AFTD
The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Volume X, Issue 3 Fall 2013

AFTD's Food for Thought Campaign Spreads Awareness Across the United States and Canada

From September 29th through October 6th, grassroots supporters of AFTD participated in the first-ever FTD awareness week across the United States and Canada. Fifty-six people from 25 states and 5 Canadian provinces hosted Food for Thought fundraising and awareness-raising events: from dinners in hosts' homes and community bake sales to online recipe web pages and dessert nights with silent auctions, people put their own special touches on the campaign involving food and FTD education. The goals of the campaign were to educate family, friends and community members about FTD, attract the attention of local media to the topic of FTD and raise money to support AFTD's mission.

At Susanna Foo Gourmet Kitchen: Philadelphia Food for Thought Co-Chair Bryan Dalesandro, Owner & Chef Susanna Foo, General Manager Gabriel Foo and Food for Thought Co-Chair Pop Shenian before the October 11th event.

AFTD provided each host with informational brochures, FTD awareness bracelets, a DVD of *It Is What It Is* (a documentary featuring four families' journeys with FTD) and an AFTD-Team t-shirt. A Food for Thought toolkit for event hosts was available on AFTD's website, along with the opportunity to create a Givezooks! fundraising page for people who may not be able to attend an in-person event.

(See Food for Thought, pages 4-5)

Inside This Issue

Get Involved! *Advocate for FTD in Your State*

In response to the National Plan to Address Alzheimer's Disease and the call for individual states to take ownership of creating an Alzheimer's and Related Disease Plan for their respective state, AFTD has taken the initiative to create a document entitled "AFTD Guidance for State Alzheimer's Plans." This Guidance identifies the primary challenges for people coping with an FTD disorder that are substantially different from Alzheimer's disease and need to be addressed by a state plan in order to be truly inclusive of FTD. It also emphasizes the importance of having representatives from the FTD and other dementias population included in the creation of these plans.

"This is a huge step forward in ensuring that FTD and related disorders have a voice in each state's Alzheimer's Plan," said AFTD Executive Director Susan Dickinson. "As the country's resource for FTD information and support, AFTD decided that creating this document as an aid for those drafting state plans was a priority for our organization and the community we serve."

AFTD is looking for help educating state and local governments about the needs of people living with FTD and advocating for those needs to be addressed in state Alzheimer's and Related Disease Plans.

(See Get Involved, page 10)

Spotlight On...Deanna Angelo, AFTD Board of Directors

Deanna Angelo

August 3, 2009 was a dark day for Deanna Angello and her family. It was the day that changed her life forever. It was the day she heard the words "frontotemporal dementia" as her father's diagnosis.

For two years, Deanna could not speak about what was happening to her dad, even to her closest friends. As a business professional in the pharmaceutical industry, Deanna had hoped that her experience and connections would provide the answers she needed to save her dad from FTD.

"I quickly learned that despite the research being done, a cure does not exist for FTD at this time," said Deanna. "And that's when I refocused my energy: If a cure does not exist, then we must work to find one. That takes research…research takes money. So I will raise money to fund FTD research."

Deanna joined AFTD's Board of Directors in 2012, and shortly thereafter, she set a personal goal: to raise $50,000 to support AFTD's mission in honor of her father. Deciding how she would fundraise was an easy choice for the woman who attributes her athleticism to her dad—she would run, climb, swim and bike her way to the goal she set. In the last 18 months, she has raised almost $30,000 and will keep going until she reaches her goal.

In 2012, Deanna ran the New York City Half Marathon, climbed to Base Camp of Mt. Everest, participated in both the New York City and DC triathlons and ran in the Army 10-Miler. This year, she competed in the Mt. Tremblant Half Ironman in Canada, the New York City Triathlon, the Hamptons Half Marathon, the Army 10-Miler and the New York City Marathon.

"All the training, the physical and mental effort, the pain, the sacrifices...they were all worth it," said Deanna. "My dad is the inspiration behind each endurance event, and he's the reason I finish each one."

As an AFTD Board Member, Deanna has seen the progress in FTD research that has been made possible with the funds raised through AFTD.

"It's encouraging to know that more researchers are seeing the importance of studying FTD and making strides towards drug development," said Deanna. "Every new discovery brings us all closer, but there's so much more that needs to be done. I'm just trying to do my part."

AFTD News Briefs

AFTD's first postdoctoral fellow, **Todd Cohen, Ph.D.**, recently secured an assistant professorship with his own lab at UNC-Chapel Hill. Congratulations, Todd!

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AFTD's latest annual report has recently been released. To review the last fiscal year's accomplishments, visit the annual report page of AFTD's website.

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Save the Date! **The 9th International FTD Conference will be held from Oct. 22nd-25th in Vancouver, British Columbia.** AFTD will once again be a sponsor of the event, which includes three days of scientific reports and one day for caregivers. For more information, visit www.ftdvancouver2014.com.

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Two new support groups have begun, in Bayshore, NY (Long Island) and Salt Lake City, UT (this group meets in the evenings). For a complete list of support groups, visit the regional page on AFTD's website.

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On October 1, online radio host **Lori La Bey of Alzheimer's Speaks** interviewed AFTD Executive Director Susan Dickinson along with FTD caregivers Cheryl Sparks and Paul Lester about what FTD is, the caregiving challenges it presents and the importance of more research. The recording can be found on Alzheimer's Speaks website.

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Registration for **AFTD's Education Conference and Annual Meeting** will open in late December on AFTD's website. The conference will take place in White Plains, NY on March 14th and feature a Keynote Address by former NBC News Senior Medical Correspondent Robert Bazell.

IN THE SPIRIT OF THE SEASON, PLEASE GIVE!

"I was blessed to find AFTD's website, and it has been my source of information and lifeline for the past six years." -- Lucy Carter, caregiver

Your tax deductible donation enables AFTD to:

- Fund an IT healthcare project - an online, video-chat speech language therapy tool for PPA
- Coordinate and support a network of 73 independent support groups
- Educate staff at care facilities through **Partners in FTD Care**
- Create a website to support kids who have family members affected by FTD
- Support our nationwide Food For Thought Awareness event

Thank you for making a difference in the lives of those fighting this disease!

To make your gift online, go to www.theaftd.org

AFTD Awards Pilot Grant to Dr. Emily Rogalski

Dr. Emily Rogalski

AFTD proudly awards the 2013 AFTD Pilot Grant to Dr. Emily Rogalski for her project ***"Internet-based speech therapy: Improving quality of life and access to care."*** Dr. Rogalski's proposal was chosen from a field of 42 applications received by AFTD this year.

One goal of Dr. Rogalski's project was to improve access to therapy by providing Internet-based, video-chat, speech therapy sessions. With this pilot grant award, Dr. Rogalski and her colleagues will create a user-friendly web portal for the video-chat therapy sessions, homework assignments and follow-up to assess the benefits of this type of online speech language therapy. The web portal will be individualized for each patient and the home exercises will be personalized in order to improve patients' functional communication skills. The results of the study will be used to make recommendations to speech and language therapists who treat primary progressive aphasia (PPA) and to explore the feasibility of using web-based, video-chat therapy.

PPA is a degenerative FTD disorder in which language disturbance—aphasia—is a key feature. There are no effective medications to treat PPA, but research suggests that speech therapy may allow people with PPA to communicate more effectively throughout the duration of their illness and thus contribute to improved mood, promote independence and enhance their overall quality of life. However, access to speech therapy is limited, as therapists experienced in working with PPA patients are often restricted to specialized centers.

Dr. Rogalski has a Ph.D. in neuroscience and is an assistant professor at Northwestern University in the Cognitive Neurology and Alzheimer's Disease Center.

Food for Thought

(Continued from page 1)

The success of the campaign is due in large part to four amazing Food for Thought Volunteer Liaisons: Vikki Indermuehle, Zoy Kocian, Ashley Linsmeier and Jan Sharp. These energetic women worked closely with AFTD to provide support to each event host, answering questions about Food for Thought and providing materials to make the organization process run smoothly.

"The amount of helpful information and materials provided was fantastic; the support by Zoy was great; and the event t-shirt, bracelets and brochures were amazing!" said event host Hillarie Higgins of Madison, WI, who held an outdoor bake and crafts sale in honor of her mother.

Eugenia Thornton of Frederica, DE learned of her husband's FTD diagnosis just a few weeks before the awareness week took place. She put together a fundraiser at Cowboy Up Saloon, spoke with three local newspapers, and had more than 100 attendees at her event. "I was overwhelmed with the support in my community, especially from the press," said Eugenia.

On October 11, AFTD held a culminating Food for Thought event outside Philadelphia at Susanna Foo Gourmet Kitchen. Approximately 140 people enjoyed delectable food stations, a silent auction and an inspiring speech by Honorary Chair, Phil Martelli, famed Head Basketball Coach of St. Joseph's University in Philadelphia.

At the time of the printing of this newsletter, the grassroots campaign and the Philadelphia Food for Thought event each raised approximately $50,000 in support of AFTD's mission. AFTD would like to thank each event host, the Food for Thought Volunteer Liaisons, our corporate sponsors and all who attended or donated to an event. AFTD shares the success of the first Food for Thought campaign with all of you!

Ashley Linsmeier – Florida

Bev DeRusha – Alberta, Canada

Bonnie Shepherd – Utah

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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 the AFTD website. All donors will receive letters of acknowledgement and families will receive a list of donors. To contribute electronically via our website, go to www.theaftd.org.

PA Representative Meehan's FTD Statement on the Congressional Record

On October 3, 2013, Representative Patrick Meehan (R PA-7) entered a statement about FTD into the Congressional Record. The congressman urged his colleagues in the U.S. House of Representatives to learn more about FTD in order to help constituents struggling with the disease or caring for a loved one and to support medical research on the causes, treatments and cure for FTD. AFTD is extremely grateful to Congressman Meehan, whose district includes Radnor where the AFTD office is located, for his support of our work and for submitting his statement during AFTD's first annual Food for Thought Week, in spite of the fact that the federal government was partially shut down. To read the congressman's statement go to: http://ow.ly/qmdZE

Your Pharmacist: An Important Member of the Care Team

by Laurel Cox

My career in pharmacy has taken on additional value because of personal experience as a family member of someone diagnosed with FTD. People with FTD and their caregivers have a hard enough time dealing with the life adjustments. It can be overwhelming to find the additional energy needed to master the medications. Knowing how to utilize resources, such as your doctor and pharmacist, in the most effective way will allow you to focus on the many other demands for your time and attention.

The doctor is the key to correct diagnosis and management. The pharmacist is an important part of the healthcare team and can be an asset to managing care. In addition to dispensing prescription medication, the pharmacist can also provide information about the drugs and explain doctors' instructions so that the individual can use these medications safely and effectively.

You can make the prescribing doctor's job easier by considering some of the following suggestions:

Go to one pharmacy only. This allows a collaborative relationship between the doctor and pharmacist to watch for side effects, drug interactions and possible medication adherence issues. Some of the medications and/or unusual dosing will raise red flags for the pharmacist. Explaining the diagnosis for FTD should help them tailor their monitoring to fit your loved one's situation.

The pharmacist can do a lot for you in addition to filling medications. If your loved one ends up on a complicated drug regimen, they can help with suggestions on spacing and time frames between medications that you may have difficulty coordinating. They have the training and experience to know what medications can be taken at the same time, with or without food, and which require strict spacing. If your loved one misses a dose and you don't know if you should skip or try to catch up, they can answer that question.

The doctor is the key to correct diagnosis and management. The pharmacist is an important part of the healthcare team and can be an asset to managing care.

One option for organizing a drug regimen is to use a medication regimen table. This essentially is a pill box on paper. It will assist you in filling their pill box by organizing the time frames and how the medications should be taken. Bring this with you to your pharmacy when you have a new medication added or a dosing adjustment and they should be able to help you incorporate it in the best way possible. If you have a very busy pharmacy, call ahead to set up an appointment for some help and explain why. Remember communication is the key to any relationship. Some pharmacies also have a bubble pack service that provides pre-packaged, individual dosing that could eliminate confusion or stolen medications when introducing new caregivers into your life.

Side effects from medications are another complicated thing for caregivers to manage. A common question when this occurs is "Is this the disease progressing or is this a side effect?" Whatever you do, try to take notes. When did the person start the new medication? When did you first notice the changes? What makes it worse or better? If an uncommon twitching or physical manifestation begins, please consider videotaping it. When life's drama peaks it can be the hardest time to think *get the smart phone or video camera and record this.* But sometimes that can make the difference for the healthcare professionals with diagnosing or determining if this could be a side effect or disease progression.

Also keep in mind that over-the-counter medications, herbal supplements, alcohol and some dietary factors such as grapefruit can play into the drug interaction picture as well. Keep these in mind when taking your notes for the healthcare provider's review

As a pharmacist with a father-in-law living his way through FTD, I have helped his caregiver, my mother-in-law, implement many of the above suggestions. We have re-worked his medication regimen many times. I have evaluated new behaviors or symptoms against the medication regimen for the possibility of side effects. Sometimes she just asks me if a pill can be split in half or not. Your pharmacist can help you in this manner as well. It is important for you, as a person with FTD or their caregiver, to have as much support as possible. Remember, the pharmacist is someone with particular expertise and ability to simplify one part of the experience.

Laurel Cox, Pharm.D, R.Ph, is a pharmacist in Oregon. Her father-in-law is affected with FTD.

FTD Symptom or Pain: *How Can You Tell?*

Behavior changes are a hallmark of someone with FTD, but underlying health issues can also prompt changes in behavior. As you investigate what is causing new behaviors, consider this – the person could be in pain.

When pain or another condition is driving behaviors, it is a challenging scenario. Someone with Alzheimer's disease (AD) who has a sore foot or muscle will stop walking. But the compulsive behaviors common with someone with FTD will keep them on their feet in spite of the pain. People with AD typically retain a range of facial expressions. FTD patients may not show emotion or have the ability to communicate.

It is challenging for both family and professional caregivers to determine if pain has prompted new behaviors, but not impossible. Some common sense approaches and careful observation can help solve the mystery. One strategy is to anticipate that conditions, like arthritis or an infection, may develop. Remember, one illness, like dementia, does not preclude the onset of another.

If the person is verbal, ask them how they feel but avoid asking "yes" or "no" questions. Asking the question "Is something hurting you?" may not be as helpful as saying "show me where it hurts." While helping them with personal care, check for range of motion in arms and legs and check their skin and feet for signs of sores or blisters. Resistant behavior could mean it hurts to move in certain ways. If acetaminophen use is approved by the doctor, treat them with acetaminophen and observe to see if their behaviors improve.

Include physical, occupational or speech therapies in pain evaluation and treatment. A therapist can introduce exercises, heat and cold treatments, massage, positioning, transfer techniques and devices to help with mobility.

Don't discount vague reports from family or care providers that something is different or not right. Ask them to look back in time; incremental changes may not be noticed day to day. This is particularly important following an incident such as a fall as there may be injury or pain that has not been addressed.

It is a study in trial and error, but careful observation and these common sense approaches can reap rewards. For more information, see AFTD's **Partners in FTD Care** handout on *"What to do About..." Evaluating and Managing Pain*.

Giving a Hand to Our Helping Hands!

by Rachael Baffa

Across the United States and Canada, there are volunteers for AFTD that share common and persistent goals of raising awareness, gaining understanding and supporting the fight against frontotemporal degeneration. AFTD genuinely values our volunteers and their involvement and dedication to help people affected by FTD.

AFTD Volunteer Brianna Sullivan

A reliable and responsive intern, Brianna Sullivan, works remotely from Boston, where she analyzes data from the AFTD HelpLine to obtain a better understanding of who is contacting AFTD and for what reason they are getting in touch with the association.

Pursuing her Master's Degree in Public Health at Boston University, Brianna originally planned on working with organizations that provided mental health and social support to low-income mothers suffering from anxiety and depression. However, in 2010, Brianna became all too familiar with FTD when her father was diagnosed.

"Processing his diagnosis and dealing with all of the challenges of having a father with FTD was hard enough," stated Brianna. But when complications arose and her father suddenly passed away, Brianna recalls losing all sense of drive, motivation and inspiration. Brianna also remembers feeling a strong sense of isolation because the diagnosis is so rare.

While trying to get her life back on track last summer, Brianna "stumbled upon the volunteer form on the AFTD website," just as the association was rolling out their first official graduate-level internship program. Some people believe in the saying "perfect timing," and for Brianna—and AFTD—the timing couldn't have been better.

"Information from a regular volunteer form leads us to projects that are wonderfully, mutually beneficial," said Sharon Denny, Program Manager. Brianna's evaluation of the HelpLine allows AFTD to learn more about the service and the needs of the FTD community via the retrieved data.

As the FTD population grows, so does the need for innovative volunteers that are as intellectually curious as Brianna. Brianna believes that "compassion for people and families affected by FTD and some free time – even if just a few hours a week – are really valuable assets in and of themselves."

Rachael Baffa, whose father is affected with FTD, is a volunteer writer for AFTD.

Get Involved!

(Continued from page 1)

Thirty states currently have an Alzheimer's and Related Disease Plan, but 14 of them were published in 2010 or earlier and may be due for an update in the near future. Another 11 states are actively developing a plan, (see table below) including Pennsylvania, which began the process in June 2013 and provided the impetus for AFTD to become more directly involved.

Published Alzheimer's and Related Disease Plans by State/Government and Publication Year.

HAS PLAN		**DEVELOPING PLAN**	**NO PLAN**
YR Pub	**30 States**	**13 States & DC**	**7 States & 5 Territories**
2007	ND	AK, AZ, DE, HI, MS, NE, NH, NJ, NC, OH, PA, RI, Washington DC, WI	American Samoa, CT, GA, KS, MT, Northern Marianas Islands, Puerto Rico, SD, US Virgin Islands, WA, WY
2008	IA, KY, MI, VT		
2009	IL, LA, NY, OK, SC, TN		
2010	CO, MO, TX		
2011	AR, CA, MN, VA, WV		
2012	ME, MA, OR, UT		
2013	FL, ID, IN, MD, NM, NV, RI		

Since August, AFTD's Guidance document has been used by people involved in state plans in Maryland, Illinois, Utah, Texas and Delaware. Because AFTD's Guidance document was created for a plan that does not yet exist, it can be used, with little or no revision, in any state that does not have an Alzheimer's plan. In states that do have a plan, the Guidance can still be used in a variety of ways, depending on where the state is in the process of implementing or updating its plan.

This leaves 26 plans that have not benefitted from AFTD's Guidance—and your help is needed to get this document into the right hands for the greatest impact. AFTD has created some simple steps (posted on the website at: http://ow.ly/qonIf) that anyone can follow to find out more about their state's plan (or lack thereof) and find the right person to receive "AFTD Guidance for State Alzheimer's Plans" so that it can be included in an Alzheimer's and related disease plan. You can download an electronic copy from AFTD's website at http://ow.ly/qoogL or call (toll-free) 1-866-507-7222 to ask for a hardcopy to be sent by postal mail.

If you are interested in getting involved to ensure your state has an Alzheimer's plan that addresses issues especially relevant to FTD, contact Matt at 267-514-7221 ext. 2529 or msharp@theaftd.org. If you have been involved with developing a state Alzheimer's plan, AFTD would appreciate hearing from you about the experience and your thoughts on how to use AFTD's Guidance most effectively.

AFTD's "With Love" Campaign 2014 is Almost Here!

In January, AFTD will launch its third annual "With Love" campaign. For the past two years, more than 35 AFTD supporters have helped raise $85,000 with this Valentine's Day-centered campaign.

Again this year, we encourage the AFTD community to share their own "With Love" story—their personal journey with FTD. For many, FTD steals the ability to express emotions and convey feelings with their closest family and friends. Despite the many things that FTD takes from an affected person, there are many courageous, enduring and beautifully defiant stories of love within the FTD community.

AFTD's
With Love
Campaign 2014

If you have a story to tell, please take part in raising awareness and funds to support AFTD's mission. For more information on setting up your own personal fundraising web page, visit http://theaftd.givezooks.com/campaigns/with-love-campaign-2014

THE AFTD-TEAM

Memory Lanes: Bowling to Strike Out Pick's Disease

On July 21st, Casey Greemore and Nicholas Krapelin hosted a bowling event at Merrimack Ten Pin in Merrimack, NH to benefit AFTD. Casey's mom, Lenora, was diagnosed with FTD in 2012. The event raised $1,500.

George F. Sidoris Memorial Golf Outing

The brother-and-sister duo of George and Christine Sidoris held the 8th Annual George F. Sidoris Memorial Golf Outing in memory of their father on August 17th in Willoughby, OH. This year's event raised more than ever before, with a total of $16,500.

Help Josh Find a Cure for FTD Golf Outing

The Pierce family after the golf outing.

Don Pierce held the first Help Josh Find a Cure for FTD Golf Tournament in Lemont, IL on August 2nd in honor of his son, Josh, who is affected with FTD. The event, which was held at the Ruffled Feathers Golf Club, drew 140 golfers and 200 attendees for dinner and netted $15,900 to benefit AFTD. An article ran on DailyHerald.com about the event as well.

Untouchables Car Show

On August 18th, Mike Kipp and Peggy Richter participated in the Untouchables Car Show in Kalama, WA where they held a raffle to raise money for AFTD and collected $1,064 in donations.

6th Annual Quest for the Cure Golf Outing

The last hole at the Quest for the Cure.

The Walter Charitable Fund, led by former AFTD Board Chair Beth Walter, held the 6th Annual Quest for the Cure Golf Outing on September 16th in Sacramento, CA. Topping all previous years, 124 golfers joined the Walter family to raise $35,000.

Philadelphia Art Show Open House

On October 5th-6th, Philadelphia resident Addie Kaplan held an art show open house to sell some of her husband's paintings. Patrick Ross Arnold, a former art professor, is now affected with FTD. The sale generated $1,448 for AFTD's mission.

Body of Work – Art Show

Amanda McDorman hosted an art show of her mother's work on October 12th in Newport Beach, CA. Mary Kathleen Turner was an accomplished artist before becoming affected with FTD. The show raised more than $11,550 for AFTD.

Shoot for Scooter Golf Outing

In a departure from the past three years, the Scaggs and Sealfon families have taken the 5K walk/run known as Scoot 4 Scooter and turned it into Shoot 4 Scooter in 2013. On October 20th, the members of Dave Scaggs' family chose to honor him with a golf tournament. The event, which raised $5,000 for AFTD, brought out 39 golfers and 75 attendees for dinner.

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