



AFTD news

Bruce Willis Announcement Brings FTD Awareness to Millions Worldwide

The family of Bruce Willis announced via Instagram on February 16 that the beloved actor has been diagnosed with FTD.

The statement, also published on AFTD's website, was signed by members of Willis's family: his wife, Emma; his ex-wife, Demi Moore, and their daughters Rumer, Scout, and Tallulah; and Mabel and Evelyn, the two daughters he shares with Emma.



In March 2022, Willis, 67, retired from acting due to a diagnosis of aphasia, a condition that affects one's ability to speak and to understand language. However, his symptoms have since progressed and are no longer limited to challenges with communication, leading to his recent diagnosis of FTD.

"Ours is just one family with a loved one who suffers from FTD, and we encourage others facing it to seek out the wealth of information and support available through AFTD," the family wrote. "And for those of you who have been fortunate enough to not have any personal experience with FTD, we hope that you will take the time to learn about it, and support AFTD's mission in whatever way you can."

The Willis family's announcement had an instant and significant impact on FTD awareness around the world. The number of visitors to AFTD's website (theaftd.org) on February 16, the day of the announcement, was up more than 100 times compared to a typical day.

The announcement garnered widespread attention from major national and international media outlets. AFTD staff members, Board members, and volunteers were interviewed to share critical context, insight, and personal experiences.

AFTD CEO Susan L-J Dickinson, MSGC, appeared on *NBC Nightly News with Lester Holt* on the night of the announcement, reaching a national television audience of millions. She was also quoted in a *New York Times* article on Willis's diagnosis, along with Bruce Miller, MD, of the University of California, San Francisco – one of the country's leading FTD experts, and a member of the AFTD Medical Advisory Council (MAC).

Fellow MAC members quoted in prominent articles included MAC chair Bradford Dickerson, MD (in the *Washington Post*) and Bradley Boeve, MD (in France's *Version Femina*). Dr. Miller also talked about FTD in a February 17 appearance on *Fox and Friends*. Meanwhile, AFTD Senior Director of Programs Sharon Denny, MA, spoke with the British news channel Sky News and the German periodical *Westfälische Rundschau*.

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AFTD News Briefs

L.A. Rams Coach Dons AFTD Cleats During Game

Zac Robinson, quarterback coach and pass game coordinator for the Los Angeles Rams, wore special cleats adorned with the AFTD logo during the Rams’ December 4 game against Seattle. Robinson’s late father, Rusty, was diagnosed with FTD several years ago. The coach wore the cleats both to support AFTD and raise FTD awareness during the NFL’s “My Cause My Cleats” event, in which players and coaches wore custom cleats promoting charities, organizations, and causes. “You [have] to just truly cherish every single day,” Robinson said of his father’s FTD journey. “It was really hard on our family, especially my mom, who was there every single day.” He added, “Just raising the awareness is the biggest thing. Whatever comes from that is all great.” Robinson was the Rams’ assistant quarterback coach during its Super Bowl-winning 2021 season.

Penny Dacks Appears on *Remember Me* Podcast

AFTD Senior Director of Scientific Initiatives Penny Dacks, PhD, discussed the different types of ongoing FTD research and how people living with FTD can get involved on the November 29 episode of the *Remember Me* podcast. Dr. Dacks told hosts Rachael Martinez and Maria Kent Beers that hope is building for effective FTD treatments, and that those interested in participation have a growing number of opportunities to get involved in clinical trials and other ongoing research projects. Dr. Dacks also discussed genetic testing and genetic counseling, and explained what clinical trials are and what participation may entail. She further suggested signing up with the FTD Disorders Registry to learn about potential research opportunities and help stay up to date on the latest developments. “What you do matters,” Dr. Dacks said.

HEALING THROUGH SHARING OUR FTD STORY

"We have to stop and remember that the person they were is not the person they are, and it's going to keep changing. I hope we can get people to look at the dementias differently."

– Dawn O'Gara, former FTD care partner and current AFTD volunteer



Dawn O'Gara's father, Jim Tobin, was a well-respected veteran who enjoyed spending time with his grandchildren. Nine years ago, Dawn and her family noticed changes in Jim's personality – he became passive and less aware of others' feelings, spent less time with his family, and ate more frequently.

Jim felt nothing had changed with his behavior. The inability to understand one's illness and its impact on family members is a hallmark symptom of FTD, otherwise known as anosognosia. Dawn's mother reacted to these changes as directed at her and struggled to recognize that there could be a medical explanation. Dawn and her siblings encouraged their parents to seek a firm diagnosis. Though physicians initially thought he had Parkinson's disease or schizophrenia, Jim was diagnosed with bvFTD in 2014 at the age of 64.

Using AFTD's website to educate herself about FTD, Dawn found comfort in the amount of information and support available. When Jim moved into a long-term care facility, Dawn felt a renewed sense of purpose to raise awareness, becoming an

AFTD Ambassador and fundraising volunteer to share her family's journey and offer support to others navigating an FTD diagnosis.

Jim passed away in August 2022. While it was a difficult time for her family, Dawn remains committed to sharing her dad's story, reassuring others that they are not alone and to be patient with their loved ones as well as themselves.

"When you tried to explain [my dad's FTD diagnosis] or his behaviors, people just didn't understand," Dawn said.

Dawn and Jim's story reminds us why awareness is an essential part of AFTD's mission. Each FTD journey is unique, and by sharing each family's experience, we can stimulate greater understanding of the disease, leading to earlier and more accurate diagnosis, responsive and quality care services, and more funding for FTD research.

"I love being an ambassador. Going out and sharing his story, making people more aware through the educational presentations that I do, and being there for other families...it's healing for me."

*Every story brings awareness to make things better for the next family.
Every story moves us closer to a future free of FTD.*

Will you join Dawn in raising awareness and supporting AFTD's mission to #endFTD?

By making a tax-deductible gift, you can help AFTD amplify the stories of other people and families affected by FTD, provide information and resources, and advance research that brings forward treatments and a cure. 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**.



Spotlight on...

Julie Kelly, AFTD Board of Directors



Julie Kelly

Growing up, Julie Kelly was like a third sister to her best friends, identical twins Cathy Pfeifer and Jeannette Ekstrand. The trio went to high school together in suburban Chicago. While attending Indiana University for her BS in finance, Kelly lived with Pfeifer during her first two years, and the two frequently road-tripped to Miami University to visit Ekstrand.

Cathy eventually married David Pfeifer, the current chair of AFTD's Board. Then Kelly married -- both twins were bridesmaids in her wedding -- and moved to Philadelphia, while Pfeifer and Ekstrand moved to Denver. The trio kept in contact over the years, though in time, Kelly noticed something different about Pfeifer.

"I noticed a change in Cathy's personality, but I thought we had just grown distant; we were raising kids and working, we were busy," Kelly said. "After I first began to notice signs that something was wrong, David called me and told me that Cathy had been diagnosed with FTD."

Ekstrand was subsequently diagnosed with FTD as well. Pfeifer died in 2016, two years after her diagnosis; Ekstrand died two years later.

"When they passed, it caught all of us by surprise because they were so young and vibrant," said Kelly. "I think of them every day. I miss them."

After her friends died of FTD, Kelly felt an urge to somehow make a difference. An invitation from David

Pfeifer to join the AFTD Board's Investment Subcommittee gave her the chance to give back. After two years of serving on the subcommittee, she is set to join AFTD's Board in May.

Serving on the board helps to keep "Cathy and Jeannette's memory alive," Kelly said. "Let's try to solve this riddle called FTD; let's get families the help they need and work towards a cure in our lifetime."

"Let's get families the help they need and work towards a cure in our lifetime," said Kelly, who has lost two dear friends to FTD.

As a Board member, Kelly hopes to support AFTD's efforts to expand its outreach to medical professionals, lawmakers, and the general public. She notes that FTD isn't going away on its own, and there needs to be ongoing support for FTD research, advocacy, and education. As a financial advisor with 28 years of experience in wealth management, Kelly also brings expertise on personal wealth, running a business, balancing finances, and more.

"Our heart is with everyone who is suffering from this horrible disease, and we're trying to make it better," Kelly said. "We're hoping what we're working on will allow us to have FTD behind us in the future."

Online and In-Person Registration Open for 2023 AFTD Education Conference

On May 5, persons diagnosed with FTD, current and former caregivers and care partners, researchers, and healthcare professionals will gather in St. Louis and online to connect, learn, and engage at AFTD's 2023 Education Conference.

The conference will feature presentations from researchers sharing promising discoveries and new perspectives on care and support, as well as sessions where people with lived experience of FTD will share insights from their journey.

Attendees will have the chance to hear from and connect with leading FTD experts, including this year's Keynote Speaker, Bruce Miller, MD, of the University of California, San Francisco. Dr. Miller is a behavioral neurologist studying the underlying mechanisms of neurodegenerative disorders, and is a world-renowned expert on the diagnosis and management of dementia.

To register for the AFTD Education Conference, visit www.theaftd.org/education-conference-2023. AFTD highly encourages anyone who cannot make it to St. Louis in person to register for the free livestream.

Plenary sessions will focus on the difficulties finding effective long-term FTD care in the U.S. healthcare system and the unique needs of FTD care partners. Additionally, recent recipients of AFTD research grants will present findings from their work and offer reasons

for hope in the session "Promising Paths to Discovery."

Two rounds of breakout sessions will give attendees the chance to more deeply explore topics that interest them.

Certain sessions will be available simultaneously to both

those joining the conference in St. Louis as well as those attending online. Other sessions will be exclusively online, such as the afternoon session on improving FTD care in rural and underserved communities, or solely in person, like the AFTD Persons with FTD Advisory Council's morning panel "Building Our Own Toolbox." For many attendees, the most impactful aspect of the AFTD Education Conference is spending time with others who also have FTD in their lives.

"After an FTD diagnosis, families can often feel isolated, as they're facing a disease that not many have heard of," said AFTD Support and Education Director Esther Kane, MSN, RN-CDP.

"By coming to the Education Conference, though, families can tangibly experience an entire community of people, convened by AFTD, that understands and will stand by them throughout their journey."

If you are coming to St. Louis, AFTD Comstock Travel Grants are available for people diagnosed with FTD and their care partners to help subsidize any associated travel and lodging costs. To apply for a travel grant, visit www.theaftd.org/living-with-ftd/resources/comstock-grants.



A panel discussion from the 2022 AFTD Education Conference.



AFTD Senior Director of Programs Sharon Denny spoke at the 2022 AFTD Education Conference.

Why Attend the AFTD Education Conference?

Nearly **85 percent** of 2022 AFTD Education Conference attendees said they found the overall conference to be either "**excellent**" or "**very good.**" Following is some of the feedback they offered:

- "Provided a wide range of information for all involved in FTD."
- "Highly informative and timely."
- "Seeing attendees from all across the world helped me not to feel so isolated."
- "Thank you for the whole entire conference. I feel so supported and encouraged."
- "Excellent, inspiring, uplifting and informative."

AFTD Now Offering CME Credits to Healthcare Professional Webinar Attendees

As part of an ongoing organizational effort to provide vital FTD education to healthcare professionals, AFTD held its first webinar offering continuing medical education (CME) credits on February 22.

Guest speaker Howard Rosen, MD, of the University of California, San Francisco offered insight on the differences between behavioral variant FTD (bvFTD) and other forms of dementia, including Alzheimer's disease, allowing healthcare professionals to make earlier and accurate bvFTD diagnoses.

Because there is no single test that can conclusively diagnose FTD during life, the disease remains difficult to differentiate from Alzheimer's, Parkinson's disease, or other psychiatric conditions. Doctors and neurologists arrive at an FTD diagnosis by evaluating results from procedures such as brain scans with their own observations. On average, it takes families 3.6 years after symptoms emerge to get a diagnosis of FTD.

"Many families have struggled to get a timely and accurate FTD diagnosis," said AFTD Education Program Manager William Reiter. "AFTD is pleased to offer our first education program specifically created for doctors and



Simon Ducharme, MD



Howard Rosen, MD

other healthcare professionals in an effort to change that."

AFTD launched its Healthcare Professional Webinar series in June 2022, offering continuing education credits (CECs) via Rush University to those who attend the webinars live. (All AFTD webinars are recorded and archived on AFTD's YouTube page, at youtube.com/TheAFTD.)

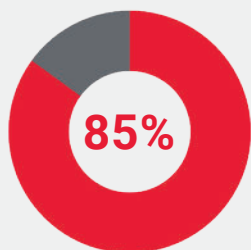
The first three Healthcare Professional Webinars focused on providing person-centered care for people diagnosed with bvFTD, primary progressive aphasia, and the two movement disorders that fall under the FTD umbrella, corticobasal syndrome and progressive supranuclear palsy.

Nurses and social workers who work with persons diagnosed with FTD and attended these webinars were eligible to apply for CECs.

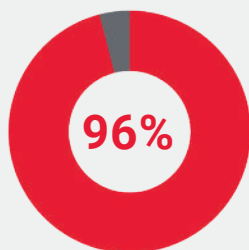
AFTD expanded the scope of this series in February by offering CME credits to physicians, along with CECs. More than 270 people attended the February webinar with Dr. Rosen (a member of AFTD's Medical Advisory Committee).

The next webinar offering CME credits will be held April 13; Dr. Simon Ducharme of the Douglas Mental Health University Institute and the Montreal Neurological Institute will talk about treatments for people living with bvFTD.

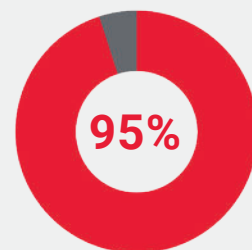
Statistics from AFTD's First Webinar Offering CME Credits



Registrants who identified themselves as a healthcare professional



Described February 22 webinar as "excellent" or "very good"



Said they will apply what they learned in the workplace

Bruce Willis Announcement

Continued from page 1

AFTD volunteer Chuck Anastasia talked about his late wife's FTD journey in an interview that aired on the ABC-TV affiliate in New Hampshire. And AFTD Board member Kristin Holloway – this year's recipient of the Susan Newhouse & Si Newhouse Award of Hope (see page 11) – detailed her husband's FTD diagnosis for the NBC affiliate in Washington, DC. (Additional examples of the AFTD community speaking to the media can be found at theaftd.org/newsroom/media.)

In their statement, the Willis family said, "Bruce always believed in using his voice in the world to help others, and to raise awareness about important issues both publicly and privately."

They continued: "We know in our hearts that – if he could today – he would want to respond by bringing global attention and a connectedness with those who are also dealing with this debilitating disease and how it impacts so many individuals and their families."

FTD Awareness After Willis Announcement: By the Numbers

1.2 Million

Visitors to theaftd.org in the month following the announcement – up nearly 19x from the prior month

More than 100%

Increase in calls and emails to AFTD's HelpLine after the announcement

Almost double

The number of people following @theAFTD on Instagram (was 3,416 and is now 6,150)

AFTD Staff Attend International FTD Conference in France

Experts in the FTD field from around the world gathered in Lille, France from November 2-5 for the biannual conference of the International Society for Frontotemporal Dementias (ISFTD).

AFTD had a strong presence at the conference, operating an information booth that shared AFTD resources, hosting a networking breakfast, and beginning a mentorship program that paired AFTD Holloway Postdoctoral fellows with senior FTD researchers. Staff who attended were encouraged by the progress in FTD research and the number of early-career researchers choosing to focus on FTD basic and clinical science.

The conference's agenda featured scientific presentations on various topics related to FTD, from its clinical and biological features to different therapeutic approaches for

alleviating symptoms. Highlights of the scientific sessions included the reveal of a new model that could reduce the number of people needed to participate in a clinical trial, as well as a discussion of how speech can be affected by FTD, and how the clinical presentation of FTD can be different depending on the language spoken.

Each day also included a "poster blitz" featuring printed materials from researchers detailing findings from their latest projects. A vast amount of FTD research and insight was on display at the conference, with research from over 200 projects on display during the poster exhibition.

ISFTD 2022 also included a Caregiver Day so that people in France living with FTD could discuss supports available to people affected by FTD around the world. AFTD Senior Director of

Programs Sharon Denny, MA, presented on local experiences in supporting American caregivers, while AFTD CEO Susan L-J Dickinson, MSGC, moderated a discussion that presented feedback from patient associations.

"I was really taken by the industry sessions that occurred at the end of Caregiver Day," said AFTD Director of Research Engagement Shana Dodge, PhD, MA. "Several years ago, the idea of running clinical trials in FTD was just theoretical. Now, there are a number of opportunities to participate in research for experimental therapies. During the industry session, seven representatives from companies with ongoing clinical trials, or clinical trials about to start recruitment, presented information about their trials."

The next ISFTD conference is scheduled for 2024 in Amsterdam.

Those We Honor... Those We Remember

Gifts received from October 1, 2022 – February 15, 2023

In Memory Of

James S. Abbott
Steven Aboloff
Charles Adams
Rebecca Ann Adams
Ann Addvensky
Stanley Afek
Laura Ahlbeck
Michael P. Alban
Julianne M. Allen
Robin K. Allen
William "Bill" M. Allen
Sharon Altoff
Donald Alan Anderson
Donna Voss Anderson
Gary E. Anderson
Marguerite Anderson
Joanne Andrews
Michael J. Angello
Marie Annette Nichols
Linda Arlene Clark
Mark Arnold
Delma Arrigoitia
Steven Atkins
Anna Held Audette
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Emerson R. Avery
Harold Axe
Christina Bain
Darlene Baker
Bernadette Balcer
Craig Michael Bancroft
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Johnny Maxine Barber
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Trish Bellwoar
Betsy Bennett
David Berkowitz
Paul Bernard
Kenneth Alan Bernhard
Deborah Graham
Bernstein
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Gary Besonen
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Kimberly Booten
Lynda Bordoni Wolff
Mark Botteon
Joy Spartian Bowen
David Bower
Clarke Bowers
Lynn Boyce
Susan Hoene Boyle
Annie Brady
Richard Benjamin
Braxton
Eileen Brennan
Donna Gale Brenner
Winfred Brickmeier
Dan Brill
Marsha Bristow Bostick
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Susan Brody
Catherine Broer
Kathy Brooks
Mike Broom
Michelle Brown
Barbee Lee Bruce
Ken Brunner

Jayne Burczyk
Margie Burgess
Lawrence Burnetski
Sylvia Buttefield
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Patricia Taylor Canavan
Mikel J. Cannon
Steven Michael Carb
Cindy Cardosi
Peter G. Carey
Virginia Carlin
Charmian Carr
Robert C. Carter
Gertrude Caruso
John Caruso
Tony Castagna
Willis H. Caterson
Beverly Cavitt
Maria Cervoni
Bruce L. Chalmers
Robin Kjorness
Chandler
Su-Ling Chang
Linda Charbonneau
Frederick Charleston, Sr.
Gary G. Cheatle
Beatrice Childs
Nancy Rice Chislak
Michele Chollet
Andrew Choo
Joanne Christman
Alexandra Clark
Donald Clement
Lawrence T. Cline
Benjamin Coburn III
Ann Cockrell Davis
Charles Cole
Michael J. Coletti
Gail Colfelt
Craig Comstock
David Conkle
Barbara Conley
Stephen Conneally
Denise Connelly
Imogene Cook
M. Russell Cooney
Mary P. Copeland
Sharon Cornwell
Tom A. Cox
William Crane
Don Creedy
Don Crispin
Lisa Ann Crook
Hazel Heather Croxon
Faye Cunningham
Joseph M Cutuli
Jean Dallia
James Dalrymple
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Rohini Daniels
Denny A. Dantimo
Billie Jean Davis
Mike Davis
Robert Samuel Davis
Steve Dawson
Simon DeBeer
Joseph DeBella Sr.
Elvira R. Deeley
Dorothy DeFelices
Clark Deffner
Mary Frances Deitemeier
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George T. Demkow
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Barbara DeRocher
Richard Desautels
Linda DeSent
Robert A. Desiano
Anneliese Dessart
Jeanne deVecchis
Julie Marie Dickmeyer
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Barry Doane
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Craig Donath
Eleanor Dondiego
Kenneth V. Douglass
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Diane B. Drayson
Barry John Driscoll
Leslie Dubiel
Pamela Duncan
Ronald Duncan
Dani Duniho
Kyle S. Durkin
John Dystrup
William W. Eaton
Carole Edelman
Lynda Edsey
Gail Edwards
John G. Edwards
Steven A. Edwards
Mary Sue Eilrich
Mark Eissler
Archibald S. Elliot
David William Elliott
Ayad Elzarad
Richard Engborg
Charles V. Engel
Frank Engelkraut
Christine Engelmann
Carol Ann Esposito
James C. Esque
Anne R. Everard
Cheryl D. Everhart
Lillian Fabrikant
Richard Fallinger
Robert Farber
Bill Fehon
Andrew Stewart
Feinberg
Jerre Feintheil
Michael E. Fenoglio
Kathleen Feron
Mary Ann Fields
Claudette Filipkowski
Mickey Finch
Carol Finkle
Theresa Fiola
Linda J. Fiore
Diane G. Fitzgerald
Pamela Fitzsimmons
Miller
Janet Flaccus
Lawrence Flon
Rosalie Fogarty
Maryellen Tracey Forte
Julia Rose Foster
Ronnie Ray Fowler
James Framstad
Angelina Francisco
Marsha Francisco
Eugene Herbert Frank
Charles E. Franklin
Steven Frantz
Karen Freeman
Bruce Douglas French
Detlef Frey
Bernard Fridovich
Laurena Friedel
Evelyn Friedman
Larry D. Friesen
Reon Friesen
Joseph C. Fry
Jo-An Kathleen Fultz
Robert L. Gallagher
Brady Gardner
John Gardner
Eileen Garvey
John J. Garvey
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Frank Gauger
Anne B. Geremia
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Alexandra Gerry
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Valerie Gilbert Ottman
Victoria Glandon
Mary Louise Gold
Wayne Golden
Marilyn Goldner
Jeffrey Joseph Gomes
Jane Gorden
William L. Gordon
Keith Gotsch
Howard Gould
Joan Gove
David Gragg
Charles Edward Grainger
Dan Graves
Helen R. Greenfield
Zelda Greenspun
Linda L. Greenwald
George Greenway
Susan Gregor
Jeff & Rob Grems
Susan Grengs
Virginia Griffin-Chapman
Linda Groh
Ferris L. "Sonny" Grooms
Karl Grow
Jeffrey Gugliotta
Wanda Guirguis
Mary Gutierrez
Dorcas Haanstad
Dean J. Hadley
Karl Hagerup Jensen
Susan L. Haire
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Patricia A. Hall
Richard Michael Halliday
Therese M. Harlett
Sean Harrigan
Jeffrey Harrington
Marguerite Harrington
Nancy L. Harshe
Pamela Rose Harvalis
Donna Hastings
Sherrie Hatch
Darrell D. Hatt
John M. Headley
Harold Hedaya
Gary Heinz
John D. Heizman
A. Brandt Henderson
Peter Henning
Robert L. Hermann
Lee Herron
John Hershberger
Laura Hespos
Herbert "Andy" Higham
Julia Lancaster Hilliard
Randal Scott Hillman
David Hochschild
Caleb Thomas Hodsdon
Roger T. Hohlweck
Stephen Holt
Robin Holtz
Janet Lee Holzworth
Elizabeth "Betty"
Hoolahan
James David Hopper
Margaret Horine Adair
Garfield H. Horn
Gary Hosley
Alex Houlding
Ray D. Howell
Linda Howerton
Linda K. Hubbard
Sandra Hubenak
Joyce Huebner
Charles Huel Gunter
Pamela Jane Grant
Hughes
Linda Hutchison
Linda Hutmacher
James Ieda
Kara Ike
Tommy Ippock
Claud E. Ivie

Cappy Jackson
Michael Jacobson
Valentina Jesionek
Robert N. Johnson
Ruby Lee Jurden
Kathleen "Kathy" Kalafatis
Vincent J. Kane
Charlotte Kanemori
Eileen Kaplan
Nicholas Kavala
Dorothy Kavka
Maureen Keeney
James David Keith
Mary Lee Kelahan
Redmond
David A. Kish
Alan Klein
Lee Ann Klein
Jean Klemens
Robert Carl Knight
David Kohl
Peter Kohudic
Mark B. Koogler
Ronald Lee Kortemeyer
Ralph Kosnowski
Joe Kowsky
John Kretekos
Judith Krueger
Kathleen Verna Krueger
Catherine M. Kuhmichel
Diane Kukac
Donna Kunesch
Connie Leigh Kunkle
Craig Kuykendall
Michelle Joan Kyriacou
Charles LaCombe
Tim LaFone
Terry B. Lahita
Anthony LaMartina
Harold J. Lanolos
Christopher Lane
Enid Asher Lang MD
Mary Ann Lange
Lawrence L. Larsen
Peter J. Larsen
Charles Alfred Lawson II
Larry Leifer
Lois A. Lenahan
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Joseph Dell Leonard
Robert Lepp
Michael LeRoy
Arnette Lester
Suzanne J. Levine
Ruth S. Levy
Anet Linsley
Marvin Loewy
Vaughn Lombardo
Fredda London
Lorraine Love
Howard A. Lovett
Sandra Jones Lowe
David Lowell
Barbara L. Lucente
Pamela M. Luchsinger
Donald Ray Lucke
Kenneth Ludwig
John Luzzi
Julia Lynch
Mark C. Lyons
John Mackey
Roderick Mahurin
Anne Louise Maksymik
Phyllis Malloy
Edward Malon
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Patricia K. Marino
Vito Marino
Mark Cushman
Thomas Ray Markowski
Fides Marquez
Travis Martin
Dawn Massong Bobby
David Joseph Matthews
Angela Mattia
Robert Matusiak

Norman Matz
Nancy Mauney
Vernon Maunay
Heather Maunard
Edward James McAndrew
John J. McCarthy
Ronald McCarthy
Stephen McCarthy
Leon McCoy
Hope McCullough
Sylvia McDaniel Brooks
Ula McGee
Robert McGlaughlin
Timothy McGlynn
Martin J. McGreevy
William McKenna
Virginia McParland
David Megahan
Moussa I. Menasha
Kevin Mercado
Judith Ann Messerli
Robert William Metcalf
Carol Frances Meyer
Margaret Mikus
Jay L. Miller
Kathleen "Kay" Lee Miller
Jewel Mills
Naomi S. Mindlin
Carol Miner
David Mitton
Dennis Mixdorf
Marcia Ann Molay
Barbara Monay
Judith Mooney
Barbara Moore
David W. Moore
Jerry W. Moore
Christopher C. Mores
Thomas Edgar Morgan
Christina Morrison
Richard R. Morrison
Gale W. Moser
Charles E. Moses
Leonard Moskowitz
Francine S. Nagin
Edward Needle
Lynne Suzanne Neft
William H. Neveker
Vera Latrelle New
Si Newhouse
Susan Newhouse
Lonnie Dean Nielsen
Jeffrey L. Niemiec
Louis Nieto
Terry Stan Niloff
Barry Nolte
Scott Norman
Dennis Nulph
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Nancy Otto
James Daniel Owens
Leonard Owens
Ricky Padgett
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Karen Panks
Janet Panzer
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Judith Papesh
Margaret Pappas
Donna Jean Pedrick
Paradis
Paul Parenti
Hugh M. Parrish
Alan Pasquesi
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Dave Patton

Donations made in the name of a loved one bring help and support for families affected today – and hope for a future free of FTD.

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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 and select "Donate+"

AFTD and ADDF Award Drug Discovery Grant for Finding Drug Targets

AFTD and the Alzheimer's Drug Discovery Foundation (ADDF) work together to advance and support encouraging drug discovery research through the Accelerating Drug Discovery for FTD grant program.

This partnership provides essential funding for projects that focus on lead optimization (designing a drug after identifying a compound that shows promise in treating a disease) and testing promising drugs using FTD-relevant cell or animal models. The preclinical research supported by the Accelerating Drug Discovery in FTD program is an essential prelude for obtaining regulatory permission to begin clinical trials in people.

Kenneth Kosik, MD, of the University of California, Santa Barbara, has been awarded an Accelerating Drug Discovery for FTD grant.

Kenneth Kosik, MD, the Herriman Professor of Neuroscience at the University of California, Santa Barbara, has been awarded an Accelerating Drug Discovery for FTD grant for his research studying the LRP1 cellular receptor, which facilitates the spread of the tau protein. Under normal circumstances, the tau protein helps



Kenneth Kosik, MD

maintain the structure of neurons in the brain; however, in diseases like FTD, tau can take on an abnormal form and accumulate in a way that causes neurodegeneration.

According to Dr. Kosik's research, a knockdown of the LRP1 receptor significantly reduced the spread of tau, which has difficulty diffusing across the outer membrane of brain cells without the receptor due to its larger size. Dr. Kosik observed that genetically engineered mice with fewer LRP1 proteins were resistant to tau spreading.

Dr. Kosik is hoping to identify compounds that can block the LRP1 receptor, with the goal of creating an oral medication that can stop the spread of tau proteins, halting the progression of FTD.

Dr. Kosik will be testing his candidate compounds in cellular and mouse models relevant to FTD-tau and Alzheimer's disease. He and his team will be looking for promising drugs that could be useful across tauopathies.

2023 Hope Rising Benefit Raises Crucial Funds for AFTD's Mission



Left: L-R: Hope Rising Benefit Co-Chair David Zaslav, AFTD CEO Susan L-J Dickinson, AFTD Board member Kristin Holloway, Emma Heming Willis, AFTD Board members Donald E. Newhouse and Rita B. Choula, Hope Rising Benefit Co-Chair Anna Wintour, AFTD Board member Kathy Mele
Right: Benefit Chair and AFTD Board member Donald Newhouse speaks at Hope Rising 2023.

More than 400 supporters joined together on March 14 at AFTD's seventh annual Hope Rising Benefit in New York City, raising more than \$1.8 million in support of our work to support those affected by FTD and drive research to a cure.

The benefit honored and celebrated the power of FTD stories. "It isn't the fact that someone faces FTD that defines their story -- we share these stories because they can bring hope," AFTD CEO Susan L-J Dickinson told attendees. "We share these stories because they reflect the resilience of people and families fighting through horrific lived experiences to connect, inform, and help others around them."

The event honored advocate, philanthropist, and AFTD Board member Kristin Holloway with the Susan Newhouse & Si Newhouse Award of Hope. In April 2017, Kristin's husband Lee Holloway, a gifted technology pioneer who co-founded the web security and performance company Cloudflare, was diagnosed with behavioral variant FTD.

At the benefit, Holloway spoke honestly about the difficulty of maintaining hope despite the challenges of FTD. "This disease brings hopelessness, a darkness so vast it can be very, very hard, if not impossible, to navigate," she said. "It can be hard to feel anything but grief, anger, despair and, well, hopelessness... [But] as challenging and confounding as the darkness of this journey can be today, seeing all of you in this room gives me a certainty that we will bring an

end to this disease."

Fellow AFTD Board member and AARP Senior Director of Caregiving Rita B. Choula delivered the night's keynote speech, in which she recounted losing her mother to FTD in 2020. Choula drew attention to the difficulty FTD caregivers often face in talking about their journeys, as well as the profound economic challenges they may experience as they navigate supporting a loved one.

"Family caregivers from all backgrounds find it difficult to talk about their own emotional stress associated with the role," she said. "It is so difficult for many of them to admit the often overwhelming costs that come with providing care."

The benefit marked one of Emma Heming Willis's first public appearances since the family announced in February that her husband, the beloved retired actor Bruce Willis, was diagnosed with FTD.

"Thank you for welcoming me, AFTD, to my new home," Willis wrote in an Instagram post following the event. "It's not the room I ever dreamed of being in, but let me tell you, it's a room of fierce love and resilience. I'm here to join the cause alongside all of you."

All of Hope Rising's proceeds went directly to support AFTD's mission. Leading supporters of the event included Bank of America, Judy and Leonard Lauder, and Warner Bros. Discovery.

“Coming Together for Change”: AFTD Volunteers Gather Virtually



AFTD. The volunteers then shared their experiences, successes, and challenges in conducting AFTD awareness events and fundraising activities. The virtual gatherings gave volunteers and staff the chance to think about what each individual can do to spread FTD awareness and raise critical funds for AFTD’s mission.

“Calling all AFTD volunteers!” Recently, the AFTD Volunteer and Events Departments co-hosted virtual gatherings for our AFTD volunteers, giving them the opportunity to connect with AFTD staff and with each other.

The sessions were held March 15 and 21, with one for volunteers in the eastern U.S. and one for those in the western half.

The virtual gatherings had a rare energy, as participants discussed the value of sharing and amplifying their FTD stories – **after all, every FTD story counts.**

Staff from both departments spoke with AFTD volunteers and gave them a general overview of the current state of

The dynamic virtual gatherings had a rare energy, as participants discussed the value of sharing and amplifying their FTD stories – after all, every FTD story counts. One attendee noted that, in the world of political advocacy, telling your personal story as a constituent is most important to legislators. Similarly, every AFTD volunteer has their own unique and precious story, and only they can tell it!

The virtual gatherings also helped to engage those from more isolated, often rural areas, allowing them to feel part of a network united in its effort to change the story of FTD. Attendees voiced their enthusiasm to identify opportunities to engage with their local communities. They also said they hoped that more virtual gatherings might be held in the near future. All volunteers who attended were formally invited to join us, either in person or virtually, at AFTD’s 2023 Education Conference in St. Louis in May.

Thank you to each of our awareness volunteers, support group volunteers, fundraisers, and event organizers who do such a wonderful job in spreading awareness and raising funds so critical for AFTD’s mission.

AFTD Thanks Our Volunteers!

It's that time of the year: **THANKYOU, VOLUNTEERS!**

With National Volunteer Appreciation Week and the AFTD Volunteer Appreciation Dinner fast approaching, AFTD is reminded once again how grateful we are for our volunteers. That they donate their time, energy, and talents to serve others in their time of need is truly humbling. AFTD volunteers also share their experiences, knowledge, and wisdom to those who understand the unique challenges of FTD.

We want to continue to thank our volunteers for their dedication and the impact they have had on the lives of the families we serve. The work our volunteers do is at the core of our mission, improving the quality of life of people affected by FTD and driving research to a cure.

This year, National Volunteer Appreciation Week is being held from April 16 to April 22, kicking off with virtual appreciation opportunities to celebrate our volunteers and highlight all the ways they advance our shared mission.

Then, the AFTD 2023 Education Conference is coming to the Marriott St. Louis Grand on May 5! Join us for this unique opportunity to connect with people who understand your journey, learn about available resources and supports, and engage with experts to gain insight on the latest in FTD research and approaches to care. If you are unable to make it to St. Louis, you can livestream the conference online. The AFTD Education Conference is free of charge, whether you attend virtually or in person.

There will be a special AFTD Volunteer Appreciation Dinner in St. Louis on May 4, the day before the conference, at 6:30 p.m. All AFTD volunteers are invited to enjoy a good meal and connect with other volunteers and AFTD staff. We will express our personal appreciation and celebrate our common passion and commitment to make the FTD journey easier for the next family.

In short, this is the time of year when we extend our appreciation for all AFTD's volunteers, at all levels. Thank you to our Ambassador team, leading the charge and diligently networking with local professionals and organizations. Thank you again to those who hold spaces of comfort and compassion as support group volunteers, and to those who bring people together for connection through Meet & Greets and volunteer orientation.

Thank you to everyone who has hosted a grassroots fundraising event – the money you raise helps to support families and allows researchers to look into faster FTD diagnosis, better treatment, and ultimately, prevention of FTD.

Thank you to all who have shared their stories, spread awareness, and educated their communities about FTD and AFTD. Thank you to those who offer their time and professional advice through pro bono legal advice, research grant reviews, or service on one of AFTD's Advisory Councils. Thank you to our talented and dedicated Board members.

To everyone who drives AFTD's mission through the gift of their time and talents, we say: Thank you.



AFTD's with love campaign



This year, through our 12th annual With Love campaign, we asked individuals to share their stories from the heart. We were touched by the response from our community!

We saw 40 community members share their personal stories through creative expression about how love has sustained, inspired, or uplifted them through an FTD journey. Together, their voices were a collective show of force – the force of love – against this disease.

AFTD would like to extend a heartfelt thank you to everyone who contributed to the success of this year's campaign, raising \$48,000 to advance AFTD's mission. We are grateful for our generous campaign sponsor, The Rainwater Charitable Foundation, for their \$10,000 matching gift; to the hundreds of people who read these stories and donated; and, of course, to our fundraisers, who bravely shared their stories of love from the heart.

Colleen Franzreb	Terry Walter
Heather Reis	Cathy Foutz
Anthony Cordasco	Scott Gehret
Gary Radin	Hazel Espiritu
David Andrews	Dan Keuning
Kat Primeau	Robin Albright
Melissa Fernandez	Claudia Seitz-Ricklick
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Melissa Fisher	Rev Lisa Kidd
Corinna German	Jillian Queeney
Julia Tufts	(Condran)
Steven Long	Michael Flynn
Liz Matthews	Elizabeth Dorman
Susan Scarff	Marsha Francisco
Jamie Hale	Bob Boerschel
Dawn O'Gara	Jack George
Linda Tarpley	Kim Urban
Kristin Pursley	Kimalee Z'Dorne
Jamie Lee Manning	BreAnne Poe-Ford
Erin Walla	Tiffani Russo
Martina Rutledge	Lanette Wolf

AFTD-Team race season

Last year we had a successful and fun AFTD-Team Race Season! We participated in five events across the country: the Austin Marathon in February, the Colfax Marathon (Denver) in May, the TCS New York City Marathon and the Philadelphia Marathon in November, and the Dallas Marathon in December. The AFTD-Team comprised over 184 runners logging a combined 1,365 miles and raising over \$110,000 for AFTD's mission.

On behalf of AFTD and the community we serve, we would like to thank all our runners, joggers, and walkers for their resilience in participating in this active campaign. Special shout out to the individuals and families who, in addition to going the distance, raised vital funds through one of last year's five races:

Austin Marathon

Kelly Canavan
Aphasia Research and
Treatment Lab, UT Austin
Linda Esper
Lauren Lindley
Zoy Kocian
Kacy Kunesh

Colfax Marathon

Mike & Gretchen Samuels
Fenoglio Family
Jaclyn Schurk

Dallas Marathon

Matthew Reed
Team Ryan
Lauren Shaw
Motivated by Margaret!
Lisa Kelly
Team Rick
Anna Kuykendall
Gina Sapp
Team Patty

TCS New York City Marathon

Emily Mauck
Sally Mauck
Veronica Wolfe
Josef Pohl
Alex Sepesy
Brian Strohm
Bre Vandenberg
Jules Brouwer
Ali Vandenberg
Mary Noa-Kempner
Annie Zomback
Ann Vandenberg
Popkin Shenian
Jenna Zomback





Philadelphia Marathon

Team Jack Attack
James Staten
Anni, Katie, Kari, Cathy,
Alison & John
Michael Hespos
Barbara Stoff
Gus Hirschboeck
Nathaniel Tracer
Beth Byerley
Patti Del Guercio
Michael Mullan
Elizabeth Graham

Thomas Spsychalski
Shana Dodge
Jane Koetje
Kimberly Torres
Deborah Stoff
Julia Ramberg
Megan Keller
Joe Pang
Amy Robles
Joyce Lis
Lorraine Lauer

INDEPENDENT EVENTS

WITH FLYING COLORS:

The Delapré family hosted the inaugural Hope in Color event on October 15, 2022, at the Balboa Yacht Club in Corona Del Mar, CA. Hope in Color was created in honor of Mary Delapré who was diagnosed with FTD in March 2020 at 54 years old. As a costumer by trade, Mary has always loved design and color palettes. The evening included a cocktail hour with a silent auction, a gourmet dinner with a live auction, and a speech by AFTD Senior Director of Scientific Initiatives Penny Dacks. A total of \$92,500 was donated to support AFTD's research initiatives.

LOVE STORY:

Bob Powers from Oregon continued to tour his original play, *Chasing Rainbows: A Story of Love, Loss, and Finding Purpose*, on January 18 at the Clocktower Cabaret in Denver after two successful performances in Portland, Oregon and Lucca, Italy. Bob wrote the play in memory of his husband, Donald Clement, who was diagnosed with PPA in 2013 and passed away in 2021. He raised \$1,600 in Denver, for a new grand total of \$17,000 raised for AFTD's mission.

MEMORIES OF MOM:

Juna, Adam, and Sam Pfeifer celebrated the memory of their mother, Cathy, on the sixth anniversary of her passing after living with FTD and ALS. The siblings created a fundraising page where they shared text and images of their mother. They hope that "this page serves as a reminder of who she was to our family, her friends, and so many other people she made smile and laugh throughout her life." Together, they raised \$12,600 for AFTD's mission.

HOPE AND HOOPS:

Spencer Cline, an alumni member of the Babson College men's basketball team, hosted another fundraising night during the team's game on February 18 in memory of Spencer's father, who was diagnosed with FTD in his mid-40s and died in 2012. Their fundraiser launched in the lead-up to their game against MIT—which Babson won 92-57—and raised \$8,000 for AFTD's mission.

FOR ALL WHO CARE:

Robert Cathey organized a fundraiser through GoFundMe in memory of his sister, Nancy, who was living with FTD and passed away on December 9, 2022. Robert recognized the physical and emotional commitment that his brother-in-law put in as primary caregiver for his wife of 44 years, so he wanted to raise funds in honor of all care partners and caregivers. At the time of writing, his page has raised over \$4,000 for AFTD's mission.

STRENGTH IN UNITY:

Amun Tanveer and the fraternity brothers of Pi Kappa Alpha at the University of Cincinnati hosted a mock casino night to benefit AFTD on November 18, 2022. Amun's brother, Abrar, has previously hosted fundraising events for AFTD. Both brothers do what they do in memory of their father, who was living with PPA and passed away in December 2019. Amun and the Pi Kappa Alpha Fraternity raised over \$2,700 to support AFTD's mission.

TO A "T":

Hannah Poirier created a design to spread awareness of FTD and sold her design on t-shirts, long sleeves, and crewnecks through Custom Ink in honor of her mother, who was diagnosed with FTD in June 2022. With the help of her father, David, Hannah raised \$2,300 and donated it to support AFTD's mission.



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