



## Researchers Discover Gene Mutation on Chromosome 9 That Causes FTD and ALS

A ten-year hunt to identify the gene mutation that can trigger either FTD or ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease) or both in the same family has finally yielded fruit. On September 21st, two separate groups of investigators published findings linking an abnormally long sequence of DNA in a gene known as *C9ORF72* as the trigger in these families. AFTD Medical Advisory Council (MAC) member Rosa Rademakers, Ph.D.,



*Dr. Rosa Rademakers*

led one of the teams that made this discovery. Additional authors on her paper included five MAC members and AFTD Postdoctoral Fellow Alexandra Nicholson, Ph.D.

The finding is groundbreaking for several notable reasons: The mutation is responsible for a greater proportion of familial FTD and ALS than any previously identified genetic change. In one of the papers, preliminary estimates state that this mutation causes at least 12% of familial FTD and 22%

of familial ALS. In the other paper, the frequencies of the mutation in familial cases were even higher. Another interesting finding was that the researchers found this same mutation in a small percentage of sporadic cases (i.e., patients in which there was no family history of FTD or ALS). This means that for some patients with apparently sporadic disease, there may be a genetic cause. More research will need to be done to better understand the presence of the mutation in sporadic cases.

“The identification of this mutation opens completely new areas of research into these diseases,” said Dr. Rademakers.

*(see Chromosome 9, page 4)*

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### The AFTD-Team: A toolkit and support for our grassroots special forces

For those over the age of 35, the hit TV series “The A-Team” may be a fond memory, complete with the charismatic Mr. T, his massive gold-chain necklaces and punchy one-liners. The show was about a group of unlikely yet competent ex-special forces who work as soldiers of fortune while the Army chases them for crimes they didn’t commit.

As staff at AFTD sat down to create a toolkit to help grassroots fundraisers organize their thoughts and efforts, a connection was made between AFTD and this 80s TV show. Grassroots fundraisers for AFTD are indeed a group of “special forces,” dedicating their time and resources to work towards a common goal—raising awareness and funds for care and a cure for FTD.

And so, “The AFTD-Team” was created, and hopefully, along with it, a greater sense of community and bond among all grassroots fundraisers across the country.

*(see The AFTD-Team, page 6)*

## Spotlight On...Earl Comstock, AFTD Board of Directors

**E**arl Comstock was just 17 years old when his father was diagnosed with FTD. The family lost its breadwinner, as his father was unable to continue his job as professor of mathematics. He required full-time care, and Earl's mother became his father's caregiver. Earl, his brother and sister all learned how to help their mother care for their father. Though finances were a struggle, all three children graduated from college. Earl earned a B.A. from University of California at Santa Barbara and a law degree from George Mason University.

As the son of AFTD founder Helen-Ann Comstock, it is no surprise that Earl decided to help further the mission of the organization by joining the Board of Directors in 2009 and chairing the Advocacy Committee of AFTD.


Earl lives with his wife and daughter in Washington, D.C., where he has worked for the US Senate and as a consultant for the past 20 years. Given his years of experience working with Congress, his mother reached out to him a few years ago for assistance with getting Congressional support for research for FTD.

"AFTD has been successful, with the help of Senator Arlen Specter, in getting Congressional direction to NIH (National Institutes of Health) to focus on some research efforts on FTD," said Comstock. "In particular, we were able to work with NIH

to create a database that collects FTD patient information."

In the past few years, with Congress no longer earmarking funds and federal budgeting difficulties, advocating for federal dollars dedicated to FTD has proven very challenging. Now AFTD is focusing on advocating to maintain NIH funding and working with other organizations that have similar research interests.

Over the coming year, Earl also hopes to work with staff and volunteers to build out the advocacy resources AFTD can offer. AFTD plans on increasing the amount of information on the website to help caregivers and patients understand and access federal or state healthcare programs and other benefits as well as understand their legal rights and responsibilities especially in terms of decision making powers and competency.

In the meantime, Earl and the Advocacy Committee will continue to raise awareness for FTD among legislators and help them to understand the beneficial impact that funding FTD research brings to their constituency. 



Earl Comstock

## AFTD News Briefs

**Save the Date:** AFTD's Caregiver Conference and Annual Meeting will be held in Atlanta on April 27, 2012. Details to come!

**New diagnostic guidelines** for behavioral variant FTD have been published. A chart delineating the new criteria for bvFTD can be found on AFTD's website.

Family caregivers of a person with FTD are invited to **participate in a research study** sponsored by the Department of Physiological Nursing at University of California, San Francisco. The study aims to provide caregivers with training that will improve their quality of life; participation can be in-person or via videoconference. For more information contact Judy

Mastick, RN at 415-476-5503 or judy.mastick@nursing.ucsf.edu.


**FTD awareness cards** are now available on AFTD's website for download. These cards may be helpful in public situations when an FTD patient may not be able to control his/her language or behavior.

The University of Pennsylvania will host a **caregiver conference** on Saturday, Feb. 4th from 8 a.m to 5 p.m. Details to come.

AFTD is pleased to present an **electronic newsletter for caregivers**. To sign up for the bi-monthly newsletter, send an email to amaher@theaftd.org with "Gateway sign-up" in the subject line.

Turn everyday purchases into a meaningful gift to AFTD! AFTD has teamed up with Capital One to offer an **AFTD credit card**--a percentage of each purchase made with the card will be donated to AFTD. Visit the "donate" page of the website for program details.

There are **new FTD support groups** in the following locations: Albany, NY; Albuquerque, NM; Atlanta, GA; Dallas, TX; Melbourne, FL; Northern NJ; Pittsburgh, PA and Twin Cities area, MN. Check AFTD's website for a complete listing of support groups.


The **8th International Conference on FTD** will be held Sept. 5-7, 2012 in Manchester, England. Visit the website at [www.ftd2012.org](http://www.ftd2012.org) for details. 

## Partners in FTD Care


In the summer newsletter, AFTD announced a new long-term care training initiative to help facilities become better partners in care with FTD families.

Since that time, the AFTD Committee on Long-term Care Facility Education has aptly named the initiative “Partners in FTD Care” and has rolled out the program with its first, quarterly e-newsletter for healthcare professionals at the end of September.

Partners in FTD Care education materials are available for purchase at cost on AFTD’s website under the “Healthcare Professionals” tab. A link to the first newsletter is also available online.

Anyone who would like to receive the quarterly e-newsletter or would like additional information on the program should email [ftdcare@theaftd.org](mailto:ftdcare@theaftd.org). 

## Dr. Bill Seeley Awarded MacArthur Grant

AFTD congratulates William Seeley, M.D., associate professor of neurology at University of California, San Francisco, who recently won a \$500,000 MacArthur Fellowship for his research into FTD. The no-strings-attached, five-year fellowship allows Dr. Seeley the freedom and creativity to delve into FTD research on his own terms. Dr. Seeley’s work with von Economo neurons provides a window into the cause of the unique symptoms seen in FTD patients and holds great potential for both diagnosis and treatment advances. 



*Dr. Bill Seeley, neurologist researching FTD at University of California, San Francisco. Photo courtesy the John D. & Catherine T. MacArthur Foundation.*

## Join Us in Making a Difference This Holiday Season!

**“AFTD is making a huge difference in the lives of those who are caregivers and those who get this horrible disease.”**

*-- FTD Caregiver*

The holiday season is almost upon us, and with it comes a time of giving thanks. AFTD is grateful for you and your generous support. With your help, AFTD will continue to meet the growing needs of the FTD community. Your gift will assist in sustaining the work of AFTD, the only international organization working toward both **Care and a Cure for FTD.**

**Your support carries all of us forward!**

A tax-deductible donation enables AFTD to:

- Fund the first grants for FTD Drug Discovery
- Coordinate a network of 62 independent support groups
- Educate staff at care facilities through Partners in FTD Care
- Create *The Gateway*, an electronic newsletter exclusively for FTD caregivers.


Thank you for helping AFTD make a difference in the lives of those affected by this devastating disease.

**To make your gift online, go to [www.theaftd.org](http://www.theaftd.org)**

## AFTD Welcomes Sharon Hesterlee, Scientific Director

**O**n October 1, Sharon Hesterlee, Ph.D., joined the staff of AFTD as its first scientific director. She brings over 13 years experience in non-profit research management including her previous role as a Senior Vice President at the Muscular Dystrophy Association, where she oversaw a portfolio that included neurodegenerative diseases. For the last two years she has served as Scientific Director at Parent Project Muscular Dystrophy (PPMD) and will be splitting her time between AFTD and PPMD.

For AFTD, Sharon will bring to bear her particular expertise in moving promising research findings from the academic world into clinical development. To this effect, Sharon has negotiated over \$30 million in contracts with industry and nonprofit drug development groups, has been involved in the planning of numerous meetings to identify and remove

barriers to therapy development for muscular and neurodegenerative disease and she co-chairs the Working Group on Drug Development Funders for the Health Research Alliance. She also currently serves on the Council for the National Institute of Neurological Disorders and Stroke and on the Board of Directors for the Health Research Alliance and the University of Arizona's School of Mind, Brain and Behavior. Sharon received her Ph.D. in neuroscience from the University of Arizona in 1999. 



*Sharon Hesterlee, Ph.D.*

## Chromosome 9 *(continued from page 1)*

Investigators discovered this genetic change by painstakingly comparing the DNA samples of affected and unaffected volunteers from families with a positive history of FTD with TDP-43 protein deposits in their cells and/or ALS (see box). This feat has been likened to looking for a single phone number in the New York City phone book when you don't know the name of the person for whom you are looking. Although the problem in these families had been previously localized to a region of chromosome 9, through further analysis the investigators were able finally to zero in on the exact mutation—a sequence of the letters “GGGGCC” that is normally repeated less than 23 times but was continued from 700 to 1600 times in the family members with FTD and/or ALS. The longer sequence is known as an “expanded repeat.”

Although an important step forward in understanding these diseases and how they may be linked, the route from mutation to disease symptoms may not be straightforward. The gene in which the expanded repeat occurs is known by the very generic name “chromosome 9 open reading frame 72” or *C9ORF72*, which

Beth Walter, Board Chair of AFTD, is gratified to finally know the cause of the combination of FTD and ALS that took her husband, two brothers-in-law, mother-in-law and husband's aunt. Her family has been actively involved in this research for many years. “It's a tremendous breakthrough in FTD research,” said Walter, “and we're one step closer to treatment and cure.” Walter's family is one of many that were part of almost a decade's worth of research through three clinics in Vancouver, San Francisco and Minnesota. When asked



*Mike and Beth Walter*

if she felt the numerous trips to the clinics to provide blood draws, scans and cognitive testing were worth it, she replied, “Absolutely. This new finding drives home what our family has known all along. Without the active participation of patients and their families in this important, albeit tedious work, it takes infinitely longer to get to the answers. The fact that all three brothers participated fully, including brain donation, I am certain was of great value to the effort.”

Dr. Adam Boxer, associate professor of neurology at University of California San Francisco, is the clinician who is credited with coordinating the information from all three sites and identifying one very large kindred with the gene mutation on chromosome 9. “We could not have made this discovery with the active partnership of our families,” said Boxer. “Participation in clinical studies is critical to making progress in FTD research.”

## AFTD Awards 2011 Pilot Grant to Fenghua Hu, Ph.D.


**A**FTD has awarded its 2011 pilot grant for research to Dr. Fenghua Hu, research assistant professor at Cornell University. Dr. Hu will receive \$60,000 for a one-year grant to fund her study of signaling mechanisms of progranulin.

While the cause of most forms of FTD is unknown, in approximately 15% of patients, the disease is linked to a genetic mutation. In some of the FTD patients, the gene that codes for the protein progranulin becomes mutated, thereby decreasing the level of progranulin. Dr. Hu's research will



*Fenghua Hu, Ph.D., AFTD 2011 pilot grant recipient*

focus on gaining a better understanding of the normal mechanisms in the cell that control progranulin function, with a goal of identifying potential steps in the process that could be targets for therapeutic intervention.

“We are very happy to be able to support a promising young investigator who is doing important work in revealing the disease process at work,” said Virginia M-Y Lee, Ph.D., who led AFTD's Medical Advisory Council in reviewing the grant applications. 

basically means that not enough is known about its function to give it a more descriptive name. And, although most disease-causing mutations are found in the part of the gene that encodes instructions for making a corresponding protein, this mutation occurs in a part of the *C9ORF72* gene that isn't used by the cell to make a protein, a so called “non-coding region.” Even so, investigators were able to determine that the expanded repeat in the non-coding region does decrease the amount of protein made by *C9ORF72* and speculated that this may cause all or part of the symptoms.

Lessons learned from other diseases may provide an alternative explanation for how an expanded repeat in the noncoding region of a gene can lead to symptoms. In the last several years, scientists have discovered that the RNA (a sort of intermediate step between DNA and building a protein) produced from a gene with an expanded repeat can form clumps in the cells and bind to proteins that regulate the activity of many other genes. So a single expanded piece of DNA in one gene can potentially affect the activity of many other genes and lead to disease—the equivalent of a riot instigator in a crowd. It's not yet known if this is what occurs in the *C9ORF72* mutation.


“This is a classic scientific finding, in that this one new discovery opens up several sets of new and interesting questions,” concurred Boeve. “Why do some people with this mutation develop FTD, others ALS and still others both? Why do some families seem to show that signs of the disease in one generation may begin at a much younger age than in another generation? We know that this mutation and those found in an unrelated gene, *PGRN*, both cause FTD with TDP-43 pathology. How can two apparently separate genetic mechanisms cause the same type of syndrome and pathology?”

“What we have discovered is a single genetic change that is related to both FTD and ALS,” said Adam Boxer, M.D., Ph.D., a collaborator on the paper from UCSF. “This will allow us to better understand the common pathological process and should be a big leap forward in the effort to develop biomarkers and to identify appropriate targets for therapeutic intervention in both diseases.”

While the implications of the new *C9ORF72* finding are followed up by the scientific community, many families are probably wondering how the finding affects them directly. The researchers caution that this discovery will not

change the reality of care or treatment in the short term. “It is a difficult thing to acknowledge—that an exciting finding like this, as much as it opens new doors to understanding the disease and will undoubtedly shorten the time to an effective therapeutic, nonetheless does not change the options available today,” noted Susan Dickinson, executive director of AFTD.

It will take at least several months for a laboratory to develop a clinical test that can tell a family if this is the mutation that is causing disease in their kindred. Typically such tests must go through a certification process to ensure that they are reliable. And while a test will enable definitive diagnosis and pre-symptomatic testing in relatives who wish to know if they carry the mutation, it will not immediately bring with it additional tools for treatment.

“The pace of science is never fast enough,” acknowledged Dickinson. “But advances like this, which are the result of dedicated teamwork on the part of clinicians, researchers, patients and their families, prove that, working together, we will eventually succeed in developing treatments and a cure.” 

## Donations Honor Loved Ones

Gifts received from June 15 - October 1, 2011

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*AFTD would like to acknowledge Faye Oliveri and Joseph Becker as major donors to AFTD. They were inadvertently omitted from our annual report, and we apologize for this error.*

## The AFTD-Team (continued from page 1)

"There is something very special about the bonds forged between people who are united in a cause to defeat a disease like FTD," said Susan Dickinson, executive director of AFTD. "It is our hope that volunteers—from Connecticut to California—will embrace what being part of The AFTD-Team means... that while each supporter may be engaging in different ways of raising money and awareness, they are all part of a team with a very important end goal. When the contributions of each individual are added up, the impact is huge."

Along with a branded logo, the Association has also created a tagline for The AFTD-Team: **Yeah...I'm here to Fight This Disease.**

"We wanted to have a definitive phrase that captured the energy and drive that our fundraisers bring to their events... something that said, 'Listen up, FTD... I mean business,'" said Angie Maher,

**THE AFTD-TEAM**

**Yeah...I'm here to Fight This Disease.**

communications & marketing manager at AFTD. "And I'm really happy that we could incorporate a new "FTD" moniker—Fight This Disease. You'll be seeing The AFTD-Team logo and tagline on t-shirts, bracelets and other items in the future."

The centerpiece of The AFTD-Team is a 12-page toolkit for grassroots fundraisers. This packet is designed to help fundraisers on the ground to organize their thoughts and energy into a successfully planned and orchestrated event to raise awareness and funds for AFTD. There are useful tools in the packet, including fundraising ideas, sample letters, a sample press release and how to handle expenses and donations. The AFTD-Team toolkit can be found on AFTD's website and downloaded as a .pdf file.

"This toolkit should be helpful for all levels of events—from ideas for those who are thinking about holding their first fundraiser to tips for those who have already completed multiple events," said Maher. "There is something for everyone."

**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 the 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*, then *Get Involved*, and click on *Donate*, then *Contribute Electronically*.

In addition to the toolkit, AFTD has also purchased a peer-to-peer fundraising system that allows individual fundraisers to set up their own webpage from which they can raise money for AFTD. Givezooks.com now enables AFTD to use the power of online fundraising to reach more donors with ease. AFTD's page can be found at: <http://theaftd.givezooks.com>.

For those who don't have the time to organize and host their own fundraiser, AFTD recommends forming a team to participate in an existing walk or run. This means that another organization hosts the event, but allows individuals to raise money for the charity of their choice. Go to [www.runningintheusa.com](http://www.runningintheusa.com) to find local events that you can participate in to raise money for AFTD. From this link, click on "races" for a map of the U.S., and choose the appropriate state.

To download a copy of The AFTD-Team toolkit, visit <http://www.theaftd.org/about/get-involved/the-aftd-team>.

For additional information or questions on The AFTD-Team, the toolkit or the online peer-to-peer fundraising system, contact Angie Maher at [amaher@theaftd.org](mailto:amaher@theaftd.org).

Look out, FTD...we're here to **Fight This Disease.** 


**New AFTD Staff**

This spring, AFTD welcomed two new staff members to the organization. AFTD's first Development Manager Pam McGonigle started with the organization in April, and new Communications & Marketing Manager Angie Maher began her employment in May.

Pam has more than 12 years of experience in nonprofit organizations with a proven track record in developing and implementing fundraising strategies, plans and programs that yield enhanced visibility and increased revenue streams. She sits on the board of another national nonprofit and holds three Paralympic medals in track and field. Pam will work to expand the fundraising program, direct appeal campaigns and lead the organization's first fundraising events.



*Angie Maher and Pam McGonigle*

Angie has 15 years of communications and marketing experience, including the last six years with nonprofit organizations. Angie holds a degree in English and brings strong writing skills to AFTD. Her major responsibilities are creating awareness for FTD/AFTD, working with grassroots fundraisers and producing effective communications vehicles for the organization. 

## Adult Children: Remote Caregiving for a Parent with FTD

The challenges faced by a caregiver of someone with FTD are varied and often seem endless. From finding a good doctor, financial advisor and lawyer to the daily care issues of meals, activities and cleanliness, there's very little that a caregiver doesn't shoulder.

But what happens when the caregiver is an adult child, possibly with a young family or his or her own? And what if he or she no longer lives in the same town or even the same state? What needs to be done first, and how can one make it happen?

Angela Kimble, whose mother died this year following four years of FTD, emphasizes the importance of dealing with the big issues quickly: driving privileges, guardianship, housing, nutrition, and getting financial and legal dealings in order while the parent can still find necessary documents.

Dave Dillon, a volunteer regional coordinator for AFTD, vividly describes the frustration of repeatedly having to explain FTD to people who confuse any dementia with Alzheimer's disease.

"When people would ask about my Mom, and I said she had something called frontotemporal dementia (FTD), they would look at me with a blank stare," said Dave. "They would inevitably ask: 'Is it like Alzheimer's?' And I would say 'no,' and start to explain about behavior and personality changes rather than memory issues. But *Alzheimer's* is a household word, and it's the thing people want to grasp onto when they hear 'dementia' for their ability to relate and understand. It made it extremely challenging to continue to try to talk about."

He also remembers the difficulty of finding literature and other resources that adequately explained what was happening to his mother, who moved all too quickly from reliable babysitter for his young daughter to needing babysitters and adult daycare for herself.

Many caregivers have found solace, affirmation, and valuable information in *What If It Isn't Alzheimer's?* edited by AFTD board member Lisa Radin and her son, Gary. AFTD Medical Advisory Council member Andrew Kertesz penned *The Banana Lady and Other Stories of Curious Behavior and Speech*, which profiles 19 patients, as described by their caregivers, and discusses the underlying biology.

Angela's mother was diagnosed with unspecified FTD at the age of 62 years, only 18 months into a second marriage. Soon Angela and her brother were scrambling to help their stepfather provide adequate



Caregiver Dave Dillon (r), pictured with his father, mother and newborn daughter.

care in a situation that changed daily. She remembers the "sheer luck" of finding, in her mother's psychiatrist, a doctor who understood FTD intimately, largely because his own wife was an FTD patient. He encouraged Angela to keep looking until she found the right neurologist for her mother.


The pain and frustration of being more than half a continent away from home haunts Kelly Drake every day. Diagnosed four years ago, Kelly's father suffers particularly acute manifestation of behavioral FTD. Her mother continues to work while pasting together adult daycare and home health aids to forestall the necessity of placing her husband in an institutional setting. Tethered to the west coast as she tries to build an independent consulting business in a foundering economy, Kelly spends a lot of time on the phone or sending emails to bolster her mother's spirits and get updates on

her Dad, all while dealing with her own sense of loss and "perpetual mourning."

Most caregivers slowly learn that they need to put themselves first. Maintaining their own physical, emotional, and social health is crucially important in negotiating what seems like an endless stream of crises. Dave recalls the moment when he recognized how FTD had overtaken his own life.

"It's like a bizarre comedy sketch," said Dave. "What's Mom going to do next? Her unpredictability is a challenge, but it's also a juggling act as I also try to help my wife, be attentive and caring to my daughter, fill the gap for my father and still set some boundaries."

Angela's mother deteriorated rapidly... word loss that eventually devolved into nonsensical speech, pronounced apathy, and inability to drive, work or care for herself. Angela describes feeding her young daughter—"food all over the place, on her bib, in her hair, on the floor"—and then visiting her mother and seeing the same thing. "Sometimes, it was too much," said Angela.

All of these adult children say that one of their greatest sources of comfort is through connecting with other FTD caregivers, who understand the disease and are uniquely qualified to offer meaningful support. AFTD, as the hub of this growing community, is the best place to start when looking to find or create such a connection. If there is no existing group in your area, many caregivers take the initiative to start one: Dave worked with his father to develop an FTD support group in San Diego. Angela helped to found a similar group in Houston, and she remains involved in group activities even after her mother's death. Kelly maintains an FTD-focused blog (<http://www.ftdistntjustflowersanymore.wordpress.com>) as a way of reaching out to other caregivers. 

Contributor Karen Williams is a freelance writer and editor located in Weymouth, MA. Her childhood friend was diagnosed with FTD in early 2011.



## Taking on FTD: Howard Glick

Each morning starts with a familiar routine for Howard Glick as he collects his laptop and heads to his “office” at Starbucks in Upper Manhattan. The exact time varies, but he starts early, returns often, and continues his work at all hours of the night back in his apartment. There is a lot to do when you are telling the world what it’s like to live with FTD.

“Simply put,” wrote Howard, “I eat and breathe my efforts seven days a week. I am relentless in my efforts to further public awareness and help others.”

Howard started writing a blog in July 2011 about his experiences with frontotemporal degeneration with the intention of advocating for and supporting others like himself. His symptoms started manifesting themselves in 2004, but were diagnosed and treated as bipolar disorder for 6 ½ years. A 2006 SPECT scan showed early indicators of degeneration that were not recognized, but progression was clear in a 2010 PET scan and Howard learned he had behavioral variant FTD (bvFTD).

The prospects were daunting for a 53-year-old, divorced father of two who had lost his career, loving relationships and his future over the course of six years. When he researched FTD on the Internet, he began to fear his mortality and was afraid he would become depressed. A life-long friend suggested Howard have coffee with him and his wife every morning at 6:30 to stay connected. Days stretched into months, and Howard realized that death was not imminent and he needed to rebuild his life.



*Howard Glick, FTD patient and blog writer*

Howard adjusted his lifestyle to better manage his nutrition, erratic sleep and energy, and behavior symptoms. Through research and a gregarious personality, he found experts in FTD and legal planning and engaged their help. He transitioned from morning “coffee with David” to the neighborhood Starbucks, where in short order a medical writer he met suggested he write a blog. Thus, Howard’s new mission was born.

*“After six years with the wrong diagnosis and treatment, I feel I have my life back,” he said. “I love every minute of it.”*

*--Howard Glick*


Howard started the FTD/Dementia Support Group blog in July 2011 to help people diagnosed with FTD to help themselves and to increase awareness of FTD. “I didn’t realize at the time that awareness of FTD was built upon family, caregiver and medical community experience,” he said. “Virtually no one diagnosed and living the disease communicated what it’s like to live with it.”

Symptoms of behavioral variant FTD usually include decreased self-awareness and insight, and many people are unaware of their own behavior and personality changes. “But FTD is such a complex and variable disease,” said Sharon Denny, AFTD program director, “it doesn’t follow many rules. Howard offers a rare, honest and very poignant view of the toll this disease takes through the eyes of the person

diagnosed. The result is quite extraordinary: an articulate, first-person account of what it is like to live with FTD.”

Friends confirm that Howard has always created the interesting and successful life he’s wanted, whether on a kibbutz, serving in the Israeli army or rising to the upper tier of marketing for a leading global manufacturer of innovative, high-tech business equipment. It exhausts Howard to manage symptoms, navigate disjointed health care and social services, maintain an apartment and make do on his “retro-economical” Social Security disability income in New York. But Howard is grateful, too. “After six years with the wrong diagnosis and treatment, I feel I have my life back,” he said. “I love every minute of it.”

Howard’s efforts to articulate what life with bvFTD is like have extended to numerous on-line forums and support groups worldwide for FTD/Dementia. Between his blog and email communications he reports he has received over 4,500 correspondences since July. “It feels good to know I am making a difference in people’s lives,” he said.

“Though I am exhausted and am aware every fleeting moment of the symptoms of FTD,” Howard wrote, “I have decided I am going to ignore FTD and press forward to create for myself a happy, productive life. FTD is just going to learn to coexist with a Howard Glick that will manage the symptoms. FTD can hang out, but it’s not going to rule my life.” 

Howard Glick’s blog can be found at: <http://earlydementiasupport.blogspot.com/>. Contact Howard directly via email at [howardjglick@gmail.com](mailto:howardjglick@gmail.com).

## Awareness & Fundraising **Brandon Cline: Biking Across America**

**O**n June 18, Brandon Cline began his 3,600-mile cross-country trek on a bicycle in Charlottesville, VA in honor of his father, Larry, who has FTD. He finished his journey in Portland, OR on August 22 and raised more than \$4,000 for AFTD. Here's a quick look at his experience.

**AFTD:** Why did you choose a cross-country bike trek?

**BC:** It was actually my stepmom who first suggested I do the ride as a fundraiser. She had contacts within AFTD to handle the fundraising logistics. I had donated to the Association in the past, but I had wanted to something more meaningful. By tying this ride to my dad's dementia, it gave me a cause for which to ride, and educated my family, friends, and blog readers on the disease and AFTD.

**AFTD:** You were on the road for more than two months. What did you do for lodging/meals?

**BC:** I camped the majority of the trip. I had a tent and sleeping bag with me, so usually I would set up in a town park, behind a church or school, or occasionally in a willing person's backyard. I actually was woken up by the police in a small town in Kansas for camping behind an abandoned house; they ended up being really nice and letting me sleep the rest of the night there, but recommended I notify the local police in the future. So that's generally what I'd do -- ride into a town, find the library, ask for the local police number, and ask if there was a place I could set up camp for the night. One to two days each week would be rest days for my legs, so that's generally when I would stay with family, friends, friends of friends, or use hosting sites like CouchSurfing.org or WarmShowers.org. It was my first time using those sites, but it was amazing experiencing the kindness and hospitality of complete strangers. No hotels, I'm kind of frugal like that.

**AFTD:** What was the hardest part about the trip?

**BC:** A lot of people ask if I was lonely on the trip, but truthfully, with cell phone calling, texting, internet messaging, email and video chat, going off alone on your bike isn't quite what it used to be. The hardest part for me was headwinds -- I didn't realize this when planning my trip, but prevailing winds travel west to east. My direction? East to west. The most intense winds were in Wyoming. It wasn't that they were just physically challenging, but they also had a strong mental effect. Needless to say, it was a great practice in patience; getting frustrated wasn't making me go any faster, so I figured I might as well accept that the wind is as much a part of the terrain as mountains or valleys.

**AFTD:** What was the best part about the trip?

**BC:** Definitely the people I met. I was amazed at how strangers were so gracious to offer me their food, beds and homes. One of my favorite examples is a young couple in middle-of-nowhere Kansas whom I found through CouchSurfing.org. I ended up helping them move the cows from one pasture to another and feeding their goats, geese and chickens (all firsts for me). Then, out of the blue, the woman invited me to her mother's birthday party that night! So I piled in a jeep with the husband and wife and her father, mother, two brothers, one brother's baby son and the other's girlfriend. We went to a small pizza shop, the husband immediately ordered a round of shots, and we spent the rest of the night enjoying each others' company over pizza and Blue Moons. I had become a member of her family for a night. Amazing.



*Brandon Cline, making his way across the United States on his bike.*

**AFTD:** Was it what you expected?


**BC:** For the most part, yes. I expected it to be physically challenging, and it was. I thought it would be a great adventure, and it was. I expected to get lonely, though technology made it easier. I expected to meet amazing people, and I did. What I

didn't expect was the level of kindness I would be shown. I've always felt that people are inherently good, and this trip absolutely supported that feeling.

**AFTD:** Any "lessons learned" for potential trekkers?

**BC:** If you have any interest in it, go for it! Tell everyone that you're going to do it, so they can encourage you to get out there. Plan a route and go! Or don't plan a route, but go! Don't worry about top-of-the-line gear; an old road or mountain bike frame and sturdy wheels will do. Give yourself 2.5 - 3 months. Take your time. Take smaller roads, but not gravel roads. Meet people. Smile. And carry pepper spray for the dogs in Kentucky.

**AFTD:** Did the trip change your reflections or understanding of your dad's disease?

**BC:** The trip didn't change my understanding of my dad's disease as much as it did the magnitude of generosity of AFTD fundraising. Every time I checked the AFTD website, there were new fundraising events hosted by family or friends of a loved one with FTD. Whether it was a breakfast and FTD info session, silent auction, or a marathon, every event opened me to people's passion and creativity in fundraising for AFTD. And the thoughtfulness shown through donations for my own fundraising event revealed to me how generous people are in supporting a worthy cause. 

# THE AFTD - TEAM

## 6th Annual George F. Sidoris Memorial Golf Outing

Siblings Christine and George Sidoris held their 6th Annual George F. Sidoris Memorial Golf Outing on September 3. The event was a great success with 96 golfers, beautiful weather and \$10,000 raised for AFTD. In addition to their loyal friends who support the event each year, the Sidorises had some corporate sponsors as well. Tequila Petron, Breitling Swiss Watch brand, Roberto Coin Italian Jewelry designer, Hyde Park Jewelers and Rolex Watch all donated to the event. The Sidoris event is pictured below.



## Mystery Novel Features FTD

Authors Adrian Eissler and Fred Ward donated 20% of presales from their recently released book, *Felony Dementia*. The novel was sold to 27 people in the AFTD community before its official release on September 23. Adrian's father was affected by FTD.

## Breakfast with Bob: Cooking for a Cure

"Breakfast with Bob: Cooking for a Cure" was hosted by Kathy and Bob Renney in Detroit Lakes, MN on October 2. Bob, an avid cook, is affected with FTD, and his wife Kathy held the event to honor him and his love of cooking. The event drew in 100 people (from a town of 400) and dished up almost \$2,600 for AFTD through donations and 75 silent auction items.



## Robert M. Hatfield Foundation Golf Tournament

On October 13, Matt Hatfield, President of The Robert M. Hatfield Foundation, with the help of family and friends, hosted a golf tournament at the Renaissance Vinoy Golf Club in St. Petersburg, Florida. The Robert M. Hatfield Foundation was created in memory of Matt's father, a lifelong golf enthusiast, who passed away from FTD in October 2010. The event was attended by 45 golfers and raised \$5,250 for AFTD. Matt is pictured to the left, addressing the golfers before the tournament.

## Al McNulty Benefit for Dementia Research

Joel McNulty of Overland, KS, organized the first Al McNulty Benefit for Dementia Research on July 30th at Danny's Bar and Grill in Lexena, KS. Six local bands provided entertainment for supporters who raised almost \$1,000 for AFTD through donations and a silent auction. Joel also engaged his local TV station to do a story about his father, Al, who is affected with FTD.

## Nick Basile Runs Chicago Marathon for AFTD

Nick Basile ran in the Chicago Marathon on Sunday, October 9, in memory of his father, Bill Basile. He finished the race, despite cramps in his legs. Family and friends in custom-made "AFTD/Billy Basile/Chicago Marathon" t-shirts cheered Nick on at miles 4.5, 10.5 and 22. The \$10,255 Nick raised for AFTD will be matched 2:1 by the Alzheimer's Drug Discovery Foundation in support of FTD Drug Discovery.



*Bob and Kathy Renney with their seven hardworking grandchildren.*



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