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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

4770 Buford Hwy NE Atlanta, GA 30341

Phone: (800) 232-4636

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24 Hours/Every Day

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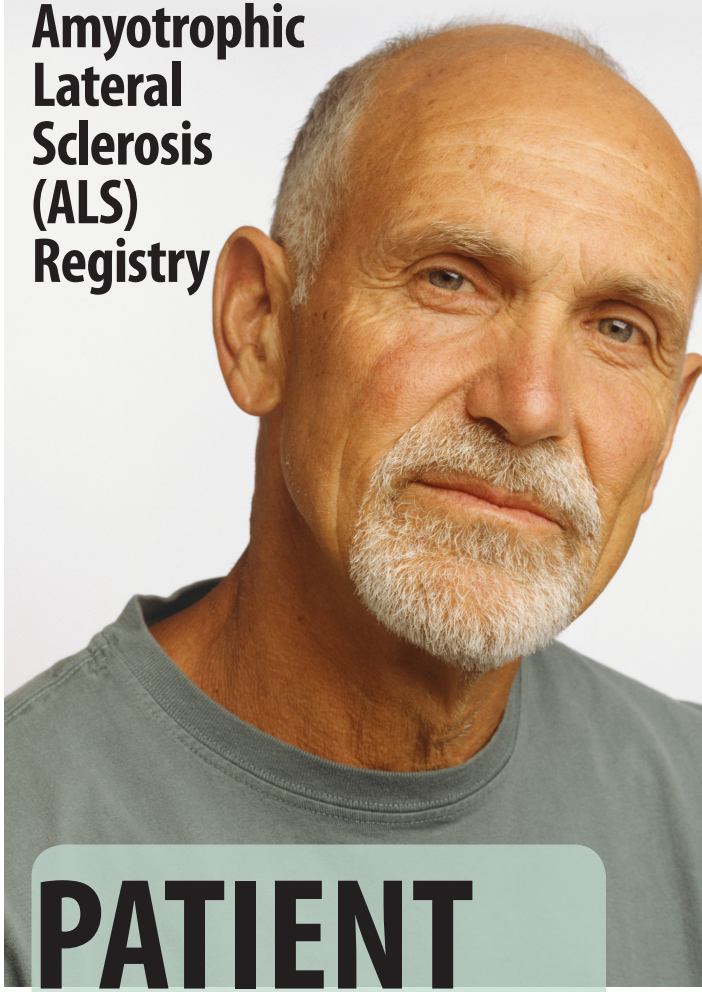
www.atsdr.cdc.gov

www.cdc.gov/als

CS216408-A

The National Amyotrophic Lateral Sclerosis (ALS) Registry



PATIENT GUIDE

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

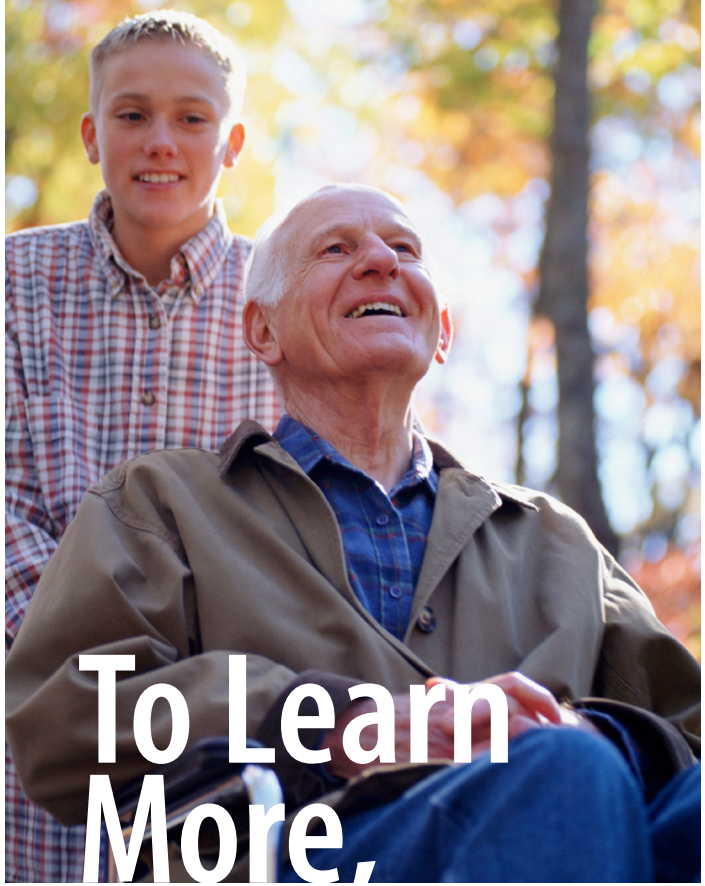
What is the National ALS Registry?

The National ALS Registry is a program to collect, manage, and analyze data about people with ALS. It is important to include as many people with the disease as possible to get the most accurate information.

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 who are living with ALS. This information can help doctors and scientists learn more as they work toward a cure.

The goal of the 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, and
- improve care for people with ALS.



or to register, visit www.cdc.gov/als

How does the National ALS Registry work?

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

People living with ALS can visit www.cdc.gov/als to participate in the registry. They will be asked questions about things like their health, job, and family histories.

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

What about data privacy?

Registry information will be stored on a secure web portal. That means only certain ATSDR researchers will have access to the data as they are collected.

Doctors and scientists requesting registry data will not have access to information that would identify individual patients. Any information that is published about people in the registry will only be group information and will not identify you.

What can the ALS Registry do for me?

The main purpose of the registry is to gather information that can be used in the fight to defeat ALS. Even if you choose not to register, you can find important information at the registry website.

Resources available through the registry include

- clinical trials information,
- ALS clinic information,
- fact sheets, and
- reports and journal articles.