

Web Appendix to *"Health Advocacy Organizations and the
Pharmaceutical Industry"*

By Rothman et al., published in the American Journal of Public Health,
1/13/11

HAO Disclosure Practices



Included in this document:

- A) A roster of HAOs that received grant money from Eli Lilly Co. in the first two quarters of 2007, with each HAO's grant amount and disclosure practices listed.
- B) The National Health Council record.
- C) A Dec. 2008 screenshot from the NBCC/F website used in this study.

Organization Name	Grant Amount	Web Disclosure
Afr Amer Reach and Teach	\$1,000	0 ("no")
Alzheimer's Association	\$130,000	1 ("yes")
Amer Assoc of Ppl w Disab	\$2,500	1
Amer Brain Tumor Assoc	\$10,000	1
Amer Diabetes Assoc- National	\$75,000	1
Amer Foundation for Suicide Prevention - National	\$25,000	1
Amer Heart Assoc - Ntl	\$1,000	1
Amer Lung Assoc- Metropolitan Chicago	\$3,000	1
Anxiety Disorders Assoc of Amer	\$139,798	0
Arthritis Foundation - NY	\$11,250	0
Atten Deficit Disorders Resources	\$5,000	0
Atten Deficit Disorders Resources - Souther Region	\$3,000	0
CA Inst for Mental Health	\$25,000	0
Cancer Services of New Mexico	\$2,500	0
CenterPoint Human Services	\$4,000	0
Central Washington Comprehensive Mental Health	\$500	0
Cerebral Palsy of Colorado	\$500	0
CHADD - Ntl	\$50,000	0
Chdrn and Adults w Attn Deficit Hyperactivity	\$5,000	0
Children's Brain Tumor Foundation	\$8,500	0
Children's Hlth Fund	\$25,000	0
Cystic Fibrosis Found	\$3,500	0
Depression and Bipolar Support Alliance -TX	\$17,500	0
Didi Hirsch Comm Mental Health Cntr	\$5,000	1
Fam for Depression Awarenss	\$55,000	0
Georgia Cancer Foundation	\$5,000	0
Georgia Doty Hlth Edu Fund	\$5,000	0
Georgia Parent Support Network	\$25,000	0
Grassroots Empowerment Project	\$5,000	0
Hope Street Kids	\$5,000	1
Idaho Federation of Families	\$2,000	0
Indiana Minority Health Coalition	\$5,000	0
Korean Health, Education, Information and Research	\$1,500	0
Leukemia and Lymphoma Society	\$10,000	1
Lupus Foundation of America - Ntl	\$5,000	0
MAGIC Foundation	\$20,000	1
March of Dimes	\$7,500	0
MHA - Broward Country	\$5,000	0
MHA - CA	\$25,000	0
MHA - Colorado	\$2,500	1
MHA - Delaware	\$1,000	0
MHA - Franklin County	\$7,500	0
MHA - Greater Dallas	\$7,500	0
MHA - Greater Houston	\$2,500	0
MHA - Greater Indianapolis	\$5,000	0

MHA - Greater Kanawha Valley	\$5,000	0
MHA - Greater Tampa Bay	\$3,000	0
MHA - Hawaii	\$2,500	0
MHA - Heartland	\$500	0
MHA - Illinois	\$32,000	0
MHA - Indiana	\$16,000	1
MHA - Knox County	\$500	0
MHA - Licking County	\$500	0
MHA - Louisiana	\$4,000	0
MHA - Maryland	\$8,000	0
MHA - Michigan	\$30,000	0
MHA - Minnesota	\$5,000	1
MHA - Montana	\$2,500	0
MHA - National	\$325,000	1
MHA - Nebraska	\$1,000	0
MHA - New York City	\$15,000	0
MHA - New York State	\$15,000	0
MHA - NJ	\$2,500	0
MHA - North Carolina	\$15,500	0
MHA - North Dakota	\$7,500	1
MHA - Palm Beach County	\$15,000	0
MHA - San Diego County	\$5,000	0
MHA - San Francisco	\$7,500	1
MHA - South Carolina	\$12,000	0
MHA - Summit County	\$500	0
MHA - Texas	\$20,000	0
MHA - Tulsa	\$6,500	1
MHA - Wisconsin	\$2,500	1
MHA - Southeastern Penn	\$5,000	1
MHAiation - Passaic County	\$1,000	0
MHAiation of OC	\$6,435	0
Michigan Assoc for Children with Emotional Disorde	\$10,000	0
Michigan Minority Mental Health Coalition	\$4,500	0
Muscular Dystrophy Assoc	\$5,000	0
N. Carolina Mental Hlth Consumers' Org	\$3,000	0
NAMI - AZ	\$1,000	0
NAMI - California	\$20,000	0
NAMI - Central Iowa	\$500	0
NAMI - Colorado	\$9,000	1
NAMI - Dallas	\$1,000	0
NAMI - DeKalb	\$5,000	0
NAMI - DuPage County	\$1,000	0
NAMI - Florida	\$5,000	0
NAMI - Franklin County	\$500	0
NAMI - Georgia	\$500	1
NAMI - Greater Chicago	\$3,000	0
NAMI - Greater Cleveland	\$500	0

NAMI - Greater Des Moines	\$500	0
NAMI - Greater Kansas City	\$5,000	0
NAMI - Gwinnett	\$1,941	0
NAMI - Hamilton County	\$1,000	0
NAMI - Indiana	\$21,000	0
NAMI - Inland Valley	\$3,000	0
NAMI - Iowa	\$1,000	0
NAMI - Kentucky	\$9,600	0
NAMI - Kern County	\$3,000	0
NAMI - Lexington	\$5,000	0
NAMI - Louisville	\$1,500	0
NAMI - Maine	\$5,000	0
NAMI - Marin	\$1,000	0
NAMI - Maryland	\$1,500	0
NAMI - Metropolitan Houston	\$1,000	0
NAMI - Miami	\$500	0
NAMI - Minnesota	\$6,000	1
NAMI - Mississippi	\$10,000	0
NAMI - Missouri	\$500	0
NAMI - National	\$525,000	1
NAMI - Nevada	\$5,000	0
NAMI - New Mexico	\$2,500	0
NAMI - North Carolina	\$9,500	0
NAMI - NY Metro	\$10,000	1
NAMI - NY State	\$25,000	0
NAMI - Ohio	\$15,000	0
NAMI - Ohio	\$25,000	0
NAMI - Oregon	\$10,500	0
NAMI - Palm Beach County	\$5,000	0
NAMI - Queens-Nassau	\$1,000	0
NAMI - San Fernando	\$4,950	0
NAMI - Sonoma County	\$2,500	0
NAMI - South Carolina	\$11,000	0
NAMI - Tennessee	\$15,000	0
NAMI - Texas	\$10,000	1
NAMI - Virginia	\$29,000	0
NAMI - VT	\$1,000	0
NAMI - West Virginia	\$2,500	0
NAMI - Wisconsin	\$7,000	0
National Brain Tumor Foundation -Ntl	\$50,000	0
National Coalition for Cancer Survivorship	\$130,000	1
National Kidney Foundation - Illinois	\$7,500	0
National Mental Health Assoc - GA	\$15,000	0
Neupathy Action Foundation	\$4,000	0
Nikkei Concerns	\$370	0
NJ Mental Health Institute	\$15,000	1
Ntl Breat Cancer Coalition Fund - Ntl	\$50,000	0

Ntl Cancer Survivors Day Foundation - Ntl	\$20,000	1
Ntl Fibromyalgia Association	\$25,000	0
Ntl Kidney Foundation - Ntl Capital	\$5,000	1
Ntl Lung Cancer Partnership	\$50,000	1
Ntl Minority Health Month Foundation	\$15,000	0
Ntl Osteoporosis Foundation	\$129,800	1
Open Arms Perinatal Services	\$500	0
Pajaro Valley Community Health Trust	\$2,000	1
Pancreatic Cancer Action Ntwrk - Patient & Liaison S	\$50,000	1
Paralyzed Veterans of Amer	\$6,500	1
Patient Advocate Foundation	\$50,000	1
Prevent Cancer Foundation	\$175,000	1
Seattle Mental Health	\$500	1
South Dakota Urban Indian Health	\$500	0
Suicide Prevention Action Network USA, Inc	\$80,000	0
Turner Syndrome Society of the United States - Ntl	\$25,000	0
Wellness Community- Central Indiana	\$20,000	0
Wellness Community- Ntl	\$37,500	1
Wisconsin Ovarian Cancer Alliance	\$2,500	0
Women Heart	\$5,000	0
Women's Health Virginia	\$5,000	0
Y-Me Ntl Breast Cancer Org	\$37,500	1

+ Acts as if org

time spent -

Start w/ what gov't and Lilly did

"Reasonable consumer" disclosure
→ Not only the corp. but the NATIONAL HEALTH COUNCIL HAO has to disclose

- How do they inform the public that they've taken money and where from

GUIDING PRINCIPLES for VOLUNTARY HEALTH AGENCIES in CORPORATE RELATIONSHIPS

I. Why are Relationships Between Voluntary Health Agencies and Corporations Appropriate?

Voluntary Health Agencies (VHAs) consider first and foremost their mission and serving their constituents in all decisions, including whether to enter into a relationship with a for-profit entity. In many cases, activities that fulfill a VHA's mission cannot be accomplished as well alone as they can be through collaboration and alliances among like-minded organizations. It is for this reason that VHAs have increasingly sought to forge appropriate and productive collaborative relationships with corporations and/or others.

Corporate involvement in the mission of not-for-profit organizations has taken many forms over the years. Corporations have made outright grants to charities. They have underwritten the cost of established programs and developing programs. They have enabled not-for-profit organizations to conduct fundraising programs of various kinds. These traditional forms of corporate gifts have historically been extensions of a company's own commitment to philanthropy and have not been directly related to the company's marketing endeavors. More recently, corporate relationships have closer connections to the commercial activities of the company, such as establishment of its corporate image, and marketing of its products and services.

Companies are increasingly basing decisions regarding relationships with not-for-profit organizations on whether these relationships support business goals. This creates significant opportunity for not-for-profit organizations to enhance their ability to accomplish their mission in areas where the interests of the not-for-profit and for-profit organizations overlap. However, these relationships should be entered into thoughtfully, with careful consideration given to possible unintended effects, especially regarding the organization's relationship with the public.

The need arises, therefore, for voluntary health organizations to establish guidelines that help them take full advantage of these new opportunities, but that also serve as safeguards against any possible negative impact these corporate relationships might have on the VHA's public image and integrity, whether real or perceived.

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For these reasons, the appropriate rationale for engaging in corporate relationships must be to:

- Increase the dissemination of health information and education to the public using the additional resources provided by the corporate partner that would not otherwise be available to the VHA.
- Leverage the VHA's resources by employing corporate resources to help develop, produce and implement VHA mission-related programs, materials, and activities.
- Offer the VHA new means of raising funds and increasing public awareness, which are the indispensable fuel for its mission-related activities.
- Increase the overall capacity of the VHA to fulfill its mission.

II. Why Should VHA Industry Guiding Principles be Developed for Corporate Relationships?

VHAs fill gaps in service to people who have, or are at risk of developing, chronic diseases and/or disabilities, primarily through the generous support of volunteers and the donating public. They improve health by providing patient and family services, community services, public and professional education, medical research support, and health-related advocacy. For VHAs to remain viable and to fulfill this critical need, public trust is absolutely essential. Relationships between VHAs and corporations must be constructed so as to enhance and never to detract from this integrity and credibility. Damage to the credibility of any single VHA, resulting from less than scrupulous practices or inappropriate corporate relationships, can negatively impact the faith of the donating public and the public credibility of VHAs in general. Because of this, the National Health Council seeks to establish a common set of Guiding Principles for Corporate Relationships to which all its member VHAs will adhere.

This common set of principles for VHA members will:

- Enable the public to better understand the purpose of corporate relationships and appreciate the diligence that is exercised to ensure that the public's trust and faith are not violated by these relationships.
- Inform corporations of the standards and practices under which VHAs will consider collaborating and forming corporate relationships.

do that if it's not listed

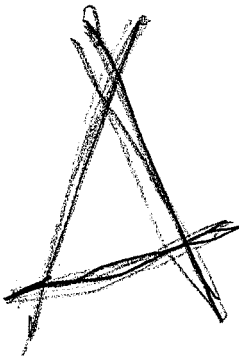
- Establish that health claims resulting from a corporate relationship must be accurate and beneficial to intended audiences.
- Assist VHAs with limited budgets and resources to learn from the experience of other VHAs and have a solid foundation from which to establish their own corporate relationships.

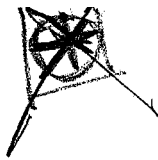
III. What Is a Corporate Relationship?

There are a variety of corporate relationships that are typical of most VHAs' efforts to work with and gain support from corporations. Some relationships involve a monetary exchange; some involve in-kind services; and others are educational and awareness-building in nature. All such relationships are entered into in order to support and advance the mission of the VHA.

The definitions that follow are to help define the nature of these relationships and enable the public to better understand the terminology:

- Sponsorships: The corporation provides financial or in-kind support for a specific VHA activity or program, which could support education, research, awareness, and/or fundraising. In return, the VHA publicly recognizes the support of the corporation and/or product.
- Health message promotions: VHA gives a corporation the right to use its name, logo or message in the corporation's product advertising, promotional or educational materials.
- Licensing: VHA licenses a company to develop, produce, market and/or distribute a mission-related product that is marketed as a VHA brand product, e.g., VHA brand cookbooks, books, videos and other mission-related educational materials.
- Certification: VHA certifies or recognizes that a particular product or service of a company complies with or satisfies an applicable or relevant VHA standard or criteria; this is distinct from an explicit endorsement or recommendation to buy a particular brand product or service.
- Strategic alliance: A mutually beneficial relationship between a VHA and a corporation. Typically, the VHA helps supply a health education message or service that is delivered through a company delivery system to better serve people with the particular health interest or condition. It is often a collaborative effort to improve the health information or service provided to the individual. It may not necessarily involve a monetary exchange.





- Cause Marketing: This generally implies that a donation to the VHA or cause by a corporation is triggered with the purchase of a product that is “marketed” to the public to benefit the VHA, most commonly based on sales during a specific period.

The definitions above describe the basic types of corporate relationships but are not necessarily separate and distinct. There may be overlap, and hybrid arrangements can exist.

IV. What Should be the Guiding Principles for Corporate Relationships?

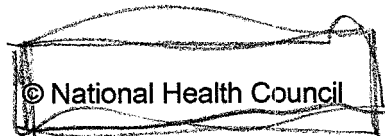
Public Stewardship

- Mission-related benefit: Corporate relationships must have a meaningful VHA mission-related benefit to the general public or particular constituencies of the VHA.
- Independence: While VHAs accept financial support and other benefits from corporations, the VHA will always exercise independent judgment in all its decision-making.
- Consumer Communications: Materials from the corporation or VHA directed to the public will contain terms or statements such that a reasonable individual will understand the nature and extent of the corporate relationship.
- Disclosure: The VHA will disclose financial and other benefits it receives from a corporate relationship, when asked. When a purchase by a consumer causes a donation to be made to the VHA, the portion of the sale to be received by the VHA will be disclosed. Proprietary or confidential information of the corporation will not be disclosed by the VHA.
- Endorsement: The VHA will make it clear to a reasonable consumer if the VHA is endorsing a product and, in such case, whether it is endorsing a specific feature or attribute of the product or the product’s efficacy. Special scrutiny, including regulatory guidelines, must be applied when prescription and over-the-counter drugs and devices are involved to avoid unintended endorsement, suggestion of product superiority, or bias for or against a specific product.
- Exclusivity: In general, there will not be exclusive arrangements in promotions or certifications, although exclusivity is acceptable for sponsorships and licensed products. Regarding corporate promotions or certifications, exclusivity may be granted to a corporation or product for a particular activity for a specified time period if there is sufficient benefit to the VHA and public, and there is no prohibition against the VHA engaging in different types of activities with competing corporations/products.

- Consistency: A VHA will not enter into a relationship with a product or corporation that is inconsistent with the VHA's principles, public positions, policies or standards.
- Privacy: Each VHA shall have written guidelines that will protect the privacy of individuals that participate in its corporate relations activities and/or programs.

Organizational Stewardship

- Policies: The VHA will have Board-approved written policies for corporate relationships, including procedures for review and approval of corporate relationships, and ongoing review and evaluation of such relationships.
- Compliance: The VHA will have a mechanism to assure compliance with its corporate relations policy by state/local divisions of the VHA as well as by the national component.
- Advance Review and Approval: Any use of the VHA name, logo and identifying marks in a corporate relationship must be reviewed and approved by the VHA in writing in advance of their use, including in statements, advertising or other materials from the corporation. The use of a VHA's name/logo and identifying marks should be specific as to usage and a defined period for usage.
- Written Agreement: The VHA will have a written agreement between the VHA and corporation prior to implementation of the corporate relationship.



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American Journal of Public Health study on health advocacy organizations

1 message

Nancy Hughes <nhughes@nhcouncil.org>
To: "smr4@columbia.edu" <smr4@columbia.edu>

Thu, Jan 13, 2011 at 9:59 AM

Dr. Rothman:

I saw a notice this morning that the American Journal of Public Health will be releasing your study on health advocacy organizations and corporate relationships. Please see below. Would it be possible to get a copy of the report?

The National Health Council is the national organization representing approximately 50 of the leading patient advocacy organizations in this country, which control our governance. Our membership also includes the broad spectrum of health care interests (<http://www.nationalhealthcouncil.org/pages/member-roster.php>). A basic requirement for NHC membership for patient advocacy organizations is that they must meet the Standards of Excellence® Certification.

Standard 9 (starting on page 13 of <http://www.nationalhealthcouncil.org/forms/soe.pdf>) reads as follows:

At a minimum, organizations must disclose amounts received from corporations identified on Schedule B of their Form 990 (more than the greater of \$5,000 or 2% of the total amount of contributions reported on line 1e of Part 1 of Form 990 (2007), line 1 h of Part VIII of Form 990 (2008)). The disclosure information should be posted on the organization's website in an easily accessible location within six months of the close of the organization's fiscal year.

I look forward to reading the study.

Nancy

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NBCC/F Annual Reports

The NBCC/F Annual Report reviews the policy, research and fundraising accomplishments of NBCC and NBCCF throughout the year. The report also highlights NBCC/F news mentions, recaps NBCC/F events, and gives NBCC/F an opportunity to thank the donors that have given so generously to the fight against breast cancer.

[Lost Password?](#)

- [2006 NBCC/F Annual Report](#) *(Adobe Acrobat PDF file format)*
- [2005 NBCC/F Annual Report](#) *(Adobe Acrobat PDF file format)*
- [2004 NBCC/F Annual Report](#) *(Adobe Acrobat PDF file format)*
- [2003 NBCC/F Annual Report](#) *(Adobe Acrobat PDF file format)*
- [2002 NBCC/F Annual Report](#) *(Adobe Acrobat PDF file format)*

NBCCF 990 Tax Documents

- [2006 NBCCF 990](#)
- [2005 NBCCF 990](#)