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## Patient Advocacy Organizations: Institutional Conflicts of Interest, Trust, and Trustworthiness

**Susannah L. Rose, Ph.D. [Associate Professional Staff member]**

Department of Bioethics at the Cleveland Clinic; an Assistant Professor at Case Western Reserve University; and a Lab Fellow at the Edmond J. Safra Center for Ethics at Harvard University. She specializes in empirical and normative analysis focusing on ethics and health policy.

### Patient Advocacy Groups

Patient advocacy organizations (PAOs) provide patient- and caregiver-oriented education, advocacy, and support services. PAOs are formally organized nonprofit groups that (a) concern themselves with medical conditions or potential medical conditions and (b) have a mission and take actions that seek to help people affected by those medical conditions or to help their families.<sup>1</sup> Examples of PAOs include the American Cancer Society, the National Alliance on Mental Illness, and the American Heart Association. These organizations advocate for, and provide services to, millions of people with physical and mental conditions — such as cancer, mental illness, diabetes, and cardiovascular disease — via their outreach, meetings, counseling, websites, and published materials.<sup>2</sup> A PAO usually seeks to raise public awareness of a disease's symptoms, risk factors, and treatment options and promotes research to cure or to prevent that disease.<sup>3</sup>

Additionally, these organizations often play significant roles in educating the public and lobbying government officials with the aims of increasing research funding for research and treatment as well as changing legislation related to the diseases they represent.<sup>4</sup> They lobby for increases in spending by the National Institutes of Health (NIH) and the U.S. Department of Defense. Some organizations even financially support research themselves. For example, the American Cancer Society, with revenues of nearly \$1 billion in 2011, sponsors significant clinical research and continuing education for oncology clinicians, along with sponsoring many other local and national activities.<sup>5</sup>

In the past decades, many of these groups have been very successful in achieving their goals.<sup>6</sup> One reason is that because many PAOs were started and are run by patients or former patients with serious diseases, they have credibility with the public, legislators, and government agencies (such as the NIH) and are therefore frequently consulted.<sup>7</sup> For example, PAO representatives sit on NIH committees that review research proposals and

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participate in congressional hearings. However, there are concerns that the independence of some PAOs is being threatened by their financial conflicts of interest.

## PAOs and Conflicts of Interest

According to *Conflicts of Interest in Medical Research, Education, and Practice*, published by the Institute of Medicine (IOM) of the National Academy of Sciences,<sup>8</sup> conflicts of interest (COI) can exist at the individual level — for example, with a physician or researcher — but can also exist at the institutional level — for example, with PAOs.<sup>9</sup> “Institutional conflicts of interest arise when an institution’s own [secondary] interests or those of its senior officials pose risks of undue influence on decisions involving the institution’s primary interests.”<sup>10</sup> This definition is based on political philosopher Dennis Thompson’s conceptualization of conflicts of interest.<sup>11</sup> PAOs may legitimately have various missions and activities, but their primary interest is to benefit the constituents for whom they claim to advocate. These constituents might be their own members or, more broadly, people with the disease or condition the PAO focuses on, along with their family members.

A PAO’s secondary interests or commitments might include financial rewards or other personal or institutional gains; within limits, these might be “legitimate and even desirable goals.”<sup>12</sup> For example, PAOs need to raise money in order to perform their advocacy activities, but such financial interests are secondary to the organization’s primary commitments. A PAO should therefore weigh the risks and benefits of receiving donations, which can both advance and compromise its mission. In turn, appealing to the IOM’s definition, it is acceptable for an organization to receive financial support when gaining that support does not supersede the organization’s primary obligations to its constituents. But, according to the IOM, it is often difficult for an organization to balance its primary interests with its need to survive financially.

## Conflicts of Interest, Bias, and Increased Risk of Harm

According to the handful of studies that have investigated the financial ties between PAOs and the pharmaceutical industry, between 30 and 71 percent of PAOs have such relationships.<sup>13</sup> Two studies have been published that focus on U.S.-based PAOs. One study, conducted by Sheila Rothman and colleagues, reviewed the disclosures of advocacy groups that received funds from the pharmaceutical company Eli Lilly (as reported by the company’s grant office).<sup>14</sup> Lilly donated \$3,211,144 to advocacy groups during the first two quarters of 2007, and “the funding was closely aligned with the company’s therapeutic areas of interest. . . . Neurosciences, endocrinology, and oncology received 94% of Lilly’s grants.”<sup>15</sup> A study by Jessica Marshall and Peter Aldhous reports that some prominent U.S. PAOs, including the American Heart Association, received up to \$23 million from the drug industry.<sup>16</sup> Others, such as the Depression and Bipolar Support Alliance, reported that over half of their funding came from industry and that most of that funding came from pharmaceutical companies. Table 1 provides some examples of total donations received but does not show the number of donors or the percentage of PAO funding from each donor, because the PAOs included in this study did not disclose this information. This omission is significant: when a large portion of an organization’s funding comes from one source, that

donor may have more influence on the organization — and perhaps more corrupting influence — than a collection of potentially competing, for-profit donors might have.<sup>17</sup> Not surprisingly, the authors of this study note that “groups in our survey that received no industry funding seemed to be for diseases that drug companies have little opportunity to profit by,” supporting the claim that drug companies donate to PAOs for profit motives. Sheila Rothman and her colleagues reached similar conclusions.<sup>18</sup>

Further evidence of the significant financial ties between PAOs and industry comes from the public donation disclosures recently provided by several drug makers as a result of lawsuits and new laws affecting the drug companies’ donations to physicians, researchers, and others.<sup>20</sup> For example, GlaxoSmithKline (GSK), one of the largest drug companies in the U.S., states that it works closely with many PAOs; it publishes a list of all donations to physicians and organizations on its website.<sup>21</sup> In total, GSK gave approximately \$5,050,000 to 105 PAOs during the first three quarters of 2009, with an average of nearly \$48,095 per PAO; donations ranged between \$500 and slightly over \$1 million.<sup>22</sup> These figures indicate that the amount of money given to PAOs is significant both in terms of the total amount donated to PAOs and the amount that some individual PAOs receive.

Although the appropriateness of PAOs receiving funds from pharmaceutical firms is debated in the academic literature, there is no way to know ahead of time the risks and benefits of any particular donation.<sup>23</sup> Marcia Angell, former editor-in-chief of the *New England Journal of Medicine*, raises significant concerns about PAOs’ dependence on drug company money in her book, *The Truth About the Drug Companies: How They Deceive Us and What to Do About It*.<sup>24</sup> COI arising from financial dependence on drug makers may lead PAOs to advocate for drugs to enter the marketplace more quickly, despite the potential harms associated with expedited drug review.<sup>25</sup> PAOs might also be more likely to advocate for insurance coverage of drugs that yield minimal or no benefits. They may also be more likely to promote the use of certain drugs despite known risks; the American Pain Foundation, for example, allegedly downplayed the risks of opioid drugs and sought to increase their usage, potentially increasing the risk of addiction. That Foundation recently closed down.<sup>26</sup>

Good intentions do not immunize PAOs from bias that may harm their constituents. No one, not even a committed professional or advocate, is immune to the bias that results from conflicts of interest or financial gain.<sup>27</sup> Numerous studies have found that even established and respected researchers and physicians are influenced by drug company money and gifts, which can bias study conclusions and encourage increased prescribing of potentially harmful medications.<sup>28</sup> There is no reason to believe that PAOs are any less susceptible to such influence. In fact, there is little oversight of relations between PAOs and their for-profit donors, which in itself increases the potential for undue influence.<sup>29</sup> Similar concerns regarding the lack of oversight have been raised regarding the physician professional groups that develop clinical care guidelines.<sup>30</sup>

According to an investigation by Senator Charles Grassley, the National Alliance on Mental Illness (NAMI), which is one of the leading nonprofit advocacy groups for mental illness in the U.S.,<sup>31</sup> relies very heavily on contributions from drug companies.<sup>32</sup> Between 2006 and 2008, NAMI received over \$23 million — about three-quarters of its donations — from drug

companies.<sup>33</sup> In particular, NAMI received significant donations from the manufacturers of the psychiatric medications it promoted. Furthermore, “NAMI has long been criticized for coordinating some of its lobbying efforts with drug makers and for pushing legislation that also benefits industry.”<sup>34</sup> Specifically, it is implicated in promoting the use of certain antidepressants — selective serotonin reuptake inhibitors — and opposing the black-box warnings (the FDA’s most serious safety warning) while downplaying the growing evidence that those antidepressants increase the risk of suicide and suicidal ideations among children and adolescents.<sup>35</sup> When the FDA reviewed the evidence on the side effects of these drugs, it ultimately approved the black-box warnings, indicating that there were, in fact, significant concerns regarding the use of these drugs in certain populations.

Whether or not industry relationships altered NAMI’s actions or positions, financial dependency on drug companies increases the *risk of harm* to individuals and patient communities. What makes the NAMI case more compelling is that it did not disclose its financial relationships with the drug companies until government investigations uncovered the conflicts of interest.<sup>36</sup> The problem is not unique to NAMI; as stated above, detailed disclosure of industry financial support is uncommon among PAOs.

Clearly, NAMI and many other PAOs are attractive recipients and partners for industry, due to their credibility and their growing political influence.<sup>37</sup> When drug makers lobby government officials for funding and appeal to the FDA for drug approvals, their profit motives are readily apparent, but when PAOs advocate for the same things, government officials and the public are likely to assume that the PAOs are acting independently and without bias in the best interests of the people they represent. While PAO-industry partnerships provide industry with credibility in promoting their products, they undeniably provide the PAOs with financial support and resources. The problem is that the missions of drug makers and PAOs can diverge. Drug companies primarily want to increase profits, while PAOs — at least in principle — want to provide safe and effective treatments for people diagnosed with various medical conditions. However, as the NAMI case suggests, harm might result if the PAO is biased (in its support of a particular class of drugs). If NAMI was not so reliant upon money from the companies that manufactured these drugs, there would be less concern that its actions were the result of financial conflicts of interest.

### COI Policies: Trust versus Trustworthiness

The IOM report on conflicts of interest focuses almost entirely on *trust* — stating that a primary objective for COI policies is to promote and maintain trust — and only mentions the role of *trustworthiness* in passing.<sup>38</sup> Neither term, however, is defined in the report, so the implications of its policy proposals are not clear. To explore the appropriate target for institutional COI policies, I will analyze the relation between trust and trustworthiness, drawing from the literature on trust, including the work of Avner Ben-Ner and Louis Putterman, who state:<sup>39</sup>

[W]hen we say that “A trusts B” we mean that A believes that there is a sufficiently high probability that B will not harm her, or that B will live up to his commitments.... Whereas A trusts B to some degree or none as a function of characteristics of A and B and of the situation in question, B’s degree of

trustworthiness is an objective attribute of B alone, reflecting his predilection to act in certain ways in certain circumstances.<sup>40</sup>

This description implies that many factors may affect the degree to which constituents trust a PAO. Constituents (or “trusters”) are likely to trust a PAO when they believe that the organization is doing what it says it will do and that it is not harming the people it says it is trying to help. Furthermore, the target of that trust is usually something specific: one may trust a PAO to advocate for policies related to a particular medical condition, while not trusting it on other matters. Rather than say, “A trusts B,” then, it is more to the point to say, “A trusts B to do X.”<sup>41</sup> It is also important to note that Ben-Ner and Putterman’s definition implies that constituents are vulnerable or dependent upon the entity being trusted. Trustworthiness, on the other hand, is not based on how people *perceive* PAOs.<sup>42</sup> Rather, it is a description of what the organization actually is and does. To be trustworthy, an entity must have certain attributes, which Margaret Levi and Laura Stoker say fall along two dimensions.<sup>43</sup> The first is “moral values that emphasize promise keeping, caring about the trustor, incentive compatibility, or some combination of all three.”<sup>44</sup> The second is competence to perform the tasks it is supposed to carry out.

These dimensions of trustworthiness are relevant when considering what policies and procedures may help PAOs behave in ways that are consistent with being trustworthy. For example, COI policies are supposed to reduce the risk of harm to people. To formulate or assess such policies, it is what PAOs actually do that is important, not what people think about them. And, because trust can be misplaced, we should try to enhance PAOs’ trustworthiness and not merely people’s trust in PAOs. As Russell Hardin, a political scientist and author of many books and publications on theories of trust, explains, developing trust in an entity makes sense only if that entity first develops trustworthiness and only if our trust in it is a result of that trustworthiness. We should therefore promote trustworthiness in PAOs, since we want assurance that their financial relationships are not biasing their actions in ways that increase their constituents’ risk of harm.<sup>45</sup>

A PAO can increase its constituents’ trust in it in several ways. One is to act in accordance with its primary interests, abide by its commitments and mission, and publicize these trustworthy actions to its constituents. In other words, it can actually *be* trustworthy and signal this to constituents. I call trust in trustworthy organizations *appropriately placed trust*. Rather than promoting unsubstantiated trust, we should promote appropriately placed trust. Furthermore, because (a) constituents who trust a PAO are more likely to use its services and (b) a trustworthy PAO’s services are more likely to be beneficial and less likely to do harm, appropriately placed trust may increase the benefit to constituents.

Trust, however, is not always appropriately placed; people may *misplace trust* by trusting an organization that acts in untrustworthy ways. Public relations and marketing intended to promote trust can mask untrustworthy actions and therefore promote misplaced trust. That is why COI policies should not try to promote unqualified or inappropriate trust; that is, trust that is based on one’s opinion, feeling, or impression — but not one’s actual knowledge — that the organization is trustworthy.

## Developing Policies to Promote Trustworthiness

Promoting trust in PAOs might at least help ensure that people support them, but it can also increase the risk of harm to constituents, particularly when the constituents do not realize that someone else's interests are being put before their own. Therefore, COI policies should promote only appropriately placed trust by motivating a PAO to honor its primary commitments, to be truthful, and to change its behavior, policies, and procedures, if it has not been trustworthy so far. Granting that this will be easier said than done, I offer preliminary suggestions for policies in four areas.

First, PAOs could decide to limit the amount of funding they receive from the pharmaceutical industry. It might be possible for many PAOs to limit their pharmaceutical support to a small portion of their budgets so that the organizations would not become overly dependent upon industry funding. Similarly, David Rothman and his colleagues propose that professional medical associations should not accept funds from the pharmaceutical and medical device firms, granting only a few exceptions.<sup>46</sup> A less extreme alternative, he suggests, would be to restrict an organization's funding from industry interests to a small portion of the organization's budget; for example, no more than 25 percent. In addition, industry donors should have no say in how the money is spent. Such funding restrictions may be feasible for many PAOs, though probably not for all, as PAOs may have fewer funding options than many professional medical organizations have. While professional organizations often have membership dues and other sources of income, PAOs are typically not membership organizations and often provide their services for free.

Second, there should be as much administrative separation as possible between a PAO's fundraisers and its policymakers. The practice of having PAO executives serve as both the primary policy drivers and the primary fundraisers blurs important boundaries. PAO executives can develop strong personal relationships with industry executives, which may introduce bias into important decisions. If an organization's leaders are biased by financial ties to industry, which, as stated above, unconscious bias occurs among even the most ethical professionals, then that may affect the whole organization, given the power they have to shape its policies and practices. Unfortunately, smaller PAOs may not be able to afford separate staff for fundraising and organizational leadership, while large PAOs whose executives are raising significant amounts of money may not be eager to forgo that success.

A third approach is for PAOs to develop mechanisms to oversee and assess their funding relationships and to evaluate whether they are acting in a trustworthy manner. For example, a PAO might create a committee, consisting mainly of independent members, to help develop and implement organizational COI policies. For example, the American Association of Medical Colleges has proposed the use of such COI review committees for academic institutions.<sup>47</sup> A COI review committee with the knowledge and power to make informed, impartial decisions could also serve as a counterweight to PAO employees, leaders, and board members whose job (and often whose passion) is to raise as much money as possible.

A fourth approach is greater transparency, with full disclosure of financial relationships. Such disclosure is recommended more often than it is practiced.<sup>48</sup> According to Archong

Fung and colleagues, who wrote *Full Disclosure: The Perils and Promise of Transparency*, disclosures must provide meaningful information and be easy to interpret so that the public can make their own *valid* judgments about whether or not to trust the institution.<sup>49</sup> PAOs should consider providing, on their websites, a list of all their donors and how the donations are used. However, several studies have found that the disclosure of financial conflicts of interest can have mixed and sometimes even paradoxical results.<sup>50</sup> For example, people may have greater trust in others who disclose a conflict of interest simply because they have been honest enough to reveal it, even if what has been revealed suggests that the conflicted individuals are more likely to provide biased advice on account of that conflict. It may follow that disclosure among PAOs could increase the public's trust, even if the information disclosed gives one reason to question their independence and trustworthiness. This seems counterintuitive to proponents of disclosure, who have generally assumed that disclosing COI would make people more skeptical and less trusting. I conclude, however, that while transparency is a good first step, it probably cannot reduce the risks of conflicts of interest in and of itself.

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43. See Levi and Stoker, *supra* note 39.
44. *Id.*, at 476.
45. See Hardin, *supra* note 39.
46. See Rothman et al., *supra* note 31.
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48. See Lo and Field, *supra* note 10; see AAMC Task Force, *supra* note 48; Campbell EG. Public Disclosure of Conflicts of Interest: Moving the Policy Debate Forward. *Archives of Internal Medicine*. 2010; 170(8):667. [PubMed: 20421548] Ehringhaus S, Korn D. U.S. Medical School Policies on Individual Financial Conflicts of Interest: Results of an AAMC Survey, in Colleges. 2004 Association of American Medical Colleges McCrary SV, Anderson CB, Jakovljevic J, et al. A National Survey of Policies on Disclosure of Conflicts of Interest in Biomedical Research. *New England Journal of Medicine*. 2000; 343:1621–1626. [PubMed: 11096171]
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**Table 1**

Examples of Patient Advocacy Organizations, Total Donations, and Percentage of Donations from Pharmaceutical Companies<sup>19</sup>

PAO	Total revenue (\$)	Percent from pharmaceutical industry
Depression and Bipolar Support Alliance	3,522,919	>50
Colorectal Cancer Coalition	310,000	81
Restless Legs Syndrome Foundation	1,430,765	44
Children and Adults with ADHD	4,633,856	22
Narcolepsy Network	232,239	35
Breast Cancer Action (Does not accept company donations)	0	0

Source: J. Marshall and P. Aldhous, "Swallowing the Best Advice?" *New Scientist* 192 (2006): 18–22, available at <<http://www.newscientist.com/article/mg19225755.100-patient-groups-special-swallowing-the-best-ad-vice.html>> (last visited July 1, 2013).