

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, 15, 25, and 40 and by adding Section
6 50 as follows:

7 (410 ILCS 513/10)

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

9 "Employer" means the State of Illinois, any unit of local
10 government, and any board, commission, department,
11 institution, or school district, any party to a public
12 contract, any joint apprenticeship or training committee
13 within the State, and every other person employing employees
14 within the State.

15 "Employment agency" means both public and private
16 employment agencies and any person, labor organization, or
17 labor union having a hiring hall or hiring office regularly
18 undertaking, with or without compensation, to procure
19 opportunities to work, or to procure, recruit, refer, or place
20 employees.

21 "Family member" means, with respect to an individual, (i)
22 the spouse of the individual; (ii) a dependent child of the
23 individual, including a child who is born to or placed for

1 adoption with the individual; (iii) any other person qualifying
2 as a covered dependent under a managed care plan; and (iv) all
3 other individuals related by blood or law to the individual or
4 the spouse or child described in subsections (i) through (iii)
5 of this definition.

6 "Genetic information" means, with respect to any
7 individual, information about (i) the individual's genetic
8 tests; (ii) the genetic tests of a family member of the
9 individual; and (iii) the manifestation or possible
10 manifestation of a disease or disorder in a family member of
11 the individual. Genetic information does not include
12 information about the sex or age of any individual.

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

21 "Genetic services" means a genetic test, genetic
22 counseling, including obtaining, interpreting, or assessing
23 genetic information, or genetic education.

24 "Genetic testing" and "genetic test" mean ~~means~~ a test or
25 analysis of human ~~a person's~~ genes, gene products, DNA, RNA, or
26 chromosomes, proteins, or metabolites that detect genotypes,

1 mutations, chromosomal changes, ~~for~~ abnormalities, or
2 deficiencies, including carrier status, that (i) are linked to
3 physical or mental disorders or impairments, (ii) indicate a
4 susceptibility to illness, disease, impairment, or other
5 disorders, whether physical or mental, or (iii) demonstrate
6 genetic or chromosomal damage due to environmental factors.
7 Genetic testing and genetic tests do ~~does~~ not include routine
8 physical measurements; chemical, blood and urine analyses that
9 are widely accepted and in use in clinical practice; tests for
10 use of drugs; ~~and~~ tests for the presence of the human
11 immunodeficiency virus; analyses of proteins or metabolites
12 that do not detect genotypes, mutations, chromosomal changes,
13 abnormalities, or deficiencies; or analyses of proteins or
14 metabolites that are directly related to a manifested disease,
15 disorder, or pathological condition that could reasonably be
16 detected by a health care professional with appropriate
17 training and expertise in the field of medicine involved.

18 "Insurer" means (i) an entity that transacts an insurance
19 business and (ii) a managed care plan.

20 "Licensing agency" means a board, commission, committee,
21 council, department, or officers, except a judicial officer, in
22 this State or any political subdivision authorized to grant,
23 deny, renew, revoke, suspend, annul, withdraw, or amend a
24 license or certificate of registration.

25 "Labor organization" includes any organization, labor
26 union, craft union, or any voluntary unincorporated

1 association designed to further the cause of the rights of
2 union labor that is constituted for the purpose, in whole or in
3 part, of collective bargaining or of dealing with employers
4 concerning grievances, terms or conditions of employment, or
5 apprenticeships or applications for apprenticeships, or of
6 other mutual aid or protection in connection with employment,
7 including apprenticeships or applications for apprenticeships.

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

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

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

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

26 (Source: P.A. 90-25, eff. 1-1-98.)

1 (410 ILCS 513/15)

2 Sec. 15. Confidentiality of genetic information.

3 (a) Except as otherwise provided in this Act, genetic
4 testing and information derived from genetic testing is
5 confidential and privileged and may be released only to the
6 individual tested and to persons specifically authorized, in
7 writing in accordance with Section 30, by that individual to
8 receive the information. Except as otherwise provided in
9 subsection (b) and in Section 30, this information shall not be
10 admissible as evidence, nor discoverable in any action of any
11 kind in any court, or before any tribunal, board, agency, or
12 person pursuant to Part 21 of Article VIII of the Code of Civil
13 Procedure. No liability shall attach to any hospital,
14 physician, or other health care provider for compliance with
15 the provisions of this Act including a specific written release
16 by the individual in accordance with this Act.

17 (b) When a biological sample is legally obtained by a peace
18 officer for use in a criminal investigation or prosecution,
19 information derived from genetic testing of that sample may be
20 disclosed for identification purposes to appropriate law
21 enforcement authorities conducting the investigation or
22 prosecution and may be used in accordance with Section 5-4-3 of
23 the Unified Code of Corrections. The information may be used
24 for identification purposes during the course of the
25 investigation or prosecution with respect to the individual

1 tested without the consent of the individual and shall be
2 admissible as evidence in court.

3 The information shall be confidential and may be disclosed
4 only for purposes of criminal investigation or prosecution.

5 Genetic testing and genetic information derived thereof
6 shall be admissible as evidence and discoverable, subject to a
7 protective order, in any actions alleging a violation of this
8 Act, seeking to enforce Section 30 of this Act through the
9 Illinois Insurance Code, alleging discriminatory genetic
10 testing or use of genetic information under the Illinois Human
11 Rights Act or the Illinois Civil Rights Act of 2003, or
12 requesting a workers' compensation claim under the Workers'
13 Compensation Act.

14 (c) If the subject of the information requested by law
15 enforcement is found innocent of the offense or otherwise not
16 criminally penalized, then the court records shall be expunged
17 by the court within 30 days after the final legal proceeding.
18 The court shall notify the subject of the information of the
19 expungement of the records in writing.

20 (d) Results of genetic testing that indicate that the
21 individual tested is at the time of the test afflicted with a
22 disease, whether or not currently symptomatic, are not subject
23 to the confidentiality requirements of this Act.

24 (Source: P.A. 90-25, eff. 1-1-98.)

25 (410 ILCS 513/25)

1 Sec. 25. Use of genetic testing information by employers.

2 (a) An employer, employment agency, labor organization,
3 and licensing agency shall treat genetic testing and genetic
4 information in such a manner that is consistent with the
5 requirements of federal law, including but not limited to the
6 Genetic Information Nondiscrimination Act of 2008, the
7 Americans with Disabilities Act, Title VII of the Civil Rights
8 Act of 1964, the Family and Medical Leave Act of 1993, the
9 Occupational Safety and Health Act of 1970, the Federal Mine
10 Safety and Health Act of 1977, or the Atomic Energy Act of
11 1954.

12 (b) An employer may release genetic testing information
13 only in accordance with Sections 15 and ~~Section~~ 30 of this Act.

14 (c) An employer, employment agency, labor organization,
15 and licensing agency shall not directly or indirectly do any of
16 the following:

17 (1) solicit, request, require or purchase genetic
18 testing or genetic information of a person or a family
19 member of the person, or administer a genetic test to a
20 person or a family member of the person as a condition of
21 employment, preemployment application, labor organization
22 membership, or licensure;

23 (2) affect the terms, conditions, or privileges of
24 employment, preemployment application, labor organization
25 membership, or licensure, or terminate the employment,
26 labor organization membership, or licensure of any person

1 because of genetic testing or genetic information with
2 respect to the employee or family member, or information
3 about a request for or the receipt of genetic testing by
4 such employee or family member of such employee;

5 (3) limit, segregate, or classify employees in any way
6 that would deprive or tend to deprive any employee of
7 employment opportunities or otherwise adversely affect the
8 status of the employee as an employee because of genetic
9 testing or genetic information with respect to the employee
10 or a family member, or information about a request for or
11 the receipt of genetic testing or genetic information by
12 such employee or family member of such employee; and

13 (4) retaliate through discharge or in any other manner
14 against any person alleging a violation of this Act or
15 participating in any manner in a proceeding under this Act.

16 (d) An agreement between a person and an employer,
17 prospective employer, employment agency, labor organization,
18 or licensing agency, or its employees, agents, or members
19 offering the person employment, labor organization membership,
20 licensure, or any pay or benefit in return for taking a genetic
21 test is prohibited.

22 (e) An employer shall not use genetic information or
23 genetic testing in furtherance of a workplace wellness program
24 benefiting employees unless (1) health or genetic services are
25 offered by the employer, (2) the employee provides written and
26 informed consent in accordance with Section 30 of this Act, (3)

1 only the employee or family member if the family member is
2 receiving genetic services and the licensed health care
3 professional or licensed genetic counselor involved in
4 providing such services receive individually identifiable
5 information concerning the results of such services, and (4)
6 any individually identifiable information is only available
7 for purposes of such services and shall not be disclosed to the
8 employer except in aggregate terms that do not disclose the
9 identity of specific employees.

10 (f) Nothing in this Act shall be construed to prohibit
11 genetic testing of an employee who requests a genetic test and
12 who provides written and informed consent, in accordance with
13 Section 30 of this Act, from taking a genetic test for the
14 purpose of initiating a workers' compensation claim under the
15 Workers' Compensation Act.

16 (g) A purchase of commercially and publicly available
17 documents, including newspapers, magazines, periodicals, and
18 books but not including medical databases or court records or
19 inadvertently requesting family medical history by an
20 employer, employment agency, labor organization, and licensing
21 agency does not violate this Act.

22 (h) Nothing in this Act shall be construed to prohibit an
23 employer that conducts DNA analysis for law enforcement
24 purposes as a forensic laboratory and that includes such
25 analysis in the Combined DNA Index System pursuant to the
26 federal Violent Crime Control and Law Enforcement Act of 1994

1 from requesting or requiring genetic testing or genetic
2 information of such employer's employees, but only to the
3 extent that such genetic testing or genetic information is used
4 for analysis of DNA identification markers for quality control
5 to detect sample contamination.

6 (i) Nothing in this Act shall be construed to prohibit an
7 employer from requesting or requiring genetic information to be
8 used for genetic monitoring of the biological effects of toxic
9 substances in the workplace, but only if (1) the employer
10 provides written notice of the genetic monitoring to the
11 employee; (2) the employee provides written and informed
12 consent under Section 30 of this Act or the genetic monitoring
13 is required by federal or State law; (3) the employee is
14 informed of individual monitoring results; (4) the monitoring
15 is in compliance with any federal genetic monitoring
16 regulations or State genetic monitoring regulations under the
17 authority of the federal Occupational Safety and Health Act of
18 1970; and (5) the employer, excluding any licensed health care
19 professional or licensed genetic counselor that is involved in
20 the genetic monitoring program, receives the results of the
21 monitoring only in aggregate terms that do not disclose the
22 identity of specific employees.

23 (j) Despite lawful acquisition of genetic testing or
24 genetic information under subsections (e) through (i) of this
25 Section, an employer, employment agency, labor organization,
26 and licensing agency still may not use or disclose the genetic

1 test or genetic information in violation of this Act.

2 (k) Except as provided in subsections (e), (f), (h), and
3 (i) of this Section, a person shall not knowingly sell to or
4 interpret for an employer, employment agency, labor
5 organization, or licensing agency, or its employees, agents, or
6 members, a genetic test of an employee, labor organization
7 member, or license holder, or of a prospective employee,
8 member, or license holder.

9 (Source: P.A. 90-25, eff. 1-1-98.)

10 (410 ILCS 513/40)

11 Sec. 40. Right of action.

12 (a) Any person aggrieved by a violation of this Act shall
13 have a right of action in a State ~~the~~ circuit court or as a
14 supplemental claim in a federal district court against an
15 offending party. A prevailing party ~~and~~ may recover for each
16 violation:

17 (1) Against any party ~~person~~ who negligently violates a
18 provision of this Act, liquidated damages of \$2,500 ~~\$1,000~~
19 or actual damages, whichever is greater.

20 (2) Against any party ~~person~~ who intentionally or
21 recklessly violates a provision of this Act, liquidated
22 damages of \$15,000 ~~\$5,000~~ or actual damages, whichever is
23 greater.

24 (3) Reasonable attorney's ~~attorney~~ fees and costs,
25 including expert witness fees and other litigation

1 expenses.

2 (4) Such other relief, including an injunction, as the
3 State or federal court may deem appropriate.

4 (b) Article XL of the Illinois Insurance Code shall provide
5 the exclusive remedy for violations of Section 30 by insurers.

6 (c) Notwithstanding any provisions of the law to the
7 contrary, any person alleging a violation of subsection (a) of
8 Section 15, subsection (b) of Section 25, Section 30, or
9 Section 35 of this Act shall have a right of action in a State
10 circuit court or as a supplemental claim in a federal district
11 court to seek a preliminary injunction preventing the release
12 or disclosure of genetic testing or genetic information pending
13 the final resolution of any action under this Act.

14 (Source: P.A. 90-25, eff. 1-1-98.)

15 (410 ILCS 513/50 new)

16 Sec. 50. Home rule. Any home rule unit of local
17 government, any non-home rule municipality, or any non-home
18 rule county within the unincorporated territory of the county
19 may enact ordinances, standards, rules, or regulations that
20 protect genetic information and genetic testing in a manner or
21 to an extent equal to or greater than the protection provided
22 in this Act. This Section is a limitation on the concurrent
23 exercise of home rule power under subsection (i) of Section 6
24 of Article VII of the Illinois Constitution.