

The Purpose of the Registry:

Research is a priority to increase our limited knowledge of amyotrophic lateral sclerosis (ALS). The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) established the National ALS Registry in 2010 to collect and analyze information from people who have ALS in the United States. This offers people living with ALS a way to help advance our understanding of the disease.

How Clinicians Can Help the Registry:

As a clinician, you can talk to people living with ALS about the National ALS Registry, even if they may have heard about it from other sources. People who have ALS can support research by contributing to the ALS database. This research could lead to determining how disease patterns change over time and could identify potential common risk factors. **Free continuing education credits are available for healthcare professionals.**

Clinicians Can Talk with Patients about National ALS Registry Research and Resources:

- **Enrollment and risk factor surveys:** People living with ALS contribute crucial information to the Registry by completing the surveys. The more surveys completed, the more data the Registry can analyze to find answers.
- **National ALS Biorepository:** People living with ALS who have joined the National ALS Registry can donate biospecimens to the National ALS Biorepository and help advance ALS research in biomarker discovery and therapeutic development. This is a free service.
- **Notification system for clinical trials and epidemiological studies:** The Registry notifies people living with ALS about opportunities to participate in clinical trials and other research studies.
- **Publication resources:**
 - Reports and journal articles
 - Printed and electronic materials about the Registry
- **Sources for the national estimate (prevalence and incidence rate) of people living with ALS:**
 - National ALS Registry online portal (self-registration)
 - National administrative databases
 - Centers for Medicare and Medicaid Services
 - U.S. Department of Veterans Affairs



Contact Information:

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This is a **free service.**

There is no cost to people with ALS, or to their families, to join the National ALS Registry and the National ALS Biorepository.

