



## Efforts to Undermine Public Health

# Health Advocacy Organizations and the Pharmaceutical Industry: An Analysis of Disclosure Practices

Sheila M. Rothman, PhD, Victoria H. Raveis, PhD, Anne Friedman, BA, and David J. Rothman, PhD

Health advocacy organizations (HAOs) are influential stakeholders in health policy. Although their advocacy tends to closely correspond with the pharmaceutical industry's marketing aims, the financial relationships between HAOs and the pharmaceutical industry have rarely been analyzed.

We used Eli Lilly and Company's grant registry to examine its grant-giving policies. We also examined HAO Web sites to determine their grant-disclosure patterns. Only 25% of HAOs that received Lilly grants acknowledged Lilly's contributions on their Web sites, and only 10% acknowledged Lilly as a grant event sponsor. No HAO disclosed the exact amount of a Lilly grant.

As highly trusted organizations, HAOs should disclose all corporate grants, including the purpose and the amount. Absent this disclosure, legislators, regulators, and the public cannot evaluate possible conflicts of interest or biases in HAO advocacy. (*Am J Public Health*. Published online ahead of print January 13, 2011: e1–e8. doi:10.2105/AJPH.2010.300027)

**HEALTH ADVOCACY ORGANIZATIONS (HAOs)** are among the most influential and trusted stakeholders in US health policy, pursuing an agenda that includes expanding government support for medical research and the availability of health care services. In addition, HAOs advocate for members' unrestricted access to all drugs, devices, and diagnostic tools relevant to their health conditions, almost always favoring branded drugs over generics, new screening technologies over older ones, and open formularies rather than closed ones. These positions closely correspond to the marketing aims of pharmaceutical and device companies; each position would help to increase product sales. Yet, despite the overlapping interests of HAOs and the pharmaceutical industry, the financial relationships between them have remained relatively unexplored. We conducted the current study in an effort to fill this knowledge gap.

This investigation is feasible because data on industry contributions to HAOs have recently become publicly available, which allows for an examination of HAOs' disclosure practices. In response to US Department of

Justice criminal prosecutions and state legislative mandates, some drug and device companies now report on their Web sites the precise dollar amounts of the grants and gifts they make to HAOs. Thus, it is now possible to analyze which HAOs the industry selects for funding and the HAOs' degrees of transparency in reporting that funding.

We selected Eli Lilly and Company for analysis because it was the first company to make its grant registry public. The Lilly registry identifies the HAOs receiving support and the exact level of support each HAO receives. Lilly's registry provides specific information about the company's grant-giving policies and practices; this information is made even more useful when supplemented by Lilly's financial reports on its best-selling drugs. On the other side of the grant equation, it would be reasonable to expect HAOs to be fully transparent about their grantors, given the credibility that HAOs enjoy. An examination of the Web sites of the HAOs that received funding from Lilly makes it possible to determine the degree to which each HAO has disclosed its Lilly funding.

### ACTIVITIES OF HEALTH ADVOCACY ORGANIZATIONS

HAOs range in size from national organizations with thousands of members concerned with a widespread disease (diabetes, cancer) to smaller organizations that have a narrower focus (alpha-1 antitrypsin deficiency, trisomy 18). Typically, HAOs conduct campaigns to promote disease awareness, update members about new diagnostic tests and drugs, facilitate physician referrals, deliver health care services, and advocate for policies that they believe are in their members' best interests. HAO leaders and members testify at congressional and state hearings, lobby legislators, negotiate with regulators, serve on federal advisory panels, and inform the media.

HAOs are highly effective advocates, deftly putting a human face on advocacy around a particular disease. As an oncology journal editorial explained, "There is one activity that lobbyists or public relations firms, no matter how well paid, will never be able to perform in place of advocacy groups. This is the ability to acknowledge what it



actually means to be a cancer patient.”<sup>1</sup>

HAOs appeal to members and to the community at large for support—“Help Find a Cure. Donate Today”<sup>2</sup>—and conduct well-publicized fundraising events, from weekend races to annual galas. But what information do they share with members and the public about their funders? This question, always relevant to public charities, has now assumed exceptional importance. In part, this reflects an intensified commitment to transparency as evidenced by congressional investigations, particularly by Senator Charles Grassley; new information from the US Department of Justice about pharmaceutical and device company payments to physicians and professional medical associations; preliminary findings from a handful of researchers, in the United States and abroad,<sup>3–6</sup> about HAOs operating under a “veil of secrecy”<sup>7</sup>; and media exposés of some HAOs’ dependence on drug company funding.<sup>8,9</sup>

HAOs’ advocacy agenda overlaps with industry marketing interests, making the need to evaluate disclosure practices more urgent.<sup>10,11</sup> “A message’s credibility is greater when delivered by impartial third parties than by entities seeking to profit from it,” observed a public relations firm. “Advocacy groups who know a company and its values can be counted on to speak out for it and relevant issues in times of need.”<sup>12</sup> Although HAOs are not legally required to disclose the names of their corporate sponsors, their advocacy activities and the level of public trust that they enjoy makes transparency more obligatory.

## THE CHANGED MISSION OF HEALTH ADVOCACY ORGANIZATIONS

Organizations that once served the public interest have become devoted to their members’ interests. This transformation also enhances the need to evaluate levels of transparency. In the opening decades of the 20th century, philanthropic citizens joined with public health officials and civic-minded physicians to spearhead campaigns against deadly diseases.<sup>13</sup> Although each organization targeted a specific disease, they allied to advance sweeping social changes. Attentive to the needs of the poorest and most vulnerable members of the population, they promoted such public health measures as tenement house reform, urban playgrounds, child labor laws, and maternal and child health care.<sup>14</sup>

Private individuals and charitable foundations—not corporations—openly underwrote the campaigns. The National Tuberculosis Association, established in 1904, was supported by John D. Rockefeller and Jacob Schiff.<sup>15</sup> When the American Society for the Control of Cancer, later the American Cancer Society, began its work in 1913, the *New York Times* reported: “Rich Women Begin a War on Cancer.”<sup>16</sup> The same newspaper also informed readers that the Association for the Prevention and Relief of Heart Disease, later the American Heart Association, was organized by “philanthropic New Yorkers” dismayed by the number of school-children and industrial workers who were “suffering from heart disease in this city.”<sup>17</sup>

Contemporary HAOs advocate almost exclusively for members’ special interests. AIDS activists inaugurated the new HAO model in the 1980s. They advocated to make AIDS research a priority<sup>18</sup>; to make experimental drugs available to all AIDS patients, not only those in clinical trials; and to speed up the Food and Drug Administration (FDA) drug approval process for AIDS drugs.<sup>19</sup> Unlike their predecessors, they were confrontational, aggressively picketing the FDA and holding marches and vigils.<sup>19</sup> A circumscribed angle of vision and hard-line tactics soon became the hallmarks of other HAOs, including those focusing on breast cancer,<sup>20,21</sup> mental illness,<sup>22</sup> and epilepsy.<sup>23</sup>

## METHODS

Eli Lilly’s Grant Office released the Lilly Grant Registry (LGR) on May 1, 2007.<sup>24,25</sup> We obtained the data for this study from the LGR. Because we wanted to identify an unobtrusive measure for our analysis of disclosure patterns before HAO policies might be affected by pharmaceutical companies’ disclosures, we selected Lilly, the first pharmaceutical company to publicly release its grant registry, and examined its grant giving and the grants it awarded to HAOs during the first 2 quarters of 2007.

We designed data-collection methods that made maximum use of the publicly available information about Lilly’s grant-giving criteria and the detailed funding information in the LGR.<sup>24</sup> First, we analyzed Lilly’s funding criteria. Lilly’s Grant Office specified the therapeutic areas for which Lilly

would accept grant requests and the types of programs it would support. One area so identified was “patient advocacy and consumer education programs.”<sup>26</sup> Lilly’s grants policy, as specified in the LGR, was not to make “unrestricted educational grants”; rather, “the purpose of the grant must be designated,” and awarded funds could only be used for the stated grant purpose.<sup>26</sup> To determine whether there were links between Lilly’s grant giving and its marketing goals, we gathered information from the company’s 2007 annual report on the net sales of its best-selling pharmaceutical products and the aggregated net sales for each of the company’s therapeutic areas.<sup>27</sup>

Second, we used the LGR information to compile a list of HAOs receiving Lilly grants. We defined HAOs as not-for-profit organizations concerned with health care in which both the leadership and membership were drawn predominantly from the general public. The LGR listed 188 organizations that met these criteria. They included groups concerned with specific diseases and disabilities and with general health issues. National organizations, chapters of national organizations, and regional, state, county, and community organizations were represented. We then organized the information obtained from the LGR about HAOs’ grant awards, making use of the following LGR categories:

- “Requestor”: The name of the HAO that received the award.
- “Program/Project Description”: Stated purpose of the award. The program or project description



varied from a named event to a broad statement of purpose.

- “Individual Payment Amount”: Exact dollar amount awarded.

Third, we then searched the World Wide Web to identify the Web sites associated with these 188 HAOs. We chose to examine the HAOs’ Web sites because the Internet is now recognized as a primary information portal for obtaining information about health and disease. Health organizations regard their Web sites as their public face. HAOs update them regularly to keep members and the public informed of activities and to disseminate information about disease management, clinical trials, and policy issues. They also use Web sites to solicit donations.

We identified the HAOs’ Web sites by searching on Google.com for the exact name or acronym of the HAO, as listed in the LGR under Requestor. When the Google search returned an exact match, that HAO Web site was included in data collection. An exact match occurred for 161 (86%) of the 188 HAOs listed on the LGR. These 161 Web sites constituted the sample for the current study. The other 27 eligible HAOs could not be matched to a Web site and were excluded from further study.

Fourth, we accessed each of the 161 Web sites to determine the disease or health category the HAO addressed. We classified the HAOs into therapeutic areas on the basis of the Segment Information table in Lilly’s 2007 annual report.<sup>27</sup> Lilly pharmaceuticals cover 6 therapeutic areas: neurosciences (mental disorders and

disabilities and neurologic disorders), oncology, endocrinology, cardiovascular, animal health, and other pharmaceuticals.<sup>27</sup> We obtained information on each HAO’s geographic scope (national, chapter, regional, county, etc.) from the HAO’s Web site.

Finally, we conducted a systematic click search of the 161 HAO Web sites to identify information about the specific Lilly grant and to determine the degree to which the HAO acknowledged its relationship with Lilly. The secure areas of Web sites, restricted to HAO members, were not included in this click search. When HAOs were chapters of national organizations and did not manage their own Web sites, the parent organization Web site was subjected to the click search. The click search was carried out between September 30, 2008, and January 12, 2009.

The following activities were performed during the click search:

1. We clicked through every available page on the HAO Web site and systematically searched for reference to the program/project description and the individual payment amount. These pages typically covered the following topics: organizational history (“About Us”), current news and reports, action updates, events, strategic plans, advocacy pages, lobbying toolkits, policy positions, donation information, clinical trials, and annual and regional conferences. If the Lilly grant did not specify an event, the entire Web site was examined for information about Lilly funding.
2. We applied a systematic click-search pattern to site maps and search engines on the HAO Web site.
3. We searched HAO Web sites for their 2007 annual report and their 2007 federal tax Form 990, and when we found those forms, we examined them for information about the Lilly grant.
4. When Lilly was acknowledged or mentioned on the HAO Web site or in a document posted or linked to it, we searched to see whether the program/project description was listed and whether an individual payment amount, by exact amount or by range, was specified.

We used the information collected from the click search of HAO Web sites to create 4 dichotomous yes/no variables: (1) Lilly was acknowledged in the HAO’s 2007 annual report, (2) Lilly was acknowledged on a corporate sponsors page, (3) Lilly was acknowledged as a grant event sponsor, and (4) the amount of the Lilly grant was reported. A fifth variable, “Lilly acknowledged anywhere,” was a summary of the 4 variables. We used SPSS version 16 (SPSS, Chicago, IL) to perform statistical analysis on the data.

## RESULTS

Examination of the LGR information revealed that during the first 2 quarters of 2007, Lilly gave \$3 211 144 to HAOs, representing 10.22% of its total grant giving. The funding was closely aligned with the company’s therapeutic areas of interest. HAOs active in

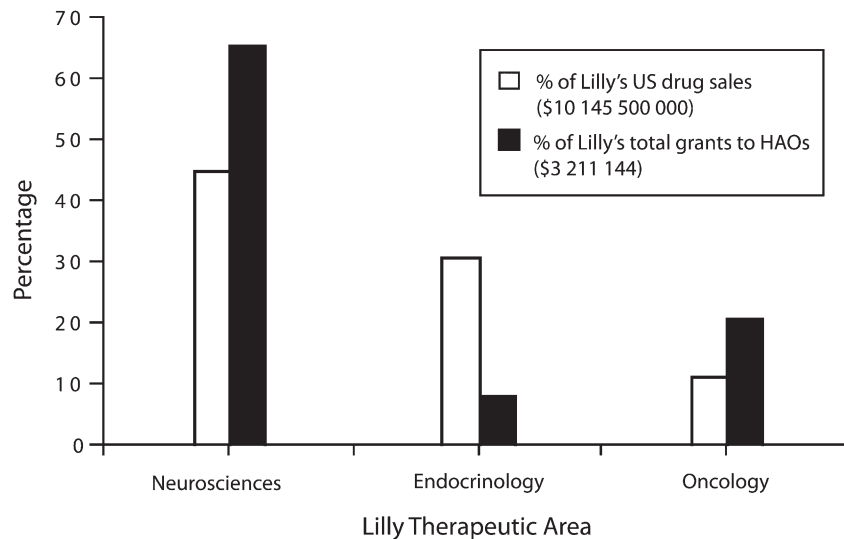
Lilly’s 3 main therapeutic areas (accounting for 87% of its total US sales)—neurosciences, endocrinology, and oncology—received 94% of Lilly’s grants to HAOs. The match of therapeutic area to HAO was not consistent; neuroscience and oncology HAOs received proportionately more grant funds than Lilly’s sales percentages in these therapeutic areas, and endocrinology received less. But overall it was evident that the company targeted HAOs concerned with its areas of therapeutic interest.

### Grants Made by Therapeutic Area

Lilly’s grants to HAOs also mirrored its therapeutic areas with the strongest sales. In 2007, Lilly reported annual US net sales of \$10 145 500 000.<sup>27</sup> Of this total, 45% came from neurosciences, 31% from endocrinology, 11% from oncology, and 13% from miscellaneous health (Figure 1). Lilly only reports sales on an annual basis, but there is no reason to believe that therapeutic sales patterns varied substantially between the first and second halves of 2007.

*Neurosciences.* Lilly’s 2 best-selling products in 2007, Zyprexa and Cymbalta, were approved by the FDA for mental and neurological disorders such as schizophrenia, bipolar mania, and depressive disorders.<sup>27</sup> Of Lilly’s 8 new drug applications to the FDA, 4 were in this category. During the first 2 quarters of 2007, 66% of Lilly’s HAO grants went to organizations concerned with neurosciences.

*Oncology.* Lilly’s fifth-best-selling product was Gemzar, approved



**FIGURE 1—Lilly and Company's US sales and grants to US health advocacy organizations (HAOs), by therapeutic area, 2007.**

for treating a variety of cancers, including lung cancer, pancreatic cancer, bladder cancer, metastatic breast cancer, and recurrent ovarian cancer.<sup>27</sup> Lilly's 10th-best-selling product was Alimta, a treatment for lung cancer.<sup>27</sup> Of Lilly's 8 new drug applications to the FDA, 4 were in this category. During the first 2 quarters of 2007, 21% of Lilly's HAO grants

went to organizations concerned with oncology.

**Endocrinology.** Lilly's third- and fourth-best-selling products were Humalog for the treatment of type 1 and type 2 diabetes and Evista for osteoporosis.<sup>27</sup> Other diabetes-related drugs included Byetta for glucose control and weight reduction. Two of the 8 Lilly products under FDA review were in this

category. During the first 2 quarters of 2007, 8% of Lilly grants went to HAOs concerned with endocrinology.

#### Lilly Funding Acknowledged on Web Sites

Of the 161 sample HAOs that received Lilly funding, 137 (85%) were in neurosciences (n=114), endocrinology (n=6), and

oncology (n=17). In terms of geographic scope, endocrinology and oncology HAOs were predominantly national organizations. Specifically, 4 of the endocrinology HAOs that received funding had a national scope, and 2 were chapters of national organizations. Similarly, 13 of the oncology HAOs were national, 1 was a chapter, and 3 had a regional or local scope. The neurosciences and miscellaneous health categories of HAOs had organizations in all 3 geographic scope categories. For the neuroscience HAOs, the majority (n=93) were chapters, 11 were national, and 10 were regional or local. Most of the HAOs in the miscellaneous health category were either national (n=12) or regional or local (n=10); only 2 were chapters.

As an aggregate, 25% of HAOs acknowledged Lilly funding anywhere on their Web site. Eighteen percent acknowledged Lilly in their 2007 annual report, 1% acknowledged Lilly on a corporate sponsors page, and 10% acknowledged Lilly as the sponsor of the grant event reported in the LGR (Table 1).

**TABLE 1—Health Advocacy Organizations (HAOs) That Acknowledged Lilly Funding on Their Web Sites, by Therapeutic Area: United States, 2007**

HAO Therapeutic Area	No.	Lilly Acknowledged Anywhere, % (no.) <sup>a</sup>	Lilly Acknowledged in 2007 Annual Report, % (no.)	Lilly Acknowledged on Corporate Sponsors Page, % (no.)	Lilly Acknowledged as Grant Event Sponsor, % (no.)	Lilly Grant Amount Reported, % (no.)
Neurosciences	114	18 (20)	11 (13)	2 (2)	7 (8)	1 (1)
Endocrinology	17	59 (10)	47 (8)	0 (0)	29 (5)	0 (0)
Oncology	6	67 (4)	50 (3)	0 (0)	17 (1)	0 (0)
Miscellaneous health	24	25 (6)	21 (5)	0 (0)	8 (2)	0 (0)
Total	161	25 (40)	18 (29)	1 (2)	10 (16)	0.6 (1)

<sup>a</sup>The percentage of HAOs acknowledging Lilly anywhere is less than the sum of the composite variable because some HAOs acknowledged Lilly in multiple places on their Web site.



### Grant Disclosure by Therapeutic Area

We then explored HAO disclosure information by Lilly's therapeutic areas.

**Neurosciences.** Disclosure rates were low among the 114 neuroscience HAOs. Eighteen percent acknowledged Lilly anywhere on their Web site. Eleven percent acknowledged Lilly in their annual report, 2% acknowledged Lilly on the corporate sponsors page, and 7% acknowledged Lilly as a grant event sponsor. One neuroscience HAO, Mental Health America Southeastern Pennsylvania, disclosed the amount of Lilly funding, but funding was disclosed as a range, not an exact amount.

**Oncology.** Of the 6 HAOs concerned with oncology, 67% acknowledged Lilly anywhere on their Web site. Fifty percent acknowledged Lilly in their annual report, none acknowledged Lilly on a corporate sponsors page, and 17% acknowledged Lilly as a grant event sponsor. None disclosed the amount of the Lilly grant.

**Endocrinology.** Of the 17 HAOs concerned with endocrinology, 59% acknowledged Lilly anywhere on their Web site. Forty-seven

percent acknowledged Lilly in their annual report, none acknowledged Lilly on a corporate sponsors page, and 29% disclosed Lilly as a grant event sponsor. None disclosed the amount of the Lilly grant.

**Miscellaneous health.** Disclosure rates were low among the 24 miscellaneous health HAOs; 25% acknowledged Lilly anywhere on their Web site. Twenty-one percent acknowledged Lilly in their annual report, none acknowledged Lilly on a corporate sponsors page, and 8% acknowledged Lilly as a grant event sponsor. None disclosed the exact amount of the Lilly grant.

HAOs exhibited significant differences in disclosure rates by their therapeutic area of interest ( $\chi^2 [3]=19.387; P<.001$ ). Post hoc tests demonstrated that HAOs concerned with endocrinology and oncology disclosed at a significantly higher rate than those concerned with neurosciences.

### Neuroscience Disclosure by Geographic Scope

National organizations were the most common type of grant recipient for the oncology, endocrinology,

and miscellaneous health HAOs. However, sufficient diversity the neuroscience HAOs differed sufficiently to examine disclosure of Lilly funding by HAO geographic scope, e.g., national, chapter, or other (Table 2).

**National organizations.** Of the 11 national neuroscience HAOs, 36% acknowledged Lilly anywhere on their Web site. Sixty-four percent acknowledged Lilly in their annual report, 18% acknowledged Lilly on a corporate sponsors page, and 55% listed Lilly as a grant event sponsor. None disclosed the amount of the grant.

**Chapters.** Of the 93 neuroscience chapters, 88 were chapters of 2 national organizations: the National Alliance on Mental Illness (NAMI) and Mental Health America. Fourteen percent of the chapters acknowledged Lilly on their Web site. Four percent acknowledged Lilly in their annual report, 1% acknowledged Lilly on a corporate sponsors page, and 1% acknowledged Lilly as a grant event sponsor. One chapter, Mental Health America of Southeastern Pennsylvania, disclosed the amount of funding and reported it as a range.

**Other organizations.** Of the 10 neuroscience county and regional HAOs, 30% acknowledged Lilly anywhere on their Web site. Twenty percent acknowledged Lilly in their annual report, none acknowledged Lilly on a corporate sponsors page, and 10% acknowledged Lilly as a grant event sponsor. None disclosed the amount of the Lilly grant.

There was no significant difference in the neuroscience HAO disclosure rates among national, chapter, and other organizations ( $\chi^2 [2]=4.58; P=.101$ ).

## DISCUSSION

Lilly's grants went primarily to HAOs working in its areas of therapeutic interest and in areas related to its best-selling products. Lilly has acknowledged this type of correlation between its business interests and its grant giving. Its "Principles for Interacting with Health Care Professional Associations" state that grantees should be committed to "market oriented solutions to important health care issues" and that Lilly expects to "build long term relationships . . . based on mutual support." The

**TABLE 2—Neurosciences Health Advocacy Organizations (HAOs) That Acknowledged Lilly Funding on Their Web Sites, by Geographic Scope: United States, 2007**

HAO Geographic Scope	No.	Lilly Acknowledged Anywhere, % (no.) <sup>a</sup>	Lilly Acknowledged in 2007 Annual Report, % (no.)	Lilly Acknowledged on Corporate Sponsors Page, % (no.)	Lilly Acknowledged as Grant Event Sponsor, % (no.)	Lilly Grant Amount Reported, % (no.)
National	11	36 (4)	64 (7)	18 (2)	55 (6)	0 (0)
Chapter	93	14 (13)	4 (4)	1 (1)	1 (1)	1 (1)
Other	10	30 (3)	20 (2)	0 (0)	10 (1)	0 (0)
Total	114	18 (20)	11 (13)	3 (3)	7 (8)	0.9 (1)

<sup>a</sup>The percentage of HAOs acknowledging Lilly anywhere is less than the sum of the composite variable because some HAOs acknowledged Lilly in multiple places on their Web site.



principles state that organizations receiving grants are not “obligated or directed to use these funds in a manner that benefits the company or its products,”<sup>28</sup> but the distribution of grants makes clear that formal stipulations were not required to satisfy Lilly’s marketing interests.

Lilly has cited the public release of its grant registry as evidence of its commitment to transparency: “We regularly publish U.S. grant funding on line and encourage advocacy organizations to consider their own transparency efforts.”<sup>28</sup> But as the present analysis has demonstrated, HAOs generally did not follow this recommendation. Only 25% of the HAOs that received Lilly grants acknowledged Lilly’s contributions on their Web sites. Only 10% acknowledged Lilly as the sponsor of a grant event. None disclosed the amount of a Lilly grant. Thus, in most cases, neither policymakers nor the public can readily learn about the financial relationship between an HAO and Lilly.

This lack of transparency is disappointing because, either by design or through a convergence of interests, the HAOs in the current study pursued activities that promoted the sale of Lilly products. In the area of neurosciences, Lilly gave NAMI \$450 000 for its Campaign for the Mind of America. NAMI has advocated that cost should not be a consideration when prescribing for patients. “For the most severely disabled,” insisted NAMI, “effective treatment often means access to the newest medications such as atypical anti-psychotic and anti-depressive agents. . . . Doctors must be allowed

to utilize the latest breakthrough in medical science . . . without bureaucratic restrictions to the access for life-saving medications.”<sup>29</sup> To the degree that NAMI’s campaign succeeded, the market for Lilly’s neuroscience drugs expanded.

In the area of oncology, Lilly granted the National Breast Cancer Coalition (NBCC), which represents 25 state and national organizations, \$50 000 to support its annual advocacy training program. Researchers have concluded that the NBCC is “a powerful force in Washington politics—and everybody knows it.”<sup>20</sup> One industry trade magazine has called the NBCC “one of America’s most powerful pressure groups” and has described its president as one of “the most influential people in the industry.”<sup>30</sup>

The NBCC advocated for a “comprehensive strategy to end the [breast cancer] epidemic,” including greater access to screening, insurance coverage for participation in clinical trials, and expanded Medicare coverage for all oral cancer drugs.<sup>20,31</sup> The organization conducted advocacy training sessions for survivors and organized a “lobby day”: “Advocates held over 400 meetings with federal officials. . . . In that single day NBCC advocates persuaded 40 additional House members and 10 additional Senators to commit to cosponsoring one of NBCC’s top legislative priorities.”<sup>32</sup> In 2007, NBCC members served on 11 influential national committees, including the National Advisory Council of the Agency for Healthcare Research and Quality, the Cochrane Collaboration Consumer

Coalition, the Roundtable on Evidence-Based Medicine of the Institute of Medicine, and the Task Force on Conflicts of Interest in Clinical Research of the Association of American Medical Colleges.<sup>33</sup> In all these ways, the policies and practices implemented by NBCC fit Lilly’s criterion of “mutual support.”

In the area of endocrinology, Lilly granted the American Diabetes Association (ADA) \$250 000 for its Cardiovascular Risk Initiative.<sup>34</sup> The program taught patients and providers strategies for preventing cardiac disease among people with type 2 diabetes, including weight management and better drug use to control glucose levels.<sup>35</sup> Personal connections also linked the ADA to Lilly. One of the ADA’s major supporters and officers, Joe Cook Jr, was a Lilly vice president before becoming the CEO of Amylin Pharmaceuticals in 1998. Amylin Pharmaceuticals partners with Lilly in developing and marketing Byetta.<sup>36</sup> As the ADA noted, “A logical relationship evolved between the Cooks and ADA. Ultimately, Joe . . . helped raise funds for the organization.”<sup>37</sup>

### Limitations

This analysis is based on data drawn from the LGR, sales reports of Eli Lilly over 2 quarters in 2007, and the content of the Web sites of HAOs that received Lilly funding. Before industry-wide and HAO-wide conclusions are drawn, further research is necessary to establish whether other companies and HAOs fit the patterns described here. Moreover, this investigation of HAO transparency practices focused on publicly

accessible information posted on HAO Web sites. It is possible that some HAOs may have distributed printed materials that included an acknowledgment to Lilly or that some HAOs may have posted acknowledgments on a members-only section of their Web site that was not open to the public.

These limits recognized, the disclosure patterns we reported are not likely to be unique. The National Health Council, an industry-funded umbrella organization of HAOs, has promulgated standards that do not encourage transparency. “Companies are increasingly basing decisions regarding relationships with not-for-profit organizations on whether these relationships support business goals,” it informed members. Rather than give guidance on procedures to avoid or manage conflicts of interest, the National Health Council told HAOs “to enhance their ability to accomplish their mission in areas where the interest of the not-for-profit and the for-profit organizations overlap.” The organization acknowledged the “possible negative impact [on] . . . public image and integrity, whether real or imagined,” so it concluded that HAOs should “disclose financial and other benefits it receives from a corporate relationship, when asked.”<sup>38</sup>

### Conclusions

HAOs are powerful stakeholders in shaping health policies, and they enjoy considerable public trust. Thus, they should become far more detailed in disclosing corporate grants, including the grant’s purpose and amount. HAOs



should also disclose their industry relationships when testifying before legislative or regulatory committees, serving on advisory panels, and communicating with the media.

Absent substantial changes in HAO reporting practices, state and federal regulations should require that HAO–industry relationships become transparent. To this end, the Sunshine Act provisions in the recently enacted US health reform law, which require companies to report gifts to physicians, should be amended to include company payments to HAOs. Federal income tax regulations should also mandate public disclosure of HAO donors and sums on Form 990. If these changes were implemented, legislators, regulators, and the public would more easily be able to follow the money and evaluate possible biases and conflicts of interest in HAO advocacy. ■

### About the Authors

Sheila M. Rothman is with the Division of Sociomedical Sciences, Mailman School of Public Health, Columbia University, New York, NY, and the Center for the Study of Society and Medicine, College of Physicians and Surgeons, Columbia University. Victoria H. Raveis is with the Psychosocial Unit on Health, Ageing, and Community, New York University College of Dentistry, New York. At the time of the study Anne Friedman was with the Center on Medicine as a Profession, College of Physicians and Surgeons, Columbia University. David J. Rothman is with the College of Physicians and Surgeons, Columbia University.

Correspondence should be sent to Sheila M. Rothman, Center for the Study of Society and Medicine, College of Physicians and Surgeons, Columbia University, 630 West 168th St, PH 15-25, New York, NY 10032 (e-mail: smr4@columbia.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints/Eprints” button.

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### Contributors

S.M. Rothman, D.J. Rothman, and V.H. Raveis conceptualized and designed the study. S.M. Rothman and A. Friedman collected the data. S.M. Rothman, V.H. Raveis, and D.J. Rothman wrote and revised the article. S.M. Rothman supervised all aspects of the study.

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### Human Participant Protection

No protocol approval was required because no human research participants were involved in this study.

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