

July 2018–June 2019

## 2019 Annual Report

# A Vision for Hope



The Association for  
Frontotemporal Degeneration  
FIND HELP • SHARE HOPE





**FTD**  
The Association for  
Frontotemporal Degeneration  
FIND HELP • SHARE HOPE

**AF**  
**BELLCO COLFAX MARATHON**  
21227  
JORDAN,  
DENVER, CO  
CORRAL, E  
The Association for  
**21227**  
DAVIDA PERMANENTLY  
**COLFAX MARATHON** **DaVita**  
**2018**

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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,

A handwritten signature in black ink that reads "Gail Andersen". The signature is fluid and cursive, with a long, sweeping underline.

Gail Andersen  
AFTD Board Chair

# awareness



AFTD worked with producers from CBS's 60 Minutes on a piece they ran in May devoted entirely to FTD. One of the lead producers on the story, Rome Hartman, said that he was compelled to tell the story of FTD because of how little known it is, and how hard it is to diagnose. "I wish [FTD] didn't exist," Hartman said. "But given that it does, I'm grateful for the chance to have met these people and shared their stories with our audience."

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 "cruellest 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](http://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





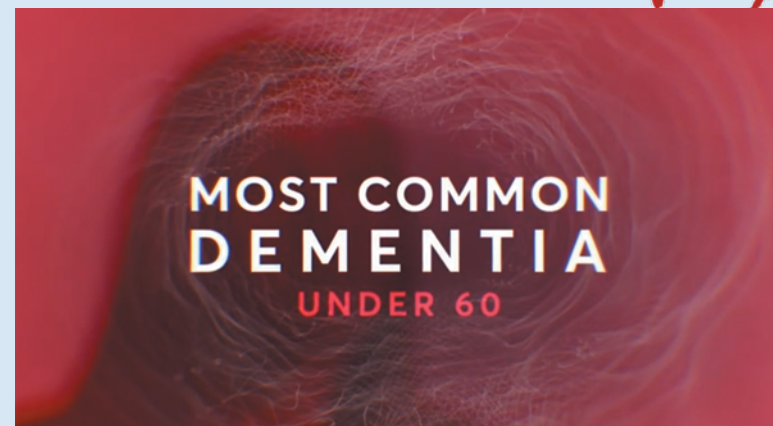
international coalition of FTD organizations, AFTD hosted on theaftd.org an interactive map that allowed people to share their FTD stories and let us know where they are writing from. Nearly two hundred people contributed to the map, representing two dozen countries, ranging from Australia to Brazil,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

AFTD kicked off World FTD Awareness Week with a full-page ad in the Sunday,

< Versions of this ad ran in the Sept. 23, 2018 issue of the New York Times and on the Times website on Sept. 25.

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.



A scene from a 30-second AFTD public service announcement that aired on Discovery Inc. cable networks



# support



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.

*Members of the AFTD community found connection and learning at the AFTD Education Conference in Los Angeles.*





# Finding Support: FY 2018 to FY 2019



**↑20%**  
AFTD-Affiliated  
Support Group  
Volunteers

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



**↑29%**  
Comstock  
Grants  
distributed



Website  
visitors  
**↑42%**  
317,206  
total

**↑37%**  
Members of  
AFTD's  
Facebook Group



**↑28%** Members of  
AFTD's Facebook  
Group for Young Adults



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



# research

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.

*Anthony Fitzpatrick, PhD*



*Leonard Petrucelli, PhD*



*Magdalini Polymenidou, PhD*





“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** – Paschal 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)

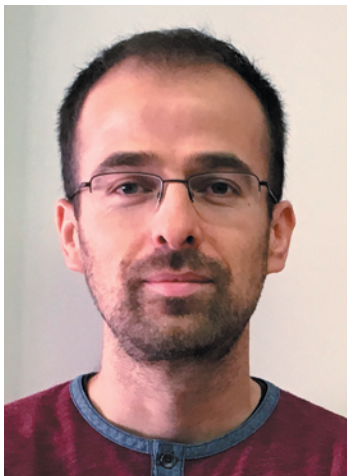
**Basic Science Postdoctoral Fellowship** – Ming-Yuan Su, PhD, University of California, Berkeley (US)

**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.

Paschal Kratsios, PhD



Liam Chen, PhD



Oriol Dols Icardo, PhD





# 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.*





“The time is now – we’ve got to get the word out about this disease specifically.”

– Brian Fox, AFTD Volunteer

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.



AFTD volunteers Joanne Linerud and Amy Shives, and community member Laure MacPherson, connected at the 2019 AFTD Education Conference.



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



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.



# volunteers and the AFTD-Team



*Members of the AFTD-Team at the Austin Marathon*



*AFTD Volunteers Shana Nissen and Kayla Boehmer raised funds for AFTD's mission with successful Food for Thought events!*

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.

*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 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.



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).



Volunteer Deb Scharper held the second annual Crusade for a Cure Golf Tournament in Iowa, with funds going toward AFTD's mission.



Runners turned out in droves for the Colfax Marathon in Denver, CO!



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



# named funds and donors



AFTD CEO Susan L-J Dickinson addresses attendees of the third annual AFTD Hope Rising Benefit in New York City

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**

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 The Sally Bursch Cihos Charitable Fund  
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 Credit Suisse Securities (USA) LLC  
 Goldman Sachs Private Wealth  
 Management - Martin Packouz/  
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 The Swid Family  
 The ALS Association, National Office  
 The Connecticut Frontotemporal  
 Dementia Foundation, Inc.  
 The Durst Organization

**10,000–19,999**

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Barbaralee Diamonstein-Spielvogel  
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 Florence V. Burden Foundation at the  
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 and Family Member, Frederick Childs  
 and his daughter, Elizabeth Childs  
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 The David E. Reese Family Foundation  
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 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  
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**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  
 Cleary Gottlieb Steen &  
 Hamilton LLP  
 Mr. Mike Dircksen  
 Douglas Elliman Real Estate  
 Eaton Corporation  
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 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  
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 FTD Researchers  
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 Family Foundation  
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 James and Elaine Wolfensohn  
 Shirley Young



**2,500–4,999**

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 Mr. Jeffry Bleiman  
 Ms. Hillary Blumberg  
 Sister Louise Boyce  
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 Colfax Marathon Partnership, Inc.  
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 Mr. and Mrs. Robert Dickinson  
 Diversified Lighting Associates, Inc.  
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 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.  
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 Mr. George Lyngarkos  
 Mercer Inc.  
 Louise Miller and Sadguna Bhatt  
 Charitable Fund  
 Gillian and Sylvester Miniter  
 Monsen Partners LLC  
 Mr. & Mrs. Douglas Morgan

Myers Family Charitable Fund with the  
 American Endowment Foundation  
 Orscheln Industries Foundation, Inc.  
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 Mr. & Mrs. Edward Quinn  
 Stephanie and Jack Seibald  
 Ms. Gerda Spears  
 Mr. and Mrs. Mackenzie de B. Strathy  
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 Mr. Stuart Waldman  
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 Josh and Judy Weston  
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 The Nicholas and Marguerite White  
 Legacy Fund  
 Mrs. Joan C. Zlotnick

**1,000–2,499**

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 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

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 Brninski  
 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 -  
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AFTD CEO Susan L-J Dickinson, Emily Ingalls, AFTD donor and volunteer Donald Newhouse,  
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*Ms. Lynn A. Surprenant*  
 Ruth and Andrew Suzman  
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Mr. and Mrs. Ravi Trehran  
Mr. Rick Trombley  
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Department of Neurology  
Ms. Diane S. Urch  
Ms. Karen L. Wakefield  
Susan Waterfall  
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Dr. John Whitmarsh  
Willard City Schools  
Kenneth Wong

## Sustainers of Hope

We are grateful to our recurring donors, who have generously committed to donate to AFTD on a monthly or annual basis to sustain our work throughout the year.

Mr. Brad Adams\*  
Ms. Jennifer Allen  
Ms. Elizabeth Alvarado  
Ms. Patti Bohr  
Mr. Alejandro Bolivar-Cervoni  
Ms. Teri Bond  
Dr. Thomas Brobyn  
Dr. Abraham Bromberg  
Mr. William Bua  
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Mr. Jordan Daniels  
Mr. Matt Davy  
Mrs. Linda Deubert  
Dr. Joanne Douglas  
Mrs. Erica Einfeld  
Mr. Marwan Elrakabawy  
Mr. Dennis Erlick

Mr. Stephen Fenoglio\*  
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Cj Widenhouse  
Ms. Marta Wilde  
Mr. & Mrs. Ryan Windhorst  
Mrs. Cynthia Winters  
Ms. Dorothy Yeh  
Ms. Jody Zorn

\*Denotes \$1,000 or more given through recurring donations in FY2019.

# fundraisers

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*

Kathryn Brucato  
*Brigantine Triathlon*

Greg Dickinson  
*Charity Bar Crawl*

Berg Larsen Group of Coldwell Banker  
Burnet Listing  
*Fundraiser*

Nicole DeLeve  
*Tyler'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*



**Food for Thought**

Steven Bellwoar  
Colleen Franzreb  
Terry Pontious, Linda  
Michalakes, Jim  
Cermak & Michelle  
Kelly  
Terry Walter  
Sarah DeLuca  
Natalie & Paul  
DeYoung Ahotaeiloa  
Pang Family  
Bonnie Shepherd  
Nanci & Emily  
Anderson  
Ryan Windhorst  
Sharon DeFelices  
Karine Adalian  
Shana Nissen &  
Dionne Coston  
Cindy Odell  
Kayla Boehmer  
Susan Butterfield,  
Joanne Linerud &  
Karen Bainbridge  
Eliana Fischel

### **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  
Stacey Travis-Treacy  
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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



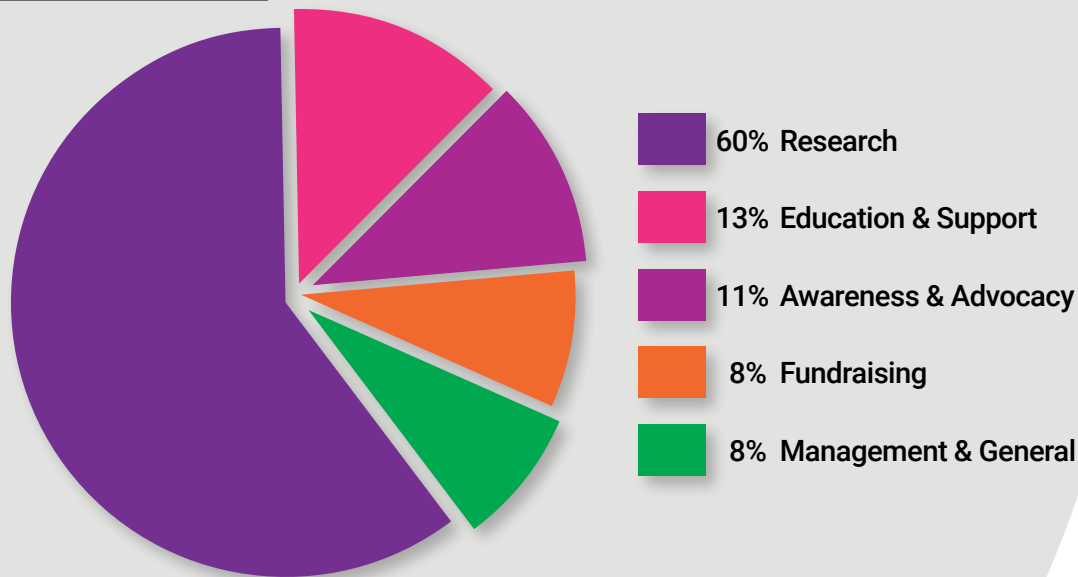
# financial reports *fiscal year ending 6/30/19*

## Statement of Activities

### Revenue and Support

Contributions	\$ 7,194,459
Investment and Other Income	\$ 463,415
Special Event Revenue (Hope Rising), Net	\$ 1,729,348
<b>Total Revenue</b>	<b>\$ 9,387,222</b>
<b>Total Expenses</b>	<b>\$ 7,063,264</b>
<b>Change in Net Assets</b>	<b>\$ 2,323,958</b>

### Expenses



## Statement of Financial Position

### Assets

Cash & Cash Equivalents	\$ 7,029,660
Contributions Receivable	\$ 10,012,880
Investments	\$ 3,966,729
Other Assets	\$ 147,104
<b>Total Assets</b>	<b>\$ 21,156,373</b>

### Liabilities and Net Assets

#### Liabilities

Accounts Payable & Accrued Expenses	\$ 130,678
Deferred Revenue	\$ 35,000
Research Grants Payable	\$ 1,867,789
<b>Total Liabilities</b>	<b>\$ 2,033,467</b>

#### Net Assets

<i>Net Assets Without Donor Restriction</i>	
Undesignated	\$ 3,895,429
Board Designated	\$ 3,940,589
<i>Net Assets With Donor Restriction</i>	<i>\$ 11,286,888</i>
<b>Total Net Assets</b>	<b>\$ 19,122,906</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 21,156,373</b>

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



2700 Horizon Drive, Suite 120, King of Prussia, PA 19406

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# outlook



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.

A handwritten signature in black ink, reading "Susan L-J Dickinson". The signature is fluid and cursive, with a long horizontal line extending from the end.

Susan L-J Dickinson, MS  
Chief Executive Officer



# AFTD leadership

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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.



The Association for  
Frontotemporal Degeneration  
FIND HELP • SHARE HOPE

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King of Prussia, PA 19406

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