

# STATE OF NEW YORK

9724

## IN SENATE

May 23, 2024

Introduced by Sen. PERSAUD -- read twice and ordered printed, and when printed to be committed 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 a condition or disease that is currently  
5 or has been subject to a research study by the National Institutes of  
6 Health Rare Diseases Clinical Research Network or affects fewer than two  
7 hundred thousand United States residents per year.

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

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

14 3. The council shall consist of fifteen members, including the commis-  
15 sioner or such commissioner's designee, the superintendent of financial  
16 services or such superintendent's designee, and nine members to be  
17 appointed by the governor. Two members shall be appointed by the speaker  
18 of the assembly, two members shall be appointed by the temporary presi-  
19 dent of the senate. Membership of such council shall consist of resi-  
20 dents of the state of New York and include, but not be limited to, indi-  
21 viduals with expertise in rare diseases, including physicians, nurses  
22 and other health care professionals with experience researching, diag-  
23 nosizing or treating rare diseases; members of the scientific community  
24 engaged in rare disease research; representatives from the health insur-  
25 ance industry; a representative of the biopharma industry; individuals  
26 who have a rare disease and caregivers of a person with a rare disease;  
27 and representatives of rare disease patient organizations. The members  
28 of the rare disease advisory council shall receive no compensation for

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

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1 such member's role on the council, but shall be allowed for such  
2 member's actual and necessary expenses incurred in the performance of  
3 such member's duties as council members. Time served on a previously  
4 convened body shall not count towards the term of office for membership  
5 on the rare disease advisory council.

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

9 b. If a vacancy occurs for an unexpired term, the council, by a major-  
10 ity vote, shall fill such vacancy in a timely manner and in compliance  
11 with the requirements set forth in subdivision three of this section.

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

14 5. a. The initial meeting of the council shall occur within ninety  
15 days after the effective date of this section. The council shall meet at  
16 least once per quarter in person or via an online meeting platform as  
17 determined by the chair. Such meetings shall comply with article seven  
18 of the public officers law.

19 b. The council shall provide opportunities for the public to have  
20 updates and provide public comment and create and maintain a public  
21 website or utilize an existing website where meeting minutes, notices of  
22 upcoming meetings, and public comments can be submitted.

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

24 a. identifying best practices that could improve the awareness of rare  
25 diseases and referring people with rare diseases to specialists;

26 b. evaluating barriers to treatment, including financial barriers on  
27 access to care;

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

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

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

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

44 g. any other priorities as identified by the department or a majority  
45 of the council.

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

51 b. This report shall be submitted to the governor, the speaker of the  
52 assembly, the minority leader of the assembly, the temporary president  
53 of the senate, the minority leader of the senate, the senate chair of  
54 the committee on health, and the chair of the assembly committee on  
55 health, one year following the effective date of this section and by

1 each January thirtieth thereafter and shall be posted on the depart-  
2 ment's website.

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

8 § 2. This act shall take effect on the thirtieth day after it shall  
9 have become a law. Effective immediately, the addition, amendment and/or  
10 repeal of any rule or regulation necessary for the implementation of  
11 this act on its effective date are authorized to be made and completed  
12 on or before such effective date.