

AN ACT concerning health.

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

Section 5. The Genetic Information Privacy Act is amended by changing Sections 10, 15, 25, and 40 and by adding Section 50 as follows:

(410 ILCS 513/10)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(410 ILCS 513/15)

Sec. 15. Confidentiality of genetic information.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

test or genetic information in violation of this Act.

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

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

(410 ILCS 513/40)

Sec. 40. Right of action.

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

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

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

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

expenses.

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

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

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

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

(410 ILCS 513/50 new)

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