The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
Bureau of Environmental Health

Information Booklet

The Prevalence of Amyotrophic Lateral Sclerosis and Multiple Sclerosis and Ecologic Evaluation of Selected Environmental Factors in Southeastern Massachusetts

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What was the purpose of this epidemiologic investigation?

The purpose of this investigation was to identify all persons with amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) living in 30 Southeastern Massachusetts communities (all of Plymouth County plus Cohasset, Raynham, and Weymouth) during the period 1998 through 2003, calculate prevalence estimates for the study area and individual communities, and evaluate the geographic occurrence of these diseases in relation to environmental concerns in specific areas in Southeastern Massachusetts.

Why was the investigation done?

The investigation was conducted in response to resident concerns about the unusual number of persons diagnosed with ALS in the Middleborough area and MS in communities abutting the South Weymouth Naval Air Station area.

How were patients included in the study?

Any individual whose medical record indicated a diagnosis of ALS or MS before or during the surveillance period of January 1, 1998 through December 31, 2003 and who had a neurologist visit during this six-year period as a resident of the surveillance area was eligible for inclusion in the study. The primary sources of cases were neurologists and hospitals serving the study area. The Massachusetts Department of Public Health contacted these sources to identify cases. DPH staff abstracted clinical information for each case. Secondary case sources were also used to identify missing cases and included patient advocacy groups and death certificates.

What is Amyotrophic Lateral Sclerosis?

Amyotrophic Lateral Sclerosis (ALS) is a progressive, fatal neuromuscular disease involving both upper and lower motor neurons. The causes of ALS (also known as Lou Gehrig's disease) are not fully understood. It is characterized by a degeneration of motor nerve cells in the brain and spinal cord, leading to muscle weakness. As the disease progresses, total paralysis and the inability to speak or swallow can result. For the vast majority of people with ALS, the mind and senses remain intact and unaffected.

What are the causes of ALS?

ALS is characterized in the epidemiological and medical literature as a complex or multi-factorial disease. Both genetic and environmental factors are thought to contribute to the disease. It is the complex interaction between genetic factors and environmental factors that makes ALS a difficult disease to study. Researchers have proposed environmental risk factors for ALS including heavy metals, solvents, and agricultural chemicals, as well as a history of trauma to the brain and spinal cord. However, none of these risk factors have been reported consistently.

How many people have ALS in the U.S.?

ALS is estimated to affect some 18,000 people in the United States at any given time. The annual incidence is about 2 per 100,000 and prevalence is about 4-6 per 100,000 based upon the scientific literature. The mean duration of the disease is 3 years. ALS is about 20% more common in males than in females. Age at onset may vary from 40 to 70 years old.

What was the prevalence of ALS in Southeastern Massachusetts?

About 44% of cases reported were verified as definite or probable ALS after applying standardized diagnostic criteria. The prevalence for Southeastern Massachusetts based on all verified diagnoses of ALS was 2.4 cases per 100,000 population.

Was the prevalence of ALS significantly higher in Southeastern Massachusetts than expected?

No, the estimated prevalence of ALS in Southeastern Massachusetts (2.4 per 100,000) was not statistically significantly greater than what has been observed in a study outside Massachusetts (3.9 per 100,000), which was selected as the comparison area because the data collection methods were similar to those employed in the Massachusetts study. However, few studies use the comprehensive methods employed in this study and these are based on very small numbers with widely varying prevalence estimates. Therefore, the comparison of prevalence with currently available values from the scientific literature cannot be precise.

Does the ALS prevalence estimate found in this study represent the true prevalence of ALS in Southeastern Massachusetts?

The number of ALS cases reported by neurologists and hospitals was greater than the number of cases that the prevalence estimate was based on. Some medical records were incomplete and the medical records of cases reported as ALS by patient advocacy groups could not be reviewed and verified. It was concluded that some of these reported cases are likely definite or probable ALS and that the actual prevalence in Southeastern Massachusetts is likely somewhat higher than 2.4 per 100,000 but still not higher than would be expected based upon the scientific literature. Nevertheless, this observation underscores the need for broader disease surveillance efforts in order to obtain more precise estimates of the occurrence of this disease. In response, the statewide Massachusetts ALS Registry was initiated and has adopted revised methods based on the lessons learned from this study so that more precise estimates of ALS prevalence can be determined in Massachusetts.

Did the pattern of ALS in Middleborough or elsewhere in Southeastern Massachusetts appear unusual?

No, there were no ALS cases identified in Middleborough during the study period. Among the 43 ALS cases identified in the entire 30-community study area, there did not appear to be statistical clustering.

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is a chronic disease that steadily weakens the central nervous system. MS affects nerve fibers found in the brain and spinal cord. The inflammation of nervous tissue causes the loss of myelin. Myelin is a fatty material that protects the nerve fibers in the brain and spinal cord. With the loss of myelin, many areas of scar tissue (sclerosis) form along the covering of the nerve cells causing the messages to and from the brain to be altered.

What are the causes of MS?

The cause of MS is not known. Factors that may affect the onset and outcome of MS are climate, diet, environment, family history, physical and emotional stress, infections, and vaccines. MS is more common in women and in caucasians. Although there is little evidence for a single or unique environmental cause of MS, some research studies have reported associations between MS and exposures to organic solvents, metals, low temperatures, and trauma.

How many people have MS in the U.S.?

MS affects between 250,000 – 400,000 persons in the U.S. The estimated rate of persons with MS in the U.S. ranges from 39 to 173 per 100,000 and can be as high as 230 per 100,000 in northern North America. MS is frequently diagnosed in adults between the ages of 20 and 40, with prevalence highest in the 40 – 59 year age range. The ratio of MS in women to men is almost 3 women for every man.

What was the prevalence of MS in Southeastern Massachusetts?

It was found that 70% of cases reported by hospitals and neurologists were verified as definite or probable MS following verification of diagnosis using standardized diagnostic criteria. This study identified a prevalence of 103 per 100,000 based on verified cases of definite or probable MS in Southeastern Massachusetts for the 1998-2003 study period.

Was the prevalence of MS significantly higher than in comparison populations outside Massachusetts?

No, comparison of the estimated prevalence of MS in Southeastern Massachusetts was statistically significantly lower than that reported for the comparison area outside of Massachusetts for the same time period. However, as observed with ALS, there are few studies to compare our prevalence estimate with that used the same in-depth case finding methods and their prevalence estimates vary considerable.

Does the prevalence estimate represent the true prevalence of MS in Southeastern Massachusetts?

As with ALS, there were a number of cases reported by health professionals whose medical records were incomplete and, therefore, could not be included in the reported prevalence estimate. A number of MS cases were also reported by patient advocacy groups as having a diagnosis of MS, but they were not reported to the study by neurologists or hospitals. Because their medical records could not be reviewed, they also could not be included in the prevalence estimate. Some of these cases are likely definite or probable MS and, therefore, it is concluded that the prevalence for Southeastern Massachusetts was likely higher than 103 per 100,000

during the study period. However, it does not appear that prevalence is higher than expected for the general population, based on the scientific literature.

Did the pattern of MS in the vicinity of the South Weymouth Naval Air Station or elsewhere in Southeastern Massachusetts appear unusual?

The prevalence of MS in the 3-town area abutting the South Weymouth Naval Air Station (Abington, Rockland, and Weymouth) was higher than that for the total study area (144 per 100,000 and 109 per 100,000, respectively) for 1998-2003. Prevalence in the 3-town area was not found to be statistically significantly different from the reference population or the total study area. Statistical cluster detection methods were used to further explore the prevalence around the South Weymouth Naval Air Station (SWNAS). These found a greater concentration of individuals diagnosed with MS living in communities abutting the SWNAS than elsewhere in the surveillance area. However, within those communities, individuals with MS did not tend to live closer to the base than others. In addition, the population in the 3-town area increased more than elsewhere in the study area, as reflected in the 2000 U.S. Census data. Since population data are used in estimating prevalence, the estimates derived could be artificially higher in the 3-town area.

Has the pattern of MS in the 3-town area abutting SWNAS changed based on more recent data?

Yes, the evaluation of hospitalization data, as an approximation of the occurrence of MS, shows a decrease in hospitalizations among Rockland and Weymouth residents but hospitalizations increase somewhat among Abington residents.

What were the summary conclusions of the ALS/MS Study in Southeastern Massachusetts?

- The prevalence of ALS was not found to be elevated in the study area as a whole. Further, no geographic patterns were observed suggesting that environmental factors played a primary role in the occurrence of ALS in any of the 30 communities studied.

- The prevalence of MS was not found to be elevated in the study area as a whole during the 1998 - 2003 surveillance period nor in comparison to an area outside of MA that used similar surveillance methods during the 1998 - 2001 period.

- The prevalence of MS was statistically significantly higher in the 3-town area adjacent to the SWNAS compared to the 30 town study area; however, examination of residence of individuals in relation to the SWNAS did not suggest that opportunities for environmental exposures related to the base played a primary role in the occurrence of MS.

- The results of this study cannot rule out the possibility that environmental or occupational exposures may have played a role in some individual diagnoses of either MS or ALS.

However, it is unlikely that residences near the base played a primary role in the overall pattern of MS in the 3-town area adjacent to SWNAS.

- A comparison of the most recent hospitalization data for MS suggests that MS hospitalizations during the 2004 - 2009 period are lower in Weymouth and Rockland compared to hospitalizations during the 1998 - 2003 study period, however, MS hospitalizations in the town of Abington are somewhat higher.

What is MDPH doing to better understand the prevalence of ALS and MS in Massachusetts?

1. MDPH is now conducting ALS surveillance statewide consistent with Section 26 of Chapter 140 of the Massachusetts Acts of 2003 and should summarize statewide and community surveillance estimates.

2. MDPH will provide copies of the ATSDR/MDPH Health Consultations on Gerson Properties and Middleborough Plating to local health, legislative representatives, and community residents upon completion.

3. MDPH/BEH is currently funded by the U.S. Centers for Disease Control and Prevention (CDC) Environmental Public Health Tracking branch to continue development of health and environmental electronic surveillance systems. As part of that effort, MDPH will make community-level ALS data available to the public on the MDPH website.

4. MDPH will continue to monitor the occurrence of MS using available electronic systems, such as hospitalization data.

Where can I get more information?

The full report is available on the MDPH/BEH website under “Environmental Health Investigations” at www.mass.gov/dph/environmental_health

If you have questions, you can contact:

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