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The National Amyotrophic Lateral Sclerosis (ALS) Registry

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A myotrophic lateral sclerosis (ALS) is a progressive and often fatal neuromuscular disease. Most people die within 2–5 years of being diagnosed with ALS (Mitsumoto, Chad, & Pioro, 1998). Community concerns about perceived clusters of cases of ALS have challenged public health agencies to consider the possible contribution of environmental contaminants to the development of this disease. The general categories of possible environmental risk factors that have been investigated include heavy metals, trace elements, solvents and other volatile organic chemicals, ionizing and non-ionizing radiation, and agricultural chemicals.

Several investigations have been conducted of heavy metal exposure, particularly lead, as a risk factor for ALS. Some case-control studies demonstrated a positive association between past exposure to lead and risk of ALS (Armon, Kurland, Daube, & O'Brien, 1991; Kamel et al., 2002; Roelofs-Iverson, Mulder, Elveback, Kurland, & Molgaard, 1984). Also, the epidemiologic literature offers some support for an association between ALS and past exposure to organic solvents (Gunnarsson, Lindberg, Söderfeldt, & Axelson, 1991; McGuire et al., 1997).

In addition, certain occupations, such as military work, have been listed as a risk factor for ALS (Nicholas et al., 1998; Schulte, Burnett, Boeniger, & Johnson, 1996; Sutedja et al., 2009; Weisskopf et al., 2005). Several other potential risk factors have been evaluated in the scientific literature including infectious agents (Fang et al., 2011), nutritional intake (Okamoto, Kihira, Kobashi et al., 2009; Wang et al., 2011; Woolsey, 2008), physical activity, and trauma (Beghi et al., 2010; Okamoto, Kihira, Kondo et al., 2009; Piazza, Siren, & Ehrenreich, 2004; Strickland, Smith, Dolliff, Goldman, & Roelofs, 1996).

The uncertainty about the incidence and prevalence of ALS, as well as the lack of knowledge about the role of environmental exposures in the etiology of ALS, has created a need for structured data collection. In 2008, President Bush signed the ALS Registry Act into law, allowing the Agency for Toxic Substances and Disease Registry (ATSDR) to create the National ALS Registry. The purpose of the registry is to quantify the incidence and prevalence of ALS in the U.S., describe the demographics of persons with ALS, and examine risk factors for the disease.

When the law was enacted, ATSDR was already conducting four pilot projects (during 2006–2009) to determine the feasibility of creating a National ALS Registry. Results from these pilot projects showed that approximately 80% of ALS patients could be found through

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existing national databases. Combined methodologies would be needed, however, to identify a larger portion of individuals with ALS.

In 2009, ATSDR implemented the National ALS Registry using a two-pronged approach to better describe the epidemiology of ALS in the U.S. and its potential risk factors. The first approach uses existing national administrative databases, including Medicare, Medicaid, Veterans Heath Administration, and Veterans Benefit Administration records to identify prevalent cases based on an algorithm developed through the pilot projects. The National ALS Registry is the first national surveillance system to use existing administrative data as a major source of case ascertainment.

The second approach, implemented in the fall of 2010, uses a secure web portal to capture cases not included in the national administrative databases. This approach allows patients to self-identify and enroll in the ALS registry and take risk factor surveys. Current risk factor surveys include sociodemographic characteristics, occupational history (most recent and longest held jobs), military history, cigarette smoking, alcohol consumption, physical activity, family history of neurodegenerative diseases, and disease progression. In the near future, ATSDR expects to include additional surveys on residential history, pesticide exposures, occupations and hobbies involving toxic exposures, trauma (e.g., traumatic brain injury and electrical shocks), caffeine consumption, reproductive history, and health insurance information.

In addition, ATSDR is concurrently implementing surveillance activities that will allow for timely population-based case estimates of ALS in smaller defined geographic areas (i.e., at the state and metropolitan levels). Currently, Texas, Florida, New Jersey, Philadelphia, Chicago, Atlanta, Detroit, Los Angeles, and San Francisco are participating. These local surveillance activities will actively identify neurologists who diagnose or provide care for persons with ALS and check their medical records to find possible cases of ALS that have not been reported to the registry. This process will help ATSDR evaluate the registry's completeness by comparing state and local data to data from the same areas collected in the registry. If some areas or groups are not well represented in the registry, ATSDR will find ways to reach these populations.

ATSDR is also developing a system to inform persons with ALS about new research studies. When researchers send ATSDR information about their studies, ATSDR will verify that the study has been approved by the researcher's institutional review board. Then the agency will e-mail information about the study to registrants who have agreed to be contacted about such projects. Registrants will have to contact the researcher if they want to be in the study.

Finally, ATSDR is funding a feasibility study for the creation of a national bank of biological specimens—blood, saliva, and tissue—known as a bioregistry. These samples would come from people in the ALS registry. Linking the specimens to the information collected from registry participants will make the registry even more useful.

Many environmental causes have been implicated as the etiology of ALS. This disease, however, remains without a definite etiology. Moreover, the true burden of ALS is not known in the U.S. The National ALS Registry is responding to these scientific gaps by

collecting nationwide data on disease prevalence, assessing risk factors for the development of ALS, and exploring ways of facilitating research on ALS. The registry web portal can be accessed at www.cdc.gov/als.

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