



# The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

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## AFTD Unveils 2015-2018 Strategic Plan

Over the past few years, successful program work and advocacy have produced unprecedented growth for AFTD, and the 13-year old organization is emerging as a national force combating FTD. Fueled by a passionate core of Board members and staff, and a growing, vital base of volunteers and donors, AFTD has successfully implemented its first multi-year strategic plan (enacted November 2009), broadened its impact in all areas of the organization’s mission, and expanded organizational capacity.

In summer 2014, AFTD’s Board of Directors determined to chart a thoughtful, proactive course for the next three years. Drawing on information gathered from across a

community of individuals, families, researchers and advocates, the resulting strategic plan will rely upon proven strategies of leverage and collaboration to realize progress across all of AFTD’s targeted mission areas.

### Pursuing Five Key Goals

We have organized AFTD’s 2015-2018 Strategic Plan around five connected goals:

**Goal I. Accurate Diagnosis, Quality Care:** People will receive a timely and accurate diagnosis and have access to high quality medical care.

**Goal II. Effective Support:** Every person with FTD and their caregiver(s) will have access to high quality, effective support services.

**Goal III. Awareness:** FTD will be commonly recognized and understood.

**Goal IV. Increased Support:** AFTD will diversify and increase its funding.

**Goal V. Strategic Sustainability:** AFTD will continue to mature into a sustainable organization with strategic and effective: leadership, marketing, technology and professional governance practices.

### Expanding AFTD’s Impact: January 2015 – June 2018

Based on existing support trends, and multi-year efforts identified in our Strategic Plan, AFTD projects that over the next three years its income will nearly double to \$3 million. Each year of the Plan, nearly 40% of funds spent will be focused on research to drive development of accurate diagnosis and therapeutics for this disease.

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## AFTD’s HelpLine Offers Vital Information, Resources, and Support

Since 2005, people who need information, resources or support regarding FTD have been able to rely upon AFTD’s toll-free HelpLine. Begun as part of AFTD founder Helen Ann Comstock’s vision of support for individuals and families facing FTD, the HelpLine fields questions from caregivers, professionals



*From left to right, Matthew Sharp, Kerri Barthel, and Sharon Denny, three AFTD staff who play key roles for the HelpLine.*

and, increasingly, persons diagnosed.

Three key staff – Matthew Sharp, M.S.S., Program Manager, Kerri Barthel, M.S.W., Volunteer Manager, and Sharon S. Denny, M.A., Program Director – ensure that each HelpLine

inquiry receives an individualized, timely response.

*(Continued on page 8)*

## Spotlight On... Kathy Mele, AFTD Board of Directors

An elementary school and English as a Second Language (ESL) teacher, Kathy Mele also chairs the Board of the National Dance Institute, an organization that teaches dance in New York City's public schools.

Kathy became an AFTD Board Member in June 2014. As a caregiver for her mother, Susan, who has lived with primary progressive aphasia (PPA) for the past 15 years, she brings a passion to her role with the organization, and interest in strengthening all areas of AFTD's mission.

She first engaged AFTD through the organization's website, which offered materials that helped her to better understand FTD, and to learn ways to better support her mother in her journey.

As her mother's PPA has progressed over time, Kathy's perspective has evolved with it. For example, during one difficult phase of the disease, she found her focus shifting from concern about challenging behaviors to a focus on the bigger picture. "Your family member

might do something that is not easy to handle, they may lash out, and there are going to be moments of incredible stress..." she says. "For me I learned that the bottom line was... was my mom safe? And was she as comfortable as we could make her?"



*Kathy Mele and her mother Susan at a New Year's Eve party.*

Kathy and her father began to find shared strength in their roles as caregivers. "It helps when family members can support each other through an experience of loss of a loved one's presence in their lives," she says. Together, they also began to seek more ways to help others living

with FTD. This process led Kathy to take on a Board role with AFTD, helping the organization strengthen its sustainability and impact. Most recently this work saw her establish an AFTD named fund, the Suzy Fund, dedicated to her mother's kindness and generous spirit.

Supporting research to help to find a cure for FTD is one of Kathy's goals for her time on the Board. She sees AFTD's awareness efforts, to ensure effective diagnosis and high-quality care, as well as the organization's extensive support offerings (such as its respite grants for full-time caregivers), to be equally crucial contributions.

Ideally, she looks toward a day when individuals and families facing an FTD diagnosis have access to a social worker or other care coordinator, who would assist them in navigating the challenges ahead.

Today, knowing that her mom is well cared-for, safe, and still part of her and her family members' lives has brought her more of a sense of peace.

## AFTD NEWS BRIEFS

**Food for Thought Liaisons:** AFTD is seeking volunteers to help lead the 2015 Food for Thought campaign. If you're interested in this volunteer position, contact Liz at [eneal@theaftd.org](mailto:eneal@theaftd.org) for more information.

Two AFTD **telephone support groups** anticipate openings soon: our parents group for people with a diagnosed spouse or partner who have children in the home, and our group for persons diagnosed with FTD. Contact [info@theaftd.org](mailto:info@theaftd.org) or call 866-507-7222.

AFTD is excited to introduce our **two newest regional coordinators:** Amy Eissler, who is taking over the Northwest region, and Michelle Grant, who is joining regional coordinator Ashley Linsmeier in the South Atlantic region. Feel free to reach out and say hello — they would love to hear from you! You can find their contact information on the following link: [www.theaftd.org/get-involved/volunteer/regional-coordinator-contact-information](http://www.theaftd.org/get-involved/volunteer/regional-coordinator-contact-information).

AFTD Board Officer Bonnie Shepherd shared on a podcast regarding her family's journey with FTD, from getting an accurate diagnosis and caring for her husband to finding a way to have a positive impact on the FTD community after his passing. **Listen to her powerful story** here: [www.ccmixer.org/files/BonnieShepherd/49371](http://www.ccmixer.org/files/BonnieShepherd/49371).

The volunteer network pages on AFTD's website have been revised. **Learn more about volunteering** with AFTD, access the volunteer form, find your regional coordinator, explore some volunteer opportunities and see a list of our recent volunteers who have assisted in addressing AFTD's mission. [www.theaftd.org/get-involved/volunteer](http://www.theaftd.org/get-involved/volunteer)

*AFTD Board Officer  
Bonnie Shepherd*



# AFTD relies on the generous support of individuals like you to achieve our vision!

We take pride in helping our community. You can take pride knowing your gift will bring care, support and hope to individuals and families across the country. In the words of one donor:

*"I value AFTD's work, and look forward to each newsletter that bears encouraging reports on progress in your efforts to ensure a cure for this tragic condition in the future. Thank you for your continuing dedication to this cause."*

*David Wagner*



*David and his partner Paul T. Schleyer*

David's sense of hope suits a time when growing awareness and interest from government, clinicians, researchers and industry stakeholders mean that there has never been more momentum in our community's fight against FTD. AFTD can seize this opportunity for impact, driving vital new research, novel supports and growing advocacy for change – but we need your help.

Join David Wagner and make a charitable gift to AFTD today by visiting our website at [www.theaftd.org](http://www.theaftd.org) and clicking "Donate Now", or exploring the "Ways to Give" menu. Help us ensure quality care, find a cure – and perhaps one day prevent this disease!

## AFTD Welcomes its First Director of Development & Communications

In early February 2015, AFTD hired its first Director of Development & Communications, Ben C. Freeman. Ben brings more than ten years of experience in nonprofit development and communications, and prior background in technology and IT systems.

For a decade, he served as Development Director for the Paraprofessional Healthcare Institute, a nonprofit dedicated to improving the quality of care for elders and people living with disabilities, by improving direct-care workforce training and employment.

At PHI, Ben built a development team that supported the nonprofit's growth from \$4 million to \$9 million in annual revenue. That evolution saw PHI more than double its staff capacity and range of impact, build vital infrastructure for scale, and evolve into a national authority in its targeted field.

Ben brings a cultivated sense of strategic leadership and management, skills in foundation engagement, relationship building, and project management, and a strong background writing and editing for a variety of contexts.

He joins a development team with considerable talent and expertise. He will work in close coordination with two staff—Pamela E. McGonigle, M.A., Development Manager, and Liz Neal, Grassroots Event Coordinator—who helped make

2014 the best fundraising year AFTD had seen in its history, securing more than twice the amount raised in any prior year. "I'm grateful for the opportunity to join AFTD at this moment in its history," Ben says, "and welcome the chance to collaborate with the Board, staff, and volunteers to strengthen the organization's profile, impact, and sustainability."

Consciously integrating fundraising and communications direction in a single role provides a chance for AFTD to capitalize on unparalleled momentum for its work. Ben will work collaboratively with the Executive Director, Board and other members of our staff to engage AFTD's growing, dedicated community.

"The organization's 2015-18 Strategic Plan provides a powerful vision for engaging and inspiring donors, volunteers and other stakeholders," he says. "Targeted fundraising and communications effort are a vital link in urging these individuals to join us in combating FTD."

Elevating AFTD's national visibility – and helping the organization grow to sustain a \$3 million budget over a three-year period, will be key goals for Ben's work. He will soon begin efforts to recruit a Communications Manager, expanding the organization's ability to be responsive to emerging opportunities for awareness across social media and web communications, public relations, marketing and dissemination efforts.



*Ben Freeman*

# 2015-2018 Strategic Plan *(Continued from page 1)*

An additional 25% of expenditures will be devoted to expanding effective support mechanisms and developing and piloting new, unique resources for our community. Significant resources each year will also be invested in raising awareness, advocacy, educating professionals and strengthening core functions of the growing organization.

## A Blueprint for Collaboration

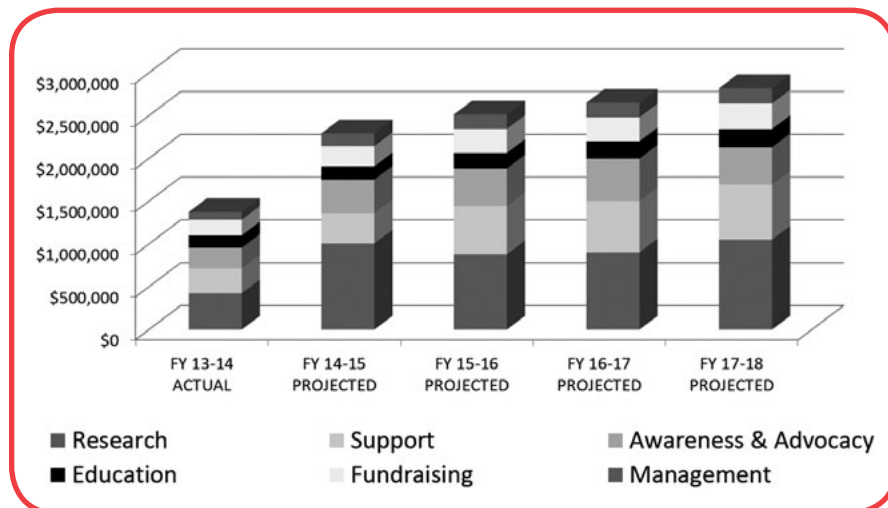
“AFTD’s Strategic Plan sets direction at a crucial juncture for our community – and provides a means for each of us to collaborate in effectively challenging FTD,” said AFTD Board Chair Jary Larsen, Ph.D. “Together, we can work toward accurate diagnosis, ensure the best quality care and a more understanding world for individuals and families impacted, and develop effective therapeutics for this disease.”

AFTD Executive Director Susan Dickinson adds: “Partnership with AFTD volunteers and donors, researchers, care professionals, advocates and individuals and families has helped AFTD’s work to achieve unprecedented momentum...” She continues: “Our Strategic Plan will serve as a blueprint to capitalize on this opportunity, to improve the lives

of individuals and families living with FTD today, and ensure a future in which the disease is effectively diagnosed, treated and one day, prevented.”

## Seizing an Opportunity

In adopting this Strategic Plan, AFTD’s Board recognized the value of the moment – that support and collaboration from a growing base of volunteers, funders, researchers and peer organizations have positioned AFTD to sustain significant growth across all areas of the organization’s mission.



*AFTD Expenses by Mission Area, FY14 – FY18*

Investment in research initiatives is weighted toward the early years of the Strategic Plan to reflect spending of a \$1 million research gift received in March 2014 and creation of an FTD Contact Registry during AFTD’s current fiscal year. Should income exceed projections, AFTD has also identified a range of initiatives that are primed for

accelerated implementation.

Over the course of the plan’s implementation, we will maintain and deepen the impact of existing AFTD programs, and invest \$2.1 million or more in new initiatives and organizational infrastructure.

We remain committed to ensuring that the portion of AFTD’s annual budget spent on management and fundraising will not exceed 20% in any year, a goal the organization has consistently met or exceeded.

## Implementing Our Vision

AFTD’s Board reviewed and adopted the 2015-2018 Strategic Plan at its meeting held on December 12, 2014. The plan outlines goals and strategies for January 2015 through June 2018. An action plan that details the timeline, tactics, measures and budget impact has also been developed and

will be continually reviewed by the Board to guide and monitor implementation of the plan.

For more information on AFTD’s Strategic Plan – and to find out ways in which you can help us to achieve the organization’s mission, please access [www.theaftd.org/about/strategic-plan](http://www.theaftd.org/about/strategic-plan) or contact us at [info@theaftd.org](mailto:info@theaftd.org).



## 2015 Drug Discovery Awards

**A**FTD is proud to announce the recipients of our 8th annual Drug Discovery grant program, which is run in partnership with the Alzheimer's Drug Discovery Foundation (ADDF). Since 2007, AFTD and the ADDF have collaborated to fund 24 programs, awarding more than \$2.7 million in competitive research grants. ADDF has generously matched AFTD's contribution 2:1, in this joint program dedicated to advancing drug discovery targeting FTD.

In the 2014 competition, **Charlotte Teunissen, Ph.D.** of the VU Medical Center in Amsterdam and Matthew Disney, Ph.D. of The Scripps Clinic in Florida were each awarded \$150,000 to support their medical research efforts.

Dr. Teunissen is a world expert in biomarker discovery research and has led the creation of protocols for cerebrospinal fluid (CSF) biobanking and the validation and review of novel biomarker assays.

These are critical steps in standardizing biomarker tests for use in clinical practice. Biomarkers are crucial to FTD research – as they will ultimately

make it possible to identify during a patient's life which brain changes are responsible for his or her symptoms.



Charlotte Teunissen, Ph.D.

Dr. Teunissen's project, "Novel diagnostic CSF biomarkers for pathological subtypes of FTD," builds on her earlier discovery of biomarkers in CSF that could distinguish between two distinct subtypes of behavioral variant FTD: those associated with the protein tau and those associated with TDP-43.

The ability to aggregate patients according to bvFTD subtype is particularly important in light of emerging efforts in FTD drug development and upcoming clinical trials. Dr. Teunissen's group will now focus on creating a clinic-ready version of two biomarkers and validating their use in well characterized bvFTD patient volunteers.

**Dr. Matthew Disney** is a leading expert in the area of RNA binding to small molecules, designing experiments that have improved our understanding

of how RNA interacts with such molecules, and creating "RNA-binding drugs." The American Chemical Society awarded him the Eli Lilly Award in Biological Chemistry for his research in this field.

Dr. Disney's project, "Lead optimization and pre-clinical testing of small molecules that modulate toxicity of cFTD/ALS" is a result of that expertise combined with his interest in the *C9orf72* gene mutation, which can cause hereditary FTD or ALS. RNA toxicity has lately been identified as one route to nerve cell death in FTD and ALS caused by the *C9* mutation. Dr. Disney has designed unique molecules that can bind to the pathological *C9* gene



Matthew Disney, Ph.D.

repeat expansions, thereby blocking the formation of toxic RNA – a step that could potentially slow the progression of *C9orf72*-related FTD or ALS.

This study will focus on optimizing a lead compound, "tweaking" its structure to: improve its ability to bind to the *C9* repeat sequence; ensure that it can cross the blood-brain barrier; and establish it as a potential drug development candidate for *C9* FTD patients.

## FTD Impact Survey

In summer 2014, we asked persons diagnosed with FTD, caregivers and family members to participate in an online two-question survey on the impact of FTD on their lives.

We received 828 completed surveys—57 from persons diagnosed and 771 from caregivers and family members. Although the majority of responders were from the United

States, individuals from Europe and Australia also replied. We extend a heartfelt thanks to everyone who found time to complete the survey.

Notably, through the survey, caregivers and family members were able to identify FTD symptoms that caused the most difficulty on a daily basis. Those most prominently named in survey responses were:

problems with language and communication; unpredictable, compulsive, inappropriate behavior; apathy and loss of feelings for others; loss of judgment and lack of emotional control; and an inability to plan and complete regular daily tasks. The full analysis can be found on the AFTD webpage under the *For Researchers/AFTD Research Analysis* tab.

# Donations Honor Loved Ones *Gifts received from October 16, 2014 - February 15, 2015*

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Families who wish to direct memorial donations to AFTD are encouraged to call our office. AFTD can mail you donation materials, or you can download them from our website. All donors will receive letters of acknowledgment, and families will also receive a list of donors. To contribute online, visit [www.theaftd.org](http://www.theaftd.org) and select "Donate Now."

## AFTD's Facility Outreach Volunteer Project: An Opportunity to Raise Awareness

by Shaleea Shields, AFTD Volunteer

For people diagnosed with FTD and their caregivers, the lack of knowledge around these disorders can be a frustrating challenge. Through work by dedicated volunteers, AFTD's facility outreach project is designed to educate providers about FTD. Work is now underway to educate key professional resources, including community health provider, long-term care and adult day center staff. With support and assistance from AFTD, volunteers take initiative to meet with these staff to raise awareness, providing vital information on these disorders, and on how the needs for individuals diagnosed with FTD are different from those for individuals living with other dementias. Drawing from organizational

materials, volunteers share information about AFTD as an informational and collaborative resource, and introduce them to the organization's dedicated initiative for professionals, Partners in FTD Care.

**Shaleea:** Margie Simon of St. Louis, MO is an outstanding example of a facility outreach volunteer. Through her work she has met with more than 20 different professionals. As a caregiver myself, it was my pleasure to interview Margie about her work:

### What made you want to volunteer in this capacity?

**Margie:** My young brother-in-law (my sister's husband) was diagnosed

in 2007 and died one year ago on February 10th. There are not many resources in the Saint Louis area for families like ours who receive this diagnosis. Most of the support services come through the Alzheimer's Association and are not specific to FTD. When Keith died, I did not want his death to be in vain. I wanted everyone to know that dementia affects young people as well.

### What type of feedback have you received?

**Margie:** Most of the feedback has been very positive. People want to know more about this young onset dementia. I always bring Keith's before and after pictures

## AFTD's HelpLine (Continued from page 1)

HelpLine inquiries ensure that AFTD is in touch with the current trends and most pressing needs for our community. Questions typically center on the need

for information, for local resources, for practical help from physicians and attorneys and for a need to reduce the isolation keenly felt by both the persons diagnosed and their caregivers.

"We make it a priority to offer accurate, reliable information for all who contact us through the HelpLine," said Matthew Sharp. "Through this resource, we're able to serve as a trusted voice to members of our community, often at a time when making a personal connection can be crucial."

Over the past four years, demand for the HelpLine has sharply increased. In 2014, AFTD saw more than 2,100 HelpLine inquiries, a total of 17% more calls than in the prior year.

We expect to see a continued increase in volume for our HelpLine inquiries through 2015 and beyond. In order to maintain a high quality of personalized service for

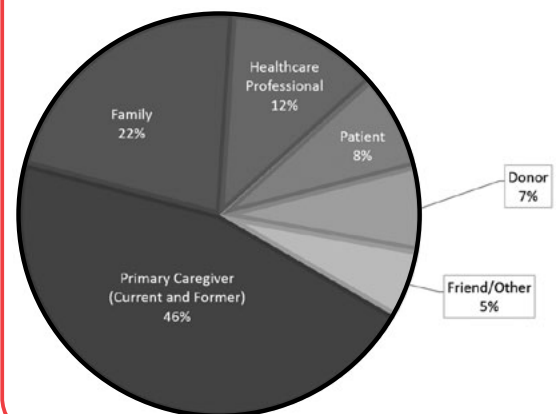
each person served by this resource, we are recruiting a Community Support Services Manager, and we will also continue to develop new procedures to maximize the Helpline's quality and efficiency.

"The HelpLine is a core aspect of AFTD's work, said Sharon S. Denny. It offers us a chance to interact directly with our community, and secures vital input to inform the design of programs across all of the areas of our mission, including our research and advocacy efforts."

As one example, after documenting that persons diagnosed seeking information on their own behalf represent an increasing percentage of individuals contacting AFTD through the HelpLine, we have responded by offering new targeted resources. These include a new telephone support group for individuals diagnosed, a dedicated section of the organization's website, and targeted new elements for our Annual Conference.

*"Through this resource, we're able to serve as a trusted voice to members of our community, often at a time when making a personal connection can be crucial."*

### AFTD Helpline Contacts: 2014



## Accessing AFTD's HelpLine

Toll-free at (866) 507-7222 | [Info@theaftd.org](mailto:Info@theaftd.org)



to make more of an impact. Putting a face to the disease has helped me connect with others in the community.

I also had the chance to speak with AFTD Volunteer Manager Kerri Barthel, MSW about the crucial role volunteers play for this facility outreach effort.

**How much do volunteers mean to projects such as this?**

**Kerri:** While we don't have the capacity to reach out directly to the individual communities and facilities across the country, AFTD has found that by collaborating with volunteers, we can achieve growing impact. Volunteers are integral to the Association's mission to increase awareness. Dedicated volunteers on the ground from across the country help to spread the word and share information.

**If people want to get involved and follow in Margie's footsteps, how do they get started?**

**Kerri:** We welcome and encourage others to join Margie's efforts! For those interested in joining our national volunteer network in this role, the first step is to complete our volunteer form which can be found on our website, [www.theaftd.org/get-involved/volunteer](http://www.theaftd.org/get-involved/volunteer). Once we receive the form, the regional coordinator volunteer, the "local" ambassador for AFTD who coordinates and supports volunteers throughout the region, will reach out directly. The regional coordinator will provide information about the volunteer program, provide project details and offer support: Before the first facility visit, volunteers participate in an orientation and project training.



Margie Simon and her brother-in-law Keith.

Please view the volunteer form on our website, then send it to [kbarthel@theaftd.org](mailto:kbarthel@theaftd.org) to get involved. Volunteers who work to educate can make such an impact!

# Giving a Hand to Our Helping Hands!

By Kathy Urban, AFTD Volunteer

When Mary Campbell lost her mother-in-law to FTD, she felt compelled to give back to the organization that helped her so much during that difficult time. Giving back and raising awareness are driving forces in her decision to volunteer: "I think, no matter what, we are always responsible to help educate and inform people about FTD," she says.



Mary Campbell

with their contact information. The regional coordinators in their area will then contact them directly to talk more in depth about volunteer opportunities. Mary has also developed a postcard to promote the AFTD's newly created Kids and Teens website ([www.AFTDkidsandteens.org](http://www.AFTDkidsandteens.org)), designed to garner interest in the website and the resources it offers to help young family members who are facing a loved one's FTD diagnosis.

Mary's career as a graphic designer and her desire to volunteer align perfectly. The use of graphics and illustrations play a strong role in influencing our decisions, activities and how we might spend our time and money. Mary has served as an AFTD volunteer for more than 18 months, offering her graphic design skills to help the organization disseminate important information in ways that catch a viewer's eye, and motivate action.

Attending an AFTD event or conference will likely bring you into contact with Mary's work. To support our volunteer recruitment efforts, she created a colorful flyer that interested parties can fill out and hand in

Having had the experience of helping to care for her mother-in-law, Mary encourages others to share their stories, "I've been surprised to find so many other people who have gone through some of the same things that my partner and I went through, and every little bit of advice

or guidance you can offer helps. Even if it's just listening and empathizing, it can make a huge difference to someone who feels like they are alone in dealing with this disease."

To find out more about how you can volunteer for AFTD, visit us online at [www.theaftd.org/get-involved/volunteer](http://www.theaftd.org/get-involved/volunteer)

**Has frontotemporal degeneration (FTD) affected your life?**

It's time to take action and volunteer!

Get involved today by joining a national network of volunteers making positive changes for those affected by FTD. The Association for Frontotemporal Degeneration (AFTD) needs the time and talents of volunteers everywhere to help raise awareness about FTD.

Opportunities range from leadership roles to residential facility outreach to touring exhibitions.

Together we will explore projects that benefit our kids and teens. AFTD will provide you with guidance to ensure that you have a satisfying and rewarding experience that will meet your individual goals and help make a difference.

Are you ready to take action?

**I'm ready to take action!**

Name: \_\_\_\_\_  
 Phone #: \_\_\_\_\_  
 E-Mail: \_\_\_\_\_  
 Area of Interest: \_\_\_\_\_

**Learn More!**

Contact:  
 Kerri Barthel  
 Volunteer Manager  
 267.514.7221  
[kbarthel@theaftd.org](mailto:kbarthel@theaftd.org)  
 Or visit:  
[www.theaftd.org/get-involved](http://www.theaftd.org/get-involved)

**AFTD Kids and Teens**  
 Explore. Learn. Connect.

AFTDKidsandTeens.org is an interactive website for children and teens affected by a parent's FTD. The site helps kids learn about FTD, to discover positive ways to deal with the changes it brings, and to realize that they are not alone.

Two distinct sections provide age appropriate information for younger kids and for teens.

Because strength grows from sharing experiences and strategies, children and teens are encouraged to submit drawings, poetry, stories or video diaries to publish on the website.

Visit AFTDKidsandTeens.org today and share this valuable resource with your kids.

For more information and/or to submit artwork to the site, email [kidsandteens@theaftd.org](mailto:kidsandteens@theaftd.org) or call 1-866-507-7222.

Scan this QR code and go right to our new site!

AFTD The Association for Frontotemporal Degeneration  
 Training to improve the quality of life

[www.theaftd.org](http://www.theaftd.org)

AFTD Kids and Teens Postcard

FTD Volunteer Mailer

# THE AFTD-TEAM



## NYC Marathon

AFTD was lucky to have two runners participate in the 2014 New York City Marathon. Ben Austin and Guglielmo Ravalli both chose to honor a loved one by selecting AFTD as their charity and took to the streets of New York on a very windy November morning to complete the race. They not only represented AFTD on an international stage, they also raised a combined \$14,832!

*If you have entered a marathon or other athletic endeavor and would like to fundraise for AFTD, contact Liz at [eneal@theaftd.org](mailto:eneal@theaftd.org). We'll send you some AFTD swag and help you publicize your run!*

## Doodles: A Five Year Journey

Acclaimed author and illustrator Nancy Carlson drew a picture every day for the past five years, while simultaneously caring for her husband after he was diagnosed with FTD. The result was "Doodles."

Nancy sold pieces of the collection during an exhibit that ran during December 2014 and January 2015 in Minnesota, and donated a portion of the proceeds to AFTD.

## A Concert for Hope

Linda Parsons hosted a concert in Canton, Ohio to raise awareness of FTD. A family of talented musicians, Linda and her son debuted "A Symphony for Douglas," which was written in honor of Linda's husband.



## Letter Writing Campaign in Memory of Arnette

Paul Lester once again sent letters to friends and family over the holiday season with an update on his own life, the busy lives of his two kids, and a request for donations in memory of his wife, Arnette, who passed away from FTD-related complications in 2013. Paul raised over \$8,500.



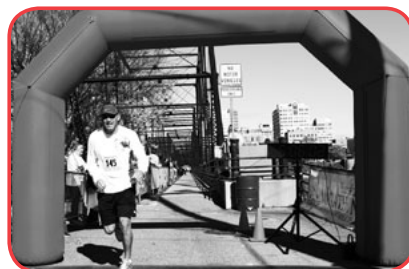
## End Dementia Night

The Musselman High School girls volleyball team once again hosted a fundraiser for AFTD, raising over \$600 in honor of their coach, Shawn Martz, whose family has been affected by FTD.

## Lillian's 8th Birthday

Instead of birthday gifts, Lillian Van Son decided to ask for donations to AFTD. Lillian's dad, Jeff, passed away from FTD in 2012. Lillian's older brothers have also dedicated past birthdays to their dad.

## Harrisburg Marathon



AFTD Board of Directors member Pop Shenian represented AFTD while participating in the Harrisburg Marathon in November. Pop is no stranger to bringing FTD awareness to the capital; both at the state and national level, he has been a key player in AFTD's government advocacy efforts.

## Riverdale Country School Dance-a-thon

The Riverdale Country School once again held a dance-a-thon in memory of Rachel Goldring, the mother of Jason, a Riverdale student. Both Jason and his sister Olivia have held several fundraisers at their school to support AFTD.

# THE AFTD-TEAM

AFTD's

With Love  
Campaign 2015

## With Love Campaign Meets its \$50,000 Goal

AFTD would like to extend a heartfelt thank you to everyone who donated to our 2015 With Love campaign, and in particular, to all of the fundraisers who shared their personal stories of love and life with FTD, and helped us to meet our \$50,000 goal for the campaign.

This year's With Love campaign focused on the story of Rona, who cares for her husband Ken. Rona describes how her reality differs from the future she had planned for, but she and Ken remain an unstoppable team in their fight against FTD.

In previous years, people who created fundraising pages were able to share their stories. This year, we did things a bit differently. We allowed anyone who made a donation

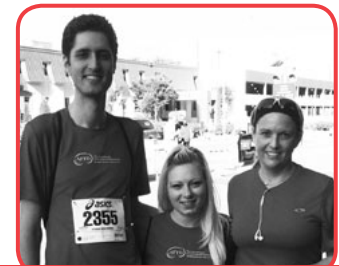
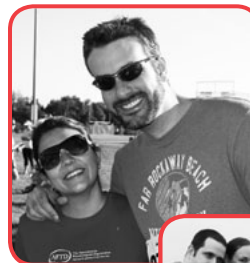
to With Love or created a fundraising page to contribute a picture of themselves and their loved one to be added to a slideshow on the main campaign page.

The slide show is a touching tribute to all of the caregivers and people diagnosed with FTD whose love drives them to continue to fight this disease. It can be viewed at [www.theaftd.org/get-involved/host-an-event/event-showcase](http://www.theaftd.org/get-involved/host-an-event/event-showcase).

Once again this year, Beth Walter and the Rainwater Charitable Foundation each provided generous \$10,000 matching gifts to With Love. We are extremely grateful for their continued support of AFTD and their love for the FTD community.

## Walk the Walk with AFTD

Winter is finally over! This spring, AFTD invites you to dust off your exercise gear and take to the streets (or trails or swimming pools) for FTD awareness. AFTD is looking for athletes across the country to participate in local athletic events in support of the organization. Whether you prefer running, cycling, swimming or all three, AFTD will help you find a local event and other members of the FTD community in the area to join you! To start your team, contact Liz at [eneal@theaftd.org](mailto:eneal@theaftd.org).



## Memorial Benefit

Sarah DeLuca and her family hosted an event in memory of Sarah's father, who passed away from FTD in 2014. The event raised more than \$3,500!

### Fundraiser in Honor of Dad

Ashley Bay hosted an online fundraiser in honor of her father, who is diagnosed with FTD. Ashley's fundraiser resulted in a \$1,300 donation to AFTD!

## The Robert M. Hatfield Foundation, Inc. Golf Tournament

On November 6th, 2014, the Robert M. Hatfield Foundation, Inc. held its fourth annual golf tournament in St. Petersburg, FL. The tournament raised \$7,000 for AFTD!





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

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