



The Commonwealth of Massachusetts  
Executive Office of Health and Human Services  
Department of Public Health  
250 Washington Street, Boston, MA 02108-4619

CHARLES D. BAKER  
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Secretary

MONICA BHAREL, MD, MPH  
Commissioner

Tel: 617-624-6000  
www.mass.gov/dph

Dear Practice Manager, Physician, or Keeper of Medical Records:

This letter serves as the Massachusetts Department of Public Health's (DPH) annual request for reporting of Amyotrophic Lateral Sclerosis (ALS) cases. We sincerely appreciate the past and future cooperation of all neurologists and health care facilities statewide in reporting all patients having been evaluated for or diagnosed with ALS. As you are aware, clinical research and interventions are often limited by incomplete epidemiologic data. Further, important public health questions have been raised regarding the possible increases in incidence of ALS. The DPH ALS Registry addresses this need with comprehensive disease surveillance, serving a valuable role for the community of patients, providers, researchers, and others concerned with ALS throughout the Commonwealth.

**DPH is requesting that you report any patients who reside in Massachusetts, have been evaluated for or diagnosed with ALS, and who visited your facility between January 1, \_\_\_\_\_ (YEAR) and December 31, \_\_\_\_\_ (YEAR).**

Please return the Report Form to:

**Massachusetts Department of Public Health  
Bureau of Environmental Health  
c/o ALS Registry Coordinator  
250 Washington Street, 7<sup>th</sup> Floor  
Boston, MA 02108**

Included are the ICD-10 codes for ALS and associated illnesses that we are asking your office to report (second page). Upon receipt of this information, we will contact your office for an appointment to access the patients' medical records to abstract relevant patient and diagnostic information. The original records will not leave your office and we will make every effort to be as unobtrusive as possible when abstracting this information. If you are a **practice manager or are reporting on behalf of the entire neurology department**, please include a list of the neurologists in your department or practice.

For questions, please contact Tom Quail, RN, LNC at 617-624-5743. Thank you for helping to improve our understanding of ALS occurrence in the Commonwealth.

Sincerely,

Alicia Fraser, MPH, DSc- Director, Environmental Epidemiology Program  
Tom Quail, RN, LNC - ALS Registry Clinical Coordinator

**\*\*Please include a list of all physicians in your practice with this letter. Thank you.**

## Diagnosis Codes:

- **ICD 10 code** G12. 2: Diagnosis of Motor Neuron Disease
  - G12.20 Motor neuron disease, unspecified
  - G12.21 Amyotrophic lateral sclerosis
  - G12.22 Progressive bulbar palsy
  - G12.23 Primary lateral sclerosis
  - G12.24 Familial motor neuron disease
  - G12.25 Progressive spinal muscle atrophy
  - G12.29 Other motor neuron disease

★ If your facility uses ICD-9 codes, please contact the ALS Registry Coordinator at 617-624-5757 so we can provide you with the list of ICD 9 codes that correspond to our request.

The Massachusetts ALS Registry, as established by Section 26 of Chapter 140 of the Acts of 2003, is conducted in accordance with state law. DPH regulation 105 CMR 300.192 authorizes DPH to collect medical records and other identifiable information from health care providers on individuals diagnosed with or evaluated for ALS, which allows covered entities under the Health Insurance Portability and Accountability Act (HIPAA) to disclose protected health information to DPH without obtaining written authorization of the data subject. Additionally, under Massachusetts General Laws Chapter 111, all information collected is strictly confidential and anyone providing information to DPH as part of this surveillance will not be liable for any damages related to the disclosure.