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# FACTS about ALS

Many people know ALS as Lou Gehrig's Disease, named after the famous baseball player who had to retire in 1939 because of it. ALS is a disease that causes nerve cells to stop working and die. This leads to muscle weakness, paralysis, and eventually death.

No one knows what causes most cases of ALS. Scientists may find that many factors together cause it.

## About ATSDR

The Agency for Toxic Substances and Disease Registry (ATSDR) is the federal agency charged with identifying environmental health hazards and working with federal, tribal, state, and local agencies to address them. ATSDR uses registries to track information to learn more about possible relationships between toxic substances and diseases.

**For More Information,  
please contact:**

### ATSDR

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Phone: (800) 232-4636

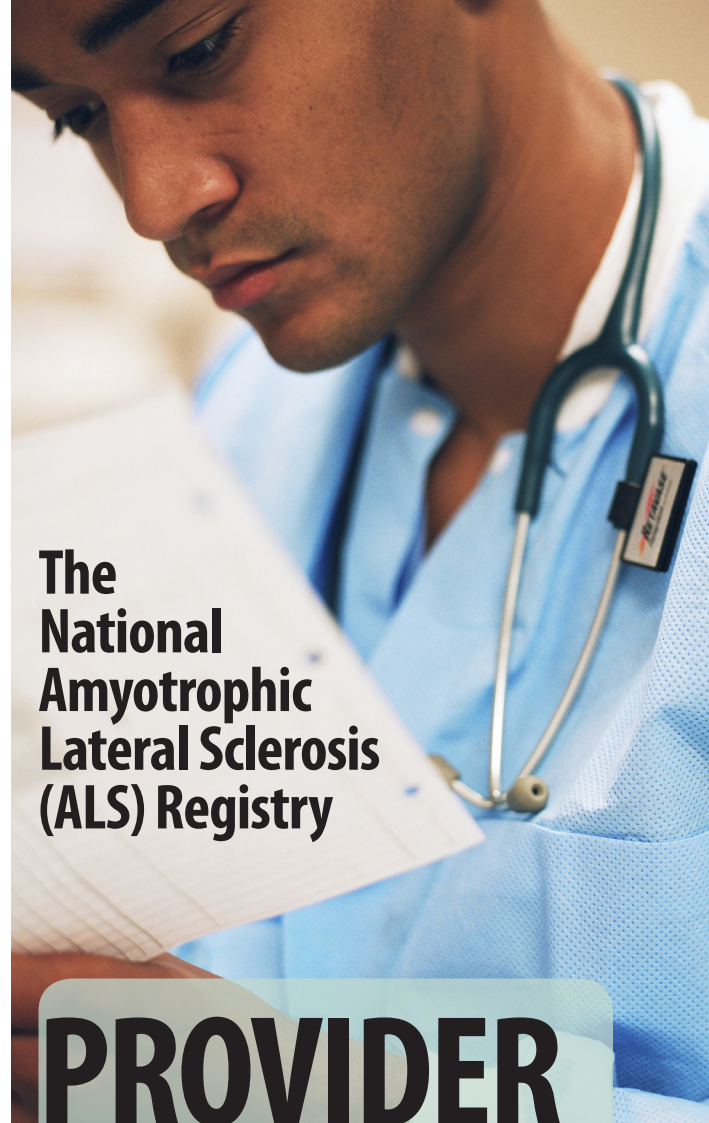
TTY: (888) 232-6348

24 Hours/Every Day

Email: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)

[www.atsdr.cdc.gov](http://www.atsdr.cdc.gov)

**[www.cdc.gov/als](http://www.cdc.gov/als)**



## The National Amyotrophic Lateral Sclerosis (ALS) Registry

# PROVIDER GUIDE



**U.S. Department of  
Health and Human Services**  
Agency for Toxic Substances  
and Disease Registry



# Goals of the National ALS Registry

The National ALS Registry is a program to collect, manage, and analyze data about people with ALS.

Because learning more about ALS is an important step in the battle to defeat it, the Agency for Toxic Substances and Disease Registry (ATSDR) has developed a national registry to gather information from people across the U.S. who are living with ALS.

The goal of the National ALS Registry is to gather information that can be used to

- estimate the number of new cases of ALS identified each year,
- estimate the number of people who have ALS at a specific point in time,
- better understand who gets ALS and what factors affect the disease,
- examine the connection between ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, or in some cases progress to ALS, and
- improve care for people with ALS.



# Resources for doctors and patients

## Registry Information Sources

National Registry information comes from two main sources: existing national databases and people living with ALS.

ATSDR is coordinating with the Centers for Medicare and Medicaid Services and the U.S. Department of Veterans Affairs to gather information from their databases.

People living with ALS can visit [www.cdc.gov/als](http://www.cdc.gov/als) to participate in the registry through a secure web portal. They will be asked questions about things like their health, occupational, and family histories.

Resources available through the registry web site include

- clinical trials information,
- ALS clinic information,
- fact sheets
- reports and journal articles, and
- continuing education credits for health professionals.