

STATE OF NEW YORK

1296

2025-2026 Regular Sessions

IN ASSEMBLY

January 9, 2025

Introduced by M. of A. PAULIN, SAYEGH, LUCAS -- read once and referred to the Committee on Health

AN ACT to amend the public health law, in relation to establishing the rare disease advisory council

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. Title 2-F of the public health law is amended by adding a
2 new section 245 to read as follows:

3 § 245. Rare disease advisory council. 1. For the purposes of this
4 section, "rare disease" means any disease or condition which affects
5 less than two hundred thousand persons in the United States.

6 2. a. There shall be established within the department a rare disease
7 advisory council to identify best practices, raise awareness regarding
8 rare diseases, evaluate barriers to access to care, and to make recom-
9 mendations to the legislature and the governor.

10 b. An existing body or previously convened body, whether dissolved or
11 not, may be repurposed to meet the requirements of this section.

12 3. a. The council shall consist of at least fifteen members, including
13 the commissioner or such commissioner's designee, the superintendent of
14 financial services or such superintendent's designee, and nine members
15 to be appointed by the governor. Two members shall be appointed by the
16 speaker of the assembly, two members shall be appointed by the temporary
17 president of the senate. Membership of such council shall consist of
18 residents of the state of New York and include, but not be limited to,
19 individuals with expertise in rare diseases, including physicians, nurs-
20 es and other health care professionals with experience researching,
21 diagnosing or treating rare diseases; members of the scientific communi-
22 ty engaged in rare disease research; representatives from the health
23 insurance industry; a representative of the biopharma industry; individ-
24 uals who have a rare disease and caregivers of a person with a rare
25 disease; and representatives of rare disease patient organizations.

EXPLANATION--Matter in italics (underscored) is new; matter in brackets
[-] is old law to be omitted.

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1 b. The council shall prioritize the representation of patient and
2 caregiver voices while ensuring no single disease state is dispropor-
3 tionately represented.

4 c. The members of the rare disease advisory council shall receive no
5 compensation for their role on the council, but shall be allowed their
6 actual and necessary expenses incurred in the performance of their
7 duties as council members.

8 d. Time served on a previously convened body shall not count towards
9 the term of office for membership on the rare disease advisory council.

10 4. a. Council members shall serve up to two four year terms commencing
11 from the date of their appointment. Members may serve beyond their term
12 expiration at the pleasure of the appointing authority.

13 b. If a vacancy occurs for an unexpired term, the council, by a major-
14 ity vote, shall fill such vacancy in a timely manner and in compliance
15 with the requirements set forth in subdivisions two and three of this
16 section.

17 c. The council shall annually elect a chair from amongst its members.
18 A chair is eligible for reelection.

19 5. a. The initial meeting of the council shall occur within the first
20 one hundred eighty days after the effective date of this section. The
21 council shall meet at least once per quarter in person or via an online
22 meeting platform as determined by the chair. Such meetings shall comply
23 with article seven of the public officers law.

24 b. The council shall provide opportunities for the public to hear
25 updates and provide public comment and create and maintain a public
26 website or utilize an existing website where meeting minutes, notices of
27 upcoming meetings, and public comments can be submitted.

28 6. The council's focus shall include, but not be limited to:

29 a. identifying best practices that could improve the awareness of rare
30 diseases and referral of people with potential rare diseases to special-
31 ists;

32 b. evaluating barriers to treatment, including financial barriers on
33 access to care;

34 c. establishing best practices and protocols to include in state plan-
35 ning related to natural disasters, public health emergencies or other
36 emergency declarations to enable the continuity of care for rare disease
37 patients and ensure safeguards against discrimination for rare disease
38 patients are in place;

39 d. convening public hearings, making inquiries, and soliciting
40 comments from the general public in the state to assist the council with
41 a first-year landscape or survey of the needs of rare disease patients,
42 caregivers, and providers in the state;

43 e. providing testimony and comments on pending legislation and regu-
44 lations before the legislature and other state agencies that impact New
45 York's rare disease community;

46 f. consulting with experts on rare diseases to develop policy recom-
47 mendations to improve patient access to, and quality of, rare disease
48 specialists, affordable and comprehensive health care coverage, relevant
49 diagnostics, timely treatment, and other needed services;

50 g. advising the Medicaid drug utilization review board in their review
51 of products or medications for the treatment of rare and orphan
52 diseases, and drugs or biological products within the emerging fields of
53 personalized medicine and non-inheritable gene editing therapeutics.
54 All advisory council recommendations shall be presented in writing to
55 members of such board and explained to members of such board by repre-
56 sentatives of the advisory council during their public meetings. The

1 advisory council has no authority on any matter relating to Medicaid,
2 nor may it require such board to follow its recommendations; and

3 h. any other priorities as identified by the department or a majority
4 of the council.

5 7. a. The council, in consultation with the department shall prepare a
6 written report summarizing its findings and recommendations from the
7 council which shall include a list of existing, publicly accessible
8 resources on research, diagnosis, treatment, coverage options and educa-
9 tion relating to rare diseases.

10 b. This report shall be submitted to the governor, the speaker of the
11 assembly, the minority leader of the assembly, the temporary president
12 of the senate, the minority leader of the senate, the senate chair of
13 the committee on health, and the chair of the assembly committee on
14 health, one year following the effective date of this section and by
15 each January thirtieth thereafter and shall be posted on the depart-
16 ment's website.

17 c. Any recommendations of the council shall be posted on the depart-
18 ment's website and incorporated into any future "Prevention Agenda: New
19 York State's Health Improvement Plan". The recommendation shall also be
20 shared at a public meeting of the New York state health equity council
21 for their consideration.

22 8. The council may identify public, private, and other available fund-
23 ing sources and may accept and utilize funds from such sources to imple-
24 ment the provisions of this section, including, but not limited to,
25 state funds appropriated for rare disease research, treatment, educa-
26 tion, programming, and related activities.

27 § 2. Of the monies appropriated in chapter 53 of the laws of 2024,
28 enacting the aid to localities budget, for services and expenses related
29 to rare disease of which a portion may be transferred to state oper-
30 ations, \$100,000 shall be allocated by the department of health and for
31 use by administration and support to implement this act. To implement
32 this act, the department may use this allocation for personal services.

33 § 3. This act shall take effect on the thirtieth day after it shall
34 have become a law. Effective immediately, the addition, amendment and/or
35 repeal of any rule or regulation necessary for the implementation of
36 this act on its effective date are authorized to be made and completed
37 on or before such effective date.