



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

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Samuel I. Newhouse Foundation Supports \$5.75M AFTD Biomarkers Initiative

The Samuel I. Newhouse Foundation has awarded AFTD a grant of \$5.75 million to create the FTD Biomarkers Initiative. The gift, which will be paid over five years, was announced by Donald Newhouse, president of Advance Publications, Inc., at an October 1 event held at One World Trade Center to kick off the first World FTD Awareness Week.

Where they have been identified, biomarkers are used regularly by medical professionals for diagnosing patients and measuring a treatment's effectiveness. For example, in heart disease, blood pressure and cholesterol have long been used as biomarkers.

The issue of accurate diagnosis is not only a huge problem for patients and families, it is a huge barrier for researchers and their work to develop the first effective drugs

for advancing FTD research and care: diagnostic and progression biomarkers. These biomarkers could then be used in clinical trials to measure efficacy of a drug being tested.



Donald Newhouse, Stacie Weninger, Joanne Kotz and Donald's daughter Kathy Mele at the October 1 event.

to treat this disease. The new initiative will focus on identifying two types of biomarkers that are of critical importance

“Identifying biomarkers will foster greater attention to FTD by both the academic research community and the pharmaceutical industry,” noted **David S. Knopman, M.D.**, of the Mayo Clinic in Rochester, Minnesota, who chairs AFTD’s Medical Advisory Council, “and it will enable researchers to direct specific therapies to the right patients.”

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AFTD Rolls Out Support Groups Initiative

In every region, support groups play an increasingly important role for the FTD caregiver community. With the support of its Board of Directors and a generous Hearst Foundations grant, AFTD recently began rolling out a new initiative that seeks to connect support group facilitators to AFTD, and to connect them with each other, in new ways. “We are inviting current and new support group facilitators to affiliate formally with AFTD and receive expanded benefits,” explained AFTD Support Services Manager Bridget Moran, M.P.H.

To date, 24 group facilitators from groups in 14 states have agreed and completed the affiliation process. Moran noted that

this affiliation process is ongoing for both existing and newly-forming groups. Benefits provided to group facilitators that affiliate with AFTD are enhancements to the informal supports the organization offered previously. These will include: membership in a network specifically dedicated to improving care and support for people facing FTD; opportunities to attend ongoing training by FTD experts; a forum for collaboratively developing best practices in FTD support; and access to AFTD resources and branded materials to promote the group and increase community recognition.

(Continued on page 4)

Spotlight On... Sue Laden, AFTD Board of Directors

"My father had Parkinson's for 27 years," said Sue Laden. "And my mother kept him at home and really took care of him—while she also had a life—in an amazing way. When I asked her how she did it, she said: 'You just put one foot in front of the other and you keep on walking.'"

She would offer that advice to any family now beginning a journey with FTD: "Hang in..." she noted... "and seek out through AFTD a forum where you can get support from others."

Sue lost her husband, the economist Dr. Ben E. Laden — a proud and loving husband, father, brother, son and grandfather — to FTD in January 2009. "Nobody should have to go through what all of us have gone through with this," she added.

Sue and her family were AFTD's first major donors, and their commitment to the organization and our community has grown through the years. She and her family have set up the Laden Memorial Fund, in memory of her husband.

"Hang in..." she noted... "and seek out through AFTD a forum where you can get support from others."

She began serving on AFTD's Board in spring 2015, following in the footsteps of her daughter Francine Laden, Sc.D., whose six-year term with the Board ended in early 2015.

Being part of an organization uniquely dedicated to care and a cure for FTD is part of what drives Sue's commitment to service on our Board. "AFTD provides

amazing support for people going through this process... and people who are recently in need of comfort," she noted. "And at the same time, our research work is so important because it has the potential to prevent or cure people who are suffering from FTD."

As for her own role in strengthening the organization's work: "I hope I can make as much of a contribution to AFTD as my daughter has..." she said.

Sue brings significant experience in nonprofit leadership, fundraising, and communications—and serves as publisher of the Biblical Archaeology Review and president of the Biblical Archaeology Society, a nonprofit, non-denominational organization dedicated to education and dissemination of information about archaeology in the Bible lands.

AFTD NEWS BRIEFS

RNA Metabolism in Neurological Disease meeting

The 10th Annual Brain Research Conference, *RNA Metabolism in Neurological Disease*, took place in Chicago October 15-16, 2015. AFTD and Isis Pharmaceuticals were proud to co-sponsor this year's cutting-edge symposium, part of the Elsevier Global Conferences Series.

Paul Taylor, M.D., Ph.D., of St. Jude Children's Research Hospital, and Fen-Biao Gao, Ph.D., of the University of the Massachusetts Medical School, brought together basic and clinical researchers to share and discuss the latest findings in RNA metabolism thought to underlie FTD and other neurological disorders. "RNA metabolism is especially complex in neurons," noted Dr. Gao. "Our progress in understanding such changes has set the stage for the development of RNA-based therapeutics."

Thanks To AFTD Regional Coordinators

Two Regional Coordinators have stepped down after many years of service. Ashley Linsmeier was a South Atlantic Region Coordinator, and Katie Brandt was coordinator for the New England Region. AFTD thanks Ashley and Katie for their dedicated contributions to our community.

Support Group Changes

Mary Beth Riedner is stepping down from her role as facilitator of AFTD's phone-based language group. She has been facilitating for the past 1 1/2 years. Catherine Pace-Savitsky is stepping down from facilitating AFTD's phone-based parent support group. Catherine served as AFTD's second Executive Director, and has served as a support group facilitator

since 2009. Marise Rowell is now taking lead of the support group for parents, and Deborah Thelwell is taking the lead of the language group.

New Support Resource

Caregivers of individuals diagnosed with FTD/ALS now have a new telephone support group. Contact AFTD Support Services Manager Bridget Moran, M.P.H. at bmoran@theaftd.org for more information.

Research Opportunities

Are you seeking opportunities to participate in research? AFTD has added searchable tables to our website's [Currently Recruiting Clinical Trials and Studies](#) page. Updated quarterly, research opportunities are organized by targeted condition, as well as the country and region where each opportunity is located.

BECOME A MONTHLY DONOR:

Help Caregivers and Families Take a Much-Needed Break



The Griffith family: Kathleen, Parks, and their two children. Photo by Kathleen's brother, Stephen Dey.

Kathleen Griffith had long talked about taking her children to Disney World, but with her husband Parks Griffith facing FTD and Kathleen his primary caregiver, it just wasn't an option.

Then, in August, AFTD's Comstock Respite and Travel Program, which provides up to \$500 to people and families impacted by FTD, so that they can take some time to renew their energy, opened up new possibilities. Griffith was finally able to take her 8-year-old son and 10-year-old daughter on a "dream trip" to the Magic Kingdom.

"Watching a parent decline like this takes an emotional toll. They still need to be kids, to have a kid's life," Kathleen said. "For us to be able to go to Disney World ... The question of 'Where's Daddy?' Everyone could turn that off. They could be kids." The magical getaway lasted just four days, but it had a lasting effect.

"Having these amazing times together helps us all to care for Parks," added Griffith.

A modest grant has had a huge impact for the entire Griffith family. Won't you help us make an impact on the lives of even more caregivers and families?

Recurring donations allow AFTD to stimulate research and fund services for those affected by FTD, such as our Comstock Respite and Travel Program. **Become a monthly donor today** and help establish a sustained source of income for AFTD.

Use the enclosed envelope, or visit www.theaftd.org/get-involved/ways-to-give/monthly-giving.

Save the Date: 2016 AFTD Education Conference

Planning is now underway for the 2016 AFTD Education Conference – please save the date!

The Conference will be held in Minneapolis on **May 13th, 2016** at the DoubleTree by Hilton Hotel Minneapolis-Park Place. The keynote speaker, accomplished children's author and illustrator Nancy Carlson, will share her personal journey with FTD as a caregiver to her husband, Barry.

Alvin C. Holm, M.D. of Bethesda Hospital/HealthEast Care System.

Registration for the Education Conference will open in January 2016. Currently, AFTD has

corporate and individual conference sponsorship opportunities available. For more information about sponsorship opportunities, please contact AFTD Development Manager Pam McGonigle at pmcgonigle@theaftd.org.



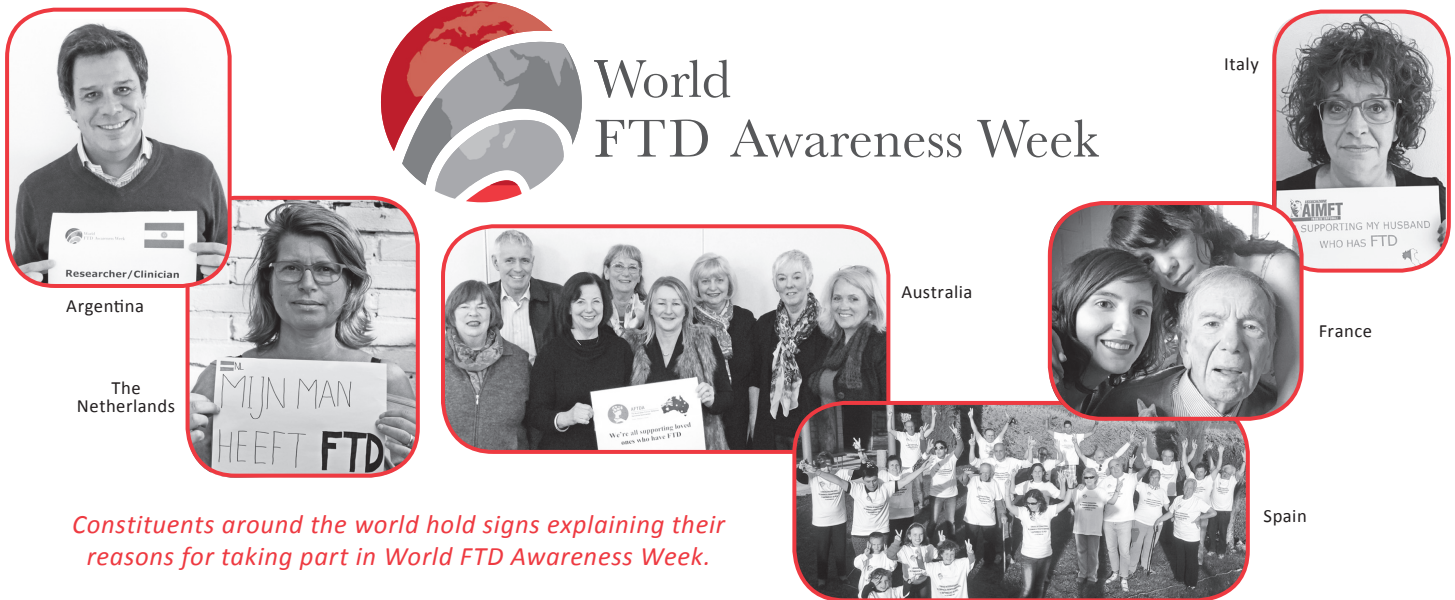
AFTD offers modest financial assistance for individuals with FTD and caregivers interested in

Other confirmed speakers include Bradley F. Boeve, M.D. and David S. Knopman, M.D., both of Mayo Clinic Rochester, Darby J Morhardt, Ph.D., of Northwestern's Cognitive Neurology and Alzheimer's Disease Center and

AFTD's annual Education Conference provides opportunities for all members of the FTD community – researchers, medical professionals, caregivers and persons living with FTD – to meet in person and share resources, while becoming updated on the latest developments in FTD care and cure.

attending an FTD education conference. Comstock Travel Grants may be used to defray the cost of travel, lodging, and conference fees in order to attend. For more information, see: www.theaftd.org/life-with-ftd/resources/travel-grants.

Ten Countries Make their Voices Heard During First



Constituents around the world hold signs explaining their reasons for taking part in World FTD Awareness Week.

From conferences in Australia and The Netherlands, to a concert and an art gallery event in Spain to a citywide proclamation in Canada, constituents around the world made their voices heard in the fight against FTD during the first-ever World FTD Awareness Week, October 4-11, 2015.

In 2013 and 2014, AFTD convened national FTD Awareness Weeks in the United States, anchored by its Food for Thought grassroots campaign. In the days leading up to the inaugural World FTD Awareness Week, AFTD Executive Director Susan Dickinson M.S.CGC summed up the motivation for this growing international effort by saying, “Everything we need to accomplish begins with awareness.”

The week launched with a special event at One World Trade Center that saw more than 200 attendees. Participants viewed a short film adapted by Joe Becker from his feature *It Is What It Is...* and heard from speakers who shared their families’ stories, including AFTD Board Chair Jary Larsen, Ph.D. and AFTD volunteer Nicole Savini, a television producer.

Over the week that followed, 20 international events and 61 Food for Thought events hosted by supporters in the United States worked to raise FTD awareness with activities, events, conferences and online social media campaigns. “With communities coming together from around the globe to spread awareness and to raise the funds for the crucial work to fight

this disease, it’s a time of growing hope,” said Dickinson.

Special FTD Awareness advertisements were created by AFTD volunteer Jody Zorn (see page 9). With support from a generous donor, these were placed as full-page ads in two Sunday editions of the *New York Times*, and are now appearing in monthly publications, most recently the 11/23 issue of *The New Yorker*. In Australia, constituents hosted an inaugural Asia Pacific FTD/MND Scientific meeting. France’s first FTD Day was co-hosted by the French National Reference Center for Rare Dementias and the nonprofit France-DFT. (Visit www.theaftd.org/newsroom/world-ftd-awareness-week for a list of events that were open to the public.)

Support Groups Initiative (Continued from page 1)

Rona Klein, who runs a support group in Winston-Salem, NC., recently committed to affiliation. She explained, “AFTD offers the support I need, to provide correct, specific information to what people are dealing with in FTD. Without these resources, my group would only be able to use broad, dementia-related information.”

AFTD has revised the online listing of Support Groups on its website’s regional pages. (See www.theaftd.org/get-involved/regions). These listings now enable visitors to easily find support group information for each state, and to see if the group leaders have affiliated with AFTD. The listings

will be updated as more are identified and when groups’ facilitators complete the affiliation process. “AFTD’s mission and goals have always included offering assistance to FTD support groups,” added Moran. “Increasing the number of strong, effective FTD-focused support groups is one of the best ways AFTD can help people to manage symptoms and preserve some quality of life,” she said. “Through this initiative, we will have the opportunity to ensure that all those living with FTD and their caregivers have access to high quality and FTD-specific support systems and services.”

Preparations Underway for FTD Economic Burden Study

For AFTD Board Member and Recording Secretary Gail Andersen, her husband's compulsive spending was "a good example of how people with FTD can have a lot of cognitive capability, but no judgment." While Andersen was at work, her husband was online, buying things the family didn't need and running up extravagant credit card bills. "So I took the credit cards away," Andersen explains, "and then discovered he'd memorized the numbers."

Families caring for an individual with FTD identify that this disorder exacts a heavy financial toll, both before and after diagnosis. Medical expenses – for visits to multiple doctors, including specialists in distant cities; for a seemingly endless array of diagnostic tests; for misprescribed medications; for genetic screening; and for home health and long-term care – contribute significantly to financial hardship.

However, the economic burden of FTD extends far beyond the cost of diagnosis and treatment. Symptoms often begin when patients are in their prime earning years and have children living at home or in college who still depend on them financially. When symptoms worsen to the point that the individual with FTD can no longer work or is fired, the subsequent drop in income can pose dire and immediate challenges to the family's finances.

If outside care is unavailable or unaffordable, spouses or partners often have little choice but to give up careers and become caregivers, resulting in additional loss of income. At the same time, new expenses, such as care for children who can no longer be entrusted to the affected parent or legal fees necessitated by behavioral indiscretions, place additional strains on the family budget.

Individuals with FTD may also spend money on risky investments, shopping sprees or email/phone scams. As bills mount and resources are depleted, families are forced to give up homes, college educations or plans for retirement. "So many families are completely wiped out," says Andersen.

"These findings will help to shape health policy, drive research agendas, promote allocation of appropriate financial and community resources and provide much needed support to patients and families currently living with FTD."

Previous research on the economic burden of neurodegenerative disorders has largely focused on Alzheimer's. "FTD may be even more costly than Alzheimer's disease because of the lost contribution of two salaries and the added cost of caring for a young-onset patient," notes Murray Grossman, Director of the FTD Center at the University of Pennsylvania. Edward Huey, Assistant Professor of Psychiatry and Neurology at Columbia University College of Physicians and Surgeons observes that when patients lose jobs, they also lose insurance coverage and adds, "As a result of their young age and behavioral symptoms, patients with FTD often have to be placed in more expensive facilities with more supervision."

However, an important new research effort will focus specifically for the first time on the financial, social, and psychological hardships associated with FTD. Sponsored by AFTD and headed by Dr. James Galvin, Professor and Associate Dean for Clinical Research at the Charles E. Schmidt College

of Medicine at Florida Atlantic University, the study will ask family members and caregivers of FTD patients to complete a questionnaire detailing their experience with the diagnosis and management of FTD, interactions with healthcare providers, resource availability and utilization, health-related quality of life, and the challenges they have faced. The results will be stratified by FTD subtype, allowing Dr. Galvin's research team to determine if the costs associated with each differ. In addition, the team will compare the economic burden of FTD to that of Alzheimer's disease.

The study will represent an important advance in our understanding of the far-reaching consequences of FTD for families, the healthcare system and society at large. In addition, it is expected to provide much-needed quantitative data to support and expand advocacy efforts, inform policymakers and increase research funding to develop effective treatments. "We anticipate that the results of this study will have a profound impact on our ability to advocate for services and resources that our patients and their families both need and deserve," notes AFTD Executive Director Susan Dickinson.

Dr. Galvin adds: "These findings will help to shape health policy, drive research agendas, promote allocation of appropriate financial and community resources and provide much needed support to patients and families currently living with FTD."

Your participation will be vital to the success of this important research project. Please watch the AFTD website for more information on the launch of this survey, as well as directions for accessing and completing the survey.

Donations Honor Loved Ones *Gifts received from June 16 - October 15, 2015*

In Memory Of

James S. Abbott
Harold Abramson
Bruce Jeffrey Adler
Laura Ahlbeck
William "Bill" M. Allen
Christine Andrey
Anna Held Audette
Emerson R. Avery
Norma Benson
David Berkowitz
Raylene Jean Biren
Sandra Bishop
Lynn Bloch
Nancy Bloom
John "Jay" D. Blossom III
James "Jim" William Bope
Lonnie Bradshaw
Nancy Bresky
Edward Marks Butler
William J. Butterworth III
Richard B. Carpenter
Willis H. Caterson
Arthur Cavara
Peter Chase
Robert N. Chipfield
Anna Mary Christiana
Sophie Chrobak
Linda Arlene Clark
Lawrence T. Cline
Daniel Channing Cole
Edward "Bruce" Coon
John J. Cox
Linda L. Csanadi
Ernest L. Davis
Wilfred Denise
Eleanor Dondiego
Wadley Hugh Duckworth
Pamela Duncan
Ronald Duncan
Janet Dunne
Michael James Dziatkowicz
Frank Englekraut III
Jerry Feldscher
Michael E. Fenoglio
Andrew Fitze
Angela Flood
Mary Fox
Mary Ann Fredheim
Bernard Fridovich
Donna Rae Garrett
Victoria Glandon
Raymond Salvatore Gomez
Patrick Grady
David Gragg
Jane Grant

Lewis Grant
Patricia Gray
Carol Diane Greene
Marsha Corns Greenlee
Albert Charles Hall
Richard Hanechak
James J. Hansen
Donna C. Harold
Kathleen "Kate" O'Brien Hartig
Evelyn A. Hayes
Harold Hedaya
Richard Lloyd Heilman
John D. Heizman
Bernard Heitz
Robert L. Hermann
Beverly Hill
Nan Hochstein
Richard "Dick" Huddleston
Pamela Hughes
Jan Hupfauer
Robert E. Johnson
Karen Stevens Jones
Bobbie Kallemeyn
Jan Karwowski
Lauri Gail Berman Katz
James C. Kearney
Scott A. Kibort
Eugene Klein
Steve Koppa
Otto Kostka
John M. Kretekos
James E. Krouse
Rose Kuchera
Robert J. LaMarre
Peter J. Larsen
Arnette Lester
Howard Levy
Deborah "Debi" Elizabeth Lewis
Jacqueline Farr Lloyd
Adelaide Miller Ludy
Jordan "Tam" Tamar Macy
Phyllis Malloy
Tom MacKnight
Donald B. Marcum
Susan Marcus
Sarah Mast
Gary Matusch
Robert Matusiak
Edward McAndrew
Ronald McCarthy
Terry McDevitt
Judith Lorraine
Gailhard McDonald
Thomas McMahon
Larry B. Meares
Madeline Miele
Barbara Mikolajczyk

Robert Miller
Carol Morris
Raymond Charles Murray
Michael J. Murray
Judy Grummon Nelson
Alice Neuman
Susan Newhouse
Marie Annette Nichols
Joseph Palmisano
Camilla Perry
Debbie Pike
Albert Anthony Pondelli
Thomas Potter on his birthday
Camilla Perry
Bette Phillips
Joseph Wayne Plageman
Neil Radin
Bob Rednick
Jimmie Wayne Reed
Scott Hayward Reed
Lorraine Reboul
Virginia Faye Reeder
Jessie Reid
Barry Rein
Steve Riedner
Carol Ann Rockett
Carol Rosey
Rosellen Roy
Tom Ruhlman
Leroy Melvin Ruttinger
Evelyn B. Sambur
Ronald Schlie
John "Jack" Schloerb
Rick Schmid
Avon Howard Schulthies
Richard L. Scott
Matthew Sevcik
Shirley Shaw
Ned James Shepherd
George F. Sidoris
Judith Skubis
John D. Sousa
Judy Stitt
Ruth Strauss
Robert J. Sykes Jr.
Janet DeBruyn Thomas
Howard Thorn
Lois Ann Thornton
Shirley Marie Tinker
Stephen M. Tipton
Charlotte Turner
Janet L. Valley
Richard Van Dyke
Judy van Roekel
Jeff Van Son
Maureen B. Vazquez
Beverly Waite

Stanley Wallack
Kathleen M. Wallenfang
Michael G. Wallis
Jane V. Ward
Dwight H. Warrington Sr.
Susan Watson
Judith May Weiler
Rosemary "Cookie" Weiten
Lewis Weston
William "Bill" White
James E. Wilcox
Marjorie Ann Gately Wild
Tim Williams
Carole Mary Zalenski

In Honor Of

Lydia Adalian
Randy Baker
John Baumgartner
Steve Bellwoar and Family
Trish Bellwoar
David Birnbaum
Joy Spartin Bowen
Vicki L. Branecki
Ronald Campbell
John Carlson
Donald Carnig's birthday
Frank Carpentieri
Su-Ling Chang
Charles Cole
Helen-Ann Comstock
Annie Dalton
Scott Dalton
Charles Darrow
David Dosser
Twila Eisley
Harald W. Feige
Shelley D. Fischel
Diane Fitzgerald
Courtney Gasque &
Matthew Politano marriage
Olin Gentry
Helen Granzeier
Gary P. Griffith
Alice Hale
G. Simon Harak
Margie Harrington
Julie Jackson
Debbie Johnson
Douglas Johnson
Debby Kallaher
James C. Kehoe
Rita Khoury
Faye Olivieri Kozich
Donna Kunesch
Kacy Kunesch

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

Erin Lester &
Brent Coffey marriage
Dale W. Lutz
Lily Matusiak &
Paul Scanlon's wedding
Bunny McMurrer
Trenton McNally
Clare McNamara
Virginia Miller
Cynthia Mongelli
Shellie Morcom

Charlotte Murray
Louis Nieto
Andrew Nissen
Larry Olivieri
Rhoda M. Oswald
Stewart Peterson
Mary Catherine Pfeifer
Joshua Pierce
Janis Pitts
Isaac Rabino
Linda Rabino

John Radosta
Hector Roach
Donna Rose
Karen Rowe
Lori Ruhlman
Kirk Ryder
Joyce Shenian
Sharon V. Snyder
Ellen Solomon
John Stackhouse
Richard St. Jean

Jeanette Stoothoff
Bill Struzzi
Judith L. Temple
Barbara Tinsley
Robert Traurig
Barry Wank
Dennis White
Elaine White
John D. Wilson
Judy Windhorst
William Zorka

In lieu of flowers...

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 Now."

NAPA Adds Expert on Related Dementias to Advisory Council

AFTD is pleased to report that Lewy Body Dementia Association Director of Programs Angela Taylor has been appointed to fill a vacated seat on the National Alzheimer's Project Act (NAPA) Advisory Council. NAPA formally included FTD and other related dementias in its priorities in 2014; however, until now, there were no representatives with exclusive expertise in a non-Alzheimer's dementia.



Angela Taylor

challenges and issues related to the non-Alzheimer's dementias and that the National Alzheimer's Project will continue to benefit all those affected by these diseases.

The appointment follows early 2015 NAPA meetings, during which both Sharp and Taylor requested changes to the composition of the Advisory Council, with Sharp advocating to add a seat specifically for the related dementias.

"This appointment signifies critical progress," he noted. "But we hope that The Council and the Department of Health and Human Services will continue to give serious consideration to establishing a dedicated seat for the related dementias, to ensure that all relevant perspectives are brought to bear on the task at hand."

During the most recent NAPA meeting, on October 26th, Sharp

reminded the Council that developing biomarkers for diagnosis and disease progression in FTD was a key recommendation to come out of the 2013 Alzheimer's Disease-Related Dementias Research Summit. He shared AFTD's recent announcement of an FTD Biomarkers Initiative (see page 1), and noted: "Success in developing biomarkers for FTD will inform similar initiatives for Alzheimer's and all of the related neurodegenerative disorders."

The composition of NAPA's Advisory Council is particularly important as preparations begin for the 2nd Alzheimer's Disease-Related Dementias (ADRD) Research Summit, scheduled to take place at NIH in March 2016. In accordance with The National Plan to Address Alzheimer's Disease, NINDS is convening the Summit to review progress on research recommendations developed at the first (2013) ADRD Summit for FTD, Lewy Body and vascular dementias, and to update priorities and timelines to advance research targeting these non-Alzheimer's dementias.

"With this appointment, the Advisory Council is making a significant step toward including the perspective of the related dementias," said Matthew Sharp, M.S.S., AFTD Program Manager. "In this area, the Council has appointed a dedicated, knowledgeable and articulate advocate." Adding Ms. Taylor's perspective and expertise will be one key step to ensure that the National Plan includes the

AFTD Welcomes Research Manager, Debra Niehoff



AFTD is pleased to welcome new staff member Debra Niehoff, who holds a Ph.D. from The

Johns Hopkins University School of Medicine. She joined AFTD in October as Research Manager, working under the guidance of Scientific Director Nadine Tatton, Ph.D.

A neuroscientist by training, Debra served most recently as an instructor at Bucks County Community College, where she taught psychology

and served as the coordinator of the College's neuroscience program, one of the first in the country at the two-year college level. Her experience also includes scientific and medical writing - she is the author of two popular science books, and ran her own biomedical communications company - as well as eight years of service on the Board of a drug and alcohol treatment facility in Bucks County, PA. These efforts have provided a base of interpersonal, organization, and communication skills that will benefit AFTD's mission.

"I am excited to join the team and eager to contribute to AFTD's research," said Niehoff, who

will administer and develop AFTD's grants programs, oversee planning for the FTD Treatment Study Group, support the FTD Biomarkers Initiative, and assist AFTD's Scientific Director in a range of other research efforts.

"The opportunity to be part of an organization committed to supporting research on this level - and improving public understanding of FTD through education and advocacy - is both professionally and personally fulfilling to me," she noted. "The passion AFTD staff bring to improving the lives of those with FTD and their caregivers is truly compelling."

Biomarkers Initiatives *(Continued from page 1)*

"I had never heard of this rare disease before my beautiful wife, Suzy, was diagnosed in 2005," said Newhouse at the beginning of his remarks. He went on to share that his brother, Si, is also diagnosed with FTD: "In a tragic twist to our family's journey, we face a second case of FTD without any genetic link between the two. And so this disease that can steal such crucial things from a human being does not feel rare to my family."

"We went looking for ways to combat this disease," Newhouse continued. "We met a number of gifted clinicians who provided the best care possible, but... the best we have today is still not very good. And so we searched for a way to change that and were directed to AFTD."

Both Newhouse and Dickinson called for international collaboration, as well as cooperation across industry, academia and medicine. "We will convene experts from around the world to help us award funds to the best ideas and the best science wherever they find them," said Newhouse. "And we will welcome partners from the pharmaceutical and biotech industries, from NIH, from the FDA and from other organizations who want to join in the cause."

"We each have something we can give to make a difference."

Stacie Weninger, Ph.D., Executive Director for the F-Prime Biomedical Research Initiative, will chair the Scientific Advisory Board (see sidebar) that will guide this multi-year effort. In late 2015, the Board will meet to review the current state of knowledge regarding FTD biomarkers and craft the first Request for Applications, to be issued early in 2016. AFTD anticipates awarding half of the available funds in 2016 and issuing a second, equivalent round of funding two years later, depending upon the number and quality of applications.

In closing this announcement, Newhouse issued a call to action: "Everyone has something unique and valuable to offer, and I urge each of you to join AFTD and engage yourself to whatever your passion directs you. Whether this be a gift to provide current caregivers with respite, a donation to fund a young scientist at the start of his or her career, the volunteering of your expertise or the running of a support group so families can connect and feel less lonely. We each have something we can give to make a difference."

AFTD is grateful for this Samuel I. Newhouse Foundation gift, and optimistic for the transformative gains that our community will make as a result of it.

Giving a Hand to Our Helping Hands!

By Kathy Urban,
AFTD Volunteer

Jody Zorn has been a volunteer with AFTD for just about eight months, but her impact has been incredible so far! She brings vital experience and talent as an Associate Creative Director at an ad agency in New York City. In fact, she played two key roles in making the first World FTD Awareness Week a success!

Jody designed two full-page ads which appeared in two Sunday editions of *The New York Times*, and formed the basis of a special www.theaftd.org/learnmore website page. Those ads are now running in monthly publications, most recently *The*

New Yorker. She also created a logo for World FTD Awareness Week that was adopted by the international community (see page 4).



Jody dances with her father at her wedding.

Jody shared, "I got involved with the organization because my father passed away from the disease last December. I had never heard of FTD before he was diagnosed and knew it wasn't a well-known disease. I wanted to help change that in any way I could. I figured my time and expertise in advertising would be worth more than any money I could ever give."

Ben Freeman, Development &

Communications Director at the AFTD, has had the opportunity to work with this AFTD volunteer on several projects. Of her work on the awareness advertisements, he commented: "Jody had a very clear vision of what she could achieve with the designs, and then worked with us to make sure we were able to get what AFTD needed from the project. That mix of having a particular skill and knowing how to use it in collaboration made for an excellent process from start to finish, and the results clearly resonated for our community and others who didn't know about FTD prior to seeing the ads."

Those connected with FTD have most likely faced the challenges of explaining it to others. Through Jody's creative and extraordinary work, she is helping to foster awareness of the disease among a growing audience. Look for future efforts by this talented volunteer.

Food for Thought Volunteer Liaisons: Key to a Successful Campaign

AFTD's Food for Thought campaign (FFT) reaches such a wide audience – and plays such a significant role in the organization's grassroots fundraising -- thanks to the many event hosts who participate across the country. To manage a growing number of events, AFTD relies on FFT volunteer liaisons to take the lead in supporting hosts. The liaison is the host's primary AFTD contact, and their go-to person to address questions throughout the planning process. The liaison's goal is to make the host's experience a positive one, in which they feel connected to AFTD and supported as a member of the AFTD-Team.

For the third year in a row, the campaign had a fantastic group of dedicated volunteer liaisons. They all attended a training to prepare and brought enthusiasm and professionalism to the position. This year's team consisted of eight volunteer liaisons, with three, Meghan Roscoe, Erin

Hopper and Margie Simon, returning to this role for a second year.

Host Jennifer Morabito commented, "I was contacted by [FFT liaison] Deanna Rice as I was planning my FFT event, and she was so helpful and supportive that I really feel like I have been included in an amazing group. Thank you!"

"AFTD is lucky to have such a caring and committed group of individuals. The FFT campaign was so successful again this year because of their assistance and responsiveness. It was very much a team effort," said Kerri Barthel, AFTD volunteer manager.

AFTD is truly grateful for the time and effort put forth by the liaisons over the past five months. They represented AFTD well and provided guidance to those raising funds and FTD awareness with compassion and patience. AFTD looks forward to recruiting and working with volunteer liaisons again next year.



2015 Food for Thought Liaisons

Tina Ho
Oregon

Erin Hopper
Arizona

Charlene Martin-Lillie
Minnesota

Deanna Rice
Virginia

Meghan Roscoe
Connecticut

Elaine Rose
Maryland

Margie Simon
Missouri

Cathy Sperrick
New York

THE AFTD-TEAM

AFTD-Team Hosts *Food for Thought* During World FTD Awareness Week

The first-ever World FTD Awareness Week (see story on page 4) featured strong participation from community members in the United States, through the third annual *Food for Thought* campaign. AFTD volunteers hosted 61 *Food for Thought* events in 32 states and Washington, D.C., as people in nine countries joined forces to host 20 additional awareness events!



Oregon

Northwest Regional Coordinator Amy Eissler paused for a break following the Cause and Event Race. Amy raised FTD awareness among race volunteers and members of the FTD team, as well as other racers who wished to learn more.



Michigan

Diane Cole and her daughter Lisa Weber welcomed patrons of Fire and Ice Pizzeria & Creamery in St. Joseph, Michigan during World FTD Awareness Week.



California: Pot Luck for Returning FFT Host

Long-time AFTD grassroots event host Brandee Waite gathered a group of friends and family known as Team Bev in Sacramento, CA for a 5K/10K relay run, followed by a combination pot-luck and catered brunch.



Maryland: Cindy's Cakes

A team of bakers backed Jennifer Morabito and her *Food for Thought* effort. Event organizers accepted pre-orders for mini-cakes, named in memory of Jennifer's mother, each costing \$3, which were distributed in Central Maryland. The event raised \$1,013.



Texas: Dine-in Movies

Food for Thought host Shana Nissen selected San Antonio's Alamo Draft House as the site of her event, which capitalized on the trend of dine-in movies. Participants enjoyed dinner and were shown two FTD documentaries. Pictured here are Shana's husband Andy's mother, and their friend Annalisa. Proceeds from ticket sales benefited AFTD, and the event raised \$1,400.



Arizona: Rummage & Bake sale

Cheryl Johnson hosted an all-day Rummage & Bake sale in Phoenix Arizona. The event brought together artists, food, and wares of all types, while offering FTD information and fostering awareness, including sharing a "Faces of FTD" display. The event has raised \$1,835.



Who Do You Love?

AFTD invites you to take part in a special social-media campaign that will launch this winter. Help us to share a new video with the world, to raise awareness and raise funds for AFTD! Help us tell the FTD story to a wider audience! E-mail AFTD Grassroots Events Coordinator Bridget Graham at bgraham@theaftd.org to learn more.

THE AFTD-TEAM

Food for Thought Arizona



In Phoenix, attendees enjoyed a five-course dinner as host Kathy Ritchie teamed up with CenPho Advocates for Dementia Awareness. The event raised more than \$3,500.

Every Bite Helps

Brian and Sharon Rose hosted "A Bite to Fight FTD" in honor of Brian's mother, Donna Rose. Participants video-recorded themselves getting ready to enjoy a favorite sandwich, accompanied by an FTD awareness message. The event raised \$8,675.



Oklahoma Delivers Awareness with Baked Goods

Oklahoma FFT host Heather Miller used her talent for baking to promote FTD awareness and raise funds.

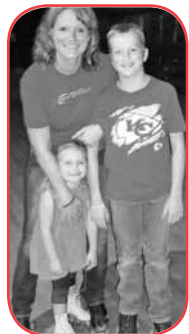


Wisconsin Restaurants Join the Team

In Madison and Milwaukee, four restaurants hosted donation boxes and distributed educational materials. Tip Top Tavern (managing partner Alfred B. Rasho pictured with organizer Hillarie Higgins) also donated sales proceeds. The Food for Thought event raised over \$700.

Cupcakes for Grandma

Ed Fitzgerald's grandkids made and sold electronic cupcakes, then baked real ones for a party with Grandma at their home. The event raised \$235.



Nebraska Hits the Rink for FTD

Kerri Unger invited her McCook, Nebraska community to travel back in time and join a roller-skating party with vintage skates in an old barn. The Food for Thought event raised \$340.

On Board

AFTD Board members raised more than \$90,000 for Food for Thought! Steve Bellwoar's event brought in more than \$82,000; Bonnie Shepherd's raised more than \$5,500, and Gail Andersen's event raised \$2,180.

New Tournament in Alabama

The inaugural John Baumgartner FTD Golf Tournament was held October 12th in Alabama. Hosted by an individual recently diagnosed with FTD, John Baumgartner, and his family and friends, the event raised over \$13,000.



Connecticut Bake Sale

Arden Courts in Connecticut hosted a brief presentation by Megan Roscoe of the Connecticut FTD Foundation, and showed a DVD about families dealing with FTD. Arden Courts staff provided a bake sale, with proceeds of \$230 benefiting AFTD.

Longest Running

AFTD's longest running grassroots fundraiser, the 10th Annual George F. Sidoris Memorial Golf Outing was held August 15 at Lost Nation Golf Course in Willoughby, OH, raising \$21,300.

A.C. Marathon

Russell Zomback completed the Atlantic City Marathon on October 18th in memory of his father, and raised \$4,730.

New York Targets Young-Onset Dementia

New York's Abandon Brewing Company hosted an October 3rd event. Guests enjoyed food with beer pairings and live music. The Food for Thought event raised over \$10,000.

Louisiana Teacher Inspires Students

In Louisiana, Nancy Buckman's students motivated her to host an FFT event. She posted daily photos in memory of her sister Linda, with a recipe and information about FTD.



Flying Colors

With his friends, Danny Hedaya participated in the July 26th Color Me Rad 5K NYC MetLife race, raising more than \$23,000 for FTD research in memory of Danny's father, Harold Hedaya.

Run, Rock and Roll

Kenda Greenwood completed in the Rock 'n' Roll Marathon during the second week of October to promote awareness, and raised \$1,065 to support AFTD's mission.



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