

From Hope to Action

July 2021–June 2022

2022 Annual Report



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From Hope to Action



Dear friends,

AFTD would not exist today without hope. Twenty years ago, Helen-Ann Comstock held hope that families living with FTD could have more resources and information than she did when her husband was diagnosed in the late 1970s. She hoped, too, that awareness of FTD would grow, both among healthcare professionals and the public. And she hoped that policymakers and researchers alike would recognize FTD science as a cause worthy of attention and dedicated investment.

Fueled by hope, Ms. Comstock acted, founding our organization in 2002. In the two decades since, AFTD has cultivated a community of creative and dedicated volunteers, healthcare professionals, and FTD-focused researchers, all contributing to a growing understanding that not all dementia is Alzheimer's, and that together, we can treat and cure FTD.

Inside this Annual Report, you will find a special section highlighting the many ways AFTD has brought hope to action during our first 20 years. We know that our work is far from complete – but momentum is growing. AFTD's staff, Board, and volunteers have worked harder than ever during our last fiscal year (July 2021 through June 2022) to realize our vision of a world with compassionate care, effective support, and a future free of FTD.

From a personal standpoint, I was most inspired and energized by being able to reconnect with AFTD's community in person again. In April, AFTD held our first in-person Education Conference since 2019, after two

years of virtual conferences necessitated by the pandemic. I deeply valued being able to meet, talk to, and learn from others who understand the FTD journey. Our 2022 Conference was also livestreamed on the internet, and hundreds joined online to connect, learn, and engage. Future AFTD Education conferences – including next year's, to be held on May 5, 2023, in St. Louis – will retain this hybrid model. If you cannot join us in person, I highly recommend following along online.

Returning to in-person events – while following all pandemic-related safety guidance – was a theme of the past year. Our volunteers connected with others in local communities, facilitating vital discussions in support groups, leading fundraisers, and racing for our shared cause at events in cities like Austin, Denver, New York – and even in their own neighborhoods, thanks to the Charity Miles app.

AFTD is advancing research, both in funding innovative science targeting this disease, and convening vital discussions to build our field. In December 2021, we brought together more than 200 people from academia, pharma, and government to collaborate on ways to accelerate FTD treatment development. We also convened the first-ever Holloway Summit, hosted by my fellow AFTD Board member Kristin Holloway, to discuss how digital assessment tools – think wearable trackers and smartphone apps – can be useful in tracking and even diagnosing FTD.



As a former FTD caregiver to my beloved wife, I know firsthand how scary, lonely, and overwhelming the FTD journey can be for families, and I cannot imagine how much more difficult it became during the pandemic. But I'm proud to say that our community kept its resolve throughout, and that AFTD continued to provide high-quality supports in an ever-changing world – a testament to the ideals of hope and meaningful action from which AFTD was forged 20 years ago. And I hold on deeply to the hope for a future day when families no longer need to worry about this disease. I believe we can get there together, through dedicated action.

Sincerely,

A handwritten signature in black ink, appearing to read "David Pfeifer". The signature is fluid and stylized, with a large loop at the end.

David Pfeifer
AFTD Board Chair

awareness

Raising FTD awareness is crucial to every part of AFTD's mission. AFTD is turning hope into action by engaging with medical and healthcare professionals, researchers, community stakeholders, policymakers, and our dedicated network of volunteers to offer vital information about the unique challenges of an FTD diagnosis.

This past year, 501,854 people visited theaftd.org to learn about FTD, connect with peers, and discover ways to become involved with our mission. In Fall 2021, a new section of our website focusing on **FTD Genetics** debuted, including expanded information on the causes of FTD, the importance of genetic counseling, and options for no-cost genetic testing. AFTD is also reaching a growing audience through social media, with more than 20,000 followers across Facebook, Instagram, LinkedIn, and Twitter.


To mark **World FTD Awareness Week**, AFTD worked with the other members of the World FTD United coalition to present a **Global Conversation on FTD**. People and families affected, health professionals, and researchers submitted short videos and stories to capture the lived experience of FTD and share reasons for hope. The Global Conversation comprised four hours of personal stories, presentations from FTD researchers and clinicians from around the world, and information on finding resources and support through AFTD and other organizations around the globe.

HIS WIFE SAID MIDLIFE CRISIS.

HIS THERAPIST SAID DEPRESSION.


HIS DOCTOR SAID ALZHEIMER'S.

NO ONE SAID FTD.




Short for **frontotemporal degeneration**, FTD brings devastating, progressive changes in behavior, personality, language and movement. It's the most common dementia for people under 60. But FTD is still far too little known today, even for doctors and health professionals. On average, getting an accurate diagnosis takes nearly 4 years. And today, there are no effective treatments. Learn more: www.theaftd.org/FTDinfo

If you have questions about FTD or young-onset dementia, AFTD is here to help. Visit: www.theaftd.org/FTDinfo



The Association for Frontotemporal Degeneration
FIND HELP • SHARE HOPE




If you have any questions about AFTD and its mission, please call (866) 507-7222 or email info@theaftd.org

The first doctor said depression.

The second said stroke.


The third said Alzheimer's.

No one said FTD.




Short for **frontotemporal degeneration**, FTD brings devastating, progressive changes in behavior, personality, language and movement. It's the most common dementia for people under 60. But FTD is still far too little known today, for doctors and health professionals. On average, even getting an accurate diagnosis takes nearly 4 years. And today, there are no effective treatments. Learn more: www.theaftd.org/aboutFTD

If you have questions about FTD or young-onset dementia, AFTD is here to help. Visit: www.theaftd.org/aboutFTD

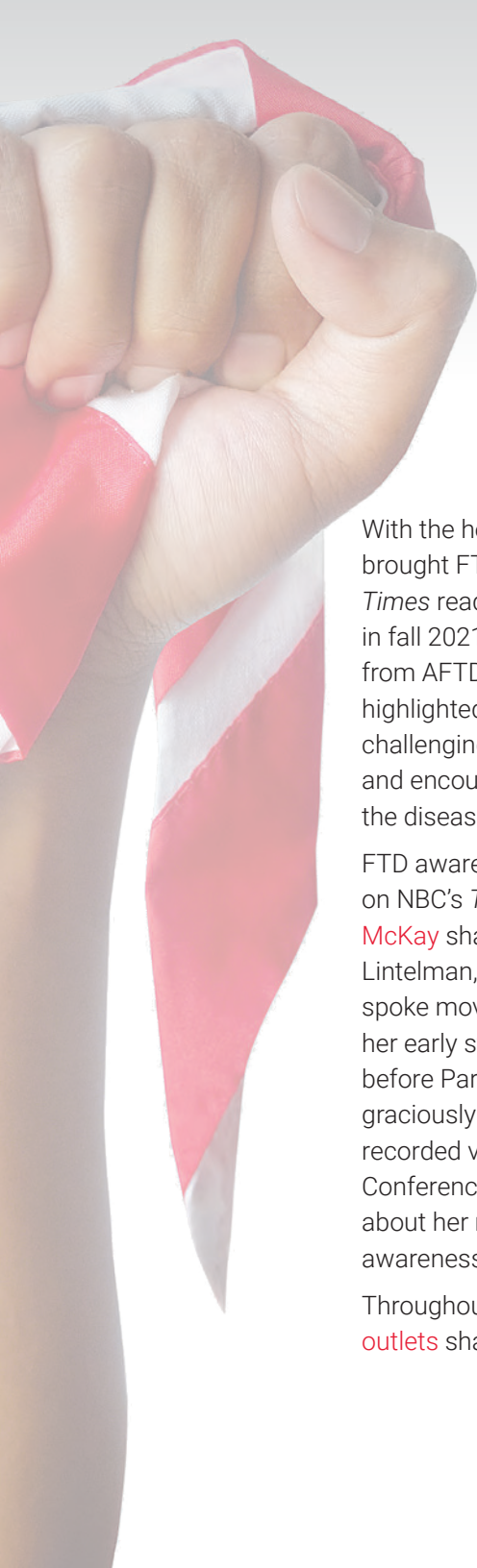


The Association for Frontotemporal Degeneration
FIND HELP • SHARE HOPE



If you have any questions about AFTD and its mission, please call (866) 507-7222 or email info@theaftd.org

With support from a generous donor, AFTD placed digital and print ads in the New York Times during World FTD Awareness Week, featuring a campaign created by volunteer Jody Zorn.



World FTD United

With the help of a generous donor, AFTD brought FTD awareness to *New York Times* readers with **print and digital ads** in fall 2021. Designed with creative input from AFTD volunteer Jody Zorn, the ads highlighted FTD's young age of onset and the challenging diagnostic journey many face, and encouraged readers to learn more about the disease by visiting our website.

FTD awareness reached a national audience on NBC's *The Voice*, as contestant **Parker McKay** shared that her late mother, Tracey Lintelman, was diagnosed in 2020. Parker spoke movingly about her mom's FTD, from her early symptoms to her death shortly before Parker's *Voice* audition. Parker graciously shared her story via a pre-recorded video at the 2022 AFTD Education Conference and continues to talk publicly about her mom's life and FTD journey, raising awareness among her friends and fans.

Throughout the year, numerous **media outlets** shared FTD stories. A special FTD-

focused issue of *Rare Revolution Magazine* featured AFTD CEO Susan L-J Dickinson, MSGC, former AFTD Board member Debbie Fenoglio, and FTD Disorders Registry Director Dr. Dianna Wheaton.

Family members, care partners and caregivers, advocates, and AFTD staff were featured across media platforms, including the podcasts *Dementia Dialogue* and *Rodger That*, radio venues like NPR's *Fresh Air* and KJZZ in Phoenix, the YouTube show *Just Ask Dr. Macie*, and the North Carolina-based *The News & Observer*. Every story helps to bring more FTD awareness to the public – and serves as a call to action.

Growing Awareness on Social Media: FY21 to FY22

Facebook followers	up 5%
Twitter followers	up 12%
Instagram followers	up 39%
LinkedIn followers	up 40%



Nicole Petrie's mom Cheryl was diagnosed with FTD in 2015 at age 51. In early 2020, Nicole moved back home to Wisconsin to help her dad, as her mom was beginning to need full-time supervision and care. During this time, Nicole started making TikTok videos, sharing her FTD caregiving journey alongside moments of love, joy, and laughter. While busy with her career as a model, Nicole plans to continue raising FTD awareness and encouraging more dialogue to destigmatize dementia.

“So many people are afraid of dementia and those who are diagnosed – it drives family and friends away because there is a lack of education and understanding about what FTD is. Sharing videos of my mom where she's happy, smiling, and dancing will hopefully change some people's minds and they will lean in to help those affected instead of disappearing,” Nicole said. “Being a caregiver can be incredibly difficult and people need to be supported on this journey – I'd like to see more awareness about FTD, so there's less confusion surrounding a diagnosis and we don't have to be as scared of it, and people living with it receive more support.”

support

Providing support – in the form of current and accurate information, tailored resources and guidance, and direct assistance – has been central to AFTD’s mission since the organization was founded 20 years ago. AFTD’s staff continues to expand to meet the needs of our community, deepening our capacity to help all who face FTD.

The **AFTD HelpLine**, accessible via email and phone, often serves as the first point of contact for people to learn more about the disease, find care and support options, and get help navigating their FTD journey.

In early 2022, AFTD welcomed its first **HelpLine Manager**, Stephanie Quigley, MSW, LSW, CDP. Stephanie leads two professional social workers dedicated to responding to inquiries. Additionally, to ensure this valuable resource is accessible to more people, AFTD began offering translation services for the HelpLine in the beginning of our 2021-2022 fiscal year. Throughout the year, staff provided information and guidance to 2,325 people.

Last year, we distributed 446 **Comstock Grants** to people impacted by FTD. Named in honor of AFTD founder Helen-Ann Comstock, the Comstock Grant program alleviates the economic burden a diagnosis can bring – a burden that has been worsened by the COVID-19 pandemic. Respite Grants can

be used by care partners for scheduling time and services that benefit their physical and emotional well-being, and Quality of Life Grants help persons diagnosed access services or supports that directly address their needs or interests.

FTD support groups are an essential resource for the people we serve, giving persons diagnosed, care partners, and family members an opportunity to join their peers to share care strategies and coping skills. Over the past year, 93 AFTD-affiliated volunteer support group leaders led 72 groups across the country, offering opportunities to build vital connections with others who are living with an FTD diagnosis, in person and virtually.



AFTD’s e-newsletter, **Help & Hope**, highlighted news and current events from our community, including updates on FTD research, ways to find support, and personal stories to encourage those who are navigating a diagnosis. As FTD awareness increases, **Help & Hope’s** distribution has grown to include more than 10,000 readers monthly.



Members of an FTD-focused support group in Massachusetts meet up virtually via Zoom to share with and learn from one another.



Finding Support: FY21 to FY22



Visitors to
theaftd.org
↑20%



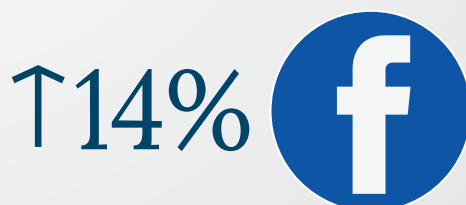
↑47%
Comstock
Grants
awarded



AFTD-Affiliated
Support Group
Volunteers: 92



HelpLine
calls and
emails
answered:
2,325



↑14%

AFTD's Facebook
Group Membership



Katrina Hellman's husband Darren was diagnosed with semantic variant primary progressive aphasia in 2015 at age 49. She became an AFTD support group volunteer in 2016 and has hosted multiple Food for Thought events to increase FTD awareness and raise funds to advance our work.

“AFTD has been a lifeline for me and my family,” she said. “The organization does so much to provide support for people affected by FTD and to enable access to so many well-informed resources. I have attended nearly every Education Conference following Darren's diagnosis, and the Comstock Grants have been so helpful – it's such a generous thing to support families as they face this disease. I hope that in the future, FTD is more well-known, because it will mean there are more avenues of support, and more resources will be available for those in need.”

research

By investing in ambitious initiatives and building strategic partnerships, AFTD has become a leader in advancing the science of FTD. Community engagement leads the way.



In October 2021, AFTD released *Frontotemporal Degeneration: A Voice of the Patient Report*, summarizing findings from our March 2021 Externally Led Patient-Focused Drug

Discovery meeting and our FTD Insights Survey, conducted with the FTD Disorders Registry. Designed as a resource for the FDA, this report offers robust data and powerful stories about the experiences of people living with FTD disorders, and what they and their care partners most want in potential treatment options. Both the report and data from the FTD Insights Survey will assist the FDA in making decisions about new treatments and clinical trials, and are pivotal

to advancing therapeutic development.

Partnerships enable AFTD to combine resources and knowledge with peer nonprofit organizations, industry leaders, and academic researchers to advance the development of tools and technologies that can lead to breakthroughs benefiting people affected by neurodegenerative disease. For example, AFTD partnered with the Rainwater Charitable Foundation and CurePSP to support the Federated Brain Banking Platform, an initiative at the University of California, San Francisco, and three other sites to streamline research calibration.

Additionally, early in 2022, AFTD joined with 20 partnering biopharma and advocacy organizations to collaborate on the validation of neurofilament as a biological indicator that symptoms of FTD will soon emerge in people carrying an FTD genetic variant, a critical step for designing prevention clinical trials. The project is the first FTD-focused initiative under the aegis of the Foundation for the National Institute of Health's Biomarkers Consortium.



The **FTD Treatment Study Group** met for its biannual meeting in December 2021. AFTD convened almost 200 participants from academic research institutions, the biopharmaceutical industry, peer nonprofit advocacy organizations, and government agencies to collaborate on ways to accelerate the development of effective FTD treatments in a pre-competitive space. The hybrid meeting featured presentations from six companies on trial designs that are actively recruiting, demonstrating how far drug development has progressed in the decade since the first FTSG meeting in 2011.

AFTD convened almost 200 expert participants from across our field for the 2021 meeting of the FTD Treatment Study Group.



AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD, speaks at the 2021 FTD Treatment Study Group meeting.



Awards and Grants

Treat FTD Fund for Clinical Trials –

Simon Ducharme, MD, FRCP(C), McGill University (Canada); Paul Edison, MD, PhD, Imperial College London (UK); Wave Life Sciences (US)

Diagnostics Accelerator – Qinwen Mao, MD, PhD, University of Utah (US); Wesley Horton, MS / Foundation for the National Institutes of Health (US)

Accelerating Drug Discovery for FTD – Kenneth Kosik, MD, UC Santa Barbara (US)

Pathways for Hope Pilot Grant – Aaron Burberry, PhD, Case Western Reserve University (US); Meysam Yazdankhah, PhD, Neural Stem Cell

Institute (US)

Well-Being in FTD Pilot Grant – Alinka Fisher, PhD, Flinders University (Australia)

Clinical Research Training Scholarship – Indira Garcia Cordero, PhD, American Brain Foundation (US)

FTD Biomarkers Initiative – Wesley Horton, MS, Foundation for the National Institutes of Health (US)

Holloway Postdoctoral Fellowships – Suborno Jati, PhD (US); Julia Faura Llorens, PhD (Belgium)*; Eric Anderson, PhD, co-funded with ALS Association (US)*

*awarded July 2022



Qinwen Mao, MD, PhD, received an award

through the Diagnostics Accelerator initiative for her work to develop a plasma biomarker that could accurately diagnose individuals with TDP-43-associated FTD, and effectively differentiate between tau-associated FTD, Alzheimer's disease, and normal aging diagnoses.

“Today, clinicians are diagnosing diseases like FTD on visible symptoms, but we don't have a clear picture of what is going on inside the brain,” Dr. Mao said. “Having a biomarker is a gold standard – without it, we cannot progress toward earlier, targeted treatments. FTD is devastating to families, and we urgently need an accurate and reliable test to differentiate the syndromes. AFTD's support has given me the courage and inspiration to dedicate my focus to developing a test that can be easily used by clinicians to accurately diagnose people before the disease has progressed. This is my passion, and AFTD has opened up so many opportunities for me to pursue it.”



In May 2022, AFTD Board member Kristin Holloway hosted the inaugural **Holloway Summit** in Miami, bringing together 60 internationally renowned leaders in FTD science, neurodegenerative research, and digital tool design. Attendees shared progress in the development of tools to assess FTD symptoms, focusing on emerging technologies that allow researchers to use smartphones, wearable trackers, or other devices to remotely gather data – known as digital biomarkers – from research participants.



Leaders in FTD science, neurodegenerative disease research, and digital tool development gathered for the first annual Holloway Summit in May.

education and advocacy



Members of AFTD's Persons with FTD Advisory Council talk about their experiences at AFTD's 2022 Education Conference.

AFTD's education initiatives help people navigate a diagnosis, and inform healthcare professionals about FTD symptoms and ways to care for persons diagnosed. By reaching a growing network of people directly impacted, professionals, and key community stakeholders, AFTD is helping to advance diagnosis, improve care management, bring forward accessible support options, and drive research engagement.

AFTD's **2022 Education Conference**, held simultaneously in person in Baltimore and online via livestream, welcomed more than 1,150 attendees from 28 countries to connect, learn, and engage. The agenda included nine plenary sessions, 10 breakout sessions, and 34 speakers, including members of AFTD's Board, Medical Advisory Council, and Persons with FTD Advisory Council. Recorded sessions can be viewed on AFTD's YouTube channel at youtube.com/TheAFTDorg.

In collaboration with clinicians and care professionals, AFTD presented five **Educational Webinars** throughout the year on FTD care management and support options. Additionally, AFTD and the FTD Disorders Registry jointly presented three **Perspectives in FTD Research webinars** aimed at helping



AFTD Board member Rita Choula presented the Keynote Address at AFTD's 2022 Education Conference.

those affected by FTD to become informed participants for current and future FTD research and clinical trials.

As of June 2022, AFTD offers **Continuing Education Credits (CECs)**, which are essential for medical professionals and care service providers to maintain licenses and certifications. By offering credits for attending specific healthcare-focused webinars, AFTD has expanded our reach to professionals who can have an impact on people living with FTD, raising essential awareness about the unique nature of the disease and how to care for individuals who



AFTD's 2022 Education Conference featured a panel on the diverse experiences of FTD caregivers, led by AFTD Board member Halima Amjad, MD, PhD.



are diagnosed.

The publication *Partners in FTD Care* teaches medical professionals and care service providers about the symptoms and progression of FTD to promote better knowledge of the disease and to improve care quality. This past year's editions highlighted genetic causes of FTD, the challenges of receiving an accurate diagnosis, and how FTD affects families. More than 3,500 healthcare professionals receive the newsletter.

In 2021, New York State senator Michelle Hinchey introduced a resolution, since adopted by the state, designating Sept. 26 through Oct. 3 FTD Awareness Week in New York. Her father, former U.S. Rep. Maurice Hinchey, had primary progressive aphasia

and passed away in 2017. Committed to FTD awareness and advocacy, Senator Hinchey invited AFTD staff to join her on October 1 for a Facebook Live event, sharing her family's journey to bring state and national attention to the urgent needs of all affected by FTD.



Nupur Ghoshal, MD, PhD, of Washington University in St. Louis found a passion for studying neurology early in her career. Today, she is a dedicated researcher and educator, committed to helping families as they navigate FTD diagnoses. Dr. Ghoshal has been an active member of AFTD's community, recently co-presenting an AFTD/FTD Disorders Registry webinar about the need for biological samples in clinical trials.

“When I started meeting with families affected by FTD at the beginning of my fellowship, I immediately felt all in. I knew this was what I needed to do – I wanted to find a way to help fix this. As a physician-scientist, I have the opportunity to change things for the better by sharing what I've learned through my research and work as a neurologist. If I can put something out into the world that changes someone's understanding of FTD or helps make people more willing to engage in research, I know what I am doing is making a difference and it inspires me to do more.”

volunteers and the AFTD-Team



AFTD recognized our amazing volunteers at the first Volunteer Appreciation Dinner in three years!

Twenty years ago, Helen-Ann Comstock and a group of volunteers, driven by their hope to improve the quality of life of people affected by FTD and drive research to a cure, founded AFTD. Today, our volunteer network takes action every day to advance AFTD's work across our mission pillars of awareness, education, support, research, and advocacy.

During the 2022 AFTD Education Conference, we welcomed new and returning volunteers to our first **Volunteer Appreciation Dinner** since 2019 to celebrate the AFTD-record 348 grassroots volunteer activities that took place over the past year. Also acknowledged were the 69 volunteers serving as professional, medical, or scientific

advisors; 12 as Ambassadors; seven on AFTD's Persons with FTD Advisory Council; 18 on AFTD's Board of Directors; and 138 serving as speakers, liaisons, or facilitators for Meet & Greets, support groups, and table settings throughout the year.

The 2021-2022 Race Season saw more than 250 **AFTD-Team** members participate in marathons, half-marathons, 5Ks, and more, raising funds that will provide help and bring hope to people facing FTD. Logging more than 1,824 miles across races in Austin, Denver, New York, Philadelphia, and Dallas, volunteers raised more than \$140,000 to drive AFTD's work.

AFTD-Team members also logged miles on the Charity Miles app by running, walking, and biking. In July 2021, The Jackie Pang Memorial Fund sponsored a 10,000-mile challenge, pledging \$1 for every mile tracked on the app on AFTD's behalf – which our community completed in just 10 days!

AFTD's ninth annual **Food for Thought** campaign took place from Sept. 26 through Oct. 10, 2021. By gathering with family and friends, in person and virtually, 53 volunteer fundraisers across 22 states raised \$158,000 in support of AFTD's work and educated their communities about FTD. Three companies

working to advance FTD therapies joined or hosted Food for Thought events during last year's campaign to raise awareness and engage their staff in AFTD's mission: Alector, Denali Therapeutics, and Wave Life Sciences.

Returning for a second year, the **#FTDhotshotchallenge** social media campaign generated awareness and engagement to new audiences throughout the United States and Canada. Together, more than 30 fundraising volunteers raised \$101,000 in support of AFTD's research initiatives.

Volunteers and supporters returned to the golf course for the **2021 Driving Hope Golf Tournament** on August 15 at the Colorado National Golf Club in Erie, CO and on October 18 at The Seawane Club in Hewlett, NY. Driving Hope pays tribute to all who are impacted by FTD and raises funds to sustain AFTD's mission. Together, the two





tournaments raised more than \$105,000, nearly doubling 2020's total.

With Love, AFTD's month-long online campaign held each February, featured 29 volunteers inspired by Valentine's Day, creatively expressing how love sustained and uplifted them during their FTD journey. As a collective show of love and support, their stories helped to raise \$70,000.

A significant number of additional volunteers hosted their own independent grassroots fundraisers outside of AFTD's branded campaigns, raising over \$381,000 combined for our mission.



AFTD's Support Group Volunteers helped to ensure that -- even during the difficulties of the pandemic -- anyone who needed help along the FTD journey could find it, whether in person or online.



“Fundraising for AFTD gave me an opportunity to open up about my dad's diagnosis and share some of my family's story. Talking about FTD and its impact was a way for me to grieve and begin accepting this into my life.” – Spencer Cline

In February 2022, Spencer Cline and members of his basketball team at Babson College in MA (pictured on cover), organized an AFTD fundraiser, increasing FTD awareness in his community and raising more than \$11,000 to drive AFTD's work. Just seven years old when his father Lawrence was diagnosed with FTD in 2006, Spencer has fond memories watching and playing basketball with his dad before Lawrence's death in 2012. By hosting an event around their favorite sport, Spencer found a perfect opportunity to further AFTD's mission while honoring his father.

“Sharing this with my team was really special. I had never told so many people about FTD at once. Everyone was very supportive and genuinely interested in learning more about the disease. This experience has made me excited to keep sharing my story because I realize how important it is to raise awareness. I hope that as more people understand this disease, we can move toward a cure in my lifetime.”

CELEBRATING AFTD's 20th Anniversary



AFTD was founded in **November 2002** by Helen-Ann Comstock (left) after she lost her husband Craig to FTD. Ever since, AFTD has worked to turn hope into action, driven by a vision for a future free of FTD. On our 20th anniversary, we are looking back at how far we have come, and celebrating that this work has been – and always will be – driven by our community.



"I knew we needed to get research focused on FTD – but it was hard to get that exclusive focus when so much money was going to Alzheimer's disease research. I was told quite clearly that I needed to start my own organization – so I did it. From the very beginning, I wanted a focus of the organization to be on supporting caregivers, advocacy, and research. It all had to start somewhere – I'm very proud of what we were able to accomplish in those early days, based out of what was little more than a closet!"

– Helen-Ann Comstock, AFTD Founder



"Getting involved with founding AFTD was so important because it addressed huge unmet needs – the most important being patient care, education, and research that puts us on a solid course for discovering disease modifying therapies for FTD."

– John Q. Trojanowski, PhD (1946–2022), a founding member of AFTD's Medical Advisory Committee (MAC), who was instrumental in advancing neurodegenerative disease research, focusing on the underlying causes of proteinopathies such as FTD



"AFTD has helped me channel my energy and frustration, and has given me something to feel passionate about. It feels good to be doing something in an area where so little has been done."

– Joyce Shenian, an AFTD founding Board member whose husband passed in 2002 following an FTD diagnosis

"Every new donor brings us closer to an effective treatment and also brings one more person who understands and cares about FTD. For a rare disorder, that is very important and very heartening."

– Helen-Ann Comstock



The Association for
Frontotemporal Degeneration
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In a **2006** *Nature* article, AFTD MAC members Christine Van Broeckhoven, PhD and Michael Hutton, PhD reported new mutations on the *PGRN* gene believed to be responsible for hereditary FTD in approximately five percent of families with the disease.

Shortly after the identification of the *PGRN* mutation, a collaboration among several researchers, including members of AFTD's MAC, published data in *Science* identifying TDP-43 as a cause of around 30-40% of all FTD disorders.

"Some very exciting discoveries have been made that have identified specific molecules involved in FTD brain pathology. We want to keep this momentum going, and ensure that these findings are translated from the laboratory to the clinic as fast as possible," Helen-Ann Comstock said at the time.

In **2007**, we asked our community to join us in the grassroots campaign **"Tell 10 People about FTD"** to raise awareness and funds to support the FTD Drug Discovery research venture. The response was enthusiastic, and it became an annual event, evolving into today's Food for Thought and *With Love* awareness campaigns.



In 2006, Sylvia Mackey's husband John Mackey, an NFL Hall of Fame tight end, was diagnosed with FTD, inspiring her determination to raise awareness and advocate for families impacted. It was through Ms. Mackey's campaigning that the NFL created the **"88 Plan"** – honoring John's jersey number – for players affected by neurological diseases. The plan continues to provide financial support for NFL players and their families. Ms. Mackey joined the AFTD Board in **2008**, continuing her work to raise FTD awareness among a growing audience.

"It's important for us to get the word out about FTD because so many people still don't know about this disease. Its impact is devastating and there's so much more that needs to be done in terms of advocacy and research."

A donation in **2009** enabled AFTD to create the Respite Care Financial Assistance program for care partners and caregivers. In the first year, AFTD issued 20 grants, and today provides financial support to approximately 450 people each year through the Comstock Grants program, which was officially named in honor of AFTD's founder in **2010**.

In **2011**, following 10 years of research, Rose Rademakers, PhD, a member of the AFTD MAC, was among a group of investigators to publish findings that a mutation in a noncoding region of the *C9orf72* gene can lead to FTD and ALS.

"It's a tremendous breakthrough in FTD research and we're one step closer to treatment and a cure. Without the active participation of people who are diagnosed and their families in this important, albeit tedious work, it takes infinitely longer to get to the answers."

– former AFTD Board chair Beth Walter, whose husband Mike Walter was diagnosed with FTD and passed away in 2006. The family long suspected there was a genetic component to Mike's diagnosis, as his two brothers and several family members had also been affected. This discovery provided an answer for many families, like the Walters, and opened a new avenue of investigation for researchers.

"This will allow us to better understand the common pathological process and should be a big leap forward in the effort to develop biomarkers and to identify appropriate targets for therapeutic intervention in both diseases."

– Adam Boxer, PhD, whose work has focused on the biological basis of FTD, was a coauthor of one of the papers characterizing the *C9orf72* mutation and served as an AFTD MAC member.



"The AFTD grant allowed me to [have time] just taking care of myself. I can't tell you how good it felt. The respite rebuilt something inside of me. It brightened my spirits. I felt lighthearted and free. It enabled me to carry on as a caregiver for my husband with refreshed determination."

– Kris, one of the first grant recipients

In **2015**, AFTD funded an FTD economic burden study to determine the true financial impact of an FTD diagnosis. Years of anecdotal information suggested that caring for someone with FTD could cost double what it did for someone with Alzheimer's disease.

The resulting article, "The Social and Economic Burden of Frontotemporal Degeneration," published in the November 2017 edition of *Neurology*, demonstrated that FTD's impact extended far beyond average day-to-day costs. Loss of income, rising health premiums, and caregiver stress were also accounted for in the study, which continues to serve as a benchmark for discussing FTD's far-reaching effects.



"These findings will help to shape health policy, drive research agendas, promote allocation of appropriate financial and community resources, and provide much needed support to families currently living with FTD."

– James Galvin, MD, MPH, who led and co-wrote the comprehensive study, collecting data from 674 people living with FTD.



The AFTD Think Tank was initiated in **2016** to ensure that the perspectives of people living with an FTD diagnosis are included in AFTD's work. Members assisted with shaping AFTD goals and programs, including informing the annual Education Conference agenda. In 2020, the Think Tank evolved into the Persons with FTD Advisory Council.



"It is wonderful to be able to discuss and share ideas with AFTD staff. Having the opportunity to work together to find new solutions to old challenges, while creating a better understanding of the needs of those living with FTD, is extremely rewarding."

– Teresa Webb, RN, co-chair of the Persons with FTD Advisory Council. Teresa was diagnosed with logopenic primary progressive aphasia in 2010.

"What is exceptional here is the fact that I, a person with FTD, was invited to participate as a representative for people with FTD at the decision table within the community. It is important that someone with the disease is included at every step in the development of what you will see today."

– Amy Shives, MEd, speaking during the 2019 Education Conference in Los Angeles. Amy is a former member of the Persons with FTD Advisory Council. She was diagnosed with behavioral variant FTD in 2012.

When Helen-Ann's husband Craig was initially diagnosed with Alzheimer's disease in 1978, she went looking for more information – only to find just a couple sentences on the disease in her copy of the *Encyclopedia Britannica*. Central to Helen-Ann's founding vision was making FTD information easily accessible to people across the United States and beyond. AFTD's website, launched in **2003**, quickly became an invaluable resource for people looking for more information about the disease, as well as ways to engage and connect with peers for support.

"It was six years ago that I was scrambling to put together the first website - this new website takes us to a whole new level and better reflects not only how far [AFTD] has come, but the progress that has been made in the whole field of FTD."



– Kent Jamison, a founding AFTD Board member, in 2009 reflecting on the website's launch and growth. In 2004, the website was visited by 2,500 visitors monthly – today, we are reaching more than 40,000 people per month.

"AFTD is only as strong as the people who join with us, and encouraging respite is a great way to help caregivers maintain the strength they need in a most difficult role."

– Helen-Ann Comstock

The most common
dementia under age 60...

Don't face FTD alone.

AFTD www.theaftd.org

Providing support to people and families navigating a diagnosis has always been central to AFTD's mission. Then, as today, FTD support groups were convened by volunteers who saw an urgent need for connection in their communities. What began as a small handful has grown to include more than 90 AFTD-affiliated support groups led by trained volunteers, providing vital opportunities for people to connect with their peers.

"AFTD offers the support I need to provide correct, specific information for what people are dealing with in FTD. Without these resources, my group would only be able to use broad, dementia-related information."

– Rona Klein, former FTD caregiver and former AFTD support group volunteer, commenting in 2015 about the reorganization of AFTD's support groups.

At the **2022** AFTD Education Conference, FTD caregiver Marian Grems shared her experiences with those gathered both in Baltimore and online via livestream. She has been volunteering with AFTD since 2018 as a support group facilitator and grassroots events host.

"The research, partnerships, and AFTD support programs really do make a difference. It's amazing how much AFTD has accomplished in such a short time. When my husband was diagnosed in 2000 it was a bleak, lonely journey; by the time my son was diagnosed in 2012, support and information were much more readily available. Looking to the future, I see nothing but positive advancements."



named funds and donors



AFTD CEO Susan L-J Dickinson speaks at AFTD's Hope Rising Benefit in March 2022, the first in-person Hope Rising since 2019.



At AFTD's Hope Rising Benefit, AFTD Board member and volunteer Donald Newhouse received the Susan Newhouse and Si Newhouse Award of Hope in honor of his philanthropic commitment to AFTD's mission. (Pictured L-R: AFTD CEO Susan L-J Dickinson, Mr. Newhouse, Hope Rising Benefit Chair David Zaslav, Hope Rising Host Paula Zahn)

AFTD Named Funds honor or memorialize a loved one. Established with a minimum donation of \$25,000, Named Funds are among AFTD's most generous gifts, with donations advancing the science of FTD and improving care and support for people currently living with the disease. AFTD is proud to recognize these individuals and their families for their contributions.

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Established by Kathi and Peter Arnow

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The Mike Walter Catalyst Fund
Established by the Mike Walter Family

AFTD is grateful to everyone who provided support for our mission over the last year. We rely on donations like these to advance FTD research, bring support to families, and raise awareness of this disease.

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Fundraisers

The AFTD-Team hosted 522 grass-roots events and Facebook fundraisers over the past year, raising more than \$781,000 to support AFTD's mission. (All events listed here brought in at least \$1,000, listed in descending order. AFTD is grateful for the creativity, passion, and dedication shown by the entire AFTD-Team!

Independent Events

Nagin Family
IMO Francine Nagin
 Sidoris Family
16th Annual George F. Sidoris Memorial Golf Outing
 Spencer Cline
Babson Men's Basketball
 Kilgallin Family
IHO Carol Kilgallin
 Deb Scharper
5th Annual Crusade for a Cure Golf Tournament
 Matthew Hatfield
Robert M. Hatfield 11th Annual Quest for the Cure Golf Tournament
 Kathryn Nutaitis
Staying out of Trouble for George Grozan
 Paul Lester
15th Annual Letters for Arnette
 Rachel Yost
IMO Lynn Lower
 Jack Yablonowitz
March Madness

Ben Watkins
Trans-Am Bike Race
 Sam Heffron
Half Marathon
 Moretti & Marcy Families
6th Annual CWM Golf Outing
 Deb Scharper
Table Setting
 Alejandro Bolivar-Cervoni
IHO Maria Cervoni
 King Family
5th Annual Tami Sue Golf Outing
 Bill's Best Brewery
 5K
 Papus Keita
Cleveland Marathon



Race Season

Team Jack Attack
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 Kiersten Martin
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Gerda Spears

Debbie Kohl

Peggy Freylack

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Kacy Kunesh

Jayne Getsinger

Janet Timko

Dianna Smith

Nancy Cahill Kolas

Denise Parker

Steven Law

Karen Strobel

Colleen Hoolahan Hall

Anna Lebsock

Cindy Odell

Sandy Perry

Laurie Giannola

Jeanne Bancroft

Alyssa Raine O'Brien

Kristen Nave

Sheryl Lebauer Whitman

Jeffry Borten

Nicole Kane Knepper

Greg Scott Evans

Richard Levine

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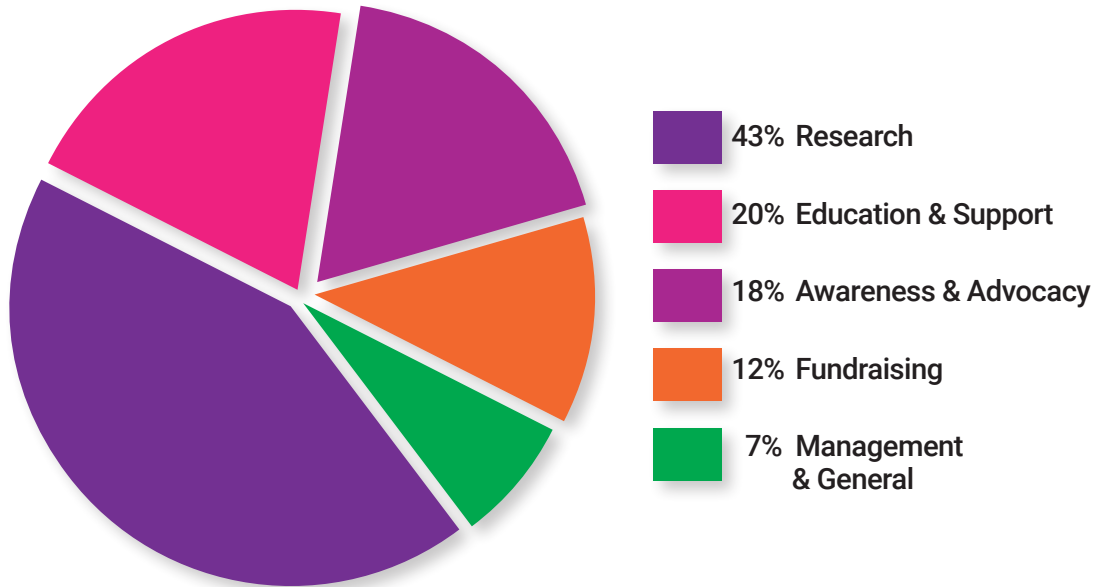
financial reports *fiscal year ending 6/30/22*

Statement of Activities

Revenue and Support

Contributions	\$ 9,971,491
Special Events	\$ 2,150,504
Other Income	\$ 16,706
Total Revenue and Support	\$ 12,138,701
Total Expenses	\$ 8,835,985
Change in Net Assets Before Other Income (Loss)	\$ 3,302,716
Investment Income (Loss)	\$ (3,618,583)
Change in Net Assets	\$ (315,867)

Expenses



Statement of Financial Position

Assets

Cash & Cash Equivalents	\$ 101,450
Contributions & Grants Receivable	\$ 7,867,440
Investments	\$ 36,665,426
Other Assets	\$ 162,653
Total Assets	\$ 44,796,969

Liabilities and Net Assets

Liabilities

Accounts Payable & Accrued Expenses	\$ 324,157
Research Grants Payable	\$ 1,795,659
Other Liabilities	\$ 107,578
Total Liabilities	\$ 2,227,394

Net Assets

Net Assets without Donor Restrictions	
Undesignated	\$ 31,676,938
Board Designated	\$ 2,842,000
Net Assets with Donor restrictions	\$ 8,050,637
Total Net Assets	\$ 42,569,575
Total Liabilities and Net Assets	\$ 44,796,969

The Association for Frontotemporal Degeneration is a 501(c)(3) organization.



outlook

Dear friends,

AFTD enters its third decade with an ambitious new Strategic Plan, a growing staff, and a clear vision for a future free of FTD. This organization was built on a deep reserve of hope, and hope continues to sustain and strengthen both AFTD and the community we serve. As we look to the next year and beyond, we stand ready to continue transforming that hope into meaningful action.

If you have not yet read our new Strategic Plan, which covers the three-year period from July 2022 through June 2025, I encourage you to do so. (You can find it on our website at theaftd.org/about-us/strategic-plan.) Before assembling this plan, we sought opinions from our most important stakeholders – those living with FTD and their loved ones – along with researchers, healthcare professionals, and AFTD’s Board and staff. Based on that input, we worked with careful intention to create a Strategic Plan that is bold, forward-looking, and expansive – while also tightly focused on the aspects of our mission that our community values most.

We know that one of the most frustrating aspects of the FTD journey is difficulty obtaining a correct diagnosis. The need for

disease-modifying treatments grows more urgent every day. In the coming years, we will work to advance FTD diagnosis, therapeutics, and a cure for all. To that end, our Strategic Plan tasks AFTD with deepening our engagement with FTD researchers, finding new FTD-focused scientific investigators to support and collaborate with, and investing in the tools necessary to continue advancing FTD research.

We know that the hardships brought on by FTD are exacerbated by a lack of high-quality care options. Our Strategic Plan calls for AFTD to respond to this dearth of supports by creating new ways for families to connect to FTD-specific resources, particularly those in currently underserved groups (rural, Black, Latinx, AAPI, veterans, and LGBTQ+ communities among them). We will also continue to identify best practices in FTD care and distribute them more effectively to families and healthcare professionals, and to attend specifically to the needs of families facing an FTD-causing genetic variant by disseminating accurate information on genetic risk, counseling, and testing.

We know that too few people are aware of FTD, resulting in greater isolation and struggle for families affected. Over the next three years, AFTD will pursue an advocacy



agenda to ensure that the needs of FTD families are recognized by federal and state lawmakers; take an analytic-based approach to drive greater FTD awareness via our website and social media channels; and further energize and mobilize our incredible volunteer and donor base, while expanding it along the way.

I encourage you to read our entire Strategic Plan yourself. As you have read in this Annual Report, when Helen-Ann Comstock founded AFTD 20 years ago, she was fueled by little more than hope for a world without FTD in it. With your help and ongoing support, AFTD will convert that hope into action, and make that world a reality.

Sincerely,

Susan L-J Dickinson, MSGC
AFTD Chief Executive Officer

AFTD leadership

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CELEBRATING
AFTD's 20th Anniversary



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

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The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE