

AFIDnews

Find Help and Share Hope via AFTD's New Website...

AFTD has redesigned and updated our website. Through this effort, we seek to deliver more streamlined information, to better help members of our community to find resources that can help, and to foster new ways to connect and be part of our mission.

Designed to be easier to navigate for both care partners and persons diagnosed with FTD, the website offers new information and resources for different stages of the FTD journey:

What Is FTD – Learn more about FTD, its various subtypes, and genetic information.

Living with FTD – Access practical information about coordinating FTD care, managing symptoms, and legal and financial planning, along with various ways for persons diagnosed and care partners to find support and access important resources to help them on their journey.



Get Involved – Discover ways to join our community, whether on a local or national level, by hosting a grassroots event, volunteering for AFTD, or advocating on behalf of persons diagnosed and their care partners. This section also shows how you can support AFTD's mission by making a tax-deductible gift.

Research and Clinical Trials

- Find out about ongoing studies and clinical trials that can allow you to participate in furthering FTD research.

The new website also has sections for FTD-focused researchers and healthcare professionals who want to learn more about this disease.

The new website reflects the results of in-person focus groups and surveys that drew input from hundreds in our community. It is part of a larger branding update that

sees AFTD updating its logo, tagline, and the look of many of our resources over the course of 2018.

How does it look? We welcome your feedback! Send any comments or questions to AFTD's Communications Manager, Matt Ozga, at mozga@ theaftd.org.

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Advancing Research:

FTD Treatment Study Group Meets in Washington D.C.

On March 8 and 9 AFTD hosted the eighth meeting of the FTD Treatment Study Group (FTSG) in Washington DC, convening more than 110 FTD researchers, funders and regulators for two days of presentations and discussion on ways to

design effective clinical trials for FTD.

By studying the experience in other rare diseases, AFTD seeks to dramatically shorten the time it will take to get the first drug approved for FTD.

The conference, "Clinical Trials

Methodology and Outcome Measures for FTD," was co-hosted by the National Institute for Neurological Disorders and Stroke, with additional sponsorship provided by a number of nonprofit and for-profit partners (see page 8). Participants included 50 representatives from 27 different pharmaceutical and biotech companies, as well as regulators from the Food and Drug Administration (FDA), which is responsible for oversight of

clinical trials and ultimate approval of any drugs.

Designing effective FTD

clinical trials presents specific challenges. Both because FTD is still challenging to diagnose and because it is a rare disease, the population of people available for such trials is small.

(Continued on page 8)

AFTD Welcomes Five New Staff

In recent months, AFTD has welcomed new staff members to its office in Radnor, PA, reflecting the organization's expanding work to address the needs of the community it serves.

Lauren Gauthier joined AFTD as Online Community Coordinator last August. Her career spans 16 years, mostly spent in the nonprofit sector. In her previous roles she developed social media strategy, created and implemented innovative and successful marketing campaigns, and grew the digital audience, influence, reach and impact of multiple organizations. As Online Community Coordinator, Lauren works to deepen AFTD's engagement with its community through social media, e-newsletters and other forms of digital communications.

In January, **Jeff Thompson** became AFTD's Office Manager. Jeff brings close to 30 years of experience in staff accounting, information technology support, and customer relationship management skills from organizations with both local and global scale. He brings vital experience supporting back office functions in the nonprofit

world – most recently in the higher education environment, where he worked closely with directors to streamline processes and implement new systems.

Trudy Bowman joined AFTD as Development Coordinator in February. With a B.S. in Health Policy and Administration from Penn State University and over two years of experience volunteering with a foundation, Trudy brings experience in relationship-building and strategic planning to her role. Trudy will play a key role in fundraising appeals, donor engagement, corporate and foundation fundraising, donation processing, acknowledgment and recognition.

Elizabeth R. Young joined AFTD as Executive Assistant/Event Coordinator in February. She spent the last 16 years as administrative assistant at several banks, supporting

the managing director and other team members in their efforts to assist bank clients at nonprofit healthcare systems and hospitals throughout the U.S. Prior to that, she was the administrative assistant/meeting planner for a nonprofit continuing education firm. She holds a B.S. in business management from Penn State University.

Emma Tomasetti joined AFTD as Development Assistant in February. Emma has a B.A. in Business Administration from Arcadia University and experience working in the nonprofit sector, specifically in volunteer efforts, event planning, and fundraising. In her previous she assisted fundraising roles and logistical projects, handled donations, and assisted volunteers. Development Assistant, Emma plays a key role in donor engagement, donation processing, acknowledgment and recognition.

AFTD NEWS BRIEFS

AFTD Webinar: Genetics and Genetic Counseling

On March 22, Emily Dwosh, a clinical assistant professor at the University of British Columbia's Department of Medical Genetics, presented the latest edition of AFTD's Educational Webinar series. Throughout the 90-minute webinar, "An Overview of FTD Genetics and the Role of Genetic Counseling," Dwosh explained the role that genetics play in both familial and sporadic forms of FTD, clarified the difference between diagnostic and predictive genetic testing, and detailed the wide range of factors that families should consider before completing these tests. Visit AFTD's YouTube page to view the webinar in its entirety.

International Conference on Frontotemporal Dementias to Be Held in Sydney

AFTD is pleased to be a platinum

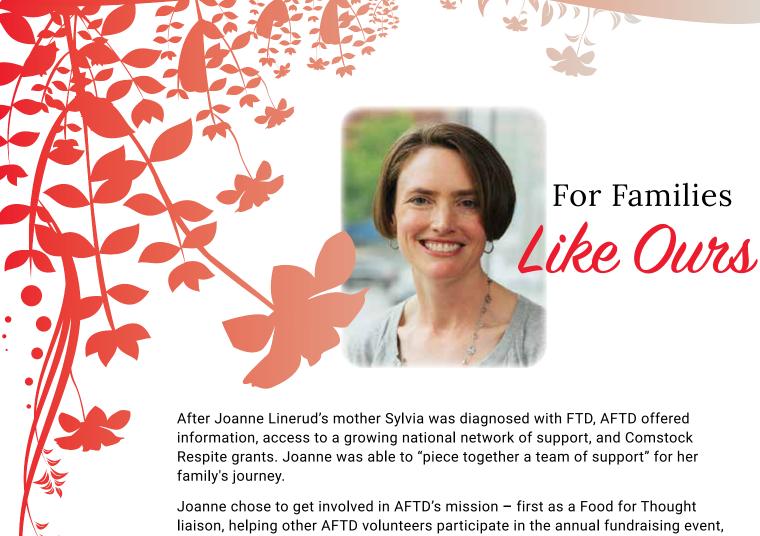
sponsor of the 11th International Conference on Frontotemporal Dementias (ICFTD), which will take place in November 2018 in Sydney, Australia. Held every two years, the ICFTD convenes experts from around the world to share recent discoveries, insights and opinions, fostering the exchange and dissemination of FTDrelated knowledge on a global scale. The 11th iteration of this event marks the first time it has been held in the Southern Hemisphere. Among the event's keynote speakers are Rosa Rademakers, PhD, a member of the AFTD Medical Advisory Council. Visit icftd2018.org.au to learn more about the 2018 ICFTD.

Thank you to an AFTD Regional Coordinator Volunteer...

Nancy Cummings has stepped down from her role as Regional Coordinator Volunteer for New York. She served in this leadership role for over three years and made a huge impact, providing guidance and offering support to so many volunteers throughout the region, and sharing ideas and making recommendations that are reflected in AFTD's national volunteer program. Nancy is continuing her volunteer service with AFTD as an affiliated support group facilitator, while AFTD Regional Coordinator Volunteer Corey Esannason is now overseeing New York, in addition to Pennsylvania and New Jersey. Thank you, Nancy.

...and We Welcome Katie Zenger!

AFTD is excited to announce the newest Regional Coordinator Volunteer. Katie Zenger, who lives in South Carolina, joined Michelle Grant as Regional Coordinator Volunteer for the South Atlantic Region. Michelle is continuing to cover North Carolina, Alabama and Kentucky, while Katie will take over South Carolina, Georgia, Tennessee, Mississippi, and Florida.



Joanne chose to get involved in AFTD's mission – first as a Food for Thought liaison, helping other AFTD volunteers participate in the annual fundraising event, and later as a Regional Coordinator Volunteer covering Washington, Wyoming and Idaho. She also works to help others affected by FTD – sharing her story, sharing AFTD's website and HelpLine, and offering the perspective of someone who understands what it's like.

Although Joanne's mother died two years ago, she remains passionately engaged with AFTD and our community. "I'm the oldest of four kids; my mom had nine grandchildren," she said. "In our family, this will not go away. But I am very hopeful that there are things coming that will be helpful for families like ours."

Research brings new hope to families facing FTD. Donors make that possible, and today we ask you to choose to support AFTD's Accelerating Drug Discovery for FTD program, conducted in collaboration with the Alzheimer's Drug Discovery Foundation (ADDF). Together, AFTD and ADDF seek to accelerate drug discovery by supporting research focused on the identification and preclinical testing of promising compounds.

If you use the envelope attached to make a gift to AFTD, your gift of any amount will be matched 2:1 by the Alzheimer's Drug Discovery Foundation.

Will you join us in bringing a better future for so many families like Joanne's – and for all who face this disease?

AFTD Announces 2017 Pilot Grant Recipients

AFTD is proud to announce our 2017 Pilot Grant awardees: Todd Cohen,

PhD, Assistant Professor at the University of North Carolina - Chapel Hill; and Haakon Nygaard, MD, PhD, Assistant Professor at the University of British Columbia.

Dr. Cohen was awarded the 2017 Basic Science Pilot Grant for his "Accelerating proposal, pathogenesis a new mouse model

of frontotemporal dementia." He previously received the first AFTD Postdoctoral Fellowship in 2009.

Dr. Cohen's project will use mice that have been genetically engineered to produce mutant tau proteins with add-ons known as acetyl groups - an abnormality that makes these proteins highly toxic and mimics one of the features of the harmful tau proteins found in FTD.

"We anticipate that by targeting the proteins that control these aberrant modifications,

we will identify new therapies that reduce tau pathology and prevent cognitive impairments in people with FTD," he notes.

Dr. Nygaard received the Susan Marcus Fund Clinical

Research Pilot Grant for his proposal, "Ambulatory assessment of

sleep disorders in FTD." He will examine sleep abnormalities common, but poorly understood clinical feature of FTD - using two portable recording devices: an actigraphy specially watch and a

designed electroencephalogram (EEG) headband.

Research on sleep disturbances usually takes place in unfamiliar and potentially stressful environment of a sleep laboratory. Dr. Nygaard's approach will allow him to monitor changes in the sleep patterns and circadian rhythm of participants in their own homes. Such changes could ultimately aid diagnosis or lead to a biomarker to assess the effectiveness of new

treatments.

providing seed funding for innovative research by early-career investigators, AFTD's Pilot Grant Program fosters additional FTD research: Previous AFTD Pilot Grant recipients have attracted more than \$7.5 million in follow-on funding and

published 26 grant-related





Todd Cohen, PhD

AFTD Announces New Research Awards in Partnership with ADDF

AFTD's partnership with Alzheimer's Drug Discovery Foundation (ADDF) advances the search for FTD treatments through the joint sponsorship of two grant programs. Accelerating Discovery for FTD funds preclinical drug discovery research, and the Treat FTD Fund supports clinical trials of novel or repurposed drugs that show promise as symptomatic or disease-modifying treatments.

We are proud to announce recent awards in both programs, including the first grant awarded through the Treat FTD Fund, made possible by generous multi-year commitments from the Samuel I. Newhouse Foundation and the Lauder Foundation, Leonard Lauder, and Ronald S. Lauder.

Barbara Borroni, MD, professor at the University of Brescia, is the inaugural recipient of a Treat FTD Fund award for her proposal, "Non-invasive brain stimulation to restore cortical plasticity and connectivity in genetic and sporadic FTD."

Dr. Borroni will test a treatment for FTD that is not a drug, but rather a noninvasive, painless form of brain stimulation known as transcranial direct current stimulation (tDCS), which uses electrodes placed on the scalp to deliver a low-intensity current that modifies brain activity.

Previous research by Dr. Borroni and her colleagues demonstrated characteristic abnormalities in brain activity in people with sporadic and genetic forms of FTD as well as those with an FTD-associated gene mutation but no symptoms. She also found that in healthy people, tDCS can target activity in the brain circuits affected by FTD. As a result, she hypothesizes that tDCS will have beneficial effects on FTD symptoms and delay disease onset in presymptomatic gene carriers.

Steven Finkbeiner, MD, PhD, Director of the J. David Gladstone Institutes in San Francisco, is the recipient of a 2017 Drug Discovery award for his proposal, "Novel human FTLD neuron and microglia cell models for drug discovery."

Dr. Finkbeiner will monitor neurons and the brain's immune cells, known as microglia, generated in the laboratory from patient-derived stem cells with a mutation in the progranulin gene, using a robotic microscopy technique that allows him to follow changes in individual cells over time. Specifically, he will be tracking fluctuations in the accumulation of FTD-associated proteins, inflammation, function, and cell survival. His goal is to develop laboratory models of FTD that accurately replicate the cellular features of the disease as the basis for screening new drugs.

AFTD Brings its 2018 Education Conference to Chicago

Persons diagnosed, their care partners, healthcare professionals and other members of our community will gather in Chicago on April 13 for AFTD's 2018 Education Conference.

The annual event offers a chance for people to meet in person, connect, and learn more about the latest FTD research and care strategies.

The 2018 Education Conference features more chances than ever for people to find help and share hope with one another, with a stronger

focus on networking than in past events.

The annual event offers a chance for people to meet in person, connect, and learn more about the latest FTD research and care strategies.

Targeted afternoon breakout sessions offer networking opportunities for persons diagnosed, healthcare professionals, AFTD volunteers, and care partners (including a special session specifically for care partners who are young adults).

Lunch also provides a chance to network. By wearing a color-coded ribbon, you can easily see others who live in the same region of the U.S. as you.

The Education Conference also gives the opportunity for participants to hear from some of the leading voices of the AFTD community, including the Rev. Tracey Lind, who will present the day's keynote address.

The former dean of Trinity Episcopal Cathedral in Cleveland, Rev. Lind retired in 2017 shortly after being

> diagnosed with primary progressive aphasia. She is a published author and

exhibiting photographer, and speaks frequently about the insights and lessons she has gained from a life complicated by FTD.

The Conference Event Host for 2018 is Northwestern University, whose earlier FTD caregiver conferences provided vital assistance to

in 2011; his wife, Marie, is his care

partner. (For more on the Hendersons,

symptoms, which included apathy,

uninhibited behavior, and struggling

Brandt's

early

see our interview on page 9.)

detailed



individuals and families affected by FTD. Noted speakers will include members of Northwestern's Feinberg School of Medicine, including M.-Marsel Mesulam, MD, the Director of Northwestern's Cognitive Neurology and Alzheimer's Disease Center and a member of the AFTD Medical Advisory Council; Sandra Weintraub, PhD, Professor of Psychiatry and Behavioral Sciences; and Darby Morhardt, PhD, Research Associate Professor at the Cognitive Neurology and Alzheimer's Disease Center.

Find out more about the conference via AFTD's website at www.theaftd. org. Portions of the conference will be broadcast and archived via AFTD's Facebook page: www.facebook.com/TheAFTD/

Webinar Delivers Information on FTD Care

AFTD Program Director Sharon Denny joined FTD advocates Brandt and Marie Henderson to present a webinar on January 16, through a webinar series sponsored by the Administration for Community Living (ACL), part of the U.S. Department of Health and Human Services.

Denny gave a general overview of FTD and

its subtypes, and explained the unique challenges faced by both persons diagnosed with FTD and their caregivers/care partners.

focus on how much Brandt can do today."

The three presenters spoke about the high levels perienced by FTD.

The three presenters spoke about care strategies and approaches

She highlighted three primary factors that contribute to the high levels of stress and isolation experienced by FTD care partners: the disease's younger age of onset compared to other dementias, the fact that its symptoms are poorly understood by the general public, and FTD's status as a rare disease.

The Hendersons spoke about their personal experience with FTD. Brandt was diagnosed with behavioral variant FTD

with formerly simple tasks. to FTD and

"We are living with an unknown; everyone progresses differently with this disease," Marie said. "So we try to

The three presenters spoke about care strategies and approaches – communication, behavioral, environmental, medication – that can benefit both the person diagnosed and their care partner. They noted that the best care intervention is "a well-informed, empowered individual and care partner," and pointed out resources that can help people affected by FTD.

Even when living with the uncertainty of FTD, caregivers/care partners and persons diagnosed can work to maintain their highest possible quality of life. "We are living with an unknown; everyone progresses differently with this disease," Marie said. "So we try to focus on how much Brandt can do today."

The final 10 minutes of the webinar are devoted to a Q&A session. The entire hour-long webinar, entitled "Frontotemporal Degeneration: the Importance of Knowledge, Advocacy, and Support to Advance Quality Care" is available on the ACL's YouTube page, at www.youtube.com/watch?v=QuvEHzTgopg

The webinar was hosted by the ACL's National Alzheimer's and Dementia Resource Center and was presented in partnership with the American Society on Aging.

Those We Honor... Those We Remember October 16, 2017 - February 15, 2018

Gifts received from

Donations in the name of a loved one bring help and courage for families affected today – and hope for a future without FTD.

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Advancing Research... (Continued from page 1)

Differences within FTD subtypes—clinical diagnoses, underlying disease pathology, and etiology (genetic vs. sporadic)—are additional factors that researchers looking to recruit individuals to an FTD clinical trial need to navigate.

The 2018 FTSG conference aimed to take a creative approach to resolving these issues. AFTD cast a broad net in recruiting speakers for the invitation-only conference, bringing in experts from other rare disease communities, such as ALS and neuro-oncology, which have decades of experience addressing similar challenges. Specific topics discussed included: patient recruitment, design of outcome measures that improve quality of life (rather than just lengthening it), and strategies to encourage

data sharing across trials.

"By sharing their learnings, these colleagues can help us advance our own strategies, effectively cutting



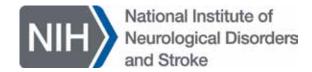
years from the time it could take us to generate meaningful results from a trial," said AFTD Scientific Director Nadine Tatton, PhD. "We were pleased and encouraged by the level of collaboration in the room, and by participants' interest in continuing these important discussions."

Additional sessions presented a survey of the landscape of FTD clinical trials conducted to date, and explored ways the current "age of big data" (as typified by patient registries, natural histories, and wearable technologies) can improve how clinical trials are executed.

AFTD founded FTSG in 2010 to promote scientific interactions and collaborations between academia and industry, with the ultimate goal of accelerating the development of effective treatments for FTD and related disorders. Organizers plan to publish a summary of the meeting, to promote broadly throughout the research community.

AFTD extends sincere gratitude to our 2018 FTSG Conference Sponsors!

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Giving a Hand to Our Helping Hands! AFTD Volunteer: Dr. A. Brandt Henderson

For more than three years, AFTD volunteer Dr. A. Brandt Henderson has used his professional background as a public speaker to be a voice and an advocate on behalf of our community. He and his wife Marie have participated in interviews and presentations alongside AFTD staff to share their experiences resulting from Brandt's FTD diagnosis. He also volunteers as a member of AFTD's Think Tank, a committee of persons diagnosed that meets monthly and advises AFTD staff and Board.

We asked Brandt to share with us about his experiences as an AFTD volunteer.

What is your connection to FTD? I was diagnosed with FTD in 2011 after a year and half of testing. I knew something was seriously wrong with my brain and demanded we figure it out.

Why did you want to volunteer with AFTD? Marie and I were totally blown away by the diagnosis and sought out all the information we could find. We want to help patients and caregivers in any way we can, even if that simply means validating their experiences with FTD. It can be an isolating

disease that is little understood by the medical/pharma community, let alone by families.

Tell us about the role your wife has played with your various AFTD speaking engagements. Marie shares my dedication to share our experience of FTD. We've spoke about FTD on a radio show, in webinars, and at a panel discussion at the 2017 AFTD Education Conference in Baltimore – perhaps our most satisfying "on stage" experience together.

What do you see as the greatest value of the Think Tank? What one thinks one needs and what the professional community believes is necessary are not always in sync. The Think Tank is a sounding board for the priorities and direction of AFTD, which have in the organization's history been centered on caregivers, not patients.

How has your experience as an AFTD volunteer made you feel? When having to retire and having lost some faculties, it is fulfilling to contribute in some manner to the understanding of the disease and its impact on families. It was particularly satisfying to address the staff and management of a pharmaceutical company, as



Brandt and Marie Henderson and their family

they were truly fascinated by our experiences.

What would you tell persons diagnosed who are considering volunteering with AFTD? There are multiple ways to contribute, and AFTD staff understand that some of us have symptoms (such as apathy, speech issues and failing executive function) that can restrict what we can and can't do. They are always willing to work with our strengths.

AFTD is grateful for volunteers like Brandt. AFTD's Program Director Sharon Denny notes, "Brandt's commitment to FTD awareness and education is tremendous. He is thoughtful, articulate and completely authentic in sharing his experiences to help others to understand the impact of the disease."

Take Action and Get Involved Today!

AFTD's national volunteer network is made up of people just like you who are offering support and spreading awareness about FTD. You can join our growing network of volunteers across the country in making a difference for all families affected by this disease.

There are a wide range of volunteer opportunities available:

Lead a support group.
Conduct facility outreach.
Organize a Meet & Greet in your area.
Tell your FTD story.
Host a fundraiser.

Represent AFTD at a community event.

Visit www.theaftd.org/get-involved/volunteer to learn more. Then, scroll down the page and click on Contact Your AFTD Regional Coordinator to get started.





As an AFTD volunteer, I have found my voice. It is empowering to educate people about FTD. I am doing what I can to help bring awareness to this devastating disease. – Deb Nash, AFTD Midwest Regional Coordinator Volunteer



With Love

FTD can take away so much, but not the love we have for those we hold dear. Through AFTD's annual With Love campaign, this past February saw community members honor or remember loved ones impacted by FTD.

A record-setting number of hosts – 29 – participated. Nine returning hosts from 2017 were joined by 20 new volunteers, all courageously sharing their stories of love to spread FTD awareness and raise funds to support AFTD's mission.

As part of this year's campaign, we asked community members to share the name of the person they fight FTD for, with love. The response was powerful — more than 185 names were shared. AFTD staff filled out a heart for each name, creating a "Wall of Love" that we shared on social media on Valentine's Day.

This year's campaign raised more than \$51,000. We would like to extend a huge thank you to everyone involved in its success! Two generous campaign sponsors, Beth Walter and The Rainwater Charitable Foundation, pledged vital matching donations. Hundreds made donations. Most of all, thank you to our campaign hosts, who generously shared their stories of love to spread awareness and raise important funds:

With Love 2018 Hosts

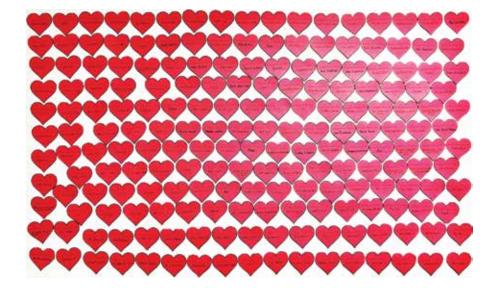
Amy O'Bryant
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Athanasia Harvalis
Chuck Anastasia
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Corey Compa
Debbonnaire Kovacs
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Elaine Rose
Elizabeth Hubenak
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Kathryn Caruso Lynda Ares Mary Revels Maxwell Barrile Melissa Fisher Michael Garcia Nicole McLaughlin

Sabrina Smith Shana Nissen Susan Eissler Susan Scarff Suzanne Dana Tiffani Moore Zoy Kocian





WALL OF LOVE



Letter Perfect: AFTD Board Member Paul Lester hosted his 11th annual letter-writing campaign in memory of his late wife Arnette. Paul sent paper letters and – using the online platform Classy – electronic versions too. After all the letters went out, his campaign raised \$16,499. Over the past 11 years, Paul's letter-writing campaign has raised more than \$118,000 for the fight against FTD.

On Course: Debbie Baumgartner and her husband Johnny (who has FTD) hosted the 3rd Annual John E. Baumgartner III Golf Tournament on October 16, 2017 at the Ballantrae Golf Club in Pelham, AL. The event brought in \$8,100, bringing the John Baumgartner Foundation's three-year total gifts to AFTD to more than \$38,000!

Google AFTD: For the week of November 27 – December 1, 2017, the Google campus in Irvine, CA supported AFTD through its annual Giving Week campaign. On November 29th, AFTD Board Member Beth Walter and AFTD Southwest Regional Coordinator Volunteer Kathy Urban joined Google staffer Rob Radtke in presenting AFTD information to his colleagues. Thank you to Rob, who invited AFTD to be part of this initiative. He raised funds throughout the week, which Google in turn generously matched.

Remembering Connie: Employees at the company Evine in Minnesota held a social media campaign during the week of Thanksgiving in Connie Kunkle's memory, raising \$3,000. Connie, a popular host for Evine's home shopping channel, passed away from FTD in 2016. Her co-workers miss her greatly and wanted to do something special in her name.



#InkFTD: A t-shirt campaign was launched on the online retail company Custom Ink to help spread awareness of FTD. Each t-shirt was \$20 and all of the proceeds went to AFTD. The host (who asked to remain anonymous) sold 154 t-shirts and was able to donate \$1,825.

Better to Sell A Candle...

Amy Shillady of Maryland sold handmade soy candles in honor of her mother, who has FTD. She sold out in just two weeks and was able to donate \$1,000 to AFTD.



Off to the Races

Last AFTD-Team Race Season truly saw us finish a step ahead. We collaborated with seven race events across the country; more than 275 teammates ran or walked 1,250 miles and raised more than \$68,000. One family led the field: Team Jack-Attack. Bringing 47 of AFTD's 65 runners for the Philadelphia Marathon, the Pang family also brought in \$28,000 of the \$40,000 raised through that race alone.

Start stretching, because we have begun targeting cities for the AFTD-Team's 2018 Race Season. We have a few races in mind already, but we could always use the opinions from those of you with sneaks on the ground in local communities. We are looking for quality walks, runs or high endurance events (i.e. a Spartan Race or a bike race) in the following cities:

Boston

D.C.

Los Angeles

Seattle

If you've got a race in mind in your community – or if you'd rather convene an ice-cream eating contest this summer – write AFTD's GRE Coordinator Bridget Graham at bgraham@theaftd.org



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