



# The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

Volume IX, Issue 2

Summer 2012

## FTD Meeting Builds Momentum in Drug Development

**A**s drug companies frustrated with the high failure rate of therapies in Alzheimer's disease eye the FTD population as a better proving ground for anti-dementia drugs, FTD researchers and clinicians convened in Washington, DC on June 4th to ensure that those companies would not be disappointed. Close to 70 experts spent the day considering how best to design clinical trials of new therapies for FTD, keeping in mind the "lessons learned" from other disease areas and seeking input from federal regulatory agencies.

Sponsored by the National Institute of Neurological Disorders and Stroke and AFTD's Frontotemporal Degeneration Treatment Study Group (FTSG), speakers included representatives from the academic world, the National

*"This is the kind of coalition that we need if we are to discover effective treatments for FTD. The initiative has now gained real momentum."*

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

Institutes of Health, the Food and Drug Administration and the corporate world of biotechnology and pharmaceutical companies. The goal was to better understand how regulators like the FDA would view trials in FTD. Participants also sought to understand if FTD's status as a "rare" disease offered any benefits in the speed at which a drug could be tested.

"The meeting had a great collaborative spirit that led to a productive exchange of ideas and a punch list of what we need to accomplish to bring effective new treatments to our patients. All of us left the meeting energized and feeling optimistic about the progress we will make within the next year," said Dr. Adam Boxer of UCSF, Chair of the

FTSG Steering Committee.

*(see Meeting, page 4)*

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### FTD and Everest: Conquering Mountains

**A**s new AFTD Board Member Deanna Angello can attest, inspiration sometimes comes from the most unlikely places.

After she learned that her father had FTD in August 2009, Deanna, an employee of pharmaceutical giant Pfizer, was crushed to discover that not only was there no cure for FTD, but no treatments existed either. With overwhelming feelings of helplessness, Deanna took some time to process the new reality that her dad would not be the same man, mentor and hero that she had grown up knowing. And then she decided to venture out from the low-lying valley to tackle the mountain ahead—literally.

In the middle of February 2012, Deanna set up a Givezooks! fundraising page through AFTD. She set an ambitious goal of raising \$50,000 by year's end; in return, she promised to accomplish several feats of physical endurance that would challenge the fittest of athletes.



*Deanna Angello with  
Mt. Everest in the background*

*(see Mountains on page 5)*

## Spotlight On...Jary Larsen, Ph.D., AFTD Board of Directors

**A**s a neuropsychologist in the San Francisco Bay Area, Jary Larsen is no stranger to degenerative brain diseases. But while correlations can be made between his day job and his volunteer position as a member of AFTD's Board of Directors, his connection to the organization goes much deeper.

In 2006, Jary's brother was diagnosed with FTD. Because Jary's father, who had been diagnosed with Parkinson's disease, also displayed symptoms of FTD prior to his death, Jary sought out researchers who would be interested in including his large extended family in their FTD research. It was through participation in this research that the Larsen family learned that both their brother and father were carriers of the progranulin mutation, which was first identified as a genetic cause of FTD in 2006.

That same year, Jary attended the 5th International FTD Conference in San Francisco. Two years later, he was in Rotterdam for the 6th International meeting, where he met Helen-Ann Comstock and Susan Dickinson, founder and executive director of AFTD, respectively. Following that conference, they asked Jary to meet with them in Philadelphia, and in short order, Jary found himself on the planning committee for the 7th International FTD Conference held in Indianapolis in 2010.

"In the middle of planning for Indianapolis, I was invited to be on the AFTD Board of Directors," Jary said. "I had come to know so many people associated with AFTD, I knew it was going to be a rewarding experience."

Jary has served on several AFTD committees, including Research, Advocacy, Governance, and Audit. The bulk of Jary's committee work has been with the Governance committee, which he currently chairs.


"In the last two years, the Governance committee rewrote AFTD's by-laws to establish the transition from a volunteer-run organization to an employee-based organization" Jary said. "It's been heartening to see the organization grow and sustain itself."



*Jary Larsen*

As of April, Jary has a new title within AFTD: chair-elect. Next year, Jary will take the reins from current Board Chair, Beth Walter.

When asked what he sees for the future of AFTD, Jary said, "It's a very exciting time with regard to research. There have been many advances in understanding the genetics of FTD, most recently the discovery of the chromosome 9-linked ALS-FTD mutation. I am proud that AFTD provided early seed money in the form of a pilot grant in the search for this specific mutation. Breakthroughs like this recent discovery inform us not only about FTD, but also may give us a better understanding of other brain disorders.

"It's also great to see the organization growing and funding more research," Jary continued. "For a rare disease like FTD, awareness is so important...and we're making that happen." 

## AFTD News Briefs

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The **8th International Conference on FTD** will be held Sept. 5-7, 2012 in Manchester, England. AFTD is proud to be a major sponsor of the conference and the Caregiver Program on Sept 6. Visit the website at [www.ftd2012.org](http://www.ftd2012.org) for details.

.....  
There are **new FTD support groups** in the following locations: Toronto, Canada and Burlington, NC. Check AFTD's website for a complete listing of support groups.

.....  
On April 12, 2012, the Houston Area Frontotemporal Dementia Caregiver **support group celebrated its two-year anniversary** with Dr. Paul Schulz, Professor of Neurology, UT-Houston, giving a presentation on FTD to a packed audience of family, friends and medical providers of those diagnosed with FTD.

.....  
On Tuesday, May 15, 2012, the Department of Health and Human Services released **a plan to fight Alzheimer's disease** with some

specific goals to be reached by 2025. Related dementias, including FTD, as part of this plan as well. Look for more on this plan in the next issue of the newsletter.

.....  
**FTD made front-page news** in the Los Angeles Times and New York Times in February and May, respectively. Two affected families spoke with reporters and gained national attention for FTD. Visit the newsroom of AFTD's web site for links to these well-crafted articles.

# AFTD *presents* Care & Cure

*An Evening to Celebrate a Decade of Dedication*

Please join AFTD for our **10th Anniversary “Care & Cure” Event in Philadelphia on October 19, 2012!**

Mark your calendars and be part of an evening to celebrate a decade of dedication!

## What:

AFTD's 10th Anniversary Event

Enjoy music, an auction and learn more about AFTD's progress towards care and a cure. Speciality food stations provided by Suzanna Foo, Plate Restaurant & Bar and other local restaurants.

Cost: \$125/person

## When:

Friday, October 19, 2012

6:00 p.m. - 9:30 p.m.

## Where:

The Pyramid Club

1735 Market Street, 52nd Floor

Philadelphia, PA 19103

Presenting Sponsor:



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For more information, visit AFTD's Care & Cure Event page on our website. Questions should be directed to Pam McGonigle at [pmcgonigle@theaftd.org](mailto:pmcgonigle@theaftd.org).

## AFTD Brings Education Conference to Atlanta

On Friday, April 27, approximately 180 people attended the AFTD Education Conference and Annual Meeting at the Westin Buckhead in Atlanta, Georgia. AFTD partnered with staff of the Alzheimer's Disease Research Center at Emory University to provide local expertise on the topic of FTD. Conference sponsors included: Walter Charitable Fund, Alzheimer's Association, Emory University Woodruff Health Sciences Center, The Fountainview Center for Alzheimer's Disease and Novartis. AFTD Board Chair Beth Walter opened the conference with a welcome that included a special tribute by Margaret Boggs-Hatfield honoring Michelle Brown, former Executive Director of the Emory Medical Care Foundation and FTD patient. Dr. William Hu, assistant professor, Department of Neurology Center for Neurodegenerative Diseases at Emory, gave the clinical address entitled *FTD 2012: Progress and Challenges*.

AFTD designed four breakout sessions for conference attendees based on their loved one's stage of FTD:

- **Finding True North: Refocusing in Light of a New Diagnosis** – led by Susan Peterson-Hazan, MSW, LCSW, Emory ADRC Education Core Co-Leader; Eleanor Vaughan, caregiver, author of “The Gift of Now”
- **Holding Steady at the Helm: Caring and Coping with FTD at Home after Diagnosis** – led by Michelle Hammond-Susten, LCSW, Emory ALS Clinic Social Worker; Matt Sharp, M.S.S., AFTD Program Coordinator; William Hu, M.D.
- **Expanding the Crew: Partnering with Facility Staff in Residential Care** – led by Sharon Denny, M.A., AFTD Program Director; Andrea Kipples, MSN, BSN, Nurse Practitioner, Emory ADRC
- **Staying on an Even Keel: The Role of Hospice and Palliative Care in Late Stage Care** – led by Janet Cellar, RN, CNS, Emory ADRC Administrator; Nicole Yarab, RN, ALS Nurse Clinician, Emory ALS Center

(see Atlanta, page 6)

## Meeting *(continued from page 1)*

Additional meeting sponsors included the Agouron Institute, Alzheimer's Drug Discovery Foundation, The Bluefield Project, Omeros, The Tau Consortium, Lilly USA, Plexxikon and Bristol-Myers Squibb.

The need for such a meeting is clear. Running a clinical trial to approve a new drug is a complex process that is both expensive and time-consuming. Mistakes can be costly and may delay or prevent the approval of a drug, but the more that is understood in advance about the criteria chosen to evaluate if a drug is safe and effective, the greater the chance of success. The FTD community has embraced this concept and wants to ensure that testing of new drugs for this disease will happen as quickly and efficiently as possible.

"The June 4 meeting brought together the NINDS, NIA, FDA, pharmaceutical companies, clinicians, and scientists," said Dr. Marsel Mesulam of Northwestern University and Chair of AFTD's Medical Advisory Council (MAC). "This is the kind of coalition that we need if we are to discover effective treatments for FTD. The initiative has now gained real momentum."



*FTSG meeting held on June 4 in Washington, D.C.*

The day was planned to maximize interaction and discussion between academic experts on FTD, regulators, and industry representatives who are interested in perhaps sponsoring a clinical trial in FTD. During the first

session five members of AFTD's MAC presented "state of the art" knowledge on diagnosis and progression of the various subtypes of FTD, as well as the measures currently available (imaging, fluid biomarkers, neuropsychiatric instruments) to measure effect of a drug during a trial. Throughout the day presenters from the FDA and the European Medical Agency (Europe's counterpart to the FDA), provided information and insight into how the regulators view different aspects of proposed trials.

Dr. Lynne Yao of the FDA talked about clinical trial design for rare disease. She made the point that "for rare disease you need critical planning up front—it's very important to get it right the first time" and also that "the patient community will tell you what's really important to them."

Dr. Ilan Irony of the FDA gave an overview on the topic of biomarkers (levels of a protein or brain imaging) and stressed that the FDA can only accept them as outcomes in a clinical trial if the biomarker has been shown to predict reliably how a person's function improves. There was general consensus that good biomarkers are needed for FTD (AFTD's research collaboration with the Alzheimer's Drug Development Foundation has been focused on the development of biomarkers).

Against this backdrop of basic information from the FTD and regulatory experts, investigators presented three potential clinical trial designs as "straw men," each followed by a panel and engaged discussion from the audience.

First, Dr. Michael Gold of Allon Therapeutics presented some "lessons learned" during Allon's testing of a drug

for Progressive Supranuclear Palsy (PSP). He pointed out that participants overall progressed more quickly than predicted and that they tended to experience a lot of falls, which sometimes resulted in significant injury. The company also felt that the burden placed on caregivers had been underestimated and that the measurements used to determine if the drug was working properly could benefit from refinement. A panel of experts weighing in after Dr. Gold's presentation felt that it was possible to diagnose people with PSP fairly efficiently but recruiting for trials for this disease was still difficult because it is so rare.

In the second case study presented at the meeting, Dr. Adam Boxer of UCSF talked about the feasibility of conducting a trial in a type of FTD due to a deficiency of the progranulin protein. He showed that mice that lack progranulin develop an FTD-like disease, and people with FTD due to a mutation in the gene that codes for progranulin have measurably lower levels of this protein in their cerebrospinal fluid. Investigators anticipate that a drug that can elevate levels of progranulin in people may slow or stop the progression of the disease, and hope that measuring progranulin levels in the cerebrospinal fluid will reflect whether or not the drug is working. Dr. Boxer then outlined a hypothetical clinical trial to test such a drug. The expert panel for this session brought up the need to really understand the relationship between increased progranulin and improvement of a person's symptoms before relying on progranulin measurements alone.

Finally, Dr. Elizabeth Finger of the University of Western Ontario provided the third case study building on an exploratory trial she had conducted to see if an intranasal version of the hormone oxytocin, which is associated with promoting social behaviors, could improve the symptoms associated with behavioral variant FTD. Fundamental

## Meeting *(continued from page 4)*

questions revolved around whether participants would need to be sorted by the underlying “pathology” or cellular cause of the disease, and how long the treatment would need to go before a change in behavior could be seen. The expert panel felt that symptomatic relief for behaviors associated with FTD was very worthwhile and that the measurements used to determine if the drug was working would really depend on the nature of the population enrolled in the study.

Dr. Christina Sampaio, of the Cure Huntington’s Disease Foundation, who previously worked for the European Medical Agency (Europe’s counterpart to the FDA), presented a series of slides covering responses from the Neurology Division of the Center for Drug Evaluation and Research at the FDA to specific questions submitted in advance of the meeting.

“I thought the feedback from the FDA representatives was very helpful. It was

very rewarding to see discussions get down to the nuts and bolts issues of clinical trials and to walk away with a better sense of their size, complexity, potential designs and the knowledge that




*FTSG meeting attendees: Adam Boxer, M.D.; Irene Litvan, M.D.; Yolande Pijnenburg, M.D. and Niels Daniel Prins, M.D., Ph.D.*

we are not asking study sponsors to do the impossible,” said Dr. Mike Gold of Allon Therapeutics.

A final expert panel convened at the end of the meeting to sum up over all messages. Dr. Jim Kupiec of Pfizer pointed out that most drugs fail either

because the company has rushed into development without first determining that the drug really does work, or because the study design is faulty: the drug was tested in the wrong population for the wrong length of time or the wrong measurements were used. Dr. Yao suggested that the FDA would help work through concerns with applicants and admonished the group not to skip steps because it hurts in the long run: “Fast doesn’t always equal efficient,” she cautioned.

The meeting concluded with participants, including those from the FDA, planning to publish a paper on the key findings that would be available to guide any group planning a clinical trial in FTD. “We are extremely pleased with the level of engagement from all parties during this meeting,” said Susan Dickinson, AFTD executive director. “We will work hard to keep everyone at the table so we can proceed wisely and efficiently toward definitive clinical trials for our patients.” 

## Mountains *(continued from page 1)*

On April 11, 2012, Deanna left New York City for the rugged terrain of Nepal. Over the course of 15 days, she trekked to a height of 17,000 feet to the base camp of Mt. Everest, the world’s tallest mountain. Here’s what she had to say about that experience.

**AFTD:** Why did you choose to climb Everest?

**DA:** To me, Everest represents conquering the impossible. I’ve always believed that if you think you can do something, you will succeed. But if you think you can’t, you will inevitably fail. Successfully making it to Everest Base Camp is synonymous to what I envision for FTD -- to one day conquer it and find effective treatments, and ultimately a cure, so no family will have to endure what mine has.

**AFTD:** How did you prepare for the long, difficult climb?

**DA:** Most people who do Everest aren’t fortunate to have the benefit of altitude training prior to hiking in the Himalayas, so you have to make sure you are as fit as possible. I prepared by spending a lot of time at the gym, doing several spin classes a

week, running and other cardio, working with a trainer to improve my flexibility and mobility, and my overall hip strength. From a physically fit

perspective, I felt great most of the trip, but it was the mental aspect and the effects of altitude sickness that wore me down, but certainly did not knock me out!

**AFTD:** What was the climb like? Was it what you expected?

**DA:** This is the hardest thing I’ve done in my life. Triathlons and marathons challenge me in a different way than Everest *(continued on page 10)*



*Deanna Angello at Base Camp, Mt. Everest*

## Donations Honor Loved Ones

*Gifts received from February 1 - May 31, 2012*

### In Honor Of:

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Uchu Amenomori  
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Glenn G. Andrews  
John Auld  
Phyllis Avery  
Sidney Barnes  
Billy Basile  
Steve Benesh  
Betsy Bennett

## Atlanta *(continued from page 3)*

The sessions were interactive with plenty of pertinent questions for the professionals as well as for other caregivers who were going through similar situations.

Following the breakouts, attendees had the choice of networking or sitting in on one of three optional sessions: meditation, regional FTD advocacy or people diagnosed with FTD. This year was the first time AFTD's conference included a session specifically for people affected with FTD; nine individuals diagnosed with bvFTD or PPA attended this session, during which they discussed their common experiences and needs for support. For most of these people this was the first time they had met others who also have an FTD diagnosis. Several indicated a strong desire to share their stories for the benefit of the whole community,

and one immediate outcome was a series of articles published by Forbes.com in May and June, which related the stories of five different FTD patients from their own perspectives.



*AFTD Board Chair Beth Walter opens the conference.*

To wrap up the day, attendees reconvened for AFTD's Annual Meeting. AFTD Executive Director Susan Dickinson chronicled the organization's key achievements over the past year, which centered around the theme of growth: the addition of new staff, the rise in number of people registered with AFTD, a steady increase in the number of HelpLine contacts and website visits, the creation of new resources for

families, the education of more healthcare professionals and a greater awareness of FTD through grassroots fundraising and media contacts. Participants viewed a 90-second clip of

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

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

**Atlanta** *(continued from page 6)*

AFTD's film *It Is What It Is*, a documentary that chronicles the lives of four families directly affected by FTD and has won several awards for its production excellence. Filmmaker Joe Becker and film participants Bill Brown, Michele Van Son, and Chris and Christopher Yurkanan were present and recognized for their efforts in creating the film.

Tim Langmaid, senior managing editor of CNN Medical, delivered the keynote address at the end of the day. His message, entitled *It's More than a Relationship*, drew on conversations he has had with family members of people affected with FTD. He spoke about the heightened sense of concern, compassion and urgency when people face a diagnosis of FTD and how

the connection between loved ones becomes more. Mr. Langmaid's message seemed to strike a chord with many in the audience, as they approached him after his speech to shake his hand and thank him for his words.

Following the conference, approximately 100 people attended a reception hosted by the AFTD at the hotel. Guests engaged with several of the speakers, facilitators and AFTD staff and board members over food and wine. To access some of the materials presented at the Atlanta conference, visit AFTD's "Past Caregiver Conferences" page under the "Support and Research" section of [www.theaftd.org](http://www.theaftd.org). Next year's conference is set for April 12 in Salt Lake City, Utah. 

## Primary Progressive Aphasia – Early Treatment Can Make a Difference

Living with Primary Progressive Aphasia (PPA), a subtype of FTD, is a study in adaptation. This is the chief message delivered by Christina Wieneke, Research Project Manager for Language in Primary Progressive Aphasia in the Cognitive Neurology and Alzheimer's Disease Center of Northwestern University. She is involved in one of the largest PPA research studies to date.

"Aphasia" is a general term used to refer to deficits in language functions, including speaking, understanding what others are saying, repeating things we have heard, naming common objects, and reading and writing. In the early stages, memory, reasoning and visual perception are not affected. So individuals with PPA can function normally in many routine daily living activities despite the aphasia.

Slowed or choppy speech, uninformative content, trouble following conversations, mistakes in pronunciation, can all be symptoms of PPA, which is classified under one of three subtypes. **Agrammatic variant PPA**, sometimes known as non-fluent aphasia, is characterized by challenges with grammar, motor speech or producing speech correctly. The issue with **semantic variant PPA** is difficulty understanding what words mean. Those diagnosed with the third subtype, **logopenic variant PPA**, have trouble with word-finding and sentence repetition.

Typically, unlike those with the behavioral variant of FTD, individuals with PPA are aware of their failing ability to communicate, which may prompt issues of depression. Certainly family members and co-workers can note the deficiencies. Diagnosis can involve neurological evaluations, MRI scans, PET scans and neuropsychological evaluations.

"Once a diagnosis is made, we focus on the person," said Christina. "We refer them to a speech and language therapist

as soon as possible. No matter which of the three subtypes is present, the therapist can address the symptoms and offer immediate strategies that can be adapted as the disease progresses."

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*"The goal is not to help the client improve and eventually 'graduate' from therapy, but rather to identify coping mechanisms that can be adapted as things change."*

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--Christina Wieneke,  
Northwestern University  
Research Project Manager

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With input from the individual and the family, the therapist will suggest methods that vary according to the individual's issues. They can include:

- Simply slowing down when speaking.
- Developing a cue or sign the affected individual can use when they want help finding a word.
- Creating a communication notebook with clearly labeled pictures to simplify interaction or even stimulate conversation.
- Helping the individual to talk around a word.
- Identifying the word by referring to the opposite – (It's not black, it's "white.")
- Gesturing to indicate actions.

"The therapist must understand that, unlike treatment of language loss resulting from a stroke, the goals of therapy for someone with PPA are quite different," said Christina. "The goal is not to help the client improve and eventually 'graduate' from therapy, but rather to identify coping mechanisms that can be adapted as things change.


"The sooner a diagnosis is made, the sooner strategies can be designed," she continued. "We focus on developing a care plan while the person is still able to

communicate. It is a rare advantage that those affected can have input as to what their issues are and how they can best be helped."

Christina explained that the urgency is not an issue of 'use it or lose it.' The sooner the strategies are put into place, the easier it will be for the person to learn them. Also, as the symptoms progress, it will be easier for them to adapt the strategies later.

Unfortunately, language problems continue to get worse as PPA progresses. Also, in time, because the areas of the brain that control language are located so closely to those involving behavior, people with PPA may develop behavioral changes similar to those in behavioral variant FTD, and, conversely, those with behavioral variant FTD may develop language impairments. People with PPA also may eventually develop problems with movement, dexterity or swallowing.

The research taking place at Northwestern University includes some of the most comprehensive PPA investigations ever undertaken. It involves neuropsychological testing, magnetic resonance imaging (MRI) scans and PET scans. The participants also take part in a variety of language and naming experiments, and some that involve voice recording. Finally, those who donate their brains for study provide critical data to aid in understanding the pathology of the disease and changes in the brain.

"The clues we gather as we conduct our research link dramatically with what we learn in studies of the brain tissue later on," said Christina. "It provides critical data for studies that can last for years and years. Our ultimate goal of research is to find effective treatments for the disease because that is really what we want and what I hope to see soon." 

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

## Joanne Douglas on Living with PPA

Joanne Douglas was an articulate bio-chemistry professor at the University of Alabama at Birmingham when she began to notice changes in her speech about five years ago. It became halting, and she had difficulty understanding what people said and what she read in scientific papers. Eventually, she was unable to lecture and had to give up her professorship. Today, at age 48, Joanne is determined to adapt her lifestyle and remain as capable as possible.

"I want to choose how I experience and live this illness," Joanne said. She can still communicate because she has devised strategies. Ironically, silence is a key component of the adaptations she has developed.

"I prepare for a conversation I will have by spending the day before in silence," she said. "I rest and think about what I will say. The next day I can communicate but only for about 40 minutes. Speaking is 'effortful' for me, so that is the limit for me on any given day."


A quiet environment with a minimum of background noise and with one person speaking at a time is the most comfortable for Joanne. She avoids restaurants and social events. She asks people to refrain from interrupting her or changing the subject

too abruptly, and she prefers that they not try to finish her sentences for her. If she is having a challenge finding a word, she would rather find her own way, unless she has invited them to help her. Being interrupted is distracting.



Joanne Douglas

Joanne has developed a separate set of strategies to cope with the emotional difficulties of having PPA. She is passionate about spreading the word about FTD and PPA. She notes that articles and literature are rarely written from the point of view of the person with the disease. She feels her ability to share a first-person account of the experience is a gift she can offer.

"None of us knows what the future will bring, and it doesn't pay to dwell on the past," she said. "If I have a degenerative disease, NOW is the best time for me. I want to live intentionally and live well. If someone is kind enough to speak to me, I want to show courtesy and speak to them," Joanne explained. "I want to be treated as a whole person, not as a patient. I am still who I am at my absolute core. I am still who I am with FTD." 

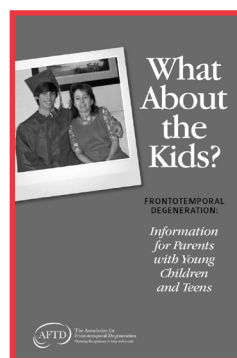
*Contributor Elaine Rose is a writer and caregiver to her husband with FTD.*

## What About the Kids? Booklet Now Available

"Will Daddy get better?" "Can I catch Mom's FTD?" Many people with frontotemporal degeneration (FTD) are parents of young children or teens when symptoms first develop and the disease is diagnosed. Thoughts turn quickly to how best to help children understand and cope with the changes confronting the family.

*What about the Kids?*, a new publication from the Association for Frontotemporal Degeneration (AFTD), is one of the first resources to offer guidance and practical tips for people who have children at home when a spouse or partner has FTD. The booklet, the result of AFTD's Task Force on Families, reflects the expertise of caregivers and professionals in the field of children's bereavement, clinical social work and FTD.


"I'm excited about the availability of this important resource," said Paul Lester, a member of the task force. "Too many families like mine have tried to know what's best for our kids when mom or dad has FTD and had nowhere to turn. This resource will provide practical ideas to help parents better support their children in the midst of a difficult and stressful illness."



Children are smart and intuitive; they sense the changes that FTD brings. A parent may want to talk with his children, but not know where to start. He may be fearful of upsetting the child or feeding a teen's anger. *What about the Kids?* reminds parents that listening is more important than talking.

According to the booklet, the most valuable message parents can send is to adopt an approach to the disease that conveys open, honest communication and respect for the needs of each family member. Children watch and learn from how the well-parent uses communication skills, information, support and resources for himself.

Over the course of the disease, FTD creates ever-changing obstacles and unique challenges for families. *What About the Kids?* offers guidance on how to help children move through their personal development and strengthen the family as a whole.

The publication was first released in April, and a second printing was needed in early June. It can be downloaded from AFTD's website or requested at [info@theaftd.org](mailto:info@theaftd.org). This booklet was made possible through the financial support of David J. Goldring & Family and Friends & Family of Jeffrey Van Son. 

## The AFTD-Team: Overflowing with Support

The past few months, and particularly May, have been a hotbed of grassroots fundraising for AFTD--so much so that we need a little extra space to share all the activity! Many thanks to all who have stepped forward to raise money for care and a cure. For information on how you can join the AFTD-Team, please visit the fundraising page of our website.

### Fifth Grader Educates Others About FTD

As part of her fifth-grade citizenship project for Pine Hill School in Massachusetts, Eva Martin chose to educate her classmates and their families about FTD and do a fundraising project for AFTD. Eva's nana, Elsie Rodgers, was affected with FTD and passed away in 2010. Eva contacted AFTD for information to use at her school expo, and she also raised \$400 for AFTD by sewing items and selling them.



*Eva Martin and her AFTD display.*

### 3rd Annual Scoot for Scooter Event Raises \$20,000

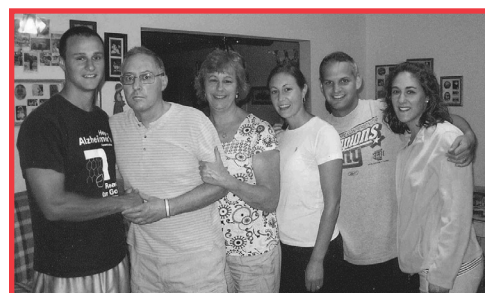
The family of Dave Scaggs held their 3rd Annual Scoot for Scooter 5K Race on May 20 in Mt. Airy, MD. Approximately 500 people attended this year's event to raise funds and awareness for FTD care and research.

Their three-year fundraising total now stands at \$100,000! *At right: Allyson Scaggs Sealfon and brother J.D. Scaggs, event organizers and children of Dave Scaggs, who is affected with FTD.*



### CT Foundation Donates \$10,000 to AFTD

On March 3rd, Harvey's Hugs of Hope hosted their first annual wine tasting event to benefit their foundation, The Connecticut Frontotemporal Dementia Foundation. Over 25 wines were tasted by more than 130 people in an evening that included raffle prizes, music, food, and great conversation. The event was held in memory of Kevin Harvey, who passed away in January 2012 from FTD. The Foundation made a \$10,000 donation to AFTD to further research.



*l to r: Keith, Kevin, & Esther Harvey, Meghan & Jim Roscoe, Shannon Harvey*


## Mountains *(continued from page 5)*

did. No matter how physically strong you are, Everest throws so many other elements at you all at once, which is what makes this the greatest challenge. Eight days of constant elevation gain, changing weather patterns, high winds, and sleep and oxygen deprivation take a toll on even the fittest. I was surprised at how much the mental component of this affected me. It is not anything you can prepare for, and everyone deals with the high elevation differently. It takes sheer determination and there are some difficult moments along the way where you can't believe you are actually doing this. For me, I thought of my dad as I kept perspective on why I was doing this. It was a life-altering experience, but you have to be open to going out of your comfort zone, immersing yourself in the Nepalese culture and embracing the magnificence of Everest.

**AFTD:** You have a few other fundraising events planned for this year. What else is in store for you?

**DA:** NYC triathlon, Army 10-miler in Washington, DC and the NYC Marathon in November. The Army 10M will be particularly special as my father is an Army veteran, and I will run in honor of him.

**AFTD:** What, if any, new perspectives have you gained about FTD as a result of your fundraising efforts?

**DA:** That raising awareness about the disease is equally as important as raising dollars. As I continue to do work with AFTD, and learn about other families' stories of tragedy and loss, I am more determined than ever to ensure that FTD is something that everyone I know and meet knows about, and that FTD gets the same level of attention as Alzheimer's. 

# THE AFTD-TEAM

## Arpiar & Alice Saunders Run Marathon in Honor of Father



Arpiar and Alice Saunders completed their first 26.2-mile run on May 6 at the Providence Cox Sports Marathon in Rhode Island. The siblings created a Givezooks! campaign through AFTD and raised \$5,315 in honor of their father who is affected with FTD. Eight friends and family participated in the event with four running 13.1 miles and four running the full Marathon. Alice finished with an impressive 3:49:20, and Arpy came in right after her with a time of 3:59:41. Their father joined Arpy at the finish line as he crossed. When asked about the experience, Alice said, "It's been an honor to raise money for AFTD."

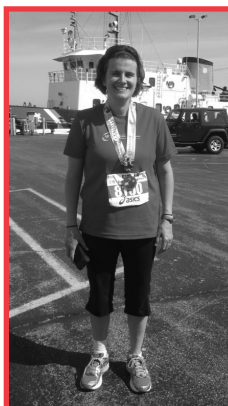
## 5th Annual Quest for the Cure Golf Event Raises \$30,000

AFTD Board Chair Beth Walter and her family held their 5th Annual Quest for the Cure Golf Outing on May 7 in California. The event raised more than \$30,000 with 127 golfers attending and 30 volunteers making the day possible. In the past five years, the Walter Foundation has raised more than \$130,000 for AFTD.



## Men Run 1/2 Marathon in Memory of Friend's Mother

Brendan Hermes and Joe Ciccione ran the Long Branch 1/2 Marathon in Oceanport, NJ on May 6 in memory of their friend's mother. Brendan and Joe have been friends with AFTD Board Member Bryan Dalesandro since college, and together, they raised \$3,110 to help find care and a cure for FTD. *Below: Brendan Hermes, Joe Ciccione and Bryan Dalesandro.*



## Nicole Greenway Runs 1/2 Marathon

On May 20, Nicole Greenway ran her personal best in the Rite Aid Cleveland 1/2 Marathon in memory of her mother who passed away from FTD. She said it was unseasonably hot, but she thought of her mom during the race and did well. Nicole raised \$630 for FTD care and research.

## Staff & Friends Walk for AFTD

Sixteen people, including a few staff members of AFTD, laced up their sneakers to walk and run on May 20 in King of Prussia, PA to raise money to fight FTD. Several participants set up online fundraising pages through Givezooks! and as a group raised \$6,135--well over the fundraising goal of \$5,000! Several people attended a brunch at Executive Director Susan Dickinson's house following the event where families were able to share their journeys with FTD and spend time with staff members.





The Association for  
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*Opening the gateway to help and a cure*

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