



THE BRAINS BEHIND SAVING YOURS:

CONTACTS

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IDEAS Study Spurs Related Research to Impact Dementia Care

-Coordinated studies will become a powerful tool for the Alzheimer's research community-

Washington, DC and Chicago, June 8, 2017 — The milestone <u>Imaging Dementia – Evidence for Amyloid Scanning (IDEAS) Study</u> is working with government and academic researchers to launch three add-on studies to expand the impact of the core study where more than 18,000 people with cognitive decline but an unclear diagnosis will receive an amyloid PET scan.

Participants in the \$100 million IDEAS Study may elect to participate in one or all of the related research studies, which are designed to expand the understanding of the aging brain and provide insight for potential dementia treatments. Similar to the groundbreaking Alzheimer's Disease Neuroimaging Initiative (ADNI), IDEAS and its add-on studies will create a massive database of information and samples that scientists worldwide can access and analyze.

The three add-on studies are:

Amyloid Neuroimaging and Genetics Initiative (ANGI) Study will correlate the clinical information and brain imaging data collected in the IDEAS study with genetic information obtained from more than 3,000 study participants. The goal is to identify genetic factors that contribute to cognitive impairment, dementia and other disorders. Previous research has identified more than 20 genes associated with risk for, or protection against, Alzheimer's. However, the role of these genes in amyloid deposition has not been well-studied. ANGI represents an unprecedented opportunity to gain greater insights into the role of genetics in Alzheimer's and other dementias. This study is funded by the Alzheimer's Association.

The **Brain Health Registry** (**BHR**) is an online registry and database for recruiting, screening, and monitoring progression of brain diseases. BHR will collect health, lifestyle and cognitive data from IDEAS participants, which will be correlated with the amyloid PET results from the IDEAS Study. Participants can also invite a caregiver or study partner to join; they can work together as a team to advance brain health research. IDEAS participants can learn more about the brain through newsletters and online resources, and can find out about upcoming opportunities to participate in clinical trials and other research studies. The goals are to improve scientists' understanding of brain aging, learn more about safe ways to use the Internet for brain health screening, and help speed the discovery of treatments for Alzheimer's and other brain diseases. This study is funded by the Alzheimer's Association.

Caregivers' Reactions and Experience: Imaging Dementia - Evidence for Amyloid Scanning (CARE) Study represents a unique opportunity to integrate clinical science with data on how patients and caregivers make decisions about, and cope with, the onset and progression of Alzheimer's. This project will recruit and survey 3,500 pairs of IDEAS Study participants and their care partners, linking PET scan, clinical report and comprehensive Medicare claims data to survey responses. The goal of the CARE Study will be to estimate the effect of amyloid PET results on how people with Alzheimer's and care partners plan for the future, including advance care planning and future health care utilization. In addition, the study will investigate the impact of the amyloid PET scan results on the care partner, including burden, depression and their own health care utilization This study is funded by the U.S. National Institute on Aging.

"We're very excited by the creation and linking of these important research initiatives," said James Hendrix, PhD, Alzheimer's Association Director of Global Science Initiatives. "IDEAS is already a landmark research study, especially for clinicians and imagers. Through these three add-on studies, it now has the potential to become a powerful research tool for the entire Alzheimer's and dementia research community."

"Together, the IDEAS Study and the three add-ons have the potential to be the largest, most impactful set of coordinated studies on Alzheimer's disease and other dementias," Hendrix said. "There is an enormous investment in the IDEAS Study from the public, private, and philanthropic communities. Through launching the add-on studies, and linking them all together, we're leveraging the huge IDEAS Study population to answer even more questions about Alzheimer's disease, other dementias, their genetic origins and impact."

The related trials are not covered under Medicare, as is the IDEAS Study, but are free to participants. Some may provide modest compensation. The Alzheimer's Association is leading the effort to contact interested participants; participating physicians are not required to aid in recruitment for the add-on studies.

IDEAS Study – Passing the Half-Way Point

After one year, IDEAS has registered nearly half of its expected 18,488 patient enrollees across 824 study sites. This four-year research effort will determine whether a brain positron emission tomography (PET) scan that detects amyloid plaques, a core feature of Alzheimer's disease, can improve clinical decision-making and patient outcomes for Medicare beneficiaries. Before brain amyloid PET scans, amyloid plaques could be seen only during autopsies, making it much harder to give living patients a definitive diagnosis.

"We are imaging the brains of living people, many of whom have Alzheimer's disease, to determine whether they have one of the hallmarks of the disease, amyloid plaque, which in turn will aid in our diagnosis. Doctors and families may make different decisions with a more precise diagnosis," said Gil D. Rabinovici, MD, of UC San Francisco, who is the IDEAS Study chair. "This will be especially important for people with an unclear Alzheimer's diagnosis. In many cases, ruling out Alzheimer's can be as valuable as confirming it."

While the study is no longer accepting new dementia expert centers, additional physicians at enrolled practices may be added and new PET Centers are also still being accepted at this time.

Additional information may be found on the <u>IDEAS Study website</u>. Patients must be enrolled through a <u>dementia specialist</u> who is participating in IDEAS. The IDEAS Study is led by the <u>Alzheimer's Association</u> and managed

by the <u>American College of Radiology (ACR)</u> and the <u>American College of Radiology Imaging Network (ACRIN).</u>

About the Alzheimer's Association

The <u>Alzheimer's Association</u> is the leading voluntary health organization in Alzheimer's care, support and research. It is the largest nonprofit funder of Alzheimer's research. The Association's mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Its vision is a world without Alzheimer's. Visit alz.org or call 800.272.3900.

About the American College of Radiology

The American College of Radiology (ACR), founded in 1924, is a professional medical society dedicated to serving patients and society by empowering radiology professionals to advance the practice, science and professions of radiological care.

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