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**For more information about
the
Emory Alzheimer's
Disease Research Center
or the content of this
newsletter, please call
Cornelya Dorbin
404-712-1416
or visit our website at
www.alzheimers.emory.edu**

**Aducanumab Update from Emory Cognitive Neurology Clinic
February 2022**

Aducanumab (Aduhelm) is an infusion medication approved by the FDA on June 7, 2021, as a treatment for patients with very mild Alzheimer's disease. In clinical trials, aducanumab showed a small amount of benefit in some patients but also caused side effects including brain bleeding and swelling. The medication is expensive (cost of drug, infusion center, office visits for monitoring, multiple MRI brain scans, etc.). A preliminary Medicare coverage determination (January 2022) suggested that aducanumab may be covered in context of new clinical trials to understand how helpful aducanumab is for Medicare beneficiaries, however details of how these trials would occur and who would offer them remain unknown. A final decision on insurance coverage from Medicare and other entities has not been made but is expected later in 2022. Emory Healthcare, along with other institutions like Cleveland Clinic, Mount Sinai, Mass General Brigham, and the Veterans Affairs Hospital System, has decided not to add aducanumab to its pharmacy formulary. This means that aducanumab will not be available for infusion within the Emory Healthcare system. The decision was based on review of all available data on aducanumab including the amount of benefit to patients, safety and risk of side effects, and value/cost to patients. This decision may be revisited in the future if additional data becomes available. Once there is more information about insurance coverage, our Emory Cognitive Neurology team will determine if there are any options for referring eligible patients to external sites for aducanumab infusions.

What is Clinical Research?

What is clinical research and what does it entail for participants? These are two of the most commonly asked questions. The development of new medical treatments and cures would not happen without clinical research and the active role of research participants. Clinical research is medical research that studies health and disease in people. It is how we learn better ways to prevent, detect, or treat diseases. It helps determine the safety and effectiveness of new treatments, and is a key research tool for advancing medical knowledge and patient care for future generations. There are many reasons why you might choose to participate in a clinical trial. You may choose to join in order to test new treatments that might work better than those currently available, to receive regular monitoring by medical professionals, or help others including future family members that may be at risk for a particular disease. Whatever your motivation, you can make a difference by participating in research.

Not all clinical research studies are the same.

Involvement in a clinical research study is a partnership between researchers and volunteer participants, who work together towards a scientific discovery. We interviewed two people that participated in clinical studies to get their feedback on their experience in clinical studies at Emory ADRC. A former participant age 83, stated, "I have really enjoyed my experiences in clinical research at the Alzheimer's Disease Research Center. I feel more people should be involved." Another participant age 78 stated, "My experience in clinical studies at ADRC has been valua-

ble to me. It has given me information about part of my body that I have neglected. The people doing these studies are top in their profession. It hasn't cost me anything but time and time is what I am trying to get more of."

Not all clinical research studies are the same. Different studies are looking for participants who fit certain profiles, defined by criteria such as current cognitive functioning, age, race or ethnicity, or family history. The length of participation in a clinical study varies depending on the topic being studied. Some clinical trials last a few months, and some may last several years. Involvement typically consists of cognitive and/or physical assessments or multiple visits to study sites for further testing. In addition, some clinical research studies include the collection of spinal fluid, saliva, blood specimens, or MRI scans that will be used for testing new technologies or therapies. Prior to joining a clinical research study, there is open communication with staff members to help you understand why the study is set up a certain way, and to let you know what you can expect. That way you can make an informed decision about consenting to join the trial.

Joining a clinical research study is simple. Once you identify a study you are interested in, contact the study coordinator. You can usually find this contact information in the description of the study, or you can contact the ADRC center directly. The research staff will ask you a few questions over the phone to determine if you meet basic qualifications for a particular study. This is done to ensure that we help you match with a study that is the very best fit for who you are and what you might want to do. Researchers will then look over the information you have provided and suggest one or more studies that are a good fit. At that point, a staff member from that study will contact you, provide more information, and get you enrolled in the study.

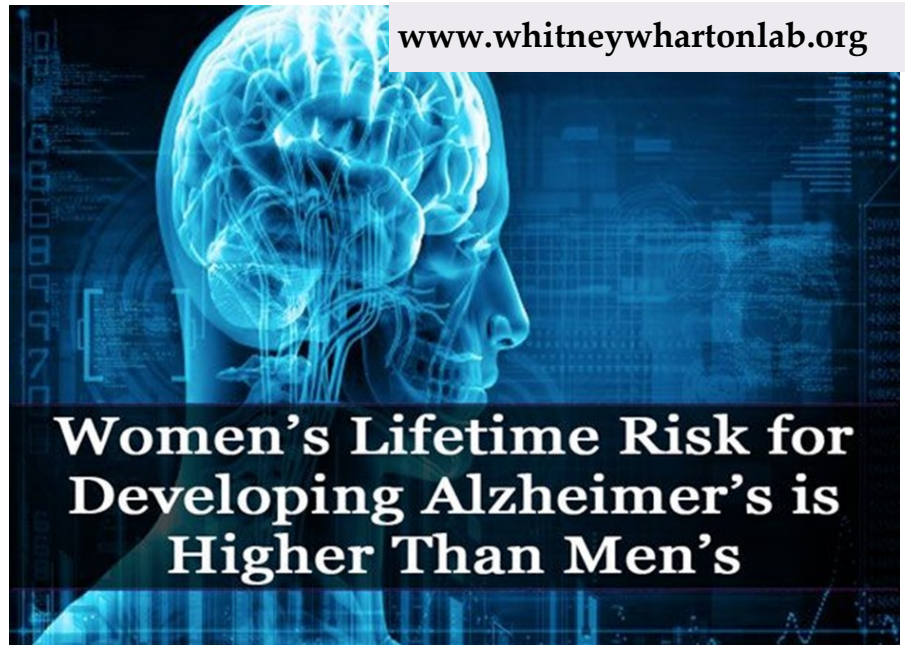
You can find more information regarding clinical trials at our website: www.Alzheimers.emory.edu or you call contact us via phone at (404) 727-6050.

Understanding Women's Lifetime Risk for Alzheimer's

Women are more likely than men to develop Alzheimer's disease (AD), and research suggests this is not only because women have a longer life expectancy than men.

This increased risk is likely due, in part, to fluctuating sex hormones across the lifespan. Sex hormones likely have direct actions on AD brain biomarkers ($A\beta$ and tau levels), as well as indirect actions via inflammation, sleep disruptions, and reduced brain blood flow, all of which are risk factors for AD. We would like to invite you to participate in a study examining the relationship between brain and systemic sex

hormones on known AD biomarkers. We are recruiting men and women 45 years and over. You do not need a study partner to participate. Participants will complete 3 study visits annually. At each year, we will collect medical and medication history, cognitive testing and questionnaires (stress, sleep, exercise, nutrition). Participants will also undergo blood draw for sex hormone and inflammatory markers. At Baseline and Year 2, participants will undergo lumbar puncture for spinal fluid collection, neuroimaging and will take home a non-invasive sleep monitor to wear for 1 night. At each visit, participants will receive \$100, for a total of \$300 over the entire study. Additionally, participants will receive the results of their in home sleep study, so that you may track your sleep patterns over time.

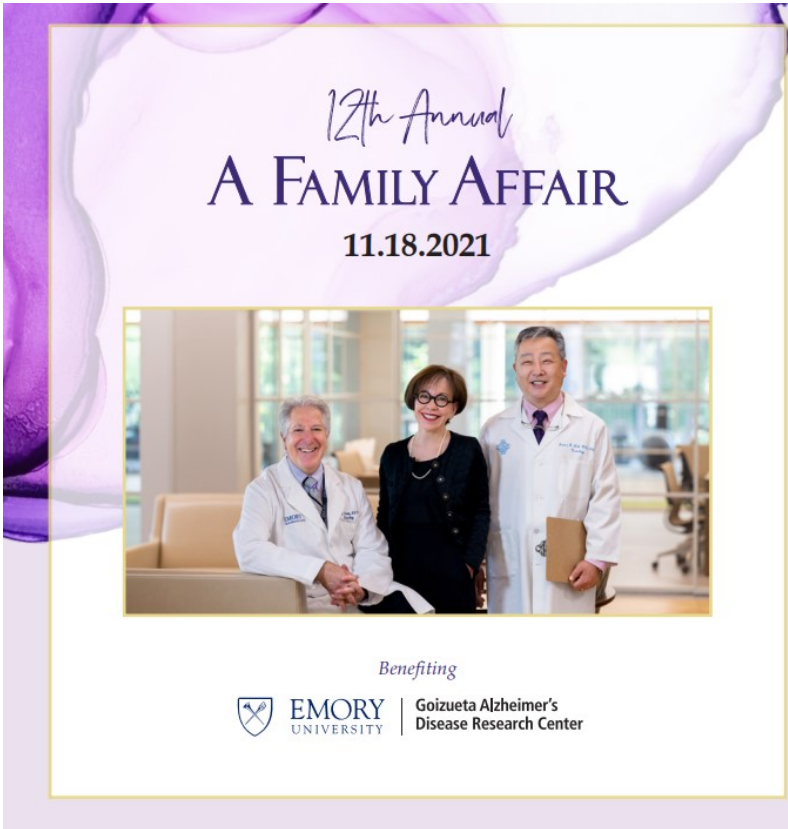


How to access the Georgia Memory Net

The Georgia Memory Net (GMN) is a statewide network of clinical centers supported by the Georgia Department of Human Services. GMN's five Memory Assessment Clinics (in Albany, Atlanta, Augusta, Columbus, and Macon) are dedicated to providing earlier diagnosis for persons living with Alzheimer's disease and similar dementia illnesses and customized care plans for the families who care for them. The network starts with primary care providers. All Medicare-eligible adults are entitled to a fully covered Annual Wellness Visit with their providers. For more information email info@gamemorynet.org



A FAMILY AFFAIR 2021: Thank you for your support



Thank you all for continuing to support *A Family Affair*. This year's event raised more than **\$1 Million** to advance discovery toward a cure. For this year's momentous event, we were honored to have Anne Barge Clegg serve as Event Chair and Ken Jarvis as honorary Chair. Alzheimer's disease is not only deadly but a growing concern. The number of people living with it is expected to more than double, reaching 14 million by year 2050. Therefore, the **Goizueta Alzheimer's Disease Research Center (GADRC)** is committed to conducting clinical trials and extensive research to improve the living conditions of those with Alzheimer's and to ultimately find a cure. Funds generated through A Family Affair help fund GADRC's lifesaving work. Each year this program brings together the families touched by Alzheimer's, their friends who want to be supportive, and the scientists of the ADRC

who are battling the disease in the research labs and clinics. Save the Date for the annual program set for Thursday, November 10, 2022. For information contact **Kiana Matthews** at 470-259-2450



Diversity In Action

Touched by Alzheimer's through multiple loved ones, Ken Jarvis has become a significant champion of the Goizueta Alzheimer's Disease Research Center. More specifically, Ken aims to bring increased attention to health disparities within the Alzheimer's arena. To pave the way for further progress, he has launched a matching gift challenge at Emory in honor of his wife. This challenge will jumpstart Alzheimer's research performed by and for African Americans and other underrepresented communities.

KEN JARVIS
Honorary Chair, A Family Affair

Emory Cognitive Empowerment Program

Through a unique partnership with Georgia Institute of Technology the **Charlie and Harriet Shaffer Cognitive Empowerment Program** aims to provide people with Mild Cognitive Impairment (MCI), and their care partners and families an opportunity to participate in comprehensive lifestyle programs that promote joy, purpose, health, and wellness. Members of the program will receive personalized assessments and goal setting sessions designed to empower them as they seek to implement healthy brain interventions. The program is for patients and families in Emory's Cognitive Neurology Clinic who receive a diagnosis of MCI due to presumed Alzheimer's Disease or other related conditions. The program is a unique comprehensive lifestyle program that addresses the following domains via various interventions:

Physical Activity | Cognition | Functional Independence | Social Engagement | Wellbeing | Education

The Cognitive Empowerment Program also encompasses an innovative in-home sensing component which will collect a variety of data to identify the positive impacts that the program has on your life. Sensors will be placed in members' homes in various locations. The sensors will not collect any audio or visual data, but instead will collect data on motion, medication use, driving, temperature, sleep patterns and more.

The program activities will primarily occur at 6 Executive Park Dr. NE, Atlanta, GA 30329. Members of the Cognitive Empowerment Program will attend interventions twice weekly for 12 months, from approximately 10:00 am to 3:00 pm. Currently, the Cognitive Empowerment Program is only accepting referrals from the Emory Cognitive Neurology clinic. If you are interested in joining the program, please contact our office at 404.712.5555 or speak with your Emory Cognitive Neurology provider during your next clinic visit.

Sleep intervention in persons with Memory Loss

Dr. Glenna Brewster is an Assistant Professor in the Nell Hodgson Woodruff School of Nursing at Emory University. She is interested in developing interventions to improve sleep disturbances in persons living with memory loss and their caregivers/care partners. For this study, they are recruiting persons living with memory loss and their caregivers/care partners who both are experiencing sleep problems to participate in a 6-week study involving two data collection visits and a 4-week intervention. Participants will complete some questionnaires, wear a watch to monitor their sleep, and discuss their experience with the intervention. Each person will receive \$100 for complete participation in the study. Understanding how chronic conditions (obesity and hypertension) are associated with sleep disturbances, depression, anxiety and fatigue in Black/African American caregivers of persons living with memory loss. For this study, we are recruiting Black/African American caregivers between ages 30-85 of persons living with memory loss. Participants will complete two visits over three months and will received \$25 for the completion of each visit. For more information or if you are interested in participating in either of the studies, email: glenna.brewster@emory.edu.

Interested in donating your brain to the Emory Alzheimer's Disease Research Center?

Participation in the autopsy program through the Emory ADRC requires, at a minimum, a one-time visit to Emory for collection of baseline measures.

The visit takes approximately 3 hours and includes: Consent interview | Interviews with the participant and study partner to review | Medical history | Family history | Current activities and concerns | Cognitive testing | Physical and neurological exam | Retinal imaging (includes dilating eyes, similar to regular eye exams). Additionally, we will contact you periodically (not more than once per year) to update your research record. If you would like to participate or have further questions, please call Samantha

Heldenberg at 404-712-7542 and let her know you are interested in completing a "one-time HONOR visit for autopsy purposes".



Clinical Trials & Research Studies Spring/Summer

Emory Goizueta Alzheimer's Disease Research Center
6Executive Park Drive NE, Atlanta, GA 30329
404-712-0212 www.alzheimers.emory.edu

RESEARCH STUDY	ELIGIBILITY	CONTACT PERSON
<p>Honor Research Registry: Longitudinal study of changes in memory and other cognitive skills</p>	<ul style="list-style-type: none"> • Aging people with no memory problems • People of any age with MCI, Alzheimer's disease or other forms of dementia • Willing to participate in additional research studies, Study partner available to participate in visits 	<p>Samantha Heldenburg Shelden@emory.edu 404-712-7542</p>
<p>Registry for Remembrance: An initiative to increase awareness & participation in neurology research</p>	<ul style="list-style-type: none"> • Ethnic individuals of African Ancestry, Aging people over 60 with no memory problems • People of any age with mild cognitive impairment, Alzheimer's disease or other forms of dementia, Study partner available to for all visits 	<p>Crystal Davis 404-727-6696 Cpdavis@emory.edu</p>
<p>Emory Healthy Aging Study – This study is the largest clinical research study ever conducted in Atlanta. It is designed to further our scientific understanding of how we age, so that we can better understand, prevent and treat diseases of aging.</p>	<ul style="list-style-type: none"> • ≥ 18 years of age • Read and speak English fluently 	<p>To participate, simply sign up online at www.healthyaging.emory.edu, complete a brief health history questionnaire and occasionally respond to various surveys and complete online memory tasks.</p>
<p>Metformin in Alzheimer's dementia Prevention (MAP)– Two year study to test the efficacy of metformin in the prevention of cognitive decline associated w/ Alzheimer's disease.</p>	<ul style="list-style-type: none"> • Diagnosis of MCI • 55 - 90 years old • NOT on Diabetic Medication • BMI ≥ 25 	<p>Tiffany Thomas tthom5@emory.edu 404-712-7422</p>
<p>AHEAD-45—A 4-year infusion study to reduce amyloid accumulation as measured by PET imaging</p>	<ul style="list-style-type: none"> • Cognitively Normal • 55 - 80 years old 	<p>Amber Osborne anosbor@emory.edu 404-712-4463</p>
<p>Tele-STELLA - This study seeks to understand how to help family members who care for someone with dementia cope with and manage challenging behaviors and mood related to dementia. It uses videoconference sessions over the Internet.</p>	<ul style="list-style-type: none"> • Caregiver of a family member with Alzheimer's Disease or a similar dementia • Provide personal care and/or supervision for four or more hours per week • Family member with dementia has two or more bothersome behaviors (e.g., repeating questions, pacing, or refusing to help with personal care) 	<p>Danielle Verble Dverble@emory.edu 404-712-7085</p>

22nd Emory Brain Health Forum

To register call 404.712.1416

Alzheimer disease (AD) afflicts millions of people in the United States—one in eight Americans over age 65—and accounts for approximately \$200 billion in direct healthcare costs and \$210 billion in unpaid caregiving each year. By 2050, AD prevalence is projected to be 11 million to 16 million. Research is currently focused on the prevention or delay of AD onset through other means, such as changes in lifestyle and treating other chronic health conditions. We will share information about risks assessments, disease prevention and new therapeutic advances in dementia and Chronic Traumatic Encephalopathy (CTE). Registration is open to the public and we encourage you to reserve your space TODAY. Join in-person or via Zoom. Visit www.alzheimers.emory.edu. Be sure to invite a friend, colleague or loved one to this comprehensive program. Call Cornelya Dorbin at 404-712-1416 to register.



Goizueta Emory Alzheimer's Disease Research Center

THANK YOU!



EMORY UNIVERSITY

As a 501(c)(3) not-for-profit organization, the Emory Goizueta Alzheimer's Disease Research Center serves patients, families and communities throughout the Southeast region with the generous support of your individual and corporate donations.

**Goizueta Alzheimer's
Disease Research Center**

Contributions to support the Emory Goizueta Alzheimer's Disease Research Center

Enclosed is my tax deductible gift of \$_____. Please note that this contribution is:

In Memory of: In Honor of: _____

Please send acknowledgement of this donation to:

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Donor Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Please make checks payable to:

Emory Alzheimer's Disease Research Center

c/o Emory Univ. Health Sciences Development

1440 Clifton Road, Suite 112

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Memory Assessment Clinic

12 Executive Park Drive NE
Atlanta, GA 30329
404-778-3873



Emory Goizueta Alzheimer's Disease Research Center
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