

# There are many **unknowns** about ALS. People living with ALS can help future generations.



The National Amyotrophic Lateral Sclerosis (ALS) Registry allows persons with ALS to fight back, help defeat ALS, and help future generations.

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

## The National ALS Registry

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

## About the Registry

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

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.

Researchers use the data to look for changes in disease patterns over time. They try to determine if there are 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 be counted, you can help find answers to important questions about ALS.

The 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.



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## Join the Registry

This is the first step in unlocking more opportunities to help.

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. Or you can contact the Registry at (800) 232-4636 or email [als@cdc.gov](mailto: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 17 different surveys, and they ask about things such as your 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.

On average, a 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 personal, private data provides crucial information for the Registry. As more people with ALS complete these surveys, the Registry has more data. Every piece of data helps researchers better understand the disease and its possible causes.
- ▶ Researchers across the world can use these data for studies.

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## Help by donating specimens to the National ALS Biorepository

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

Donating these specimens can provide scientists with key DNA and chemical exposure data, and the specimen can be matched with survey data to give researchers a more complete picture to study. Analysis of these types of specimens has already proven useful in studying ALS and other diseases.

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## 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.

## 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](https://cdc.gov/als).



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention  
Agency for Toxic Substances and Disease Registry