



## 101ST GENERAL ASSEMBLY

### State of Illinois

2019 and 2020

SB1307

Introduced 2/7/2019, by Sen. Chapin Rose

#### SYNOPSIS AS INTRODUCED:

410 ILCS 513/31  
410 ILCS 513/31.1  
410 ILCS 513/31.2  
410 ILCS 513/31.3  
410 ILCS 513/31.5  
410 ILCS 513/31.7

Amends the Genetic Information Privacy Act. In provisions concerning uses and disclosures for treatment, payment, health care operations, health oversight activities, and public health activities; uses and disclosures of information to a health information exchange; business associates; and establishment and disclosure of limited data sets and de-identified information, provides that various uses or disclosures of a patient's genetic information may not (rather than may) occur without the patient's consent. Effective immediately.

LRB101 06900 CPF 51932 b

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 31, 31.1, 31.2, 31.3, 31.5, and 31.7 as  
6 follows:

7 (410 ILCS 513/31)

8 Sec. 31. Uses and disclosures for treatment, payment, and  
9 health care operations. ~~A Notwithstanding Sections 30 and 35 of~~  
10 ~~this Act,~~ a covered entity may not, without a patient's  
11 consent:

12 (1) use or disclose genetic information for its own  
13 treatment, payment, or health care operations;

14 (2) disclose genetic information for treatment  
15 activities of a health care provider;

16 (3) disclose genetic information to another covered  
17 entity or health care provider for the payment activities  
18 of the entity that receives the information;

19 (4) disclose genetic information to another covered  
20 entity for health care operations activities of the entity  
21 that receives the information, if each entity has or had a  
22 relationship with the individual who is the subject of the  
23 genetic information being requested, the genetic

1 information pertains to such relationship, and the  
2 disclosure is for the purpose of (A) conducting quality  
3 assessment and improvement activities, including outcomes  
4 evaluation and development of clinical guidelines,  
5 provided that the obtaining of generalizable knowledge is  
6 not the primary purpose of any studies resulting from such  
7 activities; patient safety activities; population-based  
8 activities relating to improving health or reducing health  
9 care costs, protocol development, case management, and  
10 care coordination, contacting of health care providers and  
11 patients with information about treatment alternatives;  
12 and related functions that do not include treatment; (B)  
13 reviewing the competence or qualifications of health care  
14 professionals or health care providers, evaluating  
15 practitioner and provider performance, health plan  
16 performance, conducting training programs in which  
17 students, trainees, or practitioners in areas of health  
18 care learn under supervision to practice or improve their  
19 skills as health care providers, training of non-health  
20 care professionals, accreditation, certification,  
21 licensing, or credentialing activities; or (C) health care  
22 fraud and abuse detection or compliance; and

23 (5) disclose genetic information to other participants  
24 in an organized health care arrangement in which the  
25 covered entity is also a participant for any health care  
26 operations activities of the organized health care

1 arrangement.

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

3 (410 ILCS 513/31.1)

4 Sec. 31.1. Uses and disclosures for health oversight  
5 activities.

6 (a) ~~A Notwithstanding Sections 30 and 35 of this Act, a~~  
7 covered entity may not disclose genetic information, without a  
8 patient's consent, to a health oversight agency for health  
9 oversight activities authorized by law, including audits,  
10 civil, administrative, or criminal investigations;  
11 inspections; licensure or disciplinary actions; civil  
12 administrative or criminal proceedings or actions; or other  
13 activities necessary for appropriate oversight of (i) the  
14 health care system; (ii) government benefit programs for which  
15 health information is relevant to beneficiary eligibility;  
16 (iii) entities subject to government regulatory programs for  
17 which health information is necessary for determining  
18 compliance with program standards; or (iv) entities subject to  
19 civil rights laws for which health information is necessary for  
20 determining compliance.

21 (b) For purposes of the disclosures permitted by this  
22 Section, a health oversight activity does not include an  
23 investigation or other activity in which the individual is the  
24 subject of the investigation or activity and such investigation  
25 or other activity does not arise out of and is not directly

1 related to (i) the receipt of health care; (ii) a claim for  
2 public benefits related to health; or (iii) qualification for,  
3 or receipt of, public benefits or services when a patient's  
4 health is integral to the claim for public benefits or  
5 services, except that, if a health oversight activity or  
6 investigation is conducted in conjunction with an oversight  
7 activity or investigation relating to a claim for public  
8 benefits not related to health, the joint activity or  
9 investigation is considered a health oversight activity for  
10 purposes of this Section.

11 (c) If a covered entity is also a health oversight agency,  
12 the covered entity may use genetic information for health  
13 oversight activities permitted by this Section.

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

15 (410 ILCS 513/31.2)

16 Sec. 31.2. Uses and disclosures for public health  
17 activities. ~~Genetic Notwithstanding Sections 30 and 35 of this~~  
18 ~~Act, genetic~~ information may not be disclosed without a  
19 patient's consent for public health activities and purposes to  
20 the Department, when the Department is authorized by law to  
21 collect or receive such information for the purpose of  
22 preventing or controlling disease, injury, or disability,  
23 including, but not limited to, the reporting of disease,  
24 injury, vital events such as birth or death, and the conduct of  
25 public health surveillance, public health investigations, and

1 public health interventions.

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

3 (410 ILCS 513/31.3)

4 Sec. 31.3. Business associates.

5 (a) ~~A Notwithstanding Sections 30 and 35 of this Act, a~~  
6 covered entity may not, without a patient's consent, disclose a  
7 patient's genetic information to a business associate and may  
8 allow a business associate to create, receive, maintain, or  
9 transmit protected health information on its behalf, if the  
10 covered entity obtains, through a written contract or other  
11 written agreement or arrangement that meets the applicable  
12 requirements of 45 CFR 164.504(e), satisfactory assurance that  
13 the business associate will appropriately safeguard the  
14 information. A covered entity is not required to obtain such  
15 satisfactory assurances from a business associate that is a  
16 subcontractor.

17 (b) A business associate may disclose protected health  
18 information to a business associate that is a subcontractor and  
19 may allow the subcontractor to create, receive, maintain, or  
20 transmit protected health information on its behalf, if the  
21 business associate obtains satisfactory assurances, in  
22 accordance with 45 CFR 164.504(e)(1)(i), that the  
23 subcontractor will appropriately safeguard the information.

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

1 (410 ILCS 513/31.5)

2 Sec. 31.5. Use and disclosure of information to an HIE. A  
3 ~~Notwithstanding the provisions of Section 30 and 35 of this~~  
4 ~~Act,~~ a covered entity may not, without a patient's consent,  
5 disclose the identity of any patient upon whom a test is  
6 performed and such patient's genetic information from a  
7 patient's record to a HIE if the disclosure is a required or  
8 permitted disclosure to a business associate or is a disclosure  
9 otherwise required or permitted under this Act. An HIE may not,  
10 without a patient's consent, use or disclose such information  
11 to the extent it is allowed to use or disclose such information  
12 as a business associate in compliance with 45 CFR 164.502(e) or  
13 for such other purposes as are specifically allowed under this  
14 Act.

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

16 (410 ILCS 513/31.7)

17 Sec. 31.7. Establishment and disclosure of limited data  
18 sets and de-identified information.

19 (a) A covered entity may not, without a genetic information  
20 test subject's consent, create, use, and disclose a limited  
21 data set using information subject to this Act or disclose  
22 information subject to this Act to a business associate for the  
23 purpose of establishing a limited data set. The creation, use,  
24 and disclosure of such a limited data set must comply with the  
25 requirements set forth under HIPAA.

1 (b) A covered entity may not, without a genetic information  
2 test subject's consent, create, use, and disclose  
3 de-identified information using information subject to this  
4 Act or disclose information subject to this Act to a business  
5 associate for the purpose of de-identifying the information.  
6 The creation, use, and disclosure of such de-identified  
7 information must comply with the requirements set forth under  
8 HIPAA. A covered entity or a business associate may disclose  
9 information that is de-identified in accordance with HIPAA.

10 (c) The recipient of de-identified information shall not  
11 re-identify de-identified information using any public or  
12 private data source.

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

14 Section 99. Effective date. This Act takes effect upon  
15 becoming law.