Program Will Boost Enrollment in Alzheimer's Prevention Trials

Fran Lowry | December 09, 2015

GeneMatch, a program designed to identify volunteers willing to take part in Alzheimer's disease research on the basis of their apolipoprotein E ε4 (APOE-ε4) genetic status and other risk factors, has been launched by the Banner Alzheimer's Institute, Phoenix, Arizona.

The APOE-ε4 gene is considered to be the major genetic risk factor for late-onset (after age 60 years) Alzheimer's disease. Individuals with two copies of the ε4 allele are at particularly high risk.

The GeneMatch program will become a valuable resource for the field of Alzheimer's research by addressing a significant obstacle: the majority of Alzheimer's disease studies are delayed because of difficulty recruiting study participants, its founders say.

"GeneMatch, which has opened to nationwide enrollment, is a key part of the future of Alzheimer's prevention research because it has the potential to accelerate recruitment to aid in the discovery of treatments that may slow or prevent the progression of Alzheimer's disease," Eric M. Reiman, MD, executive director of the Banner Alzheimer's Institute, professor of psychiatry, University of Arizona, Phoenix, and director, Arizona Alzheimer's Consortium, said at a webcast press briefing held to announce the launch of the new program.

Many More Study Volunteers Needed

"A few years ago, we proposed an Alzheimer's Prevention Initiative to help launch new studies in Alzheimer's prevention research. We proposed the idea of conducting prevention trials in healthy people who, based on their genetic background and age, are at the highest imminent risk for developing Alzheimer's," Dr Reiman told Medscape Medical News.

To conduct such genetic tests, many thousands of individuals would be needed.

"We realized there would be many individuals, including a quarter to a third of the population, with one copy of the APOE-ε4 gene who could be potentially empowered by the opportunity to participate in other prevention trials, so the idea of providing a shared resource to encourage the field to rapidly evaluate the range of promising intervention therapies so that we could find one that worked as quickly as possible has been a long-standing dream," he said.

GeneMatch will enroll people aged 55 to 75 years living in the United States who are interested in participating in Alzheimer's-related studies and who have not been diagnosed with dementia or other cognitive impairment at the outset. The program intends to enroll tens of thousands of individuals.

In 2012, the Alzheimer's Prevention Registry, a web-based recruitment program, was formed to facilitate enrollment into research studies. The registry is a partnership of 12 groups, including the Alzheimer's Association TrialMatch, Banner Health, the Cleveland Clinic, the Mayo Clinic, and others.

"Many people are not aware that there are research studies for them to take part in," Jessica Langbaum, MD, principal scientist at the Banner Alzheimer's Institute and principal investigator for GeneMatch, told Medscape Medical News.

"When you are healthy, you don't think about joining a research study. You only tend to think about that when you are faced with a diagnosis. The registry was a way for us to educate and motivate the general public about the
prevention research studies that were coming down the pipeline, and also to give an opportunity for people who were ready and willing to let us know they were interested in participating in a particular research study," Dr Langbaum said.

To date, more than 180,000 people have joined the registry.

"GeneMatch is another mechanism for us to take the registry one step further and recruit people who want to be matched to research studies based on their genetic information," she said.

Becoming involved in GeneMatch is simple and straightforward, Dr Langbaum said. After reviewing information on the website (www.endALZnow.org/GeneMatch), which includes an instructional video, and consenting to join the program, individuals will be provided with a cheek swab kit, which they send back to the laboratory for APOE genetic testing.

The information is loaded into the GeneMatch program in a strictly confidential way, and individuals will be made aware of research studies for which they are a potential match.

GeneMatch does not store genetic samples, and strict privacy and security safeguards are in place, Dr Langbaum said.

"We don't disclose genetic information," she said. "This is not a free, direct-to-consumer genetic testing program. This is an opportunity for us to collect information on APOE, the best established genetic risk factor for Alzheimer's disease, at later ages and then use it as a way to match people to research studies. It's really going to help with recruitment."

Time to Move Forward

"The key point here is that the field of Alzheimer's disease has discovered enough about the natural history of the disease to identify certain genes and biological markers that can reasonably stratify groups of people into lower or higher risks of developing cognitive decline," Jason Karlawish, MD, from the Perelman School of Medicine, University of Pennsylvania, Philadelphia, told Medscape Medical News.

"That, together with the discovery of potential therapeutics, has readied the field to do clinical trials, to test the model of precision medicine for the brain," Dr Karlawish said.

"The GeneMatch program is a concrete operationalization of that model. The logic is to recruit people who are willing to be in research studies that will test potential therapies to see if they alter the natural history of the disease or not. We're still in the state of experiment here," he said.

Although GeneMatch will not disclose to participants any genetic information, the research trials that recruit GeneMatch participants may decide to do so, Dr Langbaum said.

"The study or studies that GeneMatch refers to may or may not disclose, but the participants in GeneMatch always have the choice to decide what's right for them," she said.

For Dr Reiman, learning about his genetic risk would be welcome.

"We still do not have ways to prevent Alzheimer's disease, but for some people, learning about their genetic risk can still be empowering," he said.

"Imagine you are in your 60s and you had two copies of the APOE-ε4 gene. In a sense, this is very sobering…"
information, but not certain for developing Alzheimer's disease. If it were me, I'd want to know about the opportunity to participate in prevention trials to see if I could in some way contribute to preventing the disease. This would represent a good opportunity to advance the field. Yes, it might be sobering to know, but I would still want the knowledge so that I could enroll in prevention trials."

_GeneMatch is funded by the Banner Alzheimer's Institute and the National Institutes of Health._

Medscape Medical News © 2015  WebMD, LLC

Send comments and news tips to news@medscape.net.

Cite this article: Program Will Boost Enrollment in Alzheimer's Prevention Trials. _Medscape_. Dec 09, 2015.

This website uses cookies to deliver its services as described in our Cookie Policy. By using this website, you agree to the use of cookies.

close