



OnPoint: Issue Brief

A Publication by the Massachusetts Association of Health Plans

Volume XXVIII, March 2026

Hidden Influence: How Pharmaceutical Funding of Patient Advocacy Organizations Undermines Patient Interests & Impacts Prescription Drug Costs

Prescription drug prices are higher in the United States than in any other nation. In 2024, U.S. spending on prescription drugs reached \$806 billion, driven by the ever-increasing prices charged by pharmaceutical manufacturers.¹ Prescription drugs continue to reach record high prices, with launch prices as high as \$4.25 million for a one-time treatment.²

In Massachusetts, prescription drugs continue to drive health care spending. In 2023, spending on prescription drugs reached \$15.2 billion, driven by the exorbitant cost of brand name drugs. Prescription drug spending represented the largest share of overall total health care expenditures in 2023, rising 11.6% from 2022-2023 alone, accounting for 24.7% of the increase in total health care spending.³

As prescription drug costs continue to drive health care spending for consumers and employers, transparency and accountability in the pharmaceutical industry have become a focus for policymakers across the U.S. In particular, funding from pharmaceutical manufacturers, often provided through grants or donations to patient advocacy organizations (PAOs), has raised concerns about how industry funding may be used to shape policy debates. These financial relationships have prompted scrutiny of pharmaceutical companies' strategies to advance their interests through third-party organizations, rather than the mission or value of PAOs themselves.

What are patient advocacy organizations and why are they important?

PAOs have long played a critical role in the health care system by amplifying patient voices, providing education and support, and ensuring that lived patient experiences inform policymaking. Their participation in public policy discussions is essential to ensuring that patient perspectives remain central to decisions about coverage, access, and affordability.

There are currently no legal requirements in the U.S. for disclosure of pharmaceutical industry sponsorship to PAOs by either party to the transaction. There is a growing concern that these sponsorships interfere with the objectivity of advocacy groups and lead them to take public positions that are often favorable to the drug industry.

Do Patient Advocacy Organizations Represent Patients or the Pharmaceutical Industry?

In 2018, the Kaiser Pre\$cription for Power Database was established to explore the financial relationships between the pharmaceutical industry and patient advocacy organizations on a national level. Kaiser found that in 2015, only 57% of the largest PAOs in the United States publish the amount of donations they receive from pharmaceutical companies on their websites or in their annual reports.⁴ Of those published, just 5% are published in exact figures, while most donations are published in ranges.

In 2015, 14 pharmaceutical companies alone contributed more than \$116 million to PAOs across the U.S. Some drugmakers gave seven-figure donations to PAOs whose communities depend on blockbuster medicines made by those companies, calling into question whose interests they truly represent. For example, in 2015, a national PAO representing the interests of individuals with inflammatory bowel disease accepted \$2.7 million from one drugmaker who makes the top prescription drug that costs \$77,000 for a year's supply for treating inflammatory conditions like Crohn's disease and colitis.

In 2023, Public Citizen, a nonprofit consumer advocacy organization, analyzed grants made by the Pharmaceutical Research and Manufacturers of America (PhRMA), the nation's most powerful pharmaceutical company trade group, and its member companies between 2010 and 2022. Public Citizen found that between 2010 and 2022, the drug industry's main lobbying group and member companies provided at least \$6 billion in grants to more than 20,000 organizations.⁵ The analysis found that the total amounts to three and a half times more than the total lobbying spending, and seventy times more than the campaign contributions, dispersed by the PhRMA Network over that time. Further, 13 of the nation's largest and most powerful PAOs received more than \$10 million from the PhRMA Network, for a total of \$266 million. The analysis also documents instances where grant recipients engaged in policy advocacy, public communications, or lobbying activities aligned with pharmaceutical industry positions, including on drug pricing and coverage policy, raising concerns about potential conflicts of interest and transparency.

Influence at Play: How Pharma Funding Can Sway Patient Advocacy

While funding plays an important role in ensuring financial viability for PAOs, it may create conflicts of interest and compromise the independence of these organizations.

For example, a 2019 study found that the nation's leading mental health patient advocacy organization receives nearly two-thirds of its donations from pharmaceutical companies.⁶ Under pressure from a Congressional investigation, the mental health PAO revealed that the funding may have influenced its lobbying on FDA black-box warnings for antidepressants, arguing that the warnings could deter treatment while downplaying risks of untreated mental illness. This example clearly illustrates how financial ties to industry can create potential conflicts of interest for PAOs as the organizations' actions directly contradicted the interests of the patients they represent.

Current U.S. Action and Industry Practices

Federal Legislative Efforts

Currently, in the United States there are no federal requirements for disclosure of pharmaceutical industry contributions to patient advocacy organizations. However, federal efforts to require public reporting have been ongoing over the last decade, but have been unsuccessful.

Most recently, U.S. senators reintroduced the Open Payments Expansion Act this congressional session in a continued effort to require pharmaceutical and medical device manufacturers to publicly report their financial relationships with tax-exempt PAOs. The proposed bill, S.2710, would expand upon the Physician Payment Sunshine Act by adding "patient advocacy organizations" to the list of entities that pharmaceutical manufacturers are required to include in their open payments reporting.⁷ In 2010, as part of the Patient Protection and Affordable Care Act, Congress began requiring the disclosure of payments and transfers of value from biologic, drug, device, and medical supply manufacturers to physicians and teaching hospitals. However, there is no required reporting of payments to PAOs or nonprofits. The Open Payment Expansions Act would require disclosure of indirect payments or other transfers of value to PAOs made by manufacturers through third parties. The legislation is based on the principle that transparency would allow for a better understanding of the potential for conflicts of interest and a way to mitigate potential harm to patients.

National Codes of Conduct and Industry Standards

While no formal legislative action has been taken at the federal level, the National Health Council (NHC) and the Pharmaceutical Research and Manufacturers of America (PhRMA) have created their own codes of conduct regarding interactions between pharmaceutical companies and PAOs. PhRMA, a trade association representing pharmaceutical companies, established a code of conduct entitled “Principles on Interactions with Patient Organizations” that states pharmaceutical companies must respect the values and independence of PAOs, stating that “All interactions with patient organizations must be consistent with the patient organization’s mission and adhere to high ethical standards. The independence of patient organizations must be respected.”⁸ However, the code of conduct does not include a requirement or recommendation for public disclosure of funding to PAOs. The NHC, a nonprofit association consisting of over 100 PAOs in the U.S., implemented a Standards of Excellence Certification Program pertaining to accounting, evaluation, and reporting of financial contributions.⁹ However, the standards permit patient advocacy organizations to circumvent disclosure of company-specific support by just requiring an aggregate value for total corporate sponsorship.

Currently, less than one-fourth of PAOs in the U.S. reported having disclosure policies for public reporting of pharmaceutical industry financial relationships, and the organizations that do report are not required to complete a full disclosure.

State Level Legislation and Initiatives

At the state level, Nevada is currently the only state that has enacted legislation to increase transparency in the pharmaceutical industry. In 2017, Nevada passed legislation requiring nonprofit PAOs that receive contributions from pharmaceutical manufacturers or pharmacy benefit managers to report annually the amounts, sources, and forms of these donations, with the information made publicly accessible.¹⁰ The legislation also requires that the annual reports either be posted on the nonprofit’s own publicly accessible website or submitted to the Nevada Department of Health and Human Services if the nonprofit does not maintain a website.

Massachusetts has also considered, but ultimately not enacted, legislation to increase transparency into pharmaceutical funding of PAOs. During the 2023–2024 legislative session, House Bill 1201, *An Act to Promote Transparency in Prescription Drug Prices*, proposed to require pharmaceutical manufacturers to annually disclose payments and other transfers of value to PAOs, consumer advocacy organizations, voluntary health agencies, and disease-specific advocacy coalitions, and directed the Health Policy Commission to publish a public report analyzing the impact of such funding on health care public policy in the Commonwealth.¹¹ These provisions were reported favorably by the Joint Committee on Health Care Financing and were attached to Senate Bill 749, *An Act Relative to Pharmaceutical Access, Costs and Transparency (PACT Act)*. However, while the PACT Act was enacted in 2024, the provisions related to transparency into pharmaceutical funding of patient advocacy organizations were not included in the final law.

Active Legislative and Organizational Disclosure Efforts in Other Countries

In comparison to the United States, several countries have established laws that require the disclosure of pharmaceutical industry contributions to patient advocacy organizations.

- **The United Kingdom:** In 2021, the Association of British Pharmaceutical Industry (ABPI), helped create the ABPI Code of Practice to require pharmaceutical companies that are members to publicly disclose annual lists of patient advocacy organizations (PAOs) to which they provide financial or significant indirect/nonfinancial support. The 2024 ABPI Code of Practice, effective January 2025, strengthens these requirements by mandating that companies include links to these disclosures on the Disclosure UK database, improving accessibility and transparency.¹² While pharmaceutical companies in the U.K. are not required to be members of the ABPI, they currently have 150 full members, who supply 85% of the pharmaceuticals consumed in the U.K.
- **Australia:** Medicines Australia, the trade association that represents pharmaceutical companies in Australia, promulgates the Medicines Australia Code of Conduct that establishes guidelines for interactions with PAOs, including transparency reporting requirements related to patient advocacy organization funding.¹³
- **France:** In 2013, France signed a law requiring biannual reporting through an online database of information on direct and indirect benefits, dates of exchanges, and monetary values between pharmaceutical companies and PAOs.¹⁴

Policy Recommendations

Despite Massachusetts' leadership in health care cost transparency and oversight, there is currently no state requirement for pharmaceutical manufacturers or patient advocacy organizations to disclose financial relationships. This lack of transparency is particularly concerning given the prominent role patient advocacy organizations play in the Commonwealth's policymaking process. PAOs regularly testify before the Massachusetts Legislature, submit comments to state agencies, and engage in public-facing campaigns related to prescription drug pricing, coverage, and access. Without clear disclosure of industry funding, policymakers and the public may lack critical context needed to fully evaluate advocacy positions that can influence legislation, regulatory decisions, and, ultimately, prescription drug spending in Massachusetts.

To increase transparency into pharmaceutical company practices and ensure PAOs execute on their intended role in the health care system of representing patient interests, MAHP recommends strengthening disclosure and transparency around pharmaceutical industry funding and payments. Unlike payments to health care providers, pharmaceutical manufacturers are not legally required to report donations, grants, or other financial support provided to PAOs. Consistent with Massachusetts' history of aggressive transparency and public accountability, enhanced disclosure would build on existing state practices and align with public interest.

Importantly, greater transparency is not intended to undermine patient voices or question the legitimacy of advocacy organizations. Rather, transparency helps ensure that patients, policymakers, and the public have appropriate context when evaluating advocacy positions that may influence legislative or regulatory outcomes.

MAHP further recommends that Governor Healey's newly established Health Care Affordability Working Group evaluate and advance policy options to increase transparency into pharmaceutical manufacturer funding of patient advocacy organizations as part of its efforts to address the underlying drivers of health care costs in Massachusetts.

PAOs play an important role in informing policy by testifying before the Legislature and other government agencies, and influencing public opinion. It's vital that policymakers and the public understand the funding sources behind these organizations, and any potential conflicts of interest that could influence their advocacy positions. MAHP recommends the Legislature enact transparency reporting requirements for pharmaceutical manufacturer donations to patient advocacy organizations. Such disclosures would promote public trust, preserve the integrity of patient advocacy, and align with the Commonwealth's broader commitment to transparency in the health care system.

Endnotes

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