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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 or contact Massachusetts-ALS-Registry@state.ma.us.

Results and Conclusion

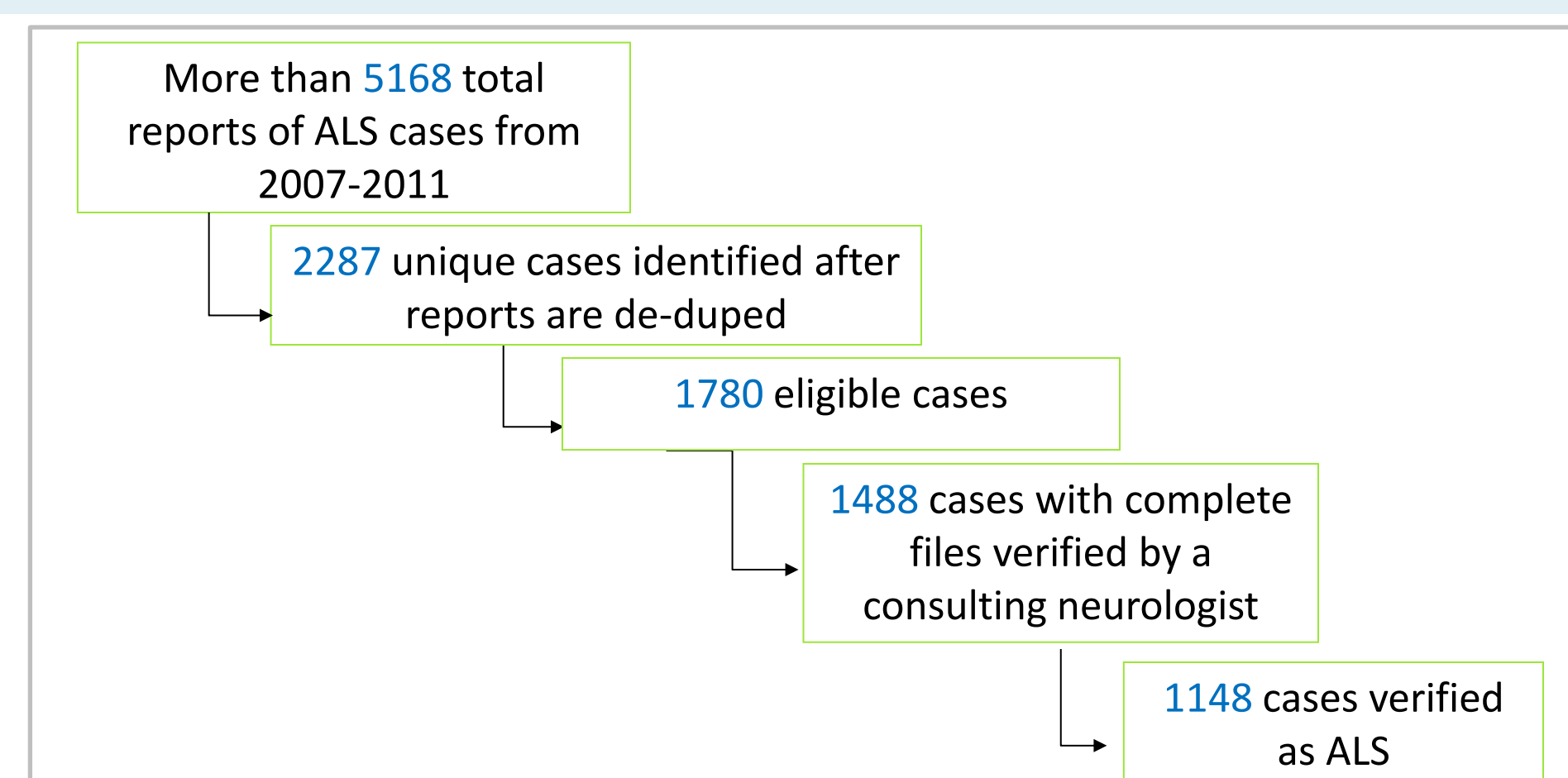


Fig 1. Flow diagram of the 2007-2011 reported ALS cases through the registry verification process.

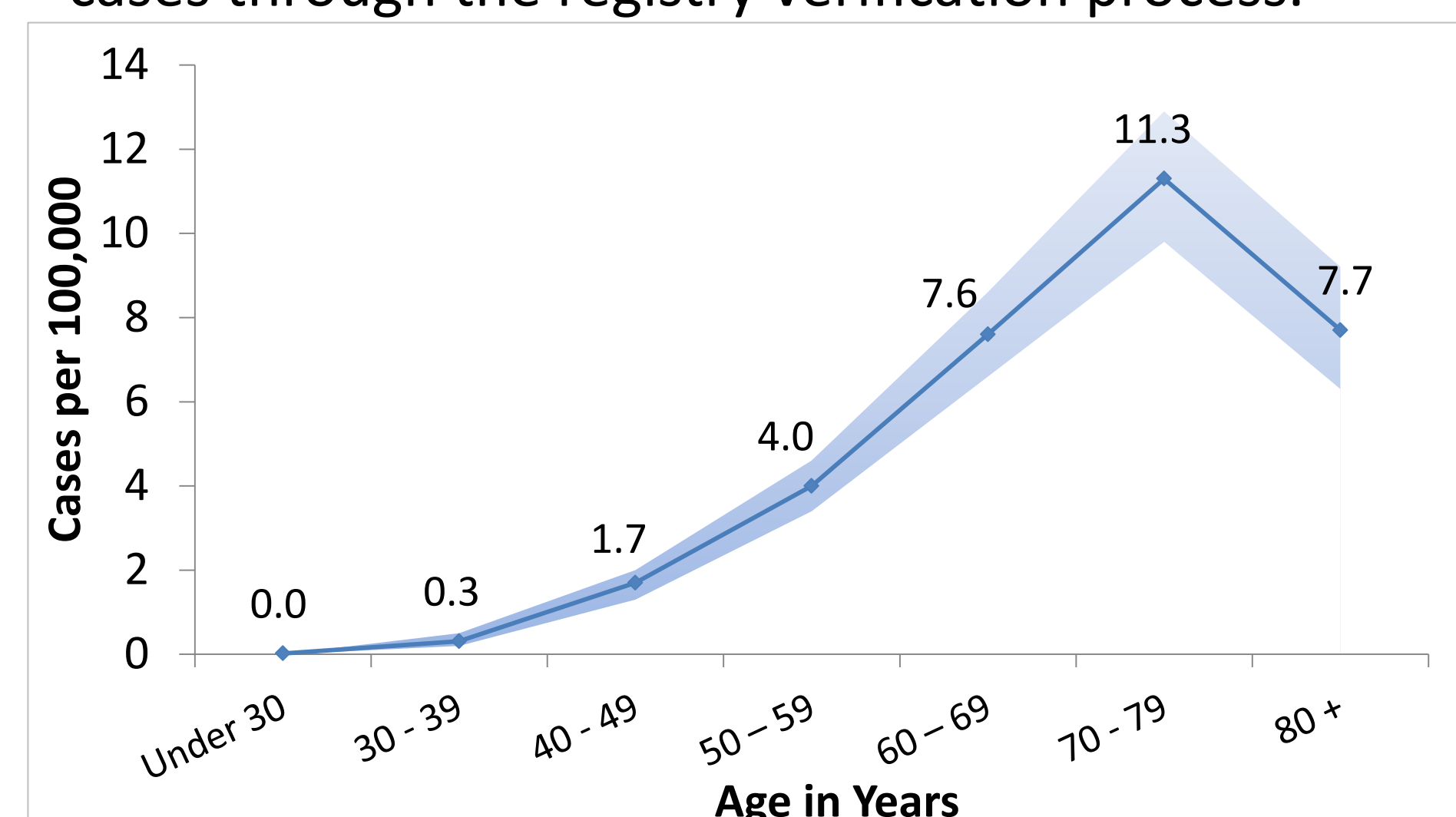


Fig 3. Age-specific incidence rate from 2007-2011.

Characteristic	Total No. (% of cases)	2009 Population of MA (% of population)
Age group (years)		
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)
Sex		
Female	384 (46.5)	3,372,286 (51.7)
Male	442 (53.5)	3,156,118 (48.3)
Total	826 (100.0)	6,528,404 (100.0)

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

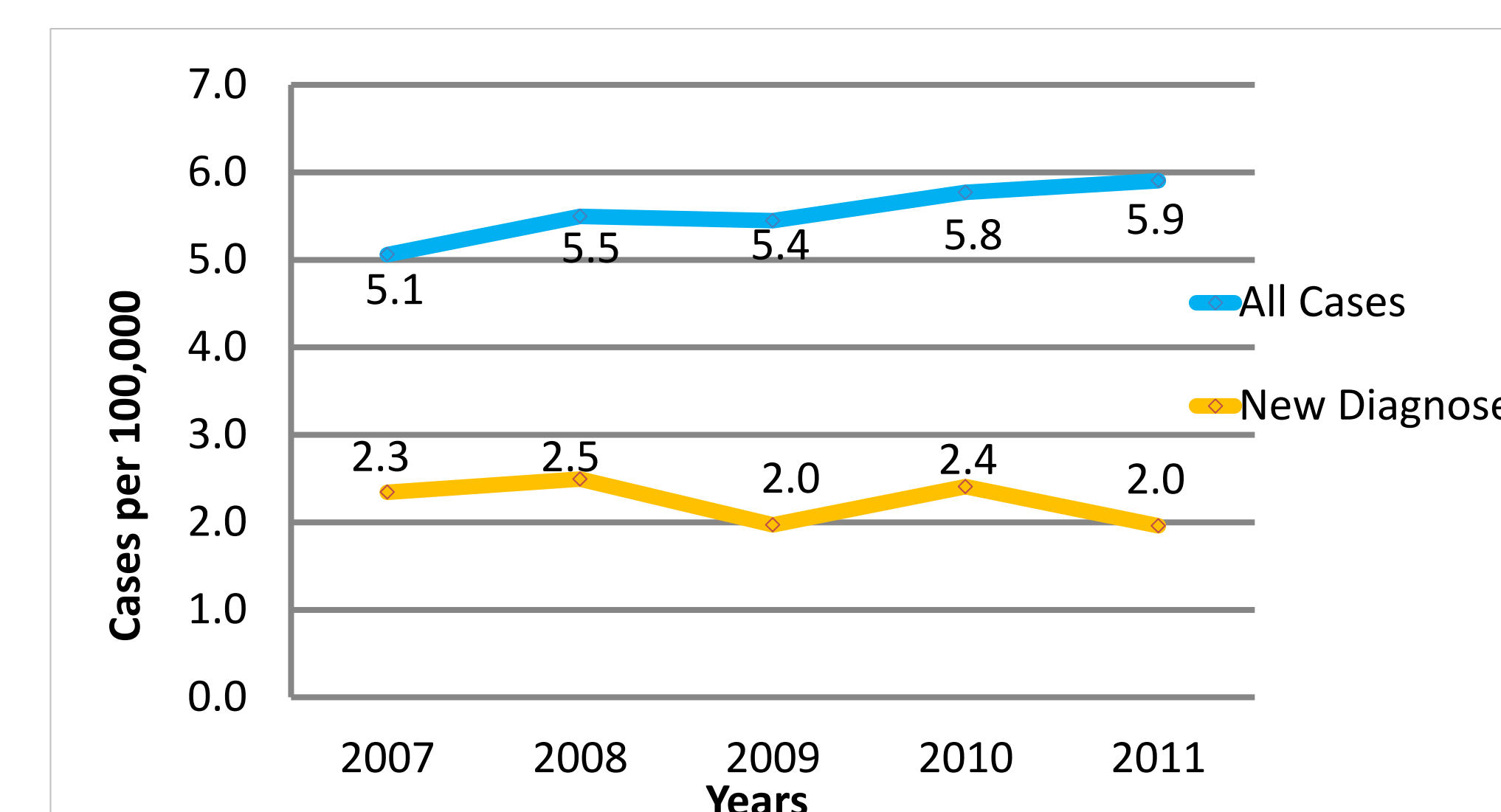


Fig 2. Age-adjusted incidence rate (new diagnoses) and prevalence rate (all cases) of ALS from 2007-2011.

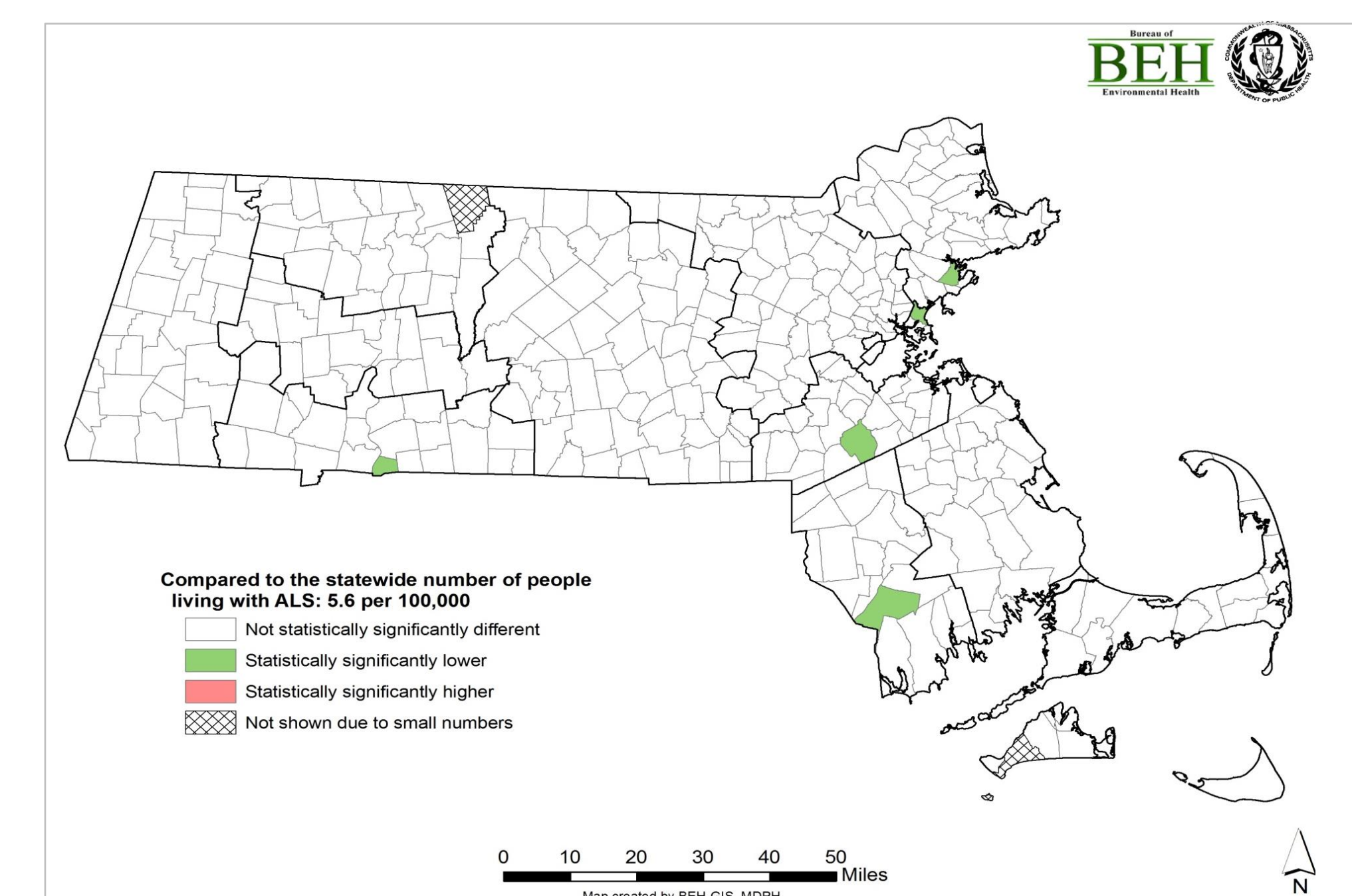


Fig 4. Map of Massachusetts, highlighting areas that are statistically significantly different to the statewide prevalence rate.

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.