

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 Assem-
bly, do enact as follows:

1 Section 1. The public health law is amended by adding a new article
2 20-C to read as follows:

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

6 Section 2020. Definitions.

7 2021. Duty to report.

8 2022. Establishment of registry.

9 2023. Duties of the department.

10 2024. Duties of the commissioner.

11 § 2020. Definitions. As used in this article, the following terms
12 shall have the following meanings:

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

16 2. "MND" means motor neuron disease, a group of progressive neurologi-
17 cal disorders that destroy motor neurons, the cells that control skele-
18 tal muscle activity such as walking, breathing, speaking, and swallow-
19 ing. This group includes diseases such as amyotrophic lateral
20 sclerosis, progressive bulbar palsy, primary lateral sclerosis, progres-
21 sive muscular atrophy, spinal muscular atrophy, Kennedy's disease, and
22 post-polio syndrome.

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

LBD10901-01-5

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

7 2. All patients diagnosed with ALS or MND shall be provided with writ-
8 ten and verbal notice regarding the collection of information and
9 patient data on ALS and MND. Patients who do not wish to participate in
10 the collection of data shall affirmatively opt out in writing after
11 ample opportunity to review such notice, provided that the mere inci-
12 dence of a patient with ALS or MND shall be the sole required informa-
13 tion for the registry under section two thousand twenty-two of this
14 article for any patient who chooses not to participate.

15 § 2022. Establishment of registry. 1. The department shall establish
16 an ALS and MND registry for the collection of information on the inci-
17 dence and prevalence of ALS and MND. The department may consult with ALS
18 and MND experts, including neurologists, patients living with ALS and
19 MND, and ALS and MND researchers to assist in the development and imple-
20 mentation of such registry, and to determine what data shall be
21 collected.

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

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

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

38 § 2023. Duties of the department. 1. ALS and MND reports and data
39 shall be maintained by the department in a manner suitable for research
40 purposes and shall be made available to people as set forth in section
41 two thousand twenty-two of this article.

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

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

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

6 § 2024. Duties of the commissioner. The commissioner may promulgate
7 any regulations necessary to implement the provisions of this article,
8 including but not limited to:

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

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

14 3. Establishing procedures to maintain confidentiality of information
15 collected by providers and provided to members of the department pursu-
16 ant to this article. This shall include a procedure to ensure that
17 confidential patient information is deidentified prior to being provided
18 to authorized participants under this article.

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