



# AFTD news

## AFTD and Target ALS Announce Partnership

On October 15, AFTD and Target ALS announced a new partnership, including a call for research proposals to encourage innovative research in hopes of developing treatments for FTD and ALS. The initiative reflects the growing recognition that these two degenerative disorders have important genetic, clinical and pathological features in common.

At the center of the partnership is a \$5 million multi-year grant-making initiative to advance the scientific study and development of biomarkers and treatments for FTD/ALS, with Target ALS and AFTD each contributing \$2.5 million towards the grants.

This groundbreaking partnership

represents a new funding opportunity for FTD investigators and offers hope to families that share a mutation in the C9orf72 gene, which has been found to be the most common genetic cause of both FTD and ALS. Evidence

*This groundbreaking partnership offers hope to families with a mutation in the C9orf72 gene, the most common genetic cause of FTD and ALS.*

of a continuum between the two diseases is further supported by increasing awareness that some people face a dual diagnosis of FTD and ALS. Today, there is no known cure for either disease.

“This is an exciting opportunity to expand the FTD/ALS drug and

biomarker development pipeline rapidly by fostering collaboration among scientists from academia and the pharma/biotech industry,” said AFTD’s Chief Executive Officer, Susan L-J Dickinson. “We’re proud to take this crucial step with Target ALS and the scientific communities we support, working toward viable treatments and accurate diagnoses of ALS and FTD.”

As part of the partnership, Target ALS will also provide AFTD-funded fellows with ALS-focused projects access to scientific tools and resources at minimal cost, and will work with AFTD to organize special joint research meetings for their respective scientific communities over the next two years.

*(Continued on page 5)*

### INSIDE THIS ISSUE

- Spotlight/  
Ian R.A. Mackenzie.....2
- News Briefs.....2
- Fall Appeal.....3
- World FTD Awareness..... 4
- Hope Rising.....4
- Donations.....6-7
- ALLFTD.....8
- Save the Date.....8
- New Volunteer Program.....9
- The AFTD-Team.....10-11

## Bringing Vital Perspective to Federal Research Grant Reviews...

Members of our community had the chance to participate in a U.S. Department of Defense (DoD) program that presents funding opportunities for FTD research.

For over 25 years, the DoD’s Congressionally Directed Medical Research Programs (CDMRP) has funded research into medical conditions that impact military

members and their families, as well as the general public. Congress allocates the CDMRP funds each year in response to requests from persons diagnosed, their families, and disease advocates.



*AFTD Board chair Gail Andersen and former Board member Susan Eissler were consumer advocates in the federal Peer Reviewed Medical Research Program.*

Several projects and programs fall under the CDMRP umbrella, including the Peer Reviewed Medical Research Program (PRMRP).

*(Continued on page 5)*

## Spotlight on... Ian R.A. Mackenzie, M.D., AFTD Medical Advisory Council

“Momentum toward finding useful therapies for FTD is really accelerating,” Ian R.A. Mackenzie, M.D., recently said. As the new chair of the AFTD Medical Advisory Council, Dr. Mackenzie is in a unique position to ensure that this momentum continues to be channeled toward the kind of important and ambitious research that may one day result in a future free of FTD.



*Ian R.A. Mackenzie, Ph.D.*

The head of neuropathology at Vancouver General Hospital and a professor at the University of British Columbia, Dr. Mackenzie is a medically trained neuropathologist with clinical and research interest in molecular pathology and the genetics of neurodegenerative disease, especially FTD/ALS.

When Dr. Mackenzie began his career in the 1990s, he largely focused on Alzheimer’s – “because that’s where all the excitement was at the time,” he said.

He soon realized, however, that he could make a greater impact by focusing on a less well known dementia. “I wanted to find more of a niche where I thought I could make more of a unique contribution,” he said.

In the late 1990s, he moved to Vancouver, where he started seeing increasing numbers of FTD cases in his diagnostic work. At the time, he said, the only well characterized cases of FTD shared a so-called tau pathology – an abnormal accumulation of the protein tau in the brain. “It seemed like there was a group

[of FTD cases] about which very little was known in terms of pathology,” he said.

Dr. Mackenzie started looking at and organizing non-tau cases of FTD, eventually identifying a pattern that led to the discovery that accumulation of the protein TD-43 is associated with mutations in the C9orf72 and GRN genes, which can cause not only FTD, but also ALS.

Dr. Mackenzie’s involvement with AFTD has lasted over a decade, and he describes it as being very rewarding. “I am appreciative of the fact that AFTD has been advancing efforts in promoting the science of FTD – notably by taking the initiative in working to identify biomarkers.

“It is wonderful this relatively small organization is still able to make serious contributions to support the basic science behind FTD,” he continued. “I’m glad to be able to help.”

## AFTD NEWS BRIEFS

### AFTD Medical Advisor Wins Breakthrough Prize

Virginia M.-Y. Lee, PhD, a founding member of AFTD’s Medical Advisory Council, was awarded a Breakthrough Prize in Life Sciences on September 5. Dr. Lee is the director of the University of Pennsylvania’s Center for Neurodegenerative Disease Research. Her work led to the discovery, in the mid-2000s, of the link between accumulations of the protein TDP-43 in the brain to the development of both FTD and ALS. The Breakthrough Prize, funded by a cadre of high-profile technology figures including Facebook’s Mark Zuckerberg and Google’s Sergey Brin, comes with a \$3 million award that Dr. Lee can use for any purpose.

### Chronicling AFTD’s Volunteer Roots

AFTD chronicled its formation and history as an organization in the recent publication “A Vision for Hope: The Early History of the Association for Frontotemporal Dementia.” The publication follows the journey of AFTD Founder Helen-Ann Comstock, starting with her husband’s onset of FTD in the late 1970s, through the formation of AFTD in 2002, and important advancements until 2008. The 37-year timeline highlights AFTD’s progression from a volunteer labor of love to a growing nonprofit, now employing more than 20 full-time staff and serving as a leading international expert on FTD and young-onset dementia.

### National Dementia Summit Scheduled for March 2020

The second National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers will be held on March 24 and 25, 2020 in Bethesda, Md. The meeting aims to bring together experts with varying backgrounds to identify techniques that can be used to improve care, services, and supports of persons diagnosed with dementia and their care partners. The event is sponsored by the U.S. Department of Health and Human Services and many other private sector organizations, which included AFTD in 2017.

### AFTD Hosts Social for FTD Researchers

On October 19, AFTD hosted its third annual FTD Social, timed to coincide with the 2019 Society for Neuroscience annual meeting in Chicago. Over 80 students, postdoctoral fellows, early-career investigators, and senior researchers, including current and prior AFTD grant recipients, attended this networking event, co-sponsored by the Tau Consortium. AFTD Research Manager Debra Niehoff notes, “Our interactions with researchers at the FTD Social have been a valuable strategy for increasing awareness of AFTD’s grant programs and building relationships in the FTD research community.”



## A VOICE IN THE FIGHT AGAINST FTD

*"AFTD has allowed me and my family to have a voice and fight this disease. They provide families with much needed education and support, and there's so many opportunities to help. I truly feel my work as a volunteer has given me a purpose in life to fight back against FTD."*

**Deb Scharper, FTD Care Partner & AFTD Volunteer** (above, far right)

Deb Scharper signed up to volunteer as soon as she found AFTD online. Her former husband, Tommy, had just been diagnosed with FTD after years of puzzling behavior, and she was ready to fight back.

She began by organizing support groups in the Midwest. From there she took on a volunteer leadership position. Today, her family organizes fundraising events to benefit AFTD, including an annual golf outing, and she often speaks publicly about her FTD experience.

Tommy now lives in a nursing home. "We suspect Tommy's dad had FTD as well," she

adds. "So as a family, we participate in research that we hope will lead to the first approved FTD treatments, and a cure."

AFTD's work depends on thousands of volunteers, donors, and fundraisers like Deb and her family. Together, we raise awareness and educate more health professionals on best practices in FTD care. We answer more than 2,200 HelpLine inquiries each year, and drive cutting-edge research through transformative partnerships with the Alzheimer's Drug Discovery Foundation, the Diagnostics Accelerator, and Target ALS.

We hope that you'll choose to support AFTD's work with a tax-deductible donation – helping our organization to bring a voice to thousands of families in the fight against FTD. Simply use the enclosed envelope or visit [www.theaftd.org](http://www.theaftd.org) and click on the **Donate+** Button at the top of the page.

# World FTD Awareness Week 2019 Marked Around the Globe

People impacted by FTD came together September 22-29, 2019 in a show of worldwide unity to tell their stories and offer hope during the fifth annual World FTD Awareness Week.

To commemorate the event, World FTD United, a coalition of international organizations of which AFTD is a member, launched an interactive world map that paints a global picture of FTD through stories shared by persons diagnosed and care partners. As of December 1, 275 people representing 221 cities in 21 countries have used the map to tell their stories and raise global FTD awareness.

Chandi of Canada wrote of her life-altering diagnosis: "I am 52 years old and was diagnosed with FTD two years ago. I worked in the health field all my life and am now being cared for by the very people I worked with."

Melissa Fisher, who lives in Hawaii, shared how her father's diagnosis has impacted her family: "It is not only

taking him slowly away from us, but [it is also taking] my mom, his caregiver... FTD is a disease of the family."

AFTD encourages anyone affected by FTD to use the map to contribute their story and the country in which they reside.

Once again, AFTD marked World FTD Awareness Week with a series of awareness ads in the *New York Times*. Funded by the support of a generous donor and designed by AFTD volunteer Jody Zorn, the ads capture the impact FTD has on young families and AFTD's dedication to providing support.

Full-page print ads ran in the September 22 and 29 Sunday editions of the *Times*, while digital ads

were displayed to people who visited the *Times* website with a mobile device throughout the day on September 24. (A third print ad ran in the October 20 *Times*.)

As a precursor to World FTD Awareness Week, 60 *Minutes* re-aired its segment about FTD on September 15. The story, which left an immediate and measurable first impression when it aired in May 2019, includes information on FTD and profiles of impacted families.

It is increasingly important that FTD awareness is spread worldwide, and AFTD thanks all of those who contribute their voices to raise hope and spread awareness year-round.



AFTD ran three FTD awareness ads in the *New York Times* in fall 2019, including this one from September 22.

## Hope Rising 2019 Breaks Records in NYC

The fourth annual Hope Rising Benefit drew its largest attendance to date on Oct. 23, raising over \$2 million to support AFTD's mission of advancing FTD research and improving quality of life for those affected by this disease.

More than 550 people gathered in New York for the benefit, which marked the most successful fundraiser in AFTD's history.

Event speakers included Rome Hartman, producer for 60 *Minutes*, and Donald E. Newhouse, benefit chair and president of Advance Publications Inc., who lost both his wife, Susan Newhouse, and his brother, Si Newhouse, to FTD.

Hartman spoke about the impact of a recent 60 *Minutes* segment about FTD.

"We hope that our story captured some of the essential truths about this disease," he said. "It is often very confusing a n d

frightening, both for people living with FTD and for caregivers, because a timely and accurate diagnosis is still so elusive for so many. And - perhaps most striking to me - people coping with FTD display remarkable courage and determination."

Bank of America CEO Brian Moynihan was the recipient of the Susan Newhouse and Si Newhouse Award of Hope, in recognition of the company's sustained philanthropic commitment to AFTD's mission.

AFTD CEO Susan L-J Dickinson described how support from organizational partners, donors and volunteers has allowed AFTD to make advances in its mission. She also introduced AFTD volunteer Amanda Dawson, who shared the powerful story of her family's journey with FTD in the event's keynote address.



Keynote Speaker Amanda Dawson, who lost her father to FTD, addresses the audience at Hope Rising 2019.

Journalist Paula Zahn returned as event host and Tony- and Grammy-nominated star Joshua Henry closed the evening with a musical performance.

The event was later covered in *Vogue*, *Women's Wear Daily*, *SELF*, and *New York Social Diary*.



(L-R) Hope Rising Benefit Vice Chair Kathy Newhouse Mele, Benefit Chair Donald E. Newhouse, Benefit Co-Chair Anna Wintour, AFTD CEO Susan L-J Dickinson, and AFTD Board Chair Gail Andersen

## AFTD and Target ALS Partner... *(Continued from page 1)*

The program is modeled in part after a successful Target ALS grant-making initiative launched in 2016 that has since resulted in the development of innovative therapeutic approaches in four of the five projects funded.

“This request for proposals represents a major milestone for our organization and proof of our impact, having already introduced a

collaborative approach that infused new energy to the search for viable treatments for ALS,” said Target

*“We’re proud to take this crucial step with Target ALS and the scientific communities we support, working towards viable treatments and accurate diagnoses of ALS and FTD,” said AFTD CEO Susan L-J Dickinson.*

ALS’ Chief Executive Officer, Manish Raisinghani. “This is an exciting partnership with AFTD as it enables

us to extend our model and impact for both ALS and adjacent diseases like FTD.”

Target ALS is a New York-based nonprofit that works to foster collaboration to accelerate ALS drug discovery and development. In February 2019, it joined the ALS Association to cosponsor an AFTD workshop on TDP-43 biomarkers in Miami.

## Federal Grant Reviewers... *(Continued from page 1)*

Research applications submitted to the PRMRP undergo two types of review: peer review by scientists and consumer review by advocates representing the collective view of our community. This partnership allows the scientific and consumer reviewers to work collaboratively to evaluate and recommend applications for funding.

FTD was one of more than 50 topic areas Congress identified for PRMRP funding in both 2018 and 2019. The money allocated by Congress for PRMRP research – \$330 million in 2018 and \$350 million in 2019 – is divided among the year’s topic areas as determined by the review process.

AFTD worked directly with DoD program staff to identify priorities for FTD-related applications to the 2018 and 2019 PRMRP awards, known as “areas of encouragement.” In addition, AFTD was invited to recommend experts in FTD research and members of the AFTD community to serve as scientific and consumer reviewers.

Three members of the AFTD

community were selected to participate as PRMRP consumer advocates in 2018, including AFTD Board chair Gail Andersen.

Andersen, who lost her husband to FTD in 2012, described the experience as very positive and felt her input was valued throughout

*Three members of our community were selected to participate as PRMRP consumer advocates in 2018, including AFTD Board chair Gail Andersen.*

the process.

“I thought it was a really great opportunity for FTD research and AFTD,” she said. “I’m passionate about research and finding a cure for this devastating disease, so I support any way that we can expand our reach and get more funding for FTD.”

*“As care partners we have something valuable to contribute because we know what would be useful,” said former AFTD Board member Susan Eissler.*

Andersen encourages researchers to participate in the program by submitting a proposal to the DoD.

“The first step to getting this funding is submitting research,” she added.

Susan Eissler, a former AFTD Board member and long-time AFTD volunteer, described her experience

as an “opportunity to serve the cause.” Eissler, who lost her husband to FTD, emphasized the importance of including care partners in the research review process.

“The consumer reviewer is there to put a human face on the panel and see if the research would be successful,” she said. “As care partners we have something valuable to contribute because we know what would be useful.

“It seems like scientists are more and more aware of what’s going on and there’s such a wide variety of approaches to make that happen,” Eissler continued. “It’s encouraging to me as a caregiver to know that all these bright, talented people are working so hard on this.”

This program presents an ongoing opportunity for AFTD community members to volunteer by providing insight into how research could affect quality of life for all those living with FTD. To learn more about participating, contact the AFTD HelpLine.

# Those We Honor... Those We Remember

*Gifts received from June 16, 2019 – September 30, 2019*

## In Memory of

James S. Abbott	Joanne Christman	James "Jimmy" Lee Fort	Geoffrey L. Krajci
Jeffrey E. Abraham	Charles "Chuck" Cole	Carolyn Foster	Maureen Krause
Lois Addington Brown	Adelle Clevens	Virginia "Ginger" F. French	Eric Collins Kuntz
Robin K. Allen	Larry Cline	Jo-an Kathleen Fultz	Larry Leifer
Valerie (VJ) Jeanne Anastasia	Betty Colavecchi	Mary Monica "Mimi" Garber	Lynn H. Lessmann
Ernie Applewhite	Daniel Channing Cole	John "Jay" Gardner	Arnette Lester
Billy C. Ard	Gail Colfelt	Joel Gensler	Nick Leuschen
Daniel Asadoorian	Craig Comstock	Grant Patrick Giddings	Muriel Lisignoli
Robert J. Asam	Sharon Cornwell	Jeffrey Goldner	Kathleen J. MacLaren
Mark Audino	Mike Costilla	Annette Goldschmidt	Raymond Marien
Patricia Augustin	Robert Crow	Vicki Gorman	James G. May
William F. Babcock	Joso Curkovic	Susanne Gravelle	William Patrick McCauley
Lulu Baishya	Cheryl Damron	Shawn Graves	Willis H. McCauley
Mahesh Baishya	Connie Daniels	Paul Greenaker	Mary L. McCormack
Marie Ginette Baptiste	John Andrew "Andy" Deal	Steven Paul Grossnickle	Katherine Mersereau
Mary Baumhover	Mary Jo McCombs Delaney	Dean J. Hadley	Don Milligan
Connie Becker	Anthony DeMark	Darrel Hansen	Patricia Mize
Carol Ann Bedell	William J. DeVoti	Larry Hargis	Amanda Moher
Brad Bederman	Pamela Dircksen	Therese M. Harlett	Barbara Monay
Donald Behan	Donna M. DiTeodoro	Eleanor R. Harrington	Robert H. Moore
Trish Bellwoar	Elizabeth Dolica	Madeline Harrington	Carl Moretti
Paul Berkowitz	Dorothy Dolphin	Karen Hartsell	Charles H. Morse
Sandra Bishop	Eleanor Dondiego	Pam Hatfield	Christopher Morse
John Boling	John J. Donovan	Maggie Herrod	Betty Multop
Shirley Boschen	Diane Dorcey	John Frederick Hicks	James Neary
Jillian Bradley	Sandra Downs	Ruth Hoffman	Susan Newhouse
Steven Braun	Robin Draper	Deborah Horn	Bud Nichols
Catherine Broer	Adelard "Duke" Dumaine	James Howard	JoAnn Nichols
Kathryn Brooks	Pamela Duncan	Sharon Hoy	Marie Annette Nichols
Kathy Brooks	Robert Earl Weaver	James Huemoeller	Patricia "Tish" Ellen Niffenegger
James L. Burdette	James Craig Edelen	David B. Hunsucker	Tyrone R. Nixon
William Mark Butler	Chris Edmondson Yurkanan	James Ieda	Lawrence Carl Olivieri
Wally Butterfield	Anne Ehler	Claud E. Ivie	Marie Oshanna
Donald Campbell	Mary Einhorn	Jay Jackson	Stephen Passaretti
Ellen B. Carl	Jeannette Lyne Ekstrand	Terry Jackson	Madhuri Patel
Jean Chaney	Gina J. Emmerling	Gary L. Johnson	John D. Pergolski
Albert Charles Hall	Charles V. Engel	Gerard Kane	Barbara Perlin
JoAnn Chelist	Frank Engelkraut III	Robert Charles Kayser	Camilla Perry
Michele Chollet	Mary Jo Enneking	Ralph Kissel	Christopher Pfaendtner
Frank Christensen	Marcia A. Esterkamp	Eugene Klein	Kimberly Phares
Kathy Christie	Ken Farnham	Theresa L. Kornfeind	David Pierce
	Susan Terry Foley		

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

Jonathan Powell	Tom Temple	Gary Anderson	Tara Leifer
Forster Puffe	Sylvia B. Tendler	Carolyn Asplin	Joe Leonard
Ronald F. Ralph	Loreen Ruth Thomas	Robert Austin	Paul Lester
Tyler K. Reed	Jack Thompson	Vicki Axe	Tracey Lind
James Revels	Bryan Tinsley	Roy Bohr	Rachel Ann Linder
Elaine Richmond	Karen L. Toomey	Ken Brunner	Richard Lyga
Carol Ann Rockett	Beth Townsend	Su-Ling Chang	Vimlesh Maheshwari
Kenneth Rotatori	Robert C. Tryder	Rick Childs	Faye “Billie” McCormick
Sally Roy	Bill Van Berg	Ross Clevens	Kathy Mele
Tom Ruhlman	George Van Son	Marsha Cohen	Rashelle Morcom
Pat Ruppi	Jeffrey Van Son	Judy Comstock	Brian Moynihan
Stephen Gary Sackel	James Vowell	Ed Costello	Donald Newhouse
Seymour “Stony” Sarokin	Beverly Waite	George T. Demkow	Cindy Odell
Angelo William Savino	Beth Wal	Brad Dworkin	Neal Powell
Steve Schefter	Judith Waldow	Charlene M. Eckert	Carol Rao
John Jack Schloerb	Michael G. Wallis	Christine Engelmann	Johanna Rayman
Nancy Marie Scholz	John B. Warren	Judith Erlick	Karen Reed
Evan Schrier	Dwight H. Warrington Sr.	Maloney Family	Ruby Reyes Flowers
Rodger Sesna	Judith May Weiler	Bill Fehon	Calen Rodgers Aultman
Marcia Sherman	Sylvia Weisman	Mark Fox	Donna Rose
Jean R. Simpson	Thomas Whathey	Maria Gonzalez	Patrica Ryan
Roberta Sitler	John H. Whittaker	Ronald L. Gordon	Kirk Ryder
Rick C. Sivik	Jerry Wilcox	Majorie J. Gordon-Neal	Amber Sherrill
Mildred Sliclen	Page Freeman Wilhite	Helena Guroko	Reid Smiley
Jessie J. Smith	Douglas Albert Williams	Rachel C. Hadas	Ellen Solomon
Joyce Smith	Ellen Williams	Marguerite Harrington	Teresa Spencer
Lois Smith	Robert Steven Winters	Harrison Hedaya	Jeanette Stoothoff
Pamela Smith	Marilyn Wolf	Victoria Heller	Phil Thomas
Susie Sprouse	Deborah Woodcock	Jean Herbert	Jim Tully
Susan Snyder Stevenson	Sue Young	Beverly Hernandez	Kris Vanin
Elizabeth Stoia	Julie Marie Dickmeyer	Gary Hosley	Michael Vanin
Jeanne Stolier	Zerhusen	Charles Ice	Michael R. Walker
Mike Strohm	Zac Zronek	Aurora Shai Jackson	Mike Walker
Wanda Lee Sullivan		Mark Johnson	Barry Wank
Wendy Suzman		Marvin Johnson	David Wetzl
Robert J. Sykes Jr.		Nancy Jospey	Judy Windhorst
Albert Sylanski	Lydia Adalian	Christopher Lane	Tsippi Wray
Judith L. Temple	Rebecca Adams		

**In Honor of**

***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 select “Donate+”

# NIH-Funded Research Consortium Targets FTD's Progression – and Treatments

The National Institutes of Health (NIH) has awarded a significant grant to combine and continue research efforts into the progression and treatment of FTD.

The multi-year, \$63 million grant merges two existing studies – Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS) – to form the new ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration research consortium, or ALLFTD.

ARTFL and LEFFTDS were separately launched earlier this decade to study FTD's "natural history," or its progression in an untreated person over time. The LEFFTDS study follows individuals from families with a known genetic mutation

causing FTD, while ARTFL focuses on those without known mutations, but will also enroll individuals with a strong familial history. Advocacy by AFTD, combined with the efforts of researchers in the U.S. and Canada, led to NIH funding for both studies.

The ALLFTD consortium allows researchers to work collaboratively to advance FTD knowledge for future clinical trials. The group aims to better understand the course of the disease – from early indicators to the onset of more mature symptoms – and develop ways to measure its progression. Data will also be used to compare familial and sporadic forms of FTD, presenting the opportunity to identify therapies targeted to disease subtypes – with a specific focus on FTD biomarkers, which are urgently need to guide and support clinical trials.

The consortium consists of 18

participating medical centers and is led by researchers at the Mayo Clinic in Rochester, Minn., and the University of California, San Francisco (UCSF).

The consortium's co-principal investigators are Bradley Boeve, M.D., of the Mayo Clinic, Howard Rosen, M.D., of UCSF – both members of the AFTD Medical Advisory Council – and Adam Boxer, M.D., Ph.D., of UCSF.

ALLFTD offers the opportunity to translate experiences of living with FTD into data that scientists can understand, offering hope to all those affected by this disease. AFTD works to help move this important research forward and encourages those interested in participating in the ALLFTD studies to visit our website to learn more.

## Save the Date: AFTD's 2020 Education Conference



The next AFTD Education Conference will take place  
**Friday, April 17, 2020 in Baltimore**

Join us for an enriching and informative day. Learn more about FTD, talk to experts – and, most importantly, share experiences and form connections with people who understand this disease.

**More information about the 2020 conference will be available on [theaftd.org](http://theaftd.org) and AFTD's social-media channels, and registration will open early in the new year. Stay tuned!**



# AFTD Launches New Volunteer Program

AFTD's volunteers devote themselves to bringing help and hope to families facing FTD all across the country. We are extremely grateful for everyone who has donated their time and talents to educate, inform and empower our community with FTD support and information.

In order to make this experience more streamlined and more impactful for our volunteers, AFTD has recently taken steps toward restructuring our volunteer program. Our new-look volunteer program launched in early November.

With change comes new beginnings. AFTD recently brought aboard two full-time **Volunteer Coordinator** staff members, Annamarie Given and Jeni Cardosi. They will be the primary first point of contact for volunteers, working to develop strong connections with each of them. Annamarie and Jeni will ensure that every AFTD volunteer is matched with an activity that meets their interest and maximizes their talents. They both have strong backgrounds working remotely, managing many people

*AFTD Volunteer Ambassadors will represent our community by speaking publicly about FTD, conducting outreach, and networking with local health providers and other resources.*



*AFTD Volunteer Coordinators Annamarie Given and Jeni Cardosi*

simultaneously, and an appreciation for volunteerism, having been volunteers themselves in a variety of roles.

As a result of this new structure, AFTD's volunteer leadership has been redefined. The Regional Coordinator Volunteer position has been phased out, and **Ambassadors** will represent AFTD's volunteer leadership moving forward. Ambassadors will work to build connections at the community level within a specifically defined geographic area. Within those areas, Ambassadors will identify opportunities to establish and maintain a visible presence, representing our community by speaking publicly about FTD, conducting outreach, and networking with local health providers

and other resources.

Over the past 10 years, AFTD has been fortunate to work and collaborate with 30 dedicated Regional Coordinator Volunteers. AFTD Volunteer Manager Kerri Keane shared, "AFTD is a stronger organization with a growing volunteer program thanks to the leadership of the Regional Coordinators, who managed our volunteers across the country, established professional relationships locally, and, most recently, shared insight and perspective during the development of our new program structure. They have each represented AFTD with grace, professionalism and a true passion for AFTD's mission." AFTD would like to thank all 30 Regional Coordinators for their volunteer leadership and service.

AFTD is excited about the launch of the new volunteer program. "AFTD volunteers bring such dedication and heart, and we want to build on the momentum and success of our volunteer program to expand its scope and impact to deepen our reach and have a stronger local presence," AFTD CEO Susan L-J Dickinson said. "I see the restructuring of our volunteer program as mission-critical."



*Just a few of the amazing Regional Coordinator Volunteers AFTD has worked with over the last several years!*

# THE AFTD-TEAM



## Food for Thought 2019

AFTD's Food for Thought 2019 campaign saw 46 events in 25 states (plus Canada), and raised \$155,000!

**An Electric Evening:** Steve Bellwoar, a Pennsylvania-based AFTD Board member, hosted the sixth annual Colonial Electric Food for Thought event featuring nine holes of golf, dinner and a short presentation from AFTD's Senior Director of Programs, Sharon Denny. The event raised \$94,900, bringing the grand total to \$495,122 raised over the past six years—continuing its title as our flagship Food for Thought event.

**Pizza Party:** Lisa Nolte of Washington invited family and friends over for pizza, wine and beer. It must have been good because nearly 40 people attended, including old friends, neighbors and FTD support group members. Attendees were shown slides, handed gift bags and bracelets, and together raised \$11,281.

**Wining and Dining:** Theresa Walter of California hosted her fourth annual event at JayJay Gallery, featuring fabulous foods, tastings from eight different wineries, and artists contributing raffle prizes and silent auction items. With help from AFTD Board member Beth Walter, the evening brought in \$10,027.

**Brews and Bites:** Nanci and Emily Anderson of Minnesota hosted the second annual "Gary's FUB" event at Excelsior Brewing Company. Close to 200 people joined for live music, food trucks, raffles and a silent auction. A great time was had by all; the event raised \$8,669.



**Having a Ball:** Elisabeth Lynch of New Jersey served up homemade meatballs to family and friends in memory and honor of two special people. Those who could not attend still got to enjoy the traditional family food by ordering "take out" and making an online donation. A dear friend, Renee Fallor, hosted the event at her house; it raised \$7,680.

**Sum Fun:** The Pang Family of New Jersey held the second annual Dollars for Dim Sum, serving 500 handmade dumplings, 250 handmade skewers and 150 handmade spring rolls to family and friends at their house. AFTD's Development Manager, Amanda Knight, attended and reported back that the evening was a delicious success—raising \$4,403.



**Coffee Break:** Steven and Taylor Long of Texas hosted their event at The Coffee Dog in Bastrop. One of their first visitors was a general surgeon from Houston who had not previously heard about FTD. Even more awareness was spread to the rest of the visitors and a total of \$3,057 was raised.

**Tasty Treats:** Ryan Windhorst of Illinois linked up with multiple Dairy Queen locations to donate a portion of a day's sales, plus donations from an online fundraising page for people who couldn't make it out for ice cream. A sweet event with an even sweeter result of \$2,509 raised.

**Taco 'bout Teamwork:** Karen Hosley of Massachusetts teamed up with her local Chipotle Mexican Grill to donate 33% of sales during a four-hour, one-day window to AFTD. The guacamole must have been extra fresh because the event raised \$2,493.

**Perfect Pairing:** Bonnie Shepherd and Catherine Sharpsteen of Utah served appetizers and soft drinks, paired with information and presentations about FTD to attendees. The evening was informative and successful, raising \$1,784 for AFTD.

**Sweet Surprise:** Elizabeth Soriero of New Jersey hosted her event in conjunction with BeautyCounter, where portions of proceeds from purchases were donated to AFTD. In addition, anyone who donated directly to AFTD through her Classy page received Marianne's sugar brownies. Whether it was the products or treats, people were pleased to participate and raised \$1,311.

**Social Sharing:** Dan Keuning of Colorado decided to utilize social media for his event. He created a Facebook fundraiser, spreading FTD awareness to his followers and raising \$1,270 directly for AFTD.

**Giving Back:** Diane Cole of Michigan collaborated with Coach's Bar and Grill again for a giveback day. The restaurant owner graciously donated 10% of sales within a 12-hour window for one entire day. Many people dined-in, having known about FTD previously or not (but now do), and raised \$1,000.

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

Amber Dickson  
Amy Shives  
Barbara Coats  
Brandee Waite  
Bridget Graham  
Chrissy Pikos  
Dawn Ducca  
Donna Wert

Elizabeth Hubenak  
Esther Harvey  
Eugenia Thornton  
Helen Jevnikar  
Jerry Horn  
Joanne Linerud  
Jourdan Hendricks  
Karine Adalian

Katherine Helton  
Kathy & Sara LaFone  
Katrina Hellman  
Louise O'Connor  
Melissa Bisette  
Nicole DeLeve  
Nova Cook  
Patrick Gutierrez

Rachael Martinez  
Ruth Wilcox  
Sandra Pontious Leech  
Sandy Anglin  
Susan Butterfield  
Tara Jones

### AFTD Special Events Manager Bridget Graham extends a heartfelt thank you to all eight of the 2019 Food for Thought Liaisons for their extraordinary effort this campaign!

Ariel Harden  
Elaine Rose  
Jennifer Morabito  
Jerry Horn

Meghan Roscoe  
Susan Butterfield  
Terry Pontious  
Traci English

# THE AFTD-TEAM

**Hole in One:** The inaugural Driving Hope Golf Tournament was held on August 15 at the Seawane Club in Hewlett, NY and raised \$42,902. The event was co-hosted by committee members consisting of AFTD Board members Brian Rose, Danny Hedaya, Kathy Mele and Michael Stowell, and AFTD Volunteer Joan Berlin. An incredibly successful first annual event brought in 64 golfers, 80 dinner guests and over 100 supporters.



**The Big 1-4:** The fourteenth annual George F. Sidoris Memorial Golf Outing was held on July 20 at the Lost Nation Municipal Golf Course in Willoughby, Ohio and raised \$27,900. The day saw 124 golfers, 140 dinners and 40 hole sponsors (a record high!) at \$250 each. This event is AFTD's longest running grassroots fundraiser, and has donated over \$234,000 in total. Congratulations to the Sidoris Family and thank you for your continued and notable support.

**Tee Up:** The second annual Buffalo Trace Charity Open was held on August 24 at Colorado National Golf Club in Erie and raised \$10,022. Attendees could participate in 18 holes of golf and/or the Ryder Cup Meal. Hosted by AFTD Board Member Michael Stowell, the event has donated over \$19,000 in total the past two years.

**Breaking Records:** The third annual Crusade for a Cure Golf Tournament, hosted by former AFTD Regional Coordinator Volunteer Deb Scharper, was held on August 31 at the Sunny Brae Golf Course in Osage, Iowa and raised \$8,750. Over the past three years, Deb's tournament has donated a total of over \$23,000 to AFTD.

**Serving Up Support:** Brian Delaney of Georgia hosted the first annual Mary Jo Open on August 9 at the Chestnut Hill Tennis Facility in Acworth. The tennis-centric event raised \$5,828 towards AFTD's mission.

**Winning the Cup:** The Walker Cup is an annual Pennsylvania-based golf tournament held in Michael R. Walker's name, father of Cortney Walker Rohr. Each year a different charity is designated as the beneficiary and AFTD was chosen for the third time this year (previously 2014 and 2016), receiving \$4,350 in donations.

**Day for Dad:** Brian Fox of Nebraska owns Cornhusker Auto Wash and pledged to donate 100% of proceeds from all car washes, detailing, and oil change services on July 10 to AFTD and the Alzheimer's Association. Brian purchased the business from his father, Mark, who was diagnosed with FTD at age 62 and moved into a nursing home two years later. It was a successful day of business and turned out a \$4,000 donation to AFTD.

**In Memory of Tim:** Lauren Rowans of Florida hosted a fundraising page in memory of her husband, Timothy Rowans, who passed away from FTD on September 1, 2019. The page, which was created in lieu of flowers, raised \$3,032.

**Heroic Response:** Dom Fabich and Amanda Dawson of Oregon organize monthly fundraisers through Local Heroes, a nonprofit dedicated to local musical talent with a focus on house music, techno and disco. They host Studio Session events featuring DJs in Northeast Portland and donate 10% of ticket sales to AFTD, with a recent donation of \$2,500.

**Celebrating Carl:** The fourth annual CWM Golf Outing was held on July 13 in Michigan and raised \$2,335. Hosted by the Morettis and Marcys, the day celebrates and remembers Carl Moretti, who passed away from FTD in 2015. Over the past four years, the event has raised a total of \$6,535 for AFTD and our mission.



**Here's to Al:** Joel McNulty of Kansas hosted the ninth annual Al McNulty Dementia Benefit on September 13 at Red Room in Overland Park. The evening featured live music and a silent auction, and raised \$2,055. The past nine events have raised over \$10,500 in total towards AFTD's mission.

**Tip of the Cap:** Cindy Odell of Pennsylvania continued her fundraiser of selling "I Am Fighting FTD" hats on Custom Ink. This batch raised \$1,178 for a total of \$2,392 donated from sales of the product.

**Remembering Tami Sue:** The fourth annual Tami Sue Golf Outing and Party was held on September 14 in Ohio and raised \$1,450. Hosted by Suzanne and Calvin King, the day celebrates and remembers their daughter, who passed away from FTD in 2016. Since the inaugural outing, this event has donated a total of \$8,180 towards the fight against FTD.



**Hot Dog!** Nicole DeLeve of Kansas hosted the third annual Fresh, Tasty and Daring Hot Dog Fundraiser on July 27 at Limitless Brewing. Guests could top their dog with more than 40 different toppings, combining flavors to make hot dogs from around the world. The event raised \$1,059 for a grand total of \$2,206 over the past three years.



The Association for  
Frontotemporal Degeneration  
**FIND HELP • SHARE HOPE**

2700 Horizon Drive, Suite 120  
King of Prussia, PA 19406

[www.theaftd.org](http://www.theaftd.org)

Prsrt. Std.  
U.S. Postage  
**PAID**  
Williamsport, PA  
Permit #33

*If you prefer to receive this newsletter via email or would like to be removed from our mailing list, email [info@theaftd.org](mailto:info@theaftd.org) or call 866-507-7222.*

**AFTD**

[www.theaftd.org](http://www.theaftd.org)

phone: 267.514.7221

toll-free phone: 866.507.7222

## Board of Directors

**Gail Andersen**  
Chair, Ohio

**David Pfeifer**  
Vice Chair, Colorado

**Brian Rose**  
Treasurer, New York

**Stephen Fenoglio**  
Recording Secretary, Texas

**Helen-Ann Comstock**  
Founder, Pennsylvania

• **Steve Bellwoar**  
Pennsylvania

• **Rick Childs**  
Massachusetts

• **Sandra Grow**  
Ohio

• **Matt Hatfield**  
Florida

• **Daniel Hedaya**  
New York

• **Kacy Kunesh**  
Texas

**Jary Larsen, Ph.D.**  
California

**Paul Lester**  
North Carolina

**Kathy Mele**  
New York

**Michael Stowell, Ph.D.**  
Colorado

**Kimberly Pang Torres**  
New Jersey

**Beth Walter**  
California

## Staff

**Susan L-J Dickinson, M.S.**  
Chief Executive Officer

**Sharon S. Denny, M.A.**  
Senior Director of Programs

**Ben C. Freeman**  
Development &  
Communications Director

**Christine Stevens, M.B.A.**  
Chief Financial Officer

**Nadine Tatton, Ph.D.**  
Scientific Director

**Deena Chisholm, M.P.H.**  
Education Program Manager

**Bridget Graham**  
Special Events Manager

**Kerri Keane, M.S.W.**  
Volunteer Manager

**Amanda Knight**  
Development Manager

**Bridget Moran-McCabe, M.P.H.**  
Support Services Manager

**Debra Niehoff, Ph.D.**  
Research Manager

**Matt Ozga**  
Communications Manager

**Matthew Sharp, M.S.S.**  
Program Manager

**Jeff Thompson**  
Office Manager

**Lauren Gauthier**  
Online Community Specialist

**Victoria Addison**  
Digital Content Writer

**Ann Schoonover, M.S.W., L.S.W.**  
HelpLine Advisor

**Jeni Cardoso**  
Volunteer Coordinator

**Annamarie Given**  
Volunteer Coordinator

**Emma Tomasetti**  
Development Coordinator

**Elizabeth R. Young**  
Executive Assistant

## Medical Advisory Council

**Ian R.A. Mackenzie, M.D.**  
Chair, University of British  
Columbia, Vancouver

**Bradford C. Dickerson, M.D.**  
Chair Elect, Harvard University

**Bradley F. Boeve, M.D.**  
Mayo Clinic, Rochester

**Dennis W. Dickson, M.D.**  
Mayo Clinic, Jacksonville

**Karen Duff, Ph.D.**  
Columbia University

**Bernardino Ghetti, M.D.**  
Indiana University

**Jill Goldman, M.S.**  
Columbia University

**Murray Grossman, M.D., Ed.D.**  
University of Pennsylvania

**Edward Huey, M.D.**  
Columbia University

**Michael Hutton, Ph.D.**  
Eli Lilly & Co. UK

**David S. Knopman, M.D.**  
Mayo Clinic, Rochester

**Walter A. Kukull, Ph.D.**  
University of Washington

**Virginia M.-Y. Lee, Ph.D.**  
University of Pennsylvania

**Carol F. Lippa, M.D.**  
Thomas Jefferson University

**Irene Litvan, M.D.**  
University of California, San Diego

**Mario Mendez, M.D., Ph.D.**  
University of California,  
Los Angeles

**M.-Marsel Mesulam, M.D.**  
Northwestern University

**Bruce L. Miller, M.D.**  
University of California,  
San Francisco

**Jill Murrell, Ph.D.**  
Indiana University

**Chiadi Onyike, M.D.**  
Johns Hopkins University

**Creighton Phelps, Ph.D.**

**Rosa Rademakers, Ph.D.**  
Mayo Clinic, Jacksonville

**Howard Rosen, M.D.**  
University of California,  
San Francisco

**John Q. Trojanowski, M.D., Ph.D.**  
University of Pennsylvania

**For permission to reprint articles, please contact [info@theaftd.org](mailto:info@theaftd.org) or call 267-514-7221.**