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

Vannalyn Abille  
*Massachusetts Department of Public Health*

Alicia Fraser  
*Massachusetts Department of Public Health*

Robert Knorr  
*Massachusetts Department of Public Health*

Follow this and additional works at: [http://escholarship.umassmed.edu/chr_symposium](http://escholarship.umassmed.edu/chr_symposium)  
Part of the [Civic and Community Engagement Commons](http://escholarship.umassmed.edu/civicengagement), [Clinical Epidemiology Commons](http://escholarship.umassmed.edu/clinical_epidemiology), [Community-Based Research Commons](http://escholarship.umassmed.edu/communitybasedresearch), [Community Health and Preventive Medicine Commons](http://escholarship.umassmed.edu/community_health), [Environmental Public Health Commons](http://escholarship.umassmed.edu/environmentalpublichealth), [Epidemiology Commons](http://escholarship.umassmed.edu/epidemiology), [Nervous System Diseases Commons](http://escholarship.umassmed.edu/nervoussystemdiseases), and the [Translational Medical Research Commons](http://escholarship.umassmed.edu/translationalmedicalresearch)

This work is licensed under a [Creative Commons Attribution-Noncommercial-Share Alike 3.0 License](http://creativecommons.org/licenses/by-nc-sa/3.0/).
**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.