Test lets volunteers check Alzheimer's risk, join clinical trials

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People interested in helping test Alzheimer's drugs can volunteer and get their cognitive abilities monitored on a new website run by Alzheimer's researchers.

The website, www.aptwebstudy.org , is run by a team including San Diego's Alzheimer's Therapeutic Research Institute.

Those 50 and older are invited to sign up for the screening, said Alzheimer's researcher Dr. Paul Aisen. He directs ATRI, part of the University of Southern California. ATRI, Harvard Medical School and the Cleveland Clinic are collaborating on the initiative.

Called the Alzheimer's Prevention Trials Webstudy, the program is designed to recruit people for clinical trials, Aisen said. It's funded by a $24.7 million grant from the National Institutes of Health and supported by the Global Alzheimer's Platform Foundation.

The program is designed to identify apparently normal people at higher risk for Alzheimer's, which causes problems with memory, thinking and behavior. These people can then be given experimental therapies before major deterioration sets in.

Its purpose is to provide a large pool of ready volunteers who can quickly be enrolled in any Alzheimer's trial they qualify for, Aisen said. That will speed up the launch of new trials, and hopefully result in faster answers about whether new Alzheimer's therapies work.

Those who sign up will fill out a brief questionnaire about their assessment of their cognitive abilities, and then take a 20-minute test to assess those abilities, Aisen said. The test will be repeated over time to look for early signs of deterioration. Participants are asked to repeat it once every three months. They will receive reminders by email.

No exact number has been set, but Aisen said he hopes to get "tens of thousands" of volunteers signed up.

Alzheimer's disease is the sixth-leading cause of death in the United States. It's unique among major killers because there is no approved treatment to prevent the disease or even slow its progression. Existing approved drugs temporarily slow down the deterioration, but don't affect its underlying causes, which are complex and not fully understood.

About 6 million Americans have Alzheimer's or mild cognitive impairment, which can lead to Alzheimer's, according to the National Institutes of Health. If current trends continue, that number is projected to reach 15 million by 2060.

Alzheimer's is the largest single cause of dementia in older adults. A toxic protein called beta amyloid is involved in the disease, with another protein, called tau.

While there's still a need for more basic research into how Alzheimer's starts and develops, understanding of the disease has increased greatly over the last several years, Aisen said. That has led to a profusion of clinical trials for various drugs, including nasally inhaled insulin, nicotine patches and other drugs specifically developed for Alzheimer's. That means more participants are needed.

There's no geographic restriction on applying, but those taking part in clinical trials must be willing to travel to one of 35 sites in the United

States where they can be tested in person. More sites may be added later.

In-person testing will involve either a brain scan or a spinal tap to look for beta amyloid, he said. That will only be done for participants whose tests indicate they might benefit from a clinical trial. This makes the testing more efficient, and reduces expenses.

"If we see that your scores are steadily declining, even though you have absolutely no symptoms, that tells us a lot about the risk of there being amyloid in your brain," he said.

Those chosen will be given another consent form, which will explain the study's purpose, potential benefits and risks.

Participant information is confidential and protected, Aisen said. While the program needs to reach individuals through an email address, their identifying information is not given to anyone not working with the program. Participants can still take part in the program without volunteering for clinical trials. The online test data will be aggregated for research, but individual identities won't be revealed.

Moreover, if participants get cold feet after signing up, they can delete their information, Aisen said.

The program has been planned to last five years with current funding, he said. After that, the goal is to make the program self-supporting, by contracting directly with sponsors of clinical studies.

clinical-trials.html