

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

MEMORY MATTERS

CAN HEALTHY LIFESTYLE CHANGES PROTECT BRAIN HEALTH?

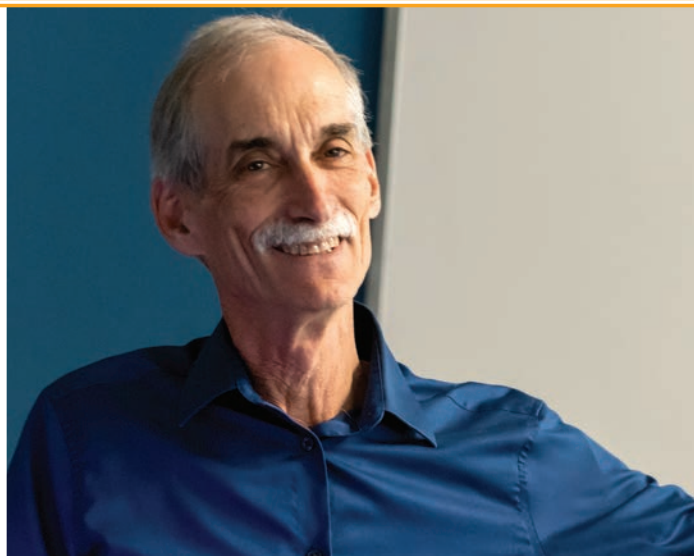
National POINTER study now recruiting
volunteers in southern New England to find out

FROM ONE CAREGIVER TO ANOTHER

Katie Brandt shares her incredible story
and her valuable advice



BUTLER HOSPITAL



MEMORY MATTERS

WELCOME

from Dr. Stephen Salloway
Director, Memory and Aging Program

There's no denying, the last several months have been incredibly difficult.

The arrival of the COVID-19 pandemic threw individual lives and society as a whole into disarray. Fear of the unknown and uncertainty about the best course of action defined our day-to-day lives and the greater national and international dialogue for weeks. At the same time, our ability to come together physically for support and comfort was greatly diminished, just when we needed it most.

But when the initial shock passed, the strength of the human spirit, the ingenuity of the human mind and the ability of society to press on was remarkable, and continues to be.

I can't help but be struck at how the entire experience of the coronavirus pandemic mirrors that of the individual and collective fight against Alzheimer's in so many ways.

Worldwide, nearly 50 million people have Alzheimer's or related dementia. It is itself a pandemic, and one that has been plaguing humanity in ever greater numbers over the last several decades. The timeframe for the fight against Alzheimer's may be much longer than that of COVID-19, but the importance of discovering how to end it is just as urgent.

It too fills us with uncertainty and inspires fear. It too can leave those it affects feeling disconnected from loved ones, the rest of society and the life we once knew. It too throws people's lives into disarray and exacts a devastating toll on society.

But it too can be conquered.

And as we see with efforts to "flatten the curve" of coronavirus, it too will require an organized and concerted effort to conquer. It requires vast amounts of research and the understanding that the process of decoding this disease will require trial and error, but that even failed trials bring the success of more information and another step forward. It requires ingenuity in science and healthcare. It requires the strength of the human spirit, as those who volunteer to join together in the fight give of themselves in many and varied ways. And in all these efforts, it requires us to press on.

And press on we have, and we shall.

Even in the time of coronavirus, the fight to end Alzheimer's goes on and indeed there's a growing feeling that we might just be on the precipice of our own curve; that moment when you reach the top of what once seemed an insurmountable climb, and suddenly the path forward to what lies beyond becomes clear.

Together, we can get there.

Study Spotlight:

U.S. POINTER

alzheimer's association®



BUTLER HOSPITAL
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The Miriam Hospital
Lifespan. Delivering health with care®



Butler Hospital, part of the Care New England Health System, in collaboration with The Miriam Hospital, part of the Lifespan Health System, has been chosen as one of five prominent healthcare networks across the United States to conduct **a large-scale study testing whether healthy lifestyle interventions can reduce the risk of cognitive decline in older adults who are at increased risk for it.**

The U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) is sponsored by the Alzheimer's Association and is the first such study to be conducted in a large, diverse group of Americans across the United States.

Approximately 2,000 total volunteers will be enrolled nationally and followed for two years. The U.S. POINTER study's initial site and coordinating center is at Wake Forest School of Medicine, Winston-Salem, North Carolina. Other sites in California, Illinois and Texas have already begun enrollment.

Locally, the POINTER New England study site will enroll 400 volunteers from across Rhode Island and surrounding areas beginning this summer. The study site will be based at Butler Hospital's Memory and Aging Program and conducted through a collaboration with the Weight Control & Diabetes Research Center at The Miriam Hospital, the Alzheimer's Association Rhode Island Chapter and the Alzheimer's Association Massachusetts/New Hampshire Chapter.

"We are so excited that Rhode Island and the southern New England region has been selected as the fifth and final site for the landmark US POINTER Trial," said Dr. Stephen Salloway, Director of the Memory and Aging Program at Butler Hospital and the Principal Investigator for the Rhode Island site.

continued on next page



“Rhode Island has the right size and community spirit to successfully carry out this study and our team at Butler is looking forward to working closely with the Weight Control & Diabetes Research Center at The Miriam Hospital, the Alzheimer’s Association, and our community partners. We are calling on everyone in the Rhode Island area aged 60 to 79 to consider volunteering,” Dr. Salloway said.

Executive Director for the Alzheimer’s Association Rhode Island Chapter Donna McGowan said, “The Alzheimer’s Association is thrilled to be launching this clinical trial with the Butler and Miriam Hospitals and other scientific partners across the country. With over 24,000 people living with Alzheimer’s in Rhode Island alone, we look forward to working with Dr. Salloway and his team on this landmark study that will ultimately benefit millions of Americans.”

The U.S. POINTER study was inspired by a recent two-year study in Finland, called the FINGER study, which showed that a lifestyle program combining physical exercise, healthy eating, brain exercises and health monitoring protected memory and other thinking abilities in older adults. The U.S. POINTER study will test whether the FINGER lifestyle programs tested in Finland might also work for Americans.

“We are privileged to be one of five centers in the US POINTER trial and are excited to work with experts at Butler and the Alzheimer’s Association to conduct this landmark study,” said Director of the Weight Control & Diabetes Research Center at The Miriam Hospital Rena Wing, Ph.D.

“The Miriam Hospital is famous for its research showing that lifestyle approaches, including increasing physical activity and eating a healthy diet, are important for preventing heart disease and diabetes, but the POINTER study would be the first to investigate how a multi-component lifestyle intervention could potentially help prevent cognitive decline.”

Join  **U.S.POINTER**
alzheimer’s  association®

Volunteers aged 60-79 who do not have any problems with memory or thinking and do not regularly exercise will be randomly placed into one of two lifestyle interventions. One group will have a more structured lifestyle program, while the other group will have a more self-guided lifestyle program. Each program will encourage increased physical exercise, a healthier diet, cognitive and social stimulation, and management of heart and vascular health.

Participants in both groups will attend small group meetings during the two-year study, where they will receive information about how to make healthy lifestyle changes. Volunteers in both groups will also be evaluated for changes in thinking abilities every six months using “gold-standard” cognitive assessment tools. Vascular and metabolic health, physical function, mood, and quality of life will also be assessed.

In light of the challenges presented by COVID-19, appropriate precautions will be taken to ensure the health and safety of all trial participants and staff. The first phase of the enrollment process will begin remotely; after the first enrollment phase is complete, participants will be brought in with special care, adhering to all safety guidelines set forth by Care New England and the Rhode Island Department of Health.

For more information, visit **butler.org/POINTER**, e-mail **pointer@butler.org** or call **401-POINTER (401-764-6837)**.



 **401-POINTER**

 **butler.org/POINTER**

Staff Spotlight:

SAM SLEZAK, MS

Sam Slezak originally set out to become a trainer for professional athletes. Today, he's a research coordinator at the Memory and Aging Program at Butler Hospital. While working with aging seniors doesn't come with the bright spotlight of training athletic superstars, the impact of his work is undoubtedly much more worthy of one, with the potential to help lengthen and improve the lives of millions of people.

Slezak studied Kinesiology (the science of body movement) at the University of Rhode Island with the goal of becoming a trainer for a professional sports team. But graduate work on a research study focused on resistance training interventions for older, sedentary people steered his interests on a different path.

Slezak joined the Memory and Aging Program (MAP) in November, 2017 after earning his Master of Science in Kinesiology. Now, three years later, he's one of just five project managers across the country helping to coordinate the POINTER trial, a major national study aimed at evaluating whether healthy lifestyle interventions can help to protect brain health.

"During grad school I found I really enjoyed doing research – especially the process of planning and production of the study – and so that's why research was on my radar as a



possible field after graduation. When I saw the study coordinator position at the Memory and Aging Program working with the older adult population as I had done during my graduate program, I thought it was the perfect fit," Slezak says.

Over the last few years he's helped to coordinate several major studies at MAP. He was the lead coordinator for the TRAILBLAZER trial and co-coordinator for the TAURIEL, TANGO and Periscope trials as well, organizing the participant recruitment and screening as well as the overall operation of those trials.

Slezak says his experience working with the program over the last few years has not been what most people would probably assume.

"People think this job must be all doom and gloom, that it's sad and depressing, but in reality most of the time it's really upbeat," Slezak says.

"The staff and study participants are enthusiastic about what they're doing, so working here is

A passion for physical fitness is fueling his leadership of a landmark study to protect brain health.

quite the opposite of sad. The feeling in the field overall today is upbeat, forward-thinking and positive. Even when studies come to a close and the results aren't what you hoped for, still everyone looks forward to the future and working together in a positive way to use what's been learned to come up with a treatment."

Slezak has also watched as the field has shifted toward a greater focus on prevention. A growing body of research points to healthy lifestyle habits like social and intellectual activity, nutrition and exercise as a key factor in staving off cognitive decline and perhaps even helping to prevent conditions like dementia and Alzheimer's disease.

The U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) trial is the first study to test just that in a large, diverse group of Americans. *(Read more about the study on page 2.)*

Locally, the POINTER New England study site will enroll 400 volunteers and will be conducted through a collaboration between the Memory and Aging Program, the Weight Control & Diabetes Research Center at The Miriam Hospital, the Alzheimer's Association Rhode Island Chapter and the Alzheimer's Association Massachusetts/New Hampshire Chapter.

With his background in Kinesiology and his experience coordinating major studies, Slezak has the perfect skills set to be project manager for POINTER. It's a challenge he says he's looking forward to.

"When I heard about the POINTER trial my ears perked up, because it falls right in my wheelhouse," he says.

"Coming from my background, the concept that exercise and diet is medicine is no secret. But even though the general public knows it's good for you, most people still don't do it regularly. A huge portion of the population is sedentary, especially as they age," Slezak says. "So I'm really curious to see, if a landmark study like this can demonstrate that being physically active and maintaining a healthy diet slows down memory loss, will that be the push people need?"

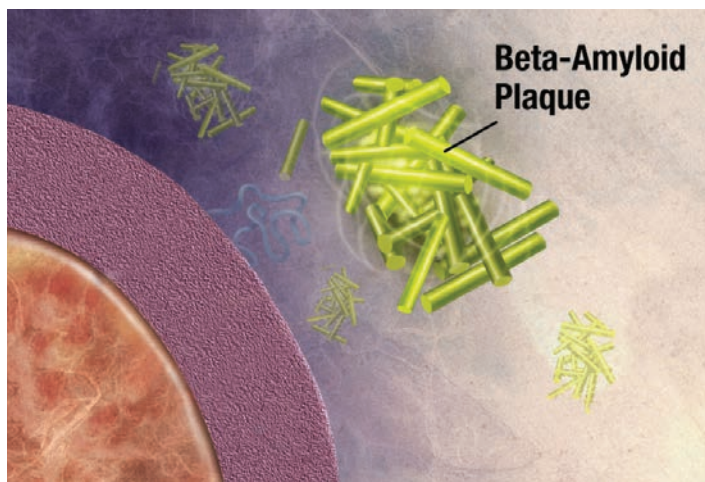
"There are medications for the hypertension and high cholesterol that can come from a sedentary lifestyle. But there are no medications to slow down the onset of dementia that everyone can take and have great results with. So if the results of this study are positive and it leads to a movement for people to become more active, it would be great."

Managing the POINTER study will more or less be Slezak's sole focus at the Memory and Aging Program over the next two years. He'll be managing the recruitment of 400 people, as well as production of the study itself, including bringing those 400 participants back into the office every 6 months over the two-year course of the study.

Slezak says it's a tall order, but one that he and the Memory and Aging team are up to.

"The 400-participant requirement for this study is really big – bigger than any study that I've worked on thus far. So that will be a huge milestone for the team and for the program as the last of the five POINTER sites. I have no doubts that our team will rise to the occasion and meet or exceed expectations."

PROGRAM NEWS



Aducanumab Submitted to FDA for Approval; Could Become First Treatment to Meaningfully Change Course of Alzheimer's

It was announced on July 8 that aducanumab, an investigational drug for the treatment for Alzheimer's disease, has been submitted to the U.S. Food and Drug Administration (FDA) for approval with a request for Priority Review.

Rhode Island contributed to the largest number of participants enrolled in the studies that led to the submission for approval, through study sites at the Memory and Aging Program at Butler Hospital and the Alzheimer's Disease and Memory Disorders Center at Rhode Island Hospital, both of which are affiliates of the Warren Alpert Medical School of Brown University. If approved, aducanumab would become the first therapy to reduce the clinical decline of Alzheimer's disease and would also be the first therapy to demonstrate that removing amyloid beta from the brain resulted in better clinical outcomes.

The drug's makers, Biogen and Eisai Co., Ltd. (Tokyo, Japan), completed the submission of

the Biologics License Application (BLA) to the FDA. The submission includes clinical data from the Phase 3 EMERGE and ENGAGE studies, as well as the Phase 1b PRIME study. Stephen Salloway, MD, MS, director of neurology and the Memory and Aging Program at Butler Hospital and the Martin M. Zucker professor of Psychiatry and Human Behavior and professor of neurology at the Warren Alpert Medical School of Brown University served as co-chair of the global investigator steering committee for the aducanumab Phase 3 studies.

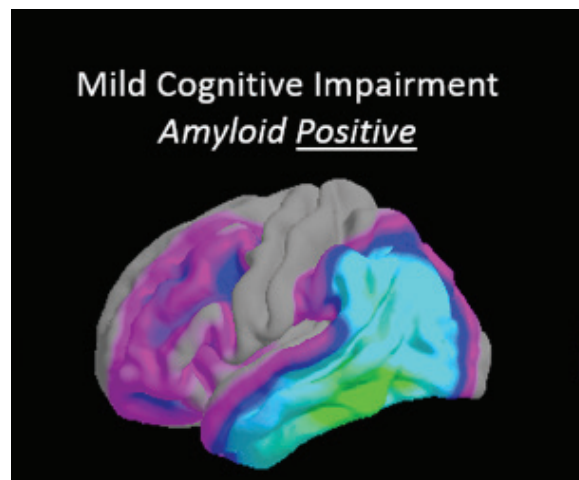
"The submission of aducanumab for FDA approval represents a milestone in the fight against Alzheimer's disease and we are excited that so many Rhode Islanders contributed to making this happen," Dr. Salloway said.

"For many people living with the early stages of Alzheimer's disease, maintaining independence for as long as possible is the ultimate goal. If we can help slow the progression from one stage to the next, this could preserve independence, which, in turn, could have truly meaningful benefits for people living with the disease and their loved ones. Aducanumab represents a potential breakthrough that we hope will provide a treatment foothold in the fight against Alzheimer's disease."

The completion of the BLA submission followed a planned pre-BLA meeting with the FDA. The FDA now has up to 60 days to decide whether to accept the application for review, at which point, if accepted, Biogen expects the FDA will also inform the Company whether the BLA has been granted Priority Review designation. The BLA will then be subject to review by the FDA to make a determination on the potential approval of aducanumab.

Drug Studied at MAP Becomes First to Be Approved by FDA for Diagnosing Alzheimer's

The FDA has approved Tauvid (flortaucipir F18) for intravenous injection as the first drug used to help image the tau pathology in the brain associated with Alzheimer's. The approval comes after results of the national A16 study showed that PET imaging used in combination with flortaucipir tracer was successful in confirming the presence of tau in the brain, helping to establish an Alzheimer's diagnosis. Butler Hospital was one of 27 sites across the U.S. to participate in the study.



New MAP Study to Test Whether Smartphone Technology Can Detect Preclinical Alzheimer's

An exciting new study, called the **DigiCog AD Study**, has launched at the Memory and Aging Program, conducted by Louisa Thompson, Ph.D. through a Clinician Scientist Fellowship Grant Award from the Alzheimer's Association. The study will evaluate how to use smartphone (app-based) and online cognitive tests, as well as other digital assessment tools, to detect subtle changes in memory and thinking that occur prior to the onset of major clinical symptoms of Alzheimer's. If you are interested in participating in this study, please join the Butler Hospital Alzheimer's Prevention Registry at butler.org/ALZregistry, or contact a member of the MAP Outreach Team at memory@butler.org or (401) 455-6402.



PROGRAM NEWS

DIAN-TU Study Receives Open Label Extension

The topline results for the first phase II/phase III clinical trial of drugs to treat people genetically predisposed to early-onset Alzheimer's disease were released on February 10. Study investigators found that gantenerumab was associated with improvements in measures of amyloid and tau proteins and improvement in an overall measure of neurodegeneration (when nerve cells in the brain lose function over time).

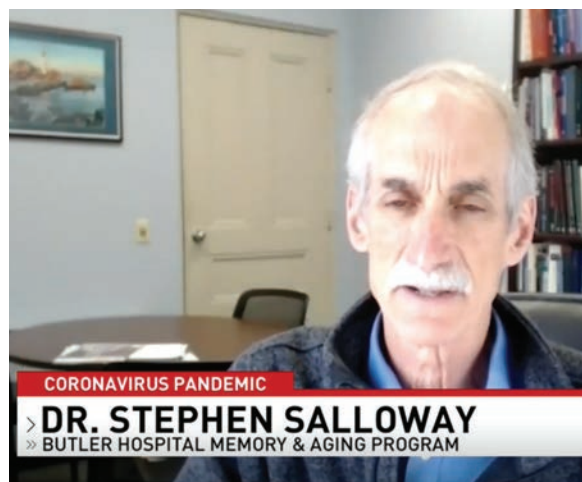
On April 2 it was announced that an exploratory open-label extension (OLE) will be conducted to study the effect of gantenerumab over a longer period of time in this population. The extended study is expected to last two years and will be open to participants of the initial phase II/phase III clinical trial. Memory and Aging Program Director Dr. Stephen Salloway will continue on as the Project Arm Leader for the exploratory OLE.



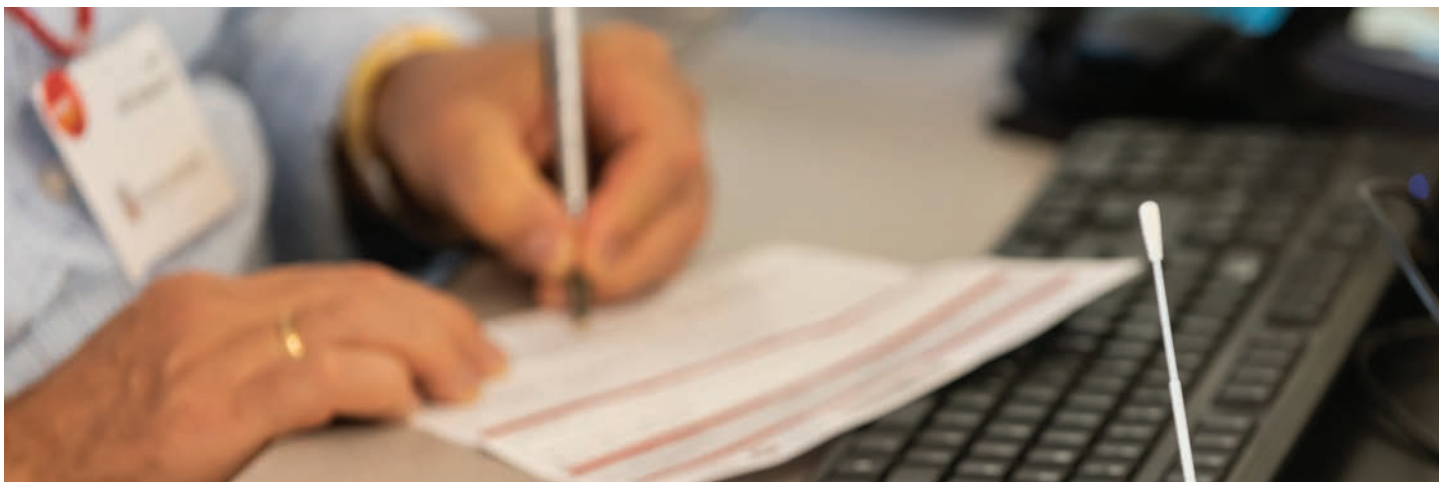
Media Coverage: How The Fight to End Alzheimer's Continues, Even in the Time of Coronavirus

The COVID-19 pandemic brought many aspects of life and society to a halt, but research to help end Alzheimer's continued. WJAR NBC10's Barbara Morse and the Providence Journal's G. Wayne Miller delved into this topic with interviews featuring Memory and Aging Program Director Dr. Stephen Salloway, as well as other major figures in the field of Alzheimer's research including Alzheimer's Association Chief Science Officer Maria Carrillo and leading Alzheimer's researchers in Europe.

Visit memoryandaging.org for links to view and read the interviews.



See more about all of these stories on our blog: memoryandaging.org



STUDIES NOW ENROLLING

The Memory and Aging Program is currently recruiting volunteers for a number of ongoing studies. If you're interested in participating, please join the Butler Hospital Alzheimer's Prevention Registry at butler.org/ALZregistry or contact the Outreach Team at memory@butler.org or (401) 455-6402.

ARIAS Study

The ARIAS study seeks to understand what changes to the retina can detect AD risk 10 to 20 years before memory symptoms occur, and to develop a 3-D imaging atlas of AD-related changes in the retina for use by researchers worldwide. Participants will be evaluated at four time-points during the 36-month study period. At each study visit, participants will undergo basic eye exams, medical history, assessment of vital signs, neuropsychological assessment, full retinal imaging scan, and blood sample for measurement of plasma beta-amyloid and tau levels.

Digi-Cog AD Study

This study will evaluate how to use smartphone (app-based) and online cognitive tests, as well as other digital assessment tools, to detect subtle changes in memory and thinking that occur prior to the onset of major clinical symptoms of Alzheimer's. The project's goal is important to developing more effective strategies for the early detection of Alzheimer's disease to facilitate treatment research, and give patients and providers a greater window for treatment and care planning.

Caregiver Profile:

KATIE BRANDT

Caregiver to both her young husband and father with dementia, now she's supporting others through the caregiver journey.

At the start of 2009, Katie Brandt's life was the picture of happiness. She was married to her college sweetheart, Mike. The couple, both 29, had just started a family with the arrival of their son Noah the year before. Katie was a devoted daughter to her own parents, and enjoyed her career as an evaluation specialist for the state child welfare agency. But in the space of just 3 short weeks an unfathomable chain of events forever changed Katie's life...

It was the end of February when Mike was diagnosed with Frontotemporal Degeneration (FTD), a form of dementia. Just four days later, Katie's mother passed away suddenly from a heart attack. And unbelievably, just 17 days after that her 59-year old father was diagnosed with early-onset Alzheimer's Disease.

In the months and years that followed, Katie was left to deal with immense grief while also acting as caregiver for not only her young son but also her husband and her father. She quit her job, moved in with her dad, and for the next four years she was the full-time caregiver her family needed. She quickly found that she couldn't safely care for two adult men with dementia and her infant son at the same time, so she found a neurorehabilitation center not far from her father's house to help care for Mike.

"It was a trial by fire entry into the world of caregiving," Katie says.

Although her story is one of immeasurable loss and sadness, the path she has chosen to take in

the wake of her loss has also made it a story of incredible courage, love, learning, growing and now, inspiration for others. As she writes on her blog at loveisouthereftd.org:

"Carried by the current of swift and irrevocable change, I recognized early on that I wouldn't be able to swim against the tide. So, I learned to ride the wave."

Now, more than ten years later, not only is she still riding that wave, she's a buoy to others who are caring for a loved one with dementia.

"When my husband passed away, I had so much energy from the grief that experience caused that I felt this need to take that and do something positive with it. When my son started kindergarten and dad began an adult day program, I was able to turn my attention to meaningful work in the field of dementia and caregiving."

Katie is the Director of Caregiver Support Services and Public Relations for Massachusetts General Hospital's Frontotemporal Disorders Unit. She's also Co-Chair of the National Alzheimer's Project Act (NAPA) Advisory Council on Alzheimer's Research Care and Services, and an FTD Caregiver support group facilitator in Boston for the Association for Frontotemporal Degeneration (AFTD).

Through those roles she has channeled both her grief and her love into providing invaluable support for others who find themselves dealing with the experience of caring for a loved one with dementia.



Katie shares her family's journey with young-onset dementia at the 2019 gala event to benefit the Mass General Hospital Frontotemporal Disorders Unit.

Here, in her own words, Katie shares some valuable lessons she's learned as a caregiver, and that she now shares with others through her work...

FEELINGS FIRST

One of the things that helped me as I was interacting with my husband was approaching situations with the idea of “feelings first.” My biggest goal was always to connect with him emotionally and to promote a positive feeling. I definitely didn’t get it right all the time, but the great news is there’s always an opportunity for a do-over, sometimes literally within minutes.

For example, I might say to him, “Let’s put a sweatshirt on because it’s cold outside.” If I approached him with the sweatshirt and tried to do it in a hurry because I was in a rush and that didn’t go so well, I could put the sweatshirt down and then approach him again. Maybe the second time around I might start with a big smile and a hug. I might say “I found the sweatshirt you wanted!” and then guide him one step at a time. It surprised me how more than anything else, adding positive emotions to my actions was one of my most valuable tools in helping Mike and Dad get through their days.

THE RELATIONSHIP IS FAR MORE IMPORTANT THAN “THE PROMISE”

One of the other big things that comes up a lot when I work with families is this idea of the promise. A loved one might say, “I promised to

keep my loved one at home.”

I want to acknowledge that our healthcare workers, skilled nursing staff and memory care professionals can provide amazing supports to families caring for a loved one with dementia. It’s not a failure to choose to have a memory care program or skilled nursing facility as part of your care team. In fact, it can be a wonderful experience.

Because of Mike’s behavioral challenges and our son’s young age, it was incredibly difficult for me to have meaningful family visits without support. At each visit, a staff member would assist me in shared activities between Mike and Noah, help keep Mike engaged and even take family photos. By recognizing our family’s goals of care, they provided support that allowed us to facilitate family moments that built new memories of joy. They also helped me to continue to build and develop my relationship with Mike in new and different ways.

I work with caregivers who feel they’re not their loved one’s caregiver anymore if they have to reach out and get support from a residential program. You may not be the only caregiver, but you’re still the most important caregiver. By making decisions and providing loving support, you are contributing to their care.



Katie's son Noah says that this is his favorite family picture, taken when he was just 2 1/2 years old, because he and his dad are both wearing their favorite color, orange.

It was an unexpected gift that when Mike moved into his skilled nursing facility that I could embrace my role as Mike's wife again. When I was at home juggling laundry, meals, medication, behavior management, and activities it made it so hard to also take that deep breath and just hold Mike's hand. He loved Harry Potter, so I would read aloud to him when we were at the facility together. And it allowed me to focus on our relationship in a way that I didn't have the bandwidth to do at home.

There were people out there to help me do all those daily tasks of caregiving. But there was one thing that no one else could do. I was the only person who could be Mike's wife.

I was able to care for my Dad at home for seven years. Today I'm so thankful to the staff in the memory care center where my dad now lives. Now he's able to develop new relationships and enjoy activities with his peers. Dad is still a big part of our lives. We have FaceTime calls and visits all the time. There is a richness that's been added to his life and I'm still a fully engaged caregiver.

SELF CARE IS CRITICAL

I talk a lot about the importance of self-care, even if it's just a few minutes to devote a little attention to yourself. Self-care was so easy to go by the wayside when I was a full-time caregiver. We know that caregiving can be a threat to your health because you may put off routine appointments or moments of rest. A moment of self-care for the caregiver can be critical to keep everything running for our whole family.

FACE THE UNKNOWN BY FOCUSING ON THE PRESENT

One of the things that life has taught me is that there are a lot of unknowns. For me, living life in the present and focusing on building new memories of joy with the people that I love helped to mitigate some of those future worries. Being empowered with the knowledge about what I could do to promote brain health for myself and my family was also helpful.

Some caregivers worry about whether or not these conditions will be inherited by other family members. Families should know that there are amazing genetic counselors who can talk with you about genetic risk and predispositions for developing Alzheimer's Disease or a related dementia. It's important that if you have concerns, you reach out and talk with an expert. Make an appointment with a genetic counselor that has expertise in your loved one's specific condition.

RESILIENCE: A CAREGIVER ORIGIN STORY

When I was learning how to be a caregiver, I read a lot, hoping to find a book that would help me connect with the emotional changes I was experiencing in my new role. Years into my journey, I came upon one book that spoke to me, *Supersurvivors: The Surprising Link Between Suffering and Success*, written by psychologists Lee Daniel Kravetz and David B. Feldman. This book is not even about caregiving, instead it

focuses on how individuals cope in the wake of trauma. Kravetz and Feldman acknowledge the impact of suffering after trauma and how it can change the trajectory of an individual's life forever. This resonated with me because I felt a deep sense of traumatic loss after my husband's diagnosis and the demise of our dreams for a shared future. I saw myself as someone healing from a great wound. My suffering and grief were real and present, but so was my resilience. I was not weaker because of my trauma. In fact, I felt a fiery drive to do something with the energy that grief had created inside me.

Suddenly, I had an origin story.

Think about the origin stories of superheroes. Superman's home planet is destroyed. Storm loses her family in the wake of war. Batman's parents are killed by a violent criminal. Their stories begin with trauma. The difficult experiences create a new set of skills and a new determination to move forward with purpose. Resilience is about making a choice to take the next step. It looks different for everyone. For some of us, making the decision to get out of bed and face the day is an act of resilience. For others, it may mean a new calling. What matters is that you make a choice to continue to live your life in a way that brings you what you need.

I have met many resilient caregivers along my journey over the past decade. One common thread that I see amongst them is the ability to ask for help when they need it. We all need someone in our life who can tell us when it is time to take a break or accept support. Let others look out for you as you are looking out for your loved one. Taking breaks and practicing self-care can strengthen you for the important tasks of caregiving.

As you work to develop your advocacy skills in honor of your loved one, remember to use those same skills to advocate for yourself. Reach out and let people know about your circumstance so you can get support. Feel comfortable with

letting people know what you're going through and allow yourself to ask for that support in whatever way feels good to you. Reach out to a mental health professional for therapy. Seek out a support group that's the right fit for you. And, sometimes it's not about connecting with a whole group of people but meeting that one special person who you feel a kindred spirit with.

Even during COVID-19, there are many different ways to connect with others. The opportunities are robust, with virtual support groups, educational events and even Memory Cafes. Community isn't cancelled. You don't have to go it alone; you can bring a friend with you or make a new one along the way.

Remember, even Batman had Robin.

Learn more about Katie and her work, as well as resources for FTD support at loveisouthereftd.org.

See page 14 for a list of additional resources for online caregiver support and connection.



Katie continues to be a caregiver for her dad while he lives in a memory care assisted living program.

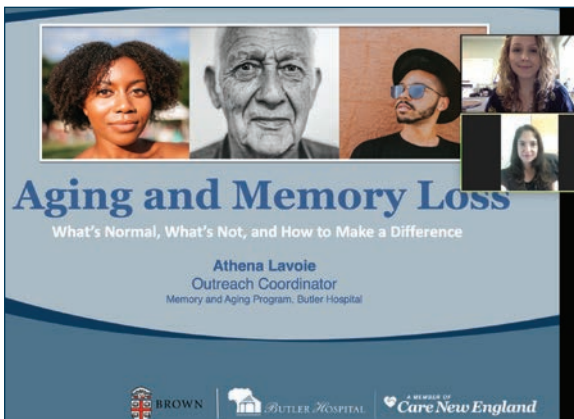
IN THE COMMUNITY



Memory Sunday Shines a Light on Disparities in Alzheimer's Incidence and Research for African Americans

Memory Sunday is observed annually on the second Sunday in June. Through communities of faith, the movement seeks to raise awareness and action about the disparate effect of Alzheimer's on the African American community. African Americans are twice as likely as whites to develop the disease, and yet they are under-represented in research studies. The Memory and Aging Program was grateful to partner with Berea Boston for this

year's celebration, which was hosted virtually, live on Facebook. To learn more about this movement and what you can do to help, visit balmingilead.org.



Memory and Aging Program Now Offering Virtual Alzheimer's Education Presentations

The Memory and Aging Program Outreach Team is offering virtual presentations for any organization that would like to help educate their members about Alzheimer's disease. During the presentation participants will learn:

- What is healthy aging and what is not;
- The difference between Alzheimer's and dementia;
- Recent advances in imaging and research, as well as local research opportunities for those with normal memory or slight cognitive decline;
- Tips that everyone can use to keep their brain healthy and engaged

To find out more and book a presentation, e-mail Outreach Coordinator Athena Lavoie at atlavoie@butler.org or call (401) 455-6402.

THANK YOU

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

Berea Boston
The King's Cathedral

Progreso Latino
Rotary Club of Fall River

RESOURCES

Prompted by Pandemic, Virtual Resources Grow

The COVID-19 pandemic presented unique challenges for individuals with Alzheimer's disease and other dementias, as well as for their caregivers. Fortunately, the Alzheimer's community rose to the challenge.

The result is that there are now more online and virtual resources available than ever for those affected by Alzheimer's and for seniors in general, providing critical at-home support and assistance for a wide variety of needs:

Alzheimer's Association

Rhode Island: alz.org/ri

Massachusetts/New Hampshire: alz.org/manh

The Alzheimer's Association has greatly increased the availability of its already robust offering of online resources. In addition to free online educational webinars, local support groups are also now available to join virtually, either by computer, smartphone or regular telephone. Many educational presentations are also available in Spanish and there are new webinars specific to COVID-19 as well.

Rhode Island Office of Healthy Aging

oha.ri.gov/resources/helpful-links

Here you can find a host of resources and supports, from coronavirus-related tips and resources just for seniors, to help for those who've lost health coverage or need assistance with housing, food, transportation and many other needs.



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

Volunteer Profile

CAITLIN MCMANUS



Family history, compassion, a sense of moral obligation and an intense interest in the workings of the brain...

These are the things that drove Caitlin McManus to intern at the Memory and Aging Program at Butler Hospital at the end of her senior year at Rhode Island College this past semester.

Thanks in part to that internship, the recent college grad now knows exactly what will come next for her: graduate studies in Psychology and a PhD in Neuropsychology in preparation for a career researching Alzheimer's disease and dementia.

"Ever since I started at RIC in Psychology I've had it in the back of my mind that this is what I want to do," McManus says.

"I have a family history of Alzheimer's disease on my father's side and a long line of family members who've had the disease. So I've seen first-hand how devastating the effects of it can be, not only on the patient but on family members as well. It's made me feel a moral obligation to help fight this disease and it has given me a sense of purpose to help however I can."

So when McManus had the opportunity to do an internship, she says the Memory and Aging Program was her first choice.

"I'd been keeping an eye on what the Memory and Aging Program was doing for a while, just out of interest and thought an internship would

be the perfect opportunity to get involved. It was the first place I reached out to. I kind of went all in on it and was lucky enough to hear back right away.”

McManus began her Internship in January, working about 10 hours per week at the program. She spent much of her time assisting in the program’s outreach office and working with Butler’s Alzheimer’s Prevention Registry, a database of people who’ve indicated they’re interested in participating in research studies.

“I would reach out by email or phone to trial participants and potential participants to answer any questions and help them to enroll in the registry if they needed assistance,” McManus says. “I also did a lot of shadowing of the research staff, observing of cognitive testing and learning about the tools involved. I really wanted to be available to anyone who needed help, so I did a lot of everything, really.”

McManus says her internship was cut short due to the outbreak of COVID-19, but in the time that she spent at the program she says the thing that struck her most was how immediately welcoming the entire team was, to both her and to study participants and their families.

“They all made it so easy for me to just settle in and feel comfortable. It was just so clear that they wanted me to get as much as possible out of the experience. I couldn’t have asked for more support. Even though it was such a short

amount of time, I really did get an immense amount of knowledge out of it; things I couldn’t have learned in a classroom,” McManus says.

“For a lot of people who have a family member who may be suffering from memory loss, it’s very easy to feel isolated and alone with that. It’s so important to know that there are all these people at the Memory and Aging Program, an entire team who understand those feelings,” she continued.

“They understand the experience and are more than willing to have a personal touch. They treat everybody as an individual. You’re not just a patient there, you’re a person who has individual thoughts and emotions about this and you’re not going to be alone, no matter what.”

McManus says she looks forward to returning to the program as a volunteer as soon as COVID-19 restrictions are lifted. She’ll begin her graduate studies in Psychology at RIC next year and looks forward to joining the fight against Alzheimer’s as a neuroscientist someday – maybe even at the Memory and Aging Program.

“I can absolutely see myself working there one day and would love to apply someday to be a research assistant,” she says. “But regardless, I’ll volunteer there as long as they’ll have me.”

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.

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