



AFTD news

AFTD Joins Diagnostics Accelerator Initiative

In January, AFTD announced it will leverage support from our generous donors to invest \$2.5 million in the *Diagnostics Accelerator* program, an initiative of the Alzheimer’s Drug Discovery Foundation (ADDF).

AFTD’s investment will be matched by an additional \$2.5MM from the *Diagnostics Accelerator* initiative, which received initial funding from Bill Gates, ADDF co-founder Leonard A. Lauder and other philanthropists. The result will be \$5 million dedicated to the development of FTD biomarkers.

A biomarker – such as blood pressure for cardiovascular disease or blood-sugar level for diabetes – provides measurable evidence of underlying disease. Biomarkers are an essential tool for the early diagnosis and effective treatment of many conditions.

“Today there are no biomarkers for FTD,” said ADDF’s Founding Executive

Director and Chief Scientific Officer Howard Fillit, M.D. “The \$5 million in new FTD research will include awards to fund exploration for new biomarkers that can help accurately diagnose and track the progression of FTD. It will also enable us to add an FTD arm to



Alzheimer’s Drug Discovery Foundation

large validation studies funded by the *Diagnostics Accelerator*.”

AFTD has enjoyed a longstanding research partnership with the ADDF, forged through a shared belief that advances in the scientific knowledge base regarding one form of dementia may lead to breakthroughs in other related conditions. AFTD’s most recent

investment represents an expansion of the scope of AFTD’s FTD Biomarkers Initiative, launched in 2016.

Overall, the *Diagnostics Accelerator* program will provide more than \$35 million toward more effectively diagnosing all forms of dementia.

“We know today that addressing neurodegenerative disease in any form requires a collaborative effort,” said AFTD CEO Susan L-J Dickinson, M.S., CGC. “AFTD has a long history of research collaboration with the ADDF, and we are grateful to be joining forces again, in collaboration with Bill Gates and other generous funders.

“ADDF and AFTD’s partnership may expand based on emergent opportunities as we continue to pursue our organizational missions,” she added.

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Our Plan, Our Future: AFTD Unveils 2019-2022 Strategic Plan

In December 2018, AFTD’s Board of Directors voted to adopt a new Strategic Plan for our work through June 30, 2022. The plan – now publicly available via AFTD’s website – presents our vision to advance a world with compassionate care, effective support, and a future free of FTD.

Written with input from a range of experts – including many with lived experience of the disease – the plan will amplify AFTD’s work as the leading authority focused on FTD, and will guide us in sustaining the

organization at the scale needed to fulfill our mission.



It focuses on advancing early and accurate diagnosis of FTD, developing new treatment options, educating health professionals, and bringing AFTD’s national impact into local communities.

AFTD will create new resources to inform and empower our constituents; expand our education, awareness and advocacy efforts; and work to help people access vital FTD care and support in their own local communities.

(Continued on page 4)

Spotlight on...Kacy Kunesh, AFTD Board of Directors

Kacy Kunesh traveled the world after graduating from the University of Texas at Austin, working as a development and communications specialist in Europe and the Middle East. But after her mother Donna received a diagnosis of behavioral variant FTD at age 59, Kacy decided it was time to come home.



Kacy Kunesh

"I found myself sitting in a very nice office overlooking the Dubai International Financial Centre, and I just wasn't present," said Kacy, who joined the AFTD Board of Directors in 2017. "I told my CEO that as much as I loved my job, my mind and my heart were in Texas."

Like many FTD families, the Kuneshes endured a lengthy series of misdiagnoses – it took years before specialists correctly identified Donna's condition. Kacy's father Bob took early retirement to

become a full-time care partner, and Bob and Donna uprooted their lives in Houston to move closer to Donna's medical team.

Kacy quickly learned to trust her instincts when making caregiving decisions. She also determined that living as an FTD care partner should be meaningful – for herself, her family and others facing similar situations who could benefit from her experiences.

"I found myself having to repeatedly make fight-or-flight choices to make sure my mother remained safe and healthy," she said. "I decided that I didn't want to just survive – I needed to be an agent of change, so no one else will have to walk in my shoes."

An essential part of Kacy's journey with AFTD has included advocating for the

needs of younger care partners like herself. She is active in AFTD's Young Adult Facebook Support Group, and has led discussions at several AFTD Education Conferences. She has also been an invited speaker to illuminate the challenges faced by caregivers and dementia families.

She hopes her future work as a Board member – and as an advocate for greater FTD awareness, advocacy and education – will help further the understanding and treatment of FTD.

"I feel like I represent a demographic not typically thought of as affected by dementia," she said. "But it has affected every decision I've ever made since the moment

we got the diagnosis. And I'm not alone. We are the successors who are inheriting all the challenges FTD presents, and I want to see a cure in my lifetime."

"I feel like I represent a demographic not typically thought of as affected by dementia," Kunesh said. "But it has affected every decision I've ever made since the moment we got the diagnosis."

AFTD NEWS BRIEFS

Development Manager Joins AFTD Staff

Amanda Knight joined AFTD as Development Manager in November 2018. She brings more than eight years of progressive nonprofit development experience, including four years with the Greater Philadelphia Chapter of the ALS Association, where she managed donor databases and supported a wide range of the organization's fundraising efforts. As a member of AFTD's development and communications team, Amanda manages individual giving (including annual campaigns); corporate and foundation fundraising; AFTD's donor database and foundation metrics; donation processing and acknowledgement; and the expansion of the organization's digital fundraising.

AFTD Seeks Education Program Manager

AFTD is now hiring an Education Program Manager. This vital addition to our staff will develop and implement FTD education initiatives for healthcare professionals – a crucial component of reaching and better serving all persons affected by FTD. The Education Program Manager will identify strategic opportunities to engage a wide range of professionals who influence the physical, emotional, social, economic and spiritual aspects of care for people with FTD and their families. The full job posting can be found on AFTD's website.

AFTD Thanks a Regional Coordinator Volunteer

New England Regional Coordinator Volunteer Doreen Putnam has stepped down from her volunteer leadership role after almost two years in the position. Her passion for the AFTD community, teamwork approach, and professional perspective will be missed. She will, however, continue to be an AFTD volunteer – raising awareness, sharing information and supporting care partners on their journey. AFTD Volunteer Manager Kerri Keane is now overseeing the region. If you live in New England, feel free to contact Kerri directly at kkeane@theaftd.org to get involved.

National Volunteer Appreciation Week: April 7-13

Thank you to all of our volunteers for the valuable contributions you have made to help us achieve our mission! Each year, AFTD celebrates the accomplishments of all our volunteers during National Volunteer Appreciation Week. Through your service, AFTD is able to have a broader impact, giving us a stronger presence on the ground in communities across the country. AFTD put together a tribute video to our volunteers, which you can watch at theaftd.org.

OUR PLAN, OUR FUTURE

Neuroscience has been a major area of interest for me for more than 15 years. It became personal when my father received his FTD diagnosis. Like many families facing this disease, we knew what that meant: from then on, we would only have a finite amount of time with him, and we should make the most of it. Still, I can't help but think what our experience might have looked like if there were viable treatment options available to people with FTD. That is one of the main reasons why I've dedicated my career to FTD research, and why I'm proud to serve AFTD's mission as a 2017-2019 Postdoctoral Fellow.

Organizations like AFTD are doing important work by bringing greater awareness to this condition, educating clinicians in an effort to reduce misdiagnosis, and funding research in the hopes of a future free of FTD.



Joseph-Patrick Clarke, Ph.D.
University of Pittsburgh
Recipient of AFTD's 2017-2019 Postdoctoral Fellowship

As detailed in this issue's cover story, AFTD has released its **FY2019-22 Strategic Plan**. Developed with input from FTD experts – including scientists, health professionals, and many whose expertise originates from lived experience of the disease – our plan seeks a world with compassionate care, effective support, and a future free of FTD.

Since 2002, AFTD has worked with our community to make crucial gains on behalf of all facing FTD. Our plan builds from those experiences, and offers a road map to realizing the future that we all so urgently seek.

Achieving that goal will require contributions from each of us. Dr. Clarke chose to dedicate his career to FTD research. **Today AFTD asks that you choose to support our mission with a charitable gift.**

By making a donation of any size, you can support increased public awareness and provider education, early and more accurate diagnosis, crucial advancements in research, more accessible support services, and national advocacy efforts to benefit all affected by FTD.

Every contribution to this mission – whether from AFTD volunteers, advocates, or through feedback from those we serve – is essential. The engine that makes that shared work possible is donor support.

We hope you'll join us by making a gift using the enclosed envelope or by donating online at theaftd.org. Together, we can bring a future free of FTD closer with each passing day.

To make your gift online, go to www.theaftd.org and click on the **Donate button** at the top of the page.

AFTD Brings Annual Education Conference to Los Angeles

Hundreds of people whose lives have been affected by FTD will attend the 2019 AFTD Education Conference in Los Angeles for a day of learning, sharing and connecting with others in the AFTD community.

Leading experts from UCLA, USCF, the University of Washington and elsewhere will present on recent advances in understanding FTD as well as new perspectives on research, care and support. Afternoon breakout sessions will focus on clinical issues and care strategies, and will also provide the opportunity to network with others who understand the FTD journey.

Other breakout sessions will focus on behavioral variant FTD, primary progressive aphasia, and FTD/ALS.

Emmy Award-nominated actor Martha Madison – best known for her role as Belle Black on *Days of Our Lives* – will offer this year's Keynote

Address. Madison has been an FTD care partner to her mother, Barbara Baggs, for more than 15 years. She is an active AFTD volunteer and was featured in an AFTD public service announcement in 2017, in which she delivered the awareness message "Think It's Alzheimer's? Think Again."

Actress, activist and FTD care partner Martha Madison will offer this year's Keynote Address.

Register for the conference at tinyurl.com/AFTD2019, but hurry – registration closes on April 29. The conference will run from 8:45 a.m. to 5:30 p.m. at the Los Angeles Airport Marriott. A social reception open to all attendees will immediately follow.

AFTD offers modest financial assistance, in the form of Comstock Travel Grants, for people with FTD and care partners wishing to attend.



**FIND HELP.
SHARE HOPE.**

These grants are designed to defray the cost of travel, lodging and conference fees. More information can be found on the Comstock Grants section of AFTD's website.

For those who can't make it in person, portions of the 2019 AFTD Education Conference will be live-streamed. Visit theaftd.org for more information. Archived videos and audio recordings of plenary and most breakout sessions will be made available in the days following the conference.

2019-2022 Strategic Plan... *(Continued from page 1)*

"AFTD strives to be a voice for all people affected by this disease. At the same time, we know that there are communities we haven't reached," said AFTD CEO Susan L-J Dickinson, M.S., CGC. "Our new Strategic Plan endeavors to find those who've slipped through the gap and aid them in receiving the attention and care they need."

AFTD's new Strategic Plan will amplify our work as the leading authority focused on FTD.

As highlights of this work, AFTD will:

- Expand the scope and impact of its volunteer program.
- Advance early and accurate

diagnoses and the development of successful treatments.

- Empower our community to advocate for high-quality dementia care and healthcare professional education.

This ambitious plan will require AFTD to expand its staff by approximately 50 percent by June 2022, in a sustainable way. Achieving the impact that this community deserves will require support from thousands of volunteers

"Our Strategic Plan would not have come together without the valuable input of the people we serve," said AFTD CEO Susan L-J Dickinson.

and donors.

"Our Strategic Plan would not have come together without the valuable input of the people we serve. Now, we must work together to make our shared vision a reality. My hope is that when you read this plan, you will envision a future we can all be proud to be part of," Dickinson said.

If you would like to learn more about this plan and our vision for the future, and how you can help to make it possible, please read more on page three of this newsletter, and at theaftd.org.

AFTD Convenes Industry Leaders, Researchers for TDP-43 Workshop

In February, AFTD hosted a workshop on the development of TDP-43 biomarkers for FTD and ALS, bringing together researchers, scientists and key opinion leaders from industry and academia to consider the possibility for improved diagnostic tools in dementia.

The meeting – held in Miami on February 27 – builds on AFTD’s ongoing commitment to developing FTD biomarkers. Biomarkers provide measurable evidence of current or potential disease. Validated biomarkers regularly used in clinical practice include high blood pressure for coronary artery disease and blood sugar levels for diabetes.

“As any family living with FTD knows, this disease is extremely challenging to diagnose,” said AFTD Chief Executive Officer Susan L-J Dickinson. “Currently, a person with behavioral variant FTD endures more than three years of delayed diagnosis, typically complicated by a series

of misdiagnoses along the way. Creating effective biomarkers would point the way toward faster, more accurate diagnoses – and, potentially, drug development.”

In recent years, TDP-43 has emerged as a potential biomarker for both FTD and ALS. “TDP-43 is a protein that forms abnormal clumps in the neurons, or brain cells, of about half of people living with FTD,” said AFTD Research

AFTD convened a group of researchers, scientists and key opinion leaders from industry and academia to consider the possibility for improved diagnostic tools in FTD and ALS.

Manager Debra Niehoff, Ph.D. “A biomarker that allowed us to detect and measure TDP-43 would aid in FTD diagnosis and could also help researchers recruit people into the right clinical trials.”

The assembled scientists and researchers discussed the potential for fluid biomarkers, which can be measured in blood, serum or cerebrospinal fluid, and imaging biomarkers, which can be seen on scans. Participants stressed that the ability to distinguish FTD

associated with TDP-43 from FTD associated with tau, the other protein commonly affected in FTD, is a key unmet need in clinical practice.

Because TDP-43 is often found in very small quantities, many researchers have not discovered how much is needed to measure for an effective biomarker, Dr. Niehoff said. “It’s a big outstanding question we need to resolve,” she said. “For example, in brain imaging, there has to be enough to recognize a signal against your background.”

The meeting also offered an update on scientists funded by the FTD Biomarkers Initiative.

“We are very pleased with the progress our grant recipients are making” Dr. Niehoff said. “All of this work and investment moves us closer to the possibility of a much-needed FTD biomarker.”

AFTD thanks the generosity of the workshop’s co-sponsors, Target ALS and the ALS Association.

AFTD gives special thanks to the sponsors of the TDP-43 Workshop, Target ALS and the ALS Association.



Those We Honor... Those We Remember

Gifts received from October 16, 2018 – February 15, 2019

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In Honor of

Honor a Loved One or 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 select "Donate+"

AFTD Pilot Grants Highlight Emerging Approaches to FTD Research

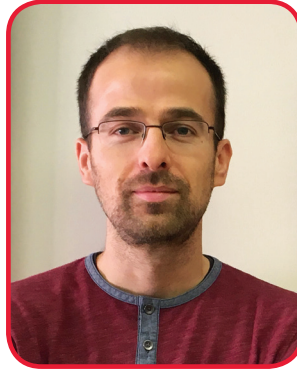
AFTD awarded its 2018 Pilot Grants to Paschalis Kratsios, Ph.D, of the University of Chicago, and Liam Chen, Ph.D., of Johns Hopkins University. The Pilot Grant program annually confers funding to early-career investigators focused on FTD.

“AFTD’s Pilot Grants lay the groundwork for tomorrow’s scientific breakthroughs by providing seed funding for innovative research projects,” said Debra Niehoff, Ph.D., AFTD’s research manager. “The program exemplifies the way AFTD prioritizes cutting-edge science in the future of FTD research.”

Dr. Kratsios received the 2018 Basic Science Pilot Grant. He will use the funds

to re-engineer the genome of the roundworm *Caenorhabditis elegans* in order to study human disease-causing mutations. By developing transgenic worms with the C9orf72 mutation – the most common seen in FTD – Dr. Kratsios hopes to learn why the gene

“AFTD’s Pilot Grants program exemplifies the way AFTD prioritizes cutting-edge science in the future of FTD research,” AFTD Research Manager Dr. Debra Niehoff said.



Paschalis Kratsios, Ph.D.

defect has such a toxic effect on brain cell degeneration.

“Genetically engineered mice have been a mainstay in FTD research,” Dr. Niehoff said. “Ultimately, this new animal model could point to new strategies for developing FTD treatments.”

Dr. Chen received the Susan Marcus Memorial Fund Clinical Research Pilot Grant. He plans to examine the transcription of information needed to make proteins encoded in genes into



Liam Chen, Ph.D.

the molecular messenger RNA (mRNA).

“Before it can serve as a template for protein synthesis, mRNA must first be edited by cutting and sewing the segments needed for a job, just as a film editor splices footage to craft a movie,” Dr. Niehoff said. “In healthy brain cells, the protein TDP-43 acts as a quality control manager during the editing process, but TDP-43 oversight is lost in FTD. As a result, the mRNA contains ‘extra footage’ that can lead to the formation of defective proteins.”

Dr. Chen will attempt to identify these extraneous pieces of RNA, called *cryptic exons*, in postmortem FTD brain tissue. FTD-specific cryptic exons could potentially serve as biomarkers or starting points for future drug development.

AFTD Joins NIH-Funded Biomarkers Consortium

AFTD has joined the Biomarkers Consortium, an ongoing project sponsored by the Foundation for the National Institutes of Health (FNIH). As a partner in this organization, AFTD will have the opportunity to identify and develop high-impact biomarkers to advance the diagnosis, treatment and scientific knowledge base of FTD.

There are currently no scientifically validated biomarkers available for FTD, but scientists and healthcare professionals agree that such developments are essential for the future understanding and treatment of FTD. The Alzheimer’s Drug Discovery Program recently launched the *Diagnostics Accelerator* program, of which AFTD’s FTD Biomarkers Initiative

is a member, to speed the discovery of dementia biomarkers. [See page 1 of this issue for more information on the *Diagnostics Accelerator* program.]

Some potential FTD biomarkers have already emerged, though they

As a partner in the Biomarkers Consortium, AFTD will have the opportunity to identify and develop high-impact biomarkers to advance the diagnosis, treatment and scientific knowledge base of FTD.

remain unvalidated and should not be considered definitive at this time. Neurofilament light chains – a marker of nerve damage that has been validated as a biomarker for ALS and multiple sclerosis – is currently under investigation as a possible FTD biomarker.

As a partner of the Biomarkers Consortium, AFTD will have access to research funding, collaboration and data sharing with other public- and private-sector members.

“Collaboration and partnership are at the center of scientific discovery,” said AFTD Scientific Director Nadine Tatton, Ph.D. “AFTD is proud to partner with the FNIH in this important endeavor, which will hopefully speed the development of biomarkers for FTD. As there is currently no standard course of treatment and no cure for FTD, the ability to accurately recognize signs of disease and progression as early as possible is urgently needed.”

Giving a Hand to Our Helping Hands!

AFTD Volunteer: Amy Almeida

AFTD volunteer Amy Almeida and her family used AFTD's resources for care partners throughout her mom's FTD journey. She was inspired to become an AFTD volunteer for two reasons. First, she wanted to give back after AFTD helped her family provide her mom with the highest-possible quality of life. She was also inspired to act after getting to know fellow AFTD volunteer and AFTD-affiliated support group facilitator Katie Brandt, who has turned her own family's FTD journey into her life's work. Amy's interactions with Katie ignited her drive to do the most she can for the AFTD community.

Amy has volunteered for AFTD for more than four years, as both an affiliated support group facilitator and a community awareness volunteer. AFTD is grateful for Amy's dedicated service to our community and organization.

What has been the most cherished memory you've made while volunteering for AFTD?

I was approached to become a support

group facilitator, and despite having some doubts about my suitability for such a role, I took it on and have been facilitating a group for four and a half years. I cherish the feedback I receive after I've helped caregivers through a rough patch. It is extremely rewarding to be able to use my experiences as an FTD caregiver to help others traveling a similar journey.

As a community awareness volunteer, why do you participate in table settings?

I enjoy table settings because you often meet people who have never heard about FTD before. It's incredibly rewarding to educate people about this devastating disease. Being able to provide resources to health professionals who may have never seen a case of FTD gives me hope that families will not have to struggle to be correctly diagnosed in the future.

How do you see your volunteer efforts contributing to AFTD and its mission?



Amy Almeida with her mother, Elizabeth

AFTD's motto is "Find Help - Share Hope." I see my volunteer efforts as embodying this phrase. Table settings let me point persons diagnosed, their families and health professionals to vital AFTD resources, enabling them to find help. Facilitating a support group enables me to share hope with other FTD caregivers simply by validating their experiences and sharing my own.

What would you tell someone considering volunteering with AFTD?

It's a good way to give back to an organization that has helped so many people affected by FTD. There are opportunities to do as much or as little as you'd like. Volunteering with AFTD doesn't have to be a huge time commitment.

Volunteer Advocacy in Action in Washington, DC

When it comes to advocacy, AFTD uses a variety of channels to be a voice for the community, advocating for research and appropriate, affordable services. Volunteers play a key role in this mission area by partnering with AFTD and sharing their stories at the National Alzheimer's Project Act (NAPA) Advisory Council meetings. These courageous volunteers present comments to ensure that FTD remains a part of the dementia conversation on a federal level.

NAPA became law in 2011. It authorizes the Department of Health and Human Services to develop and maintain a National Plan for Alzheimer's disease and related dementias, with input from a public-private council on Alzheimer's Research, Care and Services. The

NAPA Advisory Council recommends ways to expand, coordinate and condense programs in order to improve the health outcomes of people with dementia.

Since 2012, AFTD staff and volunteers have been attending NAPA Council meetings and providing input from the perspective of those affected by FTD. The meetings are held quarterly in Washington, DC and are open to the public. Over the years, several volunteers have raised their hand and presented comments.

Middle Atlantic Regional Coordinator Volunteer Sarah Sozansky Beil shared why she provided comments to the Council last summer. "I felt that having been directly impacted, I was obligated to tell my story so that FTD is recognized by lawmakers

and other community members -- so they don't forget the devastating effects it can have on families," she said. "It was important for me to show the members that people affected by FTD can be younger, and that they may even have young kids.

"The experience was extremely rewarding," Beil continued. "I felt like I was making a difference. It is our job to tell our stories and ensure that members of Congress and other government officials hear us. They cannot know how devastating the disease is unless we speak up and advocate for ourselves."

If you are interested in volunteering to make comments at a NAPA Council meeting, please contact AFTD Program Manager Matt Sharp at msharp@theaftd.org.



FTD strikes at the heart of who we are, bringing progressive, irreversible changes to behavior, personality, language and movement. This past February, through AFTD's *With Love* 2019 Campaign, hosts responded by sharing their stories of love and raising funds to support AFTD's mission.

A record setting number of hosts—31—courageously shared their stories and together, raised more than \$47,000! Of those 31 hosts, 23 were first-time *With Love* hosts (and 17 were first-time fundraisers all together).

Hosts shared their stories of love on Classy, the primary fundraising platform for the *With Love* campaign, as well as via Facebook fundraisers – a new option for this year's campaign. Community members interested in supporting the campaign could make a donation, post a picture of their loved one(s) and share a message of hope on our "Wall of Love" – also new to this year's campaign.

AFTD shared powerful host stories via Facebook and Instagram, raising awareness and showing the world that **love is more powerful than any disease.**

AFTD would like to extend a huge thank you to everyone who was involved in the success of this year's campaign: our two generous campaign sponsors, Beth Walter and The Rainwater Charitable Foundation; the more than 300 people who made donations; and of course, our campaign hosts who courageously shared their stories of love to spread awareness and raise funds.

Carol Almeranti	Jacquelyn Syberg	Laynie Dratch	Sarah Morazzini
Cheri Connely	Karine Adalian	Leonard Broyles	Sheryl Whitman
Christine Groth	Kat Primeau	Lisa Kesecker	Susan Scarff
Cindy Odell	Kathy Fimian	Lori Cox	Tara Jones
Dale Latimer	Katie Caruso	Melissa Fisher	Terry Pontious
Debonnaire Kovacs	Katrina Hellman	Nicole Totton	Tiffani Moore
Dom Fabich & Amanda Dawson	Kimberly Sullivan Chu	Rachael Martinez	Victoria Van Kirk
Elizabeth Hubenak	Krista Glodt	Ruth Scott	

Race Season

The AFTD-Team has done it again: set a record-breaking Race Season! AFTD collaborated with six races across the country during 2018 and had more than 245 teammates run or walk approximately 1,325 miles and raise over \$75,000! Our final two races of the season (the Philadelphia Marathon and the Dallas Marathon) are responsible for raising \$63,000 of that total. This could not have been possible without the phenomenal efforts of:

Team Jack Attack	Alison, Bo and Martha	Darcy Topolski	Reller Thomas
Poppy's Posse	Joe Fischel	Amber Dickson	



Martha Madison, from *Days of Our Lives*, and her sisters Alison and Bo ran in the Dallas Marathon in honor of their mother, who is currently living with FTD.

THE AFTD-TEAM

A MEMORIAL FOR THE PHILADELPHIA MARATHON FRONTOTEMPORAL DEGENERATION

FALL OPEN HOUSE

KEN BRUNNER'S HANDMADE BOWLS

Ken has been hand at work, hand-crafting wooden bowls, since 1998. Unique handmade bowls will be available. All donations made will be given to the Association for Frontotemporal Degeneration. Light refreshments will be served. We hope you will join us!

NOVEMBER 10, 2018
1:00-4:00
9171 Ridge Drive
Mousethorpe, WI 53572



Heart and Bowl: For the second time, Ken Brunner of Wisconsin, who has FTD, and his wife Cindy invited people to their house to buy Ken's handmade wooden bowls. After successfully selling \$3,020 worth of bowls during their first event, round two sold an impressive \$4,760 – all of which was donated to AFTD.

Ken Brunner, who has FTD, showing off his impressive handmade wooden bowls.

Topping Their Goal:

Nicole DeLeve of Kansas held two fundraisers that raised a combined total of \$1,574. One event was her second annual "Fresh, Tasty and Daring" hot dog fundraiser, where participants could top their hot dogs with over 40 toppings. At the other, Nicole baked and sold over 300 gourmet cupcakes to honor the birthday of her father, who passed away from FTD.



Just half of the toppings available at Nicole DeLeve's hot dog fundraiser.

Love Letters: AFTD Board member Paul Lester hosted his 12th annual letter writing campaign in memory of his late wife Arnette. Paul sent old-fashioned paper letters, but he also used the convenience of the online fundraising platform Classy to send electronic versions. After all letters were sent out, his campaign raised a total of \$15,133. Over the past 12 years, his letter writing campaign has raised more than \$133,000 towards the fight against FTD.

A Search for Support: For the second year in a row, Rob Radtke designated AFTD as one of the charities for Google Giving Week and raised \$6,940. As a Google employee himself, Rob's efforts kicked off in 2017 when he lived in California, but he continued his support of AFTD in 2018 from his current home base of Zurich, Switzerland.

Sold!: During the months of September and October, the Berg Larsen Group, a real estate team affiliated with Coldwell Banker Burnet in Minneapolis, pledged to donate \$100 to AFTD for every new property they list for sale. It was a successful two months for the #BLGTeam – they donated \$1,700 to AFTD.



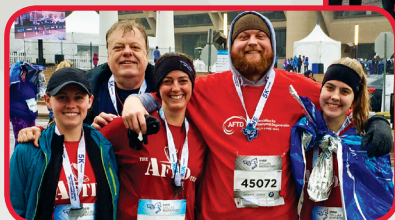
The sales team at the Berg Larsen Group, featuring Nanci Anderson, whose husband is currently living with FTD.

Generous Gathering: Ken Simon of California hosted an 80th birthday party for his dad. In lieu of gifts, he asked attendees for donations to AFTD in honor of his mom, who is currently living with FTD. The party was a great time for all and raised \$1,421 towards our mission.

Putting the Fun in Fundraiser: Camp Ramah in the Berkshires, an overnight camp in upstate New York, held a summer fundraiser in memory of a camper's father who passed away from FTD in 2017. Together, the campers were able to raise and donate \$1,025.



The AFTD-Team at the Philadelphia Marathon, our biggest team yet: 90 participants.



AFTD Special Events Manager Bridget Graham and the Topolski Family stuck around after a cold and rainy Dallas Marathon to snag one picture together.



Poppy's Posse was a sub-team of the AFTD-Team at the Philadelphia Marathon and came out in full force.



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

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