

ASSEMBLY BILL NO. 2980
(Second Reprint)

To the General Assembly:

Pursuant to Article V, Section I, Paragraph 14 of the New Jersey Constitution, I am returning Assembly Bill No. 2980 (Second Reprint) with my recommendations for reconsideration.

This bill requires health care professionals who screen for, diagnose, or provide therapeutic services to patients with amyotrophic lateral sclerosis ("ALS") or motor neuron disease ("MND"), to confidentially report within six months of when a patient is diagnosed with ALS or MND certain information to the New Jersey State Health Assessment Data ("NJSRAD") System.

The bill also allows the Department of Health ("DOH") to enter into agreements to share the data reported to the NJSRAD System with the Centers for Disease Control and Prevention, local health officers, or researchers, provided the data is disclosed in a manner that protects confidentiality.

The bill requires the DOH to develop and make available on its Internet website educational materials providing information about the NJSRAD System, including information on how to access datasets, statistics, and information regarding ALS and MND reported to the data system.

I commend the bill's sponsors for their efforts to address the crucial need to support ALS patients, identify new treatments, and promote research to find a cure. This bill will provide invaluable information to the providers who treat patients living with this devastating disease and the researchers working every day to develop more effective treatments.

To provide technical consistency with the DOH's operations of its NJSRAD system and ensure secure data sharing, I am recommending minor technical changes to clarify the role of the NJSRAD System

as a platform that displays information gathered by the DOH from various sources and to clarify the protocols for sharing data obtained pursuant to the bill with researchers.

Therefore, I herewith return Assembly Bill No. 2980 (Second Reprint) and recommend that it be amended as follows:

Page 2, Section 1, Lines 27-28:

Delete "New Jersey State Health Assessment Data System" and insert "department"

Page 2, Section 1, Line 33:

After "the" insert "department for display on the"

Page 3, Section 1, Line 7:

Delete "the New Jersey State Health Assessment Data System" and insert "it"

Page 3, Section 1, Line 17:

After "professional." insert "The department shall use the New Jersey Integrated Population Health Data Project (iPHD) protocols or a successor program to share data to researchers."

[seal]

Respectfully,

/s/ Philip D. Murphy

Governor

Attest:

/s/ Kate E. McDonnell

Chief Counsel to the Governor