OVERVIEW FOR

The U.S. National ALS Registry

There are many unknowns about ALS. People living with ALS can help join the fight against ALS!

About the National ALS Registry

The National Amyotrophic Lateral Sclerosis (ALS) Registry empowers people living with ALS to share their journey.

Research today may lead to better understanding and potential treatments tomorrow. By signing up for the U.S. National ALS Registry and taking brief risk factor surveys, people living with ALS can help find answers.

How the Registry Works

Because there is so much that we don’t know, dedicated research is a priority. The U.S. National ALS Registry provides a pathway for greater knowledge.

The Centers for Disease Control and Prevention (CDC) Agency for Toxic Substances and Disease Registry (ATSDR) established the U.S. National ALS Registry in 2010 to collect and analyze data about people living with ALS.

Its purpose is to gather data to better understand ALS. The information is used to:

- Estimate how many new cases of ALS are diagnosed each year;
- Estimate how many people are living with ALS;
- Better understand who gets ALS;
- Better understand what factors affect the disease;
- Enhance research to find the cause(s) of ALS.

The Registry collects and analyzes existing data, as well as new data provided by people living with ALS who choose to participate. This is important because ALS is a non-notifiable disease in the U.S., so participants must choose to join.

Researchers use the data to look for changes in disease patterns over time. They try to determine common risk factors and identify them. It’s important to include as many people as possible to get the most accurate information. If you choose to register, you can help find answers to important questions about ALS.

The U.S. National ALS Registry also funds research to increase the efforts of learning about this disease. Since 2010, the Registry has funded over one dozen studies in the U.S. and internationally. The Registry works with some of the world’s leading research institutions, to study what may cause ALS such as heavy metals, pesticides, certain genetic traits, and cyanobacteria.

How You Can Help

Joining the Registry is one way you can fight back and help create a better future for people with ALS. There are several ways you can play a role in advancing research.

1

Join the Registry

This is the first step in unlocking more opportunities to join the fight against ALS.

HAVE QUESTIONS? NOT SURE IF YOU HAVE ENROLLED?

There are people who can help. You can ask a family member, caregiver, friend, or your local ALS chapter, office, or clinic. You can also contact the Registry at **877-442-9719** or email **als@cdc.gov**.

2

Support the fight by taking the risk factor surveys

The Registry offers the opportunity for people living with ALS to complete risk factor surveys. There are multiple different surveys asking about various aspects of participants' lives such as age, family history of neurological diseases, possible environmental exposures, your work history, and physical activity. This is a chance for you to share your story.

PRIVACY POLICY

The U.S. National ALS Registry will never share your personal data.
All information is free of any identifying factors.

On average, each survey will take about 5 minutes to complete, and you do not need to complete all the surveys at one time.

Why it's important:

- Your de-identified data provides crucial information for the Registry. As more ALS patients complete the surveys, there is more data our researchers are able to analyze. Every piece of data helps researchers better understand the disease and its possible risk factors.
- Researchers across the world can use these data for studies.

3

Help by donating specimens to the U.S. National ALS Biorepository

With your consent, you can also choose to donate biological specimens to the U.S. National ALS Biorepository. This facility collects and stores these samples for scientific study. Collection of the specimens (e.g., blood, saliva) is done in your own home. This service is free to patients.

Donating these specimens can provide scientists with key DNA and enable molecular analysis to discover markers for disease diagnosis or therapeutic target. Analysis of these types of specimens has already proven useful in studying ALS and other diseases.

4

Learn more about clinical trials and research studies, and if you can participate

You can choose to receive emails informing you about clinical trials and epidemiological studies that may interest you. You can start this when you first join the Registry or any time after.

Be Part of Something Bigger.

You can be a part of something bigger by joining the National ALS Registry. Learn more at **cdc.gov/als**.

CDC ATSDR