



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

# 20112012

JANUARY 1, 2011 – JUNE 30, 2012 ANNUAL REPORT



# MISSION



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

- ★ 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.

“Dear Friends— In last year’s report, I wrote that we were a community ‘finding our voice.’ It is with great pride and enthusiasm that I write to you now as we are indeed using that voice.”

Spreading the word about FTD is at the core of our work at The Association for Frontotemporal Degeneration. Without awareness, we have no education. Without education, we have no push for research. Without research, we have no catalyst for drug development. Without drug development, we have no potential for a cure. Our community has recognized this, and we have committed ourselves to drive the change necessary to achieve our goals.

Our caregiver outreach voice has been heard. Families like the Bryants and Frenches have stepped forward to speak with newspapers like the *Los Angeles Times* and *The New York Times* about FTD and how it has affected their families. Many of the distinguished members of AFTD’s Medical Advisory Council contributed to these articles, giving weight to the importance of FTD awareness.

Our awareness and fundraising voice has been heard. Twenty-two individuals participated in AFTD’s

“With Love” campaign in February, our first-ever online fundraiser. Together, they raised almost \$30,000 by sharing their personal journeys with FTD and asking friends and family to support their efforts to bring FTD out of the shadows.

Our research voice has been heard. In June 2012, FTD researchers and clinicians met with government regulators, pharmaceutical and biotech companies as a collective group to discuss how to design clinical trials of new therapies for FTD treatment. This group, the FTD Treatment Study Group, seeks to understand how to best work with the FDA to get trials approved in an efficient and timely manner. The effort is focused and the promise is great, but it took our voice to accomplish.

The list goes on, and for that, we are grateful. However, there is still much work to do. We may be small in numbers, but we are mighty...and we are committed to Fighting This Disease.



With Warm Regards,

Beth Walter  
Board Chair

**ON THE COVER:** Bill’s Best BBQ Sauce makers, the Fehon family, donate 10 percent of their sales to AFTD as Bill is affected with FTD.

# RESEARCH



Promote and fund research into finding the cause, therapies and cures for frontotemporal degeneration.

“The FTD Treatment Study Group (FTSG) is bringing together academic researchers, pharmaceutical industry scientists, the NIH and FDA to accelerate FTD drug development. In developing treatments for neurodegenerative diseases, it seems possible that some genetic forms of FTD will be the first curable causes of dementia.” –Dr. Adam Boxer

With the addition of Scientific Director Sharon Hesterlee, PhD to the AFTD staff, the research portion of the organization’s mission has expanded direction and energy. When she joined AFTD in October 2011, Sharon was tasked with moving promising findings from the academic world into clinical development.

AFTD wasted no time in creating a conduit between academia and clinical work. The Frontotemporal Degeneration Treatment Study Group (known as FTSG) came under AFTD’s wing in the fall of 2011, and on June 4, 2012, AFTD and the National Institute of Neurological Disorders and Stroke co-hosted a meeting of 70 FDA regulators, academics and pharmaceutical and biotech company representatives. The response to the meeting was overwhelmingly positive and generated a genuine enthusiasm for collaborative work in drug development and clinical trials.

To ensure that FTD research continues into the future, AFTD funded several new projects. Three researchers

received grants totaling \$300,000 through AFTD’s partnership with the Alzheimer’s Drug Discovery Foundation. AFTD also awarded a two-year \$110,000 postdoctoral fellowship to Dr. Alexandra Nicholson and a pilot grant to Dr. Fenghua Hu for \$60,000.

In October 2011, five members of AFTD’s Medical Advisory Council made medical history for their part in the discovery of a gene mutation on chromosome 9, known as *C9orf72*, which causes FTD and amyotrophic lateral sclerosis (ALS). This find should propel efforts to develop biomarkers and identify targets for therapeutic intervention in both FTD and ALS.

Finally, in partnership with the National Institutes of Health, AFTD helped develop and launch a national FTD-specific testing module and has joined a research consortium to develop induced pluripotent stem cells that can model diseased brain cells in the laboratory.



Adam Boxer, MD, PhD, associate professor of neurology at University of California San Francisco, is chair of the FTSG Steering Committee. Much of his research focuses on designing clinical trials for FTD.

# SUPPORT



Provide information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers.

“When I started this lonely journey more than 10 years ago, there was little support for FTD families like mine. There are very few people who understand this devastating disease, and AFTD’s support groups, HelpLine and other services remind us we are not alone in dealing with this, and have been invaluable for me.”

—Gail Andersen

Providing support to families and loved ones affected by FTD is an ever-present priority for AFTD. Whether the support was financial, educational or emotional, AFTD stepped up to help. For example, the Comstock Caregiver Respite Program, named after AFTD founder Helen-Ann Comstock, grants \$500 to deserving care givers so that they can take some time to renew their energy. Between January 1, 2011 and June 30, 2012, AFTD awarded more than \$57,000 through this program. In addition, 32 people received travel grants totaling almost \$12,000 to attend six FTD conferences around the country, all of which AFTD attended and supported financially.

AFTD’s HelpLine—phone and email support for those with questions about FTD—responded to 2,010 inquiries from people diagnosed with FTD, caregivers and healthcare professionals. AFTD’s program staff handled each call and email with professional courtesy and a broad knowledge of FTD.

The number of FTD support groups around the country and Canada has grown to 70, with 21 new groups offering a place for people to connect with others who walk a similar path with FTD. As a growing number of people with FTD are reaching out to the organization, AFTD has made efforts to understand and respond to their needs. AFTD held a first-ever session for patients at its annual caregiver conference in 2012. Nine people shared their experiences and a desire for information on living well with FTD and more avenues of support.

In the spring of 2012, the AFTD Task Force on Families with Children wrote and published a booklet entitled *What About the Kids?*, a practical guide for parents to help their children when a parent has FTD. Already in its second round of printing, *What About the Kids?* has proved a useful resource for young families in the FTD community.



Gail Andersen is a member of the AFTD Parents’ Phone Support Group and the AFTD Task Force on Families with Children.



# EDUCATION



Educate health care professionals about frontotemporal degeneration and how to improve patient care.

“Healthcare professionals need to learn how to serve people with FTD and their families. AFTD is in a unique position to help, and the new **Partners in FTD Care** initiative is already making a difference.”  
—Jill Shapira, PhD, RN, Nurse Practitioner

The *American Journal of Alzheimer's Disease & Other Dementias* published an article in 2011 co-authored by AFTD Executive Director Susan Dickinson and Program Director Sharon Denny on the topic of caregivers and researchers partnering for brain donation. Dr. Mary Guerriero Austrom at Indiana University School of Medicine led the study of 30 caregivers to determine factors that might limit or deter people from participating in brain donation.

AFTD sponsored an online continuing medical education (CME) course in March 2011, featuring AFTD Medical Advisory Council member Dr. Mario Mendez. Additionally, the organization sponsored a CME course on FTD, hosted by Columbia University in December 2011. The half-day course, attended by 85 medical professionals, focused on the difficulty of making a correct diagnosis. Susan Dickinson led the caregiver portion of the course.

The largest on-going educational initiative that AFTD unveiled was **Partners in FTD Care**. In partnership with AFTD's Long-Term Care Education committee, the organization created a three-pronged system that brings together health professionals, experts and families to promote understanding of FTD and to develop best practices in community care.

The three elements of **Partners in FTD Care** include an education packet for long-term care staff, a quarterly e-newsletter featuring a case study and discussion questions and an online forum for health professionals. The packet and e-newsletter were introduced in the fall of 2011, and healthcare professionals may now register for the online forum, which was introduced in the summer of 2012. To date, more than 300 packets have been sent to professionals in care settings, support group leaders and families striving to educate the facility staff taking care of their loved ones.



Jill Shapira, PhD, RN, nurse practitioner at UCLA, actively participates in AFTD's Committee on Long-Term Care Education and was instrumental in the creation of the **Partners in FTD Care** initiative.

# AWARENESS



Bring about greater public awareness of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it.

“What a long way we have come since those early days only ten years ago. I’ve sent your message on to Maine, Pennsylvania, and South Carolina. It will help to spread the word beyond the few to the many, and your contact is invaluable.” —Tess Parrish, former AFTD Board Member

Last summer, AFTD began the process of ramping up awareness of FTD. It started with the creation of a 12-page fundraising guide that features ideas, planning suggestions, sample communications, tips on handling expenses and donation information. In addition, the guide prominently displays the new name and logo for the group of “special forces” from California to Connecticut to Canada who run marathons, bike across the country and create online fundraisers to benefit AFTD. These individuals are now part of a community called “The AFTD-Team.”

To further the spirit of community among the AFTD-Team members, the organization designed t-shirts with the new logo and definitive tag line “Yeah...I’m here to Fight This Disease.” Any person who raises \$250 or more receives one of these shirts and joins the growing number of people who are giving voice to a disease that often silences their loved ones.

In an effort to make fundraising even easier, AFTD implemented an online fundraising platform called Givezooks!, enabling individuals to easily set up their own fundraising page from which they can tell their story about FTD and ask for support from family and friends electronically. In seven months’ time, 35 people have raised more than \$63,000 through this online tool.

With input from our community via Facebook, AFTD designed and offered the first-ever FTD awareness bracelet. The red-and-white silicone bracelet serves as a conversation starter for whomever wears one and creates the opportunity to educate another person about this little-known disease called FTD. The AFTD-Team has hit the ground running, and our plan definitely has come together.



Jessecca Hager, Robin Mellor, Arianne Hager and Michael Hager at AFTD’s Staff & Friends Walk on May 20, 2012 in King of Prussia, PA. Robin, who is affected with FTD, her three children (pictured) and several other family members spent the day with AFTD staff to raise awareness of FTD.

# 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.

“Patients, caregivers and families need to know that they are not alone. I urge everyone suffering from dementia to ask for access to the medical knowledge, resources and support that will enable them to confront FTD with dignity and compassion.” –Bonnie Shepherd, AFTD Board Member

In October 2011, the Social Security Administration added two more forms of FTD to the list of conditions for Compassionate Allowances. Applications for disability benefits from people diagnosed with either corticobasal syndrome or progressive supranuclear palsy will now be “fast-tracked” for expedited processing. These two diagnoses join behavioral variant FTD and primary progressive aphasia, resulting in all forms of FTD being included on the list of medical conditions receiving Compassionate Allowances.

At the beginning of 2012, AFTD Board Members Earl Comstock and Pop Shenian along with AFTD Program Coordinator Matt Sharp visited the Washington, DC offices of Pennsylvania Senators Bob Casey and Pat Toomey to make them aware of the work AFTD is doing on behalf of patients and families across the country. AFTD added its voice to several successful advocacy efforts last year, including a campaign to maintain current levels of funding for the National Institutes of Health in the

House and Senate appropriations bills for the 2013 national budget. AFTD also supported several bills in the house and senate related to the reauthorization of the Prescription Drug User Fee Act (PDUFA).

In May 2012, the Department of Health and Human Services published the National Plan to Address Alzheimer’s Disease (NAPA), which establishes specific strategies and actions to realize the ultimate goal of prevention and treatment of Alzheimer’s disease and related dementias, such as FTD, by the year 2025. AFTD submitted comments on an early draft of the National Plan, explaining the different challenges posed by FTD relative to Alzheimer’s and requesting changes to address those differences. AFTD is encouraged by the inclusion of FTD and other dementias in this plan and sees it as a critical step forward in recognizing the different needs of people facing a less common form of dementia.



Jenny Hinsman is AFTD’s regional network coordinator for the Middle Atlantic region of the United States.



# 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 the last 18 months, \$.81 of each dollar donated went directly to research, education, support and advocacy. Your donations make progress possible!*

### Gifts of \$100,000+

Anonymous

### Gifts of \$50,000–\$99,999

Anonymous

Susan M. Hill

Walter Charitable Fund, Inc.

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Scout for Scooter

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“ Know this...you are an incredible blessing to the FTD community. When I count my blessings, AFTD is at the top of the list along with God, my family and my local support team. Your work is vitally important. ”

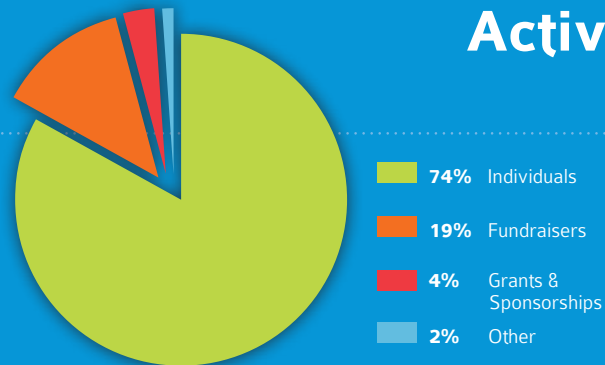
— Paul Lester, caregiver

“ There are definitely more marathons in our future, so hopefully we can start up another fundraiser. It’s been an honor to raise money for AFTD. ”

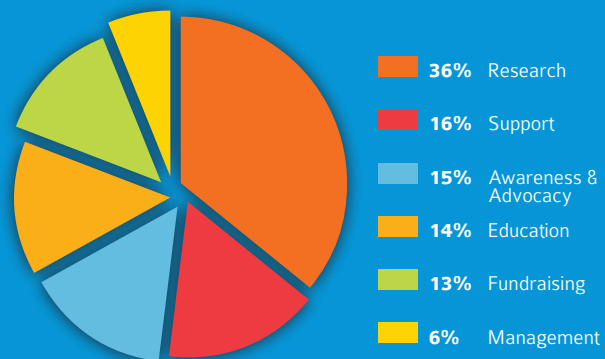
— Alice Saunders, marathon runner & AFTD fundraiser, May 2012

→					
<b>Gifts of \$2,500 - \$4,999</b>	<b>Gifts of \$1,000 - \$2,499</b>				
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18-Month Income By Source | \$1,495,030



18-Month Expenses | \$1,441,674



## Statement of Financial Activities as of 6.30.2012

### ASSETS

Cash	\$1,177,780
Equipment	\$8,526
Security Deposit	\$4,155
<b>Total Assets</b>	<b>\$1,190,461</b>

### LIABILITIES

Accounts Payable	\$22,089
Research Grants Payable	\$60,000
<b>Total Current Liabilities</b>	<b>\$82,089</b>

### NET ASSETS

Unrestricted	\$951,633
Temporarily Restricted	\$156,739
<b>Total Net Assets</b>	<b>\$1,108,372</b>

**TOTAL LIABILITIES & NET ASSETS \$1,190,461**

“Everyone who tells someone else about FTD takes our whole community forward one step. Awareness is key to everything AFTD does...and our community plays a large part in bringing this disease to the main stage. Do not discount your voice...it can make a real difference in finding care and a cure.”

The driving force behind everything that AFTD does can be summed up in two words: CARE and CURE. The care side of what we do focuses on the immediate needs of our families—getting and sharing information about FTD, working with support groups to connect caregivers with one another and offering a HelpLine to answer questions are just a few examples of ways that we strive to achieve the “care” part of our mission.

The cure side is future-focused: we are working today to fund, promote and encourage tomorrow’s research into the causes, treatments and potential cure for FTD. Scientific research, clinical trials and drug development all take time and money, and we recognize that we must strike a balance between providing today’s care and ensuring tomorrow’s cure.

The unifying theme underlying both care and the cure is awareness. Everything that we work toward, be it providing caregiver respite grants or funding a

pilot research grant, hinges on people knowing what FTD is. Most of the people reading this report never heard of FTD until a friend or loved one received a diagnosis, which probably left more questions. That is a scenario that must change if we want to succeed in achieving our mission.

Doctors must be educated about FTD for more accurate diagnoses. Long-term facility staff must learn how quality care for FTD patients is different than that for Alzheimer’s patients. Researchers must know that the study of FTD is shedding valuable light on other neurodegenerative diseases. And extended families, neighbors and friends must understand that the disease is now doing the talking for our loved ones, and that a little compassion goes a long way for a family living with FTD.

We can all play a part in FTD awareness...and we invite you to join us by doing what you can, with what you have, where you are.



Best Wishes,

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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