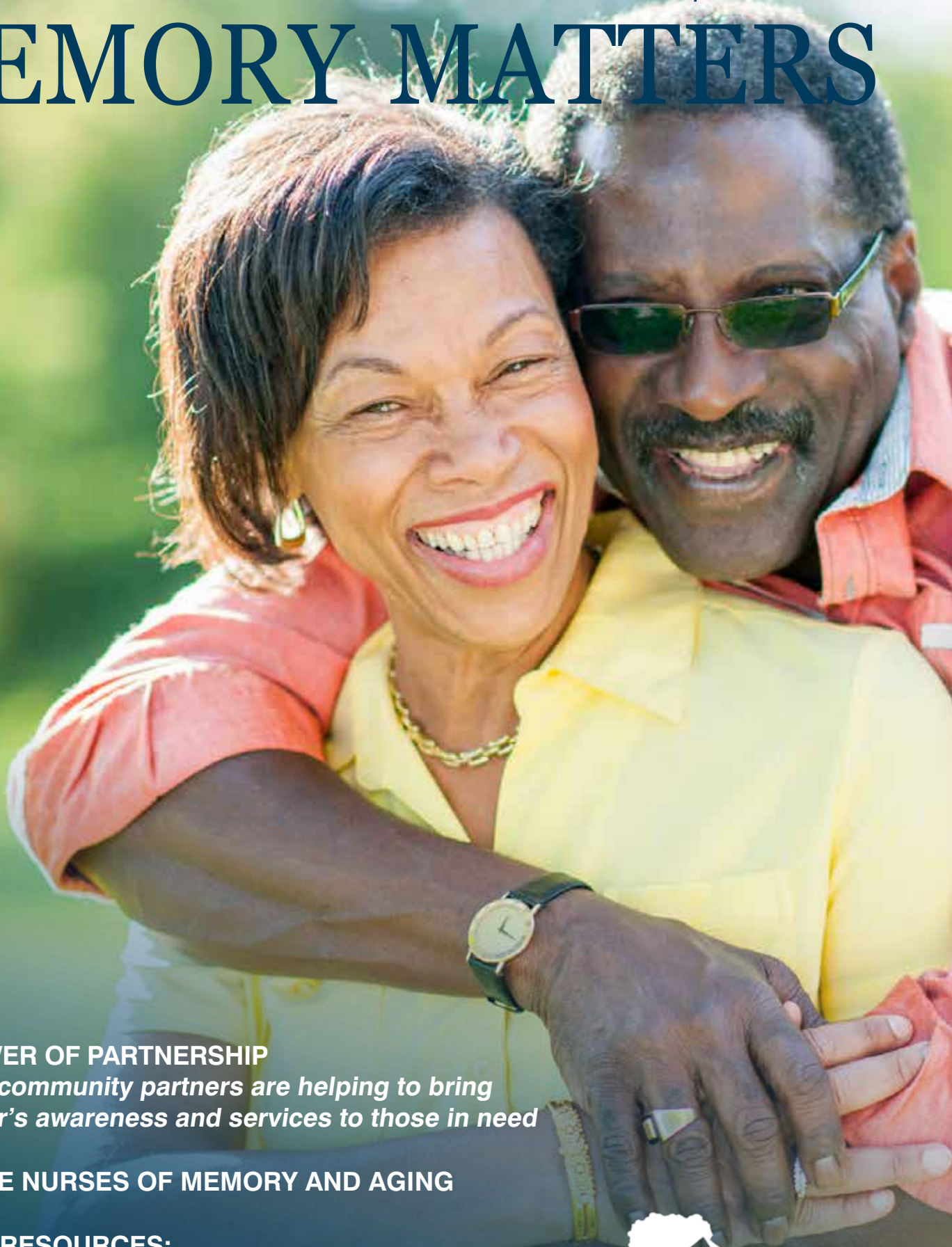


BUTLER HOSPITAL'S MEMORY AND AGING PROGRAM MAGAZINE | MARCH, 2022

# MEMORY MATTERS



## THE POWER OF PARTNERSHIP

*See how community partners are helping to bring Alzheimer's awareness and services to those in need*

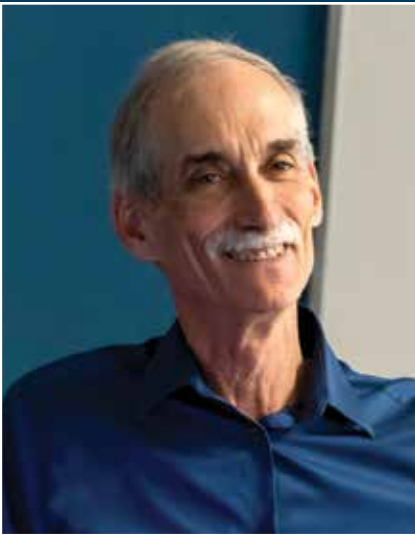
## MEET THE NURSES OF MEMORY AND AGING

## VIRTUAL RESOURCES:

*Videos and a dementia-focused music app*



**BUTLER  
HOSPITAL**



# MEMORY MATTERS

## WELCOME

Stephen Salloway, MD, MS

Director, Memory and Aging Program and Neurology at Butler Hospital;

Martin M. Zucker Professor of Psychiatry and Human Behavior, Associate Director, Center for Alzheimer's Disease Research, Brown University

This year the Memory and Aging Program at Butler Hospital marks 28 years of Alzheimer's research and care. Our program has conducted more than 100 studies and trials in our quest to help bring an end to Alzheimer's as we know it today.

As is the way with research, most of those studies didn't pan out as we'd hoped, but they all provided critical learnings that create the stepping stones needed to advance our work to the next level.

Throughout that evolution, there are three things that have sustained our efforts, and that will continue to sustain our efforts in to the future until our goal is reached.

Those things are perseverance, participation and partnership.

The journey to end Alzheimer's is just that – not

a race, but an extended journey that can only be won through persistent dedication to the goal and an understanding that every stop along the way is a critical sign marker for which direction to go in next.

This journey is not for the faint of heart, but the perseverance of those who have remained committed to seeing it to the end provides the motivation required to keep putting one step in front of the other.

And that brings me to the participation and partnership aspects of the journey.

Every step of the way is owing to the commitment and selflessness of our study participants, whose passion provides the fuel for our progress.

In addition to our study participants, the community partnerships that have formed around our shared goal have been instrumental in propelling our mission forward as well. From our educational and outreach partners, to our academic and scientific partners, our foundation and individual donors, and our Community Advisory Board, our fight has truly become an impressive team effort.

In this issue of Memory Matters, we highlight just a few of those partnerships. But we are truly grateful for every participant and partner who has joined us along the way, as well as to those who will join us in the future.

Here's to finding the end of this journey together.



## Study Update: ARIAS

# Investigating the Use of a Retinal Eye Exam to Predict Future Alzheimer's Risk

In 2019, the ARIAS Study launched here at the Memory and Aging Program. Since then, more than 135 people have generously volunteered for the study. Their participation has allowed this important research to go on. In May, the study will conclude participant enrollment and further data analysis will begin to understand what changes to the retina can detect AD risk 10 to 20 years before memory symptoms, and to develop a 3-D imaging atlas of AD-related changes in the retina for use by researchers worldwide.

The study is enrolling 330 men and women between the ages of 55 and 80 qualifying as either healthy volunteers, individuals at high-risk for pre-clinical disease, mild cognitive impairment, or mild AD. After providing informed consent, each participant is evaluated at 4 time-points during the 36-month study period: 1) baseline (study entry); 2) 12 months post-enrollment; 3) 24 months post-enrollment; and 4) 36 months post-enrollment.

At each study visit, participants undergo basic eye exams, medical history, assessment of

vital signs, neuropsychological assessment, full retinal imaging scan, and blood sample for measurement of plasma beta-amyloid and tau levels. A blood sample for biobanking and cheek swab for APOE classification is collected at baseline visit only. Additional clinical and experimental endpoints include measures of gait, sleep quality, social and psychological health, sleep architecture, and pupillometry.

Participants are asked to provide consent to allow review of medical records (including clinical reports and image files for CT/MRI and amyloid PET neuroimaging) and CSF biomarker evidence of AD, if available. A subset of participants in each group is asked to take an over-the-counter herbal supplement (Longvida curcumin; Verdure Sciences, Inc., [www.longvida.com](http://www.longvida.com)) for two days prior to their baseline exams.

If the initial cross-sectional analyses of these pilot data indicate that there are reliable group differences in the binding of this food-safe product to deposits containing beta-amyloid protein, in the inner regions of the retina, then this procedure may be expanded and additional time points may be added with a future protocol addendum to be considered by the IRB.



## Community Advisory Board Spotlight:

# Morris Akinfolarin is Bringing Alzheimer's Education to Rhode Island's African Community



Muraina “Morris” Akinfolarin has been a passionate and powerful advocate for the African community in Rhode Island for more than 30 years. His goal: to create opportunity and enrich lives within the largely immigrant community. Here’s why he’s now added Alzheimer’s education to that mission...

### **A Long History of Service and Advocacy**

Akinfolarin is a founding member and current executive director of Oasis International, a nonprofit organization serving the African immigrant and low-income communities of Providence, Rhode Island’s West End, Elmwood, Upper Southwest, Lower Southwest, and Washington Park neighborhoods. He and others founded the organization more than 30 years ago as a way to develop opportunities for themselves as recent immigrants and to create continued opportunity for others in their communities for generations to come.

Though he’s also worked a full time job as a Resident Engineer for Rhode Island’s Department of Transportation throughout that time as well, Oasis International quickly became his passion and his calling.

“It’s been a wonderful journey,” he says. “We started in 1990 and didn’t know then how it would turn out. But it’s become a real center for the African American community in Rhode Island, and I’m proud of the work we’ve done to promote culture, community, economic empowerment, and youth leadership development. In those areas we have achieved a lot. Our programs have helped to create doctors, engineers, and architects in our youth. That by itself has brought blessings to our community.”

### **A Growing Focus on Health and Wellness – And A Commitment to Dispelling Cultural Myths About Alzheimer’s**

Health and wellness is another important focus of the organization, and one that has grown in recent years. When it comes to Alzheimer’s,

African Americans are twice as likely as whites to develop the disease and yet they are under-represented in research studies. That's why Akinfolarin is working hard to educate the community about Alzheimer's, and to dispel harmful myths about the disease that have been culturally engrained for generations.

It's a mission that's born from personal experience.

"Before I moved to the U.S., a couple of my aunts had Alzheimer's," Akinfolarin says. "In the African community, there's a belief that people with this condition are not sick, they are possessed, they are a witch. I stayed with one of my aunts in her house to care for her and show them that is not the case. I educated my family that she is not going to hurt you, she is not a witch, she just has a medical issue and she needs help."

"As an immigrant, we know we still lack this education in our communities here in the U.S. Many people still don't understand what it is and are running away from their loved ones instead of helping them, not knowing. So we are trying to educate them that it is a disease, and these are innocent people that need help."

### **To aid in that effort, Akinfolarin joined the Community Advisory Board at the Memory and Aging Program at Butler Hospital.**

The board brings together individuals from diverse and under-represented communities across the state to help provide greater Alzheimer's education and resources to those communities.

"It's been an excellent experience for me, to meet people in research, hospitals, [Brown] University, and community leaders, all working on the same thing. We get to share ideas and brainstorm how to continue and improve on what we're doing," Akinfolarin says.

"Our elders need help. Here in the U.S. we have large populations who don't really understand what it means to have Alzheimer's or dementia. And so part of our mission is to re-educate the community so they can take that back to their own households here, and to family in their home country. That has been very helpful for us

to be the torch bearer of that message in our communities."

Akinfolarin says educating about Alzheimer's and overcoming health inequities requires a joint effort, both within the African American community and outside of it as well.

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*"We have to work together on it as a family, just like any other disease. We don't run away from those with cancer, so why should we from those with Alzheimer's."*

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"The more we do outreach within the community, the better outcome we'll have. And that means educating not just the old but also the young. This is important for our youth to learn about, too – their education needs to be carried along throughout life, not just waiting until they get older."

"We need to get the politicians involved as well. That's very important because they hold a lot of keys that we don't have. There's been a lot of support so far, but we need it to continue and there has to be a voice from them to support health equity and funding for research."

"We need to integrate this education into all the foundational institutions – government, schools, faith based. We've got a lot of work to do."

*Join the*

### **Community Advisory Board**

If you're interested in helping to make a difference in the fight against Alzheimer's for diverse and underserved communities, consider joining the Memory and Aging Program Community Advisory Board.

**For more information:  
(401) 455-6402  
[memory@butler.org](mailto:memory@butler.org)**

# PROGRAM NEWS



## RI Government, Health, Community Leaders Rally to Spark Participation in Alzheimer's Prevention Research

Last fall, Rhode Island state government officials, members of Rhode Island's faith-based community, leaders at Butler Hospital and The Miriam Hospital, and the Alzheimer's Association gathered at the State House to raise awareness of the need for Rhode Islanders of all backgrounds to participate in a landmark Alzheimer's clinical trial.

Under the leadership of Pastor Howard Jenkins, president of the Rhode Island Ministers Alliance, the group called on members of Black, Indigenous, and People of Color (BIPOC) communities to get involved in the U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER). It is critical that all populations, especially communities most affected by memory loss and dementia, are aware of and are invited to participate in scientific research so that findings are applicable to all Americans.

Black Americans are twice as likely to develop Alzheimer's, and Hispanic Americans are one and a half times more likely to develop the disease. Yet much of the Alzheimer's research to date has not included sufficient numbers of Black, Hispanic, Asian and Native Americans to be representative of the U.S. population.

The event at the State House was aimed at changing that in Rhode Island and Southern New England, beginning by working with faith-based community leaders to increase BIPOC participation in U.S. POINTER. Read more on the blog at [butler.org/memoryandaging](https://butler.org/memoryandaging).



## MAP Director Dr. Stephen Salloway Talks About Impacts on Caregivers to *Public Health Post*

What are the impacts on those who care for a loved one with Alzheimer's?

In a recent article from Public Health Post, MAP Director Dr. Stephen Salloway shares his professional and personal insights on that question, along with his thoughts on how Alzheimer's research may help to lighten the load. Visit our blog for a link to read the article:

[butler.org/memoryandaging](https://butler.org/memoryandaging).

See more news and resources at: [butler.org/memoryandaging](https://butler.org/memoryandaging)



## CMS Weighs Decision on Coverage for Aduhelm

In January, the Centers for Medicare & Medicaid Services (CMS) issued a draft decision that proposes coverage of treatments targeting amyloid for Alzheimer’s disease, including aducanumab (Aduhelm™), be conditional on patients enrolling in a CMS-approved randomized controlled clinical trial. That proposal will greatly limit access to patients who may benefit from treatment.

The preliminary decision issued by CMS proposes that Medicare provide coverage for aducanumab, the first FDA-approved therapy to address the underlying biology of Alzheimer’s disease, and other yet approved anti-amyloid monoclonal antibodies, under the coverage with evidence development pathway. In this instance, reimbursement would be provided to Medicare beneficiaries on the condition they participate in a randomized controlled trial.

A final decision on coverage for Aduhelm is expected from CMS by April 11.

“Regardless of the CMS’s decision, I, and my team, will continue to fight for the rights of our patients to receive the gold standard of care they’ve come to expect from the Memory and Aging team at Butler Hospital,” said MAP Director Dr. Stephen Salloway.



## MAP Director and Participant Featured in Voice of America TV Show, VOA/TEK

MAP Director Dr. Stephen Salloway and AHEAD Study participant Dave Kalberer of Attleboro, MA, were featured in an episode of VOA/TEK last fall.

The episode focuses on how exciting studies aimed at developing early detection and intervention of

Alzheimer’s could prevent the development of symptoms in people at risk of the disease. To view the episode, visit our blog at [butler.org/memoryandaging](https://butler.org/memoryandaging).



Volunteer Spotlight:

**James O'Toole**

***Studying the Intersection of Mind and Body***



James O'Toole is fascinated by the interplay between mind and body. So much so that he's set to graduate this spring from the University of Rhode Island (URI) with a double major in Psychology and Biology.

His interests and studies make him a great volunteer at the Memory and Aging Program (MAP) – and his experience as a volunteer is in turn helping to shape his future career as a physician assistant.

"I personally believe that the mind and body are connected in so many ways that we don't fully comprehend yet," O'Toole says.

"There's such an interconnection between the two that we actually get a physical feeling when we're sad or stressed. And just as neurological issues can affect the body, the body can affect the brain and our feelings. Understanding that connection is key to understanding how to help people in so many different ways."

The desire to help people is the motivation behind much of what O'Toole does. In addition to his studies and the volunteer work he does at MAP, he works as an Emergency Medical Responder (EMR) at URI. When he becomes a PA, he hopes to work in a mental health facility.

"I'm not exactly sure yet what my specialization would be, but I definitely want to work on the



clinical side, seeing patients every day and seeing their growth and recovery,” he says. “Having the baseline of what I’m learning now in school, as an EMR, and at the Memory and Aging Program will provide great foundation and a nice steppingstone to that work.”

O’Toole first learned about the Memory and Aging Program from MAP Cognitive Neuroscientist Jessica Alber, PhD, who is also an assistant professor at URI’s Ryan Institute for Neuroscience.

“I took a class with her last spring semester. I knew I needed to start an internship, and when she mentioned she was working on creating a new screening process to identify possible Alzheimer’s disease in people before symptoms start, I thought that was really interesting. She’s also just so passionate about her work at the program, which I find inspiring.”

O’Toole began his internship with MAP at the start of summer. Since then, he’s been working with Dr. Alber on the ARIAS study, grading cognitive tests and organizing data. The study is focused on evaluating the use of biomarkers in the retina as a screening method to identify preclinical Alzheimer’s disease.

“Luckily my family has been pretty blessed with not having a history of Alzheimer’s, but I know a lot of people who have loved ones with the disease and I see how hard it is for them every day,” he says. “When I see that, I want to be able to help. But there’s not much I can do, so I feel like helping out in this study lets me help them out too, in a way.”

O’Toole says the experience has taught him a lot about how much goes into research and how critical it is for research into Alzheimer’s to

grow and advance.

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*“It’s been a super informative experience. I feel like it’s really important for people to know just how much work and effort actually gets put into each research study going on at Butler. It’s an exhaustive amount of work that needs to be done for each study. It’s reassuring that this much work goes into it, but I definitely didn’t expect it.”*

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In addition to the ARIAS study, O’Toole is working on an independent study with Dr. Alber using some of the same research and data from ARIAS. He says that experience has also helped him to build the skills he’ll need for the future while further opening his eyes to the need for more research into early detection and prevention.

“Working with Dr. Alber has really helped me cultivate some of the skills I’ll need in the future when working with patients as well as when doing research,” he says. “It’s shown me the quality of work that needs to be put into this setting.”

“I think we really do need more research in this area of pre-clinical detection. If people who already have Alzheimer’s had been able to get care early on the outcome might be a bit better now. It’s an important thing that needs to be looked at and I’m just glad to be able to say I had some small part in doing that.”

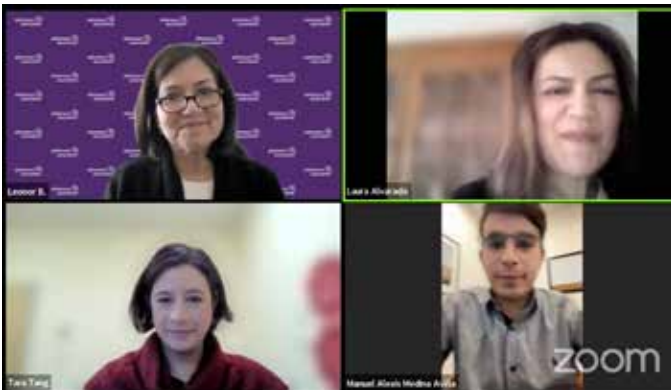
## IN THE COMMUNITY



### MAP Volunteers at MLK Food Drive

Helping hands fuel happy (and healthy) hearts! In January, members of the MAP Outreach and POINTER Study teams volunteered with the Ministers Alliance of Rhode Island and The Elisha Project to pack food for their food drive held in honor of Martin Luther King, Jr. Day.

“It was wonderful getting out in the community and lending a helping hand, and we are so grateful to these organizations for all they are doing for the community,” said MAP Outreach Coordinator Lulu Saraiva.



### MAP on Facebook Live en Español with the Consulate General of Mexico in Boston

MAP Outreach Manager Tara Tang took part in a Facebook Live presentation on Alzheimer’s hosted by the Consulate General of Mexico in Boston on January 20.

The presentation was hosted entirely in Spanish and focused on education about Alzheimer’s disease symptoms, prevention and research. The goal was

to spread awareness among the Hispanic community, who are more likely to develop Alzheimer’s than white people and yet are under-represented in Alzheimer’s research studies.

Tang shared information about Alzheimer’s prevention and the U.S. POINTER Study. The presentation also included insights from Leonor Buitrago of the Alzheimer’s Association Massachusetts/New Hampshire Chapter. The presentation is available to view on the Consulate General of Mexico in Boston Facebook page at [facebook.com/ConsulmexBoston](https://www.facebook.com/ConsulmexBoston).



Tara Tang

## MAP and Progreso Latino Team Up to Spread Alzheimer’s Awareness on “Senior Soundings”

The partnership between the Memory and Aging Program and Progreso Latino extended to cable television recently, when Progreso Latino Community Wellness Specialist Dilenia Cruz and MAP Outreach Manager Tara Tang teamed up to tape an episode of “Senior Soundings.”

The episode focused on Alzheimer’s disease and how the two organizations are partnering to help bring awareness about the disease and research opportunities to the Latinx community.

Senior Soundings airs on Statewide Channel A (Cox Channel 13, Full Channel Channel 13, Verizon Channel 32) which is seen in all RI homes that have cable-TV.



Dilenia Cruz

**Want to arrange an in-person or online presentation for your organization or community group? Contact us at (401) 455-6402 or [memory@butler.org](mailto:memory@butler.org).**

## Thank You

*Thank you to the following individuals and organizations that have recently partnered with us to help raise awareness about Alzheimer’s disease and research opportunities:*

Age Friendly RI  
Alzheimer’s Association Rhode Island Chapter  
Alzheimer’s Association Massachusetts/New Hampshire Chapter  
Carney Institute of Brain Health  
Consulate General of Mexico in Boston  
Cranston Senior Center

MLK Center, Newport, RI  
Progreso Latino  
RI Ministers Alliance  
Senior Soundings  
The Village Common of Rhode Island



## Staff Spotlight:

# The Nurses of Memory and Aging

Nurses are often required to be an incredible combination of medical professional, project manager and caretaker, and our nurses here at the Memory and Aging Program (MAP) rise to the challenge and then some.

Their knowledge, skill and compassion help to bring all the various aspects of medical research and clinical care together in a way that both provides the best in care for individual patients while also serving the needs of the greater good by supporting the development of better treatments for future patients to come.

Here, three MAP nurses share what drives the work they do every day, their wishes for the patients of today and their hopes for the fight against Alzheimer's in the future.



**Cheryl Kechichian, RN**  
**Nurse Coordinator**

*Cheryl has worked as a registered nurse in a variety of settings including hospitals, community centers, home care, and long term care. Eventually she decided that working with adults and elders with memory issues was her calling, and she joined the Memory and Aging program in 2007.*

*“I started my medical career as a certified nursing assistant when I was 16.*

*I really loved working with the elderly and had always wanted to work in an environment where I could make a difference and enhance the quality of life for them. I was also close to my grandparents, who both developed different forms of memory loss, and that cemented my desire to work in research for memory loss.*

I've worked in a variety of settings throughout my career, including hospitals, nursing homes, home care and community clinics. I also attended Northeastern University towards a degree in Information Sciences, and after that I worked in the health insurance industry, with software development, testing and design.

But eventually I began to miss working with the elderly and found myself seeking an opportunity to work in this field again. I found it here at the Memory and Aging Program.

*My favorite part of this job is the contact I have with patients. I enjoy talking to and supporting them in any way I can. The patients and their families can be very inspiring on many levels. They all have interesting life experiences and family histories that are very intriguing.*

I do wish that more people understood the vast amount of work and time that goes into research and getting FDA approval for any drug. It can take many painstaking years and there are so many steps required. Due to the mounting regulatory and paperwork associated with research, some days can be overwhelming with paperwork, but it's a very important and necessary part of working in this field.

The most rewarding times are the moments when I can make a patient smile and know that they are comfortable and feeling cared for.



**Vanessa Rua, RN, BSN  
Nurse Coordinator**

*Vanessa graduated with a Bachelor of Science in Nursing and a Bachelor of Arts in Psychology from Rhode Island College. She began her career as a registered nurse in the acute medical-psychiatric unit at Rhode Island Hospital, but says she'd always been interested in research and learning about new technologies, therapies, and medications. That interest led her to join the Memory and Aging Program team in 2017.*

*“I wanted to find a nursing opportunity that would place me on the forefront of providing cutting-edge care through research.*

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Here at the Memory and Aging Program, my day-to-day work can include everything from working closely with patients to ensure that the study protocol is being followed, to conducting medical history reviews and clinical intakes, coordinating study visits and multiple sub-studies, administering IV, medication reconciliation, data management, adverse event reporting, and performing psychometric testing.

*Ultimately, a research nurse has to be whatever the person in front of them needs the nurse to be; whether it's shifting from clinical care, to being an educator, to serving as an advocate for patients, or acting as a liaison within an interdisciplinary team. The complexities of research nursing are what make the role both challenging and rewarding.*

This role has allowed me the opportunity to forge great relationships with patients and caregivers while continuing to provide meticulous care and support throughout their healthcare journey here at MAP.

One particularly memorable experience was being able to present the Memory and Aging Program Citizen Scientist Award certificate to one of my research patients, the first participant in the world to complete the A4 clinical trial.

Participating in clinical trials is a great way to make the choice to exert power over the disease, embrace hope for the future, and help find treatments and cures. But I do also wish that more people, especially caregivers, would contact their Alzheimer's Association chapter to learn more about all the wonderful resources available to them.

For me, the most rewarding part of my job is just having the privilege to be a part of

someone's story. To truly say I've made a difference in someone's life is the ultimate reward."



**Lisa Williams, BSN  
Nurse Coordinator, Infusion Specialist**

*Lisa has over 28 years of nursing experience in the areas of oncology, infusion therapies, and home care. She specialized in home infusion therapies, with more than 25 years' experience in IV insertion and medication administration.*

*“Before joining the Memory and Aging Program in 2017, I had worked for 20 years or so in nursing management, specializing in home IV therapy.*

That role didn't have much patient interaction, but there was a situation where I had to make some home care visits and I realized I missed actually 'being a nurse.'

The opportunity at MAP allowed me to use my 25-plus years of experience in IV therapy, and I was also excited to learn and be involved more in the Alzheimer's research process.



As a clinician of 34 years, I've observed and empathize with the devastating effects Alzheimer's disease can have on patients, caregivers and families.

In my role at MAP, I typically start my day early ordering the IV investigational research medications and preparing and organizing the infusion suite for participants. I complete the required documentation for each research trial, administer the IV medications per protocol, and monitor vital signs, the tolerance of the monoclonal antibody and manage the infusion room schedule.

*While the patients are receiving treatment, we do a lot of chatting and laughing about current events, weather, entertainment, sports, and family events. I feel so fortunate to be able to spend a significant amount of time talking and developing trusting relationships with study participants and caregivers during their infusions.*

I'm able to really get to know them, hear them talk about their children and grandchildren, their vacations and holidays, their life experiences and past work and passions. Nurses don't often have enough time to communicate with patients, but most of the infusions are at least an hour so I have a captive audience! I absolutely love coming to work every day, and I try to make their experience here enjoyable and fulfilling.

I wish people realized how overwhelming Alzheimer's disease is for patients and caregivers. I don't think people really understand how the lack of control, feelings of helplessness and isolation can affect both of them. I feel while we are working towards a treatment, there needs to be more state and

federal community resources available.

For me, the most rewarding part of what I do is being part of the research process, seeing the hope the participants have, and knowing I may be part of finding the treatment or better yet cure that is so needed to help fight this disease. I was able to infuse the world's first dose of Aduhelm outside of a clinical trial last June and being part of that moment was an emotional experience, knowing we were one step closer to a potential treatment for Alzheimer's.

## Community Partner Spotlight:

# Laurie Mantz is On a Mission to Improve Dementia Care

For nearly a decade, Laurie Mantz has been working to improve care for people living with Alzheimer's and other forms of dementia. Over the last five years she's turned that mission into a thriving business, training healthcare professionals, first responders and family caregivers on how to provide evidence-based, person-centered dementia care. She's also opened Memory Cafés at nine locations throughout Rhode Island.

Now, thanks to a new grant awarded through CareLink, she's bringing her training directly into homes free of charge, where people with dementia and their family caregivers can benefit the most.

Mantz is founder and CEO of Dementia Training for Life, LLC. She is a registered and licensed occupational therapist, educator and certified dementia care practitioner and trainer. She is also a family member; both of her grandmothers died from complications due to dementia.

Driven by her personal and professional experience with dementia, Mantz has become a staunch advocate for the rights of both the individuals diagnosed with dementia and their caregivers. She has marched on Capitol Hill, testified at both the NH and RI state capitals, and is a member of the Lt. Governor's Executive Board for the Rhode Island State Plan for Alzheimer's disease and Related Disorders.

Here, she shares the story behind her business, some key pieces of advice for dementia caregivers, and the exciting new chapter of her mission that will be unfolding in the year ahead...

### ***Why and how did you become involved in dementia care, and what prompted you to found Dementia Training for Life?***

My first experience with dementia was as a family member. I lived through it with both grandmothers as well as my dad, so I know first-hand what a challenge it can be.

Professionally, I worked for many years as an occupational therapist and a clinical educators, so I did a lot of work helping other therapists

coming up in ranks and a lot of teaching, and eventually became executive director of a memory care community.

During that time I heard from a lot of family members that doctors and nurses didn't necessarily understand the complexities of dementia diseases. So, I started doing training in my community on a part-time basis. That was in 2013 when I was still living in New Hampshire. In 2017 I moved to Rhode Island and decided to make it a full-time business, and that's how I founded Dementia Training for Life.

***What sort of services does Dementia Training for Life provide?***

Initially the focus was only on providing training to medical professionals, but over time the scope has expanded to people living with dementia and their care partners as well. It was very obvious through research and experience that when individuals are diagnosed with dementia, they tend to self-isolate and become disconnected from their communities, which is the last thing they should do.

So I decided to open Memory Cafés across Rhode Island where people living with dementia and their care partners can gather socially,



knowing how important socialization is to slowing down the disease. But it's also a place where they can get emotional support from each other and take away new skills and knowledge about how they might

interact or do something new at home that they didn't think about before that would bring joy to their lives and increase their circle of friends. The Cafés have been on hold since COVID hit, but we're hoping to get them back up and running again soon.

***What do you find to be the most common misconceptions about dementia or dementia care for medical professionals and other caregivers?***

The most common misconception is that dementia is the disease. Dementia is not the disease, it's the result of a disease. There are over 120 diseases that can cause cognitive decline and they all present in different ways. For example, Lewy body disease presents with movement and sleep disturbances, whereas Alzheimer's presents with more memory and perception disturbances. Understanding those differences makes it much easier to know what to expect and to prepare and respond accordingly.

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**What are some key pieces of advice that you give to people living with dementia and their care partners?**

**Many people don't recognize how much environment plays into abilities and difficulties.** Simple adaptations can go a long way toward making a person more independent, but you've got to keep it simple. Advances in technology are wonderful but if you think about how someone's been doing self-care for 60 years and then you throw something new at them you're actually making it harder for them.

For example, providing pump soap instead of bar soap – providing bar soap allows that muscle memory to go to work for them and then they know what to do, whereas pump soap might be interpreted as lotion. Another example is an electric toothbrush. You might think you're making the process easier, but it might really just be more confusing.

**Another key is to get into their world, wherever they are at the moment, and assume the role that they're giving you at the moment.** Their behavior may have been set off by a sound, a hallucination, or something else happening in their body that they can't control. It's important to understand that it's beyond their control and get on the bandwagon and go for the ride, unless their health or wellbeing is at risk.

Don't get hung up on the factual details they're getting wrong, but instead think about the emotion that they're feeling and what they may be trying to convey at that level. It's really hard to help and support someone who's frightened and it's even harder when you become upset. Remember that the behavioral responses we see in all forms of dementia are really a means

of communication – it's up to us to figure out what they're trying to communicate.

**I also understand how difficult it can be to navigate the family dynamics when a loved one is living with dementia.** I think the most important thing is open and honest communication. I also suggest designating a person in the family to act as the lead in advocating and supporting the needs and wants of the individual that's been diagnosed.

**You've just received a grant to provide no-cost, in-home services. What are the details of those services and how can interested people participate?**

Yes, I'm very excited about this. The Alzheimer's Disease Program Initiative [ADPI] awarded a three-year, \$904,000 grant to CareLink [an East Providence nonprofit healthcare group] to provide new services and treatments for Rhode Island adults with Alzheimer's disease and other forms of dementia.

Through that grant, I'll be working with CareLink to provide evidence-based programs for people with mild to moderate dementia right in their own home. We'll provide services like speech language pathology and occupational therapy free of charge, with the goal of helping them to live in their homes longer, more safely, and with a better quality of life.. We're really hoping to close that gap for people, asking, "What do I do now?"

We're especially trying to provide services for individuals living alone and those in under-served communities.

**Anyone interested in learning more and applying for free, in-home services is encouraged to visit [www.carelinkri.org](http://www.carelinkri.org) or email [adpidementia@carelink.org](mailto:adpidementia@carelink.org).**

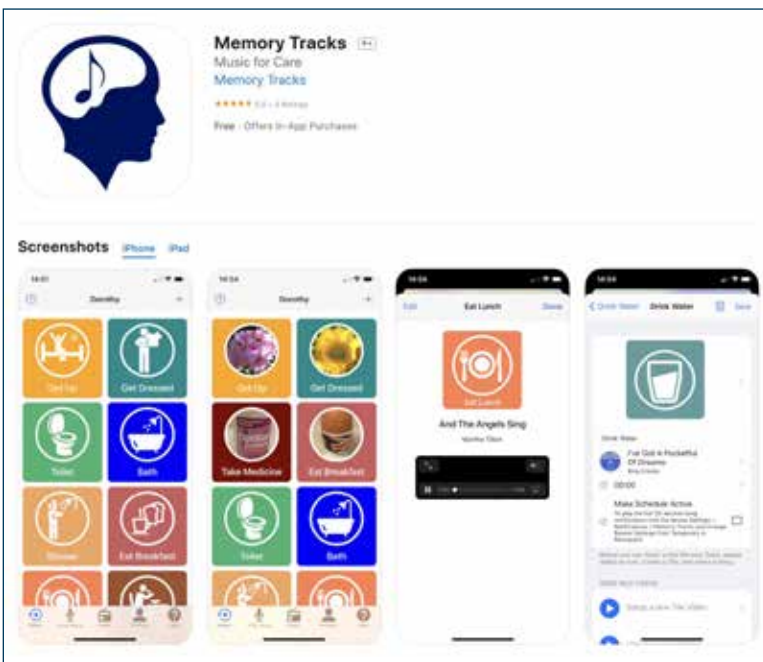
# RESOURCES



## Carney Conversations: Getting a Jump on Alzheimer's

Our partners at the Brown University Carney Institute for Brain Science host regular virtual “Carney Conversations” featuring Brown experts on various brain-related topics.

Recently, Brown Professor and Memory and Aging Program Director of Imaging Research Hwamee Oh, PhD participated in a fascinating discussion about early diagnosis and risk factors in Alzheimer's disease. Watch the video on our blog at [butler.org/memoryandaging](http://butler.org/memoryandaging).



## Memory Tracks: A Music App for People with Alzheimer's (and anyone who likes the oldies)

Music can be particularly soothing and comforting for those with Alzheimer's and dementia – especially music from the past.

Check out the Memory Tracks app, which pairs everyday activities with recommended classic songs to help make the activity easier and more enjoyable.

Just search “Memory Tracks” on the Google Play or Apple app stores to download for free.

# MEMORY MATTERS

## Thank you!

Without our participants, their families, and caregivers, Alzheimer's research would not advance. The Memory and Aging Program staff is continually inspired by the families who decide to join clinical research studies. We would like to express our deepest gratitude to all of our registry participants and their families for their contribution to the science that will lead to the end of Alzheimer's disease.

You are receiving **Memory Matters Magazine** because of your current or past relationship with Butler Hospital's Memory and Aging Program or with the patients and family members we serve. If you would like to be removed from the mailing list and not receive future editions, please contact us at [memory@butler.org](mailto:memory@butler.org) or (401) 455-6402.

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#### Memory and Aging Program

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IT'S NOT ALWAYS EASY FIGURING OUT HOW TO ENHANCE MY DIET AND GET IN MORE EXERCISE AND SOCIAL ACTIVITIES, BUT THE EFFORT IS INVIGORATING AND

**HELPED ME BETTER PLAN, PREPARE AND FOLLOW UP ON MY GOALS.**

POINTER Study Participant  
Age 70, Providence, RI

Join  **U.S.POINTER**  
alzheimer's  association\*

**Can changing to a healthy lifestyle protect memory in older adults?**

*We need your help to stop memory loss and Alzheimer's disease! Learn more about the opportunity to participate in this national study, open to qualifying individuals between the ages of 60 and 79:*

 **401-POINTER**

 **[butler.org/POINTER](http://butler.org/POINTER)**