

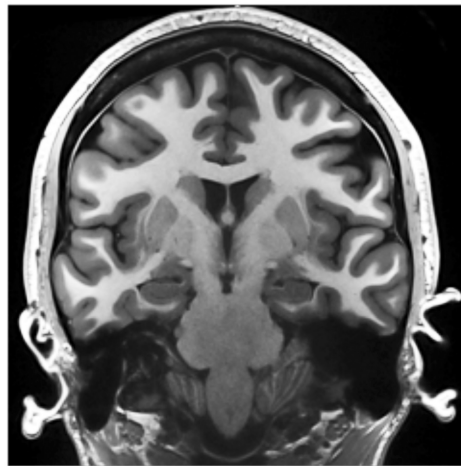


## NIH Funds Large-Scale Study for Brain Imaging

The National Institutes of Health recently awarded a grant of 10 million dollars to the University of California, San Francisco (UCSF) for an ambitious five-year longitudinal imaging study of frontotemporal dementia, called the Frontotemporal Lobar Degeneration Neuroimaging Initiative. The goal of the study, led by Howard Rosen, M.D., of the UCSF Department of Neurology, is to learn more about how to use brain imaging to follow patients with FTD over time.

### ■ STUDY TO ENROLL 240 PATIENTS

Two centers, UCSF and the Mayo Clinic in Rochester, Minnesota, will collaborate to enroll 120 patients with FTD, along with 120 cognitively normal controls over five years, and to follow each participant for a year with neurological



MRI scan shows the frontal and temporal lobes of the brain.

examinations, cognitive and behavioral assessments, and brain imaging. The study is being funded primarily by the National Institute on Aging, with co-

funding from the National Institute of Neurological Disease and Stroke. Dr. David Knopman will lead the Mayo team.

### ■ ROLE OF NUEROIMAGING

The role of neuroimaging in FTD has expanded greatly over the last few years. Using various techniques, investigators around the world have demonstrated that imaging can detect specific abnormalities in the brains of FTD patients that help to differentiate FTD from other diseases such as Alzheimer's disease (AD). Brain imaging has also helped to explain the unique problems with socio-emotional function and language that develop in FTD. More recently, researchers have begun to look into the utility of using imaging to study FTD over time. Unlike cognitive testing scores, which can vary

*(See Brain Imaging, page 4)*

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## AFTD Builds Caregiver Support Group Network

The number of support groups for people caring for someone with frontotemporal dementia has increased nearly threefold since 2006. The Association for Frontotemporal Dementias connects the individual groups and is the catalyst for a growing network of support and education resources for FTD families. "Caregivers are so grateful to find they are not alone," says AFTD Program Director Sharon S. Denny. AFTD interacts with 41 different groups that span the na-

tion and extend into Canada. Some groups are sponsored by medical centers that address FTD, some by a local Alzheimer's Association chapter, and still others by caregivers who join together for mutual support. AFTD sponsors three support groups that meet by telephone conferencing. The Association provides assistance to and networking among the growing number of caregiver groups. According to Denny the goal is to support group leaders, many of whom volunteer their time, and con-

nect them to broader resources and developments in the field. Since 2006, the Association has invited all FTD caregiver group facilitators to participate in quarterly conference calls with guest speakers. AFTD also hosts an e-mail listserv for facilitators to post questions they encounter and get input from other group leaders. In addition to effectively serving participants, strong support groups contribute to important FTD awareness and advocacy efforts.

*(See FTD Caregiver Support, page 8)*

## Spotlight On.... Bill Brown, AFTD Board Member

Bill Brown is a man with a mission. He pinpoints the starting date as June 16, 2006, the day his wife Michelle was diagnosed with frontotemporal dementia. Since then he has been working to bring national and global awareness to FTD. "That's the crux," says Brown, "to make this disease well known within all kinds of communities."

Brown, who works as an account director for DDB Worldwide Communications Group Inc., counts his family as fortunate in that it was only a six-month time period from their first visit to the general practitioner until they received Michelle's diagnosis. "It takes some families years to get a correct diagnosis," says Brown.

That is not to say that knowing what is going on has made it any easier for Brown, Michelle, or their three children, Weston, Alex and Harrison, now ages 18, 15 and 10, respectively. "My kids don't know Michelle now as their mother; they know her as a woman they go and visit,"



Bill Brown and children (from left) Harrison, Alex and Weston

says Brown.

At the time of the diagnosis Brown says he was struck by two things in particular: how little FTD-specific support there was for caregivers and how little money was dedicated to FTD-specific drug discovery research. "Michelle's neurologist gave me a pamphlet from the Alzheimer's Association. There was no resource for FTD." So, Brown started an FTD caregiver support group and in that process he became connected with the Association for Frontotemporal Dementias.

With the caregiver support group established, Brown turned his attention to fundraising for FTD research. "My wife used to cook quite a bit, and she taught our daughter, Alex, to cook. So, we gathered recipes from families affected by FTD from all over the world and produced a cookbook, *Food That Delights*, in 2007." The Brown children, and their school and community, assisted with production and distribution. Proceeds from the book were matched by the AFTD/ADDF Drug Discovery Campaign, yielding a total of about \$40,000.

Last year due to increasing professional commitments, Brown handed off facilitation of the support group to Darlene Ryan, a fellow AFTD Board member. "I am concentrating my efforts for FTD on raising awareness on the national level," Brown explains. His family recently told their story to the *Dallas Morning News* and made FTD front-page news. "I am making a legacy for my wife. I don't want the FTD diagnosis to be her legacy. I want her to have a legacy in her kids and in having made others aware."

## AFTD NEWSBRIEFS

**AFTD's Annual Appeal** is now underway! Please make your donation today via our website or standard mail to be part of the advances we are making in FTD research, awareness and support.

On November 20, 2009, the **NYC Area Consortium on FTD** will present a day of educational sessions on FTD diagnosis and management. AFTD offers small travel grants to help caregivers who want to attend. See the conferences page at [www.ftd-picks.org](http://www.ftd-picks.org) for details.

Fort Worth, Texas is the place to be on May 21, 2010 for a caregiver education day and **AFTD's 3rd annual public meeting**. Save the date and watch for more information.

### Lovett Challenge Success

AFTD thanks everyone who made contributions to the Lovett Family Challenge. Since the family issued the challenge on May 1, 2009, AFTD has raised 52 percent more in donations than during the same period in 2008, and we have exceeded the \$100,000 challenge! We are tremendously grateful to Phil Lovett and his family for their generosity and dedication to the cure of FTD.

AFTD will sponsor an educational day for caregivers on October 6, 2010, on the first day of the **2010 International Conference on FTD**, which will be at Indiana University, Indianapolis, Ind.

The **Medicare Adult Day Care Services Act** (H.R. 3043) is federal legislation that would allow eligible individuals to receive Medicare coverage for day program services. Visit the National Adult Day Services Association at [www.nadsa.org/advocacy/default.asp](http://www.nadsa.org/advocacy/default.asp) to learn more.

Copies of a new ***Foods That Delight*** cookbook are now available. At \$20 each, it makes a great gift that offers tasty new recipes while raising awareness and supporting AFTD. Get yours today at [www.aftdgolf.com](http://www.aftdgolf.com).

Send us news of events in your area! E-mail news items to [info@ftd-picks.org](mailto:info@ftd-picks.org)

## Morgan Family Funds Grant; Match Doubles Impact

# Identifying Targets for Drug Discovery Strategies in FTL and ALS

Drug discovery research in the field of protein TDP-43 received a boost in August 2009, with the announcement of a one-time grant of \$120,000 to Manuela Neumann, M.D. of the Institute of Neuropathology, University of Zurich.

The grant was made possible by the initiative and generosity of Meredith and Douglas Morgan, who contacted the Association for Frontotemporal Dementias in December 2008, indicating a desire to make a gift of \$60,000 in support of research on frontotemporal lobe degeneration and amyotrophic lateral sclerosis (ALS). Researchers had long suspected that there was a connection between the two diseases and in 2006 this link was identified as the protein TDP-43 by Virginia M.-Y. Lee, Ph.D. and John Q. Trojanowski, M.D., Ph.D. (founding members of the AFTD Medical Advisory Council). Accumulation of abnormal TDP-43 occurs in about half of all FTD cases and

*Morgan Family  
AFTD/ADDF  
Award recipient  
Manuela  
Neumann, M.D.,  
Institute of  
Neuropathology,  
University of Zurich*



in all ALS cases.

Once Susan L-J Dickinson, M.S., executive director of AFTD, helped the Morgans identify their funding intent, Dickinson contacted AFTD's partners at the Alzheimer's Drug Discovery Foundation (ADDF) who agreed to match the Morgan gift and to help manage *The Morgan Family AFTD/ADDF Award for TDP-43 Research*. Working with Dickinson, Diana Shineman, Ph.D., assistant director of scientific affairs for ADDF, reached out to leading researchers in the area of TDP-43 to submit proposals.

Dr. Neumann's project focuses on the fact that the TDP-43 in diseased cells has extra groups of phosphate attached to it; although researchers don't yet know what is cause and what is affect, they know that in patients with FTD and/or ALS this abnormally phosphorylated TDP-43 clumps together in the nerve cells and doesn't work properly. Dr. Neumann proposes to identify the specific molecules (called kinases) that control TDP-43 phosphorylation and thus, hopefully, identify valuable targets for drug discovery strategies in FTL and ALS.

"AFTD seeks to promote and fund research into finding the cause, therapies, and cures for the frontotemporal dementias," said Dickinson. "It is very gratifying when we can work with generous donors like the Morgan Family, use our connections to help them leverage their dollars, and make concrete progress toward our goals."

### 2009 AFTD Research Grant:

## Project Will Provide Insight Into the Disease Process at Earliest Stages

The Association for Frontotemporal Dementias is pleased to announce John C. van Swieten, Ph.D. is the recipient of the 2009 AFTD Research Grant. Dr. van Swieten, of the Erasmus Medical Centre in Rotterdam, The Netherlands, will be conducting a clinical trial, *Resting-State functional MRI in Presymptomatic Mutation Carriers of MAPT or PGRN Mutation*.

"Dr. van Swieten has been a leader in FTD research for many years," said Virginia M.-Y. Lee, Ph.D., head of AFTD's grant review committee and member of the Medical Advisory Council. "His proposed project will provide insight into the disease process at its earliest stages, even before symptoms develop."

Dr. van Swieten will use the \$60,000 award to collect pilot data for a longitudinal study, following individuals from two large families in which there is a known FTD mutation being passed down from generation to generation (one

*2009 AFTD Research  
Grant recipient  
John C. van Swieten,  
Ph. D.,  
Erasmus Medical  
Centre, Rotterdam,  
The Netherlands*



family has a mutation in the *MAPT* gene, the other in the *PGRN* gene). Because the mutations have been identified as the cause of FTD in these families, members of these families can be tested for the mutation and know long before the onset of the disorder whether or not they carry the mutation and will thus develop FTD.

The project uses a new imaging technology called Resting-state functional MRI to get detailed images of the frontal and temporal lobes of these mutation-positive, presymptomatic individuals. In this way Dr. van Swieten will capture

the very first signs of the disease – long before the person would be diagnosed clinically – and track the changes that occur throughout the course of the illness. The results of this study have important implications both for early, accurate diagnosis of FTD and for being able to measure any impact of a potential therapeutic during clinical trials.

AFTD awards \$60,000 annually in support of a pilot project in either basic or clinical science. This year more than 30 applicants from labs around the world submitted grants. This is more than three times the amount in any previous year. Bradley F. Boeve, M.D., chair of the AFTD Medical Advisory Council, applauded the increase, noting that the applicants included both recognized leaders in the field of FTD as well as investigators from other specialties, who bring new expertise and perspective to the biological problems in FTD.



## COMMON TYPES OF IMAGING FOR FTD

### CT scan (Computed Tomography Imaging or CAT scan):

A non-invasive procedure using X-rays that creates images of the soft tissue, bone, and blood vessels. Images can be created of the brain to evaluate for bleeding, tumors or other injury. Sometimes atrophy or shrinkage of the brain can be detected and that might be suggestive of FTD.

### MRI (Magnetic Resonance Imaging):

A non-invasive procedure that uses magnets and radio waves to create images of the brain and other organs. MRI is the procedure of choice for most brain disorders, as it creates images from multiple angles and provides a detailed view of many brain structures not visible by CT scan. Atrophy or shrinkage of the brain that might be suggestive of FTD can be identified by MRI.

### PET (Positron Emission Tomography):

A type of nuclear medicine scanning that involves capturing cross-sectional images of the brain, much like CT scanning. The images that are created are functional rather than the structural images of CT and MRI. Functional images capture how various parts of the brain are working, which makes it a diagnostic tool for neurodegenerative conditions such as FTD. Areas of the frontal or temporal lobes that are not as active as they should be may indicate FTD.

### SPECT (Single Photon Emission Computed Tomography):

A type of nuclear medicine scanning that is very similar to PET. SPECT measures blood flow and activity levels in the brain, which make it a diagnostic tool for identifying behavioral and cognitive problems in persons with neurodegenerative conditions such as FTD.

### Functional MRI (fMRI):

A specialized type of MRI scan that shows changes in blood flow in the brain. It can help to identify areas of brain activity which, if decreased in the frontal and temporal lobes, may indicate FTD. Unlike PET and SPECT scans, fMRI is non-invasive and is done in an MRI scanner.

## Brain Imaging Study Reflects Funding Shift

*(Continued from page 1)*

from day to day due to many factors such as sleep quality and medication use, brain structure and function can be measured very precisely and reproducibly, so that imaging is an attractive technique for following the changes in the brain due to disease. One of the most useful applications of this approach will be for clinical trials of potential treatments for FTD, where neuroimaging may be able to show that a treatment has altered the natural course of the disease, for instance slowing down or reversing the brain shrinkage (atrophy) that would normally occur. Having accurate measures of the normal rates of change in FTD will be critical for planning future medication trials that will use imaging as an outcome.

### ■ SEVERAL TYPES OF IMAGES

Although imaging is clearly useful for measuring brain changes in FTD, there is no consensus on the best type of imaging for this purpose. Structural imaging with Magnetic Resonance Imaging (MRI), which measures the size and shape of the brain, gives us different information than studies of metabolism, such as glucose consumption studies obtained using Positron Emission Tomography (PET). Because different investigators have tended to use different imaging techniques, it has been difficult to compare the results across the various studies. The new project, which will begin in late 2009, will address this problem by obtaining several different types of images in each patient. In addition to structural MRI and PET, the study will employ some very promising new MRI techniques, including imaging to measure the blood content (perfusion) in the brain and the integrity of the wiring (axons) connecting various parts of the brain using a technique called diffusion tensor imaging (DTI). It is possible that one or both of these techniques could replace PET scanning, which is expensive and requires exposure to radiation. This would lower the cost of clinical trials and make it possible for more pa-

tients to enroll because MRI scanners are commonly available. Another possibility that will be investigated is that a combination of images, such as structural MRI, PET and DTI, will provide a better explanation of how a patient is doing than any one of these image types alone. The study will also include serial assessments of the chemistry in the blood and cerebrospinal fluid (CSF, the fluid the surrounds the brain), to see how these relate to changes in the brain images.

### ■ BUILDS ON ESTABLISHED TECHNIQUES

The new study takes advantage of an infrastructure that was developed for the Alzheimer's Disease Neuroimaging Initiative (ADNI), which began in 2004 and is pursuing very similar goals in Alzheimer's Disease. ADNI established procedures that make it possible to obtain comparable images at different centers, and ADNI has also established procedures for ensuring high quality data. This study will use many of the ADNI techniques for acquiring brain imaging, and will employ some of the ADNI investigators to analyze the data and monitor the image quality. In these ways, the study takes advantage of techniques used for the study of AD to study FTD.

### ■ FUNDING OFFERS HOPE

The funding of this study reflects a change at the NIH toward an increased focus on studies of unusual forms of neurodegenerative disease, including FTD. It acknowledges the fact that not all patients have AD, and that diseases like FTD need a concerted effort. This acknowledgement comes at a time when increased knowledge about the biochemical changes leading to FTD offers new hope for treatments, and the images acquired from this study will be of great assistance in planning these studies.

*This article was contributed by AFTD Medical Advisory Council member Howard J. Rosen, M.D., a board-certified physician in both Internal Medicine and Neurology. Dr. Rosen has been with the University of California, San Francisco Memory and Aging Center since 1999.*

## RESEARCH NEWS ROUND-UP: BRAIN DONATION, SHARED DATABASE

### NIH to Co-Sponsor FTD Workshop

In early February 2010, the Association for Frontotemporal Dementias is joining the National Institute of Neurological Disease and Stroke (NINDS) and the National Institute on Aging (NIA) to host a meeting of senior frontotemporal dementia researchers in Miami, Florida. The goal of the workshop will be to design a database specifically dedicated to collecting information on FTD patients. The database will be linked to the National Alzheimer's Coordinating Center (NACC), the central repository for data on all patients seen across the country at Alzheimer's Disease Centers (ADCs).

To date, investigators only have a few data fields within the NACC to report information specifically relating to FTD. Having a full set of data fields tailored to the symptoms and features seen in FTD will enable clinicians to report much more accurately on these patients. Even more importantly, the fact that these data will be shared across all of the ADCs means that research will proceed faster.

"We are extremely pleased to partner with both NIA and NINDS on this important project," says AFTD Board of Directors Chair Helen-Ann Comstock. "Their willingness to jointly sponsor this effort is deeply appreciated, and will help speed us along the path to getting potential treatments into the clinic for our patients."

### PARTNERS IN RESEARCH

Susan Dickinson, AFTD executive director and Mary G. Austrom, Ph.D., director of the education core at Indiana University's Alzheimer Disease Center (IADC) presented a poster titled Partnering for Brain Donation at the National Institutes of Health in Bethesda, Maryland on October 26, 2009. The project is one of only 37 funded out of more than 200 applicants under the new Partners in Research program, which emphasizes the partnership between a community organization and a large academic institution. Publication of results is expected in fall 2010.

## Researchers Collaborate to Identify Genetic Risk Profile for FTD

On July 15, 2009, the Association for Frontotemporal Dementias sponsored a meeting of researchers in Vienna, Austria to discuss a new collaborative project designed to identify whether there is a genetic risk profile for frontotemporal dementia. "Approximately 20 laboratories performing the leading research on FTD from around the world will be collaborating on this project," notes Susan Dickinson, executive director of AFTD. "It is this level of cooperation that will drive knowledge forward faster."

Research has established that approximately 15 percent of FTD is inherited due to mutations in genes such as *MAPT* and *PGRN*. Approximately another 50 percent is sporadic (happening by chance). This current study focuses on the group in between, the approximately 35 percent of cases that are termed "familial" because these families display more FTD-related diagnoses than one would expect to see by chance, even though there is not a direct hereditary pattern. Researchers have long suspected that there is some

John Hardy, Ph. D., is the lead investigator of the project on which more than 20 national and international laboratories will collaborate.



sort of risk or predisposition being inherited in these families. The goal of this study is to identify the genes that may be playing a role in this predisposition.

This type of investigation is called a Genome-Wide Association Study (GWAS) and the concept is fairly simple: collect samples from a large number of FTD patients, create a genetic profile of the population as a whole, and compare it with a genetic profile from a population of people without FTD. This strategy eliminates the "noise" of individual genetic variation and enables the researchers to see if there is any difference between the two populations. Any area where a differ-

ence is observed provides the researchers with direction on where to look for genes that may convey risk for the disease.

At the meeting in Vienna, lead investigator John Hardy, Ph.D. led the researchers in a discussion of the logistics of sharing biological samples and clinical information among labs. All samples and data will be anonymous. He anticipates that collection of the samples will take about 6 months before genetic analysis in Dr. Andrew Singleton's lab at the National Institutes of Health can begin, and that results should be available in approximately 18 months. There are at least two other current GWAS studies, being led by investigators at the University of Pennsylvania, that are attempting to create a risk profile for more specific FTD sub-populations. It is a promising technology that is being employed in many rare diseases.

"The great thing about this project is that every group working on the disease is participating in a free and open way," notes Dr. Hardy.

## Donations Honor Loved Ones *Gifts received July 1, 2009 – October 30 2009*

### In Honor Of:

James S. Abbott  
Sandy & David  
Birnbaum  
Michelle Brown  
Larry Cline  
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Rose Tippet  
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Beverly Waite  
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Karen Sue Cleveland

### PHILADELPHIA

**Below:** Sylvia Mackey, wife of former NFL player John Mackey and AFTD Board member, shares her experiences as a caregiver and advocate in the keynote address at the Penn conference.



## AFTD Sponsors Caregiver Conferences

**D**uring 2009 the Association for Frontotemporal Dementias is providing sponsorship support to four regional educational conferences for caregivers.

The University of Pennsylvania hosted its 3<sup>rd</sup> bi-annual conference in Philadelphia on July 10 and Northwestern University in Chicago its 2nd annual conference on August 10. Massachusetts General Hospital hosted its first conference October 29 and the New York FTD Consortium's inaugural event is planned for November 20.

These events are a tremendous way for families and professionals to learn about research advances in FTD as well as practical information targeted to caregivers. In addition, attendees often say that a highlight of the day is the camaraderie they feel being with others who face similar challenges.

AFTD is very pleased to support these opportunities for caregiver education and networking.

**Below, left:** AFTD Executive Director Susan Dickinson welcomes caregivers at the conference in Philadelphia on July 10, 2009. Nearly 200 people attended the day long conference, the third bi-annual caregiver education day organized by The University of Pennsylvania.

**Below, right:** Members of the on-line FTD Support Forum meet the night before the FTD Caregiver Conference at Penn. People traveled from states such as California, New Mexico, Rhode Island, Georgia and Florida to attend the conference.





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

Laura Dezarn  
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**Below:** More than 160 caregivers and professionals attended the FTD/PPA Educational Conference at Northwestern University. Northwestern's Cognitive Neurology and Alzheimer's Disease Center (CNADC) began offering an annual regional conference in 2008 (photographs by Teresa Crawford).



**Below, left:** Mary O'Hara, MA, LSW poses a question to caregivers Lorene Schlie and Mary Beth Riedner during a panel discussion.

**Below, right:** Tiffany Chow, M.D., Baycrest Brain Health Center in Toronto, delivers the keynote address, "The Road to Fearless Caregiving."



CHICAGO

More than 85 people filled the room for the first FTD Educational Symposium in the Boston area on October 29, 2009. Caregivers were so eager for information that a larger venue has already been secured for next year's event.



**Left:** Keynote speaker Lisa Radin, author of the book *What if it's Not Alzheimers* and AFTD board member with Brad Dickerson, M.D., Director of the Massachusetts General Hospital FTD Clinic.

**Right:** Emily Levy, facilitator of the Boston area support group and key coordinator of the conference with Kent Jamison, Ph. D., former AFTD Board member.



BOSTON

## FTD Caregiver Support Groups Vary According to Needs and Goals

(Continued from page 1)

### ■ UNIQUE NEEDS DRIVE GROUPS

The first FTD caregiver support group was initiated in the Philadelphia region by AFTD founder and Board of Directors chair, Helen-Ann Comstock, in 1996. The group started under the auspices of the Delaware Valley Chapter of the Alzheimer Association when Comstock was its executive director. “I knew from my own experience that there were many things only other FTD caregivers could understand,” said Comstock. “The typically younger age of onset and behavioral and communication changes presented unique challenges that existing dementia caregiver groups did not address.”

One of the first caregivers in the Philadelphia group was Lisa Radin, now its facilitator and AFTD board member. Her passion for educating others about FTD was ignited and led to co-editing the book *What If It's Not Alzheimer's*. In 2004 the group's sponsoring Alzheimer's chapter had requests from people caring for a parent who felt they didn't fit with existing groups, and Radin's son and co-editor Gary, started one for adult children who care for a parent with young-onset dementia.

Whether at clinics, community agencies or caregiver homes, expansion of the FTD support network continues because patients and families make their needs known. The genesis of Raleigh, North Carolina FTD caregiver support group typifies many beginnings. “Our group was formed in 2007 at the request of caregivers of patients with FTD seen at the University of North Carolina at Chapel Hill Memory Disorders Clinic,” says Charlene Riedel-Leo, M.S.W. “Most of our support group members had attended Alzheimer's support groups in the past, but the instant feedback I got and continue to receive from new members is that it is so nice to have a place to come to talk about the behaviors that come along with FTD and to receive the support, compassion and great ideas that come from the group,” Riedel-Leo says. One such idea started several months ago, Club FTD, a day program for patients that also



Los Angeles/Orange County Area FTD Caregiver Support Group participates in a memory walk to raise awareness of FTD.

provides needed respite for caregivers.

### ■ SUPPORT AND EDUCATION TOGETHER

According to Denny, people attend FTD groups for emotional support and to learn how to provide the best care possible for a loved one. “Each group approaches it differently, but all find that they need to be flexible and address both education and support” she says.

One longstanding group adapted its early format to find the right balance. The London, Ontario Canada Pick's Support Group started in September 1998. Magdalen Carter, M.S.W., R.S.W., began by connecting a few caregivers who came to the Alzheimer Outreach Services of the McCormick Home. Neurologist and AFTD Medical Advisory Council member Dr. Andrew Kertesz attended regularly to provide medical information, but after that first year, “we decided to change the format and focus more on caregiver issues and problem solving,” says Carter.

Some FTD caregivers create their own groups apart from any sponsoring organization. Caregiver-led groups strive to balance sharing and support with education by inviting guests such as physicians, elder care attorneys and nursing home providers to address participants' concerns.

In cities such as Boston, Mass., and Fort Worth, Texas, the support group facilitators are the key organizers of educational conferences to reach many more FTD

caregivers. The Boston conference was held in October 2009, and the Fort Worth conference is planned for May 2010.

### ■ REACHING THOSE NOT YET SERVED

Despite expansion of the caregiver support network there remain many families facing FTD alone. AFTD and other groups are exploring ways to reach caregivers who are geographically dispersed or who have particular needs. In late 2005, the Association started the first telephone support group for caregivers who cannot access an in-person group. Of the three telephone support groups AFTD sponsors, the newest one is a pilot group that started in April 2009 and is designed for parents caring for a spouse with FTD who have school-aged children at home. The Memory and Aging Center at the University of San Francisco recently adopted telephone conferencing as a way to extend the reach of their group for adult children of people with FTD, and two efforts in Canada are piloting the use of telephone conferencing and Web conferencing to reach people in rural areas. “AFTD will continue to connect the groups that share our passion,” says Denny, “and one day, all FTD caregivers will find the support they need.”

*Review the full network of Caregiver Support Groups by visiting AFTD's website ([www.ftd-picks.org](http://www.ftd-picks.org)) and looking on the regional pages.*



**FRANCE:****Memory Center Provides Comprehensive Care for FTD Patients**

In 1991 Florence Pasquier, M.D., Ph.D. and Dr. Florence Lebert, M.D., Ph.D, combined their medical specialties of neurology and psychiatry to open a multidisciplinary Memory Center in Lille, France, dedicated to the clinical care of people with young-onset dementia.

Now known as the Lille-Bailleul Memory Center, the Center operates across two locations: at the University hospital in Lille, and at a local hospital in the town of Bailleul. “The cooperative venture enables the practitioners to see patients in two completely different environments,” said Dr. Pasquier, noting that the university hospital serves an urbanized area with a population of about 4 million; whereas the rural hospital serves a town with a population of 15,000.

Services provided by the Lille-Bailleul Memory Center include evaluation, diagnosis, and pharmaceutical treatment, as well as a range of continuing care management such as social care and family support. The center hosts a support group for caregivers and publishes a newsletter with information on FTD/Picks that is available on their website. The Bailleul Memory Center is located in a building unit that serves as both an in-patient hospital and a nursing home dedicated to patients with young-onset dementia, and offers a specific outdoors area for young patients with behavioral problems.

In 2008, Lille-Bailleul Memory Center cared for a total of 2,743 patients, approximately 135 of whom had FTD. According to Dr. Pasquier, “We have active social workers that try to help each family, and a network of nurses, and psychol-

Lille-Bailleul  
Memory Center  
directors and  
founding members  
Florence Pasquier,  
M.D., Ph.D. (left)  
and Florence  
Lebert, M.D., Ph.D



ogists working with these social workers that can go and visit families at home in the area. The social workers can inform the families about all the available resources to improve life at home, as well as options for respite care and temporary or long term placements at institutions.” The social workers also connect with each family’s general practitioner and give information on family associations such as Flandre Alzheimer, which was created by Florence Lebert with Bertille Foulon in Bailleul and is dedicated to patients with FTD and young onset dementia.

Drs. Pasquier and Lebert also collaborate with basic research scientists at INSERM and have contributed to numerous articles related to understanding frontotemporal dementia.

*For more information on the FTD Unit at the Lille-Bailleul Memory Center visit their website: <http://www.alzheimer-adna.com/DFT/DegenerescenceFT.html>.*

*To read more about the center’s current research activities visit <http://www.alzheimer-adna.com/Gb/english.html>.*

**AFTD Helps New Caregiver Support Groups Start-up and Grow**

“There are still so many empty areas on our United States and Canadian regional resources maps,” says Sharon Denny, Association for Frontotemporal Dementias program director, referring to graphics on the Association’s website illustrating the location of caregiver support groups. “We encourage anyone thinking about starting a local group to let us know so we can help.”

AFTD provides assistance to family members, professionals and organizations who want to develop FTD caregiver support groups. The Association helps new groups in a variety of ways, depending on their needs.

When caregivers register with AFTD, they are asked if they want to be notified of new opportunities for support. “By searching the registration database, the staff can identify how many people

in a particular area may be interested in a new group,” says Denny. “The database also lets AFTD e-mail announcements of new groups and provide contact information.

AFTD protects confidentiality and never allows any other individuals or groups to access the registration database. “We have used the registration database to introduce, by mutual agreement, two or three caregivers living near each other who may otherwise have no opportunity to realize they share similar experiences,” says Denny. “This alone has led to the start of several groups.”

AFTD does not directly sponsor any in-person support groups. Rather, it provides networking, materials and suggestions for how to find a location, get the word out, and access facilitator training. The Association “pairs more experienced

facilitators with newer ones as mentors,” says Denny. “When a new group’s details are set, it is added to the regional resources pages on AFTD’s website.”

In the coming year, AFTD will issue a manual for support group facilitators, incorporating essential information on FTD, how to run a support group, and resources needed by caregivers. Another focus of expansion is to pilot new ways to support caregivers in underserved areas, and those who share unique concerns, such as parents of young children, young adults, and children and teens

“Our initial goal is to make sure that caregivers in each state and province have access to FTD specific supports, says Denny. “From there we will continue to stimulate the development of a broad and diverse network to reach all those in need.”

## Regional Network Energizes Local Awareness Efforts

Although they started just months ago, the volunteer leaders of the Association for Frontotemporal Dementias Regional Advocacy Network are hard at work. Activities are underway across the United States and Canada to raise awareness of frontotemporal dementia.

Armed with brochures, newsletters and fact sheets, AFTD Regional Coordinators are conducting outreach in their home states to ensure that information about FTD and the Association is available at any local medical centers and community agencies that may need it. Coordinators are also creating opportunities for public awareness through a range of media outlets.

Middle Atlantic Regional Coordinator Jenny Hinsman arranged a show on FTD for *RealWomen on Health*, an online radio broadcast. The Oct. 15, 2009 show featured Bradley Boeve, M.D., chair of AFTD's Medical Advisory Council, and Sharon Denny, AFTD Program Director. Hinsman also arranged the Sept. 26, 2009 radio broadcast of *The Medical View* on WWDB in Philadelphia. This show featured Murray Grossman, M.D., Ed. D., an AFTD Medical Advisory Council member, who provided an overview of FTD and research opportunities, and Susan Grant and Cindy Dilks who discussed the upcoming FTD documentary called *Planning for Hope*.

Frontotemporal dementia was also the topic of a segment on Channel 10/ABC local morning show *Sacramento and Company* on Oct. 13, 2009, thanks to the efforts of Beth Walter, AFTD Board of Directors vice chair, and her sister-in-law Terry Walter. The show featured information on FTD and introduced the recently published *Foods That Delight* cookbook.

Two regional coordinators are using existing Alzheimer's disease awareness platforms as springboards for FTD awareness. Susan Gustafson, regional coordinator for Canada's Western Provinces was interviewed for a local publication of the Alzheimer's Society to increase awareness of the range of dementias and FTD in particular as a major cause of early onset dementia. Jodee Kalmen, in the Southwest Region set as her personal challenge to raise the profile of FTD in the midst of a local Memory Walk Oct. 17, 2009, saying "I will personally walk to each and every booth and hand them the AFTD materials and say a blessing that our word is carried to many."

The *RealWomen on Health* show is archived at: <http://www.blogtalkradio.com/realwomenonhealth>

The *Sacramento and Company* segment is archived at: <http://www.sacandco.net/>

The *Medical View* is archived at: <http://www.thehealingconsciousness.com/medicalview>

### CNN to Spotlight FTD

AFTD Executive Director Susan Dickinson was interviewed in the Association's Radnor, Penn. offices by CNN Medical Unit Producer Val Willingham, center, for a segment on frontotemporal dementia. The piece features the family of Kenneth Sparks who was diagnosed with FTD three years ago and Dr. Murray Grossman, AFTD Medical Advisory Council member, pictured far right. AFTD is very grateful to CNN, the Sparks family and Dr. Grossman for this important opportunity to make the public more aware of FTD.



## Mark your Calendar: May 2010 Caregiver Conference in Fort Worth

The Fort Worth caregiver support group and the University of North Texas Health Sciences Center (UNTHSC) are teaming up to present the first FTD educational conference in the U.S. South Central region in May 2010. Darlene Ryan, AFTD board of directors treasurer and facilitator of the support group, is a prime mover behind the conference.

Ryan's husband, Dick, was diagnosed with FTD in 2003. The multitude of challenges they have faced has propelled her to become a vocal advocate for FTD education. "There is a lot of energy at UNTHSC to present a very informative and enjoyable event for FTD families and caregivers in our region," said Ryan. "We are especially pleased to have the conference dovetail with the AFTD Annual Meeting, which will take place late afternoon and lead into a reception for all of our attendees."

The conference will be held on Friday, May 21, 2010 on the campus of UNTHSC and will feature presentations on current FTD research, caregiver concerns such as legal/financial planning and planning for assisted living or nursing home care. UNTHSC is a leader in the training of primary care physicians and will conduct a session on how to work with your primary care physician.



# Tell 10 People Events Honor Family and Support AFTD

## 4<sup>th</sup> Annual Sidoris Golf Outing

On September 5<sup>th</sup>, 2009 the friends and family of George F. Sidoris gathered for the fourth year to remember him and support AFTD. “The weather was perfect,” said his son George J. Sidoris of Mentor, Ohio, a former AFTD Board member, who with the help of an enthusiastic committee organized the annual event.



“We had a great turnout, great people and great fun. It’s really just one big party with a cause,” said Sidoris. The event is by invitation, which makes it an especially enjoyable social event for all. This year the registration fees of 72 golfers and 92 attendees, along with sponsorship support, raised \$11,000. AFTD is especially grateful to George and ten sponsors who have supported the event since its inception including: Dibart Custom Cabinets, Federated Auto Parts, E-Business Express, the Gilmour family, the Gudin family, George’s sister Christine, his wife MaryJayne, and their children George, Lauren and Michael who continue to expand the circle of people invested in changing the future of FTD.

## Jaycees Family Day FUNdraiser

Chad Thomsen was a former Jaycees International member who met and married his wife Roxanne while in the Jaycees, an organization that promotes leadership development and community service. On September 20 the Raleigh Jaycees ran a Family Day FUNdraiser at Adventure Landing in North Carolina in memory of Roxanne who died this past June, two years after being diagnosed with FTD. More than 65 people came out on a beautiful day to have fun, socialize and support AFTD. Their generous efforts contributed over \$1,000 to help our cause.

## Bowling Tournament

The family and friends of Richard Perry hosted a 9-Pin No-Tap bowling tournament Oct. 28 in Nebraska City, Neb., to support AFTD’s Drug Discovery Campaign. The



The Perry Family

tournament was a fitting way to honor Rich who started bowling at the age of four and made bowling his profession when he bought a local bowling center in Nebraska City. Rich ran Perry Lanes for eight years before FTD impacted his life. All funds generated from the tournament will be matched 2:1 by AFTD partner, the Alzheimer’s Drug Discovery Foundation.

## Cowtown Marathon

Brandee Waite, a physician and assistant professor of physical medicine and rehabilitation at UC–Davis Medical Center, put together a team to run in the Sacramento, Calif., Cowtown Marathon to honor her mother, Beverly Waite, who has been diagnosed with FTD. Brandee, her siblings, husband and friends finished the Oct. 4 marathon, raising awareness of FTD and nearly \$1,000 in support of the Association.



Team Bev Waite raised almost \$1,000 to support AFTD.

## Repeat Marathoners

Kendra Gibson of Wendell, N.C., ran her first half marathon in November 2008, in honor of her mother, to raise money for AFTD. With the help of family and friends she raised more than \$2,000. On Nov. 8, Kendra will be running the Outer Banks Marathon/Half Marathon again and is hoping to raise even more.

## Foods That Delight

The Walter Charitable Fund is raising money to support FTD with proceeds from a new cookbook, *Foods that Delight*. The book includes favorite recipes solicited from local chefs and is available through the Walter Charitable Fund for \$20, shipping included. All proceeds will support AFTD’s research initiatives. To order online, visit [www.aftdgolf.com](http://www.aftdgolf.com).

*AFTD is very grateful to the hosts and supporters of all the Tell 10 People events. Together we are raising the funding needed to help families currently affected and to change the future for all. Every dollar raised directly supports our mission. Thank you all! For information on upcoming events or planning an event in your community visit AFTD’s website.*



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