Caregivers are encouraged to join us at the 5th International Conference on Frontotemporal Dementias in San Francisco on September 6-8, 2006. The meeting, which is being sponsored by the Memory and Aging Center and the Alzheimer’s Disease Research Center, both of UCSF, will be held at the Grand Hyatt Hotel on Union Square. Five to seven hundred researchers, clinicians, and caregivers from around the world are expected to participate. A special dinner for caregivers, hosted by AFTD, will be held the first night.

“In the past, we have found that bringing caregivers and the researchers together results in a valuable learning experience for everyone,” notes Helen-Ann Comstock, chairman of AFTD. “Caregivers can learn firsthand what advances are on the horizon, and researchers have the opportunity to gain perspective on the day-to-day realities of FTD.”

On September 6 there will be parallel tracks of meetings, one for caregivers and the other for FTD professionals. In the morning caregivers will hear presentations on genetics, diagnosis, medical and behavioral management, and recent advances in research. A panel of researchers will host a Q&A session. After lunch caregivers will join the scientists and clinicians to hear about historical perspectives on FTD. Later in the afternoon the caregiver track will continue with sessions on legal and ethical issues unique to FTDs, clinical stages of the disorder, problems with healthcare delivery in the US, and familial risks and issues.

Early this year AFTD reached a milestone in its development, with the hiring of its first Executive Director. Catherine Pace-Savitsky, MA, comes to AFTD from UC San Francisco, where she worked for three years in the Memory and Aging Center, managing their FTD Program Project Grant.

In addition to taking over daily management of the Association, Ms. Pace-Savitsky will represent the association at public events, coordinate advocacy efforts, oversee communications with caregivers, and assist the Board of Directors in formulation and implementation of the organization’s goals and policies. Projects that she feels especially passionate about include: developing a resource database of FTD clinicians, services, and support groups; advocating for legislation to protect patient rights; and expanding AFTD’s volunteer network at the grassroots level.

Ms. Pace-Savitsky looks forward to growing AFTD, so it will have a stronger presence in the medical community, and be of greater service to caregivers and patients. “I welcome all questions, comments and suggestions from caregivers,” she says. “If they can help identify their most pressing needs, we can design effective programs and policies to help.”
Spotify On……
Joyce Shenian, Founding Secretary, AFTD

“I have since met families for whom the diagnostic process has taken much longer, sometimes five years,” says Joyce. “So I guess, in retrospect, we were somewhat lucky.”

Joyce cared for her husband at home until his death in 2002; they were years when she willingly put her life on hold. “The day after he passed away, I woke up and thought: What am I going to do with my life?” she recalls. The answer came in the form of Helen-Ann Comstock (whom she knew through her volunteer work with the Alzheimer’s Association), and an invitation to join her as a founding board member of AFTD.

“AFTD has helped me channel my energy and frustration, and given me something to feel passionate about,” notes Joyce. “It feels good to be doing something in an area where so little has been done.”

As Recording Secretary of AFTD Joyce’s responsibilities include: insurance coverage, event planning and publicity materials. She sees publicity as a key to many facets of the AFTD mission. “Heightened awareness of the FTDs and our Association will increase both public understanding and professional recognition of these diseases,” she says. “This will better enable us to raise money and, I hope, help address the issue of misdiagnosis.”

Joyce serves on other community boards in the Philadelphia area. She is a licensed Real Estate Broker in Massachusetts and Pennsylvania.

AFTD is grateful for these gifts, received Nov. 23, 2005 — April 24, 2006. We use these funds to create a supportive and informative network and to fund FTD research.

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AFTD is building a resource database of clinical sites that have experience or specialize in diagnosis and treatment of FTD. Currently it includes about 40 sites in North America, but plans are for the database to expand in size and encompass international sites. You can access this service by contacting the office through the website, or calling the AFTD helpline.

Join AFTD’s volunteer network! Have you developed a resource for FTD patients or caregivers in your local community? Do you have a special talent or expertise that you would be willing to share with the wider FTD community? Email or call the AFTD office with your idea, and we will connect you with our growing network of volunteers.

The pilot telephone support group has been a huge success. Plans are underway to expand to two or three groups within the next few months. Call the helpline or email info@ftd-picks to get on the waiting list of participants.

New on the AFTD website: a comprehensive article explaining the genetics of AFTD, and what you can do to determine if FTD might be inherited in your family. A special section provides tips for how to broach the discussion with family members, and lists professional resources. This piece will soon be available in booklet form, as well.
As caregivers know, one of the most problematic issues with FTD is getting an accurate diagnosis. Because the first symptoms of FTD are often of social behavior or language, rather than memory or cognition, standard “dementia” tests come back negative. The result is that patients with FTD often go undiagnosed for years or, worse, are misclassified as psychiatric patients.

Neuropsychologist Katherine Rankin, Ph.D. sees this issue as one that signals a need for clinicians to broaden not only their definition of “dementia”, as they have in recent years, but also the diagnostic tools they use to identify it. “A major contributor to misdiagnosis is the general misconception that anyone with a dementia can be identified by screening with standard neuropsychological tests, which measure memory and cognition,” she says. “In reality, changes in social behavior and personality are often the first neurologic signs of a neurodegenerative disorder. We clinicians need to recognize these social changes as symptoms of what they often are: non-Alzheimer’s dementia.”

In her clinical research program at the Memory and Aging Center at UCSF, Dr. Rankin has been working on this issue for the past 6 years. The problem is that none of the standard tests neurologists use to assess social cognition and behavior are appropriate for use with dementia patients. The tests rely upon self-report questionnaires, which are inappropriate for a person who has lost insight into his own behavior. They also require the patient to understand complex language—again, one of the first abilities compromised in many of the FTDs. So Dr. Rankin is adapting these standard assessments and using new brain imaging technologies to develop novel diagnostic tests specifically tailored to the FTD population.

Her results are promising. By adapting a number of standard psychological tests, Dr. Rankin has been able to measure changes in insight, empathy, and social personality. Moreover, her tests distinguish Alzheimer’s disease from FTD, as well as among the various FTD subtypes. Her data show distinctive patterns of loss (both quantitative and qualitative). See Diagnosis, page 4

Caregiver Tip: Communicating Effectively with Your Doctor

Your relationship with the patient’s physician is a critical one: not only does it impact the medical care your loved one receives, but it also determines your own success in handling the new trials of daily life. We polled a number of caregivers and clinicians, and asked them to identify tools and strategies a caregiver can use to foster a positive relationship that results in effective teamwork.

Become familiar with the various members of your professional clinical team. In addition to the neurologist, there may be a nurse specialist, social worker, genetic counselor, and others. Each of them has an area of expertise. Introducing yourself to each of them and understanding their role on the team will enable you to direct specific questions to the relevant professional, and get an answer faster.

Prepare for a clinical visit. Have a family meeting before the visit, and ask for other caregivers’ inputs as to what the current issues are. Prepare a list of questions for the physician. One clinician reports that in her experience “just the fact of a family meeting can provide the comfort and confidence caregivers need to get “unstuck” from what may have seemed an impossible tangle of issues.”

On clinic day. It is important that the major caregiver attend with the patient. Bring your list of questions. Be prepared: know medicines and doses, bring films and previous test results. Be direct about what you want from the appointment and the physician.

Between appointments. If there are significant changes (for the better or worse) keep your doctor informed. Do not feel you have to wait for the scheduled appointment: this could delay effective care, and you will become increasingly frustrated. Have a discussion with a member of the clinical team, or leave a succinct message for the doctor that conveys the basic facts of the issue. The physician may decide to see the patient sooner, or make a change in medication.

Read the information the clinician gives you. It may answer some of your questions; it may also help you think of more. It will definitely help you become more familiar with See Communicating, page 4
Dr. Rankin is also using new brain diagnostic assessment to be referred to a specialist for further patients, to identify those who should serve with their clinician screen his or her behaviors, can help the non-assessments, a simple checklist of observations that suggest that measurement of these social deficits can provide useful information for differential diagnosis of these various diseases. One of these assessments, a simple checklist of observed behaviors, can help the non-specialist clinician screen his or her patients, to identify those who should be referred to a specialist for further diagnostic assessment.

Dr. Rankin is also using new brain imaging techniques to look inside the operating brains of FTD patients, and correlate specific brain lesions with the symptoms that the patient displays. In this way she has produced tantalizing data that suggest that specific areas of the brain are responsible for empathy, “warm” vs. “cold” personality, self-awareness, and social sensitivity.

Dr. Rankin’s innovative work offers exciting promise. It is providing new insight into the normal relationship between brain and personality. It also gives new hope for the clinical ability to differentiate between an array of brain impairments, distinguishing psychiatric problems, memory, personality, and emotional deficits from one another. For FTD patients specifically, her results are opening up a new arsenal of diagnostic tools available to the clinician. And with new options for effective treatment of the FTDs on the horizon, accurate diagnosis in the living patient is becoming more important than ever.

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