

Announcement

Amyotrophic Lateral Sclerosis (ALS) Awareness Month — May 2016

May is Amyotrophic Lateral Sclerosis (ALS) Awareness Month. ALS, also known as Lou Gehrig's disease, is a progressive, fatal, neurodegenerative disorder of upper and lower motor neurons. The cause of ALS is not known, and no cure exists. Persons with ALS usually die within 2–5 years of diagnosis.

In October 2010, the Agency for Toxic Substances and Disease Registry (ATSDR) launched the congressionally mandated National ALS Registry (<https://wwwn.cdc.gov/als/Default.aspx>) to collect and analyze data regarding persons with ALS in the United States. The goals are to determine the incidence and prevalence of ALS, characterize the demographics of those living with ALS, and examine potential risk factors for the disease. ATSDR released the first National ALS Registry report in July 2014 for persons living with ALS in the United States during October 19, 2010–December 31, 2011 (1) and expects to release the second report this summer that covers 2012–2013. During the period covered by the first report, approximately 12,000 persons were identified with ALS, or approximately four in every 100,000 persons. ALS is more common in whites, males, non-Hispanics, and persons aged 60–69 years. These findings are consistent with well-established European ALS registries and small epidemiologic studies that have been conducted in the United States.

ALS, like most noninfectious diseases, is not a notifiable disease in the United States. To collect data on cases, the Registry uses data from existing national databases, including the Centers for Medicare & Medicaid Services and the U.S. Department of Veterans Affairs, as well as information provided by persons with ALS through the Registry's secure online system. Online registrants also can take brief surveys regarding potential risk factors for the disease (e.g., occupational, military, smoking, alcohol, and residential histories).

In the fall of 2016, the Registry will launch the National ALS Biorepository. The Biorepository is a tool for all qualified researchers to request a wide variety of high-quality biologic samples, collected from a national sample of enrollees in the National ALS Registry, to help study ALS. For example, researchers might be able to analyze genetic variations as well as possible biomarkers in patients with ALS. Both in-home (e.g., blood, urine, and hair) and postmortem specimens (e.g., brain, spinal cord, and cerebral spinal fluid) will be collected from interested patients enrolled in the Registry. Furthermore, epidemiologic data from completed patient surveys will be matched with patient specimens, making the Biorepository a rich data source for researchers to better understand ALS.

ATSDR is collaborating with the ALS Association (<http://www.alsa.org>), Muscular Dystrophy Association (<http://www.mda.org>), Les Turner ALS Foundation (<http://lesturnerals.org>), and other organizations to make all persons with ALS and their families aware of the opportunity to enroll in the National ALS Registry. Additional features have been added to enhance the Registry for patients and researchers, including state and metropolitan area–based ALS surveillance to assist in evaluating the completeness of the Registry and to provide local incidence and prevalence data; a research notification system to link persons with ALS to researchers who are conducting epidemiologic studies and clinical trials; Registry-funded external research to better understand the etiology of ALS and to prioritize topics for future risk factor surveys that persons with ALS will be able to participate in through the National ALS Registry web portal; and mobile “apps” to help find the nearest ALS clinics and support groups.

Reference

1. Mehta P, Antao V, Kaye W, et al. Prevalence of amyotrophic lateral sclerosis—United States, 2010–2011. *MMWR Surveill Summ* 2014;63(No. SS-7).