# STATE OF NEW YORK

10292

# IN ASSEMBLY

May 17, 2024

Introduced by COMMITTEE ON RULES -- (at request of M. of A. Paulin) -- 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:**

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

**§ 245. Rare disease advisory council. 1. For the purposes of this section, "rare disease" means a condition or disease that is currently or has been subject to a research study by the National Institutes of Health Rare Diseases Clinical Research Network or affects fewer than two hundred thousand United States residents per year.**

**2. a. There shall be established within the department a rare disease advisory council to identify best practices, raise awareness regarding rare diseases, evaluate barriers to access to care, and to make recommendations to the legislature and the governor.**

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

**3. The council shall consist of fifteen members, including the commissioner or such commissioner's designee, the superintendent of financial services or such superintendent's designee, and thirteen members to be appointed by the governor with the advice and consent of the senate. Membership of such council shall consist of residents of the state of New York and include, but not be limited to, individuals with expertise in rare diseases, including physicians, nurses and other health care professionals with experience researching, diagnosing or treating rare diseases; members of the scientific community engaged in rare disease research; representatives from the health insurance industry; a representative of the biopharma industry; individuals who have a rare disease and caregivers of a person with a rare disease; and representatives of rare disease patient organizations. The members of the rare disease advisory council shall receive no compensation for such member's role on the council, but shall be allowed for such member's actual and necessary**

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

LBD15543-01-4

expenses incurred in the performance of such member's duties as council members. Time served on a previously convened body shall not count towards the term of office for membership on the rare disease advisory council.

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

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

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

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

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

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

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

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

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

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

e. providing testimony and comments on pending legislation and regulations before the legislature and other state agencies that impact New York's rare disease community;

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

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

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

b. This report shall be submitted to the governor, the speaker of the assembly, the minority leader of the assembly, the temporary president of the senate, the minority leader of the senate, the senate chair of the committee on health, and the chair of the assembly committee on health, one year following the effective date of this section and by each January thirtieth thereafter and shall be posted on the department's website.

**8. The council may identify public, private, and other available funding sources and may accept and utilize funds from such sources to implement the provisions of this section, including, but not limited to, state funds appropriated for rare disease research, treatment, education, programming, and related activities.**

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