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Joining the National ALS Registry offers the chance to participate in research and be counted.



Great News!

New password expiration options

Previously, passwords to the Registry would expire every 6 months – causing difficulty in accessing the Registry if the patient could no longer remember or find their password.

Now, patients can set their password intervals based on their preference to 6 months, 1 year, or indefinite. This applies to new or previously enrolled persons with ALS.

- The Registry collects anonymous demographic information, such as occupational history and residential history, of thousands of persons representing every state. These data are used by researchers to describe who gets ALS and the possible causes.
- Over 90,000 risk factor surveys have been completed by registered persons with ALS.

Funding research activities

The National ALS Registry is also funding research to explore potential causes of ALS. Findings from these studies will further ALS research and help prioritize future risk factor surveys.

- The Registry has funded 19 studies to date and funded two new studies in Fall 2020.
- The most recently funded studies include Serological profiling and Biomarkers.

Serological profiling of the human virome and ALS risk in a military population; Harvard University

This study will examine blood samples collected from healthy young U.S. armed forces service members, including persons who later developed ALS and persons who remained healthy. The purpose of the study is to determine whether past neurotropic viral infections acquired years before the onset of ALS are associated with an increased risk for ALS.

Pre-disease biomarkers of persistent organic pollutants, immune system, and ALS; Harvard University

This research study will measure the levels of persistent organic pollutants (POPs) in blood samples of persons with ALS that were collected years before the onset of ALS to learn if pre-ALS POPs levels are associated with the risk of developing ALS and survival of persons with ALS.

[Click here](#) for a more detailed description of all studies funded by the Registry.

October 19th marks the tenth anniversary of the National ALS Registry.

Learn more about the Registry's role in the fight against ALS, and how it's grown over the years: <https://www.atsdr.cdc.gov/features/alsregistryanniversary/index.html>.

The National ALS Registry Website has been redesigned, making it easier to navigate. Check it out at www.cdc.gov/als.

National ALS Biorepository

The National ALS Biorepository is part of the National ALS Registry. The Biorepository may help scientists better understand the cause(s) of ALS.

- Since December 2016, over 9,800 samples from the National ALS Biorepository have been distributed to 11 research teams. [Learn more](#)



Research Notification

Researchers are using the National ALS Registry to recruit patients for IRB-approved studies and clinical trials. This helps connect persons living with ALS and researchers as they seek the causes to this often-fatal disease. Learn more:

<https://www.cdc.gov/als/ALSRegistryResearchApplicationInfo.html>

- The Registry's Research Notification System was used by Amylyx Pharmaceuticals to recruit persons with ALS who are registered for participation in the clinical trial *Evaluation of the Safety, Tolerability, Efficacy and Activity of AMX0035, CENTAUR-ALS*. The results of this study were recently reported in the New England Journal of Medicine. The results indicate the experimental two drug treatment of Sodium phenylbutyrate–taurursodiol resulted in lower functional decline than placebo as measured by the ALSFRS-R score over a period of 24 weeks. Learn more <https://www.nejm.org/doi/full/10.1056/NEJMoa1916945>

Have any questions or feedback on our newsletter?

We invite you to reach out to us.

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