

AFTD

Opening the gateway to help and a cure

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Join the AFTD Grassroots Network

If you've been wondering how to help AFTD raise awareness, here's your chance! AFTD officially launched its new Grassroots Advocacy Network at the organization's annual meeting on June 20, 2008.

While AFTD's four-fold mission includes advocacy (the other elements are research, support, and education), to date the organization has not had sufficient resources or momentum to address issues relating to awareness and advocacy. This spring that changed, as new Board member Bill Brown (Texas) joined Louise O'Connor (Canada) as co-chair of the AFTD Advocacy Committee. They, along with a small corps of



volunteers and staff, have been meeting regularly and designing a campaign that makes it easy for people to get involved.

The long-term goals of the advocacy campaign include raising awareness of AFTD, working with legislators to se-

cure funding for research, improving community services for families, and educating the medical community about FTD. Among these goals, the committee realizes that raising awareness is essential in order to accomplish the other objectives, so awareness has become the advocacy campaign's top priority.

To raise awareness, AFTD is developing a Grassroots Advocacy Network across the United States and Canada. A network is only as strong as its members, so AFTD needs you to join the network today!

There are two ways to get involved. As a Grassroots Advocate, you'll be called upon to

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AFTD's First Public Annual Meeting a Great Success

On June 20 caregivers from across the country joined the AFTD Board of Directors and staff in Baltimore for the organization's first public annual meeting. Attendees from as far as California, Texas, North Carolina and Maine gathered to learn about AFTD's accomplishments since it was founded just five years ago and to find out how to become more involved in AFTD's mission and future projects.

Those in attendance included AFTD's Board members and staff, caregivers and families of those with FTD, donors, and medical professionals who serve FTD families. AFTD was honored to welcome Walter Koroshetz, MD, Deputy Director of the National Institute of Neurologic Disorders and Stroke, to the meeting.

Helen-Ann Comstock, AFTD's founder and current Board Chair, gave a warm welcome to the group and noted that AFTD has grown from a start by one person at the end of 2002 to an organization with a 16 member Board of Direc-

tors, a 16 member Medical Advisory Council, numerous volunteers, and three staff members. She emphasized the power there is when people work together for a common cause. She said that much remains to be accomplished and challenged those at the meeting to join AFTD in "opening the gateway to help and a cure for FTD."

Helen-Ann then introduced Susan Dickinson, AFTD's Executive Director, who gave an overview of the organization's accomplishments and plans. Susan focused on priority goals for 2008, which include growing the new grassroots network and awareness campaign (see top of page 1), redesigning the website to provide easier navigation and more interactive features, exploring the development of a caregiver respite program, identifying partners to educate health care professionals, and engaging a growing number of partners in the effort to drive FTD research forward.

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Spotlight On... Darlene M. Ryan, AFTD Board Member

around-the-clock care in a nursing home while Darlene raises their son and works to pay for his care.

Darlene's experience as CEO of a pharmaceutical company in Texas for 10 years, and the fact that she has served on a number of nonprofit boards, quickly brought her to the attention of AFTD. In 2005, she was invited to join AFTD's Board of Directors. "I want to pave the way for families to get faster, more accurate diagnoses. I also want to encourage researchers to remember the human side of this from the perspective of the affected families." Darlene strongly believes in the value of research and has arranged for Dick to participate in FTD studies, including an autopsy. Having a son, Darlene is particularly interested in research exploring the extent to which FTD is hereditary, saying she is "haunted by the urgency of getting answers."

Even while juggling the tasks of raising her son, working, caring for her husband, and serving on the AFTD Board, Darlene still

wishes she could do more. She explains, "I feel compelled to do whatever I can. As long as I'm having to live with the agony of watching my husband and family suffer with this massive problem, there should be some good that comes of it for others." In addition to serving on the AFTD Board, Darlene also participates in a support group in the Dallas/Fort Worth area to help other families and to "provide hope for families after a devastating diagnosis of FTD."

Darlene learned the value of developing a support system four years ago when she connected online with a group of about a dozen women, all of whom have husbands with FTD. They met in person shortly thereafter at the first AFTD Caregiver Conference in Philadelphia and have become a very close-knit group over the years. She encourages all caregivers dealing with FTD to try and develop a similar support network. "It's the support of these friends that has kept me sane the past few years," she says.

Darlene Ryan handles most challenges by jumping in with both feet. But when her husband, Dick, who is now 68, started behaving differently, it took a year of searching for an accurate diagnosis before she knew where to jump in. Dick was finally diagnosed with FTD in 2003. By this time, Darlene had already moved out of the house with her son in order to protect them from Dick.

Because of the way that FTD has affected Dick's brain, he is at high risk for falls and other injuries. He receives

AFTD



News

An educational conference on FTD and Primary Progressive Aphasia for caregivers and professionals will be held at Northwestern University on August 11. AFTD is sponsoring a reception and caregiver scholarships to assist those in need with travel expenses (for more information please contact AFTD).

Just In! The second edition of *What If It's Not Alzheimer's?* edited by Lisa and Gary Radin, provides updated and comprehensive information for FTD caregivers. It is a valuable resource for both experienced caregivers and those facing a new diagnosis of FTD. Order a copy from amazon.com or through the AFTD office.

Join Us in Rotterdam! The 6th International Conference on Frontotemporal Dementias will take place in Rotterdam, The Netherlands, from

September 3rd to the 5th. AFTD Chair Helen-Ann Comstock will provide the Introduction to the Caregiver meeting track, and AFTD is hosting a dinner for caregivers. For more information go to www.ftd2008.org



The second largest city of the Netherlands, Rotterdam is considered the gateway to the Hague and Amsterdam.

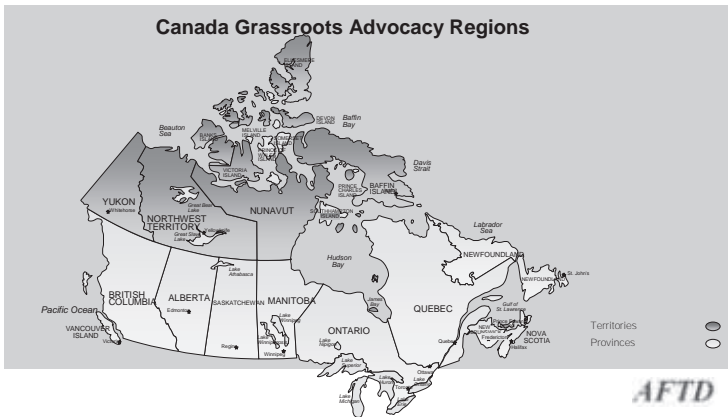
AFTD would like to thank **Michelle Stafford and Marie Sykes** for organizing "FTD Night at the Philadelphia Soul" – a fundraiser where friends enjoyed food and fun while cheering on Philadelphia's arena football team.

AFTD Needs You! AFTD derives its strength from hundreds of volunteers and donors across North America. If you would like to join our team please send an email to info@ftd-picks.org, and we will send you a volunteer form on which you can indicate your experience and interest.

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

Awareness

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identify pressing issues in your region, participate in letter-writing campaigns, contact your representatives, and tell us your stories of living with FTD.

If you have good organization and recruitment skills, you might consider

you with the tools you'll need to be a successful Regional Leader or Grassroots Advocate. Funding priorities have been identified, such as a brand new website with a resource-rich, easy-to-navigate advocacy section and informational materials to edu-

becoming a Volunteer Regional Leader who serves as the primary representative and ambassador of AFTD regarding advocacy efforts in your assigned region.

The advocacy committee is already working hard to provide

cate volunteers about the advocacy process and key FTD issues.

The committee also wants your input on what issues should be addressed, such as disability benefits, training in long-term care facilities, and increased research funding. You'll have the opportunity to share your ideas about awareness and advocacy priorities through polls, surveys, and other methods of communication.

Ready to sign up? It's easy: Simply send an email to advocacy@ftd-picks.org and indicate the best way to contact you. AFTD will send you a brief questionnaire to collect your information and any specific volunteer interests you have. Thank you in advance for helping AFTD achieve its goal of getting families, patients, and caregivers the benefits and support that they deserve and require.

Knocking on Doors ~ Louise O'Connor, Co-Chair, Advocacy Committee

I didn't think many people in my Canadian city knew about FTD. I wasn't even sure whether my local politician knew about it, but I was certain that he didn't know my name. I decided that had to change.

Phil McNeely is a seasoned, professional politician who knows how to get elected – more importantly, he knows how to get things done. Because health care research in Canada is funded mostly by the government, I needed Phil's support.

It turned out that Phil needed my support, too. A provincial election was on and Phil was running again. When I phoned his campaign office and asked to meet him, his campaign manager suggested that I show up that Saturday and help Phil knock on doors. I wasn't sure what I was getting myself into, but I knew that FTD was worth it.

That Saturday, I accompanied the campaign team to a nice residential neighborhood. I was paired with Anna Marie, Phil's wife. We knocked on doors and invited people to meet Phil, their Member of Provincial Par-

liament. While walking the neighborhood, I talked to Anna Marie about FTD. When she expressed interest and concern, I knew she would be an asset to our advocacy campaign. Afterwards, when we all went for coffee, I explained who I was and my concerns about FTD. The team listened attentively.

This was just the beginning. I sent a follow-up letter to Phil, asking for help for the many families struggling with FTD. Since then, I've had two meetings with him to determine a work list to push through the Provincial political system. Phil's Special Assistant, Christine Pelletier, keeps me apprised about care options being explored and research being funded. I also sent emails to each political candidate in the province, hoping they would show similar interest in making FTD part of the health care agenda (for those interested in contacting their representatives, a sample letter is available on the AFTD website).

I attended community events and talked to political candidates about FTD. At an all-candidates meeting in



Louise O'Connor and Phil McNeely

my constituency, I asked candidates what they were prepared to do to help families struggling with FTD. Later, several people approached me to talk about the disease. Since the election, I've been invited to several political receptions, including one held on Parliament Hill that specifically dealt with dementia. Among the attendees were the Speaker of the House of Commons, the Deputy Leader of the Opposition, and the Parliamentary Secretary to the Minister of Health.

My ultimate goal is to meet with the Minister of Health to request more health care funding for research, home care, and staff training. And I know I can do it, because it all starts with knocking on doors.

Research Landscape Analysis to Guide AFTD's Research Funding

AFTD has contracted with the Alzheimer's Drug Discovery Foundation (ADDF) to perform a survey of all research being conducted in the field of FTD. The goal of this project will be to identify gaps in current research activities and use this information to guide AFTD's research investments so they can have maximum impact in the near future.

"AFTD deeply values our partnership with ADDF," says Board member Phil Lovett. "We are confident that this Analysis will enable both of our organizations to make better strategic investment in FTD research, and

thus speed our way to development of effective treatments."

The project, which is anticipated to take about five months, will be jointly funded by ADDF and AFTD and performed by ADDF. The first step will be to survey a wide range of public and private funders, research and publication databases and patent applications. With this information in hand, a gap analysis will reveal "holes" in the landscape, important areas which are currently not being addressed and where research grants could have a major impact in facilitating advancement of scientific and medical knowledge. AFTD

and ADDF anticipate publishing an article which shares these results with the broader research community.

"This study will be extremely valuable for everyone working in the field of FTD," says Dr. Bradley F. Boeve, Chair of AFTD's Medical Advisory Council. "We will work with ADDF to ensure that the analysis is based upon as comprehensive data as possible, and we anticipate that the knowledge gained will help us chart a strategic course for AFTD's research investments over the coming years."

Medical Advisory Council: Report from the Chair

Bradley F. Boeve, MD



MAC Chair Brad Boeve, MD and Vice-Chair Bernardino Ghetti, MD at the Annual MAC meeting in Chicago in April 2008.

A report from Medical Advisory Council Chair Brad Boeve, MD, was presented to the Board of Directors during their annual meeting in Baltimore on June 20. To date, AFTD has distributed \$205,000 for basic research and \$100,000 for drug discovery. This year the organization plans to award an additional \$270,000 for research.

In order to enhance representation on the Council from the various medical specialties and institutions that are leading the field of FTD, MAC members nominated (and the Board of Directors approved) four new members: Jill Goldman, MS (genetic counselor at Columbia University), Jill Murrell, PhD (molecular geneticist at Indiana University), Rosa Rademakers, PhD (molecular geneticist at Mayo Clinic, Jacksonville) and Howard Rosen, MD (clinician and neuroimaging expert at University of California, San Francisco). Several other worthy candidates were viewed highly for presentation to the AFTD Board at a later date, as positions become available.

This past February the National Institute of Neurologic Diseases and Stroke (NINDS) sponsored a workshop that brought together researchers from around the globe working on

new FTD research findings relating to TDP-43 and progranulin. Several MAC members participated in discussions to determine next steps to build upon these findings.

In an effort to educate the wider medical community about FTD and support more accurate and quicker diagnosis, the MAC has approved posting of clinical diagnostic criteria on the Healthcare Professionals section of the AFTD website.

Council Members also have begun a discussion about the most effective ways AFTD might leverage its unique position in the FTD community to keep driving research in the field forward. Two specific ideas which have generated interest are: pursuing funding for a consensus workshop on pathology nomenclature for FTD; and generating strategic discussions with potential public and private partners about the creation of a consortium of designated FTD Centers across the United States.

Meeting *Continued from page 1*



AFTD Board Members Joyce Shenian and Colleen Quinn (left) greet guests as they arrive at the Annual Meeting.

Susan's presentation was followed by the keynote speech by Chiadi Onyike, MD, MHS, Assistant Professor in the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine. Dr. Onyike and his associates – Mary Anne Wylie, RN, MS, and Susan Newhouse, LCSW-C – spoke about the clinical and research programs in FTD at their university. The talk was well-received, sparking a lively question-and-answer session about coping with FTD, including how to support young children who have a parent with the disease.

The meeting concluded with a wine and cheese reception, which allowed many of the attendees to meet face-to-face for the first time. "It was a wonderful opportunity for board members and staff to meet with volunteers and family members, many for the first time" says Comstock. "AFTD was created for patients, caregivers and families, and it is from these elements that we derive our strength. It is important for us to hear directly from constituents about their needs and concerns."

Right: Sylvia Mackey and Board member Joanne Sackheim.



Above: Keynote speaker Chiadi Onyike, MD, MHS.



Above: Board member Kent Jamison (left) and members of the Walter family. Below: Paul Lester and Board member Louise O'Connor.



AFTD Welcomes New Board Members, Thanks Outgoing Members for Their Dedication and Service



AFTD welcomes Beth Walter (left), Bill Brown and Susan Eissler to its Board of Directors. We would also like to recognize departing Board members Joe Becker, PhD and Kenna Ramirez, for their commitment and service to helping families affected by FTD. Dr. Becker was a founding member of the AFTD Board who has been especially interested in raising funds for research.

During their annual meeting the AFTD Board of Directors honored outgoing Medical Advisory Council member Jordan Grafman, Ph.D. Ms. Comstock credited Dr. Grafman with giving her the idea to found AFTD, and providing vital advice and encouragement throughout the past five years. Pictured here: Founding Board members Joyce Shenian and Helen-Ann Comstock with Dr. Grafman.



Donations Honor Loved Ones *Gifts received February 1, 2008 — June 30, 2008*

In Honor Of:	James M. Wilson, III	Alan M. Chedester	Joseph E. Mann, Jr.	Alice Sandifer
Cindy Cardosi	Judy Windhorst	Craig Comstock	Mary Mazzara	Popkin Shenian
Karen Cleveland	In Memory Of:	Michael Xavier Crowe	Edward McAndrew	Edie Fox Siegel
Arlene & Bill DuComb –	Toivo O. Aho	William W. Eaton, II	Frank Melville	Priscilla Smiley
50 th Anniversary	Robert Anding	Paula Escamilla	Gale Warren Moser	Anne Spinnelli
Iona Eddelmon	Helen Baker	Kathy Evans	John R. Musser, Jr.	Robert J. Sykes, Jr.
George Edwards	Phyllis R. Bambrick	Anne Marie Favreau	Orville (Jake) S. Nelson	Donald J. Tabone
Janice Ehrmann	Julia Fullerton Bell	Eugene Gluszak	Marie J. Newman	Irene Titus
Dr. Robert Ehrmann	Vernon Bigsby	Christiane Gochtovtt	Helen Barbara Nichols	Mark Tooker
Harold Fechtner	Marilyn Bolyard	Lauri Lynn Grant	Helen Therese O'Brien	Karen Ulmaniec
Grover G. Grimm	Delmar Bowers	Melody Hicks	Alan Owen	Robert J. Volkenant
Harold Hedaya	Janice Brooks	Linda K. Hubbard	Jess B. Potter, Sr.	Col. Stephen Walker
Jim Hipp	Danny Brown	James Clement Kearney	John Querio	Gale H. Weaner
Jim Kearney	Robert E. Bryan	Maxwell C. Kirkpatrick	Neil Radin	Barbara Weiss
Arnette Lester	Tom Buchholz	Otto Kostka	Carlos M. Ramirez	John (Jack) E. Wilhelm
Ronald Martling	Gordon "Barry" Bullock	Barbara Kranseler	Louis T. Romeo	Joseph M. Wilson, Sr.
Janet Potter	Sonja Burchett	William Kriz	Leonard Rosenman	Patricia Winner
Paul Reeve	Willis H. Caterson	Elizabeth A. Livingston	Abraham Sack	Stephen W. Wright
Paula Scott	Maynard Center	Joseph Lotito	Ivan J. Sacks	

Golf Tournament Raises \$25K for AFTD

When Beth Walter's husband, Michael, died of FTD at the age of 59, she wasn't alone in her journey. Michael's older brother, Phillip, had already died of the disease, and his younger brother, Steven, would die of FTD only eight months after Michael. Three wives lost three husbands in a span of four years.

The brothers were determined to make meaning of their diagnoses by participating in research and arranging for autopsies of their brain tissue after they died. Beth and her sisters-in-law decided to carry on their husbands' legacies by organizing a golf tournament to raise money for

FTD research and services. *Quest for the Cure* was held on April 28 in Lincoln, California, just north of Sacramento. They raised \$25K for AFTD – a fantastic achievement, especially for an inaugural event.

Beth graciously shared with us her experience organizing the golf tourna-



Several members of the Walter family attended AFTD's annual meeting on June 20. From left to right: Terry Walter (Steve's wife), MaryJean (Walter) Bohager (Phil's wife), Robert Walter (Michael's son), Meghan (Walter) Wilmont (Phil's daughter), Beth Walter (Michael's wife), Laura (Walter) Bulger (Phil's daughter), and Jennifer Walter (Phil's daughter). Also at the meeting but not shown: Michelle (Walter) Shawyer (Phil's daughter).

ment, including what she's learned and what's ahead, with the hope of inspiring others to coordinate fundraising events in their own communities.

How did you happen to choose a golf tournament as your fundraising event?

One of my sister-in-law's sisters lives in

a golf community and suggested we organize a golf tournament. It was truly our first thought of fundraising and we had no idea just how labor intensive such an event could be. When people asked us why we thought we could put together a golf tournament, our standard answer was, "Nobody told us we couldn't!"

How long did it take to plan it? Did you have a committee?

We started planning in October 2007, but really got to work in January 2008. It was truly not enough time, so we worked like crazy to accomplish what we did. Our five-person committee consisted of me, my sisters Barbara and Vanessa, my sister-in-law

Terry, and her sister Judy. We also brought in someone from a local marketing company to help us.

What were the best ways to get the word out about the event?

Our own contacts were extremely beneficial – business and personal. Press re-

AFTD Research Grant Helps Scientists Study Familial FTD

A generous grant from AFTD, awarded in October 2006, has allowed two researchers from the University of British Columbia to create a mouse model of a familial form of FTD caused by mutations in the *PGRN* gene. This gene regulates progranulin, a protein that plays a role in brain development.

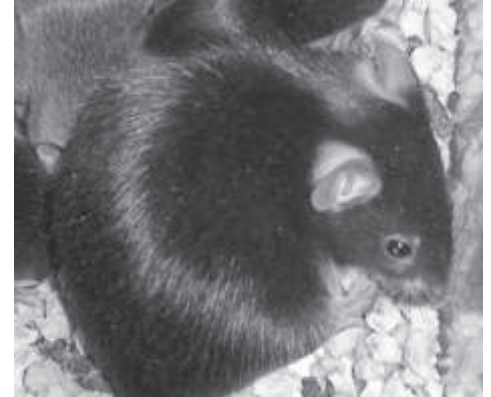
Dr. Blair R. Leavitt, Assistant Professor of Neurology, and Dr. Ian R.A. Mackenzie, Professor of Neuropathology, have successfully designed a mouse model of this form of FTD through the manipulation of mouse embryonic stem cells. Mouse models are crucial to the study of diseases such as FTD because they allow researchers

to study the pathogenesis of the disease in ways not currently possible in humans.

Once the results are published, Drs. Leavitt and Mackenzie will make these mice available to collaborators investigating *PGRN* mutations in FTD.

Drs. Leavitt and Mackenzie have leveraged the preliminary results generated through AFTD's seed grant into a full research proposal seeking five years of funding from the Canadian Institutes for Health Research.

AFTD thanks Drs. Leavitt and Mackenzie for their dedication to FTD research!



Drs. Leavitt and Mackenzie bred the mice by color. Brown mice are normal controls, while black mice have the genetic mutation.

Golf Tournament..... Continued from page 6

Was it difficult to find sponsors since FTD is not as well known as other diseases?

Yes, I spent a lot of time explaining the disease. However, most of our sponsors were business contacts that knew me personally and therefore knew of my husband's illness. There were several affiliated with the medical community since Steven's daughter, Jeanine, is a doctor. We also had some individuals who sponsored a golf hole in honor of a loved one, as we also did for Phillip, Michael, and Steven.

Were participants mostly families affected by FTD, or were there others there as well?

It was generally business associates of mine, sponsor participants, and about a dozen families who had some connection to FTD. If our newspaper article had hit a bit earlier, we might have generated more participation from others dealing with FTD.

How did you educate the public during the event?

The newspaper article was huge. The direct mail brochure we sent out in-

cluded similar information and provided the link to the AFTD website. Letters to potential sponsors included information regarding the disease and the AFTD organization. A local legislator played in the tournament and spoke briefly about the importance of raising funds to fight FTD. And, the entire Walter family was there – I introduced each family member, talked about how the disease had affected our lives, and asked for continued support of our efforts.

What kind of feedback did you receive about the event?

All in attendance felt it was a wonderful event and asked if we were planning on doing it annually – which we are. I can't tell you how many emails and phone calls I received from FTD family members. There are several I still communicate with and we've developed a kind of support network.

Will you do anything differently next year?

We're already working on the 2009 tournament. We modified our logo so we can use it from year to year. We're meeting with local clubs to select our course for 2009 and will change each

year to keep the event fresh. We're contemplating other events – but until we have this one nailed down I'm doubtful that will occur.

What advice do you have for others who want to organize fundraisers in their communities?

Taking on a golf tournament is an extremely ambitious endeavor – which we found out after the fact! If you're planning an event, tap into your own resources and make the most of those, especially in your first year. For example, if you play bridge once a week, organize a bridge tournament – stick with something you know. If you work in an industry that provides you with contacts and resources of a specific nature, see if you can come up with something that will appeal to them specifically. Know what motivates your community.

Interested in hosting a golf tournament or other type of event to benefit AFTD? See the "Tell 10 People" information at www.ftd-picks.org and contact our office toll free at 1-888-507-7222. We'll be happy to provide you with information and materials.

The Association for Frontotemporal Dementias
1616 Walnut Street, Suite 1100
Philadelphia, PA 19103



AFTD

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www.FTD-Picks.org 267-514-7221 toll free 866-507-7222

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