AFTD

The Association for
Frontotemporal Dementias

Opening the gateway to help and a cure

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7th International Conference Convenes Leaders in FTD

The 7th International Conference on Frontotemporal Dementias attracted nearly 600 representatives of the FTD community – among them caregivers, researchers, physicians and other health care professionals - from countries all over the world and as far away as Japan, Australia, Sweden and The Netherlands. The conference, which was held Oct. 6-8 in Indianapolis, included in-depth presentations and discussions on emerging discoveries in the science and medicine of FTD, as well as a full-day of programming for family caregivers on FTD diagnosis, medical management, legal and financial issues, and support services.

Each of the 76 scientists engaged as speakers in the scientific program gave accounts of their latest discoveries, while an additional 166 scientists displayed their data in posters that were available for viewing for the duration of the conference. A handful of presentations reported on work funded by grants from AFTD, including Adam Boxer, M.D., Ph.D., reporting on the phase 2 trial of davunetide (see story on page 3); Einar Sigurdsson, Ph.D., describing his work to develop the concept of a tau vaccine; and John van Swieten, Ph.D., who is following pre-symptomatic tau- and progranulin-mutation carriers via functional MRI, to document the first signs of disease in the brain.

(See 7th International Conference, page 4)

Guests at the conference include Colleen Quinn, AFTD Board member; Jill Goldman, M.S., AFTD Medical Advisory Council member; and Edward Huey, M.D.

Inside This Issue

Task Force Identifies Needs of Families with Children

Since February, the Association for Frontotemporal Dementias' Task Force on Families with Children has been researching the needs of people caring for spouses with FTD while also caring for children and teens at home. The group will report its findings and recommendations by year's end and has begun identifying priority projects for development in 2011.

During the research phase of work, the task force:

- compiled anecdotal data on needs of parents and children from people in AFTD's telephone support group, caregiver support groups, or who contacted AFTD's HelpLine.
- reviewed literature on grief, anticipatory grief, burden of care in young-onset dementia, and children as caregivers.
- searched for existing models of support for children in areas of FTD, dementia, bereavement, and disability.
- conducted a survey of 24 young adults who were living at home when a parent was diagnosed with FTD.

(See Task Force, page 5)

Spotlight On...Sylvia Mackey, Member, AFTD Board of Directors

If you have not met her, you might think Sylvia Mackey has spent her life on the sidelines living in someone else's shadow – a rather large shadow cast by a famous six-foot, two-inch, 220-pound football star. You see, Sylvia Mackey has been married since 1963 to her college sweetheart, pro football Hall of Famer John Mackey.

But Sylvia Mackey has never lived life on the sidelines. The former print and runway model, who hosted Baltimore's "Showcase 13" television show, is an outspoken woman who has shown remarkable strength, especially after her husband was diagnosed with frontotemporal dementia in 2006. Soon after that, Sylvia Mackey took to the field, so to speak, to become an advocate for her husband and people like him living with FTD. She's been scoring touchdowns ever since.

After Sylvia Mackey advocated for her husband and other players, the NFL created the "88 Plan" – named for the number John Mackey wore on his jersey throughout his career. The plan, she says, is for "players who have devastating neurological diseases that can wipe a family out financially." It provides $88,000 annually for health care at a continuing care facility and $50,000 per year for adult day care – money well spent on players who took to the field long before multi-million dollar contracts were the norm.

In 2009, Sylvia Mackey was elected to the AFTD Board of Directors, where she has continued her work as a public speaker and key member of the Awareness Committee.

"It's important for us to get the word out about FTD because so many people still don't know about this disease," she says. "Its impact is devastating and there's so much more that needs to be done in terms of advocacy and research."

In 1971, during Super Bowl V, John Mackey was part of one of the most famous plays in NFL championship history, catching a pass from quarterback Johnny Unitas and running a then Super Bowl-record 75-yard touchdown reception. (Baltimore won the game, 16-13). Thirty-nine years later, John Mackey, age 69, is back in Baltimore but now lives at a memory care facility, where Sylvia Mackey visits him nearly every day.

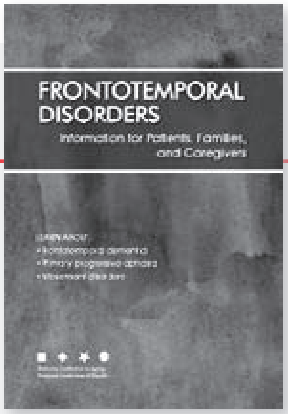
AFTD News Briefs

Northwestern University's FTD and PPA Caregiver Education and Support Conference is scheduled for Monday, March 21, at the Robert H. Lurie Medical Research Center in Chicago. The conference, sponsored in part by AFTD, is presented by the Cognitive Neurology and Alzheimer's Disease Center (CNADC) of Northwestern's Feinberg School of Medicine. For more information, call 312-908-9023 or email CNADC-Admin@northwestern.edu.

People diagnosed with FTD are invited to take a short online survey so that AFTD is better able to develop programs and services that meet patients' needs. To participate, go to http://www.surveymonkey.com/s/AFTDfirstperson.

The National Institute on Aging has a new consumer-friendly booklet, *Frontotemporal Disorders: Information for Patients, Families, and Caregivers.* The free, 30-page booklet explains the disorders, symptoms, and management in layman's terms. To read the booklet or order copies, visit www.nia.nih.gov/Frontotemporal or call 1-800-438-4380.

The first caregiver support group in the Pacific northwest began meeting in August in Washington. The group meets on the first Monday of each month in Longview, about 45 miles north of Portland, Ore. For information, call 360-430-4549. Another monthly support group in that region is available to caregivers of people with FTD who are seen at the Oregon Health and Science University clinic in Portland. For details, contact Katherine Wild, Ph.D. at wildk@ohsu.edu.



FRONTOTEMPORAL DISORDERS

Information for Patients, Families, and Caregivers

AFTD is considering offering a telephone support group for caregivers of people in the late stages of FTD, as well as for caregivers grieving the death of loved ones. For information, call 866-507-7222 or email info@ftd-picks.org.

New information on finding physicians and other health care professionals with expertise in FTD and related disorders is available on the AFTD website. Go to *Support & Resources,* click on *Managing Health Care* and go to *Finding a Doctor or Other Health Professionals.*

AFTD Pilot Grant Awarded to Yale

The 2010 FTD Pilot Grant has been awarded to Stephen Strittmatter, M.D., Ph.D., at the Yale School of Medicine. The award will enable Dr. Strittmatter to pursue his current work in identifying a key molecule in the development of a specific subset of frontotemporal dementias, those linked to an insufficient amount of the protein progranulin (PGRN).

Scientists know that PGRN deficiency causes dementia with a specific pathological change in brain cells: namely, the buildup of a second protein called TDP-43. But PGRN operates in the fluid space outside of the brain cells, while TDP-43 exists inside of the cell. To date, scientists have not known how PGRN communicates its message across the cell membrane. Dr. Strittmatter believes he has discovered the intermediary protein that sits on the cell membrane and serves as a "receptor" for PGRN, translating its message to the inside of the brain cell and affecting TDP-43. If this is indeed the case, it represents a significant step forward in both understanding the disease pathway and in pointing the way toward potential treatment.

"If we want to intervene in this disease process, we need to understand the molecular pathway at work," Dr. Strittmatter says. "As a general rule, the cell surface receptor makes a good target for design of a therapeutic."

Stephen Strittmatter, M.D., Ph.D.

Dr. Strittmatter plans to use this award to further characterize this cell receptor protein and better understand how it binds with PGRN as well as how it then translates a chemical message to the inside of the cell, disrupting the normal biology of TDP-43.

"This is extremely exciting work, which we are proud to support," says Virginia Lee, Ph.D., chair of AFTD's Grant Review Committee. Lee adds that the committee received 34 applications this year, signaling continued growth in interest in FTD from researchers across a variety of disciplines.

Phase 2 Clinical Trial Completed at UCSF

A 12-week study enrolling patients with three subtypes of FTD has shown that the compound davunetide is safe and well-tolerated by patients with progressive supranuclear palsy, progressive non-fluent aphasia and corticobasal degeneration. Although the short study did not reveal a therapeutic effect, it did demonstrate that the study design used was effective in these patients, says Adam Boxer, M.D., Ph.D., who presented the results in October at the 7th International Conference on FTD in Indianapolis.

The study enrolled 12 patients, eight of whom received the drug while four received placebo. The patients used the nasal spray twice daily, and visited the clinic three times over the 12 weeks. They were followed by clinical exam, MRI scans, and a lumbar puncture at the beginning and end of the study. Dr. Boxer reported that demand was high among families to be included in the study, that the clinical measures used to track the patients through the study were well-tolerated, and that the method of drug delivery, via intranasal spray, worked well. "We did not obtain evidence that davunetide was effective in improving patients' clinical status…. Nonetheless, we are hopeful that some of the biomarker measurements that we collected, including cerebrospinal fluid levels of tau protein and functional MRI scans, may be useful in detecting davunetide effects in this group," Dr. Boxer says. "Overall, the data obtained from this study have been extremely helpful in the design and planning of our larger, pivotal davunetide study for PSP."

Adam Boxer, M.D., Ph.D.

The trial, completed at the University of California, San Francisco, was funded jointly by AFTD, the Alzheimer's Drug Discovery Foundation, CurePSP, and an unrestricted grant from Allon Therapeutics, Inc.

Allon, which owns davunetide, next plans a larger study to measure efficacy of the drug in 300 PSP patients over one year; recruitment for these patients is underway in North America and Australia and will soon begin in Europe. For more information, see www.clinicaltrials.gov: NCT01110720.

International Conference

(Continued from page 1)

Louise O'Conner, a former AFTD Board member, speaks with volunteers about advocacy.

AFTD Medical Advisory Council Members (from left) Rosa Rademakers, Ph.D. , Ian R.A. Mackenzie, M.D., and Karen Duff, Ph.D. , enjoy the company of friends and associates during the caregivers' dinner.

For the caregiver program, 16 leaders in their fields provided perspectives on the biology of the frontotemporal dementias, insights on the presentation of various clinical syndromes, potential therapeutic directions, as well as challenges and available supports in caring for people with FTD. Among these caregivers were AFTD's new volunteer regional network coordinators, who engaged in a day of formal training (see story on page 7).

"The conference provided a wonderful opportunity for family caregivers to meet and talk with FTD leaders from all over the world," says AFTD Executive Director Susan Dickinson, M.S.

Dickinson, along with AFTD Program Director Sharon Denny, M.A., served as a presenter in the caregiver program and provided an overview of AFTD's mission, resources, programs and services. Several members of AFTD's Medical Advisory Council also served as speakers in the caregiver program and include Marsel Mesulam, M.D., of Northwestern University, Chicago, who provided an introduction to the frontal and temporal lobes, Tiffany Chow, M.D., of the University of Toronto, who discussed the different initial presentations of FTD; Council Chair Bradley F. Boeve, M.D., of Mayo Clinic, Rochester, Minn., who presented "FTLD: The Journey to Diagnosis"; and Michael Hutton, Ph.D. of Eli Lilly & Co., U.K., who presented "FTD Research – Present and Future." A special treat for attendees was a presentation by Arne Brun, M.D., Ph.D., of Lund University, Lund, Sweden. Dr. Brun, who was an early leader in the field of FTD research and hosted several of the early international conferences spoke on the history of FTD research.

Many of the presenters in the caregiver program provided slides from their talks for the AFTD website. (To access those, go to *Support and Resources* and click *Past Caregiver Conferences.*)

While in Indianapolis, AFTD hosted a meeting of fledging nonprofit groups from other countries. Patient advocates from Argentina, Australia, England, France, Germany and The Netherlands joined AFTD to discuss ways to best work together to share resources and spread awareness of FTD. During a town hall meeting, the professional researchers discussed the benefits of formalizing their international collaborations, as well. A committee was formed to explore the establishment of an international society of FTD researchers.

The 7th International Conference on Frontotemporal Dementias was led by Bernardino Ghetti, M.D., of Indiana University. Dr. Ghetti, who served as Conference president, is vice chair of the AFTD Medical Advisory Council.

Abstracts from the conference were published in a special supplement of the journal *Dementia and Geriatric Cognitive Disorders.* A four-part series on the science that was presented at the conference can be found at www.alzforum.org.

The International Conference on Frontotemporal Dementias 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. Plans are already underway for the 8th International Conference on Frontotemporal Dementias, which will be held September 5-7, 2012 in Manchester, England.

Conference presenter Greg Jicha, M.D. (left), Thona Pappas, M.S.W., and Founding Board Member Kent Jamison, Ph.D., attend a reception at the Eiteljorg Museum.

Task Force Identifies Needs

(Continued from page 1)

The burden of care is higher with virtually no supports available

Studies show that family caregivers of people with FTD experience more burdens of care compared with caregivers of Alzheimer’s disease patients. (Riedijk et al., 2006, Freyne et al, 1999, De Vugt et al., 2006). One recent study (Svanberg, 2010), is the first to directly examine the needs of children in families affected by FTD.

The task force found that the principal concerns of the well parent and children include: dealing with the changing family relationships and structure, addressing genetics, helping children find their own ways to communicate and cope with the situation, and addressing grief and loss.

Anger, sadness, fear and confusion were the most common emotions expressed by the 24 young adults who responded to the AFTD survey, “Reflecting Back: Experiences of Children and Teens.” Of the respondents, 58 percent provided regular care for their affected parent, while 74 percent provided regular assistance with household tasks or care of siblings. The survey invited respondents’ comments on their understanding of the diagnosis, emotional support, coping and suggestions for others. One comment epitomized the experience of many: “I was too young to feel that old.”

> *“I was too young to feel that old.”*

An emerging framework for services and supports

“It is vitally important to recognize and understand (children’s) unique experiences,” says Elise Gaul, M.S., a bereavement specialist and task force member, “and to remember that caring adults can help children find ways to express themselves, build coping skills, and move forward with a sense of balance and wholeness in their lives.”

Members of the Task Force on Families with Children (from left) AFTD Program Director Sharon Denny, M.A., and caregivers Gail Andersen and Paul Lester, attend a caregivers’ dinner at the 7th International Conference on FTD.

With effective supports, the increased burden of having a parent with FTD can coincide with increased resilience, coping and maturity on the part of children, says AFTD Program Director Sharon Denny, M.A., a task force member. “Supports for children and teens must be integrated into a holistic approach that also assists parents and extended families who care for someone with FTD. The goal must be to foster resilience in children and teens over time given the ambiguous nature of disease progression and the gradual losses of FTD,” Denny says.

A study in children’s bereavement by Sandler and Wolchik (2008) complements Svanberg’s initial conclusions and recommendations, and offers a framework for services and supports that help children build resilience within the context of their individual lives. Adaptation occurs over time and is shaped by the child’s particular environment, individual risk and protective factors.

Elise Gaul, M.S.

The lack of resources and services for families with children is undeniable. The United Kingdom is at the forefront in addressing the needs of young caregivers and offers several models for programs that could be adapted for families affected by FTD. The task force identified only one program model in the U.S.

Members of the AFTD Task Force on Families with Children include Gail Andersen, caregiver; AFTD Program Director Sharon Denny, M.A.; Elise Gaul, M.S., L.P.C., C.T., bereavement coordinator, David Bradley Children’s Bereavement Program and director, Camp Erin-Philadelphia at Penn Wissahickon Hospice; Paul Higgins, M.Ed.., middle school counselor; Paul Lester, caregiver; Darby Morhardt, M.S.W., L.C.S.W., research associate professor and director of education, Cognitive Neurology and Alzheimer’s Disease Center at Northwestern University; Linda Nee, L.C.S.W., clinical research social worker, National Institutes of Health.

Donations Honor Loved Ones *Gifts received July 1, 2010 – October 15, 2010*

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2010 Survey of Medical Centers Underway

Sharon Denny, M.A., AFTD program director, responds to a HelpLine question.

One of the questions most often asked of staff members responding to the Association for Frontotemporal Dementias' HelpLine is "where can I find a doctor who understands this disease?" To ensure that AFTD has the most current and complete information, our staff is once again surveying U.S. and Canadian medical centers that provide diagnostic or clinical services, or conduct research in the frontotemporal dementias. Responses to the survey will improve AFTD's ability to respond to inquiries and direct patients and families to appropriate resources.

In 2006, the survey was sent to 32 centers, all part of the federally funded Alzheimer's Disease Research Center network. In 2009, that number increased to 45 as AFTD became aware of more medical centers addressing FTD. This fall, the Association sent out a revised survey to 80 medical centers.

The survey asks the medical centers to identify services they provide including diagnostic evaluation, clinical care, and specific FTD research. Other questions were added this year on the availability of genetic counseling, brain autopsy, and patient and family support services. The survey is designed so that AFTD has the most current information to share with constituents, including contact information for staff members at the various medical centers.

"AFTD does not recommend any specific center or physician when people contact the HelpLine," says Program Director Sharon Denny. "We do, however, provide the most direct contact information and web links so that people are able to assess several possible resources based on the situation, geographic criteria and other parameters provided. The increase in possible resources means patients and families can explore and compare several options to determine what best fits their needs."

> *Responses to the survey will improve AFTD's ability to respond to inquiries and direct patients and families to appropriate resources.*

Responses to the survey are due December 1 and will be incorporated in the first quarter of 2011 into AFTD's data system. Simultaneously, AFTD is improving the technology used so that staff members are able to track, search and share appropriate information more efficiently.

For more information or to be included in the survey of medical centers, call AFTD or email info@ftd-picks.org.

Patient Survey Now Online

The Association for Frontotemporal Dementias would like to hear from people with FTD about important issues affecting them. To help facilitate that, a short online survey, titled "First Person Informal - A Survey of People Diagnosed with FTLD," was launched in late September and will be available into the start of 2011. AFTD will review responses regularly; a summary of survey responses will be compiled next spring. All responses to the survey are anonymous; providing contact information is voluntary. To access the survey, go to http://www.surveymonkey.com/s/AFTDfirstperson.

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

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In lieu of flowers…

Families who wish to direct memorial donations to AFTD are encouraged to call our office. AFTD can mail you donation materials or you can download them from the AFTD website. All donors will receive letters of acknowledgement and families will receive a list of donors.

To download materials from our website, go to *About AFTD* and *Get Involved*, and click on *Donate* and *Contribute Electronically*.

Regional Coordinators Gather in Indiana

The Association for Frontotemporal Dementias' seven regional network coordinators gathered together for the first time at the 7th International Conference on FTD, held in October in Indianapolis. By attending the conference, these volunteers, who are all current or former FTD caregivers, were able to meet face to face to further develop their roles as AFTD volunteer leaders. While there, they attended a full day of educational sessions geared toward caregivers, gaining valuable information on the most up-to-date information on FTD treatments, resources, and research. They also helped AFTD connect with caregivers, medical professionals, and other conference attendees from around the world.

The regional coordinators volunteer as ambassadors for AFTD in assigned regions of the U.S. and Canada. They help raise public and professional awareness of FTD, provide critical communications links, and serve as points-of-contact for AFTD at the local and regional levels.

"This was a wonderful opportunity," says Herb van Roekel, coordinator for AFTD's south Atlantic region. "I was able to meet each of the regional coordinators, AFTD Board members and staff, as well as leading researchers and clinicians specializing in FTD. I am excited and proud to be representing AFTD."

On hand for the planning and strategy meeting are (from left) AFTD Program Coordinator Matt Sharp, M.S.W., and Regional Coordinators Susan Gustafson, Dave Dillon, Kathy Ullrich, Carol Maglich, Susan Eissler, Herb van Roekel, and Jenny Hinsman.

In addition to attending the caregiver program, the coordinators participated in a planning and strategy meeting, where they met with Beth Walter, chair of the AFTD Board of Directors. AFTD founder Helen-Ann Comstock and Medical Advisory Council Member John Trojanowski, M.D., Ph.D., joined the group to provide their unique perspectives on the regional coordinator position and the importance of this role to the continued growth and success of AFTD.

AFTD's new film, "It Is What It Is" (see story on page 8), was shown as a segue into a discussion on how to most effectively use the film for outreach and awareness. The meeting concluded with each coordinator defining an individual project based on their particular interests and the priority needs in their geographical regions. Those projects will be planned in collaboration with AFTD staff and implemented over the next 12 months.

"These regional coordinators have been tremendously generous with their time and talents over the past year, as we have worked to establish the network," says AFTD Program Coordinator Matt Sharp, M.S.W. "I am excited about what we can accomplish together, and have no doubt that they will play a critical role in AFTD's expanding role in awareness and advocacy."

To contact the AFTD coordinator for your region, go to *Support and Resources* on AFTD's website, select *U.S.* or *Canadian Regions*, then click on the region of interest.

'It Is What It Is'

Filmmaker on Documenting FTD

During filming at her Illinois home, caregiver Mary Ann Coon talks about FTD and its impact on her family and husband Bruce, who has the disease.

Joseph Becker, founder and CEO of ThinkFilm, is an award-winning writer, director and producer with hundreds of film and television projects and six feature film screenplays to his credit. Becker is perhaps best known for his production work during seven seasons of the Golden Globe and Emmy Award-winning series "The West Wing" on NBC, and the series "K Street" on HBO, both set in Washington, D.C. But he has also written and directed documentaries for the Discovery Channel on topics as diverse as sharks, Native Americans, and the brain. In September, Becker completed a short film, titled "It Is What It Is," for AFTD. He recently spoke with AFTD about that film and his experience meeting and interviewing people affected by FTD.

AFTD: You approached AFTD about collaborating on a film after seeing a piece on frontotemporal dementia by CNN. What about the subject interested you?

JB: I had directed a five-part documentary series on the brain and was thinking about doing a follow-up. As I was Googling around for information, I saw the CNN report on FTD. I was totally fascinated…and was curious to learn more. I called AFTD, and talked with (Program Director) Sharon Denny. Over the next several months, the idea for the project grew out of our conversations and my desire to raise awareness about FTD. We talked a few more times and, eventually, the idea for this project grew out of AFTD's interest and my desire to raise awareness about FTD.

AFTD: Why is it important that people understand this disease? What do you think is the essential story?

JB: I suppose most people know about brain diseases such as Alzheimer's and Parkinson's. Those afflictions don't lack press or spokespeople, for example Nancy Reagan and Michael J. Fox. But I think it's fair to say FTD is largely unknown. So raising FTD's public profile - increasing awareness - is what this is about. Also, what makes FTD so extraordinarily pernicious is not only its devastating effect on the lives of patients but also on their families and friends - ultimately their caregivers. That's the core of this story - this heartbreaking journey of love of the caregivers.

> *"These are true love stories."*

AFTD: You did a lot of research for the film and AFTD put you in touch with several families who were interested in participating. What was most striking about your conversations?

JB: Every single person I spoke with left a profound and indelible impression. Each had their unique perspective in dealing with the disease - but there were also many commonalities. The lengthy and difficult process in getting a diagnosis for their husband or wife or friend, the issues with trying to provide care at home or finding the right care facility - those things came up over and over in our conversations. Most of all, it was the candor and honesty of everyone I spoke with that really knocked me out. Everyone was so willing to share - to help others.

AFTD: You and your crew visited and filmed four families in four different cities all within five days. What was that like? How did the experience affect your crew?

JB: This may sound odd but shooting this film was one of the best experiences I've ever had. What some might see as a depressing subject was, for me, inspiring. Listening to folks tell their stories, it was sad - yes, poignant - yes, heartbreaking - all of that, but it was also uplifting. These are true love stories. Sometimes after we'd get back into our car after we interviewed someone, the crew and I would sit in silence as their words echoed in our heads. Nobody wanted to be the first to break the spell. It was really a charmed shoot, too - we were on a tight schedule and everything fell our way. Truth be told, it was my producer, Jonathan Zurer, who made that happen. Rege Becker on camera and Dennis Towns on audio made it look and sound terrific. Me, I was just along for the ride. What a ride!

> *"…shooting this film was one of the best experiences I've ever had."*

AFTD: The challenges in your work change so much depending on the subject – whether dealing with sharks underwater or filming in the heart of Washington, D.C. What did you find most challenging about this project?

JB: The real challenge on this film was keeping my composure during the interviews.… In the end, I hope that all the folks we met will see (that) the film was worthy of their contribution and sacrifice. I hope it is.

AFTD's film, "It Is What It Is," documents FTD and its impact on caregivers, families, and people with the disease. The 16-minute film is available for use in presentations. For information, email info@ftd-picks.org or call 866-507-7222.

What's So Funny?

Caregiving with a Smile

It's an ordinary day and my mom and I are struggling to get her dressed. She just can't seem to convince her brain to put on the pants. And I'm losing patience. I've tried negotiating, I've tried explaining, I've even tried bribing ("If you put on your pants, we can get ice cream!"), but it seems like she will never get in those pants. I reach for the last tool in my bag of tricks: The Hokey Pokey.

"Okay, mom, here goes," I belt out. *"You put your right leg in...."* She stares at me. I try again. *"You put your right leg in...."* Nothing. If you have a loved one with FTD, you know this look. She's just not there. "Mom!" I plead, *"You put your right leg in... and you shake it all about."* I jump around shaking my leg and singing, *"you do the hokey pokey...."* The truth is, I'm desperate. And then it happens.

FTD is not funny.
But that doesn't mean there's nothing to laugh about.

My mom cracks a smile and starts to laugh. I see her wake up. I can almost see the neuro-whatever-you-call-thems firing in her brain. She's back and she's with me. Mom tells me I look silly, and (hallelujah!) picks up her right leg, shakes it all about, and shoves it into her pants. Victory! Okay, well, not exactly. There's still the left leg. Mini victory!

I'll be honest; the Hokey Pokey doesn't always work. And I am certainly not always dancing and singing with my mom. But having that light moment erases the frustration I felt just a few minutes before. It gives me a burst of energy, which helps me face the next challenge (in this case, the left leg). And, for a moment, I am with my old mom, the one with a sharp wit, who can clearly see that I look ridiculous. When you're dealing with a disease like FTD, and you've been told again and again that you can do nothing, that is definitely something.

Countless studies have analyzed the health benefits of laughter. Laughter boosts levels of endorphins, the body's natural painkillers, and suppresses levels of epinephrine, the stress hormone. Research even claims that laughter can be as good for your heart as exercise (yes, you *can* skip the gym to watch *Seinfeld*!). But if you're a caregiver of someone with FTD, it can be really difficult to see what's so funny.

Laura Federico, M.S.W., an FTD support group leader and care consultant for New York's Alzheimer's Association, says it can be helpful to separate yourself from the "nuts and bolts of the disease." She says, "If you see an opportunity when you can laugh, please do."

Melissa G.'s father has FTD and requires total care. "Humor keeps me sane," she says. "When I brush my dad's teeth, brush his hair, clip his nose and ear hairs... I often make myself and my dad laugh when I sing the song from "The Wizard of Oz" when they are all getting primped. *"Snip, snip here, snip, snip there and a couple of tra la las...."*

FTD is not funny. But that doesn't mean there's nothing to laugh about. Federico says, caregivers should allow themselves to recognize that "some things are just funny. And the person with dementia recognizes that it is funny as well." Case in point, my mom has recently become convinced that my sister and I are the most beautiful and coveted women on earth. No matter where we go, no matter how single, married, or old a man may be, she commands his attention and declares, "She's beautiful isn't she? I made her." While excruciatingly embarrassing, we have to admit, it's also hilarious.

When my mom was diagnosed with FTD, my father told her, "We've laughed every day up to this point, so why don't we just laugh our way through the rest of the way." My family followed his lead and we're healthier and happier because of it. After a recent run-in with police involving dairy theft, my dad remarked, "Yeah, she stole an ice cream but it's not like she poked a kid in the eye with the end of a Nutty Buddy!"

So some humble advice: When faced with a moment where FTD is winning the war on your wits, take a moment and follow me (singing, please!). You put your *whole* self in and you shake it all about. You do the hokey pokey and you turn yourself around, and you smile. Finding your smile will help you cope, it will push you forward, and it will make you a better caregiver.

And that's what it's all about. (clap, clap)

Contributor Nicole Savini is field producer of the Peabody and Emmy Award-winning series, "The Colbert Report" on Comedy Central. Her mother, Kathy, has FTD. To read the complete, unedited version of this article as written for AFTD, go to Newsroom *on our website and click on* In the News.

Awareness

Regional Coordinator Shines Light on FTD

This is not my husband, Susan thought, tiptoeing around the house. But dementia never occurred to her. She, like most people, considered it a disease of the elderly, a common misconception that often leads to late diagnosis when the affliction strikes early.

(“Disappearing Dave,” *The Globe and Mail*, Toronto, Sept. 22, 2010)

Susan Gustafson never suspected her husband’s increasingly erratic, strange and baffling behavior had anything to do with dementia. At 53, he was too young for dementia, or so she thought. But in 2008, Gustafson learned otherwise when husband Dave was diagnosed with FTD.

“We equate dementia with Alzheimer’s, and Alzheimer’s with grandpa,” she says in a recent article about FTD by writer Erin Anderssen of Toronto’s *Globe and Mail.*

In the two years since Dave Gustafson’s diagnosis, Susan Gustafson has worked to raise awareness about FTD, spotlighting its impact on people with the disease, as well as its affect on caregivers, family and friends. Earlier this year, she took part in a television spot promoting the start of Alzheimer’s Awareness Month in Manitoba (Shaw Television, Winnipeg, Manitoba, Jan. 5, 2010). The piece included information on FTD, its symptoms, and the many challenges caregivers face. As AFTD’s regional coordinator for Canada’s western provinces, a volunteer position, she continues to raise awareness about the disease, and about AFTD programs and services.

Dave and Susan Gustafson

“Awareness efforts are so important to a better public understanding of FTD,” she says. “By working with the media, I hope to reach other caregivers and families who need information and support.”

Lee’s Story: *A First-Person Account*

Lee Cerny was diagnosed in May with behavioral variant frontotemporal dementia (bvFTD). In September, he allowed AFTD to share that experience when his first-person written account was posted online. He says writing about bvFTD has helped him understand the changes he is experiencing. His hope, Lee says, is that his first-hand account of living with bvFTD will help others.

To read “Lee’s Story” in his own words, go to *Support and Resources* on www.ftd-picks.org, click *Sharing Our Stories* and select *First-Person Accounts.* To read a blog he writes about living with bvFTD, go to http://bvftd.blogspot.com/.

AFTD invites other people who have been diagnosed with FTD to share their thoughts, feelings, and experiences through short written pieces that can be posted online. First-person accounts from people with FTD can increase awareness and improve understanding of the disease and its impact in ways other accounts cannot. For more information or to submit written accounts, email info@ftd-picks.org or call 866-507-7222.

Lee Cerny

MAC Member on FTD and Identity

Howard Rosen, M.D., a member of the AFTD Medical Advisory Council, was interviewed for a NPR member station report on frontotemporal dementia (“Dementia That’s Neither Alzheimer’s Nor Easy,” KJJZ, 91.5 FM, Tempe, Ariz., July 6, 2010). Reporter Peter O’Dowd spoke with Dr. Rosen, a neurologist at the University of California San Francisco’s Memory and Aging Center, about families of patients with FTD and the likelihood they will struggle with questions of identity.

“The disease really attacks the personality in such a way that you’re not the same person anymore,” Dr. Rosen says in the broadcast. The disease raises philosophical questions about identity and how people define themselves, he adds.

In the report, O’Dowd cites estimates that 3 to 15 percent of people diagnosed with dementia have FTD. Dr. Rosen says, if the patient is younger, “the chances are much higher that it’s FTD – probably about 50/50 – versus Alzheimer’s.”

‘Dementia in Your 30s’

AFTD Executive Director Susan Dickinson was featured in an *iVillage* report on a young mother’s struggle with frontotemporal dementia (“Aggressive Dementia in Your 30s? It Happened to This Mom,” *iVillage*, New York, Aug. 17, 2010). The article focused on Tracy Mobley, a Missouri woman who began exhibiting symptoms of dementia in her thirties at a juncture when she was working a full-time job while also caring for her family.

Dickinson spoke with *iVillage* writer Alex Berg about FTD and its impact on younger people who are often at the height of their careers or busy raising families.

“Many of these people are still in the active years of parenting, so it’s a lot more complicated than for an older person,” Dickinson says in the article.

Tell 10 People Events

Newlyweds Honor Mother of the Groom

Julie and Rob Radtke on their wedding day with Rob's mother, Carol, his father, Bob, and his grandmother Jeannette Polinski.

When Rob Radtke and Julie Alderson decided to marry this year, they had already lived on their own, acquiring many of the things a newly married couple might need. So instead of asking for place settings and gravy boats, the couple asked wedding guests to celebrate their marriage by donating to The Association for Frontotemporal Dementias in honor of Rob's mother.

"Julie and I wanted to raise awareness of FTD and we wanted to honor my mother, whom we both love very much," Radtke says. His mother, Carol Radtke, was diagnosed with frontotemporal dementia seven years ago.

"Since then, we have seen first-hand how destructive this disease can be and how hard it can hit a family," he says. "We have also been very surprised to learn that, despite the severity and prevalence of this disease, the fight against it has barely just begun.

"AFTD's mission is to address all of our society's FTD related deficiencies, and we support them wholeheartedly," he adds.

Rob Radtke and wife Julie were married on June 26 at the Radtke family's house on Torch Lake in Kewadin, Mich. They live in Carlsbad, Calif.

George and Christine Sidoris organize the golf outing each year in memory of their father.

Golfers Support Research

Despite blustery winds and unseasonably cool temperatures, nearly 100 golfers came out in force on Sept. 4 for the George F. Sidoris Memorial Golf Outing to benefit AFTD. By doing so, the golfers, along with several event sponsors, helped raise $10,000 for FTD biomarker research. The golf outing, now in its fifth year, was held at the Lost Nation Golf Course in Willoughby, Ohio. It was organized by George J. Sidoris, a former member of the AFTD Board of Directors, and his sister, Christine, in memory of their father, who had FTD.

"We didn't have the best conditions for golfing," says George J. Sidoris. "But it was still a great event. We're happy to do it for such a worthy cause."

Help Meet the Danis Challenge

Help AFTD raise awareness and funds for biomarker research by taking part in the Danis Challenge Letter-Writing Campaign. By sending letters and emails to family and friends, as well as posting messages to friends and associates in your social networks, you can help raise awareness and funds for FTD biomarker research. Also, when you participate in this campaign, every dollar you raise will be matched three times – once by the Danis family of Texas and twice by the Alzheimer's Drug Discovery Foundation. For details and help getting started, call Chuck McDevitt, AFTD's communications director, at 267-514-7221, ext. 2530, or email him at cmcdevitt@ftd-picks.org. Please join AFTD as we raise awareness about FTD and fund the quest for biomarkers.

Event Marks Friend's Return

"Team Ross" competed in a Night of Trivia, a July 6 benefit for AFTD at The Grapevine, a wine, cheese and tasting bar in San Jose, Calif. Following the trivia competition and fundraiser, The Grapevine donated 20 percent of the evening's sales, as well as proceeds from a raffle, to AFTD.

"Team Ross" is made up of family and friends of Ross Abinanti, a California man with FTD, who wandered from his home last year and went missing for several days in June and July. After more than 1,500 people from the Santa Clara County community took part in a 10-day search - many distributing flyers and posting messages to social media networks - Abinanti was found alive by children from a local little league team. Abinanti's friends and family took part in the Night of Trivia fund-raising event to mark the one-year anniversary of his safe return.

AFTD is grateful to the organizers and supporters of the Tell 10 People events. For information about forthcoming events, visit the AFTD website.

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Opening the gateway to help and a cure

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