



## 104TH GENERAL ASSEMBLY

### State of Illinois

2025 and 2026

HB4897

by Rep. Nabeela Syed

#### 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, 2027 by a health insurer, life insurer, disability insurer, or long-term care insurer authorized to transact insurance in this State, a health insurer, life insurer, disability 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: (1) preventing a life insurer, disability insurer, or long-term care insurer from accessing an individual's medical record as part of an application; or (2) prohibiting a life insurer, disability insurer, or long-term care insurer from considering a clinical diagnosis, such as a manifest disease or disorder, included in an individual's medical record for insurance purposes to the extent otherwise allowable by law. Effective July 1, 2026.

LRB104 17552 BDA 30980 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, disability insurer, or  
9 long-term care insurer authorized to transact insurance in  
10 this State may not:

11 (1) cancel, limit, or deny coverage or establish  
12 differentials in premium rates based on genetic  
13 information collected, used, or stored for health care  
14 treatment; or

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

20 This subsection applies to any policy, contract, or plan  
21 that is offered, entered into, issued, amended, or renewed on  
22 or after January 1, 2027 by a health insurer, life insurer,  
23 disability insurer, or long-term care insurer authorized to  
24 transact insurance in this State.

25 (g) Nothing in this Section may be construed as:

26 (1) preventing a life insurer, disability insurer, or

1       long-term care insurer from accessing an individual's  
2       medical record as part of an application; or  
3               (2) prohibiting a life insurer, disability insurer, or  
4       long-term care insurer from considering a clinical  
5       diagnosis, such as a manifest disease or disorder,  
6       included in an individual's medical record for insurance  
7       purposes to the extent otherwise allowable by law.

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

9               Section 99. Effective date. This Act takes effect July 1,  
10       2026.