

2024 Regular Session

SENATE BILL NO. 239

BY SENATOR MCMATH

DISEASE CONTROL. Provides relative to amyotrophic lateral sclerosis. (gov sig)

1 AN ACT

2 To enact Part IX of Chapter 1 of Title 40 of the Louisiana Revised Statutes of 1950, to be
3 comprised of R.S. 40:31.71 through 31.74, relative to amyotrophic lateral sclerosis;
4 to provide for legislative findings; to establish an amyotrophic lateral sclerosis
5 surveillance system; to require reporting to the Louisiana Department of Health; to
6 provide for exemptions to reporting requirements; to provide for confidentiality; to
7 provide for reporting requirements for the department; to provide for an effective
8 date; and to provide for related matters.

9 Be it enacted by the Legislature of Louisiana:

10 Section 1. Part IX of Chapter 1 of Title 40 of the Louisiana Revised Statutes of 1950,
11 comprised of R.S. 40:31.71 through 31.74, is hereby enacted to read as follows:

12 **PART IX. LOUISIANA AMYOTROPHIC LATERAL**

13 **SCLEROSIS REGISTRY**

14 **§31.71. Legislative findings**

15 **The legislature hereby finds and declares that:**

16 **(1) Amyotrophic lateral sclerosis, or ALS, most often takes at least a year**
17 **to be diagnosed and is a diagnosis of exclusion, meaning that it becomes the**

1 diagnosis after other options are exhausted.

2 (2) The average time living with the disease is two to five years, and is
3 often shorter and seldom much longer unless invasive measures are taken, such
4 as a tracheostomy.

5 (3) It costs over two hundred thousand dollars a year to live with a
6 trache, so ninety percent of the ALS population in the United States chooses not
7 to undergo the procedure.

8 (4) Because the disease progresses so rapidly, patients most often do not
9 attend an ALS clinic or long-term care clinic where their diagnosis would or
10 could be reported to the Centers for Disease Control and Prevention (CDC), the
11 organization tasked with counting those with ALS.

12 (5) The CDC program uses payor information and self-reporting to
13 create their data and acknowledges their numbers are likely low, but they are
14 beholden to the methods outlined by Congress.

15 (6) Several studies have been done to show that in states with
16 implemented efforts to count those living with ALS, the number dramatically
17 increased in each state.

18 (7) Louisiana currently reflects very few people with ALS north of Baton
19 Rouge, likely because they remain uncounted.

20 (8) The only state, Massachusetts, that has ALS as a mandatory
21 reportable disease has become a hub for ALS research.

22 §31.72. ALS disease surveillance system

23 A. The Louisiana Department of Health shall establish an amyotrophic
24 lateral sclerosis (ALS) surveillance system within the office of public health to
25 collect, analyze, interpret, and disseminate data relative to individuals living
26 with ALS in Louisiana.

27 B. In establishing the surveillance system, the department shall require
28 reporting sources to report information on ALS to the office of public health.

29 §31.73. Confidentiality

1 **Notwithstanding any other provision of the law to the contrary,**
 2 **individual identifying data in the surveillance system shall be confidential and**
 3 **shall not be subject to discovery. Data shall not be released for any child unless**
 4 **express written informed consent of a parent or legal guardian has been**
 5 **obtained. Data gathered by the office shall be used only for the purposes set**
 6 **forth in this Part.**

7 **§31.74. Report**

8 **The department shall produce an annual report on the results obtained**
 9 **through the surveillance system to be submitted to the secretary of the**
 10 **Louisiana Department of Health and the House and Senate committees on**
 11 **health and welfare.**

12 Section 2. This Act shall become effective upon signature by the governor or, if not
 13 signed by the governor, upon expiration of the time for bills to become law without signature
 14 by the governor, as provided by Article III, Section 18 of the Constitution of Louisiana. If
 15 vetoed by the governor and subsequently approved by the legislature, this Act shall become
 16 effective on the day following such approval.

The original instrument and the following digest, which constitutes no part
 of the legislative instrument, were prepared by Amanda Trapp.

DIGEST

SB 239 Engrossed

2024 Regular Session

McMath

Proposed law provides for legislative findings relative to amyotrophic lateral sclerosis (ALS).

Proposed law requires the Louisiana Department of Health to establish an ALS surveillance system and requires reporting sources to report information on ALS to the office of public health.

Proposed law provides for confidentiality of data reported to the department.

Proposed law provides for exemptions to reporting requirements for children unless the parent or guardian of the child provides written consent.

Proposed law provides for reporting requirements for the department.

Effective upon signature of the governor or lapse of time for gubernatorial action.

(Adds R.S. 40:31.71-31.74)