



# **ALS Prevalence Study: Herculaneum, Jefferson County, Missouri**

## **What was the purpose of this study?**

The purpose of this study was to identify all persons with Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, living in Jefferson County, Missouri.

## **Why was this study done?**

This study was done to respond to concerned residents about the number of persons with ALS in the Herculaneum area. Community residents are concerned about the impact of releases from an active lead smelter in their community.

## **Who conducted this study?**

This study was conducted by the Missouri Department of Health and Senior Services with funding from the Agency for Toxic Substances and Disease Registry, a federal public health agency located in Atlanta, Georgia.

## **What is ALS?**

ALS is characterized by progressive muscle weakness in the entire body, and a lethal outcome typically within 2-5 years after onset.

## **What is the cause of ALS?**

The cause of this devastating disease remains largely unknown, but may involve genetic, environmental, infectious, and autoimmune processes. The disease is rare before age 40, but increases with advancing age, peaking at around age 70.

## **How many people have ALS?**

ALS is a rare disease. It is estimated that there are 4 to 6 patients with ALS for every 100,000 people in the U.S. and other countries.

## **How was this study conducted?**

### **1. Participant Selection**

Persons with ALS were identified by:

- Reviewing existing records from hospitals, emergency room and office visits, nursing home admissions, rehabilitation facilities, and death certificates;
- Mailing to all practicing doctors in neurology, primary care providers and nursing home administrators; and
- Confirming self-referrals of persons with ALS.

## 2. Inclusion Criteria

To qualify as a study participant, all of the following criteria must be met:

- Residence in Jefferson County;
- Clinical visits between January 1, 1998 and December 31, 2002; and
- Confirmed diagnosis of possible, probable, or definite ALS by a neurology doctor.

## 3. Data Collection and Quality Assurance

- Medical records were reviewed by trained medical professionals and neurology specialist to confirm diagnosis of ALS.

## 4. Mapping of Cases

- Using a specialized computer program, the street addresses of all persons with confirmed ALS diagnosis were mapped on the Jefferson County map in order to identify any unusual accumulation of cases in one area.

## **What were the main findings of the study?**

The main findings of this study are:

1. The prevalence of ALS in Jefferson County was 3.9 per 100,000 population; in other words, there were about 4 people with ALS for every 100,000 Jefferson County residents.
2. The majority of people with ALS were men and white non-Hispanic.
3. The mean age of the patients with ALS was 65 years.
4. The age group with the highest occurrence for ALS was older than 75 years.
5. The prevalence of ALS in Jefferson County was not unusual, when compared to other areas of the U.S. or around the world.
6. There was an accumulation of cases identified around the lead smelter, which included three ALS patients.

### **What are the limitations of this study?**

The limitations of this study are:

1. This study was not designed to study risk factors for ALS; therefore we cannot evaluate what factors may be associated with ALS in the Herculaneum area.
2. This study did not include those persons who have moved away from Jefferson County and may have later developed ALS.
3. The accumulation of ALS cases detected in the study was based on a small number of ALS patients.

### **What follow-up activities are planned?**

The Missouri Department of Health and Senior Services, in collaboration with the federal Agency for Toxic Substances and Disease Registry and other state health departments, has submitted a grant to the National Institutes of Health (NIH) to conduct a study to investigate whether lead exposure is associated with the development of ALS.

### **Who can I contact if I want more information?**

For more information, please contact:

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