

1 TO THE HOUSE OF REPRESENTATIVES:

2 The Committee on Human Services to which was referred Senate Bill No.
3 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 House propose to the Senate that the bill be amended by striking out all
6 after the enacting clause and 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 provider” means a person, partnership, corporation,
15 facility, or institution licensed or certified or authorized by law to provide
16 professional health care service in this State to an individual during that
17 individual’s medical care, treatment, or confinement.

18 (3) “Registry” means the statewide amyotrophic lateral sclerosis
19 incidence registry.

1 § 172. REGISTRY ESTABLISHED

2 The Commissioner shall establish, maintain, and operate a statewide
3 amyotrophic lateral sclerosis incidence registry.

4 § 173. DUTY OF HEALTH CARE PROVIDERS

5 A health care provider that screens for, diagnoses, or provides therapeutic
6 services to patients with amyotrophic lateral sclerosis shall report to the
7 Department all individuals diagnosed as having amyotrophic lateral sclerosis
8 not later than six months after the date of diagnosis. The report shall include
9 information on each individual’s primary occupation and industry of
10 employment and other elements determined by rule to be appropriate.

11 § 174. CONFIDENTIALITY

12 (a)(1) All identifying information regarding an individual patient or health
13 care provider is exempt from public inspection and copying under the Public
14 Records Act and shall be kept confidential.

15 (2) Notwithstanding subdivision (1) of this subsection, the
16 Commissioner may enter into data sharing and protection agreements with
17 researchers or state, regional, or national amyotrophic lateral sclerosis
18 registries for bidirectional data exchange, provided access under such
19 agreements is consistent with the privacy, security, and disclosure protections
20 in this chapter. In the case of researchers, the Commissioner shall also first
21 obtain evidence of the approval of their academic committee for the protection

1 of human subjects established in accordance with 45 C.F.R. Part 46. The
2 Commissioner shall disclose the minimum information necessary to
3 accomplish a specified research purpose.

4 (b) The Department may disclose aggregated and deidentified information
5 from the registry.

6 § 175. ANNUAL REPORT

7 Annually, on or before January 15, the Department shall submit a written
8 report to the Governor, the House Committee on Human Services, and the
9 Senate Committee on Health and Welfare containing the statewide prevalence
10 and incidence estimates of amyotrophic lateral sclerosis, including any trends
11 occurring over time across the State. Reports shall not contain information that
12 directly or indirectly identifies an individual patient or health care provider.

13 § 176. RULEMAKING

14 The Commissioner shall adopt rules pursuant to 3 V.S.A. chapter 25 to
15 implement this chapter, including rules to govern the operation of the registry,
16 data reported to the registry, and data release protocols.

17 Sec. 2. 18 V.S.A. § 177 is added to read:

18 § 177. EDUCATIONAL MATERIALS

19 Within six months after a diagnosis, a health care provider shall provide
20 each patient diagnosed with amyotrophic lateral sclerosis with written
21 educational materials developed by the Commissioner about the symptoms and

1 health effects associated with amyotrophic lateral sclerosis, including
2 information on how to participate in the National Amyotrophic Lateral
3 Sclerosis Registry.

4 Sec. 3. DEPARTMENT OF HEALTH; EDUCATIONAL MATERIALS

5 (a) On or before July 1, 2023, the Commissioner of Health shall develop
6 written educational materials for patients and health care providers that provide
7 information about the symptoms and health effects associated with
8 amyotrophic lateral sclerosis, including information on how to participate in
9 the National Amyotrophic Lateral Sclerosis Registry.

10 (b)(1) On or before July 1, 2023, the educational materials developed
11 pursuant to this section shall be made available on the Department of Health’s
12 website.

13 (2) The Department, in cooperation with the appropriate professional
14 licensing boards and professional membership associations, shall ensure the
15 information is made available to all licensed health care providers in Vermont
16 on or before July 1, 2023.

17 Sec. 4. EFFECTIVE DATES

18 This act shall take effect on July 1, 2022, except that Sec. 2 (educational
19 materials) shall take effect on July 1, 2023.

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1 (Committee vote: _____)

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Representative _____

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FOR THE COMMITTEE