AFTD

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

Volume XIV, Issue 2 **Summer 2017**

AFTD's 2017 Education Conference:
Hundreds Gather to Learn and Connect

On May 5th, AFTD's 2017 Education Conference brought together 320 people from across the nation – more attendees than any prior year – for an informative and engaging day in Baltimore, Maryland.

The day began with opening remarks by AFTD Board Chair Gail Andersen, and from Sheryl Whitman, a community member diagnosed with the logopenic variant of primary progressive aphasia four years ago.

Dr. Halima Amjad delivering the keynote address at AFTD's 2017 Education Conference.

"For those of us diagnosed, the annual conference is a learning experience, and a teaching experience." Whitman said. "It's a time for those newly diagnosed with FTD to meet others on the same journey. And it's a chance for a lot of us to actually meet other people diagnosed with FTD, face to face, for the first time."

Chiadi Onyike, M.D., Director of the Johns Hopkins Frontotemporal Dementia and Young-Onset Dementias Program, provided an update on the latest medical research and developments. Later, Dr. Onyike joined Dianna Wheaton, PhD, director of the FTD Disorders Registry, for an "Ask the Experts" Q&A session.

Attendees had the chance to participate in three breakout sessions, grouped by themes: FTD care strategies, support and networking, and clinical issues. AFTD made a conscious effort to provide more breakout session options in 2017 based on feedback from previous years' conferences. The sessions were uniformly well received.

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Inside This Issue

AFTD-Team Races Show a Community Gaining Momentum

The AFTD-Team's 2017 Race Season is off to a strong beginning. In May 2017, during one weekend alone, more than 115 community members in three cities raised awareness and raised funds in support of AFTD's mission.

Team members joined the Colfax Marathon in Denver, the Fit Foodie 5K in Austin, and the King of Prussia 10 Miler 5K in Pennsylvania, evidence of an increasingly mobile community of volunteers dedicated to addressing this disease. The AFTD-Team just completed its fourth race of the season in June – and checked off a new city for the team – when more than 45 people participated in the Seattle Super Run.

Thus far, teammates have run or walked more than 645 miles combined and raised more than $11,200 to support AFTD's mission.

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Spotlight On... Brian Rose, AFTD Board of Directors

In 2008, Donna Rose's family began to worry that she was developing depression. It was seemingly the only way to explain the changes in her personality, her son Brian recently recalled. But her behavior got steadily stranger. One example of many: "My dad asked her to go get butter at the supermarket," he said. "She came back with a mop."

In 2012, doctors incorrectly labeled her condition early-onset Alzheimer's, but a reevaluation showed that Donna actually had behavioral variant FTD. Although this disease was unfamiliar to him, Brian – a relationship manager at Credit Suisse in New York – reasoned that there must be an organization out there devoted to it. "I was lucky enough to find AFTD," he said.


AFTD Board Member
Brian Rose

Brian's relationship with AFTD has grown ever since, and he joined AFTD's Board this year. "I want to help other people avoid having this diagnosis and being faced with no treatments, no cure and really no hope…" he said.

Brian is passionate about supporting research, and about finding unique ways to raise awareness of FTD. During the 2015 AFTD Food for Thought campaign, he encouraged friends, family and colleagues to share pictures of themselves enjoying their favorite sandwiches, along with the hashtag #ABiteToFightFTD. Last year, he organized a concept around ice cream, which he dubbed "Game of Cones."

"People find it fun," he said. "Some people gave money, some people just posted their favorite ice cream on Facebook." (Brian's favorite ice cream, for the record, is a salted-caramel flavor made by a Brooklyn ice cream parlor.)

Brian sees empowerment in how AFTD grassroots campaigns "give each individual the opportunity to feel successful and, in a way, liberated, to explain FTD to their peers and colleagues and loved ones."

In May, he attended his first AFTD Education Conference in Baltimore, and experienced first-hand our "very strong, meaningful, and compassionate" community. In doing so, he says, "I really got a sense of the breadth of people impacted by this disease – and the camaraderie that we share." That sense of connection and joint purpose is vitally important to AFTD's mission, and we are grateful to have Brian join our Board.

AFTD NEWS BRIEFS

New AFTD Educational Webinar

In May, Katherine Rankin, Ph.D., neuropsychologist and professor in the UCSF Department of Neurology, presented the third installment in AFTD's Educational Webinar series. In "Exploring Distinct Subtypes of Behavioral Variant FTD," Dr. Rankin described how researchers have identified specific patterns of nerve cell loss that lead to four distinct subtypes of bvFTD. Her presentation can help individuals diagnosed, families and healthcare professionals better understand how bvFTD diagnoses can present so differently; it also suggests new perspectives on managing FTD. Watch the full webinar by visiting www.youtube.com/TheAFTDorg.

AFTD Sponsors Dementia Action Alliance Conference

AFTD was proud to sponsor the Dementia Action Alliance's first-ever "Re-Imagine Life with Dementia" conference in Atlanta on June 25th-27th. The conference addressed many topics pertaining to dementia, such as the need to address dementia-related stigma, a better understanding about living with dementia, and ways to better accommodate people who have dementia. Caregivers, service providers and medical professionals were in attendance, as was AFTD Program Manager Matt Sharp.

FTD Disorders Registry Continues Its Momentum

Since debuting earlier this year, the FTD Disorders Registry has exceeded expectations, attracting more than 800 enrollees since its launch. The Registry's early momentum shows clear interest on the part of the FTD community to share their stories and help advance the science behind FTD research. Anyone with a connection to FTD – persons diagnosed, caregivers, family members, etc. – is encouraged to sign up. AFTD and the Bluefield Project to Cure Frontotemporal Dementia co-founded the Registry with generous support from the Rainwater Charitable Foundation's Tau Consortium program. For more information, visit ftdregistry.org.

Bring *Connection, Help and Hope* to Others Affected

Terry Ryan (right) and her sister Kay Glendy flank their mother in this 2014 photo.

Terry Ryan practically had to beg her mother to go to the neurologist. For several years, Terry had watched her develop unusual symptoms: when she spoke, what she said wasn't making the sense it once had; when she walked, she took tiny, halting steps. Her mother grew obsessive and paranoid; when she wanted to have a conversation she would go out into a field, away from "recording devices."

But when her mother eventually gave in and went to the doctor, Terry says she was not prepared for the diagnosis: the semantic variant of primary progressive aphasia. "I had no idea what that was," Terry said.

AFTD helped to point Terry toward the information, resources and support she'd been unable to find anywhere else. She learned about the differences between Alzheimer's disease and FTD, and what she could expect as her mother's disease progressed.

Recently, Terry made the commitment to become a monthly donor to AFTD. "I know that without regular support, AFTD would not be able to make continued progress in researching FTD, nor would they be able to offer the education and support for patients and caregivers and family members like myself."

Will you bring help and hope to others by joining Terry as an AFTD monthly donor today? If you would like to provide predictable support we can count on to sustain and expand AFTD's mission, complete the online form via www.theaftd.org (Get Involved -> Ways to Give -> Monthly Giving). Or contact AFTD Development Manager Pam McGonigle at pmcgonigle@theaftd.org or by calling 267-514-7221.

AFTD Pilots New "Quality of Life" Grants for Persons Diagnosed

In July 2017, AFTD began piloting a new Quality of Life grant to help persons diagnosed with FTD to access needed services or supports that they could not otherwise afford.

For the pilot, AFTD will award 20 Comstock Quality of Life Grants. Each pilot grant will be provided via a pre-paid debit card containing $500 to offset the costs of health care services, communications tools, transportation (such as rides in taxis or accessible vans) and other services that improve quality of life for the person diagnosed.

Grant recipients do not need to worry about saving receipts or applying for reimbursement - once the pre-paid card is provided, it can be freely used. For this pilot program, AFTD will rely on grant recipients to provide feedback to help make the application and award process run as smoothly and efficiently as possible.

"For the pilot, AFTD will award 20 Comstock Quality of Life Grants...in order to qualify, applicants must be diagnosed with an FTD disorder."

In order to qualify for this pilot program, applicants must be diagnosed with an FTD disorder. Applicants must also be residents of either the U.S. or Canada and provide copies of a diagnostic report showing how the diagnosis of FTD was made.

Pending the results of the pilot, the Quality of Life Grants will be incorporated into AFTD's overall Comstock grant program. For more information about this new resource for persons diagnosed, access www.theaftd.org, Life with FTD -> Resources -> Comstock Grants.

AFTD Staff and Board Members Visit Capitol Hill

On May 4, AFTD Program Manager Matt Sharp joined AFTD Board member Stephen Fenoglio in Washington, DC to visit the offices of three prominent Texas lawmakers: Sen. Ted Cruz, Sen. John Cornyn and Rep. Michael McCaul.

Fenoglio – AFTD's new Board lead for advocacy and a former congressional staffer – was able to schedule visits to the members of Congress during his trip east to attend the 2017 Education Conference in Baltimore.

The timing of these visits coincided with the overdue passage of the FY17 federal budget as well as the vote in which the American Health Care Act passed the House. The significance of both votes meant that it was a very hectic day for Congress, so Sharp and Fenoglio met with aides rather than the legislators themselves.

The visits were productive nonetheless. At each visit Sharp and Fenoglio were able to talk about AFTD's mission and educate Congressional staff on FTD and how it differs from Alzheimer's. They also described the inclusion of FTD in the National Alzheimer's Project and how it is considered to be a "related dementia" in terms of NIH's "Alzheimer's Bypass Budget." At each visit Sharp and Fenoglio asked for the Congressman's continued support for Alzheimer's and related dementia research at the levels specified by the annual bypass budget.

"Personal experience meant that at least one Congressional staffer was able to empathize with the experience of FTD as a rare disease. Another saw parallels to a grandmother's dementia story."

Personal experience meant that one Congressional staffer was able to empathize with the experience of FTD as a rare disease. Another saw parallels to a grandmother's dementia story. Each office Sharp and Fenoglio visited was receptive and supportive of funding dementia research at NIH. It was a positive sign when, the following day, President Trump signed the FY17 budget, which included an additional $325 million for NIH research on Alzheimer's and related dementias.

AFTD HIRES ITS FIRST CFO

AFTD's staff expanded this summer, as Christine Stevens, M.B.A. joined the organization in July as its first-ever Chief Financial Officer. Stevens brings significant leadership experience to her role, having held high-level roles in both nonprofit and for-profit organizations. Her established track record of achieving impressive organizational growth in these roles makes her an excellent fit for AFTD as it continues its own growth trajectory.

Christine Stevens, M.B.A.

Stevens spent the early portion of her career working for entrepreneurial startups, building teams and systems to enable growth at rapidly developing companies. Then, in 2002, she left the for-profit industry to begin her own small business in Wayne, PA, where she directed all aspects of an award-winning, profitable operation from the ground up.

Most recently, Stevens worked at the Philadelphia-based nonprofit Women Against Abuse, which advocates for people who have experienced domestic violence. She joined that organization in 2008 as its Director of Finance, and in 2015 she was promoted to Vice President of Finance. In recognition of her work there she was named the Nonprofit CFO of the Year by the *Philadelphia Business Journal* in 2013.

Stevens holds an M.B.A. from Northeastern University, and a B.A. in Economics from St. Lawrence University.

"I am very excited to join the passionate and dedicated staff at AFTD," Stevens said. "I'm grateful to join in expanding AFTD's work to support individuals and families affected by FTD, and to aid in the search for a cure for this disease."

Second Hope Rising Benefit to Be Held This October

Left to right: AFTD Board Members Danny Hedaya and Kathy Newhouse Mele, AFTD donor and volunteer Donald Newhouse, AFTD Board Chair Gail Andersen, and AFTD CEO Susan L-J Dickinson.

On Thursday, October 12, AFTD's second Hope Rising Benefit will be held at The Pierre Hotel in New York City. The event will be hosted by Benefit Co-Chairs Dr. Henry Louis Gates, Jr., David Geffen, Donald Newhouse and Anna Wintour, joined by two Benefit Vice-Chairs, AFTD Board members Kathy Newhouse Mele and Daniel Hedaya.

AFTD will present U.S. Senator Charles E. Schumer with the Susan Newhouse & Si Newhouse Award of Hope, in recognition of his decades-long work as a strong proponent of biomedical research, and his ability to foster bipartisan support for these efforts. The event will feature Tony and Grammy Award winner Cynthia Erivo, and will be hosted by Paula Zahn.

Last year's inaugural Hope Rising benefit drew more than 400 attendees. It received media coverage from the *Huffington Post* to *Crain's New York* among other outlets, and raised more than $1 million to benefit AFTD's mission.

If you would like to learn more information about the Hope Rising benefit, please access www.theaftd.org/newsroom/aftds-2017-hope-rising-benefit (www.theaftd.org, News & Events > AFTD's 2017 Hope Rising Benefit), email benefit@thaftd.org, or call AFTD's Development & Communications Director, Ben Freeman, at (267) 758-8647.

Donations Honor Loved Ones

Gifts received from March 16 – June 15, 2017

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Donate to AFTD...

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
and select
"Donate to AFTD."

Fostering Community Impact at AFTD's 2017 Volunteer Summit

Since its beginning, AFTD has had a generous and passionate group of volunteers. The dedication and devotion that they share with us is inspiring, and we are grateful to each volunteer for making such an impact.

On May 4, the day prior to its 2017 annual Education Conference, AFTD hosted its annual Volunteer Summit in Baltimore, MD. Reflecting the importance of this vital group, the Summit brought together affiliated support group leaders and other key volunteers for a day-long program focused on volunteer impact across AFTD's national community. The 45 volunteers who attended shared information and experiences, learned from one another in a supportive environment and further explored volunteer roles and opportunities.

The Summit included a presentation on the history of AFTD's volunteer program. At the Summit, AFTD recognized the more than 300 essential volunteers who drive our mission. These included ten regional coordinator volunteers, 11 Food for Thought liaisons, and 71 affiliated support group leaders – the most who have ever participated in each of these roles.

Attendees share their perspectives at AFTD's 2017 Volunteer Summit.

The Summit offered a chance to reflect on how AFTD volunteers help to raise awareness. In less than one year, volunteer efforts on the ground in local communities reached more than 6,000 people through table settings and meet-and-greet activities. Yet, there is still a huge need to increase FTD awareness in residential facilities. One way AFTD has helped to respond: Facility outreach visits by volunteers. To support volunteers in this important role, AFTD offers facility outreach trainings; a record total of 31 volunteers participated in the last three trainings.

AFTD thanks all past, present and future volunteers willing to take on this work and commit to so many areas of our mission.

Persons Diagnosed Connect Through AFTD's 2017 Education Conference

Approximately 60 members of the AFTD community gathered at a local Baltimore restaurant the night before the 2017 Education Conference for a special dinner for persons diagnosed.

The event, held at the Pratt Street Ale House in Baltimore's Inner Harbor, marked the sixth year that persons diagnosed held their own pre-conference dinner.

The event was organized by Susan Suchan and Sheryl Whitman, with help from Howard Glick. Sheryl (who was also the 2017 AFTD Education Conference's opening speaker), said that the annual dinner gives persons diagnosed the rare opportunity to interact with others who know firsthand what it's like to live with FTD.

"It's a really, really nice atmosphere – a friendly, fun environment," said Whitman, who was diagnosed with logopenic variant primary progressive aphasia (lvPPA) four years ago. "When people come for the first time, they tend to be apprehensive and nervous. But after they realize it's a relaxed, fun atmosphere, they just go with the flow."

> *"When people come for the first time, they tend to be apprehensive and nervous. But after they realize it's a relaxed, fun atmosphere, they just go with the flow."*

Many caregivers accompanied their loved ones to the dinner, giving them the chance to bond with their fellow caregivers, Whitman added. She noted that the ratio of caregivers to persons diagnosed was roughly one-to-one.

The event is carefully planned each year to accommodate the needs of people with FTD. The Pratt Street Ale house reserved a private room for this year's group and accommodating staff turned the TVs off to minimize distracting stimuli.

For many persons diagnosed, the evening is a way to ease into the following day's packed conference-day schedule.

The dinner "makes the next day a lot easier" for persons diagnosed, Whitman said. During the conference, she recalls people who attended the dinner bumping into each other and saying, "Hey, I remember you from last night!"

"It helps people feel less alone," she said.

Giving a Hand to Our Helping Hands!

Having been provided little direction after his mother was diagnosed with FTD, Scott Cain wanted to find a way to help others facing the disease. As an AFTD volunteer, he quickly found his calling: facility outreach. Amidst his personal and professional responsibilities, he has found the time to not only conduct outreach visits with administrators at local senior care communities, but also to assist with training other AFTD volunteers for facility outreach.

Tell us a little bit about your experiences so far.

I've been surprised how open and available everyone I've connected with in the senior care community has been in wanting to learn more about FTD and AFTD. The first administrator I met with was not only interested, she invited me to the next monthly lunch meeting of a professional organization she had established for senior health providers. I met so many people. I was off and running, which led to several more outreach appointments… Additionally, I have [assisted with] two facility outreach trainings this year and have enjoyed being able to help by simply sharing my experiences.

Why did you want to volunteer with AFTD?

Part of me felt like there was no way I could make a difference because I'm just one person in Northwest Arkansas. But I got over that quickly. I know that many hands make light work, so we're all needed, and that anything I did could potentially help AFTD and people dealing with FTD.

How has the overall volunteer experience made you feel?

Thankful. I'm thankful to be allowed to partner with AFTD, and to be able to spread the word about the great AFTD resources. I'm thankful that people in senior community care have been willing to listen to me even though I'm coming from outside their world. I do think about my mother when I'm conducting a visit and I feel like I'm doing a little something for her by helping others.

What you have learned from your volunteer experiences so far?

It's not that hard! Preparation is important, of course, so I have put in time preparing for outreach meetings. But the process itself is fulfilling and enjoyable.

What would you say to people who are considering volunteering with AFTD?

Step out there and try it. You'll be glad you did.

One of AFTD's Mid Atlantic Regional Coordinator Volunteers, Sarah Sozansky Beil, who facilitates the volunteer facility outreach trainings, shared: "Scott really engages everyone during the trainings, helping them to understand how the process works and sharing how he approaches the administrators and answers their questions. I honestly cannot say enough good things about him!"

AFTD's 2017 Education Conference…

(Continued from page 1)

Many attendees agreed on the two highlights of the day's programming: a panel discussion featuring three pairs of caregivers and persons diagnosed, and the conference's keynote address.

During the panel discussion, moderator Lisa Gwyther, L.C.S.W. asked panelists about their respective FTD experiences. The discussion, by turns moving and funny, offered an intimate look at the varying ways in which FTD affects some of our closest relationships, whether between spouses or between mother and daughter.

The keynote address was delivered by Dr. Halima Amjad, assistant professor of medicine at Johns Hopkins University School of Medicine in Baltimore. Her father, an immigrant from Pakistan who became a successful dentist in the Philadelphia area, is currently living with primary progressive aphasia. She described the many challenges of having a close loved one with FTD, from the difficulties getting a diagnosis to the behavioral problems that come with the disease.

But Dr. Amjad's speech also highlighted unexpected moments of expression from her father, despite the challenges of FTD. "Though he couldn't express himself well with words, he cried at my wedding," she said, "and that let me know how he felt when his words couldn't."

AFTD's 2017 Education Conference offered new ways for all affected by FTD to share experiences and discover more about the disease. For the staff and Board in attendance, it also offered an invaluable opportunity to hear vital perspectives from across our community. It's not too early to think about next year's AFTD Education Conference, to be held in Chicago, IL on Friday, April 13, 2018.

AFTD-Team Races...

(Continued from page 1)

"When you lace up sneakers to run a 5K for AFTD, you're achieving more than you think," said Susan L-J Dickinson, AFTD's CEO. "It not only raises public awareness, it also fosters new connections and tells others affected by FTD in your area that they aren't alone."

AFTD Team Races: Thanks to our Fundraisers

AFTD is grateful to the following individuals, who along with putting in the miles, took their participation to the next level by fundraising via the Classy fundraising platform.

Colfax Marathon Team
Fenoglio Family Racers – $3,416
Colleen Seymour – $654
Valerie Jordan – $525
Peter Pressman – $502
Fit Foodie 5K Team
Kacy Kunesh – $1,811
Alice's Angels 2017 – $751
Steph McLain – $557
Craig Tomes – $502
Shana Nissen – $176
Deborah Price – $50
Seattle Super Run Team
Steve Zamberlin – $340

UPCOMING RACES

The AFTD-Team Races season's not over yet!
Join us in Chicago or Philadelphia later this year:

- **Chicago Super Run (IL): August 19**
- **Chicago Marathon (IL): October 6-8**
- **Philadelphia Marathon (PA): November 17-19**

Don't see your city represented?
Email bgraham@theaftd.org to be part of changing that!

Recipe: AFTD's Food for Thought 2017

Serving: All 50 States
Prep Time: Now
Cook Time: Sept. 24 – Oct. 8, 2017
Ingredients: Food, Drink & Education

Directions:

1. It's time to start thinking about AFTD's 5th Annual Food for Thought Campaign: team up with friends and family, or plan something yourself. Any event – big or small – as long as it involves food and a little FTD education.
2. Your event can take place any day during the two-week period from September 24th through October 8th, 2017.
3. Planning an event is easy. AFTD staff and volunteers are here to help. Share your story, raise awareness and raise vital funds to support AFTD's mission in your community!
4. Put your state on the map to show nationwide resolve against this disease. Email AFTD's Grassroots Events Coordinator Bridget Graham at bgraham@theaftd.org to get started.

THE AFTD-TEAM

AFTD GRE Coordinator Bridget Graham with comedians Chris Roach, Joey Kola and Joe Starr

Comedy for a Cause

Comedian and actor Chris Roach – currently playing the character Mott on CBS's *Kevin Can Wait* starring Kevin James – hosted a Comedy Fundraiser Night at the Governor's Comedy Club in Long Island. The night brought in laughs, a crowd of 215 people and $1,540 in donations to AFTD.

Tacos conveniently sized and packaged for mobility.

Walking Tacos

Darrell Hawley of Michigan and his family setup a "walking taco" stand during their neighborhood's yard sale. Hungry yard-sale goers stopped by to enjoy a delicious snack and learn about FTD. After selling out in only an hour and half, Hawley donated $56 in sales to AFTD.

FTD Relay

AFTD Northwest Regional Coordinator Joanne Linerud and three teammates ran a 50-mile relay from Mount Rainier to the Tacoma waterfront in Washington State in memory of Joanne's mother, who had FTD. The runners donned AFTD-Team t-shirts and exchanged custom AFTD car magnets with fellow runners to spread FTD awareness.

Joanne and teammates Christina Swenson, Heather Darrington and Vickie Skinner – deterred neither by the mileage nor by the local fauna.

UNDFTD

Undefeated

Daniele Vincent of Portland, Oregon, and her family designed and sold t-shirts to sell as a fundraiser after their community showed an outpouring of support when Daniele's husband was diagnosed with FTD. The "UNDFTD" logo on the t-shirts stands for the fact that "FTD will not defeat us," Daniele said. The first batch sold and raised $600, donated to AFTD.

A Month for Doughnuts

Voodoo Doughnuts in Denver donated 25 percent of sales from the "doughnut of the month" to AFTD. The fundraiser was held during the month of May to coincide with the AFTD-Team being an Official Charity Partner of the Colfax Marathon. The "Homer," a traditional doughnut with pink frosting and rainbow sprinkles (think Homer Simpson), brought in a $1,000 donation for AFTD.

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

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