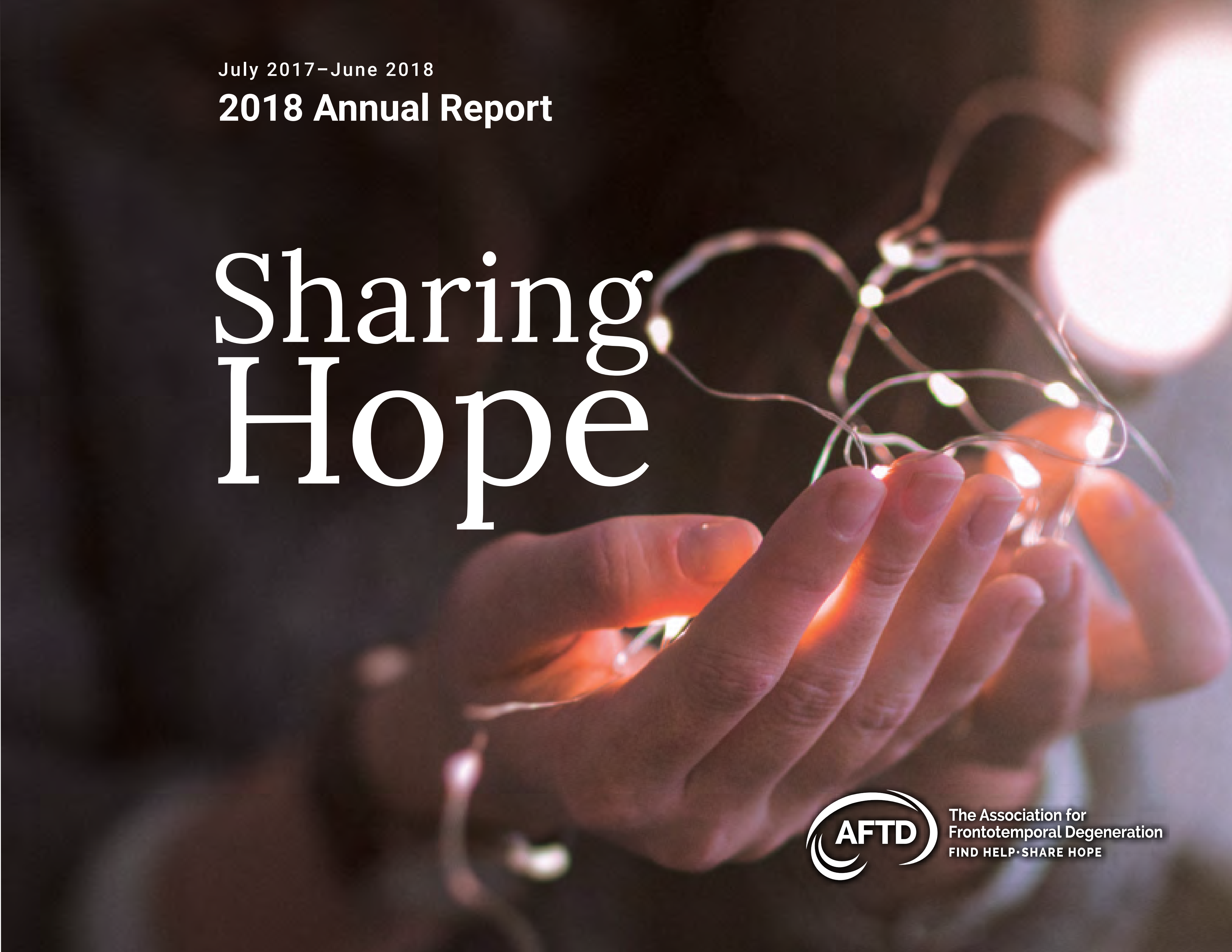
July 2017–June 2018

2018 Annual Report

Sharing Hope



The Association for Frontotemporal Degeneration
FIND HELP · SHARE HOPE

Background photos on cover, inside front cover, p. 3, p. 5, p. 7, p. 11, inside back cover and back cover courtesy of Unsplash.com

inside:

Dear Friends,

During my time as AFTD Board Chair, I have formed powerful bonds with countless people whose lives – like mine, and those of my family – have been changed forever by FTD. But although we were brought together by the challenges, grief and loss that FTD inflicts, hope is what made us into a thriving, dedicated community. "Sharing Hope," the theme of this annual report, underscores the most profound part of AFTD's mission: accelerating the day when families are no longer devastated by this disease.

That day will only come when we fully understand FTD; hence, research is critical. Over the past year, AFTD has provided funding for a broad range of innovative research proposals, allowing talented investigators in the U.S. and abroad to examine the causes of this disease and to test out potential treatments and therapies.

Among the general public, too few today know how completely life-altering an FTD diagnosis can be. Our hope is that AFTD's pioneering study on the economic and social impact of FTD, published last November in *Neurology*, brings this fact into the light. Among other sobering statistics, the study shows that the economic burden FTD imposes on families is nearly twice that of Alzheimer's.

The more who know about FTD, the greater the hope for a breakthrough in the fight against it. AFTD's 2017 series of public service announcements emphasized that not all dementias are the same, with the tagline "Think It's Alzheimer's? Think Again. Think FTD." The short film *VJ & Chuck* offered an intimate portrait of a marriage as FTD forever disrupts lives and families. You can find all these videos on our YouTube channel, **www.youtube.com/TheAFTDorg**, and I hope you share them far and wide.

Last year more than 340 AFTD volunteers personally shared hope, hosting Meet & Greet events throughout the country and continuing to grow our network of in-person support groups. And nearly 2,300 people seeking information, advice and assistance from AFTD's HelpLine received a personal response from our staff – which continues to grow, providing help and sharing hope with more people each year.

As our community expands, so too does the generosity of those who back our mission. Notably, AFTD was honored by the creation of the David Geffen Fund, a 10-year commitment that will contribute

$2 million annually for our mission. I'd like to thank the David Geffen Foundation and the Samuel I. Newhouse Foundation for generously contributing to this fund.

Hope is the reason I choose to devote my time to AFTD, and I am heartened by how it continues to be shared and amplified throughout this community. Much work remains, but I hope you share my sense that a better future is closer than ever.

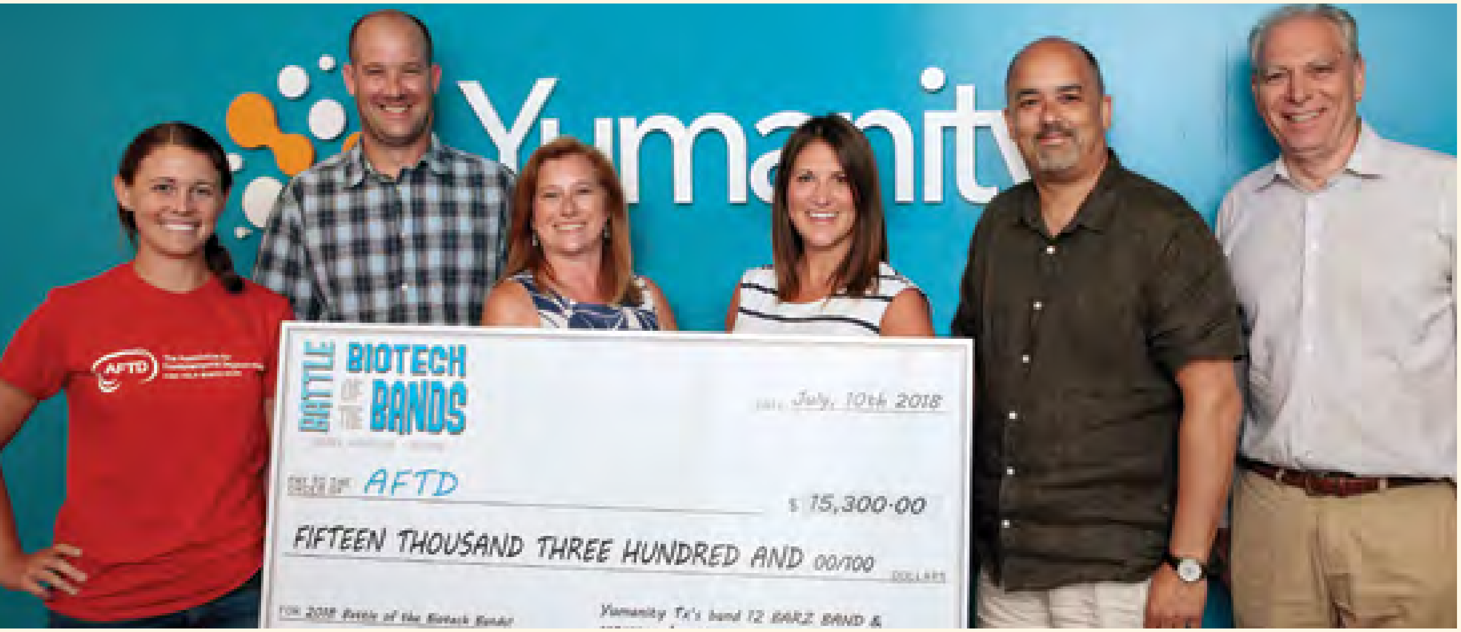
Sincerely,

Gail Andersen

Gail Andersen
AFTD Board Chair

> "Hope is the reason I choose to devote my time to AFTD."

awareness



In May, the 12 Barz Band performed at the annual Battle of the Biotech Bands in Boston – and chose AFTD to be their charity recipient. The band – whose members include representatives from Yumanity Therapeutics, Biogen and other biotech companies – rocked out to Chicago and Stevie Wonder songs, and raised more than $15,000 on AFTD's behalf while spreading awareness of FTD.

Raising FTD awareness is central to AFTD's mission. Awareness promotes public understanding and helps families get accurate diagnoses for their loved ones. Awareness alerts health professionals to the realities of FTD, and it can even spark new research. Over the last 12 months, members of our community have bravely chosen to share their stories. AFTD is grateful for your resilience and your courage, and is honored to partner with you in telling the story of FTD.

VJ and Chuck Anastasia welcomed filmmaker Joseph Becker of ThinkFilm, Inc., into their home to document VJ's FTD journey. The resulting short film, *VJ & Chuck*, powerfully shows how VJ's 2013 diagnosis of primary progressive aphasia has changed every aspect of their lives. Narrated by longtime AFTD volunteer Teresa Webb, *VJ & Chuck* premiered in November and has been viewed by thousands on AFTD's YouTube channel.

World FTD Awareness Week 2017 took place from September 24 through October 1, 2017. AFTD marked the occasion by joining forces with our international allies in the World FTD United coalition to raise awareness around the globe; ten countries representing four different continents participated. In the U.S., AFTD again placed two full-page awareness ads in Sunday issues of the *New York Times*, thanks to the support of a generous donor. Designed by volunteer Jody Zorn, the ads urged readers to rethink their take on dementia: "*Think It's Alzheimer's? Think Again.*"

That tagline also appeared in six public-awareness videos produced by AFTD in partnership with Discovery Inc. Each video featured a prominent AFTD community member, such as actress Martha Madison and sports broadcaster Wes Durham. These brief videos can be found through AFTD's YouTube page, findable on the site under theAFTDorg. We hope you'll share our video resources with your friends, family members and colleagues.

The hiring of AFTD's first Online Community Coordinator has significantly bolstered our social network impact. Between June 2017 and June 2018, AFTD's Twitter followers grew by 34%, while the number of Facebook followers went up 52%.

Finally, you may have noticed that AFTD now offers a new logo, tagline and new resources. In April 2018 we rolled out a completely redesigned website at www.theaftd.org. Designed with the marketing firm Teramark, the site built on a process consulting caregivers, persons diagnosed and other volunteers. It is designed to allow people and families affected to more easily access the information and resources they need, and to more easily make connections with others, as they seek to *Find Help. Share Hope.*

The September 24, 2017 issue of the New York Times *featured this full-page ad promoting awareness of FTD and AFTD.*

A still from the film VJ & Chuck *featuring VJ and Chuck Anastasia.*

Actress Martha Madison and sportscaster Wes Durham appeared in AFTD's "Think FTD" series of PSAs.

support

Members of the AFTD community finding support and hope at the AFTD Education Conference

For many facing FTD, whether as a care partner or a person diagnosed, finding help and support for their journey can be an extraordinary challenge.

AFTD's HelpLine – the only such resource devoted exclusively to providing information and guidance about FTD – remains a vital first point of contact. Last year, our staff responded to nearly 2,300 phone and email inquiries, answering with compassion, urgency and the type of straightforward information families dealing with FTD need. Our e-newsletter Help & Hope began providing information for both care partners and people with FTD on a monthly basis.

We continue to expand our national network of support. Last year, 80 AFTD-trained and -supported volunteers – including health professionals and care partners alike – led targeted support groups in 32 states. Many have recently recommitted to lead their groups for an additional two years. Eight remote AFTD-affiliated groups provided a safe space online or by phone, offering support that can reach underserved rural areas.

AFTD volunteer support group facilitators offer one of the few available resources designed specifically and exclusively for people whose lives have been touched by FTD. They offer vital opportunities for problem-solving, resource sharing and emotional support between people facing a common experience, and chip away at the isolation far too common for families navigating an FTD diagnosis.

The Very Rev. Tracey Lind embraces Regional Coordinator Volunteer Doreen Putnam at the AFTD Education Conference.

Last year, AFTD awarded 180 Comstock Grants to members of our community. AFTD recognizes the need for care partners to look after their own well-being, and offers Respite Grants that can be used to arrange respite care. Travel Grants, to subsidize the costs of travel, lodging, registration fees and/or respite care for travel to FTD-related conferences, are also available.

Last year AFTD piloted a new Comstock Grant. Developed with invaluable input from AFTD's Think Tank – a group of persons diagnosed with FTD that meets regularly to help further our mission – the AFTD Quality of Life Grant represents the only organized program designed to empower those living with FTD to purchase equipment, services or supports that they could not otherwise afford. The pilot was a success, and we are now in the process of rolling out additional Quality of Life Grants to deepen the support we provide for people living with FTD.

Support on the Rise: FY 2017 to FY 2018

↑17%
AFTD-Affiliated
**Support Group
Facilitators**

U.S. States with
**Support
Groups**
Led by AFTD-
Affiliated Facilitators

↑22%
Members of **AFTD's
Closed Facebook**
Support Group

↑35% Members of
**AFTD's Facebook
Support Group**
for Young Adults

Filmmaker Joe Becker, the director of VJ & Chuck, with Teresa Webb, the film's narrator

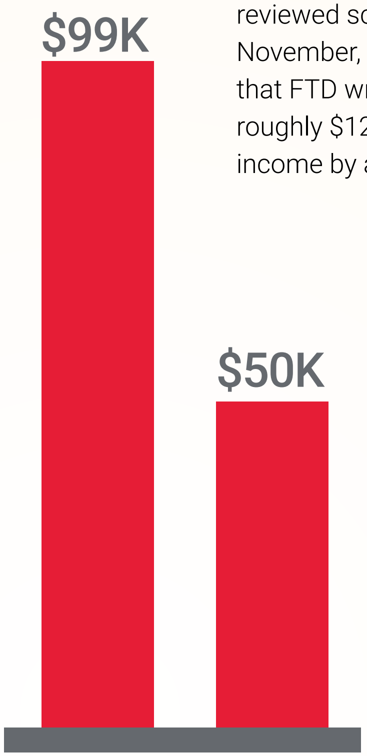
> "Support means feeling like they're part of a community and making connections to others going through the same thing."
>
> \- Gary Radin
> AFTD Volunteer

Gary Radin was in his mid-twenties when his father, Neil, was diagnosed with FTD. With his mother, Lisa (a former AFTD Board member), he provided care for him until his passing. Gary draws on his personal experiences as facilitator of a long-running support group for adult children. Whether providing care at home or from a long distance, young adult children of people with FTD face unique challenges – challenges that arise just when many are establishing careers, or raising young families. In Gary's group, members "share experiences, stories, circumstances, and challenges"; they exchange practical advice, offer emotional support, and highlight key resources, such as the AFTD website. For group members, "support means feeling like they're part of a community and making connections to others going through the same thing," Gary said.

research

AFTD continues to be a global leader in funding cutting-edge FTD research. The ongoing partnership between the scientific community, AFTD and our generous donors has the potential to produce remarkable scientific breakthroughs, helping to further our understanding of this disease – and create hope for a world without it.

AFTD funded and co-wrote a study detailing the economic and social burden that FTD inflicts on families. Published in the peer-reviewed scientific journal *Neurology* in November, our economic burden study shows that FTD wreaks a yearly financial toll of roughly $120,000, and can reduce household income by as much as 50 percent.



Median household income 12 months before an FTD diagnosis is in the $75-99K range. AFTD's study on the economic burden of FTD shows that 12 months later, median income falls to around $50K.

Over the past year, AFTD funded the research of several promising investigators in the U.S., Canada and Europe. These awards include the first grants awarded through our TreatFTD initiative, which promotes innovative approaches to FTD clinical drug trials.

AFTD also awarded our first-ever pilot grant for nonpharmacological therapies and tools for FTD, the latest addition to our ongoing Pilot Grant program. A return-on-investment analysis of this program proves that it gets results: From 2005-2016, AFTD awarded $955,000 in Pilot Grant awards, resulting in more than $7.5 million in follow-on funding.

In October, AFTD convened the initial grantees of the FTD Biomarkers Initiative to update the Scientific Advisory Board as well as AFTD staff and Board members on their progress in identifying biomarkers for FTD. Later, we awarded an additional Biomarker grant to researchers leading the ARTFL clinical program at the University of California, San Francisco.

AFTD held its biennial meeting of the FTD Treatment Study Group (FTSG) in March, convening representatives from 27 pharmaceutical and biotech companies, along with government regulators and academic researchers, to identify and formulate creative responses to the challenges of getting the first drugs approved for use in FTD.

A year ago, in March 2017, AFTD and the Bluefield Project to Cure Frontotemporal Dementia launched the FTD Disorders Registry, the first online database to compile the self-reported experiences of people affected by FTD and to match them with research and clinical trial opportunities. One year after its launch, the Registry had already attracted more than twice its original registrant goal.

Thomas Kukar, PhD

Steven Finkbeiner, MD, PhD

Adam Boxer, MD, PhD

> “Without an award from AFTD, this app would not happen.”
>
> - Lauren Massimo, PhD

Awards and grants

AFTD Biomarker Awards – Adam Boxer, MD, PhD, and Howard Rosen, MD, University of California, San Francisco (US)

The Susan Marcus Memorial Fund Clinical Research Pilot Grant – Haakon Nygaard, MD, PhD, University of British Columbia (Canada)

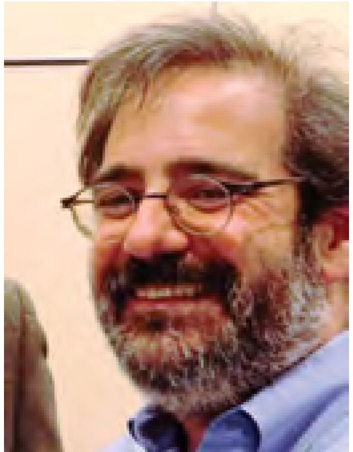
Basic Science Pilot Grant – Todd Cohen, PhD, University of North Carolina, Chapel Hill (US)

Nonpharmacological Therapies and Tools for FTD Pilot Grant – Lauren Massimo, PhD, CRNP, University of Pennsylvania (US)

TreatFTD Fund Grant – Barbara Borroni, MD, University of Brescia (Italy)

Accelerating Drug Discovery in FTD (in partnership with the Alzheimer’s Drug Discovery Foundation) – Thomas Kukar, PhD, Emory University (US); Steven Finkbeiner, MD, PhD, J. David Gladstone Institutes (US)

Howard Rosen, MD



Haakon Nygaard, MD, PhD

Todd Cohen, PhD

Lauren Massimo, PhD, CRNP

Nonpharmacological Therapies and Tools for FTD Pilot Grant

In June, AFTD awarded its first-ever Pilot Grant for Nonpharmacological Therapies and Tools to Dr. Lauren Massimo, an assistant professor at the University of Pennsylvania’s FTD Center. Dr. Massimo is using the grant to convene a team of neuropsychologists and smartphone app developers, who will work on an app that will help persons diagnosed overcome apathy, “a common and highly debilitating symptom for people with FTD,” she says. The app will use alerting mechanisms to signal persons diagnosed to perform a customized range of activities, including grooming, exercising, completing household chores and taking prescribed medications. The AFTD Pilot Grant award “allowed this team to come together,” Dr. Massimo said. “Without an award from AFTD, this app would not happen.”

education and advocacy

AFTD Volunteers Amy Bouschart-Callea and Frank Callea welcome attendees to the 2018 AFTD Education Conference.

Educating members of the public, the medical community, and state and federal legislatures about FTD is central to achieving AFTD's mission.

Unique among other U.S. organizations, we produce substantive, medically accurate, FTD-focused resources for healthcare professionals and families. Over the last year, three new installments in our Educational Webinar series brought attention on the FTD Disorders Registry, the genetics of FTD, and two promising brain-stimulation technologies that researchers hope can be used in assessing and treating FTD.

AFTD's Partners in FTD Care initiative produced three new, highly informative newsletters, focusing on ALS with FTD, accurate diagnosis, and apathy, a common symptom. Two new members of the Partners advisory committee are now bringing additional clinical and community-care experience to the creation of new issues, strengthening an already highly knowledgeable group.

The 2018 AFTD Education Conference took place in Chicago in April, drawing 341 attendees from 37 states and Canada for a powerful day of information, support and networking. Drawing from the experiences of AFTD's Think Tank, an advisory group of persons diagnosed, the conference was specifically designed to be more inclusive of all attendees.

Education Conference attendees took part in breakout sessions on improvisational theater (this page) and positive care strategies (opposite).

On Capitol Hill, AFTD continued its strong advocacy on behalf of persons diagnosed and their families. Our staff worked closely with Sen. Charles Schumer's office to draft language to be included in a key congressional report encouraging the National Institutes of Health (NIH) to expand its FTD clinical research network. Working directly with staff from the U.S. Defense Department, AFTD helped to get FTD included for funding through the Peer-Reviewed Medical Research Program. These were key wins for our community.

In October 2017, AFTD sponsored the National Alzheimer's Project Act's summit on dementia care, held on the NIH campus, ensuring that the care needs of people with FTD were addressed. AFTD allies Sharon Hall and Teresa Webb spoke at the summit and served on stakeholder panels, where they helped guide federal research priorities in dementia care and services from the standpoint of a care partner and person diagnosed, respectively.

AFTD Research Manager Debra Niehoff leads an educational breakout session.

The Very Reverend Tracey Lind was diagnosed with primary progressive aphasia in 2016, leading her to step down from her prestigious position as Dean of Trinity Episcopal Cathedral in Cleveland. She has chosen to be completely transparent about her diagnosis, both "to give it meaning and purpose" and to "destigmatize this dreaded disease by speaking about it from the inside out," as she said during her Keynote Address at the 2018 AFTD Education Conference.

volunteers and the AFTD-Team

Volunteers provide the vital energy and momentum that drive AFTD's mission. We are grateful for every volunteer – and the myriad ways they demonstrate resilience and resolve to make a difference.

During the last 12 months, 340 active volunteers led the charge in bringing AFTD's presence to local communities across the country. They held fundraisers, led support groups in 32 states, led table settings at community events to spread awareness, performed outreach to educate staff at local facilities, and hosted Meet & Greet events in cities from Seattle to Mobile to Fargo.

AFTD Volunteer Elizabeth Soriero and AFTD Regional Coordinator Volunteer Corey Esannason

Our 11 highly committed Regional Coordinator Volunteers helped stimulate volunteer activity in each of their regions. AFTD recognized these individuals, along with our invaluable AFTD-affiliated support group facilitators and other key volunteers, at our annual Volunteer Leadership Summit, held immediately prior to our 2018 Education Conference in Chicago.

Volunteers inform AFTD's work on a daily basis. An all-volunteer Think Tank, comprised of persons diagnosed with FTD, helps us to better serve, include and empower these vital constituents. A devoted committee of healthcare professionals helm the Partners in FTD Care initiative, enabling us to offer the most up-to-date information on FTD care and management. More people continue to step up and give generously of their time and effort each year.

AFTD volunteers who host or participate in a grassroots fundraising event become members of the AFTD-Team, dedicated to fighting this disease. Last year, during our flagship fundraising campaign, Food for Thought volunteers raised more than $178,000 – a new record – and spread FTD awareness, all while providing delicious meals for friends, loved ones and community members. A total of 63 Food for Thought events took place in 34 states!

AFTD Volunteers Cindy Odell and Barbara Wilt

With Love, a campaign centered around Valentine's Day, raised more than $52,000 from a record 29 hosts, while the AFTD-Team Race Season raised more than $68,000 during 2017. Races – and fundraising – continue in 2018!

Members of the AFTD-Team at the Colfax Marathon in Denver.

The furriest member of the AFTD-Team shows her support.

AFTD Volunteer Cathy Sperrick hosted a Food for Thought event at a brewery in New York.

A huge crowd turned out for the Philadelphia Marathon!

> “Meeting people who understand FTD is invaluable.”

For people who have FTD in their lives, there is no substitute for connecting with others who understand. For that reason, AFTD encourages and supports volunteers who host Meet & Greet events. Jerry Horn of Alabama organized one of the 14 Meet & Greets held last year, bringing people together to talk about their experiences, learn about resources and exchange information. “Meeting people who understand FTD is invaluable,” he said. “Forging these bonds is such an important part of the FTD journey.”

AFTD Volunteer Jerry Horn with AFTD Volunteer Manager Kerri Keane and fellow Volunteer Martha Allegri

named funds and donors

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 Mrs. Kathi and Mr. Peter Arnow

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

Susan Marcus Memorial Fund
Established by Mr. & Mrs. Lawrence Neubauer

Laden Memorial Fund
Established by the Laden Family

The Suzy Fund
Established by the Newhouse Family

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

The Mimi Fund
Established by her loved ones

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

AFTD relies on donations to fulfill our mission of advancing research, raising awareness and providing support. We are immensely grateful to all who have strengthened AFTD with their generosity over the last year, and we look forward to continuing these partnerships.

1,000,000+

David Geffen Foundation
Samuel I. Newhouse Foundation Inc.

100,000+

Discovery Inc.
Katherine Farley & Jerry Speyer
George L. Ohrstrom, Jr. Foundation
Leonard & Judy Lauder Fund
U.S. Trust, Bank of America Private Wealth Management

50,000+

The Chang/Farley Gang
Citi Private Bank
Tad Smith
Mr. Larry Gagosian
Patricia M. & Victor F. Ganzi
The Revocable Trust of Jack C. Nichelson
Larry and Jillian Neubauer
Mr. & Mrs. Gary Johnson
John Malone
The Ralph and Ricky Lauren Family Foundation
Rochester Area Community Foundation
Sotheby's
Sullivan & Cromwell
Mrs. Beth Walter
William Randolph Hearst Foundation

20,000+

Anonymous
Mr. & Mrs. Peter Arnow
Charter Communications
Christie's
Colonial Electric Supply
The Connecticut Frontotemporal Dementia Foundation, Inc.
The Durst Organization
Mr. Russ Gent
J.P. Morgan
Mrs. Susan Laden
Mr. Philip H. Lovett
McDermott Will & Emery LLP
NFP
Mr. & Mrs. Timothy Romani
Scripps Networks Interactive
Mrs. Bonnie Shepherd
Carol Sutton Lewis & William M. Lewis, Jr.
Mr. & Mrs. Andrew B. Suzman
UBS

10,000+

Mr. Jack Adler
AD Philanthropic Fund
Angel Shine Foundation/Allyson Tang & Thomas Widmann

10,000+, continued

Arthur S. Kranseler Trust
Arts & Business Council of Greater Boston
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Biogen
Ms. Lisa Boyce & Mr. Kevin O'Neill
Mr. Timothy L. Broer
Calvin Klein Family Foundation
Mary Beth Repasy Fund for Progressive Supranuclear Palsy Research of The Dayton Foundation
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Mr. John McNellis
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Stacey & Eric Mindich
The Parsons Family Foundation
Ms. Yvonne S. Quinn
The Rainwater Charitable Foundation
Joanna S. & Daniel Rose
Mr. Jack Rowe
Janine Shelffo & Stephen McGrath
Mr. Bevan Slattery
Mr. & Mrs. Alan Soiefer
Alice M. and Thomas J. Tisch Fund
Dr. John Whitmarsh
Mr. Christopher Yurkanan

5,000+

AbbVie
Alzheimer's Drug Discovery Foundation
Ms. Gail Andersen
Mr. & Mrs. Walter Anderson
Anonymous
Arete Foundation
Mary & Dick Benioff
Magda & Edward Bleier/Dana Foundation
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CBRE
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Mr. Paul Lester
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Morgan Stanley Global Impact Funding Trust, Inc.
John Morning
Muchnic Foundation
The Newman Foundation, Inc.
Michelle Ores & Charles Schorin
Mr. Martin Packouz
Pappy Van Winkle Classic
Arnold S. Penner
Mr. Fran Pollart
Mr. & Mrs. Edward Quinn
Renaissance Charitable Foundation
Mr. Larry Rodger
Mr. Mark Schroyer
Mr. Arthur J. Sommers
Mr. Jerry I. Speyer
Emma & Mackenzie Strathy
Sydney Licht & Tom Summer
Nan & Stephen Swid


AFTD Regional Coordinator Volunteer Deb Scharper and a friend at the First Annual Crusade for a Cure Golf Tournament

donors

5,000+, continued

The Bluefield Project to Cure Frontotemporal Dementia
Mr. Marc A. Toles
Wachtell, Lipton, Rosen & Katz
Mrs. Terry L. Walter
Gretchen Beidl & Michael Willner
Ms. Candace Young

2,500+

Alector
Anonymous
Mr. Joseph A. Becker
Mr. John B. Beinecke
Mr. Joseph W. Bellwoar
Mr. Mark Bleiman
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Mr. Paul Buckley
Mr. Michael Burns
Patricia K. Carey
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Cure PSP
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Greater Kansas City Community Foundation
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Mr. Jonathan E. Robinson
Rudnick Charitable Foundation, Inc.
Ms. Deb Scharper
Stephanie & Jack Seibald
Mrs. Tam Smith
Mr. Bob Smith
TauRx Therapeutics, Ltd.
Ms. Sarah Tipton

AFTD CEO Susan L-J Dickinson speaks at AFTD’s second annual Hope Rising Benefit in New York

2,500+, continued

Lulu & Anthony Wang
Mr. & Mrs. John C. Weicher
Mr. David N. White
Shirley Young, Chair of the US-China Cultural Institute

1,000+

Mr. Brad Adams
Susan Ahlcrona
Mr. Joddy Allen
AmazonSmile Foundation
American Plumbing, Inc.
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Mr. & Mrs. Ryan Baldino
Mr. Stephen Balek
Ms. Kathleen Bambrick Meier
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Lt. Gen. Michael J. Basla
Mr. & Mrs. Andrew Bellwoar
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Mr. Daryl Boehmer
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Mr. & Mrs. Matthew J. Campanella
Dr. Anne Campbell
Rev. James Cardosi
Mrs. Lucy R. Carter
Champion Fiberglass
Rick Childs & Family
Ms. Lisa Church
Mr. James Clifford
Dr. & Mrs. Joseph S. Cohen
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Mrs. Helen-Ann Comstock
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Mr. & Mrs. Alec Dafferner
Mr. Aaron Daniels
Courtney & Jon Davis
Mr. Owen Davis
Mrs. Linda Deubert
Hester Diamond
Mr. & Mrs. Robert DiNicola
Mr. Mike Dircksen
Ms. Lori Dondiego
Mr. Conor Drury
Mr. John Duncan
Mr. Alan Einhorn
Mr. & Mrs. Mark Espinosa
Annabel Fan & Doug Hseih
Mr. Richard Feintuch
Mr. Stephen Fenoglio
Mrs. Susanna Foo
Charlotte Feng Ford
Stacye & David Frahm
Mr. Darren A. Friesen
FTD Research Community

At Hope Rising (left to right): AFTD CEO Susan L-J Dickinson, AFTD donor Donald Newhouse, journalist and TV host Paula Zahn, Sen. Charles Schumer (NY)

donors

1,000+, continued

Mr. Ronald Fultz
Ms. Evelyn Galante
Mr. Tom Gannon
GE Foundation
Good Done Great
Mr. Peter C. Gould
Graycor Services LLC
Mr. & Mrs. George Greenway
Mr. Douglas Grigg
Ms. DeeAnn Hall
Jennifer Hand & Tom Tierney
Mr. John R. Hastings
HCR Manorcare - Arden Courts Memory Care Communities
Mr. & Mrs. Adam Cohen
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Mr. Thomas Hilfiger
Ms. Susan Hirsch
Ms. Joanne Ho
Mr. & Mrs. Craig Holleman
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Amy & John Jacobsson
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Mr. Daryl Jesperson
Mr. Thomas Jones
Mr. & Mrs. Mitchell Julis
Just Give
Mr. Robert Juza
Ms. Rebecca A. Kepner
Mr. Emre Kiciman
Mr. Mike Kipp
Ms. Jenny Klatt
Ms. Jennifer Klingler
Carol H. & Robert D. Krinsky
Mr. Armin A. Krueger
Mr. & Mrs. Neal Kulick
Patricia & Andrew Langer
Dr. Jary Larsen
Dr. Virginia M.-Y. Lee, PhD
Nina & Ralph Levene
Mr. Willliam C. Lex
Elinor Lipman
Sarah Long & David F. Solomon
Mr. Ryan Lower
Mr. Mitchell Lower
Ninah & Michael Lynne
Sylvia Mackey Speaks
Maracle Builders LLC
Mr. & Mrs. George Maroulis
Mrs. Maria Amelia Marques
Mrs. Kathryn McAndrew
Mrs. Melody McKernan
Ms. Lauren McMahon
Mediamorph Inc.
Mr. George S. Merlo
Mr. Jason Messerli
Mrs. Julie Miller
Mrs. Kim Millman
Mr. David A. Misenhimer
Mr. Richard Owen Monsen
Hiroko & Satoru Murase
Brooke & Daniel Neidich
Mrs. Anita L. Nelsen
Mr. & Mrs. Will Nesbitt
Helen Stambler Neuberger
Ms. Marla Nissan
Ms. Jill Nolte
Novartis
Mr. & Mrs. Michael D. Nunno
Elizabeth Olson
Mr. Joe W. Pang
Mr. Joel Panzer
Dr. Soham Patel
Martha & Mark Patricof
PH Logistics
Dr. Creighton Phelps
Mr. John H. Pickett
Ms. Sara R. Pikofsky
Mr. & Mrs. Edward Quinn
Mrs. Alison Riddiford
Ms. Sheila Robbins
Robert Derector Associate
Mr. & Mrs. Judd Robertson
Robinson Miller LLC
Rock Environmental Inc.
Mr. Mark Roithmayr
Mr. Charles J. Rose
Mr. Russell Rosenblum
Rosenblum Family Foundation
Rostair Foundation
Mr. Steven Rulison
Mr. & Mrs. Sol Sackel
Sackel Limited Partnership
Mr. Ron Sakoda
Salesforce.org
Mr. Tom Saponas
Saponas Foundation
Ms. Alice Saunders
Ms. Beth Schatman
Mr. Walter Schepp
The Schroeder Family Trust
Mr. Michael Scott
Anne Marie & Robert F. Shapiro
Mr. Popkin C. Shenian
Ms. Amy Shillady
Ms. Dorsi Smith
Mrs. Carol Smith
Ms. Allison Smoot
Ms. Cathy Sperrick
Mr. Ryan Steglich
Strong Foundation of New York
Mr. Lawrence Summers & Ms. Elisa New
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TIAA, FSB
TPG Architecture
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Universal Electrical Service
US Ceiling Corp
USAA Life Insurance Company
Ms. Pamela M. Van Zandt
Mrs. May D. Vandeveire
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Mr. Scott Dean Waitzer
Ms. Karen L. Wakefield
Mr. Stuart Waldman
Waterfall Family Foundation
Ms. Fredda Weiss
Ms. Cheramy White
Mr. & Mrs. William Willard
Nina Wortzel-Hoffman
Mrs. Joan C. Zlotnick

fundraisers

The AFTD-Team was out in full force over the past year, hosting 245 grassroots events and bringing more than $432,000 to support AFTD's mission! The events listed on this page each raised more than $1,000. We are incredibly appreciative of our volunteers for their determination and drive, and we share in their hope that one day we will live in a world free of FTD.

Independent Events

George & Christine Sidoris
12th Annual George F. Sidoris Memorial Golf Outing

Paul Lester
11th Annual Letters for Arnette

12 Barz Band
Battle of the Biotech Bands

Debbie Baumgartner
3rd Annual John E. Baumgartner III Golf Tournament

Deb Scharper
1st Annual Crusade for a Cure Golf Tournament

Pam & Matthew Hatfield
Robert M. Hatfield 7th Annual Quest for the Cure Golf Tournament

Sharon & Rod Hall
2018 FTD Calendar

Diane Cole
Chuck's Celebration of Life

Cindy & Ken Brunner
Wooden Bowl Sales

Dawn Zeremba
Evine Social Media Campaign

Suzanne & Calvin King
2nd Annual "Tami Sue" Golf Outing & Party

Matt Pelton
Hiking the AT for AFTD

Rachel Lower
"I Love You, Mom"

Anonymous
"Help Save the Brain" Shirts

Jon Moretti
2nd Annual CWM Memorial Golf Outing

Juliet Bornia
Big Sur Marathon

Kaj Malden
In Memory of Jacqueline Malden Phelps

Kaitlyn Heffron
Hiking the PCT for AFTD

Amy Shillady
Soy Candle Sales

Lucy Carter
House Restaurant Event

Food for Thought

Steve Bellwoar
Cathy Sperrick
Bonnie Shepherd
Terry Walter
Deanda Welch
Kathy Ritchie
Molly Trimmer
Chuck Anastasia
Ryan Windhorst
Lucy Carter
Katrina Hellman
Joan Harper
Rachel Castellanos
Diane Cole
Rona Klein
Jennifer Morabito
Mary Beth Mixdorf
Shirley Gordon

Race Season

Team Jack Attack
Frank Callea
Daniel Ranti
Joe Fischel
Marisa Lutz
Patti Del Guercio
Debbie Fenoglio
Joe Pang
Kerry Verdi
Stephanie Potter
Rachel Lower
Susan L-J Dickinson
Karen Dalley
Jane Carter

With Love

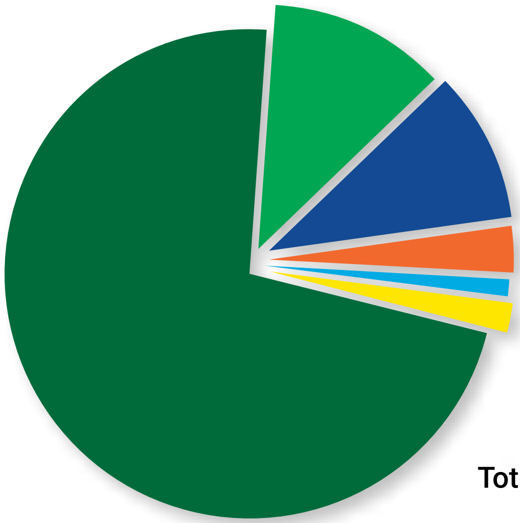
Emily Anderson
Suzanne Dana
Kathryn Primeau
Melissa Fisher
Zoy Kocian
Jamie Hale

Via Facebook

Randee Curry
Gary Johnson
Jamison Sep
See Aytch
Cassie Jonaitis
Randi Davis
David White
Maggie Braun
Alyssa McCray
Ashley Olhausen
Lorrie Cox
Laurie Kozakiewicz

financial reports *fiscal year ending 6/30/2018*

Income



🟩 73% Foundations

🟩 12% Special Events

🟦 10% Individuals

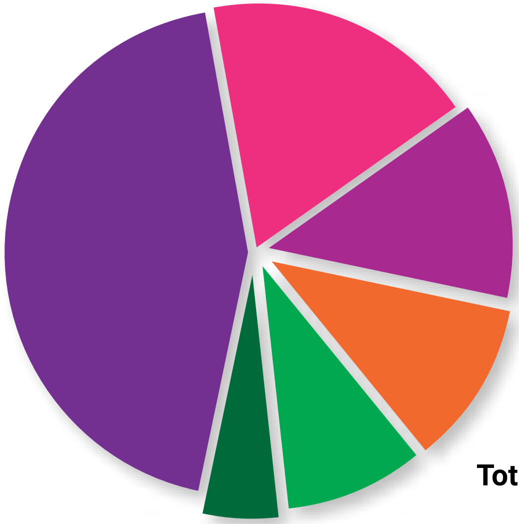
🟧 3% Grassroots Fundraisers

🟦 <1% Corporations & Matching

🟨 2% Other

Total Income: $14,819,666

Expenses



🟪 44% Research

🟥 18% Awareness & Advocacy

🟪 13% Support

🟧 11% Fundraising

🟩 9% Management & General

🟩 5% Education

Total Expenses: $4,626,842

Statement of Financial Position

as of 6/30/2018

Assets

Cash & Cash Equivalents	$	6,165,087
Contributions Receivable	$	11,233,007
Accounts Receivable	$	11,195
Prepaid Expenses	$	114,014
Equipment	$	11,770
Security Deposit	$	8,672
Total Assets	**$**	**17,543,745**

Liabilities and Net Assets

Liabilities		
Accounts Payable & Accrued Expenses	$	86,625
Deferred Revenue	$	47,500
Research Grants Payable	$	610,672
Total Liabilities	**$**	**744,797**
Net Assets		
Unrestricted		
Undesignated	$	1,792,053
Board Designated for Reserves	$	3,524,594
Total Unrestricted	$	5,316,647
Temporary Restricted	$	11,482,301
Total Net Assets	**$**	**16,798,948**
Total Liabilities and Net Assets	**$**	**17,543,745**

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

outlook

> “Thank you for sharing your support and ideas, your time and resources… and your hope.”

Every year, I pause to reflect on the honor it is to support AFTD's mission and serve this community.

Throughout my tenure at AFTD, my daily work has been fueled by the stories I hear -- from persons diagnosed seeking medically accurate information; from care partners looking for practical advice; from researchers and healthcare professionals grateful for AFTD's leadership in advancing FTD science.

Today, AFTD stands stronger than ever, more capable of providing help and sharing hope with all affected by FTD. Thanks to support from people like you, we stand poised to extend our reach even farther.

Over the next year, AFTD will continue supporting cutting-edge research into FTD's symptoms, causes and, potentially, treatments. We will convene researchers investigating TDP-43, a protein whose accumulation in the brain is associated with the presence of FTD. Our research team will also award the second round of grants through our FTD Biomarkers Initiative, a program we hope will foster earlier and more accurate diagnosis.

In November, AFTD will sponsor the 11th International Conference on Frontotemporal Dementias in Sydney, Australia, with staff and Board members on hand to collaborate with global leaders in FTD science. The following March brings the Alzheimer's Disease-Related Dementias Summit, hosted by the National Institutes of Health; AFTD is sponsoring that as well. And we look forward to uniting our own community on May 3, 2019 in Los Angeles, for the annual AFTD Education Conference.

Our staff will continue to share FTD information and education, both directly through the AFTD HelpLine and generally through Educational Webinars, newsletters and social media. The AFTD-Team, comprising volunteers who support AFTD with grassroots fundraising and awareness efforts, will further expand its presence. Look for us – or better yet, join us – at marathons in Philadelphia, Austin and Dallas.

I'm so proud of the work we've accomplished over the last year, and I look forward to serving this community in an even more comprehensive and profound way over the next year, and beyond: We will soon debut our ambitious, forward-thinking strategic plan for 2019–2022.

Thank you for sharing your support and ideas, your time and resources – and most of all, for sharing your hope for compassionate care, effective support and a future free of FTD.

Susan L-J Dickinson, MS, CGC
Chief Executive Officer

AFTD leadership

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Gail Andersen, Chair
Ohio

Michael Stowell, PhD, Vice Chair
Colorado

Paul Lester, Treasurer
North Carolina

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

Kathy Mele
New York

David Pfeifer
Colorado

Brian Rose
New York

Beth Walter
California

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Rosa Rademakers, PhD
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John Q. Trojanowski, MD, PhD
University of Pennsylvania

The Association for Frontotemporal Degeneration
FIND HELP·SHARE HOPE

290 King of Prussia Road, Radnor Station Building 2, Suite 320, Radnor, PA 19087
HelpLine: 866.507.7222 or info@theaftd.org | Office: 267.514.7221

Staff

Susan L-J Dickinson, MS, CGC
Chief Executive Officer

Sharon S. Denny, MA
Program Director

Ben C. Freeman
Development & Communications Director

Christine Stevens, MBA
Chief Financial Officer

Nadine Tatton, PhD
Scientific Director

Kerri Keane, MSW
Volunteer 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

Trudy Bowman
Development Coordinator

Lauren Gauthier
Online Community Coordinator

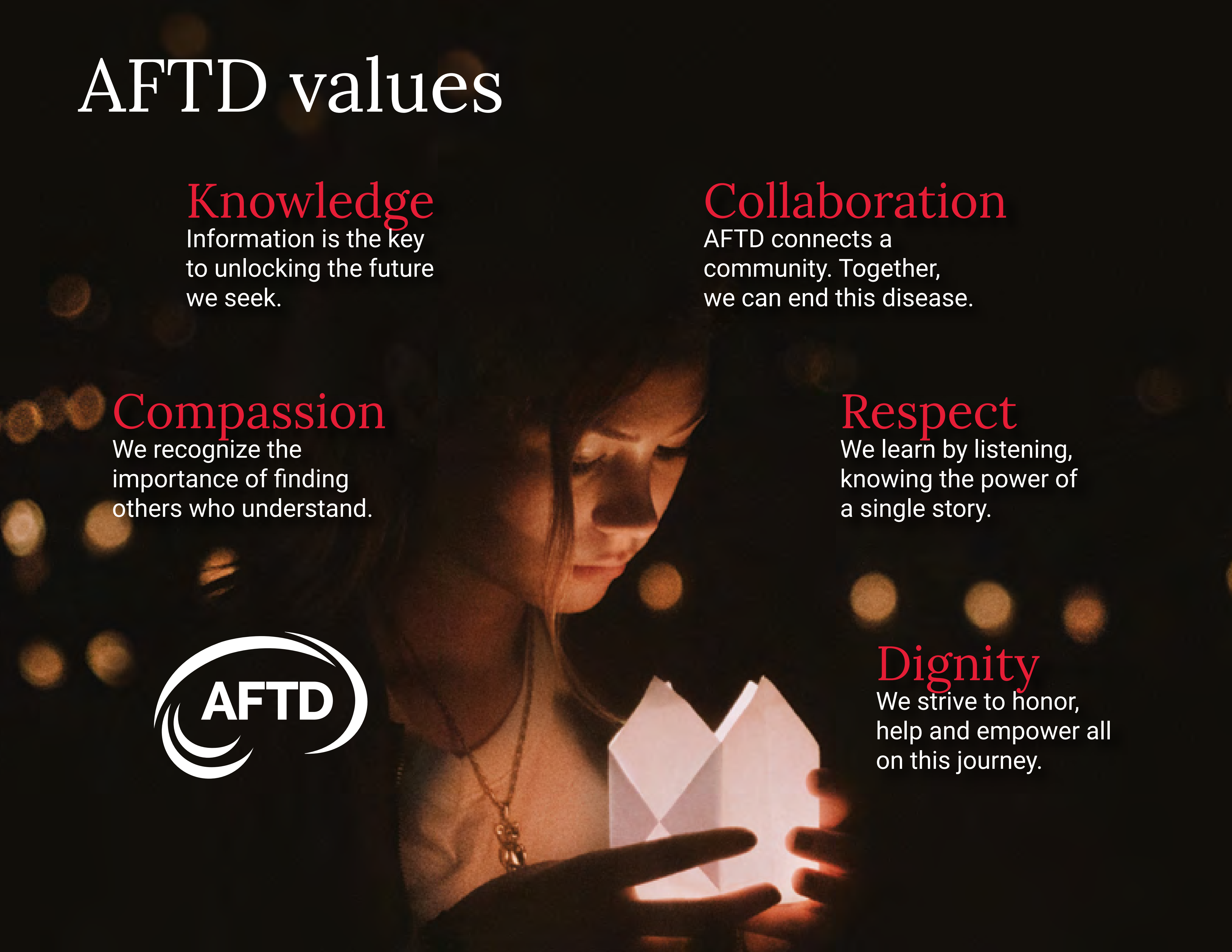
Bridget Graham
Grassroots Events Coordinator

Cameron Kelsall, MA
Staff Writer

Harold Perkins III, MPH
Programs and Services Assistant

Emma Tomasetti
Development Assistant

Elizabeth Young
Executive Assistant



AFTD values

Knowledge

Information is the key
to unlocking the future
we seek.

Collaboration

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

Compassion

We recognize the
importance of finding
others who understand.

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.

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