

AFTD.....Annual Report 2005

By Helen-Ann Comstock, Chair

WORKING TO ACCOMPLISH OUR MISSION

I am pleased to report that 2005 truly has been a landmark year for our young organization, with the awarding of our first research grant, the establishment of an office and a toll-free number, and an increase in number of people contacting AFTD for information and making donations. Most of this work was accomplished through the efforts of AFTD's volunteer Board of Directors and Medical Advisory Council. As seen below, significant progress was made toward all aspects of our mission.

1. Promote and fund research

1) We awarded our first research grant. With the recommendation of a committee of the Medical Advisory Council, a grant of \$35,000.00 was awarded to Eileen Bigio, MD, Professor of Pathology (Neuropathology), Northwestern University Feinberg School of Medicine, Chicago, IL.

Dr. Bigio will work to identify the abnormal proteins in FTLD-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 groundwork for determining the cellular defects present in FTLD-MND, and ultimately to address means of preventing or treating this disorder.

2. Provide information, education and support to persons diagnosed with FTD and their families and caregivers

1) We updated our **brochure** and distributed two issues of our **newsletter** to several hundred individuals on our ever-growing mailing list. Our November 2005 issue of the newsletter was mailed to more than 700 people, and over 400 downloaded this newsletter from our website. Educational materials continue to be available on our website and on request.

2) AFTD's **website** continues to grow. A year ago our site was averaging 90 visits a day; now it sometimes reaches as high as 200 a day. In the month of October alone, the site received over 6,600 visits. More than 600 individuals are now registered with us through our website. Importantly, our homepage consistently comes up in the top 10, and often first, when a variety of different key words related to FTD are searched using Google or Yahoo.

3) We responded to more than 200 inquiries through our website and initiated a toll-free **Helpline** to handle caregiver requests. In 2005 such requests

were responded to by volunteers and members of our Medical Advisory Council, but at the end of 2005 a healthcare professional began to respond to these calls.

- 4) Our first **Telephone Support Group** began in December. The pilot group has younger Pick's disease caregivers as its focus. After evaluation, additional groups focusing on each of the other frontotemporal dementias will be started.
- 5) AFTD was one of the sponsors of the first **FTD Caregiver Conference**, held November 11, 2005, on the campus of the University of Pennsylvania. AFTD also underwrote the cost of videotaping presentations from this conference and they may be viewed on our website. In addition, DVDs of the conference are available for purchase.
- 6) AFTD gave **stipends to nine caregivers** from the U. S. and Canada to enable them to attend the November FTD Caregiver Conference.
- 7) Still to be done: Update the results of the caregiver surveys and create a report suitable for submission to a professional journal.
- 8) Establish a Volunteer Program.

3. Educate physicians and allied health professionals about FTD

- 1) AFTD underwrote half the cost of publishing a special Supplement to the publication ALZHEIMER DISEASE AND ASSOCIATED DISORDERS. This international journal goes to neurologists who specialize in or have an interest in dementia. The supplement to the October-December, 2005 issue (Volume 19) contains the reports given at the July 2004 FTD Symposium.
- 2) ALZHEIMER'S CARE QUARTERLY: The July-September, 2005 issue (Vol. 6 No. 3) focuses on "Atypical Dementias." AFTD worked with the editor and arranged for an article about AFTD, as well as articles by an FTD patient and members of AFTD's Medical Advisory Council.
- 3) Still to be done: Develop an information sheet on diagnosis.
Meet with representatives from School of Nursing to develop training materials for nurses, LPNs and nursing assistants.

4. Create public awareness of FTD

Much needs to be done in this area. We have met only part of our goals.

- 1) AFTD worked to publicize the November 2005 FTD Caregiver Conference, and we did produce one article about AFTD and FTD for publication in a professional journal, ALZHEIMER'S CARE QUARTERLY.

2) Still to be done: Develop an article about AFTD and FTD and send to selected newspapers and magazines. Contact the Health editors of major newspapers with information about FTD and AFTD.

5. Advocacy

1) As a result of AFTD's advocacy, working with Senator Arlen Specter and his staff, the Senate Report to accompany FY2005 Labor HHS appropriations bill included the following recommendations to the National Institutes of Health (NIH):

"The Committee requests the NINDS, in conjunction with NIA and NIMH, to provide a report to the Committee by March 31, 2005 on grant funding and research expenditures for Pick's disease and other frontotemporal dementias. The Committee further requests that the NINDS conduct an epidemiology study of frontotemporal dementias and hold a workshop for researchers, clinicians, and advocates to assess the current state of frontotemporal dementia research, treatment, and needs."

A copy of the Senate Report on NIH expenditures for Pick's disease and other frontotemporal dementias may be obtained by contacting the AFTD office via phone or e-mail.

The epidemiology study and the workshop have yet to be accomplished.

2) In addition, with the help of Senator Specter and Representative Rob Andrews, AFTD worked with both Senate and House staff to include FTD language in the Senate and House Reports to accompany the FY2006 Labor HHS appropriations bill. This bill became Public Law 109-149 on December 30, 2005. The language is as follows:

Senate Report 109-103

Picks Disease- The Committee urges the NINDS to initiate funding for Picks drug discovery efforts that focus on specific targets relevant to treating the mechanisms underlying brain degeneration due to frontotemporal dementia [FTD]. The Committee further encourages the NINDS to conduct multicenter treatment trials for symptomatic management of Pick's disease and other FTDs. The Committee encourages the Institute to focus on methods for discovering the causes of this family of diseases, improving diagnostic accuracy, and providing longitudinal characterizations so that the success of intervention can be determined.

House Report 109-143

Frontotemporal dementia (FTD).--The Committee encourages NINDS to support research into drug discovery efforts that focus on specific targets relevant to treating the mechanisms underlying brain degeneration due to

frontotemporal dementia (FTD) such as Pick's disease. The Committee is interested in research that will focus on methods for discovering the causes of this family of diseases, improving diagnostic accuracy, and providing longitudinal characterizations so that the success of intervention can be determined.

6. Funding

In 2005 AFTD was supported by memorial contributions and contributions from board members, as well as grants from the Maine Community Foundation and the Potamkin Foundation.