

STATE OF NEW YORK

2398

2025-2026 Regular Sessions

IN SENATE

January 17, 2025

Introduced by Sens. PERSAUD, BORRELLO, CLEARE, SALAZAR, SKOUFIS -- read twice and ordered printed, and when printed to be committed to the Committee on Codes

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:

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

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

20 (b) No person who lawfully possesses information derived from a genet-
21 ic test on a biological sample from an individual shall incorporate such
22 information into the records of a non-consenting individual who may be

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

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1 genetically related to the tested individual; nor shall any inferences
2 be drawn, used, or communicated regarding the possible genetic status of
3 the non-consenting individual.

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

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

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

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

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