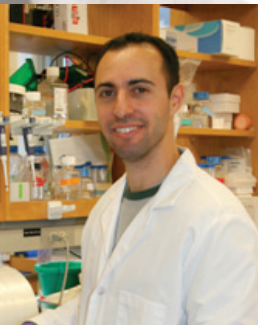




2009

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

Promote and fund research into finding the cause and cure for the frontotemporal dementias (FTD);

Provide information, education, and support to persons diagnosed with frontotemporal dementias and their families and caregivers;

Educate physicians and allied health professionals about FTD and how to improve patient care;

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

Advocate with public officials and promote public and private programs that provide appropriate, affordable and high-quality long-term health care and social services;

Facilitate the international exchange of ideas.

Staff

Susan L-J Dickinson, MS

Executive Director

Sharon S. Denny, MA

Program Director

Matthew Sharp, MSS

Program Coordinator

Michelle Leahy

Office Manager

Board of Directors

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Founder and Chair

Beth Walter

Vice Chair

Susan Eissler

Recording Secretary

Darlene M. Ryan

Treasurer

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Bruce L. Miller, MD

Jill Murrell, PhD

Rosa Rademakers, PhD

Howard Rosen, MD

John Q. Trojanowski, MD, PhD

Dear Friends,

What an exciting year 2009 was for The Association for Frontotemporal Dementias! We:

- Awarded more research dollars than ever before, including support for the first FTD postdoctoral fellowship;
- Worked with more caregivers and patients than ever before through the Helpline, email, website, and a growing number of support groups;
- Expanded staff from three part-time to four full-time positions to develop more programs to meet the needs of our families; co-sponsored twice the number of regional conferences as in any previous year; started a Caregiver Respite Grant program; and created a telephone support group dedicated to the special needs of parents caring for a spouse with FTD who also have school-aged children;
- Turned a mistake on Dr. Sanjay Gupta's blog into an opportunity to raise awareness about FTD, with the result that AFTD and one of our families were featured on CNN; and
- Created our first strategic plan, which recommitted us to the full breadth of our mission, crafted a vision, and charted a course for the next few years.



As I leave the position of chair I am immensely proud of all that has been accomplished since I founded the organization in November, 2002. And I am immensely grateful to all those who have served on the board and staff who, together with you, have made AFTD what it is today.

I will stay actively involved in advancing AFTD's mission, but I am pleased to turn over the leadership to Beth Walter and a new generation of board members and caregivers who have the passion and commitment to move the organization forward. And, most importantly, I urge *you* to become involved in shaping the future for all FTD families to come. There is nothing we cannot achieve if we work together and focus our efforts with energy, faith, compassion, and hope.

With my very best wishes,

Helen-Ann Comstock

Founder and Chair

Our Accomplishments



Advocating for Services

The AFTD Grassroots Network continues to grow across the US and Canada as a way to engage patients, families and professionals in outreach on behalf of those confronting frontotemporal dementias. The new AFTD program coordinator is implementing training and development for regional volunteer leaders to further grow the network.



Supporting Patients & Families

In 2009, with support from a generous donor, AFTD introduced the Respite Care Financial Assistance program. Sixty grants, totaling \$30,000, were awarded to full-time family caregivers to arrange respite for themselves.

AFTD sponsored caregiver education conferences this year in four US cities, with two new regions addressing caregivers' thirst for information. The University of Pennsylvania and Northwestern University were joined by Massachusetts General Hospital and the New York City Area Consortium on FTD.

In response to growing need, AFTD started a new telephone support group specifically for people who have a spouse with FTD and school-age children. It is the third phone group directly run by the Association.

Six new local caregiver support groups started, bringing to 41 the number of FTD groups operating across the US and Canada.

Last year, staff responded to more than 1000 calls and emails via the HelpLine. In December, AFTD hired a program coordinator in part to ensure a response within one business day.

Educating Professionals and the Public

In July AFTD launched a fully revamped, more user-friendly website as the cornerstone of our public presence and educational outreach efforts. The site already offers expanded information for caregivers, and a section for health professionals is in development.

The newsletter, published three times a year, grew to 12 pages with sections that address research developments, caregiver education, and AFTD awareness and advocacy activities.

AFTD is developing relationships with national nursing and assisted living providers to increase awareness and education of professional caregivers and facility care options for our community.

Raising Awareness

In March, 2009 a question about frontotemporal dementia was posted on Dr. Sanjay Gupta's CNN medical blog. The answer made no mention of FTD, discussing only Alzheimer's disease. AFTD worked with the editorial team at CNN to turn this mistake into an opportunity for awareness. A feature story on FTD appeared on CNN and CNN.com in December and generated significant media recognition.

AFTD started a Facebook page mid-year to connect with members of our community who use social networking sites.

Throughout 2009, AFTD's *Tell 10 People* campaign inspired local families to host events to raise awareness and funds for our mission. Creative new events ranged from a bowling tournament in Nebraska, to a Texas Hold'em poker tournament in Illinois, and an amusement park Family Fun Day in North Carolina. Marathon runners took our message to the streets of Virginia, Los Angeles, Long Island and Sacramento. And annual golf outings in Ohio and Sacramento grew in participants and local sponsors.



Funding for Research

In 2009 AFTD awarded an unprecedented \$330,000 in support of research:

In February the Laden Family Research Fellowship was awarded to Todd Cohen, PhD at the University of Pennsylvania. This two-year, \$110,000 award, is the first fellowship ever awarded specifically for the study of frontotemporal dementia.

The Morgan Family funded a \$60,000 grant to identify potential therapeutic targets in FTD caused by the TDP-43 protein; the grant was matched by the Alzheimer's Drug Discovery Foundation (ADDF), and a total of \$120,000 was awarded to Dr. Manuela Neumann at the University of Zurich. In our continuing partnership with ADDF, AFTD also awarded the second year of FTD Drug Discovery grants; a total of \$300,000 (\$100,000 from AFTD, \$200,000 from ADDF)

was awarded to three investigators.

The 2009 AFTD Research grant for a pilot study was awarded to Dr. John van Swieten at Erasmus Medical Center, Rotterdam, to follow presymptomatic FTD gene mutation carriers via MRI brain scan, and thus capture the first signs of developing disease in the brain.

Finally, AFTD and ADDF conducted a comprehensive survey of all research funded over the past decade that relates to FTD.

The Strategic Research Analysis: 1998-2008 identified funding trends that will enable AFTD to direct its grant dollars and advocacy efforts to have the greatest impact.





Donor Honor Roll

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.

\$50,000 & Above

Anonymous | Philip H. Lovett | Radford D. Lovett

\$15,000 & Above

Arnow Family Fund, Inc | Harold Hedaya Family Fund |
Walter Charitable Fund, Inc.

\$5,000 & Above

Anonymous | Helen-Ann Comstock | Sally Deuemeyer | Susan Eissler |
Marcia Halligan | Helen Hiebert | Holt Family Fund | Susan Laden |
Kevin and Jane Quinn | George J Sidoris | Arthur Sommers



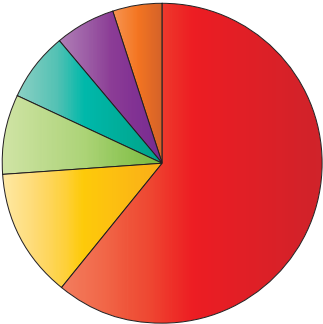
\$1,000 & Above

Kara Baldino | Robin Berkley | Anita Berkowitz | Marjorie Bogosian | Timothy Broer |
Mary Ann Clayton | Earl W. Comstock & Anne E. McInerney | Linda Deubert |
Mr. & Mrs. Drew Dinsmore | Constance L. Drayton | Mr. & Mrs. Randi Ehm |
Alan Einhorn | Trevor Eissler | Ernest Maier, Inc. | Wayne Everard | Robert Glandon |
John C. Haas | Jean L. Heffron | Mr. & Mrs. Kenneth R. Hermann | Anna Hill |
Alfred E. Hoffman | John Mackey Fund, Inc. | Paul Lester | Emily Levy |
Katharine Lovett Loeb | W. Radford Lovett, II | MaxBermuda | Kathryn McAndrew |
Judith McLachlin | McNellis Family Fund | Mr. & Mrs. Timothy Mowrey | NetJets, Inc. |
Jillian Neubauer | Pfizer Foundation | Mr. & Mrs. Edward Quinn | Colleen Quinn |
Lisa Radin | Raleigh Jaycees | Susan Reddy | Bruce L. Richardson | Frances Richter |
Alison Riddiford | Daniel Sackheim | Joanne Sackheim | Saponas Foundation |
Michael Scott | Sevenoff, LLC | Joyce Shenian | Bonnie Shepard | Curtis Thomsen |
Beth Walter | John and Alice Weicher | Leighton B. Welch | Mary Wong

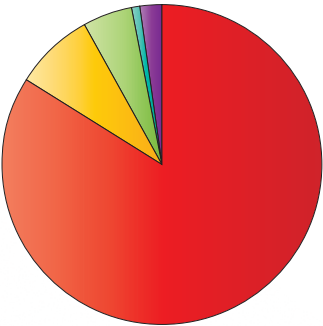
\$500 & Above

Anonymous | Mark Abbott | Gail Anderson | Robin Andrews | Armando Anido |
BP Foundation | James Cardosi | Mr. & Mrs. Doug Comstock | Bryan Dalesandro |
Lori Keith Douglas | Debbie Fenoglio | Dale Gasque | GlaxoSmithKline Foundation |
Alissa Hackmann | Heidi Homerding | Mr. & Mrs. Charles Horn |
Mr. & Mrs. David Huttenbuhler | Jennifer Iannotti | Sidney Krakower | Francine Laden |
Jary Larsen | James E. Leader | Mr. & Mrs. Raymond Malejko | Walter McKee |
Katie McLain | Melville Miller | Louise O'Connor | Zbyslaw Petryka |
Logan Pickett | R & R Mechanical Contractors | Mr. & Mrs. Samuel Register |
Elizabeth Rem | Frances Richter | Mr. & Mrs. Michael Roche | James Ryan |
Herbert & Judith Shanks | Scott Sodoma | May Anne Stepp | Nan Stowell |
Marie Sykes | Chris Ward | Curry Wood

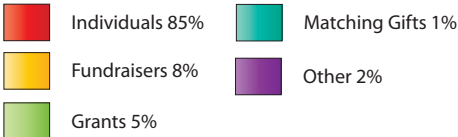
Financial Report



2009 Expenses \$706,132



2009 Income by Source \$730,153



Statement of Financial Position

As of December 31, 2009

Assets

Cash & Cash Equivalents	\$ 854,931
Accounts Receivable	1,682
Prepaid Insurance	902

Total Current Assets	\$ 857,515
Security Deposit	1,500

Total Assets	\$ 859,015
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Liabilities

Accounts Payable and Accrued Expenses	784
Grants Payable	125,750

Total Current Liabilities	\$ 126,534
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Net Assets

Unrestricted	563,443
Temporarily Restricted	169,038

Total Net Assets	\$ 732,481
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Total Liabilities and Net Assets	\$ 859,015
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Looking Forward to 2010

Dear Friends,

With a newly minted strategic plan as our roadmap the Association for Frontotemporal Dementias is working to harness growing momentum for our cause—and already in 2010 we are seeing significant results.

February witnessed the start of the first clinical trial of a disease-modifying drug for FTD. Though it is a small trial, this is a seminal event and one that we hope will signal to pharmaceutical companies that our community is both ready and eager to partner with them in finding treatments. Indeed, AFTD is working with the National Institutes of Health and the private sector to ensure that the infrastructure and tools are in place for larger trials, when promising compounds become available.

Our wonderful program staff, Sharon Denny and Matt Sharp, continue to interact with a growing number of patients and caregivers—by answering your inquiries, providing support for your awareness and fundraising events, and working with the volunteer leaders who have stepped up to help us establish and operationalize AFTD's grassroots network. These interactions both help us spread the word about the resources and programs we are developing and ensure that we keep in touch with the most pressing needs of our families. As our office continues to grow you can be assured that this will continue to be an organization that is guided by and responsive to these needs.

Finally, I invite you to join us in Indianapolis October 6-8, for the 7th International Conference on Frontotemporal Dementias. Researchers from around the world will convene for three days devoted exclusively to FTD, and AFTD is proud to be co-hosting a Caregiver program and dinner on the first day, Wednesday, October 6. In addition to a slate of informative speakers, the day will afford the opportunity to interact with caregivers, clinicians and researchers alike. We hope to see you there.

With warm wishes for the year ahead,

A handwritten signature in black ink, appearing to read 'Susan L-J Dickinson', with a long, sweeping horizontal line extending to the right.

Susan L-J Dickinson, *Executive Director*



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