

finding our voice

July 2016-June 2017

2017 Annual Report



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

getting heard

*NBC's Today Show ran a
segment that highlighted
the symptoms of FTD.*



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Dear Friends,

As AFTD's Board Chair, it is a profound honor to mark the organization's 15th year. In 2002, AFTD founding Board Member Helen-Ann Comstock and other volunteers established the only national organization dedicated to help and hope for FTD. The theme of this annual report, "Finding our Voice," reflects the countless ways people in our community have raised their voices in response to FTD since then.

This past year, our voices joined to connect and comfort. AFTD volunteers held Meet and Greets and local events from Alaska to Alabama. We have now trained more than 70 AFTD-affiliated support group leaders, who bring FTD-specific assistance to communities across the country. Nearly 2,500 times, members of our community reached out to AFTD's HelpLine for support and resources.

Together, we tell the story of FTD. Media coverage of FTD grew as Terry Jones of Monty Python, former US Congressman Maurice Hinchey and UNC Tar Heels announcer Woody Durham publicized their diagnoses—and became powerful forces for awareness. But you don't have to be well-known to speak up for increased funding, resources and support. AFTD volunteers like Colleen Seymour reached wide audiences through prominent TV appearances. Many more told their stories to press, friends and colleagues.

Some of the most profound voices are those of persons diagnosed. At our annual Education Conference, Sheryl Whitman, who is living with primary progressive aphasia, opened with a poignant reminder that those diagnosed are not alone. Later, patient-caregiver pairs shared stories of how FTD tries our closest relationships—and how working together can sustain those bonds.

With their voices, our donors made it possible for AFTD to invest more—and more widely—in FTD research than in any other year. This year AFTD awarded research grants to investigators in the US, Spain, Italy, Germany and the UK.

In March, AFTD helped to launch the FTD Disorders Registry (ftdregistry.org). Hundreds touched by FTD have already shared their stories through this groundbreaking medium for teaching researchers about the true nature of FTD. Increasingly, the pharmaceutical industry turns to AFTD as a trusted resource to help them better understand the needs of the FTD community.



Our shared progress is a testament to everyone who has made AFTD's mission their own. Only by joining our voices together can we help all who face FTD, and effectively advance hope for a world without this terrible disease.

Sincerely,

A handwritten signature in black ink that reads "Gail Andersen".

Gail Andersen
AFTD Board Chair



*Only by joining our voices together
can we help all who face FTD."*

awareness



Donald Newhouse (right) and Dr. Ted Huey talked about FTD on NBC's Today Show.

Personal stories give a glimpse into the challenges and heartbreak of FTD. Last year, we helped make millions aware of FTD as stories from our community prominently featured in major media.

During [2016 World FTD Awareness Week \(September 25-October 2\)](#), AFTD helped to get voices heard. AFTD volunteer and donor Donald Newhouse and AFTD Medical Advisory Council member Ted Huey, MD, appeared on [NBC's Today Show](#). The segment, "Dementia at Any Age," captured more than 4 million viewers. AFTD's "Hope Rising" event received coverage in the [Huffington Post](#) and other media outlets.

With support from a generous donor and creative work by AFTD volunteer Jody Zorn, new FTD awareness ads ran in the [Sunday New York Times](#). One ad, "Think It's Alzheimer's? Think Again," reached more than 63,000 viewers through Facebook alone. The ads also ran in Westfair Communications publications.

Other stories brought attention to FTD. In June 2017, the family of former New York Congressman Maurice D. Hinchey announced that he has the primary progressive aphasia variant of FTD. Their story was widely covered by media outlets throughout New York state. In February 2017, AFTD volunteer Colleen Seymour shared her family's story with Denver's 9News.

AFTD's website reached more than 287,000 visitors—[up 25% from the previous year](#). Our Twitter feed, @AFTDCure, surpassed 1,000 subscribers. And our public Facebook pages received likes from more than 5,500 followers.

AFTD helped anchor a [World FTD United campaign](#), encouraging people from around the globe to change their social media profile pictures to feature the message, "You're not alone! We're in this together." (Visit the World FTD United Facebook page to find out more about international awareness efforts.)

Finally, Discovery Communications repeatedly aired the FTD awareness Public Service Announcement (PSA) they developed for AFTD, reaching more than 100 million viewers.

SHE LEFT HER SON AT THE MOVIES AND WENT SHOPPING.
SHE TOLD THE CEO "THAT DRESS MAKES YOU LOOK FAT."
HIS MOTHER DIED AND HE HAD NO REACTION.

THINK IT'S ALZHEIMER'S? THINK AGAIN.

SHE STARTED STARING AT ME WITH A BLANK STARE.
SHE RAN AFTER THE DUCKS AT THE PARK. SHE'S 55.
HE GOT LOST COMING HOME FROM WORK.
HE WOULD COMB HIS HAIR WITH A TOOTHBRUSH.

“ *He would repeat over and over,
‘Proud to be your dad.’”*

- Alice Saunders

Alice Saunders' father, Arpy Saunders (bottom right), died of FTD in 2014 at the age of 72. At the end, his vocabulary was reduced to a handful of phrases that he would repeat into his daughter's voicemail for minutes at a time: "Proud to be your dad," and "I love you." After Arpy's death, Alice's boyfriend, Greg Ralich (top, with Alice), surprised her with a recording of these voicemails. Alice shared her story with Boston's WBUR in June, bringing new attention to FTD and the emotional toll it takes on families.



Left: Arpy Saunders with two of his children, Alice and Arpy, on his birthday a few weeks before he died.

Above: Top and left photos courtesy of Robin Lubbock/WBUR. Left: Photo courtesy of Greg Ralich.

support



Members of the FTD community gathered in Baltimore for the 2017 AFTD Education Conference

Anyone who has experienced the FTD journey knows that each day presents a new and unique set of challenges. AFTD knows just how hard life with this disease can be, and offers a range of essential supports that help those affected learn from each other, improve their quality of life, and feel less alone.

AFTD's first point of contact with this community is often our toll-free [Helpline](#). Over the past year, we fielded nearly 2,500 phone calls and emails from people who are in need of frank information and an understanding voice, and who help AFTD ensure that our work is responsive to our community's most urgent needs.

AFTD's network of support groups continues to expand, fostering connections and building relationships in local communities. Last year, a total of 71 [AFTD-affiliated support group facilitators](#) led

groups in 27 states. AFTD ensures that each of these leaders is well-trained and ready to support others facing this disease.

AFTD continues its firm commitment to supporting those affected through our [Comstock Grant](#) program. In the last year, we've issued tens of thousands of dollars in the form of Respite Grants (to give caregivers a day off from their responsibilities) and Travel Grants (which subsidize travel to our annual Education Conference). In all, we awarded 180 of these grants last year.

AFTD furthered its commitment to providing direct support for persons diagnosed through initiatives like our [Zoom support group](#) and our [Think Tank](#). With guidance from these individuals, we designed a Quality of Life Grant for persons diagnosed, to be piloted early in our 2018 fiscal year.



 **↑20%**
Social Media
Connections

↑24%
Website
Visitors



↑22%
Total Number of
Donations

↑37%
Grassroots
Fundraisers



↑237%
Grant Dollars
Awarded

↑30% 
AFTD-Affiliated
Support Groups

AFTD Trending

A snapshot of growth
FY 2017 vs. FY 2016

“

*By speaking on behalf of persons diagnosed,
I try to help others understand the needs of
people living with FTD.”*

- Teresa Webb
AFTD Volunteer

Since being diagnosed with primary progressive aphasia in 2010, Teresa Webb (below) has worked tirelessly to increase the visibility of people diagnosed. She's spoken up for the FTD community in a number of ways: for example, by advising filmmaker Joe Becker for an upcoming short movie on FTD, and by closely collaborating with AFTD's Think Tank to give persons diagnosed a stronger voice in advising AFTD's work. This fall, she will represent the FTD community at the National Research Summit on Dementia Care at the National Institutes of Health in Bethesda, Maryland.



research



High-Impact Pilot Grants



AFTD's support for innovative research and talented investigators has had a remarkable impact over the last decade. For example, AFTD Pilot Grants, awarded annually to early-career scientists, have been the stepping stone to \$7.53 million in follow-on funding and resulted in more than two dozen publications in scientific journals.

With generous support from our donors, AFTD is emerging as a global leader in FTD science, fostering a vibrant international community of researchers working from bench to bedside and at every stage of their careers.

AFTD awarded the first \$2 million of the **FTD Biomarkers Initiative**, funded by the Samuel I. Newhouse Foundation to develop the biological measures that will enable accurate diagnosis and the development of effective therapeutics for FTD. The initiative generated interest from 63 scientific teams in North America, Europe, and Australia; six innovative projects in the United States, the United Kingdom and Germany received awards.

A second new initiative, TreatFTD—made possible by multi-year support from the Samuel I. Newhouse Foundation and the Lauder Family—promotes

innovative clinical trial design and the testing of drugs for FTD. A partnership between AFTD and the Alzheimer's Drug Discovery Foundation (ADDF), **TreatFTD** generated 10 novel ideas from around the world; awards for the most meritorious projects will be announced in fall 2017.

AFTD sponsored the **10th International Conference on FTD**, which drew 750 researchers from around the world to Munich in early September. Featured among the hundreds of presentations were a report from Dr. James Galvin on the forthcoming **FTD economic burden study**, and a poster on AFTD's program for a **network of support groups** across the US. For caregivers, AFTD founder Helen-Ann Comstock led a panel on **FTD care and support needs** around the world.

Christian Haass, PhD



Kathryn Bowles, PhD



Jonathan Rohrer, MD, PhD



“*The Registry gives our whole community a voice in driving important research.*”

- Dianna Wheaton, PhD (right)
Director of the FTD Disorders Registry



Awards, grants and fellowships

AFTD Biomarker Awards

Randall Bateman, MD, Washington University in St. Louis (US); Christian Haass, PhD, Ludwig-Maximilians University and DZNE (Germany); Leonard Petrucelli, PhD, Mayo Clinic Jacksonville (US); Jonathan Rohrer, PhD, University College London (UK); Judith Steen, PhD (two awards), Boston Children's Hospital (US)

The Susan Marcus Memorial Fund Clinical Research Pilot Grant

Paola Caroppo, MD, PhD, the IRCCS Foundation Carlo Besta Neurological Institute (Italy)

2016 Basic Science Pilot Grant

María Llorens-Martín, PhD, the Center for Networked Biomedical Research in Neurodegenerative Diseases (Spain)

Accelerating Drug Discovery in FTD (in partnership with ADDF)

Xinglong Wang, PhD, Case Western Reserve University (US); Justin Ichida, PhD, USC (US)

2017-2018 Postdoctoral Fellowships

Kathryn Bowles, PhD, Icahn School of Medicine at Mount Sinai (US); Joseph-Patrick Clarke, PhD, University of Pittsburgh School of Medicine (US)

The FTD Disorders Registry

With generous support from the Rainwater Charitable Foundation's Tau Consortium program, AFTD and the Bluefield Project to Cure Frontotemporal Dementia launched the FTD Disorders Registry in March 2017. The first online database devoted to compiling self-reported data from people affected by FTD, the Registry enrolled more than 750 people in its first three months.

María Llorens-Martín, PhD



Paola Caroppo, MD, PhD



Randall Bateman, MD



education and advocacy



AFTD Medical Advisory Council member Dr. Bradley F. Boeve of the Mayo Clinic in Rochester, MN

In partnership with world-class scientific researchers and healthcare professionals, AFTD educates our community on the most up-to-date, medically accurate information and care strategies. AFTD also advocates for more research into FTD's causes and more resources to support persons diagnosed and their loved ones.

In October 2016, AFTD launched its [Educational Webinar series](#) with "The Journey to an FTD Diagnosis," led by AFTD Medical Advisory Council member Dr. Bradley Boeve of the Mayo Clinic. Subsequent webinars featured Dr. Katherine Rankin on bvFTD subtypes and Dr. Alvin Holm on FTD management strategies. Our webinars have drawn widespread interest and thousands of views on YouTube.

AFTD's [Partners in FTD Care](#) newsletter continued to give healthcare professionals and families carefully vetted, detailed information on every aspect of caring for someone with FTD. Informed by a panel of experts and rotating guest contributors, recent *Partners* issues have focused on occupational therapy, comfort care and hospice in advanced FTD and ways families can participate in vital FTD research.

The [2017 AFTD Education Conference](#) in Baltimore was our largest ever, drawing 325 attendees from around the country. Highlights included opening remarks by Sheryl Whitman, who is living with FTD, and a panel featuring three patient-caregiver pairs, moderated by Lisa Gwyther of the Duke Family Support Program. Dr. Halima Amjad of Johns Hopkins delivered the keynote, sharing a powerful

Brandt Henderson (left) and his wife and caregiver, Marie, spoke at the 2017 AFTD Education Conference. "Although the experience of each person with FTD is unique, there are common threads," said Brandt. "Marie and I were pleased to share how we navigate our lives as they are being impacted by the insidious effects of FTD."

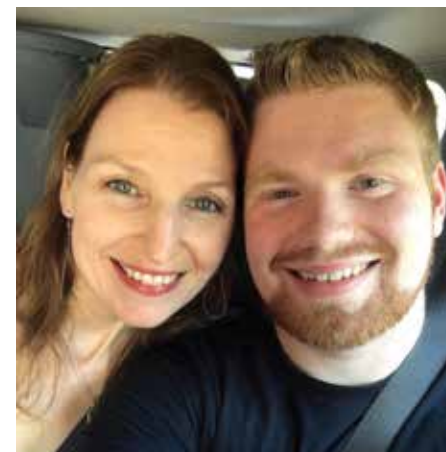


story of her father's FTD diagnosis and the impact FTD has made on her own medical career.

AFTD continues to make our presence felt in Washington, DC. These efforts have paid off: In recent years, the **National Institutes of Health nearly doubled its FTD funding**, helping to support the ARTFL and LEFFTDS initiatives and a brand new FTD Gene Sequencing Initiative. AFTD Program Manager Matt Sharp brings an FTD perspective to every quarterly meeting of the National Alzheimer's Project Act (NAPA) Council. In May, Sharp and AFTD Board member Stephen Fenoglio also visited several Congressional offices to advocate for a greater federal focus on FTD.

"I want to thank AFTD for the best Webinar I have attended. I am feeling more encouraged than ever. I will be recommending it to other caregivers and going back to this one again and again."

- FTD Caregiver



Justin and his mother, Kathy

"Taking action isn't hard. You don't need experience. You just need to be driven."

*- Justin Peavey
FTD Advocate*

*Dr. Halima Amjad, Keynote Speaker
2017 AFTD Education Conference*



An FTD-causing genetic mutation runs in Justin Peavey's family. His grandmother, great-aunt and uncle all succumbed to FTD. When Justin was in middle school, his mother learned she inherited the mutation, and has a 95 percent chance of developing the disease. Justin immediately took action. His efforts to advocate for those affected and to raise funds for AFTD culminated in a speech at the Massachusetts State House in February 2017 about the need for more FTD research.

volunteers and the AFTD-Team

AFTD is headquartered just outside of Philadelphia. But our engaged, committed and ever-expanding network of volunteers makes this organization truly national in scope. Whether raising money for FTD research, visiting residential care facilities to help spread FTD awareness, or leading local support groups, our invaluable volunteers make their voices heard.



Custom bracelets made by Wendy Miller-Anello for her With Love campaign

More than 225 volunteers from across the country represented AFTD throughout the year. AFTD volunteers set up awareness tables at more than two dozen events nationwide to teach people that not all dementia is Alzheimer's. Volunteers forged connections by running 16 Meet & Greet events across the country, including events in South Dakota and Alaska.

Guiding these efforts were our 10 Regional Coordinator Volunteers, passionate representatives of AFTD who manage all volunteer activity in their parts of the country. On May 4, the day before the AFTD Education Conference, we recognized them and other key volunteers at an appreciation lunch, held during the annual AFTD Volunteer Leadership Summit.

Any volunteer who helps strengthen AFTD by organizing and participating in a grassroots fundraiser becomes a member of the AFTD-Team. This year was a strong one for the Team. Our sixth annual Valentine's Day-themed With Love campaign brought in more than \$90,000, a new record. Meanwhile, AFTD-Team members

throughout the US organized 55 events in 31 states during our Food for Thought campaign. This year, Food for Thought brought in more than \$153,000 for AFTD's mission.

The AFTD-Team also took part in races across the country. During a single May weekend, the AFTD-Team raced in Denver, Austin and King of Prussia, PA. More than 115 AFTD-Team members participated that weekend, covering more than 500 miles and raising nearly \$10,000. Additional races over the past year include the Philadelphia Marathon last November, and the Seattle Super Run in June.



Steve Fenoglio and his daughter Gayle Taliaferro doing pull-ups at the Fit Foodie 5K in Austin



A young AFTD volunteer proudly participates in a Food for Thought event.

“This was my first in-person encounter with AFTD and I came away both energized and inspired. Many thanks for your warm welcome. See you at the next event!”

- AFTD-Team Member

The AFTD-Team at the 2017 Colfax Marathon in Denver



“Telling the stories of our loved ones is so important.”

- Michelle Hinchey



In June 2017, the family of former New York Congressman Maurice D. Hinchey announced that he is living with primary progressive aphasia as well as additional symptoms, including Parkinsonian Syndrome. A range of broadcast and print media outlets—from the Daily Freeman and WBNG-TV in upstate New York to Roll Call in Washington, DC—reported the news of Hinchey’s diagnosis. His family have since become staunch advocates for greater public and private funding toward FTD research, as well as more accessible resources for those facing the disease. “As a Congressman, he fought to improve the lives of the people he served,” his daughter Michelle said. “Now it’s our turn to give back to him. Telling the stories of our loved ones is so important—it raises awareness, fosters help for those affected and promotes research to bring hope to future generations.”

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+

Samuel I. Newhouse Foundation, Inc.

100,000+

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(Left to right) AFTD Board members Dr. John Whitmarsh and Mrs. Beth Walter, with her sons Michael and Robert

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2,500+

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*AFTD Chief Executive Officer
Susan L-J Dickinson,
speaking at the Hope Rising
benefit in New York City*

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*At the Hope Rising benefit:
 (left to right) AFTD Board Member
 Danny Hedaya, AFTD donor
 Donald Newhouse, journalist
 and TV host Paula Zahn, AFTD
 Board Member Kathy Mele,
 Discovery Communications
 president/CEO David Zaslav*



donors

1,000+ continued

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Ms. Sandy Lipsman
Mrs. Janice M. Little
Mr. Matt Longhouse
Mr. George Lyngarkos
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Mr. and Mrs. Judd Robertson
Mr. Charles J. Rose
Mr. Stephen Rosenblatt
Mr. Steven Rulison
Mr. and Mrs. Sol Sackel
Mr. Ron Sakoda
Kerri and Eytan Saperstein
Mr. Tom Saponas
Schneider Electric
Mr. Michael Scott
Nancy Seaman and Alan Schwartz
Ms. Allison Sellon
Mrs. Joyce Shenian
Ms. Jan Shepherd

Ms. Arlene P. Shulman
Mr. Randolph A. Siegel
Helene and Christopher Smith
Mr. and Mrs. Thomas S. Stark
Mr. Ryan Steglich
Mr. Richard Stolz
Strong Foundation of New York
Mr. John Sweeney
Ms. Lisa Tauchen
The Beatitudes Campus
The Cozen O'Connor Foundation Inc.
Mr. John B. Tiller
Mrs. Seran Trehran
Ms. Ashlie Trotter
Ms. Judy Turner
Mrs. Candice Umin
Universal Electrical Service
Ms. Diane S. Urch
Ms. Pamela Van Zandt
Ms. Karen L. Wakefield
Mr. Stuart Waldman
Mrs. Terry L. Walter
Waterfall Family Foundation
Judy and Josh Weston
Dr. John Whitmarsh
Ms. Nina Wortzel-Hoffman
Mr. James F. Yahner
Mr. David Yorkin
Mr. Todd Zaborski
Mr. Scott Zelnick
Ms. Anna Zimmerman



*AFTD donor Tam Smith and
her husband Bob Smith*

fundraisers

Over the past year, amazing members of the AFTD-Team brought 133 grassroots events to local cities and towns across the country, raising more than \$400,000 to help end FTD! Each of the events listed on this page raised more than \$1,000. We sincerely appreciate all who volunteer for these special events. Your passion, creativity and devotion to our mission inspire AFTD and our community every day.

Independent Events

George & Christine Sidoris <i>11th Annual George F. Sidoris Memorial Golf Outing</i>	Suzanne & Calvin King <i>1st Annual "Tami Sue" Golf Outing & Party</i>
Paul Lester <i>Letters for Arnette</i>	Chris Roach <i>Comedy Fundraiser Night</i>
Aryeh & Brandon Portnoy <i>Brandon's Catch-A-Thon</i>	Jon Moretti <i>1st Annual CWM Memorial Golf Outing</i>
Debbie Baumgartner <i>2nd Annual John E. Baumgartner III Golf Tournament</i>	Amy Totten <i>Running IMO John Totten</i>
David Pfeifer <i>In Memory of Cathy Pfeifer</i>	Brian Rose <i>Credit Suisse Jeans Day</i>
Gretta Walter <i>Racing to Remember</i>	Voodoo Doughnuts <i>The Homer</i>
Pam & Matthew Hatfield <i>Robert M. Hatfield 6th Annual Quest for the Cure Golf Tournament</i>	Russell Zomback <i>Marathon for Dad</i>
Lisa Tauchen <i>In Memory of David Tauchen</i>	
Leah Strauss <i>Ruth Ehrenkranz Strauss FTD Memorial Fund</i>	
Sarah Ezrin <i>In Honor of Len (Leonard) Karetny</i>	
Cortney Walker Rohr <i>Walker Family Golf Tournament</i>	
The Pondelli Family <i>Team at 2017 Disney Princess 1/2 Marathon</i>	

*AFTD Volunteer Drew Linerud
after his first-place finish at
the Seattle Super Run*



Food for Thought

Steve Bellwoar
Bonnie Shepherd
Debbie Fenoglio
Brian Rose
Kathy Ritchie
Lucy Carter
Tam Smith
Terry Walter
Ryan Windhorst
Jordan Daniels
Kristena Corbett
Chuck Anastasia
Gail Andersen
Jennifer Morabito
Rona Klein
Barbara Sidders
Cheryl Johnson



With Love

Beth Walter
Team Alice
Leigh Knosher
Kat Primeau
Lisa Pessah-Bloom
Lynda Ares
Bonnie Shepherd
Cindy Odell
Diane Illis
Wendy Miller-Anello

AFTD-Team Walk/Runs

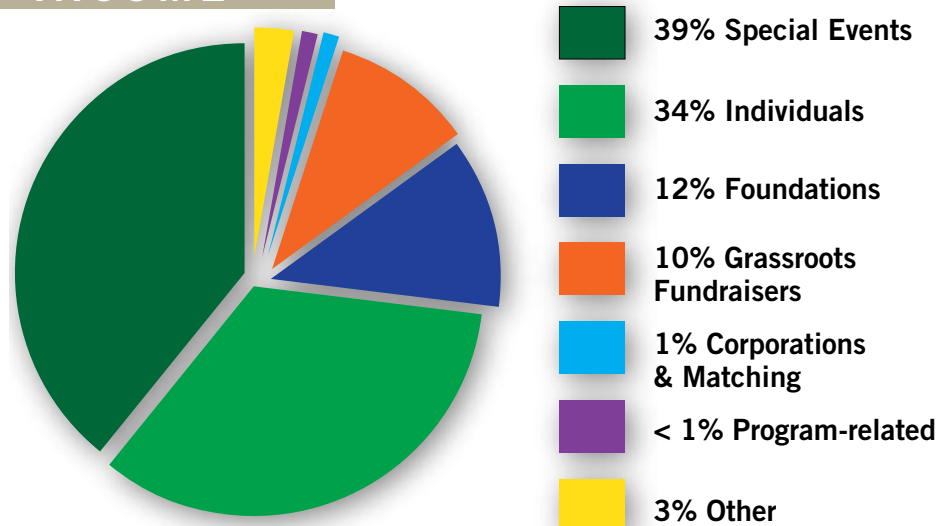
Fenoglio Family
Kelly Tyler
Joe Fischel
Hillary Horgan
Kacy Kunesh
Amy Vernon
Eric Simon
Popkin Shenian
Kaitlyn Sphon
Taylor Sphon
Colin Whitmarsh



statements of financial position

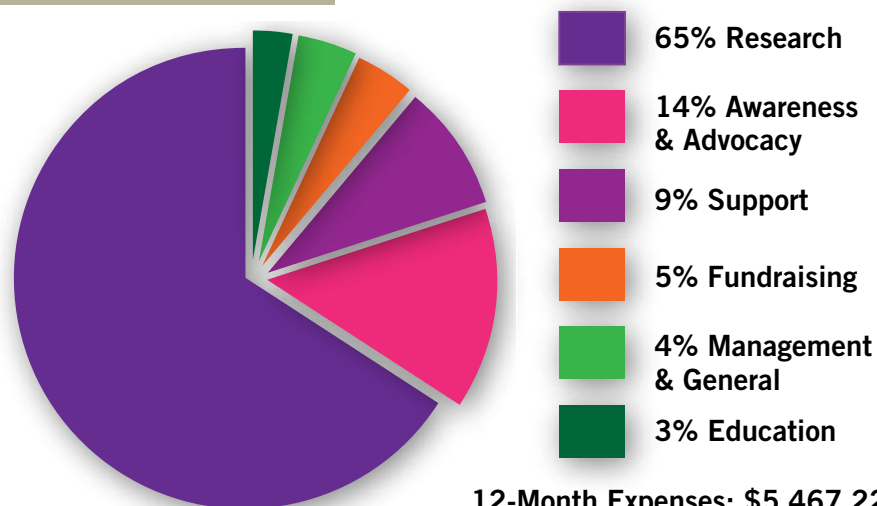
as of 6.30.2017

INCOME



12-Month Income: \$4,134,982

EXPENSES



12-Month Expenses: \$5,467,227

Assets

Cash & Cash Equivalents	\$4,785,312
Contributions Receivable	\$3,055,000
Accounts Receivable	\$ 9,320
Prepaid Expenses	\$ 81,369
Investment in FTD Disorders Registry LLC	\$ 300,591
Equipment	\$ 19,526
Security Deposit	\$ 8,672
Total Assets	\$8,259,790

Liabilities and Net Assets

Liabilities

Accounts Payable & Accrued Expenses	\$ 38,848
Deferred Revenue	\$ 123,000
Research Grants Payable	\$ 1,141,227
Total Liabilities	\$ 1,303,075

Net Assets

Unrestricted

Undesignated	\$1,653,609
Board Designated for Reserves	\$1,416,489
Total Unrestricted	\$3,070,098

Temporary Restricted

Total Net Assets	\$6,956,715
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Total Liabilities and Net Assets	\$8,259,790
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The Association for Frontotemporal Degeneration is a 501(c)(3) organization.

outlook



Since this November marks AFTD's 15th anniversary, let's take a moment to recognize how far we've come. We've grown from an all-volunteer organization to one with 18 full-time employees, all working to help our community, and to advance hope for a future without FTD.

AFTD has set some ambitious goals for the next year, and I am confident we can meet them as a community—through the combined power of our voices.

Ending FTD requires an investment of time and resources that only AFTD is

prepared to make. This year we will host several meetings to stimulate collaboration in FTD research. The most notable is an upcoming FTD Treatment Study Group meeting. Representatives from the pharmaceutical industry, biotech and academia will join federal officials (from the National Institutes of Health and the Food and Drug Administration) to address barriers to accurate diagnoses and effective treatments. The FTD Disorders Registry continues to gain new registrants at a pace that has exceeded our expectations. We are awarding our first grants under the TreatFTD

their own voices to bring AFTD volunteer impact to communities throughout the country.

To reach more people online, we will make greater use of digital media. A new AFTD Online Community Coordinator will engage our constituents through social media. Look for a newly designed AFTD website by spring 2018.

Donors and fundraisers speak powerfully through their financial support of the organization—and everyone at AFTD, from Board to staff, is grateful for the thousands of supporters who help us

***We can meet our goals as a community—
through the combined power of our voices.”***

initiative, which will result in new clinical trials of FTD treatments. We will publish our Economic Burden Study, which will powerfully chronicle the financial—and physical—toll that FTD inflicts on caregivers.

AFTD will pilot a new Comstock grant, the Quality of Life Grant, giving persons diagnosed the opportunity to purchase something that makes their lives better: a specific type of therapy, a smartphone, or even a new haircut. We will also continue to expand our national network of support groups by recruiting and training group facilitators. I'd like to especially acknowledge the continued hard work of our Regional Coordinator Volunteers, who lend

to sustain a growing staff of professionals, and a growing scope of impact. We answer more Helpline calls, host more education events and Meet and Greets, and create more innovative supports than anyone could have thought possible 15 years ago.

It is an honor to speak on behalf of the FTD community. Thank you for bringing your own voice to this work—it is essential.

Sincerely,

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

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

AFTD at work

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Ohio

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Rosa Rademakers, PhD
Mayo Clinic, Jacksonville

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University of Pennsylvania

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Support Services Manager

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Matt Sharp, MSS
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Lauren Gauthier
Online Community Coordinator

Bridget Graham
Grassroots Events Coordinator

Jamie Barnaba
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Harold Perkins, MPH
Program & Services Administrative Assistant



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Radnor Station Building 2 | Suite 320 | 290 King of Prussia Road, Radnor, PA 19087
866-507-7222 (toll free) www.theaftd.org

“AFTD has been a huge source of support. We will continue to use your resources and information throughout our FTD journey.”

“AFTD responded right away when I reached out with questions about my own possible FTD diagnosis. I cannot thank this organization enough.”

the AFTD community

Those diagnosed, their families and loved ones

Caregivers and healthcare professionals

Researchers and scientists

Industry and civic leaders

Public policy shapers

Collaborators with a shared mission

Friends around the world

“After my diagnosis, I was so confused and depressed—but AFTD was there for me. I want you to know how important and helpful your compassionate support has been for me throughout the years.”

“AFTD has really helped me advocate for my mom, to be the voice she needs.”

