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

Volume VII, Issue 2 Summer 2010

# AFTD Founder Completes Term as Chair of Board

Helen-Ann Comstock, left, completes her term as chair of the Board of Directors. Beth Walter continues the Association's mission as chair.

> *I have tremendous confidence in the team that will move us on our way to greater achievements.*
>
> Helen-Ann Comstock

When Helen-Ann Comstock's husband, Craig, was diagnosed in 1978 with Pick's disease, he was just 44 and in the prime of his life. Seven years later, the respected mathematics professor, researcher, husband, and father was gone.

Left feeling isolated because of a disease few people had heard of let alone understood, Comstock was prompted to act, and her action turned into advocacy. She became executive director of an Alzheimer's Association chapter and started an FTD support group. She served as chair of the Pennsylvania Council on Aging and on the boards of the Philadelphia Corporation for Aging and the Center for Advocacy for the Rights and Interests of the Elderly. She organized the 1999 Conference on Pick's Disease and FTD and, in 2000, the FTD Consensus Criteria Conference.

Convinced of the need for an organization dedicated specifically to improving the lives of families coping with FTD and to advancing research into treatment and a cure, Comstock founded the Association for Frontotemporal Dementias in November

*(See Founder Completes Term, page 4)*

## Inside This Issue

## International Conference Set for October Join Us in Indianapolis!

The 7th International Conference on Frontotemporal Dementias, which is scheduled for October 6-8 in Indianapolis, will convene researchers from around the world to discuss emerging discoveries in the science and medicine of FTD. The first day will also feature a program for caregivers on FTD diagnosis, medical management, legal and financial issues, and support services. At the end of the first day, a dinner, sponsored by the Association for Frontotemporal Dementias at the Eiteljorg Museum, will enable families to mingle informally with each other and researchers.

"The International Conference on Frontotemporal Dementias provides a wonderful opportunity for family caregivers to meet with FTD leaders from all over the world," says AFTD Executive Director Susan Dickinson. "Prominent scientists and caregivers have designed a conference that will provide information on the latest developments in FTD, as well as discussion on emerging scientific discoveries."

For more information on the conference or to register, go to www.ftd2010.org or call 317-274-2106. Registration fees for the conference are purposely kept low for family caregivers; travel grants are available through AFTD. For more information about travel grants, e-mail info@ftd-picks.org or call 866-507-7222.

## Spotlight On.... Francine Laden, AFTD Board of Directors Vice Chair

Francine Laden, Sc.D.

The questions posed by Francine Laden's son, Ari, at first concerning his grandfather's deteriorating condition and then his death, would often give her pause.

"One thing that struck me from the beginning, when my son first started asking," Laden explains, "was that he really wanted to understand why this had happened. He would ask, 'Why didn't we take him to a scientist? Why aren't the scientists working to figure this out?'"

Ari, now 7, was only one and a half when Ben E. Laden was diagnosed with frontotemporal dementia. Francine's daughter, Sydney, now 4, wasn't even born. Mr. Laden passed away in 2009.

"My children were really too young to understand the illness, but they certainly experienced its effects."

Laden, who lives in Boston with her husband, Allan Heff, and their children, is an associate professor of environmental epidemiology at the Harvard School of Public Health and Brigham and Women's Hospital at Harvard Medical School. There, she focuses primarily on environmental causes of chronic diseases.

In her private life, Laden devotes a significant amount of time to furthering research about FTD through her involvement with the Association for Frontotemporal Dementias. She was recently appointed vice chair of its Board of Directors.

Laden first became acquainted with the Association a few years after her father was diagnosed. An Internet search led her and her family to AFTD, and the relationship grew from there. The family made a significant contribution to AFTD in 2007.

"My family had money we wanted to donate in a way that would be meaningful to us," she explains. "We were impressed by the work AFTD was doing and the fact that our contribution could make a big difference." Laden credits AFTD with helping the family – herself, mother Susan and brothers Jonathan and Paul – form a plan as to how to direct the funds. "We decided to start a two-year fellowship program to get young researchers committed to studying FTD. Although there is a need for funding in many areas, our family is most interested in research targeted on understanding causes of FTD in order to prevent it in the first place," she says.

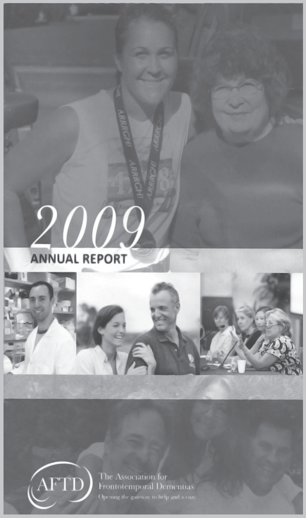
In addition to her vice chair duties, Laden is liaison to the board's Medical Advisory Council and serves as a member of the board's research committee. She is also active in promoting and explaining brain donation. Speaking from personal experience, Laden says, "Brain donation can be very difficult both procedurally and emotionally. But the study of the tissue is very important to gaining knowledge about FTD – for both families and researchers."

## AFTD NEWS BRIEFS

**AFTD has moved up** – from a second-floor to larger third-floor office. We are now in Suite 320.

**The search for FTD-specific biomarkers** is the focus of the AFTD/ADDF 2010 Drug Discovery Request for Proposals, which are due by September 9. For more information, go to *Research* and then *AFTD Research Initiatives* at www.ftd-picks.org.

**New information on hospice and facility care options** for people diagnosed with FTD is available online at www.ftd-picks.org. Go to *Support & Resources* and then *Managing Health Care.* Materials from the May 21 Fort Worth FTD Caregiver Conference are also available. Go to *Support & Resources* and then *Past Caregiver Resources.*



To read the **2009 AFTD Annual Report** go to *About Us* and then *Annual Reports* at www.ftd-picks.org or call 267-514-7221 to receive it by mail.

**Las Vegas is home to our newest caregiver support group**, our first in Nevada. The group, which plans to start meeting in August 2010, will be led by Lisa Radin, an AFTD founding board member and co-editor of *What If It's Not Alzheimer's? A Caregiver's Guide to Dementia.* For details, e-mail lradin@iglide.net or call AFTD toll-free at 866-507-7222.

**Maryland and Texas** now offer two new caregiver support groups, which started in April. The Kensington, Md., group in the metropolitan Washington, D.C. area meets the last Monday of each month from 6:30 to 7:30 p.m. For details, e-mail Elaine Rose at errose36@gmail.com or call AFTD.

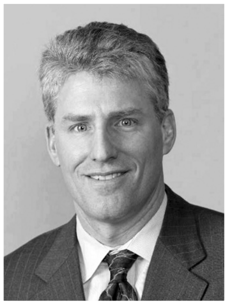
The Bellaire, Texas, group in the Houston area meets the second Thursday of each month from 6:30 to 8 p.m. For details, contact Angela Kimble at angelakimble@hotmail.com or 713-851-9943; or Chris Ward at cward@kingwoodcable.com or 713-253-5936.

# AFTD Welcomes New Members to Board, MAC

At the annual meeting in May of the Board of Directors of the Association for Frontotemporal Dementias, the following officers were named:

**Beth Walter,** chair; **Francine Laden, Sc.D.,** vice chair; **Darlene Ryan,** treasurer; and **Susan Eissler,** recording secretary.

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



**Earl Comstock,** of Washington, D.C., has a law degree from George Mason University. He worked as a legislative director prior to joining a law firm in D.C.

He continues to work in Washington where he started his own consulting business. Comstock is the son of Helen-Ann Comstock, the founder of AFTD. He is particularly interested in advocacy and public policy issues.

**Bryan Dalesandro,** of Wynnewood, Pa., is a client relationship manager at CMS Companies, a financial services firm just outside of Philadelphia. A CERTIFIED FINANCIAL PLANNER™ professional and Chartered Financial Consultant®, Dalesandro is especially interested in AFTD fund development and finance. His mother has been diagnosed with corticobasal degeneration.

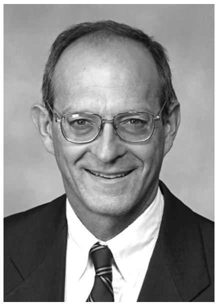
**Jary Larsen, Ph.D.,** of San Francisco, is a research psychologist at the East Bay Institute for Research and Education. In addition to his professional interest in FTD research, he is committed to research on a personal level. He has a brother who has FTD.

**Emily Levy,** of Brookline, Mass., is a principal at Synergy Partners, a biotech consulting company. Levy cofounded the first support group for caregivers in the Boston area and organized the first FTD Caregiver Education Day in New England. She is part of Team Alice, a group that organized to help a friend diagnosed in 2007 with FTD. Levy is particularly interested in caregiver issues, research, and fund development.

***AFTD also welcomes the following physicians to its Medical Advisory Council:***

**Bradford C. Dickerson, M.D.,** is a neurologist and founding director of the Massachusetts General Hospital FTD Unit. Dr. Dickerson is committed to the inter-disciplinary clinical care of patients with FTD and related disorders.

As a scientist, he is also working on identifying imaging and behavioral measures that can be used for earlier, more confident diagnosis, as well as monitoring for change over time. One purpose of his research is to determine whether treatments under development can slow disease progression.



**David Knopman, M.D.,** is professor of neurology at the Mayo Clinic, Rochester, Minn., and the Mayo Clinic College of Medicine. He is also consultant in neurology at the Mayo Clinic and a co-investigator in the Mayo Alzheimer's Disease Research Center. His research and clinical interests focus on dementing illnesses. Dr. Knopman has authored more than 200 articles on various topics in dementia and was named deputy editor of *Neurology* in October 2009. He has been involved in FTD research since 1988.

**Ian R.A. Mackenzie, M.D.,** is professor of pathology and laboratory medicine at the University of British Columbia, Vancouver, consultant neuropathologist of Vancouver Acute and British Columbia Cancer Agency, and head of Vancouver Acute's neuropathology division. Dr. Mackenzie has broad expertise in neuropathology and the use of brain tissue banks in the care of patients with neurological disorders.

His research program centers on neuropathology and the molecular genetics of neurodegenerative disease. He is the Canadian representative to the International Society of Neuropathology and an editorial board member for several neuropathology journals.

AFTD gratefully acknowledges those founding members of the Board of Directors who, like founder Helen-Ann Comstock, recently completed terms on the board. A listing of those members appears on page 6.

## 2010 RESPITE GRANTS AVAILABLE

**AFTD expects to award 60 respite grants in 2010.**

### ELIGIBILITY

To be eligible, a primary unpaid caregiver must not receive respite services through Medicaid. Also, they must live in the United States or Canada with a patient diagnosed with an FTLD disorder.

People may apply for one $500 grant during each calendar year; those who received a grant in 2009 and are still eligible may apply again.

### APPLYING

A completed application form and documentation of diagnosis are required. Respite services should be used within six months of award approval.

For more information and an application, visit www.ftd-picks.org and click on the *Day Programs and Respite* tab under *Finding Support*, e-mail info@ftd-picks.org or call toll-free 866-507-7222.

> It is pretty amazing to me how just one entire day of not being a full-time caregiver can help make the other days less difficult.
>
> *Lorene Schlie, Illinois*
> *Grant Recipient*

# Program Named for AFTD Founder

The AFTD respite care financial assistance program has been named the Comstock Caregiver Respite Program in honor of Helen-Ann Comstock, AFTD founder.

"Since Helen-Ann began her journey as a caregiver for her husband, Craig, it seems fundamentally appropriate to use her name to commemorate a program that provides other caregivers with some relief in their journey with FTD," says Beth Walter, AFTD board chair.

The respite program, which provides grants to full-time, primary caregivers, was started in 2009 with an initial donation of $10,000. Additional donations and an allocation by the board enabled AFTD to award $30,000 in grants to 60 caregivers by the year's end.

Through the respite program, caregivers arrange short-term care for their loved ones so that caregivers can take a break from the constant emotional and physical demands of caring for someone with FTD.

Last year, some recipients applied funds toward costs of day programs. Others brought care into their homes so they could run errands or dine with friends. Still others arranged overnight care for their loved ones at home or in respite facilities, while they traveled to weddings and other celebrations. In the case of a woman caring for her mother, the grant facilitated a vacation at a nearby destination with her husband. Still another primary caregiver was able to take a break after carefully arranging travel plans for her husband, who has FTD. While he visited with family members he had not seen in several years, she stayed at home and had a break from her regular caregiver duties.

"This has been an absolutely wonderful program," Helen-Ann Comstock says. "I am very proud that it will carry the Comstock name.

"AFTD is only as strong as the people who join with us, and encouraging respite is a great way to help caregivers maintain the strength they need in a most difficult role," she says.

*Help caregivers receive the respite they need. Make a donation to AFTD designated for the Comstock Caregiver Respite Program. Each and every dollar provides financial assistance for respite for FTD caregivers.*

# Founder Completes Board of Directors Term

*(Continued from page 1)*

2002. "At the time, there was very little information about FTD and very little money funding research," she says.

Today, just eight years later, AFTD is overseen by a 14-member board, all current or former caregivers. It is guided by a 24-member Medical Advisory Council made up of physicians, clinicians and researchers from leading academic healthcare centers. It has gone from a volunteer-run nonprofit to a professional organization with a staff of five. It has a budget of nearly $1 million and has awarded over $800,000 in research grants. AFTD also has created and funded a two-year postdoctoral fellowship and entered into a partnership that has awarded the first grants ever in FTD drug discovery. In addition, it funds a respite program for caregivers, bolsters a network of caregiver support groups and responds to over 1,000 Help-Line inquiries each year.

In May, at the annual AFTD board meeting, Comstock completed her term as chair. She was succeeded by Beth Walter who, like Comstock, lost her husband to FTD.

"Together we have accomplished much. But there is so much more to do. I have tremendous confidence in the team that will move us on our way to greater achievements," Comstock says.

"I am honored and humbled to follow Helen-Ann as chair," Walter says. "She is a remarkable woman."

# Danis Family Challenge: Help Fund Biomarker Research

## Gifts will be matched 3:1 and increase the total funds to be awarded to $460,000

Lee and Susan Danis celebrated their 40th wedding anniversary on June 20 at the assisted living facility in Texas where Susan now lives. Lee, who after all those years of marriage still refers to Susan as "my sweetheart," has issued a challenge to other donors to help speed the path to FTD drug discovery by matching his gift of $40,000.

Susan Danis was diagnosed last summer with primary progressive aphasia. "My motivation for this gift is love for her and concern for my two daughters who, without a cure, might have to fight this disease themselves," Lee Danis says. "I am losing my wife to this terrible disease. My hope is that some of my friends will also give in her honor."

### ■ Initial Gift Could Triple in Size

Once the full $80,000 is in hand, the Alzheimer's Drug Discovery Foundation (ADDF), AFTD's drug discovery partner, has generously agreed to match that total dollar for dollar with an additional $80,000 from their coffers.

The Danis gift, its challenge and the match will add an additional $160,000 to the amount being awarded for the development of FTD biomarkers.

"This generous gift is a tremendous boost for our research efforts," says Beth Walter, AFTD board chair. "We are so grateful to Mr. Danis and to ADDF, and urge new donors to help us meet this challenge so their dollars can have maximum impact for our patients."

> *My motivation for this gift is love for her and concern for my two daughters who, without a cure, might have to fight this disease themselves.*
>
> *Lee Danis*

### ■ Can Finding FTD Biomarkers Help?

A biomarker, which is short for biological marker, is anything that can be measured to indicate the biological status of an organism. In practice, a biomarker is usually a protein or other substance that can be measured in the blood or cerebrospinal fluid, or it can be a compound that attaches to a specific protein in the brain that "lights up" on imaging, such as a PET scan. Examples of biomarkers include cholesterol or blood pressure to assess cardiovascular health.

Biomarkers can be used to determine the protein that is causing disease, and thus provide an accurate diagnosis. They can identify disease in the early stages, before symptoms become evident. They can track progression of disease, determine which patients qualify for clinical trials, demonstrate drug-target interaction in the brain, and measure effect of a drug on disease progression.

### ■ Seeking FTD Biomarker Researchers

"Currently there are no reliable biomarkers for FTD," says AFTD Executive Director Susan Dickinson. "But it is clear that success in all aspects of our clinical mission hinges upon their development." This is why the current Drug Discovery Request For Proposals issued by AFTD and ADDF calls for applications related to FTD biomarkers. Initial funding dedicated to the program was $300,000; with realization of the Danis challenge the amount available for award will increase to $460,000.

"Anything to do with my wife, Susan, has always been, and will always be, the highest priority in my life," Mr. Danis says. "I try not to dwell on how things are now. Instead, I think of how blessed I am to have had 40 years with this incredible woman."

*To make a contribution to the biomarker challenge and have your donation matched 3:1, please go to www.ftd-picks.org or call AFTD.*

## Year 3 FTD Drug Discovery Awards

The Association for Frontotemporal Dementias and the Alzheimer's Drug Discovery Foundation (ADDF) announced the Year Three awards of the FTD Drug Discovery Program in mid-February. Receiving $100,000 each, the grantees are: Philip Van Damme, M.D., Ph.D., VIB, Leuven University; Einar M. Sigurdsson, Ph.D., New York University School of Medicine; and W. Haung Yu, Ph.D., Taub Institute - Columbia University.

The goal of the AFTD/ADDF partnership is to accelerate the development of novel therapies for the frontotemporal dementias. The program is based on an initial three-year agreement under which AFTD provided $100,000 each year and ADDF provided $200,000 each year to fund the program. The program has been extended to a fourth year that is focused on the quest for biomarkers.

***More information about the awards and a summary of each project are available online under Research at www.ftd-picks.org.***

# Donations Honor Loved Ones *Gifts received March 2, 2010 – June 30, 2010*

**In Honor Of**
James S. Abbott
Leigh Ann Alexander's Birthday
Sharon Heidingsfelder Ammann
Michael J. Angello
Bill Anketell
Marcelo Bailliet
Donna Barraclough
Edgar E. Barton
Ginny Beadell
Jon Berkley
Sandra Bishop
Michael C. Brandt
Janine Briggs
Daniel S. Capalia
Larry Cline
James Coleman
Garth Collins
Susan Croll
Susan Danis
Wilfred Denise
Axel Dikkers
Shanique Ebanks
Gail Edwards
George Edwards
Janice P. Ehrmann
Mary Einhorn
Frank Engelkraut
Michael E. Fenoglio
Francis Floystrop
Dr. Sebastian J. Furio
George Terry Gardner
Steve Gebhardt
Charlotte Ginsberg
Vicki Glandon
Wanda Guirguis
Dub Ham
Brenda Heck
Phyllis Treby Hentz
Mary Hesprich
Stephen Hickman
Paul Higgins
Harvey Hook
Linda Howerton
William S. Jeremiah
Gwen C. Johnson
Donna Klinedinst
Peter Kohudic Jr.
Peter J. Larsen
Arnette Lester
Jeannine Lester's Birthday
Ed and Christine Loch's Marriage
Adam & Stacia Looney
Luther C. MacGilvray's 80th Birthday
Phyllis Malloy
Robert Matusiak
Jennifer McConathy
Members of the FTD Support Forum – Past & Present
Louise Miller
Janet Mills
Dennis Mixdorf
Arthur Moyer
John M. Nies
Eugenoula Papadopoulos
Chuck Pasic
Jim Peifer
Camilla Perry
Pohl/Smith Engagement
Carol Radtke
Jeff Raymond
Joanne Sackheim
Lynne C. Sanders
Dave "Scooter" Scaggs
Paula Scott
Jacqueline Schneider
Russell Schubert
Paula Scott
Lewis Silver
Sam Snyder
The Sparks Family
John E. Stackhouse
Diane Stephen
Carol Sumrall
Hue Thai
Stephen Tipton
Basil L. Tivy
Ellen Trosclair
Richard Van Dyke
Jeff Van Son
Bruce Viemeister
Matt Warenzak
Arlene Wayne
Christy Cain Weaver
James Williamson
Judy Windhorst
Samuel J. Zlotnick

**In Memory Of**
Glenn G. Andrews
Judy Anthes
Nadia Aquilino
Emerson Avery Jr.
Ronald Ballard
David W. Benton
Paul Douglas Berry
Lee Russell Birch
Sandy Birnbaum
James BonDurant
Lorraine Brassard

# AFTD Thanks Outgoing, Founding Members of Its Board of Directors

*AFTD is forever grateful to these founding members of the Board of Directors who recently completed terms:*

**KENT JAMISON** served as vice chair and representative to the Medical Advisory Council. He was responsible for the Association's first website and responded personally to caregiver inquiries before AFTD employed staff.

**JOYCE SHENIAN** served on the committee for the 1999 Conference on Pick's Disease and FTD. She served on the board first as treasurer and then secretary. Her responsibilities have included event planning and public relations materials.

**LISA RADIN** helped organize the 1999 Conference on Pick's Disease and FTD and has led caregiver support groups. She co-edited *What If It's Not Alzheimer's? A Caregiver's Guide to Dementia* and was keynote speaker in May at the Fort Worth Caregiver Conference.

> *These founding members of the Board of Directors have been remarkable advocates for caregivers and people with FTD.*
>
> Susan Dickinson
> AFTD Executive Director

# Fort Worth Conference Provides Education and Support

Nurse Barbara Harty leads a breakout session on care facilities options for people with FTD, during the May 21 Fort Worth Caregiver Conference. More than 120 people registered for the conference, which was held at the University of North Texas Health Science Center.

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

**In Memory Of** *(continued)*
Janice Brooks
Tom Buchholz
Graham Miles Burch
Cindy Cardosi
George E. Carlson Jr.
James F. Carr
Rodney A. Cassner
Jill E. Clayton
Karen Cleveland
Phyllis Coats
Emilie Cobb
Norton Coleman
Paulette Crivello
Ann C. Davis
Jim Doran
Nancy Driscoll
Mary Ellen Einhorn
William Eissler
Kathryn Griffith Evans
Beverly Ann Freeman
Mary “Mimi” Freeman
Carl Friedman
Evelyn Friedman
Sebastian J. Furio
Regina A. “Jeannie” Gass
David P. Gates
Lynn Glantz
Loraine L. Gleiser
Janie M. McManus Gruber
Albert Charles Hall
Mary Hall
Rodney Gale Hallman
Jewel B. Heck
Dr. Harold Hedaya
Frederick W. “Skip” Heidingsfelder
Robert Hermann
John Hinton
Howard Huff
Dorothy Huston
Roger T. James
Karen Jones
Roger Kaiser
Peter Kalmen
James Kearney
Frank Woodward Keeney III
Otto Kostka
Frank Laird
Lawrence L. Larsen
Marlyn Lawrentz
John Lee
Rosa Marrero
William R. McAfee Jr.
Edward J. McAndrew
Jennifer McConathy
Michael McDonald
Mary McKee
Susan W. Mertz
James Mitchell
John Mockler
Gale Warren Moser
Marie J. Newman
Phyllis Neyer
Terry O’Connor
Harold G. Olson
Roz Pedinoff
Julienne Prineas
William W. Proett
Margaret Pyle
Neil Radin
David Toner Rasmussen
Richard Raybourne
Harvey Ribbens
Diana Richardson
Elsie Rodgers
Juan Rodriguez
Margie Rowell
Susan Rynier
Vicenta Sablan
William Sackheim
Thaddeus Samulski
William Sandt
Frank Schmidt
Judy Schmidt
Frank Schmitt
Linda Schuster
Josie Schwartz
Popkin Shenian
Anthony Sica
Jon Simkovitz
Ardis Skindrud
Mildred Slicien
Julianne Smok
Henry R. Sodano
Thomas Solboe
Robert Sowlles
Karen Stevens
John Stewart
Joan Stuit
Eve M. Swanson
Robert Sykes Jr.
William Tetzlaff
Rabbi Moshe Tutnauer
Carmella Vernick
Dan Viola
Ann Wallace
Michael Wallis
Mike Walter
Barbara Weiss
Rosemary “Cookie” Weiten
John E. Wilhelm
Elliot Winograd
Stephen J. Zelensky

---

## *AFTD Task Force on Families with Children*

# Helping Children of Parents with FTD

*“My mother showed up at my choir solo in her housedress over her nightgown and she wouldn’t go sit down. I was real upset and going to cry when my teacher asked me what was wrong. She thought [my mother] was my grandmother.” – Sally, age 12.*

“As a parent of five children – four of whom are of school age – I searched for resources to help support my children in dealing with their dad’s disease,” says caregiver Gail Anderson. “I found nothing that would help me explain this disease to my young children.”

AFTD is working to change that, and Anderson is helping. The newest program initiative of the Association for Frontotemporal Dementias, the Task Force on Families with Children, focuses on the unique needs of younger families.

How do you talk with children about an ill parent’s odd behavior or declining self-care? How do you ensure the safety of young children if the parent’s judgement is affected. How do you nurture your children’s emotions? In short, how do you balance everyone’s needs.

“The goal of the task force is to learn and to lead,” says AFTD Program Director Sharon S. Denny. “We aim to understand the range of concerns facing parents and children. We also want to lead the way in making educational materials, resources and effective supports readily available.”

AFTD decided to make the task force a high priority because of a very positive response to a telephone support group tailored to people caring for a spouse with FTD, while also caring for school-age children at home.

“When given access to the tools and support they need, caregivers and families can adjust with resiliency and hope to the challenges of FTD,” Denny explains, adding that the telephone support group communicates twice monthly.

**The task force will produce resource materials within the next nine months, and identify additional projects for development.**

Task force objectives are to:

- articulate the needs of families, children and teens,
- think expansively about what information and supports are needed,
- identify priorities for development by AFTD, and
- be a catalyst with medical centers, schools and community-based services to develop necessary supports.

Core members of the task force have diverse professional backgrounds and expertise. Members include two FTD caregivers who also are raising young children, a children’s bereavement specialist, a researcher, an educator and middle school guidance counselor, and a licensed clinical social worker experienced in working with people with neurodegenerative disorders and their families.

*The task force welcomes input and can be contacted at info@ftd-picks.org or 866-507-7222.*

# Hospice: A Refuge for FTD Patients and Families

From its beginnings during the Middle Ages – when hospice was a place for weary travelers to rest – up until today, when it is a service covered by Medicare and most private health insurers, hospice retains its core focus. It is a refuge from pain and suffering.

For families coping with frontotemporal dementias, it can be an especially valuable resource. Just ask Darlene Ryan, an AFTD board member whose husband, Dick, is living in a nursing home in Forth Worth, Texas. “Dick had progressed to a point where he was falling and having serious injuries. And I was crying all the time, at the end of my rope emotionally,” Darlene says. “With FTD, it’s hard to know when to begin hospice but I thought I should check in with a hospice agency.”

### ■ As Necessary

Dick Ryan was diagnosed with progressive supranuclear palsy nearly seven years ago and has been a hospice patient off and on for more than 18 months. Darlene is familiar with the benefits of hospice care from when her father, who died of cancer, was a hospice patient. She knows that if a loved one has a terminal illness, hospice is an option to explore at any time.

Patients must be certified to receive hospice care. As is typical with the certification process, Dick’s physician and the hospice medical director had to state that, if the disease ran its normal course, Dick had six months or less to live. Since no doctor can make such a determination with absolute certainty, Dick would need to be recertified periodically. As hospice is designed to stop and start as needed, Dick has cycled in and out of hospice as his condition has changed. Though there is no limit on the number of times he can be recertified, Darlene can choose to stop hospice at any time.

### ■ PALLIATIVE CARE

When someone is ill, their care usually combines components that are both curative and palliative. When FTD patients enter hospice care, however, they and their families understand they are not seeking treatments that would cure the illness. They are seeking palliative care only – care intended to maintain the patient’s quality of life and to relieve pain and suffering. Hospice focuses on the emotional, spiritual, psychological, and physical needs of the patient, and recognizes the important role family and friends play as caregivers. Hospice is designed to improve quality of life; it does not just prepare a patient for death.

### SEEKING HOSPICE CARE:

- **Identify a hospice agency.** Ask for recommendations from your doctor or other healthcare professionals, as well as other FTD caregivers.
- **Inquire about costs.** Hospice is covered by almost all health insurance plans.
- **Determine if the patient is ready for hospice.** Most hospice agencies will provide a free initial consultation.

### ■ Services, Equipment, Medication

For Dick, the care he receives through hospice is more consistent and structured than the care nursing home staff can provide. For Darlene, weekly counseling with a hospice social worker brings relief from episodes of debilitating sadness and guilt.

A nurse monitors Dick and provides routine care with the help of home health aides who assist with activities of daily living. His care could include therapies or medications to control symptoms and manage pain. It could also include occupational and physical therapies, and speech-language therapy to manage swallowing problems and help prevent food aspiration while eating, a frequent cause of pneumonia in dementia patients. A nutritionist is available to monitor his dietary needs and Darlene and the nursing home caregivers have 24-hour phone access to doctors and nurses.

Hospice would provide medical equipment to make it possible for Dick to live at home if that is what his family decided. If Dick needed inpatient care to manage pain and symptoms, the hospice team would arrange a short-term hospital stay.

### ■ ADVOCATING FOR HOSPICE

Hospice is often not thought of as an option for people with FTD or other dementias because dementia affects the mind first and then the body. FTD families may need to be proactive about providing hospice care well before the patient’s mind has degenerated to the extent that it can no longer control the body.

A family member or friend visits Dick each day; a nurse from hospice is there once a week. Together they are helping him live the rest of his life as peacefully as possible. “Hospice has lightened my load,” Darlene says. “It is helping me to move on.”

*Writer Elaine Rose, of Silver Spring, Md., is a caregiver and AFTD volunteer.*

## ONTARIO, CANADA:

# Collaboration at Baycrest Benefits Patients with FTD

> *Since the [Baycrest] Ross Memory Clinic and Mountainview Club day program are in the same circle of care, the providers in the day program can report to the clinicians, very specifically, any changes in clients' behaviors or responses to stimuli and medications. This approach offers many opportunities for cross-sharing of health information, benefiting both the clients and the clinicians.*
>
> *Tiffany W. Chow, M.D.*

A collaborative approach to caring for people with FTD sets the standard of care for patients at Baycrest. It's an approach that makes all the difference, according to Tiffany W. Chow, M.D., a clinician-scientist at Baycrest's Rotman Research Institute and assistant professor of neurology and psychiatry at the University of Toronto.

"Baycrest's structure enables us to pull all the components of care together," says Dr. Chow, who heads an FTD Workgroup. "When a patient comes to our Memory Clinic, we are able to explain very clearly what is happening, and we offer an action plan. The support services the patient and family need are all in one place."

A health sciences center affiliated with the University of Toronto, Baycrest is internationally renowned for its wide array of programs and services for the well to very frail older adult. Since its founding in 1918, Baycrest has evolved into a world-class developer of innovations in aging that enhance quality of life by optimizing physical and mental wellbeing.

### ■ ROSS MEMORY CLINIC

In 2005, the healthcare center expanded its research and client services to meet the needs of the region's FTD community. At the Sam and Ida Ross Memory Clinic, one of Baycrest's three Brain Health Centre Clinics, Dr. Chow and clinician-scientist Morris Freedman, M.D. (who is director of the clinic), provide care to approximately 50 active patients with FTD.

"Patients are referred to the Ross Memory Clinic because of changes in behavior or problems they may be having with memory or language," Dr. Chow says. "These patients are usually referred to us by family physicians after they exhibit symptoms that have proven not to be mid-life stress, a flare-up of bipolar disorder, or a typical memory disorder, such as Alzheimer's disease."

### ■ THOROUGH EXAM, THOROUGH PLAN

The first visit to the Ross Memory Clinic generally takes three to four hours and includes time for intake, evaluation and explanation of an action plan. That action plan often includes a recommendation that the patient participate in The Samuel Lunenfeld Mountainview Club, a Baycrest day program that has been tailored to meet the specific needs of FTD clients, usually involving more one-to-one care.

Although factors such as distance from the program can sometimes preclude a patient's participation in the Mountainview Club, the biggest barrier to participation is often the family's hesitancy to let go of the direct patient care. However, when they realize their loved ones are enjoying the program, caregivers rapidly expand the number of days clients attend each week from the minimum requirement of two.

### ■ FLEXIBILITY IN DAY PROGRAMMING

The Mountainview Club, which operates Monday through Friday, provides clients with appropriate social, cultural, recreational and educational activities, as well as respite for caregivers. In addition, staff members educate families and caregivers about FTD, behavioral modification techniques, home safety, caregiver stress management, and community services and resources. The day program staff works closely and in collaboration with the nurse clinicians at the Ross Memory Clinic. As a result, both provide a stronger continuum of care for patients, their families, and caregivers.

### ■ CONTINUED 'CIRCLE OF CARE'

"Since the Ross Memory Clinic and the Mountainview Club day program are in the same circle of care, the providers in the day program can report to the clinicians, very specifically, any changes in clients' behaviors or responses to stimuli and medications," Dr. Chow says. "This approach offers many opportunities for cross-sharing of health information, benefiting both the clients and the clinicians."

### ■ COLLABORATION ASSISTING RESEARCH

Dr. Chow, whose clinical research is dedicated to finding meaningful interventions for patients with behavioral disturbances due to dementia, says research plays an important role at the Ross Memory Clinic and Mountainview Club.

"There are many researchers interested in this patient population who want to learn more about how the frontal and temporal lobes contribute to behavior and memory," she explains. The research includes an ongoing clinical trial with memantine, as well as identification of best practices for online caregiver support groups and day programs.

"Many outpatients and their caregivers have been keen to participate in research, even flying in from out of the province," Dr. Chow notes.

*For additional information about the Sam and Ida Ross Memory Clinic, visit www.baycrest.org or call 416-785-2444.*

**AWARENESS**

## *Lifetime, CNN* Help Diffuse Isolation

The Sparks family of Rhode Island is not only raising awareness about frontotemporal dementias, they are also helping other families cope with the disease.

"It's such an isolating disease," says Cheryl Sparks, whose husband, Kenny, was diagnosed with FTD five years ago. "Even now, it's such a lonely, lonely disease."

In December, Cheryl and Kenny Sparks, along with daughter Alexandra and son Graham, agreed to be interviewed by CNN television for a segment on FTD. The television spot, and follow-up coverage on the network's website, led to a four-fold increase in AFTD website hits and HelpLine inquiries.

*After the segments aired, the family was inundated with phone calls, e-mails and letters.*

Not long after, Cheryl Sparks was contacted by a representative from Lifetime Television who wanted to produce a segment on FTD and the impact it has had on the Sparks family. The family agreed to the interview and Lifetime aired the piece on May 30 during a Sunday morning *Health Corner* segment.

"I think we've made a difference by doing the CNN and Lifetime segments," she says.

"Afterwards we were inundated with phone calls and e-mails. We received letters from people from all over the world. Some just wanted to say, 'Before I saw your family on TV, I didn't know anyone else who was affected by FTD.'"

## AFTD Expands Staff With New Communications and Marketing Director

Chuck McDevitt recently joined the AFTD staff as director of communications and marketing, a new position.

"I am so happy to be part of AFTD," McDevitt says. "It provides a great service and is an exceptional source of support for caregivers and people with frontotemporal dementias."

McDevitt has more than 20 years experience as a media, communications and marketing specialist, with a particular emphasis on nonprofit and healthcare communications. He has overseen communications and marketing for an animal welfare organization, an international religious organization, and a school and museum of fine arts. He also worked as an associate in the communications and development offices at two academic healthcare centers and as a writer for a daily newspaper in Philadelphia, where he lives.

McDevitt is responsible for raising awareness about FTD while promoting AFTD, its mission, and the people it serves. He oversees the website, marketing materials, e-communications and media relations.

"I am so impressed by the caregivers I've met. They work so hard on behalf of their loved ones, while supporting and strengthening each other along the way," McDevitt says. "I look forward to partnering with them to raise awareness about FTD. Together we can work to promote the AFTD vision of a world where FTLD is understood, and each and every person affected by it finds the support they need."

## Educational 'Webinar' Draws Hundreds

More than 700 people registered for an April 29 online seminar on the cognitive and behavioral aspects of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), frontotemporal dementia (FTD) and primary progressive aphasia (PPA). The Association for Frontotemporal Dementias was pleased to join with CurePSP to sponsor the event, which addressed concerns common to these progressive neurological disorders. The seminar was presented by Brad Boeve, M.D., chair of the AFTD Medical Advisory Council.

Dr. Boeve noted that while PSP, CBD, FTD and PPA generally have been considered as distinct disorders, there is growing evidence of their similarities. One of the main distinctions is the parts of the brain's frontal and temporal lobes that are affected most.

Dr. Boeve reviewed the areas of the brain responsible for complex problem solving, social behavior, language, motivation and memory, and described the clinical features of each of the four syndromes. He noted the frequent overlap of cognitive and behavioral symptoms across the disorders and described some of the medications and behavioral interventions that may be helpful.

"I enjoyed the webinar greatly," Dr. Boeve says. "It is a wonderful way to educate and support patients and families." The event generated a very positive response in comments and questions to AFTD's HelpLine, as well as visits to the website. The Association is investigating Internet-based technology as a way to expand education efforts.

The webinar is archived and can be accessed at *Past Caregiver Conferences* at www.ftd-picks.org.

# Tell 10 People Events Honoring Family, Friends, Mentors

## ‘Scoot for Scooter’ Honors Coach, Scores Big

Family, friends and players support the coach and AFTD at the first-ever Scoot for Scooter.

More than 1,000 people turned out May 16 for the first-ever Scoot for Scooter 5k and 1-mile run and walk, benefitting AFTD. The event, held in Sandy Spring, Md., in honor of Dave “Scooter” Scaggs, raised $40,000, far exceeding the organizers’ goal of $20,000.

Scaggs, a retired soccer and basketball coach now living in Pennsylvania, was diagnosed in 2008 with FTD. To help honor him, many of his former players took part in the run and walk, held at Sherwood High School, where he once served as athletic director. One former player traveled all the way from California to participate, stay the night, and then fly home the next day.

“The key to our success was a large, dedicated committee and a caring community of family, friends and neighbors,” says Scaggs’ daughter Allyson Sealfon. “Everyone pulled together and did their part.”

Allyson’s brother, Jon David Scaggs, agrees but adds, “The turnout was because of who dad was and is; not because of what we did.”

For more information, photos and video from Scoot for Scooter, go to www.scoot4scooter.com.

## Running 10 Miles to Tell 10 People

A record 30,000 people registered for the 31st annual Broad Street Run in Philadelphia. Among those participating in the 10-mile run on May 2 were members of Team 95North led by Rick Lyons, an advertising and marketing specialist at the 95North marketing firm in Pennsylvania

“It was a great run on a very hot day. But we made it to the finish line, raised awareness for AFTD and celebrated,” Lyons says.

Lyons knows the importance of raising awareness of FTD because of a friend’s experience with the disease. He urged runners to join the team to increase awareness and help support the work of AFTD.

## ‘Quest for the Cure’

The Walter Charitable Fund sponsored its third annual Quest for the Cure Golf Tournament on April 26 and raised $25,000 on behalf of AFTD research initiatives. The tournament, held this year at the Whitney Oaks Golf Club in the foothills of the Sierra Nevada Mountains in Rocklin, Calif., has raised $75,000 on behalf of AFTD in just three years.

“It was a wonderful day. The spirit of generosity at Quest for the Cure is just incredible,” says Beth Walter, president of the Walter Charitable Fund and chair of AFTD’s Board of Directors.

Golfers at Quest for the Cure help raise funds for AFTD research initiatives.

The Walter Charitable Fund and the annual Quest of the Cure Golf Tournament honor the memory of five Walter family members who died from FTD.

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

The Association for Frontotemporal Dementias
Radnor Station Bldg. 2, Suite 320
290 King of Prussia Road
Radnor, PA 19087
www.ftd-picks.org

Prsrt. Std.
U.S. Postage
Paid
Lansdale, Pa.
Permit #444

*If you would prefer to receive this newsletter via e-mail or want to be removed from our mailing list, e-mail us at info@ftd-picks.org.*

**AFTD** www.ftd-picks.org phone 267-514-7221 toll-free phone 866-507-7222

## Board of Directors

**Beth Walter**
**Chair**, *California*
**Darlene M. Ryan**
**Treasurer**, *Texas*
**Francine Laden, ScD**
**Vice Chair**, *Massachusetts*
**Susan Eissler**
**Recording Secretary**, *Texas*

**Earl W. Comstock**
*Washington, D.C.*
**Bryan Dalesandro**
*Pennsylvania*
**Jary Larsen, PhD**
*California*
**Emily Levy**
*Massachusetts*
**Philip H. Lovett**
*New York*
**Sylvia Mackey**
*Maryland*
**Zbyslaw J. Petryka, PhD**
*California*
**Colleen Quinn**
*Washington, D.C.*
**Bruce L. Richardson**
*Colorado*
**Joanne Sackheim**
*California*

## Staff

**Susan L-J Dickinson, MS**
Executive Director
**Sharon S. Denny, MA**
Program Director
**Chuck McDevitt**
Communications & Marketing Director
**Matthew Sharp, MSW**
Program Coordinator
**Michelle Leahy**
Office Manager

## Medical Advisory Council

**Bradley F. Boeve, MD**
**Chair,** *Mayo Clinic, Rochester*
**Bernardino Ghetti, MD**
**Vice Chair,** *Indiana University*
**Thomas D. Bird, MD**
*University of Washington*
**Tiffany W. Chow, MD**
*University of Toronto*
**Bradford C. Dickerson, MD**
*Harvard University*
**Denis Dickson, MD**
*Mayo Clinic, Jacksonville*
**Karen Duff, PhD**
*Columbia University*
**Jill Goldman, MS**
*Columbia University*
**Murray Grossman, MD, EdD**
*University of Pennsylvania*
**Michael Hutton, PhD**
*Eli Lilly &Co. UK*
**Andrew Kertesz, MD, FRCP c**
*University of Western Ontario*
**David S. Knopman, MD**
*Mayo Clinic, Rochester*
**Walter A. Kukull, PhD**
*University of Washington*
**Virginia M.-Y. Lee, PhD**
*University of Pennsylvania*
**Carol F. Lippa, MD**
*Drexel University*
**Irene Litvan, MD**
*University of Louisville*
**Ian R.A. Mackenzie, MD**
*University of British Columbia, Vancouver*
**Mario Mendez, MD, PhD**
*University of California, Los Angeles*
**M.-Marsel Mesulam, MD**
*Northwestern University*
**Bruce L. Miller, MD**
*University of California, San Francisco*
**Jill Murrell, PhD**
*Indiana University*
**Rosa Rademakers, PhD**
*Mayo Clinic, Jacksonville*
**Howard Rosen, MD**
*University of California, San Francisco*
**John Q. Trojanowski, MD, PhD**
*University of Pennsylvania*

*For permission to reprint articles please contact info@ftd-picks.org.*

AFTD is a non-profit, 501(c)(3), charitable organization. A copy of AFTD's official registration and financial information may be obtained from the PA Department of State by calling toll free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.