STATE OF NEW YORK

6413

2025-2026 Regular Sessions

IN SENATE

March 13, 2025

Introduced by Sen. SCARCELLA-SPANTON -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to establishing a state amyotrophic lateral sclerosis (ALS) and motor neuron disease (MND) registry

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. The public health law is amended by adding a new article 20-C to read as follows:

ARTICLE 20-C
STATE AMYOTROPHIC LATERAL SCLEROSIS AND MOTOR NEURON DISEASE REGISTRY

Section 2020. Definitions.
2021. Duty to report.
2022. Establishment of registry.
2023. Duties of the department.
2024. Duties of the commissioner.

§ 2020. Definitions. As used in this article, the following terms shall have the following meanings:

1. "ALS" means amyotrophic lateral sclerosis, a neurological disorder that affects motor neurons, the nerve cells in the brain and spinal cord that control voluntary muscle movement and breathing.

2. "MND" means motor neuron disease, a group of progressive neurological disorders that destroy motor neurons, the cells that control skeletal muscle activity such as walking, breathing, speaking, and swallowing. This group includes diseases such as amyotrophic lateral sclerosis, progressive bulbar palsy, primary lateral sclerosis, progressive muscular atrophy, spinal muscular atrophy, Kennedy's disease, and post-polio syndrome.

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

LBD10901-01-5

§ 2021. Duty to report. 1. Every physician, nurse practitioner, physician assistant and general hospital that diagnoses or is treating a patient diagnosed with ALS or MND shall give notice no later than one hundred eighty days of each case of ALS or MND coming under their care, to the department, in a format to be determined by the commissioner, except as otherwise provided in this article.

2. All patients diagnosed with ALS or MND shall be provided with written and verbal notice regarding the collection of information and patient data on ALS and MND. Patients who do not wish to participate in the collection of data shall affirmatively opt out in writing after ample opportunity to review such notice, provided that the mere incidence of a patient with ALS or MND shall be the sole required information for the registry under section two thousand twenty-two of this article for any patient who chooses not to participate.

§ 2022. Establishment of registry. 1. The department shall establish an ALS and MND registry for the collection of information on the incidence and prevalence of ALS and MND. The department may consult with ALS and MND experts, including neurologists, patients living with ALS and MND, and ALS and MND researchers to assist in the development and implementation of such registry, and to determine what data shall be collected.

2. All information maintained by the department under the provisions of this section shall be confidential except as necessary to carry out the provisions of this section and shall not be released for any other purpose.

3. The department may enter into an agreement to provide data collected in the ALS and MND registry to the federal centers for disease control and prevention, or successor agency, to local health officers, or health researchers for the study of ALS and MND for public health and research purposes. Data shall be provided in summary, statistical, aggregate, or other form such that no individual person can be identified.

4. On or before January first, two thousand twenty-seven, the department shall create and maintain a public website called the "New York state ALS and MN Disease registry" which shall include information on the incidence and prevalence of ALS and MND in the state by county, and demographic information on affected patients.

§ 2023. Duties of the department. 1. ALS and MND reports and data shall be maintained by the department in a manner suitable for research purposes and shall be made available to people as set forth in section two thousand twenty-two of this article.

2. All information collection under this article shall be confidential insofar as the identity of individual patients is concerned and shall be used solely for the purposes as provided in this article. Access to such information shall be limited to authorized employees of the department as well as persons and organizations identified in section two thousand twenty-two of this article with valid scientific interest and qualifications, as determined by the commissioner, who are engaged in demographic, epidemiological, or other similar studies related to public health.

3. The department shall maintain an accurate record of all people who are given access to the information contained in the ALS and MND registry. Such a record shall include the name of the person authorizing access, the name, title and organizational affiliation of persons given access, dates of access, and the specific purposes for which information is to be used.

4. Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided under this article, or who uses information provided under this article in a manner other than that prescribed by the commissioner, may be denied further access to any confidential information maintained by the department.

§ 2024. Duties of the commissioner. The commissioner may promulgate any regulations necessary to implement the provisions of this article, including but not limited to:

1. Establishing the form, content, and manner by which providers shall report ALS and MND information into the registry established under section two thousand twenty-two of this article;

2. Prescribing the permissible uses for the information made available under this article; and

3. Establishing procedures to maintain confidentiality of information collected by providers and provided to members of the department pursuant to this article. This shall include a procedure to ensure that confidential patient information is deidentified prior to being provided to authorized participants under this article.

§ 2. This act shall take effect on the ninetieth day after it shall have become a law. Effective immediately, the addition, amendment and/or repeal of any rule or regulation necessary for the implementation of this act on its effective date are authorized to be made and completed on or before such effective date.