

# STATE OF NEW YORK

5762

2019-2020 Regular Sessions

## IN ASSEMBLY

February 19, 2019

Introduced by M. of A. PAULIN, SAYEGH, ENGLEBRIGHT, GRIFFIN, FAHY, SIMON, BARCLAY, CROUCH, DeSTEFANO, JACOBSON, SCHMITT -- 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. The public health law is amended by adding a new article  
2 27-L to read as follows:

### ARTICLE 27-L

#### RARE DISEASE ADVISORY COUNCIL

##### Section 2799-u. Rare disease advisory council.

6 § 2799-u. Rare disease advisory council. 1. There shall be established  
7 within the department a rare disease advisory council to advise and  
8 consult on policy matters relating to rare disease. For the purposes of  
9 this section, rare disease shall mean any disease or condition that  
10 affects less than 200,000 people in the United States.

11 2. The council shall be composed of twenty-one members consisting of:  
12 seventeen members shall be appointed by the governor, two members shall  
13 be appointed by the speaker of the assembly, and two members shall be  
14 appointed by the temporary president of the senate. The governor shall  
15 designate the commissioner, or his or her designee, as chair of the  
16 council, and the superintendent of the department of financial services,  
17 or his or her designee, as co-chair of the council. The council shall at  
18 all times include in its membership the following, which shall be  
19 appointed by the governor: two physicians licensed and practicing in the  
20 state with experience researching, diagnosing, or treating rare  
21 diseases; one registered nurse or advanced practice registered nurse  
22 licensed and practicing in the state with experience treating rare  
23 diseases; two hospital administrators from hospitals in the state that  
24 provide care to persons diagnosed with a rare disease, one of whom must

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

LBD07491-01-9

1 represent a hospital in which the scope of service focuses on rare  
2 diseases of pediatric patients; three persons age eighteen or older who  
3 either have a rare disease or are a caregiver of a person with a rare  
4 disease; two representatives of a rare disease patient organization that  
5 operates in the state; one pharmacist with experience with drugs used to  
6 treat rare diseases; one representative of the biotechnology industry;  
7 one representative of health insurance companies; one member of the  
8 scientific community who is engaged in rare disease research; and one  
9 genetic counselor with experience providing services to persons diag-  
10 nosd with a rare disease or caregivers of those persons.

11 3. Members of the advisory council shall serve at the pleasure of the  
12 appointing authority. Vacancies on the advisory council shall be filled  
13 in the same manner as the original appointment. Members of the advisory  
14 council shall receive no compensation for their services, but may be  
15 reimbursed for necessary and actual expenses incurred in the performance  
16 of their duties hereunder.

17 4. The advisory council shall meet at least three times in each calen-  
18 dar year. The council shall meet at the request of its chairs.

19 5. The advisory council's duties may include, but are not limited to:

20 a. Convening public hearings, and receiving and considering reports  
21 and testimony from individuals, the department, health care providers,  
22 and public or private organizations recognized as having expertise in  
23 rare diseases, as well as other interested parties, to assist the coun-  
24 cil in developing recommendations under this section;

25 b. Studying the economic burden of the treatment of rare diseases with  
26 regard to quality of care, health care coverage, and access to treatment  
27 and services;

28 c. Developing recommendations pertaining to the impact of particular  
29 health care coverage and the impact of particular coverage on the  
30 provision of treatment and care services;

31 d. Identifying best practices for rare diseases that could improve  
32 treatment of rare diseases in New York state; and

33 e. Developing a list of existing, publicly accessible resources on  
34 research, diagnosis, treatment, coverage options, and education relating  
35 to rare diseases, which shall be published on the department's website  
36 upon completion.

37 6. The council shall prepare and submit a written report no later than  
38 October first, two thousand twenty, and biennially thereafter, to the  
39 governor, speaker of the assembly, and temporary president of the senate  
40 that sets forth the findings and recommendations of the council on  
41 matters within the scope of its duties as set forth in this section.

42 § 2. This act shall take effect immediately.