
Transparency in Consumer Advocacy Organizations Funding: The Past, the Present and the Future

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Overview



- I) Advocacy Organizations as essential components of civil society
- II) The history and mission of Health Advocacy Organizations
- III) The Record of Financial Disclosure
- IV) Recommendations

Advocacy Organizations and the Health Care System



Not-for-profit organizations are an important part of the health care delivery system

- Represent diverse public concerns
- Operate in many spheres
 - Environment
 - Education
 - Health

History of Health Advocacy Organizations



- Established in the United States in the first decades of the 20th century
- Organized by concerned citizens to improve the health of their communities
- Funded by Philanthropists
- Mission equated with the public interest

History of Health Advocacy Organizations



Their altruistic missions made Health Advocacy Organizations highly trusted groups.

Medical Agenda: Tuberculosis as the Paradigm

- Educate the public about disease and its symptoms
- Raise money to establish sanatoriums
- Fund and advance scientific knowledge

Social and Economic Agenda:

- Advocated for legislation and regulations to eliminate social and economic conditions linked to the targeted disease:
 - Tenement House Reform
 - Child Labor Laws
 - Parks and Playgrounds

Transforming the Health Advocacy Leadership and Mission



AIDS advocacy becomes the new model

AIDS advocates:

- Gained knowledge about their disease
- Worked with pharmaceutical companies to design and disseminate drugs to treat their disease
- Participated in clinical trials to find a vaccine against AIDS



Transforming the Health Advocacy Leadership and Mission

- AIDS advocacy became the model for other disease groups:
 - Breast Cancer
 - Epilepsy
 - Mental Illness
- Established identity-based advocacy organizations
- Patients became leaders



The New Mission of Health Advocacy Organizations



- Expand government funding for research and services
- Promote:
 - Unrestricted access to drugs, devices, and diagnostic tools
 - Open Formularies
 - Elimination of “fail first” policies
 - Easy access to unproven therapies
 - Branded drugs over generics

Health Advocacy Organizations as powerful stakeholders



- Effectively communicate unmet patient needs
- Put an intimate face on advocacy
- Train members to “Tell their stories” to
 - State and federal officials
 - The media
 - Friends and neighbors

The Public Perception of Health Advocacy Organizations



- Viewed as worthy causes - advocate for vulnerable groups
- Objective and unbiased
- Citizens donate money to them
- Citizens participate in their events

Pharmaceutical Industry and Advocacy Organizations



Industry attracted by:

- Effectiveness of advocacy organizations' strategy
- Their ability to put a intimate face on an illness

“There is one activity that lobbyists or public relation 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.”

The Joint Agenda



Pharmaceutical Industry also favor

- Open Formularies
- Elimination of “fail first” policies
- Broad access to unproven therapies
- Branded drugs over generics

Advocacy Organizations and industry



Advocacy Organizations recognize common interests

- Accept industry donations
- Request industry grants
- Promote industry products
- Rarely disclose industry funding

First Analysis of Disclosure Practices



In 2007 Eli Lilly placed its Grant Registry online. The registry provides:

- Names of organizations that request grants
- The grant event

It became possible to study the financial relationships between a pharmaceutical company and health advocacy organizations

Example of Drug Company Data

The Lilly Grant Registry



2008 - 4th Quarter



Requestor	Program/Project Description	Individual Payment Amount
Academy for Health Care Education, Inc	Lung Cancer Exchange	\$75,000
Advanced Strategies in Medicine	Clinical Considerations in the Management of Fibromyalgia	\$109,338
Adventure House	First Place - Housing, 2008 Lilly Reintegration Awards	\$5,000
AKM Inc, Advancing Knowledge in Healthcare	Management of Recurrent and Refractory Ovarian Cancer	\$-58,387
Alamo Breast Cancer Foundation	Patient Advocate Support Programs at SABCS	\$25,000
Alexander Valley Regional Medical Center	Heroes in the Fight Charitable Award Program	\$500
Alliance for Patient Access	Comparative Effectiveness Education Initiative	\$10,000
Alliance Medical Center	Heroes in the Fight Charitable Award Program	\$500
Alzheimer's Association - Greater Indiana	Annual Fundraiser	\$10,000
American Academy of Child and Adolescent Psychiatry - National	AACAP's 55th Annual Meeting International Reception	\$80,000
American Academy of CME, Inc	Osteoporosis in the 21st Century: Implications for Clinicians and Researchers	\$27,252
American Academy of Family Physicians - National	"Establish and Evaluate Effectiveness of Group Visits for Hispanic Diabetic Patients in a Residency Clinic"	\$2,000
American Academy of Family Physicians - National	Learning Link.org Sub Tract: "Managing Coexisting Pain and Depression"	\$200,000
American Academy of Family Physicians - National	"Effectively and Efficiently Integrating a Self-Management System for Diabetes into the Office Setting"	\$2,000
American Academy of Physician Education	BRAIN SCAN Management of Neurologic Disorders in Primary Care: Fibromyalgia Vignette	\$-197
American Academy of Physician Education	BRAIN SCAN Management of Neurologic Disorders in Primary Care: Bipolar Disorder Vignette	\$-197
American Association for Cancer Research	Seventh Annual AACR International Conference on Frontiers in Cancer Prevention Research	\$10,000
American Association for Cancer Research	Aging and Cancer: Two Sides of the Same Coin?	\$10,000
American Association for Geriatric Psychiatry - National	Getting a Handle on the Depression/Pain Dyad Before the Tide Swells	\$100,573
American Association of Directors of Psychiatric Residency Training	"The Mind at its Best: Empathy, Learning, and Belief"	\$5,000
American Cancer Society - Great Lakes Division	2009 Fundraiser	\$25,000
American Cancer Society - Houston Chapter	Lilly Oncology on Canvas Charitable Award Program - Best Entry by a Health Care Professional	\$1,000
American Chemical Society - Division of Medicinal Chemistry	Division of Medicinal Chemistry Predoctoral Fellowship Program	\$24,000
American Chemical Society - Indiana Section	9th Annual Indiana Local Section American Chemical Society Poster Session	\$3,800
American College of Neuropsychopharmacology - National	Addiction Medication Development Series	\$50,000
American College of Osteopathic Obstetricians and Gynecologists	ACCOG 2008 Fall Conference	\$2,500
American College of Physicians Foundation	Depression HEALTH TIPS	\$32,500
American College of Psychiatrists	The Stanley Dean Award for Research in Schizophrenia	\$10,000
American Diabetes Association - Albany	Enriching the Lives of Those Living With Diabetes in High Risk Communities	\$10,650

Examination of the Grant Registry of Eli Lilly



Using the data based on Eli Lilly

First:

- Identified all 181 HAOs that received grants
- The purpose of the grant
- The exact amount of the grant

Second:

- Identified the websites of the 181 Health Advocacy Organizations
- Searched the sites to learn: Did they acknowledge Lilly's funding?

Findings

- Only 25% of the organizations acknowledged the pharmaceutical company on their website
- Only 10% acknowledged the purpose of the grant
- None of the 181 organizations acknowledged the sum

“It is impossible for policy makers or the public to know about the financial relationships between the organizations and industry.”

- Rothman, SM, Raveis VH, et al, “Health Advocacy Organizations and the Pharmaceutical Industry: An Analysis of Disclosure Practices,” American Journal of Public Health January 13, 2011 e1-e8.

Health Advocacy Organizations Acknowledgements of Lilly Funding

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.) ^a	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)

^aThe 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.

Next Steps



- 14 pharmaceutical and device companies now disclose grants to health advocacy organizations and other institutions
- The registries provide:
 - The names of the requestors
 - The grant event
 - The exact sum
- It is now possible to study the financial relationship between industry and medical organizations

Goal of the Project



Create Data Visualization Charts

To allow the public to follow the money
To learn more about the relationships
between industry and medicine

Data Visualization Chart



Institutional Categories by Grants Disbursed in 2010:

Medical Communications Organizations

Academic Medical Centers

Professional Medical Associations

Health Advocacy Organizations

Research Organizations

Other Health Provider Associations

Number of educational grants 2010



In 2010 the 14 pharmaceutical companies gave:

20, 345 grants

Patient Advocacy Organizations received

4,033 grants

Money for Educational Grants 2010



- In 2010 14 companies spent on educational grants

- \$734, 643, 766

- Patient advocacy organizations received

\$ 95, 769, 456

Information on Grants to Advocacy Groups



Qualified Name	Amount Received	% of Total \$	# of Grants
Patient Advocate Foundation	\$8,911,483.00	9.31%	27
Merck - Allocated funds for ACHAP	\$6,000,000.00	6.27%	1
National Kidney Foundation	\$5,404,226.00	5.64%	219
Merck	\$4,369,926.00	4.56%	1
American Heart Association	\$3,644,156.00	3.81%	219
National Alliance on Mental Illness	\$3,401,100.00	3.55%	283
National AIDS Fund	\$2,868,883.00	3.00%	5
American Cancer Society	\$2,645,548.00	2.76%	168
National Psoriasis Foundation	\$2,167,470.00	2.26%	14
Arthritis Foundation	\$2,118,774.68	2.21%	443
CancerCare	\$2,072,879.00	2.16%	42
American Diabetes Association	\$1,965,425.00	2.05%	98
Cancer Support Community	\$1,492,500.00	1.56%	43
Leukemia and Lymphoma Society	\$1,327,815.50	1.39%	85
Prevent Cancer Foundation	\$1,311,588.00	1.37%	24
Michael J. Fox Foundation for Parkinson's Rese	\$1,250,200.00	1.31%	5
Lymphoma Research Foundation	\$1,161,000.00	1.21%	22
Accordia Global Health Foundation	\$1,131,165.00	1.18%	5
Mental Health America	\$1,017,200.00	1.06%	83
Susan G. Komen for the Cure	\$1,002,062.50	1.05%	52
National Coalition for Cancer Survivorship	\$925,000.00	0.97%	22
National Osteoporosis Foundation	\$865,840.00	0.90%	16
Epilepsy Foundation	\$784,080.00	0.82%	27
Lupus Foundation of America	\$745,300.00	0.78%	25
Depression and Bipolar Support Alliance	\$732,100.00	0.76%	17
Alzheimer's Association	\$719,102.50	0.75%	45
National Coalition for Cancer	\$711,500.00	0.74%	8
Lance Armstrong Foundation	\$690,050.00	0.72%	7
Crohn's and Colitis Foundation of America	\$661,851.79	0.69%	57
Global Healthy Living Foundation	\$655,000.00	0.68%	7
Breast Cancer Research Foundation	\$642,500.00	0.67%	9
Breast Cancer Network of Strength	\$600,000.00	0.63%	6
National Minority AIDS Council	\$588,610.00	0.61%	5
PKD Foundation	\$576,225.00	0.60%	6
Cystic Fibrosis Foundation	\$571,650.00	0.60%	19
...
Grand Total	\$95,769,465.66		4033

Conclusions



The analysis will allow us to learn about:

Financial relations between industry
and patient advocacy organizations
Insure ethical and patient-centered
decision-making.