

1 TO THE HONORABLE SENATE:

2 The Committee on Health and Welfare to which was referred Senate Bill
3 No. 90 entitled “An act relating to establishing an amyotrophic lateral sclerosis
4 registry” respectfully reports that it has considered the same and recommends
5 that the bill be amended by striking out all after the enacting clause and
6 inserting in lieu thereof the following:

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

8 CHAPTER 4A. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

9 § 171. DEFINITIONS

10 As used in this chapter:

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

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

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

18 § 172. ESTABLISHMENT OF AMYOTROPHIC LATERAL SCLEROSIS

19 REGISTRY

20 (a) The Commissioner shall establish a uniform statewide population-based
21 amyotrophic lateral sclerosis registry system for the collection of information

1 determining the incidence of amyotrophic lateral sclerosis and related data.
2 Pursuant to 3 V.S.A. chapter 25, the Commissioner shall adopt rules necessary
3 to effect the purposes of this chapter, including the data to be reported and the
4 effective date after which reporting by health care facilities and health care
5 providers shall be required.

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

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

18 § 173. PARTICIPATION IN PROGRAM

19 (a) Any health care facility diagnosing or providing treatment to patients
20 with amyotrophic lateral sclerosis shall report each case of amyotrophic lateral
21 sclerosis to the Commissioner or the Commissioner’s authorized representative

1 in a format prescribed by the Commissioner within 180 days of admission or
2 diagnosis. If the facility fails to report in a format prescribed by the
3 Commissioner, the Commissioner’s authorized representative may enter the
4 facility, obtain the information, and report it in the appropriate format. In these
5 cases, the facility shall reimburse the Commissioner or the authorized
6 representative for the cost of obtaining and reporting the information.

7 (b) Any health care provider diagnosing or providing treatment to patients
8 with amyotrophic lateral sclerosis shall report each case to the Commissioner
9 or the Commissioner’s authorized representative within 180 days of diagnosis.

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

1 § 174. CONFIDENTIALITY

2 (a)(1) All information reported pursuant to this chapter is exempt from
3 public inspection and copying under the Public Records Act and shall be kept
4 confidential.

5 (2)(A) All identifying information regarding an individual patient,
6 health care provider, or health care facility contained in records of interviews,
7 written reports, and statements procured by the Commissioner or by any other
8 person, agency, or organization acting jointly with the Commissioner in
9 connection with amyotrophic lateral sclerosis morbidity and mortality studies
10 is exempt from public inspection and copying under the Public Records Act,
11 shall be kept confidential, and used solely for the purposes of studying
12 amyotrophic lateral sclerosis.

13 (B) Nothing in this section shall prevent the Commissioner from
14 publishing statistical compilations relating to morbidity and mortality studies
15 that do not identify individual cases or sources of information.

16 (b) Notwithstanding 1 V.S.A. § 317(e), the Public Records Act exemption
17 created in this section shall continue in effect and shall not be repealed through
18 operation of 1 V.S.A. § 317(e).

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. GRANT APPLICATIONS TO FUND AMYOTROPHIC LATERAL
8 SCLEROSIS REGISTRY

9 The Department of Health shall seek and apply for grants to fund the
10 amyotrophic lateral sclerosis registry established in 18 V.S.A. chapter 4A. As
11 part of its fiscal year 2024 budget presentation, the Department shall describe
12 any grants applied for or awarded for this purpose or other identified funding
13 sources.

14 Sec. 3. REPORT; REGISTRY EXPANSION

15 On or before December 1, 2022, the Department of Health shall submit a
16 written report to the House Committees on Health Care and on Human
17 Services and to the Senate Committee on Health and Welfare exploring the
18 benefits of expanding the amyotrophic lateral sclerosis registry established in
19 18 V.S.A. chapter 4A by broadening the scope of neurodegenerative diseases
20 addressed in the registry or by partnering with at least three neighboring states
21 to collect data from a larger population, or both.

1 Sec. 4. EFFECTIVE DATES

2 (a) Except as provided in subsection (b) of this section, this act shall take
3 effect on July 1, 2022.

4 (b) Sec. 1 (amyotrophic lateral sclerosis registry) shall take effect on July 1,
5 2023.

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9 (Committee vote: _____)

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Senator _____

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FOR THE COMMITTEE