

## Patient-Advocacy Charities' Dark Ties: Updates

10.06.17 | Linda J. Rosenthal, JD



Recently, in [Patient Advocacy Nonprofits' Dark Ties to Industry](#), we highlighted the murky, questionable relationships of pharmaceutical companies with patient-advocacy groups. “Patient groups are supposed to represent patients,” we wrote. “But many have deep ties to industry.” The national media is now covering two new research projects uncovering “the incestuous connections between patient-advocacy groups and the healthcare industry.” According to [\[a\] report](#) in the Journal of the American Medical Association, “[m]ore than eight in 10 patient groups take money from the medical industry,” and “[a] quarter of the largest patient-advocacy groups in the U.S. get more than \$1 million each year from the industry.” In addition, over one-third of the patient groups “had current or former industry executives on their boards....” A second study published in [JAMA Internal Medicine](#) reported similar conclusions. Powerhouses including the American Diabetes Association, the Arthritis Foundation, and the Epilepsy Foundation are among the patient-advocacy groups implicated in these study findings. While that fact alone “doesn’t necessarily mean that these groups have been compromised,” the public has the “right to know more.” Part of the goal of publicizing this problem is spurring “action on the part of the patient-advocacy nonprofits to come out into the sunlight and make necessary reforms and disclosures” including the establishment of conflict-of-interest policies.

### *Patients Step Up*

Consumers and patient advocates hoping for reform are not sitting idly by while patient-advocacy-group officials try to sweep this problem under the rug.

Just last month, there was a big win by “[patient advocates in Nevada](#)” who –

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*...goosed a bill in the legislature requiring insulin makers to disclose the profits they make on the drug necessary to the survival of the 1.25 million Americans who live with Type 1 diabetes. The cost of insulin has risen more than threefold over the last decade, only to be met with a truly stunning silence from patient advocacy nonprofits.*

Feeling “abandoned by their advocacy groups, diabetes patients organized a campaign on Twitter, using the hashtag #insulin4all.” They had to “go it alone” without help from “advocacy groups like the American Diabetes Association.”

The reason, according to a news report publicizing this accomplishment, is that “many of the dozens of U.S. diabetes advocacy organizations, large and small, garner significant portions of their funding from insulin manufacturers.” But they don’t necessarily disclose this. For example, the Nevada Diabetes Association –

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*does not list its financial sponsors on its website or on its IRS Form 990. Executive Director Sarah Gleich says, ‘We disclose what we have received, and the IRS does not require that we publicly publish from whom. No one is giving out their invitation list to the party.’*

The result of this lobbying effort is that the Nevada legislation will “require such contributions be openly disclosed.”

### *The Feds Take An Interest in These Charities*

In a related story, the IRS is looking into “the tax-exempt status of a charity funded by pharmaceutical companies, threatening a lifeline the industry uses to help patients buy expensive drugs for cancer, multiple sclerosis and other diseases.”

The Chronic Disease Fund, a 501(c)(3) patient-assistance organization, is “funded largely by drugmakers.” For instance, some 95 percent of the almost \$130 million the group gave out in “co-payment support in its public programs in 2011 went to patients taking drugs made by the very companies that had donated the money...”

A key issue is whether the Chronic Disease Fund provides “impermissible” benefits to these corporate donors. According to arguments by IRS attorneys in federal-court filings in several states including California and Pennsylvania, the donations “are nearly all returned to those same pharmaceutical manufacturers as payments for the drugs they make.” The regulators characterize the Chronic Disease Fund as a mere “conduit.”

The Internal Revenue Service, seeking “information related to the probe,” has reportedly contacted drug giants Johnson & Johnson, Teva, Bayer AG, Biogen, and Novartis.

### *Conclusion*

These newest developments suggest that the concerns raised by charity and medical-ethics experts are being heard and investigated. There may yet be sunlight on these dark practices.