



Summer 2023 Newsletter

| Most Common Questions During a Memory Clinic Visit | Why It Matters | New Additions to the Easton Center | Clinical Trials | Upcoming Events |

The Mary S. Easton Center for Alzheimer's Research and Care at UCLA has very active teams working on basic research, drug discovery, biomarkers for early diagnosis and clinical activity including clinical trials, cognitive testing, and patient care.

Addressing the Most Common Questions that Arise During a Memory Clinic Visit



By: <u>Leila Parand, MD</u>, Assistant Health Science Professor of Neurology, Neurobehavior Specialist

It's not uncommon to have many questions during an initial evaluation at the Memory Clinic. Here I will try to address the questions that historically have come up and provide answers to recent questions surrounding the new FDA-approved drug Legembi® (Lecanemab).

What will happen during the visit to the Memory Clinic?

A baseline assessment will be done to determine current cognitive changes. Partners, family members, or caregivers are encouraged to attend appointments to provide their perspectives. Specific questions relating to cognitive functioning will be asked, as well as baseline cognitive testing. Some of the cognitive domains tested include language abilities, memory, attention, and visuospatial functioning, in addition to other cognitive domains. Orders for additional testing may be placed, including more in-depth neuropsychological testing, imaging studies, and labs. Depending on the results of the evaluations in the Memory Clinic, a patient may receive a diagnosis, or further monitoring and testing may be needed.

Referrals for support to other care teams may include genetic counseling, social worker counseling, the sleep clinic, and physical, occupational, and speech therapy. Patients with an established diagnosis and more advanced symptoms may be referred to the Alzheimer's and Dementia Care Program, and patients who have mood symptoms are often referred to geriatric psychiatry. The specialists work together as a team the co-manage the patient's care.

Additional resources on where to find help in deciding on day programs, caregivers, or living facilities may be discussed at the visit, along with receiving referrals for home health services if needed.

What are some ways at home I can prevent the progression of cognitive decline?

Maintaining a healthy diet, exercising, and engaging in stimulating and social activities are ways to help cognitive functioning.

Diet

The Mediterranean diet and MIND diet, a combination of the Mediterranean diet and DASH (Dietary Approaches to Stop Hypertension) diet, are associated with better cognitive function and slower rates of cognitive decline. The recommendation is to enrich the diet with healthy foods, such as fruits, vegetables, olive oil, nuts, beans, poultry, whole grains, and fish. At the same time, the goal is to limit unhealthy foods, such as fried foods, baked goods, red meat, cheese, and butter. Here is a link describing the MIND diet: https://www.healthline.com/nutrition/mind-diet

Exercise

Aerobic exercise (moderate) for 30 minutes a day/5 days a week or more strenuous exercise for 1 hour a day/3 days a week has been shown to lower the risk of developing Alzheimer's disease and improve cognitive functioning. If you have not been exercising, it is better to start off slow and increase in increments the time you spend exercising per week. A brisk walk, jogging, swimming, and pedaling in a chair are all ways to exercise.

Mental Stimulation

Maintaining stimulating and social activities is good for cognitive functioning. Doing new activities, walking around outdoors, socializing with friends and family, and even passive stimulation, such as attending a concert or being in a room with others, has benefits.

Where can my loved one find activities to participate in?

Additional resources for activities may be found through OPICA (Optimistic People in a Caring Atmosphere), Wise and Healthy Aging, the UCLA Longevity Center, and by contacting Alzheimer's LA to find resources close to you.

https://www.opica.org/

https://www.wiseandhealthyaging.org/ https://www.semel.ucla.edu/longevity

https://www.alzheimersla.org/

Where can I find information on Alzheimer's Disease Clinical Trials at UCLA?

Visit the Kagan Clinical Trials Website:

https://eastonad.ucla.edu/research-clinical-trials/kagan-clinical-trials-program

Contact **Lorena Macias** at **310-794-6191** or email at <u>LorenaMacias@mednet.ucla.edu</u> Also, your **UCLA physician** may place a referral electronically to our research team.

How does the new drug Legembi® work, and who is it for?

Leqembi, or lecanemab, is a monoclonal antibody against aggregates of amyloid beta. This drug was fully approved by the FDA on July 6th, 2023. The drug is for patients who have a diagnosis of mild cognitive impairment or mild Alzheimer's disease with positive test results for Alzheimer's markers.

What are the steps needed to determine if my loved one is eligible for Legembi®?

Let your primary care physician or dementia specialist know that you are interested in Leqembi. At UCLA, patients will need cognitive tests in addition to imaging or cerebrospinal fluid studies to make sure there is not another cause of their symptoms, make sure they are not at high risk of more serious side effects (brain bleeds or swelling) in the brain, and to identify the biological markers that the drug is designed to target amyloid plaques. Genetic testing will be done to identify patients who are at higher risk of serious side effects. Each case will be reviewed by a board of clinicians to determine eligibility.

Does insurance cover Legembi®?

The Centers for Medicare and Medicaid Services (CMS) will now expand coverage of the drug. Medicare will require providers to put their patients in a CMS-approved registry and report on the outcomes that they see. Medicare is expected to cover at least 80% of the infusion cost. The expected cost is about \$26,500 per year for the infusions, with over \$5,000 out-of-pocket costs per year unless supplemental insurance covers it. CMS is currently determining potential coverage for additional tests such as amyloid PET scans and genetic testing.

What are the side effects of Legembi®?

The most concerning side effects are infusion—related reactions (26% vs. 7% in placebo), small areas of bleeding (microhemorrhages) in the brain (17% vs. 9% in placebo), and edema (swelling) in the brain (13% vs. 2%). Side effects are more common in patients who have the APOE £4 gene.

What are the benefits of Legembi®?

Over 18 months of observation, patients on Leqembi experienced moderately less decline in measures of memory, judgment, and other cognitive abilities compared with patients taking a placebo. It is thought that patients, on average, experience a delay in progression by about 5 months over an 18-month period with consistent treatment.

Why is Leqembi® not for people with more advanced Alzheimer's?

It has not been studied in patients with advanced Alzheimer's disease and the risks associated with more advanced Alzheimer's may be more severe. Also, similar drugs did not slow the progression of the disease process with more advanced Alzheimer's.

How will Legembi® be administered and monitored at UCLA?

For patients who are prescribed Leqembi, they will visit the clinic regularly. Infusions are given every two weeks in an infusion center. The infusion lasts for 30 to 60 minutes. Patients may need to stay longer to monitor for any adverse effects.

They will also need to come in periodically for brain scans to make sure that there are no signs of swelling or bleeding in the brain, as patients with these side effects usually have no outward symptoms. Additionally, there may be additional MRI scans for patients who do experience new neurological symptoms. For patients who have side effects, they may need to pause or discontinue treatment depending on the type and severity of the side effect.

▲ TOP

Underrepresentation of Black and Hispanic Participants in Alzheimer's and Parkinson's Disease Research: Why It Matters



By: Jennifer Adrissi, MD, MS, Assistant Professor of Neurology

Alzheimer's disease (AD) and Parkinson's disease (PD) are the two most common neurodegenerative disorders, with 6.7 million living with AD and about 1 million with PD in the United States, with these numbers expecting to rise dramatically over the coming decades with the U.S. population over the age of 65 rising significantly. These disorders affect people of all backgrounds, races, and ethnicities. Older African American and Hispanic adults are disproportionately affected by AD with African Americans being

twice as likely and Hispanics being 1.5 times as likely to develop the disease compared to non-Hispanic Whites (Potter et al., 2009; Samper-Ternent et al., 2012). For PD, Hispanic men have been shown to be at greatest risk of being diagnosed (Van Den Eeden, 2003). There is no current reliable estimate of how many Black people are living with PD in the United States due to disparities in PD awareness and diagnosis.

Even though these disorders affect everyone and there is a growing proportion of racial and ethnic minority older adults in the country, racial and ethnic minorities have been significantly underrepresented in the research that shapes our understanding of these diseases and their treatments. Minority participation rates have been reported to be lower than 5% in dementia randomized control trials (RCTs) (George et al., 2014). A study of 33 RCTs in PD showed that only 6% of the participants were non-White, with only 1.7% identifying as African American and 1.3% as Hispanic (Schneider, 2009). The underrepresentation of Black and Hispanic participants in research has consequences, because the information that we learn through these studies is not able to be confidently generalized to these groups. We know that there are differences in some details of how diseases present in different groups. Essentially, there are gaps in our knowledge of these disorders in certain groups because they are not being studied.

There are several contributors to the underrepresentation of Black and Hispanic participants in AD and PD research, including time and resource constraints, lower neurologist referral rates, mistrust of the

research community, and lack of information/education on research opportunities. Finding solutions to this disparity in research representation is important so that the individuals who participate in the studies and inform our understanding of these diseases reflect those who are living with the diseases in the community. This has become increasingly important as precision medicine grows in the field. Precision medicine is an approach to treatment development that considers differences in people's genes and environments. With insufficient research on minority communities, they are essentially being "left out of the conversation," and their data is not adequately represented in the development of new therapies.

One approach that has been shown to help address underrepresentation in research is community-based participatory research (CBPR) strategies. CBPR uses community engagement and partnerships to increase trust and develop mutually beneficial research questions and effective, sustainable recruitment and study design. My research focus is the use of CBPR methods to increase access to specialized care and research opportunities in PD and AD within the Black community. One of my most recent projects involved partnering with community organizations to create educational workshops in the community and testing how these workshops affected the understanding of PD and PD research in the Black community. Other strategies that have been used to increase the representation of Black and Hispanic participants in PD and AD research include engaging the help of primary care physicians, incorporating research navigators/advocates, and using proactive, targeted advertisement.

This is an exciting time for scientific discovery in neurodegenerative disorders, one which has fostered increased curiosity and hope. Now, we must also commit to the science of recruitment of underrepresented groups in this research to fill the gaps in our understanding of AD and PD in these groups and promote more equitable access and outcomes.

References:

George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014; 104(2):e16–31.

Potter G, Plassman B, Burke J, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and Whites. Alzheimers Dement 2009; 5:445–453.

Samper-Ternent R, Kuo YF, Ray LA, Ottenbacher KJ, Markides KS, Al Snih S. Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and Non-Hispanic Whites. Journal of the American Medical Directors Association 2012; 13:254–259.

Schneider MG, et al. Minority enrollment in Parkinson's disease clinical trials. Parkinsonism Relat Disord. 2009; 15(4):258–62.

Van Den Eeden SK, Tanner CM, Bernstein AL, Fross RD, Leimpeter A, Bloch DA, Nelson LM. Incidence of Parkinson's disease: variation by age, gender, and race/ethnicity. Am J Epidemiol. 2003; 157(11):1015-22.

▲ TOP

New Additions to the Easton Center

Please join us in welcoming new faculty and staff members to the Easton Center.



Photo: Alejandra Sánchez López, MD, Assistant Clinical Professor

Dr. Sánchez holds a dual-appointment as Assistant Clinical Professor in the Neurology Department and Geriatric Medicine Division. She is a bilingual (Spanish/English) board-certified geriatrician and fellowship trained in Behavioral Neurology with passion and expertise in cognitive impairment and neurodegenerative diseases.

She received her medical degree from Universidad Autonoma de Baja California in Tijuana, Mexico. She completed internal medicine residency and chief residency at Jacobi Medical Center/Albert Einstein College of Medicine in the Bronx. Thereafter, she completed a Geriatrics Fellowship at University of California, San Francisco (UCSF), followed by a Behavioral Neurology Clinical Fellowship at the UCSF Memory and Aging Center. After training, she worked as an Associate Medical Director at the Sutter Health Ray Dolby Brain Health Center in San Francisco, where alongside a multidisciplinary team, she evaluated and cared for patients with memory disorders.

In her role as a clinician-educator, she will provide care to patients with cognitive and behavioral changes in the UCLA Mary S. Easton Center for Alzheimer's Research and Care, including Memory Clinics at Westwood Neurology and Olive View-UCLA Medical Center, as well as care for older adults in the inpatient geriatrics service at the Santa Monica Hospital. She is thrilled to be part of UCLA clinical and research efforts to support families and patients with Alzheimer's disease and other cognitive disorders.



Photo: Katy Figueroa, Clinical Research Coordinator, Vossel Lab

Katy graduated from the University of Southern California with a Bachelor of Science in Computational Neuroscience with a minor in Computer Programming in 2022. As an undergraduate, she joined a lab examining the relationship between roundworm movement and Parkinsonian speech. Recently, she worked in a lab where she analyzed relationships between exercise, diet, and cognition in patients with Parkinson's disease. She is interested in healthcare accessibility in

underserved communities of color. Katy is excited to contribute to Alzheimer's disease research in the Vossel Lab at the UCLA Easton Center.



Photo: Karen Elrayes, Clinical Research Coordinator, Vossel Lab

Karen Elrayes graduated from UCLA with a bachelor's degree in Molecular Cell and Developmental Biology. Her passions are medicine and music, as well as their intersection. She enjoys playing the flute to memory care patients as a form of music therapy. As an undergraduate student, Karen worked under Dr. Chloe Boyle as a Research Assistant in two studies: 1) Clinical Studies of Sleep and

Healthy Aging Research on Depression for Younger Women and 2) Aging and Reward System Response

to Inflammation and Anxiety (ARIA). She looks forward to joining the Vossel Lab team and doing her part in contributing to Alzheimer's research.



Photo: <u>Karina Muñoz</u>, Easton Center's Dementia Care Team Navigator at Olive View

Karina Muñoz received her Bachelor of Arts in Psychology from California State University, Northridge, in 2019. As an undergrad student, she volunteered to assist underrepresented students in acknowledging their oppression and daily struggles through art. Karina was also a caregiver for her grandmother, who

instilled the values of compassion, empathy, and courage. After graduation, she worked with children in a subacute setting providing emotional support and a sense of safety. This is where she discovered her passion for advocating for those less fortunate and disadvantaged. Karina then went on to become a pediatric and geriatric social worker for patients dealing with respiratory issues and supporting patients in acclimating to their new lifestyle. Karina is driven to provide aid to patients while establishing connections with their families; therefore, she is excited to contribute to the mission of Olive View-UCLA Medical Center.

Clinical Research Opportunities

If you would like to advance Alzheimer's disease research, please consider being a study participant. Below are the current recruiting trials. For a complete list of enrolling studies, visit our website at https://eastonad.ucla.edu/.

OBSERVATIONAL STUDIES:

- Alzheimer's Disease Neuroimaging Initiative 3 (ADNI3) Protocol
- Alzheimer's Disease Research Center Biomarkers in Neurodegenerative Disease (ADRC-BIND)
- ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD)
- The Relationship of Hate to Dehumanization: An Exploration in Neurotypical and Frontotemporal Dementia (FTD Hate Study)
- Longitudinal Early-Onset Alzheimer's Disease Study (LEADS)
- Biomarkers for Vascular Contributions to Cognitive Impairment and Dementia (MarkVCID)
- Music Stimulation to Improve Cognition (MUSIC)
- New Imaging Dementia Evidence for Amyloid Scanning Study (New IDEAS)
- National Institute on Aging Alzheimer's Disease Family Based Study (NIA-AD-FBS)

INTERVENTIONAL STUDIES:

SUVEN-502 Study



For more information on our upcoming lectures and events, please visit the Easton Center <u>Community</u> <u>Calendar</u>.

Preserve Your Mental Health: Your Mind Matters

Date: Saturday, September 9, 2023 Time: 11:00 AM – 1:00 PM (PDT)

Location: Alpha Phi Alpha Fraternity, Inc. House

3712 W. 54th Street Los Angeles, CA 90043

Join us for another DYNAMIC interactive panel discussion focused on brain health, the mental health impact of Alzheimer's disease and the overlapping of symptoms, related social determinants of health, effects of medications on cognition, Alzheimer's disease from a life-span approach, and caregiver self-care management.

Please share with a friend/colleague/community organization and **REGISTER TODAY** as seating is limited! Download the flyer and scan the QR Code to register or go to: bit.ly/ABWPMind

Understanding Alzheimer's and its Impact In the Black Community

Date: Thursday, September 14, 2023 Time: 10:00 AM – 2:00 PM (PDT)

Location: Faithful Central Bible Church – The Living Room

400 W. Florence Ave. Inglewood, CA 90301

Collaboration of Alzheimer's Los Angeles, Faithful Central Bible Church, and Mary S. Easton Center for Alzheimer's Research and Care at UCLA.

Who should attend: Professionals, nonprofessionals, clergy, community members, and caregivers.

For more information, please contact Petra Niles, MSG, PNiles@alzla.org at Alzheimer's Los Angeles.

Celebrating Hispanic Heritage Month (In Spanish)

Date: Saturday, September 16, 2023 Time: 10:00 AM – 1:30 PM (PDT)

Location: 115 S. Taylor Ave, Montebello, CA 90640

In celebration of Hispanic Heritage Month, the ELHA Lab will join Alzheimer's Los Angeles and other community partners for an afternoon full of music, dancing, raffles, and tasty food. Community members will hear from special guests including Chef Juan Mondragon who will speak on staple cultural dishes and the sustainment of healthy lifestyle habits.

For more information in Spanish, download the flyer.

Memory and Aging: What You Need to Know

Date: Tuesday, September 19, 2023
Time: 3:00 AM – 4:00 PM (PDT)
Location: Santa Monica Public Librar

Location: Santa Monica Public Library

601 Santa Monica Blvd. Santa Monica, CA 90401

Monica Moore, MSG, Community Health Program Manager, will discuss the way the brain changes with age, what is normal, what is not, and what you can do about it. The latest research surrounding brain health will be discussed as well as practical tips to stay focused and mentally sharp.

RSVP: Library@santamonica.gov

Newsletter Editorial Team:

Easton Center Director: Keith Vossel, MD, MSc

California Alzheimer's Disease Center (CADC) Director: Timothy Chang, MD, PhD

Co-Directors of Training and Education Activities: Monica Moore, MSG, Mirella Díaz-Santos, PhD, and

<u>Jennifer Adrissi, MD, MS</u> Editor: Nancy Osuch

Mailing Address:

Mary S. Easton Center for Alzheimer's Research and Care at UCLA 710 Westwood Plaza, Room C-224 Los Angeles, CA 90095-1769

| https://eastonad.ucla.edu/ | Center: (310) 794-3665 / Clinic Appointments: (310) 794-1195 |

| Subscribe | Unsubscribe from this List | Update Subscription Preferences |

Copyright © 2023 Mary S. Easton Center for Alzheimer's Research and Care at UCLA. All rights reserved.

