$652,190.**



According to federal IRS form 990 tax filings, PSM had total revenue of \$652,190 in 2014. Of that, \$602,500 came from membership dues, and \$49,690 came from “all other contributions, gifts, grants, and similar amounts not included above.”

[Partnership for Safe Medicines, IRS Form 990, [8/7/15](#)]

**2013: PSM had a total revenue of \$1,123,767.**

According to federal IRS form 990 tax filings, PSM had total revenue of \$1,123,767 in 2013. Of that, \$1,062,658 came from membership dues, \$52,690 came from “all other contributions, gifts, grants, and similar amounts not included above,” and \$8,419 came from PSM’s Interchange conference.

[Partnership for Safe Medicines, IRS Form 990, [11/7/14](#)]

**2012: PSM had a total revenue of \$484,590.**

According to federal IRS form 990 tax filings, PSM had total revenue of \$484,590 in 2012. Of that, \$432,350 came from membership dues, \$40,800 came from “all other contributions, gifts, grants, and similar amounts not included above,” and \$11,440 came from PSM’s Interchange conference.

[Partnership for Safe Medicines, IRS Form 990, accessed [7/31/13](#)]

**2011: PSM had a total revenue of \$985,279.**

According to federal IRS form 990 tax filings, PSM had total revenue of \$985,279 in 2011. Of that, \$925,760 came from membership dues, \$5,000 from “government grants,” \$46,000 came from “all other contributions, gifts, grants, and similar amounts not included above,” and \$8,519 came from PSM’s Interchange conference.

[Partnership for Safe Medicines, IRS Form 990, [11/14/12](#)]

**2010: PSM had a total revenue of \$197,359.**

According to federal IRS form 990 tax filings, PSM had total revenue of \$197,359 in 2011. Of that, \$145,300 came from membership dues, \$46,000 came from “contributions, gifts, grants, and similar amounts received,” and \$6,059 came from “other revenue.”

[Partnership for Safe Medicines, IRS Form 990, [9/15/11](#)]

**2009: PSM had a revenue of \$15,000.00, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [4/29/10](#)]

**2008: PSM had a revenue of \$22,000, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [8/13/09](#)]

**2007: PSM had a revenue of \$50,000, entirely from membership dues.**

[Partnership for Safe Medicines, IRS Form 990, [8/12/08](#)]

**OTHER PSM MEMBERS HAVE THEIR OWN DEEP FINANCIAL TIES TO THE PHARMACEUTICAL INDUSTRY.**

**The Academy of Managed Care Pharmacy is a member of PSM.**

[Partnership for Safe Medicines, [12/21/20](#)]

- **The Academy of Managed Care Pharmacy explicitly offers “access” as a benefit to their corporate members.**

“AMCP Corporate Membership provides a great way to network with the leaders and decision makers within managed care pharmacies. AMCP’s members include almost 8,000 pharmacists, physicians, nurses and other professionals who touch the lives of more than 270 million. The online searchable membership directory is a great asset to grow your company’s network.”

[Academy of Managed Care Pharmacy, accessed [12/21/20](#)]

- **Academy of Managed Care Pharmacy’s “platinum” corporate members are all biopharmaceutical companies.**

[Academy of Managed Care Pharmacy, accessed [12/21/20](#)]

**The ADAP Advocacy Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **ADAP Advocacy Association’s “Leaders” include Gilead and Merck, and their “Gold” and “Silver” members include AbbVie, Thera Technologies, and Janssen.**

[ADAP Advocacy Association, accessed [12/21/20](#)]

**The Association for Accessible Medicines is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Association for Accessible Medicines’ members include pharmaceutical companies like Teva Pharmaceuticals and Mallinckrodt Specialty Generics, among others.**

[Association for Accessible Medicines, accessed [12/21/20](#)]

**The Colorado Bioscience Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Colorado Bioscience Association is sponsored by pharmaceutical companies and counts many drug makers among their members.**

[Colorado Bioscience Association, accessed [12/21/21](#)]

**The Community Access National Network is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Community Access National Network counts PhRMA, BIO, and other pharmaceutical companies among their partners.**

[Community Access National Network, accessed [12/21/20](#)]

**The Health Distribution Alliance is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Health Distribution Alliance has “129 manufacturer members” including some of the largest drug makers.**

“Manufacturers considering an HDA membership are primarily engaged in developing, manufacturing or labeling healthcare products. [...] HDA has 129 manufacturer members.”

[Health Distribution Alliance, accessed [12/21/20](#)]

**The Health Care Institute of New Jersey is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Health Care Institute of New Jersey's members are nearly all pharmaceutical companies.**

[The Health Care Institute of New Jersey, accessed [12/21/20](#)]

**The International AntiCounterfeiting Coalition is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The International AntiCounterfeiting Coalition includes many pharmaceutical companies among their members, including Abbott, Genentech, GSK, Allergan, Pfizer, and Novartis, among others.**

[International AntiCounterfeiting Coalition, accessed [12/21/20](#)]

**The Kansas Pharmacists Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **Novo Nordisk is a "Bronze Corporate Member" of the Kansas Pharmacists Association.**

[Kansas Pharmacists Association, accessed [12/21/20](#)]

**The Minnesota Pharmacists Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **Novo Nordisk is a "Business Partner" of the Minnesota Pharmacists Association, with its logo on their homepage.**

[Minnesota Pharmacists Association, accessed [12/21/20](#)]

- **To have a business partner logo on the Minnesota Pharmacists Association homepage, requires a sponsorship of at least \$20,000 per year.**

[Minnesota Pharmacists Association, accessed [12/21/20](#)]

**The National Alliance of State Pharmacy Associations is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The National Alliance of State Pharmacy Associations counts PhRMA and many drug makers among their "associate members."**

[National Alliance of State Pharmacy Associations, accessed [12/21/20](#)]

- **Associate members of the National Alliance of State Pharmacy Associations pay at least \$5,000 per year for membership.**

"Membership Dues I am registering a for-profit organization. I understand I will be invoiced \$5,000 for annual dues."

[National Alliance of State Pharmacy Associations, accessed, [12/21/20](#)]

**The National Association of Chain Drug Stores is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The National Association of Chain Drug Stores allows drug manufacturers to be associate members, with annual dues ranging from \$2,800 to nearly \$10,000.**  
[National Association of Chain Drug Stores, accessed [12/21/20](#)]

**The National Association of Manufacturers is a member of PSM.**  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **Pfizer and Bayer are sponsors of the National Association of Manufacturers.**  
[National Association of Manufacturers, accessed [12/21/20](#)]
- **PhRMA and BIO are members of the Council of Manufacturing Organizations.**  
[National Association of Manufacturers, accessed [12/21/20](#)]

**The Nebraska Pharmacists Association is a member of PSM.**  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Nebraska Pharmacists Association website includes a “thank you” to Pfizer.**  
“The NPA would like to thank Pfizer for its support in creating policy allowing pharmacists to vaccinate without barriers.”  
[Nebraska Pharmacists Association, accessed [12/21/20](#)]

**NeedyMeds is a member of PSM.**  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **NeedyMeds is funded in part by pharmaceutical companies.**  
“NeedyMeds receives funding from a number of sources: Grants Donations Sale of PAPTracker, software designed to help local programs enroll applicants in programs and track usage. Syndication of our information, advertisements on the website, partnering with pharmaceutical manufacturers to help them establish and operate their PAPs.”  
[NeedyMeds, accessed [12/8/20](#)]

**New Hampshire Pharmacists Association is a member of PSM.**  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **New Hampshire Pharmacists Association is sponsored by Janssen, Sanofi, Novartis, Sunovion, Adapta, Teva Oncology, and Boehringer Ingelheim.**  
[New Hampshire Pharmacists Association, accessed [12/21/20](#)]

**New Mexico Pharmacists Association is a member of PSM.**  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **New Mexico Pharmacists Association accepts drug manufacturers as members.**  
“The members of the New Mexico Pharmacists Association (NMPhA) are professionals from all areas of pharmaceutical care settings. Registered pharmacists, pharmacy technicians. Academia, government, pharmaceutical manufacturers.”  
[New Mexico Pharmacists Association, accessed [12/21/20](#)]

**The Pharmaceutical Industry Labor-Management Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Pharmaceutical Industry Labor-Management Association includes trustees representing Pfizer, Johnson & Johnson, Bayer, Merck, AstraZeneca, Novartis, Eli Lilly, GSK, Astellas, Genentech and Takeda.**  
[Pharmaceutical Industry Labor-Management Association, accessed [12/21/20](#)]

**The Pharmaceutical Security Institute is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Pharmaceutical Security Institute was established by major pharmaceutical companies and has 37 pharmaceutical manufacturer members.**  
“In 2002, the Security Directors from fourteen major pharmaceutical companies established the Institute in Washington, D.C. Working with its members, PSI developed improved systems to identify the extent of the problem and to assist in coordinating international inquiries. Today, PSI membership includes thirty-seven pharmaceutical manufacturers from many nations. The Institute established representational offices with staff in Miami, Florida; Singapore; and Stockholm, Sweden.”  
[Pharmaceutical Security Institute, accessed [12/21/20](#)]

**Rx Partnership is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **Rx Partnership lists GSK, Merck, Novartis, AbbVie, and Pfizer as their “pharmaceutical partners.”**  
[Rx Partnership, accessed [12/21/20](#)]

**The Texas Pharmacy Association is a member of PSM.**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **The Texas Pharmacy Association has a Pharmacy Partners Council that includes PhRMA and at least eight major pharmaceutical manufacturers.**  
[Texas Pharmacy Association, accessed [12/21/20](#)]
- **Membership for the Texas Pharmacy Association’s Pharmacy Partners Council costs at least \$5,000 per year.**  
[Texas Pharmacy Association, accessed [12/21/20](#)]

**Leadership & Lobbying**

**MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION**

Name	Position	Reportable compensation from the organization
MARVIN SHEPHERD	PRESIDENT	\$10,000.00
SAMUEL LOUIS	VICE PRESIDENT	\$5,000.00
SHABBIR SAFDAR	TREASURER/SECRETARY	\$-

KIMBERLY NEW	BOARD MEMBER	\$5,000.00
SUSAN WINCKLER	BOARD MEMBER	\$5,000.00
KENNETH MCCALL	BOARD MEMBER	\$5,000.00

[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

**PSM’s methods strongly resemble the pharmaceutical industry’s influence playbook.**

“Meanwhile, the Partnership for Safe Medicines has spent its expanded budget in ways that resemble Big Pharma’s traditional playbook: It relies on allies with top-notch reputations. In some cases, it has given money to groups like the sheriffs’ organization, which then put their own names on anti-importation ads. Meanwhile, public-relations firms with ties to the PhRMA-backed nonprofit have ghost-written articles about the issue, recruited law-enforcement officers to sign their names to them and then pitched them to newspapers around the country.”

[Bloomberg, [10/23/19](#)]

**SHABBIR IMBER SAFDAR, CURRENT EXECUTIVE DIRECTOR OF PSM AND HEAD OF THE SAFDAR GROUP, HAS RECEIVED MILLIONS FROM PSM, SOME OF WHICH HAS BEEN FUNNELED TO LOBBYISTS ON PSM’S BEHALF.**

**Shabbir Imber Safdar is executive director of PSM.**

Shabbir Imber Safdar has served as the Executive Director of the Partnership for Safe Medicines since 2017. Before that, he was the Director of Outreach and has served as a consultant to PSM for nearly a decade. Shabbir is passionate about patient safety and the dangers of counterfeits, having seen first-hand the dangers of counterfeits in countries around the world where a closed, secure drug supply chain doesn’t exist.”

[Partnership for Safe Medicines, accessed [12/20/20](#)]

- **2018: PSM paid the Safdar Group \$563,149 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]
- **2017: PSM paid the Safdar Group \$569,376 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [7/20/18](#)]
- **2016: PSM paid the Safdar Group \$135,648 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [6/20/17](#)]
- **2015: PSM paid the Safdar Group \$126,236 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [6/16/16](#)]
- **2014: PSM paid the Safdar Group \$318,773 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [8/7/15](#)]
- **2013: PSM paid the Safdar Group \$435,651 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [11/7/14](#)]
- **2012: PSM paid the Safdar Group \$296,321 for “consulting.”**  
[Partnership for Safe Medicines, IRS Form 990, [7/31/13](#)]
- **2011: PSM paid the Safdar Group \$190,442.**  
[Partnership for Safe Medicines, IRS Form 990, [11/14/12](#)]

**Safdar said that he represented both name brand and generic pharmaceutical manufacturers at PSM.**

“I currently serve as the Executive Director for the Partnership for Safe Medicines (PSM), a policy coalition that researches and educates the patients, police and policymakers about the criminal drug counterfeiting trade in America. My work at PSM is incredibly challenging. I steer a coalition of members of the pharmaceutical supply chain that typically don’t agree on anything, and outright fight each other on many public policy issues. And yet through careful strategy, they all participate in PSM’s work educating the public and fighting counterfeits. Patient advocates, licensed healthcare professionals such as pharmacists, wholesalers and distributors, and even the two sides of the manufacturing industry, research and generic, are all part of the PSM coalition.”

[Shabbir Safdar LinkedIn profile, accessed [12/20/20](#)]

**Safdar claimed credit for building PSM into the organization it is today by leading “outreach efforts to members and ally groups.”**

“Director of National Outreach. Dates Employed: Jan. 2013 – Jan. 2017. Employment Duration: four yrs one mo. Location: San Francisco Bay Area. Directed the Partnership’s outreach efforts to members and ally groups focused on raising awareness of counterfeit medicines in America. Identify unique ways to talk about the counterfeit medicine issue and how it’s related to domestic public policy proposals such as importation. It was through this tenure at PSM that I built much of the organization as it exists today.”

[Shabbir Safdar LinkedIn profile, accessed [12/20/20](#)]

**March 2011: Jones Public Affairs Inc. registered to lobby for the Safdar Group, on behalf of PSM.**

According to federal lobbying disclosures, Jones Public Affairs registered on March 15, 2011 to lobby Congress for client “The Safdar Group (on behalf of the Partnership for Safe Medicines).”

Jones Public Affairs, Lobbying Registration, [3/15/11](#)]

- **Lobbyists Deborah Danuser, Berna Diehl, and Tara Goodin worked at Jones Public Affairs on behalf of PSM.**

[Jones Public Affairs, Lobbying Registration, [3/15/11](#); Lobbying Disclosure Report, [3/29/13](#)]

- **Deborah Danuser wrote that she worked at Jones Public Affairs and “served as the day-to-day account lead for a wide variety of non-profit and pharmaceutical clients, including [...] PhRMA’s Partnership for Safe Medicines.**

“Served as the day-to-day account lead for a wide variety of non-profit and pharmaceutical clients, including the Coalition for Patients’ Rights, PhRMA’s Partnership for Safe Medicines, Principal Medical Group, Susan G. Komen for the Cure, Melanoma Research Foundation, Lamaze International, Sanofi, Bristol-Myers Squibb and Sigma-Tau Pharmaceuticals.” [Deborah Danuser LinkedIn profile, accessed [12/22/20](#)]

- **Berna Diehl also led communications for the National Pharmaceutical Council when she was at Jones Public Affairs.**

“ABOUT BERNA DIEHL: Berna Diehl brings more than 20 years of communication experience to her clients, with a special focus on strategic positioning and media relations in health and science. During her eight-year tenure as Senior Vice President at JPA Health Communications, she led communications initiatives for organizations including Intuitive Surgical, Provista Diagnostics, Healthcare Ready, Medicines360, the NIH’s National Center for Complementary and Integrative Health, the Melanoma Research Foundation, Lamaze International, Children’s Hospital Association, National Pharmaceutical Council and others.” [Brighton Communications, accessed [12/22/20](#)]

- **The National Pharmaceutical Council was created by biopharmaceutical companies.**

“The National Pharmaceutical Council (NPC) is a health policy research organization dedicated to the advancement of good evidence and science, and to fostering an environment in the United States that supports medical innovation. Founded in 1953 and supported by the nation’s major research-based biopharmaceutical companies, NPC focuses on research development, information dissemination, education and communication of the critical issues of evidence, innovation and the value of medicines for patients.” [National Pharmaceutical Council, accessed [12/22/20](#)]

- **The National Pharmaceutical Council's members are all drug companies.**

[National Pharmaceutical Council, accessed [12/22/20](#)]

- **At Jones Public Affairs, Tara Goodin managed communications for PSM and pharmaceutical companies Sigma-Tau and Bristol-Myers Squibb.**

“JPA Health Communications. Total Duration: five yrs two mos. Title: Account Supervisor. Dates Employed: July 2011 – Aug. 2013. Employment Duration: two yrs, two mos. Location: Washington D.C. Metro Area. Communications project manager for patient advocacy groups, non-profit organizations, professional associations and other health industry organizations. Managed awareness campaigns and events, developed public health messaging, drafted news announcements and cultivated media interest on important health issues. JPA clients represented included: American College of Nurse-Midwives, The Partnership for Safe Medicines, Cancer Support Community, Melanoma Research Foundation, Personalized Medicine Coalition, Lamaze International, Principal Medical Group, Sigma-Tau Pharmaceuticals, among others. Title: Senior Account Executive. Dates Employed July 2010 – July 2011 Employment Duration: one yr one mo Location: Washington D.C. Metro Area. Public affairs executive charged with execution of national health awareness campaigns for the Cancer Support Community and organization of Capitol Hill briefings, conferences and announcements for The Partnership for Safe Medicines. Also prepared toolkits for Sanofi Oncology to ready patient communities for new therapy approvals and facilitated internal communications programs for Sigma-Tau Pharmaceuticals. Developed and managed agency’s proprietary patient advocate community profiling tool. Title: Account Executive. Dates Employed: July 2008 – July 2010. Employment Duration: two yrs, one mo. Location: Washington D.C. Metro Area. Communications professional who developed tailored public affairs materials, including press releases, public service announcements, blogs, newsletters and advocacy toolkit materials for a variety of clients. Organized international patient advocacy roundtables on behalf of Bristol-Myers Squibb. Established and maintained reporter relationships to secure client media attention. Conducted patient surveys to understand how to communicate needs to health care industry leaders.”

[Tara (Goodin) Rabin LinkedIn profile, accessed [12/22/20](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year	Date Posted
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	Registration		2011	4/15/11
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	1st Quarter - Report	\$20,000.00	2011	4/20/11
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	2nd Quarter - Report	\$40,000.00	2011	7/20/11
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	3rd Quarter - Report	\$30,000.00	2011	10/20/11
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	4th Quarter - Report		2011	1/20/12
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	1st Quarter - Report	\$10,000.00	2012	4/5/12
<a href="#">JONES PUBLIC AFFAIRS, INC.</a>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	2nd Quarter - Report		2012	7/19/12



<u>JONES PUBLIC AFFAIRS, INC.</u>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	3rd Quarter - Report	2012	10/22/12
<u>JONES PUBLIC AFFAIRS, INC.</u>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	4th Quarter - Termination	2012	3/29/13
<u>JONES PUBLIC AFFAIRS, INC.</u>	THE SAFDAR GROUP (ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES)	4th Quarter - Amendment	2011	7/17/13

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

**PSM SENIOR ADVISOR SVEN BREGMANN AND HIS VENTURE GLOBAL LLC HAVE BEEN THE CONDUIT FOR PSM'S LOBBYING FOR THE PAST SEVERAL YEARS.**

**2018: PSM paid \$180,000 to Venture Global for “consulting.”**

[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

**Venture Global was founded by Sven Bergmann, who previously worked for cigarette maker Altria.**

“Sven Bergmann is the Founder and Managing Partner for Venture Global. Sven advises trade associations and Fortune 500 companies on Corporate, Marketing, Communications and Anti-Illicit Trade Strategies. [...] Before becoming a Managing Partner for Venture Global, Sven was an Executive with Altria for over 10 years. In his most recent assignment, he led External & Government Affairs for Altria’s Brand Protection Group, where he engaged with industry partners and government officials to shape trademark protection and enforcement policy in the United States and abroad. During his tenure, he became a leading voice and trusted advisor on illicit trade issues for Governments, Chambers of Commerce, Trade Associations and Industry.”

[Venture Global, accessed [12/22/20](#)]

- **Bergmann has been identified as a “senior advisor” for PSM.**

“The Partnership for Safe Medicines Sven Bergmann Comprised of over 45 non-profit organizations committed to the safety of prescription drugs and protecting consumers against counterfeit, substandard or otherwise unsafe medicines. [...] Contact: Sven Bergmann Senior Advisor PSM SBergmann@VentureGlobal.com”

[Oregon Association of Chiefs of Police, accessed [12/22/20](#)]

**Venture Global is secretive about their clients, but does disclose that they work for pharmaceutical companies and tobacco companies.**

“At Venture Global, we advise Fortune 500 companies, Venture Capital Funds, Private Equity Investors, Governments and Trade Associations on Corporate Strategy, Growth Strategies and Anti-Illicit Trade Strategies. Our clients span across a wide range of sectors, including luxury goods, consumer packaged goods, industrial, shipping, logistics, pharmaceutical, liquor and tobacco across three continents and multiple countries. Due to the nature of our work, confidentiality is of utmost importance. This trust and confidentiality have allowed us to build a client roster containing some of the most valuable and recognizable brands in the world. Together, our clients generate over \$260 billion in annual revenue and include many of today’s Fortune 50. While we cannot disclose the companies we work for, you are able to understand our thinking through our blog, articles written by our founder, and published speeches.”

[Venture Global, accessed [12/22/20](#)]

- **2019: Venture Global participated in a pharmaceutical anti-counterfeiting conference in Zurich.**

“Upcoming Speaking Engagements 2019 Pharma Anti-Counterfeiting Conference, Zurich” [Venture Global, accessed [12/22/20](#)]

### **2019-2020: Nicole Semenza lobbied for Venture Global on behalf of PSM.**

According to federal lobbying disclosures, on March 1, 2019, Nicole Semenza of Nicole Semenza, LLC, registered to lobby for “Venture Global on behalf of The Partnership for Safe Medicines.” Semenza terminated her lobbying for them on January 1, 2020.

[Nicole Semenza LLC, Lobbying Registration, [3/1/19](#); Lobbying Disclosure Report, [3/13/20](#)]

- **Semenza was an employee of Venture Global.**

“Director of Legislative Affairs and Advocacy: Nikki Semenza Nikki is based in DC and manages legislative affairs and advocacy development for Venture Global across our network of clients. Nikki is our resident expert for Government Affairs, Public Health Policy and Advocacy.”

[Venture Global, accessed [12/22/20](#)]

### **2020: Stephanie Burgess lobbied for Venture Global on behalf of PSM.**

According to federal lobbying disclosures, on February 7, 2020, Stephanie Burgess of Stephanie A. Burgess Inc. registered to lobby for “Venture Global on behalf of The Partnership for Safe Medicines” [Stephanie A. Burgess Inc., Lobbying Registration, [2/7/20](#)]

- **Burgess is the “Director of Government Affairs & Law Enforcement Engagement at Venture Global LLC”**

[Stephanie Burgess LinkedIn profile, accessed [12/22/20](#)]

- **Burgess’ role at Venture Global includes lobbying Congress and the Administration.**

“Lobby Congress and the Administration on behalf of clients on a range of policy issues”

[Stephanie Burgess LinkedIn profile, accessed [12/22/20](#)]

### **2019-2020: All of the lobbying disclosure reports for PSM included a contact email address that had the domain “@ballardspahr.com.”**

All of the federal lobbying disclosure records filed by Nicole Semenza LLC and Stephanie A. Burgess Inc. included either the contact email address “nyakwebaj@ballardspahr.com” or rogerseb@ballardspahr.com.

[Nicole Semenza LLC, Lobbying Registration, [4/15/19](#); Lobbying Registration Amendment, [4/30/19](#); Lobbying Registration Lobbying Disclosure Reports, Q1 2020, [5/22/19](#); Q2 2019, [7/22/19](#); Q3 2019, [10/21/19](#); Q4 2019, [1/21/20](#); Stephanie A. Burgess Inc, Lobbying Registration, [4/4/20](#); Lobbying Disclosure Reports, Q1 2020, [4/20/20](#); Q2 2020, [7/20/20](#); Q3 2020, [10/20/20](#)]

- **The email address “rogerseb@ballardspahr.com” belongs to Emory Rogers, a Ballard Spahr compliance manager, in their government relations group.**

“Emory Rogers is a Compliance Manager in Ballard Spahr’s Government Relations, Regulatory Affairs and Contracting Group. He has more than a decade of experience in government relations, communications, regulatory and legislative analysis, and compliance at the federal and state levels. Emory provides a comprehensive range of compliance services and monitors federal and state ethics and campaign finance developments to keep clients ahead of changes and prepared to respond. He provides administration and compliance services to PACs and Super PACs, including having served as Treasurer. Emory tracks campaign finance and lobbying disclosure filing requirements for all 50 states and at the federal level and prepares and files relevant disclosure reports on behalf of clients. He assists in developing coalition, legislative, political, and outreach strategies to achieve clients’ policy goals and initiatives. Before joining a law firm, Emory was a Legislative & Communications Coordinator for a large trade association.”

[Ballard Spahr, accessed [12/22/20](#)]

- **The email address “nyakwebaj@ballardspahr.com” belongs to Jeannette Nyakweba, a Ballard Spahr attorney, practicing “political and election law with a focus on lobbying, public policy and campaign finance.”**

“Jeannette Nyakweba practices political and election law with a focus on lobbying, public policy and campaign finance. She advises corporations (for profit and non-profit), PACs, and trade associations on federal, state, and local campaign finance laws and regulations; pay-to-play rules; lobbying and ethics laws; and Foreign

Agents Registration Act (FARA) compliance. For clients involved in political activity, Jeannette vets TV and direct mail advertisements, reviews contribution and sponsorship requests and directs registration and reporting for federal and state political committees. In addition, Jeannette manages Ballard’s 50 state lobbying, campaign finance and gift rule compliance program for clients, including tracking state-level legislative and regulatory changes.”  
 [Ballard Spahr, accessed [12/22/20](#)]

- **Ballard Spahr maintains a practice in Life Sciences and Technology that represents pharmaceutical and biotechnology companies.**

“Our attorneys counsel frontline businesses engaged in innovation, development, and commercialization activities, and the institutions that support them through research, product development, formulation, production, and distribution. One of the consistent features of these businesses is that their value is premised almost entirely on their intellectual property. As a result, they often are capital intensive and have growth potential. With perspectives from both inside and outside the industry, we provide guidance to companies negotiating regulatory, technological, organizational, and financial challenges. Our clients range from start-ups to established corporations in the fields of: Pharmaceuticals, Biotechnology, Medical Devices, Bioinformatics.”  
 [Ballard Spahr, accessed [12/22/20](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year	Date Posted
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	Registration		2019	4/15/19
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	Registration - Amendment		2019	4/30/19
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	1st Quarter - Report		2019	5/22/19
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	2nd Quarter - Report		2019	7/22/19
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	3rd Quarter - Report		2019	10/21/19
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	4th Quarter - Report		2019	1/21/20
<a href="#">NICOLE SEMENZA LLC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	1st Quarter - Termination (No Activity)		2020	3/13/20
<a href="#">STEPHANIE A. BURGESS INC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	Registration		2020	4/4/20
<a href="#">STEPHANIE A. BURGESS INC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	1st Quarter - Report	\$5,000.00	2020	4/20/20

<a href="#">STEPHANIE A. BURGESS INC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	2nd Quarter - Report	2020	7/20/20
<a href="#">STEPHANIE A. BURGESS INC</a>	VENTURE GLOBAL ON BEHALF OF THE PARTNERSHIP FOR SAFE MEDICINES	3rd Quarter - Report	2020	10/20/20

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

**Q1 2020: PSM lobbied Congress on “S. 3384- Lowering Prescription Drug Prices for America’s Seniors and Families Act of 2020” and “price gouging.”**

According to federal lobbying disclosures, in the first quarter of 2020, PSM’s lobbyist, Stephanie Burgess, lobbied Congress on “Issues related to H.R. 5663- Safeguarding Therapeutics Act; S. 3384- Lowering Prescription Drug Prices for America’s Seniors and Families Act of 2020; drug importation; prescription drug importation; counterfeit drugs; counterfeit medical supplies; price gouging; COVID-19.” [Stephanie A. Burgess Inc, Lobbying Disclosure Report, [4/20/20](#)]

**Q2-Q4 2019: PSM lobbied Congress on bills related to importing drugs from Canada.**

According to federal lobbying disclosure records, in the second quarter of 2019, PSM lobbyist, Nicole Semenza, lobbied Congress on “Importation; opioid crisis; counterfeit drugs; H.R.447 - Affordable and Safe Prescription Drug Importation Act; H.R.478 - Safe and Affordable Drugs from Canada Act of 2019; S.61 - Safe and Affordable Drugs from Canada Act of 2019; S.97 - Affordable and Safe Prescription Drug Importation Act; S.1801 - Affordable Medications Act.” In the third quarter of 2019 she lobbied Congress on “Proposals to require Registries/Registrars to Lock & Suspend Domain Names Used to Facilitate Illegal Online Drug Sales; Proposals to require online Search/Social/Marketplace Platforms to Report Illegal Online Drug Information to Federal/State Authorities (duty to report); H.R. 4510 - Criminalizing Abused Substance Templates Act of 2019; S.954/H.R. 2070 - Providing Officers with Electronic Resources Act; S.400/H.R. 1098 - Blocking Deadly Fentanyl Imports Act; Issues related to importation; opioid crisis; counterfeit drugs; H.R.447 - Affordable and Safe Prescription Drug Importation Act; H.R.478 - Safe and Affordable Drugs from Canada Act of 2019; S.61 - Safe and Affordable Drugs from Canada Act of 2019; S.97 - Affordable and Safe Prescription Drug Importation Act; S.1801 - Affordable Medications Act.” In the fourth quarter of 2019, Semenza lobbied for PSM on “Proposals to require Registries/Registrars to Lock & Suspend Domain Names Used to Facilitate Illegal Online Drug Sales; Proposals to require online Search/Social/Marketplace Platforms to Report Illegal Online Drug Information to Federal/State Authorities (duty to report); H.R. 4510 - Criminalizing Abused Substance Templates Act of 2019; S.954/H.R. 2070 - Providing Officers with Electronic Resources Act; S.400/H.R. 1098 - Blocking Deadly Fentanyl Imports Act; Issues related to importation; opioid crisis; counterfeit drugs; H.R.447 - Affordable and Safe Prescription Drug Importation Act; H.R.478 - Safe and Affordable Drugs from Canada Act of 2019; S.61 - Safe and Affordable Drugs from Canada Act of 2019; S.97 - Affordable and Safe Prescription Drug Importation Act; S.1801 - Affordable Medications Act; Discuss the NPRM on federal drug importation from OMB (RIN 0910-AI45 Importation of Prescription Drugs).”

[Nicole Semenza LLC Lobbying Disclosure Reports, Q2 2019, [7/22/19](#); Q3 2019, [10/21/19](#); Q4 2019, [1/21/20](#)]

**IN ITS EARLIEST YEARS, PSM’S EXECUTIVE DIRECTORS WERE EXECUTIVES AT PHRMA: SCOTT LAGANGA AND JAMES CLASS.**

**PhRMA senior Vice President Scott LaGanga was executive director of PSM for 10 years.**

“A nonprofit organization that has orchestrated a wide-reaching campaign against foreign drug imports has deep ties to the Pharmaceutical Research and Manufacturers of America, or PhRMA, the powerhouse lobbying group that includes Eli Lilly, Pfizer and Bayer. A PhRMA senior vice president, Scott LaGanga, for 10 years led the Partnership for Safe Medicines, a nonprofit that has recently emerged as a leading voice against Senate bills that would allow drug importation from Canada. LaGanga was responsible for PhRMA alliances with patient advocacy groups and served until recently as the nonprofits principal officer, according to the partnerships tax forms.”

[Pharma & Healthcare Monitor Worldwide, 4/20/17]

- **2007-2016: Scott LaGanga was executive director of PSM.**

[Partnership for Safe Medicines, IRS Form 990, [8/12/08](#); [8/13/09](#); [4/29/10](#); [9/15/11](#); [11/14/12](#); [7/31/13](#); [11/7/14](#); [8/7/15](#); [6/16/16](#); [6/20/17](#)]

**2017: LaGanga stepped down from PSM “to avoid the appearance of a conflict of interest.”**

“In February, LaGanga moved to a senior role at PhRMA and stepped down as executive director of the Partnership for Safe Medicines just as the groups campaign to stop import legislation was revving up. [...] The partnership’s new executive director, Shabbir Safdar, said LaGanga resigned from the group to avoid the appearance of a conflict of interest. That’s why Scott’s not the executive director anymore, he said. PhRMA declined to make LaGanga available for an interview.”

[*Pharma & Healthcare Monitor Worldwide*, 4/20/17]

**2014: PSM’s executive director was Scott LaGanga, Senior Vice President, Public Affairs - Advocacy, at PhRMA.**

“Executive Director Scott A. LaGanga Senior Vice President, Public Affairs - Advocacy, Pharmaceutical Research and Manufacturers of America Scott serves as Executive Director of the Partnership for Safe Medicines (PSM), a public-private partnership of more than 70 organizations dedicated to combating counterfeit and unsafe medicines around the globe. In this capacity, Scott has led the development of the annual PSM Interchange forum, which brings together public and private-sector leaders, including frequent participation by Food and Drug Administration Commissioner Margaret Hamburg. In late 2010, he successfully launched PSM’s first international partnership, PSM India, as well as PSM China in late 2012. In addition, Scott A. LaGanga serves as Vice President of Public Affairs and Alliance Development at the Pharmaceutical Research and Manufacturers of America (PhRMA), which represents the country’s leading innovative biopharmaceutical research and biotechnology companies. In this role, he leads a team responsible for third-party stakeholder relations and coalition development, which includes frequent outreach to patient groups, health care providers, business leaders, organized labor, venture capitalists and academic institutions. Additionally, Scott is a member of PhRMA’s executive team and helps manage global public policy issues on behalf of the organization.”

[Partnership for Safe Medicines, INTERCHANGE 2014 Program, [9/18/14](#)]

**2011: PSM’s executive director Scott LaGanga said “whether we work for pharmaceutical companies, non-profit organizations, government entities or advocacy groups – we must all work together to protect patients from these illicit goods.”**

“The Partnership for Safe Medicines Interchange 2011 opened at 8:30am with remarks by Scott LaGanga, Executive Director of PSM. Said LaGanga, last year’s Interchange focused on who are the actors in the world of counterfeit medicines: the criminals, the victims and law enforcement that works to stop the criminals and help the victims. This year’s Interchange focuses on policy actions to combat this public health issue. Said LaGanga, ‘The counterfeit drug issue isn’t going away.’ He cited the Pharmaceutical Security Institute reported a 2.5 percent increase in pharmaceutical crime worldwide in 2010, with more than 200 incidents in the U.S. He said that while counterfeit drug crime continues to grow, so does the progress of law enforcement and policymakers, with approximately 1,200 arrests in medicine crime in 2010. Said LaGanga, ‘The Interchange is an opportunity to share thoughts on how we can unite in the fight against counterfeit drugs. Whether we work for pharmaceutical companies, non-profit organizations, government entities or advocacy groups – we must all work together [sic] to protect patients from these illicit goods.’”

[Partnership for Safe Medicines, [10/27/11](#)]

**2014: PSM had an ex officio board member, James Class, who was an executive director at Merck, and previously had worked at PhRMA and as executive director of PSM.**

“Ex-Officio Board Member James N. Class, Ph.D. Executive Director, Mid Europe Commercial Operations, Merck & Co., Inc. Dr. James N. Class is Executive Director, Mid Europe Commercial Operations, Merck & Co., Inc. Prior to 2007, Dr. Class worked at PhRMA and as a liaison between anti-counterfeiting groups. He was the Executive Director for the United States’ division of the Partnership for Safe Medicines.”

[Partnership for Safe Medicines, INTERCHANGE 2014 Program, [9/18/14](#)]

- **2001-2010: Class was in leadership positions at PhRMA.**  
“Policy, Govt Affairs, Alliance Development. Company Name: PhRMA. Dates Employed: May 2001 – July 2010. Employment Duration: nine yrs three mos. Location: Washington D.C. Metro Area International Government Affairs, AVP, 2007-2010 Alliance Development, Director, 2004-2007 Policy Communications / State Government Affairs, Consulting, 2001-2004.”  
[James Class LinkedIn profile, accessed [12/22/20](#)]
- **2005-2007: Class was executive director of PSM.**  
[James Class LinkedIn profile, accessed [12/22/20](#)]
- **2010-2017: Class was an executive at Merck.**  
“Policy, Ops, Strategy. Company Name: Merck. Dates Employed: July 2010 – Oct. 2017. Employment Duration: seven yrs, four mos. Location: Multiple Corporate Strategy Office, Exec Director (Merck HQ in NJ), 2015-2017 Regional Commercial Ops Lead, Exec Director (MSD Intl in Luzern, Switzerland), 2014-2015 Planning and Execution Lead, Director (MSD Russia), 2012-2014 Global Public Policy, Director (Merck Washington DC Office), 2010-2012.”  
[James Class LinkedIn profile, accessed [12/22/20](#)]
- **2017-Present: Class is a policy director for Gilead.**  
“Company Name: Gilead Sciences. Total Duration: three yrs, two mos. Title: Executive Director, Policy. Full-time. Dates Employed: Jan 2020 – Present. Employment Duration: one yr. Location: Washington D.C. Metro Area. Title: Senior Director, Policy. Dates Employed: Nov. 2017 – Jan. 2020. Employment Duration: two yrs, three mos. Location: Washington D.C. Metro Area.”  
[James Class LinkedIn profile, accessed [12/22/20](#)]

**2007-2010: James Class was an ex officio director of PSM.**

[Partnership for Safe Medicines, IRS Form 990, [8/12/08](#); 8/13/09;4/29/10; 9/15/11]

**MARVIN SHEPHERD, PRESIDENT OF PSM**

**Marvin D. Shepherd is the president of the board of directors of Partnership for Safe Medicines.**

“Governing Board Marvin D. Shepherd, Ph.D., Board President Professor Emeritus, College of Pharmacy, University of Texas-Austin.”

[Partnership for Safe Medicines, accessed [12/20/20](#)]

- **2018: PSM paid board president Marvin Shepherd \$10,000.**  
[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]
- **2017: PSM paid board president Marvin Shepherd \$10,000.**  
[Partnership for Safe Medicines, IRS Form 990, [7/20/18](#)]

**2017: In an article for the Canadian Medical Association Journal, Partnership for Safe Medicines was listed as a “conflict” or “competing interest” for Shepherd.**

“Conflict of interest statement Competing interests: Marv Shepherd is President, Board of Directors, Partnership for Safe Medicine.”

[PubMed.gov, [9/25/17](#)]

**THOMAS KUBIC, VICE PRESIDENT OF PSM**

**Thomas Kubic is the board Vice President of PSM, and was formerly the president and CEO of the Pharmaceutical Security Institute.**

[Partnership for Safe Medicines, accessed [12/20/20](#)]

- **The Pharmaceutical Security Institute was established by major pharmaceutical companies and has 37 pharmaceutical manufacturer members.**

“In 2002, the Security Directors from fourteen major pharmaceutical companies established the Institute in Washington, D.C. Working with its members, PSI developed improved systems to identify the extent of the problem and to assist in coordinating international inquiries. Today, PSI membership includes thirty-seven pharmaceutical manufacturers from many nations. The Institute established representational offices with staff in Miami, Florida; Singapore; and Stockholm, Sweden.”

[Pharmaceutical Security Institute, accessed [12/21/20](#)]

## **KRISTINA ACRI, PSM AND PhRMA CONSULTANT**

### **Kristina Acri serves as consultant for both PSM and PhRMA.**

Consultant. Company Name: PhRMA. Dates Employed: 2002 – Present. Employment Duration: 18 yrs. The Partnership for Safe Medicines Consultant. Company Name: The Partnership for Safe Medicines. Dates Employed: Jan 2019 – Present. Employment Duration: two yrs. Location: San Francisco Bay Area.”

[Kristina Acri LinkedIn profile, accessed [12/20/20](#)]

- **Acri is a professor of economics at Colorado College, and specializes in “strengthening intellectual property rights protection in developing countries, specifically in the context of pharmaceutical” companies.**

“Dr. Kristina M. L. Acri, née Lybecker, is an Associate Professor of Economics and Chair of the Department of Economics and Business at Colorado College in Colorado Springs, CO. She received her Ph.D. in Economics from the University of California, Berkeley. Kristina’s research analyzes the difficulties of strengthening intellectual property rights protection in developing countries, specifically in the context of the pharmaceutical and environmental technology industries.”

[Kristina Acri LinkedIn profile, accessed [12/20/20](#)]

- **Acri has previously worked for PhRMA and IFPMA.**

“She has also worked with the US Food and Drug Administration, Reconnaissance International, PhRMA, IFPMA, the National Peace Foundation, the OECD, the Fraser Institute, and the World Bank, on issues of innovation, international trade, and corruption.” [Kristina Acri LinkedIn profile, accessed [12/20/20](#)]

- **IFPMA is the International Federation of Pharmaceutical Manufacturers and Associations, and their members include major pharmaceutical companies and PhRMA.**

[IFPMA, accessed [12/20/20](#)]

## **SAMUEL LOUIS, PSM ADVISORY BOARD MEMBER**

### **Samuel J. Louis is a member of the PSM Advisory Board and an attorney with the Holland & Knight law firm.**

“Samuel J. Louis, JD, Partner, Holland and Knight. Former Deputy Criminal Chief of the Program Fraud Group, Department of Justice.”

[Partnership for Safe Medicines, accessed [12/20/20](#)]

- **Louis is a member of Holland & Knight’s health care and life sciences practice, advising clients on health care regulatory issues and issues of drug distribution.**

“PRACTICES Litigation and Dispute Resolution | Healthcare & Life Sciences | Healthcare Litigation | Healthcare Fraud and Abuse | Healthcare White Collar Defense and Investigations | White Collar Defense and Investigations INDUSTRY Healthcare & Life Sciences Sam J. Louis is a litigation attorney in Holland & Knight’s Houston office. Mr. Louis’ practice involves providing advice and counsel regarding healthcare regulatory issues, white collar criminal defense, corporate internal investigations, Foreign Corrupt Practices Act (FCPA) and compliance with federal regulations that govern food and drug distribution.”

[Holland & Knight, accessed [12/20/20](#)]

- **2010: Louis won an award from the Department of Homeland Security for a counterfeit pharmaceutical prosecution.**  
 “During his tenure with the DOJ, Mr. Louis oversaw a healthcare fraud task force and a global anti-counterfeiting task force, each comprised of local, state and federal law enforcement, private industry officials and community organizations. Through the former, he was responsible for securing the return of more than \$60 million to government and private healthcare programs. In the latter, he investigated and prosecuted global anti-counterfeiting targets, including foreign nationals trafficking in counterfeit, unapproved and adulterated medicines and the diversion of pharmaceutical drug products. [...]. Director’s Award, Counterfeit Pharmaceutical Prosecution, DHS, Immigration and Customs Enforcement, 2010” [Holland & Knight, accessed [12/20/20](#)]
- **The Holland & Knight healthcare and life sciences practice represents drug makers.**  
 “Holland & Knight’s Healthcare & Life Sciences Team assists the full range of industry participants, from providers, payors and networks to manufacturers, distributors and suppliers, in all aspects of their operations.” [Holland & Knight, accessed [12/20/20](#)]
- **2018: PSM paid board members Samuel Louis, Kimberly New, Susan Winckler, and Kenneth McCall each \$5,000.**  
 [Partnership for Safe Medicines, IRS Form 990, 11/13/19]

#### **JAMES DAHL, FORMER VICE PRESIDENT OF PSM AND SECURITY DIRECTOR FOR EISAI.**

**2015: James Dahl was Vice President of the board of PSM.**

[Partnership for Safe Medicines, IRS Form [990, 6/16/16](#)]

- **James Dahl was global product security director for pharmaceutical company Eisai prior to joining the board of PSM.**  
 [James Dahl LinkedIn profile, accessed [12/22/20](#)]

#### **PSM HAS PAID MILLIONS TO OTHER FIRMS THAT HAVE TIES TO ASTROTURF GROUP AND THE PHARMACEUTICAL INDUSTRY.**

**2018: PSM paid \$3,738,748 to Strategic Consulting Inc., for “consulting.”**

[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

- **Strategic Consulting Inc. is run by Kira Swencki (aka, Kira Lieberman), who is a PR professional.**  
 “Owner President. Company Name: Strategic Consulting / Issue Management Media. Dates Employed: 001 – Present. Employment Duration: 19 yrs. Kira is currently the owner of Issue Management Media / Strategic Consulting, where she works towards the execution of media, project management and advocacy initiatives. In all her capacities, Kira has focused her work on managing programs that foster better understanding and appreciation of issues through education and advocacy.” [Kira Swencki LinkedIn profile, accessed [12/16/20](#)]
- **2018: Alliance for Patient Access paid more than \$9,551,612 to Strategic Consulting Inc.**  
 [Alliance for Patient Access, IRS Form 990, [11/14/19](#)]

**2017: PSM paid 720 Strategies \$350,000 for “consulting.”**

[Partnership for Safe Medicines, IRS Form 990, [7/20/18](#)]

- **2016: Alliance for Patient Access paid \$501,548 to 720 Strategies.**  
 [Alliance for Patient Access, IRS Form 990, [11/14/17](#)]



- **720 Strategies did work for PhRMA and uses it as a case study on their website.**

“Facing a climate of substantial health care policy change and reputational challenges, the biopharmaceutical industry’s national trade association, the Pharmaceutical Research and Manufacturers of America (PhRMA), and its member companies sought an advocacy solution to convey the industry’s value and commitment to positive change in health care policy through its member company employees. [...] To address these challenges, 720 Strategies developed and continues to implement an integrated advocacy and communications program called We Work For Health (WWFH) – a grassroots initiative that unites health consumers, pharmaceutical company employees and retirees, vendors, suppliers and other partners to demonstrate how these diverse groups work together to deliver life-saving, life-enhancing advancements in medicine, while also serving as a driving force for our nation’s economy. As the first initiative in PhRMA’s history to secure the approval of member companies to directly engage their employees in a cohesive, industry-sponsored grassroots program, WWFH aims to help advance policies that promote medical innovation in the U.S. What started as a pilot program in three states in 2008 has expanded to include 14 states in 2015. WWFH has flourished into an alliance of biopharmaceutical employees, retirees, vendors, suppliers and other local business groups, labor unions, concerned patients and academic and community partners who share the common goal of preserving medical innovation in the country.”

[720 Strategies, accessed [12/9/20](#)]

- **720 Strategies designed and built a “Science Ambassadors” program for PhRMA specifically to lobby Congress, with a focus on communicating “PhRMA’s commitment to promote access to health care and prescription drugs.”**

“Established to engage biopharmaceutical scientists and researchers across the country to join together to help advance the industry, the Science Ambassadors program is a multifaceted approach to communicating PhRMA’s medical innovation agenda within local communities and with Members of Congress. The program leverages ambassadors’ extensive research and development experience in helping to shape the dialogue about the role and value of medical innovation in bettering health care in the U.S. and around the world – not only on the innovation of new medicines, but on the industry’s commitment and contribution to overall health and well-being. The program includes a dedicated website with congressional contact capability, as well as a speaker’s bureau of research scientists who carry the industry’s message in their local community. These communications reinforce PhRMA’s commitment to promote access to health care and prescription drugs, encourage prevention and healthier living, and innovations that help families live longer, healthier lives.”

[720 Strategies, accessed [12/9/20](#)]

### **2011: PSM paid \$200,000 to the Herald Group.**

[Partnership for Safe Medicines, IRS Form 990, [11/14/12](#)]

- **The Herald Group is a public affairs firm that maintains a Health Care & Life Sciences practice, representing pharmaceutical clients like Lilly and Bayer.**

[The Herald Group, accessed [12/22/20](#)]

## **Drug Pricing Legislation**

### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

#### **PSM “blasted” bills to lower prescription drug costs by Elijah Cummings and other lawmakers.**

“Democratic and independent lawmakers, including two potential contenders for the 2020 presidential nomination, called on President Donald Trump to support a package of three aggressive bills intended to lower prescription drug prices. The announcement came after Trump summoned officials to the White House Tuesday (Jan. 8) following drug price hikes in the new year, and after HHS Secretary Alex Azar tweeted Wednesday that the administration would be willing to work with Democrats on drug pricing policy. Thursday, several liberal members of Congress invited Trump to cooperate with them on a three-bill package including a new bill on compulsory licensing and international reference pricing, and re-introduced measures on Medicare price

negotiation and personal prescription drug importation. [...] Sanders and fellow potential presidential hopeful Sen. Cory Booker (D-NJ) were joined in calling for bipartisan cooperation by several of their colleagues in Congress, including House Oversight and Reform Committee Chairman Rep. Elijah Cummings (D-MD); Sen. Richard Blumenthal (D-CT); Reps. Peter Welch (D-VT), Ro Khanna, (D-CA), Jan Schakowsky (D-IL); and House freshmen Ilhan Omar (D-MN) and Joe Neguse (D-CO). The group re-introduced the Medicare Drug Price Negotiation Act, which was offered last year by Cummings and Sanders. Cummings said he introduced the bill in 2017 after meeting with Trump on March 8 of that year. According to Cummings, Trump said he would be supportive of the draft of the legislation but later backed off the idea. [...] The Partnership for Safe Medicines, a coalition composed of groups including the brand-drug lobby Pharmaceutical Research and Manufacturers of America, the generic drug lobby Association for Accessible Medicines, BIO, and several pharmacist associations, opposed the recent importation bills. ‘Opening America’s drug supply chain to non-FDA approved, substandard, or counterfeit substances will only lead to greater loss of life. It is a fallacy to suggest, as drug importation advocates have, that we can safely import medications from close allies like Canada,’ said Partnership for Safe Medicines President Marv Shepherd.”  
[FDA Week, 1/18/19]

### **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

### **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

*No relevant information.*

## **Other**

### **DRUG IMPORTATION**

#### **PSM argues that drug importation from Canada is “not a viable option” for lowering prescription drug prices.**

“With the approval of the final rule for state drug importation programs (SIPs) last September, advocates and legislators are considering whether to pursue Canadian drug importation in 2021. And that’s understandable: the idea of importing drugs from Canada to lower prescription drugs costs has been floating around for about 20 years. The truth, however, is that even though several states are pursuing Canadian drug importation, it is not and never has been a viable option.”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

#### **PSM argues that drug importation schemes “don’t save enough money.”**

“Past Evidence Shows importation schemes don’t work. They compromise safety and don’t save enough money.”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

#### **PSM says that Canada’s “open supply chain,” which isn’t subject to U.S. regulators makes drug reimportation too risky and potentially dangerous.**

“A Canadian wholesaler would buy drugs from a manufacturer and sell them to a licensed U.S. importer who has been contracted to acquire Canadian medicines for a state. The importer would arrange for the drugs to be tested, repackaged and relabeled. Pharmacists and other health professionals would purchase the imported drugs and dispense them to patients. This innovation looks like a small change that only introduces a little more risk. In practice, it’s more dangerous than it seems. Because Canadian regulators license the foreign seller, U.S. regulators have no authority over them. States could terminate a contract with a foreign seller, but they could not shut them down—and bringing a Canadian wholesaler to court requires permission from the Canadian government to extradite them. Because some of the entities in this supply chain are regulated by a foreign regulator rather than a domestic one, we call it an open supply chain.”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM argues that Maine's drug importation plan would end up costing the state \$1 million more than drugs purchased in the U.S. because the foreign drugs wouldn't be eligible for rebates.**

"Maine hasn't submitted an application to HHS yet, but in January 2020 they held a hearing in which MaineCare's Director of Pharmacy Operations reported that importation would not save the state's Medicaid program any money. PSM submitted a Freedom of Access Request to see their data. When we examined it, we learned that once you factor in pharmaceutical rebates, Medicaid programs like Maine's get medicine more cheaply than Canadian provinces do. Because medicine from Canada's supply will not qualify for rebates, the 50 drugs Maine studied would cost nearly a million dollars more if Maine's Medicaid program imported them."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM argued that Colorado's drug importation scheme proposed importing name-brand drugs, when more affordable generics were available in the U.S., potentially saving them some \$43 million.**

"Could save \$43 million by using U.S. generics instead of spending \$1 million on plan development Colorado spent a million dollars this year developing their importation plan. In October, they acknowledged that they won't be submitting a plan to HHS until early 2022. After a year of work, they still haven't secured a Canadian wholesaler—that's this year's millions of budget dollars—and they had to remove Medicaid from the plan because it already gets medicine cheaper than the Canadians do. We also analyzed the list of medicines Colorado was considering for importation. We were puzzled that they were importing brand name medicines for which cheaper generics already exist on the U.S. market. We found that they could save \$43 million in a single year simply by switching to generics."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM warned that New Mexico's drug reimportation plan failed to crack down on PBMs and others that might markup the price of pharmaceuticals until they were the same price as those available domestically.**

"After a year of work by staff in half a dozen state agencies, New Mexico released their draft plan and will probably submit their final to HHS any day now. They don't have any Canadian vendors willing to participate, and like Colorado, they removed Medicaid from the plan because they already get medicine cheaper than the Canadians do. There are a number of problems with their application, including the lack of liability protection for healthcare professionals who inadvertently dispense counterfeit medicines, and a failure to restrict pharmacy benefits managers, hospitals, and insurance companies from marking up the cost of Canadian medication until it's the same price as U.S. medication."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM argues that law enforcement doesn't support drug importation.**

"What do major law enforcement organizations think about drug importation proposals? They don't like them."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **PSM: "Drug Importation Endangers Patients And The American Drug Supply, Worsens The Opioid Crisis, And Increases Law Enforcement Officers' And First Responders' Exposure To Deadly Illegal Fentanyl And Its Analogues"**

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM argues that the U.S. shouldn't allow drug importation because we need to protect the drug supply from the dangers of unsafe counterfeit drugs.**

"The Experts Agree: We Need To Protect Our Drug Supply Pharmacists, patient advocates, regulators, law enforcement and pharmaceutical companies and wholesalers share our concerns about the threat counterfeit drugs pose to American patients. Since 2000, not one head of the U.S. Department of Health and Human Services or one FDA Commissioner—no matter who appointed them—has been willing to certify the importation of drugs from other countries' supplies. As recently as May 2018, Secretary of Health and Human Services Alex Azar II remarked: ...the last four FDA commissioners have said there is no effective way to ensure drugs coming from Canada really are coming from Canada, rather than being routed from, say, a counterfeit factory in China. The United States has the safest regulatory system in the world. The last thing we need is open borders for

unsafe drugs in search of savings that cannot be safely achieved.”  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

**2018: PSM executive director Safdar refused to answer questions about whether they were fearmongering about drug importation from Canada.**

“Then there’s the ad’s kicker: ‘Importing drugs from Canada puts every U.S. patient at risk.’ Except for, you know, that it doesn’t. I laid all this out for Shabbir Safdar, executive director of the Partnership for Safe Medicines. I asked whether it was misleading to suggest that ‘drugs from Canada’ endanger Americans when the risk clearly is from counterfeit drugs that originate elsewhere. I asked how the Canadian government could be held accountable for inspecting such drugs. I asked if the partnership was engaging in baseless fear-mongering. Safdar answered none of those questions. He said by email that ‘the Partnership for Safe Medicines is committed to the safety of prescription drugs and protecting consumers against counterfeit, substandard or otherwise unsafe medicines. We are dedicated to protecting the safety of American consumers by curbing the manufacturing and sale of dangerous counterfeit drugs. Our goal is for all consumers to be aware that counterfeit medicines do exist, they are not safe and together we can take action to avoid them,’ Safdar said. ‘Our latest ads help raise this awareness.’ They don’t. They shamelessly deceive to protect the profits of U.S. drug companies at the expense of American patients, maligning Canada in the process.”

[David Lazarus, *Los Angeles Times*, 5/11/18]

**PSM HAS PROPOSED THAT PATIENTS SHOP AROUND TO LOWER THEIR PRESCRIPTION DRUG COSTS, AND PROPOSED INCREASED REGULATIONS ON PBMS AND INCREASED USE OF GENERIC DRUGS TO LOWER DRUG PRICES.**

**PSM proposed increased regulations on PBMs as a way to reduce prescription drug costs.**

“Regulate Pharmacy Benefit Managers. With the Supreme Court’s decision this last week in *Rutledge v PCMA*, states can now regulate how pharmacy benefit managers use spread pricing to extract profits from consumers and community pharmacies.”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM proposed increasing the use of generic medicines to reduce prescription drug costs.**

“Promote Generics. As in the case of Colorado, above, we suspect that states may be spending millions buying brand name drugs when there are less expensive generics available. If Colorado could save \$43 million in a single year simply by switching to generics (some of which are cheaper in the U.S. than in Canada) how much can other states save without compromising the safety of our supply chain?”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM offers “Easy Ways To Safely Save Money On Prescription Drugs.”**

“Easy Ways To Safely Save Money On Prescription Drugs Safe Savings: If you can’t safely buy drugs from foreign online pharmacies, how can you safely save money on your prescriptions? This handout offers advice. Safe Savings Tips: PSM is constantly looking for ways for you to save money safely. Follow our Safe Savings Tips feed to learn more. Prescription Assistance NeedyMeds: NeedyMeds is a nonprofit organization that helps patients find prescription assistance programs. If you need help paying for your prescriptions, start here. RxOutreach: a non-profit pharmacy working to make medications affordable for people whose income is at or below 400 percent of the Federal Poverty Level. Medicine Assistance Tool: MAT helps uninsured and financially struggling patients get access to nearly 500 healthcare and prescription assistance programs that offer medicines for free or nearly free.”

[Partnership for Safe Medicines, accessed [12/21/20](#)]

**PSM says “smart shoppers with the right information can buy what they need at a more affordable price.”**

“Americans are searching for less expensive medication, but also want assurance that the drugs they rely on are safe, untainted and regulated to ensure quality. Americans looking for better prices on prescription drugs don’t have to look far. Smart shoppers with the right information can buy what they need at a more affordable price

AND avoid the serious safety risks that accompany purchasing imported medicine.”  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

### **PSM advises patients that they can lower prescription drug costs by talking with their doctors and pharmacists and seeking “senior discounts.”**

“Talk With Your Doctor Let your doctor know that price is an important consideration in any new medication that you receive. If they want to prescribe a brand-name drug, ask for the generic. If there is not yet a generic on the market, ask if there is another drug within the same class that does have one available. If there are no alternatives, ask if your doctor has any samples you can use to see if the medication is right for you. If this is the prescription drug you need, but it is cost prohibitive, the samples can help bridge the gap while you look for a Prescription Assistance Program (PAP)—see below! Talk To Your Pharmacist If a prescription costs more than you are comfortable paying, speak with your pharmacist. Since the federal ban on gag clauses went into effect in 2019, your pharmacist can let you know about ways to lower your out-of-pocket costs including switching to a generic version of the drug, using a coupon/ discount card, or not using your insurance to fill the prescription. Sometimes a prescription costs less if you pay the cash price. Senior Discounts Seniors can also save money by using a coupon or a discount card. Ask your pharmacist if there is one that they recommend based on the medications that you take. Additionally, many pharmacies offer a 10 percent senior discount if you ask for it.”  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

### **PSM advises patients that they may be able to lower their drug costs by purchasing a 90-day supply rather than a 30-day supply of their medications.**

“90-Day Prescription You might be able to save money by purchasing a 90-day supply of your medicine instead of a 30-day supply. Your pharmacist will be able to let you know this information, and if so, ask your doctor to request a prescription for 90 days.”  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

### **PSM advises patients to compare prices among pharmacies to reduce prescription drug prices.**

“Compare Prices At Brick And Mortar Pharmacies Different pharmacies charge different amounts to fill the same prescription from city to city and state to state. You don’t have to spend your day driving around to cost compare. WeRx, RxSaver, and WellRx are just a few websites that allow patients to compare prices among brick-and-mortar pharmacies in their own neighborhoods and across the country. If you are taking multiple prescription drugs, it is vital that you fill all of your medications at one place. So finding the pharmacy that offers you the best total price may take some time, but the savings are worth your effort and time. Using one pharmacy and developing a relationship with your pharmacist is the safest way to check for drug interactions, duplications, and possible side effects—and get the best value for your money.”  
[Partnership for Safe Medicines, accessed [12/21/20](#)]

## **PSM DIRECTS PATIENTS TO PATIENT ASSISTANCE CHARITIES AND OTHER ORGANIZATIONS TIED TO THE PHARMACEUTICAL INDUSTRY.**

### **PSM directs patients to prescription assistance programs NeedyMeds, Medicine Assistance Tool, and Rx Outreach.**

“Prescription Assistance Programs Patients don’t have to turn to questionable online sellers to get the medications they need. There are hundreds of assistance programs to help patients obtain medications. These programs provide a safe alternative for patients who cannot afford to fill their prescriptions. NeedyMeds is a non-profit organization that maintains a website, NeedyMeds.com, with free information about programs that help people afford their medications and healthcare costs. In addition to their directory of prescription assistance programs, the website also offers a free drug discount card, which can save uninsured or underinsured patients up to 80 percent on the cost of their medications and manufacturer’s coupons. Medical Assistance Tool (MAT) is a free-to-use search engine that allows patients, caretakers, and healthcare providers to search for patient assistance resources offered by pharmaceutical companies. There are approximately 500 public and private assistance programs listed in MAT’s database that help those with financial need get access to their

prescription(s). Visit <https://medicineassistancetool.org> for additional information. Rx Outreach is the nation's largest non-profit, fully licensed, mail order pharmacy and PAP. It offers more than 1,000 medication strengths at affordable prices for the uninsured, underinsured, and those with high copays. Rx Outreach partners with hundreds of clinics and organizations in all 50 states. Visit <https://rxoutreach.org> or call 1-888-796-3880 to see if you qualify."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **Medicine Assistance Tool is a project of PhRMA.**

"Pharmaceutical Research and Manufacturers of America (PhRMA) created the Medicine Assistance Tool (MAT) to provide a dedicated search engine that allows users to search for financial assistance resources available to them, their loved ones or patients in their lives through the various biopharmaceutical industry programs available for patients who are eligible."

[MedicineAssistanceTool.org, accessed [12/21/20](#)]

- **NeedyMeds is funded in part by pharmaceutical companies.**

"NeedyMeds receives funding from a number of sources: Grants Donations Sale of PAPTracker, software designed to help local programs enroll applicants in programs and track usage Syndication of our information Advertisements on the website Partnering with pharmaceutical manufacturers to help them establish and operate their PAPs"

[NeedyMeds, accessed [12/8/20](#)]

- **Rx Outreach spun off of Express Scripts.**

"Based in St. Louis, MO, Rx Outreach started as a Patient Assistance Program (PAP) at Express Scripts, a Fortune 100 company also located in St. Louis. In October 2010, Rx Outreach spun off from Express Scripts and became a stand-alone nonprofit organization under the founding leadership of Michael Holmes."

[Rx Outreach, [2020](#)]

## **PSM'S BRIEFINGS FOR MEMBERS OF CONGRESS HAVE OFTEN INVOLVED REPRESENTATIVES FROM PHARMACEUTICAL MANUFACTURERS AND THEIR CONFERENCES HAVE FEATURED SPEAKERS FROM PHRMA AND OTHER DRUG COMPANIES.**

### **Fall 2019: PSM hosted a briefing for members of Congress on counterfeit drugs that included a presentation from a representative of Bristol-Myers Squibb.**

"PSM, Partners Host Fall 2019 Congressional Briefings About Counterfeit Drug Dangers [...] Armando Rivera (Bristol-Myers Squibb Security Lead and DEA veteran) showed attendees the scale of the counterfeit drug problem in the Americas by summarizing cases involving fake cancer drugs in Mexico, counterfeit rheumatoid arthritis treatments Canadian wholesaler T.C. Medical sold to U.S. medical practices, and counterfeited respiratory treatments that led to the deaths of sixteen premature babies in Colombia."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

### **2016: PSM hosted a Congressional briefing that featured presentations from representatives of Pfizer and Boehringer Ingelheim Pharmaceuticals.**

"Current Threats to American Patients from Counterfeiters,' March 7-8, 2016 [...] Panel topics and speakers included: [...]. 'Protecting Patients from Counterfeit Medicines,' Aaron Graham, Executive Director, Brand Safety & Security, Boehringer Ingelheim Pharmaceuticals, Inc. 'Counterfeit Medicines: Threat to Patient Health and Safety,' John Clark, Vice President and Chief Security Officer at Pfizer, Inc."

[Partnership for Safe Medicine, [3/16/17](#)]

### **2017: PSM hosted a Congressional briefing featuring presentations from representatives from Bristol-Myers Squibb, Novartis, and Pfizer.**

"The Partnership For Safe Medicines Congressional Briefing March 16 -17, 2017 [...] Speakers included: [...] 'Drug Importation Safety Concerns with Biologic Medicines,' Amy Lyons, Vice President of Corporate Security, Bristol-Myers Squibb; 'Criminal Intent and Counterfeit Medicines,' Clive Timmons, Global Head of Security,

Novartis; 'Counterfeit Medicines from Canada,' John Clark, Vice President and Chief Security Officer, Pfizer." [Partnership for Safe Medicines, [3/15/17](#)]

**2018: "The 2018 PSM Interchange brought together policymakers, [and] pharmaceutical manufacturers" and others to discuss counterfeit drugs.**

"The 2018 PSM Interchange brought together policymakers, counterfeit drug victims, pharmaceutical manufacturers, patient advocates, law enforcement, and healthcare professionals to discuss solutions to the deadly impacts that counterfeit drugs are having upon U.S. Citizens. Carrie Luther, Lisa Hicks, and Jennifer Hodge shared with attendees their experiences of losing their sons to counterfeit pills made with fentanyl." [Partnership for Safe Medicines, accessed [12/21/20](#)]

**The 2014 PSM "Interchange" brought together policymakers and pharmaceutical company representatives and included an introduction and an introduction to the keynote address from PhRMA.**

"The 2014 PSM Interchange brought together policymakers, pharmaceutical manufacturers, patient advocates, law enforcement, healthcare professionals, and anti-counterfeiting companies to discuss the problem and solutions to the global scourge of pharmaceutical counterfeiting. [...] Introduction - Scott LaGanga, Executive Director Partnership for Safe Medicines; Senior Vice President, Public Affairs - Advocacy, Pharmaceutical Research and Manufacturers of America (PhRMA) [...] Keynote speaker Howard Sklamberg, J.D., Deputy Commissioner for Global Regulatory Operations and Policy, Food and Drug Administration Introduced by Scott LaGanga, Executive Director, Partnership for Safe Medicines; Vice President, Public Affairs - Advocacy, Pharmaceutical Research and Manufacturers of America" [Partnership for Safe Medicines, accessed [12/21/20](#)]

- **2014: The PSM "Interchange" was sponsored by Allergan, Merck, Genentech, Abreos Biosciences, Celgene, Johnson & Johnson, and Eli Lilly.**

[Partnership for Safe Medicines, INTERCHANGE 2014 Program, [9/18/14](#)]

**2013: PSM's "Interchange" brought "together policymakers and pharmaceutical manufacturers" and included an introduction from their executive director who worked for PhRMA.**

PSM's 4th annual Interchange conference was held October 24, 2013 at the Knight Conference Center at The Newseum, 555 Pennsylvania Ave., NW, Washington, D.C. Each year, the PSM Interchange brings together policymakers, pharmaceutical manufacturers, patient advocates, law enforcement, healthcare professionals, and anti-counterfeiting companies to discuss the problem and solutions to the global scourge of pharmaceutical counterfeiting. [...] 8:30 a.m. - Conference opener Introduction - Scott LaGanga, Executive Director Partnership for Safe Medicines; Senior Vice President, Public Affairs - Advocacy, Pharmaceutical Research and Manufacturers of America (PhRMA)" [Partnership for Safe Medicines, accessed [12/21/20](#)]

**2012: PSM's "Interchange" brought "together policy makers, pharmaceutical manufacturers" and included talks from their executive director who was a senior executive at PhRMA.**

"PSM's annual Interchange conference was held on September 28, 2012 at the National Press Club (Washington DC). The annual Interchange brings together policymakers, pharmaceutical manufacturers, patient advocates, law enforcement, healthcare professionals, and anti-counterfeiting companies to discuss the problem and solutions to the global scourge of pharmaceutical counterfeiting. [...] Friday Sep. 28, 2012, 8:30 a.m. - Opening Remarks & Opening Speaker Introduction - Scott LaGanga, Executive Director Partnership for Safe Medicines; Senior Vice President, Public Affairs - Advocacy, Pharmaceutical Research and Manufacturers of America (PhRMA) [...] 12:00 - 1:30 p.m. - Luncheon Speaker Introduction - Scott LaGanga, Partnership for Safe Medicines [...] 1:30 - 2:00 p.m. - Understanding Drug Safety & Security: Impact On Industry Moderator - Scott LaGanga, Partnership for Safe Medicines [...] 3:15 - 3:45 p.m. - Keynote Speaker Introduction - Scott LaGanga, Partnership for Safe Medicines."

[Partnership for Safe Medicines, accessed [12/21/20](#)]

- **2012: PSM's "Interchange" included a panel discussion with PhRMA's president and CEO and the president and CEO of the Generic Pharmaceutical Association.**

"1:30 - 2:00 p.m. - Understanding Drug Safety & Security: Impact On Industry Moderator - Scott LaGanga, Partnership for Safe Medicines John Castellani, President and Chief Executive Officer, Pharmaceutical Research and Manufacturers of America (PhRMA) Ralph G. Neas, President and Chief Executive Officer, Generic Pharmaceutical Association (GPhA)" [Partnership for Safe Medicines, accessed [12/21/20](#)]

## **2020: PSM JOINED A LAWSUIT WITH PHRMA AGAINST DRUG IMPORTATION FROM CANADA.**

**November 2020: PhRMA issued a press release jointly with the Partnership for Safe Medicines announcing they were suing to stop a federal rule allowing states to import medicines from Canada.**

"Today, the Pharmaceutical Research and Manufacturers of America (PhRMA), Partnership for Safe Medicines (PSM) and Council for Affordable Health Coverage (CAHC) initiated litigation in the U.S. District Court for the District of Columbia challenging action by the U.S. Department of Health and Human Services (HHS) and Food and Drug Administration (FDA) permitting pharmacists and wholesalers, pursuant to state-sponsored programs, to import certain prescription drugs from Canada into the United States without drug manufacturers' authorization or oversight (85 Fed. Reg. 62,094 Oct. 1, 2020) (the 'Final Rule'). PhRMA Executive Vice President and General Counsel James C. Stansel stated: 'It is alarming that the administration chose to pursue a policy that threatens public health at the same time that we are fighting a global pandemic. FDA has noted it is struggling to keep up with approving medicines while working around the clock to support COVID-19 therapeutics and vaccine development. Despite this, the administration is willing to divert precious FDA resources away from these efforts and to expose Americans to the risks that come with drug importation schemes. 'It is particularly disturbing that the administration is punting the responsibility for demonstrating safety and cost savings to state governments despite the clear requirement under federal law that the Secretary of HHS must certify that imported drugs both pose no additional risk to public safety and will lead to significant savings for the American consumer. In fact, the Final Rule fails to overcome the well-documented safety concerns regarding importation expressed for nearly two decades by previous HHS Secretaries across party lines or to make any showing that the proposal would result in any—let alone significant—cost savings to American consumers. The bottom line is that the administration has violated federal law by proceeding without proper certification and, in doing so, is putting the health and safety of Americans in jeopardy.' PSM Executive Director Shabbir J. Safdar stated: 'Since the start of the COVID-19 pandemic, the key role of FDA in ensuring the availability of safe and effective medicines and the integrity of the American pharmaceutical supply chain has become even more clear. Once we weaken the longstanding defenses in place for our drug supply, as this Final Rule does, we open floodgates that cannot be closed. This makes absolutely no sense from a policy standpoint, which is why HHS and the FDA have long opposed and refused to effectuate importation measures like those in the Final Rule from ever seeing the light of day. For nearly 20 years, HHS and FDA heads, appointed by both Republican and Democratic administrations, have seen the dangers of these proposals and always declined to pursue them. The Trump Administration has defied this wisdom for seemingly political reasons at the worst possible time. 'The Final Rule would create large gaps in track and trace requirements, which were enacted to help ensure safety of our drug supply chain. It encourages diversion of drugs intended for Canada, a country that opposes the Trump Administration's proposal. And it poses liability issues for pharmacists who would be left dispensing medicine from an untraceable supply chain. 'This policy was pursued over the objections of everyone in the supply chain that today safely transits life saving medicine from the factory floor to the patient. Safety must always come first.' [...] Additional information about the complaint: The complaint alleges the Final Rule disregards key protections of the Federal Food, Drug, and Cosmetic Act, 21 U.S.C. § 301 et seq. (FDCA) that are designed to ensure patient safety. Section 804 of the FDCA, 21 U.S.C. § 384, authorizes HHS to permit both the importation of drugs by pharmacists and wholesalers for commercial distribution and the importation of drugs by individual patients. Section 804 is effective, however, only if the HHS Secretary certifies to Congress 'that the implementation of this section will—(A) pose no additional risk to the public's health and safety; and (B) result in a significant reduction in the cost of covered products [(i.e., certain prescription drugs)] to the American consumer.' § 384(l)(1). In this Final Rule, Secretary Azar has made conclusory statements as to safety and cost savings in his 'certification' with no supporting evidence and while punting the responsibility for safety and cost savings to state governments. The complaint, therefore, alleges the Secretary's certification is contrary to Section 804 and unsupported by



the record. In addition, there is no indication that the Final Rule will reduce costs to actual American patients. In the preamble to both the proposed and Final Rule, HHS has acknowledged that it cannot quantify the savings, if any, that would result from its rule, even classifying it as “not economically significant” for purposes of review by the Office of Management and Budget. Indeed, in the budget document released with the rule, the cost savings chart was left blank, suggesting cost savings could not be calculated. Furthermore, aspects of the Final Rule are contrary to the FDCA, violate manufacturers’ First Amendment rights and raise serious questions under the Fifth Amendment Takings Clause. As such, PhRMA, PSM and CAHC are asking the Court to hold unlawful, set aside and permanently enjoin implementation of the Certification and Final Rule.”

[PhRMA press release, [11/23/20](#)]

## **2019: PSM WAS EXPOSED FOR BUYING OFF LAW ENFORCEMENT OFFICERS’ OPPOSITION TO DRUG IMPORTATION SCHEMES.**

### **2019: PSM funded a \$900,000 TV ad blitz in Washington, D.C., by the National Sheriffs’ Association opposing plans to import prescription drugs from other countries.**

“Grim-faced sheriffs peered from Washington D.C.-area television screens in hundreds of ads this summer, imploring the country’s leaders to reject proposals to import cheaper prescription drugs from other countries. Importing drugs would ‘put lives I’m sworn to protect at risk,’ Kentucky Sheriff Keith Cain declared from beneath the brim of a white cowboy hat in one of the spots. It, like the others, warned that deadly counterfeit medicines would slip through loose foreign safeguards and overwhelm law-enforcement agencies. The ads concluded by telling viewers they were paid for by the National Sheriffs’ Association, which represents 3,000-plus U.S. sheriffs. In reality, the ad blitz was secretly paid for by at least \$900,000 in grants from the Partnership for Safe Medicines, a nonprofit that’s been funded and operated by the pharmaceutical industry’s trade association. It was a lucrative arrangement for the financially strapped sheriffs’ group, which had been rejected by six banks last year as it sought to refinance its real estate assets to pay overdue bills, according to its internal records. The organization pocketed proceeds of at least \$125,000, according to internal emails obtained through more than a dozen public records requests.”

[Bloomberg, [10/23/19](#)]

### **By 2019, PSM was the largest grant-provider to the National Sheriffs’ Association.**

By 2019, PSM was the largest grant-provider to the National Sheriffs’ Association.

“In recent years, the National Sheriffs’ Association (NSA) has struggled with its finances. In 2018, it sold \$1.8 million in investments to pay off debt and overdue staff salaries, internal documents show. It turned, with increasing success, to trying to win grants from corporations and other nonprofits, such as the Partnership for Safe Medicines. By 2019, the PhRMA-backed nonprofit had become the sheriffs’ biggest grant-provider. An internal financial document from April shows that the partnership had provided \$908,926 to the sheriffs’ group in the previous six months — almost half the \$1.9 million in grants that the law-enforcement group received in that period. In a June email exchange, a leader of the sheriffs’ group told a member that the ad campaign against drug importation was an important moneymaker that would be used to pay staff salaries and operational expenses. ‘NSA has received a grant from the Partnership for Safe Medicines for this NSA initiative that covers ALL the ad buys and that earns NSA \$125,000 over about the next 3 months,’ wrote Tim Woods, the group’s deputy executive director.”

[Bloomberg, [10/23/19](#)]

- **2018: PSM gave \$910,000 to the National Sheriffs Association.**  
[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]
- **2018: PSM gave \$118,000 to the National Association of Drug Diversion.**  
[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]
- **2018: PSM gave \$15,500 to the National Fraternal Order of Police Foundation.**  
[Partnership for Safe Medicines, IRS Form 990, [11/13/19](#)]

### **Sven Bergmann wrote an op-ed and testimony for a Colorado sheriff opposing drug importation.**

“Sheriff Justin Smith of Larimer County, Colorado, has also opposed drug imports — with an assist from the Partnership for Safe Medicines. Smith signed his name to an op-ed in The Coloradoan newspaper in March that criticized drug importation, and he signed testimony opposing a Colorado importation proposal for state lawmakers in April. Drafts of both the op-ed and the testimony were supplied to Smith by Sven Bergmann, a consultant working with the nonprofit, internal emails show. ‘We tried to capture your points and they flowed nicely into the piece,’ Bergmann wrote in an email to Smith. Bergmann didn’t respond to emails and phone messages seeking comment.”

[Bloomberg, [10/23/19](#)]

### **Bergmann ghost wrote an article for a retired police commander who now believes that Bergmann “was working not for public safety, but the pharmaceutical industry.”**

“One retired cop who was recruited into the anti-importation effort says he feels bitter about the experience. Shortly after Tim Hampton retired as a commander from the Phoenix police department in 2017, he says he got a call from Sven Bergmann, the Partnership for Safe Medicines’ consultant. They discussed the opioid epidemic, particularly how the synthetic painkiller fentanyl has harmed countless U.S. communities. (‘We saw it nonstop, it was everywhere,’ Hampton recalled. ‘People were dropping like flies.’) Eventually, Hampton says, Bergmann sent him a ghost-written article and asked if he’d put his name on it. The article was mostly about the fentanyl crisis, but it took some jabs at drug-importation proposals. It cited the Freeh report and suggested that nationwide drug importation ‘could flood the Grand Canyon State’ with fentanyl. Hampton didn’t know much about drug importation, but took Bergman’s word for it. Now, he said, he realizes that Bergmann lured him in with the fentanyl issue. ‘That’s where they put the hook in.’ Hampton agreed to put his name on the article, and it ran in a number of small Arizona newspapers that touted his law enforcement credentials. One headline blared: ‘Fentanyl is killing Arizonans, is Congress OK with that?’ Now, Hampton said, he knows that importing drugs through FDA-approved pathways won’t lead to a new scourge of fentanyl. And he thinks Bergmann was working not for public safety, but the pharmaceutical industry. ‘I should have done some more homework,’ Hampton said. ‘You can’t trust these guys in the pharma industry as far as you can throw them.’”

[Bloomberg, [10/23/19](#)]

## **PARTNERSHIP TO IMPROVE PATIENT CARE**

Website: <http://www.pipcpatients.org/>

### **Financials**

*Because the Partnership to Improve Patient Care isn’t a formal non-profit organization, they don’t file tax returns like the other groups. Therefore, we don’t have the same kind of insight into their financial situation the way we do into other groups in this report.*

### **THE PARTNERSHIP TO IMPROVE PATIENT CARE IS A PROJECT OF A LOBBYING FIRM, AND ITS LEADERS REFUSE TO SAY HOW MUCH FUNDING COMES FROM PHARMACEUTICAL COMPANIES.**

**“Unlike most groups that say they represent patients, PIPC is neither a non-profit nor a separate legal entity from the lobbying firm.”**

“Sara van Geertruyden, PIPC’s executive director, is also a partner in Thorn Run Partners, a lobbying and public affairs firm that counts PIPC and many drug companies as clients and hires other firms to lobby on comparative effectiveness research. Unlike most groups that say they represent patients, PIPC is neither a non-profit nor a separate legal entity from the lobbying firm.”

[USA Today, [7/11/16](#)]

**Wall Street Journal: PIPC “was founded by the drug industry’s principal lobby in Washington, the Pharmaceutical Research and Manufacturers of America.”**

“Schrader and fellow House Democrats Allyson Schwartz of Pennsylvania and Ron Kind of Wisconsin were joined in their announcement by a pharmaceutical industry-funded advocacy group, the Partnership to Improve Patient Care. The group was founded by the drug industry’s principal lobby in Washington, the Pharmaceutical Research and Manufacturers of America.”  
[Wall Street Journal, [5/19/09](#)]

- **PIPC “was formed by the drug industry in November 2008 to lobby against binding government effectiveness**

“The Partnership to Improve Patient Care, for example, headed by former congressman Tony Coelho (D-Calif.), was formed by the drug industry in November 2008 to lobby against binding government effectiveness studies, which could be used to determine what insurance companies must cover.”  
[Washington Post, 1/7/10]

**PIPC’s steering committee includes PhRMA and BIO.**

“Steering Committee Members [...] BIO is the world’s largest trade association representing biotechnology companies, academic institutions, state biotechnology centers and related organizations across the United States and in more than 30 other nations. BIO members are involved in the research and development of innovative healthcare, agricultural, industrial and environmental biotechnology products. BIO also produces the BIO International Convention, the world’s largest gathering of the biotechnology industry, along with industry-leading investor and partnering meetings held around the world. [...] The Pharmaceutical Research and Manufacturers of America (PhRMA) represents the country’s leading biopharmaceutical researchers and biotechnology companies. PhRMA’s mission is to conduct effective advocacy for public policies that encourage discovery of important new medicines for patients by pharmaceutical and biotechnology research companies. Their members are committed to finding tomorrow’s cures and treatments for some of the most serious diseases such as Cancer, Alzheimer’s Disease, Cystic Fibrosis and Parkinson’s.”  
[Partnership to Improve Patient Care, accessed [12/17/20](#)]

- **2018: BIO gave at least \$140,000 to lobbying firm Thorn Run Partners for “general support.”**

According to their IRS Form 990 tax filings, in 2018, BIO gave \$140,000 to Thorn Run Partners, characterized as “general support.”  
[BIO, IRS Form 990, [11/15/19](#)]

**PIPC is backed by drug companies, biotechnology firms, and medical device makers.**

“In addition to trade groups for drug makers, biotechnology firms and medical-device companies, his Partnership to Improve Patient Care also includes in its steering committee the Easter Seals, the National Alliance for Hispanic Health and the National Alliance on Mental Illness. Mr. Coelho says he recruited about 120 other groups to sign on in support of the cause.”  
[New York Times, [9/11/09](#)]

**PIPC is funded by “the powerful pharmaceutical and biotech industry lobbies” and includes “some minority and women’s groups, mostly as nonpaying members.”**

“It’s a big concern for drug and biotech companies too since they could lose out if a treatment they’ve developed is found to be less effective than a competitor’s. But a drug company’s bottom line isn’t likely to draw as much public sympathy as a disabled person’s needs. That makes Coelho a good face for the Partnership to Improve Patient Care, which formed as the issue began to surface last fall and is funded by groups including the Easter Seals, Friends of Cancer Research, the Alliance for Aging Research, the Advanced Medical Technology Association and the powerful pharmaceutical and biotech industry lobbies. The partnership also includes some minority and women’s groups, mostly as nonpaying members. These groups say they can be underrepresented in studies of medical procedures and want to ensure that doesn’t happen with the stimulus money.”  
[Associated Press, 3/12/09]

**PIPC Chairman Tony Coelho refused to say how much the drug industry funded PIPC.**

“Since 2010, former Rep. Tony Coelho, D-Calif., has led the Partnership to Improve Patient Care, which has been

a leading critic of comparative effectiveness research. Its work is paid for in part by the pharmaceutical industry - though he won't say how much - and other patient groups."  
[USA Today, 5/31/16]

- **“Coelho wouldn't say how much of PIPC's money comes from drugmakers.”**

“Coelho wouldn't say how much of PIPC's money comes from drugmakers and said that no one in his 50 years in Washington has questioned his integrity. He resigned from Congress in 1989 as he faced expected congressional and Justice Department investigations into his failure to report junk bond purchases with loans from a friend who was a savings-and-loan official.”

[USA Today, [7/11/16](#)]

**PIPC's executive director said she advocates for patients and denied that PIPC has tried to conceal their ties to the drug industry.**

“Sara van Geertruyden, PIPC's executive director, is also a Thorn Run public relations partner. She said the group advocates for patients and denied that PIPC is a proxy for pharmaceutical-industry interests or that it has concealed its industry ties.”

[Reuters, [9/11/20](#)]

- **PhRMA refused to say if they were directing proxies like PIPC.**

“Nicole Longo, spokeswoman for the PhRMA trade group, did not answer detailed questions from Reuters about whether it was directing a campaign through proxies to undermine ICER (Institute for Clinical and Economic Review).”

[Reuters, [9/11/20](#)]

**PIPC IS AN “ASTROTURF” GROUP THAT “ADVOCATES FOR INDUSTRY”**

**“It is clear that the PIPC advocates for industry.”**

“Formed in November 2008, the group says it advocates for CER (Clinical and Economic Research) centered on patient and provider needs and represents patients, physicians, researchers and other groups. With members like the Pharmaceutical Research and Manufacturers of America (PhRMA), the Advanced Medical Technologies Association (AdvaMed) and the Biotechnology Industry Organization, however, one House aide said it is clear that the PIPC advocates for industry.”

[Congressional Quarterly HealthBeat, 3/13/09]

**“Groups including PIPC are parroting the industry arguments while claiming to represent patients - without disclosing their industry ties, according to a Reuters review of the groups' press releases, blogs, webcasts and letters.”**

[Reuters, [9/11/20](#)]

**PIPC is “the most notable” among astroturf groups “when it comes to drug prices.”**

“While many industries fund purported grass-roots groups in what's known as astroturfing, critics say it's especially troubling at a time when research shows Americans want Congress and the White House to do something about high drug prices. The most notable of these when it comes to drug prices is the Partnership to Improve Patient Care, which is chaired by former representative Tony Coelho, D-Calif. PIPC's steering committee includes PhRMA, Easter Seals and several industry groups.”

[USA Today, [7/11/16](#)]

**2019: PIPC was “not pushing a specific strategy to lower drug costs overall.”**

“While the Partnership to Improve Patient Care--whose members include Pharmaceutical Research and Manufacturers of America and Biotechnology Innovation Organization -- is taking aim at ICER and insurers, it is not pushing a specific strategy to lower drug costs overall. PhRMA also posted its own blog this week calling for changes to ICER's value assessment framework, including moving away from the QALY (Quality Adjusted Life Year) metric. Sara van Geertruyden, executive director of the coalition, said tackling drug costs is a significant

issue, but not the group’s current focus. ‘The issue we are tackling today is making sure as we move down that path, that we don’t do it in a manner that discriminates against patients,’ van Geertruyden said.”  
[Inside Health Policy, 6/28/19]

## **PIPC’S LEADERSHIP HAS RECEIVED FUNDING FROM BIO. PHARMA AND BIO HAVE SEATS ON PIPC’S “STEERING COMMITTEE.**

### **PhRMA “established and is financing” PIPC.**

“Be very, very suspicious of new interest groups with noble-sounding names that are run by uber-lobbyist Tony Coelho. A case in point is the organization that calls itself the ‘Partnership to Improve Patient Care.’ As the Wall Street Journal explains, it’s a coalition that the Pharmaceutical Manufacturers of America (PhRMA) established and is financing, with the ostensible goal of making sure research into the effectiveness of new treatments focuses on the best interests of the patients. The real goal? To give the drug industry more control over that research, lest better information curb the use of unnecessary medical treatments and, in the process, diminish [sic] industry profits.” [Jonathan Cohn, The New Republic, [5/19/09](#)]

### **2018: BIO gave at least \$140,000 to Thorn Run Partners for “general support.”**

According to their IRS Form 990 tax filings, in 2018 BIO gave \$140,000 to Thorn Run Partners, characterized as “general support.”

[BIO, IRS Form 990, [11/15/19](#)]

### **PIPC is backed by drug companies, biotechnology firms, and medical device makers.**

“In addition to trade groups for drug makers, biotechnology firms and medical-device companies, his Partnership to Improve Patient Care also includes in its steering committee the Easter Seals, the National Alliance for Hispanic Health and the National Alliance on Mental Illness. Mr. Coelho says he recruited about 120 other groups to sign on in support of the cause.”

[New York Times, [9/11/09](#)]

### **PIPC’s steering committee includes PhRMA and BIO.**

[Partnership to Improve Patient Care, accessed [12/17/20](#)]

## **Leadership and Lobbying**

*PIPC is effectively a project of public affairs firm Thorn Run Partners, fronted by former Congressman Tony Coelho. As it is not a nonprofit organization, it doesn’t provide publicly available tax filings, and therefore we have no insight into its executive compensation practices.*

### **“Unlike most groups that say they represent patients, PIPC is neither a nonprofit nor a separate legal entity from the lobbying firm.”**

“Sara van Geertruyden, PIPC’s executive director, is also a partner in Thorn Run Partners, a lobbying and public affairs firm that counts PIPC and many drug companies as clients and hires other firms to lobby on comparative effectiveness research. Unlike most groups that say they represent patients, PIPC is neither a non-profit nor a separate legal entity from the lobbying firm.”

[USA Today, [7/11/16](#)]

### **PIPC is led by employees of Thorn Run Partners, a DC lobbying and PR firm “that counts nearly a dozen drugmakers as clients.”**

“Two such groups – the Partnership to Improve Patient Care (PIPC) and Value our Health – are led by employees of Thorn Run Partners, a Washington-based lobbying and public relations firm that counts nearly a dozen drugmakers as clients. PIPC denied it is part of a larger industry-financed proxy campaign to undermine ICER’s impact. Thorn Run declined to comment, and Value Our Health did not respond to inquiries.”

[Reuters, [9/11/20](#)]

**Thorn Run Partners' clients included Patient Services Inc., a company that had close ties with Turing Pharmaceuticals and disgraced CEO Martin Shkreli.**

"Thorn Run's lobbying clients also include the drug company-funded patient group Patient Services Inc., according to the Center for Responsive Politics. PSI's close relationship with Turing Pharmaceuticals, best known for its indicted former CEO Martin Shkreli and massive price increases last year, was detailed in a May story by Bloomberg."

[USA Today, [7/11/16](#)]

**TONY COELHO, PIPC CHAIRMAN / DC INSIDER EXTRAORDINAIRE**

**"Drug and device makers have enlisted support from patient and medical groups to form the Partnership to Improve Patient Care, which has signed up former Congressman Tony Coelho to carry the banner."**

"Drug and device makers have enlisted support from patient and medical groups to form the Partnership to Improve Patient Care, which has signed up former Congressman Tony Coelho to carry the banner for ensuring that CE studies are well-designed, promote continued medical innovation, and protect patient access to 'advanced treatment options.'"

[Pharmaceutical Executive, May 2009]

- **2016: Coelho claimed that Ted Kennedy asked him to lead PIPC.**

"Coelho said the late Sen. Ted Kennedy, D-Mass., asked him to chair the group because of his political background, his disability and because he wouldn't let anyone 'unduly influence' him in efforts to get patients' voices heard." [USA Today, [5/31/16](#)]

- **Coelho said he "decided to run the industry-backed" PIPC "because of his own concerns, not those of the Pharmaceutical Research and Manufacturers of America," while acknowledging that "PhRMA agrees with me."**

"For his part, Mr. Coelho, the former congressman, said he had decided to run the industry-backed coalition because of his own concerns, not those of the Pharmaceutical Research and Manufacturers of America. 'Just because PhRMA agrees with me, that means my views don't have any value? That belittles me,' he said in an interview."

[New York Times, [9/11/09](#)]

**New York Times: "Drug lobbyists have enlisted the help of Tony Coelho, a former Democratic congressman who cites his battle with epilepsy to make their case."**

"The top lobbyists for every major sector of the health care industry publicly insist they are squarely behind the Obama administration's health care reform. But as the debate gets down to the details, the lines dividing friend from foe are getting blurry. Each industry group is also working quietly to scuttle or reshape some element of the administration's proposals that might hurt profits — usually some measure aimed at cost control. The drug industry, for example, struck a deal with the Obama administration and is now waging a major advertising campaign to help push the health care overhaul. But the drug makers also abhor one of its cost-cutting components: a government initiative to study the effectiveness of treatments that the companies fear could mean lower payments for certain drugs. So drug lobbyists have enlisted the help of Tony Coelho, a former Democratic congressman who cites his battle with epilepsy to make their case. 'I don't want some government folks making a decision because of a cookie-cutter approach to health care saying, 'We will only approve the three most common drugs,' so then my drugs are not approved, and I am going to have seizures,' said Mr. Coelho, the chairman of an industry-backed group called the Partnership to Improve Patient Care. 'And it is going to cost people a lot more money because I am going to be in an emergency room.'"

[New York Times, [9/11/09](#)]

- **Democratic Congressman Kurt Schrader said that Coelho is an effective advocate because of his personal medical history.**

“Mr. Coelho, who is not a registered lobbyist, says he does not press policy makers directly about the issue but advises lobbyists for his coalition’s members. He also speaks publicly about the subject in radio interviews and elsewhere. In May, he joined a conference call with three Democratic lawmakers who were introducing legislation for the kind of independent review his group proposed. A similar amendment to the House’s health care bills is now pending, and the Senate Finance Committee has incorporated the same model in its draft legislation as well. Representative Kurt Schrader, an Oregon Democrat who was on the conference call, said Mr. Coelho’s medical history lent a special credibility to the cause. ‘It helps him say to patients and consumers that this is about them,’ Mr. Schrader said, ‘and not about advocating the interest of any one provider or industry.’”

[*New York Times*, [9/11/09](#)]

- **Associated Press: “A drug company’s bottom line isn’t likely to draw as much public sympathy as a disabled person’s needs. That makes Coelho a good face for the Partnership to Improve Patient Care.”**

“It’s a big concern for drug and biotech companies too since they could lose out if a treatment they’ve developed is found to be less effective than a competitor’s. But a drug company’s bottom line isn’t likely to draw as much public sympathy as a disabled person’s needs. That makes Coelho a good face for the Partnership to Improve Patient Care, which formed as the issue began to surface last fall and is funded by groups including the Easter Seals, Friends of Cancer Research, the Alliance for Aging Research, the Advanced Medical Technology Association and the powerful pharmaceutical and biotech industry lobbies. The partnership also includes some minority and women’s groups, mostly as nonpaying members. These groups say they can be underrepresented in studies of medical procedures and want to ensure that doesn’t happen with the stimulus money.”

[*Associated Press*, [3/12/09](#)]

**Jonathan Chait: Coelho “is an innovator at pushing the boundary between politics, special interests, and the mutual profit thereof.”**

“In the course of following the health care debate, in which millions upon millions of dollars have been spent to persuade Democrats to tailor their legislation to the interests of various components of the health care industry, one thought may have occurred to you: Is Tony Coelho making any money off of this? Coelho, if you don’t know, is an innovator at pushing the boundary between politics, special interests, and the mutual profit thereof. If these massive sums of health care influence money had passed through town without Coelho getting a taste, it would be, in a way, almost crushing -- like learning that the Victoria’s Secret models held a sex party in the Clinton living room, but Bill spent the whole evening reading a book in his upstairs study.”

[Jonathan Chait, *The New Republic*, [1/6/10](#)]

- **The New Republic: “Be very, very suspicious of new interest groups with noble-sounding names that are run by uber-lobbyist Tony Coelho.”**

“For those of you following the health reform debate, here are three good pointers: 1) Be suspicious of new interest groups with noble-sounding names. 2) Be very suspicious of uber-lobbyist Tony Coelho. 3) Be very, very suspicious of new interest groups with noble-sounding names that are run by uber-lobbyist Tony Coelho.”

[Jonathan Cohn, *The New Republic*, [5/19/09](#)]

- **The New Republic: “If the drug industry’s financing” of PIPC “doesn’t give you pause,” Tony Coelho’s “place at the head of it should.”**

“As for Coelho, the former Democratic congressman, he’s a longtime advocate for people with disabilities, which is admirable enough. But he also has a reputation--well-deserved, as far as know--as one of Washington’s slickest operators. If the drug industry’s financing of this effort doesn’t give you pause, his place at the head of it should.”

[Jonathan Cohn, *The New Republic*, [5/19/09](#)]

**SARA VAN GEERTRUYDEN (NEE, TRAIGLE), PIPC EXECUTIVE DIRECTOR, PARTNER AT THORN RUN PARTNERS.**

**Sara Van Geertruyden is executive director of PIPC.**

“Executive Director Sara van Geertruyden counsels and manages PIPC, a diverse group of healthcare organizations representing patients, healthcare providers, researchers and innovators, and other groups to promote comparative effectiveness research that supports patient access, informed healthcare decision-making and continued medical progress. In this role, she is responsible for assuring that the voice of PIPC’s members is heard by those implementing CER programs, including PCORI (Patient Centered Outcomes Research Institute). She came to PIPC as a healthcare and welfare policy expert with 20 years of experience. Previously, she worked for former Senator John Breaux from 1996-2003. In 2003, she joined the healthcare policy group at Patton Boggs LLP, and in 2011 she joined Thorn Run Partners. She received a BA from Wake Forest University and a JD from Catholic University.”

[Partnership to Improve Patient Care, accessed [12/17/20](#)]

- **Van Geertruyden is a partner at Thorn Run Partners.**

“Sara Traigle van Geertruyden joined Thorn Run Partners in January 2011 as a healthcare and welfare policy expert with 14 years of experience. Sara began her career on Capitol Hill, working for former Senator John Breaux (D-LA) from 1996-2003, first as a projects assistant handling Congressional appropriations and advising constituents on the federal grant process, and ultimately spending over three years as a legislative assistant overseeing Senate Finance Committee issues for health and welfare.”

[Thorn Run Partners, accessed [12/17/20](#)]

- **2003-2010: Van Geertruyden was an associate at Squire Patton Boggs.**

[Sara Van Geertruyden LinkedIn profile, accessed [12/17/20](#)]

- **Van Geertruyden represented pharmaceutical companies when she worked for Patton Boggs.**

“In 2003, she joined the law firm Patton Boggs where she practiced in the public policy group handling regulatory and legislative issues related to health care, welfare, and appropriations for clients. Sara has represented clients including hospital systems, pharmaceutical companies, health care provider associations and coalitions. Her scope of work in health policy combines expertise in working with all of the major health care agencies, including the Medicaid Payment Advisory Commission (MedPAC), the Centers for Medicare and Medicaid Services, the Administration on Aging, and the Food and Drug Administration. Sara has also been closely monitoring and engaging the newly created Medicaid and CHIP Payment and Access Commission (MACPAC), the Federal Coordinated Health Care Office, and the Center for Medicare and Medicaid Innovation.”

[Thorn Run Partners, accessed [12/17/20](#)]

**At Patton Boggs, Van Geertruyden lobbied for major pharmaceutical companies.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/17/20](#)]

Registrant Name	Client Name	Filing Type	Amount Reported	Date Posted	Filing Year
Squire Patton Boggs	ABBOTT LABORATORIES	MID-YEAR REPORT	\$120,000.00	8/16/04	2004
Squire Patton Boggs	ABBOTT LABORATORIES	YEAR-END REPORT	\$240,000.00	2/14/05	2004
Squire Patton Boggs	AMYLIN PHARMACEUTICALS INC	MID-YEAR REPORT	\$60,000.00	8/9/06	2006
Squire Patton Boggs	BOSTON SCIENTIFIC CORP	MID-YEAR REPORT	\$40,000.00	8/16/04	2004



Squire Patton Boggs	BOSTON SCIENTIFIC CORP	YEAR-END REPORT	\$60,000.00	2/14/05	2004
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	MID-YEAR REPORT	\$100,000.00	8/14/03	2003
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	YEAR-END REPORT	\$120,000.00	2/17/04	2003
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	MID-YEAR REPORT	\$200,000.00	8/16/04	2004
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	YEAR-END REPORT	\$200,000.00	2/14/05	2004
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	YEAR-END REPORT	\$240,000.00	2/7/07	2006
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	MID-YEAR REPORT	\$360,000.00	8/6/07	2007
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	YEAR-END AMENDMENT	\$200,000.00	7/15/08	2004
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	FIRST QUARTER REPORT	\$80,000.00	4/14/09	2009
Squire Patton Boggs	BRISTOL-MYERS SQUIBB	SECOND QUARTER REPORT	\$80,000.00	7/18/10	2010
Squire Patton Boggs	CUBIST PHARMACEUTICALS INC	FOURTH QUARTER REPORT	\$10,000.00	1/19/10	2009
Squire Patton Boggs	CUBIST PHARMACEUTICALS INC	FOURTH QUARTER AMENDMENT	\$10,000.00	1/26/10	2009
Squire Patton Boggs	EISAI INC	REGISTRATION		8/9/07	2007
Squire Patton Boggs	EISAI INC	YEAR-END REPORT	\$120,000.00	2/7/08	2007
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	YEAR-END REPORT	\$360,000.00	2/17/04	2003
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	MID-YEAR REPORT	\$540,000.00	8/16/04	2004
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	YEAR-END REPORT	\$500,000.00	2/14/05	2004
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	MID-YEAR REPORT	\$760,000.00	8/16/05	2005
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	YEAR-END REPORT	\$760,000.00	2/10/06	2005
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	MID-YEAR REPORT	\$160,000.00	8/4/06	2006
Squire Patton Boggs	HOFFMANN-LA ROCHE INC	YEAR-END REPORT	\$160,000.00	2/9/07	2006
Squire Patton Boggs	KOS PHARMACEUTICALS INC	REGISTRATION		3/17/06	2006
Squire Patton Boggs	KOS PHARMACEUTICALS INC	MID-YEAR REPORT	\$360,000.00	8/9/06	2006
Squire Patton Boggs	PFIZER INC	MID-YEAR REPORT	\$160,000.00	8/16/05	2005
Squire Patton Boggs	PFIZER INC	YEAR-END REPORT	\$120,000.00	2/10/06	2005
Squire Patton Boggs	PFIZER INC	MID-YEAR REPORT	\$140,000.00	8/8/06	2006
Squire Patton Boggs	PFIZER INC	YEAR-END REPORT	\$120,000.00	2/11/07	2006
Squire Patton Boggs	PFIZER INC	MID-YEAR REPORT	\$120,000.00	8/13/07	2007

Squire Patton Boggs	PFIZER INC	YEAR-END REPORT	\$140,000.00	2/11/08	2007
Squire Patton Boggs	PFIZER INC	YEAR-END REPORT	\$140,000.00	2/14/08	2007
Squire Patton Boggs	PFIZER INC	SECOND QUARTER REPORT	\$50,000.00	7/20/08	2008
Squire Patton Boggs	PFIZER INC	SECOND QUARTER REPORT	\$50,000.00	7/19/10	2010
<b>TOTAL</b>			\$6,880,000.00		

[U.S. Senate Lobbying Disclosure Database, accessed [2/22/21](#)]

### Van Geertruyden (nee, Traigle) previously lobbied for the Treatment Effectiveness Now (TEN) Project

[Squire Patton Boggs, Lobbying Registration, [12/15/04](#); Lobbying Disclosure End of Year Report, [2/14/05](#); Mid-Year Report, [8/16/05](#)]

- **Treatment Effectiveness Now Project lobbied on “access to psychiatric medications.”**  
[Squire Patton Boggs, Lobbying Disclosure End of Year Report, [2/14/05](#)]
- **The TEN Project was affiliated with Georgetown University and was “dedicated to ensuring access” to treatment for patients with “co-occurring physical and mental conditions.”**  
“Treatment Effectiveness Now (the TEN Project) is a private, non-profit policy action organization, affiliated with Georgetown University Department of Psychiatry, dedicated to ensuring access to effective health care for patients with co-occurring physical and mental health conditions.”  
[Treatment Effectiveness Now Project, via Internet Archive, [7/25/06](#)]
- **The TEN Project identified “benefit design and reimbursement” as key barriers to effective treatment.**  
“The TEN Project was created to respond to the crisis in access to services as it impacts those persons who have the greatest illness-related morbidity and mortality: persons who have co-occurring psychiatric and physical health disorders. Morbidity and mortality associated with the co-occurrence of physical and mental disorders is greater than the morbidity and mortality of each disorder separately. Yet there remain significant gaps between what we know to be effective treatment for these patients and access to those services. The barriers to care are many and include benefit design and reimbursement as well as long standing stigma relating to mental illness and its treatment. Over the next two years, pending fiscal, legislative and policy initiatives in state and federal governments will determine whether or not citizens who have comorbid illnesses will gain or retain access to life-saving and recovery-enhancing treatments.”  
[Treatment Effectiveness Now Project, via Internet Archive, [7/25/06](#)]
- **Treatment Effectiveness Now Project was funded in part by PhRMA.**  
According to PhRMA’s IRS Form 990 tax filings, PhRMA gave TEN Project \$10,000, characterized as general contribution in 2010. [PhRMA, IRS Form 990, [11/11/11](#)]
- **TEN Project’s founder was Dr. Carol Alter, who previously worked for Bristol-Myers Squibb.**  
“Dr. Alter has over 25 years of experience in diverse settings including clinical practice, research, administration, healthcare delivery, and the pharmaceutical industry, with a focus on psychiatric care of patients with medical illness. She is the author of numerous peer-reviewed manuscripts, monographs, and book chapters related to psychosomatic medicine and access to psychiatric care. As Director of Psychosomatic Medicine, Policy and Community Outreach and Associate Professor in the Georgetown University Department of Psychiatry, she led a model Collaborative Care program in the Montgomery Cares safety-net clinics, which is now available to over 20,000 Montgomery Cares patients. She also authored a report, funded by The Substance Abuse and Mental Health Services Administration (SAMHSA), which examined the financial issues related to implementation of Collaborative Care for the District of Columbia, served as Medical Director for Policy & Advocacy at Bristol-Myers Squibb Company, and founded a policy-

action organization, Treatment Effectiveness Now, focused on issues of access to care for patients with co-occurring mental and physical disorders.”

[Mindoula press release, [9/20/16](#)]

- **1997-2001: Alter was “medical director” at Bristol-Myers Squibb.**

[Carol Alter LinkedIn profile, accessed [12/17/20](#)]

- **2003-2014: Alter was “scientific and medical advisor” at FoxKiser.**

[Carol Alter LinkedIn profile, accessed [12/17/20](#)]

**FoxKiser provides strategic advice and counsel to pharmaceutical and biotechnology companies.**

“For more than 25 years, professionals at FoxKiser have provided strategic advice and counsel to pharmaceutical and biotechnology companies. During that time, the firm has been involved in more than 100 product approval and life cycle management projects, through which it has earned a reputation for creativity and success. During the past five years FoxKiser has built on its long and successful track record in counseling companies by moving into development and company formation whereby FoxKiser—with its subsidiaries, affiliates, and third parties—is identifying, financing and managing cutting-edge innovation.”

[FoxKiser, accessed [12/17/20](#)]

## **THAYER SURETTE ROBERTS, PIPC DEPUTY DIRECTOR, VICE PRESIDENT AT THORN RUN PARTNERS**

**Thayer Surette Roberts is deputy director of PIPC.**

“Deputy Director Thayer Surette Roberts joined PIPC as its deputy director in March of 2019. In this role she works with PIPC’s diverse membership of patients, healthcare providers, researchers, and other groups to ensure that patient centrality is at the center of our nation’s health care system. Prior to joining PIPC, Thayer served as the Senior Director of Alliance Development at Research!America where she worked closely with the organization’s membership of patient advocacy organizations, academia, scientific societies, and industry to convene appropriate parties and to develop programs to advocate for a policy and regulatory climate that supports medical innovation. Thayer received a BA from Boston College.”

[Partnership to Improve Patient Care, accessed [12/17/20](#)]

- **Roberts is a senior Vice President at Thorn Run Partners.**

“Thayer Surette Roberts Senior Vice President [...] Thayer Surette Roberts joined Thorn Run Partners in March of 2019 bringing a decade of experience in advocacy, coalition building, and strategic partnerships. Ms. Roberts provides a deep expertise in convening stakeholders with shared areas of interest and developing impactful third-party engagement strategies to move the needle on clients’ policy priorities. Ms. Roberts brings with her a comprehensive understanding of health policy, as well as a broad network of relationships within the patient advocacy and health policy communities. She has a keen knowledge of the policy priorities of all stakeholders in the innovation ecosystem, having worked closely with academia, patient groups, and industry.”

[Thorn Run Partners, accessed [12/17/20](#)]

- **2015-2019: Roberts worked for Research!America.**

“Research!America. Total Duration: three yrs, six mos. Title: Senior Director of Alliance Development and Membership. Dates Employed: Jan. 2019 – March 2019. Employment Duration: three mos. Location: Washington D.C. Metro Area. Establish and grow relationships with pharmaceutical companies, patient groups, research universities and others in the innovation ecosystem to grow the Research! America alliance and form partnerships and opportunities for collaboration. Manage partner engagement and revenue generation for Research! America’s signature events and create programs to highlight the importance of federal funding for medical research and innovation friendly policies. Title: Director of Alliance Development and Membership. Dates Employed: Oct 2015 – Jan 2019. Employment Duration: three yrs, four mos. Location: Washington D.C. Metro Area.” [Thayer Surette Roberts LinkedIn profile, accessed [12/17/20](#)]

- **Thorn Run Partners described Roberts' role at Research!America as working closely with members and partners to "develop programs to advocate for a policy and regulatory climate that supports medical innovation."**

"Prior to joining Thorn Run Partners, Ms. Roberts served as the Senior Director of Alliance Development for a nonprofit membership-based organization dedicated to championing medical research both in the public and private sector. In this role she worked closely with the organization's 400+ members and partners to convene appropriate parties and to develop programs to advocate for a policy and regulatory climate that supports medical innovation." [Thorn Run Partners, accessed [12/17/20](#)]

- **Research!America's founding board members included Raymond Sackler and Theodore Cooper, CEO of Upjohn Co.**

"Jan. 1989: Research!America officially launches with former Sen. Lowell Weicker as president, CEO and key spokesperson. Edwin C. "Jack" Whitehead, founder of the Whitehead Institute for Biomedical Research, is the founding board chair. Other founding Board members: Theodore Cooper, MD, chairman and CEO of Upjohn Co. and his associate Ed Greissing, vice president of government affairs; renowned medical research advocate Mary W. Lasker; Robert Dresing, president and CEO of the Cystic Fibrosis Foundation; former Speaker of the House Thomas O'Neill; Surgeon General C. Everett Koop, MD; Raymond Sackler, MD, president of the Raymond and Beverly Sackler Foundation, Inc.; Terry Lierman, president of Capitol Associates, Inc.; John Donnelly, VP of public affairs at The National Multiple Sclerosis Society and later VP of public affairs at Research!America; Carol Scheman, director of federal relations at the Association of American Universities; Virginia Weldon, VP for public policy at Monsanto; Willa Hsueh, MD, senior member of The Methodist Hospital Research Institute; Michael Goldberg, PhD, executive director of The American Society for Microbiology; former Utah Senate Minority Leader Patricia Jones; William R. Hendee, PhD, VP of science and technology for the American Medical Association; and William Anlyan, MD, chancellor of Duke University, who would later become chair of the Research!America Board of Directors." [Research!America, accessed [12/26/20](#)]

- **Research!America's founding financial supporters included PhRMA, and pharmaceutical companies Bristol-Myers Squibb, Johnson & Johnson, Merck & Co., Inc., Novartis International, and Pfizer Inc.** [Research!America, accessed [12/26/20](#)]

## PATIENTS RISING / PATIENTS RISING NOW

Website: <https://patientsrising.org/>

Website: <https://patientsrisingnow.org/>

### Patients Rising and Patients Rising Now are Astroturf groups for Big Pharma.

### PATIENTS RISING AND ITS AFFILIATE PATIENTS RISING NOW ARE "ASTROTURF" GROUPS.

#### ***Boston Globe: Patients Rising is a "front group" funded by the pharmaceutical industry.***

"The pharma industry and a variety of allies and front groups it funds are attempting to raise safety fears and argue the legislation would create a bonanza for trial lawyers, surefire ways to get conservatives to balk. One recent op-ed by an author affiliated with an industry-funded group called Patients Rising said closing the loophole could result in safety problems like the tragic thalidomide birth defects of the last century." [Boston Globe, [3/23/18](#)]

#### **Patients Rising and Alliance for Patient Access are "astroturf" groups without "formal affiliations with the pharmaceutical industry's largest trade organizations in Washington."**

"Alliance for Patient Access and Patients Rising do not have formal affiliations with the pharmaceutical industry's

largest trade organizations in Washington. Such groups are commonly called ‘Astroturf’ groups by critics who claim they are masquerading as grass-roots organizations.”  
[Washington Post, [1/22/19](#)]

### **HealthNewsReview.org referred to Patients Rising and Patients Rising Now as “astroturf” groups.**

“There’s nothing like a new Astroturf group to confuse the public. Astroturfers gather ordinary citizens from the grassroots to advocate for various causes while in reality shilling for the trade associations, PR firms, corporations, and political organizations that set them up. Now along comes a new patient advocacy organization, Patients Rising and its sister group, Patients Rising Now, which debuted in late summer shortly after the House of Representatives passed the 21st Century Cures Act. Recall that the Cures Act would weaken already weak standards for FDA approval of medical devices opening the door for potentially harmful products to get on the market.”

[HealthNewsReview.org, [2/10/16](#)]

### **Groups like Patients Rising and the Alliance for Patient Access deliberately make it difficult to understand their ties to the pharmaceutical industry.**

“The political war over prescription drug practices is spawning a frenzy of activity by outside lobbying groups, some with names that mask their ties to industry and one that has gone to great lengths to disguise its origins. The increase in advertising, advocacy and pressure tactics is aimed at thwarting some efforts to control drug costs proposed in the Democratic-controlled House, such as allowing Medicare to negotiate drug prices, as well as ideas pursued by the Trump administration to curb prices. The operations of these groups often dovetail with work by corporate lobbying shops. Most, but not all, disclose industry funding sources on their websites. Some of the more active groups are the Alliance for Patient Access and Patients Rising. Those names make it hard for people to understand their ties to industry, consumer advocates say. The Alliance for Patient Access has launched digital and radio advertisements in recent weeks opposing the Trump administration’s plans to cut Medicare reimbursement for drugs administered in hospitals and doctor’s offices. Patients Rising has a strong presence on social media.”

[Washington Post, [1/22/19](#)]

### **PATIENTS RISING ADVOCATES FOR MORE PHARMACEUTICALS, “NO MATTER WHAT THE PRICE.”**

#### **Patients Rising “makes clear it doesn’t buy the argument drug prices are too high.”**

“The group makes clear it doesn’t buy the argument drug prices are too high. A commentary on its website from The Tampa Tribune, ‘Price controls on drugs every bit as absurd as a nationwide salary cap for cancer patients,’ by Dr. Thomas Stossel, the American Cancer Society Professor of Medicine and a visiting scholar at the American Enterprise Institute, argues that instead of cost controls we need to make sure that financially-needy patients find their way to assistance programs to help pay for treatment,’ a remedy that might help patients but does nothing to put the brakes on the high underlying price. The group’s pushback against the high drug price argument aims largely at Dr. Peter Bach, the epidemiologist at New York City’s Memorial Sloan Kettering, who has spoken out about the high price of cancer drugs. Patients Rising doesn’t like Bach’s DrugAbacus that lets users evaluate the value of their cancer drugs on dimensions such as cost, side effects, and benefits. A post by Terry Wilcox for Vital Options International last summer notes, ‘Cancer patients don’t see value in economic terms,’ and advises readers: ‘Beware drug price calculators that give insurance companies and hospitals the ability to quantify a cancer patient’s life.’”

[HealthNewsReview.org, [2/10/16](#)]

- **Patients Rising’s principles include advocating for “timely access” to medical treatments, but does not include affordability of those treatments.**

“Our Principles. We stand up for patients’ rights and dignity. We advocate for timely access to the treatments patients need. We engage with patients, medical professionals and policy experts to have solution-oriented discussions and to keep healthcare transparent. We give a platform to patients and advocates to raise awareness of chronic and life-threatening illnesses. Our goal is to create a lasting impact on the future of healthcare in the United States. We envision a healthcare system where no

patient is deprived of access to the treatments they need when they need them.”  
[Patients Rising, accessed [12/8/20](#)]

**Patients Rising is “advocating for more drugs no matter what the price, no matter how effective or ineffective they happen to be.”**

“It’s pretty clear after dissecting the activities of this new patient advocacy group that it’s advocating for more drugs no matter what the price, no matter how effective or ineffective they happen to be. Is the group’s agenda the same as that of patients?”

[HealthNewsReview.org, [2/10/16](#)]

**PATIENTS RISING WAS CREATED TO PUSH BACK ON THE IDEA THAT DRUGS WERE UNAFFORDABLE.**

**Patients Rising was created to “push against the developing meme of unaffordable drugs” and coincided with the timing of an advertising campaign by PhRMA.**

“The group, co-founded by Jonathan Wilcox, a corporate communications and public relations consultant and adjunct professor at USC’s Annenberg School of Communications and his wife Terry, a producer of oncology videos, aims to accomplish all that through workshops, webcasts at conferences, social media, and sharing patient stories, a staple of these groups. Its goals are in sync with the zeitgeist of the medical marketplace — Joe Biden’s Moonshot, the Cures Act, the FDA’s eagerness to push more drugs into the hands of patients. Astroturf groups, of course, are nothing new in the commerce of medicine, but the emergence of a new patient advocacy group to push against the developing meme of unaffordable drugs couldn’t have come at a better time. The Pharmaceutical Research and Manufacturers of America (PhRMA) announced the other day plans for a several million dollar advertising campaign aimed at federal and state lawmakers, policy analysts, and other political influencers, according to the Wall Street Journal. The aim is to polish up the industry’s image in light of rising drug prices and promote the industry’s role in developing new drugs and advancing medical science. The ads will feature patients who’ve been helped by new medicines, putting the patient story front and center in any discussion of the drug industry and drug costs, said Robert Zirkelbach, senior vice president of communications at PhRMA.”

[HealthNewsReview.org, [2/10/16](#)]

**PATIENTS RISING AND PATIENTS RISING NOW ADVOCATE FOR “TRANSPARENCY” TO REDUCE HEALTH CARE COSTS BUT ARE THEMSELVES OPAQUE.**

**Patients Rising Now advocates on “affordability of healthcare.”**

“Patients Rising Now works at community, state and federal levels to activate patients in support of reforms and legislation aimed at advancing patient access to and affordability of healthcare.”

[Patients Rising, accessed [12/8/20](#)]

**Patients Rising Now describes itself as “dedicated to demanding transparency in health care.”**

“We are a 501c4 group dedicated to demanding transparency in health care.”

[Patients Rising Now, accessed [12/10/20](#)]

- **Patients Rising Now was created under a provision of the tax code that allows it to not disclose its funders.**  
“Patients Rising Now does not focus exclusively on Duchenne treatments. Rather, its expertise is in the technical, dense area of health economics. The organization, which was created under a section of tax law that allows it to not disclose its direct donors, has agitated about ICER’s reviews of drugs for several other conditions, including migraines, forms of cancer, and psoriasis. It has an affiliated charity, Patients Rising, which does disclose its donors, who include major pharmaceutical companies such as Amgen, Celgene, and Novartis. (Sarepta is not listed as a contributor on the group’s website.)”  
[Boston Globe, 7/25/19]
- **Headline: “Hard-to-trace groups work to kill proposals to lower drug prices.”**

[The East Bay Times (California), 1/23/19]

**Terry Wilcox called for more transparency in the health insurance industry to help lower costs.**

“Bring pricing transparency not only to prescription drug delivery but also to insurance companies to address the record premiums, deductibles and coinsurance — all of which reduce access and impede quality of life. Deductibles have risen by 300 percent since 2006 and coinsurance costs have nearly doubled. The number of privately insured Americans with high-deductible plans has risen by 40 percent since just 2011.”

[Terry Wilcox, op-ed, Inside Sources, [5/23/18](#)]

**Terry Wilcox called for focusing less on health care industry stock prices and more on patients affected to help reduce drug prices.**

“Focus on the road — not the street. How the stock market reacts to drug pricing proposals is not nearly as important as the patients who are being affected. Stock prices of PBMs and other industry players have increased rapidly in recent years. They have benefited from the cronyism and oligopoly in the market. Similarly, reformers must ignore — or deeply discount — the protests of lobbyists and trade groups who claim the sky will fall with every reform that disrupts their clients’ status quo.”

[Terry Wilcox, op-ed, Inside Sources, [5/23/18](#)]

- **Without any apparent irony, Terry Wilcox called for policy makers to ignore “the protests of lobbyists and trade groups who claim the sky will fall with every reform that disrupts their clients’ status quo.”**

“Focus on the road — not the street. How the stock market reacts to drug pricing proposals is not nearly as important as the patients who are being affected. Stock prices of PBMs and other industry players have increased rapidly in recent years. They have benefited from the cronyism and oligopoly in the market. Similarly, reformers must ignore — or deeply discount — the protests of lobbyists and trade groups who claim the sky will fall with every reform that disrupts their clients’ status quo.”

[Terry Wilcox, op-ed, Inside Sources, [5/23/18](#)]

## Financials

### PATIENTS RISING AND THEIR ADVOCACY BRANCH, PATIENTS RISING NOW, APPEAR TO RELY SIGNIFICANTLY — IF NOT ENTIRELY — ON FUNDING FROM THE PHARMACEUTICAL INDUSTRY.

**The only corporate sponsors listed on Patients Rising’s website were pharmaceutical companies.**

[Patients Rising, accessed [12/8/20](#)]

- **1/27/21: Patients Rising indicated that the only companies that have contributed in the past 12 months were pharmaceutical companies Amgen, Pfizer, Takeda Oncology, Celgene, and Janssen.**

“SUPPORTERS. Our Supporters include companies who contributed over the past 12-months — updated quarterly. For more information on corporate membership or general support for Patients Rising’s programs, please contact Melanie Marconi at Email. Patients Rising University Supporters: Amgen is one of the world’s leading biotechnology companies. Amgen is a values-based company deeply rooted in science and innovation. They transform new ideas and discoveries into medicines for patients with serious illnesses. The world’s largest research-based pharmaceutical company. Pfizer Inc discovers, develops, manufactures and markets leading prescription medicines and many of the world’s best-known consumer brands. Takeda Oncology endeavors to deliver novel medicines to patients with cancer worldwide through their commitment to science, breakthrough innovation and passion for improving the lives of patients. They combine leading scientific minds with their global resources to find innovative ways to improve cancer treatment. Patients Rising Concierge Supporters: Celgene Corporation, headquartered in Summit, New Jersey, is a patient-focused integrated global biopharmaceutical company engaged primarily in the discovery, development and commercialization of novel therapies for the treatment of cancer and inflammatory diseases through gene and protein regulation. The Pharmaceutical Companies of Johnson & Johnson, Janssen fights ‘sickness with science, improves access with ingenuity, and heals hopelessness with heart’. They focus on areas of medicine

where they can make the biggest difference: Cardiovascular & Metabolism, Immunology, Infectious Diseases & Vaccines, Neuroscience, Oncology, and Pulmonary Hypertension. Takeda Oncology endeavours to deliver novel medicines to patients with cancer worldwide through their commitment to science, breakthrough innovation and passion for improving the lives of patients. They combine leading scientific minds with their global resources to find innovative ways to improve cancer treatment.”

[Patients Rising, accessed [1/27/21](#)]

- **Patients Rising University claimed that the funding they received from pharmaceutical companies did not influence their programs or positions.**

“Patients Rising University receives grants from a number of corporate supporters, which fund the educational programs and initiatives. None of the Patients Rising’s or Patient Rising University’s programs or positions are influenced in any way by our funders.”

[Patients Rising University, accessed [12/8/20](#)]

#### **Patients Rising Now lists pharmaceutical companies Amgen, Celgene, and Sarepta as “Patient Champions.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. Patient Champions Amgen Celgene Sarepta.”

[Patients Rising Now, accessed [12/11/20](#)]

- **Patients Rising Now’s “Patient Champions” are entitled to an “annual one-on-one meeting with PRN executive and policy director,” “quarterly policy and advocacy calls with PRN senior leadership and policy team,” and “issue briefings with PRN senior leadership.”**

“Corporate Memberships are available at the following levels: Patient Champions Annual one-on-one meeting with PRN executive and policy director quarterly policy and advocacy calls with PRN senior leadership and policy team Issue briefings with PRN senior leadership. Complimentary invitation to all PRN events, including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September 2020) and our National Patient Access Town Hall (October 2020). Logo placement at annual State of the Patient Address & Summit and the Patients Rise on the Hill Day Receive PRN’s monthly outreach e-newsletter. Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]

#### **Patients Rising Now lists pharmaceutical companies AbbVie, Boehringer Ingelheim, Johnson & Johnson, Merck, and Pfizer as “Patient Allies.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. [...] Patient Allies: AbbVie, Boehringer Ingelheim, Johnson & Johnson, Merck, Pfizer”

[Patients Rising Now, accessed [12/11/20](#)]

- **Patients Rising Now “Patient Allies” are entitled to an “annual one-on-one strategy meeting with PRN senior leadership” and “issue briefings with PRN senior leadership.”**

“Corporate Memberships are available at the following levels: [...] Patient Allies: annual one-on-one strategy meeting with PRN senior leadership, issue briefings with PRN senior leadership, complimentary invitation to all PRN events, including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September 2020) and our National Patient Access Town Hall (October 2020). Logo placement at annual State of the Patient Address & Summit and Patients Rise on the Hill Day. Receive PRN’s monthly outreach e-newsletter. Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]



**Patients Rising Now lists pharmaceutical companies Allergan, PTC Therapeutics, Sanofi, and Takeda, and pharmaceutical trade organization BIO as “Patient Friends.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. [...] Patient Friends: Allergan, Biotechnology Innovation Organization, PTC Therapeutics, Sanofi, Takeda.”

[Patients Rising Now, accessed [12/11/20](#)]

- **Patients Rising Now “Patient Friends” are entitled to “issue briefings with PRN senior leadership.”**

“Corporate Memberships are available at the following levels: [...] Patient Friends | Issue briefings with PRN senior leadership. Complimentary invitation to National Patient Access Town Hall (October 2020) – Washington, D.C. Receive PRN’s monthly outreach e-newsletter Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]

### **PATIENTS RISING STARTED WITH JUST UNDER \$200,000, SAW REVENUE INCREASE TO MORE THAN \$1 MILLION BEFORE LEVELING OFF AT MORE THAN \$600,000.**

**2015: Patients Rising started with \$175,000 in “gifts, grants, contributions, and membership fees received.”**

[Patients Rising, IRS Form 990, [5/16/16](#)]

**2016: Patients Rising brought in more than \$1 million in revenue through “contributions and grants.”**

According to their 2016 IRS Form 990 tax filings, Patients Rising received \$1,013,075 in “contributions and grants.” Just \$9 additional dollars in revenue were reported from “investment income.”

[Patients Rising, IRS Form 990, [11/14/17](#)]

- **2016: Patients Rising reported receiving no revenue from “federated campaigns,” “membership dues,” “fundraising events,” “related organizations,” or “government grants.”**

[Patients Rising, IRS Form 990, [11/14/17](#)]

**2016: Patients Rising may have received \$25,000 from PhRMA.**

“Additional industry astroturf groups are part of the anti-drug pricing influence campaign. Americans for Tax Reform ran ads last year against Trump’s proposed international pricing index for drugs under Medicare. The Alliance for Patient Access, which has received funds from BIO and PhRMA in the past, has advertised in opposition to Medicare drug pricing reforms, and Patients Rising, which got \$25,000 from PhRMA in 2016, is reportedly promoting the same agenda.”

[Center for Media and Democracy, PR Watch, [1/13/20](#)]

**2017: Patients Rising brought in nearly \$615,000 in revenue through “contributions and grants.”**

According to their 2016 IRS Form 990 tax filings, Patients Rising received \$614,717 in “contributions and grants.” Just \$3 additional dollars in revenue were reported from “investment income.”

[Patients Rising, IRS Form 990, [11/9/18](#)]

- **2017: Patients Rising reported receiving no revenue from “federated campaigns,” “membership dues,” “fundraising events,” “related organizations,” or “government grants.”**

[Patients Rising, IRS Form 990, [11/9/18](#)]

**2018: Patients Rising brought in nearly \$660,000 in revenue through “contributions and grants.”**

According to their 2016 IRS Form 990 tax filings, Patients Rising received \$657,691 in “contributions and grants.” Just \$6 additional dollars in revenue were reported from “investment income.”

[Patients Rising, IRS Form 990, [10/23/19](#)]

- **2018: Patients Rising reported receiving no revenue from “federated campaigns,” “fundraising events,” “related organizations,” or “government grants.”**  
[Patients Rising, IRS Form 990, [10/23/19](#)]
- **2018: Patients Rising reported receiving \$567 in “membership dues.”**  
[Patients Rising, IRS Form 990, [10/23/19](#)]

## **PATIENTS RISING HAS DISCLOSED THAT IT RECEIVES FUNDING FROM DRUG MAKERS.**

### **Patients Rising has disclosed receiving funding from pharmaceutical companies like Amgen, Celgene, Pfizer, and others.**

“Tufts said he wrote the article after conversations with representatives of the nonprofit group Patients Rising, which discloses direct funding from Amgen, Celgene, Pfizer, and other big drug companies. Tufts, who said he came under attack on Twitter after his article appeared, said he does not receive any money from Patients Rising or industry.”

[Boston Globe, 3/23/18]

### **Patients Rising’s website lists “large drug companies among their supporters.”**

“On their websites, the Alliance for Patient Access and Patients Rising list large drug companies among their supporters. The alliance does not disclose funding levels, while Patients Rising does list funding ranges.”

[Washington Post, [1/22/19](#)]

### **Patients Rising said their funding comes from “unrestricted grants” “from diverse corporate supporters.”**

“WHERE OUR MONEY COMES FROM: UNRESTRICTED GRANTS: To realize these programs, Patients Rising seeks and receives unrestricted educational grants from diverse corporate supporters.”

[Patients Rising, accessed [12/8/20](#)]

### **Patients Rising claimed that their programs or positions were not “influenced in any way by our donors.”**

“WHERE OUR MONEY COMES FROM: UNRESTRICTED GRANTS: To realize these programs, Patients Rising seeks and receives unrestricted educational grants from diverse corporate supporters. None of Patients Rising’s programs or positions are influenced in any way by our donors.”

[Patients Rising, accessed [12/8/20](#)]

### **The only corporate sponsors listed on Patients Rising’s website were pharmaceutical companies.**

[Patients Rising, accessed [12/8/20](#)]

- **Patients Rising listed Amgen, Pfizer, Takeda Oncology, Celgene, and Janssen as their only supporters.**  
“Our supporters include companies who contributed over the past 12-months — updated quarterly. For more information on corporate membership or general support for Patients Rising’s programs, please contact Melanie Marconi at Email. Patients Rising University Supporters: Amgen is one of the world’s leading biotechnology companies. Amgen is a values-based company deeply rooted in science and innovation. They transform new ideas and discoveries into medicines for patients with serious illnesses. The world’s largest research-based pharmaceutical company, Pfizer Inc., discovers, develops, manufactures and markets leading prescription medicines and many of the world’s best-known consumer brands. Takeda Oncology endeavours to deliver novel medicines to patients with cancer worldwide through their commitment to science, breakthrough innovation and passion for improving the lives of patients. They combine leading scientific minds with their global resources to find innovative ways to improve cancer treatment. Patients Rising Concierge Supporters: Celgene Corporation, headquartered in Summit, New Jersey, is a patient-focused integrated global biopharmaceutical company engaged primarily in the discovery, development and commercialization of novel therapies for the treatment of cancer and inflammatory diseases through gene and protein regulation. The Pharmaceutical Companies of Johnson & Johnson, Janssen fights ‘sickness with science, improves access with ingenuity, and heals hopelessness with heart’. They focus on areas of medicine where they can make the biggest difference: Cardiovascular & Metabolism, Immunology, Infectious Diseases

& Vaccines, Neuroscience, Oncology, and Pulmonary Hypertension.”  
[Patients Rising, accessed 12/8/20]

- **July 2019: Sarepta was not listed on the Patients Rising website as a supporter.**  
“It has an affiliated charity, Patients Rising, which does disclose its donors, who include major pharmaceutical companies such as Amgen, Celgene, and Novartis. (Sarepta is not listed as a contributor on the group’s website.)”  
[Boston Globe, 7/25/19]
- **July 2019: A Sarepta drug was reviewed by think tank ICER.**  
“Exondys 51, a Sarepta Therapeutics drug that was approved in 2016 after significant debate over its efficacy, is among the treatments being reviewed by ICER. The group is also reviewing Golodirsen, another Sarepta treatment that is currently under Food and Drug Administration review, and Emflaza, a treatment from PTC Therapeutics.”  
[Boston Globe, 7/25/19]
- **December 2020: Patients Rising Now lists Sarepta as “Patient Champion.”**  
“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. Patient Champions Amgen Celgene Sarepta.” [Patients Rising Now, accessed [12/11/20](#)]
  - **Patients Rising Now “Patient Champions” are entitled to an “annual one-on-one meeting with PRN executive and policy director,” “quarterly policy and advocacy calls with PRN senior leadership and policy team,” and “issue briefings with PRN senior leadership.”**  
“Corporate Memberships are available at the following levels: Patient Champions: annual one-on-one meeting with PRN executive and policy director, quarterly policy and advocacy calls with PRN senior leadership and policy team Issue briefings with PRN senior leadership. Complimentary invitation to all PRN events, including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September 2020) and our National Patient Access Town Hall (October 2020). Logo placement at annual State of the Patient Address & Summit and the Patients Rise on the Hill Day. Receive PRN’s monthly outreach e-newsletter Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.” [Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising University lists pharmaceutical companies Amgen, Celgene, and Pfizer among its supporters.**

“Patients Rising University receives grants from a number of corporate supporters, which fund the educational programs and initiatives. None of Patients Rising or Patients Rising University’s programs or positions are influenced in any way by our funders. We also work in partnership with a number of like-minded non-profit organizations to reach patients, caregivers, health professionals and policymakers through a range of communications channels. This allows us to have a broader reach and magnify the impact of our mission grants. Our partners and supporters enhance our ability to help patients across disease states, strengthen our conversations with stakeholders in all sectors of the healthcare system – patients, caregivers, health professionals, researchers, payers, innovators, regulators and legislators – and create the multiplier effect so the voices of patients will be heard. In essence, our partners and supporters are valued members of the Patients Rising community. Their generous financial and in-kind support allowed Patients Rising University to launch in Spring 2018. [...] SUPPORTERS LegalZoom works to make sure that legal solutions are available to everyone. Amgen is one of the world’s leading biotechnology companies. Amgen is a values-based company, deeply rooted in science and innovation to transform new ideas and discoveries into medicines for patients with serious illnesses. Celgene Corporation, headquartered in Summit, New Jersey, is a patient-focused integrated global biopharmaceutical company engaged primarily in the discovery, development and commercialization of novel therapies for the treatment of cancer and inflammatory diseases through gene and protein regulation.

The world's largest research-based pharmaceutical company, Pfizer Inc discovers, develops, manufactures and markets leading prescription medicines and many of the world's best-known consumer brands."  
[Patients Rising University, accessed [12/8/20](#)]

- **Patients Rising University claimed that the funding they received from pharmaceutical companies did not influence their programs or positions.**

"Patients Rising University receives grants from a number of corporate supporters, which fund the educational programs and initiatives. None of Patients Rising or Patient Rising University's programs or positions are influenced in any way by our funders."

[Patients Rising University, accessed [12/8/20](#)]

### **PATIENTS RISING NOW'S REVENUE MORE THAN DOUBLED IN A SINGLE YEAR.**

**2018: Patients Rising Now reported \$330,000 in total revenue on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now had \$330,000 in total revenue.

[Patients Rising Now, IRS Form 990, [11/12/19](#)]

- **2018: Patients Rising Now reported receiving \$195,000 from "membership dues" on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now received \$195,000 in "membership dues."

[Patients Rising Now, IRS Form 990, [11/12/19](#)]

- **2018: Patients Rising Now reported receiving \$135,000 from "all other contributions, gifts, grants, and similar amounts" on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now received \$135,000 in "all other contributions, gifts, grants, and similar amounts not included above." Above included categories were "membership dues," "fundraising events," "related organizations," and "government grants (contributions)."

[Patients Rising Now, IRS Form 990, [11/12/19](#)]

- **2018: Patients Rising Now reported no revenue for the prior year (2017) on their federal tax filings.**

According to their 2018 IRS Form 990, Patients Rising Now reported no revenue in 2017. [Patients Rising Now, IRS Form 990, [11/12/19](#)]

**2019: Patients Rising Now reported \$750,115 in total revenue on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now had \$750,115 in total revenue.

[Patients Rising Now, IRS Form 990, [7/11/20](#)]

- **2019: Patients Rising Now reported receiving \$420,015 from "membership dues" on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now received \$420,015 in "membership dues." [Patients Rising Now, IRS Form 990, [7/11/20](#)]

- **2019: Patients Rising Now reported receiving \$330,100 from "all other contributions, gifts, grants, and similar amounts" on their federal tax filings.**

According to their IRS Form 990, Patients Rising Now received \$330,100 in "all other contributions, gifts, grants, and similar amounts not included above." Above included categories were "membership dues," "fundraising events," "related organizations," and "government grants (contributions)."

[Patients Rising Now, IRS Form 990, [7/11/20](#)]

### **PATIENTS RISING NOW HAS A "CORPORATE MEMBERSHIP PROGRAM" WHOSE ONLY MEMBERS APPEAR TO BE PHARMACEUTICAL COMPANIES AND TRADE ASSOCIATIONS.**

Patients Rising Now maintains a "corporate membership program" that was created to "advance our policy

**and advocacy work at the local, state and federal levels.”**

“The Patients Rising Now (PRN) Corporate Membership Program engages our corporate partners on a regular basis. This program was designed to advance our policy and advocacy work at the local, state and federal levels. The program supports mutually beneficial priorities by creating an opportunity to exchange ideas around public policy goals.” [Patients Rising Now, accessed [12/11/20](#)]

**The Patients Rising Now corporate membership program “supports mutually beneficial priorities by creating an opportunity to exchange ideas around public policy goals.”**

“The Patients Rising Now (PRN) Corporate Membership Program engages our corporate partners on a regular basis. This program was designed to advance our policy and advocacy work at the local, state and federal levels. The program supports mutually beneficial priorities by creating an opportunity to exchange ideas around public policy goals.” [Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now corporate members participate in annual lobbying efforts in Congress.**

“Corporate members participate in both in-person and virtual events, including quarterly member policy and advocacy calls, issue briefings, as well as our larger events including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September) and our National Patient Access Town Hall (October).” [Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now corporate members’ “perspectives are used to inform our advocacy.”**

“PRN cultivates these partnerships so that we can understand the viewpoints of everyone involved in the fight for patient access, innovation, and regulatory reforms that support both. All member stakeholder perspectives are used to inform our advocacy on behalf of patients.”  
[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now corporate members “help activate and mobilize the patient voice.”**

“Current Corporate Members Patients Rising Now is an organization focused on all patients living with chronic and life-threatening illnesses in the United States. We work with our partners to help activate and mobilize the patient voice through our active PRN Delegate Recruitment Program.”  
[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now: “Corporate partnerships are critical to the success of our work.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all.”  
[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now lists pharmaceutical companies Amgen, Celgene, and Sarepta as “Patient Champions.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. Patient Champions: Amgen, Celgene, Sarepta.” [Patients Rising Now, accessed [12/11/20](#)]

- **Patients Rising Now “Patient Champions” are entitled to an “annual one-on-one meeting with PRN executive and policy director,” “quarterly policy and advocacy calls with PRN senior leadership and policy team,” and “issue briefings with PRN senior leadership.”**

“Corporate Memberships are available at the following levels: Patient Champions: annual one-on-one meeting with PRN executive and policy director, quarterly policy and advocacy calls with PRN senior leadership and policy team, issue briefings with PRN senior leadership. Complimentary invitation to all PRN events, including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September 2020) and our National Patient Access Town Hall (October 2020). Logo placement at annual State of the Patient Address & Summit and the Patients Rise on the Hill Day. Receive PRN’s monthly outreach e-newsletter Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now lists pharmaceutical companies AbbVie, Boehringer Ingelheim, Johnson & Johnson, Merck, and Pfizer as “Patient Allies.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. [...] Patient Allies: AbbVie, Boehringer Ingelheim, Johnson & Johnson, Merck, Pfizer.”

[Patients Rising Now, accessed [12/11/20](#)]

- **Patients Rising Now “Patient Allies” are entitled to an “annual one-on-one strategy meeting with PRN senior leadership” and “issue briefings with PRN senior leadership.”**

“Corporate Memberships are available at the following levels: [...] Patient Allies: annual one-on-one strategy meeting with PRN senior leadership, issue briefings with PRN senior leadership. Complimentary invitation to all PRN events, including the annual Patients Rising Now State of the Patient Address & Summit and Patients Rising Now on the Hill (September 2020) and our National Patient Access Town Hall (October 2020). Logo placement at annual State of the Patient Address & Summit and Patients Rise on the Hill Day. Receive PRN’s monthly outreach e-newsletter Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now lists pharmaceutical companies Allergan, PTC Therapeutics, Sanofi, and Takeda, and pharmaceutical trade organization BIO as “Patient Friends.”**

“Corporate partnerships are critical to the success of our work. We look forward to building these ongoing relationships that leverage our mutual strengths and provide strong benefits to all. To that end, we have developed five levels of corporate membership which are detailed below. [...] Patient Friends: Allergan, Biotechnology Innovation Organization, PTC Therapeutics, Sanofi, Takeda.” [Patients Rising Now, accessed

[12/11/20](#)]

- **Patients Rising Now “Patient Friends” are entitled to “issue briefings with PRN senior leadership.”**

“Corporate memberships are available at the following levels: [...] Patient Friends | Issue briefings with PRN senior leadership. Complimentary invitation to National Patient Access Town Hall (October 2020) – Washington, D.C. Receive PRN’s monthly outreach e-newsletter. Recognition in PRN’s annual State of the Patient Report and member recognition on the PRN website.”

[Patients Rising Now, accessed [12/11/20](#)]

**2018: Patients Rising Now reported no “benefits paid to or for members” on their federal tax forms.**

According to their IRS Form 990, Patients Rising Now reported no “benefits paid to or for members” in 2018.

[Patients Rising Now, IRS Form 990, [11/12/19](#)]

**2019: Patients Rising Now reported no “benefits paid to or for members” on their federal tax forms.**

According to their IRS Form 990, Patients Rising Now reported no “benefits paid to or for members” in 2019. [Patients Rising Now, IRS Form 990, [7/11/20](#)]

**Patients Rising has a “concierge” program designed to help patients navigate the health care world.**

“Patients Rising Concierge ASK US ANYTHING Our team of Patient Navigators is available to answer questions and provide individualized support. We help connect patients to the services they need.”

[Patients Rising, accessed [12/8/20](#)]

- **The Patients Rising Concierge program is supported by pharmaceutical companies.**

The Patients Rising Concierge program webpage includes an image carousel of “our supporters” that includes the corporate logos of pharmaceutical companies Takeda Oncology, Johnson & Johnson, Celgene, Baxter, and Allergan.

[Patients Rising, accessed [12/8/20](#)]

**PATIENTS RISING HAS PAID TO USE THE PHARMACEUTICAL INDUSTRY’S PREFERRED PR FIRM.**

**2016: Patients Rising paid \$116,819 to 720 Strategies for professional services.**

[Patients Rising, IRS Form 990, [11/14/17](#)]

- **720 Strategies did work for PhRMA and uses it as a case study on their website.**

“Facing a climate of substantial health care policy change and reputational challenges, the biopharmaceutical industry’s national trade association, the Pharmaceutical Research and Manufacturers of America (PhRMA), and its member companies sought an advocacy solution to convey the industry’s value and commitment to positive change in health care policy through its member company employees. [...] To address these challenges, 720 Strategies developed and continues to implement an integrated advocacy and communications program called We Work For Health (WWFH) – a grassroots initiative that unites health consumers, pharmaceutical company employees and retirees, vendors, suppliers and other partners to demonstrate how these diverse groups work together to deliver life-saving, life-enhancing advancements in medicine, while also serving as a driving force for our nation’s economy. As the first initiative in PhRMA’s history to secure the approval of member companies to directly engage their employees in a cohesive, industry-sponsored grassroots program, WWFH aims to help advance policies that promote medical innovation in the U.S. What started as a pilot program in three states in 2008 has expanded to include 14 states in 2015. WWFH has flourished into an alliance of biopharmaceutical employees, retirees, vendors, suppliers and other local business groups, labor unions, concerned patients and academic and community partners who share the common goal of preserving medical innovation in the country.”

[720 Strategies, accessed [12/9/20](#)]

- **720 Strategies designed and built a “Science Ambassadors” program for PhRMA specifically to lobby Congress, with a focus on communicating “PhRMA’s commitment to promote access to health care and prescription drugs.”**

“Established to engage biopharmaceutical scientists and researchers across the country to join together to help advance the industry, the Science Ambassadors program is a multifaceted approach to communicating PhRMA’s medical innovation agenda within local communities and with Members of Congress. The program leverages ambassadors’ extensive research and development experience in helping to shape the dialogue about the role and value of medical innovation in bettering health care in the U.S. and around the world – not only on the innovation of new medicines, but on the industry’s commitment and contribution to overall health and well-being. The program includes a dedicated website with congressional contact capability, as well as a speaker’s bureau of research scientists who carry the industry’s message in their local community. These communications reinforce PhRMA’s commitment to promote access to health care and prescription drugs, encourage prevention and healthier living, and innovations that help families live longer, healthier lives.”

[720 Strategies, accessed [12/9/20](#)]

## PATIENTS RISING HAS USED FIRMS TIED TO THE PHARMACEUTICAL INDUSTRY SINCE ITS INCEPTION.

The contact person on the Patients Rising announcement press release was Peggy Frank of Initiate PR.

“Patients Rising, Launched to Fight for Access to Vital Therapies and Services for Patients with Life-Threatening Diseases; New Non-Profit Organization Calls for Faster, Responsible Access to Medications, while Minimizing Insurance Obstacles and Maintaining Patient Safety [...] CONTACT: Initiate PR Peggy Frank, 818-735-3591.”

[Patients Rising press release, via Business Wire, 8/25/15]

- **Initiate PR was a public relations firm that worked for biopharmaceutical companies.**

“CORPORATE COMMUNICATIONS IPR and our predecessor company have supported many companies through merger/acquisition, and often the larger acquiring company became our client. [...] We took our client Orexigen to IPO.” [InitiatePR.com, via Internet Archive, [7/23/19](#)]

- **Orexigen was a pharmaceutical company focused on obesity treatment.**

“Drugmaker Orexigen Therapeutics Inc OREX.O said on Monday it filed for Chapter 11 bankruptcy protection and will also file a motion to pursue an auction and sale process of substantially all its assets. The company, which focuses on the treatment of obesity, said it expects proposed bids to be submitted by May 21 and the sale is intended to be concluded by July 2.”

[Reuters, [3/11/18](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Reportable compensation from related organizations	Total
TERESSA WILCOX	EXECUTIVE DIRECTOR	\$116,250.00	\$97,192.00	\$213,442.00

[Patients Rising Now, IRS Form 990, [7/11/20](#)]

### PATIENTS RISING/PATIENTS RISING NOW EXECUTIVE DIRECTOR TERRY WILCOX HAS SEEN HER SALARY GROW BY MORE THAN 170 PERCENT IN THE LAST FOUR YEARS – FROM \$78,000 TO MORE THAN \$210,000.

**2016: Patients Rising paid executive director Teresa Wilcox \$78,500.**

[Patients Rising, IRS Form 990, [11/14/17](#)]

**2017: Patients Rising paid executive director Teresa Wilcox \$81,426.**

[Patients Rising, IRS Form 990, [11/9/18](#)]

**2018: Patients Rising paid executive director Teresa Wilcox \$95,401.**

[Patients Rising, IRS Form 990, [10/23/19](#)]

**2019: Terry Wilcox’s total compensation from Patients Rising and Patients Rising Now was \$213,442.**

According to their IRS Form 990, Patients Rising Now paid Terry Wilcox, the organization’s executive director, \$116,250 in 2019. Patients Rising paid Terry Wilcox \$97,192 in 2019.

[Patients Rising Now, IRS Form 990, [7/11/20](#)]



- **2019: Patients Rising Now reported a balance due of \$36,010 on a \$36,368 loan to executive director Terry Wilcox.**

According to their IRS Form 990, Patients Rising Now reported a balance of \$36,010 outstanding on a \$36,368 loan to executive director Terry Wilcox. The purpose of the loan was described as “temporary financial aid to employee provided prior to initiating payroll.” [Patients Rising Now, IRS Form 990, [7/11/20](#)]

- **2018: Patients Rising Now gave a \$36,368 loan to executive director Terry Wilcox as “temporary financial aid to uncompensated employee.”**

According to their IRS Form 990, Patients Rising Now gave their executive director, Terry Wilcox a \$36,368 loan. The purpose of the loan was described as “temporary financial aid to uncompensated employee.” [Patients Rising Now, IRS Form 990, [11/12/19](#)]

**TERRY WILCOX DOESN'T APPEAR TO HAVE AN EMPLOYMENT HISTORY IN THE PHARMACEUTICAL INDUSTRY, BUT INDUSTRY EXECUTIVES HAVE ENDORSED HER WORK.**

**Terry Wilcox was “endorsed” on LinkedIn for her video skills by Elyse Spatz Caplan.**

[Terry Wilcox LinkedIn profile, accessed [12/12/20](#)]

- **2013-Present: Elyse Spatz Caplan is the director of patient advocacy at Novartis.**

[Elyse Spatz Caplan LinkedIn profile, accessed [12/12/20](#)]

**Terry Wilcox was “endorsed” on LinkedIn for her public relations skills by Stefan Glueck.**

[Terry Wilcox LinkedIn profile, accessed [12/12/20](#)]

**Terry Wilcox was “endorsed” on LinkedIn for her “storytelling” skills by Stefan Glueck.**

[Terry Wilcox LinkedIn profile, accessed [12/12/20](#)]

- **March 2020-Present: Stefan Glueck is VP and Head of Global Franchise Oncology MA at Regeneron Pharmaceuticals.**

[Stefan Glueck LinkedIn Profile, accessed [12/12/20](#)]

- **2014-2020: Glueck was VP of GMA Early Assets at Celgene.**

[Stefan Glueck LinkedIn Profile, accessed [12/12/20](#)]

**Terry Wilcox was “endorsed” on LinkedIn for her public relations skills by Bert Thomas.**

[Terry Wilcox LinkedIn profile, accessed [12/12/20](#)]

- **Bert Thomas is vice president for business development at pharmaceutical company Bio-Thera Solutions and previously worked for Wyeth and other drug companies.**

“Bert is the Senior Vice President, Business Development of Bio-Thera Solutions, Ltd., a China-based pharmaceutical company dedicated to developing innovative new therapies to fight some of the world’s most challenging diseases. Prior to joining Bio-Thera Solutions, Bert was the Chief Executive Officer of the Sarcoma Foundation of America (SFA), an organization focused on funding sarcoma research and raising public awareness of the disease. Before joining SFA, Dr. Thomas held the positions of Director, Corporate Alliances and Interim Head of Development at the American Association of Cancer Research (AACR). Prior to the AACR, Dr. Thomas held positions of progressive leadership in Research and Development and Business Development across 16 years in the Pharmaceutical Industry, working for Genetics Institute, Wyeth, Guilford Pharmaceuticals, MGI Pharma, Procept and Adolor Corporation.”

[Bert Thomas, accessed [12/20/20](#)]

**Terry Wilcox follows a number of major pharmaceutical companies on LinkedIn, such as Pfizer, GSK, Novartis, Roche, Eli Lilly, Amgen, and others.**

[Terry Wilcox LinkedIn profile, accessed [12/12/20](#)]

## TERRY WILCOX HOSTS A PATIENTS RISING PODCAST THAT FREQUENTLY HAS GUESTS WITH TIES TO THE PHARMACEUTICAL INDUSTRY.

### **Patients Rising hosted a talk by Stacey Worthy, Director of Public Policy for Alliance for the Adoption of Innovations in Medicine (Aimed Alliance)”**

“The Alliance for the Adoption of Innovations in Medicine (Aimed Alliance), a not-for-profit organization seeking to improve healthcare in the US, said many of the barriers to treatment that prevent patients from receiving quality care as prescribed by their physicians, may be discriminatory cost-saving measures proscribed by current law. Stacey L. Worthy, Director of Public Policy at the Aimed Alliance, was critical of insurance practices that create and impose these barriers, including: [...] Speaking at a forum and webcast in Sacramento arranged by the advocacy organization PATIENTS RISING, Ms. Worthy said, ‘These practices serve to financially exclude patients with a pre-existing condition, create a blatant conflict of interest for the physician, take up valuable physician time trying to obtain approval for the treatments, and in the end, just serve to save company money.’”  
[Patients Rising press release, via Business Wire, 4/6/16]

- **Aimed Alliance is funded by major pharmaceutical companies.**

“We seek collaboration with a diverse range of health care stakeholders, including patient advocacy organizations, industry groups, state and federal governments, and charitable foundations. We look for ways that we can leverage each other’s strengths to achieve meaningful and lasting improvements to the U.S. health care system. These relationships underpin Aimed Alliance’s network, and they bolster Aimed Alliance’s efforts to enhance policy and optimize practices across numerous sectors. Financial and in-kind support from our alliance members allows us to promote solutions for access to high-quality health care for all Americans. [...] AbbVie [...] Amarin Corporation [...] Amgen [...] Bristol-Myers Squibb [...] Greenwich Biosciences [...] Janssen [...] Regeneron [...] Sanofi [...] Takeda [...] UCB.”  
[Aimed Alliance, accessed [12/11/20](#)]

### **9/11/20: The Patients Rising Podcast posted an episode called “What Goes Into Drug Prices” with guest “Dr. Robert Popovian, VP of Government Relations at Pfizer.”**

“What Goes Into Drug Prices Sept. 11th, 2020 | 46:12 | S1:E29 Get an inside look into the drug supply chain and the factors that impact your bill at the pharmacy counter. Dr. Robert Popovian, VP of Government Relations at Pfizer, joins Terry to discuss how benefit design and rebates impact the cost of your medicine. Plus Kate speaks with Jackie Price, a double lung transplant recipient, on cystic fibrosis and the importance of organ donors.” [Patients Rising Podcast, [9/11/20](#)]

- **The Patients Rising Podcast identified pharmacy benefit managers and rebates paid to them by pharmaceutical companies as the main drivers in high prescription drug prices.**

“On this episode of the podcast, Terry and Bob discuss what goes into a drug price. They pull the curtain to reveal the group of middlemen between drugmakers and the patient that drives up the drug prices patients pay. They highlight the bizarre system of drug rebates, which is the money that pharmaceutical companies pay back to pharmacy benefit managers (PBMs) to get a drug listed on a formulary. For instance, drugmakers may rebate back \$50 million of a \$100 million medicine order. The real price of that drug, then, is the total that PBMs paid for it. I.e., \$50 million, not \$100 million. Though you won’t hear it from the media, net drug prices (list prices minus rebates) have actually fallen or stayed flat in recent years. Due to health benefit designs that charge patients off the list price, patients don’t notice these savings. Terry interviews Dr. Robert Popovian, VP of Government Relations at Pfizer, to discuss how benefit design and rebates impact medicines’ cost. Dr. Popovian notes that it’s not only PBMs that are driving up the prices of drugs but also pharmacists, wholesalers, brokers, and insurers. Yet PBMs are the main culprit. He explains the rebate system’s perverse consequence: higher-priced drugs are actually preferred to lower-priced ones because they will generate a bigger rebate. As a result, higher-priced medicines end up on benefit design formularies. This means higher costs for ordinary patients. The difference between the list price and the net price after rebates – the so-called gross-to-net bubble – has been increasing in recent years as rebates continue to grow. Rebates now make up nearly 50 percent of a drug’s list price – about \$175 billion out of \$450 billion of total drug

spending each year. The net price of insulin has been flat or has fallen in recent years, but insulin rebates have increased driving the list price up. Since deductibles and coinsurance are based on the list price, patients feel like the insulin price is increasing. This Kabuki theater system frustrates patients, patient advocates, and drug price reformers. Due to market distortions, roughly one-quarter of prescriptions cost more with an insurance card than paying cash. Dr. Popovian also highlights the problem of spread pricing, where PBMs charge payers a far higher price than what they reimburse pharmacists and pocket the difference. He notes that Ohio has lost \$200 million annually from spread pricing in its Medicaid program.”

[Patients Rising Now, [9/16/20](#)]

**Patients Rising Executive Director Terry Wilcox said she credited Pfizer Vice President Robert Popovian for her “education on rebates.”**

Wilcox: “Before we get deeper into this discussion, I want to define ‘rebates’ because I’ll be honest: when I started Patients Rising, rebates and the term ‘rebates’ were not really on my radar. And I credit mostly Adam Fein at Drug Channels and you with my education on rebates. Now, as a result, rebates have been something that Patients Rising has been very vocal about eliminating because they can be a huge driver of patient drug costs. So can you define ‘rebates’ a little bit for us?” Popovian: That’s a good question. So rebate contracting is a tactic. It’s a way that pharmacy benefit managers and/or insurers contract with the pharmaceutical industry to be able to get coverage for their medicines. [...] But rebate contracting as an entity has a problem because it creates perverse incentives in the marketplace and misaligned incentives. And the way it works is the pharmaceutical industry goes to the insurer and says ‘if you cover this drug, and instead of paying the retail price which is \$100 you as an entity will have to only pay \$50 because we will rebate back to you the \$50 back. [...] The way that the rebate contracting works has created an environment higher priced medicines with higher rebates are preferred over lower cost alternatives.”

[Partial Transcript, Patients Rising Podcast, [9/11/20](#)]

**Patients Rising Executive Director got Pfizer Vice President Robert Popovian to admit that pharmaceutical companies using rebates as a negotiating tactic with PBMs and insurers is “one of the major drivers of price increases of name-brand drugs.”**

Wilcox: “So you can easily say that because of this, the rebates themselves and the fact that pharmaceutical companies are using this as a negotiation tactic is one of the major drivers of price increases of name-brand drugs. And this is just like a never-ending cycle. Correct?” Popovian: “It is correct because what has happened over time rebates or concessions that are put—because it’s not just about rebates, right?—we talked about rebates, fees, all the other concessions that go have been growing exponentially and in 2019 that dollar amount was equal to over \$175 billion. So just to put it in context, in the U.S. for both infusion drugs, which are drugs that are administered in a physician’s office, or retail drugs that when you go and pick up these medicines at the pharmacy counter, we spent between \$450 and \$500 billion annually, combined. So, of those, \$178 billion is provided back in the form of some type of a concession back into the system. So, the net spending is not \$450, \$500 billion, it’s more closer to \$300 billion or \$350 billion. So, that’s why there’s a growing list price issue in the U.S. PBM contracting, insurer contracting rebates are driving that behavior, and the people that are being hurt the most are the consumers and the patients. And that’s because of the way the benefit design is set up for pharmaceuticals.”

[Partial Transcript, Patients Rising Podcast, [9/11/20](#)]

**JONATHAN WILCOX WAS A FEDERAL GOVERNMENT EMPLOYEE AND FREQUENT SPOKESMAN FOR PATIENTS RISING, THOUGH ANY COMPENSATION HE RECEIVED IS NOT DISCLOSED ON TAX FORMS.**

**December 2017-April 2018: Jonathan Wilcox was Director of Strategic Communications at the Centers for Medicare and Medicaid Services.**

[Jonathan Wilcox LinkedIn profile, accessed [12/12/20](#)]

**April 2018-October 2018: Jonathan Wilcox was Director of Communications for the U.S. Department of Health and Human Services.**

[Jonathan Wilcox LinkedIn profile, accessed [12/12/20](#)]

**October 2018-January 2019: Jonathan Wilcox was Director of Communications for Congressman Darrell Issa.**

[Jonathan Wilcox LinkedIn profile, accessed [12/12/20](#)]

**April 2019-January 2021: Jonathan Wilcox is Senior Advisor to the Director at the U.S. Trade and Development Agency.**

[Jonathan Wilcox LinkedIn profile, accessed [2/22/21](#)]

- **USTDA “strategically facilitates export opportunities for U.S. companies and supports sustainable development in dynamic markets all around the world.”**

“USTDA strategically facilitates export opportunities for U.S. companies and supports sustainable development in dynamic markets all around the world. In fiscal year 2020 alone, USTDA identified more than \$1 billion in U.S. exports to emerging economies as a result of programming that facilitated early-stage infrastructure development. During the most recent 10-year evaluation period, USTDA identified \$112 in exports for every \$1 invested in its programming, a record return for the Agency. Since 1992, USTDA’s program has contributed to more than \$74 billion in U.S. exports.”

[USTDA.gov, accessed [12/11/20](#)]

**2016: Jonathan Wilcox refused to answer questions about who funded Patients Rising.**

“Wilcox had to catch a plane before we could explore that issue and before I could ask about who funds Patients Rising. He didn’t respond to my requests to finish the conversation.” [HealthNewsReview.org, [2/10/16](#)]

**Jonathan Wilcox refused to say how much money Patients Rising received from the pharmaceutical industry or name any donors and dismissed the notion that he was getting rich from the effort.**

“Jonathan Wilcox, co-founder of Patients Rising, told CNBC last month that, while costs are a concern, ‘patients and their medicines are the last place we should be cutting,’ Wilcox declined to say the percentage or amount of contributions he gets from industry or to name any of the others in his ‘wide range of support.’ He invited an inspection of his one car and small “rented house” to measure what the tremendous financial rewards have been running the group.”

[USA Today, [7/11/16](#)]

**Terry and Jonathan Wilcox previously worked for Vital Options International, which received major sponsorship from drug companies like Genentech, Eli Lilly, and Bristol-Myers Squibb.**

“Both Wilcox and his wife had worked with Vital Options International, another patient advocacy group with a special mission of generating global cancer conversations. She is a former executive director. A search of its website showed that drug industry heavy hitters, such as Genentech, Eli Lilly, and Bristol-Myers Squibb, had in the past sponsored some of the group’s major activities, including The Group Room and Advocacy in Action, which offer educational patient-driven content filmed at oncology conferences.”

[HealthNewsReview.org, [2/10/16](#)]

**PATIENTS RISING DOESN’T APPEAR TO COMPENSATE ITS DIRECTORS, ALL OF WHOM WHO HAVE TIES TO BUSINESS AND THE PHARMACEUTICAL INDUSTRY.**

**Patients Rising’s board of directors is chaired by John Kabateck, the California Executive Director of the National Federation of Independent Businesses.**

“JOHN KABATECK Board Chair. John is the founder and president of Kabateck Strategies, the premier California public affairs firm focused on helping clients to become more relevant, involved and impactful through strategic positioning and targeted coalition strategies. For the past 25 years, he has led strategic coalition development and implementation in California’s public policy and political arenas. As California Executive Director of the National Federation of Independent Business, California’s leading small business organization, Kabateck was responsible for the recruitment, outreach, and involvement of upwards of 23,000 small and independent business owners from sectors including retail, restaurants, manufacturing, and agriculture.”

[Patients Rising, accessed [12/8/20](#)]

**Jeffrey Oldham, a member of the Patients Rising board of directors, previously worked for PhRMA.**

“JEFFREY OLDHAM Board Member President, JTO Public Affairs Jeff is Founder and President of JTO Public Affairs, a healthcare consultancy based in Washington, DC. He services Fortune 500 and trade association clients across the healthcare spectrum. In that capacity, he assists in coalition management, message development and implementation of strategic programs to help his clients meet their legislative goals in DC and beyond. Jeff brings over 20 years’ grassroots/public affairs experience to the table. Previously, he was Managing Director and Partner at 720 Strategies, a Washington, DC-based public relations & public affairs firm. Additionally, Jeff served as Deputy Vice President of the Pharmaceutical Research & Manufacturers (PhRMA) where he oversaw operations for the Partnership for Prescription Assistance (PPA) the nation’s largest clearinghouse to match patients in need to pharmaceutical assistance programs.”

[Patients Rising, accessed [12/8/20](#)]

## **PATIENTS RISING EMPLOYEE KATE PECORA ALSO WORKS FOR PHARMACEUTICAL COMPANIES.**

**Kate Pecora is a correspondent for Patients Rising and writes weekly blog posts and appears on the Patients Rising podcast.**

“Kate Pecora. Correspondent Kate Pecora is an impassioned advocate for rare and chronic disease, disability justice, and healthcare policy. She is diagnosed with Spinal Muscular Atrophy Type III, and lives in Boston, Massachusetts. Kate is currently (e)traveling across the country in search of the most compelling stories of patient access, affordability, and quality. Want to share your story and join the Patient’s Rising Community? Reach out to Kate for opportunities to join her weekly blog posts and interviews on the Patients Rising Podcast.”

[Patients Rising, accessed [12/9/20](#)]

- **2018: Kate Pecora was a “Patient Advocacy Intern” at pharmaceutical company Sarepta Therapeutics.**  
[Kate Pecora LinkedIn profile, accessed [12/9/20](#)]
- **2017-Present: Kate Pecora is a “Patient Ambassador” for pharmaceutical company Biogen.**  
[Kate Pecora LinkedIn profile, accessed [12/9/20](#)]
- **2019-Present: Kate Pecora has been a “Rare Disease Patient Advocacy Intern” and a “Specialist, Patient Affairs” at pharmaceutical company Sarepta Therapeutics.**  
[Kate Pecora LinkedIn profile, accessed [12/9/20](#)]

## **PATIENTS RISING IS TRAINING PEOPLE TO ADVOCATE BEFORE CONGRESS, WITH INSTRUCTORS WHO HAVE DEEP TIES TO THE PHARMACEUTICAL INDUSTRY.**

**December 2020: Patients Rising Now introduced an “advocacy master class” to train people to advocate in Congress.**

“We are thrilled to announce the launch of our Patient Advocacy Master Class, an immersive experience unlike any advocacy training you’ve completed before! We believe that patients and caregivers hold the power to move the needle in healthcare & create a better tomorrow for patients and caregivers by raising their voice! This 14-week interactive and comprehensive course will teach you all about advocacy on and off the hill and provide you with the tools and tactics you need to be an effective healthcare advocate. Designed as a mini-college course, students will receive a curriculum with weekly reading, watching, and listening to be completed at your own pace. Course participants will come together for live virtual sessions to engage with fellow classmates and hear from leading advocates. There are only 50 seats available for the inaugural course starting in the new year. Don’t miss out on what will be an unparalleled experience.”

[Patients Rising Now, accessed [12/8/20](#)]

- **Brooke Abbott, an instructor for the Patients Rising Now advocacy master class, has served on advisory boards for pharmaceutical companies Pfizer, Janssen, and AbbVie.**  
“Brooke Abbott Brooke is the creator of The Crazy Creole Mommy Chronicles & IBDMoms. She owns &

operates The Crazy Creole Mommy Life, Inc. She is an advocate often representing the Crohn's & Colitis Foundation & The Digestive Disease National Coalition on Capitol Hill. She is also a member of the IBD Social Circle. Brooke has written for The Right Start blog, Single Mom Planet, Mommybites, The Toddler Blog, Mom. Me, and more. She is currently featured in Everyday Health, HealthCentral & inflammatoryboweldisease.net. Brooke has sat on advisory boards for Pfizer, Single Mom Planet Foundation, WEGO Health, The HollyRod Foundation & HealthVoices. Currently she sits on advisory boards for the Crohn's & Colitis Foundation, Janssen Pharmaceuticals, & AbbVie. Brooke has been featured in The Phoenix Ostomy Magazine, US Weekly, LifeScript, LA Parent, Ostomy Connection, Prevention Magazine, A Women's Health & CCFA.org. Brooke & her son currently reside in Los Angeles.”  
[Patients Rising Now, accessed [12/10/20](#)]

- **Abbott will teach the course on federal lobbying.**  
“Week 9: Advocacy on the Hill with Brooke Abbott.”  
[Patients Rising Now, accessed [12/10/20](#)]
- **Stephanie Fischer is an instructor for the Patients Rising Now advocacy master class.**  
“As a rare disease patient and stroke survivor, Stephanie Fischer is passionate about explaining public policy so that patients and their families can understand why it matters and feel empowered to engage legislators and regulators. She serves on the Pennsylvania Rare Disease Advisory Council and on the board of Narcolepsy Network. Stephanie’s previous roles include the Patient Advocacy and Partnerships Director for AllStripes, a technology start-up focused on accelerating rare disease drug development, and the Chief Patient Engagement and Communications Officer at the EveryLife Foundation for Rare Diseases.” [Patients Rising Now, accessed [12/10/20](#)]
- **2005-2012: Fischer worked for BIO as Communications Director.**  
“Director, Communications. Company Name: Biotechnology Industry Organization (BIO). Dates Employed: Jan. 2005 – Oct. 2012 Employment Duration seven yrs 10 mos. Location Washington D.C. Metro Area • Developed and implemented strategic communications programs to support the goals of BIO’s Health Section and build awareness of BIO as a leading voice in health-related issues. • Responded to media inquiries on health policy and intellectual property, and engaged media proactively on key public policy issues such as biosimilars, reauthorization of PDUFA and patent law reform. • Communicated value of biotechnology to state and federal policymakers, the public and other key audiences by writing letters to the editor, guest editorials, press releases and content for BIOtechNOW, BIO’s editorial website. • Coordinated with Alliance Development team to build and strengthen relationships with patient and medical specialty groups through collaborations on content for BIO web properties.”  
[Stephanie Fischer LinkedIn profile, accessed [12/10/20](#)]
- **2012-2015: Fischer was Communications Director for PhRMA.**  
“Senior Director, Communications. Dates Employed: Dec. 2013 – Sept. 2015. Employment Duration: one yr., 10 mos. Location: 950 F Street NW, Suite 300, Washington, DC 20004. • Developed strategy and led proactive and reactive communications on science advocacy and regulatory issues including implementation of the Prescription Drug User Fee Act (PDUFA). • Created materials in lay language to convey importance of policy issues to policymakers, patients and the public. • Worked with colleagues in multiple departments as well as external stakeholders on initiative to increase participation in clinical trials among diverse patient populations. • Developed and maintained relationships with national and trade media. Title: Director of Communications. Dates Employed: Oct 2012 – Dec 2013. Employment Duration: one yr, three mos. Director of Communications focusing on science and regulatory affairs as well as intellectual property.”  
[Stephanie Fischer LinkedIn profile, accessed [12/10/20](#)]
- **2018-2020: Fischer was a “patient engagement consultant” for pharmaceutical company Ovid Therapeutics.**  
[Stephanie Fischer LinkedIn profile, accessed [12/10/20](#)]

- **Chelsey Hickman is an instructor for the Patients Rising Now advocacy master class.**

“Chelsey Hickman Chelsey is a skilled government relations professional with nearly 20 years of experience in the U.S. Senate, the U.S. House of Representatives, and the private sector. Chelsey worked on Capitol Hill for over 10 years, covering a broad range of issues, including budget, tax, water, energy, interior, transportation, defense and foreign affairs. During her time on the Hill, Chelsey served as the Chief of Staff to Rep. Kay Granger of Texas, a senior member of the House and the top Republican on the powerful House Appropriations Committee, which oversees all federal spending. Prior to her work on Capitol Hill, Chelsey worked as a technical writer and editor. Chelsey’s areas of expertise include coalition-building, grassroots organization, strategic planning, project management, writing, and editing. She works on a wide array of clients covering a variety of issues, and has made patient advocacy a particular focus. Chelsey was one of the key architects of the Race to Yes initiative, which resulted in the first-ever FDA approval for a treatment for Duchenne muscular dystrophy.”

[Patients Rising Now, accessed [12/10/20](#)]

- **2020: Hickman was a lobbyist for Patients Rising Now.**

[Winning Strategies Washington, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

- **2020: Hickman was a lobbyist for pharmaceutical company Kaléo.**

[Winning Strategies Washington, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

“Kaléo is a new type of pharmaceutical company, dedicated to building innovative solutions for serious and life-threatening medical conditions.”

[Kaléo, accessed [12/10/20](#)]

- **March 2020: Hickman registered as a lobbyist for pharmaceutical company Phlow Corporation.**

[Winning Strategies Washington, Lobbying Registration, [3/20/20](#); Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

- **2020: Hickman registered as a lobbyist for pharmaceutical company Rising Pharma Holdings, Inc.**

[Winning Strategies Washington, Lobbying Registration, [3/25/20](#); Lobbying Disclosure Report, Q1 2020, [5/6/20](#); Q2 2020, [7/8/20](#)]

- **Jenn McNary is an instructor for the Patients Rising Now advocacy master class.**

“Jenn McNary is a trusted voice in the rare disease community, as a mother, public speaker and fierce advocate. Formerly, as the director of outreach and advocacy at a Massachusetts-based nonprofit foundation, she was responsible for the organization of the largest FDA advisory committee hearing in history, with over 1000 Duchenne advocates, families, clinicians and researchers in attendance. There are currently only three drugs approved for Duchenne, Exondys51, Vyondys53 and Emflaza, though in various roles, Jenn was involved in the approval process for all three. Jenn has unique experience in the drug development field, as a parent of children enrolled in the clinical trials, an advocate engaging with the regulators and as a consultant helping to develop programming for patients. Currently, Jenn is consulting in the biotechnology space with an expertise in caregiver/patient engagement, including bringing the patient voice to drug development and solving barriers to access. Her other activities include serving as the Founder of One Rare, a non-profit formed to meet the needs of young adults with rare and chronic conditions and raising her four children in Massachusetts.”

[Patients Rising Now, accessed [12/10/20](#)]

- **2016-2017: McNary was a consultant for Marathon Pharmaceuticals.**

[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

- **2018-2019: McNary was a “patient advocacy consultant” for Centogene.**  
[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

**Centogene services pharmaceutical companies to “accelerate the development of new orphan drugs.”**

“CENTOGENE is a rare disease company focused on transforming clinical, genetic, and biochemical data into medical solutions for Patients. With headquarters in Rostock, Germany and further operations in Berlin, Germany as well as Cambridge, Massachusetts, USA, CENTOGENE is dedicated to transforming the science of genetic information into solutions and hope for patients with rare diseases and their families. CENTOGENE provides the full spectrum of modern methods and technology for human genetics analysis; it is active in research and is constantly developing new and innovative products for human genetics. We are committed to ‘un-rare’ rare diseases by using our worldwide knowledge in the rare disease market, understanding of epidemiology, analyzing clinical heterogeneity of the more than 3800 diseases and developing innovative biomarkers. Based on this knowledge we are bringing rationality to treatment decisions and, thereby, accelerate the development of new orphan drugs.”  
[Centogene, accessed [12/10/20](#)]

- **2020: McNary was a panel member at a BIO conference on ICER.**  
“Panel Member, Company Name: Biotechnology Innovation Organization. Freelance Dates Employed: June 2020 – Present. Employment Duration: seven mos. Get Engaged! How to Talk to ICER and Anyone Else Forming Opinions About Your Care Coverage.”  
[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]
- **2020: McNary is a “Consultant, AMT-130 Team” for uniQure.**  
[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

**uniQure is a gene therapy development company.**

“uniQure is delivering on the promise of gene therapy -- single treatments with potentially curative results. We are leveraging our modular and validated technology platform to rapidly advance a pipeline of proprietary and partnered gene therapies to treat patients with hemophilia, Huntington’s disease and other severe genetic diseases. We are advancing a focused pipeline of innovative gene therapies. We are currently conducting a pivotal phase 3 trial in our lead indication, hemophilia B, and have initiated a phase 1/2 trial in Huntington’s disease. Our pipeline of adeno-associated virus (AAV)-based gene therapies has been developed using an innovative technology platform, supported by industry-leading proprietary commercial-grade manufacturing capabilities.”  
[uniQure, accessed [12/10/20](#)]

- **2019-Present: McNary is an “advocacy coordinator” for Enzerna Biosciences.**  
[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

**Enzerna Biosciences is a gene therapy company.**

“Enzerna Biosciences, Inc is a pre-clinical stage company that is leveraging its proprietary RNA editing technology to develop long-term curative gene therapies for rare genetic disorders.”  
[Enzerna Biosciences, accessed [12/10/20](#)]

- **2019-Present: McNary is a “patient engagement consultant” for Fulcrum Therapeutics.**  
[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

**Fulcrum Therapeutics develops drugs to treat genetic diseases.**

“We launched Fulcrum Therapeutics with a bold vision: To change the course of genetically defined diseases by treating them at their root cause. Our approach to drug discovery generates significant insights into disease biology and allows us to think creatively about the best way to modulate and balance



gene expression. The result: A patient-focused product engine designed to systematically identify and validate cellular drug targets that can modulate gene expression to treat the known root cause of genetically defined diseases.”

[Fulcrum Therapeutics, accessed [12/10/20](#)]

- **2017- Present: McNary is manager of J. McNary Consulting, “seeking opportunities” in the pharmaceutical sector.**

“Manager, Company Name: J. McNary. Consulting Dates Employed: May 2017 – Present. Employment Duration: three yrs, eight mos. Location: Greater Boston Area. EDUCATOR, and PATIENT ADVOCATE with 18 years experience on the front lines of the RARE DISEASE CLINICAL TRIAL, DRUG APPROVAL and REIMBURSEMENT PROCESS, seeking consulting and speaking opportunities within the non-profit, pharmaceutical, medical, regulatory and/or financial sectors. A deeply informed, widely recognized voice for patients and their families and a trusted interpreter of patient experience for caregivers, clinicians, KOLs, regulators, legislators, and corporate stakeholders alike. Experience in the areas of drug development, clinical trial design, endpoint development, the regulatory process, access, reimbursement, patient reported data, caregiver and patient advisory boards and disease state education both in the community and within a company.”

[Jennifer McNary LinkedIn profile, accessed [12/10/20](#)]

- **Charla Penn is an instructor for the Patients Rising Now advocacy master class.**

“Charla Penn is one of WSW’s health care policy specialists. She works extensively with hospitals, provider associations, pharmaceutical and biotechnology companies, insurers, and non-profits to navigate the transforming health care landscape on issues of reimbursement and access to care. Clients rely on Charla for her expertise in reimbursement policy, as well as her legislative skills and policy analysis. Charla helps clients develop, manage, and implement comprehensive government relations strategies, often tackling some of the more complicated and technical aspects of Washington, DC as part of the process, including reviewing and analyzing pending regulations, submitting official comments to pending rules, and crafting responses to Requests for Information. Charla is able to translate complex policy matters into actionable items for clients, and gives them the context they need to make the best decision for their organization. With close relationships in key offices in both the House and Senate, particularly with the professional staff on the Ways & Means and Energy & Commerce Committees, Charla gives clients access to key decision-makers as well as to timely information and ahead-of-the curve intel to help them plan or react quickly, decisively, and effectively.”

[Patients Rising Now, accessed [12/10/20](#)]

- **2020: Penn was a lobbyist for pharmaceutical company Kaléo.**

[Winning Strategies Washington, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

**“Kaléo is a new type of pharmaceutical company, dedicated to building innovative solutions for serious and life-threatening medical conditions.”**

[Kaléo, accessed [12/10/20](#)]

## Lobbying

### PATIENTS RISING NOW IS REPRESENTED BY A LOBBYING FIRM WITH OTHER PHARMACEUTICAL CLIENTS.

**7/1/19: Winning Strategies Washington filed a lobbying registration form on behalf of client Patients Rising Now.**

[Winning Strategies Washington, Lobbying Registration, [7/1/19](#)]

- 2019: Patients Rising Now paid Winning Strategies Washington at least \$80,000 to lobby Congress on their behalf.**  
 According to lobbying disclosure reports for the third and fourth quarters of 2019, Patients Rising Now paid Winning Strategies Washington \$40,000 in each quarter to lobby Congress on their behalf.  
 [Winning Strategies Washington, Lobbying Disclosure Reports, Q3 2019, [10/15/19](#); Q4 2019, [1/17/20](#)]
- 2020: Patients Rising Now paid Winning Strategies Washington at least \$120,000 to lobby Congress on their behalf.**  
 According to lobbying disclosure reports, Patients Rising Now paid Winning Strategies Washington \$40,000 in each of the first three quarters of 2020. The specific lobbying issue reported each quarter was “Patient access to treatments and innovation.”  
 [Winning Strategies Washington, Lobbying Disclosure Reports, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]
- Winning Strategies Washington has not disclosed any specific bills they have lobbied on for Patients Rising Now.**  
 [U.S. Senate Lobbying Disclosure Database, accessed [12/23/20](#)]

### WINNING STRATEGIES WASHINGTON REPRESENTS PHARMACEUTICAL COMPANIES.

**2020: Winning Strategies Washington lobbied for pharmaceutical company Kaléo.**

[Winning Strategies Washington, Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

- “Kaléo is a new type of pharmaceutical company, dedicated to building innovative solutions for serious and life-threatening medical conditions.”**  
 [Kaléo, accessed [12/10/20](#)]
- 2019: Winning Strategies Washington was paid at least \$160,000 to lobby Congress on behalf of pharmaceutical company Kaléo.**  
 [Winning Strategies Washington, Lobbying Disclosure Report, Q1 2019, [4/16/19](#); Q2 2019, [7/19/19](#); Q3 2019, [10/15/19](#); Q4 2019, [1/17/20](#)]

**March 2020: Winning Strategies Washington registered as a lobbying firm on behalf of pharmaceutical company Phlow Corporation.**

[Winning Strategies Washington, Lobbying Registration, [3/20/20](#); Lobbying Disclosure Report, Q1 2020, [4/17/20](#); Q2 2020, [7/15/20](#); Q3 2020, [10/15/20](#)]

**2020: Winning Strategies Washington registered as a lobbying firm on behalf of pharmaceutical company Rising Pharma Holdings, Inc.**

[Winning Strategies Washington, Lobbying Registration, [3/25/20](#); Lobbying Disclosure Report, Q1 2020, [5/6/20](#); Q2 2020, [7/8/20](#)]

**2019: Winning Strategies Washington was paid at least \$10,000 to lobby on “Drug pricing legislation” on behalf of Circassia Pharmaceuticals, Inc.**

[Winning Strategies Washington, Lobbying Disclosure Report, Q3 2019, [10/22/19](#)]

### Drug Pricing Legislation

## H.R. 3 ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

### **Terry Wilcox penned an op-ed opposing the “Lower Drug Costs Now Act.”**

“However, prescription drug legislation soon to be voted on in the House of Representatives threatens the decades-long research pipeline responsible for these lifesaving cures and life-altering treatments. Speaker Nancy Pelosi’s ‘Lower Drug Costs Now Act’ would create de facto price controls on prescription drugs by tying their costs to those in countries where governments set drug prices. According to a recent analysis by the nonpartisan Congressional Budget Office, these prescription drug price controls would reduce drugmakers’ revenues by as much as \$1 trillion over the next decade, resulting in 15 fewer drugs developed over that timeframe. (The FDA approves about 30 new drugs annually.) Manufacturers that refuse the government’s price diktats would receive a fine of between 65 and 95 percent of annual sales. (That’s revenue, not just profit.)”

[Terry Wilcox, op-ed, Real Clear Health, [11/25/19](#)]

- **Terry Wilcox wrote that the “Lower Drug Costs Now Act” would “create defect price controls on prescription drugs,” that would “reduce drugmakers’ revenues” resulting in less new drug development.**

“However, prescription drug legislation soon to be voted on in the House of Representatives threatens the decades-long research pipeline responsible for these lifesaving cures and life-altering treatments. Speaker Nancy Pelosi’s ‘Lower Drug Costs Now Act’ would create de facto price controls on prescription drugs by tying their costs to those in countries where governments set drug prices. According to a recent analysis by the nonpartisan Congressional Budget Office, these prescription drug price controls would reduce drugmakers’ revenues by as much as \$1 trillion over the next decade, resulting in 15 fewer drugs developed over that timeframe. (The FDA approves about 30 new drugs annually.) Manufacturers that refuse the government’s price diktats would receive a fine of between 65 and 95 percent of annual sales. (That’s revenue, not just profit.)”

[Terry Wilcox, op-ed, Real Clear Health, [11/25/19](#)]

### **Terry Wilcox wrote that proponents of H.R. 3 fail to mention other countries with lower prescription drug costs often achieve those lower costs by not offering the “newest and best treatments from their populations.”**

“What proponents of this bill don’t mention is that other countries partially achieve their drug savings by excluding the newest and best treatments from their populations. According to the Galen Institute, just 62 percent of modern medicines introduced between 2011 and 2018 are available in Germany, 60 percent in the U.K., 50 percent in Japan, and 48 percent in France. These countries also freeload off U.S. research and development, which is responsible for most drug breakthroughs. Americans subsidize the latest drug treatments for the rest of the world.”

[Terry Wilcox, op-ed, Real Clear Health, [11/25/19](#)]

### **Terry Wilcox wrote that H.R. 3 would lead to higher drug costs.**

“The kicker: The CBO expects that the legislation would actually lead to higher costs for new drugs because, to recoup revenues, manufacturers would be forced to charge more for new cures that haven’t reached socialized markets and received a reference price. Talk about unintended consequences.”

[Terry Wilcox, op-ed, Real Clear Health, [11/25/19](#)]

## H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

## S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information.*

**PATIENTS RISING SEEMS TO FOCUS ON HEALTH CARE COSTS ADDED BY INSURANCE COMPANIES AND PHARMACY BENEFIT MANAGERS (PBMS), WHILE DOWNPLAYING THE ROLE OF PHARMACEUTICAL COMPANIES IN SETTING PRICES.**

**PATIENTS RISING REPEATEDLY DOWNPLAYED OR IGNORED THE ROLE OF DRUG MAKERS IN SETTING PRESCRIPTION DRUG LIST PRICES.**

**Patients Rising said that “all sides must seek to put cost in context,” then failed to mention the role of pharmaceutical companies in setting drug prices.**

“Patients Rising points out that all sides must seek to put cost in context: Hospitals and clinics may double the price they charge patients for pharmaceuticals; pharmaceutical benefits managers may negotiate discounts that are never passed on to the patients; and co-pays, the amount patients pay out of their own pockets, is determined by their insurance company. All of these issues have to be taken into consideration to help patients get ‘the right treatment, right now.’”

[Patients Rising press release, via Business Wire, 3/30/16]

**A Patients Rising University post argues that the cost of diabetes is “more than the cost of insulin, that’s for sure.”**

“THE DIVERSE COST OF DIABETES CARE. Patients Rising University takes a wide view on the cost of diabetes. It’s more than the cost of insulin, that’s for sure.”

[Patients Rising, [3/5/20](#)]

- **The Patients Rising University article about the cost of diabetes downplays the cost of insulin, which “hits a patient’s pocket hard,” but discusses the cost of medical supplies instead.**

“The numbers are quite stunning. According to the American Diabetes Association, over 30 million Americans are living with diabetes. The total spending on diabetes grew 26 percent over five years: from \$245 billion in 2012 to \$327 billion in 2017. The US healthcare system spends \$1 in \$7 on treating diabetes and its complications. Diabetics spend about 2.3 more on medical expenses than their non-diabetic counterparts. On average, patients with diabetes spend \$16,752 out-of-pocket per year, of which \$9,601 is attributed to diabetes. What about the cost of medicine? The daily regimen with insulin (or some newer treatments) hits a patient’s pocket hard. But medical supplies and health care services are also a significant cost burden. Below is a breakdown of how the cost is distributed in diabetes care: In-patient care: 30 percent of the medical spend. Prescription medications to treat diabetes-related complications: 30 percent of the total spend. Anti-diabetes agents and diabetes supplies, including insulin pumps: 15 percent of the spend. Doctor’s office visits: 13 percent of the spend. There are indirect ways of looking at the cost of diabetes too: Absenteeism, that could lead to lost wages for the patient. Inability to work due to disease-related disability. Pain and suffering. Unpaid caregiver time.”

[Patients Rising, [3/5/20](#)]

- **Patients Rising University advises patients when searching for a health insurance plan to “ensure that the plan covers prescription drugs,” noting that government insurance programs and private plans pay for the majority of diabetes-related expenses.**

“Government-sponsored insurance (Medicare, Medicaid, military) pays for a majority of diabetes costs in the US (67.3 percent) while private insurance covers 30.7 percent of the cost. Uninsured patients cover the remaining 2 percent of costs. When looking for a health insurance plan, diabetes patients must ensure that the plan covers prescription drugs, supplies and essential medical services.”

[Patients Rising, [3/5/20](#)]

- **Patients Rising University advises diabetes patients to find out whether their insulin is covered by their insurance plan.**

“Are all your supplies and services covered by your healthcare policy? These include: [...] Prescription medications and accessories: insulin or other medication, syringes and needles. Insurance plans do not

always cover all the available insulins; it is important for you to know if your specific brand of insulin or other prescription treatment is in your health plan's formulary. Another important term is your medication's "tier" in the formulary. Generic or "preferred" medications are usually placed on lower tiers and have lower out-of-pocket costs than higher-tiered medications."

[Patients Rising, [3/5/20](#)]

- **Patients Rising University advises diabetes patients that they may see out-of-pocket costs increase if their doctors prescribe them a new treatment.**

"If your doctor and you have decided that switching your treatment is vital – either a new type of insulin or a new treatment – the next step is to ascertain coverage policies by your health plan. Your doctor may have to request a coverage exception if the treatment is not covered by your plan. Visit Juvenile Diabetes Research Foundation's website to find additional information on how to navigate switching your treatment. If the new treatment is covered, make sure you understand your share in the price of the medication based on where it is placed in your health plan's formulary. You could potentially see an impact on your out-of-pocket cost."

[Patients Rising, [3/5/20](#)]

- **The Patients Rising University advice for reducing costs associated with diabetes includes not skipping doses or treatments, talking to health care providers about financial limitations, shopping around online pharmacies for better prices, and accessing pharmacy assistance programs.**

"HOW CAN PATIENTS AND THEIR FAMILIES REDUCE THE COST OF CARE THEY INCUR? Avoid skipping doses or treatment to prevent unwanted fluctuations in your blood sugar levels and associated complications such as heart disease, kidney disease, infections, vision damage, all of which can aggravate your health and further add to your cost of care. Speak to your care provider, either doctor, nurse, pharmacist or a care coordinator at the clinic, about financial concerns with your care. The American Association of Diabetes Educators offers several resources to find affordable insulin, tools for healthcare savings, and more. Online retailers can sometimes offer good deals. Prescription medications are usually cheaper with mail-order pharmacies than retail pharmacy stores. FDA's BeSafeRx provides tips on identifying a safe and reputable online resource for your medications. Pharmacy Assistance Programs. Most pharmaceutical manufacturers offer patient assistance programs that can reduce your co-pays but do not contribute toward your annual deductible."

[Patients Rising, [3/5/20](#)]

**In an essay about the costs of type 1 diabetes, a Patients Rising member says that her insulin is "completely covered" by her insurance and that her glucose tabs are just \$1.50 per bottle.**

"My insulin, Novolog (fast-acting) and Tresiba (long-lasting), are completely covered, along with my test strips, alcohol pads, needles, lancets and ketone strips. The pharmacy I use has reduced prices and my glucose tabs are about \$1.50 a bottle, along with other pharmacy items not related to diabetes that I may need."

[Patients Rising, [7/10/20](#)]

- **No other mention of pharmaceutical costs are mentioned in the essay about the costs of type 1 diabetes.**

[Patients Rising, [7/10/20](#)]

**Patients Rising called on "patients, policy makers and payors to work together to bring patients the best that medical innovation has to offer" but didn't include pharmaceutical companies.**

"CMPI and Patients Rising call on patients, policy makers and payors to work together to bring patients the best that medical innovation has to offer."

[Patients Rising press release, via Business Wire, 4/25/16]

**Patients Rising said that "any discussion of healthcare spending...should look at healthcare as a whole not just target new therapeutics."**

"ICER says its proposals are intended to address what its members see as the rising cost of healthcare. However, Patients Rising has long maintained that any discussion of healthcare spending should be based on fact, not

rhetoric, and should look at healthcare as a whole not just target new therapeutics.”  
[Patients Rising press release, via Business Wire, 5/24/16]

**Patients Rising co-founder Jonathan Wilcox wrote that “while much of the country debates drug prices,” the “problems of systemic insurance design” shouldn’t be ignored.**

“While much of the country debates drug prices, we are unwise to ignore the real harm that patients in South Dakota say they are experiencing in the form of barriers to medical access and just chalk it up to one more intractable health care policy fight. These problems of systemic insurance design aren’t going away, and will be waiting for the next president in 2017 - whoever he or she is. It’s a shame that the necessary reform conversation won’t begin until after the election. South Dakotans need help now.”

[Jonathan Wilcox, op-ed, Argus Leader (Sioux Falls, South Dakota), 10/31/16]

**Terry Wilcox called for reducing prescription drug prices by bringing “prices in line with the NET price or average sales price and phas(ing) out the complicated rebate system, which drives up list prices.”**

“Bring prescription drug prices in line with the NET price or average sales price and phase out the complicated rebate system, which drives up list prices. Azar has started by asking the pharmaceutical industry to lower their prices. This is one of the best ways to do it. According to new data from IQVIA, the NET price paid for medicines has barely risen at all. It will not be easy to unravel the rebate structure, but a system that is constantly having to explain itself needs reform. As innovators, this is the moment to lead the change.”

[Terry Wilcox, op-ed, Inside Sources, [5/23/18](#)]

## **PATIENTS RISING REGULARLY ATTACKS INSURANCE COMPANIES AND “COPAY ACCUMULATORS,” WHILE SUPPORTING COPAY ASSISTANCE PROGRAMS**

**2015: Patients Rising blamed insurance companies for creating financial barriers between patients and necessary treatments.**

“Patients Rising says high co-pays and other insurance practices often stand between a patient and their best treatment option. These obstacles can be made worse by delays in the government approval processes.”

[Patients Rising press release, via Business Wire, 9/16/15]

**Patients Rising points to “copay accumulators” and pharmacy benefit managers as two key reasons for high out-of-pocket costs and reducing “access” to health care.**

“ACCESS’ It’s a word you hear Patients Rising use a lot. But what do we mean when we use it? When we talk about access what we’re really talking about is... A patient’s right to ACCESS quality healthcare and dignified treatment. [...] High Out of Pocket costs: You may have insurance, but what is your deductible? Jordan has multiple sclerosis and a \$7900 deductible, What is your premium? Jordan also has a monthly premium of \$570 (the math: that’s about \$15K/year before his insurance lifts a finger for him) Copay Accumulators: Jordan’s insurance also used a ‘copay accumulator’ which does not apply the value of any copay coupons (the only thing that made his expensive treatments affordable) towards his deductible. So the insurer gets the value of the coupon AND Jordan’s deductible. Pharmacy Benefit Managers: A ‘middleman’ between you and your drug coverage. PBMs negotiate lower drug prices with manufacturers but rarely pass savings on to customers. They can also tell insurers not to cover a drug, and in some cases that means a patient with a rare disease may not have access to the only treatment available for their disease.”

[Patients Rising, [7/18/19](#)]

**Patients Rising: “From our perspective, patient assistance programs are a valuable tool that helps every patient get access to the treatment prescribed by their doctor – no matter how high their insurance premiums.”**

“Patient Assistance Programs provide access to life-saving treatments Every year, millions of patients rely on patient assistance programs to gain access to life-saving treatments. What are patient assistance programs? If a patient can’t afford to pay their insurance co-pay, non-profit organizations step in and provide direct financial assistance to patients in need. In many cases, drug companies themselves support patient assistance programs

as a way to provide access for those who can't afford ever-increasing insurance co-pays. The programs, according to BioWorld.com, 'provide a safety net for patients with the greatest financial need to ensure they could have access to life-saving medications. That sense of compassion still undergirds the efforts of many programs.' These programs are sizable. USA Today reported earlier this year that '100 million prescriptions are filled each year with co-pay coupons.' The Partnership for Prescription Assistance says that 'nearly 10 million patients get access to patient assistance programs.' From our perspective, patient assistance programs are a valuable tool that helps every patient get access to the treatment prescribed by their doctor — no matter how high their insurance premiums."

[Patients Rising, [10/18/16](#)]

**Patients Rising said that insurance companies were attacking patient assistance programs as “part of their effort to impose price controls and value frameworks.”**

“Insurance companies and their allies have long targeted patient assistance programs, which they see as an impediment to higher profits. Increasingly, interest groups are targeting patient assistance programs as part of their effort to impose price controls and value frameworks. The latest agenda-driven campaign is being advocated by Peter A. Ubel, MD; and Peter B. Bach, MD.”

[Patients Rising, [10/18/16](#)]

**Patients Rising dismissed the concern that copay assistance programs weaken pressure on drug companies to reduce prescription drug prices saying that it was merely “public outcry” and it shouldn't outweigh patients' access.**

“Insurance companies and their allies have long targeted patient assistance programs, which they see as an impediment to higher profits. Increasingly, interest groups are targeting patient assistance programs as part of their effort to impose price controls and value frameworks. The latest agenda-driven campaign is being advocated by Peter A. Ubel, MD; and Peter B. Bach, MD. You probably recognize that last author. Peter Bach is the cost-guru and director of Memorial Sloan Kettering's Center for Health Policy and Outcomes, who wants his flawed 'Drug Abacus' tool to replace doctors in deciding every patient's treatment. 'Co-pay assistance programs reduce public outcry over outrageous drug prices,' the pair write in The Annals of Internal Medicine. 'but, co-pay assistance programs act as an artificial price support, which lessens the incentive for consumers to factor cost into their decisions and further weakens the pressure on pharmaceutical companies to lower the price of their product.' Notice Peter Bach's priorities: public outcry trumps patients getting help.”

[Patients Rising, [10/18/16](#)]

**Patients Rising said that limiting copay assistance was “against medicine's tradition of benevolence” agreeing with an opinion piece that bans on copay assistance programs were “unethical” and “patient unfriendly.”**

“Limiting co-pay assistance is against medicine's tradition of benevolence. Thankfully, a pair of patient advocates have refuted the latest attack on patient assistance programs. In a piece at LinkedIn, Dr. Robert Goldberg, vice-president of the Center for Medicine in the Public Interest, and Dr. Rafael Fonseca, the Getz family professor of cancer, chair of the department of medicine and distinguished Mayo investigator at Mayo Clinic in Phoenix, argue that laws that ban co-pay assistance are unethical. 'To create a disincentive as this for people facing serious medical illness appears to me as a fundamental violation of medicine's stance of benevolence,' they write in a piece published at LinkedIn. 'Rather this has the appeal of altruism, sacrifice the few for the benefit of the many.' 'Lastly, government regulations that eliminate this co-pay assistance are demonstrably patient unfriendly. Commercially insured patients can receive this directly and in another study by Dusetzina she shows that the average copay for specialty medications is only \$35. In another study it was shown that 90 percent of myeloma patients pay less than \$100 per month for lenalidomide, a backbone for the treatment of this disease.”

[Patients Rising, [10/18/16](#)]

**Patients Rising said that “copay coupons are one way a drug manufacturer can make their drug affordable for patients.”**

“Copay coupons are one way a drug manufacturer can make their drug affordable for patients. The copay coupon works like this: A Patient is prescribed a drug and signs up for a copay coupon Then the Patient goes to the pharmacy to get their drug The Patient uses the manufacturer's copay coupon to pay whatever the insurer will

not cover (often minus a typical copay amount of \$5-30) The pharmacy processes the coupon which means the manufacturer pays the copay for the patient” [Patients Rising, [8/18/18](#)]

**Patients Rising said that copay coupons can be positive when an illness has just one treatment, but might encourage the use of a more expensive drug for an illness with several treatments, which in turn may raise out-of-pocket costs.**

“DOES THAT MEAN COPAY COUPONS ARE A BAD THING? No. If you are a patient with a rare disease (like hypoparathyroidism) and you only have one drug option (Natpara) to treat your condition, having copay coupons makes great sense. Copay coupons can make that drug more affordable for you. However, if you have a condition that has multiple treatment options (like psoriatic arthritis), then copay coupons might make you more likely to choose a more expensive drug. This means insurers pay those higher costs – a financial burden they pass down to their customers.” [Patients Rising, [8/18/18](#)]

**Patients Rising implied that copay coupons are a way for drug makers to make a patient “feel obligated to stay on that particular drug.”**

“But it’s not just the insurers who want your money. Manufacturers want to sell their expensive drugs. If they get you started on a drug that is \$9000/month there is a good chance that when your coupons run out, you will feel obliged to stay on that particular drug; you may even need to, even if it means paying enormous copayments until your deductible is satisfied.”

[Patients Rising, [8/18/18](#)]

**Patients Rising advises patients to contact their insurance companies if they are offered a copay coupon.**

“HOW TO AVOID BEING TRAPPED. Make sure you know what you are getting into when you are offered copay coupons for a drug. Contact your insurer and make sure that the value of the copay coupon will be applied to your annual deductible. If your insurer does not accept the copay coupon towards your deductible, then make sure you are aware what your out of pocket costs will be once the coupon runs out.”

[Patients Rising, [8/18/18](#)]

**Patients Rising: “The CoPay Accumulator is the latest barrier helping to raise the out of pocket costs of patients even further. What can you do about it?”**

[Patients Rising, [3/26/18](#)]

**Patients Rising blamed copay accumulators for rising out-of-pocket costs.**

“A new patient barrier to access is here courtesy of your health insurer and pharmacy benefit manager and it is known as the ‘CoPay Accumulator’. Remember this term: CoPay Accumulator. As we wrote last week, it’s beginning to affect patient out-of-pocket costs across the country. Health insurance gives us peace of mind. At least we hope it does. We pay for it so that we’re covered for medical emergencies, routine health needs, and prescription drugs. But lately, more and more of the cost burden is being placed on us by our insurers. This is especially true if we have a chronic illness.” [Patients Rising, [3/26/18](#)]

**Patients Rising blamed copay accumulators, co-insurance payments, and rising deductibles for increasing patient costs, but made no mention of rising drug prices.**

“Patients living with a chronic or life-threatening illness are experiencing rising copays. This is on top of already hefty co-insurance payments and rising deductibles. There is no end in sight for us. As we rang in 2018 a few short months ago, little did we know what our pharmacy benefit managers (PBMs) had in store for us. Many PBMs and the insurers they work with are no longer going to count copay assistance cards as part of meeting our deductibles. This new policy flies in the face of what’s best for us. It’s outrageous not to mention discriminatory.”

[Patients Rising, [3/26/18](#)]

**Patients Rising said that copay accumulators were how pharmacy benefit managers to hurt patients with chronic illness making “out-of-pocket costs unsustainable.”**

“Those of us who rely on expensive therapies for treating chronic diseases — many of which there are no generics for — are the most vulnerable. We desperately need the medicine. We’re fighting to live productive lives often



working full-time to afford things like the direct out of pocket costs associated with our illness. For many of us, the new CoPay Accumulator programs will make our out of pocket costs unsustainable. It's just one more in an ever-growing list of things that PBMs are doing that hurt us." [Patients Rising, [3/26/18](#)]

**Patients Rising said that copay coupons were an increasingly popular way for drug makers to "offset prescription drug costs."**

"Copay Coupons Are An Increasingly Popular Way To Offset Prescription Drug Costs. Copay coupons are aid that drug manufacturers provide directly to patients to help them cover their copay costs, which can easily reach hundreds of dollars per prescription ... The health care consultancy IMSQuintiles estimates that 19 percent of total prescriptions were filled using copay coupons in 2016, nearly 50 percent more than in 2013."

[Patients Rising, [5/2/18](#)]

**Patients Rising said that copay accumulators would force many patients to stop using their medications and called for protecting copay coupons.**

"The "cheaper alternative" for many patients on fixed incomes is not taking their needed medications at all. In other words, it's true that copay accumulator programs will decrease patient use of their medicines. But at what cost? Patients Rising argues that copay coupons must be protected. Patients and legislators must rise up to make their voices heard."

[Patients Rising, [5/2/18](#)]

**Patients Rising called copay assistance "a lifesaver for many" patients with chronic illnesses.**

"Copay assistance often comes in the form of a qualifying award granted from the manufacturer of their medicine. This award helps offset patient out of pocket costs for high deductibles and copays. Due to the high costs associated with chronic illnesses, copay assistance is a lifesaver for many. Many patients not only need it, they depend on it. At the end of the day, this assistance can be the difference between paying their rent, buying groceries, or taking their medicine."

[Patients Rising, [3/20/18](#)]

**Patients Rising claimed to be "committed to helping patients find ways to ease the financial burden of cancer."**

"The financial burden of cancer can be overwhelming for patients. It's difficult enough to manage our medical decisions, let alone navigate the insurance paperwork. Here at Patients Rising, we're committed to helping patients find ways to ease the financial burden of cancer. That's why we're sharing tips, suggestions and ideas to help lighten the burden. We're also educating patients about the underlying factors contributing to the financial burden of cancer."

[Patients Rising, [9/14/16](#)]

**The Patients Rising guide to the financial burden of cancer does not lay any of the blame of the high costs of cancer treatment on drug makers, but blames insurance companies for exploiting "loopholes by charging patients more to receive a treatment in pill form."**

"Insurance policies are contributing to the financial burden of cancer. 'Commercial insurers in the United States have increasingly shifted medical care costs to patients through higher premiums, deductibles, and coinsurance and copayment rates,' the National Cancer Institute concludes in its analysis of Financial Toxicity and Cancer Treatment. 'The 2014 Commonwealth Fund Biennial Health Insurance Survey indicated that 23 percent of insured adults aged 19 to 64 years experienced out-of-pocket costs equal to 10 percent or more of household income.' The National Cancer Institute explicitly names oral cancer treatments as an area where policies are contributing to the financial burden of cancer. Some insurance companies exploit loopholes by charging patients more to receive a treatment in pill form. 'Oral cancer drug-based treatments are frequently covered under patient pharmacy benefits' specialty tier, requiring high coinsurance that patients pay out of pocket,' the National Cancer Institute reports. 'These trends in treatment cost and changes in insurance coverage suggest that financial distress associated with acute and chronic cancer is highly prevalent, even among persons with health insurance.'"

[Patients Rising, [9/14/16](#)]

**Patients Rising Now called on people to urge CMS to reverse their regulation on copay accumulators.**

“Patient Action Alert: Save Copay Assistance Programs. Patients Rising Now is mobilizing a patient advocacy campaign to urge CMS to protect copay assistance programs. Take action here and urge CMS to protect patients!”

[Patients Rising Now, [2/22/20](#)]

**November 2019: Patients Rising Now advised people to avoid insurance plans with copay accumulators during the open enrollment period.**

“Here’s the first thing every patient should check before picking a health insurance plan during open enrollment: Does the plan have a copay accumulator? Insurance companies use copay accumulator programs to increase a patient’s out-of-pocket costs, and they are especially costly for patients living with chronic diseases, such as psoriatic arthritis and multiple sclerosis. ‘Picking the wrong plan during open enrollment can mean a year of red tape, endless insurance appeals, or painful side effects from failing on the wrong treatment,’ advises Terry Wilcox, executive director at Patients Rising, which has been a leader in the fight against copay accumulator programs. ‘Avoid any health insurance plan with a copay accumulator,’ she advises.”

[Patients Rising Now, [11/11/19](#)]

**Patients Rising Now praised legislation in Illinois and Virginia that banned insurance companies from using copay accumulators.**

“In contrast to the federal government’s protection of insurance co-pay accumulators, states are taking action to protect patient access to patient assistance programs. Last month, Illinois Governor J. B. Pritzker signed into law comprehensive regulation of pharmacy benefit managers. Authored by Rep. Greg Harris, HB 465 included a provision to require insurance companies to count manufacturer coupons, discounts and co-pay cards toward a patient’s deductible, banning ‘copay accumulator’ schemes. Earlier this year, West Virginia and Virginia became the first states in the country to ban insurance companies from using copay accumulator programs from counting against a plan’s deductible or out-of-pocket limit.”

[Patients Rising Now, [9/9/19](#)]

**February 2020: Patients Rising Now criticized a proposed regulation that would allow insurers to “ignore copay assistance programs when calculating out-of-pocket costs of deductibles, coinsurances, and copays.”**

“Patients struggling with the high cost of health insurance can expect even higher out-of-pocket costs in 2021, under an insurance regulation proposed by the Centers for Medicare & Medicaid Services. Last month, the obscure federal agency under the Department of Health and Human Services released the ‘Notice of Benefit and Payment Parameters Rule for 2021,’ an annual set of proposed regulations governing health insurance plans. Under the proposed CMS regulations, insurance companies could completely ignore copay assistance programs when calculating out-of-pocket costs of deductibles, coinsurances, and copays. [...] Patient advocates say that regulatory language is a devastating change to how insurance companies calculate a patient’s out-of-pocket costs and give a green light to what’s become known within the healthcare sector as copay accumulator programs. ‘This loophole will allow insurance companies to dramatically increase patients’ out-of-pocket in 2021,’ explains Terry Wilcox, executive director of Patients Rising, a national patient advocacy non-profit organization that helps patients overcome insurance barriers to access.”

[Patients Rising Now, [2/22/20](#)]

**Patients Rising Now called copay accumulators “discriminatory” and said they put patient health at risk and cause “deliberate financial toxicity and clinical harm.”**

“Speaking for patients fighting serious diseases, health plan copay accumulator programs are a discriminatory practice that limits access to needed medicines and puts patients’ health at risk. Therefore, our goal is to work with stakeholders to advance policy solutions that protect patients from deliberate financial toxicity and clinical harm, especially when patients are medically underserved and/or are treated with medications that have no generic alternatives.”

[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now defended patient assistance programs saying they were necessary as a “safety net” for those who lack health insurance.**

“Many state, non-profit and corporate prescription assistance and access programs (PAPs) help patients obtain free or nearly free medicines if they qualify. Serving as a safety net for the millions of Americans who lack health insurance or whose insurance does not sufficiently cover the cost of the medications they need, PAPs have been in existence for decades and come in different forms – some provide cash subsidies to needy patients, others offer free or discounted products, product coupons, and copayment assistance.”

[Patients Rising Now, accessed [12/11/20](#)]

**Patients Rising Now said that opponents of patient assistance programs would sacrifice the “needs of financially needy Americans whose health will suffer because they can’t get the medicines their doctors prescribed.”**

“Yet, health insurers and other opponents claim PAPs remove the incentive for patients to seek less-expensive alternative treatments and both pharmacy benefit managers and federal and state lawmakers are taking action to stop drug manufacturers and nonprofit charities from offering prescription assistance. The consequence of these actions is obvious: in effort to reduce patients’ demand for branded medicines, opponents of PAPs are sacrificing the needs of financially needy Americans whose health will suffer because they can’t get the medicines their doctors prescribed.” [Patients Rising Now, accessed [12/11/20](#)]

## **PATIENTS RISING BLAMES PBMS FOR RISING PRESCRIPTION DRUG COSTS.**

**“Pharmacy benefit managers – the health care industry’s secretive corporate middlemen – are driving up the costs of prescription drugs and vital treatments.”**

[Patients Rising, [10/14/16](#)]

**Patients Rising blamed pharmacy benefit managers for the rising cost of insulin, asserting that drug makers were offering steep discounts for the medication.**

“Pharmacy benefit managers – the health care industry’s secretive corporate middlemen – are driving up the costs of prescription drugs and vital treatments. According to the Wall Street Journal, over the past several years, patients have watched insulin prices rise – ‘yet most of the revenue from the increases isn’t going to the drug manufacturers. It is largely the middlemen that benefit.’ ‘The price increases—top-selling insulins have more than doubled in price since 2011—reflect the growing role of middlemen known as pharmacy-benefit managers who negotiate rebates and fees based on list prices,’ the Journal reports. ‘Net prices, or what drugmakers retain after discounts, have stayed the same or fallen in the past two years as the pharmaceutical companies compete to offer ever-deeper discounts to stay on the preferred drug lists at insurers and the PBM middlemen.’ So, who is pocketing the difference? The Financial Times reports that the largest pharmacy benefit manager in the country, Express Scripts, ‘reported net profits of \$773.5 million last year.’ That’s net profits – money that goes to Express Scripts after all of its expenses. Remember: they are a corporate middleman. They didn’t create anything.”

[Patients Rising, [10/14/16](#)]

**Patients Rising argued that pharmacy benefit managers effectively pressure drug companies to raise their prices.**

“Pharmacy benefit managers use accounting gimmicks to score higher profits. Think of it like the way retail outlets advertise their big annual sales and product markdowns. When you see the Black Friday sale for ‘75percent off,’ it’s based on the suggested retail price. The higher the suggested retail price, the bigger the savings. Under their contracts, pharmacy benefit managers earn profits based on the ‘savings.’ So, when a price goes up, so do their profits. ‘Because rebates are based on a percentage of a drug’s list price, PBMs have benefited as the price of drugs has skyrocketed in recent years,’ the Wall Street Journal explained earlier this month, ‘...these rebates also can encourage drug companies to increase prices more sharply than they would have done otherwise.’ ‘For example, if a drugmaker wants to raise the price it gets for a drug by 6percent to drive sales growth and offset research costs, it has to raise the sticker price even more than that to offset the percentage it rebates to PBMs,’ Ron Cohen, chief executive of drugmaker Acorda Therapeutics Inc., told the

Journal. 'So you get this pressure year after year that tends to escalate the price increases.'"  
[Patients Rising, [10/14/16](#)]

**Patients Rising blamed pharmacy benefit managers for patients' higher out-of-pocket costs.**

"Pharmacy benefit managers' schemes directly cost patients more money with higher out-of-pocket costs. That's because co-pays are often based on a percentage of the retail price of a prescription. Again, it all has to do with the order of the discount. Patients are paying BEFORE the PBM gets its rebate. The Journal shares the story of an insulin patient who used to pay \$40 for a six-week supply of insulin. Come January, she'll pay \$600 — 'because, instead of a fixed-dollar-amount copay, her insurance plan charges 30percent of the pharmacy price of insulin.' In other words, PBMs and insurance companies benefit from higher drug prices. Higher sticker prices mean higher co-pays and higher rebates."  
[Patients Rising, [10/14/16](#)]

**"PBMs rely on secrecy to maintain their control of the prescription drug market."**

[Patients Rising, [10/14/16](#)]

**Patients Rising said that drug makers give PBMs discounts on prescription drugs that aren't passed on to consumers and called for exposing "the relationship between PBMs and insurers."**

"Remember, pharmacy benefit managers (PBMs) came about because insurers were too busy dealing with claims to negotiate with drug manufacturers. PBMs are the ones doing the negotiating, supposedly on our behalf! Drug manufacturers give them discounts (sometimes up to 55percent) in return for PBMs telling insurers to put specific drugs on their formularies. But PBMs and insurers aren't passing those savings onto us. They're keeping the profits for themselves. In closing, PBMs have gone unregulated by states and the federal government. But now, some states are taking action and Sen. Susan Collins has introduced a bill on the federal side. It's time to expose the relationship between PBMs and health insurers and force them to do what they're supposed to do: operate in patients' best interests."  
[Patients Rising, [3/26/18](#)]

**Wilcox argued that generic drug manufacturers operate on slim profit margins and that price increases among generic drugs were due to "drug distribution channels that are filled with middlemen."**

"Because generic drug manufacturers don't need to recoup research and development (R&D) and advertising costs, they only make a marginal profit above the cost of manufacturing. Warren points to a handful of well-publicized examples of generic drugs like insulin where the list prices have skyrocketed in recent years. Yet these examples do not indict the entire generic drug market but rather the drug distribution channels that are filled with middlemen actually responsible for these price increases. Consider: While the list price of insulin has more than doubled since 2011, the net price has remained flat. What's the difference between the list price and the net price? The net price includes the billions of dollars of rebates that drug manufacturers pay to pharmacy benefit managers (PBMs), which are middlemen between manufacturers and insurers. Rebates are estimated to make up about one-third of total list prices, according to the Berkeley Research Group, and are responsible for nearly all of the list price increases of recent years."  
[Terry Wilcox, op-ed, The Hill, [1/4/19](#)]

**Wilcox blamed PBMs for increased drug prices.**

"Why do drug manufacturers pay these dramatic rebates? Because they need to in order to get on insurance plan formularies, whose vast scale allows generic drugs to be profitable. At PBMs' behest, competition among drugmakers to offer ever-greater rebates to access these preferred drug lists is the driving force behind list price increases. [...] In theory, these rebates to PBMs are supposed to be passed on to patients in the form of lower drug prices. In practice, they drive up list prices and are partially used by insurers to lower overall employer plan costs. While lower premiums are nice, this is cold comfort for the sick patients who pay significantly more for their prescription drugs as a result. Under this system, the sick subsidize the healthy."  
[Terry Wilcox, op-ed, The Hill, [1/4/19](#)]

Wilcox, in an essay called "How to Lower Drug Prices," wrote that focusing on drug list prices was "a

**simplistic solution to a complex cost calculation.”**

At his State of the Union Address earlier this month, President Trump said his ‘next major priority’ is to lower the cost of prescription drugs. This is one of Trump’s few policy initiatives that could garner bipartisan support. But patients and patient advocates are skeptical. They’ve heard this goal before. Further, solely focusing on lowering the list prices of prescription drugs is a simplistic solution to a complex cost calculation, which also includes skyrocketing co-payments, deductibles, premium, and other out of pocket costs.”

[Terry Wilcox, op-ed, Real Clear Health, [2/22/19](#)]

**Wilcox: “Any effective drug pricing reform must lower the drug prices that patients actually pay, independent of whether or not such reforms – given the complex nature of the prescription drug supply chain – actually lower list prices.”**

[Terry Wilcox, op-ed, Real Clear Health, [2/22/19](#)]

**Wilcox wrote that major pharmaceutical companies have lowered their “net” prices even as list prices have continued to increase and attributed that increase to paying rebates.**

“Consider: While list prices have grown by 37 percent over the last decade, net prices (list prices minus rebates) have remained essentially flat. According to SSR Health, net drug prices fell by more than five percent last year, with major drugmakers, including Johnson & Johnson, Merck, and Novartis disclosing that they’ve actually lowered their net prices in recent years. In 2019, nearly all list price increases have been in response to the need to cover growing rebate costs.”

[Terry Wilcox, op-ed, Real Clear Health, [2/22/19](#)]

**Wilcox blamed drug company rebates as the driving factor behind out-of-pocket costs soaring for “the sickest patients.”**

“Currently, rebate dollars are mostly passed on to insurance companies which use them to lower overall premium costs. With average premiums more than doubling between 2013 and 2017, these savings are nice. But they come at the expense of the sickest patients who see their out-of-pocket prescription drug costs soar – with no direct relief – as a result.”

[Terry Wilcox, op-ed, Real Clear Health, [2/22/19](#)]

**Wilcox praised a Trump Administration rule to require drug company rebates be used to offset prescription drug costs for patients rather than supporting premium reduction.**

“The HHS rule would reform the drug supply chain to require that rebates directly go to offset prescription drug costs rather than premiums. This reform promises to significantly reduce drug prices for those who need them most and are responsible for generating the rebates in the first place. The rule is limited to Medicare and Medicaid because similar action in the private market requires congressional approval. If policymakers can get their heads around this complex issue and resist the urge to fall back on bumper-sticker solutions, this reform should generate the type of bipartisan support needed to finally bring some real cost relief to patients.”

[Terry Wilcox, op-ed, Real Clear Health, [2/22/19](#)]

**August 2019: Patients Rising Now supported proposed Trump Administration rules that targeted “backdoor rebates” and encouraged “direct discounts to those who receive their health care through Medicare/Medicaid.”**

“Patients Rising Now welcomes the proposed changes by the Trump Administration aiming to lower costs for patients by targeting backdoor rebates and encouraging direct discounts to those who receive their health care through Medicare/Medicaid. The current drug supply chain directly disadvantages those who use health care the most through perverse incentives that create access barriers disproportionately affecting patients living with chronic and life-threatening illnesses. These patients have waited years for reform of this deeply flawed system that has permitted the PBM industry and health insurers to collect billions in rebates on medicine without passing on the savings. The HHS policy outline is a solid start, and also a helpful reminder of how truly outrageous the current system is. It’s time for rebates negotiated in the name of patients to directly benefit those patients. The entire system is currently driven by “kabuki pricing constructs” that do not benefit patients. At best rebates are subsidizing premium costs for all members, with little-to-no direct drug cost relief for chronically

ill patients who need it most. At worst they are using these rebates to bolster profits. A recent survey by the Pharmacy Benefit Management Institute reveals that more than two-thirds of insurers use rebate payments to offset their overall spending on drug costs. Only 11 percent use rebates to offset member premiums. And just 4 percent report using rebates to reduce patient out-of-pocket costs at the point of sale. Our goal is to work with the administration and all stakeholders to advance policy solutions that are transparent and directly benefit the bottom line for all patients.” [Patients Rising Now, [8/6/19](#)]

**November 2020: The Patients Rising Podcast discussed ways that pharmacy benefits managers “profit at patients’ expense” and drive up prescription drug prices.**

“On this episode of the podcast, Terry and Bob discuss how pharmacy benefit managers (PBMs), middlemen between drug manufacturers and insurers, profit at patients’ expense. PBMs collect hundreds of billions of dollars worth of rebates each year from drug companies but then don’t pass these on to patients in the form of lower drug prices. Manufacturers pay these massive rebates to PBMs in order to get placed on insurers’ formularies. (Formularies are the lists of medicines that insurers agree to cover.) Rebates increase the prices of medications because they inflate list prices, which insurers generally charge patients a percentage of in the form of coinsurance. This convoluted and opaque pricing system often incentivizes PBMs and insurers to choose not the lowest-priced drug to put on their formulary, but the one with the biggest rebate. Eliminating this kickback scheme is perhaps the most important public policy reform to lower prescription drug prices. Bob interviews Dr. Madelaine Feldman, president of the Coalition of State Rheumatology Organizations, who discusses the recent revolution in treatments for autoimmune disorders. However, despite these wonder therapies existing, getting access to them is very difficult because even with insurance, they are too expensive. Dr. Feldman explains how the rebate dynamic boosts the prices that patients have to pay: Drug manufacturers bid against each other via rebate size to get selected by PBMs to get placed on formularies. As rebates grow in this competitive bidding process, so do list prices. A drug with, say, an \$800 rebate and a \$1,000 list price is chosen by the PBM to go on the formulary. Even though insurers and PBMs enjoy this \$800, they still charge patients a 20 percent coinsurance payment on the list price — i.e., another \$200. Drugmakers and patients could cut out the whole middle, inflationary apparatus of PBMs and insurers and still pay and earn the same amount: \$200. Absent middlemen, patients would save their premiums, and drugmakers would save these rebates and direct some to patients, reducing drug prices. PBMs try to obscure their inflationary impact by talking in terms of “savings,” but these savings — as demonstrated by the model above — incentivize higher prices. And real prices — not abstract costs or savings — are what really matter to patients. Dr. Feldman argues that education and legislation at the state level are needed to fix this broken pricing dynamic.”

[Patients Rising Now, [11/7/20](#)]

**July 2020: The Patients Rising Podcast discussed pharmacy benefit managers and drive up prescription drug prices, like how “70 to 85 percent of the price of insulin is rebates.”**

“In this week’s episode of the Patients Rising Podcast, Terry and Bob discuss the role of Pharmacy Benefit Managers (PBMs) in raising the price and reducing the supply of medications. PBMs are middlemen between drug manufacturers and insurers. They drive up drug prices because they demand substantial “rebates” from manufacturers in return for access to insurance companies’ formularies (the list of drugs that insurers promise to cover). Rebates have gotten so out of control that they now account for most of drug prices. For instance, 70 to 85 percent of the price of insulin is rebates. By some estimates, all the recent increases in prescription drug list prices in recent years are attributable to rising rebate demands. Net prices (list prices minus rebates) have actually fallen in recent years. PBMs use these rebate dollars — some \$150 billion per year — to pad their profits and pay their insurer clients, which then use the money to offset what they need to charge in premiums. Lower insurance premiums are nice, but this is cold comfort for those with rare and chronic diseases who face higher medication costs as a result. Under this bizarre rebate structure, which former CDC chief Scott Gottlieb calls ‘Kabuki’ theater, the sick end up subsidizing the healthy because they are the ones who generate these massive rebates. Terry interviews AJ Loiacono the CEO of Capital Rx, one of the only transparent PBMs on the market. His approach gets lower drug prices for his self-insured clients, including employer groups, unions, and municipalities. Rather than taking a cut of the medications’ cost, his company charges on a fixed rate. In other words, it charges around \$5 to dispense either a \$50 drug or a \$5,000 drug. Traditional PBMs charge a percentage of the drugs’ price, so they charge roughly \$500 for a \$5,000 drug. This dynamic incentivizes

most PBMs to push more expensive medications on their clients, raising prices for everyone. Loiacono also explains how his group passes along the rebate checks they receive to their clients, so there is no rent-seeking. This removes the conflict of interest in the drug distribution system. He also highlights how his company has streamlined the prior authorization process, which has posed a major hurdle for countless patients.”  
[Patients Rising Now, [7/3/20](#)]

**Patients Rising Now criticized the Trump Administration for rescinding a proposed rule that would have banned “drug rebate kickbacks.”**

“In a big win for insurance companies and pharmacy benefit managers, the Trump administration announced it would no longer pursue its proposal to ban drug rebate kickbacks. Patient advocates say the move blocks reform that would lower what patients are forced to pay out-of-pocket for the medicines they need. ‘The proposed rule would have lowered drug prices for all Americans by finally ensuring that patients receive the benefit of negotiated drug discounts, not plan sponsors and PBMs,’ said Ted Okon, executive director of the Community Oncology Alliance. ‘Killing this rule is a gift handed to the nation’s multi-billion-dollar middlemen corporations, the pharmacy benefit managers.’ ‘By rescinding this rule, corporate PBM middlemen will continue to pocket billions of dollars in record profits from the shadowy network of negotiated rebates, while patients bear the burden of high costs,’ he added. Okon’s prediction that the move boosts the bottom line of corporate PBM middlemen has already proven true. Stat News reports that the announcement ‘led to an immediate uptick in stock prices for PBMs: CVS shares were up 7percent in early trading, and Express Scripts (ESRX) shares increased by 10percent.’ The decision to walk away from drug rebate reform has also received pushback on Capitol Hill. ‘The administration’s decision today to allow the corrupt practice of middlemen negotiators pocketing patients’ money through rebates is a clear victory for big healthcare and a loss for patients,’ Senator Mike Braun of Indiana said in a statement.”  
[Patients Rising Now, [7/23/19](#)]

**Patients Rising Now blamed PBMs and insurance companies for driving up the out-of-pocket costs for prescription drugs.**

“This PBM scheme directly costs patients more money through higher out-of-pocket costs. That’s because co-pays are often based on a percentage of the retail price of a prescription. Insurance companies charge patients based on list price – before the rebate. As a result, some patients can find it more expensive to use their insurance to pay for medicine.”  
[Patients Rising Now, [7/23/19](#)]

**Patients Rising said insurance companies create “barriers to access and affordability” and “secretive pharmacy benefit managers” create “expensive markups.”**

“Healthcare should be about a patient working with their care provider to find the right treatment. Period. Of course, that’s not how it really works. There are insurance barriers to access and affordability. Expensive markups by secretive pharmacy benefit managers. And callous value frameworks that value everything but the patient.”  
[Patients Rising Stories, accessed [12/10/20](#)]

**Patients Rising said that “affordable healthcare” can be achieved in part through “transparent prices” for pharmaceuticals and “sharing in the rebates.”**

“Affordable Healthcare. This can be achieved by addressing: Coinsurance – the percent you pay of covered medical services after the deductible. Copays – a flat fee you pay for covered medical services after the deductible. Premiums – the monthly cost of having health insurance. List prices – transparent prices for services before discounts. Sharing in the rebates – cost-sharing should be calculated using a drugs’ rebate-applied-adjusted cost, not the list price. Ending Surprise Billing – upfront cost transparency for services would prevent surprise bills after a service.”  
[Patients Rising Stories, accessed [12/10/20](#)]

**Terry Wilcox called for bringing more transparency to PBMs to help lower drug prices.**

“Bring transparency to pharmacy benefit managers, which are middlemen that control and cartelize the

prescription drug supply chain. PBMs are largely responsible for what Food and Drug Administration chief Scott Gottlieb calls “Kabuki drug pricing.” Prescription drug delivery is a Byzantine maze of backdoor deals that must be exposed through real transparency reforms — not just more streamlined secrets. As Azar articulated in his speech this week, PBMs must also stop placing pharmacists under a gag clause to prevent them from informing patients they could get their drugs cheaper by paying cash.”

[Terry Wilcox, op-ed, Inside Sources, [5/23/18](#)]

## **PATIENTS RISING DIRECTS PATIENTS IN NEED TO PATIENT ASSISTANCE CHARITIES AND GOFUNDME**

### **Patients Rising called patient assistance programs “absolutely critical.”**

“Patient assistance programs are absolutely critical,’ says Wilcox of Patients Rising”

[Patients Rising Now, [2/22/20](#)]

### **The Patients Rising University financial primer on “Navigating the Costs of Care” refers patients to NeedyMeds, the Partnership for Prescription Assistance, the SamFund, and websites for raising donations from individuals like GoFundMe.**

“ADDITIONAL RESOURCES. Resources shared during the Navigating Cost of Care Webinar Truth About Budgeting (mentioned by Terry) Copay Accumulators (referencing copay accumulators) NeedyMeds NeedyMeds educates and empowers all those seeking affordable healthcare. A national non-profit, NeedyMeds achieves its mission by providing information on healthcare programs, offering direct assistance and facilitating programs. NeedyMeds is funded by small grants, donations, sponsorships, subscriptions to PAPTracker, and syndication of some of our database information. NeedyMeds also works with the patient assistance programs of several pharmaceutical distributors. The Partnership for Prescription Assistance: The Partnership for Prescription Assistance® (PPA), a nationwide effort sponsored by America’s biopharmaceutical research companies, has helped more than 10 million uninsured and underinsured Americans get information about programs that provide prescription medicines for free or nearly free. PPA provides a single point of access to more than 475 patient assistance programs, including nearly 200 offered by biopharmaceutical companies. The SamFund: The Samfund provides support for young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. Through direct financial assistance and free online support and education, The Samfund helps young adults move forward towards their personal, professional, and academic goals. Raising Funds GoFundMe Fundly MightyCause” [Patients Rising University, accessed [12/8/20](#)]

- **NeedyMeds is funded in part by pharmaceutical companies.**

“NeedyMeds receives funding from a number of sources: Grants Donations Sale of PAPTracker, software designed to help local programs enroll applicants in programs and track usage Syndication of our information Advertisements on the website Partnering with pharmaceutical manufacturers to help them establish and operate their PAPs.”

[NeedyMeds, accessed [12/8/20](#)]

- **The Partnership for Prescription Assistance is a partnership of pharmaceutical companies.**

“The Partnership for Prescription Assistance®(PPA), a nationwide effort sponsored by America’s biopharmaceutical research companies, has helped more than 10 million uninsured and underinsured Americans get information about programs that provide prescription medicines for free or nearly free. PPA provides a single point of access to more than 475 patient assistance programs, including nearly 200 offered by biopharmaceutical companies.” [Patients Rising University, accessed [12/8/20](#)]

- **The Partnership for Prescription Assistance is a project of PhRMA.**

“Additionally, Jeff served as Deputy Vice President of the Pharmaceutical Research & Manufacturers (PhRMA) where he oversaw operations for the Partnership for Prescription Assistance (PPA) the nation’s largest clearinghouse to match patients in need to pharmaceutical assistance programs.”

[Patients Rising, accessed [12/8/20](#)]



- **The SamFund's advisory council includes Bayer's head of digital communications.**

"Each of our Advisory Council members brings a specific area of expertise to The Samfund, and all are passionate about, and committed to, helping The Samfund grow. All of our Advisory Council members volunteer their time and expertise with the support of the companies they work for. We are grateful for their involvement and dedication. Mark Bennett, Bayer Corporation Director, Head of Digital Communications: Mark is responsible for developing and overseeing all digital communications and social media efforts for Bayer Corporation in the United States. This includes a coordinated and proactive social media program designed to enhance the company's visibility, engagement and reputation in the United States. Mark serves as a special advisor on social and digital media for The Samfund." [The SamFund, accessed [12/8/20](#)]

## **PATIENTS RISING CALLED FOR REPEALING THE AFFORDABLE CARE ACT TO PREVENT ICER'S "VALUE FRAMEWORKS" FROM KILLING PEOPLE.**

**2017: Patients Rising co-founder Jonathan Wilcox wrote a Washington Times op-ed, titled "Health care repeal needed to keep people from dying."**

[Jonathan Wilcox, op-ed, Washington Times, 8/7/17]

**Patients Rising co-founder Jonathan Wilcox implied that value frameworks advocated by ICER were problematic in the health care system and suggested reform of the entire health care system as a solution.**

"It's unimaginable that any of the senator's colleagues would suggest that since Mr. McCain soon turns 81, survived a previous cancer, and has several additional health challenges, maybe it's best to limit how much the system invests in him because he probably doesn't have that long to live. Sound harsh? It sure does — but millions of other patients are facing that judgment every day. A nationwide movement is ongoing and accelerating to apply a rigid, formulaic process to determine if patients are too costly to treat and their lives too expensive to save. This is the ongoing fight for patient access to advanced medicines and therapies for those facing a chronic disease or serious illness, and it's the intellectual fault line running down the middle of any serious debate about the future of health care in America. [...] Something new is taking hold in health care: value frameworks. These are complicated mathematical formulas on patients, rigid price controls on advanced medications and, ultimately, limits on the kind of treatment access John McCain is receiving right now. This is all in the name of 'system management,' and it is being prominently advanced by the most influential think tank few have heard about: the Boston-based Institute for Clinical and Economic Review (ICER). Backed by millions of dollars from one foundation, ICER has aligned with the insurance industry and pharmacy benefit managers (PBMs) to impose value frameworks and cut costs by restricting treatment — some say recklessly. For example, Dr. Robert Goldberg of the Center for Medicine in the Public Interest estimates that not only will ICER's value frameworks fail to enhance treatment options for patients suffering from the blood cancer multiple myeloma, they will cut off and kill 44,000 of them. ICER has also turned its harsh light on treatments for lung cancer, cardio disease, osteoporosis, arthritis, psoriasis, migraines and several other serious conditions. Like a three-card monte street hustle, no matter how the data gets shuffled, the result is always the same: widespread patient treatment is too expensive and it's time to cut people off. Just last year, ICER enjoyed easy access to the Obama administration, including its Health and Human Services Agency. And it bet big that President Hillary Clinton would have fused ICER's frameworks and federal policy. That obviously didn't happen, but ICER is still burrowing into Washington, boasting that the Veterans Administration will apply its estimates to deciding what medicines veterans will receive. Dr. Goldberg adds: 'This would only mean that unlike Senator McCain, thousands of veterans will be denied access to treatments that could save their lives.' That's what makes this an ideal time to set straight once and for all what should be the default setting of the health care system: getting the right patient the right treatment at the right time. It's a movement in search of a natural leader. Someone willing to take on entrenched interests, call out corrupt policies and tell the truth about what is happening to powerless patients. Sounds like a mission for a maverick to me."

[Jonathan Wilcox, op-ed, Washington Times, 8/7/17]

**Terry Wilcox acknowledged that some of the statements about ICER made by Patients Rising and Patients Rising Now were "a bit of a stretch."**

“On social media and on its affiliated website ‘ICER Watch,’ Patients Rising Now has described ICER as a ‘dangerous,’ insurance company-backed ‘Trojan Horse’ and a ‘mysterious group’ with the power to block new treatments from development and roll back the Affordable Care Act. ‘The reports that ICER develops are routinely used by the insurance industry to deny patients’ access to life-saving treatments,’ the group claims on its Eventbrite page for the ICER meeting. Patients Rising’s executive director, Terry Wilcox, said she knows that some of those statements are a bit of a stretch. ‘I know ICER’s not in charge of their health care today,’ she acknowledged in an interview. However, she argued, if ICER finds that a drug is not cost-effective, it could exacerbate problems people already have getting insurance policies to cover Exondys 51.”

[Boston Globe, 7/25/19]

## **PATIENTS RISING OPPOSED DRUG IMPORTATION FROM CANADA.**

**2019: Terry Wilcox questioned the practicality of drug importation from Canada as a means to lowering prescription drug prices, saying the prescription market in Canada wasn’t large enough to serve U.S. states.**

“The Senate hosted yet another hearing earlier this month on prescription drug pricing. But state legislators are getting tired of waiting for federal action to address their residents’ prescription drug costs. So far this year 16 states have introduced 27 bills to allow prescription drug imports from Canada. Importing prescription drugs from Canada enjoys popular support. A Kaiser poll last month found that four-fifths of respondents support importing drugs from Canada. A 2016 survey of American adults found that 8 percent of respondents said they or someone in their household had imported prescription drugs. But as a matter of broad public policy, wholesale importation is not a solution to lowering drug costs. Canada’s population of 37 million isn’t much bigger than the combined sizes of Florida and Illinois, the two largest states currently pursuing importation legislation. The Canadian drug supply is nowhere near the scale that would be necessary to provide drugs to the massive American market.”

[Terry Wilcox, op-ed, Inside Sources, [4/18/19](#)]

**2019: Terry Wilcox said that prescription drug importation from Canada wasn’t safe because many websites purporting to be Canadian in fact are not Canadian.**

“Wholesale prescription drug importation from Canada is not just impractical. There’s also a significant question of safety, especially as news of state-sanctioned import programs could lead U.S. consumers to trust other ‘Canadian’ sources for prescriptions. Countless American patients have learned the hard way that ‘Canadian’ online pharmacies are often not Canadian. In recent years, thousands of patients across the country have been exposed to counterfeit drugs. Some have suffered serious injury, and some have died, as a result. An FDA operation in 2005 suggested that just 15 percent of purportedly Canadian online prescription drug purchases originate in Canada; the rest of these drugs come from distant countries, including China and Turkey. Health Canada has acknowledged it cannot guarantee the safety of drugs purchased on these online platforms that advertise themselves as ‘Canadian.’”

[Terry Wilcox, op-ed, Inside Sources, [4/18/19](#)]

**August 2020: Patients Rising Now criticized President Trump’s Executive Orders to lower prescription drug prices by allowing drug importation and creating an international price index for medications.**

“On this week’s episode of the Patient’s Rising podcast, Terry and Bob discuss President Trump’s executive orders on prescription drug prices. Recently, Trump signed a series of Executive Orders that direct U.S. Health and Human Services to take steps to try to lower drug prices. The orders include: [...] Finalizing a rule allowing states to develop importation plans for certain prescription drugs. Yet as Terry has written, drug importation is more style than substance. As a matter of broad public policy, wholesale importation is not a solution to lowering drug costs. Canada’s population of 37 million isn’t much bigger than the combined size of Florida and Illinois, the two largest states currently pursuing importation legislation. The Canadian drug supply is nowhere near the scale that would be necessary to provide drugs to the massive American market. According to a study published last year in Health Economics, if just 20 percent of U.S. prescriptions were filled using Canadian prescription drug sources, the Canadian drug supply would run out in 183 days. There are also legitimate safety concerns associated with importation. Creating an international price index so that Medicare does not pay more for drugs than any economically comparable OECD country. Yet as Terry has written, international price indexes

threaten innovation on which patients in the rare disease community depend. While the president claims that his pricing plan will fight ‘global freeloaders,’ it does this by copying the freeloaders’ strategy of setting prices. The administration seems to want to have its cheaper drugs and eat what’s needed to create them too. According to a paper by the National Bureau of Economic Research, cutting prices by 40 to 50 percent in the United States – as Trump’s proposal implies – will lead to between 30 and 60 percent fewer research and development projects being undertaken in the early stage of developing a new drug. The authors conclude: ‘A short-run benefit for consumers could lead to a long-run negative impact on social welfare.’”

[Patients Rising Now, [8/2/20](#)]

## **Other Statements on Drug Pricing**

### **Patients Rising, funded by the pharmaceutical industry, fought passage of the CREATES Act.**

“Beyond their overt muscle, the industry groups and their member companies spend money on front groups and donations to other organizations that carry their message. Some of the organizations fighting the CREATES Act have innocuous-sounding names: Patients Rising, Patients Alliance for Drug Safety Protections, and Alliance for the Adoption of Innovations in Medicine.”

[Boston Globe, 3/23/18]

### **September 2016: Patients Rising signed a letter expressing concerns about the safety of generic drugs that would be approved by the FDA if the “Creating and Restoring Equal Access to Equivalent Samples Act of 2016” or “CREATES Act of 2016,” were passed.**

“On behalf of these Americans, we are greatly concerned about legislative proposals now being considered that would force the sale of medicines carrying serious risks to generic marketers for comparison (bioequivalence) testing and permit separate generic REMS without what we feel are sufficient safeguards to prevent harmful exposure to patients, medical professionals, and others. Although our organizations recognize the value of generic drugs and biosimilars to patients and the medical community, we are also aware that medicines subject to REMS – and especially those approved with restrictive ‘Elements to Assure Safe Use’ (ETASU) – can cause terrible birth defects, organ damage, and even death when not handled and administered with the utmost care. For this reason, we believe all developers of generic versions of REMS drugs should be required to demonstrate their capabilities to adhere to the same rigorous standards as those employed by the brand name to ensure safe use. Accordingly, we have significant misgivings about current legislative proposals, such as the recently introduced ‘Creating and Restoring Equal Access to Equivalent Samples Act of 2016’ or the ‘CREATES Act of 2016,’ that discount the need for REMS with ETASU. [...] Although the goal of speeding the development of less expensive generic medicines and biosimilars is laudable, we urge legislators to act with an abundance of caution when considering proposals such as the CREATES Act. If the current system is changed, then it must include a robust FDA process that goes beyond reviewing self-attestation forms and includes a review of a product developer’s actual capabilities and its safety history, require evidence demonstrating that safety will remain the same and a public process for review of separate generic REMS before they are approved. We understand the need to increase competition in the drug marketplace but ask that policymakers thoughtfully consider the health and safety of patients with serious and life threatening health conditions before moving forward with any proposal.”

[Patients Alliance for Drug Safety Protections, letter to Sen. Chuck Grassley, Sen. Patrick Leahy, Sen. Mike Lee, and Sen. Amy Klobuchar, [9/21/16](#)]

### **May 2017: Patients Rising signed on to a letter to Reps. Gus Bilirakis and Kurt Schrader thanking them for including a GAO review in their Lower Drug Cost Through Competition Act.**

“Dear Representative Bilirakis and Representative Schrader: On behalf of the Patients’ Alliance for Drug Safety Protections, a coalition of public health, patient advocacy, health professional, and disease organizations, we thank you for including a Government Accountability Office (GAO) study on Risk Evaluation and Mitigation Strategies (REMS) in HR 749, the Lower Drug Cost Through Competition Act. Our organizations represent millions of Americans with serious diseases, such as cancer, multiple sclerosis, kidney disease and other life-threatening conditions, many of whom rely on drugs and treatments that would not be available to them without REMS. A GAO study will provide up-to-date, accurate and objective information on the need for REMS

to alleviate the risks of potentially fatal complications, severe allergic reactions, birth defects, organ damage, and serious infections that may result from the inappropriate use or mishandling of high-risk drugs. Also of importance, the study can demonstrate the importance of FDA-mandated restrictive REMS protocols, known as Elements to Assure Safe Use (ETASUs), to advance patient safety and protect public health. Moreover, this study can provide data to help decide whether some existing REMS are still needed and to develop an evidence-based pathway for those that are no longer necessary. We realize the need for rapid development of generic drugs, and appreciate the positive impact lower-cost treatments have had on the well-being of patients and their families. However, these improvements cannot jeopardize these same patients' safety. The REMS protocols help to ensure that patients get the drugs they need without unnecessary risk. Once again, thank you for including the GAO report in HR 749."

[Patients Alliance for Drug Safety Protections, letter to Rep. Gus Bilirakis and Rep. Kurt Schrader, [5/5/17](#)]

- **H.R. 749, the Lower Drug Cost Through Competition Act, would have required the FDA to prioritize review of generic drugs.**

"This bill amends the Federal Food, Drug, and Cosmetic Act to revise provisions regarding review and approval of generic drug applications or supplements to generic drug applications for drugs: (1) for which there is a shortage, or (2) that have not been recently introduced to the market by more than one manufacturer and for which tentative approval has not been granted to more than two applications. The Food and Drug Administration (FDA) must prioritize the review of such submissions and act on them within 180 days. The FDA may expedite the inspection of a facility proposed to manufacture such a drug. Beginning FY2019, the FDA must award a transferrable generic drug priority review voucher to the sponsor of such an application once the drug has a sustained market presence. A voucher may be used to have the FDA review and take action upon a generic drug application within 180 days of submission. The FDA must establish an additional user fee for applications subject to a voucher. This voucher program is terminated at the start of FY2024. The FDA must periodically report on generic drug applications filed before FY2018 that are still pending. For a new drug application to be eligible for a priority review voucher as a tropical disease product application, the application must include new, essential clinical investigations. The Government Accountability Office must study the FDA's program for drug risk evaluation and mitigation strategies."

[H.R. 749, [2/3/17](#)]

**2017: Patients Rising praised President Trump's nominee to lead the Food and Drug Administration, Scott Gottlieb, for working to "lower prescription drug prices for patients."**

"Scott Gottlieb will work to lower prescription drug prices for patients. Scott Gottlieb is expected to get to work on lowering prescription drug prices for patients. Prior to his nomination, Gottlieb identified health care costs as a top concern and offered policy recommendations for achieving greater savings for patients. On prescription drug prices, Gottlieb's proposals, according to Vox, would encourage 'cheaper generic products, which would help bring down drug costs.' In addition to encouraging greater competition and quicker access to generic drugs, Gottlieb is keenly aware of the 'byzantine model for selling drugs' that sends money meant for patients to corporate middlemen. 'The convoluted arrangement by which drugs are priced and sold arose accidentally as a result of litigation,' he explains. 'But now that this inept system is firmly entrenched, bringing rationality to the selling model is going to disrupt inter-reliant business practices.'"

[Patients Rising, [3/21/17](#)]

**Patients Rising Executive Director Terry Wilcox wrote that the federal government should not adopt prescription drug price controls but should instead rely on market-based solutions to lower drug prices.**

"But there is one Democratic policy priority that President Trump seems like he might support: prescription drug price controls. Last month, Trump introduced a new prescription drug pricing plan that would tie the prices of Medicare Part B drugs, which are administered in doctors' offices, to an International Pricing Index based on 16 other developed countries. Congress should ignore this price control siren song and support legislation that adopts market-based facets of prescription drug programs — like Medicare Part D — that are lowering drug costs while increasing access."

[Terry Wilcox, op-ed, Real Clear Health, [11/15/18](#)]

**Wilcox wrote that drug list prices “have little to no effect on patients’ pocketbooks” and blamed insurance plans for the rising prescription drug costs.**

“There’s no question that drug prices are a concern of patients. I hear about them every day. Yet the list prices that President Trump rails against have little to no effect on patients’ pocketbooks. Rather, their financial worries come from their insurance premiums, deductibles, and copay costs, which have roughly doubled over the last few years.”

[Terry Wilcox, op-ed, Real Clear Health, [11/15/18](#)]

**Wilcox argued that price controls would limit the ability of drug companies to invest in new drug development.**

“Yet cost concerns are often secondary to worries over the potential clogging of the drug development pipeline, which patients hope will lead to medical breakthroughs to save their lives or livelihoods. Price controls reduce the ability of drug companies to invest in new cures. Bringing a new drug to market can cost as much as \$2 billion dollars, and only 1 out of 10 drugs make it through the arduous clinical trial process into development. The entire drug development process from discovery to launch takes about 10 to 15 years.”

[Terry Wilcox, op-ed, Real Clear Health, [11/15/18](#)]

**Wilcox argued that enacting price controls would limit access to medicines because pharmaceutical companies simply wouldn’t make them available to the market.**

“According to a paper by the National Bureau of Economic Research, cutting prices by 40 to 50 percent in the United States — as Trump’s proposal implies — will lead to between 30 and 60 percent fewer research and development projects being undertaken in the early stage of developing a new drug. The authors conclude: ‘A short-run benefit for consumers could lead to a long-run negative impact on social welfare.’ Patients who live in countries with drug price controls, including Australia, Canada, and the UK, only have between one-third and two-thirds of newly launched medicines available. That’s because if the government and drug manufacturers don’t agree on a price, the drug will not make it to the country’s market at all. Last week, for instance, the National Institute of Health and Care Excellence (NICE) announced it would not cover a new ovarian cancer therapy for routine use in the UK, disappointing patients. Adding another middleman between new drugs and patients — as government price controls do — would similarly reduce market access here at home.”

[Terry Wilcox, op-ed, Real Clear Health, [11/15/18](#)]

**December 2018: Patients Rising Now opposed a proposed rule from the Centers for Medicare & Medicaid Services on Drug Pricing Transparency, saying the proposed rule would “increase patient confusion.”**

“PRN supports policy changes that arm patients with information on treatment options so that they can make the best decisions in light of all factors, including cost. We offer our comments and responses to the Drug Pricing Transparency proposal (the Proposed Rule) to further that goal. PRN is concerned that requiring publication of WAC within televised drug advertisements will foster misinformed, rather than informed patient decisions. CMS outlined a set of approaches to price transparency and informed patient decisions that would be far more helpful to patients than requiring publication of WAC in televised advertisements. As further detailed below, we urge CMS to pursue those alternatives in lieu of the WAC-related measures outlined in the Proposed Rule. Requiring Manufacturers to Include Wholesale Acquisition Cost (WAC) in Televised Drug Ads Will Increase Patient Confusion and Could Deter Appropriate Use of Effective Treatments. PRN believes that health care coverage should mean access to care, and that patients have both the right and responsibility to be informed participants in their healthcare decisions. In our comments to the HHS Blueprint to Lower Drug Prices and Reduce Out-of-Pocket Costs, we generally supported the Administration’s goal of reducing costs to federal programs, but only if there was no constriction in patient access to prescribed treatments. We believe that the Proposed Rule’s requirement to include WAC in televised drug advertisements would have an indirect, and likely unintended, adverse effect on patient treatment access.”

[Patients Rising Now, Terry Wilcox letter to Administrator Seema Verma, [12/17/18](#)]

- **Patients Rising Now said the CMS proposed rule on Drug Pricing Transparency was unworkable because CMS lacked authority to require certain changes to pharmaceutical company television ads.**

“Even if WAC were a valuable piece of information, there is no assurance that it would be reliable over time.”

In theory, a drug manufacturer could set and advertise a low WAC and then raise this 'list price.' CMS cannot require advertisers to invest in new and revised TV ads each time their WAC changes.”  
[Patients Rising Now, Terry Wilcox letter to Administrator Seema Verma, [12/17/18](#)]

- **Patients Rising Now proposed transparency changes that focused on increasing transparency of insurance plan benefits.**

“PRN supports the alternative approaches that CMS presented in its Proposed Rule. With respect to an enhanced ‘drug pricing dashboard,’ PRN believes that patients need to be able to access information that is relevant to their particular situation. For example, enhancing the drug dashboard so that a patient could access detailed information on their plan-specific out-of-pocket costs, would be valuable to patients as they make treatment decisions. We also support devising a new payment code so that clinicians can be appropriately paid for the time spent discussing all treatment options in light of both their effectiveness and costs. Similarly, PRN believes that any plan selection tools that could allow patients to optimize their health care dollars would be a significant improvement. We urge CMS to explore these options and to assess any additional suggestions from stakeholders to enhance the information available to patients.”

[Patients Rising Now, Terry Wilcox letter to Administrator Seema Verma, [12/17/18](#)]

**May 2020: Patients Rising Now criticized a CMS rule that would “gut patient assistance programs and cancel co-pay coupons.”**

“Sadly and surprisingly, the Center for Medicare and Medicaid Services has sided with the bottom line of insurance companies and delivered devastating financial harm to patients – at a time when many simply cannot afford it. The 2021 Notice of Benefit and Payment Parameters should have put patients first. Instead, it will gut patient assistance programs and cancel out the co-pay coupons that millions are using to make up for the shortfalls of insurance design. As a result, patients will lose an essential tool that millions use to cut through the barriers to coverage. We urge CMS to reconsider this flawed decision, and instead follow President Trump’s very clear direction to his administration: Lower patient out-of-pocket costs and enhance patient access to the treatments they need and deserve.”

[Patients Rising Now, [5/12/20](#)]

**December 2020: Patients Rising Now praised a Trump Administration rule to increase price transparency in health insurance and require disclosure of prescription drug prices paid by insurance companies.**

“On the cusp of an administrative change, the Trump government has finalized a price transparency ruling for private health insurance companies, so patients and enrollees are aware of their true health care costs in advance, which can help them make informed decisions before seeking care. The final rule follows an Executive Order that was issued in 2019 to improve transparency in the U.S. healthcare system. [...] For prescription drugs, the rule requires payers to disclose the in-network price after accounting for the rebate, along with the patient’s share in the cost of the drug.”

[Patients Rising Now, [12/2/20](#)]

- **Patients Rising Now said the rule would improve transparency, expose fraud, reduce waste, and generate economic stimulus.**

“In a conversation with Patients Rising Now’s executive director Terry Wilcox, Cynthia Fisher, founder and chairman of Patient Rights Advocate, said that this ruling will allow patients to compare prices like they currently compare hotel costs on Priceline. She believes that transparency around health care prices will put patients first, increase healthcare quality, expose overbilling and fraud, reduce waste, and generate an economic stimulus.”

[Patients Rising Now, [12/2/20](#)]

## PART 3: PHARMA FUNDED CHARITY FOUNDATIONS/ INDEPENDENT ASSISTANCE GROUPS

The pharmaceutical industry donates large sums of money each year to independent charity foundations that cover the premiums, copays, and sometimes even travel costs of patients who encounter financial barriers to medications and care. Drug companies can translate these donations into profits – especially for Medicare patients – by contributing money to charities that focus on the specific patient populations that take their drug. Since anti-kickback statutes prohibit drug companies from directly assisting Medicare beneficiaries, investigational reports from the media and Congress have shown that drug companies use these charities as a conduit to facilitate the patient’s adherence – and the drug company’s reimbursement by the taxpayer-funded program. The schemes have led to settlements with the Department of Justice after allegations of violating anti-kickback statutes.

Settled Allegations of Illegal Kickbacks	No Formal Allegations Against Them
Patient Services Inc.	HealthWell Foundation
Patient Access Network Foundation	Patient Advocate Foundation

### **2020: Four patient assistance charities had settled allegations of participating in illegal kickback schemes, paying a total of \$13 million to settle the charges.**

“PSI is the fourth foundation to settle allegations of kickbacks. In total, the four foundations (PSI, The Assistance Fund, Chronic Disease Fund, and Patient Access Network Foundation) have paid \$13 million. In addition, the U.S. Attorney’s Office has collected more than \$840 million in total from eight pharmaceutical companies (United Therapeutics, Pfizer, Actelion, Jazz, Lundbeck, Alexion, Astellas and Amgen) to resolve allegations that they used third-party foundations as instruments for kickbacks.”

[U.S. Attorney, District of Massachusetts, [1/21/20](#)]

## HEALTHWELL FOUNDATION

Website: <https://www.healthwellfoundation.org/>

Documents:

**HealthWell Foundation has posted three letters written by the U.S. Department of Health and Human Services Office of the Inspector General, providing guidance to patient assistance charities with respect to anti-kickback statutes and operations to avoid violating charitable missions.**

[U.S. Department of Health and Human Services OIG Letter 1](#)

[U.S. Department of Health and Human Services OIG Letter 2](#)

[U.S. Department of Health and Human Services OIG Letter 3](#)

### **HealthWell acknowledges receiving funding from pharmaceutical companies but maintains their independence and uses the OIG opinions to say they cannot disclose their donors.**

“In addition to individual contributions, HealthWell receives donations from a number of sources both within and outside the health care industry. These include pharmaceutical manufacturers, biotech companies, foundations and other health care organizations. The HealthWell Foundation is entirely independent. It is not controlled or influenced by any of its donors. The assistance that HealthWell provides to patients is based on objective criteria that we apply consistently and in accordance with all applicable laws. As a copayment assistance foundation, HealthWell operates within a complex regulatory framework. The regulations governing the health care industry, as well as a favorable Advisory Opinion that the Office of Inspector General (OIG) issued to HealthWell, set

standards that HealthWell must meet to stay in compliance with applicable laws. According to the OIG opinion, HealthWell may not disclose the identity of its donors. This ensures that we are able to operate independently and in the best interest of our patients.”

[Healthwell Foundation, accessed [12/28/20](#)]

## Financials

### **2019: HEALTHWELL RECEIVED AT LEAST \$240.5 MILLION FROM THE PHARMACEUTICAL INDUSTRY, AND PROBABLY MORE THAN \$404 MILLION—OR UP TO 84 PERCENT.**

**The HealthWell Foundation receives a “majority” of its funding from the pharmaceutical industry.**

“The HealthWell Foundation is, like other CPAPs, funded in majority by donations from the pharmaceutical industry, and we are required to operate independently from our donors.”

[HealthWell Foundation, 2019 Annual Report, accessed [1/26/21](#)]

- **2019: \$481 million of the HealthWell Foundation’s revenue came from “donations and other income.”**

[HealthWell Foundation, 2019 Annual Report, accessed [12/10/20](#)]

- **2019: More than \$480 million of HealthWell’s revenue — 99 percent — came with “donor restrictions.”**

According to their audited financial reports, for the year that ended December 31, 2019, the HealthWell Foundation had total revenue of \$481,424,153. Of that, \$480,360,372, or 99.77 percent, came “With Donor Restrictions.” Just \$1,063,781 of HealthWell’s revenue came “Without Donor Restrictions.”

[HealthWell Foundation And Affiliate Consolidated Financial Statement, [7/6/20](#)]

- **2019: 84 percent of HealthWell’s revenues—as much as \$404 million—came from just 4 donors.**

“During the year ended December 31, 2019, the Foundation received approximately 84 percent of its total revenue and support from four donors.”

[HealthWell Foundation And Affiliate Consolidated Financial Statement, [7/6/20](#)]

**HealthWell claimed to have individual donors, but did not disclose how much of their revenue came from individual versus corporate donations.**

“2019 represented a year of remarkable growth for the HealthWell Foundation. Donations in excess of \$480 million allowed us to provide a financial lifeline to more than 150,000 underinsured Americans, making 2019 another record year for the Foundation and our most impactful year to date. As the demand for our services continues to grow dramatically year over year, we are honored that our dedicated corporate and individual donors recognize the critical need that we are filling and continue to place their trust in HealthWell.”

[HealthWell Foundation, 2019 Annual Report, accessed [1/26/21](#)]

### **ADDITIONAL FINANCIAL INFORMATION**

**2019: The HealthWell Foundation had more than \$510 million in total revenue.**

[HealthWell Foundation, 2019 Annual Report, accessed [12/10/20](#)]

- **2019: \$481 million of the Healthwell Foundation’s revenue came from “donations and other income”**

[HealthWell Foundation, 2019 Annual Report, accessed [12/10/20](#)]

- **2019: \$28.8 million of the HealthWell Foundation’s revenue came from “investment income”**

[HealthWell Foundation, 2019 Annual Report, accessed [12/10/20](#)]

**2015: The HealthWell Foundation received at minimum more than \$10 million from drug companies, accounting for at least 15 percent of its revenue.**

[Kaiser Health News, accessed [12/28/20](#)]



# Healthwell Foundation

**MISSION STATEMENT:** HELP ELIGIBLE PATIENTS WITH CHRONIC OR LIFE-ALTERING CONDITIONS AFFORD THEIR MEDICAL TREATMENTS.

WEBSITE [↗](#)

Form 990

\$10,375,000

TRACKED DONATIONS IN 2015

\$67,991,986

ANNUAL REVENUE IN 2015

## TRACKED DONATIONS FROM PHARMACEUTICAL COMPANIES

Company	Tracked Donations to Healthwell Foundation
<a href="#">Bristol-Myers Squibb Co.</a>	\$6,425,000
<a href="#">GlaxoSmithKline PLC</a>	\$2,700,000
<a href="#">Merck &amp; Co. Inc.</a>	\$1,000,000
<a href="#">AstraZeneca PLC</a>	\$200,000
<a href="#">Pfizer Inc.</a>	\$50,000

[Kaiser Health News, accessed 12/28/20]

**2006: HealthWell's president, Stephen Weiner said he hoped to broaden HealthWell's donor base beyond pharmaceutical companies.**

"Mr. Weiner, the president of HealthWell's board, said he hoped to broaden HealthWell's donor base so the foundation was not so dependent on drug companies. Until that happens, the charity may face questions about its motives, he acknowledged. 'The diversification of the funding base is very important to us,' he said."

[New York Times, [4/8/06](#)]

## Leadership

**2006: HealthWell was created by Covance, "a for-profit health care consulting company," and all of HealthWell's employees worked for Covance.**

"The awkwardness may not end there, because HealthWell is not a typical charity. It was created in 2004 by Covance, a for-profit health care consulting company based in Princeton, N.J., whose business includes conducting clinical trials for drug makers. Covance had \$1.3 billion in sales last year. All of HealthWell's employees work for Covance, which selected Mr. Weiner and HealthWell's other original trustees. And some of Covance's biggest clients are the same drug companies that HealthWell solicits for donations."

[New York Times, [4/8/06](#)]

- **Covance provides contract research services for drug development to pharmaceutical companies.**

"Covance by Labcorp is a leading global life sciences company, which provides contract research services to the drug, medical device and diagnostics, crop protection and chemical industries. Employing over 26,000

people worldwide, we provide comprehensive drug development solutions and are on a mission to advance health and power clear, confident decisions.”  
 [Covance, accessed [2/19/21](#)]

- **Covance claims to have helped “develop 100 percent of the top 50 prescription drugs in the marketplace today.”**

“As the drug development business of Laboratory Corporation of America Holdings (Labcorp) and the world’s most comprehensive drug development #CRO service company, we have helped pharmaceutical and biotech companies develop 100 percent of the top 50 prescription drugs in the marketplace today.”  
 [Covance LinkedIn profile, accessed [2/19/21](#)]

## MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
KRISTA ZODET	PRESIDENT	\$298,728.00	\$25,735.00	\$324,463.00
ALAN KLEIN	CHIEF DEVELOPMENT OFFICER	\$293,157.00	\$26,373.00	\$319,530.00
SHELA HALPER	SENIOR DIRECTOR, EXTERNAL RELATIONS	\$198,000.00	\$29,471.00	\$227,471.00
COLLIN ALEXANDER	CONTROLLER	\$124,656.00	\$37,717.00	\$162,373.00
VIRGINIA DUNN	SEN ASSOCIATE DIR COMMUNICATIONS & MARKETING	\$108,900.00	\$37,447.00	\$146,347.00
FRED ASIEDU LARBI	DIRECTOR OF OPERATIONS	\$117,913.00	\$11,096.00	\$129,009.00
SUSAN GOLDEN	ASSOCIATE DIR ANALYTICS & PROCESS IMPROVEMENT	\$104,872.00	\$22,392.00	\$127,264.00
ROBIN A HIDALGO	SOLUTIONS ARCHITECT	\$101,245.00	\$13,901.00	\$115,146.00
DAVID L KNOWLTON	VICE CHAIR & SECRETARY	\$24,656.00		\$24,656.00
NANCY CARTERON MD FACR	BOARD MEMBER	\$20,156.00		\$20,156.00
SUZANNE M MILLER PHD	BOARD MEMBER	\$16,313.00		\$16,313.00
JERRI SCARZELLA BSN	VICE CHAIR & TREASURER	\$14,063.00		\$14,063.00

[HealthWell Foundation, IRS Form 990, [7/24/20](#)]

## KRISTA ZODET, HEALTHWELL FOUNDATION PRESIDENT

### **1999-2005: Krista Zodet held multiple positions with pharmaceutical company Covance.**

“Covance. Total Duration: six yrs, six mos. Title: Account Manager. Dates Employed: March 2003 – Sept. 2005. Employment Duration: two yrs, seven mos. As an account manager at Covance, I was responsible for managing the daily interactions with program clients and providing them with strategic counsel regarding program design, emerging industry or product trends, opportunities for service enhancements, and new services. I also

participated in the proposal writing process pertaining to new business and service expansion and worked with operations and business support staff to establish reimbursement and patient assistance parameters and the corresponding standard operating procedures. As part of senior staff, I worked with my colleagues to grow existing business by demonstrating a thorough understanding of service lines and identifying opportunities for new business. Title: Lead Associate. Dates Employed: Jan. 2003 – March 2003. Employment Duration: three mos. As a lead associate I provided work direction to program specialists and program associates related to program operations and responded to inquiries from operations staff regarding product and program issues such as third-party payment and patient assistance. I also handled complex reimbursement calls, addressed customer complaints, and monitored calls and quality performance standards of the program specialists and program associates. In addition, I generated client reports, identifying program trends and opportunities for intervention with payers and worked with client services staff to finalize and deliver client reports. Title: Program Associate. Dates Employed: April 1999 – Jan. 2003. Employment Duration: three yrs. 10 mos. As a program associate, I was responsible for responding to reimbursement and coverage issues for various pharmaceutical products and medical procedures, screening patients for patient assistance programs, and tracking and reporting product-specific hotline trends. Through this position, I gained experience in several therapeutic areas including rheumatoid arthritis, transplantation, HIV/AIDS, dialysis, nuclear medicine, spinal surgery, hemophilia, and umbilical cord blood collection. I also acquired a working knowledge of coding and reimbursement in various settings including hospital inpatient, outpatient, pharmacy, and physician offices.”

[Krista Zodet LinkedIn profile, accessed [12/27/20](#)]

### **ALAN KLEIN, HEALTHWELL FOUNDATION CHIEF DEVELOPMENT OFFICER**

**2014-2015: Klein was senior vice president of corporate development at ETX Pharma, Inc.**

[Alan Klein LinkedIn profile, accessed [12/27/20](#)]

**2003-2014: Klein was executive vice president for corporate development at biotech company Sequella Inc.**

[Alan Klein LinkedIn profile, accessed [12/27/20](#)]

**2002-2003: Klein was vice president at drug company Gene Logic.**

[Alan Klein LinkedIn profile, accessed [12/27/20](#)]

**2001-2002: Klein was senior director for business development at drug company CuraGen Corporation.**

[Alan Klein LinkedIn profile, accessed [12/27/20](#)]

**1993-1997: Klein was a manager for business development at drug company PharmaKinetics Laboratories Inc.**

[Alan Klein LinkedIn profile, accessed [12/27/20](#)]

### **VIRGINIA DUNN, HEALTHWELL FOUNDATION SENIOR ASSOCIATE DIRECTOR OF COMMUNICATIONS AND MARKETING**

**2004-2011: Dunn was an associate director of corporate communications for drug company Entremed.**

[Ginny Dunn LinkedIn profile, accessed [12/27/20](#)]

### **STEPHEN M. WEINER, HEALTHWELL FOUNDATION BOARD OF DIRECTORS CHAIR**

**Stephen M. Weiner is the founding chair of Mintz Levin’s National Health Law practice.**

“Mr. Stephen Weiner is the Founding Chair of Mintz Levin’s National Health Law practice. He has had over 30 years of experience in the health care field as a policy maker, educator and attorney. He represents health care service providers in a broad array of legal matters. He works and has worked with providers in undertaking strategic positioning; structuring payer strategies and clinical integration initiatives; and in mergers, acquisitions, strategic affiliations, ‘demergers’ and joint venture arrangements, including between tax-exempt and for-profit organizations.”

[HealthWell Foundation, accessed [12/10/20](#)]

- Mintz Levin has a Life Sciences practice that has been involved in \$30 billion worth of life sciences transactions and has represented pharmaceutical companies in intellectual property litigation and initial public offerings.

[Mintz Levin, accessed [12/10/20](#)]

## NANCY CARTERON, HEALTHWELL FOUNDATION BOARD OF DIRECTORS MEMBER

2014-2019: Nancy L Carteron received 25 payments totaling \$31,913.65 in general payments from drug makers.

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

### Lobbying Activities

*The HealthWell Foundation did not appear to engage in any registered federal lobbying activities directly or via a professional lobbying firm.*

### Prescription Drug Cost Legislation

#### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

*No relevant information.*

#### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

#### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

*No relevant information.*

## **PATIENT ACCESS NETWORK FOUNDATION (PAN FOUNDATION)**

Website: <https://www.panfoundation.org/>

Documents: [Code of Conduct and Ethics](#)  
[Compliance Program Summary](#)

### Financials

#### 2019: THE PATIENT ACCESS NETWORK FOUNDATION (PAN FOUNDATION) RECEIVED 68 PERCENT OF ITS CONTRIBUTIONS FROM JUST FOUR DONORS IN THE PHARMACEUTICAL INDUSTRY—\$295 MILLION

2019: The PAN Foundation received 68 percent of its contributions from its four largest, who were all probably in the pharmaceutical industry.

“The Foundation receives contributions and promises to give from other organizations or individuals, primarily within the pharmaceutical drug industry. The Foundation’s four largest donors represented 68percent and 58percent of total contributions in 2019 and 2018, respectively. Changes in economic conditions can directly affect a donor’s ability and willingness to make future contributions to the Foundation. In addition, changing regulations within the pharmaceutical drug industry could further limit a donor’s ability and willingness to make future contributions to the Foundation.”

[Patient Access Network Foundation financial statements and accompanying information, [5/19/20](#)]

- **2019: 99 percent of the PAN Foundation’s “contributions receivable” came from just two donors.**

“As of December 31, 2019, approximately 99 percent of the Foundation’s contributions receivable were

provided by two donors. As of December 31, 2018, approximately 83 percent of the Foundation’s contributions receivable were provided by three donors.”

[Patient Access Network Foundation financial statements and accompanying information, [5/19/20](#)]

**2019: 100 percent of the contributions received by the PAN Foundation, \$434,035,433, came “with donor restrictions.”**

According to their audited financial statements for the year that ended December 31, 2019, \$434,035,433 in contributions to the PAN Foundation came “With Donor Restrictions.” The PAN Foundation received no contributions that came without donor restrictions that year.

[Patient Access Network Foundation financial statements and accompanying information, [5/19/20](#)]

**The PAN Foundation “receives contributions and promises to give from other organizations or individuals, primarily within the pharmaceutical drug industry.”**

“The Foundation receives contributions and promises to give from other organizations or individuals, primarily within the pharmaceutical drug industry.”

[Patient Access Network Foundation financial statements and accompanying information, [5/19/20](#)]

- **The PAN Foundation 2019 Annual report listed approximately 475 donors who gave at least \$100, but did not appear to list any pharmaceutical companies.**

The PAN Foundation thanked supporters in their 2019 annual report: “Without the generosity of our donors, PAN would not have been able to help thousands of seriously ill patients access their treatment over the past 15 years. All supporters contributed \$100 or more in 2019.” The report listed approximately 475 donors.

The list did not appear to include any pharmaceutical companies.

[PAN Foundation annual report 2019, [August 2020](#)]

## **ADDITIONAL FINANCIAL INFORMATION**

**2019: PAN Foundation had more than \$451 million in total support and revenue.**

[PAN Foundation, 2019 Audit Financial Statements, accessed [12/9/20](#)]

**2019: \$434 million of the PAN Foundation’s revenue came from “contributions.”**

[PAN Foundation, 2019 Audit Financial Statements, accessed [12/9/20](#)]

**2019: \$17.1 million of the PAN Foundation’s revenue came from “net investment income.”**

[PAN Foundation, 2019 Audit Financial Statements, accessed [12/9/20](#)]

**2015: The PAN Foundation received at minimum more than \$32 million from drug companies.**

[Kaiser Health News, accessed [12/28/20](#)]

# Patient Access Network Foundation

**MISSION STATEMENT:** TO HELP UNDERINSURED PEOPLE WITH LIFE-THREATENING, CHRONIC AND RARE DISEASES GET THE MEDICATIONS AND TREATMENT THEY NEED BY PAYING FOR THEIR OUT-OF-POCKET COSTS AND ADVOCATING FOR IMPROVED ACCESS AND AFFORDABILITY.

WEBSITE [↗](#)

Form 990

\$32,392,500

TRACKED DONATIONS IN 2015

\$819,426,010

ANNUAL REVENUE IN 2015

## TRACKED DONATIONS FROM PHARMACEUTICAL COMPANIES

Company	Tracked Donations to Patient Access Network Foundation
<a href="#">Pfizer Inc.</a>	\$16,870,000
<a href="#">AbbVie Inc.</a>	\$14,537,500
<a href="#">AstraZeneca PLC</a>	\$675,000
<a href="#">GlaxoSmithKline PLC</a>	\$300,000
<a href="#">Novartis</a>	\$10,000

[Kaiser Health News, accessed [12/28/20](#)]

## Settlements

### THE PAN FOUNDATION PAID \$4 MILLION TO SETTLED FEDERAL ALLEGATIONS THAT IT ILLEGALLY PARTICIPATED IN A KICKBACK SCHEME WITH DRUGMAKERS.

**2019: PAN Foundation paid \$4 million to settle allegations that it violated federal anti-kickback laws by working with drug makers to pay the Medicare copays for specific drugs.**

“The U.S. Attorney’s Office announced today that two foundations, Chronic Disease Fund, Inc., d/b/a Good Days from CDF (‘CDF’), and Patient Access Network Foundation (‘PANF’), have agreed to pay \$2 million and \$4 million, respectively, to resolve allegations that they violated the False Claims Act by enabling pharmaceutical companies to pay kickbacks to Medicare patients taking the companies’ drugs. The government alleged that CDF and PANF worked with various pharmaceutical companies to design and operate certain funds that funneled money from the companies to patients taking the specific drugs the companies sold. These schemes enabled the pharmaceutical companies to ensure that Medicare patients did not consider the high costs that the companies charged for their drugs. The schemes also minimized the possibility that the companies’ money would go to patients taking competing drugs made by other companies. When a Medicare beneficiary obtains a prescription drug covered by Medicare Part B or Part D, the beneficiary may be required to make a partial payment, which may take the form of a co-payment, co-insurance, or deductible (collectively, ‘co-pays’). Congress included co-pay requirements in these programs, in part, to encourage market forces to serve as a check on health care costs, including the prices that pharmaceutical manufacturers can demand for their drugs. The Anti-Kickback Statute prohibits pharmaceutical companies from offering or paying, directly or indirectly, any remuneration – which

includes money or any other thing of value – to induce Medicare patients to purchase the companies’ drugs. The law further prohibits third parties, such as co-pay foundations, from conspiring with pharmaceutical companies to violate the Anti-Kickback Statute.”

[U.S. Attorney, District of Massachusetts, [10/25/19](#)]

- **FBI: PAN Foundation used its charitable status “to shield the illegal activities of pharmaceutical companies seeking to maximize profits.”**

“Today’s settlements are a warning to all pharmaceutical companies, foundations, and others who try to subvert the charitable donation process for their own financial gain at the expense of American taxpayers. Both the Chronic Disease Fund and the Patient Access Network used their status as charities to shield the illegal activities of pharmaceutical companies seeking to maximize profits,’ said Joseph R. Bonavolonta, Special Agent in Charge of the FBI Boston Division. ‘The FBI and our partners will continue to hold organizations accountable, and to protect and preserve the Medicare system, and the taxpayers who fund it, from kickback schemes like these.”

[U.S. Attorney, District of Massachusetts, [10/25/19](#)]

- **PAN Foundation allowed Bayer, Astellas, Dendreon, and Amgen to use the foundation as a conduit to pay kickbacks to Medicare patients taking their drugs.**

“It is further alleged that, from 2011 through 2014, PANF permitted four pharmaceutical companies – Bayer, Astellas, Dendreon, and Amgen – to use PANF as a conduit to pay kickbacks to Medicare patients taking their drugs.”

[U.S. Attorney, District of Massachusetts, [10/25/19](#)]

### **2018: Pfizer settled allegations that it illegally provided kickbacks to the PAN Foundation.**

“Pfizer will pay the government nearly \$24 million as part of a settlement to resolve allegations that it funneled money through a foundation resulting in illegal kickbacks. The company is not admitting wrongdoing or liability as part of its agreement with the Department of Justice. According to the settlement, from 2012 through 2016, Pfizer made donations to the Patient Access Network (PAN) Foundation, a copay assistance nonprofit organization, and then used a specialty pharmacy to steer Medicare patients taking its drugs toward the foundation to cover their copays.”

[Kaiser Health News, [5/24/19](#)]

- **Pfizer worked with PAN Foundation to create and finance a fund to treat patients with irregular heartbeat as it raised prices on its drug to treat irregular heartbeat.**

“Tikosyn, a Pfizer drug to treat an irregular heartbeat, was also part of the alleged scheme, according to the settlement. The drugmaker raised the list price of 40 Tikosyn capsules from \$220 to \$317 in the final three months of 2015. It cost Medicare \$107 million in 2016 before rebates. Planning a price increase, Pfizer worked with the PAN Foundation to ‘create and finance a fund’ for Medicare patients with a specific irregular heartbeat, the settlement says. ‘For the next nine months, Tikosyn patients accounted for virtually all of the beneficiaries of PAN’s fund.”

[Kaiser Health News, [5/24/19](#)]

## **Leadership**

### **The PAN Foundation was created by AmerisourceBergen.**

“Similarly, the Patient Access Network Foundation, another new co-pay charity, was created and is staffed by the Lash Group, a subsidiary of AmerisourceBergen, another large for-profit health care company.”

[New York Times, [4/8/06](#)]

## MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
DONALD BARONE	CHAIR	\$16,000.00		\$16,000.00
GRANT LAWLESS	VICE CHAIR	\$12,000.00		\$12,000.00
CONSTANCE GARCIA	SECRETARY	\$12,000.00		\$12,000.00
MIRIAM ATKINS	DIRECTOR	\$12,000.00		\$12,000.00
DEANNA BANKS	DIRECTOR	\$12,000.00		\$12,000.00
MARTIN BIEBER	DIRECTOR	\$12,000.00		\$12,000.00
JONAS DE SOUZA	DIRECTOR	\$12,000.00		\$12,000.00
JEFFREY KING	DIRECTOR	\$12,000.00		\$12,000.00
SUSAN RUCKER	DIRECTOR	\$12,000.00		\$12,000.00
WILLIAM SCANLON	DIRECTOR	\$4,000.00		\$4,000.00
NORRIE THOMAS	DIRECTOR	\$9,000.00		\$9,000.00
KENNETH WELLS	DIRECTOR	\$12,000.00		\$12,000.00
DANIEL KLEIN	PRESIDENT & CEO	\$376,023.00	\$21,453.00	\$397,476.00
SCOTT SCHLENOFF	CFO & TREASURER	\$210,946.00	\$40,309.00	\$251,255.00
JOHN CROUT	COO & GENERAL COUNSEL	\$113,538.00	\$28,819.00	\$142,357.00
AMY NILES	VICE PRESIDENT, EXTERNAL A	\$211,798.00	\$31,643.00	\$243,441.00
NECHUMAH GETZ	VICE PRESIDENT OF OPERATIONS	\$209,394.00	\$15,105.00	\$224,499.00
LEENA PATEL	DIRECTOR OF DEVELOPMENT	\$176,275.00	\$14,531.00	\$190,806.00
AYESHA AZAM	DIRECTOR OF PROVIDER RELATIONS	\$166,032.00	\$12,402.00	\$178,434.00
STUART CHERANDE FRIEDMAN	DIRECTOR OF OPERATIONS	\$160,530.00	\$12,262.00	\$172,792.00

[PAN Foundation, IRS Form 990, 5/13/19]



## JONAS A. DE SOUZA, PAN FOUNDATION BOARD OF DIRECTORS MEMBER

**2013-2018: Jones A. de Souza received 35 payments totaling \$246,835.17 in associated research funding and general payments from drug makers and medical device manufacturers.**

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

## JAMES DUNLOP, PAN FOUNDATION BOARD OF DIRECTORS MEMBER

**James Dunlop worked as corporate counsel for Pfizer.**

“James Dunlop, JD, MD is a dermatologist and dermatologic surgeon with the Palo Alto Medical Foundation for Healthcare, Research, and Education (PAMF) in Santa Cruz, California and is certified by the American Academy of Dermatology. Dr. Dunlop’s practice includes patients of all ages and socio-economic backgrounds, and he has a particular interest in cutaneous oncology, transplant dermatology, and marine dermatology. He completed his dermatology residency at the University of California, San Francisco, his internship at Yale University, and graduated with honors from the University of Vermont College of Medicine. Prior to medical school, Dr. Dunlop practiced Intellectual Property law in the New York office of King & Spalding, an international law firm. He also worked for Pfizer as Corporate Counsel and received his law degree from Vanderbilt. Dr. Dunlop received a BA in English from Stetson University, graduating magna cum laude and Phi Beta Kappa. Additionally, Dr. Dunlop holds a certificate in Innovation and Entrepreneurship from Stanford University.”

[PAN Foundation, accessed [2/19/21](#)]

**2017-2019: James Dunlop received 5 payments totaling \$329.01 in general payments drug makers AbbVie and Galderma Laboratories.**

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

## NICK GRAHAM, PAN FOUNDATION BOARD OF DIRECTORS MEMBER

**Nick Graham is a managing director at New Century Capital Partners where he led its healthcare services and HCIT practices.**

“Nick Graham is a managing director at New Century Capital Partners (NCCP) and the founder and managing partner of Concentric Capital Advisors, a boutique merchant banking firm. Nick has more than 20 years of investment banking and M&A experience and leads NCCP’s healthcare services and HCIT practices.”

[PAN Foundation, accessed [12/9/20](#)]

**Graham spent eight years as a senior healthcare investment banker at Raymond James.**

“Prior to NCCP, Nick spent eight years as a senior healthcare investment banker at Raymond James (previously Morgan Keegan and Shattuck Hammond Partners).”

[PAN Foundation, accessed [12/9/20](#)]

## Lobbying Activities

### 2017-2020: THE PAN FOUNDATION SPENT \$360,000 LOBBYING CONGRESS

**2017-2002: The PAN Foundation paid Faegre Drinker Biddle & Reath at least \$360,000 to lobby the federal government on its behalf.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/27/20](#)]

- **Faegre Drinker represents pharmaceutical companies.**

“Whether as an academic medical center, research institute, cutting-edge physician practice, pharmaceutical company, device manufacturer or clinical research organization, your focus is on medical breakthroughs and new treatment options that enhance patient care. We partner with you as you seek to ensure that your clinical research programs adhere to all accepted clinical trial guidelines, including clinical trial design and agreements, Food and Drug Administration approvals and commercialization. We help you navigate institutional review board requirements and human-subject protection rules at both the federal and state levels. We can serve as an

extension of your team to help you write grants, draft budgets, develop contracts and manage data rights. We can help manage your clinical research compliance needs so that you can focus on scientific pursuits. Our attorneys, consultants and other professionals work with clinical research organizations across the industry in the U.S. and internationally.”

[Faegre Drinker Biddle & Reath, accessed [2/19/21](#)]

### **2019-2020: Faegre Drinker Biddle & Reath lobbied for the PAN Foundation on drug pricing legislation and out-of-pocket cost issues.**

According to federal lobbying disclosures, in the second and third quarters of 2019, Faegre Drinker Biddle & Reath lobbied for the PAN Foundation on “Medicare Part D Out of Pocket Costs.” In the fourth quarter of 2019, PAN Foundation lobbied Congress on “Medicare Part D Out of Pocket Costs; Drug pricing; S.2911 Seniors Prescription Drug Relief Act of 2019.” In the first quarter of 2020, the PAN Foundation lobbied on “Medicare Part D Out of Pocket Costs; Drug pricing - Independent patient assistance programs; S.2911 Seniors Prescription Drug Relief Act of 2019 - H.R. 5076/S.1872 Protecting Seniors Through Immunization Act.” In the second quarter of 2020 they lobbied on “Drug pricing - Independent patient assistance programs; H.R.6649 Lower Drug Costs for Seniors During COVID-19 Act of 2020; Drug copayment policy; H.R.6379 Take Responsibility for Workers and Families Act.” In the third quarter of 2020 they lobbied on “Eliminating Out of Pocket Costs/cost-sharing in Medicare Parts A, B, C, and D for COVID-19 treatment services; Medicare Part D Smoothing; Medicare Part D Out of Pocket Costs; H.R. 7647, Preserving Patient Savings on Drug Costs Act.”

[Faegre Drinker Biddle & Reath LLP, Lobbying Disclosure Report, Q2 2019, [7/17/19](#); Q3 2019, [10/17/19](#); Q4 2019, [1/17/20](#); Q1 2020, [4/17/20](#); Q2 2020, [7/17/20](#); Q3 2020, [10/17/20](#)]

### **JEREMY SCOTT, AN EXPERIENCED LOBBYIST FOR BIG PHARMA, LOBBIED ON BEHALF OF THE PAN FOUNDATION**

#### **October 2017-June 2019: Jeremy Scott lobbied for the PAN Foundation.**

[Faegre Drinker Biddle & Reath LLP, Lobbyist Registration, [10/23/17](#); Lobbying Disclosure Report, [7/17/19](#)]

#### **Scott advised biopharmaceutical companies on how to achieve “their federal legislative, regulatory, programmatic, policy, and grassroots advocacy goals.”**

“I have over 20 years of government relations experience – on Capitol Hill, in a nonprofit, and within a national law firm. I provide my clients with strategic counsel looking for both threats and opportunities to advance their legislative and regulatory goals, with a specific focus on oncology. • Advise biopharmaceutical/medical technology companies, patient advocacy organizations, national nursing and pharmacy associations, hospital and health systems, and other health related entities with respect to achieving their federal legislative, regulatory, programmatic, policy, and grassroots advocacy goals; • Counsel and represent clients with respect to legislative, regulatory, and grassroots advocacy efforts and proactively identify threats and opportunities, and design and implement response plans to protect and advance clients’ interests; • Represent clients before Congressional Members and staff, White House and federal agency staff, coalition partners, and other third-party stakeholders; • Develop advocacy materials including, draft legislation, report language, Congressional testimony, fact sheets, issue briefs, position papers, Congressional and federal agency correspondence, bill and regulatory analyses, government relations strategic plans, policy agendas, advocacy action alerts, regulatory comments, speeches, articles, and newsletters; • Design grassroots and grassroots advocacy campaigns, devise branding and messaging for advocacy initiatives, and undertake strategic partnerships and coalitions in support of such campaigns; • Plan and execute client advocacy events including advocacy trainings and workshops, Congressional briefings, Capitol Hill lobby days, coalition meetings, policy summits, and strategic planning retreats; and • Deliver presentations, speeches, and webinar remarks on topics, such as the Supreme Court review of health care reform, election outlook and outcomes, Congressional trends and happenings, and use of social media in advocacy.”

[Jeremy Scott LinkedIn profile, accessed [12/1/20](#)]

### **H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT**

**January 2020: PAN Foundation published an essay by former Congressman Phil Gingrey, who seemed to write promisingly of the passage of HR 3.**

“Congress may yet be able to reach its own deal on drug pricing, building on efforts in 2019. Congress, after all, included the bipartisan CREATES Act in its year-end deal, which is a positive sign that drug reform can advance. However, the CREATES Act took three years to become law and it pertains to drug patents and the development of generics and will not directly impact drug prices. In terms of Congressional action in 2020, I expect most attention to focus on two bills. The first, S. 543, the Prescription Drug Pricing Reduction Act, authored by Sens. Chuck Grassley (R-IA) and Ron Wyden (D-OR) was passed in the Senate Finance Committee in September. The second, H.R. 3, the Elijah Cummings Lower Drug Costs Now Act, passed the House of Representatives in December. Both of these bills restructure the Medicare Part D drug benefit, include an annual cap on out-of-pocket expenses that spreads the costs throughout the year, and contain provisions requiring drug companies to rebate price increases on their drugs that go above inflation. President Trump has said he will support the Grassley-Wyden, however, the Senate Majority Leader Mitch McConnell (R-KY) does not. With political pressure and public support for drug pricing legislation there is still an opportunity for passage of a drug pricing package but it is highly unlikely that giving Medicare the ability to negotiate drug prices makes it into a final deal. There will be an opportunity for the inclusion of drug pricing legislation in a larger health care package come May 22. As part of a December funding deal, Congress extended a number of important programs to both Republicans and Democrats that are set to expire on May 22 unless action is taken.”

[PAN Foundation, [1/15/20](#)]

**January 2020: PAN Foundation President and CEO Dan Klein posted a comment on a Health Affairs article encouraging Congress to action drug prices but cautioned that HR 3 didn't do enough to make prescription drugs affordable.**

“We are grateful that Members of Congress and the Administration have recognized the need to lower out-of-pocket costs for prescription medications for Medicare Part D beneficiaries. Proposed legislation in the House and Senate includes a cap on out-of-pocket costs and addresses the need to distribute these costs more evenly throughout the calendar year. Approximately 80 percent of the charitable assistance PAN provides goes towards helping pay out-of-pocket costs below the catastrophic threshold. So we caution policymakers that, even with an out-of-pocket cap, many seniors will still be unable to afford their prescription medications – forcing them to make impossible financial decisions like whether to fill their prescription, cut pills in half, or skip doses altogether. The House and Senate packages are nevertheless, a step in the right direction. Seniors need swift action that will give them relief soon. On behalf of the PAN Foundation and the patients we serve, I sincerely hope policymakers can work together to create a better system that helps Part D beneficiaries afford the treatment they need and find the peace of mind they deserve.” Dan Klein, President and CEO, PAN Foundation.

[Health Affairs, [1/14/20](#)]

**October 2019: PAN Foundation joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary

changes to the Part D benefit including: • Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135percent to 150percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.”  
[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

## **H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

## **S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

**July 2019: PAN Foundation signed on to a letter to the Senate urging them to strengthen the out-of-pocket cap in the Prescription Drug Pricing Reduction Act of 2019 and calling for additional measures in the bill.**

“We are writing to comment on the Medicare Part D Benefit Redesign provisions in your legislation, The Prescription Drug Pricing Reduction Act of 2019. Our group, MAPRx Coalition (MAPRx), is a national coalition of beneficiary, caregiver and health care professional organizations committed to improving access to prescription medications in Medicare Part D and safeguarding the well-being of Medicare beneficiaries with chronic diseases and disabilities. We greatly appreciate your leadership in improving access to prescription drugs for Medicare beneficiaries with Part D coverage. First and foremost, thank you for including a Part D out-of-pocket (OOP) cap in your legislation. Over the years, Part D has been viewed as a success due to its broad popularity among enrollees and lower than expected government expenditures. Nevertheless, serious challenges remain and the lack of an OOP cap is a hurdle for some of the most vulnerable Medicare beneficiaries. An OOP cap would be an important new patient protection for some of the most vulnerable enrollees in the Medicare program—drastically reducing costs for hundreds of thousands of beneficiaries who rely on prescription drugs to treat chronic and life-threatening conditions. Currently, many beneficiaries often cannot access the most clinically appropriate medication because financially it is out of reach. We urge you to strengthen the OOP cap in your legislation. To ensure an OOP cap is meaningful to as many beneficiaries as possible, MAPRx recommends a monthly cap (or other “smoothing” mechanism) that would allow total OOP costs to be distributed more evenly throughout the year. Such a mechanism would ease the financial strain for Medicare beneficiaries who currently are faced with paying a significant percentage of their total OOP financial burden at the beginning of each benefit year. In addition, we would like to see beneficiaries benefit from the cap sooner than your proposed start date of 2022. As you know, currently, the average Medicare beneficiary will pay approximately \$2,750 in OOP costs by the time they reach the catastrophic threshold. As such, MAPRx strongly urges the Committee to consider an OOP cap below this amount. Second, your legislation makes significant changes to the entire Part D benefit. In the short time that we have had to review the conceptual language, we have not come to a full understanding of the impact and consequences these proposed changes will have on the program or the patients we represent. As we continue to review the proposal and how it will impact beneficiaries’ costs and access to prescription drugs under Part D, we hope you will work with us to make any necessary adjustments and improvements. As you well know, significant changes could alter the dynamics of the benefit, result in unintended consequences and create barriers that would affect beneficiaries’ access to Part D prescription drugs. Current access barriers in Part D include narrowing formularies, an erosion of beneficiary protections, increased utilization management, use of preferred pharmacy networks and problems with the exceptions and appeals processes. We urge you to consider – and seek to address – these issues as you work to strengthen Part D. Finally, in addition to establishing a meaningful OOP cap, MAPRx would like Congress to address Part D Medicare beneficiary out-of-pocket costs by making additional improvements such as: improving the Part D LIS Program; eliminating cost-sharing for generics for Low-Income Subsidy (LIS) recipients; and, permitting Part D beneficiaries to seek a lower cost share for specialty medications.”

[MAPRx letter to Sens. Grassley and Wyden, [7/25/19](#)]

## PATIENT ADVOCATE FOUNDATION (PAF)

Website: <https://www.patientadvocate.org/>

Website: <https://www.npaf.org/>

Documents: [Case Management Program Disclaimer](#)  
[Financial Aid Fund Program Disclaimer](#)  
[Co-Pay Relief Program Disclaimer](#)

*Each of the program disclaimers contains language to the effect that PAF will not consider physician, provider, drug therapy, or donor when determining patient eligibility, and they contain language saying PAF will not recommend or refer anyone to a donor, provider, supplier, or product. The Case Management disclaimer also states that patients are free to switch therapies, physicians, pharmacies, or suppliers without affecting their eligibility in the program.*

### Financials

#### **2020: 85 PERCENT OF DONATIONS MADE TO THE PATIENT ADVOCATE FOUNDATION'S CO-PAY RELIEF PROGRAM CAME FROM JUST FOUR DONORS—POSSIBLY AS MUCH AS \$236 MILLION.**

#### **2019-2020: Four donors accounted for 85-96 percent of donations to the Patient Advocate Foundation's Co-Pay Relief Program.**

“During the years ended June 30, 2020 and 2019, four donors accounted for approximately 85 percent and 96 percent of donations received for the Co-Pay Relief Program, respectively.”

[Patient Advocate Foundation, financial report, June 30, 2020 and 2019, [10/13/20](#)]

- **2020: Patient Advocate Foundation received \$274 million in grants that came “with donor restrictions” – 98.6 percent of their grant revenue.**

According to their audited financial statements for the year that ended June 30, 2020, PAF received a total of \$278,137,670 in grant revenue. Of that total, 98.6 percent, or \$274,299,154, came “with donor restrictions.” Just \$3,838,516 in grants was received without donor restrictions.

[Patient Advocate Foundation, financial report, June 30, 2020 and 2019, [10/13/20](#)]

#### **2020: PAF's Co-Pay Relief Program had net assets with donor restrictions of nearly \$300 million.**

According to their audited financial statements for the year that ended June 30, 2020, PAF's Co-Pay Relief Program had net assets with donor restrictions of \$294,606,003.

[Patient Advocate Foundation, financial report, June 30, 2020 and 2019, [10/13/20](#)]

#### **2020: PAF released more than \$230 million from their Co-Pay Relief Program that had been donor restricted.**

According to their audited financial statements for the year that ended June 30, 2020, “Net assets were released from donor restrictions by incurring expenses satisfying the restricted purposes specified by donors as follows for the years ended June 30: Purpose restrictions accomplished: Co-Pay Relief Program funding (CPR) \$232,284,048.”

[Patient Advocate Foundation, financial report, June 30, 2020 and 2019, [10/13/20](#)]

#### **2019: The PAF 2019 annual report offered a four-page list of supporters that included individuals, organizations, and some of the largest pharmaceutical companies, including Abbvie, Allergan, Amgen, Boehringer Ingelheim, Celgene, Genentech, Gilead Sciences, GSK, Eli Lilly, Merck, Novartis, Pfizer, and PhRMA, among others.**

[Patient Advocate Foundation, 2019 Annual Impact Report, [5/28/20](#)]

## ADDITIONAL FINANCIAL INFORMATION

2019: PAF had \$244 million in “total revenues, gains and other support.”

[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]

- **2019: \$221 million of PAF’s revenue came from “grants.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$165,787 of PAF’s revenue came from “private and public donations.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$35,314 of PAF’s revenue came from “donated services and materials.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$16.9 million of PAF’s revenue came from “program administration.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$80,000 of PAF’s revenue came from “patient congress.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$141,650 of PAF’s revenue came from “promise of hope.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$75,000 of PAF’s revenue came from “patient action council.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]
- **2019: \$5.5 million of PAF’s revenue came from “investment return.”**  
[PAF, 2019 Annual Impact Report, accessed [12/18/20](#)]

2015: The Patient Advocate Foundation received, at minimum, more than \$14.6 million from drug makers.

## Patient Advocate Foundation Inc.

**MISSION STATEMENT:** PATIENT ADVOCATE FOUNDATION (PAF) IS A NATIONAL 501 (C)(3) NON-PROFIT ORGANIZATION THAT PROVIDES PROFESSIONAL CASE MANAGEMENT AND FINANCIAL AID SERVICES TO AMERICANS WITH CHRONIC, LIFE THREATENING AND DEBILITATING ILLNESSES. PAF CASE MANAGERS SERVE AS ACTIVE LIAISONS BETWEEN THE PATIENT AND THEIR INSURER, EMPLOYER AND/OR CREDITORS TO RESOLVE INSURANCE, JOB RETENTION AND/OR DEBT CRISIS MATTERS AS THEY RELATE TO THEIR DIAGNOSIS. PATIENT ADVOCATE FOUNDATION SEEKS TO SAFEGUARD PATIENTS THROUGH EFFECTIVE MEDIATION ASSURING ACCESS TO CARE, MAINTENANCE OF EMPLOYMENT AND PRESERVATION OF THEIR FINANCIAL STABILITY.

WEBSITE [↗](#)

Form 990

\$14,647,540

TRACKED DONATIONS IN 2015

\$76,020,912

ANNUAL REVENUE IN 2015

### TRACKED DONATIONS FROM PHARMACEUTICAL COMPANIES

Company	Tracked Donations to Patient Advocate Foundation Inc.
<a href="#">Eli Lilly and Co.</a>	\$9,500,000
<a href="#">Pfizer Inc.</a>	\$3,290,000
<a href="#">Bristol-Myers Squibb Co.</a>	\$1,078,440
<a href="#">AstraZeneca PLC</a>	\$310,000
<a href="#">Novartis</a>	\$225,600
<a href="#">Roche Group</a>	\$121,500
<a href="#">Amgen Inc.</a>	\$85,000
<a href="#">Pharmaceutical Research and Manufacturers of America</a>	\$25,000
<a href="#">Astellas Pharma Inc.</a>	\$12,000

[Kaiser Health News, accessed [12/28/20](#)]

## Leadership

### MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION

Name	Position	Reportable compensation from the organization	Reportable compensation from related organizations	Estimated amount of other compensation from the organization and related organizations	Total
ALAN J BALCH	CHIEF EXECUTIVE OFFICER	\$222,947.00	\$125,000.00	\$12,135.00	\$360,082.00
WILLIAM J NASON	CHIEF FINANCIAL OFFICER	\$204,398.00		\$24,505.00	\$228,903.00
FRANCES CASTELLOW	PRESIDENT OF OPERATIONS	\$219,867.00		\$8,103.00	\$227,970.00
ANGELA M WALKER	CHIEF OF TALENT MANAGEMENT	\$181,842.00		\$7,123.00	\$188,965.00
ERIN BRADSHAW	CHIEF OF MISSION DELIVERY	\$148,023.00		\$16,675.00	\$164,698.00
SAKHTI CHOKKALINGAM	SENIOR PEGA SYSTEMS ARCHIT	\$165,368.00		\$20,410.00	\$185,778.00
BETH MOORE	EVP OF CORPORATE COMMUNICATIONS	\$142,597.00		\$11,204.00	\$153,801.00
CHRISTINE WILSON	VP ADVOCACY COMMUNICATIONS AND MARKETING	\$152,235.00		\$6,079.00	\$158,314.00

[Patient Advocate Foundation, IRS Form 990, [11/11/19](#)]

### DEBORAH MOROSINI, PAF SCIENTIFIC COMMITTEE MEMBER

Dr. Deborah Morosini, VP of Clinical Affairs & Patent Engagement at Loxo Oncology, is a member of the scientific committee for the Patient Advocate Foundation.

[Patient Advocate Foundation, accessed [11/20/20](#)]

- **Loxo Oncology is a subsidiary of Eli Lilly.**

“Loxo Oncology at Lilly was created in December 2019, combining the Lilly Research Laboratories oncology organization and Loxo Oncology, which was acquired by Lilly in early 2019. Loxo Oncology at Lilly brings together the focus and spirit of a biotech with the scale and resources of large pharma, with the goal of rapidly delivering impactful new medicines for people with cancer.”

[Loxo Oncology, accessed [11/20/20](#)]

### DAVID M. JACKMAN, PAF BOARD OF DIRECTORS MEMBER

2013-2019: David M. Jackman received 51 payments totaling \$79,259.00 in associated research funding and general payments from drug makers and medical device manufacturers.

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

## AL BENSON, PAF BOARD OF DIRECTORS MEMBER

**2018:** Al Benson received 508 payments totaling \$4,591,116.43 in associated research funding, research payments, and general payments from drug makers and medical device manufacturers.

[OpenPayments.CMS.gov, accessed [2/19/21](#)]

### Lobbying Activities

#### 1999-2020: PAF AFFILIATE NPAF SPENT MORE THAN \$6 MILLION ON LOBBYING THE FEDERAL GOVERNMENT.

**The National Patient Advocate Foundation spent \$6,413,987.02 lobbying the federal government.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/27/20](#)]

#### **Q2 2019: NPAF lobbied on Medicare Part D out-of-pocket costs.**

According to federal lobbying disclosures, in the second quarter of 2019, NPAF lobbied Congress, stating that it had “reviewed bill language and prepared comments for Part D/lower health care cost - draft legislation, safe step act and BENES Act of 2019.”

[National Patient Advocate Foundation, Lobbying Disclosure Report Amendment, [6/12/19](#)]

### Prescription Drug Cost Legislation

#### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

**October 2019: NPAF joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including:

- Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135percent to 150percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15percent).
- Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.”

[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

#### H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT

*No relevant information.*

#### S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT

**July 2019: NPAF signed on to a letter to the Senate urging Senators to strengthen the out-of-pocket cap in the Prescription Drug Pricing Reduction Act of 2019 and calling for additional measures in the bill.**



“We are writing to comment on the Medicare Part D Benefit Redesign provisions in your legislation, The Prescription Drug Pricing Reduction Act of 2019. Our group, MAPRx Coalition (MAPRx), is a national coalition of beneficiary, caregiver and health care professional organizations committed to improving access to prescription medications in Medicare Part D and safeguarding the well-being of Medicare beneficiaries with chronic diseases and disabilities. We greatly appreciate your leadership in improving access to prescription drugs for Medicare beneficiaries with Part D coverage. First and foremost, thank you for including a Part D out-of-pocket (OOP) cap in your legislation. Over the years, Part D has been viewed as a success due to its broad popularity among enrollees and lower than expected government expenditures. Nevertheless, serious challenges remain and the lack of an OOP cap is a hurdle for some of the most vulnerable Medicare beneficiaries. An OOP cap would be an important new patient protection for some of the most vulnerable enrollees in the Medicare program – drastically reducing costs for hundreds of thousands of beneficiaries who rely on prescription drugs to treat chronic and life-threatening conditions. Currently, many beneficiaries often cannot access the most clinically appropriate medication because financially it is out of reach. We urge you to strengthen the OOP cap in your legislation. To ensure an OOP cap is meaningful to as many beneficiaries as possible, MAPRx recommends a monthly cap (or other “smoothing” mechanism) that would allow total OOP costs to be distributed more evenly throughout the year. Such a mechanism would ease the financial strain for Medicare beneficiaries who currently are faced with paying a significant percentage of their total OOP financial burden at the beginning of each benefit year. In addition, we would like to see beneficiaries benefit from the cap sooner than your proposed start date of 2022. As you know, currently, the average Medicare beneficiary will pay approximately \$2,750 in OOP costs by the time they reach the catastrophic threshold. As such, MAPRx strongly urges the Committee to consider an OOP cap below this amount. Second, your legislation makes significant changes to the entire Part D benefit. In the short time that we have had to review the conceptual language, we have not come to a full understanding of the impact and consequences these proposed changes will have on the program or the patients we represent. As we continue to review the proposal and how it will impact beneficiaries’ costs and access to prescription drugs under Part D, we hope you will work with us to make any necessary adjustments and improvements. As you well know, significant changes could alter the dynamics of the benefit, result in unintended consequences and create barriers that would affect beneficiaries’ access to Part D prescription drugs. Current access barriers in Part D include narrowing formularies, an erosion of beneficiary protections, increased utilization management, use of preferred pharmacy networks and problems with the exceptions and appeals processes. We urge you to consider – and seek to address – these issues as you work to strengthen Part D. Finally, in addition to establishing a meaningful OOP cap, MAPRx would like Congress to address Part D Medicare beneficiary out-of-pocket costs by making additional improvements such as: improving the Part D LIS Program; eliminating cost-sharing for generics for Low-Income Subsidy (LIS) recipients; and, permitting Part D beneficiaries to seek a lower cost share for specialty medications.”

[MAPRx letter to Sens. Grassley and Wyden, [7/25/19](#)]

## PATIENT SERVICES, INC. (PSI)

Website: <https://www.patientservicesinc.org/>

Documents: [Patient Policies](#)  
[Conflict of Interest Policy](#)

## Financials

### **2019: JUST FOUR DONORS MAY HAVE BEEN RESPONSIBLE FOR GIVING MORE THAN \$50 MILLION TO PATIENT SERVICES INCORPORATED.**

#### **2019: Just four donors gave Patient Services Incorporated 76 percent of their total contributions.**

“For the year ended December 31, 2019, contributions from four donors comprised approximately 76 percent of total contributions. In addition, 96 percent of contract fees receivable are due from three donors as of December 31, 2019.”

[Patient Services Incorporated, Consolidated Financial Statements, December 31, 2019 and 2018, 2/24/20]

#### **2019: Just three donors were responsible for 96 percent of contract fees receivable to Patient Services Incorporated.**

“For the year ended December 31, 2019, contributions from four donors comprised approximately 76 percent of total contributions. In addition, 96 percent of contract fees receivable are due from three donors as of December 31, 2019.”

[Patient Services Incorporated, Consolidated Financial Statements, December 31, 2019 and 2018, 2/24/20]

**2019: PSI received \$62 million that came “with donor restrictions”—about 90 percent of “contributions and contract fees.”**

According to their audited financial statements for the year that ended December 31, 2019, PSI received \$68,859,867 in “contributions and contract fees.” Of that total, \$62,086,543, or about 90 percent, came “with donor restrictions.” Just \$6,773,324 was received by PSI without donor restrictions.

[Patient Services Incorporated, Consolidated Financial Statements, December 31, 2019 and 2018, 2/24/20]

**2019: PSI had net assets with donor restrictions of \$95 million.**

“Net Assets with donor restrictions 95,223,228.” [Patient Services Incorporated, Annual Report 2019, 7/22/20]

**2019: Patient Services Incorporated listed 88 supporters in their annual report, including at least 11 pharmaceutical companies.**

[Patient Services Incorporated, Annual Report 2019, 7/22/20]

- **PSI listed Amicus Therapeutics, Inc., Boehringer Ingelheim Pharmaceuticals Inc., Catalyst Pharmaceuticals, Genzyme Corporation, Grifols USA, LLC, Lediant Biosciences, Inc., Novartis Pharmaceuticals Corporation, Pharming Group NV, Retrophin, Shire Human Genetic Therapies, Inc., and Vanda Pharmaceuticals, Inc. among their supporters.** [Patient Services Incorporated, Annual Report 2019, 7/22/20]

- **Retrophin was founded by Martin Shkreli, who is serving prison time for securities fraud related to his management of Retrophin.**

“Retrophin Inc., a biopharmaceutical company founded by now-convicted drug executive Martin Shkreli, is rebranding itself as Travele Therapeutics Inc. The new name—which company officials say is a nod to the Latin roots for truth and path—severs another tie to its founder, Mr. Shkreli, who is serving prison time for securities fraud related to his management of two hedge funds and Retrophin. He is scheduled to be released in 2023. Mr. Shkreli, who was widely scorned for raising drug prices, including those of a lifesaving drug used to treat HIV/AIDS and other immunocompromised patients, had said the name Retrophin stood for ‘Re(place) (dys)trophin.’”

[Wall Street Journal, [11/16/20](#)]

**Patient Services Inc. had close ties with Turing Pharmaceuticals and disgraced CEO Martin Shkreli.**

“Thorn Run’s lobbying clients also include the drug company-funded patient group Patient Services Inc., according to the Center for Responsive Politics. PSI’s close relationship with Turing Pharmaceuticals, best known for its indicted former CEO Martin Shkreli and massive price increases last year, was detailed in a May story by *Bloomberg*.”

[USA Today, [7/11/16](#)]

**Turing Pharmaceuticals donated to PSI to help defray out-of-pocket costs for Daraprim to treat toxoplasmosis.**

“With respect to Daraprim®, after consulting with patient advocacy groups and infectious disease doctors, Turing understands that toxoplasmosis patients are primarily concerned with timely access and minimal out-of-pocket costs. We are committed to continuing the expansion of our distribution partnerships in order to facilitate optimal patient access. In addition to participation in federal and state programs with costs as low as 1 penny per pill, and patient savings programs under which patients’ out-of-pocket expenses do not exceed \$10 per prescription, Turing contributes to Patient Services, Inc. (PSI), a longstanding independent charity that provides support for financially needy patients’ cost-sharing obligations for any toxoplasmosis therapies, consistent with PSI’s advisory opinion from the HHS Office of Inspector General.”

[Business Wire, 11/12/15]

**After announcing it wouldn't reduce the price of Daraprim after jacking it up 5,000 percent, Turing said it would donate to PSI to lower out-of-pocket costs for patients.**

"A small drugmaker that promised to decrease the price of a lifesaving drug - after raising it about 5,000 percent - now says it will not cut the list price of the drug, sold exclusively by select Walgreens pharmacies. Turing Pharmaceuticals AG, a privately held biopharmaceutical company run by former hedge fund manager Martin Shkreli, caused a furor in September when it acquired the drug, Daraprim, and immediately raised the price of the 62-year-old medicine from \$13.50 a tablet to \$750 a tablet. The price increase meant some patients or their insurers would suddenly be paying hundreds of thousands of dollars a year. On Tuesday the drugmaker said it would not cut the list price - the price charged by Walgreens, its exclusive retailer for patients who take the drug after being discharged from a hospital. However, the company made some concessions. It said it would offer discounts of up to 50 percent for hospitals, which are the first to treat patients with toxoplasmosis, a parasitic disease often contracted by eating undercooked contaminated meat. The disease can cause severe brain damage in people with compromised immune systems. Turing said it would provide the drug free to uninsured, qualified patients with income at or below 500 percent of the poverty level. It also said it would make a contribution to Patient Services Inc., an independent charity that provides financial assistance for Medicare patients."

[Pittsburgh Post-Gazette, 11/26/15]

### **ADDITIONAL FINANCIAL INFORMATION**

**2019: PSI had \$70.4 million in total revenues and other support.**

[PSI, 2019 Annual Report, accessed [12/18/20](#)]

- **2019: \$68.8 million of PSI's revenue came from "contributions and contract fees."**  
[PSI, 2019 Annual Report, accessed [12/18/20](#)]
- **2019: \$695,075 of PSI's revenue came from "interest income."**  
[PSI, 2019 Annual Report, accessed [12/18/20](#)]
- **2019: \$4,326 of PSI's revenue came from "miscellaneous income."**  
[PSI, 2019 Annual Report, accessed [12/18/20](#)]
- **2019: \$869,274 of PSI's revenue came from "gain (loss) on investments."**  
[PSI, 2019 Annual Report, accessed [12/18/20](#)]

**2019: Boehringer Ingelheim, Genzyme, Novartis and other pharmaceutical and related companies were "supporters" of PSI.**

In PSI's 2019 Annual Report, Amicus Therapeutics, Avanir Pharmaceuticals, Biotek ReMEDys, Boehringer Ingelheim Pharmaceuticals, Catalyst Pharmaceuticals, Genzyme, Leadiant Biosciences, Novartis, and Vanda Pharmaceuticals were listed as "supporters."

[PSI, 2019 Annual Report, accessed [12/18/20](#)]

**2016: 97 percent of PSI's revenue came from drug companies.**

"PSI provides help to patients with 15 rare diseases and 11 chronic illnesses. Nearly all of their funding comes from drug companies - 97 percent in 2016, according to PSI - including three companies that made HAE treatments. Shire, CSL Behring and Valeant Pharmaceuticals (which made Ruconest, which Olive-McCoy uses, before it was acquired by Pharming) - were donors, according to the charity's 2016 annual report. In 2016, a third of PSI's funding helped pay for insurance premiums, according to PSI."

[Washington Post, [4/25/18](#)]

### **Legal Settlement**

**PATIENT SERVICES, INC., PAID \$3 MILLION TO SETTLE FEDERAL ALLEGATIONS THAT PSI PARTICIPATED IN AN ILLEGAL KICKBACK SCHEME WITH THREE DRUG MAKERS.**

**January 2020: PSI paid \$3 million to settle allegations that it served as an illegal conduit for kickbacks for three pharmaceutical manufacturers – Insys, Aegerion, and Alexion.**

“Patient Services Inc. (PSI), a foundation based in Midlothian, Virginia, has agreed to pay \$3 million to resolve allegations that it violated the False Claims Act by acting as a conduit to enable certain pharmaceutical companies to provide kickbacks to Medicare patients taking the companies’ drugs by paying the patients’ copayments, the Department of Justice announced today. The amount of the settlement announced today was determined based on analysis of PSI’s ability to pay after review of its financial condition. When a Medicare beneficiary obtains a prescription drug covered by Medicare Part B or Part D, the beneficiary may be required to make a partial payment, which may take the form of a co-payment, co-insurance, or deductible (collectively, copays). Congress included co-pay requirements in these programs, in part, to encourage market forces to serve as a check on health care costs, including the prices that pharmaceutical manufacturers can demand for their drugs. The Anti-Kickback Statute prohibits pharmaceutical companies from offering or paying, directly or indirectly, any remuneration – which includes money or any other thing of value – to induce Medicare patients to purchase the companies’ drugs, and it prohibits third parties, such as copay foundations, from acting as a conduit for such payments. [...] The government alleged that PSI coordinated with three pharmaceutical manufacturers – Insys, Aegerion, and Alexion – to enable them to pay kickbacks to Medicare patients taking their drugs. PSI allegedly worked with these companies to design and operate certain funds that funneled money from the companies to patients taking the specific drugs the companies sold. These schemes allegedly minimized the possibility that the companies’ contributions to the funds would go to patients taking competing drugs made by other companies and undermined the nature of these contributions as bona fide donations. The United States previously entered into settlement agreements with Insys, Aegerion, and Alexion covering their use of PSI as a conduit to pay their patients’ copays.”

[U.S. Department of Justice, [1/21/20](#)]

- **PSI was named in a settlement between the U.S. DOJ and Aegerion Pharmaceuticals, alleging that the drug maker had “induced purchases,” but PSI was not charged and denied any wrongdoing.**

“PSI’s operating budget dropped 17 percent this year, to \$83 million. The Justice Department, in documents related to a \$35 million settlement reached with Aegerion Pharmaceuticals last year, alleged that the company had ‘induced purchases’ of its cholesterol drug using a PSI co-pay program. The U.S. Attorney’s Office for the District of Massachusetts said that PSI ‘promoted its ability to create a “reimbursement vehicle”’ in lieu of giving away the drug. PSI denied the DOJ allegations and noted that it was not charged with wrongdoing.”

[Washington Post, [4/25/18](#)]

**Leadership**

**MOST RECENTLY AVAILABLE EXECUTIVE COMPENSATION**

Name	Position	Reportable compensation from the organization	Estimated amount of other compensation from the organization and related organizations	Total
BRIAN FINK	DIRECTOR	\$6,625.00		\$6,625.00
TERRIE GLASS	DIRECTOR	\$8,250.00		\$8,250.00
JAMES ARTHUR WOOD	PRESIDENT	\$276,608.00	\$28,359.00	\$304,967.00
GARY CROSS	CHAIR	\$30,750.00		\$30,750.00
MITCH MULA	VICE-CHAIR	\$8,250.00		\$8,250.00
RUSSELL PHILLIPS JR	TREASURER	\$7,500.00		\$7,500.00
BRIAN LANDRY	SECRETARY	\$2,500.00		\$2,500.00

MICHAEL HERBERT	HIGHEST COMPENSATED EMPLOYEE	\$117,803.00	\$13,824.00	\$131,627.00
STACEY PUGH	HIGHEST COMPENSATED EMPLOYEE	\$131,802.00	\$12,945.00	\$144,747.00
WILLIAM LEACH	HIGHEST COMPENSATED EMPLOYEE	\$104,974.00	\$11,475.00	\$116,449.00
JAMES ROMANO	HIGHEST COMPENSATED EMPLOYEE	\$111,834.00	\$24,690.00	\$136,524.00
MARK BONAFE	HIGHEST COMPENSATED EMPLOYEE	\$105,109.00	\$4,952.00	\$110,061.00

[Patient Services Inc., IRS Form 990, [6/2/20](#)]

## Lobbying Activities

### 2004-2020: PSI SPENT MORE THAN \$2 MILLION ON LOBBYING THE FEDERAL GOVERNMENT.

2004-2020: PSI spent \$2,156,000 lobbying the federal government.

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

### 2020: PSI EMPLOYED LOBBYING FIRM THORN RUN PARTNERS, WHICH REPRESENTS PHARMACEUTICAL COMPANIES

Q1-Q3 2020: According to federal lobbying disclosure records, PSI spent at least \$110,000 on lobbying firms Thorn Run Partners and Health & Medicine Counsel of Washington.

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

- **Q1-Q3 2020: Thorn Run Partners lobbied on behalf of pharmaceutical and related companies, including Alkermes, Biogen, Boehringer Ingelheim, GlaxoSmithKline, and Institute for Gene Therapies.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

- **Q1-Q3 2020: Jessie Howe Brairton of Thorn Run Partners was a registered lobbyist for Alkermes, GlaxoSmithKline, and Novartis while also serving as a registered lobbyist for PSI.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

- **2006-2011: Brairton was a director of federal affairs for Eli Lilly.**

[Jessie Brairton LinkedIn profile, accessed [12/27/20](#)]

- **Q1-Q3 2020: Alex DePizzo was a registered lobbyist for Alkermes, GlaxoSmithKline, and Novartis while serving as a registered lobbyist for PSI.**

[U.S. Senate Lobbying Disclosure Database, accessed [12/18/20](#)]

### 2020: PSI EMPLOYED HEALTH AND MEDICINE COUNSEL OF WASHINGTON, WHICH REPRESENTS DRUG MAKER, PROLONG PHARMACEUTICALS.

2020: The Health and Medicine Counsel of Washington lobbied on behalf of Prolong Pharmaceuticals and Patient Services Inc.

[U.S. Senate Lobbying Disclosure Database, accessed [1/25/21](#)]

## Prescription Drug Cost Legislation

### H.R. 3: ELIJAH E. CUMMINGS LOWER DRUG COSTS NOW ACT

2017: PSI posted an update on its website noting PhRMA's opposition to drug pricing legislation introduced by Elijah Cummings.

"Senator Bernie Sanders (I-VT) and Rep. Elijah Cummings (D-MD) introduced legislation in their respective

chambers late last month (S. 2011/H.R. 4138) that would allow the Department of Health and Human Services (HHS) to negotiate drug prices under the Medicare Part D program. [...] In their press release, the bill sponsors note that President Trump supported giving HHS this authority as a candidate. However, he has not commented on the issue since assuming office. Most conservative lawmakers are likely to continue opposing price negotiations absent the President’s support for the change and such a policy has long been opposed by the Pharmaceutical Research and Manufacturers of America, which insists it would lead to government rationing and price controls.” [PSI, 11/21/17, via Internet Archive, [8/4/20](#)]

**October 2019: PSI joined a MAPRx coalition letter commenting on a draft of H.R. 3, supporting a cap on Medicare Part D out-of-pocket costs and calling for stronger low-income subsidies and an elimination of cost-sharing for generics for patients in the low-income subsidy program.**

“MAPRx strongly supports an annual OOP cap for Medicare Part D to limit the amount Medicare beneficiaries pay for covered prescription drugs. We support the provisions that create a cap on the costs for prescription drugs for Medicare Part D beneficiaries. Setting an annual OOP limit at \$2,000 would provide considerable help to beneficiaries compared with the unlimited OOP exposure under current law. The lack of an OOP cap is one of the biggest challenges inhibiting the program from being even more successful in meeting the health care needs of Medicare beneficiaries. An annual OOP cap will help ensure Medicare beneficiaries have access to vital and life-saving medicines. We believe the cap should be implemented as soon as possible, earlier than the 2022 implementation date in H.R. 3. This is especially important considering that in 2020, beneficiaries face the “OOP cliff” where they will have to pay an additional \$1,250 in out-of-pocket costs before reaching the catastrophic threshold as compared with 2019. [...] MAPRx is concerned that H.R. 3 misses an opportunity to make necessary changes to the Part D benefit including: • Strengthen the Low-Income Subsidy (LIS) program by eliminating the asset test and streamlining program administration. Also, Congress should provide full Extra Help benefits to those living on the edge of poverty. Only the lowest income individuals with Medicare receive full benefits through Extra Help. Individuals with incomes of about \$16,860 to \$18,735 (135percent to 150percent FPL in 2019) who also meet the program’s asset test are exposed to premiums, deductibles, and high coinsurance rates (15 percent). • Eliminate cost-sharing for generics for Low-Income Subsidy (LIS) recipients. Research has shown that eliminating cost-sharing can improve adherence to medication regimens.”

[MAPRx letter to Reps. Pallone, Neal, and Scott, [10/16/19](#)]

**H.R. 19 / S. 3129: LOWER COSTS MORE CURES ACT**

*No relevant information.*

**S. 2543: PRESCRIPTION DRUG PRICING REDUCTION ACT**

**July 2019: PSI wrote a memo describing the Prescription Drug Pricing Act and its prospects for passage in Congress, but didn’t explicitly take a position on the bill itself.**

[PSI, [7/25/19](#)]

- **The PSI memo on S.2543 noted an amendment to the bill that would require the GAO to study copay coupons and patient assistance programs for their impact on drug pricing expenditures made by Medicare and Medicaid.**

“As it relates to the patient assistance field, the bill comes with an amendment from Senators Hassan (D-NH), Whitehouse (D-RI), and Brown (D-OH), which would direct the Government Accountability Office to ‘study the impact of copayment coupons and other patient assistance programs on prescription drug pricing and expenditures within the Medicare and Medicaid programs.’”

[PSI, [7/25/19](#)]

- **The PSI memo noted that drug company contributions to patient assistance programs and foundations would not be excluded from the “average sale price” reported to HHS.**

“Manufacturers will have to exclude the value of coupons provided to privately insured individuals from each drug’s Average Sale Price (ASP), as reported to the HHS Secretary. Manufacturers would not have to exclude contributions to patient assistance programs or foundations.”

[PSI, [7/25/19](#)]

- **The PSI memo included quotes from PhRMA CEO Stephen Ubl and BIO's Tom DiLenge criticizing the bill.**

“After the bill was passed out of committee, PhRMA CEO Stephen J. Ubl released a statement deriding the bill, saying that it was ‘the wrong approach to lowering drug prices.’ Tom DiLenge of BIO also weighed in; ‘The proposal does almost nothing to hold insurance companies and middlemen accountable for shifting more of the cost burden onto patients.’” [PSI, [7/25/19](#)]





## METHODOLOGY

All of the material presented in this report is publicly available.

For each organization mentioned in this report, we visited their websites and the websites of their affiliates. We reviewed published media reports available on the Internet and via the LexisNexis news database and other relevant websites as well.

Where available, we reviewed nonprofit organizations' tax returns (the IRS Form 990) using the [ProPublica Nonprofit Explorer](#) and [Guidestar by Candid](#). Occasionally, more recent tax forms were available on an organization's own website as well. We also reviewed audited financial statements and annual reports published by the organizations and available on their public websites.

Information on the professional histories of organization leadership and boards of directors was gathered from the organizations' websites, the websites of other employers, professional [LinkedIn](#) profiles, and, occasionally, personal [Facebook](#) pages that were available to the public. Compensation information was collected from the organizations' tax returns.

Additionally, some information about professional backgrounds, affiliations, and relationships with the pharmaceutical industry was gathered primarily from two sites. [PubMed.gov](#), a project of the National Center for Biotechnology Information, U.S. National Library of Medicine, provided information regarding professional conflicts of interest of authors as reported in medical journals. [OpenPaymentsData.CMS.gov](#), which is managed by the Centers for Medicare & Medicaid Services, provided information on medical providers who received direct payments or other benefits or consideration from pharmaceutical companies. Similar information was taken from "[Dollars for Docs](#)," a project of ProPublica, which published information from the Open Payments Data collection.

Lobbying information about the organizations, their lobbyists, and the firms that they employ to lobby the federal government on their behalf was primarily obtained from the [U.S. Senate Lobbying Disclosure website](#), which publishes reports filed pursuant to the Lobbying Disclosure Act. Additional and background information on federal lobbying was collected from [OpenSecrets.org](#), a project of the nonprofit Center for Responsive Politics.