TO THE HOUSE OF REPRESENTATIVES:

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

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 provider” means a person, partnership, corporation, facility, or institution licensed or certified or authorized by law to provide professional health care service in this State to an individual during that individual’s medical care, treatment, or confinement.

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

§ 172. REGISTRY ESTABLISHED

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

§ 173. DUTY OF HEALTH CARE PROVIDERS

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

§ 174. CONFIDENTIALITY

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

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

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

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

§ 175. ANNUAL REPORT

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

§ 176. RULEMAKING

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

§ 177. LIABILITY

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

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

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

Sec. 2. DEPARTMENT OF HEALTH; EDUCATIONAL MATERIALS

(a) On or before December 31, 2022, the Commissioner of Health shall develop and make available written educational materials that provide information about the National Amyotrophic Lateral Sclerosis Registry, including:

(1) information regarding how to participate in the National Amyotrophic Lateral Sclerosis Registry and resources that can provide assistance with the registration process;

(2) information regarding the eligibility requirements for participation in the National Amyotrophic Lateral Sclerosis Registry; and

(3) contact information for the National Amyotrophic Lateral Sclerosis Registry and local and national research entities investigating the causes of amyotrophic lateral sclerosis.

(b) On or before December 31, 2022, the Department of Health, in cooperation with appropriate professional licensing boards and professional membership associations, shall ensure the educational materials developed pursuant to subsection (a) of this section are made available to all licensed health care providers in Vermont.

Sec. 3. GRANT APPLICATIONS TO FUND AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

The Department of Health shall seek and apply for grants to fund the amyotrophic lateral sclerosis registry established in 18 V.S.A. chapter 4A. As part of its fiscal year 2024 budget presentation, the Department shall describe any grants applied for or awarded for this purpose or other identified funding sources, such as within existing budgets or from other external funding sources.

Sec. 4. EFFECTIVE DATES

This act shall take effect on July 1, 2022, except that Sec. 1 (amyotrophic lateral sclerosis registry) shall take effect on July 1, 2023.

(Committee vote: ___________)

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Representative ___________

FOR THE COMMITTEE