



MASSACHUSETTS
Alzheimer's Disease
Research Center

KEEP IN MIND

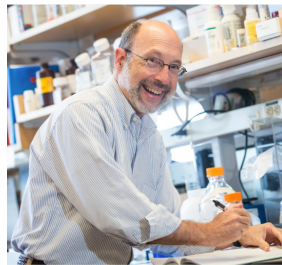
Annual Newsletter of the Massachusetts
Alzheimer's Disease Research Center

INSIDE THIS ISSUE:

- P. 2
 - #WeAreMADRC
- P. 3
 - Working Through COVID-19
 - Advancing Research Innovation
- P. 4
 - Research Teams Working Together
- P. 5
 - Biomarker Research
- P. 6
 - Modernizing Cognitive Testing
- P. 7
 - Supporting Research From Home
 - The Importance of Observational Studies
- P. 8
 - Research Heroes
- P. 9
 - Commitment to Diversity
- P. 10
 - Community Partnerships
 - Faith Communities
- P. 11
 - Latino Outreach
 - Comings & Goings
- P. 12
 - Upcoming Events

A Message From our Chief

Updates from Brad Hyman, MD, PhD.



It has been over a year since we were sitting in our research offices and received an institution wide email stating that research efforts were being shut down. We were instructed not to return to our offices until further notice. Over a year later I'm still working from my living room. Never did I imagine what this year would have in store for us!

Despite the ongoing COVID-19 pandemic and research being shut down at Mass General Brigham for a period, we continued to be productive as a center in working towards the goal of finding a cure for Alzheimer's disease (AD). We immediately began to rethink how we were doing things. Our typical in-person events ranging from outreach events to research visits, were quickly converted to virtual experiences. What brought us together during these unusual times was the common goal to find answers for our patients and research volunteers. During a time when we seemed farther apart than ever, we were reminded of our mutual goal by our new slogan "We Are MADRC." Read more about our efforts to work together to accomplish this goal on page 2.

During this "down time" we quickly realized people were relying on the internet more and more. With this, it became apparent that we needed to upgrade our website. We are forever grateful to our web developer Foster Brown and our marketing manager, Christine Brown (no relation) for the countless hours they poured into our new website, madrc.org.

Like many of you, we were horrified by the senseless killings of George Floyd, Ahmaud Arbery and Breonna Taylor, as well as by the increased incidence of anti-Asian racism here in the US. We have taken steps to think about the ways in which our institution may have perpetuated inequality and are working with community leaders to listen and actively engage a racially diverse population. MADRC remains committed to bridging the gap of inequity in healthcare and in research. On page 10 you can read about Memory Sunday, one of our initiatives to increase AD awareness in the Black community. Additionally, we are proud to announce the launch of the new Multicultural Assessment & Research Center (MARC) featured on page 11.

We have highlighted several of our research teams on page 4. One of our clinical trials, Trailblazer 2, was successful and we are excited to announce (Continued on next page)

Chief

(continued from p.1)

it will advance to phase III. From clinical trials to observational studies, we invite you to see which studies may be of interest to you. You can always call us at 617-278-0600 to learn more about studies for which you may be eligible, or visit: www.madrc.org/join-a-study/

We always love to showcase our wonderful research volunteers when they allow us to do so. In this issue we would like to highlight Dennis Chan who is a recent recipient of the National Citizen Scientist Catalyst Award by the Global Alzheimer's Platform Foundation. I am sure you will enjoy learning more about Dennis and his impact on research on page 8.

One of my favorite events that we held this year was a celebration of all of YOU who make our research possible. Our research participant appreciation event took on a new virtual format and it was amazing to connect with almost 200 research participants at once! While we of course look forward to the day where we can celebrate you all in person, we are grateful for the technology that allowed us to connect and celebrate in the midst of the pandemic. You can find a link to the recording of this event on page 8.

Have you ever marveled at how far cell phone technology has come? The power we have at our fingertips is truly amazing! In fact, our very own Kate Papp, PhD and Rebecca Amariglio, PhD are doing some cutting-edge research to use smart phone technology to help us detect Alzheimer's disease early! We invite you to learn more about this effort and other digital technology advances on page 6.

Additionally, many of our investigators have been working on groundbreaking research. From the use of blood tests to predict someone's risk of Alzheimer's disease (page 5), to the use of new imaging technology (page 5) and the study of how tau aggregation can speed up progression of AD (page 3) we are looking for answers to Alzheimer's from ALL angles. While we are still a little ways out from these new techniques being the standard of care, it gives me so much hope for the future!

Probably one of the most familiar faces of 2020 is Dr. Anthony Fauci. I was elated when our very own Katie Brandt was able to sit down with Dr. Fauci and discuss COVID-19 vaccination for the dementia community. You can find the link to this interview on page 3.

This year we said goodbye to two important members of our team who have each been with us for a very long time, Liang Yap and Jeanette Gunther. Liang managed our center for almost 20 years and Jeannette coordinated "The Memory Study" for nearly 40 years. While we said goodbye to some we have also welcomed several new members to our team. We introduce Claudia Valenzuela and Rachael Williams on page 11 of this newsletter.

I would like to take this opportunity to invite you all to check out our upcoming events section on page 12. In May, we have a special movie screening to learn about Robin Williams's battle with Lewy Body Dementia and an info session on research participation. We hope you will be able to join us for these special events!

As always, I want to thank each of you for being a part of our MADRC family. As we continue to combat these devastating diseases and create innovative ways stay in touch during these unusual times, we wish health and safety for you and your family.

-Brad

#We Are MADRC

The Massachusetts Alzheimer's Disease Research Center (MADRC) works from bench to bedside to develop novel therapies and conduct cutting-edge research so we may someday find more effective treatments for Alzheimer's disease (AD) and related dementias. In addition to fighting AD and related dementias through research, MADRC provides education and resources for people concerned about their memory as well as information to help support patients and families.

People of color are disproportionately affected by Alzheimer's disease but underrepresented in research. We work to provide access to research for racially and ethnically diverse communities, with a goal of improving equity in research. We aim to better understand the science of how AD and related dementias affect everyone living with this disease.

We hope you enjoy learning more about our work in the 2021 MADRC Newsletter. The Outreach, Recruitment and Engagement (ORE) Core is available to support you with the information and resources you need. You can find information about our work at madrc.org.

STAY CONNECTED WITH MADRC!



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MASSACHUSETTS Alzheimer's Disease Research Center



Soldiering on Amidst COVID-19

During the COVID-19 pandemic, our team worked hard to stay connected with our research participants. When visits were temporarily suspended, our team members called all our research volunteers, offered virtual education events and found other creative ways to check in.

Take a look at how we stayed the course during this most remarkable year: <https://bit.ly/MADRC2020>

Dr. Fauci Talks COVID-19 Vaccine and Dementia

Katie Brandt, Director of Caregiver Support Services and Public Relations for the **MGH Frontotemporal Disorders Unit** and Co-Chair of the National Alzheimer's Project Act (NAPA) Advisory Council for Alzheimer's Research, Care and Services, interviewed Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases, ahead of the January NAPA Council meeting.

The interview focused on the impact of the COVID-19 vaccine for our dementia community with emphasis on the safety and importance of the vaccine for all members of the community, including individuals living with dementia, caregivers at home, direct care workers in assisted living memory care and skilled nursing facilities. To see the full interview: <https://bit.ly/BrandtFauci>



Advancing Research Innovation in the Lab

MADRC scientists are dedicated to making research discoveries that lead to new, more effective ways to understand, diagnose and treat Alzheimer's disease and related dementias. Many of these advancements start as basic science research in the laboratory, involving teams of experts that collaborate using biological, anatomical, physiological, and behavioral methods to better understand features of disease. Researchers take results from such studies and use it to understand the disease and develop treatments.

This past year, our chief Dr. Bradley Hyman uncovered clues into why Alzheimer's disease may worsen quickly in some patients and slowly in others. This work studied the brains of patients who died with Alzheimer's disease and found that certain forms of tau were linked to a more rapid progression of disease during life. When these forms of tau were treated with antibodies, they were prevented from spreading. These findings could be used in future research to help inform how rapidly a patients' disease will progress and, importantly, this work suggests that targeting these proteins may be useful in treating Alzheimer's disease.

Another one of our researchers Dr. Ted Zwang, Instructor of Neurology, is studying what triggers the onset of Alzheimer's disease and how damage to the brain can spread and worsen over time. He is taking a novel approach of studying Alzheimer's progression by watching mice play in virtual reality (which is sort of like watching mice play video games.) Ted says that "watching mice play in virtual reality could help us understand the causes and timing of dysfunction." In his experiments, healthy, young mice are taught to run through a carefully crafted virtual reality world in search of rewards. The mice are monitored as they age or as Alzheimer's pathology develops. While the mice play in virtual reality, Dr. Zwang and his team measure changes in mouse brain activity. These experiments will help us understand how aging and disease changes individual neurons, and results in behavior changes. This allows us to differentiate harmful features from coincidental ones, which is important as we search for aspects of Alzheimer's disease that could be treated to prevent or slow cognitive decline.



MADRC Research Teams Working Together Toward a Cure

Though we are named the Massachusetts Alzheimer's Disease Research Center or affectionally, "MADRC", we are unequivocally dedicated to researching and finding a cure for Alzheimer's disease and related dementias. Within our larger ADRC, we have several different units and centers comprised of researchers who are at the forefront of this great research. In this article we will spotlight each of the 5 different units that comprise MADRC.

The **Alzheimer's Clinical & Translational Research Unit** (ACTRU) takes a multidisciplinary, basic science to clinic translational approach for designing patient-oriented clinical trials and observational studies for aging, dementia, and other neurodegenerative disorders. Their work led by Dr. Steven Arnold includes advanced digital health assessments, neuroimaging, and ultra-sensitive molecular biomarker detection technologies in blood, cerebrospinal fluid and brain tissue. This team aims to advance knowledge about complex brain disorders, invent and test diagnostic and mechanistic biomarkers of brain disease and implement innovative proof of concept trials to speed therapeutic development. They have some innovative, novel studies that are targeting brain disease in unique ways. You can learn more about ACTRU by visiting their website at: www.actru.org/.

We also have a team that focuses on the second most common type of progressive dementia, Lewy body dementia. Lewy body dementia is associated with protein deposits in the brain called Lewy bodies, that affect chemicals in the brain and lead to changes in thinking, movement, behavior and mood. The **Lewy Body Dementia Unit** (LBDU) provides diagnosis and treatment

for patients with Lewy body dementias including Parkinson's disease associated dementia, as well as patients with mild cognitive impairments arising in these diseases. Management of cognitive, motor, sleep, psychiatric, and other nonmotor manifestations of these diseases is provided. Ancillary services provide disease-focused physical therapy, occupational therapy, and speech therapy. Their social work staff provide opportunities for caregiver support. The LBDU is a Lewy Body Dementia Association Research Center of Excellence.

Another unit, The **Frontotemporal Dementia Unit** (FTDU), focuses on brain disorders that affect the frontal and temporal lobes of the brain. These lobes are associated with personality, behavior and language. The FTDU is an interdisciplinary team of clinicians and researchers who are dedicated to the belief that, through the application of scientific approaches, we will advance our collective understanding of brain function and dysfunction which will ultimately improve our ability to diagnose, monitor, and treat patients with Frontotemporal Dementia (FTD) and related disorders, including Primary Progressive Aphasia (PPA), Semantic Dementia (SD), Corticobasal Degeneration Syndrome (CDS), and Progressive Supranuclear Palsy (PSP). This team is particularly interested on the impact of these illnesses on the family and other parts of the social network.

The **Cerebral Amyloid Angiopathy (CAA) Research Center** is a group of MGH physician-investigators, scientists, and other research staff that focus on the development, diagnosis, and treatment of CAA. CAA is an important cause of cerebral hemorrhage in the elderly. It is currently one of the few kinds of stroke without effective prevention or treatment strategies. Their research is divided into a clinical program that focuses on the molecular epidemiology of CAA and a laboratory program studying its pathogenesis. These studies offer a promising approach for devising and testing new candidate treatments for preventing progression of CAA. One study, Vascular Pathology in Early and Asymptomatic Cerebral Angiopathy aims to identify signature markers through MRIs and memory/attention testing to learn more about the (Continued on next page)

Research Teams *(Continued)*

progression of both Cerebral Amyloid Angiopathy and memory loss. To learn more: www.angiopathy.org/research-center.

Lastly, the **Center for Alzheimer Research and Treatment (CART)** is located on the BWH campus of Mass General Brigham and offers both clinical trials and observational studies that help discover if new treatments can stop Alzheimer's disease (AD) from advancing or delay symptoms of AD. The CART team has been at the forefront of understanding that brain changes related (AD) begin up to 15-20 years before a person notices symptoms. Using potential new treatments much earlier before brain destruction occurs is critical in the fight against AD.

In early 2021 we learned that the phase II Trailblazer Study showed promising results for individuals with MCI and Early AD. A portion of individuals in this study showed cognitive improvements. CART will be repeating this study and enrolling participants in the phase III study. This trial

will evaluate if a new investigational drug is safe and effective and determine if it will slow cognitive impairment and reduce the amyloid plaque in people with early-stage AD. This monoclonal antibody therapy was developed to reduce the number of amyloid plaques in the brain. The researchers will measure cognition and changes in the brain using MRI and PET scans. Dr. Gad Marshall, lead investigator of this trial, hopes the Trailblazer II Study will be effective in the fight against Alzheimer's Disease.

The only way to advance our knowledge is through research. Each of these 5 units within MADRC works together to find a cure for Alzheimer's disease and related dementias. We share resources, insights and even patients who we think could benefit from an offering in a different unit. Through collaboration across our vast center, we hope to find answers to Alzheimer's disease and related dementias. To learn more about the studies at each of these centers: www.madrc.org/join-a-study/.

Improving Understanding of Disease in Biomarker Research

Alzheimer's Disease Blood Test

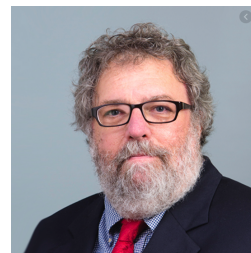


Can a blood test predict risk for Alzheimer's disease? The findings of a report authored by investigators at Brigham and Women's and Mass General Hospitals, seems to indicate yes. Jasmeer Chhatwal, MD, PhD at Mass General, is first author of the report published in Nature Communications last fall.

The group analyzed a blood test for a fragment of the protein tau (NT1), which is a hallmark of Alzheimer's disease. The blood test has been evaluated in Harvard Aging Brain Study (HABS) participants. HABS is a cohort of cognitively normal, older adults being closely followed over time. The study authors report that increased levels of NT1 in participants blood was highly predictive of the risk of cognitive decline and Alzheimer's disease.

While the team cautions that a blood test for routine clinical care is likely a few years away, it could ultimately save a lot of time and money by replacing more cumbersome and expensive testing methods such as lumbar punctures and brain imaging.

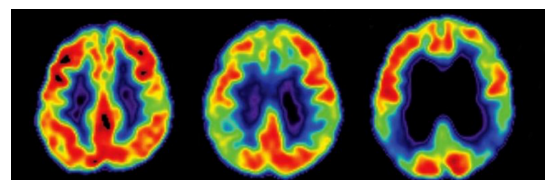
PET Imaging



Positron Emission Tomography (PET) Imaging is helping lead researchers to an improved understanding on how to fight Alzheimer's disease and related dementias. There are two naturally occurring proteins in the brain amyloid and tau. When these proteins accumulate at toxic levels it leads to destruction in the brain.

Dr. Keith Johnson's lab has been on the forefront of science, pioneering an improved understanding of what happens to amyloid and tau proteins by evaluating brain changes through PET Imaging technology. He and his team have been involved in groundbreaking research over many years, leading the way for researchers to better visualize amyloid and tau and monitor changes over time.

If you would like to get involved with PET imaging research, check out our website: madrc.org/join-a-study/.

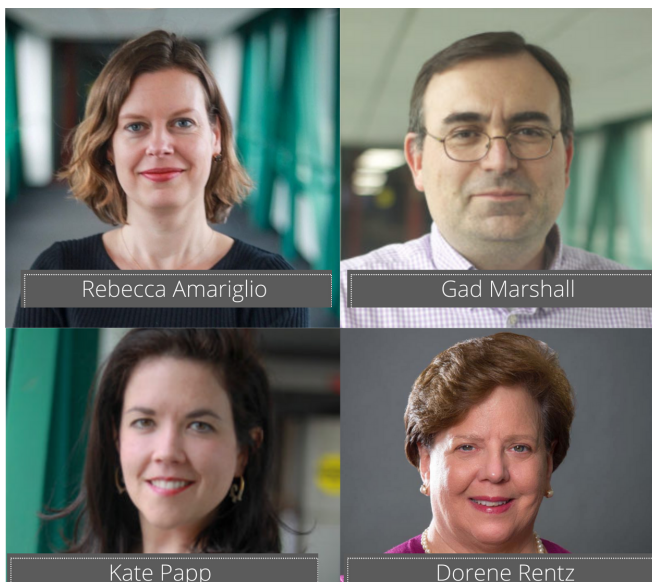


Modernizing Cognitive Tests With Digital Technology

Smartphone Test Detects Early Alzheimer's Disease

Kate Papp, PhD and Rebecca Amariglio, PhD at the Harvard Aging Brain Study are developing novel cognitive tests on Smartphones to detect early warning signs of Alzheimer's disease. Drs. Papp and Amariglio have been investigating the earliest changes in cognition that distinguish typical aging from Alzheimer's disease. Previously researchers would have to bring participants into the clinic for a cognitive examination. With memory and thinking tests on Smartphones, research participants can take the tests at home, making them more accessible and less time consuming. As part of the study, participants receive monthly text messages requesting that they match faces and names or grocery items and prices. The results have shown that performance on the matching tests is related to markers of amyloid and tau pathology in the brain.

These smart phone assessments will eventually be compared with blood tests, neuroimaging and genotyping which requires participants to come into the clinic. Since COVID-19 has limited the number of people being brought onsite, these remote tests have proved advantageous. Drs. Papp and Amariglio hope that speeding up assessment of cognitive function will also speed up future research trials.

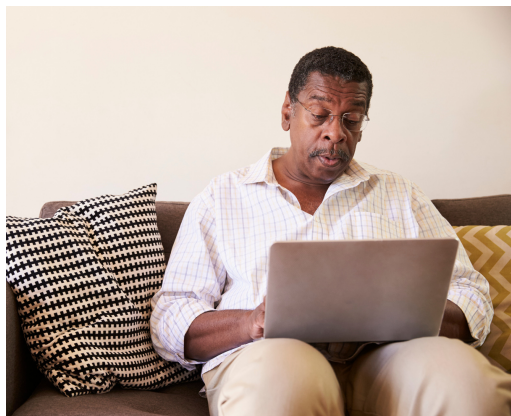


Instrumental Activity of Daily Living (IADL)

Dr. Gad Marshall hopes to advance and modernize cognitive testing using smartphones in a three-year IADL study to determine if newly developed automated telephone, smartphone, and computer-based daily functioning tests can help doctors track early changes in daily tasks. The tests can be done in office or at home and will be compared to standard paper and pencil memory and thinking tests and MRI and PET scans of the brain. This study also aims to learn more about mood and behavior, especially apathy or lack of motivation and interest. Mood and behavior are important to study in order to improve early detection and treatment of Alzheimer's disease.

Can a Digital Clock Drawing Test Detect Early Alzheimer's Disease?

Dorene Rentz, PsyD and colleagues published in *Neurology* on April 6, 2021, new work on a time-honored clock drawing test using a digital pen to monitor cognitive changes with each pen stroke. This technology detects the correctness of the drawing and more subtle nuances of performance such as spatial patterns and organizational features not captured on traditional paper and pencil tests. The authors found the subtle features of the digital clock drawing could differentiate patients with Alzheimer's disease from healthy controls and normal controls who had amyloid and tau accumulation in the brain.



Supporting Research From Home

Many people with a family history of Alzheimer disease (AD) or who have memory concerns have asked if there are prevention research opportunities they can do from home. The Alzheimer's disease Prevention Trials (APT) Webstudy engages people in their own homes, on their computers, and uses technology to identify those potentially at risk for Alzheimer's. Anyone aged 50 or over can participate in the APT Webstudy:

www.aptwebstudy.org

Digital tools are the wave of the future and show promise of providing a quick and inexpensive way to detect those at-risk for Alzheimer's disease. Early detection allows individuals to take advantage of clinical trials aimed at preventing Alzheimer's disease. MADRC hopes to introduce additional digital tools into the Memory Study cohort.

Cutting-Edge Prevention Research

The team at the Center for Alzheimer Research and Treatment (CART) has been on the forefront of understanding that brain changes related to Alzheimer's disease (AD) begin up to 15-20 years before a person notices symptoms. Damage that has occurred in the brain from disease can prevent new medications from being effective. Using potential new treatments much earlier, before brain destruction occurs, is critical in the fight against AD.

A new Alzheimer's disease Prevention Trial called the AHEAD Study aims to break new ground in research by finding a treatment that targets memory loss earlier. Dr. Reisa Sperling, Director of the Center for Alzheimer Research and Treatment (CART) at Brigham and Women's Hospital is one of the leaders of this prevention trial. The study opened in

2021 and is recruiting both English and Spanish speakers age 55 and older who do not have symptoms but are at risk for getting Alzheimer's disease. For more information call 857-307-0345.



The Importance of Observational Studies

Observational studies are critically important for learning about diseases and developing new theories of how diseases impact people.

Observational studies help scientists fight AD and related dementias by providing the data needed to answer important research questions.

We are always interested in having new research participant volunteers! Visit madrc.org to learn more about how you can get involved with research.

CLINICAL TRIALS

VERSUS

OBSERVATIONAL STUDIES

COMPARING THE 2 TYPES OF RESEARCH

 Clinical trials	 Observational studies
<p>Determine new ways to treat or prevent disease</p> <p>Involve an intervention with a drug or treatment to discover if it is safe and effective</p> <p>Participants are randomly assigned into groups and either receive an investigational treatment or are in the control group which will receive standard of care or placebo</p> <p>Neither the study team nor the participants know in which group they will be</p> <p>Clinical evaluations such as memory tests, MRI, PET scan, physical exams, lumbar punctures and blood draws may be performed</p> <p>Safety and efficacy is closely monitored by research team</p>	<p>Determine new ways to detect and track disease</p> <p>No treatments or interventions are involved</p> <p>Clinical evaluations such as memory tests, MRI, PET scan, physical exams, lumbar punctures and blood draws may be performed</p> <p>Evaluations may help identify new tests, procedures, biomarkers that improve how we diagnose or monitor people living with disease</p> <p>Study may help inform development of a clinical trial</p> <p>May involve one or more visits</p>
	MASSACHUSETTS Alzheimer's Disease Research Center



Our Research Heroes

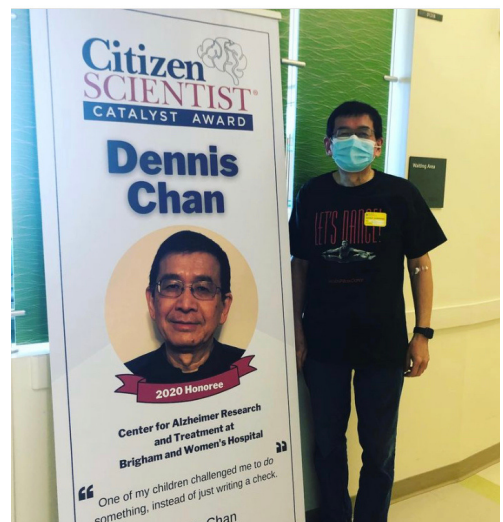
Research would not be possible if it wasn't for our amazing participant volunteers. This past October, we held our first virtual MADRC Research Participant Appreciation Symposium. The event was named in honor of Stephen D. Johanson, a dedicated MADRC research volunteer who not only participated in clinical trials but also contributed the ultimate gift of donating his brain to research. Anthony Everett of WCVB-TV's Chronicle made a special appearance, thanking all the volunteers who donate their time to research and even gave a personal history of how Alzheimer's disease has affected his family. Attendees received updates about cutting-edge research by MADRC investigators and heard touching testimonials from Dennis Chan and Mike Belleville as to why they decided to participate in a research trial. We encourage you to view the event at: <http://bit.ly/ParticipantAppreciation>



Left to right: Stephen D. Johanson and Mike Belleville

We also want to acknowledge Dennis Chan for recently receiving the Global Alzheimer Platform Foundation's National Citizen Scientist Catalyst Award in recognition of his outstanding research efforts and support. Dennis participates in the A4 Alzheimer Prevention Trial at Brigham and Women's Center for Alzheimer Research and Treatment. He poignantly stated that he finds volunteering in a clinical trial a rewarding experience and an opportunity "to set an example for my children of what it means to help make the world a better place."

Dennis is a member of the National Alzheimer Clinical Trial Consortium Advisory Board and a valued member of our research community.



Finally, we salute all of our Research Ambassadors who volunteer their time to participate in our studies and speak at MADRC community events to educate others about research. To learn more about our Research Heroes, visit: <https://bit.ly/ResearchHeroes>



"My patients often want to participate in research studies because they may benefit from a treatment, and also because they want to help find a cure for this disease. For many of them and their families, this is an important part of their lives at this time."
- Dr. David Caplan

Research is at the Heart of What We Do

We need to answer important questions in the quest to cure this disease and the only way we can do this is through research. Please consider helping us by learning more about research opportunities. MADRC currently has several clinical trials and observational studies underway.

MADRC studies are enrolling participants who are Cognitively Normal (no memory loss or dementia) (CN), have Subjective Cognitive Decline (SCD), Mild Cognitive Impairment (MCI), Alzheimer's Disease (AD), Frontotemporal Dementia (FTD), Lewy Body Dementia (LBD) and other related dementias. Time commitment to participate in these studies varies and can range from one visit to multiple visits over a five-year period. Some studies compensate participants for their time and support is provided for travel and parking costs.

To learn more about what it is like to participate in a clinical trial: <http://bit.ly/ResearchParticipationGuide>

For a complete list of studies, visit:

<https://www.madrc.org/join-a-study/>

A Road Map to Research Participation

Have you ever considered participating in clinical research?

Did you know the first person to be cured of Alzheimer's disease will be in a clinical trial? Research participation is a great opportunity to contribute to research by either receiving new experimental treatments or being observed over time. Research participants help us work towards finding a cure for Alzheimer's disease and related dementias. There are many ways Alzheimer's research is conducted. The two most common types of studies are clinical trials and observational studies.

What is a clinical trial?

Clinical trials are research studies used to test the safety and effectiveness of a new therapy. During clinical trials, participants are randomized into two or more groups and receive the new treatment or a placebo. Often described as a "sugar pill," a placebo is used to observe the effects of the experimental medication compared to no treatment. During the study, both you and the study team will be blinded (not know) which group you are in. Your safety is monitored closely during the course of a study.

Observational studies are different from clinical trials because no treatment is involved. However, they are still extremely important for us to understand how brain diseases develop. During observational studies, scientists perform clinical evaluations, such as memory and thinking tests and physical exams, collect images and carry out medical tests, like blood draws and lumbar punctures to observe changes in your brain over time. These studies are a great option for those who would prefer fewer visits to the research center and/or are not interested in receiving experimental treatment.

What is involved in a clinical trial?

The following pages will give you an idea of what it's like to participate in clinical research and observational studies. Every study is different, but these are some of the most common components of participation.

Aging & Memory Loss Road Map Series

- I. Dementia Diagnosis
- II. Research Participation
- III. Caregiving

Contents:

- Thinking about participating?...1
- What is a clinical trial?...1
- What is involved?...1
- Step 1: Pre-screening2
- Step 2: Screening Visit...2
- Step 3: MRI and PET Scans...3
- Step 4: Lumbar Puncture...3
- Step 5: Baseline/Randomization Visit...4
- Memory Testing4
- Study Drug Administration...5
- Labs and EKGs.....5
- Clinical Trial FAQs6
- Testimony from Participants...7
- Resources...8

Diversifying Research Opportunities and Outreach Initiatives

Commitment to Diversity

Statement on Racial Injustice

The staff of the Massachusetts Alzheimer's Disease Research Center (MADRC), are fully committed to racial and social justice. We value ALL people and strive every day to help bridge the gap of inequity in healthcare and research.

MADRC's work is informed by collaboration with a number of organizations that focus on serving specific communities such as African Americans and Latinos. We value our discussions with the leaders of these groups as they provide valuable perspectives to incorporate into our community outreach and education programs.

The horrific, violent crimes in Minnesota, Georgia and elsewhere recently against Black people, including George Floyd, Ahmaud Arbery and Breonna Taylor, underscore the fact that there is much more work to be done to combat racism and inequity across the country and here in our own community. We continue to stand with the members of the Black community as we work toward change and combat hatred.

#WeAreMADRC

We have taken steps to think about the ways in which our institution may have perpetuated inequality and are working with community leaders to listen and actively engage a racially diverse population. MADRC remains committed to bridging the gap of inequity in healthcare and in research.

Across Mass General Brigham our staff has joined focus groups and work groups to find ways to be more inclusive and bridge divisions that may exist. Our team put out the above statement on racial injustice earlier this year and posted it on our website.

Building Community Partnerships

MADRC announced its recent alliance with Union Capital Boston (UCB). UCB is a nonprofit organization that invests in civic engagement by building relationships, providing resources and rewarding members for community involvement. Together MADRC and UCB will be working to educate and inform underserved communities about local Alzheimer's disease research opportunities within their neighborhoods.

Our team has collaborated on several educational forums offered to UCB members on networking nights.

Some of the topics covered included: Understanding Alzheimer's Disease, What does it mean to Participate in Research and Understanding your Rights as a Research Participant.

Several staff members gave presentations including Mike Kincade, Communications and Outreach Coordinator, Martha Muniz, Director of Recruitment and Rachael Williams, Research and Clinical Program Manager.

Outreach to Faith Communities

Memory Sunday -- the second Sunday in June -- is an initiative of The National Brain Health Center for African - Americans, a program of The Balm in Gilead. Since 2018, MADRC has led Memory Sunday New England, an annual event held in African American/Black faith communities.

This impactful event brings together churches and health organizations to provide families with education and resources about Alzheimer's disease and related dementias.

As part of Memory Sunday, faith communities incorporate education into religious services and related programs about the prevalence of Alzheimer's disease in the Black community. This includes discussion about ways to reduce the risk of developing Alzheimer's disease, support available for caregivers as well as raising awareness about the importance of research and participation in research studies. People of color are disproportionately affected by Alzheimer's disease, but are underrepresented in clinical trials and Alzheimer's disease research.

Memory Sunday New England has grown each year and MADRC now partners with more than 20 great organizations including the Balm in Gilead, the City of Boston Age Strong Commission and Berea Seventh Day Adventist Church in Roxbury (which has been involved with the event since the first year).

To see a complete list of our collaborators and learn more about Memory Sunday visit:

<http://bit.ly/MemorySunday2021>

PLEASE JOIN US FOR

MEMORY SUNDAY 2021

SIGNS OF CHANGE

JUNE 13, 2021

A day to raise awareness about memory loss, aging and Alzheimer's disease. Let's talk about how you can reduce your risk and be part of the race to find a cure. Let's talk with experts and laity to be informed and enlightened as we search for treatments and a cure.

For more information: Nancy Coppelman
617.278.0383 ncoppelman@bwh.harvard.edu
madrc.org/memory-sunday/ Facebook: [@MemorySundayNE](https://www.facebook.com/MemorySundayNE)



MEMORY SUNDAY NEW ENGLAND

COMMUNITY ♦ AWARENESS ♦ SUPPORT

© Memory Sunday New England

Reaching Latino Populations



The Multicultural Alzheimer's Prevention Network (MAPP) is helping improve access to research and enhancing our understanding of how to better treat and support some of the hardest hit patients and families in communities crippled by Alzheimer's Disease and related dementias. This team offers several studies including the Boston Latino Aging Study (BLAST), and an online study on the impact of COVID-19 on the wellbeing and cognition of older adults in the United States and Latin America. Jairo Martinez and Paola Garza work specifically with the Latina/o/x/e community to promote studies, encourage research involvement and provide brain health education. Learn more about their work here: www.madrc.org/about/diversity/

MGH Opens Multicultural Center

The Multicultural Assessment & Research Center (MARC) was recently launched at Massachusetts General Hospital. MARC offers culturally and linguistically appropriate neuropsychological services to diverse adult patients with cognitive difficulties.

The center also offers exciting research opportunities. Directed by Yakeel T. Quiroz, PhD and Paula Aduen, PhD, the center can be reached via email at: MARC@MGH.Harvard.edu or by phone at (617) 643-5883.

Comings & Goings

This year a cornerstone of the Memory Study team, Jeanette Gunther, retired after nearly 40 years! We will miss her dearly but wish her all the best in retirement. Stepping into Jeanette's shoes is the very capable Judy Johanson who will take over as the MADRC Longitudinal Cohort Coordinator.

The BWH CART team recently welcomed Claudia Valenzuela as Research Assistant and Recruitment Specialist. Claudia holds a Bachelor of Science in Neuroscience and Cognitive Science with an emphasis in Development and Aging from University of Arizona. She has worked as a research assistant in the Cognitive Neuroscience Lab of Language at U of A on the Neural Correlates of Visual Metaphor Processing project. Currently, she assists in conducting telephone screens, memory screens, and will be assisting in community outreach efforts to bring awareness about ongoing clinical trials, especially in the Latino Community.

MADRC welcomed Rachael Williams to its team as the Research and Clinical Program Manager. Rachael recently received her Master of Science in Medical Sciences from Brown University. She has worked as a research program manager for the Crimson Care Collaborative, a network of seven student faculty clinics across the Harvard network where she grew her passion for serving underserved communities and working with marginalized populations. In her role with MADRC, Rachael ensures research compliance and safety for our research participants, and helps to keep the center running as smoothly as possible. Rachael will soon be moving onto medical school and we wish her the best!



Stay Connected With MADRC Virtual Events

MADRC has launched a program for those interested in getting an inside look at what it's like to be involved with research studies. "Let's Talk Research Participation" is a virtual information session targeting people concerned about their own memory or who have a family history of Alzheimer's disease or related dementia.

Join one of our virtual sessions to hear from people currently enrolled in research studies who will share their experience. You'll also get an overview of the different types of research being conducted by MADRC and get answers to your research questions. Sessions will be held on May 26th and June 23rd from 7-8PM. Learn more or register online here:

<http://bit.ly/RsrchTalk>



The MADRC Outreach team, in conjunction with the Lewy Body Dementia (LBD) Unit, recently hosted a virtual viewing of the movie SPARK. SPARK reveals the true story about Robin Williams and his battle with undiagnosed LBD. This educational film delves deeper into the disease, its biology, myriad of clinical symptoms and its impact on both the person with LBD and the primary caregiver.

For a schedule of upcoming MADRC events:

www.madrc.org/events/

