

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 Sections 10 and 20 as follows:

6 (410 ILCS 513/10)

7 Sec. 10. Definitions. As used in this Act:

8 "Authority" means the Illinois Health Information Exchange
9 Authority established pursuant to the Illinois Health
10 Information Exchange and Technology Act.

11 "Business associate" has the meaning ascribed to it under
12 HIPAA, as specified in 45 CFR 160.103.

13 "Covered entity" has the meaning ascribed to it under
14 HIPAA, as specified in 45 CFR 160.103.

15 "De-identified information" means health information that
16 is not individually identifiable as described under HIPAA, as
17 specified in 45 CFR 164.514(b).

18 "Disclosure" has the meaning ascribed to it under HIPAA, as
19 specified in 45 CFR 160.103.

20 "Employer" means the State of Illinois, any unit of local
21 government, and any board, commission, department,
22 institution, or school district, any party to a public
23 contract, any joint apprenticeship or training committee

1 within the State, and every other person employing employees
2 within the State.

3 "Employment agency" means both public and private
4 employment agencies and any person, labor organization, or
5 labor union having a hiring hall or hiring office regularly
6 undertaking, with or without compensation, to procure
7 opportunities to work, or to procure, recruit, refer, or place
8 employees.

9 "Family member" means, with respect to an individual, (i)
10 the spouse of the individual; (ii) a dependent child of the
11 individual, including a child who is born to or placed for
12 adoption with the individual; (iii) any other person qualifying
13 as a covered dependent under a managed care plan; and (iv) all
14 other individuals related by blood or law to the individual or
15 the spouse or child described in subsections (i) through (iii)
16 of this definition.

17 "Genetic information" has the meaning ascribed to it under
18 HIPAA, as specified in 45 CFR 160.103.

19 "Genetic monitoring" means the periodic examination of
20 employees to evaluate acquired modifications to their genetic
21 material, such as chromosomal damage or evidence of increased
22 occurrence of mutations that may have developed in the course
23 of employment due to exposure to toxic substances in the
24 workplace in order to identify, evaluate, and respond to
25 effects of or control adverse environmental exposures in the
26 workplace.

1 "Genetic services" has the meaning ascribed to it under
2 HIPAA, as specified in 45 CFR 160.103.

3 "Genetic testing" and "genetic test" have the meaning
4 ascribed to "genetic test" under HIPAA, as specified in 45 CFR
5 160.103. "Genetic testing" includes direct-to-consumer
6 commercial genetic testing.

7 "Health care operations" has the meaning ascribed to it
8 under HIPAA, as specified in 45 CFR 164.501.

9 "Health care professional" means (i) a licensed physician,
10 (ii) a licensed physician assistant, (iii) a licensed advanced
11 practice registered nurse, (iv) a licensed dentist, (v) a
12 licensed podiatrist, (vi) a licensed genetic counselor, or
13 (vii) an individual certified to provide genetic testing by a
14 state or local public health department.

15 "Health care provider" has the meaning ascribed to it under
16 HIPAA, as specified in 45 CFR 160.103.

17 "Health facility" means a hospital, blood bank, blood
18 center, sperm bank, or other health care institution, including
19 any "health facility" as that term is defined in the Illinois
20 Finance Authority Act.

21 "Health information exchange" or "HIE" means a health
22 information exchange or health information organization that
23 exchanges health information electronically that (i) is
24 established pursuant to the Illinois Health Information
25 Exchange and Technology Act, or any subsequent amendments
26 thereto, and any administrative rules promulgated thereunder;

1 (ii) has established a data sharing arrangement with the
2 Authority; or (iii) as of August 16, 2013, was designated by
3 the Authority Board as a member of, or was represented on, the
4 Authority Board's Regional Health Information Exchange
5 Workgroup; provided that such designation shall not require the
6 establishment of a data sharing arrangement or other
7 participation with the Illinois Health Information Exchange or
8 the payment of any fee. In certain circumstances, in accordance
9 with HIPAA, an HIE will be a business associate.

10 "Health oversight agency" has the meaning ascribed to it
11 under HIPAA, as specified in 45 CFR 164.501.

12 "HIPAA" means the Health Insurance Portability and
13 Accountability Act of 1996, Public Law 104-191, as amended by
14 the Health Information Technology for Economic and Clinical
15 Health Act of 2009, Public Law 111-05, and any subsequent
16 amendments thereto and any regulations promulgated thereunder.

17 "Insurer" means (i) an entity that is subject to the
18 jurisdiction of the Director of Insurance and (ii) a managed
19 care plan.

20 "Labor organization" includes any organization, labor
21 union, craft union, or any voluntary unincorporated
22 association designed to further the cause of the rights of
23 union labor that is constituted for the purpose, in whole or in
24 part, of collective bargaining or of dealing with employers
25 concerning grievances, terms or conditions of employment, or
26 apprenticeships or applications for apprenticeships, or of

1 other mutual aid or protection in connection with employment,
2 including apprenticeships or applications for apprenticeships.

3 "Licensing agency" means a board, commission, committee,
4 council, department, or officers, except a judicial officer, in
5 this State or any political subdivision authorized to grant,
6 deny, renew, revoke, suspend, annul, withdraw, or amend a
7 license or certificate of registration.

8 "Limited data set" has the meaning ascribed to it under
9 HIPAA, as described in 45 CFR 164.514(e)(2).

10 "Managed care plan" means a plan that establishes,
11 operates, or maintains a network of health care providers that
12 have entered into agreements with the plan to provide health
13 care services to enrollees where the plan has the ultimate and
14 direct contractual obligation to the enrollee to arrange for
15 the provision of or pay for services through:

16 (1) organizational arrangements for ongoing quality
17 assurance, utilization review programs, or dispute
18 resolution; or

19 (2) financial incentives for persons enrolled in the
20 plan to use the participating providers and procedures
21 covered by the plan.

22 A managed care plan may be established or operated by any
23 entity including a licensed insurance company, hospital or
24 medical service plan, health maintenance organization, limited
25 health service organization, preferred provider organization,
26 third party administrator, or an employer or employee

1 organization.

2 "Minimum necessary" means HIPAA's standard for using,
3 disclosing, and requesting protected health information found
4 in 45 CFR 164.502(b) and 164.514(d).

5 "Nontherapeutic purpose" means a purpose that is not
6 intended to improve or preserve the life or health of the
7 individual whom the information concerns.

8 "Organized health care arrangement" has the meaning
9 ascribed to it under HIPAA, as specified in 45 CFR 160.103.

10 "Patient safety activities" has the meaning ascribed to it
11 under 42 CFR 3.20.

12 "Payment" has the meaning ascribed to it under HIPAA, as
13 specified in 45 CFR 164.501.

14 "Person" includes any natural person, partnership,
15 association, joint venture, trust, governmental entity, public
16 or private corporation, health facility, or other legal entity.

17 "Protected health information" has the meaning ascribed to
18 it under HIPAA, as specified in 45 CFR 164.103.

19 "Research" has the meaning ascribed to it under HIPAA, as
20 specified in 45 CFR 164.501.

21 "State agency" means an instrumentality of the State of
22 Illinois and any instrumentality of another state which
23 pursuant to applicable law or a written undertaking with an
24 instrumentality of the State of Illinois is bound to protect
25 the privacy of genetic information of Illinois persons.

26 "Treatment" has the meaning ascribed to it under HIPAA, as

1 specified in 45 CFR 164.501.

2 "Use" has the meaning ascribed to it under HIPAA, as
3 specified in 45 CFR 160.103, where context dictates.

4 (Source: P.A. 99-173, eff. 7-29-15; 100-513, eff. 1-1-18.)

5 (410 ILCS 513/20)

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

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

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

19 (1) rules for, or determination of, eligibility
20 (including enrollment and continued eligibility) for, or
21 determination of, benefits under the plan, coverage, or
22 policy (including changes in deductibles or other
23 cost-sharing mechanisms in return for activities such as
24 completing a health risk assessment or participating in a
25 wellness program);

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

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

9 (4) other activities related to the creation, renewal,
10 or replacement of a contract of health insurance or health
11 benefits.

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

15 This subsection (b) does not apply to insurers that are
16 issuing a long-term care policy, excluding a nursing home fixed
17 indemnity plan.

18 (c) An insurer may consider the results of genetic testing
19 in connection with a policy of accident and health insurance if
20 the individual voluntarily submits the results and the results
21 are favorable to the individual.

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

25 (e) A company providing direct-to-consumer commercial
26 genetic testing is prohibited from sharing any genetic test

1 information or other personally identifiable information about
2 a consumer with any health or life insurance company without
3 written consent from the consumer.

4 (Source: P.A. 98-1046, eff. 1-1-15.)