



AFTD news

FTD Disorders Registry Upgraded to Help Further Advance FTD Science

The FTD Disorders Registry is a powerful tool in the effort to discover treatments and a cure for FTD. By sharing their lived experience with FTD, persons diagnosed with FTD, former and current care partners, and family members provide crucial information that helps advance FTD science. In addition, registering allows the FTD Disorders Registry to send information regarding clinical research opportunities that you qualify for and allows you to see how your experience compares with others on the FTD journey.

Next year, the Registry will deploy a new interface for both families affected by FTD and researchers that features a more robust suite of data-collection tools and a more versatile communication system for keeping in touch with participants. Overseeing this transformation is new Registry Director Carrie Milliard, MS, CGC, CCRC. Milliard, who joined the Registry in early July, brings 20 years of clinical research experience to her new role, including data management, clinical research, and genetic counseling.

“I love being in the rare-disease space,” she said. “The Registry is really important; it lets us fuel the coming trials and drive efforts towards a cure for FTD.”

Milliard said that the Registry’s platform upgrade – the product of direct feedback from Registry participants over the years – represents a major transformation. In addition to connecting people affected by FTD to research-participation opportunities, the platform will make it easier for scientists to access de-identified datasets, and will provide tools to aid in clinical research.

“People living with the disease, their care partners, their families – you are all the missing piece to the puzzle that is FTD,” Milliard said. “With the coming updates to the registry, we will be able to empower research participants while directly facilitating research that effectively utilizes the data they’ve contributed.”



Milliard said that the Registry upgrade focuses on three key goals:

- **Empowering and engaging the community.** The new platform enables participants to contribute data over the long term, allowing them to offer greater insight on topics relevant to them. Registry participants will also have more control over their profile and communications preferences, providing a more personalized experience.
- **Creating a secure data resource for researchers.** The Registry is home to a wealth of data, but that data has been underutilized to date. The new platform will feature a dedicated portal for researchers to parse available datasets, easing their access to data to advance their important work. Like the current Registry, personally identifiable information (name, contact information) is not shared with researchers.
- **Facilitating research with new tools.** Through the new platform, the Registry will be better able to empower people to find the clinical-research studies right for them. Moreover, the platform’s suite of tools will let scientists collect data remotely and stay connected with participants, all while protecting participants’ identities.

One of Milliard’s long-term goals at the Registry is to ensure that the data contributed by participants is better implemented and shared with researchers. “We need to make better use of the data we have; we need to make sure it’s utilized, analyzed, and disseminated,” she said.

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AFTD News Briefs

New York Times Magazine Publishes Story on Genetic FTD

In July, the *New York Times Magazine* published a cover story chronicling the experiences of a family that has lived with the threat of inheriting genetic FTD for generations. The article’s author, Robert Kolker, consulted with members of AFTD’s staff for insight into FTD: CEO Susan L-J Dickinson, MSGC, Director of Research Engagement Shana Dodge, PhD, and Director of Research and Grants Debra Niehoff, PhD. The article introduces Barb, the youngest of nine children. (The article does not identify its subjects by last name to protect their privacy.) After Barb’s mother and two of her siblings began showing FTD symptoms, she learned that her family carried an FTD-causing genetic mutation associated with the tau protein. While her family members were divided as to whether they should be tested themselves, Barb ultimately made the decision to undergo testing and learned she does not carry the mutation.

A Response to the New York Times Magazine from AFTD CEO Susan Dickinson

Susan Dickinson’s response to the July 23 New York Times Magazine article “The Vanishing Family” was published in its August 6 issue. Below is its full text:

Robert Kolker’s compassionate reporting on one family’s discovery of their inheritance of a genetic variant that can lead to frontotemporal dementia captures the cruel nature of this disease, and the resilience of those affected. The family’s painful diagnostic journey, and individual members’ reckoning with what to learn about their own genetic fates, underscore that FTD requires a compassionate response from medical professionals, employers, insurers, and policymakers. The majority of FTD cases are not inherited, but research into genetic FTD is bringing new hope for disease-modifying treatments for all. Biopharma investment is likely to continue to grow as more families get access to diagnoses, and the FDA’s evolving openness to adaptive trial designs for rare diseases like FTD can also speed the path to the first approved treatments. Families need our help today. And they are ready to take action. A community that has been through so much can offer support and understanding to fellow travelers on a heartbreaking journey.

Making a planned gift is a powerful way to support AFTD’s mission and the people we serve.

Choose to plan for a future free of FTD by joining AFTD’s Legacy Circle today. Please contact development@theaftd.org or visit tinyurl.com/AFTDLegacy for more information.

“Making a planned gift is a way of guaranteeing AFTD will be provided for and will thrive for many years to come.”
– Member of AFTD’s Board & Legacy Circle



VOLUNTEER STORIES BRING HELP & HOPE

"I don't know of another organization that sparks as much enthusiasm among its volunteers as AFTD."

– Jerry Horn, former care partner and current AFTD Ambassador

Jerry Horn remembers his wife Deborah showing signs of FTD as early as 2009, though she wouldn't receive her diagnosis of semantic variant primary progressive aphasia until 2014, when she was 62 years old.

"The day she was diagnosed, it suddenly hit me that our lives were going to change forever," Jerry said. "My brain was in overdrive; I realized that I was going to be thinking for two people, making every single decision. I would need to plan not only for myself, but for my wife as well."

Facing FTD together, Jerry and Deborah wanted to learn as much as they could about the disease. Early in her diagnosis, Deborah wrote a letter to her neurologist detailing her symptoms, and Jerry later attended a conference on Alzheimer's sponsored by a nearby hospice facility in late 2016.

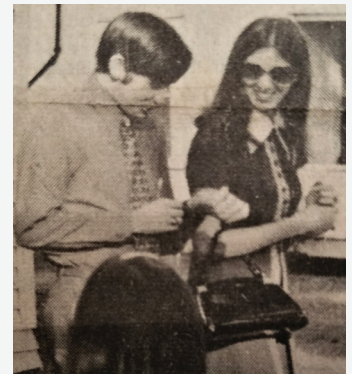
"I asked one of the presenters, 'What research is being done about FTD?' He didn't have an answer, but a lady approached me later, asking if I knew of any local FTD support groups. After contacting AFTD for help, I teamed up with the hospice's executive director, who helped me launch the first FTD support group in Alabama."

For 30 years, Deborah had worked as a speech pathologist. As her FTD progressed, Deborah lost over 90% of her speech and language capabilities, as well as her ability to write and do simple math – leading to her forced early retirement in 2011.

Daily tasks also became difficult, taking a toll on Jerry's ability to support Deborah. "Getting her teeth brushed, taking a bath, getting dressed, taking medication – all of these things became impossible for her to do without assistance," he said. Still working over 50 miles away from their home, Jerry soon realized the danger of leaving Deborah alone for long periods of time. To ensure her comfort and safety, Jerry used local care services and a home health aide as needed until Deborah passed away in April 2019.

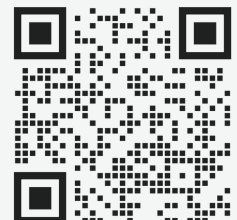
Today, as an AFTD Ambassador, Jerry continues to raise awareness and advocate for FTD families who are suddenly faced with the financial and emotional burdens that come with a diagnosis.

"I have a great deal of knowledge about this disease, and I want to share that with others, so they don't feel alone," he said. "I've been inspired by the growth in the organization and the level of awareness that's driven by our volunteer army."



Every story moves us closer to a future free of FTD.

Will you join Jerry and so many other volunteers in supporting AFTD's mission to #endFTD? Making a tax-deductible gift today can help AFTD amplify the stories of other people and families affected by FTD and ensure no one faces this disease alone. Use the enclosed envelope, visit theaftd.org and **click on the Donate+ button** at the top of the page, or use the QR code.



Spotlight on... Margaret Sutherland, PhD, AFTD Board of Directors



Margaret Sutherland, PhD

Before she worked at the Chan Zuckerberg Initiative's Neurodegeneration Challenge Network, AFTD Board member Margaret Sutherland, PhD was program director at the National Institute for Neurological Disorders and Stroke (NINDS), serving as the program lead overseeing a variety of disease portfolios. While at NINDS, Dr. Sutherland took notice of the then-recent discovery of the *C9orf72* genetic mutation, and its clinical association with FTD and ALS.

"I was interested in learning more about the basic science, genetics, and clinical aspects of FTD," said Dr. Sutherland. "While learning about FTD, I found the scientists, clinicians, and family members

affected by it eager to share their knowledge and experiences."

Dr. Sutherland said that one of her first major encounters with AFTD was a workshop that had been brought together to create an FTD clinical-assessment module to assist the data collection efforts of the National Alzheimer's Coordinating Center. AFTD co-organized the workshop with the National Institute on Aging (NIA) and NINDS. It was at the workshop that Dr. Sutherland first met AFTD founder Helen-Ann Comstock and AFTD CEO Susan L-J Dickinson.

"At that time, a number of the NIA-funded Alzheimer's Disease Research Centers were also seeing

people living with FTD, but the route to an FTD clinical assessment and diagnosis by these centers was variable," she said. "This FTD module was a foundational tool that has been widely adopted and further developed by Alzheimer's Disease Research Centers in the U.S. and utilized in FTD natural-history studies and clinical trials."

While at NINDS, Dr. Sutherland took notice of the then-recent discovery of the *C9orf72* genetic mutation, and its clinical association with FTD and ALS.

Working with AFTD on projects like the FTD module during her time at NINDS provided opportunities for Dr. Sutherland to learn about the lived experience of FTD from families affected by the disease, giving her more insight into its devastating impact. She said that her role as program manager at the Chan Zuckerberg Initiative has allowed her to contribute time and effort to organizations and communities that can benefit from the help she provides.

"It's an amazing feeling to see how your service benefits others," Dr. Sutherland said. "I hope my time on the AFTD Board will provide opportunities to work on research that drives new discoveries for therapies, and resources that create new opportunities and support for persons and families affected by FTD."

Global Advocates Make Their Presence Felt During World FTD Awareness Week 2023

Families, healthcare professionals and other advocates around the globe marked World FTD Awareness Week 2023 by sharing their stories and working to educate the public about FTD.

World FTD Awareness Week is organized each year by World FTD United, a coalition of international FTD-focused organizations, of which AFTD is a member.

Each day of World FTD Awareness Week 2023 (Sept. 24 – Oct. 1) focused on a specific theme and action items. The theme for Sept. 26, for example, was “volunteer”; participants were encouraged to support an FTD-focused organization or cause by donating their time. On Sept. 28, a day of advocacy, participants could register for the newly launched AFTD Advocacy Action Center and tell their federal legislators about FTD. (See page 11 for more details about the AFTD Advocacy Action Center.)

“Educate,” the theme for Sept. 29, called for people affected by FTD to share AFTD’s diagnostic checklists with friends and healthcare professionals. (The diagnostic checklists detail the symptoms of primary progressive aphasia and behavioral variant FTD, and are available in English and Spanish.) The week closed on a commemorative note, as participants honored or remembered loved ones with FTD or celebrated someone who has supported their own journey.

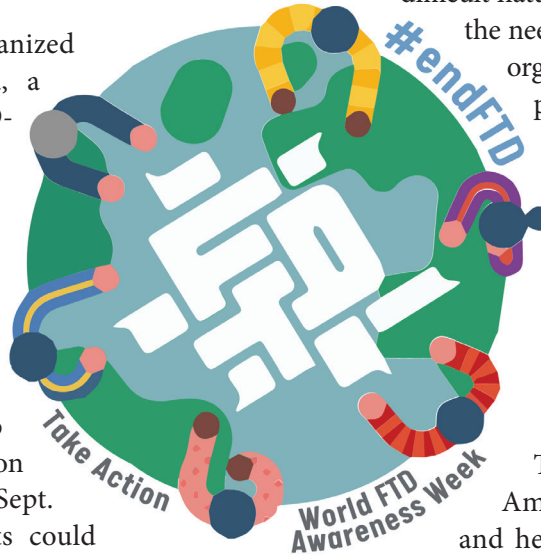
AFTD helped to bring FTD awareness to the national airwaves on Monday, September 25. That morning,

Emma Heming Willis, the wife of Bruce Willis, appeared on NBC’s *Today* alongside AFTD CEO Susan L-J Dickinson. Heming Willis told viewers about the difficult nature of the FTD journey and emphasized the need for FTD families to get support from organizations such as AFTD. “As a care partner, it’s so important to be able to ask for help,” she said.

Heming Willis worked throughout the week to spread FTD awareness, publishing in-depth interviews with FTD experts every day on her Instagram and YouTube accounts. Among her interview subjects were AFTD Brand Ambassador and TikTok influencer Nicole Petrie; AFTD Ambassador Sandra Gonzalez-Morett and her sister, Diana Gonzalez-Morett; and Maria Kent Beers and Rachael Martinez, hosts of the FTD-focused podcast *Remember Me*.

Advocates from around the globe also showed their support for World FTD Awareness Week. Just days before the week officially began, Australian journalist and FTD advocate Daisy Dumas, whose mother had FTD, raised awareness by running the Sydney Marathon. And in Chile, advocates from a recently formed FTD organization took to the streets to ensure that FTD was represented during a dementia-focused march.

AFTD created a complete guide to the week’s activities, along with a special social-media toolkit that helped our community easily participate. Learn more by visiting theaftd.org/world-ftd-awareness-week-2023.



World FTD Awareness Week 2023 by the Numbers

Diagnostic Checklist Downloads

- 2,299** Behavioral Variant FTD (plus **15** in Spanish)
- 720** Primary Progressive Aphasia (plus **10** in Spanish)

Instagram

- 113** posts and Stories
- 403,725** Views from Posts, Stories, and Videos
- 598** hours and 12 minutes of Video Content Viewed

Total social media followers: **+488** (Twitter, Facebook, Instagram, LinkedIn)

Acclaimed Play *UnRavelled* Examines Art, Science, and Dementia

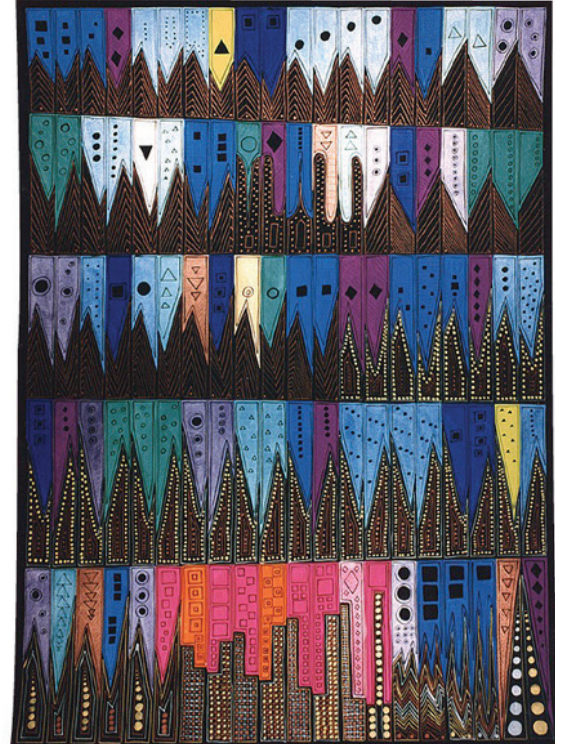
AFTD staff and Board members attended a performance of the play *UnRavelled* at the San Francisco Conservatory of Music on July 21. AFTD sponsored the play to raise FTD awareness and elevate the stories and perspectives of our resilient community.

Written by Jake Broder, an Atlantic Fellow at the Global Brain Health Institute, *UnRavelled* examines how the Canadian scientist Anne Adams (1940–2007) developed as a painter following her FTD diagnosis and became a remarkable artist. (See the article on the next page for more information about the link between FTD and artistic creativity.)

Through her story, the play also uncovers the mystery of French composer Maurice Ravel's (1875–1937) similar diagnosis almost 100 years earlier. It ended with a symphonic performance of Ravel's most famous composition, *Boléro*.

“Ravel and Dr. Adams were in the early stages of primary progressive aphasia, a form of frontotemporal dementia, when they were working,” said Dr. Bruce Miller, co-director of the Global Brain Health Institute. “The disease apparently altered circuits in their brains, changing the connections between the front and back parts and resulting in a torrent of creativity.”

“Hope embedded in this story brings together doctors, nurses, caregivers, mothers, daughters, fathers, and people living with different subtypes of dementia,” said Jake Broder, who spent several years studying neuroscience and interviewing Dr. Miller to create the play. (Dr. Miller, an emeritus member



A painting by Dr. Anne Adams, who was diagnosed with FTD.

of AFTD's Medical Advisory Council, treated Adams.) “They have wept, shared, and seen themselves and their loved ones in a new way for the first time, experiencing something more than just pain when thinking about dementia,” Broder added.

The play was also sponsored by the University of California, San Francisco (UCSF) and The Global Brain Health Institute. UCSF is a leading university in FTD research and has a Memory & Aging Center that focuses on dementias including FTD. The Global Brain Health Institute is a leader in the global community dedicated to protecting the world's aging populations from threats to brain health.

Immediately following the performance, AFTD CEO Susan L-J Dickinson, MSGC joined a panel to discuss the play, FTD, and how FTD research is advancing. “*UnRavelled* uses art to shine a light on our community and raise awareness,” she said. “Although the ‘torrent of creativity’ that both Anne Adams and the composer Ravel experienced as their PPA advanced is extremely rare, the play so poignantly portrays how FTD impacts all of the relationships in a family, not just the person with the diagnosis.”

Studies Highlight Link Between FTD and Creativity

Michael Hala, a former IT executive, was never an artistic person. But following his FTD diagnosis, he began to show an inclination toward visual creativity that took his wife, Barbara Hala, by surprise.

“He was enrolled in a young-onset dementia day program at a local junior community college that did arts and crafts,” Barbara said. “Mike came home from the program one day with his beautiful painting.

“It’s bittersweet,” she added, “but our family will always cherish this painting.”

Researchers – including Bruce Miller, MD, a distinguished professor of neurology at the University of California, San Francisco – have long studied the apparent link between FTD and artistic creativity. In a letter published in the medical journal *The Lancet* in 1996, Dr. Miller wrote about three persons diagnosed with FTD who went on to become “accomplished painters.” One began painting at age 56 despite having “shown no previous interest in art” and eventually won awards at local art shows.



A painting by Michael Hala, who is living with an FTD diagnosis.

In a CBS News report that aired earlier this year, Dr. Miller recounted stories of persons diagnosed who newly took up crafts such as welding and knitting. “People who were not visual before [FTD] become very visually occupied,” he said.

Researchers are beginning to understand why this phenomenon exists. A 2023 study published in *JAMA Neurology* theorized that the atrophy pattern of FTD may give a boost to the visual cortex, which they believe makes visual experiences more intense for persons diagnosed. This is supported by multiple studies that show areas of the brain responsible for visual processing get stronger for a time as other areas of the brain atrophy due to FTD.

Researchers note that it remains exceedingly rare for a person with FTD to become an artistic savant overnight. But the physical link between the creative impulse and the changes in the brain caused by FTD is becoming increasingly clear.

AFTD Awards 2023 Fellowships and New Scholarship

AFTD recently presented two 2023 Holloway Postdoctoral Fellowships and a 2023 Clinical Research Training Scholarship to researchers looking into potential FTD therapeutics and interventions.

Made possible through the support of the Holloway Family Fund, Holloway Postdoctoral Fellowships provide critical funding for the next generation of FTD researchers. Awardee Marc Shenouda, PhD, of the University of Toronto, will use the funding to support a project targeting TDP-43 aggregation in the brain, which is linked to the development of both FTD and ALS. His lab identified a small molecule, called JRMS, that stops these toxic clumps of TDP-43 from forming. He aims to test JRMS in a mouse model and work with chemists to render JRMS more drug-like in preparation for eventual clinical testing in people living with ALS and FTD.

Awardee Jackie Poos, PhD, of Erasmus Medical Center in the Netherlands, will use the funding to develop and evaluate an individualized, virtual reality social-cognition game to differentiate presymptomatic FTD mutation carriers from non-carriers. She will also

pilot-test the feasibility of remote assessment using a portable headset. Currently, clinical social-cognition assessments are not sensitive enough to detect mild deficits in the earliest phases of FTD, and do not accurately reflect the complexity of behavior outside the clinic. If successful, this virtual reality-based approach could improve access to accurate diagnosis.

Also made possible through the support of the Holloway Family Fund with additional support from the American Brain Foundation in collaboration with the American Academy of Neurology, the Clinical Research Training Scholarship is a new AFTD funding opportunity. The first awardee, Tanav Popli, MD, of the University of Michigan, will use functional magnetic resonance imaging to customize the delivery of high-definition transcranial direct current stimulation to persons with semantic variant PPA, nonfluent PPA, or logopenic PPA. If this noninvasive, nonpharmacological therapy proves to have beneficial effects on language function, it could improve the quality of life and maintain functional independence for those affected by PPA.

Those We Honor... Those We Remember

Gifts received from June 1, 2023 – September 30, 2023

In Memory Of

James S. Abbott
Ross Abinanti
Charles Adams
Rebecca Ann Adams
Rosetta Adkins
William Ahearn
Laura Ahlbeck
Lawrence Albert
Sharon Alexander
Janna Allen
Robin K. Allen
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Richard Myers
Robert Nabrzeski
Francine S. Nagin
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Kenneth Nelson
Susan Newhouse

Donations made in the name of a loved one bring help and support for families affected today – and hope for a future without FTD.

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Michael Zapico
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David Zimmerman

In Honor Of

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AFTD Triathlon Team
George Allen
Laura Allgire
Jay Altick
The Bellwoar Family
Merry Bergan
Robert Andrew Berry
Julia Winston Bethurum
Murphy
Bob Boerschel
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Kenny Clancy
Kara Abshire & Justine Cline
Serina Cline
Ronald Collom
Helen-Ann Comstock
Margaret Cotten
Barb Dawson
Michael DeMartini
Doug Devries
Jenny Dore
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The Eissler Family
Chuck Elkins
Judith Erlick
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Eleanor Holcombe
Richard Hollingsworth
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Ann Huzinec
Ed Jackson
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Honor a Loved One or Remember Their Legacy

Families wishing to direct memorial donations to AFTD are encouraged to call our office at (267) 514-7221. AFTD can mail you donation materials, or you can download them from our website. All donors will receive letters of acknowledgment, and families will also receive a list of donors. To contribute online, visit www.theaftd.org and select "Donate+"

FTD Disorders Registry (continued)

“I’m looking ahead to generating my own research questions, and learning from people with lived experience of FTD.”

The Registry upgrade will also allow participants to see how the data they provided is being used in FTD research. When Registry data are presented or published, participants will see how their data helped to shape them.

Milliard encouraged everyone affected by FTD to join the Registry, emphasizing the importance of research participation. “The more people willing and able to participate in research on FTD, the greater our chances of attracting research investment and creating new, effective treatments. We’d love to have you involved in any way,

even if it’s just answering quick questions about your lived experience.”

In July, AFTD and the Registry strengthened their relationship as closely affiliated organizations, with the latter leveraging the operations and staff support at AFTD. Now functioning as a close affiliate of AFTD, the FTD Disorders Registry will be able to forge stronger working relationships and collaborate more closely on joint projects with AFTD staff.

The FTD Disorders Registry was co-founded by AFTD and the Bluefield Project to Cure Frontotemporal Dementia, with generous support from the Rainwater Charitable Foundation.

AFTD Convenes “Research Roundtable”

AFTD held its inaugural FTD Research Roundtable on September 5-7 in Arlington, Virginia, convening representatives from more than a dozen biopharmaceutical companies, the U.S. Food and Drug Administration (FDA), and the European Medicines Agency, as well as nonprofit partners, academic researchers, and advocates focused on advancing FTD research towards treatments and a cure.

Introducing the event, AFTD CEO Susan L-J Dickinson and AFTD Board Chair Kimberly Pang Torres said, “Given that FTD is a rare disease, and clinical-trial recruitment remains a challenge, this year’s Research Roundtable will focus on improving clinical trial efficiency and power. How can we work around the inherent limitations of FTD clinical trials to maximize their impact?”

Speakers described the current state of clinical trials and discussed potential solutions to the challenges of conducting trials for a rare, heterogeneous disease like FTD. Attendees engaged in lively discussions about how the field



can leverage current resources and collaborate to overcome barriers to success.

The FTD Research Roundtable was chaired by Dr. Adam Boxer (UCSF) and Dr. Michael Gold (Neumora Therapeutics), with collaborative leadership from Dr. Michelle Campbell (FDA), Dr. Howard Feldman (UCSD), Dr. Serena Hung (Arkuda Therapeutics), Dr. Rodney Pearlman (Bluefield Project to Cure FTD), and Dr. Penny Dacks (AFTD).

The Research Roundtable evolved from the FTD Treatment Study Group (FTSG), and was established to foster

discussion and shared problem-solving between the biopharma companies that are developing treatments for FTD and the regulatory agencies that will evaluate the benefits and risks of these treatments.

FTSG focused on motivating companies to conduct FTD clinical trials. As more biopharmaceutical companies began FTD clinical and pre-clinical trials, the FTD Research Roundtable was developed to promote precompetitive collaboration between companies and overcome challenges to developing treatments and diagnostics for FTD.

AFTD Launches New “Action Center” as Part of Renewed Advocacy Push

The AFTD Advocacy Action Center, launched on September 28, gives the AFTD community an important new tool to advance policies and legislation that directly benefit the needs of all affected by the disease.

To sign up and make your voice heard, visit the Advocacy Action Center at theaftd.org/get-involved/advocate.

By signing up to become an AFTD advocate, you can connect directly with federal and state lawmakers to convey the importance of expanding FTD research, increasing funding for dementia care and services, and ensuring that policymakers understand the unique needs of families living with this disease. You will be able to share your stories with legislators, via email, phone calls, social-media messages, and even video.

The Advocacy Action Center also features an updated list of comments AFTD has submitted to federal agencies and other policymakers on a variety of issues, as well as other advocacy-related news.

AFTD launched the Advocacy Action Center as part of a concerted effort to develop a new, robust advocacy program (as outlined in our most recent Strategic Plan, which runs from July 2022 through June 2025). To oversee the development and implementation of that program, AFTD has hired its first Director of Advocacy and Volunteer Engagement, Meghan Buzby. She will create and coordinate strategies to increase engagement by advocates and other AFTD volunteers to better support our mission.

“AFTD’s community is passionate about advocacy, and ready to make a difference,” Buzby said. “The Advocacy Action Center will help mobilize our community on the issues that matter the most to them: growing FTD awareness among legislators, showing support for innovative FTD research, and emphasizing the need for FTD-appropriate services in the dementia-care space.”

“For anyone looking to make a difference for our community, simply sign up at the AFTD Advocacy Action Center,” she added.

Newly registered AFTD advocates are already making their voices heard. The initial round of advocates can contact their senators and representatives to tell them to help AFTD’s public education efforts by including information about FTD in their next newsletter for constituents – the first of many direct actions the Advocacy Action Center will help coordinate.

With FTD awareness at an all-time high thanks to the Willis family’s sharing the FTD diagnosis of beloved actor Bruce Willis, coordinated advocacy at the federal level has the chance to make more impact than ever before.

“The time for action is now,” said Matt Sharp, AFTD Advocacy Manager. “Regardless of your political affiliation, we can agree that the needs of FTD families remain underrepresented within the halls of Congress. The AFTD Advocacy Action Center lets us marshal the power of this dedicated community to truly influence federal and state policy.”

Special Thanks to Our 2023 Research Roundtable Members:



AFTD's Support Group Volunteers Readier than Ever to Provide Help on the FTD Journey

AFTD's support group network is continuing to evolve and grow! While groups previously only met in person, both in-person and virtual options are now available to support those on the FTD journey, no matter where they are. This robust and versatile network is possible thanks to the efforts of AFTD's Support Group Volunteers (SGV), who often bring FTD support and resources to places that need them most.

"Massachusetts has support groups near Boston and in the western part of the state, but there is nothing in the central part of the state, where I live, or in Rhode Island," said SGV Christine Beauchaine, who started an in-person group to ensure people in those places have access to support. "I love knowing that I may have reassured someone that they've been seen and heard and that they aren't alone."

Beauchaine noted that care partners are often unprepared for their role due to a lack of training and support. She recalled how she struggled as a care partner for her husband, and wanted to help others become better partners on the FTD journey.

AFTD provides training and support for people who want to start their own support groups. "AFTD provided training through webinars, Zoom meetings, and materials they sent me," said SGV Al Papesh.

"They continue to provide me and other group leaders with materials instrumental for our success. Even though my wife passed away in April of 2017, it provides me satisfaction in knowing the group is a place for care partners to share their thoughts and ask questions."

AFTD "continue[s] to provide me and other group leaders with materials instrumental for our success," said Support Group Volunteer Al Papesh.

While some who become SGVs, such as Beauchaine and Papesh, bring lived experience of the FTD journey, others, like Stacey Juthapan, bring professional experience to their facilitator roles. Having worked with people with primary progressive aphasia, Juthapan knew how few resources were available to the newly diagnosed and wanted to make a difference for them.

To others pondering making a difference by starting a group themselves, Juthapan says the best way to start is simply to take the first step. "You don't need all the 'right' answers or years of experience,"



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AFTD-trained Support Group Volunteers facilitating 77 support groups throughout the United States as of June 30, 2023

Juthapan said. "Just be yourself – that's more than enough."

For those looking for support, Juthapan, Beauchaine, and Papesh recommended attending a support group, whether virtual or in-person, to see if they are a good fit. "I believe that there is power in sharing our stories and connecting with others in similar situations," Juthapan said. "Support groups are here for you to connect, share, listen, and learn."

To learn more about becoming a Support Group Volunteer, visit theaftd.org/volunteer-form.

AFTD Ambassadors and Volunteers Raise Awareness Through Media Outreach

In recent months, AFTD Ambassadors and volunteers have worked to spread FTD awareness through media outlets, both domestic and international, and other public-facing opportunities.

During World FTD Awareness Week 2023 (see p. 5), AFTD Ambassador Terry Walter shared her family's FTD journey while spreading awareness and information during a live appearance on the CBS morning show *Good Day Sacramento*. She also spoke about her role as an Ambassador and promoted the AFTD fundraising campaign Food for Thought. Terry's own Food for Thought event took place on October 7. (See page 14 for more information about Food for Thought 2023.)

Also during World FTD Awareness Week, AFTD Ambassador Dawn Kirby spoke to the radio station WBGL in Champaign, Illinois. She and her husband are former caregivers for their daughter, Kara. Kirby detailed her family's FTD journey and her work as an Ambassador. During the interview, WBGL shared a special keyword that listeners could text to receive a link to AFTD's website, bringing more awareness to FTD and more FTD information for listeners.

In an interview with NJ.com published in late August, AFTD Ambassador Sandra Gonzalez-Morett and her sister Diana discussed their mother's FTD diagnosis, the ways they've tried to manage her symptoms, and the complex emotions of the FTD journey, as well as how their experiences shaped their short film about FTD caregiving, *Pedacito de Carne*. The story was subsequently published in print in the Newark *Star-Ledger*. In mid-October, Sandra and Diana again shared their story and discussed the impact of FTD on families in an interview for the PBS show *¿Que Pasa NJ?*

As part of an August *GoodRx* feature, Ambassador



Melissa Fisher shared the difficulties of being a long-distance care partner. Fisher talked about making the long journey from her home in Oregon to her parents in Hawaii, and the uphill battle she is facing as a care partner for multiple people, including her father, who is living with FTD.

Finally, AFTD Ambassador Katie Zenger was part of a press conference at the South Carolina State House earlier this year to mark the release of the South Carolina Statewide Plan to Address Alzheimer's Disease & Related Dementias. Zenger, a consultant, played a crucial role in drafting the plan, which addresses the changing landscape of FTD and other neurodegenerative diseases.

AFTD thanks all our volunteers for their help in spreading awareness! To learn how you can get involved, visit theaftd.org/get-involved/volunteers-network or email an AFTD Volunteer Coordinator at volunteer@theaftd.org.

AFTD's food for thought



AFTD's 11th annual Food for Thought campaign saw 70 events held in 29 states, plus Canada and Japan, and raised a new record of **\$207,686** to advance our mission! Below are the fundraisers that raised over \$2,500 (at the time of this writing) from their event:

SPARKING AWARENESS: Steve Bellwoar, a Pennsylvania-based AFTD Board alumnus, hosted the 10th annual Colonial Electric Food for Thought event in memory of his mother, Trish. It featured nine holes of golf, a cocktail hour, a seated dinner, and an FTD presentation. Steve raised more than **\$130,000**, bringing his 10-year total to **\$919,450+**!

HOP TO IT: Julie Smith and a committee of volunteers hosted Hops for Hope in New Prague, Minn. to honor and support families in their community who are facing FTD and ALS diagnoses. The day featured delicious beer and food, music, and lots of friends raising **\$20,452** for AFTD's research efforts.

GOOD EATING: Emma Heming Willis and Nicole Petrie teamed up to raise funds in honor of Emma's husband, Bruce Willis, and Nicole's mother, Cheryl. They shared recipes on their joint fundraising page: roasted tomato caprese salad from the Willis family's favorite chef, Ina Garten, and Swedish pancakes that Nicole's great-grandmother and mother would make on special Sunday mornings. The duo raised **\$9,043** to support AFTD's mission.

DINO-MYTE: Heather Sellers raised **\$4,181** by hosting an online cooking class in memory of her mother, Suzy, who passed away from FTD in July 2022. She shared FTD facts and grief tips using short videos starring "Uncle Dino," a seven-foot inflatable T. rex.

PIZZA HER HEART: Debbie Elkins of W.Va. raised **\$3,098** by hosting two restaurant giveback nights at Husson's Pizza and Buffalo Wild Wings in honor of her husband, who is living with FTD.

FEAST OF LOVE: Jamie Hale's first Food for Thought event raised **\$2,779** in honor of her husband, Kenny. Held at Golden Bond Assisted Living, it included food, beverages, and over a dozen raffle baskets.

HONORING JUDY: Ryan Windhorst raised **\$2,616** by sharing one of his mom's favorite recipes on his social media. His mother, Judy Windhorst was diagnosed with FTD in 2007.

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

Ann Bercher	Jim Capobianchi	Martina Rutledge
Barbara Todd	Joanne Linerud	Melissa Dube
Bonnie Shepherd	Julie Smith	Melissa Fisher
Brandee Waite	Karine Finken	Michael Toukan
Brain Disease Advocates	Kathy and Sara LaFone	Nicole DeLeve
Colleen Franzreb	Katarina Dominguez	Nicole Petrie
Dan Keuning	Kay Webb	Niki Toscani
Deborah Binkley	Kiley Kocian	Paul Larsen
Diana Gathright	Kim Rice	Rachel Silva
Diana & Sandra Gonzalez-Moret	Kristen Celusniak	Rebecca Wellner
Donna Champion	Lauren Rose	Robin Staver
Elizabeth Perry	Libba Adams	Sharon DeFelices
Esther Harvey	Lisa Jacobs	Sheila Walker
Jamie Hale	Liz Matthews	Stephanie Berry
Jen Morabito	Liz Zadnik	Steve Akers
Jennifer Keepes	Lynda Nagle	Susan Newman
Jerry Horn	M. Taffett	Terry Pontious
Jessica McGuire	Margie Wood	Terry Walter

CAMPAIGN SPONSORSHIP SHOUTOUT: Philadelphia-based Passage Bio joined this year's Food for Thought campaign by hosting a food drive, collecting nonperishable items for local nonprofit food banks. We deeply appreciate Passage Bio's generous sponsorship of this year's campaign, furthering AFTD's mission for the people we serve, and for raising awareness of this disease.



AFTD's Events Department would like to extend an additional, special "thank you" and recognition to the four Food for Thought Liaisons who went above and beyond in helping make this campaign a success!

Zoy Kocian	Meghan Roscoe
Susan Meagher	Elaine Rose

INDEPENDENT EVENTS

THANK YOU, SIDORIS FAMILY: The 18th annual George F. Sidoris Memorial Golf Outing was held on July 29 at the Lost Nation Municipal Golf Course in Willoughby, Ohio. Through their tremendous efforts, they raised \$58,000 for AFTD's mission. This event is AFTD's longest-running grassroots fundraiser and has donated a grand total of over \$373,250! Congratulations to the Sidoris Family and thank you for your continued and notable support!



ROSE TO THE OCCASION: Christin Rose and her family hosted the First Annual Kim Rose Cure for Dementia Wings & Rings Golf Outing on June 30 in honor of Christin's mother-in-law, who was diagnosed with FTD in 2018. Their event raised \$31,542 and brought an immeasurable amount of awareness. The event was so successful that they have already started planning a second event for next year!

CWM-PRESSIVE!: On July 17, the Moretti family hosted the 8th Annual CWM Golf Outing at the Yankee Springs Golf Course in Wayland, Mich., in memory of Carl Moretti, who passed away from FTD in 2015. The day featured an 18-hole shotgun start, a four-person scramble format, an award for best dressed, closest to the pin, and the longest drive, as well as a concert and dinner raising \$14,828.

LOOKING SHARP: On September 2, Deb Scharper held her 7th Annual Crusade for a Cure Golf Tournament at the Sunny Brae Golf Course in Osage, Iowa. She raised \$12,000, bringing her grand total to \$61,833 for AFTD's mission and research efforts.

SHE IS IRONMAN: Laura Krey from Jackson, Wyo., raised over \$5,942 by competing in the famous Ironman race in New York on Sept. 23 in honor of her parents, Peter and Gianna. Peter was diagnosed with FTD over five years ago, and Gianna is the family's rock throughout it all.

AFTD IN ACTION: Several members of AFTD's staff raised \$4,430 for our mission by participating in the Marsh Creek Triathlon on Sept. 17 in Downingtown, Pa. Together, Michael Mullan (Volunteer Services Manager), Ray Frattone (Education Coordinator), and Bridget Graham (Events Director) crossed the finish line.



SHARING THE LOVE: Justin Cline and Kara Abshire spread the love on their wedding day, asking guests to make donations to AFTD in lieu of gifts in memory of Justin's father, Larry Cline, who passed from FTD in 2012. Their guests generously donated \$4,369 to advance AFTD's mission.

THE WALKING SPREAD: Tammy Clement and her husband, Barry, attended the Alzheimer's Walk event on Sept. 9. The duo wanted to spread awareness for the disease that her husband faced, and hand out information to anyone who asked during the walk. They raised FTD awareness and \$2,698 for our mission.

WINNING IN THE WINDY CITY: Hannah McCarthy laced up her shoes and crossed the finish line in the Chicago Marathon on Oct. 8 in honor of her father, Mike, who died from FTD. Hannah's father loved running and was always supporting his daughter at her cross-country races. She raised \$2,534 and spread much-needed FTD awareness.

AFTD's driving hope tournament



AFTD's 2023 Driving Hope Golf Tournaments were held at the Colorado National Golf Club in Erie, Colo. on Aug. 13 and the Metropolis Golf Club in White Plains, N.Y. on Oct. 10. Attendees enjoyed two fantastic days on the courses, and we were astounded by the immense generosity of our sponsors, participants, and supporters. The events raised a record \$152,182 for our mission!

AFTD would like to extend a sincere thank you to everyone who supported these events, especially our generous sponsors:

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The Mike Walter Named Fund

George L. Ohrstrom Jr. Foundation

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Joe & Kathy Mele

Steven Newhouse

Hole Sponsors

Law Offices of Adam J. Roth

Alan and Joan Berlin

Blake and Brian Rose

Bronze Sponsor

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AFTD would also like to take this opportunity for a special shoutout to the tournament's committee: Daniel Hedaya, Brian Rose, Michael Stowell, Joan Berlin, and Jason Nagin.



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