The Association for Frontotemporal Degeneration
FIND HELP·SHARE HOPE

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AFTD INSIGHTS
Frontotemporal Degeneration News & Community Updates

AFTD Launches First-Ever Advocacy Agenda

AFTD is committed to advancing policies that will improve the lives of all those impacted by FTD, and drive research to find a cure. In pursuit of those goals, we recently collaborated with our partners—policymakers, regulators, researchers, healthcare providers, persons living with FTD, and their families and friends—in laying out the priorities that will guide our efforts.

The product of that collaboration is FTD's first formal advocacy agenda. At the federal level, our priorities are to:

1. Promote innovation in FTD research and drug development
2. Expand access to quality dementia care and support services
3. Support FTD family caregivers
4. Increase awareness of FTD and the unmet needs of the FTD community among state and federal legislators

A list of specific policies AFTD will be supporting and tracking can be found on our website – visit theaftd.org/get-involved/advocate and click the button labeled "AFTD Policy Priorities."

The dementia field is dynamic, and defined by constant change. A timely example of that is the new pressure on federal research funding resulting from the priorities of the new administration. AFTD has been closely monitoring the impact of recent policy changes at the National Institutes of Health (NIH) and is deeply concerned that they will significantly disrupt biomedical research that is critically important to the families we serve.

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Paving the Path Forward: AFTD Puts New Strategic Plan into Action

The AFTD Board has approved a Strategic Plan that will guide the organization through the end of the 2028 fiscal year. Created with a range of stakeholders, the plan will enable AFTD to build on the momentum of the last few years in pursuit of accurate, early diagnoses, effective treatments, and greater access to support for all members of a family on the FTD journey.

"AFTD's new Strategic Plan maps out a highly collaborative and productive three years, in which our Board and staff will work alongside researchers, healthcare professionals, and policymakers to advance education, drive groundbreaking scientific developments, and improve FTD care," said AFTD CEO Susan L-J Dickinson. "I invite each person reading this to partner with AFTD as we carry out this critically important work."

The plan is developed around four main goals that focus AFTD's organizational priorities in areas where our leadership can have the greatest impact:

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AFTD News Briefs

AFTD HelpLine Now Offers Option to Schedule Calls

For nearly 20 years, the AFTD HelpLine has offered information, guidance, resources, and emotional support to families on the FTD journey, whether via telephone (866-507-7222) or email (info@theaftd.org). Now, people seeking help can choose to schedule a call with one of the trained and highly knowledgeable social workers who comprise AFTD's HelpLine staff. Visit theaftd.org/aftd-helpline to schedule a call today.

Earn CME Credits by Watching Recorded AFTD Webinars

Since 2022, medical professionals who attend the live broadcasts of AFTD's Healthcare Professional Educational Webinars have been eligible to receive continuing medical education (CME) credits from our partners at Rush University. But starting soon, healthcare professionals will be able to get CME credits from watching special recordings of these webinars, any time that is convenient for them. The first in this series, "Differentiating, Diagnosing and Managing Behavioral Variant FTD," will be available soon – stay tuned to the AFTD website for details.

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

When Lana's husband Joe was diagnosed with FTD in 2015, they "were told there was nothing we could do" – an experience far too common for the FTD community.

But using AFTD's resources, Lana learned more about the disease and what to anticipate as Joe's symptoms progressed. "There was absolutely nothing out there about FTD other than through AFTD – I needed something to help me understand what just happened to us," she said.

Encouraged to connect with other care partners, Lana joined a local AFTD-affiliated support group to share her experiences, hear from others, and learn much-needed coping skills and strategies for navigating Joe's diagnosis.

Though Joe passed away in 2022, Lana now volunteers as a support group co-facilitator and is committed to staying informed about progress in FTD research, advocating for timely diagnosis and better care management options, and assisting other people on this journey.

"Knowledge about FTD is so much better than when Joe was diagnosed seven years ago," she said. "But the disease needs more exposure to reduce stigma and ensure more primary care physicians know about it."

Lana and Joe Leonard

Joe on a ski trip

Lana and Joe with their children

Will you give today to drive AFTD's work on behalf of all facing this disease? Use the enclosed envelope or the QR code to donate.

Your support enables us to raise greater awareness among the public, healthcare professionals, and policymakers. You also help advance research toward the first disease-modifying treatments and sustain and expand our programs that assist people impacted by FTD, like Lana and Joe.

Together, we can support all on this journey.
Together, we are paving the path toward a future free of FTD.

Your gift makes it possible for:

106 AFTD volunteers to facilitate **91** support groups across the United States, providing support and connection for people affected by FTD

AFTD HelpLine staff to respond to more than **3,900** inquiries annually with guidance and resources

AFTD Comstock Grants, worth up to $500 each, to be distributed to over **750** people living with FTD and their care partners to assist with the financial burden of a diagnosis

Spotlight on… Kyle Birmingham, CFA, AFTD Board of Directors

Kyle Birmingham, CFA

Kyle Birmingham remembers his late mother, Melody Ticknor, as a "consummate volunteer." Before being diagnosed with FTD, Melody generously donated her time to causes and groups she felt passionately about – her church, the local youth soccer league, an organization supporting low-income families on Philadelphia's Main Line. At her funeral, "half the pews were filled with folks she volunteered with," he said.

Birmingham committed himself to carrying on Melody's legacy by becoming a volunteer himself. He found AFTD, connected with a former AFTD Board member, and joined the Board's Investment subcommittee, where his background in finance – he is the co-founder of the financial-services company Quorus – informed his work to provide a financial base that will help AFTD to grow its impact. "AFTD is no longer this plucky start-up – we're a full-fledged organization that's going to be here for a long time," he said.

His family's own FTD journey was a lengthy one; after several incorrect diagnoses beginning in 2016, Melody passed away in 2021 at age 66. Everyone's FTD experience is unique, and for Birmingham, the intense day-to-day labor of FTD caregiving crowded out his ability to emotionally process his mom's disease. "It was so hard when we were going through it to make space to deal with any of the emotions," he said. "I had my worker hat on the whole time." It wasn't until after Melody died that there was finally room to process things. "You have this time and space to think, 'What just happened? What was I feeling in those moments?'," he said. "I still feel like I'm doing so much work to put the pieces together."

In 2024, Birmingham went to Houston to attend his first AFTD Education Conference, which he said helped him gain perspective on his family's experience. And while he valued the information and resources he received, what stood out most was the sense of community he felt "just by being in a room full of people who understood and could share stories."

Birmingham officially joined the AFTD Board last year in Houston. As a Board member, he will work to "ensure we're well set up for success, and we're as strong an organization as we can be." He also wants to step a bit outside of his comfort zone by getting involved in organizing fundraising events to support AFTD's mission.

But most of all, being an AFTD Board member lets Birmingham "reconnect with the memory of my mom and make sense of the journey we went on as a family," he said. Growing up, Birmingham admired the positive difference Melody made in people's lives through her volunteer work. Now, as an AFTD Board member and parent to two young girls, he wants to "set that example for my own kids."

2025 AFTD Holloway Summit Focuses on FTD Risk Factors

Can the risk of developing FTD be changed by environmental exposures, lifestyle, diet, and other factors? Are the genetic risks fully understood? These are questions regularly asked by affected families and at-risk individuals.

FTD risk factors were the focus of the third AFTD Holloway Summit, which convened academic scientists, nonprofit partners, persons with lived experience, and AFTD staff and Board members in Miami Beach, Fla., in January.

Summit co-chairs Kaitlin Casaletto, PhD (University of California, San Francisco) and AFTD Medical Advisory Council Chair-Elect Chiadi Onyike, MD, MHS (Johns Hopkins University) led discussions of the many factors that could contribute to FTD risk, such as occupation, lifestyle, or head trauma.

Discussions at the Holloway Summit were based on the premise that many factors could, at least theoretically, contribute to risk of FTD. A 2020 *Lancet* report summarized 12 modifiable or lifestyle factors that influence the likelihood of dementia later in life, including early-childhood education levels, hearing loss, hypertension, obesity, and smoking. Lessons learned from Alzheimer's disease and ALS, whose disease mechanisms overlap with FTD, were also woven throughout the program.

Unfortunately, it's difficult to fully identify the factors directly linked to FTD onset and progression. Not only are risk factors such as head trauma or environmental toxin exposure rarely documented, FTD itself is often difficult to diagnose.

At the Holloway Summit, vibrant discussions centered on the accelerating efforts to identify risk factors for FTD. A panel discussion highlighted resources available for risk-factor research and the ethical considerations in conducting and communicating risk-factor research. Holloway Summit attendees will produce a consensus article that will be shared with the FTD community.

Academic scientists, nonprofit partners, and others engaged in vibrant discussions centered on the accelerating efforts to identify risk factors for FTD.

The field of risk-factor research in FTD is relatively new. While the Holloway Summit was foundational in supporting further research, there are currently no known risk factors beyond genetics. Caution should be taken in analyzing any risk-factor studies; repeated confirmatory research, studies of large populations, and significant time is necessary to identify risk factors with any certainty.

The annual AFTD Holloway Summit is made possible through the generous support of AFTD Board Member Kristin Holloway and the Holloway Family Fund.

"Navigating [my husband's] FTD diagnosis was such a difficult and confusing time, and wondering about preceding risk factors only added to that uncertainty," she said. "While risk-factor research in FTD is still early, I was proud to see researchers convened at this year's Holloway Summit discussing the best ways to get better answers for these questions at the forefront of people's minds impacted by FTD."

Join AFTD's 2025 Education Conference via Zoom on May 2

The 2025 AFTD Education Conference will be livestreamed via Zoom on May 2, offering a valuable opportunity to connect with others who understand, learn from FTD experts, and engage with AFTD's community.

As in the past few years, the 2025 Education Conference will be a hybrid event: attendees can either join us online or in person at the Omni Interlocken Hotel in Broomfield, Colo., outside Denver. Visit theaftd.org/education-conference-2025 to register today.

The conference will feature a diverse slate of sessions focused on a range of topics relevant to FTD, including caregiving, research, advocacy, and improving quality of life for persons diagnosed and care partners. All attendees will be able to find the information and support they need, no matter where they are on the FTD journey.

Sessions available via Zoom will include:

- **Living Well with an FTD Diagnosis**
  Members of AFTD's Persons with FTD Council will discuss how they live fulfilling, meaningful lives despite their diagnoses – and how care partners can provide support along the way.
- **FTD: At the Crossroads of Neurodegenerative Disease**
  Dr. Penny Dacks of AFTD joins two leading FTD researchers, Dr. Michael Benatar of the University of Miami and Dr. Corey McMillan of the University of Pennsylvania, for a look into the work currently being done to bridge the research and clinical-care gaps between FTD and ALS.
- **Join AFTD's Movement for Change!**
  AFTD Advocacy and Volunteer Engagement Director Meghan Buzby will discuss how volunteering can amplify your impact and how your voice can drive the change needed for a brighter future for those affected by FTD. **UPDATE:** Emma Heming Willis is now confirmed and will be joining Meghan for this session!

The conference's Keynote Address will also be livestreamed. This year's Keynote Speaker is Katie Brandt, MM, of Massachusetts General Hospital's FTD Unit. Katie's life has been twice touched by dementia: her father had Alzheimer's while her late husband was diagnosed with FTD when he was just 29. Her Keynote Address will focus on how she has channeled her experiences into helping others facing FTD through her advocacy and support work.

AFTD is grateful to Alector for supporting our 2025 Education Conference as this year's Registration Sponsor.

AFTD Launches First-Ever Advocacy Agenda *(continued)*

In February, NIH announced it would be capping all facility and administrative costs, known as "indirect costs," at 15% of new grants, even though these costs can amount to as much as one-third of a project's budget. Academic medical centers and other research institutions rely on these funds to cover the shared infrastructure needed to efficiently support multiple grants, which includes equipment maintenance, data storage, utilities, compliance with patient-privacy measures, and more. Indirect costs also support the recruitment and training of the next generation of researchers who will continue this vital work.

This sudden, significant, and dramatic shift in NIH funding will impede ongoing research and threaten future research. For the 2026 fiscal year, which will begin on October 1, 2025, AFTD and our partners in dementia advocacy will be requesting at least $51.3 billion for the NIH. This funding level would allow the agency's budget to keep up with inflation and promote meaningful growth of approximately 6%.

AFTD is also concerned about continued reports of disruptions to federal funding already awarded, such as the layoffs of nearly 1,200 staff and scientists at NIH earlier this year – which, at press time, have included approximately 10% of the staff at NIH's Center for Alzheimer's and Related Dementias. Research institutions and researchers depend on consistent and predictable funding sources, and must have confidence that their positions will not be eliminated without cause and thoughtful consideration. These changes will disrupt research that will improve the lives of people and families living with dementia.

As AFTD works to implement its advocacy agenda in 2025, we will continue to urge robust investment in biomedical research. Join our efforts by visiting the AFTD Advocacy Action Center at theaftd.quorum.us to receive regular updates on our efforts and to take part in current opportunities to write to your members of Congress about the importance of funding both the NIH and FTD research at the strongest possible levels. Meanwhile, AFTD will support, monitor, and actively advocate for these and other relevant issues in order to remain responsive to the community we serve.

Make your voice heard

In response to new cuts to federal funding and staffing, AFTD issued a call to action encouraging our community to tell their members of Congress to support research institutions at a level that will allow vital FTD research to continue. By adding your voice, you can help influence policy and legislation related to medical research, caregiving, and dementia care and services that impact the FTD community. Visit theaftd.quorum.us and click the Take Action button to get started.

Those We Honor... Those We Remember

Gifts received from October 1, 2024 – February 15, 2025

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David E. Stikkers
Bradford A. Strine
Ann Sumner
Susan M. Sutherlin
Merlin L. Swackhamer
Robert J. Sykes, Jr.
Albert Sylanski
Daniel R. Sztraicher
John Tabak
John Targarona
Salvatore A. Tavormina
Judi M. Terhorst
Joanne Terlep
Marji Theodoroff
Donna Jay Thistle
Calvin L. Thomas
Laurence Thomas
Christine Thomsen
Howard Thorn
Robert Thurston
Gabriele Tille-Hoefs
Stephen M. Tipton
James R. Tobin
Gretchen Sue Toles
Karen Toms Johnson
Dominic Paul Toscani
Beecher Trail
Carolyn Jo Treptow
Scott Turville
Dale Tyler
Julie Unger
Sharon Utley
Teresa Ann Valois
Jeffrey Van Son
William Robert Van Velkinburgh
Lawrence Vihtelic
Gary E. Vinciguerra
Douglas Vorhies
James Vowell
Justin M. Wade
Sally Waggoner
Beverly Waite
Robert Francis Wald
Joseph Walder
Lawrence James Wall
Timothy J. Walsh
Steven Walter
Kari Ward
Dwight H. Warrington Sr.
Ann Elizabeth Waters
Susan Watson
Susan Waxman
Charles Francis Wedel
Mary Weflen
Sally Weintraub
Rosemary Weiten
Cynthia White
Ted White
William J. White
Barbara Whitmarsh
Fletcher D. Wicker
Gary L. Wiggins
Carroll Lee Wilkinson
Patricia Jane Willard Heil
Douglas Albert Williams
Moyese Williams
James Wilson
Dale Joseph Wimmer
Judy Windhorst
James S. Wolcott
Kendall Wong
Deborah Woodcock
Glenda Woods
Ralph Worthington
Charles Wosaba
Reed Young
Stephen Yturralde
Anthony Zanette
James C. Zeger
John Victor Zeok
David Allen Zimmerman
Thomas Glenn Zimmerman
Linda Zugrave

In Honor Of

Bill Allen
Kay Almy
Dean Anglin
Vicki Axe
Connie Bajek
Brenda Ball-Reichard
Esme Banks
Ted M. Beal
Steven P. Bellwoar
Hank Benedict
Alan Berlin
Julia Winston Bethurum Murphy
Laurie Beyer
Bob Boerschel
Viva Boerschel
Diane Bogle
The Bruckliers
John Bustard

Honor a Loved One or Remember Their Legacy

Families wishing to direct memorial donations to AFTD are encouraged to call our office at (866) 507-7222. 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.”

Those We Honor… Those We Remember *(continued)*

Frank Callea
Ed Cellupica
Christina Chavez
Beth Cheatham
Bridgette Chorbajian
The Chorbajians
Anne Clark
Serina Cline
Katie Coke
Pamela Cole
Andrew Collins
Mack & Cameron Colwell/Childress
Helen-Ann Comstock
Marion Connor
Susan Cowden
Leighanne Danna
Regina Day
Mary Jo Dean
William "Bill" Dennis
Susan L-J Dickinson
Suzanne Doll
Daren Doolittle
Jenny Dore
Peter Durant
Barbara Ebert
Charles Elkins II
Christine Ellersick
David Fagin
Jan Paul Favero
Stephen Fenoglio
Gregory W. Fletcher
Debbie Fossett
J & J Frenkel
Allan Frost
Cathy Hatanaka Fujimoto
Peter Gaess
Ron Gastrock
Nancy Goodman
Paul Gorton
Christine Graham
Dave Graham
Rita Granado-Gentile
Emily Greene
Marian Grems
Marie Greway
Pat Hearity
Daniel Hedaya
Victoria Heller
Sherri Helms
Maya Henry
Colleen "Terry" Hill
Theresa Hill
Paul Hirschboeck
Terri Lynn Hoch Fletcher
Kristin Holloway
Rebecca Hook
Nancy Howerter
Ann Huzinec
Tammy Jaxtheimer
Brother Joe
Nancy Jospey
Phillip Kanter
Jayne Kelly
Debra Joan Kem
Robert Kem
James & Theresa Kilgore
Donna Klinedinst
John Koller
Judy Kozubal
Joan Krysinski
Elissa Kuhr
Ben & James Langan
Joyce Langeliers
Janice Lee
Joann Lee
Ron LeLeux
Cindy Lemaire
Carl Lemieux
Peter Lerner
Michael Leroy
Teresa Lewis
Tracey Lind
Paula Lindberg
Hut Lindner
Normand Lizotte
Tammy Renee Long
Todd M
Mike Mannuzza
Guy Margolin
Sonia Marqués
Dan Martin
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Carol Mauro
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Sue McDonald
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Charlotte McKim
Christine McNerney
Larry Mealer
Julie Mezmur
Travis Moffatt
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Stanley Smokler
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Rosanne Stoneking
Susan Marie Sweeney
Clay Swindell
Maryanne Szkaraknik
Almudena Tamayo
Michael Tarpley
Dennis Tebout
Melanie Thrower Rabenhorst
Michael Todd
Toni Toler
Kenneth Troup
James Tully
Ryan Urban
Thomas Varner
Beth Walter
Terry Walter
Marianne Warley
Lisa Wauters
Glen Webb
Jerry L. White
Kimberly Williamson
Cathy & Douglas Wirt
Deborah Wolfe
Jeff Wolin
Timothy Yerkes
Liz Zadnik
Angie Zamberlin

AFTD Debuts Research-Focused E-Newsletters

One of the core tenets of AFTD's mission is to support and fund research focused on diagnosis, treatment, and finding a cure. Two new research-focused AFTD newsletters aim to keep you informed about the latest advancements as we strive for a future free of FTD.

Both newsletters will be sent out six times a year and will include sections highlighting FTD news briefs and upcoming AFTD events.

Subscribe today to receive the latest research updates straight to your inbox!

Tailored for researchers and professionals, this newsletter takes a deeper scientific look into an FTD research topic and includes a section highlighting funding opportunities.

Scan the QR code to subscribe to FTD Research Spotlight.

Designed for the broader FTD community, this version presents the same research topic or similar but in clear, layperson-friendly language for ease in understanding.

Scan the QR code to subscribe to FTD Science Digest.

AFTD Puts New Strategic Plan into Action *(continued)*

Goal 1 - Advance diagnosis, treatments, and cures for all.

The new Strategic Plan emphasizes the importance of developing tools that facilitate early and accurate diagnosis, and will expand our efforts to educate clinicians on identifying the different forms of this disease. We will nurture a community of committed and connected researchers while empowering potential research participants, including those diagnosed and those at risk of developing FTD.

Developed with input from a range of stakeholders, AFTD's new Strategic Plan will help us pave the path forward to a future free from FTD.

Goal 2 - Ensure that high-quality FTD care and support are accessible to anyone affected by the disease, at every stage of their journey.

Resources like AFTD's HelpLine, website, Comstock Grants, and support group network provide unique support and information to our community. Our Strategic Plan calls for scaling these services to reach even more affected families while deepening our understanding of unmet needs. We will advance research to better understand the factors that impede wellbeing for individuals and families affected by FTD, which includes establishing AFTD as a central resource for tracking and disseminating emerging best practices in FTD care and support.

Goal 3 - Advance awareness of FTD and advocate for equitable policy change to improve the lives of those impacted by FTD.

Expanding public awareness of FTD and AFTD and growing a national network of grassroots advocates are crucial steps to advancing our mission. AFTD will establish and maintain a consistent presence in Washington to influence policy issues relevant to families, while keeping a keen interest on influencing policy in key states like New York and California.

PAVING THE PATH
FORWARD

Goal 4 - Ensure organizational effectiveness and sustainability to deliver meaningful impact.

To accomplish these goals and remain a reliable FTD resource for years to come, AFTD must have a strong infrastructure and an engaged, mission-oriented staff. Strategies under Goal 4 include strengthening and diversifying revenue streams, investing in staff development and retention, growing our vital national volunteer network, and developing metrics to assess our impact.

As a member of the community, you are encouraged to read our new Strategic Plan when it becomes available in June. Visit theaftd.org/about-us/strategic-plan.

AFTD's 2024 Volunteer Survey: Key Takeaways

Last year, in partnership with the consulting firm VQ Volunteer Strategies, AFTD surveyed nearly 250 past and current volunteers, who provided valuable insight into our approach to volunteer engagement – including what's working well, and what can be improved. This in-depth assessment – which comprised an online survey, stakeholder interviews, and an analysis of AFTD's volunteer materials – will allow us to more efficiently engage with our incredible volunteers, pointing them toward activities that best match their personal passions while supporting AFTD's mission.

AFTD volunteers believe their work has meaning. All survey respondents – 100% of them – said they believe their work has a positive impact. Nearly all respondents agreed that current volunteer opportunities match their skills (97%), align with their interests (97%), provide variety (94%), and fit into their schedules (93%).

AFTD volunteers are motivated. Volunteers were asked why they choose to devote their time to AFTD. A majority said they relished the chance to make a difference in the lives of the AFTD community (65%) and to honor a loved one (61%). Meanwhile, approximately one-third are motivated by the chance to be part of a community (35%), share their skills (34%), or contribute to the science of FTD (32%).

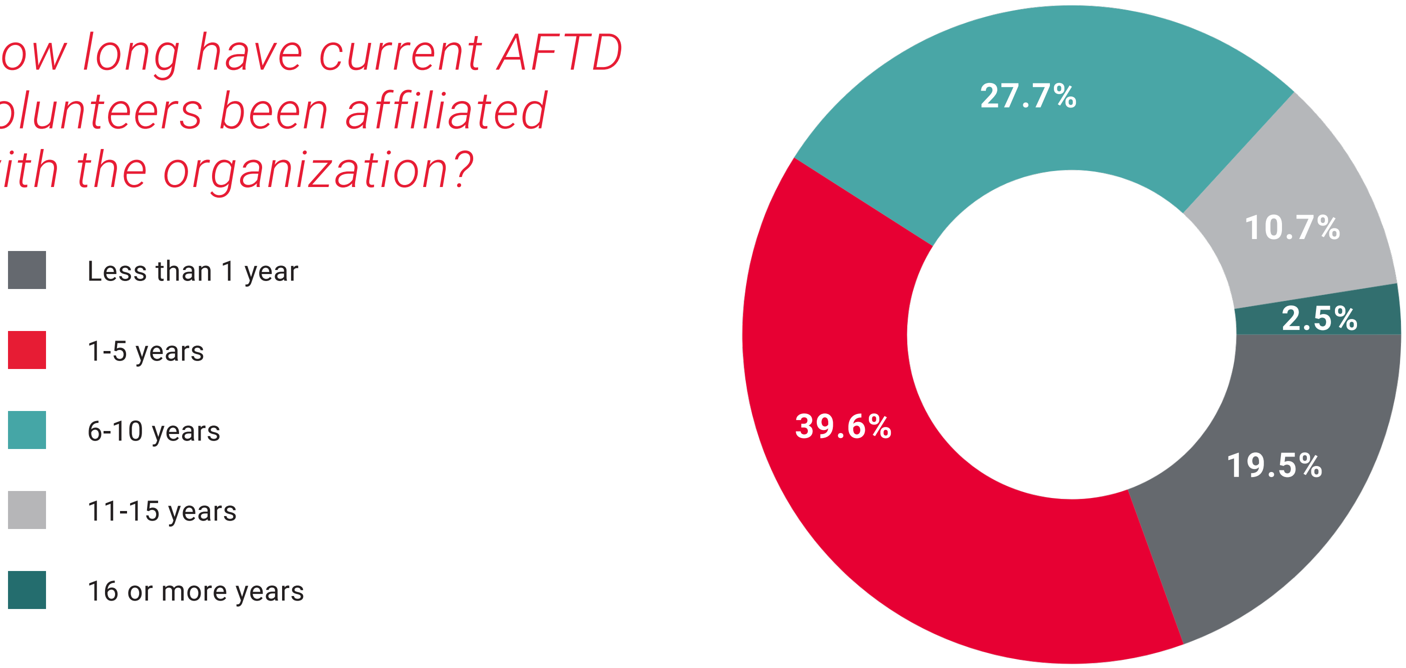
AFTD volunteers want to do more. Respondents said they would be able to make a greater impact by volunteering with AFTD if: they could try out different volunteer roles without making a long-term commitment (28%); there were more short-term opportunities available (28%); they had more flexibility in their volunteer commitment (17%); volunteer roles had more leadership opportunities (11%).

Our volunteers have spoken! Based on feedback from our survey, AFTD's volunteer staff plans to undertake the following steps over the next several years:

- Develop a unified strategy for volunteer engagement so that AFTD can engage volunteers more efficiently and with greater impact.
- Better equip volunteers for success with resources and training.
- Give volunteers more opportunities to connect with others in their area who care about AFTD's mission.

Volunteers are the heart and soul of AFTD. Thank you again – and special thanks to everyone who completed the online survey. AFTD remains committed to helping you make a difference!

How long have current AFTD volunteers been affiliated with the organization?



Who's Who in Federal Health Policy

As AFTD works to implement our policy agenda, we will be engaging many members of Congress, particularly those with the greatest influence over health policy. (See the cover story of AFTD Insights to learn about AFTD's 2025 policy agenda.)

This year, key committees in the U.S. House and Senate are expected to consider policies related to insurance coverage, drug pricing, telehealth, access and affordability of care, and other important issues – all of which have the potential to improve quality of life for families affected by FTD.

In the House, the committee with jurisdiction over most healthcare sector and public health programs is the Energy and Commerce (E&C) Committee, currently chaired by **Rep. Brett Guthrie** (R-KY). Rep. Guthrie has been an E&C Committee member for several years; this is his first year as chair. His Democratic counterpart, **Rep. Frank Pallone** (NJ), is the committee's ranking member. Rep. Pallone has served on E&C for nearly two decades, and since 2015 has been either chair or ranking member of the full committee.

In the Senate, the Health, Education, Labor, and Pensions (HELP) Committee has jurisdiction over many aspects of healthcare. (Two notable exceptions are Medicare and Medicaid). **Sen. Bill Cassidy** (R-LA) is serving in his first term as Chair of the HELP Committee. Sen. Cassidy is a gastroenterologist, and was a member of the House before being elected to the Senate. **Sen. Bernie Sanders** (VT), an independent who caucuses with the Democrats, serves as the committee's ranking member.

Do your representatives serve on these committees? Find out:

- House E&C members: energycommerce.house.gov/representatives
- Senate HELP members: help.senate.gov/about/members

If you haven't already, we encourage you to sign up for AFTD's Advocacy Action Center to learn about the latest updates on policies relevant to the AFTD community, and how you can work with us to engage our elected officials. Visit theaftd.quorum.us to learn more and sign up.

Rep. Brett Guthrie (R-KY)

Rep. Frank Pallone (D-NJ)

Sen. Bill Cassidy (R-LA)

Sen. Bernie Sanders (I-VT)

AFTD's with love campaign

AFTD volunteers shared stories of their FTD journey to spread hope and love during February's *With Love* campaign. This year, *With Love* raised **$22,502**, bringing our 14-year total to $786,245! We are also grateful for the continued generosity of The Rainwater Charitable Foundation, which has donated $10,000 as a matching gift to further AFTD's mission each year since 2013.

AFTD thanks the amazing fundraising volunteers who participated in *With Love*, along with the countless donors and supporters who contributed to advancing AFTD's mission. Some took things to an extra level by undergoing physical challenges like a taking part in a triathlon or joining the AFTD-Team at the Austin Marathon. Thank you all for sharing your stories, spreading love and awareness, and raising funds!

Camille Dunn
Marypat Mcgrath
Kasey Claytor
Terry Walter
EmployHQ
Scott Oxarart
Natalie White
Liz Matthews
Stephanie
Cournoyer
Kristin Pursley
Kay Webb
Libba Adams
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Jack London
Scott Gehret
Lisa Ozbirn
Diana Erickson
Charles Bodner
Debbie Strauch
Linda Thompson
Missy Zentgraf
Sandra Gonzalez-Morett
Alma Valencia

AFTD-Team race season

The 2024 AFTD-Team Race Season concluded with big smiles and over **$171,000** raised to advance our mission! We had runners from all across the country and the U.K. join us in six races: the Austin Marathon in February, the Los Angeles Marathon in March, the Colfax Marathon in May, the TCS New York City Marathon and Philadelphia Marathon in November, and the Dallas Marathon in December. Keep an eye out for the new races in 2025, like the TD Five Boro Bike Tour in May and the Honolulu Marathon in December!

Each of our Race Season participants holds a special place in AFTD's heart. We couldn't do this without the amazing fundraisers and their supporters, who dedicated time and effort to help AFTD raise funds and spread awareness across the country.

Austin Marathon

Melissa Schmitz
UT Austin Aphasia and Dementia Research Labs
Patrick and Maureen Mele
Stephen Fenoglio
LeAnn Zezula
Kelly Canavan
Melina Westerlind
Sidney Schmitz
Susan Eissler
Steph McLain
Zoy & Kiley Kocian
Mary Sloup
Michael Mullen

Los Angeles Marathon

Morganne & Anne Hodson
Julie Pierrat
Tara, Connor, & Levi Rice with Cliff Feiman
Virginia & Shawn Alexander with Katie Smith
Zoe Pierrat
Taylor Sanchez

Colfax Marathon

Caitlin Lee
Alex Rose
Maurice Lee
Gretchen Samuels
Chloe & Jacques Decalo
Jessica Cristadoro-Weck
Steffen Weck
Linda Taylor
Jaclyn Schurk

TCS New York City Marathon

Barbara Chang
Janice Lee
Tessa Mackey
Andrew Lipsky
Elizabeth Hollingsworth
Sara Frese
Alex Sepesy
Abrar Tanveer
Kris Bucknall
Popkin Shenian
Andrew Frese

Philadelphia Marathon

Lauren Pearlman
Steve Kelly
Andrew Gaess
Team Jack Attack
Molly & Chase Trimmer
Emily Chorbajian
Mairead Deeley-Wood
Ashley Vitiello
Samantha Faller
Brian Scheff
Ariana Scheff
Gus Hirscheboeck
Mamie Clark
Heath Eckert
Katherine Lopez
Jennifer Booe
Casey & Kelly Hanna
Emily Schaeffer
David Irwin
Kim Jenny
Sarah Lopata
Ashlyn Stienstra

Dallas Marathon

Maura & Sean Huzinec
Darcy Topolski
Regina Sapp
Sheridan Ellis
Lisa Kelly
Warren Sapp
Claire McLain
Anna Kuykendall

INDEPENDENT EVENTS

Former AFTD Board member **Michael Stowell** hosted another holiday auction in memory of his stepfather Ned Shepherd, who passed away from FTD in 2011. The online fundraiser auctioned off premium goods, raising $9,020 for the fight against FTD. In addition to this annual tradition, Michael added an in-person tasting at North Boulder Liquor on November 23. To date, this event has raised $26,946 to further AFTD's mission!

Brothers **Juanmari, Sebastian, and Jose Molina** ran, swam, and biked in the Haines City, Fla., Half Ironman on December 15 in honor of their father, who was diagnosed with FTD in 2024. Along with completing over 70 miles of grueling athleticism, they raised a grand total of $5,730.

Sisters **Linnea and Erika Lehmkuhl** launched a special pre-order for their new project Coolmud in honor of their father Jack, who was diagnosed with FTD in 2022. Coolmud is their way of sharing Jack's art with the rest of the world by putting it on t-shirts to spread FTD awareness. During this special sale, the sister duo raised $4,000 for AFTD's mission.

Kristin Hickinbotham and her sister **Anna Casper** ran in the Monterey Bay Half Marathon in November to honor their mother, Marie Smith, who was diagnosed with FTD in early 2024. The sister team conquered the course and raised a total of $3,592 to further AFTD's mission.

Edwin Pagan took FTD awareness and fundraising international this past September at the Berlin Marathon, where he competed in one of the world's largest marathon races in memory of a family friend, Jackie Pang, who had FTD and passed away in 2020. He raised $2,400 to support AFTD's mission.

Billie Kelsch-Sheeran and her nephew hosted the Sheeran Memorial Play for Mike Fundraising Event on December 27 in Austin, Texas. This day of fun on the links included a raffle to raise funds in honor of Billie's husband, Michael, who was diagnosed with bvFTD in 2023. A total of $2,150 was raised for AFTD's mission.

AFTD Ambassador **Spencer Cline** and his team hosted the 4th annual Babson College men's basketball fundraiser on January 25 in memory of Spencer's father, Lawrence, who was diagnosed with FTD in his mid-40s and died in 2012. This year they raised $1,553, bringing their total raised to $27,797.

Emma Randolph recently turned 14 and commemorated the occasion by holding a fundraiser leading up to her birthday, collecting donations in honor of a family member impacted by FTD. She raised $1,500 for AFTD's mission.

Kate Kelly, daughter of AFTD Board member Julie Kelly, ran the Syracuse Half Marathon on October 20 in honor of her mother's work for AFTD and in memory of Cathy Pfeifer and Jeannette Ekstrand. She conquered 13.2 miles and raised $1,500 to fight FTD!

Secure Planning Group hosted their 9th annual SPG Invitational Golf Tournament at the Philmont Country Club in Huntingdon Valley, Pa., on October 18. It was a fun day on the fairways with lots of FTD awareness spread and $1,000 donated to advance AFTD's mission.

The Association for Frontotemporal Degeneration
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Georgia

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