



## 103RD GENERAL ASSEMBLY

### State of Illinois

2023 and 2024

**HB4142**

by Rep. Nabeela Syed

#### SYNOPSIS AS INTRODUCED:

410 ILCS 513/20  
215 ILCS 5/224.5 new

Amends the Genetic Information Privacy Act. Provides that an insurer may not seek information derived from genetic testing for use in connection with a policy of life insurance. Provides that an insurer may consider the results of genetic testing in connection with a policy of life insurance if the individual voluntarily submits the results and the results are favorable to the individual. Amends the Illinois Insurance Code. Provides that an insurer must comply with the provisions of the Genetic Information Privacy Act in connection with the amendment, delivery, issuance, or renewal of a life insurance policy; claims for or denial of coverage under a life insurance policy; or the determination of premiums or rates under a life insurance policy.

LRB103 34088 RPS 63905 b

1 AN ACT concerning regulation.

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 or life insurance. Except as  
12 provided in subsection (c), an insurer that receives  
13 information derived from genetic testing, regardless of the  
14 source of that information, may not use the information for a  
15 nontherapeutic purpose as it relates to a policy of accident  
16 and health 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 life insurance or policy of  
24 accident and health insurance if the individual voluntarily  
25 submits the results and the results are favorable to the  
26 individual.

1 (d) An insurer that possesses information derived from  
2 genetic testing may not release the information to a third  
3 party, except as specified in this Act.

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

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

10 Section 10. The Illinois Insurance Code is amended by  
11 adding Section 224.5 as follows:

12 (215 ILCS 5/224.5 new)

13 Sec. 224.5. Use of information derived from genetic  
14 testing. After the effective date of this amendatory Act of  
15 the 103rd General Assembly, an insurer must comply with the  
16 provisions of the Genetic Information Privacy Act in  
17 connection with the amendment, delivery, issuance, or renewal  
18 of a life insurance policy; claims for or denial of coverage  
19 under a life insurance policy; or the determination of  
20 premiums or rates under a life insurance policy.