

CHAPTER 346

AN ACT concerning amyotrophic lateral sclerosis and motor neuron disease and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

C.26:5B-7 Definitions relative to amyotrophic lateral sclerosis and motor neuron disease; reporting of data; patient and health care provider confidentiality; accessing the New Jersey State Health Assessment Data System.

1. a. As used in this section:

“Amyotrophic lateral sclerosis” means a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.

“Health care professional” means a person licensed to practice a health care profession pursuant to Title 45 of the Revised Statutes.

“Motor neuron disease” means a group of progressive neurological conditions that destroy motor neurons, which are the cells that control skeletal muscle activity such as walking, breathing, speaking, and swallowing, and include amyotrophic lateral sclerosis, progressive bulbar palsy, primary lateral sclerosis, progressive muscular atrophy, spinal muscular atrophy, Kennedy’s disease, and post-polio syndrome.

b. (1) Consistent with federal and State privacy laws, the Department of Health shall require health care professionals, who screen for, diagnose, or provide therapeutic services to patients with amyotrophic lateral sclerosis or motor neuron disease, to confidentially report to the department all known cases of amyotrophic lateral sclerosis and motor neuron disease in a manner to be specified by the department no later than six months following a patient’s amyotrophic lateral sclerosis or motor neuron disease diagnosis.

(2) Any information reported to the department for display on the New Jersey State Health Assessment Data System pursuant to this subsection shall be reported in a manner to protect against the disclosure of any confidential or personal identifying information of any patient or health care professional.

(3) The department may enter into agreements to provide the data reported to it pursuant to this subsection with the federal Centers for Disease Control and Prevention and any other successor agency, local health officers, or researchers of the study of amyotrophic lateral sclerosis or motor neuron disease for public health and research purposes. Any data provided to the federal Centers for Disease Control and Prevention and any other successor agency, local health officers, or researchers of the study of amyotrophic lateral sclerosis or motor neuron disease pursuant to this paragraph shall be reported in a manner to protect against the disclosure of any confidential or personal identifying information of any patient or health care professional. The department shall use the New Jersey Integrated Population Health Data Project (iPHD) protocols or a successor program to share data to researchers.

c. The New Jersey State Health Assessment Data System shall record and compile information received pursuant to this section for research and statistical purposes only.

d. Nothing in this act shall be construed to authorize the disclosure of any confidential or personal identifying information.

e. No later than 12 months following the effective date of this act, the Commissioner of Health shall develop and make available on its Internet website written educational materials that provide information about the New Jersey State Health Assessment Data System, including information on how to access the datasets, statistics, and information regarding amyotrophic lateral sclerosis and motor neuron disease reported to the New Jersey State Health Assessment Data System pursuant to subsection b. of this section.

2. The Department of Health, in consultation with the Public Health Council, shall adopt rules and regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), as are necessary to effectuate the purposes of this act.

3. This act shall take effect immediately.

Approved January 20, 2026.