

UPDATED

AUGUST 2023

NEW REACH OF PHARMA'S HIDDEN HAND

HIDING IN PLAIN SIGHT

AN UPDATE TO

THE HIDDEN HAND

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

PATIENTS FOR AFFORDABLE DRUGS[™]

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INTRODUCTION

The role of drug company money in financing patient organizations has been well-documented and widely reported.^{1,2,3} One study found that more than 80 percent of the top 104 patient advocacy groups in the United States with annual revenues greater than \$7.5 million accept funding from drug and medical-device companies.⁴

The pharmaceutical and health products industry spent a record \$373.7 million on lobbying and political contributions in 2022 to block legislation that would lower drug prices and maintain its pricing power.⁵ The lion's share of this money came from drug companies and their trade associations. Not reported, however, is spending to fuel advocacy groups fighting reforms—some relatively new to the scene and some established groups taking a higher profile.

The influence of pharmaceutical funding shows up in in three types of groups:

1. **Legitimate and well-respected organizations** that advocate for and support patients organized most often around specific diseases
2. **Front groups founded and funded by pharma** to advocate for policies and actions that will benefit the industry
3. **So-called charitable organizations** funded by the pharmaceutical industry to cover out-of-pocket costs of drugs for patients in order that the drugmaker can in turn charge high prices and leverage the relatively small out-of-pocket support to gain the much larger payment for the balance of the cost from government and private payers.⁶ The purpose of this structure is made clear by the fact that 97 percent of such charities will not cover costs for uninsured patients.⁷

To help policymakers and news media gain a clearer picture of these relationships, and their impact on the actions of even the most legitimate and respected groups, Patients For Affordable Drugs published a report, “The Hidden Hand,” in 2021. That report detailed how the industry influences which policies patient groups typically do and do not support, and how groups under pharma’s direction actually advocate for pro-pharma positions in favor of higher prices for drugs.

This update to “[The Hidden Hand](#)” looks at three groups that have been established or taken a more prominent role in drug pricing issues since the original report was published. Those groups are: **The Haystack Project, No Patient Left Behind, and The Community Oncology Alliance.**

Patients For Affordable Drugs (P4AD) is the only national patient organization focused exclusively on lowering prescription drug prices. Since our launch a little over six years ago, we have mobilized a community of hundreds of thousands of patients and allies who support efforts to shape and achieve system-changing policies that make prescription drugs affordable for all people in the United States. P4AD is independent, bipartisan and does not accept funding from any organizations that profit from the development or distribution of prescription drugs.

Executive summaries of our research findings follow. Detailed, documented findings can be found [here](#).

EXECUTIVE SUMMARY

The Haystack Project

According to its website, The Haystack Project has worthy and important goals.⁸ As stated, “Haystack Project is a non-profit enabling rare and ultra-rare disease patient advocacy organizations to highlight and address systemic obstacles to patient access.”

1 Fabbri, A., Parker, L., Colombo, C., Mosconi, P., Barbara, G., Frattaruolo, M. P., Lau, E., Kroeger, C. M., Lunny, C., Salzwedel, D. M., & Mintzes, B. (2020, January 22).

Industry funding of patient and Health Consumer Organisations: Systematic review with Meta-analysis. The BMJ. <https://www.bmj.com/content/368/bmj.l6925>

2 Liu, A. (2019, October 9). Big Pharma's shelling out big-time to patient organizations. Is there any quid pro quo? Fierce Pharma. <https://www.fiercepharma.com/pharma/big-pharma-paid-patient-advocates-big-time-there-any-quid-pro-quo>

3 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>

4 Thomas, K. (2017, March 1). More than 80 percent of patient groups accept drug industry funds, study shows. The New York Times. <https://www.nytimes.com/2017/03/01/health/patient-groups-drug-industry-money.html>

5 Chen, J. (2023, May 3). Pharma spent record amount on lobbying in 2022; PBMS are now in spotlight. MMITNetwork. <https://www.mmitnetwork.com/aishealth/spotlight-on-market-access/pharma-spent-record-amount-on-lobbying-in-2022-pbms-are-now-in-spotlight-2/>

6 Johnson, C. Y. (2018, April 25). Mother, wife, million-dollar patient: Why drug companies see rare-disease patients as human jackpots. The Washington Post. <https://www.washingtonpost.com/graphics/2018/business/million-dollar-patient/>

7 (2019, August 6). Most independent charity drug assistance programs exclude the uninsured. Johns Hopkins Bloomberg School of Public Health. <https://publichealth.jhu.edu/2019/most-independent-charity-drug-assistance-programs-exclude-the-uninsured>

8 The Haystack Project. The Haystack Project. (n.d.). <https://haystackproject.org/>

Although high pharmaceutical prices are a major systemic obstacle to patient access for all drugs—including those for rare and ultra-rare diseases—Haystack does not advocate for lower prescription drug prices—rather it warns that lower prices could harm patient access to treatment.^{9,10,11}

Haystack’s policy positions are fully aligned with those of the pharmaceutical industry. Like pharma, Haystack supported elements of the Inflation Reduction Act (IRA) to lower out-of-pocket costs for people on Medicare, but did not offer support for provisions to lower the prices of prescription drugs, including Medicare drug price negotiation and limits on annual price increases tied to the rate of inflation. This approach to policy can be explained by the following facts:

- Haystack receives funding from at least 18 pharmaceutical companies as shown on its website,¹²



- Haystack acknowledges that it “employs corporate resources to develop, produce, and implement mission related programs, materials, and activities.”¹³
- Records indicate it receives as much as 99 percent of its funding from drug companies;¹⁴
- Haystack Project’s conflict of interest policy does not address corporate sponsorships influencing policy positions.¹⁵
- Haystack’s CEO, Deanna Darlington, spent more than 20 years working in the pharmaceutical industry at seven different drug companies.
- Haystack’s Board has featured significant representation from individuals connected to pharmaceutical companies:¹⁶
 - Former Haystack Project CEO Jim Caro previously worked for Sanofi, Wyeth Pharmaceuticals, and Connect 4 Strategies.
 - Secretary of the Haystack Project’s board of directors Bela Sastry is an in-house lobbyist for Sunovion Pharmaceuticals.
 - Haystack Project’s first chairperson, Cynthia Goss, works at biopharmaceutical company Insmed, Inc., and previously worked at Astellas, Regeneron, and Otsuka.
 - Board member Lisa Steelman previously worked at Janssen Pharmaceuticals and was the Illinois Task Force chair for PhRMA.
 - Chevese Turner, a Haystack Project director and one-time interim CEO, previously worked at pharmaceutical companies Eisai, MGI Pharma, and Novartis.
 - Amgen senior vice president of global government affairs Victoria Blatter joined the board of directors in March, 2023.
- Haystack was founded by a pharmaceutical industry lobbyist — Saira Sultan Chirico, who is also President and CEO of the pharmaceutical lobbying firm Connect 4 Strategies;¹⁷

9 Heath, S. PatientEngagementHIT. (2021, December 3). High Drug Costs Bar Care Access, medication adherence for 13M adults. PatientEngagementHIT. <https://patientengagementhit.com/news/high-drug-costs-bar-care-access-medication-adherence-for-13m-adults>

10 Pakizegee, M. (2019). Pathways for Paying for Rare Disease Treatments. Hmpgloballearningnetwork.com. <https://www.hmpgloballearningnetwork.com/site/jcp/article/pathways-paying-rare-disease-treatments>

11 Haystack Project Comments on Medicare Drug Price Negotiation Program Guidance, April 14, 2023. <https://static1.squarespace.com/static/5966cc2220099e91326caec/t/643eaa9f7302cc1c715388fa/1681828511386/Haystack+IRA+Implementation+guidance+comments+%28002%29.pdf>

12 Haystack Project 2022 Year in Review. <https://static1.squarespace.com/static/5966cc2220099e91326caec/t/63ab5c643e747d1cca5a9c2d/1672174704917/2022-year-in-review+FINAL.pdf>

13 See page 8 of detailed findings.

14 Haystack Project 2022 Year in Review. <https://static1.squarespace.com/static/5966cc2220099e91326caec/t/63ab5c643e747d1cca5a9c2d/1672174704917/2022-year-in-review+FINAL.pdf>

15 See page 30 of detailed findings.

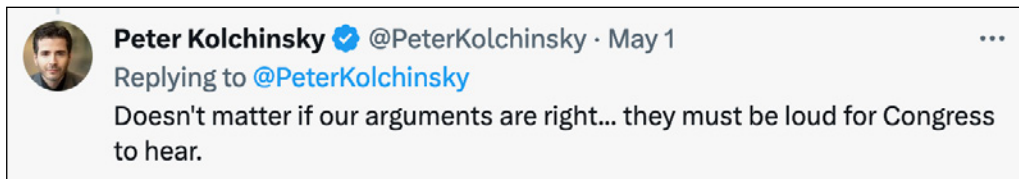
16 See page 21 of detailed findings.

17 Saira Sultan, JD, consultant. The Haystack Project. <https://haystackproject.org/resources-3/2019/4/14/saira-sultan-jd-consultant>

- Haystack Project was formally incorporated in 2019, using Sultan Chirico's home address;
- According to U.S. Senate records, Saira Sultan Chirico and her company, Connect 4 Strategies, are registered lobbyists for several pharmaceutical companies, including Akcea, Orexo, and Ferring Pharmaceuticals;¹⁸
- Haystack is staffed by Connect 4 Strategies with professionals who come from the drug industry;¹⁹
 - Saira Sultan, Connect 4 Strategies' president and CEO, spent ten years working for Sanofi and Pfizer.
 - Kathleen Shoemaker, a senior advisor at Connect 4 Strategies previously worked at Eli Lilly.
 - Jami Earnest, who works on scientific strategy at Connect 4, previously worked for Johnson & Johnson "where she launched over twelve pharmaceutical products and supported four blockbuster franchises."
- Paul Stickler, a senior advisor at Connect 4 Strategies, previously worked at AbbVie and Eton Pharmaceuticals.
- Connect 4 Strategies is a registered federal lobbyist for at least eight pharmaceutical companies: Akcea Therapeutics, Biomarin Pharmaceutical, Ferring Pharmaceuticals, Imara, Mast Therapeutics, Orexo US, Recordati Rare Diseases, and Therabron Therapeutics.²⁰
- Connect 4 Strategies boasts about "creating a new pharmacy group to increase policy support."
- Connect 4 Strategies advertises work done for gene and cell therapeutic companies highlighting its "experience across reimbursement, clinical development, policy and advocacy."²¹

Haystack harnesses legitimate concerns of rare and ultra-rare disease groups who are working to promote new treatments and cures. But it clearly is structured and functions to promote the interests of drug companies, and through Connect 4 Strategies, actually works directly for drug companies.

No Patient Left Behind



NPLB Overall Position

Founded by Venture Capitalist Peter Kolchinsky, Managing Partner of RA Capital, No Patient Left Behind (NPLB) describes itself as a non-profit organization. This descriptor is more than a little misleading because NPLB is focused primarily on maximizing profit for its funders and the entire pharmaceutical industry.

NPLB could be renamed "No Pharma Investor Left Behind," because its underlying purpose is to ensure the pharmaceutical industry can charge unlimited prices for new drugs for an extended period of time

not less than 14 years.²² NPLB is built on the core notion that unlimited pricing controlled by drug companies is necessary to attract investment in drug development. NPLB fails to give adequate credit to the billions of dollars in taxpayer funding through the National Institutes of Health (NIH) and other federal agencies that lays the basic science foundation for virtually every drug that is approved by the Food and Drug Administration (FDA), and that investors leverage for profit.^{23,24} In fact, "the amount invested per approved drug by the NIH is comparable to that of reported investment by the biopharmaceutical industry."

18 See page 2 of detailed findings.

19 Connect 4 strategies. Connect 4 Strategies. (n.d.). <https://www.connect4strategies.com/> and page 4 of detailed findings.

20 See page 14 of detailed findings.

21 See page 15 of detailed findings.

22 Morrison, C. (2022, July 8). Biotech leaders urge fixes to bad senate drug deal. RApport. <https://rapport.bio/all-stories/fix-the-senate-drug-pricing-bill-an-open-letter>

23 Bentley University Newsroom. (2023, April 28) New study shows NIH investment in new drug approvals is comparable to investment by pharmaceutical industry. Bentley University. <https://www.bentley.edu/news/new-study-shows-nih-investment-new-drug-approvals-comparable-investment-pharmaceutical>

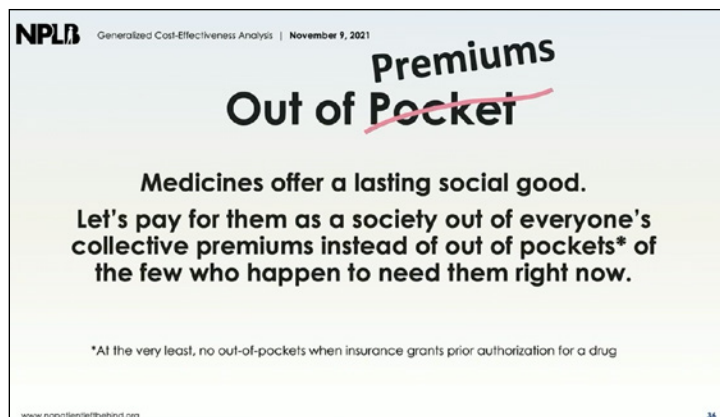
24 No patient left behind: How public funding, incentives, and private funding function together to enable all of us to get what we want: new medicines. (n.d.) <https://nopatientleftbehind.docsend.com/view/mxht62ee3dk25eu>

As a cornerstone of the policy framework it promotes, NPLB claims to support a requirement that all drugs go generic “without delay” and that “the prices of drugs that can’t or won’t go generic should be regulated once their patents expire.”^{25,26} NPLB apparently defines undue delay as longer than 14 years.²⁷ It calls this concept “contractual genericization,” and features calls for such a policy prominently on its website.²⁸ But although NPLB centers its advocacy around this idea, it only pays lip service to this key concept.²⁹ Our research found no evidence that it has ever offered or supported actual legislation to implement this key element of its grand design. It also claims to advocate to “extend insurance to everyone in America,” but our research could find no evidence that NPLB has engaged with advocates who support universal health coverage or proposed actual legislation to extend health insurance coverage to every American.³⁰ Its principal work centers around ensuring unfettered pricing power for the pharmaceutical industry.

In fact, NPLB is fully a creature of the drug industry founded and funded by RA Capital, a Boston-based biopharma venture capital and investment management firm with approximately \$10 billion in assets under management.³¹ NPLB’s face is RA Capital’s Managing Partner, Peter Kolchinsky.³² Although it has attracted a limited number of patients who sincerely embrace its world view, its so-called “grassroots” representation consists primarily of employees of RA Capital, pharmaceutical company executives, and other venture capitalists.^{33,34}

Like drug companies, NPLB advocates for insurance reforms to “eliminate out-of-pocket costs for patients.”³⁵ But NPLB does not offer policies that would cover the cost of such reforms which—unless prices were lowered—would result in higher premiums that must be paid for by patients,

consumers, employers, and taxpayers. Since out-of-pocket payments account for 14 percent of U.S. drug spending of nearly \$580 billion, the cost of eliminating out-of-pocket payments would be \$81 billion.^{36,37} But NPLB never explains where that \$81 billion would come from. It simply says quite directly — as in the slide from a NPLB presentation deck below — that we should shift spending from out-of-pocket costs to premiums.³⁸



NPLB Is Managed And Governed By Individuals With Financial Ties The Industry

No Patient Left Behind is operated and governed by managers and board members — all of whom have direct financial ties to the pharmaceutical industry.

- Peter Rubin, Executive Director, served as a registered lobbyist for the trade association PhRMA and various drug companies for about 17 years. He was Deputy Vice President of Federal Affairs for PhRMA from 2000-2006.³⁹
- The Co-Chairs of NPLB’s advisory board are a pharmaceutical CEO and a partner of a pharmaceutical Venture Capitalist firm.⁴⁰
- Every member of NPLB’s advisory board/steering committee has ties to the pharmaceutical industry.

25 No patient left behind: Our priorities. No Patient Left Behind | Our Priorities. (n.d.). <https://www.nopatientsleftbehind.org/our-priorities>

26 Sagers, J. (2022, June 23). How to kill the conversation that makes innovation possible. RApport. <https://rapport.bio/all-stories/how-to-kill-the-conversation>

27 Small molecule parity. Small Molecule Parity. (n.d.). <https://www.nopatientsleftbehind.org/small-molecule-resources>

28 No patient left behind: Life science builders. No Patient Left Behind | Life Science Builders. (n.d.). <https://www.nopatientsleftbehind.org/life-science-builders>

29 No patient left behind: Life science builders. No Patient Left Behind | Life Science Builders. (n.d.). <https://www.nopatientsleftbehind.org/life-science-builders>

30 No patient left behind: Our Strategy. No Patient Left Behind | Our Strategy. (n.d.). <https://www.nopatientsleftbehind.org/about/strategy>

31 RA Capital. (2023, July). What We do. RACAP.com. <https://www.racap.com/about-us/what-we-do>

32 RA Capital. (2023, July). Social Responsibility. RACAP.com. <https://www.racap.com/about-us/social-responsibility>

33 DLA Piper’s At the Intersection of Science and Law podcast (Mar 21, 2022). The moral imperative: Balancing innovation, regulation and prescription drug availability. <https://omny.fm/shows/at-the-intersection-of-science-and-law-1/the-moral-impertative-balancing-innovation-regulation-and-prescription-drug-availability?t=25m>

34 No patient left behind: Life science builders. No Patient Left Behind | Life Science Builders. (n.d.). <https://www.nopatientsleftbehind.org/life-science-builders>

35 No patient left behind: Our Strategy. No Patient Left Behind | Our Strategy. (n.d.). <https://www.nopatientsleftbehind.org/about/strategy>

36 Cubanski, J. (2019, May 23). How does prescription drug spending and use compare across large employer plans, Medicare part D, and Medicaid?. KFF. <https://www.kff.org/medicare/issue-brief/how-does-prescription-drug-spending-and-use-compare-across-large-employer-plans-medicare-part-d-and-medicaid/>

37 Roehrig, R., Turner A (2020, September). Projections of the Non-Retail Prescription Drug Share of National Health Expenditures. Altarum. <https://altarum.org/sites/default/files/uploaded-publication-files/Altarum%20Projections%20of%20the%20Non-Retail%20Dru.pdf>

38 No Patient Left Behind. (2021, December 4). The failure to communicate value. YouTube. <https://www.youtube.com/watch?v=ayss4682k6k>

39 See page 39 of detailed findings.

40 See page 41 of detailed findings.

NPLB Wants Drug Companies To Be Paid Based On Criteria Not Used For Any Other Players In The Health Care System

NPLB advocates for a version of value pricing that credits the drug maker for any and all benefits of treatment, including the ability to return to work, savings from commuting to the doctor for care, relieving caregiver burden, the value of hope, value of knowing, equity, and even population growth.⁴¹ As seen in this video, **NPLB encourages drug companies to use this approach to pricing to justify charging the highest possible price, making crystal clear its underlying mission.**⁴²

While NPLB advocates that drug companies receive compensation for any and all value associated with their drugs, no one else in the U.S. health care system is paid based on this method of valuation. The doctors and nurses who diagnose patients and administer drugs are not compensated based on such broad criteria. Likewise, surgeons who repair spinal injuries permitting a person to be able to walk again and resume a normal, productive life aren't paid based on these broad criteria. Only pharma demands payment for non-direct benefits of its products, and if we extended this pricing framework to all other health care sectors, we would bankrupt the system.

NPLB Funding Is Not Fully Or Clearly Disclosed

No Patient Left Behind does not clearly disclose its funding amounts and sources, except to state: "NPLB was founded by RA Capital Management, a Boston-based firm that invests in companies developing drugs, medical devices and diagnostics."⁴³ NPLB acknowledges the conflict of interest implicit in its structure and funding, but blithely dismisses it: "You might even wonder whether we're just a front to help investors make more money. We could (and do) deny it, but that's ultimately for you to decide."⁴⁴

The exact finances and funding of No Patient Left Behind are opaque because of its legal structure. We could not find any registration of NPLB as a distinct legal entity. According to research for this report, it is not registered as a nonprofit organization with the IRS, even though it describes itself as a nonprofit organization. NPLB appears to be operating as a fund within the non-profit Hopewell Fund which serves as a fiscal sponsor under Internal Revenue Service regulations.

Quick Snapshot: Community Oncology Alliance

The Community Oncology Alliance (COA) has been regularly appearing at Congressional hearings and in the news media recently. The group describes itself as a "grassroots network of community oncology practices to advocate for public policies that benefit patients."⁴⁵ While its positioning paints a very sympathetic picture, it is in fact merely a trade association for oncology practices that deliver infusion services supplying treatment and drugs. It is funded by 75 pharmaceutical companies, trade associations and distributors.⁴⁶ An example of COA's interests: Maryland Oncology Hematology is a community oncology provider. It is owned by the US Oncology Network which owns more than 500 sites of service and which itself is owned by giant drug distributor, McKesson.^{47,48} While COA states that high drug prices are a problem, it actively works to undermine the implementation of state drug affordability boards, and it opposes efforts to lower the prices of certain Part B infused drugs for which its members are paid based on a percentage of the price.^{49,50,51} COA claims to advocate for patients, but resists reforms that would lower the prices of prescription drugs for patients that are provided through its member businesses.

41 Hogan Lovells (2022, July 1). Demy-Colton panel explains how to future-proof your market access strategy. JDSupra. <https://www.jdsupra.com/legalnews/demy-colton-panel-explains-how-to-9198398/>

42 No Patient Left Behind. (2021, December 14). The failure to communicate value. YouTube. <https://www.youtube.com/watch?v=ayss4682k6k>

43 No patient left behind: Our why. No Patient Left Behind | Our Why. (n.d.). <https://www.nopatientleftbehind.org/about/why>

44 No patient left behind: Our why. No Patient Left Behind | Our Why. (n.d.). <https://www.nopatientleftbehind.org/about/why>

45 (2023, March 20). Who we are. Community Oncology Alliance. <https://communityoncology.org/who-we-are/>

46 (2023, June 22). Become a corporate member. Community Oncology Alliance. <https://communityoncology.org/become-a-corporate-member/>

47 The US Oncology Network. (2022, March 23). Empowering local cancer care. <https://usoncology.com/our-company/>

48 S&P Global Market Intelligence. (2010, November 2). McKesson Acquires US Oncology Services for US\$2.16 Bil. <https://www.spglobal.com/marketintelligence/en/mi/country-industry-forecasting.html?id=106593655>

49 Community Oncology Alliance. (2023, May 25n.d.). COA Position Statement on Prescription Drug Affordability Boards. <https://mycoa.communityoncology.org/education-publications/position-statements/coa-position-statement-on-prescription-drug-affordability-boards>

50 Community Oncology Alliance. (2023, May 25n.d.). COA Position Statement on Prescription Drug Affordability Boards. <https://mycoa.communityoncology.org/education-publications/position-statements/coa-position-statement-on-prescription-drug-affordability-boards>

51 Community Oncology Alliance. (n.d.). COA Position Statement on Sequestration Cuts. <https://mycoa.communityoncology.org/education-publications/position-statements/coa-position-statement-sequestration-cuts>

METHODOLOGY

To develop this report, the Patients For Affordable Drugs 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, a project of the National Center for Biotechnology Information; OpenPaymentsData.CMS.gov, which is managed by the Centers for Medicare and Medicaid Services; "Dollars for Docs," a project of ProPublica; OpenSecrets.org, a project of the nonprofit Center for Responsive Politics; and the U.S. Senate Lobbying Disclosure website, which publishes reports filed pursuant to the Lobbying Disclosure Act.

DETAILED FINDINGS

HAYSTACK PROJECT

HAYSTACK PROJECT IS DRIVEN BY BIG PHARMA LOBBYIST, SAIRA SULTAN CHIRICO

Saira Sultan Chirico, a lobbyist for and former employee of pharmaceutical companies founded and operates Haystack Project

2016: SAIRA SULTAN CHIRICO STARTED THE HAYSTACK PROJECT

12/21/18: Saira Sultan Chirico posted on LinkedIn reflecting on two years of the Haystack Project.

“As I reflect on the last two years and look ahead to 2019, I am struck by how many of you I’ve gotten to know and appreciate, both personally and professionally. The Haystack Project has been a labor of love in more ways than one! We’ve conquered a lot of issues, each with their own language and acronyms (!) and substantively, thoughtfully, and credibly weighed in on issues as far ranging as 340b, DRGs, ICER, and more. We’ve examined systemic barriers to access that impact us now or will when new treatments come to market for rare and ultra-rare diseases. Our Hill visits have been well received. And most importantly, we are over two dozen strong now and speak with a much larger voice together than we do alone. You’ve all supported each other, welcomed new members as they accelerate through their own learning curves, and thought carefully about solutions to each other’s reimbursement challenges. I’m so proud to be a part of what we’ve accomplished these last two years at the Haystack Project.” [LinkedIn, [12/21/18](#)]

SAIRA SULTAN CHIRICO PREVIOUSLY WORKED 10 YEARS FOR DRUGMAKERS PFIZER AND SANOFI IN GOVERNMENT AFFAIRS

Sultan spent 10 years working in the pharmaceutical industry for Sanofi and Pfizer.

“Saira brings a decade of experience working with market access, health outcomes, and commercial teams in pharmaceutical companies, including Pfizer and Sanofi. Saira is an experienced project management lead for large cross-functional efforts at Medtronic, Pfizer, Sanofi, and more. [...] Complementing her 10 years in pharmaceuticals, Saira’s time at Medtronic gives her an in-depth understanding of the unique needs of the device industry.” [Haystack Project, [4/14/19](#)]

- **2011-2014: Sultan was a senior director for reimbursement and government relations at Pfizer.**
[Saira Sultan LinkedIn profile, accessed [5/9/23](#)]
- **2004-2011: Sultan was a director of government affairs at Sanofi.**
[Saira Sultan LinkedIn profile, accessed [5/9/23](#)]

1999-2001: Sultan worked in government affairs for Medtronic.
[Saira Sultan LinkedIn profile, accessed [5/9/23](#)]

SAIRA SULTAN CHIRICO IS PRESIDENT AND CEO OF CONNECT 4 STRATEGIES, AN ASSOCIATION MANAGEMENT COMPANY AND LOBBYING FIRM FOR PHARMACEUTICAL COMPANIES

Saira Sultan is president and CEO of Connect 4 Strategies, a “life science” lobbying and consulting firm.

“President & CEO, Connect 4 Strategies, LLC Sep 2014 - Present · 8 yrs 9 mos Washington DC Metro Area Strategic consulting in health policy and reimbursement, serving life science companies, patient and provider groups, and medical device companies as they license in assets, create and implement reimbursement strategies, launch products, grow market share, and increase their profile among patient groups. Expertise in both commercial and government payer strategies. Advise and grow lobbying, policy, and corporate relations functions for patient groups and medical societies. Help groups navigate administrative agencies in the Executive Branch. 25 years of developing creative solutions and common ground in partnership with hospital groups, manufacturers, medical societies, clinical pathway developers, and the Federal government.” [Saira Sultan LinkedIn profile, accessed [5/9/23](#)]

SULTAN CHIRICO IS A LOBBYIST FOR PHARMACEUTICAL COMPANIES

According to U.S. Senate records, Saira Sultan Chirico and her company, Connect 4 Strategies, are registered lobbyists for several pharmaceutical companies, including Akcea, Orexo, and Ferring Pharmaceuticals.

[U.S. Senate Lobbying Disclosure Database, accessed [5/15/23](#)]

NB: For further information on Sultan Chirico and Connect 4 Strategies federal lobbying activities, [see below](#).

2019: Haystack Project was formally incorporated, using Sultan Chirico's home address

2019: HAYSTACK PROJECT WAS INCORPORATED IN MARYLAND AND OBTAINED NON-PROFIT STATUS FROM THE IRS

The Haystack Project is incorporated in the State of Maryland with a principal address of 6005 GLOSTER ROAD, BETHESDA MD 20816.

"Department ID Number: D19496975 Business Name: HAYSTACK PROJECT, INC. Principal Office: 6005 GLOSTER ROAD BETHESDA MD 20816." [Maryland Business Express, HAYSTACK PROJECT, INC.: D19496975, accessed [5/10/23](#)]

2019: Haystack Project obtained non-profit status, created a board of directors that "did not have any immediate or direct financial or corporate interests in HP's work."

"Non-profit status drew more patient groups to the organization. We are 60+ groups strong at year's end, and growing! Non-profit status also meant finding a CEO and establishing a Board of Directors. These positions were volunteer in 2019 and may be for one more year as we consider funding sources. We were careful to choose a Board that could provide guidance and advice, but did not have any immediate or direct financial or corporate interests in HP's work. While that has its benefits, the Board did suggest a Corporate Council, which could provide HP more direct counsel as well." [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

2019: Haystack Project noted that a board of directors without financial conflicts of interest "has its benefits," but the board saw fit to create a "Corporate Council, which could provide HP more direct counsel as well."

"We were careful to choose a Board that could provide guidance and advice, but did not have any immediate or direct financial or corporate interests in HP's work. While that has its benefits, the Board did suggest a Corporate Council, which could provide HP more direct counsel as well." [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

HAYSTACK PROJECT'S INITIAL ADDRESS WAS SAIRA SULTAN CHIRICO AND JOSEPH CHIRICO'S HOME

2019: The Haystack Project's address was 6005 Gloster Road, Bethesda, MD, 20816.

[IRS, Haystack Project Determination Letter, EIN 83-3367375, [3/27/19](#)]

- **Saira Sultan is the Haystack Project's registered agent.**

"Resident Agent: SAIRA SULTAN CHIRICO, 6005 GLOSTER ROAD, BETHESDA MD 20816" [Maryland Business Express, HAYSTACK PROJECT, INC.: D19496975, accessed [5/10/23](#)]

6005 Gloster Road, Bethesda, MD, 20816 was owned by Joseph Anthony Chirico and Sara Sultan Chirico.

[Maryland Department of Assessments and Taxation, accessed [5/9/23](#)]

JOE CHIRICO WAS HAYSTACK PROJECT'S TREASURER

January 2019-Present: Joe Chirico is director and treasurer of the Haystack Project.

[Joe Chirico LinkedIn profile, accessed [5/8/23](#)]

2019: Chirico was listed on Haystack Project's tax returns as the organization's treasurer.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

SAIRA SULTAN CHIRICO WAS AMONG HAYSTACK PROJECT'S INITIAL BOARD MEMBERS

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Saira Sultan Chirico was listed among Haystack Project's initial board of directors on their Articles of Incorporation.
[Haystack Project, Articles of Incorporation, [3/12/19](#)]

2019: HAYSTACK PROJECT PAID \$90,000 TO SULTAN CHIRICO FOR "CONSULTING"

2019: Haystack Project reported to the IRS that it paid \$90,000 to Saira Sultan Chirico for a "CONTRACT FOR CONSULTING SERVICES."

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

HAYSTACK PROJECT MAY RECEIVE MORE THAN 99 PERCENT OF ITS FUNDING FROM PHARMACEUTICAL COMPANIES

Haystack Project claimed that its initial board of directors had no "immediate or direct financial or corporate interests in HP's work," but recommended the creation of a "Corporate Council, which could provide HP more direct counsel as well"

2019: Haystack Project obtained non-profit status, created a board of directors that "did not have any immediate or direct financial or corporate interests in HP's work."

"Non-profit status drew more patient groups to the organization. We are 60+ groups strong at year's end, and growing! Non-profit status also meant finding a CEO and establishing a Board of Directors. These positions were volunteer in 2019 and may be for one more year as we consider funding sources. We were careful to choose a Board that could provide guidance and advice, but did not have any immediate or direct financial or corporate interests in HP's work. While that has its benefits, the Board did suggest a Corporate Council, which could provide HP more direct counsel as well." [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

2019: Haystack Project noted that a board of directors without financial conflicts of interest "has its benefits," but the board saw fit to create a "Corporate Council, which could provide HP more direct counsel as well."

"We were careful to choose a Board that could provide guidance and advice, but did not have any immediate or direct financial or corporate interests in HP's work. While that has its benefits, the Board did suggest a Corporate Council, which could provide HP more direct counsel as well." [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

A “Year In Review” document showed that Haystack Project financial sponsorships start at \$5,000 and go up to \$75,000 annually

2019: Haystack Project’s sponsorship levels started at \$5,000 and went up to \$75,000.



[Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

2019: Most of Haystack Project’s initial nonprofit funding may have come from pharmaceutical giant Amgen

2019: HAYSTACK PROJECT HAD REVENUE OF NEARLY \$95,000.

2019: Haystack Project reported to the IRS that it had total revenue of \$94,730.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- 2019: The Haystack Project reported to the IRS that it raised nearly \$95,000 from “monthly and ad hoc calls with patient groups.”

4a (Code _____) (Expenses \$ 25000. including grants of \$ _____) (Revenue \$ 94730.)
ENGAGED A THIRD PARTY POLICY CONSULTANT TO PROVIDE MONTHLY & AD HOC CALLS WITH PATIENT GROUPS. CALLS WERE FOCUSED ON IDENTIFYING ISSUES RELATED TO SYSTEMATIC BARRIERS TO ACCESS AND TREATMENTS. CONSULTANT PROVIDED GROUPS WITH GUIDANCE ON THE RULES REGULATIONS AND LAWS THAT IMPACT THE PATIENTS' CARE INCLUDING PROPOSALS CURRENTLY PENDING BY POLICY MAKERS. CONSULTANT HELPED COLLECT AND COLLATE & COMPARTMENALIZE WHICH PATIENT EXPERIENCES RELATE BACK TO WHICH CURRENT AND PENDING LAWS, REGULATIONS AND PROPOSALS. PATIENT GROUPS LEARNED FROM EACH OTHER ALSO.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- 2019: Haystack Project reported to the IRS that it had \$92,800 in “program service revenue” from “stakeholders education” and “patient group networking”

Program Service Revenue		Business Code	
2 a	STAKEHOLDERS EDUCATION		75000.
b	STAKEHOLDERS EDUCATION		12800.
c	PATIENT GROUP NETWORKI		5000.
d			
e			
f	All other program service revenue		
g	Total. Add lines 2a-2f		92800.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- 2019: Haystack Project reported to the IRS that it had \$1,025 in revenue from a “donation.”

Miscellaneous Revenue		Business Code	
11 a	DONATION	621990	1025.
b			
c			
d	All other revenue		
e	Total. Add lines 11a-11d		1025.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- 2019: Haystack Project reported to the IRS that it had \$905 in “other contributions, gifts, grants.”

Form 990 (2019) **HAYSTACK PROJECT, INC.**

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII

			(A) Total revenue	
Contributions, Gifts, Grants and Other Similar Amounts	1 a	Federated campaigns	1a	
	b	Membership dues	1b	
	c	Fundraising events	1c	
	d	Related organizations	1d	
	e	Government grants (contributions)	1e	
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	905.
	g	Noncash contributions included in lines 1a-1f	1g \$	
	h	Total. Add lines 1a-1f		905.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

2019: Haystack Project’s Year In Review report said it would “recognize” financial sponsors in its pages, but only offered thanks to one company—Amgen

2019: Haystack Project’s Year In Review document indicated it would “recognize” financial sponsors for “their support.”

“Non-profit status has also allowed Haystack Project to request sponsorships. We reached out to a very limited number of entitles in 2019 and we recognize them for their support in the pages to come. Thank you to Hogan Lovells for their legal guidance!” [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

- 2019: With its non-profit status certified by the IRS, Haystack Project began soliciting corporate sponsors, with the help of legal guidance from Hogan Lovells.

“Non-profit status has also allowed Haystack Project to request sponsorships. We reached out to a very limited number of entitles in 2019 and we recognize them for their support in the pages to come. Thank you to Hogan Lovells for their legal guidance!” [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

- **Hogan Lovells maintains a practice in Pharmaceuticals and Biotechnology.**

“Pharmaceuticals and Biotechnology: Drug companies face pressure from many directions – from a foreboding regulatory landscape, from competitors with alternative brands or generics, from insurers pushing back on prescription drug costs and reimbursement. Whether you’re a global pharmaceuticals company or a biotechnology startup, **accomplishing** business goals in such a highly regulated industry requires practical, integrated legal analysis and advice. At the same time, you can find opportunities in maximizing the benefits of statutes that encourage new drug development.” [Hogan Lovells, accessed [5/11/23](#)]

2019: Haystack Project thanked Amgen for their support.

“Thank you to Amgen for their support in allowing some of this work to continue. While we will continue to build on the good work done over the last three years ... and will happily pivot as new and amazing opportunities come along ... we have begun another "listening tour" with our dedicated patient group participants to hear what they want to prioritize in 2020.” [Haystack Project, 2019 Year In Review, accessed [5/10/23](#)]

2020: Haystack Project’s revenue skyrocketed to nearly \$400,000, as pharmaceutical companies were 9 of 10 corporate sponsors

2020: HAYSTACK PROJECT HAD NEARLY \$400,000 IN REVENUE

2020: Haystack Project had \$391,539 in total revenue, including \$145,539 in “contributions and grants” and just \$246,000 in “program service revenue.”

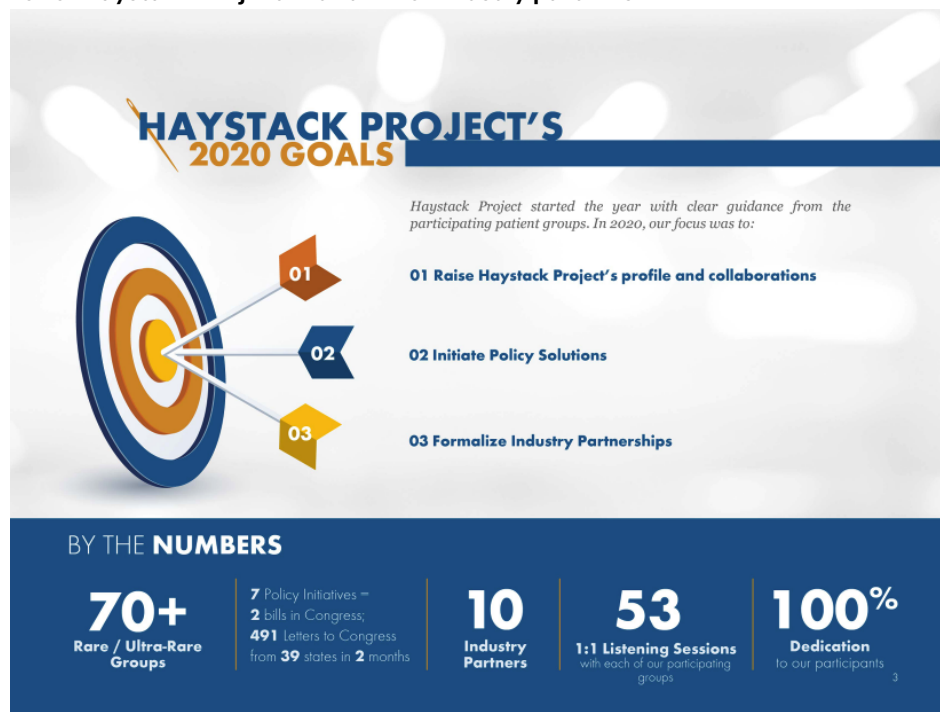
[Haystack Project, IRS Form 990, [6/16/21](#)]

2020: HAYSTACK PROJECT ANNOUNCED A GOAL OF “FORMALIZ[ING] INDUSTRY PARTNERSHIPS.” RESULTING 9 PHARMACEUTICAL COMPANIES SIGNING ON

2020: One of Haystack Project’s goals was to “Formalize Industry Partnerships.”

[Haystack Project, 2020 Year In Review, accessed [5/10/23](#)]

2020: Haystack Project counted 10 industry partners.



[Haystack Project, 2020 Year In Review, accessed [5/10/23](#)]

2020: Haystack Project listed Akcea, Amgen, AstraZeneca, Aurinia, BioMarin, Illumina, Mitsubishi Tanabe Pharma America, Ipsen, and Recordati Rare Diseases as 9 of their 10 corporate sponsors.

GET Involved

As we complete our patient group listening sessions, we are building out new initiatives for 2021, so keep an eye out for details on HEAT, AEI, and Rope Bridge, which will join our existing RCPC and POV initiatives.

AEI
Advocacy Empowerment Institute

HEAT
Health Equity in Access to Treatments

RCP
Rare Cancer Policy Coalition

ROPE BRIDGE
COLLABORATIVE

POV
Patients Unleashed Value

Haystack Project has many opportunities to support our ongoing work. Request a sponsorship brochure today and join the growing ranks of the partners we are so grateful and honored to work with.

Hogan Lovells

AKCEA
THERAPEUTICS

AMGEN

AstraZeneca

Aurinia

BIOMARIN

illumina

Mitsubishi Tanabe Pharma
America

IPSEN
Innovation for patient care

RECORDATI
RARE DISEASES
GROUP

14

[Haystack Project, 2020 Year In Review, accessed [5/10/23](#)]

HAYSTACK PROJECT SAID EXPLICITLY THAT CORPORATE (PHARMACEUTICAL) FUNDING PAID FOR “PROGRAMS, MATERIALS, AND ACTIVITIES” OF THE ORGANIZATION

2020: Haystack Project said it “employs corporate resources to develop, produce, and implement mission related programs, materials, and activities.”

“Haystack Project’s Corporate Council will critically affect the lives of rare and ultra-rare patients and their caregivers. As the only organization focused solely on reimbursement, value, and patient access for the rare and ultra-rare community, our educational efforts continue to grow in size and impact. The Corporate Council increases the overall capacity of Haystack Project to fulfill its mission. Haystack Project accepts financial support from corporations to increase the education and awareness of systemic barriers to appropriate reimbursement and assessment of value in rare and especially ultra-rare conditions. Haystack Project employs corporate resources to develop, produce, and implement mission related programs, materials, and activities.” [Haystack Project, 2020 Year In Review, accessed [5/10/23](#)]

2021: Haystack Project’s revenue reached almost half a million dollars—less than 1 percent from “membership dues”

2021: HAYSTACK PROJECT’S REVENUE WAS MORE THAN \$480,000, WITH LESS THAN 1 PERCENT COMING FROM “MEMBERSHIP DUES”

2021: Haystack Project had \$482,707 in total revenue, including \$478,580 in “contributions and grants” and \$4,127 in “program service revenue.”

[Haystack Project, IRS Form 990, [undated](#), accessed 5/12/23]

- **2021: Haystack Project received just \$4,127 in membership dues.**

[Haystack Project, IRS Form 990, [undated](#), accessed 5/12/23]

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- Haystack Project charges annual dues for “patient advocacy group” membership ranging from \$50 to \$900 annually.

Patient Advocacy Group Membership

Join the Haystack Project as a Patient Advocacy Group below.

MEMBER BENEFITS

- Receive advocacy updates.
- Participate in monthly policy calls.
- Attend in-person meetings.
- Advise on content -- and have the opportunity to sign on -- to letters to policymakers on ultra-orphan issues.
- Participate in Hill and other meetings as appropriate.

MEMBER ORG ANNUAL GROSS REVENUE*	ANNUAL DUES
Less than \$25,000	\$50
Between \$25,001-\$50,000	\$75
Between \$50,001-\$100,000	\$150
Between \$100,001-\$250,000	\$200
Between \$250,001-\$500,000	\$300
Between \$500,001-\$750,000	\$400
Between \$750,001-\$1,000,000	\$500
Between \$1,000,001-\$2,000,000	\$700
Greater than \$2,000,001	\$900

*Based on most recent IRS-990 reporting.

[Haystack Project, accessed [5/11/23](#)]

2021: HAYSTACK PROJECT’S “CORPORATE COUNCIL” WAS COMPRISED OF 13 PHARMACEUTICAL COMPANIES

2021: Haystack Project indicated it had 13 “Industry Partners”

[Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]

2021: Haystack Project’s “Corporate Council” was made up of 13 pharmaceutical companies.

CORPORATE COUNCIL

Haystack Project's Corporate Council will critically affect the lives of rare and ultra-rare patients and their caregivers.

As the only organization focused solely on reimbursement, value, and patient access for the rare and ultra-rare community, our educational efforts continue to grow in size and impact.

The Corporate Council increases the overall capacity of Haystack Project to fulfill its mission. Haystack Project accepts financial support from corporations to increase the education and awareness of systemic barriers to access and appropriate assessment of value in rare and especially ultra-rare conditions. Haystack Project employs corporate resources to develop, produce, and implement mission related programs, materials, and activities.

Logos of 13 pharmaceutical companies: AKCEA AMGEN, AstraZeneca, Aurinia, Biogen BiOMARIN, bluebird bio, illumina, IPSEN, Mitsubishi Tanabe Pharma, RECORDATI RARE DISEASES, ultragenyx, ZOGENIX.

[Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]

2021: HAYSTACK PROJECT IDENTIFIED PHARMACEUTICAL COMPANIES AMGEN AND BIOGENESIS AS BEING FINANCIAL SUPPORTERS OF TWO REPORTS PRODUCED BY THE ORGANIZATION

2021: Haystack Project said it received support from Amgen and Biogenesis for its “Patient Oriented Value” reports.

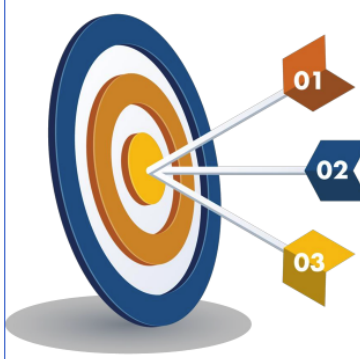
“PATIENT ORIENTED VALUE (POV)©Reports provide insight into the patient journey, articulate disease burden from the patient perspective, reveal real-world care gaps and communication deficiencies, and better understand treatment priorities and perceived value from the patient perspective. HAYSTACK PROJECT POV In partnership with the Melanoma Research Foundation and with support from Amgen, we completed a Patient Oriented Value© (POV) Report in Uveal/Ocular Melanoma (UM/ OM). In partnership with the Choroideremia Research Foundation and with support from Biogen, we are nearing completion on a POV report in Choroideremia, a rare inherited disorder that causes progressive vision loss and ultimately leads to complete blindness.” [Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]

2021: HAYSTACK PROJECT IDENTIFIED DOZENS OF PHARMACEUTICAL COMPANIES AS “POTENTIAL PARTNERS ON OUR RADAR”

2021: One of Haystack Project’s goals was “increase Industry partnerships.”

HAYSTACK PROJECT’S 2021 Goals

As usual, Haystack Project started the year with clear guidance from our member patient groups. In 2021, our focus was to:



- 01 Raise Haystack Project's profile and collaborations**
 - » Improve profile, including social media
 - » **Increase Industry partnership** and establish Alliance Partnerships
- 02 Continue to drive Policy Solutions**
 - » Re-introduction of HEART and Access to Rare Indications Act
 - » Support Telehealth Flexibilities post COVID
 - » Advance policies on Telehealth, Out of Network Care and Value Assessments
- 03 Increase Educational Programming**
 - » Advocacy Empowerment Institute (AEI)
 - » Health Equity in Access to Treatment (HEAT)
 - » Rope Bridge Collaborative
 - » ICER

BY THE NUMBERS

90+ Rare / Ultra-Rare Groups	2 bills in Congress 4+ policy priorities 1500+ letters to Congress	13 Industry Partners	7 Alliance Partners	100% DEDICATION to our participants
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[Haystack Project, 2021 Year In Review, accessed 5/10/23]

2021: Haystack Project identified dozens of pharmaceutical companies as “potential partners on our radar.”

POTENTIAL PARTNERS On Our Radar



Logos of potential partners include: Amicus Therapeutics, Takeda, BeiGene, Genentech, ALEXION, AstraZeneca Rare Disease, ACADIA, biocryst, HOMOLOGY Medicines, Inc., APPLIED THERAPEUTICS, anavex, neurocrine, santhera, novocure, PTC, arrowhead pharmaceuticals, Spark, SpringWorks, bridgebio, mirum, agios, AVROBIO, TRAVERE THERAPEUTICS, X4 PHARMACEUTICALS, Boehringer Ingelheim, Intercept, Orchard therapeutics, blueprint MEDICINES, REGENXBIO, saniona, nKarta THERAPEUTICS, YOWA KIRIM, NOVARTIS, IOVANCE BIOTHERAPEUTICS.

[Haystack Project, 2021 Year In Review, accessed 5/10/23]

2022: Haystack Project's Corporate Council grew to 18 pharmaceutical members, with potentially more on the way

NB: Haystack Project tax forms for 2022 are not yet available.

2022: HAYSTACK PROJECT RECEIVES FUNDING FROM THE 18 PHARMACEUTICAL COMPANIES ON ITS "CORPORATE COUNCIL"

2022: Haystack Project receives funding from its corporate council, which is filled with pharmaceutical companies.

"Haystack Project's Corporate Council will critically affect the lives of rare and ultra-rare patients and their caregivers. As the only organization focused solely on reimbursement, value, and patient access for the rare and ultra-rare community, our educational efforts continue to grow in size and impact. The Corporate Council increases the overall capacity of Haystack Project to fulfill its mission. Haystack Project accepts financial support from corporations to increase the education and awareness of systemic barriers to access and appropriate assessment of value in rare and especially ultra-rare conditions. Haystack Project employs corporate resources to develop, produce, and implement mission related programs, materials, and activities." [Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

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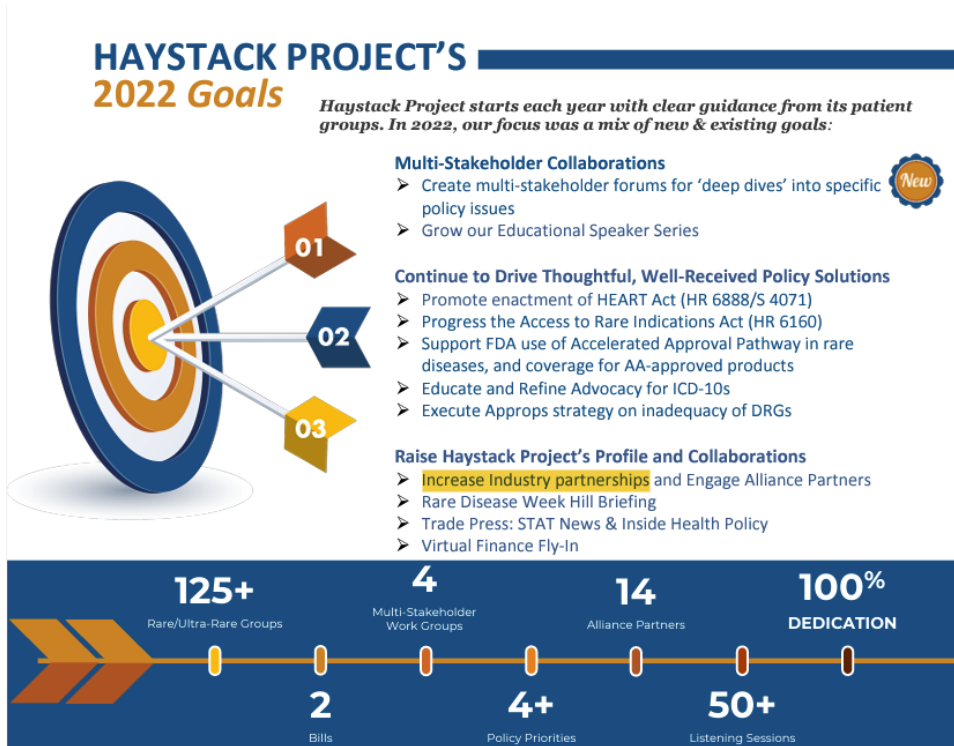
The Corporate Council increases the overall capacity of Haystack Project to fulfill its mission. Haystack Project accepts financial support from corporations to increase the education and awareness of systemic barriers to access and appropriate assessment of value in rare and especially ultra-rare conditions. Haystack Project employs corporate resources to develop, produce, and implement mission related programs, materials, and activities.

AKCEA ALEXION AMGEN
APPLIED THERAPEUTICS AstraZeneca Aurinia Biogen
BiOMARIN bluebirdbio GRAIL
illumina IONIS IPSEN Mitsubishi Tanabe Pharma
SANOFI ucb ultragenyx ZOGENIX

[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

2022: HAYSTACK PROJECT IDENTIFIED DOZENS OF PHARMACEUTICAL COMPANIES AS “POTENTIAL PARTNERS ON OUR RADAR”

2022: One of Haystack Project’s goals was “increase Industry partnerships.”



[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

2022: Haystack Project identified dozens of pharmaceutical companies as “potential partners on our radar.”



[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

March 2023: Haystack Project's monthly newsletter included a thank you to 18 pharmaceutical and biotechnology company sponsors

March 2023: Haystack Project's monthly newsletter included a thank you to 18 pharmaceutical and biotechnology company sponsors.



[Haystack Project, [March 2023](#)]

HAYSTACK PROJECT'S LEADERSHIP AND STAFF INCLUDES PHARMACEUTICAL INDUSTRY LOBBYISTS AND SENIOR EXECUTIVES

Haystack Project is staffed by Saira Sultan Chirico's pharmaceutical lobbying firm, Connect 4 Strategies, whose employees have significant pharmaceutical industry experience

CONNECT 4 STRATEGIES PROVIDES STAFFING FOR THE HAYSTACK PROJECT

"Connect 4 Strategies is a healthcare consultancy that works alongside clients in the pharmaceutical, medical device, and biotech arenas."

[Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies indicates on its website that it provides staffing for Haystack Project.

PATIENT/PROVIDER GROUPS

- Staffing Haystack Project – a coalition of ultra-rare patient organizations
- Craft Creative Solutions for patient organizations representing conditions like Pancreatic and other rare cancers, Alzheimer's, Osteoporosis, Sickle Cell Disease and more...

[Connect 4 Strategies, accessed [5/9/23](#)]

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AT LEAST 4 OF CONNECT 4 STRATEGIES' SIX EMPLOYEES HAVE PRIOR PHARMACEUTICAL INDUSTRY EXPERIENCE

Saira Sultan, Connect 4 Strategies' president and CEO spent ten years working for Sanofi and Pfizer.

"Saira Sultan has represented corporate, nonprofit, and government interests in the legislative and regulatory health policy arena for more than 20 years in Washington, D.C. She has had repeated success in designing business solutions by identifying and creating advocacy opportunities and translating them into strategic legislative and regulatory results. Saira brings a decade of experience working with market access, health outcomes, and commercial teams in pharmaceutical companies, including Pfizer and Sanofi. Saira is an experienced project management lead for large cross-functional efforts at Medtronic, Pfizer, Sanofi, and more." [Connect 4 Strategies, accessed [5/9/23](#)]

Kathleen Shoemaker, a senior advisor at Connect 4 Strategies previously worked at Eli Lilly.

"Kathleen Shoemaker, PharmD, MBA, CPHIMS SENIOR ADVISOR Dr. Kathleen Shoemaker has over 20 years of experience working on payer strategies, outcomes research, quality measures, registries and Health IT. Health care delivery across pharmacy and Medicare Advantage have been a particular focus. Most recently, Kathleen led Strategic Alliances for Premier, where she provided business development and sales support for professional medical societies, associations, and medical schools using Premier's technology solutions for registry, reporting, learning management, and other services to meet strategic quality, research, and education goals. Kathleen managed top-tier Premier clients while successfully meeting an annual multi-million dollar sales target. Before Premier, Kathleen was at the American Heart Association, where she was responsible for the strategic Health IT, quality measures (including PROMs), data, and registry development direction for AHA's quality and credentialing programs suite. In addition, Kathleen supported the association's grant writing and funding efforts. Kathleen came to AHA from Eli Lilly, where she engaged national quality organizations, payers, and employers. She developed government payer strategies for Medicaid and Medicare Parts C and D. She also led projects focused on Medicare Part B, quality measures, HIT strategy, and payment models." [Connect 4 Strategies, accessed [5/9/23](#)]

Jami Earnest, who works on "SCIENTIFIC STRATEGY FOR PATIENT ACCESS AND HEALTHCARE QUALITY EXPERTISE" at Connect 4 Strategies, previously worked for Johnson & Johnson "where she launched over twelve pharmaceutical products and supported four blockbuster franchises."

"Jami S. Earnest, PharmD, MS, BCPP SCIENTIFIC STRATEGY FOR PATIENT ACCESS AND HEALTHCARE QUALITY EXPERTISE Jami Earnest has over 25 years of commercial experience creating and leading scientific strategies that ensure patient access to new medications and novel treatments. As a senior leader for the United States Pharmacopeia (USP), Jami led the teams that created healthcare quality standards used in federal and state regulations for pharmaceutical manufacturers, healthcare settings, healthcare providers and payers. Her extensive interagency work with FDA, CMS, FDA, NIH, and other federal agencies earned her the FDA Commissioner's Award for Sustained Contributions. Prior to USP, Jami served as a Scientific Director for Johnson & Johnson, where she launched over twelve pharmaceutical products and supported four blockbuster franchises through her role on brand teams and leadership of field-based medical and outcomes support services." [Connect 4 Strategies, accessed [5/9/23](#)]

Paul Stickler, a senior advisor at Connect 4 Strategies, previously worked at AbbVie and Eton Pharmaceuticals.

"Paul Stickler SENIOR ADVISOR Paul Stickler has over 30 years of pharmaceutical commercial experience. Starting as a primary care sales representative at Abbott Laboratories (Abbvie) and advancing to Sr. Vice President, Commercial at Eton Pharmaceuticals, Paul has led every major aspect of commercialization from primary care to rare disease. He designed, built and executed commercial plans that added value / revenue across many therapeutic areas (genetics, endocrinology, hepatology, neurology, psychiatry, cardiology, pediatrics, neonatology), biologics, hospital systems / IDNs / GPOs, contracting, business development, distribution (building specialty pharmacy networks including patient reimbursement and support center) and built out infrastructure (sales, marketing, training, operations teams). While at Eton Pharmaceuticals, a rare disease startup, Paul built a team and infrastructure and launched the pediatric endocrinology product Alkindi Sprinkle in an expedited period. Before Eton Pharmaceuticals, Paul was Vice President of Commercial Operations at Recordati Rare Diseases, a billion-dollar global pharmaceutical company focused on orphan and rare disease products. At Recordati, Paul successfully led sales and marketing activities for many orphan drug products including Cystadane, Carbaglu, and Panhematin. Before Recordati, Paul held sales and marketing leadership roles at leading pharmaceutical companies including Lundbeck Inc where he led the launch of Xenazine and Sabril, Ovation Pharmaceuticals, and Abbott Laboratories (Abbvie)." [Connect 4 Strategies, accessed [5/9/23](#)]

CONNECT 4 STRATEGIES' WEBSITE ADVERTISES THEIR WORK ON BEHALF OF PHARMACEUTICAL COMPANIES, INCLUDING CREATING A NEW "GROUP TO INCREASE POLICY SUPPORT"—POSSIBLY "ASTROTURFING"

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Connect 4 Strategies advertises their work creating a “new pharmacy group to increase policy support.”

“Successfully operated as a profit center for an association, by implementing public policy programs, creating a new pharmacy group to increase policy support, and new partnering opportunities.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies advertises work they did for gene and cell therapeutic companies highlighting their “experience across reimbursement, clinical development, policy and advocacy.”

“A unique set of clients when it comes to reimbursement are the cell and gene therapy companies. We’ve worked closely with several and to say the work is ‘multi-variable’ is an under-statement.... Connect 4 is built for these, since our core team has over 25 years of experience – each! And we bring a wealth of experience across reimbursement, clinical development, policy and advocacy. Not to mention, we were ‘at the front’ protecting market access interests as previous wholesale changes were made to reimbursement structures, and apply that experience now.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies advertises their work serving as spokesperson on federal lobbying campaigns and preparing corporate teams and health care stakeholders network to interact with the federal government.

“STRONG STRUCTURAL SUPPORT AIDS CORPORATE AND NONPROFIT SUCCESS Successfully operated as a profit center for an association, by implementing public policy programs, creating a new pharmacy group to increase policy support, and new partnering opportunities. Served as spokesperson on all Federal lobbying and regulatory policy matters for a trade association. Successfully advised companies on establishing a Washington function. Prepared corporate leadership team and Commercial, Legal, Medical, Market Access and Health outcomes teams for dozens of successful interactions with government officials, paving the way for credible and thoughtful partnerships with the Federal Government. Deployed a large network of healthcare stakeholders across disciplines to create teaming opportunities for clients that lead to thoughtful solutions.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies advertises its prior work for pharmaceutical companies on pricing and reimbursement issues.

“EACH THERAPY AND DISEASE AREA IS AN OPPORTUNITY TO CREATE TAILORED SOLUTIONS Led extensive emerging trends analysis on the future of oncology practice, driving key commercialization decisions as well as policy and political strategies to support assets. Worked closely with key thought leaders in oncology. Effectively identified and executed tandem regulatory and reimbursement strategy across FDA and CMS for re-launch of orphan oncology asset, allowing for new pricing and commercialization strategies to significantly raise market value to reflect new investment in the product. Successfully developed strategies for expedited review and preferential reimbursement for opioid abuse deterrent formulations and built a payer strategy in anticipation of an indication. Achieved fastest ever quality measure change upon product approval, significantly driving uptake in inpatient vaccine sales. Advanced new narrative for identifying and treating pain with key government officials to successfully ensure review of ICD-9/10 codes, opioid overutilization programs and implementation of the IOM Report on Pain. Worked across IOM, FDA, NIH, CMS, and CDC. Successfully created and negotiated adoption of new emerging health risk standard for expediting vaccines CPT codes, removing enormous barrier to provider uptake and reimbursement for a vaccine even before FDA approval. Worked closely with patient groups, FDA, NVPO, HHS, CDC and the AMA. Ensured broadest possible vaccine use recommendation at ACIP/CDC and advanced timely reimbursement change at CMS to reflect recommendation, ensuring physician payment and expedited use. Worked closely with CMS leadership, FDA, NVPO, CDC, HHS, and the White House. Positively amended CMS coverage policy of weight loss therapies if used for treatment of diabetes, metabolic syndrome, and related diagnoses in anticipation of an FDA approval. Worked with payer and pharmaceutical trade associations and CMS.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies says it’s “at the front” of “protecting market access interests.”

“Connect 4 is built for these, since our core team has over 25 years of experience – each! And we bring a wealth of experience across reimbursement, clinical development, policy and advocacy. Not to mention, we were ‘at the front’ protecting market access interests as previous wholesale changes were made to reimbursement structures, and apply that experience now.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies claimed “We exposed competing financial interests fighting for their piece of the pie rather than securing sound public policy.”

“Hired to work with Congress to update a statute made obsolete by the substance abuse epidemic facing our country, Connect 4 got to work dissecting what the Department of Health and Human Services could do unilaterally and where Congress needed to step in. We quickly began running parallel tracks, and saw opportunities for FDA, CMS, CDC, ONC and others to support SAMHSA’s efforts. Hampering access to medication assisted therapy and sustaining the stigma of treating addiction has no place

during our current national crisis. We exposed competing financial interests fighting for their piece of the pie rather than securing sound public policy, and worked with our client to shape creative solutions that worked for patients. A multi-prong, multi-agency approach finally led to success. After years of failed attempts to change the statute, Connect 4 drove a regulatory and congressional strategy that increased access to evidence based treatments for the treatment of addiction.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies advertises its work conducting revenue stream analysis for pharmaceutical start-ups.

“Revenue Stream Analysis SUPPORTING START-UP INNOVATION Many of our valued clients are small start-up, early clinical stage companies whose CEOs are beating the bushes for investors. They need more than a “back of a paper napkin” estimate of revenue but less than a full blown plan of action to change the world. We have lots of experience in getting the details right without overwhelming the client, or overshadowing their immediate needs. Keeping it simple, for both the CEO and the investors they’re engaging, is a sure fire way to build a longer term partnership. Our revenue estimates look at claims data when available, cross referenced to a setting-of-care mix and payer mix. We understand and work with the arcane reimbursement rules in each setting of care and across each payer every day, so we can keep costs down when serving CEOs’ initial investor presentation needs, and build on the analysis as warranted. As products move from bench to market, we build out strategies to overcome any reimbursement challenges on an as-needed basis, understanding that the goal is sometimes sale of the asset or the company itself.” [Connect 4 Strategies, accessed [5/9/23](#)]

Connect 4 Strategies advertised their work helping to “relaunch” a drug with a “new pricing strategy and...marketing plans.”

“Relaunching a drug has its own challenges. Connect 4 has recent experience in working on a relaunch, where the company discovered their new pricing strategy and accompanying contracting and marketing plans might be jeopardized by an old J code that was never retired by CMS. We identified the problem, educated the client on the countless implications for Medicare and commercial payers, and worked through the issue with the Regulatory, Commercial, and Market Access teams to ensure a positive change in time for launch.” [Connect 4 Strategies, accessed [5/9/23](#)]

2016: SULTAN CHIRICO WROTE THAT LOWERING PRESCRIPTION DRUG PRICES MIGHT RESULT IN WHOLESALERS INCREASING PRICES FOR “VALUE-ADDED SERVICES” THEY PROVIDE

2016: Sultan posted a blog on Connect 4 Strategies’ website arguing that lower prescription drug prices through “more conservative price inflation strategies,” wholesale distributors may increase costs for “value-added services” adjacent to their distribution role.

“The heavy scrutiny by Congress, payers, and the media on drug price hikes may be having its intended impact – giving manufacturers pause with respect to the frequency and/or magnitude of price increases. There’s another effect that bears keeping in mind, on the wholesalers that have long operated with a margin-dependent business model that factors price increases into revenue projections. McKesson’s Q3 earnings call (and resulting 23% drop in share price) may be the canary in the coal mine for the wholesale industry. The company’s CEO, John Hammergren explained that ‘[w]hat we have seen this year to-date, our fewer products with price increases, and those price increases are at lower rates than both prior year results . . . we now expect full-year branded pharmaceutical pricing trends to be meaningfully below those experienced in Fiscal 2016.’ If manufacturers adopt more conservative price inflation strategies, wholesalers will have to adjust and adapt to survive. This may mean unbundling value-added services from their distribution role, and negotiating separate payment for these offerings. It could also involve the types of belt-tightening strategies McKesson has already initiated with its decision to sell its San Francisco headquarters facility and acquire a portion of that space through a lease. Manufacturers, providers, and payers may also find that wholesaler strategies toward a sustainable business model involve more aggressive and/or strategic adjustments to their customer, drug, and manufacturer mix.” [Connect 4 Strategies, [11/22/16](#)]

- **Sultan’s blog post was titled: “Who Gets Hurt When Drug Prices Don’t Go Up”**

[Connect 4 Strategies, [11/22/16](#)]

2019: SULTAN CHIRICO WROTE THAT CAPPING OUT-OF-POCKET COSTS FOR PRESCRIPTION DRUGS COULD RESULT IN ULTRA-RARE DISEASE PATIENTS BEING EXCLUDED FROM MEDICARE ADVANTAGE PLANS

June 2019: Sultan posted a blog on the Connect 4 Strategies website arguing that a cap on out-of-pocket costs for prescription drugs might result in “ultra-rare disease patients” seeing their treatment centers being excluded from Medicare Advantage plans.

“In these days of deeply divided government, partisanship and extreme politics, it seems remarkable that both houses and both parties came together just before the long weekend to release a drug pricing proposal. A cap on out-of-pocket (OOP) costs in Part D makes a great deal of sense, especially since the supplemental insurance plans seniors rely on to defray Medicare cost sharing do not apply to Part D. I’ve long struggled with the thought that seniors need to have “skin in the game.” After all, supplemental insurance isn’t free. And seniors on fixed incomes in retirement need to manage risk. So the fact that so many have coalesced so quickly around this policy change is heartening. It is also a long-overdue recognition that the complex web of drug pricing isn’t something that patients can unravel and just “make smarter choices” the way consumers do with washing machines or other commodities. That said, the offset may have unintended consequences that would ultimately fall on our most vulnerable patients. To offset some of the cost of a Part D OOP cap, the bipartisan, bicameral proposal would invert responsibility for catastrophic coverage from 80% on the government’s shoulders to 80% on private insurers. The premise is that the dramatic, albeit gradual, shift in costs to insurers will force them to choose lower priced drugs and negotiate better prices with drug companies. This seems unlikely. However, an equally important outcome —one that is far more certain and far less likely to be gradual — is that premiums will go up, and could go way up, as insurers follow their historical tendency to over-estimate additional risk and make themselves whole. Middle-class elderly (fixed income, modest savings) will end up even more squeezed than they are today, left to manage the cost of premiums without the Part D assistance available to lower-income beneficiaries. [...] Unfortunately, the economics of rising premiums for stand-alone Part D coverage will make it inaccessible for patients of modest means newly enrolling in Medicare. These patients won’t choose MA plans. They will be forced into MA plans with no way to get back to the FFS-MediGap coverage combination if they need it. What should not be lost on any of us is how rare and especially ultra-rare disease patients, for whom treatment options have little price elasticity, will be the proverbial canary in the coal mine. They will be the first to see their equally rare expert academic centers or providers not make the MA networks. The MA perks that draw healthy enrollees focused on maintaining, and even improving their health through lifestyle modifications and care management are of little value to sicker individuals needing very specific care from very specialized clinicians. Requiring insurers to absorb 80% of top-end risk on the highest-cost patients is not something plans can realistically recoup with better discounts. They could, however, recoup it with less generous coverage and higher premiums. Its taking from Peter to pay Peter. Maybe partisan bickering and deadlocked legislators is a better option until we have something more realistic to offer to the most vulnerable among us.” [Connect 4 Strategies, [6/9/19](#)]

CONNECT 4 STRATEGIES IS A FEDERAL LOBBYING REGISTRANT FOR AT LEAST 8 PHARMACEUTICAL COMPANIES

Connect 4 Strategies is a federal lobbyist for pharmaceutical companies AKCEA THERAPEUTICS, BIOMARIN PHARMACEUTICAL, FERRING PHARMACEUTICALS, IMARA, MAST THERAPEUTICS, OREXO US, RECORDATI RARE DISEASES, and THERABRON THERAPEUTICS, among other clients.

Client Name	Report Type	Amount Reported	Filing Year
AKCEA THERAPEUTICS, INC.	1st Quarter - Report	\$30,000.00	2019
AKCEA THERAPEUTICS, INC.	2nd Quarter - Report	\$45,000.00	2019
AKCEA THERAPEUTICS, INC.	3rd Quarter - Report	\$45,000.00	2019
AKCEA THERAPEUTICS, INC.	4th Quarter - Report	\$30,000.00	2019
AKCEA THERAPEUTICS, INC.	Registration		2019
AKCEA THERAPEUTICS, INC.	1st Quarter - Report	\$10,000.00	2020
AKCEA THERAPEUTICS, INC.	2nd Quarter - Report	\$30,000.00	2020
AKCEA THERAPEUTICS, INC.	3rd Quarter - Report (No Activity)		2020
AKCEA THERAPEUTICS, INC.	4th Quarter - Report (No Activity)		2020
AKCEA THERAPEUTICS, INC.	1st Quarter - Report (No Activity)		2021
AKCEA THERAPEUTICS, INC.	2nd Quarter - Report (No Activity)		2021
AKCEA THERAPEUTICS, INC.	3rd Quarter - Termination (No Activity)		2021
BIOMARIN PHARMACEUTICAL INC.	2nd Quarter - Report	\$10,000.00	2016
BIOMARIN PHARMACEUTICAL INC.	3rd Quarter - Report	\$20,000.00	2016
BIOMARIN PHARMACEUTICAL INC.	4th Quarter - Termination (No Activity)		2016
BIOMARIN PHARMACEUTICAL INC.	Registration		2016
FERRING PHARMACEUTICALS, INC.	2nd Quarter - Report	\$20,000.00	2019
FERRING PHARMACEUTICALS, INC.	3rd Quarter - Report	\$20,000.00	2019

Client Name	Report Type	Amount Reported	Filing Year
FERRING PHARMACEUTICALS, INC.	4th Quarter - Report	\$20,000.00	2019
FERRING PHARMACEUTICALS, INC.	Registration		2019
FERRING PHARMACEUTICALS, INC.	1st Quarter - Report (No Activity)		2020
FERRING PHARMACEUTICALS, INC.	2nd Quarter - Report (No Activity)		2020
FERRING PHARMACEUTICALS, INC.	3rd Quarter - Report (No Activity)		2020
FERRING PHARMACEUTICALS, INC.	4th Quarter - Report (No Activity)		2020
FERRING PHARMACEUTICALS, INC.	1st Quarter - Report (No Activity)		2021
FERRING PHARMACEUTICALS, INC.	2nd Quarter - Report (No Activity)		2021
FERRING PHARMACEUTICALS, INC.	3rd Quarter - Report (No Activity)		2021
FERRING PHARMACEUTICALS, INC.	4th Quarter - Report (No Activity)		2021
FERRING PHARMACEUTICALS, INC.	1st Quarter - Report (No Activity)		2022
FERRING PHARMACEUTICALS, INC.	1st Quarter - Termination (No Activity)		2022
IMARA, INC.	1st Quarter - Report		2017
IMARA, INC.	2nd Quarter - Report (No Activity)		2017
IMARA, INC.	3rd Quarter - Report (No Activity)		2017
IMARA, INC.	4th Quarter - Report (No Activity)		2017
IMARA, INC.	Registration		2017
IMARA, INC.	1st Quarter - Report (No Activity)		2018
IMARA, INC.	2nd Quarter - Report (No Activity)		2018
IMARA, INC.	3rd Quarter - Report (No Activity)		2018
IMARA, INC.	4th Quarter - Report (No Activity)		2018
IMARA, INC.	4th Quarter - Termination (No Activity)		2018
MAST THERAPEUTICS, INC.	4th Quarter - Report (No Activity)		2014
MAST THERAPEUTICS, INC.	Registration		2014
MAST THERAPEUTICS, INC.	1st Quarter - Report	\$15,000.00	2015
MAST THERAPEUTICS, INC.	2nd Quarter - Amendment	\$15,000.00	2015
MAST THERAPEUTICS, INC.	3rd Quarter - Amendment	\$20,000.00	2015
MAST THERAPEUTICS, INC.	3rd Quarter - Report	\$15,000.00	2015
MAST THERAPEUTICS, INC.	4th Quarter - Report	\$40,000.00	2015
MAST THERAPEUTICS, INC.	1st Quarter - Report	\$30,000.00	2016
MAST THERAPEUTICS, INC.	2nd Quarter - Report	\$30,000.00	2016
MAST THERAPEUTICS, INC.	3rd Quarter - Report	\$30,000.00	2016
MAST THERAPEUTICS, INC.	4th Quarter - Termination	\$10,000.00	2016
OREXO US, INC.	4th Quarter - Report	\$60,000.00	2014
OREXO US, INC.	Registration		2014
OREXO US, INC.	1st Quarter - Report	\$30,000.00	2015
OREXO US, INC.	2nd Quarter - Amendment	\$30,000.00	2015
OREXO US, INC.	3rd Quarter - Amendment	\$70,000.00	2015
OREXO US, INC.	3rd Quarter - Report	\$50,000.00	2015
OREXO US, INC.	4th Quarter - Report	\$70,000.00	2015
OREXO US, INC.	1st Quarter - Report	\$60,000.00	2016
OREXO US, INC.	2nd Quarter - Report	\$60,000.00	2016
OREXO US, INC.	3rd Quarter - Report	\$20,000.00	2016
OREXO US, INC.	4th Quarter - Report (No Activity)		2016
OREXO US, INC.	1st Quarter - Amendment (No Activity)		2017
OREXO US, INC.	1st Quarter - Report (No Activity)		2017
OREXO US, INC.	2nd Quarter - Report (No Activity)		2017
OREXO US, INC.	3rd Quarter - Report	\$20,000.00	2017
OREXO US, INC.	4th Quarter - Report	\$20,000.00	2017
OREXO US, INC.	1st Quarter - Report	\$30,000.00	2018
OREXO US, INC.	2nd Quarter - Report	\$30,000.00	2018
OREXO US, INC.	3rd Quarter - Report	\$30,000.00	2018
OREXO US, INC.	4th Quarter - Report (No Activity)		2018
OREXO US, INC.	1st Quarter - Report (No Activity)		2019

Client Name	Report Type	Amount Reported	Filing Year
OREXO US, INC.	2nd Quarter - Report	\$20,000.00	2019
OREXO US, INC.	3rd Quarter - Report	\$10,000.00	2019
OREXO US, INC.	4th Quarter - Report	\$70,000.00	2019
OREXO US, INC.	1st Quarter - Report	\$60,000.00	2020
OREXO US, INC.	2nd Quarter - Report	\$60,000.00	2020
OREXO US, INC.	3rd Quarter - Report	\$60,000.00	2020
OREXO US, INC.	4th Quarter - Report	\$60,000.00	2020
OREXO US, INC.	1st Quarter - Report	\$60,000.00	2021
OREXO US, INC.	2nd Quarter - Report	\$40,000.00	2021
OREXO US, INC.	3rd Quarter - Report	\$40,000.00	2021
OREXO US, INC.	4th Quarter - Report	\$40,000.00	2021
OREXO US, INC.	1st Quarter - Report	\$60,000.00	2022
OREXO US, INC.	2nd Quarter - Report	\$60,000.00	2022
OREXO US, INC.	3rd Quarter - Report	\$30,000.00	2022
OREXO US, INC.	4th Quarter - Report	\$30,000.00	2022
OREXO US, INC.	1st Quarter - Report	\$30,000.00	2023
RECORDATI RARE DISEASES	2nd Quarter - Report (No Activity)		2017
RECORDATI RARE DISEASES	3rd Quarter - Amendment	\$130,000.00	2017
RECORDATI RARE DISEASES	4th Quarter - Amendment	\$10,000.00	2017
RECORDATI RARE DISEASES	Registration		2017
RECORDATI RARE DISEASES	1st Quarter - Amendment	\$90,000.00	2018
RECORDATI RARE DISEASES	1st Quarter - Report	\$10,000.00	2018
RECORDATI RARE DISEASES	2nd Quarter - Report	\$50,000.00	2018
RECORDATI RARE DISEASES	3rd Quarter - Report	\$30,000.00	2018
RECORDATI RARE DISEASES	4th Quarter - Report	\$30,000.00	2018
RECORDATI RARE DISEASES	1st Quarter - Report	\$30,000.00	2019
RECORDATI RARE DISEASES	2nd Quarter - Amendment	\$30,000.00	2019
RECORDATI RARE DISEASES	2nd Quarter - Report	\$10,000.00	2019
RECORDATI RARE DISEASES	3rd Quarter - Report	\$30,000.00	2019
RECORDATI RARE DISEASES	4th Quarter - Report	\$10,000.00	2019
RECORDATI RARE DISEASES	1st Quarter - Report (No Activity)		2020
RECORDATI RARE DISEASES	2nd Quarter - Report (No Activity)		2020
RECORDATI RARE DISEASES	3rd Quarter - Report (No Activity)		2020
RECORDATI RARE DISEASES	4th Quarter - Report (No Activity)		2020
RECORDATI RARE DISEASES	1st Quarter - Report (No Activity)		2021
RECORDATI RARE DISEASES	2nd Quarter - Report (No Activity)		2021
RECORDATI RARE DISEASES	3rd Quarter - Report (No Activity)		2021
RECORDATI RARE DISEASES	4th Quarter - Report (No Activity)		2021
RECORDATI RARE DISEASES	1st Quarter - Report (No Activity)		2022
RECORDATI RARE DISEASES	2nd Quarter - Report (No Activity)		2022
RECORDATI RARE DISEASES	3rd Quarter - Report (No Activity)		2022
RECORDATI RARE DISEASES	4th Quarter - Termination (No Activity)		2022
THE HAYSTACK PROJECT	1st Quarter - Report		2018
THE HAYSTACK PROJECT	2nd Quarter - Report		2018
THE HAYSTACK PROJECT	3rd Quarter - Report (No Activity)		2018
THE HAYSTACK PROJECT	4th Quarter - Report (No Activity)		2018
THE HAYSTACK PROJECT	Registration		2018
THE HAYSTACK PROJECT	1st Quarter - Report (No Activity)		2019
THE HAYSTACK PROJECT	2nd Quarter - Report (No Activity)		2019
THE HAYSTACK PROJECT	3rd Quarter - Report (No Activity)		2019
THE HAYSTACK PROJECT	4th Quarter - Report (No Activity)		2019
THE HAYSTACK PROJECT	1st Quarter - Report (No Activity)		2020
THE HAYSTACK PROJECT	2nd Quarter - Report		2020
THE HAYSTACK PROJECT	3rd Quarter - Report (No Activity)		2020

Client Name	Report Type	Amount Reported	Filing Year
THE HAYSTACK PROJECT	4th Quarter - Report		2020
THE HAYSTACK PROJECT	1st Quarter - Amendment		2021
THE HAYSTACK PROJECT	1st Quarter - Report		2021
THE HAYSTACK PROJECT	2nd Quarter - Report		2021
THE HAYSTACK PROJECT	3rd Quarter - Report		2021
THE HAYSTACK PROJECT	4th Quarter - Report		2021
THE HAYSTACK PROJECT	1st Quarter - Report		2022
THE HAYSTACK PROJECT	2nd Quarter - Amendment		2022
THE HAYSTACK PROJECT	2nd Quarter - Report		2022
THE HAYSTACK PROJECT	3rd Quarter - Report		2022
THE HAYSTACK PROJECT	4th Quarter - Report		2022
THE HAYSTACK PROJECT	1st Quarter - Report		2023
THERABRON THERAPEUTICS, INC	2nd Quarter - Report (No Activity)		2015
THERABRON THERAPEUTICS, INC	3rd Quarter - Report	\$10,000.00	2015
THERABRON THERAPEUTICS, INC	4th Quarter - Report	\$10,000.00	2015
THERABRON THERAPEUTICS, INC	Registration		2015
THERABRON THERAPEUTICS, INC	1st Quarter - Report	\$10,000.00	2016
THERABRON THERAPEUTICS, INC	2nd Quarter - Report	\$10,000.00	2016
THERABRON THERAPEUTICS, INC	3rd Quarter - Report	\$10,000.00	2016
THERABRON THERAPEUTICS, INC	4th Quarter - Termination	\$10,000.00	2016

[U.S. Senate Lobbying Disclosure Database, accessed [5/15/23](#)]

Haystack Project CEO Deanna Darlington spent more than 20 years working in the pharmaceutical industry

2021: Deanna Darlington became Haystack Project's CEO and chairman of the board.

"Thank you for the opportunity to serve as Haystack's CEO. I have enjoyed seeing the organization grow to new heights and am honored to have played a part. I will still be a part of this great group as a Board member. I'd like to welcome Deanna Darlington to the CEO role and look forward to seeing the amazing places she will take Haystack Project and its members. Deanna Darlington Incoming CEO and Chairman of the Board" [Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]

- **2014-2021: Darlington was director of patient advocacy and allied development at Amgen.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **2010-2014: Darlington was senior director of government affairs at Onyx Pharmaceuticals.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **2009-2010: Darlington was director of oncology external affairs at Novartis.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **2006-2009: Darlington was director of reimbursement at Amgen.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **2004-2006: Darlington was payer relations manager at Pharmion.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **1998-2003: Darlington was director of US pricing and reimbursement at Pharmacia.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]
- **1997-1998: Darlington was reimbursement program administrator at GlaxoSmithKline.**
[Deanna Darlington LinkedIn profile, accessed [6/7/23](#)]

2012-2013: Darlington was a registered federal lobbyist for Onyx Pharmaceuticals

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	Registration		2012
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	3rd Quarter - Report	\$10,000.00	2012
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	4th Quarter - Report	\$90,000.00	2012
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	1st Quarter - Report	\$70,000.00	2013
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	2nd Quarter - Report	\$80,000.00	2013
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	1st Quarter - Amendment	\$130,000.00	2013
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	3rd Quarter - Report	\$80,000.00	2013
ONYX PHARMACEUTICALS	ONYX PHARMACEUTICALS	4th Quarter - Termination (No Activity)		2013

[U.S. Senate Lobbying Disclosure Database, accessed [6/7/23](#)]

Many of Haystack Project's board of directors have prior pharmaceutical industry experience

FORMER HAYSTACK PROJECT CEO JIM CARO PREVIOUSLY WORKED FOR SANOFI, WYETH PHARMACEUTICALS, AND CONNECT 4 STRATEGIES

2020: A Haystack Project press release identified Jim Caro as the organization's CEO.

"Media Contact: Jim Caro CEO Haystack Project Jim.caro@haystackproject.org" [Haystack Project, [7/9/20](#)]

James Caro was listed on Haystack Project's tax returns as the organization's president.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- **Caro was listed among Haystack Project's initial board of directors on their Articles of Incorporation.**

[Haystack Project, Articles of Incorporation, [3/12/19](#)]

Caro worked at Connect 4 Strategies.

[Haystack Project, [4/14/19](#)]

Caro was Executive Director of Global Professional Affairs at Wyeth Pharmaceuticals.

[Haystack Project, [4/14/19](#)]

Caro was Senior Director in Sanofi's Public Affairs Team

[Haystack Project, [4/14/19](#)]

- **2002-2018: Caro previously worked for drugmaker Sanofi US.**

[Jim Caro Facebook profile, accessed [5/9/23](#)]

Caro was in senior management positions with the American Pharmacists Association and the American Society of Health System Pharmacists.

"Jim's career has focused on improving patient outcomes through collaboration among advocacy organizations and the pharmaceutical industry. His senior management roles at the American Pharmacists Association and the American Society of Health System Pharmacists gave Jim the opportunity to lead pharmacists' professional development and educational programs, as well as create and support the organizations' public policy initiatives." [Haystack Project, [4/14/19](#)]

SECRETARY OF THE HAYSTACK PROJECT'S BOARD OF DIRECTORS BELA SASTRY IS AN IN-HOUSE LOBBYIST FOR SUNOVION PHARMACEUTICALS

6/8/21: Bela Sastry, Haystack Project's secretary, signed the organization's bylaws, which were adopted by the board of directors.

"ARTICLE XV – ADOPTION OF BYLAWS These bylaws were approved and adopted at a meeting of the Board of Directors on: Secretary: Bela Sastry Signature Bela Sastry Date June 8, 2021" [Haystack Project, Organizational Bylaws, [6/8/21](#)]

2019: Bela Sastry was listed on Haystack Project's tax returns as the organization's secretary.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

2017-Present: Bela Sastry is senior director of federal government affairs for Sunovion Pharmaceuticals.

[Bela Sastry LinkedIn profile, accessed [5/9/23](#)]

- **2015-2017: Sastry was director of federal legislative affairs & alliance development at medical device manufacturer, Baxter.**
[Bela Sastry LinkedIn profile, accessed [5/9/23](#)]
- **2009-2015: Sastry was director of federal government affairs at AstraZeneca.**
[Bela Sastry LinkedIn profile, accessed [5/9/23](#)]

HAYSTACK PROJECT'S FIRST CHAIRPERSON, CYNTHIA GROSS, WORKS AT BIOPHARMACEUTICAL COMPANY INSMED, INC., AND PREVIOUSLY WORKED AT ASTELLAS, REGENERON, AND OTSUKA

2019: Cynthia Gross was listed on Haystack Project's tax returns as the chairman of the board.

[Haystack Project Inc., EIN: 83-3367375, IRS Form 990, received [5/18/20](#)]

- **January 2019-August 2020: Gross was chair of the Haystack Project board of directors.**
[Cynthia Gross LinkedIn profile, accessed [5/11/23](#)]
- **Gross was listed among Haystack Project's initial board of directors on their Articles of Incorporation.**
[Haystack Project, Articles of Incorporation, [3/12/19](#)]

2022-Present: Gross is "US Head of Strategic Policy and Pricing" at biopharmaceutical company Insmed.

[Cynthia Gross LinkedIn profile, accessed [5/11/23](#)]

2020-2021: Gross was "Strategic Head, Global Immuno-Oncology, Cell and New Product Planning for Market Access & Pricing" at Astellas Pharma.

[Cynthia Gross LinkedIn profile, accessed [5/11/23](#)]

2013-2019: Gross was "Global & US Strategic Market Access & Public Affairs Lead for Inflammation, Immunology and Oncology" at Regeneron Pharmaceuticals.

[Cynthia Gross LinkedIn profile, accessed [5/11/23](#)]

2003-2010: Gross was "Senior Director of Market Access, Reimbursement and Healthcare Policy/Advocacy" at Otsuka America Pharmaceuticals.

[Cynthia Gross LinkedIn profile, accessed [5/11/23](#)]

HAYSTACK PROJECT DIRECTOR LISA STEELMAN PREVIOUSLY WORKED AT JANSSEN PHARMACEUTICALS AND WAS THE ILLINOIS TASK FORCE CHAIR FOR PhRMA

Lisa Steelman is on the Haystack Project board of directors.

[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

- **2022-Present: Steelman is a vice president for state strategies and growth at Aetna.**
[Lisa Steelman LinkedIn profile, accessed [5/11/23](#)]
- **2020-2021: Steelman was vice president and head of state government affairs for the Association of Accessible Medicines.**
[Lisa Steelman LinkedIn profile, accessed [5/11/23](#)]
- **2003-2014: Steelman was director of state government affairs at pharmaceutical company Novartis, where she was elected "PhRMA Illinois Chair and Vice Chair, serving over six years."**
"Director - State Government Affairs Novartis · Full-time Jul 2003 - Apr 2014 · 10 yrs 10 mos Midwest Region · Remote
With \$56.7 billion in sales, Novartis is one of the world's largest research driven pharmaceutical and health care companies."

Elected by industry peers as the PhRMA Illinois Chair and Vice Chair, serving over six years. Built an extensive and highly engaged strategic alliance network of elected officials, government representatives, industry representatives, and special interest groups.” [Lisa Steelman LinkedIn profile, accessed [5/11/23](#)]

- **2004-2010: Steelman was Chair and Vice Chair of PhRMA’s Illinois Task Force.**
[Lisa Steelman LinkedIn profile, accessed [5/11/23](#)]
- **2000-2003: Steelman did pharmaceutical sales for Janssen Pharmaceuticals.**
[Lisa Steelman LinkedIn profile, accessed [5/11/23](#)]

CHEVESE TURNER, A HAYSTACK PROJECT DIRECTOR AND ONE-TIME INTERIM CEO, PREVIOUSLY WORKED AT PHARMACEUTICAL COMPANIES EISAI, MGI PHARMA, AND NOVARTIS

Chevese Turner is on the Haystack Project board of directors.
[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

- **2008-2009: Turner was a senior oncology policy specialist at Eisai Pharmaceuticals.**
[Chevese Turner LinkedIn profile, accessed [5/11/23](#)]
- **2005-2008: Turner was a senior oncology representative at MGI Pharma.**
[Chevese Turner LinkedIn profile, accessed [5/11/23](#)]
- **2000-2002: Tuner was director of product marketing at the Pharmaceutical Education & Research Institute, Inc.**
[Chevese Turner LinkedIn profile, accessed [5/11/23](#)]
- **1998-2000: Tuner was a cardiovascular sales specialist at Novartis.**
[Chevese Turner LinkedIn profile, accessed [5/11/23](#)]

Chevese Turner was the Haystack Project “Acting CEO.”

“Chevese Turner will serve as Acting CEO while Haystack undertakes a search for a more permanent candidate. She is steeped in Haystack’s mission given her role on the Board, and she brings over 20 years in non-profit leadership to the role.” [Twitter, @HaystackProject, [1/20/23](#)]

MARCH 2023: HAYSTACK PROJECT ANNOUNCED THAT AMGEN LOBBYIST VICTORIA BLATTER WAS JOINING THE ORGANIZATION’S BOARD OF DIRECTORS 3/30/23: Haystack Project announced that Amgen senior vice president of global government affairs Victoria Blatter was joining its board of directors.

“March 30, 2023. Haystack Project is pleased to announce the appointment of Victoria Blatter, MPH to the organization’s board of directors. Haystack Project announced today that Victoria Blatter, MPH will join Haystack Project’s board of directors. Blatter brings over 20 years of leadership in industry and government, legislative expertise and a wide breadth of knowledge around patient access to care. [...] Blatter is the recently retired Senior Vice President, Global Government Affairs for Amgen where she was responsible for federal and state legislative issues and managing relationships with U.S. agencies, legislatures and governmental administrations. She was also responsible for international lobbying and diplomacy in Washington, D.C. Prior to joining Amgen, she worked at Merck & Co., Inc. as Vice President of U.S. Policy and Federal Government Relations and previously served as professional staff for the U.S. Senate Special Committee on Aging and as minority staff director for the U.S. House Select Committee on Aging’ Subcommittee on Retirement Income and Employment.” [Haystack Project, [3/30/23](#)]

- **2011-2022: Blatter was Senior Vice President Global Government Affairs and Policy at Amgen.**
[Victoria Blatter LinkedIn profile, accessed [5/12/23](#)]
- **1997-2010: Blatter was Vice President, Federal Policy and Government Relations at Merck.**
[Victoria Blatter LinkedIn profile, accessed [5/12/23](#)]

Haystack Project staffers and consultants have pharmaceutical industry experience

HAYSTACK PROJECT POLICY CONSULTANT CARA TENENBAUM IS A LOBBYIST FOR GISKIT PHARMA

Cara Tenenbaum was a policy consultant for the Haystack Project.

[Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]

- **2021-Present: Tenenbaum is a principal at Strathmore Health Strategy.**
[Cara Tenenbaum LinkedIn profile, accessed [5/11/23](#)]
- **November 2019-January 2021: Tenenbaum was a director at Pyxis Partners/HCM Strategies, working on stakeholder affairs and government relations for clients in the pharmaceutical arena.**
“Director Pyxis Partners /HCM Strategists Nov 2019 - Jan 2021 · 1 yr 3 mos Responsible for strategy and implementation of stakeholder affairs and government relations for clients in the pharmaceutical and advocacy arenas -Identified and cultivate partnerships aligned to client policy and legislative priorities -Developed Capitol Hill strategy for watchdog organization -Provided legal and policy analysis of pending court cases related to client work -Worked with patient advocacy groups to forward priorities of mutual interest, including in areas related to reproductive health, opioid use and other women's health issues” [Cara Tenenbaum LinkedIn profile, accessed [5/11/23](#)]

Tenenbaum is a registered federal lobbyist for Giskit Pharma.

[ProPublica, accessed [5/15/23](#)]

M. Kay Scanlan, a Haystack Project Consultant, Worked at Biogen and at Law Firms that Serviced the Pharmaceutical Industry

2021: Haystack Project paid M. Kay Scanlan \$142,960 for “consulting.”

[Haystack Project, IRS Form 990, [undated](#), accessed 5/12/23]

- **2021: “Kay Scanlan” was a “senior policy consultant” for Haystack Project.**
[Haystack Project, 2021 Year In Review, accessed [5/10/23](#)]
- **2005-Present: Scanlan is a consultant on health policy and reimbursement strategy.**
“M Kay Scanlan has over 20 years of health policy and reimbursement strategy experience. As an HHS Office of General Counsel (OGC) attorney representing CMS, Kay worked on a wide array of reimbursement issues and policy initiatives. While at OGC, Kay was lead attorney on a wide array of Medicare, Medicaid, and insurance reform policy and regulation teams, including development of the national coverage process, coverage and payment for drugs, biologicals, diagnostic tests, and innovative medical devices.” [M. Kay Scanlan LinkedIn profile, accessed [5/12/23](#)]
- **2000-2002: Scanlan was an associate at the Arnold & Porter law firm where she was recruited to build a “reimbursement-focused healthcare group.”**
“Kay was recruited away from CMS to develop a reimbursement-focused healthcare group at Arnold & Porter. Her work there was instrumental in delivering the creative strategies and high rates of success necessary to build a strong reputation for the Firm’s new Healthcare Group. While at Arnold & Porter, Kay developed and executed strategies on several emerging issues.” [M. Kay Scanlan LinkedIn profile, accessed [5/12/23](#)]
- **May 2003-2004: Scanlan was director of reimbursement strategy at Biogen.**
“Kay went on to focus on strategic consulting for life sciences stakeholders, serving as a reimbursement strategy consultant to Biogen through CMS’ implementation of the Medicare Modernization Act’s introduction of the Part D drug benefit and Part B ASP-based pricing.” [M. Kay Scanlan LinkedIn profile, accessed [5/12/23](#)]
- **2006-2008: Scanlan was a senior reimbursement advisor at the King & Spalding law firm.**
[M. Kay Scanlan LinkedIn profile, accessed [5/12/23](#)]
 - **King & Spalding maintains a practice in “Life Sciences and Healthcare” that services pharmaceutical and biologics companies and medical device manufacturers.**
“Life Sciences and Healthcare Our team guides life sciences and healthcare companies through the complex compliance obligations, transactions and litigation that enable them to advance the breakthrough treatments and services that improve patient health. We combine extensive life sciences industry capabilities and our long history as a leading

healthcare industry adviser to counsel clients across the delivery system on FDA law, health law, product liability, M&A, appellate litigation, data privacy and security, government advocacy and more. An established leader in life sciences and healthcare. We have a long history as the firm of choice for pharmaceutical, biologics and medical device manufacturers and major hospitals and health systems. The Chambers and Legal 500 guides consistently rank our practice and its lawyers among the best in the life sciences and healthcare field. At the forefront of industry innovation. We assist development-stage clients operating in emerging areas where technology intersects with medical care, including precision medicine, artificial intelligence, and innovations in digital health. Bringing the right resources to the table. We anticipate shifting market trends and grow and evolve our team to help our clients respond to them. Most recently, we have expanded our capabilities in food and beverage litigation, biologics counseling, global human global human capital and compliance, and government contracts, among other areas.” [King & Spalding, accessed [5/12/23](#)]

CYNTHIA ROTHBLUM-OVIATT, A SCIENCE ADVISOR AT HAYSTACK PROJECT AND CONNECT 4 STRATEGIES, WORKED FOR THE AMERICAN SOCIETY FOR EXPERIMENTAL NEUROTHERAPEUTICS, WHICH WAS SPONSORED BY MAJOR PHARMACEUTICAL COMPANIES

July 2020-August 2022: Cynthia Rothblum-Oviatt was a science advisor at the Haystack Project.

[Cynthia Rothblum-Oviatt LinkedIn profile, accessed [5/11/23](#)]

- **August 2020-October 2021: Rothblum-Oviatt was a science policy fellow/advisor to Connect 4 Strategies.**
[Cynthia Rothblum-Oviatt LinkedIn profile, accessed [5/11/23](#)]
- **December 2021-August 2022: Rothblum-Oviatt was a science advisor at the American Society for Experimental Neurotherapeutics.**
[Cynthia Rothblum-Oviatt LinkedIn profile, accessed [5/11/23](#)]
- **The American Society for Experimental Neurotherapeutics counts major pharmaceutical companies like Biogen, Eisai, Takeda, among many others as “Recent ASENT Corporate Partners.”**
[ASENT 2023 Annual Meeting Prospectus, accessed [5/11/23](#)]
- **Past sponsors of the American Society for Experimental Neurotherapeutics included AbbVie, Celgene, Janssen, Merck, Novartis, Pfizer, and Sanofi, among other pharmaceutical companies.**
[ASENT 2023 Annual Meeting Prospectus, accessed [5/11/23](#)]

HAYSTACK PROJECT USED A PUBLIC RELATIONS CONSULTANT WHO WORKS IN THE PHARMACEUTICAL INDUSTRY

2020: Haystack Project issued a press released and listed Berry & Company Public Relations as the media contact.

“Haystack Project is a 501(c)(3) non-profit organization enabling rare and ultra-rare disease patient advocacy organizations to coordinate and focus efforts that highlight and address systemic reimbursement obstacles to patient access. Our core mission is to evolve health care payment and delivery systems with an eye toward spurring innovation and quality in care toward effective, accessible treatment options for rare and ultra-rare patients. We strive to amplify the patient and caregiver voice in these disease states where unmet need is high and treatment delays and inadequacies can be catastrophic. For more information, visit <https://haystackproject.org>. Media Contacts: Jenna Urban Berry & Company Public Relations” [PR Newswire, 7/9/20]

- **Berry & Company advertises their work in the pharmaceutical, biotechnology and medical device industries.**
“Over the past 20+ years Berry & Company clients have included established and emerging leaders in all areas of healthcare and medical research. In every engagement, our goal is to build a partnership that positions us to meet each client's needs with superior precision and insight. It is a formula that has helped us establish and maintain many lasting service relationships. More than 50% of our business today is with clients who have been with us for at least five years. For several of our clients, we have provided ongoing PR support for more than a decade. We are a good fit for clients of any size and at any stage in their growth. We understand the communications needs of development stage companies. For many, we are the first public relations agency they have ever used. We have also been chosen by leading global companies in pharmaceuticals, biotechnology and medical devices. They appreciate our responsiveness and efficiency, with access to our senior team of professionals who are actively engaged in their account every day.” [Berry & Company, accessed [5/12/23](#)]

THERE IS NO INDICATION THAT HAYSTACK PROJECT LEADERS ARE RARE DISEASE PATIENTS

NB: There's no indication that any of Haystack Project's leadership are rare disease patients, however, we cannot be certain. Hidden on Haystack Project's website are bios of some of the founding members of the organization's board of directors. None of those profiles indicate that any of them are rare disease patients. We cannot rule out the possibility that rare diseases have personally touched the lives of Haystack Project leadership.

Bios for some of Haystack Projects founding leadership make no mention of them being rare disease patients

A Haystack Project bio for “Cynthia Goss, Chairman of the Board” is blank.

April 14, 2019

Cynthia Goss, Chairman of the Board

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Comments on ICER Value Framework ...

Joe Chirico, Treasurer

[Haystack Project, [4/14/19](#)]

A Haystack Project bio for “Joe Chirico, Treasurer” makes no mention of being a rare disease patient.

“Joe Chirico, Treasurer Joe has more than thirty years of experience in financial and non-profit management. His experience has been focused on the financial growth and development of mid-sized commercial enterprises. He serves on a variety of boards associated with commercial and industrial growth, environmental sustainability, the food economy and education.” [Haystack Project, [4/14/19](#)]

A Haystack Project bio for “James Caro, Chief Executive Officer, Ex Officio Board Member” makes no mention of being a rare disease patient.

[Haystack Project, [4/14/19](#)]

A Haystack Project bio for “Bela Sastry, Secretary” is blank.

April 14, 2019

Bela Sastry, Secretary

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James Caro, Chief Executive ...

Saira Sultan, JD, Consultant

[Haystack Project, [4/14/19](#)]

A Haystack Project bio for “Saira Sultan, JD, Consultant” makes no mention of being a rare disease patient.

“Saira Sultan, JD, Consultant Saira Sultan has represented corporate, nonprofit, and government interests in the legislative and regulatory health policy arena for more than 20 years in Washington, D.C. She has had repeated success in designing business solutions by identifying and creating advocacy opportunities and translating them into strategic legislative and regulatory results. Saira brings a decade of experience working with market access, health outcomes, and commercial teams in pharmaceutical companies, including Pfizer and Sanofi. Saira is an experienced project management lead for large cross-functional efforts at Medtronic, Pfizer, Sanofi, and more. Focusing in areas such as oncology, rare and extremely rare therapies, vaccines, and specialty products in sickle cell, pain, addiction, cell and gene therapy and more, Saira has worked extensively with CMS, FDA and Capitol Hill. Her insight and skill in working cross-functionally in a corporate environment, as well as with advocacy organizations and key trade associations serves her clients well. Saira's leadership at the Association of Community Cancer Centers (ACCC) allowed her to build strong relationships with the oncology community and gain insights into the evolution of oncology care. She continues to work closely with many oncology organizations, identifying emerging trends that have led to repeated success in tackling coverage, coding and payment of marketed and pipeline Part B and D products. The Government Affairs and Policy team at ACCC, under Saira's direction, raised significant revenue, improved the

Association's profile, as she became a sought after speaker on oncology policy issues. Complementing her 10 years in pharmaceuticals, Saira's time at Medtronic gives her an in-depth understanding of the unique needs of the device industry. Representing Medtronic at a time when CMS was completely revamping device reimbursement in hospital outpatient departments, gave her the opportunity to work closely with CMS and key stakeholders. Saira built a successful coalition of varied stakeholders that ensured reimbursement for Class III devices reflecting their value to patients. Additionally, Saira brings House and Senate experience, including work on the Ways and Means Committee, and roles as senior legislative counsel for Senator Mike DeWine (R-OH) and Chief Counsel to one of the Senate Healthcare Subcommittees. She handled all healthcare issues under the Senate HELP Committee's jurisdiction, including extensive negotiations with FDA and industry on the Balanced Budget Act of 1997 and the first reauthorization of the Prescription Drug User Fee Act. She spearheaded passage of the first Better Pharmaceuticals for Children. Saira holds a JD from the University of Virginia in Charlottesville, VA." [Haystack Project, [4/14/19](#)]

HAYSTACK PROJECT IS ESSENTIALLY A TRADE ORGANIZATION FOR "RARE AND ULTRA-RARE DISEASE PATIENT ADVOCACY ORGANIZATIONS" WITHOUT ITS OWN REAL PATIENT PRESENCE

Haystack project has at least 135 patient advocacy organizations that are "participants"

Haystack Project identifies more than 135 organizations that are “participants” in the Haystack Project.

Participants



[Haystack Project, accessed [6/7/23](#)]

Haystack Project described itself as a “non-profit enabling rare and ultra-rare disease patient advocacy organizations.”

“Haystack Project is a non-profit enabling rare and ultra-rare disease patient advocacy organizations to highlight and address systemic obstacles to patient access. Our core mission is to evolve health care payment and delivery systems to make innovative quality treatments accessible to the patients they were meant to reach.” [Haystack Project, accessed [6/7/23](#)]

A video of testimonials about the Haystack Project includes anonymous “members” and the leaders of various rare disease organizations.

[Vimeo, Haystack Project, accessed [6/7/23](#)]

Haystack Project accepts “individual contributions” starting at \$5, but makes no indication of how many individual members it might have, if any

NB: Haystack Project’s IRS Form 990s don’t shed any additional light on how many individual contributors it might have, in part because of how the reporting is done on the Form 990, which only requires lump-sum reporting of categories such as “membership dues” and “All other contributions, gifts, grants, and similar amounts not included above.”

Haystack Project accepts individual contributions, starting at \$5.



Individual Contributor

from \$5.00

Amount:

Select Amount ▾

DONATE

Share

[Haystack Project, accessed [6/7/23](#)]

The “Patient Story” section of the Haystack Project website includes links to 10 news articles, none of which mention the Haystack Project

NB: There's no indication from the Haystack Project that they have any connection to the patients mentioned in the stories linked below. The organization may have just plucked news stories about rare diseases from the media and put them on the Haystack Project website. However, we also cannot be sure that Haystack Project does not have a connection to the patients.

The “Patient Stories” section of the Haystack Project’s website links to 10 news articles.

[Haystack Project, accessed [6/7/23](#)]

- The Haystack Project links to a Boston Globe story about a boy with “the ultra-rare genetic condition, cerebral adrenoleukodystrophy” that does not mention the Haystack Project.
[Boston Globe, [4/1/23](#)]
- The Haystack Project links to a STAT News story about a boy with severe combined immunodeficiency that does not mention the Haystack Project.
[STAT, [12/21/22](#)]
- The Haystack Project links to a STAT News story about patients with hereditary Ehlers-Danlos syndrome that does not mention the Haystack Project.
[STAT, [12/12/22](#)]
- The Haystack Project links to a Fox News story about a patient with the neurological disorder Stiff Person Syndrome that does not mention the Haystack Project.
[Fox News, [12/12/22](#)]
- The Haystack Project links to a STAT News op-ed about how the FDA should be more flexible in assessing treatments for rare diseases that does not mention the Haystack Project.
[Karen Quandt, STAT, [9/7/22](#)]
- The Haystack Project links to a STAT News story about the health care needs of Black women are often ignored by the medical establishment that does not mention the Haystack Project.
[STAT, [12/21/21](#)]
- The Haystack Project links to a STAT News story about children with rare diseases caused by mutations in two genes, STXBP1 and SLC6A1, and the high drug prices needed to treat them that does not mention the Haystack Project.
[STAT, [6/3/21](#)]

- **The Haystack Project links to a STAT News op-ed about the FDA’s evaluation of a drug to treat ALS that does not mention the Haystack Project.**
[Mary Catherine Collet, STAT, [4/30/21](#)]
- **The Haystack Project links to a Wall Street Journal essay about the care required for a patient with the rare Wolf-Hirschorn syndrome that does not mention the Haystack Project.**
[Heather Lanier, Wall Street Journal, [7/23/20](#)]
- **The Haystack Project links to a New York Times story about families dealing with a diagnosis of rare disease and the care required for patients with rare diseases that does not mention the Haystack Project.**
[New York Times, [7/7/20](#)]

MISCELLANEOUS

Haystack Project’s conflict of interest policy does not address corporate sponsorships influencing policy positions

Haystack Project maintains a conflict-of-interest policy, but the purpose is to protect the non-profit status in transactions, with no mention of adopting the advocacy positions of the organization’s financial sponsors.

“Conflict of Interest Policy for Haystack Project, Inc. Article I Purpose. The purpose of the conflict of interest policy is to protect Haystack Project, a tax-exempt organization's (Organization) interest when it is contemplating entering into a transaction or arrangement that might benefit the private interest of an officer or director of the Organization or might result in a possible excess benefit transaction. This policy is intended to supplement but not replace any applicable state and federal laws governing conflict of interest applicable to nonprofit and charitable organizations.” [Haystack Project, Conflict of Interest Policy, accessed [5/11/23](#)]

An article at the top of Haystack Project’s website was written by two academics, each of whom have received more than \$2 million in funding from pharmaceutical and biotechnology companies

5/11/23: The top story on Haystack Project’s website is an article by Darcy Krueger and Emanuel Maverakis.

[Haystack Project, accessed [5/11/23](#)]

“Darcy Krueger is neurologist, director of the Tuberous Sclerosis Clinic at Cincinnati Children’s Hospital Medical Center, and professor of clinical pediatrics and neurology at the University of Cincinnati College of Medicine.” [Haystack Project, [6/1/22](#)]

- **2015-2021: Krueger has received \$79,562.09 in “general payments,” \$18,028.48 in “research payments,” and \$2,700,368.37 in “associated research funding” from pharmaceutical and biotechnology companies.**
[OpenPaymentsData.CMS.gov, accessed [5/11/23](#)]

“Emanuel Maverakis is a dermatologist, a professor of dermatology, and a clinical investigator in the Department of Medical Microbiology and Immunology at the University of California Davis.” [Haystack Project, [6/1/22](#)]

- **2015-2021: Maverakis has received \$17,375.64 in “general payments,” \$8,181.02 in “research payments,” and \$2,825,290.78 in “associated research funding” from pharmaceutical and biotechnology companies.**
[OpenPaymentsData.CMS.gov, accessed [5/11/23](#)]

Haystack Project has taken advocacy positions that complement PhRMA and BIO

April 2023: Haystack Project joined PhRMA and BIO in commenting on CMS' implementation of the Inflation Reduction Act's small biotech exemption.

"The Biotechnology Innovation Organization (BIO) and Pharmaceutical Care Management Association (PCMA) also submitted comments on the small biotech exception ICR, as well as two advocacy groups, the Haystack Project and No Patient Left Behind (NPLB)." [Inside Drug Pricing, 4/17/23]

At least one member of Haystack Project's board of directors has significant experience in the health insurance industry

Christina Nyquist is on the Haystack Project board of directors.

[Haystack Project, 2022 Year In Review, accessed [5/10/23](#)]

- **Nyquist is vice president of federal affairs at Point32Health, a family of health insurance plans in New England.**
"Vice President, Federal Affairs Point32Health Apr 2021 - Present · 2 yrs 2 mos Point32Health is the combined organization of heritage Tufts Health Plan and Harvard Pilgrim Health Care. Our family of insurance plans serve over 2 million members in five New England States. We cover commercial enrollees as well as Medicaid, Medicare Advantage and ACA individual marketplace members. As Head of Federal Affairs, I am a strategic partner will all business units and responsible for the development of federal policy and execution of advocacy strategy." [Christina Nyquist LinkedIn profile, accessed [5/11/23](#)]
- **2009-2017: Nyquist was vice president at insurance company Aetna.**
[Christina Nyquist LinkedIn profile, accessed [5/11/23](#)]
- **1991-2009: Nyquist was a senior federal government relations leader at Blue Cross Blue Shield.**
[Christina Nyquist LinkedIn profile, accessed [5/11/23](#)]

5/10/23: The Haystack Project corporate status in Maryland is not “in good standing”

5/10/23; The Haystack Project is not “in good standing” because it hasn’t filed its annual report with the State of Maryland.

Department ID Number: D19496975

Business Name: HAYSTACK PROJECT, INC.

Principal Office: [i](#) 6005 GLOSTER ROAD
BETHESDA MD 20816

Resident Agent: [i](#) SAIRA SULTAN CHIRICO
6005 GLOSTER ROAD
BETHESDA MD 20816

Status: INCORPORATED

Good Standing: THIS BUSINESS IS NOT IN GOOD STANDING

[What does it mean if a business entity is not in good standing or forfeited?](#)

Reason(s) Entity is NOT in Good Standing: Annual Report Due For 2023 » [File Annual Report](#)

[Please review the Good Standing Checklist.](#)

Business Type: CORPORATION

Business Code: 04 ORDINARY BUSINESS - NON-STOCK

[Maryland Business Express, HAYSTACK PROJECT, INC.: D19496975, accessed [5/15/23](#)]

NO PATIENT LEFT BEHIND

NPLB WAS CREATED BY PETER KOLCHINSKY AND RA CAPITAL, A BIOPHARMA VENTURE CAPITAL AND INVESTMENT MANAGEMENT FIRM

Kolchinsky said he created NPLB to sway public sentiment and Congress

KOLCHINSKY CREATED NPLB TO SWAY CONGRESS AND ADVOCATE FOR HIS PROPOSED A GRAND BARGAIN OF PRICE CONTROLS ON DRUGS IN EXCHANGE FOR LOW OUT-OF-POCKET COSTS FROM INSURANCE COMPANIES

Kolchinsky said that NPLB was created to “steadily chip away at the misunderstandings that the public, media and Congress have about the drug industry.”

“These are the kinds of analogies that we’ve been putting on the No Patient Left Behind website in order to steadily chip away at the misunderstandings that the public, media and Congress have about the drug industry. We’re funding research to try to give the world a more holistic view of the ecosystem. So, we’ve got this cool project that’s underway where we integrate the entire industry into a single P&L statement in order to show what drives this industry. Why do we need to do that? Well, because when Congress decides that it’s gonna judge our industry by the profitability of a few pharmas, that’s basically like saying, ‘Well, all artists are rich ‘cause look Beyonce makes a lot of money.’ It’s like, no, for the most part, being an artist is not very lucrative. And you have to show people the totality of an ecosystem to show that there’s a ton of money that’s being invested in these smaller companies. And their hope in many cases is that they get chosen as a winner by those big pharmas. They get acquired for a large amount of money, and that money then flows back into the ecosystem and drives the growth of new small companies that represent the seeds of the next decades’ medicines. So, we wanna show the world this holistic ecosystem model. We’ve attracted hundreds of supporters from the drug industry who are signing up, basically saying, ‘Yes, I agree. Our medicines should go generic without undue delay.’ [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

Kolchinsky described NPLB as the “nonprofit advocacy version of the book that I wrote.”

“There’s a non-profit organization called No Patient Left Behind that is basically the non-profit advocacy version of the book that I wrote that’s trying to bring about you know restoration of the biotech social contract.” [YouTube, No Patient Left Behind, [12/14/21](#)]

Kolchinsky summarized his book and position saying that the biopharma industry should agree to medicines going generic or price controls if they can’t go generic, in exchange for “low out-of-pocket costs for patients.”

“So, if our industry could support regulations that fix that market failure, when our medicines don’t go generic without undue delay, if we accepted that yes, there should be some price controls essentially that knock those prices down to a level as if they’d gone generic, but it’s in exchange, we also win low out-of-pocket costs for patients, I believe that we will have a far more harmonious healthcare system and innovation system in the US, with spillover to the rest of the world.” [DLA Piper, At the Intersection of Science and Law, partial transcript, [3/21/22](#)]

RA CAPITAL, WHICH FUNDS NPLB, SAYS THE NONPROFIT ADVOCATES FOR INSURANCE REFORMS AND ELUCIDATES THE “FULL SOCIETAL VALUE OF ALL MEDICINES” WHILE PRESERVING INNOVATION IN THE “DRUG DEVELOPMENT ENTERPRISE”

According to RA Capital, NPLB, which it “helped to found and continue[s] to support, “advocates for insurance reforms that would allow all patients to afford the treatments they need.”

“Additionally, we helped to found and continue to support No Patient Left Behind, a non-profit dedicated to promoting affordability of today’s medicines and the development of better ones. More specifically, NPLB advocates for insurance reforms that would allow all patients to afford the treatments they need, draws attention to the full societal value of all medicines and the merits of ensuring that all drugs go generic without delay, and educates lawmakers and the public about the workings of the biomedical ecosystem to protect it against misguided policies.” [RA Capital, accessed [5/18/23](#)]

- **According to RA Capital, NPLB “draws attention to the full societal value of all medicines and the merits of ensuring that all drugs go generic without delay, and educates lawmakers and the public about the workings of the biomedical ecosystem to protect it against misguided policies.”**

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RA Capital said it launched NPLB to “advocate for reforms that preserve innovation in the drug development enterprise.”

To advocate for patients not being able to afford the medicines they need, we launched a non-profit called No Patient Left Behind. We help patients get access to their medicines and advocate for reforms that preserve innovation in the drug development enterprise. This organization largely emerged from the pages of the book *The Great American Drug Deal* written by Managing Partner Peter Kolchinsky.” [RA Capital, accessed [5/18/23](#)]

Kolchinsky said that NPLB is made up of “hundreds of supporters from the drug industry,” calling it “really grass roots”

Kolchinsky said that NPLB as “attracted hundreds of supporters from the drug industry.”

“We’ve attracted hundreds of supporters from the drug industry who are signing up, basically saying, ‘Yes, I agree. Our medicines should go generic without undue delay.’” [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

Kolchinsky referred to NPLB as “really grassroots.”

“We have some time to continue to build awareness in Congress and with the general public of what kinds of reforms really would serve the public interest in the long run. It’s really grassroots. We’re trying to teach through simple animations, trying to get to people, even at a high school level, so that they get what’s happening to them at the pharmacy. So, I would urge everybody to check out no patient left behind. If you’re passionate about this cause, please support the organization.” [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

Peter Kolchinsky is founder of NPLB and founder and managing director of RA Capital

KOLCHINSKY FOUNDED BOTH RA CAPITAL AND NPLB

Peter Kolchinsky is the founder of NPLB and founder and managing director of RA Capital Management.

“Peter Kolchinsky Steering committee Founder of NPLB. Founder and Managing Director, RA Capital Management” [NPLB, accessed [5/17/23](#)]

RA Capital Management invests in “funding and creating companies developing new medicines.”

“Peter Kolchinsky is a father, scientist, investor, teacher, and author. He researched HIV at Harvard, where he earned his PhD, and then co-founded RA Capital Management, a Boston-based life-sciences investment firm focused on funding and creating companies developing new medicines.” [NPLB, accessed [5/17/23](#)]

KOLCHINSKY ESPOUSES A VIEW THAT BRANDED PHARMACEUTICALS SHOULD MOVE TO GENERIC WITHOUT UNDUE DELAY

Kolchinsky claims to want branded drugs to move quickly into the generic realm to “ensure they offer America value for what it invests in branded medicines.”

“Hearing the stories of how patients couldn’t afford the treatments they needed, he wrote *The Great American Drug Deal*, which makes the case for the reforms that No Patient Left Behind fights for. He’s spoken with policymakers, students, and drug and insurance companies on the importance of lowering out-of-pocket costs to achieve affordability and requiring that all drugs go generic without undue delay to ensure they offer America value for what it invests in branded medicines. Peter continues to manage RA Capital with the goal of fulfilling the hopes of patients still waiting for their cures and supports No Patient Left Behind so those new medicines will be accessible to all the patients they’re meant for.” [NPLB, accessed [5/17/23](#)]

RA Capital provides funding for NPLB, and a patient assistance program called Harbor Path

According to RA Capital, NPLB, which it “helped to found and continue[s] to support, “advocates for insurance reforms that would allow all patients to afford the treatments they need.”

“Additionally, we helped to found and continue to support No Patient Left Behind, a non-profit dedicated to promoting affordability of today’s medicines and the development of better ones. More specifically, NPLB advocates for insurance reforms that would allow all patients to afford the treatments they need, draws attention to the full societal value of all medicines and the merits of ensuring that all drugs go generic without delay, and educates lawmakers and the public about the workings of the biomedical ecosystem to protect it against misguided policies.” [RA Capital, accessed [5/18/23](#)]

5/5/21: Natalie Kostich, a senior program manager at RA Capital, wrote that RA Capital was “funding NPLB and has helped HarborPath.”

“Full disclosure. In fall 2020 I started work at RA Capital Management, a biotech investment firm that is funding NPLB and has helped HarborPath modernize and expand its roster of medicines. I know how fortuitous this relationship was for my family. It also underscores the absurdity of the health insurance system, and how difficult it must be to navigate for people without such a serendipitous set of connections. I have a master’s degree and couldn’t figure it out. [...]

Natalie Kostich is a senior program manager at RA Capital Management.” [Natalie Kostich, Harbor Path, [5/5/21](#)]

- **5/5/21: Kostich referred to NPLB as a “new nonprofit.”**

“That’s when I contacted someone certain to empathize: Lynda Gorov, executive editor of No Patient Left Behind (NPLB), a new nonprofit dedicated to making medicines affordable for everyone in America, in part by putting an end to copays, deductibles and other out-of-pocket costs that should be covered by insurance. She made a few suggestions, and then made the one that really mattered. She suggested I reach out to Ken Trogon, Harbor Path’s founder and president, who has a longstanding relationship with Merck & Co., which manufactures the drug my dad needed and has a patient assistance program for it.” [Natalie Kostich, Harbor Path, [5/5/21](#)]

2023: RA Capital Management, through all its funds, has approximately \$10 billion in assets under management, in at least 8 investment funds, investing in biopharmaceutical companies developing new drugs

RA CAPITAL HAS INVESTED IN AT LEAST 200 PHARMACEUTICAL, BIOTECH, AND MEDICAL DEVICE COMPANIES, INCLUDING CURRENT AND PREVIOUS INVESTMENTS

RA Capital invests in life science companies developing drugs.

“RA Capital Management is a multi-stage investment manager dedicated to company formation and evidence-based investing in healthcare and life science companies developing drugs, medical devices, diagnostics, services, and research tools. The firm’s portfolio of private and public companies spans the globe and most therapeutic areas across all stages from discovery through commercialization. We are committed to fostering diversity at RA, in our portfolio companies, and in the broader biotech community.” [RA Capital, accessed [5/18/23](#)]

RA CAPITAL HAS INVESTED IN AT LEAST 200 PHARMACEUTICAL, BIOTECH, AND MEDICAL DEVICE COMPANIES

RA Capital was previously invested in at least 120 biopharmaceutical, biotechnology, and medical device companies.



[RA Capital, accessed [5/18/23](#)]

RA CAPITAL MANAGEMENT HAS ABOUT \$10 BILLION IN ASSETS UNDER MANAGEMENT

4/3/23: RA Capital Management LP reported to the SEC that it had nearly \$10 billion in assets under management in pooled investment vehicles and corporations.

Type of Client	(1) Number of Client(s)	(2) Fewer than 5 Clients	(3) Amount of Regulatory Assets under Management
(a) Individuals (other than high net worth individuals)	0	<input type="checkbox"/>	\$
(b) High net worth individuals	0	<input type="checkbox"/>	\$
(c) Banking or thrift institutions	0	<input type="checkbox"/>	\$
(d) Investment companies	0		\$
(e) Business development companies	0		\$
(f) Pooled investment vehicles (other than investment companies and business development companies)	8		\$ 9,513,563,233
(g) Pension and profit sharing plans (but not the plan participants or government pension plans)	0	<input type="checkbox"/>	\$
(h) Charitable organizations	0	<input type="checkbox"/>	\$
(i) State or municipal government entities (including government pension plans)	0	<input type="checkbox"/>	\$
(j) Other investment advisers	0	<input type="checkbox"/>	\$
(k) Insurance companies	0	<input type="checkbox"/>	\$
(l) Sovereign wealth funds and foreign official institutions	0	<input type="checkbox"/>	\$
(m) Corporations or other businesses not listed above		<input checked="" type="checkbox"/>	\$ 136,772,800
(n) Other:	0	<input type="checkbox"/>	\$

[SEC, RA CAPITAL MANAGEMENT, LP (CRD # 160174/SEC#:801-73980), Form ADV, filed [4/3/23](#)]

- 4/3/23: RA Capital Management LP reported to the SEC that 73 percent of its assets were “Non Exchange-Traded Equity Securities,” 23 percent were “Exchange-Traded Equity Securities,” and 4 percent were “cash and cash equivalents.”

(b) Asset Type	End of year
(i) Exchange-Traded Equity Securities	23 %
(ii) Non Exchange-Traded Equity Securities	73 %
(iii) U.S. Government/Agency Bonds	0 %
(iv) U.S. State and Local Bonds	0 %
(v) Sovereign Bonds	0 %
(vi) Investment Grade Corporate Bonds	0 %
(vii) Non-Investment Grade Corporate Bonds	0 %
(viii) Derivatives	0 %
(ix) Securities Issued by Registered Investment Companies or Business Development Companies	0 %
(x) Securities Issued by Pooled Investment Vehicles (other than Registered Investment Companies or Business Development Companies)	0 %
(xi) Cash and Cash Equivalents	4 %
(xii) Other	0 %

Generally describe any assets included in "Other"

[SEC, RA CAPITAL MANAGEMENT, LP (CRD # 160174/SEC#:801-73980), Form ADV, filed [4/3/23](#)]

12/31/21: An RA Capital brochure on file with the SEC claimed that RA Capital had more than \$10.1 billion in regulatory assets under management.

“As of December 31, 2021, RA Capital has approximately \$10,147,001,376.00 of Regulatory Assets Under Management (calculated under the guidance in Form ADV instructions), all managed on a discretionary basis.” [SEC, RA CAPITAL MANAGEMENT, LP (CRD # 160174/SEC#:801-73980), Part 2 Brochures, filed [4/3/23](#)]

RA CAPITAL MANAGEMENT LP OPERATES AT LEAST 8 INVESTMENT FUNDS

RA Capital Management LP operates at least 8 investment funds.

Related Entities	TYPE	General Partner, Manager, Trustee, or Director	Name of Country/English Name of Foreign Financial Regulatory Authority
RA CAPITAL HEALTHCARE FUND, LP	Private Fund	RA CAPITAL MANAGEMENT HEALTHCARE FUND GP, LLC; RA CAPITAL MANAGEMENT, LP	
RA CAPITAL HEALTHCARE INTERNATIONAL FUND, LTD.	Feeder Fund	DEREK CANDY, DIRECTOR; MICHAEL SAULNIER, DIRECTOR; RA CAPITAL MANAGEMENT, LP; SHERRI FLEMING, DIRECTOR	Other - CAYMAN ISLANDS MONETARY AUTHORITY
RA CAPITAL NEXUS FUND, L.P.	Private Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND GP, LLC	
RA CAPITAL NEXUS INTERNATIONAL FUND, L.P.	Feeder Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND GP, LLC	Other - CAYMAN ISLANDS MONETARY AUTHORITY
RA CAPITAL NEXUS II FUND, L.P.	Private Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND II GP, LLC	
RA CAPITAL NEXUS INTERNATIONAL FUND II, L.P.	Feeder Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND II GP, LLC	Other - CAYMAN ISLANDS MONETARY AUTHORITY
RA CAPITAL NEXUS III FUND, L.P.	Private Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND III G.P, LLC	
RA CAPITAL NEXUS INTERNATIONAL FUND III, L.P.	Feeder Fund	RA CAPITAL MANAGEMENT, LP; RA CAPITAL NEXUS FUND III GP, LLC	Other - CAYMAN ISLANDS MONETARY AUTHORITY

[SEC, RA CAPITAL MANAGEMENT, LP (CRD # 160174/SEC#:801-73980), Form ADV, filed [4/3/23](#)]

KOLCHINSKY AND SHAH OWN AND CONTROL THE GENERAL PARTNERS THAT OPERATE THE RA CAPITAL INVESTMENT FUNDS

Kolchinsky and Shah own and control the general partners of RA Capital's investment funds.

"This brochure provides information about the qualifications and business practices of RA Capital Management, LP ('RA Capital' or the 'Adviser'). [...] RA Capital's affiliate, RA Capital Nexus Fund III GP, LLC, serves as general partner of Nexus III and the Nexus III Offshore Fund. RA Capital's affiliate, RA Capital Nexus Fund II GP, LLC, serves as general partner of Nexus II and the Nexus II Offshore Fund. RA Capital's affiliate, RA Capital Nexus Fund GP, LLC, serves as general partner of the Nexus Fund and the Nexus Offshore Fund. RA Capital's affiliate, RA Capital Healthcare Fund GP, LLC, serves as general partner of the Healthcare Master Fund. RA Capital currently serves as investment adviser of the Healthcare Funds, the Nexus Funds, and the Account. The general partners are owned and controlled by Messrs. Kolchinsky and Shah. Mr. Richard H. Aldrich is a passive minority owner of RA Capital and is not involved in the day-to-day management of the Adviser or any Advisory Client account." [SEC, RA CAPITAL MANAGEMENT, LP (CRD # 160174/SEC#:801-73980), Part 2 Brochures, filed [4/3/23](#)]

RA CAPITAL'S INVESTMENT PHILOSOPHY IS NOT ABOUT THE VALUATION OF A COMPANY, BUT ABOUT "HOW MUCH MORE VALUE THERE IS TO CREATE"

RA Capital says, "What matters more than valuation is how much more value there is to create."

Do you have a valuation range you stick to? We'll invest in companies with valuations ranging from essentially nothing (newcos we form) to, let's say, \$10B. What matters more than valuation is how much more value there is to create." [RA Capital, accessed [5/18/23](#)]

When RA Capital invests in a company it typically assumes a seat on the company's board of directors.

"Do you take board seats? When we invest in private companies, a member of our team almost always joins the board as an observer or director. The people who take those positions then serve as conduits for all of the resources of our firm for the benefit of the company. Do you stay on the board when a private company goes public? If a member of our team is a director of a company, then in many cases they will remain on the board after the company goes public. Observerships terminate at the IPO." [RA Capital, accessed [5/18/23](#)]

RA Capital's website includes a testimonial from the CEO of Imbria Pharmaceuticals.

"Working with RA Capital has been a transformative experience for Imbria. From leveraging the strength of the TechAtlas team to better understand an emerging competitive landscape to brainstorming new approaches with seasoned company-building

pros, my relationship with both RA Capital and the RA Venture Team is beneficial in every way. I sincerely look forward to our interactions.' D.A. GROS CEO of Imbria Pharmaceuticals" [RA Capital, accessed [5/18/23](#)]

RA CAPITAL IS A "PLATFORM FOR DRUG HUNTING"

RA Capital bills itself as a "platform for drug hunting and company formation."

"I'm a drug hunter – could your maps help me? Yes. Beyond the maps, RA Capital/TechAtlas is a platform for drug hunting and company formation." [RA Capital, accessed [5/18/23](#)]

- **A "drug hunter" is "someone that wants to bring new medicines to society."**

"If you're here reading about drug discovery for fun, you're probably a drug hunter. You might be someone on your way to a leadership role in pharma or biotech. Maybe you're decades into your career and already leading an R&D division. You don't have a PhD in drug hunting, and it's unlikely to be in your job description. But something makes you different from others you work with. Most likely, you found Drug Hunter because medicine is more than just your profession. You're here because you love what you do. What Does a Drug Hunter Actually Do? A drug hunter is someone that wants to bring new medicines to society. Drug hunters are the visionary product leaders of biopharma: they know what a drug has to accomplish to be valuable to society, and they make the plans to get it there. To make their vision for a new drug happen, drug hunters pull and push everyone needed around them. Drug hunters feel personal ownership of drug discovery programs and a sense of responsibility for helping projects advance. Drug discovery teams thrive with effective drug hunters as project champions. Drug hunters bring the why to the project team. Why should we make this molecule? Why is this study important? Why is this drug going to make an impact on society? They also focus on the how. How do we find the molecules we are looking for? How will we know if this drug actually works? How will we get this drug to society? These questions transcend any individual function that's typically encountered in drug discovery and usually require a team to find answers. Without the drug hunter's emphasis on the why & how, projects become paralyzed or lose direction." [DrugHunter.com, [1/26/22](#)]

RA CAPITAL ADVERTISES THEIR SERVICES IN HELPING COMPANIES TO PREPARE FOR COMPETITION FROM GENERIC DRUGS

RA Capital advertises their research capabilities as helping to maximize commercial success and prepare companies for price competition through use of generics or multiple branded agents.

"Reimbursement Strategy What could payers or policymakers do to increase the degree of price competition or restrict use of branded products in the future in a particular disease area? In the face of such hurdles, how can companies still achieve commercial success? Payers typically take advantage of generics and multiple branded agents in the same class to exact discounts, and policymakers are slow to change the rules. Therefore, the optimal strategy to maintain future profits is to remain innovative and develop such superior products that payers cannot deny their value to patients. Sometimes our maps delineate a development endpoint where further improvements are unlikely and companies must prepare for price competition." [RA Capital, accessed [5/18/23](#)]

NPLB'S LEADERSHIP TEAM HAS DIRECT TIES TO THE PHARMACEUTICAL INDUSTRY

NPLB's executive director, Peter Rubin, was a lobbyist for PhRMA, Sanofi, and Merck

Peter Rubin is the executive director of NPLB.

[NPLB, accessed [5/17/23](#)]

2016-2018: Rubin was Vice President, Head of Government Affairs and Policy at Organovo.

[Peter L. Rubin LinkedIn profile, accessed [5/17/23](#)]

2010-2011: Rubin was senior director of federal affairs at Sanofi.

[Peter L. Rubin LinkedIn profile, accessed [5/17/23](#)]

2006-2008: Rubin was senior director of federal affairs at Merck.

[Peter L. Rubin LinkedIn profile, accessed [5/17/23](#)]

2000-2006: Rubin was deputy vice president of federal affairs at PhRMA.

[Peter L. Rubin LinkedIn profile, accessed [5/17/23](#)]

Rubin was a registered federal lobbyist for Sanofi, Merck, Organovo, and PhRMA.

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
ORGANOVO, INC.	ORGANOVO, INC.	2nd Quarter - Report	\$60,000.00	2017
ORGANOVO, INC.	ORGANOVO, INC.	1st Quarter - Report	\$70,000.00	2017
ORGANOVO, INC.	ORGANOVO, INC.	1st Quarter - Amendment	\$60,000.00	2017
ORGANOVO, INC.	ORGANOVO, INC.	3rd Quarter - Termination	\$40,000.00	2017
ORGANOVO, INC.	ORGANOVO, INC.	3rd Quarter - Report	\$50,000.00	2016
ORGANOVO, INC.	ORGANOVO, INC.	4th Quarter - Report	\$50,000.00	2016
ORGANOVO, INC.	ORGANOVO, INC.	Registration		2016
ORGANOVO, INC.	ORGANOVO, INC.	1st Quarter - Amendment	\$50,000.00	2016
ORGANOVO, INC.	ORGANOVO, INC.	2nd Quarter - Report	\$50,000.00	2016
AETNA INC.	AETNA INC	1st Quarter - Report	\$1,090,000.00	2016
AETNA INC.	AETNA INC	1st Quarter - Report	\$870,000.00	2015
AETNA INC.	AETNA INC	2nd Quarter - Report	\$510,000.00	2015
AETNA INC.	AETNA INC	3rd Quarter - Report	\$690,000.00	2015
AETNA INC.	AETNA INC	4th Quarter - Report	\$1,010,000.00	2015
AETNA INC.	AETNA INC	1st Quarter - Report	\$630,000.00	2014
AETNA INC.	AETNA INC	2nd Quarter - Report	\$460,000.00	2014
AETNA INC.	AETNA INC	3rd Quarter - Report	\$430,000.00	2014
AETNA INC.	AETNA INC	4th Quarter - Report	\$1,030,000.00	2014
AETNA INC.	AETNA INC	2nd Quarter - Report	\$430,000.00	2013
AETNA INC.	AETNA INC	1st Quarter - Report	\$570,000.00	2013
AETNA INC.	AETNA INC	3rd Quarter - Report	\$410,000.00	2013
AETNA INC.	AETNA INC	4th Quarter - Report	\$1,170,000.00	2013
AETNA INC.	AETNA INC	1st Quarter - Report	\$1,248,884.00	2012
AETNA INC.	AETNA INC	2nd Quarter - Report	\$820,000.00	2012
AETNA INC.	AETNA INC	3rd Quarter - Report	\$760,000.00	2012

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
AETNA INC.	AETNA INC	4th Quarter - Report	\$1,280,000.00	2012
SANOFI US SERVICES INC.	SANOFI US SERVICES INC	1st Quarter - Report	\$1,860,000.00	2011
AETNA INC.	AETNA INC	2nd Quarter - Report	\$902,453.00	2011
AETNA INC.	AETNA INC	3rd Quarter - Report	\$1,009,998.00	2011
AETNA INC.	AETNA INC	2nd Quarter - Amendment	\$902,453.00	2011
AETNA INC.	AETNA INC	4th Quarter - Report	\$914,888.00	2011
AETNA INC.	AETNA INC	1st Quarter - Report	\$1,083,703.00	2011
SANOFI US SERVICES INC.	SANOFI US SERVICES INC	4th Quarter - Report	\$950,000.00	2010
SANOFI US SERVICES INC.	SANOFI US SERVICES INC	3rd Quarter - Report	\$1,380,000.00	2010
SANOFI US SERVICES INC.	SANOFI US SERVICES INC	2nd Quarter - Report	\$870,000.00	2010
MERCK & CO. INC.	MERCK & CO INC	3rd Quarter - Report	\$1,110,000.00	2008
MERCK & CO. INC.	MERCK & CO INC	2nd Quarter - Report	\$1,170,000.00	2008
MERCK & CO. INC.	MERCK & CO INC	1st Quarter - Report	\$1,040,000.00	2008
MERCK & CO. INC.	MERCK & CO INC	Year-End Report	\$2,530,000.00	2007
MERCK & CO. INC.	MERCK & CO INC	Mid-Year Report	\$2,300,000.00	2007
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$9,260,000.00	2006
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$8,840,000.00	2006
MERCK & CO. INC.	MERCK & CO INC	Year-End Report	\$1,980,000.00	2006
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$6,260,000.00	2005
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$7,220,000.00	2005
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$8,040,000.00	2004
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$8,480,000.00	2003
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$7,560,000.00	2003
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$6,200,000.00	2002
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$8,060,000.00	2002
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$5,780,000.00	2001
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$5,500,000.00	2001
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Mid-Year Report	\$3,980,000.00	2000
PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA	Year-End Report	\$3,500,000.00	2000

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

The Co-Chairs of NPLB's advisory board are a pharmaceutical CEO and a partner of a pharmaceutical VC firm

NPLB ADVISORY COMMITTEE CO-CHAIR KEITH MURPHY HAS SPENT HIS CAREER IN THE PHARMACEUTICAL INDUSTRY

Keith Murphy is the co-chair of NPLB's advisory board.

[NPLB, accessed [5/17/23](#)]

2017-Present: Murphy is CEO and Founder of Viscient Biosciences, a pharmaceutical manufacturing company.

[Keith Murphy LinkedIn profile, accessed [5/17/23](#)]

2017-2022: Murphy was founder and executive chairman of Organovo Holdings.

[Keith Murphy LinkedIn profile, accessed [5/17/23](#)]

- **Organovo is a biotechnology company developing new drugs.**

"Organovo is a clinical stage biotechnology company that is developing drugs that are demonstrated to be effective in three-dimensional (3D) human tissues as candidates for drug development. The company's lead molecule is on the path for Phase 2 investigation in inflammatory bowel disease and has potential application in metabolic disease and oncology. The company has proprietary technology used to build 3D human tissues that mimic key aspects of native human tissue composition, architecture, function and disease." [Organovo, [3/21/23](#)]

Murphy previously worked at pharmaceutical companies Amgen and Alkermes.

"Keith Murphy is a scientist, inventor, and entrepreneur who has focused on advancing breakthrough medical technologies. He studied chemical engineering at MIT and worked on successful drug development, first for kids for pituitary deficiencies at Alkermes in Massachusetts, and then for cancer and osteoporosis at Amgen in California." [NPLB, accessed [5/17/23](#)]

- **1997-2007: Murphy worked as a senior engineer/group leader, a global operations leader, and a senior director at Amgen.**
[Keith Murphy LinkedIn profile, accessed [5/17/23](#)]
- **1993-1997: Murphy worked in process development at pharmaceutical company Alkermes.**
[Keith Murphy LinkedIn profile, accessed [5/17/23](#)]

NPLB ADVISORY COMMITTEE CO-CHAIR SARA NAYEEM HAS SPENT HER CAREER INVESTING IN PHARMACEUTICAL COMPANIES AND IS ON THE BOARD OF DIRECTORS OF SEVERAL BIOPHARMA COMPANIES

Sara Nayeem is a co-chair of the NPLB advisory board.

[NPLB, accessed [5/17/23](#)]

2021-Present: Nayeem is a partner at Avoro Ventures.

[Sara Nayeem LinkedIn profile, accessed [5/17/23](#)]

Avoro Capital invests in biopharmaceutical companies.

"Thoughtful Investing to Advance Biopharmaceutical Innovation Avoro Capital is a global life sciences investment firm with a focus on supporting emerging biotechnology companies." [Avoro Capital, accessed [5/17/23](#)]

- **Avoro Capital is invested in at least 57 pharmaceutical and biotechnology companies.**
[Avoro Capital, accessed [5/17/23](#)]

2009-2021: Nayeem rose from senior associate to principal and then to partner at New Enterprise Associates.

[Sara Nayeem LinkedIn profile, accessed [5/17/23](#)]

- **At New Enterprise Associates, Nayeem focused on venture capital investments in biopharmaceutical companies.**
 “Sara Nayeem is a mother, investor, and advocate for the biomedical innovation ecosystem. Sara received her AB in Biology from Harvard University, and then went on to experiences that spanned the medical, financial, and entrepreneurial worlds. She worked as an investment banking analyst at Morgan Stanley while deferring medical school at Yale University. Drawn to the business and policy aspects of medicine, she decided to pursue an MD / MBA at Yale, eventually going back into investment banking in Merrill Lynch’s healthcare group. Sara then found her way to venture capital at New Enterprise Associates, where she focuses on biopharmaceutical investments.” [NPLB, accessed [5/17/23](#)]

- **New Enterprise Associates has invested in 230 life sciences companies.**

Our Companies		
Q Search		230 Results
Sector	Investment Stage	Company Status
All	All	All
TECHNOLOGY	Seed	Private
Enterprise	Early	IPO/Public
Consumer	Growth	Acquired
HEALTHCARE	Public/PIPES	
Life Sciences		
Digital Health		

[New Enterprise Associates, accessed [5/17/23](#)]

- **New Enterprise Associates’ investments include at least 82 pharmaceutical companies.**

Our Companies		
Q pharmaceutical	x	82 Results

[New Enterprise Associates, accessed [5/17/23](#)]

Nayeem is on the board of Vanqua Bio.

“Sara currently serves on the board of Vanqua Bio Inc., a biotechnology company focused on developing novel therapies for Parkinson’s disease and other neurological disorders, and as a board observer for Scribe Therapeutics, a private molecular engineering company developing CRISPR-based in vivo therapies.” [Avoro Capital, accessed [5/17/23](#)]

- **Vanqua Bio is a biopharmaceutical company.**

“Founded in 2019, Vanqua Bio is a biopharmaceutical company focused on discovering and developing next-generation medicines for neurodegenerative diseases. Our novel drug-development approach combines advanced insights into critical neuronal cell pathways with cutting-edge assays to advance needed therapies. Our lead program targets glucocerebrosidase (GCase) as a potential treatment for Parkinson’s disease (PD) and all forms of Gaucher disease (GD). Additional programs address overactivation of the innate immune system in central and peripheral disorders, including Alzheimer’s disease.” [Vanqua Bio, accessed [5/17/23](#)]

Nayeem is a board observer for Scribe Therapeutics.

“Sara currently serves on the board of Vanqua Bio Inc., a biotechnology company focused on developing novel therapies for Parkinson’s disease and other neurological disorders, and as a board observer for Scribe Therapeutics, a private molecular engineering company developing CRISPR-based in vivo therapies.” [Avoro Capital, accessed [5/17/23](#)]

- **Scribe Therapeutics is a platform for “CRISPR-based genetic medicine.**
“Scribe is molecular engineering the most advanced platform for CRISPR-based genetic medicine. Our integrated technologies, designed to be the best for therapeutic use, offer key advantages” [Scribe Therapeutics, accessed [5/17/23](#)]
- **Scribe Therapeutics has partnered with Eli Lilly, licensing technology to the drugmaker.**
“Scribe Therapeutics Inc., a genetic medicines company unlocking the potential of CRISPR to transform human health, today announced a strategic collaboration with Prevail Therapeutics, a wholly owned subsidiary of Eli Lilly and Company, granting Prevail exclusive rights to Scribe’s CRISPR X-Editing (XE) technologies for the development of in vivo therapies directed to specified targets known to cause serious neurological and neuromuscular diseases.” [Scribe Therapeutics, [5/16/23](#)]
- **Scribe Therapeutics has a deal with Sanofi that could be ultimately worth \$1 billion.**
“Nature Biotechnology – Sanofi also turned to Scribe Therapeutics’ CRISPR platform to develop off-the shelf NK cell therapies for oncology, paying \$25 million up front in a deal that could be worth \$1 billion.” [Scribe Therapeutics, [2/15/23](#)]

Every member of NPLB’s advisory board/steering committee has ties to the pharmaceutical industry

NPLB BOARD MEMBER D.A. WALLACH IS THE CO-FOUNDER AND GENERAL PARTNER IF A BIOPHARMA VENTURE CAPITAL FIRM

D.A. Wallach is on the NPLB board.

[NPLB, accessed [5/17/23](#)]

2020-Present: Wallach is co-founder and general partner of Time BioVentures, a venture capital firm.

[D.A. Wallach LinkedIn profile, accessed [5/17/23](#)]

- **2021: Time BioVentures partnered with Eli Lilly and Johnson & Johnson in investing in Iterative Scopes, a gastroenterology precision medicine company partially owned by Eli Lilly.**
“Time BioVentures is pleased to announce its follow-on investment in Iterative Scopes \$30M Series A financing, alongside a syndicate led by Obvious Ventures with participation by Eli Lilly, Johnson & Johnson Innovation, Breyer Capital, and Seae Ventures. [...] Iterative Scopes is a pioneering company aiming to bring cutting-edge precision medicine to gastroenterology. [...] In addition to taking an equity stake in Iterative Scopes, Eli Lilly has begun to use the company’s software for help with patient selection and assessment during clinical trials that are critical to the success of their products. Lotus Mallbris, M.D., Ph.D., Vice President of Immunology Development at Eli Lilly and Company, will also be joining the Iterative Scopes board of directors.” [Time BioVentures, [8/3/21](#)]
- **Time BioVentures is currently invested in at least two therapeutics companies, including Kling Biotherapeutics.**
“Time BioVentures founded Kling in 2021 in Amsterdam, NL, building upon a rich body of intellectual property that originated at the Amsterdam Medical Center. Kling’s intuitive but original approach to discovering drugs by investigating cured patients has generated an impressive portfolio of targets and early-stage therapeutic programs, which we believe will form the foundation for a generationally important drug discovery platform.” [Time BioVentures, accessed [5/17/23](#)]

NPLB BOARD MEMBER DAVID BEIER WAS A LOBBYIST FOR PhRMA, BIO, AND BIG PHARMA COMPANIES, AND NOW INVESTS IN PHARMACEUTICAL COMPANIES

David Beier is on the NPLB board.

[NPLB, accessed [5/17/23](#)]

Beier previously worked at Genentech and Amgen, and is managing director of Bay City Capital, a life science venture capital firm.

“He served as a senior corporate officer for long periods at both Genentech and Amgen. David is Managing Director of Bay City Capital, a San Francisco-based life science venture firm.” [NPLB, accessed [5/17/23](#)]

Bay City Capital invests in biopharmaceutical companies.

“Bay City Capital funds have invested in a total of 100 portfolio companies covering a broad range of life science sectors, including biopharmaceuticals, drug discovery and research tools, medical devices, diagnostics, healthcare IT, nutrition, and agribusiness.” [Bay City Capital, accessed [5/17/23](#)]

- **Bay City Capital has invested in at least 45 biopharmaceutical companies.**

[Bay City Capital, accessed [5/17/23](#)]

2017-2020: Beier was a board member at Arcus Biosciences, a biopharmaceutical company.

[David Beier LinkedIn profile, accessed [5/17/23](#)]

2003-2013: Beier was senior vice president Amgen, “responsible for supervising Global government affairs, federal, state, and international.”

“Senior Vice President Amgen Dec 2003 - Jan 2013 · 9 yrs 2 mos Washington D.C. Metro Area Responsible for supervising Global Government affairs, federal, state, and international. During my tenure also communications (internal and external) and philanthropy and patient assistance programs. Also coverage, reimbursement, payor planning, and, in part, health economics.”

[David Beier LinkedIn profile, accessed [5/17/23](#)]

1989-1998: Beier was vice president of government affairs at Genentech.

[David Beier LinkedIn profile, accessed [5/17/23](#)]

Beier was a registered federal lobbyist for PhRMA, BIO, and several pharmaceutical companies.

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
AMGEN, INC.	AMGEN INC	2nd Quarter - Amendment	\$1,920,000.00	2010
AMGEN, INC.	AMGEN INC	1st Quarter - Report	\$3,070,000.00	2010
AMGEN, INC.	AMGEN INC	2nd Quarter - Report	\$1,920,000.00	2010
AMGEN, INC.	AMGEN INC	2nd Quarter - Report	\$3,400,000.00	2009
AMGEN, INC.	AMGEN INC	3rd Quarter - Report	\$3,000,000.00	2009
AMGEN, INC.	AMGEN INC	4th Quarter - Report	\$3,290,000.00	2009
AMGEN, INC.	AMGEN INC	1st Quarter - Report	\$2,520,000.00	2008
AMGEN, INC.	AMGEN INC	2nd Quarter - Report	\$2,850,000.00	2008
AMGEN, INC.	AMGEN INC	Mid-Year Report	\$9,080,000.00	2007
AMGEN, INC.	AMGEN INC	Year-End Report	\$7,180,000.00	2007
AMGEN, INC.	AMGEN INC	Mid-Year Report	\$4,600,000.00	2006
AMGEN, INC.	AMGEN INC	Year-End Report	\$5,620,000.00	2006
AMGEN, INC.	AMGEN INC	Mid-Year Report	\$2,400,000.00	2005
AMGEN, INC.	AMGEN INC	Year-End Report	\$3,320,000.00	2005
AMGEN, INC.	AMGEN INC	Mid-Year Report	\$2,120,000.00	2004
AMGEN, INC.	AMGEN INC	Year-End Report	\$2,840,000.00	2004
HOGAN LOVELLS US LLP	BIOTECHNOLOGY INDUSTRY ORGANIZATION	Mid-Year Report	\$400,000.00	2004
AMGEN, INC.	AMGEN INC	Mid-Year Report	\$2,120,000.00	2003
AMGEN, INC.	AMGEN INC	Year-End Report	\$2,840,000.00	2003
HOGAN LOVELLS US LLP	BIOTECHNOLOGY INDUSTRY ORGANIZATION	Mid-Year Report	\$300,000.00	2003
HOGAN LOVELLS US LLP	BIOTECHNOLOGY INDUSTRY ORGANIZATION	Year-End Report	\$380,000.00	2003
HOGAN LOVELLS US LLP	EMDEON CORP FORMERLY WEB MD CORP	Mid-Year Report	\$450,000.00	2003
HOGAN LOVELLS US LLP	GENENTECH	Mid-Year Report	\$40,000.00	2003
HOGAN LOVELLS US LLP	GENENTECH	Year-End Report	\$60,000.00	2003
HOGAN LOVELLS US LLP	GENERIC	Registration		2003
HOGAN LOVELLS US LLP	GENERIC	Year-End Report		2003
HOGAN LOVELLS US LLP	METABOLIFE INTERNATIONAL INC	Registration		2003
HOGAN LOVELLS US LLP	METABOLIFE INTERNATIONAL INC	Year-End Report	\$20,000.00	2003
HOGAN LOVELLS US LLP	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA (PHRMA)	Mid-Year Report	\$180,000.00	2003
HOGAN LOVELLS US LLP	SUNESIS PHARMACEUTICALS	Year-End Termination Amendment		2003
HOGAN LOVELLS US LLP	SUNESIS PHARMACEUTICALS	Year-End Termination Amendment		2003
HOGAN LOVELLS US LLP	SUNESIS PHARMACEUTICALS	Registration		2003
HOGAN LOVELLS US LLP	VIACALL	Year-End Report	\$20,000.00	2003

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
HOGAN LOVELLS US LLP	BRISTOL-MYERS SQUIBB CO INC	Year-End Report		2002
HOGAN LOVELLS US LLP	EMDEON CORP FORMERLY WEB MD CORP	Mid-Year Report	\$120,000.00	2002
HOGAN LOVELLS US LLP	GENENTECH	Year-End Report	\$60,000.00	2002
HOGAN LOVELLS US LLP	GENENTECH	Mid-Year Report	\$100,000.00	2002
HOGAN LOVELLS US LLP	GUARDIAN INDUSTRIES CORP	Year-End Report		2002
HOGAN LOVELLS US LLP	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA (PHRMA)	Mid-Year Report	\$200,000.00	2002
HOGAN LOVELLS US LLP	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA (PHRMA)	Year-End Report	\$260,000.00	2002
HOGAN LOVELLS US LLP	VIACALL	Year-End Report	\$20,000.00	2002
HOGAN LOVELLS US LLP	VIACALL	Registration		2002
HOGAN LOVELLS US LLP	VIACALL	Mid-Year Report	\$20,000.00	2002
HOGAN LOVELLS US LLP	BRISTOL-MYERS SQUIBB CO INC	Year-End Report	\$60,000.00	2001
HOGAN LOVELLS US LLP	EMDEON CORP FORMERLY WEB MD CORP	Registration		2001
HOGAN LOVELLS US LLP	GENENTECH	Year-End Report	\$40,000.00	2001
HOGAN LOVELLS US LLP	PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA (PHRMA)	Year-End Report	\$340,000.00	2001
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$520,000.00	1999

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

NPLB BOARD MEMBER GUNNAR ESIASON IS PART OF SEVERAL ORGANIZATIONS THAT RECEIVE SIGNIFICANT FUNDING FROM BIG PHARMA, AND HE'S WRITTEN PAPERS IN SUPPORT OF THE BIOPHARMACEUTICAL INDUSTRY

Gunnar Esiason is on the NPLB board of directors.

[NPLB, accessed [5/17/23](#)]

2014-Present: Esiason is executive vice president for strategy and advocacy at the Boomer Esiason Foundation.

[Gunnar Esiason LinkedIn profile, accessed [5/17/23](#)]

- **The Boomer Esiason Foundation's partners include pharmaceutical companies AbbVie, Chiesi, Vertex, and Viatris.**

Our Partners



[Boomer Esiason Foundation, accessed [5/17/23](#)]

Esiason was a keynote speaker/presenter at a Research!America National Research Forum.

[Gunnar Esiason LinkedIn profile, accessed [5/17/23](#)]

- **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;

PATIENTS FOR AFFORDABLE DRUGS

patientsforaffordabledrugs.org

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 [5/17/23](#)]

- **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 [5/17/23](#)]

2022-Present: Esiason is a “principal, thought leadership” at Florence Healthcare.
[Gunnar Esiason LinkedIn profile, accessed [5/17/23](#)]

- **Florence Healthcare’s website includes a testimonial from a Pfizer executive.**
“Florence’s platform is helping Pfizer to respond to the changing environment ... and further progress research with the capability to perform remote monitoring where approved by regulatory authorities and ethics committees.’ Rob Goodwin VP and Head of Operations in Global Product Development Pfizer” [Florence Healthcare, accessed [5/17/23](#)]

2020: Esiason wrote a white paper blaming Medicare for investors “hesitating to dip into the awesome innovative power of the biopharmaceutical industry.”

“The failure to address the growth of antibiotic resistance is due to the disincentivized antibiotic market, and the proof is in the numbers. Between 1980 and 2009, the FDA approved 61 new antibiotics, while only 15 have since made it through approval in the past decade.¹² The byproduct is investors hesitating to dip into the awesome innovative power of the biopharmaceutical industry.” [Gunnar Esiason, Pioneer Institute, [10/20/20](#)]

Esiason pointed to major pharmaceutical companies not developing new antibiotics as evidence that the “market must be fixed.”

“Market reform is the key to creating a sustainable antibiotic ecosystem. One need not look further than the large pharmaceutical companies abandoning antibiotic development.²⁵ The market must be fixed.” [Gunnar Esiason, Pioneer Institute, [10/20/20](#)]

Esiason wrote that antibiotic-resistant microbe “crisis” threatened the “robust Massachusetts pharmaceutical industry.”

“Antibiotics are among a special class of drugs that tie together much of the health industry and our biomedical progress. Locally, a mounting antibiotic crisis not only threatens livelihoods, but also the robust Massachusetts pharmaceutical industry. Antibiotics are used tangential to many of the innovative therapies developed in the Bay State, and their collective failure threatens the biomedical success that has been achieved in the antibiotic era.” [Gunnar Esiason, Pioneer Institute, [10/20/20](#)]

NPLB BOARD MEMBER HEIDI WAGNER IS A PHARMACEUTICAL INDUSTRY LOBBYISTS AND IS ON THE BOARD OF WAVE LIFE SCIENCES, AN RA CAPITAL INVESTMENT

Heidi Wagner is a board member at NPLB.
[NPLB, accessed [5/17/23](#)]

March 2023-Present: Wagner is senior vice president of global government affairs at ElevateBio.
[Heidi Wagner LinkedIn profile, accessed [5/17/23](#)]

- **ElevateBio services biopharmaceutical companies and develops its own “cellular, genetic, and regenerative medicines.”**
“In addition to enabling a broad breadth of biopharmaceutical companies in the development of their novel cell and gene therapies, ElevateBio is also building a highly innovative pipeline of cellular, genetic, and regenerative medicines. ElevateBio aims to be the dominant engine inside the world’s greatest scientific advancements harnessing human cells and genes to alter disease.” [ElevateBio, [5/16/23](#)]

2019-Present: Wagner is on the board of directors of Wave Life Sciences.
[Heidi Wagner LinkedIn profile, accessed [5/17/23](#)]

- **Wave Life Sciences has partnerships with drugmakers GSK and Takeda.**

“Our collaboration with GSK aims to advance transformative oligonucleotide therapeutics, including WVE-006 for alpha-1 antitrypsin deficiency (AATD). The collaboration combines GSK’s unique insights from human genetics, as well as its global development and commercial capabilities, with Wave’s PRISMTM platform and oligonucleotide expertise. [...]”

Our collaboration with Takeda Pharmaceuticals aims to accelerate the development of innovative, first-in-class therapies that address central nervous system (CNS) disorders. As part of this strategic partnership, Takeda has an option to a global 50:50 co-development and co-commercialization profit share for select CNS targets, including huntingtin (WVE-003 for Huntington’s disease) and C9orf72 (WVE-004 for amyotrophic lateral sclerosis and frontotemporal dementia).” [Wave Life Sciences, accessed [5/17/23](#)]

- **RA Capital was invested in Wave Life Sciences**

[RA Capital, accessed [5/23/23](#)]

2018-2020: Wagner was senior vice president of government affairs and policy at Global Blood Therapeutics.

[Heidi Wagner LinkedIn profile, accessed [5/17/23](#)]

- **2022: Global Blood Therapeutics, a biopharmaceutical company, was acquired by Pfizer.**

“Pfizer Inc. (NYSE: PFE) announced today the completion of its acquisition of Global Blood Therapeutics, Inc. (GBT), a biopharmaceutical company dedicated to the discovery, development and delivery of life-changing treatments that provide hope to underserved patient communities starting with sickle cell disease (SCD). The acquisition reinforces Pfizer’s commitment to SCD, building on a 30-year legacy in the rare hematology space.” [Pfizer, [10/5/22](#)]

2009-2018: Wagner was a vice president of global government affairs at Alexion Pharmaceuticals.

[Heidi Wagner LinkedIn profile, accessed [5/17/23](#)]

- **Wagner was senior vice president of global government affairs at pharmaceutical company Alexion.**

“Heidi is a policy expert with experience on Capitol Hill and multiple international boards. As SVP of Global Government Affairs for Alexion, she helped craft and pass the Biologics Price Competition and Innovation Act as part of the ACA.” [NPLB, accessed [5/17/23](#)]

1998-2009: Wagner was a director of government affairs at Genentech.

[Heidi Wagner LinkedIn profile, accessed [5/17/23](#)]

Wagner was a registered federal lobbyist for pharmaceutical companies Alexion, Genentech, and Global Blood Therapeutics.

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	1st Quarter - Report	\$154,180.00	2020
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	2nd Quarter - Report	\$131,000.00	2020
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	3rd Quarter - Report	\$130,000.00	2020
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	4th Quarter - Report	\$170,000.00	2020
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	1st Quarter - Report	\$143,280.00	2019
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	2nd Quarter - Report	\$139,818.00	2019
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	3rd Quarter - Report	\$137,500.00	2019
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	4th Quarter - Report	\$154,100.00	2019
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$361,497.00	2018
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	3rd Quarter - Amendment	\$27,500.00	2018
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	Registration		2018
GLOBAL BLOOD THERAPEUTICS	GLOBAL BLOOD THERAPEUTICS	4th Quarter - Report	\$103,000.00	2018
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$343,697.88	2017
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$275,000.00	2017
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$299,245.00	2017
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$308,894.00	2017
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$331,555.00	2016
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$306,100.00	2016
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$315,300.00	2016
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$300,000.00	2016
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$300,000.00	2015

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$300,000.00	2015
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$300,000.00	2015
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$300,000.00	2015
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$250,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Amendment	\$285,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$285,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$285,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$285,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$285,000.00	2014
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$225,000.00	2013
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$225,000.00	2013
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$275,000.00	2013
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$275,000.00	2013
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$105,000.00	2012
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$350,000.00	2012
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$350,000.00	2012
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$360,000.00	2012
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$105,000.00	2011
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$105,000.00	2011
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$105,000.00	2011
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$105,000.00	2011
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	1st Quarter - Report	\$80,000.00	2010
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$150,000.00	2010
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	2nd Quarter - Report	\$100,000.00	2010
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	3rd Quarter - Report	\$100,000.00	2010
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$100,000.00	2010
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	Registration		2009
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	Registration		2009
ALEXION PHARMACEUTICALS, INC.	ALEXION PHARMACEUTICALS, INC.	4th Quarter - Report	\$80,000.00	2009
GENENTECH, INC	GENENTECH INC	2nd Quarter - Report	\$770,000.00	2009
GENENTECH, INC	GENENTECH INC	3rd Quarter - Report	\$630,000.00	2009
GENENTECH, INC	GENENTECH INC	1st Quarter - Report	\$700,000.00	2009
GENENTECH, INC	GENENTECH INC	1st Quarter - Report	\$591,000.00	2008
GENENTECH, INC	GENENTECH INC	2nd Quarter - Report	\$562,000.00	2008
GENENTECH, INC	GENENTECH INC	3rd Quarter - Report	\$570,000.00	2008
GENENTECH, INC	GENENTECH INC	4th Quarter - Report	\$775,000.00	2008
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$941,000.00	2007
GENENTECH, INC	GENENTECH INC	Year-End Report	\$940,000.00	2007
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$780,000.00	2006
GENENTECH, INC	GENENTECH INC	Year-End Report	\$730,000.00	2006
GENENTECH, INC	GENENTECH INC	Year-End Report	\$730,000.00	2006
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$992,000.00	2005
GENENTECH, INC	GENENTECH INC	Year-End Report	\$820,000.00	2005
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$740,000.00	2004
GENENTECH, INC	GENENTECH INC	Year-End Report	\$1,000,000.00	2004
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$540,000.00	2003
GENENTECH, INC	GENENTECH INC	Year-End Report	\$640,000.00	2003
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$680,000.00	2002
GENENTECH, INC	GENENTECH INC	Year-End Report	\$780,000.00	2002
GENENTECH, INC	GENENTECH INC	Year-End Report	\$700,000.00	2001
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$580,000.00	2000
GENENTECH, INC	GENENTECH INC	Year-End Report	\$660,000.00	2000
PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	Registration - Amendment		2000
PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	Mid-Year Report		2000
GENENTECH, INC	GENENTECH INC	Mid-Year Report	\$520,000.00	1999
GENENTECH, INC	GENENTECH INC	Year-End Report	\$520,000.00	1999
PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	Mid-Year Report	\$20,000.00	1999
PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	PHARMACEUTICAL CARE MANAGEMENT ASSOCIATION	Year-End Report		1999

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

NPLB BOARD MEMBER JESSICA SAGERS SHAPES “INTERNAL AND EXTERNAL NARRATIVES” AT RA CAPITAL, WHERE SHE PREVIOUSLY MANAGED INVESTMENTS IN DRUG COMPANIES, AND IS ON BIO’S INVESTOR ADVISORY COMMITTEE

Jessica Sagers is on the steering committee at NPLB.

[NPLB, accessed [5/18/23](#)]

Sagers is head of engagement at RA Capital Management.

[NPLB, accessed [5/18/23](#)]

- **“As Head of Engagement, Jessica Sagers directs a concerted effort at RA Capital Management to analyze, design, and shape internal and external narratives.”**

[RA Capital RAoport, [5/13/20](#)]

2019-2020: As an associate at RA Capital, Sagers managed investments in drug companies.

“RA Capital Management (“RA Capital”) is a multi-stage investment manager dedicated to evidence-based investing in public and private healthcare and life science companies that are developing drugs, medical devices, and diagnostics.” [Jessica Sagers LinkedIn profile, accessed [5/18/23](#)]

2021-Present: Sagers is an investor advisory committee member at BIO.

“Investor Advisory Committee Member Biotechnology Innovation Organization Jan 2021 - Present · 2 yrs 5 mos The BIO Investor Advisory Committee is a network of biotech investment leaders working to advise BIO’s management and Board of Directors on policy and other initiatives to enhance biotech investment, business development, partnering, and diversity, equity, and inclusion. The Committee also assists in the economic evaluation of policy ideas that impact the incentives to invest in innovative biotechnology products and supports educational efforts regarding the biotech investment ecosystem.” [Jessica Sagers LinkedIn profile, accessed [5/18/23](#)]

NPLB BOARD MEMBER JIM GREENWOOD IS THE FORMER PRESIDENT AND CEO OF BIO, ADVISES RA CAPITAL, AND IS A BIG PHARMA LOBBYIST AT DLA PIPER

Jim Greenwood is a member of the NPLB steering committee.

[NPLB, accessed [5/18/23](#)]

Greenwood is the former president and CEO of BIO.

“From 2005 through 2020 Greenwood served as the President and CEO of the Biotechnology Innovation Organization and grew it into a world-class trade association for more than 1,000 biopharmaceutical companies.” [NPLB, accessed [5/18/23](#)]

- **2005-2022: Greenwood was president and CEO of BIO.**

[Jim Greenwood LinkedIn profile, accessed [5/18/23](#)]

- **Greenwood is the chairman of the board of the BIO Ventures for Global Health nonprofit.**

“James C. Greenwood Chairman, BVGH Board of Directors; Past President & CEO, Biotechnology Innovation Organization; DLA Piper” [BIO Ventures for Global Health, accessed [5/18/23](#)]

- **BVGH connects biotechnology and pharmaceutical companies with governments and nonprofits around the world.**

“About BVGH BIO Ventures for Global Health (BVGH) is a nonprofit organization based in Seattle, Washington working at the crossroads of the private and public sectors to advance research and improve health. BVGH connects people, resources, and ideas across biotechnology and pharmaceutical companies, governments, and nonprofits to solve global health issues. BVGH Programs BVGH strategically develops and manages programs across the for-profit and non-profit sectors to accelerate research and development (R&D) for poverty-related diseases; build biomedical R&D capacity in low- and middle-income countries (LMICs); and improve cancer patient care in Africa.” [BIO Ventures for Global Health, accessed [5/18/23](#)]

Greenwood chairs the Life Sciences Health, Policy and Regulatory Group at the DLA Piper law firm.

“From 2005 through 2020 Greenwood served as the President and CEO of the Biotechnology Innovation Organization and grew it into a world-class trade association for more than 1,000 biopharmaceutical companies. He currently chairs the Life

Sciences Health, Policy and Regulatory Group at the DLA Piper law firm and serves as an advisor to RA Capital.” [NPLB, accessed [5/18/23](#)]

Greenwood is an advisor to RA Capital.

“From 2005 through 2020 Greenwood served as the President and CEO of the Biotechnology Innovation Organization and grew it into a world-class trade association for more than 1,000 biopharmaceutical companies. He currently chairs the Life Sciences Health, Policy and Regulatory Group at the DLA Piper law firm and serves as an advisor to RA Capital.” [NPLB, accessed [5/18/23](#)]

2020-Present: Greenwood is a senior policy advisor at DLA Piper.

[Jim Greenwood LinkedIn profile, accessed [5/18/23](#)]

- **Greenwood is a registered lobbyist at DLA Piper for pharmaceutical and other health care companies.**

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	1st Quarter - Report	\$30,000.00	2023
DLA PIPER LLP (US)	BIOHAVEN PHARMACEUTICALS, INC.	1st Quarter - Report	\$50,000.00	2023
DLA PIPER LLP (US)	ILLUMINA, INC.	1st Quarter - Report	\$270,000.00	2023
DLA PIPER LLP (US)	IMMUNOCORE, LLC	1st Quarter - Report	\$50,000.00	2023
DLA PIPER LLP (US)	INTRA-CELLULAR THERAPIES, INC.	1st Quarter - Report	\$40,000.00	2023
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	1st Quarter - Report	\$60,000.00	2023
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	1st Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	2nd Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	3rd Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	4th Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	BIOHAVEN PHARMACEUTICALS, INC.	Registration		2022
DLA PIPER LLP (US)	BIOHAVEN PHARMACEUTICALS, INC.	4th Quarter - Report	\$20,000.00	2022
DLA PIPER LLP (US)	GENENTECH USA, INC.	1st Quarter - Report	\$50,000.00	2022
DLA PIPER LLP (US)	GENENTECH USA, INC.	3rd Quarter - Report	\$50,000.00	2022
DLA PIPER LLP (US)	GENENTECH USA, INC.	2nd Quarter - Report	\$50,000.00	2022
DLA PIPER LLP (US)	GENENTECH USA, INC.	4th Quarter - Termination	\$50,000.00	2022
DLA PIPER LLP (US)	ILLUMINA, INC.	3rd Quarter - Report	\$730,000.00	2022
DLA PIPER LLP (US)	ILLUMINA, INC.	4th Quarter - Report	\$340,000.00	2022
DLA PIPER LLP (US)	ILLUMINA, INC.	2nd Quarter - Report	\$890,000.00	2022
DLA PIPER LLP (US)	ILLUMINA, INC.	1st Quarter - Report	\$1,180,000.00	2022
DLA PIPER LLP (US)	IMMUNOCORE, LLC	Registration		2022
DLA PIPER LLP (US)	IMMUNOCORE, LLC	4th Quarter - Report	\$50,000.00	2022
DLA PIPER LLP (US)	INTRA-CELLULAR THERAPIES, INC.	Registration		2022
DLA PIPER LLP (US)	INTRA-CELLULAR THERAPIES, INC.	4th Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	INTRA-CELLULAR THERAPIES, INC.	3rd Quarter - Report	\$10,000.00	2022
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	2nd Quarter - Report	\$60,000.00	2022
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	3rd Quarter - Report	\$60,000.00	2022
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	1st Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	Registration		2022
DLA PIPER LLP (US)	IQVIA HOLDINGS, INC.	4th Quarter - Report	\$60,000.00	2022
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	4th Quarter - Termination		2022
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	1st Quarter - Report	\$40,000.00	2022
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	2nd Quarter - Report	\$60,000.00	2022
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	3rd Quarter - Report	\$30,000.00	2022
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	2nd Quarter - Report	\$30,000.00	2021
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	3rd Quarter - Report	\$30,000.00	2021
DLA PIPER LLP (US)	AMERIHEALTH CARITAS	4th Quarter - Report	\$30,000.00	2021
DLA PIPER LLP (US)	FLIPT, LLC	2nd Quarter - Report		2021
DLA PIPER LLP (US)	FLIPT, LLC	3rd Quarter - Report	\$40,000.00	2021
DLA PIPER LLP (US)	FLIPT, LLC	4th Quarter - Termination (No Activity)		2021
DLA PIPER LLP (US)	FLIPT, LLC	Registration		2021
DLA PIPER LLP (US)	GENENTECH USA, INC.	3rd Quarter - Report	\$20,000.00	2021
DLA PIPER LLP (US)	GENENTECH USA, INC.	4th Quarter - Report	\$50,000.00	2021
DLA PIPER LLP (US)	GENENTECH USA, INC.	Registration		2021
DLA PIPER LLP (US)	GLOBAL PLASMA SOLUTIONS INC.	2nd Quarter - Report	\$70,000.00	2021
DLA PIPER LLP (US)	GLOBAL PLASMA SOLUTIONS INC.	3rd Quarter - Report	\$50,000.00	2021

Registrant Name	Client Name	Report Type	Amount Reported	Filing Year
DLA PIPER LLP (US)	GLOBAL PLASMA SOLUTIONS INC.	Registration		2021
DLA PIPER LLP (US)	ILLUMINA, INC.	3rd Quarter - Report	\$920,000.00	2021
DLA PIPER LLP (US)	ILLUMINA, INC.	Registration		2021
DLA PIPER LLP (US)	ILLUMINA, INC.	2nd Quarter - Report	\$40,000.00	2021
DLA PIPER LLP (US)	ILLUMINA, INC.	4th Quarter - Report	\$820,000.00	2021
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	4th Quarter - Report	\$20,000.00	2021
DLA PIPER LLP (US)	SAB BIOTHERAPEUTICS, INC.	Registration		2021

[U.S. Senate Lobbying Disclosure Database, accessed [5/18/23](#)]

NPLB BOARD MEMBER PATRICIA FRASER WORKS AT NIMBUS THERAPEUTICS, AN RA CAPITAL INVESTMENT, AND PREVIOUSLY WORKED AT SANOFI GENZYME AND EMD SERONO

Patricia Fraser is on the NPLB board of directors.

[NPLB, accessed [5/18/23](#)]

March 2023-Present: Fraser is Head of Pharmacovigilance at Nimbus Therapeutics.

[Patricia Fraser LinkedIn profile, accessed [5/18/23](#)]

- Nimbus claims to be “successfully drugging the undruggable.”**
 “Over more than a decade of pioneering technologically-driven methods of drug discovery, Nimbus has used cutting-edge tools to make therapeutic progress against the most challenging of targets – successfully drugging the undruggable, mapping the uncrystallizable and advancing multiple innovative therapeutics to the clinic.” [Nimbus Therapeutics, accessed [5/18/23](#)]
- RA Capital is invested in Nimbus Therapeutics.**



[Nimbus Therapeutics, accessed [5/18/23](#)]

2020-2023: Fraser was executive director of drug safety at Ionis Pharmaceuticals.

[Patricia Fraser LinkedIn profile, accessed [5/18/23](#)]

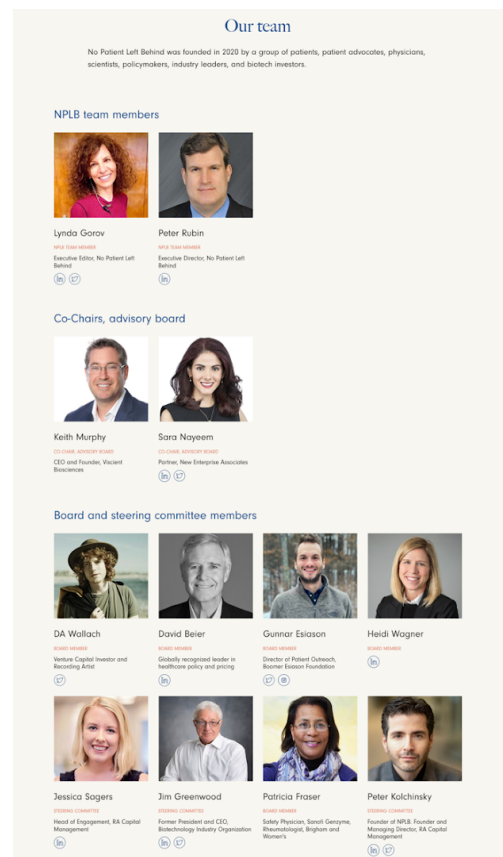
2017-2020: Fraser was global safety officer at Sanofi Genzyme.

[Patricia Fraser LinkedIn profile, accessed [5/18/23](#)]

2012-2017: Fresher was Senior Medical Director, Therapeutic Area Head for Fertility and Immunology Global Drug Safety at EMD Serono.

[Patricia Fraser LinkedIn profile, accessed [5/18/23](#)]

AN ARCHIVED VERSION OF THE NPLB WEBSITE SUGGESTS THE STRUCTURE OF THE ORGANIZATION, CONSISTING OF “TEAM MEMBERS,” “CO-CHAIRS, ADVISORY BOARD,” AND A “BOARD AND STEERING COMMITTEE”



2021: NPLB’s “team members” were Lynda Gorov, NPLB’s executive editor” and Peter Rubin, NPLB’s executive director.

[NPLB, via Internet Archive, captured 6/16/21, accessed [5/22/23](#)]

2021: NPLB’s co-chairs of the advisory board were Keith Murphy and Sara Nayeem.

[NPLB, via Internet Archive, captured 6/16/21, accessed [5/22/23](#)]

2021: NPLB’s “board and steering committee members” were DA Wallach, David Beier, Gunnar Esiason, Heidi Wagner, Jessica Sagers, Jim Greenwood, Patricia Fraser, and Peter Kolchinsky.

[NPLB, via Internet Archive, captured 6/16/21, accessed [5/22/23](#)]

- **2021: Greenwood was identified on the NPLB website as the “former President and CEO, Biotechnology Industry Organization.**

“Jim Greenwood STEERING COMMITTEE Former President and CEO, Biotechnology Industry Organization” [NPLB, via Internet Archive, captured 6/16/21, accessed [5/22/23](#)]

- **Fraser was identified as a “safety physician, Sanofi Genzyme.”**

“Patricia Fraser BOARD MEMBER Safety Physician, Sanofi Genzyme, Rheumatologist, Brigham and Women’s” [NPLB, via Internet Archive, captured 6/16/21, accessed [5/22/23](#)]

“LIFE SCIENCE BUILDERS”—NPLB’S MEMBERSHIP LIST

Kolchinsky and NPLB co-chair Keith Murphy have described NPLB as a group of “grass roots,” “life science builders,” “supporters from the drug industry”

Kolchinsky said that NPLB as “attracted hundreds of supporters from the drug industry.”

“We’ve attracted hundreds of supporters from the drug industry who are signing up, basically saying, ‘Yes, I agree. Our medicines should go generic without undue delay.’” [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

Kolchinsky referred to NPLB as “really grassroots.”

“We have some time to continue to build awareness in Congress and with the general public of what kinds of reforms really would serve the public interest in the long run. It’s really grassroots. We’re trying to teach through simple animations, trying to get to people, even at a high school level, so that they get what’s happening to them at the pharmacy. So, I would urge everybody to check out no patient left behind. If you’re passionate about this cause, please support the organization.” [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

June 2021: Keith Murphy described NPLB as a “group of Life Science Builders,” supporting biopharma innovation, elimination of out-of-pocket costs, and moving all drugs go generic “without undue delay.”

“I want to stress that I agree fully that the current barriers to patient access to medications are a national problem, and that industry needs to be proactive in working towards solutions. To that end I have begun making strenuous efforts as board co-chair of No Patient Left Behind (NPLB), a national non-profit founded by Peter Kolchinsky of RA Capital. NPLB is dedicated to making medicines available for everyone in America, by making them affordable for all and by continuing to bring them into existence by retaining strong incentives for innovation. We see ourselves as a group of ‘Life Science Builders,’ supportive of efforts to preserve biopharma innovation, eliminate patient out-of-pocket costs, and make sure all drugs go generics without undue delay. We also are opposed to the practices in our industry which extract ‘rent payments’ without providing additional innovation or true value. I am passionate about a future in which novel therapies continue to come to market in record numbers, and then are available to all as quickly as possible.” [Targeted News Service, 6/30/21]

- **Murphy said that NPLB wants to make drugs “available for everyone in America...by continuing to bring them into existence by retaining strong incentives for innovation.”**

“I want to stress that I agree fully that the current barriers to patient access to medications are a national problem, and that industry needs to be proactive in working towards solutions. To that end I have begun making strenuous efforts as board co-chair of No Patient Left Behind (NPLB), a national non-profit founded by Peter Kolchinsky of RA Capital. NPLB is dedicated to making medicines available for everyone in America, by making them affordable for all and by continuing to bring them into existence by retaining strong incentives for innovation. We see ourselves as a group of ‘Life Science

Builders, supportive of efforts to preserve biopharma innovation, eliminate patient out-of-pocket costs, and make sure all drugs go generics without undue delay. We also are opposed to the practices in our industry which extract 'rent payments' without providing additional innovation or true value. I am passionate about a future in which novel therapies continue to come to market in record numbers, and then are available to all as quickly as possible." [Targeted News Service, 6/30/21]

NPLB's website lists nearly 150 "Life Science Builders" made up of "innovators," "biotech investors," and "industry advisors," each of whom are tied to the pharmaceutical industry

[SEE APPENDIX 1: Life Science Builder List, below](#)

NPLB's "Life Science Builder" Jonathan Kfoury criticized the Inflation Reduction Act as a drag in biopharma investment and suggested that companies should raise the prices of new drugs

KFOURY WROTE THAT DRUG MAKERS MAY "MITIGATE" LOSSES ATTRIBUTED TO THE INFLATION REDUCTION ACT BY RAISING PRICES ON NEW DRUG

Jonathan Kfoury wrote that drug manufactures "may try to mitigate" revenue loss due to the Inflation Reduction Act by "setting higher list prices than they otherwise would have for newly launched drugs."

"It is also worth noting that there are several additional potential consequences of these provisions. First, manufacturers may try to mitigate their revenue loss by setting higher list prices than they otherwise would have for newly launched drugs." [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

Kfoury advised emerging biopharma companies to "invest earlier than before in a pricing and market access function and strategy."

"The priorities are slightly different for emerging biopharma companies. They too will need to assess revenue impacts, reevaluate their portfolio strategy and investments, and emphasize comparative data in their clinical programs. But beyond that, they will also need to reevaluate their partnership strategy, invest earlier than before in a pricing and market access function and strategy, and reevaluate their strategy for capital raising in the face of some investment headwinds." [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

KFOURY WARNED THAT THE INFLATION REDUCTION ACT MIGHT DISSUADE GENERIC DRUG MAKERS FROM ENTERING THE MARKET BECAUSE OF PRICE CONTROLS

Kfoury wrote that Inflation Reduction Act provisions may "disincentivize generic manufacturers" from entering the market because Medicare-negotiated prices might not be sufficiently attractive for them.

"Additionally, these provisions may disincentivize generics manufacturers from entering the market, given their pricing advantage relative to Medicare-negotiated branded drugs may not be sufficiently attractive for them to generate significant volume and revenue. As of 2018, unbranded generics represent 84% of prescription drug volume in the U.S. but only 35% in a group of 32 other OECD (Organization for Economic Cooperation and Development) countries." [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

KFOURY LINKED TO AN NPLB LETTER TO CONGRESS AS EVIDENCE THAT THE "HEALTH CARE INVESTING COMMUNITY" WOULD REDUCE INVESTMENTS IN NEW DRUGS AS A RESULT OF THE INFLATION REDUCTION ACT

Kfoury wrote that "many from the health care investing community publicly stated" that even before the Inflation Reduction Act was passed "it made them 'extremely cautious and hesitant to fund any new small molecule projects for disease of aging'" and linked to a NPLB document.

"The types of programs that would likely be the most impacted are concentrated in three areas: small molecules, LCM programs and diseases disproportionately affecting the elderly. The effects will be felt not only by large and mid-cap biopharmas, but also by emerging (often pre-revenue) biopharma companies. In fact, many from the healthcare investing community publicly stated in July that even before the act was passed, it made them 'extremely cautious and hesitant to fund any new small molecule projects for diseases of aging.'" [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

- **Kfoury linked to a of “healthcare investors” hosts by No Patient Left Behind and signed by Peter Kolchinsky and several other NPLB affiliates.**

[Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

- **The July 2022 letter refers to the signatories as “healthcare investors whose funds manage \$86B of capital.”**

“Dear Speaker Pelosi, Majority Leader Schumer, Leader McCarthy, Leader McConnell, America's Lawmakers, Patient Advocates, and Fellow Americans: We are healthcare investors whose funds manage \$86B of capital. For many years we have invested heavily in innovative new medicines to treat and cure diseases. We are now deeply concerned about the unintended consequences of the provision in the proposed drug pricing bill that makes small molecule drugs eligible for price negotiation just 9 years after FDA approval (as compared to 13 years for biologics). This would inevitably disincentivize investment in and steer funds away from small molecule drugs for diseases of aging, even though the costs and risks associated with their development are the same.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

Kfoury wrote that it was “difficult to estimate the extent of the Inflation Reduction Act’s impact at an industry level.”

“There are several specific steps manufacturers should take to best position themselves for sustained growth in the era of the Inflation Reduction Act While it is difficult to estimate the extent of the Inflation Reduction Act’s impact at an industry level, there are several specific steps that pharmaceutical manufacturers should take today to better prepare themselves to navigate the new normal that it has established.” [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

KFOURY ADVISED DRUG COMPANIES TO INTEGRATE “PRICING/MARKET ACCESS INSIGHT” INTO THEIR CLINICAL TRIAL PROTOCOLS TO BUILD THE JUSTIFICATIONS FOR THEIR PRICING DECISIONS

Kfoury advised pharmaceutical companies to design clinical trials to integrate “pricing/market access insight...to ensure clinical trials will both generate the data required for approval and evaluate the metrics that will support future pricing potential.”

“Evolve the organization to prepare for future negotiations: The Inflation Reduction Act will alter the way in which manufacturers can best position themselves from a pricing and market access standpoint. While the concept of value-based pricing has been gaining traction over the past several years, comparative data and real-world cost-effectiveness evidence will become more important than ever as manufacturers seek to defend their pricing decisions both in Medicare negotiations and across payer channels. Success in future negotiations will be dependent on clinical data being developed today and in the near future. Manufacturers are advised to take a cross-functional approach to clinical trial design, integrating pricing/market access insight into clinical planning to ensure clinical trials will both generate the data required for approval and evaluate the value metrics that will support future pricing potential.” [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

NEVERTHELESS, KFOURY WROTE THAT THE INFLATION REDUCTION ACT MADE PROGRESS “IN REDUCING COST AND INCREASING ACCESS TO INNOVATIVE MEDICINES,” EVEN IF IT CREATED UNCERTAINTY FOR THE PHARMACEUTICAL INDUSTRY

Kfoury wrote that the Inflation Reduction Act would make progress in “reducing costs and increasing access to innovative medicines,” while introducing uncertainty for biopharmaceutical manufacturers.

“Despite the progress the Inflation Reduction Act makes in reducing cost and increasing access to innovative medicines, it also introduces a considerable degree of uncertainty for biopharmaceutical manufacturers. Amid this uncertainty, there are clear steps that manufacturers should take to plan and move forward in this new reality they are facing.” [Jonathan Kfoury, Alex Guth, Jenny Mackey & Hayley Tessler, LEK, [9/9/22](#)]

“Life Science Builder” Andy Acker broke ranks with his NPLB colleagues, writing that the pharmaceutical industry could manage the Inflation Reduction Act’s reforms

ACKER EXPRESSED OPTIMISM THAT THE PHARMACEUTICAL INDUSTRY COULD “MANAGE BOTH LOST OF EXCLUSIVITY AND REGULATORY CHANGES” DUE TO THE IRA

Andy Acker, a NPLB “Life Science Builder,” wrote that he was optimistic that the pharmaceutical industry “will be able manage both loss of exclusivity and regulatory changes” resulting from the Inflation Reduction Act.

“Plugging revenue holes is increasingly becoming a necessity for large-cap pharmaceutical companies. Over the next five years, more than \$160 billion in drug sales are expected to be lost to patent expirations and competition from generics and biosimilars. 5 At the same time, the Inflation Reduction Act, passed in 2022, will allow the U.S. federal government to negotiate pricing for select drugs, starting in 2026. While the impact of these and other provisions remain uncertain, some drugmakers have already warned about negative impacts to certain research initiatives and/or sales. We are optimistic that the industry will be able manage both loss of exclusivity and regulatory changes (global prescription drug sales are projected to reach \$1.6 trillion by 2028, up 40% from 2022⁶). But for many large pharmaceutical companies, maintaining growth will require increased business development activity, including mergers and acquisitions. The upcoming challenges underscore the need to identify the companies most at risk – and those that could stand to benefit. As we have noted over the past year, large-cap pharmaceutical companies have an estimated \$500 billion in available cash to replenish product pipelines.” [Andy Acker, Janus Henderson, [4/13/23](#)]

ACKER WROTE THAT THE IRA’S CAPS ON OUT-OF-POCKET EXPENSES SHOULD IMPROVE “HEALTH OUTCOMES AND POTENTIALLY DRIVE HIGHER SALES VOLUMES FOR BIOPHARMA”

Acker wrote that the Inflation Reduction Act’s capping of out-of-pocket expenses “should...improv[e] health outcomes and potentially driving higher sales volumes for biopharma.”

“Overall, we believe the new legislation will help improve patient affordability, which we’ve long believed should be the linchpin of any reform. In 2022, the out-of-pocket spending threshold for Medicare Part D is \$7,050, after which ‘catastrophic coverage’ kicks in and patients pay 5% of all Part D drug costs, with no upper limit. While the initial \$7,050 cost burden is shared among patients, Medicare and insurance plans, the Kaiser Family Foundation estimates that more than 1.4 million Part D enrollees incurred annual out-of-pocket expenses of at least \$2,000 in 2020.¹ As such, capping out-of-pocket expenses should reduce costs for these seniors and potentially lead to better drug adherence among patients – improving health outcomes and potentially driving higher sales volumes for biopharma.” [Andy Acker, Janus Henderson, [8/18/22](#)]

ACCORDING TO ACKER, THE “STING” FROM THE IRA WOULD BE MANAGEABLE FOR THE BIOPHARMA INDUSTRY, COSTING LESS THAN 2% OF INDUSTRY SALES, WHICH WAS “LARGELY ALREADY REFLECTED IN SHARE PRICES”

Acker wrote that the “sting” felt by the biopharma industry from the Inflation Reduction Act “will be a manageable one.”

“Undoubtedly, the biopharma industry will feel a sting from drug pricing changes, but we believe it will be a manageable one. For example, the Congressional Budget Office (CBO) estimates that limiting drug price increases in Medicare to the rate of inflation will cost the industry an estimated \$25 billion over the next decade, or less than 0.25% of global pharmaceutical revenues over that time.² Furthermore, the provision could eliminate the ‘bad actors’ that had historically exacted large annual price hikes, helping to improve the industry’s reputation.” [Andy Acker, Janus Henderson, [8/18/22](#)]

Acker wrote that the Inflation Reduction Act’s drug pricing reform would only cost the biopharma industry less than \$200 billion over 10 years, or “under 2% of sales.”

“In the end, drug pricing reform is estimated to cost the global biopharma industry less than \$200 billion in total revenue over 10 years (under 2% of sales). While the amount is not immaterial, we believe it is manageable and largely already reflected in share prices, which have traded with the overhang of drug pricing legislation for more than six years.” [Andy Acker, Janus Henderson, [8/18/22](#)]

Acker said that he believed that the revenue loss to biopharma because of the Inflation Reduction Act was “manageable and largely already reflected in share prices.”

“In the end, drug pricing reform is estimated to cost the global biopharma industry less than \$200 billion in total revenue over 10 years (under 2% of sales). While the amount is not immaterial, we believe it is manageable and largely already reflected in share prices, which have traded with the overhang of drug pricing legislation for more than six years.” [Andy Acker, Janus Henderson, [8/18/22](#)]

- **Acker wrote that the Inflation Reduction Act “legislation was largely what the market expected.”**

“But we also believe the legislation was largely what the market expected, and removes an overhang of uncertainty for the sector. And in the end, improved affordability should be a win for both patients and investors.” [Andy Acker, Janus Henderson, [8/18/22](#)]

ACKER WROTE THAT BECAUSE THE IRA WAS LARGELY WHAT THE MARKET EXPECTED, IT WOULD ACTUALLY REDUCE UNCERTAINTY, CREATING A “WIN FOR BOTH PATIENTS AND INVESTORS” IN IMPROVED AFFORDABILITY

Acker wrote, “improved affordability should be a win for both patients and investors.”

“But we also believe the legislation was largely what the market expected, and removes an overhang of uncertainty for the sector. And in the end, improved affordability should be a win for both patients and investors.” [Andy Acker, Janus Henderson, [8/18/22](#)]

NPLB Life Science Builder Tim Shannon said that the price of pharmaceuticals in the U.S. subsidizes medicine in the rest of the world, which is the cost of leadership

Tim Shannon said that the price of pharmaceuticals in the U.S. subsidizes the rest of the world’s medicine, because that’s the cost of leadership in science and medicine.

“If you look at the profitability of drugs elsewhere in the world, if we didn't have the United States there wouldn't be an industry. There wouldn't be an investment in the industry. I think that's just a fact. It's a very difficult issue to deal with, so obviously our government cannot do anything to force other governments to price their drugs differently. That's nearly impossible. Companies tend to make them available, again because they feel some obligation to do so in countries where they can at least break even. Again, I would say I think there are more rational ways to reduce cost than what I would call blunt instruments, which are going to impact investment. Again, I'd like to find ways to reduce fuss in ways to actually encourage investment. I think that there are ways to conceive of that doing, but again, they're difficult to do. At the end of the day I think this is the way I look at it, the US subsidizes a lot of things in the world. The one I always think of is the defense of the free world. We are the world's military and we invest in the military in the US knowing that. We know that the world depends on us and we are willing to step up because it's in our best interest as a company. To me, that's the cost of leadership and leadership in the free world. I think there's the same cost to the leadership in science and medicine. There should be an expectation if we are going to be a leader, that we are going to foot more of the bill. As I would say, what's the alternative? If we don't do that, who is going to do it? I don't know the answer to that. I think it's likely to be no one, or it's going to be someone that actually we don't want being the leader in doing that. Again, I just don't think that's the world we want. I think the expectation that prices in the US should be the same as prices in the other world are just that they're just not consistent with US leadership in science and medicine.” [BioWorld Insider Podcast, partial transcript, [4/21/23](#)]

POLICY POSITIONS & ADVICE TO BIOPHARMA INDUSTRY

Around the time Kolchinsky created NPLB, he proposed a mission statement for the biotech industry, pledging investment in drug development to address needs not met by generic drugs

KOLCHINSKY PROPOSED: “WE WILL INVEST IN DRUG DEVELOPMENT TO ADDRESS THE HEALTHCARE NEEDS THAT ARE NOT YET MET BY THE KNOWN USES OF GENERIC DRUGS”

2020: Kolchinsky proposed a mission statement for the biotech industry: “We will invest in drug development to address the healthcare needs that are not yet met by the known uses of generic drugs.”

“So what should we as an industry commit to so that it shows that we are aligned with what society really wants and deserves from us? I propose this: We will invest in drug development to address healthcare needs that are not yet met by the known uses of generic drugs.” [RA Capital RAport, [3/29/20](#)]

- **Kolchinsky wrote that the proposed mission statement “applies to all of drug development for all our remaining unmet needs...it’s all in the public’s interest.”**

“And this statement applies to all of drug development for all our remaining unmet needs. Whether that means we will repurpose an old drug for a new use, reformulate an old drug to make it safer or more effective, invent an entirely new drug, or launch a similar competitor to another branded drug, it's all in the public's interest.” [RA Capital RAport, [3/29/20](#)]

LATER KOLCHINSKY SUMMARIZED HIS BELIEF THAT THE BIOPHARMACEUTICAL INDUSTRY SHOULD ESSENTIALLY SWAP PRICE CONTROLS FOR LOW OUT-OF-POCKET COSTS FOR PATIENTS

Kolchinsky summarized his book and position saying that the biopharma industry should agree to medicines going generic or price controls if they can't go generic, in exchange for "low out-of-pocket costs for patients."

"So, if our industry could support regulations that fix that market failure, when our medicines don't go generic without undue delay, if we accepted that yes, there should be some price controls essentially that knock those prices down to a level as if they'd gone generic, but it's in exchange, we also win low out-of-pocket costs for patients, I believe that we will have a far more harmonious healthcare system and innovation system in the US, with spillover to the rest of the world." [DLA Piper, At the Intersection of Science and Law, partial transcript, [3/21/22](#)]

Kolchinsky said that NPLB was created to "steadily chip away at the misunderstandings that the public, media and Congress have about the drug industry."

"These are the kinds of analogies that we've been putting on the No Patient Left Behind website in order to steadily chip away at the misunderstandings that the public, media and Congress have about the drug industry. We're funding research to try to give the world a more holistic view of the ecosystem. So, we've got this cool project that's underway where we integrate the entire industry into a single P&L statement in order to show what drives this industry. Why do we need to do that? Well, because when Congress decides that it's gonna judge our industry by the profitability of a few pharmas, that's basically like saying, 'Well, all artists are rich 'cause look Beyonce makes a lot of money.' It's like, no, for the most part, being an artist is not very lucrative. And you have to show people the totality of an ecosystem to show that there's a ton of money that's being invested in these smaller companies. And their hope in many cases is that they get chosen as a winner by those big pharmas. They get acquired for a large amount of money, and that money then flows back into the ecosystem and drives the growth of new small companies that represent the seeds of the next decades' medicines. So, we wanna show the world this holistic ecosystem model. We've attracted hundreds of supporters from the drug industry who are signing up, basically saying, 'Yes, I agree. Our medicines should go generic without undue delay.'" [DLA Piper, At the Intersection of Science and Law, partial transcript [3/21/22](#)]

Kolchinsky, NPLB, and RA Capital have advocated for a more holistic approach to calculating a drug's "value," advising pharma companies that it could lead to higher prices that would support further innovations

NPLB'S WEBSITE ADVOCATES FOR A GENERALIZED COST-EFFECTIVENESS ANALYSIS (GCEA) TO MEASURE THE VALUE OF A PHARMACEUTICAL PRODUCT AND POSSIBLY JUSTIFY HIGHER PRICES

NPLB claims that when a drug's "societal value" is considered, "medicines are worth a lot more than some give them credit for."

"Medicines do so much more than help the patient that's treated today. Considering a drug's societal value shows we may value them a lot more than we had thought. Turns out, when you do broader math, medicines are worth a lot more than some give them credit for. [NPLB, accessed [5/22/23](#)]

NPLB says that "cost-effectiveness analysis" underestimates the value of a medicine to society.

"Some health economists often overlook these elements of value. Right now, many health economists rely on outdated 'cost-effectiveness analysis' (CEA) to assess a drug's value and whether it's worth its price. By ignoring all the petals of the 'value flower' or only including a few, CEAs underestimate the value of a medicine to society. These over-simplified analyses argue that, at their price, some medicines weren't worth inventing. Insurers then use this bad math to deny coverage and charge high co-pays, even for life-saving treatments prescribed by a physician. When valuable new medicines are undervalued, we get fewer of them, and society ends up worse off." [NPLB, accessed [5/22/23](#)]

NPLB said that insurance companies use "bad math to deny coverage and charge high co-pays."

"Some health economists often overlook these elements of value. Right now, many health economists rely on outdated 'cost-effectiveness analysis' (CEA) to assess a drug's value and whether it's worth its price. By ignoring all the petals of the 'value flower' or only including a few, CEAs underestimate the value of a medicine to society. These over-simplified analyses argue that,

at their price, some medicines weren't worth inventing. Insurers then use this bad math to deny coverage and charge high co-pays, even for life-saving treatments prescribed by a physician. When valuable new medicines are undervalued, we get fewer of them, and society ends up worse off." [NPLB, accessed [5/22/23](#)]

NPLB advocates for assessing the value of a medication through “generalized cost-effectiveness analysis,” which they say will show drugs to be more “worth it.”

“Instead of doing conventional CEA, we can do better math, called generalized cost-effectiveness analysis (GCEA), which asks a broader set of questions that more fully capture the value of a medicine. For example: What will the savings be when this drug goes generic? Will this drug ease the burden on caregivers? Does this drug benefit healthy people by lowering everyone's risk? In calculating whether a medicine may be worth its price, generalized math includes at least some of the elements of value that conventional CEA ignores, often showing that medicines are much more “worth it” than simple CEA may suggest. And when the math show that a drug is well worth its price to society, we should ask insurance to make it properly affordable to the patients who need it--that's NPLB's mission.” [NPLB, accessed [5/22/23](#)]

MAY 2021: KOLCHINSKY AND NPLB EXECUTIVE DIRECTOR PETER RUBIN ADVISED DRUG COMPANIES TO RECALCULATE THE “VALUE” OF THEIR PRODUCTS, WHICH COULD JUSTIFY HIGHER PRICES

Kolchinsky and Rubin wrote “Drug prices are market-based and must remain so.”

“Drug prices are market-based and must remain so There is a false notion among lawmakers, the public, the media, and even Specialist health economists that there is no real drug pricing market (which some say therefore justifies price controls). They argue that because patients don't actually pay the real prices of drugs, drug companies therefore can just charge what they want.” [NPLB, “When simpler isn't better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

Kolchinsky and Rubin defended the profit margins of pharmaceutical companies, claiming they were only about 10 percent, when accounting for all pharmaceutical companies.

“Some observers express surprise that companies would dare to set prices based on society's willingness-to-pay, unconstrained by what critics see as the immorality of charging a lot even if the product cost little to make. Some call for more transparency into each drug's cost of development and justification for its price. And yet, for all of the drug industry's presumed pricing power, what's little appreciated is how low its collective profit margins are. When factoring in all branded drug revenues and all expenses to make and market those drugs as well as develop new ones, the industry's net profit margins are only about 10% (lower certainly than the impression that many have when they selectively focus on just the companies that are most successful at any one time).⁹ These modest profits are an indicator that the market is functioning and that buyers have sufficient leverage in their negotiations with sellers.” [NPLB, “When simpler isn't better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

Kolchinsky and Rubin claim that pharmaceutical companies might not be pricing their drugs to account for their full “value.”

Drug makers submit cost-effectiveness dossiers to various regulatory agencies around the world (for now, mostly outside the US). At the very least, these companies should be consulting Generalist health economists on how to do more comprehensive math. There's no sense in undervaluing one's own invention. And even if those agencies demand that cost-effectiveness be done narrowly using Special math, that approach's limitations (and the results of taking an alternative Generalist approach) could be included in the customary discussion section in which authors are supposed to call out their methodology's shortcomings. Asserting objections to Special math might not let the drug companies win higher reimbursement in other countries, but, akin to how a defense attorney objects in the moment to an inappropriate statement by prosecution, it could preserve the right to appeal the verdict in the future, at least with policy makers and even the court of public opinion, which has proven to be influential.” [NPLB, “When simpler isn't better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

Kolchinsky and Rubin advocate that pharmaceutical companies change the way they value new drugs to build a “history” that could help “shift many drugs that were deemed to be over-priced to being considered well-worth their price.”

“Policy makers in the US appear increasingly willing to indict the value of new medicines, declaring them over-priced, based on how much less Europe and other countries have been paying for them. And so citing a long history of consistent objections on the basis of Generalized math in the published literature and even in commentary in cost-effectiveness dossiers would be useful. We don't have a history of Generalized math yet. But if we get started now, in a few years when the drug pricing debate will still

be raging, we will. That means drug companies should be consulting Generalists, measuring things like disease risk-aversion and the reassurance value a drug offers, modeling population growth, estimating when their drugs will go generic, and estimating the price of those generics. These tasks are achievable and will demonstrate that new medicines have far more value than Specialists acknowledge. It will probably shift many drugs that were deemed to be over-priced to being considered well-worth their price.” [NPLB, “When simpler isn’t better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

- **Kolchinsky and Rubin say that drug company valuations of their drugs don’t need to be “precise to be compelling.”**
“These valuations needn’t be precise to be compelling. They just need to show that under a wide range of plausible assumptions, drugs offer consumer surpluses. In other words, that their value is at least as great and likely greater than their prices.” [NPLB, “When simpler isn’t better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

Kolchinsky and Rubin said that drug companies fail to value their own drugs properly, using the wrong math.

“The US is making four mistakes. 1) We’re not properly insuring patients, leaving what should be societal investment decisions to rest too heavily on patients. 2) Even when we consider the societal value of medicines, we’re hiring Specialist health economists instead of Generalists to value them; even drug companies make this mistake when evaluating their own drugs. 3) We’re increasingly letting over-simplified Special cost-effectiveness math dictate how little society (via insurance) will pay for medicines instead of listening to the marketplace of patients, physicians, insurance plans, and employers. 4) We’re failing to convince other countries, via diplomacy, to contribute to funding innovation by paying more for branded medicines that they too will eventually enjoy as inexpensive generics.” [NPLB, “When simpler isn’t better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

NOVEMBER 2021: KOLCHINSKY ADVISED BIOTECH EXECUTIVES TO CALCULATE THE VALUE OF THEIR PRODUCTS MORE BROADLY, SAYING THAT NPLB WAS GOING TO “PRIME THE PUMP” FOR DRUG COMPANIES IN THIS METHOD

2021: NPLB posted a video of Kolchinsky speaking at the Collaborating for Novel Solutions Summit, advising biotech executives how to calculate the value of their novel drugs more broadly.

The Failure to Communicate Value

NPLB Generalized Cost-Effectiveness Analysis | November 9, 2021

Bottom line for Biotech CEOs

DON'T LET ANYONE DO CEA ON YOUR DRUG BEFORE YOU'VE PUBLISHED A GCEA ON YOUR DRUG.

Ideally, that means:

- **Commission a GCEA about 9 months before starting a registration study.**
 - Use crude inputs for values you believe your drug will offer.
 - Do sensitivity analysis to identify variables that make the most difference and that are worth measuring carefully.
 - E.g. does drug reduce burden on caregivers? If yes, then measure that as best you can.
- **In parallel with registration study, measure all variables you care to include in GCEA.**
- **Upon completing registration study, update GCEA.**
 - In sensitivity analysis, demonstrate that ignoring many of your values (e.g. that drug goes generic) would underestimate value of the drug.
 - This is a vaccination against what ICER, NICE, Australia, Canada, and others might claim using CEA.
- **Publish GCEA before approval.** Don't need to input intended price. Just need to show magnitude of value below which price would still be cost-effective.
- **When finally launch drug and price, public will be surprised to see that your market price is below the upper limit on what GCEA showed as cost-effective.**

www.nopatientsleftbehind.org

that your companies are doing virtually nothing to counter the bad

COLLABORATING FOR NOVEL SOLUTIONS SUMMIT

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[YouTube, No Patient Left Behind, [12/14/21](#)]

Kolchinsky described NPLB as the “nonprofit advocacy version of the book that I wrote.”

“There’s a non-profit organization called No Patient Left Behind that is basically the non-profit advocacy version of the book that I wrote that’s trying to bring about you know restoration of the biotech social contract.” [YouTube, No Patient Left Behind, [12/14/21](#)]

Kolchinsky said that NPLB was commissioning a “GCEA model of Trikafta” to “prime the pump” for biotech companies.

“We’re commissioning—we’ve commissioned a GCEA model of Trikafta, and we’re going to be working on a series of these in order to prime the pump so that your companies can then contract with the Analysis Group or PrecisionHEOR and they will say, ‘oh yes we’ve done a GCEA. We did a bunch with No Patient Left Behind, we can do one for you. We can pull off a similar model. Your drug is similar to Trikafta in some ways, let’s pull that model off the shelf, adjust it’...” [YouTube, No Patient Left Behind, [12/14/21](#)]

- **Trikafta is a treatment for cystic fibrosis.**

[FDA, [10/21/19](#)]

2022: RUBIN ADVISED PHARMACEUTICAL COMPANIES TO REFRAME THE “SOCIETAL VALUE OF INNOVATION AND JUSTIFY A LIKELY MARKET PRICE”

2022: NPLB’s Peter Rubin participated in a webinar where he discussed how drugmakers could frame the “societal value of innovation and justify a likely market price.”

“Panelist Peter Rubin, Executive Director, No Patient Left Behind (NPLB) discussed how manufacturers can convey the value of their product to a broader audience prior to launch. Rubin provided an overview of the ‘ISPOR value flower’, which provides an enhanced societal view of a therapy’s cost-effectiveness, as compared to the ‘simple math’ budgetary view of innovation espoused by many health economists. Rubin suggested that a traditional cost-effectiveness analysis (CEA) often comes in less than market price because economists overlook many benefits that medications provide to society as a whole. Rubin encouraged manufacturers to highlight these ‘real world values,’ such as genericization and relieving caregiver burden, to better capture the societal value of innovation and justify a likely market price. Rubin advised manufacturers to design studies to support a generalized cost-effectiveness analysis (GCEA) and be prepared to ‘frame the debate’ in providing a broader rationale for innovative therapies in supporting patients and families.” [JD Supra, [7/1/22](#)]

Criticisms of federal legislation NPLB opposes price caps on drugs, claiming it would stifle innovation in a “moderately profitable” pharmaceutical industry

THE SAME DAY THAT KOLCHINSKY AND NPLB/RA CAPITAL’S DAVID BEIER WROTE OBJECTING TO PRICE CAPS IN AN RA CAPITAL PUBLICATION, NPLB POSTED A VIDEO MAKING THE SAME ARGUMENT

Kolchinsky and David Beier wrote that capping drug price increases at the rate of inflation would likely lead to drug companies increasing “prices at launch to account for any perceived future loss in revenue.”

“Limiting drug price increases to inflation would be a big political win for the administration, but is not likely to save money in the long run, as drug companies may simply increase prices at launch to account for any perceived future loss in revenue. Furthermore, net prices of drugs are already growing at rates below inflation. There would also be some kinds of drugs that may not be developed because of too much uncertainty about market size and therefore an inability to engage in price discovery post-launch. (Shifting the inflation cap so that it only kicks in five years after a drug’s launch would solve that problem.)” [RA Capital RAport, [8/20/21](#)]

- 8/20/21: NPLB posted a video on YouTube suggesting that biopharma investors have an “~15% annual return on investment.”



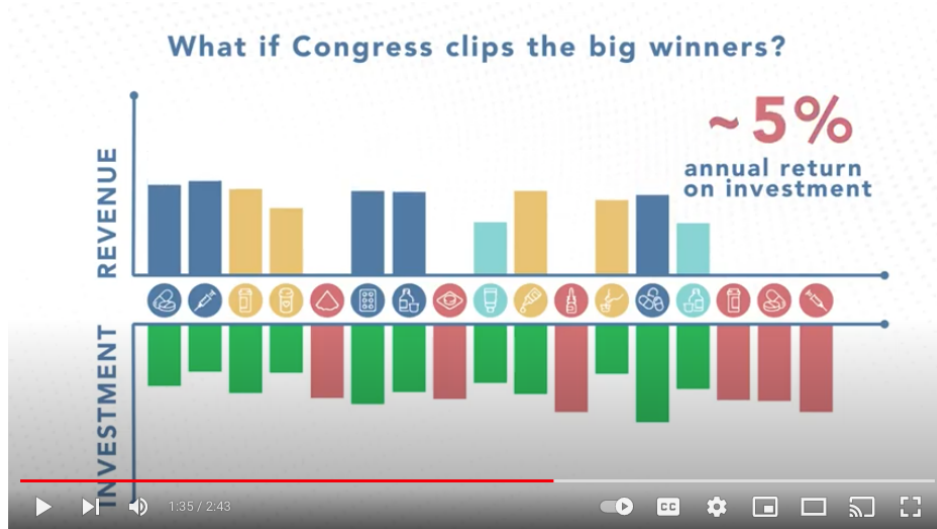
The Investor's Paradox

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[YouTube, No Patient Left Behind, [8/20/21](#)]

- 8/20/21: NPLB posted a video on YouTube suggesting that if Congress instituted pharmaceutical price controls, biopharma investors would see “~5% annual return on investment.”



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NPLB CLAIMED THAT THE PHARMACEUTICAL INDUSTRY AS A WHOLE WAS “ONLY MODERATELY PROFITABLE”

NPLB claims that “top-down price controls would cut deeply into” pharmaceutical research and development because the “whole industry is only moderately profitable.”

“One Income Statement for the Biopharma Ecosystem With: Harvard & MIT |Funding: Fully funded The profitability of the drug industry cannot be judged by measuring its larger and more successful companies and ignoring unknown or struggling competitors. We’re compiling an integrated income statement for the drug industry to determine its overall profitability. So far,

our analysis shows that the whole industry is only moderately profitable and that top-down price controls would cut deeply into R&D.” [NPLB, accessed [5/22/23](#)]

NPLB has repeatedly objected to a period of less than 13 years on the market before Medicare should be allowed to negotiate the price of a drug

AUGUST 2021: KOLCHINSKY AND NPLB/RA CAPITAL’S DAVID BEIER WROTE THAT THE “SKY WON’T FALL” IF BIDEN’S DRUG PRICING PLAN WERE ENACTED, BUT IT WOULD STIFLE INNOVATION AND COULD LEAD TO HIGHER INITIAL LIST PRICES FOR NEW DRUGS

August 2021: Beier and Kolchinsky wrote that “the sky won’t fall” if the “Biden drug pricing” were passed, but there would be fewer “innovative medicines, fewer jobs, and a less competitive position relative to China.”

“What if the Biden drug pricing plan passes? No, the sky won’t fall. But unanswered policy questions about the plan leave the biotech industry with two competing future scenarios, neither of which looks particularly promising: 1. A nation with far fewer new innovative medicines, fewer jobs, and a less competitive position relative to China, or 2. A bureaucratic muddle that leaves investors so uncertain that they sit on the sidelines, leaving patients with fewer and less innovative treatment options in the future.” [RA Capital RApport, [8/20/21](#)]

Beier and Kolchinsky argued that drug reimportation wouldn’t lower prescription drug prices in the U.S., it would only increase the prices elsewhere.

“Importing drugs from Canada simply wouldn’t work. Canada has only one-tenth of the US’s population and it frankly doesn’t want to send its drugs our way. While a few individuals might be able to buy drugs from Canada, if that happened at scale, Canada’s inventory would be quickly cleared out, leaving nothing for Canadians. It’s not like drug companies would keep shipping limitless amounts of drugs to Canada at low prices knowing that they were being rerouted to the US. And drug companies could also start selling drugs to Canada at US prices, with the result that Canada might not buy them, depriving patients. The end result of reimportation is that it doesn’t lower prices in the US but actually raises them elsewhere.” [RA Capital RApport, [8/20/21](#)]

Beier and Kolchinsky wrote that capping drug price increases at the rate of inflation would likely lead to drug companies increasing “prices at launch to account for any perceived future loss in revenue.”

“Limiting drug price increases to inflation would be a big political win for the administration, but is not likely to save money in the long run, as drug companies may simply increase prices at launch to account for any perceived future loss in revenue. Furthermore, net prices of drugs are already growing at rates below inflation. There would also be some kinds of drugs that may not be developed because of too much uncertainty about market size and therefore an inability to engage in price discovery post-launch. (Shifting the inflation cap so that it only kicks in five years after a drug’s launch would solve that problem.)” [RA Capital RApport, [8/20/21](#)]

Beier and Kolchinsky, speaking on behalf of NPLB, wrote that they supported “affordable monthly caps on all out-of-pocket costs...not just for Medicare but for all commercial health insurance plans.”

“Non-profit organizations like No Patient Left Behind advocate for mandating low, affordable monthly caps on all out-of-pocket costs (disclaimer: the authors serve on No Patient Left Behind’s Advisory Board and Steering Committee). It’s straightforward: the most impactful way to take the undue financial burden off of patients is to reduce out-of-pocket costs, not just for Medicare but for all commercial health insurance plans.” [RA Capital RApport, [8/20/21](#)]

JANUARY 2022: NPBL CRITICIZED THE BUILD BACK BETTER LAW BECAUSE OF A PROVISION TO REDUCE THE TIME PERIOD BEFORE MEDICARE COULD NEGOTIATE A DRUG’S PRICE

January 2022: NPLB criticized portions of the Build Back Better Act, saying that the proposal to reduce the period before Medicare is allowed to negotiate the price of a drug would ultimately lead to higher prices and less insurance coverage of those drugs.

“Lowering prescription drug pricing has been a hotly debated issue well before 2022 and is expected to continue in 2022. In November 2021, as part of the Build Back Better Act, President Biden announced the Prescription Drug Pricing Plan aimed at lowering prescription drug pricing. [...] NPLB further criticizes that the legislation will only help a small percentage of seniors and analogized the proposal to truncate the time period before which drug manufacturers need to negotiate pricing with Medicare to home mortgages—that is, the shorter the mortgage period, the higher the payment, and that the higher drug prices will

ultimately cause employers and health plans to impose more barriers to patient access. NPLB urges Congress, among other considerations, to increase the time period before government negotiation applies to 14 years for all drugs so that ‘small molecule R&D will not be discouraged relative to biologics R&D’ and to ‘[keep] as closely as possible to what we know works’, in line with the industry’s and investors’ general expectations for patent protection and time needed to recoup drug research and development costs, among other factors. This NPLB Letter has already garnered widespread support from biotechnology and pharmaceutical companies, investors, and researchers.” [JD Supra, 1/11/22]

- **NPLB’s position was supported by biotech and pharmaceutical companies, investors, and researchers.**

“This NPLB Letter has already garnered widespread support from biotechnology and pharmaceutical companies, investors, and researchers.” [JD Supra, 1/11/22]

JUNE 2022: RA CAPITAL WROTE THAT GENERIC COMPETITION WAS ITS OWN FORM OF PRICE CONTROLS AND THAT IF SUCH CONTROLS WERE LEGISLATED IT WOULD STIFLE INNOVATION

RA Capital suggested that with “price controls” venture capitalists would turn away “from biotech and look for a return in other sectors – maybe social media, video games, or energy...we might get another Netflix instead of a cure for Alzheimer’s disease.”

“With price controls for new drugs on the table, investors will redeem their money from biotech and look for a return in other sectors – maybe social media, video games, or energy. Biotech innovators will struggle to get projects funded, and many won’t be funded at all. As a society, we might get another Netflix instead of a cure for Alzheimer’s disease. But even if you don’t care about any of that and think venture capitalists (and the retirees and pensioners who trusted VCs with their money) can invest elsewhere, cutting the list prices of drugs won’t help patients. We have to deal with high out-of-pocket costs at the pharmacy counter regardless of how drugs are priced.” [RA Capital RApport, [6/23/22](#)]

RA Capital claimed that drugs going generic was its own form of “built-in price controls.”

“Besides, drugs already come with their own built-in price controls. After a period of reward, they go generic, so their high prices are temporary, like a home mortgage. Consider statins. Lovastatin cost \$3000/year when it came out (in 1980s money!), and now it costs less than \$200/year. Like hundreds of other drugs, it was temporarily expensive, but competition eventually brought down the price and it continues to keep millions of people out of hospitals, preventing suffering and avoiding the expense of surgeries to treat heart attacks and strokes.” [RA Capital RApport, [6/23/22](#)]

RA Capital said, “the only way we create more generic drugs is by incentivizing the invention of new drugs with the temporarily high prices we pay for them while they are branded.”

“Generic drugs save Americans billions of dollars every decade and always will. But the only way we create more generic drugs is by incentivizing the invention of new drugs with the temporarily high prices we pay for them while they are branded. Society’s signals to investors about what it’s likely to pay for new medicines in the future come from what society is willing to pay for new medicines today.” [RA Capital RApport, [6/23/22](#)]

RA Capital said that consumers won’t see savings if list prices of drugs go down because “it’s what insurers charge us at the pharmacy counter that hurts consumers’ wallets.”

“What companies charge for drugs is not the problem Congress and the public think it is. It’s what insurers charge us at the pharmacy counter that hurts consumers’ wallets. And that will not go down as drug list prices go down.” [RA Capital RApport, [6/23/22](#)]

RA Capital defended high drug prices, saying, “Today’s prices encourage and support our current level of innovation.”

“The key to innovation is offering a high enough reward to both innovators and investors. Today’s prices encourage and support our current level of innovation. The key to getting value is ensuring that all drugs go generic without delay, so the prices of drugs that can’t or won’t go generic should be regulated once their patents expire to ensure society gets value for its investment in innovation. And the key to affordability is proper insurance, so high copays, deductibles, and other out-of-pocket costs should be eliminated or drastically lowered to make appropriate care affordable.” [RA Capital RApport, [6/23/22](#)]

JULY 2022: NPLB OBJECTED TO RECONCILIATION LEGISLATION BECAUSE OF A 9-YEAR LIMIT ON SMALL MOLECULE DRUGS BEFORE “PRICE CAPS” COULD BE INSTITUTED

July 2022: A letter to Sen. Schumer and Sen. Wyden signed by Kolchinsky, Murphy, Rubin, and Beier referred to an earlier NPLB letter commenting on proposed legislation as “grassroots feedback from leading biotech researchers and funders.”

“Grassroots feedback from leading biotech researchers and funders explains that this arbitrary Medicare distortion will shift R&D from low-copay, easy-to-genericize pills to higher-copay, harder-to-copy injectables, and saddle patients with even more costs: unlike pills, injectables often require a visit to the doctor or infusion center (and associated costs for administration).” [RA Capital RAReport, [7/8/22](#)]

Kolchinsky, Murphy, Rubin, and Beier called on Congress to create a \$100 per month out-of-pocket cap, force PBMs and insurance companies to pass savings on to consumers, and allow Medicare to “negotiate deeper discounts for ALL drugs ONLY AFTER 14 years on the market.”

“This bill must be fixed before passage. Congress can do better. It should further revise the bill to: Do more for beneficiaries by eliminating the deductible and creating a \$100/month out-of-pocket cap. Guarantee insurers and PBMs pass savings on to beneficiaries. Empower Medicare to negotiate deeper discounts for ALL drugs ONLY AFTER 14 years on the market. With the above changes, we are confident that we can achieve our shared goals of making today’s medicines affordable for patients while ensuring that we can all look forward to better and affordable medicines tomorrow.” [RA Capital RAReport, [7/8/22](#)]

July 2022: NPLB circulated a letter signed by 1,000 “investors, researchers, patients, and development stage biopharma companies,” advocating changes to Senate legislation on prescription drug prices.

“No Patient Left Behind (NPLB), a non-profit organization dedicated to eliminating patients’ out-of-pocket costs and ensuring that drugs go generic without undue delay, today released a coalition letter signed by more than 1000 investors, researchers, patients, and development stage biopharma companies urging fixes to the Senate reconciliation drug bill.” [PR Newswire, [7/27/22](#)]

- **The letter used research from “leading biopharma investors” concerned that 9 years wasn’t enough time to recoup the costs of research and development of new drugs.**

“Rubin also cited a new analysis of the bill by leading biopharma investors. The analysis finds the bill’s imposition of price caps on small molecules after just 9 years and 13 years for large molecules will dry up investment in small molecule drugs to treat disease of aging. The report emphasizes that: ‘9 years is too short a time post approval to generate a positive return. Small molecules are not cheaper to develop than large ones. They are not less risky. The calculus for funding their development is essentially the same as for biologics.’ The new report lists small molecule companies in each state that likely will be negatively impacted by the current legislation.” [PR Newswire, [7/27/22](#)]

July 2022: An analysis of proposed drug pricing legislation signed by Kolchinsky and hosted on NPLB’s website explicitly states that these “healthcare investors” only invest in a product if they see “evidence of a sufficient return.”

“Investors have capital to invest in small companies only because our own investors- ranging from individuals to pension funds to university endowments - trust us to make sound decisions that will generate a positive return for them. When a professional investor fails to generate a positive enough return, their investors shift their money elsewhere, to another manager or another sector. We may personally want to see a project funded because we can see the good it would do, but we must say ‘no’ because we do not see evidence of sufficient return. This is why few new antibiotics are developed, for example.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

July 2022: The NPLB legislative analysis said, “Even today, investors avoid funding drug development when we know a successful drug would have only 9 years to generate returns,” calling such investments “mistakes.”

“Even today, investors avoid funding drug development when we know a successful drug would have only 9 years to generate returns. When a drug does go generic after such a short time, it’s often because the drug’s development took longer than we expected and, by the time we finally completed Phase 3 trials, there were just 9 years left of patent protection. At that point, while those 9 years on the market make it worth it to push the drug over the line and market it, the initial investment was clearly not justified. We try to avoid such mistakes.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

The NPLB legislative analysis claimed that instituting price controls after 9 years would effectively half the profitability of a drug.

“And while many seem to think that marketed drugs just need to recoup their own direct development costs, they actually have to justify the whole portfolio of projects we funded just to yield those few successes. And since it generally takes 4-6 years for a drug’s sales to ramp up, it’s the last 8-10 years that a drug has on the market that drive the returns needed to justify the whole

portfolio of investments from which that drug emerged. So cutting the average time a small molecule can collect a reward from 14 to 9 is really cutting in half the profits that sustain an entire portfolio of small molecule B&D investments.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

The NPLB legislative analysis effectively threatens Democrats that “the American public will be reminded that the problem they want solved...was created by a Democratic congress that ignored basic economics.”

“And so it is with medicines. Seniors with diseases waiting for their cures will immediately see the impact of Congress's error when the innovation these patients care about has been defunded. As others age and discover that no one is working on their diseases, we will hear calls for Congress to fix the problem, just as we hear calls for Congress to create incentives for antibiotics. The American public will be reminded that the problem they want solved wasn't a problem at all before 2022 and was created by a Democratic congress that ignored basic economics and set a precedent by imposing price controls on an R&D-intensive industry, destroying it just as many told them they would.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

The NPLB legislative analysis suggests that investors wouldn't accept launching new drugs at higher prices because insurance companies would avoid paying the higher prices.

“Some think that if the ‘mortgage’ period were shortened from an average of 14 to 9 years, then companies would just plan to generate the same profits they need to make the investment calculus work by charging more, just as you can buy the same house with a 9- or 14-year mortgage but pay more per year for the former than the latter. And yet, investors are going to be hard-pressed to just assume that a drug could be launched at a higher price without consequences. Insurance plans restrict access to more expensive drugs, so we would have to assume that, at a higher price, fewer patients would get treatment. That would mean that we would need to assume that the price would need to be yet higher so as to generate enough profit to justify investing in the development of the drug, but then that would drive insurance plans to restrict use even more. Ultimately, this kind of recursive cycle of more restrictions and higher prices leads to an alternate conclusion, that it makes more sense to respond to the promise of price controls after 9 years by simply not risking capital on developing the drug in the first place.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

- **The NPLB legislative analysis said that new antibiotics aren't launched at higher prices because “there are drug prices investors don't find plausible.”**

“This is not a hypothetical. There are drug prices investors don't find plausible: Novel antibiotics are rarely used, but investors do not simply talk themselves into funding their development by assuming that a novel antibiotic can just be launched at a much higher price. We know that the higher the price, the more restricted the antibiotic would be, so there is little investment in new antibiotics and infectious disease specialists continue to bang the drum about how badly we need better antibiotics.” [Letter to Chuck Schumer, Nancy Pelosi, Mitch McConnell and Kevin McCarthy, [7/25/22](#)]

AUGUST 2022: NPLB BOARD MEMBER DAVID BEIER WAS MORE MEASURED THAN HIS NPLB/RA CAPITAL COLLEAGUES, EXPRESSING OPTIMISM ABOUT THE STATE OF THE PHARMACEUTICAL INDUSTRY IN THE WAKE OF THE INFLATION REDUCTION ACT, BUT OFFERED TO SWAP YEARS BEFORE PRICE CAPS FOR AN INCREASED DISCOUNT RATE

David Beier wrote that he was “optimistic about the ability of modern bioscience to deliver new treatments and cures” despite the passage of the Inflation Reduction Act.

“The passage of the Inflation Reduction Act last week is an important milestone in the history of American biotechnology. I've been honored to participate in that history from a variety of perspectives: White House adviser, congressional staff, senior biotech executive, public company board member, lawyer, and venture capital investor. Those experiences shape the lens through which I view the industry's evolution and its future. Over the past four decades, our freedom to innovate has been underpinned by – and helped create – a marketplace that was open enough to fully reward risk-taking investors devoting capital to cutting edge science. And so I am disappointed by the new law's price-setting provisions and market distortions. But I remain optimistic about the ability of modern bioscience to deliver new treatments and cures. The arc of the industry's progress bends toward access and availability to new medicines for patients.” [David Beier, RA Capital RApport, [8/26/22](#)]

Beier seemed to praise the United States' inability to “dictate drug prices” before the Inflation Reduction Act.

“It's no coincidence that a majority of new drugs are invented for the American market and that as a consequence, the United States has the bulk of global life science employees. Until the Inflation Reduction Act, the United States stood alone as a country without the ability to dictate drug prices (despite some government intrusions into a free market, including Medicaid rebates, VA pricing and sales at discounts to safety net hospitals, and opportunists' clamoring for price controls over the past two decades),

relying instead on intermediaries to negotiate prices on behalf of government-sponsored plans.” [David Beier, RA Capital RApport, [8/26/22](#)]

Beier suggested increasing the time from 9 to 13 years at which Medicare could negotiate the price of a small molecule by increasing the “minimum discount from 35% to 42%” to make it budget-neutral.

“More important, that disparity is likely to reduce investment in cancer and Alzheimer’s drugs, which are primarily diseases of aging covered by Medicare. This flaw could be easily fixed by evening out the period of repose before government price setting to 13 years, which is still lower than the average of 14 years drug companies have enjoyed since the passage of Hatch-Waxman nearly 40 years ago. Since the IRA doesn’t set a floor level for how low CMS could set a price during the “negotiation” period, investors already will presume that prices will be set lower than the minimum discount thresholds defined in IRA and used by the CBO to score the bill. Therefore, if fixing the law by changing 9 to 13 requires an offset, that’s possible by increasing the post-13-year minimum discount from 35% to 42%. This would be a budget-neutral change with a profoundly positive impact on restoring the incentives for small molecule R&D for diseases of aging, which would lead to societal savings and long-term benefits for patients, which is to say all of us.” [David Beier, RA Capital RApport, [8/26/22](#)]

● **This proposal to swap years for an increased discount rate was supported by NPLB.**

“Protect small molecule innovation in cancer & other diseases of aging Treat small and large molecules the same, start discounts for both at 13 years • Fix can pay for itself • Starting small molecule price discounts at 13 vs. 9 years post FDA approval would • Protect innovation for the elderly with minimal impact on CBO savings • Result in \$6B less savings over 10 year budget-window • Fix is budget neutral when paired with an increase in the minimum government discount • Increase minimum long monopoly drug discount from 35% to 42%” [NPLB, [August 2022](#)]

Beier said the move from 9 to 13 years would be a “minor fix” to the Inflation Reduction Act.

“A minor fix to the new law to equalize Medicare price setting for small and large molecules at 13 years after FDA approval can keep us on track towards our shared goals of creating more medicine, ensuring broad access to those medicines, and keeping America the global leader in biotech.” [David Beier, RA Capital RApport, [8/26/22](#)]

OCTOBER 2022: KOLCHINSKY WROTE THAT MOST OF THE INFLATION REDUCTION ACT’S “HARMFUL EFFECTS ON INNOVATION” WOULD “LIKELY BE REVERSED” IF ALL DRUGS WERE GIVEN 13 YEARS BEFORE MEDICARE NEGOTIATED THEIR PRICES

Kolchinsky wrote that “most of the IRA’s harmful effects on innovation will likely be reversed” if small molecules couldn’t be negotiated until 13 years after FDA approval, as opposed to the 9 years under the IRA.

“So we’re left with Alnylam acting rationally under the IRA. Other companies will have to do the same. And patients will be worse off for it. And yet, the IRA can be fixed: change nine to 13 and most of the IRA’s harmful effects on innovation will likely be reversed.” [RA Capital RApport, [10/31/22](#)]

MARCH 2023: NPLB POSTED “SURVEY RESULTS” SAYING THAT BIOPHARMA INVESTORS WERE ALREADY MOVING THEIR MONEY OUT OF SMALL MOLECULE PROGRAMS, BUT INVESTORS SPLIT WITH DRUG COMPANY EXECUTIVES ABOUT WHETHER SUCH PROGRAMS WERE RISKY INVESTMENTS

March 2023: Steve Potts, writing at NPLB, claimed that survey results of venture investors indicated they were moving away from making investments in small molecule programs as a result of the Inflation Reduction Act.

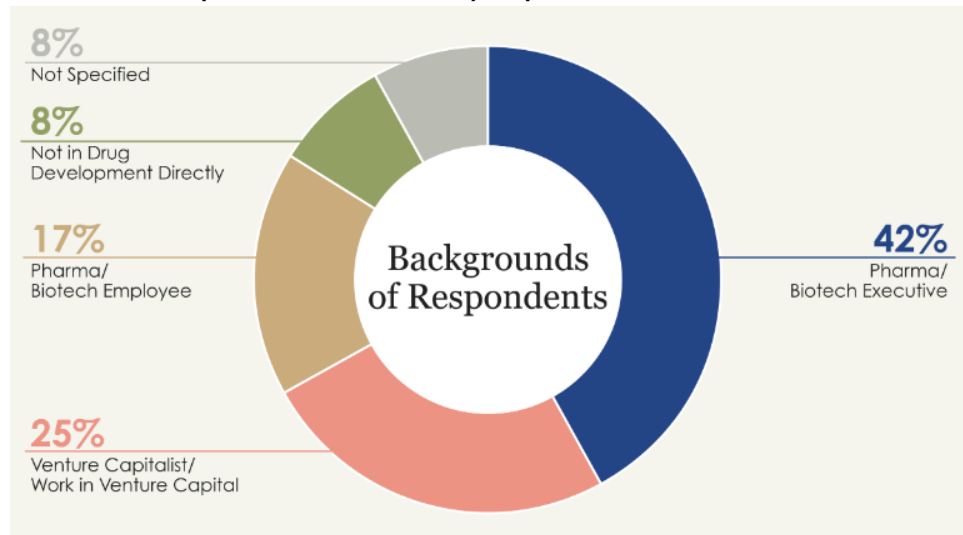
“While out raising funds this year for several promising oncology programs, I have noticed strong shifts in investor sentiment away from funding small molecule drug development for widespread diseases and especially diseases of the aging population. I wanted to gather more quantitative data to gauge how appetites for funding small molecule innovation have changed over the nine months since the Inflation Reduction Act – with its Medicare “negotiation” of small molecules at nine-years post launch – became the law of the land. So I launched a survey, and the data is fascinating. But the implications are sobering for patients. Bottom line: investment in small molecule drug development is shrinking quickly. The vast majority of venture investors responding to my survey have moved away from funding small molecule programs for Medicare patient populations as a result of the IRA.” [NPLB, [3/31/23](#)]

● **Potts is the CEO of Anticipate Bioscience, which specializes in small molecule drug development, and a board member at Phoenix Molecular Designs, a precision oncology company.**

[Steve Potts LinkedIn profile, accessed [5/22/23](#)]

- **2018-Present: Potts is the Founder, Medical Affairs & Disease Awareness in Targeted Therapies at Lighthouse by Celerity Biosciences, where he is “engaged in a. Number of consulting projects with large pharma and smaller biotech.”**
[Steve Potts LinkedIn profile, accessed [5/22/23](#)]

- **Less than 20 percent of Potts’ survey respondents didn’t have a direct financial stake in drug development.**



[NPLB, [3/31/23](#)]

- **Potts’ survey data show a discrepancy between venture capitalists and biotech executives and employees as to what they consider risky investments in drug development.**

Completely regardless of IRA and return on investment, how do small molecules compare to antibodies in terms of the development and approval risk?

	OVERALL	VENTURE CAPITALISTS	BIOTECH EXECUTIVES	BIOTECH EMPLOYEES
I consider small molecules to be less risky to develop as successful drugs	25%	42%	19%	23%
I consider antibodies (all types - bi-specifics, ADCs, etc.) to be less risky to develop as successful drugs	27%	32%	23%	15%
I consider both classes to have equal risks	48%	26%	58%	62%

[NPLB, [3/31/23](#)]

SPRING 2023: KOLCHINSKY WROTE AN OPEN LETTER TO “FRIENDS AND PEERS IN BIOTECH, ESPECIALLY CEOs,” ASKING FOR THEIR HELP IN FIXING THE INFLATION REDUCTION ACT AND OPPOSING RAPID MEDICARE NEGOTIATION OF PRICES

Spring 2023: Kolchinsky and Peter Thompson, General Partner at OrbiMed Advisors, wrote an open letter to their “friends and peers in biotech, especially CEOs,” calling on them to help fix the Inflation Reduction Act.

“To all our friends and peers in biotech, especially CEOs, The treatment of NDA-path drugs in the Inflation Reduction Act materially degrades the investment case for these treatments in age-related diseases and thus jeopardizes future biotechnology progress and the health of America’s seniors. We worry that many people in our own industry fail to see the magnitude of the IRA’s impact on the economics of drug development. Some executives may think that fixing the IRA’s nine-year provision isn’t a priority for them. Their companies might be working on drugs for younger populations, so the IRA is at worst a glancing blow. Or they work on biologics, which enjoy 13 years of market pricing before CMS steps in. Or they are targeting a single orphan indication and are for now exempt from the IRA’s price setting.” [NPLB, “Why fixing the IRA matters to all of us,” [Spring 2023](#)]

Kolchinsky and Thompson claimed that the Inflation Reduction Act “prevents us from following the science” but their argument was about investments.

“The law prevents us from following the science - biologics simply can't reach certain key drug targets inside cells that recent advances in biology implicate in disease causality and progression. By undervaluing small molecule treatments the IRA steers investment away from some of the richest areas of emerging scientific knowledge.” [NPLB, “Why fixing the IRA matters to all of us,” [Spring 2023](#)]

Kolchinsky and Thompson expressed dismay at President Biden’s proposals to allow Medicare to negotiate the price of more drugs, sooner after they reach the market.

“Because until we shift direction, we should not expect that future policy will be more accommodating. Those working on biologics should worry that future legislation will chip away at their incentives. Those working on medicines for younger patients should worry that future policy will impact commercial prices. Make no mistake: it's already happening. President Biden's recently released budget is clear about his goals: ‘allowing Medicare to negotiate prices for more drugs and bringing drugs into negotiation sooner after they launch.’ The proposal specifically called for shortening the exemption to negotiation for both small molecules and biologics to 5 years, doubling the number of drugs Medicare would be required to negotiate, and extending the inflation rebate provisions to the commercial market.” [NPLB, “Why fixing the IRA matters to all of us,” [Spring 2023](#)]

MAY 2023: NPLB BOARD MEMBER JIM GREENWOOD SAID THAT MEDICARE NEGOTIATION OF DRUG PRICES “COULD SIGNIFICANTLY IMPAIR OUR NATION’S ABILITY TO INNOVATE NEW MEDICINES,” AND CALLED ON POLITICIANS TO “STOP DEMONIZING...BIOPHARMA COMPANIES”

Greenwood wrote that the Inflation Reduction Act, giving Medicare the ability to negotiate drug prices “could significantly impair our nation’s ability to innovate new medicines.”

“The Inflation Reduction Act of 2022 has added a fresh new set of obstacles for pharmaceutical companies’ drug development pipelines. Among its provisions is the requirement that the Department of Health and Human Services “negotiate” drug prices within the Medicare Program. These price controls could significantly impair our nation’s ability to innovate new medicines; such damage could fall disproportionately on biopharmaceutical companies trying to develop medicines to treat mental illness. This is because eligibility for price controls occurs 9 years after FDA approval for small molecules, but 13 years after approval for biologics. This matters because it is only small molecules with low molecular weight that can cross the blood-brain barrier and impact the brain at the cellular level and thus treat mental and neurodegenerative illnesses. That is, this aspect of the IRA disincentivizes investors and pharmaceutical companies that otherwise would be inclined to tackle the challenging task of developing medicines to treat mental illness. The IRA’s requirements mean that even if such businesses succeed in developing a new, effective drug to treat a mental illness, they may never recover their R&D investment.” [Jim Greenwood, DLA Piper, [5/9/23](#)]

Greenwood wrote that Congress must amend the IRA to make drugs subject to Medicare price negotiations 13 years after FDA approval.

“This is why Congress must make a technical correction in the IRA equalizing the number of years after FDA approval so that both small molecule drugs and biologics become subject to Medicare price controls at 13 years. The cost of this amendment would be minuscule compared to the price we pay as a nation. And this change would also be a potential boon for the development of urgently needed drugs to treat neurodegenerative diseases like Alzheimer’s, Parkinson’s and ALS.” [Jim Greenwood, DLA Piper, [5/9/23](#)]

Greenwood wrote that the Inflation Reduction Act may reduce the “number of new therapeutics created.”

“The Inflation Reduction Act (IRA) significantly impacts the US economic model for prescription drug innovation through the imposition of mandatory negotiations in which federal officials set a ceiling price for certain drugs and biologics. The price controls that the IRA imposes on medicines offered through Medicare may have the unintended consequence of reducing the number of new therapeutics created to respond to unmet medical needs. Moreover, it could also bring about a profound shift in investment, including a shift away from small molecule pills and toward complex biologics.” [Jim Greenwood, Alex Pinson, Jamie Gregorian, DLA Piper, [10/18/22](#)]

Greenwood quoted Eli Lilly’s CEO criticizing the IRA for distinguishing between small molecule drugs and large molecules.

“When the protections on the clinical data expire on a drug, another company can copy that medicine using the innovators’ clinical data and offer it for a much lower price. This is the system established in the Hatch-Waxman Act, and it has resulted in the vast majority of drugs being available as low-cost generics. The median time period before small molecule drugs typically face a generic competitor is fourteen years. For biosimilars, essentially the lower priced version of a large molecule permitted to enter

the market, the period is twelve years after the approval of the original large molecule drug. Eli Lilly's CEO, David Ricks, observed that 'the most damaging thing about [the Inflation Reduction Act]

is that it sends a signal to investors and capital allocators ...that small molecules...are worth a lot less.' He is among number of industry stakeholders who have already raised concerns about the potential harmful impacts on small molecule valuations because of the shortened reward period for small molecule medicines compared to large molecules." [Jim Greenwood, Alex Pinson, Jamie Gregorian, DLA Piper, [10/18/22](#)]

June 2022: Greenwood wrote "It's time for politicians to stop demonizing what is arguably America's most indispensable industry...biopharma companies."

"Something else is required of our political class. It's time for politicians to stop demonizing what is arguably America's most indispensable industry in this emerging pandemic era. Too many politicians make contradictory comments when it comes to biopharma companies, alternately praising the Herculean response of industry in innovating vaccines and antivirals at lightning speed while advocating innovation-killing price controls that would cripple our ability to do it again." [Jim Greenwood, DLA Piper, [6/6/22](#)]

Kolchinsky, NPLB and RA Capital have generally espoused the necessity of generic drug competition, but an article on NPLB's website questioned the safety and efficacy of generic drugs

KOLCHINSKY, NPLB AND RA CAPITAL'S POSITION ON GENERIC DRUGS HAS BEEN THAT THEY ARE NECESSARY TO KEEP DRUG PRICES AFFORDABLE OVERALL

Kolchinsky summarized his book and position saying that the biopharma industry should agree to medicines going generic or price controls if they can't go generic, in exchange for "low out-of-pocket costs for patients."

"So, if our industry could support regulations that fix that market failure, when our medicines don't go generic without undue delay, if we accepted that yes, there should be some price controls essentially that knock those prices down to a level as if they'd gone generic, but it's in exchange, we also win low out-of-pocket costs for patients, I believe that we will have a far more harmonious healthcare system and innovation system in the US, with spillover to the rest of the world." [DLA Piper, At the Intersection of Science and Law, partial transcript, [3/21/22](#)]

RA Capital claimed that drugs going generic was its own form of "built-in price controls."

"Besides, drugs already come with their own built-in price controls. After a period of reward, they go generic, so their high prices are temporary, like a home mortgage. Consider statins. Lovastatin cost \$3000/year when it came out (in 1980s money!), and now it costs less than \$200/year. Like hundreds of other drugs, it was temporarily expensive, but competition eventually brought down the price and it continues to keep millions of people out of hospitals, preventing suffering and avoiding the expense of surgeries to treat heart attacks and strokes." [RA Capital RAport, [6/23/22](#)]

RA Capital said, "the only way we create more generic drugs is by incentivizing the invention of new drugs with the temporarily high prices we pay for them while they are branded."

"Generic drugs save Americans billions of dollars every decade and always will. But the only way we create more generic drugs is by incentivizing the invention of new drugs with the temporarily high prices we pay for them while they are branded. Society's signals to investors about what it's likely to pay for new medicines in the future come from what society is willing to pay for new medicines today." [RA Capital RAport, [6/23/22](#)]

MACH 2021: NPLB POSTED AN INTERVIEW WITH AN AUTHOR WHO WAS CRITICAL OF GENERIC DRUG MANUFACTURERS QUALITY CONTROL, WITH NPLB POSING QUESTIONS ABOUT WHETHER IMPROVING QUALITY WOULD MAKE THE COST MODEL UNSUSTAINABLE AND IF PATIENTS SHOULD "TRASH THEIR MEDICINE CABINET"

3/3/21: NPLB wrote warning of adulterated generic drugs, highlighting a book about the problems with generic drug manufacturers.

"'Before I embarked on this project,' the investigative journalist Katherine Eban writes in her 2019 book, *Bottle of Lies: The Inside Story of the Generic Drug Boom*, 'I had always assumed that a drug was a drug.' She was wrong. Generic drugs—'bioequivalents' of brand-name drugs sold at significantly lower prices—have saved millions of lives across the globe and

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become ubiquitous in the United States. Indeed, nine of every 10 prescriptions dispensed in the U.S. is a generic. Quite literally, we can't live without them. But as Eban discovered, you don't always get what you pay for. In a narrow sense, *Bottle of Lies* tells the story of Ranbaxy Laboratories Ltd., an Indian generic drug manufacturer that pleaded guilty to seven federal criminal charges as part of a record \$500 million settlement in 2013. For years, the company had falsified data to push adulterated drugs on the American market. Had an insider not blown the whistle to the U.S. Food and Drug Administration, Ranbaxy's deception would likely have gone unnoticed. But Ranbaxy's fraud was the rule, not the exception, Eban says. And nothing changed with its guilty plea. *Bottle of Lies* offers a disturbing window into the generic drug industry in India (and, to a lesser degree, China), where the pressure to generate profits by any means necessary is matched only by the FDA's fecklessness. This perfect storm of globalization, avarice, and lax regulation has given rise to what Eban calls both 'the world's greatest public health innovation' and 'one of its greatest swindles.' Drawing on a decade of reporting, Eban—a *Vanity Fair* contributor who has previously investigated CIA interrogations, gun trafficking, and counterfeit pharmaceuticals—crafts a narrative that grows more infuriating by the page. It's a systemic indictment warning us that the pills we take might not be what we think they are." [NPLB, [3/3/21](#)]

An NPLB interview with author Katherine Eban raised concerns of lax FDA oversight of generic drug manufacturers, who could be including "impurities...toxic particulate matter, [and] carcinogens."

"NPLB: The generic industry took off in India because plants there produced cheap drugs. What were the most common problems you found in those facilities? Eban: The biggest problem that *Bottle of Lies* focuses on is fraud, which is that these companies are either manipulating or inventing quality data to present to regulators to make it appear as though they have a perfect product to get approval. But the truth underneath that faked data is that the drugs are not bioequivalent, have impurities, have toxic particulate matter, carcinogens—[and] the FDA is essentially closing its eyes to because it has been announcing its inspections [of overseas facilities] in advance, maybe months in advance. I should add that right now, [regulation is] even worse because overseas inspections have been suspended [due to] COVID. So the FDA is almost entirely relying on data from these plants. And we know what the data is like." [NPLB, [3/3/21](#)]

Eban told NPLB she thought it was "fairly common" that "bad drugs actually make it to the market."

"NPLB: How often do bad drugs actually make it to the market? Eban: I think it's fairly common. I get emails every single day from patients who are just at the end of their rope, they don't know who to turn to for help. Their drugs don't work. This can lead to all kinds of consequences—hospitalizations, suicides. In the book, I focus on these Cleveland Clinic cardiologists who realized that their heart transplant patients were suffering organ rejection when they were switched to an Indian-made immunosuppressant." [NPLB, [3/3/21](#)]

Eban blamed Indian culture for some of the bad manufacturing of generic drugs.

"NPLB: The book talks about the Indian culture of *jugaad*. Could you describe what that means? Eban: It's essentially the art of the shortcut. Indian life is really onerous and highly bureaucratic, and a corporate culture has developed where the ability to navigate around obstacles is really prized. The problem is when these regulations that can mean the difference between life and death are viewed as the obstacles that one is going to navigate around. My investigation showed that this is really a prevalent view. In the book, I feature an FDA investigator named Peter Baker, who inspected, I think, 86 plants in India and China over four years and found evidence of fraud in four-fifths of them." [NPLB, [3/3/21](#)]

Eban claimed that as many as 4/5ths of Indian and Chinese generic drug manufacturers showed evidence of fraud.

"NPLB: The book talks about the Indian culture of *jugaad*. Could you describe what that means? Eban: It's essentially the art of the shortcut. Indian life is really onerous and highly bureaucratic, and a corporate culture has developed where the ability to navigate around obstacles is really prized. The problem is when these regulations that can mean the difference between life and death are viewed as the obstacles that one is going to navigate around. My investigation showed that this is really a prevalent view. In the book, I feature an FDA investigator named Peter Baker, who inspected, I think, 86 plants in India and China over four years and found evidence of fraud in four-fifths of them." [NPLB, [3/3/21](#)]

NPLB questioned whether improving the quality of generic drugs would make the financial model unsustainable.

"NPLB: Right now, 90 percent of drugs dispensed in the U.S. are generics, and they account for just 22 percent of prescription spending. The system runs on cheap drugs. Would quality make it unsustainable? Eban: I believe there is a hidden cost to these cheap drugs—in hospitalizations, re-admissions, stabilized patients who become unstable. But the problem is that cost has not been assessed. Insurance companies don't have a number for that. So we need to understand what the costs are in order to solve it. Attached to that idea is that we have to incentivize quality. What is the incentive for drug makers to make a higher-quality and

possibly higher-cost drug? Are they getting rewarded in the marketplace? No, because nobody's measuring the quality." [NPLB, [3/3/21](#)]

NPLB asked whether consumers should “trash their medicine cabinet” to clean out potentially bad generic drugs.

“NPLB: Is this the kind of thing where people should trash their medicine cabinet? Eban: When I was selling the book, I was speaking with different editors at different publishing houses, and I had a conversation with a guy where I could hear the sound of plunking into the garbage can. As we were talking, he was going through his desk drawer tossing bottles.” [NPLB, [3/3/21](#)]

NPLB has lashed out at insurance companies, hospitals and PBMs for high drug prices

Kolchinsky and Rubin say that the U.S. doesn't properly insure patients.

“The US is making four mistakes. 1) We're not properly insuring patients, leaving what should be societal investment decisions to rest too heavily on patients. 2) Even when we consider the societal value of medicines, we're hiring Specialist health economists instead of Generalists to value them; even drug companies make this mistake when evaluating their own drugs. 3) We're increasingly letting over-simplified Special cost-effectiveness math dictate how little society (via insurance) will pay for medicines instead of listening to the marketplace of patients, physicians, insurance plans, and employers. 4) We're failing to convince other countries, via diplomacy, to contribute to funding innovation by paying more for branded medicines that they too will eventually enjoy as inexpensive generics.” [NPLB, “When simpler isn't better: A case for generalizing cost-effectiveness math to avoid undervaluing medicines,” [May 2021](#)]

July 2021: Kolchinsky blamed PBMs and hospitals for high drug prices.

“America's byzantine drug pricing systems are chock-full of middlemen. These intermediaries benefit from the spread between inflated list prices (which hurt patients on the hook for high out-of-pocket costs) and the much lower net prices received by manufacturers. That hidden fee stack not only drives the profits of PBMs but also funds all kinds of services provided by hospitals and clinics. The way that hospitals benefit from inflated list prices is sometimes harder to understand. But it's a common theme across different kinds of drugs dispensed at hospitals and clinics across the country that's not just a problem for the drug industry but is turning out to be freakonomically bad for the middlemen themselves. An NBC News piece last week about the federal drug pricing law called 340B shows how hospitals and clinics can buy drugs on the cheap (sometimes even receiving them for free), jack up their prices for patients/insurers, and use the difference to pay for all kinds of other stuff. This practice is akin to money laundering in that hospitals are obscuring their expenses, making drugs seem more expensive so as to make the services appear less expensive, or even free. Unlike actual money laundering, hospitals aren't breaking the law here – the 340B law was designed to have drug prices subsidize services and hospitals are arguably just going with the flow – but they are now discovering how the dishonesty of 340B can backfire.” [RA Capital RAport, [7/14/21](#)]

A NPLB video blamed “Big Insurance” for denying coverage of expensive drugs by ignoring or underestimating certain value.



The Value of Medicines

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[YouTube, No Patient Left Behind, [12/6/22](#)]

NPLB DOESN'T APPEAR TO BE A LEGAL ENTITY, INSTEAD IT'S PROBABLY A FUND WITH THE HOPEWELL FUND WITH SUPPORT FROM MISSION EDGE

The exact finances and funding of No Patient Left Behind are opaque because of its legal structure. We could not find any registration of NPLB as a distinct legal entity: it is not registered as a nonprofit organization with the IRS. NPLB appears to be a fund within the nonprofit Hopewell Fund, with some nonprofit services provided by Mission Edge, a smaller nonprofit services organization based in San Diego, CA.

Hopewell Fund

THE NPLB WEBSITE INDICATES THAT THE ORGANIZATION IS MANAGED BY THE HOPEWELL FUND

The NPLB website's Terms of Services, makes clear that the organization is managed by the Hopewell Fund.

“These Terms govern the use of this Application, and, any other related Agreement or legal relationship with the Owner in a legally binding way. Capitalized words are defined in the relevant dedicated section of this document. The User must read this

document carefully. This Application is provided by: Hopewell Fund 1201 CONNECTICUT AVENUE NW WASHINGTON, DC 20036 Owner contact email: hello@nopatientleftbehind.org” [NPLB, accessed [5/18/23](#)]

THE HOPEWELL FUND OFFERS “FISCAL SPONSORSHIP” AND “HOSTING AND INCUBATION” TO NONPROFIT STARTUPS THROUGH A RESTRICTED FUND WITHIN THE HOPEWELL FUND

Hopewell Fund offers “fiscal sponsorship” to legal entities that do not have tax-exempt status, allowing those entities to raise money into a restricted fund that Hopewell grants to other organizations that support the designated mission.

“Hopewell offers comprehensive fiscal sponsorship to projects that already exist as a legal entity but do not have tax-exempt status. While you run your operations, finances, and programs, Hopewell accepts donations into a restricted fund and grants them to organizations that support your mission.” [Hopewell Fund, accessed [5/19/23](#)]

Hopewell Fund provides project hosting and incubation services for philanthropists, establishing a restricted fund within Hopewell for a project.

“Our project hosting and incubation experience enables philanthropists to more quickly achieve social goals on even the most complex endeavors. Working in partnership with a dedicated project team, we will establish a restricted fund within Hopewell for your project and put together a suite of support to help you get your project off the ground and scale more quickly and cost-effectively than if you were launching a new nonprofit. Our team can provide full financial management, hiring and human resources support, and spinoff services should your project eventually benefit from becoming an independent entity.” [Hopewell Fund, accessed [5/19/23](#)]

Hopewell manages donor collaboratives, helping to establish project infrastructure, create advisory boards, and manage project activities.

“Hopewell manages many projects on which multiple donors work toward a common goal. We provide a neutral platform that enables donors to work together efficiently. We have built collaboratives from the ground up and helped leading donors establish their project’s infrastructure, set up its advisory board, and coordinate advisory board members and project activities.” [Hopewell Fund, accessed [5/19/23](#)]

Hopewell can support advocacy campaigns and provide some lobbying assistance through a sister 501(c)(4) organization.

“As a 501(c)(3) public charity, the Hopewell Fund has the capacity to engage in advocacy and a limited amount of lobbying. Hopewell’s projects can benefit from our staff and in-house counsel’s compliance expertise to launch campaigns that seek to impact policy at the state, federal, and international level. We also have the capability to host projects that focus on lobbying and political activities through our sister 501(c)(4) social welfare organization, the Sixteen Thirty Fund.” [Hopewell Fund, accessed [5/19/23](#)]

2021: THE HOPEWELL FUND ACCEPTED A \$100,000 DONATION EARMARKED FOR NPLB FROM THE SIX STRING GIVING FOUNDATION, THE CHARITABLE ARM OF DEEP TRACK CAPITAL, A LIFE SCIENCES INVESTMENT FIRM

2021: The Six String Giving Foundation gave \$100,000 to the Hopewell Fund, earmarked for NPLB.

[Six String Giving Foundation, IRS Form 990, via ProPublica, [7/26/22](#)]

HOPEWELL FUND 1828 L ST NW WASHINGTON, DC 20036	N/A	PC	No Patient Left Behind program	100,000
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[Six String Giving Foundation, IRS Form 990, via ProPublica, [7/26/22](#)]

The Six String Giving Foundation is associated with Deep Track Capital.

[Deep Track Capital, accessed [5/18/23](#)]

Deep Track Capital is an investment firm that exclusively invests in the life sciences industry.

“Deep Track Capital is a Greenwich, Connecticut-based investment firm focused exclusively on the life sciences industry. We develop long term partnerships with management teams of leading innovative public and pre-IPO biotechnology companies. In addition to capital, we seek to invest our time and expertise, while leveraging our network for the benefit of our partners. We aim to lead transactions while building large syndicates, and also to invest in rounds led by other qualified investors.” [Deep Track Capital, accessed [5/18/23](#)]

3/31/23: Deep Track Capital's biggest holdings were in Iveric Bio, Jazz Pharmaceuticals, Immunovant, and Insmed, Inc.

Company	Class	Value (\$1,000s) ▼	Change (\$1,000s)	Change (%)	Shares Held
IVERIC BIO INC	COM	240,240	-50,935	(17.493)	6,500,000
JAZZ PHARMACEUTICALS PLC	SHS USD	158,592	43,143	37.37	1,200,000
IMMUNOVANT INC	COM	156,979	-48,096	(23.453)	7,432,717
INSMED INC	COM PAR \$.01	120,640	41,495	52.429	6,500,000

[NASDAQ, [3/31/23](#)]

HOPEWELL FUND'S RECENT TAX FILINGS AREN'T YET PUBLICLY AVAILABLE, AND THOSE THAT ARE PRE-DATE NPLB'S CREATION

Hopewell Fund's tax filings aren't yet publicly available after 2019.

[ProPublica Nonprofit Explorer, accessed [5/19/23](#)]

2020: NPLB was created.

[Harbor Path, [11/16/20](#)]

Mission Edge

MAY 2021: NPLB BECAME A MISSION EDGE "FISCAL SPONSORSHIP" CLIENT

5/1/22: NPLB started as a Mission Edge client.

Our Fiscally Sponsored Projects

The screenshot shows a dashboard interface for Mission Edge. At the top, there are options for 'Customize cards', 'Filtered by Project Name', and 'Sort'. Below this is the NPLB logo. The main content area displays details for a project titled 'No Patient Left Behind'. The details include:

- FS MODEL:** Model A
- FS START DATE:** 2022-05-01
- SOCIAL IMPACT:** Advance the "biotech social contract" that promises society both affordability and innovation
- WEBSITE:** <https://www.nopatientsleftbehind.org/>

[Mission Edge, accessed [5/18/23](#)]

NPLB’s website indicates it is a “Mission Edge Project.”

Copyright, No Patient Left Behind 2021
A Mission Edge Project

[NPLB, accessed [5/18/23](#)]

MISSION EDGE IS A NONPROFIT ORGANIZATION THAT PROVIDES BUSINESS SERVICES TO OTHER NONPROFIT ORGANIZATIONS

Mission Edge, a nonprofit organization, does not have yet publicly available tax documents for 2022.

[Mission Edge, accessed [5/19/23](#)]

Mission Edge is a nonprofit services firm.

“Our mission is your mission Serving nonprofits Incorporated as a nonprofit and operating like a true social enterprise, Mission Edge specializes in fiscal sponsorship, accounting, and HR services. We are dedicated to helping nonprofits scale their organization and ultimately create more positive social change via their missions.” [Mission Edge, accessed [5/18/23](#)]

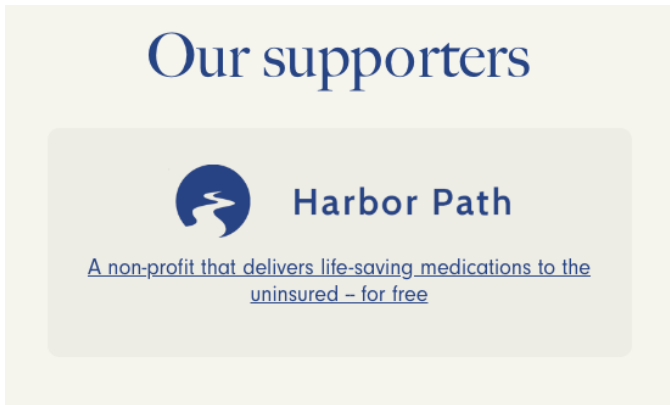
Mission Edge provides clients with a “turn-key nonprofit organization” that gives them the “ability to start a nonprofit project in a matter of weeks.”

“Model A Fiscal Sponsorship Your turn-key nonprofit organization Model A Fiscal Sponsorship offers you the ability to start a nonprofit project in a matter of weeks, with Mission Edge providing all the operational support you need including: 501(c)(3) structure to operate within Full cycle accounting, financial reports, and inclusion in our annual audit and tax filing Comprehensive human resources management, employment, compliance, & benefits administration Strategic support to grow your organization Designed for: Nonprofit organizations and charitable initiatives looking to focus on growth and impact without the burden of forming and maintaining their own 501(c)(3).” [Mission Edge, accessed [5/18/23](#)]

RA CAPITAL AND NPLB SUPPORT HARBOR PATH, A PATIENT ASSISTANCE ORGANIZATION, AND MAY BE USING DATA COLLECTED FROM THAT NONPROFIT’S PROGRAM

NPLB lists Harbor Path as a “supporter” and “partner”

NPLB’s website lists Harbor Path, “A non-profit that delivers life-saving medications to the uninsured - for free” as their only “supporter.”



[NPLB, accessed [5/22/23](#)]

NPLB lists “Free medicines for the people who need them now” as a “research project” for which Harbor Path is their partner and funding from RA Capital.

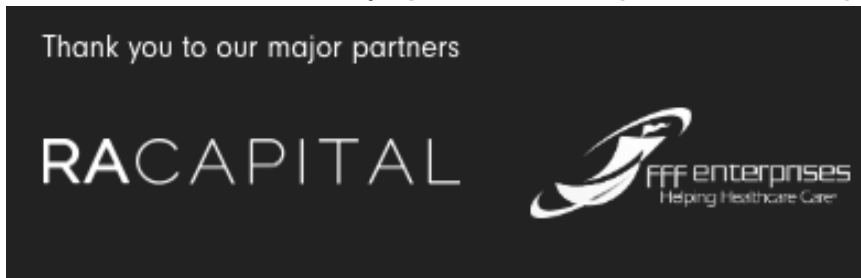
“Free medicines for the people who need them now With: Harbor Path |Funding: RA Capital We’re not content to focus on theoretical ways to help uninsured patients afford drugs. We support Harbor Path, a North Carolina-based non-profit that gets uninsured people their prescription drugs for free within 48 hours. Unlike many patient-assistance charities, Harbor Path helps applicants even if they’re undocumented. Because compassion doesn’t abide by bureaucracy.” [NPLB, accessed [5/22/23](#)]

Harbor Path is a North Carolina patient assistance program, whose “major partners” are RA Capital and FFF Enterprises

Harbor Path is a nonprofit organization that unifies the application for patient assistance programs for people who can’t afford their prescription medications.

“Pharmaceutical manufacturers provide medication to help those who are uninsured. These are called patient assistance programs (PAP). We bring together these different programs to create a simple, easy application process for hospitals and clinics to help their patients gain access to our database of drugs.” [Harbor Path, accessed [5/22/23](#)]

Harbor Path identifies their major partners as RA Capital and FFF Enterprises.



[Harbor Path, accessed [5/22/23](#)]

FFF Enterprises is a drug distributor.

“FFF purchases directly from biopharmaceutical manufacturers and ships only to healthcare providers. With a spotless safety track record, FFF continually blazes new trails when it comes to fulfilling its mission: Helping Healthcare Care.” [FFF Enterprises, accessed [5/22/23](#)]

- **FFF Enterprises manufacturing partners include some of the world’s largest pharmaceutical companies.**

[FFF Enterprises, accessed [5/22/23](#)]

Manufacturing Partners



2020-2021: NPLB AND RA CAPITAL “HELPED ARRANGE A SIGNIFICANT DONATION TO HARBOR PATH, AND NPLB “DECIDED TO TREAT” HARBOR PATH TO A NEW WEBSITE AND NEW CUSTOMER ENGAGEMENT SOFTWARE

2020: NPLB and RA Capital Management “helped arrange a significant donation” to Harbor Path.

“Full disclosure: No Patient Left Behind, via Boston-based RA Capital Management, heard about Harbor Path’s need for auto-injectors to counteract opioid overdoses in mid-2020 and helped arrange a significant donation of them by the manufacturer.” [Harbor Path, [11/16/20](#)]

NPLB and RA Capital “decided to treat Harbor Path to a modernized website and a customer engagement software program...to better capture data about diseases.”

“Full disclosure: No Patient Left Behind, via Boston-based RA Capital Management, heard about Harbor Path’s need for auto-injectors to counteract opioid overdoses in mid-2020 and helped arrange a significant donation of them by the manufacturer. Then it decided to treat Harbor Path to a modernized website and a customer engagement software program called Zendesk to better capture data about diseases, as well as make it simpler to sign up patients, track patients, and get patients their medications – and find patients who are falling through the cracks. The relationship continues to this day.” [Harbor Path, [11/16/20](#)]

KOLCHINSKY AND HARBOR PATH INTIMATED THAT RA CAPITAL WAS USING DATA FROM HARBOR PATH TO “STUDY HOW PEOPLE FELL THROUGH THE CRACKS”

Kolchinsky said that he wanted to study “how people fell through the cracks” and used Harbor Path to direct patients to assistance programs or offer direct help.

“Peter Kolchinsky, a scientist and managing partner of Boston-based RA Capital Management, which invests in biotechnology, immediately saw the possibilities of expanding Harbor Path’s drug arsenal and of helping it reach patients on the margins or hidden in the shadows. He said he also believes that pharmaceutical companies are responsible for being the backstop, or safety net, for people who need treatment they can’t afford. ‘I thought: We’ve got to study how people fell through the cracks and then we have to close those holes,’ Kolchinsky said. ‘As much as possible, Harbor Path needs to be a conductor and get patients to the patient assistance or other programs they need. But when it has nowhere to send them, it needs to be able to help them.’ To streamline that process, No Patient Left Behind, a nonprofit Kolchinsky founded in 2020 to help make medicines affordable for everyone in America, treated Harbor Path to a modernized website and a customer engagement software program called Zendesk. The goal is to better capture data about diseases, as well as make it simpler to sign up patients, track patients, and get patients their medications - and find patients who are falling through the cracks.” [Harbor Path, [11/16/20](#)]

2020-2021: HARBOR PATH’S INCOME INCREASED NEARLY TRIPLED AFTER RA CAPITAL GOT INVOLVED WITH THE ORGANIZATION, AND NPLB LIFE SCIENCE BUILDER GREG WEAVER WAS ADDED TO HARBOR PATH’S BOARD

2020: Harbor Path’s total revenue was \$10,900,690.

[ProPublica, accessed [5/23/23](#)]

2021: Harbor Path’s total revenue was \$29,463,428.

[HARBORPATH Inc., IRS Form 990, via ProPublica, [8/4/22](#)]

2021: Greg Weaver became a member of the Harbor Path board of directors.

[HARBORPATH Inc., IRS Form 990, via ProPublica, [8/4/22](#)]

- **Weaver is an NPLB “Life Science Builder.”**

[NPLB, accessed [5/23/23](#)]

HARBOR PATH STARTED A “SMALL COMMERCIAL ARM THAT OVERSEES PATIENT ASSISTANCE PROGRAMS FOR DRUG COMPANIES” AFTER RA CAPITAL GOT INVOLVED WITH THE NONPROFIT

Following RA Capital’s contact with Harbor Path, Harbor Path started a “small commercial arm that oversees patient assistance programs for drug companies.”

“To streamline that process, No Patient Left Behind, a nonprofit Kolchinsky founded in 2020 to help make medicines affordable for everyone in America, treated Harbor Path to a modernized website and a customer engagement software program called Zendesk. The goal is to better capture data about diseases, as well as make it simpler to sign up patients, track patients, and get patients their medications - and find patients who are falling through the cracks. Harbor Path currently serves 3,000 to 4,000 patients at any given time, a number that could expand exponentially as the organization starts appealing to individual donors and different sorts of foundations, and makes its presence known to more doctors, clinics and hospitals nationwide. For now, to offset the nonprofit’s expenses, Harbor Path has started a small commercial arm that oversees patient assistance programs for drug companies.” [Harbor Path, [11/16/20](#)]

MAY 2021: AN RA CAPITAL EMPLOYEE WROTE A TESTIMONIAL FOR HARBOR PATH, INDICATING THAT NPLB HAD DIRECTED HER TO HARBOR PATH FOR HELP WITH HER FATHER'S MEDICATIONS

5/5/21: Natalie Kostich, a senior program manager at RA Capital, wrote that RA Capital was “funding NPLB and has helped HarborPath.”

“Full disclosure. In fall 2020 I started work at RA Capital Management, a biotech investment firm that is funding NPLB and has helped HarborPath modernize and expand its roster of medicines. I know how fortuitous this relationship was for my family. It also underscores the absurdity of the health insurance system, and how difficult it must be to navigate for people without such a serendipitous set of connections. I have a master’s degree and couldn’t figure it out. [...]

Natalie Kostich is a senior program manager at RA Capital Management.” [Natalie Kostich, Harbor Path, [5/5/21](#)]

5/5/21: Kostich referred to NPLB as a “new nonprofit.”

“That’s when I contacted someone certain to empathize: Lynda Gorov, executive editor of No Patient Left Behind (NPLB), a new nonprofit dedicated to making medicines affordable for everyone in America, in part by putting an end to copays, deductibles and other out-of-pocket costs that should be covered by insurance. She made a few suggestions, and then made the one that really mattered. She suggested I reach out to Ken Trogdon, Harbor Path’s founder and president, who has a longstanding relationship with Merck & Co., which manufactures the drug my dad needed and has a patient assistance program for it.” [Natalie Kostich, Harbor Path, [5/5/21](#)]

- **Kostich wrote that Harbor Path’s founder had a “longstanding relationship with Merck & Co.”**

“She suggested I reach out to Ken Trogdon, Harbor Path’s founder and president, who has a longstanding relationship with Merck & Co., which manufactures the drug my dad needed and has a patient assistance program for it.” [Natalie Kostich, Harbor Path, [5/5/21](#)]

NPLB’s website directs patients struggling to afford medications to patient assistance foundations like the PAN Foundation and HealthWell, and even PhRMA, for financial assistance

April 2021: An NPLB blog post pointed patients struggling to afford cancer drugs to patient assistance organizations, including PAN Foundation and HealthWell Foundation.

“Cancer can quickly deplete the bank accounts of patients who find themselves suddenly unable to work or with steep out-of-pocket expenses they mistakenly thought their health insurance would cover. It can also take time to match a patient’s diagnosis and needs with the financial resources. But there is help. That can include money to cover chemotherapy, as well as related treatments, and non-medical expenses such as utilities and transportation. Among the resources: Copay and other help paying for drugs. Nonprofits that offer this include CancerCare, Co-Payment Assistance Foundation, PAN Foundation and HealthWell Foundation. Drug manufacturer patient assistance programs. Medicare recipients who qualify based on financial need can use these outside the normal Part D drug coverage.” [NPLB, [4/5/21](#)]

- NPLB also linked to a PhRMA resource page for patient assistance programs.
- Copay and other help paying for drugs. Nonprofits that offer this include [CancerCare](#), [Co-Payment Assistance Foundation](#), [PAN Foundation](#) and [HealthWell Foundation](#).
- Drug manufacturer [patient assistance](#) programs. Medicare recipients who qualify based on financial need can use these [outside the normal Part D drug coverage](#).

<https://www.phrma.org/en/Advocacy/Access/Patient-Assistance> many resources, these are income-dependent. They [NPLB, [4/5/21](#)]

NPLB’s website advises patients in need of financial assistance to afford their medications to contact a co-pay assistance program

“Learn more about these resources CancerCare CancerCare provides financial assistance for treatment-related costs such as transportation, home care and childcare. It... Good Days Good Days provides patients with financial assistance for insurance premiums, copays, travel, and diagnostic testing for... Healthwell Foundation The Healthwell Foundation is a non-profit organization that provides underinsured Americans with assistance for prescrip... Leukemia & Lymphoma Society The Leukemia & Lymphoma Society supports people with blood cancers. Its financial assistance programs include patient ai... National Organization for Rare Disorders The National Organization for Rare Disorders provides assistance to rare-disease patients for medication, copays, insura... PAN Foundation The goal of the PAN Foundation is to help underinsured people with life-threatening, chronic, and rare diseases get need... Patient Advocate Foundation The Patient Advocate Foundation provides financial aid to those with chronic, debilitating, or life-threatening illness... Patient Services, Inc. Patient Services, Inc. provides financial assistance for medications, copays, insurance premiums, travel costs, and othe... The Assistance Fund The Assistance Fund provides patients facing high medical costs with financial assistance for copays, insurance premiums...” [NPLB, accessed [5/22/23](#)]

APPENDIX 1: LIFE SCIENCE BUILDER LIST

NPLB Group Identification	Name	NPLB Grouping	Actual	Source
Innovators	Adam Rosenberg	Neurological Disorders	Venture Partner at RA Capital; former president & CEO of Rodin Therapeutics until its acquisition by Alkermes in 2019	RApport (RA Capital) https://rapport.bio/all-stories/venture-partnering-adam-rosenberg
Innovators	Adrian Rawcliffe	Cancer	CEO Adaptimmune	Adrian Rawcliffe LinkedIn profile https://www.linkedin.com/in/adrawcliffe/
Innovators	Andrew Levin MD PhD	Pain	Managing Director RA Capital; co-founder and CEO of Clear Creek Bio	Clear Creek Bio https://clearcreekbio.com/team/andrew-levin
Innovators	Aoife Brennan MB CHB	Rare Diseases	CEO of Synlogic Inc., creating Synthetic Biotic medicines	Aoife Brennan LinkedIn Page https://www.linkedin.com/in/aoife-brennan-28351b2a/
Innovators	Axel Bolte	Rare Diseases	Co-founder, Senior Advisor and Member of Board of Directors Inozyme Pharma	Inozyme Pharma https://www.inozyme.com/our-company
Innovators	Barry Greene	Genetic Disorders	CEO of Sage Therapeutics	Barry Greene LinkedIn profile https://www.linkedin.com/in/barrygreene/
Innovators	Bharatt Chowrira PhD	Immune Disorders	President and chief business, legal & operating officer of PureTech Health, a biotherapeutics company	Bharatt Chowrira LinkedIn profile https://www.linkedin.com/in/bharattchowrira/
Innovators	Bill Newell	Cancer	CEO of Sutro Biopharma	Bill Newell LinkedIn profile https://www.linkedin.com/in/bill-newell-9684953/
Innovators	Burt Adelman MD	Atherosclerosis	Co-Founder and Chairman of the Board of Verve Therapeutics	Verve Therapeutics https://www.vervetx.com/leadership-team/burt-adelman-md/
Innovators	Cedric Francois MD PhD	Blindness	Co-Founder & Chief Executive Officer/President of Apellis Pharmaceuticals	Apellis Pharmaceuticals https://apellis.com/people/cedric-francois-md/
Innovators	Chandra Vargeese PhD	Neurological Disorders	Chief Technology Officer and Head of Platform Discovery Sciences of Wave Life Sciences	Chandra Vargeese LinkedIn profile https://www.linkedin.com/in/chandra-vargeese-129237a/
Innovators	Christian Henry	Genetic Diseases	President & Chief Executive Officer of Pac Bio, a gene sequencing company	PacBio https://www.pacb.com/leadership/christian-henry/
Innovators	Dan Grau	Neurological Disorders	Chairman of Lusaris Therapeutics	Lusaris Therapeutics https://lusaristx.com/divi_overlay/daniel-grau-mphil/
Innovators	Daphne Zohar	Immune Disorders	Founder and CEO of PureTech Health	PureTech Health https://lusaristx.com/divi_overlay/daniel-grau-mphil/
Innovators	Dave Van Meter	Glaucoma	President & CEO of Ivantis, a medical device manufacturer which was acquired by Alcon	
Innovators	David Epstein	Cancer	CEO of Seagen, formerly Novartis CEO	Fierce Pharma https://www.fiercepharma.com/pharma/transition-and-tumult-seagen-names-former-novartis-oncology-chief-epstein-new-ceo
Innovators	David Katz PhD	Cushing's Syndrome	Chief Science Officer of Sparrow Pharmaceuticals	Sparrow Pharmaceuticals https://sparrowpharma.com/leadership

NPLB Group Identification	Name	NPLB Grouping	Actual	Source
Innovators	David-Alexandre Gros MD	Autoimmune Disorders	CEO of Eledon Pharmaceuticals	David-Alexandre Gros LinkedIn profile https://www.linkedin.com/in/dagros/
Innovators	Doug Fambrough PhD	Rare Diseases	Director Oncorus, a biopharmaceutical company, previously co-founder, president & CEO of Dicerna Pharmaceuticals	Oncorus https://www.oncorus.com/about/
Innovators	Eamon Brady	Heart Failure	CEO of WhiteSwell, a medical device company	WhiteSwell https://whiteswell.com/#about
Innovators	Frank Watanabe	Psoriasis	President & CEO of Arcutis Biotherapeutics	Arcutis https://www.arcutis.com/leadership/frank-watanabe/
Innovators	Gabriel Otte	Colorectal Cancer	Founder and former CEO of Freenome, a biotech company, and partner of Healthcare Co-op, a health care VC firm	Gabriel Otte LinkedIn profile https://www.linkedin.com/in/gabrielotte/
Innovators	Gil Beyen	Cancer	CEO of Erytech Pharma	Gil Beyen LinkedIn profile https://www.linkedin.com/in/gil-beyen-a83a462/
Innovators	Gino Santini	Chronic Pain	Board member of Intercept Pharmaceuticals, Collegium Pharmaceutical, Horizon Pharma, and Allena Pharmaceuticals	Gino Santini LinkedIn profile https://www.linkedin.com/in/gino-santini-06121511/
Innovators	Glenn Batchelder	Parkinson's Disease	Venture Partner at Pivotal bioVenture Partners, Chairman of Synchronicity Pharma, XyloCor Therapeutics	Glenn Batchelder LinkedIn profile https://www.linkedin.com/in/glenn-batchelder-7a0a027/
Innovators	Greg Mann	Cancer	SVP of Public Relations and Investor Relations at Nkarta, a biotech company, previously VP of Investor Relations at Gilead Sciences	Greg Mann LinkedIn profile https://www.linkedin.com/in/greg-mann-29b4a81/
Innovators	Greg Weaver	Depression	CFO of atai Life Sciences, a biopharmaceutical company	atai Life Sciences https://ir.atai.life/news-releases/news-release-details/atai-life-sciences-participate-upcoming-march-investor
Innovators	Gregory Verdine PhD	Cancer	Co-founder, president & CEO of Fog Pharma, director at Wave Life Sciences	Fog Pharma https://fogpharma.com/team/gregory-verdine-ph-d/
Innovators	Gustav Christensen	Hereditary Angioedema	Board of directors at Morpnic, former CEO of Dyax, a biopharma company	Morpnic https://morpnic.com/leadership/board-of-directors-gustav-christensen/
Innovators	Ilan Ganot	Duchenne Muscular Dystrophy	Co-Founder and Strategic Advisor to the CEO of Solid Biosciences, a gene therapy company	Solid Biosciences https://www.solidbio.com/about/solid-team/ilan-ganot-co-founder-president-and-ceo
Innovators	Jeffrey Goldberg	Immuno-oncology	Former CEO of Immunitas Therapeutics, a genomics company	BusinessWire https://www.businesswire.com/news/home/20191218005153/en/Jeffrey-Goldberg-Appointed-Chief-Executive-Officer-and-Director-of-Immunitas-Therapeutics
Innovators	Jeremy Levin DPhil MB CHB	Neurological Dis	Chairman & CEO of Ovid Therapeutics, board member of Lundbeck, chairman of Opthea, board member and chairman emeritus of BIO	Jeremy M. Levin LinkedIn profile https://www.linkedin.com/in/jeremylevin/
Innovators	Jim Greenwood	Industry Leader	DLA Piper Life Sciences lobbyist, former CEO of BIO	DLA Piper https://www.dlapiper.com/en/people/g/greenwood-james
Innovators	John Kollins	Migraine	Co-founder, president & CEO of Satsuma Pharmaceuticals	Satsuma https://www.satsumarx.com/john-kollins/
Innovators	John Maraganore PhD	Genetic Disorders	Former CEO of Alnylam Pharmaceuticals	John Maraganore LinkedIn profile https://www.linkedin.com/in/john-maraganore/

NPLB Group Identification	Name	NPLB Grouping	Actual	Source
Innovators	John Tucker	Heart Failure	President & CEO of SC Pharmaceuticals	SC Pharmaceuticals https://www.scpharmaceuticals.com/about/leadership/
Innovators	Jose Juves	Neurological Disorders	Senior Vice President, Head of Communications & Corporate Affairs, Global Portfolio Division of Takeda Pharmaceuticals, formerly SVP at Wave Life Sciences	Jose Juves LinkedIn profile https://www.linkedin.com/in/jose-juves-b4275524/
Innovators	Keith Murphy	Organ Damage Repair	CEO and Chairman of Viscient Bio, former CEO of Organovo	Organovo https://organovo.com/keith-murphy/
Innovators	Ken Rhodes PhD	Neurological Disorders	Vice President, Rare Neurology & Discovery Biology at Pfizer, formerly SVP at Wave Life Sciences	Ken Rhodes LinkedIn profile https://www.linkedin.com/in/ken-rhodes-7673754/
Innovators	Ken Takanashi	Migraine	Board member of Satsuma Pharmaceuticals, EVP and COO of Shin Nippon Biomedical Laboratories	Satsuma https://www.satsumarx.com/ken-takanashi-mba-cpa/
Innovators	Kevin Buchi	Rare Diseases	Director of Benitec Biopharma, previously VP of Teva Pharmaceuticals	Benitec https://ir.benitec.com/corporate-governance/board-committees
Innovators	Kurt Graves	Type 2 Diabetes	Executive chairman of i2o Therapeutics, an oral biologics company	Kurt Graves LinkedIn profile https://www.linkedin.com/in/kurt-graves-6847645/
Innovators	Laura Shawver PhD	Cancer	President & CEO of Capstan Therapeutics, board member at ARS Pharmaceuticals, Nkarta, Cleave Therapeutics, Relay Therapeutics	Laura Shawver LinkedIn profile https://www.linkedin.com/in/laura-shawver-9319a87a/details/experience/
Innovators	Laurie Keating	Rare Diseases	Board Chair of PepGen, director of Imago BioSciences, director Immuneering Corporation, former EVP and Chief Legal Officer of Alnylam Pharmaceuticals	Laurie Keating LinkedIn profile https://www.linkedin.com/in/laurie-keating-34395475/
Innovators	Marcos Milla PhD,	Autoimmune Disorders	Venture Partner at Samsara BioCapital, previously at Janssen	Marcos Milla LinkedIn profile https://www.linkedin.com/in/marcos-milla-0792843/
Innovators	Mark Corrigan MD	Charcot Marie Tooth	Co-founder, board member, and acting CEO of Tremeau Pharmaceuticals, chairman of Elio Therapeutics, board member of Nabriva Therapeutics and Wave Life Sciences	Mark Corrigan LinkedIn profile https://www.linkedin.com/in/mark-corrigan-m-d-57485316/
Innovators	Mark Velleca MD PhD	Cancer	Venture partner at Hatteras Venture Partners (investing in biopharmaceuticals), President & CEO StrideBio, board chair Black Diamond Therapeutics,	Mark Velleca LinkedIn profile https://www.linkedin.com/in/mvelleca/
Innovators	Marsha Fanucci	Rare Diseases	Board of Directors at Cycleron, Syros Pharmaceuticals, FORMA Therapeutics, and Alnylam Pharmaceuticals	Marsha Fanucci LinkedIn Profile https://www.linkedin.com/in/marsha-fanucci-61230914/details/experience/
Innovators	Matthew Kane	Cancer	CEO Tune Therapeutics, co-founder and former CEO of Precision BioSciences	Tune Therapeutics https://tunetx.com/employee/matt-kane/
Innovators	Michael Ehlers MD PhD,	Rare Diseases	Chief Scientific Officer and Venture Partner at Apple Tree Partners, co-founder and board chair at Replicate Bioscience, Aulos Bioscience, Ascidian Therapeutics, Intergalactic Therapeutics, formerly EVP at Biogen and SVP at Pfizer	Michael Ehlers LinkedIn profile linkedin.com/in/michael-ehlers-52a87616/details/experience/
Innovators	Michael Gilman PhD	Cancer	CEO of Arrakis Therapeutics, formerly SVP at Biogen Idec	Michael Gilman LinkedIn profile https://www.linkedin.com/in/mzgilman/details/experience/
Innovators	Michael Hayden MD PhD	Neuro/Psychiatric Diso	Former President of Global R&D, CSO, Teva Pharmaceutical Industries	World Neuroscience Innovation Forum https://neuroscienceinnovationforum.org/speakers/michael-hayden-md/
Innovators	Michael Narachi	Neurological Disorders	President & CEO of CODA Biotherapeutics, board member of BIO, former board member of PhRMA, former VP of Amgen	Mike Narachi LinkedIn profile https://www.linkedin.com/in/mike-narachi-biotech/

NPLB Group Identification	Name	NPLB Grouping	Actual	Source
Innovators	Michael Panzara MD	Neurological Disorders	Chief Medical Officer at Neurvati Neurosciences, previously at Genzyme and Biogen	Nuervati https://neurvati.com/leadership/michael-a-panzara-md
Innovators	Michael Weiss	Lymphoma	Chairman, President & CEO of TG Therapeutics	TG Therapeutics https://www.tgtherapeutics.com/our-company/leadership-team/
Innovators	Mike Grey	Rare Diseases	Chairman of the board of Mirum Pharmaceuticals, board member Horizon Therapeutics	Horizon https://www.horizontherapeutics.com/company/leadership-team/
Innovators	Milind Deshpande PhD	Infectious Diseases	Venture Partner RA Capital, board member Clear Creek Bio, Triana Biomedicines, Availar Therapeutics, Nayan Therapeutics, Spero Therapeutics, former president & CEO of Achillion Pharmaceuticals	Milind Deshpande LinkedIn profile https://www.linkedin.com/in/milind-deshpande-phd-4547961b/details/experience/
Innovators	Nancy Thornberry MD	Obesity	Founding CEO & Chair, R&D, Kallyope, former SVP at Merck	Kallyope https://kallyope.com/team/nancy-thornberry/
Innovators	Pablo Cagnoni MD	Cancer	Executive Partner at Flagship Pioneering a life sciences VC firm, CEO of Laronde, an eRNA therapeutics company, formerly SVP at Novartis	Pablo Cagnoni LinkedIn profile https://www.linkedin.com/in/pablo-cagnoni-81a23415/details/experience/
Innovators	Patricia Fraser MD	Lupus	Head of pharmacovigilance at Nimbus Therapeutics, formerly an executive at Ionis Pharmaceuticals, Sanofi Genzyme, and EMD Serono	Patricia Fraser LinkedIn profile https://www.linkedin.com/in/patricia-fraser-80293099/
Innovators	Paul Bolno MD	Neurological Disorders	President & CEO of Wave Life Sciences, formerly VP of GlaxoSmithKline	Paul Bolno LinkedIn profile https://www.linkedin.com/in/paul-bolno-4506a19/
Innovators	Paul Hastings	Cancer	President and CEO at Nkarta Therapeutics, chair of BIO's executive committee	Paul Hastings LinkedIn profile https://www.linkedin.com/in/paul-hastings-25365a6/
Innovators	Perry Karsen	Genetic Disorders	Chair of the board of Graphite Bio and Nitrase Therapeutics, formerly an executive at Celgene	Perry Karsen LinkedIn profile https://www.linkedin.com/in/perry-karsen-297b4b110/details/experience/
Innovators	Peter Lanciano	Cancer	Director of Sojournix, which has received funding from RA Capital, chairman of Peripha Gen a gene therapy company	Peter Lanciano LinkedIn profile https://www.linkedin.com/in/peter-lanciano-92a37a4/details/experience/
Innovators	Peter Thompson MD	Cancer	General Partner OrbiMed Advisors, CEO Terremoto Biosciences, chairman Silverback Therapeutics, co-founder & director Corvus Pharmaceuticals, Cleave BioSciences	Peter Thompson LinkedIn profile https://www.linkedin.com/in/peter-thompson-0b069a1b/details/experience/
Innovators	Peter Wirth	Cancer	Chairman Forma Therapeutics, Venture Partner with Quan Capital Management, previously with Genzyme	Forma/Novo Nordisk https://www.formatherapeutics.com/team/peter-wirth-j-d/
Innovators	Pratik Shah PhD	Neurological Disorders	Executive chairman of Design Therapeutics, chairman of ARS Pharmaceuticals	Pratik Shah LinkedIn profile https://www.linkedin.com/in/teaks9/details/experience/
Innovators	Rachel King	Leukemia	Co-founder, former CEO, board member of GlycoMimetics, previously executive in residence at New Enterprise Associates, formerly SVP at Novartis, board member at BIO	GlycoMimetics, https://ir.glycomimetics.com/corporate-governance/board-of-directors
Innovators	Rahul Ballal PhD	Sickle Cell Anemia	CEO Mediar Therapeutics, board member Enliven Therapeutics, Agios Pharmaceuticals, Vaderis Therapeutics, former CEO of Imara	Rahul Ballal LinkedIn profile https://www.linkedin.com/in/ballal/details/experience/
Innovators	Rahul Kakkar MD	Autoimmune Disorders	Entrepreneur Partner at Polaris Partners, former CEO of Pandion Therapeutics before it sold to Merck, previously an executive at AstraZeneca	Polaris Partners https://polarispartners.com/partner/rahul-kakkar/
Innovators	Ramin Farzaneh-Far MD	Complement Disorders	Venture Partner at RA Capital; former executive chairman of PepGen, previously Ra Pharmaceuticals, Gilead Sciences	Ramin Farzaneh-Far LinkedIn profile https://www.linkedin.com/in/ramin-farzaneh-far-05665b49/details/experience/

NPLB Group Identification	Name	NPLB Grouping	Actual	Source
Innovators	Rick Klausner MD	Cancer	Founder, Chief Scientist and Board Co-chairman of Altos Labs, board member Fog Pharma Chairman of Altos Labs	Fog Pharma https://fogpharma.com/team/dr-rick-klausner/
Innovators	Riley Ennis	Colorectal Cancer	Co-founder and Chief Product Officer of Freenome, previously at Foundation Medicine and Syros Pharmaceuticals	Freenome https://www.freenome.com/team/team-founder-riley-ennis/
Innovators	Robert Gould PhD	Genetic Disorders	Operating partner at Khosla Ventures, former president and CEO of Fulcrum Therapeutics and Epizyme	Khosla Ventures https://www.khoslaventures.com/team/robert-gould/
Innovators	Ron Cohen MD	Parkinson's Disease	CEO at Acorda Therapeutics	Ron Cohen LinkedIn profile https://www.linkedin.com/in/ron-cohen-m-d-396113/
Innovators	Ruth Thieroff-Ekerdt MD	Neurological Disorders	EVP Clinical Development at Cambrian BioPharma, Founder and Member of Panda Consulting, a consultancy for pharmaceutical program development, previously an executive at Bayer and Schering	Ruth Thieroff-Ekerdt LinkedIn profile https://www.linkedin.com/in/ruth-thieroff-ekerdt-0559969/details/experience/
Innovators	Scott Rakestraw PhD	Neurological Disorders	Venture Partner at RA Capital, president, founder & managing director of The Branta Group, a health care capital investment firm, previously an executive with Orchid Biosciences and Altus Pharmaceuticals	Scott L. Rakestraw LinkedIn profile https://www.linkedin.com/in/scott-l-rakestraw-622b23b/details/experience/
Innovators	Stephen Hoffman MD PhD	Rare Diseases	Co-founder & managing partner Trekk Venture Partners, board of directors at AcRx Pharmaceuticals, chairman Apic Bio	Stephen Hoffman LinkedIn profile https://www.linkedin.com/in/sjhoffmanphdmd/details/experience/
Innovators	Steve Lufkin	Infectious Diseases	CEO of Selux Diagnostics, formerly at Aventis Pharmaceuticals	Steve Lufkin LinkedIn profile https://www.linkedin.com/in/stevelufkin/details/experience/
Innovators	Steve Sherwin MD	Cancer	Board of directors at Biogen, venture partner at Third Rock Ventures, previously at Genentech, board member of Neurocrine Biosciences	Biogen https://www.biogen.com/company/leadership/bio-sherwin-stephen.html
Innovators	Ted Love MD	Sickle Cell Anemia	President & CEO of Global Blood Therapeutics, board member of Seattle Genetics and Royalty Pharma, board member BIO	Ted Love LinkedIn profile https://www.linkedin.com/in/ted-love-14341711/
Innovators	Tim Noyes	Kidney Disease	Advisor at RA Capital, CEO of Arcuate Therapeutics, previously with Proteon Therapeutics and Trine Pharmaceuticals	RA Capital https://www.racap.com/about-us/our-team
Innovators	Tim Springer PhD	Ulcerative Colitis	Harvard professor and billionaire, founding investor in Moderna, resident professor at Pfizer, founder and investor in Scholar Rock and Morphic Rock Therapeutics, board member and investor in Ab Initio Biotherapeutics	Timothy Springer https://timothyspringer.org/people/timothy-springer
Innovators	Troy Ignelzi	Neuropsychiatry	CFO Karuna Therapeutics, board member CinCor Pharma and Vendanta Biosciences, formerly CFO of scPharmaceuticals	Troy Ignelzi LinkedIn profile https://www.linkedin.com/in/troy-ignelzi-b787847/details/experience/
Innovators	Vicki Sato PhD	Infectious Diseases	Chair of the board at Vir Biotechnology, Venture Partner at Arch Venture Partners, retired from Vertex Pharmaceuticals and the board of Bristol Myers Squibb	Arch Venture Partners https://www.archventure.com/team/vicki-sato-ph-d/
Innovators	Vikram Sheel Kumar MD	Cancer	Co-founder & CEO of Clear Creek Bio, co-founder of Scicarta Inc., and Dimagi health informatics companies, former venture partner at RA Capital	Vikram Sheel Kumar LinkedIn profile https://www.linkedin.com/in/vskmd/
Innovators	Wendell Wierenga PhD	Endocrine Disorders	Director at Crinetics, Cytokinetics, Dermata Therapeutics, former executive at Upjohn/Pfizer	Wendell Wierenga LinkedIn profile https://www.linkedin.com/in/wendell-wierenga-7580524/details/experience/
Innovators	Wendye Robbins MD	Fibrotic Diseases	Board member RAPT Therapeutics, former president & CEO Blade Therapeutics, previously president & CEO Limerick BioPharma	Wendye Robbins LinkedIn profile https://www.linkedin.com/in/wendye-robbins-705a652/details/experience/

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Innovators	Ypke Van Oosterhout PhD	Immune Disorders	Founder & CEO of Xenikos an immunotherapy medicines company	Ypke van Oosterhout LinkedIn profile https://www.linkedin.com/in/ypke-van-oosterhout-74242011/
Innovators	Yvonne Greenstreet MBChB	Genetic Disorders	CEO of Alnylam Pharmaceuticals, previously SVP at Pfizer and GlaxoSmithKline	Yvonne Greenstreet LinkedIn profile https://www.linkedin.com/dr-yvonne-greenstreet-2b00389/
Biotech investors	Aaron Davis	Biotech investors	Aaron is co-founder and chief executive officer of Boxer Capital, LLC. After joining Tavistock Group as portfolio manager, Aaron scaled Tavistock Group's public healthcare investing activities and formed Boxer Capital. Aaron leads the firm's research team, deal structuring and portfolio management. Aaron is currently chairman of the board of Civi Biopharma and is a member of the board of directors of iTeos Therapeutics (NASDAQ: ITOS), Mirati Therapeutics (NASDAQ: MRTX), Odonate Therapeutics (NASDAQ: ODT), Rain Therapeutics (NASDAQ: RAIN), Tango Therapeutics (NASDAQ: TNGX), and Flare Therapeutics.	Mirati Therapeutics https://www.mirati.com/about/executive-leadership/#board-of-directors
Biotech investors	Adam Mikkelson	Biotech investors	Partner at Camber Capital Management, board of directors of Masimo, a medical device company	Adam Mikkelson LinkedIn profile https://www.linkedin.com/company/masimo-corporation/
Biotech investors	Alex Karnal	Biotech investors	Co-Founder and Chief Investment Officer of Braidwell, an investment firm focused on biotechnology, pharmaceuticals, medical devices and diagnostics; co-founder, CEO & board chairman of the Institute for Life Changing Medicines; on the board of BIO	Institute for Life Changing Medicines https://www.lifechangingmedicines.org/alexkarnal
Biotech investors	Andreas Wicki PhD	Biotech investors	CEO of HBM Partners a biopharma investment firm, board member of Harmony Biosciences, Buchler, and Pacira Pharmaceuticals	HBM Partners https://www.hbmpartners.com/en/team/personen/wicki-andreas.php
Biotech investors	Andy Acker	Biotech investors	Portfolio manager at Janus Henderson Investors, responsible for global life sciences and biotech investment strategies	Janus Henderson https://www.janushenderson.com/en-us/advisor/bio/andy-acker/
Biotech investors	Andy Schwab	Biotech investors	Founder and managing partner of 5AM Ventures, a life sciences VC firm; led the firm's investments in and served on the Boards of Bird Rock Bio, Blue Light Therapeutics, Camp4 Therapeutics, Cleave Therapeutics, DVS (acquired by Fluidigm), Enliven, Escient Pharmaceuticals, Flexion Therapeutics (NASDAQ: FLXN), Ikaria (acquired by Mallinckrodt and spun-out), Ilypsa (acquired by Amgen), Novome, Pear Therapeutics (NASDAQ: PEAR), Precision NanoSystems (acquired by Danaher), Purigen and TMRW	5AM Ventures https://5amventures.com/team/
Biotech investors	Arjun Goyal MD	Biotech investors	CEO and Chairman of Viscient Bio, former CEO of Organovo	Vida Ventures https://vidaventures.com/vida-team/
Biotech investors	Art Pappas	Biotech investors	Managing Partner at Pappas Capital, a life sciences VC firm and member of BIO; currently a director at Allievex and Sorriso Pharmaceuticals; previously an executive at Glaxo Holdings and Abbott International and Merrell Dow Pharmaceuticals; member of the Investor Advisory Committee at BIO	Pappas Capital https://www.pappas-capital.com/team/art-pappas-mba/
Biotech investors	Bob Deresiewicz MD	Biotech investors	Director at Asher Biotherapeutics; formerly a senior managing director and partner at the Wellington Management Company, investing in biotech companies	Bob Deresiewicz LinkedIn profile https://www.linkedin.com/in/bob-deresiewicz-1853458/
Biotech investors	Brook Byers	Biotech investors	Named partner at Kleiner Perkins, a major VC firm; Founding president and then chairman of four biotechnology companies that were incubated in Kleiner Perkins offices; currently on the board of ArsenalBio	Kleiner Perkins https://www.kleinerperkins.com/people/brook-byers/

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Biotech investors	Bruce Booth DPhil	Biotech investors	Partner at Atlas Venture, a biotech VC firm; currently chairman of Arkuda Therapeutics, AvroBio (NASDAQ: AVRO), Hotspot Therapeutics, Kymera Therapeutics (NASDAQ: KYMR), Matchpoint Therapeutics, Nimbus Therapeutics, and Vigil Neuroscience (NASDAQ: VIGL). He also serves on the board of Magenta Therapeutics (NASDAQ: MGTA), Sionna Therapeutics, and several seed stage companies. He previously served on the boards of past Atlas companies Avila (acquired by Celgene), Lysosomal Therapeutics (acquired by Bial), Padlock (acquired by BMS), Prestwick (acquired by Biovail), Rodin Therapeutics (acquired by Alkermes), Stromedix (acquired by Biogen), and several other ventures. Previously an advisor to Takeda and UCB	Atlas Venture https://atlasventure.com/profile/bruce-booth
Biotech investors	Christoph Westphal MD PhD	Biotech investors	Co-founder & General Partner at Longwood Fund, a VC firm dedicated to novel health care companies; previously co-founder, CEO, and lead investor in Momenta Pharmaceuticals, Inc. (NASDAQ: MNTA, acquired by J&J in 2020), Alnylam Pharmaceuticals, Inc. (NASDAQ: ALNY), Acceleron Pharma, Inc. (NASDAQ: XLRN, acquired by Merck in 2021), Sirtris Pharmaceuticals, Inc. (NASDAQ: SIRT, acquired by GSK in 2008), Verastem (NASDAQ: VSTM), and TScan Therapeutics (NASDAQ: TCRX). o-founder of Alnara Pharmaceuticals (acquired by Eli Lilly in 2010); co-founder/CEO of DEM Bio Pharma, co-founder/CEO of ImmunelD; co-founder/CEO of Immunitas Therapeutics; co-founder of Tome Biosciences; co-founder of Pyxis Oncology (NASDAQ: PYXS); and co-founder of Concert Pharmaceuticals (NASDAQ: CNCE, acquired by Sun Pharma in 2023).	Longwood Fund https://www.longwoodfund.com/people/christoph/
Biotech investors	Clay Thorp	Biotech investors	General Partner at Hatteras Venture Partners, a health care VC firm; Chairman of PhaseBio Pharmaceuticals (PHAS). He is also on the boards of Clearside Biomedical (Nasdaq: CLSD), GeneCentric Therapeutics, StrideBio, Inc., and Seaport Diagnostics. He is a board observer with Tune Therapeutics, Artizan Biosciences, Myeloid Therapeutics, Veralox, Inc., and BITT. Clay is also on the Strategic and Scientific Advisory Board of Bria Biosciences.	Hatteras Venture Partners https://www.hatterasvp.com/people/clay-b-thorp/
Biotech investors	Corey Goodman PhD	Biotech investors	Managing Partner of venBIO Partners, a VC firm whose limited partners include large pharmaceutical companies; hair of the Board of ALX Oncology, Tollnine, and Second Genome. He is a member of the Board of Checkmate and NFlection. He chaired Labrys Biologics until its acquisition by Teva.	venBio http://www.venbio.com/corey.html
Biotech investors	DA Wallach	Biotech investors	General Partner at Time BioVentures, a VC firm focused on health care and biotech companies,	DA Wallach LinkedIn profile https://www.linkedin.com/in/dawallach/
Biotech investors	Dan Lyons PhD	Biotech investors	Portfolio Manager at Janus Henderson Investors, responsible for co-managing the biotechnology strategy	
Biotech investors	David Beier	Biotech investors	Managing Director at Bay City Capital, a life sciences VC firm; previously in government affairs at Amgen and Genentech	David Beier LinkedIn profile https://www.linkedin.com/in/dbeier/details/experience/
Biotech investors	David Goeddel PhD	Biotech investors	Managing Partner at the Column Group, a VC firm investing in early-stage drug discovery companies; "first scientist hired by Genentech"; co-founded Tularik, which was acquired by Amgen; chairman of the boards of A2 Biotherapeutics, Hexagon Bio, and Tenaya Therapeutics, on the board of NGM Biopharmaceuticals	The Column Group https://www.thecolumngroup.com/member/david-v-goeddel-phd/
Biotech investors	David Socks	Biotech investors	Co-founder & CBO HilleVax, a biopharmaceutical company; co-founder and board member of Phathom Pharmaceuticals; former board chair of Eleusis, a psychedelic medicines company; former venture partners at Frazier Healthcare Partners	David Socks LinkedIn profile https://www.linkedin.com/in/david-socks-3b1b4436/

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Biotech investors	Gaurav Aggarwal MD	Biotech investors	Managing Director at Vivo Capital, a health care investment firm; investor and previously served on the boards of Auspex Pharmaceuticals (acquired by Teva), Hyperion Therapeutics (acquired by Horizon), NextWave Pharmaceuticals (acquired by Pfizer), Piramed (acquired by Roche) and Flowcardia (acquired by CR Bard). Other successful investments include Amarin, ISTA Pharmaceuticals and Spinal Concepts. In addition to his role as an investor, Gaurav was the Chief Business Officer of Ocera Therapeutics, a publicly traded clinical stage company developing therapies for orphan liver conditions.	Vivo Capital https://vivocapital.com/Team/gaurav-aggarwal/
Biotech investors	Graham Walmsley MD PhD	Biotech investors	Co-founder & managing member of Logos Global Management, a biotech investment firm; currently serves on the board of Akero Therapeutics (NASDAQ: AKRO), ALX Oncology (NASDAQ: ALXO), and Olema Pharmaceuticals (NASDAQ: OLMA).	Logos Capital Management https://www.logoscapital.com/
Biotech investors	Howie Furst MD	Biotech investors	Partner at Deerfield Management, on the therapeutics team; board member of Appello Pharmaceuticals	Appello Pharmaceuticals https://appellopharma.com/team.html
Biotech investors	Jack Nielsen	Biotech investors	Partner at Vivo Capital, a life science VC firm; member of the Board of Directors of Aligos Therapeutics, ALX Oncology, Harmony Biosciences, Instil Bio, Macologix, and Reata Pharmaceuticals Inc.; previously at Novo Nordisk	Vivo Capital https://vivocapital.com/team/jack-b-nielsen/
Biotech investors	Jakob Loven PhD	Biotech investors	Managing partner at Nextech Invest, "a global, cancer therapeutics-focused venture capital firm"; board member of A2 Biotherapeutics, Arrakis, IconOVir, Hexagon, Boundless, Laronde, Scorpion and Flare. He is a former board member of Vividion (acquired by Bayer (ETR: BAYN)), Kronos (NASDAQ: KRON), Arvinas (NASDAQ: ARVN), and board observer of Kinnate (NASDAQ: KNTE), Turning Point Therapeutics (NASDAQ: TPTX) and Autolus (NASDAQ: AUTL).	Nextech Invest https://www.nextechinvest.com/team/
Biotech investors	Jamie Topper MD	Biotech investors	Managing Partner at Frazier Life Sciences, a life sciences VC firm; invested in certa Pharma BV (sold to AstraZeneca), Amunix Pharmaceuticals (sold to Sanofi), Calistoga Pharmaceuticals (co-founder, sold to Gilead Sciences), Mavupharma (sold to AbbVie), Rempex (sold to The Medicines Company), Incline (co-founder, sold to The Medicines Company), Alnara (sold to Lilly), Portola (co-founder, NASDAQ: PTLA), CoTherix (sold to Actelion), and Threshold (NASDAQ: THLD). He currently represents Frazier on the boards of Alpine Immune Sciences (NASDAQ: ALPN), AnaptysBio (NASDAQ: ANAB), Lassen Therapeutics, NewAmsterdam Pharma (NASDAQ: NAMS), Phathom Pharmaceuticals (NASDAQ: PHAT), and Seraxis. In addition, Jamie is a board observer for Alcresta Therapeutics.	Frazier Healthcare Partners https://www.frazierhealthcare.com/team/james-topper?strategy=life-sciences
Biotech investors	Janice Bourque	Biotech investors	Managing Director at Hercules Capital in the Life Sciences Group; previously president and CEO of the Massachusetts Biotechnology Council	Janice Bourque LinkedIn Profile https://www.linkedin.com/in/janicebourque/
Biotech investors	Janis Naeve PhD	Biotech investors	Partner at Cota Capital, a VC firm; previously head of the corporate venture group at Amgen	Cota Capital https://www.cotacapital.com/team/janis-naeve/
Biotech investors	Jay Lichter PhD	Biotech investors	Member of Avalon BioVentures, a biotech VC firm; chairman of Janux Therapeutics; led investments in or is on the board of AristaMD, Fortis Therapeutics, Inc., Avelas BioSciences, Inc., COI Pharmaceuticals Inc., and Sova Pharmaceuticals, Inc.	Janux Therapeutics https://www.januxrx.com/team/jay-lichter-ph-d/

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Biotech investors	Jean-Francois Formela MD	Biotech investors	Partner at Atlas Venture, a biotech VC firm; director and co-founder of IFM Therapeutics, Intellia Therapeutics (NASDAQ: NTLA), and Korro Bio. Jean-François also serves on the boards of Ikena Oncology (NASDAQ: IKNA) and Scorpion Therapeutics. His prior investments include Adnexus (acquired by BMS), ArQule (NASDAQ: ARQL, acquired by Merck), Arteaus Therapeutics (acquired by Eli Lilly), CoStim Pharmaceuticals (acquired by Novartis), Exelixis (NASDAQ: EXEL), Horizon Therapeutics (NASDAQ: HZNP), NxStage (NASDAQ: NXTM, acquired by Fresenius), and Translate Bio (NASDAQ: TBIO, acquired by Sanofi).	Atlas Venture https://atlasventure.com/profile/jean-francois-formela
Biotech investors	Jon Edwards PhD	Biotech investors	Managing director at Red Tree Venture Capital; previously investments include Synthorx (THOR; acquired by Sanofi), Phathom Pharmaceuticals (PHAT), Checkmate Pharmaceuticals (CMPH; acquired by Regeneron), Impact Biomedicines (acquired by Celgene), Sydnexis Inc., Xenikos B.V., and Breakpoint Therapeutics GmbH. Dr. Edwards held board seats in all the aforementioned companies (observer seats in Synthorx and Checkmate Pharmaceuticals). He has also held board seats on Z-Factor Ltd., UltraHuman Ltd., and Palladio Biosciences and was a board observer with ApicintX Ltd. and Capella Bioscience; currently is a board member at Excellergy, Sardona Therapeutics, and Rondo Therapeutics.	Red Tree Venture Capital https://redtreevc.com/team/
Biotech investors	Jonathan Leff	Biotech investors	Partner, Chairman of the Deerfield Institute at Deerfield Management, on the therapeutics team, focused on biotech and pharmaceuticals	Deerfield Management https://deerfield.com/team/jonathan-leff
Biotech investors	Josh Resnick MD	Biotech investors	Senior Managing Director at RA Capital; previously a managing partner within Merck's early-stage therapeutics venture fund	RA Capital https://www.racap.com/about-us/our-team
Biotech investors	Martin Heidecker PhD	Biotech investors	Chief Investment Officer at AMR Action Fund, a biotech VC firm; previously Managing Director USA of Boehringer Ingelheim Venture Fund; Board member of MassBio	Martin Heidecker LinkedIn profile https://www.linkedin.com/in/martin-heidecker-454b308/
Biotech investors	Matthew Perry	Biotech investors	President at BVF Partners LP, a biotech investment firm; board member at Xoma Corp, Cti Biopharma, and Nordic Biotech	Bloomberg https://www.bloomberg.com/profile/person/7544968
Biotech investors	Michelle Dipp MD PhD	Biotech investors	Co-Founder and Managing Partner at Biospring Partners, a life science "growth equity firm"; Board of Directors of two Biospring portfolio companies, Abzena and Kiniciti; previously an SVP at GlaxoSmithKline	Biospring https://biospring.com/who-we-are/#about-michelle-dipp-md-phd
Biotech investors	Nimish Shah	Biotech investors	Investor at Venrock Healthcare, a VC firm; co-founder and Board Director of Apogee Therapeutics and a Board Observer for Dianthus. He previously served as a Board Director for InstilBio (NASDAQ: TIL) and Board Observer for LianBio (NASDAQ: LIAN), Biohaven Pharmaceuticals (NYSE: BHVN) and Viridian Therapeutics (NASDAQ: VRDN).	Venrock https://www.venrock.com/teammember/nimish-shah/
Biotech investors	Nina Kjellson	Biotech investors	General partner at Canaan, investing in Biopharma and digital health companies; currently invested in IntrepidiaBio, PACT Pharma, Tizona Therapeutics, Trishula Therapeutics, Tyra, and Vineti;	Canaan https://www.canaan.com/team/nina-kjellson
Biotech investors	Otello Stampacchia PhD	Biotech investors	Managing director at Omega Funds, a life sciences VC firm;	Omega Funds https://omegafunds.com/team/otello-stampacchia/
Biotech investors	Peter Kolchinsky PhD	Biotech investors	Managing Partner at RA Capital; Founder of NPLB	
Biotech investors	Pieter Boelhouwer	Biotech investors	Partner and managing director of strategy and operations at RA Capital	RA Capital https://www.racap.com/about-us/our-team

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Biotech investors	Rajeev Shah	Biotech investors	Managing partner at RA Capital; previously at Altus Pharmaceuticals, a spinoff of Vertex Pharmaceuticals	RA Capital https://www.racap.com/about-us/our-team
Biotech investors	Rich Aldrich	Biotech investors	Founding partner of Longwood Fund; helped to found Sirtris Pharmaceuticals (NASDAQ: SIRT acquired by GlaxoSmithKline); Concert Pharmaceuticals (NASDAQ: CNCE) where he serves as Chair of the Board; and Longwood portfolio companies Alnara Pharmaceuticals (acquired by Eli Lilly in 2010), Verastem (NASDAQ: VSTM), Axial Therapeutics, and TScan Therapeutics. Rich also serves as a Director of Longwood portfolio companies Axial, Renovia, Sitryx Therapeutics, and Colorescience; co-founder of RA Capital Management; founding employee of Vertex Pharmaceuticals; served in management positions at Biogen	Longwood Fund https://www.longwoodfund.com/people/rich/
Biotech investors	Rob Hopfner PhD	Biotech investors	Managing director at Pivotal BioVenture Partners; currently a member of the Board of Directors of Evomune, Inozyme Pharma (NASDAQ: INZY), Oculis SA, Plexium, Rallybio (NASDAQ: RLYB), and Vaxcyte (NASDAQ: PCVX), and he led Pivotal's investments in Exscientia and Arcutis (NASDAQ: ARQT). Rob brings a broad range of venture investing experience, from early / seed stage company building work through later stage investing. Past investments include Acix Therapeutics (sold to Nicox S.A.), Civitas Therapeutics (sold to Acorda Therapeutics), Dermira (sold to Lilly), Hyperion Therapeutics (sold to Horizon Pharma), Imara Therapeutics (NASDAQ: IMRA), Kezar Life Sciences (NASDAQ: KZR), Madrigal Pharmaceuticals (NASDAQ: MDGL), Merus BV (NASDAQ: MRUS), NextWave Pharmaceuticals (sold to Pfizer), Protez Pharmaceuticals (sold to Novartis), and Vtesse (sold to Sucampo Pharmaceuticals). Rob was previously a Managing Director at Bay City Capital and prior to that worked in DuPont / Merck Pharmaceuticals' Business Development & Strategy group.	Pivotal BioVenture Partners https://pivotalbiovp.com/team-members/#rob-hopfner-bio
Biotech investors	Rob Perez	Biotech investors	Operating partner at General Atlantic, a VC firm; Current Board Affiliations Immunocore, PANTHERx, PathAI, Third Harmonic Bio, Vir Biotechnology; previously CinCor Pharma board member; previously president & CEO of Cubist Pharmaceuticals, which was sold to Merck	General Atlantic
Biotech investors	Sara Nayeem MD	Biotech investors	Partner at Avoro Capital Advisors, a biopharmaceutical investment firm; currently serves on the board of Vanqua Bio Inc., a biotechnology company; board observer for Scribe Therapeutics	Avoro Capital https://avorocapital.com/news/team_members/sara-nayeem/
Biotech investors	Scott Gazelle MD PhD	Biotech investors	Founder of Greybird Ventures, a diagnostics VC firm; on the Board of Atlas 5D and Ceres Nanosciences, and as Chair of the Board of Hummingbird Diagnostic, Angstrom Bio and Genetika+.	Greybird Ventures https://greybirdventures.com/bio/scott-gazelle/
Biotech investors	Steve Squinto PhD	Biotech investors	Chief investment officer and managing partner of J.P Morgan Life Sciences Private Capital; executive chairman at Gennao Bio; previously was an executive partner at OrbiMed Advisors (health care investment management firm), and served as interim chief executive officer at Passage Bio, Inc.; co-founder of Alexion Pharmaceuticals; previously at Regeneron Pharmaceuticals	Stephen Squinto LinkedIn profile https://www.linkedin.com/in/stephen-squinto-bb99499/
Biotech investors	Thilo Schroeder PhD	Biotech investors	Managing partner at Nextech Invest, "a global, cancer therapeutics-focused venture capital firm"; board member of Revolution Medicines (NASDAQ: RVMD), Circle Pharma, Cargo Therapeutics, Atavistik Bio, MOMA Therapeutics, Exo Therapeutics and Alterome Therapeutics. Past board seats include Blueprint Medicines (NASDAQ: BPMC), Silverback Therapeutics (NASDAQ: SBTX), Peloton Therapeutics (acquired by Merck (NYSE: MRK), PMV Pharma (NASDAQ: PMVP), Black Diamond Therapeutics (NASDAQ: BDTX), and IDEAYA Bioscience (NASDAQ: IDYA).	Nextech Invest https://www.nextechinvest.com/team/

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Biotech investors	Tim Shannon MD	Biotech investors	General partner at Canaan, investing in Biopharma and digital health companies; currently invested in Arvinas, Halda Therapeutics, IDEAYA Biosciences, Normunity, Vivace Therapeutics; previously invested in Civitas Therapeutics (Acquired by Acorda Therapeutics), CytomX, NextCure, Novira Therapeutics (Acquired by Johnson & Johnson), Rallybio	Canaan https://www.canaan.com/team/tim-shannon
Biotech investors	Walter H. Moos PhD	Biotech investors	Co-founder & managing director of Pandect Bioventures, a biotech and pharmaceutical VC firm; board member Rigel Pharmaceuticals, Circle Pharma, Valitor; past CEO & chairman ShangPharma Innovation; previously chairman and CEO of MitoKor (Migenix) and a vice president at Chiron (Novartis) and Warner-Lambert/Parke-Davis (Pfizer)	Walter Moos LinkedIn profile https://www.linkedin.com/in/walter-h-moos-7710804/details/experience/
Biotech investors	Wende Hutton	Biotech investors	General partner at Canaan, investing in Biopharma and digital health companies; currently invested in Antiva Biosciences; Glooko, Hyalex Orthopaedics, OncoResponse, Qlaris Bio; previously invested in Alsius Corporation (Acquired by Zoll), Apieron (Acquired by Aerocrine), BiPar Sciences, Inc. (Acquired by Sanofi-Aventis), Calibra Medical (Acquired by LifeScan / Johnson & Johnson), Chimerix, Dermira, Labrys Biologics (Acquired by Teva Pharmaceutical), Northstar Neuroscience, Transcend Medical (Acquired by Alcon / Novartis)	Canaan https://www.canaan.com/team/wende-hutton
Industry advisors	Bruce Dobbs	Industry advisors	Vice President Corporate Finance & Marketing at Singh Biotechnology; facilitator for NCS Madison, an Independent Business Information, Business Development and Peer-to-Peer Networking Services Company	NCS Madison https://ncsmadison.com/cfo-east/facilitators/
Industry advisors	Catherine Arnold	Industry advisors	Partner at Centerview Partners, an investment banking firm; Ms. Arnold's recent life science transactions and advisory include: • The \$40b acquisition by AstraZeneca of Alexion, • \$12.5b sale of Biohaven to Pfizer with simultaneous spin of neuroscience assets into a new publicly traded company, • \$11.5bn sale of Acceleron to Merck • \$6.7bn acquisition of Arena Pharmaceuticals by Pfizer, • Sanofi's strategic review and bid for Horizon Therapeutics, ultimately acquired by Amgen for \$28bn, • Pfizer's spin out of select autoimmune assets; previously an executive at Roche Pharmaceuticals,	Centerview Partners https://www.centerviewpartners.com/ourteammember.aspx?employee=Catherine%20J.%20Arnold#top
Industry advisors	Jeffrey Solomon	Industry advisors	President of TD Cowen, a division of TD Securities	TD Cowen https://www.cowen.com/profile/jeffrey-solomon/
Industry advisors	Jonathan Kfoury	Industry advisors	Partner Emeritus in L.E.K. Consulting's Chicago office, focused on life sciences and healthcare; previously a manager at Cubist Pharmaceuticals	LEK https://www.lek.com/leadership/jonathan-kfoury
Industry advisors	Julia Gaebler PhD	Industry advisors	Chief business officer at Lucy Therapeutics, a biotech company; board member at Atlas5D, a medical device company; previously a VP at Milestone Pharmaceuticals; previously partner at Health Advances, a health care industry consultancy; previously an executive at Biogen Idec and Amylin Pharmaceuticals	Julia Gaebler LinkedIn profile https://www.linkedin.com/in/juliaaagaebler/details/experience/
Industry advisors	Rick Wiessenstein	Industry advisors	Managing Director, Washington Research Group - Health Care Services & Pharmaceutical Policy at TD Cowen, a division of TD Securities	TD Cowen https://www.cowen.com/profile/rick-weissenstein/