

Widespread conflicts of interest among patient-advocacy organizations uncovered in study

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Over the past few decades, hundreds of patient-advocacy organizations have emerged in the United States, promoting disease research and influencing FDA and health insurer policies. Now, a new study reveals a large proportion of these organizations have funding or other connections with drug or medical device makers, yet do not adequately disclose the details of these connections or have publicly accessible policies in place describing how they manage them. The study, led by medical ethicists at the Perelman School of Medicine at the University of Pennsylvania and published this week in the *New England Journal of Medicine*, suggests that patient advocacy organizations should at least do more to acknowledge their industry connections.

"Our findings provide support for a new 'sunshine' law to oblige drug, device, and biotechnology companies to report the payments they make to patient organizations in the same way the must report payment to physicians and teaching hospitals," said lead author Matthew McCoy, PhD, a postdoctoral fellow in the department of Medical Ethics & Health Policy at Penn Medicine. "Greater transparency would allow citizens, researchers, policymakers, and others to assess conflicts of interest of patient-advocacy organizations in a way that is not currently possible, and would make it easier for patient-advocacy organizations that accept little or no [industry](#) support to differentiate themselves from those that are heavily dependent on such support."

Media reports in recent years have highlighted the fact that some industry-funded patient-advocacy organizations often seem to take industry's side on policy issues, for example by failing to support drug-price reform measures, and by pushing insurers to cover expensive drugs whose benefits to patients are questionable.

In the new study, one of the largest and most comprehensive to date, the team examined websites and annual reports for 104 US-based patient-advocacy organizations with annual revenues of \$7.5 million or more.

Results showed that the vast majority of the organizations received [industry funding](#). More than 80 percent (86 out of 104) explicitly reported such support, and most of the remaining organizations left open the possibility of industry support by providing no donor information. Only one of the 104 patient-advocacy organizations stated plainly that it didn't accept industry funding.

Information on donated amounts was typically provided in broad ranges, and in some cases not disclosed at all. But, among the 59 organizations that published donated amounts, 23 (39 percent) reported receiving at least \$1 million annually.

The study revealed other connections to industry besides financial support. More than one-third (37/104) of the reviewed organizations reported having one or more board members that were also executives at pharmaceutical, biotech or medical device companies. For 12 of the organizations, the industry executive held a leadership position on the board.

Despite these extensive connections with industry, only 12 of the patient-advocacy organizations had published policies addressing such institutional conflicts of interest.

"What we're seeing is that institutional conflicts of interest are the norm among larger patient-advocacy organizations, and that disclosure and management of these conflicts is limited," said senior author Harald Schmidt, PhD, an assistant professor of Medical Ethics & Health Policy at the Perelman School of Medicine at the University of Pennsylvania.

The authors suggest that patient-advocacy organizations should at least have more rigorous disclosure practices, which could include fully identifying donation amounts, sponsors, and uses, along with any other connections to industry.

In a 2009 report on conflicts of interest in medical research and practice, a National Institute of Medicine panel also recommended legislation to mandate disclosures of industry payments to patient-advocacy organizations. However, current laws cover only industry payments to doctors and [teaching hospitals](#).

Provided by Perelman School of Medicine at the University of Pennsylvania

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