

ASSEMBLY, No. 3202

STATE OF NEW JERSEY 219th LEGISLATURE

INTRODUCED FEBRUARY 25, 2020

Sponsored by:

Assemblyman RONALD S. DANCER

District 12 (Burlington, Middlesex, Monmouth and Ocean)

Assemblyman DANIEL R. BENSON

District 14 (Mercer and Middlesex)

SYNOPSIS

Establishes the New Jersey Rare Disease Advisory Council.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 2/25/2020)

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. Such
15 diseases are referred to as genetic diseases. Genetic disease can be
16 passed down from generation to generation, explaining why certain
17 rare diseases run in families. It is also estimated that about half of
18 all rare diseases affect children;

19 c. Environmental factors such as diet, smoking, or exposure to
20 chemicals also play a part in causing rare diseases. These factors
21 may directly cause, or interact with, genetic factors that increase the
22 severity of rare disease;

23 d. Rare diseases can be chronic, progressive, debilitating,
24 disabling, severe, and life threatening. A person suffering with a
25 rare disease faces a wide range of challenges, including, but not
26 limited to: delays in obtaining a diagnosis; being misdiagnosed; a
27 shortage of medical specialists who are familiar with, and can
28 provide treatment for, rare diseases; the prohibitive cost of
29 treatment; and the inability to access therapies and medication that
30 are used by doctors to treat rare diseases but have not been
31 approved by the Federal Food and Drug Administration for that
32 specific purpose;

33 e. In recent years, researchers have made considerable progress
34 in developing diagnostic tools and treatment protocols for, and in
35 discovering ways to prevent a variety of, rare diseases. However,
36 much more remains to be done in the areas of rare disease research
37 and the search for new therapeutics; and

38 f. It is therefore an appropriate public policy for the State of
39 New Jersey to establish an advisory body, whose membership
40 would be comprised of persons with suitable qualifications for this
41 purpose, to examine the issues that affect persons with rare
42 diseases, to educate medical professionals, government agencies,
43 and the public about rare diseases as an important public health
44 issue, and to encourage and fund research in the development of
45 new treatments for rare diseases.

46
47 2. There is established the New Jersey Rare Disease Advisory
48 Council in the Department of Health.

1 a. The advisory council shall consist of 16 members as follows:

2 (1) the Commissioners of Health, Human Services, Children and
3 Families, and Environmental Protection, or their designees, as ex
4 officio members; and

5 (2) twelve public members to be appointed by the Governor,
6 who shall include: two physicians licensed to practice in this State
7 who have expertise in treating patients with rare diseases, one of
8 whom shall be a pediatrician who provides care to children with
9 rare diseases; a registered professional nurse licensed in this State
10 who has expertise in providing care to patients with rare diseases; a
11 patient advocate employed by a general hospital in this State; two
12 representatives of general hospitals in this State, one of whom shall
13 represent a religiously-affiliated hospital; a representative of the
14 New Jersey Office on Minority and Multicultural Health; a
15 representative of the health insurance industry, a representative of
16 the pharmaceutical industry; a representative of the scientific
17 community who is engaged in rare disease research; a parent of a
18 child with a rare disease; and a person with a rare disease.

19 b. Vacancies in the membership of the advisory council shall
20 be filled in the same manner provided for the original appointments.
21 The public members of the council shall serve without
22 compensation but may be reimbursed for traveling and other
23 miscellaneous expenses necessary to perform their duties within the
24 limits of funds made available to the council for its purposes.

25 c. The advisory council shall organize as soon as practicable
26 after the appointment of its members and shall select a chairperson
27 and vice-chairperson from among its members. The chairperson
28 shall appoint a secretary who need not be a member of the council.

29 d. The advisory council may meet at the call of its chair and
30 hold hearings at the times and in the places it deems appropriate and
31 necessary to fulfill its charge. The council shall be entitled to call
32 to its assistance, and avail itself of the services of the employees of,
33 any State, county, or municipal department, board, bureau,
34 commission, or agency as it may require and as may be available to
35 it for its purposes.

36 e. The Department of Health shall provide staff services to the
37 advisory council.

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. assist the Commissioner of Health in establishing and
45 implementing a rare disease registry program to serve as a single
46 repository of information on all rare diseases diagnosed in this
47 State;

1 c. conduct a thorough and comprehensive study of all issues
2 relating to the quality and cost-effectiveness of, and access to,
3 treatment and services provided to persons with rare diseases in this
4 State, and to develop policy recommendations on those issues;

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

7 e. develop effective strategies to raise public awareness of rare
8 diseases in this State.

9
10 4. The advisory council shall apply for, and accept, any grant
11 of money from the federal government, private foundations, or
12 other sources, which may be available for programs related to rare
13 diseases.

14
15 5. The advisory council shall report to the Governor and,
16 pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the
17 Legislature, no later than December 31st of each year, on the
18 activities of the advisory council and its findings and
19 recommendations on issues relating to the quality and cost-
20 effectiveness of, and access to treatment and services to, persons
21 with rare diseases in this State.

22
23 6. The Commissioner of Health, pursuant to the
24 "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-
25 1 et seq.) shall adopt rules and regulations necessary to effectuate
26 the purposes of this act.

27
28 7. This act shall take effect immediately.

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31 STATEMENT

32
33 This bill establishes the 16-member New Jersey Rare Disease
34 Advisory Council in the Department of Health.

35 The membership of the advisory council will consist of: the
36 Commissioners of Health, Human Services, Children and Families,
37 and Environmental Protection, or their designees, as ex officio
38 members; and twelve public members to be appointed by the
39 Governor, including two physicians licensed to practice in this State
40 who have expertise in treating patients with rare diseases, one of
41 whom is a pediatrician providing care to children with rare diseases;
42 a registered professional nurse licensed in this State who has
43 expertise in providing care to patients with rare diseases; two
44 representatives of general hospitals in this State, one of whom
45 represents a religiously-affiliated hospital; a patient advocate
46 employed by a general hospital in this State; a representative of the
47 New Jersey Office on Minority and Multicultural Health, the health
48 insurance industry, the pharmaceutical industry, and the scientific

1 community who is engaged in rare disease research; a parent of a
2 child with a rare disease; and a person with a rare disease.

3 The purpose of the advisory council will be to: act as the
4 advisory body on rare diseases to the Legislature and State
5 departments, agencies, commissions, authorities, and private
6 agencies that provide services to, or are charged with the care of,
7 persons with rare diseases; assist the Commissioner of Health in
8 establishing and implementing a rare disease registry program in
9 this State; conduct a thorough and comprehensive study of all issues
10 relating to the quality and cost-effectiveness of, and access to
11 treatment and services provided for, persons with rare diseases in
12 this State, and to develop policy recommendations on those issues;
13 identify effective research-based strategies that have been
14 developed to help diagnose, treat, and prevent rare diseases; and
15 develop effective strategies to raise public awareness of rare
16 diseases in this State.

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

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