STATE OF NEW YORK

5123

2025-2026 Regular Sessions

IN ASSEMBLY

February 12, 2025

Introduced by M. of A. SOLAGES, SEAWRIGHT, BURDICK, CUNNINGHAM, SLATER, RAGA, SANTABARBARA, GALLAHAN, SIMON -- Multi-Sponsored by -- M. of A. DAVILA -- read once and referred to the Committee on Governmental Operations

AN ACT to amend the civil rights law, in relation to requiring genetic testing results only be received by patients and health care providers providing direct care while health insurance companies only receive a record that the genetic testing was performed for payment purposes

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

Section 1. Subdivision 3 of section 79-l of the civil rights law, as added by chapter 497 of the laws of 1996, is amended and a new subdivision 12 is added to read as follows:

3. (a) All records, findings and results of any genetic test performed on any person shall be deemed confidential and shall not be disclosed without the written informed consent of the person to whom such genetic test relates. This information shall not be released to any person or organization not specifically authorized by the individual subject of the test. Unauthorized solicitation or possession of such information shall be unlawful, except for the unintentional possession of such information as part of a health record created prior to the effective date of this section and provided no action adverse to the interests of the subject are taken as a result of such possession. [~~Nothing in this section shall preclude the release of such information, with the subject's consent, to a health insurer or health maintenance organization of any information reasonably required for purposes of claims administration, provided, however, that further distribution within the insurer or to other recipients shall require the subject's informed consent in each case.~~]

(b) No person who lawfully possesses information derived from a genetic test on a biological sample from an individual shall incorporate such

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

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information into the records of a non-consenting individual who may be genetically related to the tested individual; nor shall any inferences be drawn, used, or communicated regarding the possible genetic status of the non-consenting individual.

(c) No findings or results of any genetic test shall be released to any health insurer or health maintenance organization required for purposes of claims administration. All health insurers or health maintenance organizations shall accept records without the test result confirming that the genetic test was performed and the records, findings or results were received by the health care provider providing direct care for the purposes of claims administration.

12. (a) No health insurer or life insurer shall require any records, findings or results of any genetic test be provided to such insurer. The health care provider and/or the policyholder shall provide any necessary records to the insurance company to confirm such genetic test was completed and the records, findings, or results of such test were received by such provider.

(b) No health insurer or life insurer shall base their policies on genetic test records, findings or results or being provided access to genetic test records, findings or results.

(c) No health insurer or life insurer shall take adverse action against a policyholder or potential policyholder for not having access to the records, findings or results of a genetic test.

§ 2. This act shall take effect on the ninetieth day after it shall have become a law and shall apply to policies and contracts issued, renewed, modified, altered, or amended on or after such date.