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 and 20 as follows:

(410 ILCS 513/10)

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

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

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

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

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

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

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

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

"Genetic testing" and "genetic test" have the meaning ascribed to "genetic test" under HIPAA, as specified in 45 CFR 160.103. <u>"Genetic testing" includes direct-to-consumer commercial genetic testing.</u>

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

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

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

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

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

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

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

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

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

"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.

"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.

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

"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.

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

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

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

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

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

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

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

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

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

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

specified in 45 CFR 164.501.

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

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

(410 ILCS 513/20)

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

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

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

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

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

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

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

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

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

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

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

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

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

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