RESOLVE
to make
a difference.

2015 Annual Report
July 2014-June 2015

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

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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 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.

Support for Pilot Grants and Postdocs

Jennifer Yokoyama, PhD
Susan Marcus Memorial Fund Pilot Grant recipient
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.
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.”
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, PMHNP-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.
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.

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.

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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
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."

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 self-advocate 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."
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 ready-made 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
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AQR Capital Management LLC
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Nancy Carlson
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**12**
In Martinsburg, West Virginia, the Musselman High School Volleyball team hosted a benefit night for AFTD.
1,000+ (continued)

Joanne Ho
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Cheramy White
John Whitmarsh
Mary Wisneski
Todd Zaborski

Sean Derrow and his girlfriend Margot took part in the Cambridge 5K Freedom Run.
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

**Income**
- 55% Individuals
- 28% Fundraisers
- 11% Foundations
- 5% Corporations & Matching
- <1% Program-related
- <1% Other

12-Month Income: $2,187,801

**Expenses**
- 45% Research
- 15% Support
- 13% Awareness & Advocacy
- 12% Fundraising
- 9% Education
- 6% Management

12-Month Expenses: $1,960,235

**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 $1,918,275
- Temporarily Restricted $803,223

Total Net Assets $2,721,498

**Total Liabilities and Net Assets** $3,039,423
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,

Susan L-J Dickinson, MS, CGC
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Business Manager
Bridget Moran, MPH
Support Services Manager
Pamela E. McGonigle, MA
Development Manager
Matthew Sharp, MSS
Program Manager
Elizabeth Neal
Grassroots Coordinator
Jamie Barnaba
Development & Business Assistant