The National Amyotrophic Lateral Sclerosis (ALS) Registry

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.

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.

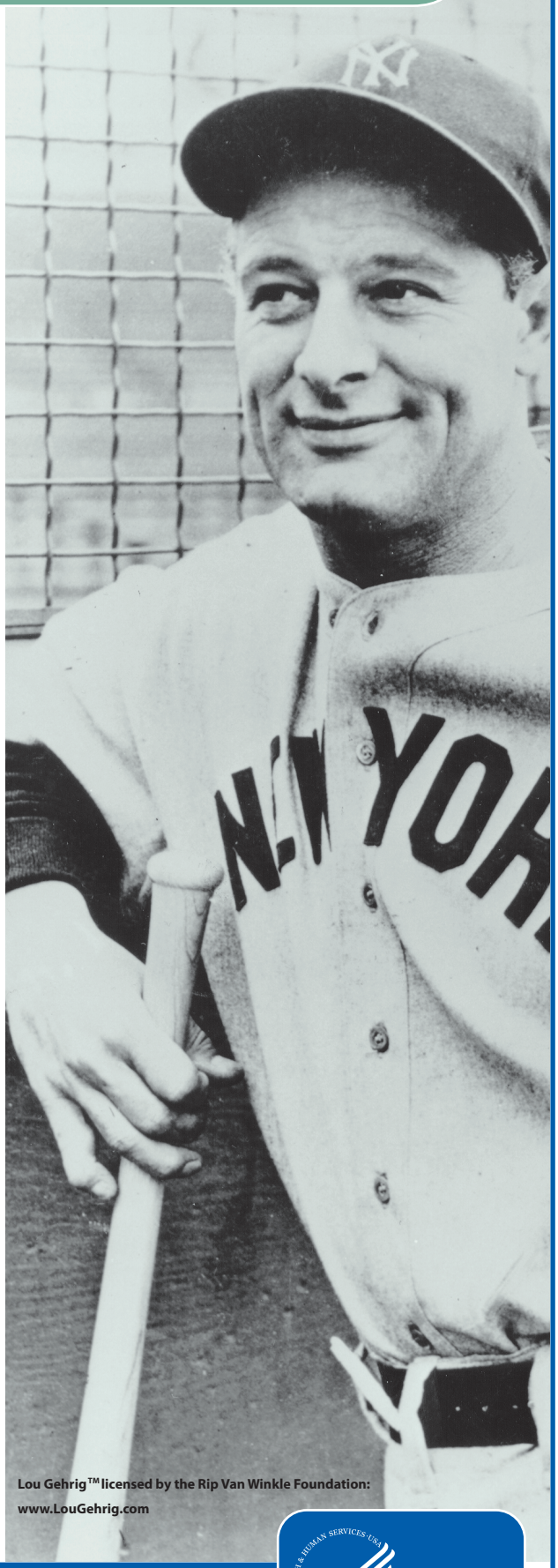
Because learning more about ALS is an important step in the battle to defeat it, the Agency for Toxic Substances and Disease Registry (ATSDR) has developed this registry to gather information from people who are living with ALS. This information can help doctors and scientists learn more as they work 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 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, and in some cases progress to ALS, and**
- **improve care for people with ALS.**

To Learn More, or to Register, Visit

www.cdc.gov/als



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Agency for Toxic Substances and Disease Registry
Division of Health Studies

ATSDR

How does the National ALS Registry work?

Information in the National Registry 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 coordinating with the Centers for Medicare and Medicaid Services and the U.S. Department of Veterans Affairs to gather information from their databases.

Selected states and cities will also gather data about the number of people in their areas diagnosed with ALS. Data from these smaller scale projects will be used to evaluate the completeness and accuracy of the data in the National ALS Registry.

What about 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 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 so, you can find important information at the registry website. Resources available through the registry include

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

Visit the Registry Website

www.cdc.gov/als

For more information, please contact:

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