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H.258

Introduced by Representatives Cina of Burlington, Browning of Arlington,
and Yacovone of Morristown

Referred to Committee on

Date:

Subject: Health; amyotrophic lateral sclerosis; registry

Statement of purpose of bill as introduced: This bill proposes to establish an
amyotrophic lateral sclerosis registry.

An act relating to establishing an amyotrophic lateral sclerosis registry

It is hereby enacted by the General Assembly of the State of Vermont:

Sec. 1. 18 V.S.A. chapter 4A is added to read:

CHAPTER 4A. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

§ 171. DEFINITIONS

As used in this chapter:

(1) “Amyotrophic lateral sclerosis” or “ALS” means a progressive
neurodegenerative disease that affects nerve cells in the brain and the spinal
cord.

(2) “Health care facility” has the same meaning as in section 9432 of
this title.

1 (3) “Health care provider” has the same meaning as in section 9432 of
2 this title.

3 § 172. ESTABLISHMENT OF AMYOTROPHIC LATERAL SCLEROSIS
4 REGISTRY

5 (a) The Commissioner shall establish a uniform statewide population-based
6 amyotrophic lateral sclerosis registry system for the collection of information
7 determining the incidence of amyotrophic lateral sclerosis and related data.
8 Pursuant to 3 V.S.A. chapter 25, the Commissioner shall adopt rules necessary
9 to effect the purposes of this chapter, including the data to be reported and the
10 effective date after which reporting by health care facilities and health care
11 providers shall be required.

12 (b) All cases of amyotrophic lateral sclerosis diagnosed or treated in the
13 State shall be reported to the representative of the Department of Health
14 authorized by the Commissioner to compile the amyotrophic lateral sclerosis
15 data, or any individual, agency, or organization designated to cooperate with
16 that representative.

17 (c) The Commissioner shall establish a training program for the personnel
18 of participating health care facilities and a quality control program for
19 amyotrophic lateral sclerosis data. The Commissioner shall collaborate in
20 studies with clinicians and epidemiologists and publish reports on the results of
21 such studies. The Commissioner shall cooperate with the National Institutes of

1 Health and the Centers for Disease Control and Prevention in providing
2 amyotrophic lateral sclerosis incidence data.

3 § 173. PARTICIPATION IN PROGRAM

4 (a) Any health care facility diagnosing or providing treatment to patients
5 with amyotrophic lateral sclerosis shall report each case of amyotrophic lateral
6 sclerosis to the Commissioner or his or her authorized representative in a
7 format prescribed by the Commissioner within 180 days of admission or
8 diagnosis. If the facility fails to report in a format prescribed by the
9 Commissioner, the Commissioner's authorized representative may enter the
10 facility, obtain the information, and report it in the appropriate format. In these
11 cases, the facility shall reimburse the Commissioner or the authorized
12 representative for the cost of obtaining and reporting the information.

13 (b) Any health care provider diagnosing or providing treatment to patients
14 with amyotrophic lateral sclerosis shall report each case to the Commissioner
15 or his or her authorized representative within 180 days of diagnosis.

16 (c) All health care facilities and health care providers who provide
17 diagnostic or treatment services to patients with amyotrophic lateral sclerosis
18 shall report to the Commissioner any further demographic, diagnostic, or
19 treatment information requested by the Commissioner concerning any person
20 now or formerly receiving services. Additionally, the Commissioner or his or
21 her authorized representative shall have physical access to all records that

1 would identify cases of amyotrophic lateral sclerosis or would establish
2 characteristics of the amyotrophic lateral sclerosis, treatment of the
3 amyotrophic lateral sclerosis, or medical status of any identified patient with
4 amyotrophic lateral sclerosis. Willful failure to grant access to such records
5 shall be punishable by a fine of up to \$500.00 for each day access is refused.
6 Any fines collected pursuant to this subsection shall be deposited in the
7 General Fund.

8 § 174. CONFIDENTIALITY

9 (a) All information reported pursuant to this chapter shall be confidential
10 and privileged. The Commissioner shall take strict measures to ensure that all
11 identifying information is kept confidential.

12 (b) All identifying information regarding an individual patient, health care
13 provider, or health care facility contained in records of interviews, written
14 reports, and statements procured by the Commissioner or by any other person,
15 agency, or organization acting jointly with the Commissioner in connection
16 with amyotrophic lateral sclerosis morbidity and mortality studies shall be
17 confidential and privileged and shall be used solely for the purposes of the
18 study. Nothing in this section shall prevent the Commissioner from publishing
19 statistical compilations relating to morbidity and mortality studies that do not
20 identify individual cases or sources of information.

1 § 175. DISCLOSURE

2 (a) The Commissioner may enter into agreements to exchange confidential
3 information with any other amyotrophic lateral sclerosis registries in order to
4 obtain complete reports of Vermont residents diagnosed or treated in other
5 states and to provide information to other states regarding their residents
6 diagnosed or treated in Vermont.

7 (b) The Commissioner may furnish confidential information to other states'
8 amyotrophic lateral sclerosis registries or health researchers in order to
9 collaborate in a national amyotrophic lateral sclerosis registry or to collaborate
10 in amyotrophic lateral sclerosis control and prevention research studies.

11 However, before releasing confidential information, the Commissioner shall
12 first obtain from such state registries, agencies, or researchers an agreement in
13 writing to keep the identifying information confidential and privileged. In the
14 case of researchers, the Commissioner shall also first obtain evidence of the
15 approval of their academic committee for the protection of human subjects
16 established in accordance with 45 C.F.R. part 46.

17 § 176. LIABILITY

18 (a) No action for damages arising from the disclosure of confidential or
19 privileged information may be maintained against any person, or the employer
20 or employee of any person, who participates in good faith in the reporting of

1 amyotrophic lateral sclerosis registry data or data for amyotrophic lateral
2 sclerosis morbidity or mortality studies in accordance with this chapter.

3 (b) No license of a health care facility or health care provider may be
4 denied, suspended, or revoked for the good faith disclosure of confidential or
5 privileged information in the reporting of amyotrophic lateral sclerosis registry
6 data or data for amyotrophic lateral sclerosis morbidity or mortality studies in
7 accordance with this chapter.

8 (c) Nothing in this section shall be construed to apply to the unauthorized
9 disclosure of confidential or privileged information when such disclosure is
10 due to gross negligence or willful misconduct.

11 Sec. 2. EFFECTIVE DATE

12 This act shall take effect on July 1, 2019.