



Brain Health and Memory Center Newsletter

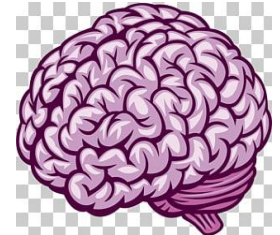
Welcome to the Brain Health and Memory Center's Summer 2019 Newsletter

There's lots to tell you about since our last edition, including a review of the Town Hall event we announced last year, some new research studies, and information about how to become involved in future studies.

A Brain Health Town Hall



On May 1, 2019 the Brain Health and Memory Center (BHMC) hosted about 75 people at Case Western Reserve University's Veale University Center for a special gathering. No progress would be made toward treating or preventing Alzheimer's disease and other dementias without the



generous volunteers who sign up for drug studies, observational studies, and research registries. Our Town Hall event was set up as a thank-you to those who have recently participated in some of our clinical research studies, and to encourage the wider community to learn about clinical research studies they may be eligible for. The event began with presentations by Alan Lerner, MD, BHMC director, and by Lin Mei, MD PhD, a CWRU research scientist and director of the Cleveland Brain Health Initiative who directs brain health research at the cellular level. A highlight of the morning's session was learning about the experiences of couples who participated in two of our studies. They talked about their experiences as study participants, what prompted them to sign up for a study, and what their participation has meant to them, which encouraged many interesting questions from the audience. *Continued on page 2*

What is a research registry and is it right for you?

Not everything we do here at the Brain Health and Memory Center involves testing new medications, and not everyone who contacts us to learn about our research is a good fit for every study we have. A research registry may be right for people who don't fit any of our current studies but want to stay in the loop to learn about other studies that we may be running. Research registries use observational methods, not treatment interventions, and may keep track of participants for several years. Like all of our research, participation in a registry is voluntary and participants can withdraw at any time.

Some research registries can keep you informed about upcoming studies, and the registry allows us to contact you when a study comes along that you might be eligible for. Participating in this kind of registry might include a blood draw and completing tests of memory and *Continued on page 2*

Our First Brain Health Town Hall Event

Continued from page 1 Following that was a question-and-answer discussion by our team of dedicated research coordinators and nurses, who described current studies and answered questions from the audience about what's involved in joining a clinical research project. We received support for this event from the Alzheimer's Disease Neuroimaging Initiative (ADNI) and from the Global Alzheimer's Platform Foundation (GAP). GAP representatives were on hand to present Citizen Scientist Awards to some of our research participants. These awards celebrated the winners' participation in research studies, their support of local research, and their encouragement for others to join in clinical research. Our participants are now eligible for GAP's Citizen Scientist Award at the national level.



Brain Health and Memory Center research volunteers at Town Hall on May 1st receive Citizen Scientist Awards from the Global Alzheimer's Platform Foundation. Photo by Susie Sami.

We are already looking forward to next year's Town Hall when we will build on what was successful this year which was: thanking our participants, educating everyone about clinical research, and promoting brain health research.

About research registries

Continued from page 1 thinking ability. Signing up for this kind of registry does not mean you ever have to enroll in a clinical drug trial, it just means we can contact you about a study that you might be interested in.

Another type of registry is for long term follow up of those who enroll. This kind of registry uses repeat visits to follow participants' memory- and thinking-related abilities over several years or longer. Participants return to the research office annually for review of symptoms, to provide blood samples or other specimens, and for tests of memory and thinking. People with memory concerns, a family history of dementia, and those diagnosed with mild cognitive impairment (MCI) or dementia are often good candidates for this kind of research registry. People without those symptoms may be able to sign up as well, since some registries enroll people who have no family history or memory symptoms as cognitively normal controls. Participation in these registries may include the opportunity to learn about research studies that are testing new drugs or interventions.

The BHMC currently has registries that are enrolling new participants. If you would like to learn about our registries please contact Fran Lissemore at fran.lissemore@uhhospitals.org or (216)464-6203.

Programs for Caregivers

The Savvy Caregiver

Are you providing care at home for a family member with dementia or a serious memory problem? We invite you to attend a structured educational workshop designed to help you develop knowledge and skills related to caregiving, and learn how to best help your loved one. There is no cost to participate, and the 6 part workshop is offered five times a year. If you are interested please contact Marianne Sanders, the workshop facilitator, at (216)464-6462 or Marianne.Sanders@uhhospitals.org.

Care Partner Respite Project

The Brain Health and Memory Center offers a program supported by a generous donor that provides no-cost respite care services in the home for overwhelmed family care partners. A UH Registered Nurse will work with you to set up a care plan, assign the appropriate service and schedule visits with a UH home health aide to fit your needs. The respite visits have a 2-hour minimum, with a maximum of 24 hours. For more information please contact Marianne Sanders at (216)464-6462 or Marianne.Sanders@uhhospitals.org.

Resources for Cognitively Normal People

Acti-v8 Your Brain is a research-based brain health initiative from the [Global Alzheimer's Platform Foundation](#) centered around eight pillars of brain health. This program provides information to help keep your brain healthier longer. Visit activ8yourbrain.org to learn more.

apt webstudy

If you are age 50 or over and interested in Alzheimer's prevention research, then you may want to learn more about the **APT Webstudy**. It is an online memory and thinking observational study supporting enrollment in Alzheimer's clinical trials. Participants will have their memory assessed 4 times per year, and will be tracked over time. If it is found you are at an increased risk for developing Alzheimer's you may be invited for an in-person evaluation that may include additional memory tests, brain scans, and blood tests. If eligible you will have the opportunity to enroll in a clinical trial aimed at preventing the cognitive decline associated with Alzheimer's. There is no cost to join, and everything is done online. Click [HERE](#) to learn more about the APT Webstudy.



Research Studies for People Who Are Cognitively Impaired

Cholesterol and Dementia- The Efavirenz Study

High levels of cholesterol in the brain are associated with a higher risk of developing Alzheimer's disease (AD). Research with animals has shown that the FDA-approved drug Efavirenz (EFV) causes beneficial changes in brain cholesterol. Our EFV study will see if similar changes in brain cholesterol occur in people with mild cognitive impairment (MCI) or dementia due to Alzheimer's Disease treated with EFV compared to a placebo. EFV is already used to treat other diseases but because it has not been approved to treat dementia, it is considered an experimental drug in this study. This study will also help us to confirm the safety and tolerability of EFV in people with dementia or MCI. People between 55-85 years old who have been diagnosed with AD or MCI who are not on a statin such as Lipitor or Crestor are eligible for this study, which involves taking a capsule once a day and an in-office visit where study related tests will be administered. If you are interested please contact Maria Gross at (216)464-6454 or Maria.Gross@uhhospitals.org.



T2 Protect AD is a clinical trial testing the investigational drug Troriluzole in people with mild to moderate Alzheimer's disease. The study is designed to determine whether this new drug can protect against, slow down, or potentially improve memory and thinking problems that increase as Alzheimer's disease progresses. The study is one year long and it is now enrolling people diagnosed with mild to moderate Alzheimer's disease between the ages of 50 and 85. Those eligible for this study will have been taking a medication for memory loss for at least 3 months and will have a study partner who can participate with them. If you are interested, please contact Parianne Fatica at Parianne.Fatica@uhhospitals.org or (216)464-6474. Go to www.T2protect.org to learn more about the study.



Alzheimer's Disease Neuroimaging Initiative continues long term study of AD
ADNI-3, continuing the ADNI-2 study, is recruiting new participants. The 5 year study looks at connections among clinical symptoms, cognitive ability, medical imaging, and genetics over time to understand Alzheimer's disease from its earliest stages. Participants may take cognitive tests, give blood and/or cerebrospinal fluid, and may have magnetic resonance imaging (MRI) and positron emission tomography (PET) scans. The study is recruiting people 55-90 years old who have been diagnosed with Alzheimer's disease or mild cognitive impairment (MCI). If you are interested and have a study partner, please contact Parianne Fatica at Parianne.Fatica@uhhospitals.org, or (216)464-6474. Go to www.adni3.org to learn more about the study.

GRADUATE II

The **GRADUATE II** study tests how safe and effective an investigational drug is slowing the progression of early or mild Alzheimer's disease. The study is about 3 years long. To qualify, participants must have mild Alzheimer's disease or memory problems that may be the early symptoms of the conditions. Additionally, participants must be 50 to 90 years old and have someone they see frequently who can be their study partner. If you would like to learn more about GRADUATE II please contact Susie Sami at (216)464-6467 or Susie.Sami@uhhospitals.org or visit GRADUATE-study.com for more information.

ADMET 2 Study Investigates Apathy in Dementia

Does your loved one seem disengaged or detached? The **ADMET 2** study tests an existing drug, called methylphenidate, for its effectiveness in treating apathy in dementia. Also known as Ritalin, the drug is currently used to treat people with Attention Deficit Hyperactivity Disorder. In the ADMET 2 study, we are testing to see whether it can improve apathy in patients with dementia, and whether it makes caring for people with apathy easier. Apathy is a lack of interest or concern for things that most people find moving or exciting. Participation includes six clinic visits and three phone calls in a six-month period after a baseline visit. ADMET 2 requires the participation of a study partner. If you would like to learn more about ADMET 2 please contact Susie Sami at (216)464-6467 or Susie.Sami@uhhospitals.org. Visit www.ADMET.com for more information.

Cleveland Alzheimer's Disease Research Center

In July the major medical research institutions in Cleveland received a special designation- a National Institutes of Health *Alzheimer's Disease Research Center*. This \$4+ million grant award is a collaboration among University Hospitals, Cleveland Clinic, Louis Stokes VA Medical Center, the Metro Health System, and Case Western Reserve University to coordinate research to better understand Alzheimer's disease and develop better ways to diagnose it, and support scientists looking for potential treatments. Community outreach and engagement is an important part of this effort as well. Contact the center at CADRC@case.edu or (833)311-ADRC (2372). Read more about it [here](#).



The Brain Health and Memory Center invites you to join our

co-workers, friends, and family in the fight to end Alzheimer's. You can register to walk with our team on **Sunday October 6, 2019** at the Cleveland Metroparks Zoo, or make a donation to our team [HERE](#). Check out these pictures of our group from last year's walk!



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