

SENATE BILL NO. 2682
(First Reprint)

To the Senate:

Pursuant to Article V, Section I, Paragraph 14 of the New Jersey Constitution, I herewith return for Senate Bill No. 2682 (First Reprint) with my recommendations for reconsideration.

Senate Bill No. 2682 (First Reprint) establishes a 20-member New Jersey Rare Disease Advisory Council ("Council") in the Department of Health to examine the treatment and services provided to persons with rare diseases in this State. Among other things, the Council is charged with evaluating the quality of treatment and services available to individuals with rare diseases, identifying effective research-based strategies to help diagnose, treat, and prevent rare diseases, and advising public and private agencies that provide services to individuals with rare diseases.

I share the sponsors' goal of improving our understanding of rare diseases and the services provided to treat them, and I am proud to join them in convening a variety of perspectives to tackle some of the most significant issues facing residents suffering from rare diseases. There are thousands of known rare diseases, and thousands of residents who live with one in New Jersey. We know that residents who have a rare disease are often left with fewer treatment options and multiple diagnoses because of the limited research and diagnostic tools available in this sphere. We also know that for many of these individuals, even a small disruption in their network of care can present risks. The Coronavirus disease 2019 (COVID-19) pandemic highlighted this regrettable truth.

I offer recommendations today that strengthen the bill by appropriately adjusting the roles of the different branches in the appointment process and modifying certain responsibilities to more closely align with the advisory nature of the Council. My recommendations also incorporate additional perspectives by including

epidemiologists and nurses, recognizing the value of their experiences and expertise in this field.

Therefore, I herewith return Senate Bill No. 2682 (First Reprint) and recommend that it be amended as follows:

<u>Page 3, Section 1, Line 6:</u>	Delete "and fund"
<u>Page 3, Section 2, Line 20:</u>	Delete "Senate" and insert "public"
<u>Page 3, Section 2, Line 20:</u>	Delete "is" and insert "shall be"
<u>Page 3, Section 2, Line 20:</u>	After "by the" insert "Governor, upon recommendation of the"
<u>Page 3, Section 2, Line 21:</u>	Delete "is" and insert "shall be"
<u>Page 3, Section 2, Line 21:</u>	After "by the" insert "Governor, upon recommendation of the"
<u>Page 3, Section 2, Line 22:</u>	After "Senate" insert ", which public members shall be any of the following: an epidemiologist, a registered nurse or nurse practitioner licensed to practice in this State with experience in providing care to patients with rare diseases, or a pediatrician or other physician licensed to practice in this State with experience in providing care to patients with rare diseases"
<u>Page 3, Section 2, Line 23:</u>	Delete "General Assembly" and insert "public"
<u>Page 3, Section 2, Line 23:</u>	Delete "is" and insert "shall be"
<u>Page 3, Section 2, Line 24:</u>	After "by the" insert "Governor, upon recommendation of the"
<u>Page 3, Section 2, Line 25:</u>	Delete "is" and insert "shall be"
<u>Page 3, Section 2, Line 25:</u>	After "by the" insert "Governor, upon recommendation by the"
<u>Page 3, Section 2, Line 25:</u>	After "Assembly" insert ", which public members shall be any of the following: an epidemiologist, a registered nurse or nurse practitioner licensed to practice in this State with experience in providing care to patients with rare diseases, or a pediatrician or other physician licensed to practice in this State with experience in

providing care to patients with rare diseases"

Page 4, Section 2, Line 15:

Delete "four" and insert "five"

Page 4, Section 2, Line 16:

Delete "four" and insert "five"

Page 4, Section 2, Line 17:

Delete "four" and insert "six"

Page 5, Section 3, Line 14:

Delete "establish and implement a repository of" and insert "develop recommendations for"

Page 5, Section 3, Line 14:

After "standards" insert "encompassing"

Page 5, Section 3, Line 15:

Delete in its entirety

Page 5, Section 3, Line 16:

Delete "informed of"

Page 5, Section 4, Lines 34-37:

Delete in their entirety

Page 5, Section 5, Line 39:

Delete "5." and insert "4."

Page 5, Section 6, Line 47:

Delete "6." and insert "5."

Page 5, Section 6, Line 48:

Delete "shall" and insert "may"

Page 6, Section 7, Line 4:

Delete "7." and insert "6."

Respectfully,

[seal]

/s/ Philip D. Murphy

Governor

Attest:

/s/ Parimal Garg

Chief Counsel to the Governor