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WORLD'S HIGHEST FREE-STANDING MOUNTAIN



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

FOR DAD
AND AFTD



mission

- ★ PROMOTE AND FUND RESEARCH INTO FINDING THE CAUSE, THERAPIES, AND CURES FOR FRONTOTEMPORAL DEGENERATION
- ★ PROVIDE INFORMATION, EDUCATION AND SUPPORT TO PERSONS DIAGNOSED WITH AN FTD DISORDER, AND FOR THEIR FAMILIES AND CAREGIVERS
- ★ EDUCATE HEALTH PROFESSIONALS ABOUT FRONTOTEMPORAL DEGENERATION AND HOW TO IMPROVE PATIENT CARE
- ★ BRING ABOUT GREATER PUBLIC AWARENESS OF THE NATURE AND PREVALENCE OF FRONTOTEMPORAL DEGENERATION AND THE NEEDS OF THOSE WHO ARE COPING WITH IT
- ★ 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.



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

DEAR FRIENDS - As I look back on my first year as Board Chair of this wonderful organization, I am struck by the fact that we are a community that is finding our voice. Two seminal events underscore this theme...

In December, after two years of discussions with our various constituents, the Board voted to change our name from The Association for Frontotemporal Dementias to The Association for Frontotemporal Degeneration. Our motivation was to ensure that AFTD is a place where people dealing with a wide variety of clinical presentations and disease processes can find a common “home”. Importantly, the word “Degeneration” also captures the essence of the FTD experience: it is a one-way journey of progressive loss. We are taking control of some of the vocabulary around these diseases, and thus hopefully shifting the framework within which they are viewed.

With our identity in hand, we created a short film that documents the stories of four families’ journeys with FTD. We are tremendously grateful to the families that opened their lives and homes to us, but it is important to note that for each family featured there were ten more who were eager to help with the project, and in

many ways this is the story of all of our families. Entitled *It Is What It Is*, this film is our first call to action, and we encourage you to use it to spread awareness of FTD.

There can be no doubt that awareness is key to all of the ambitious goals we have set for ourselves. More accurate diagnosis, better support systems for families, more funding and creative, efficient collaborations for researchers are all important objectives upon which we have set our sights. But the first step toward each is awareness.

I invite you to join us. Raise your voice. Tell your neighbors, physicians, family members about FTD. And be proud that you are member of a community that is taking control of its own destiny. It is what it is, but it’s not what it should be.

Working together, we will change the future.



With Warm Regards,

A handwritten signature in black ink that reads "Beth Walter". The signature is fluid and cursive, written on a white background.

Beth Walter
Board Chair

research

PROMOTE AND FUND RESEARCH
INTO FINDING THE CAUSE,
THERAPIES, AND CURES FOR
FRONTOTEMPORAL DEGENERATION

WE ENVISION OUR ORGANIZATION at the hub of the wheel that is driving research forward: providing information, funding grants, enhancing communication and coordinating efforts among those invested in conquering frontotemporal degeneration.

AFTD was founded first and foremost to advance research into treatment and a cure. The organization pursues this goal both by funding research and by forming strategic partnerships that will speed scientific results into drug discovery.

In 2010 AFTD co-sponsored a number of scientific meetings designed to promote collaborations and development of common resources for FTD research. The first meeting, co-hosted with the National Institute of Neurological Disorders and Stroke and the National Institute on Aging, brought 40 clinical researchers together to craft a national database that will collect common data on patients seen at institutions across the US.

AFTD was also a founding member of the Frontotemporal Dementia Treatment Study Group, which sponsored three meetings with researchers and representatives from pharmaceutical and biotech companies to stimulate corporate interest in FTD research.

In partnership with the Alzheimer's Drug Discovery Foundation, AFTD awarded \$300,000 to three academic scientists who are working on novel approaches to developing the first FTD treatments.

AFTD also provided seed funding for research projects at Yale University and Columbia University.



Todd Cohen, Ph.D. is the first AFTD Postdoctoral Fellow. Working in the laboratory of Dr. Virginia Lee at the University of Pennsylvania, Dr. Cohen has just published a key paper that sheds light on how the tau protein becomes abnormal in FTD.

support

PROVIDE INFORMATION, EDUCATION AND
SUPPORT TO PERSONS DIAGNOSED WITH
AN FTD DISORDER, AND FOR THEIR
FAMILIES AND CAREGIVERS

ONE OF THE BIGGEST things that AFTD has to offer families dealing with a new diagnosis is a sense of community-the opportunity to connect with healthcare professionals and other families who understand first-hand what you are going through.

Most families face significant confusion and anxiety when confronted with frontotemporal degeneration. Caring for families affected now is critical to our mission. AFTD provides accurate information, compassionate support, and a community that understands.

AFTD reaches a growing number of patients and families every year. In 2010, staff fielded an average of 100 HelpLine calls and emails and nearly 6,000 people visited the AFTD website each month. Staff helped five new FTD caregiver support groups to start, and provided continuing education to a network of 49 groups by years' end.

In a major new initiative, AFTD formed a Task Force on Families with Children to improve resources for people caring for an ill spouse while parenting children at home. An online survey invited people diagnosed with FTD to help the Association better understand and address their needs. Thirty-three people responded in the first three months.

The respite grant program entered its second year and was named the Comstock Caregiver Respite Program in honor of Helen-Ann Comstock, AFTD's founder. \$30,000 was awarded to 60 unpaid caregivers to arrange a brief respite from their responsibilities.

AFTD provided financial and program support to a caregiver conference in Fort Worth, Texas in May and to the 7th International Conference on FTD in Indianapolis in October, and awarded more than \$6,000 in caregiver travel grants.



Jim Cardosi was a devoted caregiver to his wife, Cindy, throughout her illness with FTD. For the past three years Jim has led one of AFTD's telephone support groups, sharing his experience and supporting others as they face the challenges of caring for a loved one.

education

EDUCATE HEALTH PROFESSIONALS
ABOUT FRONTOTEMPORAL DEGENERATION
AND HOW TO IMPROVE PATIENT CARE

EDUCATION IS THE MOST POWERFUL WAY to improve access to quality services for those affected by FTD. Through new partnerships and initiatives, AFTD is teaching professionals about the disorders and increasing their understanding of the needs of patients and families.

Informed medical professionals are the key to accurate, timely diagnosis and quality, compassionate care. AFTD is working with medical experts, academic centers and care facilities to ensure that doctors, nurses and long-term caregivers have the knowledge and skills to serve FTD patients and their families.

In 2010 AFTD expanded community outreach and training of health professionals. Staff and board members presented training sessions for employees at three nursing facilities, and spoke at a conference hosted by the Alzheimer's Association in New York City. Key volunteers have been trained to begin similar outreach within their regions.

Medical Advisory Council members contributed to two opportunities this year. Andrew Kertesz, MD co-authored a review article published in *The American Family Physician* targeted at primary care physicians to promote more accurate and timely diagnosis of FTD.

In partnership with CurePSP, AFTD co-hosted a webinar during which Brad Boeve, MD spoke on the cognitive and behavioral issues related to FTD. More than 700 people attended the live session.

Relationships have been solidified with expert nurse educators, health care corporations and caregivers committed to addressing the critical need for training in FTD among care facility staff. A committee will begin work in early 2011 on a new initiative to develop training modules about FTD for nursing home, assisted living and group home staff.



Darby Morhardt, MSW, directs the education services at Northwestern University's Cognitive Neurology and Alzheimer Disease Center. She collaborates frequently with AFTD on projects such as AFTD's Task Force on Families with Children and *Frontotemporal Disorders*, a booklet recently published by NIA.

awareness

BRING ABOUT GREATER PUBLIC
AWARENESS OF THE NATURE AND
PREVALENCE OF FRONTOTEMPORAL
DEGENERATION AND THE NEEDS OF
THOSE WHO ARE COPING WITH IT

TELL 10 PEOPLE: Anyone can participate – young or old, individuals or groups. The idea is to select an activity you enjoy and feel comfortable sharing with others. Tell them about FTD and ask them to support the Association's mission by participating in your event.

Raising awareness is the key to success for all of AFTD's mission goals. It is an issue that galvanizes and engages all aspects of our community – patients, families and professionals. Together, we are making a difference.

In partnership with thinkfilm, inc., AFTD produced *It Is What It Is*, a short documentary film that poignantly presents the story of four families. The film is available on DVD and comes with a 12-page booklet describing frontotemporal degeneration. It is a vital new tool that makes it easier to introduce others to the impact of an FTD diagnosis.

Families from across the US and Canada held more Tell 10 People events than ever to spread the word and raise funds for AFTD. In Maryland, Allyson Sealfon and her committee raised an amazing \$40,000 in the inaugural Scoot for Scooter 5K that attracted over 1000 people.

Lee Danis of Fort Worth, Texas issued a \$40,000 challenge grant for drug discovery, and people from across the US responded by hosting events and launching Facebook and letter-writing campaigns to raise the matching funds. Russell Zomback ran in the NYC Marathon in memory of his father. Over 55 individual sponsors supported him.

The Pontrelli Family held a luncheon of celebration in New York's Little Italy. The Walter and Sidoris families continued their wonderful traditions of hosting golf tournaments to benefit AFTD. And in January the Hickman family traveled to Tanzania to climb Mt. Kilimanjaro in honor of their father and husband, Stephen (see cover). This is just a handful of the many creative and fun events hosted by volunteers throughout the year. Each of them introduces a new group of people to our cause.



Michelle Van Son is one of the caregivers who generously shares her family's story in the documentary film *It Is What It Is*. Michelle's husband, Jeff, was diagnosed with FTD in 2009, when he was 38 and the couple's three children were preschoolers.

advocacy

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

POWERFUL MOVEMENTS are built on grassroots outreach. Your personal contacts, letters and stories fuel the momentum. AFTD is connecting a network of people across the US and Canada who will take action to change the future of FTD!

AFTD continues to call for more resources, supports, and services, for patients and families living with a degenerative neurological disease. Developing relationships with policy makers, public officials and peer organizations to advocate for more funding for research, more financial supports for patients and families and more appropriate care options.

In February 2010, the Social Security Administration included primary progressive aphasia among the conditions eligible for expedited review under the Compassionate Allowances Program for disability benefits. Led by colleagues at Northwestern University, AFTD supported this successful campaign by sharing lessons learned from our efforts to include FTD when the program was created.

AFTD's new advocacy committee continues to nurture existing relationships with key policy makers while also fostering connections to new partners. The Committee has also employed a three-pronged strategy to grow the Association's impact on issues important to our community:

1) To monitor ongoing and emergent issues and join advocacy campaigns that impact the FTD community led by peer organizations such as the American Brain Coalition, NORD and Genetic Alliance.

2) To train and prepare the volunteer regional coordinators to be on-the-ground leaders to develop AFTD's regional network as a volunteer base for advocacy. Initial training takes place in October, with follow up meetings throughout the year.

3) To maintain key relationships with government and industry decision makers and be ready to respond to changes in political leadership.

At the 7th International Conference on FTD in Indianapolis, AFTD hosted a meeting of peer organizations from ten other countries. Together, the groups agreed to form an international affiliation and to share resources by linking their websites as well as written materials.



Sue Gustafson is an elementary school principal and caregiver to her husband, Dave. She has also worked energetically throughout 2010 as AFTD's volunteer Regional Coordinator in Canada. She and the other coordinators across the US are connecting families and professionals in their region with resources and with AFTD.

gratitude

WE ARE DEEPLY GRATEFUL TO ALL OF THE
GENEROUS DONORS WHO PARTNER
WITH US EACH YEAR TO CHANGE THE
FUTURE FOR FTD FAMILIES AND THE
PROFESSIONALS WHO CARE FOR THEM

HOW YOUR CONTRIBUTION HELPS:

Your contributions allow AFTD to make important advances in all areas of our mission. In 2010 \$0.85 of each dollar donated went directly to research, education, support and advocacy. Your donations make progress possible!

Gifts of \$100,000+

Anonymous

Gifts of \$40,000+

Lee Danis

Susan Laden

Scout for Scooter

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"THANK YOU, SO MUCH, for reminding me of the amazing depth of the human spirit. I may be losing my mom, in a devastating and awful way, but I am gaining and growing so much from this experience, being touched by people like you. Thank you! Those two words seem woefully inadequate." - grateful caregiver

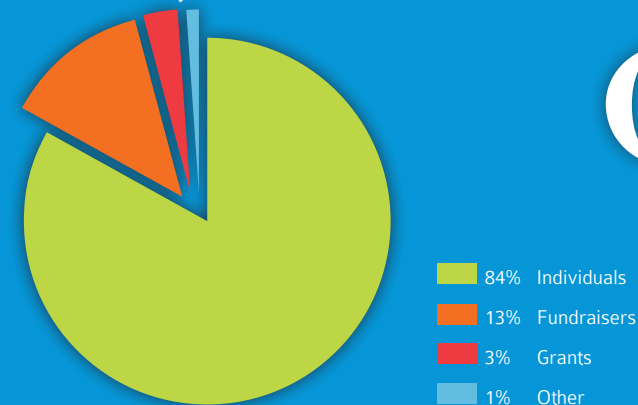
"YOUR GENEROUS SUPPORT of FTD patients, families, and all those affected is greatly appreciated. It is hard to find comfort in such a rare and disheartening disease. You, however, provide hope that we may soon be the final generation to suffer lasting effects of FTD!" - grateful caregiver

➤					
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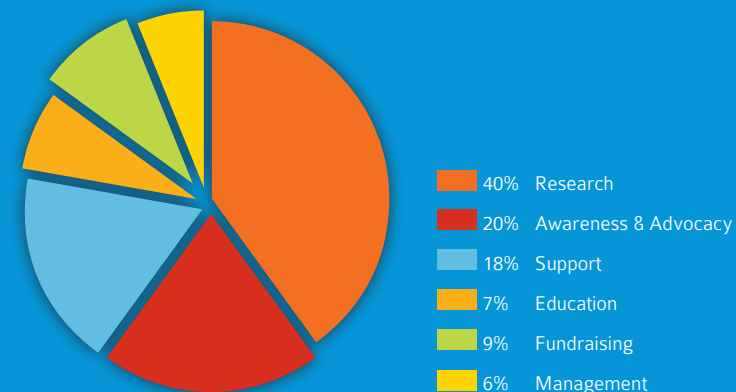
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2010 Income By Source | \$1,162,948



2010 Expenses | \$843,423



outlook

Statement of Financial Activities as of 12.31.2010

ASSETS

Cash	\$1,101,773
Equipment	\$3,039
Security Deposit	\$2072
Total Assets	\$1,106,884

LIABILITIES

Accounts Payable	\$3,523
Research Grants Payable	\$51,355
Total Current Liabilities	\$54,878

NET ASSETS

Unrestricted	\$889,122
Temporarily Restricted	\$162,884
Total Net Assets	\$1,052,006

TOTAL LIABILITIES AND NET ASSETS	\$1,106,884
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DEAR FRIENDS - As 2011 progresses we recognize the increasing power of this organization to effect change. This power derives from you: the patients, families and professionals who share a commitment to AFTD's mission, and we are extremely encouraged by the increasing number of you working with us to ensure that our message is heard!

In less than two months we have sold out of an initial order of 500 copies of *It Is What It Is*, and are heartened to hear how many caregivers are showing the film to their physicians, family and friends. More copies are on their way, and will remain available through the website.

In March Dr. Mario Mendez presented a lecture on FTD for physicians that attracted more than 300 participants via the Internet—the previous record for attendance on that medical school website was 15! And this spring more families than ever are hosting awareness and fundraising events, each ensuring that one more community has heard of these diseases and the devastating affect they have on an individual and all who care about him or her.

In 2010 the number of contributions to AFTD increased by 28%, and total donations topped \$1 million for the first time. This support fuels AFTD's growing impact. We are hiring our first Development Manager and Scientific Director, creating new programs to support

families with children and to educate nursing facility staff in FTD, and awarding a second postdoctoral fellowship to encourage emerging researchers. Earlier this year AFTD awarded more money than ever before through the FTD Drug Discovery program, and became a founding member of a consortium of physicians and researchers driven to stimulate drug companies' interest in FTD clinical trials.

We are gaining momentum, and we are making a difference. Each person who gets involved strengthens our communal voice and accelerates our ability to make change a reality. We urge you to join us.

Educate. Donate. Advocate.



With Best Wishes for 2011,

Susan L-J Dickinson, MS
Executive Director

We envision a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.

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Radnor Station Building 2 | Suite 320 | 290 King of Prussia Rd.
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