



Every FTD Story Counts



2023 Impact Report

July 2022 - June 2023





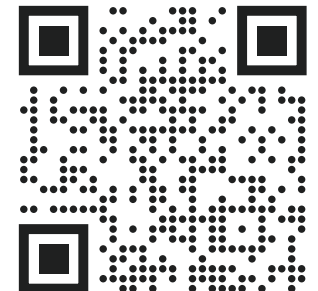
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The Association for Frontotemporal Degeneration

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 theaftd.org



Dear friends,

My FTD story began in 2016, when I first noticed that my mom, Jackie, had begun acting unusually quiet and withdrawn around me. What was going on? Was it stress? Depression? We soon got our answer: FTD. From there, our whole family took action. First, we turned to AFTD to educate ourselves about a disease we knew nothing about – while some cases are genetic, our family has no history of FTD. Then we started fundraising to support AFTD’s mission. We recruited friends and other family members to take on the Philadelphia Marathon’s 8K in my mom’s honor. Even though we’re not a family of runners, we were willing to crawl our way to the finish line if that’s what it took to raise FTD awareness.

I’m telling you this story by way of introduction: I became AFTD’s newest Board Chair earlier this year. But I’m also telling it because my FTD story counts. So does yours. In fact, **every FTD story counts** – and this year’s Impact Report proves that point time and again.

A single story can have long-lasting power. In February, AFTD proudly partnered with the family of beloved actor Bruce Willis to help them share his FTD diagnosis story with the world. Millions who had previously never heard of FTD became driven to learn more about the disease, its impact on families, and the ongoing quest for effective treatments. Traffic to AFTD’s website surged, with 1.2 million visiting in the month after the announcement, and calls and emails to the AFTD HelpLine doubled. For people struggling to understand why their loved ones’ behavior had changed, Mr. Willis’s diagnosis may have offered the final, decisive clue.

Despite a growing global awareness of FTD, misdiagnosis remains a frustrating fact of life for families living with the disease. Increasingly, AFTD devotes our time to sharing the FTD story with doctors and other healthcare professionals; these educational efforts promote quicker diagnoses and care practices that accurately correspond with FTD’s unique symptoms. New AFTD resources – diagnostic checklists for the two most common FTD subtypes, released in English and Spanish versions – allow people experiencing symptoms to more easily explain

their concerns to doctors. And throughout the year, FTD experts have imparted their knowledge in AFTD-hosted webinars offering continuing education credits to healthcare professionals.

Sharing stories can fortify the bonds of community. During our last fiscal year, AFTD convened nearly 1,000 people affected by FTD, both online and in person, for our 2023 Education Conference. I was on hand in St. Louis and saw hundreds of attendees exchanging hugs, words of encouragement, and practical information about FTD care. AFTD staff also spent much of their time connecting with representatives from government and biopharma, telling them the story of FTD and explaining the urgent need for approved treatments. Our community, as always, made their own voices and perspectives heard all year long.

That community has been an immeasurable source of strength for my family since FTD entered our lives seven years ago. While my mom died in 2020, our FTD story isn’t over. AFTD’s Board and staff remain committed to paving the way for a future free of FTD. And we can’t achieve that without a community of volunteers, supporters, healthcare professionals, and families all sharing their valuable stories with the world.

Sincerely,



Kimberly Pang Torres
AFTD Board Chair



Awareness

People and families affected by FTD face years of uncertainty and isolation, as the disease remains too little known and too often misdiagnosed. Raising awareness among medical and care professionals, community stakeholders, policymakers, and the public is vital.

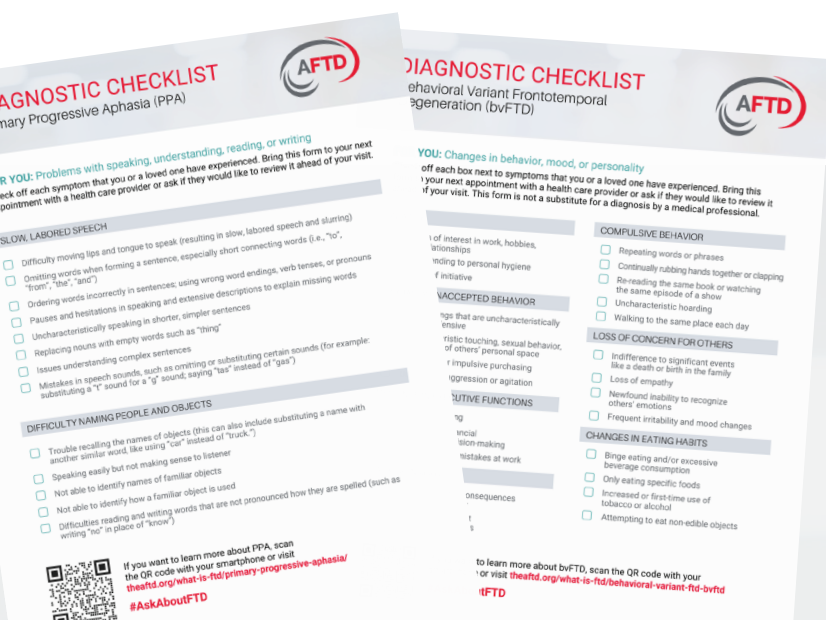
Working with a growing network of dedicated volunteers, AFTD is engaging with more people than ever before and supporting them as they share their stories to promote greater awareness of the urgent needs of the community we serve.

AFTD is proud to partner with World FTD United, a global coalition of FTD organizations, for **World FTD Awareness Week**. For 2022, we launched **#AskAboutFTD** to encourage discussion about symptoms and outreach to healthcare professionals. As part of the campaign,

AFTD created new diagnostic checklists for the two most common variants: bvFTD and PPA.

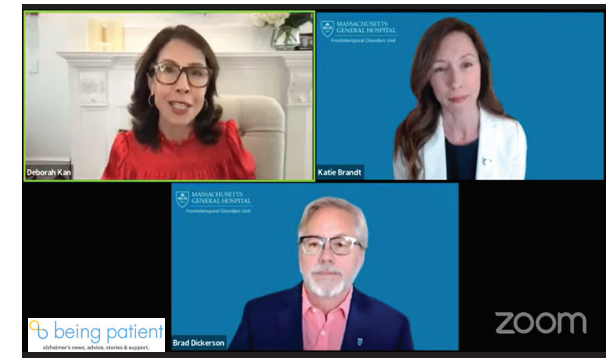
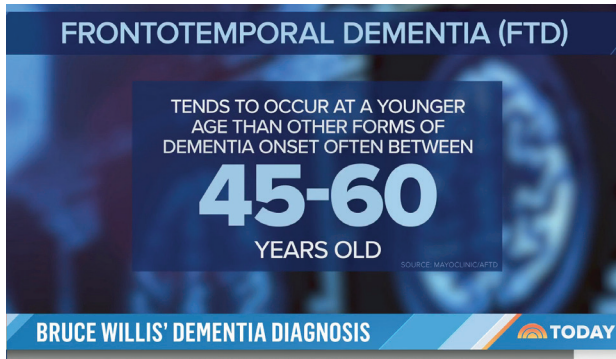
While FTD is misdiagnosed, it is also underdiagnosed. Insights from recent studies, including the 2021 FTD Insights Survey, emphasize the need for targeted educational outreach and increased awareness among under-resourced communities. To expand our current programs and distribution of resources, AFTD established **partnerships with peer nonprofit organizations**, such as the ALTER Program, which partners with African American faith communities to create dementia-friendly and inclusive environments for persons diagnosed and their families, and Lorenzo's House, an organization that empowers youth and families living with young-onset dementia.

To ensure accurate and up-to-date information and resources are accessible to a growing, global community of people impacted, **AFTD's website** can now be viewed in 10 additional languages: Danish, Dutch, French, German, Italian, Polish, Portuguese, Spanish (Mexico), Spanish (Spain), and Swedish.



Diagnostic Checklists

Diagnostic checklists were downloaded **23,275 times** from September 25, 2022 – June 30, 2023. These checklists assist both family members and clinicians with recognizing common symptoms while encouraging earlier referrals to medical specialists.



Throughout the year, AFTD's staff, Board of Directors, Medical Advisory Council, and various community members shared their FTD stories and perspectives across multiple media outlets.

41 Print or Online Publications

- AFTD representatives were quoted nationally and internationally after the Willis family announcement, including in **CNN**, **The New York Times**, **Washington Post**, and the **Daily Mail**.
- Community members were also featured in **The Healthy** by **Reader's Digest** and the American Society on Aging's **Generations**.

15 Radio Appearances

- AFTD's CEO Susan Dickinson joined Andrea Bozoki, M.D., from UNC Chapel Hill for a series of interviews in cities across the country, reaching **11.6 million** listeners.

10 Broadcast Segments

- AFTD's CEO Susan Dickinson appeared on **NBC Nightly News with Lester Holt** on February 16, 2023, reaching **53.4 million** viewers

6 Podcasts

- AFTD Ambassador Deb Scharper was featured on **RAREcast** hosted by the nonprofit Global Genes
- Former caregiver Katie Brandt and AFTD Medical Advisory Council chair Brad Dickerson, M.D., joined Being Patient's **Live Talk**

72 Awareness Interviews

"At the start of our FTD journey, his primary care doctor said he may be dealing with depression. It was such a long and frustrating process to get to a diagnosis because every time you see a new doctor, it's like starting over. **We must bring awareness to where people are and make the information simple so everyday people can easily understand how to get help.**"

- *Malcoma Brown-Ekeogu, care partner to her husband, shared her perspective on seeking an accurate diagnosis in a recent edition of Partners in FTD Care about the Black/African American experience with FTD*

Family of Bruce Willis Shares That He Has FTD

“After our family shared the news, I felt like I wasn’t alone with this anymore,” Emma Heming Willis said. “I felt like I could breathe, and finally seek the support our family needed. I found a community full of people who understand, and I found a chance to make a difference – to help end this disease.”

In February 2023, the family of Bruce Willis announced that he had been diagnosed with FTD.

Thanks to the Willis family’s decision to share their story, global attention brought to the disease generated an unprecedented level of engagement among new audiences, inspiring others to learn more about FTD, seek guidance and support, and raise further awareness.

Since the announcement through June 30, 2023, AFTD’s website was visited by nearly 1.6 million people and our social media audience across multiple platforms has grown by more than 50 percent when compared to last year.

AFTD is grateful to partner with Emma Heming Willis and the rest of Bruce’s family as we work together to raise more awareness about FTD and support all on this journey.



Sisters Diana and Sandra Gonzalez-Morett care for their mom, Diana, who is living with bvFTD. They recently made a film – Pedacito de Carne – to examine the FTD journey from the perspective of a Latina millennial caregiver. Sandra also serves as an AFTD Ambassador.

*“It’s my pleasure to be a resource and amplify these messages because I speak a second language and come from a different culture; it’s important to think and talk about [FTD]. We were always told that my uncle had Alzheimer’s. Culturally, and even as a family, we didn’t talk much about it. **I think about how my mom’s experience might have been different had we known and talked about it.**”*

- Sandra Gonzalez-Morett (pictured right)

AFTD's Growing Audience on Web and Social Media

AFTD continues to attract social media followers, as our audience across Facebook, Instagram, X (formerly known as Twitter), TikTok, YouTube, and LinkedIn grew to 31,861 – a more than 50% increase over the prior year.

Since joining TikTok last September, AFTD's video posts have been viewed 10,266 times, raising awareness with a whole new segment of people.



5,339 Likes

People engaged with AFTD's content



5,135,202 Impressions

Views of AFTD's content by individual users



5,192 Shares

Content shared to raise awareness among new audiences



184,593 Link Clicks

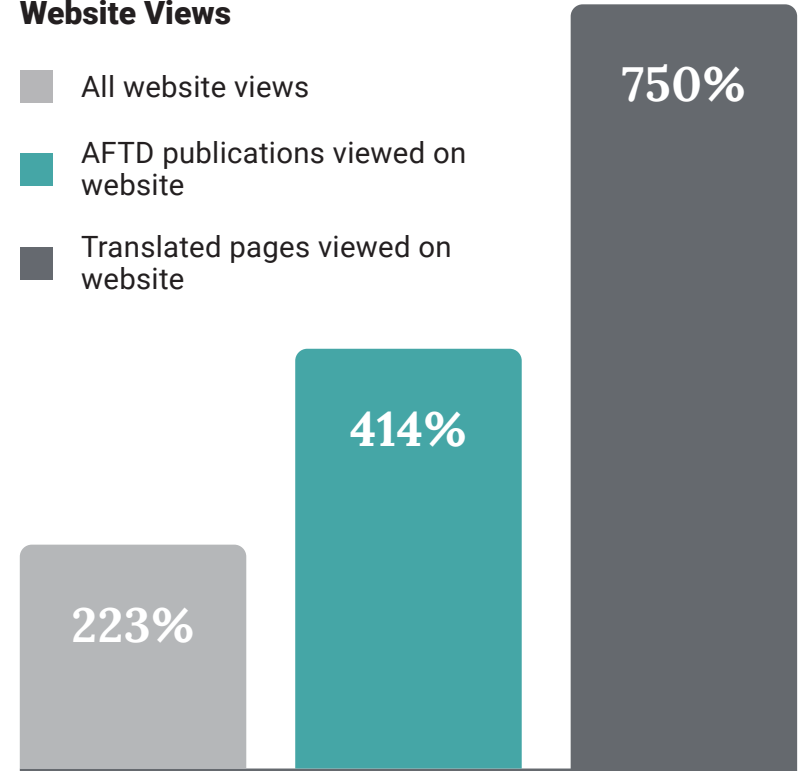
People learning more and getting involved with AFTD's mission

Percent Growth of Website Views

■ All website views

■ AFTD publications viewed on website

■ Translated pages viewed on website



“The more we talk about FTD, the more we can create a dignified space for those who are affected. As more places like schools and police departments become aware of FTD, families will have less traumatic experiences.”

- Diana Gonzalez-Morett (pictured left)

Support

Supporting people on the FTD journey was a primary focus for Helen-Ann Comstock when she founded AFTD over 20 years ago as a former caregiver to her husband Craig.

Today, we continue this important work through our many support programs to improve the quality of life for persons diagnosed, care partners and caregivers, and family members. Guided by input from clinicians, researchers, dementia care specialists, and people living with FTD, we offer a wide variety of resources to provide support for every stage of the disease journey.

AFTD's **HelpLine**, accessible via email and phone, often serves as the first point of contact for people seeking to learn about FTD and options for care and support, and to receive tailored guidance specific to their journey. The HelpLine is monitored by three social workers trained to provide up-to-date information on locating providers with FTD experience, ways to manage FTD's distinct language and behavior symptoms, and accessing community support. To ensure this resource is available to all who need assistance, the HelpLine offers translation services for more than 200 languages.

Named for AFTD's founder, the **Comstock Grant program** helps to alleviate some of the financial burden that comes with an FTD diagnosis. Grants can be used by care partners to tend to their physical and emotional well-being, while persons diagnosed can use the funds to access services or supports that directly address their needs or interests to improve their quality of life. Grants can also assist with the cost of traveling to AFTD's Education Conference or other FTD-related educational events.



3,379 HelpLine inquiries responded to by staff – a **45% increase** over last year.



748 Comstock Grants distributed, worth up to **\$500** each – a **68% increase** over last year.



102 AFTD-trained volunteers facilitating **77 support groups** throughout the United States.



8,965 members finding peer support in AFTD's Facebook group and **469 members** in the Young Adult group.



16,715 *Help & Hope* subscribers – a **24% increase** over last year.

FTD support groups – led by trained and dedicated AFTD volunteers – are a vital resource for the people we serve, providing an opportunity for care partners, family members, and persons diagnosed to share their stories, learn ways to advocate, and gain much-needed coping skills and strategies for navigating a diagnosis. Virtual meeting platforms have enabled AFTD to facilitate support groups that meet diverse needs of people throughout the country.

In response to feedback from community members, AFTD transitioned **Help & Hope**, our digital newsletter, from a monthly publication to a weekly thematic bulletin focusing on topics such as tips and advice, ways to find help and support, current events, community stories, and updates on advocacy, research, and volunteer opportunities.

Approximately 40 percent of FTD cases are understood to be familial, a subset of which is known to be genetic, and this past year, we expanded our **support for families facing a genetic form of FTD**. In November 2022, AFTD welcomed its first Manager of Genetic Initiatives, Kim Jenny, MS, LCGC, who is engaging with those affected by familial FTD to develop and update materials that are responsive to their unique needs.



Bob Meddaugh, Persons with FTD Advisory Council member



2023 Education Conference attendees



David Brotherton is a care partner to his wife, Marybeth, who is living with primary progressive aphasia.

“There’s no reason to hide an FTD diagnosis and not say what it is because that doesn’t help anybody. We wanted to make sure her friends and relatives knew what was going on. **AFTD has been very helpful as we try to better understand the problem.**”

- David

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“In the future, [I wish] that the doctors would know about FTD more. It took a tremendous amount of time to get to a diagnosis.”

- Marybeth

Education

Each year, AFTD's education initiatives help a growing number of people navigate a diagnosis while informing healthcare professionals about FTD's symptoms and how to best care for those living with the disease.

AFTD's 2023 Education Conference was held on May 5 in St. Louis, MO and broadcast online to a global audience. For the first time,

registration was free for all who wished to attend. The agenda featured 20 sessions and 49 speakers, including keynote speaker Bruce Miller, M.D., people with lived experience of FTD, researchers, and healthcare professionals. Recordings from select sessions are available on AFTD's YouTube channel.

■ Health Care Professional ■ Living with FTD ■ Care Partner ■ Family Member/Friend ■ Former Care Partner ■ AFTD Staff & Board

947 total conference attendees from 24 countries

Susan Eissler, an AFTD Ambassador and former care partner, and her son Adrian discussed the power of sharing FTD stories at the 2023 Education Conference.

"I found AFTD soon after my husband's diagnosis and have been involved for the last 15 years. As a volunteer, I've had the opportunity to provide feedback on state legislation regarding FTD and other dementias and I'm seeing a growing awareness of FTD within local dementia organizations. We've come such a long way with the amount of knowledge we have about the disease."

- Susan (right)

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"I was only in high school when we realized that FTD traces back through multiple generations of our family. Now at 43, I'm at the early stage of things. At first, I thought, 'A lot of people are having these issues – it's the middle of COVID' but after some reflection, I realized that I was having the same symptoms some of my dad's family experienced, like anxiety and depression. **With AFTD, I appreciate the resources that show preventive practices to stay as healthy as possible while waiting for helpful drugs and a cure.**"

- Adrian (left)



2,296

Healthcare professionals on AFTD's mailing list
(a **142% increase** over last year)

4,600

Partners in FTD Care subscribers
(a **31% increase** over last year)

5,049

Total views of AFTD's four
accredited Educational Webinars



Connecting at FTD in the Arts



Dr. Bruce Miller

Prior to the conference, we hosted **FTD in the Arts** for members of the community to share creative works inspired by their personal FTD journeys, as well as a networking breakfast for persons with FTD, a yoga class to promote mindfulness and relaxation, and a session on familial FTD and emerging clinical trials.

Resources for Healthcare Professionals

For live attendees of our **Healthcare Professional Education Series** webinars, AFTD offers continuing education credits and continuing medical education credits, which are necessary for healthcare professionals to maintain their licenses and certifications to practice. AFTD presented four accredited webinars focused on person-centered care for various FTD disorders, differentiating symptoms and diagnosing, and developing non-pharmacological care management protocols.

Geared toward educating the medical community, **Partners in FTD Care** highlights FTD's unique symptoms and progression. In the past year, this triannual newsletter addressed topics such as what assistance families need after receiving a diagnosis and how to transition a person living with FTD into a long-term care facility.

Resources to Improve FTD Care

To inform and assist care partners with navigating an FTD diagnosis, AFTD offers an **extensive and growing library of resources**, including awareness cards, healthcare provider letters, and checklists to help recognize possible symptoms and coordinate an approach to address concerns and challenges, including aggressive behavior.

Advocacy

People who are personally impacted by FTD are the most powerful voices in advocating for earlier and more accurate diagnosis, advancements in treatments, and improved access to care management and support options, and in reducing the stigma that often comes with a diagnosis.

Together AFTD staff, Board members, volunteers, and the community we serve are raising critical awareness about the needs of all who face this disease and ensuring FTD remains a priority in policy discussions centered on all forms of dementia.

Seven members of AFTD's staff serve on **national-level committees and working groups** to ensure the lived FTD experience is included in discussions on how to accelerate research, improve access to diagnosis, allocate resources, develop models of dementia care, and improve the quality of life for persons diagnosed, care partners, and families. These stakeholder assemblies are sponsored by organizations such as the National Institute of Aging, the Milken Institute, and the National Institute of Neurological Disorders and Stroke, among others.

In the past year, many FTD advocates, including several AFTD Ambassadors, have **engaged with their state's representatives**. Former Ambassador Corey Esannason met with staff from New York Senate Majority Leader Andrea Stewart-Cousins's office where she discussed distinctions between FTD and Alzheimer's and advocated for the need to include FTD and related dementias in discussions on funding for services and resource provisions.

AFTD staff and Board members met with New York State Senator Cordell Cleare to inform the senator and her staff about the Biomarker Evaluation in Young Onset Dementia and Diverse Populations (BEYONDD) study, which aims to address the under-inclusion of diverse populations in research and clinical care for young-onset dementias like FTD.



AFTD staff, Board members, and volunteers with New York State Senator Michelle Hinchey

“We need increased awareness to help people and their families understand what they are up against and to encourage a stronger understanding of FTD in our medical community. **When my father was first diagnosed, AFTD was an extraordinary resource for my family.**”

- An excerpt from Senator Michelle Hinchey's speech shared on the New York State Senate floor as she recalled Resolution 992, marking FTD Awareness Week in the state. Her father, former U.S. Rep. Maurice Hinchey, had primary progressive aphasia and passed away in 2017.

The **Persons with FTD Advisory Council** is designed to ensure the insights and voices of people living with FTD are included in the development of AFTD’s policies, programs, and services. Today, seven Council members collaborate with Advocacy Manager, Matthew Sharp, MSS, on incorporating the Council’s perspective as we update, refine, or create new tools and resources, such as the Comstock Quality of Life grants. The Council also provides input on programming for the annual Education Conference and regularly contributes to *Help & Hope*.

During the 2023 Education Conference, the Council delivered a pre-recorded plenary presentation, *Being Thankful in Our Own Words*, examining the role that care partners, family, friends, and strangers have in ensuring people living with FTD are respected as individuals while preserving their dignity and autonomy.

Council members at the 2023 Education Conference, where they hosted a session for others living with FTD to connect and learn effective strategies for navigating a diagnosis.



At a recent National Alzheimer’s Project Act (NAPA) Advisory Council Meeting, AFTD Ambassadors Terry Walter and Katie Zenger shared their stories to help educate federal officials on FTD.

“Our journey started in 1981 when my husband’s mother was diagnosed with ALS. Eventually, many in my husband’s family had a diagnosis of ALS or FTD. Now, we’ve had 26 years of this disease. Even though we didn’t know what was going on at the time, we still had each other. **I think of people who live in smaller communities with no support, and that’s what drives me to continue spreading awareness.**”

- Terry (top)

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“When it comes to having an awareness of what FTD is, we need to break the assumption that dementia equals Alzheimer’s. It’s critical for me to use the networks that I have to improve understanding of the disease and increase services for loved ones and caregivers. **If I can help make this journey a tiny bit easier for another family to come together to get through it instead of breaking apart, I will have done something good with my life.**”

- Katie (bottom)

Volunteers and the AFTD-Team...

Over twenty years ago, AFTD was founded by a group of volunteers to make this journey better for the next family. Today, our national volunteer network is essential to driving AFTD's mission – each action vital to raising awareness in communities throughout the country, supporting others who are navigating a diagnosis, conducting educational outreach to healthcare professionals, advocating for treatments and accessible care and support options, and raising funds to support this work.

The 2022-2023 **AFTD-Team Race Season** saw team members participate in marathons, half-marathons, 5Ks, and more, raising funds and vital awareness across the country. AFTD was represented at races in Austin, Dallas, Denver, Los Angeles, Philadelphia, and New York.

In Fall 2022, AFTD held its 10th annual **Food for Thought** campaign, supporting volunteers from 20 states (plus Canada and Ecuador) to educate their communities about FTD while raising funds to support our mission.

Supporters joined AFTD for our annual **Driving Hope Golf Tournaments** held at the Metropolis Golf Club in White Plains, New York and at the Colorado National Golf Club in Erie, Colorado in August 2022. The tournaments honor all who are affected by FTD while raising funds to advance AFTD's mission. Together, these events raised more than \$132,000.

Every February, the **With Love** campaign features stories shared by care partners, caregivers, family members, and friends, showing how love sustains people as they navigate an FTD diagnosis. Paying tribute to loved ones, each story increases awareness of the lived experience of this disease while raising funds to drive our work.

Many volunteers also hosted their own **independent fundraisers** to advance AFTD's mission, including golf tournaments, galas or benefit dinners, bike rides, and other marathons outside of the AFTD-Team.



AFTD's Ambassadors at their annual summit. To learn more about these volunteer leaders, visit theaftd.org/about-us/aftd-ambassadors.



Staff and Board members honored nearly 80 volunteers at our third annual Volunteer Appreciation Dinner.

362 volunteers helped advance AFTD's mission.

15 Ambassadors representing **13 states** took part in **50 awareness activities**, including media appearances, political advocacy events, fundraisers, and healthcare professional education opportunities.

\$855,854 raised by **540 fundraising events**.

Food for Thought

\$159,090 raised through **44** events

With Love

\$48,914 raised through **41** virtual fundraisers

AFTD-Team

\$129,876 raised by **168** participants across **6** races

Independent Events

\$297,596 raised by **44** fundraising events



Shelby Buckley on Mt. Denali



AFTD-Team, Philadelphia Marathon



Sharifnia Family, Colfax Marathon



Ball to End Dementia



“I was at a very low place when I found AFTD, and I didn't know how much I needed it until I found it – being a part of this organization saved my life. As a volunteer with AFTD, it makes me feel good when we're raising funds for things like the Comstock Grant program to help people – knowing that impact can make you feel like you're a part of something bigger than yourself.”

- Jennifer Morabito, an AFTD Ambassador and former caregiver for her mom

Research

As a leader in advancing the science of FTD, AFTD works with a diverse, global community to further the discovery of biomarkers and the development of effective therapies. We also inform a growing network of researchers and clinicians about the needs of people living with FTD, while empowering all who are impacted to become informed volunteer research participants.

Building on the FTD Treatment Study Group, the **FTD Research Roundtable** launched in January 2023 as a pre-competitive forum where stakeholders engaged in FTD-focused drug development, including representatives from industry and regulatory agencies, work to identify and overcome barriers and propose best practices for designing clinical trials requiring fewer participants. To date, 16 companies have joined the Roundtable, underscoring the need for collaboration and an increased investment in neurodegenerative research.



AFTD Board member Kristin Holloway with Holloway Postdoctoral Fellow Julia Faura Llorens, Ph.D., and AFTD MAC member Rosa Rademakers, Ph.D., at the 2022 International Society for Frontotemporal Dementias conference in Lille, France.

“We need to have a multifaceted approach to the treatment of FTD. [There is] room for nonpharmacological interventions to complement and possibly enhance the effects of current medications. In many cases, individuals are dealing with decades of accumulated protein aggregates. Even if the medication is able to clear pathological aggregates, the neural circuits would have been significantly altered by the disease. So, our hope is that by harnessing the brain’s plasticity, we can restore functionality in regions affected by the disease.”

- Alexandru Iordan, Ph.D., recipient of a Well-Being in FTD Pilot Grant

“My research is focused on identifying early evidence of brain degeneration due to FTD by exploring innovative measures. I previously developed a 15-minute virtual reality game designed to measure social cognition in people living with FTD and those who are at risk of developing the illness. **I spoke to AFTD staff and learned about the grant, which we are currently using for the next phase of our research:** evaluating the game to see if it's working effectively and using what we learn to create a virtual reality version.”

- Jackie Poos, Ph.D., recipient of a 2023 Holloway Postdoctoral Fellowship

Three AFTD-funded researchers spoke at the 2023 Education Conference about the value of sharing the lived experience of FTD with the research community.



Since 2021, the Holloway Family Fund has enabled AFTD to expand our Postdoctoral Fellowship program and establish the **Holloway Summit**, an annual meeting designed to convene global leaders in FTD-focused research to propose solutions for therapeutic development.

Building on the knowledge that the *C9orf72* mutation can cause both FTD and ALS, AFTD, with support from the Holloway Family Fund, has **partnered with The ALS Association** to launch the Digital Assessment Tools for FTD and ALS Awards to drive collaborative digital tool development at the intersection of both diseases. This technology enables researchers to collect data remotely, reducing the need for people living with a diagnosis to visit specialists in person for evaluation.

In collaboration with the FTD Disorders Registry, AFTD presented three **Perspectives in FTD Research** webinars on topics exploring different types of research studies and ways people affected by FTD can engage with researchers to advance therapeutic development. Recordings of the webinars can be viewed on AFTD's YouTube channel.

AFTD hosted the *Familial FTD: Resources, Needs, and Emerging Opportunities* session at our 2023 Education Conference, with attendees affected by familial forms of FTD and representatives from biopharma. Five companies with active clinical trials presented information on their approach to treating the disease and audience members emphasized the urgent need for treatment options.

The **FTD Disorders Registry**, co-founded by AFTD and the Bluefield Project to Cure FTD, provides a safe and secure platform for persons diagnosed, caregivers, and family members to share their unique experience of FTD with the research community. As engaging with researchers is vital to therapeutic development, the Registry also serves as a resource for people affected to learn about opportunities to participate in studies seeking volunteers.

Awards and Grants

2023-2025 Holloway Postdoctoral Fellowships

- Marc Shenouda, Ph.D., "Targeting TDP-43 aggregation as therapeutics for ALS/FTD." Canada
- Jackie Poos, Ph.D., "Virtual reality social cognition game for preclinical frontotemporal degeneration." Netherlands

Accelerating Drug Discovery for FTD

Awarded in partnership with the Alzheimer's Drug Discovery Foundation (ADDF)

- Ana Martinez, Ph.D., and Ankar Pharmaceuticals, "TTBK1 Inhibitors as a new therapeutic approach for FTD and other related disorders." U.S.
- Robert Williams, Ph.D., and Pelagos Pharmaceuticals, "Selecting lead candidate REV-ERB agonist for the treatment of FTD." U.S.

Clinical Research Training Scholarship

Awarded in partnership with the American Brain Foundation and American Academy of Neurology

- Tanav Popli, M.D., "Personalized HD-tDCS in primary progressive aphasia." U.S.

Diagnostics Accelerator

Awarded in Partnership with ADDF

- Matthew Pase, Ph.D., "Plasma neuroinflammatory biomarkers for the diagnosis of dementia subtypes." Australia

Pathways for Hope Pilot Grant

- Steven Boeynaems, Ph.D., "Aberrant protein condensation as a driver of neuroinflammation in ALS/FTD." U.S.
- Daniel Mordes, M.D., Ph.D., "Defining the role of TBK1 loss-of-function in FTD." U.S.

Well-Being in FTD Pilot Grant

- Alexandru Iordan, Ph.D., "Social network modulation in behavioral variant frontotemporal dementia." U.S.

To learn more about these and other funded projects, visit the Grants Portfolio section on AFTD's website.



Alexandru Iordan, Ph.D.



Rhoda Au, Ph.D.



Jackie Poos, Ph.D.



6,081 Registry participants as of June 30, 2023 – **1,486** of whom are diagnosed with FTD and **2,588** who self-identified as biological family members.

Named Funds.....

Established with a minimum of \$25,000 through individual donations and fundraising efforts, **AFTD Named Funds** honor or remember a loved one. AFTD is proud to recognize these individuals and families, and their generous contributions to advance our shared mission.

The Dr. Lawrence Albert Memorial Fund

Established by Kathi and Peter Arnow

Kevin M. Harvey Memorial Fund

Established by The Connecticut Frontotemporal Dementia Foundation, Inc. via the Harvey Family

The Suzy Fund

Established by the Newhouse Family

The Lynn Surprenant Memorial Fund

Established by the Simonson/Surprenant Family

The Trish Bellwoar Fund

Established by Steve Bellwoar

The Holloway Fund for Help and Hope, in Honor of Lee Holloway

Established by the Holloway Family

The Jackie Pang Memorial Fund

Established by the Pang and Torres families

The Stephen C. Swid Fund for Education & Care

Established by Nan Swid

Joseph C. Fry Memorial Fund

Established by Virginia Fry

Laden Memorial Fund

Established by the Laden Family

Shepherd/Stowell Fund In Honor of Care Partners

Established in tribute to all Care Partners and Caregivers

The Mike & Beth Walter Family Fund for Genetic FTD Initiatives

Established by the Mike Walter Family

Hope Rising Benefit - March 14, 2023



LEFT: CEO of Warner Bros. Discovery David Zaslav, and AFTD Board members Kathy Newhouse Mele and Donald E. Newhouse with Emma Heming Willis.

CENTER: Mr. Newhouse with AFTD Board member Kristin Holloway, recipient of the 2023 Susan Newhouse and Si Newhouse Award of Hope for her commitment to furthering FTD research.

RIGHT: AFTD Board member Rita Choula delivering the evening's keynote speech.

Donors

We are grateful to everyone who chooses to make a gift to support AFTD's mission. Donations drive every aspect of our work to support persons diagnosed and care partners, advance innovative research, educate healthcare professionals, and vastly increase FTD awareness around the world.
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“Having an organization that recognizes, understands, and is supportive of this journey – no matter what was going on – when the rest of the world was not understanding...it’s been priceless.”

– Anna Kuykendall, former caregiver and current AFTD volunteer

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“My husband’s journey began in February of 2017, and it’s been very rocky ever since. It has been an insidious journey because this illness robs a person of much of who they were. **When I found AFTD in 2022, it really was a lifeline. The Comstock Quality of Life and Respite grants were really a blessing.**”

- Ann H., care partner for her husband who was diagnosed with bvFTD at the age of 55.

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Our recurring donors, who have generously committed to donate to AFTD on a monthly or annual basis, help sustain our work throughout the year, bringing help & hope to all who face FTD.

**Denotes \$1,000 or more given through recurring donations in FY2023.*

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“The support groups were incredibly helpful. It’s not like you can get that kind of advice from just anybody.”

– Jason Fehon, whose father Bill had FTD.

Fundraisers

Members of our community hosted 549 fundraisers over the past year, raising awareness and vital funds to support AFTD's mission. We are grateful for the creativity, passion, and dedication shown by these volunteers!

**All fundraisers named here raised \$1,000 or more, listed in descending order.*

Independent Events

The Delapré Family
Hope in Color

The Sidoris Family
17th Annual George F. Sidoris Memorial Golf Outing

Christin Rose
1st Annual Kim Rose Cure for Dementia Golf Outing

Denise Lange & Shannon Fuller
St. Paddy's Day Party with a Purpose

Bob Powers
Chasing Rainbows

The Pfeifer Family
In memory of Cathy Pfeifer

Deb Scharper
6th Annual Crusade for a Cure Golf Tournament

Christian Clark
GoFundMe

Spencer Cline
Babson Men's Basketball

Tara Simonson
Brooklyn Half Marathon

Paul Petras
Labor Day Run

Todd Hartzog
Dustin Snyder Memorial Golf Outing

Matthew Hatfield
The Robert M. Hatfield 12th Annual 2022 Golf Tournament

The Moretti & Marcy Families
7th Annual CWM Golf Outing

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100 for 100

Edwin Pagan
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Susan Gotsch
Flying Pig Marathon

Soraya Sharma
Ball to End Dementia

The Pondelli Family
Team AI 2023 Disney Princess 1/2 Marathon

Paul Lester
16th Annual Letters for Arnette

Tribute Fundraisers

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In memory of Virginia McParland

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In honor of Ravi Kumar

The Fry Family
In memory of Joseph C. Fry

Alicia Camarillo
In memory of MJ Camarillo

Brooke Floyd
In memory of Betty Jane Houtz (Burgess)



“AFTD has made a lot of difference. The support we’ve received has taken away a lot of the loneliness, and I feel that I have more hope right now than I have had in the previous year and a half since being diagnosed – it’s meant so much to be able to talk to people at the organization and receive help.”

- Linda Dunagan, who is living with bvFTD

The AFTD-Team



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Sally Mauck
Elica Sharifnia
James Staten
Patrick Mele
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Team Jack Attack
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Susan Eissler
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“In every family where dementia or Alzheimer’s diagnoses are thrown around, you’re left in unknown territory until you get involved and really begin to understand what you can do for your children and grandchildren. When Helen-Ann Comstock founded AFTD, it changed my life. I saw passionate people who were committed to using every dime that came through the door to solve the problem. **AFTD is playing a role in the future of all of our families.**”

- Wanda Smith, whose family is affected by FTD. Wanda is committed to sharing her story to raise awareness and drive engagement in research, which she believes is vital to discovering treatments and interventions targeting the disease.

Financial Reporting

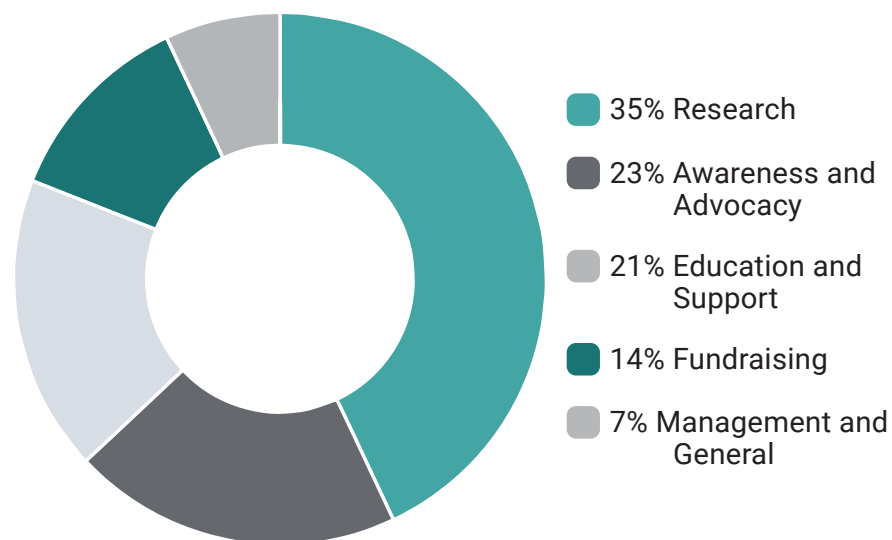
Fiscal year ending 6/30/2023

Statement of Activities

Revenue and Support

Contributions	\$7,035,647
Special Events	\$1,803,277
Other Income	\$43,029
Total Revenue and Support	\$8,881,953
Total Expenses	\$9,972,711
Change in Net Assets before Other Income (Loss)	\$(1,090,758)
Investment Income (Loss)	\$3,576,147
Change in Net Assets	\$2,485,389

Expenses



Statement of Financial Position

Assets

Cash & Cash Equivalents	\$288,666
Contributions and Grants Receivable	\$5,362,244
Investments	\$41,012,688
Other Assets	\$806,747
Total Assets	\$47,470,345

Liabilities and Net Assets

Liabilities

Accounts Payable & Accrued Expenses	\$496,632
Research Grants Payable	\$1,052,178
Other Liabilities	\$866,571
Total Liabilities	\$2,415,381

Net Assets

Net assets without donor restrictions

Undesignated	\$34,732,656
Board designated	\$2,178,649
Net assets with donor restrictions	\$8,143,659
Total Net Assets	\$45,054,964
Total Liabilities and Net Assets	\$47,470,345

Message from the CEO.....

Dear friends,

February 16, 2023 was a day unlike any in AFTD's history. When the Willis family made the bold, brave decision to go public with Bruce Willis's FTD diagnosis, they forever changed the landscape in which our organization and our community operate. With FTD suddenly headline news, persons diagnosed who once struggled to explain their symptoms could now tell people they are living with the same disease as Bruce Willis. Families who had been unable to understand their loved ones' behavioral and personality changes could find answers in articles and news clips from mainstream media sources. AFTD has long known that a single story can spark a profound change, and this past year proved it. **Truly, every FTD story counts.**

Over the next year and beyond, AFTD will build on the momentum the Willis family began when they so generously shared their story. Because of them, awareness of FTD is greater than ever before. Yet families still wait years for an accurate diagnosis. High-quality, compassionate FTD care remains elusive for many. And of course, there are currently no effective treatments, and no cure – but momentum is growing there as well.

AFTD is making significant strides in advocacy. In September 2023, we launched our AFTD Advocacy Action Center, allowing registrants to communicate directly with members of Congress with the click of a button. More than 150 people signed up to become an AFTD advocate within hours of the Action Center's launch, and – under the guidance of our first-ever Director of Advocacy and Volunteer Engagement, Meghan Buzby – we look forward to mobilizing our powerful, compassionate community to advocate for better care and more funding for research.

Research, of course, is what will one day produce the first approved treatments for FTD. AFTD will continue to grow our relationships with biopharmaceutical companies, government agencies such as the Food and Drug Administration, and our nonprofit partners to ensure that the development and testing of these treatments advances as swiftly and efficiently as possible. AFTD events such as the Research Roundtable and the Holloway Summit have already started important conversations among these sectors. Numerous clinical trials are underway, and we have great hope they will result in the type of breakthrough AFTD has been working toward for over two decades.

Our community is ready to participate in research. Our community is ready to advocate – for ourselves and on behalf of future FTD families. Our community is ready to tell the story of FTD, because when we share our stories, we change the future. Every FTD story counts.

Sincerely,



Susan L-J Dickinson, MSGC
AFTD Chief Executive Officer



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