

Amyotrophic Lateral Sclerosis (ALS) Oregon Public Health Division Response February 19, 2015

Background

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a degenerative disease that affects the nervous system, leading to loss of motor control (voluntary movement). The disease is progressive and fatal. In the U.S., more than 12,000 people (3.9 cases per 100,000 people) have ALS. Most cases, up to 95 percent, occur sporadically, with no known cause; about 5 to 10 percent are inherited. Currently, the causes of the sporadic cases are not known; researchers are investigating links to other neurologic disorders and the role of factors including: environmental (such as exposure to infectious or toxic agents), physical trauma, and behavioral and occupational.

Oregon Public Health Division Response

The Oregon Public Health Division (PHD) is committed to protecting the health of Oregonians. PHD responds to concerns about diseases and the environment as follows:

1. We collect data and identify trends. ALS is not a reportable disease in Oregon, so we don't have reports of illness. We collect and analyze data on all deaths that occur in Oregon. In Oregon in 2013, there were 139 deaths from ALS; the total number of deaths from all causes was 33,931. ALS is the 19th cause of death in Oregon males, and 20th in females. Death rates for ALS have remained relatively stable over time.
2. When we hear from physicians, local health departments, community members, policy makers or the media about a particular disease and possible environmental toxins, we review what is known in the published medical literature about the causes of the disease. In the case of ALS, there are no known environmental causes of illness.
3. If we determine there is an increase in the number of cases of a disease for which there are known environmental causes, we may work with other state and federal agencies that can coordinate an assessment of possible environmental exposures. For issues that involve suspected chemical exposures, our Environmental Public Health section has a cooperative agreement with the Agency for Toxic Substances and Disease Registry (ATSDR) in the U.S. Department of Health and Human Services. ATSDR may collaborate with PHD to conduct assessments to try to determine if exposures to chemicals that are known to affect human health have occurred. We have contacted ATSDR, and because there are no known environmental toxins related to ALS, there are no plans for environmental assessment at this time.

Collaborative Efforts to Identify Currently Unknown Causes of ALS

PHD has a process in place by which external researchers doing studies to identify currently unknown causes of disease may request our collaboration. Studies designed to discover currently unknown causes of ALS would require significant resources and data from multiple parts of the country, not just Oregon.

Because data on ALS and its causes are lacking, the CDC's ATSDR has implemented the National ALS Registry for persons in the U.S. with ALS. The purpose of the registry is to collect information to help scientists learn more about who gets ALS and its causes.

<http://wwwn.cdc.gov/als/AboutRegistry.aspx>

PHD is hopeful that national researchers can identify a specific cause of ALS so we can implement measures to prevent people from getting this terrible disease.

Resources

- National Institutes of Health
http://www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail_ALS.htm
- Centers for Disease Control and Prevention
<https://wwwn.cdc.gov/als>