



AFTD news

2021 FTSG Meeting Sees Development of FTD Treatments Gaining Ground

On December 8 and 9, 2021, AFTD held its biannual meeting of the FTD Treatment Study Group (FTSG). This meeting – designed to accelerate the development of effective treatments for FTD disorders by creating a pre-competitive space where companies will be willing to work together – convened almost 200 representatives from academic research, biopharma, advocacy organizations, and government agencies.

FTSG is an invitation-only meeting, bringing together experts from across the field to address pressing FTD research needs. The 2021 event was held both in person in Silver Spring, Maryland, and online via livestream. FTSG allowed researchers to offer insights from their own work and collaboratively brainstorm on ways to ensure the success of future clinical trials.



The meeting was chaired by scientific leaders Adam Boxer, MD, PhD, of the University of California, San Francisco; Michael Gold, MS, MD, of AbbVie, Inc.; and Howard Feldman, MD, of the University of California, San Diego. AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD, and AFTD Director of Research and Grants Debra Niehoff, PhD, organized the event in partnership with the co-chairs.

Momentum in FTD research is building. Following the first AFTD-led FTSG meeting more than a decade ago, in 2011, leading experts concluded that research had advanced to where scientists could start developing FTD therapies. Today, multiple biopharma companies are investing in active clinical trials for potential treatments. At FTSG 2021, six biopharma companies presented their design for trials that are actively recruiting FTD participants. More are on the horizon.

(Continued on page 4)

INSIDE THIS ISSUE

- Spotlight on Dr. Halima Amjad.....2
- News Briefs.....2
- Spring Appeal.....3
- FTSG (continued).....4
- New Grants.....5
- Donations.....6-8
- Brain Banking.....8
- Volunteer Profile.....9
- Volunteer Appreciation.....9
- The AFTD-Team.....10-11

Remembering John Q. Trojanowski, Founding AFTD Medical Advisory Council Member

On February 8, John Q. Trojanowski, MD, PhD, a founding member of the AFTD Medical Advisory Council (MAC), died at age 75. Dr. Trojanowski was a groundbreaking figure in the study of neurodegenerative diseases. He was a tremendous friend to AFTD and a powerful advocate for the community we serve.



A neuropathologist by training, Dr. Trojanowski made critical contributions to advancing understanding of the biological basis of neurodegenerative disorders, particularly Alzheimer’s and FTD. His

work helped define the framework of FTD neuropathology used today.

In partnership with his wife and lifelong professional partner, Virginia M.-Y. Lee, PhD, Dr. Trojanowski and their team made discoveries that transformed the field of FTD research. Their 1991 discovery regarding the role of the protein tau in the tangles seen in Alzheimer’s disease represented a breakthrough for all tauopathies. Later, they identified the TDP-43 protein as the primary pathology found in both ALS and about half of all people with FTD.

(Continued on page 5)

Spotlight on...Dr. Halima Amjad, AFTD Board of Directors

Halima Amjad, MD, MPH, knew she wanted to be a doctor since she was a child, but her career trajectory wouldn't be determined until her father was diagnosed with FTD in 2008.

Dr. Amjad, a geriatrician and assistant professor of medicine at the Johns Hopkins University School of Medicine, has dedicated much of her medical career to dementia research and assisting other families impacted by dementia, including FTD. "I feel an obligation and duty to provide what service and support I can," she said.

"It's entirely my dad's illness and journey that brought me to doing the work in my career," she added.

In his late 50s, her father, who immigrated from Pakistan to the U.S. in the 1970s, began having trouble with his language and finding words. The once easygoing, humorous, and

laid-back dentist that Dr. Amjad and her family once knew became gruff, indifferent, and easily frustrated. A diagnosis of primary progressive aphasia (PPA) followed.



Dr. Halima Amjad

Despite her medical background, Dr. Amjad said that she didn't know much about FTD at the time. She turned to online resources and attended support groups and conferences to learn more. An AFTD event she and her mother attended provided her first opportunity to connect with others who truly understood the FTD experience.

"We've always appreciated the opportunity to see and connect with other families," Dr. Amjad said. "We have used tips that other caregivers have shared for dealing with issues like incontinence and wandering."

Dr. Amjad, who delivered the keynote address at AFTD's 2017 Education

Conference, joined AFTD's Board in April. Along with her personal FTD experiences, Dr. Amjad said she intends to add to the Board the "view of a clinician and a geriatrician that straddles primary care as well as specialty dementia care."

Dr. Amjad continued: "I [intend] to leverage those experiences – my knowledge of the healthcare system and challenges families living with dementia are facing – while also thinking of how AFTD can advance education and awareness about FTD."

As PPA continues to affect her 72-year-old father, who has spent the last two years on hospice, Dr. Amjad said that she and her family value the remaining time they get to share with her "soft-hearted, generous" father.

"We cherish all of the time that we've had with him, even if he couldn't speak or we couldn't do everything," she said. "The moments we could still sit with him, laugh with him, smile with him, watch our videos, look at our pictures—it's something we all hold dear."

AFTD NEWS BRIEFS

AFTD and FTD Disorders Registry Co-Presenting Special Webinar Series

Today, there are more opportunities to participate in FTD research, including studies designed for FTD-diagnosed persons, care partners, family members, and those at risk for developing FTD. Finding studies and understanding what it takes to participate can be confusing. The "Perspectives in FTD Research" webinar series, co-presented by AFTD and the FTD Disorders Registry, examines specific aspects of the FTD research process to help you become an informed research participant. The first two "Perspectives in FTD Research" webinars of 2022 – "FTD Biology and Testing: Why Do You Need My Samples?" and "Amplifying Your Voice in FTD Research: Why Am I Asked So Many Questions?" – are available to view at AFTD's YouTube site (youtube.com/theAFTDorg). Future webinars in the series will be announced in the coming months.

AFTD Medical Advisor Awarded Million-Dollar Grant for FTD-FUS Research

Rosa Rademakers, PhD, a member of the AFTD Medical Advisory Council, was named the 2021 recipient of the Generet Prize for Rare Diseases. She was awarded one million euros

(about \$1.15 million) from the King Baudouin Foundation in Belgium to study FTD-FUS, a type of FTD that involves an accumulation of the FUS protein. Dr. Rademakers told AFTD that she and her team have collected nearly 60 brains from persons who had FTD-FUS, saying that she believes "we can make a difference now." Dr. Rademakers was a recipient of an AFTD Pilot Grant in 2008, and today leads the VIB Center for Molecular Neurology at Antwerp University in Belgium. She is the first woman to receive the Generet Prize.

Persons with FTD Advisory Council Adds New Member

Cindy Odell of North Carolina recently joined AFTD's Persons with FTD Advisory Council. Cindy was diagnosed with behavioral variant FTD in 2011. Prior to her diagnosis, she was a caregiver for four family members, all of whom had dementia, including her husband. Since her own diagnosis, she has focused on being an advocate for those with FTD, and she volunteers for AFTD whenever possible. The Persons with FTD Advisory Council was established in 2020. Its members, all of whom are living with an FTD diagnosis, ensure that the insights of persons with FTD are considered in the development of AFTD's policies, programs, and services.

Hope to Make a Difference



Liz Matthews (far right) with her family in 2005.

“Hope can bring you together with others, and lead you to make a difference. Hope can help you find ways to honor those you love.”

– Liz Matthews, AFTD volunteer

Liz Matthews is driven by hope and resolve, shaped by her experience as a child of someone who lived with FTD. Growing up in a quiet town in New Jersey, Liz had a happy childhood, enriched by her dad’s infectious energy and sense of humor.

A decade ago, Liz’s dad, David Matthews, began behaving erratically; on occasion, he displayed uncharacteristic aggression toward his loved ones and friends. In 2014, when Liz was ten and her dad was 50, David was diagnosed with behavioral variant FTD. He passed away in 2016.

“It was such a stressful and chaotic time for all of us,” said Liz. “I remember feeling confused, and that life was so unfair.”

Today, Liz remembers her dad for his joyful personality and all he accomplished before his FTD diagnosis. An avid runner and accomplished piano player, David earned his private pilot’s

license after putting himself through dental school. “My dad believed you could do anything — giving up was never an option, and I try every day to live up to the way he approached life.”

Her dad’s determination and positive spirit inspire Liz to do all she can to raise FTD awareness as an AFTD volunteer. By participating in Charity Miles and AFTD’s *With Love* campaign, Liz also hopes to raise funds to help drive AFTD’s mission. Intent on helping others on this journey, Liz plans to study neuroscience when she starts college this fall, and hopes to advance future therapies and a cure for this disease.

“Hope is more than an emotion — it is an experience that we can manifest into making a change,” she said. “It’s wonderful to have joined with an organization like AFTD that’s committed to this community and the research necessary to end FTD.”

Will you join Liz in supporting AFTD’s mission? Together, we can turn hope into action and transform the journey for all who face FTD. By making a tax-deductible gift of any amount, you can advance AFTD’s work to improve the quality of life of people living with FTD and drive research to a cure. Simply use the enclosed envelope, visit theaftd.org and **click on the Donate+ button** at the top of the page, or **use the QR code.**



FTD Treatments Gaining Ground

(Continued from page 1)

More than 30 meeting participants delivered presentations at FTSG 2021. Sessions focused on promising therapies, the development of more participant-friendly and efficient clinical trials, and ways to report and share clinical-trial outcomes.

Representatives from the National Institutes of Health (NIH) and the U.S. Food and Drug Administration (FDA) participated, including Billy Dunn, MD, Director of the FDA's Office of Neuroscience.



During the meeting, researchers were able to hear the lived experience of those affected by FTD, via direct testimony from advocates, presentations of survey data from the FTD Disorders Registry, and information from AFTD's *Frontotemporal Degeneration: A Voice of the Patient Report*, which summarized our March 2021 Externally Led Patient-Focused Drug Development meeting.

Researchers discussed ways to evaluate the efficacy of potential treatments. They also talked about ways to make participating in research easier for persons diagnosed and their families—for example, by better communicating with them, and better helping them to weigh the benefits of trial participation against any potential risks.

Attendees also discussed the importance of sharing research results, both to further the science of FTD and



to speed the path to making effective treatments a reality. “Data-sharing agreements should be done in the beginning, not the end” of clinical trials, said Dr. Feldman. Attendees agreed that sharing data from clinical trials would maximize impact, while also better respecting the time and energy that research participants devote to them.

“The 2021 FTD Treatment Study Group meeting showed us that hope is on the horizon for approved treatments,” Dr. Dacks said. “Delivering on that will take all of us working together, from health professionals, academic

researchers, biopharma leaders, regulatory experts, and funders to advocates and people and families with lived experience with FTD.”

New therapies for FTD can be created only through the participation of people who have lived experience with FTD. As a vital way to help advance this research, AFTD encourages anyone with lived experience – persons diagnosed, caregivers, and family members – to join the FTD Disorders Registry. Joining the Registry can connect you with opportunities for participation in clinical research, and will allow you to maintain your privacy while sharing insights to help advance understanding of FTD. Visit FTDRegistry.org to learn more.

Thank you to the generous sponsors of the 2021 FTSG meeting:



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Remembering John Q. Trojanowski

(Continued from page 1)

Dr. Trojanowski and Dr. Lee co-directed the University of Pennsylvania's Center for Neurodegenerative Disease Research, where they oversaw research into Alzheimer's, Parkinson's, FTD, and other neurodegenerative diseases. Dr. Trojanowski was a respected mentor and guide to many of the next generation of FTD researchers.

In 2003, Dr. Trojanowski, along with more than a dozen other FTD-focused medical clinicians and researchers from around the country, became a founding member of the AFTD Medical Advisory Council, a crucial step in solidifying our organization's and our community's knowledge of FTD care and science.

"Along with his beloved wife Virginia and their Penn colleague, Dr. Murray Grossman, John was instrumental in establishing AFTD as the nation's leading organization focused on FTD," AFTD founder Helen-Ann Comstock said.

Dr. Trojanowski was motivated to become involved with AFTD because it "addressed huge unmet needs [in FTD] care, education, and research."

"John's boundless, detailed knowledge of dementia, along with his unceasing compassion for those affected by FTD, guided AFTD's mission for nearly 20 years," she added. "I am forever thankful for John and his accomplishments."

Dr. Trojanowski said he was motivated to become involved with AFTD because the organization "addressed huge unmet needs – the most important being patient care, education, and research that puts us on a solid course for discovering disease-modifying therapies." He continued to serve on the Council until his death.

"As momentum builds in FTD research, we owe a great debt to Dr. Trojanowski," said AFTD's CEO, Susan L-J Dickinson, MSGC. "Even as many of us mourn his loss, we are grateful for his life's work – and his outstanding contributions to FTD science."

AFTD/ADDF Grantees to Study Potential FTD Treatments and Biomarkers

AFTD grants support scientists as they conduct vital research into advancing our understanding of FTD. Several newly awarded grants are driving hope for a future where FTD can be detected earlier in the disease process and effectively treated.

Launched in 2016 in partnership with the Alzheimer's Drug Discovery Foundation (ADDF), the Treat FTD Fund supports early-stage clinical trials of new and repurposed drugs to disrupt the progression of FTD or provide relief from FTD symptoms. In recent months, Treat FTD Fund awards have gone to Simon Ducharme, MD; Paul Edison, MD; and Wave Life Sciences.

Dr. Ducharme, an associate professor in the department of psychiatry at McGill University in Montréal, will evaluate nabilone, a drug that targets the brain's endocannabinoid system, a chemical signaling pathway linked to neuroinflammation and other neurodegenerative processes, as a symptomatic treatment in FTD. Nabilone has shown some benefit in the treatment of behavioral

symptoms in Alzheimer's disease, but Dr. Ducharme's project will be its first clinical trial in FTD.



Simon Ducharme, MD

A senior clinical lecturer at Imperial College London and an honorary professor at Cardiff University in Wales, Dr. Edison will conduct a multisite international Phase 2 clinical trial of semaglutide, a drug already approved for the treatment

of type 2 diabetes. In the brain, semaglutide and related drugs reduce inflammation, decrease levels of the FTD-associated protein tau, and improve communication between brain cells, all of which could slow or halt neurodegeneration.

As part of its FOCUS-C9 clinical trial, Wave Life Sciences, a biotechnology company located in Cambridge, Massachusetts, will evaluate a new drug (WVE-004) as a potential treatment for FTD and ALS cases associated with a mutation in the gene *C9orf72*, the most common genetic cause of FTD. WVE-004

blocks the production of dipeptide repeat proteins that result from a *C9orf72* mutation. The FOCUS-C9 trial is novel in that it is a "basket" trial, meaning that it will assess WVE-004's effects in persons who have different diseases associated with *C9orf72* – specifically, FTD, ALS, or ALS with FTD.

AFTD is also pleased to announce an award through ADDF's Diagnostics Accelerator initiative to Qinwen Mao, PhD, a professor at the University of



Qinwen Mao, PhD

Utah School of Medicine. The Diagnostics Accelerator – a funding initiative whose partners include AFTD, Bill Gates, and other funders – seeks to address the urgent need for FTD biomarkers. A biomarker that could differentiate tau-associated FTD from TDP-43-associated FTD could expedite clinical trials by enabling researchers to match participants to tau-specific or TDP-43-specific drugs. Dr. Mao has identified a monoclonal antibody that is highly specific for the pathological form of TDP-43 found in FTD, and will use her Diagnostics Accelerator funding to develop an assay that can be used to detect TDP-43 in blood.

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Gifts received from October 16, 2021 – February 15, 2022

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Brain Banking Collaboration Will Improve Researcher Access to Vital Tissue

AFTD has partnered with the Rainwater Charitable Foundation and CurePSP to support an integrated brain banking platform to streamline access to valuable brain tissue for research on FTD.

“Opening up these resources to the research community will surely get us to effective treatments for persons diagnosed sooner,” says Todd Rainwater, Trustee of the Rainwater Charitable Foundation.

Access to human brain tissue is a critical resource to advance the understanding of FTD disorders and the development of therapies and diagnostic tools. Once a brain is donated, researchers need to know that the donation exists, how the tissue is stored, and where to find it,

and to be assured that the sites where the tissue is stored can fulfill their requests.

The Federated Brain Banking Platform Initiative is a pilot program to solve this problem by streamlining researchers’

Access to human brain tissue is a critical resource to advance the understanding of FTD disorders and the development of therapies and diagnostic tools.

access to existing tissue in the four leading brain banks. The project is spearheaded by William Seeley, MD, director of the Neurodegenerative Disease Brain Bank at the University of California, San Francisco, in collaboration with the Icahn School of Medicine at Mount Sinai, Boston University, and the Mayo Clinic.

The Rainwater Charitable Foundation

is the lead funder for the infrastructure investment needed for this project. AFTD and CurePSP are founding co-funders, with AFTD awarding a \$200,000 grant for one year in the fall of 2021. AFTD’s Senior Director of Scientific Initiatives, Penny Dacks, PhD, said, “This will be a tremendous resource for researchers striving to reduce the time for diagnosis and to develop treatments for our community.”

AFTD deeply respects the commitment and the strength of families who choose to donate the tissue of their loved one for research. We and our funding partners share a commitment to ensuring that that this gift is used and shared to the fullest extent to advance the understanding and treatment of FTD.

Give a Hand to Our Helping Hands!

AFTD Volunteer: Veronica Wolfe

When Veronica Wolfe's mother was diagnosed with bvFTD in 2018, her family initially struggled to find information about the disease. Once her mother's neurologist pointed them to AFTD's website, however, Veronica committed to learning all she could about FTD and AFTD's resources. She joined a support group and attended a few virtual Meet & Greets, and in 2020 she was compelled to become an AFTD volunteer herself.

Since then, Veronica has been an active fundraiser – organizing an independent event, participating in Food for Thought, and joining the AFTD-Team for the New York City Marathon. "It's easy to see the benefit of fundraising and contributing to the

overall mission of AFTD," she shares. "What I've found to be even more important is the visibility fundraising provides to the disease, even within my small community. Raising awareness has been extremely rewarding."

"Volunteering has been rewarding and extremely satisfying," Veronica said. "Each experience has provided a slightly different sense of fulfillment."

In February, Veronica hosted a virtual Meet & Greet to bring together those with the unique experience of being an only child with a parent who has FTD. "Although these have all been completely different [volunteer] experiences, I feel like it's a small way to support my mother, connect with others going through a similar

situation, and process things for myself," she said. "Volunteering has been rewarding and extremely satisfying... each experience has provided a slightly different sense of fulfillment."

When asked what she would tell someone considering becoming an AFTD volunteer, Veronica said, "Do it! AFTD makes it easy, regardless of whether you're filling a pre-existing need or creating your own event! The support from AFTD has been great – the process of organizing individual events, Meet & Greets, and fundraisers has been seamless. I was guided every step of the way. I hope to continue to contribute to the organization however I can in the future!"

AFTD Celebrates Volunteer Appreciation Week

Every year, AFTD honors the time and energy our volunteers so generously devote in support of our mission during National Volunteer Appreciation Week (April 17-23). AFTD values our volunteers every day of the year, but this nationally recognized week offers a special opportunity to express our immense gratitude for their presence in our community.



Our volunteers allow AFTD to share hope with more families on the FTD journey and serve our community in more impactful ways than we could do alone. They are important champions of our mission, and we accomplish so much more with their help.

AFTD volunteers channel their own personal stories, strengths, and professional backgrounds to make

a difference for families affected by FTD. In 2021, AFTD volunteers offered safe and compassionate spaces to their support group members. They connected with people across the country by hosting Virtual Meet & Greets, facilitating volunteer orientation, and supporting our Zoom needs.

Through table settings, presentations, and outreach, volunteers educated healthcare professionals, families impacted by dementia, and local community members about FTD and AFTD resources at virtual and in-person events. Volunteers also raised critical funds and awareness by organizing and hosting creative grassroots fundraisers.

Volunteers are important champions of our mission, and we accomplish so much more with their help.

These examples showcase just a handful of the ways our volunteers support AFTD's mission. Thank you to our Ambassador team for your exemplary volunteer service and leadership. Thank you to our Board and Medical Advisory Council for your continued dedication to AFTD and our community. Thank you to the Persons with FTD Advisory Council for advocating on behalf of others with FTD and providing your essential perspective. Thank you to everyone who contributes their knowledge and expertise in support of our research, advocacy, and education mission areas. Thank you to everyone who has made others on the FTD journey feel less alone by sharing your personal stories.

To everyone who strengthens our community through the gift of your time and talents, we express a heartfelt thank you.

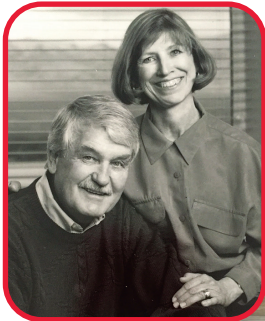
With Love



This year's *With Love* campaign – which took place throughout February – highlighted two vital energies: celebration of AFTD's 20th anniversary and the power of storytelling.

When Helen-Ann Comstock and like-minded volunteers launched our organization in 2002, they knew all too well what it was like to face an FTD journey without resources, help, and support. They knew that people who truly understand this journey can be a powerful resource to families impacted by the disease.

In February, 27 volunteers shared their personal stories, creatively expressing how love sustained, inspired, or uplifted them through an FTD journey. Together, their voices were a collective show of force – the force of love – against this disease.



Ned & Bonnie Shepherd



Costello Family



Simon Family



Shakeel & Abrar Tanveer

AFTD would like to extend a heartfelt thank you to everyone who contributed to the success of this year's campaign, which has raised \$67,000 to advance AFTD's mission. We are grateful for our two generous sponsors, The Mike Walter Catalyst Fund and The Rainwater Charitable Foundation; the hundreds of people who made donations; and, of course, our fundraisers, who bravely shared their stories of love.

Bonnie Shepherd
Colleen Franzreb
Kenneth Simon
Dave Andrews
Liz Matthews
Kristin Pursley
Theresa Walter

Greg Zugrave
Keli Schubert
Kenneth McCullough
Jamie Lee Manning
Melissa Fisher
Heather Hoff
Jerry Horn

Abrar Tanveer
Marsha Francisco
Jillian Queeney (Condran)
Jamie Hale
Jill Taylor
Susan Dunbar
Susan Scarff

Dawn O'Gara
Estrella Bibbey
Wendy Riding
Sonja Crawford
Doreen Rivers
Barbara Frank

THE AFTD-TEAM

Race Season

Dallas Marathon

After taking 2020 off to ensure the health and safety of our community, the AFTD-Team was back in full force for our 2021 Race Season, and the wait certainly paid off! More than 160 people logged a combined 1,270 miles at the Colfax Marathon (Denver) in October, the TCS New York City Marathon and Philadelphia Marathon in November, and the Dallas Marathon in December. Together, the AFTD-Team raised more than \$124,000 for AFTD’s mission.

On behalf of AFTD and the community we serve, we would like to thank all our runners, joggers, and walkers for their energy and resilience. Special shout out to the individuals and families who, in addition to going the distance, raised vital funds at last year’s races:



Colfax Marathon



Colfax Marathon

Fenoglio Family Racers
Melissa Autry

Alex Sepesy
Joe Fischel
Lauren Conner (Rowans)
Jim Driscoll

Brianna Amoroso
Erin Ralph
Kelly Canavan
Kevin Ralph
Linda Nelsen
Katerina Placek
Shana Dodge
Chelsea Amoroso
Kyle Leone
Susan Dickinson
James Staten

Diane Wilkes
Elaine Rose

TCS New York City Marathon

Brian Strohm
Steve Smith
Maggie Sepesy
Popkin Shenian
Ben Freeman
Melissa Fisher

Philadelphia Marathon

Team Jack Attack
Ross Gilardi
Kiersten Martin
Jonathan Nagin
Meghan Leone

Dallas Marathon

Grace Vroom & Joe Patterson
Julianne Cary &
Lauren Braun
Tammy DiPasquale
Bianca Cihak
Courtney DiPasquale
Anna Kuykendall



Nothing But Net:

The Babson College men’s basketball team hosted a fundraiser in memory of

player Spencer Cline’s father, who was diagnosed with FTD in his mid-40s and died in 2012. Their fundraising page was launched in the lead-up to their February 12, 2022, game against Clark University—which Babson College won 85-61—and raised \$11,474 for AFTD’s mission.

Walking for George: Kathryn Nutaitis and family organized a walk in memory of George Grozan on December 11, 2021, in Strongsville, OH. George had FTD and died on November 18, 2021, at the age of 48. Proceeds from the walk and t-shirt sales helped the family raise \$8,169 for AFTD’s mission.

Memories of Lynn: Rachel Yost and the Lower family hosted a memorial page for Lynn Lower of Blue Bell, PA who died on February 1, 2022, after living with FTD for seven years. The page shared memories of who Lynn was before the disease, and raised \$5,758 for AFTD’s mission.

Sisters Showing Love: Sisters Amy and Kerry Kilgallin created a fundraising page to raise FTD awareness in honor of their mother who was recently diagnosed with PPA. Through the support of family and friends, they were able to raise \$4,384 for AFTD’s mission.

A Good Run: Sam Heffron ran a half marathon on October 24, 2021, in Lincoln, NE in honor of his family, which has been affected by FTD for the past seven years. Through his efforts, Sam spread critical FTD awareness and raised \$3,624 for AFTD’s mission.

Letters from the Heart: Former AFTD Board Member Paul Lester hosted his 15th annual letter-writing campaign in memory of his late wife, Arnette. He sent both paper and electronic versions of his letter to family and friends asking for their continued support. After all letters were sent out, his campaign raised a total of \$3,143. Over the past 15 years, his letter-writing campaign has raised more than \$166,000 towards the fight against FTD.



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