



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

Volume XI, Issue 3

Fall 2014

NIH Awards \$30 Million for FTD Research

Researchers studying FTD will receive more than \$30 million over the next five years in grants from the National Institutes of Health (NIH). The funding will be used to further scientific collaboration and investigate new treatments in the quest to find a cure for FTD.

FTD received a total of four major grants, each independently peer reviewed, that will allow for building reliable clinical networks to better understand, diagnose and treat FTD and related variants; recruiting FTD-causing gene mutation carriers for study; and study of a specific genetic mutation that is the most common cause of both inherited FTD and inherited ALS.

“The FTD community is extremely gratified to be the recipient of this unprecedented level of funding that we believe is the result of the tremendous

momentum underway in FTD science,” said Jary Larsen, Board Chair of AFTD. “What started with FTD’s recent inclusion in national research priorities to cure Alzheimer’s disease and other dementias by 2025, has now catapulted into what promises to be significant progress in learning about this debilitating neurodegenerative disease.”

Three of the grants, totaling \$5.9 million per year, are being funded by the NIH’s National Institute of Neurological Disorders and Stroke (NINDS), National Institute on Aging (NIA) and the National Center for Advancing Translational Sciences (NCATS). The three projects will enable scientists to collaborate on research approaches for FTD, with the goal of treating patients more effectively. NIH has created a joint oversight committee to ensure coordinated and efficient development

of all three of these projects; AFTD has a seat on this advisory committee.

A fourth grant is part of \$29 million in research earmarked for the Rare Diseases Clinical Research Network, a network of 22 consortia dedicated to furthering translational research and investigating new treatments for patients with rare diseases. The major focus of this grant is to study ALS, including the disease variant of ALS with FTD.

“This unprecedented funding for FTD research addresses key recommendations from NIH’s planning efforts around Alzheimer’s Disease-Related Dementias,” said NINDS Program Officer Margaret Sutherland, Ph.D. “Research will contribute to our knowledge of FTD’s natural history, while accelerating biomarker and genetic discoveries for these devastating neurological disorders.”

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2nd Annual Food for Thought Campaign

After a tremendously successful week of fundraising and awareness building, AFTD’s 2nd annual *Food for Thought* campaign has come to a close. This year’s campaign, which was held during FTD Awareness Week, October 5-12, included every type of event imaginable, from bake sales and lemonade stands to champagne receptions and internet-based fundraisers.

Though they all had their own personal touch, each event was conceived with the same intention - to bring FTD awareness to friends and family in the local community. Together they spread the word about FTD in small towns and big cities throughout the country. This year’s campaign shattered records with 81 events in 36 states, Washington, D.C. and two Canadian provinces.



Tori Tinsley, in Georgia, hosted two bake sales and sold prints of her artwork, inspired by her family’s journey with FTD.

(Continued on page 8)

Spotlight On... Gail Andersen, AFTD Board of Directors

“Our story started in 1999, six months after our triplets were born,” explained Gail Andersen, who joined the AFTD Board of Directors in March 2014. “My husband (Larry) was having difficulty at work, and, in August 1999, he was diagnosed with early-onset Alzheimer’s.” At the time, Larry Cline was only 43 years old.

The couple went to an Alzheimer’s clinic near their home in Mason, Ohio, for further information. There, they were told that Larry had been misdiagnosed, and that he suffered from depression, not Alzheimer’s. Over the years, however, Larry’s behavior continued to change. In addition to raising five children – Brandon, now 28, Justin, now 21, and Spencer, Serina and Jason, now 16 – Gail and Larry also had demanding careers. They both held full-time engineering positions near their home in Mason, OH.

“In 2004, Larry started to have trouble at work,” said Gail. A neurologist confirmed

a change in Larry’s IQ, but could not give a reason for the career-ending change. Then, in 2005, Larry’s brother was diagnosed with ALS, at the University of California, San Francisco (UCSF). After participating in a UCSF research study in 2006, Larry received a definitive diagnosis: Behavioral Variant FTD (bvFTD).

Needing support for herself and her children, Gail joined the first AFTD telephone support group



Gail Andersen

for caregivers who were also parenting young children.

Larry entered a long-term care facility in 2009. As she worked with the staff to ensure that Larry received appropriate care, Gail was struck by the lack of knowledge—even among professionals—about FTD. And she turned into a passionate advocate. “You have got to collect and understand all of the medical

information, to serve as a communicator between the physicians and the facility,” she added. Larry passed away in 2012.

Gail’s advocacy led to an invitation to join AFTD’s Task Force on Families with Children, a group that develops new resources for families, including the new website, www.aftdkidsandteens.org. The site provides a forum where kids and teens can ask questions, find answers, and share experiences.

Recently retired from a 30-year career at Procter & Gamble, Gail, 53, is using her talents for innovation, leadership, and organization to benefit AFTD. She currently leads the AFTD Task Force for Strategic Planning.



The Andersen Family

“AFTD has done so much to drive awareness and advocacy, and I believe that is a large part of why NIH is funding FTD,” said Gail. “My vision is that FTD becomes a household term; that there is a drive to fund research and to develop a cure. No other families should have to go through what we have.”

AFTD NEWS BRIEFS

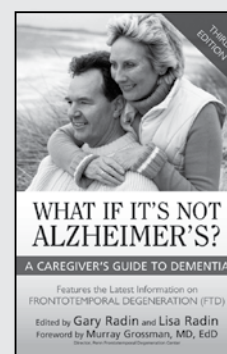
AFTD seeks a graduate intern to manage an exciting pilot project in the use of music in FTD. The project will provide iPods to persons with FTD, develop personalized playlists and evaluate the impact on quality of life. See the posting to learn more. www.theaftd.org/about/our-staff

Participate in Research! There are a number of clinical trials recruiting FTD patients—go to the AFTD website or www.clinicaltrials.gov to stay informed of the opportunities that exist. YOU are a key partner in the quest for effective diagnosis and treatments. www.theaftd.org

theaftd.org/life-with-ftd/participate-in-research/clinical-trials-laypersons

AFTD’s latest annual report is available for download on our website. Take a moment to appreciate the progress we are making together! www.theaftd.org/about/annual-reports

AFTD T-Shirts are a terrific way to spread awareness! Shirts are available in adult and youth sizes for only \$10. They can be purchased online at www.theaftd.org/get-involved/aftd-t-shirts or over the phone at (267)514-7221 ext 2527. Help spread awareness and buy today!



The 3rd Edition of *What If It's Not Alzheimer's* is now available, with expanded information on the disease as well as how to manage symptoms and cope with daily life. Order online or find it in some bookstores. List price \$19.00

Keep the Momentum Going For Care and a Cure Become a Monthly Donor



Ryan Windhorst with his wife Stephanie and their two sons, Jackson and Maddox

"My mother was diagnosed with FTD in 2007, and as a result my family has been donating monthly to AFTD for several years. It's a win-win situation: Easy for us and a source of predictable income for AFTD." – Ryan Windhorst

Go to www.theaftd.org,
click on the **Donate Now** button
at the top of the page.
In the field marked "Recurring Donation,"
select **YES!**

Your monthly donation will help establish a sustained source of income for AFTD. Recurring donations allow AFTD to stimulate research and fund services for those affected by FTD. It's the easiest way to give and to ensure that AFTD moves toward a world where FTD is understood, effectively diagnosed, treated, cured, and ultimately prevented.

**Your monthly donation will mean so much to someone fighting this disease!
Become a Sustainer of Hope Today**

Join Us in San Diego Next April!

Come to San Diego on April 24, 2015 for the next AFTD Education Conference. The day will offer a full schedule of informative and engaging sessions tailored specifically for people interested in FTD disorders.

We are honored to be joined this year by many experts in FTD science and clinical care. Douglas Galasko, M.D., and Irene Litvan, M.D., both of the University of California, San Diego, will present trends and the latest developments in FTD research. Jill Shapira, RN, PhD, will lead an interactive session on thinking strategically about FTD symptom management, and Maribeth Gallagher, DNP, Hospice of the Valley, will share expertise on individualized music in dementia care.

Because the lived experience of FTD brings the most salient expertise, the program will also feature two persons diagnosed

with FTD to speak about what it means to live well with the disease, and Dan Browning, former caregiver for his wife and healthcare and medical research reporter for the

Minneapolis Star Tribune, who will deliver the keynote address. Breakout sessions will offer interactive discussions on managing from diagnosis to daily life for those interested in: movement disorders; language disorders; behavior changes; comfort care and end of life considerations; and living with a diagnosis of FTD.



The conference will be held at the DoubleTree Mission Valley, San Diego. Watch AFTD's

website for complete details and registration, and hotel information. Conference registration will open in January.

Funding for FTD Researchers

(Continued from page 1)

Following are brief summaries of each of the four grants:

1. Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL)

- A five-year grant to build a reliable clinical network, linking 14 U.S. and Canadian FTD clinical centers, 11 of which are led by AFTD Medical Advisory Council (MAC) members. As the network expands, it will boast the world's largest single cohort of FTD spectrum patients.

- Research will study and explore potential new treatments for behavioral variant FTD (bvFTD), primary progressive aphasia (PPA), corticobasal syndrome (CBS) and progressive supranuclear palsy (PSP).

- Adam Boxer, M.D., Ph.D., and Howard Rosen, M.D., both at the University of California, San Francisco (UCSF), will lead this consortium.

2. Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS)

- A five-year, multi-site grant that will recruit presymptomatic and symptomatic mutation carriers with one of the three most common FTD-causing genes: *C9ORF72*, *GRN* and *MAPT*.

- Results will provide key information in the quest for biomarkers to improve early diagnosis and to track disease progression. This information is necessary to measure therapeutic efficacy in any candidate drug.

- Importantly, all of the LEFFTDS sites are also in the ARTFL network. LEFFTDS will be led by two members of AFTD's Medical Advisory Council: Brad Boeve, M.D., of Mayo Clinic, Rochester, MN, and Howard Rosen, M.D., of UCSF.

3. Program Project Grant for C9ORF72 mutation

- A multi-year basic science award that will enable research on the C9ORF72 mutation found in patients with ALS, FTD and FTD/ALS.

- Under the leadership of Leonard Petrucelli, Ph.D., the project will

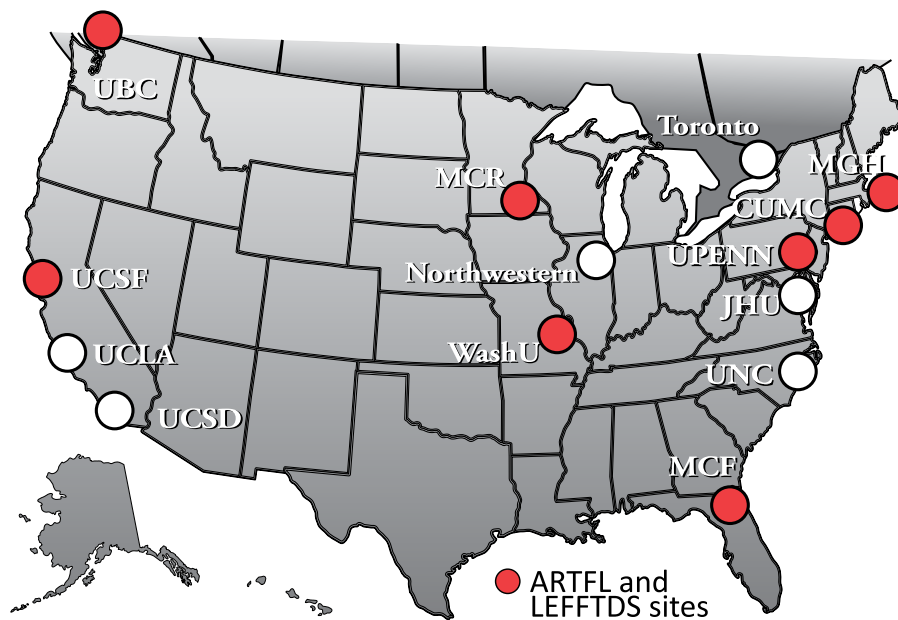


From left to right: Drs. Michael Benatar, University of Miami and Richard Bedlack, Duke University of CREATE; and Drs. Howard Rosen and Adam Boxer, University of California San Francisco of ARTFL.

rare diseases.

- The major focus is ALS and motor neuron disease, which encompasses the 20% or more of ALS patients who also develop FTD. It will study many of the same issues in ALS and related disorders as the ARTFL.

FTD Clinical Research Network Sites



bring together investigators with various areas of expertise at the Mayo Clinic, Jacksonville, FL, to study this mutation, which is the most common genetic cause of ALS and a major genetic cause of FTD.

4. The Clinical Research in ALS and related disorders for Therapeutic Development (CREATE) Consortium

- A five-year grant similar to ARTFL (described in #1 above) that creates a network of clinics focused on a set of

- AFTD is one of the patient advocacy groups with a seat on the Advisory Committee.

The four awards are the culmination of the tireless advocacy efforts on the part of FTD clinicians, researchers, patients and family members. They come on the heels of NIH's recent decision to include FTD in national research priorities to cure Alzheimer's disease and other dementias by 2025.

"This is a very exciting era in neurodegenerative disease research, and FTD research is helping to lead the way to insights that will inform all of these diseases, including Alzheimer's, Parkinson's and ALS," said Creighton Phelps, Ph.D., Deputy Director of the Division of Neuroscience, NIA and the Director for the Alzheimer's Disease Centers Program. "After 30 years in the field, I am more hopeful now than I have ever been that the first therapeutics for these diseases are within sight."

International Conference Brings Together Hundreds of Researchers, Clinicians and Caregivers

On October 23-25, more than 550 researchers from 30 countries on 5 continents convened in Vancouver, British Columbia for the 9th International Conference on Frontotemporal Dementias (ICFTD). Three days of scientific sessions ranging from clinical syndromes and genetics to neuropathology and drug trials were punctuated by ample opportunity for the scientists to discuss recent findings and form new collaborations.

“[FTD] is an incredibly exciting and compelling area to be working in,” noted Ian Mackenzie, M.D., in his remarks opening the conference. “Our patients and their families are counting on us to drive our science forward to create the first therapeutics for this disease,” noted Howard Feldman, M.D. Both physicians hold appointments at the University of British Columbia and served as co-chairs for the meeting.

Fifty-two oral presentations and 319 scientific posters provided the means for researchers to share results and talk through new hypotheses. Five of the talks focused on the treatment of FTD, and included results

from recent clinical trials or outlined specific strategies that may enter clinical testing soon. AFTD graduate intern Brianna Sullivan presented a poster that analyzed calls to AFTD’s HelpLine over a 12-month period.



Dr. Brad Boeve and Genetic Counselor Emily Dwosh answered questions during the Vancouver Caregiver Program.

In addition to scientific presentations, the meeting featured a one-day caregiver conference, which offered general information on FTD as well as presentations on diagnosis and treatment, disease management and support. More

than 200 caregivers and persons themselves diagnosed with FTD convened for this program, which included ample time for participants to ask questions of the internationally-recognized speakers. Slides from these talks can be downloaded from the event archive on AFTD’s website.

AFTD also participated in a meeting of peer advocacy organizations from around the world, in which the groups discussed their most pressing challenges and how collaborations across international boundaries can advance this work. During the meeting advocates from 10 different countries agreed to host an international FTD Awareness Week in October, 2015.

“Over the past two years the international FTD research community has made remarkable advances in our understanding of the basis and nature of this devastating disease,” said Mackenzie. “For the first time, I think we have a legitimate reason to be optimistic that effective therapies will soon be available.”

The 10th ICFTD will be in Munich August 31 – September 2, 2016.

Pilot Grants Awarded for Basic and Clinical Science

This year, AFTD was proud to award two Pilot Grants: one Basic Science grant, as well as the newly established Susan Marcus Memorial Pilot Grant for Clinical Research. AFTD’s Board of Directors awarded the grant recipients \$60,000 each for a single-year project.

Dr. Thomas Kukar received the 2014 Basic Science Pilot Grant. Dr. Kukar holds his Ph.D. in medicinal chemistry, and is an assistant professor in the Department of Pharmacology at the Emory University School of Medicine. The recipient of the 2014 Susan Marcus Memorial Pilot Grant in Clinical Research is Dr. Jennifer Yokoyama, who holds her Ph.D. in pharmaceutical sciences and pharmacogenomics, and is an assistant adjunct professor in the Department of Neurology at the University of California, San Francisco.

“We are grateful to the Marcus family for choosing to memorialize Susan (Marcus) with this significant contribution to FTD research,” said AFTD Scientific

Director Nadine Tatton, Ph.D. AFTD received 29 applications for the 2014 Pilot Grants, including 11 from outside the United States. The Pilot Grants program is designed in part to help younger independent investigators test novel theories. Dr. Tatton led the Medical Advisory Council (MAC) review team through three levels of application review.

Dr. Kukar’s research, “*Identification of the signaling receptor that mediates the neurotrophic activity of Progranulin (PGRN)*,” will seek to provide insight into how PGRN, a multi-functional, secreted growth factor, protects neurons from neurodegeneration. Mutations in the progranulin gene (GRN) are one of the most common genetic causes of FTD. Dr. Kukar’s investigation promises to provide critical insight into how PGRN protects neurons from neurodegeneration and to discover new targets for the development of drugs for FTD.

Dr. Yokoyama’s work, “*RNA signatures of frontotemporal dementia and ALS due*

to C9ORF72 expansion,” will focus on neurodegenerative diseases caused by repeat expansion of C9ORF72. This genetic mutation was recently identified as the most common cause of both familial FTD and familial amyotrophic lateral sclerosis (ALS). With this pilot project, Dr. Yokoyama hopes to provide the foundation for larger grant applications. Further grants are needed for research to predict which clinical syndrome will develop; for tracking disease progression; and for screening for disease-modifying compounds.

“There is not enough funding for young investigators with new, untested ideas,” said Tatton. “These pilot grants fill an important niche in the research pipeline that is tackling the many aspects of FTD that we do not yet understand.

“We continue to receive outstanding applications for this program, and we thank our families and donors—like the Marcus family – who enable us to provide this important seed money for FTD research.”

Donations Honor Loved Ones *Gifts received from June 16 – October 15, 2014*

In Memory Of

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AFTD *is grateful for these gifts, which fund research, education and support.*

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	Gary Lee Garner	Daniel P. Penque	Dennis Wollenberg
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	Howard Glick	Bette Phillips	

In lieu of flowers...

Families who wish to direct memorial donations to AFTD are encouraged to call our office. AFTD can mail you donation materials, or you can download them from the AFTD website. All donors will receive letters of acknowledgment, and families will receive a list of donors. To contribute electronically via our website, go to www.theaftd.org.

2nd Annual Food for Thought Campaign

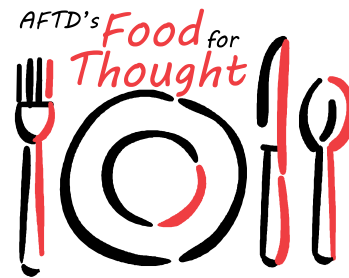
(Continued from page 1)

Food for Thought featured a team of volunteer liaisons, including Amy Eissler; Cheryl Johnson; Erin Hopper; Jennifer Pillion-Walker; Margie Simon; Zoy Kocian; Meghan Roscoe; and Michelle Grant, each trained to support the event hosts throughout their event-planning process. AFTD is sincerely thankful for the months that the liaisons spent ensuring that *Food for Thought* would be a success.

The 2nd annual *Food for Thought* campaign saw several return hosts as well as dozens of newcomers. Among the repeat hosts were the gang at

Porter Road Butcher in Nashville, TN, who once again donated 10% of a day's sales to AFTD, and Heather Miller in Oklahoma, who baked cookies for her second "Baking Memories" fundraiser. Many first-time hosts brought new and creative ideas to the campaign, including Sandy Karger, who hosted "Sweet Treat" with desserts and champagne at her home in Pennsylvania, and Kerri Unger, who hosted a spaghetti dinner at her church in Nebraska.

As of the time of printing this newsletter, funds raised through events and corporate sponsorships total over \$160,000!



"The real success of *Food For Thought* is that it is bringing our community together," said AFTD Executive Director Susan Dickinson. "The knowledge that people in 81 different communities came together at the same time to learn about this disease and to support our efforts toward care and a cure is very moving. Our families may be scattered across the country, but when we band together we are a formidable force that *will* change the future."



Kennedy Ho, one of AFTD's Food for Thought Youth Ambassadors, baked dozens of treats to bring to her dance studio in Oregon.



Wendy Miller-Anello hosted a wine and chocolate event in Massachusetts.



AFTD Board member Steve Bellwoor (far right) hosted a Clicquot Veuve reception in Pennsylvania.

Sally Sloop hosted an event in North Carolina in memory of her friend, Arnette Lester.



Angela Kimble and her daughters hosted a lemonade stand in Texas.



Brandee Waite and the members of "Team Bev" participated in a 5k in California.



Porter Road Butcher, in Nashville, TN, donated 10% of their profits one day during Food for Thought.

MARK YOUR CALENDAR FOR OCTOBER 4-11, 2015 WHEN FTD AWARENESS WEEK GOES INTERNATIONAL!

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Giving a Hand to Our Helping Hands!

By Kathy Urban, AFTD Volunteer

Information technology employs the quiet masterminds of business. These highly skilled professionals are invaluable, bringing numerous highly specialized skills and knowledge to many organizations.

David Driggers began volunteering with AFTD in July 2014, where he has successfully combined his passion and expertise. Capitalizing on his health and science technology experience, David is contributing to AFTD's mission in searching for hard-to-find medical information. Years ago, David was diagnosed with Spasmodic Dysphonia, a rare neurological voice disorder. He turned his diagnosis into his livelihood by starting a medical information retrieval business. He helped clients by customizing in-depth research reports for their rare and chronic medical conditions.

David currently works with AFTD Scientific Director Nadine Tatton, to

track the results of AFTD Pilot Grants that date back to 2005. "I have been capturing awardee outcomes such as: the number of FTD-focused



David Driggers with his mother.

publications that came as a result of AFTD's direct funding; follow-on funding from the NIH [National Institutes of Health] or other agencies; grant data presented at meetings; FTD consortia collaborations; and patent applications." David uses databases

such as PubMed, ClinicalTrials.gov, and the NIH RePORTER to collect information for AFTD's customer relationship management database.

David's mother lost her battle with FTD in 2010. "We laughed and cried throughout the crazy and unpredictable behaviors the disease brought," David says. "We were blessed that she retained her loving nature throughout the course of the disease and recognized family until her passing." David's mother donated her brain to the Mayo Clinic (Jacksonville, FL) for research, revealing that a strong belief in the power of research definitely runs in the family.

By lending his expertise to AFTD's need for specialized data mining, David has been a tremendous asset to AFTD's mission. Everyone brings unique talents as volunteers, and the opportunities are limitless.

Raise Your Voice!!!

Momentum is building, both in the nation's capital and across the country, for more services, resources and support to help people cope with all forms of dementia, including FTD. By authorizing the National Alzheimer's Project (NAPA) in 2010, Congress declared finding effective treatments, cures, and prevention for dementia a national priority. Earlier this year, FTD was formally included in NAPA priorities to cure Alzheimer's disease and other dementias by 2025, and more attention is now being paid to the disease as a research target by the National Institutes of Health (see related article, Page 1). But there is still a long way to go, and a substantial increase in funding is needed before the treatments and cures people so desperately hope for become a reality.

AFTD will continue to advocate for FTD to remain a key NAPA focus, and for greater awareness of FTD everywhere. But we need your help. Legislators and policy makers in Washington and throughout the U.S. need to hear directly from you, the real experts on FTD, who live and work with the disease every day. Hearing from the family members and caregivers who have experienced firsthand the full range of behavioral and cognitive symptoms involved and know how hard the emotional, social and financial challenges really are, is the best way for policymakers and legislators to understand FTD. Our elected officials need to know how the symptoms of FTD combine with an earlier age of onset to strain the nation's healthcare and legal systems.



AFTD Board Member Popkin Shenian and caregiver Lisa Sheridan at the October NAPA Advisory Council meeting in Washington, D.C.

NAPA's National Advisory Council meetings, held quarterly in Washington, are an important forum for caregivers to put a face on FTD. For example, Lisa Sheridan and her brother, Kevin, attended the Council's October meeting, where Lisa shared their family's experience caring for their mother, diagnosed with primary progressive aphasia, and the challenges they have faced accessing appropriate residential care for her in Pennsylvania. Earlier in the year, AFTD Regional Coordinator Katie Brandt traveled from Massachusetts to tell her story of caring for husband, who later died of the disease.

The time to speak out is now! Any FTD caregiver is welcome to speak at a NAPA meeting or related event. We also encourage you to look for other opportunities, closer to your home, to share your story and inform elected officials and policy makers about the changes needed to help people meet the challenges of FTD and related dementias.

If you are interested in attending a meeting in Washington, or are thinking about speaking at an advocacy event closer to home, please contact Matt Sharp at msharp@theaftd.org to discuss your plans. Matt will be happy to help prepare comments, discuss key points to make, or direct you to resources, such as AFTD's Guidance for State Alzheimer's Plans (available online at: www.theaftd.org/get-involved/advocacy/current-initiatives).

NEW: AFTD's Young Adult Facebook Group

by Sarah Sozansky, AFTD Volunteer, Age 27



Are you a young adult in your 20s or 30s? Do you have a parent, loved one or friend battling FTD? Do you often feel like it's hard to relate to other people your age? Now you have a community through AFTD's Young Adult Facebook Group! This is a closed group, meaning that your comments and posts are not visible on your newsfeed by anyone not admitted to the group.

During a young adult session at AFTD's 2014 annual conference in White Plains, NY, AFTD staff was

soliciting ideas on how to reach more young adults. One idea was to create a Facebook group for people our age, a place where those of us with parents or loved ones with FTD could come together and talk to each other within a supportive environment. The response to this idea was overwhelming. Brianna Sullivan, a volunteer at AFTD, took charge of creating the group, and it has been booming since its launch this past summer. There has been an outpouring of posts from young adults around the country who feel comfortable discussing

their feelings with other people their age.

Now that the group is up and running, we are recruiting any young adults whose parents or loved ones are affected by FTD. Joining is simple: Use your Facebook email address to send an e-mail to AFTD at youngadults@theaftd.org. A volunteer administrator regularly checks these e-mails and will invite you to join the group as soon as possible. We hope this on-line forum will help young adults feel more connected to others who have come face-to-face with this horrific disease!

THE AFTD-TEAM

AFTD's With Love Campaign 2015

The fourth annual *With Love* campaign will begin in January and AFTD invites you to share your story of love that withstands the trials of FTD. For many, FTD steals the ability to express the love that the affected person feels for their family and friends. *With Love* tells the stories of the kind of love that is strong enough to overcome this obstacle and thrive throughout the journey with FTD. If you have a story of enduring love, please consider helping us raise awareness and funds this Valentine's Day.



Josh for the Cure

The Pierce family and friends held the Second Annual Josh for the Cure Golf Outing and Dinner on July 25 in Lemont, IL. They hold this event in honor of Josh, a young father of two who has been diagnosed with FTD. The event raised \$15,000, which will be used to fund research.

Concert in Memory of Paula Scott

Mikaela Hamilton hosted a concert featuring several bands and a raffle in memory of her grandmother, Paula Scott. The concert was a huge success and raised nearly \$3,000 for AFTD!



George F. Sidoris Memorial Golf Outing

The Sidoris family held their 9th annual golf outing on July 26 in Willoughby, OH. The event, AFTD's longest running independent fundraiser, raised over \$18,000 and broke its previous record for number of golfers! We look forward to year 10!

Hiking the Appalachian Trail

Brandon Cline and Katherine Vance spent their summer hiking up (and then down) the East Coast on the Appalachian Trail and raised over \$8,500 in the process. This is not Brandon's first major athletic endeavor for AFTD; in 2011, he rode his bike from Virginia to California. To read about his latest adventure, visit the blog he and Katherine kept during their journey. www.nicedayforahike.wordpress.com



Birdies for Charity

Gabe Lysen participated in a program through the American Junior Golf Association where friends and family could sponsor him for every birdie he shot during the summer. Gabe shot 32 birdies and raised over \$2,000 for AFTD!

Spartan Race for AFTD

On September 20 at Citizen's Bank Park in Philadelphia, Kristin Rossi took on the 3-mile obstacle course in honor of her mother-in-law, who has FTD. Kristin raised over \$700 for AFTD!

Honky Tonk Prom

Nikki Powers hosted a "Honky Tonk Prom" in Ohio in honor of her father. The event raised \$655 for AFTD!

Frozen Yogurt Fundraiser

Justin Peavey worked with a local frozen yogurt shop in Massachusetts to have a percentage of sales on September 23 donated to AFTD. This is just one of many fundraisers Justin has coordinated for AFTD.



The Association for
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Opening the gateway to help and a cure

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