



# AFTD news

## World FTD Awareness Week 2018 Observed Around the Globe

The fourth annual World FTD Awareness Week, held September 23-30, 2018, united people with FTD, care partners and health professionals to tell the world about FTD.

World FTD United, an international coalition of organizations and professionals (including AFTD), marked the yearly event by launching an interactive storytelling campaign that continues today.

Anyone affected by FTD is encouraged to use the interactive world map to share their story and the country in which they are located. As of December 1, 176 people – representing 164 cities in 24 countries – have used the map to tell their FTD

stories and raise awareness.

The stories already submitted to the map represent the full spectrum

of his misdiagnosis: “I have been receiving diagnoses of depression for at least five years. Just last December I was diagnosed instead with bvFTD.”



The map can be accessed here: [tinyurl.com/telltheworldaboutFTD](http://tinyurl.com/telltheworldaboutFTD)

of life with FTD, whether told by a person diagnosed or a current or former care partner. Nigel Snape of the United Kingdom told the story

Brita Z. of Germany wrote of her daughter’s diagnosis at age 39: “It is very hard for our son-in-law and her kids (9 and 11). FTD robbed her life with her family.”

Global collaboration to address FTD gained significant momentum at the recent 11th International Conference on Frontotemporal Dementias, held in November in Sydney, Australia. More than 600 delegates from 37 countries convened to collaborate and learn from one another.

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## Hope Rising 2018 Draws Record Crowd to Show Support for AFTD’s Mission

More than 500 AFTD supporters joined the third annual Hope Rising Benefit, held on October 17 at the Pierre Hotel in New York City. The event raised more \$1.9 million to support AFTD’s mission of advancing FTD research and improving quality of life for all affected by this disease.

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Leonard A. Lauder, chairman emeritus of The Estée Lauder Companies Inc., received the Susan Newhouse & Si Newhouse Award of Hope, in recognition of his decades of support for dementia research.

Mr. Lauder founded the Alzheimer’s Drug Discovery Foundation (ADDF) with his brother Ronald in 1998. ADDF and AFTD have been key partners since 2007. “We all know that the brain is the last frontier of medicine,” Lauder said. “We can’t explore this frontier at a leisurely pace. We have to speed up progress, and to do this, we need an entirely new model of research – one that is smarter, more strategic, and much more collaborative.”

*(Continued on page 4)*

## Spotlight on...David Pfeifer, AFTD Board of Directors



David Pfeifer

After experiencing FTD firsthand as a care partner for his wife Cathy, David Pfeifer felt compelled to help others facing a similar situation. The Colorado-

based architect

and father of three joined AFTD's Board of Directors in April 2018, intent on sharing the knowledge he had gained during his family's FTD journey.

David started noticing changes in his wife's behavior in 2011. "Cathy was extraordinarily active, healthy and vibrant; we had a truly wonderful life," he says. "FTD came into the picture very subtly, when Cathy began to exhibit unusual ways of communicating and we didn't know why."

A neuropsychological examination led

to a diagnosis of behavioral variant FTD (bvFTD) in the fall of 2014. At the time, David and Cathy's children – then aged 15, 13 and 11 – all lived at home.

"Our experience with bvFTD was a bit unusual because my wife didn't exhibit some of the more challenging symptoms," David says. "She was quite sweet and dear throughout her journey with the illness. Increasingly, though, she simply became unable to be by herself. With three kids going to school and living their lives, it became very challenging to care for her at home."

Shortly after Cathy's diagnosis, David first became aware of AFTD.

"Like many people going down this path, I tried to learn everything I could about FTD. I spent some time on the website and absorbed as much information as I could."

David's research led him to former AFTD Board Vice Chair Debbie Fenoglio, who

lived in nearby Denver. "We quickly became friends, and that was my real introduction to AFTD. Through her, I became aware of all that AFTD has to offer – the research programs, resources and recommendations for handling various situations."

Cathy Pfeifer died on Dec. 7, 2016, 11 months after moving into a memory care facility. She was 49 years old. But even after her passing, David remained an engaged AFTD volunteer, attending local conferences and organizing successful grassroots events in the Denver area.

His dedication to the community ultimately prompted him to join AFTD's Board.

*"I wanted to remain connected to this group of people who are helping others living with FTD, David said."*

"I wanted to remain connected to this group of people who are committed to helping others," he says. "When someone receives an FTD diagnosis, to be able to reach out to someone in the community as soon as possible can make all the difference."

## AFTD NEWS BRIEFS

### Congress Increases Funding for NIH Dementia Research in FY19 Budget

For the fourth year in a row, Congress voted to increase funding for dementia research through the National Institutes of Health (NIH). On September 28, President Trump signed the bipartisan Fiscal Year 2019 Defense/Labor-HHS appropriations bill into law. This funding bill included an unprecedented increase of \$425 million for Alzheimer's and dementia research funding at NIH, bringing total funding to just over \$2.3 billion. While most of that funding will go to Alzheimer's disease, this bill will allow for an estimated \$89 million specifically for FTD research in FY 2019.

### Next AFTD Educational Webinar to Focus on PPA

Dr. Emily Rogalski of Northwestern University will explore the aspects of primary progressive aphasia that persons living with PPA, their families and health providers should know in the next installment of the AFTD Educational Webinar series. Her presentation will address PPA clinical syndromes and the latest in diagnosis and treatment of the disorder, including speech therapy and augmentative and alternative communication tools. She will introduce PPA pathology and genetics, and discuss their relevance to current and emerging areas of research. The webinar will be held December 13, and will remain archived on AFTD's YouTube page afterward.

### AFTD to Sponsor 2019 Alzheimer's Disease-Related Dementias Summit

AFTD is a co-sponsor of an upcoming dementia summit hosted by the National Institutes of Health. The Alzheimer's Disease-Related Dementias (ADRD) Summit, held March 14-15, 2019 in Bethesda, MD, will address research priorities for several non-Alzheimer's forms of dementia, including FTD, Lewy body dementia, vascular dementia and others. It will also review progress made on the research recommendations that came out of the 2013 and 2016 ADRD summits.

### AFTD Adds Staff Writer

Cameron Kelsall joined AFTD as Staff Writer in September 2018. After earning his M.A. in English and Creative Writing from Ohio University, he spent two years working as a staff writer for *HemOnc Today*, a leading medical news source for hematology and oncology, winning the APEX Award for excellence in media during his tenure there. More recently, he served as editor of *Journal of Clinical Pathways*, a peer-reviewed periodical focused on value-based medical care. As a member of AFTD's development and communications team, Cameron creates and curates relevant content for AFTD's print and online platforms while aiding in applying for grants and facilitating donor-related communications.



## *Supporting Families* FROM THE BEGINNING

“For so long, we wondered what was going on with Mom,” says Amber Dickson. Her mother’s behavior was changing in strange, uncharacteristic ways, yet a doctor told her that everything was normal.

Then Amber’s sister saw a public service announcement on television. Produced by AFTD and Discovery, Inc., the PSA highlighted the various symptoms of FTD – symptoms that matched their mother’s. With this information in hand, Amber’s mother soon got an official diagnosis of behavioral variant FTD.

“Her diagnosis came with a lot of emotions,” Amber says, “but I was also able to find a sense of calm in knowing that we had an answer and would be able to navigate from there.”

“I know for a fact that without [AFTD and its PSA], we would not be any closer to an accurate diagnosis today,” she adds.

Today, Amber is a committed AFTD volunteer and fundraiser. “I choose to support AFTD because they have supported my family and me from the very beginning of my Mom’s diagnosis,” she says.

**AFTD supports families from the beginning -- and through every stage of this journey. That's only possible with your help. As year end approaches, will you choose to support AFTD's mission by making a tax-deductible charitable donation? You can use the enclosed envelope, or visit [www.theaftd.org](http://www.theaftd.org) and click Donate.**

# Penn FTD Center Scientist Receives AFTD's First Pilot Grant for Nonpharmacological Research

AFTD has awarded Lauren Massimo, Ph.D., CRNP, the inaugural AFTD Pilot Grant for Nonpharmacological Therapies and Tools.

Dr. Massimo, an assistant professor in the University of Pennsylvania School of Nursing and a member of the Penn Frontotemporal Degeneration Center, will head a team that includes Penn neuropsychologists and smartphone application developers who will use the grant to develop and test an app that will help persons diagnosed with FTD overcome apathy.

"Apathy is a common and highly debilitating symptom for people with all FTD syndromes," said Dr. Massimo. "It has a huge impact on patients



*Lauren Massimo, PhD, CRNP*

and caregivers. For patients, it's associated with overall functional decline and mortality. For caregivers, a lot of stress and burden is associated with apathy, as they have to perform a lot of activities for people with FTD."

In her proposal, Dr. Massimo hypothesized that the app could provide a framework for symptom management in people with behavioral variant FTD, and that regular use of the app would contribute to the achievement of everyday goals and activities of daily life in the population. She further surmised that app use could result in increased functional activity, leading to beneficial returns for care partners, as well.

Dr. Massimo and her team have tested a model version of the app. "The second stage is a clinical trial, and we hope that this Pilot Grant will provide the preliminary data we need to pursue a larger grant from the National Institutes of Health," she said.

Dr. Massimo notes that the app is person-centered and can be adapted to the needs of each individual. It will guide users in selecting and scheduling activities that are meaningful to them, provide alerts that prompt them to initiate these activities, and deliver digital badges or other rewards for completing them.

"AFTD's award allowed the team to come together," Dr. Massimo said. "Without this award, this app would not happen."

## Hope Rising 2018... *(Continued from page 1)*

*(R-L) The Very Rev. Tracey Lind, AFTD Donor Donald E. Newhouse, Rev. Lind's spouse Emily Ingalls, AFTD CEO Susan L-J Dickinson.*

The Very Rev. Tracey Lind, dean emeritus of Trinity Episcopal Cathedral in Cleveland, moved and lifted the audience describing her personal journey with FTD since receiving her diagnosis in 2016.

"One of the challenges for people living with FTD and other types of dementia is that we lose the ability to tell our own stories and advocate on our own behalf," Rev. Lind said. "That is why, for as long as I am able, I'm determined to tell my story, in hopes that others will do the same, and bring this growing public health crisis out of the shadows and into the light."

AFTD CEO Susan L-J Dickinson described the gains that AFTD has been able to make in its mission thanks to their philanthropic support. She thanked donors and volunteers for making this event - and so much work - possible.

Donald E. Newhouse, president of Advance Publications, served as Benefit Chair. His co-chairs were David Zaslav, president and CEO of Discovery Inc. and inaugural recipient of the Susan Newhouse &

*Journalist Paula Zahn returned as host for the benefit.*



*Leonard A. Lauder receives the Susan Newhouse & Si Newhouse Award of Hope from event chair Donald Newhouse.*



Si Newhouse Award of Hope, and Anna Wintour, editor-in-chief of Vogue and artistic director of Condé Nast.

Journalist Paula Zahn returned as event host. Tony and Grammy Award winner Renée Elise Goldsberry provided musical entertainment, including an upbeat rendition of "If You Knew Susie" and a song from *Hamilton*, in which she originated the role of Angelica Schuyler.

# FTD and AFTD Now Included in Federal Research Portfolio

AFTD has been added to the International Alzheimer's and Related Dementias Research Portfolio (IADRP), an online database of worldwide research projects supported by public and private funding. This represents the first time an organization focused on the study of a dementia other than Alzheimer's disease has been included.

IADRP (pronounced "eyedrop") provides a comprehensive overview of the dementia research landscape that can be used to identify shared priorities and funding gaps, as well as to coordinate funding strategies and avoid duplication of

research efforts. AFTD uploaded its research portfolio in August, inaugurating the database's "Related Dementias" section.

"Researchers, funders and policymakers utilizing IADRP will

*For the first time, an organization focused on the study of a dementia other than Alzheimer's disease has been included in the IADRP database.*

be able to learn more about the awards we have made across all of our funding programs, including the two we support in partnership with the Alzheimer's Drug Discovery Foundation," said Debra Niehoff, Ph.D., AFTD's research manager.

The database, which is organized and categorized using the Common Alzheimer's and Related Dementias Research Ontology, currently includes information from more than 40 research organizations worldwide, representing more than 9,000 research projects and 5,000 individual researchers.

"Participating in IADRP will help raise awareness of AFTD's important contribution to research and increase both the number and diversity of applications to our grant program," Niehoff said.

For more information, visit the IADRP website at [iadrp.nia.nih.gov](http://iadrp.nia.nih.gov).

## World FTD Awareness Week... *(Continued from page 1)*

Stateside, World FTD Awareness Week commenced with a full-page ad in the September 23 issue of the *Sunday New York Times*. Designed by AFTD volunteer Jody Zorn and made possible through a generous donor, the ad communicated a straightforward message: "They said I was too young for dementia. They were wrong." AFTD's message continued to reach new audiences on September 25, when a banner version of our ad displayed all day on the *Times* mobile homepage.



*A scene from a 30-second AFTD public service announcement now airing on Discovery Inc. cable networks*

AFTD also debuted a new public service announcement, created in collaboration with Discovery, Inc.,

highlighting the FTD experiences of three key members of our community: AFTD Board member Daniel Hedaya, AFTD volunteer Olivia Goldring and advocate Katie Brandt.

"We don't have a cure for FTD today, but we do have a cure for the isolation that comes along with an FTD diagnosis," Brandt says in the video, currently available to view at [youtube.com/TheAFTDorg](http://youtube.com/TheAFTDorg).

FTD awareness is critical year-round. AFTD lauds all with the courage and conviction to tell their stories. Thank you to everyone who has lent their voice to raise awareness, bring help and share hope.

**They said I was too young for dementia. They were wrong.**

While few expect it earlier in life, dementia can strike adults of any age. The most common form for people under 60 isn't Alzheimer's, it's frontotemporal degeneration (FTD). FTD brings changes to personality, behavior, language and movement - striking at the heart of who we are and our loving families. Find information, help and support here: [www.health.org/youngdementia](http://www.health.org/youngdementia)

*Versions of this ad ran in the Sept. 23 issue of the New York Times and on the Times website on Sept. 25.*

# Those We Honor... Those We Remember

*Gifts received from June 1, 2018 - October 15, 2018*

## In Memory of

|                           |                           |                         |                                   |
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*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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## **Honor A Loved One, or Remember Their Legacy**

Families wishing to direct memorial donations to AFTD are encouraged to call our office at (267) 514-7221. 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 **click Donate.**

# Alector Receives Orphan Drug Designation for FTD Therapy

In August, the U.S. Food and Drug Administration (FDA) granted orphan drug designation to Alector for the continued development of AL001, a human recombinant monoclonal antibody designed for the treatment of FTD caused by mutations in the progranulin gene.

In order to better understand FTD-related challenges, the California-based biotechnology company reached out to AFTD during the development phase of AL001, which is “an immuno-neurology drug designed to repair the immune system to elicit a therapeutic benefit,” according to Arnon Rosenthal, Ph.D., Alector’s chief executive officer.

The FDA grants orphan drug designation to therapies designed to aid in the diagnosis, prevention and/or treatment of rare diseases, which they define as those affecting fewer than 200,000 people in the U.S. Receiving an orphan drug designation qualifies the company for a range of incentives intended to support continued development of the drug, including tax credits and exemption from regulatory fees. AL001

is one of a number of drugs currently vying for approval to be the first FDA-approved therapeutic option for persons diagnosed with FTD.

“The main focus [of AL001] is people with progranulin gene mutations – a rare subgroup of people with FTD,” said Nadine Tatton, Ph.D., AFTD’s scientific director. “The level of progranulin in the blood of a mutation carrier is about half the level you would see in a healthy

*“What a person diagnosed considers an important outcome can be very different from the opinions of a researcher,” said AFTD Program Director Sharon Denny.*

individual. Alector has developed a therapy that can increase the blood levels of progranulin, an antibody that binds to its target and converts the person to producing normal progranulin levels.”

Earlier this year, Dr. Tatton visited Alector’s headquarters in San Francisco, along with AFTD program director Sharon S. Denny, M.A. They were joined by research scientists working on AL001, persons affected by FTD and their care partners, and former AFTD

Board Chair Jary Larsen, Ph.D.

“Alector is in the process of moving its therapies from basic science and drug development into the clinical setting,” said Denny. “They reached out to us because they want to learn more about the impact of the disease as it plays out in peoples’ lives.”

Alector has initiated a phase 1 clinical trial of AL001 to test the safety and tolerability of the therapy. The trial currently seeks volunteers with a progranulin gene mutation who have been diagnosed with FTD, as well as progranulin gene mutation carriers who are asymptomatic and healthy volunteers. More information about the clinical trial can be found on the Featured Studies section of AFTD’s website.

“Our meeting with Alector reflects increasing awareness that the person diagnosed is an important part of the clinical trial landscape,” Denny said. “What a person diagnosed considers an important outcome can be very different from the opinions of a researcher. AFTD can act as a bridge between the FTD community and the scientific world.”

## Save the Date: AFTD’s 2019 Education Conference

**AFTD invites you to join us for our 2019 Education Conference on May 3, 2019 in Los Angeles, California.**

Mark your calendars now for a day filled with learning, sharing and connecting with others who understand.

**Registration opens in January.**

Follow AFTD’s website and social media accounts for the most up-to-date information!





# Giving a Hand to Our Helping Hands!

## AFTD Volunteer Nanci Anderson

As care partner for Gary, her husband of 38 years, AFTD Volunteer Nanci Anderson of Minnesota feels she has a renewed purpose – to support her husband, family and others on the FTD journey. She says she is fortunate to have the support of her professional networks, community members, friends and family as she works to raise FTD awareness and funds for AFTD in the Midwest.

### Why did you want to volunteer?

Gary is participating in an FTD study, which has been difficult for him. My daughters and I felt that if he can “give” like that there must be something we can do, so we signed up to volunteer. We feel that expanding the awareness and visibility of this disease will make the biggest impact, bringing about hope and change. We will not let ourselves simply sit around and say “why me.”

### What activities have you done for AFTD to date?

One of my first activities as a volunteer was representing AFTD at the 2018 Meeting of the Minds Conference in St. Paul, MN, where there were

1,200 attendees. It was a tremendous success: Our AFTD table drew a constant stream of people curious about FTD and wanting to know more about AFTD.

My daughters took on AFTD’s With Love campaign in February 2018. They designed a beautiful Facebook page sharing our story. This was a big step for us – it was the first time we publicly shared our story beyond close family and friends. The outpouring of support was amazing, and

we raised over \$6,000.

I am a realtor, and after hearing my

story, my team Berg Larsen Group of Coldwell Banker Burnett chose AFTD as its charity. For every new listing in the months of September and October, they donated \$100 to AFTD.

Most recently, my daughters and I organized our first (and not last!) Food for Thought event at a restaurant,

which was a great success. We initially thought around 25 people would participate, but in the end we drew more than 100. The restaurant jumped in to support our efforts and donated 25% of net profits from the evening to AFTD.



Nanci and Gary Anderson (middle) surrounded by loved ones

### For people who are considering volunteering with AFTD, what would you say to them?

Find what you are passionate about. Don’t be afraid to share your

story. AFTD has so many resources to guide and help you. You can make a difference.

### Anything else you wish to share?

Be bold! Think big!

“When it comes to engaging personal and professional networks, Nanci’s efforts are a great example for volunteers to follow,” said AFTD Midwest Regional Coordinator Volunteer Deb Scharper. “It is amazing to think about the number of people she has already reached through her volunteer service to AFTD.”

## Creating “Hotspots” of Engagement Across the U.S.

AFTD’s volunteer presence continues to grow throughout the country, reaching more people every day. Although we are headquartered in the Philadelphia area, we’ve been able to identify numerous U.S. cities as AFTD “hotspots” – areas that are building local momentum and energy thanks to our passionate and committed volunteers!

Hotspots (including but not limited to Austin, Seattle and Denver) are notable for attracting a range of volunteer-driven activities, including races, support groups and Meet & Greets – all of which bring those affected by FTD together.

These activities combine to create momentum. For example, AFTD-Team races attract runners and walkers while also fundraising for AFTD and raising awareness. Support group facilitator volunteers take the lead in bringing

*Communities are building local momentum and energy thanks to our passionate and committed volunteers!*

care partners together to share with and support one another, and offer a chance to socialize with others who understand FTD. Volunteers who plan and facilitate Meet & Greets provide the opportunity for those who are affected by FTD, personally or

professionally, to connect and learn from each other.

We know there is strength in numbers. By bringing the community together in various ways, AFTD is establishing a sense of community and connection that increases activity and momentum and raises much needed awareness. AFTD is grateful for everyone who has stepped up to engage with our community.

Let us know if your city has become an AFTD hotspot! And if you want to put your city on the map, reach out to us and become an AFTD volunteer today. Visit the National Volunteer Network section of our website to find out how.



**AFTD's Food for Thought 2018 campaign saw 74 events in 35 states, Canada and London and raised more than \$160,000.**

**Hole in One:** Steve Bellwoar, a Pennsylvania-based AFTD Board member, hosted the fifth annual Colonial Electric Food for Thought event, featuring nine holes of golf, dinner and a short presentation from AFTD CEO Susan L-J Dickinson. The event raised \$69,098, bringing the grand total to \$375,000 raised over the past five years and securing its title as our flagship Food for Thought event.

**Slice of Success:** Colleen Franzreb of Massachusetts hosted a pizza party with her family that quickly became a viral event. They raised \$14,232, more than double their initial goal: a pleasant and well-earned surprise for everyone involved.



**Dine and Donate:**

Terry Pontious, Linda Michalakes, Jim Cermak and Michelle Kelly of Ohio hosted a sit-down dinner with raffle baskets. The event

received more attention than anticipated, resulting in the addition of unplanned dinners-to-go. A grand total of \$10,339 was easily raised.

**It's an Art:** Terry Walter of California hosted her third annual event at JayJay Gallery, featuring delicious bites and inspiring art auctions. With help from AFTD Board member Beth Walter, the evening brought in \$6,840.

**Pizza Party!:** Nanci Anderson and Emily Anderson of Minnesota were joined by over 100 people, including their local FTD Support Group, at Olive's Fresh Pizza. Online and cash donations were accepted, and the restaurant additionally donated 25% of the evening's earnings, bringing the grand total raised to \$5,000.

**Fun in the Sun:** Sarah DeLuca of Missouri held her event at Rusted Route, a local outdoor venue. The afternoon was filled with food trucks, music, bouncy houses and beautiful weather – all combining to raise \$4,500.

**A Cut Above:** Lucy Carter of Tennessee collaborated with Porter Road Butcher, which provided a percent of their online sales to her event. After crunching the numbers, Lucy raised a total of \$3,500.

**Mahalo!:** Natalie and Paul Ahotaeiloa of Utah held a Hawaiian Plate Sale, cooking and selling platters of Hawaiian food consisting of kalua pork, katsu chicken, teriyaki chicken, rice and macaroni salad. The food must have been delicious, because the sale raised \$3,422.

**It All Adds Up:** The Pang Family from New Jersey hosted Dollars for Dim Sum, serving more than 500 handmade dumplings to family and friends at their house. Raising \$3,008, the evening was a scrumptious success—just ask AFTD Grassroots Events Coordinator Bridget Graham, who attended and ate her fair share.

**Mahalo Part 2:** Bonnie Shepherd from Utah ordered food from Natalie and Paul Ahotaeiloa's event and hosted her own Hawaiian-style dinner party. Her guests had lots of fun and even more food, raising \$3,000 and taking home plenty of leftovers.

**Soup's On:** Sharon DeFelices of Pennsylvania organized online soup sales, prepared and donated by 14 local restaurants and caterers. Rainy weather encouraged soup consumption, resulting in \$2,575 raised.

**Cherry on Top:** Ryan Windhorst of Illinois organized multiple local Dairy Queens to donate a portion of sales during one entire day; those unable to visit were encouraged to donate online and share some ice cream with a loved one. He and his family also hosted a "Sundae Sunday" featuring an ice cream buffet. The three events raised a total of \$1,921.

**Sweets for Science:** Shana Nissen and Dionne Coston of Texas hosted a dessert-centered event featuring a silent auction, raffle and presentation from three neurologists from the University of Texas. More than 20 people attended and raised \$1,218.



**Tasty Treats:** Kayla Boehmer of Iowa hosted two bake sales at her church. Patrons were inquiring, generous and hungry – helping to raise \$1,212.

**Meat Pie Moment:** Susan Butterfield, Joanne Linerud and Karen Bainbridge of Washington hosted their event during the grand opening of Premier Meat Pies, owned by Karen herself. Approximately 50 to 60 people attended the evening, which featured a bagpiper, a raffle and an educational presentation, raising \$1,175.

**Family Favorites:** Eliana Fischel of Washington, DC hosted a small dinner party for 12 guests and served her dad's (who has FTD) favorites, like lasagna, "eggs with green things in them," plain green beans and margaritas. Attendees, along with other family and friends, raised \$1,058.

**Thank you to additional hosts, who also raised funds and awareness to support AFTD's mission:**

Amber Dickson  
Amber Dietz  
Amy Shives  
Anna Gensler  
Barbara Loewy & Tammy Loewy  
Brandee Waite

Cheri Connely  
Chrissy Pikos  
Chuck Anastasia  
Cindy O'Dell  
Darlene Bursch  
Deborah DiScenza  
Diane Cole

Donna Wert  
Elizabeth Soriero  
Esther Harvey  
Gene Thornton  
Jamie Gordon  
Jan Keller  
Jen Morabito

Jennifer Zucati  
Jerry Horn  
Lori Cox  
Karine Adalian  
Kathleen Babiasz  
Kathy LaFone & Sara LaFone

Lisa Radin  
Lynda Ares  
Mary Anne Upham  
Matthew Dineen  
Melissa Fisher  
Michael Stowell

Nicole DeLeve  
Patrick Gutierrez  
Peter Foster  
Rona Klein  
Shirley Gordon  
Stephanie McLain  
Susan Eissler

Tam Smith  
Valerie Matney  
Vickie Eubank  
Wynne Cerone  
Zoy Kocian

# THE AFTD-TEAM

**Still Going Strong:** The thirteenth annual George F. Sidoris Memorial Golf Outing was held on July 21st in Mentor, OH and raised \$27,800. This event is AFTD's longest running grassroots fundraiser, and, with over \$206,000 raised in total, is also AFTD's highest earning. Congratulations to the Sidoris Family, and thank you for your continued and notable support!

**Birthday Presence:** Lisa Boyce of Florida celebrated her 60th birthday and in lieu of gifts, she requested donations be made in memory of David Gates, who passed away from FTD at the age of 42. Generous donations were made online and in person at her birthday party, totaling an impressive \$19,880, a great accomplishment to kick off a new decade of life.

**Club and Grub:** On September 15 in Broomfield, CO, the inaugural Buffalo Trace Charity Open and Ryder Cup Meal drew golfers to the greens and hungry supporters to the dinner table. Hosted by AFTD Board Member Michael Stowell and joined by AFTD Board Member David Pfeifer, the event raised \$9,150.



**Fun on the Fairway:** The second annual Crusade for a Cure Golf Tournament, hosted by AFTD Regional Coordinator Volunteer Deb Scharper, was held on September 1st at Sunny Brae Golf Course in Osage, IA. The day was a great success, raising \$7,479 and beating last year's total.

**Aurora Blue:** The Aurora, CO Police Department participated in a weeklong fundraiser, where the over 700 employees had an opportunity to learn about FTD and make a donation to AFTD. Thank you to the men and women of the department for serving and donating \$2,815.

**Racing for a Cure:** Kathryn Brucato of New Jersey ran in the Brigantine Triathlon on August 4th and raised \$2,092. She ran alongside family and friends, all in honor of her father, Richard Anderson, who was diagnosed with FTD in 2012.

**Celebrating Tami Sue:** The third annual Tami Sue Golf Outing and Party was held on September 8th in Ohio and raised \$1,500. Hosted by Suzanne and Calvin King, the day celebrates and remembers their daughter, who passed away from FTD in 2016.

**Business Casual:** The third annual Credit Suisse Jeans Day was hosted on September 28th in New York, NY and raised \$1,170. Hosted by AFTD Board Member Brian Rose, this one-day event—which usually spans an entire month—raised more than the previous year.

**Remembering Carl:** The third annual CWM Golf Outing was held on July 14th in Michigan and raised \$1,100. Hosted by the Morettis and Marcys, the day celebrates and remembers Carl Moretti, who passed away from FTD in 2015.

**AFTD extends a heartfelt thank you to all nine of the 2018 Food for Thought Liaisons for their extraordinary effort this campaign!**

- |                     |                     |                  |
|---------------------|---------------------|------------------|
| • Ariel Harden      | • Meghan Roscoe     | • Teresa Webb    |
| • Elaine Rose       | • Sarah DeLuca      | • Terry Pontious |
| • Jennifer Morabito | • Susan Butterfield | • Traci English  |



## AFTD-Team Race Season

The AFTD-Team participated in the Los Angeles Rock 'n' Roll Half Marathon and 5K on October 28th and raised \$3,221. We had 25 people on our team, running through the streets of LA and spreading FTD awareness. A special shout-out to Vincent Marchetta and Ben Austin for their fundraising efforts.



Since activating Facebook fundraisers on behalf of AFTD in October 2017, our supporters have raised over \$118,500 in the fight against FTD! A huge thank you to everyone who created a Facebook fundraiser in the past year. We sincerely appreciate your bravery in sharing your story so publicly – and a special shout-out to those who raised \$1,000 or more:

- See Aytch
- Maggie Braun
- Julianne Rouquette Cary
- Lorrie Cox
- Randee Curry
- Randi Davis
- Natalie Fahey
- Carrie Feron
- Gary Johnson
- Cassie Jonaitis
- Laurie Korczynski Kozakiewicz
- Martha Madison
- Alyssa McCray
- Bekkah Norris
- Ashley Olhausen
- Linda Rk
- David Rosenstein
- Deborah Scanlan
- Jamison Sep
- Gene Thornton
- David White



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