

STATE OF MAINE

—  
IN THE YEAR OF OUR LORD  
TWO THOUSAND TWENTY-TWO

—  
S.P. 724 - L.D. 2007

**An Act To Create the Amyotrophic Lateral Sclerosis Incidence Registry**

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 22 MRSA c. 255-A is enacted to read:

**CHAPTER 255-A**

**AMYOTROPHIC LATERAL SCLEROSIS**

**§1411. Registry established**

The Maine Center for Disease Control and Prevention shall establish, maintain and operate a statewide amyotrophic lateral sclerosis incidence registry, referred to in this chapter as "the registry."

**§1412. Duty of health care providers**

A physician, surgeon, nurse practitioner, physician assistant or other health care practitioner and a hospital or other health care facility that screens for, diagnoses or provides therapeutic services to patients with amyotrophic lateral sclerosis shall report to the department all persons diagnosed as having amyotrophic lateral sclerosis no later than 6 months from the date of diagnosis. The report must include, but is not limited to, information on each person's usual occupation and industry of employment and other elements determined by rule to be appropriate.

**§1413. Confidentiality**

Information that directly or indirectly identifies individual persons contained within the registry is confidential and protected by applicable law, including section 42, subsections 2 and 5 and chapters 401 and 857. Information within the registry may be disclosed in aggregated, de-identified form. Information that directly or indirectly identifies individual persons contained within the registry may be disclosed only in a manner consistent with applicable state and federal confidentiality laws and policies. The department may establish data sharing and protection agreements with state, regional and national amyotrophic lateral sclerosis registries for bidirectional data exchange, in a

manner consistent with applicable state and federal confidentiality laws and policies. The department may disclose the minimum information necessary to accomplish a specified research purpose only upon successful completion of the research disclosure approval process established by the department and as permitted under applicable human subject research protections, state and federal laws and the department's confidentiality policies and processes.

**§1414. Annual report**

The department shall prepare and submit to the Governor annual reports containing statewide prevalence and incidence estimates of amyotrophic lateral sclerosis, including any trends occurring over time across the State. The reports may not contain any information that directly or indirectly identifies individual persons.

**§1415. Rules**

The department shall adopt rules to implement this chapter, including, but not limited to, rules governing the operation of the registry, reporting to the registry and data release protocols. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.