



AFTDnews

AFTD Publishes Landmark Report to Bring Federal Attention to FTD

In October, AFTD published *Frontotemporal Degeneration: A Voice of the Patient Report*, which summarizes and analyzes data and perspectives from more than 1,750 people living with FTD, care partners, caregivers, and other family members.

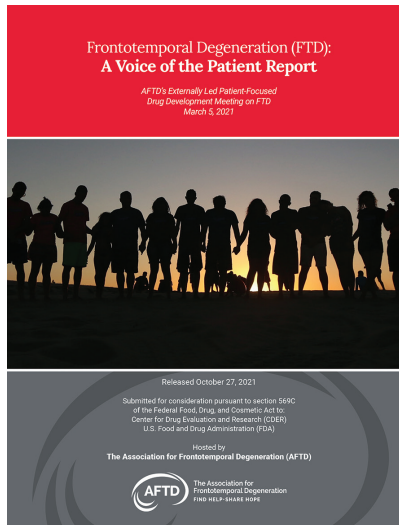
The report comprises information shared by participants in the AFTD-hosted Externally Led Patient-Focused Drug Development (EL-PFDD) meeting, held in March 2021. It also includes data from the pre-meeting FTD Insights Survey, conducted by AFTD and the FTD Disorders Registry.

The 75-page document provides the U.S. Food and Drug Administration (FDA) quantitative and qualitative data outlining the lived

experiences of persons who are directly affected by FTD. It is designed to help FDA regulators understand the experiences and priorities of people living with FTD disorders and what they and their care partners/caregivers most want to see in treatment options. The FDA uses Voice of the Patient reports as a source of information when making decisions about new treatments and therapies.

The report is available for download from AFTD’s website. It offers key insights on the broad range of FTD symptoms, which symptoms appeared first and which were the most challenging, impacts on quality of life, experiences with treatments, and hopes for future treatments.

(Continued on page 4)



INSIDE THIS ISSUE

- Spotlight on...
Dr. Joseph Marquez..... 2
- News Briefs..... 2
- Fall Appeal..... 3
- Save the Date..... 4
- World FTD Awareness Week... 5
- Donations..... 6-7
- Missed Donations..... 8
- Why Volunteer..... 9
- Volunteer Opportunities..... 9
- The AFTD-Team..... 10-11

New AFTD Resource Offers Guidance on FTD Genetics

Visitors to AFTD’s website can now find a comprehensive new section on FTD genetics. This resource offers guidance on everything from the most common genetic variants associated with FTD, to guidance on genetic counseling, no-cost testing options, and understanding results (theaftd.org/ftd-genetics).

Multiple studies since 2009 have identified 40 percent or more cases of FTD as familial. The “FTD Genetics and You: Learning More” page provides an overview of the three genes – C9orf72,

GRN (progranulin), and MAPT (tau) – that account for a majority of inherited FTD cases.

The FTD Genetics section also includes a page on genetic counseling and how it can be beneficial in understanding genetic links to FTD, and whether to pursue genetic testing. The “Genetic Counseling” page summarizes the value of a genetic counselor, the goal of a genetic consultation, and what a genetic counselor’s risk assessment report entails.

The new section of AFTD’s website contains crucial information about genetic variants that lead to some cases of FTD plus information on genetic counseling and testing.

(Continued on page 4)

Spotlight on...Dr. Joseph C. Marquez, AFTD Board of Directors

Joseph C. Marquez, M.D., joined AFTD's Board of Directors earlier this year. The founder and head of the department of urology at a large multispecialty practice in Seattle, Dr. Marquez brings clinical expertise and personal experience about how FTD affects the body.

"As a urologist, I encounter patients with FTD through problems they have with incontinence," Dr. Marquez said. "One of the biggest challenges that [FTD] caregivers have is managing incontinence, and I saw that on a personal level with my own aunt."

Dr. Marquez watched his beloved aunt, who he said was like "a parent in many regards," begin to change due to the unyielding symptoms of her behavioral variant FTD. She was 59 when she got her diagnosis.

"[My aunt] was a very lively, social

person who traveled the world, had many interests, and made many friends," he recalled. "I was struck by how – as the disease progressed and her ability to communicate declined – those social connections started to fall apart."

Dr. Marquez was familiar with FTD prior to his aunt's diagnosis, and immediately sought out specialists who could provide more answers.

"I was already clued into the diagnosis and that's why I knew to specifically search out centers like the University of California, San Francisco," he said. His aunt began participating in clinical and observational trials at UCSF.

Following his aunt's death in 2017, Dr. Marquez, along with his mother, uncle, and cousin, began participating in

observational trials at UCSF to continue to advance genetic FTD research.

"The privacy concerns around genetic disease of all sorts, but especially dementia, as well as the stigma and the potential for genetic discrimination – [these] are all topics that I think about deeply," Dr. Marquez said.

Dr. Marquez intends to apply his knowledge of the clinical aspects of FTD to the Board, along with his general understanding of molecular biology and genetics.

"I hope to be able bring this information to the Board and be an influence around the boots-on-the-ground clinical things people are dealing with in FTD," he said.

"While on the AFTD Board, he also hopes to be an "influence to clinicians of all specialties in raising awareness about FTD and the varying presentations of it."



Dr. Joseph C. Marquez

AFTD NEWS BRIEFS

AFTD Expands HelpLine and FTD Content Accessibility

Two new AFTD resources provide FTD information and support to people whose first language is not English. "¿Qué es la Degeneración Frontotemporal (DFT)?" is a downloadable Spanish-language resource that provides a broad overview of FTD, and explains in more detail the symptoms of each FTD disorder. Download this booklet in PDF format at theaftd.org/what-is-ftd/disease-overview. Additionally, AFTD's telephone-based HelpLine (866-507-7200) now offers translation services in over 200 languages, including Spanish, Mandarin, and Hindi.

Diagnostics Accelerator Grant and FTD Insights Fellowship Awarded

AFTD is funding two projects that will further our understanding of FTD. Megan Barker, PhD, of Columbia University Medical Center, was awarded an FTD Insights Fellowship. Dr. Barker will analyze data collected through the FTD Insights Survey – conducted in 2020 by AFTD and the FTD Disorders Registry – to learn from those with lived experience of FTD. Meanwhile, a team of researchers at the Foundation for the National Institutes of Health, led by Wesley Horton, MS, received funding through the Alzheimer's Drug Discovery Foundation's Diagnostics Accelerator initiative, supported by AFTD and other partners. Mr. Horton and the project team will evaluate and compare methods used to measure blood levels of neurofilament proteins, a potential biomarker for identifying individuals with MAPT, GRN, or C9orf72 mutations, which are likely to progress to symptomatic FTD.

All In for the Next Family



Melissa Fisher (center) with her children, mother, and father in 2016.

“This disease can be so insidious. Telling your story over and over, only to have no one believe you – you feel pushed away, ignored, and isolated.” – Melissa Fisher, FTD care partner

Following several years of misdiagnoses, Melissa Fisher’s father, Mark Moriarty, was diagnosed with behavioral variant FTD in 2018. “People see a physically healthy person, so they don’t believe us as caregivers that he has an illness. It makes it incredibly difficult for people living with FTD to access proper care,” she said.

While helping her mother navigate Mark’s diagnosis, Melissa lost track of how many times she described her father’s symptoms and behaviors while trying to get her family the answers and assistance they needed. “I’ve spoken with police officers, psychiatrists, social workers, insurance agents, nurses, neurologists, and so many others! I had to convince each one of them that something was wrong or explain to them what this disease is.”

This experience, which she says has caused an enormous amount of stress and anguish for her

family, opened her eyes to a pervasive lack of understanding about FTD.

Through her family’s journey, Melissa realized that others confront similar challenges, and she is determined to find a way to help improve the experience for all people facing the disease.

Today, she serves as an AFTD Ambassador. An AFTD grassroots events fundraiser, she recently ran the New York City Marathon in support of AFTD. She strongly believes that educating healthcare professionals and service providers will lead to necessary changes to provide better support and resources for FTD caregivers, care partners, and their loved ones.

Melissa is all in to #endFTD. “This is a disease of the collective. It touches all of us. I will do anything to help the next family not have to go through the nightmare we did.”

Will you join Melissa to help improve the quality of life of people impacted by FTD? A tax-deductible gift of any amount advances AFTD’s work to raise awareness, educate the medical community, and provide resources and support to all affected by this disease. Simply use the enclosed envelope, visit theaftd.org and **click on the Donate+ button** at the top of the page, or **use the QR code**.



FTD Genetics Section (Continued from page 1)

The “About Genetic Testing” page provides in-depth insight into how genetic testing works and what happens during the process. While genetic testing can provide valuable information, and offer a better understanding of an individual’s risk of developing symptoms in the future, it does come with associated risks, such as feelings of anger, depression, increased anxiety, or guilt about the test results, as well as potential insurance repercussions.

For those considering genetic testing, the “About Genetic Testing” page provides in-depth insight into how testing works and what happens during the process.

The genetic testing process can be financially burdensome to many. The “No-Cost Genetic Testing” section can help individuals considering testing to learn more about their options, such as sponsored testing programs, and includes a guide to finding available no-cost testing.

“Voice of the Patient” Report (Continued from page 1)

Helen, who participated in the EL-PFDD meeting, described the pain of watching her husband Geoff’s language decline because of his primary progressive aphasia: “I have watched the steady deterioration in his language. The ability to find words, his reducing vocabulary, slower listening processing time, the ever-reducing appetite for emailing, telephoning, reading, and speaking. His vocabulary is now just a handful of words.”

The report specifies which FTD-related symptoms respondents find most troublesome and how they are affecting quality of life.

Jill from New York relayed the story of her late husband Deven, who was posthumously diagnosed with behavioral variant FTD: “Strangers from other countries asked Deven for money, and he said yes again and again. Deven disregarded increasingly

strident warnings from me and from other family and friends. He made and repeatedly broke promises to stop hemorrhaging what became thousands of dollars to his online friends.”

The report also outlines the steps families are willing to take to participate in FTD research initiatives and clinical trials. Jessica from the U.K., who shares a C9orf72 mutation with her FTD-diagnosed mother, said that “I’m doing everything I can in my power to help fight this. I want researchers to know that I am available” to participate in research.



AFTD

CONNECT. LEARN. ENGAGE.

AFTD 2022 EDUCATION CONFERENCE

APRIL 8, 2022
Baltimore, MD

Save the Date! The AFTD 2022 Education Conference will take place April 8 at the BWI Airport Marriott, outside Baltimore, or online via a free livestream. Registration will open in January.

Up to 250 people will be able to attend in person, in accordance with federal and local guidelines. For the safety of all, proof of vaccination and masks will be required.

“Global Conversation” Highlights World FTD Awareness Week 2021



Your story matters!
Visit <https://worldftdunited.net>



Design by Raffaele Viorani 2021

AFTD collaborated with the international coalition World FTD United to produce a Global Conversation on FTD, a four-hour long video of vital information and perspectives from around the world that premiered during World FTD Awareness Week 2021 (Sept. 26 – Oct. 3).

People and families affected, health professionals, and researchers submitted short videos and stories, capturing the lived experience of FTD, offering care and support strategies, and sharing reasons for hope.

Visit worldFTDunited.net to watch the Global Conversation.

Also during World FTD Awareness Week, AFTD partnered with New York State Senator Michelle Hinchey for a virtual information session on FTD. The session followed the recently adopted resolution, sponsored by Sen. Hinchey, designating Sept. 26 through

Oct. 3 as FTD Awareness Week in New York.

“For the first time ever, the state of New York has recognized FTD Awareness Week through a resolution that we put forward because we believe that it’s incredibly important for more people to understand this disease,” Sen. Hinchey said.

AFTD continued to promote FTD awareness with ads placed in the *New York Times*. Throughout World FTD Awareness Week, the *Times* featured digital and print ads, created with input from AFTD volunteer Jody Zorn and designed to bring FTD awareness to millions. Print ads appeared in the Sept. 26 and Oct. 3 Sunday print editions, and visitors to the *Times* website via a mobile device saw a powerful set of digital ads on Sept. 29.

People and families affected, health care professionals, and researchers submitted short videos and stories for the Global Conversation, capturing the lived experience of FTD.

AFTD’s flagship grassroots fundraising and awareness campaign, Food for Thought, ran from Sept. 26 to Oct. 10. The campaign returned for its ninth year, raising critical funds in support of families affected by FTD.

Meanwhile, the #FTDhotshotchallenge, a community-driven grassroots campaign, made its return for the second year -- this time in official partnership with Food for Thought. The challenge, created by AFTD volunteers in 2020, rallied AFTD supporters and FTD advocates to raise awareness and funds for AFTD’s research initiatives.

Participants were encouraged to film themselves taking a shot of hot sauce, tag five friends to join, and donate to support AFTD’s mission.

HIS WIFE SAID MIDLIFE CRISIS.
HIS THERAPIST SAID DEPRESSION.
HIS DOCTOR SAID ALZHEIMER’S.
NO ONE SAID FTD.

Short for frontotemporal degeneration, FTD brings devastating, progressive changes in behavior, personality, language and movement. It’s the most common dementia for people under 60. But FTD is still far too little known today, even for doctors and health professionals. On average, getting an accurate diagnosis takes nearly 4 years. And today, there are no effective treatments. Learn more: www.theftd.org/FTDinfo

The first doctor said depression.
The second said stroke.
The third said Alzheimer’s.
No one said FTD.

Short for frontotemporal degeneration, FTD brings devastating, progressive changes in behavior, personality, language and movement. It’s the most common dementia for people under 60. But FTD is still far too little known today, for doctors and health professionals. On average, even getting an accurate diagnosis takes nearly 4 years. And today, there are no effective treatments. Learn more: www.theftd.org/aboutFTD

Those We Honor... Those We Remember

Gifts received from July 1, 2021 – October 15, 2021

In Memory of

James S. Abbott	Jeff Corcoran	Anita R. Gilmore	Jan Katz	Jane Moore
Rebecca Ann Adams	Rodney Corcoran	Susan Ginella	Richard Kelley	Virgil V. Moore
Laura Ahlbeck	Mike Costilla	Malcolm Goldsmith	Brad Kent	Constance Morales
Lawrence Albert	Edward J. Crane	Harold Autry Goodwin	Steve Kent	Pat Moran
William E. Alexander	JoDee Hannon Dailey	David Gragg	Kenneth Kilduff	Carl Moretti
Robin K. Allen	Connie L. Dake	Shawn Graves	Carole Kipp	Gale W. Moser
William M. Allen	Connie Daniels	Jeff Grems	Peter Kohudic	Maureen Mroczka
Daria Amoroso-McCue	Denny A. Dantimo	Robert Grems	Mary Ann Kouneski	Joseph Muthana
Gary Anderson	Steve Dawson	Gary Parks Griffith	John Kretekos	Lynne Suzanne Neft
Joanne Andrews	James Day	Judie Guttadauro	Vera Kroll	Susan Newhouse
Michael J. Angello	JaneAnn Dennis	Mary Hall	James E. Krouse	Marie Annette Nichols
Nancy Marjorie April	George H. Dentler	Douglas L. Hamilton	Donna Kunesh	Mike Oakley
Rick Arnold	Zadie Dills	Richard Hanechak	Donat Ladouceur	Timothy L. O'Neal
Claudia Atkins	Scott A. Dirk	Judith A. Hanlon	Tim LaFone	Diomi Orfanos
Beverly Aures	Todd Michael Dolan	James E. Hanna	Robert Lee Lambert	Robert Orr
Sharon Autry	John J. Donovan	Darrel Hansen	Richard E. Lancaster	Rhoda M. Oswald
Craig Michael Bancroft	Keith Drake	Theresa Hansen	Christopher Lane	Martin Ottem
Norman Barstow	Pam Duncan	Therese M. Harlett	Mary Ann Lange	Douglas Owens
Emily Bartosiak	Gwenn W. Dunn	Nancy L. Harshe	Edna Lees	Tamara S. Pamer
Jerry M. Baston	Esther S. Eckenroth	Donna Hastings	Lois Lenahan	Jackie Pang
Brad Bederman	William Roberts Eissler	Darrell D. Hatt	Arnette Lester	Joyce Odell Parker
Elisabeth Beeman	Denise Elson	John M. Headley	Cindy Lewis	Alan Pasquesi
Timothy E. Benim	Linn Emerick	H. Clay Heath	Ernest L'Heureux	Lona R. Patane
Fouad Bensouda	Richard Engborg	Mark Heberling	Paul L'Heureux	Madhuben Patel
Marilyn Bernhard	Charles V. Engel	Jodi Schoeler Hecht	Daniel Lineback	Camilla Perry
Michael E. Bibeault	James Douglas Estep	Harold Hedaya	Donald Long	Cheryl Perry
Nina Bingham	Fred H. Evans	Ruth Heminger	Kathleen Love	Jacqueline Pevec
Sandra Bishop	Jerry Falcon	Randy Hendrickson	John A. Luchsinger	William J. Pevec
Kenneth Blanc	Suzanne Carroll Fariello	Mary Henry	Eugene Wilson Luck	Cathy Pfeifer
John D. Blossom, III	George L. Farrington	Robert L. Hermann	Daniel Joseph Mackin	Kimberly Phares
Sherrill Bock	Bill Fehon	Georgia Herpel	Kathleen J. Maclaren	Bob Platt
Christine Bohannon	John Feldman	Stanley Herriff	Phyllis Malloy	Maryann Podgorski
Gregory Booen	Michael E. Fenoglio	Marvin Thomas Hester	Robert Malpede	James Carl Polk
Neal Borenstein	Emily Fifield	Kristina Spears	Susan P. Marcus	William Pordy
Michael T. Brand	Gisela Firore	Hilkhuijsen	Thomas Ray Markowski	Daniel J. Powell
Kathy Brooks	Marc Fitzgerald	Janet Lee Holzworth	Marshall Randolph	Helen Powell
William Brunk	Theresa Flanagan	Mary Honeyfield	Martin	Stan Primak
Frank L. Buczek	Perenna P. Fleming	Deborah Horn	Ronald L. May	David Proctor
Mikel J. Cannon	Barbara Brock Foley	Harriet Horwitz	Margaret Maynard	Susan Cinella Pupovac
Lan Pham Cao	Susan Terry Foley	Gary Hosley	Daria McCue	Neil Radin
Peter G. Carey	Marsha Francisco	Linda K. Hubbard	Royce V. McDonald	Dorene Radomski
John Caruso	Charles E. Franklin	James Huemoeller	Ula McGee	William Rafferty
Charles Castleforte	Barbara Freeland	Pamela Jane Grant	Evelyn McGuire	Carol Rao
Willis H. Caterson	Evelyn Friedman	Hughes	Joseph John Meehan	Raymond Reaves
Richard Christian Chapman	Peter Gacek	William J. Hurney	Joseph A. Mellodge	Heath Edward Rhoads
Linda Arlene Clark	Robert John Ganim	Andrea Sachse Hurwitz	Eric Anthony Meneskie	Harvey Ribbens
Donald Clement	Chris Gardner	Linda Hutchison	Phillip Meredith	Steven Lyle Rice
Lawrence T. Cline	Kevin Garner	Dorothy Brosch Ingram	Kevin Milbourn	Bruce Gerard Richards
Charles Cole	John J. Garvey	Claud E. Ivie	Dominic Milicia	Elaine Richmond
Kevin Coleman	Richard Gautreaux	Paul Jacobs	Pamela Fitzsimmons	Steve Riedner
Gail Colfelt	Edith Georskey	William S. John	Miller	Eddie Riggan
Craig Comstock	Anne B. Geremia	Karen Stevens Jones	William S. Miller	Marcia Robbe
M. Russell Cooney	Sue Gezgin	Patsy Ann Jones	Nick R. Monoskey	Sharon Robbins
Connie Lee Cooper	Rebecca Lynn Gill	Alice Kallus	David W. Moore	Russell Robertson

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

William Roy Robinson	Betty Stanhope	Stephen Zenger	Bob Fisch	Elizabeth McKee
Carol Ann Rockett	Robert S. Steel	Julie Marie Dickmeyer	Joe Fischel	Jame McLeskey
Sarah C. Rogers	Susan Stevenson	Zerhusen	Uncle Bob Fischel	Todd McPencow
Richard Rohl	Daniel Stezenko	Robert Zimmerman	Robert E. Fischel	Kathy Mele
Joseph A. Rokita	Anne Lutz Stivers		Ginny Fowler	Nancy Messner
William Ellis Rooker	Michael T. Stone		John J. Garvey, Jr.	Rashelle Morcom
Michael Root	Michael Strohm	In Honor of	Thomas Giles	Mark Moriarty
Aaron Rosenstein	Susan Stroka		Earl Gilmore	Dorothy Munhall
Brian Rosequist	Gretchen F. Sundius	John Agugliaro	Linda Gulnac	Julia Winston
Honey Rowan	Magalie Verna	Gordon Alexander	Jack Hartke	Bethurum Murphy
Tim Rowans	Surena	Brad Anderson	Daniel Hedaya	Ann Nave
Frederic Ruehe	Wendy Suzman	Nanci Anderson	Victoria Heller	David Nelson
Tom Ruhlman	Merlin L.	Robert August	Janice Henry	Ronald Nelson
Kevin Ryan	Swackhamer	Paul Axel-Lute	Beverly Hernandez	Alexis DeMarco &
Patricia H. Ryan	Albert Sylanski	Joseph Baldi	Colleen Terry Hill	Andrew Newhouse
David Michael Sacino	Claude Thomas	Glynn E. Behmen	Judith Holcomb	Donald Newhouse
Seymour "Stony" Sarokin	Larry Thomas	Steven P. Bellwoar	Stephen Holt	Terry Nielsen
Angelo William Savino	Julie Thomson	Trish Bellwoar	Kara Ike	Barry Nolte
Nancy Sawyer	Howard Thorn	Alan Berlin	Ed Jackson	Margaret Papas, MD
Mary Lou Porter Saxon	Milo Tiefenthaler	Joan Berlin	Bruce A. Johnson	Jennifer Parker
Paula Schimizzi	Doris Marie Tiller	Patty Billings	Alice Kalis	Alyssa Part
John Schloerb	Dale Tyler	Roy Bohr	Donald Kalscheur	Rose-Marie Pelletier
Mary Anna Schluckebier	John D. Ulrich	Elizabeth Bonaventura	Christopher Kelley	Paul Petras
Dan Schmidt	Ken Ushio	The Boulet Family	Dennis Kent	Nona Pipes
Veronica Schnapp	Richard Van Dyke	Frank Bouschart	Brian Kirk	Bob Powers
Robert John Schramm	Annmari Vitale	Susan Hoene Boyle	Jon Knight	Lisa Raines
Charles Alexander	Norman E. Vojtech	Suzanne Brooks	Ron Koch	Ginger Reeder
Scudder	Daniel R. Waber	Patricia Bryant	Catherine M.	Janet Reilly
Craig A. Seay	Beverly Waite	Judy Burch	Kuhmichel	Brian Rose
Thomas P. Seely	Richard Wallin	Frank Callea	Kacy Kunesh	Donna Rose
Kelly Sepelak	Michael G. Wallis	Patty Canavan	Michelle Kyriacou	Lauren K. Rowans
Tracey Sepesy	Mary Walter	Maria Cervoni	Allison McCormack	Mary Rutchow
Michael Setlow	Mike Walter	Su-Ling Chang	Lee	Dr. Tracey Sepesy
Norman Sheldon	Phillip Walter	Sally Cihos	Paul Lester	Paul Siedlecki
Ned James Shepherd	Steve Walter	Marcella Clark	The Very Rev. Tracey	Mark Smerdel
William G. Shimkus	Dwight H.	Brandon Cline	Lind	Ellen Solomon
Stephen W. Shippie	Warrington Sr.	Serina Cline	Paula Lindberg	Jeanette Stoothoff
Karen Goff Shulman	Rosemary "Cookie"	Helen-Ann Comstock	Pamela M.	Denise Strohm
Mary E. Coyle Siller	Weiten	Judy Comstock	Luchsinger	Phillip Thomas
Joanne M. Silva	Joel Welshons	Thomas Cox	Cindy Luckie	Deanna Thorne
Arnold Silverman	Mary Williams	John Crane	Natividad Marquez	James R. Tobin
Patricia M. Simboli	Edwin P. Wilson	Pat Crane	Antonio Marquez	Dominic Toscani
Susan Simon	Edward J. Winarski	J. Michael Davidson	Fides Marquez	James Tully
Semahat Sinharoy	Robert Steven	Mr. & Mrs. Andrew	Travis Martin	Barry Wank
Gerry Sinnott	Winters	Dobroskey	Nina Matusiak	Judy Windhorst
Leo Skaine	Tom Wirt	Shana Dodge	Anthony Mazzara	Wayne Womack
Josephine Sneckus	Madeline A. Wohl	Jenny Dore	Sheard McCulley	Ken Young
Philip F. Solverson	Deborah Woodcock	The Dubes	Jake McGarvey	Christopher Yurkanan
Jason John Spinks	Chris Edmondson	Margaret Dultz	Jody McGuire	Ira J. Zohn
John Stackhouse	Yurkanan	Richard Fagin		

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+"

Gifts made in honor or in memory of persons diagnosed, care partners, friends and family members advance AFTD's mission by bringing help and new resolve to those facing FTD today, and hope for a future without this disease.

The names listed below were mistakenly excluded from the Summer 2021 edition of AFTD News. Donations were made in honor of these community members from February 1 through June 30, 2021.

We are grateful for this vital donor support, honoring so many on an FTD journey, and deeply apologize for this error.

In Honor of

Lydia Adalian
Michael J. Angello
The Ardinger Family
Raymond Asaro
Emerson R. Avery Jr.
Mary Barnes
Arlene C. Beerman
Laurie Beyer
John Bickley
Richard Bloch
Dianna Bogert
Alejandro and Marilu Bolivar
Trudi Burns
Kimberly Sullivan Chu
Paul Cimino
Anne Clark
Brian Claycomb
Brandon Cline
Justin Cline
Sarah Coffin
Robert Dalton
Robin Dawson
James Day
George H. Dentler
Angela Dotson
Christine Drow
Thomas Drow
Mrs. Duncan
Island Ed

Robert Edesa
George L. Farrington
Stephen Fenoglio
Jay Feuer
My Frankie
Paula Frost
Liz Furse
William Gilbert
Stephen J. Greenwalt
Megan Vander Haar
Heidi Hamms
Elizabeth Hilliard
David Huebner
Melanie Ellen Hunt
Emily B. Ingalls
The Janowitz Family
Hunter Javeline
The Jerre Feintheil Family
Anne Johnston
Susan Johnston
John Kammerer, Jr.
John Kammerer, Sr.
Jonathan R. Knight
Toni Krashinski
Peter Krey
Matt Kridler
Maria Krushinski
Teresa Lewis
Nancy Lieberman

Geru Lim
John Lindsey
James MacDonald
Chris Magiet
Mireya Magiet
Victor Magiet
Cynthia Malis
Fides Marquez
William Matteson
Carolyn May
Linda McCarthy
James McGarvey
Erica McIlroy
Rory McIlroy
Fara McLaughlin
Bill Meador
Phillip Trevor Meredith
Helen Milano
Rashelle Morcom
Bernardo Munguia
Julia Winston Bethurum Murphy
Ginny Myers
Richard Myers
Francine Nagin
David Nelson
William Wesley Parker
Kelly Patton
Allegra Pearce
Cathy Pfeifer

Bob Pieri
Doug Pieri
Susan Price
Bryce Pursley
Gregory Rively
Laurie Robinette
Carlos Saldanha
Red Scarff
Richard Scheuerman
Russell Schubert
Mark Schuerman
Joe Sheets
Leslie Siwakoski
Oliver Smith
James Snee
Ellen Solomon
Michael Strohm
Clay Swindell
Linda Tompkins
Del Trautmann
Marc Van Doren
Mark Vlasic
Gillian G. Waterman
Kristina Wells
Karen Wilhelm
Ed Winarski
The Windhorst Family
Leah Portnoy Worenklein
Eileen Yaffe



#FTDhotshotchallenge

The #FTDhotshotchallenge, a community-driven grassroots initiative that combines hot sauce and social media, returned for its second year—and first as an official part of Food for Thought—and raised \$100,000 for AFTD's research initiatives!

On the challenge's launch date, September 27, The Mike Walter Catalyst Fund pledged a 1:1 matching gift for the first \$12,500 raised on the fundraising platform Classy — which was met within nine days and sparked an additional 1:1 matching gift from an Anonymous Hot Shot Hero for \$15,000. But the heat didn't

stop there! The Mike Walter Catalyst Fund pledged an additional \$12,500 milestone donation once the campaign reached \$87,500, which it did with the help from a corporate matching gift.

AFTD would like to thank our generous sponsors, the 30 people who created fundraising pages, the 200+ donors, and all who handled the heat to spread FTD awareness. AFTD would also like to recognize the volunteers behind the #FTDhotshotchallenge for the past two years including: Amanda Dawson, Keri Allen, Caroline Dultz, Kacy Kunesch, Sheryl Whitman, Jennifer Lee, Nicole Petrie, and others!

Why Volunteer with AFTD?

Looking to get involved and help support AFTD's mission? Join dedicated volunteers from across the country, helping families affected by FTD find support, resources, and hope in their communities.

Volunteering with AFTD gives you the opportunity to:

- Connect with others affected by FTD by hosting an in-person or virtual Meet & Greet
- Support others on the FTD journey by facilitating a support group, whether in person or virtually
- Share your story, FTD information, and AFTD resources by staffing a table setting at a local health fair, conference, or other community event
- Raise critical funds and awareness in support of AFTD's mission
- Educate healthcare professionals

AFTD's Volunteer Network also hosts a series of virtual gatherings, providing the chance for volunteers to connect with each other, engage with AFTD staff, and learn new skills that not only support your volunteer efforts but your professional and personal work as well.

All of AFTD's activities can be done virtually or in person, depending on current and local guidelines and your own comfort level. Come join AFTD's volunteer network and make a difference today! Take a look at this list of AFTD's volunteer opportunities, or take the first step by visiting our website at theaftd.org/get-involved/volunteers-network.

AFTD Volunteer Opportunities

Community Awareness	Table Settings	Raise awareness by representing AFTD at conferences and other community events
	Meet & Greets	Facilitate an informal gathering (in-person or virtual) to connect with others affected by FTD
	Media Coverage	Consider sharing your story with the media -- we will help connect you to an appropriate outlet
Support Groups	Face-to-Face Groups	AFTD will help you plan an in-person or virtual FTD caregiver support group (professional experience not required)
	National Groups	Facilitate a national FTD caregiver support group (professional experience not required)
Fundraising	Food for Thought	Use our template to easily plan and organize a food-based fundraising event (late September/early October)
	With Love	Follow our easy instructions to create a fundraising page and share your FTD story online (every February)
	Runs/Walks	Make your race more meaningful by organizing a team to represent AFTD at an established run/walk event
	Independent Events	Plan and host your own fundraiser
Coordinating Volunteers	Food for Thought Liaison	Support other AFTD volunteers who are hosting a food-related fundraising event (summer/fall)
Administration	Zoom Support	Provide technical support for staff and volunteers during virtual events
	Office Help	Assist staff at our King of Prussia, PA office



Food for Thought 2021

AFTD's 9th annual Food for Thought campaign comprised 42 events in 31 states (plus Canada) and raised \$100,000! Below are the events that raised \$1,500 or more:

It's Electric: Steve Bellwoar, a Pennsylvania-based AFTD Board Alumnus, hosted the eighth annual Colonial Electric Food for Thought event virtually this year, sharing a video message of himself and AFTD's CEO Susan L-J Dickinson, and asking his past attendees to consider continuing supporting AFTD's mission. As a thank you to supporters this year, Steve and his colleagues look forward to treating them to a meal individually, and hopefully seeing everyone altogether next year in person! The event raised \$60,168, bringing the grand total to \$629,540 raised over the past eight years, continuing its title as our flagship Food for Thought event.

Team McGarvey: Jim Capobianchi and the McGarvey family hosted an event in their Pennsylvania hometown, featuring delicious food and good music. The event included a silent auction of 20 donated gift-basket items and a 50/50 raffle. More than 150 people attended and helped to raise \$12,997.

Garage Sale: Fran Jensen and her family in Alabama asked their local community to donate items to be sold at a garage sale to benefit AFTD's mission. At the event, the Jensen family educated the community about FTD, shared how the disease affects their family, and explained AFTD's mission. Through sales and direct donations, supporters raised \$4,200.



Cooking with Kyle: Kyle Jackson in Illinois hosted his second annual virtual cooking class, called "Pappardelle Portobello Ragu Pasta Cooking Class & FTD Education." Thirty families tuned into the livestream to cook a tasty meal and learn about FTD together. Kyle kicked off the Zoom cooking class with a brief overview of FTD and how it has impacted their family.

Kyle raised \$3,256 through the event.

Having a Souper Time: Kyle Walchak hosted a soup contest in Pennsylvania between friends and family, and saw an impressive 52 people participate. Through an entry fee, participants raised \$3,136 to support AFTD's mission. Guests learned about FTD, and then voted on their favorite soups, with prizes awarded to tastiest creations.

Healthy Snacks & FTD Facts: Ryan Windhorst in Illinois posted his online fundraiser on Facebook with daily facts about FTD throughout the Food for Thought campaign. He also partnered with a local food prep business, Namken Nutrition, which donated a portion of all healthy protein bar sales to the fundraiser. In total, \$2,978 was raised to support AFTD's mission.

Remembering Gary: For their fourth annual fundraiser, the Anderson family of Minnesota went virtual, encouraging their friends and family to donate in honor of their loved one, Gary, who passed away in 2019 after living with FTD. Through the event, they raised \$3,232 in Gary's memory, and in support of AFTD's mission.

Pickles for Pick's Disease: Philadelphia's Fishtown Pickle Project joined the campaign for its second year by donating a portion of all pickle sales towards AFTD's mission. They additionally reached out to other local businesses, and each created a different pickled creation and donated a portion of sales. Altogether, the fundraiser raised \$2,847.



Kara's Krew: Debra Ford, Dawn Kirby, and Kirsten Jewell teamed up with a local restaurant, Joe's Pizza in Paris, Illinois, for their Food for Thought fundraiser. Customers ate their favorite food (pizza!)

and learned about FTD. In the restaurant, the family displayed a board with information about their loved one living with FTD, Kara, who is 32 years old. Together, the family raised \$1,650 for AFTD's mission.

IHO Ned: Utah-based AFTD Board Alumna Bonnie Shepherd has joined our Food for Thought campaign every year since its inception. This year she kept things simple and safe by created a fundraising page on Classy, which she generously kicked off with a personal donation. Having raised a total of \$1,515 this year, Bonnie looks forward to getting back to her in-person events in 2022.



TIMFEST IV: Kathy LaFone and Sara LaFone hosted their fourth annual TIMFEST, an event honoring their beloved husband and father, Tim LaFone, who passed in 2015

and had been living with FTD. Friends and family gathered to put FTD "on its last leg" while listening to music and enjoying delicious snacks. Online and in-person donations raised \$1,550 for AFTD's mission.



Thank you to all the additional hosts who raised funds and awareness to support AFTD's mission:

Alector Inc.	Esther Harvey	Marian Grems	The Caregiver Solutions Info Show
Amanda Hall	Jerry Horn	Melanie Axel Lute & Kate Koisor	The Pang Family
Amy Pohl	Joanne Linerud	Melissa Dube	The Remember Me Podcast
Amy Shives	Julie Edwards	Nicole DeLeve	UVA Department of Neurology
Beth Andrews	Karen Smith	Patrick Guitterez	Veronica Wolfe
Brandee Waite	Lori Friedman	Terry Pontious	Wave Life Sciences
Deanna Lindberg	Lynda Nagle	Terry Walter	Zoy Kocian
Denali Therapeutics			

AFTD would like to thank the seven Food for Thought liaisons that helped make this national campaign a success!

Cass Hanlon	Jen Morabito	Meghan Roscoe	Traci Saylor
Elaine Rose	Maureen Stroka	Ron Jackson	

THE AFTD-TEAM

The Big 1-6: The sixteenth annual George F. Sidoris Memorial Golf Outing was held on July 18, 2021, at the Lost Nation Municipal Golf Course in Willoughby, Ohio, and raised \$34,091 for AFTD's mission. This event is AFTD's longest running grassroots fundraiser and has donated over \$277,650 in total! Congratulations to the Sidoris Family and thank you for your continued and notable support.

Tee-rific Time: The fifth annual Crusade for a Cure Golf Tournament, hosted by AFTD Ambassador Deb Scharper, was held on September 4 at the Sunny Brae Golf Course in Osage, Iowa, and raised \$8,000. Over the past four years, Deb's tournament has donated \$39,000 to AFTD's research initiatives.

Celebrating Carl: The sixth annual CWM Golf Outing was held on July 10 in Michigan and raised \$5,064. Hosted by the Morettis and Marcys, the day celebrates and remembers Carl Moretti, who passed away from FTD in 2015. Over the past six years, the event has raised a total of \$16,349 for AFTD and our mission.

50/50: AFTD Ambassador Deb Scharper hosted a table setting on behalf of AFTD where she also conducted a 50/50 raffle and collected \$2,100 in donations towards AFTD's mission. She additionally educated community members about FTD and how the disease affects families that experience the diagnosis.

A Par-Tee for Tami: Suzanne and Calvin King hosted the fifth annual "Tami Sue Golf Outing and After Party" on September 11 in memory of their daughter, Tami, who passed away from FTD in 2016. This year's event raised \$2,000, making their total contributions to AFTD since the inaugural event \$10,180.

Bill's Best 5K: Bill's Best Brewery in Glenside, Pennsylvania, held a 5K on October 9. Entry was \$30 a person and participants received a t-shirt and one pint of beer. Bill's Best covered 100% of the costs so that 100% of the funds raised went to AFTD. Through the event, they raised \$1,310 for AFTD's mission.

Running for a Cure: Papus Keita ran the Cleveland Marathon on October 24 in honor of his father-in-law, Ken Young, who is living with FTD, and for all who are living with an FTD diagnosis. Papus chose to fundraise for AFTD's mission and raised \$1,033 for his participation in the race.

Driving Hope

AFTD's 2021 Driving Hope Golf Tournament was held in person this year after last year's virtual outing. The Colorado National Golf Club in Erie, Colorado, hosted us on August 15, and the Seawane Club in Hewlett, New York, hosted us on October 18. All were excited to get back outside together, and it shows: The events combined to bring in more than \$100,000 for AFTD's mission!

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

Amidebio	Buffalo Trace Distillery	Joe and Kathy Mele	The Mike Walter Named Fund
Angelo Gordon	DAX Real Estate	Mack Real Estate	The Seibald Family
Aspen Wealth Strategies	Donald Newhouse	Magnetar Capital	Whitmore Group
Blue Sand Securities LLC	IBERIABANK First Horizon	Parking Systems	

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



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

2700 Horizon Drive, Suite 120
King of Prussia, PA 19406
www.theaftd.org

Prsrt. Std.
U.S. Postage
PAID
Williamsport, PA
Permit #33

If you prefer to receive this newsletter via email or would like to be removed from our mailing list, email info@theaftd.org or call 866-507-7222.

AFTD

www.theaftd.org

phone: 267.514.7221

toll-free phone: 866.507.7222

Board of Directors

- | | | | |
|---|---------------------------------------|---|---|
| David Pfeifer
Chair, Colorado | ● Christian Barrow
Quebec | Daniel Hedaya
New York | Kristin Schneeman
Connecticut |
| Kimberly Pang Torres
Vice Chair, New Jersey | ● Rick Childs
Massachusetts | Kristin Holloway
California | Michael Stowell, Ph.D.
Colorado |
| Brian Rose
Treasurer, New York | ● Rita Choula
Maryland | Jary Larsen, Ph.D.
California | Beth Walter
California |
| Kacy Kunesh
Recording Secretary, Texas | ● Sandra Grow
Ohio | Joseph Marquez, M.D.
Washington | |
| Helen-Ann Comstock
Founder, Pennsylvania | ● Matt Hatfield
Florida | Donald Newhouse
New Jersey | |

Medical Advisory Council

- | | |
|---|---|
| Ian R.A. Mackenzie, M.D.
Chair, University of British Columbia, Vancouver | Virginia M.-Y. Lee, Ph.D.
University of Pennsylvania |
| Bradford C. Dickerson, M.D.
Chair Elect, Harvard University | Carol F. Lippa, M.D.
Thomas Jefferson University |
| Bradley F. Boeve, M.D.
Mayo Clinic, Rochester | Irene Litvan, M.D.
University of California, San Diego |
| Dennis W. Dickson, M.D.
Mayo Clinic, Jacksonville | Mario Mendez, M.D., Ph.D.
UCLA |
| Howard Feldman, M.D.
University of California, San Diego | M.-Marsel Mesulam, M.D.
Northwestern University |
| Bernardino Ghetti, M.D.
Indiana University | Bruce L. Miller, M.D.
UCSF |
| Jill Goldman, M.S.
Columbia University | Jill Murrell, Ph.D.
Indiana University |
| Murray Grossman, M.D., Ed.D.
University of Pennsylvania | Chiadi Onyike, M.D.
Johns Hopkins University |
| Edward Huey, M.D.
Columbia University | Creighton Phelps, Ph.D. |
| Michael Hutton, Ph.D.
Eli Lilly & Co. UK | Rosa Rademakers, Ph.D.
University of Antwerp |
| David S. Knopman, M.D.
Mayo Clinic, Rochester | Howard Rosen, M.D.
UCSF |
| Walter A. Kukull, Ph.D.
University of Washington | John Q. Trojanowski, M.D., Ph.D.
University of Pennsylvania |

Staff

- | | | |
|--|--|---|
| Susan L-J Dickinson, M.S.G.C.
Chief Executive Officer | Debra Niehoff, Ph.D.
Scientific Director | Jeni Cardosi
Volunteer Coordinator |
| Penny Dacks, Ph.D.
Senior Director of Scientific Initiatives | Lauren Gauthier
Social Media & Online Communications Manager | Erin Ficca, MA
Support Services Coordinator |
| Sharon S. Denny, M.A.
Senior Director of Programs | Bridget Graham
Special Events Manager | Adriana Fraser, MA
Digital Content Writer |
| Ben C. Freeman
Senior Director of Advancement | Amanda Knight
Development Manager | Annamarie Given
Volunteer Coordinator |
| Christine Stevens, M.B.A.
Chief Financial Officer | Anzhela Matsyshen
Digital Marketing Manager | Elizabeth Graham, MA
Development Writer |
| Elizabeth R. Young
Executive Assistant | Bridget Moran-McCabe, M.P.H.
Support Services Manager | Ann Schoonover, M.S.W., L.S.W.
HelpLine Specialist |
| Cynthia Brown-Smith, MSHRD, PHR
Director of Human Resources | Matt Ozga
Content & Media Relations Manager | Josephare Lector, M.S.W.
HelpLine Advisor |
| Shana Dodge, Ph.D., M.A.
Director of Research Engagement | William Reiter, M.A.
Education Program Manager | Emma Tomasetti
Development Coordinator |
| Esther Kane, RN-CDP
Support & Education Director | Matthew Sharp, M.S.S.
Advocacy Manager | Shifur Bakaul
Development Assistant |
| PJ Lepp
Director of Marketing and Communications | Jeff Thompson
Office Manager | Samantha DeMarco
Administrative Assistant, Research |
| | | Raymond Frattone
Administrative Assistant, Programs |

For permission to reprint articles, please contact info@theaftd.org or call 267-514-7221.