ALS Surveillance in Massachusetts: A one-of-a-kind registry for tracking an elusive disease

Vannalyn Abille
Massachusetts Department of Public Health

Et al.

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## Background

Amyotrophic Lateral Sclerosis (ALS) is a progressive and fatal neuromuscular disease with an etiology not yet fully understood. The Massachusetts Argeo Paul Cellucci ALS Registry is a unique population-based surveillance system used to monitor the occurrence of ALS throughout the state and to explore possible environmental causes of the disease.

## Methods

The Registry gathers annual reports of ALS cases from physicians, hospitals, and clinics in accordance with state regulations.

- Medical records are obtained and abstracted for each case, and eligible cases are reviewed by a consulting neurologist to confirm diagnosis.
- Necessary clinical and demographic information are recorded in a database and used by the Massachusetts Department of Public Health (MDPH) to prepare reports containing community-specific and statewide prevalence and incidence estimates. The data are also used to investigate spatial and temporal patterns and constitute a rich resource for researchers to explore environmental risk factors and whether they may impact disease rates.

## Results and Conclusion

The result is a first-in-the-nation registry that allows for comprehensive capture of all ALS cases and complete verification of all reported cases.

From 2007-2011, 826 new ALS cases were reported to MDPH. The average age-adjusted incidence rate from 2007-2011 was 2.2 ALS cases per 100,000 population per year, and the average age–adjusted prevalence was 5.6 per 100,000 - both comparable to the range of estimates reported in scientific literature. MDPH evaluated ALS occurrence similarly by community and other variables like age and family history.

## Future of the Registry

Data are available to inform patient service needs and epidemiologic studies. Researchers can apply for access with the MDPH’s IRB. A data report for years 2007 – 2014 is planned for release in early 2018. Future data updates and more information can be found on the ALS Registry website [www.mass.gov/dph/ALS](http://www.mass.gov/dph/ALS) or contact [Massachusetts-ALS-Registry@state.ma.us](mailto:Massachusetts-ALS-Registry@state.ma.us).