



130th MAINE LEGISLATURE

SECOND REGULAR SESSION-2022

Legislative Document

No. 2007

S.P. 724

In Senate, March 9, 2022

An Act To Create the Amyotrophic Lateral Sclerosis Incidence Registry

Received by the Secretary of the Senate on March 3, 2022. Referred to the Committee on Health and Human Services pursuant to Joint Rule 308.2 and ordered printed.

A handwritten signature in black ink, appearing to read "D M Grant", is positioned above the printed name of the Secretary of the Senate.

DAREK M. GRANT
Secretary of the Senate

Presented by Senator CLAXTON of Androscoggin. (GOVERNOR'S BILL)
Cosponsored by Representative OSHER of Orono.

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

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

3 **CHAPTER 255-A**

4 **AMYOTROPHIC LATERAL SCLEROSIS**

5 **§1411. Registry established**

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

9 **§1412. Duty of health care providers**

10 A physician, surgeon, nurse practitioner, physician assistant or other health care
11 practitioner and a hospital or other health care facility that screens for, diagnoses or
12 provides therapeutic services to patients with amyotrophic lateral sclerosis shall report to
13 the department all persons diagnosed as having amyotrophic lateral sclerosis no later than
14 6 months from the date of diagnosis. The report must include, but is not limited to,
15 information on each person's usual occupation and industry of employment and other
16 elements determined by rule to be appropriate.

17 **§1413. Confidentiality**

18 Information that directly or indirectly identifies individual persons contained within
19 the registry is confidential and protected by applicable law, including section 42,
20 subsections 2 and 5 and chapters 401 and 857. Information within the registry may be
21 disclosed only in aggregated, de-identified form and in a manner consistent with Maine
22 Center for Disease Control and Prevention confidentiality policies. The department may
23 disclose the minimum information necessary to accomplish a specified research purpose
24 only upon successful completion of the research disclosure approval process established
25 by the department and as permitted under applicable human subject research protections,
26 state and federal laws and the department's confidentiality policies and processes.

27 **§1414. Annual report**

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

32 **§1415. Rules**

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

SUMMARY

This bill requires health care practitioners and health care facilities to report diagnoses of amyotrophic lateral sclerosis to the Department of Health and Human Services in order for the Maine Center for Disease Control and Prevention to create and maintain a statewide registry for surveillance of the disease in the State. The bill provides confidentiality protections regarding information that directly or indirectly identifies individual persons. The bill requires the department to complete annual reports containing statewide prevalence and incidence estimates of amyotrophic lateral sclerosis, including any trends occurring over time across the State. The bill also requires the department to adopt routine technical rules to implement the registry.