



CHANGING THE FUTURE OF FTD

2016 Annual Report: A Year for Awareness



July 2015-June 2016

The Association for
Frontotemporal Degeneration

Opening the gateway to help and a cure

AFTD's 2016 fiscal year was unprecedented for building awareness. The photo on the cover is from one of two full-page ads created by volunteer Jody Zorn, who lost her father to FTD. Thanks to support from a generous donor, the ads appeared in the *New York Times* during the first World FTD Awareness Week. Members of the AFTD community have helped reprint them without charge in more than a dozen additional publications.

HIS WIFE SAID MIDLIFE CRISIS.

HIS THERAPIST SAID DEPRESSION.

HIS DOCTOR SAID ALZHEIMER'S.

NOBODY SAID FTD.

Frontotemporal Degeneration (FTD) is the most common cause of dementia for people under 60, affecting more than 50,000 in the U.S. alone. Onset strikes earlier in life—when few anticipate dementia—and accurate diagnosis can take years. Families lose active parents and breadwinners without knowing what's stealing away the person they love. And when a diagnosis is made, there are no effective treatments. Help to change that reality today. www.theAFTD.org/learnmore



Inside:

- 2 Research
- 4 Support
- 6 Education and Advocacy
- 8 Awareness
- 10 Volunteers and the AFTD-Team
- 12 Named Funds and Donors
- 15 Fundraisers
- 16 Statements of Financial Position
- 17 Outlook

CHANGING THE FUTURE OF FTD



Dear Friends,

I have the proud honor of taking the reins as AFTD's Board Chair at an exciting time in our evolution. Significant progress is occurring across every area of our mission, and each passing month brings promise for new advances to improve the lives of those touched by FTD, and drive research for a cure.

All progress in AFTD's work begins with awareness. In fall 2015, the first World FTD Awareness Week kicked off with a special event held at One World Trade Center in New York City. Displays featured participants and events from 10 countries around the world, while community members in the US held Food for Thought events in 32 states. With generous donor support, full-page ads designed by AFTD volunteer Jody Zorn ran prominently in the lead section of the *New York Times* two Sundays in a row—and were later included in 12 other national and regional publications.

Momentum continued throughout the year, as more members of our community than ever before stepped up to engage in AFTD's mission work. Susan Suchan, a brave advocate herself diagnosed with PPA, delivered the welcome address at AFTD's education conference. More than 700 caregivers

participated in AFTD's Economic Burden Study, and trained volunteers with access to AFTD's knowledge and expertise stepped up to launch new support groups in communities across the country. With the generous support of two large multi-year donations from the Samuel I. Newhouse Foundation, we were excited to announce new research initiatives to stimulate clinical trials and fund the quest for FTD biomarkers.

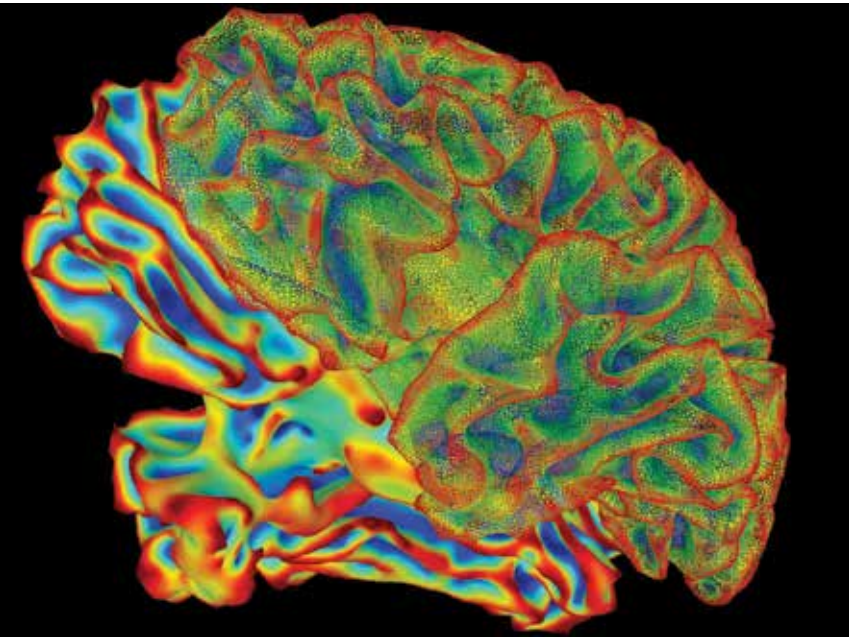
Engagement in this important work brings meaning and hope to my own family's journey with FTD. As you read these pages, I urge you to reflect on the progress we are making together, and to join us by sharing your story, your time, your talents and your resources to advance our work to end this disease. Together, we can bring a better future into focus for all impacted by FTD.

Sincerely,

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

Gail Andersen
AFTD Board Chair

RESEARCH



Thanks to the generosity of the families that help to support our mission, we made **milestone advances in driving FTD research** toward accurate diagnosis and treatment.

- A grant of \$5.75 million from the Samuel I. Newhouse Foundation funded a novel multi-year initiative to **identify biomarkers in FTD**, which will enable more accurate diagnosis and offer new means to measure the effectiveness of potential therapeutics in clinical trials. The initial call for proposals for this 5-year program produced exciting ideas from 60 research teams from academic institutions and pharmaceutical and biotech firms around the world.



Keith St. Lawrence, PhD, Drug Discovery Award Recipient

The Quest for FTD Biomarkers

AFTD is on the hunt for new biological indicators, or biomarkers, for FTD. Stacie Weninger, PhD, Chair of the AFTD Biomarkers Initiative Scientific Advisory Board, says, "AFTD has assembled an amazing group of scientists with different backgrounds, all working together to develop much-needed biomarkers for FTD. This initiative will accelerate our search for effective therapeutics and improve our ability to diagnose patients."

From left: Donald Newhouse, AFTD donor; Stacie Weninger, F-Prime; Joanne Kotz, F-Prime; and Kathy Newhouse Mele, AFTD Board member.



- A second gift from the Samuel I. Newhouse Foundation of \$5 million over 10 years was matched by an equal gift from the Lauder Family Foundation; together these gifts will fund a new \$10 million **program to TreatFTD**. A collaborative effort between AFTD and the Alzheimer's Drug Discovery Foundation (ADDF), The *TreatFTD* Fund is aimed at stimulating innovative clinical trials for both novel and repurposed therapeutics in FTD.
- Since 2007, AFTD has funded **FTD Drug Discovery** by partnering with the ADDF, which matches AFTD's contributions 2:1. This year, an anonymous donation allowed AFTD to double its annual contribution from \$100,000 to \$200,000, resulting in a total of \$600,000 in funds for this program. Grants went to three researchers: Mari DeMarco, PhD, of the University of British Columbia; Edward Huey, MD, of Columbia University; and Keith St. Lawrence, PhD, of the Lawson Health Research Institute.



Edward Huey, MD

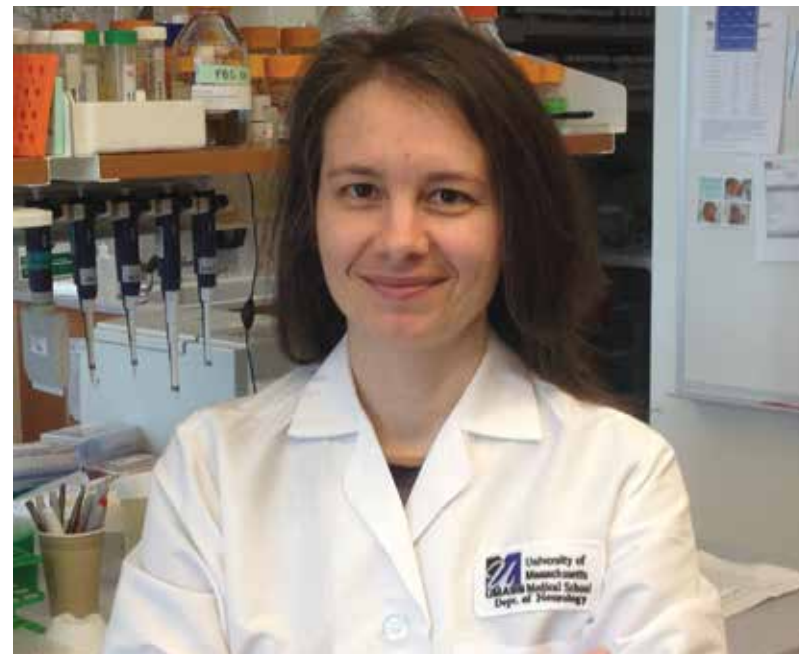


Mari DeMarco, PhD

- The **Susan Marcus Memorial Fund Clinical Research Pilot Grant** was awarded to Roy Hamilton, MD, an Assistant Professor of Neurology at the University of Pennsylvania. His research project, "Transcranial direct current stimulation as a treatment for Primary Progressive Aphasia," will test whether a painless form of brain stimulation can improve language abilities in people with PPA.
- Sandra Almeida, PhD, received AFTD's 2015 Basic Science Pilot Grant. She is an Assistant Professor of Neurology at the University of Massachusetts Medical School. Her project will involve "reprogramming" skin cells from patients with the *C9ORF72* gene mutation (the most common mutation in FTD) to generate stem cells.

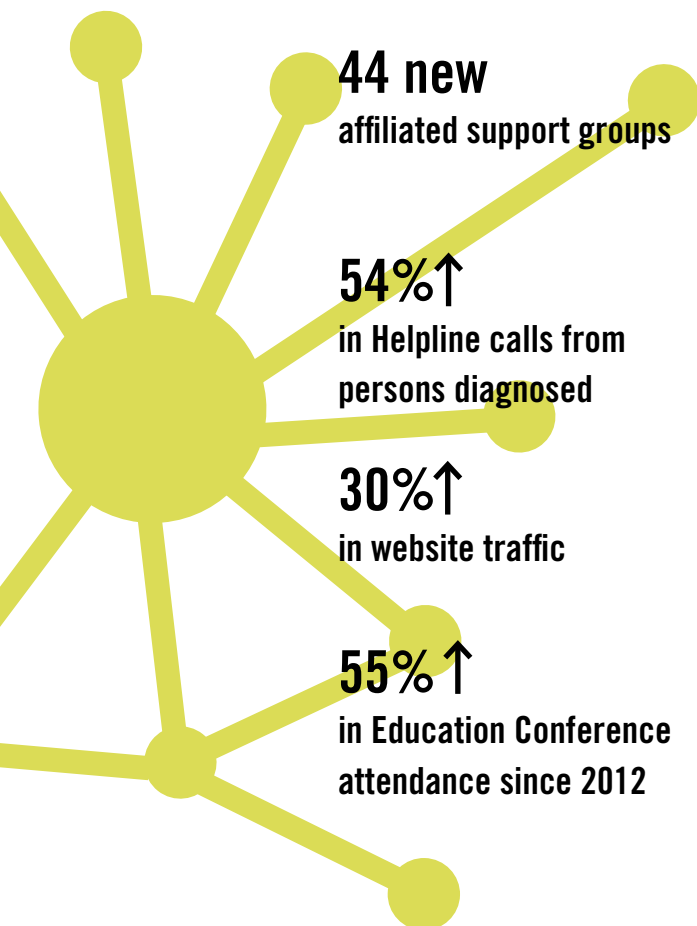


Roy Hamilton, MD



Sandra Almeida, PhD

SUPPORT



AFTD understands the unique challenges this disease presents, and we are committed to developing the **resources and connections** to support members of our community in their daily lives.

In response to requests from **FTD support group leaders** across the country, AFTD created a formal program to strengthen skills and offer valuable support for these leaders in their important work. Leaders attend trainings, discuss challenging situations and gain access to AFTD's network of experts so they can offer group members the most current and accurate FTD information. In the first 10 months of the program, 55 leaders became AFTD affiliates, benefiting a total of 44 support groups.

AFTD also created two **new phone groups**: one for caregivers of people with FTD/ALS (in partnership with the ALS Association: Greater Philadelphia Chapter), and one for male caregivers, addressing the specific needs and concerns of each group.

This past fiscal year, nearly 2,200 people contacted **AFTD's Helpline**—including caregivers, family members, individuals living with a diagnosis and the professionals who care for them.

AFTD awarded a total of \$79,000 to 169 people via **Comstock Respite and Travel Grants**, enabling them



Emotional Support at the Conference

Pictured above: FTD Advocate Susan Suchan and AFTD Board Member, Paul Lester.

In the middle, AFTD Volunteer, Teresa Webb gives support to a fellow Education Conference attendee. Pictured below is AFTD founder, Helen-Ann Comstock with AFTD Board Member, Bonnie Shepherd.

to take a break or travel to an FTD conference to expand their knowledge and network of support.

On May 13, 2016, 270 people joined AFTD for the **Annual Education Conference** in Minneapolis, Minnesota—the largest attendance to date. Doctors Bradley Boeve and David Knopman from the Mayo Clinic in Rochester, Minnesota, and Dr. Darby Morhardt of Northwestern University's Feinberg School of Medicine, were among the experts who presented.

AFTD proudly opened the Conference with a welcome from Susan Suchan, who is diagnosed with primary progressive aphasia (PPA). More than 40 others diagnosed with an FTD disorder joined us for the day—the most ever. Dementia advocate and volunteer fundraiser, Teresa Webb, worked with AFTD Program Manager, Matt Sharp, to develop a full-day program for persons diagnosed, to create a place to share their experiences and explore different strategies for coping with daily life.

We continue to develop programs aimed at providing more resources for those diagnosed with an FTD disorder. Our goal is to create the most comprehensive community of support we can for everyone touched by this disease.

Nancy Carlson:

Illuminations of FTD

Nancy Carlson is an accomplished author and illustrator of more than 60 children's books. In 2012, her husband was diagnosed with FTD, making her the caregiver and breadwinner for the family. Despite numerous daily and financial challenges, Nancy continues to draw and post fun and inspirational doodles daily on her website and Facebook page. She also maintains a busy national speaking schedule on both her books and the FTD journey, visiting many schools, conferences and libraries each year. Nancy delivered a clever and heartwarming keynote address at the Annual Education Conference in Minneapolis, where she auctioned several of her drawings, with proceeds benefiting AFTD.



EDUCATION AND ADVOCACY



Families receiving an FTD diagnosis need a reliable **resource for answers and strategies**. They also deserve a **tireless advocate** to increase investment in research and improve available services. AFTD strives to be both for a growing community of families, patients and their healthcare providers.

The first place to learn about FTD, www.theaftd.org, drew more than 231,000 visitors in FY 2016. More than 3,700 people visited our Kids and Teens site www.aftdkidsandteens.org.

We continued to educate healthcare professionals and family caregivers through **Partners in FTD Care**, a collaborative program presenting case studies and management strategies. Topics included kids in an FTD home, communications in primary progressive aphasia (PPA) and long-term care. We featured two guest experts: Maya Henry, PhD, CCC-SLP, Assistant Professor, Department of Communication Sciences and Disorders at The University of Texas at Austin; and Robin Riddle, CEO of the Brain Support Network.

We launched a new advisory group, the **Think Tank**, comprising persons diagnosed with FTD who are willing to share valuable firsthand experiences

Partners in
FTD Care

with AFTD staff and board members. Sharon S. Denny, MA, AFTD Program Director and Think Tank Facilitator says, “Engaging more individuals who have been diagnosed is critical. The community benefits when we help all stakeholders understand what it’s like to live with this disease.”

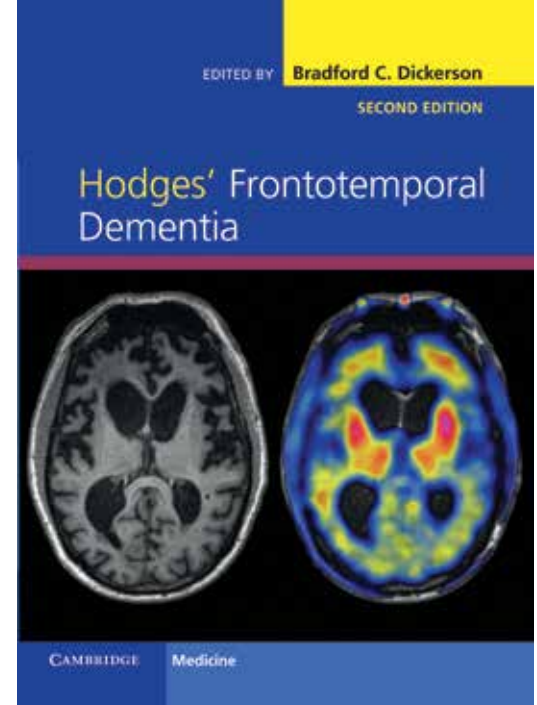
In its advocacy role, AFTD co-sponsored the second **national summit on Alzheimer’s Disease-Related Dementias** in March 2016. The meeting, hosted by the National Institute of Neurological Disorders and Stroke (NINDS) at NIH, helped chart a course that will guide research into non-Alzheimer’s dementias over the next three years.

(Left to right) Mark Diamond, MD, Jonathan Rohrer, MD, PHP, William Seeley, MD and Chiadi Onyike, MD, socialize at the FTD Treatment Study Group welcome reception.



In April, AFTD hosted a meeting of the **FTD Treatment Study Group**, also co-sponsored by NINDS. It drew 94 attendees from academia, government and industry, including representatives from 23 pharmaceutical and biotech companies. The conference “showcased an explosion in knowledge about FTD,” said Walter J. Koroshetz, MD, Director of NINDS. “And it’s all because of the collaboration between scientists, those affected with the disease, their families and their doctors.”

Board Advocacy Lead Pop Shenian and AFTD Program Manager Matt Sharp represented AFTD at each of the quarterly meetings of the **National Alzheimer’s Plan Advisory Council**, reminding the Council that not all dementia is Alzheimer’s.



FTD, Through Our Eyes

For the first time, a medical textbook on FTD includes a chapter from the caregiver and family’s perspective. Hodges’ Frontotemporal Dementia (second edition, 2016) includes a chapter written by AFTD Executive Director, Susan L-J Dickinson, MS, CGC, and Jill Shapira, PhD. “This revision brings crucial patient and family perspectives to physicians in training, scientists and clinicians,” says the book’s editor, AFTD Medical Advisory Council member, Brad Dickerson, MD (below).



AWARENESS



AFTD's continuous effort to amplify the voices of our constituents is key to building awareness of this disease. This past year, thanks to collaboration with an expanding circle of partners, **we reached more people than ever before** with the message that “not all dementia is Alzheimer's.”

In the winter, AFTD launched its **first social media campaign**, anchored by a short film created by students from Boston University. Titled *Who I Love*, the film features people sharing something they love best about a family member, then cuts to an FTD caregiver speaking about how FTD stole that very quality from their loved one. This film, and other documentaries, can be seen on AFTD's YouTube channel: www.youtube.com/TheAFTDorg.

FTD Advocates around the world made their voices heard during the first-ever **World FTD Awareness Week**, October 4-11, 2015. AFTD kicked the week off with a special event in New York City at One World Trade Center. Participants viewed a short film adapted by Joe Becker from his feature, *It Is What It Is*, and heard from speakers who shared their families' stories, including donor and volunteer

Donald Newhouse and television producer Nicole Savini. Advocates in 10 other countries celebrated the week, with conferences in Australia and the Netherlands, a concert and an art gallery event in Spain, and a citywide proclamation in Ottawa, Canada.

We took a significant step forward in introducing FTD to a broader audience by placing **full-page ads in major publications**. Created by AFTD volunteer and graphic designer Jody Zorn, the ads first ran in the *New York Times* on two consecutive Sundays in October during World FTD Awareness Week. Through contributions from other members of our community, these powerful ads ran in a dozen other publications, including *Allure*, *Architectural Digest*, *Fairfield Business Journal*, *New Yorker*, *Vogue*, *Vanity Fair* and *Westchester Business Journal*.



NOT ALL DEMENTIA IS ALZHEIMER'S



Truth in Advertising

Volunteer Jody Zorn lost her father to FTD in 2014. An Associate Creative Director at a New York City ad agency, Jody set out to create ads that capture the problem of inaccurate diagnosis and the isolation it brings to the individual and their family. Jody explained, "I got involved with AFTD because my father passed away from the disease. I had never heard of FTD before he was diagnosed and knew it was not a well-known disease. I wanted to help change that in any way I could. I figured my time and expertise in advertising would be worth more than any other donation I could make." Above: Jody Zorn dances with her father at her wedding.

THE FIRST DOCTOR SAID DEPRESSION.

THE SECOND SAID STROKE.

THE THIRD SAID ALZHEIMER'S.

NO ONE SAID FTD.



Frontotemporal Degeneration (FTD) is the most common cause of dementia for people under 60, affecting more than 50,000 in the U.S. alone. Onset strikes earlier in life—when few anticipate dementia—and accurate diagnosis can take years. Families lose active parents and breadwinners without knowing what's stealing away the person they love. And when a diagnosis is made, there are no effective treatments. Help to change that reality today. www.theAFTD.org/learnmore



VOLUNTEERS AND THE AFTD-TEAM



AFTD was **founded by volunteers**. We are led today by an all-volunteer Board of Directors, and advised by volunteer medical, research and care professionals.

AFTD continues to expand its impact via a strong, knowledgeable and passionate volunteer network. This past year, **more than 360 volunteers** worked to give AFTD a regional and local presence, through activities and programs organized by Volunteer Regional Coordinators in seven U.S. regions.

AFTD volunteers serve as support group facilitators. They host grassroots fundraisers, conduct outreach to residential facilities and service providers, attend health fairs and host Meet & Greets. They connect with people in their community to help carve out a

better and more hopeful outlook for others on the path with this disease. AFTD volunteers are **key in changing the future of FTD**.

Every grassroots fundraiser, organizer and participant who helps to raise funds to support AFTD's mission is a member of the AFTD-Team. Through special campaigns year-round and independent events, The AFTD-Team declares: ***We're Here to Fight This Disease.***

AFTD held its **third annual Food for Thought** campaign during World FTD Awareness Week, October 4 through 11, 2015. AFTD-Team volunteers hosted 61 Food for Thought events in 32 states and Washington, D.C., raising more than \$174,500.

Danny Hedaya and Friends

With his friends, Danny Hedaya participated in the July 26th Color Me Rad 5K at the MetLife Stadium in NYC, raising more than \$27,000 for FTD research. The team ran in honor of Danny's father, Harold Hedaya, a well-respected physician who passed away from FTD in 2009. Danny shared, "We ran to have fun, remember my father, bring awareness and hope for others and most importantly, to support research for a future without FTD."





In spring and summer 2016, The AFTD-Team took on **five races across the country**. We participated in the King of Prussia 10 Miler and 5K Walk/Run (PA), the Cambridge 5K – Freedom Run (MA), the Fit Foodie Race (TX), the Shamrock Shuffle (CT) and Flashback 5K (MD). In total, over 130 AFTD-Team members ran (or walked) approximately 400 miles and raised more than \$10,000 to fight FTD.

AFTD's **fifth annual With Love** campaign raised funds and awareness online. Twelve community members shared their stories and raised funds to honor a loved one impacted by FTD. Through their work and two generous matching gifts from Beth Walter and the Rainwater Charitable Foundation, **With Love 2016** raised a record high of \$60,977.



Susan Eissler, Mega-Volunteer

Susan Eissler hosted a 2015 Food for Thought tea in proper Downton Abbey style. She has volunteered for AFTD for more than 10 years, contributing in many pivotal roles including Board member, Recording Secretary, Program Lead, South Central Regional Coordinator, Support Group leader, Meet & Greet host and grassroots fundraiser. Susan represents the heart, creativity and commitment of AFTD's community.

NAMED FUNDS AND DONORS

Named funds are established in memory or in honor of a loved one. Created with a minimum individual donation of \$25,000, they help AFTD to advance research and improve care and support for individuals impacted by FTD. We are proud to recognize these individuals and their families for their special contributions to our community.

The Dr. Lawrence Albert Memorial Fund

Kevin M. Harvey Memorial Fund

Susan Marcus Memorial Fund

Laden Memorial Fund

The Suzy Fund

The Mike Walter Fund for Research

Donors are essential partners in helping AFTD to transform its vision of the future into actions that produce results. We are grateful for the determination our community has shown during FY 2016 and hopeful for deeper gains in the years ahead through your continued support.

1,000,000+

Samuel I. Newhouse Foundation, Inc.

100,000+

William Randolph Hearst Foundation
Mr. James Tomilson Hill

50,000+

Mrs. Susan Laden
Mr. Philip H. Lovett
Mr. and Mrs. Lawrence Neubauer
Mrs. Beth Walter

20,000+

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Betz Family Charitable Fund
Bloomberg Philanthropies
The Florence V. Burden Foundation
Colonial Electric Supply
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Dementia Foundation
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10,000+

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The New York Times Company
The Rainwater Charitable Foundation
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The Dayton Foundation
Mr. and Mrs. Anthony Wang

WITH GRATITUDE
TO OUR DONORS

*AFTD donor Donald Newhouse with
his wife Suzy, who passed away in
August 2015*



5,000+

Alzheimer's Drug Discovery Foundation
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2,500+

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 Mr. Don Heyden
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Fundraiser Brian Rose, with his mother and son

1,000+ continued

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Ms. Cheramy White
The Windhover Foundation
Mrs. Mary Wisneski
Ms. Nina Wortzel-Hoffman
Mr. Todd Zaborski



***AFTD supporter and Medical Advisory
Council member, Dr. Virginia Lee***

FUNDRAISERS

Each of these grassroots events brought in **\$1,000 or more** during FY 2016.

Overall, 104 events across the United States secured more than \$328,000 to fuel the fight against FTD. We appreciate the support given by AFTD volunteers through their time, energy, hard work and bold creativity to host these powerful events, which are the driving force behind our shared work.



John E. Baumgartner III (third from left), his son Will (in blue) and supporters at his 2015 golf tournament

Independent Events

Karine Adalian
In Honor of Lydia

Deanna Angello
Strong Body Strong Mind

Debbie Baumgartner
1st Annual John E. Baumgartner III Golf Tournament

Maggie Frey
In Memory of Detlef Frey

Brittany Hatfield
Los Angeles Marathon

Matthew Hatfield
The Robert M. Hatfield 5th Annual Golf Tournament

Danny Hedaya
Color Me Rad 5K

Paul Lester
In Memory of Arnette Lester

Stephanie McLain
Premier Music Academy

Joel McNulty
6th Annual Al McNulty Benefit

Maja Murphy
In Memory of Father

Justin Peavey
Center Stage Theatre Co., Legally Blonde Jr. Show

Julianne Pondelli
Team Al - 2016 Disney Princess 1/2 Marathon

Rick Ranti
Laura's Legacy Campaign

Alice Saunders
Charity Spin Class

George J. Sidoris and Christine Sidoris
10th Annual George F. Sidoris Memorial Golf Outing

Michael Stowell
Pappy Van Winkle Classic Sponsored by Buffalo Trace Distillery

Russell Zomback
Marathon for Dad

Food for Thought

Karine Adalian

Gail Andersen

Steve Bellwoar

Kirsten DeHaai

Sarah DeLuca

Jamie Farid

Sylvia Gentry

Cheryl Johnson

Jennifer Morabito

Shana Nissen

Lisa Radosta

Kathy Ritchie

Brian and Sharon Rose

Bonnie Shepherd

Sally Sloop

Cathy Sperrick

With Love

Joanna Dauber

Amy Eissler

Jamie Hale

Emily Levy

Stephanie McLain

Wendy Miller-Anello

Lisa Radin

Bonnie Shepherd

AFTD-Team Walk/Runs

Joan Braxton

Susan Dickinson

Brenda Elkin

Kacy Kunesch



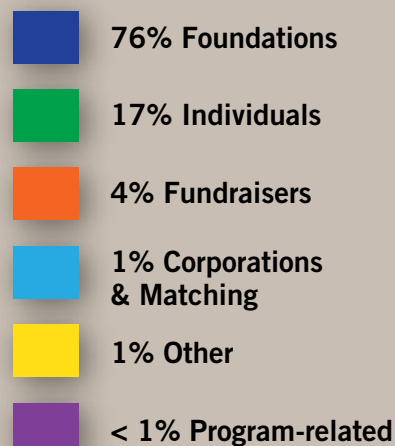
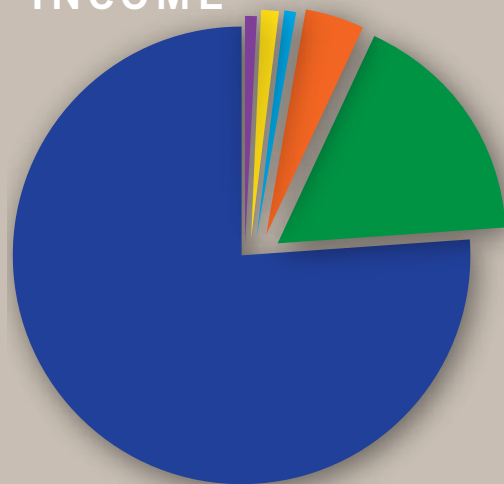
WITH THANKS
TO OUR
GRASSROOTS
VOLUNTEERS



STATEMENTS OF FINANCIAL POSITION

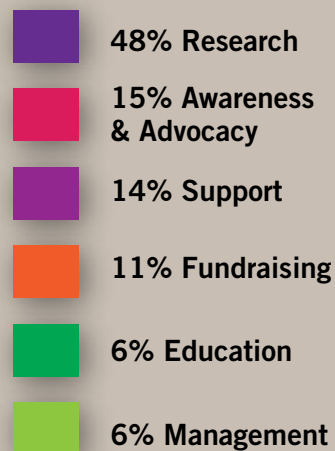
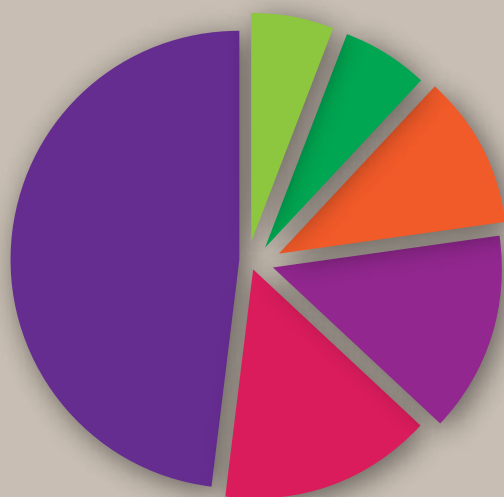
as of 6.30.2016

INCOME



12-Month Income:
\$8,183,534

EXPENSES



12-Month Expenses:
\$2,671,249

Assets

Cash & Prepaid Expenses	\$2,675,338
Contributions Receivable	\$5,750,000
Accounts Receivable	\$ 21,036
Investment in FTD Disorders Registry LLC	\$ 279,578
Equipment	\$ 20,176
Security Deposit	\$ 6,289
Total Assets	\$8,752,417

Liabilities and Net Assets

Current Liabilities

Accounts Payable & Accrued Expenses	\$ 9,468
Deferred Revenue	\$ 300,000
Research Grants Payable	\$ 125,000
Total Current Liabilities	\$ 434,468

Net Assets

Unrestricted	\$2,196,410
Temporarily Restricted	\$6,121,539
Total Net Assets	\$8,317,949
Total Liabilities and Net Assets	\$8,752,417

OUTLOOK

As we look toward a new year, we depend on both proven programs as well as novel approaches to change the future of FTD.

In September, AFTD co-sponsored the 10th International Conference on FTD in Munich, Germany. More than 600 scientists from around the world shared results and ideas on how to better understand and treat FTD. We presented the initial results of AFTD's Economic Burden Study, as well as a poster on our groundbreaking program to build a nationwide network of independent support group leaders. AFTD co-hosted meetings for caregivers, for our expert Medical Advisory Council and for the emerging worldwide network of nonprofit organizations dedicated to developing care and a cure for FTD.

With this group of peer organizations, AFTD hosted the second World FTD Awareness Week, September 25-October 2, 2016. We marked the occasion with the inaugural Hope Rising Benefit in New York City, as well as more than 100 Food For Thought events.

Our \$5.75MM initiative in pursuit of discovering FTD biomarkers critical to the development of diagnostics and therapeutics will make its first round of investments. Guided by a panel of experts in FTD, ALS and Alzheimer's, we will also issue our first call for proposals under the new, \$10 million TreatFTD Fund program. Through this program, AFTD and the Alzheimer's Drug Discovery Foundation will support innovative study designs

and promising therapeutics—both repurposed and novel—to bring into clinical testing for FTD.

Finally, we will launch the FTD Disorders Registry, an online database where persons diagnosed, their family members and caregivers can contribute data from their own experiences. This information will empower our community as full partners in developing, testing and implementing more effective and compassionate management and treatment strategies of all kinds. Your voice will be instrumental as we work to enhance quality of life along the path to better treatments and a cure for FTD.

It is a promising time for those of us committed to eradicating this disease. Still, much work remains. Crucial partners on this path, AFTD's donors are the reason we've reached this point—and your support continues to be essential to changing the future of FTD.

AFTD's board, staff and volunteers are focused resolutely on achieving swift progress in the mission at hand, committed to our core values of knowledge, collaboration, respect, dignity and compassion. We value your support, and invite you to join us in advancing this important work.

Sincerely,



Susan L-J Dickinson, MS, CGC
Executive Director



THIS YEAR,
AFTD WILL
AWARD MORE
RESEARCH
FUNDING THAN
EVER BEFORE.

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The Association for
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Opening the gateway to help and a cure

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