



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 some 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. Help us find the cause(s) of ALS.

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:**

The National ALS Registry

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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 for doctors and patients

The National ALS Registry is a program to collect 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 collect and organize 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 whose cases progress to ALS, and
- improve care for people with ALS.

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 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, but are not limited to,

- Clinical trials information,
- Research notification mechanism, a tool for recruiting PALS for clinical trials and other research studies <http://go.usa.gov/Kq284>
- ALS clinic information,
- fact sheets,
- reports and journal articles, and
- continuing education credits for health professionals.