

COMMITTEE ON FINANCE WASHINGTON, DC 20510-6200

April 6, 2009

#### **Via Electronic Transmission**

Michael J. Fitzpatrick Executive Director National Alliance on Mental Illness Colonial Place Three 2107 Wilson Blvd., Suite 300 Arlington, VA 22201 Anand Pandya, M.D.
President
Board of Directors
National Alliance on Mental Illness
Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201

Dear Mr. Fitzpatrick and Dr. Pandya:

The United States Senate Committee on Finance (Committee) has jurisdiction over the Medicare and Medicaid programs and, accordingly, a responsibility to the more than 80 million Americans who receive health care coverage under these programs. As Ranking Member of the Committee, I have a duty to protect the health of Medicare and Medicaid beneficiaries and safeguard taxpayer dollars authorized by Congress for these programs.

For the last three years, the Committee has been investigating various aspects of the pharmaceutical industry, including consulting arrangements and industry funding for Continuing Medical Education (CME). My staff has also examined several issues related to non-profit organizations, and I have read newspaper accounts documenting the strong ties between the pharmaceutical industry and non-profit charities. I am hoping that you can provide me with some additional insight into these relationships.

Based upon reporting in the *New York Times*, I have come to understand that money from the pharmaceutical industry shapes the practices of non-profit organizations which purport to be independent in their viewpoints and actions.<sup>[1]</sup> Specifically, it is alleged that pharmaceutical companies give money to non-profits in an attempt to garner favor in ways that increase sales of their products. In a recent opinion piece in the *Journal of the American Medical Association*, several leading thinkers in medicine called on medical societies to better control these ties to pharmaceutical companies in order to guard against possible conflicts of interest.<sup>[2]</sup>

Accordingly, I would appreciate an accounting of industry funding that pharmaceutical companies or foundations established by these companies have provided to the National Alliance on Mental Illness (NAMI). (The term "industry funding" means

<sup>[1]</sup> The New York Times "Charities Tied to Doctors Get Drug Industry Gifts," June 28, 2006.

Rothman, David, "Professional Medical Associations and Their Relationships With Industry: A Proposal for Controlling Conflict of Interest," *JAMA*. 2009; 301(13):1367-1372 (doi:10.1001/jama.2009.407).

any transfer of value from a pharmaceutical company, including but not limited to grants, donations, and sponsorship for meetings or programs, etc.) This request covers the period of January 2005 to the present.

Because reporting practices vary widely from one charitable organization to another, I would appreciate you also placing this income into a chart, detailing annual amounts of industry funding from pharmaceutical companies. For each year, please provide the following information for NAMI:

- 1. Year;
- 2. Name of company;
- 3. Amount of funding; and
- 4. Reason(s) that the funding was provided.

In addition, please explain NAMI's policies for accepting industry funding by answering the following questions. For each question, please respond by first repeating the enumerated question followed by the appropriate answer.

- 1) Please describe the policies for accepting industry funding and whether or not NAMI allows companies to place restrictions or provide guidance on how funding will be spent.
- 2) If NAMI allows companies to place restrictions on industry funding, then please explain all restrictions and/or guidance for each transfer of value from a pharmaceutical company since January 2005. For every transfer of value with a restriction, please provide the following information: year of transfer, name of company, and restriction placed on funding.

In cooperating with the Committee's review, no documents, records, data or information related to these matters shall be destroyed, modified, removed or otherwise made inaccessible to the Committee.

I look forward to hearing from you by no later than April 27, 2009. All documents responsive to this request should be sent electronically in PDF format to Brian\_Downey@finance-rep.senate.gov. If you have any questions, please do not hesitate to contact Brian Downey or Paul Thacker at (202) 224-4515.

Sincerely,

Charles E. Grassley Ranking Member

Chuck Andley



April 27, 2009

Senator Charles E. Grassley Ranking Member Committee on Finance United States Senate Washington, DC 20510-6200

Dear Senator Grassley:

NAMI, the National Alliance on Mental Illness, received your letter dated April 6, 2009 stating your interest in the relationship between the pharmaceutical industry and non-profit charities and requesting information about the support NAMI receives from the pharmaceutical industry. NAMI shares your interest in transparency and is pleased to provide the information you requested.

In the interest of making this response clear and useful to you, please note the following in your review of the attached documents:

- The finances reported here pertain only to NAMI National. While NAMI has
  approximately one thousand local affiliates, each affiliate operates
  independently and, where appropriate, has its own 501(c)(3) designation
  governing its operations and finance. NAMI National bears no fiduciary
  responsibility for those affiliates, and is therefore unable to report on or detail
  their individual financial relationships.
- As a self-help and advocacy organization whose membership is comprised of people living with serious mental illness and their families, NAMI does not represent physicians or providers. NAMI does not publish medical journals or offer Continuing Medical Education (CME) programs.

You have asked that NAMI address the following questions specifically:

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

NAMI accepts charitable contributions from corporations, foundations, individuals and members to improve the lives of people with mental illness and their families. These corporate relationships are governed by NAMI's Guidelines for Business Support Relationships, a NAMI policy originally

developed and approved by the Board of Directors in 2004, and recently revised. This policy ensures that at all times NAMI will maintain an independent position on issues affecting the welfare of people with mental illness. NAMI does not engage in product promotion, endorsement, licensure or certification of any product, service or program.

Please find attached the Board-adopted policies which govern these relationships.

Corporate contributions support the important work of NAMI. These contributions allow NAMI to exercise its independent voice and unique expertise in family and consumer issues through the creation and provision of education programs operating in nearly every state serving hundreds of thousands of consumers and families; outreach to diverse communities; providing millions of Americans with up-to-date information on mental illness through the NAMI Web site and HelpLine; and educating America about mental illness.

All contributions to NAMI are recorded in accordance with generally accepted accounting principles (GAAP) and in accordance with Financial Accounting Standards Board (FASB) 116 & 117 (Accounting for Contributions Received and Contributions Made & Financial Statements of Not for Profit Organizations). All contributions (member, individual, foundation, and corporate) are recorded as unrestricted, temporarily restricted, or permanently restricted in accordance with donor specifications. When the restrictions are satisfied the contributions are released into unrestricted funds. NAMI is audited annually by an independent auditor and has received an unqualified report every year. The auditors check each major donation to ensure that proper accounting has taken place.

2. If NAMI allows companies to place restrictions on industry funding, then please explain all restrictions and/or guidance for each transfer of value from a pharmaceutical company since January 2005. For every transfer of value with a restriction, please provide the following information: year of transfer, name of company, and restrictions placed on funding.

Attached you will find a chart detailing the contributions to NAMI National from pharmaceutical companies from January 2005 through April 17, 2009. This chart is organized by year and company and lists transfers of value, whether they were restricted or unrestricted, and for what purposes the contributions were made.

The attached accounting of pharmaceutical companies' contributions references specific NAMI programs for which funds were designated. In order to present this information to you in a usable format, we have also

provided a program narrative to accompany the financial details. Our intent is to give context to the nature of each contribution.

We look forward to a continued dialogue regarding the issues you have raised, and hope that should you have any further questions you will allow NAMI the opportunity to provide you with the information to satisfy them.

Sincerely,

Michael J. Fitzpatrick, M.S.W.

**Executive Director** 

National Alliance on Mental Illness

Anand Pandya, M.D.

President

**Board of Directors** 

National Alliance on Mental Illness



## NAMI National Board of Directors Operating Policies and Procedures

## 8.6 Guidelines for Business Support Relationships<sup>1</sup>

#### 8.6.1 Introduction

NAMI enters into relationships with corporations, other businesses and professional associations to provide meaningful mission-related benefits to its members, mental health professionals and the general public. Benefits include health education, information, disease awareness, advocacy and resources.

NAMI seeks and secures such direct and in-kind financial support in order to fund programs and services. Some of these funders are pharmaceutical, managed behavioral healthcare, other health related businesses or associations that make products or offer services used by people with mental illness or the professionals who serve them. NAMI believes it is not only ethically sound but also equitable to engage such support of NAMI's programs designed to benefit people with mental illness, so long as such relationships do not compromise or otherwise inappropriately influence the policies and operations of NAMI.

NAMI is committed to avoiding conflicts of interest or the appearance of conflicts of interest in all of its relationships, including those with any corporate, other business or professional association funders. Therefore, NAMI's Board of Directors has determined that accepting such support, as well as NAMI's relationship to these donors, shall be guided by the principles provided under Sections 8.6.2 through 8.6.5 of these Policies and Procedures.

## 8.6.2 Definition of Acceptable Business Support Relationships

The following terms help to define the nature of corporate, other business, or professional association relationships and acceptable forms of such relationships:

## 8.6.2.1 Sponsorships

A "sponsorship" is a corporate, other business or professional association funder that provides unrestricted educational grants of financial or in-kind support for a specific NAMI activity or program that could include peer support, education, research, awareness, and fundraising. Typically, a sponsorship provides for recognition of the entity providing the support.

## 8.6.2.2 Strategic Alliance

A "strategic alliance" is an agreed-upon relationship between NAMI and a corporate, other business or professional association sponsor to carry out NAMI's defined goals. Under no circumstance may the funder implicitly or explicitly use such an alliance as an endorsement of their products or services. (An example would be where NAMI provides

<sup>&</sup>lt;sup>1</sup> NAMI National Board of Directors' Operating Policies & Procedures, Section 8.6 – adopted March 2009

a health education message or service that is delivered or supported by a company or association where the purpose is to improve health information, awareness and outcomes related to mental illness.)

### 8.6.2.3 Cause Marketing

"Cause marketing" is where a corporate, other business or professional association sponsor supports NAMI or a particular cause formally supported by NAMI by providing unrestricted financial donations, in-kind assistance or other resources. The sponsor may gain public recognition for such public support of NAMI, but may not tie this support to any commercial return or other financial benefit to the sponsor.

## 8.6.3 Excluded Activity

NAMI **shall not** engage in the following types of relationships with corporate, other business or professional association funders:

#### 8.6.3.1 Endorsement

NAMI will not endorse, license, certify, or in any way imply support for any sponsor's product, service or program, including recognizing or certifying the quality or standards of any particular product, service, or program.

#### 8.6.3.2 Product Association

NAMI's name and logo may not be associated with specific branded products. references to NAMI's website, phone number or address for the purposes of referral to NAMI may be permitted with NAMI's written approval.

## 8.6.4. Guiding Principles for Corporate Relationships

- 1. NAMI shall at all times maintain an independent position on issues affecting the welfare of people with mental illness. The potential effect of such positions on the commercial interests of any sponsor shall not be a relevant factor in the NAMI's decision-making process.
- 2. NAMI will solicit and accept support only for projects and activities that are consistent with its mission.
- 3. NAMI will accept funds for projects relating to the communication of information only when it has final editorial approval over content and distribution.
- 4. NAMI will neither endorse nor accept conditions that allow the perception that NAMI endorses any products, devices, treatments or services NAMI may require a disclaimer explicitly stating this policy be included in any publication;
- 5. NAMI will accept support for projects or programs only with assurances that the privacy of people with mental illness and their families will be protected, including requiring specific, prior written permission in order to waive such privacy.

- 6. NAMI will accept support for professional meetings and symposia only when the program content and selection of speakers are approved by NAMI or an independent body designated for that purpose by NAMI.
- 7. NAMI shall, at all times, maintain complete control and sole discretion over all funds received.
- 8. NAMI will ensure that programs for which it accepts funding do not adversely affect NAMI's nonprofit, tax-exempt status.
- 9. The use of NAMI's name and logo in any print, electronic or other form not produced by NAMI is not permitted without specific, prior written permission from NAMI.
- 10. Corporate, other business and professional association sponsors, as well as their agents, vendors and trade associations, are expected to work collaboratively with NAMI's national office on issues directly affecting NAMI state organizations and local affiliates.
- 11. NAMI retains sole discretion with regard to how the support it receives in the form of educational grants or in-kind gifts from corporate, other business or professional association sponsors will be applied, invested or expended.

#### 8.6.5. Affirmative Disclosure

NAMI will, unless otherwise prohibited by law, disclose the sources of financial support it receives from corporations, other businesses and professional associations as listed in the annual filing of IRS Form 990, which will be posted on the NAMI Web site.

### **NAMI**

## GUIDELINES FOR CORPORATE RELATIONSHIPS<sup>1</sup>

#### I. Introduction

NAMI enters into relationships with corporations to provide meaningful mission-related benefits to NAMI members, its affiliates, mental health professionals and the general public. Benefits include health education, information, disease awareness, advocacy and resources.

Among the diverse sources of support that NAMI seeks and secures in order to fund programs and services is direct and in-kind financial support from businesses and corporations. Some of these "vested interest" companies (defined as pharmaceutical and managed behavioral healthcare companies) make products or offer services that are used by people with mental illness or the professional people who serve them. NAMI believes it is not only ethically sound but also equitable to engage businesses and corporations to support NAMI programs designed to benefit people with mental illness.

NAMI is committed to avoid conflict of interest, or even its appearance, in its relationships with "vested interest" corporations. Therefore, NAMI's Board of Directors has determined that acceptance of support from businesses and corporations, and NAMI's relationship to these donors, shall be governed by the following principles:

#### **II. Definition of Corporate Relationships**

The following terms help to define the nature of corporate relationships relating to "vested interest" organizations. Acceptable forms of corporate interactions include:

- 1. *Sponsorships*: Corporations provide unrestricted educational grants of financial or inkind support for a specific NAMI activity or program that could include peer support, education, research, awareness, and fundraising. Typically, a sponsorship includes recognition of the company providing the support.
- Strategic Alliance: A mutually beneficial relationships between NAMI and a corporation.
   NAMI provides a health education message or service that is delivered or supported by a company. The goal of this collaborative effort is to improve health information, awareness and outcomes about mental illness.
- 3. *Health Message* Promotion: NAMI provides its name to a **non-(product) branded** campaign, promotion or communication vehicle that provides education or awareness.

<sup>&</sup>lt;sup>1</sup> NAMI Guidelines for Corporate Relationships, adopted by NAMI National Board of Directors, December 2004.

4. *Cause Marketing*: A corporation shows it support of NAMI and/or our "cause" by providing unrestricted financial donations, in-kind assistance or other resources. Typically, the company gains recognition by indicating publicly its support of NAMI.

NAMI **does not** engage in the following types of interactions with vested interest corporations:

- 1. Endorsement: NAMI will not endorse any corporate product, service or program.
- 2. *Licensing*: NAMI will not license products, services or programs for corporate "ownership."
- 3. *Certification:* NAMI will not recognize or certify the quality or standards of particular products, services or companies.
- 4. *Product Association*: NAMI's name and/or logo should not be associated with specific branded products. References to NAMI's Website, phone number and address, for the purposes of referral information to NAMI, are an exception.

#### **III. Guiding Principles for Corporate Relationships:**

- NAMI shall at all times maintain an independent position on issues affecting the welfare
  of people with mental illness. The potential effect of such positions on the commercial
  interests of a corporate sponsor shall not be a relevant factor in the NAMI's decisionmaking process. NAMI will solicit and accept support only for projects and activities
  that are consistent with the organization's mission.
- NAMI will accept funds for projects relating to the communication of information only when it has complete editorial and managerial control and final and exclusive approval authority over all materials.
- 3. NAMI will neither endorse, nor allow the perception that it endorses, any products, devices, treatments or services. A disclaimer explicitly stating NAMI's non-endorsement policy may be required on written materials.
- 4. NAMI will accept support for projects or programs only with assurances that the privacy of people with mental illness and their families will be protected unless specific written permission by participants waiving privacy has been given.
- 5. NAMI will accept support for professional meetings and symposia only when the program content and selection of speakers are to be determined by NAMI or an independent body.
- 6. NAMI shall, at all times, maintain complete control and sole discretion over all funds received. Should NAMI determine in its discretion that any project for which it has received restricted or designated funds can no longer be satisfactorily carried out, NAMI

- reserves the right to determine how any remaining funds shall be handled, including their application to other NAMI uses.
- 7. NAMI will ensure that programs for which it accepts funding do not adversely affect its nonprofit status.
- 8. The use of NAMI's name and logo on any written, video or electronic materials not produced by NAMI is not permitted without specific permission from NAMI for that usage.
- 9. Vested interest corporations, as well as their agents, vendors and trade associations, are expected to work collaboratively with NAMI's national office on issues directly affecting NAMI individual state and local affiliates.
- 10. NAMI retains sole discretion on how the support it receives in the form of educational grants or in-kind gifts from vested interest corporations will be applied, invested or spent by NAMI.

# Contributions by Company Calendar Year 2005

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Company	Amount	Company Totals		Program
Abbott Laboratories	\$350,000		Restricted For Program Use	Campaign & Bipolar Awareness Day
Abbott Laboratories	\$15,000	\$365,000	Restricted For Program Use	State Policy Exchange
AstraZeneca Pharmaceuticals LP	\$2,000		Restricted For Program Use	Bipolar Awareness Day
AstraZeneca Pharmaceuticals LP	\$250,000		Unrestricted	Campaign
AstraZeneca Pharmaceuticals LP	\$45,000		Restricted For Program Use	Convention
AstraZeneca Pharmaceuticals LP	\$1,000		Unrestricted	Gala
AstraZeneca Pharmaceuticals LP	\$10,000		Restricted For Program Use	HelpLine
AstraZeneca Pharmaceuticals LP	\$750,000	\$1,058,000	Restricted For Program Use	Peer to Peer
Bristol Myers Squibb Company	\$775,000		Unrestricted	Campaign
Bristol Myers Squibb Company	\$200,000	\$975,000	Unrestricted	Gala
Eli Lilly & Company	\$950,000		Unrestricted	Campaign
Eli Lilly & Company	\$50,000		Restricted For Program Use	Convention
Eli Lilly & Company	\$20,000		Restricted For Program Use	Exemplary Psychiatrist Awards
Eli Lilly & Company	\$10,000		Unrestricted	Gala
Eli Lilly & Company	\$150,000		Restricted For Program Use	In Our Own Voice
Eli Lilly & Company	\$2,000		Restricted For Program Use	Leadership Institute
Eli Lilly & Company Eli Lilly & Company	\$50,000	¢1 222 000	Restricted For Program Use	MultiCultural Action Center
		φ1,232,000	nestricted for Frogram 058	Manufactural Action Center
Eli Lilly & Company Foundation	\$4,360	\$4,360	Unrestricted	Matching Gifts
Forest Pharmaceuticals, Inc.	\$750		Unrestricted	Employee Giving
Forest Pharmaceuticals, Inc.	\$200,000		Unrestricted	Campaign
Forest Pharmaceuticals, Inc.	\$15,000	\$215,750	Restricted For Program Use	State Policy Exchange
GlaxoSmithKline	\$150,000		Unrestricted	Campaign
GlaxoSmithKline	\$20,000		Restricted For Program Use	Convention
GlaxoSmithKline	\$10,000		Unrestricted	Gala
GlaxoSmithKline	\$15,000		Restricted For Program Use	State Policy Exchange
GlaxoSmithKline	\$130	\$195,130	Reimbursement	Travel
McNeil Consumer	\$5,000		Restricted For Program Use	Convention
McNeil Consumer	\$100,000	\$40E 000	Restricted For Program Use	NAMI Beginnings
MCNell Consumer	\$100,000	\$105,000	Restricted For Frogram Ose	NAMI Beginnings
Merck Partnership for Giving	\$11,344	\$11,344	Unrestricted	Matching Gifts
Ortho McNeil Janssen Pharm Inc	\$30,000		Restricted For Program Use	Convention
Ortho McNeil Janssen Pharm Inc	\$25,000		Unrestricted	Gala
Ortho McNeil Janssen Pharm Inc	\$1,800		Honorarium	Honorarium
Ortho-McNeil Pharmaceuticals	\$350,000		Unrestricted	Campaign
Ortho-McNeil Pharmaceuticals  Ortho-McNeil Pharmaceuticals				Child & Adolescent Action Center
	\$100,000	¢544.500	Restricted For Program Use	
Ortho-McNeil Pharmaceuticals	\$4,700	\$511,500	Unrestricted	Convention Exhibitor
Otsuka America Pharmaceuticals	\$15,000		Unrestricted	Campaign
Otsuka America Pharmaceuticals	\$5,000		Restricted For Program Use	MultiCultural Action Center
Otsuka America Pharmaceuticals	\$1,500		Unrestricted	DC Walk
Otsuka America Pharmaceuticals	\$5,000	\$26,500	Unrestricted	Gala
Pfizer Inc	\$595,000		Unrestricted	Campaign
Pfizer Inc	\$5,000		Unrestricted	DC Walk
Pfizer Inc	\$15,000		Unrestricted	Gala
Pfizer Inc	\$5,000		Honorarium	Honorarium
Pfizer Inc	\$9,874	\$629,874	Reimbursement	Travel
Shire	\$5,000	\$5.000	Unrestricted	Gala
		<del>+0,000</del>		
Solvay Pharmaceuticals	\$125,000		Unrestricted	Campaign
Solvay Pharmaceuticals	\$20,000	A4=0.00	Restricted For Program Use	Exemplary Psychiatrist Awards
Solvay Pharmaceuticals	\$25,000	\$170,000	Unrestricted	Gala
Wyeth Pharmaceuticals	\$40,000		Restricted For Program Use	Fundraiser - APA
Wyeth Pharmaceuticals	\$150,000		Unrestricted	Campaign
Wyeth Pharmaceuticals	\$50,000		Unrestricted	Gala
Wyeth Pharmaceuticals	\$134,350		Restricted For Program Use	Legislative Round Table
Wyeth Pharmaceuticals	\$15,000	\$389,350	Restricted For Program Use	State Policy Exchange
Total	\$5,893,808	\$5,893,808		1
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## Contributions by Company Calendar Year 2006

		Company		
Company	Amount	Totals	Purpose	Program
Abbott Laboratories	\$300,000		Unrestricted	Campaign
Abbott Laboratories	\$1,350		Unrestricted	Convention Exhibitor
Abbott Laboratories	\$50,000	\$351,350	Unrestricted	Gala
Akzo Nobel Organon USA Inc.	\$1,000	\$1,000	Unrestricted	Gala
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Amgen FND Matching Gifts	\$400	\$400	Unrestricted	Matching Gifts
AstraZeneca Pharmaceuticals LP	\$117,000		Unrestricted	Campaign
AstraZeneca Pharmaceuticals LP	\$65,000		Restricted For Program Use	Convention
AstraZeneca Pharmaceuticals LP	\$25,000		Unrestricted	Gala
AstraZeneca Pharmaceuticals LP	\$575,966		Restricted For Program Use	Peer to Peer
AstraZeneca Pharmaceuticals LP	\$15,000		Restricted For Program Use	State Policy Exchange
AstraZeneca Pharmaceuticals LP	\$1,109	\$799,075	Reimbursement	Travel
Avanir Pharmaceuticals	\$600	\$600	Unrestricted	Gala
	<b>4000</b>	<del></del>		- Cana
Bristol Myers Squibb Company	\$5,000		Unrestricted	DC Walk
Bristol-Myers Squibb Company	\$850,000		Unrestricted	Campaign
Bristol-Myers Squibb Company	\$200,000	\$1,055,000	Unrestricted	Gala
Cephalon INC	\$5,000	\$5,000	Unrestricted	Campaign
Eli Lilly & Company	\$100,000		Restricted For Program Use	CIT Resource Center
Eli Lilly & Company	\$50,000		Restricted For Program Use	Convention
Eli Lilly & Company	\$10,000		Unrestricted	Gala
Eli Lilly & Company	\$150,000		Restricted For Program Use	Medicare Part D Education
Eli Lilly & Company	\$50,000	\$360,000	Restricted For Program Use	MultiCultural Action Center
Eli Lilly & Company Foundation	\$400,000		Unrestricted	Campaign
Eli Lilly & Company Foundation	\$150,000		Restricted For Program Use	In Our Own Voice
Eli Lilly & Company Foundation	\$3,735	\$553,735	Unrestricted	Matching Gifts
Forest Pharmaceuticals, Inc.	\$5,500		Unrestricted	Employee Giving
Forest Pharmaceuticals, Inc.	\$235,000		Unrestricted	Campaign
Forest Pharmaceuticals, Inc.	\$5,000		Restricted For Program Use	Convention
Forest Pharmaceuticals, Inc.	\$10,000		Unrestricted	Gala
Forest Pharmaceuticals, Inc.	\$15,000	\$270,500	Restricted For Program Use	State Policy Exchange
GlaxoSmithKline	\$225,000		Unrestricted	Campaign
GlaxoSmithKline	\$20,000		Restricted For Program Use	Convention
GlaxoSmithKline	\$10,000		Unrestricted	Gala
GlaxoSmithKline	\$50		Unrestricted	Matching Gifts
GlaxoSmithKline	\$15,000	\$270,050	Restricted For Program Use	State Policy Exchange
Janssen	\$390,000		Unrestricted	Campaign
Janssen	\$60,000		Restricted For Program Use	Child & Adolescent Action Center
Janssen	\$25,000	\$475,000	Restricted For Program Use	Convention
Johnson & Johnson	\$25,000	\$25,000	Unrestricted	Gala
Johnson&Johnson Matching Gifts Program	\$850	\$850	Unrestricted	Matching Gifts
McNeil-PPC, INC	\$75,000	\$75,000	Restricted For Program Use	NAMI Beginnings
Merck Partnership for Giving	\$11,092	\$11.092	Unrestricted	Matching Gifts
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Novartis Pharmaceuticals Corporation	\$10,000	\$10,000	Unrestricted	Gala
Ortho McNeil Janssen Pharm Inc	\$300,000		Unrestricted	Campaign
Ortho McNeil Janssen Pharm Inc	\$25,000		Restricted For Program Use	Convention

	Company		
Amount	Totals	Purpose	Program
\$25,000		Unrestricted	Gala
\$250,000		Restricted For Program Use	NAMI Basics
\$10,000	\$610,000	Restricted For Program Use	State Policy Exchange
\$30,000		Unrestricted	Campaign
\$5,000	\$35,000	Unrestricted	Gala
\$540		Unrestricted	Matching Gifts
\$710,000		Unrestricted	Campaign
\$25,000		Unrestricted	Gala
\$15,000		Restricted For Program Use	State Policy Exchange
\$1,428	\$751,968	Reimbursement	Travel
\$350	\$350	Unrestricted	Matching Gifts
\$313	\$313	Unrestricted	Matching Gifts
\$125,000		Unrestricted	Campaign
\$50,000		Unrestricted	Gala
\$15,000	\$190,000	Restricted For Program Use	State Policy Exchange
\$10,000		Unrestricted	Gala
\$280,000		Unrestricted	Campaign
\$30,000		Restricted For Program Use	Convention
\$185,500		Restricted For Program Use	Depression Survey
\$50,000		Unrestricted	Gala
\$15,000		Restricted For Program Use	State Policy Exchange
\$95	\$570,595		Travel
\$6,421,879	\$6,421,879		
	\$25,000 \$250,000 \$10,000 \$30,000 \$5,000 \$5,000 \$15,000 \$15,000 \$1,428 \$350 \$313 \$125,000 \$50,000 \$15,000 \$10,000 \$280,000 \$185,500 \$50,000 \$15,000 \$15,000 \$15,000 \$280,000 \$15,000 \$15,000 \$15,000 \$15,000 \$15,000 \$15,000 \$15,000	Amount         Totals           \$25,000         \$250,000           \$10,000         \$610,000           \$30,000         \$35,000           \$540         \$710,000           \$25,000         \$15,000           \$15,000         \$751,968           \$350         \$350           \$313         \$313           \$125,000         \$50,000           \$15,000         \$190,000           \$10,000         \$280,000           \$30,000         \$15,000           \$50,000         \$50,000           \$15,000         \$570,595	Amount         Totals         Purpose           \$25,000         Unrestricted           \$250,000         Restricted For Program Use           \$10,000         \$610,000           Restricted For Program Use           \$30,000         Unrestricted           \$5,000         Unrestricted           \$710,000         Unrestricted           \$25,000         Unrestricted           \$15,000         Restricted For Program Use           \$1,428         \$751,968           Reimbursement           \$350         \$350           Unrestricted           \$125,000         Unrestricted           \$15,000         Unrestricted           \$10,000         Unrestricted For Program Use           \$10,000         Unrestricted           \$280,000         Unrestricted For Program Use           \$15,000         Restricted For Program Use           \$50,000         Unrestricted           \$15,000         Restricted For Program Use           \$50,000         Unrestricted           \$15,000         Restricted For Program Use           \$50,000         Restricted For Program Use           \$50,000         Restricted For Program Use           \$50,000         Res

# Contributions by Company Calendar Year 2007

	1 1	Company	T	
Company	Amount	Totals	Purpose	Program
Abbott Laboratories	\$100,000		Restricted For Program Use	Bi Polar Awareness Day
Abbott Laboratories	\$200,000		Unrestricted	Campaign
Abbott Laboratories	\$50,000	\$350,000	Unrestricted	Gala
	0.72.222			
AstraZeneca Pharmaceuticals LP	\$150,000		Restricted For Program Use	ASK Project
AstraZeneca Pharmaceuticals LP	\$35,000		Restricted For Program Use	Convention
AstraZeneca Pharmaceuticals LP	\$50,000		Unrestricted	Gala
AstraZeneca Pharmaceuticals LP	\$2,300		Honorarium	Honorarium
AstraZeneca Pharmaceuticals LP	\$25,000		Restricted For Program Use	Leadership Institute
AstraZeneca Pharmaceuticals LP	\$3,000,000	<b>***</b> 077 000	Restricted For Program Use	NAMI Connection
AstraZeneca Pharmaceuticals LP	\$15,000	\$3,277,300	Restricted For Program Use	State Policy Exchange
Bristol Myers Squibb Company	\$400,000		Unrestricted	Campaign
Bristol Myers Squibb Company	\$300,000		Restricted For Program Use	Family to Family
Bristol Myers Squibb Company	\$200,000		Unrestricted	Gala
Bristol-Myers Squibb Company	\$200,000	\$1,100,000	Unrestricted	Campaign
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Corcept Therapeutics	\$10,000	\$10,000	Unrestricted	Gala
Eli Lilly & Company	\$450,000		Unrestricted	Campaign
Eli Lilly & Company	\$10,000		Unrestricted	Gala
Eli Lilly & Company	\$75,000		Restricted For Program Use	In Our Own Voice
Eli Lilly & Company	\$150,000	\$685,000	Restricted For Program Use	MultiCultural Action Center
Eli Lilly & Company Foundation	\$550	\$550	Unrestricted	Matching Gifts
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Forest Pharmaceuticals, Inc.	\$3,250		Unrestricted	Employee Giving
Forest Pharmaceuticals, Inc.	\$225,000		Unrestricted	Campaign
Forest Pharmaceuticals, Inc.	\$20,000		Restricted For Program Use	Convention
Forest Pharmaceuticals, Inc.	\$25,000		Unrestricted	Gala
Forest Pharmaceuticals, Inc.	\$15,000	\$288,250	Restricted For Program Use	State Policy Exchange
Olassa Osaiita IZiina	<b>#</b> 400,000		Linna atriata d	0
GlaxoSmithKline	\$100,000		Unrestricted	Campaign
GlaxoSmithKline	\$500	\$400 FCF	Honorarium	Honorarium Matabia a Citta
GlaxoSmithKline	\$65	\$100,565	Unrestricted	Matching Gifts
Johnson & Johnson Matching Gifts Program	\$1,700	\$1,700	Unrestricted	Matching Gifts
McNeil-PPC, Inc.	\$1,500	¢1 500	Unrestricted	APA Donations
WICHEII-PPC, IIIC.	\$1,500	\$1,500	Onestricted	APA Donations
Merck Partnership for Giving	\$2,200	\$2,200	Unrestricted	Matching Gifts
Novartis Pharmaceuticals Corporation	\$10,000	\$10,000	Unrestricted	Gala
Ortho McNeil Janssen Pharm Inc	\$225,000		Unrestricted	Campaign
Ortho McNeil Janssen Pharm Inc	\$25,000		Restricted For Program Use	Convention
Ortho McNeil Janssen Pharm Inc	\$25,000		Unrestricted	Gala
Ortho McNeil Janssen Pharm Inc	\$250,000		Restricted For Program Use	NAMI Basics
Ortho McNeil Janssen Pharm Inc	\$75,000		Restricted For Program Use	NAMI Beginnings
Ortho McNeil Janssen Pharm Inc	\$10,000	\$610,000	Restricted For Program Use	State Policy Exchange
Otsuka America Pharmaceutical, Inc.	\$30,000		Unrestricted	Campaign
Otsuka America Pharmaceuticals	\$5,000	\$35,000	Unrestricted	Gala
Pfizer Foundation Matching Gifts Program	\$660		Unrestricted	Matching Gifts
	\$45,000		Unrestricted	
Pfizer Inc Pfizer Inc	\$255,000		Unrestricted	Campaign Campaign
Pfizer Inc	\$45,000		Unrestricted Unrestricted	Campaign
Pfizer Inc	\$250,000		Unrestricted	Campaign
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		Company		
Company	Amount	Totals	Purpose	Program
Pfizer Inc	\$200,000		Unrestricted	Campaign
Pfizer Inc	\$55,000		Unrestricted	Campaign
Pfizer Inc	\$20,000		Restricted For Program Use	Convention
Pfizer Inc	\$25,000	\$895,660	Unrestricted	Gala
Sanofi-Aventis U.S. Inc	\$10,000	\$10,000	Unrestricted	Gala
Shire	\$25,000	\$25,000	Unrestricted	Gala
Solvay Finance (America), Inc.	\$25,500		Restricted For Program Use	Fundraiser - APA
Solvay Pharmaceuticals	\$150,000		Restricted For Program Use	ASK Project
Solvay Pharmaceuticals	\$235,000		Unrestricted	Campaign
Solvay Pharmaceuticals	\$50,000		Unrestricted	Gala
Solvay Pharmaceuticals	\$15,000	\$475,500	Restricted For Program Use	State Policy Exchange
Vanda Pharmaceuticals Inc.	\$120,000		Unrestricted	Campaign
Vanda Pharmaceuticals Inc.	\$5,000		Restricted For Program Use	Convention
Vanda Pharmaceuticals Inc.	\$25,000	\$150,000	Unrestricted	Gala
Wyeth Pharmaceuticals	\$150,000		Unrestricted	Campaign
Wyeth Pharmaceuticals	\$35,000		Restricted For Program Use	Convention
Wyeth Pharmaceuticals	\$100,000		Restricted For Program Use	Depression is Real
Wyeth Pharmaceuticals	\$50,000		Unrestricted	Gala
Wyeth Pharmaceuticals	\$15,000		Restricted For Program Use	State Policy Exchange
Wyeth Pharmaceuticals	\$75,000	\$425,000	Restricted For Program Use	Women & Depression
Total	\$8,453,225	\$8,453,225		

### Contributions by Company Calendar Year 2008

Company   Company   Company   Program   Program   Program   Section   Sect		<del> </del>		T	
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Company	Amount	Totals	Purpose	Program
Pfizer Foundation Matching Gifts Program	\$360		Unrestricted	Matching Gifts
Pfizer Inc	\$357,000		Unrestricted	Campaign
Pfizer Inc	\$25,000		Restricted For Program Use	Convention
Pfizer Inc	\$25		Unrestricted	Employee Giving
Pfizer Inc	\$50,000		Unrestricted	Gala
Pfizer Inc	\$10,000		Restricted For Program Use	State Policy Exchange
Pfizer Inc	\$567	\$442,952	Reimbursement	Travel
Shire	\$250,000		Unrestricted	Campaign
Shire	\$150,000		Restricted For Program Use	Child & Adolescent Action Center
Shire	\$50,000	\$450,000	Unrestricted	Corporate Membership
Solvay Finance (America), Inc.	\$20,000	\$20,000	Unrestricted	Campaign
Validus Pharmaceuticals, Inc.	\$12,000	\$12,000	Restricted For Program Use	Convention
Vanda Pharmaceuticals Inc.	\$10,307	\$10,307	Unrestricted	Fundraiser - APA
VMS, Inc	\$2,008		Honorarium	Honorarium
VMS, Inc	\$12,000	\$14,008	Honorarium	Honorarium
Wyeth Pharmaceuticals	\$70,000		Unrestricted	Campaign
Wyeth Pharmaceuticals	\$25,000		Restricted For Program Use	Convention
Wyeth Pharmaceuticals	\$20,000		Restricted For Program Use	Depression Initiative
Wyeth Pharmaceuticals	\$20,000		Restricted For Program Use	Depression is Real
Wyeth Pharmaceuticals	\$50,000		Unrestricted	Gala
Wyeth Pharmaceuticals	\$30,000		Restricted For Program Use	Leadership Institute
Wyeth Pharmaceuticals	\$20,000	\$235,000	Restricted For Program Use	State Policy Exchange
Total	\$7,890,361	\$7,890,361		

# Contributions by Company Calendar Year 2009

		Company		
Company	Amount	Totals	Purpose	Program
Abbott Laboratories Employee Giving	\$172	\$172	Unrestricted	Employee Giving
AstraZeneca Pharmaceuticals	\$1,600		Unrestricted	Convention Exhibitor
AstraZeneca Pharmaceuticals LP	\$35,000		Restricted For Program Use	Convention
AstraZeneca Pharmaceuticals LP	\$50,000		Restricted For Program Use	Depression Initiative
AstraZeneca Pharmaceuticals LP	\$25,000		Restricted For Program Use	Exemplary Psychiatrist Awards
AstraZeneca Pharmaceuticals LP	\$50,000		Unrestricted	Gala
AstraZeneca Pharmaceuticals LP	\$100,000	\$261,600	Restricted For Program Use	Peer to Peer
Bristol-Myers Squibb Company	\$250,000		Unrestricted	Campaign
Bristol-Myers Squibb Company	\$56,250		Restricted For Program Use	Depression Initiative
Bristol-Myers Squibb Company	\$125,000		Restricted For Program Use	Family to Family
Bristol-Myers Squibb Company	\$75,000	\$506,250	Unrestricted	Gala
Eli Lilly & Company	\$338,000		Unrestricted	Campaign
Eli Lilly & Company	\$112,500	\$450,500	Restricted For Program Use	MultiCultural Action Center
Forest Pharmaceuticals, Inc.	\$250		Unrestricted	Employee Giving
Forest Pharmaceuticals, Inc.	\$50,000	\$50,250	Unrestricted	Corporate Membership
GlaxoSmithKline	\$500	\$500	Honorarium	Honorarium
Johnson & Johnson Matching Gifts Program	\$200	\$200	Unrestricted	Matching Gifts
Ortho McNeil Janssen Pharm Inc	\$150,000	\$150,000	Restricted For Program Use	NAMI Beginnings
Otsuka America Pharmaceuticals	\$50,000	\$50,000	Restricted For Program Use	MultiCultural Action Center
Pfizer Foundation Matching Gifts Program	\$125	\$125	Unrestricted	Matching Gifts
	·			•
VMS, Inc	\$106	\$106	Reimbursement	Travel
Total to April 17, 2009	\$1,469,702	\$1,469,702		

#### NAMI: PROGRAM NARRATIVE

#### **ASK Project**

The ASK Project was designed to assess and report on America's Schizophrenia Knowledge (ASK). In February 2008, Harris Interactive conducted a nationwide survey of 1,000 Americans, including 250 people living with schizophrenia and 250 caregivers of those living with schizophrenia. Results were presented in the publication: *Schizophrenia: Public Attitudes*, *Personal Needs* and reported to national media. NAMI National and local NAMI affiliates utilized the report for public education purposes.

#### **Basics**

NAMI Basics is NAMI's signature education program for parents and other caregivers of children and adolescents living with mental illnesses. The program was developed around elements that have been extensively tested and found to be highly effective in the field, including:

- Recognition of mental illness as a continuing traumatic event for the child and the family
- Sensitivity to the subjective emotional issues faced by family caregivers and well children in the family
- Recognition of the need to help ameliorate the day-to-day objective burdens of care and management
- Gaining confidence and stamina for what can be a lifelong role of family understanding and support
- Empowerment of family caregivers as effective advocates for their children

The NAMI Basics course is taught by trained teachers who are the parent or other caregivers of individuals who developed the symptoms of mental illness prior to the age of thirteen. All instruction and course materials are free to class participants.

NAMI Basic's goals are: to give the parent/caregiver the fundamental information necessary to be an effective caregiver; to help the parent/caregiver cope with the traumatic impact that mental illness has on the child living with the illness and the entire family; to provide tools for the parent/caregiver to use even after completing the program that will assist in making the best decisions possible for the care of the child; and , to help the parent/caregiver take the best care possible of the entire family – especially themselves.

#### The course includes:

- Introduction to the normative stages of emotional reactions of the family to the trauma of mental illness
- Insights into an empathic understanding of the subjective, lived experience of the child living with the mental illness

- Current information about Attention Deficit Disorder, Major Depression, Bipolar Disorder, Conduct Disorder, Oppositional Defiant Disorder, Anxiety Disorders, Obsessive Compulsive Disorder, Childhood Schizophrenia and Substance Abuse Disorders
- Current research related to the biology of mental illness and the evidence-based, most effective treatment strategies available, including medications used to treat mental illness in children and adolescents
- Specific workshops to learn problem solving, listening and communication skills
- Examples of strategies that have been found helpful in handling challenging behaviors in children and adolescents
- Information about the systems that are major players in the lives of children and adolescents with mental illness the school system and the mental health system
- Exposure to personal record keeping systems that have proven to be effective for parents/caregivers in their interactions with the school and healthcare systems
- Information on planning for crisis management and relapse
- Information on locating appropriate supports and services within the community
- Information on advocacy initiatives designed to improve and expand services, with an emphasis on personal advocates for the parent/caregiver and child on an individual level

#### **Beginnings Magazine**

NAMI Beginnings is the Child & Adolescent Action Center's quarterly magazine that publishes articles about child & adolescent mental health.

#### **Bipolar Education and Bipolar Awareness Day**

Bipolar Disorder Awareness Day was created to increase awareness of bipolar disorder, promote early detection and accurate diagnosis, reduce stigma, and minimize the devastating impact on the nearly six million Americans presently affected by the illness. Bipolar Disorder Awareness Day takes place during Mental Illness Awareness Week. Education materials, activities and outreach for this effort are provided to NAMI affiliates for use in their own communities.

#### Campaign for the Mind of America (renamed the Campaign for a Better Tomorrow 2009)

For the past 30 years, NAMI has been dedicated to improving the lives of people with mental illness.

The Campaign provides unrestricted general support for NAMI's cornerstone activities of support, education and advocacy. People who live with serious mental illness and their families turn to NAMI for its support programs, educational materials, and advocacy for systems change. Stigma and systemic biases present recurring barriers to their access to appropriate treatment and services; NAMI helps them overcome those barriers.

At the National level, NAMI provides support through the NAMI signature education programs<sup>1</sup> for people living with mental illness and their families. More than 200,000 individuals have graduated from these programs. NAMI's national office provides program development, resources and training for more than 1,500 trainers and peer mentors who deliver hundreds of programs each week.

NAMI's public education is focused on changing public attitudes about mental illness and providing information about mental illness to people seeking help. NAMI educates millions of Americans about mental illness through newsletters, brochures, a toll-free Helpline, and the NAMI Web site. The Web site receives more than 600,000 unique visitors each month; the HelpLine receives nearly 50,000 inquiries yearly. NAMI utilizes the media as a conduit to getting its messages out – both through the news media and with public service advertising. National and local NAMI public education campaigns increase awareness about specific mental illnesses or related issues.

NAMI's advocacy provides a unique voice for people who live with mental illness and their family in state and federal public and private-sector policies that facilitate research, end discrimination, reduce barriers to successful life in the community and promote timely, comprehensive and effective mental health services and supports.

NAMI accepts unrestricted grants or charitable contributions from pharmaceutical companies to support NAMI's mission through the Campaign. Support for each year's Campaign came from multiple sponsors. Decisions about the direction and content of each Campaign was at NAMI's sole discretion and in accordance with NAMI's "Guidelines for Corporate Relationships" and "Guidelines for Business Support Relationships."

The theme, strategies and tactics of the Campaign change annually. Campaign activities in recent years included:

2005: NAMI conducted research in late 2003 to learn which, if any, community leaders saw mental illness as a significant problem for their community and were willing to help. The Campaign developed a strategy to bring individuals from law enforcement, the criminal justice system, emergency departments, education and local government to become strong allies for mental health. The Campaign was launched in five pilot states in 2004 and expanded to 12 states in 2005.. Media coverage included more than 25 media impressions. Local partners included such organizations as parent teacher associations (PTAs), state hospital associations, sheriffs' departments, county commissioners, and state chapters of AARP and the American College of Emergency Room Physicians. NAMI and its partners communicated that access to treatment for mental illness is a priority, mental illness is a community issue and the failure to appropriately treat people with mental illness can result in unintended consequences.

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<sup>&</sup>lt;sup>1</sup> "Signature Programs" = Programs that are administered and maintained by NAMI National. NAMI's Signature Programs currently include: Family-to-Family, NAMI Provider Education Program, Peer-to-Peer, NAMI Connection Recovery Support Group, In Our Own Voice, NAMI Basics, Hearts & Minds, Parents & Teachers as Allies, and NAMI Support Group training.

2006: Key objectives in the 2006 Campaign were similar to those used in 2005 but the key issues were expanded to include the development of new community partnerships, the decriminalization of mental illness, access for parity coverage for mental illness, mental health system redesign, protection of Medicaid eligibility and services children and adults with serious mental illness and improvements to the Medicare Part D Prescription Drug program. Strategies included the continued development of new relationships with community leaders at the local level, mobilization of NAMI's grassroots advocates, and use of the media to raise awareness of the needs of people living with mental illness.

2007: Building on the experiences learned from 2006, the Campaign took on a more national focus in 2007. Key Campaign strategies included expanding NAMI's advocacy capacity by building a more diverse membership, promoting mental illness research on Capitol Hill, educating America about mental illness through a comprehensive media/public education campaign, empowering and supporting consumers through NAMI's signature education programs operating hundreds of locations throughout the United States, holding Medicare Prescription Drug Plans accountable to their members, protecting access to Medicaid for people with mental illness and using NAMI's *Grading the States* report to invest more in the mental health system.

2008: Key Campaign objectives focused on fulfilling the goals established in NAMI's Strategic Plan and moving the organization from "Good to Great." The Campaign was organized into NAMI's three key organizational areas of Support, Advocacy and Education. Priorities for support focused on improving NAMI's signature education programs by increasing enrollment in these free programs, reaching out to participants from diverse communities, identifying "best practices," and evaluating program outcomes. Public education efforts focused on making NAMI a household word through a variety of education tactics, including public service advertising and media outreach tool kits. Advocacy efforts focused on eliminating disparities, advocating for better housing, advocating for veterans, improving access to inpatient care, improving access to treatment, ending inappropriate jailing and improving access to all treatments. Public education focused on anti-stigma efforts and making NAMI a household name.

2009: The Campaign is again focused on the three cornerstones of NAMI: Education (support), Awareness (education) and Advocacy. Examples of strategies/tactics for education include expansion of NAMI's signature education programs to underserved and underrepresented populations, including veterans and Hispanic families, as well as to families with children with mental illness and the faith community. NAMI will expand efforts to educate the American public about mental illness. Efforts will include the launch of a TV public service campaign, the development of more than 30 e-newsletters on specialty topics, and the re-development of NAMI's Web site that currently receives over 600,000 visitors each month. Advocacy efforts will include supporting NAMI grassroots advocates in their efforts to obtain state level parity for mental health care, gain access to treatment, and increased support for improved access, treatment and services for people living with mental illness.

#### **Child and Adolescent Action Center**

The NAMI Child & Adolescent Action Center (CAAC) works to improve the lives of children and adolescents living with mental illnesses and their families through advocacy, support and education. CAAC offers resources and technical assistance to NAMI affiliates at the state and local levels.

NAMI's Child & Adolescent Action Center focuses on mental health systems' reform that promises to improve the lives of children and adolescents with mental illnesses and their families. CAAC's goal is to build and support grassroots advocacy to ensure an expanded systems' reform agenda at the local, state and national levels. Currently, CAAC is working in the following areas:

- Ending the practice of forcing families to relinquish custody of their child to secure mental health services through federal legislation, changes in funding mechanisms for healthcare treatment and services, raising awareness about the issue and offering alternatives to policymakers to help end this practice;
- Focusing the policy debate on ensuring the early identification of mental illnesses and early intervention with effective treatment and services so that children do not lose critical developmental years to an undiagnosed illness;
- Ensuring improved treatment outcomes for children and adolescents by advancing promising practices and evidence-based practices in treatment and services;
- Focusing attention on the crisis of youth with mental illnesses in the juvenile justice system and the failure of schools to properly address the academic and functional needs of students with mental illnesses;
- Partnering with organizations focused on children and adolescents, with a focus on diverse communities and eliminating existing healthcare disparities;
- Strengthening support for the work of NAMI state and affiliate leaders on child and adolescent issues:
- Helping to educate all child-serving professionals especially school professionals about the early warning signs of mental illnesses in children and adolescents to help address the fact that nearly 80% of youth with mental health needs fail to be identified and to receive treatment and services. We recently expanded our *Parents and Teachers as Allies* program, which is a two-hour in-service program that focuses on educating school professionals about mental illnesses and how best to intervene; and
- Supporting parents and caregivers of children with mental illnesses by lobbying federal and state legislators and by providing information, referrals and resources to families and youth.

#### **Connection Recovery Support Group**

Launched in 2007 with an ambitious goal of bringing a support group meeting to within driving distance of every community every night of the week by 2010, NAMI Connection has grown rapidly in its short life. Major training, marketing and outreach efforts have tapped all corners of the NAMI organization as we've worked to fulfill that vision.

NAMI Connection is a 90-minute weekly support group run by persons who live with mental illness for other persons with any diagnosis who also live with mental illness. NAMI Connection is a recovery support program for adults living with mental illness that is expanding in communities throughout the country. These groups provide a place that offers respect, understanding, encouragement, and hope.

NAMI Connection groups offer a positive environment to sharing the challenges and successes of coping with mental illness. Each group:

- Meets weekly for 90 minutes
- Is offered free of charge
- Follows a flexible structure without an educational format
- Does not recommend or endorse any medications or other medical therapies

All groups are confidential - participants can share as much or as little personal information as they wish. Support groups are open to all adults with mental illness, regardless of diagnosis. Participants are welcome to drop by and share feelings, difficulties, or successes.

Much like Alcoholics Anonymous (AA), the Connection model is built on developing a community-based, standard support model that welcomes participants no matter where they are in the country. Meetings are guided by NAMI Connection's Principles of Support. Support groups are open to all adults with mental illness, regardless of diagnosis.

Unlike AA, NAMI has built this national network of support groups in just two years – a feat made possible only by a substantial investment by both the funding company and NAMI staff and volunteers. Initial steps include creation of the program, curriculum development, hiring of staff, coordination with NAMI affiliates around the country and training. Since its launch in 2007, NAMI Connection has hosted more than 80 trainings, for more than 1,400 facilitators, who among them are running nearly 300 support groups that didn't exist two years ago. These consumer volunteers are supported by a host of others who assist in everything from meeting logistics to promotion and trouble shooting. In some states, the NAMI Connection effort has had a galvanizing effect on the NAMI presence and has re-energized and grown NAMI's grassroots base, engaging many consumers who had never known NAMI prior to their involvement in the Connection support group.

#### **Convention/Convention Exhibitor**

The NAMI Convention is the annual gathering of nearly 3,000 mental health activists and advocates from all over the U.S. and several foreign countries. Our attendees include:

- Consumers
- Family members
- Health and social policymakers from both the public and private sectors
- Treatment professionals

All our attendees have one overarching reason for attending the NAMI Convention -- to improve the lives of people who live with mental illness and the lives of their loved ones. Our attendees

are responsible for securing or recommending mental health services, products, and information for themselves, loved ones, clients, and patients diagnosed with serious mental illnesses. They are eager for the latest information, treatment options, coping strategies, and support services. NAMI members are fierce advocates for people with mental illness, and our attendees are also looking for help with advocacy activities -- especially in the areas of local, state, and federal legislation, housing, criminal justice, disability rights, parity, employment, and education -- to name a few.

Convention exhibitors purchased booth space at the NAMI Convention as an exhibitor.

#### **Corporate Membership**

NAMI's Corporate Membership, created in 2009, is designed to further the dissemination of NAMI information to its corporate partners and help focus them on NAMI's mission and vision to better serve people who live with mental illness and their families.

Benefits of corporate membership status include participation in a variety of NAMI meetings, including the Corporate Sponsors meeting and State Policy Exchange. Corporate membership also includes recognition as a sponsor of the NAMI Convention, exhibit space and registrations.

#### **CIT Resource Center**

The mission of the CIT Resource Center is to supply mental health care, law enforcement, advocacy workers and people who live with mental illness with the latest information about Crisis Intervention Team (CIT) training. The NAMI CIT Technical Resource Center serves as a repository of information about CIT programs nationwide. The Center facilitates ongoing communications between CIT programs and engages in national networking to establish standards and promote the expansion of CIT.

The Center produces an e-newsletter, *CIT in Action*, and maintains a list-serv, which provides announcements and urgent news on jail diversion, CIT, and forensic issues.

#### **Depression Initiative**

In 2009, NAMI is launching a major initiative that will utilize national and state resources to increase visibility and awareness of depression. This initiative will focus on activities to promote better access to treatment and services, continuity of care, and adherence to treatment for those who live with depression. Components of this program include:

• A National Survey. NAMI will initiate a national public opinion survey to determine public attitudes and awareness about depression, treatments, continuity of care and outcomes and serve as a baseline for future efforts. An Advisory Committee consisting of national key opinion leaders and NAMI national staff will guide the process. NAMI will contract with a national public opinion research firm to conduct the study. Results will be disseminated to the national media.

- Women and Depression Outreach. NAMI's recently created materials on "Women and Depression" provide rich resources for this effort. Building on this, NAMI will create and promote an expanded initiative on women and depression with new and improved sections to the Web site. Interactive components to create a better understanding of depression (ie "Test your Depression Knowledge,"), the importance of appropriate treatment and the role of support will be developed. Additional content on supporting loved ones with depression, seeking-help guides, and related topics can be developed. NAMI is currently in discussions with a major national women's magazine about ways to better educate women about mental illness. NAMI will continue to build relationships with women's leadership groups to expand its efforts beyond the usual boundaries of the mental health arena.
- Grassroots Tool Kit Development and Dissemination. Education and promotional tactics
  will be packaged for NAMI members in a toolkit for easy implementation in local
  markets. Working with NAMI's state and affiliate leaders, an initiative aimed at
  providing the tools and technical assistance in support of successful local media outreach
  will be implemented. Messages will be focused on all facets of depression, including
  recognition, diagnosis and treatment and adherence to treatment.

#### **Depression is Real**

The *Depression Is Real Coalition* is a group of physician, consumer and constituency groups that has come together to create an educational campaign about depression. These groups are concerned about confusing messages in popular culture suggesting that depression is "just the blues" or a "made-up disease." The goal of the Coalition is to help people living with depression, their families, friends and the general public to understand these essential facts about depression.

- Depression is a serious and debilitating disease that affects every aspect of a person's health. Depression affects 15 million Americans a year, as well as their family members, friends, and co-workers.
- Depression has serious and potentially fatal consequences. In fact, untreated depression kills thousands of Americans each year through suicide and by intensifying the symptoms of life-threatening illnesses like cancer and heart disease.
- There is hope for those living with depression because proven therapies and effective medicines exist. People can recover if they receive proper treatment.

The Depression Is Real Coalition's campaign involves public service announcements and public education activities.

#### **Depression Survey**

NAMI implemented a national public opinion survey on depression. The study, conducted by Harris Interactive, polled 3,500 people living with depression. The focus on the survey was to assess the personal and financial costs of depression and to emphasize the urgent need for care, resources, access and support. Results were released nationally with an emphasis on five key media markets. NAMI developed press materials and briefings and worked with local NAMI affiliates to release the findings nationally and in five states.

#### DC Walk

NAMIWalks is a national program implemented by local NAMI affiliates to raise awareness about mental illness and promote positive messages of recovery and hope. The program structure is similar to walks for other non-profit health organizations such as Alzheimer's disease, breast cancer, etc. Since 2003, 100,000 individuals have participated in NAMIWalks in 80 cities. The NAMIWalk in Washington, DC, was sponsored by NAMI National.

#### **Employee Giving/Matching Gifts**

Matching Gifts and Employee Giving programs allow employees to involve their employer with the work of their favorite non-profit organization. Many companies will match the donations employees make to the organizations they support, as well as provide employee giving options. Many employees in the pharmaceutical industry choose to support NAMI in their annual charitable gifts and many companies match those gifts as standard practice. This type of gift is received by NAMI from employees and companies in many industries.

#### **Exemplary Psychiatrist Awards**

Since 1992, NAMI's Exemplary Psychiatrist Awards program allows NAMI members and affiliates in every state, city, and community throughout the country to nominate and honor publicly the contributions that many psychiatrists make to improving the lives of people with psychiatric disorders. The criteria for these awards recognize psychiatrists who have "gone the extra mile" with NAMI members and have made substantial contributions to local or state NAMI activities. The event is held at the annual meeting of the American Psychiatric Association to ensure visibility and recognition for the awardees.

#### **Family-to-Family**

Family-to-Family is NAMI's free 12-week signature education program for family caregivers of individuals with severe mental illnesses that discusses the clinical treatment of these illnesses and teaches the knowledge and skills that family members need to cope more effectively.

The course is taught by trained family members. All instruction and course materials are free to class participants. Over 175,000 family members have graduated from this national program.

#### Family-to-Family includes:

- Current information about schizophrenia, major depression, bipolar disorder (manic depression), panic disorder, obsessive-compulsive disorder, borderline personality disorder, and co-occurring brain disorders and addictive disorders
- Up-to-date information about medications, side effects, and strategies for medication adherence
- Current research related to the biology of brain disorders and the evidence-based, most effective treatments to promote recovery

- Gaining empathy by understanding the subjective, lived experience of a person with mental illness
- Learning in special workshops for problem solving, listening, and communication techniques
- Acquiring strategies for handling crises and relapse
- Focusing on care for the caregiver: coping with worry, stress, and emotional overload
- Guidance on locating appropriate supports and services within the community
- Information on advocacy initiatives designed to improve and expand services

#### <u>Fundraiser – American Psychiatric Association Meeting</u>

Companies have approached NAMI and other non-profit health organizations with an opportunity to help educate psychiatrists about their organizations in the exhibit area of the APA annual convention. To increase participation, the companies have often made arrangements to provide charitable donations to these organizations. At one booth, for example, participants could "vote" for their favorite charity. The company made a donation to each organization based on the number of votes it received.

#### **Gala**

Since 2004, NAMI has held an annual gala to celebrate its achievements and draw attention to mental illness and the promise of recovery. Guests include members of Congress, political leaders, and prominent researchers and scientists. NAMI presents its annual researcher award at this event.

By bringing together opinion leaders from a variety of arenas to raise the profile of mental illness with a focus on forward progress through research, NAMI is able to educate the public, reduce stigma, and establish connections that assist our efforts to improve the quality of life for those impacted by this spectrum of diseases.

#### **Hearts & Minds**

Hearts & Minds is a multimedia program about healthy, accessible, and affordable lifestyle changes designed to reduce cardiac risk among people with mental illness.

Research has demonstrated that people living with severe psychiatric conditions may have an increased risk of heart disease and related conditions, in part because of serious side effects resulting from the use of medications. NAMI addresses the issue of integrating mental and physical health concerns through the Hearts & Minds program. The program includes a 13-minute inspirational video and a 26-page booklet. The purpose of the program is to raise awareness and provide information on: diabetes, diet, exercise, and smoking.

The program also includes basic information on addictions, recovery, stigma, and treatment. Along with information on diabetes and sleep apnea, Hearts & Minds contains tips for exercise and diet -- including a shopping list template, recipes, and a food diary.

#### **HelpLine**

NAMI provides support, referrals and information to individuals and family members coping with serious mental illness through a telephone and email helpline. HelpLine staff and volunteer associates respond to approximately 50,000 incoming telephone, e-mail, and postal requests from across the country each year. Individuals are seeking information on specific illnesses including referrals for services and information relating to children and adolescents and the elderly, among other topics.

#### Honorarium

Honorarium paid to NAMI for NAMI staff participation in advisory boards or related activities. These events usually include participation by other non-profit health organizations. Occasionally NAMI staff members, along with representatives from other non-profit health organizations, participate in an industry-sponsored advisory committee to offer the consumer/family perspective on a variety of issues, including broad-based health care reform, leadership development, and current issues related to mental illness. One example is participation on the PALS (Patient Advocacy Liaisons) board of directors, consisting of representatives from several national non-profit health organizations representing cancer, diabetes, HIV/AIDS, etc. and focused on broad issues relating to healthcare and patient advocacy.

#### In Our Own Voice

In Our Own Voice (IOOV) is a unique public education program developed by NAMI in which two trained consumer speakers share compelling personal stories about living with mental illness and achieving recovery. IOOV is a one-and-a-half hour interactive, multimedia presentation by consumers that offers hope and provides insight into the recovery now possible for people with mental illness. IOOV is an opportunity for those who have struggled with mental illness to gain confidence and to share their individual experiences of recovery and transformation.

Throughout the IOOV presentation, audience members are encouraged to offer feedback and ask questions. Audience participation is an important aspect of IOOV because the more audience members become involved, the closer they come to understanding what it is like to live with a mental illness and stay in recovery.

IOOV presentations are given to consumer groups, students, law enforcement officials, educators, providers, faith community members, politicians, professionals, inmates, and interested civic groups. All presentations are offered free of charge.

The goals of IOOV are to meet the need for consumer- run initiatives, to set a standard for quality education about mental illness from those who have been there, to offer genuine work opportunities to people on their paths to recovery, to encourage self-confidence and self-esteem in presenters, and to focus on recovery and the message of hope.

#### **Leadership Institute**

The Leadership Institute is held twice annually and offers leadership and organizational development opportunities to assist NAMI state organizations and local affiliates to meet the NAMI mission. The Leadership Institute builds the capacity of our organization by enhancing the ability of our leaders, most of whom are volunteers, to manage, govern, teach and advocate. In 2009, the Institute will provide over 15 workshops for 800-1,000 NAMI leaders. Workshops are organized in basic, intermediate and advanced levels.

#### **Legislative Round Table**

In October 2005, NAMI convened a bipartisan group of more than two dozen state legislators to discuss state level mental health policy issues and to develop an agenda for state level mental health transformation.

#### **Medicare Part D Education**

Upon enactment of the Medicare Part D drug benefit in 2003, NAMI began a major undertaking to educate Medicare beneficiaries living with serious mental illness and their families about the new program. This effort included printed educational materials and web-based tools to assist beneficiaries in selecting among competing Prescription Drug Plans (PDPs) and Medicare Advantage (MA) plans. These efforts were coordinated with larger campaigns undertaken by the Centers for Medicare and Medicaid Services (CMS) and state-level SHIPS that were engaged in direct counseling with beneficiaries. In addition, NAMI staff made presentations to NAMI state and local affiliates in nearly 40 states from 2004 - 2006. In 2006 when the benefit went into effect, NAMI staff managed a Web-based consumer helpline to assist beneficiaries with serious mental illness with the transition to the program.

#### **Multicultural Action Center**

People of color face life-threatening disparities in access to high quality mental healthcare. Many reports, including the *Surgeon General's Report on Cultural, Race and Ethnicity* (2001) and the Institute of Medicine's 2003 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, point to the great disparities of minority mental health in this country and the resulting toll on our society. NAMI recognizes that diversity goes beyond race and ethnicity, and the Multicultural Action Center strives to represent and advocate for America's broad cultural and life groups that are outside the mainstream.

In response to this national crisis, NAMI created the Multicultural Action Center (MAC). This center works to focus attention on system reform to ensure access to culturally competent services and treatment for *all* Americans and particularly to help and support families of diverse communities who are dealing with mental illness. MAC's goals include:

- Advance NAMI's policy agenda and address issues which disproportionately affect diverse communities.
- Support NAMI grassroots advocacy and outreach efforts.

- Build diverse leadership at all levels of the organization.
- Develop and promote culturally competent support programs and practices.
- Develop strong partnerships with other similar organizations.
- Decrease stigma through public education that address specific cultural barriers.

#### Peer-to-Peer

Peer-to-Peer is a unique, experiential learning program for people with any serious mental illness who are interested in establishing and maintaining their wellness and recovery. It is another of NAMI's signature education programs, a free course for consumers that contains individual relapse prevention planning, a debriefing/storytelling week, and an advance directive for psychiatric care.

The course was written by a person with a psychiatric disability who is also a former provider and manager in the mental health field and a longtime mutual support group member and facilitator. An advisory board comprised of NAMI consumer members, in consultation with Joyce Burland, Ph.D., author of the NAMI Family-to-Family Education program, helped guide the curriculum's development.

Peer-to-Peer consists of nine two-hour units and is taught by a team of three trained "Mentors" who are personally experienced in living well with mental illness. Mentors are trained in weekend-long training sessions, supplied with teaching manuals, and are paid a stipend for each course they teach. Participants come away from the course with a binder of hand-out materials, as well as many other tangible resources: an advance directive; a "relapse prevention plan" to help identify tell-tale feelings, thoughts, behavior, or events that may warn of impending relapse and to organize for intervention; mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public.

#### **State Policy Exchange Meeting**

The purpose of this annual meeting is to examine current public policy issues that impact people living with mental illness and their families. NAMI's corporate sponsors receive briefings on federal and state policy related to services for individuals living with serious mental illness. Issues addressed at the State Policy Exchange include Medicaid financing of mental health services, Medicare coverage of mental health services, and specific state level reform issues including coverage for the uninsured and insurance parity legislation. The meeting also includes interactive discussion about strategies for state level advocacy to address gaps in services and increasing awareness of mental illness among policymakers.

#### **Travel**

NAMI, along with other national non-profit health organizations, occasionally participates in conferences, meetings and advisory boards in order to lend our unique perspective and expertise regarding the consumer and caregiver perspective of mental illness. Those who host these gatherings accept responsibility to cover the travel expenses of NAMI staff members. NAMI either receives travel stipends or seeks reimbursement for direct costs incurred with travel to these meetings.

#### **Women & Depression**

This monograph was developed as an addition to our successful line of NAMI publications focused on the unique challenges with mental illness within targeted populations. This resource is widely available for consumers, families, practitioners and the general public. Our initial distribution was 50,000 copies through our affiliate network. The monograph is available on our website which reaches over 6 million unique visitors a year.