The Association for Frontotemporal Dementias

AFTD

Opening the gateway to help and a cure

Volume V Issue 3 November 2008

FTD Fast-Tracked for Disability Benefits

On October 27, 2008, Michael J. Astrue, Commissioner of Social Security (SSA), announced the national rollout of the agency's Compassionate Allowances initiative, a way to expedite the processing of disability claims for applicants whose medical conditions are so severe that they obviously meet Social Security's standards. Frontotemporal Dementia (FTD) is one of 50 conditions on the list for expedited approval.

"This is wonderful news for our patients," said Susan Dickinson, Executive Director of the AFTD. "Many of our families spend years trying to make the case that their loved one qualifies for disability benefits. But with a rare disease like FTD, which most people have not even heard of, this can be an uphill battle." Under the new Compassionate Allowances initiative the wait for benefits may be as short as 6-8 days.

Kent Jamison, PhD, Vice Chair of AFTD, described the challenges FTD patients and families face in obtaining disability benefits in a letter to Walter J. Koroshetz, M.D., Deputy Director, National Institute of Neurological Disorders and Stroke in November 2007. Jamison's letter highlighted the key issues that delayed approval of benefits. His concerns and input from FTD caregivers were reflected in the testimony presented to the SSA by government officials and in the decision to include FTD among the first disorders covered by the Compassionate Allowances program.

"We applaud the Social Security Administration for taking this compassionate and much-needed step," said Helen-Ann Comstock, Founder and Chair of AFTD. "We are grateful to representatives from the National Institutes of Health and the National Organization for Rare Disorders for their efforts to bring about this change in Social Security procedures. This program will make a huge difference in the lives of patients and families across the country."

"There is nothing more frustrating than trying to receive help from the

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Inside this Issue

Rotterdam Success Includes Meeting of International Caregiver Groups

The Sixth International Conference on Frontotemporal Dementias was held in Rotterdam, The Netherlands, September 3-5 and was chaired by John van Swieten, MD of the Erasmus Medical Center. More than 350 researchers and clinicians from around the world came together to share results of current research programs and ideas for how to collaborate moving forward. In addition to being a major sponsor of the conference, AFTD hosted a Caregiver Dinner and a series of smaller, focused meetings with our international counterparts.

"The meeting was a wonderful opportunity to meet FTD leaders from around the globe," said Helen-Ann Comstock, AFTD Chair. Susan Dickinson, AFTD Executive Director added, "This year it was a special honor to consult with a growing number of caregivers in other countries who are interested in founding their own patient advocacy and support organizations." AFTD was well represented in Rotterdam by Medical Advisory Council Chair, Brad Boeve, MD, and other Medical Advisory Council members, many of whom were included among those presenting at the meeting.

Dr. Klaas Jansma and Kathy Cleveland-Bull were speakers for Caregiver Day.

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Spotlight On…

George Sidoris, AFTD Board Member

When AFTD Board member George Sidoris talks about his father, it is evident how much the man has influenced his personal and professional life. "My father always taught me to treat people the way you want to be treated. I've been so successful in sales because of him," said George, who is currently Vice President of Worldwide Sales for Veeam Software. "I'm basically an extension of him."

That closeness made it particularly difficult when George found out that his father had frontotemporal dementia. At first, George and his family were puzzled by his father's symptoms. "We had no clue," George explained. "We thought he may have had a minor stroke or depression. It was only after a few years of painful guessing and wondering that a doctor finally diagnosed him." George described the process of getting an accurate diagnosis as "mental torture that left our family helpless."

Once his father was diagnosed, George started seeking information about FTD. "I searched the Internet for clues and found the AFTD website and a Yahoo! support group," George said. "I found the information so helpful, and the people were so nice and understanding."

George's involvement with AFTD as a family caregiver prompted him to get involved as a Board member. "I felt compelled to join since I was involved with AFTD already and I wanted to help raise money for the cause," he stated. Even though his job requires him to travel around the globe, George still finds time to devote to AFTD and further its mission and objectives.

George was serious about his desire to increase funding for FTD research, awareness, and education. This summer, he and his sister, Christine, organized their third annual golf tournament in Ohio to raise money for AFTD. The event has become increasingly successful: During its first year, the tournament raised $7,000; this year's event raised $13,000. George credits the tournament's success to sponsorships and prize donations – for example, two tickets for floor seats at a Cleveland Cavaliers game – and to a strong support system. "Because of the effect of this disease on my family, it has given me the opportunity to involve family members, friends, and strangers to rally and raise funds in hopes that someday, this cruel disease will be defeated."

George blends his ambition with compassion in such a way that his vision fits perfectly with the goals of AFTD. "I want to bring about awareness of FTD so that it receives attention similar to the attention that has been given to Alzheimer's disease," he proposed. "But ultimately, I want to help find a cure."

AFTD News

AFTD's new website is coming! The roll-out of an expanded, easier to use website is on track for early in 2009. Watch for it at www.ftd-picks.org.

Twenty-one scientists have applied for funding under **Year Two of the AFTD/ADDF drug discovery program**. Medical Advisory Council members Andrew Kertesz, MD, FRCP, University of Western Ontario, and Jill Murrell, PhD, Indiana University School of Medicine, are representing AFTD in the review process.

Brad Dickerson, MD, has started a new **FTD program at Massachusetts General Hospital** in Boston. Anyone in the area interested in more information may contact Daisy Sapolsky at MGHFTDunit@partners.org

On October 14 **AFTD Board members Helen-Ann Comstock, Phil Lovett and Walt McKee and Executive Director, Susan Dickinson** met with leaders at both the National Institute for Neurological Diseases and Stroke (NINDS) and the National Institute on Aging (NIA) to discuss ways to increase government programs for research and services for FTD. In the coming months AFTD will build on these advocacy efforts.

FTDsupportforum.com registered its 1,000th member within nine months of its reorganization. This on-line support group provides a place for safe, secure communications for people who have been diagnosed with FTD and for FTD caregivers.

Camp Building Bridges was a tremendous success! The program, held July 6-12 in Davis, OK, was organized by Tracey and Allen Mobley as a pilot program for teens aged 12-16 who have a parent/grandparent with Alzheimer or FTD. Ten participants enjoyed fun activities and a day of education targeted to young caregivers. Organizers are hoping to offer the program again in 2009.

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

Applications Sought for Laden Family Fellowship

At the 6th International Conference on Frontotemporal Dementias, Brad Boeve, MD, Chair of the AFTD Medical Advisory Council, announced that AFTD is funding a new fellowship.

The two-year fellowship, made possible by a generous grant from the Laden family, is open to MDs and PhDs in the US or Canada conducting basic or clinical research on frontotemporal dementia. A key part of the application is the personal statement, in which applicants should explain why they are interested in developing a career in this area.

"This is a great mechanism to attract the best and brightest young researchers to do work in FTD," says Boeve. "We are grateful to the Laden Family for making this investment in the future of our field."

For more information about this funding opportunity, including application instructions, see http://www.ftd-picks.org/files/0908LadenFamilyFTDFellowship.pdf. The deadline for applications is January 5, 2009.

AFTD Awards Two 2008 Research Grants

The AFTD Board of Directors has awarded two research grants: one to Rosa Rademakers, PhD. at the Mayo Clinic in Jacksonville, FL, and the other to Mark Gluck, MD, at Rutgers University, NJ. This second grant is the first clinical research project the organization has ever funded.

"This is the fourth year that AFTD has funded research, which is our investment in a more hopeful future," says Helen-Ann Comstock, Founder and Chair of AFTD. "This year we are especially grateful for a large donation from an anonymous donor, which has enabled us to award two grants." In 2008, for the second year in a row, more than half of AFTD's budget is devoted to research.

Dr. Rademaker's study, titled "MicroRNA Dysregulation in Frontotemporal Lobar Degeneration" aims to determine whether changes in miRNA levels in the brain may contribute to the development and presentation of FTD. Micro RNAs (miRNAs) are a recently identified class of small molecules that appear to play a role in gene expression.

Although the study of miRNA biology is still in its infancy, particularly in the human brain, a number of recent studies have suggested that miRNAs may play a role in neurodegeneration. Recently researchers have shown that specific miRNAs are decreased in expression in Alzheimer's disease and Parkinson's disease brains.

Rosa Rademakers, Ph.D., was awarded an AFTD grant to study the role of miRNA in FTD.

Dr. Gluck's project is titled "Insensitivity to Negative (Penalizing) Feedback for Inappropriate Behaviors in FTD Linked to Orbito-Frontal Dysfunction," and builds upon observations he and his co-investigator on the project, Murray Grossman, MD, EdD, at the University of Pennsylvania, have made in caring for FTD patients. Their preliminary studies with patients who suffer from the behavioral presentation of FTD suggest that one key reason these patients seem incapable of stopping embarrassing behaviors is that they have lost their sensitivity to negative social feedback. Translated into the daily experiences of the caregiver, this would explain why the caregiver's negative reactions to the behaviors—such as getting angry or embarrassed or removing something their loved one enjoys as a "penalty" for the behavior—do not work. The patient continues with the disturbing behavior, seemingly uncaring about the impact the behavior has on family and friends.

The same preliminary data, which are based upon brain imaging as well as behavior, suggest that FTD patients retain their ability to learn from positive feedback. If these preliminary results are supported in the expanded study over the coming year, this could have an immediate impact by suggesting behavioral therapies for FTD. Rather than trying to "punish" the patient for inappropriate behaviors, the caregiver can employ the strategy of "rewarding" him or her for *not* engaging in those behaviors.

"We are especially excited to be funding this clinical study that may produce valuable information for our families in the short term," says Brad Boeve, MD, Chair of the AFTD Medical Advisory Council (MAC). "If these results pan out, they will improve quality of life for our patients and their caregivers and also have potential to facilitate more accurate and speedy diagnosis."

A number of basic and clinical science teams applied for the $60,000 awards, and the applications were reviewed by a committee of their peers from AFTD's MAC. "Our strategy is to select the most promising ideas, those that are based on rigorous science but that are not likely to be funded by the government or private industry," explains Virginia M-Y Lee, PhD, Chair of AFTD's grants review committee. "Under this strategy, our dollars serve as seed monies to produce pilot data that the investigator can then use to apply to these other sources for larger, full-scale studies."

AFTD Welcomes New Program Director

Sharon S. Denny, Program Director

Sharon S. Denny, MA, joined AFTD as Program Director in September 2008. She brings more than twenty-five years of experience in the development and delivery of innovative, responsive services to people with disabilities, including those with serious psychiatric illness and traumatic brain injury.

Sharon directs our caregiver and patient support and educational initiatives, including the 1-800 HelpLine and Web Inquiries.

"Sharon has hit the ground running and already is implementing some thoughtful, creative changes that enable AFTD to better meet the needs of our families," said Susan Dickinson, Executive Director. "We look forward to her leadership on several new program initiatives in the areas of support, education and outreach over the coming year."

After receiving her Bachelor's degree in Psychology from the College of the Holy Cross Sharon worked in community mental health for many years. She has earned a Master's degree in Psychology from West Chester University and a certificate in Non-Profit Management. Prior to AFTD, Sharon worked as a program development consultant for non-profits serving people with a variety of disabilities.

UCSF Pioneers Art Group for FTD Patients

When Tremaine Thomas began working at the Memory and Aging Center at the University of California – San Francisco, he knew he had found a creative place to work, but he didn't know just how much art would play a role in his position.

"Our director, Dr. (Bruce) Miller, is such an advocate for art therapy programs, and he has an art background," explained Thomas. Since Thomas is also interested in art, their goals for the Center were a perfect fit.

Since January 2008, Thomas has coordinated the Center's art program, which provides people with FTD and other types of dementia an opportunity to create art in a supportive setting. Participants meet at the same time as the Center's monthly caregiver support group, which allows caregivers to bring their relatives to the Center while the caregivers meet in a nearby room. Thomas described the arrangement as a win-win situation, noting that while the program started with three patients, nine people currently participate on a regular basis. "Now both the caregivers and the patients have their own support groups," said Thomas.

The idea for an art program was born from a multidisciplinary collaboration between the Center, the Alzheimer's Association, and the community. Thomas learned about the Alzheimer's Association's Memories in the Making® art program and contacted Angel Duncan at the Northern California and Northern Nevada Chapter. Duncan shared information about the program and helped Thomas find individuals to participate in the Center's new service by providing referrals. When Nancy Ballard, a local artist interested in art as a therapeutic activity, offered to lead the group, "everything just fell into place," Thomas recalled.

Thomas helps during the program's monthly gatherings and has found great joy in getting to know the patients. "We focus on process, not outcome," explained Thomas. "When we encourage them to express themselves creatively, it's almost like they forget their diagnosis for awhile, because they enjoy the process so much."

Thomas fondly told a story of one patient with Primary Progressive Aphasia who, early in the program, painted a picture of someone with a black spot for a mouth. When the patient was encouraged to use brighter colors to paint the mouth, her mood noticeably improved. "You really get to know the patients," Thomas stated. "It's wonderful to see them kind of lose themselves in the art."

Thomas also suggested encouraging all kinds of creative expression with individuals who have FTD or other dementias. "It doesn't just have to be painting or drawing – it could be sculpture or other kinds of creative expression, like writing or singing," said Thomas. "The key is to provide individualized attention and to help the person get into their own 'bubble' where they can lose themselves for awhile and just create."

While the art program has been a valuable addition to the services available at the Memory and Aging Center, it hasn't been without challenges. "We basically have no budget," noted Thomas. "Finding space for our meetings has been a problem, and getting the word out and raising awareness are big challenges."

Thomas is more than willing to help increase awareness about the benefits of art therapy and even train others to start similar programs. *Anyone wanting to start an art program like UCSF's should investigate Memories in the Making® at the nearest Alzheimer's Association or contact Thomas at tthomas@memory.ucsf.edu.*

Donations Honor Loved Ones

Gifts received July 1, 2008 — October 30, 2008

In Honor Of:
James S. Abbott
Dr. Lawrence Albert
Sandra Birnbaum
Sandy & David Birnbaum
Calvin L. Bourgeault
Dennis Braddy
Lawrence T. Cline
Gail Edwards
George Edwards
Janice Ehrmann
Robert & Janice Ehrmann: 50th Wedding Anniversary
Mary Einhorn
Lester Fong
Ruth Franz
Evelyn Friedman
Lawrence T. Cline
Carl LaGrassa: 80th Birthday
Arnette Lester
Ron Martling
Janet Mills
Alan Peiken
Juan Rodriguez
Paula Scott
Christopher Smith
Kathleen Smith
Eve M. Swanson
Roxanne Thomsen
Ellen Trosclair
University School Class of 1958
Carmella Vernick
Judy Windhorst
Mary Yazinski

In Memory Of:
Arthur “Art” Andrews
Glenn G. Andrews
Emerson Avery, III
Robert E. Barr
Alethia Ann Becker
Traci Beck’s Father
Betty Fullen Benoit
Julia Fullerton Bell
Janine Blanpain
Jimmy Ralph Bryant
Robert Thomas Buchholz
John Alan Bullock
Maynard Center
Frances Cole
Craig Comstock
Paulette Crivello
Michael X. Crowe
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S. Gordon Elkins
Margaret Faulkner
Anne Marie Favreau
James E. Ford
Ruth Franz
Susan E. Fulton
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Gale Warren Moser
John R. Musser, Jr.
Marie J. Newman
Terrance O’Connor
Dan & Lolly Phillips
Neil Radin
Diana Richardson
Patricia Ann Rountree
Karen Goff Shulman
Vincent Simone
Mary Small
Kathleen Smith
Shirley P. Sterling
Robert J. Sykes, Jr.
Dr. Harold Teplitz
Sam Waddell
Carol Lynn Waggoner
Gregory Byron White
John “Jack” Wilhelm
Stephen W. Wright
Mary Yazinski
Barbara Zainer

Tell 10 People Events Support AFTD

We are so grateful for the creative energy of AFTD families! This fall, three very different efforts raised awareness about FTD and promoted our mission goals. Each family chose an approach that honors their loved one in a special way while helping to improve the future for others. ***Thank you. You inspire our work.***

Pace for Pick's 5K. Erin Budd's friends and family sponsored a 5K Run/Walk on Saturday, October 18th at the Delmar Middle School/High School in honor of her father, Greg Budd, who has Pick's Disease. The race, raffle, and silent auction were so successful that the whole town must have turned out to help celebrate Greg’s birthday and raise awareness of Pick’s Disease. The event raised over $12,000!

Delmar is a small community in southern Delaware where the Budd family has deep roots. Greg was a beloved teacher and coach there for 31 years until retiring several years ago. Erin's mom, Linda, currently teaches physical education there. Erin had such a positive experience hosting the event that she is eager to advise others who may want to hold a 5K run for AFTD.

Tom's Trees. Paula Radvansky is using her talents as an artist to honor her brother and help raise money for AFTD. Paula's brother, Tom Buchholtz, died in 2007. He was a mechanical engineer and worked for NASA contractors at the Johnson Space Center. Tom loved the open spaces of Texas and the activities they offered, like camping and hunting. Paula has dedicated several paintings to Tom, including an abstract landscape of Texas black oaks, *Tom's Trees*.

Paula is participating in several arts and crafts sales with the first in Southlake, Texas. Half of the proceeds from the sale of prints of *Tom's Trees* will be donated to AFTD. Visit Paula's web page to see *Tom's Trees* and learn how buying the prints can help AFTD: http://www.pennylanedesigns.com/tomsplace.htm.

Carmella and Barry Vernick

A Very Personal Appeal. Barry Vernick was volunteering at the AFTD office when he felt moved to do more. He realized that his experiences as a caregiver for his wife Carmella held a quiet power that could help others. He wrote a letter to everyone in his email address book asking them to honor Carmella and invest in a better future for others by donating to AFTD. To demonstrate his support of AFTD’s mission, he offered to match the first $1,000 donated.

Barry’s letter is a touching tribute to his wife of 45 years, the woman he “first fell in love with ...watching her deconstruct a poem.” He wrote, “Oh my, could she tell you what a poem was about!” Carmella was also an avid student who earned two master’s degrees and was a few credits shy of a doctorate. At 68, Carmella can no longer speak and can barely write due to FTD. “Every single day,” said Barry, “I feel completely blessed that I am able to care for my wife. Every single day, I feel an overwhelming sadness that my wife is so ill.” Within 30 minutes of Barry’s appeal, donations began arriving. Barry’s match was met within a few days and the donations keep coming in.

Rotterdam

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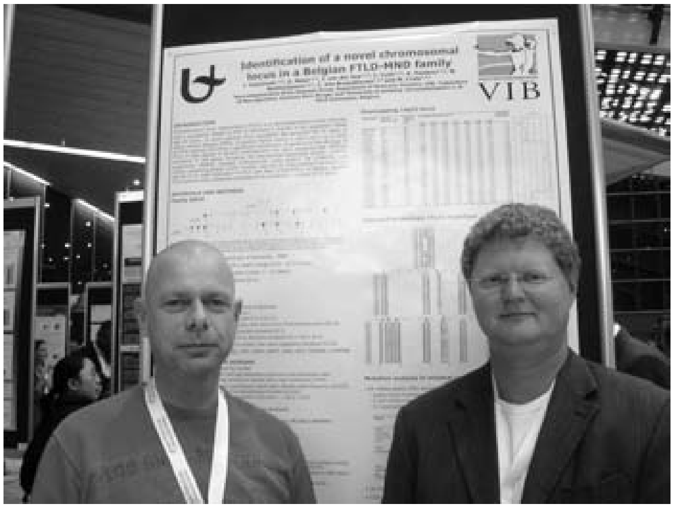
Professional attendees participated in three days of research presentations, which for the first time included a half-day on FTD biomarkers—tools that will be necessary to test potential drugs in the clinic. Other topics included: TDP-43, progranulin, tau, the genetics of FTD, and diagnostic tools and criteria.

A total of 160 posters were presented during the refreshment breaks, with time allotted to confer with the authors. Marc Cruts, PhD, from the University of Antwerp, Belgium, presented a poster on his work searching for a novel gene mutation in one FTD family—work that is currently being funded by AFTD.



Marc Cruts, PhD presents a poster of his AFTD funded research project to Brad Boeve, MD

The first day of the conference was Caregiver Day and included a track of meetings for more than 200 caregivers who attended from The Netherlands, Britain, Switzerland and other European countries. Presentations to this audience included a welcome by Comstock and van Swieten and a keynote address by Kathy Cleveland-Bull, a motivational speaker from the U.S. whose mother and twin sister both suffer from FTD. The lay audience viewed a new video produced by Dutch psychiatrist Klaas Jansma, which featured the everyday life of three FTD patients, each with a different set of symptoms. Preliminary results from a Dutch study on the different stressors experienced by FTD and Alzheimer caregivers were presented, as well.

Susan Dickinson and Helen-Ann Comstock provide information about AFTD to conference attendees.

Caregiver Day also featured the opportunity for conversation between the caregivers and researchers during breaks between sessions, and was capped off by the AFTD-sponsored Caregiver Dinner, held at the Royal Maas Yacht Club. More than 100 caregivers, scientists and clinicians attended the dinner.

AFTD organized an international meeting of caregivers and professionals who provide services to FTD families in their own countries, as well as persons who are interested in starting FTD patient advocacy and support groups. Various organizational models, funding structures and mission goals were discussed by representatives from The Netherlands, Switzerland, France, Germany, Italy, Britain and Argentina. Contingents from France and Argentina have stated an interest in being affiliated with AFTD, and possible ways to structure this relationship are under consideration. The international group of caregiver leaders will stay in touch and share resources as they are developed.

Helen-Ann Comstock with Jari, a caregiver from the US who has several family members with FTD.

AFTD also hosted a meeting of clinicians to discuss the implications of use of the word "dementia" in the U.S. and other countries. A brief report on this discussion and the recent survey of caregivers' views on the word "dementia" conducted through the AFTD network will be posted soon on the AFTD website.

Finally, an international planning committee was formed to begin plans for the next International Conference, which will be held in Indianapolis, Indiana, USA, in the early fall of 2010.

John van Swieten, MD with Arjenne Romeijn and Kirstin Klijnsma, graduate students who helped with conference details.

Go to http://www.ftd-picks.org/?p=news/2008confnotes to view Susan Dickinson's daily blog from Rotterdam.

UK: Pick’s Disease Support Group

FTD patients, families and professional care providers in the UK find information and support in the Pick’s Disease Support Group (PDSG). PDSG was founded in 1995 by Penelope Roques (right, with her new puppy) and Dr. Martin Rossor, with whom she worked at the National Hospital for Neurology and Neurosurgery at Queen Square in London. “When we started the PDSG we thought there would only be a few members,” said Roques. “We have been shocked at how many people now belong.”

The PDSG publishes a quarterly newsletter, hosts an annual education and support seminar, and sponsors a website where carers can register to join an online discussion forum. www.pdsg.org.uk

Benefits

From page 1

government, only to be denied because there is no ‘proper diagnosis’ of what is wrong with a person,” wrote one caregiver. “My father was finally diagnosed with Picks disease about 10 years ago, but has been suffering from this disease for well over 20 years.….By the time the doctors came to the conclusion that he had Picks disease, he had already been out of work for so long, that we were told he no longer qualified.”

Accessing disability income is just one part of the financial challenge families face when a wage earner becomes disabled. The loss of health insurance coverage can be financially devastating, as well. For people under age 65 who qualify for Social Security Disability, there is a mandatory two-year waiting period before they can receive healthcare benefits under Medicare. Because this is a significant issue for the many families of FTD patients who become disabled prior to 65, AFTD has joined with other disability organizations to advocate for legislation that would eliminate the 2-year wait. For more information on this issue, please see the accompanying article.

AFTD is pursuing details of the Compassionate Allowances program and is coordinating with members of our Medical Advisory Council to compile recommendations for families on the application process. Watch AFTD’s website (www.ftd-picks.org) for updates. For more information and a complete list of the disorders included in the program, go to www.socialsecurity.gov/ compassionateallowances.

Help AFTD End the 2-Year Wait for Medicare

A national advocacy effort is starting this month to end the mandatory waiting period for Medicare health benefits for people with disabilities. AFTD has joined other patient advocacy groups in the NORD (National Organization for Rare Disorders) Coalition to press for legislation that will end the wait for all people with disabilities.

In 2007, HR 154 was sponsored by Rep. Gene Green (D-TX) and co-sponsored by more than 100 fellow representatives. It will be reintroduced in the next Congressional session. The NORD Coalition is building momentum for the issue through a press conference with Rep. Green November 10th, national and local press campaigns, and letter writing efforts. Participating agencies are identifying individuals and families who have been affected by the two-year wait and are willing to share their story.

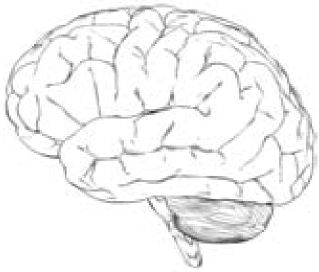
Please help us tell your story. Let us know if you have experienced problems in medical coverage due to the two-year wait for Medicare and are willing to speak or write about it. The Coalition’s goal is to have a contact identified in each congressional district for a truly national response. Contact us at info@ftd-picks.org and watch AFTD’s website for more information.

AFTD to Research Caregiver Attitudes on Brain Donation

AFTD is proud to announce that it has been awarded one of 38 grants under a new competitive funding program from the National Institutes of Health which aims to involve patients and caregivers as partners in the medical research process.

The study, titled “Frontotemporal Dementia Caregivers and Researchers: Partnering for Brain Donation” will be conducted by AFTD and academic research partner Indiana University (IU).

Through a series of focus groups with caregivers held in three U.S. cities, AFTD and IU will identify and explore the issues, attitudes and concerns that caregivers identify as potential barriers to brain donation. The results of the study will be presented at a national meeting, submitted to a peer-review journal, and used to design appropriate, effective educational materials for families and researchers. “Many families feel that brain donation is the ultimate gift they can make,” says AFTD Executive Director Susan Dickinson. “If more families participated, research could proceed faster. We want to understand what prevents more caregivers from making this choice, and if there are better ways to communicate the importance of their partnership in driving FTD research forward.”



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

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