

The Association for Frontotemporal Dementias

AFTD

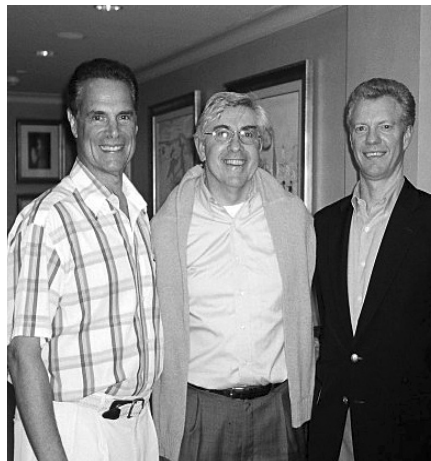
Opening the gateway to help and a cure

Volume IV Issue 1

April 2007

Leaders Meet to Devise an FTD Road Map for Research

On January 18 and 19 thirty-three leaders in the field of FTD, representing 17 different institutions and five countries, met to assess the current state of FTD research and treatment. The workshop was held in Miami, Florida and involved researchers, clinicians, staff from the National Institute of Neurological Disorders and Stroke (NINDS), National Institute on Aging (NIA), and a research foundation. Representatives from AFTD included Helen-Ann Comstock, Chair, Philip Lovett, Board member, and Catherine Pace-Savitsky, Executive Director. Several members of AFTD's Medical Advisory Council also were among the participants.



Walter J. Koroshetz MD, Deputy Director, NINDS, and AFTD Board members Robert Potamkin and Philip Lovett

(For a complete list of participants, see the AFTD website.) The workshop was funded by NINDS, NIA and AFTD.

The purpose of the workshop was 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

Participants were divided into four workgroups: Imaging and Biomarkers; Pathology; Potential Therapeutics;

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Susan L-J Dickinson, MS
Newsletter Editor

AFTD Grant Leads to Collaborations

The first AFTD research grant, awarded for calendar year 2006 to Eileen Bigio, MD of Northwestern University, has been completed. Although the project did not produce the results expected, it has led to a number of collaborations that will help drive understanding of FTD forward.

"We were thwarted in the experiments we had initially planned, but have been pleasantly surprised at the new directions that have opened up to us," says Dr. Bigio. "That's both the beauty and the frustration of doing this kind of work."

Dr. Bigio had received the \$35,000 grant to study the ubiquitinated proteins that are found in the "inclusions" that char-

acterize brain cells in FTLD-MND (the type of FTD that occurs with ALS, or Lou Gehrig's disease). Although her team was successfully capturing 1-2,000 inclusions from each slice of tissue scanned, it was not enough to yield significant results. About the time Dr. Bigio was coming to this conclusion, Drs. Lee and Trojanowski, from the University of Pennsylvania,

published their identification of TDP-43 as the disease protein of the inclusions in FTLD-U. Dr. Bigio is the Neuropathology Core leader at Northwestern's Alzheimer's Disease Center, which is leading a collaborative project on FTD between Northwestern, Washington University, Rush University, and University



A sample of brain tissue: the black spots are Lewy bodies composed of abnormal protein deposits

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Spotlight On..... Lisa Radin, AFTD Board member

learned that there was no one to guide her along this path. "There was very little to read that could give us insight into the journey we would be taking," Lisa recalls. With no model to follow, Lisa and her adult children cobbled together a clinical care team—seeking out new specialists whenever Neil displayed a new symptom. Their son Gary moved back home and, along with Gary's sister Geri, they cared for Neil until his death three years later.

Lisa and Neil Radin succeeded at something many married couples can't imagine: they shared both a personal and professional life, as they worked together from home running their own business. "We were very close," Lisa says. "We got along well, and knew each other's strengths and weaknesses."

So when Neil was diagnosed with Pick's disease at age 55, Lisa was set on a path toward losing the person who was a partner in all aspects of her life. And she soon

Since then, Lisa has dedicated most of her time to being a guide to other caregivers. She works for the Alzheimer's Assn., Delaware Valley Chapter, where, in addition to her main responsibility as a special events coordinator, Lisa facilitates two FTD support groups and fields FTD calls on their Contact Center Helpline. She has been on the AFTD Board since its inception. Most notably, Lisa and Gary conceived of and

edited the first book ever dedicated to providing information and support to FTD caregivers. *What If It's Not Alzheimer's?: A Caregiver's Guide to Dementia* contains chapters on all aspects of FTD: medical, financial, legal, logistical, and a section on the importance of caring for your own needs. Her favorite chapter is titled "From Loss to Life: Managing Emotions and Grief."

"As a caregiver, you are grieving from the day you get the diagnosis," says Lisa. "It's not an easy journey; there's so much to cope with emotionally, physically and financially. My hope is that our book can make someone's life easier, and give some guidance so they don't feel so alone. This book lets people know that here I am: I've gone through it and I've survived."

Lisa and Gary's book can be ordered from AFTD. All proceeds go to the Neil L. Radin Caregivers Relief Foundation.

Grant *page 1*

of Texas, Southwestern.

This project, funded by the National Alzheimer's Coordinating Center, has pooled a cohort of nearly 300 autopsied cases with the pathology of FTD, and is now collaborating with the U Penn group to further study TDP-43.

"Our repository of samples from

FTD cases, all well-characterized both clinically and pathologically, is a natural place to further the investigation of TDP-43. How many of our samples contain this protein? Is there a specific clinical sub-type that does or does not involve TDP-43? These are important questions that need to be answered so that TDP-43 research

can be used to develop therapeutic intervention for FTL-D-U, the most common sub-type of FTD," says Bigio.

"This kind of collaboration among labs is critical, especially in a rare disorder like FTD," says Murray Grossman, Chair of AFTD's Medical Advisory Council. "We all need to work together to advance the pool of knowledge."

AFTD



News

Many thanks to all who donated to AFTD following our November newsletter appeal; contributions more than doubled compared to the previous year! These monies will fund the research grants AFTD will award in 2007.

Two new FTD support groups have formed; one in Los Angeles, CA and one in New York, NY. Details can be found on the AFTD website <http://www.ftd-picks.org/?p=caregiver.supportgroups> or by contacting Joanne Sackheim at josacks1@aol.com (Los Angeles) or Jill Goldman at (212) 305-7382 (New York).

The 59th annual meeting of the Academy of Neurology will take place April 25-May 4, 2007 in Boston. Several presentations will be made on FTDs throughout the week. AFTD will have an information booth at

the conference, and we invite all health care professionals attending this meeting to visit us there.

The **2007 FTD Caregiver Conference** will be held on June 22nd at the University of Pennsylvania, in Philadelphia. For conference details including a list of speakers please visit the AFTD website at www.ftd-picks.org/files/CC07_Flyer.pdf Once again, AFTD will host a Caregiver Reception and will offer grants to caregivers needing financial assistance to attend.

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.

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

Caregiver Tip....Personal Health Records

Picture yourself in an emergency room, standing by the bed of a family member. He or she needs treatment now, but first the doctor requires some information: Any allergies? What medicines is the patient currently on? When was his last EKG or tetanus shot? What's the name and emergency number for his neurologist?

If you're like most of us, that information is in a number of different piles or file drawers—some at home, others in various doctors' offices and medical records rooms scattered across a region—and certainly not the first thing you think of in an emergency. But reality is that the information in that paperwork might one day be needed to save your loved one's life, and certainly it could help get speedier and more effective medical care during normal visits to the doctor.

The idea of a personal health record is just that: a single place where a patient's entire medical history is gathered and stored. Several new tools—ranging from free to moderate to pricey, and paper-based to high-tech—are available to help you take the lead in collecting and organizing the various

pieces of data that could prove critical in medical care situations. Below is an outline of the steps you can take to create a personal health record.

Gather the Information

Start by making a list of all current physicians. Contact each office, and discuss the best way to get a copy of the patient's full medical record, including diagnostic tests. The office will require a medical release form (signed by the patient or legal guardian), and may charge you for copying and postage.

Get Organized

For those people who do not want to use a computer, a plain file or binder works fine. Organize the papers (by specialist and/or by date—most recent first—are most common). Use tabs so you will be able to find specific information efficiently.

If you have access to a computer, a growing number of institutions and companies are producing health record software that can be downloaded

from the internet. Products from the Centers for Disease Control, national medical centers, insurance companies and community hospitals are available online for free. Go to www.myphr.com for links to software products.

A third option—the easiest, but most expensive—is to contract with a company to enter and maintain all of the information for you. Two of these options are LifeKey and MedsFile.com (see boxes). (Before going with this option, make sure you are comfortable with the level of privacy and security the company provides.)

Keep it Accessible

Regardless of whether you go high-tech or low-tech, you should have a single sheet of paper which lists the patient, main caregiver and primary physician with contact information, diagnoses, current medications, and any allergies. Keep this in a central place and make sure all caregivers know where it is. Most important, make sure to keep it up-to-date. Computerized files are certainly easier to keep with you, as they can be stored on a disc or portable USB device that fits in your pocket. If you



LifeKey is a portable keychain device that contains your full medical record. Carry it with you, and any medical caregiver with a computer can have access to your records in less than a minute. (Cost: about \$200 per year.) www.mylifekey.com



Medsfile maintains your personal health record online, where it is always current and accessible to any caregiver with internet access to whom you give your password. (Cost: \$3 to \$4 per month) www.medsfile.com

See Health Records, page 6

The Potamkin Prize for Research in Pick's, Alzheimer's and Related Diseases

was established in 1988 by the Potamkin family in honor of Luba Potamkin, who had Pick's disease. The \$100,000 award is given each year by the American Academy of Neurology to a researcher whose work has significantly advanced knowledge of these diseases.

Present at the FTD Workshop held in Miami in January were Luba's son and AFTD Board member Robert Potamkin, and these winners of the Potamkin Prize. Standing: Virginia Lee, PhD, University of Pennsylvania; John Hardy, PhD, National Institute on Aging; Karen Duff, PhD, Columbia University; Michael Hutton, PhD, Mayo Clinic, Jacksonville. Seated: John Q. Trojanowski, MD, PhD, University of Pennsylvania; Christine Van Broeckhoven, PhD, DSc, University of Antwerp; Bernardino Ghetti, MD, Indiana University



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Gifts received October 17, 2006 – February 28, 2007

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Children's Support Group Helps Those with Affected Parent

Illustrations for this article were provided by Schuyler Beauvais-Nikl

Terencia Beauvais-Nikl had 30 years experience as a nurse in neurology, psychiatry, and intensive care when her husband, Richard, was diagnosed with FTD. "It's like every piece of my nursing experience needed to be in place before I had to face this in my own family," she jokes. Marshalling her resources, Terencia started the first adult FTD caregiver support group, in Denver. She knew that making a connection with others who were dealing with FTD in a spouse would provide critical support that she was going to need to make it through the next several years.

But there was no place for Terencia and Richard's two children, Schuyler and Mackenzie, then ages 5 and 9 (now 12 and 16), to create a similar support network to help them face the myriad of emotions—grief, anger, sadness, fear, denial, guilt and embarrassment, to name a few—that confronted them. "I was isolated in far fewer areas than my children," Terencia recalls. "I have coping mechanisms; I have friends I can talk to. But children are not accustomed to creating those

kinds of networks for themselves." So this past summer, with financial support from AFTD and the Alzheimer's Association, Terencia organized the first support group for children who have a parent with FTD. For the past nine months six children, ages 8 to 16 (three boys and three girls) have met as



a group with two therapists—one male and one female—to try to make sense of their new and challenging family life.

"These children are in a very confusing, life-altering situation," says Tricia Mettler, MA, ADTR, LPC, one of the group's therapists. "They are forced to grieve for the loss of a parent who physically is still here. It's confusing for the adults in the family, and worse for the kids."

Ms. Mettler explains that children with an affected parent face a very difficult combination of factors. On the cusp of adolescence, they have not yet fully separated from their parents—so when one of their parents starts acting wacky, and the child is forced to learn that that parent can't be relied upon, it is threatening on the most personal level. (The fact that Dad got undressed in public or goes through the garbage every night is not just about Dad—it is about them, as well.)

The resulting fear and grief, combined with the fact that kids at this age are not yet good at verbalizing their feelings, can be truly immobilizing, and result in even further isolation.

In group, the therapists' first goal is to create a safe environment, where the children feel secure enough to open up to each other. They do movement and experiential exercises to promote trust and comfort, and then move on to drawing as one way they can express their feelings. Ms. Mettler says that the children were able to form a cohesive group quickly, recognizing that this is one room they can sit in and know that, without saying a word, other people understand what they are going through.

"I can tell *See Children, page 6*

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

	In Memory Of:			
Family & Friends of	Dano Agresta	David Freud	Ken Nolan	Popkin Shenian
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From Our Families.....

Lindsey Elkin

My grandmother, Barbara Weiss, has played an active role in a vast majority of my childhood memories. She used to take my sister, Eryn, and me to the mall, play games with us, and babysit us when my parents went away.

When I was around eleven, I noticed that my grandma began to act a little different. We particularly noticed these changes at my sister's Bat Mitzvah. My grandma had prepared a speech, but when she tried to read it she couldn't get her words out. At the time, we all laughed with her, and thought her nerves and excitement disabled her speech. It wasn't until several months later that we realized it wasn't a laughing matter, and there existed a real problem. At the young age of 65, my grandmother was diagnosed with FTD.

Shortly after her diagnosis, my grandfather became ill and passed away. Without his support, my grandmother's disease advanced quickly. Before we knew it, she was unable to perform everyday tasks that most people take for granted. She became unable to dress herself or go to the bathroom by herself, and pretty soon we had no choice but to move her into an assisted care facility.

Seeing the effect this disease has had on my grandma has been a very difficult experience for us, but it is important to look back and remember the Barbara Weiss that existed before her diagnosis.

Grandma had been a teacher and an excellent artist. She was always very organized, and precise with every detail. Shortly before my grandfather got sick, my grandparents took our entire family, nearly 30 of us, on a cruise through the Caribbean. My grandmother meticulously planned every detail of this amazing trip; she even coordinated matching tee shirts for us all to wear. Today, we have a different kind of fun. Time spent with her is filled with silly fun, like singing songs and nursery rhymes. Grandma still enjoys her art, even though she no longer is able to paint at the same level.

This past fall my younger brother Jake celebrated his Bar Mitzvah. We were all a bit nervous about how my grandma would handle this situation, and whether or not she would be able to enjoy herself. Little did we know she would be the life of the party. She laughed and cried during the candle lighting ceremony, and not once did she leave the dance floor.

I know that FTD is a progressive dis-



Lindsey (right) with her grandmother, sister Eryn and brother Jake at Jake's Bar Mitzvah

ease, and that eventually, my grandma could become mute. I also recognize that unlike Alzheimer's, where the person is unaware of what is happening to him, FTD is a disease where the person knows something is wrong, but is unable to do anything about it. It is as though grandma is trapped in her own body.

Observing the change that my grandmother has undergone over the past few years has motivated me to do all I can to find a cure for this disease that has robbed her of the life she once had. The few who still care to visit my grandmother see that she is still a wonderful person despite this disease. No matter how much worse my grandmother may get in the future, she will always be grandma to me.

Lindsey, 17, is a high-school junior who lives outside Philadelphia

Leaders Meet *from page 1*

and Genetics and Epidemiology. These workgroups met first, and a status report and list of recommendations from each then fueled a full-group discussion.

The findings from the Workshop are being compiled into a report that will summarize the current status of FTD research and treatment and present a prioritized list of recommendations and specific steps to implement these recommendations. Phil Lovett comments,



Creighton H. Phelps, PhD, National Institute on Aging; M-Marsel Mesulam, MD, Northwestern University

“Participants hope that this report will accelerate us along the path to new treatment strategies for FTD.”

“There was a real feeling of excitement and collegiality during the meetings,” says AFTD Chair, Helen-Ann Comstock. “Several participants remarked that the meeting will be considered ‘historic’, and a breakthrough in FTD research. AFTD expects the results of this workshop to give us a road map for future planning and action.”

Children *from page 4*

people what my father does, and they understand. It’s such a relief” says one of the teens, who admits that his mother had to persuade him to give the support group a try. “I went to the first meeting just expecting it to be a lecture about how we should appreciate our fathers, and how he is going to move out and die. But it was the exact opposite. In this last meeting I asked some of the other kids how their father left [home], and what happened after that. It was such a relief, because this disease is so unpredictable.”

As they have become more comfortable with each other, the children have moved beyond their common experiences and emotions, to sharing strategies for coping with them. Terencia has noticed that after a few months with the group Schuyler is no longer tense all of the time his father is around, no longer focused on worrying about

how his Dad is going to embarrass him next. And Mackenzie no longer screams when Richard pokes at her persistently, she just calmly tells him that he needs to stop. They can verbalize more of their feelings to their mother, and have learned to accept some aspects of their situation. Just as important, they now know that they have the right to walk away from others. They don’t have to deal with everything—they still get to be children sometimes.

Most important, says Mettler, the children can laugh together. “They need to be able to laugh at the craziness they experience and know that someone else understands what they mean,” she says.

In addition to meeting with the children once a month, the two therapists are available to the families by phone. AFTD hopes to support similar groups for children across the country.

Health Records

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stick with paper, make sure the full file is easy to grab in an emergency.

Keep it Current

The easiest way to do this is to take a self-addressed, stamped envelope with you to all clinical appointments, and ask to have a copy of all test results and physician notes sent to you.

Get it Done!

It takes work to establish a personal health record, but with a system in place it is not too hard to maintain, and the benefits will be myriad. Less risk of medical mistakes, more accurate and efficient communication among members of the clinical team and higher quality care are some of these. Best of all, this is one area of life where you can take control, and fulfill your role as the most important member of the care-giving team.

AFTD

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