

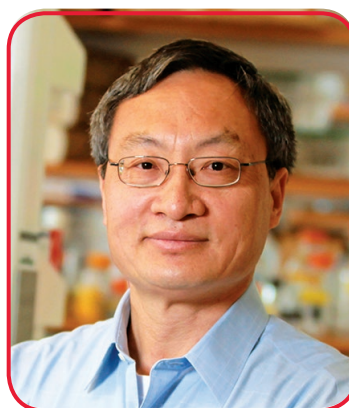
AFTDnews

COVID-19 and FTD Research: Challenges and Silver Linings

The COVID-19 pandemic has brought significant new challenges for families facing FTD, and it has also brought new obstacles for the scientists seeking to better understand and treat this disease. Dedicated researchers across our field speak to a strong sense of determination to treat and cure FTD despite the obstacles—and identified changes made in this difficult operating environment that could bring future advances. At the outset of the pandemic, many labs shut down to prevent the spread of COVID-19. This restricted operations and brought some studies to a temporary halt.

“We lost about three months...but we’re doing the best we can,” said Fen-Biao Gao, PhD, a professor of neurology at the University of Massachusetts Medical School and the Governor Paul Cellucci

Chair in Neuroscience Research. A researcher in basic science, Gao’s studies use different approaches to try to find the underlying mechanisms of FTD and other neurodegenerative



Fen-Biao Gao, PhD

diseases. While Dr. Gao has been able to continue aspects of his work, such

as manuscript reviews, from home, lab experiments were largely placed on hold.

“We’ve since started up again,” he noted, and while he is hopeful that conditions will allow for studies to move forward without shutting down again, he added that “the pace is slower now than it was pre-COVID, because people don’t stay in the lab as long for the sake of safety.”

One of AFTD’s first Postdoctoral Fellows, Todd Cohen, PhD, now helps train graduate students and other postdocs as an assistant professor at the University of North Carolina Neuroscience Center. He has spent much of the pandemic working from home, writing academic papers while helping to care for his children.

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Zoey’s Extraordinary Playlist Brings FTD Awareness to National TV

Zoey’s Extraordinary Playlist, which (Levy) better connect with her father Mitch (Peter Gallagher), who is unable to speak due to progressive supranuclear palsy (PSP). Show creator Austin Winsberg drew inspiration for the story from his late father’s journey with PSP. “I was not even aware of this disease before my



A scene depicting the cast of NBC’s
Zoey’s Extraordinary Playlist

Branded as a musical “dramedy,” the show follows a young woman who, after an incident in an MRI machine, gains the ability to hear the innermost thoughts of people around her as songs and musical numbers. This newfound ability helps Zoey (Jane

father was diagnosed,” Winsberg told AFTD. “Writing about everything I went through at the time [was] both therapeutic and healing. It also had the added benefit of creating national awareness around a relatively rare disease.

(Continued on page 5)

Spotlight on...Aisha Adkins, FTD Caregiver

Aisha Adkins never thought she would find herself in a caregiver role so early in life, but after her mother, Rose, was diagnosed with FTD, she placed her career on hold to help with her care.

Rose first started showing symptoms around eight years ago. Adkins, who was in college at the time, recalls her mom being unable to remember recipes and losing her sense of direction. But soon, what started as memory challenges progressed: Rose would overreact to simple mistakes made around the house and became obsessed with certain television programs. Realizing something was wrong, the family decided it was time to consult a doctor.

Rose's symptoms were initially attributed to stress; after a second opinion, she was misdiagnosed with Alzheimer's disease.

"She was then prescribed medications that were ineffective, as she seemed to get worse at a rapid pace," Adkins said. "So, I joined some support groups online and did some preliminary research and saw there are other options, that it could be another type of dementia."

The family sought yet another opinion. "Almost immediately the doctor was able to pinpoint her condition as FTD," Adkins said, adding that the diagnosis came as a relief: "It was nice to have some answers, or at least be able to put a name to what was going on."

Shortly after Rose was diagnosed, Adkins and her father decided it best that he continue to work to retain health benefits. So Adkins, who had just started a job in healthcare at the time, put her career on hold to become a full-time caregiver for her mom, whose increasingly disruptive behavior cast doubt on her ability to safely stay home alone.

"At the time I assumed I would take off for a few months and maybe get professional caregiving help shortly thereafter," she said. "I wasn't fully aware of the scope of what

I was choosing to do." Adkins has now been a full-time caregiver for the last eight years.

Early on, the challenges of the role became apparent to Adkins. For example, caring for a parent with a life-altering diagnosis significantly altered her career trajectory. "I initially started to panic a bit, but quickly remembered that I'm here because my mom needs me," she said.

As time went on, Adkins felt her concerns over work grow, as did worries about her own health (worries exacerbated by her lack of employer-based health insurance). To find a sense of balance, she had to get creative. She started to use writing and music as therapeutic outlets and worked to improve her diet and exercise, boosting her energy and stamina, which in turn helped her care for her mom.

"Everyone's care journey is different, and being able to learn coping mechanisms to deal with these things has been very, very helpful," she said. "I think it's something all caregivers need."

Yet Adkins also emphasizes the feeling of isolation that comes with FTD caregiving – notably for younger adults whose peers, finding themselves consumed by early careers and newfound independence, may not understand.

"Being a millennial caregiver can be incredibly isolating because it doesn't represent the quintessential American experience," she said. "It can be really difficult to find people to relate to what you're going through."

Adkins, who recently decided to go back to school to earn a master's degree at Georgia State University's Andrew Young School of Public Studies, has immersed herself in new opportunities to do research and work around caregiving. She is involved in multiple projects and organizations that aim to make a difference in the caregiving field, specifically in improving dementia and care outreach to African-American communities, and by advocating for caregiver rights.

She has also launched her own organization to help raise awareness of millennial caregivers and the unique challenges they face. She hopes her work will help provide a sense of support and community for millennials and people of color.

"I would love to see a world where young adult caregivers, particularly those in marginalized communities, have the support they need," she said. "I'm really passionate about filling in the gaps and am looking forward to opportunities to make a difference and a better future for folks."



Aisha Adkins (left) and her parents, Ron and Rose

AFTD NEWS BRIEFS

World FTD Awareness Week Begins Sept. 27

World FTD Awareness Week 2020, an annual event that brings together FTD advocates from around the globe, will take place from September 27 to October 4. FTD advocates worldwide will participate in the week's events, including a 24-hour World FTD Marathon, which will feature FTD presentations from across the globe. World FTD Awareness Week is organized each year by World FTD United, an international coalition of FTD-focused organizations of which AFTD is a member. For more information, visit AFTD's website.

AFTD Sponsors Virtual Dementia Care Summit

AFTD was a sponsor of the 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. Hosted by the National Institute on Aging, in conjunction with the Department of Health and Human Services as part of the National Alzheimer's Project Act, the Dementia Care Summit was moved to an all-virtual platform in 2020 due to the COVID-19 pandemic. The event took place over the course of three days in July and August. Among the scheduled speakers was Laurie Scherrer, a Pennsylvania woman living with FTD, who also spoke at the 2019 AFTD Education Conference.



A Message from AFTD's CEO

Susan L-J Dickinson, MSGC

I hope that this finds you and your family safe and connected during these last weeks of summer.

We know that for many, the COVID-19 pandemic has brought new challenges. Stress and uncertainty are weighing on us differently these months.

Know that you aren't alone in your journey. AFTD offers expert information and resources, tailored to the challenges of this time. Our HelpLine (1-866-507-7222, info@theaftd.org) can provide guidance and connect you with resources. Virtual and in-person support groups led by AFTD volunteers can provide guidance and connection. And our private Facebook groups can connect you with peers who understand.

With scientists and leading organizations across our field, AFTD is working to fund, catalyze and sustain research to better understand this disease, and advance the first treatments. While COVID-19 has brought new challenges to many research institutions, we remain hopeful about progress and breakthroughs in the months and years to come.

In a time of isolation for some, I want to encourage you to reach out and become part of this work. AFTD will be offering webinars throughout the year, to provide the latest information. We will also be providing new ways to get involved as a volunteer.

I'd especially ask you to consider taking part in one or more of several online campaigns we're planning for World FTD Awareness Week (September 27 through October 4, 2020). Host a virtual Food for Thought event, or a small gathering with your friends and family if safety permits. Join a 24-hour World FTD Marathon, featuring webinars and presentations from around the world.

During that same week, a group of volunteers will be unveiling a special new FTD challenge designed to raise funds within our community and beyond it, and to share stories from families affected. Stay tuned to learn more in the coming weeks!

If you have the means, please consider making a donation in support of one of these events and campaigns this September. I know that, for our volunteers around the country, it will be gratifying to know that they've reached out to others beyond their local communities. **Any donation you make in support of AFTD's mission – whether through one of these campaigns, or through the enclosed envelope – can share hope with others, bringing our programs to thousands of families in 2020 and beyond.**

AFTD was founded through the resilience of families who faced FTD. In their resolve, they found a community and a shared purpose: to advance a future free of FTD. I hope that you will draw strength by being part of this community, and from making your actions and your voice heard within our mission.

Sincerely,

Susan L-J Dickinson, MSGC
AFTD CEO

COVID-19 and FTD Research (Continued from page 1)

"I would definitely say we took a hit in terms of productivity," he told AFTD. "But we're fortunate to be well-funded and the science is moving forward." Continuing FTD research is "more important than ever," he noted, in light of the struggles for families now contending with both a pandemic and FTD.

Missing Connection, and Thinking Ahead

Andrew Arrant, PhD, an assistant professor of neurology at the University of Alabama at Birmingham, shared his perspective as an early-career researcher. A 2019 AFTD Basic Pilot Grant recipient, Arrant works in a lab seeking to better understand the pathologies and mechanisms of FTD. While restrictions initially slowed operations, Arrant and his fellow researchers were able to maintain existing studies, and can now pursue new experiments.

Outside the lab, social distancing restrictions and canceled in-person events have meant that Arrant has seen fewer opportunities to connect, both with other researchers and with the community of people and families affected by FTD. He said that he finds himself missing "the really rich interactions that can be incredibly valuable for feedback and generating ideas."

In the clinical environment, bringing in new study participants is a challenge, and researchers have turned their attention to preparations that will help to move studies forward as they can safely resume. "We're all thinking ahead to address hurdles... to set ourselves up for success now, before we get the go-ahead to open the floodgates," and once again start enrolling participants in clinical studies, said Nupur Ghoshal, MD, PhD, a neurologist and clinical investigator at the Washington University School of Medicine in St. Louis.

"It's not how we're used to doing science," she notes, but she is optimistic about the impact her team will be able to have as things get back online. Sourcing personal protective equipment and needed

research equipment, and tending to administrative tasks have been priorities in the meantime.



Todd Cohen, PhD

Potential for the Future

The ALLFTD network, a National Institutes of Health-funded research consortium focused on measuring and tracking the FTD disease process in preparation for clinical trials, has also been responding to challenges brought on by the pandemic.

Designed to maximize data collection and sharing across multiple research sites, the consortium relies on a longitudinal approach, studying the presentation and progression of FTD in people and families over time. Where COVID-related restrictions have limited opportunities to bring in research participants and collect new data in person, the consortium is brainstorming new ways to continue research, as technology including telehealth creates opportunities for in-home appointments and testing methods.

Across the border in Vancouver, Ian Mackenzie, MD, a professor of pathology and laboratory medicine at the University of British Columbia, and chair of AFTD's Medical Advisory Council, has faced similar challenges in navigating a separate longitudinal study, and also noted the role telemedicine could play in advancing research.

"By being forced to do certain things remotely or with telemedicine – if we go through the process to get it set up and realize it can be relatively effective – this creates potential for the future that could be extremely beneficial," he added.

Obstacles for Brain Donation

A pathologist, Dr. Mackenzie has also faced challenges in collecting tissue samples, as protocol at his facility now requires COVID-19 testing before an autopsy can be performed. This has resulted in a 24-hour delay that can interfere with sample

collection. Dr. MacKenzie and his team's response in some cases has been to pursue collaboration with facilities whose policies allow autopsy for COVID-19 positive cases.

Tammarn Lashley, MD, PhD, an associate professor of neurology at University College London, described a similar dynamic. A recent recipient of an AFTD FTD Biomarkers award, Dr. Lashley began the pandemic in a unique, yet fortunate, position, able to continue analyzing existing data and brain tissue in relation to her study. But the year has also created barriers to brain donation, which can prevent collection of tissue samples that could otherwise lead to important insight into FTD.

"FTD being such a heterogenous set of diseases, we need the postmortem samples to confirm diagnosis," she said. "So, we will have lost quite a number of cases due to the pandemic."

Policies in this area vary by facility, a situation that can leave families who have planned to donate a loved one's brain with additional questions and challenges.

Challenges to Progress, and Challenges for Families

One of the ALLFTD consortium's co-principal investigators, Bradley Boeve, MD, a neurologist at the Mayo Clinic and member of AFTD's MAC, noted that "COVID has clearly slowed progress in FTD on many fronts." He added: "Startup activities for ALLFTD have been delayed, and productivity will be far less than originally planned for 2020 and likely beyond."

He continues: "But these challenges are dwarfed by the impact on persons diagnosed and their families. Many have told me that they feel even more isolated than before, and many are concerned about seeing local health care providers due to fear of possible COVID infectivity."

Researchers are dedicated to advancing FTD science in the ways that they can during this time. Jennifer Yokoyama, PhD,



Bradley Boeve, MD

COVID-19 and FTD Research

an associate professor at the University of California, San Francisco, whose work focuses primarily on the genetics of neurodegeneration, has been able to utilize this time to better focus on data and perform analyses that may have otherwise been deprioritized to pursue new experiments. While challenges have arisen surrounding staffing and sample collection, she remains optimistic.

"We're doing the best we can to compensate quickly," she said. "It's important that we continue our research

through whatever this pandemic may bring – and keep reminding people we're still here, and that people are still impacted by FTD."



Ian Mackenzie, MD

Moving Research Forward

Despite the challenges and concerns that this pandemic will have continued impact on research and the families AFTD serves, FTD research continues to advance. The recent launch by Alector, Inc. of its INFRONT-3 phase 3 trial, testing the efficacy of a treatment for people at risk for progranulin-based FTD, has brought optimism; the company also took the step

of issuing a public statement declaring its intent to sustain clinical timelines through the pandemic where possible, in compliance with local, state and federal guidelines.

For families looking to make a difference in research during this time, AFTD will promote opportunities for engagement in research throughout the year ahead and beyond. The Featured Studies page on our theaftd.org website, reachable under the Research & Clinical Trials tab, offers a current range of studies recruiting for participation. And if you have not yet signed up, the FTD Disorders Registry (ftdregistry.org) offers a vital way to get involved in ensuring future treatments and a cure for FTD.

Zoey's Extraordinary Playlist (Continued from page 1)

"I could never have anticipated the tremendous outpouring of emails and messages I got from other people who all had been touched by PSP," he said.

Over the course of the first season, the show tackled many topics related to FTD, including diagnosis and symptom management, the challenges of caregiving, and grief and loss. Winsberg hoped to portray Mitch's care and disease progression in a way that was true to his own family's experience with the disease; his father's condition declined rapidly, and he died within nine months of diagnosis. "Virtually every family story we told in season one of *Zoey's Extraordinary Playlist* was based on something that happened in my own house," he said.

"It was very important to me that the depiction of PSP on the show be incredibly real and true to my own experience," Winsberg added, noting that an on-set medical advisor was consulted to ensure authenticity. "Because I had a front row seat to the

daily progression of the disease with my own father, it was easy for me to recall the various stages and the many setbacks we all encountered along the way."



Jane Levy and Peter Gallagher of NBC's *Zoey's Extraordinary Playlist*

For many navigating an FTD journey of their own, the show has provided an authentic sense of human connection and empathy, both of which Winsberg hoped to foster.

"I can't get over what a great job Peter Gallagher is doing; his face looks exactly as my husband's did," said viewer Loretta Morash Moskaluk, whose husband had PSP and died a year ago. "I find it difficult to watch, and sometimes I need to walk away from it. I always cry; it's so close to home for me, but I am so thankful it is bringing awareness to this terrible disease."

Winsberg said that Gallagher did a "copious amount of research" into PSP to help him play the role. He was "so accurate in his depiction of someone suffering from PSP that I

often felt like he was channeling my Dad," Winsberg said.

When Robert Chambers, whose wife is in the late stages of FTD, watched the show, he felt a strong emotional connection – and appreciated the inclusion of music in the plotline.

"Regardless of how quickly this disease runs its course, or how despondent the person may seem, I have been amazed at how music brings a sudden stimulation and recognition," he said. "I am happy that this dreadful disease is being brought to the attention of so many who don't understand the condition or the ramifications it has on the family. Thank you, Austin Winsberg, for your contribution to FTD awareness."

The show, which first aired in January, was recently renewed for a second season. While details have yet to be announced, both Levy and Winsberg

have expressed interest in exploring the idea of moving forward after

loss, as well as the origins of Zoey's musical abilities.

The series is available to stream on Hulu and YouTube.

"I could never have anticipated the tremendous outpouring of emails and messages I got," said Zoey creator Austin Winsberg.

Those We Honor... Those We Remember

Gifts received from February 1, 2020 – June 30, 2020

In Memory of

James S. Abbott	Peter Chase	Susan Terry Foley	Donald Idecker	Stephen E. Maupin
Ross Abinanti	Jayant Chaudhari	Lorraine June Forgey	Claud E. Ivie	Christine Mazurek
Jeffrey E. Abraham	JoAnn Chelist	Frances Rose Forst	Joseph Jarzembowski	Ronald McCarthy
Lynda Adams	Gregory W.	Richard Frankel	William S. John	Scott McCray
Stephen Adams	Chetwood	Charles E. Franklin	Peggy Johnson	Royce V. McDonald
Oscar R. Agmi	Beatrice Childs	Mimi Oblinger Freeman	Brian Jonaitis	George Patrick
Laura Ahlbeck	Chris Clements	Bernard Fridovich	Terry Jones	McGrath
Michael P. Alban	Lawrence T. Cline	Evelyn Friedman	Harold Kahn	Martin J. McGreevy
Lawrence Albert	George Coffman	Jo-an Kathleen Fultz	Marcus R. Kamp	Clare McNamara
Robin K. Allen	Charles Cole	Robert Gallagher	Amy Barbour Kane	William McNamer
Elizabeth A. Amend	Michael Coletti	Robert L. Gallagher	Eileen Kaplan	Robert Meineke
Donna Voss Anderson	Gail Colfelt	John Gardner	Norman I. Katz	Robin Mellor
Elizabeth Anderson	Craig Comstock	David Gaudin	Nicholas Kavala	Ian Miller
Gary E. Anderson	David Conkle	Anne B. Geremia	Karen Keller Colby	Louise Miller
Billy C. Ard	Denise Connelly	Anthony Giacobbe	Thomas J. Kelly	Mary Pachter Millman
Robert J. Asam	Mary P. Copeland	John J. Gibbs	Alan Klein	Alexandra Milmoie
Robert M. Ashcraft	Maryann M. Corey	Sofoclis Glykis	Eugene Klein	Michael A. Minelli
Susan Marie Aubertin	James Cosentino	Clifford Gocha	Lawrence Klein	Nancee Modres
Mary Guerriero Austrom	Rene Crete	Howard Gould	Scott W. Kluth	Brian Monaghan
Emerson R. Avery	Debra G. Crider	David Gragg	Joe Kowsky	Barbara Monay
Harold Axe	Edward B. Cybulski	Susanne M. Gravelle	Fredric Kraver	Alfred Moreau
Betty J. Bales	Virginia L.	Shawn Graves	Margaret Kronen	Susan Churchwell
Robert Emerson Beach	Dalesandro	Dennis Green	Diane Kukac	Morris
Kathleen G. Beal	Connie Daniels	Harriet Green	Robert Kunesh	Bob Morrison
Joseph Bevivino	Frederick J. Davis	Gerson Greenburg	Connie Kunkle	Wilma Mosier
Dolores A. Bisgrove	Michael Davis	Lynette Grieve	Mary Ann Lange	Ben Mosiman
Diana E. Bishop	Katie Decker	Sandra Griffith	Gertrude Broaden Lanns	Joseph R. Moulton
Sandra Bishop	George T. Demkow	Wayne A. Gritton	Donna Lapsker	Steven A. Murphy
Deven Black	Renee Diamond	Karl Grow	Sarah Lapsker	Mark Nebel
Cindy Boehmer	Pamela Dirksen	Gerald Grzywacz	Christa Lawson	Sidney Nettles
George Warren Booz	Roger William	Raymond Hamill	Arthur Elwood Leathley	Peter Norlander
Mark Botteon	Donnellan	Darrel Hansen	Maxine O. Leathley	Iris Okura
Jean M. Bower	Carol Lynn	Therese M. Harlett	Kurt Arlen Legred	Diane Osborne
Clarke Bowers	Dougherty	Geoff Harris	Sandria Leifer	Martin Ottem
Dean A. Bowman	George Scott	Pamela Rose Harvalis	Karen Leon	Deborah J. Page
Sharon Boynton	Downing	Kevin Harvey	Arnette Lester	Jackie Pang
Anna E. Brackett	Kathleen Dreffs	Donna Hastings	Suzanne J. Levine	John J. Pappas
Michael T. Brand	Catherine Drerup	Robert Hatfield	Glenn B. Lewis	Alexandria Papworth
John Brannen	Pamela Duncan	Darrell D. Hatt	Jeff Lewis	Kathleen Pelley
Phyllis Breuer	Ronald Duncan	Gregory Hauber	John C. Lewis	Camilla Perry
Catherine Broer	Gwenn Dunn	Alfred E. Hayes	Pat Lewis	Joel Petoff
Kathryn Brooks	Kyle Steven Durkin	Auge Hays	Gary London	Frederick Petrella
Donald L. Brown	Charlene M. Eckert	John M. Headley	Kenneth Ludwig	Kimberly Phares
Barbara Bruggeman	Mark Eissler	Mark Heberling	Donald Lee Mabry	Linda D. Phillips
John Buonanno	Christine	Harold Hedaya	Patricia Linton	Robert Pickett
Sheryl Burcher	Engelmann	Ernestina Hernandez	MacFadgen	Janis Pitts
Charles W. Burger	Linda Calvert	Georgia Herpel	Myra Malacara	Judith Poehler
Bruce Burgess	Eriksen	M. Thomas Hester	Phyllis Malloy	Marlene Poretsky
Lawrence Burnetski	Amy Evans	Garnett E. Hicks	Susan P. Marcus	Ferdinand Post
Nancy Buttorff	Peter L. Fabriziani	Jody Kay Hill	Neville Markens	John J. Primeau
Ronald Alan Campbell	Suzanne Fanning	Kenneth E. Hinze	Richard Marks	Elisabeth Rfloski
Lan Pham Cao	Karen Fedgo	Kenneth Edwin Hinze	Rosa Marrero	Ronald F. Ralph
Cindy Cardosi	Karen L. Fedgo	Kathleen A. Hirschy	Douglas Marsh	Kathryn Ranelli
Donald Carow	Deborah Feindt	Jay F. Hoffman	Andy L. Martin	Kenneth L. Ray
Neil Castleberry	Michael E. Fenoglio	Donald Ray Houlette	Marshall Randolph Martin	Liane Deere Ray
Willis H. Caterson	Kathleen Feron	Linda K. Hubbard	Donna Maser	Steven Rebholz
Susan R. Caulo	Janet Flaccus	Joyce Huebner	Matthew Sanderson	Scott Hayward Reed
Bruce L. Chalmers	Donald W. Folberth	Robert Hunter	Matherne	Malcolm Reid

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

Mary Lou Reilly
Scott Reinewald
Pamela J. Richey
Elaine Richmond
Steve Riedner
Mark Robinson
Elliott Rodin
Maureen Rose
Brian Rosequist
Carol Rosey
David J. Roth
Deanna Careen Rush
Richard A. Rutherford
Patricia H. Ryan
Joanne Sacco
Chelsea Sackel
Stephen Gary Sackel
Eileen Salerno
Barry Sandler
Anthony Savona
Carol Sbarboro
David Marshall Scaggs
David Kevin Schafer
Cindy Schink
Annette Schley
Alexander Schmidt
Jeanne Scott
Charles Alexander
Scudder
Steven J. Seitz
Rick Shaheen
Katherine Shaw
Nancy Lee Shillady
Joanne M. Silva
Semahat Sinharoy
Susan Skarda
James Edward
Slaughter
Vicky Sprouse
Candice Sroczyński
John Stackhouse
Dawn Ellen Stadler
Jeffrey Stasa
Robert S. Steel
John Steinhart
Thomas H. Stevens
Susan Stevenson
Jeanne Stulier
Seymour Stony
Sarokin
Joel Storch
Rich Strizki
Mike Strohm

Merwin Stroup
Karen Sturgis
John M. Sugden
James K. Sutter
Wendy Suzman
Deborah Lynn Sweet
Robert J. Sykes Jr.
Albert Sylanski
Marcia Ann Tambellini
Catherine Taylor
Jackie Taylor
Judith L. Temple
Randall Thomas
Caleb Thomas Hodsdon
Milo Tiefenthaler
Barbara Tinsley
Clyde K. Tobin
Cynthia Town
Karen Traxler
Christopher Morgan
Trimper
Anne Tryder
Denise Ulloa
Robert Unger
Tessa Valladares
Scot Van Airsdale
Bess Vance
Carla VanDorn
Nayda Veeman
Daniel Wachspress
Randel R. Wagner
Marianne Waldman
Beverly L. Walker
Michael G. Wallis
Steven Walter
James F. Ward
Jane V. Ward
Kari Ward
Mary Kimberly Ware
Dwight H. Warrington
Murray Wayne
Mary Weflen
Arthur Weidner
Rosemary Weiten
Joel Welshons
William K. Werth
Barbara Whitmarsh
Terry Wilharm
Ethelanne Wilhem
Douglas Albert Williams
Moyese Williams
Edwin Wilson
Robert Steven Winters

Deborah Woodcock
Laura Yanishefsky
Russell F. Yeager
Theodore M. York
Robert Young
Christine Youngclaus
Dorothy J. Zajac
Harry R. Zeigler
Julie Marie
Dickmeyer Zerhusen
Joyce Holmes Ziegler

In Honor of

Lydia Adalian
Rebecca Adams
JoAnne Andrews
Eddie Arwine
Sharon Baldzicki
Craig Bancroft
Bruce Bateman
Trish Bellwoar
Dan Berendzen
Roy Bohr
The Bora Family
Neal Borenstein
Tom P. Breneman
Andy Bursch
Sandy Cannon
Susan Castagna
Tony Castagna
Maria Cervoni
Su-Ling Chang
Sally Cihos
Joy Cobb
Helen-Ann Comstock
David M. Conant
John Conner
Allison Costantino
Tom A. Cox
Ray Cyrus
Michael Daigle
Amanda Dawson
Thomas J. Dury
Steven A. Edwards
Judith Erlick
William Farley
Bill Fehon
Jim Fiori
Diane Fitzgerald
Zandra Flemister

Scott Forst
Ginny Fowler
Paula Frost
Terri Kay Garrison
Michael H. George
John K. Gilhooly
Earl Gilmore
Rosaura Gilmore
Joan Gove
Marie Greway
Alice Guiney
Roy Hamilton
Helen Havens
Janet Hawbaker
Judy Hayde
Gary Heinz
Victoria Heller
Beverly Hernandez
Mary Hesprich
Colleen Terry Hill
Judy Hilliard
Gary Hosley
Pete Jackson
Jonathan R. Knight
Michelle Kyriacou
Joyce Langeliers
Larry Largent
Paul Lester
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Lynn Lower
Elisabeth Lino Lynch
Randi Mallett
Martha Mann
Travis Martin
Jan Materka
Cathy McDonald
Robert McGlaughlin
Kerry McGreevy
Charlotte McKim
Landon McLain
Jame McLeskey
Ann Miller
Daniel Monen
Rashelle Morcom
Mark Moriarty
Tara Winslow Morr
Charlotte Murray
Hall Newbegin
Donald Newhouse
Rhoda M. Oswald
Bill Ott
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Greg Pavek
Terry Peetz
Kiem Lee Pham
Aryeh Portnoy
Marie Rabago
Lisa Raine
Jan Ramsey
Alicia Ray
Karen Reed
Gregory Rively
Sherry Robertson
Donna Robinson
Jean Robinson
Donna Rose
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Susan Smith
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Ellen Solomon
Richard B. Stander
Jeanette Stoothoff
Maureen Stroka
Sue Sue
Susan Marie Sweeney
Jeff Tarkington
The Staff of the Parker
Adult Day Care Program
Jim R. Tobin
Barbara Todd
Michael Todd
Mr. & Mrs. James Tully
Karen Turns
Barbara Walker
Deborah Welshons
Melissa Wettstein
Jerry Wiggins
Judy Windhorst
Women of the ECLA -
Eve Circle
Kenneth Wood
Tsippi Wray
Karen Zander

Honor a Loved One or Remember Their Legacy

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

Giving a Hand to Our Helping Hands! AFTD Ambassador Susan Meagher

"Everyone's FTD journey is different," AFTD Ambassador Susan Meagher recently said. "If you are one of the primary caregivers, your opportunity to volunteer with AFTD may not come until after that part of the journey is over."

Like her sister and fellow AFTD Ambassador Joanne Linerud, Susan did not become an AFTD volunteer until after their mother died of ALS-FTD in 2016. "We knew just how lonely the journey can feel," Susan said. "The way we felt supported by AFTD – we wanted to support others in the same way and pay it forward."

Encouraged by Joanne, Susan began her current Ambassador role in early 2020. Like other Ambassadors, her goals were to speak publicly about AFTD, conduct outreach and provide FTD information to local health providers. She was especially eager to make connections with people who live in her local community in Montana. "I'm not afraid to put myself out there and say, 'Hey, AFTD's awesome.'"

But after the pandemic hit, Susan – like everyone else – found herself having to adjust her strategies in an ever-evolving



Susan Meagher and her sister, Joanne Linerud, both AFTD Ambassadors

new reality. "I've definitely had to shift my process as far as reaching out to medical professionals and spreading awareness," she said.

In July, Susan hosted a Virtual Meet & Greet – a Zoom-based version of the popular AFTD volunteer activity, adapted for the COVID era. (See page 9 for more

information on Virtual Meet & Greet.) "My goal was to let people facing FTD in Montana know that they're not alone," she said. One important way to do that, she said, was to share AFTD's resources with them, including the AFTD website and its numerous publications and newsletters.

But, she added, "the next step is knowing that there's someone in your area that you can call up – that's really, really important." For someone with FTD in their life, talking to someone who has lived similar experiences and is familiar with the same terminology can seem surreal, particularly after years of confusion in the lead-up to a diagnosis.

Overall, Susan says she is proud to represent AFTD as a volunteer. "I'm grateful that AFTD has put faith in me to help other people," she said. "Allowing people who have had FTD in their lives to speak in the name of AFTD – there's a lot of trust involved in that, and it feels very empowering."

600+ Attend 2020 Education Conference Online

More than 600 people "attended" AFTD's 2020 Education Conference, which, due to the coronavirus pandemic, was held as a series of webinars over the course of a month.

Between April 7 and May 7, AFTD presented five webinars designed to help families better manage the FTD journey during the unique and difficult circumstances presented by COVID-19.

All told, 634 unique viewers found help and shared hope by watching at least one of the AFTD Education Conference webinars.

The webinar series began on April 7 with "Coordinating & Managing FTD Care in a Changing World." Jennifer Pilcher, PhD, founder of the healthcare consultation group Clear Guidance, discussed ways to manage an FTD diagnosis during a time of rapid and significant change.

The following week, AFTD Ambassador

Corey Esannason presented "Self Care, Mindfulness and Remaining Positive." She modeled useful breathing and movement techniques that can bring calm and focus to an increasingly uncertain time.

All told, 634 unique viewers found help and shared hope by watching at least one of the AFTD Education Conference webinars.

AFTD CEO Susan L-J Dickinson spoke with Bruce Miller, MD, director of the University of California, San Francisco Memory and Aging Center, for the third webinar, "Ask the Expert: FTD and COVID-19." Dr. Miller, who is also a member of AFTD's Medical Advisory Council, discusses how the two diseases intersect, and talks about the latest advances in FTD research.

In "The Playlist of My Life," the Very Rev. Tracey Lind, who is living with primary

progressive aphasia (PPA), presents a talk about the concept of "building a toolbox for FTD" – compiling aspects of FTD care that are person-centered, promote the dignity of the person diagnosed, and allow them to live their best lives.

Finally, in "Building a Future Free of FTD: AFTD's Mission in a Changing World," Dickinson and AFTD Board Chair David Pfeifer share highlights from the past year of AFTD's work and present its vision for the future.

Originally scheduled to be held in Baltimore on April 17, the in-person AFTD Education Conference was canceled in early March, as the country began to gradually shut down due to coronavirus concerns.

All five webinars in the series are available to view at www.theaftd.org/aftds-2020-education-conference-webinar-series. For a full list of conference sponsors, consult the Spring 2020 issue of AFTD News.

Making a Difference During COVID-19

During these challenging and uncertain times, AFTD is extremely grateful for the steadfast commitment of our volunteers across the country. As the COVID-19 pandemic continues, we know many of our volunteers are anxious to resume their efforts to help advance our mission and make an impact.

Whether you are considering gearing back up to volunteer again, or you want to get involved by volunteering for the first time, there are ways you can help make a difference in today's ever-changing environment. Whatever activity you choose, AFTD staff will provide you with support and guidance every step of the way.

The following are some of the ways you can help as a volunteer:

- Facilitate a phone or virtual support group for caregivers
- Plan and host a Virtual Meet & Greet with local families affected by FTD (see below)

- Participate in AFTD's Annual Food for Thought fundraising campaign
- Join Charity Miles and raise FTD awareness and funds with every step you take
- Share your story on your Facebook page and through your social media accounts

It is important to acknowledge that even as different parts of the country move towards reopening, the trajectory of the pandemic is uncertain, and a risk still remains. Caregivers and people with FTD may face higher risk for COVID-19 infection, and/or developing complications if infected. The stress of caregiving can weaken immunity, and for persons diagnosed, FTD symptoms may make maintaining recommended hygiene guidance especially difficult.

Following is some guidance on how we will be leading and coordinating volunteer activities in the months ahead:

1) AFTD will prioritize virtual volunteer activities until safer conditions become more widespread.

We believe virtual volunteer activities are the safest and best option in the current uncertain environment. They can also have the added benefit of opening up new opportunities for connection, support, and awareness.

2) Face-to-face volunteer activities and events may be feasible in some situations.

In a changing environment, there will be circumstances in which AFTD will be promoting small in-person events and volunteer opportunities. In-person events and volunteer opportunities should only move forward if local, state and federal guidelines permit, and if risk can be mitigated for the volunteer, their family and the activity participants.

If you would like to learn more about the volunteer opportunities listed above and how best to conduct them safely, please contact your Volunteer Coordinator or email us at volunteer@theaftd.org.

Take Action Today: Host a Virtual Meet & Greet

In response to COVID-19, AFTD has developed a new volunteer activity to keep people in the FTD community connected while remaining at home: Virtual Meet & Greets. During a time when the isolation common to FTD may hit harder than ever, the flexibility and remote nature of this new activity will provide a vital space for all those affected to come together.

Virtual Meet & Greets are informal gatherings facilitated through Zoom, a free web-based video conferencing platform. They offer a safe space for members of our community to share their stories and local resources, learn about AFTD and its programs, and discover how to get involved.

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Virtual Meet & Greets allow attendees to share their stories, learn about AFTD and its programs, and discover how to get involved.

All that volunteers need to host this event are a computer and a webcam.

AFTD will work closely with volunteers as

they plan their Virtual Meet & Greets, offering two new training tools and providing support every step of the way. AFTD looks forward to our compassionate volunteers hosting Virtual Meet & Greets!

"Amid social distancing and much of the population staying at home, connecting with others feels especially important right

now," says Annamarie Given, AFTD Volunteer Coordinator. "Our hope in developing Virtual Meet & Greets is to provide a meaningful, rewarding, and positive experience for our volunteers that also encourages connection with others. We would

love to see Virtual Meet & Greets continue alongside our other volunteer activities."

To learn more about how to host a Virtual Meet & Greet, please contact volunteer@theaftd.org and

your Volunteer Coordinator will reach out to schedule a time to talk through next steps.



THE AFTD-TEAM

Race Season

Prior to the COVID-19 pandemic, the AFTD-Team was able to meet for the Austin Marathon weekend in February. This year marked the second year that AFTD has been an Official Charity Team of the marathon, and it was another success! We had 29 members of our community, plus a few members of the AFTD staff, run and walk together to help spread critical FTD awareness throughout the streets of Austin. In addition, AFTD-Team members raised **over \$5,550** through the weekend's efforts.

We would like to acknowledge and thank the AFTD-Team members who went the extra mile and fundraised for AFTD:

Kacy Kunesch
Kristin Schaffer

Stacey Fletcher
Stephanie Grasso

Steven Long



Remembering Tom: Jacquelyn Breneman, of Michigan, created a fundraising page in memory of her father, Tom P. Breneman, who passed away in June. Tom was 61 years old when he passed and had been fighting a multi-year battle with FTD. In lieu of flowers, the Brenemans asked their family and friends to send memorial donations to AFTD. Through the fundraising page, the family raised \$5,920 to support AFTD's work.

Tee-rific Time: The Robert M. Hatfield Foundation hosted the Ninth Annual Quest for the Cure Golf Tournament at the Bardmoor Golf & Tennis Club in Florida. This year's event raised \$5,250, increasing their total tournament giving history to \$63,150 donated to AFTD's mission.

Crossing the Finish: Brian Strohm, of Kansas City, MO, was set to run the Rock the Parkway Half Marathon & 5K on Saturday, April 4 in his hometown, until the event was rescheduled due to COVID-19. Prior to the date changes, he was able to raise \$1,490 for AFTD's mission and is now looking forward to running the race on a future date.

Colorway for a Cause:

Kristen Gillette, owner of Peg & Jane Yarn Co., hosted a Colorway for a Cause fundraiser where 10% of sales of all products between mid-February to mid-April went towards AFTD's mission. This was in honor of her friend, Larry Largent, who was diagnosed with FTD in 2018. The two met in college back in 2007. The new colorway that Kristen designed is based off of Hatteras Island, off the coast of North Carolina, a special place to Larry, his wife Erica, and their three daughters.



A colorway from Kristen Gillette's Colorway for a Cause fundraiser



A flyer promoting Corey Compa's Spring Bling Fling

Spring Bling Fling:

Corey Compa, an employee at Artis Senior Living Center in Huntingdon Valley, PA, helped to host a Spring Bling Fling event to raise funds and awareness for AFTD's mission. The event included shopping new and gently used jewelry, accessories, handbags, and tchotchkes. The senior living center has a population of residents diagnosed with FTD, who were able to attend the event as well.

THE AFTD-TEAM

Charity Miles

In response to the COVID-19 pandemic, and to offer our community a safe way to foster connection and support AFTD's mission during this time, we have partnered with the Charity Miles app. This free smart phone app allows users to track their miles moved, turning workouts into a fundraiser for AFTD.

Since we began this initiative in April, our community has shown great dedication, support, and commitment to helping us raise awareness and funds during such a critical time for our work.

In the first two months on the app, our AFTD runners, walkers, and bikers were sponsored by the Mike Walter Catalyst Fund—for every mile a member completed, the Fund donated \$1 designated towards support programs and grants. Thanks to all who participated in April and May, the AFTD-Team was able to raise **over \$47,000** to

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

Additionally, our AFTD-Team was able to raise more awareness and funds in July when we announced our sponsorship with Alector, Inc. Every mile that a community member logged on our behalf, Alector matched \$1/mile up to 20,000 miles. In just 22 days, our Charity Miles athletes achieved our July goal to help secure \$20,000!

AFTD thanks Alector for their generous donation, which will advance AFTD's mission – bringing help and support to improve the quality of life for people affected by FTD and driving research to a cure.

To all our walkers, runners, and bikers logging miles on the Charity Miles app, thank you for your continued support through this initiative!



Maggie Sepesy from Nebraska joined the AFTD-Team to honor and remember her mom, who passed away in February. She shares, "My hope is that these fundraising dollars and all the initiatives will help so one day no one will have to endure what my mom or family went through."



Norma Morrison from Iowa walks and bikes to honor her husband Bob who passed away from FTD. She shares, "I'm so grateful that Charity Miles has given us the opportunity to support AFTD financially through an activity Bob and I so loved to do together."



Jorge Rodriguez from California joined the app to make a difference in the greater community: "I chose to run and hike for AFTD's mission because of the great impact I can have on someone's life."



Daniel Hare from Nebraska runs and bikes for AFTD's mission to "raise funds and awareness to honor and support those that have or currently are battling FTD," and hopes that his efforts will "result in others being able to defeat the disease, restoring their health and well-being."



AFTD Ambassador Melissa Fisher from Oregon is inspired by everyone on the AFTD-Team and shares: "I've vowed to raise awareness and funds for this organization that gives all of us hope and so much help."



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