

AFTD

Opening the gateway to help and a cure

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Caregivers and Researchers to Convene

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 health-care delivery in the US, and familial risks and issues. *See Conference, page 4*

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AFTD Hires Executive Director

Helen-Ann Comstock

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 ex-

panding 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."



Catherine Pace-Savitsky

Susan L-J Dickinson, MS
Newsletter Editor



Spotlight On.....² Joyce Shenian, Founding Secretary, AFTD

something to feel passionate about," notes Joyce. "It feels good to be do-

Joyce Shenian's husband, Popkin, had just retired from an executive position with General Electric Company, Plastics Division, and they were in the process of moving from Massachusetts to Philadelphia when he first starting displaying symptoms of his illness. As the symptoms became more pronounced, they sought medical help, but were extremely dismayed when every clinician they saw gave them a completely different diagnosis. It took a long 18 months of consultations in different cities before two neurologists agreed that Popkin had a type of FTD.

"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

ing something in an area where so little has been done."

As Recording Secretary of AFTD Joyce's responsibilities include: insurance coverage, event planning and public relations 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

Donations Honor Loved Ones *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.*

In Honor Of:

- Abe Sack's 90th Birthday
- James S. Abbott
- Helen-Ann Comstock
- Joseph Field
- Dr. Lynn Field
- Grace Ginkle
- Grover Grimm
- Gwen Johnson
- Nancy Kohudic
- Peter Kohudic
- Paul Reeve

In Memory Of:

- Jane Ward
- Virginia Banis
- Jessie Becker
- David Bingham, Jr.
- Celeste Bobela
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News

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.

*Send us news of events in your area!
mmeyers@ftd-picks.org*

Developing Tools for More Accurate Diagnosis of FTDs

Katherine Rankin, PhD

As caregivers know, one of the most problematic issues with FTD is getting an accurate diagnosis. Because the first symptoms of FTD are most often ones 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

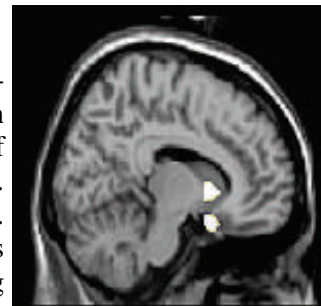
tests, which measure memory and cognition,” she says. “In reality, changes in social behavior and personality are often the first neurologic signs of a neurodegenerative disorder. We clinicians need to recognize these social changes as symptoms of what they often are: non-Alzheimer’s dementia.”

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 qualita-



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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.”



Before the appointment. Contact the office ahead of time if you know you’ll want to speak with someone outside the presence of the patient. The medical team can then orchestrate the visit to accommodate your need.

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*

Conference page 1

Days 2 and 3 of the conference are reserved for more technical scientific and clinical sessions, during which researchers will share their work in basic research on the disorder, the development of new diagnostic tools, the distinction between FTD subtypes,

and progress in the development of new treatments. Caregivers and other lay people are welcome at these sessions, as well.

Caregiver registration for the conference is \$75, which covers the cost of attendance for all 3 days of the conference. As in the past, AFTD will be offering scholarships for those caregivers who would like to attend the

conference but have financial concerns that would prevent them from otherwise attending. Please contact AFTD directly for more information. For additional conference information or to register, see the link on the AFTD website or go directly, at: (<https://www.cme.ucsf.edu/cme/CourseDetail.aspx?coursenumber=MNR07002#TravelLodging>)

Communicating page 3

the disorder, and will enable you to be a more effective member of the team.

Join a caregiver support group. Many caregivers report that it is their peers who are able to provide them with the most helpful advice on the logistical problems of daily life.

Address your issues, too. FTD specialists are well aware that this is a disorder that affects not just the patient, but all of the people involved in

the patient's care. If there is a special situation or need you, the caregiver, has, you should communicate this to the doctor. It is relevant, because it is probably impacting the patient's daily life, too; the physician may have experience or suggestions from addressing similar issues with other families.

So the message is unanimous: clear and timely communication with your clinician, using the strategies and tools suggested above, will help you to foster a positive and effective relationship

with the clinical team. This may result in more effective care for the patient; it will definitely impact your own experience, and help you feel like you are one member of the support team, and not facing it alone.

Do you have other strategies that have promoted a positive and effective relationship with your medical team? Please email us to share them with other caregivers! info@ftd-picks.org

Diagnosis page 3

tive) t h a t 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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