

Building a Future **Free of FTD**



July 2019–June 2020

2020 Annual Report

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Dear Friends,

I hope my letter finds you reading this from a place of safety and well-being. I know that for so many of you, this pandemic has compounded an already challenging FTD journey. AFTD is here to help – and we dedicate ourselves every day to providing the latest resources, information, and support to help with growing day-to-day challenges. Whatever your situation today, please know that you are not alone.

What unites us today is a fierce determination to make things better for the next family. Most importantly, what unites us today is a sense of hope. That spirit guided Helen-Ann Comstock when she and like-minded volunteers founded AFTD in 2002, and it guides every aspect of our work today. With support from our donors, AFTD is transforming hope into action.

With your support, AFTD provides help for the journey. Last year, the AFTD HelpLine responded to a record number of 2,546 calls and emails, and more than 493,000 people found information and targeted resources through our theaftd.org website. A total of 105 AFTD-affiliated volunteers now lead support groups across the country, with an additional seven offering phone support groups. And while it wasn't possible to convene our Education Conference in person in spring 2020, a powerful online webinar series drew more than 630 people

to learn vital information, gain important resources and hear new perspectives on the FTD journey, from expert clinicians and people and families affected.

With your support, AFTD is accelerating research. Through partnerships with the Alzheimer's Drug Discovery Foundation and the Diagnostics Accelerator, we are funding leading-edge research targeting biomarker development and promising approaches to therapeutics. Notably, evidence of a genetic overlap between FTD and ALS has provided a unique opportunity to advance hope for families that carry the *C9orf72* mutation. A new partnership with Target ALS has resulted in funding for six research teams that will work to develop and validate biomarkers, which are critical to diagnosis and monitoring disease progression, as well as for developing potential treatments for both FTD and ALS.

With your support and our engagement, FTD is becoming more recognized by both health professionals and families around the world, thanks in large part to the hundreds of AFTD volunteers, family members, care partners and friends who are speaking out about this disease to raise awareness. Local media channels are highlighting the journeys of persons diagnosed and caregivers. And 575 volunteer-led AFTD grassroots events last



year brought new attention to the needs of all impacted by FTD, while raising vital funds to drive AFTD's mission.

None of us expected this road to be easy, and few could have anticipated the impact 2020 would have for so many of us. But as I consider the years ahead, the resilience and courage you've all shown by being part of this mission gives me a profound sense of hope – that together, we will build a future free of FTD.

Sincerely,

David Pfeifer
AFTD Board Chair

awareness

Raising awareness is fundamental to improving the lives of people living with FTD today, as well as advancing research towards a cure tomorrow. The strong foundation of FTD awareness that we are building will carry us to a future when FTD is known, understood and effectively diagnosed.

During the 2019 **World FTD Awareness Week**, AFTD joined its partners in the World FTD United coalition to invite people to share their FTD journeys through an interactive world map, hosted at theaftd.org. In just one week, 228 people from 231 cities throughout 21 countries participated, spurring greater awareness and highlighting the need for improved resources in communities across the world.

Last fall, the **New York Times** featured three AFTD awareness ads, illustrating the devastating effects of an FTD diagnosis. With help from AFTD volunteer Jody Zorn, we turned a national spotlight on the impact of FTD and pointed millions of readers to the help and support our organization offers for families affected.

Increasingly, mainstream media outlets are sharing personal journeys about living with FTD. The story of Lee Holloway – who is living with bvFTD and whose wife Kristin is an AFTD Board member – was featured in the May 2020 issue of **WIRED**. The in-depth article highlighted the many complex challenges that evolve as this disease progresses, and the intensely emotional journey for many families.

In January, AFTD Board member Jary Larsen, PhD, spoke to the **Boston Globe** about his brother's bvFTD diagnosis in 2006. In the subsequent article, Dr. Larsen strongly advocates for families to participate in research, which he believes is crucial to advancing better diagnoses and potential treatments.



Jary Larsen, PhD, of AFTD's Board, shared the story of his brother's FTD diagnosis with the Boston Globe.



Dan Keuning helped to raise FTD awareness by speaking frankly with his local NBC affiliate about his diagnosis.

Local news stations across the country featured thoughtful interviews with caregivers and persons diagnosed with FTD, bringing crucial attention to the need for improved diagnosis and support. Dan Keuning, who was diagnosed with bvFTD in 2018, shared his personal journey



Dementia steals lives too soon.

And it can strike sooner than you think. The most common dementia under 60 is FTD. Today, there's no way to prevent this cruel disease – no cure, and no way to slow its progression. AFTD works every day to realize a world with compassionate care, effective support, and a future free of FTD. Our research can bring new hope for families facing dementia, ALS, or any other neurodegenerative disease.

If you have questions regarding young-onset dementia, or if you need support, we have information and resources that can help:
theaftd.org/NYT



Models are for illustrative purposes only. If you have any questions about AFTD and its work to address FTD, please call (866) 507-7222 or email info@theaftd.org.

with an NBC affiliate in Denver. Additionally, AFTD Ambassador Deb Scharper shared her experiences as an FTD care partner with a CBS affiliate in Iowa. These and other interviews are helping to raise crucial awareness about FTD on the local level.

FTD awareness ads, created by AFTD in collaboration with volunteer Jody Zorn, that appeared in the New York Times in fall 2019.



In a few years, she'll be helping mom tie hers.

No one dreams of dementia. No one plans for it young.

FTD – the most common dementia under 60 – turns children into caregivers. This cruel disease steals away precious time we thought we had with those we love. AFTD works every day to change that, and our research can bring new hope for any family facing dementia, ALS, or any other neurodegenerative disease.

If you have questions regarding young-onset dementia, or if you need support, we have information and resources that can help:
www.whatisFTD.info



Models are for illustrative purposes only. If you have any questions about AFTD and its work to address FTD, please call (866) 507-7222 or email info@theaftd.org.



October 20, 2012.
They wrote their own vows.

Today, she fights to understand them.

Dementia steals lives too soon.

We all hope for love to endure in sickness and in health. Frontotemporal degeneration (FTD) devastates lives and steals the future we dream of at moments like these. FTD can challenge our ability to speak or process language, and it can bring other progressive changes in behavior, personality, and movement. AFTD works every day to change that. Our research can bring new hope for families facing dementia, ALS, or any other neurodegenerative disease.



If you have questions regarding young-onset dementia, or if you need support, we have information and resources that can help:
theaftd.org/NYT



The Association for Frontotemporal Degeneration
FIND HELP. SHARE HOPE

Models are for illustrative purposes only. If you have any questions about AFTD and its work to address FTD, please call (866) 507-7222 or email info@theaftd.org.

“I hope that by advocating and raising awareness I can be a part of normalizing living with dementia for everyone who is affected,” says Aisha Adkins, whose mom was diagnosed with FTD in 2013. Aisha is committed to increasing the public’s understanding about FTD, and she hopes to build a future with more support for those diagnosed and their care partners, particularly young adults such as herself. “AFTD’s network of support has been so important – being able to connect with others who understand the nuances of FTD is a great asset as a young caregiver,” she adds.



support



This year saw AFTD's work to provide information, resources and support become even more essential for the families we serve. In March, AFTD added a "COVID-19 and FTD" section to our website. Written by FTD experts and AFTD staff, this robust collection of strategies and practical advice has helped our community adapt to our changing world.

The [AFTD HelpLine](#) is often the first point of contact for people in their FTD journeys. Throughout the year, AFTD staff responded to 2,546 emails and phone calls with guidance, information, and resources tailored to the needs of people facing FTD. AFTD's website drew more than 493,000 visitors, seeking the latest news, resources and support. And our monthly e-newsletter [Help & Hope](#) highlighted FTD news, provided updates about FTD research and AFTD events, and shared advice from medical experts for persons diagnosed and care partners.

In March we published [Walking with Grief: Loss and the FTD Journey](#), a 48-page "roadmap" designed to help families navigate the grief that can accompany every aspect of life with FTD. *Walking with Grief* draws from interviews and discussions with dozens of people with FTD, care partners and family members.



Last year, AFTD awarded 252 [Comstock Grants](#) to assist with the complex needs of people in our community. Through the Respite Grant, care partners can schedule time and services that are beneficial to their well-being, while the Travel Grants help subsidize the costs of traveling to FTD-related conferences. The AFTD Quality of Life grants provide those living with FTD assistance to purchase equipment, support or access to services.

Finding FTD support locally is easier than ever through AFTD's website. People seeking help can now search within their state for support groups, medical centers, useful resources, and ways to get involved. And our network of AFTD-affiliated support group volunteers continues to grow. There are now 105 volunteers leading groups safely online and in-person in communities across the country.

Finding Support: FY 2019 to FY 2020

U.S. States with
Support
Groups

Led by AFTD-
Affiliated Facilitators



↑21%

Members of
AFTD's
Facebook Group
6,300 total



↑18% Members of
AFTD's Facebook
Group for Young Adults



Website
visitors

↑56%
493,790
total

Grief changes you – it's there from day one of this journey," says Elaine Rose,

whose husband was diagnosed with FTD and passed away in 2012. As a support group volunteer and contributor to AFTD's *Walking with Grief*, published in March, Elaine is committed to helping others navigate the profound changes that come with an FTD diagnosis. Elaine found that listening to others' stories while helping to write the booklet was its own kind of therapy: "Working with AFTD and hearing others share their journeys gave me permission to grieve the changes in myself and the changes in relationships around me."

research

Advancing vital research to better understand the biological basis and progression of FTD has always been central to AFTD's mission. With the support of our generous donors, passionate advocates, and committed Board, we are advancing the science targeting FTD.

A new and dynamic collaboration between **AFTD and Target ALS** recently invested \$5 million to fund six research partnerships, bringing together researchers from the biotechnology-pharmaceutical industry and academia. Now that we know both FTD and ALS can be caused by a shared mutation of the *C9orf72* gene, this unique partnership supports groundbreaking research to identify biomarkers and potential therapeutic targets, develop compounds for clinical trials, and determine specific technologies that can better detect disease progression and the efficacy of therapeutic interventions for these related conditions.

Since 2005, AFTD has supported early-career investigators through our annual **Pilot Grants**, which provide funding for innovative studies in the field of FTD research. These investigators, in the early stages of establishing an independent research program, are given the opportunity to build a strong foundation on which to continue their work further into their careers. Additionally,

the **AFTD Postdoctoral Fellowship** program is essential to enriching the field of FTD research by supporting the next generation of talented and ambitious investigators studying neurodegenerative diseases.

TreatFTD, a \$10 million grant-making initiative between AFTD and the Alzheimer's Drug Discovery Foundation (ADDF), is designed to bring both novel and repurposed treatments into clinical testing for FTD and related disorders. Two new studies were funded in December 2019. One is testing the safety and efficacy of a pharmaceutical approved to treat Parkinson's disease, for people with bvFTD. The second study is testing a non-invasive brain stimulation approach called transcranial Alternating Current Stimulation (tACS), to

determine whether it can improve behavior and brain activity for people with FTD.

In November, AFTD and ADDF announced a major investment of \$1.2 million to the Bluefield Project to Cure FTD through the **Diagnostics Accelerator** program, which aims to fast track the development of diagnostic tests and novel biomarkers for early, effective detection of distinct but related dementias.

Launched in 2016, the **FTD Biomarkers Initiative** is a multi-year initiative designed to spur biomarker discovery and validation. In the second round of awards, AFTD funded a three-year, \$1.1 million study investigating the role of neuroinflammation as it relates to neurodegenerative diseases, potentially leading to the development of a test



Rodney Pearlman, PhD



Oriol Dols Icardo, PhD

that could accurately determine disease progression and help to assess disease-modifying therapies.

Since 2007, the AFTD's **Accelerating Drug Discovery for FTD**, in partnership with ADDF, has been supporting research to discover

and develop pharmaceutical interventions targeted for treating FTD. Our 2019 award recipient, Dieter Edbauer, MD, will study the efficacy of an antibody injection to treat protein aggregation caused by a mutation in the *C9orf72* gene, a leading cause of neurodegeneration.

Awards and grants

Basic Science Pilot Grant – Andrew Arrant, PhD, University of Alabama at Birmingham (US)

Susan Marcus Translational Research Pilot Grant – David Butler, PhD, Neural Stem Cell Institute at the Regenerative Research Foundation (US)

TreatFTD – Giacomo Koch, PhD, Santa Lucia Foundation (Italy); Emiliano Santarnecchi, PhD, Harvard Medical School (US)

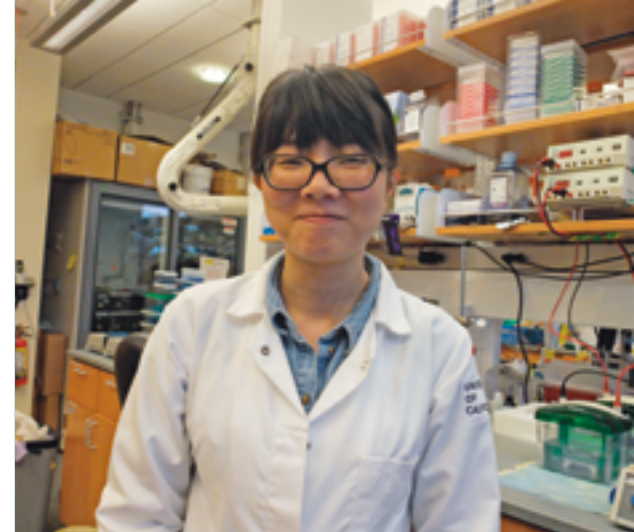
Basic Science Postdoctoral Fellowship – Ming-Yuan Su, PhD, University of California, Berkeley (US)

Clinical Research Postdoctoral Fellowship – Oriol Dols Icardo, PhD, Institut de Recerca de l'Hospital de la Santa Creu I Sant Pau (Spain)

Accelerating Drug Discovery for FTD – Dieter Edbauer, MD, German Center for Neurodegenerative Diseases (Germany)

Diagnostics Accelerator – Rodney Pearlman, PhD, The Bluefield Project to Cure FTD (US); Judith Steen, PhD, Boston Children's Hospital (US)

FTD Biomarkers Initiative – Tammaryn Lashley, PhD and Kerstin Sander, PhD, University College, London (UK)



The recipient of the 2019–2021 AFTD Postdoctoral Fellowship for Basic Science, Ming-Yuan Su, PhD is examining a C9orf72 protein complex, which is involved in key aspects of cellular functioning, to better understand the ways in which FTD and ALS progress and develop, potentially illuminating the path to future drug development for the treatment of both diseases. Receiving an AFTD fellowship “has been a prestigious opportunity for me,” she said,

and I am very honored that AFTD supports my work and has allowed me and my institution to share our expertise with the people who are affected by FTD and the whole scientific community.”



Judith Steen, PhD

education and advocacy

FTD education is vital to ensuring that persons diagnosed, care partners and families impacted by this disease have better access to support, accurate diagnosis and high-quality care. AFTD works every day to provide reliable information, through print and digital media, to educate the public, healthcare professionals and policymakers.



In response to COVID-19, AFTD moved its 2020 Annual Education Conference online. *The AFTD Education Conference: Webinar Series* was hosted between April 7 and May 7. With the support of generous sponsors and presenters, we featured five webinars delivering content relevant to both FTD and the pandemic.

Over the course of the series, 634 unique viewers tuned in to gain insights on care strategies for persons diagnosed with FTD in a changing world, tips to help manage caregiver stress, the current state of FTD research, practical daily care advice from the perspective of someone diagnosed with FTD, as well as how AFTD is continuing to build a future free of the disease.

During the past year, AFTD published three *Partners in FTD Care* newsletters, aimed at both healthcare professionals and care partners, delivering guidance on such topics as medications and FTD, palliative care options and resistant behaviors in persons diagnosed.

We continue to expand the *AFTD Educational Webinar* series, in which FTD clinicians and researchers offer in-depth insights and expert advice. Last year, webinars addressed the clinical experience of persons with overlapping FTD and ALS symptoms, as well as the distinct symptoms of corticobasal syndrome and corticobasal degeneration.

Through our *education outreach initiative*, AFTD staff works closely with volunteers to initiate conversations about FTD with healthcare professionals, using materials and resources developed by staff in partnership with FTD experts. Opening this dialogue is imperative to creating and improving a network of care and support for families affected by FTD in communities throughout the United States.





Prior to the pandemic, our volunteers proudly represented AFTD at public events throughout the country, bringing FTD education with them wherever they went!



Sisters and AFTD Ambassadors Joanne Linerud and Susan Meagher began volunteering with AFTD after their mother, who was diagnosed with FTD, passed away in 2016. They are similarly passionate about creating connections with and supporting families who are affected by FTD, and to increasing awareness about the unique challenges it presents. “I really enjoy building a network of resources and support in my area so that no one is left to do this on their own,” Joanne said. As Ambassadors, both sisters look forward to developing contacts with healthcare professionals, service providers, researchers and care partners to ensure everyone knows about this disease and the array of resources AFTD provides.

“I want to pay it forward for others who will need help and I want to be a part of what drives the whole mission forward,” Susan said.

volunteers and the AFTD-Team

Nicole DeLeve of Kansas representing AFTD



The momentum AFTD has made toward building a future free of FTD is due in large part to the passion, resilience and determination of our volunteers. Whether engaging with healthcare professionals to advance knowledge of FTD, leading support groups to help guide others on this journey, hosting informational meetings within their communities to raise awareness, or fundraising in support of AFTD's work, volunteers are at the core of what we do every day. Despite the extraordinary challenges brought about by the COVID-19 pandemic, more than 310 volunteers drove our mission forward over the past year, maintaining vital connections and providing mutual support during a time of increased isolation.

Launched in November 2019, our new **AFTD Ambassador program** will further expand FTD awareness through targeted outreach and networking with local health providers, businesses and community members, engaging them as stakeholders in improving resources, support and care. To date, we have trained 13 volunteers to be Ambassadors, and they work closely with AFTD Volunteer Coordinators Jeni Cardosi and Annamarie Given.

In fall 2019, our flagship **Food for Thought** campaign brought together care partners, family members, friends and neighbors over good food and drink to increase FTD recognition and raise vital funding in support of AFTD's mission. Last year, 52 hosts held 47 events in 25 states, raising nearly \$161,000!

Timed to coincide with Valentine's Day, the **With Love** campaign encourages people affected by FTD to share their stories of love and memories with friends and family, far and wide. The campaign continues to grow – in February 2020, with the generous support of The Mike Walter Catalyst Fund and The Rainwater Charitable Foundation, a record 41 people raised \$74,337 in honor of their cherished loved ones.



Volunteer Amy Shillady made and sold candles to support AFTD's mission!

Top, volunteers from North Carolina join AFTD staff to represent our shared mission at a conference.

For many AFTD-Team members, running or walking on AFTD's behalf is an expression of their strength, hope and determination. Throughout 2019, 240 runners and walkers raised \$81,295, proudly sharing AFTD's mission with thousands of their fellow competitors.

When COVID caused races to be canceled around the country, AFTD quickly found a unique outlet to continue bringing volunteers together. In April 2020, we partnered with the mobile app **Charity Miles** and encouraged people to walk, bike or run in support of AFTD. In our first three months on the app, 633 participants joined and began tallying up the miles and donations, reaching an astonishing 73,711 miles; and with the generous sponsorship of The Mike Walter Catalyst Fund, they raised \$48,467.

No matter the occasion or scale, every opportunity taken by our driven volunteers increases the public's understanding of FTD and the effects this disease has on so many families. We could not do it without you!

Pictured: Daniel Hare, middle left; Maggie Sepesy, middle right; Norma Morrison, bottom.

Thank you to all of the AFTD-Team members who walked, ran or biked to support AFTD's mission through the Charity Miles app!



Before signing up for Cincinnati's Flying Pig Marathon, Abrar Tanveer, above, whose father had FTD, would never have considered himself a runner, let alone a marathoner. But he committed himself to the race, both as a personal goal and to raise awareness and support for AFTD's mission. "AFTD understands this disease doesn't just affect one person but affects the entire family – it's a resource for everyone," Abrar said. John Kammerer, below,



decided to run the same race to honor his father, who is currently living with FTD. Like Abrar, he fundraised on behalf of AFTD, and both young men were surprised to learn that they had attended the same high school. "It's been great to build a friendship with Abrar and share something positive with him while going through this," John said. While they were unable to compete in this year's race, both have continued training and look forward to someday seeing each other at the finish line.

named funds and donors



AFTD CEO Susan L-J Dickinson speaks at AFTD's 2019 Hope Rising Benefit in New York City.

AFTD Named Funds honor or memorialize a loved one. Established with a minimum donation of \$25,000, AFTD Named Funds are among AFTD's most generous gifts. Named Fund donations advance the science of FTD and improve 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

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 Catalyst Fund

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

Bank of America Corporation

Christie's

Discovery Inc.

Hughes Hubbard & Reed LLP

Judy & Leonard Lauder

Paul, Weiss, Rifkind, Wharton & Garrison LLP

William Randolph Hearst Foundation

50,000-99,999

Charter Communications

Citi

The Farley Chang Gang

Patricia M. & Victor F. Ganzi

George L. Ohrstrom, Jr. Foundation

Mr. & Mrs. Gary Johnson

Community Foundation, Rochester Area

Community Foundation

Stavros Niarchos Foundation

Mrs. Beth Walter

20,000-49,999

Mr. & Mrs. Peter Arnow

Colonial Electric Supply

Cravath, Swaine & Moore LLP

The Durst Organization

20,000-49,000, cont'd.

Goldman Sachs Private Wealth
Management - Martin Packouz/James
Herring
Mrs. Lindy Kowsky
Mrs. Susan Laden
Lambert Living Trust
Carol Sutton Lewis &
William M. Lewis, Jr.
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The Edward John & Patricia Rosenwald
Foundation
Shearman & Sterling LLP
Mrs. Bonnie Shepherd
Mr. George J. Sidoris
The Connecticut Frontotemporal
Dementia Foundation, Inc.
The Rainwater Charitable Foundation

10,000-19,999

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Credit Suisse Securities (USA) LLC
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Florence V. Burden Foundation at the
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& Family Member, Frederick Childs & his
daughter, Elizabeth Childs
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Liberty Broadband
Allison F. & Joseph J. Magliocco
Marsh
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Supranuclear Palsy Research of
The Dayton Foundation
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Mercer
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Mr. Joseph Pizzurro
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Mr. & Mrs. Timothy Romani & Family
Spencer Stuart
Katherine Farley & Jerry Speyer
Barbaralee Diamonstein-Spielvogel &
Carl Spielvogel
Emma & Mackenzie Strathy
Sullivan & Cromwell LLP

Sydney Licht & Tom Summer
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Lulu & Anthony Wang
Allyson Tang & Thomas Widmann
Willkie Farr & Gallagher LLP

5,000-9,999

AbbVie
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Loretta & Walter Anderson
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Anonymous
Barr Family Giving Fund
Mary & Dick Benioff
Brazill Brothers & Associates, Inc.
Cleary Gottlieb Steen & Hamilton LLP
CMS Cameron McKenna Nabarro
Olswang LLP
Miss Diane Deterline
Patricia Ralph Fowler &
Gordon B. Fowler Charitable Trust
Mr. Michael Fricklas
Goldman Sachs & Co.
Allen & Lola Goldring Foundation
Mr. Robert Griffith
Caroline & Tim Harrison
The Robert M. Hatfield Foundation, Inc.
HCR ManorCare
Mrs. Susanne Louise Hedaya
Houlihan Lokey, Inc.
Minalie Chen & Jackson Hsieh
Illinois Tool Works Inc.
Mr. Michael Irvine
Mr. Kevin Jameson
Johnson & Johnson Matching
Gifts Program
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Passage Bio Inc.
Patterson Belknap Webb & Tyler LLP
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Mr. & Mrs. Larry Rodger
Mr. Scott Rose
Joanna S. & Daniel Rose
Michelle Ores & Charles Schorin
Shell Oil Company Foundation
Mr. Arthur J. Sommers
Michael H.B. Stowell &
FTD Researchers
The Bluefield Project to Cure
Frontotemporal Dementia
The Newman Foundation, Inc.
The Sister Project, Inc.
Thrivent Financial
Alice & Tom Tisch
Richard L. & Lois S. Werner
Family Foundation
Ms. Betty Woods

2,500-4,999

Mr. Joseph W. Bellwoar
Mr. Jeffrey Bleiman
Mr. Michael Burns
Mr. Matt Camp
Mrs. Patricia Carey
Mr. & Mrs. Peter Carey
Carol & Richard Chadakoff
Chicago United Industries
Mr. Michael Cooney
Credit Suisse Americas Foundation
CurePSP
Alec & Libby Dafferner
Mr. Stanley DeRocher
Ms. Alice B. Diamond

2,500-4,999, continued

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 Diversified
 Bruce Dixon
 Christine Farin/Deloitte
 Fidelity Investments
 Fiori
 Gary's FUB Team
 Mr. Jeffrey Ryan Gilmore
 Grossnickle Eye Center
 Dr. Don Hendricks
 Mr. & Mrs. Terry Hergenrader
 Mr. & Mrs. David A. Hogan
 Lynn & Ralph Huber
 Mr. David A. Hutchison
 Illuminations, Inc.
 Mr. Emre Kiciman
 Elise & Oren Klein
 Kunz-Powell & Associates, Inc.
 Meena Lakdawala-Flynn,
 Goldman Sachs Gives
 LCN Capital Partners L.P.
 Lighting Solutions
 Lowenstein Sandler LLP
 Mr. Peter Lyon, Goldman Sachs Gives
 Dr. & Mrs. Joseph Mele
 Mr. Bernhard Metzger
 Dr. Koren Miller
 Gillian & Sylvester Miniter
 Ms. Ellyne L. Myers
 NADA Foundation
 Nike
 Mr. Timothy Oberweger
 Sabah Oney
 Mr. Joe W. Pang
 Penn Lighting Associates
 Mr. David C. Pfeifer
 Pfizer
 Rose Fogarty Benefit

Mr. Matthew Rosen
 Mr. Mark Schroyer
 Mrs. Ruth Scott
 Stephanie & Jack Seibald
 Mr. & Mrs. Kevin Sellitti
 Ms. Catherine Sharpsteen
 Mrs. Tam Smith
 Mrs. Denise Strohm
 Mr. Mitchell Sukonick
 Trust of Donna Taylor
 The Standard
 Seran & Ravi Trehan
 Ms. Lia Van Otterloo
 Mr. & Mrs. John C. Weicher
 Estate/Trust of Stanford L. Weiss
 The Nicholas & Marguerite White
 Legacy Fund

1,000-2,499

Mr. Brad Adams
 Alliance Data
 Alzheimer's Drug Discovery Foundation
 AmazonSmile Foundation
 Anonymous
 Ms. Mary Auth
 Mrs. Connie C. Babcock
 Mr. & Mrs. Ryan Baldino
 Ms. Elizabeth "Betsy" Bartosiak
 Mr. & Mrs. Lee M. Bass
 Mr. Joseph A. Becker
 Mr. John Bellando
 Ms. Joan L. Beranbaum
 Mrs. Miriam Berg
 Ms. Tamara Blankestijn
 The Bretscher Family Foundation
 Mr. Paul Brickmeier
 Broadmead Inc.
 Ms. June I. Brush
 Mr. Marc Bruyns
 Ms. Whitney Burke
 Mr. Donald B. Cameron

Mr. & Mrs. Robert Cannon
 Rev. James Cardosi
 The Tim & Barb Cerny Foundation
 Cherokee Rental, Inc
 Mr. James Cobb
 Ms. Lori Cohen
 Ms. Kristina Colby
 Colonial Hill Foundation
 Mrs. Helen-Ann Comstock
 Cornhusker Auto Wash, Inc.
 Ms. Elizabeth Crumpacker
 CustomInk LLC
 Mr. & Mrs. Joseph F. Daniels
 Mr. Kevin DeAcosta
 Mr. Joseph Debella
 Mr. & Mrs. Joe Del Guercio
 Mrs. Linda Deubert
 Dr. Aneesha Dhargalkar
 Mr. John Dickson
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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.

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fundraisers

Over the past year, the AFTD-Team flexed their creative muscles and displayed their passion and energy by hosting an extraordinary 623 grassroots events and Facebook fundraisers. Together, they shared information, educated the public, and raised more than \$789,000 in support of AFTD's mission. (All events listed here brought in \$1,000 or more, with the highest-raising events in each category listed first.) AFTD thanks the incredible AFTD-Team for their efforts.

Independent Events

Brian Rose, Danny Hedaya, Michael Stowell and Kathy Mele
1st Annual Driving Hope Golf Tournament

George Sidoris and Christine Sidoris
13th Annual George F. Sidoris Memorial Golf Outing

Paul Lester
12th Annual Letters for Arnette

Rob Radtke
Google Giving Week

Lauren Massarella and Michelle Anderson
Hallowpalooza



Abrar Tanveer
Flying Pig Marathon

Jason Strohm, Brian Strohm
and Tracy Ortiz

Run Like Mike

Michael Stowell
2nd Annual Buffalo Trace Charity Open

Deb Scharper
*3rd Annual Crusade for a
Cure Golf Tournament*

Jacquelyn Breneman
IMO Tom Breneman

Brian Delaney
1st Annual Mary Jo Opening

Dominique Fabich
and Amanda Dawson
Local Heroes

John Kammerer
Flying Pig Marathon

Matthew Hatfield
*Robert M. Hatfield 9th Annual Quest
for the Cure Golf Tournament*

Cortney Walker Rohr
The Walker Family Golf Tournament

Brian Fox
Cornhusker Auto Wash

Becky Tinsley
IMO Bryan Tinsley

Lauren Rowans
IMO Timmy Rowans

Team AI
*2020 Disney Princess
Half Marathon*

Moretti and Marcy Families
4th Annual CWM Golf Outing

Paul Petras
Stone Steps 50K Trail Run

Joel McNulty
9th Annual AI McNulty Benefit

Cindy Odell
Custom Ink Hats

Brian Fox
Softball Fundraiser

Brian Strohm
Rock the Parkway

Suzanne and Calvin King
*4th Annual "Tami Sue"
Golf Outing & Party*

Amy Shillady
Soy Candles

Nicole DeLeve
Tyler's Troopers



Food for Thought

Steve Bellwoar

Lisa Nolte

Terry Walter and Beth
Walter

Elisabeth Lynch and
Renee Faller

Emily Anderson and
Nanci Anderson

The Pang Family

Taylor Long & Steven
Long

Ryan Windhorst

Karen Hosley

Bonnie Shepherd and
Catherine Sharpsteen

Nicole DeLeve

Elizabeth Soriero

Diane Cole



With Love

Faith Ott

Bonnie Shepherd

Scott Rose

Colleen Quinn

Kali Tormoen

Maria Kent Beers and
Michelle Fiori

Victoria Tinsley

Jillian Condran

Kimberly Sullivan
Chu

Natalie White

Gina Alderucci

Susan Illis

Kristin Pursley

Melissa Fisher

Via Facebook

Tanya Steel

Vicki Axe

Lisa Anne

Bob Beede

Lisa Shochat Ades

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Dan Keuning

Tommy Tilert

Jeff Kaplan

Frank Ashcraft

David Rosenstein

Deborah Kemp

Kacy Kunesh

Greg Rotatori

James Geremia

Brooke Sepelak

Gerri Borenstein

John Perrone

Amy Johnson

Lauren Jonaitis



Race Season

Team Jack Attack

Tamara Blankestijn

Josef Pohl

Anne Collins
Hodsdon

Martha, Bo and
Alison

Popkin Shenian

Joe Fischel

Brian Strohm

Barbara Todd

Team Mamma Fish

Patti Del Guercio

Sabrina Solorzano

Laura Kupsch

Morganne Hodsdon

Fenoglio Family
Racers

Tara Huzinec

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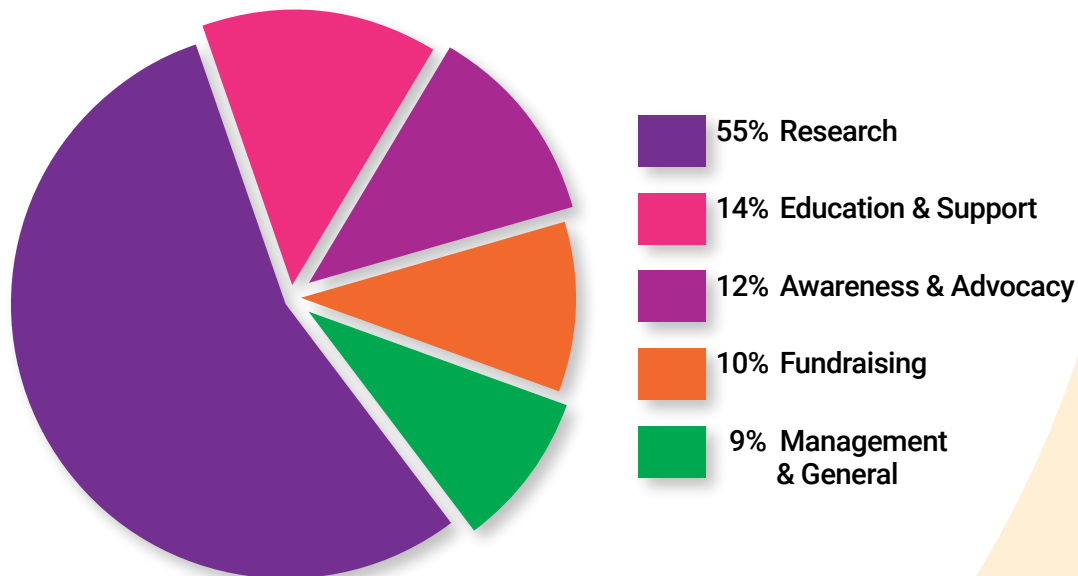
financial reports *fiscal year ending 6/30/20*

Statement of Activities

Revenue and Support

Contributions	\$ 7,481,677
Special Events	\$ 1,916,356
Investment and Other Income	\$ 263,201
Total Revenue	\$ 9,661,234
Total Expenses	\$ 7,857,293
Change in Net Assets	\$ 1,803,941

Expenses



Statement of Financial Position

Assets

Cash & Cash Equivalents	\$ 7,698,944
Contributions Receivable	\$ 10,894,890
Investments	\$ 5,183,886
Other Assets	\$ 110,863
Total Assets	\$ 23,888,583

Liabilities and Net Assets

Liabilities

Accounts Payable & Accrued Expenses	\$ 189,482
Deferred Revenue	\$ 640,000
Research Grants Payable	\$ 1,831,754
Payroll Protection Program Loan	\$ 300,500
Total Liabilities	\$ 2,961,736

Net Assets

Net Assets without Donor Restrictions	
Undesignated	\$ 5,284,684
Board Designated	\$ 4,959,454
Net Assets with Donor restrictions	\$ 10,682,709
Total Net Assets	\$ 20,926,847
Total Liabilities and Net Assets	\$ 23,888,583

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



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outlook



Hope starts with AFTD's donors and volunteers, each of you helping to build a future in which FTD is comprehensively understood, accurately diagnosed, and effectively treated. Your commitment provides hope for a world in which this disease is cured – and even prevented. Your dedication brings that reality closer day by day.



In a challenging year for so many, I want to share a message of hope with you. Hope that we can put this pandemic behind us soon. Hope to advance AFTD's mission and realize our vision – to the benefit of so many families. Hope starts with AFTD's donors and volunteers, each of you helping to build a future in which FTD is comprehensively understood, accurately diagnosed, and effectively treated. Your commitment provides hope for a world in which this disease is cured – and even prevented. Your dedication brings that reality closer day by day.

With your help, AFTD has grown to become a global leader in the fight against FTD. Today, more than 105 AFTD volunteers provide vital support groups for other families facing FTD, so that no one faces this journey alone. Together, we raise our voices to advocate for improved resources. Together, AFTD's Ambassadors and hundreds of other care partners, family members and people with FTD drive education and awareness, sharing FTD stories through local and national media outlets to ensure that the most common form of dementia under 60 is more widely known year to year.

Together, we invest in and drive groundbreaking research that could dramatically change the landscape of diagnosis and treatment for FTD. A growing number of innovative biopharmaceutical companies are set to advance clinical trials for FTD therapies— trials that will be driven by the passion of the families who enroll. And our partnerships – with the Alzheimer's Drug Discovery Foundation (ADDF), Target ALS, and ADDF's Diagnostics Accelerator – are funding work that could move the needle for not only FTD, but other forms of dementia and neurodegenerative disease. Researchers and health professionals targeting FTD have adapted to new and difficult working conditions this year with poise, creativity, and determination.

I am proud to share with you that this coming March, AFTD will be hosting a virtual Patient Focused Drug Development meeting with representatives from the FDA. I hope that you'll join us as we bring voices from our community to ensure that the research priorities of all whom we serve inform the FDA's understanding of this disease as it considers approval for potential treatments.

While my message is one of hope, I want to acknowledge the losses experienced by our families this year. There are many for whom the future we seek will arrive too late. AFTD's Board and staff dedicate our work to the memory of those who have been lost, and we carry it forward in honor of the people and families struggling today. Your experience does not go unwitnessed – and your voices and your passion drive our unwavering commitment to realizing a future free of this disease.

With warm wishes for the holidays and the year ahead –

Susan L-J Dickinson, MSGC
AFTD Chief Executive Officer

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AFTD values

Knowledge

Information is the key to unlocking the future we seek.

Collaboration

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

Respect

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

Compassion

We recognize the importance of finding others who understand.

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
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2700 Horizon Drive, Suite 120

King of Prussia, PA 19406

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