

AFTD

Opening the gateway to help and a cure

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December 2005

Caregiver Conference A Big Success

More than 200 caregivers and 50 health professionals from across the US, Canada and Scotland attended an FTD Caregiver Conference at the University of Pennsylvania last month. Topics presented during the conference addressed the broad array of concerns FTD caregivers face on a daily basis, including: diagnosis, management and treatment, genetics, occupational and physical therapy, daily life resources, long-term care, and legal and financial planning.

Highlights of the conference included a welcome from Nora Dowd Eisenhower, Secretary of the Pennsylvania Department of Aging, and a keynote speech by Dr. Dan Gottlieb, a family therapist who is featured regularly on PBS radio. Dr. Gottlieb's talk, "The Heart of Giving Care" was, in the words of one caregiver, "an extremely moving and motivating presentation," that won a standing ovation from all in attendance.



At the conference: Nora Dowd Eisenhower, Harriet Withstandley, Helen-Ann Comstock, Joyce Shenian, and keynote speaker Dr. Dan Gottlieb.

In addition to the plenary sessions, a number of smaller breakout sessions provided the opportunity for attendees to listen, share experiences, and ask questions of the speakers in a more intimate setting. At the end of the day, many caregivers reflected on the value of having connected with others who understand the challenges and emotions they face on a daily basis.

Among the attendees were 25 care-

givers from the Pick's Disease Support Group, a phone- and internet-based support group that was founded over 20 years ago in the U.K. Some of these members, though long-time friends and confidants via the internet, met face-to-face for the first time.

"The responses we received, in person and through formal evaluation forms, were extremely positive," says AFTD President Helen-Ann Comstock. "Clearly, we have struck a chord with what caregivers need most: information and coping tools, delivered in a compassionate setting. If we can find co-sponsors at other sites throughout the country, it's an experience we would like to offer again, to more people."

The Center for Neurodegenerative Disease Research at the University of Pennsylvania, AFTD, and the Delaware Valley Chapter of the Alzheimer's Association hosted the event, and were joined by co-sponsors Pfizer, Inc. *See Conference, page 4*

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AFTD Awards First Research Grant

Earlier this fall the AFTD awarded its first research grant to Eileen Bigio, MD of Northwestern University. The \$35,000 award will fund her laboratory work investigating the abnormal proteins found in FTLN-MND.

"I am honored to be the recipient of the first AFTD research grant and excited to have the opportunity to begin characterizing the ubiquitinated proteins in FTLN-MND," says Dr. Bigio. "Our AFTD-funded Research Technologist has just started work in

our lab, and we are hoping that over the next year we can make some real progress on this goal."

Dr. Bigio is a professor of pathology and Director of the Neuropathology Division at the



Elaine Bigio, MD

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Spotlight On...

Fytie L. Drayton, Founding Treasurer, AFTD

Philadelphia native Fytie Drayton is a partner in her husband's 17-year battle with Pick's Disease. Dick Drayton was ill for seven years before finally receiving the correct diagnosis in 1995 from Dr. Grossman at the University of Pennsylvania. She recalls the relief that the accurate diagnosis brought for the whole family, after years of Dick's deteriorating behavior, speech, and personality change.

Knowing the neurological cause of

Dick's disease freed Fytie to get the help they needed: appropriate medical care, increasing nursing support, and understanding and aid from family, friends, and the local Pick's support group. Her work with AFTD has brought her into contact with others who have similar stories, and she is especially proud of the work AFTD is doing to spread the word. "We need to bring this disease to national attention, to educate people that not all dementias are Alzheimer's," she says. "There are many more people with FTD than are currently recognized."

Museum of Art, where she has been involved in American decorative arts and architecture for 44 years. She is an avid world traveler; among her favorite destinations have been Botswana and Kenya, where she has traveled with her grandsons. She is pictured here, during a recent trip to the pyramids in Egypt.

We extend our condolences to Fytie upon the death of her husband Dick, and our heartfelt gratitude for her work the past three years as AFTD Treasurer. She will continue to serve on the Board, where her warmth and insights are a tremendous asset.

Donations Honor Loved Ones

AFTD is grateful for these gifts, received June 1—Nov. 22, 2005.

We use these funds to create a supportive and informative network for those living with FTD, and to fund research in the hopes that future generations will no longer have to face the challenges of these diseases.

In memory of:

David H. Bingham, Jr.
David Bonyne
Dorothy Bullock
Christine G. Chambers
Craig Comstock
Richard Drayton

Phyllis Feigenbaum

David Freud
Rose Guidroz
Robert Hermann
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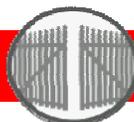
Joan Stuit

Diana Wantz

In honor of:

Grover Grimm
Keith W. Ingram
Peter Kohudic Mr. Potter
Linda Santangelo

AFTD



News

The annual AFTD Solicitation Drive is underway!

Please give generously, as your dollars will help us continue to support cutting-edge research and caregivers' needs throughout the coming year. All donations are tax-deductible to the full extent allowed by law.

AFTD's Advocacy efforts scored a win! Thanks to coordinated efforts with **Senator Arlen Specter** and his staff, the Senate Report that accompanied the FY2005 Labor HHS appropriations bill included wording that called upon the National Institute for Neurological Disorders and Stroke to: report the level of their support for FTD research, conduct an epidemiology study of FTD, and hold a workshop to assess the current state of FTD research, treatment, and needs. A copy of the report on research expenditures for Pick's disease and FTD is available on request to the AFTD office.

AFTD's first Telephone Support Group started in December. The pilot group is limited to 8 caregivers, a coordinator, and a professional facilitator, and focuses on Pick's disease. Based

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

on feedback from this experience, AFTD will hold future telephone support groups for each of the FTDs.

The July/September 2005 issue of *Alzheimer's Care Quarterly* highlights atypical dementias, and features articles by AFTD Board Chair **Helen-Ann Comstock**, as well as Jennifer Farmer, Genetic Counselor, and AFTD's Medical Advisory Council members **Tiffany Chow, and Murray Grossman**. In addition, Susan Grant wrote an article from the patient perspective.

AFTD is helping to fund publication of a Supplement to *Alzheimer's Disease and Associated Disorders*, a professional journal for neurologists who specialize in dementia. The Supplement will contain the reports given at the July 2004 FTD Symposium, as well as information on AFTD.

AFTD's Goals for 2006: Check AFTD's website for a complete list of the goals adopted for 2006 at the November 12, 2005, meeting of the Board of Directors.

Research Report:

Untangling Tau: a Promising Path to Therapy

John Q. Trojanowski, MD, PhD and Virginia M-Y Lee, PhD

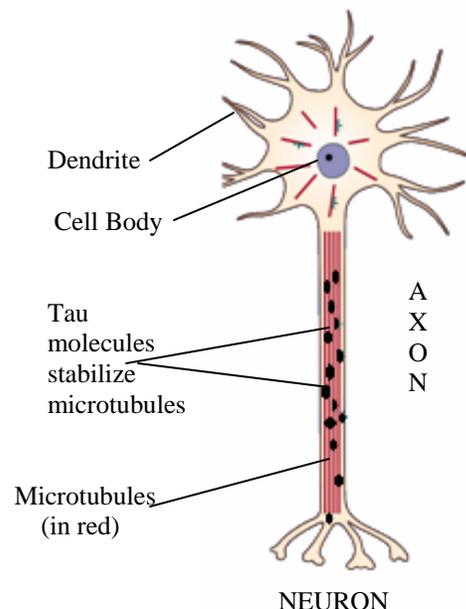
Drs. Trojanowski and Lee are (respectively) Directors of the Institute on Aging and the Center for Neurodegenerative Disease Research at the University of Pennsylvania. A growing body of evidence from labs around the world supports their hypothesis, originally published 14 years ago, that abnormal forms of the protein tau lead to loss of nerve cell function in the brain. Here, they explain the fundamentals of their theory and the direction in which it is leading researchers today.

The neuron (pictured at right) is the basic building block of the nervous system. When functioning normally, the dendrites receive an electrical impulse from a neighboring neuron. That impulse travels through the cell body and down the axon, where it leaves the cell and is passed across a small space to the dendrites of the next neuron. In

this way electrical signals travel through the brain.

Tau is a protein present in neurons that, when functioning normally, binds to the microtubules (MTs) that run the length of the axon and ensures that the electrical signal travels swiftly and efficiently. There is growing evidence that when abnormal versions of tau are produced by the neuron, it cannot bind to and stabilize the MTs. This leads to loss of nerve function, brain degeneration and memory loss. Some of this evidence is:

- An abnormal (hyperphosphorylated) version of tau is found in the plaques and tangles that are diagnostic for Alzheimer disease (AD). This form of tau has lost the ability to bind to and stabilize MTs, thereby impairing axonal transport.
- A mutation in the *tau* gene causes



a hereditary form of FTD, known as FTDP-17.

- By manipulating the *tau* gene, researchers have created animal models in the worm, fly, and mouse that mimic the disease process occurring in the brains of humans

See Tau, page 4

Caregiver Tip: Put an FTD patient or caregiver on your Holiday “to do” list

Cathi Hawkinson

Imagine my surprise two years ago as I watched my husband open his gifts on Christmas morning and there was no gift for me. As he opened his box of beloved books, I realized with a chuckle that we had been so busy trying to keep up with our family traditions that no one had thought to take my husband shopping! So with that in mind, I decided to put together a list of simple things that anyone can do to help those of us dealing with FTD.

It's all common sense. In my husband's case, he has lost his ability to speak and has trouble walking, but he can still read and enjoy books. Gift certificates to a local book store or Amazon.com would make his day. Food or movie certificates are a great idea, as long as mobility is not an issue. And if getting out is a problem



for the patient, DVDs, books on tape, a magazine subscription, music CDs, or his favorite wine or beer are always appreciated. But before you buy, ask about the patient's current condition, as things change constantly.

It doesn't have to cost money to be thoughtful. Email a picture of your family or grandkids. If you were a coworker, email what's going on at work. Better yet, remind him of a funny story or tell him how much he meant to you and others. Too often those words are wasted at funerals.

And don't forget the caregiver!! We need your support more than you can possibly know. So here are a few suggestions: occasional phone calls, emails or cards of support; a gift certificate to a local take-out restaurant, a

bookstore, or a personal treat (for a woman: a haircut, manicure/pedicure, or massage; for a man, to a local driving range or an online hobby catalog). If the caregiver can't leave the house, then do something that will brighten the home. Buy a bud vase and supply a flower once in a while. Get friends to arrange a Saturday night dinner. Drop off a pound of special coffee or a dessert. You can't imagine what that means when one is home 24/7.

Shopping itself may require time that the caregiver no longer has. Offer to run an errand, but be specific: "I'm going to Target and have ten minutes, can I pick up anything for you?"

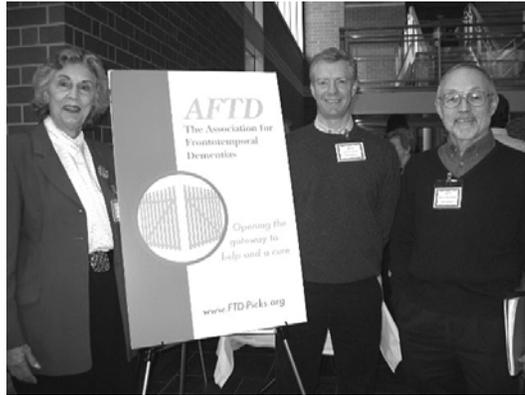
Intermittent thoughts of kindness can go a very long way in making our lives bearable during the holidays and beyond.

Cathi Hawkinson lives in Peoria, Illinois and is a full-time caregiver for her husband Jeff, who has had FTD for six years. Jeff recently received a palm-type device to assist in communication. If you are interested in knowing about the device or just have questions, Cathi invites you to email them at: jhawk13@insightbb.com.

Conference page 1

and Novartis, Inc. Representatives from a number of resource domains, including hospice, eldercare, home nurses, and durable medical equipment companies, were available for consultation.

The conference was free for all attendees, and AFTD awarded travel stipends to nine caregivers



(ranging from \$100 to \$500) to enable them to take part. For the full conference agenda, and to view a video of any of the sessions, see the AFTD website (www.ftd-picks.org). A DVD of the full conference, produced professionally for AFTD by WHYY in Philadelphia, is available for purchase through the website.

AFTD Board members Helen-Ann Comstock, Phil Lovett and Bruce Richardson

Bigio page 1

Northwestern University Feinberg School of Medicine in Chicago, IL. She is also Director of the Neuropathology Core at that institution's Alzheimer Disease Center.

Dr. Bigio will work to identify the abnormal proteins in FTLN-MND using state-of-the-art proteomic methods, including laser capture microdissection and multi-dimensional liquid chromatography-mass spectrometry. Her goal is to identify and characterize the insoluble protein deposits in this disorder. This will lay the ground-

work for determining the cellular defects present in FTLN-MND, and will ultimately address means of preventing or treating this disorder.

"We are extremely pleased to be able to fund Dr. Bigio's innovative and exciting work," says Murray Grossman, MD, EdD, Chair of AFTD's Medical Advisory Committee. "This is precisely the type of research that needs to be completed in the laboratory before we can get targeted therapeutics to the clinic."

Fewer than three years have

passed since AFTD's founding. With this award the association realizes one of the most challenging aspects of its mission, to fund research to speed results from the laboratory to the clinic.

Announcing! 5th International Conference for FTDs

**Sept. 6-8, 2006 San Francisco
Grand Hyatt Union Square**

*Sept 6 : Special Caregiver Sessions Track and AFTD Caregiver Dinner
Caregiver registration: \$75-100
Watch the AFTD website for further details and application forms for caregiver stipends!*

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suffering from AD, FTD, and other neurodegenerative diseases.

Perhaps the most exciting work currently being conducted in our field is that which extends this theory of abnormal tau to the quest for treatments: if neurodegenerative disease results from a lack of tau and the resulting destabilization of MTs, then MT-stabilizing drugs should have a thera-

peutic effect in AD, FTD, and other tauopathies. Indeed, a study recently completed in our lab suggests that this is a promising avenue. Transgenic mice that display the signs of neurodegenerative disease (deposits of abnormal tau around the nerves, reduced number of MTs and slow axon transport within neurons, and impaired motor behavior) were treated with an MT-stabilizing drug. The results were

encouraging: fast axonal transport was restored, the numbers of MTs in the axon increased, and motor function improved.

Though this work is not yet ready to be tested in humans, it is an exciting advance, and suggests a definite mechanism by which it may be possible to develop new therapeutic candidates for treatment of human neurodegenerative diseases.

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