Charting a Course for Care and the Cure

The Association for Frontotemporal Degeneration

Education Conference & Annual Meeting

2012 Conference Sponsorship Packet for Individuals/Families

when:

Friday, April 27, 2012
11:30 a.m. - 6:00 p.m.

where:

Westin Buckhead Atlanta
3391 Peachtree Road NE
Atlanta, GA 30326

hosted by:

AFTD
The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

About the Conference

AFTD's education conference is a day dedicated to the patients, families and professionals who comprise our growing community. Although each family's experience is unique, there are many struggles and issues that are common to all. AFTD seeks each year to provide valuable information that individuals can use while affirming their experiences with this rare disease. The half-day structure, breakouts and social reception are deliberate efforts to invite informal networking among participants, facilitators and AFTD board and staff.

For the 2012 conference, AFTD proudly collaborates with colleagues at the Emory University School of Medicine to plan and lead the education sessions. Dr. William Hu, Assistant Professor of Neurology, will provide the main address on advances in medical research and care. In addition to his work with patients at Emory Dr. Hu conducts clinical research on FTD and the development of biomarkers.

Who Should Attend

This conference is a great way for caregivers to connect with other caregivers, as well as with healthcare and medical professionals and organizations that provide support or resources for caregivers and patients. Conference sponsorship opportunities are listed at the back of this packet.

Why Your Sponsorship Matters

To keep the cost of attending this conference to a minimum, AFTD does not charge a registration fee. Your sponsorship helps AFTD cover the costs of lunch, the facilities and the networking social following the conference.

2011 Boston Recap

On Friday, June 10, 2011 approximately 170 people attended the AFTD Caregiver Conference and Annual Meeting at the Cambridge Marriott in Boston, Massachusetts. Joining family caregivers were members of AFTD's board of directors and several professionals who received continuing education credits for their participation. Caregivers came from across the U.S. and as far away as France and Nigeria. Participants attended breakout sessions, which permitted more focused discussions.

Author of nine novels and *New York Times* essayist Elinor Lipman gave the opening address entitled *The Beginning, the Middle, the End: An FTD Wife's Story*. Ms. Lipman drew laughs and tears from the audience as she recounted the different stages of life with her husband Bob, who passed away from FTD in 2009.

Dr. Bradford Dickerson, neurologist and director of the Frontotemporal Disorders Unit at Massachusetts General Hospital, gave the keynote address, *Frontotemporal Degeneration: New Tools for Early Diagnosis and Monitoring Set the Stage for Treatment Trials*. Dr. Dickerson spoke about the spectrum of diseases that comprise FTD and how their "overlap" with one another further complicates accurate diagnosis. He also spoke of the advances in diagnostic imaging as well as the importance of developing biomarkers for FTD.

Past Conference Locales:

2011 - Boston, MA
2010 - Fort Worth, TX
2009 - Los Angeles, CA
2008 - Baltimore, MD

Frontotemporal Degeneration:
Fast Facts

Frontotemporal degeneration (FTD), also commonly referred to as frontotemporal dementia, fronto-temporal lobar degeneration (FTLD), or Picks disease, is a disease process that causes changes in behavior and personality, language and/or motor skills, and a deterioration in a person's ability to function.

FTD is distinct from other forms of dementia in two important ways:

- Onset of FTD often occurs in a person's 50s and 60s; the average age of diagnosis is about 60, which is a full 10 years before the average Alzheimer patient is diagnosed. Thus, FTD can affect work and family in a way dementia in older patients does not.
- The hallmark of FTD is a gradual, progressive decline in behavior and/or language (with memory usually relatively preserved). As the disease progresses, these deficits cause significant impairment in social and/or occupational functioning and result in an increasing dependency on caregivers.

FTD affects an estimated 50,000-60,000 Americans (Knopman, 2011; CurePSP, www.psp.org).

FTD represents an estimated 10%-20% of all dementia cases. It is recognized as one of the most common presenile dementias (meaning it occurs in a younger population).

The prevalence world wide is uncertain with estimates of FTD amongst people ages 45 to 64 between 15-22 per 100,000 (Knopman, 2011).

Frontotemporal degeneration is characterized by progressive atrophy of the brain, particularly the frontal and/or temporal lobes, the parts of the brain that control "executive functions" such as decision-making, personality, social behavior and language.

Currently, there are no treatments to slow or stop the progression of FTD. However, research is advancing and initial clinical trials are underway.

The course of the disease ranges from 2 to over 20 years, with a mean course of 8 years from the onset of symptoms.

Because of the nature of these symptoms (and the fact that a patient is often "too young" for dementia to be considered), FTD is often initially misdiagnosed as a psychiatric problem or movement disorder, such as Parkinson's disease. Alzheimer's disease is another common misdiagnosis.

Subtypes of FTD are identified clinically according to the symptoms that appear first and most prominently. Clinical diagnoses include behavioral variant FTD (bvFTD), primary progressive aphasia (PPA) which affects language, and the movement disorders progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD).

Accurate diagnosis is crucial, as some medications used to treat other disorders may be harmful in a person with FTD.

Existing care facilities and programs may not be appropriate for—indeed, many do not accept—younger individuals as patients without additional education and support about FTD.

The Association for Frontotemporal Degeneration:
Who We Are

mission:

The Association for Frontotemporal Degeneration (AFTD) is a non-profit organization whose mission is to:

- Promote and fund research into finding the cause, therapies and cures for frontotemporal degeneration
- Provide information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers
- Educate physicians and allied health professionals about frontotemporal degeneration and how to improve patient care
- Bring about greater public awareness of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it
- Advocate with public officials and promote public and private programs that provide appropriate, affordable and high-quality, long-term health care and social services
- Facilitate the international exchange of ideas.

vision:

We envision a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.

past, present & future:

The Association for Frontotemporal Degeneration was founded (as the Association for Frontotemporal Dementias) by Helen-Ann Comstock in 2002. The organization is the product of her experience as an FTD caregiver and collaboration with scientists, physicians and other caregivers who echoed the need for increased attention to these devastating diseases.

In the nine years since its inception, AFTD has grown into an organization that has raised and donated more than $1 million to FTD research. With a small but energetic staff, a dedicated board of directors of past or present caregivers and a top-notch medical advisory council comprised of FTD doctors and researchers from across the USA and Canada, AFTD has become *the* information and support resource for FTD patients and their families.

In addition to the most up-to-date information on FTD research, AFTD provides many resources for caregivers in terms of educational materials, support group listings, newsletters, long-term care options and respite grant opportunities. AFTD also partners with some long-term care facilities through a program called "**Partners in FTD Care**," an AFTD-driven educational initiative to help educate facility staff on how to better care for FTD patients.

The work to provide care and to find a cure for FTD patients continues. AFTD will be at the forefront of supporting and funding research until a cure for FTD is found.

Individual/Family Conference Sponsorship:
2012 Opportunities & Benefits

Keynote Address Sponsor (limited to one individual/family) – $10,000:

- Opportunity to name the Keynote Address at the AFTD annual meeting
- Introduction about the honoree prior to the Keynote Address
- Recognition in AFTD's annual meeting program
- Recognition in AFTD's annual report
- Recognition on AFTD's website
- Recognition in AFTD's newsletter

Individual/Family Sponsor – $1,000:

- Recognition in AFTD's annual meeting program
- Recognition in AFTD's annual report
- Recognition on AFTD's website
- Recognition in AFTD's newsletter

>> Elinor Lipman, 2011 Annual Caregiver Conference Keynote Speaker, novelist and *New York Times* essayist. Ms. Lipman lost her husband Bob to FTD in 2009.

AFTD 2012 Conference Sponsorship:
Individual/Family Application

Charting a Course for Care and the Cure

Contact Information:

Company/organization name:____

Contact name: ______________________ Email address: ________________________

Street address: ____

City/State/Zip: ____

Phone number: ____

Individual/Family Sponsorship Category:

☐ Keynote Address Sponsor - $10,000
☐ Individual/Family Sponsor - $1,000

Payment Information:

Total amount due: $ ____________

☐ Payment by check enclosed (make payable to "AFTD")
☐ Payment by credit card ☐ Visa ☐ Mastercard

Credit Card Number: _________________________ Expiration Date: ________

Name on Card: ____

Signature: ____

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Please email advertisement files as .pdfs to amaher@theaftd.org. Completed applications can be sent via email or postal mail. **Payments, ads and applications must be received by March 15, 2012.**

Please mail to:
AFTD
290 King of Prussia Road
Radnor Station Bldg 2, Suite 320
Radnor, PA 19087
267.514.7221

For more information on AFTD, visit our website at www.theaftd.org
Questions? Contact Angie Maher: amaher@theaftd.org or 267.514.7221 x2530