

Dear IDEAS Study participant,

Thank you for taking part in the IDEAS (Imaging Dementia—Evidence For Amyloid Scanning) Study. Through this study, scientists hope to learn how amyloid PET images of the brain may help your doctor better treat you and others living with dementia.

When you enrolled in the IDEAS Study, you indicated interest in additional research studies. Below are brief descriptions of three IDEAS Add-On Studies, approved by the IDEAS Study team, for which you may qualify. Unlike the IDEAS Study, these are not covered through Medicare; however, there is no cost for participation. Some may even provide modest compensation. You can take part in as many of these studies as you'd like, even if you're already participating in another clinical trial or research study.

We hope you will consider participating in these important studies to help scientists expand their understanding of the aging brain and provide insight for potential dementia treatments. One of my Alzheimer's Association® colleagues will contact you soon with more information about these studies.



Sincerely,

Maria C. Caville

Maria Carrillo, Ph.D. Chief Science Officer, Alzheimer's Association Chair, IDEAS Study Steering Committee

## **WE'LL BE IN TOUCH.**

An Alzheimer's Association staff member will contact you with more information regarding the following IDEAS Add-On Studies. If you have immediate questions, please call the IDEAS Add-On Study information line at 888.270.7606.



The goal of the Amyloid Neuroimaging and Genetics Initiative (ANGI) Study is to pair the clinical information and brain imaging data collected in the IDEAS study, or other related studies, with DNA obtained from a saliva sample. DNA is the hereditary material in our body made up of a series of genes that determines traits such as eye and hair color and other more complex physical characteristics. The information and DNA samples collected as part of the

ANGI Study will be used to help scientists identify genetic factors contributing to cognitive impairment, dementia and other disorders.

All participation in ANGI is done by phone and mail, or online. Subjects who express interest in ANGI will be asked to read and sign an informed consent form, share their contact and demographic information and provide a saliva sample. The saliva kit will be mailed to the National Cell Repository for Alzheimer's Disease at Indiana University, where DNA will be extracted from the saliva sample and stored for future research use.

ANGI presents a unique and extraordinary scientific opportunity for new discoveries related to brain imaging, clinical information and genetic findings that can have a major impact on dementia care. Scientists hope the research made possible by ANGI will ultimately lead to the development of new therapies that will slow or prevent cognitive impairment and dementia.





The Brain Health Registry is a free online study that collects information about participants' memory, health and lifestyle in order to improve scientists' understanding of brain aging and help speed the discovery of treatments for Alzheimer's and other brain diseases. After enrolling, you will have a chance to

learn how to participate in other research studies, including clinical trials.

Brain Health Registry researchers will connect your online data with information collected in the IDEAS Study to further their understanding of brain health. Care partners are also encouraged to enroll. Their participation can help scientists learn more about the caregiving experience and how it affects their health.

For most people, participation in the Brain Health Registry online study requires less than three hours per year. Follow these easy steps to join:

- 1. Sign up: Register at brainhealthregistry.com.
- 2. Tell us about yourself: Answer guestions about your health and lifestyle.
- 3. Take brain tests: We use short tests, similar to games, to assess your memory, attention and thinking abilities.
- 4. Invite a study partner: Your care partner, or someone else who knows you well, will have a chance to enroll and answer questions about themselves and you.
- 5. Come back again and again: Every six months, you'll receive an email asking you to retake brain tests and answer follow-up questions. This will help researchers track changes in the brain over time.

If you are already a Brain Health Registry participant, a representative will contact you with directions to re-register, so we know you are also in the IDEAS Study. In the meantime, we hope you will continue to participate in the Brain Health Registry.



The CARE Study aims to give a voice to patients and their care partners (i.e., spouse, adult child or another individual involved in decision-making) by interviewing and documenting the experiences of 3,500 participant pairs. The study will help researchers understand how patients and care partners react to memory problems, as well as how they respond to the results of the amyloid PET scan tests taken during the IDEAS Study.

Participation in the CARE Study is voluntary. If you are eligible to participate and choose to enroll, a trained interviewer will call you to conduct a 30- to 40-minute telephone interview, inquiring about your experiences with doctors, your health care preferences, and your understanding of your diagnosis and treatment options. Your care partner will also be invited to participate in a separate but similar telephone interview. Documenting both perspectives will help us understand your experiences. You and your care partner will each receive \$20 upon completing the CARE Study telephone interviews.

The CARE Study research team will link your information from the IDEAS Study, including your amyloid PET scan results and Medicare utilization, to help expand scientific discoveries.