

# STATE OF NEW YORK

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7172

## IN SENATE

January 10, 2020

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Introduced by Sen. RIVERA -- read twice and ordered printed, and when printed to be committed to the Committee on Rules

AN ACT to direct the department of health to convene a work group on rare diseases and providing for the repeal of such provisions upon the expiration thereof; and to repeal article 27-L of the public health law relating 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. Article 27-L of the public health law, as added by a chap-  
2 ter of the laws of 2019 amending the public health law relating to  
3 establishing the rare disease advisory council, as proposed in legisla-  
4 tive bills numbers S. 4497 and A. 5762, is REPEALED.

5 § 2. The department of health, in collaboration with the department of  
6 financial services, shall convene a workgroup of individuals with exper-  
7 tise in rare diseases, including physicians, nurses and other health  
8 care professionals with experience researching, diagnosing or treating  
9 rare diseases; members of the scientific community engaged in rare  
10 disease research; representatives from the health insurance industry;  
11 individuals who have a rare disease or caregivers of a person with a  
12 rare disease; and representatives of rare disease patient organizations.  
13 The workgroup's focus shall include, but not be limited to: identifying  
14 best practices that could improve the awareness of rare diseases and  
15 referral of people with potential rare diseases to specialists and eval-  
16 uating barriers to treatment, including financial barriers on access to  
17 care. The department of health shall prepare a written report summariz-  
18 ing opinions and recommendations from the workgroup which includes a  
19 list of existing, publicly accessible resources on research, diagnosis,  
20 treatment, coverage options and education relating to rare diseases.  
21 This report shall be submitted to the governor, speaker of the assembly  
22 and temporary president of the senate no later than two years following  
23 the effective date of this act and shall be posted on the department of  
24 health's website.

25 § 3. This act shall take effect on the same date and in the same  
26 manner as a chapter of the laws of 2019, amending the public health law

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

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1 relating to establishing the rare disease advisory council, as proposed  
2 in legislative bills numbers S. 4497 and A. 5762; provided, however,  
3 that the provisions of section two of this act shall expire and be  
4 deemed repealed two years after such effective date.