

NEWS

Most patient advocacy groups accept funding from pharma

BY EMILY KOPP, KAISER HEALTH NEWS

2 MARCH 2017

High-profile advocacy groups for individuals with cancer, Alzheimer's, HIV and other diseases almost always accept funding from pharmaceutical firms, and many fail to report any contributions, new research shows.

At least 83 percent of the United States' 104 largest patient advocacy groups take contributions from the drug, medical device and biotech industries, raising questions about whether they consistently put patients first, according to a paper published 1 March in the *New England Journal of Medicine*.

"If you're a policymaker and you want to hear from patients, there's a danger if there's an undisclosed or underdisclosed conflict of interest," says study investigator **Matthew McCoy**. "The 'patient' voice is speaking with a pharma accent."

Of the 18 nonprofits not reporting pharmaceutical money, all but five failed to disclose their donors at all. Just one of the 104 nonprofits stated explicitly that it does not accept industry money.

Executives or former executives in the pharmaceutical industry serve on a third of the organizations' boards, the researchers found.

These possible conflicts of interest are troubling, experts say, because while patients and drugmakers both want better treatments, they often have opposing goals.

Patients want cheaper medicine; the pharmaceutical industry wants to maximize revenue. Patients want information about the efficacy of certain drugs; the industry often seeks faster approvals for drugs, at which point the incentive to collect information about a drug has diminished, according to

Vinay Prasad, assistant professor of medicine at Oregon Health and Science University.

“Who is setting the narrative of what patients want?” he says. Prasad is cited by the researchers but did not help conduct the study.

Research into the relationship between patient advocacy groups and the pharmaceutical industry is nascent, but the study finds that drug dollars prop up a higher proportion of patient groups than some previous papers suggest.

Fuzzy math:

A **survey of patient advocacy executives** published in the *Journal of the American Medical Association (JAMA)* in January, for example, found that 67 percent of groups reported industry donors.

The latest study focused on larger groups that receive at least \$7.5 million in revenue each year, which likely churned up more industry funding than a broader approach might have, says McCoy, a postdoctoral fellow in advanced biomedical ethics at the University of Pennsylvania.

Also, pharmaceutical companies might funnel money to patient advocacy groups through other nonprofits, which would be harder to trace. “A patient organization may have gotten \$1 million from the Making People’s Lives Better Fund. ... That second degree of interrogation is not something we captured,” says McCoy.

About one-fifth of the patient advocacy groups studied accepted \$1 million or more from drugmakers, but exactly how much those groups accepted is fuzzy. Half of the organizations disclosed their donations in ranges rather than precise amounts, and most of those reported their highest donations with an unbounded upper range, according to the study.

Neither the new study nor the *JAMA* study examined how often a patient organization lobbied Congress, wrote letters to lawmakers or took stances on legislation.

But transparency in pharmaceutical ties is important even for advocacy groups with little presence on Capitol Hill, says **Susannah Rose**, who worked on the *JAMA* study.

Aside from steering legislation, the groups are important stakeholders in the delivery of care, research funding and patient assistance.

“Advocacy groups often give a voice to people who do not have a voice,” says Rose, scientific director of research in the Office of Patient Experience at the Cleveland Clinic and an expert in bioethics.

Conflicts of interest:

But whereas academic research centers, physicians and other medical professionals often feel pressure to reveal their associations with industry and face institutional checks against potential conflicts of interest, patient advocacy groups are too often overlooked, she says.

The paper comes at a time of both growing influence and heightened scrutiny of patient advocacy groups.

Pharmaceutical industry giant Pfizer said 24 February it had received a **subpoena related to its support of patient advocacy programs** that offer financial assistance for Medicare patients' copays. Johnson & Johnson disclosed 27 February it had **also received a subpoena** from the U.S. Attorney's Office for the District of Massachusetts, seeking information about its support of organizations that pay for patient assistance. Those follow similar subpoenas sent to four drugmakers in 2015 and 2016 — Gilead Sciences, Jazz Pharmaceuticals, Valeant Pharmaceuticals and Biogen.

U.S. officials have not commented about the probe. But they could be trying to assess whether drugmakers are covering patients' copays for expensive drugs and leaving taxpayers with the bill for the remainder of the cost, says **Joel Hay**, professor of pharmaceutical economics and policy at the University of Southern California. Hay has served as a paid expert witness in lawsuits against drugmakers. Pharmaceutical companies cannot subsidize the purchase of their products by Medicare.

Paying a relatively small subsidy for patients' copays can also "take the pressure" off Congress to pass reforms that meaningfully slash drug prices in a way that undercuts the bottom line, says Prasad.

The Pharmaceutical Research and Manufacturers of America, the drug industry's trade association, responded to questions about the new study in a statement: "While we cannot speak for particular organizations, we have heard from many patients who are concerned about the growing out-of-pocket cost burden when trying to access needed health care services and treatments."

Kaiser Health News' coverage of prescription drug development, costs and pricing is supported in part by the **Laura and John Arnold Foundation**.

This story originally appeared on Kaiser Health News. It has been slightly modified to reflect Spectrum's style.