



# AFTDnews

## COVID-19 and FTD: AFTD Resources Can Help

The COVID-19 pandemic that has gripped the world over the last several months has brought new and compounded challenges for people living with FTD, their care partners and family members, and health professionals who provide essential care and assistance.

The restrictions set in place to contain the virus have upended care routines, increasing caregiver burden and bringing new worries about safety. People already dealing with the stress of an FTD diagnosis may now be facing even greater feelings of frustration, anxiety, and grief. Visits to care facilities are restricted, and isolation and difficulties with communication are adding their own hardships.

AFTD's staff, Board and expert advisors are responding to the

new and newly evolved needs of our community. Members of the AFTD Medical Advisory Council (MAC), a group comprising two dozen of the world's leading experts on FTD, have



begun contributing "Expert Letters" to our website detailing specific aspects of what it means to deal with FTD during the pandemic.

Some examples include Dr. Ted Huey of Columbia University, who suggests

ways to handle and cope with some of the challenges of living with FTD during this time, and Dr. Irene Litvan of the University of California, San Diego wrote about how to lower the risk of COVID-19 while living with FTD. Other leading FTD experts, including Dr. Beth Rush of the Mayo Clinic Florida, have also contributed Expert Letters.

Additionally, AFTD is adding COVID-specific resources to our website. Since March, we have published a guide to handling hospitalization and other emergency medical visits during the pandemic, strategies friends and family can use to provide help and support from a distance, and ways to ensure that persons living with FTD maintain proper hygiene at a time when hand-washing has never been more important.

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## AFTD and Target ALS Announce Grants for Research Targeting Treatments and Biomarkers

On May 5, Target ALS and AFTD announced \$5 million in funding awards for work by six research teams to aid in the discovery of biomarkers and viable treatments for ALS and FTD, which overlap in genetic causes and biological mechanisms.

By joining forces, Target ALS and AFTD are leveraging the combined expertise of researchers in two fields, fueling collaboration in support of the most promising ideas. These newly funded projects will inform, and potentially result in, both viable treatments and the

biomarkers critically needed to enable accurate diagnosis and measure disease progression.

"We're proud to join Target ALS in announcing funding for these crucial funding efforts," AFTD CEO Susan L-J Dickinson said. "With the challenges that the COVID-19 pandemic is adding for the families we serve, we want them to know that we are working as hard as ever to bring momentum for a day when treatments can halt FTD and ALS in their tracks."

*(Continued on page 8)*

# Communications Strategist Kristin Holloway Joins AFTD Board

In April, AFTD announced that Kristin Holloway, a communications professional whose husband, Lee, has FTD, has joined its Board of Directors.

Lee Holloway was diagnosed with behavioral variant FTD (bvFTD) in April 2017, after he began to experience a sequence of unexplained changes in behavior and personality. A gifted technology pioneer, Lee co-founded Cloudflare, a company dedicated to making the Internet safer, faster and more reliable.

“As a care partner for a loved one with FTD, it’s important for me to do what I can to make a difference for those living with this disease, and for the family and friends supporting them,” Holloway said. “By joining the AFTD Board, I can now dedicate time and energy into helping other families that are emotionally and financially impacted by FTD.”

An article in the May 2020 issue of WIRED thoughtfully chronicles the Holloway family’s journey with FTD, capturing the



Lee and Kristin Holloway

impact the disease has had on Lee’s own life, as well as that of his loved ones and colleagues.

To honor Lee’s legacy, in 2019, Kristin and the Holloway family established The Holloway Fund for Help at Hope at AFTD to help others navigate the challenges

of an FTD diagnosis. Donations to the fund will be designated to AFTD’s support programs and its research initiatives.

“Knowing the full scope of the struggles families face in having to care for a loved one with FTD, our goal with this fund is to help others as they navigate the challenging road ahead,” Holloway said.

With more than 10 years of experience as a communications strategist for high-growth technology companies, Holloway’s expertise adds to that of the like-minded professionals, business leaders and philanthropists providing Board leadership for AFTD. Her involvement with the organization and passion for helping others in this journey will be instrumental in AFTD’s work to raise awareness, a crucial step toward bringing about compassionate care, effective support, and a future free of FTD.

## AFTD NEWS BRIEFS

### AFTD Moves into New Office

On December 6, AFTD moved to a new office in King of Prussia, PA, to better position its staff to support all affected by FTD. The new location will help to foster greater collaboration between staff, Board members, volunteers, and others who understand the FTD journey. AFTD held an Open House in February to share the new space with members of the community.

### Alzheimer’s and Dementia Spotlights FTD Research

The January 2020 issue of the medical journal *Alzheimer’s and Dementia* features a special topic section dedicated to recent advancements in FTD research. The collection of articles highlights the work of two natural history studies of FTD, Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS). The National Institutes of Health awarded a significant grant to combine the two studies last spring, forming the ALLFTD research network, of which AFTD is a partner. The published articles include new findings that a physically and mentally active lifestyle could help slow the progression of FTD. The journal was published online January 8 and is openly accessible.

### AFTD Adds New Staff

AFTD welcomed the addition of several new staff members in 2020. As Fundraising Coordinator, Brittany Andrews will work to expand AFTD’s grassroots fundraising network by cultivating, supporting, and implementing national branded campaigns as well as independent, host-generated events. AFTD also welcomed Elizabeth Graham, Development Writer, who is responsible for creating and maintaining AFTD’s development-related communications, as well as researching corporate and

foundational support opportunities. In the role of Development Assistant, Emily Bradley will support donation processing and assist in donor engagement activities. Finally, April Scott has joined AFTD as Administrative Assistant, and will support AFTD’s Programs team in advancing FTD awareness, support, education and advocacy.

### Terry Jones, Monty Python Co-Founder Who Had PPA, Dies

Terry Jones, a founding member of the Monty Python comedy troupe, died on January 21. Jones and his family announced his diagnosis of primary progressive aphasia (PPA) in 2016 and shared his journey to increase awareness of the disease. Media coverage of his passing helped to draw attention to FTD, as Monty Python troupe members and fans around the world expressed condolences and remembered the famed actor and screenwriter. After the announcement of his death, Jones’s family also shared that he donated his brain to the Institute of Neurology, part of University College London, to help advance FTD research.

### AFTD-Funded Researcher Publishes Breakthrough Study

AFTD-funded research that provides new and important insights into the tau protein and its connections to a range of neurodegenerative diseases, including FTD, was published in the scientific journal *Cell* on February 6. The study, spearheaded by Anthony Fitzpatrick, PhD, of Columbia University’s Zuckerman Mind Institute, provides unprecedented insights into the protein’s structure that could advance the fight against FTD and other forms of dementia and neurodegenerative disease. The research was funded in part by the FTD Biomarkers Initiative, a major AFTD funding opportunity to spur the discovery and development of FTD biomarkers. Dr. Fitzpatrick was awarded a Biomarkers Initiative grant in 2018.



## A Message from AFTD Board Chair

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### David Pfeifer

I hope that this finds you and your loved ones safe and connected in these challenging times.

I became AFTD's Board Chair in April. I'm writing to introduce myself, and to share part of my story.

I'm an architect. I live in Denver, Colorado, where I've been working remotely this spring. I'm father to three kids: two in college, one in high school. These months have brought us back under one roof, and it's been wonderful to spend so much time with them here at home.

It's an unfortunate reality that people can suffer today from both FTD and ALS. We lost both my wife Cathy and my sister-in-law Jeanette Ekstrand to these terrible conditions. Cathy was diagnosed with ALS/FTD in fall 2014, after years experiencing unusual symptoms related to communication and behavior. She passed away in December 2016, and my sister-in-law Jeanette passed away in April 2019. Both were mothers of three children.

When my wife was diagnosed, I was fortunate to discover AFTD. The people I met helped when we needed it most, and I learned about resources for families going through this incredibly challenging journey.

In AFTD I found a passionate group of Board members, staff, volunteers, and donors working toward a common purpose: *We envision a world with compassionate care, effective support, and a future free of FTD.*

The struggle to end FTD isn't the fight we would've chosen. A pandemic has only made it harder. But your courage, grace, and determination bring me hope – along with a great sense of responsibility taking on stewardship of this organization. I promise to bring my all to this.

**During a challenging time, AFTD's work is only possible with support from our donors.** If you have the means, I hope you'll join me in supporting this vital organization using the enclosed envelope. Gifts that are unrestricted or targeted to Support or Research can bring AFTD's impact to more people across the country. It has never been needed more.

My family has been through a lot, and the challenges that may yet lie ahead are profound. But I know we can overcome them together, if we bring our collective resolve to the effort.

Sincerely,

David Pfeifer  
AFTD Board Chair



## AFTD would like to thank the following sponsors for their generous support of the 2020 AFTD Education Conference Webinar Series:

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**GIVING  
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## #GivingTuesdayNow

#GivingTuesdayNow took place on May 5, in response to the COVID-19 pandemic. For families facing FTD, the pandemic is adding unique complications to an already challenging journey.

With the help of 75 generous supporters, AFTD surpassed our #GivingTuesdayNow fundraising goal, raising over \$25,000, all to benefit AFTD's support programs for families. The Mike Walter Catalyst Fund also generously matched donations up to \$10,000 dollar-for-dollar. Thank you to all who supported AFTD's programs and grants by participating in #GivingTuesdayNow!

## COVID Response (Continued from page 1)

The pandemic caused the cancellation of AFTD's 2020 Education Conference, which had been scheduled to take place in Baltimore in April. But in its place, AFTD put together an Education Conference Webinar Series. The five webinars in the series included information to help families better manage their journeys in the ever-changing environment, each presented someone whose life has been touched by FTD.

The sponsors of our Baltimore conference generously sponsored the Education Conference Webinar Series as well (see below for more information).

*Know that together, we can move past the challenges presented by COVID-19 – and that you're not alone in this.*

To access these resources, and many more, visit the dedicated

COVID-19 page we have established on our website at [theaftd.org/living-with-ftd/covid-19-and-ftd](https://theaftd.org/living-with-ftd/covid-19-and-ftd).

Know that together, we can move past the challenges presented by COVID-19 – and that you're not alone in this. If you have any immediate questions or concerns you would like to discuss with us, contact AFTD's HelpLine by calling 866-507-7222, or emailing [info@theaftd.org](mailto:info@theaftd.org).



# AFTD Announces 2019 Pilot Grants in Basic Science and Translational Research

AFTD is proud to announce the most recent recipients of our Pilot Grants, which provide seed funding to promising FTD researchers: Andrew Arrant, PhD, of the University of Alabama at Birmingham, and David Butler, PhD, of the Neural Stem Cell Institute at the Regenerative Research Foundation.

Dr. Arrant was awarded the 2019 Basic Science Pilot Grant for his proposed investigation into a common cause of genetic FTD: mutations in the progranulin gene. These mutations result in a loss of the progranulin protein the gene encodes, and a corresponding loss of its many protective actions in the brain. Therapies that restore its

levels could be effective in FTD – if they target the specific function that's most critical to preventing degeneration.

Dr. Arrant's project will tackle this question by modifying progranulin to create a form that acts only on lysosomes, structures that are part of the cell's waste disposal system. As a result, they'll be able to determine if this is the key to progranulin's ability to protect brain cells. The answer could guide drug development toward more precise treatments for progranulin-associated FTD.

Dr. Butler, recipient of the 2019 Susan Marcus Translational Research Pilot Grant, will evaluate a unique type of

antibodies, known as intrabodies, to determine if they can be used to reduce the abnormal accumulation of the protein tau that can occur in FTD.

Unlike naturally occurring antibodies, which act outside the cell, intrabodies are laboratory-engineered antibodies that remain inside cells and can be further modified to create designer proteins with additional desirable features. Dr. Butler's intrabodies will bind to tau and also have a molecular "tag" to direct the bound protein to the cell's waste disposal system. He will test his intrabodies in a novel 3-D cell culture model; if they are effective, he hopes to ultimately develop them as anti-tau therapies.

## AFTD Volunteer Katie Brandt Brings FTD Perspective to NAPA

Katie Brandt, an AFTD volunteer who has dedicated her career to dementia advocacy, is using her newest role as co-chair of the National Alzheimer's Project Act (NAPA) Advisory Council to ensure FTD is included in the national conversation about dementia care.

NAPA was established in 2011 to leverage and expand the federal government's efforts to help change the trajectory of Alzheimer's disease and related dementias (ADRD). The legislation established a national plan that is informed by input from the public-private Advisory Council on Alzheimer's Research, Care and Services, which makes recommendations to help inform spending priorities to improve health outcomes for people with ADRD and reduce the financial burden of these conditions.

Brandt, who has served as a member of the Council since 2017, was named co-chair in August 2019. A care partner to her late husband Mike, who was

diagnosed with FTD at age 29, and to her father, who is currently living with Alzheimer's, she brings a different viewpoint to a council seat typically held by medical professionals.

"I feel incredibly honored to be a voice for families and never take it for granted how important these opportunities are," she said. "We can't choose whether or not FTD is in our lives, but it's been very empowering to choose to raise my voice and find a way to take back some of the power that FTD tried to take from my family."

Brandt is also the Director of Caregiver Support Services and Public Relations for the Massachusetts General Hospital Frontotemporal Disorders Unit and facilitates a Boston-area AFTD-affiliated support group she attended during Mike's illness. She is also a featured speaker at the 2020 AFTD Education Conference [see page 4 for more details].

During her time as a Council member, Brandt frequently raised FTD issues

during meetings. In October, during her first

meeting as co-chair, she brought a former FTD caregiver to speak about their experience.

The Council allows public testimony during their quarterly meetings to help inform their recommendations for priority actions, and Brandt encourages participation from people affected by FTD. "I am extending an invitation for persons diagnosed, care partners, and family and friends to submit a public comment or join me at a meeting to raise their voice for FTD awareness," she said.

"It's essential that we raise awareness about the fact that dementia does not just impact the elderly and is not just about memory loss, and it's equally important to expand research and build hope that there will be treatments and a cure."



Katie Brandt, MM

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*Gifts received from October 1, 2019 – January 31, 2020*

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Helen Walker  
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Helen Walser  
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Susan Watson  
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Libby Webb  
Greg Richard Wegner  
Judith May Weiler  
Ken Weina  
Barbara Weiner  
Harold Weinstein  
Leonard "Lennie" Weissman  
Rosemary Cookie Weiten  
Amelia Wellington  
Sunny Lynne Joffe Wergen  
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Harry R. Zeigler  
Julie Marie Dickmeyer Zerhusen  
Donna Ziegler  
Edward Ziobro  
Jack Zlotnick  
David Paul Zomback

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Maryann Abbott  
Rebecca Adams  
Stephen Adams

Akili Smith Knockout League  
Farwa Ali  
Judith Amdur  
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Melanie Anderson  
Jane Christine Angell  
Michael J. Angello  
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Jennifer Ator  
Harold Axe  
Vicki Axe  
Sharon Baldzicki  
Anne S. Bartlett  
Brooks P. Bartlett  
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The Bartosiak Family  
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Steven P. Bellwoar  
Trish Bellwoar  
The Bellwoars  
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Roy Bohr  
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Susan Croll  
Jean Dallia  
Jordan Daniels  
George T. Demkow  
Gregory DePriest  
Suzanne Doll  
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David A. Dosser  
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Dani Duniho  
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Rick Dye  
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The Eissler Family  
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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](http://www.theaftd.org) and select "Donate+"

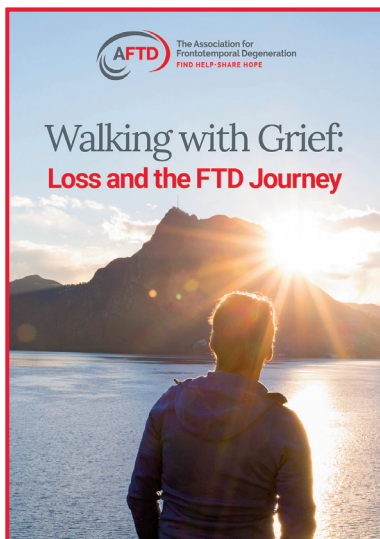


# New AFTD Resource Offers Shared Insight on Grief and the FTD Journey

Feelings of grief and loss are common throughout the progression of FTD, from diagnosis to disease progression to life after a person diagnosed has died. For some those grief responses have been heightened by the added challenges of a pandemic. It's important to set aside time to process and honor those feelings.

A new AFTD resource, *Walking with Grief: Loss and the FTD Journey*, offers first-hand accounts, information and strategies to deal with the grief that is so frequently a part of the lives of all who are touched by this disease.

In assembling the 48-page booklet, AFTD Support Services Manager Bridget Moran-McCabe, MPH, drew from the best resource available: firsthand accounts and perspectives from people on their own FTD journeys. We are grateful to all who shared their stories and expertise with us.



"For many individuals and families facing FTD, the disease is so all-consuming that they lack time to tend to their own grief," Moran-McCabe said. "Grief is intensely personal; it's different for everyone, yet it's something all need to find time to honor, particularly given the unique type of loss presented by FTD." *Walking with Grief* helps people on their own journey to honor their grief through the stories of others who went through similar experiences.

Long-time AFTD volunteer and former FTD care partner Elaine Rose contributed much of the writing for the booklet, a process that she says helped her to cope with the death of her husband, who had FTD.

"Grief is never an easy concept, but the long goodbye of FTD is especially difficult," Rose said. "It can be such a

solitary journey, so we've tried here to give guidance and a road map to staying whole throughout the process."

This resource shares information about the type of loss most common for those affected by FTD: "ambiguous loss," or loss that occurs when a person diagnosed is physically present, but mentally or emotionally absent. It expands upon the concept of "anticipatory grief," or feelings of loss and dread that family members experience when they imagine life upon the death of a loved one. It also includes poetry by Rachel Hadas and Lori Ruhlman.

Regardless of where you are in the journey, *Walking with Grief* is intended to help open the door to conversations between family and friends, through online support forums, and in support groups, and to help all those grieving to know they are not alone.

*Regardless of where they are in the FTD journey, Walking with Grief is intended to help anyone who may be grieving to know they are not alone.*

*Walking with Grief* is available in digital form on AFTD's website,

and print copies can be ordered through the AFTD online store.

## Target ALS... (Continued from page 1)

AFTD first announced its partnership with Target ALS in October 2019. The newly announced grants, to which organization is contributing \$2.5 million, form the center of this partnership.

"Funding collaborative efforts has led to the most promising research coming out of our Innovation Ecosystem, the model we created in 2013 to bring the best minds together and achieve impactful research results," said Target ALS Chief Executive Officer Manish Raisinghani, Ph.D. "Partnering with AFTD has been an incredible step forward in that commitment, now reaching a

critical milestone as we fund grantees who represent collaboration between researchers from academia, private industry and the nonprofit sector."

*"With the challenges that the COVID-19 pandemic is adding for the families we serve, we want them to know that we are working as hard as ever to bring momentum for a day when treatments can halt FTD and ALS in their tracks," said AFTD CEO Susan Dickinson.*

The six collaborative projects will assess promising potential ways to detect—and therapeutic strategies to address—ALS/FTD pathology. The selected consortia receiving funding are:

- Eikonizo Therapeutics, VIB-KU Leuven, Mayo Clinic, UZ/KU Leuven
- Novation Pharmaceuticals, Inc., Université de Montréal/CRCHUM
- Expansion Therapeutics, Scripps Research Institute
- Merck & Co., University of Pennsylvania, University of Pittsburgh
- QurAlis, Harvard University, University of Massachusetts Medical School
- Biogen, University of Massachusetts Medical School, University of Michigan Medical School

For a brief overview of each award, visit the website of AFTD or Target ALS.



# Giving a Hand to Our Helping Hands! AFTD Volunteer Marc Toles

A former caregiver to his wife, Marc Toles (MI) wanted to give meaning to what he and his family went through during their FTD journey. After his wife passed away, he resolved to help others facing FTD – and begin his own healing process – by becoming an AFTD volunteer.

Marc has been a standout volunteer for the past year and a half, taking on a variety of impactful roles that address AFTD's mission, from providing support as an AFTD-affiliated Support Group Volunteer to raising awareness through various outreach efforts. AFTD is grateful for his volunteer service. In his own words, Marc shares his experience as an AFTD volunteer.

## How has your experience as a volunteer made you feel?

There is a real sense of peace and accomplishment that comes from

seeing people “get it” after I’ve presented information to them.

## Please tell us a little bit about the support you’ve received from AFTD as a volunteer.

In a word, tremendous. As an organization AFTD makes itself available for support, guidance, information, and especially encouragement and gratitude.

## What is the most fulfilling/rewarding part of volunteering?

Knowing that, in my own small way, I AM making a difference.

## What would you tell someone considering volunteering with AFTD?

If you are looking to find support, gratitude and meaning in doing volunteer work, you’ve come to the right place.



Marc Toles and his wife, Gretchen

AFTD Education Program Manager Deena Chisholm has worked directly with Marc and has seen firsthand how he has worked to bring hope to others on this journey. “AFTD celebrates selfless individuals like Marc, who channel their civic virtues through volunteerism and devoted to a cause bigger than themselves,” she said. “Marc helps to drive AFTD’s progress towards a future free of FTD.”

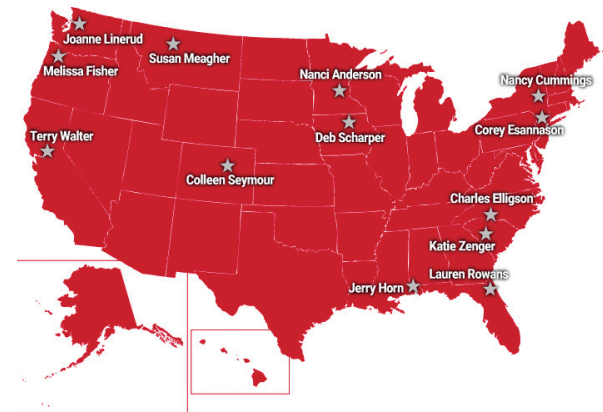
# Meet AFTD’s Ambassadors, Our New Volunteer Leaders

With the recent launch of our restructured volunteer program, AFTD has created an important new volunteer leadership position: AFTD Ambassador. Our inaugural team of Ambassadors comprises 13 volunteers from across the country who have been active in a variety of ways to support our mission. They will help us to expand our reach in local communities as we work to increase FTD awareness and inspire hope nationwide.

AFTD Ambassadors’ essential job function is to spread awareness within their designated geographical area. They will identify opportunities for awareness-raising, establish

and maintain a visible presence, represent AFTD by speaking publicly about FTD, conduct outreach, and network with local health providers and other professional resources.

AFTD is proud to introduce our first team of Ambassadors! “This is quite a milestone for the organization,” Volunteer Program Manager Kerri Keane said. “Ambassadors are key to the success of our new volunteer program structure. This leadership team brings a wealth of knowledge, experience, and skills that set them apart. As AFTD representatives, they truly embody what we look for in our leaders, and we are grateful for their service.”



## AFTD’s inaugural Ambassador team:

- Jerry Horn: Alabama
- Terry Walter: California
- Colleen Seymour: Colorado
- Lauren Rowans: Florida
- Deb Scharper: Iowa
- Nanci Anderson: Minnesota
- Susan Meagher: Montana
- Nancy Cummings: New York
- Corey Esannason: New York
- Charles Elligson: North Carolina
- Melissa Fisher: Oregon
- Katie Zenger: South Carolina
- Joanne Linerud: Washington



# THE AFTD-TEAM

With Love

FTD can be heartbreaking, striking at the core of who we are and bringing irreversible changes to people's lives. But while FTD can steal so much, it can never take away from the love that brings us together. In February, through AFTD's With Love 2020 Campaign, individuals and families responded to this devastating disease by sharing their stories of love to raise awareness and crucial funds to support AFTD's mission.

A record-setting 37 hosts courageously shared their FTD journeys, posted pictures with loved ones, and asked their social networks to contribute to their online fundraisers. Through this year's campaign, With Love hosts raised over \$66,000 to help improve the quality of life of people affected by FTD and drive research to a cure.

AFTD would like to extend a heartfelt thank you to everyone who contributed to the success of this year's campaign. We are grateful for our two generous sponsors, AFTD Board Member Beth Walter and The Rainwater Charitable Foundation; the hundreds of people who made donations; and, of course, our 37 campaign hosts, who bravely shared their stories with the world to show that love is more powerful than any disease.

Amy O'Bryant	David Burns	Heather Gheen	Maria Kent Beers & Michelle Fiori	Rachel Ramsey
Bonnie Shepherd	Diana DeFatta	Jerry Horn	Maureen Stroka	Scott Rose
Bridget Shultz	Eileen Dorman	Jill Olson	Megan Riordan	Sonja Crawford
Carrie Benton	Elaine Rose	Jillian Condran	Melissa Fisher	Susan Eissler
Christe Konopitski (Kendra Scott)	Erin Walla	Kali Tormoen	Natalie White	Susan Illis
Colleen Quinn	Faith Ott	Kathryn Zenger	Norm Davis	Susan Scarff
Danielle Donovan	Genine Rosa	Kimberly Sullivan Chu	Norma Morrison	Victoria Tinsley
	Gina Alderucci	Linda Green		



## Race Season

In the Summer 2019 AFTD News, we shared stats on the first two races of the AFTD-Team 2019 Race Season. The Austin Marathon (Austin, TX) and the Colfax Marathon (Denver, CO) saw a combined 106 teammates raise \$12,900 for AFTD. The final three races of the season, which took place later in the year, made this the most successful Race Season yet.

The TCS New York City Marathon (New York, NY), Philadelphia Marathon (Philadelphia, PA) and Dallas Marathon (Dallas, TX) brought an additional 98 teammates and raised a combined \$67,600, for a grand total of 240 teammates, 1,400 miles and \$80,500 raised for AFTD's mission!

Special shout out to the individuals and families who, in addition to going the distance, raised vital funds through the final races:

Team Jack Attack	Popkin Shenian	Laura Kupsch	Sherry Harlass	Maura Huzinec
Tamara Blankestijn	Joe Fischel	Morganne Hodsdon	Kathryn Brucato	Kathleen Gilhooly
Josef Pohl	Brian Strohm	Tara Huzinec	Scott Payonk	Amber Dickson
Anne Collins Hodsdon	Team Mamma Fish	Lucas Rogers	Michael Layser	Bruce Dixon
Martha Madison & Bo Yates				





# THE AFTD-TEAM

## Charity Miles

AFTD recently announced a new partnership with Charity Miles, a free smartphone app that turns miles into money! Through this partnership, we're able to offer the opportunity to build connection with others and support AFTD's mission, while staying active and safe during COVID-19.

Throughout April, The Mike Walter Catalyst Fund donated \$1 to AFTD's mission for every mile logged on Charity Miles. These funds, designated for support, provide critical

guidance, resources and assistance to so many on the FTD journey.



The momentum that our community generate was so remarkable, this generous offer was graciously extended through the end of May. As of our mid-May press time, more than 540 supporters have signed up on the app, and we've moved more than 26,000 miles together! Thank you to everyone who turned a hike, bike ride, run, or walk into a fundraiser for AFTD.

**Hey Google:** Rob Radtke designated AFTD as one of the charities for Google Giving Week 2019 and raised \$13,872. A Google employee himself, Rob first raised money for AFTD in 2017 when he lived in California. He has continued his support of AFTD in each of the past two years from his current home in Zurich, Switzerland.



## Spooky Success:

Lauren and Michelle of The Sister Project blog hosted the inaugural Hallowpalooza in Illinois on October 26 at The Village Club of Western Springs. The event was held in memory of their mother, June, who

had FTD and passed away in April 2019, and to honor her love for autumn and Halloween. The night featured an open bar, food, DJ, and a costume contest, with \$12,658 raised to support AFTD.

**Mike's Minions:** Siblings Jason, Brian and Tracy ran the Kansas City Marathon on October 19 in memory of their father, Mike, who had FTD and passed away in April 2019. They dubbed themselves "Mike's Minions" and raised \$10,128 towards AFTD's mission.

**Lester's Letters:** AFTD Board Member Paul Lester hosted his 13th annual letter-writing campaign in memory of his late wife, Arnette. He sent both paper and electronic versions of his letter, with the help of the online fundraising platform Classy. After all letters were sent out, his campaign raised a total of \$6,695. Over the past 13 years, his letter writing campaign has raised more than \$140,000 towards the fight against FTD.

**Remembering Bryan:** Becky Tinsley of Texas hosted a fundraising event on October 26 in memory of her husband, Bryan, who had FTD and passed away on October 20, 2018. The party raised \$3,425. With an additional \$1,950 raised through Facebook, Becky donated a grand total of \$5,375 toward AFTD's mission.



## Magical Moments:

The Pondelli Family ran the Disney Princess Half Marathon at Walt Disney World in Florida on February 23 and raised \$2,828 for AFTD.

Kathleen, Julianne and Jeana

have been running the race for the past nine years in memory of beloved husband and father, Al, who passed away from FTD in 2014.

**Going the Distance:** Paul Petras of Ohio ran the Stone Steps 50K Trail Run in Cincinnati on October 27. He completed the race in 5.5 hours, took fifth place overall, and raised \$2,186 for AFTD's mission in the process.



## Play Ball!:

Brian Fox of Nebraska co-hosted a softball fundraiser on October 5 at Millard West High School, where FTD awareness t-shirts and bracelets were

sold during the game. Although the game was rained out, over 100 supporters still came together and gathered inside to raise \$1,664 for AFTD.

**That's Lit:** Amy Shillady of Maryland makes homemade soy candles named for her mother, Nancy Lee, who was diagnosed with FTD in 2016, and donates all proceeds to AFTD. On November 23, she made 200 candles with the help from family and friends. They sold out in 10 days, resulting in a \$1,200 donation.







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