

AFTD

OPENING THE GATEWAY TO HELP AND A CURE

VOLUME II | ISSUE 1

JULY 2005

:: SPOTLIGHT ON ::

FTD Caregiver conference is Nov. 11

A day-long conference on frontotemporal dementia (FTD) will be held for caregivers Friday, Nov. 11 at the University of Pennsylvania. There is no charge to attend the conference.

The conference will take place in the BRB II-III auditorium on campus from 8:30 a.m. until 5 p.m. It is sponsored by the Center for Neurodegenerative Disease Research (CNDR), the Association for Frontotemporal Dementias (AFTD) and the Delaware Valley Chapter of the Alzheimer's Association.

Experts in the field of FTD will review medical causes and treatments; individual management of patient needs from nursing, social work, and physical/occupational therapy perspectives; family counseling; and disease management.

Dr. Daniel Gottlieb, a well-known psychologist and family therapist, author and

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From left to right: Front row: Fytie Drayton, Lisa Radin, Kenna Ramirez, Darlene Ryan; Back row: Walter McKee, Kent Jamison, Helen-Ann Comstock, Robert Kemp, Joseph Becker, Colleen Quinn, Joyce Shenian

Board Expands

With seven new members elected to the Board of Directors, AFTD's board has reached the maximum allowed by its by-laws. The new board members are: Philip Lovett (New York), Walter S. McKee (Maryland), Colleen Quinn (Washington, DC), Kenna Ramirez (formerly Texas, now Spain), Bruce Richardson (Colorado), Darlene Ryan (Texas), and Joanne Sackheim (California).

Two founding board members, Tess Parrish and Lawrence Shor, will not be able to serve a second term. Both helped the Association get off the ground. Tess was instrumental in creating the first two newsletters in 2004. After a long medical career, Larry has retired and wants to pursue non-medical ventures. Their contributions to the establishment of AFTD are very much appreciated and their participation at board meetings will be missed.

At a meeting of the Board of Directors on February 25, 2005, the following officers were re-elected: Helen-Ann Comstock, Chair; Kent S. Jamison, Vice Chair; Joyce Shenian, Recording Secretary; Fytie Drayton, Treasurer. In addition, the Board voted to appoint Bradley F. Boeve, M.D., neurologist

at the Mayo Clinic in Minnesota, to the Medical Advisory Council.

Following is brief information on the new board members.

Philip Lovett, New York, is a founding partner of Millenium Partners, where he directs the company's operations and development activities. He will focus on fundraising and the status of research on FTD.

Walter S. McKee, Rockville, Md., was a full-time caregiver for his wife, Mary, who passed away at age 71 in February 2004.

She had been afflicted with Pick's disease for approximately nine years. He holds a BSEE from the University of Maryland and served the last 34 years of his career with The Communications Satellite Corporation (COMSAT). He still attends weekly meetings of a Caregiver Support Group sponsored by Holy Cross Hospital in Silver Spring, Md., in order to assist current caregivers, and weekly meetings of a Hospice Caring, Inc. Bereavement Group in Bethesda, Md.

Colleen Quinn, MPT, Washington, D.C., lost her father at age 62 this year to Pick's disease. He had been diagnosed for eight years. She has a Master's in Physical

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:: NOTES ::

AFTD FIRST OFFICE OPENS

The association has moved into an office in downtown Philadelphia, according to Helen-Ann Comstock, AFTD Chair. The address is 100 N. 17th Street, Suite 600, Phila., Pa., 19103. The office numbers are: (267) 514-7221 and toll free (866) 507-7222. Equipment has been purchased and we are happy to welcome a part-time office manager, Martha Meyers. Marty will work from 10 a.m. - 2p.m. Mondays and Thursdays. Messages left on other days will be responded to in a timely manner. The toll-free number is for requests for brochures, newsletters, materials, information about conferences, etc. Caregiver questions regarding behaviors and medical issues will be forwarded to a healthcare professional. A Helpline is expected to be available by the end of the summer.

MEDICAL ADVISORY UPDATE

The Medical Advisory Council discussed a call for grant proposals to support research in frontotemporal dementia. Through the generosity of the AFTD, a grant will support work in FTD for one year. The hope is this will be an annual grant. The Medical Advisory Council also discussed the importance of "spreading the word" about FTD among professionals. A paper is being prepared for the Journal of the American Medical Association, and symposia at professional meetings are planned. The Medical Advisory Council was concerned to learn about a statement from the FDA regarding the use of a class of medications that experienced physicians find very useful in the treatment of individuals with FTD. Together with the Alzheimer's Association and several other organizations involved in the care of individuals with a neurodegenerative condition, we are planning a statement responding to the FDA.

- from Murray Grossman, M.D., EdD Chair, Medical Advisory Council

WEB SITE UPDATE

At the Board meeting, Kent Jamison, Ph.D., Vice Chair of the Association, said the web site is averaging 2,700 "hits" a month. Approximately 450 individuals are registered on the web site with about one new person being added every day. The Board approved plans to develop a fully automated database to deal with the increasing number of people the Association is serving.

The AFTD is grateful for gifts received in honor of those affected by FTD and in memory of those who have died.

We use these funds to create a supportive and informative network for those living with FTD, as well as to fund research in the hopes that future generations will no longer have to face the challenges of these diseases. The following tributes were given during the period October 2004 - May 2005.

Checks may be made payable to "AFTD" and sent to our new office address.

:: IN HONOR OF ::

- George Byron
- Barbara Caponigri
- Dick Drayton
- John Ferris
- Mimi Freeman
- Grover Grimm
- Linnea Grimm
- Mrs. Haas
- Colleen Howe
- Peter Kohudr
- Mrs. Arthur Kransler
- Dale Love
- Doris Malley
- Helga Mueller
- Sheri Navon
- Helen B. Nichols
- The O'Brien Family
- Sylvia Siegel
- Janie Smith

:: IN MEMORY OF ::

- Evan R. Andersen
- Nadia Aquilino
- Walter Bast
- Celeste Bobela
- Christine Chambers
- Craig Comstock
- John F. Deacon
- Irene R. Donahue
- Rebecca Fisher
- Stephen Gregg
- Robert L. Hermann
- L.J. Hopler, Jr.
- Regina Kujawski
- Edward J. McAndrews
- Mary McKee
- Maxine Metzger-Lyda
- Dennis Murphy
- Virginia Pearson
- Dorothy Powell
- Mike Putzier
- John (Jack) Renshaw
- Dolores Ritchie
- Douglas Rogers
- Dennis Sauer
- Wayne Schrader
- Henry A. Serre
- Popkin Shenian
- George F. Sidoris
- Raymond Southard
- Barbara Jo Stromberg
- Joan Stuit
- Jean Alice Thomsen
- Philip S. Walter
- Barbara Ward
- Karen White
- John B. Wilson
- Kent Woodworth

Special thanks go to the following for their very generous grants:

Potamkin Family Foundation #1 Inc., Colleen J. Howe Foundation, Maine Community Foundation

TIME TO REGISTER!

:: What ::

The Frontotemporal Dementia Caregiver Conference

:: Location ::

Campus of the University of Pennsylvania
 BRB II-III Auditorium,
 421 Curie Boulevard
 Philadelphia, Pa 19104

:: Date ::

Friday, November 11, 2005

:: Time ::

8:30 am to 5:30 pm

:: Program ::

See details at

www.FTD-picks.org or
<http://www.uphs.upenn.edu/cndr/retreat.html>

NAME _____

AFFILIATION _____

ADDRESS _____

City & Zip _____

Email _____ Phone: _____

LUNCH ? VEGETARIAN ?

Send Registration to:

Jennifer Farmer
 Center for Neurodegenerative Disease Research
 3 Maloney, 3600 Spruce St. Hospital UPENN
 Philadelphia, PA 19104

FAX TO: 215 349-5909

Email to: Farmerj@uphs.upenn.edu
 or Call Jennifer Farmer at
 866.507.7222

For additional information:

Association for Frontotemporal Dementias www.FTD-Picks.org
 Alzheimer's Association www.alz-delawarevalley.org/

Joseph Becker, PhD Washington	Colleen Quinn Washington, D.C.	Thomas D. Bird, MD University of Washington	Michael Hutton, PhD Mayo Clinic, Florida	Bruce L. Miller, MD U. of California, San Francisco
Helen-Ann Comstock Chair Pennsylvania	Robert Potamkin Florida	Bradley F. Boeve, MD Mayo Clinic, Minnesota	Andrew Kertesz, MD, FRCP [®] University of Western Ontario	John C. Morris, MD Washington University
Constance L. Drayton (Fytie) Treasurer/Corr. Secretary Pennsylvania	Lisa Radin New Jersey	Tiffany W. Chow, MD University of Toronto	Virginia M.-Y. Lee, PhD University of Pennsylvania	Linda E. Nee, MSW NINDS/National Institutes of Health
Kent S. Jamison, PhD Vice-Chair Connecticut	Kenna Ramirez Spain	Bernardino Ghetti, MD Indiana University	Carol F. Lipka Drexel University	John Q. Trojanowski, MD, PhD University of Pennsylvania
Robert A. Kemp California	Darlene Ryan Texas	Jordan Grafman, PhD NINDS/National Institutes of Health	Irene Litvan, MD University of Louisville	
Philip H. Lovett New York	Bruce L. Richardson Colorado	Murray Grossman, MD, EdD Chair University of Pennsylvania	M.-Marsel Mesulam, MD Northwestern University	
Walter McKee Maryland	Joanne Sackheim California			
	Joyce Shenian Recording Secretary Pennsylvania			

100 N. 17th Street, Suite 600, Phila., Pa., 19103. :: tel. (267) 514-7221 :: toll free (866) 507-7222.

New board members :: from page 1

Therapy from the University of Miami and a B.S. in Biology from Fairfield University. She works as a physical therapist treating adults and children in hospitals and in outpatient settings. She attended the 1999 Conference on Pick's Disease and Frontotemporal Dementias as well as the 2004 Satellite Meeting in conjunction with the 9th International Conference on Alzheimer's Disease and Related Disorders.

Kenna Ramirez, formerly of El Paso, Texas, now residing in Spain, is caregiver for her husband, Carlos, who was diagnosed with FTD in 2003. Carlos was Mayor of El Paso, Texas, from 1997 – 2001. Kenna plans to bring about awareness of frontotemporal dementias to the Hispanic population and to assure that

appropriate educational materials are available.

Bruce L. Richardson, Boulder, Co., is a caregiver for his wife Diana, who initially showed symptoms in the late 1990s and was formally diagnosed with Pick's Disease in 2001 at the age of 58. He was a CPA and started his career with Coopers & Lybrand and then spent almost 30 years in the financial side of the land development and homebuilding business in the Denver/Boulder area. In his spare time he is a woodworker, specializing in furniture.

Darlene Ryan, Fort Worth, Tx., is a business owner; her husband was diagnosed with FTD in December 2003, and they have a 15-year-old son.

Joanne Sackheim, MSW, LCSW is a

licensed clinical social worker who has been in private practice for 30 years. Her husband William was a writer-producer for films and TV and a two-time Emmy winner. He was diagnosed with Pick's in 1998 and died in December, 2004. Mrs. Sackheim was on the Board of the National Women's Political Caucus for six years. She has taken the group training course with the Alzheimer's Association and done some group counseling in her work at her former employment at a county hospital. With two other caregivers, she arranged a dinner party at the Alumni House at the University of California-San Francisco for California Caregivers and Dr. Bruce Miller addressed the group.

FTD Caregiver conference :: from page 1

host to "Voices in the Family," a call-in show aired on National Public Radio, will be the luncheon keynote speaker. His topic is Psychosocial Impact on Families.

Other speakers and their topics include:

H. Branch Coslett, M.D. on Diagnostic Overview; Murray Grossman, M.D. on Treatment; Jennifer Farmer, M.S. on Family History and Genetics; Keith M. Robinson, M.D. on Rehabilitation; Valerie T. Cotter, M.S.N., C.R.N.P., F.A.A.N.P. on Staging and Long-Term Care; Danita Vetter, M.A., C.G.C. on Daily Life

Resources; ad Paul L. Friedman, Esq., on Legal and Financial Planning.

Breakout sessions to offer further discussion about relevant topics presented during the talks will be moderated by speakers from the morning and afternoon sessions. There will be morning breakout sessions for Diagnostic issues, Management and treatment issues, Genetics and OT and PT. Afternoon breakout sessions include family counseling, clinical progression/staging, daily life resources, and legal and long-term planning.

There is no charge to attend, but space is limited and you must register before October 15, 2005. Registration materials may be obtained from the following web sites:

www.uphs.upenn.edu/cndr, http://wernicke.med.upenn.edu, www.FTD-Picks.org, www.alz-delawarevalley.org or by calling the AFTD office at (866) 507-7222.

AFTD will be giving six or more grants of up to \$500 each to family caregivers who want to attend the conference but need financial assistance. A grant form is available at the www.FTD-Picks.org web site or by calling (866) 507-7222.

AFTD members on the planning committee are Joyce Shenian, Lisa Radin and Helen-Ann Comstock.

The 5th International Conference on Frontotemporal Dementias is being planned for September 2006 in San Francisco.

Parrish served board with enthusiasm

Tess Parrish, a "retired" housewife, raised four children, and enjoys her eight grandchildren, all of whom were part of a great support system during the difficult years facing Pick's. She even managed to work on and secure a BA in art education from the University of New Hampshire in 1967.



Tess Parrish

None of that, however, prepared her for the work and the commitment and the love that would be necessary when her husband, Hugh Parrish, was diagnosed with Pick's in 1997, thanks to the assistance of Fytie Drayton and Dr. Murray Grossman. The illness had started much earlier with the first noticeable symptoms in about 1990. Hugh died in 2002 at the age of 77 after four and a half years in care.

Her earnestness in learning about Frontotemporal Dementias eventually led

her to the newly-founded Board of Directors of The Association for Frontotemporal Dementias, where she served through 2004.

"It has been a great joy and satisfaction to me to see how far AFTD has progressed in just a few years," she says. "I guess you could say that I was with Helen-Ann (Comstock) and the rest from the beginning. The present makeup of the Board is outstanding and promises a great future."

"What has surprised me most about AFTD is the way that Helen-Ann's dream has come true. Not being an "organization man," I wasn't aware of how much has to go into planning and executing the founding and continuing strength of such a group. Both the members of the Board and the professionals on the Medical Board are dedicated to making AFTD succeed, and it is obvious to me that it will."

Tess says she sees AFTD's mission as threefold: education, research, and fundraising. "I also feel that the connection between caregivers and the organiza-

tion is of the utmost importance."

Down the road five years, she says she is hopeful that AFTD will have been able to sponsor more research, to connect with, encourage, and inspire caregiver organizations, and to educate the general public and local medical professionals throughout the country on understanding and coping with the ravages of FTD.

Tess says caregivers are such an important part of the success of this venture that it "is vital that they be welcomed into and made a strong part of future conferences. They need to hear about and understand the latest research and be ready to play their part in supporting and educating other caregivers."

She pointed out that the web site (www.ftd-picks.org) is a very important tool for caregivers. "The ordinary caregiver may not be able to participate at the Board level, but they must reach out into their own communities and help other caregivers receive the support they can offer."

Survey: Most care still given at home

Kent S. Jamison, Ph.D and Vice Chair of the Association for Frontotemporal Dementias, reported results of our 2004 survey Feb. 25. Complete details are available online at www.FTD-picks.org. The results from these 105 respondents cannot be considered "scientifically" representative.

The results are based on a one-page survey filled out by 105 caregivers reporting on 101 persons with dementia. (In a few instances, more than one person from the same family filled out a survey.) While most (71%) were primary caregivers, a few were other family members or friends.

Three-quarters of those responding may be thought of as falling into one of two principle groups: One group, about one-quarter (28%) are dealing with someone diagnosed with Pick's disease; another 40% are dealing with someone diagnosed with FTD where the type of FTD is as yet undetermined. The remaining quarter are splintered into a wide assortment of much smaller groups, some distinguished by a

specific disorder (such as semantic dementia), others by their supporting role to the primary caregiver (such as a son or daughter or even a father or mother), and a few by the fact the person is no longer at home.

Primary caregivers usually are a spouse between the ages of 51 and 64. Three-quarters of these primary caregivers are dealing with someone still at home. The contrast in age of onset with Alzheimer's is striking. Over half were under the age of 60 when they were diagnosed and only 10% were 75 or over; with Alzheimer's, these proportions would typically be flipped. The youngest was 33, the oldest 88.

Forty-four percent were still working at the time they were diagnosed, yet just 2% still are working.

Most primary caregivers responding still are dealing with early stages of diagnosis. Two-thirds have been diagnosed within the last three years; half within the last two.

Respondents were asked to rate the per-

son's level of functioning in four areas on a scale of 1) not a problem to 5) severe loss. One third of the respondents characterize their loved one as having a severe loss in functioning in one or more areas.

Respondents report the greatest loss is planning ability, but this is not the loss that gives caregivers the greatest difficulty. Social behavior (19%) ranked highest, followed by speech difficulty (16%). More than four out of 10 respondents (43%) wrote in a function in addition to the four that were listed, including financial management.

More than half (55%) say they are in a support group, with 42% responding it is an FTD-specific support group. Most of those who aren't, would like to be. Seven out of 10 (71%) indicated they are interested "in connecting with another caregiver whose family member has been diagnosed with a similar frontotemporal dementia."