

Memory Matters



A publication for the patients, families and friends of the Johns Hopkins Memory & Alzheimer's Treatment Center
Spring/Summer 2009

We Walk the Path Together: A Journey to Hope

This past November more than 100 people joined the Memory Center clinicians and staff for a day of learning and discussion. *A Journey to Hope*, conference on memory loss, was a smashing success. Sylvia Mackey, wife of NFL Hall of Famer John Mackey and co-chair of Patient and Family Advisory Council, presented a keynote address that empowered and inspired all attendees.



Picture: Richard O'Brien, M.D., (left) and Constantine Lyketos, M.D., (right) during the discussion panel

The conference offered a supportive environment for families to meet and share concerns about daily challenges in caring for their loved ones. Participants traveled from as far as North Carolina and New York to gain knowledge about the latest dementia care approaches. One of the conference highlights was the discussion panel, moderated by Constantine Lyketos, M.D., director of the Memory Center. The discussion demonstrated participants' eagerness to become better and more informed caregivers. *(continued on page 2)*

This is a newsletter for you. We encourage you and your family to share your comments and story ideas with us. Feel free to call Marina Tompkins, LGSW, at 410-550-9031 or e-mail mtompki2@jhmi.edu.

Introducing the Patient and Family Advisory Council

If you have received care from the Johns Hopkins Memory and Alzheimer's Treatment Center (Memory Center), you have experienced an approach found nowhere else. While the Memory Center hosts renowned physicians and promotes innovative diagnostic approaches, ultimately, its focus on the needs of patients and families sets it apart from the rest. Our philosophy of care and support enhances the experience of each person who walks through our doors and ensures that no one copes alone with a memory-related illness.

The recently formed Patient and Family Advisory Council (PFAC)—led by Memory Center family members, Sylvia Mackey and Helen Hovdesven—offers patients and families the opportunity to share concerns, give praise and influence our Center. Both Mrs. Mackey and Mrs. Hovdesven are caregivers to a family member suffering the effects of dementia. "If I can share what I know now, then I can make a difference," says Mrs. Mackey.

Aimed at involving Memory Center patients and families in planning, decision-making and improvement efforts, the PFAC allows its members to contribute to the mission of the Memory Center. "We are dedicated to quality care," says Marina Tompkins, LGSW, coordinator of caregiver programs. "Patient and family involvement is an integral step in fulfilling our commitment."

PFAC will assist Memory Center leadership with:

- Designing and planning patient care areas and new programs
- Developing patient and family education and communication materials, both written and visual
- Giving feedback on projects and initiatives presented by staff

Are you interested in learning more or being a part of the PFAC?

Come join us at our PFAC Open House!

Saturday, April 4, 2009, Noon to 12:45 p.m.

The Johns Hopkins Hospital, Turner Auditorium
720 Rutland Avenue, Baltimore, Maryland 21205

Space is limited. Please RSVP to 410-550-9031.
Lunch and parking vouchers will be provided.



JOHNS HOPKINS
MEDICINE

JOHNS HOPKINS BAYVIEW MEDICAL CENTER



Calendar of Events

Mar. 23-25: Alzheimer's Association Annual Public Policy Forum
Omni Shoreham Hotel, Washington, D.C.
Info: Alzheimer's Association, 202-393-7737

Mar. 23: National Early Stage Summit
12:30 p.m. to 3 p.m., Omni Shoreham Hotel, Washington, D.C.
Info: Alzheimer's Association, 202-393-7737

Mar. 28: Conference for Caregivers—Caring for Those Who Care
8 a.m. to 3:30 p.m., Harford Community College Chesapeake Center
Info: 443-412-2175

Apr. 2: Conference for Alzheimer's and Dementia Caregivers
9 a.m. to 3:30 p.m., Salisbury University
Info: Alzheimer's Association, 410-561-9099

Apr. 4: 15th Update on the Treatment of Alzheimer's and Related Disorders: Defining the Standard of Care
7 a.m. to 4:15 p.m., The Johns Hopkins University School of Medicine, Thomas B. Turner Building
Info: Marina Tompkins, LGSW, 410-550-9031

Apr. 4: Open House for Patient and Family Advisory Council
Noon to 12:45 p.m., The Johns Hopkins Hospital, Turner Auditorium
Info: Marina Tompkins, LGSW, 410-550-9031

Apr. 18: Caregiver Conference
9 a.m. to 3 p.m., Annapolis Senior Center
Info: Alzheimer's Association, 410-561-9099

Apr. 18: Alzheimer's Association's Memory Ball 2009
7 p.m. to 12 a.m., Hilton Baltimore
Info: Alzheimer's Association, 410-550-9099

May 9: Dementia at Midlife: A Conference on Younger-Onset Alzheimer's and Related Dementias
9 a.m. to 3 p.m., Hilton Hotel in Columbia
Info: Alzheimer's Association, 410-561-9099

May 25: Memorial Day—Clinic Closed

May 30: Holistic Health Seminar on Memory Loss
9 a.m. to 2 p.m., Epworth United Methodist Chapel
Info: 410-550-2281

Oct. 31: A Journey to Hope Conference
9 a.m. to 2 p.m., Johns Hopkins Bayview, Asthma & Allergy Center
Info: 410-550-2281

Nov. 14: Pythias A. and Virginia I. Jones Annual African American Community Forum
Location and time TBD
Info: Alzheimer's Association, 410-561-9099

We Walk the Path Together: A Journey to Hope

(continued from page 1)

The Memory Center is already starting to plan for the 2009 conference, which will be held on Saturday, Oct. 31, and will offer information on the most current and upcoming research developments, and practical tips for caring for a loved one with Alzheimer's. We hope to see you there!



Pictured: Memory Center faculty Gwenn Smith, Ph.D., (left) and Esther Oh, M.D., (right) used the conference as an opportunity to meet families.

Research Focuses on Plaques in the Brain

The medications currently approved by the Food and Drug Administration (FDA) to treat Alzheimer's disease work by temporarily increasing brain cells' ability to communicate with one another, but they do not affect the underlying disease processes that are causing brain cells to die. New research is targeting beta-amyloid, a protein that clumps into plaques in the brain. It is these plaques that are the features of Alzheimer's and researchers are currently developing several treatments that may clear beta-amyloid from the brain or prevent it from forming in the first place.

If you or your loved one has Alzheimer's disease, and you are interested in learning more about clinical research, talk to your doctor or call our research clinical trials line at 410-550-6493.



What Happens Next?

In the fall of 2007, John*, a successful 59-year-old business owner, felt that something was different. He experienced difficulty with putting thoughts together and found that his mind was “fuzzy.” One day driving home on I-695, John forgot where he was going and could not recognize once-familiar signs. The green exit signs were no longer readable. Cars were passing him by and John could sense his anxiety growing. He pulled onto the shoulder and immediately called his wife. “That was the day,” John says, “Alzheimer’s disease entered my life.”

In the United States, every 71 seconds a new person is diagnosed with Alzheimer’s disease and by mid-century it will be every 33 seconds. If you or a loved one has recently been diagnosed with Alzheimer’s, mild cognitive impairment, Frontotemporal dementia or another type of dementia, you probably have questions, such as:

Are there limitations to what I can do now?

Yes, due to changes in the brain, there are activities you gradually may not be able to do, such as working, cooking or driving. At the Memory Center, we will help you focus on your strengths and what you can do rather than what you can’t.

How do I move forward?

A diagnosis brings changes, but not all are bad. Today, John attends an early stage memory loss discussion group with his wife. They have made new friends and go to dinner with couples from the group. John also participates in a social activity club, where he connects with others who have memory problems and enjoys his days filled with friends and laughter. Initially, many individuals are hesitant to participate in a discussion group or club. However, apprehensions dissolve once they experience the benefits of support and realize they aren’t alone on their new path.

If you have questions about your memory problems, call 410-550-6337.

** Name has been changed to maintain privacy.*

You gain strength, courage and confidence by every experience in which you really stop to look fear in the face.

—Eleanor Roosevelt

The Johns Hopkins Memory & Alzheimer’s Treatment Center

Director

Constantine Lyketsos, M.D.

Co-directors

Richard O’Brien, M.D., Ph.D.
Christopher Durso, M.D.

Faculty

Marilyn Albert, Ph.D.
Paul Dash, M.D.
Hochang Lee, M.D.
Christopher Marano, M.D.
Michelle Mielke, Ph.D.
Abhay Moghekar, M.D.
Esther Oh, M.D.
Vani Rao, M.D.
Paul Rosenberg, M.D.
Ned Sacktor, M.D.
Gwenn Smith, Ph.D.
Martin Stienberg, M.D.
Sevil Yasar, M.D., Ph.D.

Fellows

Cynthia Fields, M.D.
Dami Salami, M.D.

Caregiver Programs

Director

Ann Morrison, RN, Ph.D.

Coordinator

Marina Tompkins, LGSW

Clinic Manager

Marcy Post, RN, MSN

Clinic Nurse

Jennifer Mason, RN, BSN

Clinic Office Assistant

Jessica Belford
Nicole Thornton

Tips for Living with Alzheimer’s Disease

- Get help with daily tasks. Think about using services that can take care of everyday activities like shopping, cooking, bill paying and housekeeping.
- Use memory aides. Labels, lists, notebooks and sticky notes can help you cope.
- Make home safety improvements, such as installing grab bars in the bathroom to minimize falls. Enroll in the Medic Alert + Alzheimer’s Association Safe Return program to help you if you cannot find your way home or have a medical emergency.
- Plan for the future. Make plans now for your future care so your family can honor your wishes.
- Protect yourself from solicitors and potential fraud. Do things that will limit solicitors calling you on the phone or sending you mail. Get your phone number registered on the National Do Not Call List.
- Talk to friends about your memory loss because they may not know how “to be with you” after you disclose your diagnosis. Put them at ease.

—Courtesy of the Alzheimer’s Association



Memory & Alzheimer's Treatment Center Research Participants Honored

On Saturday, Oct. 4, 2008, the Memory Center sponsored a Research Participant Appreciation Forum. More than 130 research participants, scientists and community members joined for a day of celebration, education and support of Alzheimer's research. Attendees were provided with the latest information on research to treat, prevent and ultimately cure Alzheimer's disease by Johns Hopkins investigators. The event was sponsored by the Johns Hopkins Institute for Clinical Translational Research.

Ernestine Jolivet was the 2008 recipient of the Research Ambassador Award, acknowledging her efforts to increase African American participation in clinical research. Ernestine Jolivet discusses the importance of African American participation in Alzheimer's research.

In Her Own Words... Ernestine Jolivet

"After losing my mother to Alzheimer's disease in 1992, and my father to cardiovascular dementia 13 years later, our family decided to turn a family tragedy into a positive outcome. My parents always encouraged us to be part of the solution to a problem.

"I am a strong advocate for eradicating Alzheimer's disease and related disorders. The more I learned about this disease, the more I found that there was a lack of African American participation in research that would help early diagnosis and treatment. This made me want to become a part of the solution by becoming a research participant.

"Since becoming a research participant I feel obligated and compelled to challenge other African Americans to participate in research so they too can become a part of the solution. 'Each one, reach one, each one, teach one.' You can make a difference by getting involved in research trials and educating your respective communities about memory loss. Won't you become a part of the solution? Be a voice for the voiceless!!"



Pictured: Crystal Evans, community relations manager, right, and Ernestine Jolivet, left

Contact us!

Johns Hopkins Memory & Alzheimer's Treatment Center
5300 Alpha Commons Dr.,
Floor 4
Baltimore, MD 21224
hopkinsmedicine.org/memory

Clinic Information
410-550-6337
Research Clinical Trials
410-550-6493
Community Outreach
410-550-2281



JOHNS HOPKINS
MEDICINE

JOHNS HOPKINS
BAYVIEW MEDICAL CENTER

Patient and Family Support Groups

Support groups offer patients and loved ones a safe place to speak with others who have similar concerns and questions about coping with memory loss or related disorders. Support groups provide mutual support, practical information and help members learn more about living with memory loss. Support groups are free and open to the public.

Memory Loss Discussion Group

If you have been recently diagnosed with Alzheimer's disease or mild cognitive impairment and are interested in meeting with other individuals who share your same diagnosis, please contact Marina Tompkins, LGSW, at 410-550-9031 or e-mail mtompki2@jhmi.edu.

Caregiver Support Group, offered twice a month

Second Thursday of every month

12:30 to 1:30 p.m.

Hopkins ElderPlus, Mason F. Lord Building, East Tower, 1st Floor

Second Wednesday of every month

6 to 7:15 p.m.

Plaza Conference Room, John R. Burton Pavilion

For more information about caregiver support groups, call Susan Guido or Deny Stiasny at 410-550-7044.