



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

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FTD Disorders Registry: The Future of FTD Research

Having a centralized location of recorded personal experiences is crucial to understanding how a disease affects a patient and their family. Yet one has not existed for FTD - until now.

The FTD Disorders Registry is a secure electronic database that collects information from people diagnosed with any of the FTD disorders, and from their caregivers and family members. The Registry will launch its first phase in mid-May, and participants will be able to join and get FTD research updates. Participants will be notified when the first Registry research surveys will be available, anticipated in late June 2016. Input from Registry participants will lead to better understanding of the impact

of the disease on individuals and their families. It will also fuel future research, including studies by scientists to learn more about the natural history of FTD by following participants over time, or to develop and test new therapeutics.



FTD DISORDERS
REGISTRY

AFTD's Executive Director, Susan Dickinson, stated, "We are excited to make this important resource available and emphasize that it is an asset that we - the community of patients and caregivers - will own."

Dianna Wheaton, M.S., Ph.D., was appointed Director of the FTD Disorders Registry in January 2016. Dianna is a genetic counselor and researcher with more than 20 years of experience running a rare eye disease

registry which successfully enrolled participants for clinical trials to test new therapies. "We encourage anyone who has been affected by FTD: persons diagnosed, family members, and/or caregivers, to join the Registry," Dianna said. "Their specific insight is the only way we can drive future research and fully understand the scope of the impact FTD has had on our community."

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FTD Research Momentum Showcased in National Meetings

AFTD was spotlighted on the national stage throughout the week of March 28th, during a series of meetings in the Washington D.C. area that built crucial momentum for research. Each meeting benefited from the strong leadership of AFTD staff, Board and Medical Advisory Council members.

"The AFTD/NINDS joint meetings this week showcased an explosion in knowledge about FTD," said Walter J. Koroshetz, MD, Director of the National Institute on Neurological Disorders and

Strokes (NINDS). "And it's all because of the collaboration between scientists, our affected persons, their families and their doctors."

March 29-30: ADRD Summit 2016

AFTD was honored to co-sponsor the 2016 Alzheimer's Disease-Related Dementias (ADRD) Summit.

The two-day summit was attended by more than 400 researchers, medical professionals, advocates and family caregivers, who came to learn about advances in ADRD research and offer input to guide continued progress.

(Continued on page 8)



*AFTD Board Chair, Jary Larsen and
AFTD Executive Director, Susan Dickinson,
show gratitude to FTSG 2016 sponsors.*

Spotlight On... Stephen Fenoglio, AFTD Board of Directors

The odds of losing two siblings to FTD seem extremely high, but for AFTD Board Member Stephen (Steve) Fenoglio, Esq. those odds became his reality. His sister Libby, a Wichita Falls, Texas teacher and school principal, died at the age of 56 in 2010, and his brother Michael, a prominent Denver surgeon, was taken at 57 years old in 2012.

Experiencing these tragic losses, Steve committed himself to raising much-needed awareness, and providing a network of support to others adjusting to lives dramatically altered by FTD.

"Fighting and beating this disease is personal to me; I don't want others – family, friends or strangers – to go through the Hell we did," he says.



A resident of Austin, Steve runs his own law practice, specializing in oil and gas, administrative, utility and gaming law. He has represented hundreds of nonprofits in matters before federal and state courts and agencies, and is an active supporter of The Arc of the Capital Area and the Rocky Mountain Elk Foundation.

Steve chairs an Austin FTD support group that meets the second Tuesday of every month at 1 p.m., at Austin Groups for the Elderly. Readers can find contact information at www.theaftd.org/get-involved/regions/south-central.

He is also an active supporter of AFTD

grassroots events, helping to anchor a team of more than 25 participants, raising awareness and raising funds, to fight FTD at the June 2015 Austin Fit Foodie 5K. Community members are encouraged to join him at this year's event in June.

Steve brings personal values, vocational skill and mission commitment to his role on the Board. "Using my law background and personal experiences as guidance, I hope to provide a focused view of what's important for caregivers and their families, as well as legal analysis when needed."

"One day I hope to say, or that my children can say, that through AFTD's leadership we fought this disease and we won."

He adds: "I will advocate for succinct and accurate diagnosis, while providing a pathway of dignity during the

patient's journey. One day I hope to say, or that my children can say, that through AFTD's leadership we fought this disease and we won."

AFTD NEWS BRIEFS

FTD Biomarkers Initiative Issues Request for Proposals

Biomarkers - physiological signs or molecules used to diagnose disease, track disease progression, or monitor the response to treatment - are urgently needed by physicians and FTD researchers. To accelerate biomarker discovery, AFTD has leveraged Samuel I. Newhouse Foundation support to launch a new funding opportunity for researchers, the FTD Biomarkers Initiative. We issued the initiative's first Request for Proposals on January 15. Researchers affiliated with academic, medical or for-profit organizations worldwide were invited to apply. Letters of Intent were due April 15. A group of applicants will be invited to submit full proposals by July 15, with award notifications by September 1. Find more information here: www.theaftd.org/research/ftd-biomarkers-initiative

Join the AFTD Volunteer Team and Make a Difference!

As the cornerstone of AFTD's volunteer program, the Regional Coordinator serves as the principal point of contact for volunteers in their assigned regions, providing guidance and support to help them achieve their individual goals, while furthering AFTD's mission. AFTD is currently recruiting lead volunteers across the country. To learn more, contact Kerri Barthel, Volunteer Manager, by phone at 267-758-8652 or by email at kbarthel@theaftd.org.

National Volunteer Week: April 10th - 16th

AFTD wants to thank each of our volunteers who has signed up to make a difference. Your investment of time and talent is key to our growing impact. Thanks to more than 250 volunteers who have engaged with AFTD over the past year. Your work is ensuring that the journey will be a little easier for the families to come. An AFTD video thanks our volunteers online at: www.youtube.com/watch?v=KKPEsqKKYMA

Thank you, AFTD Regional Coordinators

Two regional coordinators stepped down at the end of 2015, Lorene Schlie (Midwest Regional Coordinator) and Rachael Baffa (Southwest Regional Coordinator). AFTD thanks these individuals for their contributions and commitment to our community.

FTD Economic Burden Survey

The numbers are in: Over the past few months, more than 1,100 respondents took the time to provide essential, first-hand information on the economic impact of FTD, and it is deeply appreciated. A preview of the study results will be presented at the International Conference on Frontotemporal Dementias in Munich in September, and the full results will be submitted to a scientific journal before year's end. The results will provide new opportunities for all to broaden FTD awareness, advocate for better services and secure additional research funding.



A Recipe For Hope

When their mother, Donna Rose, was diagnosed with FTD in October 2012, siblings Brian and Sharon Rose sought ways to make a difference. They responded by launching creative grassroots campaigns, designed to raise funds to support AFTD's mission, while providing rare opportunities for fun, learning and support.

Their 2014 Food for Thought® campaign sought financial donations as well as simple and tasty recipes - *5 ingredients, 5 steps or less* - that caregivers can use to stay healthy. Their 2015 campaign, "A Bite to Fight FTD," used social media to raise awareness. Participants were asked to use the hashtags #AFTDteam and #ABiteToFightFTD to post a video/



picture of themselves enjoying a favorite sandwich.

"These campaigns offered a forum to explain our situation ... and ways to get people who are suffering involved in the broader cause," Sharon said.

In creating their campaigns, Brian and Sharon knew that any contribution - big or small - can make a huge difference. They raised significant funding to support the fight against FTD - and made crucial donations themselves.

"Our hope is for there to be hope," Brian said. "We are dealing with a degenerative disease, where the day of diagnosis will be the healthiest day for our loved one going forward. Hope for FTD patients is that the day of diagnosis is not the beginning of a slow decline, but rather the beginning of a healing process...and that they can look forward to better days in their future."

This Mother's Day, make a gift of any size to support that hope - and speed the day that FTD is effectively diagnosed, treated, and ultimately cured. Make a difference any way you can, by using the attached envelope, or accessing this link: www.tinyurl.com/fightFTD

AFTD Welcomes New Staff

AFTD has expanded its ability to deliver effectively on the organization's mission, by adding three new staff.



Joining AFTD in October as Grassroots Events Coordinator, **Bridget Graham** earned her B.S. in Speech Communication from Millersville University of Pennsylvania. Reporting to AFTD's Development & Communications Director, she brings experience in marketing and business administration to her role, with specific expertise in social media. Her primary focus is on empowering community members to raise funds to fight FTD, through a range of campaigns year round. Bridget notes, "I hope to contribute to the growth of our Grassroots Events program, and its role as an empowering outlet for people in our community."



Darlene Blevins joined AFTD as Communications Manager in November. Also reporting to AFTD's Development and Communications Director, she brings more than 15 years of experience in advertising and marketing, planning and writing content for both non-profit and for-profit environments, while contributing to overall communications strategy. Darlene earned her B.A. in English from Florida International University and is currently working toward an M.S. in Nonprofit Management, graduating in October 2016. She will manage AFTD's Communications efforts, and provide social media strategy expertise. "I am honored to have the opportunity to use my varied background in communications to develop and expand AFTD's branding and messaging," she said.



Harold "Hal" Perkins, III joined AFTD as Programs and Services Assistant this February. His background includes customer service, sales associate, and print sales roles. He has a Bachelor's degree in Health Science from La Salle University, and is currently working toward an M.P.H., graduating in August 2016. Reporting to AFTD's Volunteer Manager, he provides administrative support to help the organization sustain and expand its program impact. "I am thrilled to be part of the AFTD team and am looking forward to assisting the FTD community," Hal said.

Please join AFTD's Board and staff in welcoming these new colleagues!

AFTD Announces Recipients of 2015 Pilot Grants for Basic and Clinical Research

An “out-of-the-box” idea could lead to a scientific breakthrough – a prospect that’s at the heart of the AFTD Pilot Grant program. AFTD Pilot Grants provide seed funding for investigators to test novel ideas and gather data they can use to support an application for a larger research grant. In addition, Pilot Grants awarded to innovative early-career researchers may kindle a long-lasting commitment to FTD research.

In 2015, AFTD awarded two Pilot Grants – a Basic Science Pilot Grant, and the Susan Marcus Memorial Fund Clinical Research Pilot Grant. We are proud to announce the recipients of these awards: Sandra Almeida, Ph.D. and Roy Hamilton, M.D., M.S..

Dr. Almeida, an assistant professor of neurology at the University of Massachusetts Medical



Dr. Sandra Almeida

School, received AFTD’s 2015 Basic Research Pilot Grant. Her proposal, “Reducing repeat toxicity in iPSC cortical neurons of *C9ORF72* FTD patients,” takes advantage of the discovery that adult skin cells can be “reprogrammed” to produce stem cells – immature cells that can develop into many kinds of specialized tissues. Dr. Almeida directs stem cells that began as skin cells of patients who have a mutation in the *C9ORF72* gene (the most common mutation in FTD) to develop into neurons (brain cells) that have the same *C9ORF72* mutation as the one found in a patient’s brain. Dr. Almeida will attempt to correct some toxic effects of the *C9ORF72* mutation in these

laboratory-grown neurons.

AFTD awarded its 2015 Susan Marcus Memorial Fund Clinical Research Pilot Grant to Dr. Roy Hamilton, an assistant professor of Neurology at the University of Pennsylvania. His research project will evaluate a safe, noninvasive form of brain stimulation known as transcranial direct current stimulation, or tDCS, as a treatment for primary progressive aphasia (PPA). The results of several small studies suggest that tDCS can improve language abilities in people diagnosed with PPA, but more research is needed before concluding that the treatment is effective.

If Dr. Hamilton’s study confirms earlier results, it would justify investment in the large-scale investigations needed to obtain approval of tDCS for use in clinical practice.



Dr. Roy Hamilton

FTD Disorders Registry *(Continued from page 1)*

By sharing their experiences in an online database, persons diagnosed with FTD and their families will create a community resource for learning about the ‘natural history’ of the disease that can be shared within the registry community and with research scientists interested in learning more about FTD. The Registry will provide a research-ready patient community to accelerate clinical trials for drugs or treatments for the condition, and assist with the design of patient-centered studies and care practices. All research participant information will be made anonymous by removing names and other personal identifiers, and

Join the Registry. Tell your story
Advance the science. www.ftdregistry.org

replacing them with an ID code to protect the person’s identity.

AFTD and the Bluefield Project to Cure Frontotemporal Dementia created the FTD Disorders Registry LLC in March 2015, to be the independent, nonprofit organization that will manage and provide funding for the new registry. Current funding is provided by the founding organizations and Rainwater Charitable Foundation’s Tau Consortium.

AFTD’s development partners in building The FTD Disorders Registry are the Banner Health Alzheimer’s Prevention Initiative, Provoc, and Freeflow Digital. Readers can learn more by accessing: www.ftdregistry.org

2015 Drug Discovery Awards: Top Proposals Focus on Advancing FTD Diagnosis and Treatment

Since 2007, AFTD has supported innovative research by partnering with the Alzheimer's Drug Discovery Foundation (ADDF) to support the *Accelerating Drug Discovery for Frontotemporal Degeneration grant program*.

To date, this program has awarded more than \$2.7 million to support drug discovery, with the ADDF contributing two dollars for every dollar contributed by AFTD. This year, an anonymous donation allowed AFTD to double its annual contribution from \$100,000 to \$200,000, resulting in a total of \$600,000 in grant funding available to applicants.

Based on a November 2015 review by the program's Scientific Review Committee, AFTD is proud to announce Drug Discovery grants for two researchers: Mari DeMarco, Ph.D., DABCC, of the University of British Columbia and Edward Huey, M.D., of Columbia University.



Dr. Mari DeMarco

Dr. DeMarco's project focuses on developing a new method for detecting an FTD-associated protein, TDP-43, which could be a potential biomarker. Current methods to detect TDP-43 rely primarily on the use of antibodies, an approach plagued by technical challenges. Dr. DeMarco's assay will utilize mass spectrometry, an alternative she believes will be more selective and cost-effective. The new method will be applied to evaluate TDP-43 concentration in cerebrospinal fluid samples from individuals diagnosed with FTD compared to other neurodegenerative disorders, such as Alzheimer's disease.

Dr. Huey will evaluate the effectiveness of low-dose lithium as a

treatment for behavioral symptoms in FTD. These symptoms are a major source of distress for caregivers and are notoriously resistant to most types of psychoactive medications. Preliminary data suggest that low doses of lithium may reduce agitation and aggression in individuals with FTD. Dr. Huey's study will further evaluate the safety and effectiveness of the low-dose regimen.

Positive results would address a critical unmet need and greatly benefit families and caregivers.



Dr. Edward Huey

As a result of this year's increase in the level of funding, the Scientific Review Committee was able to recommend funding for a third proposal, which will examine a novel brain imaging technique for measuring cerebral blood flow, an indicator of brain activity. The details of this third Drug Discovery award are currently being finalized and a formal announcement will follow.

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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 our website. All donors will receive letters of acknowledgment, and families will also receive a list of donors. To contribute online, [visit www.theaftd.org](http://www.theaftd.org) and select "Donate Now."

Think Tank Offers Vital Perspective on AFTD's Work

During a self-evaluation process to meet current Strategic Plan goals, AFTD identified a primary need: the development of a formal mechanism to hear and learn from the perspectives of stakeholders diagnosed with FTD. Following formative discussions, which included initial input from FTD self-advocate and dedicated AFTD volunteer Howard Glick, AFTD recently launched its newest advisory group: the Think Tank.

"By holding a mirror up to AFTD through the eyes of people with a diagnosis, we can broaden our responsiveness," explained Sharon S. Denny, M.A., AFTD Program Director, who, along with AFTD Program Manager Matthew S. Sharp, M.S.S., facilitates the group's monthly

meetings via webcam. In addition to Howard Glick, Think Tank members include Gary Peacock, Susan Suchan and Teresa Webb, as well as AFTD Board Member Paul Lester. Think Tank member Gary Peacock explained, "Participation in Think Tank meetings has given me a meaningful outlet, a forum where I can share my thoughts and experiences, which hopefully benefit others and AFTD staff. In a word.....Priceless."

Susan Suchan added: "The AFTD Think Tank is the opportunity to enrich the research process of FTD through the lived experience; sharing a different perspective."

Currently, the Think Tank is considering and offering guidance on ways that AFTD communications can be more helpful to

those diagnosed. AFTD has also asked for input on specific priorities for the next fiscal year that address the needs of persons diagnosed. Development of the FTD Disorders Registry has drawn on insights from the Think Tank in its design phase.

Teresa Webb shared, "It is wonderful to be able to discuss and share ideas with AFTD staff. Having the opportunity to work together to find new solutions to old challenges, while creating a better understanding of the needs of those living with FTD, is extremely rewarding."

For information about the Think Tank or joining this advisory group, please contact AFTD Program Director Sharon Denny via email at sdenny@theaftd.org or by telephone at 267-758-8650.

National Meetings *(Continued from page 1)*

The recommendations from the first ADRD Summit (in 2013) established the importance of ADRD research and the benefits of including FTD and other forms of dementia in the national conversation about Alzheimer's. The 2013 Summit built momentum that led to several recent milestones for FTD research, including the NIH-funded development of the ARTFL/LEFFTDS clinical networks and the launch of AFTD's multi-year, Samuel I. Newhouse Foundation-funded Biomarkers Initiative.

The Summit was hosted by NINDS, in collaboration with the National Institute on Aging (NIA) and ten co-sponsors, including AFTD.

This year's Summit included a special morning session focused on FTD, with reports on advances since 2013, and updated recommendations made possible by increased funding from Congress.

The Summit included a new session co-chaired by AFTD's Executive Director, Susan Dickinson, focused on the unique role that non-governmental organizations (NGOs) can play in bringing communities together to stimulate ADRD research. A special joint component to the session convened several

groups to discuss the need to refine and revise the national vocabulary around all dementias. The full 2016 recommendations can be found at: <https://www.meetings.ninds.nih.gov/Home/Tab1/11958>

March 30-April 1: FTD Clinical Research Meetings

AFTD and NINDS together hosted two additional meetings in Bethesda, MD:

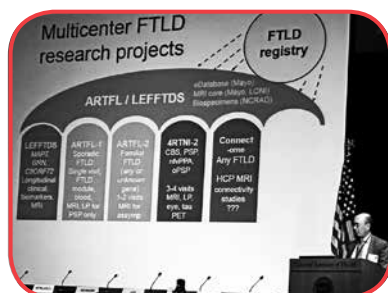
On March 30th, an Investigators Meeting brought together researchers from the 15 different sites for the ARTFL/LEFFTDS clinical research networks, to discuss progress during the network's first year; work through tactical issues, and establish efficiencies, to foster progress in FTD clinical research.

The 2016 FTD Treatment Study Group (FTSG) Conference was formally cohosted by AFTD and NINDS from March 31st to April 1st.

Nearly 100 attendees from academia, government and industry (including more than 16 pharmaceutical and biotech companies) discussed issues of common interest in drug development and clinical trial design for FTD, and learned about new resources for clinical investigators. Representatives from the U.S.



Left to right, Marc Diamond (Center for Alzheimer's & Neurodegenerative Disease), Jonathan Rohrer (National Hospital for Neurology and Neurosurgery and UCL Institute of Neurology), William Seeley (UCSF Neurodegenerative Disease Brain Bank) and Chiadi Onyike (Johns Hopkins University) socialize at the FTSG welcome reception.



Associate Professor of Neurology at UCSF, Adam Boxer, giving his presentation on the ARTFL/LEFFTDS 'natural history' network.

FDA and European EMA participated in a panel discussion to answer questions on the regulatory aspects of drug development and clinical trials for FTD.

The Conference offered a meaningful opportunity to explore for collaboration, to expedite the discovery and development of improved diagnostics, robust biomarkers and effective treatments.

David Knopman, Chair, AFTD Medical Advisory Council added: "Experience from many other fields has shown that until we have a true understanding of the biology of the disease, we won't have a good chance of success. The presentations this week gave me the sense that we were closing in on that core understanding of FTD."

AFTD founder Helen-Ann Comstock noted: "When I started the organization in 2002, very few were working on FTD. I am amazed by the progress represented by these meetings, and am deeply grateful for the hope they offer to everyone coping with FTD."

Giving a Hand to Our Helping Hands!

How do you begin to say thank you to a volunteer who has dedicated so many years to supporting AFTD's mission? Susan Eissler is an inspiration. Through her various positions as a volunteer over the past nine years, she has inspired many to get involved and make a difference in the fight against FTD.

Susan served on AFTD's Board of Directors for six years. After losing her husband to FTD, her primary interest was research, but she also recognized the importance of all aspects of AFTD's work. In order to learn more about AFTD's programs, she became the Program Committee Chair for the Board. At the same time, she wanted to understand what was being asked of volunteers and became the Regional Coordinator volunteer for the South Central region.



"I admire and respect her tenacity and inquisitive nature," said Kerri Barthel, AFTD Volunteer Manager. "Her experiences in these various roles have provided a valuable perspective."

This April marks Susan

Eissler's sixth year as a Regional Coordinator volunteer. "Susan has been a key factor in the development of the organization. The insights she brought to the Board from her role as a Regional Coordinator were key in the Board's ability to design a volunteer program that pushed the envelope for our organization," said Susan Dickinson, AFTD Executive Director.



"Susan is one of the most dedicated people with whom I have worked at AFTD. She gives tirelessly of herself. She is bright, articulate, and hardworking. In addition to serving on the Board and overseeing a region, she has actively run a support group in the Austin area, and was fundamental in the founding of other support groups," said Jary Larsen, AFTD Board Chair.

Volunteer Kacy Kunesch shared, *"As a Regional Coordinator, Susan's willingness to help and support families has positively impacted so many in our region. I am personally appreciative for her ongoing support and we are all so grateful to have her in the AFTD family."*

Susan's dedication and passion demonstrate the power of what one person can achieve. Thank you, Susan, for all of your valuable contributions to AFTD.

A New Friendship, and New Avenues of Support

Andrea Maga and Missey Toomey ran into great fortune when they met in 2011 while both visiting Elderhaus, an adult daycare facility in Fort Collins, Colorado. Elderhaus provided each of them respite from caring for husbands who had both been diagnosed with FTD. The facility formed a special group just for FTD patients, which planned activities that kept in mind the challenges of FTD.

Both Elderhaus and a new friendship were unexpected gifts in the midst of FTD. Andrea (husband, Joe) and Missey (husband, Taft) began taking walks and going out to dinner together. This enabled Andrea and Missey to experience the beginnings of regular support as they faced this disease together.

Both women acknowledge that one of the most difficult aspects of this disease is losing friends. Countless people feel

uncomfortable around FTD and simply do not understand it; even close friends may slowly fade away. The burgeoning friendship between Missey and Andrea,



Missey Toomey, Andrea Maga, and Kathy Urban.

as well as the one between Taft and Joe, proved to be invaluable. "There's nothing like having people around who know exactly what you're going through," they said.

With the help of Bridget Moran, AFTD Support Services Manager, Missey and Andrea began the process of starting a new support group, focused on

By Kathy Urban, AFTD Volunteer

FTD caregivers. "Missey and Andrea are a great example to others across the country of how forming a local group is beneficial, and proof that having someone to go through their experiences with can make it even more rewarding and meaningful," said Bridget.

Missey and Andrea's support group is a great resource for caregivers of this complex disease. "We talk about everything from the tasks – how to do this and that, to the emotional side of it. It's also very important to separate the disease from the person," said Missey.

Education and advocacy of this disease are true passions for both Andrea and Missey. They would like to see increased awareness of FTD and a faster and more accurate diagnosis. With both Missey and Andrea co-facilitating their own FTD support group, they are incredible leaders in this charge.

THE AFTD-TEAM

AFTD's
With Love
Campaign 2016

This past February, AFTD held its fifth annual *With Love* campaign, raising \$60,782, the campaign's most successful year yet. During one 48-hour period, donors provided more than \$15,000!

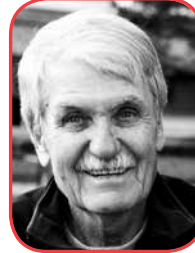
The 12 individuals and teams who shared their stories and raised funds to support AFTD's mission were the campaign's driving force:



Team Alice (Brookline, MA), *For Alice, With Love, and to #endFTD*, \$7,650 raised.



Stephanie McLain (Round Rock, TX), *For Mom, With Love*, \$2,930 raised.



Bonnie Shepherd (Salt Lake City, UT), *With Love to Ned 2016*, \$2,800.



Lisa, Geri and Gary Radin, *Remembering Neil Radin with Love*, \$2,835.



Amy Eissler (Beaverton, OR), *Fight FTD with LOVE*, \$1,325.



Joanna Dauber (Philadelphia, PA), *Measure your life in LOVE- In Honor of Linda A. Dauber*, \$1,104.



Jamie Hale (Dracut, MA), *Save the Memories of Love*, \$1,055.



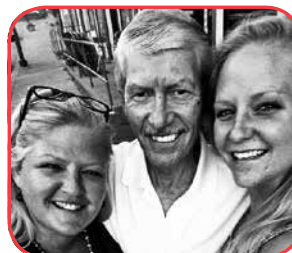
Deb Nash (Osage, IA), *Skate for a CURE- Dames of Anarchy*, \$869.



Rebecca Hixon (Easton, PA), *Everything Was Done WITH LOVE*, \$620.



Ken Weinlaeder, (Iowa), *Books*, \$200.



Erin Walla (Iron Mountain, MI), *My Favorite Teacher*, raised \$100.



Jennifer Jedow, *Paying it Forward for Dad*, \$25.

Special thanks to all who convened fundraisers, and all who supported them!



As part of the *With Love* campaign, AFTD released a special awareness video, titled "Who I Love", directed by a student-led team at Boston University. Thanks to promotional efforts by many of our readers, in a short time the video has been seen by more than 7,500 people. Access it here, and pass it on! www.tinyurl.com/WhoILoveFTD



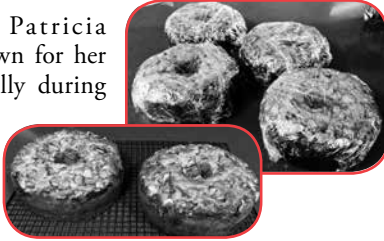
THE AFTD-TEAM

Grassroots Events Highlights: October through March 2016



Matt Hatfield - The Robert M. Hatfield 5th Annual 2015 Golf Tournament was held on November 6th, 2015 in Saint Petersburg, FL and raised \$9,000.

Patricia Buchanan - Patricia Buchanan's mother was known for her Jewish Apple Cakes, especially during the holidays. Unfortunately, Patricia's mother passed away from FTD in 2008. This past holiday season, Patricia decided to bake and sell her mother's Jewish Apple Cakes with the proceeds benefitting AFTD. Patricia also lost her aunt, grandfather and uncle to FTD and her youngest brother is currently battling the disease. She baked and sold cakes from November 2015 to January 2016, and raised \$600.



Brittany Hatfield - Brittany Hatfield ran in the Los Angeles Marathon on February 14th, 2016 in honor of the Rose family. Brittany's friend Alana Rose's parents are both diagnosed with different types of degenerative diseases. Her mother was diagnosed with Primary Progressive Aphasia eight years ago and her father was recently diagnosed, showing signs of Dementia and Aphasia. Brittany set a fundraising goal of \$6,000 - which AFTD was the beneficiary - and ended up raising \$6,345.

Lauren Malizia - After a family member was diagnosed with FTD in 2015, Lauren Malizia of Los Angeles, CA decided to donate 50% of her etsy.com sales to AFTD during a one-week period. Lauren is the plush doll maker, designer and creator behind WubDolls. Her little monster dolls are called "WUB" to mean "Will you be..." so the consumer can name them after whatever purpose in life they so desire. During just that one week of sales, Lauren was able to donate \$230 to AFTD.



Paul Lester - AFTD Board Member Paul Lester hosted his 9th annual appeal, ...In Memory of Arnette Lester, raising more than \$8,750 to support AFTD's mission.

Bill's Best BBQ Sauce

During the 90's, Bill Fehon created the recipe for what is now Bill's Best Original Organic BBQ Sauce, making it for his family and friends. In 2009, Bill was diagnosed with FTD and eventually could no longer make his famous sauce. Bill's family—



his wife Diane and five sons, Aaron, Jason, Anders, Jeremy and Garrett—decided to take his original recipe and put it into production. Since that day, Bill's Best Organic BBQ Sauce has grown from a one sauce business operating out of Diane's kitchen, to a three sauce business operating out of a working facility.

Since 2011, Bill's Best Organic BBQ Sauce has donated 10 percent of sales to AFTD – what Diane Fehon refers to as “helping to raise awareness of FTD, one bottle at a time.” Now located in Glenside, PA, Bill's Best Organic BBQ Sauce creates, bottles and distributes three sauces: Bill's Best Original Organic BBQ Sauce, Bill's Best Spicy Organic BBQ Sauce and Bill's Best Honey Organic BBQ Sauce. Available online at Amazon and in stores like Whole Foods, one can purchase a bottle of delicious, local ingredient-based and family owed sauce that helps fight FTD!



**Walking
to
#EndFTD**

The AFTD-Team has been out early this spring, joining runs in Connecticut (the Shamrock Shuffle 5K in Watertown) and Maryland (the Flashback 5K in Towson). Thanks to all who took part. An upcoming 5K offers an exciting opportunity to connect, raise awareness, and raise funds to support the fight against FTD. Join us and walk to #endFTD this spring/summer!

May 22 - King of Prussia 10 Miler 5K Walk/Run (PA)

June 5 - Cambridge 5K - Freedom Run (MA)

June 25 - The Fit Foodie Race (Austin, TX)

July 16-17 - Humana Rock 'n' Roll Chicago (IL)

August 13 - Griffith Luau 5k & Kids 1k Run/Walk (Los Angeles, CA)

The top fundraisers for each of these events will receive special prizes in recognition, and coverage in AFTD's newsletter. Email AFTD's Grassroots Events Coordinator Bridget Graham at: bgraham@theaftd.org to sign up today!

Reflect, Renew and Explore

AFTD CONFERENCE 2016
MINNEAPOLIS, MN

How Can I Host A Grassroots Event? Learn More at AFTD's Education Conference

There's still time to register for AFTD's 2016 Education Conference, to be held May 13, 2016 in Minneapolis, MN. At the Conference, Bridget Graham, AFTD Grassroots Events Coordinator, and Pam McGonigle, M.A., AFTD Development Manager will be leading a participative lunch for grassroots events hosts. Hear others reflect on their experiences, and learn about exciting ways you can raise awareness, raise funds and support AFTD's mission year round! Find more information and register here: www.theaftd.org/newsroom/aftd-2016-education-conference



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