

# AFTD

Opening the gateway to help and a cure

Volume 1 Issue 1

February 2004

## Association Founded to Support Families, Research

### Mission Statement

- To promote and fund research into finding the cause, therapies, and cures for the frontotemporal dementias;
- To provide information, education, support and advocacy to persons diagnosed with FTD, their families and caregivers;
- To educate physicians and allied health professionals about the FTDs and how to improve patient care;
- To bring about greater public awareness of the nature and prevalence of the frontotemporal dementias and the needs of those who are coping with them;
- To advocate with public officials and to promote public and private programs that provide appropriate, affordable and high-quality long-term health care and social services.



AFTD Board of Directors at their founding meeting in Philadelphia January, 2003. From left: Fytie Drayton, Joseph Becker, Joyce Shenian, Jordan Grafman (advisor), Tess Parrish, Helen-Ann Comstock, Lisa Radin, Kent Jamison. Absent: Lawrence Shor, Robert Kemp, Robert Potamkin. For a full list of board members and the Medical Advisory Council, see page 4

The AFTD is a national non-profit organization, founded by Helen-Ann Comstock in November, 2002. Accomplishments over the first year include: assembling a Medical Advisory

Council composed of leading scientists from across the U.S. and Canada; garnering IRS 501(c)(3) non-profit tax status for the association; participating in the 4th Interna-

tional Conference on Frontotemporal Dementias in Lund, Sweden; printing an AFTD brochure; and developing a website.

*See Association Founded, page 4*

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## Acting Chair of Medical Advisory Council Sees Needs, Sets Goals

**Murray Grossman, MD, EdD**

Frontotemporal dementia (FTD) is not Alzheimer's disease (AD). The needs of individuals with FTD and their families differ substantially from those with AD since this condition usually occurs at a younger age. Because the clinical characteristics are different, physical and psychological support mechanisms must be tailored to their individual needs and must be in place over a different time span to help these younger patients and their families.

Much work is needed to attain these goals. Crucial functions of the Association for Frontotemporal Dementias (AFTD) are to include public education and political advocacy along with the dissemination of information to patients and caregivers.

But the AFTD must do more. The clinical symptoms and signs of FTD differ from AD, as do the genetics and underlying biochemical and pathological abnormalities.

*See Grossman, page 4*



## Spotlight On...

### Helen-Ann Comstock, Chair, AFTD

Helen-Ann Comstock lost her husband, Craig, to Pick's disease after he was diagnosed in 1978 at the age of 44. It is due to her perseverance that the Association for Frontotemporal Dementias came into existence in 2002 and is now recognized as the source for information and research to so many people whose lives have been impacted by these unrelenting diseases. She is the Chair of the AFTD board and an in-

spiration to us all.

Following her husband's death, Helen-Ann served as the Executive Director of the Delaware Valley Chapter of the Alzheimer's Association from 1985 to 2000. She started the strong and active Pick's support group in the area and was its leader for two years. In 1999 she organized the Conference on Pick's Disease and Frontotemporal Dementia and, in 2002, the follow-up Consensus Criteria conference. She has been active in Pennsylvania state advocacy issues, especially the Family Caregiver Sup-

port Program. She serves on the Penna Council on Aging and on the boards of the Philadelphia Corporation for Aging and CARIE. She is a graduate of Gettysburg College.

Helen-Ann's intimate understanding of caregivers' problems and deep gratitude to her three children, sisters and friends, who were actively involved in the care of Craig, have fueled her desire to build a broad support network for all families faced with FTD. Under her leadership the AFTD has a strong and positive future.

## News from the Web

[www.FTD-Picks.org](http://www.FTD-Picks.org) *Kent Jamison, PhD, Vice Chair*

If you haven't seen the recent upgrades to our site, please take a look! Throughout the winter we have added descriptions of each of the separate disorders, and revamped the Overview (click on the ellipse on the home page). Now you will find much more information to access.

In December we had 800 visits to the site, nearly double the number the month before. The number of people who have registered with us is now

close to 100. Based on the first forty or so, most of those registering are recent caregivers, along with some researchers and health care professionals. Most are primary caregivers in their sixties, and there are just about as many men as women.

People have been very positive. "Thank you so much for this website. We are all in need of as much interaction with other FTD families as possible" (wife in her six-

ties caring for her husband with FTD). "This is wonderful for both of us" (wife caring for her husband diagnosed with Corticobasal degeneration). Comments such as these have been received from caregivers dealing with many of the FTD subtypes.

If you haven't registered with us, please do so. Your participation and comments will provide helpful guidance as we develop the website.

## Report from Lund, Sweden:

### 4th International Conference on FTD

The 4<sup>th</sup> International Conference on Frontotemporal Dementias was held in Lund, Sweden, April 24-26, 2003. AFTD Chair Helen-Ann Comstock was invited to speak about AFTD. Her comments and the founding of the association received coverage in the international press, and conference attendees from around the world expressed interest in and support for AFTD.

AFTD Medical Advisory Council members Tiffany Chow, Murray Grossman, Andrew Kertesz, Virginia

Lee, Bruce Miller, and John Trojanowski presented papers at the conference. Results on the first controlled study of a medicine for FTD were presented. The study found that trazodone can confer benefits on behavioral problems in FTD, although the very high dosage used was found to make some patients drowsy. For more information on Trazodone, see [www.medicinenet.com/trazodone](http://www.medicinenet.com/trazodone).

For a complete report on the conference, see the AFTD website ([www.FTD-Picks.org](http://www.FTD-Picks.org)).



## FTD Conference

*July 14-16, 2004 Philadelphia*

A symposium for FTD will be held at the University of Pennsylvania as a satellite meeting of the World Alzheimer's Congress. AFTD is arranging special sessions for caregivers during the discussion period following each session. Watch the website as plans develop over the coming months!

*Send us news of events  
in your area!  
[tess1929@aol.com](mailto:tess1929@aol.com)*

## Donations Honor Loved Ones

The AFTD is grateful for the gifts received over the past year both in honor of those affected by FTD and in memory of those who have died.

The organization plans to 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 honor of:*

Evan R. Andersen  
Helen August  
Richard Drayton  
Paula Scott  
Michael Sherrick  
Ben Strick  
Joan Stuit

Please make checks out to "AFTD" and mail to the address on page 4.

*All donations are fully tax-deductible.*

### *In memory of:*

Walter Bast  
Alithea Becker  
Myron Jack Black  
Herbert S. Brenner  
Craig Comstock  
Irene R. Donahue  
Paul L'Heureux  
Lois Mallory  
Kenneth Nolan  
Hugh M. Parrish  
T. Williams Roberts

*Special Thanks to the Gordie Howe Foundation for their generous contribution in honor of Colleen Howe.*

## Concert Raises Funds for AFTD

On September 20, 2003 some 250 people attended the Gateway Benefit Concert at the Sunshine Community Church in Comstock Park, Michigan. The concert was organized by Tom and Sue Stuit in honor of their wife and mother, Joan, who is diagnosed with Corticobasal degeneration.

Sue and her friends in the band performed a variety of show

tunes, religious music, and old standbys. Everyone had a great time, audience and performers alike, but the best part was that the community at large is now aware of AFTD and our mission to help those affected by this disorder. More than \$2,000 was raised from the event, and all proceeds were donated to AFTD.

Thank, you, Tom and Sue!



Photo by Alan Tutt

*Darcy Davis-Beghein, Sandy Igersoll and Sue Stuit sing "Fat Baby".*

## **Caregiver Tip:** Activities to Stimulate the Mind and Body

Activities are the everyday tasks that provide our lives with meaning, shape our identity, and allow us to accomplish our daily routines. Dementia can rob a person of the ability to initiate or complete a task.

Caregivers need to know that a balance of activities that are success-oriented and meaningful to the individual can help promote physical and psychological well-being. Activities do not need to be complex; tasks can be simplified, or given in one-step directions, to promote continued independence and success.

There are many activities you can plan with your loved one who is suffering from dementia. These ideas are from occupational therapist Lisa Fagan, OTR/LCALAA.

**Exercise and Physical Activities:** taking a walk; dancing; raking leaves or gardening; vacuuming; exercises.

**Creative Activities:** Art projects; playing musical instruments.

**Relaxation:** listening to music; watching TV or a movie; getting a hand massage; singing religious hymns or saying prayers; petting a cat or dog.

**Cognitive Stimulation:** listening to stories or poems; playing simplified word or card games; reminiscing (recalling family events).

**Purposeful Activities:** assisting with household chores (setting the table, folding laundry); assisting with meal preparation; providing self-care (bathing, dressing, grooming); giving pet care.

This tip can be found in chapter 12: "Challenging the Mind" in *What If It's Not Alzheimer's?*, edited by Lisa and Gary Radin.

*What If It's Not Alzheimer's?*, the first comprehensive guide dealing with FTD, is designed as both a resource and a reference guide for caregivers. Several members of the AFTD Board of Directors and Medical Advisory Council contributed chapters to the book, which includes four sections entitled: A Medical Focus; Managing Daily Care; Caregiver Resources; and Caring for Yourself.

Copies of the book may be ordered by phone from Prometheus Books at : 800 421-0351 or on the web at : [www.Prometheusbooks.com](http://www.Prometheusbooks.com) or [www.amazon.com](http://www.amazon.com).

## Association Founded from page 1

The Board of Directors held their first meeting in Philadelphia in January, 2003. During this meeting by-laws and a budget were approved, officers elected, and members of the

Medical Advisory Council were nominated. Dr. Grafman attended as an adviser, and Drs. Trojanowski and Grossman gave updates on FTD research.

On November 17-18 the Board convened its second meeting, at the Na-

tional Institutes of Health in Washington DC. A budget and list of priorities for 2004 were approved, Dr. Grafman conducted a tour of the National Institute of Neurological Disorders and Stroke (NINDS), and Dr. John Hardy gave a lecture on the genetics of FTD.

## Grossman from page 1

The enormous consequences of these differences underline the importance of developing reliable diagnostic criteria for identifying FTD and distributing this knowledge to physicians seeing patients who may have the disease.

As our scientific knowledge expands, we will be moving into an era of treatments designed for specific neurodegenerative conditions. Thus, another important role for the AFTD is to act as an advocacy group for re-

search funding which will allow scientists to improve our understanding of frontotemporal dementias and find treatments and cures for these conditions.

I believe that these are among the central roles of the AFTD: support for the caregivers, public advocacy, and rapid movement of knowledge from the scientific laboratory to an involved public. The Medical Advisory Council of the AFTD will be involved in pursuing these goals over the next several months. Together, we hope that we can improve the care and quality of

life of individuals and their families over both the short term and the long term.

Dr. Grossman is founder of the Cognitive Neurology section of the Department of Neurology at the University of Pennsylvania, where he is an Associate Professor. He is currently the Editor-in-Chief of the scientific journal *Cognitive and Behavioral Neurology*. Dr. Grossman's research focuses on advancing our understanding of the neural basis for language and cognitive disorders in neurodegenerative diseases and the development of therapies for these conditions.

## AFTD Caregiver Survey Enclosed

***Please Respond!***

One of the key purposes of the AFTD is to identify the needs of our community and to design, coordinate, and help deliver services to meet these needs. In order to fulfill this role we need to hear from you.

Enclosed in this newsletter is a copy

of the AFTD Caregiver Survey. The answers to these questions will help us begin to develop a profile of our community, our needs, and the goals that should guide our Association over the coming year. All information you provide will remain confidential

and will not be shared without your permission.

Please take the time to fill out the survey and mail it back to us. A few minutes now may mean help is there when you or another caregiver needs it weeks or months from now.

# AFTD

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