



# AFTDnews

## First Annual Holloway Summit Focuses on Digital Assessment Tools for FTD

Leaders in FTD science, neurodegenerative disease research, and digital tool development gathered in Miami on May 18-20 for the first annual Holloway Summit, to discuss digital assessment tools and their potential applications in tracking FTD symptoms and aiding in clinical trials.

Hosted by AFTD Board member Kristin Holloway, the 2022 Holloway Summit was the first in an series that will focus on a different topic each year. In 2021, Ms. Holloway generously established the Holloway Family Fund at AFTD, making the Holloway Summit series possible.

The phrase “digital assessment tools” refers to emerging technologies that allow researchers to use smartphones, wearable trackers, or other devices to remotely gather data on a person’s symptoms or function. For clinical trials, such tools have the potential to reduce travel burden, lower costs, and answer research questions with fewer participants.

At the Holloway Summit, attendees discussed and shared progress in the development of tools to assess FTD symptoms, evaluating cognition and behavior; speech and language; motor speech and swallowing; gait and posture; and functioning in activities of daily living.



Attendees highlighted the remarkable potential that digital assessment tools have to allow people living with FTD to participate in clinical trials from the comfort of their own homes. Eliminating the burden of having to travel to a research center both encourages greater clinical trial participation and can help to increase diversity in such trials (by including people who live in rural communities, for example).

“The application of digital assessment tools has game-changing potential for FTD clinical trials,” said AFTD CEO Susan L-J Dickinson. “Our fervent hope is that they accelerate the development of effective treatments that our community so desperately needs.”

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## 1,200+ Join AFTD’s Annual Education Conference to Connect, Learn, and Engage

AFTD’s Annual Education Conference brought together more than 1,200 people on April 8 for an opportunity to connect, learn, and engage with others who truly understand the disease.

Persons diagnosed with FTD, care partners, caregivers, researchers, health care professionals, and industry experts attended

the 2022 Education Conference, both at the BWI Airport Marriott near Baltimore and virtually. Nearly 200 people attended in Maryland for the first in-person

Conference experience since 2019, while more than 1,000 registrants from 29 different countries joined via livestream.



Conference Keynote Speaker Rita Choula

The day contained presentations focusing on the latest strides in FTD research, the diverse care partner experience, and the language of dementia, presented by experts in FTD. Attendees also participated in interactive virtual and in-person breakout sessions that offered practical information for persons diagnosed, care partners, and healthcare professionals.

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## Spotlight on...Jary Larsen, PhD, AFTD Board of Directors

Jary Larsen's late brother Peter learned to play the clarinet and saxophone as an adult. A life-long jazz and classical music fan, Peter soon became adept at both. But he gradually lost the ability to play the instruments, or even put them together, as his FTD symptoms worsened. Peter died in 2013 at the age of 64, seven years after his diagnosis.

Jary has held onto his brother's clarinet, and even tried to learn to play it himself, although never to the same level that Peter did. But Jary has found other ways to honor his brother's memory, including by serving on the AFTD Board of Directors.

As detailed in a January 2020 *Boston Globe* article, Peter had a variation in the gene GRN, which has been linked to FTD. In the years since his brother's diagnosis, the article said, Jary "determined that at least 20 relatives going back four generations" also had the GRN gene

variant, including his father.

Jary, who previously served as AFTD Board Chair from 2013 to 2016, said he was "absolutely thrilled to be invited to return to the Board" in 2019. A neuropsychologist at the University of California, San Francisco, Jary's initial Board-related interest was FTD research. But since becoming affiliated with AFTD, he said, "it did not take me long to



Dr. Jary Larsen

learn that while research is extremely important, it's built on the back of advocacy, support, and all of the other services AFTD is providing," including support groups, Comstock grants, informational publications, and events such as the AFTD Education Conference.

Indeed, Jary said that attending the Education Conference each year has been the highlight of his Board tenure. "I always find it interesting to meet people who have found AFTD, to hear

their stories, and to see how they've benefited from AFTD – and to see the level of resilience that families facing FTD have," he said. "AFTD is creating this environment that is extremely welcoming of individuals with FTD."

For Jary, however, it always comes back to research. By funding research directly through awards such as Pilot Grants and Holloway Fellowships, and by increasingly cultivating relationships with pharmaceutical companies, AFTD is "laying the groundwork to help facilitate FTD research – not just basic research to try to understand the mechanisms of the disease process, but also to work specifically toward clinical trials," he said.

Jary says he is proud to represent AFTD at a time when "we are understanding these disorders more than ever, and doing a better job of educating neurologists and psychiatrists about how to diagnose these disorders." But, he added, "that doesn't mean our job is done. In fact, it's made us that much more aware of how much more work has to be done."

## AFTD NEWS BRIEFS

### AFTD Awards Latest Round of Pilot Grants

AFTD Pilot Grants provide seed funding to early-stage researchers, helping to fuel a career-long interest in FTD research. AFTD is proud to announce the recipients of the most recent round of Pilot Grants. Pathways for Hope Pilot Grants have been awarded to Aaron Burberry, PhD, of Case Western Reserve University (to research bacterial suppressors of neural inflammation in cases of FTD associated with a C9orf72 gene variation), and to Meysam Yazdankhah, PhD, of the Regenerative Research Foundation (for his proposal "Co-promoting autophagy and proteasome function to lower tau in FTD neurons"). Additionally, Alinka Fisher, PhD, of Flinders University in Australia, was awarded a Well-Being in FTD Pilot Grant to study potential applications of the behavioral intervention known as Positive Behavior Support for persons diagnosed with FTD.

### CECs Available for Some AFTD Webinars

AFTD has begun to offer continuing education credits (CECs) to attendees of certain installments in the AFTD Educational Webinar series. Attendees who watched AFTD's June 22 Healthcare Professional Educational Webinar on person-centered care in behavioral variant FTD (featuring Cynthia Clyburn and Dr. Lauren Massimo of the University of Pennsylvania) were eligible to apply for CECs via Rush University, which accredited the presentation. The next webinar to offer CECs will be held August 11, on primary progressive aphasia, and will feature Dr. Darby Morhardt and Dr. Emily Rogalski of Northwestern University; registration information is available at [theaftd.org](http://theaftd.org). All AFTD Educational Webinars are recorded and can be viewed on AFTD's YouTube channel. CECs are only available to those who watch the webinars live, however.

Helen-Ann Comstock, her husband Craig, and family in the 1970s.

# Support for the FTD Journey

*"This disease hits people when they are in the prime of their life. It can be financially devastating for so many."*

– Mark P., current FTD caregiver

The Comstock Grant program provides vital support, which Helen-Ann Comstock aimed to do when she founded AFTD in 2002, as a caregiver herself to her husband Craig.



In 2015, Mark P.'s wife Julia, who was working as a real estate agent, had trouble focusing and organizing her busy schedule. Following a series of appointments with multiple specialists, she was diagnosed with primary progressive aphasia at the age of 57.

Shortly after her diagnosis, Mark's wife retired. As her symptoms progressively worsened, Mark cut back on his work hours to better provide care for her.

Early in their journey, Mark visited AFTD's website and attended an annual Education Conference to learn more about her diagnosis. He also found information about the Comstock Grant program.

"There are significant expenses incurred with an FTD diagnosis – accessing help for at-home care, adult daycare services, specialized providers, and the everyday practicalities needed to maintain an adequate level of care and support – these things add up quickly," he said.

Since 2009, the Comstock Grant program, named in honor of AFTD's founder, Helen-Ann Comstock, has distributed more than 2,380 grants, up to \$500 each, to provide direct financial support to people navigating an FTD diagnosis. Quality of Life grants enable persons diagnosed to access services to improve their daily lived experience, while Respite grants help family care partners meet their own needs while caring for a loved one at home.

Mark knows the severe economic burden that FTD can impose on all affected by this disease. For him, and many others, the Comstock Grant program is a meaningful way to help alleviate some of the distress caused by an FTD diagnosis.

"A Comstock Grant can help with something as basic as me being able to take my wife to have her hair cut at the salon she went to before her diagnosis, since where she lives now cannot provide her that service," he said. "This financial support gives people a little breathing room when caring for someone with FTD."

**Will you make a donation today to support the Comstock Grant program,** to provide help and bring hope to people who are navigating an FTD diagnosis? A gift of \$500 can fund one grant, or any amount of your choosing will advance AFTD's work to improve the quality of life of people living with AFTD and drive research to a cure. Simply use the enclosed envelope, visit [theaftd.org](http://theaftd.org) and **click on the Donate+ button** at the top of the page, or **use the QR code.**



# Education Conference

(Continued from page 1)



L-R: AFTD Advocacy Manager Matt Sharp; Teresa Webb, Jennifer Lee, Cindy Odell, Anne Fergusson of AFTD's Persons with FTD Advisory Council

AFTD Board member Rita Choula, MA, Director of Caregiving with the AARP Public Policy Institute, delivered the event's keynote address, in which she shared her family's FTD journey. Choula, a former FTD caregiver for her late mother, called for those present to take bold, assertive action, whether advocating for themselves or a loved one who has been diagnosed, raising awareness within their community, or simply normalizing the lived experience of FTD.

"Being bold for all of us looks like advocating for those living with FTD with our state, local, and federal legislators when the opportunities present. Being bold means telling your story," she said. "This may be a rare disease by definition, but there is nothing rare about what those in this room – and virtually across the country – live with every single day."

AFTD's Persons with FTD Advisory Council, which works to inform AFTD's work from the perspective of people who are living with the disease, shared their vital perspectives in a session entitled "Guess Who's Here? We're Still Here!" To close the conference, AFTD's founder Helen-Ann

*"This may be a rare disease by definition, but there is nothing rare about what those in this room – and virtually across the country – live with every single day," said Conference Keynote Speaker Rita Choula.*

Comstock, CEO Susan L-J Dickinson, MSGC, and Board Chair David Pfeifer reflected on AFTD's 20th anniversary. They talked about how the organization started, its current progress, and their hopes for the future.

Additional featured speakers at this year's conference included AFTD Medical Advisory Council member Chiadi Onyike, MD, MHS of Johns Hopkins University; David Irwin, MD, and Laynie Dratch, ScM, CGC of the University of Pennsylvania; Tania Gendron, PhD, of the Mayo Clinic in Florida; and Angela Taylor of the Lewy Body Dementia Association.

The next Annual Education Conference will take place in St. Louis on May 5, 2023. AFTD anticipates that it will follow the same hybrid model as the 2022 event, with the option to attend in person or virtually.

For those who were unable to attend this year's event, recorded sessions from the 2022 Education Conference can be viewed on AFTD's YouTube page at [youtube.com/TheAFTD](https://youtube.com/TheAFTD).

**AFTD thanks the following sponsors for their generous support of the 2022 AFTD Education Conference**

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# AFTD-Supported Study Identifies Potentially Useful FTD Biomarker

Neurofilament light (NfL), a recognized biomarker linked to neurodegeneration, has been shown to be a potentially useful blood-based biomarker in identifying FTD, according to a recent study.

Researchers from the Mayo Clinic in Florida and members of ALLFTD, the multi-site North American consortium of FTD-focused research centers, confirmed the efficacy of NfL biomarkers in the FTD diagnostic process in a paper published in *Cell Reports Medicine* on April 19.

The researchers measured the amount of NfL protein in 1,000 participants currently living with an FTD disorder. They found that NfL levels were elevated both in persons with varying types of FTD disorders and in people who had genetic FTD mutations but have yet to show symptoms. Persons with higher NfL levels were found to have greater disease severity.

Findings from the new study could not only contribute to earlier diagnosis, but also inform the development and design of future FTD clinical trials, the researchers said.

Leonard Petrucelli, PhD, a neuroscientist at Mayo Clinic and a fellow corresponding author of the study, said in a press release

*Persons with higher levels of the protein neurofilament light in the blood were found to have greater disease severity.*

that the researchers created an “informational database comprising cross-sectional and longitudinal NfL data, along with demographic, genetic, clinical and neuropsychological data.”

Dr. Petrucelli, a 2019 recipient of an AFTD Biomarkers Initiative grant, added that the database is available to all FTD researchers and “is sure to ignite new lines of investigation on FTD spectrum disorders.” This research was partially supported by the Biomarkers Initiative grant that Dr. Petrucelli was awarded.

While this is a promising step in FTD research, more work will need to be done before regulators and clinicians will be able to implement NfL biomarkers in standard clinical care.

Persons diagnosed and their families, along with care partners/caregivers, can help to further advance research on NfL and other potential FTD biomarkers by providing essential blood and cerebrospinal fluid samples through participation in research studies with ALLFTD and other related studies.

For more information on how to participate in research studies with ALLFTD, visit their website at [www.allftd.org](http://www.allftd.org).

## Holloway Summit

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At the Holloway Summit, attendees worked together to identify and address questions that need to be answered before digital assessment tools can reach their full potential. For example, the question of which digital biomarkers should be collected, and how they should be measured, were prominent topics of discussion.

Additionally, for digital tools to be used to their fullest in clinical trials, they must be validated to the satisfaction of the U.S. Food and Drug Administration. Attendees talked about the many steps involved in that important process, as well as the challenges of data management – how digital biomarker data are curated, managed, and privacy-protected.

Kristin Holloway’s husband, Lee Holloway, a co-founder of the internet security firm Cloudflare, was diagnosed with FTD in 2017. “There could not be a more appropriate focus for our first Summit in Lee’s honor than digital assessment tools

for FTD,” Ms. Holloway said.

Naomi Nevler, MD, of the University of Pennsylvania, and Jonathan Rohrer, MD, of University College London and the Genetic Frontotemporal Dementia Initiative (GENFI), served as Summit co-



*Dr. Adam Boxer of UCSF (left) moderates an industry panel on FTD digital biomarkers.*

chairs. AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD, and AFTD Director of Grants and Research Debra Niehoff, PhD, served as Summit planning co-leads.

Other participants in the invitation-only meeting included representatives from the pharmaceutical industry; researchers and advocates in Alzheimer’s, ALS, Parkinson’s, and autism; experts in digital tool development; and a representative from the FDA’s Digital Health Center of

Excellence. These differing perspectives offered a chance to identify challenges, lessons learned, and a way forward to improve diagnosis and evaluate treatments more effectively.

In her welcome speech for attendees, Ms. Holloway reflected on the experience of AFTD founder Helen-Ann Comstock. “In 1978, a neurologist from Stanford informed [Helen-Ann] that her husband had a form of Alzheimer’s. When she asked what she could do, he informed her to ‘take her husband home and be prepared for some changes.’

“How is it that more than 40 years later, this is still the response young families are receiving when given an FTD diagnosis?” Ms. Holloway added. “I cannot, and will not, accept this.”

Ms. Holloway’s resolve – and the compassion and insight of attendees – offered hope that we can change the paradigm of FTD diagnosis and treatments, to the benefit of so many families.

# Those We Honor... Those We Remember

*Gifts received from February 16, 2022 – May 15, 2022*

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# Donald Newhouse Honored at AFTD's 2022 Hope Rising Benefit

AFTD honored Donald Newhouse – an AFTD Board member, volunteer, and long-time supporter – at its 2022 Hope Rising Benefit on March 30 in New York City.

AFTD honored Mr. Newhouse with the Susan Newhouse and Si Newhouse Award of Hope for his leadership and contributions to a deeply personal cause: bringing forward a world with compassionate care, effective support, and a future free of FTD.

Mr. Newhouse lost his wife, Susan Marley Newhouse, to FTD in 2015. By what he describes as a “quirk of fate,” he also lost his brother Si Newhouse (then co-owner with Donald of Advance Publications) to FTD in 2017.

Paula Zahn, Emmy Award-winning

journalist and executive producer and host of Investigation Discovery's *On the Case with Paula Zahn*, emceed the event for a fifth year. *Vogue* editor-in-chief Anna Wintour and Discovery Inc. CEO David Zaslav served as Benefit Chairs.

“I am [being] honored this evening because we could not bring every family affected by FTD onto this stage,” Mr. Newhouse said during his acceptance

*“AFTD turns the hopes of the sufferers into action,” said AFTD Board member Donald Newhouse at the 2022 Hope Rising Benefit.*

speech. “I ask you to use your imagination to see more than 60,000 families and so many more from around the world crowded onto this podium, each with their



AFTD Board member Donald Newhouse

own unique story but united by the painful journey they have collectively endured.”

“As you have heard tonight, AFTD funds research and efforts to increase

awareness of FTD,” he added. “AFTD turns the hopes of the sufferers into action.”

More than 375 people attended the 2022 Hope Rising Benefit at New York's Ziegfeld Ballroom, the first in-person Hope Rising Benefit since 2019. The event drew in \$2.2 million to support AFTD's mission, the highest amount raised since the Benefit began in 2016.

## AFTD's HelpLine: A Vital Resource for Families Facing FTD

Since 2005, AFTD's HelpLine has been an essential source of support and information for persons living with FTD, their care partners and caregivers, and healthcare professionals who want to better understand the disease.

The only FTD-focused helpline available in the U.S., the AFTD HelpLine is a free service available by dialing 866-507-7222 or by emailing info@theaftd.org. Through the HelpLine, AFTD staff provide the most current, accurate, and professionally vetted information about FTD, guidance about managing symptoms, ways to access local (as well as national) resources and services, and advice on navigating life with the disease.

Once staffed entirely by volunteer AFTD Board members, the HelpLine is today managed by AFTD's dedicated HelpLine team: HelpLine Manager

Stephanie Quigley, MSW, LSW, CDP; HelpLine Specialist Ann Schoonover, MSW, LSW; and HelpLine Advisor Josephare Joseph, MSW. They ensure that each HelpLine inquiry receives an individualized, supportive, and timely response. “We do our best to be supportive and offer empathy while providing the most useful information

*No matter where an individual is along the FTD journey, the HelpLine can be a vital resource.*

possible based on each person's circumstances,” Joseph said.

In 2021, the HelpLine responded to more than 2,300 inquiries. The HelpLine team aims to answer all calls or emails within 24 hours after being received by HelpLine staff. The HelpLine has now implemented translation services containing more than 200 languages such as Hindi, Spanish, and Mandarin.

No matter where an individual is along the FTD journey, the HelpLine can be a vital resource. “We receive calls and emails from families throughout the journey, including those concerned about changes they are seeing in themselves or a loved one, those facing a new diagnosis, navigating the late stages of FTD as well as questions after a loved one has passed,” Schoonover noted.

Joseph added that the HelpLine is “an open door and can be the first step in learning more about the disease.”

The HelpLine is also available for those in need of emotional support and assistance with managing care. Respondents can be connected to local support groups, receive information on facility care options, and learn about additional support services.

# AFTD Recognizes Volunteers at Second Volunteer Appreciation Dinner

For the first time since 2019, AFTD welcomed new and returning volunteers to its annual Volunteer Appreciation Dinner on April 7 in Baltimore, thanking those who have continued their efforts to advance AFTD's mission despite unprecedented challenges over the last two years.

The event included remarks from Senior Director of Programs Sharon Denny, who shared several highlights of the Volunteer Program from the past year, including:

- 7 volunteers living with an FTD diagnosis served on AFTD's Persons with FTD Advisory Council
- 14 volunteer leaders served as Ambassadors, acting as local AFTD representatives in their communities and raising awareness through

professional outreach and speaking engagements

- 18 people served on AFTD's Board of Directors, providing leadership for the organization through a time of significant growth and change

*The dinner provided a special opportunity for our volunteer community to connect with fellow volunteers, spend time with staff, and simply enjoy a fun evening together.*

- 69 people served as advisors – professionals who volunteer their time on AFTD's Medical Advisory Council, the Partners in FTD Care Committee, on scientific review boards and as grant reviewers, among other activities
- 101 support group volunteers ran 79 FTD support groups, showing remarkable determination and resilience in adapting to virtual

meetings and extending critical support to care partners and caregivers

- 45 volunteers served as Food for Thought liaisons or orientation facilitators, hosted virtual Meet & Greet, provided Zoom support, or offered speaking engagements or presentations to raise awareness

- A record number of volunteers leveraged virtual outreach and engagement to host or participate in 608 grassroots fundraising events

In all, from July 2020 to June 2021 the number of active volunteers increased more than 14% over the year before, despite the pandemic. AFTD is grateful for all our hard-working volunteers!

## AFTD Ambassadors Convene for Volunteer Leadership Summit

On April 7, AFTD Ambassadors from around the country convened in Baltimore for the 2022 Volunteer Leadership Summit. This marked the first time Ambassadors and AFTD staff were able to meet in person since the inception of the Ambassador position in December 2019. AFTD Ambassadors are volunteer leaders who represent the organization in their area through networking, outreach, and speaking engagements.

Ambassadors spent the day connecting

with one another, reflecting on their work and accomplishments, meeting with staff, and learning about AFTD's next Strategic Plan. AFTD staff

*AFTD Ambassadors spent the day connecting with one another, reflecting on their work and accomplishments, meeting with staff, and learning about AFTD's next Strategic Plan.*

leaders from research, advocacy, and healthcare professional education met with Ambassadors to get to know each other and discuss these growing areas of focus. As important representatives for the organization, Ambassadors

will continue to work closely with staff in the coming years to help drive priorities under the new plan.

"After working with this incredible team virtually over last 2.5 years, it was so wonderful to finally meet in person and be in the same room together!" said AFTD Volunteer Coordinator Jeni Cardosi. "It's such a pleasure to support this strong, passionate, and skilled group of leaders who do so much to support AFTD's mission. We're so grateful for their dedication to this role."





**Hitting the Links:** The 11th annual Quest for the Cure Golf Tournament was hosted by the Robert M. Hatfield Foundation and took place on November 12, 2021, at the Bardmoor Golf & Tennis Club in Seminole, FL. The event raised \$8,500 for

AFTD's mission, increasing the annual Tournament's total amount donated to AFTD to \$80,764.

**A Sweet Tribute:** Jack Yablonowitz from Connecticut organized a March Madness bracket for his bar mitzvah project in memory of his zayda (grandfather), Howard Gould, who died from FTD. He asked his friends and family to donate \$18 to AFTD's mission along with their brackets. The top three brackets received sweet treats baked by Jack. Through his efforts, Jack was able to raise \$5,488.



## Running for a Cause

Abrar Tanveer participated in the Cincinnati Flying Pig Half Marathon on May 1, 2022, in memory of his father, Shakeel Tanveer, who died from FTD in 2019. This is the second time Abrar has participated in this race and fundraised

for AFTD's mission while doing so. He finished the course in under two hours, spreading critical FTD awareness throughout – and raised \$2,189 before he crossed the finish line.

**Birthday Wishes:** Alejandro Bolivar-Cervoni of Virginia has dedicated his last three birthdays to his mother, who is living with an FTD diagnosis. Before his birthday, Alejandro launches a fundraising page and asks his family and friends to "wish him a happy birthday" by making a gift in support of AFTD's mission. This year, he raised \$2,029, bringing his three-year total to \$7,806.



**Adventures with Chris:** Author Jack Livingston published his book *A Lot Like Fun – Only Different*, which features stories of his adventures with longtime friend, Chris Kelley, who is currently living with FTD. Jack is donating a portion of the proceeds from each copy sold to support AFTD's mission and has raised \$1,255 so far.

**Giving Back:** Ahmed Alnahhas from Florida set up a GoFundMe page to benefit AFTD's mission in memory of his stepfather Jose Luis Noyola, who recently died from FTD. On his page, Ahmed shares that his stepfather "would have wanted to help those who also suffer from this form of dementia and to give back to society." To date, his page has raised \$665 for AFTD's mission.



**Rocky Road:** Blake Ovard was set to host the second annual Cloud Gravel Invitational – a gravel cycling event – on June 17-19, 2022, in New Mexico's Sacramento Mountains. Unfortunately, dangerous

fire conditions caused the event to be postponed. When given the all-clear, participants will compete in one of four distances: 25, 55, 90 or 200 miles (with elevation gains ranging from 2,000 to 20,000 feet)! Blake's goal is to raise \$2,500 from the event for AFTD's mission in honor of his wife, Kim, who was diagnosed with FTD in 2015.



# THE AFTD-TEAM



The Association for  
Frontotemporal Degeneration  
FIND HELP • SHARE HOPE

## A “Thank You” From AFTD’s Fundraising Team

In the Summer 2021 issue of AFTD News, we announced that our 2020-21 fiscal year (July 2020 – June 2021) was our most successful year for our Grassroots Events program. Well, the numbers are in, and we’re honored to say that fiscal year 2021-22 (July 2021 – June 2022) was another successful year! Through volunteer-led fundraisers, a total of \$781,228 was raised to advance AFTD’s mission.

Heading into year two of the pandemic, our fundraising volunteers built on their dedication and perseverance to continue bringing international awareness to this disease and support to families on this journey.

We saw more opportunities to host in-person fundraisers and events in 2021 than 2020, but virtual – and especially hybrid – options remained a safe and inclusive alternative. Outdoor events allowed for people to resume gathering, including the successful return of our AFTD-Team Race Season campaign. Those who couldn’t participate in a formal racing event were able to log miles on the Charity Miles app, raising money and spreading awareness by posting their workouts on social media.

Our flagship campaign, Food for Thought, brought out people’s culinary skills, and last year, to spice things up, we combined it with the #FTDhotshotchallenge. A virtual campaign since its inception, With Love allowed our community to exercise their storytelling abilities through words, pictures, video – however they felt they could best express their stories of love. Finally, our fundraising volunteers got creative outside of our annual campaigns, planning and running fundraisers and events from their own imaginations.

On behalf of AFTD’s fundraising team, we want to thank all our fundraising volunteers who are driving AFTD’s mission forward.

Sincerely,

Bridget Graham, AFTD Events Director





The Association for  
Frontotemporal Degeneration  
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