



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

Volume IX, Issue 3

Fall 2012

Care & Cure Event: A Decade of Dedication

Friday, October 19th was a big day for AFTD. To celebrate its 10th anniversary, AFTD held a “Care & Cure” event in downtown Philadelphia with nearly 200 staff, board and event committee members, volunteers and supporters—from California and Canada to center city Philadelphia.

The event took place 52 floors above the city in the Pyramid Club, a private organization with breathtaking, 360-degree views of the city. Beginning at 6 p.m., guests enjoyed passed hors d’oeuvres and glasses of wine, beer and a signature drink—Billy Penn’s Pleasure—created by the Pyramid Club and courtesy of Capital Wine & Spirits, Philadelphia Distilling, Legacy Spirits Philadelphia, The Charmer Sunbelt Group and The Wine Merchant.

Guests mingled, matched faces with names and watched a video timeline of AFTD’s first ten years and the milestones achieved during that time. Several local Philadelphia restaurants, including Plate Restaurant & Bar, Susanna Foo, Sansom Street Oyster House and Yellow Juice Bar, donated their delicacies for the evening. During the evening, guests had the opportunity to bid on 43 silent auction items.



Current AFTD Board Chair Beth Walter welcomed everyone to the event. She thanked all of the donating vendors and presenting sponsor for the evening, Colonial Electric Supply.

AFTD presented a short but moving presentation that walked the audience from the past to the present and into the future

(see *Care & Cure*, page 4)

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8th International FTD Conference Recap

Over 600 scientists, clinicians, allied health professionals and caregivers met in Manchester, England from September 5-7, 2012 to focus on all aspects of FTD, from care to therapeutic approaches. AFTD, which helped sponsor the 8th International Conference on FTD, was involved in planning the parallel Caregivers’ Meeting and participated in a meeting of patient advocacy and support groups from several different countries.

A lot of the focus at the scientific conference was on the newly identified *C9orf72* mutation, which investigators discovered only last year. Other sessions focused on advances in understanding of the underlying disease process, advancing use of imaging for accurate diagnosis as well as tracking progression of disease, and management of FTD.

The *C9orf72* mutation, which is now known to be responsible for the majority of genetic cases of both FTD and amyotrophic lateral sclerosis (ALS or Lou Gehrig’s disease), takes the form of a six-letter sequence of DNA that is repeated over and over many times more than is seen in people without FTD. This type of mutation is sometimes

(see *International Conf.* on page 7)

Spotlight On...Popkin Shenian, AFTD Board of Directors

Popkin Shenian, known also as “Pop,” is no stranger to the disease called FTD. His mother Joyce was a founding Board Member of AFTD in 2002 and currently serves on AFTD’s awareness committee. His father, Dr. Popkin Shenian, a former scientist and director of Research and Development for the Plastics Division of General Electric, was diagnosed with FTD in 1994 and passed away in 2002.

More than 20 years ago, Pop started a commercial real estate brokerage company based in Philadelphia. Being in such close proximity to AFTD’s office just outside of Philadelphia, Pop was never far from the hub of AFTD activity, especially with his mother’s active role in the organization.

“It was probably inevitable and quite natural that I would one day continue the mission of the Association in honor of my father and to help other families in the fight against FTD,” said Pop. His sister, Lauren Shenian McMahon, is a member of AFTD’s research committee.


Since officially teaming up with AFTD in 2011 as a Board Member, Pop has served on the advocacy committee in an effort to make inroads with legislators on Capitol Hill.

“I was fortunate to be a close personal friend of the late United States Senator, Arlen Specter. Senator Specter was the lead on getting NIH’s budget increased by \$10 billion. He was instrumental in introducing us to key individuals,” said Pop. In addition, he met

with several staffers from the offices of Senators Toomey and Casey in the past year along with AFTD Board Member Earl Comstock and AFTD Program Coordinator Matt Sharp to advocate on behalf of AFTD.

“I completely understand the burdens of caregivers, and my personal experience with my father has enabled me to be a more effective representative for AFTD,” said Pop.

Pop also recently attended the Advisory Council of the National Alzheimer’s Plan meeting at the Department of Health and Human Services in Washington, DC on October 15 with Matt Sharp. These meetings enable representatives from the “other dementias” to give voice to their diseases and the importance of finding care and cures for them as well as Alzheimer’s.

“I’m excited that a national plan will be developed by 2013 to cure Alzheimer’s and the related dementias by the year 2025. This is a significant milestone in the work AFTD does...and I’m proud to be a part of it.” 



Popkin Shenian

AFTD News Briefs

.....
There are **new FTD support groups** in the following locations: Indianapolis, IN and Akron/Canton, OH. Check AFTD’s website for a complete listing of support groups.

.....
AFTD knows how difficult the physical and emotional demands of caregiving can be. **The Comstock Caregiver Respite Program** provides \$500 grants to full-time family caregivers for respite. More information and the application form are available on AFTD’s website.

.....
Volunteers wanted! If you are interested in helping to increase

awareness of FTD and AFTD in your community, consider volunteering for AFTD’s community outreach project. We are currently looking for people in the US and Canada to conduct visits with facility providers. If you would like to learn more about this initiative, please contact AFTD Volunteer Manager, Kerri Barthel, at kbarthel@theaftd.org or 866-507-7222.

.....
Get your **“With Love”** stories ready! AFTD will do its 2nd online Valentine’s Day fundraising campaign in early 2013, based on your “with love” stories about FTD. For more information, contact amaher@theaftd.org.

Save the Date! Join AFTD on Friday, April 13, 2013 in Salt Lake City, UT for the AFTD’s education conference and annual meeting. Details to come!

.....
Congratulations to AFTD Postdoctoral Fellow Todd Cohen, Ph.D. for garnering an auspicious K99 award from NIH. The K99 provides 5 years of funding that will help Todd advance his career from student to principal investigator in his own right.

.....
Want an easy way to give back to AFTD this holiday season? **Sign up for an AFTD credit card through Capital One.** Visit AFTD’s website for details!



In the spirit of the season, please support our efforts today.

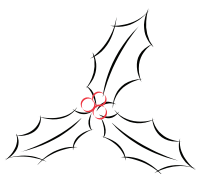


"AFTD has the perfect balance of providing up-to-date information, funding research and supporting families. They help those with FTD and their loved ones to navigate the healthcare and information maze with the goal of enhancing quality of life and, one day, finding a cure."

-- Kathi Arnow, caregiver and donor

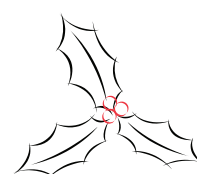
Your financial support gives our community HOPE for tomorrow!

- \$25 could pay for HelpLine support for one patient or caregiver
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- \$270 could pay for one continuing education conference call for facilitators of FTD caregiver support groups across the US and Canada
- \$500 could provide a respite or travel grant for a caregiver to get a break or connect with others in the FTD community by attending a caregiver conference
- \$1,000 could help fund research that will lead to the first approved treatments for FTD



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<http://www.theaftd.org/about/get-involved/donate/electronically>

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AFTD Creates Two New Staff Positions

Two new members of the AFTD staff joined the organization in September. Elizabeth Neal is AFTD's development and marketing assistant. With a degree in Mass Communication from York College of Pennsylvania, Liz comes with an educational background in public relations, media writing and broadcast journalism. She also has professional work experience with fundraising software and customer service inquiries.

Liz hit the ground running as an integral part of AFTD's 10th Anniversary Care & Cure Event by helping to organize the auction items and head up all behind-the-scenes logistics. Moving forward Liz will serve as AFTD's receptionist as well as supporting marketing and fundraising operations.

Kerri Barthel, MSW, has taken on the newly created role of volunteer manager. Working with people across the country and Canada who wish to be actively involved with AFTD in one way or another,


Kerri will serve as the clearing house and point person to keep AFTD's volunteers engaged with meaningful work. She will also join other members of AFTD's Program Staff in responding to HelpLine inquiries. Having received her Masters in Social Work from Temple University, Kerri has worked for several nonprofit organizations on a local and international level.



New staff members Liz Neal and Kerri Barthel

On October 20, the day following AFTD's Care & Cure Event, Kerri led a full-day AFTD volunteer meeting, which included all of AFTD's regional coordinators and several other key volunteers for the organization. She unveiled the


newly created volunteer handbook and helped to create a sense of community between all who participated. (See story on page 9.)

AFTD welcomes Liz and Kerri and wishes them well in their new roles. We are excited to be expanding the organization's capacity to engage with our community and achieve our mission. 

Care & Cure *(continued from page 1)*

of the organization. Helen-Ann Comstock spoke about her husband's battle with FTD, founding the organization, and the continuing need for support and education. Beth Walter followed with her family's story—her husband, his two brothers, his mother and his aunt all affected with FTD/ALS—and where the organization stands today with respect to growth, research and accomplishments. Finally, incoming Board Chair Jary Larsen shared his family's story battling an inherited form of FTD. Jary looked to the future with hope and a promise to families that the organization will continue its work until a cure is found.

As guests left the event, they received a very special favor—a small jar of Bill's BBQ Sauce with a custom label including the Care & Cure event logo. The Fehon family of Philadelphia makes this sauce, a homemade recipe of Bill Fehon who has been affected with FTD for several years, and sells it in 15 stores in the Philadelphia area and on Amazon.com. The Fehons donate 10 percent of the profit to AFTD.

Many thanks to those who supported this event in big and small ways. It was a great night. 



↑ *Current AFTD Board Chair Beth Walter, incoming Board Chair Jary Larsen and AFTD Founder Helen-Ann Comstock*

AFTD *presents* Care & Cure *An Evening to Celebrate a Decade of Dedication*



↑ *AFTD Board Member Sylvia Mackey with her two daughters, Laura and Lisa*



↓ *AFTD Board Member Pop Shenian, his mother Joyce and sisters Lauren and Joy*



↑ *Presenting Sponsors from Colonial Electric - Jay, Steve and Joe Bellwoar*

← *The Dalesandro family: Daniel, Bryan, Stephanie and Scott*




→ *Jason Fehon with his mother Diane who created the night's Bill's Best BBQ Sauce favors*

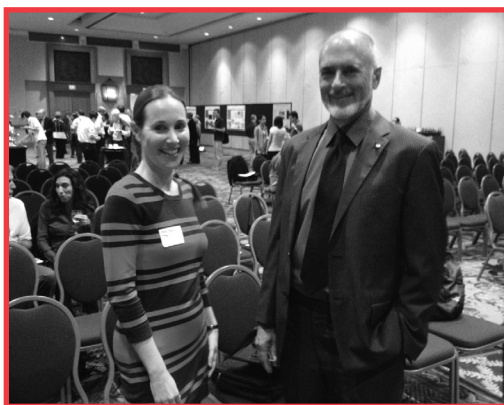


↑ *Helen-Ann Comstock, Dr. John Trojanowski, Dr. Virginia Lee, Dr. Murray Grossman and Susan Dickinson*

AFTD Co-Hosts Scientific Symposium with ALS Association

On Monday, October 15th, in conjunction with the international Society for Neuroscience meeting in New Orleans, LA, AFTD co-hosted an evening symposium with the ALS Association to highlight the latest findings on the newly discovered *C9orf72* mutation. This mutation, discovered last year by several scientists, including AFTD Medical Advisory Council (MAC) member Dr. Rosa Rademakers and other AFTD MAC members, is responsible for the majority of genetic cases of both FTD and ALS (amyotrophic lateral sclerosis or Lou Gehrig's disease). Speakers included Dr. Rademakers of the Mayo Clinic in Jacksonville, who provided more detail about the molecular nature of the

mutation; Dr. John Ravits of UCSD, who put forth the theory that the major difference between FTD and ALS is the location in the brain of the cells affected by the mutation; Dr. Clotilde Lagier-Tourenne of UCSD, who described a theoretical strategy for treating the disease that involves targeting for destruction the genetic instructions generated from the mutated gene; and Dr. Maurice Swanson of the University of Florida, who described what has been learned in myotonic dystrophy—a disease caused by a similar type of mutation. An audience of about 150 scientists attended along with AFTD's Scientific Director and two members of the AFTD Board of Directors. 



Dr. Rosa Rademakers and AFTD Board Member John Whitmarsh, Ph.D. at the C9orf72 Symposium in New Orleans.

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In lieu of flowers...

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

International Conf. *(continued from page 1)*

called an “expanded repeat” mutation. Investigators reported at the meeting that the number of times this sequence is repeated can be different from one cell type to another even in the same person. The implications of these different mutation lengths in different cells is not yet clear, but this phenomenon is also seen in other diseases caused by expanded repeats. Investigators also presented evidence that the mutation may have first arisen in a single person about 6,000 years ago. Testing for the *C9orf72* mutation is not available yet on a commercial basis, but efforts to develop such a test are under way.

From a therapeutic standpoint, investigators described a variety of experimental approaches from the use of neurofeedback to treat emotion recognition to the development of small molecule drugs to treat the underlying causes of FTD. Specifically, Dr. Thierry Hergueta of France demonstrated that eight people with FTD showed improvements in depression, impulsivity, attention and empathy after six sessions of neurofeedback and also demonstrated that the technique could be helpful for treating stress and anxiety in caregivers. Dr. Jon Tinsley of British biotechnology company Summit PLC discussed a new drug in development that would target abnormal build-up of the protein tau, which underlies a little under half of all FTD cases and most Alzheimer’s disease cases. Dr. Louis De Muynk of Belgium described his efforts to screen for compounds that could trigger increases of the progranulin protein, which is too low in people who have behavioral variant FTD due to a genetic mutation in the *PRGN* gene, and finally, Dr. Illana Gozes of Israel showed that the drug Davunetide, in testing in the U.S.

by Allon Therapeutics for progressive supranuclear palsy, may work by restoring transport of proteins down the long nerve cell axons.




Dr. Mario Mendez of UCSF speaks to caregivers of the 8th International Conference in Manchester, England.

More than 350 scientific posters were on display during breaks in the oral presentations, providing the poster authors with an opportunity to discuss their findings with other participants.

In addition to the scientific sessions, nearly 100 caregivers attended a full-day program focused on their needs for information. This provided the opportunity for some of the leading researchers to present their work directly to family members.

An additional meeting convened 30 representatives from caregiver organizations in 11 different countries. Discussion here focused on potential development of an international patient registry as well as other ways these groups can work together to share resources and information.

At the end of the meeting a biotech company based in Singapore, TauRx, issued a press release announcing that they have garnered approval from both the FDA and the European EMA to conduct a phase 3 clinical study of their compound LMTX® in behavioral variant FTD patients. As of today, no clinical sites in the US have approved participation in the study; AFTD expert advisors tell us that it may be about six months before any U.S. sites are ready to enroll patients. AFTD will stay apprised as the trial makes its way through the approval process at U.S. sites. Caregivers and patients can see a description of the trial (and in the future a list of participating clinical sites) at www.clinicaltrials.gov -- search on “TRx0237.” 

Thoughts on Care & Cure Event from Elaine Rose

Mingling at AFTD's Care & Cure event was as warm and fuzzy as it gets. The high spirits, great food and drink, a 52nd floor venue with a killer view and the up-tempo piano in the background set the mood. We were all celebrating 10 years of AFTD's amazing growth – together with staff, rank-and-file volunteers, board members, researchers, physicians, patients, family members and friends. That party reinforced for me how right it is that when I count my blessings, AFTD is always near the top.

My husband was diagnosed with bvFTD in 2007. "He's a little goofy," I told the marketing person at the residential facility where he now lives. I may have understated it somewhat. But compared to the experiences of so many other spouses, children and parents of people with FTD whom I had encountered since his diagnosis, "a little goofy" about covered it.

Of course, five years later, his condition has progressed, and it has broken our hearts. But along the way, there has been AFTD with its excellent progress. Like a beacon, they have produced a steady, thoughtful offering of information, connections and insight into care, research and the hope for treatment and a cure.

I first encountered AFTD at a conference in a downtown Baltimore hotel soon after Bob's diagnosis. The event wrapped up with a gathering where we mingled over wine and cheese. The people I met were so warm and willing to reach out to me. They knew what I was up against, and the most extraordinary

“Along the way, there has been AFTD with its excellent progress. Like a beacon, they have produced a steady, thoughtful offering of information, connections and insight into care, research and the hope for treatment and a cure.”

-- Elaine Rose

thing was this -- they were worried about me. I left feeling not only informed, but nurtured. They planted a seed of strength in my heart that I have been cultivating ever since. Most importantly, I left knowing I wanted to be a part of it.


I offered to volunteer and was tapped to do writing for the newsletter and the website. A former feature writer for general interest publications, I soon came to appreciate the

professionalism of Susan Dickinson, Sharon Denny and their cohorts. There was always an imperative to blend the science of the topics with the humanity of the issues. I had to be on my journalistic toes.

Meanwhile, I discovered another source of help in the world of support groups. My first meeting was with a group I attended by telephone sponsored by AFTD. Caregivers from all over the country were on the line. It was facilitated by an AFTD volunteer. Once again, the organization brought something unique to me and to the others on the call. That group and another

that I attended in Baltimore inspired me to start a group for caregivers who lived closer to where I live. With the help of the staff at my husband's facility, and with the support of tons of hand-outs and materials from the AFTD office, that group launched and has been added to the growing list of FTD support groups.

I have been a part of countless volunteer organizations, professional and religious, but none carried with them the gravity of these groups. This is not committee work. And it isn't group therapy either. I drew on the example of caring that I saw modeled at that AFTD conference in Baltimore to become a helpful group member. First listen. Mix compassion with information. Give reassurance that they are not alone but also offer a reality check about how to cope. Remind them that care giving is exhausting and dangerous. Help them understand how to take care of themselves. Vent. Laugh. Cry. Then come back together a month or so later and do it again.

AFTD has grown and so have I. Their 10-year anniversary coincides with my husband's 63rd birthday and the 6th year of his diagnosis. In AFTD's 10 years, my children have grown from high school and college students to adults who have seen their father deteriorate. How awful for all of us. And yet, what a blessing to have AFTD standing ready to buoy us up with its science AND its humanity. It is a cause for celebration for sure. 



Elaine Rose

Contributor Elaine Rose is a writer and caregiver to her husband with FTD.

A New Resource on FTD Genetics


Understanding the Genetics of FTD is a new publication by The University of Pennsylvania Center for Neurodegenerative Disease Research, in collaboration with AFTD. The booklet provides current and reliable information on the role that genetics plays in FTD, the genes that have been associated with hereditary FTD, and genetic testing. The booklet's completion was delayed to include information on the *C9orf72* gene mutation discovered in late 2011.

For the majority of people diagnosed with FTD, there is no family history of the disease and genetics is of little concern. However, people who have a relative somewhere in the family tree diagnosed with Alzheimer's, Parkinson's, ALS, FTD or another neurodegenerative disease may face nagging questions about potential risk. The new booklet helps individuals understand the landscape of FTD genetics and how doctors and genetic counselors can assess risk to family members.

According to the publication, approximately 40% of individuals with FTD have a family history that includes at least one other relative who has or had a neurodegenerative disease. A genetic cause can be identified as the likely cause of the disease in approximately 15-40% of all FTD cases.

Both inherited and sporadic FTD (where no family history is identified) have the same clinical symptoms, which makes evaluation of the family history a critical tool for determining the likelihood of a genetic cause.

AFTD has updated and expanded the genetics section of its website to reflect information in the new booklet. An article for families who have children or teens has been added and additional resources specific to genetics are described on new pages in this section. Children know that they can "catch" some illnesses or that some diseases "run in families." AFTD's booklet *What about the Kids?* and the Talking about Genetics with Children page on AFTD's website can help parents feel ready to discuss these questions when their children raise them. Among the new resources are links to the US Surgeon General's Family History Initiative, an online tool for gathering family information, and the Genetic Information Non-discrimination Act (GINA).

To download a .pdf of *Understanding the Genetics of FTD*, order a print copy of the booklet, or access new material on genetics visit AFTD's website: <http://www.theaftd.org/frontotemporal-degeneration/genetics> 

AFTD Volunteer Program Launched

AFTD's lead volunteers took center stage on Saturday, October 20th to kick off an invigorated volunteer program. AFTD's new Volunteer Manager, Kerri Barthel, facilitated the all-day meeting with the assistance of Rita Stevens, Business Consultant, Planning Matters LLC. Board members, regional coordinators, support group leaders and other lead volunteers from across the United States and Canada were in attendance.

The day was filled with collaboration, team building and information sharing. Volunteers heard from AFTD Program Director Sharon Denny on the volunteer structure today and its future direction. Kerri addressed the initial priorities of expanding the program's volunteer capacity and maintaining fidelity to the organization's mission, vision and values. Volunteers received concrete tools to use back home in their regions, including position descriptions and a volunteer manual.


Regional Coordinators Jenny Hinsman and Susan Eissler presented their experience with an outreach pilot project specifically geared

toward educating community health providers about FTD. Together, they reviewed the process for the pilot along with its outcomes and lessons learned. This outreach project will be expanded to each region of the US and to Canada as one way for volunteers to engage in awareness activities and build a wider infrastructure of people advancing AFTD's mission. More such projects will be developed in the coming months.



(back to front) Regional Coordinators Sue Gustafson, Jenny Hinsman, Carol Maglich, Brock Lacy, Susan Eissler, Volunteer Manager Kerri Barthel, Lorrie Cox and Katie Brandt

The volunteers brought a wealth of experience, passion and insight. During group discussions throughout the day, they shared their ideas and hopes for the future of the volunteer program.

Everyone left at the end of the day with a sense of direction and organization, enhanced support and guidance from AFTD, specific goals to achieve and a new sense of motivation to work collaboratively towards structuring and strengthening the volunteer network. AFTD is very excited to be moving the volunteer program forward and is grateful to the volunteers who willingly gave their Saturday to learn and share. 

Advocacy: Taking it to the Hill to Meet Our Families' Needs

The National Alzheimer's Project Act: From Legislation to Enactment

The United States Federal Government has put Alzheimer's and related dementias on notice: your days are numbered. In January 2011, President Obama signed the National Alzheimer's Project Act (NAPA) into law, establishing the National Alzheimer's Project under the Office of the Secretary of Health and Human Services (HHS). The ultimate goal of this project is to effectively treat and prevent Alzheimer's disease and related dementias by 2025. According to NAPA the related dementias include: frontotemporal, Lewy body, mixed, and vascular dementia which are collectively referred to as ADRD (Alzheimer's disease and related dementias). NAPA gives HHS the authority to oversee all federally funded efforts related to ADRD and coordinating these efforts to end ADRD by 2025. The National Alzheimer's Project offers a partnership between all the agencies in the federal government and any interested party from the private sector willing to take on the challenge of curing these diseases and providing care for those affected. AFTD has been advocating for NAPA to address the needs of our related dementia community, and offered our hand as a partner to ensure the ultimate goal of NAPA is accomplished for FTD as well as Alzheimer's.



The National Plan to Address Alzheimer's Disease: The Guide to Action

In May 2012, HHS established the Advisory Council on Alzheimer's Research, Care and Services. The NAPA advisory council consists of at least 22 members, including 12 non-federal members representing private caregivers, state health agencies, private health care providers, non-profit advocacy and research organizations, and the remainder representing various federal agencies. The first council meeting convened on September 27, 2011 in Washington DC.

The Advisory Council's first task was to provide HHS with an evaluation of all federally funded efforts in ADRD research, clinical care and healthcare services, along with recommendations for priority objectives and strategies for improving and expanding these efforts. HHS released the first draft of this report on May 15, 2012 entitled "The National Plan to Address Alzheimer's Disease." The National Plan is the playbook by which the Alzheimer's Project will defeat ADRD by 2025. Opportunities and potential benefits for the FTD community can be found throughout the National Plan. One example that illustrates the magnitude of NAPA and the

potential resources the project can offer is the estimated \$2 billion needed annually for medical research on ADRD. HHS must update the National Plan annually, based on the success of NAPA and recommendations from the Advisory Council on new priorities and strategies. Each year, from now and until 2025, the Secretary of HHS will present an updated National Plan to Congress and the President and make any budgetary requests and approvals she determines are required in order to meet the all goals of NAPA.


The National Alzheimer's Project and AFTD: Our Past and Future Involvement

AFTD's interest in NAPA has been and will remain focused on ensuring that the needs of our related dementia community are heard by the advisory council and addressed in the National Plan. AFTD has been offering equal measures of constructive criticism and our input to the

advisory council since March of 2012, prior to the release of the current draft of the National Plan.

Our initial message in March was that adding more inclusive language to the National Plan clearly defining the related dementias would strengthen the plan and add more potential partners to the effort. In response, the term "ADRD" was explicitly defined as including FTD, among other diseases, and language clarifying the inclusive nature of the Plan was added. Since then one or more representatives of AFTD have attended two quarterly advisory council meetings and offered comments during the public input sessions. As a result, AFTD's Scientific Director Sharon Hesterlee has been asked to participate in a scientific workshop to address research priorities for the related dementias in the spring of 2013, and Program Director Sharon Denny gave input on the unique needs of FTD patients and families to a taskforce to improve care for special populations at the beginning of October.

Get Involved: How to Help AFTD Advocate for Your Needs

AFTD will continue to speak for the needs of those confronting FTD, but nobody can tell YOUR story as well as you can. Share your experience as a FTD caregiver with the Advisory Council by attending a quarterly council meeting and speaking during the public comments session, or submit your comments in writing prior to date of the meeting. Written comments may also be sent to HHS on an ongoing basis. Everything you need to know to participate can be found at the National Alzheimer's Project Act website. Please do not hesitate to contact us with any thoughts, comments or questions you may have at info@theaftd.org. 

THE AFTD-TEAM

Barry Marcus Rides Again for AFTD

For the second year in a row, Barry Marcus completed another 108-mile bike trek in Montauk, NY on June 16th. With the support of family and friends, Barry raised \$5,578 for AFTD. His wife, Susan is affected with primary progressive aphasia, and he rides in honor of her.



One Man, Two Fundraisers in Memory of Wife

Mike Kipp of Longview, WA raised money for AFTD on two different occasions this summer. Mike's wife Carole passed from FTD earlier this year. On August 16th, Mike sold some dolls from Carole's collection, along with several members of The Three Rivers Doll and Teddy Bear Club, to raise money for AFTD. The group raised \$725 for AFTD. The following month, Mike and a few friends participated in a walk. They wore their "AFTD-Team" t-shirts and bracelets and handed out AFTD brochures at the event. Mike raised another \$1,000 through his efforts.



8th Annual George F. Sidoris Memorial Golf Outing

The 8th Annual George F. Sidoris Memorial Golf Outing took place on July 28th at Lost Nation Golf Course in Willoughby, OH. This year, the golf outing—attended by 100 golfers and 20 more dinner guests on a beautiful Saturday—raised its largest sum to date with a donation to AFTD in the amount of \$13,200.



2nd Annual Al McNulty Benefit

The 2nd Annual Al McNulty Benefit for Dementia Research took place on September 15th in Overland, KS. Event organizer Joel McNulty, Al's son, put together a great night of live music, an auction and raffle for 40 supporters. The event raised \$415 for AFTD.

1st Annual Golf Benefit Honoring Cheryl Whitcomb

The 1st Annual Golf Benefit Honoring Cheryl Whitcomb was held on September 2nd at St. Denis Golf Course in Mentor, OH. Sisters Marianne Prentice and Marcy Feather organized the fundraiser in honor of their mother who suffers from FTD. The golf event—a four-person scramble with dinner and auction—raised \$2900 for AFTD.



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