

[Third Reprint]

ASSEMBLY, No. 2980

STATE OF NEW JERSEY

221st LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2024 SESSION

Sponsored by:

Assemblywoman TENNILLE R. MCCOY

District 14 (Mercer and Middlesex)

Senator VIN GOPAL

District 11 (Monmouth)

Senator TROY SINGLETON

District 7 (Burlington)

Co-Sponsored by:

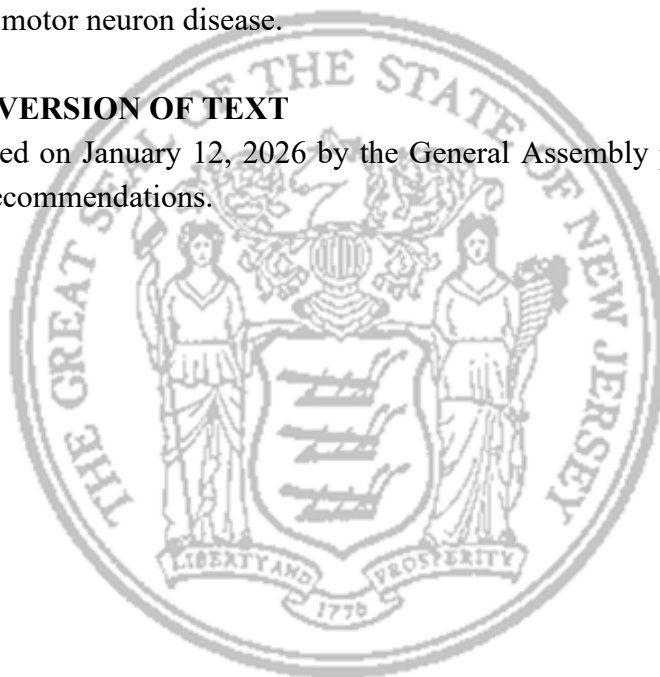
**Assemblywoman Donlon, Senators Diegnan, Amato, McKnight,
Greenstein and Zwicker**

SYNOPSIS

Requires health care professionals to report cases of amyotrophic lateral sclerosis and motor neuron disease.

CURRENT VERSION OF TEXT

As amended on January 12, 2026 by the General Assembly pursuant to the Governor's recommendations.



(Sponsorship Updated As Of: 12/18/2025)

1 AN ACT concerning amyotrophic lateral sclerosis ²and motor neuron
2 disease² and supplementing Title 26 of the Revised Statutes.

3
4 **BE IT ENACTED** *by the Senate and General Assembly of the State*
5 *of New Jersey:*

6
7 1. a. As used in this section:

8 ¹"Amyotrophic lateral sclerosis" means a progressive
9 neurodegenerative disease that affects nerve cells in the brain and
10 the spinal cord.¹

11 ¹"Health care facility" means a health care facility licensed by
12 the Department of Health pursuant to P.L.1971, c.136 (C.26:2H-1 et
13 seq.)¹

14 ¹"Health care professional" means a person licensed to practice a
15 health care profession pursuant to Title 45 of the Revised Statutes.¹

16 ²"Motor neuron disease" means a group of progressive
17 neurological conditions that destroy motor neurons, which are the
18 cells that control skeletal muscle activity such as walking,
19 breathing, speaking, and swallowing; and include amyotrophic
20 lateral sclerosis, progressive bulbar palsy, primary lateral sclerosis,
21 progressive muscular atrophy, spinal muscular atrophy, Kennedy's
22 disease, and post-polio syndrome.²

23 b. ¹(1)¹ Consistent with federal and State privacy laws, the
24 Department of Health shall require health care ¹**[facilities]**
25 professionals, who screen for, diagnose, or provide therapeutic
26 services to patients with amyotrophic lateral sclerosis ²or motor
27 neuron disease² ,¹ to confidentially report to the ²**[department]**
28 ³**[New Jersey State Health Assessment Data System**²**]** department³
29 all known ¹**[and suspected]**¹ cases of amyotrophic lateral sclerosis
30 and motor neuron disease² in a manner to be specified by the
31 department ²no later than six months following a patient's
32 amyotrophic lateral sclerosis or motor neuron disease diagnosis².

33 ¹(2) Any information reported to the ²**[department]** ³department
34 for display on the³ New Jersey State Health Assessment Data
35 System² pursuant to this subsection shall be reported in a manner to
36 protect against the disclosure of any confidential or personal
37 identifying information of any patient or health care professional.

38 (3) The ²**[Commissioner of Health may enter into data sharing**
39 and protection agreements with researchers or State, regional, or
40 national amyotrophic lateral sclerosis registries for bidirectional
41 data exchange for research purposes, provided that access to data
42 under the agreements is consistent with the privacy, security, and

EXPLANATION – Matter enclosed in bold-faced brackets **[thus]** in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹Assembly AHE committee amendments adopted December 16, 2024.

²Senate SHH committee amendments adopted June 9, 2025.

³Assembly amendments adopted in accordance with Governor's recommendations January 12, 2026.

1 disclosure protections under this act. In the case of researchers, the
2 commissioner shall first obtain evidence of the approval of the
3 researcher's academic committee for the protection of human
4 subjects established in accordance with the provisions of 45 C.F.R.
5 Part 46. The commissioner shall disclose the minimum amount of
6 information necessary to accomplish a specified research purpose.¹】
7 department may enter into agreements to provide the data reported
8 to ³【the New Jersey State Health Assessment Data System】 it³
9 pursuant to this subsection with the federal Centers for Disease
10 Control and Prevention and any other successor agency, local health
11 officers, or researchers of the study of amyotrophic lateral sclerosis
12 or motor neuron disease for public health and research purposes.
13 Any data provided to the federal Centers for Disease Control and
14 Prevention and any other successor agency, local health officers, or
15 researchers of the study of amyotrophic lateral sclerosis or motor
16 neuron disease pursuant to this paragraph shall be reported in a
17 manner to protect against the disclosure of any confidential or
18 personal identifying information of any patient or health care
19 professional.² ³The department shall use the New Jersey Integrated
20 Population Health Data Project (iPHD) protocols or a successor
21 program to share data to researchers.³

22 c. The ²【department】 New Jersey State Health Assessment
23 Data System² shall record and compile information received
24 pursuant to this section for research ¹and statistical¹ purposes only.

25 ¹d. Nothing in this act shall be construed to authorize the
26 disclosure of any confidential or personal identifying information.

27 e. No later than 12 months following the effective date of this
28 act, the Commissioner of Health shall develop and make available
29 on its Internet website written, educational materials that provide
30 information about ²【the National Amyotrophic Lateral Sclerosis
31 Registry】 the New Jersey State Health Assessment Data System² ,
32 including ²【 :

33 (1) information on how to participate in the National
34 Amyotrophic Lateral Sclerosis Registry and resources for assistance
35 with the registration process;

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

39 (3) contact information for the National Amyotrophic Lateral
40 Sclerosis Registry and for local and national research entities
41 investigating the causes of amyotrophic lateral sclerosis】
42 information on how to access the datasets, statistics, and
43 information regarding amyotrophic lateral sclerosis and motor
44 neuron disease reported to the New Jersey State Health Assessment
45 Data System pursuant to subsection b. of this section².

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

5

6 ¹**[2.]** 3.¹ This act shall take effect immediately.