

Our Plan, Our Future:

AFTD's 2019–2022 Strategic Plan



January 2019 through June 2022

Approved by AFTD's Board of Directors in December 2018

Our Plan, Our Future

Our Vision

AFTD envisions a world with compassionate care, effective support, and a future free of FTD.

Our Mission

AFTD's mission is to improve the quality of life of people affected by FTD and drive research to a cure. We work every day to advance:

- **Research.** We promote and fund research toward diagnosis, treatment, and a cure.
- **Awareness.** We stimulate greater public awareness and understanding.
- **Support.** We provide information and support to those directly impacted.
- **Education.** We promote and provide education for healthcare professionals.
- **Advocacy.** We advocate for research and appropriate, affordable services.

Our Values

Knowledge

Information is the key to unlocking the future we seek.

Compassion

We recognize the importance of finding others who understand.

Collaboration

AFTD connects a community. Together, we can end this disease.

Respect

We learn by listening, knowing the power of a single story.

Dignity

We strive to honor, help, and empower all on this journey.

AFTD's 2019-2022 Strategic Plan: Four Goals

1 Advance early and accurate diagnosis and the development of treatments.

2 Advance quality care and support.

3 Strengthen and expand AFTD's position as the leading authority on FTD.

4 Build and strengthen the organization for long-term success.

Introduction

A diagnosis of frontotemporal degeneration (FTD) can be devastating. It can create uncertainty, confusion and anxiety. People diagnosed, care partners and families wonder: Where can we learn more about it? How will the disease progress? Where can we turn for support?

AFTD launched in 2002, seeking to address such questions. Today, in a nation gradually gaining awareness of young-onset dementia, we stand as the leading national organization focused exclusively on FTD, the most common form of dementia for people under 60. Today, AFTD provides answers for families facing this disease. Today, AFTD defines a vision for a different future.

Guided by a dedicated Board of Directors and driven by thousands of equally passionate donors and volunteers, we help persons diagnosed and their care partners find the support they need to face life after a diagnosis. We educate health professionals, advocate on behalf of all affected, and spread awareness of FTD around the world. And we work closely with leading scientists – fostering, guiding and funding research to advance hope.

Yet, much work remains if we are to realize the full scope of AFTD's mission, and achieve our vision. This plan, developed with input from a range of experts – including many drawing from lived experience of the disease – charts AFTD's course through June 2022. We seek to advance the early and accurate diagnosis of FTD, promote the development of effective treatments, provide FTD education to healthcare professionals, expand our volunteer network, and bring impact to more local communities throughout the U.S. Critically, we also seek to build the infrastructure to sustain AFTD's impact for the long-term.

As you read our plan, we hope you will look for ways to join us in these efforts. Our work has always been – and remains – community-driven. We simply cannot accomplish these ambitious goals without your guidance, support, and determination.

Together, we can make a difference in the lives of all those facing FTD today, ensuring that our world is one with compassionate care, effective support and a future free of FTD. Together, we can bring forward a future free of FTD on behalf of all those we love – past, present and future.



Gail Andersen
Chair, AFTD Board of Directors



Susan L-J Dickinson, MS, CGC
Chief Executive Officer, AFTD

What is FTD?

Frontotemporal degeneration (FTD) is the most prevalent dementia for people under 60. It is not simply a memory disease, like Alzheimer's – rather, it brings progressive changes in behavior, language, movement, and personality. People affected by FTD may begin to behave inappropriately in social or work settings and can become prone to unexpected outbursts, or develop an uncharacteristic lack of compassion for loved ones. Communication can become severely impaired and people with FTD may struggle to form words, and can eventually withdraw completely.

Because so few medical professionals know about FTD even today, it can take more than 3.5 years between symptom onset and getting an accurate diagnosis. During that time, doctors may prescribe unhelpful treatments for other illnesses, such as depression, and families struggle alone.

Since FTD often strikes at such a young age, it is a uniquely devastating disease. People in their 30s, 40s, and 50s are typically unconcerned about getting dementia. They are too busy raising families, advancing their careers, paying off mortgages or planning for retirement. FTD wreaks havoc on all of those plans and concomitantly spouses, adult children and older parents can find themselves thrust into the role of care partner. Additionally, teens and young children lose a stable family foundation at a time when they need it most.

An estimated 50,000 to 60,000 people in the United States have been clinically diagnosed with FTD, making it technically a rare disease. However, there is every indication that these numbers are far too low, as FTD is frequently misdiagnosed, under-diagnosed or simply ignored.

FTD's impact on the brain means that not everyone who has the disease will fully recognize it. But a growing number are learning early in disease progression that FTD is a part of their lives, and becoming active members of our community. People with FTD provide guidance and support, volunteer to advocate and raise awareness, create art and tell their stories in ways that inform and inspire our work.

AFTD dedicates this strategic plan to the vision and courage shown by every person with FTD, care partner, and family member whose life has been touched by this disease.

AFTD History and Accomplishments

Helen-Ann Comstock founded the Association for Frontotemporal Degeneration (AFTD) in 2002, through a personal donation of \$1,000. Drawing upon her experiences as a caregiver for her late husband, who had FTD, she collaborated with a team of dedicated FTD care partners and medical professionals to establish an organization focused on advancing research for FTD, providing information, education and support, and raising awareness of this rare and uniquely devastating disease.



In the ensuing 17 years, AFTD has grown from an all-volunteer labor of love to a thriving nonprofit employing 20 full-time staff. The organization has emerged as a leading international expert on FTD and younger-onset dementia, with a dedicated Board of Directors, a thriving volunteer network, and medical and scientific advisers representing the foremost experts from around the world.

AFTD has received generous foundation and donor support, including the David Geffen Fund, contributions from which are providing \$20 million in support over a 10-year span. Alongside the support of thousands of donors and hundreds of volunteer fundraisers, these resources provide an opportunity to expand AFTD's capacity and impact dramatically, as outlined in this plan.



AFTD's Impact in 2018: *By the Numbers*



- **1,900 people** from 25 countries enrolled through AFTD's partner, the FTD Disorders Registry, to help drive FTD research.
- **7 national committees** saw participation by AFTD senior leadership, on hand to help ensure that as a broad federal plan is crafted in response to the looming dementia crisis, the unique needs of our FTD constituents will be incorporated into research design and funding, healthcare reimbursement strategies, and innovative approaches to dementia care.
- **6 FTD researchers** were awarded new grants. AFTD's research funding seeks to advance the science of FTD, focused on developing biomarkers, drug discovery, clinical research and basic science, and postdoctoral fellowships.



- **2,200 people** received guidance and information through AFTD's HelpLine.
- **340 people** gained information, guidance and a chance to connect with others who understand at AFTD's 2018 Education Conference.
- **194 people** with FTD and their loved ones received assistance through Comstock grants, financial support to foster caregiver respite, quality of life for persons with FTD, and conference travel.
- **83 support groups** were led by AFTD-trained volunteers in 32 states.



- **231,362 visitors** found vital information on AFTD's **theaftd.org** website.
- **15,000+ received AFTD news and information** through our print and email newsletters, while thousands more viewed and engaged AFTD through our social network pages and "closed" Facebook private group.
- **3 AFTD Educational Webinars** reached health professionals and families.

Strategic Themes: 2019–2022

As AFTD's staff and Board have developed the strategies and tactics to support achievement of this plan, common themes have emerged that will ground how we will approach our work.

The Work We Share

AFTD was founded by caregivers, we have increasingly engaged and collaborated with persons living with FTD, and we have always benefited from the guidance of researchers and clinicians. These deep connections have forged the organization we are today. Over the next three years, we aspire to both expand our community and deepen how we inform, support, engage and learn from all of our constituents.

Responding to the Dementia Crisis

National attention to dementia policies and services is growing. An aging population is driving health economic concerns, and scientific advances are increasing government and industry investment in FTD research. As these changes gain momentum, AFTD is the organization best positioned to ensure that people and families affected by FTD are heard in the rooms where crucial policy decisions are made.

Together, we can ensure that national solutions to the dementia crisis address the full range of dementia challenges, including those of younger onset and behavioral, language and movement presentations.

Partnerships Hold the Key

The aspects of FTD that make it complex and heterogeneous can be leveraged as strengths. By forming partnerships where interests align, we expand the resources invested in research and care for our community, and speed progress toward achieving our goals in collaboration with others.

AFTD's strong tradition of collaborating with leading research organizations focused on Alzheimer's, ALS, Parkinson's and other conditions has accelerated and strengthened our work. As we extend our efforts targeting professional education, clinical studies and quality care, we will continue this strategy, forging new partnerships and collaborations with the FDA, pharma and biotech companies, insurers, and national care providers.

Investing in Technology

AFTD is a lean organization that aspires to have a mighty impact. Our mission is broad, our constituents are diverse and geographically scattered, and we operate across many different industries and interest areas, including research, healthcare, policy, and volunteerism.

More effective use of technology has the potential to accelerate every aspect of our work. We will

use technology to reach more underserved populations, provide information faster and more efficiently, inform families of more resources that can help today, and provide more opportunities to become part of our mission.

Our Plan, Our Commitment

Over the past decade AFTD has experienced rapid growth, often being in the position of reacting to exciting opportunities and meeting challenges presented to us. With this plan, we will continue to drive the work our community needs, while establishing a sustainable infrastructure for long-term impact.

AFTD's leadership commits both to building the capacity to carry out this ambitious plan, and to being strategic about how we evaluate and prioritize additional opportunities in which to invest our resources, for the maximum benefit of our community. We will develop measures to know better where we are having a true impact in the areas of our mission work. We will integrate new expertise as we design and implement initiatives, and cultivate an ethos in which every staff member has the opportunity to maximize their professional aspirations and impact on behalf of our mission.



Four Goals



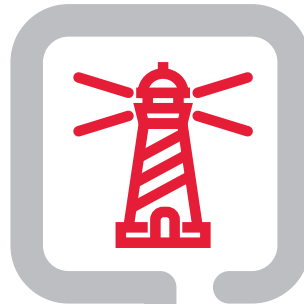
Goal 1

Advance early and accurate diagnosis and the development of treatments.



Goal 2

Advance quality care and support.



Goal 3

Strengthen and expand AFTD's position as the leading authority on FTD.



Goal 4

Build and strengthen the organization for long-term success.

**We envision a world with
compassionate care, effective
support, and a future free of FTD.**

Goal 1:

Advance early and accurate diagnosis and the development of treatments.

Mission Focus: Research, Education

Far too often, receiving a correct diagnosis of FTD is a frustrating, multi-year process rife with false leads and false hope. On average it still takes more than 3.5 years to get an accurate diagnosis. Compounding this challenge, there are currently no approved disease-modifying therapeutics for FTD today.

“Neuroscience has been a major area of interest for me for more than 15 years. It became personal when my father received his FTD diagnosis. From then on, we knew we would only have a finite amount of time with him, and we should make the most of it. Still, I can’t help but think what our experience might have looked like if there were viable treatment options available. That’s one of the main reasons why I’ve dedicated my career to FTD research, and why I’m proud to serve AFTD’s mission as a 2017–2019 Postdoctoral Fellow.”

Joseph-Patrick Clarke, Ph.D.
University of Pittsburgh

Targeted Outcomes:

Discoveries in genetic, clinical and basic science research advance how FTD is understood, hastening biomarker and drug development.

New clinical trials employ innovative trial designs and advance outcome measures.

New collaborative efforts increase funding for FTD research.

Health care professionals become more knowledgeable about FTD, and better able to diagnose and refer to quality medical support.

Research better reflects and accommodates the experience of people with FTD and their care partners.

Our Plan, Our Future

Strategy 1.1: Leading FTD research by investing in high-quality, innovative science.

- AFTD will fund leading-edge pilot studies, biomarker development, drug discovery and development, as well as clinical trials.
- We will attract, support, and engage early-career scientists as well as established investigators from a range of disciplines.
- We will leverage grant programs to stimulate new partnerships with other leaders targeting dementia and neurodegenerative disease, to increase investment in FTD research.
- We will increase the efficiency of our research funding by implementing new grants management software.

Strategy 1.2: Catalyzing partnerships and collaborative initiatives to accelerate the development of FTD diagnostics and treatments.

- AFTD will cultivate the FTD Treatment Study Group as a robust, collaborative research and innovation network for FTD.
- We will serve as the lead patient advocacy organization for the ALLFTD network of clinical research centers across North America.
- We will engage in and support collaborative efforts to secure and enable broad data sharing across all FTD stakeholders.

Strategy 1.3: Advancing healthcare professional education.

- AFTD will expand partnerships with professional associations and other organizations so that FTD is included in education offerings.
- We will promote the voice of people with FTD and care partners in professional education activities.
- We will refine and extend the reach and impact of AFTD's Partners in FTD Care initiative, to better serve both professionals and families.
- We will determine the best means to develop and deliver accredited FTD online content for professionals.

Strategy 1.4: Empowering our community to play a lead role in advancing research.

- AFTD will ensure the success and sustainability of the FTD Disorders Registry as a tool for our community to drive research.
- We will develop new ways for our community to provide input on AFTD research initiatives.
- We will foster greater inclusion of our community in the design of FTD research studies and outcome measures.
- We will develop and deliver FTD education sessions for industry partners that include direct representation from persons with FTD and their families.



“As a past chair and current member of the AFTD Medical Advisory Council, I witnessed many exciting developments. In the beginning, AFTD filled a major void by listening and giving a voice to patients and families with FTD. The advocacy came at a time when the behavioral and aphasic forms of FTD were frequently misdiagnosed. In addition to its remarkably effective activities in advocacy and education, AFTD is also becoming a critical player in the development of novel FTD treatments, the training of young investigators, and the initiation of pilot research programs.”

Marsel Mesulam, MD
Professor of Neurology
Director, Cognitive
Neurology & AD Center
Northwestern University
Member of AFTD's Medical
Advisory Council



Goal 2:

Advance quality care
and support.

Mission Focus: Support, Advocacy

The disruption and isolation so often brought on by FTD are heightened by a profound lack of high-quality care and support options. In response, we will improve quality of life for persons diagnosed and their care partners by growing AFTD's network of support, creating new digital and print resources, and empowering volunteers to educate healthcare professionals. We will identify and address the needs of underserved AFTD community members at a local level, while advocating to ensure that FTD is a priority within our nation's response to a growing dementia crisis.

Targeted Outcomes:

Improved quality of life for people with FTD and their care partners.

Identification of—and increased access to—expert resources with knowledge and experience in FTD in communities across the country.

FTD is a greater priority within the national response to dementia.

Multiple volunteer-directed initiatives advance FTD professional education at the local level.

“When my husband Chris received his diagnosis of behavioral variant FTD we had two-year-old twins at home and were still very much at the start of our lives together. AFTD helped our family in so many ways during the three years Chris lived with bvFTD. Their website served as a reference, a guide, and a way to speak with family members, health professionals and support staff who were not used to caring for a young, physically agile person with dementia. I joined AFTD's telephone support group for parents with school-aged children, and the ability to connect with people who understood was a lifeline... As someone who lives in a rural area, I also appreciated the ability to access support services remotely or through web-based platforms... I now facilitate the parents' support group, and I can say firsthand that the level of professionalism and training provided by AFTD is truly exceptional.”

Alyssa Radcliff
AFTD Support
Group Facilitator

Our Plan, Our Future

Strategy 2.1: Expanding the reach and impact of AFTD's direct support services.

- AFTD will create new resources to equip and enable people with FTD and care partners to maximize quality of life.
- We will expand AFTD's support group initiative, and increase the value-add AFTD provides to affiliated group leaders.
- We will pilot tactics to connect more AFTD HelpLine callers with local resource information.
- We will explore and address needs of underserved members of the community we serve.

Strategy 2.2: Leading national-level advocacy to influence emergent systems of dementia care.

- AFTD will ensure that FTD is a targeted area of focus in national discussions on the development and delivery of dementia care and services.
- We will facilitate participation of people with FTD and care partners in national meetings.
- We will work with institutional partners to ensure that FTD issues are included and addressed in dementia initiatives.

Strategy 2.3: Empowering AFTD's volunteers to drive professional education in local communities.

- AFTD will launch a targeted campaign for volunteer outreach to local health care professionals.
- We will train and equip a volunteer speaker's bureau for local presentations.
- We will develop a new volunteer role to connect with community providers and individuals who are newly diagnosed.

“Ten years ago, I helped develop a support group specifically for people with FTD and their loved ones. From the very beginning, I turned to AFTD for their insight, support and guidance. I often hear from the families I work with that while there are resources developed for people with Alzheimer's disease and other forms of dementia, those services don't always align with the realities of life with FTD. AFTD is the place where they fit, the place that has been designed with their needs in mind.”

Lauren Brasse, M.S.W.
Licensed Clinical
Social Worker
FTD Support Group Facilitator

Goal 3:

Strengthen and expand AFTD's position as the leading authority on FTD.

Mission Focus:

Awareness, Support

People and families affected by FTD often gain knowledge of this disease through great struggle and at great personal cost. Fostering widespread awareness of this disease is the first step to address this challenge, and to fulfill our collective mission and achieve our shared vision. AFTD will seek to inform all who can benefit from knowledge of FTD and our role in addressing it. We will empower all within our community to share their stories with others, and volunteers – our organization's strongest ambassadors – will be vital to these efforts.



Targeted Outcomes:

Increased public awareness about FTD and AFTD.

AFTD is increasingly recognized as the definitive source for current, accurate information on frontotemporal disorders.

Expert advisors inform the full breadth of our mission.

A robust national network of volunteers extends our impact within local communities.

"I love working with AFTD because of its sincere, heartfelt desire to include people with FTD in the conversation. It is extremely gratifying to hear that your opinion matters and know that they actually mean it. AFTD shows its commitment to diagnosed people through its Think Tank – a committee comprised of people with FTD, AFTD staff and Board members – of which I am proud to be a member. I received my diagnosis of FTD in 2011 at the age of 54, and the condition caused me to retire from my career as a college faculty member. But I knew that even though my formal career ended, my work wasn't done. AFTD has allowed me to put my skills to good use in this chapter of my life."

Amy Shives, M.Ed
AFTD Volunteer and Member,
AFTD's Think Tank

Our Plan, Our Future

Strategy 3.1: Delivering new resources and providing the most up-to-date FTD information to help all affected by FTD.

- On an ongoing basis, AFTD will create a growing array of new resources to inform, support and empower our constituents.
- We will deploy these resources effectively, with a focus on better reaching underserved individuals.

Strategy 3.2: Expanding the scope and impact of AFTD's volunteer program.

- AFTD will expand the ways in which volunteers can engage in our mission.
- We will increase the engagement of health professionals as AFTD support group leaders, speakers, and advocates.
- We will increase the engagement of students, people with FTD and diverse stakeholders as volunteers.
- We will increase investment in, and professional support for, our growing volunteer program.

Strategy 3.3: Expanding AFTD's marketing and outreach efforts to spread FTD awareness and increase engagement in our work.

- AFTD will inform a wider audience about FTD and our role in addressing it through our online presence, media engagement, PSAs and targeted advertising.
- We will proactively help our constituents to tell their FTD stories.

Strategy 3.4: Evolving AFTD's advisory boards to engage experts across the full range of our mission.

- AFTD will benchmark with peer organizations on advisory board structures and policies.
- We will implement a standard structure and branding across our advisory boards.
- We will design and implement processes that cultivate, engage, and recognize scientific, clinical and lay expert advisors.

"I've been so impressed at the strides that AFTD has made in the realm of advocacy on behalf of people and families affected by FTD. This begins at the grassroots level of caregiver conferences and support services... and extends all the way to a voice at the table at the National Institutes of Health where Susan Dickinson has been an extraordinarily effective advocate. Increasingly, AFTD provides important financial support for FTD research. This includes grants to attract the best young investigators to pursue research into treatments for FTD, and grants that seek to answer the toughest questions we must address such as diagnostic biomarkers for treatment trials."

Murray Grossman, MD, EdD
University of Pennsylvania
Member of AFTD's Medical
Advisory Council



Goal 4:

Build and strengthen the organization for long-term success.

Mission Focus: Sustainability

Over the past decade, driven by support from tens of thousands of donors and grassroots fundraisers, AFTD has grown dramatically. Still, we know today that we aren't yet helping all who can benefit from our work, and that the future we seek will take time to achieve. Through this plan, we will better hold ourselves accountable to driving the work that our community needs and deserves, while fostering a culture of sustainable innovation to benefit people and families proactively for years to come.

Targeted Outcomes:

Strong and diversified funding streams expand AFTD's impact and sustainability.

Strategic expansion of AFTD's staff to achieve the right-sized organization to achieve our mission.

AFTD's organizational culture maximizes leadership opportunities for staff at all levels.

Board governance and organizational infrastructure proactively meet the changing needs of a growing organization.

"When my husband Karl started displaying symptoms, it took a long time to put the puzzle pieces together and get an accurate diagnosis. Once we knew it was FTD, we needed a place to turn. I found AFTD through a specialist at Johns Hopkins School of Medicine, and I was immediately impressed by the resources it offered, and the passion of the people behind it."

Helen-Ann Comstock, AFTD's founder, identified a significant unmet need, and she created a space where every person affected by FTD can come and be heard. As a nurse by profession, I have a strong interest in clinical advancements for this condition, and it has been gratifying to see how AFTD balances the care and support side of its mission with its ongoing investment in research and medical education. I am proud to be a member of AFTD's Board of Directors, and I believe the work we are doing to both raise awareness and work toward improving the clinical understanding of FTD is essential."

Sandra Grow
Member, AFTD
Board of Directors

Our Plan, Our Future



Strategy 4.1: Better evaluating and documenting the outcomes of our work.

- AFTD will research best practices in the field to inform program outcomes measurement and data collection, and refine service delivery.
- We will create a formal community feedback mechanism to inform quality assurance and ongoing prioritization.

Strategy 4.2: Maximizing opportunities for donors, fundraisers, corporations and foundations to engage in AFTD's mission.

- AFTD will craft a three-year fund development plan, building on the gains in previous years.
- We will develop new ways to promote and recognize philanthropic support, and to better document the impact of AFTD's work for our donors.

Strategy 4.3: Investing in our staff to maximize engagement, foster professional growth and opportunities for leadership, and ensure adequate capacity to deliver on AFTD's goals.

- AFTD will expand staffing to sustain current operations at a growing scale and build new initiatives.
- We will develop and implement an ongoing training plan for all managers and staff.
- We will implement practices to expand staff diversity and inclusion.

Strategy 4.4: Developing and implementing a comprehensive IT plan.

- AFTD will implement new systems to ensure safe and reliable operations and increase efficiencies.
- We will develop processes to ensure data integrity in Salesforce and across platforms.

Strategy 4.5: Ensuring strong governance as the organization evolves and matures.

- AFTD will cultivate a robust pipeline of Board and officer candidates, to ensure a well-balanced board, representative of diverse professions, locations, ethnicities and FTD experience.
- We will benchmark best practices with peer boards, and evaluate AFTD's Board practices and committee structure for opportunities to improve effectiveness.
- AFTD will design and implement an annual board education program.

Our Plan,
Our Future

MAKE A CHANGE

Your Support is Essential

Our plan draws its inspiration from the tens of thousands of donors and volunteers who have given their all to advance our shared work since 2002. And only donors and volunteers can make fulfilling this ambitious plan possible.

If you have the means to make a tax-deductible donation, we hope that you'll do so by visiting our website at theaftd.org. Donations can be dedicated to specific AFTD mission areas and programs, including research and support. Unrestricted donations increase the sustainability of AFTD's work as a whole. Every dollar we raise is used to advance AFTD's work; more than 80% of every dollar raised goes directly to our mission and our programs, with the balance allocated to administering, managing and fundraising to sustain the organization.

To discuss a major gift, named fund opportunities, and other ways to contribute, please contact AFTD's Development Manager, Amanda Knight, by email at AKnight@theaftd.org, or by phone at 267.758.8648.

Hundreds of volunteers make our mission possible. They run support groups, hold meet and greets and stage table settings at events, raise vital funds and raise awareness through grassroots events, and tell their stories to drive media coverage. If you would like to become an AFTD volunteer, simply visit our website at theaftd.org and fill out our volunteer registration form, and we'll connect with you about next steps.

Use our resources – whether our HelpLine, our website, an AFTD volunteer-led support group, our Facebook closed group or AFTD's group for young adults, or our Comstock grants. Then be sure to tell us what you think, and how we can serve you better.

Share your response to this plan by reaching out to info@theaftd.org. Tell us what you think, what inspires you, about the challenges you face, and what you'd like to see in the years ahead.

AFTD's work has always been – and remains – community-driven. We can't do this work without your involvement, and your support.



Our Plan, Our Future

“It is a true privilege to volunteer for AFTD, and I credit them for helping me cope with my husband’s illness (bvFTD). For the 10 years he was ill, I looked to them for information, guidance and encouragement. I can sincerely tell family and friends who contribute to AFTD that they can feel good about supporting this organization, knowing firsthand that it is a powerful force for help and hope. I am a co-facilitator for an AFTD-affiliated support group in my region, and I happily serve as a liaison for AFTD’s grassroots Food For Thought fundraising campaign. I am honored when the fine staff at AFTD reach out to me to help in any way. I cannot think of a better use of my time and effort.”

Elaine Rose
AFTD Volunteer

“My spouse Tracey received her diagnosis of primary progressive aphasia in November 2016 – and on the very same day, we first learned of AFTD. So many people receive a diagnosis of FTD, a disease they’ve never heard of, and are then told there’s little that’s known or can be done about it. They need a resource that puts them first, and AFTD is that resource. It’s been a godsend in so many ways.”

Emily Ingalls
Care Partner



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

267.514.7221 - Office | 866.507.7222 - HelpLine
info@theaftd.org | www.theaftd.org