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.
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 inspiration 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 Support 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 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 sixties 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.

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Report from Lund, Sweden:
4th International Conference on FTD

The 4th 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.

For a complete report on the conference, see the AFTD website (www.FTD-Picks.org).

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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
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.

### 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 or www.amazon.com.
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 research 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.

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.