



The Association for Frontotemporal Degeneration

Opening the gateway to help and a cure

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AFTD Adopts New Name, Renews Mission

Responding to feedback from patients, families, and many medical experts, AFTD has changed its name to **The Association for Frontotemporal Degeneration**. The change was adopted in recognition of a recent shift in medical terminology, as well as a strong desire that AFTD be a place where patients and caregivers living with the wide variety of diagnoses the organization supports will feel welcome.

“The AFTD Board of Directors unanimously supported this decision,” says AFTD Board Chair Beth Walter. “We have so much important work to do, we invite everyone affected by any of these diseases to join us to spread awareness, create support services and fund the research that will produce a cure.”

The decision came after a lengthy process that included surveying the

varied constituent groups that AFTD serves: patients, caregivers, researchers and clinicians. Work led by an ad hoc committee of AFTD’s Board of Directors also included an extensive literature search and engaged discussions

*With a new name,
comes a new web address.*

*Visit us at
www.theaftd.org.*

with the organization’s Medical Advisory Council and peer organizations.

While results were not unanimous, some facts did emerge. A significant portion of families do not identify with the term “dementia” and some are offended by it. Many of the clinicians indicated that they do not use

the word “dementia” when diagnosing a person with an FTD language or movement disorder. In the literature, researchers use a variety of terms to refer to the broad group of diseases: some use “frontotemporal dementias” some use FTLD, or frontotemporal lobar degeneration (which is a broad term for the underlying disease pathology) and at least one journal has already used “frontotemporal degeneration.”

“All of our experts agree that this array of clinical disorders include different types of abnormal protein aggregation in the frontal and/or temporal lobes of the brain,” says Emily Levy, ad hoc committee chair. “So it became clear that we needed a comprehensive term that includes all of the clinical subtypes and all of the pathologies.”

(See New Name, page 4)

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Current Advances in FTD Research

A Medical Advisory Council Update from Bradley Boeve, M.D.

Interest and activity in FTD continues to build, and brings with it the hope that within the coming decade we will witness the first disease-modifying therapies. The following summary is a brief update on several current advances within the FTD research community:

Strategic Research Analysis

AFTD and the Alzheimer’s Drug Discovery Foundation (ADDF) commissioned a comprehensive review of funding from 1998 – 2008 for FTD-related issues. The intent of the analysis is to review research funding internationally, explore the pattern of research spending, and to determine where gaps and opportunities exist. A summary of the report will be published this

(See Research Advances, page 4)



Bradley Boeve, M.D.
Chair, AFTD Medical Advisory Council

Spotlight On...Emily Levy, AFTD Board of Directors

When Emily Levy finds herself at a dead end her solution is simple: build a new road. As a consultant in the biomedical field, Levy is used to finding a new way. But when Levy's friend, Alice, was diagnosed with FTD in 2007, she had no idea how many new roads she'd end up building as a result.

Alice had no close family available to help care for her through the disease. And so when Alane Airosus, a friend of Alice's from childhood asked for help, Levy and some of her other Boston-based friends set up a support system they called "Team Alice" to manage all aspects of her care. Levy took on the role of healthcare proxy, and later, foster mom to Alice's Labrador retriever (a role Levy's cat is less than pleased with).



But when Team Alice set out to learn more about FTD support in Boston, they didn't just hit a dead end: "It just felt like we were dropped into a black hole," she says. "There was nothing."

But true to her nature, Levy was determined to find her way out of the black hole and into the light.

"We started a support group thinking that when people came they would know what to do. Of course we were wrong! They were as lost as we were!" This just motivated Levy to work harder to find help for Team Alice, and the group of caregivers she had brought together. She asked the group what they needed. If there were medical questions, she'd find a doctor.

Legal questions? She found a lawyer.

As the support group continued, Levy developed a relationship with AFTD. In 2010, she joined the Board, and Research and Awareness Committees. "I thought, wow, I've just found what I didn't even know I was looking for," Levy says. What she was looking for, it turns out, was a chance to lend her skills to the broader cause. "It really has been an amazing journey to be part of the growth of the organization, and then be able to have an impact on what happens next."

As for the road ahead, Levy is ready for the challenge. "We just have to keep going. We just have to find the people who bring the drive, the money, the connections, and the will to get it done." Because, to Levy, the road may be long, and there may be some roadblocks, but the only place to stop is a cure.

Contributor Nicole Savini is a member of AFTD's Awareness Committee

AFTD NEWS BRIEFS



Mario Mendez, M.D., Ph.D.

By live webcast, 130 people participated March 2 in Grand Rounds on "The Spectrum of Frontotemporal Degeneration" at the University of North Texas Health Science Center (UNTHSC), representing the largest participation UNTHSC has had to date. The program, presented by Mario Mendez, M.D., Ph.D., of the AFTD Medical Advisory Council, was designed for general practitioners and other clinicians interested in learning more about the diagnosis and care of patients with FTD. It is available at cme.edocendo.com.

Participants are needed for a study to evaluate the safety and efficacy of the drug davunetide for the treatment of progressive supranuclear palsy. For additional information, go to www.clinicaltrials.gov, click *Search for Clinical Trials* and enter "PSP davunetide."

Grants through the Comstock Caregiver Respite Program help full-time, unpaid caregivers arrange short-term daytime or overnight care for loved ones diagnosed with FTD. For more information or to apply for a grant, go to *Support & Resources* on our website, click *Finding Support* and *Day Programs & Respite*.

Clinical Tools, Inc. is looking for caregivers to participate in a research study to help develop a website for Alzheimer's disease and dementia caregivers. The Chapel Hill, North Carolina, company recently received funding from the National Institute on Aging to develop the educational and support website. For more information or to participate in the study, go to *Newsroom* and click on *Newsfeed* on our website.

Three new caregiver support groups began meeting in January and February, bringing the total number of groups in the U.S. to 52. **A new FTD and Lewy body caregiver support group in the southwest region** met for the first time in January in San Diego, Calif. The group continues to meet from 2 to 3:30 p.m. on the first Wednesday of each month. For details and to pre-register, call Lisa Snyder at 858-622-5800.

The south Atlantic region's newest caregiver support group met for the first time in January in Cary, North Carolina. The group continues to meet at 7 p.m. on the third Tuesday of each month. For location and details, contact Tayloire Queen at thequeens@nc.rr.com or 919-796-5752.

In New England, a new caregiver support group met for the first time in February in Salem, New Hampshire. The group continues to meet every other Monday from 6 to 8 p.m. For details, email Val Pierce at foxfire20010@yahoo.com (please include "FTD Support Group" in the subject line) or call 603-401-5544.

Grants Awarded for FTD Biomarkers

The Association for Frontotemporal Degeneration (AFTD) and the Alzheimer's Drug Discovery Foundation (ADDF) recently awarded four grants to develop biomarkers for FTD. Thanks to a generous partnership with ADDF, which matches funds raised by AFTD 2:1, as well as a challenge grant from Lee Danis of Dallas (see story on page 7), \$460,000 was awarded.

"We were tremendously pleased with the applications we received; very high-quality projects were submitted by excellent scientists from a wide range of scientific specialties and institutions," says AFTD Board Member Philip Lovett. "The grants we have awarded address the full breadth of challenges we face: finding biomarkers for accurate diagnosis, as well as those that will measure progression of disease. They also incorporate a promising variety of tools available: genetics, samples from cerebrospinal fluid and brain imaging."

Receiving grants were:

William Hu, M.D., Ph.D., at the Emory University School of Medicine, Atlanta, Georgia, \$100,000 for *CSF Biomarkers of FTL-D-TDP and FTL-D-Tau - A Multi-Center Study*;

Allen Roses, M.D., at the Duke Center for Drug Discovery, Durham, North Carolina, \$125,000 for *Fine-mapping and characterization of genetic biomarkers that facilitate the acceleration of drug discovery for frontotemporal dementias*;

Marcel M. Verbeek, Ph.D., M.Sc., at the Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands, \$100,000 for *TDP-43 and tau as cerebrospinal fluid biomarkers to discriminate frontotemporal dementia subtypes*; and

Victor Villemagne, M.D., at the University of Melbourne, Melbourne, Australia, \$135,000 for *[18F]-THK523, a novel in vivo tau imaging agent*.

Biomarkers are biological factors that can be measured (like measuring cholesterol in the blood or viewing a tumor on MRI), and thus inform the clinician as to what is going on in a patient's body. Because FTD is a neurodegenerative disease that occurs in the brain - a part of the body from which it's difficult to take a direct sample - it can be hard to identify specific cause and progression of the disease without biomarkers. Biomarkers are the current quest of many neurological diseases.

To read more about these projects, please go to www.theaftd.org.

Dickerson, Lipman Slated for Annual Meeting

Join Us June 10 in Cambridge, Massachusetts

Neurologist Bradford Dickerson, M.D., and *New York Times* best-selling author Elinor Lipman will speak at The Association for Frontotemporal Degeneration's 2011 Caregiver Conference and Annual Meeting, set for June 10 in Cambridge, Mass.



Bradford Dickerson, M.D.

Dr. Dickerson, director of the Frontotemporal Disorders Unit at Massachusetts General Hospital and a member of the AFTD Medical Advisory Council, will deliver the keynote address, titled "Frontotemporal degeneration: New tools for early diagnosis and monitoring set the stage for treatment trials."

Lipman, the author of nine novels, including *Then She Found Me*, the basis for the 2008 movie of the same name starring Helen Hunt, Bette Midler and

Colin Firth, will give the opening address. Lipman lost her husband, Bob, to FTD in 2009; the *New York Times* published her acclaimed essay and tribute to him, "Sweetest at the End," in 2010.

This year's caregiver conference will provide participants

with a unique, interactive half-day education program. Attendees may choose to participate in one of four separate breakout sessions focused on the issues and challenges that may arise between caregivers and their loved ones with FTD. Along with staff members at Massachusetts General Hospital and the New Hampshire & Massachusetts Chapter of the Alzheimer's Association,

AFTD has designed sessions for spouses and partners, families with school age children, adult children, and extended family and friends of people with FTD. The sessions, each of which will be facilitated by two healthcare professionals from different disciplines, will offer unique opportunities for attendees to ask questions not only of professionals with expertise in FTD but also of caregivers in similar situations.



Elinor Lipman

Photo courtesy of Gabriel Amadeus Cooney

The caregiver conference will include a showing of the AFTD film, *It Is What It Is*, which chronicles four families as they confront FTD (see story on page 10). Conference guests are invited to a reception at day's end hosted by AFTD's Board of Directors. For more information about the conference, visit www.theaftd.org.

New Name *(Continued from page 1)*

“The term ‘degeneration’ emphasizes some of the critical characteristics of FTD – the gradual and progressive nature of the degeneration in brain cells, as well as variable degrees of the degeneration in cognitive, behavior, language, and motor functioning,” says Bradley Boeve, M.D., chair of AFTD’s Medical Advisory Council.

AFTD will now use “FTD” to mean frontotemporal degeneration, an umbrella term that encompasses both clinical and pathological diagnoses. The clinical diagnoses include: language disorders (primary progressive aphasia and its three subtypes); movement disorders (progressive supranuclear palsy and corticobasal syndrome) and the behavioral disorder, which is known by a variety of names: behavioral variant FTD, bvFTD, frontotemporal dementia and Pick’s disease. The main proteins involved in causing FTD are TDP-43, tau and FUS.

“We feel this change will be helpful to our families,” says Helen-Ann Comstock, founder of the organization.

“We believe this new overarching term - frontotemporal degeneration - will stand the test of time.”

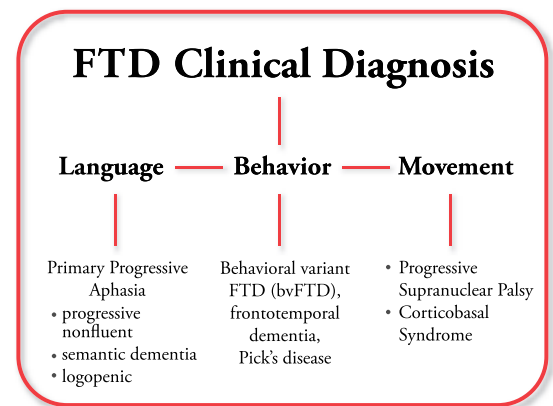
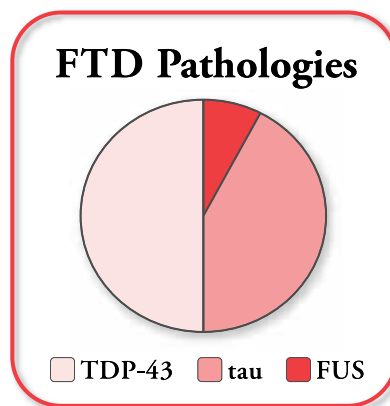
“Only our “D” has changed,” emphasizes AFTD Executive Director Susan Dickinson. “We want to assure everyone that our mission, vision, staff, brand and IRS tax-exempt status remain the same. Most important, we retain our strong work ethic and values of knowledge, positive action, collaboration, respect, dignity and compassion.”

“We have ambitious goals for 2011 and beyond,” Walter says. “They include

funding more research, educating medical professionals about these diseases, and advocating for and developing much-needed resources for our families.

“I invite everyone to join with us,” she adds. “Working as a community, I firmly believe that together we can achieve our vision of: **A world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.**

For more information about AFTD’s Strategic Plan, visit www.theaftd.org, click *About AFTD* and *Strategic Plan*.



Research Advances *(Continued from page 1)*

spring in the scientific journal, *Alzheimer’s Research and Therapy*, and will provide researchers and funding agencies with information to develop key programs while also minimizing duplication of efforts. (To see the full analysis, go to www.theaftd.org and click on *Research*, *AFTD Research Initiatives* and *Stimulating Research*.)

Funding for FTD research infrastructure

While many centers around the United States have been involved in FTD research over the past several years, there has not been any infrastructure built to foster collaborative research across many sites. Recognizing this weakness in 2010, the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute of Aging (NIA), and AFTD convened

many experts in the FTD field, and all are finalizing development of infrastructure methodology for research devoted to FTD. A key component of this project is a central database to be used by various clinical centers, so that patient data can be pooled effectively (and anonymously). This effort is taking advantage of the infrastructure already in place in NIA-sponsored Alzheimer’s Disease Centers, and expands this to include the clinical, neuropsychological, neuroimaging, biomarkers, genetics, and pathologic domains specific for FTD. This infrastructure will greatly enhance collaborative research in FTD, which is critical for quickening the pace for discovery. AFTD extends its gratitude to NINDS and NIA for devoting their efforts and attention to funding toward FTD research.

FTD clinical trials

There are a handful of FTD clinical drug trials in progress in the U.S. and abroad. Several more studies are in the development stages, and some forthcoming conferences involve experts from academia, federal agencies, and the pharmaceutical industry as preliminary data is shared and future trials are planned. Patients and families are encouraged to periodically access AFTD’s website and particularly the ClinicalTrials.gov website and enter FTD, PPA, PSP, CBS or CBD (or the full terms for these abbreviations) to remain updated on clinical trials.

PPA nomenclature and characterization

The older terminology with the two variants of primary progressive aphasia

(Continued on next page)

Dickson to Receive Prestigious Potamkin Prize



Dennis Dickson, M.D.

Dennis Dickson, M.D., a member of AFTD's Medical Advisory Council, has been selected as a recipient of the 2011 Potamkin Prize for his work in the study of dementia. Dr. Dickson, of the Mayo Clinic in Jacksonville, Fla., is the seventh member of the Medical Advisory Council to receive this award. The Potamkin Prize for Research

in Pick's, Alzheimer's, and Related Diseases honors researchers for their work in helping to advance the understanding of dementia. The award recognizes major contributions to the understanding of the causes, prevention, treatment, and cure for FTD, Alzheimer's, and related diseases.

Dr. Dickson is receiving the Potamkin Prize for his research involving tau, a brain protein that is abnormal in a number of different neurodegenerative disorders, including FTD and Alzheimer's disease.

"Neuropathology is the science that underpins all other brain sciences in that it describes the changes in the brain related to the underlying disease process," Dr. Dickson says. "Understanding the neuropathology of dementias is the first step towards developing better methods to diagnose, treat and eventually prevent these disorders."

The Potamkin Prize is made possible through the philanthropic contributions of the Potamkin family of New York, Philadelphia and Miami. Robert Potamkin is a former member of the AFTD Board of Directors. The goal of the prize is to help attract the best medical minds and most dedicated scientists in the world to the field of dementia research.

AFTD is proud to recognize all MAC members who have received the Potamkin Prize. Past prize winners include:

Karen Duff, Ph.D.

Michael Hutton, Ph.D.

Bernardino Ghetti, M.D.

Virginia Lee, Ph.D.

Bruce Miller, M.D.

John Trojanowski, M.D., Ph.D.

(Continued from page 4)

(PPA) known as progressive nonfluent aphasia (PNFA) and semantic dementia (SD) has served the field well. Considerably more knowledge has been gained in the PPA field, leading a group of experts to develop updated terminology and clinical characterization of what are now known as the three key variants of PPA – the nonfluent/agrammatic variant (formerly the PNFA variant), the semantic variant (formerly the SD variant), and the logopenic variant; the publication describing this new information will be published shortly. By applying the new criteria for diagnosis, clinicians will be able to diagnose patients more readily and accurately. This will become increasingly important for forthcoming clinical trials since each PPA variant tends to be associated with a particular dysfunctional protein.

bvFTD nomenclature and characterization

The International bvFTD Criteria Consortium is continuing their work on validating updated criteria for the diagnosis of frontotemporal dementia, or behavioral variant FTD (bvFTD). These new criteria will be published in the near future, with the hope that they will allow clinicians to better identify who has FTD (which is again important for clinical trials) and who has atypical Alzheimer's disease, atypical Lewy body disease, the "FTD phenocopy" (displaying symptoms of bvFTD without actually having the disease) or some other disorder.

Education of primary care clinicians

AFTD and several members of the Medical Advisory Council are working to communicate these research advances to primary care physicians, thereby

improving diagnosis and clinical care for FTD patients. Two education initiatives AFTD is sponsoring this year are a one-hour online CME training course and a full-day course on the neuropsychiatry of FTD at Columbia University. There is much work to be done in this area, but it is exciting to see growing demand for these learning opportunities.

Summary

These are exciting times, but our work is far from done. We are seeing progress in areas of diagnosis, care and drug development. To reach these goals, it is critical that patients and families are active participants with our research community. AFTD plays an important role in bringing our community together. I encourage you to stay informed and stay involved.

Donations Honor Loved Ones *Gifts received October 16, 2010 - January 31, 2011*

In Honor Of

Jerry L. Aden
 Dr. Lawrence Albert
 William Allen
 Renee Bachant
 Jon Berkley
 Dee & Jerry Behrens
 Steven Besch
 Brad Bishop
 Sandra Bishop
 Polly Bloor
 Richard Blount
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 Catherine W. Broer
 Michelle Brown
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 Chip Chaimberlan
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 Mary Hesprich
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 Bonnie Miller
 Louise B. Miller
 Arthur Moyer
 Nancy
 John M. Nies
 Frank Nitikman's
70th Birthday
 Charles William Pasic
 Doug Pearson
 Gibby & Doug Pearson
 Camilla Perry
 Marian Philp
 Anna Pontrelli
 Skip Schnierow's
80th Birthday
 Carol Schumaker
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Holly Shamsai
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 John Stackhouse
 Al Stevenson
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 Carol Tyler
 Helen Van Son
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 Bruce Viemeister
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 Mary Waters
 Sally Watson
 David Westmoreland
 Della Whatley
 Judy Windhorst
 Nancy B. Young
 Chris & Christopher Yurkanan

In Memory Of

Glenn G. Andrews
 Frances Angelino
 Emerson R. Avery, Jr.
 William "Bill" Basile

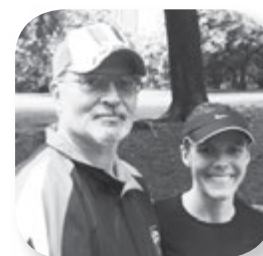
Matching Gift Programs Have Many Benefits

When Michael Angello's personality changed from mild-mannered to argumentative, his family took him from one specialist to another to determine the cause. It took four years before Angello received a proper diagnosis: the 65-year-old steelworker from Pittsburgh had FTD. Unfortunately, the Angello family's experience is not unique; too often individuals with FTD are misdiagnosed. Since her father was diagnosed with FTD, Deanna Angello has donated regularly to AFTD. And her employer, the large pharmaceutical company Pfizer, has been matching each charitable donation 1:1. This means that if she donates \$200, AFTD will receive \$400. Deanna Angello, an avid fundraiser, has been aware of Pfizer's matching gift program since she

started working there, but she notes, "Employees might not always know their company has such a program."

While no one wants to hear that their loved one has FTD, the diagnosis helps families understand their uncharacteristic and often disturbing behavior. This understanding leads to better relationships with, and care for, the person with the disease. Donations to The Association for Frontotemporal Degeneration can help raise awareness and fund research to help ensure that families receive proper diagnoses in a timely manner.

Many companies do have programs similar to Pfizer's. Matching gift programs have many benefits: they strengthen employee recruitment, cultivate positive morale



Michael and Deanna Angello

among workers, enable companies to diversify causes, improve corporate image, and, of course, allow for tax deductions. To find out if your company matches donations, check with the human resources department. If your company does not have a matching gift program, encourage them to start one.

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

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

David A. Berkowitz
Sondra Birnbaum
Norman K. Bogard
Marilyn Bolyard
Charles E. Brown
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Howard Thorn
Carmella Vernick
Robert "Robin" Logan Ward
Timothy Ware
Mary Waters
Barbara Weiss
John E. Wilhelm
Gail Wood
Deborah Woodcock
David Zomback

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

AFTD Meets the Danis Challenge

Thanks to everyone who contributed to the fall campaign for biomarker research, AFTD was able to meet the Danis Challenge by raising \$40,000. As a result, Lee Danis of Dallas and AFTD's partner in drug discovery, the Alzheimer's Drug Discovery Foundation (ADDF), have matched those funds 3:1.

Last year, Danis, whose wife, Susan, has FTD, issued a challenge to other donors to help speed the path to FTD drug discovery by matching his gift of \$40,000. The Danis gift, its challenge and the match added an additional \$160,000 to the \$300,000 already awarded for the development of FTD biomarkers (see story on page 3). Beth Walter, chair of AFTD's Board of Directors, says, "This is a tremendous boost for our research efforts."



Lee Danis (left) of Dallas issued a challenge to other donors to help speed the path to FTD drug discovery. His wife, Susan, was diagnosed in 2009 with FTD.

A biomarker, which is short for biological marker, is anything that can be measured to indicate the biological status of an organism. In practice, a

biomarker is usually a protein or other substance that can be measured in the blood or cerebrospinal fluid, or it can be a compound that attaches to a specific protein in the brain that "lights up" on imaging, such as a PET scan. Examples of biomarkers include cholesterol or blood pressure to assess cardiovascular health.

Biomarkers can be used to determine the protein that is causing disease, and thus provide an accurate diagnosis. They can identify disease in the early stages, before symptoms become evident. They can track progression of disease, determine which patients qualify for clinical trials, demonstrate drug-target interaction in the brain, and measure effect of a drug on disease progression. "Currently there are no reliable biomarkers for FTD," says AFTD Executive Director Susan Dickinson.

People with FTD Respond to On-Line Survey

There is an important change taking place in the field of frontotemporal degeneration (FTD). People diagnosed with FTD disorders want more information and support that address their needs, not just those of caregivers.

As diagnosis becomes more accurate, people with FTD may become aware of their condition at an earlier stage in the disease's progression. To date, diagnosis at a later stage has meant that support and education efforts focus primarily on caregivers. The vast majority of resources currently available are for caregivers rather than directly for people diagnosed with FTD, but AFTD is working to meet patients' needs.

Last fall, AFTD began reaching out to this important segment of the

FTD community. People diagnosed with FTD were invited to take a 12-question, on-line survey, titled "First Person Informal." The survey asked people to respond to questions related to obtaining a diagnosis, sources of information, current challenges and ways AFTD can be more helpful.

The thirty-five people who responded to the survey during the first three months it was available stressed listening to patients and expanding supports. AFTD can be most helpful, wrote one woman, if it "provides more support, coping and insight for the patient. Caregivers need support also. But there is a window of opportunity with an early diagnosis for doctors, nurses and caregivers to learn from patients and therefore learn how to help others."

Survey respondents included nearly equal numbers of men and women, ranging in age from 40 to over 70. Seventy-seven percent of those people said they have experienced symptoms for one to five years.

Fifty-seven percent were diagnosed within the past year and another 29 percent within the past two years. A range of FTD subtypes were represented; the most frequent response selected was FTD, but unsure what subtype, at 39 percent. Thirty-three percent identified language disorders, and 15 percent identified behavioral variant FTD (Pick's disease).

Was it difficult to get a diagnosis? "No," responded one person, "not after I got with the right doctors." The importance of having access to



The on-line survey for people diagnosed with FTD will help AFTD develop new initiatives and services.

a knowledgeable physician was echoed in a number of comments. Sixty-three percent of participants

indicated it was difficult to get a diagnosis; 37 percent said it was not. The often lengthy process is a source of frustration for many. "Doctors kept trying to pin me into a depressed or

h o r m o n a l woman role... . So much of my time (which I don't have) was wasted," wrote one woman.

P a t i e n t s reported

relying on the Internet to find information about the diseases, while many recognized that not all such information was reliable. In addition to the Internet (8 responses), people cited AFTD, a medical center or doctor, the National Institutes of Health, the Alzheimer's Association, the University of California, San Francisco Memory and Aging Center website, and the FTD Support Forum as helpful resources. For information on medical services,

community and other resources, the most frequent response (8) was that none are available. Other people noted that the Internet, doctors or medical centers, AFTD, the Alzheimer's Association, the VA hospital and the FTD Support Forum offered some helpful resources.

Information for caregivers fails to address the fundamental question of "how do I live with this as a patient?" People diagnosed with FTD are hungry for assistance with ways to maintain independence and dignity. Some want to know how to help family members recognize and accept changes in their prior abilities. They want to talk with other people who have a similar diagnosis. Several people who live alone noted particular concerns about not knowing what to expect.

P e o p l e responding to the survey urged AFTD to provide more support and coping skills for the patient, spread the

word about FTD, educate doctors with guidelines for screening and referral, and make current information on research and medical initiatives easily available.

People diagnosed with FTD who have not completed the survey are encouraged to do so at <http://www.surveymonkey.com/s/AFTDfirstperson>. Responses are compiled periodically and will be used to develop future materials and initiatives.

To date, diagnosis at a later stage has meant that support and education efforts focus primarily on caregivers.

Patients reported relying on the Internet to find information about the diseases, while many recognized that not all such information was reliable.

On Coping

How *Hard Times* and ‘The Snow Queen’ Gave One Caregiver Strength

*When Rachel Hadas’s husband, George Edwards, a composer and professor of music at Columbia University, was diagnosed in 2005 with dementia, Hadas turned to several old friends – Charles Dickens, Edith Wharton, and Hans Christian Andersen among them – for understanding and strength. In an excerpt from the prologue to her new book, *Strange Relation: A Memoir of Marriage, Dementia, and Poetry*, the award-winning author says literature helps her cope with loneliness, loss, and her husband’s illness.*

It’s impossible to say precisely when the symptoms of George’s illness began to show themselves. Just as most diagnosis of dementia must rely on hindsight, so [*Strange Relation*] proceeds by way of several flashbacks. I wrote most of it between 2005 and 2007, years when I was living with George but in a zone of deepening silence. During those years, literature was often my most faithful companion, so [*Strange Relation*] is in part a book about literature. More precisely, it’s about various literatures.

There were books toward which our situation steered me that I wouldn’t

have read otherwise, books with eloquent titles like *Stolen Mind*, *Death in Slow*

Motion, *Ambiguous Loss*, and *What If It’s Not Alzheimer’s?* A very different group included books and stories I had read years before and that I now saw in a new light. These included Dickens’s *David Copperfield* and *Hard Times*, Wharton’s *Ethan Frome*, James’s *The Portrait of a Lady*, and Andersen’s “The Snow Queen,” among others. Greek myths, too, took on a new urgency [and]... felt anything but remote; they were

more like pieces of a case history. And then there was poetry. Many of the poems that sustained me during this time were pieces I’d thought I already knew. But again, they spoke to me with fresh voices... .

Though many of them are certainly beautiful, these works of literature didn’t soothe or console or lull me with their beauty. On the contrary, they made me sit up and pay attention. Each in its own way, they helped me by telling me the truth, or rather a truth, about the almost overwhelming situation in which I found myself. I learned what isn’t always obvious under such circumstances: I wasn’t alone. Other people, these works reminded me, had experienced, if not precisely my dilemma, then their own, equally hard or harder. Those people had found the courage to face and describe situations which might easily have reduced them to silence. If silence was the enemy, literature was my best friend. No matter how lonely, frightened, confused, or angry I felt, some writer had captured the sensation. How does it feel when people you thought were your friends

I learned what isn’t always obvious under such circumstances: I wasn’t alone.

turn away from illness? When you’ve almost forgotten what love is like?

When you are forced to choose between unpalatable alternatives? Frost and Aeschylus and Merrill knew the answers to these questions – questions doctors don’t like to ask, let alone answer. In doctors’ waiting rooms or in the quiet evenings after George had gone to bed, or on the train to work, I read and read. Thank God I could still read.

And I could write. Some of the chapters in [*Strange Relation*] were in response to my need to record a



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conversation, a dream, a walk, or yet another doctor’s appointment. I rediscovered...that writing what you remember helps you to remember more. Turning life at its bleakest or dullest into prose was absorbing and also rewarding; the more I wrote, the more I remembered and understood.

I’m a teacher, but first and foremost I am a poet. Since my father’s death when I was 17 years old, poetry has steadily helped me not only to express what I was feeling at a given time, but also to figure out what I was thinking... For some people, help might well come from their faith in God. For me, help came from a source that seemed equally inexhaustible: poetry...

I don’t want to minimize the tragedy of George’s illness. It has gradually and relentlessly destroyed his mind and personality and has deprived me and my son of a husband and father we loved. No silver lining can restore George’s lost brilliance to himself or to us. Nevertheless, it is true that this ordeal has eloquently reminded me of the sustaining power of literature. Part of what I hope to do in [this memoir] is to share that power.

Reprinted from Strange Relation: A Memoir of Marriage, Dementia, and Poetry by Rachel Hadas © 2011. Published by Paul Dry Books, www.pauldrybooks.com.

Awareness

AFTD Film Reaches Wider Audience

After scores of caregivers and healthcare professionals contacted The Association for Frontotemporal Degeneration (AFTD) to request copies of the film, *It Is What It Is, Frontotemporal Degeneration: Tragic Loss, Abiding Hope*, AFTD revised the initial limited distribution plan and released the film earlier this month for broad individual use.

"Families have always done the most to raise awareness of FTD," says Beth Walter, AFTD board chair. "This film will make that easier for them."

The film, which runs about 17 minutes, weaves together the stories of four families facing frontotemporal degeneration. Each journey is unique, but the experiences are common to many who face these diseases: puzzling early symptoms, difficulty with diagnosis, a lack of emotional support and family hardships.

The project began in December 2009 when Joseph Becker, the founder and CEO of thinkfilm, inc., contacted AFTD after seeing a piece about FTD on CNN. Discussions led to a concept for the film, phone interviews

with families identified by AFTD, and filming last August in four cities.

The film was piloted throughout the fall with AFTD's Medical Advisory Council, board members, caregivers and health professionals. "*It Is What It Is* has been widely embraced as a moving and powerful depiction of FTD," says Sharon Denny, AFTD program director. "However, it does not present details of the diseases or reflect the real hope of current research."

The film was initially created so that it could be presented by professionals familiar with FTD who could provide context and answer questions. "However, we discovered that caregivers were eager to share the film with others and that the original plan was too limited," Denny says.

Adjustments were made to frame the contents of the film and enable wide distribution to individuals. The DVD now includes a two-minute introduction by Walter and comes packaged with printed material on FTD and progress in research.

AFTD expects the film to be



Chris (left) and Christopher Yurkanan of Austin, Texas, are among the families featured in the film.

embraced by family members, health professionals, and community service providers as a tool to promote understanding of the needs of FTD patients and caregivers. A large assisted living organization has purchased 90 copies and incorporated the film and FTD into their dementia training curriculum for staff members.

"This is so exciting for us," Walter says. "For a long time AFTD has wanted to visually show the faces of FTD and to connect new audiences with the reality of these diseases. This film will help create awareness and bring about change."

The DVD is available through AFTD for \$10 plus shipping and handling. For information, go to www.theaftd.org.



Sylvia Mackey

Mackey Joins NFL Game Plan

If she hasn't been there already, Sylvia Mackey may soon be coming to a town near you. Since August, the AFTD board member has traveled to nine cities across the U.S. – from Atlanta, New

Orleans, Washington, D.C. and Buffalo to Boston, Denver, Miami and San Francisco – to serve as a guest speaker at the "NFL Community Huddle: Taking a Goal Line Stand for Your Mind & Body." In February, Mackey took her message to Dallas just four days before the kickoff there at Super Bowl XLV.

The "NFL Community Huddle" program, which is free and open to the public, is part of a nationwide series of

forums designed to educate, motivate and mobilize communities to address issues such as dementia, depression, financial and relationship stress, and drug and alcohol abuse among athletes at all levels.

Ultimately, the goal is to develop a "game plan" or strategies for preventing and reducing the risk of dementia and addressing stigma related to brain disorders, Mackey says. The program is sponsored by the NFL and the Satcher Health Leadership Institute of Morehouse School of Medicine in Atlanta.

Mackey is married to NFL Hall of Famer John Mackey, who was diagnosed in 2001 with FTD. In addition to her role on the Board of Directors, she is a member of the AFTD Awareness Committee. Her forthcoming speaking engagements will be posted on our website calendar.

MAC Member Featured in CTV Report on FTD

Tiffany Chow, M.D., a member of the AFTD Medical Advisory Council, was interviewed by CTV News, Canada's largest private broadcaster, for a story on FTD ("Doctors warn of under-diagnosed form of dementia," CTV News, Toronto, Jan. 16, 2011). Dr. Chow, a neurologist and senior scientist at the Rotman Research Institute at Baycrest in Toronto, spoke with CTV medical reporter Avis Favaro. The broadcast notes that many cases are not diagnosed because symptoms are at first subtle and gradual or may mimic other disorders such as depression.

Tell 10 People Events

Runner Raises \$34K in Father's Memory; ADDF Matches 2:1

When Russell Zomback decided to run for the first time in the New York City Marathon, he planned on raising about \$5,000 for AFTD. He underestimated himself – by \$29,000!

By completing the Nov. 7 marathon, Zomback, of Long Island, raised \$34,000 for FTD drug discovery. Since then, the Alzheimer's Drug Discovery Foundation (ADDF), AFTD's partner in drug discovery, has matched those

funds 2:1, for a total of \$102,000!

Zomback originally planned on running the marathon in honor of his father, David. Sadly, David Zomback died on Sept. 23, 10 years after he was first diagnosed with FTD. And so Russell Zomback ran in memory of his father instead. He met his goal of finishing under 4:30, coming in at 4:29:21. Thank you, Russell!



Russell Zomback (right) ran the marathon in memory of his father, David, who died in September.

'Food for Thought' Raises \$10K

Nearly 100 people came out on Nov. 14 for "Food for Thought: Four Fabulous Courses for the Benefit of AFTD," which raised \$10,000. The Sunday afternoon luncheon was hosted by Lucy Pontrelli, M.D., and her father, Nick, in honor of Lucy's mother and Nick's wife, Anna, who has FTD. "Food for Thought," which was held at Rossini's Restaurant in midtown Manhattan, included a four-course Northern Italian feast, a selection of fine wine, live opera music, and several tributes by Pontrelli family members and friends honoring Anna, who attended the event.



Lucy Pontrelli, M.D. (center) welcomes Edward Huey, M.D., and author Elinor Lipman to "Food for Thought: Four Fabulous Courses for the Benefit of AFTD" at Rossini's Restaurant in New York.

Register Now for 'Scoot for Scooter' Dedication Balloons Available

The 2nd Annual "Scoot for Scooter" 5K & 1-Mile Walk & Run will begin at 10 a.m., rain or shine, on Sunday, May 15, at Sherwood High School in Sandy Spring, Md. The Walk & Run, which benefits AFTD, honors Dave "Scooter" Scaggs, a retired soccer and basketball coach who was diagnosed in 2008 with FTD. Last year, event organizers doubled their original fund-raising goal by raising a total of \$40,000.

New to this year's event are dedication balloons in honor of, or in memory of, loved ones with FTD.

Balloons will be printed with the honorees' names and then displayed at the event. For more information or to register, go to www.scoot4scooter.com. To purchase a balloon, go to the registration page. If you are registering for the event and wish to add a donation for a balloon, there is a field where you can indicate an honoree's name. If you are not participating in the event but would like to purchase a balloon, click *Register* (on the left), then choose the option to purchase a balloon only.

'Quest for the Cure' Set for May Register Now; Sponsorships Available

The 4th Annual "Quest for the Cure" Golf Tournament benefiting AFTD and FTD research will be held on Monday, May 9, at the Rancho Murieta Country Club, Rancho Murieta, Calif. Registration fees include 18 holes of golf, use of cart, lunch and buffet dinner, giveaways, raffle tickets and mulligans.

For more information about the day's schedule of events, fees, sponsorship opportunities and registration, go to www.AFTDgolf.com. "Quest for the Cure" has raised \$75,000 on behalf of AFTD in just three years. It is organized by AFTD Board Chair Beth Walter and her family.



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