

The Association for Frontotemporal Dementias

AFTD

Opening the gateway to help and a cure

Volume V Issue 1

March 2008

First Drug Development Grants Awarded

On January 15, 2008, four research grants totaling \$300,000 were awarded in the quest to develop the first drugs to treat FTD. The awards were made in partnership by AFTD and the Alzheimer's Drug Discovery Foundation. It was a proud and hopeful moment for the FTD community.

"Through our partnership, we are providing high risk, early stage funding for FTD drug discovery research that will ultimately improve the lives of people suffering this terrible disease, with implications for Alzheimer's disease therapeutics as well," said Howard M. Fillit, MD, ADDF Executive Director. "Today, we understand much more about the causes of neurodegeneration in FTD, so it is timely to begin testing novel approaches to discovering new compounds for drug development."

The awards were the first planned in a three-year collaboration between AFTD and ADDF, during which AFTD has pledged to raise \$100,000 per year for the project. "When we were first approached by ADDF, we recognized that we had to jump at this tremendous opportunity," says AFTD chair Helen-Ann Comstock. "But it was a big leap of faith: we had never raised this kind of money before." Spearheaded by board member Phil Lovett, family and friends in the AFTD community answered the call in a big way, and by the end of 2007 more than half of the three-year commitment was in hand. (See story, page 4)

In response to the grant announcement, twenty-one proposals were submitted from investigators in the USA, Hong Kong, Portugal and Israel. A

panel of 15 members from ADDF's Scientific Review Board and AFTD's Medical Advisory Council reviewed them, and identified the most promising four projects. "We are pleased that the ADDF/AFTD program attracted many quality applications," says Phil Lovett. "This is another indication that FTD drug discovery is receiving increasing attention from research laboratories all over the world."

The winner of this year's grant competition and a brief description of their research programs are:

**David Vocadlo, PhD, Assistant Professor of Chemistry
Simon Fraser University,
British Columbia, Canada**

One of the principal disease mechanisms at work *See Drug Awards, page 6*

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Join Us in Rotterdam!

The 6th International Conference on Frontotemporal Dementias will be held in Rotterdam, The Netherlands September 3-5, 2008. In addition to three days of scientific sessions, the conference will feature a full-day "Caregivers Track" of presentations, which will include sessions on: FTD News, Genetics and Caregivers Burden, and Patient Care. AFTD Chair Helen-Ann Comstock has been invited to give the welcoming remarks for this track, and AFTD is hosting a Caregivers Dinner at the Royal Maas Yacht Club on September 3 (pre-registration is required).

The International Conference is held every two years, and is the premier venue for clinicians and scientists working in the field of FTD to present their work and discuss current advances in clinical care as well as promising directions for research. Specific topics to be covered at this year's conference *See Rotterdam, page 6*





Spotlight On....Joanne Sackheim, AFTD Board member

Joanne and Bill Sackheim had a good life together. Bill was a successful Hollywood writer and producer; the couple had two sons, one who has followed in his father's footsteps, the other a professional photographer. Once the boys were in school, Joanne returned to university to earn a Master's degree in Social Work. In 1998 Joanne was running her own private practice from home when Bill began to act strangely.

"He turned into someone unfamiliar to me, right before my eyes," Joanne recalls. Previously a person who hated

to shop, Bill began making extravagant purchases. He would shower compulsively, up to five times a day. Joanne would awaken at 3 AM when Bill set off the house alarm going "to work". The worst was the night she woke up to the sound of the shower running and found Bill in the bathtub. A petite woman, Joanne had to call the paramedics to get Bill out of the tub and back into bed. When they checked his blood pressure, it was fine—but Joanne's was through the roof.

"I had tremendous anxiety," she recalls. "I couldn't care for him physically, so I had to hire a live-in caregiver. I had no idea what was going on at the studio, where he was still working." But the worst were the moments when Bill was aware that something was wrong. He bought books on health and the brain, and one night at dinner he remarked, "I don't understand it, but I feel like I'm losing a sense of myself."

"It still hurts my heart," says Joanne, "It is such a haunting disease, because it's so gradual. You don't know where the real person ends and where the disorder begins to take over."

Bill died two years ago, and one month later Joanne was diagnosed with breast cancer. She is in remission now, though, serving on the boards of both the AFTD and the School of Social Work at USC. She also is once again seeing some private patients.

Most exciting for her, is that Joanne has worked with AFTD to start an FTD caregiver support group in Los Angeles. It's a project that calls upon both her clinical expertise and her experience as a caregiver. "I have great empathy for anybody who is going through this," she says. "For many the financial situation is desperate. I just feel so lucky; I'm left comfortably but what about all the other people? We need advocacy for government relief and services for these people."

AFTD

The AFTD Annual Meeting will be held on June 20 in Baltimore, MD, and is open to the public. Please RSVP to the AFTD office if you plan to attend.

AFTD is initiating an advocacy campaign, led by Board member Louise O'Connor, to raise awareness for FTD at a national level. If you have an interest in participating please contact info@ftd-picks.org

On February 4-5, experts from around the world met in Washington D.C. to discuss recent advances in knowledge of progranulin, TDP-43 and the implications these molecules have for FTD research. The workshop was funded by National Institute for Neurological Diseases and Stroke. More details about this exciting workshop will be posted soon on the AFTD website.

Northwestern University (Chicago) will host an FTD Caregiver Conference in August. For more details visit www.brain.northwestern.edu

Camp Building Bridges is a respite camp for teens with a parent who has been diagnosed with FTD or a related



disorder. This special camp will be held July 6-12 in Davis, Oklahoma. Full scholarships are available.

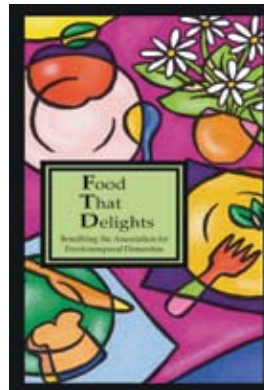
For more details visit <http://www.freewebs.com/young-hope2007/>

New FTD caregiver support groups have started in Grand Rapids, MI and Charlotte, NC. For more information on the Grand Rapids group contact Karen Bugg, R.N. at (616) 913-1044. For the group in Charlotte contact Shauna Daly at shauna4@aol.com.

Order a copy of the **Dallas Support Group cookbook** today! Contact Bill Brown at William24B@yahoo.com or the AFTD office at (267) 514-7221. Books cost \$15 and proceeds go to fund FTD Drug Discovery.

A new edition of What If It's Not Alzheimer's will be available in April, 2008. Contact the AFTD office to order advance copies or visit the publisher's website at www.prometheusbooks.com.

A new patient support group for individuals diagnosed with an early onset dementia has started in Ottawa, Canada. For more information call (613) 523-4004.



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

News

AFTD is Growing!



Catherine Pace-Savitsky and
Susan Dickinson

We are pleased to announce that on February 1, 2008, Susan L-J Dickinson, MS, CGC, joined AFTD as our new Executive Director. Susan brings several years' experience working as a consultant to patient advocacy organizations, as well as training and clinical experience as a genetic counselor. She will be working with the Board, Medical Advisory Council, and key volunteers to set a comprehensive strategic course for AFTD to address its goals in the areas of Advocacy, Support, Education, Research and Fundraising

Catherine Pace-Savitsky, MA has moved into a new position as Program Director, and will be responsible for AFTD's work in the areas of caregiver and patient support and development of education programs. This

new role will fill the ever-increasing demand for programs and services needed in the FTD community by both families and medical professionals.

"The Board is thrilled to have both Susan and Catherine in leadership roles," says Board Chair Helen-Ann Comstock. "Together they make a knowledgeable and dynamic team to work with the board and help guide our growing organization."

...And we've got a new address:

AFTD

**1616 Walnut St. Suite 1100
Philadelphia, PA 19103
(267) 514-7221**

Resources on the Web...www.Nationalcaregiverslibrary.org



The National Caregivers Library is an extensive online library for caregivers that consists of hundreds of useful articles, forms, checklists and links to topic-specific resources. Free checklists that can be downloaded from the site include lists designed to assess: a patient's driving abilities, comprehensive care needs,

home safety, net worth calculation and valuable records inventory.

The library is user-friendly, and is organized into eighteen Caregivers Resources categories, which appear in a list down the left side of the web page. These cover a wide range of topics, including: legal, financial, housing, emotional and end-of-life issues. Home care,

long-distance care and transportation are all addressed, as well.



The site is sponsored by two corporations: Fidía Advisors is a business development firm in Richmond VA, and Home Care Delivered, a home-delivery, medical supply company located in Glen Allen, VA.

AFTD Awards Second Research Grant in 2007

In December, 2007, AFTD was pleased to award a \$60,000 research grant to Professor Marc Cruts, Ph.D. from the University of Antwerp in Belgium. Dr. Cruts, whose work was selected by the AFTD Medical Advisory Council through a competitive review process, will use these funds to identify new genes in families where a genetic cause for FTD is suspected, but no mutations in the known genes (*PGRN* and *MAPT*) have been found.

Dr. Cruts's past research has identified a family in which multiple individuals suffer from FTD-ALS. Using molecular genetic mapping techniques, Dr. Cruts has

found that in this family a defective gene is located in a chromosomal region not currently recognized as the location of an "FTD gene". Research now will focus on sequencing this family's DNA to identify this specific gene defect and then test this gene in a wider sample of FTD patients to determine if mutations in this gene result in the development of FTD across a broader population of families.

This award was the second \$60,000 research grant given by AFTD in 2007 and was made possible through the generous contribution of a private donor.



Marc Cruts, PhD

Donations Honor Loved Ones *Gifts received October 16, 2007 - January 31, 2008*

In Memory Of

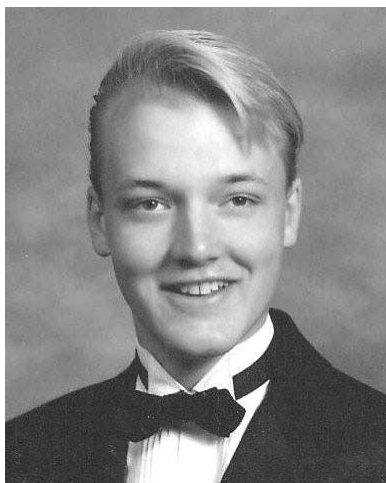
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***From Our Families.....* Jeanine Gierke**

Jeanine's son Bryan was just 31, with a young wife and infant daughter, when he was diagnosed with FTD in 2005. He died June 12, 2007. Here, Jeanine writes of the unique heartache a mother feels watching her child succumb to this disorder, and of her search to find some meaning and a way to cope.

When my son was diagnosed with Pick's Disease at thirty-one years old, it was without a doubt the worst day of my life. First came disbelief, then anger and confusion. I was devastated.

Bryan was also my friend. He was a man of character and strength. He was mature and made good decisions; he could make me laugh hysterically and he was the person I called when I needed a lift. We had an easy relationship that required little, but brought me so much happiness. When I looked at my son, I felt that I had done something right.

I watched helplessly as Bryan changed. He became emotionally flat and his personality altered so much it was hard to remember the person he once was. My sadness and frustration were overpowering as I watched him slip away an inch at a time.

For almost three years I traveled back and forth from Orlando to Salt Lake City to help with his care. My visits consisted of running errands, doing household chores, spending time with my granddaughter and giving my daughter-in-

law a much-needed break. My entire focus was on my son, his family, and how I could help. The trips were emotionally and physically exhausting.

Before long, this disease began to take a toll on me, too. I was so exhausted there was nothing left in me, for me. I no longer exercised or cared what I ate. How I looked didn't matter. Sometimes I left the house in my pajamas and slippers to take Bryan for a Slurpee at 7-11; something I never would have dreamed I would do, but at the time it seemed "normal." There were nights I would drop into bed without ever taking a shower or combing my hair for the entire day.

My extended family and employer were all very supportive. But it was difficult for me to admit that, for the first time in my life, I couldn't do it all. I was thankful for their help and at the same time felt uncomfortable accepting such generosity. My life was becoming an open book, and I felt completely exposed. This was especially difficult because I have always been an extremely private person.

When I was in Salt Lake with my son and his family I found the strength that I needed. But when I left, I would cry the entire way home to Orlando. At night I couldn't sleep, so I began to write a

journal about everything that was happening. It gave me the release I needed. I wrote and I cried, and I wrote some more and then I cried. Writing is a good outlet for people like me who want to keep things private. Seeing my sorrow on paper somehow gave me comfort, so I continued to write: more than 300 pages describing my son's life, his behaviors and the progression of the disease.

Bryan is gone now, and I am relieved that he is no longer suffering; seeing his frustration and deterioration gave me the courage to let him go.

I know my son would want me to go on living, and I really am trying. I want his life and what he went through to mean something; so I search for a purpose. Getting up each morning is still a chore, but I'm getting up. Long term I don't have a clue what to do. My immediate goal is to write a book of happy memories about Bryan. I want to give this gift to my granddaughter who is only four years old. I want her to share the happy stories about her daddy. I want her to know he was something special, that her parents loved her and each other so much. I want her to know about the daddy she may never remember. Maybe I do have a purpose; to keep his memory alive.

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

In Honor Of

Frances Angelino	Janice Ehrmann	F. Trent Hill	Edward Mann	Marian & Cam
Robert E. Barr	Anne R. Everard	Christy Hinsman	Beverly Martling	Pitkethly
Barbara Basla	John Ferris	Jim Hipp	Ron Martling	Louis T. Romeo
Dr. David Berkowitz	Tracy Forte	Roger T. James	Bucky McAfee	Joanne Sackheim
Sandra Birnbaum	John J. Gibbs - 70th Birthday	James Kearney	Jennifer McConathy	The Sandifer Family
Randy Brauer	Grover Grimm	Ann Kennedy	Debbie McLeod	Paula Scott
Michelle Brown	Alice Guiney	Karen Kohn	Ray Miller	Chris Smith
David P. Dalton	Dub Ham	Carl LaGrassa	Janet Mills	Frank Thomasson
Nancy Duncan	Harold Hedaya	Arnette Lester	Max Newton	Robert Travis
Ronald Duncan	Anna Hill	Paul Lester	Joe O'Brien	Jane V. Ward
		John Mackey	Patty Palmer	Annette Westerman

AFTD Families Raise Hope

Grassroots fundraisers help AFTD exceed its goal to fund Year One of FTD Drug Discovery

Key fundraising efforts throughout the FTD community helped make 2007 a banner year for AFTD. By year's end, nearly 400 donations toward our new Drug Discovery campaign had produced more than \$170,000. These funds bring AFTD more than halfway to our three-year pledge of \$300,000 to develop the first therapeutics for FTD.

"Drug discovery is clearly a cause our community can rally around," says AFTD Executive Director Susan Dickinson. "This year we hope to get even more of our families involved; it is always amazing to see the variety of fun and creative events people come up with."

In **Texas**, Bill Brown and his support group decided to compile a cookbook, and solicited recipes from FTD families across the country. The result: they are currently into the second printing of "Food That Delights" (note the initials!), a compilation of more than 250 user-



Christina H. asked for donations in lieu of birthday gifts

friendly recipes, many of which are dedicated to family members suffering from FTD. "At one time, most families cooked together when they gathered

for celebrations," says Brown, whose wife suffers from FTD and is now in a full-time care facility. "So this seemed like an appropriate way to honor our loved ones and the family times we all used to share."

Like many caregivers, when he announced the project Brown was overwhelmed by the support that poured in from the community. In addition to the FTD support group, the middle school honor society, youth hockey team, and the elementary school PTO all helped to make the cookbook a reality. Even the family dentist has pitched in—and has sold more than 125 copies of the book to patients who come into the office.

In **Maryland**, Christina H. told friends invited to her 7th birthday party to skip the gifts—and instead make a donation to AFTD in honor of her grandfather. And across the country many families conducted letter-writing campaigns: a low-cost and relatively low-effort activity that has produced a huge outpouring of support for the Drug Discovery program.

Events continue this year: In **Sacramento**, Beth Walter is organizing a Quest for the Cure golf tournament, which she anticipates will net more than \$15,000 for Drug Discovery (www.AFTDgolf.com) In Philadelphia Michelle Stafford is organizing an "AFTD Night" at the Philadelphia Soul's Arena Football venue. In addi-



The Brown Family

tion to a portion of the ticket price going to AFTD, the team has donated a number of signed items (including a guitar signed by Jon Bon Jovi!) which Michelle plans to auction off on ebay—again, for the benefit of AFTD.

AFTD still has more than \$100,000 to raise for the program, so we are hopeful that even more families will choose to get involved in 2008. "The more money we raise, the more drug discovery research we can support," says AFTD Board member Colleen Quinn. "We invite families in every state to consider holding some kind of event. **We're not just raising money, we are raising hope.**"

Please visit the AFTD website and click on the "Tell 10 People" icon at the top. We have ample resources to help you design an effort that is right for you, including: a list of event ideas, sample letters and invitations, and brief, clearly written explanations of FTD. Call the AFTD office, to talk through your idea and order copies of AFTD materials free of charge.

Drug Awards *from page 1*

in FTD involves the molecule tau, which plays an important role in normal brain cells by stabilizing microtubules in the neurons so they can get nutrients and function normally. In tau-related FTD, tau molecules have phosphate attached to them, which causes tau to fall off microtubules and prevents them from playing this key role. The result is the development of neurofibrillary tangles, hallmarks of FTD, and the death of brain cells.

Dr. Vocadlo's lab has developed compounds that inhibit the excess phosphorylation of tau, and thus enable this molecule to retain its important role in brain function. Dr. Vocadlo has tested these compounds in rats that have tau-related FTD, and has documented a marked decrease in the formation of neurofibrillary tangles.

This grant will enable Dr. Vocadlo to further test these compounds, and determine their mechanism of action. The goal is to identify an optimal form of these compounds that will be suitable for clinical testing as an FTD therapeutic.

Ben Bahr, PhD, Associate Professor of Pharmaceutical Sciences University of Connecticut

Dr. Bahr's approach to FTD therapy also targets the tau disease mechanism. Scientists know that our brain cells are equipped with a system to remove al-

tered or misfolded tau so the cells can continue to serve their normal function. The problem in FTD and other dementias is that these altered tau molecules build up quickly, and to such an extent that the system can't keep up, and the brain cell eventually dies because it is literally filled up with these non-functional proteins.

Dr. Bahr plans to test a number of compounds that have already been proven to enhance the function of the normal garbage "disposal" system in brain cells. His hypothesis is that if he can find a compound that works within the brain to speed removal of this altered tau, the brain cell will be able to continue functioning and the FTD-related damage will not occur.

Larry Baum, PhD, Assistant Professor of Medicine and Therapeutics

Chinese University, Hong Kong

Dr. Baum's project also involves enhancement of a protective process that occurs naturally in brain cells. When a cell undergoes stress (trauma, lack of nourishment or oxygen, for example) the proteins that perform the work of the cell begin to degrade and fold abnormally, which renders them non-functional. The cell has developed a natural response system which enables it, in times of such stress, to produce chaperone molecules which bind with the altered proteins to either re-fold them into their functional shape or re-

move them from the cell. Dr. Baum proposes to use these naturally-occurring chaperones to re-fold, or "fix" the nonfunctional tau in FTD brain cells.

Tara Spires-Jones, PhD, Instructor of Neuroscience Harvard Medical School

Dr. Spires-Jones is working with a family of proteins called sirtuins that are known to be involved in cell survival. Previously, researchers have shown that they can minimize brain cell death from Alzheimer and Parkinson disease processes by changing the activity of sirtuins in the cell. Dr. Spires-Jones will be testing a compound that affects the level of activity of sirtuins in a mouse model of FTD, to see if she can replicate this effect in FTD.

Rotterdam *from page 1*

include: breaking news; genetics, clinical presentation, biomarkers and future pharmaceutical interventions. An afternoon of smaller group sessions will focus on medication options, legal aspects of FTD, studies in the asymptomatic stage and FTD in the Netherlands.

Rotterdam is the second largest city of the Netherlands. Traditionally considered "the working city of the Netherlands" it has developed into a city of avant-garde architecture and many museums. For more information or to register for the conference, go to www.FTD2008.org.

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