

AFTD

Opening the gateway to help and a cure

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AFTD Funds Drug Discovery

Research initiatives ratified by the AFTD Board at its May meeting signal a dramatic increase in the organization's commitment to FTD research. This year AFTD will award one research grant and embark on a joint venture to finance translational, drug discovery research for FTD. A major fundraising campaign is planned to fund these programs.

"Within the past year some very exciting discoveries have been made that have identified specific molecules involved in FTD brain pathology," says AFTD chairman Helen-Ann Comstock. "We want to keep this momentum going, and ensure that these findings are translated from the laboratory to the

clinic as fast as possible."

Ms. Comstock adds that the unprecedented response to the December 2006 fundraising appeal, which for the first time was dedicated entirely to research, sent a signal to the AFTD Board. "It is very clear that our membership values research, and is willing to fund it. We heard this message, and are setting our organizational priorities accordingly."

AFTD has signed a memorandum of understanding with the New York-based Alzheimer's Drug Discovery Foundation (ADDF) to create a joint FTD Drug Discovery Program. The purpose of the Program, to which AFTD will give \$100,000 and ADDF \$200,000 for each

of the next three years, is to "catalyze and fund academic and biotechnology industry scientists worldwide to conduct early-stage, high-risk translational research leading to the discovery and development of effective therapies for FTD."

Specific objectives of the program include: to increase the number of scientists working on FTD drug discovery, to diversify the types of projects that are pursued, and to fund the "gap" that currently exists between laboratory science and a pharmaceutical product. This gap, which exists for all medical conditions,

See Drug Discovery, page 6

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Newsletter Editor*

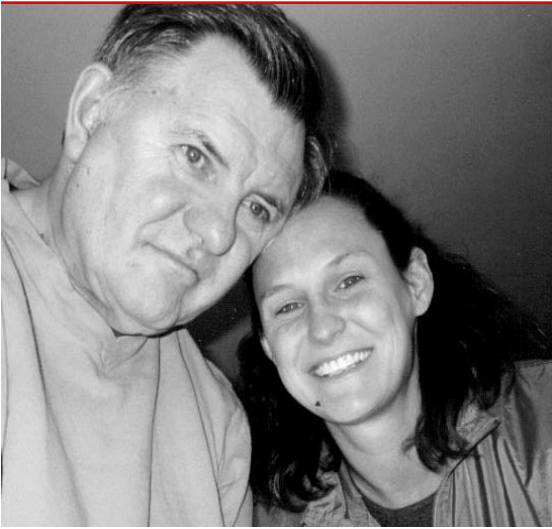
Caregiver Conference

More than 230 caregivers from across the country attended a conference at the University of Pennsylvania on June 22. Co-sponsored by AFTD, the meeting included presentations on state-of-the-art diagnosis, care and treatment of various FTDs. Professionals also shared information on advocacy, community resources, end-of-life care, and legal and long-term planning. Highlights included Dr. John Trojanowski's (UPenn) optimistic talk on the promise of new drugs and new treatments, and tips from Katie Maslow (Alzheimer's Assoc.) on how to advocate effectively for patient care and services. Lisa Radin (AFTD and Alzheimer's Assoc.) and Danita Vetter (Alzheimer's Assoc.) spoke about care for caregivers.

During breaks the attendees could learn more about available resources, and interact with researchers, clinicians, and other caregivers, who came from as far away as Montana and Colorado. AFTD provided four grants to enable families to attend the conference. Go to www.ftd-picks.org to see a video recording of the conference.



Outgoing Medical Advisory Council Chair Murray Grossman, MD, EdD was honored at the Caregiver Conference for his many years of thoughtful and caring leadership with AFTD. Dr. Grossman will continue as a member of the MAC.



Colleen was in graduate school for physical therapy, hundreds of miles from home, when her father, Ed McAndrew, was diagnosed with Pick's disease at the age of 53. Her youngest brother was still living at home, and for the previous three years the family had been seeing medical specialists, trying to figure out why their father was losing interest in the family, his job, and even his appearance.

"This was in 1996," Colleen says,

Spotlight On.....

Colleen Quinn, AFTD Board member

"before the internet was widely available. It definitely felt like we were totally alone as we dealt with this disease." Colleen's father developed additional medical problems, including seizures and a heart attack, and she recalls that not one medical professional knew what Pick's disease was before they met and treated him. "At one place," she recalls, "my mom even brought in her own notebook of information and references, so the staff would know how to handle him better."

Since joining the AFTD board in 2005, educating medical professionals in other specialties about FTD has been one of Colleen's major interests. Another has been the AFTD telephone support group, which she started two years ago and still facilitates today.

This group allows caregivers from across the country to meet and share their experiences with others—even though they may live in an isolated area. Each month they "meet" to listen, understand, and trade ideas on how to best handle logistical, emotional, and medical aspects of a situation. The program has been so successful a second group has just been started.

Colleen also helps evaluate applicants and make awards of Caregiver Grants that enable financially needy families to participate in AFTD caregiver conferences. She is proud to be on the AFTD Board, and to be able to extend support that wasn't available to her own family ten years ago.

Colleen currently lives and works as a pediatric physical therapist in Washington DC with her husband and four young children. Her father died in January, 2005.

AFTD



News

Runners Honor Grandfather and Raise Funds

On May 6 Jennifer and Chris Iannotti ran their first race—a half-marathon for her, a 10K for him—in honor of their grandfather, Joseph Robert Lotito, who died of Pick's disease on January 11. Friends and family in their hometown of Westbury, Long Island sponsored their efforts, and the brother and sister team raised \$1300 for AFTD. "PopPop did so much for us," says Jen. "We were proud to do something to honor and remember him. We hope to raise more next year!"

Have an idea for a fundraiser? Contact the AFTD office, and we'll be happy to provide you with brochures and other information to support your efforts.

The AFTD Medical Advisory Council (MAC) is proud to announce that Bradley Boeve, MD, of the Mayo Clinic in Rochester, MN, has been named the new MAC Chair. One of Dr. Boeve's first tasks will be to lead the committee that awards the 2007 AFTD research grant. Stay tuned for a report from Dr. Boeve, in our fall newsletter.

New support groups have formed in Boston and Minneapolis. See the AFTD website for more details. For those living in the Dallas/Fort Worth area, a new group will be forming in the coming weeks. Please email info@ftd-picks.org for more information.

AFTD is proud to announce a Request for Proposals for the 2007 Research Grant Award. Those interested in submitting an application for funding should visit our website for details.

AFTD is collaborating with the publishers of the *American Journal of Alzheimer's Disease & Other Dementias* to publish an issue dedicated exclusively to FTDs. Those who subscribe to this journal can expect this special issue in December 2007.

The International Conference on Frontotemporal Dementias will take place September 3-5, 2008 in Rotterdam, The Netherlands. More info can be found at www.FTD2008.org.

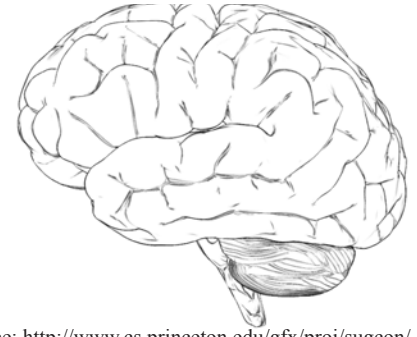


Jennifer and Chris Iannotti

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

The Importance of Brain Autopsy

An autopsy can provide closure and benefit future patients. But it is important to make arrangement ahead of time.



Source: <http://www.cs.princeton.edu/gfx/proj/sugcon/models/>

During the past year researchers have made several key advances in our knowledge about FTDs. None of these findings—nor those that will be made this year and in the years to come—would be possible without the generous participation of patients and their families. Brain autopsy can be a difficult topic to face emotionally, but it is only by seeing exactly how this disease affects the brain that we will be able to understand, treat, and hopefully someday even prevent and cure, FTD.

There are several important reasons why a family should consider arranging for a brain autopsy upon the death of their loved one.

- To get a definitive diagnosis. While a patient is alive, the clinician uses the tools that are available to him or her (MRI, CT scans, physical exam, etc) to make the most accurate diagnosis possible. However, it is only by actually looking at the affected brain tissue that a pathologist can see exactly what occurred in specific portions of the brain to produce the symptoms of FTD. The pathological diagnosis that results from the autopsy is the official diagnosis of that patient's disease.
- To provide information for family members. Because some FTDs

may be hereditary, the official diagnosis may have ramifications for the patient's first-degree relatives. With this pathological diagnosis in hand, a genetic counselor can have a much more productive and informed discussion about the potential implications and risks for family members.

- To improve clinical diagnostic techniques for future patients. Pathologists need to see the actual tissue to understand the biochemical and molecular changes that have taken place in the brain cells. They can then correlate these changes with the data that was gathered via clinical testing during life: the symptoms, MRI, CT scans and other tools the clinician had available to him or her. This entire process will help the clinician to do a better job of interpreting the information they gather from these tests, and give future patients more accurate diagnosis in a more timely manner. Accurate and timely diagnosis will become increasingly important as more effective therapies are developed for FTD.

- To better understand the disease process at work in FTD. It is only by increasing our basic understanding of what goes wrong in the brain cell—

and why—that researchers can design more targeted and effective therapies.

AFTD Board member Colleen Quinn recalls that when her father died the family knew they wanted a brain autopsy, but hadn't yet worked out the details. "On the day after he passed away I was on the phone with NIH, the funeral home, and Indiana University," she recalls. "We ended up having to delay the funeral by a day."

In the end, Colleen says, it was worth it: they got a final report that confirmed her father's diagnosis of Pick's disease and learned the fact that there was also evidence of Parkinson's disease. Though they did have to change the date of the funeral, the family was able to have an open-casket viewing, as planned. "I would absolutely encourage other families to arrange for an autopsy," she says. "But start earlier than we did."

These Centers perform brain autopsy for FTD

Indiana University*

freppers@iupui.edu
317-274-1590

University of California, San Francisco

<http://memory.ucsf.edu/Research/autopsy.html>
(415) 502 - 1053

University of Pennsylvania

Memory Clinic www.pennadc.org
215-662-7810.

Northwestern University

memoryresearch@northwestern.edu
312-695-9627.

*Note: Indiana University is the only Center that accepts brain donations from patients not previously enrolled in their research program.

Planning for brain donation

1. Make the Decision.

The first step is to make the decision to have an autopsy performed. We strongly recommend that family members have this discussion ahead of time. This will ensure that paperwork is completed and the relevant professionals understand your wishes, so when your loved one does die you can focus on more important family issues. To get optimal results, the autopsy needs to be carried out as soon as possible after death (preferably within 6 hours).

2. Find and Contact a Pathology Program.

Once a decision is made, you should contact a pathologist who is experienced in the field of FTD. Ask your neurologist, or refer to the list on the AFTD website for some of the major programs in the U.S. (Note that most of these programs are research-based, *See Brain, page 6*

Advocating for a Brother with FTD

Christina Caldwell has written hundreds of letters to raise FTD awareness and get her brother the care he needs. She wants you to join her.

I would like to introduce you to my 58-year-old brother, Dr. Allen Rocco. For more than 30 years he was a well-respected dentist in South County, Rhode Island who contributed to his community and paid his taxes. Today, Allen lives in a state hospital: an archaic, dark building with a broken elevator, windows that cannot be opened and no secure area for patients to be out-of-doors. Allen's room has a broken nightstand, a broken closet, and a bed that does not get made unless I'm there to do it. The food he is served does not bear mentioning.

So begins one of the hundreds of letters Christina Caldwell has written on behalf of her brother, who was diagnosed with Pick's disease in 2004, at the age of 55. Allen suffers from some of the more severe behavioral symptoms of Pick's, and after he was initially taken from home in an ambulance to the local hospital, he spent several months being transferred from one facility to another, the victim of a system that didn't quite know what to "do" with him. Allen was too physically healthy to stay at the medical center; he was too young to be admitted to a nursing home; and his combative behavior excluded him from entry to a slew of other facilities. (Had he committed a crime or suffered from an addiction, Christina notes, Allen would have had appropriate care from day one.) Finally, his family received the good news that a bed had opened up in the Virks Building on one of the campuses of the Rhode Island state hospital. It is this facility that Christina describes in the excerpt above. "Allen had finally reached his destination," she says, "and I looked in horror at the deplorable conditions of the building where he would most



**Never doubt
That a small group
Of thoughtful and committed citizens
Can change the world.
Indeed, it's the only thing that ever has.
--Margaret Mead**

Want to make a difference?

Advice from Katie Maslow, Associate Director for Quality Care Advocacy at the Alzheimer's Association:

Define the issue, problem or need

Determine your target (e.g. legislature, executive branch, community agency, professional association, media)

Make your ask: Put a face on the problem by telling your story. Provide documented facts. Communicate very specifically what this person or group could do to make a positive change.

Summer is a great time to call or visit your representatives in their local offices!

Interested in joining the AFTD Advocacy Committee? Email us at info@ftd-picks.org or call: 1-866-507-7222.

likely live out the rest of his life." Then came the first monthly bill: \$30,000—nearly \$1,000 per day. Christina was appalled, saddened, enraged—and motivated. She turned on her computer, and began to write Allen's story. The letters went to the governor of Rhode Island, 120 state representatives and legislators, local and national offices of AARP, the Alliance For Better Long-Term Care, and the state Attorney General. A local paper printed Allen's story, and the family was overwhelmed by the letters, email and phone calls they got from Allen's former patients.

Although few of the elected officials responded to Christina's letter, her efforts have born fruit: just this winter, Allen was moved to a more modern state facility, where he is receiving appropriate care. Christina is relieved and pleased that he is finally in the right place. But she admits to being frustrated—and even embittered—by the lack of response on the part of elected officials to her letters. "There are days when I most definitely have lost faith in the system and our government," she says. "On the other hand, my faith in human good will continues to grow." She tells of the overwhelming response from their local community, and the support she has received through AFTD. And Christina has agreed to be a founding member of the AFTD Advocacy Committee, chaired by new AFTD Board member Louise O'Connor. She urges others to join them by advocating for the FTD patients who can no longer speak for themselves. "You must believe you can make a difference," she says. "The more people who write, the louder our voice becomes, and the more likely we are to be heard."

Donations Honor Loved Ones

Gifts received March 1 - June 14, 2007

AFTD is grateful for these gifts, which fund research, information and support

In Honor Of:

Sandy Birnbaum
George Edwards
Mimi Freeman
Grover G. Grimm
Dub Ham
Ron Martling
Jennifer McConathy
Shirley Nerenhausen
Paula Scott

In Memory Of:

Dano Agresta
Nadia Aquilino
Brenda Arnett
Gail Borowick
Willis H. Catterson
Paulette J. Crivello
Stan Daniels
George Dietz
Harry L. Dietz

Phyllis Feigenbaum
William Freeman
Evelyn Geesaman
Lavada Harnapp
Robert Hermann
Albert Hinterreiter
Marie Katzenmeier
Pati Kemp
Otto Kostka
David W. Liebl

Rhoda H. Liken
Joseph R. Lotito
Robert H. Mather
Dolores McCoy
Robert E. Moore
Sharon Morrow
Dennis Murphy
John R. Musser, Jr.
Paul W. Palmer
Gregory M. Reinhart

Diana Richardson
Susan Robbins
Ilse Rose
Josephine Sansone
Robert J. Sykes, Jr.
Steven D. Walter
Diana D. Wantz
Alan Wike

From Our Families.....Bruce Richardson

Bruce Richardson's wife Diana was diagnosed with Pick's Disease in 1999, when they had been married for 33 years. He cared for her at their home until her death last year. Here, Bruce generously shares his thoughts and feelings about her illness, her death, and the ambivalence he feels now that he has been "freed" from his role as a caregiver.

Diana died in her sleep on April 7, 2006. Her death was not a surprise; I had been expecting it for many years and it brought mixed emotions. On one hand it was very sad, but on the other it was a relief – her suffering was over and my role as a caregiver was complete.

I had been a full-time caregiver for four and a half years. The first year of caregiving was the hardest. I would get mad at Diana for doing dumb, illogical things. She was "emotionally flatlined" and I couldn't carry on a conversation with her. I think it took about a year before I began to accept the fact that Diana really had no control over her emotions or actions. Once I fully understood that, I could deal with her much better.

One of the harder things was not being able to communicate with Diana. She was mute the last year of her life, and for the last three to four years she could only speak a few words at a time. I was able to tell her things but she couldn't respond. I was never sure she understood what I was saying – but I knew what I was saying, and it helped me to be able to tell her I loved her and tell her about our kids and our new grandchild.

Caregiving is a mixed bag. It is sad watching your spouse slowly fade away, but the work of daily living can crowd out the larger, emotional issues. Most married couples have fallen into a routine, where each does

certain chores around the house. Then all of a sudden, when FTD hits, one spouse is left to do everything. At the support group I belong to in Denver I have heard stories of spouses who have never cooked, never taken the car in for maintenance, never paid bills, and people who had never heard of a durable power of attorney. I was fortunate in that I am quite handy around the house, I love to cook, and I was able to deal with most everything, although I really dislike cleaning house--as anyone who has visited me can attest to.

One of the heaviest burdens of caregiving is the loneliness. Some people have a fear of being with someone with dementia – they don't know what to do or what to say. I was probably one of those people prior to Diana's illness. After her symptoms became evident we had fewer visitors and we were not invited out nearly as much as we had been previously. I have had a few people be honest with me and they said they just felt awkward being around Diana, so they stopped calling – I understand that and I am OK with it.

Another burden is having mixed emotions: the sadness of losing your spouse and the guilt feelings from being relieved of your caregiving. In my experience a caregiver comes face-to-face with this guilt at two junctures: when



they consider putting their loved one into a care facility, and when he or she finally dies. I must say, when Diana died I did feel relief, along with the sadness.

Everyone has their own view of death and of how they would like it to happen for themselves and for those they love. Some people want to squeeze every minute out of their life regardless of their condition and quality of life, and others are just willing to let nature take its course and get it over with. I take the latter view point. Two books I found very helpful were *Dying Well* by Dr. Ira Byock, and *Final Gifts* by Maggie Callanan & Patricia Kelley.

For me it was an honor and a privilege to care for Diana. There is very little I would have done differently. Other than her illness and death, the only regret I have is that I didn't recognize her unusual behavior as an illness earlier than I did. I do believe that I am a better person because of the years I spent taking care of Diana. I miss her, but I am trying to move on with my life and be a good father and grandfather for my kids.



Michael Scott Karpovich

spoke to a standing-room-only crowd of 200 caregivers at the University of Pennsylvania on June 22. Michael, who has no depth perception, is dyslexic and diagnosed as “brain damaged”, shared his experience that it is “our greatest adversities that are really what make us strong.”

Brain *from page 3*

and the patient needs to be enrolled in the program ahead of time to qualify.)

3. *Enroll in the Program.*

Each program has certain criteria for enrollment, which they can share with you. Most will require that you register with their program ahead of time to ensure that the patient meets their research criteria. They will want to see medical records and the clinical testing data you already have on the patient, and may require additional testing. They will have forms for you to sign, and specific advice on how to make arrangements with a funeral home. Many programs have extremely helpful literature, and are happy to guide you through this process. If the patient qualifies for a research program, there is little or no cost to the family.

4. *Inform the Patient's Caregivers.*

Once the forms are signed and ar-

rangements are made, make sure your physician, the nursing home (if the patient is not at home), and the funeral home understand your wishes. You should give them copies of the instructions and legal forms.

5. *When the Patient Dies.*

This process obviously takes a bit of work ahead of time, but it ensures that upon the death of your loved one, all of the relevant professionals can be in direct contact with each other, and carry out your wishes efficiently.

6. *Final Report.*

Approximately 3-12 months later many programs provide the family and their clinician with a final report on the official diagnosis, and what was learned through the autopsy. You will receive a formal written report that you can share with your own physician or with other family members.

Drug Discovery *from page 1*

metamorphoses into a canyon in the case of a rare disease like FTD, where the relatively small size of the patient population is a strong dissuader for drug companies to invest big dollars in research that might (or might not) produce a safe, effective therapeutic.

“When AFTD met with researchers and clinicians this past winter to chart a course for the near future, it became very clear that we can't sit back and wait for someone else to take the lead,”

says Comstock. “If we, the FTD patients and families, want to see drugs developed for this disorder, we need to make it happen. And we are.”

In addition to the drug discovery program, AFTD will be awarding its annual research grant this fall. To fund these ventures the AFTD is embarking on its first major fundraising campaign. Board member Phil Lovett is leading the effort to raise funds for the drug discovery venture, and will be serving on a new Development committee of the Board. The committee has secured pledges

from 100% of the AFTD Board, and each of these members is now reaching out to a network of friends and family. Plans are proceeding to apply for foundation and corporate grants, as well as appealing to the general membership.

“We will need everyone's help to fund these exciting commitments,” notes Lovett. “And we are confident that the AFTD community will step up to the plate.”

For more information on how you can contribute, visit the AFTD website at www.FTD-Picks.org.

AFTD

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