



AFTD INSIGHTS

Frontotemporal Degeneration News & Community Updates

FTD Clinical Trials and Search for Biomarkers Gaining Momentum



Members of the 2024 Research Roundtable Leadership Committee



FTD researchers gathered in Amsterdam for the 14th International Conference of Frontotemporal Dementias.

Momentum for FTD treatments is accelerating. Recent developments in FTD science have led researchers to believe that we are getting close to achieving the first viable treatments to improve quality of life for persons diagnosed – or even slow or stop disease progression.

AFTD staff and Board members who traveled to Amsterdam to attend the 14th International Conference of Frontotemporal Dementias (September 19-22) noted a clear shift in the event's tone. In previous conferences, discussions centered on attendees' hope that effective clinical trials might be on their way. At this year's conference, that hope solidified into a guarded but real confidence that treatments are coming soon.

AFTD was a gold-level sponsor of the Amsterdam conference, which was held by the International Society on Frontotemporal Dementias (ISFTD). An estimated 750 healthcare professionals and scientific investigators – including many past and current recipients of AFTD research grants – convened for four information-packed days, including a day of programming designed for local care partners.

AFTD staff had a significant presence at the ISFTD conference. Penny Dacks, PhD, AFTD's Senior Director of Scientific Initiatives, moderated a panel on clinical trials

and management, which featured a presentation by AFTD Director of Research Engagement Shana Dodge, PhD. During the care-partner day, AFTD Manager of Genetic Initiatives Kim Jenny, MS, LCGC, and AFTD Senior Director of Programs Sharon Denny, MA, gave a presentation called "Understanding Familial FTD and Charting Your Path."

Throughout the conference, attendees spoke enthusiastically about the recent, tangible advances in FTD science, including an increase in FTD-focused clinical trials and the pharmaceutical industry's clear interest in bringing FTD therapies to market. For example, the Philadelphia-based pharmaceutical company Passage Bio has been conducting a clinical trial of the gene therapy PBFT02, which uses an engineered virus to deliver a healthy copy of a gene called *GRN* into the brain. When functioning properly, *GRN* produces an important protein called progranulin. People who have a variant in *GRN*, however, cannot sufficiently create progranulin, resulting in a significantly elevated risk of developing FTD.

At the ISFTD conference, Passage Bio presented encouraging results from their Phase 1/2 PBFT02

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AFTD News Briefs

New Map Tool Improves Search for Support on AFTD Website

In August, AFTD launched our FTD Support Group and Diagnostic Center Locator, an interactive map that allows families affected by FTD to more easily find support options in their own area, including local in-person and virtual support groups facilitated by AFTD-trained support group volunteers. The map features locations for FTD diagnostic centers, which can help families obtain an accurate, speedy diagnosis. To access the map, along with list of virtual national support groups, visit the AFTD website at theaftd.org/find-support.

AFTD Introduces Guide to Managing Transition to Facility-Based Care

AFTD HelpLine staff have developed a new resource to help guide people in finding a care facility for a loved one living with FTD. “Navigating the Transition to Facility Care” offers strategies for supporting a loved one’s move into a facility, fostering a compatible dynamic with care staff, and developing a person-centered care plan. Visit bit.ly/FTDFacilityCare to download this resource. If you still have questions, the AFTD HelpLine staff is available to provide answers about this or any other aspect of the FTD journey. Contact the HelpLine at 866-507-7222 or info@theaftd.org.

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.

“I have made a planned gift to AFTD because I feel like I owe it to my husband – I want to ensure that help will always be there for others. My donation is a way that I can make sure no one else will experience anything close to what I did.”

– Member of AFTD’s Legacy Circle and former volunteer



EMPOWERED TO SPREAD AWARENESS: NICOLA'S STORY

"I feel empowered moving forward because, as I have delved in to learn more about this disease in order to truly understand it, it's helped me be more compassionate."

– Nicola Perez, current care partner

During phone calls in early 2019, Nicola Perez sensed something was different about her father, McKenzie Perritt III. At the time, McKenzie lived alone in Pennsylvania. Nicola, who lives in Texas, reached out to relatives and friends who were closer to her father, learning that McKenzie had become withdrawn and was neglecting his health. Upon visiting her father, Nicola discovered "boxes and boxes of notes" about his daily routines. McKenzie, a former police officer, was used to keeping detailed records.

"What really made it click was when one of the tenants from his rental property told me that something may be going on," Nicola said. "When I finally visited him, I just broke down because I knew right away something was wrong."

McKenzie, with Nicola's support and encouragement, visited several neurologists and chose to undergo genetic testing. In December 2019, McKenzie, then 62, learned he was living with behavioral variant FTD.



Nicola and McKenzie



McKenzie receiving an award with the Prince George's County Police Department



McKenzie and his oldest grandchild Cheyenne

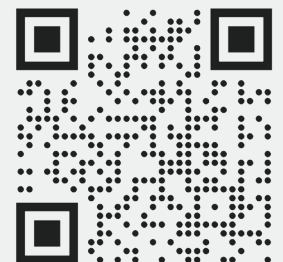
Nicola immediately started searching for more information about the disease, finding empowerment through the resources and opportunities she discovered on AFTD's website. "I'm definitely going to Dallas for the marathon in December. I'm looking forward to getting more family members to get on board," she said.

Today, McKenzie lives with Nicola and her family, and she is learning to navigate the journey as his full-time care partner. In the future, Nicola hopes to open her own facility for "people with dementia and FTD. Because of the behavioral aspect of it, [my father] wasn't able to stay at the day program I found initially."

Nicola is eager to volunteer with AFTD and raise FTD awareness within the African American community. "I wanted to share my story to encourage other people of color to understand that these are things you shouldn't be ashamed of. You should be aware and compassionate. Awareness is where it starts."

Will you join Nicola and a community dedicated to improving the quality of life for all who face FTD?

Your gift today provides support to people impacted by a diagnosis, educates healthcare professionals, sustains advocacy efforts for early and accurate diagnosis and more accessible care options, and drives research vital to biomarker discovery and therapeutic development. Use the enclosed envelope, visit theaftd.org and click on the **Donate** button at the top of the page, or **use the QR code** to donate.



*Together, we can support all on this journey. **Together, we are empowered to #endFTD.***

Spotlight on... Jill S. Goldman, MS, MPhil, CGC, AFTD Board of Directors



Jill S. Goldman, MS, MPhil, CGC

After careers in teaching and health education, Jill Goldman obtained a degree from the genetic counseling program at the University of California, Berkeley in 2000. That year, Dr. Bruce Miller, director of the Memory and Aging Center at the University of California, San Francisco, convinced her to come work with him, and Ms. Goldman has been immersed in the world of FTD genetic counseling ever since. She has also been involved with AFTD since its earliest years, serving as a member of our Medical Advisory Council before joining AFTD's Board in May.

Now at Columbia University, Ms. Goldman is a professor and genetic counselor in adult neurology; her

current patient population is made up largely of persons diagnosed with FTD or their at-risk family members. She has also facilitated a support group for FTD caregivers for nearly 25 years. "I learn a lot from the caregivers, and they learn from each other, and certainly support each other," she said. She began her support group at UCSF and brought it with her to Columbia.

Over the years, Ms. Goldman has worked closely with AFTD to ensure its information on genetics is accurate. She has reviewed numerous AFTD publications and resources related to the genetics of FTD and championed the creation of AFTD's Manager of Genetic Initiatives position, which was filled

in 2022 by Kim Jenny, MS, LCGC. "Kim has developed several support groups for people who are at [genetic] risk or deciding whether to test," Ms. Goldman said. "It's a wonderful thing she's done."

"My personal priorities are about the care and support of people [living with FTD] now," Ms. Goldman said.

Ms. Goldman will begin her Board tenure by serving on its Research subcommittee as well as the Education and Support subcommittee, where she'll push for greater FTD awareness, faster diagnoses, and more effective FTD care – three goals that she sees as related. "My personal priorities are about the care and support of people now," she said. "I know how much people struggle with getting proper medical care... There aren't that many [FTD] specialists out there in the field, although it's recognized much, much more than in the past."

But her main focus remains FTD genetics. She said she will continue to encourage those who are comfortable doing so to undergo genetic testing, which can not only help them personally, but also advance FTD science. "For drug development, it's really essential we recognize as many families as we can who have genetic FTD," she noted.

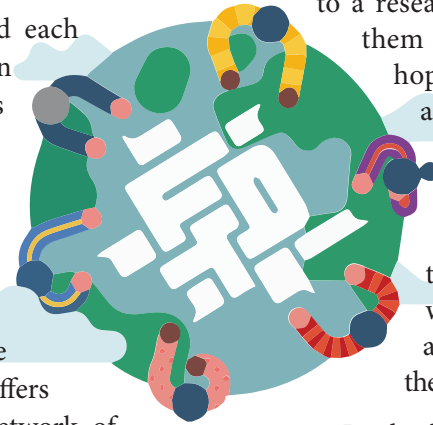
"There's a lot that's going to happen in the future" of FTD genetics, Ms. Goldman said. "I'm very happy to be involved in it."

World FTD Awareness Week: A Week of Global Unity and Action

The global FTD community took to social media together to share their FTD stories and grow the public's understanding of the disease during World FTD Awareness Week 2024, held September 22-29.

World FTD Awareness Week is facilitated each year by World FTD United, a global coalition of FTD-focused organizations that includes AFTD.

Each day highlighted a different theme, starting with “share” and ending with “celebrate.” On day two, for example, the theme was “support.” Model, activist, and AFTD Brand Influencer Nicole Petrie discussed the types of support that AFTD offers for affected families, including AFTD's network of support groups. On day six (“educate”), speech-language pathologist and dementia educator Adria Thompson, M.A., discussed AFTD's educational resources, such as webinars, fact sheets, and diagnostic checklists.



Emma Heming Willis – entrepreneur and wife of actor Bruce Willis, who is living with an FTD diagnosis – created social media content throughout World FTD Awareness Week. Each day, she shared a “quick question” she posed to a researcher or healthcare professional, asking them what aspect of their work would bring hope to those affected by FTD, or about a personal connection they have while working with the FTD community.

As always, the first day of World FTD Awareness Week aligned with AFTD's two-week Food for Thought campaign, in which AFTD volunteers hosted food-related awareness and fundraising events throughout the country. [See page 14 for more information.]

In the lead-up to World FTD Awareness Week and throughout the week, AFTD advocates successfully obtained resolutions in four states, as well as proclamations in 22 states and seven cities, that officially recognized the week. [Learn more about our advocacy efforts on page 13.]

AFTD Joins Public-Private Initiative Supporting ALS and FTD Research

AFTD has joined fellow nonprofits, biopharmaceutical companies, and the U.S. Food and Drug Administration as partners in the Accelerating Medicines Partnership for ALS (AMP ALS) initiative.

Launched by the Foundation for the National Institutes of Health (FNIH) in partnership with 16 partner organizations, AMP ALS aims to accelerate the discovery of new biomarkers and therapeutic targets for ALS. AMP ALS will also streamline the collection and management of ALS clinical research data across the United States, making deidentified data available through an online portal. By making data accessible to researchers, AMP ALS can accelerate the pace of research

and foster greater collaboration between experts of different disciplines, including between FTD and ALS scientists.

The 2011 discovery that mutations in the *C9orf72* gene can cause both FTD and ALS and observations of overlapping biological changes have revolutionized our perceptions of the disorders. We now know that FTD and ALS exist on a spectrum, and that both disorders can exist in the same person.

As the sole FTD-focused partner of AMP ALS, AFTD can help to bridge the silos of FTD and ALS clinical research, to ensure that the needs of people jointly affected by FTD and ALS are considered, and to bring the world closer to a future without these diseases.

As an AMP ALS Steering Committee member, AFTD will have the opportunity to highlight the connection between FTD and ALS. AFTD will be able to appoint FTD experts to subcommittees responsible for project design and will work to ensure that projects focused on *C9orf72* mutations incorporate input from FTD experts, as people with the mutation are at risk of developing ALS or FTD. Finally, AFTD will help ensure that AMP ALS is informed by the lived experiences of people diagnosed with FTD-ALS, their care partners, and family members.

AFTD's participation in the initiative was made possible thanks to the support of David and Weezie Reese.

A Conversation with Dr. Larry Carter, Alector's Vice President of Clinical Development

Earlier this year, the biopharmaceutical company Alector announced that the U.S. Food and Drug Administration (FDA) had granted a “breakthrough therapy designation” to latozinemab, the company’s investigational drug designed to address FTD caused by a variant in the *GRN* gene. The special designation enables expedited regulatory review of therapies intended to treat serious conditions. A Phase 3 clinical trial evaluating latozinemab, developed by Alector in partnership with GSK, is currently underway.

AFTD recently spoke with Alector Vice President of Clinical Development Lawrence (Larry) Carter, PhD, about progress being made in developing therapeutic options to treat FTD. The conversation has been edited for length and clarity.

What approach is your company using to treat FTD?

Our approach to treating FTD at Alector is to start by studying genetic forms of FTD because those are areas where underlying causes are better understood than sporadic forms of the disease. For example, FTD-*GRN* is believed to be caused by a loss of function variant, or mutation, in one of the two copies of an individual’s granulin gene that codes for the progranulin protein. If one of those genes does not produce normal levels of progranulin, then that person can have approximately half of the progranulin levels they should have, which results in the development of FTD in almost all cases.

What do you think is the most urgent need to be addressed for people facing FTD and their families?

I really think this question is best answered by those with lived experience. One of the things we hear all the time is about the tremendous impact an FTD diagnosis has on the entire family in terms of economic hardship – it has been estimated to be almost twice that of an Alzheimer’s diagnosis – and trying to manage behavior symptoms, to name just a couple. I think AFTD is a great resource for connecting families with resources, support groups, clinicians, and research opportunities. Through these interactions we can learn about the most urgent needs directly from those with lived experience.

How do you think we can empower the global FTD community to reach our shared goals?

AFTD and Alector have very similar goals with regard to empowering the community and reaching a future without this disease. The stated mission at Alector is to create a world in which neurodegenerative diseases are a thing of the past. So we also envision a future that is free of FTD. In conducting our trial, we’ve tried to raise awareness of FTD, provide no-cost genetic testing options, and help people find FTD centers of excellence because we know that we are asking a lot from patients and families who are



Larry Carter, PhD, Alector's Vice President of Clinical Development



already dealing with a lot following an FTD diagnosis. I also think helping to make people’s voices heard – either by raising awareness within their communities or by working with regulators such as the FDA or European Medicines Agency – is necessary to help everyone better understand the condition and the unmet needs people have. Also, advocating with elected officials can really go a long way to effect change and empower the broader community. People want to hear from those with lived experience.

What do you find to be the most encouraging about today’s research landscape?

This is a really exciting time with regard to all the research and clinical trials being done in FTD and other neurodegenerative conditions. If we are successful in treating FTD-*GRN*, then we will have a potential foothold and momentum that could carry over into treating other forms of FTD. Folks are starting to recognize there are common underlying pathologies to these conditions – they may manifest in different ways, but we can focus on treating the underlying causes that lead to the signs and symptoms we can observe.

What are the challenges you see and your hopes for how stakeholders can overcome these together?

I know that referring to FTD or FTD-*GRN* as a “rare disease” carries different connotations for different people, but there are real challenges when conducting clinical trials or drug development in small populations. We need to work together to

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A Tribute to AFTD's Chris Stevens, MBA, and Debra Niehoff, PhD



Chris Stevens, MBA

Over the summer, AFTD wished a fond goodbye to Chris Stevens, MBA, and Debra Niehoff, PhD, both of whom retired. These long-time staff members left indelible marks on the organization and our work to hasten a future free of FTD.

Dr. Niehoff joined AFTD in 2015 as Research Manager, later becoming Director of Research and Grants. She transformed AFTD's research-grant portfolio, reviewing countless proposals and awarding coveted AFTD grants to FTD researchers. During her tenure, AFTD significantly expanded its Postdoctoral Fellowships (now known as Holloway Postdoctoral Fellowships) and its Pilot Grant program. Dr. Niehoff also helped create and run funding opportunities such as the Digital Assessment Tools for FTD and ALS grant, launched in



Debra Niehoff, PhD

conjunction with the ALS Association, and the Diagnostics Accelerator program and Treat FTD Fund, both created in collaboration with the Alzheimer's Drug Discovery Foundation (ADDF).

Dr. Niehoff helped to advance FTD research by establishing strong relationships with FTD-focused investigators across the United States and beyond, and forged similarly strong bonds with organizations like Target ALS and CurePSP. She facilitated important meetings of FTD researchers and other stakeholders, such as the AFTD Research Roundtable and Holloway Summit, and her collaborations with early-career researchers – particularly in sessions she co-presented at the AFTD Education Conference – bridged the gap between scientists and FTD families.

Chris Stevens joined AFTD in 2017 as

its first Chief Financial Officer, and later became Director of Finance. During her tenure, AFTD experienced remarkable growth – staff increased by over 270 percent, while AFTD's investments and cash-on-hand surged to over \$46 million, from \$2.6 million. She worked closely with AFTD's Board, serving as staff lead for three subcommittees: Finance, Audit, and Investment. (She created the latter two.)

Variously responsible for AFTD's finances, IT, and human resources during her AFTD career, Ms. Stevens also managed the creation of, and relocation to, AFTD's new King of Prussia, Pa., office office in 2019. A member of AFTD's Executive Team, she provided financial and strategic support for AFTD Strategic Plans published in 2019 and 2022. When the COVID-19 pandemic hit, she introduced vital tools and technology to help AFTD pivot seamlessly to remote work. All throughout, she worked to create AFTD's culture of inclusiveness and respect, and to encourage fiscal responsibility at all levels of the organization.

AFTD deeply appreciates Dr. Niehoff and Ms. Stevens and their enormous contributions to furthering AFTD's mission.

A Conversation with Dr. Larry Carter (continued)

do the required clinical trials and convince stakeholders, including health authorities and payers, that the benefits we hope to see in studies are clinically meaningful to patients and their families.

AFTD has been a great partner in helping raise awareness about available studies and building trust in the FTD community. Once there is an effective therapy, there will still be a need to educate families and clinicians that there is now hope – that there is a treatment option where there was not one before. It will be a change to the historic narrative and that is the day I really look forward to seeing.

*Note: While the Alector trial on latozinemab has completed enrollment, several other clinical trials are actively seeking people affected by FTD-GRN to test other promising treatments. Visit AFTD's **Studies Seeking Participants** page to learn more about trials that are actively recruiting. Signing up for the **FTD Disorders Registry** is another way that persons diagnosed, care partners, and family members can participate in research.*

AFTD is sincerely grateful for Alector's ongoing dedication to our mission and the people we serve. If you are interested in learning more about their work, please visit their website at alector.com.

Those We Honor... Those We Remember

Gifts received from May 16, 2024 – September 30, 2024

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

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In Honor Of

Craig Allen
George Allen
Gordon Ayer
Steven P. Bellwoar
Joan Berlin
Julia Winston
Bethurum Murphy
Bob Boerschel
Edwina Britt
Jim Brown
John Bustard
Frank Callea
Antoinette Cerra
Michael Chang
Christina Chavez
Brandon Cline
Serina Cline
Spencer Cline
Chase Coburn
Sarah Coffin-Vetter
Mack & Cameron Colwell/Childress
Helen-Ann Comstock
Ruth Crookston
Jill Czarnowski
Sharon DeFelices
Jenny Dore
Peter Durant
Charles Elkins II
Betty Ellis
Tim Elsbecker
Douglas Ferro
Bobby Frese
Peter Gaess
John Gornell
Rita Granado-Gentile
Shallon Gray
Stephanie Haefner
Steve Harris
Daniel Hedaya

Ruth Herman
Colleen "Terry" Hill
Paul Hirschboeck
Ophelia Howard
Nancy Howerter
Ann Huzinec
Donald Kalscheur
Debra Joan Kem
Dennis Kent
Joann Lee
Vivian Lee
Ron LeLeux
Allison Love
Melissa Mattei
Christine Mc Nerney
Kathy Mele
Debra Moore
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Bennett Raphel
Melissa Rarick
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FTD Clinical Trials (continued)

clinical trial, known as upliFT-D. Increased levels of progranulin production were reported, “with elevated levels maintained for up to one year after treatment,” said Passage Bio president and CEO Will Chou, MD. Dr. Chou added that the treatment was well tolerated by trial participants.

In a significant expansion of the PBFT02 clinical trial, Passage Bio announced in July that, following positive feedback from the U.S. Food and Drug Administration (FDA), it will open enrollment to participants who have a variant in *C9orf72*, the most common gene associated with genetic FTD and ALS. Passage Bio is working on revising its trial protocol to include people with *C9orf72* variants, and plans to begin enrollment of such participants soon.

Other FTD clinical trials are expanding. In July, AviadoBio, a London-based biopharmaceutical company, announced that its ASPIRE-FTD clinical trial will open its first U.S.-based trial site, at Ohio State University’s Wexner Medical Center. ASPIRE-FTD is evaluating a treatment called AVB-101. Like Passage Bio’s PBFT02, AviadoBio’s AVB-101 is a gene therapy that introduces a functional *GRN* gene copy to restore progranulin production in people who have a *GRN* variant. As of this writing, the company is dosing the first cohort enrolled in Phase 1/2 of ASPIRE-FTD.

Genetic FTD trials will pave a path for interventions for other FTD genes, as well as for sporadic FTD.

Other clinical trials for genetic FTD are currently active, including those sponsored by the pharmaceutical companies Prevail Therapeutics, Denali Therapeutics, Alector, and Vesper Bio; others are in the planning stages. These genetic FTD trials will pave a path for interventions for other FTD genes, as well as for sporadic FTD.

Progress is also being made in the realm of FTD biomarkers. Currently, FTD does not have any validated biomarkers, which refer to something that can be objectively measured to determine the prevalence of a disease or condition. (High blood pressure, for example, is a widely accepted biomarker for heart disease.) AFTD’s 2024 Research Roundtable meeting, held August 27-29 in Arlington, Va., was devoted to biomarkers. Representatives from industry,

academia, government, nonprofit partners and other organizations convened to collaboratively examine the current landscape of FTD biomarkers, the infrastructure for developing them, and the criteria for including them in clinical trials.



The 2024 Research Roundtable took place August 27-29 in Arlington, Va.

While no biomarkers have been validated for FTD, the Foundation for the National Institutes of Health Biomarkers Consortium announced earlier this year that the FDA has accepted its letter of intent to apply for the qualification of the protein neurofilament light (NfL) in blood as a biomarker for the early detection of symptom onset in genetic FTD. The letter highlights strong evidence supporting NfL as a biomarker, with the most substantial evidence coming from international organizations – including the natural-history studies ALLFTD, with sites in the U.S. and Canada, and GENFI, with sites in Europe and Canada – that have been tracking various biomarkers for over a decade.

As FTD clinical trials and the search for biomarkers both advance, families living with FTD can help drive the science even further by joining the FTD Disorders Registry. Information provided to the Registry will contribute to our understanding of this disease and demonstrate to researchers and investors that there is a community in need of medical interventions. In return, registrants can learn about research-participation opportunities as they develop.

The Registry has been updated to include a friendlier user experience for both persons affected by FTD and for researchers. Researchers will soon have a dedicated portal that will streamline the process of identifying research-ready participants, facilitate data analysis, and foster collaboration among peers across various disciplines. Visit FTDRegistry.org to learn more.

AFTD Ambassador Completes Coast-to-Coast Bike Ride to Raise FTD Awareness



When Spencer was injured 300 miles from the finish, members of AFTD's community rallied around him on social media using the hashtag #PedalForSpencer.

Not many people would choose to complete massive feats of endurance for a cause, even one that is near and dear to their heart – which is why AFTD is so proud of Ambassador Spencer Cline, who biked the width of the United States over the summer to raise awareness about FTD.

Spencer's ride honored his father, Lawrence, who had FTD caused by the *C9orf72* gene variant and died when Spencer was 13. Spencer and his siblings each have a 50% chance of carrying the gene, which has spurred Spencer to continue spreading awareness in hopes of advancing FTD research toward effective treatments.

On June 16, Spencer dipped his bike's

back tire into the Pacific Ocean in Astoria, Ore. His goal was to replicate the feat in the Atlantic Ocean 3,650 miles later, in Charleston, S.C. Along with his future brother-in-law, Paul Petras, who joined the first half of the ride, Spencer documented each day's events on his Instagram page. In each video clip he posted, Spencer included a fact about FTD.

The journey started smoothly, but on July 1, Spencer broke his wrist in Idaho when a dog darted in front of his bike, causing him to crash. The injury required surgery and a brief hiatus while Spencer healed.

Still, the duo made admirable progress, sharing Spencer's FTD story with all they met along the way.

After 36 days, Spencer and Paul reached Jefferson City, Mo., the trip's halfway point.

But on day 46, the trek took another unfortunate turn. While riding alone near Atlanta – Paul, a teacher, had returned home for the start of the school year – Spencer was sideswiped by a large truck and thrown into a ditch. He suffered a broken collarbone and dislocated shoulder, leaving him unable to finish the ride by himself. So he asked the community to “pedal me the last 300 miles.”

On bicycles, stationary bikes, Pelotons, and even tricycles and scooters, the AFTD community rallied around Spencer, pedaling more than 1,000 miles on his behalf. Riders posted their pictures on social media and tagged #PedalForSpencer, greatly expanding the reach of Spencer's awareness effort.

On August 24, with one arm in a sling and the other holding his tire, Spencer walked the last few miles to Sullivan's Island, S.C., where he dipped his tire into the Atlantic. He had biked an amazing 90% of the country's width, all while raising awareness about FTD and over \$60,000, well surpassing his fundraising goal. And in the end, his ride did even more than that. By calling on the AFTD community, Spencer proved that empowered together, we will end FTD.

The story of Spencer Cline's trek to bring awareness of FTD is not complete without acknowledging the local news stations along the way that interviewed him, bringing FTD awareness to their audience. **Thank you.**

- KTVB 7, Boise, Idaho
- KCTV 5, Kansas City, Mo.
- WANF (Atlanta News First), Atlanta, Ga.

- WCIV (ABC News 4), Charleston, S.C.
- WPDE (15 News), Myrtle Beach/Florence, S.C.

Attention Volunteers: Spread FTD Awareness by Running an Information Table!

Stimulating greater public FTD awareness and understanding across the country is a key part of AFTD's mission. You can contribute to awareness by running an information table at an event in your area, an experience that offers you meaningful opportunities to engage, educate, and inform your community about FTD and AFTD.

The first step is finding an event where an information table would be appropriate. Examples include conferences focused on dementia, caregiving, or similar subjects; education events for healthcare professionals; and health fairs, walks, or other events focused on wellness. To find one of these events, you can do an online search, or reach out to your local or state office on aging, a nearby neurology office, a local university's medical center or a hospital. AFTD will pay to sponsor certain events.

After you identify an event in your community, reach out to an AFTD Volunteer Coordinator for next steps. (Our Volunteer Coordinators can also help you identify local opportunities.) AFTD will supply you with everything you need (tablecloth, brochures, images, etc.) to promote

FTD awareness. AFTD will also provide you with ways to keep track of people who you engage with during the event. And all our volunteers get an AFTD t-shirt for helping to raise crucial awareness.



AFTD volunteers Bruce Lipman and Erica Heffernan at an educational event sponsored by a home care agency in Evanston, Ill.

Last year, volunteers represented AFTD with information tables at 42 events across the U.S. We hope to double that total next year, but we can only do that with the help of volunteers like you. Contact volunteer@theaftd.org to get started today!

Help Us Educate Health Professionals about FTD!

AFTD's Provider Outreach Volunteer initiative is a new, entry-level opportunity for community members to collaborate with our staff to provide FTD-focused information and resources to healthcare professionals for earlier, more accurate diagnosis and improved care management options. This initiative recruits, trains, and supports volunteers to conduct targeted outreach to local healthcare providers in clinical, facility, and community-based settings.

From January to June 2024, the first cohort of 11 volunteers connected with 73 new providers in communities throughout the United States and Canada, including neurologists, physician assistants, and nurse practitioners working in clinics, dementia care and assisted living facilities, and other healthcare services.

In a follow-up survey conducted by AFTD, 100% of the

first cohort's participants said they would recommend the Provider Outreach Volunteer opportunity to someone interested in furthering our mission.

Twenty-two volunteers have signed up for the initiative's second cohort, which began outreach in October. Using suggestions from the first group to refine materials and approach strategies, the volunteers hope to foster connections with more than 110 providers, increasing the number of professionals who can recognize FTD symptoms, make a diagnosis or refer to an appropriate specialist, and inform persons diagnosed and care partners about options for care and support.

If you're interested in learning more about this volunteer opportunity, visit theaftd.org/volunteer-form or send an email to volunteer@theaftd.org.

AFTD Advocates Bring Awareness to States and Cities Across the U.S.

AFTD advocates worked with legislators in cities and states across the country to obtain resolutions and proclamations officially recognizing FTD Awareness Week 2024 (Sept. 22-29). Advocates secured resolutions in four U.S. states and proclamations in twenty-two states and seven cities – a significant win for greater FTD awareness nationwide. AFTD reached out to several of those advocates to learn more about the process.

In Washington State, Christi Ackerman worked to get a state proclamation declared, in addition to a proclamation for her hometown of Covington, a suburb of Seattle. She did so in honor of her late husband, Doug, who died in 2022 at age 56. Christi and Doug struggled for over a decade to get a correct diagnosis.



AFTD advocate Christi Ackerman (right) and her daughter, Hannah Ackerman, with the Washington State FTD Awareness Week proclamation

“I don’t want anybody to ever have the feelings I had of not knowing [what was wrong] and then finding out,” she said, noting that some of the medications prescribed to Doug for conditions such as depression and bipolar disorder may have worsened his symptoms.

Using sample language she pulled from AFTD’s Proclamation Toolkit, Christi submitted her request for an FTD Awareness Week proclamation to the appropriate state and local contacts. While the Covington proclamation required some follow-up emails, she was ultimately successful; meanwhile, the state-proclamation process was relatively straightforward. “You submit it, you wait, and you hear whether you got it,” she said.

Across the country, advocates Carrie Edwards and Natasha Smith worked together to obtain a proclamation in Virginia. Natasha is living with an FTD diagnosis, while

Carrie’s husband, Steve – a former firefighter who was at the Pentagon following the 9/11 attacks – died of FTD earlier this year.



AFTD advocates Natasha Smith (center) and Carrie Edwards (right) with Virginia’s FTD Awareness Week proclamation

Natasha contacted the AFTD HelpLine offering to become a volunteer. “I was very honest,” she said. “I said I want to be an advocate, but these are my weaknesses – can you pair me with someone who can help me tell my story?” AFTD staff matched her with Carrie, who had also told AFTD she was ready to become an advocate: “I’m ready for action, Jackson – let me get involved.”

Using AFTD’s Proclamation Toolkit, Carrie and Natasha told their stories to staffers at the governor’s office, and within days an FTD Awareness Week proclamation was signed. “Don’t be afraid to make the phone calls and develop relationships, because people want to help – that’s what staffers are for, to help constituents,” Carrie said. “The thing about FTD is it’s a bipartisan issue – everyone knows someone with dementia.”

Proclamations and resolutions help to increase awareness of FTD, foster working relationships with local politicians, and build the groundwork for shaping policies that will increase funding and improve care. It’s not too early to get started on securing resolutions and/or proclamations for the next FTD Awareness Week, which will take place September 21-28, 2025.

To help people begin preparing for next year’s awareness efforts, AFTD will be offering a December 2024 workshop to help guide anyone interested in volunteering – stay tuned for details. And if you plan on taking the first step, let us know – contact AFTD at advocacy@theaftd.org and tell us your plans!

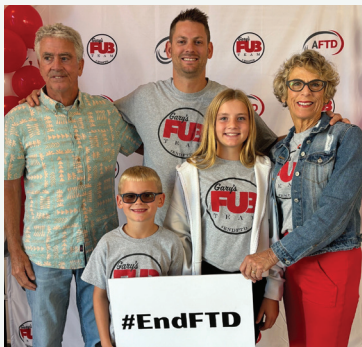
AFTD's food for thought

This year marked AFTD's 12th annual Food for Thought campaign! The campaign included 41 events across 26 states and Canada, and raised more than \$215,000 for AFTD's mission. Below are the fundraisers that raised over \$4,000 (at the time of this writing) from their event:

STEVE BELLWOAR is a passionate AFTD Board alumnus. He hosted the 11th annual Colonial Electric Food for Thought Event in memory of his mother, Trish, who passed away in 2021 from FTD. Steve raised more than \$123,000 this year, increasing his 11-year total to over \$1 million raised for AFTD's mission!

MIKE BRUCKLIER is the director of operations at Flour Bakery, which made AFTD-red Oreos at their Boston locations. During this specialty sale they brought in \$10,000 for AFTD's mission and spread FTD awareness to the entire Boston area.

NANCI ANDERSON and her daughters, Lindsay and Emily, hosted their annual event in memory of their beloved husband and father, Gary, who passed away in 2019 from FTD. In their biggest fundraiser yet, they raised almost \$16,000. Over the years they've brought their total donation to AFTD's mission to nearly \$55,000 raised through Food for Thought!



COLLEEN FRANZREB and her family changed things up this year and started "Big Time's Chili Contest" to honor her brother, Edward "Big Time" Costello. With over 10 family recipes vying for chili bragging rights, attendees put their tastebuds to the test and raised funds to further AFTD's mission. This change came with great success, and they raised \$6,884!

TERRY WALTER hosted a wine tasting event with the Woman's Club of Lincoln (Calif.) to honor her family, which has been deeply impacted by FTD and ALS. Her event raised \$4,747 from ticket sales and raffles. Over the years she has raised nearly \$48,000 to support AFTD's mission with this event!

KATARINA DOMINGUEZ'S Swim-a-Thon event blew us out of the water, bringing in a total of \$4,698 to honor her mother, who is currently living with FTD. Katarina and her team pledged to do physical challenges based on the donation size, including laps in the pool, push-ups, and pull-ups.

Thank you to all the amazing Food for Thought hosts who also raised additional awareness of FTD and funds to support AFTD's mission through the campaign:

- | | |
|-------------------------|-------------------|
| Alexa DeLuca | Kim Stasa |
| Alexia Moustatsos | Libba Adams |
| Amber Guy | Lindsey Hunt |
| Amy Bouschart-Callea | Liz Matthews |
| Barbara Todd | Liz Zadnik |
| Bonnie Shepherd | Lynda Nagle |
| Brandee Waite | Matthew Broder |
| Caroline Pryzbylowski | Melissa Dube |
| Cathy Tully | Melissa Rarick |
| Dawn Kirby | Michelle Greco |
| Fishtown Pickle Project | Nicole Deleve |
| Hannah Hickman | Noah Volz |
| Heather Sellers | Olivia Costello |
| Joanne Linerud | Patrick Gutierrez |
| Julie Smith | Sharon DeFelices |
| Karine Finken | Tim Lindsey |
| Kathy and Sara LaFone | Wendy Duckworth |
| Kay Webb | |

AFTD's Events Department wants to extend a huge thank you to the four dedicated Food for Thought Liaisons that give their time and energy to help each host every step of the way:

- | | |
|---------------|-----------------|
| Susan Meagher | Terry Pontious |
| Meghan Roscoe | Heather Sellers |

The following Independent Events have taken place since the Spring issue of AFTD Insights and raised \$5,000 or more for AFTD's mission:

THE SIDORIS FAMILY: AFTD wishes a big thank you to the Sidoris family after another successful year of their George F. Sidoris Memorial Golf Outing. Now in year 19, the golf outing is AFTD's longest-running volunteer-led fundraising event. In 2024 the family raised a record \$65,500, bringing their grand total up to \$438,750!

SPENCER AND PAUL BIKED ACROSS AMERICA: Superstars Spencer Cline, an AFTD Ambassador, and Paul Petras completed their 63-day bike across America to raise awareness and funds for AFTD's mission. They faced many obstacles, including two injuries and many popped tires, but their amazing efforts and dedication resulted in \$60,000 raised and an immeasurable amount of FTD awareness spread. [See page 11.]

CHRISTIN ROSE: Christin and her family teed off the second annual Kim Rose Cure for Dementia Golf Outing on June 28. Hosted with their family business, Wings & Rings, the event honored Christin's mother-in-law, Kim, who is currently living with FTD. It brought in a whopping \$27,800 for AFTD's mission, bringing the two-year total to \$59,342!

DAWN O'GARA: AFTD Ambassador Dawn O'Gara hosted a golf tournament on September 14 in memory of Jim Tobin. This golf tournament had layers of fun with 18 holes, dinner, contests, raffles, and much more! They raised \$9,925 for AFTD's research initiatives and Comstock Respite Grants.

THE MORETTI FAMILY: The ninth annual CWM Golf Outing was another big success, thanks to the Moretti family and all who supported them. The outing raised \$9,011 this year, bringing its nine-year total to \$47,793 raised in memory of Carl Moretti's love and passion for golf!

DEB SCHARPER: Deb Scharper hosted her eighth annual Crusade for a Cure Golf Tournament over Labor Day weekend. This year's event was extra fun thanks to a special post-dinner concert by country singer Jay Allen! Thanks to her amazing work, Deb raised \$7,000 to donate to



AFTD's mission, bringing her total to \$68,815.

LUKE SMILEY: Luke took on the challenge of participating in the Chattanooga Half Marathon in honor of his father, Reid Smiley. Not only did he run all 13.1 miles, he exceeded his fundraising goal with \$6,751 raised to further AFTD's mission!

JOE PANG: Veteran fundraiser Joe Pang and his family hosted another great Dollars for Dim Sum event on June 23. The group sold homemade dim sum and their famous dumpling sauce for all to enjoy. The group raised \$5,000 for AFTD's mission in memory of Joe's wife, Jackie Pang, who had FTD and died in 2020.

Thank you to all our other fundraisers who also raised awareness of FTD and funds to support AFTD's mission through their own events:

Anthony Mauro
Chase Coburn
Edwin Pagan
Glennis Lahr
Heather Shay
Helen McIntyre
Joyce Bustard
Kate Kelly

Marc & Julie Smith
Niki Toscani
Paridhi Tyagi
Sandy Anglin
Suzanne Costello
Taylor Howard
Todd Hartzog

DRIVING HOPE



AFTD's 2024 Driving Hope Golf Tournaments made a successful return to Colorado National Golf Club in Erie, Colo. on August 11 and Metropolis Golf Club in White Plains, N.Y. on September 16. It was a great time to reunite with old friends and meet new ones, all while boosting AFTD's mission. As always, we are humbled by the generosity of our sponsors, participants, and supporters. The events raised a total of \$164,000+ for AFTD's mission!

AFTD would like to extend a sincere thank you to everyone who supported these events, especially our generous sponsors:

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AFTD would also like to give a special shoutout to the Driving Hope committee: Betsy Bartosiak, Joan Berlin, Daniel Hedaya, Jason Nagin, David Pfeifer, Brian Rose, and Michael Stowell.



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