

# AFTD

Opening the gateway to help and a cure

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## Conference Attracts Researchers, Caregivers

An FTD Satellite Meeting in conjunction with the 9<sup>th</sup> International Conference on Alzheimer's Disease and Related Disorders, was held in Philadelphia at the University of Pennsylvania July 14-16, 2004. More than 450 people from many countries around the world attended the conference; 70 of the attendees were past and present FTD caregivers and family members from across the U. S. and Canada.

Members of the Organizing Committee were Murray Grossman, MD, EdD, Virginia M.-Y. Lee, PhD, Bruce L. Miller, MD, John Q. Trojanowski, MD, PhD, and John van Swieten,



Attending the AFTD conference were: Shannon Byron (London, Ontario), Donna Conneally (Maryland), Darlene Ryan (Texas), Louise O'Connor (Ottawa, Ontario), Ed Morrow, Sharon Morrow (Minnesota).

MD. AFTD officers worked with the Organizing Committee and Gayle Viale-Joseph, Administrator at Penn, to coordinate and support caregiver participation and caregiver events. The Association hosted a Buffet/Reception at The Inn at Penn for con-

ference speakers and members of AFTD's Board of Directors and Medical Advisory Council on Wednesday evening, July 14. Special thanks go to Joyce Shenian for organizing this event, as well as the Caregiver Dinner.

AFTD awarded six Caregiver Grants of \$300 each and one of \$100 to caregivers who requested help with the costs of attending the conference. Five of the caregivers were from

the U. S., and two were from Canada. Following the scientific sessions on Thursday, July 15, there was a reading of the play "Gorked!" by Donald Drake. The play was a sensitive, sometimes funny, and often very moving

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## Research: Critical Role of Tau Protein

**John Hardy, PhD**

*Dr. Hardy is a neurogeneticist at the NIH National Institute on Aging, where his lab investigates hereditary forms of FTD. Only 10% of all FTDs are hereditary; however, knowledge gained through this research provides important insight into causes and possible therapeutic interventions for all forms of FTD.*

In the last 5 years we have begun to understand the causes of frontal dementia. Many, but not all, cases of frontal dementia are characterized by the presence of unusual deposits of a specific protein in the dying

nerve cell. This protein is called **tau**. The aggregates of tau are called **tangles**. Six years ago our lab showed that in the hereditary variants of frontal dementia the underlying problem was a mutation in the gene that codes for the tau protein, which made it aggregate more easily. This means that in some cases of frontal dementia we know the precise cause of disease: the mutation in the tau gene, and we have a good idea as to why it causes disease: because it makes a stickier protein. About 4 years ago, we used this knowledge to make a *See Tau page 4*



## Spotlight On...

### Kent S. Jamison, PhD, Vice Chair, AFTD

Kent Jamison is a former caregiver, having lost his wife at age 53 to

Pick's disease in 1998.

As one of the founding members of the Association, Kent brings much-valued experience from the worlds of academia, government and business. He holds a PhD in psychology from Michigan State University and a BS in psychology from Purdue. For the past 35 years he has done applied social

research in advertising, for a state legislature, and for a not-for-profit trade association in the financial services industry. This breadth of experience has given him an understanding of the brain, human behavior, organizations, our health care system and not-for-profits—a unique juxtaposition of talents, all of which have come in handy in building a strong foundation for the AFTD.

Through his work with the AFTD, Kent would especially like to touch the lives of other caregivers, and prevent others from feeling as isolated

and helpless as he did. "Lots of people beat themselves up, thinking they should be able to deal with everything, but you can't. Our healthcare system doesn't provide you with a case manager; you just have to figure it out as you go," he says. Currently he serves as point person for the Association's website.

Kent is co-author of a chapter on "Financial and Legal Readiness" in the FTD Caregiver's Guide What If It's Not Alzheimer's? He is working on a memoir describing his role as caregiver and the loss of his wife.

## Report on the first Meeting of AFTD's Medical Advisory Council

On July 16, 2004 the AFTD Medical Advisory Council (MAC) held its first annual meeting in Philadelphia. In attendance were MAC members: Murray Grossman (Acting Chair), Jordan Grafman, Carol Lippa, Tiffany Chow, M.- Marsel Mesulam, Andrew Kertesz, Thomas Bird, Linda Nee, Virginia Lee, Michael Hutton, John Trojanowski, John Morris, Bruce Miller; AFTD Board members: Kent Jamison, Fytie Drayton; and Brad Boeve (guest).

Murray Grossman, Acting Chair, was unanimously elected chair of the MAC; he appointed Thomas Bird vice chair. The following items were discussed: (1)The MAC recommended



*Murray Grossman, MD, EdD*

grant to promote research in frontotemporal dementias A Research Committee, composed of Virginia M.-Y. Lee (chair), Michael Hutton, Bruce Miller and M.-Marsel Mesulam, was appointed to develop grant guidelines.

that the AFTD Board adopt a goal of raising the funds to award a two-year competitive

(2) There was consensus that physician education is a significant issue impeding accurate diagnosis and care of FTD. Ideas discussed to address this problem included: publishing more articles in mainstream medical journals, such as the Journal of the American Medical Association, and sending MAC speakers to physician meetings. An Education Committee, composed of Jordan Grafman (chair), Carol Lippa, Tiffany Chow, Andrew Kertesz and Brad Boeve, was appointed to pursue these ideas.

The next meeting of the MAC will be during the American Academy of Neurology meeting in Miami, FL, in April 2005.

## AFTD



## News

### The AFTD Annual Fundraising Drive

has begun! We need to raise \$100,000 to finance the first AFTD Research Grant in 2005, as well as establish a toll-free Caregiver Helpline. Please consider making a tax-deductible donation; all levels of contribution are appreciated.

**AFTD President and Founder, Helen-Ann Comstock**, was presented with a beautiful clock by the AFTD Board, in recognition of her hard work and vision

in founding the association.

**Caregiver Survey: have you filled this out?** This information is important as we build a profile of our membership and plan programs and services to meet your needs. If you haven't participated, please do so via the website or ask us to mail you a copy.

**Thanks** to Martha Meyers, for all the time she has donated to AFTD to help with the mailing of our first newsletter and the creation of a mailing list.

**AFTD Annual Board Meeting** will be held in January, 2005 in Bethesda, MD.

*Send us news of events in your area!  
tess1929@aol.com*

## Donations Honor Loved Ones

The AFTD is grateful for gifts received in recent months both in honor of those affected by FTD and in memory of those who have died.

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

This newsletter and the AFTD website are examples of projects funded by donations.

### *In memory of:*

Evan R. Andersen  
Rebecca Fraher  
Eva Mae Woodruff Hall  
Lawrence Lano  
Dennis Murphy

Terrence O'Connor  
Dennis Sauer  
Henry A. Serre  
Joan Stuit

Jean Alice Thomsen  
Philip S. Walter  
John B. Wilson  
Kent Woodworth

### *In honor of:*

Dr. and Mrs. John M. Salmon III

## Trail Ride Raises Funds for AFTD

Katie Ward, a senior at Urbana High School in Ijamsville, MD, lost her grandmother to Pick's disease earlier this year. Motivated by loving memories and wanting to honor her grandfather, father and aunt, who cared for her grandmother for the past several years, Katie organized a trail ride to raise money for AFTD.

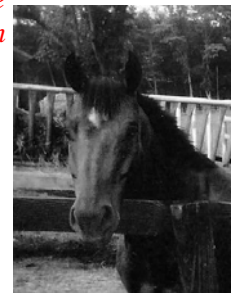
Nine people joined Katie on April 25, to ride their horses through a local park. Through donations from riders as well as sponsorships from other

friends and relatives, Katie was successful in making a very generous donation to the Association.

Katie emphasizes her respect for her grandfather, who "was so strong and selfless, and stood by my grandmother through everything." She also expresses her gratitude to AFTD.

We, in turn, would like to thank Katie! It is the support of family members, volunteers, and donors like her that makes the AFTD strong.

*Do you have creative fundraising ideas to share with other families and caregivers? Send us the details, and we can share them with the membership through the newsletter and on the web.*



*Katie's horse, Solo*

## Caregiver Tip: What's In A Name?

Here is a brief primer of terms that caregivers often hear from doctors and researchers. To keep it simple, I will not introduce all of the terms, just the ones that appear commonly.

**Frontotemporal Degeneration vs. Frontotemporal Lobar Degeneration: Frontotemporal degeneration** is a broad name for a dementia that encompasses just about every term that follows. As a clinician seeing patients, I make a *clinical* diagnosis of frontotemporal degeneration. The neuropathologist who performs brain autopsies in the laboratory would gather evidence enabling him to add the word "lobar", and thus assign a *neuropathological* diagnosis of **frontotemporal lobar degeneration**.

The next thing to keep in mind about **frontotemporal degeneration**

is that it has the same initials as **frontotemporal dementia** (FTD). Some authors use the two terms interchangeably. Others prefer to use **frontotemporal dementia** to mean the behavioral presentation (or frontal variant) of **frontotemporal degeneration**.

Some patients with **frontotemporal degeneration** have a language predominant change, as opposed to the behavioral change. This can be referred to as **primary progressive aphasia**. We split this language presentation further into patients with difficulty making the sounds of speech (**progressive non-fluent aphasia**) vs. those who have more difficulty understanding word meaning (**semantic dementia**).

Clinicians, researchers, and patholo-

## Tiffany Chow, MD

gists all need to use the same terms in talking with patients and families, to help minimize confusion. Consistent diagnostic categories are also critical in the design of research studies, so that conclusions can be accurate and specific to a particular group of patients. This is more difficult than it might seem, but this is one of the efforts being made every time we gather at meetings such as the July 2004 symposium in Philadelphia.

*Dr. Chow is a clinician-scientist at The Rotman Research Institute in Toronto, where she provides care for patients with FTD and does research in neuroimaging. She serves on the AFTD Medical Advisory Council.*



## Conference from page 1

dramatization of one family's efforts to cope with dementia. After the play, AFTD hosted a Caregiver Dinner at The Inn at Penn. This was an informal social evening, with brief encouraging comments for caregivers given by an FTD caregiver, Florence Collins. Four of the members of the FTD conference Organizing Committee attended: Murray Grossman, Virginia Lee, Bruce Miller, and John Trojanowski. Murray, Bruce and John each gave brief comments and expressed their appreciation for the work FTD caregivers do and for their participa-



*AFTD Chair H. Comstock (center) with MAC members (L to R) J. Trojanowski, T. Chow, and V. M.-Y. Lee with M. Morrison-Bogorad of the National Institute on Aging.*

tion in the conference. The playwright and members of the cast of "Gorked!" also attended the dinner and were interested to hear caregiver comments about the performance and content of the play.

The conference was a success exceeding the expectations of the Organizing Committee and AFTD. Further details about the conference and caregiver comments are posted on AFTD's web site.

## Tau from page 1

mouse with tangles, as a model for frontal dementia in humans. Researchers are now using this model in the search for effective new drugs.

Although this tau gene mutation is found in only about 5% of all cases of frontal dementia, we do see tangles in a much higher percentage of cases—perhaps 50%. Thus, we hope that our finding will have therapeutic relevance for all cases with tangles.

There are also at least three heredi-

tary forms of frontal dementia without tangles. We know where the genes for these diseases are (one is on chromosome 3, one is on chromosome 9 and one is surprisingly near to the tau gene on chromosome 17), but we haven't yet identified the genes themselves. A good analogy would be knowing what street a friend lives on, but not which house. We are working very hard in the laboratory to determine the specific "address" of each of these genes, and hope that we will

find them in the next two years. This information will be key to understanding the non-tangle form of the disease.

*Anyone who has more than two family members with FTD or anyone who has specific worries or questions, is invited to contact Dr. Hardy at [hardyj@mail.nih.gov](mailto:hardyj@mail.nih.gov). More information on the genetics of FTD, and the various subtypes of the disease can be found at [www.FTD-Picks.org](http://www.FTD-Picks.org).*

## Website Update

The Association's website continues to grow. Over the past year the number of individuals registered with us has increased from 58 to 357, and our average monthly "hits" have grown 5-

## [www.FTD-Picks.org](http://www.FTD-Picks.org)

fold, from 500 to 2500! A search for "frontotemporal dementia" in any search engine yields our website as one of the top sites every time

If you haven't registered on the site,

## Kent Jamison, PhD

consider doing so: it's a great way to ensure that you will receive the newsletter and keep current with advances in the field of FTD. Check out new postings under Latest Happenings!

# AFTD

PO Box 7191 St David's PA 19087-7191 [www.FTD-Picks.org](http://www.FTD-Picks.org)

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