

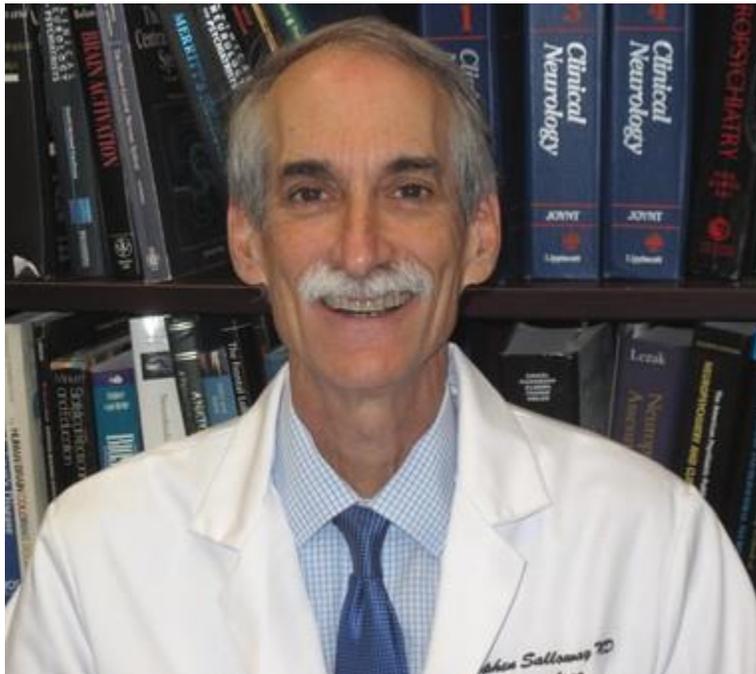
PROVIDENCE BUSINESS NEWS

# PBN

## Five Questions With: Dr. Stephen Salloway

By Nancy Kirsch

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Dr. Stephen Salloway seeks to enroll individuals between the ages of 50 and 85 with normal memory, mild memory loss or mild dementia for a major Alzheimer's research initiative at Butler Hospital. COURTESY DENISE JERUE/BUTLER HOSPITAL

*Dr. Stephen Salloway, the director of neurology and the Memory and Aging Program at Butler Hospital, is also a professor of neurology and psychiatry at The Warren Alpert Medical School of Brown University. Salloway talked with Providence Business News about a global registry of candidates for clinical trials for Alzheimer's research and Butler's role in that initiative.*

**PBN: Explain this partnership between Global Alzheimer's Platform Foundation and the Brain Health Registry to create a global registry of potential candidates for clinical trials for Alzheimer's research? Why was Providence among the venues chosen?**

**SALLOWAY:** The Global Alzheimer's Platform is a network of high-performing Alzheimer's disease centers designed to accelerate drug development for AD. The Brain Health Registry, under the direction of Michael Weiner, M.D., a leading AD researcher at the University of California Medical School, provides an opportunity for individuals 18 and older to take cognitive tests and to indicate their willingness to be contacted for prevention trials. GAP and BHR are collaborating to increase referrals to prevention trials.

As a nationally recognized AD center, the Butler Hospital Memory and Aging Program was selected as one of the original 10 GAP sites. Our program received an initial \$100,000 block grant to enhance site capability and performance. This includes hiring an outreach coordinator to work closely with community organizations, health care providers and local media to facilitate recruitment. We are also investing in technology to expand our current local registry, website and project management software. This will facilitate our partnership with national registries, like the BHR, to recruit potential candidates for prevention studies.

The Butler Hospital Memory and Aging Program was also selected as one of two test sites, along with the Cleveland Clinic, to pilot this new partnership between GAP and BHR. The Butler program was selected because of its strong national reputation and close affiliation with The Warren Alpert Medical School at Brown University.

**PBN: Who do you seek to enroll in the registry, and must they have demonstrated some memory impairment to be eligible to enroll?**

**SALLOWAY:** With advances in brain imaging and genetic testing, the AD research field has increased the emphasis on prevention and early intervention for those at risk. We are enrolling individuals, between the ages of 50 and 85, with normal memory, mild memory loss or mild dementia. Contact [www.brainhealthregistry.org](http://www.brainhealthregistry.org) or the Butler Hospital Memory and Aging Program at (401) 455-6403 or [www.butler.org/memory](http://www.butler.org/memory).

**PBN: How have you begun identifying and enrolling candidates for clinical trials, what are the obstacles to doing so, and are privacy concerns a particular issue?**

**SALLOWAY:** The Butler Hospital Memory and Aging Program has been conducting medication trials for AD for more than 20 years. Up until now, people with memory concerns have contacted us for evaluation and treatment and we discuss the option for medication trials to slow memory loss with those who are eligible. Now, we can identify people at risk years before memory loss, which opens the door for prevention trials with a number of promising medications. This requires that we engage the public in new ways, such as through the BHR, to determine who is at risk.

The main obstacles to participation are lack of awareness of the study options available and stigma and fear regarding AD. Protecting volunteers' privacy and confidentiality of health information is a priority. We work with our local institutional review boards to ensure there is ample protection of the volunteers and their health information. We also work with our information system department and outside consultants to identify the latest technology to ensure data security.

**PBN: Are you collaborating with any other entities to enroll individuals in the registry, and can you describe the scope of those collaborations?**

**SALLOWAY:** We are also collaborating with the Alzheimer's Prevention Registry run by Banner Health in Phoenix, Ariz. The APR has already registered more than 200,000 people and provides regular research updates about AD, at [www.endalznw.org](http://www.endalznw.org). It has also started the Gene Match program to help identify people at increased genetic risk of AD and refer them to studies, at [www.endalznw.org/genematch](http://www.endalznw.org/genematch).

People can now be sent a kit to “swab for AD.” Those at highest risk may be eligible for a prevention trial of an amyloid vaccine or a pill to lower amyloid to prevent memory loss.

Our collaboration with BHR and APR has several layers. BHR and APR will, on our behalf, send recruitment emails to potential candidates. Those individuals can either contact us directly or consent to have their contact information sent to us.

**PBN: How will enrolling more members in the registry further or promote Alzheimer’s research?**

**SALLOWAY:** It is critical to put the treatment of AD on par with other major diseases. This will require broad public engagement to increase awareness and overcome fear and stigma. It will also require an investment in research from new public-private partnerships. For example, a \$25 million proposal is under review at the National Institutes of Health to create a GAP registry for prevention trials, to be matched with more than \$25 million from private funders.

Prevention and early intervention trials are different from traditional clinical trials. The participants are at risk (for the disease being studied), but are currently asymptomatic. We cannot expect such individuals, without active symptoms, to show up at a memory clinic or doctor’s office. As such, we will need to reach out to them via community outreach, news stories, the Internet and other social media.

The AD research field is on the cusp of a breakthrough, similar to where cancer research was 15 to 20 years ago. Enrolling a large number of volunteers is critical for progress. I have been impressed by the altruism, generosity and courage of our participants. They are truly pioneers and want to shield their children and grandchildren from this dreadful disease.

For more information about enrolling in the registry, contact the Butler Hospital Alzheimer’s Prevention Registry at (401) 455-6403 or [www.butler.org/memory](http://www.butler.org/memory).

<http://www.pbn.com/Five-Questions-With-Dr-Stephen-Salloway,112744>