



## 104TH GENERAL ASSEMBLY

### State of Illinois

2025 and 2026

SB2994

Introduced 1/27/2026, by Sen. Rachel Ventura

#### SYNOPSIS AS INTRODUCED:

410 ILCS 513/5  
410 ILCS 513/10  
410 ILCS 513/20  
410 ILCS 513/25  
410 ILCS 513/27 new  
410 ILCS 513/40  
410 ILCS 513/50

Amends the Genetic Information Privacy Act. Adds legislative findings. Defines "neurotechnology" and "neurotechnology data". Prohibits insurers from using genetic testing or neurotechnology data (rather than only genetic testing) for nontherapeutic purposes or underwriting, with limited exceptions. Prohibits employers, employment agencies, labor organizations, and licensing agencies from requesting, requiring, or using neurotechnology data in employment decisions, subject to specified exceptions. Adds new provisions governing confidentiality, consent, privacy policies, and security requirements for entities collecting neurotechnology data. Regulates disclosure to government agencies and sets conditions for clinical research. Makes conforming changes. Effective January 1, 2027.

LRB104 17867 BDA 31303 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 5, 10, 20, 25, 40, and 50 and by adding  
6 Section 27 as follows:

7 (410 ILCS 513/5)

8 Sec. 5. Legislative findings; intent. The General Assembly  
9 finds that:

10 (a) (1) The use of genetic testing can be valuable to an  
11 individual.

12 (2) Despite existing laws, regulations, and professional  
13 standards which require or promote voluntary and confidential  
14 use of genetic testing information, many members of the public  
15 are deterred from seeking genetic testing because of fear that  
16 test results will be disclosed without consent in a manner not  
17 permitted by law or will be used in a discriminatory manner.

18 (3) The public health will be served by facilitating  
19 voluntary and confidential nondiscriminatory use of genetic  
20 testing information.

21 (4) The use of electronic health record systems and the  
22 exchange of patient records, both paper and electronic,  
23 through secure means, including through secure health

1 information exchanges, should be encouraged to improve patient  
2 health care and care coordination, facilitate public health  
3 reporting, and control health care costs, among other  
4 purposes.

5 (5) Limiting the use or disclosure of, and requests for,  
6 protected health information to the minimum necessary to  
7 accomplish an intended purpose, when being transmitted by or  
8 on behalf of a covered entity under HIPAA, is a key component  
9 of health information privacy. The disclosure of genetic  
10 information, when allowed by this Act, shall be performed in  
11 accordance with the minimum necessary standard when required  
12 under HIPAA.

13 (b) (1) Ongoing advances in technology have produced  
14 exponential growth in the volume and variety of personal data  
15 being generated, collected, stored, and analyzed, and these  
16 advances present both great promise and potential risks.

17 (2) Technology that collects data about the user's bodily  
18 and mental functions is transforming the volume and  
19 sensitivity of personal data collected from individuals and  
20 stored by companies.

21 (3) Neurotechnologies, including devices capable of  
22 recording, interpreting, and altering the response of an  
23 individual's central or peripheral nervous system to its  
24 internal or external environment, raise particularly pressing  
25 privacy concerns given their ability to monitor, decode, and  
26 manipulate brain activity.

1       (4) Data concerning the activity of the human brain and  
2 wider nervous systems, or "neurotechnology data", is extremely  
3 sensitive and can reveal intimate information about  
4 individuals, including information about health, mental  
5 states, emotions, and cognitive functioning.

6       (5) Each human brain is unique, meaning that neural data  
7 is specific to the individual from whom it is collected.  
8 Because neurotechnology data contains distinctive information  
9 about the structure and functioning of individual brains and  
10 nervous systems, it contains sensitive information that may  
11 link the data to an identified or identifiable individual.

12       (6) The collection of neurotechnology data involves the  
13 involuntary disclosure of information. Even if individuals  
14 consent to the collection and processing of their data for  
15 narrow use, they are unlikely to be fully aware of the content  
16 or quality of information they are sharing.

17       (7) Neurotechnology users cannot decide what specific  
18 neurotechnology information they would like to disclose, and  
19 they are unlikely to understand the extent to which their  
20 neurotechnology data can be decoded, currently or in the  
21 future. Neurotechnologies can collect and process information  
22 about an individual that the individual did not even know  
23 existed.

24       (8) Neurotechnologies that are deployed in medical  
25 settings or otherwise utilize the surgical implantation of  
26 invasive devices are typically regulated as medical tools that

1 produce health information. Both invasive and noninvasive  
2 wearable neurotechnologies used in medical settings are also  
3 regulated by health data privacy laws. However, when  
4 noninvasive neurotechnologies are used outside of medical  
5 settings, they are generally considered consumer products and  
6 operate without regulation or data protection standards.

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

8 (410 ILCS 513/10)

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

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

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

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

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

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

25 "Employment agency" means both public and private

1 employment agencies and any person, labor organization, or  
2 labor union having a hiring hall or hiring office regularly  
3 undertaking, with or without compensation, to procure  
4 opportunities to work, or to procure, recruit, refer, or place  
5 employees.

6 "Family member" means, with respect to an individual, (i)  
7 the spouse of the individual; (ii) a dependent child of the  
8 individual, including a child who is born to or placed for  
9 adoption with the individual; (iii) any other person  
10 qualifying as a covered dependent under a managed care plan;  
11 and (iv) all other individuals related by blood or law to the  
12 individual or the spouse or child described in subsections (i)  
13 through (iii) of this definition.

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

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

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

26 "Genetic testing" and "genetic test" have the meaning

1 ascribed to "genetic test" under HIPAA, as specified in 45 CFR  
2 160.103. "Genetic testing" includes direct-to-consumer  
3 commercial genetic testing.

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

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

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

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

18 "Health information exchange" or "HIE" means a health  
19 information exchange or health information organization that  
20 exchanges health information electronically. In certain  
21 circumstances, in accordance with HIPAA, an HIE will be a  
22 business associate.

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

25 "HIPAA" means the Health Insurance Portability and  
26 Accountability Act of 1996, Public Law 104-191, as amended by

1 the Health Information Technology for Economic and Clinical  
2 Health Act of 2009, Public Law 111-05, and any subsequent  
3 amendments thereto and any regulations promulgated thereunder.

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

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

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

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

23 "Managed care plan" means a plan that establishes,  
24 operates, or maintains a network of health care providers that  
25 have entered into agreements with the plan to provide health  
26 care services to enrollees where the plan has the ultimate and

1 direct contractual obligation to the enrollee to arrange for  
2 the provision of or pay for services through:

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

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

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

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

18 "Neurotechnology" means devices capable of recording,  
19 interpreting, or altering the response of an individual's  
20 central or peripheral nervous system to its internal or  
21 external environment. "Neurotechnology" includes mental  
22 augmentation or improving human cognition and behavior through  
23 direct recording or manipulation of neural activity by  
24 neurotechnology.

25 "Neurotechnology data" means information that is captured  
26 by neurotechnologies, that is generated by measuring the

1 activity of an individual's central or peripheral nervous  
2 systems, or that is data associated with neural activity, the  
3 activity of neurons or glial cells in the central or  
4 peripheral nervous system. "Neurotechnology data" does not  
5 include nonneural information, such as pupil dilation, motor  
6 activity, breathing rate, or other information about the  
7 downstream physical effects of neural activity.

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

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

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

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

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

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

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

25 "State agency" means an instrumentality of the State of  
26 Illinois and any instrumentality of another state which

1 pursuant to applicable law or a written undertaking with an  
2 instrumentality of the State of Illinois is bound to protect  
3 the privacy of genetic information of Illinois persons.

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

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

8 (Source: P.A. 103-508, eff. 8-4-23; 104-417, eff. 8-15-25.)

9 (410 ILCS 513/20)

10 Sec. 20. Use of genetic testing information or  
11 neurotechnology data for insurance purposes.

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

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

24 (1) rules for, or determination of, eligibility  
25 (including enrollment and continued eligibility) for, or

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

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

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

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

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

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

23 (c) An insurer may consider the results of genetic testing  
24 or may consider neurotechnology data in connection with a  
25 policy of accident and health insurance if the individual  
26 voluntarily submits the results of genetic testing or

1 voluntarily submits neurotechnology data and if the results of  
2 genetic testing or the neurotechnology data are favorable to  
3 the individual.

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

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

15 (Source: P.A. 101-132, eff. 1-1-20.)

16 (410 ILCS 513/25)

17 Sec. 25. Use of genetic testing information or  
18 neurotechnology data by employers.

19 (a) An employer, employment agency, labor organization,  
20 and licensing agency shall treat genetic testing and genetic  
21 information in such a manner that is consistent with the  
22 requirements of federal law, including but not limited to the  
23 Genetic Information Nondiscrimination Act of 2008, the  
24 Americans with Disabilities Act, Title VII of the Civil Rights  
25 Act of 1964, the Family and Medical Leave Act of 1993, the

1 Occupational Safety and Health Act of 1970, the Federal Mine  
2 Safety and Health Act of 1977, or the Atomic Energy Act of  
3 1954.

4 (b) An employer may release genetic testing information or  
5 neurotechnology data only in accordance with this Act.

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

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

15 (2) solicit, request, require, or purchase  
16 neurotechnology data of a person or a family member of a  
17 person, or require the person or family member of the  
18 person to use a neurotechnology, as a condition of  
19 employment, preemployment application, labor organization  
20 membership, or licensure;

21 (3) ~~(2)~~ affect the terms, conditions, or privileges of  
22 employment, preemployment application, labor organization  
23 membership, or licensure, or terminate the employment,  
24 labor organization membership, or licensure of any person  
25 because of genetic testing, ~~or~~ genetic information, or  
26 neurotechnology data with respect to the employee or

1 family member, or information about a request for or the  
2 receipt of genetic testing or neurotechnology data by such  
3 employee or family member of such employee;

4 (4) ~~(3)~~ limit, segregate, or classify employees in any  
5 way that would deprive or tend to deprive any employee of  
6 employment opportunities or otherwise adversely affect the  
7 status of the employee as an employee because of genetic  
8 testing, ~~or~~ genetic information, or neurotechnology data  
9 with respect to the employee or a family member, or  
10 information about a request for or the receipt of genetic  
11 testing, ~~or~~ genetic information, or neurotechnology data  
12 by such employee or family member of such employee; and

13 (5) ~~(4)~~ retaliate through discharge or in any other  
14 manner against any person alleging a violation of this Act  
15 or participating in any manner in a proceeding under this  
16 Act.

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

23 (e) An employer shall not use genetic information, ~~or~~  
24 genetic testing, or neurotechnology data in furtherance of a  
25 workplace wellness program benefiting employees unless (1)  
26 health services, ~~or~~ genetic services, or neurotechnology

1 services are offered by the employer, (2) the employee  
2 provides written authorization in accordance with Section 27  
3 or 30 of this Act, as it may apply, (3) only the employee or  
4 family member if the family member is receiving genetic  
5 neurotechnology data services and the licensed health care  
6 professional or licensed genetic counselor involved in  
7 providing such services receive individually identifiable  
8 information concerning the results of such services, and (4)  
9 any individually identifiable information is only available  
10 for purposes of such services and shall not be disclosed to the  
11 employer except in aggregate terms that do not disclose the  
12 identity of specific employees. An employer shall not penalize  
13 an employee who does not disclose his or her genetic  
14 information or neurotechnology data or does not choose to  
15 participate in a program requiring disclosure of the  
16 employee's genetic information or neurotechnology data.

17 (f) Nothing in this Act shall be construed to prohibit  
18 genetic testing of an employee who requests a genetic test and  
19 who provides written authorization, in accordance with Section  
20 30 of this Act, from taking a genetic test for the purpose of  
21 initiating a workers' compensation claim under the Workers'  
22 Compensation Act.

23 (g) A purchase of commercially and publicly available  
24 documents, including newspapers, magazines, periodicals, and  
25 books but not including medical databases, ~~or~~ court records,  
26 or consumer neurotechnology databases or inadvertently

1 requesting family medical history by an employer, employment  
2 agency, labor organization, and licensing agency does not  
3 violate this Act.

4 (h) Nothing in this Act shall be construed to prohibit an  
5 employer that conducts DNA analysis for law enforcement  
6 purposes as a forensic laboratory and that includes such  
7 analysis in the Combined DNA Index System pursuant to the  
8 federal Violent Crime Control and Law Enforcement Act of 1994  
9 from requesting or requiring genetic testing or genetic  
10 information of such employer's employees, but only to the  
11 extent that such genetic testing or genetic information is  
12 used for analysis of DNA identification markers for quality  
13 control to detect sample contamination.

14 (i) Nothing in this Act shall be construed to prohibit an  
15 employer from requesting or requiring genetic information or  
16 neurotechnology data to be used for genetic monitoring or  
17 other monitoring of the biological effects of toxic substances  
18 in the workplace, but only if (1) the employer provides  
19 written notice of the genetic monitoring or other monitoring  
20 to the employee; (2) the employee provides written  
21 authorization under Section 27 or 30 of this Act, as it may  
22 apply, or the genetic monitoring or other monitoring is  
23 required by federal or State law; (3) the employee is informed  
24 of individual monitoring results; (4) the monitoring is in  
25 compliance with any federal ~~genetic monitoring regulations~~ or  
26 State ~~genetic monitoring~~ regulations regarding genetic

1 monitoring or other monitoring under the authority of the  
2 federal Occupational Safety and Health Act of 1970; and (5)  
3 the employer, excluding any health care provider, health care  
4 professional, or health facility that is involved in the  
5 genetic monitoring or other monitoring program, receives the  
6 results of the monitoring only in aggregate terms that do not  
7 disclose the identity of specific employees.

8 (j) Despite lawful acquisition of genetic testing, ~~or~~  
9 genetic information, or neurotechnology data under subsections  
10 (e) through (i) of this Section, an employer, employment  
11 agency, labor organization, and licensing agency still may not  
12 use or disclose the genetic test, ~~or~~ genetic information, or  
13 neurotechnology data in violation of this Act.

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

21 (Source: P.A. 100-396, eff. 1-1-18.)

22 (410 ILCS 513/27 new)

23 Sec. 27. Confidentiality of neurotechnology data.

24 (a) As used in this Section:

25 "Entity" means a partnership, corporation, association, or

1 public or private organization of any character that:

2 (1) offers consumer neurotechnology products or  
3 services directly to a consumer; or

4 (2) collects, uses, or analyzes neurotechnology data.

5 "Government agency" means a State agency as defined under  
6 Section 1-7 of the Illinois State Auditing Act, a unit of local  
7 government, a school district, or any administrative unit or  
8 corporate outgrowth thereof.

9 "Processor" means a person that processes genetic data on  
10 behalf of an entity pursuant to a contract between the entity  
11 and the processor that prohibits the processor from retaining,  
12 using, or disclosing the neurotechnology data, or any  
13 information regarding the identity of the consumer, including  
14 whether that consumer has solicited or received  
15 neurotechnology, as applicable, for any purpose other than for  
16 the specific purpose of performing the services specified in  
17 the contract.

18 "Third party" means a person other than the consumer,  
19 entity, or processor.

20 (b) Except as otherwise provided in this Act,  
21 neurotechnology data and information derived from  
22 neurotechnology data is confidential and privileged and may be  
23 released only to the individual whose activity is measured or  
24 captured and to persons specifically authorized, in writing in  
25 accordance with this Section, by that individual to receive  
26 the information.

1       (c) To safeguard the privacy, confidentiality, security,  
2 and integrity of an individual's neurotechnology data, an  
3 entity shall:

4           (1) provide clear and complete information regarding  
5 the entity's policies and procedures for the collection,  
6 use, or disclosure of neurotechnology data by making  
7 available to a consumer:

8           (A) a high-level privacy policy overview that  
9 includes basic, essential information about the  
10 entity's collection, use, or disclosure of  
11 neurotechnology data; and

12           (B) a prominent, publicly available privacy notice  
13 that includes, at a minimum, information about the  
14 entity's data collection, consent, use, access,  
15 disclosure, transfer, security, and retention and  
16 deletion practices for neurotechnology data;

17           (2) obtain initial express consent from a consumer,  
18 parent, guardian, or power of attorney for the collection,  
19 use, or disclosure of the consumer's neurotechnology data  
20 that:

21           (A) clearly describes the entity's use of the  
22 neurotechnology data that the entity collects through  
23 the entity's neurotechnology product or service;

24           (B) specifies the categories of individuals within  
25 the entity that have access to neurotechnology data;  
26 and

1           (C) specifies how the entity may share the  
2           neurotechnology data;

3           (3) if the entity engages in any of the following,  
4           obtain a consumer's:

5           (A) separate express consent for:

6           (i) the transfer or disclosure of the  
7           consumer's neurotechnology data to any third party  
8           other than the entity's processors, including the  
9           name of the third party to which the consumer's  
10           neurotechnology data will be transferred or  
11           disclosed with the consumer's express consent;

12           (ii) the use of neurotechnology data beyond  
13           the primary purpose of the entity's  
14           neurotechnology product or service and inherent  
15           contextual uses; or

16           (iii) the entity's retention of any  
17           neurotechnology data provided by the consumer  
18           following the entity's completion of the primary  
19           purpose of the entity's neurotechnology requested  
20           by the consumer;

21           (B) informed express consent for transfer or  
22           disclosure of the consumer's neurotechnology data to  
23           third party persons for:

24           (i) research purposes; or

25           (ii) research conducted under the control of  
26           the entity for the purpose of publication or

1           generalizable knowledge; and  
2           (C) express consent for:  
3                 (i) marketing to a consumer based on the  
4                 consumer's neurotechnology data;  
5                 (ii) marketing by a third-party person to a  
6                 consumer based on the consumer having ordered or  
7                 purchased a neurotechnology product or service,  
8                 except that marketing under this subdivision (ii)  
9                 does not include the provision of customized  
10                content or offers on the websites or through the  
11                applications or services provided by the entity  
12                with the first-party relationship to the consumer;  
13                or  
14                (iii) sale or other valuable consideration of  
15                the consumer's neurotechnology data.  
16            (4) comply with the provisions of subsection (d)  
17            requiring a valid legal process for disclosing  
18            neurotechnology data to law enforcement or any other  
19            government agency without a consumer's express consent;  
20            (5) develop, implement, and maintain a comprehensive  
21            security program to protect a consumer's neurotechnology  
22            data against unauthorized access, use, or disclosure; and  
23            (6) provide a process for a consumer to:  
24                (A) access the consumer's neurotechnology data;  
25                (B) request and obtain the destruction of the  
26                consumer's neurotechnology data; and

1 (C) revoke any consent provided by the consumer.

2 (c-5) The requirements of paragraph (6) of subsection (c)  
3 shall be waived if:

4 (1) the entity obtains express and informed written  
5 consent from a consumer, parent, guardian, or power of  
6 attorney for participation in a clinical research trial,  
7 including the collection and use of any neurotechnology  
8 data, which at a minimum must:

9 (A) be in accordance with the good clinical  
10 practice guideline issued by the international council  
11 for harmonization of technical requirements for  
12 pharmaceuticals for human use;

13 (B) be obtained no sooner than 14 days from the  
14 initial neurotechnology data collection if the data is  
15 collected for a primary purpose unrelated to clinical  
16 research;

17 (C) be obtained separately from any other items of  
18 consent;

19 (D) be in writing on a form with text that is  
20 easily readable with size 12-point type font or  
21 larger;

22 (E) include the entity's data retention, sharing,  
23 and use policies; and

24 (F) include notice that after consent is given,  
25 there is no right to access, inspect, or require the  
26 destruction of any neurotechnology data;

1           (2) the neurotechnology data is used for clinical  
2           research purposes only.

3           (c-10) The requirements of subsection (c-5) supersede all  
4           exceptions to, and waivers of, informed consent in the federal  
5           policy for the protection of human subjects under 45 CFR Part  
6           46, to the extent permitted by federal law. Neurotechnology  
7           data of Illinois residents collected in the State may not be  
8           stored within the territorial boundaries of any country  
9           currently sanctioned in any way by the United States office of  
10           foreign asset control or designated as a foreign adversary  
11           under 15 CFR 7.4(a). Neurotechnology data of Illinois  
12           residents collected in the State may only be transferred or  
13           stored outside the United States with the consent of the  
14           resident.

15           (d) Neurotechnology data use by government agencies is  
16           regulated as follows:

17           (1) Any collection, storage, use, or dissemination of  
18           neurotechnology data by a government agency must be  
19           performed in accordance with a specific State law or  
20           executed through a search warrant or investigative  
21           subpoena.

22           (2) A government agency may not obtain neurotechnology  
23           search results from a consumer neurotechnology database:

24           (A) without a search warrant or investigative  
25           subpoena issued by a court on a finding of probable  
26           cause; or

1           (B) unless the consumer whose information is  
2           sought previously waived the consumer's right to  
3           privacy in the information.

4           (3) A government agency that legally obtains  
5           neurotechnology database search results, as set forth in  
6           paragraph (2) of subsection (d), or neurotechnology data,  
7           as set forth in this Section, may use the results during  
8           criminal investigations and judicial proceedings subject  
9           to applicable rules of criminal procedure and evidence.

10          (e) This Section does not apply to protected health  
11          information that is collected by a covered entity or business  
12          associate as those terms are defined in 45 CFR Parts 160 and  
13          164, if separate informed consent related to the collection,  
14          use, and dissemination of neurotechnology data is obtained  
15          from the consumer, parent, guardian, or power of attorney, and  
16          the covered entity or business associate follows the policies  
17          outlined in paragraph (6) of subsection (c).

18           (410 ILCS 513/40)

19           Sec. 40. Right of action.

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

25           (1) Against any party who negligently violates a

1 provision of this Act, liquidated damages of \$2,500 or  
2 actual damages, whichever is greater.

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

6 (3) Reasonable attorney's fees and costs, including  
7 expert witness fees and other litigation expenses.

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

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

13 (c) Notwithstanding any provisions of the law to the  
14 contrary, any person alleging a violation of subsection (a) of  
15 Section 15, subsection (b) of Section 25, Section 27, Section  
16 30, Section 31, or Section 35 of this Act shall have a right of  
17 action in a State circuit court or as a supplemental claim in a  
18 federal district court to seek a preliminary injunction  
19 preventing the release or disclosure of genetic testing, ~~or~~  
20 genetic information, or neurotechnology data pending the final  
21 resolution of any action under this Act.

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

23 (410 ILCS 513/50)

24 Sec. 50. Home rule. Any home rule unit of local  
25 government, any non-home rule municipality, or any non-home

1 rule county within the unincorporated territory of the county  
2 may enact ordinances, standards, rules, or regulations that  
3 protect genetic information, ~~and~~ genetic testing, and  
4 neurotechnology data in a manner or to an extent equal to or  
5 greater than the protection provided in this Act. This Section  
6 is a limitation on the concurrent exercise of home rule power  
7 under subsection (i) of Section 6 of Article VII of the  
8 Illinois Constitution.

9 (Source: P.A. 95-927, eff. 1-1-09.)

10 Section 97. Severability. The provisions of this Act are  
11 severable under Section 1.31 of the Statute on Statutes.

12 Section 99. Effective date. This Act takes effect January  
13 1, 2027.