

BUTLER HOSPITAL'S MEMORY AND AGING PROGRAM MAGAZINE | MARCH, 2021

MEMORY MATTERS

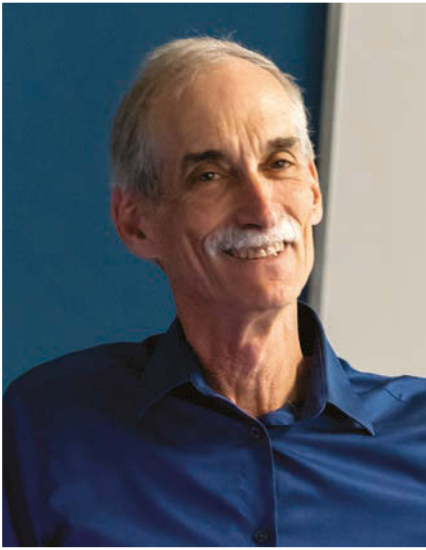
**ACHIEVING BETTER HEALTH
& MORE HOPE FOR ALL**

**A SECOND DRUG STUDIED AT
MEMORY AND AGING PROGRAM
SHOWS PROMISE IN SLOWING ALZHEIMER'S**

**HOW TO EAT FOR
BETTER BRAIN HEALTH**



BUTLER HOSPITAL
A MEMBER OF CARE NEW ENGLAND



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, Brown University

As I write this, I can't help but think about the fact that we're now at the one-year mark of what has been one of the most difficult years in recent history, thanks to the COVID-19 pandemic.

It's a milestone that no one is eager to celebrate. But as we commemorate the occasion, we do so with the knowledge that the year ahead is very likely to move us back into the lives we've missed. That is thanks to the science of medical research and the dedication of thousands who have come together to develop, test and distribute the COVID-19 vaccines in record time.

It's impossible to know when COVID will end completely. But the sense that a new day has dawned and that we're making progress back to the lives we want to live is practically a tangible thing. That excitement spurs us on — and I believe we find ourselves at a very similar juncture in the fight against Alzheimer's right now.

Right now, we await the FDA's decision in early June about whether aducanumab will

become the first treatment approved to treat and meaningfully slow the progression of Alzheimer's.

Right now we celebrate the promising results just announced that a second drug, donanemab, has also shown significant slowing in decline of memory and cognitive issues in people with early Alzheimer's.

Right now, we continue to make rapid advancements in technologies to diagnose Alzheimer's, even decades before symptoms begin.

These are all advancements that not very long ago were near to inconceivable. With this kind of momentum we are on the verge of important breakthroughs for treating and perhaps even preventing this disease.

We are on the cusp of a watershed moment that could change the lives of millions of people around the world. A new day is, indeed, dawning in the fight against Alzheimer's.

The Memory and Aging Program and our partners and colleagues in research across Rhode Island have played a large part in these advancements, as have the many Rhode Islanders who have selflessly participated in these studies.

I'm just so grateful for that collaboration and participation. It's what is fueling every step forward that we collectively take in this fight.

Just as we continue to make strides against COVID, even not knowing the endpoint in our fight, we continue to take steps forward in our fight against Alzheimer's, and the progress toward our goal is becoming just as tangible.



NOEL FIELD, In His Own Words

Why I participate in research

“I’ve been a small boat sailor all my life. I met my wife at a wedding; she was the maid of honor. As I was going through the receiving line, the bride introduced us and said ‘This is Phyllis, she sails’. And it took off from there...

A year and a half later we were married. We had four children, and now six grandchildren. She was a very good sailor herself, a very good organizer. She was the first female commodore of a yacht club on Narragansett Bay, at the Sakonnet Yacht Club. I had been commodore a few years before that.

Phyllis died of Alzheimer’s a year and 3 months ago. She had been on the Butler Hospital board of directors for 35 years and devoted a lot of time there. So after her passing I let them know I would do anything to help out. That’s how I became a participant in Alzheimer’s research at the Memory and Aging Program.

For the last year I’ve been participating in a research study at the program, showing up on a regular basis to receive an investigational drug, or a placebo, I don’t know which I’m getting. At 86, I don’t know what comes next, or if I’m really worried about it. But this was important for me to do, because of Phyllis.”

Noel Field is 86 years old and a Providence, RI native. He graduated from Moses Brown School. He earned his undergraduate degree at Brown University before serving two years in the Navy. He went on to earn his law degree at Harvard, and practiced law in Providence for decades until his retirement in 1999. For 40 years he was also a US Sailing Association certified judge, settling protests between competitive sailors.

To learn more about the Memory and Aging Program and enrolling research studies focused on Alzheimer’s prevention and treatment, visit butler.org/memory or join Butler’s Prevention Registry at butler.org/AlzRegistry to see if you qualify for any enrolling studies.



Better Health *& More Hope* for All

Racial inequities are pervasive in many aspects of culture and life, and that includes inequities in healthcare, medical research and health outcomes.

At the Memory and Aging Program we believe that everyone deserves equal access to a healthier tomorrow, and that each and every one of us can play a role in helping to make that happen.

Here's what we're doing to connect with communities that are under-represented in Alzheimer's disease (AD) research – and what you can do to help in those efforts as well, so that better health and more hope is available to all.

First, the facts:

Most people don't realize the degree of racial inequities that exist in healthcare, research and health outcomes. Here's a look at just a few of the statistics regarding people of color and Alzheimer's disease in particular:

- ***African Americans are twice as likely to develop AD than their Caucasian counterparts, and yet they are under-represented in research.*** Not only that, but of the 5.7 million Americans living with AD, 20% are African Americans and they shoulder a disproportionate share of the national costs of the disease, at 33%. Annually, the cost of AD and other dementias to African American families was \$71.6 billion. The financial costs are staggering. But the personal costs are, of course, unquantifiable.
- ***Latinos are 1.5 times more likely to develop AD than Caucasians, and the number affected is growing.*** By 2060, it is projected that 3.5 million Latinos will be living with Alzheimer's disease – that's about 60% of the total number of all people living with the disease today. Right now there are 1.8 million Latino families caring for loved ones with AD and other dementias, and there is a critical need for resources and training, from the national level to the community level.
- ***The COVID-19 pandemic has only served to deepen these disparities*** by worsening the social determinants of health that play a role in creating the disparities in the first place – things like living in poorer neighborhoods with fewer resources, physical environment, economic instability, loss or lack of health insurance, food and housing instability and the resulting stress and mental health challenges that can come from all of these challenges.

What we're doing:

We at the Memory and Aging Program have maintained a focus on improving diversity in research for some time already, and those efforts are continuously building. Here are some of the major initiatives underway:

- ***We participate in clinical studies that have specific requirements for diverse participation***, in accordance with guidance from the FDA. Our efforts are supported by the larger Butler Hospital and Care New England organization, through its top-down focus on issues of racial disparities and healthcare.
- ***We provide culturally relevant and tailored community engagement and education*** focused on brain health, AD literacy and earlier detection among individuals, families, and communities to help improve overall health. One way we do this is by offering AD and brain health education presentations in both English and Spanish.
- ***We implemented our inaugural Community Advisory Board (CAB), another critical initiative.*** Our CAB members are volunteers from varied backgrounds who help to guide our program on best practices for engaging the full community in our program, and who provide important insights on community needs with regard to education and good brain health practices.

(continued on next page)

(continued from previous page)

- ***We are increasing the diversity and multicultural knowledge of our staff, and actively seeking out opportunities to do the same among our colleagues and out in the community.*** We were recently awarded two grants focused on diversity in research, one of which will allow us to hire a Diversity Coordinator in our Outreach department.
- ***MAP Outreach Manager Tara Tang co-chairs the Diversity Across the State committee,*** a subgroup of the Long Term Care Coordinating Council of the Rhode Island Lieutenant Governor's Office. She also collaborates with a variety of diverse community organizations that aid Rhode Island's seniors, with a particular focus on how to meet needs for transportation and technology so that seniors can better access the health information and resources they need.
- ***Dr. Athene Lee, clinical neuropsychologist at the Memory and Aging Program and director of our Alzheimer's Prevention Registry, contributes both expertise and oversight regarding diversity in Alzheimer's research.*** She serves as Co-Vice Chair of the Inclusion, Diversity and Education in Alzheimer's disease – Clinical Trials (IDEA-CT) Committee of the national Alzheimer's Clinical Trials Consortium. In January Dr. Lee, who is also an assistant professor of Psychiatry and Human Behavior at Brown University, was the recipient of the department's Diversity Early Career Faculty Development Award for her project entitled, "Cross-cultural validation of existing measures on subjective cognitive decline and aging expectation."

What you can do:

- ***Learn about how AD research can help your community and share that information*** with family, friends and the organizations and networks that you're involved with. Consider working with us to host an educational presentation for your organization, church, club, or other group about AD and maintaining brain health.
- ***Share your thoughts on clinical research with us (whether you've participated in research or not).*** Letting us know your thoughts is quick and easy — simply take our survey online at bit.ly/MAPSsurvey-eng (English) or bit.ly/MAPSsurvey-esp (Spanish).
- ***Partake in conversations with our staff and clinicians about what researchers can do better.*** Please send us your thoughts at memory@butler.org, or call us at **(401) 455-6402**.
- ***Talk to your town, city and state leaders*** about policies like paid leave for caregivers, and be vocal about your support for AD trainings, initiatives and research.

Together, we can help to make tomorrow healthier for us all!

RESOURCES



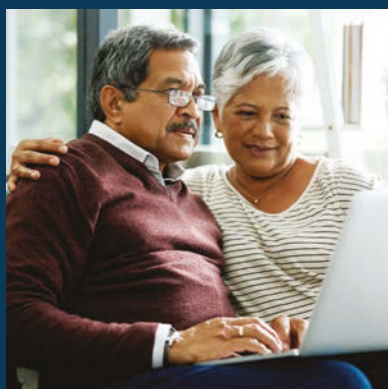
Eat for Better Brain Health, With The MIND Diet

Research has shown that a healthy diet can help to support memory and thinking as we age. What's more, there are certain foods that seem to have a particularly beneficial effect. You may have heard about the formal nutritional plan called the "MIND Diet" that has been designed around those foods. Find out what you need to know to get started with the MIND Diet, so you can eat for a healthy body and brain at butler.org/memoryandaging.



Unpacking the Science Behind Dr. Sanjay Gupta's New Book on Brain Health

Dr. Sanjay Gupta, CNN's Emmy Award-winning chief medical correspondent, recently released a new book entitled *Keep Sharp: Build A Better Brain at Any Age*. The book explores which activities and lifestyle choices help to support brain health, thinking and memory as we age, as well as insights on how those activities and choices can be incorporated into our daily lives. MAP Post-Doctoral Research Fellow Dominique Popescu, Ph.D., provides an overview of the book and how it aligns with the latest research being conducted at the Memory and Aging Program and elsewhere at: butler.org/memoryandaging



Access The 2020 Caregiver's Journey Conference Sessions Online Now at the Alzheimer's Association Rhode Island Website

Did you miss Alzheimer's Association Rhode Island Chapter's Caregiver's Journey Conference back in December? Good news - all 15 of the conference's presentations were recorded and are available to view on their website. Session topics include:

- Keynote address by Laura Baker, PhD, principal investigator of the U.S. POINTER Study on healthy lifestyle and brain health
- Clinical Trials 101: Hope in Alzheimer's Research, featuring MAP Outreach Manager Tara Tang
- From *Why Me?* to *What's Next?*
- Be An Empowered Caregiver

Watch these sessions and many more at:
caregiversjourneyconference.org/program

Staff Spotlight:

Diane Charpentier and Sarah DeForest

Making an Impact Beyond Test Results in The Research Laboratory



Diane Charpentier

As Research Technical Associates in the laboratory at the Memory and Aging Program, Diane Charpentier and Sarah DeForest draw blood, conduct EKGs and perform other laboratory services for the program's patients and research participants.

Their role is essential to helping research happen, but their impact is not limited to test results. It's also felt in the personal connections they form with patients – and that's a key part of what defines the value of working at the program for both of them.



Sarah DeForest

DeForest is a mom of two young children and an Air Force veteran who served for four years as a medic at Andrews Air Force Base. She'd been working as a phlebotomist for seven years before joining the team at the Memory and Aging Program.

"I've been working at the program for about a year now, and I really enjoy that I'm able to spend more time with patients than I would in traditional lab, where it's not so personal," she says. "I get to see the same patients every couple of weeks, and spend time with them while they get infusions, so it's a much more personal experience."

Charpentier worked in the lab at Butler Hospital for 25 years, right across the hall from the office of Memory and Aging Program Director Dr. Stephen Salloway, until she retired in 2012.



Retirement proved a bit too boring for her though, so when Dr. Salloway called to ask if she'd come to work part-time for the program she accepted. Just as with Deforest, Charpentier says the role has been an interesting and fulfilling one.

"Every study has different set of rules about what and how to draw and collect specimens, whereas it's always the same rules when you work for a traditional lab. And you do get to interact with patients much more personally than if they just came in for a one-time blood test from their doctor's office," she says.

As with any relationship, Charpentier and DeForest say that those personal connections do come with ups and downs.

"To be able to see patients getting better or being excited about being in a trial is really cool," DeForest says. "But it also has its downsides, because it's hard to see people fighting with disease. I have friends who have loved ones that struggle with Alzheimer's, but I didn't see a lot of the effects of that before working here.

"It's really eye-opening to see all that patients and caregivers go through. It makes me that much more ready to go to work, and proud to work with this team of so many smart people all doing things to fight Alzheimer's. It's very inspiring."

For Charpentier, the personal connection doesn't just come from the patients at the program, but from her own family as well.

"My mother was diagnosed with Alzheimer's disease at 55 and she died from it at 65. I wish she had been able to participate in the kinds of studies that are being done at the Memory and Aging Program now, but it was before her time," she says.

"It is still hard on the patients and caregivers, of course. But there's so much more hope now. And I think a lot of them enjoy coming here, because of those connections that we make with them. We take care of them as people, too."

PROGRAM NEWS



MAP Director Dr. Stephen Salloway and Research Participant Peter Bristol Speak at FDA Hearings on Aducanumab; Decision on Approval Delayed

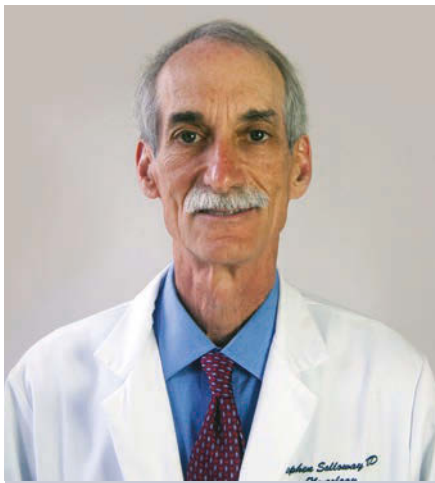
In November, a U.S. Food and Drug Administration (FDA) advisory committee held a panel discussion as part of its review process for deciding whether or not to grant approval of aducanumab as the first treatment available to slow the progression of Alzheimer's disease.

MAP Director Dr. Stephen Salloway, who also served as co-chair of the global investigator steering committee for the aducanumab phase 3 studies, was among those who spoke in support of its approval.

Peter Bristol, who was a participant in the trial of the drug at the

Memory and Aging Program, also spoke on the panel in favor of the drug's approval.

The FDA's initial feedback on whether to approve aducanumab or to wait until further studies are conducted has been sharply split. The FDA's decision on whether or not to approve the drug, originally set for March 7 of this year, has now been pushed back to early June to allow for additional time to review and weigh the clinical data.



Dr. Stephen Salloway Talks With Neurology Live About Potential Impact of Aducanumab

In February, Neurology Live interviewed Memory and Aging Program Director Dr. Stephen Salloway about the potential impact of aducanumab on Alzheimer's treatment and research, if it is approved by the FDA.

"My take is that it would open a new modern treatment era for AD. It would just be the beginning—a stepping stone, rather than the final breakthrough," Dr. Salloway said in the interview.

Get the link to read the entire interview on the Memory and Aging blog at butler.org/memoryandaging.

See more news and resources at: butler.org/memoryandaging



A second investigational drug studied at Butler Hospital shows significant results in slowing Alzheimer's symptoms

Clinical trial results announced at AD/PD™ 2021 (the Alzheimer's and Parkinson's Diseases international conference) on March 13 indicate that the investigational drug donanemab holds promise as a potential treatment for early AD.

Study results showed significant slowing of decline in a composite measure of cognition and daily function in people with early symptomatic AD who were treated with donanemab as compared to placebo. The findings were published in the New England Journal of Medicine (NEJM) the same day.

The drug was studied in the TRAILBLAZER-ALZ study, which was conducted at 61 sites across the U.S. and Canada, including at the Memory and Aging Program. MAP Director Dr. Stephen Salloway was principal investigator for the TRAILBLAZER study at Butler Hospital and is a co-author of the NEJM article.

Read more about the announcement at butler.org/memoryandaging.



Dr. Stephen Salloway Participates in Brown University Panel Discussion, *Why Diversity Matters in Research*

On March 1, MAP Director Stephen Salloway, MD, who is also a Professor of Psychology and Human Behavior and of Neurology at Brown University, participated in a virtual panel discussion hosted by the university on the topic of why diversity is so important in research. Dr. Salloway was joined in the

discussion by: Gisel Bello MD, Brown Diversity Fellow, Office of Diversity and Multicultural Affairs; Don Dizon, MD, Brown Professor of Medicine; and Taneisha Wilson, MD ScM, Brown Assistant Professor of Emergency Medicine. To view the discussion and learn more about why diversity in medical research is crucial for better health outcomes across communities, visit butler.org/memoryandaging.

Volunteer Profile

Alyssa Freeman

Amplifying positive impact through research

Alyssa Freeman has always known she wanted to build a career doing something that would help people. Until recently, she thought she'd do that by being a counselor.

But her studies and her experience volunteering at the Memory and Aging Program have steered her in a different direction – one that she says she's excited about because it will allow her to be part of larger efforts that can help far more people than she could have helped individually on her own.

"I always thought that to help people, I had to be a counselor or work with them one-on-one," Freeman says. "But at the end of my undergraduate education I became interested in the research aspect of psychology and how it can really help to change the lives of so many people all at once, by paving the road for advancements in treatments and knowledge that can lead to better outcomes."

Freeman double-majored in Psychology and Criminology at Stonehill College. She's currently pursuing a master's degree in Forensic and Legal Psychology at Roger Williams University, but she's already got her sights set on what's

next – a doctorate in Clinical Psychology.

"Psychology is such a broad field, so I've taken a wide variety of classes throughout my undergraduate and graduate education including lots of research methods classes. That really opened my eyes to the many ways to get involved in the field, and I've come to really appreciate how research can help to create better conditions and better overall lifestyles for countless people," Freeman says.

So last fall she began looking for opportunities to get involved in research and get some first-hand experience while she finishes her master's degree.

"My grandfather passed away from dementia, so when I came across the Memory and Aging Program it stood out to me and I immediately wanted to get involved and help in any way I could," Freeman says.

She began volunteering in November and says the experience has already left a big impression on her.

"Actually getting to apply everything I've learned in school in a real-life setting has been wonderful. It's also been really surprising to see how many people are involved in the research process and how much attention to detail is involved," Freeman says.



“When you learn about research in school you picture one researcher working on a study, but there are so many researchers working together on each study, and so many other people involved to help make it happen.”

Freeman has been working side by side with one of those people helping to make research happen at the Memory and Aging Program – Denise Jerue, who is a research infusion nurse.

“Right now Denise is helping the program to prepare for a new study, so I’ve been helping her to stay organized and be sort of a second eye to look through all the binders of information and make sure everything is all set. It’s really cool to see behind the scenes of a trial – how much thought, planning, work and attention to detail goes into it. It really highlights for me how much people can and should trust research,” she says.

Already, the excitement of what can come from all of that hard work, thought, planning and collaboration is apparent in Freeman as she talks about what the future might hold for Alzheimer’s research, and for herself.

“There are so many trials going on now for Alzheimer’s and there’s so much being learned about the disease – risk factors, prevention, treatments, all at the same time,” she says.

“I’ll be at RWU for another year-and-a-half and I plan to keep volunteering at the Memory and Aging Program throughout that time, and really get involved in multiple aspects of the program. It’s been a great experience already, because even though research is such a precise process, the people involved like Denise really care about every person that’s involved. So you get the best of both worlds, helping individual people but also the greater population at the same time.”

IN THE COMMUNITY



MAP Clinical Neuropsychologist Athene Lee, Ph.D. Speaks at Brain Week Rhode Island 2021 *Missed it? Select recordings are available online!*

Each year, Brain Week RI brings together Rhode Island's foremost experts on the brain to share interesting insights and enlightening conversations about the brain with the public. This year's Brain Week, held completely online March 15 - 20, featured a series of Lunchtime "Brain Talks," a session on Mindfulness, and a "Brainy-Acts" Night of Virtual Theater.

MAP Clinical Neuropsychologist Athene Lee was among the guests at the first Brain Talk, which was focused on memory, migraines and sleep. Other topics throughout the week included Language, Exercise, Neuroeconomics, Mental Illness and Racism & COVID. Visit the Brain Week RI website to learn more and to view select recordings from the week: brainweekri.org



MAP Nurses Pivot to Provide COVID-19 Vaccine to Butler Hospital Staff

In January, as the first doses of the COVID-19 vaccine were made available to healthcare workers across the country, staff at the Memory and Aging Program were among them. Not only that, but MAP nurses also jumped in to help administer the vaccine to hundreds of other staff across Butler Hospital as well - including to each other!

"The vaccine clinics were extremely well organized, it was a very upbeat, exciting atmosphere. I helped administer the vaccine to Butler staff as well. After giving one young woman her vaccine, I noticed she was teary-eyed. I was concerned I hurt her, so asked her what was wrong. She said she was just so happy to be part of it and receive her vaccine she was overwhelmed with emotion. We both ended up teary," recalls MAP Nurse Coordinator Diane Monast (shown here receiving her vaccine from MAP Nurse Coordinator Lisa Williams).



MAP Director Dr. Stephen Salloway Participates in “Carney Conversations” Panel Discussion on Advances in Alzheimer’s Research

The Carney Institute for Brain Science at Brown University hosts “Carney Conversations,” a series of free, virtual panel discussions on topics related to brain science. In November, Dr. Salloway joined Ashley Webb, Richard and Edna Salomon Assistant Professor of Molecular Biology, Cell Biology and Biochemistry at Brown for a discussion of advances in Alzheimer’s research from the bench to the bedside. View the discussion on the Memory and Aging Program blog at: butler.org/memoryandaging



Festive Holiday Fun at MAP’s First Virtual Gingerbread House Social

On December 17th the Memory and Aging Program hosted 12 people at its first virtual Gingerbread House Social for a little bit of fun and along with some healthy brain education. Susan Robertson Kane shared this photo of the gingerbread house she completed with a little help from her grandson.

THANK YOU

We are grateful to the following organizations for partnering with us to raise awareness about Alzheimer’s disease and our program, and for hosting educational presentations and events:

Age Friendly RI
 Attleboro Area Self Sufficiency Coalition
 Attleboro Rotary Club
 Alzheimer’s Association, Rhode Island Chapter
 Cranston Senior Center
 Carney Institute of Brain Health

East Providence/Seekonk Rotary
 Newport Rotary Club
 Providence College
 Oasis International
 The Village Commons

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 the **Memory Matters** newsletter because of your current or past relationship with Butler Hospital's Memory and Aging Program, our research 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 or (401) 455-6402.

Follow us!

 facebook.com/MemoryAndAging

 twitter.com/MemoryAndAging



Memory and Aging Program

345 Blackstone Boulevard
Providence, Rhode Island 02906
(401) 455-6402
butler.org/memory

A Major Teaching Affiliate of



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**

