Annual Report

2007

The Association for Frontotemporal Dementias

AFTD

Opening the Gateway to Help and a Cure

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Susan L-J Dickinson, MS
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Catherine Pace-Savitsky, MA
Program Director

Martha B. Meyers
Administrative Assistant

OUR MISSION

Promoting and funding research into finding the cause, therapies, and cures for the Frontotemporal Dementias;

Providing information, education, support and advocacy to persons diagnosed with FTD, their families and caregivers;

Educating physicians and allied health professionals about the FTDs and how to improve patient care;

Bringing about greater public awareness of the nature and prevalence of the Frontotemporal Dementias and the needs of those who are coping with them;

Advocating and promoting public and private programs that provide appropriate, affordable and high-quality long-term health care and social services.

MEDICAL ADVISORY COUNCIL

Bradley F. Boeve, MD, Chair
Mayo Clinic, Rochester

Thomas D. Bird, MD,
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LEADERSHIP

Dear Friends,

It has been just five short years since I founded The Association for Frontotemporal Dementias. As I look back to that time I can't help but think how far AFTD has surpassed my ambitious dreams of an organization that would support and advocate for those coping with FTDs. Our activities and accomplishments are due to the dedicated work of members of AFTD's Board of Directors and AFTD's Medical Advisory Council, as well as staff. I hope as you read through this report you will be motivated to join with us, as our work continues in 2008 and beyond.

I would like to give a special acknowledgment to Catherine Pace-Savitsky, AFTD's first Executive Director. During her two years in this position she worked with the Board of Directors to move this organization from a small, motivated group of caregivers to a professional advocacy organization, with an international presence, services for our families, and research grants for the scientists and physicians who are working to better understand frontotemporal dementias. AFTD has benefited immensely from Catherine's dedication and leadership.

Those of us reading this report know better than anyone how isolating frontotemporal dementias can be. But, by coming together under AFTD, we are forming a strong, vibrant and effective community. Together we are forging a more hopeful future.

Kindest regards,

Helen-Ann Comstock
Founder and Chair

Dear Friends,

2007 was truly a banner year for AFTD.

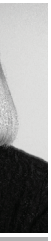
As you will read in this report, we made significant advances in all areas of our mission goals: Research, Support, Education, and Advocacy. We embarked on new partnerships with a major foundation and national peer-review journal; we built and implemented a membership database; and we started to engage our members at the grassroots level to raise funds for much-needed FTD Drug Discovery and to implement our *Tell 10 People about FTD* outreach campaign.

It has been a true honor to serve as Executive Director of AFTD these past two years, and as I read through this chronicle of 2007 I feel proud, invigorated and blessed. Proud of what we have accomplished; invigorated when I see all there is yet to be done; and blessed to be facing these challenges alongside all of you, who comprise such a caring and dedicated community.

With best wishes for 2008,

Catherine Pace-Savitsky, MA
Executive Director (2007)

Accomplishments



EDUCATING Professionals and the Public

In May at the American Academy of Neurology national meeting in Boston, AFTD hosted an exhibit booth and AFTD Medical Advisory Council members lead a half-day of presentations exclusively on FTD. This session was so heavily attended that monitors were set up in a satellite room so all of the neurologists who were interested in learning about FTD could participate.

In November AFTD and the Philadelphia chapter of the ALS Association co-hosted a scientific update meeting for families and health professionals on the relationship between FTD and ALS and how to care for patients with one (or both) diagnoses.

The National Institute on Aging asked AFTD to participate in a coalition of FTD experts to develop an informational pamphlet about FTD.

AFTD instituted weekly updates to the AFTD website, added a third issue of the newsletter, and developed written information on the importance of brain donation for research.

SUPPORTING Patients and Families

AFTD provided support to 29 caregiver support groups in the U.S. and Canada, including 6 new groups and two telephone support groups. The telephone groups are facilitated and funded by AFTD to support caregivers located in more remote areas.

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 provided financial and staffing support to three science-based caregiver conferences throughout the year: at the University of Pennsylvania, Northwestern University, and jointly with the ALS Association in Philadelphia.

FUNDING Research

This past year AFTD substantially increased its grant funding, awarding two grants for a total of $120,000 to FTD basic science research.

In addition, AFTD forged a relationship with the Alzheimer's Drug Discovery Foundation (ADDF) to develop a 3-year program which will award $900,000 to researchers identifying novel targets for FTD therapeutics. In 2007 AFTD contributed $100,000 toward this effort, which was matched by ADDF with $200,000, making a total of $300,000 awarded to the FTD Drug Discovery Project in 2007.

In January AFTD and the National Institute of Neurological Disorders and Stroke (NINDS) sponsored a workshop to develop a comprehensive Five-Year Plan to guide FTD research. Approximately two dozen leading clinicians, researchers, and advocates from around the world gathered to review the current status of FTD research and determine the gaps and barriers to research leading to a therapeutic drug trial.

ADVOCATING for Services

In the Fall AFTD launched the *Tell 10 People about FTD* campaign. Families from across the country participated and attracted attention from the media which resulted in scores of interviews with families in the U.S. and Canada.

AFTD formed an Advocacy Committee of the Board, developed an FTD Fact Sheet, and began recruiting volunteers to help develop an advocacy campaign.

AFTD issued a series of press releases announcing the FTD Drug Discovery Program and gave informational interviews to the press following Senator Pete Domenici's announcement in October that he had been diagnosed with FTD. The office began to build a database of reporters at the local and national levels who have written about FTD.

RAISING Awareness

In the Fall AFTD initiated the *Tell 10 People about FTD* campaign to raise awareness and funds for our community. Families across the country answered the call in a tremendous way.

In **Texas**, the Brown family put together a cookbook that contains recipes and special memories from FTD families across the country. The girl scouts, community hockey team, elementary school PTA—even the family's dentist—all helped support the project.

In **New York,** Jennifer and Chris Iannotti ran in a race in honor of their grandfather, Joseph Robert Lotito, who died of Pick's disease earlier in the year.

In **Florida**, the Willin family organized a "Hijack a Holiday" campaign: on Veterans Day friends and family spread throughout the community to educate people about FTD and solicit donations.

In **Pennsylvania,** Maryann and Jessie Graham organized an AppleFest at Jessie's school.

In **Indiana**, Laura Michels ran a marathon to honor her mother's memory.

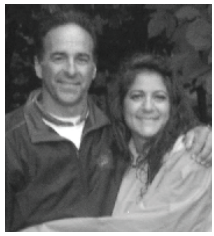
In **North Carolina,** the Lester family wrote more than 400 letters to family, friends, and business associates educating them about FTD and requesting financial support for the program.

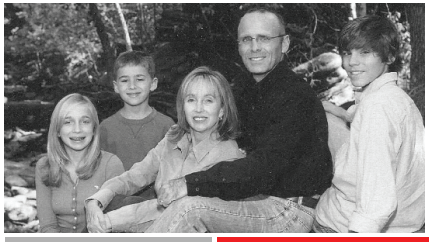
In **Maryland,** Christina H. celebrated her seventh birthday by asking friends to skip the gifts and instead donate to AFTD in honor of her grandfather.

Across the Country AFTD Board members and several additional families held small events and wrote letters to friends and family, inviting them to support the FTD community.

The funds raised through this first Tell 10 People Campaign are devoted to the first round of Drug Discovery grants: the first ever awards dedicated to the development of medicines specifically to treat FTD. The awareness raised is incalculable and is necessary to the success of all aspects of our mission, from accurate diagnosis to support services for patients and families, to garnering of more federal research dollars for FTD. The campaign continues, and we welcome all members of our community to contact the AFTD office for our help in hosting an event of your own.

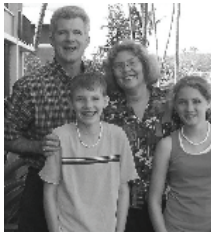
DONOR Honor Roll

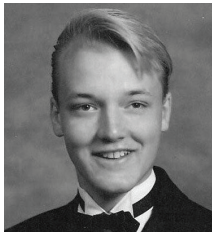




In Gratitude

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.





DONORS $50,000 and Above

Susan Laden • Philip H. Lovett • Radford D. Lovett

DONORS $20,000 and Above

Susan L. Grant • Helen Hiebert • Frank & Allen Melville
Douglas & Meredith Morgan

DONORS $5,000 and Above

Anita Berkowitz • Susan Eissler • Ernest Maier, Inc.
John Mackey Fund, Inc. • Walter Mckee • Millennium Partners
Robert Potamkin • Kevin A. Quinn
R&R Mechanical Contractors, Inc. • Arthur Sommers

DONORS $1,000 and Above

Steven & Dayna Bochco • Marge Bogosian • Jerome Borowick
Leigh Ann Burnett • Callaway Golf Co. • Helen-Ann Comstock
Earl W. Comstock • Isabella Crivello • Edward C. Driscoll
Lauren L. Fant • Linnea M. Grim • John C. Haas • Susanne,
Josh, Emil, Louise & Danny Hedaya • Leonard Hill
Anna Hill • Robert & Cara Hughes • Kenny Kranseler
Gloria LaGrassa • Paul Lester • Emily Levy • Katharine L. Loeb
Maine Community Foundation • Laura Michels
Louise O'Connor • Raymond & Laura Prill • Quest Software, Inc.
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Technical Assistance Collaborative, Inc. • Nancy Van Roy

DONORS $500 and Above

L. Jean Bachofner • Joseph Becker • Mr/Mrs Harold H. Brayman
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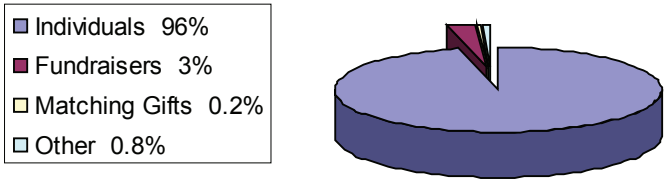
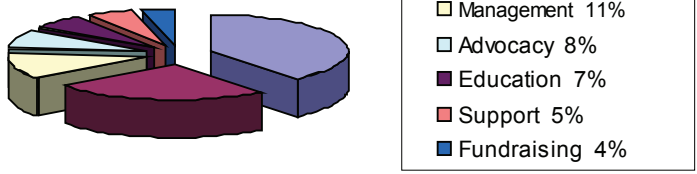
Saenger • Jay Sandrich • Karl Schoettle • Michael Scott
Brian Spillane • Gaye Weinberger • Sidney R. Williams

Income 2007 $645,820



Expenses 2007 $395,675



Statement of Financial Position

December 31, 2007

ASSETS	
Cash and Cash Equivalents	$415,487
Marketable Securities	1,809
Prepaid Insurance	- 0 –
TOTAL CURRENT ASSETS	417,296
TOTAL ASSETS	417,296
LIABILITIES	
Accounts Payable and Accrued Expenses	32,156
Research Grants Payable	60,000
TOTAL CURRENT LIABILITIES	92,156
NET ASSETS	
Unrestricted	139,826
Temporarily Restricted	185,314
TOTAL NET ASSETS	325,140
TOTAL LIABILITIES AND NET ASSETS	**417,296**

LOOKING TOWARD 2008

Dear Friends,

By the time this report is published we will be well into 2008: working hard to leverage last year's successes into positive change in the lives of those who live and work with FTD. Significant plans for 2008 include: Creating a grassroots network for a national advocacy effort; co-sponsoring the 6th International Conference on FTDs in Rotterdam; and raising funds for the second round of FTD Drug Discovery grants.

Everything we accomplish at AFTD is a result of teamwork. As we face these challenges over the coming year we invite you to join us, by signing on to the FTD Advocacy Network or perhaps hosting a *Tell 10 People about FTD* event in your own community. We are here to support all of these activities, and look forward to accomplishing more great things together in 2008.

Best Regards,

Susan L-J Dickinson, MS, CGC
Executive Director

Medical Advisory Council

Murray Grossman

Brad Boeve

The AFTD Medical Advisory Council (MAC) is comprised of 16 experts in research or related health professions in the field of frontotemporal dementia in the U. S. and Canada. The Council is charged with advising AFTD on medical and scientific issues pertaining to FTD, including reviewing research grant applications, providing expert counsel and helping to chart a long-term course for the organization that will address the most critical research and care needs of our constituency.

AFTD would like to recognize Murray Grossman, MD EdD, Chair of the MAC from 2004-2007, and Brad Boeve, MD, who assumed MAC Chairmanship in June 2007.

AFTD…..Celebrating our Leadership

On the occasion of the fifth anniversary of the founding of AFTD, we take this moment to honor those with the vision.

Founding Board, 2003

AFTD Board of Directors at their founding meeting in Philadelphia January, 2003. From left: Fytie Drayton, Joseph Becker, Joyce Shenian, Jordan Grafman (advisor), Tess Parrish, Helen-Ann Comstock, Lisa Radin, Kent Jamison. Absent:Lawrence Shor, Robert Kemp, Robert Potamkin

AFTD

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