A Vision for Hope
Dear Friends,

In 2002, Helen-Ann Comstock founded AFTD with a $1,000 donation, a determination to make things better for the next family, and a vision for hope. Nearly two decades later, thousands of volunteers, donors, researchers and healthcare professionals channel that determination toward a shared vision. As AFTD’s Board chair – as a wife and mother who lost her husband to FTD, and whose family is deeply dedicated to a future without this disease – it is a vision of profound importance to me.

As my time as Board Chair nears its conclusion, I am proud to look back on the progress we’ve made, and will continue to make. This year, AFTD’s Board approved a strategic plan that will shape every aspect of our work for years to come. I am also proud to reflect on the ways in which our shared work is gaining momentum.

Earlier this year, AFTD joined Bill Gates, Leonard Lauder, Jeff Bezos and others in supporting the Diagnostics Accelerator program, a $50MM initiative to hasten early, effective diagnosis and treatment for dementia. AFTD contributed $2.5 million to this partnership, matched by an additional $2.5 million contribution from the Diagnostics Accelerator. The result is $5 million dedicated to discovering FTD biomarkers — and an increased focus on FTD as a key to addressing the dementia epidemic.

For our fiscal year ended June 30, AFTD’s HelpLine provided an informative and supportive response to more than 2,300 calls and emails. We awarded 197 Comstock Grants for caregiver respite and travel to conferences, and provided an additional 80 awards to help individuals maximize quality of life as they face an FTD diagnosis. AFTD trained support group volunteers from across the U.S., and reached an important milestone: There are now more than 100 such volunteers leading groups across the country. These dedicated individuals bring connection, practical guidance, and hope to people who might otherwise face FTD in isolation.

AFTD also helped to bring FTD awareness to a wider national audience than ever before. In May, 60 Minutes aired a powerful story documenting FTD’s effect on families. Its impact was far-reaching, bringing significant increases in AFTD’s web traffic and HelpLine inquiries. Our dedicated partner, Discovery, Inc., broadcast a PSA on FTD to millions this past year. Hope stems directly from awareness, and FTD awareness has never been greater than it is at this moment.

As you read these pages, know that the vision of hope we can share with this community starts with you. Whether as a donor, a volunteer, a researcher or health professional, you choosing to be part of this work is what makes it possible.

I know too well that alone, we are powerless against this horrific disease. Together, we can achieve a world with compassionate care, effective support, and a future free of FTD. I place my faith in that vision – and I and my colleagues on AFTD’s Board and staff are grateful to have your help in advancing it.

Sincerely,

Gail Andersen
AFTD Board Chair
FTD awareness grows by the day, thanks to the hard work of our community — the boots on the ground who tell the world about this disease. But AFTD recognizes that the future we seek is not possible until FTD is even more widely known. AFTD will continue to work to spread FTD awareness.

In May, the “cruelest disease you’ve never heard of” was put in front of a national television audience when 60 Minutes aired a segment highlighting FTD’s unique symptoms and its devastating impact on families. AFTD worked with the show’s producers to provide background information on the disease and to connect them with members of our community, including Dr. Bruce Miller, the Very Rev. Tracey Lind, and Amy Johnson, all of whom were profiled in the piece.

More people turned to AFTD over the last year, recognizing this organization as the country’s leading expert on FTD. Traffic to theaftd.org rose by 42 percent between June 2018 and June 2019, while followers of AFTD on Facebook (53 percent) and Twitter (19 percent) also increased significantly.

World FTD Awareness Week took place at the end of September 2018. Working in collaboration with World FTD United, an
They said I was too young for dementia. They were wrong.

While few expect it earlier in life, dementia can strike adults at any age. The most common forms for people under 60 aren’t Alzheimer’s, it’s frontotemporal degeneration (FTD). FTD brings changes to personality, behavior, language and movement — striking at the heart of who we are and devastating families.

Find information, help and support here: www.theaftd.org/youngdementia

International coalition of FTD organizations, AFTD hosted on theaftd.org an interactive map that allowed people to share their FTD stories and let us know where they are writing from. Nearly two hundred people contributed to the map, representing two dozen countries, ranging from Australia to Brazil, India to Canada, Turkey to Spain.

AFTD kicked off World FTD Awareness Week with a full-page ad in the Sunday, Sept. 23, 2018 issue of the New York Times, placed with a donor’s generous support and designed by AFTD volunteer Jody Zorn. Later in the week, a digital ad for AFTD was displayed all day on the Times mobile homepage. Additionally, AFTD debuted a public service announcement to bring attention to FTD, created in collaboration with Discovery, Inc.

People from two dozen countries around the world shared their FTD stories using this interactive map, launched by World FTD United and hosted at theaftd.org.

< Versions of this ad ran in the Sept. 23, 2018 issue of the New York Times and on the Times website on Sept. 25.
The challenges of FTD can be profoundly isolating, and facing it alone only compounds those difficulties. AFTD’s vision for the future has always included practical, proven and accessible support for anyone who finds themselves on the FTD journey.

More than 2,300 times last year, AFTD staff responded to an inquiry through our HelpLine. A resource unique to AFTD, the HelpLine is a first point of contact for our community, offering personalized, informed and compassionate answers to challenging FTD questions, whether submitted by email or via our toll-free phone number. Additionally, our monthly e-newsletter Help & Hope delivers news, resources and ways to get involved.

AFTD’s national network of support continues to grow every year. By the end of June 2019, AFTD had trained our 100th support group volunteer. These vital contributors to our mission lead a total of 81 FTD support groups in 32 states. As our work expands, AFTD seeks to make groups available in all 50 states. For families facing FTD, in-person support should be no more than a short drive away.

AFTD introduced a new way to support people with FTD last year. Our Quality of Life Grant, the newest of AFTD’s Comstock Grants, provides persons diagnosed with a small stipend that they can spend toward anything that will make their lives less difficult, whether a medical procedure, a new technological device, or something as simple as some new clothes. Developed with critical input from the AFTD Think Tank, Quality of Life Grants helped to improve the lives of 80 members of our community last year.

Two other Comstock Grants remain essential to AFTD’s mission. Last year we distributed nearly 200 Respite Grants and Travel Grants – the former to help care partners arrange respite care, the latter to subsidize the cost of traveling to an FTD-related conference, including the annual AFTD Education Conference.
Amy Weeks (left) and Megan Badaglia (right) have not been personally affected by FTD. But, as social workers for OhioHealth, they saw a clear need for FTD-specific support. So in early 2019, they reached out to AFTD for help starting an FTD support group, which they now co-facilitate in Columbus each month. While they have never run a support group before, Amy and Megan say that AFTD’s highly organized orientation and training left them well prepared for the task. And although their group is new, they are already being recognized for their work, having been shortlisted for an OhioHealth Prism Award honoring those who embody the values of compassion, integrity and stewardship. “One of the goals for this group is to decrease isolation,” Megan said.

“Given the lack of understanding among the general public about FTD, this is a great place for people to come together and actually feel heard and validated.”

– Megan Badaglia
AFTD’s vision for the future is one in which the underlying biology of FTD is fully understood. Over the past year – in partnership with the research community, other disease-focused nonprofits, and our generous donors – AFTD has taken steps to advance the science of this disease toward faster and more accurate diagnoses and effective treatments.

The discovery and development of FTD biomarkers is crucial. AFTD continues to expand on its work with its long-time partner, the Alzheimer’s Drug Discovery Foundation (ADDF), which includes research focused on preclinical drug discovery, as well as the TreatFTD Initiative, an effort to pilot clinical trials in FTD. In January, AFTD committed $2.5 million to the Diagnostics Accelerator program, an ADDF initiative, in partnership with Bill Gates, Jeff Bezos, Leonard Lauder and others. The Diagnostics Accelerator program is matching AFTD’s contribution, bringing the total investment in developing FTD biomarkers up to $5 million.

The following month, AFTD hosted the TDP-43 Workshop in Miami. Generously sponsored by Target ALS and the ALS Association, the workshop brought together researchers, clinicians and key opinion leaders from industry and academia to discuss progress made in the search for improved diagnostic tools in dementia.

Over the last 12 months AFTD additionally joined the Biomarkers Consortium, an ongoing project sponsored by the Foundation for the National Institutes of Health (FNIH). As a partner in this project, AFTD will have the opportunity to identify and develop high-impact biomarkers to advance the diagnosis, treatment and scientific knowledge base of FTD.

AFTD continued to fund innovative research throughout the past year, furthering the search for FTD biomarkers by awarding four FTD Biomarkers Initiative grants to researchers in the U.S., U.K., and Switzerland.

AFTD Pilot Grants lay the groundwork for our vision for the future by providing seed funding for innovative research projects. Over the last year AFTD awarded three Pilot Grants to talented researchers with cutting-edge ideas to further our understanding of FTD in all its facets – how it develops, how it can be treated, and how care partners can provide better care for their loved ones.

Additionally, AFTD marked the 10th anniversary of our Postdoctoral Fellowships program with awards allowing two young researchers to pursue potentially groundbreaking work during the final stage of their scientific training. For the first time, AFTD provided fellowships in two discrete areas: basic science and clinical research.
"We want to provide a very safe environment where people can practice where there will not be any harm done."

– Dr. Linda Wilson

**Awards and grants**

- **AFTD Biomarker Awards** – Tammaryn Lashley, PhD, and Kerstin Sander, PhD, University College London (UK); Anthony Fitzpatrick, PhD, Columbia University (US); Leonard Petrucelli, PhD, Mayo Clinic – Jacksonville (US); Magdalini Polymenidou, PhD, University of Zurich (Switzerland)

- **Basic Science Pilot Grant** – Paschalis Kratsios, PhD, University of Chicago (US)

- **The Susan Marcus Memorial Fund Clinical Research Pilot Grant** – Liam Chen, PhD, Johns Hopkins University (US)

- **Nonpharmacological Therapies and Tools for FTD Pilot Grant** – Linda Wilson, PhD, Drexel University (US)

- **Basic Science Postdoctoral Fellowship** – Ming-Yuan Su, PhD, University of California, Berkeley (US)

- **Clinical Research Postdoctoral Fellowship** – Oriol Dols Icardo, PhD, Institut de Recerca de l’Hospital de la Santa Creu i Sant Pau (Spain)

FTD does not come with an instruction manual for care partners. But Dr. Linda Wilson, with support from the AFTD Nonpharmacological Therapies Pilot Grant, is spearheading a training program that may be the next best thing. She and her fellow researchers at Drexel University will use specially trained actors to portray particularly challenging scenarios that commonly arise in FTD care, allowing care partners to hone their skills. She will follow up with participants to see if the practice scenarios proved effective; if so, she plans to make the training more widespread.
education and advocacy

In order to bring about a future in which FTD is effectively treated, with ample support for care partners and persons diagnosed alike, AFTD works every day to educate the general public, healthcare professionals, and lawmakers at the state and federal level, ensuring that our community is well represented in the broader dementia-care conversation.

AFTD's annual Education Conference took place in Los Angeles in May 2019, convening more than 330 people – including dozens who have been diagnosed with FTD – for a day of learning, sharing and making connections. For the first time, a person with FTD – AFTD Volunteer Amy Shives – worked with AFTD staff on the conference planning committee to develop the day's programming. Also for the first time, AFTD had the day's sessions professionally livestreamed, allowing hundreds to follow along with the conference online.

AFTD staff and volunteers represented our community at events throughout the country. We made our presence felt at numerous high-profile national conferences, including Aging in America and Meeting of the Minds. And in March 2019, AFTD staff and Board members spoke up for the AFTD community at the Alzheimer's Disease-Related Dementias Summit, hosted by the National Institute of Neurological Disorders and Stroke (NINDS) – an event AFTD co-sponsored.

< Actor and FTD care partner Martha Madison delivered the keynote address at the AFTD Education Conference in Los Angeles.
Since his father’s FTD diagnosis in 2018, Brian Fox has become one of AFTD’s most active volunteers. In addition to hosting Meet & Greet events in Omaha and the Phoenix area, he recently supported AFTD’s mission by hosting a car wash at one of the businesses he owns. The “Day for Dad” fundraiser raised $4,000 and gave Brian an opportunity to educate the hundreds who stopped by, most of whom had never heard of FTD. “The time is now – we’ve got to get the word out about this disease specifically,” he said.

AFTD continued to disseminate original resources that further our goal of providing the highest-quality FTD education to healthcare professionals and families alike. Over the last 12 months, AFTD published an issue of Partners in FTD Care about ways that caregivers can cope with a loved one’s anosognosia, one of the most vexing of all FTD symptoms. We also released two installments in our Educational Webinar series – guest speakers presented in-depth looks at behavioral variant FTD and primary progressive aphasia.

The 2019 AFTD Education Conference brought together people from across the country to learn care strategies and the latest scientific information about FTD.
volunteers and the AFTD-Team

Simply put, AFTD could not function without those who selflessly devote their time to furthering our shared mission. For the vast majority of our volunteers, FTD has irreversibly altered the course of their lives. By showing the courage and resolve to help other families facing this disease, they generate vital energy and momentum toward creating a future free of FTD.

From spreading public awareness, to teaching healthcare professionals about the unique care needs of people with FTD, to raising crucial funds in support of AFTD’s mission, to hosting Meet & Greet events that helped others feel less alone, nearly 330 active volunteers took action over the last 12 months. Their efforts are an inspiration to AFTD staff, Board, and all whose lives have been touched by FTD. In May we showed our gratitude during our first-ever volunteer appreciation dinner the night before the 2019 AFTD Education Conference in Los Angeles.

AFTD was fortunate to have some truly incredible volunteers support our work in the past year. A total of 10 dedicated people coordinated volunteer activity in each region of the country. Volunteers drive our Think Tank, in which persons diagnosed help guide AFTD’s mission by imparting their invaluable perspectives, as well as our Partners in FTD Care Advisory Committee, in which health care professionals help us share FTD care strategies that have proven to be successful. A soon-to-be-published AFTD guide on grief in FTD would not have been possible without the help of volunteer Elaine Rose.

Those who choose to spend time raising crucial funds in support of AFTD’s mission hold a special place in our hearts. We refer to this dedicated group as the AFTD-Team, and over the past year we have continued to be impressed by their creativity, their devotion, and their drive.

Actor Martha Madison (right) and her sisters, Alison and Bo, ran in the Dallas Marathon on behalf of AFTD – and in honor of their mother, who is living with FTD.

AFTD Volunteers Shana Nissen and Kayla Boehmer raised funds for AFTD’s mission with successful Food for Thought events!
All across the country, AFTD-Team members hosted events for our flagship fundraising campaign, Food for Thought, which combines FTD education and community connection with delicious food and drink. Last year saw our biggest Food for Thought yet, with 74 events taking place in 35 states, plus Canada and the U.K. AFTD-Team members raised more than $170,000 toward our shared mission!

The Valentine’s Day–themed With Love campaign raised more than $47,000. A new record of 31 hosts bravely and publicly shared their stories of love. Meanwhile, more than 245 AFTD-Team members together ran or walked more than 1,300 miles to help raise a record-breaking $80,000 during AFTD’s 2018 Race Season.

Outside of our three central fundraising campaigns, members of our community host their own events. A record-breaking 59 Independent Events were held during the fiscal year, raising $186,000 towards AFTD’s mission. An additional $178,000 was raised by our friends on Facebook, through more than 420 campaigns (many of which celebrated a birthday).

After his father died of FTD in 2017, Jeff Hunter knew he “wanted to do something big” – and things don’t get much bigger than the 20,000-foot tall Denali. Jeff decided to climb to the top of North America’s tallest mountain, both to honor his dad and to motivate others to donate to support AFTD’s mission. Jeff endured temperatures as low as negative 20 degrees during the three-week climb, and while a snow storm forced him to abandon his climb at 17,000 feet, Jeff is justifiably proud of his efforts – and the $32,000 he raised. “Making it to the summit would have been nice, but my dad always used to talk about ‘building character,’” Jeff said.

“If we had a cakewalk to the top, he would have told me it was too easy.”

– Jeff Hunter
AFTD Named Funds honor or memorialize a loved one. Established with a minimum donation of $25,000, Named Funds are among AFTD’s most generous gifts, with donations advancing the science of FTD and improving care and support for people currently living with the disease. AFTD is proud to recognize these individuals and their families for their contributions.

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

- **The Michael E. Fenoglio, MD Memorial Fund**
  Established by the Rocky Mountain Surgeons Consortium

- **The Mimi Fund**
  Established by her loved ones

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

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

- **Laden Memorial Fund**
  Established by the Laden Family

- **Susan Marcus Memorial Fund**
  Established by Larry and Jillian Neubauer

- **The Suzy Fund**
  Established by the Newhouse Family

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

- **The Mike Walter Fund for Research**
  Established by the Mike Walter Family

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

1,000,000+
- David Geffen Foundation
- Samuel I. Newhouse Foundation Inc.

100,000–999,999
- Citi
- CMS
- Discovery, Inc.
- George L. Ohrstrom, Jr. Foundation
- Ms. Kristin Holloway
- Leonard & Judy Lauder Fund
- Stavros Niarchos Foundation
- U.S. Trust Bank of America Private Wealth Management

50,000–99,999
- The Farley Chang Gang
- Charter Communications
- Patricia M. and Victor F. Ganzi
- Ionis Pharmaceuticals
- Mr. & Mrs. Gary Johnson
- Larry and Jillian Neubauer
- Rochester Area Community Foundation
- Sullivan & Cromwell LLP
- The Boston Consulting Group with Alannah Sheerin, Kermit King and Neal Zuckerman
- Mrs. Beth Walter
20,000–49,999
Mr. & Mrs. Peter Arnow
Bloomberg Philanthropies
The Sally Bursch Cihos Charitable Fund
Christie’s
Colonial Electric Supply
Credit Suisse Securities (USA) LLC
Goldman Sachs Private Wealth Management - Martin Packouz/
James Herring
The Roger and Susan Hertog Charitable Fund
J.P. Morgan
Mrs. Susan Laden
Carol Sutton Lewis and
William M. Lewis, Jr.
Mr. Philip H. Lovett
McDermott Will & Emery LLP
Mr. & Mrs. Timothy Romani & Family
The Edward John and Patricia
Rosenwald Foundation
Shearman & Sterling LLP
Mrs. Bonnie Shepherd
Mr. George J. Sidoris
The Swid Family
The ALS Association, National Office
The Connecticut Frontotemporal
Dementia Foundation, Inc.
The Durst Organization

10,000–19,999
Alector
Mr. and Mrs. Steven P. Bellwoar
Rich Bonaventura and Amy Kriezberg
Ms. Lisa Boyce & Mr. Kevin O’Neill
CBRE
Deloitte
Dentons US LLP
Jennie L. and Richard K. DeSherer
Barbaralee Diamonstein-Spielvogel and
Carl Spielvogel
Ernst & Young LLP
Evercore
Florence V. Burden Foundation at the
recommendation of Foundation Director
and Family Member, Frederick Childs
and his daughter, Elizabeth Childs
Larry Gagosian
Mr. Russ Gent
Goldman Sachs & Co.
Samantha and David Goldring
Mrs. Clare T. Hall
Mrs. Margery K. Harris
Jones Lang LaSalle Brokerage, Inc.
Mrs. Dollie Jospey
KPMG LLP
Leeds Family Foundation
Liberty Broadband
Allison F. and Joseph J. Magliocco
Mary Beth Repasy Fund for
Progressive Supranuclear Palsy
Research of The Dayton Foundation
The McNellis Family Fund
Tobias Meyer and Mark Fletcher
Pappy Van Winkle Classic
Jay Penske/PMC
PricewaterhouseCoopers LLP
The David E. Reese Family Foundation
Joanna S. and Daniel Rose
Katherine Farley and Jerry Speyer
Allison Tang and Thomas Widmann
The Church Pension Group
The Dana Foundation
The McGregor Foundation
The Parsons Family Foundation
The Rainwater Charitable Foundation
The Robert J. Weiler Family Fund of The Columbus Foundation
The WANGO Fund of The Columbus Foundation
UBS
Lulu and Anthony Wang
Wilmington Trust
Ms. Betty Woods

5,000–9,999
Ms. Gail Andersen
Mr. & Mrs. Walter Anderson
Angelo Gordon & Co, L.P.
Anonymous
Deborah and Steve Barnes
Mary and Dick Benioff
Biogen
Burt Brazill
The Bretscher Family Foundation
Mr. Timothy L. Broer
Nanci and Robert Bronsteen
Patterson Belknap Webb & Tyler LLP
Minalie Chen and Jackson Hsieh
Clare Gottlieb Steen & Hamilton LLP
Mr. Mike Dirksen
Douglas Elliman Real Estate
Eaton Corporation
Wendy Flanagan and Chris O’Malley
Patricia Ralph Fowler and
Gordon B. Fowler Charitable Trust
Arlyn and Edward L. Gardner
Empire Office
Jill and Lee Goldman
Mrs. Lola A. Goldring
Mindy and Jon Gray
Caroline and Tim Harrison
HCR ManorCare & Arden Courts
Houlihan Lokey
Mr. and Mrs. Ralph Huber
Mr. & Mrs. Robert Hunter
Mr. Michael Irvine
Jeff Hunter
Ms. Lindy Kowsky
Mr. Paul Lester
Mrs. Patricia McCarthy
Michelle Ores and Charles Schorin
PayPal Giving Fund
Mr. & Mrs. David Penland
Madaleine and Arnold Penner Family
Mrs. Kathryn Pfaendtner
Mr. Fran Pollart
Mr. & Mrs. Larry Rodger
Saint Charles Borromeo Church
Mrs. Deb Scharper
Mr. Mark Schroyer
Dr. Robert G. Smith &
Mrs. Tam Smith
Mr. Arthur J. Sommers
Michael H.B. Stowell and
FTD Researchers
Sydney Licht and Tom Summer
Target ALS
The Eugene and Estelle Ferkauf
Foundation, Bobby and Arthur Kurzweil
The Newman Foundation, Inc.
The Robert M. Hatfield
Foundation, Inc.
Pamela Van Zandt
Mrs. Terry L. Walter
Richard L. & Lois S. Werner
Family Foundation
Mr. & Mrs. Greg Williams
James and Elaine Wolfensohn
Shirley Young
Myers Family Charitable Fund with the American Endowment Foundation
Orscheln Industries Foundation, Inc.
Mr. David C. Pfeifer
Mr. & Mrs. Edward Quinn
Stephanie and Jack Seibald
Ms. Gerda Spears
Mr. and Mrs. Mackenzie de B. Strathy
Sarah B. Tipton Charitable Fund
Mr. Stuart Waldman
Mr. and Mrs. John C. Weicher
Josh and Judy Weston
Ms. Cheramy White
The Nicholas and Marguerite White Legacy Fund
Mrs. Joan C. Zlotnick

Lt. Gen. Michael J. Basla
Ms. Joan L. Beranbaum
Courtney Berlin
Mr. & Mrs. Alan Berlin
Mrs. Marilyn Bernhard
Mrs. Susan T. Berte
Paul & Mariann Bevenour
Elise and Roman Bninski
Ms. Kayla Boehmer
Ms. Gloria Bonora
Mr. & Mrs. Heyward Boyce
Tom Boyce
Mrs. Eden Brown
Jason Browning
Ms. June I. Brush
Mr. Jim Bryan
Whitney Burke
Mr. Donald B. Cameron
Camp Ramah in the Berkshires, Inc.
Rev. James Cardosi
Dr. E. Jane Carter
Rick Childs
CME Wire and Cable
Dr. Joseph and Joan Cohen
Ms. Kristina Colby
Mrs. Pamela Cole
Mr. & Mrs. Doug Comstock
Mrs. Helen-Ann Comstock
Mr. John L. Connor
Ms. Elaine Cook
Judith Cooley
Dr. Jack Copley
Dr. Manon Cox and Daniel Adams
The Mary Ann and
Oliver Cross Charitable Fund
Mr. & Mrs. Alec Dafferner
Mr. Aaron Daniels
Mr. Owen Davis

Teak Tree Capital Management -
Adam Deem & Stephen Kaye
Mrs. Nicole T. DeLeve
Mr. & Mrs. Peter DeLuca
Dementia Society of America
Mrs. Linda Deubert
Ms. Alice B. Diamond
Mr. John Duncan
Mrs. Nancy W. Duncan
Mr. & Mrs. Craig Elliot
Mr. and Mrs. Mark Espinosa
Mr. Dominique Fabich
Mr. & Mrs. Mark Felder
Mrs. Debbie Fenoglio
Mr. Stephen Fenoglio
Ms. Abby Fine
NAL Express 36th St.
Mr. George Fischer
Ms. Charlotte Ford
Stacye and David Frahm
Mr. Darren A. Friesen
Mr. Ronald Fultz
Restaurant Associates
Thomas Gannon
Ms. Emily Gates
Henry Louis Gates, Jr.
Mr. & Mrs. Nicholas Giuffre
The Maryann and David Glass
Charitable Fund
Ms. Teresa Goebel
Mrs. Jennifer Goode
Luetta and Jay Gould
Jim and Marlene Greene Foundation
Mr. Douglas Grigg
Jeff Grow and Sandi Grow
Agnes Gund
Deidre Hall
Margaretann Halleck

2,500–4,999
Mr. Brad Adams
Alexandria Real Estate Equities, Inc.
Mr. Joseph W. Bellwoar
Mr. Jeffry Bleiman
Ms. Hillary Blumberg
Sister Louise Boyce
Mr. & Mrs. Ken Brunner
Mr. Michael Burns
Patricia K. Carey
Carol and Richard Chadakoff
Christ Episcopal Church
Lori Cohen
Colfax Marathon Partnership, Inc.
Mr. Chris Costello
Mr. Stanley DeRocher
Mr. and Mrs. Robert Dickinson
Diversified Lighting Associates, Inc.
Mr. Bruce Dixon
Mr. George Elf
Mr. Kenneth Giger
Ms. Tracey Goessel
Mrs. Christine Gray
Lenore and Michael Hyatt
Todd and Blanca Johnson Fund of the Marin Community Foundation
Bonnie and Bob Kaplan
Kunz-Powell & Associates, Inc.
Locust & Co. Inc.
Mr. George Lyngarkos
Mercer Inc.
Louise Miller and Sadguna Bhatt Charitable Fund
Gillian and Sylvester Miniter
Monsen Partners LLC
Mr. & Mrs. Douglas Morgan

1,000–2,499
Mr. Steven Abendschoen
Mr. & Mrs. Paul DeYoung Ahotaieola
Alpha Chi Omega House Corp
Alzheimer’s Drug Discovery Foundation
AmazonSmile Foundation
Mr. Bruce C. Anderson
Anmar Electric
Anonymous
Mr. Frank Aochi
Mrs. Connie C. Babcock
Mr. and Mrs. Kenneth Bakst
Mr. and Mrs. Ryan Baldino
Mr. Kyle Ball
Bank of America Corporation
Julie Barer
Barry Berg Group LLC
Mr. and Mrs. John Bartlett
Dr. Margaret Barton-Burke and
Mr. Thomas M. Burke

Susanne Hedaya
Mr. Daniel Hedaya
Adam and Louise Cohen
Marian S. Heiskell
Mr. Markus Helmling
Hermes Foundation
Ms. Joanne Ho
Mr. Albert N. Hobart
Holy Trinity Catholic Middle School
Houston Wire & Cable Company
Mr. Gary Howell
Ms. Kathryn Hughes
Mr. David A. Hutchison
The Intuit Family
Sharon and William Jacob III
Amy and John Jacobsson
Janklow Foundation
Mr. Daryl Jesperson
Lou Ann Jones
Nancy Jospey
Mr. Nitin Karnani
Jane Lisman Katz
Mr. and Mrs. Calvin W. King
Mr. Mike Kipp
Dr. James Kistler
Mrs. Susanne Klein
Amanda and Warren Knapp
Louis and Amie Kreisberg
Carol H. and Robert D. Krinsky
Mr. Armin A. Krueger
Martha Lampley
Patricia and Andrew Langer
Dr. Jary Larsen
Raymond Learys
Lily Lee and Tom Chang
Nina and Ralph Levene
Ms. Janet Levinger
Lichtenstein Endowment

Elinor Lipman
Ronda and Michael Lubin
Dr. Anne Lueck
Doug & Casey Mackie Family Foundation
Vishal Maheshwari
The Marcus Family Foundation
Ms. Elizabeth H. Maxwell
Mrs. Barbara E. McCarthy
Diana and Neal McGraw
Mr. George S. Merlo
Mr. Gregory Miller
Mr. David Misenhimer
Leanne Moore and Richard Gumer
Ms. Pat Moretti
Ms. Theresa Mullarkey
Satoru and Hiroko Murase
Brooke and Daniel Neidich
Mrs. Anita L. Nelsen
NEPC, LLC
Mr. and Mrs. Will Nesbitt
Helen Stambler Neuberger
Ms. Marla Nissan
Ms. Jill Nolte
Mr. and Mrs. Michael D. Nunno
Ms. Cindy Odell
Ms. Faye S. Olivieri
Ms. Elizabeth Olson
Pat Bartus Construction, Inc.
Mr. and Mrs. Mark Patriof
Penn Lighting Associates
Mrs. Diane Pergolski
Martin Petraitis
Mr. Mark Pfeffer
Dr. Creighton Phelps
Mr. John H. Pickett
Ms. Sara R. Pikofsky
Mr. and Mrs. Brad Piper
Mr. Wesley Posvar

Brotschul Potts LLC
Protestant Episcopal Diocese of Mass INC
Mr. Rob Radtke
RBC Foundation - USA
Mr. & Mrs. Allan Reeve
Mrs. Alison Riddiford
Mr. & Mrs. Judd Robertson
Mr. Mark Roithmayr
Mr. & Mrs. Daniel Roitman
Mr. Brian Rose
Mr. Charles J. Rose
Mr. Matthew Rosen
Restaur Foundation
Lauren Rubel and Maxwell Seibald
Lynn and John Savarese
Ms. Beth Schatman
Stacy Schiff and Marc De La Bruyere
Ms. Allyson Schrier
Anna Marie and Robert F. Shapiro

Pop Shenian
Mr. Glenn Siddar
Mr. Richard Silva
Mr. and Mrs. Alan H. Simon
Melisse Skelton
Ms. Doris Smith
Mr. Robert Smith
Spitzer Management, Inc.
Thomas Stark
Mr. Ryan Steglich
Bob Stewart
Strong Foundation of New York
The Albert H. Surprenant Fund,
at the recommendation of
Ms. Lynn A. Surprenant
Ruth and Andrew Suzman
The Potomac Hunt, Inc.
Tien Family Foundation
Jason Tillis
Mrs. Brookside Tinsley
The AFTD-Team hosted an incredible 625 grassroots events and Facebook fundraisers over the past year. All told, they raised more than $663,000 in support of AFTD’s mission. (All events listed brought in at least $1,000, with the highest-raising events in each category listed first.) AFTD is forever grateful for the passion, drive and creativity of all our AFTD-Team members.

Independent Events
- Jeff Hunter
  *Climbing Denali for My Dad*
- George Sidoris & Christine Sidoris
  13th Annual George F. Sidoris Memorial Golf Outing
- Lisa Boyce
  60th Birthday Party
- Paul Lester
  12th Annual Letters for Arnette Campaign
- Michael Stowell
  1st Annual Buffalo Trace Charity Open
- Pam Hatfield & Matthew Hatfield
  Robert M. Hatfield 8th Annual Quest for the Cure Golf Tournament
- Cindy & Ken Brunner
  Wooden Bowl Sales
- Deb Scharper
  2nd Annual Crusade for a Cure Golf Tournament
- Rod Radtke
  Google Giving Week
Chris Costello
Ed’s Jam Master Session

Danny Mankin
Going Down in Flames Play

Allyson Schrier
Evan Schrier Celebration of Life

Aurora, Colorado Police Department
Fundraiser

Catelyn Griffith
School Dress Down Day

Taylor Ratliff
T-shirt Fundraiser IMO Kathy Hirschy

Melissa SantaCroce, Meredith Corvo & Jennifer Lesnick
Fairfield Half Marathon

Kathy Brucato
Brigantine Triathlon

Greg Dickinson
Charity Bar Crawl

Berg Larsen Group of Coldwell Banker
Burnet Listing
Fundraiser

Nicole DeLeve
Tyier's Troopers

Suzanne & Calvin King
3rd Annual "Tami Sue” Golf Outing & Party

Gerda Spears
Jeans Day

Kenneth Simon
Dad’s 80th Birthday Party

David Biddle
IRONMAN 70.3 Chattanooga

Brian Rose
Credit Suisse Jeans Day

Doug Ekstrand
IMO Jeannette Ekstrand

Moretti & Marcy Families
3rd Annual CWM Golf Outing

Camp Ramah in the Berkshires
Summer Fundraiser

Via Facebook
Lauren Henneke
Natalie Fahey
Audrey Huey
Steven Long
Stephen Fenoglio
Scott McCormick
Jake Plante
David Rosenstein
Kacy Kunesh
Julianne Rouquette-Cary
JoAnne Duffy Kinyon
Judy Flynn
Becca Simpson
Merelene Valder
Martha Madison
Stacye Travis-Treacy
Courtney Rowan
Jessica Familetti-Zimmerman
Deborah Scanlan
Bekkah Norris
Carrie Feron
Rk Linda
Angie Pernicone
Charipar
Gene Thornton
Elizabeth Sullivan
Procaccini
Amy Bouschart-Callea
Susan Tigner
Sara Lillian LaFone
Britt McCormick
Vicki Lockhart Sorrell
Jeff Main

Race Season
Team Jack Attack
Poppy’s Posse
Joe Pang
Alison, Bo & Martha
Brooke Del Guercio
Joe Fischel
Darcy Topolski
Fenoglio Family
Racers
Krista Glodt
Kimberly Torres
Vincent Marchetta
Thomas Spychalski
Gretchen Samuels
Amber Dickson
Joan Kee-Louie
Ben Austin
Staci Mickler
Reller Thomas

With Love
Lori Cox
Kathryn Primeau
Carol Almeranti
Melissa Fisher
Kimberly Sullivan Chu
Rachael Martinez
Sarah Morazzini
Cindy Odell
**Statement of Activities**

**Revenue and Support**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$ 7,194,459</td>
</tr>
<tr>
<td>Investment and Other Income</td>
<td>$ 463,415</td>
</tr>
<tr>
<td>Special Event Revenue (Hope Rising), Net</td>
<td>$ 1,729,348</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>$ 9,387,222</strong></td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>$ 7,063,264</strong></td>
</tr>
<tr>
<td><strong>Change in Net Assets</strong></td>
<td><strong>$ 2,323,958</strong></td>
</tr>
</tbody>
</table>

**Expenses**

- 60% Research
- 13% Education & Support
- 11% Awareness & Advocacy
- 8% Fundraising
- 8% Management & General

**Statement of Financial Position**

**Assets**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>$ 7,029,660</td>
</tr>
<tr>
<td>Contributions Receivable</td>
<td>$ 10,012,880</td>
</tr>
<tr>
<td>Investments</td>
<td>$ 3,966,729</td>
</tr>
<tr>
<td>Other Assets</td>
<td>$ 147,104</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$ 21,156,373</strong></td>
</tr>
</tbody>
</table>

**Liabilities and Net Assets**

**Liabilities**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts Payable &amp; Accrued Expenses</td>
<td>$ 130,678</td>
</tr>
<tr>
<td>Deferred Revenue</td>
<td>$ 35,000</td>
</tr>
<tr>
<td>Research Grants Payable</td>
<td>$ 1,867,789</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>$ 2,033,467</strong></td>
</tr>
</tbody>
</table>

**Net Assets**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undesignated</td>
<td>$ 3,895,429</td>
</tr>
<tr>
<td>Board Designated</td>
<td>$ 3,940,589</td>
</tr>
<tr>
<td><strong>Net Assets Without Donor Restriction</strong></td>
<td><strong>$ 7,836,018</strong></td>
</tr>
<tr>
<td><strong>Net Assets With Donor Restriction</strong></td>
<td><strong>$ 11,286,888</strong></td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>$ 19,122,906</strong></td>
</tr>
<tr>
<td><strong>Total Liabilities and Net Assets</strong></td>
<td><strong>$ 21,156,373</strong></td>
</tr>
</tbody>
</table>

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

The Association for Frontotemporal Degeneration
FIND HELP · SHARE HOPE

2700 Horizon Drive, Suite 120, King of Prussia, PA 19406
HelpLine: 866.507.7222 or info@theaftd.org | Office: 267.514.7221
Hope grows because of your involvement in this mission. My colleagues and I draw inspiration and purpose from the resolve you’ve shown – and that shown by families across the country and around the globe. We know that we can’t let FTD have the last word in this story. We know that the story needs to change, and that we can only achieve that together.

AFTD is the nation’s leading organization dedicated to addressing FTD. That’s only possible through your determination and commitment, and that of thousands of donors, fundraisers and volunteers. AFTD channels your commitment to advance a vision for hope: one of a world with compassionate care, effective support, and a future free of FTD.

AFTD’s new Strategic Plan provides a road map for our efforts. Written with input from a range of experts, including many people with first-hand FTD experience, the plan focuses on advancing early and accurate diagnosis, developing new treatments, educating health professionals, and bringing AFTD’s impact into local communities. We are creating new resources to inform and empower our constituents; expanding our education, awareness and advocacy efforts; and working to help people access vital care and support in their own communities. Our plan is ambitious – but we know that with your support and your energy, we can achieve the work that it defines, and more.

AFTD is rolling out an expanded structure for our volunteer program, offering new ways to join us in advancing a vision for hope. As our staff grows, we have already brought on two full-time Volunteer Coordinators to help AFTD Volunteer Manager Kerri Keane in building a growing national program.

AFTD will continue to drive leading-edge scientific research. We recently invested in a multi-year partnership with Target ALS in support of innovative science to advance the development of biomarkers and treatments for FTD/ALS. This initiative will bring hope to families who carry a C9orf72 mutation, which brings the difficult challenges of both FTD and ALS. And AFTD will continue to provide seed funding to researchers at various points in their careers to take on the challenge of finding effective therapies for FTD.

AFTD’s Strategic Plan calls for a 50 percent expansion of our staff – and we are moving into a new, larger space that will foster greater collaboration with our community. If you are local to the Philadelphia area, be sure to be on the lookout for an open-house invitation in early 2020.

While there are growing reasons for hope, so much work remains to address this disease. Your ideas and your time and resources propel us in this mission. You are essential to AFTD’s vision for hope, a vision we can only realize with your commitment. Thank you for all that you do.

Susan L-J Dickinson, MS
Chief Executive Officer
AFTD leadership

Board of Directors
Gail Andersen, Chair
Ohio
David Pfeifer, Vice Chair
Colorado
Brian Rose, Treasurer
New York
Stephen Fenoglio, Recording Secretary
Texas
Helen-Ann Comstock, Founder
Pennsylvania
Steve Bellwoar
Pennsylvania
Rick Childs
Massachusetts
Sandra Grow
Ohio
Matt Hatfield
Florida
Daniel Hedaya
New York
Kacy Kunesh
Texas
Jary Larsen, PhD
California
Paul Lester
North Carolina
Kathy Mele
New York
Michael Stowell, PhD
Colorado
Kimberly Pang Torres
New Jersey
Beth Walter
California

Medical Advisory Council
Ian R.A. Mackenzie, MD, Chair
University of British Columbia, Vancouver
Bradford C. Dickerson, MD, Chair Elect
Harvard University
Bradley F. Boeve, MD
Mayo Clinic, Rochester
Dennis W. Dickson, MD
Mayo Clinic, Jacksonville
Karen Duff, PhD
Columbia University
Bernardino Ghetti, MD
Indiana University
Jill Goldman, MS
Columbia University
Murray Grossman, MD, EdD
University of Pennsylvania
Edward Huey, MD
Columbia University
Michael Hutton, PhD
Eli Lilly & Co. UK
David S. Knopman, MD
Mayo Clinic, Rochester
Walter A. Kukull, PhD
University of Washington
Virginia M.-Y. Lee, PhD
University of Pennsylvania
Carol F. Lippa, MD
Thomas Jefferson University
Irene Litvan, MD
University of California, San Diego
Mario Mendez, MD, PhD
University of California, Los Angeles
M.-Marsel Mesulam, MD
Northwestern University
Bruce L. Miller, MD
University of California, San Francisco
Jill Murrell, PhD
Indiana University
Chiadi Onyike, MD
Johns Hopkins University
Creighton Phelps, PhD
Mayo Clinic, Jacksonville
Howard Rosen, MD
University of California, San Francisco
John Q. Trojanowski, MD, PhD
University of Pennsylvania

Staff
Susan L-J Dickinson, MS
Chief Executive Officer
Sharon S. Denny, MA
Senior Director of Programs
Ben C. Freeman
Development & Communications Director
Christine Stevens, MBA
Chief Financial Officer
Nadine Tatton, PhD
Scientific Director
Deena Chisholm, MPH
Education Program Manager
Bridge Graham
Special Events Manager
Kerri Keane, MSW
Volunteer Manager
Amanda Knight
Development Manager
Bridget Moran-McCabe, MPH
Support Services Manager
Debra Niehoff, PhD
Research Manager
Matt Ozga
Communications Manager
Matthew Sharp, MSS
Program Manager
Jeff Thompson
Office Manager
Lauren Gauthier
Online Community Specialist
Victoria Addison
Digital Content Writer
Ann Schoonover, MSW, LSW
HelpLine Advisor
Jeni Cardosi
Volunteer Coordinator
Annamarie Given
Volunteer Coordinator
Emma Tomasetti
Development Coordinator
Elizabeth R. Young
Executive Assistant
AFTD values

Knowledge
Information is the key to unlocking the future we seek.

Compassion
We recognize the importance of finding others who understand.

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

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

Dignity
We strive to honor, help and empower all on this journey.
We envision a world with compassionate care, effective support, and a future free of FTD.