

26:2AA-7 to 26:2AA-10
LEGISLATIVE HISTORY CHECKLIST

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LAWS OF: 2021 **CHAPTER:** 135

NJSA: 26:2AA-7 to 26:2AA-10 (Establishes the New Jersey Rare Disease Advisory Council.)

BILL NO: S2682 (Substituted for A4016 (1R))

SPONSOR(S) Gopal, Vin and others

DATE INTRODUCED: 7/6/2020

COMMITTEE: **ASSEMBLY:** ---

SENATE: Health, Human Services & Senior Citizens

AMENDED DURING PASSAGE: Yes

DATE OF PASSAGE: **ASSEMBLY:** 6/24/2021

SENATE: 6/24/2021

DATE OF APPROVAL: 6/30/2021

FOLLOWING ARE ATTACHED IF AVAILABLE:

FINAL TEXT OF BILL (Second Reprint enacted) Yes

S2682

INTRODUCED BILL (INCLUDES SPONSOR'S STATEMENT): Yes

COMMITTEE STATEMENT: **ASSEMBLY:** No

SENATE: Yes

(Audio archived recordings of the committee meetings, corresponding to the date of the committee statement, *may possibly* be found at www.njleg.state.nj.us)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

A4016 (1R)

INTRODUCED BILL (INCLUDES SPONSOR'S STATEMENT): Yes

COMMITTEE STATEMENT: **ASSEMBLY:** Yes

SENATE: No

(Audio archived recordings of the committee meetings, corresponding to the date of the committee statement, *may possibly* be found at www.njleg.state.nj.us)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

VETO MESSAGE: Yes

GOVERNOR'S PRESS RELEASE ON SIGNING: Yes

FOLLOWING WERE PRINTED:

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REPORTS: No

HEARINGS: No

NEWSPAPER ARTICLES: No

RH/CL

Title 26.
Chapter 2AA.
(Rename)
Reflex
Sympathetic
Dystrophy
Syndrome
and Rare Diseases
§§1-4
C.26:2AA-7 to
26:2AA-10
§5
Note

P.L. 2021, CHAPTER 135, *approved June 30, 2021*
Senate, No. 2682 (*Second Reprint*)

1 AN ACT establishing the New Jersey Rare Disease Advisory
2 Council 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. The Legislature finds and declares:

8 a. A rare disease is defined as a disease that affects fewer than
9 20,000 people. Rare diseases are sometimes called orphan diseases.
10 There are 7,000 rare diseases affecting approximately 25 to 30
11 million Americans;

12 b. The exact cause for many rare diseases remains unknown.
13 However, 80 ¹**[%]** percent¹ of rare diseases are genetic in origin
14 and can be linked to mutations in a single gene or in multiple genes
15 which can be passed down from generation to generation;

16 c. A person suffering with a rare disease faces a wide range of
17 challenges, including delays in obtaining a diagnosis; being
18 misdiagnosed; shortages of medical specialists who can provide
19 treatment for rare diseases; and the lack of therapies and medication
20 that are used by doctors to treat rare diseases;

21 d. There is a significant link between rare disease and the
22 coronavirus 2019 (COVID-19) pandemic which heightens the
23 importance of the establishment of an advisory council to examine
24 the issues that affect persons with rare diseases in the State. Many
25 people who live with rare diseases are immunosuppressed and have
26 respiratory and neurologic issues that make the consequences of the
27 virus much more severe for them;

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:

¹Senate SHH committee amendments adopted February 9, 2021.

²Senate amendments adopted in accordance with Governor's recommendations June 24, 2021.

1 e. Additionally, those with rare diseases rely on the health care
2 system much more than those who do not have chronic and rare
3 conditions. In as much as they go to their physicians' offices,
4 medical testing sites, and hospitals more often than most, their risk
5 of exposure to the COVID-19 virus is much greater;

6 f. People who live with rare diseases are impacted by potential
7 shortages of life-saving medications and supplies due to changes in
8 supply chain resulting from the COVID-19 pandemic. People with
9 rare diseases also rely on the support of their families and home
10 health aides, and because of the social distancing and quarantining,
11 the pandemic puts them at risk of not having the support they need
12 in accessing services and treatment;

13 g. Researchers have made considerable progress in developing
14 diagnostic tools and treatment protocols for rare diseases and
15 discovering methods of prevention. However, much more remains
16 to be done in the search for new therapeutics and in understanding
17 the link between rare disease and pandemics, and

18 h. It is therefore an appropriate public policy for the State of
19 New Jersey to establish an advisory body, whose membership
20 would be comprised of qualified professionals and persons living
21 with rare diseases, that would be tasked to educate medical
22 professionals, government agencies, and the public about the
23 importance of rare diseases as an important public health issue, and
24 to encourage ²[and fund]² research in the development of new
25 treatments for rare diseases.

26

27 2. There is established the New Jersey Rare Disease Advisory
28 Council in the Department of Health which shall advise the
29 Legislature, State departments, agencies, commissions, and
30 authorities, and private agencies providing services for persons
31 diagnosed with a rare disease.

32 a. The advisory council shall consist of ¹[30] 20¹ members as
33 follows:

34 (1) the Commissioners of Banking and Insurance, ¹[Children
35 and Families, Environmental Protection,]¹ Health, Human Services,
36 and the Executive Director of the New Jersey Office on Minority
37 and Multicultural Health, or their designees, as ex officio members;

38 (2) two members of the ²[Senate] public², one of whom ²[is]
39 shall be² appointed by the ²Governor upon recommendation of the²
40 President of the Senate, and one of whom ²[is] shall be² appointed
41 by the Minority Leader of the Senate ²which public members shall
42 be any of the following: an epidemiologist, a registered nurse or
43 nurse practitioner licensed to practice in this State with experience
44 in providing care to patients with rare diseases, or a pediatrician or
45 other physician licensed to practice in this State with expertise in
46 providing care to patients with rare diseases²;

1 (3) two members of the ²**[General Assembly]** public², one of
2 whom ²**[is]** shall be² appointed by the ²Governor upon
3 recommendation of the² Speaker of the General Assembly, and one
4 of whom ²**[is]** shall be² appointed by the Minority Leader of the
5 General Assembly ²which public members shall be any of the
6 following: an epidemiologist, a registered nurse or nurse
7 practitioner licensed to practice in this State with experience in
8 providing care to patients with rare diseases, or a pediatrician or
9 other physician licensed to practice in this State with expertise in
10 providing care to patients with rare diseases²; and

11 (4) ¹**[20]** ¹² public members to be appointed by the Governor,
12 who shall include: ¹**[two physicians]** one physician¹ licensed to
13 practice in this State who ¹**[have]** has¹ expertise in treating patients
14 with rare diseases, ¹**[one of whom shall be a pediatrician who**
15 **provides care to children with rare diseases; a registered**
16 **professional nurse licensed in this State who has expertise in**
17 **providing care to patients with rare diseases]** and is associated with
18 the research department of an academic institution in this State¹; a
19 representative of general hospital or hospital system in this State
20 recommended by the New Jersey Hospital Association; a
21 representative of federally qualified health center in this State
22 recommended by the New Jersey Primary Care Association; a
23 geneticist licensed to practice in this State; a genetic counselor who
24 has experience in providing services to persons diagnosed with a
25 rare disease, their families, or their caregivers or care partners; a
26 representative of the health insurance industry recommended by the
27 New Jersey Association of Health Plans; ¹**[a pharmacist licensed to**
28 **practice in this State who has experience with persons with a rare**
29 **disease;]**¹ a representative of the ¹biotechnology industry or¹
30 pharmaceutical industry who has expertise in rare diseases
31 recommended by ¹**[the HealthCare Institute of New Jersey]** BIO
32 NJ¹; a ¹**[representative of the biotechnology industry]** pharmacist
33 licensed in this State¹ who ¹**[is]**¹ has expertise in rare diseases
34 ¹**[recommended by BIO NJ]**¹; a representative of the medical
35 technology industry who has expertise in rare diseases ¹and is
36 recommended by the HealthCare Institute of New Jersey¹; ¹**[a**
37 **representative of the Rutgers Biomedical and Health Sciences who**
38 **is engaged in rare disease research; a representative of the Rowan**
39 **University Graduate School of Biomedical Sciences who is engaged**
40 **in rare disease research; two representatives]** one representative¹ of
41 ¹a¹ rare disease patient advocacy ¹**[organizations]** organization¹;
42 ¹**[two persons]** one person¹, age 18 years or older, who ¹**[have]**
43 has¹ a rare disease; and ¹**[two caregivers]** one caregiver¹ or care
44 ¹**[partners]** partner¹ for a patient or partner with a rare disease¹;
45 one of who shall be a caregiver for a child with a rare disease¹.

1 b. Public members of the advisory council shall serve for a term
2 of three years, except that of the initial appointments, ¹【seven】
3 ²【four¹】 ²five² public members shall serve for one year, ¹【seven】
4 ²【four¹】 ²five² public members shall serve for two years, and ¹【six】
5 ²【four¹】 ²six² public members shall serve for three years. Vacancies
6 in the membership of the council shall be filled in the same manner
7 as the original appointments were made. The public members of
8 the council shall serve without compensation but may be
9 reimbursed for traveling and other miscellaneous expenses
10 necessary to perform their duties within the limits of funds made
11 available to the council for its purposes.

12 c. The advisory council shall organize as soon as practicable
13 after the appointment of ¹a majority of¹ its ¹public¹ members, and
14 the Governor shall select a chairperson and vice-chairperson from
15 among its members. The chairperson shall appoint a secretary who
16 need not be a member of the council.

17 d. The advisory council shall meet a minimum of three times a
18 year but may meet more often at the call of its chair. The council
19 may hold hearings at the times and in the places it deems
20 appropriate and necessary to fulfill its charge. The council shall be
21 entitled to call to its assistance, and avail itself of the services of the
22 employees of, any State, county, or municipal department, board,
23 bureau, commission, or agency as it may require and as may be
24 available to it for its purposes.

25 e. ¹【The Department of Health shall provide staff services to
26 the advisory council】 The Department of Health shall maintain
27 oversight of the advisory council and may delegate the
28 administration thereof to a State research university or institution
29 with expertise in either the clinical treatment of rare disease
30 patients, research of rare diseases, or health care policy pertaining
31 to rare disease patients. The Department of Health may issue a
32 request, within 180 days after the effective date of this act, for
33 proposals for a location for the advisory council to operate and for
34 staff and resources to support the operations of the council. The
35 Department of Health shall provide staff services to the advisory
36 council if the proposals submitted to the department are not
37 sufficient to meet the needs of the council¹.

38

39 3. The purpose of the advisory council shall be to:

40 a. act as the advisory body on rare diseases to the Legislature
41 and State departments, agencies, commissions, authorities, and
42 private agencies that provide services to, or are charged with the
43 care of, persons with rare diseases;

44 b. conduct a thorough and comprehensive study of all issues
45 relating to the quality ¹【and cost-effectiveness】¹ of ¹【,】¹ and access
46 to ¹【,】¹ treatment and services provided to persons with rare
47 diseases in this State, including the link between rare diseases and

1 the COVID-19 pandemic, and to develop policy recommendations
2 on those issues;

3 c. ²**[establish and implement a repository of]** develop
4 recommendations for² best practice standards ²**[to share with health**
5 **care providers that will ensure they are adequately informed of]**
6 encompassing² the most effective strategies for recognizing and
7 treating rare diseases in New Jersey;

8 d. identify effective research-based strategies that have been
9 developed to help diagnose, treat, and prevent rare diseases;

10 e. develop effective strategies to raise public awareness of rare
11 diseases in this State;

12 f. evaluate and make recommendations to improve:

13 (1) the State's Newborn Screening Program in the Department of
14 Health; and

15 (2) State Medicaid coverage for approved treatments and
16 medications for patients with a rare disease;

17 g. research and make policy recommendations to the
18 Legislature on access to health insurance specialists and other
19 needed services for patients with a rare disease; and

20 h. identify, with assistance from the public, additional research
21 topics on rare disease to inform future studies the council may
22 conduct.

23

24 ²**[4.** The advisory council shall apply for, and accept, any grant
25 of money from the federal government, private foundations, or
26 other sources, which may be available for programs related to rare
27 diseases.**]**²

28

29 ²**[5.]** 4.² The advisory council shall report to the Governor
30 and, pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the
31 Legislature, no later than December 31st, on a biennial basis,
32 starting in the second year next following the enactment of this act,
33 on the activities of the advisory council and its findings and
34 recommendations on issues relating to the quality of, and access to,
35 treatment and services for persons with rare diseases in this State.

36

37 ²**[6.]** 5.² The Commissioner of Health, pursuant to the
38 "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-
39 1 et seq.) ²**[shall]** may² adopt rules and regulations necessary to
40 effectuate the purposes of this act.

41

42 ²**[7.]** 6.² This act shall take effect immediately.

43

44

45

46

47

Establishes the New Jersey Rare Disease Advisory Council.

SENATE, No. 2682

STATE OF NEW JERSEY
219th LEGISLATURE

INTRODUCED JULY 6, 2020

Sponsored by:

Senator VIN GOPAL

District 11 (Monmouth)

Senator THOMAS H. KEAN, JR.

District 21 (Morris, Somerset and Union)

Co-Sponsored by:

Senators Singer and Pou

SYNOPSIS

Establishes the New Jersey Rare Disease Advisory Council.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 1/11/2021)

1 AN ACT establishing the New Jersey Rare Disease Advisory
2 Council 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. The Legislature finds and declares:

8 a. A rare disease is defined as a disease that affects fewer than
9 20,000 people. Rare diseases are sometimes called orphan diseases.
10 There are 7,000 rare diseases affecting approximately 25 to 30
11 million Americans;

12 b. The exact cause for many rare diseases remains unknown.
13 However, 80% of rare diseases are genetic in origin and can be
14 linked to mutations in a single gene or in multiple genes which can
15 be passed down from generation to generation;

16 c. A person suffering with a rare disease faces a wide range of
17 challenges, including delays in obtaining a diagnosis; being
18 misdiagnosed; shortages of medical specialists who can provide
19 treatment for rare diseases; and the lack of therapies and medication
20 that are used by doctors to treat rare diseases;

21 d. There is a significant link between rare disease and the
22 coronavirus 2019 (COVID-19) pandemic which heightens the
23 importance of the establishment of an advisory council to examine
24 the issues that affect persons with rare diseases in the State. Many
25 people who live with rare diseases are immunosuppressed and have
26 respiratory and neurologic issues that make the consequences of the
27 virus much more severe for them;

28 e. Additionally, those with rare diseases rely on the health care
29 system much more than those who do not have chronic and rare
30 conditions. In as much as they go to their physicians' offices,
31 medical testing sites, and hospitals more often than most, their risk
32 of exposure to the COVID-19 virus is much greater;

33 f. People who live with rare diseases are impacted by potential
34 shortages of life-saving medications and supplies due to changes in
35 supply chain resulting from the COVID-19 pandemic. People with
36 rare diseases also rely on the support of their families and home
37 health aides, and because of the social distancing and quarantining,
38 the pandemic puts them at risk of not having the support they need
39 in accessing services and treatment;

40 g. Researchers have made considerable progress in developing
41 diagnostic tools and treatment protocols for rare diseases and
42 discovering methods of prevention. However, much more remains
43 to be done in the search for new therapeutics and in understanding
44 the link between rare disease and pandemics, and

45 h. It is therefore an appropriate public policy for the State of
46 New Jersey to establish an advisory body, whose membership
47 would be comprised of qualified professionals and persons living
48 with rare diseases, that would be tasked to educate medical

1 professionals, government agencies, and the public about the
2 importance of rare diseases as an important public health issue, and
3 to encourage and fund research in the development of new
4 treatments for rare diseases.

5
6 2. There is established the New Jersey Rare Disease Advisory
7 Council in the Department of Health which shall advise the
8 Legislature, State departments, agencies, commissions, and
9 authorities, and private agencies providing services for persons
10 diagnosed with a rare disease.

11 a. The advisory council shall consist of 30 members as follows:

12 (1) the Commissioners of Banking and Insurance, Children and
13 Families, Environmental Protection, Health, Human Services, and
14 the Executive Director of the New Jersey Office on Minority and
15 Multicultural Health, or their designees, as ex officio members;

16 (2) two members of the Senate, one of whom is appointed by the
17 President of the Senate, and one of whom is appointed by the
18 Minority Leader of the Senate;

19 (3) two members of the General Assembly, one of whom is
20 appointed by the Speaker of the General Assembly, and one of
21 whom is appointed by the Minority Leader of the General
22 Assembly; and

23 (4) 20 public members to be appointed by the Governor, who
24 shall include: two physicians licensed to practice in this State who
25 have expertise in treating patients with rare diseases, one of whom
26 shall be a pediatrician who provides care to children with rare
27 diseases; a registered professional nurse licensed in this State who
28 has expertise in providing care to patients with rare diseases; a
29 representative of general hospital or hospital system in this State
30 recommended by the New Jersey Hospital Association; a
31 representative of federally qualified health center in this State
32 recommended by the New Jersey Primary Care Association; a
33 geneticist licensed to practice in this State; a genetic counselor who
34 has experience in providing services to persons diagnosed with a
35 rare disease, their families, or their caregivers or care partners; a
36 representative of the health insurance industry recommended by the
37 New Jersey Association of Health Plans; a pharmacist licensed to
38 practice in this State who has experience with persons with a rare
39 disease; a representative of the pharmaceutical industry who has
40 expertise in rare diseases recommended by the HealthCare Institute
41 of New Jersey; a representative of the biotechnology industry who
42 is has expertise in rare diseases recommended by BIO NJ; a
43 representative of the medical technology industry who has expertise
44 in rare diseases; a representative of the Rutgers Biomedical and
45 Health Sciences who is engaged in rare disease research; a
46 representative of the Rowan University Graduate School of
47 Biomedical Sciences who is engaged in rare disease research; two
48 representatives of rare disease patient advocacy organizations; two

1 persons, age 18 years or older, who have a rare disease; and two
2 caregivers or care partners for a patient or partner with a rare
3 disease; one of who shall be a caregiver for a child with a rare
4 disease.

5 b. Public members of the advisory council shall serve for a term
6 of three years, except that of the initial appointments, seven public
7 members shall serve for one year, seven public members shall serve
8 for two years, and six public members shall serve for three years.
9 Vacancies in the membership of the council shall be filled in the
10 same manner as the original appointments were made. The public
11 members of the council shall serve without compensation but may
12 be reimbursed for traveling and other miscellaneous expenses
13 necessary to perform their duties within the limits of funds made
14 available to the council for its purposes.

15 c. The advisory council shall organize as soon as practicable
16 after the appointment of its members, and the Governor shall select
17 a chairperson and vice-chairperson from among its members. The
18 chairperson shall appoint a secretary who need not be a member of
19 the council.

20 d. The advisory council shall meet a minimum of three times a
21 year but may meet more often at the call of its chair. The council
22 may hold hearings at the times and in the places it deems
23 appropriate and necessary to fulfill its charge. The council shall be
24 entitled to call to its assistance, and avail itself of the services of the
25 employees of, any State, county, or municipal department, board,
26 bureau, commission, or agency as it may require and as may be
27 available to it for its purposes.

28 e. The Department of Health shall provide staff services to the
29 advisory council.

30

31 3. The purpose of the advisory council shall be to:

32 a. act as the advisory body on rare diseases to the Legislature
33 and State departments, agencies, commissions, authorities, and
34 private agencies that provide services to, or are charged with the
35 care of, persons with rare diseases;

36 b. conduct a thorough and comprehensive study of all issues
37 relating to the quality and cost-effectiveness of, and access to,
38 treatment and services provided to persons with rare diseases in this
39 State, including the link between rare diseases and the COVID-19
40 pandemic, and to develop policy recommendations on those issues;

41 c. establish and implement a repository of best practice standards
42 to share with health care providers that will ensure they are
43 adequately informed of the most effective strategies for recognizing
44 and treating rare diseases in New Jersey;

45 d. identify effective research-based strategies that have been
46 developed to help diagnose, treat, and prevent rare diseases;

47 e. develop effective strategies to raise public awareness of rare
48 diseases in this State;

- 1 f. evaluate and make recommendations to improve:
2 (1) the State's Newborn Screening Program in the Department
3 of Health; and
4 (2) State Medicaid coverage for approved treatments and
5 medications for patients with a rare disease;
6 g. research and make policy recommendations to the Legislature
7 on access to health insurance specialists and other needed services
8 for patients with a rare disease; and
9 h. identify, with assistance from the public, additional research
10 topics on rare disease to inform future studies the council may
11 conduct.
12
13 4. The advisory council shall apply for, and accept, any grant of
14 money from the federal government, private foundations, or other
15 sources, which may be available for programs related to rare
16 diseases.
17
18 5. The advisory council shall report to the Governor and,
19 pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the
20 Legislature, no later than December 31st, on a biennial basis,
21 starting in the second year next following the enactment of this act,
22 on the activities of the advisory council and its findings and
23 recommendations on issues relating to the quality of, and access to,
24 treatment and services for persons with rare diseases in this State.
25
26 6. The Commissioner of Health, pursuant to the "Administrative
27 Procedures Act," P.L.1968, c.410 (C.52:14B-1 et seq.) shall adopt
28 rules and regulations necessary to effectuate the purposes of this
29 act.
30
31 7. This act shall take effect immediately.
32
33

34 STATEMENT
35

36 There is a significant link between rare disease and the coronavirus
37 2019 (COVID-19) pandemic. Many people who live with rare
38 diseases are immunosuppressed and have respiratory and neurologic
39 issues that make the consequences of the virus much more severe
40 for them. This link heightens the importance of the establishment
41 of an advisory council to examine the issues that affect persons with
42 rare diseases in the State.
43 Therefore, this bill establishes the 30-member New Jersey Rare
44 Disease Advisory Council in the Department of Health to advise the
45 Legislature, State departments, agencies, commissions, and
46 authorities, and private agencies providing services for persons
47 diagnosed with a rare disease.

1 The membership of the advisory council will consist of: the
2 Commissioners of Banking and Insurance, Children and Families,
3 Environmental Protection, Health, Human Services, and the
4 Executive Director of the New Jersey Office on Minority and
5 Multicultural Health or their designees, as ex officio members; two
6 members of the Senate, one appointed by the President of the
7 Senate, and one appointed by the Minority Leader of the Senate;
8 two members of the General Assembly, one appointed by the
9 Speaker of the General Assembly, and one appointed by the
10 Minority Leader of the General Assembly; and 20 public members
11 appointed by the Governor, including two physicians licensed to
12 practice in this State who have expertise in treating patients with
13 rare diseases, one who would be a pediatrician who provides care to
14 children with rare diseases; a registered professional nurse licensed
15 in this State who has expertise in providing care to patients with
16 rare diseases; a representative of general hospital or hospital system
17 in this State recommended by the New Jersey Hospital Association;
18 a representative of federally qualified health center in this State
19 recommended by the New Jersey Primary Care Association; a
20 geneticist licensed to practice in this State; a genetic counselor who
21 has experience in providing services to persons diagnosed with a
22 rare disease, their families, or their caregivers or care partners; a
23 representative of the health insurance industry recommended by the
24 New Jersey Association of Health Plans; a pharmacist licensed to
25 practice in this State who has experience with persons with a rare
26 disease; a representative of the pharmaceutical industry who has
27 expertise in rare diseases recommended by the HealthCare Institute
28 of New Jersey; a representative of the biotechnology industry who
29 has expertise in rare diseases recommended by BIO NJ; a
30 representative of the medical technology industry who has expertise
31 in rare diseases; a representative of the Rutgers Biomedical and
32 Health Sciences who is engaged in rare disease research; a
33 representative of the Rowan University Graduate School of
34 Biomedical Sciences who is engaged in rare disease research; two
35 representatives of rare disease patient advocacy organizations; two
36 persons, age 18 years or older, who have a rare disease; and two
37 caregivers or care partners for a patient or partner with a rare
38 disease; one who would be a caregiver for a child with a rare
39 disease.

40 The purpose of the advisory council will be to: act as the
41 advisory body on rare diseases to the Legislature and State
42 departments, agencies, commissions, authorities, and private
43 agencies that provide services to, or are charged with the care of,
44 persons with rare diseases; conduct a thorough and comprehensive
45 study of all issues relating to the quality of, and access to, treatment
46 and services provided to persons with rare diseases in this State,
47 including the link between rare diseases and the COVID-19
48 pandemic, and to develop policy recommendations on those issues;

1 establish and implement a repository of best practice to share with
2 health care providers that will ensure they are adequately informed
3 of the most effective strategies for recognizing and treating rare
4 diseases in New Jersey; identify effective research-based strategies
5 that have been developed to help diagnose, treat, and prevent rare
6 diseases; develop effective strategies to raise public awareness of
7 rare diseases in this State; evaluate and make recommendations to
8 improve the State's Newborn Screening Program in the Department
9 of Health and State Medicaid coverage for approved treatments and
10 medications for patients with a rare disease; research and make
11 policy recommendations to the Legislature on access to health
12 insurance specialists and other needed services for patients with a
13 rare disease; and identify, with assistance from the public,
14 additional research topics on rare disease to inform future studies
15 the council may conduct.

16 Finally, the bill requires the advisory council to report biennially,
17 to the Governor and the Legislature on its findings and
18 recommendations on issues relating to the quality of, and access to,
19 treatment and services provided to persons with rare diseases in this
20 State.

21 This bill is similar to H-7094, the "Rare Disease Community
22 Support, Resource Coordination and Quality of Life Act of 2014,"
23 that was adopted by the state of Rhode Island earlier this year.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE, No. 2682

with committee amendments

STATE OF NEW JERSEY

DATED: FEBRUARY 9, 2021

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with committee amendments Senate Bill No. 2682.

As amended by the committee, this bill establishes a 20-member New Jersey Rare Disease Advisory Council in the Department of Health.

The purpose of the advisory council will be to: act as the advisory body on rare diseases to the Legislature and State departments, agencies, commissions, authorities, and private agencies that provide services to, or are charged with the care of, persons with rare diseases; conduct a thorough and comprehensive study of all issues relating to the quality of and access to treatment and services provided to persons with rare diseases in this State, including the link between rare diseases and the COVID-19 pandemic, and to develop policy recommendations on those issues; establish and implement a repository of best practice standards to share with health care providers that will ensure they are adequately informed of the most effective strategies for recognizing and treating rare diseases in New Jersey; identify effective research-based strategies that have been developed to help diagnose, treat, and prevent rare diseases; develop effective strategies to raise public awareness of rare diseases in this State; evaluate and make recommendations to improve the State's Newborn Screening Program in the Department of Health and State Medicaid coverage for approved treatments and medications for patients with a rare disease; research and make policy recommendations to the Legislature on access to health insurance specialists and other needed services for patients with a rare disease; and identify, with assistance from the public, additional research topics on rare disease to inform future studies the council may conduct.

Finally, the bill requires the advisory council to report biennially, to the Governor and the Legislature, on its findings and recommendations on issues relating to the quality of, and access to, treatment and services provided to persons with rare diseases in this State.

COMMITTEE AMENDMENTS:

The committee amendments reduce the advisory council's membership to 20 members. Under the current provisions of the bill, the council is comprised of 30 members.

The committee amendments also reduce the number of public members on the advisory council from 20 members, as originally provided in the bill, to 12 members, and provide that the council organize as soon as practicable after the appointment of a majority of its public members.

The committee amended the bill to provide that the Department of Health is to maintain oversight of the advisory council and may delegate the council's administration to a State research university or institution as provided for in the bill.

The committee amended the bill to allow the department to issue a request for proposals for a location for the council to operate and for staff and resources to support operations. The department is to provide staff services to the council if the proposals submitted to the department are insufficient.

The committee amendments remove the requirement for the advisory council to study cost-effectiveness of treatment and services provided to persons with rare diseases in this State.

The committee amendments also make various technical and grammatical changes to the provisions of the bill.

ASSEMBLY, No. 4016

STATE OF NEW JERSEY 219th LEGISLATURE

INTRODUCED MAY 4, 2020

Sponsored by:

Assemblyman RONALD S. DANCER

District 12 (Burlington, Middlesex, Monmouth and Ocean)

Assemblyman DANIEL R. BENSON

District 14 (Mercer and Middlesex)

Assemblyman ANTHONY S. VERRELLI

District 15 (Hunterdon and Mercer)

Co-Sponsored by:

Assemblyman DePhillips

SYNOPSIS

Establishes the New Jersey Rare Disease Advisory Council.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 10/19/2020)

1 AN ACT establishing the New Jersey Rare Disease Advisory
2 Council 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. The Legislature finds and declares:

8 a. A rare disease is defined as a disease that affects fewer than
9 20,000 people. Rare diseases are sometimes called orphan diseases.
10 There are 7,000 rare diseases affecting approximately 25 to 30
11 million Americans;

12 b. The exact cause for many rare diseases remains unknown.
13 However, 80% of rare diseases are genetic in origin and can be
14 linked to mutations in a single gene or in multiple genes which can
15 be passed down from generation to generation;

16 c. A person suffering with a rare disease faces a wide range of
17 challenges, including delays in obtaining a diagnosis; being
18 misdiagnosed; shortages of medical specialists who can provide
19 treatment for rare diseases; and the lack of therapies and medication
20 that are used by doctors to treat rare diseases;

21 d. There is a significant link between rare disease and the
22 coronavirus 2019 (COVID-19) pandemic which heightens the
23 importance of the establishment of an advisory council to examine
24 the issues that affect persons with rare diseases in the State. Many
25 people who live with rare diseases are immunosuppressed and have
26 respiratory and neurologic issues that make the consequences of the
27 virus much more severe for them;

28 e. Additionally, those with rare diseases rely on the health care
29 system much more than those who do not have chronic and rare
30 conditions. In as much as they go to their physicians' offices,
31 medical testing sites, and hospitals more often than most, their risk
32 of exposure to the COVID-19 virus is much greater;

33 f. People who live with rare diseases are impacted by potential
34 shortages of life-saving medications and supplies due to changes in
35 supply chain resulting from the COVID-19 pandemic. People with
36 rare diseases also rely on the support of their families and home
37 health aides, and because of the social distancing and quarantining,
38 the pandemic puts them at risk of not having the support they need
39 in accessing services and treatment;

40 g. Researchers have made considerable progress in developing
41 diagnostic tools and treatment protocols for rare diseases and
42 discovering methods of prevention. However, much more remains
43 to be done in the search for new therapeutics and in understanding
44 the link between rare disease and pandemics, and

45 h. It is therefore an appropriate public policy for the State of
46 New Jersey to establish an advisory body, whose membership
47 would be comprised of qualified professionals and persons living
48 with rare diseases, that would be tasked to educate medical

1 professionals, government agencies, and the public about the
2 importance of rare diseases as an important public health issue, and
3 to encourage and fund research in the development of new
4 treatments for rare diseases.

5

6 2. There is established the New Jersey Rare Disease Advisory
7 Council in the Department of Health which shall advise the
8 Legislature, State departments, agencies, commissions, and
9 authorities, and private agencies providing services for persons
10 diagnosed with a rare disease.

11 a. The advisory council shall consist of 30 members as follows:

12 (1) the Commissioners of Banking and Insurance, Children and
13 Families, Environmental Protection, Health, Human Services, and
14 the Executive Director of the New Jersey Office on Minority and
15 Multicultural Health, or their designees, as ex officio members;

16 (2) two members of the Senate, one of whom is appointed by the
17 President of the Senate, and one of whom is appointed by the
18 Minority Leader of the Senate;

19 (3) two members of the General Assembly, one of whom is
20 appointed by the Speaker of the General Assembly, and one of
21 whom is appointed by the Minority Leader of the General
22 Assembly; and

23 (4) 20 public members to be appointed by the Governor, who
24 shall include: two physicians licensed to practice in this State who
25 have expertise in treating patients with rare diseases, one of whom
26 shall be a pediatrician who provides care to children with rare
27 diseases; a registered professional nurse licensed in this State who
28 has expertise in providing care to patients with rare diseases; a
29 representative of general hospital or hospital system in this State
30 recommended by the New Jersey Hospital Association; a
31 representative of federally qualified health center in this State
32 recommended by the New Jersey Primary Care Association; a
33 geneticist licensed to practice in this State; a genetic counselor who
34 has experience in providing services to persons diagnosed with a
35 rare disease, their families, or their caregivers or care partners; a
36 representative of the health insurance industry recommended by the
37 New Jersey Association of Health Plans; a pharmacist licensed to
38 practice in this State who has experience with persons with a rare
39 disease; a representative of the pharmaceutical industry who has
40 expertise in rare diseases recommended by the HealthCare Institute
41 of New Jersey; a representative of the biotechnology industry who
42 is has expertise in rare diseases recommended by BIO NJ; a
43 representative of the medical technology industry who has expertise
44 in rare diseases; a representative of the Rutgers Biomedical and
45 Health Sciences who is engaged in rare disease research; a
46 representative of the Rowan University Graduate School of
47 Biomedical Sciences who is engaged in rare disease research; two
48 representatives of rare disease patient advocacy organizations; two

1 persons, age 18 years or older, who have a rare disease; and two
2 caregivers or care partners for a patient or partner with a rare
3 disease; one of who shall be a caregiver for a child with a rare
4 disease.

5 b. Public members of the advisory council shall serve for a
6 term of three years, except that of the initial appointments, seven
7 public members shall serve for one year, seven public members
8 shall serve for two years, and six public members shall serve for
9 three years. Vacancies in the membership of the council shall be
10 filled in the same manner as the original appointments were made.
11 The public members of the council shall serve without
12 compensation but may be reimbursed for traveling and other
13 miscellaneous expenses necessary to perform their duties within the
14 limits of funds made available to the council for its purposes.

15 c. The advisory council shall organize as soon as practicable
16 after the appointment of its members, and the Governor shall select
17 a chairperson and vice-chairperson from among its members. The
18 chairperson shall appoint a secretary who need not be a member of
19 the council.

20 d. The advisory council shall meet a minimum of three times a
21 year but may meet more often at the call of its chair. The council
22 may hold hearings at the times and in the places it deems
23 appropriate and necessary to fulfill its charge. The council shall be
24 entitled to call to its assistance, and avail itself of the services of the
25 employees of, any State, county, or municipal department, board,
26 bureau, commission, or agency as it may require and as may be
27 available to it for its purposes.

28 e. The Department of Health shall provide staff services to the
29 advisory council.

30

31 3. The purpose of the advisory council shall be to:

32 a. act as the advisory body on rare diseases to the Legislature
33 and State departments, agencies, commissions, authorities, and
34 private agencies that provide services to, or are charged with the
35 care of, persons with rare diseases;

36 b. conduct a thorough and comprehensive study of all issues
37 relating to the quality and cost-effectiveness of, and access to,
38 treatment and services provided to persons with rare diseases in this
39 State, including the link between rare diseases and the COVID-19
40 pandemic, and to develop policy recommendations on those issues;

41 c. establish and implement a repository of best practice
42 standards to share with health care providers that will ensure they
43 are adequately informed of the most effective strategies for
44 recognizing and treating rare diseases in New Jersey;

45 d. identify effective research-based strategies that have been
46 developed to help diagnose, treat, and prevent rare diseases;

47 e. develop effective strategies to raise public awareness of rare
48 diseases in this State;

- 1 f. evaluate and make recommendations to improve:
2 (1) the State's Newborn Screening Program in the Department
3 of Health; and
4 (2) State Medicaid coverage for approved treatments and
5 medications for patients with a rare disease;
6 g. research and make policy recommendations to the
7 Legislature on access to health insurance specialists and other
8 needed services for patients with a rare disease; and
9 h. identify, with assistance from the public, additional research
10 topics on rare disease to inform future studies the council may
11 conduct.
12
13 4. The advisory council shall apply for, and accept, any grant
14 of money from the federal government, private foundations, or
15 other sources, which may be available for programs related to rare
16 diseases.
17
18 5. The advisory council shall report to the Governor and,
19 pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the
20 Legislature, no later than December 31st, on a biennial basis,
21 starting in the second year next following the enactment of this act,
22 on the activities of the advisory council and its findings and
23 recommendations on issues relating to the quality of, and access to,
24 treatment and services for persons with rare diseases in this State.
25
26 6. The Commissioner of Health, pursuant to the
27 "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-1 et
28 seq.) shall adopt rules and regulations necessary to effectuate the
29 purposes of this act.
30
31 7. This act shall take effect immediately.
32
33

34 STATEMENT
35

36 There is a significant link between rare disease and the
37 coronavirus 2019 (COVID-19) pandemic. Many people who live
38 with rare diseases are immunosuppressed and have respiratory and
39 neurologic issues that make the consequences of the virus much
40 more severe for them. This link heightens the importance of the
41 establishment of an advisory council to examine the issues that
42 affect persons with rare diseases in the State.
43 Therefore, this bill establishes the 30-member New Jersey Rare
44 Disease Advisory Council in the Department of Health to advise the
45 Legislature, State departments, agencies, commissions, and
46 authorities, and private agencies providing services for persons
47 diagnosed with a rare disease.

1 The membership of the advisory council will consist of: the
2 Commissioners of Banking and Insurance, Children and Families,
3 Environmental Protection, Health, Human Services, and the
4 Executive Director of the New Jersey Office on Minority and
5 Multicultural Health or their designees, as ex officio members; two
6 members of the Senate, one appointed by the President of the
7 Senate, and one appointed by the Minority Leader of the Senate;
8 two members of the General Assembly, one appointed by the
9 Speaker of the General Assembly, and one appointed by the
10 Minority Leader of the General Assembly; and 20 public members
11 appointed by the Governor, including two physicians licensed to
12 practice in this State who have expertise in treating patients with
13 rare diseases, one who would be a pediatrician who provides care to
14 children with rare diseases; a registered professional nurse licensed
15 in this State who has expertise in providing care to patients with
16 rare diseases; a representative of general hospital or hospital system
17 in this State recommended by the New Jersey Hospital Association;
18 a representative of federally qualified health center in this State
19 recommended by the New Jersey Primary Care Association; a
20 geneticist licensed to practice in this State; a genetic counselor who
21 has experience in providing services to persons diagnosed with a
22 rare disease, their families, or their caregivers or care partners;
23 a representative of the health insurance industry recommended by the
24 New Jersey Association of Health Plans; a pharmacist licensed to
25 practice in this State who has experience with persons with a rare
26 disease; a representative of the pharmaceutical industry who has
27 expertise in rare diseases recommended by the HealthCare Institute
28 of New Jersey; a representative of the biotechnology industry who
29 has expertise in rare diseases recommended by BIO NJ; a
30 representative of the medical technology industry who has expertise
31 in rare diseases; a representative of the Rutgers Biomedical and
32 Health Sciences who is engaged in rare disease research; a
33 representative of the Rowan University Graduate School of
34 Biomedical Sciences who is engaged in rare disease research; two
35 representatives of rare disease patient advocacy organizations; two
36 persons, age 18 years or older, who have a rare disease; and two
37 caregivers or care partners for a patient or partner with a rare
38 disease; one who would be a caregiver for a child with a rare
39 disease.

40 The purpose of the advisory council will be to: act as the
41 advisory body on rare diseases to the Legislature and State
42 departments, agencies, commissions, authorities, and private
43 agencies that provide services to, or are charged with the care of,
44 persons with rare diseases; conduct a thorough and comprehensive
45 study of all issues relating to the quality of, and access to, treatment
46 and services provided to persons with rare diseases in this State,
47 including the link between rare diseases and the COVID-19
48 pandemic, and to develop policy recommendations on those issues;

1 establish and implement a repository of best practice to share with
2 health care providers that will ensure they are adequately informed
3 of the most effective strategies for recognizing and treating rare
4 diseases in New Jersey; identify effective research-based strategies
5 that have been developed to help diagnose, treat, and prevent rare
6 diseases; develop effective strategies to raise public awareness of
7 rare diseases in this State; evaluate and make recommendations to
8 improve the State's Newborn Screening Program in the Department
9 of Health and State Medicaid coverage for approved treatments and
10 medications for patients with a rare disease; research and make
11 policy recommendations to the Legislature on access to health
12 insurance specialists and other needed services for patients with a
13 rare disease; and identify, with assistance from the public,
14 additional research topics on rare disease to inform future studies
15 the council may conduct.

16 Finally, the bill requires the advisory council to report biennially,
17 to the Governor and the Legislature on its findings and
18 recommendations on issues relating to the quality of, and access to,
19 treatment and services provided to persons with rare diseases in this
20 State.

21 This bill is similar to H-7094, the "Rare Disease Community
22 Support, Resource Coordination and Quality of Life Act of 2014,"
23 that was adopted by the state of Rhode Island earlier this year.

ASSEMBLY HEALTH COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4016

with committee amendments

STATE OF NEW JERSEY

DATED: JANUARY 13, 2021

The Assembly Health Committee reports favorably and with committee amendments Assembly Bill No. 4016.

As amended and reported, this bill establishes a 20-member New Jersey Rare Disease Advisory Council in the Department of Health to advise the Legislature, State departments, agencies, commissions, and authorities, and private agencies providing services for persons diagnosed with a rare disease.

The membership of the advisory council will consist of 20 members as provided for in the bill. The purpose of the advisory council will be to: act as the advisory body on rare diseases to the Legislature and State departments, agencies, commissions, authorities, and private agencies that provide services to, or are charged with the care of, persons with rare diseases; conduct a thorough and comprehensive study of all issues relating to the quality of and access to treatment and services provided to persons with rare diseases in this State, including the link between rare diseases and the COVID-19 pandemic, and to develop policy recommendations on those issues; establish and implement a repository of best practice to share with health care providers that will ensure they are adequately informed of the most effective strategies for recognizing and treating rare diseases in New Jersey; identify effective research-based strategies that have been developed to help diagnose, treat, and prevent rare diseases; develop effective strategies to raise public awareness of rare diseases in this State; evaluate and make recommendations to improve the State's Newborn Screening Program in the Department of Health and State Medicaid coverage for approved treatments and medications for patients with a rare disease; research and make policy recommendations to the Legislature on access to health insurance specialists and other needed services for patients with a rare disease; and identify, with assistance from the public, additional research topics on rare disease to inform future studies the council may conduct.

Finally, the bill requires the advisory council to report biennially, to the Governor and the Legislature on its findings and recommendations on issues relating to the quality of, and access to, treatment and services provided to persons with rare diseases in this State.

COMMITTEE AMENDMENTS:

The amendments:

- 1) make technical changes;
- 2) remove the requirement for the advisory council to study cost-effectiveness;
- 3) provide that the Department of Health (department) is to maintain oversight of the advisory council (council) and may delegate the administration thereof to a State research university or institution as provided for in the bill. The department may issue a request for proposals for a location for the council to operate and for staff and resources to support operations. The department is to provide staff services to the council if the proposals submitted to the department are insufficient;
- 4) provide that the council organize as soon as practicable after the appointment of a majority of its public members; and
- 5) reduce the council's membership from 30 to 20 members as provided for in the bill.

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:

- Page 3, Section 1, Line 6: Delete "and fund"
- Page 3, Section 2, Line 20: Delete "Senate" and insert "public"
- Page 3, Section 2, Line 20: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 20: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 21: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 21: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 22: 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"
- Page 3, Section 2, Line 23: Delete "General Assembly" and insert "public"
- Page 3, Section 2, Line 23: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 24: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 25: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 25: After "by the" insert "Governor, upon recommendation by the"
- Page 3, Section 2, Line 25: 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,

/s/ Philip D. Murphy

Governor

[seal]

Attest:

/s/ Parimal Garg

Chief Counsel to the Governor

Governor Murphy Takes Action on Legislation

06/30/2021

TRENTON - Today, Governor Murphy signed the following bills into law.

S-2682/A-4016 w/GR (Gopal, Kean/Dancer, Benson, Verrelli) – Establishes the New Jersey Rare Disease Advisory Council.

S-2725/A-4473 w/GR (Gopal/Houghtaling, Downey) – Concerns assessment of real property in counties operating under "Real Property Assessment Demonstration Program."

S-3489/A-5465 (Sweeney, Pou/Benson, Vainieri Huttel, Speight) – Changes effective date of new law concerning certain State contracts for mental health, behavioral health, and addiction services.

S-3998/A-5938 (Sarlo/Chiaravalloti) – Authorizes State Treasurer to determine salary of Director of Division of Investment.

S-3999/A-5942 (Beach/Pintor Marin) – Authorizes Secretary of State and New Jersey Motor Vehicle Commission to share voter and motor vehicle information with state-based non-profit organization for maintaining accuracy of voter registration information.

Governor Murphy Takes Action On Legislation

06/24/2021

TRENTON – Today, Governor Phil Murphy signed the following bills into law:

A-2116/S-2009 w/GR (Tully, Swain, Armato/Lagana) Requires State Treasurer to submit report to Legislature every six months identifying deadlines for applications for federal funds by State agencies.

A-4745/S3277 (Armato, Chaparro, Danielsen/Bucco, Singleton, Doherty) Raises from 45 to 57 maximum eligibility age for exempt fireman certificates and membership in New Jersey State Fireman's Association.

A-5590/S-3819 (Mazzeo, Armato, Greenwald/Sweeney, Beach) Extends period of municipal stabilization and recovery, with certain modifications, under "Municipal Stabilization and Recovery Act."

S-347/A-1992 w/GR (Smith, Vitale/Stanley, Conaway, Houghtaling) Establishes "NJ One Health Task Force."

S-619/A1635 w/GR (O'Scanlon/Lampitt, Downey) Permits use of telemedicine and telehealth to authorize patients for medical cannabis and to issue written instructions for dispensing medical cannabis. *

S-853/A-5064 w/GR (Sweeney, Beach/Verrelli, Giblin, Danielsen) "New Jersey Buy American Act"; requires certain State agency highway and bridge construction contracts to include iron and steel products made in U.S.

S-890/A-1061 w/GR (Pou, Codey/Jasey, Johnson, Verrelli) Requires DOH and DHS to identify and take appropriate steps to secure federal sources of funding to support maternal mental health.

S-3686/A-5540 (Sweeney/ Burzichelli, Freiman) Supplements Department of Transportation language provisions in FY 2021 Appropriations Act to provide flexibility for debt service payments.

Governor Murphy conditionally vetoed the following bill:

S-2682/A-4016 (Gopal, Kean/Dancer, Benson, Verrelli) – CONDITIONAL - Establishes the New Jersey Rare Disease Advisory Council.

[Copy of Statement](#)

Governor Murphy will deliver the following conditional veto to the Senate on Monday, June 28:

S-3658/A-5641 (Cunningham, Scutari/ Chiaravalloti, Mukherji, Carter) – CONDITIONAL - Eliminates mandatory minimum terms of imprisonment determined by Legislature to be of non-violent nature.

[Copy of Statement](#)

June 24, 2021

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:

- Page 3, Section 1, Line 6: Delete "and fund"
- Page 3, Section 2, Line 20: Delete "Senate" and insert "public"
- Page 3, Section 2, Line 20: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 20: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 21: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 21: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 22: 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"
- Page 3, Section 2, Line 23: Delete "General Assembly" and insert "public"
- Page 3, Section 2, Line 23: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 24: After "by the" insert "Governor, upon recommendation of the"
- Page 3, Section 2, Line 25: Delete "is" and insert "shall be"
- Page 3, Section 2, Line 25: After "by the" insert "Governor, upon recommendation by the"
- Page 3, Section 2, Line 25: 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,

/s/ Philip D. Murphy

Governor

[seal]

Attest:

/s/ Parimal Garg

Chief Counsel to the Governor