STATE OF NEW YORK

5944--A

2021-2022 Regular Sessions

IN SENATE

March 23, 2021

Introduced by Sen. RIVERA -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend chapter 74 of the laws of 2020 relating to directing the department of health to convene a work group on rare diseases, in relation to the deadline to submit a report on rare diseases and to the effectiveness thereof

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Sections 2 and 3 of chapter 74 of the laws of 2020 relating to directing the department of health to convene a work group on rare diseases, are amended to read as follows:

§ 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. The workgroup shall convene no later than December twentieth, two thousand twenty-one and this report shall be submitted to the governor, speaker

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

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of the assembly and temporary president of the senate no later than [~~two~~] three 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 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~~] three years after such effective date.

§ 2. This act shall take effect immediately.