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

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



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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

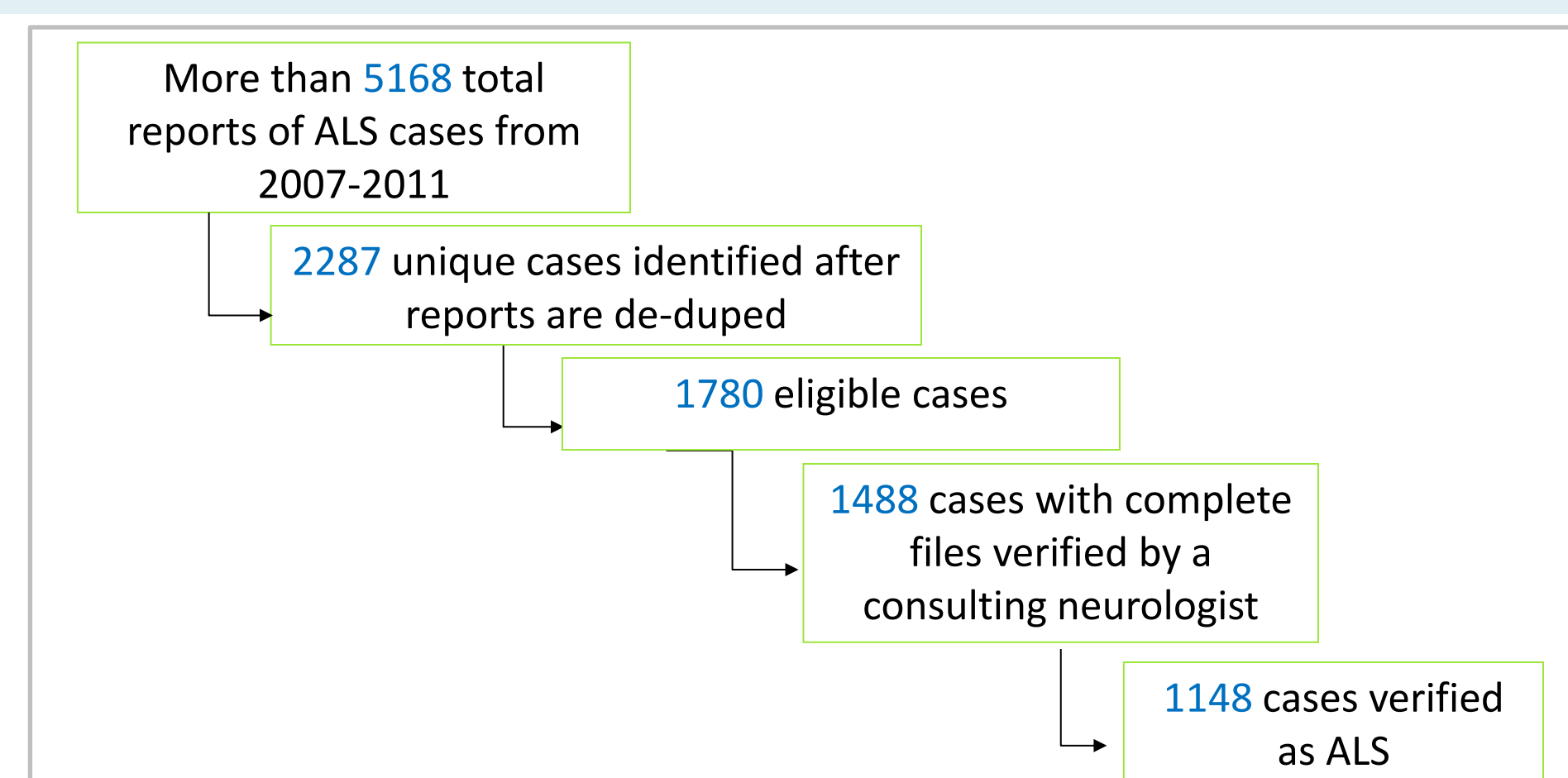
The Registry gathers annual reports of ALS cases from physicians, hospitals, and clinics in accordance with state regulations.

- 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.

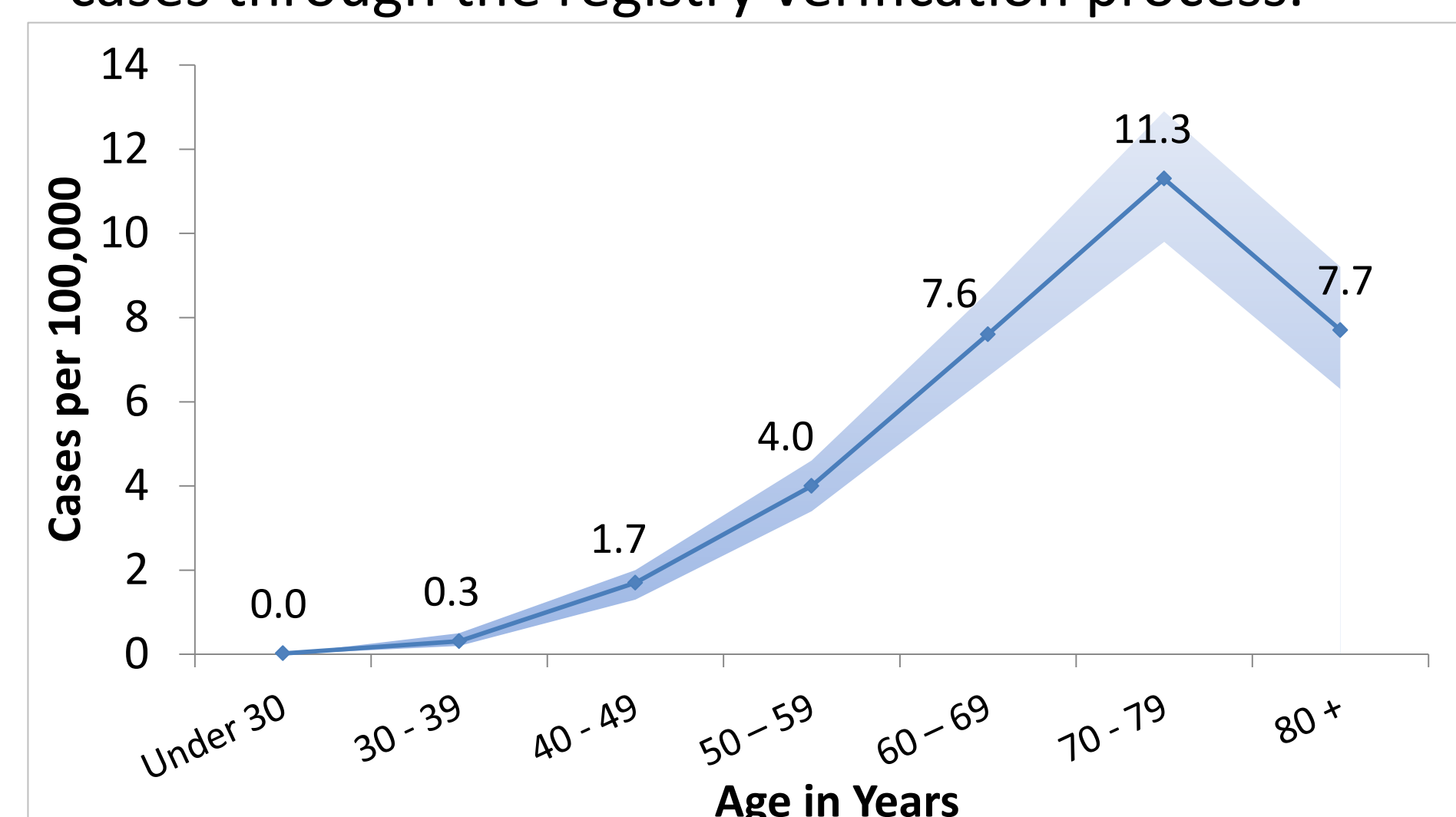
## Future of the Registry

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).

## Results and Conclusion



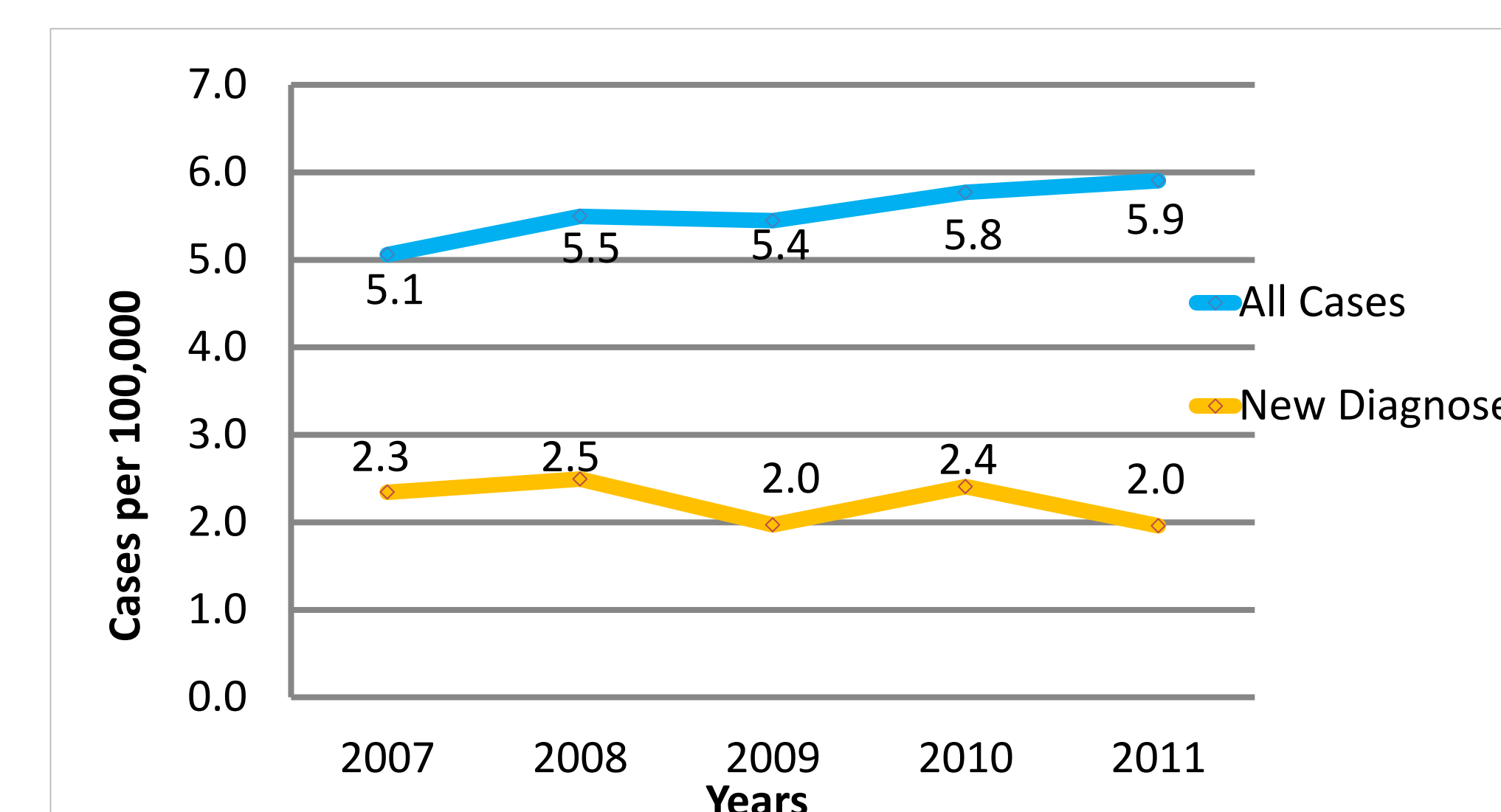
**Fig 1.** Flow diagram of the 2007-2011 reported ALS cases through the registry verification process.



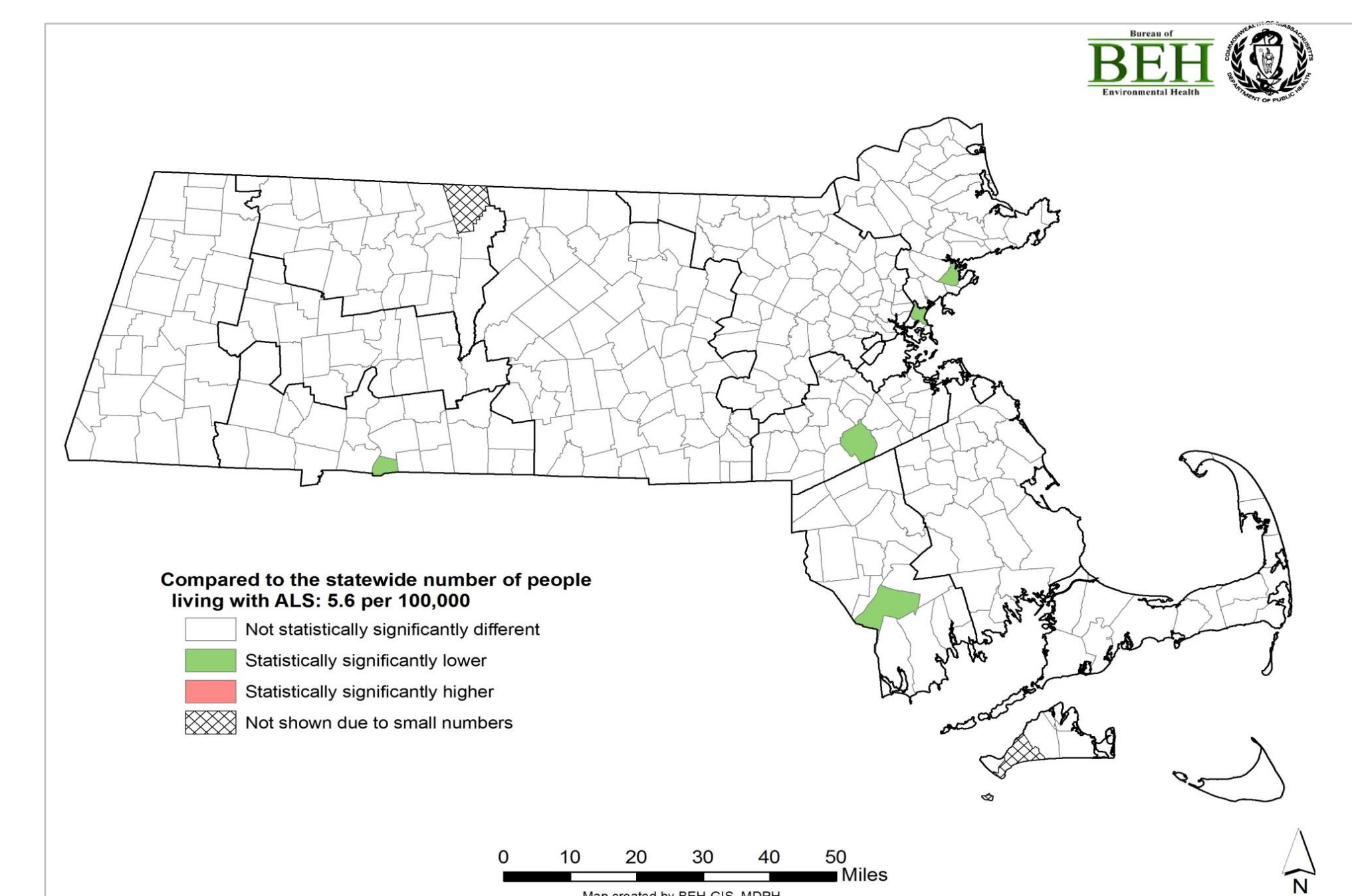
**Fig 3.** Age-specific incidence rate from 2007-2011.

Characteristic	Total No. (% of cases)	2009 Population of MA (% of population)
<b>Age group (years)</b>		
Under 30	2 (0.2)	2,536,045 (38.8)
30-39	14 (1.7)	843,045 (12.9)
40-49	82 (9.9)	984,450 (15.1)
50-59	182 (22.0)	909,046 (13.9)
60-69	235 (28.5)	616,877 (9.4)
70-79	203 (24.6)	358,831 (5.5)
≥ 80	108 (13.1)	280,110 (4.3)
<b>Sex</b>		
Female	384 (46.5)	3,372,286 (51.7)
Male	442 (53.5)	3,156,118 (48.3)
<b>Total</b>	<b>826 (100.0)</b>	<b>6,528,404 (100.0)</b>

**Table 1.** Number of identified new ALS cases, by age group and sex (2007-2011)



**Fig 2.** Age-adjusted incidence rate (new diagnoses) and prevalence rate (all cases) of ALS from 2007-2011.



**Fig 4.** Map of Massachusetts, highlighting areas that are statistically significantly different to the statewide prevalence rate.

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.