

SENATE BILL NO. 239

BY SENATOR MCMATH AND REPRESENTATIVE CHASSION

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**
18 **diagnosis after other options are exhausted.**

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

22 **(3) It costs over two hundred thousand dollars a year to live with a**
23 **tracheostomy tube, so ninety percent of the ALS population in the United States**
24 **chooses not to undergo the procedure.**

25 **(4) Because the disease progresses so rapidly, patients most often do not**
26 **attend an ALS clinic or long-term care clinic where their diagnosis would or**
27 **could be reported to the Centers for Disease Control and Prevention (CDC), the**

1 organization tasked with counting those with ALS.

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

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

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

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

12 §31.72. ALS disease surveillance system

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

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

19 §31.73. Confidentiality

20 Notwithstanding any other provision of the law to the contrary,
21 individual identifying data in the surveillance system shall be confidential and
22 shall not be subject to discovery. Data shall not be released for any child unless
23 express written informed consent of a parent or legal guardian has been
24 obtained. Data gathered by the office shall be used only for the purposes set
25 forth in this Part.

26 §31.74. Report

27 The department shall produce an annual report on the results obtained
28 through the surveillance system to be submitted to the secretary of the
29 Louisiana Department of Health and the House and Senate committees on
30 health and welfare.

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

PRESIDENT OF THE SENATE

SPEAKER OF THE HOUSE OF REPRESENTATIVES

GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____