



ALZHEIMER'S
PREVENTION
INITIATIVE

Alzheimer's Prevention Registry

Help Us End Alzheimer's Without Losing Another Generation

The time is now to join the fight against Alzheimer's. This devastating, debilitating and incurable disease affects more than 5.4 million Americans, with one new case diagnosed every 69 seconds. By 2030, that number could exceed 7.7 million.

But you can help us end Alzheimer's without losing another generation. Join the Alzheimer's Prevention Registry. Help us turn concern and fear into the energy and support needed to find treatments to slow, halt or even prevent this disease.

What is the Registry?

The Registry is a community of people interested in making an impact on Alzheimer's research to help stop the disease. It will provide regular updates on the latest scientific advances and news, as well as information on overall brain health. And to overcome one of the greatest obstacles to clinical research, the Registry will support enrollment into a variety of Alzheimer's prevention studies across the country.

Who is eligible for the Registry?

The Registry is open to anyone 18 and older.

How do I join the Registry?

Becoming a Registry member is quick and easy. Visit www.endalznow.org to sign up. You will be asked to provide basic contact and demographic information—name, date of birth and Zip code, for example—and answer a few yes/no questions about your experience with Alzheimer's.

Will I have to give personal health information?

The several questions specific to Alzheimer's will ask whether you have been diagnosed with mild cognitive impairment or dementia, whether you have a family history of Alzheimer's or dementia, and whether you

are caring for someone who suffers from the disease or dementia. Some questions are optional, allowing you to decide what information you want to share.

How will my personal information be protected?

Your information will not be shared without your explicit approval and will only be used to inform you of the most relevant Alzheimer's news and potentially to connect you to applicable prevention studies. Medical institutions and nonprofit organizations participating in the Registry, along with their partners, must agree to follow the strict federal regulations ensuring the privacy of personal health information.





What can I expect after I join?

After joining, you will have access to a personalized Registry homepage. You will periodically receive electronic newsletters with information about the latest news in Alzheimer's and prevention research, including results from clinical trials and updates on the disease. You also could learn about potential research study opportunities for which you or a loved one may be eligible.

On occasion, the Registry also will reach out to members through brief online surveys about Alzheimer's. These will take less than 10 minutes to complete and may be used to screen for potential participants in future research opportunities or to inform the design of future trials. Other surveys may be used to address relevant research topics, such as the prevalence of risk factors in the Registry community or members' attitudes toward genetic testing.

Will I be required to participate in research studies?

Individuals who enroll in the Registry are under no obligation to take part in prevention studies or other research trials. You may be notified of opportunities to learn more about pending research, but whether you pursue participation in any study is entirely up to you. Even if you express initial interest in a study, you are under no obligation to participate.

Can I withdraw from the Registry?

You can remove yourself from the Registry at any time.

Who runs the Registry?

Banner Alzheimer's Institute (BAI) created the Alzheimer's Prevention Registry as part of its mission to end Alzheimer's disease without losing another generation. The Phoenix-based nonprofit organization is part of Banner Health, one of the largest non-profit health care systems in the country.

BAI is helping to lead the fight against Alzheimer's through its cutting-edge studies in detection, treatment and prevention and through a comprehensive model of care that addresses both medical and non-medical needs of patients and their families. Two internationally known researchers, Eric M. Reiman, MD, Executive Director, and Pierre N. Tariot, MD, Director, head BAI's team of scientists, clinicians, psychologists, nurses, social workers and therapists.

How big is the Registry?

The Registry, which launched in 2012, intends to enroll as many as 250,000 people in this country.

How can I learn more?

To learn more about the Registry, visit us online at www.endALZnow.org/Registry. You also can follow us on Twitter at [@AlzRegistry](https://twitter.com/AlzRegistry) and "like" us on Facebook at facebook.com/endALZnow. We encourage you to spread the word to your friends and families as well. Together we can create a world without Alzheimer's!



Three-quarters of U.S. adults are interested in participating in general medical research studies, while more than half are interested in taking part in clinical trials.

2012 National Survey by Edge Research