



2008

Annual Report



The Association for
Frontotemporal Dementias
Opening the gateway to help and a cure



The Association for Frontotemporal Dementias

Opening the gateway to help and a cure

Our Mission

To promote and fund **research** into finding the cause, therapies, and cures for the frontotemporal dementias;

To provide **information, education** and **support** to persons diagnosed with frontotemporal dementias (FTD), their families and caregivers;

To **educate** physicians and allied health professionals about the FTDs and how to improve patient care;

To bring about greater **public awareness** of the nature and prevalence of the frontotemporal dementias and the needs of those who are coping with them;

To **advocate** with public officials and promote public and private programs that provide appropriate, affordable and high-quality long term health care and social services.

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Jill Goldman, MS
Murray Grossman, MD, EdD
Michael Hutton, PhD
Andrew Kertesz, MD, FRCP c
Virginia M.-Y. Lee, PhD
Carol F. Lippa, MD
Irene Litvan, MD
M.-Marsel Mesulam, MD
Bruce L. Miller, MD
Jill Murrell, PhD
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Howard Rosen, MD
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George Sidoris
Beth Walter

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Susan L-J Dickinson, MS
Executive Director
Sharon S. Denny, MA
Program Director
Martha B. Meyers,
Office Manager

Dear Friends,

2008 was an amazing year for AFTD! Our appeal to you to help us fund FTD Drug Discovery resulted in a phenomenal response, with an increase in contributions across the board, including a doubling of the number of donors at our highest level. We used these funds to finance more research and to expand our infrastructure, hiring a new Executive Director and creating a new Program Director position. This increase in staff enabled us to reach more of you: we added more than 2,000 individuals to our database, effectively doubling the size of our FTD community. We also met more of you in person, as we held our first annual public meeting in Baltimore in June and helped to fund a caregiver conference at Northwestern University.



A highlight for me this past year was participating in the Sixth International Conference on Frontotemporal Dementias in Rotterdam. Seeing hundreds of researchers from around the world in one room, discussing their work on our rare diseases—moreover, knowing that AFTD as a major sponsor of the meeting helped to bring them all together—was an experience that was both exciting and hopeful. While in Rotterdam I hosted a meeting of caregivers and professionals from many different countries, all of us working to create organizations that can bring comfort, relief and hope to our families. Meeting with caregivers from England, Holland, France, Germany and Argentina reminded me that FTD is, sadly, an experience that transcends both borders and languages. We look forward to expanding our collaborations with these new friends and building upon each other's efforts to improve the quality of life for FTD patients and their families.

It is because of your tremendous support and generosity that AFTD continues to grow and is able to develop programs that address the most critical needs of FTD families and the professionals who care for them. As you read about these newest initiatives on the next few pages I hope you will feel both pride and urgency: pride in what we have been able to accomplish together and urgency, knowing that there is so very much more that needs to be done.

I look forward to your continued support as we work together to bring about a world without frontotemporal dementias.

With my very best wishes,

Helen-Ann Comstock

Helen-Ann Comstock, Founder and Chair



Accomplishments

Funding for Research

In 2008 AFTD funded two research grants totaling \$120,000. One of these grants provides support for the organization's first pilot clinical research study.

In partnership with the Alzheimer's Drug Discovery Foundation, AFTD awarded the first grants for FTD Drug Discovery. The four grants totaled \$300,000.

In partnership with the Indiana University Alzheimer's Disease Center AFTD was awarded a grant from NIH under a new program titled Partners in Research. The goal of this project is to engage families and caregivers in a discussion about brain donation and the barriers that currently exist to prevent families from participating. The results will be used to design educational materials for both physicians and families that will increase participation and thus drive research forward faster.

In October AFTD met with staff at the National Institute of Neurologic Diseases and Stroke and the National Institute on Aging to advocate for more funding for FTD.

Supporting Patients & Families

The network of support groups AFTD coordinates grew from 29 to 35, including six new groups and two telephone support groups. AFTD continued to host quarterly phonecalls for the group leaders, featuring guest speakers on critical topics such as day care programs for patients.

AFTD provided information to more than 800 individuals who contacted us via info@ftd-picks.org or through our toll-free Helpline at 866-507-7222.

The Association co-sponsored a caregiver conference at Northwestern University in August.

Educating Professionals and the Public

In September AFTD was one of the sponsors of the 6th International Conference on Frontotemporal Dementias in Rotterdam, The Netherlands. More than 300 researchers from around the world attended three days of research presentations, and more than 125 caregivers attended a special day of talks geared toward the layperson. AFTD sponsored a Caregiver Dinner attended by nearly 200 caregivers and researchers.

In Rotterdam AFTD also hosted a special meeting of caregiver groups from around the world. Individuals from France, Sweden, Switzerland, The Netherlands, Britain, Germany and Argentina met to discuss their efforts to create FTD support and advocacy organizations in their own countries as well as ways all of the groups can work together on a global level. Dr. Facundo Manes, leader of a developing group in Argentina, has already teamed up with AFTD to translate some of AFTD's basic materials into Spanish.

AFTD expanded its newsletter to 8 pages.

Raising Awareness

In 2008 AFTD's Tell 10 People about FTD campaign continued to raise awareness and funds for our community. Families across the country sponsored an amazing array of creative and fun events.

In **Delaware**, Erin Budd and her family sponsored a 5K Pace for Pick's walk/run in honor of her mother.

In **Pennsylvania**, Michelle Stafford teamed up with the Philadelphia Soul, Philly's Arena Football team, to celebrate FTD Night at the arena. The team also donated a guitar signed by Soul owner Jon Bon Jovi to the cause!

In **California**, the Walter family hosted a golf tournament in memory of the three Walter brothers who have all been lost to FTD.

In **Ohio**, the Sidoris family also hosted a golf tournament, this one in memory of George Sidoris, Sr.

In **Texas**, Paula Radvansky hosted a fundraiser in her art gallery in memory of her brother, Tom, who died this past year with FTD. Paula donated a percentage of the profits from sale of her brother's favorite paintings, "Tom's Trees" to AFTD.

In **Florida**, after his wife Cindy's death, Jim Cardosi wrote a memoir of their life together and self-published it online through amazon. Titled *And Two Shall Become One*, proceeds of sales go to AFTD and to the nursing facility where Cindy was cared for.

In **North Carolina**, Kendra Gibson ran a half-marathon in honor of her mother, who has been diagnosed with FTD. A law student and mother of three young children, Kendra says she found the experience invigorating.

In **New York**, for the second year in a row Jennifer and Chris Iannotti ran a race in honor of their grandfather.

Across the country and on the internet AFTD Board members and other families hosted events and wrote letters to family and friends, inviting them to support the FTD community. We would like to especially recognize Barry Vernick, who sent an email to friends and family, informing them of his wife Carmella's illness just one month before Carmella died. The response was overwhelming.

Advocating for Services

AFTD's advocacy efforts in Washington DC paid off this October, when the Social Security Administration announced the creation of a new Compassionate Allowances initiative and FTD was one of just 50 conditions included in the initiative. Under Compassionate Allowances any patient with one of these 50 severe diagnoses will have their claim for disability benefits marked for expedited review. A process that in the past has taken months may occur in as little as a week under this new program.

In November AFTD joined the Coalition to End the Two-Year Wait for Medicare benefits. Our families have been sharing their stories to demonstrate the burden that this mandatory wait imposes upon a family already in serious financial distress.

AFTD created the framework for a grassroots network across the US and Canada as a way both to communicate national initiatives to the local level and as a way for families and professionals in a given region to find each other for services and support.





Every year hundreds of donations are made to AFTD in memory or in honor of special people. Although we do not have the space here to acknowledge each of these gifts, we are extremely grateful, and aware that these donations are the lifeblood of our organization. We use these funds to provide education, research, support and services to improve the lives of FTD patients and their caregivers.

Donor Honor Roll

\$50,000 & Above

Anonymous | Susan Laden | Philip H. Lovett | Radford D. Lovett |
Meredith & Doug Morgan

\$15,000 & Above

GFS Memorial Golf Outing | Walter Charitable Fund, Inc.

\$5,000 & Above

Anonymous | Marcia Halligan | Handel Architects, LLP | Helen Hiebert |
Walter McKee | Millennium Partners | Ed & Kathy Quinn | Kevin A. Quinn |
The Arnow Family Fund, Inc.

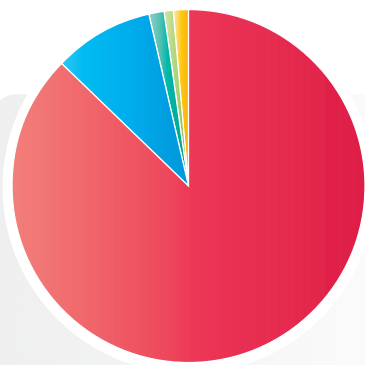
\$1,000 & Above

JoAnne Albanesi | Arthur Griffin Family Foundation | Kara Baldino |
Bank of America | Steven & Dayna Bochco | Earl Comstock & Anne McInerney |
Helen-Ann Comstock | Constance L. Drayton | Edward C. Driscoll | Alan Einhorn |
Susan Eissler | Trevor Eissler | Ernest Maier, Inc. | Goldman, Sachs, & Co. Matching Gifts |
Robert Glandon | John C. Haas Arlie & Marie Hedrick | Jean L. Heffron | Ken Hermann |
Anna Hill | Alfred E. Hoffman | Mr. & Mrs. R.D. Hubbard | Robert Hughes |
John R. Musser, Jr. Family Foundation | K & F Fund | Gloria LaGrassa | Emily Levy |
Katharine Lovett Loeb | W. Radford Lovett, II | Stephanie Luck | NetJets, Inc. |
Jillian Neubauer | Louise O'Connor | Pfizer Foundation | Rosa Potter |
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Weil, Gotshal & Manges, LLP | Marc Weiss | Leighton B. Welch

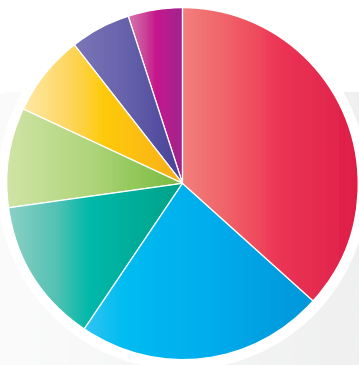
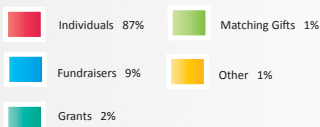
\$500 & Above

Mark Abbott | Academy of Notre Dame De Namur | Glenn Scott Andrews |
Jennifer R. Annee | Joseph Becker | BP Foundation | Bill Brown | Lori Keith Douglas |
Wayne Everard | Faurecia USA Holdings | Debbie Fenoglio |
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Red Knights International Motorcycle Club | Dolores Schwabe | Barbara Siedenburgh |
Kate Smith | Scott Sodoma | Marie Sykes | Wescap Insurance Co. |
David & Annette Westerman | Debra Winters | Melanie Young

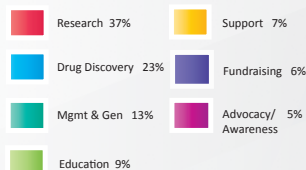
Financial Report



2008 Income **\$820,546**
by Source



2008 Expenses **\$437,226**



Statement of Financial Position

As of December 31, 2008

Assets

Cash & Cash Equivalents	\$ 768,003
Accounts Receivable	2411
Prepaid Insurance	678

Total Current Assets	\$ 771,092
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Security Deposit	950
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Total Assets	\$ 772,042
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Liabilities

Accounts Payable and Accrued Expenses	3,582
Research Grants Payable	60,000

Total Current Liabilities	\$ 63,582
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Net Assets

Unrestricted	342,563
Temporarily Restricted	365,897

Total Net Assets	\$ 708,460
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Total Liabilities and Net Assets	\$ 772,042
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Looking Forward to 2009

Dear Friends,

As you read this we will already be well into 2009, with our sights set on a new group of challenges.

Prominent among these is Strategic Planning. AFTD has grown at a tremendous rate over the past two years, and thanks to a generous donation from an anonymous supporter we are able to devote some time to take stock of our current situation and plot a course for the next three to five years. Other key projects include: design of a new, more accessible and informative website, inauguration of a Caregiver Respite Grant program, and award of the first Postdoctoral Fellowship in FTD. We are conducting a series of focus groups as part of an NIH-funded research project designed to empower patients and their families as true partners with clinicians and scientists in the research process on our rare disease. We are also greatly encouraged to hear of potential therapeutics for FTD getting close to clinical testing, and we are working with NIH and researchers to ensure that the infrastructure is in place to implement these trials as soon as possible.



I would be remiss if I did not recognize the wonderful group of people who come together to bring about AFTD's success. Sharon Denny, our Program Director, has been here less than a year but already has her finger on the pulse of this organization, helping us to address our families' most pressing needs like lack of accessible information and health insurance. Our wonderful Medical Advisory Council, led by Brad Boeve, MD, whose members from across the US and Canada have worked so hard this past year, helping us to review applications for scientific grants and re-write all of our educational materials. Our Board of Directors, all volunteers and FTD caregivers, devote so much of their time and form the heart and leadership of AFTD. And, most of all, our families across the country and the world, who partner with us to fund research, support other caregivers, hold awareness events, or share their story to advocate for improved services. This is your organization, and I am both proud and humbled to be a part of it.

Wishing you the best for 2009,

A handwritten signature in black ink, appearing to read 'Susan L-J Dickinson'. The signature is fluid and cursive, with a long horizontal line extending from the end.

Susan L-J Dickinson, *Executive Director*

The Association for Frontotemporal Dementias
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Philadelphia, PA 19103
www.ftd-picks.org



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