



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

Volume XIV, Issue 3

Fall 2017

Announcing the David Geffen Fund at AFTD

A major gift from the David Geffen Foundation will help AFTD deepen its commitment to raising awareness, funding groundbreaking research, and supporting people living with FTD.

AFTD CEO Susan L-J Dickinson announced the creation of the David Geffen Fund at our Hope Rising Benefit in New York City on October 12. Over the next 10 years, contributions to the fund will provide \$2 million annually to support AFTD's mission. [Read more about the 2017 Hope Rising Benefit on Page 8.]

Geffen, a film and music producer and philanthropist, established the fund

to honor Si Newhouse of Advance Publications and chairman of Condé Nast. Newhouse had the primary progressive aphasia (PPA) variant of FTD; he died on October 1. The

*Geffen established the fund
to honor Si Newhouse.*

David Geffen Foundation will join the Samuel I. Newhouse Foundation in providing the contributions to this fund over the next ten years.

"This fund will enable AFTD to continue to lead the way in expanding our understanding and treatment of this horrible neurodegenerative

condition," Geffen said.

The David Geffen Fund will provide unrestricted support for AFTD – helping to advance the full scope of our mission. Geffen served as a co-chair of AFTD's Hope Rising Benefit, as did Si's brother Donald Newhouse. Donald's life has been twice touched by FTD: In 2015, his wife, Susan, died 12 years after being diagnosed with PPA.

Donald has since become a critical ally and generous benefactor of AFTD. In an October 23 interview, he explained how he became involved with AFTD:

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AFTD Study Shows Economic Burden of FTD

The average annual costs of FTD are nearly double those associated with Alzheimer's disease, according to a new study funded and co-written by AFTD.

The study, entitled "The Social and Economic Burden of Frontotemporal Degeneration," appears in the November 14 issue of *Neurology*, and it can also be accessed for free online. It is the first study published in the U.S. to focus solely on quantifying the economic impact of FTD.

"For years, we have known about the extraordinary economic burden shouldered by FTD caregivers, but now we have

the numbers to prove it," said AFTD CEO Susan L-J Dickinson. "This study shows that the financial toll of FTD – nearly \$120,000 per year – is even more devastating than we imagined."

Data were gathered from 674 FTD caregivers, who filled out a detailed online survey featuring questions about the ways in which FTD has impacted their

finances, health and social lives. That data was compiled into a study by Dr. James E. Galvin of the Charles E. Schmidt College of Medicine at Florida Atlantic University, Dr. David H. Howard of Emory University and AFTD staff.

(Continued on page 5)

Money Well Spent: AFTD Pilot Grants

Organizations that fund scientific research are putting a growing emphasis on accountability – evidence that their grant programs are meeting objectives and advancing their research agendas. The evaluation of research performance – the scientific equivalent of the return on investment (ROI) analysis routine in business settings – can inform strategic planning and identify researchers who are moving the field forward.

From 2005 to 2016, AFTD invested \$4.9 million from our donors into FTD research. To better understand the contributions of the projects we fund, AFTD initiated an ROI analysis of our own research portfolio in January 2017, focusing first on the organization's Pilot Grant program, which provides “seed funding” to

early-career investigators.

Between 2005 and 2016, AFTD awarded 17 Pilot Grants totaling \$955,000 to investigators from the U.S., Canada, and four European countries.

Initial results of our ROI analysis

Pilot grants have succeeded in attracting outstanding early-career researchers to FTD research.

confirm that the Pilot Grant program has been a worthwhile investment for AFTD and our community. Collectively, recipients attracted \$7.53 million in follow-on funding, indicating deepening work into advancing FTD research. They published a total of 26 grant-related articles, with 76% publishing at

least one such article. And these publications have made notable contributions to FTD research: Half have been cited by other researchers more often than expected for a paper in the field.

“The impact of the Pilot Grant program is clearly documented by the publications and the success of the grantees in being awarded additional funding to continue the work enabled by AFTD,” notes John Whitmarsh, PhD, who chairs the AFTD Board's Research Committee. “Most importantly,” he adds, “pilot Grants have succeeded in attracting outstanding early-career researchers to FTD research.” These researchers are key allies in our community's work to achieve a world without FTD.

AFTD NEWS BRIEFS

AFTD Nominee Joins Dementia Advisory Council

On September 28, Katie Brandt was appointed to the federal Advisory Council on Alzheimer's Research, Care, and Services. AFTD nominated Katie to serve on the council, which advises the secretary of the Department of Health and Human Services on federal programs that affect people with various forms of dementia, including FTD. Katie's late husband Mike was diagnosed with FTD when he was just 29 years old. She has remained a passionate advocate for the FTD community, facilitating a support group in Boston, appearing recently in an AFTD #ThinkFTD awareness video, and working as a community resource specialist at Massachusetts General Hospital's Frontotemporal Disorders Unit.

Columbia Trial on Behavioral Symptoms in FTD

In collaboration with the Alzheimer's Drug Discovery Foundation, Columbia University is sponsoring a clinical trial to test the effects of low doses of lithium on the behavioral symptoms of persons diagnosed with FTD. Investigators are recruiting volunteer participants who have been diagnosed with behavioral variant FTD, semantic variant primary progressive aphasia (PPA) or agrammatic, non-fluent PPA with behavioral symptoms for participation in the recurring trial. A care partner will be required to provide information about the patient during interviews. For more information, contact Hannah Silverman at hs2971@cumc.columbia.edu or by calling (212) 305-6284.

FTSG Conference to Be Held March 2018

The Frontotemporal Degeneration Treatment Study Group (FTSG) will convene for a conference on March 8-9 in Washington, DC. Over the course of a day and a half of programming, the FTSG will work to strategize ways to accelerate the development of effective treatments for FTD and related disorders by promoting scientific interactions and collaborations between academia and industry. AFTD is a co-founder of FTSG.

New AFTD Regional Coordinator Volunteer

AFTD is excited to announce the newest addition to our Volunteer Leadership Team: AFTD Regional Coordinator Volunteer Rachel Castellanos. Rachel has joined Regional Coordinator Volunteer Zoy Kocian in overseeing the South Central Region. Rachel lives in Louisiana and has volunteered for AFTD in a variety of ways, including planning a successful Louisiana Meet & Greet.



*AFTD Regional Coordinator
Doreen Putnam*

Choose to Be a Source of Help and Hope

FTD stories make a difference. In 2014, at a networking event for health professionals, Doreen Putnam listened as a young woman described how her husband had been diagnosed with FTD while only in his 20s. Doreen, a certified dementia practitioner with more than two decades of experience, was so moved that she immediately signed up for AFTD volunteer training.

"I realized in that moment how devastating FTD is for families," she said. "It's so different from Alzheimer's. So many people with FTD are mid-career, and have children at home or in college."

Doreen has gone on to become an AFTD volunteer Regional Coordinator, overseeing volunteer activity throughout all of New England. She also leads an FTD support group in East Providence, RI.

"I come away every month thinking that the meeting helped people," she says. "Any time I

have a conversation with someone facing FTD – whether about changes in communication or behaviors, or just what the future holds – I know they leave with a little more hope and a little more sense of direction."

AFTD's growing volunteer network brings **help and hope** to families facing FTD. And through our support groups, webinars, publications and toll-free Helpline, we work every day to inform, empower and connect those facing an FTD diagnosis.

Bringing help today – and hastening a future without this disease – takes contributions from each of us. Today, as the end of 2017 approaches, consider a donation to the Association for Frontotemporal Degeneration. **Will you choose to make a tax-deductible donation today?**



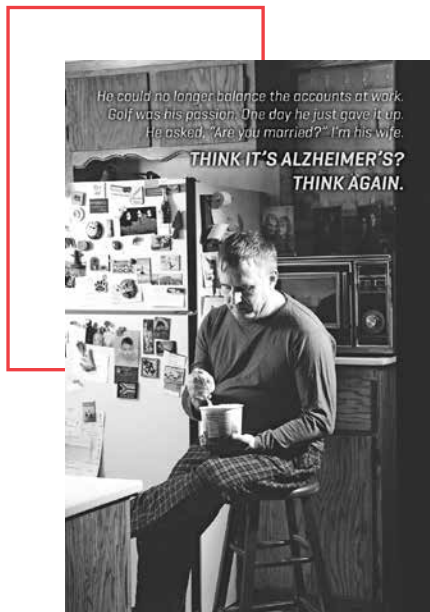
World FTD Awareness Week Rallies Community

People affected by FTD from around the globe raised their voices during the third annual World FTD Awareness Week, encouraging the world to #ThinkFTD.

From September 24 through October 1, 2017, advocates in ten countries held events and took to social media to spread FTD awareness. AFTD debuted its “Think It’s Alzheimer’s? Think Again” campaign. In a series of videos, created in collaboration with Discovery Communications and Image Factory DC, prominent members of our community told stories of their loved ones’ FTD journeys. Actress Martha Madison and sports broadcaster Wes Durham, as well as AFTD ally Olivia Goldring, AFTD Board member Danny Hedaya, former Board member Sylvia Mackey, and advocate Katie Brandt shared videos, which can be found on AFTD’s YouTube channel, www.youtube.com/TheAFTDorg.

“The one thing I want people to know about FTD is that it

exists...” Madison said in her video. Madison’s mother was diagnosed with behavioral variant FTD in 2008.



“We need people to really pay attention to the fact that this is a unique disease, and we need all hands on deck,” added Madison, best known for her recurring role on *Days of Our Lives*.

AFTD encourages others to share their FTD stories on social media using the hashtags #ThinkFTD and #EndFTD.

Bookending World FTD Awareness Week, two full-page ads ran in the September 24 and October 1 issues of the Sunday *New York Times*. Made possible by a generous AFTD donor, these ads put the #ThinkFTD message before hundreds of thousands of *Times* readers. AFTD volunteer Jody Zorn designed the ads; one is featured on this page.

FTD deserves a global response – and AFTD thanks all of those who made their voices heard to help ensure that it gets one.

FTD Biomarkers Initiative Holds First Investigators Meeting

Biomarkers — biological characteristics used to diagnose a disease, track its progression, or monitor the response to treatment — top the FTD scientific community’s “most wanted” list of research tools.

AFTD is playing a leading role in meeting this urgent need through its FTD Biomarkers Initiative, made possible by a donation from the Samuel I. Newhouse Foundation. Dedicated to funding biomarker discovery and development, the FTD Biomarkers Initiative will advance research by promoting the open sharing of data, resources, and ideas.

This fall, AFTD brought together current award recipients, scientific advisory board members, and guest

experts for the first FTD Biomarkers Initiative Investigators Meeting, held October 9-11 at Tarrytown House Estate and Conference Center in Tarrytown, New York.

Research teams headed by the five recipients of the first FTD Biomarkers Initiative awards presented work in progress. The five award recipients taking part were Randall Bateman, Washington University; Christian Haass, Ludwig-Maximilians University; Leonard Petrucelli, Mayo Clinic-Jacksonville; Jonathan Rohrer, University College London; and Judith Steen, Boston Children’s Hospital.

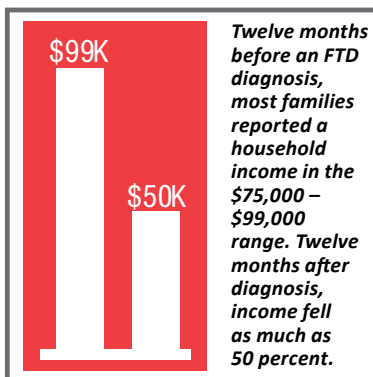
Invited guest speakers shared their experiences about the pivotal ways

biomarkers are used in each phase of drug development and the variety of resources available to support biomarker research, including the National Institute of Neurological Disorders and Stroke’s Human Cell and Data Repository, biological samples and imaging data compiled by the Europe-based GenFI network (Genetic FTD Initiative) and the NIH-supported ARTFL and LEFFFTDS networks in the U.S.

The conference concluded with a discussion of current challenges and opportunities in FTD imaging biomarkers, and left researchers with new tools and deeper collaborations in their work to advance FTD diagnosis, and pave the way for new treatments.

Economic Burden of FTD *(Continued from page 1)*

FTD is costlier than Alzheimer's because it tends to affect people earlier in life, during their prime earning years, the study's authors said. FTD is the most common dementia for people under age 60.



The study shows that an FTD diagnosis can cause household income to fall by as much as 50%. Median household income 12 months prior to an FTD diagnosis was in the \$75,000-\$99,000 range, but 12 months after diagnosis, it fell to the \$50,000-\$59,000 range.

Miscellaneous costs add up. FTD's symptoms include poor financial

decisions – 58% of caregivers reported that their loved one had made bad choices with money. Other FTD-related costs included crises involving emergency department services (19% of respondents), emergency medical services (11%), urgent psychiatric care (8%) and police intervention (6%).

The health of caregivers declines. Two out of three (67

percent) FTD caregivers reported notable declines in their health. More than half (53

percent) said they incurred higher personal health care costs.

One out of three caregivers stops working. Nearly 40 percent of caregivers surveyed said they were no longer employed following the patient's diagnosis. Those still working reported a median loss of seven full days of work over the previous four weeks because of FTD-related issues.

"By driving patients and caregivers out of the workforce, often during their peak earning years, FTD's impact can be felt long after the person diagnosed

Please help us spread the word about this ground-breaking study!

Visit theaftd.org/learnmore and download our talking points and infographic. Share them with your family, friends and professional networks to help the world better understand the devastation of FTD.



Nancy Carlson

Photo by: Craig Perman

FTD had a direct effect on the finances of children's book author and illustrator Nancy Carlson. Her husband Barry was her business manager, and

"he did everything – paid the bills, did the insurance, negotiated contracts with publishers, everything," she said. "I never asked that much about it, plus I didn't want to know."

Barry began making uncharacteristic errors, including neglecting to pay credit card bills. Unbeknownst to Nancy, he began borrowing money from friends and took out two additional mortgages on their house; he filed income taxes for eight years but failed to pay them. Nancy added: "He alienated my publishers by just being odd and not following through. That's a big loss of income for me."

When Barry was diagnosed with behavioral variant FTD in 2012, it came almost as a relief, since it explained his reckless financial behavior. Getting the diagnosis "made all the difference in the world."

All told, Nancy estimates that Barry's FTD cost the family close to a half a million dollars. He died in late 2016, four years after he was diagnosed.



Mary Ann Coon

Mary Ann first met Bruce Coon when they were both young teenagers. Eventually they married and built a life and a family together. Bruce owned a successful excavating company and made good money.

The couple had just finished building their dream home when Bruce began acting recklessly, particularly with money. Mary Ann became increasingly worried, but Bruce always dismissed her fears. After an old high school friend asked Mary Ann if her husband ever intended on paying back the tens of thousands of dollars he had borrowed, she knew something was seriously wrong.

Bruce had to leave his job and required full-time care – first from Mary Ann, then from an assisted care facility that cost thousands of dollars a month. Mary Ann says that they spent down their savings and had to borrow money from her parents. They tried to live as frugally as possible – "We were using dish soap to wash our clothes. Dinner was spaghetti or eggs every night." But they still ended up having to sell their dream house.

Bruce died in 2015 at the age of 53, and Mary Ann still feels the financial impact of her family's FTD journey. She wanted to put her sons through college, and help her daughter buy a house with her fiancé. But she can't. "All those things that as a mother I wish I could do – I just don't have the money to do it," she said.

has passed on," Dr. Galvin, the study's lead author, said.

Donations Honor Loved Ones *Gifts received from June 16 – October 15, 2017*

In Memory Of

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	Otto Kostka	Peggy Pines	Ellis G. Wachs

AFTD *is grateful for these gifts, which fund research, education and support.*

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In Honor Of

Rebecca Adams
AFTD Volunteers
Gail Andersen
Keith Atkinson
Randy Baker
The Bee Family
Robert Keith Belcher
Trish Bellwoar
Stephen Besch

A Powerful Way to Remember

Your loved one's legacy can bring hope and courage to others facing FTD. 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 and select "Donate to AFTD."

Save the Date: AFTD's 2018 Education Conference



AFTD's annual Education Conference will be held on **April 13, 2018** in Chicago, Illinois.

Join AFTD staff, persons diagnosed, caregivers and healthcare professionals
for a day of learning, sharing and support.

Registration opens in January. Be sure to stay tuned to AFTD's website
and social media accounts for more information.

AFTD Holds Second Hope Rising Benefit in NYC

In a strong demonstration of hope for a future without FTD, more than 425 people gathered at the Pierre Hotel in New York City on October 12 for AFTD's second Hope Rising Benefit.

Sen. Charles

Schumer was honored with the Susan Newhouse & Si Newhouse Award of Hope. For decades, he has been a strong proponent of biomedical research, fostering bipartisan support for these efforts.

"There is no doubt it will take a village to beat FTD and the pain it brings to families," Sen. Schumer said. "Our collective work to combat this condition through awareness and advocacy, along with federal and private dollars, has charted a path to winning the fight over a disease that so callously robs those afflicted of memories and the

fullness of human connectivity."

Guests were treated to food inspired by recipes from *Cooking with Adrienne*, a cookbook by Joan Harper about her friendship with Adrienne Zausner, who has

primary progressive aphasia.

Dr. Halima Amjad, assistant professor of medicine at Johns Hopkins and AFTD's 2017 Education Conference keynote speaker, gave a short talk about how her father's FTD has guided and informed her career in geriatrics. The night also featured the premiere of "VJ and Chuck," about the FTD journey of

Rhode Island couple VJ and Chuck Anastasia, directed by Joseph Becker of Thinkfilm, Inc.

AFTD CEO Susan L-J Dickinson announced the creation of the David Geffen Fund at AFTD, which will provide the organization with \$2 million per year over the next ten years. [See page 1 for details.] Geffen served as a co-chair for the event,

joined by Dr. Henry Louis Gates, Jr., Anna Wintour and Donald Newhouse.

Journalist Paula Zahn reprised her role as the event's host. Tony and Grammy Award winner Cynthia Erivo

provided the evening's inspired musical performance, including renditions of "If You Knew Susie" and "Let It Be," dedicated to Si and Victoria Newhouse.



L-R: Discovery Communications president/CEO David Zaslav, AFTD CEO Susan L-J Dickinson, AFTD donor Donald Newhouse, Sen. Charles Schumer, AFTD Board chair Gail Andersen



Journalist and TV host Paula Zahn hosted the 2017 Hope Rising Benefit



AFTD CEO Susan L-J Dickinson

David Geffen Fund (Continued from page 1)

"I felt that the only way I could make sense of what [Susan] was going through, what I was going through, was to see what I could do to help other people suffering from this horrendous disease," he said.

In a statement, Donald noted that

the David Geffen Fund "will greatly increase AFTD's ability to carry out its missions." He added: "David

Over the next ten years, the David Geffen Fund will provide \$2 million annually to support AFTD's mission.

Geffen is a great friend who reacted so thoughtfully to my wife and my brother having suffered from PPA."

"David Geffen's gift is an incredibly generous step forward for this organization and its mission." Susan

Dickinson said. "Expanding significantly the scope and reach of AFTD's work over the next decade, this fund will bring closer a world without FTD."

Giving a Hand to Our Helping Hands!

While caring for his wife Janet Collins Elligson at home for several years, Charles Elligson of North Carolina found support through a local FTD support group. He found information and resources through AFTD. Charles says that he could not have survived his caregiving years without both. Today, as an AFTD volunteer, he channels his personal experience with FTD into a role as an AFTD-affiliated support group facilitator, and efforts to raise awareness.



Charles Elligson with AFTD volunteers and staff

What you have learned from your volunteer experiences so far?

As a support group facilitator I have learned greater understanding of the unique way FTD presents in persons diagnosed. I've learned ways to tailor FTD information and support to fit the many unique FTD situations; and a true sense of how facilitation can contribute to group learning.

Through my awareness efforts I have discovered that people are interested and want to learn more.

Tell us about your volunteer experiences to date.

I went through the formal training to become an AFTD-affiliated support group facilitator. I also raise awareness about FTD, AFTD and caregiving through speaking engagements and table settings for various organizations and professional networks, as well as with my local church community.

How has the overall volunteer experience made you feel?

It brings deep satisfaction and true joy to know that you are using your gifts and skills to bring support group members together. They bring light, hope, and practical answers to seemingly unsolvable problems...It is also a great feeling to be able to educate the community at large about FTD and the impact it has on everyone involved. In a dark world, there's now light.

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

AFTD offers volunteers easy access, guidance on how to move forward, and support materials so you can feel confident in your volunteer role. Thanks to the support and guidance provided by Regional Coordinator Volunteers like Michelle Grant, you know you are not alone. Additionally, AFTD offers excellent ongoing training.

Anything else you wish to share?

There is hope! A year and a half after Janet's passing, her closest friend introduced me to a Presbyterian minister, Rev. Jeannette Hickman. We married a year later.

"Charles continues to surprise me with his outreach efforts, identifying new opportunities to educate the community," said South Atlantic Regional Coordinator Volunteer Michelle Grant. "We are grateful for his continued service to support AFTD's mission."

AFTD Meet & Greets: Reaching Communities Across the Country

Meet & Greet events are AFTD's fastest growing community-based volunteer activity. These informal awareness activities bring together people interested in FTD: persons diagnosed, caregivers, family members, friends, and professionals. Meet & Greets provide attendees with the opportunity to 1) connect with others, 2) learn about AFTD programs, resources and how to get involved, and 3) share local information and resources.

For many, Meet & Greets are their first opportunity to meet another

person or family affected by FTD. Those attending usually leave with new information and new friends.



Deb Nash and Mike Dirksen

Volunteers hosting these events have found them to be both fun and rewarding. Corey Esannason, one of AFTD's Middle Atlantic Regional Coordinators, said, "It was so wonderful to be able to create a space for everyone to come together."

Zoy Kocian, one of AFTD's South Central Regional Coordinator Volunteers, said, "Hosting

a Meet & Greet was a very positive experience. I found it motivating to see an AFTD-affiliated support group take shape and start as a result of the gathering."

AFTD is committed to not only reaching our FTD community across the country, but also bringing this community together. Between July 2016 and June 2017, 15 Meet & Greets were held across the country. Since July 1, 2017, there have already been seven scheduled, with many more on the horizon.

If you would like to be the catalyst in bringing your local FTD community together, please reach out to your Regional Coordinator Volunteer to learn how you can organize a Meet & Greet.



For AFTD's 2017 Food for Thought campaign, events in 33 states, Canada and the U.K. raised more than \$180,000 and counting!

Above Par

AFTD Board member Steve Bellwoar (PA) hosted the Fourth Annual Colonial Electric Charity Event. Although golf was rained out, attendees still enjoyed a spectacular raw bar, open bar service and a presentation of AFTD's progress. The event, a campaign staple, has raised \$108,000 to date.



Brew for Thought

Cathy Sperrick of New York teamed with Abandon

Brewing Company to offer patrons beer and food at the brewery's restored 19th century barn, with a beautiful view overlooking Keuka Lake. The event raised \$9,300.

Room and Board

AFTD Board member Bonnie Shepherd of Utah welcomed 54 people into her home. Guests sipped cocktails, while enjoying a light dinner and AFTD-themed desserts. A short presentation followed. All tied together for a lovely evening that raised \$8,752.



O Food Where Art Thou

Terry Walter of California hosted an evening featuring art, wine and cheese. David Wetzl, who is living with FTD, exhibited art for 100 guests. AFTD Board Members Beth Walter and John Whitmarsh cohosted; the event raised \$8,435.

Muddy for Tacos

Deanda Welch of Texas invited family and friends to her house to enjoy an impressive taco feast – but guests had to travel through three days' worth of rain and mud. The 26 people who attended enjoyed four different kinds of tacos, learned about FTD and raised \$5,455.

Five Fighting Courses

Kathy Ritchie of Arizona and The Central Phoenix Advocates for Dementia Awareness (CADA) hosted their 3rd Annual AFTD Food for Thought Dinner and Wine Tasting at Beatitudes Campus in Central Phoenix. The five-course dinner, paired with local wine, raised \$5,340.

An Answer for FTD

Molly Trimmer of Pennsylvania and her husband hosted a "Quizzo" trivia night at their house with friends and family. The 25 guests also enjoyed food, drinks and goodie bags that contained information on FTD. All told, they raised \$4,645.

Not Your Average Event

Throughout October, Chuck Anastasia, Doreen Putnam and the Rhode Island FTD Support Group partnered with a local Not Your Average Joe's; 15 percent of proceeds every Tuesday went to AFTD. Together, the efforts raised \$3,088.

Dairy Productive

Ryan Windhorst of Illinois partnered with four local Dairy Queen locations to donate a portion of one day's sales. Those unable to visit a store were encouraged to donate to his online fundraising page and share ice cream with a loved one. Total donations amounted to \$2,598.

Cookies for a Cure

Lucy Carter and Meg Warren of Tennessee offered Christie Cookies for a donation. Each cookie was accompanied by an AFTD bracelet and brochure. With an online fundraising page, the campaign raised a combined \$1,955.



Comfort Food

Katrina Hellman of Illinois and the Tremont Caregiver Support Group served

up homemade chili and desserts, including a cake that read "Fighting FTD." Attendees could check out the information table with FTD literature. The event raised \$1,880.

Awareness with Adrienne

During the two weeks of the Food for Thought campaign, Joan Harper of the U.K. donated 100 percent of proceeds from her book, *Cooking with Adrienne*, to AFTD. She also invited guests over to indulge in two recipes from the book and to learn more about FTD. Altogether, she raised \$1,854.



THE AFTD-TEAM

Thank you to all of our hosts, who raised additional funds and awareness to support AFTD's mission:



- Adriana Kipper-Smith
- Amber and Kristopher Parker
- Amy Shives
- Barb Sidders
- Brandee Waite
- Christine Groth
- Diane Cole
- Donna Wert
- Elizabeth Soriero
- Esther Harvey
- Gene Thornton
- Jamie Gordon
- Jan Keller
- Jennifer Morabito
- Joanne Linerud
- Karen Smith
- Karine Adalian
- Kathryn Caruso
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- Kristena Corbett
- Lisa Radin
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- Mary Beth Mixdorf
- Matt Dineen
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- Melonie Conselva
- Nancy Cummings
- Nicole DeLeve
- Patrick Gutierrez
- Phyllis Mason
- Rachel Castellanos
- Rachael Light
- Rebecca Cordova
- Rebecca Wetzel
- Rona Klein
- Ruth Wilcox
- Sarah DeLuca
- Scott Cain
- Shirley Gordon
- Steph McLain
- Susan Butterfield
- Tam Smith
- Tina and Kennedy Ho
- Terry Pontious
- Sandra Leach and Kimberly Pontious



Thanks to our Food for Thought Liaisons!

AFTD's Grassroots Events Coordinator, Bridget Graham, extends a huge thank you to all 10 of the 2017 FFT Liaisons for their above-and-beyond effort this campaign!

- Ariel Harden
- Jennifer Morabito
- Meghan Roscoe
- Sarah DeLuca
- Teresa Webb
- Elaine Rose
- Lark Fiore
- Rukhsana Ansari
- Susan Butterfield
- Traci English

Ohio Golf Outing: The Sidoris family hosted the 12th annual George F. Sidoris Memorial Golf Outing on July 22nd. The event raised a record high of \$25,200, bringing their grand total to more than \$178,000 donated to AFTD.

Iowa Golf Tournament: Midwest Regional Coordinator Deb Nash hosted the inaugural Crusade for a Cure Golf Tournament on September 2nd. The event raised \$6,786 for research.



Ohio Golf Party: Suzanne and Calvin King held the 2nd annual "Tami Sue" Golf Outing & Party on September 9th in memory of their daughter Tami, who passed away from FTD. The event raised \$3,000.

Michigan Golf Outing: Jon Moretti hosted the 2nd Annual CWM Memorial Golf Outing in memory of his father, Carl, on July 15th and raised \$1,640.

On the "House": Lucy Carter of Tennessee held an event at House Restaurant featuring a musical performance by a caregiver and delicious food donated by Porter Road Butcher. The evening raised \$1,000.



Hang It to Cure FTD: Sharon and Rod Hall of Georgia designed and produced a calendar featuring pictures of people diagnosed with FTD. All proceeds go to AFTD; thus far they have raised \$5,150.

Chicago Marathon: Daniel Ranti and Marisa Lutz, both from Massachusetts, ran in the Chicago Marathon on behalf of AFTD. Combined, they raised over \$8,200.

Boston Event: More than 65 members of the FTD community gathered at the Ritz-Carlton in Boston on September 25 for an evening cocktail reception. AFTD CEO Susan L-J Dickinson welcomed the guests, while AFTD Scientific Director Nadine Tatton provided a brief update on the latest in FTD research.



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Opening the gateway to help and a cure

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