U.S. National ALS Registry Talking Points

for Partner Organizations and their Teams

OVERVIEW AND PURPOSE OF THE NATIONAL ALS REGISTRY:

The ALS Registry Act (Public Law 110-373) established the Registry as part of the Centers for Disease Control and Prevention (CDC) in 2008.

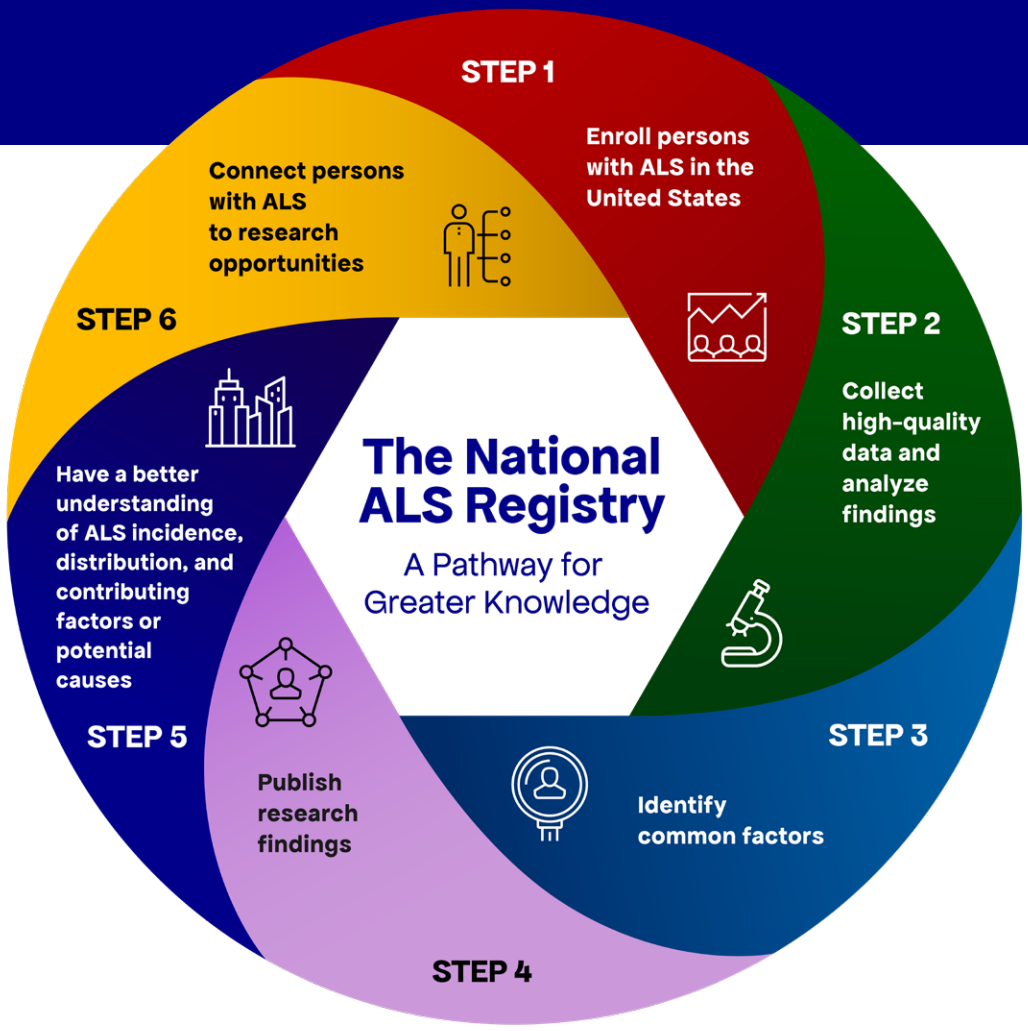
- Analyzes ALS survey data
- Identifies risk factors
- Determines and advances ALS epidemiology

Registry Mission

To determine the epidemiology of amyotrophic lateral sclerosis in the United States as well as identify and evaluate the risk factors and causes of this disease.

Registry Vision

To support and advance research opportunities to better understand ALS.



Visit **cdc.gov/als/dashboard** for current information.

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How the Registry Works:

- People living with ALS can help the National ALS Registry by completing up to 18 risk factor surveys covering topics such as occupational history and environmental exposures—helping to create a more complete picture of their ALS story.
- The Registry also comprises the National ALS Biorepository, which offers participants the opportunity to contribute biological specimens to support research into ALS biomarkers and genetics. The specimens can be matched with survey data to give researchers a more complete picture to study.

Impact of the Registry:

- The Registry encourages individuals with ALS to share their stories, enhancing ALS data and supporting research efforts.
- The Registry has funded over a dozen studies exploring potential ALS risk factors since 2010.
- The Registry publishes reports such as National ALS Disease Estimates and research publications (e.g., *Racial Disparities in the Diagnosis and Prognosis of ALS Patients in the United States*).
- Researchers around the world can request data from the Registry to better understand disease patterns and identify risk factors.
- The public, people living with ALS, and other member of the ALS community can share Registry-created public facing educational materials, graphics, and videos to promote awareness and encourage participation in the Registry.

HOW TO GET INVOLVED:

- Anyone living with ALS can enroll in the Registry by visiting cdc.gov/als.
- You don't have to do this alone: you can ask a family member, friend, or caregiver to help you.
- You can also reach out to your local chapter of ALS United, the ALS Association, or clinics for help.
- Healthcare providers and researchers can access resources and data to support their ALS research at cdc.gov/als.

WHY YOU SHOULD GET INVOLVED:

- You have the opportunity to help future generations.
- You can be a part of research from home.
- When you join the National ALS Registry, you can choose to receive emails informing you about clinical trials and epidemiological studies that may interest you.
- As more people join the Registry and complete risk factor surveys, the researchers have a more complete picture of the Registry. It's like a puzzle: as more pieces are found and put together, we can see a picture come together.

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