STATE OF NEW YORK

9132

IN ASSEMBLY

January 22, 2020

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

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:

Section 1. Article 27-L of the public health law, as added by a chapter of the laws of 2019 amending the public health law relating to establishing the rare disease advisory council, as proposed in legislative bills numbers S. 4497 and A. 5762, is REPEALED.

§ 2. The department of health, in collaboration with the department of financial services, shall convene a workgroup of 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; individuals who have a rare disease or caregivers of a person with a rare disease; and representatives of rare disease patient organizations. The workgroup's focus shall include, but not be limited to: identifying best practices that could improve the awareness of rare diseases and referral of people with potential rare diseases to specialists and evaluating barriers to treatment, including financial barriers on access to care. The department of health shall prepare a written report summarizing opinions and recommendations from the workgroup which includes a list of existing, publicly accessible resources on research, diagnosis, treatment, coverage options and education relating to rare diseases. This report shall be submitted to the governor, speaker of the assembly and temporary president of the senate no later than two years following the effective date of this act and shall be posted on the department of health's website.

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S. 4497 and A. 5762; provided, however, that the provisions of section two of this act shall expire and be deemed repealed two years after such effective date.