

# ***AFTD.....Annual Report 2006***

*By Catherine Pace-Savitsky, Executive Director*

## **WORKING TO ACCOMPLISH OUR MISSION**

I am pleased to report that 2006 has been a remarkable year of growth and development for AFTD. Some of our most remarkable accomplishments included: Early in the year our first part-time Executive Director was hired; after receiving an overwhelming number of grant applications, we awarded our second research grant; a new, state-of-the-art database was created; and there was a dramatic increase in number of people contacting AFTD for information and making donations. Many of these projects were a success due to the hard work and dedication of our volunteer Board and Medical Advisory Council. As seen below, significant progress was made toward all aspects of our mission.

### **1. Promote and fund research**

1.) In 2006 we awarded our second scientific research grant. With the recommendation of a committee of the Medical Advisory Council, a grant of \$50,000.00 was awarded to doctors Ian MacKenzie and Blaire Leavitt from the University of British Columbia. This was an increase in funding, up from \$35,000 in 2005.

Drs. Leavitt and MacKenzie are working to develop a mouse model in which they can simulate inactivation of the *PGRN* gene at different times in the life cycle and in different regions of the brain. This model will be shared by the entire research community, and will be a vital tool as scientists work to understand how the *PGRN* gene leads to FTD, as well as the best potential ways to prevent or stop progression of the disease.

2.) In late 2006 AFTD worked with the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute on Aging (NIA) to plan an early-2007 workshop to assess the current state of FTD research and treatment. The purpose of the workshop is three-fold: to review the current state of knowledge about FTD; to create a prioritized list of recommendations to move the field forward; and, to emerge with an overall blueprint to speed translation of FTD research into the clinic and into development of potential new therapeutics.

3.) AFTD expanded our donations program to include car donations as well as contributions made through eBay's "Giving Works" program

### **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 2006 issue of the newsletter was mailed to more than 700 people, and over 600 downloaded this newsletter from our website. Educational materials continue to be available on our website and by mail upon request.
- 2) AFTD's **website** continues to grow. A year ago our site was averaging just under 200 visits a day; it now averages more than 270 hits a day. More than 925 individuals are now registered with us through our website and it continues to be listed on other websites, scientific journals and press releases as the main source of FTD-related information.
- 3) We responded to more than 200 inquiries through our **website** and answered over 320 phone calls from our toll-free **Helpline** to handle caregiver requests.
- 4) Our **Telephone Support Group** continues to meet on a monthly basis. What began in 2005 as a pilot group has now turned into a very successful monthly group that serves more than 20 families from across the country. Plans are now in the works for expanding the program to include a second group for caregivers with a loved one in the "early stages" of their disease.
- 5) AFTD was one of the sponsors of the first **5<sup>th</sup> Annual International Conference for Frontotemporal Dementias** which was held in San Francisco, California in early September. AFTD had a strong presence at the meeting including an informational table, as well as hosting separate dinners for caregiver and conference presenters. Helen-Ann Comstock was honored at this meeting for her pioneering efforts in the field.
- 6) AFTD gave **stipends to eight caregivers** from the U. S. and Canada to enable them to attend the International FTD Conference.
- 7) We developed widely distributed **informational brochures** on the Genetics of FTDs, as well as resource information on the research discoveries: PRGN and TDP-13.
- 8) Established a schedule of regularly send materials and information to current **FTD support groups** as well as sponsoring **quarterly conference calls** with support group facilitators from across the US and Canada.
- 9) In November of 2006 AFTD began financially supporting a children and teens support group in Denver, Colorado. This group is facilitated by certified child/teen therapists who are working with AFTD to develop a protocol for starting other children's support groups around the country
- 10) Still to be done: Prepare an information sheet specific to children and teenagers;

Prepare a checklist of things for caregivers to be concerned about, such as changes in sleeping and eating, dehydration, stress, etc.; Do a mailing to all Alzheimer's chapters, including an explanatory letter and brochure.

### **3. Educate physicians and allied health professionals about FTD**

- 1) AFTD met with representatives from Northwestern University, UCSF and ADEAR to develop plan for an informational booklet on FTD which will be widely distributed to physicians, psychiatrists, and other allied health care professionals. Production and distribution will continue into 2007.
- 2) AFTD is working with the publishers of the American Journal of Alzheimer's Disease and other Dementias (AJADD) to publish an FTD-specific issue of the journal for 2007. This year invitations to 16 researchers in 4 countries to contribute to this special issue and has confirmed submissions from 12 of these individuals.
- 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 has reached out to several well known public individuals who have a connection to frontotemporal dementias requesting alliance and support of our organization. Working with these individuals we hope to create a broader public image of FTDs.
- 2) In light of the discovery of protein TDP-43, which links FTDs and ALS together, AFTD has begun discussion with the Philadelphia Chapter of the ALS Association to prioritize initiatives our respective groups can collaborate together on to bring awareness and support to the diseases for which we advocate.
- 3) The Association has been providing several newspaper reporters with information about FTDs for articles which were printed in newspapers across the country. One of these reporters will be writing a monthly column for the AFTD website.
- 4) 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**

AFTD applied to the American Brain Coalition, an advocacy group based in Washington, D.C. ABC advocates for increased support of research that will lead to better treatment; services and support that will improve patients' quality of life; as well as a national commitment towards finding cures for individuals with disabling neurological and psychiatric disorders

## **6. Funding**

In 2006 AFTD was supported by memorial contributions and contributions from board members, as well as grants from the Maine Community Foundation and the Potamkin Foundation. Of note, our annual appeal went out in the November 2006 issue of the newsletter with a note that all contributions received in the month of December would be put towards research. Contributions in December of 2006 were nearly double what they were in December of 2005.