

## Outreach & Recruitment Highlights and Happenings

## MADRC MISSION

The Massachusetts Alzheimer's Disease Research Center (MADRC) conducts extensive research, training and outreach programs. Our center is at the forefront of dementia research and care.

To achieve these goals, Massachusetts General Hospital (MGH) and the Brigham and Women's Hospital (BWH) work closely together under the MADRC umbrella to support our work to cure Alzheimer's disease and related dementias.

### OUTREACH, RECRUITMENT & ENGAGEMENT CORE

The Outreach Recruitment and Engagement (ORE) Core supports MADRC by getting the word out about the important work happening at our center. We are working to raise awareness about early detection, emphasize the importance of receiving a medical diagnosis for Alzheimer's disease and related dementias, and provide extensive resources for the public and medical professionals, like primary care physicians.



Dorene Rentz PsyD, Director of ORE Core (front) Mike Kincade, Communications and Outreach Coordinator; Nancy Coppelman, Co-Director of Outreach; Hadley Hustead, ORE Operations; Lenore Jackson-Pope, Co-Director of Primary Care Outreach (back)

DORENE RENTZ, PsyD leads the MADRC ORE core as the Director. She has a dual appointment to BWH and MGH neurology. Dr. Rentz is the Clinical Core Director of the Harvard Aging Brain Study, Co-Director of the BWH Center for Alzheimer Research and Treatment (CART), and Professor of Neurology at Harvard Medical School.



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### A New Decade

As we enter 2020 our team at MADRC wants to be your resource for education and information. We invite you to become part of our research home. We want to provide you with information about what is happening in the field of Alzheimer's disease (AD) and related dementia research; inform you on how our research teams are contributing to these advances; and help you get answers to the important topics you care about. The community at large is a critical player in helping us cure Alzheimer's disease. Thank you for taking the time to read our annual newsletter.

Our websites: www.madrc.org and www.bwhcart.org.







## #WeAreMADRC

#### What types of studies to we conduct?

- 1. Clinical trials in which we evaluate new experimental treatments for Alzheimer's disease and dementia
- 2. Observational studies in which we evaluate sensitive clinical assessments, biological markers, and neuroimaging techniques to track neurological changes over time.
- 3. Prevention studies are also available for individuals who are cognitively healthy but are at increased risk of developing symptoms of Alzheimer's disease.

Together we are currently recruiting for 36 research studies across several sites.



Harvard Aging Brain and Affiliated Studies Team



Alzheimer's Clinical & Translational Research Unit

## Our Research Teams

There are several centers of research excellence that collaborate under the MADRC umbrella including, but not limited to the following groups:

- BWH Center for Alzheimer Research and Treatment
- Alzheimer's Clinical & Translational Research Unit
- Harvard Aging Brain Study
- Frontotemporal Disorders Unit
- Lewy Body Dementia Unit
- Parkinson Disease and Movement Disorder Center
- Vascular Dementia Unit



BWH Center for Alzheimer Research and Treatment



Frontotemporal Disorders Research Unit

### We need your help to cure Alzheimer's disease

Right now we have a specific need for research volunteers 50 or older diagnosed with mild cognitive impairment (MCI), Alzheimer's disease dementia, and other neurodegenerative diseases, including frontotemporal dementia (FTD), primary progressive aphasia, Lewy body dementia (LBD), and late-life mood disorders like anxiety and depression.

If you would like additional information about our studies, contact Nancy Coppelman at ncoppelman@bwh.harvard.edu or call (617) 525-8381. Did you know the first person to be cured of Alzheimer's disease will be a clinical research participant?





## Research Findings from Our Team:

Our clinicians and researchers are active contributors to the field of dementia and neurology research. Here is a brief highlight of a few topics presented at the 2019 Alzheimer's Association International Conference by MADRC team members:

#### How can physical exercise decrease one's risk of developing Alzheimer's disease?

Dr. Jennifer Rabin and her research team were interested in determining if physical exercise and maintaining a healthy heart could decrease the chances of cognitive decline due to brain changes of amyloid beta plaques and brain matter loss seen in Alzheimer's disease. She studied 182 volunteers, with an average age of 73, from the Harvard Aging Brain Study (HABS), an observational study of normal older healthy adults. HABS uses neuroimaging (MRI and PET scans) to monitor individuals at risk of developing Alzheimer's disease who do not have any current symptoms. Each volunteer was asked to wear a pedometer (e.g. Fitbit) for 7 straight days from the time they woke up and were encouraged to walk 100-30,000 steps per day. To determine if physical exercise helped their memory performance, the study participants had cognitive testing for up



Jennifer Rabin, PhD

to 6 years after the study was completed. Overall, her team discovered that greater physical activity (at least 8,900 steps/day) and managing heart health, had the impact of lowering cognitive decline due to amyloid beta plaques and brain matter loss. These results provide us a treatment-free way to help delay the progression of Alzheimer's disease dementia.

## Can a clinic-based health coach increase adherence to a healthy lifestyle and improve the quality of life for individuals with, or at risk for, memory disorders?

Dr. Seth Gale, a cognitive neurologist at the Center for Alzheimer's Research and Treatment recently led a study involving patients who receive their care at BWH. Dr. Gale's clinical care team, which included a project coordinator and health coach, Hope Schwartz, explored whether a clinic-based health coach could help patients with cognitive disorders maintain brain-healthy behaviors and improve their quality of life. Thirty-seven patients with subjective cognitive decline, mild cognitive impairment (MCI), and mild dementia were enrolled in this six-month long research study and were randomly chosen to be followed by a personal health coach or to continue to receive existing counseling and education about brain health by their neurologist. Patients in the health coach group initially set personalized goals with the coach, and then received weekly motivational phone calls and in-person visits every six weeks to track their progress and address challenges. To measure



Seth Gale, MD

changes in behavior, Dr. Gale's team used questionnaires which asked patients and their caregivers about levels of physical activity, dietary intake, participation in social/cognitive activities, and overall wellness and quality of life. The study results showed that having a clinic-based health coach helped patients to adopt and sustain brain-healthy behaviors more consistently than receiving lifestyle counseling from their neurologist at typical, periodic visits. While there were no significant differences in memory and cognition between the two study groups over 6 months, we hope that a similar health coach program that lasted for 2 or more years might demonstrate some stability in cognitive function, as well as have myriad other health benefits. Dr. Gale and his team are excited about expanding this brain health research and are motivated to develop effective, scalable, cost-effective ways to help patients live a brain-healthy lifestyle.





## Common questions about what is happening in research:

### Is a blood test for Alzheimer's disease coming soon?

Diagnosing a patient with Alzheimer's disease is expensive, especially when using multiple scans or spinal fluid from a lumbar puncture during a regular checkup. However, Dr. Akinori Nakamura and his research team are studying if we can determine one's risk of developing Alzheimer's disease based on how much amyloid protein is in a person's blood. Nakamura's team recruited 201 research participants for their observational study. Seventy were cognitively normal, 46 diagnosed with mild cognitive impairment, 61 with Alzheimer's disease dementia, and 24 with other forms of dementia. The blood test was able to correctly identify 92% of people with Alzheimer's disease dementia and 85% of people without Alzheimer's

disease dementia. This equated to an overall accuracy of 88%. More research is necessary before we can use blood tests to reliably identify Alzheimer's disease.

## Why are women more susceptible to developing Alzheimer's disease?

Research has documented that about 66% of people living with Alzheimer's disease are women. However, the reasons why are complex. New research presented at the 2019 Alzheimer's Association International Conference gives some more information on this topic:

6,386 women born between 1935-1956, joined Dr. Elizabeth Rose Mayeda's study at the UCLA School of Public Health. Results showed that women who had paying jobs between early adulthood and later adulthood, including those with and without

children, had a slower memory decline. However, memory performance for women between ages 60-70, with no history of waged employment declined 61% faster than married women with children and 83% faster than women who were single mothers. These results suggest that working a paying job or factors associated with such work opportunities, may impact late-life cognitive health for women in the United States.

Dr. Erin Sundermann from UCSD School of Medicine discovered that women with minimal to moderate amyloid deposition did better on verbal memory tests compared to men with the same amyloid levels. When looking at brain scans focused on metabolism in the brain (FDG-PET), which represent the health of connections in the brain, women had higher metabolism (better brain health) compared to men with equivalent minimal to moderate amyloid deposition. However, with higher amounts of amyloid in the brain, suggesting more advanced Alzheimer's disease, there was no difference between women and men. These findings suggest women are better able to compensate for the cognitive deficits of Alzheimer's disease pathology (amyloid deposition).









### How does blood pressure effect my cognitive health?

Most people have heard about either eating a healthy diet or managing your stress to prevent any cardiovascular disease, but the same behavior modification should apply for your brain health. Results from the SPRINT MIND trial in healthy older adults in their late 60's show that aggressively maintaining a normal blood pressure helps reduce risk of mild cognitive impairment. 9,361 participants were randomly chosen into a standard treatment group or an intensive treatment group with varying blood pressure targets. The study found that after five years, intensive blood pressure treatment reduced the chance of developing



mild cognitive impairment by 19%. This was one of the first studies to demonstrate an intervention which lowers risk of mild cognitive impairment, an intermediate stage between normal aging and dementia, which is often due to Alzheimer's disease.

### Why participate in an observational trial?

Sometimes people do not want to participate in an observational study because no treatment is involved. We need observational studies because they provide clues as to how diseases like Alzheimer's develop over time. Dr. Sedipeh Shokouhi and his colleagues at the Vanderbilt University Medical Center used data from the Alzheimer's Disease Neuroimaging Initiative (ADNI), an observational Alzheimer's study, to analyze tau protein differences between men and women. Tau protein deposition, along with amyloid, are the pathologic hallmarks of Alzheimer's disease. The



researchers studied healthy volunteers and people diagnosed with mild cognitive impairment (MCI). They learned that women with MCI had more tau protein deposition throughout their brain than men with MCI. In addition, healthy women in the study had multiple parts of their brain that uniquely connected one area with another where tau levels were increased. The researchers hypothesize that having a more interconnected network of brain regions leads to faster spreading of tau protein and damage to their brain cells.

## Want to learn more? Sign up for our education registry!

MADRC offers education programs for communities and healthcare professionals! We send quarterly emails with information about research and educational events in the greater Boston community.

#### Email BWHMADRCeducation@partners.org to be added to our mailing list.

Our speaker's bureau made up of experts in the field who educate on topics such as:

- Normal versus abnormal memory in aging
- The importance of early diagnosis in Alzheimer's disease and related dementias
- · Prevention strategies for brain health, including the importance of diet and exercise
- · Advances in research, including a review of observational, prevention and treatment studies

We also offer professional educational programs, which can be customized to support the needs of clinicians at your institution. Email ncoppelman@bwh.harvard.edu for more information.





## Why do you participate in Alzheimer's research?

#### Quotes from our study participants

"My mother and sister both had AD. Not having a diagnosis, myself, I thought participating in a clinical trial was the next step. I learned about the McCourt Foundation educational forum and connected with Dr. Dennis Selkoe, my mother's neurologist and he arranged for my sister to donate her brain"

"Given my family history, I joined an AD clinical trial and became involved in the cause. I attended a neurologist appointment with my sister and asked Dr. Growdon, "How is research doing?" He responded by escorting me to the research assistant at the Harvard Aging Brain Study and this was the beginning of my comamitment"

"I joined a trial before knowing I had AD and cared for my mother. She and her identical twin Agnes both died of early onset Alzheimer's and another sibling of late onset. I am one of 10; 5 of whom carry the genetic mutation for early onset AD."

### **Memory Test**

Do you have a family history of Alzheimer's disease? Are you concerned about your memory and thinking? Would you like to have a free memory screening test?

Contact Allyson Pulsoni to schedule an appointment (617) 525-3167 or email apulsoni@bwh.harvard.edu.

Transportation is one of the biggest barriers

to clinical research participation. We know that

driving into Boston can be difficult and public transportation can sometimes be unreliable. We offer transportation for several research studies and clinical trials so participants can be transported to and from each study visit comfortably. If participants prefer to drive themselves, parking is provided at no cost to them. If you're interested in supporting our transportation program,

donate online at www.bwhgiving.org/cart.



Follow us on Facebook and twitter for more stories from our participants and research community!

f @MassADRC

🍠 @MassADRC84

Have a story you'd like to share, connect with Christine, our social media coordinator.

cbrown95@bwh.harvard.edu



## **Transportation Program**



Thank you to the students at Whittier Technical Vocational High School who raised \$7,000 and helped fund this program.







## Can Smart Phones Help Detect Memory Changes?

Dr. Gad Marshall's Lab is conducting a study called "Novel automated performance-based ADL outcomes for early AD clinical trials" to investigate how to use technology like regular phones, smartphones, tablets, and computers to help obtain an earlier diagnosis for people with memory concerns, and evaluate if this technology can also monitor over time individuals who are living with AD. Participants, who can be cognitively normal or have MCI, will complete testing on these various devices to monitor changes in daily functioning and hopefully assist clinicians in making an earlier diagnosis. Healthy volunteers should be between the ages of 65 and 90, and volunteers with MCI should be between the ages of 55 and 90. This study includes PET scans and an MRI of the brain. There is monetary reimbursement for the study as there is for most studies in clinical research. This study can be a great way to participate in research without too many visits or a big time commitment. Email cgonzalez19@bwh.harvard.edu for more information.



**Dr. Gad Marshall** is the Associate Medical Director of Clinical Trials at the Center for Alzheimer Research and Treatment, BWH, MGH and Associate Professor of Neurology, HMS. He is a behavioral neurologist who has led the development of several programs to support collaboration with primary care physicians



and other specialists both at BWH/MGH and local health centers with support of staff at the Center for Brain/Mind Medicine at BWH.

"We are partnering with clinicians, primary care providers and specialists to provide the tools needed to support, diagnose, and manage the care of patients with memory and thinking concerns. Our goal is to create a network of clinicians that will provide access to early diagnosis, high quality care and treatment, and information on community services and research opportunities. We work with our clinical partners and provide access to clinical support and education at the Center for Alzheimer Research and Treatment in collaboration with the Center for Brain/Mind Medicine at BWH."

— Gad Marshall

#### Services provided:

- Neurological and neuropsychological testing support and education.
- A Rapid Diagnostic Clinic (RDC) program for second opinion consulting and access to diagnostic support for research opportunities.
- · Community resources through our network of collaborators
- · Research and clinical trial resources

Contact Lenore Jackson-Pope for more information:

Llackson-Pope@bwh.harvard.edu or (617) 525-8381

### New Partnership with Cape Cod Neurology

The Center for Alzheimer Research and Treatment along with the Neurologists of Cape Cod and Memory Center of Cape Cod — part of Cape Cod Healthcare, teamed up to offer access to second opinion diagnostic services through the BWH CART and Center for Brain/Mind Medicine Rapid Diagnostic Clinic and access to transportation services for research at BWH. This initiative was led by Dr. Sean Horrigan and Marian Evans, CCHC practice manager.

## 

#### CAPE COD HEALTHCARE



Dr. Sean Horrigan, Cape Cod Neurologist practice phone #: (774) 470-2460





## **Research Community Initiatives**

Yakeel Quiroz, PhD, a leader in diversity initiatives, is the founder of the Multicultural Alzheimer's Prevention Program (MAPP) at Massachusetts General Hospital and currently conducting two studies for Spanish speakers. Latinos are the fastest grow-



ing subpopulation among the aged in the US and they have a higher rate of AD and related disorders than their Anglo counterparts. Despite the greater prevalence of AD, Latinos continue to be underrepresented in the research.

#### The Boston Latino Aging Study (BLAST)

BLAST is an observational study that aims to understand memory and age-related memory loss of older Latino populations. Participants must be age 60 or older and be a Spanish speaking (monolingual or bilingual) Latino. BLAST participants will receive a one-page report outlining their performance on cognitive and behavioral assessments with recommendations. Questions or referrals? **Contact Jairo Martinez at (617) 643-5880.** 



#### Multicultural Alzheimer Prevention Program (MAPP)



MAPP is an initiative to advance culturally informed understanding of Alzheimer's disease and

prevent cognitive decline. MAPP develops novel, culturally-appropriate cognitive testing for the assessment of memory disorders through the development and validation of new, reliable instruments with construct and diagnostic validity that are appropriate for multicultural populations. MAPP encompasses programs such as MUNDOS, a multicultural neuropsychology program that provides culturally and linguistically appropriate care to Latino adults and Spanish speakers. MUNDOS is available to help you with cognitive testing needs for your Spanish speaking patients. To learn more, please visit www.mapp.mgh.harvard.edu.

African American participation in Alzheimer's Disease and related dementia's research is something we care deeply about, and we are working with leaders in this community to ensure information is made available and easy to access.



### Latino Harvard Aging Brain Study (HABS)

HABS was launched more than ten years ago with the goal of elucidating the biological and clinical significance of amyloid β-protein (Aβ) accumulation in clinically normal (CN) older humans. We are now enrolling a subsample of 40 older Latinos/as into HABS. Adding this group of participants will be crucial to our understanding of ethnoracial similarities and differences in age-related brain alterations and cognitive decline, as well as to the identification of risk and protective factors for preclinical Alzheimer's disease in Latinos. This knowledge is essential to addressing research disparities that currently exist between older Latinos and their Anglo counterparts. If you have questions or would like to refer a patient, please contact the study coordinator, Ana Paola Garza at (617) 643-5250 or agarza3@partners.org





## Community Engagement

Did you know that around 21% of African Americans over age 70 have AD, while only 11% of Caucasians have AD? Additionally, African American participation in research studies is proportionally low, leading to basic questions remaining unanswered. Our team is advocating and supporting initiatives to diversify clinical trial enrollment by building relationships within minority communities. Our goal is to better understand the ethnic and socio-economic factors contributing to Alzheimer's disease. These points speak to the importance of engaging minority populations to better understand how people in the U.S.. are impacted by AD, and how diversity is fundamental to protecting public health.



Mike Kincade, Communications and Outreach Coordinator



Orett Burke, Outreach Assistant

In 2019, Mike Kincade and Orett Burke joined the Outreach, Recruit-

ment, and Engagement team at MADRC to amplify our outreach initiatives within minority communities. Mike has been working with his community leadership advisory board to determine how to best foster relationships within the community. The section below highlights two of our keystone diversity initiatives.

## Memory Sunday

On Sunday June 9th, 2019, we had our second Memory Sunday event. Memory Sunday brings attention to the burden of Alzheimer's disease and other dementias in African American christian communities.

This is accomplished by using the power of the pulpit to raise awareness, distribute facts about Alzheimer's disease, encourage participation in research studies, and support people living or caring for those with Alzheimer's disease. We presented at one church in 2018. In 2019 we ramped up our efforts and partnered with 14 different churches in Massachusetts and Rhode Island. The event was a great success and we continue to build relationships with the church communities we partnered with.

The Memory Sunday New England coalition is composed of the Alzheimer's Association, Balm in Gilead, Berea SDA, Boston University ADC, Boston City Councilor Baker's Office, Boston University School of Social Work/Center for Aging & Disability Education and Research, Butler Hospital, City of Boston Age Strong Commission, Executive Office of Elder Affairs, St. Paul AME Church (Cambridge, MA), and St. Paul's Episcopal (Dartmouth, MA).



Memory Sunday 2020 Sunday June 14, 2020

### Dr. William A. Hinton Symposium

The 2020 African American Community Forum on memory loss honors Dr. William A. Hinton, a former child of slaves who received his medical degree from Harvard Medical School in 1912. Among his many scientific accomplishments he developed a highly accurate test for syphilis as well as became the



first African-American to be promoted to the position of professor at Harvard University. This forum will educate attendees about Alzheimer's disease as well as steps to be taken after someone receives a diagnosis. For more information, please email mkincade@mgh.harvard.edu.





# **Biomarkers:** What are biomarkers and why do we need them to study Alzheimer's disease?

## What is a biomarker?

**Biomarkers** are measures of what is happening inside a living body, and are determined by results of laboratory and imaging tests. Biomarkers help us diagnose health conditions and diseases, identify health risks, monitor treatment, and highlight bodily changes over time. For example, cholesterol is a biomarker of heart health. So we draw blood and measure cholesterol to determine an individual's risk of heart-attack. In the context of Alzheimer's disease, research-ers use biomarkers to detect brain changes in people who may or may not have changes in memory or thinking. Early detection, often before symptoms arise, is a keystone to Alzheimer's research and depends on biomarkers.

[Source: NIH Alzheimer's and related Dementias Education and Referral Center]

## What is cerebrospinal fl uid?

**Cerebrospinal fl uid** (CSF) is a clear fl uid that surrounds your brain and spinal cord, provid-ing protection and insulation. In addition, CSF contains several proteins such as amyloid and tau, which give us a window into the brain and may indicate the presence of Alzheimer's disease. Like blood, CSF is naturally replenished when removed from the body. Collecting CSF is vital for diag-nosing and finding a cure for Alzheimer's disease and related dementias.

Experienced clinicians collect CSF from the spine by a **lumbar puncture (LP)**, also known as a spinal tap. The procedure involves injecting a local anesthetic and then inserting a small needle between vertebrae at the level of the hip bones to collect the fluid. Spinal fluid collection is a safe procedure that may cause minimal discomfort.

### Alzheimer's Disease Biomarkers

Amyloid Beta Protein is a normal protein that supports brain cell growth and repair. However, when its processing is abnormal, amyloid plaques can form between brain cells. Tau Protein is another normal substance that helps transport various proteins within a brain cell. If tau develops improperly, tau tangles can form within the brain cells themselves.

Amyloid plaques and tau tangles reduce brain cells' ability to communicate with each other. Together, they are the neuropathological hallmarks of Alzheimer's disease.



#### Lifespan Biobank - Biomarker Study

Dr. Steve Arnold's ACTRU is working on developing new biomarkers to detect Alzheimer's and Parkinson's disease, including markers of inflammatory status, oxidative stress, and brain metabolism. In order to fully understand how these biomarkers might help us classify neurodegenerative disease patients, we also need to understand how they behave in people across the lifespan. ACTRU is therefore interested in collecting blood and CSF from adults of all ages, both with and without neurodegenerative disease. The study involves 2 or 3 visits to their location in the Charlestown Navy Yard. The first visit consists of consenting and cognitive tests and a blood sample. The next visit involves a fasting LP. There is also the possibility of having an MRI on a 3rd visit. Paticipants must be 18+ years of age and willing to undergo an LP. Participants may be healthy, have a family history of dementia, have a diagnosis of MCI or dementia, or a neurodegenerative disease.

For more information, contact LQuinn@MGHIHP.EDU.





## A New Decade for Alzheimer's Research!

## New Prevention Studies

Dr. Reisa Sperling, Director of the BWH Center for Alzheimer Research and Treatment (CART), and Professor of Neurology at HMS, is leading an ongoing clinical trial known as the A4 study. This is a landmark international clinical trial evaluating the efficacy of anti-amyloid treatment in preventing memory



loss due to Alzheimer's disease among healthy older adults with evidence of amyloid in their brain.

This spring additional prevention studies for healthy older adults, led by Dr. Sperling, will be opening across the world and at CART. For information on prevention studies contact Allyson Pulsoni at (617) 525-3167 or apulsoni@bwh.harvard.edu.

## Aging & Memory Loss Road Map Education Series

Are you or a loved one concerned about memory loss or dementia? Has someone you know recently been diagnosed with dementia? Do you know that you can participate in a clinical research trial? Come learn from experts & have your questions answered!

Road Map to Dementia Diagnosis

**Road Map to Research Participation** 

Road Map to Caregiving

The MADRC outreach team is pleased to announce the launch of our new educational program, the Road Map series. This program is designed to support patients and families concerned with memory and thinking issues.

This program was piloted at BWH in 2019 and will be offered at MGH and in community locations in 2020. Please email *BWHMADRCeducation@ partners.org* if you would like to be notified about upcoming events.

## COVID-19

Due to concerns surrounding COVID-19, we are taking every precaution to protect our research participants, study partners, and staff. Effective March 16th, we have shut down our in-house research operations across the MADRC and CART, including clinical trials. Our staff are working remotely from their homes and participants and study partners are not coming in for visits. Our dedication to finding more effective treatments and a cure for Alzheimer's disease continues as always, however we must focus on the medical crisis at hand and follow all recommended guidelines to keep people safe.

## apt webstudy 🗞

Help us to enroll Alzheimer's trials faster by joining the Alzheimer Prevention Trials Web-study. The APT study monitors participants through regular online memory testing, then matches people to clinical trials they might consider. Sign up on the website *www.aptwebstudy.org* 

## Honoring Research Participants

This summer the MADRC will host the first centerwide research participant appreciation event. The symposium will be named after Stephen D. Johanson, a research participant and visionary who was diagnosed with younger onset Alzheimer's disease at age 59. Steve was able to envision the unimaginable despite his terminal diagnosis and was determined to fuel hope for future generations by participating in research. The symposium will be a celebration of all the visionaries who call the MADRC their research home.



Steve and Judy Johanson





## **Quick Facts:**

- Every 65 seconds someone in the Unites States develops Alzheimer's disease.
- By the year 2050, someone in the US will develop it every 33 seconds.
- Alzheimer's disease is the 6th leading cause of death in the United States.

The Massachusetts Alzheimer's Disease Research Center (MADRC) has been at the forefront of Alzheimer's and related dementia research for nearly 40 years. Our world-renown scientists, and top-notch staff, are dedicated to changing the course of the disease.

Research participant volunteers are critical to our mission. Participation opportunities are available for both healthy individuals and those living with the disease.

Partner with us to help advance research that will produce treatments and a cure for the next generation!

To learn how you can make a difference by participating in research, contact MADRC Co-Director of Outreach, Nancy Coppelman at (617)278-0383 or: ncoppeleman@ BWH. Harvard.EDU.



Bradley T. Hyman, MD, PhD., Director, Massachusetts Alzheimer's **Disease Research Center** 



Teresa Gomez Isla, MD, PhD., Assistant Director, Massachusetts Alzheimer's **Disease Research Center** 



## **7 WAYS MADRC IS** TRANSFORMING **ALZHEIMER'S RESEARCH**

#### **Expert Staff**

- Our team is second to none and includes members who:
- Are prestigious award recipients, including: the Potamkin Prize and the Met Life Prize
- Have published over 500 papers on neurodegeneration
- Serve on important national health and science organizations and committees, including: the National Academy of Medicine, the NIA Council, the NAPA Council and AAIC
- Recruit staff to support diversity and inclusion

#### Leading Cutting-Edge Clinical Research

- Sponsor and Investigator initiated studies, designed to change the course of Alzheimer's disease and related dementias.
- 34 research studies open and enrolling across MADRC affiliated research centers: 10 Clinical Trials & 24 Observational Studies
- Leading novel prevention studies

#### **Diversification of Clinical Trial Participation**

To improve heterogeneity of clinical trial results:

- Target outreach to underrepresented communities, including black and Hispanic neighborhoods
- Collaborate with Multicultural Alzheimer's Prevention Program
- Collaborate with MUNDOS Spanish clinic cognitive testing
  Partner with African American Faith Communities via Memory Sunday

#### **Ensuring Research Participant Retention**

- Ambassador Program with current and former research participants who volunteer to share their experiences with those considering research involvement and address any concerns
- Support group for research participants
- Appreciation events and ongoing education

#### Focus on Importance of Early Diagnosis

- Our team is leading research efforts to develop tools that support early recognition of cognitive issues 15-20 years before disease symptoms
- Studies focus on unique cognitive testing tools, including: Smartphone apps & computer based testing

#### **Community Outreach & Education**

- Awareness/education events hosted throughout Massachusetts
- Present to corporate groups, school groups, religious organizations
- Serve on local community boards and Mayor's Committees

#### **Professional Education & Support**

- Staff mentor graduate students, post docs and clinical fellows
- Staff have faculty appointments at Harvard Medical School
- MADRC community members provide professional education to peers
- Speakers Bureau provides research education to community

To learn more: MADRC.org or 617.278.0383 Facebook: @MassADRC Twitter: @massADRC84 #WeAreMADRC



