



# The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

Volume VIII, Issue 2

Summer 2011

## AFTD Annual Meeting and Conference Brings Caregivers Together in Boston

On Friday, June 10 approximately 170 people attended the AFTD Caregiver Conference and Annual Meeting at the Cambridge Marriott in Boston, Massachusetts. Joining family caregivers were members of AFTD's board of directors and several professionals who received continuing education credits for their participation. Caregivers came from across the U.S. and as far away as France and Nigeria.

“This was the first conference that AFTD has hosted, and we were extremely pleased by the response,” said AFTD Board Chair Beth Walter. “It is always gratifying to bring our families together, but this year we sense a growing

energy within our community, and we are excited by the potential this brings to build more resources and to speed research along.”

Author of nine novels and *New York Times* essayist Elinor Lipman gave the



Caregivers listen to Elinor Lipman give the opening address.

opening address entitled *The Beginning, the Middle, the End: An FTD Wife's Story*. Ms. Lipman drew laughs and tears from the audience as she recounted the different stages of life with her husband Bob, who passed away from FTD in 2009.

Following Ms. Lipman's address, caregivers chose to attend one of the following breakout sessions, based on their individual needs:

- *Spouse/Partner of Person Diagnosed*, led by Paul Raia, Ph.D.; Nicole McGurin, M.S.; and AFTD Regional Coordinator Kathy Ulrich
- *Adult Children of Person Diagnosed*, led by Zeina Chemali, M.D.; Stacey (see Boston, page 6)

### Inside This Issue

Spotlight On	
Bryan Dalesandro.....	2
News Briefs.....	2
Drug Discovery Year 5.....	3
New Board Members .....	3
TDP-43 Mouse Model.....	4
Postdoctoral Fellow .....	5
iPSC Consortium .....	5
Donations .....	6-7
Parents Becoming Caregivers ....	8
LTC Facility Initiative .....	9
Awareness .....	10
Tell 10 People Events .....	11

## FTD: The Next Frontier

In March, approximately 60 scientists from academia, industry and the National Institutes of Health convened in Las Vegas to discuss potential mechanisms for speeding promising compounds into clinical trials for FTD. Entitled **FTD: The Next Therapeutic Frontier**, the meeting was sponsored by the FTD Treatment Study Group (FTSG) and hosted by the Cleveland Clinic Lou Ruvo Center for Brain Health.

The two-day meeting focused on preclinical issues that currently represent hurdles in the development of therapeutics for FTD. Presentations were given on a number of animal models for various forms of FTD and on new initiatives NIH is funding to create tools and resources that support translation of scientific results into development of treatments. Representatives working in other disease areas presented successful strategies they have employed to catalyze drug discovery, and then provided advice for the best approaches for accelerating FTD drug development.

(see Frontier, page 5)


## Spotlight On... Bryan Dalesandro, AFTD Board of Directors

**W**hen Bryan Dalesandro is in, he is all in. In the short time that Dalesandro has been involved with AFTD, he has been very busy. Dalesandro joined the board in 2010 after attending a caregiver conference with his father in Philadelphia. Since then he has been an active member of three committees: development, finance and special events. This June, Dalesandro stepped up to serve as AFTD's treasurer and finance committee chair.

With a degree in finance, economics and accounting from Lycoming College, a small liberal arts school Williamsport, Pennsylvania, Dalesandro is well-suited for this position, and he is happy to put his talents to work for AFTD. "This is how I can help out," explained Dalesandro. AFTD is fortunate to have someone like Dalesandro who is a client relationship manager at CMS Companies, a Pennsylvania investment firm.

Not one to brag about his own contributions to the cause, Dalesandro marvels at the efforts of those across the country who have organized fundraisers for AFTD. "I'm quite amazed by the events people organize, from golf tournaments to runs—it's amazing." As a result of these grassroots efforts, one of the development committee's projects this year is to

develop processes for supporting the fundraisers initiated by friends and family of loved ones with FTD.

As a board member and as the treasurer and finance chair, Dalesandro hopes to raise awareness of FTD and its many manifestations. Dalesandro's mother, a nurse for more than 35 years, first presented with impaired language capabilities, was diagnosed in 2002 and passed away this March from corticobasal degeneration (CBD), a movement disorder characterized by muscle rigidity and tremors. In addition to serving as a nurse, Dalesandro's mother volunteered regularly for her local church and women's club. Fortunately for AFTD, Dalesandro is carrying forward his mother's enthusiasm for volunteer work with gusto. 

*Contributor Catherine Savini is assistant professor of English at Westfield State University in Westfield, Massachusetts.*



## AFTD News Briefs

*The Caregiver's Handbook* and *The Gift of Now* by Eleanor Vaughan offer encouragement and tools for families facing FTD. These books offer tips and suggestions for making the most of family time and enhancing the quality of that time. Eleanor will donate a portion of the proceeds from her books, which are available on [www.serving-hearts.com](http://www.serving-hearts.com), to AFTD.

### Family caregivers needed for research about caring for someone with frontotemporal dementia

Cindy Wong, RN, a nursing doctoral student, and Margaret Wallhagen, Ph.D., Professor in the Department of Physiology Nursing at the University of California, San Francisco are conducting a research study to understand


the experiences of families providing care for someone with frontotemporal dementia at home. Please e-mail or call Cindy Wong at [Cindy.Wong@ucsfmedctr.org](mailto:Cindy.Wong@ucsfmedctr.org) or 1-888-584-9203 (toll free) for more information.

**An AFTD telephone support group on grief began in April 2011.** Those who have lost a loved one to FTD are invited to join the group. For more information, contact [info@theaftd.org](mailto:info@theaftd.org).

**Three new FTD support groups in Texas were started in recent months.** A local group of men caring for their wives with FTD began in May in Fort Worth, while two general support groups got under way in Austin (June) and San Antonio (July). To find

more information on each visit, <http://www.theaftd.org/support-resources/us-regions/south-central>.

**People who have been diagnosed with FTD are invited to take a survey** designed to help AFTD understand their needs and develop new outreach. To take the confidential survey, visit <http://www.surveymonkey.com/2/AFTDfirstperson>.

**The Houston Area Frontotemporal Dementia (FTD) Caregiver Support Group celebrated its one-year anniversary** on Thursday, April 14th. The group, which meets in Bellaire, is the only known local support group specifically for FTD caregivers. 

## A Valuable Partnership: FTD Drug Discovery Enters Year 5

This summer, The Association for Frontotemporal Degeneration (AFTD) and The Alzheimer's Drug Discovery Foundation (ADDF) embark on the fifth year of a very special partnership that is funding the first grants specifically to support the development of therapeutics for FTD. "We are tremendously grateful to the Lauder family and ADDF for extending this partnership with us," states Beth Walter, AFTD board chair. "Their 2:1 match of our donations fuels important science and helps us catch the attention of researchers worldwide to work on our rare disease."


During the first four years of this program, AFTD and ADDF have awarded 15 grants totaling more than \$1.5 million. Awards have gone to investigators working in both academic and corporate environments in 7 different countries. The projects funded have run the gamut of drug development, from identification of the appropriate targets for therapeutic intervention through medicinal chemistry of potential compounds to funding of a small clinical trial.

In June, AFTD and ADDF issued a Request for Proposals (RFP) for Year Five of the FTD Drug Discovery program.

This year's RFP invites applications to develop FTD-specific biomarkers that reflect pathological and clinical differences so that appropriate patients can be selected for clinical trials and responses to investigational treatments can be monitored. The RFP also invites projects that address other issues of clinical trial design. Grants of up to \$150,000 will be awarded for a one-year duration with the possibility of follow-on funding.

Applications are available at [www.alzdiscovery.org](http://www.alzdiscovery.org). Interested parties should submit a Letter of Intent by Aug. 25, 2011. The application submission deadline date is Sept. 8, 2011.

### Help Fund Year 5 of FTD Drug Discovery

Thanks to our friends at ADDF who underwrite the cost of grant management and match AFTD's dollars 2:1, **every \$1 you donate to FTD Drug Discovery will result in \$3 going straight into the lab or clinic.** Your donation offers hope to those affected by FTD. Join the partnership by making your tax-deductible contribution either by mail in the attached envelope or online at [www.theaftd.org](http://www.theaftd.org). 

## AFTD Welcomes New Members to Board of Directors

**F**our new board members and two returning board members joined the organization on June 11.

**Helen-Ann Comstock**, Perkasie, PA, is the founder of AFTD. Her husband, Craig, was diagnosed with FTD at age 44 in 1978 and died seven years later. In order to increase research funding for frontotemporal degeneration and to provide information and support to those coping with FTD, Ms. Comstock formed the AFTD in 2002 and served as its board chair until 2010. Ms. Comstock continues to spearhead the organization's international efforts and serves on the research and advocacy committees. The Comstock Caregiver Respite Program is named in honor her and the foundation she has laid for the organization.


**Debbie Fenoglio, RN**, Denver, CO, is a retired nurse whose husband, Dr. Michael Fenoglio, was a prominent surgeon in Denver. He was diagnosed with FTD

a few years ago and had a sister who died of FTD at age 56. Ms. Fenoglio is particularly interested in research and program development.

**Amy Kamin**, New York, NY, is a business entrepreneur in the medical aesthetic market currently serving as senior vice president at EndyMed. Her mother, formally an active community leader in Pittsburgh, PA and Palm Beach, FL has been diagnosed and living with FTLD for the past decade.

**Linda E. Nee, LCSW-C**, North Bethesda, MD is a research social worker. Full time at NIH from 1968 until 2004, her research included genetic family studies of dementia. Since 2004, she has continued family studies with ADHD and now works part time with NIH. Linda was a founding member of the AFTD Medical Advisory Committee (MAC) and served on AFTD's Task Forces for Respite Care for Families and Families with Children.

**Lisa Radin**, Las Vegas, NV, was a caregiver to her husband, Neil, who died from corticobasal degeneration. A founding member of AFTD, she has facilitated FTD support groups in Pennsylvania and New Jersey and currently facilitates one in Las Vegas. Ms. Radin, with her son, Gary, conceived and edited the first book ever dedicated to providing information to FTD caregivers: *What If It's Not Alzheimer's?: A Caregiver's Guide to Dementia*.

**Popkin Shenian**, Philadelphia, PA, is the principal and owner of The Shenian Company, a commercial real estate firm. His father had corticobasal degeneration and his mother was a founding board member of AFTD. Mr. Shenian has advocated for AFTD and the community's interest with Senator Arlen Specter and twice has been key in getting verbiage about FTD research funding into the Budget Appropriations Committee document. He also serves on AFTD's advocacy committee. 



## AFTD, ADDF Fund TDP-43 Mouse Model

Earlier this spring the Association for Frontotemporal Degeneration (AFTD) and the Alzheimer's Drug Discovery Foundation (ADDF) jointly awarded a grant to the ALS Therapy Development Institute (ALS TDI) for development of a mouse model for TDP-43 pathology common to ALS and FTD patients. The \$125,000 grant, \$25,000 of which was funded by AFTD, will underwrite development of best practices aimed at ensuring that all researchers using this mouse model will produce quality-controlled, valid results that can be replicated and compared to each other.


"We are grateful to our partners at ADDF, once again, for providing invaluable support as we address key challenges in the FTD drug discovery process," said

AFTD Executive Director Susan Dickinson. "Half of all FTD patients have TDP-43 pathology. An accurate, consistent and valid model for TDP-based disease will be a valuable tool that will fuel more quality research."

TDP-43 is a protein that misfolds and accumulates in the brain of individuals with FTD and Amyotrophic Lateral Sclerosis (ALS). TDP-43 deposits have also recently been found in Alzheimer's Disease (AD) and Parkinson's Disease (PD) patient brains, which indicates that TDP-43 accumulation may be a more general phenomenon across neurodegenerative diseases.

A new animal model has recently become available that expresses mutant forms of TDP-43 relevant to disease.

This mouse model represents a new tool for drug screening and for testing novel treatments. Many reports have focused on the need to establish best practices in the use of such animal models in order to better translate findings into results in humans.

The ALS TDI previously has developed and published best practices and guidelines for the use of the "SOD1" ALS mouse model and now seeks to do the same for the TDP-43 model. The outcome of the project will standardize the use of the model, improve the interpretability and validity of preclinical animal results and improve the value of animal models for predicting success in human clinical trials. 

## Frontier *(continued from page 1)*


During the second day, two specific proposals were considered: Adam Boxer, M.D., Ph.D., of the University of California, San Francisco presented the concept of a web-based registry of animal models to test potential FTD treatments, and Michael Gold, M.D., chief medical officer at Allon Therapeutics, Inc., explored the potential for creating a similar registry of compounds that have therapeutic potential. Dr. Gold emphasized the fact that our community has two key resources that are very limited: relatively few patients and a relatively small amount of funding. He encouraged all participants to take a collaborative attitude to protect these resources and proceed efficiently overall.

Dr. Boxer, who is current chair of the FTSG Steering Committee, was pleased with the results of the meeting. "There were very productive discussions between academic scientists, clinicians and industry researchers that identified the key hurdles to expanding industry involve-

ment in drug development for FTD and potential solutions to these issues," Boxer said. "Although FTD drug development is still in its infancy, it was clear from the meeting that we will greatly benefit from experience in other neurodegenerative disorders such as Alzheimer's, Huntington's and ALS to avoid previous pitfalls and more efficiently move potential therapeutics through the development pipeline."



*FTSG Steering Committee: Michael Gold, M.D., chief medical officer at Allon Therapeutics, Inc.; Susan Dickinson, M.S., AFTD executive director; Adam Boxer, M.D., Ph.D., associate professor of neurology, UCSF; Megan Grether, Ph.D., executive director of The Bluefield Project; Jeffrey Cummings, M.D., director of Cleveland Clinic Lou Ruvo Center for Brain Health*  
*Missing: Howard Feldman, M.D., vice president and therapeutic area head, Bristol Myers Squibb; Howard Fillit, M.D., ADDF executive director*

The FTSG is a nascent organization of academic and pharmaceutical researchers and advocacy groups that is dedicated to finding new and effective treatments for FTD. Recent advances in understanding the biology and clinical features of FTD suggest that the timing is right for development of targeted FTD therapeutics, and the FTSG is founded on the premise that the best way to accelerate FTD treatments is to foster novel collaborations among these three sectors. AFTD is one of the founding members of the FTSG. 


## AFTD Awards Postdoctoral Fellowship to Alexandra Nicholson, PhD

On March 22, 2011 the AFTD Postdoctoral Fellowship for 2011-2013 was awarded to Alexandra Nicholson, Ph.D. Dr. Nicholson holds a Ph.D. in neuroscience from Northwestern University, and she is currently completing her postdoctoral training at the Mayo Clinic in Florida, where her research focuses on genetic risk factors for FTD. AFTD received nearly two dozen applications, most of very high quality. “We could have been proud to sponsor any one of the top five candidates,” notes Fellowship Review Chair, Bruce Miller, M.D. “But in the end, support for Dr. Nicholson among our panel of experts was unanimous.”

Over the next two years, Nicholson will focus on the role of growth factor progranulin (GRN) in frontotemporal degeneration (FTD). Specifically, she will study how GRN levels are controlled in the brain and how transmembrane proteins affect GRN levels. Nicholson’s work builds on recent findings that suggest low levels of GRN are at least in part responsible for aggregation of TAR DNA-binding protein 43 (TDP-43), which is found in the brains of FTD patients. Research on how certain proteins affect GRN levels will lead to a better understanding of the risk factors for FTD and of the process of neurodegeneration. Ultimately, Nicholson believes her research could lead to novel treatments and therapies for individuals suffering from FTD.

Nicholson’s passion for research in the area of neurodegenerative diseases began with her father, who suffered from Alzheimer’s disease when Nicholson was still young. Confounded by how a brain disease can leave a father unable to recognize his own daughter, Nicholson seeks to understand the cell biology responsible for devastating neurodegenerative diseases and hopes to contribute to development of effective treatments for patients with neurodegenerative illnesses like FTD.



The AFTD Research Fellowship, a two-year fellowship paying \$55,000 per year, aims to recruit the best young scientists with the hope that they will dedicate their career to researching FTD. 

*Contributor Catherine Savini is assistant professor of English at Westfield State University in Westfield, Massachusetts.*

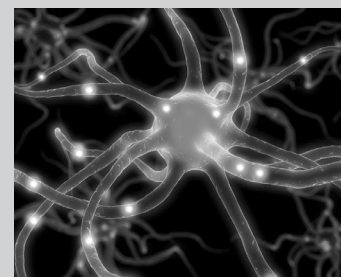
## AFTD to Join iPSC Consortium

AFTD has joined other private funders and the National Institutes of Health (NIH) in support of a project to create a central resource of induced pluripotent stem cell lines (iPSC) available to scientists conducting research on FTD and other neurodegenerative diseases.


The Consortium was initially formed in 2009 by the National Institute of Neurological Disorders and Stroke (NINDS) with \$11 million in funding through the American Recovery and Reinvestment Act. Its goal was to create iPSC that model Huntington’s disease, Parkinson’s disease and ALS. Within the first 18 months of the project, scientists had developed 87 fibroblast lines and 25 complete iPSC lines. This spring, NIH initiated an expansion of the consortium, calling on corporations, foundations and other private funders to contribute a cumulative \$8 million and expand the project to include creation of iPSC that model FTD.

iPSC, first created in 2007, harness the power of embryonic stem cells without involving an embryo. Essentially, this technology enables a researcher to take a skin cell from a

person who has inherited a disease mutation and create a nerve or muscle cell that contains that same known genetic mutation. It is a powerful modeling system for drug development.



The cells will be made available to scientists as a public resource and will enable and encourage collaborative research among academic and industry investigators, ultimately accelerating basic science discoveries and therapeutic development for late-onset neurodegenerative diseases. The partnership is coordinated by the Foundation for the National Institutes of Health.

AFTD will join other funders and NIH project leaders on the Consortium External Scientific Board, an independent forum for partners to discuss the design and execution of the project. 

## Donations Honor Loved Ones

Gifts received from February 1 - June 15, 2011

### In Honor Of:

Harold Abraham  
Jerry Aden  
Amy Banks  
Steve Banks  
Linda Bernardin  
Stephen Besch  
Sondra Birnbaum  
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Sheila Fiermonte  
Al Foltz  
Mimi Freeman

### In Memory Of:

Ashraf Abbasi  
Glenn G. Andrews  
Joann Andrews  
Emerson Avery Jr.  
Sondra Birnbaum

## Boston *(continued from page 1)*

Chamber, LCSW; Susan Dickinson, M.S. and Matt Sharp, M.S.S. of AFTD

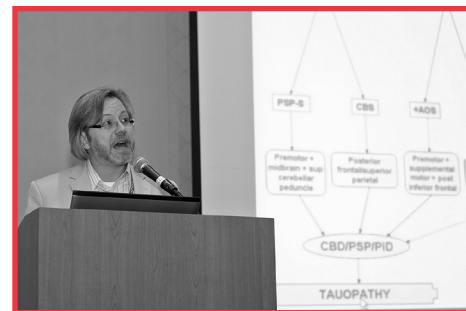
- Parenting While Caring for a Diagnosed Spouse, led by Judy Pare, RN; Sharon Denny, M.A. of AFTD; and Aly Negreira, B.A.
- Extended Family and Friends of Person Diagnosed, led by Brad Dickerson, M.D.; Kimiko Domoto-Reilly, M.D.; and Emily Levy, M.B.A.

Each session was facilitated by two healthcare professionals from different disciplines as well as an AFTD staff-person or board member. The sessions were interactive with plenty of pertinent questions for the professionals as well as for other caregivers who were going through similar situations.

At 3:30 p.m. attendees re-convened for AFTD's Annual Meeting. Ms. Walter recognized key volunteers in the room and the mounting sense of community. AFTD Executive Director Susan Dickinson chronicled the organization's key achievements over the past year, which include: donations topping \$1 million for the first time; completion of a report on the special challenges that face a family with young children; and co-hosting of three meetings with pharmaceutical and biotech companies to discuss FTD drug development. Participants were then treated to the first public showing of AFTD's film *It Is What It Is*, a documentary that chronicles the lives of four families directly affected by FTD. Filmmaker Joe Becker and Chris and Christopher Yurkanan, one of the families

highlighted in the 18-minute film, were present and stood to a round of applause to acknowledge their efforts in creating the film.

Dr. Bradford Dickerson, neurologist and director of the Frontotemporal Disorders Unit at Massachusetts General Hos-



*Bradford Dickerson, M.D., presents the keynote address at the annual caregiver conference. (photo courtesy of Karen Rodgers)*



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

Evelyn Friedman  
Susan Fulton  
David Gates  
Dr. John Gibbs  
Tom Gregerson  
Grover G. Grimm  
Mary Gutierrez  
Kathryn K. Haack  
Allen Hansen  
James Hartsock  
Bob Haslam  
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Robert Hermann  
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Jon Hickey  
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Robert L. "Robin" Ward  
Jack Wilhelm  
Jack Wolf  
John Willard Guy Wood  
Laurence F. Yerdon

**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 acknowledgement, and families will receive a list of donors.

To download materials from our website, go to *About AFTD*, then *Get Involved*, and click on *Donate*, then *Contribute Electronically*.

pital, gave the keynote address, *Frontotemporal Degeneration: New Tools for Early Diagnosis and Monitoring Set the Stage for Treatment Trials*. Dr. Dickerson spoke about the spectrum of diseases that comprise FTD and how their "overlap" with one another further complicates accurate diagnosis. He also spoke of the advances in diagnostic imaging as well as the importance of developing biomarkers for FTD.


Following the conference, approximately 100 people attended a recep-



*At the reception (from left to right): conference coordinator Joyce Shenian; AFTD board chair, Beth Walter; board member, Sylvia Mackey; and AFTD founder and board member Helen-Ann Comstock (photo courtesy of Karen Rodgers)*

tion hosted by 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 Boston conference, visit AFTD's *Past Caregiver Conferences* page under the *Support and Research* section of [www.theaftd.org](http://www.theaftd.org).

A date for next year's conference is yet to be determined, but the location will be in Atlanta, Ga. 

## When Parents Become Caregivers of Adult Children

**W**hen the late Bryan Thornley was diagnosed with FTD at age 30, he had just become the father of a baby boy. His mother, Jeanine Christoffersen, was in her mid-50s and in the best physical shape of her life. Looking back, she is thankful she had that strength to tap as she faced the ordeal to come.

Nancy and Jim Weaver, in their late 70s, are aware of the issues of the elderly. They volunteer extensively at senior centers near their Missouri home. Their familiarity with memory issues and aging is only vaguely helpful, however, as they absorb the pain of having a 52-year-old daughter Chris, formerly an instructor in a North Carolina university, who has FTD.

Soaking up Arizona sunshine during January and February helps Faye Olivieri, 72, heal from the grind of caring for her son, Larry, 48. He has multiple sclerosis and, for five years, has been living with a probable diagnosis of FTD. The weeks of respite away from her Philadelphia home, where Larry lives in a nearby apartment, were once a luxury for Faye. Now they are a life-saving necessity.



*Faye Olivieri and son, Larry in 2010.*

Parents of adult children with FTD are uniquely affected by the diagnosis. Beyond the heartache of a seriously ill child, countless other difficulties arise. They witness the derailment of their child's family life, including lost livelihoods and

marriages, and often find themselves in the role of caregiver.

"I cried for four months straight," says Nancy Weaver, describing the days following the diagnosis. "One day I realized I hadn't cried all day. Then I had to deal with the guilt I felt about that."

Nancy finally "talked herself through" the depression that had overtaken her. She found distractions in books, her community and focusing on what she could do for her daughter. Chris's father describes his own brand of coping by noting the stages of his grief -- denial and anger.

"Acceptance hasn't come yet," he says, his voice choked with emotions he cannot easily express.

The Weavers and their other three daughters negotiated a schedule where one of them visits Chris every month for a few days. Chris has two grown children. She was diagnosed shortly after marrying her second husband in 2006.

Larry Olivieri landed on his mother's doorstep four years ago, shortly after she remarried. That was the day his marriage ended and Faye's immersion in his care began. His marriage of 12 years had collapsed under the weight of his illnesses as well as the demands of his 10-year-old daughter with Down syndrome and autism, and a baby daughter.

Faye set him up in an apartment and helped him manage his carpet cleaning business until it had to close. Now, disability payments and Medicaid assistance help support the apartment and the aides who watch over him. Faye has mixed feelings.

"I am thankful for the caregivers. They make it possible for him to stay in the apartment," she says. "But I feel guilty he is not living with me. But if he lived

with me, I know I couldn't make it. What good is it if I sink? How will that help?"

"Right now we can spend time together," says Faye, who returns once a month during her stay in Arizona to see him.

.....  
*"I cried for four months straight," says Nancy Weaver, describing the days following the diagnosis. "One day I realized I hadn't cried all day. Then I had to deal with the guilt I felt about that."*  
 .....

"It's not how I had hoped I would participate in his life, but I'm grateful for the time with him."

Three hundred pages of Jeanine Christoffersen's diary reveal the "dark time" she and her other son endured as Bryan suffered

with hallucinations, disabling obsessive compulsive behaviors and confusion.

For three years, Jeanine spent a week each month away from her home in Orlando to help Bryan's family in Utah. She wanted to give his young wife, who was studying to be an LPN and was caring for their baby, a break. Jeanine did housework, bathed and dressed Bryan, and prepared the house for sale. She even slept outside Bryan's bedroom door when she feared he might wander.

"I could get him to do things," she says of Bryan, who resisted taking direction from his wife. "He seemed to revert back to being a child taking orders from his mother."

Bryan finally entered a facility but only lived another week after the move. After the intensity of her commitment to his care, Jeanine still has regrets.

"I wish I had talked to him more about how he was feeling," she says. "He must have felt lonely, but he would get agitated. I am relieved he is no longer living like that. I loved him with all my heart. That never changed even though he wasn't the same person. I knew he was in there somewhere and he still needed that love." AFTD

*Contributor Elaine Rose of Silver Spring, Maryland is caregiver to her husband who has FTD.*



## New Initiative Provides Training to Care Facilities

**A** new initiative by the Association for Frontotemporal Degeneration (AFTD) will expand the education and resources available to day programs and residential care facilities to help them become better partners in care with FTD families.

AFTD's Committee on Long-Term Care Facility Education, which began meeting in April 2011, is comprised of two caregivers and five professionals with extensive experience in the fields of dementia care nursing, social work, long-term care and education and program development.

People with FTD are served in many different settings including group homes, assisted living, special dementia care units and skilled nursing facilities. The regulations, staffing and services of these facilities can vary greatly across states and levels of care.

"We recognized," said Sharon Denny, AFTD program director, "that the most effective approach to education of facility staff is to build on our strength: to reach out through AFTD's existing networks of families and offer a committed community that will assist people who want to learn."

Denny notes that some facilities do excellent work with FTD patients now because families work hard to be advocates and teachers. "Our goal is to make it easier for families. We want to prepare facilities with the knowledge and tools they need to serve people with FTD, and create a network of facilities working with us to pioneer new FTD-specific approaches to care."

The committee has designed a three-pronged approach to achieve this goal: 1) to introduce facilities to the needs of people with FTD and their families and have them connect with AFTD, 2) to deliver regular information and case examples on how to work with FTD patients and 3) to provide a responsive mechanism for interactive problem-solving assistance and support from experts in the field to increase the frequency of successful placements and quality of services.

Beginning in August, AFTD's film *It Is What It Is* will be available in a package designed especially for care fa-


cilities that includes the DVD, new print materials for facility staff and instructions on how to connect with AFTD for continuing education opportunities. Families can purchase the special package (for \$10 domestic, \$22 international), take it to the facilities they use and encourage them to enroll for additional training and support.

Susan Hirsch, RN, education and development group specialist, HCR ManorCare, has seen the impact the film has with staff. "We are using it in the dementia training at all the Arden Court facilities, to great effect," she said. "Hearing the families' experiences really sensitizes staff to the issues and shows them how different FTD is from Alzheimer's." A guide for discussion of the film with facility staff is included in the package.

Facilities can sign up to receive a regular quarterly bulletin produced by the committee for day programs and residential care facilities starting in September. It will include information for direct caregivers on FTD behaviors and symptoms, positive ways to communicate with and engage people with FTD, and examples of interventions that work. The free bulletin will be delivered electronically to any interested day program or residential care facility and archived on AFTD's website.

In early 2012, AFTD plans to implement an interactive online forum for facility staff to share questions and issues with FTD health care experts on establishing best-practices in patient care. Jill Shapira, Ph.D., RN, UCLA FTD and Neurobehavior Clinic, feels "access to an experienced professional may be what is needed to explain a particular behavior and help staff understand and approach it differently. This alone could save many placements."

The response to and feedback received through these fundamental education components will guide additional efforts by the committee. Offering web-based training and developing partnerships for accredited continuing education courses for nurses and other health professionals are future priorities of the initiative.

For more information on the AFTD long-term care facility education initiative, email [info@theaftd.org](mailto:info@theaftd.org). 

### Committee on Long-Term Care Facility Education

**Sharon Denny, M.A.**, program director, AFTD, Radnor, PA

**Sandi Grow, RN**, caregiver, Massillon, OH

**Lisa Gwyther, M.S.W., LCSW**, director, Duke Aging Center Family Support Program at Duke School of Medicine, Durham, NC

**Geri R. Hall, Ph.D., ARNP, GCNS, FAAN**, advanced practice nurse, Banner Alzheimer's Institute, Phoenix, AZ

**Barbara Harty, GNP**, gerontological nurse practitioner and clinical research coordinator at University of North Texas Health Science Center, Fort Worth, TX

**Susan Hirsch, RN**, education and development group specialist, HCR ManorCare, Mechanicsburg, PA

**Jill Shapira, Ph.D., RN**, nurse practitioner, UCLA FTD and Neurobehavior Clinic, Los Angeles, CA

**Jan Sylanski**, caregiver, McMurray, PA


## Awareness Carol Maglich: Navigating the Stormy Sea of FTD

This March, Carol Maglich pushed her nerves aside and stood before an audience of 800 people to tell the story of her family's search for a diagnosis for her husband, Terry. The audience was gathered to hear organist Hector Olivera play a fundraising concert for people with dementia, and Maglich was responsible for the opening remarks. In her speech, Maglich rejected the euphemism "journey to a diagnosis" and instead compared the five tumultuous years that she and her family searched for a diagnosis to a shipwreck. Maglich described her family boating on peaceful seas when a storm appeared out of nowhere rocking the boat so powerfully that it capsized, leaving captain and crew struggling together to survive. Maglich's metaphor is particularly meaningful given the fact that before her husband developed FTD, the Magliches and their three children, Jen, Julie, and Joseph, enjoyed many summer weekends boating on Lake Erie with Terry Maglich as trusted captain.

Since her husband's diagnosis, Maglich has courageously taken the helm as an advocate for her husband and as the Midwest Regional Coordinator for AFTD. As regional coordinator, Maglich aims to heighten awareness of the disease

and to connect the friends and families of FTD patients with the right people. In another effort to educate her community about FTD, she, her son and her husband appeared on Cleveland Channel 3 News: <http://www.wkyc.com/news/story.aspx?storyid=130838>. Caregivers and family members of FTD patients know this takes courage.


Maglich is clear about her motivation, "Our family suffered terribly during those years in search of a diagnosis. I don't want to see another family suffer that way and lose such precious time. I got involved in order to play a part in helping families who are struggling with getting a diagnosis and guide them to AFTD to get the help and resources AFTD has to offer."

If Maglich could give one piece of advice to families and friends of individuals with FTD, she would say, "You can't do it alone. You need support." Maglich, who takes her own advice, is ever grateful for her crew of family and friends, "Team Terry." In the relentless storm of FTD symptoms, they have been and continue to be her life raft. 

*Contributor Catherine Savini is assistant professor of English at Westfield State University in Westfield, Massachusetts.*

## Regional Coordinators: Ambassadors for Awareness and Support

AFTD regional coordinators are volunteer leaders and official, authorized representatives of AFTD working to increase the Association's impact in all aspects of its mission with a particular focus on awareness, education and caregiver support. As AFTD's ambassadors, the regional coordinators provide crucial communication links and contact points for AFTD throughout the US and Canada. Regional coordinators direct people seeking help to AFTD and appropriate resources in the region; distribute information from AFTD in various forms; represent AFTD at fundraisers, awareness events and educational conferences in the region or assist with organizing and coordinating such events; and help establish new FTD caregiver support groups.

There are currently seven active coordinators across the United States and Canada, and each of them would welcome your interest and support. E-mail contacts for them are available on the US and Canadian support pages of AFTD's website. There are also seven regions (six in Canada and one in the US) in need of a coordinator. If you are a current or former caregiver and are interested in learning more about the history, mission and vision of AFTD and gaining an advanced degree of knowledge about all forms of frontotemporal degeneration, please get in touch with Program Coordinator, Matt Sharp for more information at [msharp@theaftd.org](mailto:msharp@theaftd.org) or by calling 866-507-7222. 

## Team Neon Extreme Takes on 189 Miles...and Succeeds!

Siblings Alexandra and Graham Sparks of Rhode Island gathered a group of 12 runners to form Team Neon Extreme. On May 6 and 7, Neon Extreme ran 189 miles in The Cape 13 Relay in Massachusetts from Quincy to Provincetown, Cape Cod. Their extraordinary effort raised more than \$21,000 for AFTD and FTD research, which surpassed their initial goal of \$15,000. Team Neon Extreme also succeeded in educating more people about FTD. The Sparks' father, Kenny, was diagnosed in 2004 with FTD, and the family was featured on CNN in December 2009.

*(Pictured below: Team Neon Extreme at the finish of The Cape 13 Relay)*



## Tell 10 People Events



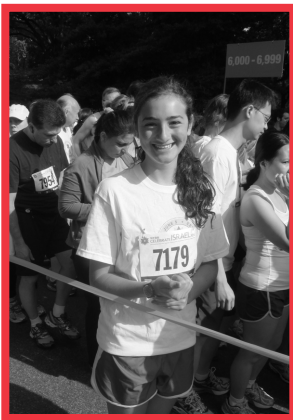
### Barry Marcus Tours NYC by Bike for AFTD

On May 1, Barry Marcus logged 42 miles in the TD Bank Five Boro Bike Tour in New York City. Barry's ride raised more than \$6500 for AFTD. He rode in honor of his wife, Sue, who has FTD.

*<< Barry Marcus at the finish line of the Five Boro Bike Tour in New York City.*

### Fourteen-year-old Runs for AFTD, Mother

Olivia Goldring, pictured to the right, ran in the New York Road Runners "Celebrate Israel 4-Mile Run" in Central Park on June 5, 2011. Olivia's goal in participating was to raise funds and awareness for AFTD. She raised over \$1300 while running in honor of her mother Rachel.



### Quest for the Cure Raises \$27,000 for AFTD

AFTD board of directors chair Beth Walter organized the 4th annual Quest for the Cure golf tournament on Monday, May 9, 2011 in Rancho Murieta, California. This year's event raised

\$27,000 for AFTD and FTD research, bringing the four-year total amount to more than \$100,000.

Hosted by the Walter Charitable Fund, the Quest for the Cure honors the memory of Walter's husband and his four family members who passed away from FTD.



### Sign Me Up, AFTD!

If you've been inspired by the fundraising feats accomplished by the AFTD community, we've got great news! You, too, can do great things to spread awareness of FTD and the work of AFTD. The most important ingredient to successful grassroots fundraising is an enthusiastic and motivated organizer.

If you would like to fundraise on behalf of AFTD, we are ready to help you! Contact Angie Maher at [amaher@theaftd.org](mailto:amaher@theaftd.org) with your ideas and questions, and let's open the gateway to help and a cure!

### Scout for Scooter Returns for Year Two

On Sunday, May 15, members of the Dave "Scooter" Scaggs family rallied their family and friends to raise money for AFTD for the second annual Scout for Scooter 5K & 1-Mile Walk & Run. This year's event raised more than \$34,000 for AFTD. Dave Scaggs is a retired soccer and basketball coach who was diagnosed with FTD in 2008.

*<< Second annual Scout for Scooter event draws another great crowd. (photo courtesy of Brian Lausch)*







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Opening the gateway to help and a cure

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