

Memory Matters



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

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Faculty Spotlight:

Chiadi Onyike, MBBS, MHS

Director, Young Onset Dementias Program



Dr. Onyike specializes in neuropsychiatry and the care of individuals who have neurodegenerative dementias. His practice focuses on conditions that develop in midlife or earlier (50 and younger).

What do you enjoy most about your work?

Identifying and explaining to patients and their families the nature of their diagnosis, and then making a plan of care that is empowering – because it can reduce the patients' symptoms, and can provide direction and promote autonomy for patients and their caregivers.

What are some of the biggest barriers to dementia treatment and care?

The biggest barrier is access to specialists with the skill and experience to make an accurate diagnosis. Early onset dementias can be challenging to accurately diagnose, and many patients and families spend valuable time seeking a diagnosis and an effective approach to managing these difficult conditions.

COVID-19 and Brain Health

As the COVID-19 pandemic continues, there is increasing evidence that the virus can significantly impact brain health. A recent report from AARP's Global Council on Brain Health summarized what is known thus far.¹

It is now clear that the SARS-CoV-2 infection can have direct effects on the brain. The symptoms include loss of taste and smell, headaches, and difficulty thinking and concentrating. For some, these symptoms only last during the period of time a person is very ill. However, for others, the symptoms can persist over time (often called "long haulers"). Additionally, those with pre-existing brain diseases – such as dementia – may be more susceptible or at greater risk for COVID than others.

The COVID-19 pandemic has also had indirect consequences for brain health, largely through its impact on mental well-being. Many have experienced feelings of anxiety, uncertainty and disrupted sleep patterns. Although physical distancing has been important for slowing the spread of COVID-19, these safety measures have also resulted in loneliness and social isolation. Notably, these types of pandemic-related stressors and disruptions of daily activities may impact one's ability to think and reason, as well as one's mood. As evidence of this, data suggests that mental health

Protecting Your Brain Health During COVID-19

Recommendations from the AARP's Global Council on Brain Health

-  Consider getting the vaccine as soon as you are able
-  Stay physically active
-  Maintain a balanced diet
-  Stay socially connected
-  Maintain a regular sleep schedule
-  Stimulate your brain
-  Don't put off necessary medical appointments
-  Take care of your mental health
-  Pay attention to signs of sudden confusion
-  Monitor changes in brain health (such as changes in thinking and memory)

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Get Social With Us! Follow us on [Facebook \(JHMemoryandAging\)](#) and [Twitter \(@JH_Memory_Aging\)](#) for 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 **Ashley Scott** at **410-550-2281** or ascott41@jhmi.edu.

ACCELERATED APPROVAL FOR AN ALZHEIMER'S DISEASE DRUG

In June of 2021, the FDA decided to provide accelerated approval of Aducanumab (brand name Aduhelm), a new drug for individuals with mild cognitive impairment or mild dementia due to Alzheimer's disease (AD). This drug was designed to clear amyloid plaques from the brain – one of the hallmark brain changes of AD.

This approval received a lot of attention because a new drug for AD hasn't been approved in nearly 20 years. Although most of the drugs that have been studied over the past decades have been designed to target AD-related brain changes, the challenge has been to see if treating these brain changes translates to improvement in memory and other mental abilities.

Aducanumab's approval has sparked some controversy. First, the FDA committee that reviewed the results of the clinical trials recommended that the drug should not be approved. Although the drug's trials showed that Aducanumab reduces levels of amyloid in the brain, the evidence for benefits on memory and thinking abilities were considered questionable. Additionally, individuals undergoing treatment need to be closely monitored with regular brain imaging because there is an increased risk of brain swelling or bleeding.

There are also concerns about accessibility. Aducanumab is administered through monthly intravenous (IV) infusion (as opposed to a pill) – a method that cannot be easily accommodated by many medical centers. Moreover, the cost of the treatment is considerable. The drug itself is estimated at \$56,000 per year, but with the added expense of infusions and regular brain imaging, the estimated costs increase to approximately \$100,000 per year. The extent to which these costs will be covered by insurance is not yet clear, and for many, these factors may serve as a barrier to drug access.

As a result of the controversy surrounding these issues, both the FDA and the U.S. Congress have begun investigations into the drug's approval process. As part of the accelerated approval process, the FDA is requiring an additional clinical trial for determining whether Aducanumab is beneficial to memory and thinking abilities. In the meantime, patients considering whether to take the drug should have in-depth discussions with physicians who specialize in memory disorders, and carefully consider the potential benefits, risks, accessibility and costs.

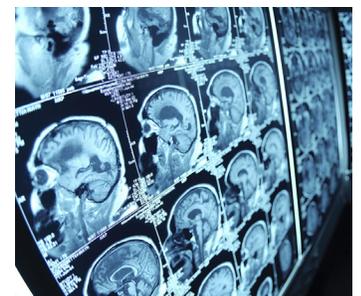


IMPORTANCE OF BIOMARKERS FOR ALZHEIMER'S RESEARCH

To better understand the changes that occur with healthy aging and Alzheimer's disease (AD), researchers are turning to the use of biomarkers – measures that can indirectly tell us what is happening in the brain. While it is still essential to evaluate mental abilities, such as memory and language, biomarkers can provide valuable information about why changes in mental abilities may be occurring.

In AD research, the most widely used biomarkers are those based on brain imaging. Brain scans from Magnetic Resonance Imaging (MRI) provide detailed pictures of the brain's structure and function, including information about the size of individual brain regions and how they are connected to one another. Positron Emission Tomography (PET) brain scans can provide information about the proteins that accumulate during the course of aging and AD, such as amyloid and tau. These imaging methods can provide an understanding of where changes are occurring in the brain.

Biomarkers from bodily fluids also provide valuable insights into what is happening in the brain. Measures from cerebrospinal fluid (a fluid that surrounds the brain) can evaluate brain proteins that may be altered during aging and AD. These measures provide information about the total amount of proteins in the brain (as opposed to the



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COVID-19 AND BRAIN HEALTH

IMPORTANCE OF BIOMARKERS

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and depression have worsened during the pandemic, especially among those with caregiving commitments and prior mental health concerns.

Researchers around the world are continuing to study the short- and long-term impact of COVID-19 on brain health. The Global Council on Brain Health's recent report includes recommendations for what you may be able to do to protect your brain health (*see image on page 1*), though it will likely be years before we have a full understanding of the impact of COVID-19 and potential coping strategies.

¹www.aarp.org/health/brain-health/global-council-on-brain-health/covid/

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amount in specific brain locations), and a much wider range of proteins can be assessed than is currently possible with brain imaging. Importantly, new methods are being developed that may allow researchers to measure these same proteins in blood.

The application of brain biomarkers has revolutionized our understanding of age- and disease-related brain changes, both among individuals with no problems with their memory and in those experiencing memory changes. Biomarkers help researchers diagnose and track the progression of AD, and are also commonly used in clinical trials to help identify appropriate patient groups and to monitor responses to drug treatments and other interventions.

For more on the use of biomarkers in this type of research, visit nia.nih.gov/health/biomarkers-dementia-detection-and-research.

CALENDAR OF EVENTS

Walk to End Alzheimer's

Join our team – in-person or virtually!

Oct. 23, 2021

In-person location: Hunt Valley Town Centre
118 Shawan Rd., Cockeysville, MD 21030

Info./Register: tinyurl.com/JHWalkTeam

Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss (virtual)

Nov. 6, 13, 20 & Dec. 4 (4-week series)

Each session is from 10 to 11:30 a.m.

Info./Register: 800-272-3900 or alz.org/maryland

Journey to Hope Conference (virtual)

November 13

9 to 11:30 a.m.

Info./Register: 410-550-7211 or anelso18@jhmi.edu

Holistic Health Seminar on Memory Loss (virtual)

June 2, 2022

9 a.m. to 12 p.m.

Info.: 410-550-2281

Alzheimer's Disease Research Center Annual Conference on Aging and Dementia

June 14, 2022

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

Owens Auditorium, Bunting-Blaustein Cancer Research Building

1550 Orleans St., Baltimore MD 21287

Info.: alzresearch.org/annual-conference.cfm

Purple Weekend: Faith-based Alzheimer's Awareness

Faith communities help raise awareness about Alzheimer's disease and related dementias, and connect members with information about services and resources, by holding "Purple Weekend" events. This includes events held during a religious gathering (held at any time throughout the year) that provide information about Alzheimer's disease and related disorders.

Info.: 800-272-3900 or mataylor@alz.org

For more information about the events listed, please use the contact information or websites provided above.

RESEARCH STUDIES SEEKING PARTICIPANTS



Help us learn more about healthy aging and the diagnosis and treatment of memory problems by volunteering for a research study. Each study has different eligibility requirements. Procedures, length of study and compensation vary.

- **Memory and Aging Study of the Johns Hopkins ADRC** – 410-550-2281
- **Magnetic Resonance Imaging (MRI) Studies in Cognitively Normal Individuals or Individuals with Mild Memory Problems** – 410-502-4797
- **Positron Emission Tomography (PET) Studies in Individuals with Mild Memory Problems** – 410-550-4192
- **Medication Trials in Individuals with Mild Memory Problems or Dementia** – 410-550-9022

For more information about research studies conducted by the Johns Hopkins Alzheimer's Disease Research Center, visit alzresearch.org.



The Johns Hopkins Alzheimer's Disease Research Center

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Community Outreach:

410-550-2281

Education Resources:

410-614-0363

Research Opportunities:

410-550-2281

Web: alzresearch.org

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Clinic Info: 410-550-6337

Web: 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, open to the public and currently held **virtually**. Call or email for more information and to receive a Zoom link.

Hopkins ElderPlus Caregivers Support Group

Second Thursday of every month, 12:30 – 2 p.m.

Info.: 410-550-8093

Frontotemporal Dementia Group

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

Fourth Wednesday of every month, 6:30 – 8 p.m.

Info.: 410-294-2409 or noto27@aol.com

Club Memory

Social group for individuals with dementia and their caregivers.

First and third Wednesday of every month, 2 – 3 p.m.

Info.: 410-550-7211 or anelso18@jhmi.edu

Web-based Family Support Resources

Supported by the Jane K. Shapiro Dementia Care Program

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

For more information about support groups in your area, visit alz.org/Maryland and click on "Support Groups."