

1 Introduced by Representative Cina of Burlington  
2 Referred to Committee on  
3 Date:  
4 Subject: Health; amyotrophic lateral sclerosis; registry  
5 Statement of purpose of bill as introduced: This bill proposes to establish an  
6 amyotrophic lateral sclerosis registry.

7 An act relating to establishing an amyotrophic lateral sclerosis registry

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

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

10 CHAPTER 4A. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

11 § 171. DEFINITIONS

12 As used in this chapter:

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

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

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

1     § 172. ESTABLISHMENT OF AMYOTROPHIC LATERAL SCLEROSIS

2             REGISTRY

3             (a) The Commissioner shall establish a uniform statewide population-based  
4             amyotrophic lateral sclerosis registry system for the collection of information  
5             determining the incidence of amyotrophic lateral sclerosis and related data.

6             Pursuant to 3 V.S.A. chapter 25, the Commissioner shall adopt rules necessary  
7             to effect the purposes of this chapter, including the data to be reported and the  
8             effective date after which reporting by health care facilities and health care  
9             providers shall be required.

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

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

1     § 173. PARTICIPATION IN PROGRAM

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

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

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

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

6 § 174. CONFIDENTIALITY

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

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

19 § 175. DISCLOSURE

20 (a) The Commissioner may enter into agreements to exchange confidential  
21 information with any other amyotrophic lateral sclerosis registries in order to

1 obtain complete reports of Vermont residents diagnosed or treated in other  
2 states and to provide information to other states regarding their residents  
3 diagnosed or treated in Vermont.

4 (b) The Commissioner may furnish confidential information to other states'  
5 amyotrophic lateral sclerosis registries or health researchers in order to  
6 collaborate in a national amyotrophic lateral sclerosis registry or to collaborate  
7 in amyotrophic lateral sclerosis control and prevention research studies.  
8 However, before releasing confidential information, the Commissioner shall  
9 first obtain from such state registries, agencies, or researchers an agreement in  
10 writing to keep the identifying information confidential and privileged. In the  
11 case of researchers, the Commissioner shall also first obtain evidence of the  
12 approval of their academic committee for the protection of human subjects  
13 established in accordance with 45 C.F.R. part 46.

14 § 176. LIABILITY

15 (a) No action for damages arising from the disclosure of confidential or  
16 privileged information may be maintained against any person, or the employer  
17 or employee of any person, who participates in good faith in the reporting of  
18 amyotrophic lateral sclerosis registry data or data for amyotrophic lateral  
19 sclerosis morbidity or mortality studies in accordance with this chapter.

20 (b) No license of a health care facility or health care provider may be  
21 denied, suspended, or revoked for the good faith disclosure of confidential or

1 privileged information in the reporting of amyotrophic lateral sclerosis registry  
2 data or data for amyotrophic lateral sclerosis morbidity or mortality studies in  
3 accordance with this chapter.

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

7 Sec. 2. EFFECTIVE DATE

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