



104TH GENERAL ASSEMBLY

State of Illinois

2025 and 2026

SB0250

Introduced 1/22/2025, by Sen. Laura Fine

SYNOPSIS AS INTRODUCED:

410 ILCS 513/20

Amends the Genetic Information Privacy Act. Removes language exempting insurers that are issuing a long-term care policy from specified provisions. Provides that, with regard to any policy, contract, or plan offered, entered into, issued, amended, or renewed on or after January 1, 2026 by a health insurer, life insurer, or long-term care insurer authorized to transact insurance in this State, a health insurer, life insurer, or long-term care insurer may not: (1) cancel, limit, or deny coverage or establish differentials in premium rates based on a person's genetic information; or (2) require or solicit an individual's genetic information, use an individual's genetic test results, or consider an individual's decisions or actions relating to genetic information or a genetic test in any manner for any insurance purpose. Provides that the provisions may not be construed as preventing a life insurer or long-term care insurer from accessing an individual's medical record as part of an application exam. Provides that nothing in the provisions prohibits a life insurer or long-term care insurer from considering a medical diagnosis included in an individual's medical record, even if the diagnosis is based on the results of a genetic test. Effective July 1, 2025.

LRB104 06028 BDA 16061 b

1 AN ACT concerning health.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

4 Section 5. The Genetic Information Privacy Act is amended
5 by changing Section 20 as follows:

6 (410 ILCS 513/20)

7 Sec. 20. Use of genetic testing information for insurance
8 purposes.

9 (a) An insurer may not seek information derived from
10 genetic testing for use in connection with a policy of
11 accident and health insurance. Except as provided in
12 subsection (c), an insurer that receives information derived
13 from genetic testing, regardless of the source of that
14 information, may not use the information for a nontherapeutic
15 purpose as it relates to a policy of accident and health
16 insurance.

17 (b) An insurer shall not use or disclose protected health
18 information that is genetic information for underwriting
19 purposes. For purposes of this Section, "underwriting
20 purposes" means, with respect to an insurer:

21 (1) rules for, or determination of, eligibility
22 (including enrollment and continued eligibility) for, or
23 determination of, benefits under the plan, coverage, or

1 policy (including changes in deductibles or other
2 cost-sharing mechanisms in return for activities such as
3 completing a health risk assessment or participating in a
4 wellness program);

5 (2) the computation of premium or contribution amounts
6 under the plan, coverage, or policy (including discounts,
7 rebates, payments in kind, or other premium differential
8 mechanisms in return for activities, such as completing a
9 health risk assessment or participating in a wellness
10 program);

11 (3) the application of any pre-existing condition
12 exclusion under the plan, coverage, or policy; and

13 (4) other activities related to the creation, renewal,
14 or replacement of a contract of health insurance or health
15 benefits.

16 "Underwriting purposes" does not include determinations of
17 medical appropriateness where an individual seeks a benefit
18 under the plan, coverage, or policy.

19 ~~This subsection (b) does not apply to insurers that are~~
20 ~~issuing a long term care policy, excluding a nursing home~~
21 ~~fixed indemnity plan.~~

22 (c) An insurer may consider the results of genetic testing
23 in connection with a policy of accident and health insurance
24 if the individual voluntarily submits the results and the
25 results are favorable to the individual.

26 (d) An insurer that possesses information derived from

1 genetic testing may not release the information to a third
2 party, except as specified in this Act.

3 (e) A company providing direct-to-consumer commercial
4 genetic testing is prohibited from sharing any genetic test
5 information or other personally identifiable information about
6 a consumer with any health or life insurance company without
7 written consent from the consumer.

8 (f) A health insurer, life insurer, or long-term care
9 insurer authorized to transact insurance in this State may
10 not:

11 (1) cancel, limit, or deny coverage or establish
12 differentials in premium rates based on a person's genetic
13 information; or

14 (2) require or solicit an individual's genetic
15 information, use an individual's genetic test results, or
16 consider an individual's decisions or actions relating to
17 genetic information or a genetic test in any manner for
18 any insurance purpose.

19 This subsection applies to any policy, contract, or plan
20 that is offered, entered into, issued, amended, or renewed on
21 or after January 1, 2026 by a health insurer, life insurer, or
22 long-term care insurer authorized to transact insurance in
23 this State.

24 (g) Nothing in this Section may be construed as preventing
25 a life insurer or long-term care insurer from accessing an
26 individual's medical record as part of an application exam.

1 Nothing in this Section prohibits a life insurer or long-term
2 care insurer from considering a medical diagnosis included in
3 an individual's medical record, even if the diagnosis is based
4 on the results of a genetic test.

5 (Source: P.A. 101-132, eff. 1-1-20.)

6 Section 99. Effective date. This Act takes effect July 1,
7 2025.