

The First National ALS Registry Report Summary

The National ALS Registry enables persons with ALS (also known as Lou Gehrig's disease) to fight back. By signing up, being counted, and answering brief questions about your disease, you can help researchers find answers to critical questions.

Learn more at www.cdc.gov/als or (877) 442-9719

ALS (amyotrophic lateral sclerosis) is a disease of the nerves and muscles that gets worse over time. Most people die from ALS within 2 to 5 years of finding out they have it. No one knows what causes ALS and there is currently **no cure.**

What is the National ALS Registry?

In 2009, the federal Agency for Toxic Substances and Disease Registry (ATSDR) started the congressionally-mandated National ALS Registry to collect and analyze data on persons with ALS in the United States.

The Registry is helping to:



Determine the number of people living with ALS in the United States



Better understand the characteristics of those living with ALS



Examine the possible risk factors for the disease

Why is this report important?

This is the first report to summarize data from the National ALS Registry, which is the only effort to identify all ALS cases among people living in the United States. The report provides information on how many people were living with ALS in the United States from October 19, 2010 through December 31, 2011. Additional annual reports are planned as we gather more data from the Registry.



What does the report tell us about ALS?



A total of 12,187 people were identified with ALS from October 19, 2010 through December 31, 2011. This means that **about 4 in 100,000 people were diagnosed with ALS (based upon 2011 census data) during the period surveyed.**

Overall, **ALS was more common among white males, non-Hispanics, and those ages 60 through 69.** White men and women were twice as likely to have ALS than black men and women (3.8 per 100,000 compared to 1.9 per 100,000).

The age ranges with the lowest number of persons with ALS were age 18 through 39 and individuals age 80 or older.



Males had a higher rate of ALS than females across all sources.

Results from this first report are consistent with findings from well-established European ALS registries, along with small-scale epidemiologic studies that have previously been conducted in the United States.

How did ATSDR get the data in this report?

Because ALS is not a reportable disease in the United States (except for Massachusetts), the Registry uses 2 ways to help identify all cases of ALS in the country. We use existing national administrative databases like Medicare, Medicaid, the Veterans Health Administration (VHA), and Veterans Benefits Administration (VBA) to identify cases.

We also use a secure web portal, launched on October 19, 2010, to identify cases that may not be included in the national administrative databases. ALS patients who have registered via the web portal can complete brief surveys that may lead to a better understanding of **possible risk factors for ALS such as genetics, environmental, and occupational exposures.**



What is ATSDR doing to make sure people with ALS join the Registry?

ATSDR is working closely with ALS advocacy and support groups, researchers, and healthcare professionals, among others, to encourage those living with ALS to join the Registry and take risk factor surveys.

What is ATSDR doing to improve the Registry?

In addition to increasing the number of people with ALS signed up for the Registry, ATSDR is:



Adding new modules to the Registry web portal to study other potential risk factors for the disease



Conducting a feasibility study for a new ALS Bioregistry to potentially provide biological samples (like hair and blood samples) from enrollees to help researchers learn more about the disease



Engaging in surveillance activities in select states and large cities to help test the completeness of the Registry



Using the Registry to recruit patient enrollees for new clinical trials and epidemiologic studies

Where can I get more information about joining the Registry?

More information about the National ALS Registry can be found online at www.cdc.gov/als or by calling us toll-free at (877) 442-9719. You can also learn more about the Registry through the local chapter of an ALS advocacy or support group:

- The ALS Association (www.alsa.org)
- The Muscular Dystrophy Association (www.mda.org)
- The Les Turner ALS Foundation (www.lesturnerals.org)

Be counted. Fight back. Make a difference.

#ALS #BeCounted



U.S. Department of Health and Human Services
Agency for Toxic Substances and Disease Registry
www.atsdr.cdc.gov