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

CHANGING THE FUTURE OF FTD

2016 Annual Report: A Year for Awareness
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.

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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,

Gail Andersen
AFTD Board Chair
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.

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 Katz, F-Prime; and Kathy Newhouse Mele, AFTD Board member.

Keith St. Lawrence, PhD, Drug Discovery Award Recipient
• 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.

• 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.
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...
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.
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.
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.

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. Hodge’s 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).
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.
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

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.
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 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.

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+
Mr. and Mrs. Peter Arnow
Betz Family Charitable Fund
Bloomberg Philanthropies
The Florence V. Burden Foundation
Colonial Electric Supply
Mr. and Mrs. Victor F. Ganzi

10,000+
Dr. Richard Bloch
FORUM Pharmaceuticals
Mrs. Clare Hall
Mr. Raymond Koenig
Mr. and Mrs. Laurence C. Leeds
Mr. Paul Lester
Mr. and Mrs. Dale W. B. Lutz
Mr. John McNellis
The New York Times Company
The Rainwater Charitable Foundation
Mary Beth Repasy Fund for Progressive Supranuclear Palsy Research of The Dayton Foundation
Mr. and Mrs. Anthony Wang

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

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
Ms. Gail Andersen
Mr. and Mrs. Steven P. Bellwoar
Biogen
The Bluefield Project to Cure Frontotemporal Dementia
Mr. Burt Brazil
Bristol Myers Squibb
Mr. Timothy Broer
Bulldog Ventures LTD
Foundation for the Carolinas Fund: The Bretscher Family Foundation
Mr. Rick Childs
The Stephen Colbert Americone Dream Fund
Mrs. Dee DeBello
Ms. Alice B. Diamond
Ms. Wendy Flanagan
Mrs. Lola Goldring
The Green Fund, Inc.
The Robert M. Hatfield Foundation, Inc.
Mr. Michael Irvine
Mr. and Mrs. William M. Lewis
Lilly USA, LLC
Mrs. Patricia Moser McCarthy
Merck Foundation
Mr. and Mrs. Sylvester Miniter
Ms. Mary Newman
Ms. Lisa Boyce and Mr. Kevin O’Neill
Orceln Industries Foundation
Mr. and Mrs. Edward J. Quinn, Jr.
Ms. Leslee Rudnick
Ms. Sandra Saner
Mr. Arthur Sommers
Mr. and Mrs. Carl Spielvogel
Sullivan and Cromwell LLP
Mr. Philip J. Swanson
TauRx Therapeutics, Ltd.
Ms. Judith L. Temple

2,500+
Alabama Power Company
Mr. Jeff Allen
Mr. Bruce Anderson
AstraZeneca Pharmaceuticals LP
Mr. and Mrs. Steve Barnes
Lt. Gen. Michael J. Basla (Ret.)
Mr. Sadguna Bhatt-Miller Family
Cydan Development
Mr. and Mrs. Richard K. DeScherer
Diversified Lighting Associates
Mr. Phil Dommer
Mrs. Nancy W. Duncan
Mr. John Duncan
Ms. Susan Eisler
Mr. George Elf
Mr. and Mrs. Ralph Huber
Hy-Tek Material Handling, Inc.
Long Shots Bar and Billiards LLC
Mr. Lawrence Low
Mr. George Lyngarkos
Mrs. Barbara McCarthy
Mr. Kenneth Papworth
Mr. Fran Pollart
Mr. Jeff Shewman
Mr. Richard Silva
Mr. and Mrs. John C. Weicher
Mrs. Jean C. Weina
Mrs. Joan C. Zlotnick

1,000+
Abandon Brewing Company, LLC
Mr. Frank Aochi
Ms. Mary Auth
Mr. and Mrs. Dal Bagley
Mr. and Mrs. Ryan Baldino
Bank of America
Ms. Emi Jo Bartus
Mr. Joseph A. Becker
Mr. Joseph Bellwoar
Mr. and Mrs. Andrew Bellwoar
Mr. David Bellwoar
Mr. and Mrs. B. Richard Benioff
Ms. Joan L. Beranbaum
Mr. and Mrs. Richard Berman
Mr. Tobias J. Bermant
Mr. Richard L. Braunstein
Ms. Joan Braxton
Ms. June I. Brush
Mrs. Patricia Buchanan
Rev. James Cardosi
Carr and Duff Inc.
Ms. Kris Carroll
Center Stage Theatre Company
Ms. Minalie Chen
Mr. Lou J. Chrobak
Mr. Charles B. Cohen
Ms. Kristina Colby
Mrs. Pamela Cole
Mrs. Helen-Ann Comstock
Mr. and Mrs. Doug Comstock
Mr. John L. Connor
Mrs. J. Lorraine Cox
Mr. Owen Davis
Ms. Donna Dean
Ms. Jonnie Val Denise

Fundraiser Brian Rose, with his mother and son

Mrs. Linda Deubert
Ms. Hester Diamond
Mr. and Mrs. Richard E. Diamond
Mr. and Mrs. Timothy Harrison
Mr. and Mrs. Robert Dickinson
Mr. John Dickson
Ms. Valerie T. Diker
R & C Donovan Family Foundation, Inc.
Mr. Glenn Dusky
Mr. and Mrs. David K. Dyck
Mr. Alan Einhorn
Mr. and Mrs. Mark Espinosa
Mr. and Mrs. John Falk
Ms. Laurette Feng
Mrs. Debbie Fenoglio
Mr. Stephen Fenoglio
Mr. and Mrs. Robert D. Fischel
Mrs. Susanna Foo
Ms. Mary Beth Fredheim
Mr. Robert Glandon
Mr. Eric Goldstein
Mr. Peter C. Gould
Grady-White Boats, Inc.
Mr. Jeffrey Gravelle
Ms. Marlene Greene
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Ms. Maria L. Gutierrez
Mr. Hees Ham
Ms. Dorothy Hamilton
Ms. Linnette C. Harvey
Ms. BJ Hauswald
Mr. Todd Heistand
Mr. Don Heyden
Ms. Carol Hillman
Ms. Joanne Ho
Mr. Albert N. Hobart
Mr. and Mrs. Craig Holleman
1,000+  continued

Houston Wire & Cable Company
Mr. Neil Hupfauer
Mr. and Mrs. David T. Hutzenbuhler
Mr. and Mrs. Philip A. Huvos
Mrs. Mary Ellen James
Mrs. Marguerite Joffe
Mrs. Amanda Johnson
Mrs. Cheryl Johnson
Mr. and Mrs. Donald Jonas
Ms. Nancy Jospey
Mr. Mike Kipp
Ms. Lindy Kowsky
Mr. and Mrs. Robert D. Krinsky
Mr. Armin A. Krueger
Kunz-Powell & Associates, Inc.
La La La LLC
Lansa SA
Dr. Jary Larsen
Dr. Virginia M.-Y. Lee
Ms. Joan Leiman
Ms. Emily Levy
Mr. Jeff Lichtenstein
Ms. Elinor Lipman
Mr. and Mrs. Richard Lobel
Locust & Co. Inc.
Mr. Louis C. Lucido
Mr. and Mrs. Karl O. Mann

Dr. Joseph C. Marquez
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Ms. Stephanie Kipp McLain
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Mr. and Mrs. Barry Miller
Mrs. Kim Miliman
Mr. David A. Misenhimer
Mr. Richard Owen Monsen
Mr. and Mrs. Douglas Morgan
Ms. Sara Moss
Mr. and Mrs. Michael Nash
Daniel M. Neidich & Brooke Garber Foundation
Mr. and Mrs. Jim Neuberger
Nick’s Roast Beef
Ms. Marla Nissan
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Mr. Tom Saponas
Ms. Alice Saunders
Ms. Julie Scearce
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Mr. Stuart Waldman
Wells Fargo Community Support Campaign
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.

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 Hedayat
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’s Food for Thought

WITH THANKS TO OUR GRASSROOTS VOLUNTEERS

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

AFTD’s Food for Thought

WITH THANKS
TO OUR GRASSROOTS VOLUNTEERS

Campaign 2016

THE AFTD TEAM

15
STATEMENTS OF FINANCIAL POSITION
as of 6.30.2016

INCOME
- 76% Foundations
- 17% Individuals
- 4% Fundraisers
- 1% Corporations & Matching
- 1% Other
- < 1% Program-related

12-Month Income: $8,183,534

EXPENSES
- 48% Research
- 15% Awareness & Advocacy
- 14% Support
- 11% Fundraising
- 6% Education
- 6% Management

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
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.
Board of Directors
Gail Andersen, Chair
Ohio
Debbie Fenoglio, Vice Chair
Colorado
Bryan Dalesandro, Treasurer
Pennsylvania
Bonnie Shepherd, Recording Secretary
Utah
Paul Lester, Treasurer
North Carolina
Helen-Ann Comstock, Founder
Pennsylvania
Jary Larsen, PhD
Immediate Past Chair
California
Deanna Angello, MBA
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