#2020BY2020RI
Closing in on our goal to build an army against Alzheimer’s that’s 2,020 heroes strong

FACING THE FUTURE, FIGHTING ALZHEIMER’S — TOGETHER
How one couple is supporting each other through prevention research

STUDY SPOTLIGHT
BAN2401 Focuses on Treating Early Alzheimer’s
I’ve spoken often in this newsletter and out in the community about the critical need to build an “Alzheimer’s Army.”

An army of people willing to help defeat this dreaded disease in whatever way they can – by participating in research, supporting research efforts through advocacy or financial support, and by lending their voice to raise awareness.

*Over this past year it has become clear – the troops are gathering.*

Our #2020by2020RI campaign to increase participation in our Alzheimer’s Prevention Registry has resulted in an influx of people willing to take part in research at the fastest rate since the Registry’s inception several years ago.

The generous support of people who contribute to our program through individual donations or by organizing fundraisers has steadily grown, with their impact being so much more than just financial.

Our outreach team has been busier than ever hosting educational presentations for private organizations and engaging the public at community events.

Our partnerships with other organizations who share our goal – from Brown University and its Carney Institute for Brain Science, to the University of Rhode Island, the Alzheimer’s Association Rhode Island chapter and many more – have continued to grow, allowing all of us to multiply our individual efforts and impact.

It has been a transformational year, not just for our program but for the advancement of Alzheimer’s research in general. The focus on early detection and prevention continues to gather momentum and is already resulting in positive steps forward in the world-wide goal to effectively put an end to Alzheimer’s by 2025.

As we move into the new year we look forward to continuing that charge forward in new and innovative ways, working in collaboration with all of you and with our partners throughout the region, across the nation, and around the world.

The clock is steadily ticking toward the end of Alzheimer’s. The troops continue to gather. And together, we are a force to be reckoned with.
With just weeks remaining, we’re closing in on our goal to grow participation in the Alzheimer’s Prevention Registry at Butler Hospital

In late May, we launched an ambitious campaign to grow the number of participants in our Alzheimer’s Prevention Registry at Butler Hospital from 1,210 to 2,020 by the start of the new year in 2020.

With weeks remaining in 2019, we’re thrilled with our progress thus far — as of early November, there are at total of 1,822 people who have joined the registry and consented to be contacted to consider participating in current and future Alzheimer’s research studies.

That’s an increase of 50% in just five short months!

But we’re not there yet. Will you help us to meet our goal so that critical Alzheimer’s research can move forward?

Please spread the word in person and online, and encourage your family and friends who are ages 40 to 85 to join the registry. Feel free to use the phrasing below on social media, or when talking in person. And THANK YOU for joining us in the fight against Alzheimer’s!

YOU can help to end Alzheimer’s by becoming one of the thousands of people to join the Alzheimer’s Prevention Registry at Butler Hospital. Learn more and join online at butler.org/ALZregistry. #2020by2020RI

SPREAD THE WORD >>
For Ray and Elaine Therriault of Chepachet, Rhode Island, life has been both a literal and figurative journey – one that they’ve happily undertaken together, fueled by an adventurous spirit.

Both natives of Providence, they first met in kindergarten. They became high school sweethearts before Ray went on to graduate from Providence College and Elaine from the nursing program at Rhode Island Hospital. They got married in 1966, and traveled the world together during the first 20 years of their 53-year marriage.

From Alaska to Panama and many places in between, they raised their two sons while moving 17 times during Ray’s career as an airman and Lieutenant Colonel in the Army. The early years included a tour in Vietnam and a period serving as a paratrooper for Ray, before he became a fixed wing and helicopter pilot. Elaine worked in general medical units in various US and Panama locations, as well for 19 years at United Health Care.

When Ray retired from the military, the couple settled back in Rhode Island and put their energy into a series of successful business ventures, including the first Mailboxes, Etc. franchise in the state and a real estate brokerage.

Now they’re facing a new journey together: the quest to help end Alzheimer’s.

Neither Ray nor Elaine have Alzheimer’s disease, or any cognitive impairment. Their involvement with the Memory and Aging Program first began when Elaine’s mother, who had Lewy Body Dementia, participated in one of the program’s studies.

After her passing, Elaine decided she wanted to be informed about her risk. So she volunteered for a research study and underwent screening for amyloid plaques in her brain, which are believed to lead to the development of Alzheimer’s. Ray followed suit and, as they’d done with everything else in their lives, they did it together.

They’re both now participants (as well as each other’s study partners) in ADNI-3, a five-year observational study aimed at determining the relationships between
Ray and Elaine are both cognitively normal, though it was discovered through the study that one of them does have plaques in the brain.

“With her family history, I thought for sure that Elaine would have [the plaques]. But it turns out she didn’t – I did, and with no family history. It was a real surprise,” Ray said. “Elaine holds it over me all the time,” he finishes jokingly.

Ray isn’t showing any symptoms of Alzheimer’s, and thus far tests have indicated no further development of the plaques. He says he’s thankful for that, of course. But he’s also thankful for the opportunity to continue monitoring their development for several years through the study – and for the chance to contribute to research he hopes will lead to an end to Alzheimer’s someday soon.

“It’s something that’s going on so much around us at our age, and I feel [participating in the study] makes me very well versed to understand and talk about it, and more comfortable that I can handle the issues,” Ray says.

“I’m not crazy about the fact that I have the potential for Alzheimer’s, but it helps me understand it and I try to do things to help. Every day you see a different article on things you can do, and I can evaluate it based on what I hear and see through the study, and talking with people from the study group.”

Elaine says she wishes others would better understand the advantages of participating in research and be less driven by fear.

“We find a lot of people don’t want to know their risk or don’t even want to get into a discussion about it. Some of them are surprised at how involved we’ve gotten and how much information we want to know,” she says.

“But it can actually really help to put your mind at ease. We had the gene testing done and found out neither one of us has any of the combination of genes that we would pass on to our kids, so that was comforting. And even if you find out something negative, like Ray did, now we have the ability to plan for that risk, both for ourselves and for our kids. It’s what the individual takes from it,” she says.

Both Ray and Elaine say they hope more people will get involved, and want to spread the word that raising your hand to participate does not mean you’ll have to do anything you don’t want to do. They also recommend finding someone to participate with, as they have done together.

“It’s really helpful to participate together. You can bounce questions off each other, and to be honest we’re happy we can do it, we’re fortunate we can and it’s kind of an honor to my side of the family, with it being so prevalent,” Elaine says.

“I would advise people to just take an exploratory trip to Butler and talk to the people at the Memory and Aging Program. There’s no commitment, it’s very professionally run and if it turns out you don’t want to do it, that’s fine,” Ray says. “But give yourself the opportunity to examine the possibility of getting involved with an Alzheimer’s study, on your own grounds and temperament and comfort level.”
Dr. Hwamee Oh Joins the Memory and Aging Program as Director of Imaging Research

Hwamee Oh, PhD, was named director of imaging research at the Memory and Aging Program in June. Dr. Oh has also joined the Butler Hospital staff as a cognitive neuroscientist and has been named Assistant Professor in the Department of Psychiatry and Human Behavior at Brown University, an affiliate of the Memory and Aging Program.

Dr. Oh is a cognitive neuroscientist with expertise in multi-platform imaging that combines functional, structural and diffusion MRI with amyloid and tau PET to detect changes in memory systems with aging and Alzheimer’s disease.

In her new role at the Memory and Aging Program, Dr. Oh will build upon and enhance research focused on using imaging to detect the development of Alzheimer’s disease before symptoms become apparent and offering patients the best chance at slowing the progression of the disease through early intervention. Read more about Dr. Oh on the Memory and Aging blog.

Sharing The Latest Alzheimer’s Research Findings and Ideas at AAIC

Memory and Aging Program Director Dr. Stephen Salloway as well as program research scientists Dr. Athene Lee, Dr. Jessica Alber and Dr. Louisa Thompson participated in AAIC, the Alzheimer’s Association International Conference, in Los Angeles in July. The team shared a poster, presented by Dr. Thompson, with conference goers entitled “Subjective cognitive decline before and after APOE and Amyloid PET disclosure in cognitively normal older adults screening for AD prevention trials.”
Appreciation Event Brings MAP Staff and Research Participants Together for Celebration of Gratitude and Hope

On June 26 the Memory and Aging Program hosted its first appreciation event for those who’ve participated in the program’s groundbreaking Alzheimer’s research studies. MAP study coordinators provided updates on the various research studies that are ongoing while attendees enjoyed a buffet lunch. The event also included some fun activities like caricature drawings and music. It was a wonderful afternoon filled with a sense of community and hope.

As MAP Director Dr. Stephen Salloway put it, “Here are some of the descriptors that come to mind when thinking of the qualities that provide the foundation for the successful fight against AD - solidarity, community, courage, grit, tenacity, trust, love, persistence, dedication, resilience and patience.” Those are the qualities embodies by our study participants, and we are so grateful for them.

SEE IT ON THE BLOG:

Memory and Aging Program Featured on WCVB’s Chronicle and WPRI News

A critical tool in the fight to end Alzheimer’s is educating the public about the disease and raising awareness of the research being done and how to get involved. Memory and Aging Program staff and participants were the focus of two incredibly moving and impactful television news pieces recently that achieved just that.

In late May, WCVB’s Chronicle profiled the work being done to defeat the disease at the Memory and Aging Program, and shared the stories of MAP research participants Peter Bristol and Dave Kalberer. In early October, Dr. Stephen Salloway and MAP research participants Diane Fitzgerald and Steve Blais were featured in a special report by WPRI News. Both of these incredibly moving and informative pieces are available to watch on the Memory and Aging blog at memoryandaging.org.

Breaking the Stigma Around Alzheimer’s Disease

MAP Study Participant Marc Archambault Featured in The Independent

Marc Archambault, a MAP research participant who has early-onset Alzheimer’s disease, is an inspiring force. Through his work with the Alzheimer’s Association of Rhode Island, speaking at seminars and meeting with lawmakers, he is working to increase awareness and conversation about the disease in Rhode Island. In July he was featured by The Independent for his efforts. In the piece, Archambault talks about the need to temper people’s fear of the disease by spreading a greater understanding of it, and to replace feelings of despair with an outlook of hope and a commitment to action through research. A link to read the article in full is available on the Memory and Aging blog at memoryandaging.org.
Exploring how the brain works is something that Louisa Thompson, Ph.D. has been fascinated with since childhood.

She often found herself thumbing through her father’s books on cognitive science and shared many an interesting conversation with him about it. (He has a master’s degree in the subject, though he is an artist by trade). And like too many others, she experienced first-hand the devastating effects of dementia when her grandmother developed the disease.

Those early experiences laid the foundation for the career that Dr. Thompson has built today.

They also shaped how she approaches her work at the Memory and Aging Program (MAP), where she is a research scientist. She is also an instructor in psychiatry and human behavior at Brown University, where she recently completed a fellowship in post-doctoral research, and she is a licensed neuropsychologist.

In her role at MAP, Dr. Thompson is on the front lines of medical science in the fight against Alzheimer’s disease. At the same time, she’s also deep in the trenches of caring for those affected by the disease in the clinical setting. It’s a dual role that requires a special combination of qualities: a compassionate and caring nature, an objective and scientific mind, and a dogged determination to persist in finding answers even when progress feels painstakingly slow.

**Going Beyond a Diagnosis**

“I really love working with older adults in the clinical setting, but I also wanted to be able to give patients more impactful recommendations and guidance, beyond just giving them a diagnosis,” Dr. Thompson says.

“That’s a big part of what brought me here to the Memory and Aging Program. I feel like research and clinical practice really complement each other,” she says.
“My research makes me a better practitioner on the clinical side, and providing clinical care makes me more connected to the population that I’m researching.”

Dr. Thompson joined the Memory and Aging team as a research fellow in 2017, drawn to the program because of its affiliation with Brown University, its reputation in the field, and the opportunity to work with a leader in the field whom she’d seen in the news, MAP Director Dr. Stephen Salloway.

In her time at the program, Dr. Thompson’s work has been primarily focused on developing better methods for the early detection of Alzheimer’s disease, before symptoms become apparent. Early detection provides a much greater ability to slow or even one day prevent its progression, as research in that area continues.

**Developing New and Better Methods of Detection – The First Step in Prevention**

Dr. Thompson is currently working to expand the research opportunities available to participants of the program’s Alzheimer’s Prevention Registry. The registry pairs people ages 40 to 85 with ongoing and future studies for which they may qualify. (Registry sign-up is available online at butler.org/ALZregistry.)

“I’m developing a protocol for cognitive assessment that people could participate in every one to two years to get their memory checked. I’m also interested in developing new types of technology and tools that make assessments easier, more standardized and better at capturing a wide range of data,” Dr. Thompson says.

“Things like using digital pens to measure cognitive speed and spatial thinking during drawing tests, as well as using smart phone apps or tablets to do assessments at home, in the primary care setting and even out in the community.”

Dr. Thompson will also be the primary psychologist for a new study, called “ARIAS,” that’s set to begin by the end of this year. The study is evaluating the use of a simple eye exam to detect certain changes in the eye, specifically the presence of amyloid plaques similar to those found in the brains of people affected by Alzheimer’s, and determine if that can be used as a reliable biomarker of developing disease.

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But what happens after the screening if someone finds out they’re at high risk or already showing signs of the disease? Is it worth knowing? Finding the answers to those important and common questions make up the other major component of Dr. Thompson’s work.

Working alongside MAP Neuropsychologist Dr. Athene Lee, Dr. Thompson is researching the impact on people who choose to find out their genetic risk for Alzheimer’s or if they have biomarkers that indicate they’ll likely develop the disease. The research is ongoing, but the pair presented preliminary data at last year’s Clinical Trials on Alzheimer’s Disease conference and this summer’s Alzheimer’s Association International Conference.

“The data analysis is still ongoing, but two things have become apparent early on. One, learning this type of info isn’t for everybody, so the most important first step is education and making sure participants have time to think about how they would feel,” Dr. Thompson says.

“The other thing is that it’s largely well tolerated by the people who do decide they want to know. They’re generally glad they have the information and don’t regret going through it.”

Fostering A Commitment to Finding an End to Alzheimer’s

Dr. Thompson is also passionate about educating the public about what it means to participate in a research study.

“People don’t necessarily realize they can make really significant contributions to Alzheimer’s research even if they don’t have Alzheimer’s,” she says.

“Especially with the growing focus on prevention, we’re always looking for cognitively healthy adults with no symptoms to participate in our research, and not just drug trials. There are other studies people can participate in that are purely observational and don’t involve a drug or lifestyle intervention.”

While Dr. Thompson shares the frustration and disappointment that participants feel when studies fail to provide the results or discoveries that were hoped for, she remains committed to the ultimate goal of unraveling the mysteries of Alzheimer’s and she hopes others will, too.

“It’s important to keep in mind the broader picture and that every piece of the puzzle, even if it’s a negative finding, is really important to steering the research in the right direction, and seeing that in our studies has been a really meaningful experience for me,” she says.

“We’re on the cutting edge of research here, we’re not just reading about it in the news, but we’re pioneering these trials, and that is so rewarding.”
What is the BAN2401 Alzheimer’s Study?
This is an 18-month, randomized, double-blind study enrolling approximately 1,566 participants across 200 sites worldwide. The participants for this study must be between the ages 50 – 90 and have a diagnosis of mild cognitive impairment (MCI) or mild Alzheimer’s disease (AD). After the completion of the main 18-month study phase and if you meet the eligibility criteria, you will receive an invitation to participate in an optional open-label extension study phase.

What is the purpose of the BAN2401 Study?
The purpose of this study is to test the safety and effectiveness of an investigational drug, BAN2401, in treating participants who have mild cognitive impairment (MCI) or mild Alzheimer’s disease (AD). Participants in the study will be randomly assigned to receive either the investigational drug or placebo, which is an inactive substance designed to look like a medication, but has no effect. Both the investigational drug and placebo will be administered intravenously every 2 weeks.

Eligibility
Men and women between the ages of 50 – 90 who have a diagnosis of mild cognitive impairment (MCI) or mild Alzheimer’s disease (AD). All participants must have a study partner who spends at least 8 hours per week with them and would be able to support them throughout the duration of the study. There is a screening phase during which you will answer several questionnaires to help determine whether you are eligible.

If you are interested in learning more about the BAN2401 study, please call (401) 455-6402 or send an e-mail to memory@butler.org. Ask about the “BAN2401 Study.”
There are very few moments that set the course for where the rest of our lives will lead.

But Gregory Pappas of Plymouth, Massachusetts experienced just that type of moment recently, thanks to the Memory and Aging Program at Butler Hospital.

A senior at Providence College, Pappas is majoring in Psychology with a minor in Biology and is also involved in the neuroscience program there.

When it came time to complete an internship, a former classmate and a professor both recommended Butler Hospital. With its dual focus on both research and clinical care, Pappas says the Memory and Aging Program was the perfect fit.

From January to May, 2019 he spent 10 hours each week at the program, shadowing the research staff, observing as study participants underwent cognitive assessments, and assisting with administrative tasks for the various studies.

“Within the first week I knew that neuroscience was the type of work I wanted to do, and I have Butler to thank for that.”

“My internship was a great experience. The whole team – the research team, Dr. Salloway, Bill [Menard, research operations manager] – they all were really helpful and wanted me to learn, and I’m so thankful,” Pappas says.

But it wasn’t just the learning that convinced Pappas that neuroscience was where his life’s work should be. It was also the humanity he observed at the program.

“I have a history of dementia in my family
as well, so this was a good way for me to apply something I was learning in a personal way. And the way the staff interacts with the community and the patients is just so special,” he says.

“That [the staff and the research participants] know each other’s lives, know about their children, know how they’re doing beyond the monthly or yearly study assessments is so great. Even though Butler is nationally recognized, it is very much a community hospital, and that’s very important.”

Though his internship ended in May, Pappas’ involvement at the Memory and Aging Program did not. He continues working with the program as a volunteer.

“In my volunteer capacity, I just help out with whatever they need. I’m doing some administrative work related to one of the studies, and I also help out a lot at the community outreach events the program hosts. When I have time, I still walk around and chat with people too, to keep learning new things about the field,” he says.

Now that he’s got a clearer picture of what he wants to do with his life, Pappas says he hopes that vision will keep him involved with Butler Hospital and the Memory and Aging Program for some time to come.

“I’m planning to go to grad school, perhaps at Brown University because I already know so many of the doctors from Butler,” Pappas says. “But first I’m planning to have a gap year after I graduate from PC, because I want to have a few more research experiences. I’m looking into applying to be a research assistant at the Memory and Aging Program, but either way I’ll still continue to volunteer. This is definitely a place I’ve come to call home.”
IN THE COMMUNITY

Tarro Family Hosts Fundraiser at Siena Restaurant, Raises $13,000 for Memory and Aging Program

On September 23 Chef Anthony Tarro of Siena Restaurants RI and his family hosted a fundraiser at the restaurant’s East Greenwich location. The event raised funds for the Robert D. Tarro MD Memorial Fund, which the family established to support the groundbreaking Alzheimer’s research being done at the Memory and Aging Program.

In addition to delicious food and drink, more than 100 guests enjoyed a variety of guest speakers, including Chef Tarro, MAP Director Dr. Stephen Salloway and MAP research participant Steve Blais. Artist and MAP supporter Paul Coté donated some of his artwork to raffle off at the event, which added to the evening’s festivities as well as its success. In all, the event raised more than $13,000 for MAP research programs.

THANK YOU to the Tarro family and all who attended for your generous support of this important work!

THANK YOU

We these organizations for partnering with us to host educational presentations:

Calvary Baptist Church
Cranston Senior Enrichment Center
East Providence Senior Center
The King’s Cathedral
Narragansett Indian Tribe
Oceant State Center for Independent Living
Pawtucket Credit Union
Phyllis Siperstein Tamarisk Assisted Living Residence
St. Elizabeth Place and Terrace
South Kingstown Public Library
Washington County Elder Resource Group
Wilfred Manor
MAP Joins Alzheimer’s Association RI’s Walk To End Alzheimer’s

The Memory and Aging Program was proud to support our community partner, Alzheimer’s Association Rhode Island, by forming a team to walk in the Association’s annual Walk to End Alzheimer’s at Roger Williams Park in Providence on October 6. Our team raised $843 to support the Association’s work, and we also shared information about research opportunities with other Walk participants.

Memory Sunday at Calvary Baptist Church

On June 9, members of the Memory and Aging Program team celebrated Memory Sunday with the congregation of Calvary Baptist Church in Providence. Memory Sunday is celebrated at churches across the nation on the second Sunday in June to bring awareness to the fact that African Americans are twice as likely to develop Alzheimer’s as whites. African Americans are also under-represented in research. It was a wonderful opportunity to share in the congregation’s Sunday service while also sharing information about Alzheimer’s disease, local resources for those affected and their caregivers, and how to get involved in research.

Upcoming Events

We’re always adding new events. Stay up to date by following us on social media:

facebook.com/MemoryAndAging

twitter.com/MemoryAndAging
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.

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