



AFTD news

Department of Defense to Offer Funding for FTD Research

It likely comes as no surprise that the U.S. Department of Defense (DoD) funds medical research on combat-related conditions affecting servicemen and women. Less well known, however, is that the DoD also supports research more broadly through the Congressionally Directed Medical Research Program (CDMRP). Established in 1992, the CDMRP is allocated funds annually by members of the House or Senate in response to requests from persons diagnosed, their families, and disease advocates.

Programs and projects falling under the CDMRP umbrella include the Peer-Reviewed Medical Research Program (PRMRP), so called because applications are evaluated by a peer review panel consisting of scientists with expertise in a specific topic area

as well as consumer advocates who represent the perspective of patients and caregivers.

Each year, the topic areas targeted for funding through the PRMRP are identified by Congress, and the money



allocated – \$330 million for 2018 – is divided among all of that year’s topic areas. Thanks to supporters on the Hill, led by Senator Chuck Schumer, FTD was designated one of the 52 PRMRP topic areas for 2018.

AFTD worked directly with DoD program staff to identify priorities for FTD-related applications to the 2018 PRMRP awards, known as “areas of encouragement.” These areas include research to develop laboratory and animal models, increase understanding of the neural basis for behavioral symptoms, identify FTD biomarkers, improve diagnosis, pinpoint risk factors for FTD, and develop symptomatic treatments.

In addition, AFTD was invited to recommend experts in FTD research and members of the AFTD community to serve as scientific and consumer reviewers.

For more information about the PRMRP, including funding opportunities, visit the CDMRP website at cdmrp.army.mil/prmrp.

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Facebook Group Brings Help and Support

Upon learning of an FTD diagnosis, finding help and support from others who have faced the reality of the disease can be a challenge. One option that AFTD offers to facilitate these types of connections is our closed Facebook group, populated by thousands of care partners and persons diagnosed who want to learn and share their firsthand knowledge of FTD.

Every day, members post messages to the group asking for advice, telling their stories, or sharing helpful resources that they have recently found. For many members, participation in the closed group is a daily necessity, and a way to feel connected in the midst of a very isolating and confusing disease.

For care partners, the group is useful as a source of practical, experiential suggestions about managing their loved ones’ FTD symptoms – “real ‘been there done that’ advice,” as Sharon Hall, a care partner for her husband and an active member of the closed Facebook group, puts it.

The AFTD closed Facebook group is a source of valuable “been there done that advice,” member Sharon Hall said.

Persons diagnosed use the group as well. Cindy

Odell, who was diagnosed with FTD in 2011, says that she is impressed by how friendly and welcoming people in the group are. She said she has belonged to similar closed Facebook groups in the past, but too often they contained “caregivers saying horrible things about their loved ones.” The closed AFTD Facebook group

(Continued on page 4)

Spotlight on... Sandra Grow, AFTD Board of Directors

Since her husband Karl was diagnosed with FTD, Sandra Grow has been driven by the need to better educate healthcare professionals about this disease, and to spread awareness of FTD throughout the general public. Over the last 10 years, she has brought this passion to AFTD's mission -- first as a volunteer and, as of April 2018, as an AFTD Board member.



Sandra Grow

She says that progress has been made in terms of awareness in recent years. "But I still think we need to educate healthcare professionals and increase public awareness that this is a disease."

More widespread awareness could improve quality of care, she said. "People aren't diagnosed early enough. With early diagnosis comes quicker care, better support, and

more attention paid to safety issues" that are often associated with FTD symptoms.

Sandra recalled Karl's journey to a diagnosis. "We noticed changes in his behavior early on," she said. These changes grew increasingly disruptive, Karl lost his job, and Sandra was left trying to figure out what was going on. "It's the same story everyone has," she said.

After neuroimaging and cognitive testing produced a diagnosis of behavioral variant FTD, Sandra found help through AFTD. "AFTD has given me so much over the years in support, education and helping to make connections. Even though this is a really sad diagnosis, I have met some wonderful people

through AFTD whom I would not have otherwise come into contact with."

Before joining the Board, Sandra was already an engaged AFTD volunteer, co-facilitating a support group in Ohio and joining the Partners in FTD Care advisory committee, where she works with fellow healthcare professionals to help produce AFTD's *Partners in FTD Care* newsletter. She has also attended five AFTD Education Conferences, which she described as the "biggest thing for me, in terms of help - meeting other people and understanding that they're out there."

Recently retired, Sandra says she is ready to devote her energy to furthering AFTD's mission as a Board member. "I feel strongly about the success of AFTD, and hope to give back to them for all they have helped and taught me - and 'pay it forward' to those that may still need help and guidance," she said.

AFTD NEWS BRIEFS

AFTD Co-Sponsoring Satellite Events at Society for Neuroscience Meeting

AFTD will be co-sponsoring two events in conjunction with the Society for Neuroscience's (SfN) annual meeting in San Diego in November. The 5th RNA Metabolism in Neurological Disease Conference, which will be held November 1-2, will review the latest research on the processes that regulate the activity, distribution, and life cycle of RNA, as well as breakdowns in these processes that have been implicated in FTD and other neurodegenerative diseases. On November 3, AFTD will collaborate with several other nonprofit organizations to host a networking reception for FTD researchers attending the SfN meeting, where they'll also have an opportunity to learn about grant programs offered by AFTD and our co-sponsors.

AFTD Volunteers Honored During National Volunteer Week

During National Volunteer Week (April 15-21), AFTD acknowledged its volunteers

across the U.S. with an appreciation video highlighting their many contributions. AFTD relies on its passionate and dedicated volunteers to help spread awareness of FTD and build a supportive community of people affected by this disease. Watch the video at www.theaftd.org/aftd-appreciates-our-volunteers, and learn how to join our national volunteer network at www.theaftd.org/get-involved/volunteer-network.

World FTD Awareness Week to Be Held in September

World FTD Awareness Week 2018 - a week of events, activism and international engagement - will begin this year on September 23. AFTD, along with its counterparts in the World FTD United coalition, are working to make this year's event the biggest ever, with countries from across the world joining our shared mission to spread awareness of this disease. Stay tuned to AFTD's website for more information as World FTD Awareness Week approaches.

AFTD Values Your Input

Your guidance can help us to make this newsletter a more valuable resource! Please send any comments, feedback or suggestions to AFTD's Communications Manager Matt Ozga at mozga@theaftd.org. Thank you!

Next AFTD Educational Webinar Scheduled for Aug. 23

Dr. Nupur Ghoshal of the Washington University School of Medicine in St. Louis will present the next installment in AFTD's Educational Webinar series on August 23. The webinar will provide a comprehensive overview of behavioral variant FTD, including signs and symptoms, care strategies, and current research. Stay tuned to AFTD's website and follow AFTD on social media for more information.

Become A Monthly Donor Today



Jim Abbott

Support AFTD's Mission Year Round:

There are a lot of different ways to become involved in AFTD's mission. For some, like Susan Miller Abbott, who volunteers as a Support Group Facilitator, choosing one way simply isn't enough.

"I also make a monthly donation to AFTD to honor the memory of my husband Jim. Giving this way means I don't have to remember to write a check each month. I feel blessed to be a part of AFTD's mission to educate the public, support FTD research and to be a resource for caregivers past, present and in the future."

- Susan Miller Abbott

By choosing to establish an AFTD monthly donation today, you can join monthly donors like Susan in demonstrating your ongoing commitment to this organization's mission, and to the people we serve. Your donation – whether \$5, \$15 or \$50 – will make a difference! It can be designated to the area of AFTD's work that you are passionate about, or kept unrestricted to support AFTD's full mission.

Will you join Susan in becoming an AFTD monthly donor today?

Go to www.theaftd.org and click on the **Donate** button at the top of the page. As you complete the form, simply choose "Make my gift a recurring donation..."

Hundreds Find Help and Share Hope at 2018 AFTD Education Conference

AFTD's 2018 Education Conference, held April 13 in Chicago, presented the latest updates in FTD research and care strategies, encouraged members of our community to connect, and gave those impacted by FTD the opportunity to find help and share hope.

It drew 341 participants, representing 37 states as well as Canada – the highest total for an AFTD conference to date. Notably, 57 registrants identified themselves as living with FTD, reflecting AFTD's ongoing commitment to better engage with this segment of our community.

The conference began with a warm welcome from AFTD Board Chair Gail Andersen. Amy Bouschart-Callea and Frank Callea, FTD advocates and AFTD volunteers, then took the stage for opening remarks, speaking candidly from the perspectives of an FTD spouse/care partner and a person diagnosed.

Researchers from Northwestern University's Cognitive Neurology and Alzheimer's Disease Center, the conference host, held discussion in the morning session. Dr. Marsel Mesulam delivered an overview of the FTD disorders, Dr. Sandra Weintraub focused on new research

developments in primary progressive aphasia, and Dr. Darby Morhardt

spoke about advances in FTD care and support.

Later, a panel discussion convened healthcare professionals, care partners and persons diagnosed to talk about the necessity of "speaking up for FTD." Panel moderator Sharon Denny, AFTD Program Director, led the discussion, in which the contributors shared the power of storytelling to "bring light to the darkness" by drawing increased awareness to FTD.

One of the conference's highlights was the Keynote Address, delivered by the Very Rev. Tracey Lind, a renowned



Left: AFTD Volunteers Amy Bouschart-Callea and Frank Callea deliver opening remarks. Below: Two members of the AFTD community take in the conference.



The 2018 AFTD Education Conference Keynote Speaker, the Very Rev. Tracey Lind



preacher and the former Dean of Trinity Episcopal Cathedral in Cleveland. Rev. Lind was diagnosed with Primary Progressive Aphasia in 2016. After making the difficult decision to retire from full-time church work, she resolved to use her diagnosis as an opportunity to become an advocate for people living with dementia, helping to "destigmatize this dreaded disease by speaking about it from the inside out."

This year, for the first time, portions of the conference were streamed live on Facebook, giving unprecedented access to those unable to attend in person. Archived videos of the conference, along with slides from presenters, are available on the AFTD website at www.theaftd.org/2018-aftd-education-conference.

The 2019 AFTD Education Conference will be in Los Angeles on Friday, May 3, 2019 – we hope that you will choose to join us!

Facebook Group... (Continued from page 1)

has been much more inclusive, she said, calling it "one of my lifelines."

Dr. Geri Hall, a highly regarded FTD expert and frequent contributor to the closed group, said that part of the group's value is that it gives people a way to talk honestly, without judgment. "There is so much social stigma and shame regarding FTD behaviors," she said. "Families need a safe place."

The group bears the AFTD name, and a small number of AFTD staff members serve as administrators and moderators. But the group is very much a product of its members, who share experiences and information

with each other in a place where those perspectives are deeply respected.

Sheryl Whitman, who lives with FTD, said that she uses the group "both to gain information shared by AFTD and others, and to extend help to other members. To me, it feels like I've had a productive day when I can help people by offering insight and helping them to understand the symptoms of FTD from the perspective of someone diagnosed."

The closed group is accessible at www.facebook.com/groups/52543721114. You can also search for The Association for Frontotemporal Degeneration, and then be sure to select the Closed Group option, distinct from our public

Facebook page. After requesting to join the group, you will be asked to answer a short question about how FTD has affected your life. An AFTD group admin will admit you to the group shortly after you submit your answer. The privacy of group members and their perspectives is of utmost importance to us, and is carefully maintained within this closed group.

"I refer people to the group all the time, and I'm always happy to see that it is growing," Sheryl Whitman said. "And what I tell people is this – the support group will be a great benefit to you."

A Symbol of Hope...



The AFTD 2018 Education Conference's keynote address was sponsored by Christopher Yurkanan of Austin, Texas as a tribute to his wife, Chris Edmondson-Yurkanan.

Chris died from the primary progressive aphasia variant of FTD on May 23, 2017.

"Chris's smile is her signature and a symbol of hope. We will conquer this disease sooner, not later. ONWARD!"

– Christopher Yurkanan

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Those We Honor... Those We Remember

Gifts received from February 16, 2018 - May 31, 2018

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	Bernard Fridovich	Thomas Craig Kohutek	Diana Richardson
	George Gardner	Arthur S. Kranseler	Elaine Richmond

Donations in the name of a loved one bring help and courage for families affected today – and hope for a future without FTD.

Scott Roberts	Ruth Strauss	Su-Ling Chang	Joel McNulty
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David Marshall Scaggs	Michael G. Wallis	Barbara Falzone	Lloyd Roos
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David Kevin Schafer	Keith Warstler	Jeff Grow	Russell Schubert
Nancy Ann (Lawlis) Schlehuser	Wallace R. Watson	Karl Grow	Kevin Searles
Dean Schlosberg	Douglas K. Wehmeier	Alice Guiney	Rebecca Simpsonn
Paula (L'Heureux) Scott	Leonard "Lennie" Weissman	Alice Hale	Roberta Sitler
Steven J. Seitz	Rosemary "Cookie" Weiten	Dennis Harmyk	Bob Smith
Popkin Shenian	Elaine White	Marguerite Harrington	Ellen Solomon
Robert Sherman	Robert Steven Winters	Beverly Hernandez	Elizabeth Stoia
Stephen G. Sherman	Deborah Woodcock	Cathy Hilliard	Jeanette Stoothoff
Lyudmila Shrage	Julie Marie Dickmeyer Zerhusen	Charles Ice	Bill Struzzi
Marshall Silverstein		John James	Wanda Sullivan
Winniford Alwood Simmons, Jr.	In Honor of	Peter Kiesch	Akram Taheri-Azar
Semahat Sinharoy		Estelle Kriticos	Becky Tinsley
Marjorie "Madge" Skoglund	Rebecca Adams	Donna & Bob Kunesh	Kenneth Torrey
William "Slapper" Slavin	Emily Anderson	Michelle Kyriacou	Karen Traxler
Steven R. Smith	George Bird	Christopher Lane	James M. Wexstten
Raymond C. Snell	Roy Bohr	Paul Lester	Sharon Key Wilson
Al Stevenson	Kiddy Bolger	Tracey Lind & Emily Ingalls	Judy Windhorst
John Dale Stewart	Ken Brunner	Travis Martin	Angie Zamberlin

Honor A Loved One... Remember Their Legacy

Families wishing to direct memorial donations to AFTD are encouraged to call our office at (267) 514-7221. 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 and click Donate.

AFTD Announces New Awards Supporting Preclinical Drug Development and Biomarker Research

AFTD is pleased to announce awards in two grant programs that support FTD drug development: Accelerating Drug Discovery for Frontotemporal Degeneration, which funds preclinical research in partnership with the Alzheimer's Drug Discovery Foundation, and the FTD Biomarkers Initiative.

Thomas Kukar, PhD, Assistant Professor at Emory University and a previous AFTD Pilot Grant recipient, was awarded a Drug Discovery grant for his proposal, "Rescue of lysosomal dysfunction, neuroinflammation, and neurodegeneration by lysosomal GRN-2 in a mouse model of PGRN deficiency and frontotemporal dementia."

Dr. Kukar will endeavor to correct deficits caused by the mutation of the GRN gene, one of the most common genetic causes of FTD, in a mouse model of FTD-GRN. Using gene therapy, he will replace small proteins known as granulins that aid in the



Thomas Kukar, PhD



Adam Boxer, MD, PhD



Howard Rosen, MD

breakdown and recycling of worn-out proteins in healthy brain cells, but are lost when the GRN gene is mutated. If adding back the missing granulins can restore normal protein recycling and

Dr. Kukar will endeavor to correct deficits caused by the mutation of the GRN gene, one of the most common genetic causes of FTD, in a mouse model.

decrease abnormal behaviors seen in untreated mice, this approach could lead to new treatments for FTD-GRN.

Adam Boxer, MD, PhD and Howard Rosen, MD of the University of California, San Francisco, received an FTD Biomarkers Initiative award for their proposal, "Individualized clinical and MRI endpoints for clinical trials in frontotemporal lobar degeneration, a

pilot study."

Their study will address an important problem in FTD clinical trials – how to gauge a drug's effectiveness in a disorder with symptoms that vary widely from person to person.

Because of this variability, "one-size-fits-all" outcome measures are poorly suited to evaluating drug responses.

Boxer and Rosen will test a different approach that may be better suited to FTD: monitoring clinical symptoms and using MRI to track changes in key brain regions over short intervals (similar to the spacing of measurements in a clinical trial) to identify the measures that are changing the most in each participant, then using these parameters to construct outcome measures for that individual. These customized profiles will then be used to track disease progression and may ultimately facilitate the evaluation of new FTD treatments.

NAPA Releases Research Recommendations to Improve Dementia Care

On April 27, the National Alzheimer's Project Act (NAPA) Advisory Council released a set of research recommendations stemming from last year's widely attended summit on dementia care hosted by the National Institutes of Health (NIH).

The NAPA council distilled nearly 700 research recommendations, submitted by a broad range of dementia stakeholders, into a list of 58 recommendations grouped into 12 broad thematic areas.

The recommendations "reflect critical scientific priorities for research on care and services for persons with dementia and their families," and "will help guide

investments by a number of public and private stakeholders in the field of [dementia] care, services, and supports," the council's final report says.

AFTD was one of the sponsors of the October 2017 summit, known officially as the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.

AFTD Program Manager Matt Sharp, who attended the summit at the NIH campus in Bethesda, Maryland, said that AFTD in this role "will continue to advocate for services appropriate for all types of dementia, but especially behavioral presentations in people under 65."

Among the 12 areas into which NAPA organized its research recommendations are:

- Clinical Approaches and the Lived Experience of Dementia
- Engaging Persons Living with Dementia and Caregivers as Members of the Research Team
- Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter
- Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers

The NAPA Advisory Council's report, including its full list of research recommendations, can be found on the summit's website.

Giving a Hand to Our Helping Hands!

AFTD Volunteer: Susan Hirsch

Susan Hirsch, MA, has been a highly engaged and active AFTD volunteer for many years. She first reached out to AFTD to help inform her role as Education and Development Specialist at HCR ManorCare. Since then, she has contributed her professional knowledge and talents to AFTD in a number of ways, most notably as a member of the Partners in FTD Care advisory committee.

What is your connection to FTD?

Fourteen years ago, my first resident with FTD moved into our memory care community... That experience was a turning point in my personal and professional life. Since then, I have continued to learn about FTD and to work with caregivers.

"Volunteering will bring hope into your life, as you see the positive effects it has on advancing research, spreading awareness and building a community."

Why did you want to volunteer with AFTD?

I had the privilege of meeting AFTD founder Helen-Ann Comstock, [whose] passion for assisting people with FTD and their caregivers inspired me. Since then, every AFTD staff member and volunteer I have met shares her commitment and dedication. Volunteering lets me give back to an extraordinary association and to others.

Tell us about your volunteer role as a member of the Partners in FTD Care committee.

I have been a committee member with the Partners in FTD Care initiative since its inception in 2011... Being on this committee has been one of my life's highlights. The knowledge and experience I've gained has helped me become a resource to HCR ManorCare, and our community, in the care of FTD.



Susan Hirsch, MA, AFTD Volunteer

For people who are considering volunteering with AFTD, what would you say to them?

Volunteering will change your life. You will partner with experts and dedicated, amazing caregivers. It will also bring hope into your life, as you see the positive effects it has on advancing research, spreading awareness and building a community.

AFTD is grateful for the contributions of volunteers like Susan. AFTD Program Director Sharon Denny says, "Susan's knowledge and compassion are invaluable to the Partners in FTD Care initiative, and we appreciate her sharing her talents as a volunteer."

AFTD Volunteer Impact: A Year in Review

Volunteers founded AFTD, and ever since have been instrumental in giving those affected by FTD the opportunity to find help and share hope. We want to highlight some of the ways our nearly 300 volunteers have made a difference for our community over the past 12 months.

Meet & Greets are informal gatherings that bring the AFTD community together to connect, learn, and share. Last year, there was a 45% increase in the number of Meet & Greets.

Table settings let volunteers represent AFTD and share resources at events such as health fairs and conferences. Table settings went up 105%, reaching more than 10,000 people, many of whom learned about FTD and AFTD for the first time.

Facility outreach visits introduce administrators to FTD information and AFTD resources. Over the past year, we have seen a 36% increase in the number of volunteers taking on this outreach initiative.

Support groups are the best intervention to find

help and share hope available today. The number of AFTD-affiliated support group leaders grew by 28%, and volunteers helped to extend our network of family-care partner support groups to four new states (SD, ND, WI, AL). Additionally, using the online platform Zoom, we opened a second support group for persons diagnosed.

Finally, our **grassroots events** continue to gain momentum. Participation in each type of event went up over the last 12 months:

- Food For Thought up 21%
- With Love up 26%
- Total AFTD-Team runners participating in Race Season up 47%
- The number of Independent Events, led by those pursuing their own passion for AFTD's mission, up 52%

THANK YOU to all who share your time with AFTD!

Visit www.theaftd.org/get-involved/volunteer-network to learn how to volunteer and help others find help and share hope.



AFTD Volunteer Chuck Anastasia and AFTD Regional Coordinator Volunteer Doreen Putnam devote their time to advancing AFTD's mission!

The Race Is On

And they're off—the AFTD-Team's 2018 Race Season is officially underway! Three great races are already in the books: Colfax Marathon (Denver, CO), Rock 'n' Roll Marathon (Seattle, WA) and Fit Foodie 5K (Austin, TX). During those three races, 118 teammates raised more than \$9,700 - but keep your hammies loose, the season's not over yet.

There are still opportunities across the country to run for the cause as AFTD's race season goes forward:

- **Los Angeles Rock 'n' Roll Marathon (CA): October 28, 2018**
- **Philadelphia Marathon (PA): November 17-18, 2018**
- **Dallas Marathon (TX): December 7-9, 2018**
- **Austin Marathon (TX): February 17, 2019**



Along with putting in the miles, some teammates took their participation to the next level by fundraising for the AFTD-Team via our Classy fundraising platform.

Seattle Rock 'n' Roll Team

Angie Zamberlin Family Team
Butterfield Family
Julie Morris
Lisa Nolte
Patrice Hollrah
Rachel Yost
Stephanie Howard
Susan Stark

Colfax Marathon Team

Fenoglio Family Racers
Peter Reaves

Fit Foodie Team

Craig Tomes
Elizabeth Hubenak
Zoy Kocian



Visit our official AFTD-Team 2018 Race Season page for fundraising opportunities, and the chance to run for free by supporting AFTD's mission.

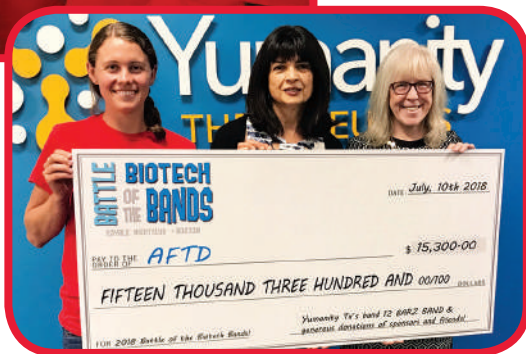


Prep Time:	Now
Cook Time:	September 23–October 7, 2018
Ingredients:	Food, Drink & Education
Serves:	All 50 States

Directions for Food for Thought 2018

1. It's time to start thinking about AFTD's 6th Annual Food for Thought Campaign. Team up with friends and family, or plan something yourself. Any event—big or small—as long as it involves food and a little FTD education.
2. Your event can take place any day during the two-week period from September 23 through October 7, 2018.
3. Planning an event is easy. AFTD staff and volunteers are here to help! Share your story, raise awareness and raise vital funds to support AFTD's mission in your community.
4. Put your state on the map to show nationwide resolve against this disease. Email AFTD's Grassroots Events Coordinator, Bridget Graham at bgraham@theaftd.org to get started.

THE AFTD-TEAM



Subterranean Biotech Blues: The Battle of the Biotech Bands brings biotech companies and innovators throughout Boston together to rock out in support of charity. At the fifth annual Battle of the Biotech Bands this past May,

AFTD was the chosen charity recipient for 12 Barz Band, a participating band whose members include representatives of Yumanity Therapeutics, Biogen, Charles River Labs, the Broad Institute, and Bluefin BioMedicine. AFTD was awarded \$15,300 from the event, and would like to extend a heartfelt thank you to all involved – especially the talented 12 Barz Band!

Bowled Over: Cindy and Ken Brunner of Wisconsin hosted an open house and sold wooden bowls, proceeds of which were donated to AFTD. Ken, who has FTD, handcrafts these wooden bowls himself. He created and sold so many, they were able to donate \$3,020.

Where There's a Wild There's a Way: Kaitlyn Heffron from Nebraska is embarking on a five-month hike of the Pacific Crest Trail to raise funds for AFTD and awareness of FTD. She's set to start mid-July and her fundraising page has already raised \$1,000.

Family Business: Bluffview Memory Care in Wisconsin hosted a "Mother and Daughter Sip n Paint" event which raised \$262, which was donated to AFTD.

Appalachian Sensation: Matt Pelton, former AFTD HelpLine Adviser, hiked the Appalachian Trail to raise funds for AFTD (\$1,965) and awareness of FTD. While working at AFTD, Matt discovered that he wants to devote his future career as a physician and researcher to understanding, learning about and treating this disease. He reached the summit of Katahdin on June 17th (three months after he left) and then on July 7th, he embarked on his next journey: Penn State College of Medicine.



Done in Love...

These campaigns remembered loved ones powerfully and raised vital funds to support our mission.

Celebration of Life: Diane Cole of Michigan held a Celebration of Life for her husband, Chuck, who passed away from FTD on April 28th after a seven-year fight. This is the first of two events she is hosting in Chuck's memory, each representing an important location to them: where they resided when he passed and where they grew up. The first event raised \$3,940.

Remembering Jacqueline: Kaj Malden's mother, Jacqueline Malden Phelps, passed away on April 1st from FTD. In her memory, he created an online donation page where he shared kind words about his mother and facts about the disease itself. His page has raised \$1,289 so far for AFTD.



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Frontotemporal Degeneration
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