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Your Health – Your Environment Blog

National ALS-Registry 5th Anniversary

Posted on October 13, 2015 by Blog Administrator

During the past five years of the National ALS Registry's existence, ATSDR has made great strides into learning more about ALS. However, we still have a long way to go to fully understand this disease. Regardless, we are extremely grateful to all PALS around the U.S. who have dedicated their valuable time and effort to help advance the science of ALS. Without these PALS, the Registry would not be what it is today.

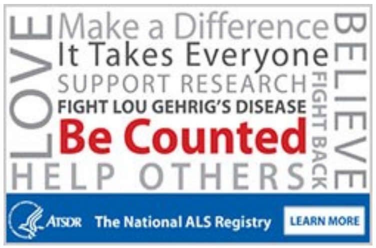
5 Years and Counting

What is ALS?

ALS, also known as Lou Gehrig's disease, is a rapidly progressive, fatal neurological disease that affects nerve cells in the brain and spinal cord, causing nerves in the muscle to die, thereby affecting voluntary muscle movement. On average, persons with the disease die within two to five years after being diagnosed. We still know very little about ALS, including its cause(s), and why ALS strikes some people and not others, as well as how to stop it.

What is the ALS Registry?

To learn more about the disease, the federal Agency for Toxic Substances and Disease Registry (ATSDR) launched the National ALS Registry in October 2010. The Registry gathers data about ALS from people who have the disease in the U.S. through an online web portal, as well as from existing national health databases (Medicare, Medicaid, and the Veterans Administration.) and from an online web portal.



Amyotrophic Lateral Sclerosis (ALS) aka Lou Gehrig's Disease

The main goals of the Registry are to:

- describe the incidence and prevalence of ALS;
- describe the demographics of those with ALS;
- and examine risk factors for the disease.

"At the heart of the matter are persons with ALS (PALS), their families, and loved ones. The ALS team here at ATSDR is honored and humbled to be working with such courageous and dedicated people. They inspire our work every day," says Dr. Kevin Horton, administrator of the National ALS Registry.

Five Years and Counting

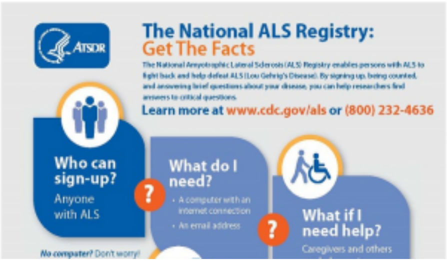
The National ALS Registry is:

- providing the first and only population-based estimate of ALS prevalence and incidence for the U.S.;
- fulfilling its Congressional mandate to describe the incidence, prevalence, demographics, and risk-factors for

persons living with ALS;

- being used as a recruitment tool for clinical trials and epidemiologic research;
- providing funds for external research;
- integrating a full-scale biorepository;
- and collaborating with all its partners to maximize enrollment.

Visit the National ALS Registry at www.cdc.gov/als.



ALS Infographic

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Categories Agency for Toxic Substances and Disease Registry (ATSDR), Division of Toxicology and Human Health Sciences

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