

BUTLER HOSPITAL'S MEMORY AND AGING PROGRAM MAGAZINE | MARCH 2020

MEMORY MATTERS

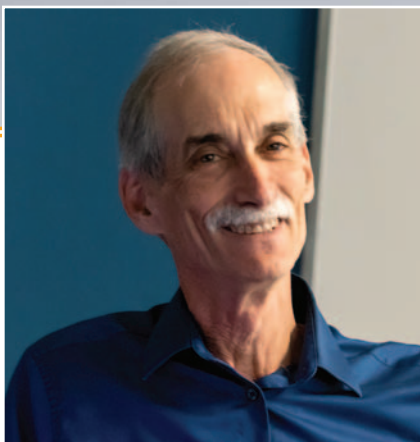
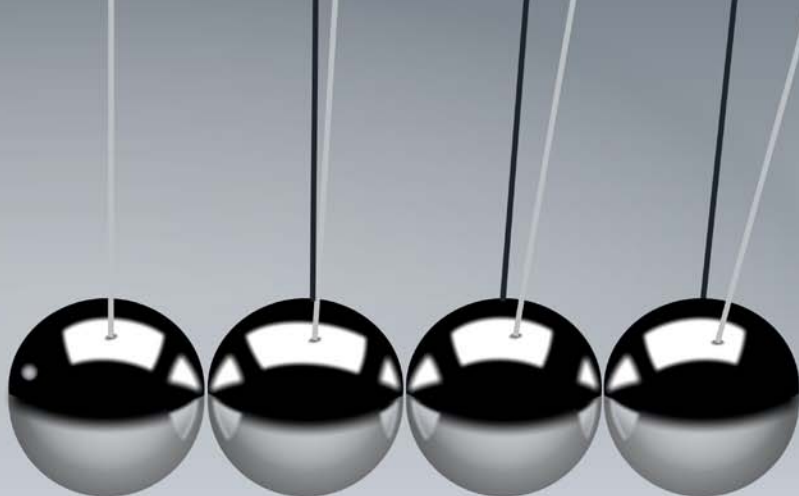
**TIME TO CHANGE
ATTITUDES ON ALZHEIMER'S**
Why this neurologist with the disease
is issuing a call to action

2 NEW STUDIES LAUNCHED

4 GREAT RESOURCES
Local support and online help for
those affected by Alzheimer's



BUTLER HOSPITAL
A MEMBER OF CARE NEW ENGLAND



MEMORY MATTERS

WELCOME

from Dr. Stephen Salloway
Director, Memory and Aging Program

***Momentum (mo-men-tum):
strength or force gained by motion
or by a series of events.***

This is perhaps the best word to describe this moment in the field of Alzheimer's research, both here at the Memory and Aging Program and around the world.

The advances of the last several years, but last year in particular, have built on each other, one after the other, to create an investment in and intensity of research not yet seen in the field. Even when those advances came in the form of trial results that didn't meet our initial hopes, they invariably have yielded critical new learnings that turned into the building blocks we're using to reach our ultimate goal.

Here at MAP we've launched two new studies since the last edition of *Memory Matters* in

November — one aimed at detecting signs of Alzheimer's in the brain decades before symptoms appear and another to investigate the effectiveness of a drug originally developed for another use as a treatment for those already suffering from the disease. Not only that, but we will be announcing another exciting study in the weeks ahead (so stay tuned!).

A second sign of our strong and growing momentum is the increase in participants of our Alzheimer's Prevention Registry at Butler Hospital, which matches willing volunteers with research studies for which they may qualify. Without participants there is no research, and so this particular sign of growth is extremely valuable. As I write this, our registry stands at more than 3,000 active participants — nearly triple the number we had at this time last year.

On the national and international level, funding for Alzheimer's research has grown tremendously. This is another critical piece to allowing research to go forward. In November Bill Gates committed to donate an additional \$10 million in funding for the Alzheimer's Association's Part the Cloud initiative. In December the Senate approved a \$350 million increase in funding for Alzheimer's and dementia research at the National Institutes of Health (NIH) for the 2020 fiscal year (bringing the total to \$2.8 billion).

With all three of these critical pieces (research, participation and funding) all growing exponentially, there is something else that's gaining new and incredible strength for those whose lives have been touched by Alzheimer's — hope.

Study Spotlight:

Dominantly Inherited Alzheimer's Network (DIAN)

The Dominantly Inherited Alzheimer Network (DIAN) is based out of the Washington University School of Medicine in St. Louis. This network works directly with families who are affected by dominantly inherited Alzheimer's disease (DIAD), a rare genetic mutation that leads to an inherited form of Alzheimer's disease (AD).

What is DIAD?

Dominantly inherited Alzheimer's disease, also known as autosomal dominant Alzheimer's disease, is a disease mutation that can occur on one of 3 genes, causing AD with more than 99% certainty. A person born with this gene mutation can expect the age of onset to be between age 30 and 50 years old and will have a 50-50 chance of passing the gene on to their children. This population makes up less than 1% of AD cases. DIAD is not the more common form of Alzheimer's disease that appears later in life.

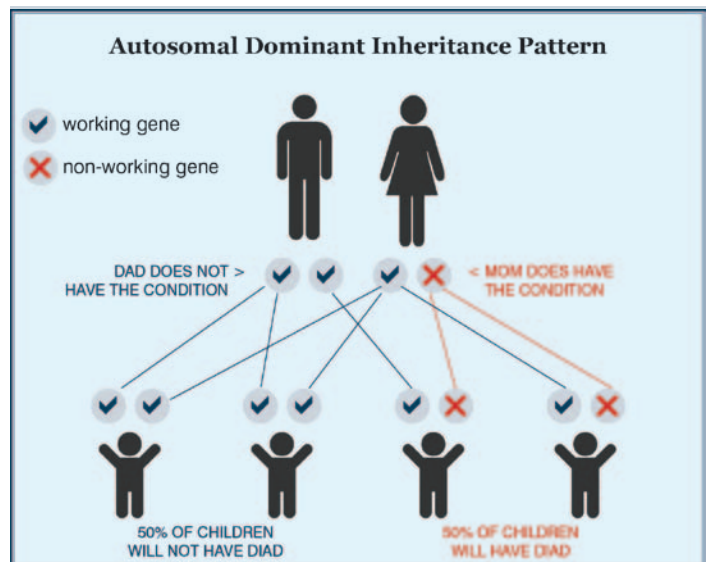
The schematic at the top right shows how these genes are passed down through families. Here the father has two working (unaffected) copies, while the mother has one working copy and one mutated copy. This mother will develop AD at relatively the same age her parent did. Children of this couple will have a 50% chance of inheriting the mutated copy from the mother. Those that do will develop the disease.

What is being done to help?

The DIAN network at Washington University has developed a triad of programs that aim to help families affected by DIAD as well as provide the AD field with a rich resource of data that can help aid in the prevention of Alzheimer's disease.

DIAN Expanded Registry

An international registry for people with confirmed or suspected DIAD in their family and for professional researchers who are part of the clinical care and research of DIAD.



DIAN Observational Study

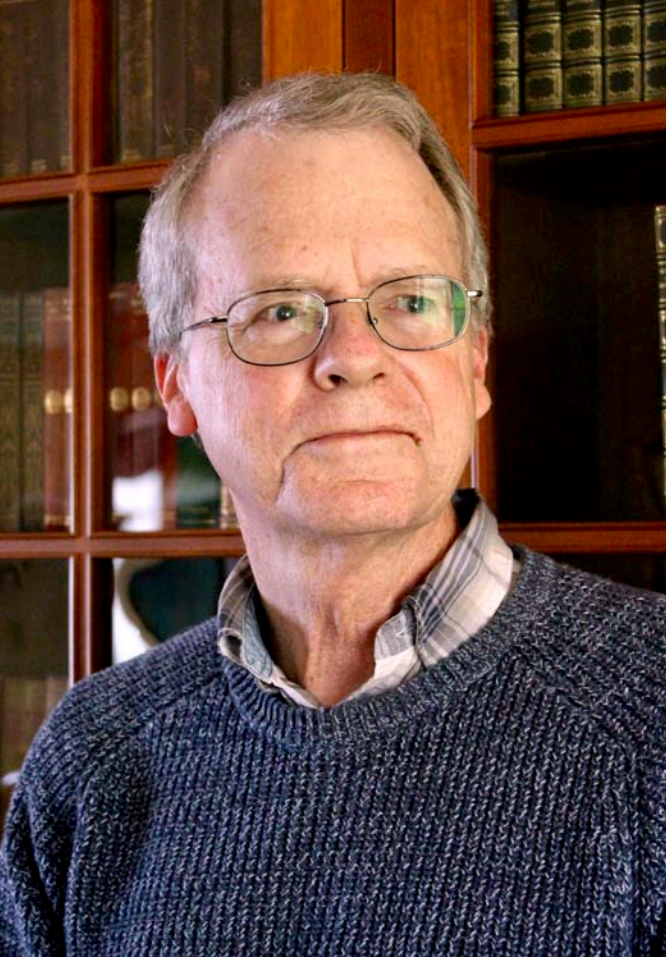
Funded by a multi-year grant from the National Institute on Aging (NIA), this observational study works with family members who have a parent with DIAD.

DIAN Trials Unit (DIAN-TU)

The DIAN-TU designs and implements trials in the DIAD population and have developed a trial platform to enable testing multiple drugs and adapt to new findings. The DIAN-TU-001 trial tested two investigational medications aimed at removing plaque and beta-amyloid from the brain. The Cognitive Run In (CRI) is recruiting with the goal of fast-tracking participants into a clinical trial of a new drug in the near future. They haven't said what this drug will be, but hope to have it running by the end of 2020.

Butler's Memory and Aging Program is honored to have worked with these families through the DIAN-TU clinical trials over the past 11 years. Through these trials there is hope to gain a better understanding on how the disease starts and progresses so the AD field can develop a breakthrough treatment.

These families are different than others who possess risk factors. In this case, we know that the people who carry the mutation will develop the disease, so researchers can begin studying the changes that occur well before symptom onset. In families with risk factors, we're not certain that the person will actually go on to develop the disease. DIAN families have nicknamed themselves the X-Men, mutant heroes sent to save the world.



IT'S TIME TO CHANGE ATTITUDES ABOUT ALZHEIMER'S

Why This Neurologist Living with
the Disease Is Issuing a Call to Action

That essay turned out to be the opening salvo in what has become Dr. Gibbs' mission: to change attitudes and assumptions about what it means to have Alzheimer's disease today, and to push both doctors and patients to seek out diagnosis at the earliest signs of the disease.

The very fact that he was able to write such an essay after more than a decade of living with Alzheimer's is an example of why he says this mission is so important.

Mounting evidence shows that early intervention and treatment offers the best chance at slowing the progression of Alzheimer's disease – and perhaps in the not-too-distant future, even the ability to halt or prevent it altogether.

Dr. Gibbs says it's time to stop letting fear get in the way of that.

"The problem is, in the past we didn't recognize the disease until people were already in the moderate to late stages of it. It didn't help that back when I first started practicing in the early '90's, there was nothing we could do," Dr. Gibbs says.

"There were no drugs, we didn't know anything about lifestyle changes – and I hated it. Not just me, but everybody [in the profession]. It was the same as cancer had been twenty years before that. Nobody talked about it. People didn't want to know. But then better cancer treatments were developed and there was reason to have

In February, 2019 Daniel M. Gibbs, MD, PhD published an unusual piece in the medical journal JAMA Neurology. It was unusual because it wasn't a report on the results of a recent study or a commentary on recent findings in the field. Instead, it was an essay in which he issued a challenge to his colleagues – a call to arms to be more aggressive in diagnosing Alzheimer's early.

It was also unusual because Gibbs wrote it from the perspective of both doctor and patient.

After spending 25 years caring for Alzheimer's patients in his Portland, Oregon neurology practice he developed the disease himself. He's now been living with it for at least 13 years.

hope, and to try and recognize and attack the disease early. That's where we are today with Alzheimer's," he says.

And yet, fear remains a powerful obstacle; there are few diseases that inspire such dread. But Dr. Gibbs says that while an Alzheimer's diagnosis is of course incredibly difficult to receive, getting it earlier rather than later provides the opportunity to maximize the time you have – both in terms of quality and quantity – and perhaps for the first time, today it also offers a measure of hope.

"We have to get rid of the fear and stigma that's attached to late-stage disease when we're talking about early disease. Because the truth is, early-stage Alzheimer's really isn't that bad," he says. "For many people that's a shocking statement to hear, but it's true. I've had it for a long time and most people would have no idea that I have a problem."

Dr. Gibbs attributes that fact to a number of things. For one, being diagnosed earlier in the disease process by definition means there will be a greater length of time before more severe symptoms develop. But more importantly, he's had the opportunity to take steps to try and slow its progression.

"We know now that you can have the hallmarks of Alzheimer's in your brain for decades without any symptoms. And even in the early stages of disease when you have mild symptoms, your life can be pretty close to normal," Dr. Gibbs says.

"The goal should be to prolong that stage as long as possible, through the lifestyle changes we now know can help and the treatments we now have. But we can't do that if we don't know there's a need. That's why it's time to shift our focus to recognizing the disease in its early stages, as early as we can, because that's where disease modification can happen."

It's a shift in thinking that will require strong effort to achieve. Even for Dr. Gibbs, recognition of his own disease didn't come quickly.

He experienced his first symptom in 2007, at age 55. He began having difficulty with his sense of smell, at times not being able to smell anything and at others smelling scents that weren't actually there. Over time he began to suspect he might have Parkinson's, since olfactory disturbances are more commonly linked with that disease.

Five years went by before Dr. Gibbs got his second clue, this time by chance. He took an at-home genetic test to learn more about his genealogy. But the kit offered the option to learn health-related genetic information as well. Given his suspicion that he may have Parkinson's disease, he decided to view those results (something he doesn't recommend most people do without medical guidance).

To his surprise, they showed that he was a carrier of two copies of the ApoE4 gene. Having one copy of the gene increases your risk of developing Alzheimer's by two to three times. Having two copies increases risk by twelve times.

"That was a shock because it totally wasn't on my radar," Dr. Gibbs says. "Both of my parents died relatively early of cancer and there was no clear history of Alzheimer's disease in the rest of my family either."

About a year later he began experiencing mild memory problems – occasional trouble recalling a colleague's name, difficulty memorizing the new phone number for his office. The impairment was so mild he may have ignored it if he hadn't known about the results of his genetic test. But he did know. He didn't have a firm diagnosis yet, but the signs were there.

In 2013, at age 62, he retired from practicing neurology.

It wasn't until 2015 that Dr. Gibbs' Alzheimer's diagnosis was confirmed. Because of his ApoE4 status, he had volunteered for Alzheimer's research studies at UC San Francisco. They involved cognitive testing and PET imaging to find and monitor tau, a protein that can build up and form "tangles" in the brain.

These tangles, along with a build-up of plaques made from another protein, amyloid, are what lead to the development of Alzheimer's. The tests left no doubt, and he was given an official diagnosis.

"Because of this chain of events I was diagnosed very early," Dr. Gibbs says. "It was surprising and frightening at first, but it has allowed me to be proactive. Now, 13 years after my first symptom, I'm still doing well."

One way that he's been proactive is by participating in Alzheimer's research studies and clinical trials.

"I loved being in the studies. I felt like I was making a contribution, even in studies where it might not have turned out to be successful for me," Dr. Gibbs says. "I also just really enjoyed it. The doctors and research nurses all became friends. Now that may just be me, but I think most people who sign up for these studies end up enjoying them, at least those I've talked to. It provides structure for life at a time when structure may be hard to find."

Dr. Gibbs points out that not only does participating in a study help research move forward for the future, it could actually help the participants who are already affected now as well. He believes it did for him.

One of the studies Dr. Gibbs participated in was a clinical trial for the drug aducanumab. It's designed to remove amyloid plaques from the brain, stopping any further damage from happening. While it's clear the drug is effective in removing the amyloid plaques, researchers are conflicted about whether that actually has any benefit in treating cognitive decline. Initial study results indicated that it didn't. But it was later found that in study participants who received the drug at a higher dose, it did.

The drug's maker, Biogen, has applied for FDA approval. If approved, aducanumab would be the first new treatment for Alzheimer's disease in 16 years. It could also open up a new era of Alzheimer's treatment where the ability to stop the disease in its tracks is within reach.

Unfortunately for Dr. Gibbs, the drug currently is no longer an option for him. He was among the study participants who had to stop taking the drug due to a side effect called ARIA (Amyloid-Related Imaging Abnormalities).

ARIA is essentially swelling or a small hemorrhage in the brain. These abnormalities are seen in a small percentage of people in the general population but the incidence was higher in those who received the drug, particularly those who received it at a higher dose, as Dr. Gibbs had. The primary symptom was headache, but the majority of patients had no symptoms and the ARIA generally resolved within four months.

Although Dr. Gibbs had to stop using the drug he still believes it helped to slow the progression of his disease and he remains hopeful that, with further refinement of the dosing regimen, it will become a significant new tool in the treatment of Alzheimer's.

"I'm quite optimistic about it. It really does remove amyloid, the controversy is whether that actually prevents or slows cognitive decline. For me, I think it did," he says. "I think in the future we'll be giving people drugs earlier, particularly anti-amyloid ones [like aducanumab]. Once the neurons are gone, they're gone. It's going to be another generation before there's any hope of figuring out how to regenerate them. But I think it is viable to have something relatively soon that prevents or slows the process of losing those neurons if the treatment is started early enough."

The other way Dr. Gibbs is working to slow his disease – and how others can try to prevent or delay the onset of Alzheimer's – is by making lifestyle changes.

Recent research has shown certain healthy lifestyle changes to be helpful in warding off and slowing dementia. Dr. Gibbs encourages everyone to incorporate these changes into their lives, but particularly those who have an increased risk for the disease.

"Many people say to me, 'why would I want to be proactive in knowing my risk or getting diagnosed when I could just do these things

anyway, even without knowing?’ I had that same conversation with my kids, because they of course have inherited at least one copy of the ApoE4 gene from me,” Dr. Gibbs says. “My argument is that one of the benefits of finding out your genetic risk or getting an early diagnosis is it really gives you a kick in the butt about actually doing those things,” he says.

“When you start thinking about these things you’re usually in your forties or fifties, which is the busiest point of your life. It’s hard to make these choices a priority at that time. But it might really help you shift your priorities if you know you have an increased risk.”

So, what are these lifestyle changes?

Dr. Gibbs follows guidelines for diet, exercise, sleep and activity that are believed to help slow disease onset and progression. He exercises regularly, making sure to get 10,000 to 15,000 steps in every day and visiting the gym every other day for a more vigorous workout. He follows the MIND diet, a variation of a Mediterranean-style diet designed specifically to prevent dementia and loss of brain function. He gets eight hours of sleep every night. And he stays mentally and socially engaged, reading two to three books per week and continuing to attend neurology conferences.

With his mission always in mind, Dr. Gibbs is now looking forward to the next chapter in the fight against Alzheimer’s disease – both in his own life, and in the larger context.



At a neurology conference in December, 2019 Dr. Gibbs met Dr. Stephen Salloway, a world leader in Alzheimer’s research who also led one of the study sites for the aducanumab clinical trial. Dr. Salloway is director of neurology and the Memory and Aging Program at Butler Hospital in Rhode Island, and is the Martin M. Zucker Professor of Psychiatry and Human Behavior and professor of neurology at the Warren Alpert Medical School of Brown University.

“I already knew him by reputation. He’s published a lot in the area of amyloid PET and ARIA, so he was really interested in my story because I had about the most severe case of

ARIA there was [in the aducanumab trial],” Dr. Gibbs says. “We talked a lot about the potential of aducanumab as a treatment and ways to possibly mitigate the ARIA side effect that can be caused by the higher doses. We’re staying in touch on the subject, and I’m optimistic about

where the future might lead with this drug.”

Aside from his plans to stay involved in research studies, Dr. Gibbs is also about to publish a book that details his Alzheimer’s journey thus far. In it, he will share the important messages of what has become his life’s mission in the hopes of encouraging others to better help themselves and inspiring doctors to help lead the way:

Know your risk. Seek an early diagnosis so you can be proactive; there are things you can do and there can be plenty of life left to live. There is much hope for the future. But we all have to be willing to move past the fear to find it.



Staff Spotlight

STEPHEN CORREIA, Ph.D.

Fighting Alzheimer's Through Research & Mentorship

In September, 2019 Neuropsychologist Stephen Correia, PhD joined the Memory and Aging Program (MAP) as Director of Research. But it wasn't the first introduction to MAP for the native Rhode Islander. Not by a long shot.

Instead, the new role has actually brought Dr. Correia full-circle in his own career while he helps to propel the careers of the next generation of neuropsychologists forward, along with the research to end Alzheimer's.

Dr. Correia first came to Butler Hospital in 2000 to complete his post-doctoral fellowship. After earning a PhD in Clinical Psychology from the University of Rhode Island he completed a fellowship in neuropsychology at Butler Hospital, followed by a fellowship in dementia research in the Department of Psychiatry and Human Behavior at Brown University.

Thus began a career-shaping

mentorship and partnership with Dr. Stephen Salloway, director of Neurology and the Memory and Aging Program at Butler Hospital and professor of Neurology and Psychology and Human Behavior at the Warren Alpert Medical School of Brown University, as well as Dr. Paul Malloy, director of Psychology and co-director of the Memory and Aging Program at Butler Hospital, and professor of Psychiatry at the Warren Alpert Medical School of Brown University.

Not only do those early experiences working at MAP with Drs. Salloway and Malloy continue to influence the trajectory of Dr. Correia's own career, but they also inspire his ongoing efforts to pay forward the mentorship he received to the next generation of neuropsychologists entering the field.

A Fascination With How The Brain Affects Behavior Launches A Career

"When I was studying psychology as an undergrad, I just became really fascinated

with it, and the part that interested me most were the brain-behavior relationships – how this organ can produce behavior and thought," Dr. Correia says.

It was that fascination that led Dr. Correia to focus much of his research on brain imaging analysis and its use as a tool to better understand how changes in the structure and function of the brain relate to changes in behavior and thought.

Over the course of his accomplished 20 year career thus far, that research has ranged from studying the changes in the brain associated with Alzheimer's disease at the Memory and Aging Program, to studying and treating the effects of traumatic brain injuries during the 14 years he served as the neuropsychology section leader at the Providence Veterans Affairs Medical Hospital.

During that time Dr. Correia has published more than 40 articles in peer-reviewed medical journals and authored or co-authored eight books, including



From left to right: Dr. Athene Lee, Dr. Stephen Salloway, Dr. Stephen Correia, Dr. Paul Malloy and Dr. Louisa Thompson

two with Dr. Salloway. He has also excelled in teaching, serving as a member of the faculty for the Department of Psychiatry and Human Behavior at Brown since 2005. There, he was awarded the Outstanding Teaching Award in Psychology in 2009 and the Toy Caldwell-Colbert Excellence in Teaching Award in 2017.

His accomplishments in both research and teaching can be in part traced back to his own early days at the Memory and Aging Program.

"The experiences I had with [Drs. Salloway and Malloy] as a fellow at Butler and at Brown really helped to frame and develop my research methodology knowledge," Dr. Correia says.

Moving the Science Forward While Paying the Mentorship Forward

Through his ongoing professorship at Brown and his new role back at the Memory and Aging Program, Dr. Correia has now taken on the same mantle as his own mentors: advancing research while also helping to advance the

development and growth of others that are new to the field.

"I've been very fortunate to have had an influence on Brown's neuropsychology training program, having mentored many interns and fellows and watched them go on to successful careers, many of them in research," Dr. Correia says.

In fact, Dr. Correia has mentored more than 100 students from colleges throughout the region through internships, fellowships and other advising opportunities. That included two of MAP's researchers while they completed their studies and fellowships at Brown. He supervised Dr. Athene Lee, now a neuropsychologist and researcher at MAP, when she completed her pre-doctoral internship rotation and fellowship at the VA. He also provided research guidance to MAP neuropsychologist Louisa Thompson.

Now, as director of research at MAP, Dr. Correia is excited to combine his own work with that of those he has mentored.

"When the opportunity arose to come back [to MAP] and make Alzheimer's research my primary focus that was very enticing to me, especially given the growth of the program in recent years and the fact that I'm now able to help shepherd the development of others' research careers in the field," Dr. Correia says.

"When I was here in the early 2000's there was of course research being done and trials for new treatments. But the thing I've noticed that's different coming back now is that the field has grown so rapidly and so much," he says.

"There's so much infrastructure that's been built to recruit research participants, develop new ideas and branch with other disciplines. The innovation over the last decade has been absolutely remarkable. Alzheimer's is a hard problem to solve, but I think that with the infrastructure and research funding in place and with research minds from the molecular level to behavioral interventions converging, we are on our way to finally discovering how to treat or cure this disease."

PROGRAM NEWS



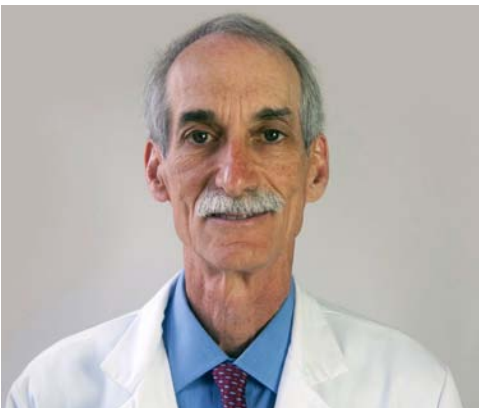
MAP Researchers Welcomed as New Faculty Members at Brown

In November, Memory and Aging Program Director of Imaging Research Hwamee Oh, Ph.D. and Research Scientist Louisa Thompson, Ph.D. were welcomed as new faculty members in the Department of Psychiatry and Human Behavior at The Warren Alpert Medical School of Brown University. Dr. Oh (pictured on the left) is a leading expert in using MRI and PET imaging in early stages of Alzheimer's disease. Dr. Thompson (at right) is developing new digital cognitive measures to detect the earliest changes in Alzheimer's disease. Dr. Stephen Correia, MAP director of research and an existing associate professor at Brown, was there to welcome them to the faculty.



Dr. Salloway Gives Keynote Address at CTAD, Speaks in Aducanumab Panel Discussion

In December, MAP founder and Director Dr. Stephen Salloway gave the opening keynote address at the international Clinical Trials on Alzheimer's Disease (CTAD) annual conference. Dr. Salloway also participated in a panel discussion regarding the results of the aducanumab clinical trial during which he said, "My feeling is sufficiently positive after careful review of the full aducanumab program...I think this is a milestone achievement for our field."



MAP Director Dr. Stephen Salloway Named Rhode Island Man of the Year

In December MAP Director Dr. Stephen Salloway was named 2019 Man of the Year by GoLocalProv for his world-leading work in the fight to end Alzheimer's.

"If there is a treatment for Alzheimer's it may very well come through Salloway's work," the media outlet said on its website.

#2020by2020RI Campaign Surpasses Goal

Last May we launched an ambitious campaign to grow our Alzheimer's Prevention Registry to 2,020 participants by the start of 2020. The registry matches willing volunteers with current or future research studies for which they may qualify and is an essential tool in allowing these critical studies to move forward. The campaign far exceeded its goal. By January there were 2,244 registry participants, an increase of 1,000+ in just 8 months!! Thank you to all who've joined to help in our efforts to find effective prevention and treatment for Alzheimer's.



New Trial to Test Drug Originally Developed for HIV as a Treatment for Alzheimer's

With a new grant from the Alzheimer's Association, MAP is teaming up with Brown University and The Miriam Hospital to conduct a phase-one clinical trial of a drug that could potentially provide a new avenue for the treatment of Alzheimer's disease. The drug, called emtricitabine (Emtriva), is from a class of therapeutics typically used to treat HIV and AIDS. Research by John Sedivy, professor of molecular biology, cell biology and biochemistry at Brown and director of the Brown Center on the Biology of Aging, has shown that the drug can potentially reduce a type of age-related cellular inflammation that has been associated with Alzheimer's. This trial will be the first step toward determining if the drug may benefit people with the disease.



ARIAS Trial to Test Retinal Screening for Early Detection of Alzheimer's

MAP, in collaboration with the University of Rhode Island and BayCare Health System in Florida, has launched a clinical trial of retinal screening processes that could help clinicians detect Alzheimer's disease possibly two or more decades before patients develop life-altering clinical symptoms.

The five-year, \$5 million Atlas of Retinal Imaging in Alzheimer's Study (ARIAS) will enroll 330 individuals between the ages of 55 and 80 years old, ranging from very healthy and low-risk adults, to persons with concerns about their memory, as well as patients with mild Alzheimer's disease. To learn more, visit memoryandaging.org.





Volunteer Profile

SUSAN SULLIVAN

A Lifelong Caregiver, Helping Others to Seek Care

“I got to see the effects of Alzheimer’s in my professional life as we worked with clients and families to manage their needs at home. And my own mother suffered and died from Alzheimer’s several years ago,” Sullivan says. “So I understand the toll this takes, on caregivers particularly. The people around the patient really have to be able to pull a lot of weight to care for loved ones. We need a cure sooner rather than later.”

Sullivan was first introduced to the Memory and Aging Program (MAP) when her mother became a patient. Her connection to the program expanded into her professional life when MAP Director Dr. Stephen Salloway and several members of his team spoke about the program at a luncheon hosted by her nursing school’s alumni group.

“The amazing commitment of the Memory and Aging team to doing outreach in the community is so wonderful. The fact that Dr. Salloway took the time to come and speak to our small group really spoke to the fact that the team is always so willing to go the extra mile to connect with the community. That’s probably what prompted me to go and explore the volunteer opportunities at the program in the first place,” Sullivan says.

For the last two years, Sullivan has herself been part of that team making connections out in the community. She says it has been an amazing experience.

“It’s a commitment of time and energy to do the training required to get started as a volunteer with the program, but it has been so valuable and worthwhile,” she says. “Most of

Susan Sullivan of East Providence, RI approaches her volunteer work at the Memory and Aging Program at Butler Hospital from a unique perspective.

She’s been a caregiver to those affected by Alzheimer’s on both a professional and personal level, allowing her the unenviable experience of witnessing countless times the effects that Alzheimer’s has on individuals and their families. But it’s just this experience that makes her such a special force in the fight against the disease.

For nearly five decades Sullivan, who retired a couple of years ago, worked as a registered nurse. She spent the last thirty of those years working in home care. After helping many of her patients and families affected by Alzheimer’s and other dementias, she sadly found herself in the same position when her own mother was struck with the disease.

“ I do think there’s something on the horizon that will make this disease more manageable and at some point it will be more like a chronic disease that can be managed. There is reason to have hope, I think.” ”

my involvement has been in efforts to educate people about the disease and to enroll people in studies, either at community events or lately more often by returning phone calls in the office to those interested in one of the program’s latest studies. I help to get them connected to the appropriate information or get them enrolled in the Alzheimer’s Prevention Registry so they can see if they qualify to participate in any of the studies.”

“It’s great to see the amount of interest in the program within the community, and also interesting to talk with people one-on-one about some of the things they’re dealing with. It speaks to how many families are affected by this disease, and how deeply.”

As her volunteer work with MAP continues, Sullivan says her goal is to continue making those one-on-one connections that will serve to help people while also helping to gain the participation that’s needed to allow the Alzheimer’s research studies being conducted at MAP to go forward.

“There’s such a thirst for knowledge in the people that I talk to out in the community and on the phone – mostly people who’ve been exposed to the disease, but not all,” Sullivan says. “We’re doing so much publicity about the prevalence and cost and toll of this disease on the entire family and even the wider community, how it takes a village to support the fight against this disease. Those outreach efforts are inspiring.”

So inspiring that Sullivan has raised her own hand to participate in research, joining the

Alzheimer’s Prevention Registry at Butler Hospital so that she can be considered for any current or future studies that might be a good fit for her. She hasn’t been contacted to participate in a study yet but she says she would certainly consider it if she were.

“I have two daughters and three granddaughters. I don’t want them to go through what I did with my mom. The possibility of getting Alzheimer’s myself is always in the back of my mind. Every time you can’t find your keys, you wonder,” Sullivan says. “My mother was younger than I am now when she first started having symptoms. So that definitely played a role in my wanting to be involved in the program as well.”

Although the prospect of developing Alzheimer’s is a scary one, Sullivan says she feels hopeful about the possibility of disease-modifying treatments being developed in the near future. Which, she says, makes it all the more important to educate people about the disease and the benefits of seeking an early diagnosis if they suspect they may be showing symptoms.

“I really encourage people to reach out for information – to the Memory and Aging Program or to their primary care physician – if they have some concerns,” Sullivan says.

“Explore what the resources are that could help. I do think there’s something on the horizon that will make this disease more manageable and at some point it will be more like a chronic disease that can be managed. There is reason to have hope, I think.”

IN THE COMMUNITY



Annual Alzheimer's Advocacy Day at the Rhode Island State Capitol

On March 4, Alzheimer's Association Rhode Island Chapter held its annual Advocacy Day at the State House and members of the MAP team were proud to be in attendance. This year's advocacy messages were focused on expanding in-home elder care services to those diagnosed with Younger-Onset Alzheimer's; establishing a dementia care coordinator position in the Department of Health; and providing free tuition at CCRI to CNA's currently working in an elder/geriatric care setting.

At left, two of our amazing volunteers, Gabrielle Dayacap and Denise Nault, share information on our research studies and opportunities to get involved during the event.

WATCH: Panel Discussion of Alzheimer's with Local Experts

Visit our blog at memoryandaging.org/resources to watch a panel discussion on Alzheimer's that was hosted by the Cranston Senior Enrichment Center and find out more about symptoms, treatment, resources and research. The discussion featured MAP Outreach Coordinator Tara Tang (pictured with microphone at right), as well as experts from the University of Rhode Island's Ryan Institute for Neuroscience and Rhode Island Geriatric Education Center, the RI Mood and Memory Research Institute, and the Alzheimer's Disease and Memory Disorder Center at Rhode Island Hospital.



THANK YOU

We are grateful to the following organizations for partnering with us to host educational presentations and appearances:

Cardi's Furniture & Mattresses
Cranston Senior Enrichment Center

Hamilton House
Lincoln Senior Center

RESOURCES

Maintain Your Brain With the 8 Pillars of Brain Health

Did you know there are ways to help keep your brain healthy, just as there are for your body? Research is increasingly showing that maintaining a healthy lifestyle can help to prevent or delay the onset of Alzheimer's disease and other dementias. Find out the eight steps to brain health at activ8yourbrain.org today and put them into practice so you'll be healthier tomorrow!

On the Blog: Stages of Alzheimer's — What to Expect and What to Do

If you or a loved one has recently been diagnosed with Alzheimer's disease, you are likely experiencing many different emotions including shock, fear, sadness, and worry. Knowing what to expect and how to plan ahead can provide a sense of control and important peace of mind. See our blog post on this topic for some helpful tips at memoryandaging.org.

Find A Memory Care Café Near You

Memory Cafés provide those with dementia an opportunity to receive intellectual and social stimulation, while also providing respite time for caregivers. There are Memory Cafés available in more than 10 Rhode Island communities (and counting!). The first and largest provider of Memory Cafés in Rhode Island is Dementia Training for Life. You can see a list of their Memory Café locations and hours at dementiatraining4life.com.

First Bilingual Alzheimer's Caregiver Support Group Launched in RI

In January, Rhode Island's first bilingual support group for Alzheimer's caregivers, Siempre Contigo (meaning "always with you") was launched in Central Falls. The support group is offered through a collaboration between Alzheimer's Association Rhode Island and Progreso Latino, an organization dedicated to serving the socioeconomic needs of Latinos in Rhode Island. The support group meets every third Friday of each month at Progreso Latino, located at 626 Broad St. in Central Falls.

Upcoming Events

Check us out on social media for the latest on upcoming events and follow us to stay informed!

 facebook.com/MemoryAndAging

 twitter.com/MemoryAndAging

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

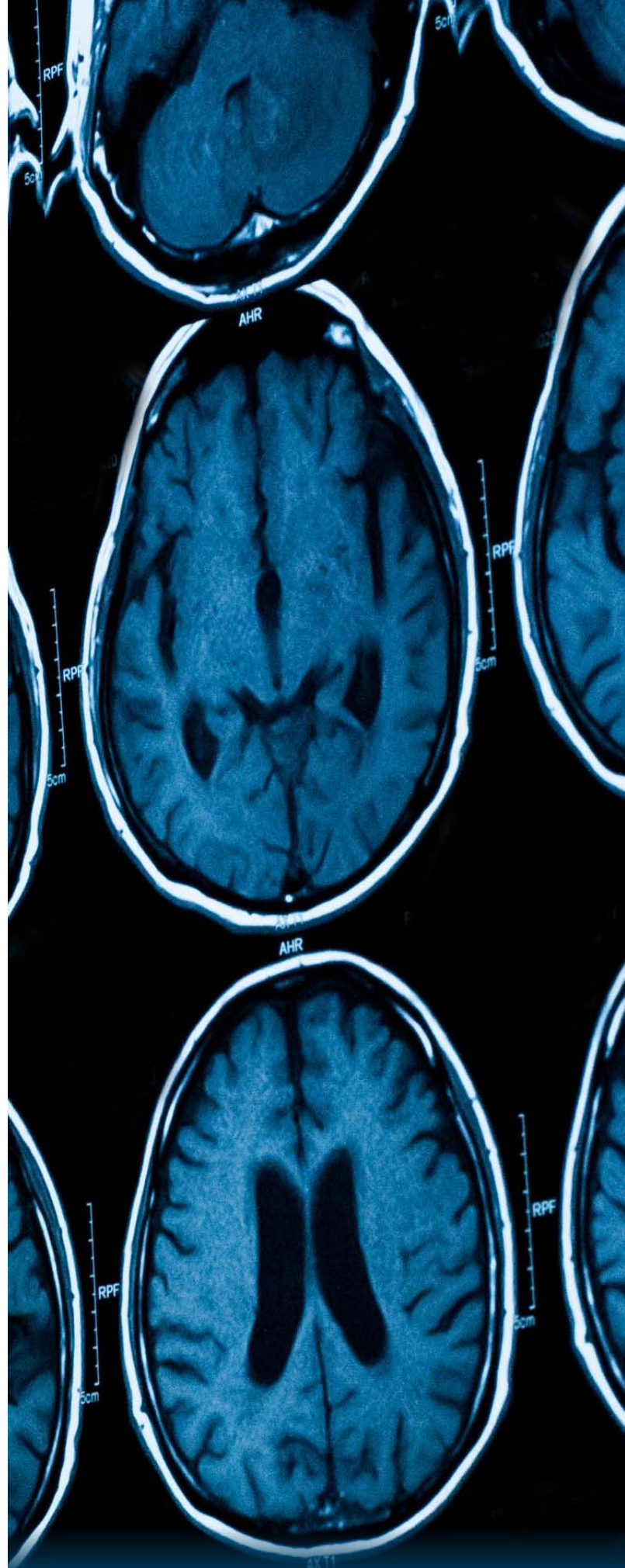
 twitter.com/MemoryAndAging



Memory and Aging Program

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

A Major Teaching Affiliate of



Pictured: MRI images of the brain