

US patient advocacy groups received majority of pharma donations in multi-country study

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A new study by Johns Hopkins Bloomberg School of Public Health researchers found that U.S.-based patient advocacy organizations received a disproportionate amount of contributions made by the world's 10 largest pharmaceutical companies in 2016.

The study assessed contributions to patient advocacy groups in seven countries and the United Kingdom and found that U.S.-based patient advocacy organizations received 74 percent of total contributions in 2016, or an estimated \$88 million dollars.

Patient advocacy organizations are [nonprofit groups](#) that focus on specific medical conditions. They are found in almost every industrialized country and seek to raise awareness, lobby for research and treatment options as well as provide patient and caregiver education, advocacy and support services.

The study was published online February 21, 2019 in the *American Journal of Public Health*.

"Patient advocacy groups have an important role when they testify in Congress, at the Food and Drug Administration, the Centers for Medicare & Medicaid Services and other government agencies," says senior co-author Gerard Anderson, Ph.D., professor in the Bloomberg School's Department of Health Policy and Management. "It is important

for policymakers to understand the funding sources for these organizations."

The report reveals a patchwork of disclosure levels among countries, with only six of the 10 [drug companies](#) disclosing their financial donations to U.S.-based patient advocacy organizations in 2016. This disclosure gap suggests that the total amount of contributions to U.S.-based patient groups was even higher, as four companies did not disclose their U.S. contributions.

In contrast, the study found that all 10 companies disclosed their 2016 financial transactions to patient advocacy organizations in France, Germany and the United Kingdom, which encourage or require such disclosure.

The authors say the findings underscore the importance of transparency given the growing role of patient advocacy groups, particularly in the U.S., and recommend moving to greater disclosure, either voluntary or regulatory.

"Patient advocacy groups have grown exponentially in the last 10 years, but the magnitude of pharmaceutical industry funding to them across countries has not been measured before," says So-Yeon Kang, MPH, MBA, lead study author and research associate in the Bloomberg School's Department of Health Policy and Management. "Patient advocacy organizations are supposed to represent their constituents' interests. Transparency is critical to avoid conflict of interests."

For their study, the researchers identified the world's 10 largest pharmaceutical companies based on total global revenue in 2016: Pfizer, Novartis, Roche, Sanofi, Merck, AbbVie, Amgen, Gilead, Janssen and GlaxoSmithKline. Together they accounted for 41 percent of pharmaceutical industry revenue that year. The study authors then

researched disclosures for contributions from these 10 companies to patient advocacy groups based in Canada, France, Germany, Italy, Japan, Spain, the United Kingdom and the U.S. The researchers collected [financial information](#) from pharmaceutical websites, funding reports and other public-facing documentation, such as annual reports.

In France, Germany and the United Kingdom, where all 10 pharmaceutical companies disclosed financial contributions to patient groups, the researchers note that in addition to robust regulatory frameworks, information about disclosures was easily accessible and content was consistent.

Other countries, including the United States, had varying amounts of disclosed information available. The researchers report that they encountered several barriers with data collection in the U.S., including different reporting styles and mixed information with various types of grants.

The six companies that disclosed contributions to U.S. groups contributed \$120 million in patient advocacy funding to the study countries—\$88 million to U.S. groups and \$32 million to groups in the remaining six countries and the U.K.

Researchers also wanted to understand the relationship between patient advocacy groups and the pharmaceutical market in the respective countries. The researchers did not find any association between companies' contributions to a country's patient advocacy groups and the country's population, pharmaceutical revenue or GDP.

"If financial support to patient advocacy organizations is really about patient education, you would expect the funding to be the same in each country," says Anderson. "This analysis shows that there's no correlation and something more than patient education influences the level of

patient advocacy organization support in a country."

The disproportionate amount of funding to U.S. patient advocacy organizations and unregulated financial disclosures highlight the importance of establishing reporting guidelines.

"Legislative actions, such as expanding the Physician Payment Sunshine Act, would insure universal disclosure compliance," says Kang. "But as an intermediary step, the industry should consider adopting a voluntary disclosure requirement at the trade association level. They already have it in Europe. Why not in the U.S.?"

Increased transparency, the authors say, would help address potential conflicts of interest associated with the pharmaceutical industry's support. "The U.S. has one of the most robust drug regulation processes," explains Anderson. "It is often the first country to adopt prescription drugs and therefore has a significant influence on a product's performance in a global market. Regulation is important because these groups can be influenced by the money they receive from drug companies."

More information: So-Yeon Kang et al, Pharmaceutical Industry Support of US Patient Advocacy Organizations: An International Context, *American Journal of Public Health* (2019). [DOI: 10.2105/AJPH.2018.304946](https://doi.org/10.2105/AJPH.2018.304946)

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