Should Patient Groups Not Required to Disclose Funding From Pharmaceutical Companies

A new study has found that more than 80% of patient advocacy groups receive funding from drug and medical device companies. The study looked at 104 of the top patient advocacy nonprofits. Combined, they report more than 7.5 million dollars in revenue in 2014, with a wide discrepancy in the way that these companies reported their donations. Patient advocacy groups exist to provide the support and information needed to navigate the modern medical system, but why are their own conflicts of interest not one of the things they disclose?

The Ties that Bind

Patient advocacy is a growing profession in the United States. Insurance companies, government, medical professionals, and the pharmaceutical industry all have fingers in the healthcare pie. People can get overwhelmed by all of the red tape and can be subjected to less than ideal care. The benefit of a health advocate is having someone focused on your needs without the conflict of an employer or any other commercial interest. But while patient advocacy on a small scale can provide incredible personal benefits, health advocacy as a whole has strong ties to the pharmaceutical and medical device community. Nearly forty percent of the organizations reviewed in this study had an industry member seated on their board.

Who Watches the Watchmen

There are times when these ties damage the recipients of service that the health advocacy groups list in their mission

statements. Many of these groups have been silent on the issue of rising drug prices or disclosing their funding sources in court proceedings. The lack of disclosure also allows other businesses to take advantage of the altruistic framework of health advocacy and use it to confuse the public, like the Global Energy Balance Network set up by Coca-Cola in 2014. Advocacy groups aren't entirely funded by pharmaceutical companies, but without a standard of disclosure, is there any way to know exactly how much influence those companies have?

Being Informed

Professional health and patient advocacy is a relatively new profession. There are no licenses or accreditations required to be a patient advocate. Combine that lack of oversight with the lack of disclosure and there is a system ripe for behind the scenes manipulation. The good that these groups can do, especially when it comes to negotiating with insurers, needs to be carefully weighed against their reluctance and even inability to speak out against harmful pharmaceutical and medical device practices. Now more than ever, you are your best health care advocate. Being informed about medical issues and options is the best weapon in your arsenal.

Sources:

- *More Than 80 Percent of Patient Groups Accept Drug Industry Funds, Study Shows* – NY Times
- *Furor Over Drug Prices Puts Patient Advocacy Groups in Bind* – NY Times
- *Working In Retirement: How To Be A Patient Advocate* – Forbes
- *Coca-Cola Funds Scientists Who Shift Blame for Obesity Away From Bad Diets* – NY Times