AFTD
The Association for Frontotemporal Degeneration
FIND HELP·SHARE HOPE

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AFTD news

Clinical Trials: Paving the Way to Effective Treatments for FTD

FTD research brings hope – hope for therapeutics that can slow or reduce symptoms, hope that the next discovery will improve quality of life for persons diagnosed and their families, hope for a future free of FTD. New treatments for FTD are closer than ever, with treatments for some causes of FTD under active testing in clinical trials. Clinical trials are studies designed to determine the safety and effectiveness of new medical interventions, including drugs, gene therapies, medical devices, or other treatments.

But the success of clinical trials depends on whether researchers can enroll a statistically robust number of participants. Persons diagnosed with FTD – and, if possible, their care partners and/or family members – are therefore encouraged to consider enrolling in a clinical trial.

Clinical trial participation can help scientists develop the first effective FTD treatments, but participants have reported other benefits as well. For example, some have said they appreciated the chance to meet and form relationships with FTD specialists; others reported gaining a sense of purpose and meaning amid their FTD journey. Trialing experimental therapeutics can also potentially improve the quality of life for persons diagnosed, should those therapeutics prove effective.

The U.S. Food and Drug Administration and other regulatory bodies have strict guidelines and processes for running clinical trials. For drug development, the approval process typically includes multiple phases:

FTD therapeutics are currently being tested in these phases

Phase 1 trials test a therapeutic drug or device to evaluate its safety and determine the dosage amount, if applicable. This phase is usually conducted on healthy individuals, without the disease.

Phase 2 trials provide preliminary safety and efficacy results of a therapeutic by testing it on a larger group of people to evaluate its effectiveness.

Phase 3 trials provide additional data, allowing researchers to compare how a therapeutic performs at different dosage levels and its interactions and side effects on different populations.

Phase 4 trials come after FDA approval of a therapeutic, and monitor its long-term safety and effectiveness.

Before enrolling, potential participants in a clinical trial will receive a detailed overview of the trial's parameters and procedures from the research team. They will also need to sign a document, known as an informed consent form, containing key details about the trial: its purpose, duration, potential risks and benefits, and any relevant contact information they will need. Informed consent documents are not binding, and participants can withdraw from the trial at any point, and for any reason.

For scientifically useful data to be produced, clinical trials have strict eligibility requirements – not everyone can enroll in any trial. In FTD, many current clinical trials testing treatments to stop or slow the progression of the disease are specific to people with a *GRN* genetic variant. Knowing your gene variant is therefore necessary before enrolling in such trials. To explore whether genetic testing is right for you, AFTD recommends speaking with a genetic counselor; visit theaftd.org/ftd-genetics/genetic-counseling to learn more.

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AFTD News Briefs

AFTD Meets with NY State Sen. Hinchey for FTD Week Announcement

AFTD staff and volunteers traveled to Albany on May 22 to meet with New York State Senator Michelle Hinchey as she recalled Senate Resolution 992 – declaring September 24 through October 1 as FTD Awareness Week in New York – and spoke to the importance of greater awareness and understanding of FTD. AFTD CEO Susan L-J Dickinson and Advocacy Manager Matt Sharp were joined by Board member Kathy Newhouse Mele and AFTD volunteer Lt. Gen. Michael Basla. The AFTD delegation met with Hinchey before the State Senate entered its afternoon session to thank her for her work on the FTD Awareness Week resolution. "The fight to bring FTD to the forefront of public awareness and to our policy discussions in the state legislature is a personal one to me," said Hinchey, whose father, U.S. Rep. Maurice Hinchey, was diagnosed with PPA and died in 2017.

Dr. Chiadi Onyike Named AFTD MAC Chair-Elect

Chiadi Onyike, MD has been named Chair-Elect of AFTD's Medical Advisory Council (MAC). His three-year tenure as Chair will begin after Bradford Dickerson, MD, the current MAC Chair, steps down in 2025. Dr. Onyike is a neuropsychiatrist, an associate professor of psychiatry and behavioral sciences at Johns Hopkins University, and director of the Johns Hopkins Young-Onset Dementias Program. His work focuses on diagnosing and caring for neurodegenerative diseases like FTD that develop around middle age or earlier. As MAC Chair, Dr. Onyike will bring a depth of experience advising national and international research agencies including the National Institutes of Health and the U.S. Food and Drug Administration.

Making a planned gift is a powerful way to support AFTD's mission and the people we serve.

Choose to plan for a future free of FTD by joining AFTD's Legacy Circle today. Please contact **development@theaftd.org** or visit **tinyurl.com/AFTDLegacy** for more information.

"Making a planned gift is a way of guaranteeing AFTD will be provided for and will thrive for many years to come."
– Member of AFTD's Board & Legacy Circle

FINDING A NEW NORMAL WITH FTD

"I felt like Dr. Jekyll and Mrs. Hyde – I was often ready to explode, and I didn't know why."

– Linda D., who is living with FTD

Before her behavioral variant FTD diagnosis in February 2022 at the age of 70, Linda couldn't understand why she, a former special education teacher and avid reader, struggled to finish books for Bible study while also becoming increasingly disorganized and prone to angry outbursts.

Due to other health concerns, Linda and her husband Mike initially believed that her symptoms were associated with those illnesses. However, significant behavioral changes prompted Linda to seek further medical guidance.

"When I learned I had FTD, I thought, 'What do I do?' The doctors didn't know exactly what I should do, but I wanted someone I could talk to," Linda said. "One of the neurologists found AFTD for me, and I couldn't get on the phone fast enough because I knew I needed help."

Through AFTD's HelpLine, Linda found information and resources that she and Mike used to educate themselves about her diagnosis. With a Comstock Quality of Life Grant from AFTD, Linda has been able to purchase supplies for her artwork.

"This is a way I can share God's kindness," she said. "I can get the materials I need to make art that I share with others. Then I can tell them what FTD is and how it relates to what I'm going through. If I can keep my hands busy, I feel better."

Additionally, a Comstock Respite Grant enabled Mike to access care services for Linda while he recovered from heart surgery. Today, Mike is balancing his love of gardening with being Linda's full-time care partner.

"AFTD has made a lot of difference," Linda said. "The support we've received has taken away a lot of the loneliness, and I feel that I have more hope right now than I have had in the previous year and a half since being diagnosed – it's meant so much to be able to talk to people at the organization and receive help."

Linda and Mike are among the more than 600 people who receive support through AFTD's Comstock Grant program each year, and we are grateful that they chose to share their FTD story.

Every story brings awareness to make things better for the next family.

Every story moves us closer to a future free of FTD.

Will you donate today to support the Comstock Grant program, to provide help and bring hope to people who are navigating an FTD diagnosis? A gift of $500 can fund one grant, and a gift of any amount will 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.

*Spotlight on…*Shoshana Derrow Krilow, Esq., AFTD Board of Directors

Shoshana Derrow Krilow, Esq.

"My dad was my best friend," AFTD Board member Shoshana Derrow Krilow recently said. "It was extraordinarily difficult to lose him – first slowly, and then [to] lose him time and time again over the course of a very long decade."

Krilow's father, Charles (Chuck) Derrow, was a native New Yorker; a physician who practiced in Columbus, Ohio for over two decades; and a man who marched to the beat of his own drummer – "quite brilliant, but always a little odd," Krilow said. When he first showed bvFTD symptoms in the late 2000s, even close family members weren't sure if there was actually a problem, or if he was just getting quirkier with age. "We thought, 'Dad's maybe a little weirder, but he's getting older,'" Krilow said.

But Dr. Derrow's strange behaviors grew more frequent, and more concerning. He couldn't calculate tips or unload the dishwasher correctly; he once made an entire pot of coffee without the pot. His wife noted that he had been feeling depressed and was having problems at work. It became clear that something was neurologically wrong: "Once he finally had imaging done, we, and he, knew right away it was FTD," Krilow said. Dr. Derrow was not yet 60 years old when he was diagnosed; he died in 2018.

A lobbyist who lives with her husband and two young children in the Washington, DC area, Krilow remembers learning about AFTD. "It started as, 'Oh, you exist – I'm devastated, help me," she said. After attending a networking event for FTD families in Bethesda, Maryland, she quickly realized the value of meeting others who understand FTD specifically. "AFTD was introducing me to other young professionals in the area who were similarly struggling with dementia, and it wasn't Alzheimer's," she said. "It was nice to be surrounded by so many people who understood what I was going through."

While Krilow joined the AFTD Board in May, she has been working with it for the last 10 years, mostly in an informal advisory role. Alongside AFTD CEO Susan L-J Dickinson and AFTD Advocacy Manager Matt Sharp, she worked with congressional staff to have FTD added as a topic area eligible for federal funding via the Peer-Reviewed Medical Research Program through the Department of Defense – a "big win," as she describes it.

Her vision for AFTD's future includes more wins of an even greater magnitude. She wants FTD to be "much better understood and recognized by federal policymakers as not Alzheimer's, with an understanding as to why that distinction is important," she said.

She added that she is ready and willing to generate ideas and leverage connections that will help drive up FTD awareness on Capitol Hill and beyond. "If there's any amount of difference I can make, I think it's my responsibility" to do so, Krilow said. "My dad used to say, 'Do the right thing in life.' This feels like the right thing."

AFTD Advancing FTD Science Through Multi-Pronged Grants Program

Thomas Kukar, PhD

Allison Lindauer, PhD

Matthew Nolan, PhD

Through a robust scientific grants program, AFTD offers crucial financial support to researchers advancing our understanding of FTD.

Many of AFTD's grants, and some offered in partnership with other organizations, support scientists during the initial stages of their work. During these early stages, researchers lay the groundwork for future clinical studies by researching the basic science behind FTD and conducting drug discovery research to find compounds that show potential as treatments. Because the formative stages of research are extensive and often take years to complete, support from grants is essential to ensuring that researchers have the resources they need for the long haul.

AFTD provides a variety of grants covering important research topics concerning FTD, such as those awarded through the Accelerating Drug Discovery for FTD program, a partnership with the Alzheimer's Drug Discovery Foundation (ADDF). AFTD grants also drive non-drug interventions. For example, Allison Lindauer, PhD, of Oregon Health & Science University, was awarded a 2020 Well-Being in FTD Pilot Grant for her project customizing the STELLA telehealth program to address the unique needs of FTD care partners based on their input.

Through the Holloway Fellowship program, made possible with the generous support of the Holloway family, AFTD helps support the next generation of FTD researchers during their training. Holloway Postdoctoral Fellowships provide the foundation for new PhDs to continue gaining research experience after graduating. Matthew Nolan, PhD, of Massachusetts General Hospital, a 2021-2023 Holloway Postdoctoral Fellow, received support for his work advancing the understanding of the role of RNA binding proteins in FTD.

Thanks to the support of AFTD's grants, many researchers have succeeded in making essential breakthroughs in the FTD space. In some cases, AFTD grants even paved the way for clinical trials.

In 2014, Thomas Kukar, PhD, of Emory University, received an AFTD Pilot Grant for his research into progranulin, a key protein regulating cellular functions reduced by FTD caused by a *GRN* gene variant. Then, in 2017, Dr. Kukar received an Accelerating Drug Discovery for FTD grant to investigate the ability of progranulin to restore the function of the lysosome, which controls a cell's waste disposal process. Dr. Kukar's work is now bearing fruit, in the form of novel therapeutics for FTD-GRN that are moving toward clinical trials in the near future.

AFTD continues to offer fellowships through the Holloway Postdoctoral Fellowship and grants through the Clinical Research Training Scholarship. Two types of AFTD Pilot Grants are available: Pathways for Hope Pilot Grants, for basic and translational research projects, and Well-Being in FTD Pilot Grants, for projects designed to improve the well-being of persons diagnosed, families, and care partners.

AFTD and ADDF continue to award Accelerating Drug Discovery for FTD grants. And in a recent collaboration with the ALS Association, AFTD now offers grants through the Digital Assessment Tools for FTD and ALS program.

For more information about AFTD's grants program, visit theaftd.org/for-researchers.

In Memoriam: Dr. Murray Grossman, 1952-2023

Murray Grossman, MDCM, EdD

Murray Grossman, MDCM, EdD, an internationally recognized leader in FTD science and a founding member of AFTD's Medical Advisory Council (MAC), died on April 4. Dr. Grossman was 71.

The Penn Memory Center announced the death on April 10.

A neurology professor at the University of Pennsylvania for over three decades, Dr. Grossman played a crucial role in AFTD's founding. In the late 1990s, he arranged for Helen-Ann Comstock, a former FTD caregiver, to use UPenn office space in suburban Philadelphia for meetings of her FTD support group. Ms. Comstock would go on to found AFTD in 2002, providing resources, support, and information for FTD families nationwide.

Along with Dr. Virginia M.-Y. Lee and the late Dr. John Trojanowski, also of UPenn, Dr. Grossman was "instrumental in establishing AFTD as the nation's leading organization focused on FTD," Ms. Comstock said.

Dr. Grossman, an author or co-author of more than 600 scientific papers, focused his research on Alzheimer's and related dementias, particularly on young-onset dementias such as FTD. He worked to identify biomarkers for neurodegenerative diseases, publishing recent studies on the viability of neurofilament light and cerebrospinal fluid as potential FTD biomarkers.

> Dr. Grossman, a neurology professor at the University of Pennsylvania for over three decades, played a crucial role in AFTD's founding.

Dr. Grossman was influential in developing diagnostic criteria for specific FTD subtypes, and was among the first researchers to recognize that persons diagnosed with movement-based disorders such as corticobasal degeneration and Parkinson's disease could also develop cognitive difficulties. Dr. Grossman also provided the first description of the nonfluent variant of primary progressive aphasia.

Dr. Grossman founded the Penn FTD Center in 2010. The center convenes experts across a range of disciplines to improve FTD care, diagnosis, and treatments. It also offers clinical genetic counseling services for FTD – a particular passion of Dr. Grossman's.

Friends and colleagues praised Dr. Grossman's energy, collaborative spirit, and enthusiasm for working with countless young contributors to FTD science. "Murray trained and mentored many of the emerging leaders in FTD research and clinical care," said AFTD CEO Susan L-J Dickinson. "He leaves the Penn FTD Center in capable and committed hands, and his legacy includes ensuring that a new generation of clinicians and scientists will continue the drive to approved treatments for FTD.

"Whether clarifying diagnostic criteria for FTD, working with genetically at-risk families, or examining potential FTD biomarkers, Murray's work was at all times informed by his deep compassion for everyone affected by FTD," Dickinson continued. "His leadership, guidance, and wisdom have been tremendously important to the growth of AFTD and will be an enduring aspect of his legacy. It was an honor and a privilege to call him a friend."

Clinical Trials *(continued)*

There are more active, ongoing clinical trials focused on FTD than ever before. While many studies are targeting FTD caused by specific genes, others address specific symptoms of FTD, while others are examining non-medical interventions to improve the quality of life of persons diagnosed and/or the FTD caregiving experience.

If you're interested in getting involved in studies, there are many ways to get started. The FTD Disorders Registry is a simple place to start. Register to share your FTD experience with researchers and learn about clinical research opportunities that may be right for you. You can learn more by visiting FTDregistry.org.

Another helpful resource is the National Institutes of Health's ClinicalTrials.gov, an online database of federally and privately funded studies on various conditions and diseases. You can also contact AFTD's HelpLine to ask questions and receive guidance on ways to get involved; you can reach the HelpLine at 1-866-507-7222 or info@theaftd.org.

Although more FTD clinical trials are underway than ever before, more are needed. The research has accelerated more quickly for some causes of FTD – like FTD-GRN – compared to others. While clinical trials are not yet available to everyone with FTD, joining the FTD Disorders Registry can help bring about new clinical trials and potential treatments. It signals to researchers and companies that people with FTD, including those with specific types of FTD, are able and willing to participate in research.

Visit bit.ly/FTDtrials for more information about clinical trial participation.

AFTD Driving Increased Collaboration Between ALS and FTD Fields

In recent years, researchers have learned more about the ways that amyotrophic lateral sclerosis (ALS) and FTD overlap. The two neurological diseases share commonalities at the molecular, cellular, and clinical levels. But despite their overlapping nature, research into FTD and ALS has tended to remain siloed. Moving away from those silos and into more collaborative research would go a long way toward accelerating the search for effective treatments for both diseases.

Over the last year, AFTD has worked to bring together the fields of FTD and ALS research, knowing that a breakthrough in one disease could lead to a breakthrough in the other. In addition:

- In March, AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD participated in the steering committee for a summit on the *C9orf72* gene variant, the most common cause of genetic FTD and ALS, at the Barrow Neurological Institute in Scottsdale, Arizona. The event, which touched on the importance of breaking down the barriers that separate FTD and ALS research, was made possible thanks to the generosity of David and Louise (Weezie) Reese.
- In April, AFTD collaborated with the Packard Center at Johns Hopkins University to host an interdisciplinary workshop focused on TDP-43, a protein that forms abnormal accumulations in some cases of FTD and ALS. The workshop brought together traditional FTD and ALS researchers with experts in computational biology to brainstorm ways to apply systems biology tools to the study of TDP-43.
- In May, AFTD and The ALS Association announced a new funding opportunity that will drive progress in collaborative digital tool development at the intersection of ALS and FTD. The Digital Assessment Tools for FTD and ALS grant will provide support to researchers developing tools using smartphones, wearable devices, or other tech to gather data on a person's symptoms and ability to function in order to expand research and care options for FTD and ALS.
- Finally, the CReATe Consortium at the University of Miami and The ALS Association have partnered with AFTD to fund two upcoming Holloway Postdoctoral Fellowships, further driving productive collaboration between the FTD and ALS fields.

"AFTD is proud to work on multiple levels to reduce the silos of FTD and ALS research and care," Dr. Dacks said.

Those We Honor... Those We Remember

Gifts received from February 16, 2023 – May 31, 2023

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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 Community Gathers in St. Louis and Online for 2023 Education Conference

AFTD's annual Education Conference brought together nearly 300 in-person attendees and more than 700 virtual attendees to connect, learn, and engage alongside fellow members of the AFTD community on May 5.

Persons with FTD, care partners, volunteers, healthcare providers, researchers, and industry professionals gathered at the Marriott St. Louis Grand, as well as virtually.

Those who arrived in St. Louis a day early had the chance to take part in pre-conference events, including a volunteer appreciation dinner and a special session on FTD in the Arts, which showcased the FTD-focused play *Chasing Rainbows* and the short film *Pedacito de Carne*.

Bruce Miller, MD

Bruce Miller, MD – the A.W. and Mary Margaret Clausen Distinguished Professor in Neurology at UCSF and a member of the AFTD Medical Advisory Council – delivered the Keynote Address. Dr. Miller reflected on the many breakthroughs in FTD science he has witnessed throughout his career, discussed the challenges that researchers face, and highlighted the growing hope as the global research community advances promising clinical trials that could one day lead to effective treatments for FTD.

"I would never have believed it when I started in this field, but over the next decade, I believe we will see effective therapies for the different forms of FTD," Dr. Miller said. "I think this reflects an enormous creativity of scientists in our field, in the different ways they're thinking about therapies – and of course, AFTD has been a major stimulant for these clinical trials."

Breakout sessions offered virtual and in-person attendees various topics to explore. During the session "What Comes Next: Supporting Kids and Teens After an FTD Diagnosis," staff from Lorenzo's House, an organization focused on young-onset dementia care, discussed insights from children and teens who have been care partners, along with strategies for supporting them during their family's FTD journey.

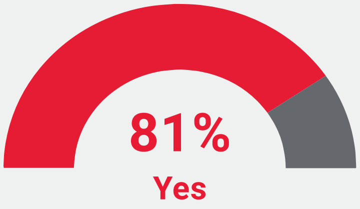
Later, at the session "Sharing Your Experiences to Advance FTD Science," AFTD Ambassadors and volunteers joined Sweatha Reddy from the FTD Disorders Registry and Nupur Ghoshal, MD, PhD, of Washington University, to share ways that persons affected by FTD can help advance our understanding of this disease and drive research towards a cure.

The above-mentioned sessions, along with most other 2023 Education Conference sessions, are available to watch on AFTD's YouTube channel at youtube.com/TheAFTDorg.

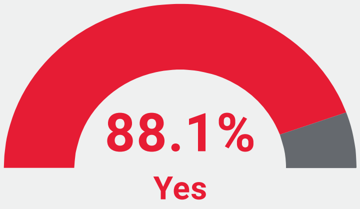
The next AFTD Education Conference will be held in Houston on May 3, 2024, with the option to attend in person or virtually. We hope to see you there!

Please rate the overall quality of the AFTD Annual Education Conference.

Did you connect directly and interact in a valuable way with others who understand your FTD journey?



Would you be likely to attend a future AFTD Education Conference in person?



AFTD Awards New Pilot Grants and Accelerating Drug Discovery for FTD Grants

AFTD recently awarded several new grants to researchers investigating the pathology of FTD and to those looking into drugs that could reverse or even halt FTD's effects.

Accelerating Drug Discovery for FTD Grants

Through the Accelerating Drug Discovery for FTD grant program, AFTD and the Alzheimer's Drug Discovery Foundation work to advance promising drug discovery research projects that could hasten FDA approval of FTD treatments.

Ana Martinez, PhD, Research Professor at the Biological Research Center of the Spanish National Council for Research, along with the biotechnology company she founded, Ankar Pharma, were awarded funding to continue the development of drugs that block an enzyme that drives chemical changes linked to the abnormal clumping of the FTD-associated proteins tau and TDP-43. By targeting this enzyme, Dr. Martinez hopes to reduce tau and TDP-43 clumping and slow or even stop the disease process.

Robert Williams and Pelagos Pharmaceuticals received funding for their research on drugs targeting disease-causing changes to essential brain cell functions like metabolism and inflammation. By reversing these disruptive effects, the Pelagos team aims to restore cell function to its normal state in FTD and ALS.

AFTD Pilot Grants

Another way AFTD advances research is through its Pilot Grants. Pathways for Hope Pilot Grants support basic research on the neurobiology of FTD and translational research to improve clinical practices and biomarkers, while Well-Being in FTD Pilot Grants fund research to improve the well-being of persons diagnosed, families, and care partners. Steven Boeynaems, PhD, an assistant professor at Baylor College of Medicine, was awarded a Pathways for Hope grant to examine similarities between the mechanisms of naturally occurring toxins such as snake venom and the toxic dipeptide repeat proteins that result from *C9orf72* gene mutations. He hopes to better understand how these toxic agents trigger inflammatory responses in the brain to pave the way for future treatments.

Daniel Mordes, MD, PhD, an assistant professor at the University of California, San Francisco, received a Pathways grant to study another disruption caused by the *C9orf72* gene: autophagy, which breaks down damaged or abnormal proteins. His project will examine a novel target for developing drugs to boost autophagy.

Finally, Alexandru Iordan, PhD, an assistant professor at the University of Michigan, received a Well-Being in FTD grant to evaluate a state-of-the-art form of brain stimulation that uses MRI to direct stimulation to a specific brain area. A positive effect on social and behavioral symptoms would support a larger follow-on trial of this novel treatment.

AFTD thanks the following sponsors for their generous support of the 2023 AFTD Education Conference!

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WAVE LIFE SCIENCES

AFTD Ambassadors Gather for Wide-Ranging Summit Meeting in St. Louis

AFTD's volunteer Ambassadors gathered for their annual summit on May 4 in St. Louis to reconnect with each other, learn more about AFTD's organizational priorities, and welcome five new Ambassadors into the fold.

Ambassadors are volunteer leaders who represent AFTD in communities across the United States. They help identify opportunities to raise awareness of FTD, conduct outreach efforts, network with healthcare professionals, and speak publicly to share their insights on FTD.

AFTD now has 15 Ambassadors, representing 13 states: California, Washington, Oregon, Iowa, Michigan, Alabama, Texas, Massachusetts, New Jersey, Maryland, South Carolina, North Carolina, and Illinois.

In addition to geographic diversity, AFTD's Ambassadors bring a range of FTD experiences from a variety of perspectives. The newest Ambassadors include a mother whose daughter had FTD and died at age 33, while another new Ambassador brings the perspective of the Latinx community. All of our Ambassadors' voices are key to raising broad FTD awareness in the U.S.

Ambassadors spoke about ways they can further help to advance several of AFTD's key mission areas, most notably FTD awareness and education.

The 2023 Volunteer Summit was held in the Marriott St. Louis Grand, site of the AFTD Education Conference. In addition to connecting with each other and learning more about AFTD, Ambassadors were able to provide input directly to AFTD staff leadership, receive guidance aimed at maximizing their impact in the upcoming year, and simply have fun spending time together in person.

Throughout the Summit, Ambassadors and staff spoke about ways that Ambassadors can help to advance several of AFTD's key mission areas, most notably awareness. In fiscal year 2023 (which ran from July 2022 through June 2023), Ambassadors took part in nearly 50 awareness activities, including media appearances, political advocacy events, fundraisers, and healthcare professional education opportunities, among many others.

AFTD CEO Susan L-J Dickinson was present at the Summit and noted the enthusiasm and energy that permeated the room.

The following day, May 5, Ambassadors were instrumental in the success of the AFTD Education Conference, welcoming families to the in-person event and facilitating some of the breakout sessions.

To learn more about AFTD's Ambassadors, visit theaftd.org/about-us/aftd-ambassadors.

Saying “Thank You” with BBQ! AFTD’s 2023 Volunteer Appreciation Dinner

AFTD appreciates the work of our incredible volunteers all year round. On May 4 in St. Louis, the night before the AFTD Education Conference, AFTD staff expressed our gratitude for our volunteers’ invaluable contributions by offering a delicious meal of St. Louis-style barbecue at our Volunteer Appreciation Dinner.

Eighty AFTD volunteers joined nearly 30 AFTD staff members for the dinner, which was held in the historic Statler Ballroom at the Marriott St. Louis Grand hotel, the site of the hotel’s original lobby. The setting was truly unique, featuring elegant marble floors and glamorously high ceilings.

> Throughout the fun and energizing evening, AFTD volunteers rekindled connections with their peers and made new friends who share their FTD journey.

AFTD Volunteer Services Manager Michael Mullan launched the evening by thanking all AFTD’s volunteers – both those present in the room and those who could not make it to St. Louis. He praised volunteers of all types: support group volunteers, fundraiser hosts, community educators, AFTD Ambassadors, and Board members, just to name a few.

AFTD CEO Susan L-J Dickinson then highlighted the historic importance of volunteers to our organization, while AFTD Senior Director of Programs Sharon Denny spoke about their accomplishments over the past year. AFTD Volunteer Engagement Coordinators Jacqueline Butler-Gamble and Carrie Johnson and AFTD Support Services Coordinator Erin Ficca recited a short poem of gratitude.

After the dinner, each volunteer was presented with some simple tokens of our appreciation, including AFTD sunglasses and an AFTD-branded sunshade for their cars.

Throughout the evening, volunteers and staff shared enjoyable conversation, laughter, and palpable enthusiasm for our volunteers’ ongoing efforts to make the FTD journey easier for the next family. Many volunteers rekindled connections from past AFTD conferences and events, while making new friends who share their FTD journey.

Volunteer Appreciation Dinners are always a fun and energizing part of the in-person AFTD Education Conference experience. We’re already looking forward to next year in Houston!

INDEPENDENT EVENTS

SLÁINTE!:

Denise Lange and Shannon and Geoff Fuller hosted a St Paddy's Day Party with a Purpose in honor of Michael Lange on March 18 at the Springdale Area Recreation Club in Raleigh, North Carolina. Michael Lange, Denise's husband, passed away from FTD in 2022. The evening featured a cornhole tournament, a costume contest, and raffle prizes, and raised over $24,000 for AFTD's mission!

NOT HALF BAD:

Christian Clark created a GoFundMe page in memory of his mother, Alexandra, who passed away from FTD at age 59 in December 2022. In addition to creating the fundraiser, Christian ran the United Airlines NYC Half in her memory on March 19. At the time of this writing, Christian's page has raised $8,943 to advance AFTD's mission.

IT'S THE BROOKLYN WAY:

Tara Simonson ran the Brooklyn Half Marathon on May 20 in memory of her mother, Lynn Surprenant, who passed away from FTD in 2020. On race day, Tara ran past the Brooklyn Museum, Botanic Garden, and Prospect Park before making her grand finish at the world-famous Coney Island Boardwalk — all while raising awareness of FTD. In addition to raising much-needed awareness, Tara also raised $7,147 to benefit AFTD's mission.

A TEE-RRIFIC EVENT:

Todd Hartzog hosted a golf outing on June 4 at the Colonial Oaks Golf Course in Fort Wayne, Indiana, to benefit AFTD and to honor the memory of his friend Dustin Snyder, who passed away from FTD in 2022. The event was a great success, with roughly 80 golfers participating in the day's activities, and raised over $5,700 in support of AFTD's mission.

DRESS FOR SUCCESS:

On March 3, Edwin Pagan organized a "Dress Down Day" with the Clifton School District (New Jersey) in memory of Jackie Pang, who passed away from FTD in 2020 at the age of 64. Thanks to Edwin's efforts, everyone participated by wearing unique outfits, and together raised $1,716 to support AFTD's mission.

IF YOU KEEP ON BELIEVING:

On February 24, Kathleen Pondelli, along with other members of the Pondelli family, ran the Disney Princess Half Marathon in memory of Al, Kathleen's husband, who died from FTD in 2014. Running in the Disney Princess Half Marathon has become a tradition for the Pondelli family since 2016. They have raised a total of $10,486 for AFTD, including $1,063 this year!

THE FAMILY THAT RUNS TOGETHER...:

Susan Gotsch and her family participated in the Flying Pig Marathon on May 5-6 in Cincinnati. Having completed the marathon in 2019 with her husband, Keith, the Gotsch family wanted to rerun it this time in memory of their beloved husband and father, as Keith passed away from FTD in July 2022. Susan and her team celebrated the marathon's 25th year and helped spread an immeasurable amount of FTD awareness. In addition, they raised over $1,400 for AFTD's mission!

HOOPS AND HOPE:

Soraya Sharma held a basketball tournament on April 15 at the Awty International School in Houston to support AFTD's mission. Teams of five players paid $25 to play in the tournament and participate in a ton of fun and a lot of school spirit. Food sales and donations boosted the amount that was donated to AFTD afterward — which resulted in $1,195 donated to AFTD's mission.

CLIMB THE HIGHEST MOUNTAIN:

Shelby Buckley embarked to climb Denali on May 19 in honor of her father, whom she previously climbed the mountain with after she graduated from high school. After their initial trip, Shelby and her father promised each other that they would climb Denali together after she graduated from college. Since then, her father was diagnosed with FTD, and the progression of the disease has prevented his ability to climb. But Shelby is dedicated to keeping her promise and climbing in his honor instead.

A Thank You from AFTD's Events Department

In the Summer 2022 issue of *AFTD News*, we announced that we had eclipsed fundraising results from 2021. This year we are pleased to announce that we've done it again! During our 2023 Fiscal Year (July 1, 2022 – June 30, 2023), our volunteer-led fundraisers raised a total of $851,000 and counting to advance AFTD's mission!

In the past year, a lot has changed for the Events Department. We've expanded even more and are now a team of four full-time employees! We have been honored to work with each and every one of you and appreciate you opening up about your FTD stories, allowing us to get to know you on a personal level to help bring much-needed awareness to this disease and support to other families on this journey.

Our fundraising volunteers took it to another level this past fiscal year. From golf tournaments to marathons to themed parties, you all made a meaningful impact on the path to end FTD! During our 2023 Fiscal Year, Food for Thought celebrated its 10th year as a campaign, and participants recognized that by incorporating the number 10 into their events in unique ways. We saw new volunteers tell stories From the Heart in February through our With Love campaign, all told in a variety of creative ways. We also saw some personal records set both in amounts raised and distance run through our AFTD-Team Race Season. At every turn, our volunteers have impressed us with their dedication, vulnerability, passion, and creativity.

From AFTD's Events Department and on behalf of all of us here at AFTD and the community we serve, we want to thank all our fundraising volunteers who are driving AFTD's mission forward. We could not do this work without you.

The Association for
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