

# Memory Matters



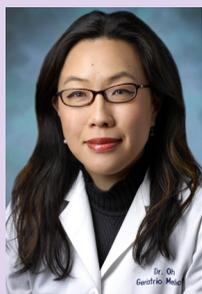
A publication of the Johns Hopkins Memory & Alzheimer's Treatment Center and Alzheimer's Disease Research Center

Fall/Winter 2019

## Physician Spotlight:

**Esther Oh, M.D., Ph.D.**

Associate Director, Johns Hopkins Memory & Alzheimer's Treatment Center



An associate professor in the Division of Geriatric Medicine and Gerontology, Dr. Oh was trained as an internal medicine physician with subspecialty training in geriatrics.

She has been caring for patients in the Johns Hopkins Memory and Alzheimer's Treatment Center since 2008.

### What do you enjoy most about your job?

I enjoy getting to know patients and families over time. I often develop a very strong bond with them, and am amazed by the strength and resilience of my patients, as well as the love and dedication of their family and friends.

### What do you think are the biggest barriers to research and care?

In terms of research, I think we need a better understanding of the underlying pathology of Alzheimer's disease and other types of dementia. In terms of care, I think we need a better reimbursement system for supporting hands-on care for patients with dementia at home, in the hospital and in long-term care facilities.

## Alzheimer's Disease Research Support Continues to Increase

For the sixth consecutive year, funding for Alzheimer's disease (AD) and related disorders (ADRD) has increased. The National Institutes of Health (NIH) budget for fiscal year 2019 included an additional \$425 million designated for ADRD research, bringing the total funding available from the NIH to \$2.4 billion annually. This reflects recognition by Congress and the public at large that it is critically important to improve treatment options for patients with ADRD.

There are currently no effective treatments for AD, which means there is not an effective way of slowing disease progression or delaying its onset. This continued increase in funding is especially important in the context of recent outcomes of clinical trials. Within the past few months, three major clinical trial programs were stopped due to evidence that the medications being tested were not effective, including those supported by Biogen, Lilly and Amgen.

The funding increase will help researchers expand their efforts to understand changes in the brain that cause the disease and search for improved approaches to treatment. It also will allow for more studies on lifestyle factors – both those that increase risk and those that reduce it – in order to provide guidance to the public on ways of reducing risk for ADRD. Additionally, the increase in funding will expand care and treatment options for patients and families dealing with dementia on a daily basis.

To learn more about research opportunities at Johns Hopkins, visit [alzresearch.org](http://alzresearch.org).

### Alzheimer's Disease

#WhatYouNeedToKnow

5.2 million  
Americans are living with  
Alzheimer's disease,  
the most common form of dementia.  
By 2025, this number will top

7 million.



 Like us on Facebook! Visit [facebook.com/jhmemoryandaging](https://facebook.com/jhmemoryandaging) to stay up-to-date on the latest information, resources, events and research opportunities related to healthy aging, memory loss and dementia.

Please share *Memory Matters* with your family and friends! To request extra copies, please contact **Mattie Smith** at **410-550-9028** or **msmit311@jhmi.edu**.

# COMPREHENSIVE SUPPORT FOR FAMILY CAREGIVERS

Founded in 2015, Called to Care<sup>®</sup>, a program of Johns Hopkins Bayview, helps families in the Greater Baltimore area address the challenges of caring for loved ones with health-related needs or limitations, including dementia. Initially funded by the Weinberg Foundation, this innovative program is designed to equip caregivers with the tools, resources and information they need to provide the best care for their loved ones.

Called to Care<sup>®</sup> provides a range of assistance to families. Educational resources include "Lunch and Learn" events and bi-monthly newsletters. Staff also link caregivers to local support groups, as well as community agencies that provide services ranging from respite care and home modification to legal and transportation assistance.

Because caregiving can be emotionally, physically and financially demanding, effective caregiving also requires that caregivers take care of themselves. Recognizing this, Called to Care<sup>®</sup> developed a **free Family Caregiver Toolbox** (*available on its website*), which provides strategies caregivers can use to manage stress and better care for themselves.

For more information about Called to Care<sup>®</sup> and its programs, visit [hopkinsmedicine.org/jhbmc/c2c](http://hopkinsmedicine.org/jhbmc/c2c) or call 410-550-8018.



*The Called to Care<sup>®</sup> team, left to right: Tammy Marsh, community relations coordinator; Linda Stewart, caregiver project manager; W. Daniel Hale, Ph.D., director; and Kimberly Monson, community program coordinator*

## UNDERSTANDING THE COMPLEXITY OF CHANGES IN THE BRAIN



One essential element in dementia research is the study of brain tissue. Over the years, this has provided critical insights into the underlying causes of memory loss and dementia in older adults. It has been well known for some time that the primary cause of dementia is Alzheimer's disease. There is, however, an increased understanding that it is most common for an individual with dementia to have more than one pathology present in the brain when they die. This includes cerebrovascular disease, Lewy body disease and other brain pathologies. The recognition that more than one disease may be responsible for declines in memory and thinking has led to the idea that treatments are likely needed for each of these disorders in order to be truly effective in delaying disease progression.

Since it is not currently possible to evaluate the presence of these various disorders with modern brain imaging techniques, the study of donated brain tissue serves many purposes. If an individual has experienced declines in mental abilities, the study of brain tissue is the only way to know for certain the cause of the changes. If an individual has remained cognitively normal throughout their life, the study of their brain tissue also is critical because it will help researchers identify ways the brain may resist the development of pathology as someone gets older.

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### *Understanding the Complexity of Changes in the Brain cont'd.*

Brain tissue also allows researchers to study the age at which pathologies begin to accumulate and how they spread to different parts of the brain over time. For example, recent studies have suggested that amyloid plaques and tau neurofibrillary tangles – the hallmarks of Alzheimer’s disease – begin to accumulate in middle age. Understanding the timeframe during which pathology accumulates and the patterns of accumulation has important implications for the timing of treatments.

**The brain tissue of participants who have been involved in research is particularly valuable, because it allows researchers to link all the information they obtained during life to the changes that can be seen under a microscope.** That is why the Johns Hopkins Alzheimer’s Disease Research Center strongly encourages its participants to agree to brain donation. The study of donated brain tissue is critical for understanding the cause of dementia on an individual level, and for developing new treatments, interventions and prevention strategies for future generations.

## CALENDAR OF EVENTS



### **Oct. 26: Walk to End Alzheimer’s**

9 a.m.

Canton Waterfront Park

3001 Boston St., Baltimore, MD 21224

**Register:** 410-561-9099 ext. 1841 or [alz.org/maryland/walk](http://alz.org/maryland/walk)

### **Nov. 2: Pythias A. and Virginia I. Jones African-American Community Forum on Memory Loss**

8 a.m. to 3 p.m.

New Psalmist Baptist Church

6020 Marian Dr., Baltimore, MD 21215

**Info./Register:** 800-272-3900 or [alz.org/maryland](http://alz.org/maryland)

### **Nov. 9: Journey to Hope**

8:30 a.m. to 2 p.m.

Johns Hopkins Asthma & Allergy Center

Johns Hopkins Bayview campus

5501 Hopkins Bayview Circle, Baltimore, MD 21224

**Info./Register:** 410-550-2281

### **April 17, 2020: Alzheimer’s Association Annual Dementia Conference**

8 a.m. to 4 p.m.

Sheraton Baltimore North Hotel

903 Dulany Valley Rd., Towson, MD 21204

**Info.:** 800-272-3900 or [alz.org/maryland](http://alz.org/maryland)

### **June 2020: Holistic Health Seminar on Memory Loss**

9 a.m. to 12:30 p.m.

Randallstown Community Center

3505 Resource Dr., Randallstown, MD 21133

**Info.:** 410-550-2281

### **June 2020: Annual Alzheimer’s Awareness Purple Weekend**

Inform your congregation about resources and information on Alzheimer’s disease by going purple during the month of June!

**Info./Register:** 800-272-3900

### **June 9, 2020: ADRC Annual Conference on Aging and Dementia**

9:30 a.m. to 2:30 p.m.

Bunting-Blaustein Cancer Research Building

The Johns Hopkins Hospital

1550 Orleans St., Baltimore MD 21287

**Info.:** 410-614-0363

**For more information about the events listed, please call the phone number or visit the web address provided above.**

# RESEARCH STUDIES SEEKING PARTICIPANTS



You can help us learn more about the diagnosis and treatment of individuals with memory problems by volunteering for a research study. Each study has different eligibility requirements for participants. Procedures, length of study and compensation vary.

- **Memory and Aging Study of the Johns Hopkins ADRC** – 410-550-9021
- **Magnetic Resonance Imaging (MRI) Studies in Cognitively Normal Individuals or Individuals with Mild Memory Problems** – 410-955-5057
- **Positron Emission Tomography (PET) Studies in Individuals with Mild Memory Problems** – gsmith95@jhmi.edu
- **Positron Emission Tomography (PET) Studies in Individuals with Dementia** – 410-955-8516
- **Medication Trials in Individuals with Mild Memory Problems** – 410-955-5057
- **Medication Trials in Individuals with Dementia** – 410-550-9022

For more information about research studies conducted by the Johns Hopkins Alzheimer's Disease Research Center, visit [alzresearch.org](http://alzresearch.org).



## The Johns Hopkins Alzheimer's Disease Research Center

### Director

Marilyn Albert, Ph.D.

### Associate Directors

Constantine Lyketsos, M.D., MHS  
Philip Wong, Ph.D.

### Community Outreach:

410-550-2281

### Education Resources:

410-614-0463

### Research Opportunities:

410-550-9054

Web: [alzresearch.org](http://alzresearch.org)

## The Johns Hopkins Memory & Alzheimer's Treatment Center

### Director

Constantine Lyketsos, M.D., MHS

### Associate Directors

Samuel Durso, M.D.  
Marilyn Albert, Ph.D.

### Clinical Associate Directors

Paul Rosenberg, M.D.  
Esther Oh, M.D., Ph.D.

Clinic Info: 410-550-6337

Web: [hopkinsmedicine.org/psychiatry/memory](http://hopkinsmedicine.org/psychiatry/memory)

## PATIENT AND FAMILY SUPPORT SERVICES

A variety of support services offer patients and caregivers opportunities to speak with others who have similar concerns and questions about coping with Alzheimer's disease or related disorders. These services also provide practical information and help members learn more about living with memory loss. The programs below are free and open to the public.

### Hopkins ElderPlus Caregivers Support Group

Second Thursday of every month, 12:30-1:30 p.m.

Johns Hopkins Bayview, 4940 Eastern Ave., Baltimore, MD  
Mason F. Lord Building, East Tower, Room E106

**Info.:** 410-550-7044

### Frontotemporal Dementia Group

Second Wednesday of every month, 10:30 a.m.-12:30 p.m.

Alzheimer's Association, 1850 York Rd., Suite D, Timonium, MD

**Info.:** 410-561-9099

### Club Memory (social club for individuals with dementia and their caregivers)

First Tuesday of every month, 2-4 p.m.

Johns Hopkins Bayview, 4940 Eastern Ave., Baltimore, MD  
Harrison Medical Library and Medicine Education Center

**Info.:** 410-550-7211 or [anelso18@jhmi.edu](mailto:anelso18@jhmi.edu)

### Web-based Family Support Resources

Supported by the Jane K. Shapiro Dementia Care Program

**Info.:** [hopkinsmedicine.org/psychiatry/memory](http://hopkinsmedicine.org/psychiatry/memory) (Click on "Patient and Family Resources.")

For more information about support groups in your area, visit [alz.org/Maryland](http://alz.org/Maryland) and click on "Support Groups."