From Hope to Action:

AFTD's 2022–2025 Strategic Plan

July 2022 through June 2025

Approved by AFTD's Board of Directors, March 9, 2022

Dedication

This plan is dedicated to people and families facing FTD. We honor the resilience and determination of all whose lives are affected by this disease today. We work in memory of all who have been lost, holding hope for a better future, for everyone we serve.

Table of Contents

Acknowledgements

Support from AFTD's community makes our work possible. Special gratitude is due to Leadership Supporters for this plan: Donald Newhouse and the Samuel I. Newhouse Foundation, The David Geffen Foundation, Kristin Holloway, and David and Weezie Reese. Each have dedicated $1 million or more to support AFTD's work over the next three years. We are grateful for all who support this mission!


Susan L-J Dickinson

Introduction: A Letter from AFTD's Board Chair and CEO


David Pfeifer

Dear Friends,

Twenty years ago, Helen-Ann Comstock founded the organization we now call AFTD, The Association for Frontotemporal Degeneration, after losing her husband Craig to FTD.

Helen-Ann knew too well the grief of an FTD journey, and sensed that thousands of families across the country were struggling in the face of a diagnosis. She also knew that the scientific community was unlikely to devote the necessary resources to FTD research until a national organization dedicated entirely to this disease advocated for it. Driven by a fervent hope for a better future for all facing FTD, she took action. She rolled up her sleeves, found like-minded volunteers, and founded our organization.

Two decades after AFTD's founding, our latest Strategic Plan – developed with input from persons diagnosed, care partners, researchers, healthcare professionals, and AFTD volunteers — charts a clear course to advance a world with compassionate care, effective support, and a future free of FTD.

Over the next three years, AFTD will rally a community to advance earlier, more accurate FTD diagnosis. We will fund, convene and inform researchers in their quest for viable treatments. We will help to ensure responsive, quality FTD care by educating healthcare professionals about symptoms and care approaches. And we will actively support families navigating an FTD diagnosis — including those facing a genetic variant form of this disease – with the best possible information and helpful resources.

We will raise awareness of FTD at an even broader scale – not just nationally, but globally. And we will strengthen our organization by making strategic hires in key new positions, all aimed at hastening a world without FTD.

AFTD has been community-driven since our founding. This plan can only be successful with your involvement. Whether you lead (or simply participate in) a support group, make a donation, start a fundraiser, host a table setting, participate in research, or share your FTD story – any steps you choose to take can help others in our community, and transform hope into action. We will be working alongside you every step of the way.

Sincerely,

Susan L-J Dickinson, MSGC
CEO, AFTD

David Pfeifer
Board Chair, AFTD

What Is FTD?

By 2050, dementia will affect more than 153 million people worldwide, up dramatically from 57 million in 2019 (*Lancet Public Health*, 2022). The most common cause of dementia for people under 60 is frontotemporal degeneration (FTD).

Frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration, or Pick's disease, FTD causes progressive changes in behavior, personality, language, and movement. Most cases occur between 45 and 64, bringing devastating personal and economic impacts to parents raising young families, and people at the height of their careers.

In 2011, FTD's estimated U.S. prevalence was around 60,000 cases (Knopman, D. S., & Roberts, R. O.). However, because FTD remains far too little known today—even to health professionals—these numbers are likely an undercount.

FTD is frequently misdiagnosed as Alzheimer's, depression, Parkinson's, or a psychiatric condition. Accurate diagnosis takes an average of 3.6 years. Even then, families in many communities learn that support and care options are limited. That there are no disease-modifying treatments. That there is no cure, and no way to prevent this devastating brain disease.

According to the National Organization for Rare Disorders, there are more than 7,000 rare diseases, impacting more than 30 million people in the U.S. alone. While FTD is classified as a rare disease – and addressing it comprehensively could offer a model to benefit many facing other rare diseases – the families that AFTD serves know that until it is cured and prevented, FTD can never be rare enough.

Each case of FTD is different. Prevalent forms include behavioral variant FTD, primary progressive aphasia, ALS-FTD, progressive supranuclear palsy, and corticobasal syndrome, each with distinct presenting symptoms, which evolve over the course of the disease.

One thing that families facing FTD hold in common is hope for a better future, for a world with compassionate care, effective support, and a future free of this disease. Addressing FTD can also hold the key to ensuring more accurate diagnosis, prevention, treatments, and a cure for other forms of dementia and neurodegenerative disease.

Through this Strategic Plan, AFTD seeks to bring the hope of our community, and of so many around the world, to action. We welcome your partnership in making that work possible.

From Hope to Action

AFTD's Vision, Mission, and Values

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 2022–2025 Strategic Plan: Four Goals

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

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

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

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

Strategic Themes

To inform creation of this Strategic Plan, AFTD conducted 16 key informant interviews, four focus groups, a survey of Board and staff, a comparative analysis of other leading disease-focused organizations, and a community survey. Major themes emerged during this discovery and validation process, forming the basis of our strategic plan.

Theme	Description
Leveraging the unique role AFTD can play in advancing research	Convening; collaboration; consensus-building
Building a community of empowered and engaged research participants	Whose perspective informs research design and government regulators
Educating health professionals	To enable access to an accurate FTD diagnosis and knowledgeable, appropriate care
Informing and supporting families facing a genetic variant that causes FTD	Providing information; creating a supportive community; enabling research participation
Expanding our reach by scaling existing programs	With an emphasis on currently underserved communities
Creating new mechanisms and programs for connection and support	For people with FTD and care partners
Enabling our community to advocate for and drive change	Empowering our community through advocacy campaigns, speaking engagements, and other volunteer programs
Enhancing AFTD's engagement with stakeholders	Refining AFTD's data systems to tailor engagement to the needs of each individual and family we serve
Ensuring the sustainability of an expanded organization	Adding staff to better channel volunteer and donor engagement, better collaborate with other organizations to advance research, and drive support and education
Strengthening infrastructure	Staff engagement and professional development; data structures and security; systems and processes that create efficiencies in how we work; measuring our impact

From Hope to Action

Strategic Plan Goals

Goal 1:

Advance diagnosis, therapeutics, and a cure for all.

Goal 2:

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

Goal 3:

Advance awareness of FTD, and expand AFTD’s national and global reach.

Goal 4:

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

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

Strategic Plan Detail by Priority Area

Priority 1: Diagnosis and Treatment

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

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 3.6 years to get an accurate diagnosis. Compounding this challenge, there are currently no approved disease-modifying therapeutics for FTD.

Objective 1.1: Foster a diverse, global community of FTD-focused scientific investigators with a 10% annual increase in the points of contact with investigators.

Strategies

1.1.1 Fund researchers to recruit and retain talent in FTD research.

1.1.2 Foster environments for collaboration, training, and networking for FTD researchers.

1.1.3 Encourage dialogue across relevant disciplines and stakeholders.

Objective 1.2: Expand, inform, and empower a research-ready community through five new or strengthened initiatives annually.

Strategies

1.2.1 Strengthen and expand the FTD Disorders Registry as a resource to engage and educate the community.

1.2.2 Enable and empower the community to make informed decisions about participation in research.

1.2.3 Continue to learn and document the diverse experiences and perspectives of the FTD community and its underserved populations to inform research design.

1.2.4 Advocate for research approaches that reflect the needs and values of the FTD community.

1.2.5 Inform regulatory bodies of the needs and values of the FTD community.

Objective 1.3: Develop or strengthen five tools and resources needed for FTD research to succeed.

Strategies

1.3.1 Strengthen and expand the FTD Disorders Registry as a key partner for FTD research.

1.3.2 Promote responsible, equitable, enduring access to quality data, research tools and resources.

1.3.3 Support development of biomarkers and clinical outcome measures for use in FTD care and research.

1.3.4 Foster consensus around best practices across U.S. and international research.

Objective 1.4: Accelerate and broaden research approaches to address unmet needs in FTD research, with ten approaches invested in by June 2025.

Strategies

1.4.1 Partner to leverage expertise and resources from related fields.

1.4.2 Accelerate progress by investment in emergent and existing research programs.

1.4.3 Support novel strategies and underutilized approaches for FTD research.

Objective 1.5: Increase the number of physicians who recognize FTD as a neurodegenerative disease and who refer to a neurology specialist.

Strategies

1.5.1 Develop criteria and recognition for clinical sites that provide accurate FTD diagnosis or referral to appropriate FTD centers (e.g., FTD Centers of Excellence designation).

1.5.2 Develop partnerships with professional organizations, academic institutions, CME/CEU providers and others to deliver FTD information and education.

1.5.3 Develop targeted resources and tools to address the unmet educational needs of multiple healthcare disciplines (physicians, nurses, long-term care staff, social workers).

Qinwen Mao, MD, PhD, recipient of an FTD-focused award through ADDF's Diagnostics Accelerator initiative

Dr. Mao focuses her work on developing a plasma biomarker that can accurately diagnose individuals with TDP-43-associated FTD, and effectively differentiate tau-associated FTD, Alzheimer's disease, or 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. 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."

Priority 2: Quality Care and Support

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

The disruption and isolation so often brought on by FTD are heightened by a profound lack of high-quality care and support options.

Objective 2.1: By 2025, facilitate the development of a framework to identify and disseminate promising practices in FTD care and support.

Strategies

2.1.1 Establish a task force of key stakeholders (professionals, care partners, persons with FTD) to guide this work.

2.1.2 Continuously identify, evaluate, and catalogue promising practices in FTD care.

2.1.3 Define and implement the best dissemination options to reach primary audiences: healthcare providers and families including persons with FTD and care partners.

2.1.4 Ensure stronger inclusion of multidisciplinary FTD care experts in AFTD's professional advisory committees.

Objective 2.2: Scale current programs and services to reach more people and underserved communities (including rural, Black, Latinx, AAPI, Veterans, LGBTQ+).

Strategies

2.2.1 Build awareness among AFTD staff in culturally responsive dementia care and provide ongoing staff training.

2.2.2 Integrate culturally responsive services into current and new support and education programs and services.

2.2.3 Identify and partner with established coalitions and allied groups for each community to understand their needs and educate them about FTD.

2.2.4 Identify and engage champions within each community, including professionals and volunteers.

2.2.5 Expand HelpLine resources and infrastructure to improve responsiveness to community needs.

Objective 2.3: Develop and provide a menu of supports and services that are responsive to the needs of families facing a genetic variant that causes FTD.

Strategies

2.3.1 Deepen AFTD's understanding of information and support needs of people who are at risk, mutation positive, and mutation negative.

2.3.2 Continue to improve and expand upon information AFTD offers on genetic risk, counseling, and testing.

2.3.3 Implement programs to meet needs that genetic-variant facing families identify as priorities.

2.3.4 Empower and enable family members to engage in ways they desire to make a difference.

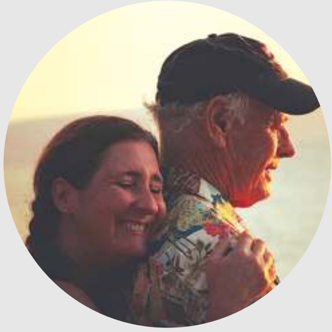
Objective 2.4: Increase the number of ways people can connect to support and resources, more quickly.

Strategies

2.4.1 Develop a tool, or tools, to enable access to consumer-recommended, FTD-knowledgeable local resources.

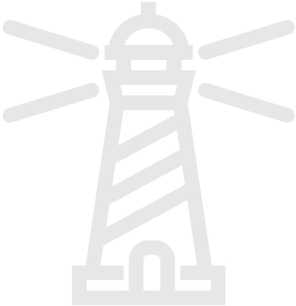
2.4.2 Expand digital and online support options for persons living with FTD and care partners. Capture metrics on use of social media, website, online groups, and other technologies.

2.4.3 Expand the number and type of volunteer roles and activities that provide diversified support options for people with FTD, care partners, and family/friends.



Melissa Fisher, FTD care partner and AFTD Ambassador, with her dad

“I'm so passionate about advocating and raising awareness of this disease because I don't want anyone to go through the nightmare my family did. This disease touches the collective – from the person diagnosed with FTD, to care partners and caregivers, family members, and the community. Right now, the systems in place to help people get an accurate diagnosis and plan for appropriate care are failing to adequately address the needs of people with dementia. If not for AFTD, families would be left entirely alone to deal with this disease. We need to fight for better – I hope in the future that improved diagnosis, treatment plans, and support options will extend to all who face FTD.”



Priority 3: Awareness and Engagement

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

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.

Objective 3.1: Increase awareness of FTD each year, as measured by analytics and trend data.

Strategies

3.1.1 Craft an integrated Marketing Communications Plan by July 2023.

3.1.2 Establish IT infrastructure to support and measure impact.

3.1.3 Define annual marketing plans and ongoing campaigns/themes to align engagement across advocacy, research, education, volunteer/fundraising efforts, and development.

3.1.4 Increase AFTD's online reach by 100% across all platforms.

3.1.5 Strategically partner to expand global awareness of FTD.

Objective 3.2: Develop an AFTD advocacy agenda and the infrastructure to pursue three priority initiatives.

Success Measures

- Priority issues and opportunities for advocacy to improve FTD diagnosis, treatments, care, and quality of life, and to reduce stigma are identified.
- AFTD's website offers a robust advocacy component to inform and engage stakeholders.

Strategies

3.2.1 Define advocacy roles at multiple levels to support the advocacy agenda.

3.2.2 Develop an advocacy agenda that includes both federal and state issues.

3.2.3 Expand tools, content, and processes to recruit and mobilize community advocates.

3.2.4 Promote agenda frequently to mobilize advocates in priority actions.

Objective 3.3: Increase volunteer engagement by 100%, as measured by number of volunteers and variety of mission-related volunteer opportunities.

Strategies

3.3.1 Conduct comprehensive baseline assessment of all volunteer activities across the organization.

3.3.2 Engage volunteers in new roles to better meet our mission.

3.3.3 Develop and implement a unified and comprehensive outreach approach and infrastructure to expand, develop, and diversify the volunteer base.

Objective 3.4: Empower 50% more donors and organizations to collaborate on sustaining and advancing AFTD's mission.

Strategies

3.4.1 Define and begin to implement a three-year fundraising plan by September 2022.

3.4.2 Continually refine development process and tools including annual assessment of efficiency and ROI.

3.4.3 Maximize how AFTD virtual and hybrid events connect, inform, support, and empower our community.

3.4.4 Identify, benchmark, and pursue new mission-aligned revenue models.

Infrastructure is critical for supporting the expansion of AFTD's programs and services to reach more people and families impacted by FTD.

Ken Simon, FTD care partner and AFTD volunteer, with his family

"Not a lot of people know about FTD – anything we can do to bring more attention to it will help advance research, leading to treatment options, accessible support and care services, and ways to prevent this disease. With more awareness, we can shorten the time it takes for people to get an accurate diagnosis, which can only help people who will face FTD. AFTD gives me hope that in the future, people will be better equipped to help everyone who is navigating this journey."

Priority 4: AFTD's Infrastructure

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

Objective 4.1: Promote a culture where AFTD staff can continue to thrive, succeed, and grow by implementing two new Human Resources Development initiatives annually, and monitoring for success.

Strategies

4.1.1 In all HR systems, policies, and procedures, integrate AFTD's values of knowledge, compassion, collaboration, respect, and dignity.

4.1.2 Continue to expand learning and development initiatives to promote Diversity, Equity, and Inclusion for staff.

4.1.3 Create succession development plans.

Objective 4.2: Drive AFTD's ability to analyze, understand, and engage with our community by implementing three high-impact technology and process enhancements annually.

Strategies

4.2.1 Strengthen internal capacity to lead and implement technology initiatives.

4.2.2 Assess and improve technology and process tools to securely drive productivity and collaboration.

4.2.3 Create consensus around priorities and a robust roadmap for success.

Objective 4.3: Implement metrics to measure AFTD's impact in each of our five mission areas.

Strategies

4.3.1 Identify and build or acquire the skill sets needed to accomplish this work.

4.3.2 Define and collect data on key metrics across our mission areas and operations.

4.3.3 Create an integrated, organization-wide mechanism to collect formal community feedback.

4.3.4 Communicate progress on key metrics to internal and external stakeholders.

Objective 4.4: Ensure that the organization has processes, policies, and procedures to identify and protect against an evolving risk landscape.

Strategies

4.4.1 Continuously identify, assess, and prioritize risks.

4.4.2 Evaluate existing processes, policies, and procedures, identify needs and gaps, and create and implement plans to address gaps and monitor risk.

Objective 4.5: Develop the composition, knowledge, and tools of the AFTD Board to ensure strong, representative, and dynamic governance as the organization continues to evolve and mature.

Strategies

4.5.1 Cultivate a robust and diverse pipeline of Board candidates.

4.5.2 Ensure Board members are engaged and find Board service to be a rewarding experience.

4.5.3 Design and implement a Board education program.

Anne and Ed Fargusson, person living with FTD and FTD care partner

“We don’t know of any other organization that is specifically focused on FTD – supporting families affected and driving critical research. FTD is central to making more people aware of the disease, advocating for more resources, and generating more understanding that not all dementias are the same – not all have the same causes and outcomes.

AFTD is critical because you are making people aware of the disease… The advocacy that AFTD does for research is critical. We need to get more people involved, so that at some point in time, this disease can be stopped.”

Brad Adams, former FTD caregiver and AFTD recurring donor

“My wife Rebecca was a generous and warm person who was driven to help others. After her mother’s death following an FTD diagnosis, Rebecca became determined to learn more about the disease that would eventually impact her… Prior to her diagnosis in 2015, Rebecca participated in FTD-focused studies, committed to playing a role in advancing research. Today, I feel an urgency to help prevent others from having to face this disease – I will do anything I can to support AFTD, carrying on Rebecca’s legacy and ensuring that research continues.”

Community Support Makes This Work Possible

AFTD's 2022-2025 Strategic Plan, by far the organization's most ambitious one to date, calls for us to add 17 positions across all of our teams, and employ more than 50 staff. We will build the organization capable of carrying out our mission across the U.S. and beyond, to realize a world with compassionate care, effective support, and a future free of FTD.

Generous donor support makes our work possible. Every dollar AFTD spends - including infrastructure, administrative, and managements costs - is dedicated to advancing our mission.

One way to support the priorities and strategies identified in this plan is to make an unrestricted gift, advancing the entirety of our work. You can also choose to restrict your donation for FTD research, drug discovery, support programs, caregiver respite, and quality of life for people with FTD.

To discuss additional giving opportunities, please email development@theaftd.org or call 267-758-8648. To make a tax-deductible donation today, please visit: **https://tinyurl.com/aftdhopetoaction**

Since our founding in 2002, AFTD's work has always been community-driven. We can't do this work without your involvement and your support.

Together, we can bring hope to action.

AFTD's Current Impact: By the Numbers

FTD's Challenges

- **60,000+ cases** in the U.S. alone (Knopman & Roberts, 2011)
- **3.6 years** to get a diagnosis, on average
- **$120,000 yearly** economic burden for families, nearly twice the burden of Alzheimer's (Galvin et al, 2017)
- **7 to 13 years** life expectancy after diagnosis
- **0 approved** disease-modifying treatments

AFTD Response

- **2,400+ AFTD HelpLine** calls answered each year
- **480,000+ visitors** to AFTD's website (**theaftd.org**) each year
- **1/3 or more** of AFTD's budget goes to research each year
- **5,170+ people** have joined the FTD Disorders Registry (ftdregistry.org)
- **320+ AFTD volunteers** drive our mission
- **450+ Comstock Respite, Travel & Quality of Life Grants** awarded each year
- **105+ AFTD support group volunteers** now lead groups across the country
- **88+ registered clinical studies** are now focused on FTD

AFTD's History: 20 Years of Resolve

2002

- AFTD founded

2003

- First meeting of AFTD's Board of Directors

2004

- First meeting of AFTD's Medical Advisory Council

2005

- AFTD HelpLine established
- First AFTD research grant awarded
- First telephone support group established
- Sponsored first FTD Caregiver Conference

2006

- First sponsored the International Conference for Frontotemporal Dementias

2007

- Drug discovery partnership with the Alzheimer's Drug Discovery Foundation launched

2008

- FTD is included among first indications covered by Compassionate Allowances under Medicare, so vital disability benefits extend to people living with the disease

2009

- Comstock Respite Grant program launched, providing small grants to support caregivers
- First Strategic Plan created
- First AFTD Postdoctoral Fellowship awarded

2010

- *It Is What It Is* premiers, documenting the FTD journey
- Founding of the FTD Treatment Study Group (FTSG), fostering research collaboration
- First AFTD Education Conference held in Fort Worth, Texas, convening families and health professionals

2011

- *C9orf72* mutation linked to FTD – five AFTD Medical Advisory Council members involved in the study

2012

- AFTD With Love campaign launched, raising awareness and funds to support our mission
- First FTSG meeting, convening researchers to advance science targeting FTD
- AFTD Comstock Travel Grants program launched, to support travel to FTD conferences
- AFTD Education Conference in Atlanta includes first session for persons diagnosed
- *What About the Kids?* resource for parents and grandparents published
- Partners in FTD Care initiative launched, to educate health professionals on best practices
- Volunteer grassroots event fundraising "AFTD-Team" formally launched

2013

- *The Doctor Thinks It's FTD. Now What?* and *Understanding the Genetics of FTD* (with UPenn) published
- *NBC Nightly News with Brian Williams* airs segment on FTD, featuring AFTD Board member John Whitmarsh and Medical Advisory Council member Bruce Miller

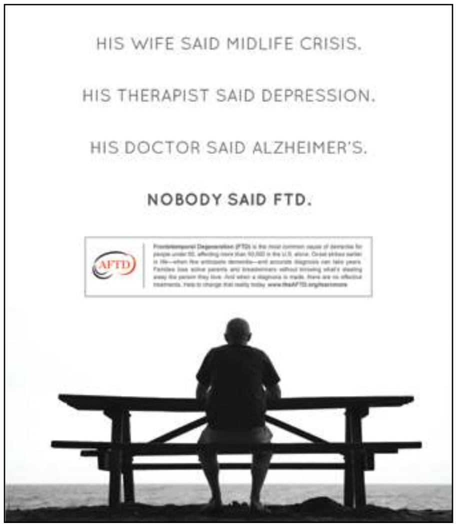
2014

- *FTD Research and Drug Development Landscape* published
- First FTD Awareness Week and Food for Thought campaign held
- Launch of AFTD Kids and Teens web resource
- Phone group for persons diagnosed launched
- AFTD receives its first gift of $1MM+, from an anonymous donor

From Hope to Action

2015

- AFTD expands support efforts with multi-year support from The Hearst Foundations
- Discovery airs first FTD PSA
- National research initiative now known as ALLFTD launched
- First-ever global World FTD Awareness Week



2016

- FTD Biomarkers and Treat FTD initiatives launched, with multi-year grants from the Samuel I. Newhouse Foundation
- AFTD Think Tank established, predecessor to AFTD's Persons with FTD Advisory Council
- *Hodges' Frontotemporal Dementia* publishes chapter written by Susan Dickinson and AFTD volunteer Jill Shapira, PhD, RN
- First AFTD social media campaign (#WhoILove)
- AFTD ads run in *New York Times* for the first time, as well as in various Condé Nast publications
- First AFTD Hope Rising Benefit held in New York City
- AFTD Educational Webinar series launched

2017

- FTD Disorders Registry launched, to empower research participation in our community
- Donald Newhouse and AFTD Medical Advisory Council member Ted Huey appear on NBC's *Today Show*
- AFTD receives 10-year, $10 million gift from The David Geffen Foundation, matched by the Samuel I. Newhouse Foundation
- AFTD economic burden study published in *Neurology*

2018

- AFTD-commissioned short film *VJ & Chuck* portrays the experience of both the care partner and the person with FTD
- AFTD Comstock Quality of Life grant program launched, to support people with FTD

2019

- AFTD joins ADDF's Diagnostics Accelerator initiative, as well as the Biomarkers Consortium, to advance research
- AFTD informs a CBS *60 Minutes* story, raising vital awareness among millions
- AFTD volunteer Ambassador Program launched to raise awareness and connect communities at the local level

2020

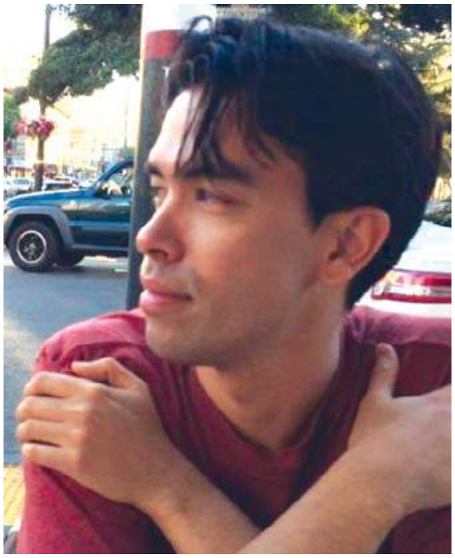
- AFTD resource on navigating grief published
- Education Conference and many resources and programs moved online, in response to COVID-19 pandemic
- AFTD Persons with FTD Advisory Council chartered

2021

- AFTD hosts Externally-Led Patient Focused Drug Development meeting with the U.S. Food and Drug Administration, and publishes the first Voice of the Patient report focused on FTD
- Sudon and Holloway Family Funds established, bringing robust multi-year support to inform AFTD's research efforts, growth, and sustainability

2022

- First Holloway Summit convenes researchers to advance digital assessment tools for FTD
- First AFTD webinar offering CEUs for health professionals



From Hope to Action

A Letter from AFTD's Founder


Helen-Ann Comstock

Dear Friends,

My husband, Craig, an accomplished mathematics professor with a Harvard PhD, began showing concerning symptoms in the late 1970s, when he was in his early 40s. We visited a neurologist, who said that my husband's odd behaviors could be the result of an undiagnosed brain tumor. The doctor also suggested that Craig may have had a disease I had never heard of before – *Alzheimer's disease*.

Today it's hard to imagine anyone not knowing what Alzheimer's is, but all those years ago a search of my local library resulted in no books on the disease. The best information I could find was two sentences in an encyclopedia.

Ultimately, a different neurologist gave Craig what turned out to be an accurate diagnosis – he didn't have Alzheimer's at all, but rather, Pick's disease, which we call FTD today. Despite finally having the right diagnosis, we were even more adrift. No one seemed to know anything about FTD, and there was almost no FTD research being funded.

I knew other families were facing FTD, and I knew they had no organization to turn to for support or information – indeed, even for a simple acknowledgment that they weren't alone. So in 2002, I opened a bank account containing $1,000 of my own funds, created a mission statement, and began building the organization we call AFTD today.

AFTD has grown into the country's leading organization focused solely on FTD. We are providing information, support, and opportunities to thousands in our community each year, a deeper level of impact than the organization has ever had. But it isn't enough. It won't be enough until the day we've ended this disease, and ensured that no family has to face the devastating losses it brings.

Twenty years ago, with little to go on beyond hope and a sense that something needed to change, I took the action I saw as necessary to help others facing FTD. Today, we have more momentum in our work to advance AFTD's mission than ever before. But each of us must take action if we are going to realize the future we seek. If you find this Strategic Plan and its vision inspiring, I encourage you to contact AFTD and offer whatever help you are able to provide, whether as a volunteer, a donor, or simply someone making a suggestion about how we can serve this community better. Every little bit helps.

The action you take today can help another family facing FTD. The action you take today can advance hope for a future free of this disease.

All best,

Helen-Ann Comstock

Helen-Ann Comstock
Founder, AFTD

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