

AFTD

Opening the gateway to help and a cure

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2006 International Conference on FTD *Garry Larkin*

The “Wow!” factor permeated the Fifth International Conference on Frontotemporal Dementias, held in San Francisco September 6 – 8. Caregivers had the opportunity, away from their stress at home, to discuss common concerns with more than 100 other caregivers from all over the country - reason enough to attend the conference. Add to that the privilege of attending scientific presentations by dozens of the most prominent doctors and scientists in the forefront of FTD research, and the opportunity to discuss medical issues in small groups and often one-on-one with those same professionals, and the result was a symposium that benefited everyone.



Jennifer Merrilees, RN, Tiffany Chow, MD, John Trojanowski, MD, PhD Photo by Karen Shuster

On the first day of the conference presentations for caregivers and for professionals were divided into two

“tracks”. In the caregiver session participants learned about current research theories, treatment options, behavioral variations, and an overview of legal issues. Crash courses in the differences between MRI and PET scans, and diagnostic testing to predict disease progression and to aid behavior management, were followed by insights into the possibilities related to tau and other theories on what causes the progressive cognitive impairment that characterizes FTD. Presentations included practical sessions on the difference between behavioral dementia and language dementia, and how different patient

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Susan L-J Dickinson, MS
Newsletter Editor

Important New Findings Generate Excitement Among FTD Researchers

Two major scientific findings published within the past few months signify a big step forward in the quest to understand the causes of FTD. In each case, though the discovery applies directly only to a subset of FTD patients, it offers hope for all by providing new clues to the overall picture of the disorder.

The hallmark of all FTDs is neurodegenerative changes in the frontal and/or temporal lobes of the brain (the areas responsible for language and other executive functions). However, that is where the commonality among all FTDs ends. A variety of different cellular malfunctions, combined with a wide array of clinical symptoms (from behavior to language to movement) make the FTDs a particularly difficult disorder for clinicians

to diagnose and researchers to decipher.

The two current sets of findings each reveal a specific cellular problem that is responsible for some cases of FTD.

On July 16 in the scientific journal *Nature* two separate groups of researchers (led by Christine Van Broeckhoven, PhD, in Belgium and a member of AFTD's Medical Advisory Council, Michael Hutton, PhD, in Florida) reported new gene mutations that appear to be responsible for hereditary FTD in approximately 5% of families with the disease. The gene involved is called *PGRN*, is located on chromosome 17, and codes for the protein progranulin.

Progranulin is a factor that stimulates cell growth and wound repair; too much progranulin has previously

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Spotlight On..... Bruce Richardson, Treasurer, AFTD

the fact that she was a sick and

Bruce and Diana Richardson had been married for about 25 years when Diana's behavior began to change. They had been happy, productive years: they had three healthy, grown children, all very adventurous and independent; Bruce was a CPA; Diana had been a stay-at-home Mom, then went back to school to get a Masters in school psychology, a field in which she worked for 15 years. She also raised Labrador Retrievers, and bred about 300 puppies over the years – a dozen of them show champions. So when Diana began to act strangely in her mid-fifties, Bruce assumed it was just some sort of mid-life crisis, a phase she would come out of.

and unpredictable: driving about 100 miles each day, on aimless trips; spending money wildly; behaving obsessive-compulsively. She became emotionally distant and spoke less (and eventually became mute in her last year). They separated, and Bruce moved from Boulder, Colorado to Maryland. But his new job there wasn't what he had expected, and during the four months he was away it became evident that Diana's erratic behavior wasn't the result of conscious choices, but of an illness.

had no control over her actions, it became much easier...I didn't like it, but I had to accept the fact that she was sick and would eventually die from this disease—and try to get on with my life as best I could."

Bruce returned home and arranged for a number of appointments with specialists, who diagnosed Diana with Pick's disease. Bruce kept her home, and was her primary caregiver from October, 2001 until April 7, 2006, the day she died. She was 63 years old.

For the last four years, Bruce hired various students from the local University, who helped with Diana's daily care in exchange for room and board and some cash payments. He became active in the Denver support group, and found solace in his amateur wood-working. "They weren't easy years," he recalls. "But Diana had always said that she never wanted to be put in a nursing home, and I made the decision to honor that."

But she didn't. She was hyperactive,

"The first year of care giving was the hardest, because I still expected Diana to 'snap out of it', and be her normal self," Bruce recalls. "Once I accepted

Bruce joined the AFTD Board last year, and is utilizing his skills as a "recovering CPA" to serve as Treasurer of the Association. He is interested in helping other caregivers by providing his insights into the journey that FTD compels a caregiver to take.

AFTD



News

Chicago area residents, save the date:

March 12, 2007. A Caregiver Education and Support Conference on Frontotemporal Dementia and Primary Progressive Aphasia will be sponsored by the Northwestern University ADRC. For more details go to: <http://www.brain.northwestern.edu>

New adult and child **FTD support groups** have been started in Denver, Colorado area. Contact Terencia Beauvais-Nikl, RN 303-985-2440 for more information.

Helen-Ann Comstock, AFTD founder and current Chair of the Board of Directors, was honored at the 5th International Conference for Frontotemporal Dementias for her work as a pioneer in the field of FTD.



Helen-Ann Comstock, holding her award, and Catherine Pace-Savitsky

In response to **AFTD's advocacy**, a meeting of key FTD researchers and clinicians will be held January 17-19, 2007, in Miami, FL. The workshop will be a joint project between the National

Institutes of Health and AFTD, and it will be sponsored by the National Institute of Neurological Disorders & Stroke. The purpose of this meeting will be to develop a five-year plan for FTD that will cover status of the field, research and clinical gaps, and identification of what is needed to develop a therapeutic trial.

AFTD's publication of "**The Genetics of FTD: Should You Worry?**" is available for viewing on line, or hard copies may be obtained by contacting the AFTD office.

New York City residents: Genetic Counselor Jill Goldman is starting a new FTD support group Contact her at (212) 305-7382 or jg2673@columbia.edu.

Send us news of events in your area!
mmeyers@ftd-picks.org

Please support AFTD! All funds raised in December will be dedicated to FTD research. With your help AFTD hopes to award two research grants in 2007.

been linked to some cancers. FTD patients with *PGRN* mutations do not produce enough functional progranulin. How this relates to the premature degeneration of nerve cells in the frontotemporal region is one of the questions these researchers plan on pursuing.

The second research finding, published in the journal *Science* on October 6, identified a specific protein, TDP-43, as the common cause of ALS (a motor neuron disease better known as Lou Gehrig's disease) and approximately 30-40% of all FTDs. Clinically, doctors have long recognized that there is a lot of overlap between FTD and motor neuron disease. Many ALS patients display symptoms of FTD, and one clinical subtype of FTD is called "FTD-MND", specifically because these FTD patients suffer from the same motor neuron problem as ALS patients.

When researchers led by Virginia Lee, PhD, at the University of Pennsylvania (also a member of AFTD's Medical Advisory Council) looked at a wide array of brain cells, they found

that the protein TDP-43 was damaged and inoperable only in affected regions of the central nervous system, and only in patients with a certain subtype of FTD (called FTD-U) or ALS, *not* in those suffering from Alzheimer's disease or in normal controls.

TDP-43 is found normally in many different organs, where its function has been implicated in editing the transcription of the genetic code and also as a scaffold protein for another motor neuron protein. It now appears that when TDP-43 does not function correctly in certain sections of the central nervous system (the frontal and temporal lobes of the brain in FTD and the spinal cord motor neurons in ALS), the result is one or both of these disorders.

Scientists in labs around the world are already pursuing studies that follow up on these results (see "AFTD Awards New

Grant"). Identification of specific genes(s) like *PGRN* and proteins like progranulin and TDP-43 is a vital step in understanding precisely what occurs in the development of a disease. Most importantly, these discoveries indicate the best approaches to take in designing more accurate diagnostics and more effective treatments.

For a more detailed discussion of this research, see the AFTD website.

AFTD Awards New Research Grant

AFTD has awarded \$50,000 to researchers Blair R. Leavitt, MDCM, and Ian Mackenzie, MD (photo), from the University of British Columbia.

These scientists will develop a mouse model in which they can simulate inactivation of the *PGRN* gene at different times in the life cycle and in different regions of the brain.

This model will be shared by the entire research community, and will be a vital tool as scientists work to understand how the *PGRN* gene leads to FTD, as well as the best potential ways to prevent or stop progression of the disease.



National Report Highlights Early Onset Dementia

A report published by the Alzheimer's Association this past June focuses the national spotlight on the phenomenon of early-onset dementias, including FTD. "*Early Onset Dementia: A National Challenge, a Future Crisis*" profiles the special problems we face, and issues a call for action, stating the need for more research, education, and services. This is the first high-profile report to document the circumstances of the early-onset dementia population, and to challenge federal and private agencies to understand and meet these needs. One of the families profiled in the report is that of AFTD Board member Darlene Ryan.

The Alzheimer's Association compiled information from a number of sources, including data from their own research as well as from the federal

Health and Retirement Survey. Key findings in the report include:

- There are an estimated 220,000 to 640,000 people with early-onset dementia in the US today.
- Because health care providers don't expect dementia in younger patients, it can take months or years before an accurate diagnosis is made.
- These patients often experience their first symptoms during what should be the height of their career, when change in job performance or behavior has professional, social, and financial implications.
- Lack of accurate diagnosis and young age combine to prevent the person from qualifying for government services available to those with later-onset dementia (disability, Social Security Disability Insurance, Medicare, and Supplemental Security Income).

Health and Retirement Survey. Key findings in the report include:

- Existing care facilities and programs may not be appropriate for younger individuals.
- Family members and other care providers often lack information and support.

Most importantly, the report includes a list of recommendations that constitute a call to action to both government and private agencies to learn more and address the needs of this population. Specific recommendations include: research into the causes and unique problems faced by this population; a national education program targeting medical professionals, employers and the public; expansion of federal programs to ensure these patients qualify for *See Report, page 6*

Donations Honor Loved Ones ⁴ Gifts received April 25, 2006—October 16, 2006

In Honor Of:

Joseph Becker, PhD
Joseph Field
Susan Grant
Grover Grimm
John Mackey
Jennifer McConathy

Joanne Sackheim
Sylvia Siegel
Janice L. Utke

In Memory Of:

Lawrence Aledort
Roy M. Andris

Nadia Aquilino
Marjorie M. Blakeley
Charles Brady
Barbara Caponigri
Arthur Chabaton
Craig Comstock
Mike Copeland

Diane M. Danhof
Richard A. Diebert
Patricia Donnelly
Richard Drayton
John S. Favuzzi
Jerry Franz
Mimi Freeman

Phyllis Feigenbaum
Irving Goldman
Ralph W. Hawkins
Robert Hermann
Norman T. Herndon
Nicholas Holt
Burt H. Hunley

Fundraising for AFTD:

Online and In-person, Members Help Build a Vibrant Organization



Ashleigh Carlon

One thing twelve-year-old **Ashleigh Carlon** knows about fundraising is that it doesn't require a large bank account or connections to people in high places to raise

money for FTD research. For the past several years Ashleigh has helped her family organize a garage sale in her home town of Sparta, Michigan, to raise funds for research in honor of her grandmother Joan Stuit, who died in 2004. "People around here love to go Garage-saling," says Sue Stuit, Ashleigh's mother, (Yes, it is a verb in their area!) "So we contacted some of mom's best friends to donate inventory and advertised in the local paper as the *Joan Stuit Memorial Garage Sale*." Late this spring Sue and Ashleigh presented a check for \$151 to AFTD, with hopes that in years to come they will be able to raise even more.

This fall **George Sidoris**, a former caregiver from Mentor, Ohio, put his fundraising skills to work by organizing a golf tournament in honor of his father, George F. Sidoris. Friends and family helped with planning, and local businesses sponsored each of the 18 holes, as well as prizes that were raffled off at the event.

Attendees paid a registration fee and were able to buy into tournament



games such as "closest to the pin front and back", "longest drive", and "lowest putt per team". The event culminated in a steak dinner and awards ceremony.

Despite freezing temperatures and rainy skies, 58 golfers participated in the event on September 2nd, and "the people that attended had a wonderful time," George reports. "The dinner was great and everyone truly made the best of the situation." In the end, George, his family and friends were able to raise more than \$7,000 on behalf of AFTD.

These are just two examples of the many ways AFTD supporters are raising not only money,

but awareness of FTD in their own communities. With their help AFTD hopes to reach our 2006 fundraising goal of \$70,000. These funds will enable AFTD to award not one, but two research grants in 2007. This is a remarkable accomplishment, especially since it was just last year that AFTD granted its first award ever.

There are several new ways you can help AFTD reach our goal:

- AFTD is now able to accept donations in the form of **securities**. This can be a beneficial way of supporting the work of the Association while, at the same time, receiving some possi-

ble tax benefits.

- **eBay** has developed a program called "eBay Giving Works" which



enables sellers to list items on eBay and donate part or all of the final sale price of the item to the charitable organization of their choice. All donations are fully tax deductible. For instructions on how to sell an item on eBay and to then have the proceeds donated to AFTD, visit <http://givingworks.ebay.com/sell/> or call us at (866)507-7222. AFTD can be found in the eBay non-profit directory under "Association for Frontotemporal Dementias" or by typing one of the following key words: FTD, AFTD, or Picks.

- AFTD has partnered with two **car donation** services that provide a means to easily and securely donate your vehicle. If you have an older vehicle that you have been thinking of trading in, or simply don't want the hassle of trying to sell yourself, explore one of these options. The net proceeds of your sale will be sent to AFTD, and your donation is fully tax deductible. Some restrictions apply, so visit www.cars4charities.org or www.donatecar.com for more information, or contact us directly at info@ftd-picks.org.

If you have a fundraising idea, please let us know! AFTD is a team effort, and we encourage you to get involved.

In Memory Of

(continued from page 4):	Paul L'Heureux	Terrance W. O'Connor	Imogene Schubert	Margaret R. Tedford
Keith W. Ingram	Raymond L'Heureux	John S. Renshaw	Henry E. Schweers	Mark Tooker
Dr. Hilard Kravitz	Dr. Howard Lovett, Jr.	Diana Richardson	Popkin Shenian	Esther Vendetti
Regina Kujawski	Mary McKee	Susan Robbins	Karen Shulman	Edward Wnorowski
Bart Lamanuzzi	Dennis Murphy	Thomas Robbins	Van Stewart	Priscilla Wolford
Ernest L'Heureux	Creda J. Myers	William Sackheim	Joan Stuit	Kent Woodworth
	Kent Nolan	Marguerite L. Santo	Robert Sykes, Jr.	Mina Wortzman

Resources on the Web

The Hartford: Talking with Drivers who have Dementia

<http://www.thehartford.com/alzheimers/index.html>

Driving is a difficult issue for any family with an older relative; for those of us who are concerned about the abilities of a loved one who is still relatively young, the issue can be even more difficult to broach. At what point does dementia create impairment in judgment? How do you balance safety against autonomy? Who has the right to make the decision when driving is no longer safe? And how do you even open the subject for discussion?

This website, sponsored by The Hartford Financial Services Group, contains information gathered from interviews with family caregivers and

individuals with dementia, as well as specialists in the fields of gerontology, medicine, and transportation. The goal of the project was “to develop a thorough guide to help families maximize the independence of the person with dementia while at the same time minimize the risk of driving accidents.”

The result is a guide, which can be downloaded from the website or ordered through the mail, that provides practical tools for every step of the process, from introducing the subject for discussion (who should do it? when? how?) to monitoring behavior (drivers are more willing to discuss the

issue with someone who has actually observed them driving) to limiting (driving at night, or during rush hour may be more confusing)--and ultimately stopping--driving.

The website also contains a section on “Tips for Caregivers” and a template for an “Agreement about Driving” to help caregivers and persons with dementia plan ahead.

To download the guide, go to <http://www.thehartford.com/alzheimer/s/brochure.html>. To order paper copies, write: The Hartford, At The Crossroads, 200 Executive Boulevard, Southington, CT 06489

From Our Families..... Kitty Roth

A new feature in our newsletter, this space will be dedicated each issue to the story of one of our families, and their experience in the journey of loss that FTD imposes on us all. We appreciate their generosity in sharing some of their intimate thoughts, emotions, and experiences, and recognize that it is through this generosity that we will all find the comfort and support of community.

From the age of 6 my husband, John, knew he would be an architect. That was what defined him. He boasted of his ability to sit at a drafting table and draw by hand more quickly and more accurately than any CAD operative.

In May of 2004, at the age of 55 and four years after being diagnosed with frontotemporal dementia, it became apparent that he was no longer capable of doing complex engineering or architectural drafting. So I set up a workstation for him at home: I purchased some “fill in the blank” watercolor pictures and his new job was to paint. While sitting in the familiar position as if at a drafting table, he worked meticulously to do his job.

He painted every picture I could find at the craft store, and eventually I began drawing for him on watercolor pads. Each night we would sit together and he would tell me what to draw. It became our special “together time”. For some strange reason, as time progressed (or, perhaps more accurately, regressed) he would only allow me to draw fish, the same one with slight variations. Each night we sat together and fifteen fish of our own design materialized. Each day he would paint them with great joy, putting them in the portfolio before they were even dry and running to our neighbors’ to show them off. He was so proud of his fish.



When John died, I hosted a party and family and friends came to toast him and talk about the good times. At the end of the evening, each person took a fish, and we had \$500 to donate to AFTD. John would have been proud. I don’t know if I did enough for John during his lifetime, but together we did make beautiful pictures.

Kitty Roth has purchased a domain name, <http://www.john'sfish.com/> and plans to sell the remaining paintings and donate the proceeds to AFTD. She has more than 400 fish left.



Bruce Miller, MD, Conference Course Director and AFTD MAC member Photo by Karen Shuster

Ontario - Canada; Hirotaka Tanabe, Professor of Neuropsychiatry and Neuroscience, Ehime University - Japan; M.-Marsel Mesulam, Professor of Neurology and Psychiatry, Northwestern University - USA. In addition, Helen-Ann Comstock was honored for her work in founding AFTD

One of the most poignant presentations came from a staff member at the University of California, San Francisco who showed scenes from a documentary she is making on the devastating effect FTD has on patients, caregivers, and families. In an annex to the main lecture room, posters summarized additional topics, with their authors available nearby to explain the significance of their graphs and narratives. In a separate room, service providers such as an assisted living center, a pharmaceutical company, a text book publisher and several non-profits, including AFTD, exhibited

their services.

After the first day of intense presentations, a caregiver dinner, sponsored by AFTD, allowed caregivers to mingle with other caregivers and a dozen professionals, who helped to interpret and elaborate on the day's program.

The final two days were devoted to in-depth research into the causes of FTD. Most frequently cited were the recent findings of the progranulin gene by researchers in Florida and Belgium, and the protein named TPD-43, by scientists at the University of Pennsylvania. While sometimes difficult to follow because of medical jargon and frequent abbreviations, from a caregiver's prospective, the thrust of these two days was that hope is on the way for FTD patients. Clinical advances from this research might not arrive soon enough to help current patients, but they will be here to benefit, or at least identify, future generations at risk for FTD.

Garry Larkin is an AFTD caregiver in Naples, Florida.

symptoms require different caregiver approaches.

Pioneers in the field of FTD research were honored at the conference. They included: Arne Brun, Professor Emeritus, Lund University - Sweden; John Hodges, Professor of Behavioral Neurology - Cambridge, England; Andrew Kertesz, Professor of Neurology, University of Western

Report

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appropriate services; and a study of work environments, to identify accommodations that may enhance patients' lives and productivity.

This report, which was prepared by Katie Maslow, Associator for Quality Care Advocacy for the Alzheimer's Association, is a vital document for the FTD community, and one which

we can use as a cornerstone in our advocacy efforts. In the coming months AFTD will be exploring appropriate avenues we can take to build upon these findings, to more specifically document and address the needs of FTD patients and families. There is also a role for individual caregivers to play: *Please send a letter or email to your elected officials, endorsing the importance of*

this report and the fact that it covers FTD as well as Alzheimer's. Challenge them to follow the recommendations, by allocating funds for research and services!

1. Go to www.alz.org.
2. Click on "Advocacy" and then "Write Congress".
3. Enter your address to get a list of your representatives and send a message!

AFTD

100 N. 17th Street, Suite 600 Philadelphia, PA 19103
www.FTD-Picks.org 267-514-7221 toll free 866-507-7222

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