

## **2014 Annual ALS Surveillance Meeting Executive Summary**

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Because much remains unknown about the causes(s) of Amyotrophic Lateral Sclerosis (ALS), the National ALS Registry was established in 2010 by the Agency for Toxic Substances and Disease Registry (ATSDR) to describe the incidence and prevalence of ALS, to describe the demographics of ALS patients, and to examine the risk factors for the disease. The first report from the Registry was published in CDC's *Morbidity and Mortality Weekly Report (MMWR)* on July 25, 2014. The report includes the first-ever prevalence estimates of ALS for the United States (US).

Each year ATSDR convenes the Annual ALS Surveillance Meeting to bring together leading ALS experts to help shape the Registry. The meeting is designed to update stakeholders on the progress of the Registry, to present the Registry data and its implications, and to discuss strategies to further enhance the Registry for all stakeholders.

### Overview of the National ALS Registry

The ALS Registry Act, enacted as Public Law 110-373 in October 2008, directs CDC/ATSDR to establish and maintain the National ALS Registry. It is the only congressionally mandated population-based registry for the U.S. ATSDR described the methodology used by the Registry. The Registry combines ALS data from existing national databases (i.e., Medicare, Medicaid, VA Health Administration, and the VA Benefits Administration) with information directly entered into a secure web portal by persons with ALS. In addition to registering, 15 risk factor surveys are also available to ALS patients on the Registry web site. These surveys will help to answer questions about the potential risk factors for ALS. ATSDR is currently in the process of analyzing the risk factor data collected so far.

ATSDR is also implementing several initiatives to strengthen the Registry including:

- The Research Notification System
- Additional risk factor surveys
- The Biorepository Pilot Study
- The State and Metropolitan-Based Surveillance Project, and
- ATSDR supported ALS research

An important aspect of the meeting is the discussion following each presentation. This discussion is critical as it generates recommendations concerning Registry issues and suggestions for enhancing the Registry.

### First Report on Registry Results

The results from the first surveillance report from the National ALS Registry, Prevalence of Amyotrophic Lateral Sclerosis – United States, 2010-2011, were presented. The report was published on July 25, 2014 in the *Morbidity and Mortality Weekly Report (MMWR)* and includes data from the date the Registry was launched, October 19, 2010, through December 31, 2011.

A total of 12,187 persons were identified as having definite ALS via the Registry, which includes those in the national databases and the persons registering on the web portal. The number and percentage of identified ALS cases were described by source, age group, and sex. Prevalence rates for ALS were presented by age group, sex, and race.

Information about potential risk factors is gathered for descriptive purposes only. Information was provided for persons responding to risk factor surveys, which included smoking history, alcohol history, education history, military history, and employment status.

### Research Notification Mechanism Update

ATSDR described the Research Notification Mechanism, which was introduced in the National ALS Registry with the objectives of linking researchers with persons with ALS (PALS), facilitating their interaction, and expediting the process of recruitment. PALS may give their consent to receive notifications when they enroll in the Registry. Researchers submit proposals to ATSDR, including a research protocol that has been approved by their institution's IRB and other documents, which are reviewed by an approval committee. If the research is approved, eligible PALS are notified about the research and if they are interested, then they contact the researchers. Since November 2012, ATSDR has used this system to link PALS with nine research studies.

### Risk Factor Data Analysis

Results were presented from the risk factor surveys completed by persons with ALS who self-enrolled in the online Registry web portal in the time period October 2010–December 2011. The results were from surveys on demographics, smoking and alcohol use history, military history, occupational history, and family history of ALS, Alzheimer's disease, or Parkinson's disease. The results of the demographic survey were presented by age, race, ethnicity, sex, and educational attainment. The results of the other surveys were presented by percent of respondents engaging in the activity, the degree to which they engaged in the activity, or by other indices.

### Outreach Challenges

ATSDR solicited information and input from the meeting participants to ensure that the National ALS Registry is having maximal impact and reaches as many PALS as possible. This request resulted in a lengthy discussion regarding challenges and potential approaches to address reaching as many PALS as possible.

### Registry Promotion and Outreach

#### ATSDR

ATSDR described its marketing strategy for generating awareness of the National ALS Registry, which focuses on working with partners and targeting different audiences. The audiences include PALS, family members and caregivers, health care providers, researchers, and ALS support organizations and entities. The metrics associated with visits to the Registry and new projects and features were also described. Some of the new products include: new web buttons that focus on particular audiences, such as caregivers and rural populations, the "Get the Facts" infographic, videos and Webinars. Although the Registry continues to be promoted through traditional printed materials and the print media, this effort continues to be expanded to include social media messaging and online ads.

#### The ALS Association

The ALS Association stressed the goal shared by members of Congress, ALS researchers, and PALS, which is for the National ALS Registry to be a powerful research engine. The ALS Association conducts a Listening Tour of each of its 38 chapters to learn about things that are important to PALS. Through these tours the chapters identified challenges such as internet access and limited knowledge about the Registry. Based on the feedback from the Listening Tour, The Association created a National

ALS Registry Toolkit to help chapters address these challenges. This toolkit has been distributed to ALS Association chapters and affiliated clinics and centers across the country.

The ALS Association also described how their outreach to health professionals, researchers, veterans, elected state officials, and the general public is impacting enrollment in the Registry. Another strategy being used by The ALS Association is their partnering with minor league baseball to promote the Registry through events at baseball parks across the country, many in rural areas that are under-enrolled in the Registry. The Association is also heavily engaged in promoting the Registry online through social media and online advertisements.

#### Les Turner ALS Foundation

The Les Turner ALS Foundation described how Les Turner, a businessman in Chicago who was diagnosed with ALS in 1976, and his family formed the foundation in 1977. An idea based on used books sales spawned the creation of the Mammoth Music Mart in 1978. This event continued for 25 years, providing funding to the foundation. Also described was how the foundation has grown over the years. The Les Turner Foundation now supports two ALS research laboratories at Northwestern University and the Les Turner/Lois Insolia ALS Center to provide services to PALS. The foundation also provides a wide variety of patient and family support programs throughout the Chicago area.

The Les Turner Foundation also described how it promotes the National ALS Registry through their team of communications professionals who work with social media and send regular e-mail blasts, through information on the Registry provided on the Les Turner webpage, through the Home and Community Advocate Team which also helps promote the Registry, and through the distribution of materials to new patients in clinics, home visits, and in support groups.

#### The Muscular Dystrophy Association

The Muscular Dystrophy Association (MDA) described how MDA is the world's leading nonprofit health agency dedicated to finding treatments and cures for muscular dystrophy (MD), ALS, and other related neuromuscular diseases. MDA has dedicated almost \$325 million to ALS research and healthcare services. MDA also promotes the National ALS Registry through MDA clinics and MDA/ALS centers, legislation and healthcare policy, support groups and educational seminars, home visits, fundraising events, and outreach and emotional support.

Also described was the tremendous research commitment MDA has dedicated to ALS and MDA's many efforts in information dissemination about the Registry. MDA described their three publications, which include promotions about the Registry and their strong social media presence.

#### CME Training Modules Update

ATSDR presented a review of data from users completing the ALS Continuing Education Module for the period October 1, 2010–June 30, 2014. Users of the module pursued different credit types, including Continuing Education (CE), Continuing Medical Education for Physicians (CME-P), Continuing Medical Education for Non-Physicians (CME-NP), Certification for Nurse Educators (CNE), Continuing Education Units (CEUs), and Certified Health Education Specialist (CHES). The user data was presented by type of user, educational level, work setting, credit type, number registered and number and percent completing the module.

#### State and Metropolitan Area Surveillance Findings Update

The goal of the State and Metropolitan Area Surveillance Project was to evaluate the completeness of the National ALS Registry. Neurologists who had diagnosed and/or provided care to an ALS patient in specified state or metropolitan areas from January 1, 2009, through December 31, 2011 were identified and requested to report their ALS cases to the project. Surveillance data was provided in three states and eight metropolitan areas including: Texas, Florida, and New Jersey, and San Francisco, California; Los Angeles, California; Las Vegas, Nevada; Chicago, Illinois; Detroit, Michigan; Atlanta, Georgia; Philadelphia, Pennsylvania; and Baltimore, Maryland.

The methods were described for identifying and recruitment of providers, case ascertainment, quality assurance, and for selection of reported cases for case verification. Results were described for the number of cases reported, age, race, ethnicity, sex, time from onset of symptoms to diagnosis, metropolitan area and by practice type. The limitations, recommendations for use of this type of active surveillance for ALS, and methods for distribution of the findings were also described.

### Mobile Service Locator Apps

ATSDR's Geospatial Research, Analysis, and Service Program (GRASP) provided an overview of the ALS Service Locator Apps. GRASP provides a Service Locator Tool to help PALS find the closest clinics, ALS Association chapters, and MDA offices by using a Zip code. The web application service locator was has been transformed onto mobile platforms. The mobile application is available in iOs and Android marketplaces. Metrics data for the mobile applications were also described.

### End of the Day Questions

During this session, the floor was opened for meeting attendees to ask questions or make comments regarding any ALS issues or concerns.

### ATSDR Funded Studies

Research is critical to learn more about the etiology of ALS. ATSDR provides funding to support ALS research studies to help the ALS community learn more about the disease and to also help prioritize new risk factor modules for the Registry. The following ATSDR-funded studies are listed on the National ALS Registry website and were presented by their principle investigators.