



AFTD Announces \$2 Million in FTD Biomarkers Initiative Awards

Biomarkers are objective, easily-measured biological features that indicate the presence of a disease, reveal how far it's advanced, or measure the response to treatment. Blood pressure, for example, is a widely-used biomarker for cardiovascular disease. To date, the lack of biomarkers for FTD has hindered both diagnosis and the development for potential treatments.

In January 2017, AFTD proudly announced the recipients of the first six awards funded through its FTD Biomarkers Initiative, with funding totaling \$2,000,000.



Randall Bateman, MD
(Washington University in St. Louis)

Project: *Human CNS tau kinetics in tauopathies*
FTD is one example of a *tauopathy* — a brain disorder characterized by the abnormal accumulation of the protein tau. Differences in forms of tau that make up these deposits could distinguish FTD from other neurodegenerative diseases. To look for an FTD-specific tau “fingerprint,” Dr. Bateman will utilize an innovative technique known as Stable Isotope Labeling Kinetics (SILK).



Christian Haass, PhD
(Ludwig-Maximilians University and DZNE)

Project: *sTREM2, PGRN and GRN as CSF markers for microglial activity, disease progression and therapeutic target engagement*
Dr. Haass and his team will develop assays to detect sTREM2, progranulin, and granulins, proteins that regulate brain inflammation. Inflammation has been linked to the development of FTD, making these proteins promising biomarker candidates.

(Continued on page 5)

Inside This Issue

Spotlight On Daniel Hedaya	2
News Briefs.....	2
Spring Appeal	3
Alzheimer Advisory.....	4
Pilot Grants	5
Donations	6-8
Regional Coordinators.....	8
Helping Hands.....	9
The AFTD-Team.....	10-11

FTD Disorders Registry: Your Perspectives Advance the Science

After an intensive design and testing process, the FTD Disorders Registry—the first online database devoted exclusively to compiling self-reported data from people affected by frontotemporal degeneration—officially launched in March 2017. AFTD and the Bluefield Project to Cure Frontotemporal Dementia co-founded this resource with generous support from the Rainwater Charitable Foundation’s Tau Consortium program.



Accessible at ftdregistry.org, the Registry gives persons diagnosed, caregivers, family members and friends affected by FTD the opportunity to teach researchers about the various FTD disorders by securely sharing their perspectives. “The Registry will be an important resource for FTD researchers,” notes Dr. Dianna Wheaton, MS, PhD, CHES, the Registry’s

(Continued on page 4)

Spotlight On... Daniel Hedaya, AFTD Board of Directors

Daniel (Danny) Hedaya was just 16 the day he heard the life-changing news about his father, Harold. He had just come home from high school to find his mom and brother waiting for him. They sat him down and broke the news: Dad had been diagnosed with FTD.

“My first reaction was probably similar to a lot of other people’s,” he said recently. He had never heard of FTD, so he jumped on Google. After wading through the search results – “the first hits were probably the flower company,” he said – he finally got to some substantive information. “It was pretty scary stuff,” he said.

Helping to promote increased awareness of FTD and access to

properly vetted FTD information are just two of the reasons Hedaya has joined AFTD’s Board of Directors. Elected to AFTD’s Board in December 2016, he is one of four new Board members the organization is grateful to welcome.



AFTD Board Member
Danny Hedaya

Hedaya has known about AFTD for years, but says that his engagement with AFTD really began following Harold’s death in 2009. He got in touch with Executive Director Susan Dickinson to express his interest in doing all he could to help AFTD achieve its mission. To date, that involvement has been chiefly in the form of highly-successful grassroots fundraising efforts and AFTD special events.

During a lunch meeting in New York

City, Hedaya, along with Dickinson and Board member Kathy Mele, brainstormed about ways to attract attention and support to AFTD’s mission. The result: Hope Rising, a gala fundraiser event held in September 2016 in New York City. The first Hope Rising Gala “was an incredible event and a big success,” he said.

Danny wants to bring the same big-picture thinking that inspired Hope Rising to the Board. “I want to bring in a new perspective to help AFTD continue to evolve,” the 30-year-old Hedaya said. “As a board member, it’s my mission and duty to do everything I can to provide the infrastructure and support to promote AFTD’s growth and impact.”

He dedicates his involvement with AFTD to his father, describing it as a “way to honor and deepen the connection with my dad.”

AFTD NEWS BRIEFS

AFTD 2017 Postdoctoral Fellowships

AFTD Postdoctoral Fellowships support early-career investigators during the final stage of their scientific training, aiming to encourage a sustained interest in FTD research. AFTD is pleased to announce the recipients of the 2017 Postdoctoral Fellowships:



Kathryn Bowles, PhD (Icahn School of Medicine at Mount Sinai),

for her proposal “Identification and validation of novel MAPT splicing factors and RNA-binding proteins.”

Dr. Bowles will seek to identify proteins that regulate the production of tau and could represent novel targets for FTD drug development.



Joseph-Patrick Clarke, PhD (University of Pittsburgh School of Medicine), for his proposal “Nucleocytoplasmic transport defects perturb granular

flux in FTD.”

Dr. Clarke will look for FTD-associated defects in the movement of proteins in and out of the cell nucleus, using neurons (brain cells) derived from FTD patients’ induced pluripotent stem cells. Drugs that correct such defects could represent potential treatments for FTD.

• Awareness in Albany

• This past February, AFTD volunteer Nancy Cummings collaborated with her local area television station in Albany, NY on a Healthy Living segment aired on Time Warner Cable. The broadcast, “Dealing with Dementia Isn’t Just for the Elderly,” featured caregiver Mary Anne Fazzone. Watch the full video at www.bit.ly/2kaMPxN.

• AFTD Webinar Series

• In January, Alvin Holm, M.D., FACP, Founder and Director of the Cognitive and Behavioral Disorders Program at Bethesda Hospital in St. Paul, Minnesota, presented the second AFTD educational webinar, “A Care Paradigm for Persons with FTD.” Dr. Holm discussed symptom-specific therapies, wellness management and environmental supports. Watch the full webinar at www.youtube.com/watch?v=6CVAakOg3hE.



taking care of mom

*Will you choose to support
AFTD's mission?*

In 2008, Jennifer Morabito's mother was dropped off at her doorstep in suburban Baltimore unannounced. Unable to handle her increasingly erratic behavior, a family member "literally brought my mom to my house with a suitcase," Jennifer remembers. Just like that, she found herself trying to care for her mom while also raising two young children.

A sweet, loving woman in her mid-50s, Jennifer's mother would now suddenly start sobbing or screaming, or throwing things without explanation. Plates and silverware slipped out of her grasp without warning. Soon, she began wandering off and getting lost. A visit to a local clinic suggested early-onset Alzheimer's, but a psychiatrist later revealed that FTD was causing these changes.

Over time, she tried placing her mom in different facilities, but had a hard time finding one that met her needs. Meanwhile, Jennifer was nearly stretched to her breaking point. "You're in a house with teeny tiny kids to take care of, plus an older adult who has emotional outbursts," she said. The stress was almost unbearable, and she had never felt more isolated and alone.

Thankfully, Jennifer discovered AFTD through its Food for Thought campaign. The

concept resonated with her instantly, she said – "it's very Italian, the whole idea of food as love." Through AFTD, she started connecting with others who were also living through an FTD journey. "AFTD's support, and the light it has brought into my life, has literally been life-saving," she said.

Last year, she became a Food for Thought liaison, helping volunteers in her area to coordinate their own events. Sometimes, her quick check-in phone calls with these volunteers can stretch for hours. "It's about knowing that someone is not just listening to you, but can absolutely understand what you're going through," Jennifer said.

Parenting young children while caring for your own mother can be a surreal and challenging experience. Few understand what it's like. But through its volunteer network, support groups and grassroots events, AFTD connects community members with vital resources and others who do understand.

That's only possible with your help. ***This Mother's Day, will you choose to support AFTD's work by making a donation? Send your gift via the enclosed envelope – or visit www.theaftd.org and click the Donate to AFTD button.***

AFTD Scientific Director Presents to National Alzheimer's Advisory Council

On February 3rd, AFTD Scientific Director Dr. Nadine Tatton joined AFTD Program Manager Matt Sharp in Washington D.C. to attend the quarterly meeting of the Advisory Council for the National Alzheimer's Project (NAPA). Dr. Tatton's address to the Council was webcast live by the federal Department of Health and Human Services (HHS) online.



Dr. Nadine Tatton

The meeting focused on addressing recruitment challenges in clinical trials for Alzheimer's and related dementias. Presenters representing the largest existing Alzheimer's and dementia-focused registries shared their experiences developing and running these essential resources, and discussed challenges and solutions for using these resources to

facilitate enrollment in clinical trials. Dr. Tatton detailed the distinct challenges of recruiting for FTD clinical trials:

- The need for greater diagnostic precision – and biomarkers – to match the right patients to the right trials.
- The narrow window of opportunity with individuals diagnosed – who currently live 6-12 years on average after diagnosis.
- The need to recruit adequate numbers, which can require multi-site studies – often, international ones.

Further, as the disease progresses, “all of the simple activities of daily life – all the things you take for granted – become severely compromised,” Dr. Tatton said. This makes being able to stay mentally and physically capable of completing a trial (including travel, imaging and other requirements) its own challenge.

In response to these challenges, Dr. Tatton told the Council, we need to design trials that are informed by the FTD patient experience.

One strength for FTD research, Dr. Tatton noted, “is an active, engaged community, who have stepped up every time we've asked them to participate in any kind of research study.” This encourages industry investment, which will lead to more trials targeting FTD, and ultimately, the development of effective treatments and a cure.

A transcript of the February 2017 NAPA Advisory Council meeting is available at: www.aspe.hhs.gov/advisory-council-february-2017-meeting-summary

Footage is available here: www.aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Feb2017

FTD Disorders Registry *(Continued from page 1)*

Director, “letting them use the collective experience of those living with FTD to inform study designs, and advance the science of FTD research.”

The FTD Registry is a HIPAA-compliant contact registry and a research registry. The contact registry is open to U.S. and international enrollment; persons diagnosed with FTD, caregivers, family members, and friends signing up will receive FTD research updates and the latest Registry news.

At present, participation in the research portion of the Registry is open to residents of the U.S. or Canada (eligibility information may vary by state or province). Research participants who create password-protected accounts and complete electronic informed consent forms will be eligible to participate in online research surveys and learn

about upcoming clinical trials. All participant data will be confidential and data used for research purposes will be de-identified so that no personally identifiable information will ever be shared.

On the first day of the Registry's promotion this spring, more than 100 new enrollees signed up. Positive community response has led to more than 400 enrollees within a few short weeks.

Two major clinical studies that will be directly supported by the Registry are the Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) and the Longitudinal

Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS), both funded by the National Institutes of Health.



The Registry should drive additional investment into research targeting FTD: “The FTD Disorders Registry can demonstrate to industry stakeholders

that our community is a ready and capable partner in the pursuit of FTD therapeutics,” said Susan L-J Dickinson, AFTD Chief Executive Officer.

“AFTD has always believed in the power of a family's FTD story,” she notes. “With the Registry, we're looking to harness that power collectively, to move the science of FTD research forward.”

AFTD Announces 2016 Basic Science and Clinical Research Pilot Grant Recipients

A fresh perspective or novel idea could initiate a new direction in FTD research. That is the rationale behind the AFTD Pilot Grant program, which provides seed funding for early-career investigators and research projects in the earliest stages of development.

Since 2014, donor support has enabled AFTD to fund two types of Pilot Grants, the Basic Research Pilot Grant and the Susan Marcus Memorial Fund Clinical Research Pilot Grant. AFTD is pleased to announce the 2016 recipients:

Maria Llorens-Martín, PhD, awarded the **2016 Basic Science Pilot Grant**, is an assistant professor in the Department



Dr. Maria Llorens-Martín

of Molecular Neurobiology at the Center for Networked Biomedical Research in Madrid. In her project, “Tau and adult neurogenesis. Therapeutic potential for frontotemporal degeneration,” Dr.

Llorens-Martín will use state-of-the-art techniques for visualizing brain cells to study the formation of new cells in the brains of mice with mutations in the tau gene that also occur in a form of familial FTD. If successful,

her work, which seeks to address an important gap in our understanding of FTD disease mechanisms, could lead to new approaches to FTD drug development.

Paola Caroppo, MD, PhD, a researcher at the IRCCS Foundation Carlo Besta Neurological Institute in Milan, received the 2016 **Susan Marcus Memorial Fund Clinical Research Pilot Grant** for her

proposal “Detection of misfolded TDP-43 protein in CSF and plasma of *GRN* and *C9orf72* mutation carriers.” Along with her colleague Fabio Moda, PhD, Dr. Caroppo will work on adapting a technique originally developed to detect very small amounts of disease-causing proteins in disorders such as Creutzfeldt-Jakob disease to measure the protein TDP-43, which accumulates in people with FTD-related mutations in the *GRN* or *C9orf72* genes. If successful, this procedure could lead to a diagnostic test for TDP-43-associated FTD.



Dr. Paola Caroppo

Biomarkers Initiative Awards (Continued from page 1)

Stacie Weninger, PhD, Executive Director of F-Prime Biomedical Research Initiative and Chair of the FTD Biomarkers Scientific Advisory Board, noted the difficulty of selecting just six of the many outstanding proposals received for funding. “It was a great problem to have,” she observes, adding, “I couldn’t be more excited about the science that AFTD is enabling through the FTD Biomarker Initiative. Discoveries made through these projects will accelerate the development of much-needed therapeutics for FTD.”

The FTD Biomarkers Initiative has been made possible by a generous multi-year donation from the Samuel I. Newhouse Foundation. Participating researchers have committed to open sharing of data with the scientific community, to benefit future FTD research. Additional awards totaling \$3,000,000 are anticipated.



Leonard Petrucelli, PhD

(Mayo Clinic – Jacksonville)

Project: *Assessing poly(GP) proteins as clinical and pharmacodynamic biomarkers of C9ORF72-associated FTD*

Dr. Petrucelli will develop an assay to detect abnormal poly(GP) proteins resulting from mutation of the *C9ORF72* gene in blood and cerebrospinal fluid (CSF), based on a new state-of-the-art technology, Simoa™ (single molecule array), capable of detecting a single protein molecule.



Jonathan Rohrer, MRCP, PhD

(University College London Institute of Neurology)

Project: *Identification of novel fluid biomarkers of tau and TDP-43 pathology*

Dr. Rohrer’s team will also use Simoa technology; in this case, to develop assays to detect tau and TDP-43. These could make it easier to distinguish people who have FTD-tau from those who have FTD-TDP-43, paving the way for the development of tau- or TDP-43-specific therapeutics.



Judith Steen, PhD

(Boston Children’s Hospital)

Project: *Quantitative profiling of tau in CSF to pilot diagnoses and monitoring treatment effectiveness in FTD patients*

Dr. Steen will use a novel mass spectrometry analytical technique developed in her laboratory, called FLEXITau, to look for abnormal forms of tau specific to FTD, patterns that could facilitate diagnosis.

Project: *Using TDP-43 as a biomarker in FTD patients*

Dr. Steen also received funding to develop a mass spectrometry assay similar to FLEXITau for detecting abnormal forms of TDP-43. This FLEXITDP43 assay will be tested initially in post-mortem brain tissue and ultimately adapted for use in blood and CSF.

Donations Honor Loved Ones *Gifts received from October 16, 2016 - March 15, 2017*

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Patricia Ryan
Kirk Ryder

Lillian Sackel for her
birthday
Madeline (Maddi) Sackel
Sol Sackel
Vivian Sackel
Barry Sandler
Lydia Sartain and family
Paul T. Schleyer
Russell Schubert
Heidi Schneider
Jacqueline Schneider
Jodi Schneider
Marty Schneider
Rory Schneider
Kiran Sethi
Joyce Shenian
Orville Sherrod
Al Shoberg
Maryann Shry
Joan R. Simon
Roberta Sitler
Karen T. Slattery
Brant Smith
Ronald Soiefer

Dottie Sokola
Ellen Solomon
Vicky Sprouse
Allan Stackhouse
Bucky Stackhouse
John Stackhouse
Kathy Stackhouse
Paul Stackhouse
Anne Stein
John Sterling
Elizabeth Stoia
Jeanette Stoothoff
Bill Struzzi
Wanda Sullivan
Sue Sweeney
Kate Taylor
Sylvia Tandler
Helen Thomas
Bruce Thomasson
David Tilkin
Karen Timmons
Barbara Tinsley
Victoria Tinsley
Jim R. Tobin

Jackie Traurig
Robert Traurig
Wendy Traurig
Kathy Turco
Bushra Uddin
Phyllis S. Umansky
Barbara Urgovitch
Helen Van Son
Michele Van Son
Gary Van Wowk
The Voss Family
James Vowell
Christine Walker
Michael R. Walker
Pam West
Jim Wexstten
Turan Behzadi Wilson
Judy Windhorst
Carol Womack
James Wooldridge Sr.
Ralph Wright
Ruth Yeats
Stephen Yturalde
Christopher Yurkanan

Donate to AFTD...

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

AFTD Regional Coordinator Volunteers: *Leading the Pack!*

AFTD would not have the robust volunteer community that exists today without the driving force of its Regional Coordinator (RCs) volunteers. We rely on their leadership to expand our mission.

Working closely with AFTD's Volunteer Manager, RCs play a vital role as the primary contact in ensuring volunteers are equipped with what they need to be successful. In 2016, Regional Coordinators helped more than 300 AFTD volunteers provide their time and talents to strengthen our awareness, education, fundraising and support efforts. In short, RCs are the agents through which AFTD volunteers are able to make an impact in local communities. AFTD's volunteer leadership team

has recently grown to ten Regional Coordinators, the largest such team since AFTD began its work. RCs are responsible for managing their regions,

offer ongoing support to the newer coordinators as they continue to gain experience in their role.

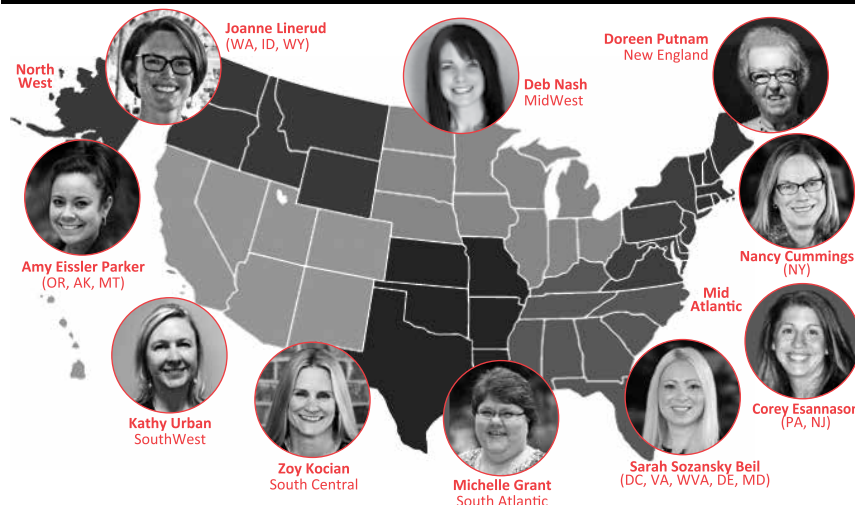
"It takes a special person to agree to become a Regional Coordinator volunteer," said Kerri Keane, AFTD Volunteer Manager. "AFTD is grateful for their willingness to step in to such a vital role and to take on the day-to-day responsibilities and projects with dedication, heart and professionalism."

To learn how you can get involved and

join AFTD's Volunteer Program, find your Regional Coordinator Volunteer's contact information online here:

www.theaftd.org/get-involved/volunteer/regional-coordinator-contact-information

AFTD Regional Coordinator Volunteers



HelpLine 866-507-7222 | info@theaftd.org | www.theaftd.org

and collaborate on a variety of goals and initiatives together as a team. There is at least one RC volunteer in each region of the U.S. Three RCs are veterans to the role, each with more than two years of experience, and

Giving a Hand to Our Helping Hands!

AFTD Volunteers in Their Own Words: Colleen Seymour

When her mother-in-law Kelly was diagnosed last year with FTD, Colleen Seymour felt an overwhelming sense of grief and a loss of control. She wondered, "What can I do?" With her mother-in-law living in another state, Colleen felt inspired to be a part of AFTD, to educate and reach out to her surrounding community. She has jumped right in, representing AFTD as a volunteer in a variety of roles and making a strong impact in Colorado. Colleen recently shared her experiences with our community.



Colleen Seymour and her mother-in-law Kelly.

I also set up an interview with Denver's local 9News program, "Colorado & Company" to share information about FTD and AFTD. The 9News program wrote an online article and promoted the February Meet and Greet on their Facebook page...

How did volunteering in these various ways make you feel?

When I was ten I watched my mom advocate for children living with disabilities, and create awareness in our local community. I learned and witnessed the importance of reaching out and initiating changes I wished to see in my community. I know how difficult it is for families to know what to do, where to turn and what questions to ask. I feel grateful to be able to help where I can, in order to get awareness out there about FTD and available resources.

"The more you help others to connect, the stronger the community you build, and the less secluded you feel."

Tell us about your volunteer experiences.

I helped organize and plan an AFTD Denver Meet and Greet [held February 15]. More than 25 people from the FTD community attended, and many got to voice their perspectives, their concerns and questions. A local neurologist attended in the hopes of learning more about resources to offer patients.

What's next on your volunteer journey?

I am one of two volunteers spearheading the AFTD-Team for the Colfax Marathon in Denver, CO on May 20-21. I plan to run the full marathon and look forward to helping raise funds and awareness with other local families and AFTD volunteers, who are also racing.

What have you learned from your volunteer experiences?

It truly takes a village to enact change. It takes a proactive community. From the volunteers who help organize events, to staff who work for AFTD, to the people who show up to meetings and support groups. We need each other to be able to be a voice and presence not only for our loved ones, but for future loved ones who have yet to be diagnosed.

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

Consider taking the time to volunteer in some capacity. The more you help others to connect, the stronger the community you build, and the less secluded you feel.

AFTD Southwest Regional Coordinator Volunteer, Kathy Urban — who collaborated with Colleen on the Denver Meet and Greet and will be joining her and AFTD Board Member Debbie Fenoglio at the Colfax Marathon — adds: "Colleen is an inspiration; she is truly passionate about community and advocacy." Further, she notes: "It's beyond exciting to see AFTD's growing presence in Denver and Colleen has been instrumental in these efforts. I'm looking forward to the upcoming Colfax Marathon; it will be a meaningful day for our local FTD community."

THE AFTD-TEAM

AFTD's

With Love
Campaign 2017

With Love Campaign 2017 Breaks Records!

Inspired by the day dedicated to love—Valentine's Day—AFTD's With Love campaign offers an opportunity for people to honor or remember a loved one impacted by FTD. This past February, 23 brave hosts shared their stories of love to spread FTD awareness and raise funds to support AFTD's mission. Over the past six years, this campaign has raised more than \$338,000 to fight this disease.

We are grateful to announce that AFTD's With Love 2017 campaign raised **\$91,735** towards the fight against FTD, exceeding the campaign's \$90,000 goal and raising significantly more than any prior year.

We would like to extend a huge thank you to everyone involved in this campaign's success: our two generous campaign sponsors, Beth Walter and The Rainwater Charitable Foundation, who pledged vital matching donations; hundreds of people who made donations; and of course, our campaign hosts, who generously shared their stories of love to spread awareness and raise important funds.

- | | | | |
|---------------------|-----------------------|--------------------|------------------|
| ♥ Beth Walter | ♥ Cindy Odell | ♥ Rita Carlson | ♥ Dave Hixon |
| ♥ Team Alice | ♥ Leigh Knosher | ♥ Elaine Rose | ♥ Ada Gerard |
| ♥ The Pessah Family | ♥ Kimberly Gube | ♥ Kathryn Caruso | ♥ Karine Adalian |
| ♥ Kat Primeau | ♥ Diane Illis | ♥ Deb Nash | ♥ Amy O'Bryant |
| ♥ Bonnie Shepherd | ♥ Wendy Miller-Anello | ♥ Kristel Stoveken | ♥ Hope DePratt |
| ♥ Lynda Ares | ♥ Jeff Main | ♥ Judith Daniel | |



Showing heart: pictures from the With Love 2017 campaigns.



Not long after her mom was diagnosed with FTD in 2014, Wendy Miller-Anello started designing and making fashionable yet functional medical bracelets to help with communication issues common to the disease. Imperfectly Perfect Jewelry participated in With Love by donating \$5 to AFTD for every piece of jewelry purchased during the month of February.



AFTD-Team Race Season: Walk/Run to #endFTD



If you're looking for an opportunity to raise funds and awareness for FTD while exploring the great outdoors, then search no further. The spring and summer seasons are home to our annual race campaigns. Whether you want to participate in a triathlon, marathon, half marathon, 5K, fun run or anything in between, the AFTD-Team wants you with us come race day!

Last season, 188 AFTD-Team volunteers covered a total of 782 miles and raised more than \$29,000. This season, our goal is to participate in races in 7 different cities and raise at least \$60,000. At press time, the AFTD-Team has confirmed a formal presence at these seven races:

THE AFTD-TEAM

Lester's Letters Mark a Decade

Late 2016 saw AFTD Board Member Paul Lester host his 10th annual letter writing campaign, in memory of his wife Arnette. Sending both paper and electronic versions of his letter, Paul



Paul Lester & Arnette

utilized the Crowdrise online platform to make donating more convenient for his contacts. After all the letters had been sent, his campaign raised a personal best of \$20,458. Over the past 10 years, Paul's letter writing campaign has raised more than \$102,000 toward the fight against FTD.

Teeing up a Cure

The Robert M. Hatfield Foundation of Florida hosted the 6th Annual Quest for the Cure Golf Tournament. Pam Hatfield and her son, AFTD Board Member Matt Hatfield, founded the organization in memory of Pam's husband and Matt's father, Robert. This year, more than 100 golfers hit the green and raised \$9,500, increasing the tournament history total to \$43,750.



Matt, Pam and Bridget G.



Catching On

For his Bar Mitzvah Project, Brandon Portnoy, 12, of Bethesda, MD held a Catch-a-Thon in honor of his Zayde (grandfather). The event, which drew local media coverage, raised \$18,648!

Brandon Portnoy

Event Round-up

Sarah Ezrin created an online memorial campaign in memory of her father-in-law Len Karetny, who recently passed away from FTD. As an in-lieu-of-flowers option, the page raised **\$4,975**.

Jennifer Triandafilou's daughter Lilly of Maryland organized a charity spin class for her bat mitzvah, in honor of her great aunt Phyllis who has PPA. Her event spun up **\$740**.

Kimberly Luken of Illinois hosted a restaurant give back night at Culvers. AFTD and FTD educational and awareness materials were placed all over the restaurant; sales proceeds brought in **\$636** donated to AFTD.

Mary Wagstaff's daughter Evie and her friend Oona of California prepared an eight-course benefit dinner for eight guests, in memory of their classmate's father, who passed away from FTD in 2016. The menu added up to **\$550** donated to AFTD.

Aloha to #endFTD

Gretta Walter of Virginia ran the Honolulu Marathon on December 11, 2016 in honor of her dad who has FTD. Determined to raise \$5,000 before race day, Gretta ended up raising \$11,015 on GoFundMe to benefit AFTD. She also ran in a shirt she designed to display the AFTD logo and hashtag #endFTD to spread awareness all 26.2 miles.



Gretta Walter and family

Jeans Days held at Sixes Elementary School (in Georgia) and Hugh Mercer Elementary School (in Virginia) raised a combined **\$439** to fight FTD.



- Fit Foodie 5K (Austin, TX): May 20, 2017
- Colfax Marathon (Denver, CO): May 19-21, 2017
- King of Prussia 10 Miler and 5K (PA): May 21, 2017
- Super Run (Seattle, WA): June 10, 2017
- Super Run (Chicago, IL), August 19, 2017
- Chicago Marathon (IL): October 6-8, 2017
- Philadelphia Marathon (PA): November 17-19, 2017



Keep an eye out for new races being added in your area, and visit our [official AFTD-Team 2017 Race Season](#) page to find for fundraising opportunities and incentives, such as bib reimbursement.



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