



Rep. Natalie A. Manley

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10100HB2189ham001

LRB101 06626 CPF 56601 a

1 AMENDMENT TO HOUSE BILL 2189

2 AMENDMENT NO. \_\_\_\_\_. Amend House Bill 2189 by replacing  
3 everything after the enacting clause with the following:

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

1 specified in 45 CFR 164.514(b).

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

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

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

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

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

26 "Genetic monitoring" means the periodic examination of

1 employees to evaluate acquired modifications to their genetic  
2 material, such as chromosomal damage or evidence of increased  
3 occurrence of mutations that may have developed in the course  
4 of employment due to exposure to toxic substances in the  
5 workplace in order to identify, evaluate, and respond to  
6 effects of or control adverse environmental exposures in the  
7 workplace.

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

10 "Genetic testing" and "genetic test" have the meaning  
11 ascribed to "genetic test" under HIPAA, as specified in 45 CFR  
12 160.103. "Genetic testing" includes direct-to-consumer  
13 commercial genetic testing.

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

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

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

24 "Health facility" means a hospital, blood bank, blood  
25 center, sperm bank, or other health care institution, including  
26 any "health facility" as that term is defined in the Illinois

1 Finance Authority Act.

2 "Health information exchange" or "HIE" means a health  
3 information exchange or health information organization that  
4 exchanges health information electronically that (i) is  
5 established pursuant to the Illinois Health Information  
6 Exchange and Technology Act, or any subsequent amendments  
7 thereto, and any administrative rules promulgated thereunder;  
8 (ii) has established a data sharing arrangement with the  
9 Authority; or (iii) as of August 16, 2013, was designated by  
10 the Authority Board as a member of, or was represented on, the  
11 Authority Board's Regional Health Information Exchange  
12 Workgroup; provided that such designation shall not require the  
13 establishment of a data sharing arrangement or other  
14 participation with the Illinois Health Information Exchange or  
15 the payment of any fee. In certain circumstances, in accordance  
16 with HIPAA, an HIE will be a business associate.

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

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

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

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

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

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

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

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

26 (2) financial incentives for persons enrolled in the

1 plan to use the participating providers and procedures  
2 covered by the plan.

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

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

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

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

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

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

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

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

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

1 specified in 45 CFR 164.501.

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

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

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

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

12 (410 ILCS 513/20)

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

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

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

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

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

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

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

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

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

25          (c) An insurer may consider the results of genetic testing  
26          in connection with a policy of accident and health insurance if



1 the individual voluntarily submits the results and the results  
2 are favorable to the individual.

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

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

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