About Amyotrophic Lateral Sclerosis (ALS)

What is ALS?

Many people know ALS as Lou Gehrig's disease, named after the famous baseball player who got the illness and had to retire in 1939 because of it. ALS is a disease that affects the nerve cells that make muscles work in both the upper and lower parts of the body. This disease makes the nerve cells stop working and die. The nerves lose the ability to trigger specific muscles, which causes the muscles to become weak and leads to paralysis.

How many people have ALS?

Although no one knows for sure, reports suggest 20,000–30,000 people in the United States have ALS; every year doctors tell about 5,000 people that they have it. Because records on ALS have not been kept throughout the country, it is hard to estimate the number of ALS cases in the United States. ALS is slightly more common in men than women. ALS is age related; most people find out they have it between 55 and 75 years of age, and live from 3 to 5 years after symptoms develop. How long a person lives with ALS seems to be related to age; people who are younger when the illness starts live slightly longer. About 5–10% of ALS cases occur within families. This is called familial ALS and it means that two or more people in a family have ALS. Familial ALS is found equally among men and women. People with familial ALS usually do not fare as well as ALS patients who are not related, and typically live only one to two years after symptoms appear.

What causes ALS?

No one knows what causes most cases of ALS. Scientists have been studying many factors that could be linked with ALS such as heredity and environmental exposures. Other scientists have looked at diet or injury. Although no cause has been found for most cases of ALS, a number of inherited factors have been found to cause familial ALS. In the future, scientists may find that many factors together cause ALS.

What is the National ALS Registry?

The National ALS Registry is a program to collect, manage, and analyze data about people with ALS. It includes data from existing national databases and information provided by patients who choose to participate. Researchers can use Registry data to look for disease pattern changes over time and try to identify whether there are common risk factors among ALS patients. Additionally, the Registry provides updated links for patient resources like ALS clinical trials. People living with ALS can add their information to the registry by clicking the button at the top right of this page.
Selected states and cities will also gather data about ALS in their areas. Data from these smaller-scale registries will be used to evaluate the completeness and accuracy of the data in the National ALS Registry.

About ATSDR

ATSDR's mission is to serve the public through responsive public health actions to promote healthy and safe environments and prevent harmful exposures. The Division of Toxicology and Human Health Studies is the part of ATSDR that conducts the National ALS Registry activities.