

## **The National ALS Registry: Get The Facts**

The National Amyotrophic Lateral Sclerosis (ALS) Registry enables persons with ALS to fight back and help defeat ALS (Lou Gehrig's Disease). By signing up, being counted, and answering brief questions about your disease, you can help researchers find answers to critical questions.

### Learn more at www.cdc.gov/als or (800) 232-4636

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Who can sign-up? Anyone

with ALS

### What do I need?

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- A computer with an internet connection
- An email address

#### No computer? Don't worry! A family member, caregiver, or friend with a computer can help you. You can also contact your local ALS chapter, office or clinic for registration assistance.



# What if I need help?

Caregivers and others can help you in person or even over the phone



# Do I need to update my information?

YES! Every six months - you'll get an email reminder

## Will my information be private?

- YES! Only approved registry scientists can see it, NOT employers or insurers
- You CANNOT be looked up in the registry by name

## What kind of information is collected?

- Basic demographics (e.g., age, sex, height, weight)
- Military history
- Physical activity
- Family history

### More information for research

A better understanding of ALS

The chance to help create a better future for persons with ALS

# YOU JOINING

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