S.90

Introduced by Senators Lyons, Terenzini, Campion, Chittenden, Cummings,
Hardy, Hooker and Perchlik

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:

<u>CHAPTER 4A. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY</u>

<u>§ 171. DEFINITIONS</u>

<u>As used in this chapter:</u>

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

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

(3) "Health care provider" has the same meaning as in section 9432 of this title.

§ 172. ESTABLISHMENT OF AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

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

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

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

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

§ 173. PARTICIPATION IN PROGRAM

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

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

(c) All health care facilities and health care providers who provide diagnostic or treatment services to patients with amyotrophic lateral sclerosis shall report to the Commissioner any further demographic, diagnostic, or treatment information requested by the Commissioner concerning any person now or formerly receiving services. Additionally, the Commissioner or his or her authorized representative shall have physical access to all records that would identify cases of amyotrophic lateral sclerosis or would establish characteristics of the amyotrophic lateral sclerosis, treatment of the amyotrophic lateral sclerosis, or medical status of any identified patient with amyotrophic lateral sclerosis. Willful failure to grant access to such records shall be punishable by a fine of up to $500.00 for each day access is refused. Any fines collected pursuant to this subsection shall be deposited in the General Fund.

§ 174. CONFIDENTIALITY

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

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

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

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

§ 175. DISCLOSURE

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

(b) The Commissioner may furnish confidential information to other states' amyotrophic lateral sclerosis registries or health researchers in order to collaborate in a national amyotrophic lateral sclerosis registry or to collaborate in amyotrophic lateral sclerosis control and prevention research studies. However, before releasing confidential information, the Commissioner shall first obtain from such state registries, agencies, or researchers an agreement in writing to keep the identifying information confidential and privileged. 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.

§ 176. LIABILITY

(a) No action for damages arising from the disclosure of confidential or privileged information may 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 facility or health care provider may 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. EFFECTIVE DATE

This act shall take effect on July 1, 2021.