



KEEP IN MIND

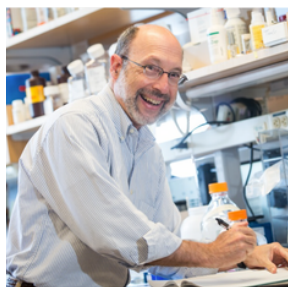
Annual Newsletter of the Massachusetts
Alzheimer's Disease Research Center

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A Message From our Chief

Updates from Brad Hyman, MD, PhD.



Dear MADRC Community,
Happy 2024, and happy Spring! I hope this newsletter finds you and your loved ones well. On behalf of all the researchers and staff at the Massachusetts Alzheimer's Disease Research Center (MADRC), we want to thank you for your commitment and dedication to our Center, as the work we do would not be possible without you. I am excited to share some of the exciting things happening at our Center.

First, I'd like to share the very exciting news that the Massachusetts General Hospital and Brigham and Women's Hospital (now called Mass General Brigham) have started treating patients with Lecanemab, the new anti-amyloid treatment for Alzheimer's disease. To learn more about these efforts, please see page 2. This is the first new drug for Alzheimer's in decades, and one of our alumni, Dr Mike Irizarry, was instrumental in developing it. We couldn't be prouder of Mike or more excited to see this groundbreaking work going forward.

I am thrilled to share the Talk with the Doctor series offered by the Outreach, Recruitment and Engagement (ORE) Core at MADRC has been a huge success. These educational lectures are offered virtually in English and Spanish, and cover topics suggested by our Research Ambassadors. For example, we have had lectures on 'Why Should I Consider Research,' 'Navigating the Caregiver Journey' and 'Cardiovascular Health = Brain Health.' If you haven't had the opportunity to join one of these educational lectures, I would highly suggest you do. Recordings from past lectures can also be found on the [MADRC YouTube Channel](#). To learn more, please see page 6.

MADRC prides itself on being at the forefront of dementia research. The Alzheimer's Clinical and Translational Research Unit (ACTRU) at MGH recently administered the first anti-sense therapy to a patient with a very rare, progressive neurodegenerative disease called Creutzfeldt-Jakob disease. Please see page 4 for more information about this new development.

Our Center continues to address the need for representation and inclusivity in our research studies. We want people from all ethnic, racial, sociodemographic backgrounds and sexual orientations to be involved in our Center. This way, what we discover can help as many people as possible. By teaming up with us, we can work together to discover better ways to diagnose and treat Alzheimer's disease and other related disorders as well as find ways to ease the burden on caregivers.

(Continued page 2)

Chief

(continued from p.1)

In an effort to make research more accessible and participant-focused, we have hired Ana Mazan, who is bilingual in English and Spanish, to help patients/participants, caregivers, and families navigate the research process. She will help individuals learn more about the various research opportunities at the ADRC and help individuals find a study that fits them best. We are very excited to have her join our team. To learn more about Ana and how she can help you, please go to page 4.

Once again, thank you for your dedication and commitment to our Center. Let's continue to work together to make the future brighter for those living with these devastating diseases.

Warmly,
Brad

A New Era For Alzheimer's Disease Treatment

By Gad Marshall, MD

In July of 2023, after more than 10 years of clinical trials of the drug, lecanemab (Leqembi), the Food and Drug Administration (FDA) granted full/traditional approval of the drug for the treatment of patients with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease (AD, with evidence of elevated amyloid plaque in their brain). This is the first time the FDA granted full approval for an AD treatment in 20 years, and also the first time it granted full approval for a disease-modifying drug, that slows down the progression of symptoms by treating the underlying pathology (amyloid).

Lecanemab is an anti-amyloid monoclonal antibody. In November 2022, the [results](#) of the Clarity AD trial, a phase 3 (last stage of testing) of lecanemab in nearly 1,800 participants with MCI or mild AD dementia, were published in the prestigious New England Journal of Medicine. They showed that lecanemab robustly removed amyloid from the brain and modestly slowed down decline in cognition and daily functioning. This prompted the subsequent FDA approval, at which time Medicare also stated that it will cover 80% of the costs of treatment with lecanemab in a clinical setting, requiring minimal information to be entered into a registry to follow treated patients. In October 2023, Medicare also stated that it will start covering positron emission tomography (PET) scans that show amyloid in the brain, making it easier to determine patients eligible for this treatment.

Since the approval of lecanemab, multiple centers across the country have set up infrastructure and personnel and have slowly rolled out this complex treatment, which requires a detailed evaluation for eligibility, counseling about the risks and benefits, infusions of the drug every 2 weeks up to 18 months, and monitoring for side effects such as infusion reactions, swelling and bleeding in the brain, the latter requiring magnetic resonance imaging (MRI) scans frequently to detect the changes in the brain since they usually are not accompanied by symptoms.

On the heels of the FDA approval of lecanemab, the [results](#) of the Trailblazer-Alz 2 phase 3 clinical trial were presented at the end of July 2023. This was a trial of another anti-amyloid monoclonal antibody, donanemab, in over 1,700 participants with MCI or mild AD dementia, which also showed robust removal of amyloid from the brain and a modest slowing of clinical symptoms. The FDA is currently reviewing these results and is expected to approve the drug later in 2024. Additionally, both lecanemab and donanemab are currently being tested in prevention trials for AD with participants who have evidence of amyloid in their brain but no significant symptoms yet (the Ahead and Trailblazer- Alz 3 trials).

Finally, in February 2024, the manufacturer of aducanumab, another anti-amyloid monoclonal antibody, announced that it will stop development and marketing of the drug. The aducanumab program has been mired by controversy following an accelerated approval by FDA of the drug in July 2021, but not full/traditional approval and a decision by Medicare not to cover the drug outside of a clinical trial setting due to equivocal results of two large phase 3 clinical trials in which one trial showed modest clinical benefit and the other did not.

While it has been a rocky journey for these new disease-modifying drugs in AD, the past few years have signaled a new era in the treatment of AD, which hopefully will open the door for more effective, tolerable, and practical treatments.

Lecanemab Updates

If you are wondering how to stay on top of all of the information related to new treatments for Alzheimer's disease, the answer is to visit the MADRC website! Visit the following link to access an expert panel presentation about lecanemab, as well as information about prescription coverage and financial assistance: bit.ly/TreatmentData



Credit: FatCamera

Can Dementia Be Prevented?

Medical professionals are often asked if there is anything that can be done to prevent Alzheimer's disease and/or other dementias. The answer is that while there are no guarantees, there are steps people can take to reduce their risk. This includes incorporating a set of brain-healthy behaviors into everyday life.

As we age, cognitive function typically declines. However, we can offset this by strengthening existing nerve networks or forming new ones. This concept is known as cognitive reserve, which involves adopting brain-healthy habits to enhance brain function. This includes the following:

Healthy sleep habits:

Scientists have found that while we sleep, our brain clears out substances such as beta-amyloid protein that accumulate during the day. Beta-amyloid protein can damage nerve cells and lead to problems with memory and thinking.

Cardiovascular exercise:

This means exercise that increases your heart rate and causes you to sweat lightly.

Eating a Mediterranean-style diet:

Research shows that eating a Mediterranean-style diet may reduce your risk of developing dementia. This means eating lots of fruits, vegetables and legumes/beans, while avoiding red meat and foods with refined sugars and/or saturated fats.

Social & Mental Activity:

Having strong social connections and participating in mentally stimulating activities can help strengthen nerve networks.

There are also several ongoing studies to support healthy brain aging. For more information about brain health, visit: madrc.org/brain-health/



ENGAGE YOUR BRAIN!

SOCIAL & MENTAL ACTIVITY

LEARN NEW SKILLS

Try something new! Take a dance, art, music, cooking or craft class.



COMMUNITY INVOLVEMENT

Engage with your community! Volunteer with a local group or join a committee.



SOCIALIZE

Connect Socially! Facetime with a friend, have lunch with a neighbor, or meet a family member for coffee.



READ & WRITE

Read a book. Write down your favorite family memories and/or craft some poetry.



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GET MOVING FOR YOUR BRAIN!

SUGGESTED INDOOR EXERCISES

- Treadmill
- Stair Climbing
- Elliptical Trainer
- Stationary Bicycle
- Group Fitness Class
- Video Exercise Class



SUGGESTED OUTDOOR EXERCISES

- Walking or Jogging
- Cycling
- Cross-Country Skiing
- Rowing
- Water Aerobics
- Swimming




Cardiovascular exercise, that increases your heart rate, makes you sweat lightly and feel slightly out of breath, shows the most benefit.

The American Heart Association suggests these target heart rates for maximum exercise benefit. →

Age	Target HR Zone 50-85%	Average Max Heart Rate, 100%
45 years	88-149 bpm	175 bpm
50 years	85-145 bpm	170 bpm
55 years	83-140 bpm	165 bpm
60 years	80-136 bpm	160 bpm
65 years	78-132 bpm	155 bpm
70 years	75-128 bpm	150 bpm

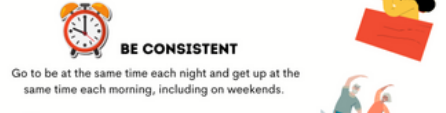
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BRAIN HEALTHY SLEEP HABITS


BE CONSISTENT

Go to be at the same time each night and get up at the same time each morning, including on weekends.




BEST BEDROOM CONDITIONS

Make sure your bedroom is quiet, dark, relaxing and that the temperature is comfortable.




THINGS TO AVOID

Do not eat large meals or drink alcohol or caffeine prior to bedtime.



NO ELECTRONICS

Keep your bedroom free of devices such as TV, computers and cell phones. These can stimulate the brain and make it harder to sleep.



Optimal Sleep Recommendations

Age Group	Recommended Hours of Sleep
18-60	7 or more hours per night
61-64	7-9 hours per night
65+	7-8 hours per night

Talk to your doctor if you have insomnia, snoring, fatigue or excessive daytime sleepiness.

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BRAIN HEALTHY FOODS

RECOMMENDED SERVINGS



Whole Grains:
3 Servings per day



Leafy Greens:
at least 1 serving per day



Vegetables:
at least one serving per day



Fish: at least one serving per week



Poultry: at least 2 servings per week



Extra virgin olive oil: 1 serving per day



Nuts: 5 ounces per week



Berries: at least 5 servings per week



Beans/Legumes: 3 servings per week

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Meet Our Newest MADRC Staff Member

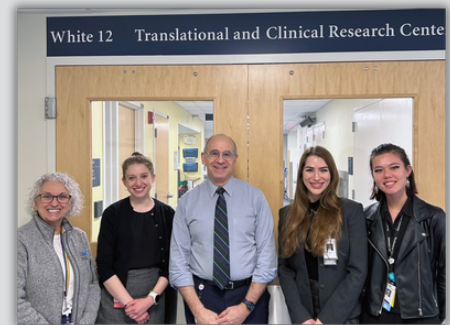
Ana Mazan recently joined the team as the new MADRC Program Coordinator. A native of Argentina, Ana says, "I am excited to assist in the accommodation and development of research opportunities for Hispanics and Latinos in the community. I look forward to designing strategies that will facilitate the study matching process and make the experience for participants positive and easy to navigate."

Ana can be reached via email at amazon@mg.harvard.edu or by phone at 617-726-1774.



ACTRU Spotlight

MGH Neurology's Alzheimer's Clinical and Translational Research Unit (ACTRU) team's photo commemorates an historic moment after administering therapy to the first patient in a trial for Creutzfeldt-Jakob disease (CJD). CJD is a rare, rapidly progressive and invariably fatal neurodegenerative dementia for which there is now no treatment. MGH is one of twelve sites around the world participating in the experiment. Photo from left to right: Alison McManus DNP, Anna Goodheart MD MSc, Steven Arnold MD, clinical research coordinator Ashley Kupferschmid, and student Kai Doran.



MADRC on the Move!

MADRC was on the move throughout 2023, bringing information about brain health, dementia, and research to the community. We hit the road and the internet to spread the word at about 80 different in-person and virtual events! We connected with people at churches, libraries, apartment buildings, conferences, health fairs, community centers, cultural festivals, and many neighborhood events. We are so grateful for all of the organizations that support our work.

We look forward to bringing information about the importance of research participation to new places and even more people throughout 2024!

If you are interested in scheduling a session in your community, call the MADRC Outreach team at (617) 278-0600 or reach us via email: MADRC@MGB.org.



MADRC staff spoke with lots of attendees of the Brazilian Independence Festival in Brighton.



MADRC joined the National Association of Hispanic Nurses to host a women's health event in Jamaica Plain.



Our Outreach team enjoyed interacting with residents of the Blue Ledge senior Living Community in Boston.

Participant Perspectives

Involvement in research studies looks different for everyone. For some people, participation may consist of completing surveys from home on their laptop or cellphone for an observational study. Another person enrolled in a clinical trial may visit the research center once or twice per month for an infusion of treatment. While yet another may meet with the research team remotely but visit the clinic in person once or twice during the year.

Each research participant's journey may differ depending on which study they are enrolled in, but they all have a common goal. They want to help advance research and ultimately end brain disease.

For Phil Cunningham, his desire to take part in research stemmed from his mother being diagnosed with "Dementia, probably from Alzheimer's Disease" in her 90's. She lived until age 98 and donated her body to science, as did Phil's father who died from cancer.



Phil Cunningham, MADRC Research Ambassador

Phil decided he wanted to advance knowledge about dementia and Alzheimer's disease while he was alive. "Perhaps selfishly, if I was destined to develop dementia, I wanted to do all I could to prevent or forestall that outcome," states Phil.

Phil enrolled in a clinical trial and participated for seven and a half years until the study ended in 2023. He says, "I joined the study as an individual, not with a group of friends or neighbors. But I found I joined a community of people much like me who were willing to share their experiences."

Astrida Schaeffer decided to get involved with research because of the high prevalence of Alzheimer's in her family on the maternal side. Astrida explains, "I do not have a diagnosis at this time, but I do have highly elevated amyloid levels. In the face of that risk legacy, I had to do something, for myself and for my daughter, for my family and friends. I've seen the impact on the patient and their loved ones too many times. I couldn't just wait passively to see if it was coming for me and hope for the best."



Astrida Schaeffer, MADRC Research Ambassador

Astrida is currently involved in a clinical trial and says, "Being a participant is very different than being a patient. I'm part of the team. It's an empowering feeling."

She says she would recommend joining a research study to others. "Sure, there is always the risk of getting the placebo and not the drug, or of the drug not succeeding, but science needs its "no" answers just as much as its "yes" answers. Figuring out what doesn't work helps narrow down to what does. I want to stop Alzheimer's, but I'm not a scientist. I can still do my bit by taking part in studies. And a bonus? Being in a study has enabled me to face down my fears of this disease, because I have more information and observation of capacities and brain health than any of my family had. I don't feel helpless anymore."

As for Phil, he says that although his trial ended, he still communicates with other research participants around the country and shares information about studies and treatments. "I have learned that there are many trials in various phases approaching dementia from different vectors. I also have learned that there is a significant need for and shortage of participants for all these clinical trials worldwide."

Phil states, "I wish I could participate in several clinical trials concurrently, but that generally is not permitted because one trial might skew the data and study outcomes of another." He adds, "You may think it is a time-consuming burden to participate. But I have realized I received back more in dividends than I had invested."

To learn more about the different types of research studies underway at MADRC, visit: madrc.org/join-a-study/ or call (617) 278-0600.

Honor a Loved One by Supporting our Work

The Massachusetts Alzheimer's Disease Research Center has been at the forefront of dementia research, treatment and care since 1984. We are leading the fight against Alzheimer's disease and related dementias by advancing research on several fronts. Our goal is to understand better how to identify, target, prevent, and fight these devastating brain diseases and someday find a cure for Alzheimer's disease and related dementias.

You can support our efforts by making a donation in memory of,

or in honor of a loved one.

Donations can be made online by visiting: madrc.org/support-us/. If you would like to donate by mail, please make checks payable to the Massachusetts Alzheimer's Disease Research Center and mail to: Massachusetts ADRC, 114 16th Street #2011, Mass General Hospital, Charlestown, MA 02129.

Research for Caregivers

Caregivers play a vital role for people living with dementia by helping them with self-care, household activities, and other aspects of daily life. Did you know that caregivers can play another important role by participating in research?

There are research studies focused on caregivers that need volunteer participants. These studies investigate a variety of areas related to caregiving, such as caregiver stress and well-being, medical decision-making, and programs and techniques to assist with caregiving.

Researchers learn valuable lessons from caregivers who take part in studies. Many studies are virtual and do not require caregivers to visit a healthcare setting.

If you are a caregiver for a person living with dementia and are interested in joining a research study, contact us at (617) 278-0600 or MADRC@MGB.ORG.

“It was nice to be a part of something that is actively looking for ways to help with research for people who have yet to live through the experience and challenges I am currently facing as a caregiver.”

-Caregiver Study Participant

Talk With the Doc(tor) Series Gets Thumbs Up

Last year MADRC launched the Talk with the Doc(tor) virtual series. This monthly program features MADRC-affiliated researchers who discuss their area of expertise and are often joined by a research study participant. These sessions have featured topics including making a difference through research, how to reduce your risk of developing dementia, and what to know about genetic testing for Alzheimer’s disease risk.

The Talk with the Doc(tor) presentations have been very well-attended and are receiving positive reviews. To register for the next session visit: madrc.org/events/.

To view past sessions, visit the MADRC YouTube channel: [ADRC MASS](https://www.youtube.com/channel/UCADRCMASS).

Caregiver Support

The many responsibilities involved in caring for a person living with dementia can be overwhelming. It is so important for caregivers to carve out some time for themselves. Taking a break occasionally to do something for yourself will allow you to continue to provide the best care for your loved one.

Check out our graphic below for some caregiver tips and visit the MADRC website to learn about [caregiver resources and support](#).

Also, be sure to register to attend Taking Care While Caretaking on June 14th from 12 - 1PM via Zoom. For more information and to register, visit: <https://bit.ly/TWTDJune2024>



CAREGIVER TIPS

1

ASK FOR HELP:
You can't do it all. Say "yes" when someone offers to help with cleaning, grocery shopping or yard work.

2

EXERCISE:
Get moving! Exercise is a great way to boost your mood and improve your health. If you can't get outside, pull up a workout on YouTube.

3

TALK:
Chatting with friends and loved ones can relieve stress. Talking with others provides emotional support and improves mental health.

4

TAKE A BREAK:
Make time for yourself and do something you enjoy. Take a bath, get a massage, start or reconnect with a hobby

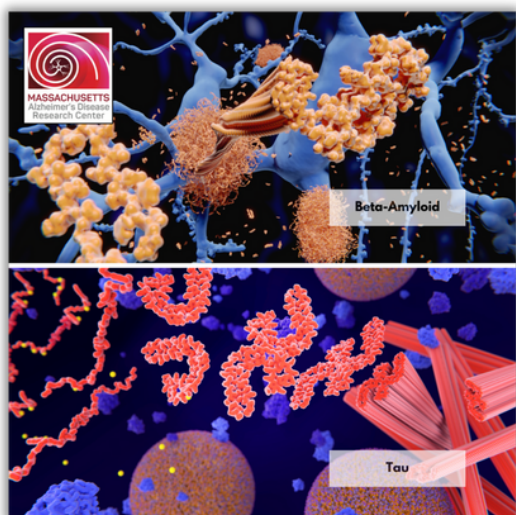
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Defining Dementia

People often ask, “What is the difference between Alzheimer’s disease and dementia?” The word “dementia” is an umbrella term used to describe a group of symptoms, including memory loss, confusion, changes in mood, difficulty with language/communicating and difficulty completing everyday tasks.

There are multiple causes of dementia, including Alzheimer’s disease, Vascular dementia, Lewy Body dementia, Frontotemporal dementia, and mixed dementia. Alzheimer’s disease is the most common cause of dementia.

Dementia is not a normal part of aging. For more information about the various types of dementia, visit bit.ly/GetTheFactsMADRC



Beta-Amyloid & Tau Explained

We hear a lot about anti-amyloid and tau-targeting treatments for Alzheimer’s disease. But what exactly are Amyloid and Tau?

Beta-amyloid is a protein naturally found in our brains and bodies. In Alzheimer’s disease, this protein can stick together, forming clumps of various sizes. Over time, these clumps can develop into plaques in the brain which may damage brain cells.

Tau is a protein found in the brain that serves many functions in healthy brain cells. In Alzheimer’s disease, an abnormal form of tau protein accumulates inside brain cells and starts to clump together in thread-like structures known as neurofibrillary tangles. This buildup disrupts normal brain function.

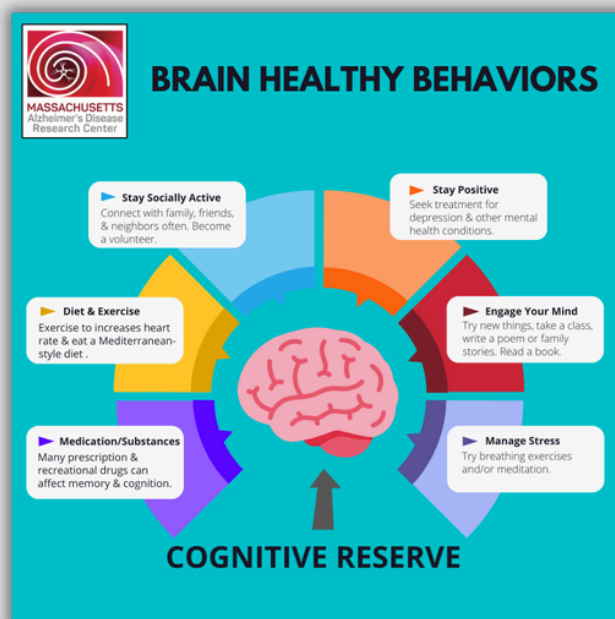
Both Beta-Amyloid and Tau take years to spread throughout the brain. While amyloid is a strong predictor of developing symptoms of Alzheimer’s disease down the road, tau relates more closely to current or upcoming symptoms in the near future, such as memory impairment and tracks well with disease severity.

Boost Your Brain!

As we age, cognitive function typically declines. However, we can offset this by strengthening existing nerve networks or by forming new ones. This concept is known as cognitive reserve, which involves adopting brain-healthy habits to enhance brain function.

Review our graphic below to learn how you can boost your brain!

For more information about brain health, take a look at our Road Map to Dementia Prevention booklet here: madrc.org/community/.



Stay in Touch With MADRC

To stay on top of all the MADRC-related news throughout the year, be sure to follow along on all of our social media platforms!

Additionally, you can sign up for our quarterly e-news, the MADRC Messenger, by adding your [email address here](#).

Stay connected with MADRC!

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