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**United States Senate**

COMMITTEE ON THE JUDICIARY  
WASHINGTON, DC 20510-6275

BRUCE A. COHEN, *Chief Counsel and Staff Director*  
KOLAN L. DAVIS, *Republican Chief Counsel and Staff Director*

May 4, 2011

**Via Electronic Transmission**

Peter L. Saltonstall  
President and Chief Executive Officer  
National Organization for Rare Disorders  
55 Kenosia Avenue  
PO Box 1968  
Danbury, CT 06813

Dear Mr. Saltonstall:

In December 2009, I asked for an accounting of industry funding that the National Organization for Rare Disorders (NORD) receives from pharmaceutical and medical device companies as well as foundations established by these companies or the insurance industry. I appreciate your response, which I have attached to this letter. I write today to follow up on any efforts by your organization to improve transparency and accountability in its relationships with the pharmaceutical and device industries.

As I stated in my previous letter, I started my inquiry, in part, as a result of accounts documenting the lack of transparency in financial relationships between the pharmaceutical industry and nonprofit health and medical organizations. Specifically, I cited the April 2008 article in *The Wall Street Journal*, which reported that industry representatives, including ten major drug companies, had formed a coalition to promote looser restrictions on off-label marketing.<sup>1</sup> The coalition had asked the National Alliance on Mental Illness (NAMI) to speak in favor of this issue.

In response to my concerns in my April 2009 letter to NAMI, NAMI began to voluntarily disclose to the public any amount of funding exceeding \$5,000 that it received from pharmaceutical companies and foundations on its website. Further, NAMI began to provide a brief description of the purpose of the funding on its website. I commend NAMI for its leadership and had hoped that when I reached out to your organization and 32 others, your organization would follow NAMI's example and begin posting similar funding information on NORD's website.

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<sup>1</sup> Alicia Mundy, "Off-Label Use of Drugs Gets a Push --- Big Pharma Lobbies Washington to Relax Rules on Marketing," *The Wall Street Journal*, April 18, 2008.

As of the date of this letter, it appears that your organization has taken steps to identify on its website the corporate or industry sponsors and their range of funding support. However, the website does not specify the purposes of that funding. If NORD is currently taking steps to further enhance the transparency of its financial relationships with the pharmaceutical and device industries, I would appreciate information regarding those steps. In particular, please state whether or not NORD will be adding information in the future about the purpose of the funding it receives. If not, please explain why not.

The Medicare Payment Advisory Commission (MedPAC) recommended in a report to Congress in March 2009 that Congress require that pharmaceutical and device companies report their financial relationships with physician groups, patient organizations, and others. More specifically MedPAC said the following:

Given the potential benefits of public reporting, we recommend that the Congress mandate the reporting of comprehensive information on industry relationships with physicians and other health care entities and that the Secretary post this information on a public searchable website.<sup>2</sup>

MedPAC then went on to say in Recommendation 5-1 that:

The Congress should require all manufacturers and distributors of drugs, biologicals, medical devices, and medical supplies (and their subsidiaries) to report to the Secretary their financial relationship with:...physician groups and other prescribers...patient organizations; and professional organizations.<sup>3</sup>

I look forward to working with you and other health and medical organizations to further increase sunshine on financial relationships.

Thank you for your cooperation and attention in this matter. I would appreciate a response by May 25, 2011. If you have any questions, please do not hesitate to contact Brian Downey for the Committee on the Judiciary at (202) 224-5225.

Sincerely,



Charles E. Grassley  
Ranking Member

Attachments

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<sup>2</sup> Medicare Payment Advisory Commission, "Public reporting of physicians' financial relationships," Report to Congress: Medicare Payment Policy, March 2009.

<sup>3</sup> *Id.*

Attachment



January 29, 2010

Senator Charles E. Grassley  
Ranking Member  
Committee on Finance  
U.S. Senate  
Washington, D.C.

C/o Brian Downey  
Brian\_Downey@finance-rep.senate.gov

Dear Senator Grassley:

This is in response to your letter dated December 7, 2009, with regard to funding that pharmaceutical, medical device companies, foundations established by these companies or the insurance industry have provided to the National Organization for Rare Disorders (NORD) since January 2006.

As the national public voice and advocate for the rare disease community, NORD fully supports the concept of transparency in disclosing the sources of its funding and, more generally, in public policies that favor disclosure. In fact, in the July 2008 edition of its NORD On-Line newsletter, NORD published an article entitled "Chuck Grassley: A Senate Health Crusader" strongly supporting your efforts on behalf of transparency and noting that you were "demanding reforms that should make the healthcare system more equitable to consumers." (See attachment.)

NORD has been recognized for its appropriate utilization of donated funds. For the past six consecutive years, NORD has received the highest (4-star) rating for sound fiscal management from Charity Navigator, a leading independent evaluator of charities.

We regularly re-evaluate our policies to assure that the various sources of our funding are well understood by our patient and public constituencies. In fact, we are in the process of developing more transparent disclosure policies with regard to all charitable and philanthropic contributions we receive. We have processes in place to assure that the philanthropy we receive from any source does not influence the information we provide or the positions we take on public policy or legislative issues, which are focused on the patients we serve. NORD's commitment to transparency and disclosure stems from our mission and our heritage. As the primary advocate of the rare disease patient community, NORD strives to focus public attention on the need for more funding for research, for access to treatments, and for fair and reasonable insurance and reimbursement options. We also provide services to patients and their families, ranging from helping them find resources for daily life issues to running patient assistance programs that enable patients in need to access treatments they cannot afford. NORD is a unique federation of voluntary health organizations and individuals who collectively represent the 30 million American patients with rare diseases, defined by federal law as diseases affecting 200,000 or fewer patients. NIH estimates there are nearly 7,000 rare diseases.

NORD was founded in 1983 from a coalition of patient organizations that advocated for the enactment of the Orphan Drug Act – a law that has served our country very well. This law aimed to address the challenge posed by the lack of development of medical products for rare diseases.

One of the goals of the law was to establish a partnership among the patient community, the pharmaceutical industry, academic scientists and the federal government to advance the development of innovative medical products. The law provided for financial incentives to entice drug companies into developing treatments for small populations of patients. Fortunately, the Congress was able to reach a consensus on how to provide the economic incentives needed to encourage orphan drug development. Since the enactment of the law, more than 340 drugs and biological products for rare diseases have been brought to market. In contrast, in the decade before 1983 fewer than ten products developed by the pharmaceutical industry came to market. For details on incentives please call FDA's Office of Orphan Product Development at (301) 827-3666 or visit the website [www.fda.gov](http://www.fda.gov).

With this brief background on NORD, in reference to your letter please find enclosed answers:

**Question #1: *Please describe the policies for accepting industry funding and whether or not NORD allows companies to place restrictions or provide guidance on how funding will be spent.***

Answer #1: NORD does have policies in place in regards to accepting industry funding for all of its programs and services. NORD does not allow industry to place restrictions or provide guidance on the utilization of funds. Any funds raised from industry sources as unrestricted grants are utilized at NORD's discretion, typically to support general operating expenses for NORD, and the list of supporters is posted on NORD's website. For programs that do utilize restricted funds, the funds are directed strictly for administering the specific programs without any influence or guidance from the industry sponsor and in accordance with OIG guidelines and prudent policies and procedures for each program. (Details included as part of Answer #2)

**Question #2: *If NORD allows companies to place restrictions on industry funding, then please explain all restrictions and/or guidance for each transfer of value from industry. For every transfer of value what restriction, please provide the following information: year of transfer, name of company, and restriction placed on funding.***

Answer #2: Although NORD has received funding from industry restricted for some of its programs i.e. Patient Assistance Programs (PAP), physician booklets and PNH meetings, the nature of restrictions are devoid of guidance from the companies and all attempts are made to maintain a safe and arms-length relationship for each of the programs with appropriate policy framework serving as a guide.

NORD has been managing PAP programs since 1988 to assist uninsured or underinsured individuals in securing life-saving or life-sustaining medications. NORD got the impetus to administer PAP programs on an ongoing basis from its mention by name in the Settlement Agreement dated September 3, 1992, in the Clozapine Antitrust Litigation in which 23 states and the District of Columbia settled with Sandoz Pharmaceutical Corporation and Caremark Inc. The settlement provided that Sandoz, "through NORD," shall provide a rebate for patients taking Clozaril who are on Social Security Disability Income. This court-ordered program was one of the points of entry for NORD into providing patient assistance programs for uninsured (or underinsured) patients who are financially eligible.

NORD administers two types of PAPs: (1) Medication Assistance Programs (MAP) that provide free drug product donated by drug and biotechnology manufacturers and (2) Premium Co-payment Assistance Programs (Co-Pay Programs) designed to assist patients who have prescription drug insurance (e.g. Medicare Part B and D as well as commercially insured), but cannot afford associated Medicare premiums and co-payments. NORD administers MAPs and disease specific Co-Pay Programs to cover qualifying Medicare beneficiaries who meet financial eligibility and disease specific criteria for various rare disorders without any influence or guidance from the sponsor.

NORD's PAPs have set the standards for fairness, equity, confidentiality and unbiased eligibility, and have gained respect from the patient communities, pharmaceutical companies, healthcare professionals, government officials, and the public. There is no conflict of interest with respect to NORD's eligibility decisions. NORD's financial arrangement with the pharmaceutical industry with regard to PAPs follows the guidance provided by the Department of Health and Human Services' Office of Inspector General (OIG), which published a notice in the November 22, 2005 Federal Register (page 70623) providing a Special Advisory Bulletin on patient assistance programs under Medicare Part D. The principles set forth in the Bulletin reflect the policies and processes that NORD follows in implementing all of its PAPs. The Bulletin explains the safeguards needed for pharmaceutical companies to subsidize PAPs run by bona fide, independent charities (which NORD is) without running afoul of the fraud and abuse and anti-kickback statutes.

"Simply put, the independent charity PAP must not function as a conduit for payments by the pharmaceutical manufacturer to patients and must not impermissibly influence beneficiaries' drug choices," the OIG document says. NORD assiduously follows the guidance provided in the Special Advisory Bulletin with regard to all Patient Assistance Programs that it runs.

NORD receives funding from one of its Corporate Council members to conduct a series of educational meetings around the U.S. for patients with a rare disease, paroxysmal nocturnal hemoglobinuria (PNH), and their families. PNH patients have not had the benefit of a strong national patient advocacy group dedicated to serving their specific needs. The meetings provide these patients and their families with an opportunity to come together in small groups, and gain the encouragement, reinforcement and hope that comes from meeting face-to-face with other PNH patients. While this Corporate Council member makes the only drug to treat this disease, these meetings are non-promotional and strictly educational in nature and consistent with NORD's mission in providing a service to patients.

Although there is a huge unmet need in the medical community for education on rare diseases, NORD is **not** a CME provider and only publishes a series of "Physician's Guide" booklets on 10 topics that are primarily funded by patient organizations. Only two booklets have been published with money from educational grants provided by companies, but in those cases, the companies have not been permitted to influence the content nor the distribution of the booklets. NORD is extremely careful to have the content reviewed by physician experts not affiliated with those companies and to clearly identify in the booklet the source of funding that made the publication possible.

***Question #3 Please explain what policies, if any that NORD plans to adopt to ensure transparency of funding in order to provide a greater public trust in the independence of your organization.***

Answer #3: While NORD has always embraced a culture of transparency and has worked hard to maintain the public's trust in its independence from industry, we are striving to make our policies in this area even stronger. NORD's financial report is posted on our website along with the list of industry donors. To further ensure transparency related to funding, we are incorporating additional new policies as follows:

- Posting of funding details on NORD's website for corporate and foundation support that exceeds \$5,000. annually
- Financial statement to have dedicated space to illustrate funding support from industry.
- Incorporating a guidance document for the role of Corporate Council members to further foster an "arms-length" policy between NORD and its Corporate Council members
- Reinforce our efforts to ensure that all NORD materials receiving any industry support identify the sources of support

**Question #4: Please explain your policies on disclosure of outside income by your top executives and board members.**

**AND**

**Question #5: Please provide the disclosures of outside income filed with your organizations by your top executives and board members.**

Answer #4 & 5: NORD does have policies in place in the by-laws for its board members and senior leaders to file conflict of interest disclosures to assure that any potential conflicts are disclosed and addressed if necessary. These by-laws undergo frequent revisions and updates in an on-going effort to maintain transparency and disclosure.

All individuals being considered for appointment to the NORD board of directors must meet very stringent qualification criteria. There is a nominating committee within NORD's board of directors that is entrusted with the responsibility of ensuring that the nominated individuals fulfill criteria prior to being appointed to the board. No member of the board of directors receives any financial remuneration for participation on NORD's board. Since the board members are not dependent on NORD for any financial support, NORD does not require board members to provide specific details of outside income except to be in compliance with requirements that are set in the conflict of interest disclosures.

NORD's efforts at maintaining a culture of transparency and avoiding conflict of interest are not limited only to the senior management and board members but also apply to all NORD staff members.

In closing, for 2009, NORD's total revenues are expected to be approximately \$14 million. Of this amount, \$3.8 million represents unrestricted monies to fund NORD's operations (i.e., the operating budget). The remaining revenues (\$10.2 million) represent funds restricted for NORD's PAPs and research funds.

Although NORD accepts unrestricted donations from pharmaceutical and medical device companies, the vast majority of donations are modest amounts. NORD also receives donations from individuals, many in memory of lost loved ones. No donation to NORD influences the policy positions we take or the information we provide, all of which are based exclusively on the needs of the patients that we represent. As an example of the care we take in our fiscal policies, we have for the past several years charged \$7.50 for each disease report purchased from our Rare Disease Database. While we regret having to charge patients for disease information, we decided we did not want to ask companies to assist us with the cost of maintaining the Database. We wanted to ensure that the medical information we provide is not only free of any industry influence, but free from any perception that a company was subsidizing the information. Names of patients or others who request disease information from NORD are never released, shared or sold to companies.

NORD has always been scrupulous about keeping the medical information we provide completely independent of industry input. We never comment on, or recommend, specific products in our written materials, conversations or communications with patients. Further, in our Rare Disease Database, we are extremely careful to publish information only from neutral sources, such as the National Institutes of Health, the FDA, and academic papers in journals. We are also very careful to have our information reviewed by medical experts without industry ties for the topic they are reviewing. The physicians who write and/or review NORD reports are not paid. They donate their time without recompense because they understand that patients will benefit from their efforts to expand awareness rare diseases. NORD does not ask researchers directly involved in studies of particular products to provide or review information for the standard therapies or investigational therapies sections of the reports. NORD holds the copyright for all reports in its Rare Disease Database.

Many companies participate in NORD's Corporate Council, created more than a decade ago to provide opportunities for companies to work with NORD to advance medical research and product development. The membership dues go into our general fund and are used for general support for our programs and to support the Corporate Council meetings; the money is not earmarked for any specific program or usage. NORD views the Corporate Council members as an important constituency because, as discussed above, they are the companies that develop and provide the medical products that patients need. At the same time, they do not influence our policies. Corporate Council members are invited to attend two or three meetings a year sponsored by NORD and also receive email updates on our activities. A list of Corporate Council members and the dues they paid is in the attached Excel chart.

The same Excel chart sets forth the annual amounts of industry funding of NORD. The chart includes the donations received from companies from 2006 through November 2009 for Patient Assistance Programs; a listing of the administrative fees to service the PAPs; a list of the Corporate Council members and the dues they paid; a listing of money received for the annual gala from companies that bought ads in the tribute journal or that purchased tables; and a listing of unrestricted donations from companies.

Senator Grassley, I would be pleased to meet with you at your convenience to address any additional questions you have about NORD or the patient and research services we provide. To reiterate, NORD supports transparency and disclosure and we always seek to conduct our organization's activities with that principle in mind.

Sincerely,

**PETER SALTONSTALL**

Peter L. Saltonstall  
President & CEO



**2006  
UNRESTRICTED GENERAL CONTRIBUTIONS**

<u>Company</u>	<u>Amount</u>	<u>Reason</u>
Allergan	\$10,268	Contribution
Actelion	\$10,000	Contribution
Allergan	\$5,000	Contribution
GTC Biotherapeutics	\$2,500	Contribution
Amgen Political Action Committee	\$459	Contribution
Johnson & Johnson	\$200	Matched Employee Gift
Sub-total Pharmaceutical Cos.	\$28,427	
Individual - Stock Donation	\$20,655	Contribution
Beatrice Snyder Foundation	\$5,000	Contribution
Nvidia Corporation	\$2,041	Contribution
Schwab Charitable Fund	\$1,000	Contribution
Vanguard Charitable Endowment	\$1,000	Contribution
New South Investment Group	\$900	Contribution
Individuals As A Group (183)	\$31,602	Contributions
Sub-total Individuals/Other Entities	\$62,198	
<b>TOTAL GENERAL CONTRIBUTIONS</b>	<b>\$90,625</b>	

**RESTRICTED FELLOWSHIP & OTHER GRANTS**

<b>FELLOWSHIP</b>		
Genzyme	\$75,000	Research Grant for Lysosomal Storage Diseases
<b>OTHER GRANTS</b>		
Medtronic Foundation	\$100,000	Grant for Awareness, Advocacy
Medtronic Foundation	\$50,000	Urban Scholarship Grant
Medtronic Foundation	\$45,000	Patient Support Group Mentoring
Medtronic Foundation	\$25,000	"Patient Link" Advocacy Grant
Catt Family Foundation	\$30,000	Grant for General Operating Exp
Ligand	\$15,000	Medicare Task Force
Allergan	\$10,000	Medicare Task Force
Baxter	\$10,000	Medicare Task Force
AstraZeneca	\$10,000	Educational Grant to update 10 Rare Disease Reports
AstraZeneca	\$39,100	Grant to produce/print booklet on Medullary Thyroid Cancer
Actelion	\$20,000	Educational Grant to update 12 Rare Disease Reports
Amyloidosis Support Group	\$20,000	Educational Grant to publish Amyloidosis Booklet
Amicus Therapeutics	\$3,000	Clinical Broadcast
<b>TOTAL OTHER GRANTS</b>	<b>\$377,100</b>	

**2007**  
**ANNUAL TRIBUTE BANQUET**

<b>Journal Ads</b>	<b><u>Company</u></b>	<b><u>Amount</u></b>	<b><u>Reason</u></b>
	Accredo Health Inc.	\$7,500	Journal Ad - Amount B
	Acorda Therapeutics	\$7,500	Journal Ad - Amount B
	Actelion Pharmaceuticals U.S.	\$10,000	Journal Ad - Amount B
	Alexion Pharmaceuticals	\$10,000	Journal Ad - Amount B
	Allergan Inc.	\$25,000	Journal Ad - Amount B
	Amicus Therapeutics	\$7,500	Journal Ad - Amount B
	AstraZeneca	\$25,000	Journal Ad - Amount B
	Barr Pharmaceuticals Inc.	\$10,000	Journal Ad - Amount B
	Bausch & Lomb	\$5,000	Journal Ad - Amount B
	Bayer Corporation	\$3,000	Journal Ad - Amount B
	BioMarin Pharmaceutical Inc.	\$15,000	Journal Ad - Amount B
	Celgene Corporation	\$10,000	Journal Ad - Amount B
	Cephalon Inc.	\$10,000	Journal Ad - Amount B
	CSL Behring	\$7,500	Journal Ad - Amount B
	Duchesnay, Inc.	\$3,000	Journal Ad - Amount B
	Genzyme Corp.	\$20,000	Journal Ad - Amount B
	INO Therapeutics	\$15,000	Journal Ad - Amount B
	Insmmed Inc.	\$5,000	Journal Ad - Amount B
	Inspire Pharmaceuticals	\$1,500	Journal Ad - Amount B
	Introgen Pharmaceuticals Inc.	\$1,500	Journal Ad - Amount B
	Johnson & Johnson	\$5,000	Journal Ad - Amount B
	Karl Storz Endoscopy-America	\$1,000	Journal Ad - Amount B
	LEV Pharmaceuticals	\$2,500	Journal Ad - Amount B
	Medtronic, Inc.	\$10,000	Journal Ad - Amount B
	Millenium Pharmaceutical	\$3,000	Journal Ad - Amount B
	Mylan Laboratories	\$5,000	Journal Ad - Amount B
	Neurochem	\$5,000	Journal Ad - Amount B
	Novartis Pharmaceuticals	\$15,000	Journal Ad - Amount B
	Orphan Europe	\$7,500	Journal Ad - Amount B
	Ovation Pharmaceuticals	\$3,000	Journal Ad - Amount B
	PTC Therapeutics	\$4,000	Journal Ad - Amount B
	Questcor Pharmaceuticals, Inc.	\$7,500	Journal Ad - Amount B
	Rare Disease Therapeutics Inc.	\$3,000	Journal Ad - Amount B
	Serono Inc.	\$5,000	Journal Ad - Amount B
	Shire Human Genetics Therapies	\$15,000	Journal Ad - Amount B
	Sigma-Tau Pharmaceuticals Inc.	\$15,000	Journal Ad - Amount B
	Swedish Orphan International	\$14,973	Journal Ad - Amount B
	Tercica Inc.	\$7,500	Journal Ad - Amount B
	Teva N.A./Teva USA	\$15,000	Journal Ad - Amount B
	Ucyclyd Pharma, Inc.	\$5,000	Journal Ad - Amount B
	ZioPharm	<u>\$1,000</u>	Journal Ad - Amount B
	Sub-total Pharmaceutical Cos.	\$348,973	
	Agvar Chemicals	\$25,000	Journal Ad - Amount B
	Bell Pottinger, USA	\$1,500	Journal Ad - Amount B

Engage Health, Inc.	\$1,000	Journal Ad - Amount B
GPhA	\$7,500	Journal Ad - Amount B
Hyman, Phelps & McNamara	\$3,000	Journal Ad - Amount B
Jennings Policy Strategies	\$500	Journal Ad - Amount B
Mark Krueger & Associates	\$7,500	Journal Ad - Amount B
NACDS	\$3,000	Journal Ad - Amount B
Sturge Weber Foundation	\$450	Journal Ad - Amount B
The Engelberg Foundation	\$7,500	Journal Ad - Amount B
The Redstone Group	<u>\$3,000</u>	Journal Ad - Amount B
Sub-total Other Entities	\$59,950	
 Total Journal Ads	 \$408,923	

### **Banquet Tables/Seats**

Shire	\$5,000	Tables/Seats
FoldRx	\$1,500	Tables/Seats
IDIS	\$1,000	Tables/Seats
LEV Pharmaceutical	\$1,000	Tables/Seats
Knopp Neurosci	\$1,000	Tables/Seats
Asklepion Pharma	\$500	Tables/Seats
PHARMA	\$5,000	Tables/Seats
Purdue Pharma	\$500	Tables/Seats
Vifor Pharma	\$500	Tables/Seats
Argent Development Group	\$500	Tables/Seats
Altus	<u>\$500</u>	Tables/Seats
Sub-total Pharmaceutical Cos.	\$17,000	
 Makovsky & Co.	 \$2,000	 Tables/Seats
Medtronic Foundation	\$1,250	Tables/Seats
Campaign for Tobacco Free Kids	\$500	Tables/Seats
Jennings Policy Strategies	\$500	Tables/Seats
Fleishman & Hilliard	\$500	Tables/Seats
Zuckerman Spaeder	\$500	Tables/Seats
Seed One Ventures	\$500	Tables/Seats
Research America	\$500	Tables/Seats
HPS Group	\$250	Tables/Seats
Individuals	<u>\$8,300</u>	Tables/Seats
Sub-total Other Entities	\$14,800	
 <b>TOTAL TRIBUTE BANQUET REVENUES</b>	 <b>\$440,723</b>	

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[illegible]

**2008**  
**ANNUAL TRIBUTE BANQUET**

<u>Company</u> <u>Journal Ads</u>	<u>Amount</u>	<u>Reason</u>
Accredo Health	\$15,000	Journal Ad - Amount B
Acordia Thwerapeutics	\$30,000	Journal Ad - Amount B
Actelion Pharmaceuticals	\$15,000	Journal Ad - Amount B
Alexion Pharmaceutical	\$15,000	Journal Ad - Amount B
Allergan Inc.	\$50,000	Journal Ad - Amount B
Amicus Therapeutics	\$7,500	Journal Ad - Amount B
Argent Development Group	\$1,500	Journal Ad - Amount B
Aton Pharma	\$2,500	Journal Ad - Amount B
Barr Laboratories Inc.	\$10,000	Journal Ad - Amount B
Baxter Healthcare	\$5,000	Journal Ad - Amount B
BioMarin Pharmaceuticals	\$30,000	Journal Ad - Amount B
Biotechnology Industry Organization	\$20,000	Journal Ad - Amount B
Celgene Corporation	\$50,000	Journal Ad - Amount B
Cephalon Inc.	\$10,000	Journal Ad - Amount B
CSL Behring	\$15,000	Journal Ad - Amount B
DOR Biopharma	\$1,500	Journal Ad - Amount B
EMD Serono	\$2,500	Journal Ad - Amount B
Genzyme Corporation	\$20,000	Journal Ad - Amount B
IDM Pharma	\$1,500	Journal Ad - Amount B
Ikaria	\$10,000	Journal Ad - Amount B
Insmmed Inc.	\$2,500	Journal Ad - Amount B
Lev Pharmaceuticals	\$15,000	Journal Ad - Amount B
Medtronic	\$10,000	Journal Ad - Amount B
Millenium Pharmaceuticals	\$1,500	Journal Ad - Amount B
Mission Pharmacal	\$2,500	Journal Ad - Amount B
Novartis Oncology	\$15,000	Journal Ad - Amount B
Ovation Pharmaceuticals	\$2,500	Journal Ad - Amount B
Pfizer	\$5,000	Journal Ad - Amount B
PHARMA	\$50,000	Journal Ad - Amount B
Prestwick Pharmaceuticals	\$2,500	Journal Ad - Amount B
Questcor Pharmaceuticals	\$10,000	Journal Ad - Amount B
PTC Therapeutics	\$6,500	Journal Ad - Amount B
Rare Disease Therapeutics	\$25,000	Journal Ad - Amount B
Recordati (Orphan Europe)	\$25,000	Journal Ad - Amount B
Sanofi Aventis US	\$25,000	Journal Ad - Amount B
Sanofi Pasteur	\$7,000	Journal Ad - Amount B
Shire Human Genetics	\$20,000	Journal Ad - Amount B
Sigma Tau Pharmaceuticals	\$50,000	Journal Ad - Amount B
Swedish Orphan International	\$9,973	Journal Ad - Amount B
Teva Neuroscience	\$7,500	Journal Ad - Amount B
Teva USA	\$7,500	Journal Ad - Amount B
Sub-total Pharmaceutical Cos.	\$611,973	
Association of American Medical Colleges	\$1,500	Journal Ad - Amount B
Agvar Chemicals Inc.	\$30,000	Journal Ad - Amount B

Generic Pharmaceutical Association	\$7,500	Journal Ad - Amount B
Hyman Phelps & McNamara	\$2,500	Journal Ad - Amount B
Mark Krueger & Associates	\$15,000	Journal Ad - Amount B
NACDS Foundation	<u>\$2,500</u>	Journal Ad - Amount B
Sub-total Other Entities	\$59,000	

**Total Journal Ads** **\$670,973**

#### **Banquet Table/Seats**

Mondo Biotech	\$1,000	Tables/Seats
Zio Pharm	\$1,000	Tables/Seats
Jerini	\$500	Tables/Seats
Hyperion Therapeutics	\$1,500	Tables/Seats
K M Pharma	\$1,000	Tables/Seats
FoldRx Pharma	\$1,000	Tables/Seats
Chelsea Therapeutics	\$500	Tables/Seats
Purdue Pharma	\$500	Tables/Seats
Momenta Pharma	\$500	Tables/Seats
Motif Biosci	<u>\$75</u>	Tables/Seats
Sub-total Pharmaceutical Cos.	\$7,575	

Individuals	\$17,175	Tables/Seats
GBS/CIDP Foundation	\$5,000	Tables/Seats
ICORD	\$2,850	Tables/Seats
HPS Group	<u>\$1,500</u>	Tables/Seats
Sub-total Individuals/Other Entities	\$26,525	

**Total Banquet Seats** **\$34,100**

#### **Program Line Listing**

Solakian, Caiafa LLC (Accounting Firm)	\$150	Program Listing
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**TOTAL TRIBUTE BANQUET REVENUES** **\$705,223**

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**2009**  
**ANNUAL TRIBUTE BANQUET**

<u>Company</u> Journal Ads	<u>Amount</u>	<u>Reason</u>
Accredo Health	\$15,000	Journal Ad - Amount Based on Size of Ad
Acorda Therapeutics	\$30,000	Journal Ad - Amount Based on Size of Ad
Actelion Pharmaceuticals, U.S.	\$10,000	Journal Ad - Amount Based on Size of Ad
Alexion Pharmaceuticals	\$15,000	Journal Ad - Amount Based on Size of Ad
Allergan Inc.	\$30,000	Journal Ad - Amount Based on Size of Ad
Amicus Therapeutics Inc.	\$7,500	Journal Ad - Amount Based on Size of Ad
AstraZeneca	\$10,000	Journal Ad - Amount Based on Size of Ad
Aton Pharma Inc.	\$3,000	Journal Ad - Amount Based on Size of Ad
Baxter BioScience	\$15,000	Journal Ad - Amount Based on Size of Ad
BioMarin Pharmaceuticals	\$20,000	Journal Ad - Amount Based on Size of Ad
Biotechnology Industry Org (BIO)	\$5,000	Journal Ad - Amount Based on Size of Ad
Biovail	\$3,000	Journal Ad - Amount Based on Size of Ad
Celgene Corporation	\$50,000	Journal Ad - Amount Based on Size of Ad
Centric Health Resources	\$3,000	Journal Ad - Amount Based on Size of Ad
Cephalon	\$15,000	Journal Ad - Amount Based on Size of Ad
CSL Behring	\$50,000	Journal Ad - Amount Based on Size of Ad
Duchesnay Inc.	\$3,000	Journal Ad - Amount Based on Size of Ad
Eisai, Inc.	\$3,000	Journal Ad - Amount Based on Size of Ad
Endo Pharma	\$10,000	Journal Ad - Amount Based on Size of Ad
Engage Health	\$1,000	Journal Ad - Amount Based on Size of Ad
Enobia Pharma	\$3,000	Journal Ad - Amount Based on Size of Ad
Genzyme Corporation	\$18,000	Journal Ad - Amount Based on Size of Ad
GPN A	\$7,500	Journal Ad - Amount Based on Size of Ad
GTC Biotherapeutics	\$2,000	Journal Ad - Amount Based on Size of Ad
Hyman Phelps McNamara	\$3,000	Journal Ad - Amount Based on Size of Ad
Kakkis EveryLife Foundation	\$10,000	Journal Ad - Amount Based on Size of Ad
Keck Graduate Institute	\$1,150	Journal Ad - Amount Based on Size of Ad
Lundbeck Inc.	\$3,000	Journal Ad - Amount Based on Size of Ad
Mark Kruger & Associates	\$15,000	Journal Ad - Amount Based on Size of Ad
Medtronic	\$10,000	Journal Ad - Amount Based on Size of Ad
Millennium	\$10,000	Journal Ad - Amount Based on Size of Ad
mondoBIOTECH	\$7,500	Journal Ad - Amount Based on Size of Ad
Novartis Oncology	\$15,000	Journal Ad - Amount Based on Size of Ad
Optherion	\$3,000	Journal Ad - Amount Based on Size of Ad
Orphan Europe	\$15,000	Journal Ad - Amount Based on Size of Ad
Pfizer	\$15,000	Journal Ad - Amount Based on Size of Ad
PhRMA	\$10,000	Journal Ad - Amount Based on Size of Ad
PTC Therapeutics	\$3,000	Journal Ad - Amount Based on Size of Ad
Questcor Pharmaceuticals	\$7,500	Journal Ad - Amount Based on Size of Ad
Rare Disease Therapeutics	\$7,500	Journal Ad - Amount Based on Size of Ad
Regeneron	\$3,000	Journal Ad - Amount Based on Size of Ad
Sanofi Aventis	\$25,000	Journal Ad - Amount Based on Size of Ad
Shire Human Genetics	\$20,000	Journal Ad - Amount Based on Size of Ad
Sigma Tau	\$10,000	Journal Ad - Amount Based on Size of Ad
Strategic Diagnostics	\$3,000	Journal Ad - Amount Based on Size of Ad
Swedish Orphan International	\$7,480	Journal Ad - Amount Based on Size of Ad
Talecris	\$10,000	Journal Ad - Amount Based on Size of Ad
Teva Neuroscience	\$15,000	Journal Ad - Amount Based on Size of Ad
ViroPharma Inc.	\$5,000	Journal Ad - Amount Based on Size of Ad
ZioPharm Inc.	<u>\$1,000</u>	Journal Ad - Amount Based on Size of Ad
<b>Sub-total Journal Ads</b>	<b>\$564,130</b>	

### Program Listing

ApoPharma Inc.	\$150	Line Listing in Program
Argent Development Group	\$150	Line Listing in Program
Copilevitz & Canter	\$150	Line Listing in Program
Simon-Kucher Pharma	\$150	Line Listing in Program
Siren Interactive	\$150	Line Listing in Program
The IDEA League	<u>\$50</u>	Line Listing in Program
<b>Sub-total Program Listing</b>	<b>\$800</b>	

### Banquet Seats

America's Health Insurance Plans	\$1,000	Tables/Seats
American Porphyria Foundation	\$200	Tables/Seats
Amyloidosis Support Group	\$800	Tables/Seats
ApoPharma	\$500	Tables/Seats
Argent Development Group	\$1,000	Tables/Seats
Benign Essential Blepharospasm	\$100	Tables/Seats
Bennu Phar/Raptor	\$1,000	Tables/Seats
Conquer Pediatric Chiari	\$1,000	Tables/Seats
Cystinosis Research Network	\$300	Tables/Seats
DesignWrite	\$500	Tables/Seats
Diplomat Specialty Pharmacy	\$500	Tables/Seats
DEBRA	\$100	Tables/Seats
DystoniaMedResearch	\$100	Tables/Seats
FoldRx Pharma	\$500	Tables/Seats
HPS Group	\$500	Tables/Seats
IDEA League	\$200	Tables/Seats
IDIS Ltd	\$1,520	Tables/Seats
Lapidus Data	\$500	Tables/Seats
Mercy Medical Airlift	\$100	Tables/Seats
MME, LLC	\$500	Tables/Seats
Neurofibromatosis	\$100	Tables/Seats
NORD Board Members	\$1,250	Tables/Seats
Palo Alto Investors	\$500	Tables/Seats
Parry Romberg Connection	\$100	Tables/Seats
Purdue Pharma	\$500	Tables/Seats
Russell-Silver Syndrome	\$200	Tables/Seats
Santhera Pharm	\$500	Tables/Seats
Simon-Kucher Partners	\$1,000	Tables/Seats
Siren Interactive	\$200	Tables/Seats
Ucyclyd/Medicis	\$500	Tables/Seats
United Leukodystrophy Foundation	\$400	Tables/Seats
Voisin Consulting	\$500	Tables/Seats
Individuals	<u>\$1,000</u>	
<b>Sub-total Banquet Seats</b>	<b>\$17,670</b>	

**TOTAL TRIBUTE REVENUES** **\$582,600**