

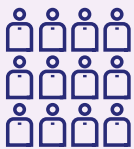
ALS - A Closer Look



Amyotrophic Lateral Sclerosis, or ALS, robs a person of their independence.

ALS attacks nerve cells in the brain and spinal cord, taking away a person's ability to move. Eventually, a person with ALS cannot move to speak, eat, or breathe. However, a person with ALS is aware of their surroundings as they can still see, touch, hear, taste, and smell.

The National ALS Registry is important to help find answers to ALS because in the United States:



It's estimated that about **30,000 people** are living with ALS. → This is prevalence.



Every **96 minutes** a person is diagnosed with ALS.

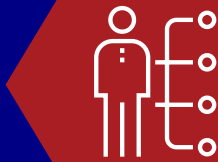


Each year, about **5,000-6,000 people** are diagnosed with ALS. → This is incidence.



A person can expect to live about **2-5 years** after an ALS diagnosis.

Currently, there is no known cause or cure for ALS.



What are Prevalence and Incidence?

→ Prevalence

The number or proportion of living cases in a specific population at a given time.

→ Incidence

The number of new patients with the disease during a prescribed period of time.

Turn the page to learn about the Registry's efforts to find answers.

Visit cdc.gov/als/dashboard for current information.

Last Reviewed: June 2024



Finding Answers to ALS Questions

ALS has no known causes, but the National ALS Registry is working to better understand the disease and its potential risk factors.

How is the Registry working to find answers?

Enrollment and risk factor surveys:

People living with ALS provide crucial information to the Registry by enrolling and completing risk factor surveys. When more surveys are completed, the Registry has more information to evaluate to help find answers to questions about ALS.

National ALS Biorepository:

The Biorepository contains biological samples from people living with ALS who have enrolled in the Registry. It provides researchers with high-quality biological samples to study the underlying causes of ALS and to develop new treatments.

Research Notification Mechanism:

The Registry informs people living with ALS about opportunities to participate in clinical trials and other research studies.

Funded research:

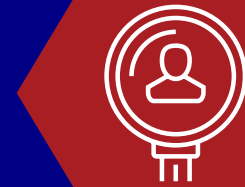
The Registry identifies areas that need investigation. Then, the Registry funds research in these areas and researchers from around the world share and publish their findings. This collaboration is key for success.

What are examples of Registry accomplishments?

- Registry participants completed over **100,000** risk factor surveys.
- The Registry has over **1,600** Biorepository participants, which make up over **75,000** samples available for researchers.
- Each year, the National ALS Registry funds research studies to learn more about risk factors contributing to the disease.

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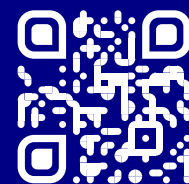


How does the Registry learn who has ALS?

People living with ALS enroll in the National ALS Registry at cdc.gov/als.

The National ALS Registry combines the administrative databases from Centers for Medicare and Medicaid Services and Department of Veterans Affairs and then uses a validated method to determine who has ALS.

Together we can find answers about ALS that can lead to treatments and cures.



Learn more at
cdc.gov/als