RESOLVE to make a difference.



2015 Annual Report

July 2014-June 2015



#### On the cover:

Volunteer, patient and self-advocate Susan Suchan brings her valuable perspective to conferences, networking and events.

See page 10.

Journalist Dan Browning at the Annual Conference, AFTD staff and volunteers at the Volunteer Summit, and Nora Allen at Porter Road Butcher's Food for Thought event.

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# RESOLVE.

Dear Friends.

AFTD is committed to improving the lives of people affected by frontotemporal degeneration and driving research to a cure. From the start, our rare disease community has held hope for more compassionate disease management and effective treatment. This annual report documents efforts to transform that hope into reality, showing steadfast resolve in the face of a disease that steals so much from our friends, loved ones and families.

Those who have shared their stories in these pages—people living with FTD, caregivers, advocates and donors—are part of a committed and generous community lending their powerful resolve to the fight against FTD.

AFTD leads in this fight. Last autumn, our Board, staff and advisors met to reflect on our progress, recommit to our values, and map out our next steps. The result was AFTD's 2015-2018 Strategic Plan, which established ambitious goals across our core mission areas. Our work over the past year and our plans for the future make it clear that the different threads of our work—targeted efforts in research, support, education, awareness and advocacy—will combine to achieve the crucial change we seek.

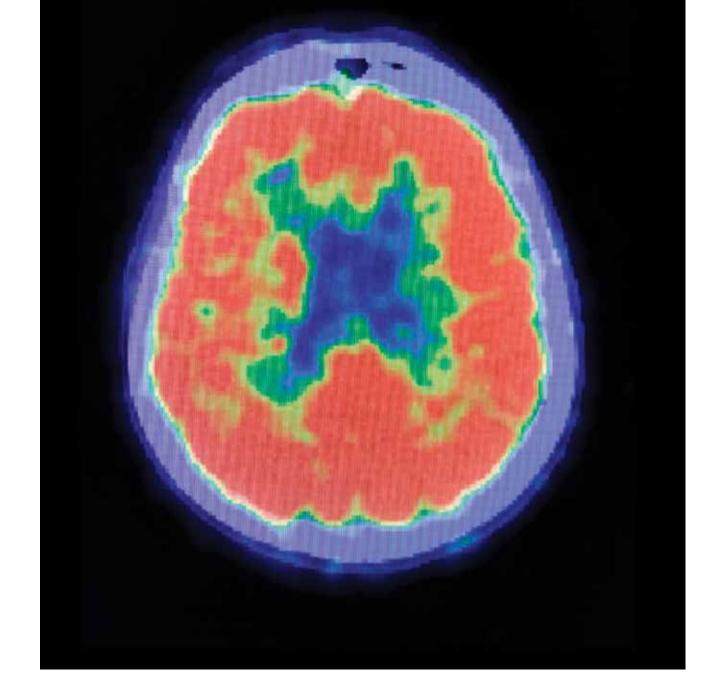
Our community continues to grow. More than 5,000 new people found AFTD last year. They contacted our HelpLine, requested information, made crucial donations, hosted awareness events, attended AFTD's Annual Education Conference, signed on as volunteers, educated providers and convened support groups to let families facing FTD know they aren't alone.

This autumn, as we join with organizations from around the globe to celebrate the first World FTD Awareness Week, I encourage you to find ways to offer your skills and determination to help us make a difference. Together, AFTD's community is hardening its resolve to dedicate the time, energy and resources to get from this moment in the course of our fight to the future we all envision. Your partnership in this work has never been more essential.

With warm regards,

Jary Larsen, PhD Board Chair







#### M. Catarina Silva, PhD, Studying How Brain Cells Change in FTD

M. Catarina Silva, PhD, recently completed a two-year postdoctoral fellowship, awarded by AFTD to promising researchers at the start of their careers. "The opportunity to work with AFTD, the FTD unit at Massachusetts General Hospital, and indirectly with patients has given science a whole new meaning for me." Under the guidance of Stephen Haggarty, PhD, at Harvard, Catarina researched the step-by-step process that occurs in brain cells as FTD develops. "I plan to work on FTD and neurodegeneration for years to come."

### advancing research in the lab and the clinic

This year, generous support from our community enabled AFTD to award more funding to advance FTD research in the lab and in the clinic than ever before. Support for pilot grants and postdoctoral fellows was doubled, funding for the FTD Drug Discovery program was continued and a special award was granted to enable the investigation of the feasibility of new PET imaging technology for FTD diagnosis.

- The first Susan Marcus Memorial Fund Pilot
  Grant in Clinical Research was awarded to
  Jennifer Yokoyama, PhD, at the University of
  California, San Francisco (UCSF), to study RNA
  signatures of FTD and ALS due to a common
  genetic mutation called C9orf72. This mutation
  is the most common cause of hereditary forms
  of both FTD and ALS.
- A pilot grant for basic science went to
   Thomas Kukar, PhD, at Emory University School of Medicine. AFTD support will enable him to pursue Identification of the signaling receptor that mediates the neurotrophic activity of progranulin, a protein that is associated with some forms of FTD.
- For the first time, AFTD awarded two postdoctoral fellowships. Hilary Archbold, PhD, at the University of Michigan, will be tracking RNA in FTD neurons, to understand how failure to properly metabolize RNA leads to nerve

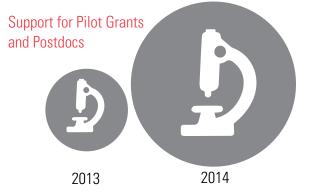
- cell death in TDP-43 FTD nerve cells. Maya Lichtenstein, MD, will be working with patients at the University of British Columbia to develop a clinical test capable of distinguishing behavioral variant FTD (bvFTD) from depression, a common misdiagnosis for FTD patients.
- AFTD's partnership with the Alzheimer's Drug
  Discovery Foundation to fund FTD drug discovery
  continues, with awards this year going to:
  Charlotte Teunissen, PhD, of the VU Medical
  Center in Amsterdam to search for FTD
  biomarkers in cerebrospinal fluid; and to
  Matthew Disney, PhD, of The Scripps Clinic in
  Florida to develop and test molecules he has
  identified that have potential to modulate



Jennifer Yokoyama, PhD Susan Marcus Memorial Fund Pilot Grant recipient

- toxicity of the *C9orf72* mutation in FTD and/or ALS.
- Gil Rabinovici, MD, of UCSF, was awarded
   \$100,000 to test a new PET ligand (originally
   developed as an Alzheimer's biomarker) in FTD
   patients. Dr. Rabinovici and colleagues hope to
   determine if this technology can distinguish
   FTD associated with deposits of the tau protein
   from those associated with other pathologies—a
   key piece of information that will contribute
   to accurate diagnosis and development of
   clinical trials for FTD patients. The study is also
   supported by the Rainwater Charitable
   Foundation and Avid Pharmaceuticals, Inc.

AFTD was also proud to support a number of scientific conferences, among them the 9th International Conference on FTD in Vancouver, British Columbia and a meeting co-sponsored with the ALS Association to explore the genetic connection between FTD and ALS.



### delivering essential support

Our unique resources help people cope with the daily challenges of FTD. More than 2,100 people contacted AFTD's HelpLine in FY2015—including caregivers, family members, individuals living with a diagnosis of FTD, and the professionals who care for them.

AFTD increased the budget for our Comstock
Respite and Travel Grant program to \$80,000,
reflecting a practice of increasing the scale of this
program each year. We were able to award 150
Comstock Respite and Travel Grants, up nearly
one-fifth from the previous year.

AFTD increasingly engages with people who have been diagnosed, working to better understand FTD from their perspective and to identify ways in which AFTD can help meet their needs.

AFTD's Annual Education Conference in San Diego, California drew 202 attendees; 123 identified as caregivers, and 24 identified as individuals living with FTD. Attendees engaged with experts in FTD research and clinical care, nonpharmacological interventions and hospice care. Two sessions were offered for attendees living with FTD. The Keynote Address was provided by Dan Browning, a journalist covering healthcare and medical research for the Minneapolis-based *Star Tribune*, who reflected

on his family's journey as his wife Liz Cummings Browning was diagnosed with FTD and ALS and passed away in May 2014.

AFTD continued to expand its focus on providing support for kids, teens, and young adults with loved ones impacted by FTD. By the end of FY 2015, AFTD's Facebook group for young adults had 113 members, 12 of whom joined together for lunch at our San Diego Education Conference. As another indicator, AFTD's Kids & Teens website resource drew more than 3,300 visitors in FY 2015.

AFTD secured a three-year, \$225,000 grant from the Hearst Foundations, the first multi-year grant from a major U.S. foundation for the organization's work. Hearst support will enable AFTD to develop new resources and mechanisms to ensure that all individuals with FTD and their caregiver(s) have access to high-quality, effective support services.



Conference Keynote Speaker Dan Browning (right) with Ken Fousel, who donated the keynote to honor Lynne C. Sanders, who died of a variant of FTD.

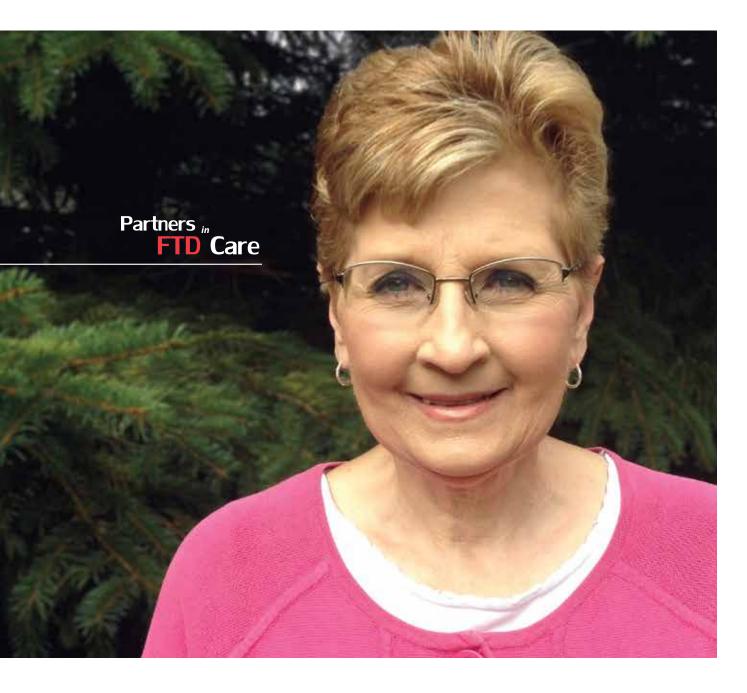




## Esther Harvey & Family, Funding Partners and Support Group Leaders

Diagnosed with FTD in 2007, Kevin Harvey passed away in 2012. In his memory, the Harvey Family has worked to increase both awareness and meaningful support for other families affected by FTD. In 2014, the family facilitated a news segment that broadcast information about FTD across Connecticut. This past year they awarded a generous grant in support of AFTD's Comstock Respite & Travel Grant Program. "Kevin's main priority in life was providing for his family. My children and I are committed in doing the same, only this time, that family is our FTD family."

Esther Harvey holds a photo of her husband Kevin. Behind her, from left: Jim and Meghan Roscoe, Shannon Harvey, and Vanessa and Keith Harvey.



#### Long-Term Care Educator Susan Hirsch

As the Education and Development Specialist for HCR ManorCare, Susan Hirsch contacted AFTD to learn more about how to help caregivers meet the needs of an individual with behavioral variant FTD. Ultimately, she was invited to join AFTD's Partners In FTD Care initiative, implemented in 2011 to provide long-term-care staff with useful information about the various FTD disorders. It offers educational resources, case studies, and accounts from the perspectives of patients and family. "The outcome has been a positive collaboration that ultimately benefits the individual's care. It is exhilarating and rewarding to work with a diverse group of caregivers and create tools that are useful to all."

### educating families and providers

Families and healthcare providers turn to AFTD for tools to help them understand this rare disease and deal with its treatment and consequences. AFTD's website www.theaftd.org drew more than 178,000 visitors in FY 2015. Our Kids and Teens resource drew more than 3,300.

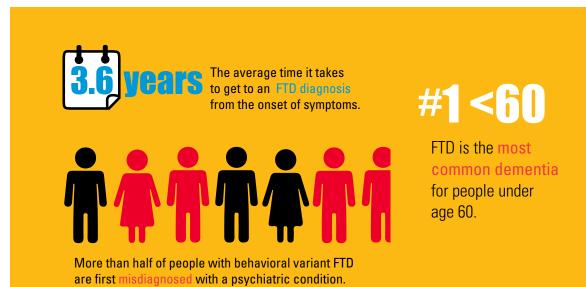
On an ongoing basis, AFTD's collaborative Partners in FTD Care program offers comprehensive new education modules for healthcare professionals and family caregivers. The primary focus is on educating professionals in care facilities, equipping them with the knowledge and understanding to deliver appropriate, effective management strategies. In FY 2015 we expanded the expert committee that informs this program, and detailed care strategies on changes in eating and managing compulsive behaviors, the loss of empathy and connection in FTD, and sexual behavior in FTD.

The Partners in FTD Care program also saw its expertise valued by other publications. An article, "Setting Goals for Care of the Person with Behavioral Variant of Frontotemporal Degeneration (bvFTD)," offered guidelines on clinical practice in the Summer 2014 issue of the *Arizona Geriatrics Society Journal*. The piece was authored by members

of the Partners in FTD Care committee: Geri Hall, PhD, ARNP, GCNS, FAAN; Maribeth Gallagher, DNP, PMHMP-BC, FAAN; Jill Shapira, PhD, ANP-BC, and Sharon Denny, MA.

#### At the 9th International FTD Conference in

Vancouver, British Columbia in October 2014, Brianna Sullivan (featured in our 2014 Annual Report) presented a poster that analyzed calls to AFTD's HelpLine from across a 12-month period as a way to provide valuable information about our community's health needs.



### resolve to raise awareness

We're using everything from food to Facebook to spread the word.

In October, AFTD and communities across the country observed the second annual FTD Awareness Week with Food for Thought grassroots awareness and fundraising events. Through 80 events in 36 states, Washington D.C., and two Canadian provinces, AFTD's Food for Thought campaign raised \$98,689, a 70 percent increase over the prior year.

Since 2012, AFTD's With Love campaign, targeted for the lead-up to Valentine's Day, has helped to generate additional engagement, awareness and support. In winter 2015, through a combination of grassroots campaigns, direct appeals and individual matches, With Love raised more than \$50,000 for AFTD.

Also since 2012, AFTD has fielded a growing team of participants at a spring 5K and 10 Miler in King of Prussia. This spring we made a significant leap of faith, bringing AFTD-Team participation to three other pre-existing races, in: North Carolina's Research Triangle; Boston, Massachusetts; and Austin, Texas. These events strengthened awareness within their targeted communities and raised more than \$92,000.

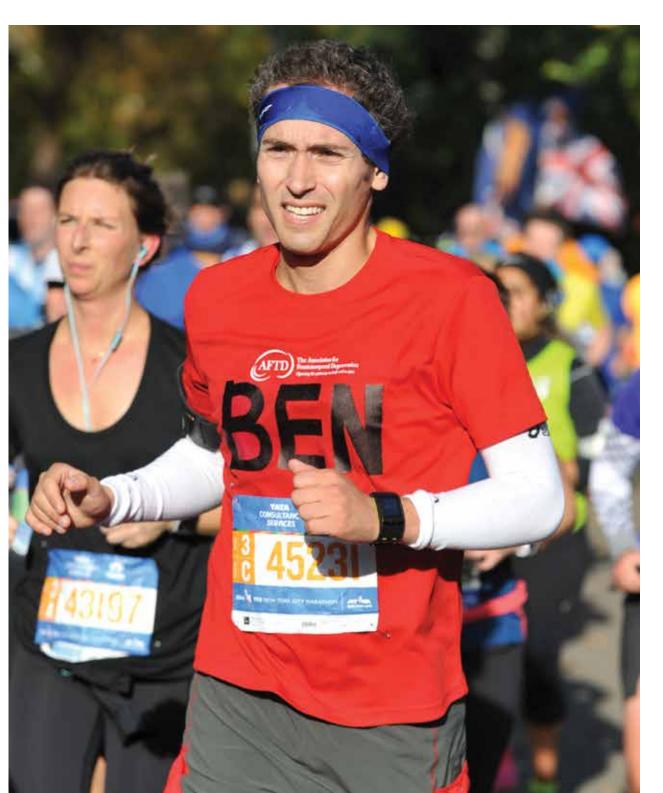
In late December we worked with Discovery
Communications to create an original Public
Service Announcement (PSA), and on December 29
both AFTD's film It Is What It Is and the PSA were
broadcast on the Discovery Life channel. AFTD also
provided key support for promotional efforts for
the film Looks Like Laury, Sounds Like Laury, which
ran on the World Channel throughout spring 2015
and drew significant new media coverage for FTD.

AFTD strengthened its social media presence—increasing our base of Twitter followers by 59 percent, and increasing membership in an AFTD online group for young adults on Facebook by 37 percent. We have also begun planning for our first social media awareness campaign. Working with a student team at Boston University, we created Who I Love, which will share stories from people who have lost loved ones to FTD alongside reactions from people learning about FTD for the first time. The video will be released in February 2016 with assistance from community members.



Kennedy Ho prepares for a Food for Thought event.





#### Ben Austin's Marathon Tribute

In 2009, Ben Austin put his life in California on pause and returned home to Massachusetts to help care for his father, Robert, during his final months with FTD. "Being so far from my family was incredibly difficult...it was the right thing to do." Five years later, he set a further example of how to do the right thing by running the 2014 New York City Marathon (his first) for FTD awareness. Ben's fundraiser, launched on what would have been his dad's 65th birthday, raised \$12,000 for AFTD. "The outpouring of support from friends, family and the FTD community was truly humbling."

Ben and his father, Robert Austin



### Susan Suchan, Advocate from the Patient's Point of View

AFTD's efforts to expand its support services so that diagnosed persons can more fully participate in its programs and services found an eager volunteer in patient selfadvocate Susan Suchan. "I believe including those diagnosed in all discussions brings knowledge to those searching for a cure, and a realistic approach to actually living with the progression of FTD," said Susan, who is diagnosed with Primary Progressive Aphasia and is an active participant in AFTD conferences, networking initiatives and grassroots events. "AFTD's work is monumental in bringing awareness, education, resources and research dollars. I am honored to participate in any way I can."





Nancy Cummings: Bringing AFTD to More Communities

Nancy Cummings has spent her entire career supporting people with varied cognitive issues by developing care programs, managing resources and building inter-agency collaborations. Her professional engagement with people with FTD and their families first introduced her to AFTD. "The staff were simply amazing in helping me better understand this disease and the myriad of associated issues, and in providing me information to share with families. I volunteered to be Middle Atlantic Regional Coordinator for AFTD in 2014 to help the organization extend its reach into my local communities. I am continually amazed at what the organization accomplishes."

### advocacy for research, investment and collaboration

The spotlight on FTD has gotten brighter now that it has been included as a priority in the National Alzheimer's Plan Act effort to cure Alzheimer's and related dementias by 2025.

With the help of our professional partners in the clinical and research world, this recognition was swiftly converted into tangible momentum last fall when National Institutes of Health (NIH) made a significant investment targeting FTD. NIH grants totaling \$30 million over the next five years are bringing together 15 clinical centers across the U.S. and Canada, formally establishing an FTD-focused clinical trial network with common protocols and data repositories.

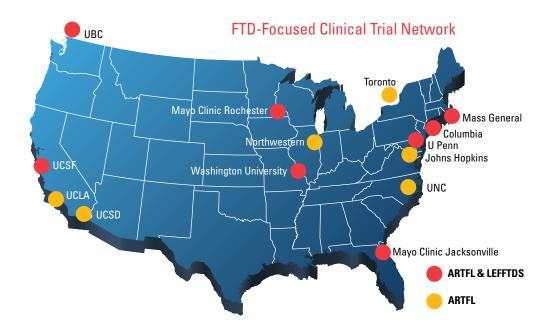
This network will support two research programs, known by the acronyms ARTFL and LEFFTDS, which will present significant new opportunities to participate in research. These opportunities will allow pooling of data from across a geographically scattered community, creating one large cohort and enabling us not only to begin to collect data that will document the natural history of FTD as it evolves, but also provide the framework of a readymade clinical trial network, appealing to pharmaceutical and biotech industries as they consider

investing in the development of FTD diagnostics and therapeutics.

In spring 2015, AFTD awarded a grant to Dr. James Galvin to conduct an economic burden study of FTD. By capturing the reality experienced by families in precise economic terms, we can establish a rationale for new diagnostics, influence reimbursement policy and inform improvements to the quality of care. Our target is that preliminary results will be ready for presentation at the 10th

International Conference on FTD, to be held in Munich in August 2016.

Growing dialogue with industry is a natural result of the increasing number of companies reaching out to better understand what we know about the science of FTD, and how they might find opportunity by taking on the challenges that lie ahead. Industry engagement is a direct result of our community's advocacy—efforts that will only continue to gain momentum going forward.



# with **gratitude** to our donors

Donors are the essential partners helping AFTD to transform its vision of the future into concrete action.

We are grateful for the determination our community has shown during FY 2015, and hopeful for deeper gains in the years ahead with your continued support.

#### 100,000+

Discovery Communications
Samuel I. Newhouse Foundation, Inc.

#### 50,000+

Susan Laden Philip H. Lovett

Lawrence and Jillian Neubauer

**Beth Walter** 

Mr. and Mrs. David Zaslav

#### 20,000+

Bloomberg Philanthropies Colonial Electric Supply Mary Ellen James Raymond Koenig Margarita McGrath Bob Menschel

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**Bonnie Shepherd** 

Mr. and Mrs. Tom Tisch

#### 10,000+

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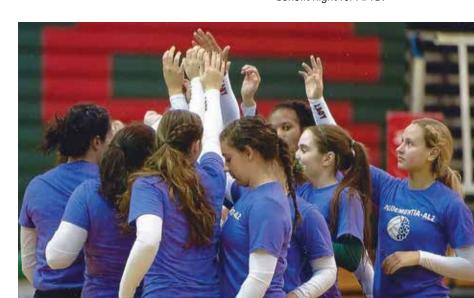
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**1,000+** (continued)

Joanne Ho

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Nicholas Vanoff

Stuart Waldman

Mr. & Mrs. John Weicher

Cheramy White John Whitmarsh Mary Wisneski Todd Zaborski Sean Derrow and his girlfriend Margot took part in the Cambridge 5K Freedom Run.



# with thanks for successful grassroots events and fundraisers

Each of these grassroots events and fundraisers brought in \$1,000 or more during FY 2015.

Overall, 141 events across the United States raised awareness and secured more than \$605,000 for the fight against FTD. AFTD appreciates the resolve shown by the members of our community, so many of whom chose to dedicate creativity, vision and hard work to hosting these powerful events.

2nd Annual "Help Josh Find a Cure for FTD" Golf Outing and Dinner

Don Pierce

9th Annual George F. Sidoris Memorial Golf Outing

George S. Sidoris and Christine Sidoris

Al McNulty Benefit for Dementia Research Joel McNulty

American Junior Golf Association Fundraiser
Gabe Lysen

**Auction for AFTD** 

David Wagner

**Color Run** Danny Hedaya

**David Gragg Memorial Event** 

Sarah DeLuca

**Doodles Art Show** Nancy Carlson **FTD Awareness** 

**Ashley Bay** 

**Golf Tournament** 

Walker Family

Hiking the Appalachian Trail

Brandon Cline and Katherine Vance

In Memory of Arnette for Drug Discovery
Paul Lester

Jason's Bar Mitzvah
Jason Goldring

Laura's Legacy Campaign

Rick Ranti

Lillian's 8th Birthday

The Van Son Family

Newhouse/Mele Dinner
Donald Newhouse & Kathy Mele

**New York City Marathon** 

Ben Austin

New York City Marathon Guglielmo Ravalli

Remembering Arnette's Contributions to Paul's Career and Subsequent Retirement

Paul Lester

**Riverdale Country School Dance-a-thon** 

Jason Goldring

The Robert M. Hatfield Foundation's 4th Annual Golf Classic

Matt Hatfield

**Strong Body Strong Mind** 

Deanna Angello

White Family Event Dennis White

Pappy Van Winkle Classic

Gentlemen of the Pappy Van Winkle Classic

With Love

Joanna Dauber Debbie Fenoglio

Lisa Lancelot

Team Alice

**Bonnie Shepherd** 

Charles Sperrazza

The Rainwater Charitable Foundation

**Beth Walter** 

Walking the Walk 2015

Andy Derrow

Susan Dickinson

Zoy Kocian

Kacy Kunesh

Elizabeth Soriero

Caroline Waldeck

**Food For Thought** 

Gail Andersen

Joe Bellwoar

Steve Bellwoar

Katie Brandt

Joan and Theresa Brzezinski

**Lucy Carter** 

Linda Ciccarelli

Debbie Fenoglio

Sylvia Gentry

Leslie Grayson

Cheryl Johnson

Sandy Karger

Wendy Miller-Anello

Joy Ortego

**Brian Rose** 

Elaine Rose

**Alice Saunders** 

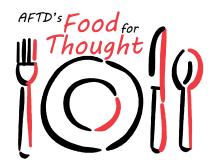
Allyson Schrier

Bonnie Shepherd

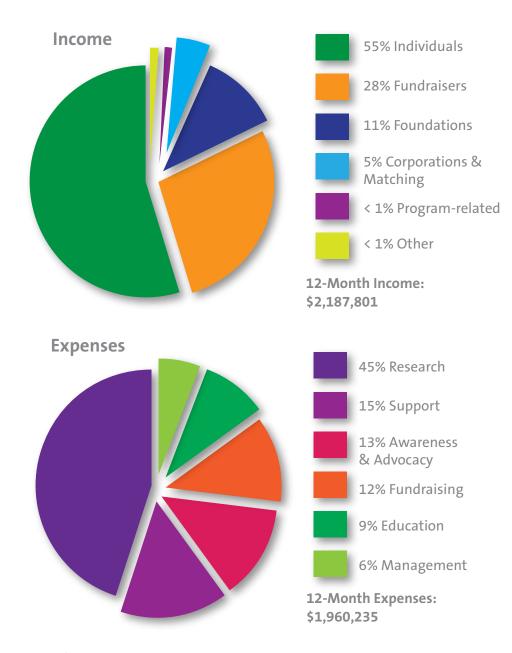
Tam Smith

Kerri Unger

Cheramy White



# statements of financial position as of 6.30.2015



#### **Assets**

Cash & Prepaid Expenses	\$2	,690,553
Contributions Receivable	\$	225,000
Accounts Receivable	\$	7,120
Investment in FTD Disorders Registry LLC	\$	95,412
Equipment	\$	15,049
Security Deposit	\$	6,289
Total Assets	\$3,039,423	

#### **Liabilities and Net Assets**

Current Liabilities		
Accounts Payable & Accrued Expenses	\$	17,925
Research Grants Payable	\$	300,000
Total Current Liabilities	\$	317,925
Net Assets		
Unrestricted	\$1	L,918,275
Temporarily Restricted	\$	803,223
Total Net Assets	\$2	2,721,498
Total Liabilities and Net Assets	\$3,039,423	

### outlook: building on the momentum

As we head into 2016, AFTD Board, staff and volunteers are busy advancing the work laid out in our Strategic Plan. The resolve of AFTD's community is bringing our shared hopes into focus, and we're invigorated by the building momentum.

At the first World FTD Awareness Week (October 4-11, 2015), organizations from 10 countries will join forces to create a truly global FTD community. In the U.S., this winter we'll offer ways to tell the world of loved ones impacted by FTD. AFTD-Team springtime runs and walks will promote awareness across the country.

Our resolve to develop a national community of support is bearing fruit. We're working with support groups across the country to improve training and offer a direct link to our exceptional resources, and to the shared wisdom of those who have gone before on this journey.

AFTD will offer more research opportunities than ever before. These include an online registry, an economic burden study and a biomarkers initiative. All will contribute to a vital understanding of the biology and process of FTD. A collaboration with NIH supports a new network of clinics across the U.S. and Canada that will lead the way in developing a picture of the natural history of FTD. And we are

engaging with a growing number of pharmaceutical and biotech companies excited at the prospect of pursuing the first therapeutics for any neurodegenerative disease.

AFTD will continue our work aligning efforts of industry, government and nonprofits towards complementary investments. We will work to improve care for people living with FTD right in their communities. And we will capitalize on growing momentum by finding new, high profile opportunities to raise awareness. This is made possible by those of you who have generously chosen to donate to AFTD—positioning us to become the organization our community deserves and so urgently needs.

Finally, save the date for the AFTD 2016 Annual Education Conference in Minneapolis: May 13, 2016. We look forward to seeing you there.

We will continue our work with passion, resilience and resolve until every person touched by this disease has the support, treatment and hope that they both need and deserve.

Sincerely,

Smyridi

Susan L-J Dickinson, MS, CGC Executive Director



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