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

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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.

DAREK M. GRANT
Secretary of the Senate

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

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 only in aggregated, de-identified form and in a manner consistent with Maine Center for Disease Control and Prevention confidentiality 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.

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.