



AFTD news

From Hope to Action: AFTD Commits to Bold 2022-2025 Strategic Plan

Earlier this year, AFTD's Board of Directors approved an ambitious new Strategic Plan to guide our mission through June 2025. Written with input from a wide range of stakeholders and put into effect during a landmark anniversary for AFTD, our new Strategic Plan seeks to bring the hope of our community to action.

"Twenty years ago, Helen Ann Comstock founded the organization we now call AFTD, the Association for Frontotemporal Degeneration, after losing her husband Craig to FTD," AFTD CEO Susan L-J Dickinson and Board Chair David Pfeifer said in a co-written statement. "Our latest Strategic Plan charts a clear course to advance a world with compassionate care, effective support, and a future free of FTD."

The 2022-2025 plan is centered around four primary goals crafted around a series of strategic themes identifying areas where AFTD's attention is most needed:

Goal 1 – Advance diagnosis, therapeutics, and a cure for all.

AFTD is addressing challenges to receiving diagnosis and care by fostering a diverse global community of FTD-

focused researchers, expanding and empowering a research-ready community of persons diagnosed and those at genetic risk, and developing and refining tools and resources for FTD research.

Goal 2 – Ensure that high quality, responsive FTD care and support are available to anyone in need, at every stage of this journey.

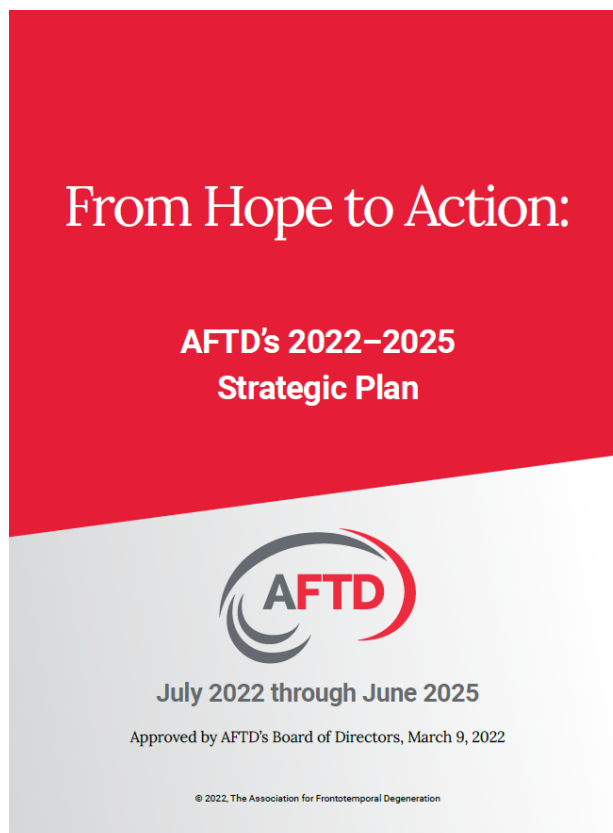
Obtaining effective FTD care can be challenging, which is why AFTD is working to actively disseminate promising practices in FTD care and support. AFTD is also working to scale current programs to reach more people in the Black, Native American, Latinx, AAPI, veteran, LGBTQ+, and rural communities.

Goal 3 – Advance awareness of FTD and expand AFTD's national and global reach.

FTD remains a too little known and too frequently misunderstood disease. AFTD

will take advantage of increasingly sophisticated analytics to refine our outreach efforts. Additionally, AFTD is developing a bolder advocacy agenda, increasing volunteer engagement, and empowering more donors to sustain and accelerate our mission.

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AFTD News Briefs

AFTD Updates Several Key Publications

In order to better serve our community, AFTD's communications team has updated several of the organization's key publications. Beginning with this issue, *AFTD News* expands to a 16-page publication, from 12 pages. (The digital version remains available for those who want to get *AFTD News* delivered by email.) *Help & Hope*, an e-newsletter designed to provide advice, resources, and words of encouragement for FTD caregivers, will now appear in your inbox weekly, instead of monthly. And *Partners in FTD Care*, which provides FTD education to healthcare professionals, has received a full graphic-design refresh, now featuring shorter articles to cater to the needs of busy doctors, nurses, and other care workers. We encourage you to share your feedback by emailing communications@theaftd.org!

Memorial Symposium Honors AFTD MAC Member and Pioneering Neuroscientist

The late John Trojanowski, MD, PhD, a member of AFTD's Medical Advisory Council, was honored at a memorial symposium at the University of Pennsylvania in September. Friends and colleagues from around the world gathered to tell personal stories of their time with Dr. Trojanowski, and to highlight his achievements over a long, prestigious career in neuroscience. Colleagues shared the breakthroughs they made while working with him, such as identifying the TDP-43 pathology as the primary driver of both ALS and at least half of FTD cases, and the discovery of the role of tau proteins in the tangles seen in Alzheimer's and other tauopathies. Many spoke of Dr. Trojanowski's warm and encouraging demeanor as a mentor, and the guidance that he provided as they forged their careers in neuroscience.

TEAMING UP TO BRING HOPE TO ACTION

“There’s a real fear around dementia that’s hard to combat, but giving people resources, tools, and guidance around care options arms them for the challenge and provides hope.”

– Brandee Waite, former FTD care partner and current AFTD volunteer



In 2009, with the help of her dad and four siblings, Brandee Waite hosted her first independent grassroots event as an AFTD volunteer. She did so in honor of her mom, Beverly J. Waite, who was living with an FTD diagnosis. Though Beverly passed away in 2014 at the age of 66 after living with FTD for 15 years, Brandee and her family remained committed to hosting an annual event to increase FTD awareness and raise funds to support AFTD’s mission.

“My family was able to provide care for my mom following her diagnosis, but I knew there had to be others who would need more support,” said Brandee. “I looked for a way we could help people facing the challenges of an FTD diagnosis. That’s how I found AFTD and we started Team Bev.”

As AFTD has grown, so has the Waite family’s annual memorial celebration. “With FTD’s progression, my mom walked a lot and enjoyed sweets – they were

our inspiration to gather with family and friends for a run or walk followed by good food.” Now a part of AFTD’s Food for Thought campaign, this year’s Team Bev event, held October 1, welcomed nearly 40 people.

“Dementia tends to be hidden away – there’s a stigma around a diagnosis. We need more awareness, because it will lead to more research and one day, I hope, better diagnostic tools and treatment options. Until then, we can inform people about the realities of FTD to better prepare them for the journey and provide more support for caregivers.”

Just like AFTD’s founder Helen-Ann Comstock was inspired to take action 20 years ago to improve the FTD journey for the next family, Brandee dedicates her time as a volunteer to ensure that no one faces FTD alone.

Together, we can improve the journey for the next family.
Together, we can bring hope to action to #endFTD.

Will you join Brandee in bringing hope to action for all who are affected by FTD?

By making a tax-deductible gift of any amount, you can help AFTD provide information, resources, and support to people who are navigating FTD, and advance research that can bring forward treatments and 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... Helen-Ann Comstock, AFTD Founder and Board Member

Helen-Ann Comstock officially founded AFTD two decades ago, but the seeds for the organization were planted many years before that. Her husband, Craig, began experiencing FTD symptoms in the late 1970s; following his death, Ms. Comstock became executive director of the Alzheimer's Association's Southeastern Pennsylvania chapter. There, she recently told AFTD, "I was always saying, 'Why aren't we doing more about the related dementias?'" – a category that includes FTD.

She started a support group for Pick's disease, as FTD was commonly called at the time, meeting in an office space in the Philadelphia suburbs provided by Dr. Murray Grossman of the University of Pennsylvania. In the late 1990s, the group's members rallied around the idea of holding a conference entirely devoted to the disease, and in May 1999, the country's first Pick's Disease Conference took place in Philadelphia.

"It was kind of a fun time," Ms. Comstock said. "We had a few Mummies come in and play, and we gave everyone little Liberty Bell favors," she added, referring to two icons of the city. A couple hundred people attended – FTD families and researchers alike – many of whom Ms. Comstock and her fellow support group members personally picked up from the airport, in the spirit of all-hands-on-deck collaboration. "People wanted to help, and they did help," she said. The conference "had a lot of heart to it.

"We included everybody in everything and got very positive feedback from people," she further reflected. "One researcher who attended told me, 'I'm trying to find a



Helen-Ann Comstock

cure for FTD, and this is the first time I've gotten to talk to somebody with the disease.' People really enjoyed that opportunity to mix."

Spurred by the conference's success, Ms. Comstock paid a visit to the National Institutes of Health to discuss the possibility of more federal funding for FTD research. She spoke with the neuropsychologist Dr. Jordan Grafman, who told her, "Until there's a national FTD organization, nothing much is going to happen. So why don't you start one?" Ms. Comstock founded AFTD in 2002.

Ms. Comstock was AFTD's Board chair for the first eight years of its

existence, and continues to serve on its Board today. "As the FTD field grows – and I do think we can take credit for a lot of that growth – we must make sure that we keep funding enough research, and keep putting time into supporting families and professionals – especially those in underserved areas," she said.

Overall, Ms. Comstock said, "I'm thrilled with our Board members and staff. I can see huge improvements in our work. We are doing a lot.

"But," she added, "there's a lot more we can be doing, without losing our grip on our main mission: to keep supporting families and advancing research to a cure."

AFTD's first Board of Directors (2003): Joseph Becker, Helen-Ann Comstock, Fytie Drayton, Dr. Jordan Grafman (advisor), Kent Jamison, Robert Kemp, Tess Parrish, Robert Potamkin, Lisa Radin, Joyce Shenian, Lawrence Shor.

AFTD's first Medical Advisory Council Chair: Dr. Murray Grossman.

AFTD Awards Four New Research Grants



Indira Garcia Cordero, PhD



Eric Anderson, PhD



Suborno Jati, PhD



Julia Faura Llorens, PhD

Through its diverse grant programs, AFTD supports promising research to further our understanding of FTD, devise new diagnostic methods, and to one day develop a treatment for FTD.

With support from the Holloway Family Fund and the American Brain Foundation in collaboration with the American Academy of Neurology, AFTD awarded its first Clinical Research Training Scholarship to Indira Garcia Cordero, PhD, earlier this year. This scholarship continues AFTD's tradition of supporting the next generation of clinician researchers conducting studies involving human participants, or working on translational research specifically designed to develop treatments or enhance diagnosis of neurologic disease.

A postdoctoral fellow at the Krembil Brain Institute in Toronto, Dr. Cordero will use brain imaging to compare brain function in people with progressive supranuclear palsy (PSP) or corticobasal syndrome (CBS) with an Alzheimer's disease pathology to people with PSP and CBS that lack such a pathology. Dr. Cordero's study will help provide context to the role of co-occurring pathologies in FTD.

Thanks to the generous support of the Holloway Family Fund, AFTD is also proud to announce the first three

recipients of grant funding from the Holloway Postdoctoral Fellowship. The fellowship supports promising young researchers during a critical phase of their training to help inspire a long-standing commitment to FTD research.

Eric Anderson, PhD, a postdoctoral fellow at the University of Pittsburgh, was awarded a postdoctoral fellowship for his research analyzing two enzymes believed to play a key role in determining the effects of *C9orf72* mutations. Because *C9orf72* is a known genetic cause of ALS as well as FTD, Dr. Anderson's fellowship is being co-founded with the ALS Association.

University of California, San Diego postdoctoral fellow Suborno Jati, PhD, received a fellowship for research focusing on chromogranin A (CgA), a protein that regulates communication between nerve cells and immune responses in the brain. CgA is found in tau protein clumps in roughly 40% of people with FTD.

Finally, Julia Faura Llorens, PhD, a postdoctoral fellow at Vlaams Instituut voor Biotechnologie in Belgium, was awarded a fellowship for her project to apply a novel technology – long-read transcriptomic sequencing – to the study of FTD. Dr. Llorens's study seeks to identify abnormal protein synthesis templates associated with TDP-43.

From Hope to Action Continued from page 1

Goal 4 – Strengthen and diversify the organization, to ensure meaningful impact for all we serve.

To ensure that we can have a meaningful impact for all we serve, AFTD is promoting a culture where staff can thrive and succeed, and is developing the tools, knowledge, and processes to ensure strong organizational governance.

“Twenty years ago, with little to go on beyond hope and a sense that something needed to change, I took the action I

saw as necessary to help others facing FTD,” said AFTD founder Helen-Ann Comstock. “If you find this Strategic Plan and its vision inspiring, I encourage you to join us and offer whatever help you are able to provide, whether as a volunteer, a donor, or simply someone making a suggestion about how we can serve this community better. Every little bit helps.”

We encourage you to read our new Strategic Plan. Visit theaftd.org/about-us/strategic-plan to download a copy.

World FTD Awareness Week Highlights the “Journey to Diagnosis”

In collaboration with World FTD United, AFTD highlighted the diverse experiences that many people face on the path to receive a diagnosis during this year’s World FTD Awareness Week, held September 25 through October 2.

The theme of World FTD Awareness Week was captured in the “Journey to Diagnosis” video, produced by World FTD United, the international coalition of FTD organizations, of which AFTD is a member. The video features shared experiences from care partners and a person living with an FTD diagnosis, as well as insights from researchers. Visit worldftdunited.net to watch the video.

World FTD Awareness Week began by kicking off the 10th annual installment of AFTD’s flagship fundraising event, Food for Thought. The event featured a mix of in-person and virtual events where community members shared food and stories of their journey, raising awareness and funds to support AFTD’s mission. You can read more about the 10th anniversary of Food for Thought on page 14.

This year’s World FTD Awareness Week featured numerous events tailored around AFTD’s new awareness campaign, Ask About FTD. Members of AFTD’s community took to social media to share the stories of their own journey with FTD, encouraging others to #AskAboutFTD to raise FTD awareness. Community members were encouraged to reach out to healthcare professionals to help them learn about FTD and write letters of support for families with a recent diagnosis.



Members of World FTD United’s Executive Committee shared a message for World FTD Awareness Week 2022.

For World FTD Awareness Week 2022, AFTD expanded our social media advocacy efforts and worked with international partners to produce a video on the journey to an FTD diagnosis.

To help promote FTD awareness on social media, AFTD also debuted its new account on the internationally popular video-sharing platform, TikTok. AFTD’s TikTok account (@theaftd) will feature videos from AFTD staff, clips from AFTD Educational Webinars, stories shared by members of our community, and more. Follow us on TikTok and help us spread FTD awareness!

AFTD also marked World FTD Awareness Week with a Q&A session hosted on Facebook Live, where AFTD staff answered questions about resources available to help families, emerging research on FTD, and the importance of early, accurate diagnosis. AFTD also released a new FTD fact sheet and diagnostic checklists to share with medical providers to aid in diagnosis.

We thank everyone who participated for making the week a success!

AFTD at 20: The Journey so Far

2002: AFTD is founded

- When Helen-Ann Comstock's husband, Craig, was diagnosed with Pick's disease -- what we now refer to as FTD -- there were scant resources available to affected families. Not wanting other families to take the journey alone, Ms. Comstock took action. She founded AFTD, the first national FTD organization, in 2002. Dr. Jordan Grafman of the National Institutes of Health (NIH) spoke about how he encouraged Ms. Comstock: "I conveyed to Helen-Ann that with NIH, the squeaky wheel gets the grease."

2004: AFTD's Medical Advisory Council (MAC) established

- Dr. Grafman became a member of AFTD's MAC, which provided expertise and scientific legitimacy to the fledgling organization. Every MAC member has experience in FTD research or working with people affected by the disease.

2005: Start of the HelpLine, support groups, and AFTD research grants

- Initially staffed by volunteers, the HelpLine is today staffed by three licensed social workers, delivering information and a sympathetic ear to thousands each year. There are now almost 100 AFTD Support groups that meet either virtually or in person. Our first research grant in 2005 totaled \$35,000. Last year alone, AFTD awarded more than \$3 million in grants to support innovative FTD research.

2009: Comstock Grant program launches

- One of AFTD's most popular programs, AFTD's Comstock Grant initiative distributed more than 440 grants last year to help persons with FTD and their care partners.

2010: First AFTD Education Conference

- The Education Conference is a staple of AFTD's work, convening hundreds of persons diagnosed, caregivers, care partners, researchers, and healthcare professionals each year to connect, learn, and engage. Please consider joining the 2023 Education Conference, either in person in St. Louis or via livestream, on May 5; registration opens in mid-January.

2012: FTSG meeting, *Partners in FTD Care*, and "AFTD-Team" launched

- FTD research got a boost in 2012, when the inaugural meeting of the FTD Treatment Study Group (FTSG) convened leading researchers. Healthcare professionals benefited from the first issue of AFTD's *Partners in FTD Care*. Reflecting growing momentum in our grassroots events volunteering, we established the AFTD-Team.

2013: FTD Awareness Week and ALLFTD launched

- A boost for FTD awareness began in 2013 with the first recognized FTD Awareness Week, the first volunteer Food for Thought campaign, and the launch of the first FTD national study – ALLFTD.

2017: FTD Disorders Registry launched

- This online database is designed to empower participation in FTD research. Sign up at ftdregistry.org.

2019: Awareness in the media, AFTD Ambassador Program launches

- FTD awareness increased nationally when CBS's *60 Minutes* aired a story on FTD. AFTD welcomed our first 12 volunteer Ambassadors.

2020: The Persons with FTD Advisory Council forms

- The Council shares the voices of people living with an FTD diagnosis to help care partners, health professionals, and others with FTD to understand the disease in a new light.

2021: *Voice of the Patient* report

- AFTD drew on the experiences from more than 1,750 people living with FTD to produce our *Voice of the Patient* report, which informs the U.S. FDA about the specific needs and priorities of our community.

2022: Inaugural Holloway Summit

- Hosted by AFTD Board member Kristin Holloway, the 2022 Holloway Summit convened leaders in FTD science to discuss digital assessment tools for FTD.

Ms. Comstock (profiled on page 4) reflected on AFTD's early years, "I think we have been very fortunate, but we've also had a very hard-working Board and a marvelous staff," she said. "I am proud of what we have accomplished and look forward to building on that. I eventually see a world where FTD is prevented – and no longer exists."

Those We Honor... Those We Remember

Gifts received from May 16, 2022 – September 30, 2022

In Memory Of

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Ross Abinanti
Lydia Adalian
Charlie Adams
Rebecca Adams
Rebecca Ann Adams
Stephen Adams
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Donations 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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Kandice Perry
Cathy Pfeifer
Kimberly Phares
Alice Carter Richardson Phillips
Beth Phillips Anderson
Jack Potash
Peter Quintiliani
Shirley Radtke
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AFTD Launches “Ask About FTD” Awareness Campaign

This fall, AFTD launched a new campaign to encourage people to “Ask About FTD” in order to help raise awareness of FTD and give people tools to help them get a timely diagnosis. The average time to diagnosis is currently 3.6 years after symptom onset. If you are active on social media, we encourage you to share your FTD journey and use the hashtag #AskAboutFTD.

AFTD updated our FTD Facts flyer and developed diagnostic checklists to help identify red flags for the two most common types of FTD: behavioral variant FTD and primary progressive aphasia. The checklists allow concerned persons to indicate the symptoms they are experiencing and provide criteria to help physicians better understand FTD. You can download them in the Resources section of our website (theaftd.org).

A diagnosis helps families understand why their loved one is acting uncharacteristically and connects them to

valuable support and resources. It also gives people hope to follow emerging FTD research. No one should have to take this journey alone.

And a diagnosis means even more today. For decades, persons diagnosed were told there was nothing they could do except try to manage the disease. That is changing, with

a growing number of experimental treatments currently in trials and more on the horizon. Some of these clinical trials target specific genes, so there could be

value in consulting a genetic counselor to discuss genetic testing.

Only early, accurate diagnosis can tell us FTD’s true global impact and help researchers unlock the medical interventions that families need. AFTD has worked for 20 years to improve quality of life for people facing FTD, and drive research for a cure. To learn more, visit our website at theaftd.org.

The #AskAboutFTD campaign is your chance to join the conversation on social media and help more people learn about this too little known disease.

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**MAY 5, 2023
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AFTD Ambassador Program Enters Its Third Year

In 2019, AFTD created a new opportunity for volunteer leadership by launching our Ambassador program. Ambassadors are AFTD volunteers who represent AFTD on the ground in their local community. 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 was happy to welcome a cohort of five new Ambassadors in May, bringing the total of Ambassadors to twelve.

“When I was asked to become Ambassador, I jumped at the chance to help educate the public and healthcare community about FTD,” Alabama Ambassador Jerry Horn said.

From July to September, Ambassadors held 10 awareness activities, including staffing booths at in-person and virtual events, and Meet & Greets. Five Ambassadors led successful campaigns for this year’s Food for Thought fundraising campaign. Additionally, the Ambassadors have committed to working on a common goal to increase the impact of collective outreach efforts by reaching out to their regional Veterans Affairs medical and caregiver resource centers.

AFTD’s diverse cohort of Ambassadors pursues a varied slate of interests to help AFTD advance its mission.

South Carolina Ambassador Katie Zenger joined a new AFTD advocacy advisory group, bringing her experience and insight from serving

on a state committee addressing research on dementia. In addition to serving on the planning committee for AFTD’s Hope Rising Benefit, New York Ambassador Corey Esannason also holds regular awareness and education presentations at healthcare facilities. Washington State Ambassador Joanne Linerud serves on the Patient Advisory Council of Passage Bio, sharing her lived experience of FTD with the pharmaceutical industry.

“I became an Ambassador to extend my reach to others in my community who need help and support, and to champion for improvements in care, treatment, and services,” said Oregon Ambassador Melissa Fisher. “When I first heard the word FTD at the diagnosis of my dad, I was lost and felt like my head was on fire. Through a friend, I connected with [AFTD] -- and that was the very first time I felt heard and understood. There is still so much that needs to be done to make this journey better, but starting from where I am and what I’ve learned, I want to pay it forward and make a difference in the lives of people impacted by FTD.”

AFTD’s Ambassadors exemplify the resilience and commitment that drive our entire volunteer community. If you would like to connect with a local AFTD rep and help us bring the world closer to a future without FTD, an Ambassador can help you get started!

To find your state’s Ambassador and their email address, visit theaftd.org/about-us/aftd-ambassadors and click on their name. You can also select “In Your State” under Get Involved, and select your state from the dropdown menu.



Corey Esannason



Melissa Fisher



Jerry Horn



Joanne Linerud



Katie Zenger

AFTD Ambassador Holds First In-Person Meet & Greet Since Pandemic Onset

AFTD Meet & Greet events are informal gatherings all about forging connections and sharing resources among local communities. AFTD volunteers act as the organizer and host, while AFTD staff promotes all Meet & Greet events on our website, via social media, and by sending targeted e-invites to contacts in the appropriate local community.

Meet & Greets had shifted entirely to the virtual world of Zoom since March 2020. But in September 2022, AFTD Ambassador Terry Walter hosted the first in-person AFTD Meet & Greet since the COVID-19 pandemic began. “After a two-year break of doing in-person Meet & Greets, I decided it was time,” she recently shared with AFTD. “Even though COVID has been winding down, I still had some COVID concerns. But the many positive experiences of previous in-person Meet & Greets kept tugging.”

The power of the in-person event took over. “The turnout was small, but the results were huge,” Terry said. “We had a person diagnosed with FTD, and a couple of former FTD caregivers. Then a family showed up that had driven two or three hours to get there: a husband and father who was recently diagnosed with FTD accompanied by his wife and daughter. Within minutes of being there, his wife commented that she had not seen her husband talk in quite a while. But there he was, talking with other attendees. There were



Terry Walter

big smiles. Although they arrived feeling alone and confused, and did not know where to turn for help, I think they left with more knowledge, resources – and the knowledge that they were not alone. This isn’t a first for me.

“While the Zoom meetings were necessary during the pandemic as a means to keep in contact, I think seeing and feeling the emotion in

person is something that cannot be replaced,” Terry continued. “That is why I am back to in-person Meet & Greets.”

Thank you, Terry! AFTD staff looks forward to working with our amazing and hard-working volunteers to hold more in-person events in the future, all while remaining COVID-safe and following all local and state health protocols.

COVID-19 and Volunteerism: How the Pandemic Has Changed the AFTD Volunteer Experience

At AFTD, we are witnessing returning momentum for in-person volunteer activities and networking events. We still strongly encourage taking all health precautions related to COVID-19. But the turtle is cautiously poking its head out again, and finding that the air is generally fine!

Nationally, the pandemic has changed the ways people choose to spend their time volunteering. Four main trends have been identified:

1. Volunteering moved to online spaces such as Zoom due to the pandemic – and in many cases remain virtual even as pandemic restrictions are lifted.
2. Volunteers are looking to maximize their impact by participating in smaller, “bite-sized” projects that still positively affect others’ lives.
3. Opportunities for personal outreach and connecting with others remain key. There is a growing realization that certain energy can only be experienced in person.
4. Volunteers want to contribute meaningfully to their cause, and actually see the impact of their efforts, rather than simply show up.



Another national volunteering trend has emerged: a lingering decline in overall volunteerism. But at AFTD, the opposite has happened. There has actually been an increase in the number of volunteers who have chosen to advance our mission, and we are tremendously grateful!

The pandemic has necessitated some creative adjustments in our volunteer activities, but the strong dedication of AFTD volunteers has sustained our mission throughout. New virtual versions of local Meet & Greets introduced new people to AFTD and to each other. Several events for younger adults caring for a parent provided support for a demographic that can often feel overlooked. Our volunteer Ambassadors sought out and found opportunities for virtual presentations and networking as in-person table settings and speaking engagements dried up. The Charity Miles app turned exercise like walking, running, and biking into a community-building and fundraising success. And AFTD support group volunteers heroically shifted to virtual options to make sure care partners and caregivers could continue to access regular peer support at a critical time.



Moving forward, the AFTD staff will continue to support volunteers by understanding and accommodating their preferences for in-person or virtual opportunities. Our Volunteer Services team, under the direction of AFTD Volunteer Manager Michael Mullan, is eager to continue to expand our dynamic network of volunteers in all communities -- urban and rural, familiar and new -- across the country.

We have much to do and opportunities for everyone, whether in person, virtual, or hybrid. Whether you lead a Meet & Greet, become a support group volunteer, start a fundraiser, or simply tell your story when people #AskAboutFTD, your creativity and support of AFTD’s mission drives this organization. Visit the Get Involved section of our website and reach out today!

food for thought 2022



AFTD's 10th annual Food for Thought campaign was held in 20 states (plus Canada and Ecuador!), and raised over \$140,000 to advance our mission. Below are the events that raised \$1,000 or more before the submission deadline:

AND STILL CHAMPION...

Steve Bellwoar, a Pennsylvania-based AFTD Board Alumni, hosted the ninth annual Colonial Electric Food for Thought event in person again after two years of going virtual. Sponsors and attendees enjoyed nine holes of golf, then cocktails and hors d'oeuvres (featuring the event's famous raw bar) followed by a seated dinner with presentations from Steve, his cousin Peter, and AFTD CEO Susan L-J Dickinson. The event raised \$112,000, bringing the grand total to \$788,000 raised over the past nine years – continuing its title as our flagship Food for Thought event.

GETTING SOCIAL

Kristin O'Keefe from New Hampshire used multiple social media accounts to promote her event far and wide. A personal chef, Kristin shared recipes favored by her husband Marty (who is living with FTD) on her own social accounts (personal and professional), as well as Marty's, raising \$4,421.

RED BARN

Kendra Clabo from North Carolina hosted her event in their recently renovated barn. Forty people donned their finest AFTD-red apparel, and gathered to enjoy charcuterie boards, signature drinks, and music. Kendra's mother, who was diagnosed with bvFTD in 2019, was the guest of honor. Together, they raised \$2,466.



DELIVERING AWARENESS

Ryan Windhorst from Illinois partnered with Namken Nutrition, a local meal-delivery service, to host a hybrid event (both in person and online via Facebook). Ryan spread FTD awareness locally and nationally and raised \$2,020 for AFTD's mission.

THE GIFT OF MUSIC

Susan Eissler from Texas honored her son, Ara, who is living with FTD at the age of 51. Each day during the first week of the campaign, Susan shared one of Ara's compositions as music was his passion and his music "was made for everyone." While Ara can unfortunately no longer compose music due to his FTD, he's still making an impact: the event raised \$1,187.

HOW SWEET IT IS

Melissa Dube from Manitoba, Canada, hosted an event through her bakery, "Cuts and Cakes." She provided complimentary homemade cakes to her customers, each of which came with FTD information. A portion of the proceeds were designated to AFTD's mission, resulting in a \$1,024 USD donation.

DECADE

Brandee Waite from California is a longtime Food for Thought host, having participated in the campaign every year! As always, she and her family participated in a 5K, in memory of her mother (who was a prolific walker), complete with a brunch and pool party back at her house afterwards. This year, Team Bev raised \$1,015.

PREVAILING

Employees of Prevail Therapeutics, a subsidiary of Eli Lilly and Company, were proud to participate in the 2022 AFTD Food for Thought campaign by cooking up two delicious recipes filled with ingredients that boost brain health at home. While cooking, the team reviewed FTD educational materials, and made a donation of \$2,500 to advance AFTD's mission.

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

Aidan O'Keefe	Keri Pinard
Anderson Family*	Libba Adams
Bobbie Chappell	Liz Matthews
Bonnie Shepherd	Lynda Nagle
Brain Disease Advocates	Marian Grems
Carolyn Driscoll (Tom's Team)	Melissa Fisher
Corey Compa	Nicole Rouse
Daniel Keuning	Nicole T. DeLeve
Denali Therapeutics	Pang Family
Domenica Toscani (Fishtown Pickle Project)*	Patrick Gutierrez
Esther Harvey	Percy Long (Team Tammy)
Jerry Horn	Poorva Bagchee
Joanne Linerud	Sarah Sharbach
Kathy & Sarah LaFone	Terry L. Walter*
Katrina Hellman*	Wave Life Science

* Raised +\$1,000 but submitted total after deadline

AFTD Fundraising Coordinator Mike Wagner wants to thank the seven Food for Thought liaisons that helped make this national campaign a success!

Elaine Rose	Ron Jackson	Terry Pontious
Jen Morabito	Susan Meagher	Traci Saylor
Meghan Roscoe		

The AFTD-Team

THE 300 CLUB



The 17th annual George F. Sidoris Memorial Golf Outing was held on July 30th at the Lost Nation Municipal Golf Course in Willoughby, Ohio, and raised \$37,600 for AFTD's mission. This event is AFTD's longest running grassroots fundraiser and has donated over \$315,250 in total! Congratulations to the Sidoris Family

and thank you for your continued and notable support. Welcome to the "300 club"!

SWINGING FOR CARL

The seventh annual CWM Golf Outing was held on July 9th in Michigan and raised \$7,025. Hosted by the Morettis and Marcys, the day celebrates and remembers Carl Moretti, who passed away from FTD in 2015. Over the past seven years, the event has raised a total of \$23,374 for AFTD and our mission.

TAKING IT TO THE STREETS



Paul Petras from Ohio ran a total of 63 miles during Labor Day Weekend in memory of the father of his girlfriend, Serina, who died from FTD. Serina rode along Paul the whole way on her bicycle, spreading FTD awareness – and displaying impressive physical fitness

– throughout the streets. Together Paul and Serina raised \$7,099 for AFTD's mission.

driving hope tournament

AFTD's 2022 Driving Hope Golf Tournament was held at Metropolis Golf Club in White Plains, New York, on August 8 and at Colorado National Golf Club in Erie, Colorado, on August 20. We had two beautiful days on the courses and were amazed by the generosity of our sponsors, participants and supporters. Through both events, a record \$132,500 was raised for AFTD's mission!

AFTD would like to extend a sincere thank you to everyone who supported the events, especially our generous sponsors (right).

AFTD would also like to take this opportunity for a special shoutout to the tournament's committee:

Daniel Hedaya, Brian Rose, Michael Stowell, and Joan Berlin.

ON A CRUSADE

The sixth annual Crusade for a Cure Golf Tournament, hosted by AFTD Ambassador Deb Scharper, was held on September 3rd at the Sunny Brae Golf Course in Osage, Iowa, and raised \$11,000. Over the past six years, Deb's tournament has donated \$49,815 to AFTD's research initiatives.

A POWERFUL STORY



Bob Powers from Oregon performed an original play, *Chasing Rainbows: A Story of Love, Loss, and Finding Purpose*, on August 19 and 20 at the CoHo Theater in Portland. Bob wrote the play in memory of his husband, Donald Clement, who was diagnosed with PPA in 2013 and passed away in 2021. The opening performance raised \$14,790 for AFTD's mission; an additional \$575 was raised when Bob performed an encore show in Lucca, Italy.

HONORING TERESA

Kenda Clabo from North Carolina held an online fundraiser during the month of July in honor of her mother, Teresa Lewis, who was diagnosed with FTD at the age of 59. Kendra and her closest friends shared Teresa's story with their networks and were able to raise \$2,214 for AFTD's mission in doing so.

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