

Patient Advocacy Nonprofits' Dark Ties to Industry

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In recent years, the secretive relationships between healthcare businesses and physicians have been exposed, leading to some much-needed reforms of the sordid practice of doctors being paid to direct patients to certain prescription drugs or to medical products or services.

Two new studies – just announced in the national media – may bring needed sunlight to another unsavory trend: the incestuous connections between patient-advocacy groups and the healthcare industry.

Patient Advocacy Organizations Cozy Up to Business

“Patient groups are supposed to represent patients. But many have deep ties to industry.”

Dr. Ezekial Emanuel, well-known University of Pennsylvania health-policy expert, is a co-author of the first study titled “Conflicts of Interest for Patient-Advocacy Organizations.

According to this 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.”

Just as alarming is that, “in addition to the financial support, at least 39 percent of patient groups had current or former industry executives on their boards, meaning industry players are helping guide and govern these organizations.”

These researchers looked at Form 990 tax records, annual reports, and websites of the largest US-based patient advocacy groups; those with annual revenues of at least \$7.5 million. “They found patient groups were failing miserably at managing their conflicts of interest. The vast majority took money from industry, and yet 88 percent of the organizations the authors looked at had not published policies for conflicts of interest.”

These include such powerhouses as the American Diabetes Association, the Arthritis Foundation,

and the Epilepsy Foundation. Of course, these findings don't necessarily mean that these groups have been compromised, according to Matthew McCoy, a postdoctoral fellow leading the research team. "I don't want to impugn them," he said. "But I think we have a right to know more. Several of the named organizations responded to this report denying any problems associated with this funding.

A second study, with similar conclusions, was published recently in JAMA Internal Medicine. Author Susannah Rose, Ph.D., reported that some 67% of a national sample of patient advocacy organizations, had received "funding from for-profit companies. Twelve percent received more than half of their funding from industry; a median proportion of 45% of industry funding was derived from the pharmaceutical, device, and/or biotechnology sectors."

"A lot of people believe and really trust in patient advocacy groups," said Dr. Rose.

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These groups are often very powerful – not only providing care and direct access to patients and physicians – but they are also big players in national and state and local governments in terms of policy development and driving research agendas....[T]hey need to maintain their independence from the industry to keep their credibility.

Patient Advocacy Groups' Unsavory Ties: Recommendations

The study authors point out that "[r]esearch for decades has shown that cozy relationships between doctors and industry – for instance, industry-sponsored medical education and free drug samples from pharmaceutical companies – can bias doctors' judgment in all sorts of negative ways." The remedy has been to bring out these relationships into the sunlight and mandate that conflict-of-interest policies be adopted. Indeed, "[medicine] has become more transparent over the past decade –

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with drug and device makers now publishing information about which doctors and teaching hospitals they give money or gifts to, and medical journals and research institutions pushing for clear disclosures on conflicts of interest. The idea is that transparency is a disinfectant that reduces the risk of bias in research and medical practice.

A similar approach – "more transparency" – is needed for the patient-advocacy groups and their business funders.

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Drop in on any of the fierce debates about drug prices or the need for new medicines in the US, and you'll find patient advocacy groups right in the middle, speaking up for the sick. These organizations represent millions of people with diseases like cancer, MS, and diabetes, and they are among the first places people turn to for help when they get sick.

“Patient groups have been seen to be knights in shining armor and above reproach,” Dr. Emanuel says. “They haven’t established [the conflict of interest] policies that everyone else — from major hospitals to researchers and journals — has had to.”

Conclusion

These important new studies, highlighted by national media attention, should spur action on the part of the patient-advocacy nonprofits to come out into the sunlight and make necessary reforms and disclosures.