All in to #EndFTD

July 2020–June 2021

2021 Annual Report

inside:

Dear Friends,

This past year has demonstrated more clearly than ever the value of community. The COVID-19 pandemic has robbed our families of in-person supports they once relied on, magnifying the isolation of the FTD journey. We have all had to adjust. I am proud to say that AFTD has found new ways to offer our full range of supports, services, and educational programs. Your support and engagement have been pivotal – demonstrating the power of a community *all in to #EndFTD*.

The resilience you have all shown has been nothing short of incredible. Local AFTD-affiliated support groups that once met in person pivoted to virtual settings. AFTD volunteers hosted successful virtual Meet & Greet events over Zoom. And, whether sharing stories of love during the With Love campaign, or feeling the burn during a vibrant, volunteer-organized #FTDhotshotchallenge, our community displayed extraordinary creativity in raising awareness and supporting our mission. The past fiscal year saw the largest number of donations received in the organization's history – helping AFTD to sustain and expand its work during a challenging year for all.

You showed up in droves for AFTD's 2021 Education Conference, held online over the course of two afternoons in May; approximately 1,200 people logged on to find help and share hope. And we found ways to support and inform families in need: AFTD's HelpLine responded to 2,383 inquiries from people with pressing FTD-related questions, while our Comstock grant program helped to alleviate the financial challenges of FTD for 303 families.

AFTD is building leadership to advance a future free of FTD. Over the past year, we brought aboard Dr. Penny Dacks as our Senior Director of Scientific Initiatives, Dr. Shana Dodge as Director of Research Engagement, Esther Kane, MSN, RN-CDP as Support & Education Director, and Cynthia Brown-Smith, MSHRD, PHR as our Director of Human Resources. And we promoted Dr. Debra Niehoff to the position of Scientific Director.

We are proud that AFTD can effectively assist so many facing FTD, but we know there is so much more to be done. To that end, two AFTD Board members made generous gifts, establishing significant funds to help expand our reach and sustain our work for years to come. AFTD Board member Kristin Holloway created The Holloway Family Fund to fuel breakthrough research and encourage the development of effective FTD treatments. Fellow Board member Donald Newhouse, meanwhile, established The Sudon Fund to accelerate and better sustain the full breadth and scope of AFTD's mission. I thank them both for going all in – and thank each of you for giving what you can to advance our shared mission.

While the pandemic continues to complicate our lives, it has not weakened our community. In fact, the opposite is true, as proven by the pages that follow. Your ardent, imaginative, and inspiring support – even amid the dual challenges of FTD and a global pandemic – was the spark behind every accomplishment detailed within this report.

I know the impact that FTD can bring to a family, and I know I'm not alone in wanting to do all I can to help others on this journey, and prevent this disease from affecting future generations. I want to thank you so very much for standing with me and all in our community, all in to #endFTD.

Sincerely,

David Pfeifer
AFTD Board Chair

awareness

This is us when we were young. And this is you. Loving father, doctor, artist, sailor… a real-life superhero who could do anything and make it look easy. But every superhero has their kryptonite.

This is a happy memory from those early days, before you started to become someone we didn't recognize. It took us almost 20 years to understand that it wasn't your fault, Dad.

At a young age, frontotemporal degeneration took everything from you, and took you from us. We're all grown up now, and we're fighting for a cure for FTD, this cruel disease that steals away so many, far too soon.

We love you, Dad. This #FTDhotshotchallenge is for you.

Paul, Michael, Amanda, & Matthew

Find out more about young dementia, read stories from our community, and take your shot: visit theaftd.org/hotshot

To Chris, my dear husband. The day we got my diagnosis… before we got home we stopped, and you put my hands in yours and you told me that you didn't know how, but you knew we'd make it. You said you'd make sure I had the best care possible… and you've done that. Your strength has never wavered.

To my kids, Erin, Gracie, Dylan, Devan, Jake, Libby, our Brady Bunch. You each have such special gifts. You're each using them now in such a positive way. You've been the greatest support system anyone could have. I want you to know that every single day, I tried my best for you.

To the world: You've probably never heard of FTD. I hadn't either when I got diagnosed with the speech variant of it at 41. I taught English for 17 years, until this disease took my career from me. I've had to readjust to life in ways I never imagined.

There aren't any effective treatments today, and I know all too well that this is a terminal disease. But I'm not giving up.

I found AFTD and a group of like-minded volunteers. Together, we've launched the #FTDhotshotchallenge. I drank a shot of hot sauce, and to be honest I usually can't even eat Taco Bell because it's too spicy. I'll do anything possible to fight this disease, and to leave a legacy for my children.

This is for my family. I love you always.

– Jennifer Lee

Find out more about young dementia, read stories from our community, and take your shot: visit theaftd.org/FTDhotshot

In fall 2020, two FTD awareness ads appeared in print editions of The New York Times*, thanks to support from a generous donor.*

Raising awareness of FTD is crucial to improving quality of life for families affected, and accelerating research to bring forward effective treatments and a cure. In collaboration with our donors and volunteers, AFTD is all in to educate the world about FTD.

In fall 2020, with the support of a generous donor, AFTD placed four ads in the *New York Times*. The ads, which appeared in print and online editions, featured letters from people affected by FTD, illustrating to millions the emotional toll this disease takes on families.

Our ad series also promoted the inaugural #FTDhotshotchallenge, an independent grassroots campaign led by more than 50 AFTD volunteers. Our community rallied around this campaign, challenging participants to drink a shot of hot sauce and share stories about FTD with family, friends, and audiences across social media.

AFTD volunteers showed their imagination and resolve by creating the #FTDhotshotchallenge, a social media awareness campaign that raised $110,000 for AFTD's mission.

Left: Grassroots advocates and FTD experts from across the globe shared FTD education and helped create awareness during the first-ever World FTD Marathon in October 2020.

Center: Kimberly Sullivan Chu talked about her mother, Linda, who died of FTD in 2020, on the Remember Me *podcast.*

For World FTD Awareness Week 2020, AFTD worked with the World FTD United coalition to present the World FTD Marathon. We hosted a six-hour block of this virtual event, drawing participation from people with FTD, care partners and former caregivers, researchers, and health professionals from North, Central, and South America. Three seminars were offered in Spanish. Advocates in Europe and Australia hosted additional sessions, contributing to more than 16 hours of vital FTD-oriented content.

To mark AFTD's 10th annual With Love campaign, we partnered with the FTD-focused *Remember Me* podcast, hosted by Maria Kent Beers and Rachael Martinez, both of whom lost a parent to FTD. Throughout February 2021, four AFTD volunteers generously shared their stories on the podcast, generating awareness and raising funds to support our mission.

Last year, nearly 420,000 people visited theaftd.org to learn more about FTD, find support, connect with others, and get involved in our mission. Across our key social media channels (Facebook, Twitter, Instagram, and LinkedIn), AFTD shared resources, support, and information to more than 25,000 followers.

Throughout the year, new media outlets shared FTD stories. Jennifer Lee, who is living with primary progressive aphasia, and Dan Keuning, diagnosed with behavioral variant FTD, were profiled in *STAT News*, a Boston Globe Media production. AFTD Medical Advisory Council members Bradford Dickerson, MD, and M.-Marsel Mesulam, MD, shared their insights with *The Washington Post*. And Board member Kristin Holloway shared her story with the *San Francisco Business Times*.

Amanda Dawson and her family struggled for years to understand the dramatic changes to her father's personality and behavior. Twenty years after the changes began, he was diagnosed with behavioral variant FTD, and Amanda found a new purpose in her life: "to find creative ways to engage people and raise awareness of FTD." Amanda and a dedicated group of volunteers created the #FTDhotshotchallenge, a social media challenge aimed at raising awareness for FTD and funds for FTD research. "My entire extended family participated," Amanda said. "We don't often talk to each other about FTD – let's be honest, it's heartbreaking. But they showed up and took the challenge, unprovoked by me. It meant the world to me." She added,

> "Everyone touched by FTD feels an urgent need for better care, treatments, and a cure. That's the dream."

support

AFTD works every day to improve quality of life for persons diagnosed, care partners, and family members. By expanding our network of support, empowering volunteers to educate medical professionals, and developing new resources, AFTD is expanding access to support and care for all affected by FTD.

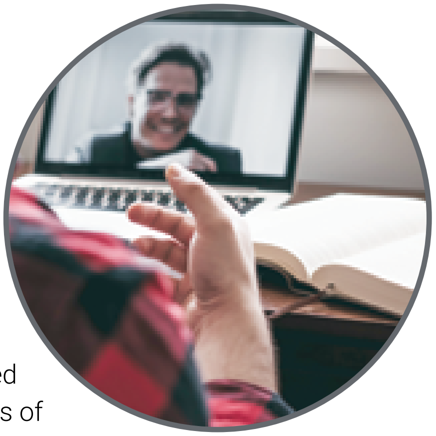
The AFTD HelpLine, accessible via email and by phone, is a frequent first point of contact for people seeking more information about FTD or help to navigate the journey. Last year, AFTD's HelpLine offered individualized guidance and assistance to 2,383 people.

AFTD's network of support adapted to pandemic conditions, ensuring that anyone who wants help can still find it through an option safely accessible to them. In the past year, 101 AFTD-affiliated volunteers facilitated 79 Support Groups, primarily online via Zoom. For people who could not previously attend support groups in person, these online meetings offered ways to find help and connection – often for the first time

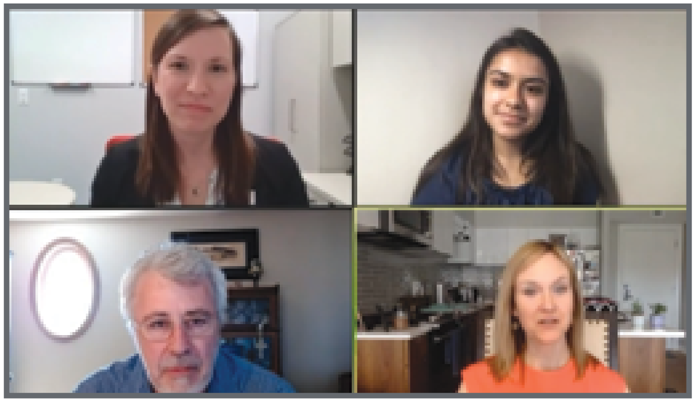
Last year, AFTD distributed 303 Comstock Grants, which help to alleviate FTD's economic burden. Respite Grants pay for services that benefit the physical and emotional well-being of FTD caregivers, while Quality of Life Grants help people living with FTD to buy anything that eases their journey.

Help & Hope, AFTD's monthly e-newsletter, offers updates about current and upcoming events, resources, engagement opportunities, and personal stories. Throughout the pandemic, this newsletter has focused on ways to connect with others, the status of FTD research and clinical trials, and ways to navigate FTD care in a changing world. *Help & Hope* reached more than 9,200 subscribers last year.

AFTD's continued growth has helped us to better meet the evolving needs of the community we serve, even in these most challenging of times. Throughout the year, we responded to the pandemic by offering tailored resources and guidance on navigating both COVID-19 and FTD, and by providing virtual opportunities to connect with others for support. With input from AFTD's Medical Advisory Council and FTD experts, we provided robust, up-to-date information about the pandemic's impact on people affected by FTD in the COVID-19 and FTD section of theaftd.org.



Throughout the year, support groups led by more than 100 AFTD-affiliated facilitators allowed those on the FTD journey to forge crucial connections, primarily through Zoom.



AFTD volunteers joined AFTD HelpLine Specialist Ann Schoonover to talk about providing FTD care when you aren't the primary caregiver.

Members of a Salt Lake City area support group took part in Food for Thought, raising funds in support AFTD's mission.

Finding Support: FY 2021

AFTD-Affiliated
Support Group
Volunteers: 101

↑83%
Comstock
Quality of Life
grants awarded:
154

HelpLine
calls and
emails
answered:
2,383

Members of
AFTD's Facebook
Group 6,892

Tanisha Gupta is passionate about helping other young adults navigating FTD. A recent college graduate, Tanisha grappled with feelings of helplessness following her mother's bvFTD diagnosis, while trying to best support her father in his role as primary caregiver. Seeing an opportunity in the rise of online engagement during the pandemic, Tanisha, along with AFTD volunteers and a local support group facilitator, worked to develop a virtual support group geared towards young adults nationwide.

> "It's very fulfilling to put my energy into something good," she said. "I can pass on what I have learned through my experience to help others who are feeling lost."

research

With support from our donors, and engagement from researchers, partner organizations, and volunteers, AFTD is advancing the science targeting FTD.

Last year, Penny Dacks, PhD, joined as Senior Director of Scientific Initiatives to lead strategy for AFTD's research programs and serve as President of the FTD Disorders Registry, building on efforts that have already enrolled 4,400 people. Debra Niehoff, PhD, was promoted to Scientific Director to administer AFTD's research grant programs, as well as plan our biennial FTD Treatment Study Group meetings. Shana Dodge, PhD, joined as AFTD's first Director of Research Engagement, to empower our community to participate in research vital to advancing treatments and a cure.

In March 2021, AFTD hosted a virtual Externally Led Patient-Focused Drug Development meeting with representatives from the U.S. Food and Drug Administration. Joined by 550 people from across our community, this one-time opportunity enabled people and families affected by FTD to share the impact of their FTD symptoms, their thoughts on genetic testing and clinical trials, and their perspectives on meaningful FTD treatment outcomes directly with the governmental agency that will one day approve them. Findings from the meeting – combined with results from an FTD Insights Survey conducted by AFTD and the FTD Disorders Registry – have been summarized in a public report released in October 2021.

Since 2005, AFTD's Pilot Grant program has provided essential funding for innovative early-career investigators who are in the process of establishing an independent research program. In the last 12 months, AFTD has awarded pilot grants to two talented researchers. Maria Catarina Silva, PhD, will seek to better understand tau protein aggregation in the brain, and generate insights and preliminary data to support therapies targeting tau-related FTD. Allison Lindauer, PhD, will test a telehealth technology approach to alleviating the burden on care partners in rural locations.

The Holloway Family Fund, established by AFTD Board member Kristin Holloway, honors her family's journey with FTD, and will drive basic, clinical, and translational research to accelerate the development of effective treatments. Notably, the Fund has enabled the expansion of AFTD's Postdoctoral Fellowship program. The first three Holloway Postdoctoral Fellowships have been awarded to researchers who will study early FTD detection and work to develop potential treatments for both

AFTD Board member Kristin Holloway established the Holloway Family Fund in April 2021. Her husband, Lee, was diagnosed with FTD in 2017.

Allison Lindauer, PhD

Awards and grants

Basic Science Pilot Grant – Maria Catarina Silva, PhD, Massachusetts General Hospital

Well-Being in FTD Pilot Grant – Allison Lindauer, PhD, Oregon Health & Science University

Accelerating Drug Discovery for FTD – Wen-Hsuan Chang, PhD, AcuraStem Incorporated; Anna Orr, PhD, Cornell University

Holloway Postdoctoral Fellowships – Matthew Nolan, PhD, Massachusetts General Hospital; Daniel Okobi, MD, PhD, University of California, Los Angeles; Hijai Regina Shin, PhD, University of California, Berkeley

FTD Insights Fellowship – Megan Barker, PhD, Columbia University Medical Center

Diagnostics Accelerator – Wesley Horton, MS / Foundation for the National Institutes of Health

C9orf72- and TDP-43-associated FTD.

Since 2007, AFTD has collaborated with the Alzheimer's Drug Discovery Foundation to drive the development of tools to diagnose and treat FTD, and to distinguish the disease from related dementias. Our Accelerating Drug Discovery in FTD grant program promotes preclinical research on promising new or repurposed drugs or therapies to treat FTD. Drug Discovery grants awarded last year will support researchers' work on different treatments targeting protein accumulation known to lead to FTD.

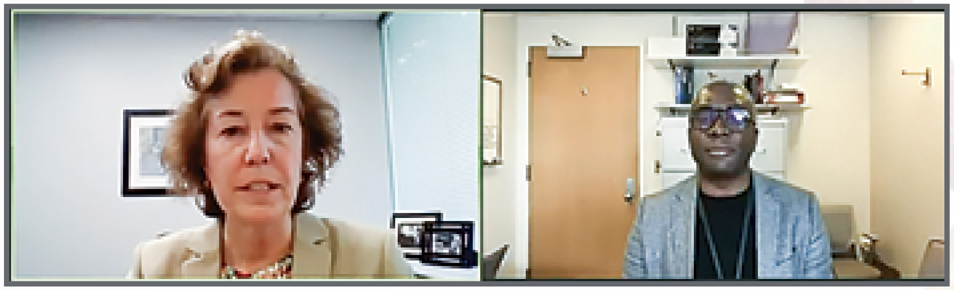
Anna Orr, PhD

Matthew Nolan, PhD

Daniel Okobi, MD, PhD, the recipient of a 2021 Holloway Postdoctoral Fellowship, has been passionate about understanding how disruptions to neurons and the neural network, such as those caused by a genetic mutation, can change a person's behavior and personality. With support from AFTD, Dr. Okobi seeks to detect subtle abnormalities that represent the earliest signs of FTD progression, which can potentially lead to earlier and accurate diagnosis.

> "There is a real need for organizations to want to support FTD research, so it is so important to me that AFTD is willing to invest in my work,"
> *Dr. Okobi said.*

education and advocacy



AFTD Senior Director of Programs Sharon Denny introduces Dr. Chiadi Onyike at the 2021 AFTD Education Conference.

Critical to our mission is educating healthcare professionals, community stakeholders, and policymakers about FTD – ensuring that FTD is diagnosed as early and as effectively as possible, and that people with FTD, care partners, and families have better access to high-quality care and support.

AFTD's 2021 Education Conference, broadcast online in May, drew the most attendees in the event's history. More than 1,200 people from nine different countries logged on to find help from FTD experts and share hope with others affected by this disease. For those unable to watch the event live, much of the Conference was recorded and can be viewed at aftdconference.org.

Over the past 12 months, *Partners in FTD Care*, an AFTD resource that identifies strategies for overcoming common challenges in FTD, published three issues focusing on logopenic variant PPA, corticobasal degeneration, and the pandemic's impact on people with FTD living in long-term care facilities.

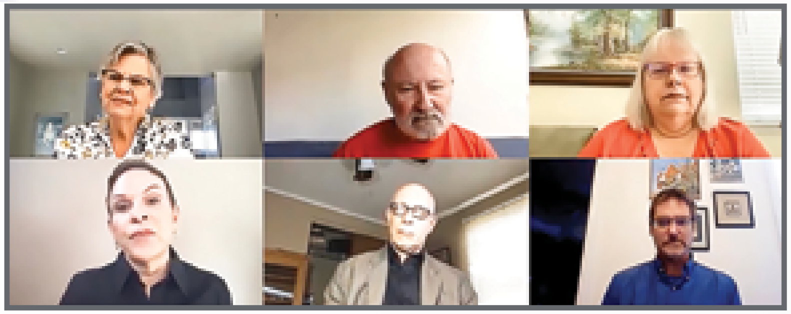
AFTD collaborated with clinicians, researchers, and professionals to develop four Educational Webinars. Topics addressed included the relationship between behavioral and physical changes in the brain, grief and FTD, genetic testing, and financial and legal planning. An additional webinar, produced in collaboration with the FTD Disorders Registry, focused on understanding familial FTD, gene therapy, and the roles that people and families can play in research.

AFTD has established three new staff positions that are essential to expanding our education and advocacy work. Esther Kane, MSN, RN-CDP, joined AFTD as our first Support & Education Director, then hired William Reiter, MA, as Education Program Manager. Both work to ensure that AFTD's educational programs advance early diagnosis and improve access to quality care and effective support. Meanwhile, Matthew Sharp, MSS, moved into AFTD's first Advocacy Manager role, in which he will coordinate our organization's growing advocacy initiatives.

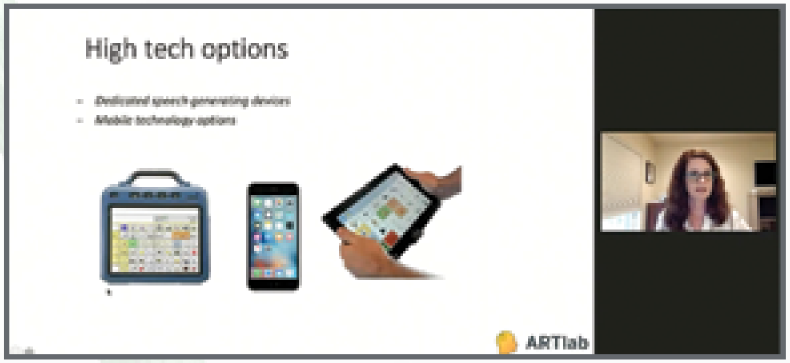
This past year also saw AFTD work with volunteers to create the Persons with FTD Advisory Council, to ensure that people living with FTD themselves directly inform how AFTD develops policies, programs, and services. Five members of the council led a panel discussion at the 2021 Education Conference, offering perspectives on the lived experience with the disease.

"As a volunteer with AFTD, I want to do as much as I possibly can to help ease the journey of others facing FTD. It's a privilege and a blessing for me to work with AFTD and all of the families I have had contact with over the years."

– Doreen Putnam, AFTD volunteer


The 2021 AFTD Education Conference featured a session presented by AFTD's Persons with FTD Advisory Council.


Movement-based FTD disorders was the focus of the Education Conference session pictured here.



Dr. Maya Henry of the University of Texas discussed primary progressive aphasia during the 2021 AFTD Education Conference.

"Educating and helping people has always been my calling," said Amy Shives, a former educator and social worker, who was diagnosed with bvFTD in 2012 at age 54.

> I get so much energy from working with my peers and finding ways to advocate for more awareness about living with FTD."

Amy has added to her already busy schedule by becoming an inaugural member of AFTD's Persons with FTD Advisory Council.

> "I want the Council to enlighten people about the lived experience of this disease. It is imperative that we do so for the betterment of people with FTD," *she said.*

volunteers and the AFTD-Team

> *"Connecting with other people who have been touched by FTD feels like finding long-lost friends who truly understand. This disease can be so isolating, but finding a community where others understand has been such a gift."*
>
> – *Kathy Urban, AFTD volunteer*

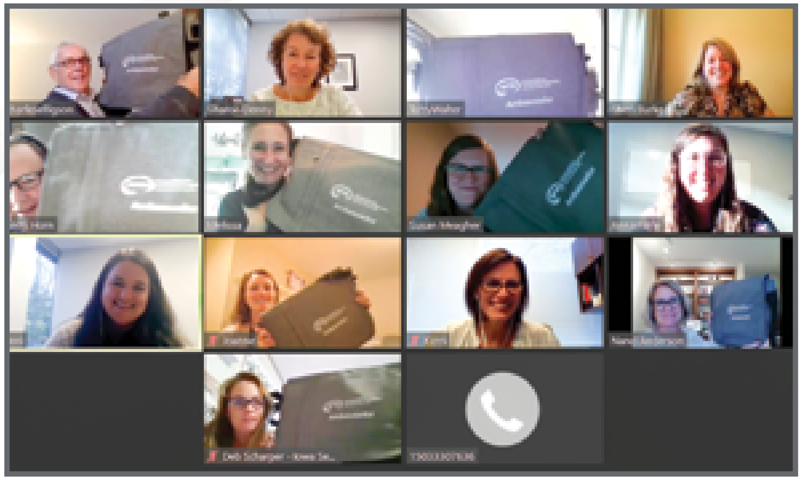
Volunteers founded AFTD in 2002; nearly 20 years later, they are crucial to advancing our mission, providing help and bringing hope to families facing an FTD diagnosis.

Despite the challenges brought about by COVID-19, AFTD's volunteer community grew this past year. More than 360 volunteers found new ways to have impact. Whether providing support for others affected by FTD, educating healthcare professionals, or driving our shared mission forward with creative and successful fundraising events, AFTD's volunteers were all in.

AFTD's volunteer Ambassadors gathered with AFTD staff for a virtual Volunteer Leadership Summit in fall 2020, identifying new ways to build relationships in their local areas, even during the pandemic. This dedicated group of 14 Ambassadors engaged with local and national nonprofit organizations, elder law attorneys, first responders, and other key stakeholders, spreading education and awareness in communities across the country.

For the 10th straight year, people affected by FTD shared their stories of love during our With Love campaign, held each February.

AFTD's
With Love
Campaign



AFTD Ambassadors gathered virtually for a Volunteer Leadership Summit, sharing ways that they can increase FTD awareness and education in their local areas.

When COVID-19 made Meet & Greet events impossible in local communities, AFTD volunteers held 18 Meet & Greets via Zoom. For some attendees who had previously been unable to attend in-person gatherings, these events provided new access to guidance and support from others who understand. Seven of these Meet & Greets were geared towards young adult care partners and family members.

AFTD's annual Food for Thought campaign, which brings people together to share food, drink, and FTD awareness, raised more than $143,000 in support of AFTD's mission. Amid pandemic restrictions, volunteers participated creatively: some gave virtual cooking demonstrations or shared favorite recipes. Others hosted virtual bake sales while sharing stories about their FTD journey. A total of 50 volunteers from 21 states hosted 40 events.

Held every February, the With Love campaign encourages people to honor and remember their loved ones diagnosed with FTD. By sharing their personal stories, participants help to raise vital awareness about the lived experience of the disease. To mark the 10th anniversary of With Love, AFTD partnered with the FTD-focused podcast *Remember Me*. This year, 29 With Love volunteers raised over $85,000! Special thanks to our two generous campaign sponsors: The Mike Walter Catalyst Fund and The Rainwater Charitable Foundation.

Every year, the AFTD-Team Race Season provides an opportunity for volunteers to raise funds, step-by-step, mile-by-mile, to help

Whether racking up miles and raising funds via the Charity Miles app or holding creative virtual grassroots events, the AFTD-Team was all in!

families who are facing FTD. After most in-person races were canceled, AFTD partnered with Charity Miles, an app that tracks physical activity, and cheered our volunteers as they ran, walked, or biked to raise funds to further AFTD's mission. Since our partnership began, 1,280 participants have moved 436,304 miles, and with help from our committed volunteers and generous sponsors, Alector and Arden Courts, an additional $50,000 was raised in support of the community we serve.

We modified AFTD's 2020 Driving Hope Golf Tournament to take place safely as pandemic conditions evolved. During a one-week period – timed alongside World FTD Awareness Week – golfers across the country joined our special event by playing in small groups at one of our participating courses, or by playing their own course and donating to AFTD. Altogether, the event raised over $46,000 for our mission.

An additional 97 volunteers hosted their own independent grassroots fundraising events outside of the above branded campaigns, raising over $283,000 combined for AFTD's mission. Notably, a dedicated group of advocates and volunteers created the #FTDhotshotchallenge, an independent campaign that raised more than $110,000.

Each year, the AFTD-Team combines delicious food and FTD education during AFTD's flagship grassroots campaign, Food for Thought.

> “Volunteering brings healing to your heart, and healing to others,”
>
> *said Terry Walter, whose husband Steven lived with ALS-FTD before he passed away in 2007. Her experience, combined with a dedication to addressing the challenges faced by families carrying the C9 mutation that causes ALS and FTD, led Terry to begin volunteering with AFTD in 2008; today she is an AFTD Ambassador. “Knowing that my own family is at risk, as well as so many others,” she says, “I will do whatever I can to help.”*

named funds and donors

JENNIFER IS AN ACTIVE VOLUNTEER AND SPOKESPERSON FOR AFTD.

SHE SHARED HER FAMILY'S STORY IN A PSA APPEARING IN *THE NEW YORK TIMES*.

DR. SU IS USING INNOVATIVE 3D CRYO-ELECTRON MICROSCOPY TO MAP PROTEINS RELATED TO THE C9ORF72 GENE. STABILIZING THESE PROTEINS COULD ULTIMATELY LEAD TO EFFECTIVE FTD AND ALS TREATMENTS.

Although it had to be held entirely online due to COVID-19 restrictions, AFTD's 2020 Hope Rising Benefit was another successful event, raising crucial funds to support AFTD's mission. Jennifer Lee and Dr. Ming-Yuan Su spoke about their passionate involvement in fulfilling AFTD's mission at Hope Rising.

AFTD Named Funds honor or memorialize loved ones on the FTD journey. Established with a minimum contribution of $25,000, AFTD Named Funds represent our mission's most generous gifts. Named Fund donations advance the science of FTD and improve care and support for families navigating this disease. AFTD is proud and grateful to recognize these contributions.

The Dr. Lawrence Albert Memorial Fund
Established by Kathi and Peter Arnow

The Michael E. Fenoglio, M.D. Memorial Fund
Established by the Rocky Mountain Surgeons Consortium

The Mimi Fund
Established by her loved ones

Kevin M. Harvey Memorial Fund
Established by The Connecticut Frontotemporal Dementia Foundation, Inc. via the Harvey Family

The Holloway Fund for Help and Hope, in Honor of Lee Holloway
Established by the Holloway Family

Laden Memorial Fund
Established by the Laden Family

Susan Marcus Memorial Fund
Established by Jillian Marcus and Larry Neubauer

The Suzy Fund
Established by the Newhouse Family

The Jackie Pang Memorial Fund
Established by the Pang and Torres families

Shepherd/Stowell Fund in Honor of Care Partners
Established in tribute to all Care Partners and Caregivers

The Mike Walter Catalyst Fund
Established by the Mike Walter Family

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

1,000,000+

The David Geffen Foundation
Ms. Kristin Holloway, establishing The Holloway Family Fund at AFTD
Mr. Donald Newhouse, establishing The Sudon Fund at AFTD
Samuel I. Newhouse Foundation Inc.

100,000-999,999

Bank of America
Discovery Inc.
George L. Ohrstrom, Jr. Foundation
Judy & Leonard Lauder

50,000-99,999

Charter Communications
Citi
The Farley Chang Gang
Ganzi Family Foundation
Mr. & Mrs. Gary Johnson

The Milburn Foundation
Joanna & Daniel Rose
Stavros Niarchos Foundation
Mrs. Beth Walter
William Randolph Hearst Foundation

20,000-49,999

Alector
Kathi & Peter Arnow
Bloomberg Philanthropies
Christie's
Eli Lilly and Company Limited
Goldman Sachs Private Wealth Management - Martin Packouz/ James Herring
Mr. Andrew Intrater
J.P. Morgan
Mrs. Susan Laden
Carol Sutton Lewis & William M. Lewis, Jr.
Mr. Philip H. Lovett
Ms. Jillian Marcus
McDermott Will & Emery LLP
The Miron Family
Mr. Laurance Nagin
Ms. Lisa Boyce & Mr. Kevin O'Neill
The David E. Reese Family Foundation
The Edward John & Patricia Rosenwald Foundation
Shearman & Sterling LLP
Mrs. Bonnie Shepherd
Sullivan & Cromwell LLP
Allyson Tang
The Connecticut Frontotemporal Dementia Foundation, Inc.
The Rainwater Charitable Foundation

10,000-19,999

Acadia Pharmaceuticals
Alzheimer's Association
Alzheimer's Drug Discovery Foundation
Anonymous
Mr. & Mrs. Steven P. Bellwoar
Biogen
Magda & Edward Bleier/ The Dana Foundation
Mr. Timothy L. Broer
Mr. Rick Childs
Colonial Electric Supply
Rocco Commisso
CurePSP
Dementia Society of America
Jennie & Richard DeScherer
Bruce Dixon
Gregory Dolphin & Family
Evercore
Florence V. Burden Foundation at the recommendation of Foundation Director & Family Member, Frederick Childs & his daughter, Elizabeth Childs
Fred & Jean Allegretti Foundation
Mindy & Jon Gray
Christina Mohr & Matthew Guerreiro
Mrs. Clare T. Hall
Brian Hamilton
Mrs. Susanne Louise Hedaya
Houlihan Lokey
Dr. Gene Huebner
Mr. Paul T. Jones
KPMG LLP
Mr. Roger Langeliers
Liberty Broadband
Allison F. & Joseph J. Magliocco
Mary Beth Repasy Fund for Progressive Supranuclear Palsy Research of The Dayton Foundation
Mr. Jonathan Nagin
NEPC, LLC
The Jackie Pang Fund
Passage Bio Inc.
Arnold S. Penner & Madaleine Penner Family Foundation
Mr. David C. Pfeifer
Prevail Therapeutics
ProMedica Senior Care
Mr. & Mrs. Edward J. Quinn, Jr.
Mr. Rhett Reese
Mr. & Mrs. Charles Riviezzo
Mr. & Mrs. Timothy Romani & Family
Mr. Arthur J. Sommers
Jerry Speyer
Dr. Michael Stowell
Sydney Licht & Tom Summer
The Bluefield Project to Cure Frontotemporal Dementia
The Green Fund, Inc.
Tobias Meyer & Mark Fletcher
UCB Biopharma SRL
Wave Life Sciences
Willkie Farr & Gallagher LLP

5,000-9,999

AbbVie
Ms. Gail Andersen
Angelo Gordon & Co, L.P.
Anonymous
Mr. & Mrs. Steve Balazs
Mr. Mark Baron
Barr Family Giving Fund
Mr. & Mrs. Ted M. Beal
Mary & Dick Benioff
Joan Beranbaum
Mr. Damon Billian
Amy Kreitzberg & Rich Bonaventura
Brazill Brothers & Associates
Denali Therapeutics
Mr. Michael Dircksen
Mr. Joseph Esposito
Ms. Virginia Frazier
Dr. Gabriel Fried
Allen and Lola Goldring Foundation
Mr. Ben Hauber
Renata Hesse
Mr. Christopher Hogan
Mr. David A. Hutchison
Mr. Michael Irvine
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2,500–4,999, continued

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We are grateful to our recurring donors, who have generously committed to donate to AFTD on a monthly or annual basis to sustain our work throughout the year.

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** Denotes $1,000 or more given through recurring donations in FY2021*

fundraisers

During a year when gathering in person was impossible for many of us, the AFTD-Team showed an inspiring amount of resolve, creativity, and determination. Together, the AFTD-Team hosted 608 grassroots events and Facebook fundraisers, raising more than $806,000 in support of our mission! (All events shown here brought in at least $1,000, and are listed in descending order for each category.) AFTD thanks our extraordinary volunteers for proving they are truly all in to #endFTD.

Independent Events

Amanda Dawson
#FTDhotshotchallenge

Jason Nagin
Olympic Distance Triathlon

Jeff Saksa
IMO Karen Saksa

Paul Lester
13th Annual Letters for Arnette

George Sidoris & Christine Sidoris
14th Annual George F. Sidoris Memorial Golf Outing

Matthew Hatfield
Robert M. Hatfield 10th Annual Quest for the Cure Golf Tournament

Barbara Todd
IHO Mike Todd

Danny Hedaya, Brian Rose & Michael Stowell
Driving Hope Silent Auction

Debbie Fenoglio
#FTDhotshotchallenge

Deb Scharper
4th Annual Crusade for a Cure Golf Tournament

Paul Petras & Serina Cline
Shawnee 50 Mile Trail Run

Brian Strohm
#FTDhotshotchallenge

Robert Powers
IHO Donald Clement

Carol Friedrichs, Russ Friedrichs & Leia Lumsden
Climbing Half Dome

Hunter Javeline
Bar Mitzvah Chesed Project

Jim Lyne
#FTDhotshotchallenge

Lauren Hafer
Sharon's Strength

Alejandro Bolivar-Cervoni
30th Birthday

Diana Thompson
#FTDhotshotchallenge

Terry L. Walter
#FTDhotshotchallenge

Caroline Dultz
#FTDhotshotchallenge

Tracey Lind
Eroding Beauty

Moretti & Marcy Families
5th Annual CWM Golf Outing

Susan Dunbar
#FTDhotshotchallenge

Nicole Petrie
Funding the Fight

Jason Strohm
#FTDhotshotchallenge

Cindy Odell
#EndFTD Masks

Blake Ovard
Cloud Gravel Invitational

Veronica Wolfe
Pilates for AFTD

Barbara Dawson
#FTDhotshotchallenge

Megan Bray
#FTDhotshotchallenge

Jack Livingston
A Lot Like Fun – Only Different

With Love

Remember Me Podcast
John Kammerer
Kendra Clabo
Anthony Cordasco
Carol Almeranti
Cathy Gardner
Julie Kelly
Kathryn Primeau
Bonnie Shepherd
Scott Rose
Melissa Fisher
Stephanie Kipp McLain
David Andrews
Kim Flanagan
Hannah Moore
Kristin Pursley

Race Season

James Staten
Veronica Wolfe
Ali Vandenberg
Deanna Lindberg
Bre Vandenberg

Charity Miles

Michelle Greco

Food for Thought

Steven Bellwoar
The Costello Family
The Pang Family
Bonnie Shepherd & Catherine Sharpsteen
Deborah Gardiner, Audrey Goninan & James Gardiner
Chase & Molly Trimmer
Lucy Carter
Niki Toscani & Laura Bolstad
Kyle Jackson
Ryan Windhorst
Darcie Moningka
Sharon DeFelices
Jessica Kyriacou
Kathy LaFone & Sara LaFone
Marian Grems

Via Facebook

Michael Halpin
Andrea Finch
Marwah
Sharon Massueras
Erin Fleury
Macy Salasel
Debbie Porter Carlin
Michael Lemaire
Marissa Kane Crozier
Gerda Spears
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Emma Delapre
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Megan Barone
Erin Walla
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Deb Conway Heiland
Caroline Dultz
Michelle Chamberlin Laskowski
Caroline Adams
Susan Fiori Hafford
Jaymi Allen
Caroline Dultz
Krista Glodt
John Perrone
Colleen Hoolahan Hall
Anna Kuykendall
Kyle Sandve
Sonya Chavis

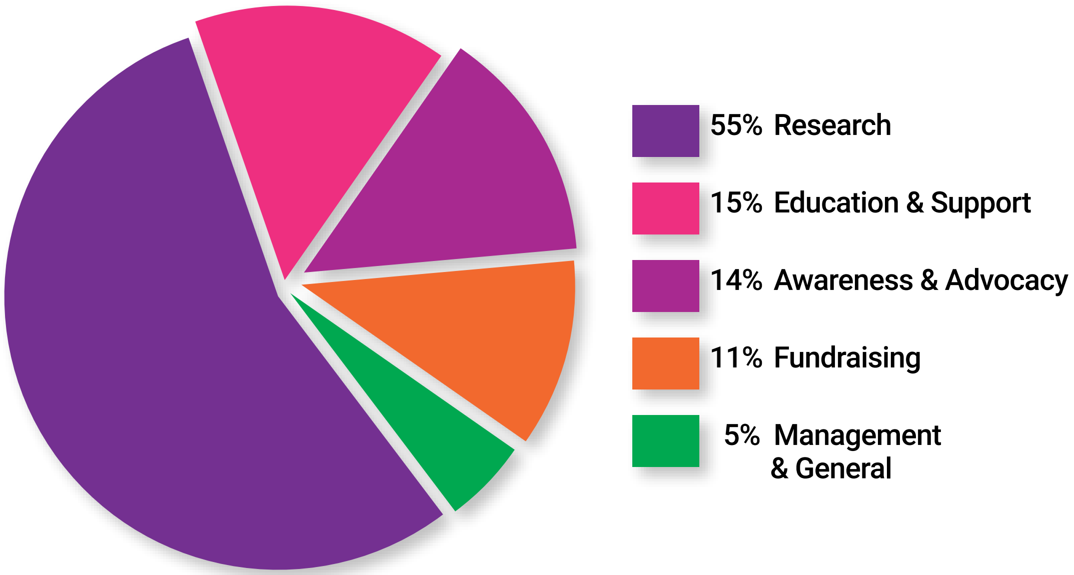
financial reports *fiscal year ending 6/30/21*

Statement of Activities

Revenue and Support

Contributions	$ 26,367,902
Special Events	$ 1,531,438
Investment and Other Income	$ 1,431,114
Forgiveness of PPP Loan	$ 300,500
Total Revenue	$ 29,630,954
Total Expenses	$ 7,672,359
Change in Net Assets	$ 21,958,595

Expenses



Statement of Financial Position

Assets

Cash & Cash Equivalents	$ 195,085
Contributions & Grants Receivable	$ 8,764,004
Investments	$ 35,715,893
Other Assets	$ 111,306
Total Assets	**$ 44,786,288**

Liabilities and Net Assets

Liabilities	
Accounts Payable & Accrued Expenses	$ 248,287
Research Grants Payable	$ 1,496,196
Other Liabilities	$ 156,363
Total Liabilities	**$ 1,900,846**

Net Assets	
Net Assets without Donor Restrictions	
Undesignated	$ 27,799,652
Board Designated	$ 6,329,870
Net Assets with Donor restrictions	$ 8,755,920
Total Net Assets	**$ 42,885,442**
Total Liabilities and Net Assets	**$ 44,786,288**

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

AFTD
The Association for
Frontotemporal Degeneration
FIND HELP·SHARE HOPE

2700 Horizon Drive, Suite 120, King of Prussia, PA 19406
HelpLine: 866.507.7222 or info@theaftd.org | Office: 267.514.7221

outlook

For people and families facing FTD, uncertainty is too often a fact of life. AFTD knows that the pandemic has introduced new uncertainty – and new challenges – to the FTD journey.

Together with our donors and volunteers, AFTD and its growing staff have responded. Support groups, Comstock grants, the AFTD HelpLine, our information-rich website, and tailored resources targeting FTD and COVID-19 have provided crucial assistance. As AFTD enters its 20th year in operation, your support has built an organization – and a community – that is all in to #endFTD.

Helping us sustain this momentum over the next several years are two significant funds: The Holloway Family Fund and The Sudon Fund. Established by AFTD Board members Kristin Holloway and Donald Newhouse, respectively, these generous gifts powerfully demonstrate AFTD's commitment to advancing quality FTD care and support, equipping healthcare professionals with the information they need to make early, accurate diagnoses, and developing effective treatments for the most common dementia under 60.

As I write, these investments are already bearing fruit: The first awards in AFTD's expanded Postdoctoral Fellowship program – now known as Holloway Fellowships – have been distributed to three talented young FTD researchers. And in spring 2022, the first annual AFTD Holloway Summit will convene FTD experts from the clinical science and technology sectors to collaborate on an action plan for developing clinically meaningful, high-quality digital biomarkers. The Holloway Summit will follow the December 2021 meeting of the FTD Treatment Study Group, an opportunity for leaders in science, academia, and government to convene and discuss ways to overcome existing barriers to the development of FTD treatments.

Another priority for the next 12 months will be deepening our engagement in communities across the country. Over the next year, AFTD will work to produce Spanish-language materials, market our Comstock grants to under-resourced demographic groups, and offer FTD education to healthcare professionals working in historically marginalized communities, among other inclusivity-focused goals. And we will continue to leverage the point of view of people with FTD – notably, through the Persons with FTD Advisory Council – knowing that their lived experience of the disease is vital to shaping our work.

In the coming weeks, we will share more information about our April 2022 Education Conference, a Baltimore-based event that will offer both in-person and virtual attendance options. And we are now developing a new three-year Strategic Plan, a roadmap to guide AFTD's priorities beginning July 1, 2022. Know that this plan is being built with input from across our community. And know, too, that your engagement in our work is what makes it possible. Together, we are all in to #endFTD.

Sincerely,

Susan L-J Dickinson, MSGC
AFTD Chief Executive Officer

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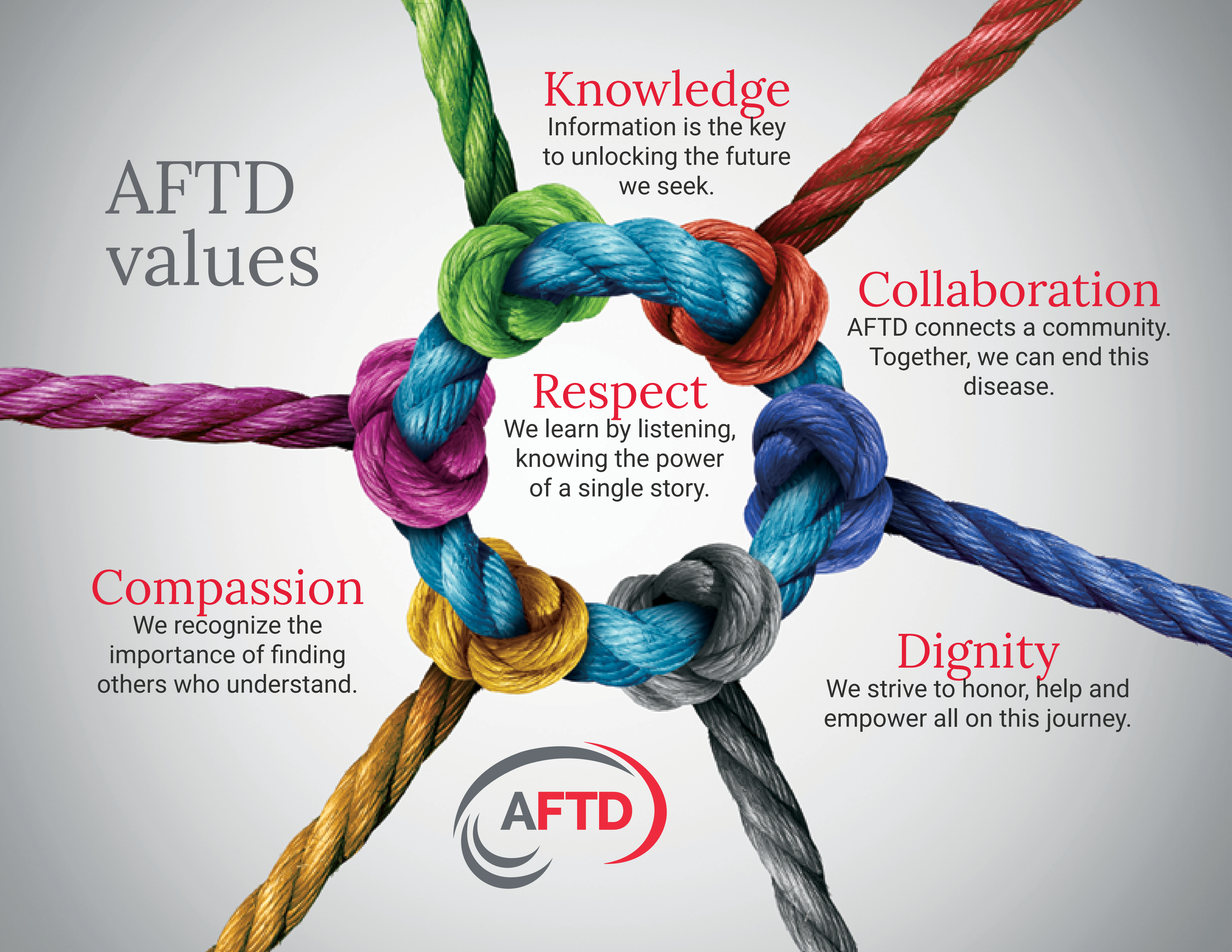

AFTD values

Knowledge

Information is the key to unlocking the future we seek.

Collaboration

AFTD connects a community. Together, we can end this disease.

Respect

We learn by listening, knowing the power of a single story.

Compassion

We recognize the importance of finding others who understand.

Dignity

We strive to honor, help and empower all on this journey.

AFTD

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

AFTD

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King of Prussia, PA 19406
267.514.7221 - Office
866.507.7222 - HelpLine
www.theaftd.org

The Association for Frontotemporal Degeneration

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