The Association for
Frontotemporal Dementias
Opening the gateway to help and a cure

Volume VI Issue 2 Summer 2009

Annual Meeting Showcases Year in Review

Patients and caregivers from throughout the Los Angeles area and beyond gathered on June 12, 2009 at the Hyatt Regency Century Plaza, where Helen-Ann Comstock, founder and Chair of the Association for Frontotemporal Dementias welcomed everyone to the annual public meeting. Comstock noted the organization's new tradition of hosting the annual meeting in a different region each year to meet the patients, families and clinicians who comprise AFTD's growing community.

The highlight of the afternoon was a keynote speech given by Mario Mendez, M.D., Ph.D., and Jill Shapira, R.N., Ph.D., who together founded and run the FTD Clinical Center at the UCLA Medical Center. Dr. Mendez provided a brief history of FTD and an overview of the clinical syndromes, diagnosis and treatment. He offered a hopeful view of the potential for new therapeutics currently nearing clinical testing. Dr. Shapira walked the audience through the experience a new family will have as they enter the UCLA clinic with a member who has a possible diagnosis of FTD. She offered valuable advice on the information to bring and the way to get the most benefit from a visit. She also expressed gratitude to the patients and their families, many of whom were in attendance, who have taught the clinicians so much about the disorder and the best way to manage it.

Mario Mendez, M.D., Ph.D., and Jill Shapira, R.N., Ph.D., co-founders and directors of the FTD Clinical Center at the UCLA Medical Center, gave the keynote address.

(See New Initiatives, page 6)

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AFTD Launches Revamped Website

Since 2003 the www.ftd-picks.org address has been a critical front door to the Association for Frontotemporal Dementias, and a gateway to reducing the isolation of confronting a rare disease. AFTD is pleased to announce that a major expansion and remodeling of the website has just been completed.

The revamped site, which retains its familiar address, improves access to accurate information and resources about frontotemporal dementias. The site also offers expanded content for caregivers, patients and health professionals.

The site retains its familiar address, and improves access to accurate information and resources.

"It was six years ago that I was scrambling to put together the first website for our newly founded Association," explained Kent Jamison, founding Board member and member of the website project team. "This new website takes us to a whole new level and better reflects not only how far the Association has come, but the progress that has been made in the whole field of FTD," Jamison added.

In addition to revised medical content and a structure that is easier to navigate, the new site, which was nearly a year in development, includes sections for *Newly Diagnosed*

(See Website, page 6)

Spotlight On.... Susan Eissler, AFTD Board Member

Just 10 years prior to her husband Bill's frontotemporal dementia diagnosis, AFTD Secretary of the Board, **Susan Eissler,** says he was at the top of his game.

"Within a year, it all fell apart," Eissler continues. "I consulted pastors, family physicians, psychologists, psychiatrists, even a neurologist. No one found a problem. It was like being one of a team of horses pulling a load up a hill, and all of a sudden, the other horse sits down and won't get up."

Ultimately, doctors diagnosed him with FTD. A daughter-in-law who was searching the Internet for information found the AFTD website and directed Eissler to it. "I attended the next available AFTD conference and met several Board members," recalls Eissler.

"After Bill was diagnosed with FTD in 2005, it became evident that this problem was widespread in the extended family as well," Eissler says. "Three of Bill's four siblings died or are currently dying from FTD. Bill's mother and two uncles also had FTD at early ages."

"Anyone who has not experienced this illness would wonder why we didn't figure out what was wrong sooner! But that is precisely the tragedy of this disease. An early diagnosis would have prevented much suffering both for the diseased and for their families," says Eissler.

Eissler's husband Bill passed away in 2007. She became an AFTD Board member last year. She serves on the Respite Care Committee, Finance Committee, Advocacy Committee and By-Laws Committee. She also volunteers as a regional representative for the South Central region. In June 2009 she became the Secretary of the Board.

Eissler is a pension actuary, who works from her home near Austin, Texas, where she relocated to be near her three sons, and their wives and eight grandchildren. She hopes to enlist the support of her family and of fellow Texans in the cause of AFTD.

"It is critical that we spread awareness of this illness," Eissler says. "We need more researchers to be interested in finding the cure for this disease and more funding for their research."

AFTD NEWSBRIEFS

AFTD is moving! We are relocating the office to Radnor, Penn., August 10, 2009. The toll free number and e-mail contact information remain the same.

The Association for Frontotemporal Dementias
Radnor Station Bldg. #2, Suite 200
290 King of Prussia Road
Radnor, PA 19087

Upcoming Caregiver Conferences:

- **Northwestern University's FTD and PPA Educational Conference** - August 10, 2009, in Chicago. Tiffany Chow, M.D. will be the keynote speaker.
- **Massachusetts General Hospital FTD Clinic** - Caregiver Education day in Boston, October 2009.
- **Toronto Alzheimer's Society** - Workshop for FTD Family Caregivers, October 1, 2009, 10 a.m. to 2 p.m.
- **New York City** - November 2009.

AFTD offers modest travel grants for caregivers requiring financial assistance to attend a caregiver conference. Contact info@ftd-picks.org

AFTD's **2008 Annual Report** is now available. View it on our website under *About AFTD* or request a print copy.

New local **FTD caregiver support groups** have started in Phoenix and Glen Ellen, Ill. For help starting a new group or to add an existing group to our listing, contact AFTD's office.

There are two opportunities this fall for caregivers to join the **Partnering for Brain Donation** study being conducted by AFTD and Indiana University. Caregiver input is sought to help identify barriers to families participating in brain donation research. Focus groups will be held October, 15, 2009, at Indiana University in Indianapolis and October 28, 2009, at Massachusetts General Hospital in Boston. *Contact AFTD for more information and to register.*

AFTD and the Alzheimer Drug Discovery Foundation (ADDF) have extended their partnership to fund **FTD drug discovery** for a 4th year. Contributions to AFTD for drug discovery will be matched at a 2-1 ratio by ADDF.

Over 200 people attended the bi-annual **University of Pennsylvania FTD Caregiver Conference** in Philadelphia on July 10, 2009. Educational sessions were videotaped and will be available on the AFTD website soon.

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

Help AFTD Meet the Challenge

This summer the Lovett family has made a generous offer: they will match every dollar donated to AFTD 1:1, up to a total of $100,000!! Every dollar will be used to advance research, support our families, educate healthcare professionals and promote awareness. Go to www.ftd-picks.org and click on Donate Now to make a contribution that is worth double the amount you give.

At AFTD a dollar is worth even more in 2009!

AFTD Welcomes New Members to the Board, MAC

At the annual Association for Frontotemporal Dementias Board of Directors meeting in June, the following officers were named: Helen-Ann Comstock, Chair; Beth Walter, Vice Chair; Darlene Ryan, Treasurer; and Susan Eissler, Recording Secretary.

AFTD is pleased to welcome the following new members to its Board of Directors:

Francine Laden, Ph.D.

Francine Laden, Ph.D., is assistant Professor of Environmental Epidemiology, Harvard School of Public Health and Brigham and Women's Hospital, Harvard Medical School. Dr. Laden, who resides in Massachusetts, lost her father to FTD this past winter, and her family has donated generously to AFTD to fund research and a fellowship. Dr. Laden joins the Board with a goal of furthering the research and education portions of AFTD's mission.

Sylvia Mackey, founder of the non-profit Mackey Fund, is a nationally known speaker on behalf of the dementia community. Ms. Mackey lives in Baltimore with her husband, former National Football League player and Hall of Fame member John Mackey, who has FTD. Sylvia joins the Board as a recognized advocacy leader, having been particularly effective in advocating with the NFL for the "88 Plan," which provides coverage for the care needs of former players with dementia.

Zbyslaw J. Petryka, Ph.D., is a retired chemist who graduated from the University of London with a doctorate in organic chemistry. Dr. Petryka dedicated his career to medical and biochemical research. His wife was diagnosed with FTD three years ago. Dr. Petryka, who resides in California, joins the Board with a particular interest in the areas of advocacy and research.

AFTD also welcomes the following individuals to its Medical Advisory Council:

Denis Dickson, M.D.

Denis Dickson, M.D., is a professor in the Department of Pathology at the Mayo Clinic and Mayo Medical School in Rochester, Minnesota. Dr. Dickson received his medical degree in 1982. He has been at the Mayo Clinic since 1992, and is the head of the Pathology Core at the Mayo Clinic's Alzheimer's Disease Center. He has studied the pathology of neurodegenerative diseases for more than two decades.

Karen Duff, Ph.D., is a professor in the Department of Pathology at the Columbia University Medical Center. Dr. Duff joins the Medical Advisory Council (MAC) having focused her research more specifically over the past few years on the pathological markers that are common to a variety of neurodegenerative syndromes, including FTD, ALS

(See Board page 4)

AFTD Office Manager Marty Meyers Retires

As office manager at the Association for Frontotemporal Dementias, Marty Meyers brought a unique understanding of the organization's history. That distinction came in part from being AFTD's first employee.

When she began caring for her mother-in-law in1985, Marty Meyers attended a support group meeting offered by the Philadelphia Geriatric Center. Also in attendance was Helen-Ann Comstock. At the time, Comstock was the executive director of the Southeastern Pennsylvania Chapter of the Alzheimer's Association, now the Delaware Valley Chapter. In need of office help, Comstock hired Meyers. Almost 20 years later when AFTD, founded by Comstock, was in need of help, Meyers became the first employee there, as well.

"I felt so fortunate that Marty was available to work with us," said Comstock, "she knew just what we needed and her dedication has been unparalleled." At AFTD Meyers helped to establish the first donation processing and acknowledgement system at the organization and devoted countless hours, many of them on a volunteer basis. Over the past five years Meyers ensured that AFTD's growing operations ran smoothly and that communication lines among the board, staff, caregivers, donors, and volunteers were always open. She dealt with everyone in a warm and cheerful manner.

AFTD wishes Meyers well in her retirement, which will afford her more time with the family of which she is very proud – three married daughters, seven grandchildren and seven great grandchildren. "The family's gain is our loss," said Susan Dickinson, Executive Director of AFTD. "We will miss her."

NY Medical Centers Form FTD Consortium

Goals Include Maximizing FTD research and Developing a Database of Patients

With three Alzheimer's Disease Centers and many other academic medical centers with research programs in dementia, New York City is a natural site for frontotemporal dementia research. Yet, such research has not been emphasized in the greater New York area – until now.

On May 8, 2009, representatives from the Association for Frontotemporal Dementias were invited to Columbia University to meet with the founding members of the New York Frontotemporal Dementia Consortium (NYFTD). The consortium includes neurologists, psychiatrists, pathologists, geneticists and neuropsychologists with expertise in FTD from Mt. Sinai School of Medicine, Weill Cornell Medical Center, Albert Einstein College of Medicine, New York University Medical Center, SUNY Downstate Medical Center, the Litwin-Zucker Research Center for the Study of Alzheimer's Disease & Memory Disorders at Long Island Jewish Medical Center, and Burke Rehabilitation Hospital.

Pictured (left to right): Richard Mayeux, M.D., M.Sc., Columbia University Medical Center; Helen-Ann Comstock, AFTD Chair; Edward D. Huey, M.D., North Shore-Long Island Jewish Research Institute; Susan Dickinson, AFTD Executive Director; and Jill Goldman, M.S., CGC, Columbia University Medical Center.

The goals of this collaboration are to maximize FTD research and develop a patient database for effective clinical research on FTD and related disorders. Bringing together these diverse groups from each medical center with unique expertise and interests will provide a mechanism for sharing clinical data and biological samples without restricting the type of research or clinical procedures being performed at each institution.

The consortium is in the beginning stages of establishing procedures and approvals for sharing anonymous, common data sets on FTD patients. Once these logistical matters are settled, the group hopes to garner competitive grant funding for significant studies on FTD.

AFTD applauds these investigators' efforts to join forces to advance knowledge of the FTDs and looks forward to facilitating their collaborations.

AFTD Medical Advisory Council, Retiring Members of the Board

(Continued from page 3)

and Parkinson's. Dr. Duff has received the prestigious Potamkin Prize from the American Academy of Neurology.

Walter Kukull, Ph.D., is a professor of Epidemiology at the University of Washington and is the director of the National Alzheimer's Coordination Center (NACC). Established in 1999, the NACC is the data coordinating center for all 30 of the NIA-funded Alzheimer's Centers. The NACC's main purpose is to collect research data from all the centers and ensure its accuracy. Currently there are about 59,000 patients in that database.

Walter Kukull, Ph.D.

Mario Mendez, M.D., PhD, is the director of the University of California, Los Angeles, FTD & Neurobehavioral Clinic and Program, a position he has held since 2001. A behavioral neurologist, Dr. Mendez has many years' experience treating FTD patients. He has published more than 40 articles on the clinical profile and course, diagnosis and treatment of FTD. He was the keynote speaker at the AFTD annual public meeting held in Los Angeles in June.

Mario Mendez, M.D., Ph.D.

AFTD thanks the following members who are retiring from the board of directors for their years of service:

Walter McKee joined the AFTD Board in 2005. During his years as a director he has served on the Governance Subcommittee and on the Caregiver Advisory Committee for the National Institutes of Health-funded study on brain donation. He has devoted a significant amount of time and energy fundraising for AFTD.

George Sidoris joined the AFTD Board in 2007. Despite his very demanding career responsibilities, George and his family have organized yearly golf tournaments to benefit AFTD. In this way they have worked to spread awareness of FTD and the services of AFTD.

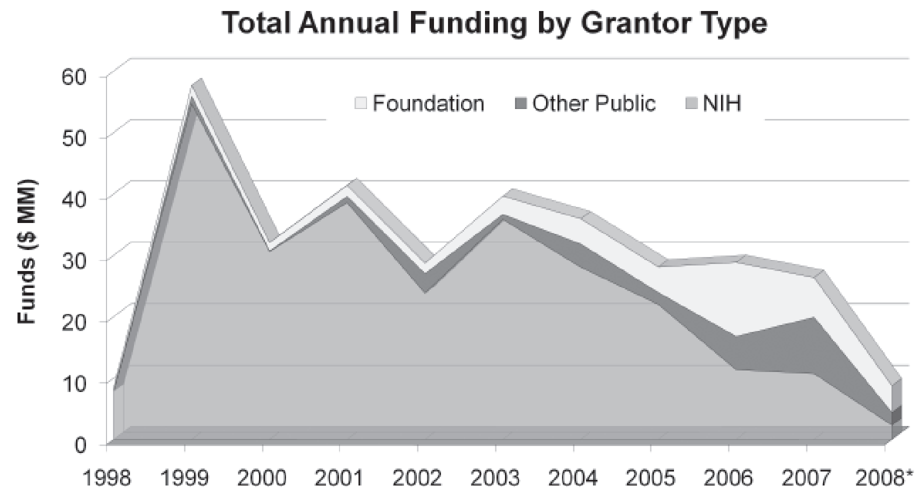
Louise O'Connor joined the AFTD Board in 2007 as its first international member. During her years as a director and co-chair of the Advocacy Committee, she has shown board members how to become more proactive with legislators and has done much to bring about awareness of FTD and the needs of FTD families in Canada. O'Connor helped establish Regional Advocacy Network Coordinators, and did significant fundraising.

‘Strategic Analysis’ to Impact Research and Fundraising

The Association for Frontotemporal Dementias, in partnership with the Alzheimer’s Drug Discovery Foundation, is completing a comprehensive study of international research being conducted on the frontotemporal dementias. *A Strategic Analysis of International Research Funding for the Frontotemporal Dementias 1998-2008* is a first-ever attempt to gather all of the relevant projects and analyze them in a meaningful way to guide strategic research investment moving forward.

Because FTD is actually a cluster of related diseases, research studies relevant to this disorder are fragmented across a number of different programs and involve various medical specialties, making it difficult to get a comprehensive picture of the state of FTD science.

Key findings from the *Strategic Analysis* include: Although the National Institutes of Health (NIH) has provided the majority of funding for FTD research, this amount has decreased five-fold over the past 10 years; the decline in NIH funding has been slightly offset by growing investment from private funders; and the majority of all grants were focused on basic disease research. The document also identifies that during the ten-year period there was only one grant funded to investigate quality-of-care during the end stages of FTD.



The majority of FTD research funding has traditionally originated from the National Institutes of Health; however, funding has declined five-fold from 1999-2007. An increase in foundation support for FTD has not been enough to completely offset the reduction in NIH funding.

“While there are some surprising aspects to the findings, this analysis overall confirms what we knew: There is not enough money being invested in the frontotemporal dementias,” says AFTD Board member and Research Liaison Phil Lovett. “This report will be a powerful tool in our efforts to advocate for more funding for our disease, both with the government and with private funders. It also provides valuable information on which aspects of FTD are already being investigated, and thus where we can most effectively invest our own research dollars.”

The first step in the analysis project entailed gathering grant information from databases and funders around the world. Then, the grants identified were reviewed to confirm that they were relevant to one of the FTDs. (Grants were divided along a continuum of seven stages of research, from basic research to clinical testing of a new drug.) Finally, the data were analyzed on a number of parameters, including clinical disease, molecular target, stage of research, and funding source.

An electronic copy of the Strategic Analysis *will be available on the AFTD website (www.ftd-picks.org) in September..*

FTD Research Consortium Forms in San Francisco

The Consortium for Frontotemporal Dementia Research, a new, well-funded, research consortium, has been formed with the ambitious goal of finding a cure within 10 years for the types of frontotemporal dementias caused by a mutation in the *progranulin* gene.

The Consortium, funded by a generous private donor, partners with The Memory and Aging Center at the University of California, San Francisco (UCSF) and the Gladstone Institute in pursuit of this laudable goal.

The Memory and Aging Center at UCSF, led by Dr. Bruce Miller, a founding member of the Association for Frontotemporal Dementias Medical Advisory Council, is a leader in the field of FTD research. The Gladstone Institute is one of the world’s premier disease-focused basic science organizations, and Gladstone’s new Center for Translational Research creates unprecedented opportunities for the development of powerful new therapies for FTD.

Researchers estimate that about five percent of frontotemporal dementias are caused by a mutation in the *Progranulin* gene. Advances in understanding about this specific form of the disease should also produce valuable insights that will advance the quest for effective therapies in other types of FTD, as well.

The goal is to find a cure within 10 years for types of FTDs caused by a specific gene mutation.

Donations Honor Loved Ones

Gifts received February 1, 2009 – June 2009

In Honor Of:

James S. Abbott
Glenn G. Andrews
Patricia VanderLeest Andrews
Jon Berkley
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James Coleman
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In Memory Of:

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Arthur S. Andrews
Glenn G. Andrews
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Rose Calla
Cindy Cardosi
Jill Clayton
Freida Jean Cleveland
Karen S. Cleveland
Juanita M. Collins
Marc J. Cooper

New Initiatives Take the Stage at Annual Public Meeting

(*Continued from page 1*)

Susan Dickinson, Executive Director of AFTD, reported on the state of the organization. Recent accomplishments include: funding a second round of drug discovery grants, implementation of a caregiver respite grant program, and expansion of the caregiver support group network to 37 groups across the United States and Canada. New initiatives AFTD is currently working on include creating an education module for healthcare professionals and strategic planning for the next three to five years. Attendees were then treated to an inaugural view of AFTD's revamped website (www.ftd-picks.org), presented by Vice Chair Kent Jamison and Program Director Sharon Denny (*see story, page 1*).

Rita and Gene Jackson visit with Kent Jamison at the Annual Meeting.

After the presentations and a question and answer session, most of the attendees joined the AFTD Board of Directors at a dinner reception, where they had an opportunity to engage with each other, the speakers and AFTD Board members from the United States and Canada.

Website Relaunches with New Features and Expanded Information

(*Continued from page 1*)

and *Healthcare Professionals* with content tailored for these audiences. Other features include expanded information on how to participate in research, and tools that encourage people to get involved with AFTD through advocacy, volunteering and fundraising.

The site strives to provide the practical information caregivers need within the context of advancing research and awareness efforts. The *Support and Resources* section has interactive maps for the United States and Canadian Regions that people can click to access contact information for support groups, medical centers and upcoming events within their region. Some parts of the map are quite empty. The graphic is a striking reminder of the need for additional resources; AFTD looks forward to the time when the map is crowded with resources in every state and province.

The *Caregiving Challenges* section houses an array of recommended interventions, tips, resources and caregiver wisdom on topics commonly faced by families caring for someone with FTD. The section also reflects a growing recognition of the need for support to those who are diagnosed with FTD. *Finding Support* lists several programs for patients, and *Sharing our Stories* offers essays by people with FTD.

Launching the site was the culmination of a long planning process coordinated by Catherine Pace-Savitsky, consultant to the project. "We worked hard to make sure that it will be easy to update and expand what is available on the site," said Jamison. "AFTD and the field overall are growing and changing rapidly," he added. "We are ready to lead the way."

Join Us on Facebook!

The Association for Frontotemporal Dementias has started a Facebook group of the same name to tap one of the fastest growing ways to connect people.

AFTD's page will have announcements of events, special initiatives, and photos related to the Association's mission.

Members are invited to post general comments and their experience with the disease on the page; medical questions will be redirected to info@ftd-picks.org., or AFTD's HelpLine at 866-507-7222 .

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

Sharon Cyphers
Mildred L. Daise
Douglas Earl Eastwood
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Sheila Fiermonte
Louise M. Fontaine
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Caregiver Respite Grants

In April 2009 the Association for Frontotemporal Dementias awarded 20 $500 grants to caregivers under its new Respite Care Financial Assistance program spending in just four weeks the $10,000 donation that initiated the program. "The response to the program has really confirmed how difficult it can be for FTD caregivers to afford time for themselves," said Susan Eissler, Chair of the Caregiver Respite Committee, "The need for respite far exceeds the resources available."

> "I feel so blessed to receive such kindness from strangers at this time of great need. I often feel helpless, hopeless and overwhelmed in dealing with the nightmare! This financial support gives me some faith that I am not alone, and gives me some respite to care for myself so I can be there for my children and the father of my children."
>
> - Cindy, cares for 53-year-old husband and their children.

Seven more grants funded by additional donations designated for caregiver respite were awarded in early June; 25 applications wait funding.

The constant physical and emotional demands of caregiving can be overwhelming. The use of respite has been shown to reduce caregiver stress which can make the experience of caring for a loved one more positive and may help enable the person with FTD to remain home longer.

Recipients of AFTD caregiver grants decide how best to use them based on their particular situations. People may purchase short-term in-home care to free themselves for errands, full-time coverage for a weekend away, or arrange for their loved one's participation in a day program. "I can see what this care has been able to provide very clearly," said one grant recipient, "an opportunity to glimpse at a former life that did not entail anxiety and worry – even if only for a few hours a week."

> "The AFTD grant allowed me to attend my sister's 60th birthday… I can't tell you how good it felt. I had four days of just taking care of myself. I slept in all four days. I talked and talked to my family…. This four day respite rebuilt something inside of me. It brightened my spirits. I felt light hearted and free. It enabled me to carry on as a caregiver for my husband with refreshed determination."
>
> - Kris, caregiver for 62-year-old husband

AFTD is committed to continuing the caregiver grants and will make additional awards as funding permits. To be eligible the caregiver and the person with FTD must reside together, be residents of the United States or Canada, and not be receiving respite services through Medicaid. A brief application form and documentation of diagnosis are required. Contact AFTD Program Director Sharon Denny at info@ftd-picks.org for more information.

Help caregivers get the respite they need! Make a designated donation to AFTD for "Caregiver Respite." Every dollar will go directly and entirely to providing financial assistance to families for respite care.

Burdening Care:
A study on informal caregivers of frontotemporal dementia patients

By Samantha Riedijk, Ph.D.

Erasmus Medical Centre, Rotterdam, The Netherlands

In their search for disease causing genes, researchers of the Erasmus MC were struck by the clinical picture of FTD. The behavior of the patient was most painful to caregivers, especially during the period when the (right) diagnosis was yet to be made. Caregivers and the social environment of the patient had great difficulty understanding the problematic behavior of the patient. Support programs for dementia caregivers did exist; however, these were focused on older caregivers of Alzheimer's Disease patients. Not surprisingly, the FTD caregivers indicated they could not find the support they needed. We realized this specific group of FTD caregivers needed more attention and initiated this study.

We started our research into the burden of FTD caregivers in order to investigate how these caregivers were keeping up, and to generate recommendations regarding how to best support them. Caregiver burden refers to the strain caregiving exerts on the psychological, physical, financial and spiritual well-being of the caregiver. A total of 63 FTD patients and their caregivers participated in our two-year follow-up study.

■ Support after institutionalization

Of the FTD patients included in our study, 34 were living in a nursing home at the start of our study and 29 were living and cared for in their home. Strikingly, both groups of caregivers reported similar caregiver burden. A possible explanation may be that despite the fact that caregivers had fewer tasks; they continued to worry over the patients. In the Netherlands, some nursing homes offer group sessions to caregivers guided by a trained psychologist. Our findings underscore the need of such provisions.

■ Coping

A caregiver may employ a variety of strategies in coping with the caregiving situation. Remarkably, nearly all caregivers tended to increase their depressive reaction pattern during the two years we followed them. This pattern implies caregivers felt more pessimistic about the future and unable to influence the hopelessness of their situation. Furthermore, caregivers reported increased emotional expression of negative emotions such as anger and frustration. Simultaneously, caregivers reported an increase in negative, non-supportive social interactions. It would thus seem that these coping strategies may damage potentially supportive relationships. We suggest professionals assess the coping strategies the caregiver employs and aid the caregiver in coping more adequately if necessary.

■ Caregiver motivation

In an in-depth interview we asked caregivers what motives they had for providing such intense care. Most caregivers indicated they provided care because they felt this was their marital duty. The second most stated motivation was the love the caregiver felt for the patient. Some caregivers indicated that it was in their nature to provide care and others revealed that it was only by seeking enough distraction they were able to provide care.

■ Adaptability

We followed the FTD caregivers and patients during a period of two years, during which most of the FTD patients reached the end-stage of the disease. However, FTD caregivers reported stable levels of psychological, physical well-being and the quality of their relationship, and physical health complaints had even decreased somewhat. We suspect the 'response shift' phenomenon may explain the stable report of well-being and relationship quality. Response shift implies that people adapt to the hardships in life by resetting their internal standards. Instead of valuing a career and health, a caregiver may now experience quality of life from small things such as a beautiful sunset or unexpected phone call from a friend. From these findings we may protract a hopeful message to caregivers at the beginning of their caregiving career, which is that in time they will find ways to experience quality of life and satisfaction from their relationship in spite of FTD.

■ Balance

Finally, we discovered that the FTD caregivers who were inclined to sacrifice themselves in their caregiving role were those who had most psychological problems and least quality of life. We expect that short psycho-educative sessions for the caregiver on selfcare; what it implies and how to do it, and paying attention to the barriers a caregiver may experience in accepting support, may improve the balance between caring for the patient and caring for the self.

■ Unprocessed grief

There may be other barriers withholding FTD caregivers from providing good care to themselves. Many caregivers experience inner conflict when they mourn a loved one who is still alive. For psychological and physical well-being it is important to grieve along the way. Health care professionals may contribute by providing psycho-education on grieving and actively offering grief counseling.

■ Conclusions and recommendations

A number of issues warrant special attention in supporting FTD caregivers. First of all, an assessment of the caregiver's coping strategies should be made. Second, it should be explored whether the caregiver is maintaining a balance in caring for the patient and caring for himself. Third, we recommend addressing the processing of grief as an inherent aspect of losing a loved one to dementia.

Dr. Samantha Riedijk is a medical psychologist at the clinical genetics department of the Erasmus Medical Centre. She lives with her husband and two children in a Rotterdam suburb.

One Caregiver's Approach: *The Mutual Benefits of a Structured Day*

Eleanor and Richard Vaughan had retired early to travel, spend time with their grandchildren and expand their volunteering in the community. Those plans took a drastic turn when Richard's behavior became increasingly peculiar and it was clear something was wrong. He started to do strange things, such as remove all the clothes from his closet and put them in the refrigerator. He put mail into the oven. Normally easygoing, Richard became much more easily agitated and quick to anger.

Richard was diagnosed with frontotemporal dementia in 2006. Eleanor researched and read voraciously to learn as much as possible about FTD, what to expect, and how to care for her husband.

Three messages resonated that Eleanor used as she designed an approach to caregiving that aims to maximize her husband's abilities and make her experience more positive: plan for success; old memories are the strongest; and structure is important.

First, Eleanor took stock of the people, places, and activities that Richard had valued most throughout his life. Recording these memories and experiences helped her capture who Richard is at his core. She then identified six initiators of action, those fundamental needs that motivate us and direct our actions: spiritual, emotional, physical, nutritional, intellectual, and social. She then worked with Richard to plan activities in each of these areas into each day to ensure his quality of life as the FTD progressed.

Eleanor and Richard have planned activities from each of the six areas into a detailed daily curriculum. Each day is scheduled from 6:30 a.m. to 10 p.m. for both of them. There is room for flexibility, but Eleanor notices that Richard's behavior is more consistent when they adhere to the routine. The neurologist told the Vaughans when he presented the diagnosis of FTD, "from this day forward, your life will be different. You can do anything you have done before or have wanted to do, but will do it differently." This principle and the need to adapt to changing abilities guide everything they do. Eleanor and Richard review the curriculum every two months and make changes.

Eleanor Vaughan devleoped a curriculum to structure her caregiving for her husband Richard.

This approach is described in more detail on AFTD's website in the Caregiving Challenges *section. For further information Eleanor Vaughan can be contacted via e-mail at richard.vaughan@comcast.net.*

Curriculum May Offer Structure and Satisfaction for Caregiver and Patient

Anecdotal evidence from caregivers and physicians indicate that having a planned structure is very helpful for FTD patients who have trouble with apathy and initiation. It allows them to remain more engaged because they don't have to make decisions about what to do. People with disinhibited behavior tend to benefit from greater activity because problem behaviors are worse when people are bored. The physical activity can also help people with sleep disturbances because they are more naturally tired at night.

Key Principles of Eleanor Vaughan's Approach

- *It is holistic* - activities from all six areas – spiritual, emotional, physical, nutritional, intellectual and social – are incorporated into each day.
- *Activities are highly individualized* - the curriculum uses personal strengths and interests from the past to inform his activities today.
- *Activities are matched to changing abilities* - activities are adapted to utilize remaining strengths, minimize frustration, and maximize success.
- *High level of involvement* - active caregiver participation contributes to the curriculum's effectiveness; it helps the person with FTD stay engaged and provides continuity across settings and transitions.
- *Consistency and familiarity* - deviating from the plan for a day or two may be necessary, but it is important to return to it the next day. The routine makes it easier to engage the person diagnosed and provides reassurance to caregiver.
- *Positive attitude* - finding hope and remaining positive in the face of such a devastating illness can be difficult. There are many ways that caregivers can positively affect life day to day and make the most of each moment.

People enter the role of FTD caregiver at many different points in the development of symptoms, and have different presenting issues with which to contend. The basic elements of this approach, however, may be helpful for caregivers in a variety of situations. Day programs can be an important element in the overall daily structure and a home-based curriculum for evening/weekend hours may benefit both the person with FTD and the caregiver.

Latin America:

Argentina Has Clinic Specifically for FTD Patients and Families

The following interview is with the founder and director of the Institute of Cognitive and Behavioral Neurology (INECO), Facundo Francisco Manes, M.D. Located in Argentina, INECO includes the first clinic and program in Latin America created specifically for FTD patients and their families.

What is the mission of INECO?

We founded INECO back in late 2005 as a way to provide a comprehensive approach to investigating cognitive and behavioral disorders in a country where psychiatry and neurology were pretty much two separate entities.

As an institution that employs neurologists, psychiatrists, psychologists, speech pathologists, occupational therapists, and music therapists, our goal is to enhance medical treatment and investigation of cognitive and behavioral disorders by generating a space for multidisciplinary approach of major issues in the field. We also provide training and educational support for these professionals.

We hope to support patients, their families, caregivers and the community in the education, information, orientation and access to available services.

In Argentina is there typically specialized care, or a protocol for caring for people with FTD?

FTD care in Argentina is not specific. At INECO, however, we founded an FTD clinic which involves diagnosis, treatment and research in the hopes of providing more relevant treatment and care for our patients. The treatment program for FTD is designed so that patients work with a focus on their main deficits (either behavioral or language), and supplement such core treatment with other therapies aimed at maintaining patient independence, as well as delaying the progression of symptoms.

Facundo Manes, M.D.

Founder and Director of INECO

What supports are available to FTD caregivers in Argentina?

There is little to no support for FTD caregivers in the community, so INECO has designed a specific program to address their needs. We offer a series of lectures for caregivers and health professionals to raise awareness about FTD. We provide free biweekly talks by specialists of different areas that target caregivers and relatives of FTD patients, generating a space where they can ask questions and get information on treatment options and prognosis of their beloved's disease. We have a webpage which to my knowledge has the most comprehensive information in Spanish for this condition on the Web: http://www.neurologiacognitiva.org.

What do you think have been the greatest advances in FTD care in the last decade?

Internationally, we are making important progress towards a comprehensive understanding of how different biological changes can bring about different symptoms within the spectrum of FTD. Research over the past ten years has allowed for a better understanding of FTD as an umbrella of multiple disorders and this is essential in our understanding of treatment options and prognosis. In Argentina (and other countries in Latin America) our work through talks to professionals and communities and articles in mass media has allowed us to raise awareness of this condition and help many families and patients to get the right diagnosis.

What is the greatest challenge facing the medical professionals who care for those with FTD and their caregivers?

We still have a lot of work to do. Primarily, we must be able to comprehensively define what FTD is, and what it is not. Many psychiatric conditions can mimic the symptoms of behavioral-variant FTD. Differential diagnosis is not always easy; yet it is crucial in order to help the family with medical, legal and economic issues. Our biggest challenges for the near future are to be able to fully characterize the symptomatic profile of the different subtypes of FTD and the progression of the disease, and to find a pharmacological treatment.

Regional Advocacy Network

The Association for Frontotemporal Dementias Regional Advocacy Network took a big leap forward this spring with nine volunteers accepting positions as Regional Coordinators. These leaders began to work with AFTD staff and Advocacy Committee members to engage more people in three specific efforts: *awareness, advocacy and resource development.*

Because FTD is a relatively rare disease, it is a challenge to gain the attention of policy makers and funders so they come to understand the needs of those affected and implement change. Through the Network, AFTD will engage, organize and support people ready to speak up for those with FTD and their families. The United States and Canada are each divided into seven geographic regions that are represented by a Regional Coordinator. The Coordinators are all current or former caregivers who bring a passion for change and a wealth of experience and skills to their positions.

Coordinators have been identified for all but the U.S. Pacific Northwest region; in Canada four regions need coordinators: Quebec, Maritime Provinces, Newfoundland/ Labrador and The Territories. Anyone interested in learning more about volunteering for one of these regions should contact the AFTD office.

Tell 10 People Events Honor Family and Support AFTD

May is Marathon Month!

Four runners pushed through the finish line to honor loved ones and raise funds, for which AFTD is very grateful:

On May 3, 2009, **Jennifer Iannotti and her brother Christopher** ran the Long Island Marathon for the third year in a row in memory of their grandfather Joseph Lotito who died of FTD three years ago. This year their run contributed more than $500 to our mission.

Nicole Geenway conquered the Marine Corp Historic Half-Marathon in Virginia on May 17, 2009, and surprised herself by raising more than $2000. Her mother, Sheila Fiermonte, died less than one year ago from FTD.

Stacy Peterson's mother Susan Deutschman was diagnosed with FTD six years ago. She ran the Los Angeles Marathon on May 24, 2009, to honor her mom, show support for her family, and help make a difference. Stacy raised more than $600 for AFTD.

Stacey Peterson celebrates with her mom and children after completing her first marathon.

Walter Golf Tournament

The Walter Charitable Fund sponsored its Second Annual *Quest for the Cure Golf Tournament* on May 4, 2009, at the Morgan Creek Country Club in Roseville, Calif. The tournament honors the memory of five Walter family members who have died from FTD-Picks. The Fund presented AFTD with a check in the amount of $25,000 at its annual meeting in Los Angeles in June *(see page 1)*.

"The spirit was just great," said Beth Walter, President of the Walter Charitable Fund and AFTD Vice Chair. "The tournament program, *Faces of FTD,* was a huge success," she added, referring to a brochure given to each golfer that featured first person stories and photos of FTD families.

AFTD is so grateful to the Walter family, and all those who have helped establish this wonderful annual event by their participation.

Next year's tournament is being planned for the last week of April 2010.

Coming this Fall

Jodee Kalmen, AFTD's Southwest Regional Advocacy Network Coordinator and a friend are planning an exciting fundraiser in Los Angeles this fall. Two performances of *Follow Your Dreams* at The Theater Playhouse will support AFTD. *Watch the website for more details.*

Walter Charitable Fund representatives present a $25,000 check to AFTD.

Sharing a Golden Moment

Jim and Elsie Rodgers celebrated their 50th wedding anniversary on July 4, 2009 and AFTD was pleased to be part of the event. Elsie was diagnosed with FTD/Picks six years ago. They decided to invite family and friends to celebrate with them by considering a donation to AFTD. "It would be an honour," Jim wrote in his card, "to know you are not only joining our celebration, but also helping others with this disease too."

Jim sent out over 60 cards featuring their wedding picture and the invitation to support AFTD. He included contribution envelopes and put the "golden rings" postage stamps on them to "entice the receiver to mail it back." Jim sent his appeal to family members, friends here and in England, and even his Congressmen and local Representatives.

His efforts have already raised more than $500 for AFTD and were featured in the "Celebrations Spotlight" of the Pittsburgh Post-Gazette. *See www.ftd-picks.org/FTD in the News for the Rodgers' story.*

Seizing an Opportunity for Awareness

The answer to a question posted on March 12, 2009, on CNN's *Paging Dr. Gupta* website missed an opportunity to increase understanding of FTD and distinguish it from Alzheimer's disease. AFTD Executive Director Susan Dickinson immediately posted a response and began working to create an opportunity for greater awareness. A message from Advocacy Committee Co-chair Bill Brown to the AFTD Facebook page prompted an additional burst of responses, describing the personal cost of FTD not being better recognized or understood.

The response from the FTD community was strong and propelled the Association to further action. Additional follow-up has led to AFTD developing new relationships at CNN that may offer more opportunities in the future. We are very grateful to everyone who responded: those who first alerted AFTD, posted a comment, joined our Facebook page, or volunteered to get more involved in future advocacy. You know the critical need to raise awareness about FTD. To read the full sequence of postings related to Dr. Sanjay Gupta's blog visit CNN's website at: http://pagingdrgupta.blogs.cnn.com/2009/03/12/understanding-frontal-lobe-dementia/

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