

**UNIFORM PROTECTION OF GENETIC
INFORMATION IN EMPLOYMENT ACT***

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

and by it

APPROVED AND RECOMMENDED FOR ENACTMENT
IN ALL THE STATES

at its

ANNUAL CONFERENCE
MEETING IN ITS ONE-HUNDRED-AND-NINETEENTH YEAR
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By
NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

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UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT

SECTION 1. SHORT TITLE. This [act] may be cited as the Uniform Protection of Genetic Information in Employment Act.

SECTION 2. DEFINITIONS. In this [act]:

(1) “Credentialing authority” means a person that provides a license, registration, or credential or certifies competence necessary for an individual to qualify for employment or to participate in an occupation or profession.

(2) “DNA” means deoxyribonucleic acid.

(3) “Employee”

(A) means

(i) an individual who is employed, was formerly employed or is applying for employment with a person who has [five] or more employees for each working day in each of 20 or more calendar weeks in the current or preceding calendar year.

(ii) an individual who uses, formerly used, or is applying to use the services of an employment agency;

(iii) a labor-organization member;

(iv) an apprentice, trainee, former apprentice, former trainee, or applicant for a training, retraining, or apprenticeship program; or

(v) an individual or applicant considered by a credentialing authority; and

(B) does not include an independent contractor.

(4) “Employer” means a person that employs an employee defined in subparagraph (3)(A)(i). The term includes an agent of the person.

(5) “Employment agency” means a person that regularly undertakes, with or without compensation, to procure one or more employees for an employer or to procure for one or more employees opportunities to work for an employer. The term includes an agent of the person.

(6) “Employment entity” means an employer, employment agency, labor organization, credentialing authority, or labor-management committee.

(7) “Family medical history” means information about a manifested disease or disorder in an individual’s family member.

(8) “Family member” means an individual, whether living or deceased, who:

(A) is related by blood to an employee and is or at any time was the employee’s child, parent, sibling, half-sibling, niece, nephew, aunt, uncle, grandchild, grandparent, first cousin, great-grandchild, great-grandparent, first cousin once-removed, great aunt, great uncle, great-great grandchild, or great-great grandparent;

(B) is covered or is eligible to be covered by an insurance or other benefit program provided to the employee by an employment entity; or

(C) has or at any time had one of the relationships specified in subparagraph (A) to an individual specified in subparagraph (B).

(9) “Genetic condition” includes a genetic trait and a genetic disease or disorder.

(10) “Genetic counseling” includes:

(A) assessing an individual’s genetic risk for an inherited genetic condition by interpreting family medical histories;

(B) educating about the inheritance, testing, management, or prevention of a genetic condition using an approach that promotes an individual’s autonomy and self-direction in decisionmaking;

(C) helping an individual to understand the risks and benefits of testing for a genetic trait to promote informed decisionmaking about whether to undergo genetic testing;

(D) communicating and interpreting test results; and

(E) providing support, informational resources, and referrals as appropriate to help an individual adapt to the medical, psychological, and familial implications of having or being at risk of having a genetic condition.

(11) “Genetic education” means the process by which an individual acquires information about an existing or suspected genetic condition of the individual or a family member of the individual.

(12) “Genetic information” means information, other than information about the age or sex of an individual, about:

(A) the individual’s genetic test;

(B) a genetic test of a family member of the individual;

(C) the individual’s family medical history;

(D) a request for, or receipt of, genetic services, or participation in clinical research that includes genetic services, by the individual or a family member of the individual; or

(E) a genetic test of:

(i) a fetus carried by the individual or a family member of the individual;

or

(ii) an embryo legally held by the individual or a family member of the individual.

(13) “Genetic monitoring” means a periodic examination of an employee to evaluate acquired modification to the employee’s genetic material, such as chromosomal damage or

evidence of increased occurrence of mutations, which may have developed in the course of employment due to exposure to workplace conditions, conducted to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.

(14) “Genetic service” means a genetic test, genetic counseling, or genetic education.

(15) “Genetic test” means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites which detects genotypes, mutations, or chromosomal changes. The term does not include an analysis of proteins or metabolites which does not detect genotypes, mutations, or chromosomal changes.

(16) “Individually identifiable genetic information” means an individual’s genetic information that includes an identification of the individual or information that could reasonably be used to identify the individual.

(17) “Labor-management committee” means a person that establishes, offers, or controls apprenticeship or other training or retraining programs, including on-the-job training programs. The term includes an agent of the committee.

(18) “Labor organization” means an organization in which employees participate which exists for the purpose, in whole or in part, of dealing with an employer concerning grievances, labor disputes, wages, rates of pay, hours, or other terms or conditions of employment. The term includes an agent of the organization.

(19) “Labor-organization member” means a member, a former member, or an applicant for membership in a labor organization.

(20) “Manifested” means that a disease, disorder, or pathological condition of an individual has been or could reasonably be diagnosed by a health-care professional with appropriate training and expertise in the relevant field of medicine. The term does not include a

disease, disorder, or pathological condition if the diagnosis is based principally on genetic information or on the results of one or more genetic tests.

(21) “Person” means an individual, corporation, business trust, statutory trust, estate, trust, partnership, limited liability company, association, joint venture, public corporation, government or governmental subdivision, agency, or instrumentality, or any other legal or commercial entity.

(22) “Record” means information that is inscribed on a tangible medium or that is stored in an electronic or other medium and is retrievable in perceivable form.

(23) “RNA” means ribonucleic acid.

(24) “Sign” means, with present intent to authenticate or adopt a record:

(A) to execute or adopt a tangible symbol; or

(B) to attach to or logically associate with the record an electronic symbol, sound, or process.

(25) “Tribunal” means a court, arbitral tribunal, or administrative agency acting in an adjudicatory capacity.

Legislative Note: *In the definition of “employer” states may replace [five] with a lesser number of employees in order to extend the coverage of the act.*

SECTION 3. APPLICABILITY.

(a) The provisions of this [act] on employee access to genetic information in Section 18, confidentiality and retention of genetic information in Section 19, and disclosure of genetic information in Sections 20 and 21 apply to genetic information possessed by an employment entity without regard to when the information was acquired.

(b) The provisions of this [act] on acquisition of genetic information by an employment

entity in Sections 5 to 12, genetic testing in Section 13, authorizations by an employee or a family member of an employee for acquisition or testing in Sections 14 to 16, and use of genetic information in Section 17 apply only to actions taken on or after the effective date of the [act].

SECTION 4. MEDICAL INFORMATION THAT IS NOT GENETIC

INFORMATION. An employment entity's acquisition, use, retention, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee does not violate this [act] even if the manifested disease, disorder, or pathological condition has or may have a genetic basis.

SECTION 5. GENERAL PROHIBITION ON ACQUISITION OF GENETIC

INFORMATION.

(a) Except as otherwise provided in this act, an employment entity may not:

(1) request, require, purchase, or otherwise acquire genetic information of an employee or an family member of the employee; or

(2) unless allowed by law other than this [act], require, offer, or provide a genetic test to an employee or a family member of the employee.

(b) It is not a violation of this act if an employment entity inadvertently requests or acquires genetic information of an employee or a family member of the employee.

SECTION 6. EXCEPTION FOR VOLUNTARY SUBMISSION OF GENETIC

INFORMATION BY EMPLOYEE. An employment entity may acquire and use an employee's genetic information if

(1) the employee voluntarily submits the genetic information to the employment entity and authorizes the employment entity's acquisition and use of the information in accordance with Section 14; and

(2) the employment entity uses the genetic information only for the purpose authorized by the employee .

SECTION 7. EXCEPTION FOR INFORMATION UNDER FAMILY MEDICAL LEAVE ACT. An employment entity may request or require family medical history from an employee to comply with the certification provisions of the Family Medical Leave Act, 29 U.S.C. Section 2613, or [state family and medical leave act].

Legislative Note: States should insert for [state family and medical leave act] the appropriate name and citation for the state's act.

SECTION 8. EXCEPTION FOR INFORMATION IN PUBLIC DOCUMENTS.

(a) Except as otherwise provided in subsection (b), an employment entity may obtain a document that is publicly available, including a newspaper, magazine, periodical, and book, even if it contains genetic information of an employee or of a family member of an employee.

(b) An employment entity may not obtain genetic information of an employee or a family member of an employee by purchasing medical or court record databases.

SECTION 9. EXCEPTION FOR INFORMATION AND TESTING FOR VOLUNTARY HEALTH OR GENETIC SERVICES. An employment entity may acquire genetic information of an employee or a family member of the employee and may offer and provide genetic testing to the employee or family member of the employee in accordance with Section 13 for use in providing voluntary health or genetic services to the employee or family member of the employee, including as part of a voluntary wellness program, if:

(1) the employee or family member of the employee authorizes the employment entity to acquire genetic information or provide genetic testing in accordance with Section 14;

(2) individually identifiable genetic information of the employee or family member of the

employee is used only to provide health and genetic services to the employee or family member of the employee;

(3) individually identifiable genetic information is provided only to the following:

(A) the employee or, if a family member of an employee is receiving genetic services, to the family member of the employee;

(B) a health-care professional if designated by the employee or family member of the employee; and

(C) a licensed health-care professional or board-certified genetic counselor involved in providing the employment entity's genetic services; and

(4) genetic information is not disclosed to the employment entity except in an aggregate form under circumstances that do not disclose the identity of the individual employee or family member of the employee.

SECTION 10. EXCEPTION FOR INFORMATION AND TESTING FOR GENETIC MONITORING. An employment entity may acquire an employee's genetic information and may offer and provide genetic testing to an employee to conduct genetic monitoring of the biological effects of workplace conditions if:

(1) the employment entity provides written notice of the genetic monitoring to the employee;

(2) the genetic monitoring is:

(A) required by state or federal law; or

(B) authorized by the employee in accordance with Section 14;

(3) the genetic monitoring is in compliance with:

(A) federal genetic monitoring law, including the Occupational Safety and Health

Act of 1970, 29 U.S.C. Section 651 et seq.[, as amended], the Federal Mine Safety and Health Act of 1977, 30 U.S.C. Section 801 et seq.[, as amended], or the Atomic Energy Act of 1954, 42 U.S.C. Section 2011 et seq.[, as amended], and regulations adopted under those acts; and

(B) the state’s genetic monitoring law, including regulations adopted under the Occupational Safety and Health Act of 1970, 29 U.S.C. Section 651 et seq.[, as amended];

(4) the employment entity pays for the genetic testing and the genetic counseling required by Section 13;

(5) Individually identifiable genetic information is provided only to the following:

(A) the employee;

(B) a health-care professional if designated by the employee; and

(C) a licensed health-care professional or board-certified genetic counselor

involved in providing the employment entity’s monitoring program; and

(6) genetic information is not disclosed to the employment entity except in an aggregate form under circumstances that do not disclose the identity of the employee.

Legislative Note: In states in which incorporating future amendments to federal statutes is an unconstitutional delegation of legislative power, “[, as amended]” should be deleted.

SECTION 11. EXCEPTION FOR CERTAIN EMPLOYERS THAT CONDUCT DNA ANALYSIS. An employer that conducts DNA analysis for law enforcement purposes at a forensic laboratory or for purposes of identifying human remains may request or require genetic information or genetic testing of an employee to the extent necessary to analyze DNA identification markers for quality control to detect sample contamination by DNA of the employee.

[SECTION 12. EXCEPTION FOR CERTAIN LEGAL PROCEEDINGS. If an

employee places the employee's health at issue in a proceeding before a tribunal in which an employment entity is a party, the employment entity may obtain under the rules of civil procedure or other applicable law genetic information about the employee without the employee's authorization only if:

(1) the genetic information is relevant to a claim or defense in the proceeding;

(2) on a motion by the employment entity, a tribunal orders the employee to take a genetic test or provide genetic information after finding that the genetic information is necessary in the interest of justice to resolve the proceeding and that the information is otherwise unavailable;

(3) the employment entity pays for the genetic test if one is ordered under paragraph 2;

and

(4) the tribunal grants a protective order to protect the privacy of the genetic information.]

SECTION 13. REQUIREMENTS FOR GENETIC TESTING. An employment entity that provides a genetic test to an employee or family member of the employee as part of health or genetic services offered under Section 9 or for a genetic monitoring program under Section 10 shall:

(1) provide genetic counseling about the risks and benefits of a genetic test before the employee or the family member of the employee authorizes the test under Section 14 unless:

(A) the individual knowingly and voluntarily waives counseling before the authorization in a signed record that contains information about the benefits of genetic counseling; or

(B) the test is part of genetic monitoring that is required by state or federal law under Section 10(2)(A);

(2) unless the individual directs otherwise, require the testing organization to report the

test result to the individual and any health-care professional designated by the individual;

(3) unless the individual directs otherwise, provide genetic counseling for the individual about a test result that indicates a disease or disorder or increased risk for a disease or disorder;

(4) require the destruction of the individual's biological sample obtained for a genetic test as soon as practicable after the test is completed unless retention of the sample is:

(A) knowingly and voluntarily authorized by the individual in a record signed by the individual;

(B) permitted by law other than this [act]; or

(C) ordered by a tribunal; and

(5) require the destruction or expungement of information generated from the biological sample other than the authorized test as soon as practicable after the test is completed unless retention of the information is:

(A) knowingly and voluntarily authorized by the individual in a record signed by the individual;

(B) permitted by law other than this [act]; or

(C) ordered by a tribunal.

SECTION 14. EMPLOYEE AUTHORIZATION FOR ACQUISITION OF GENETIC INFORMATION AND GENETIC TESTING.

(a) Except as otherwise provided by law other than this [act], an authorization of an employee or a family member of the employee for an employment entity to acquire the individual's genetic information or provide a genetic test must be knowing and voluntary and indicated in a record signed by the individual prior to the acquisition or test. An employment entity that receives an authorization may use the genetic information or analyze a genetic test

only in accordance with the authorization. The authorization may not expand the authority of the employment entity to acquire or use genetic information or to provide genetic testing beyond that permitted by this [act]. The authorization may not waive any right of the employee or the family member of the employee under federal law or the law of this state. The employment entity shall provide a copy of the authorization to the employee or the family member of the employee who signed the authorization.

(b) An authorization for an employment entity to acquire genetic information of an employee or a family member of an employee under Section 6, 9, or 10(2)(B) must:

- (1) describe the type of information that will be acquired;
- (2) describe the authorized uses of the information;
- (3) describe restrictions on disclosure of the information; and
- (4) state that the individual is entitled to a copy of the authorization.

(c) An authorization for an employment entity to provide a genetic test under Section 9 or 10(2)(B) must:

- (1) describe the test to be performed, its purpose, and the authorized uses of the test result;
- (2) inform the individual that the authorized test will be analyzed only for the purposes specified in the authorization;
- (3) explain the benefit of receiving genetic counseling about the risks and benefits of the test before the individual authorizes the test;
- (4) inform the individual that the employment entity is obligated to provide genetic counseling before the individual authorizes the test, unless the individual waives genetic counseling;

(5) if the test is part of a genetic monitoring program, inform the individual that the employment entity is obligated to pay for genetic counseling before the individual authorizes the test, unless the individual waives genetic counseling;

(6) inform the individual that the test result will be reported to the individual and a health-care professional designated by the individual unless the individual directs otherwise;

(7) explain the benefit of receiving genetic counseling about a test result that indicates a disease or disorder or increased risk for a disease or disorder and inform the individual that the employment entity is obligated to provide genetic counseling about the test result, unless the individual waives genetic counseling;

(8) if the test is part of a genetic monitoring program, inform the individual that the employment entity is obligated to pay for genetic counseling about a test result that indicates a disease or disorder or increased risk for a disease or disorder, unless the individual waives genetic counseling;

(9) include an opportunity for the individual to provide directions in a record about reporting test results and genetic counseling;

(10) inform the individual that the individual's biological sample will be destroyed as soon as practicable after the test is completed, unless the individual authorizes retention of the sample or unless otherwise ordered by a tribunal;

(11) inform the individual that data generated in the testing process that is not relevant to the authorized test will be destroyed or expunged as soon as practicable after the test is completed unless the individual authorizes retention of the information or unless otherwise ordered by a tribunal;

(12) describe restrictions on disclosures of the test result; and

(13) state that the individual is entitled to a copy of the authorization.

SECTION 15. FORM FOR AUTHORIZATION FOR ACQUISITION OF GENETIC INFORMATION. An authorization substantially in the following form, when completed and signed, satisfies Section 14(b).

AUTHORIZATION FOR ACQUISITION OF GENETIC INFORMATION

I, _____, authorize _____ to acquire
Printed name Name of employment entity

my genetic information as checked below.

PURPOSE FOR PROVIDING GENETIC INFORMATION

_____ This genetic information is provided for a voluntary genetic monitoring program conducted by _____ . _____ may use
Name of employment entity Name of employment entity
this information only for the following purposes: _____
Authorized uses

_____ This genetic information is provided for _____, a voluntary program
Name of program
offered by _____ to provide health and genetic services.
Name of employment entity
_____ may use this information only for the following purposes:
Name of employment entity

Authorized uses

_____ This genetic information is provided to _____ at my
Name of employment entity
initiative and by my voluntary submission for the following purpose: _____
Authorized uses

TYPE OF GENETIC INFORMATION

_____ Family medical history

Family medical history is information concerning diseases and disorders of family members and other relatives.

_____ My genetic test results: _____
Name of genetic test

Genetic tests are tests of DNA, RNA, chromosomes, or other material to determine your genetic characteristics. If _____ will provide the genetic tests,
Name of employment entity

a separate authorization is necessary.

NOTICE CONCERNING DISCLOSURE OF YOUR GENETIC INFORMATION

If this genetic information is provided for a voluntary genetic monitoring program or a voluntary program to that provides health and genetic services, only you, a health-care professional whom you designate, and health-care professionals involved in providing the program will have access to your individual genetic information. Otherwise,

_____ may not have access to your genetic information except in
Name of employment entity

an aggregate form that may not identify you. However, your genetic information may be disclosed to (1) certain health researchers, (2) government officials investigating compliance with laws protecting the privacy of genetic information or prohibiting genetic discrimination, (3) a public health agency if the test result concerns a life-threatening contagious disease, (4) if expressly ordered by a court, arbitral tribunal, or administrative agency, or (5) if you request and authorize a disclosure.

YOUR LEGAL RIGHTS

By signing this authorization, you do not waive any legal rights to which you are entitled. You are entitled to a copy of this authorization.

SIGNATURE OF INDIVIDUAL MAKING THIS AUTHORIZATION

Signature

Date

SECTION 16. FORM FOR AUTHORIZATION OF GENETIC TESTING. An authorization substantially in the following form, when completed and signed, satisfies Section 14(c).

AUTHORIZATION FOR GENETIC TESTING

LIMITED AUTHORIZATION

Only the genetic tests that you authorize on this form will be performed on your biological sample. These tests are voluntary.

AVAILABILITY OF GENETIC COUNSELING BEFORE SIGNING THIS AUTHORIZATION

Before you complete this authorization, it is highly recommended that you receive genetic counseling. Genetic counseling will help you assess your risk for an inherited condition based on your family medical history and will help you understand the options for prevention and management of genetic conditions. It will help you understand and evaluate the risks, benefits, and consequences for you and your family of having the test(s) listed below.

_____ will provide [and pay for] this genetic counseling.
Name of employment entity

PROPOSED GENETIC TESTS

_____ proposes to provide the following genetic tests:
Name of employment entity

_____. This test is provided as part of a genetic monitoring program. The
Name of test

purpose of this test is to monitor the effect of your exposure to _____.
Workplace condition

The result of the test will be used only for the following purposes: _____.
Authorized uses

_____. This test is provided by _____.
Name of test Name of health or genetic services program

The result will be used only for the following purposes: _____.
Authorized uses

REPORTING TEST RESULTS AND GENETIC COUNSELING

The test results will be reported to you and to a health-care professional whom you designate unless you direct otherwise. It is recommended that you receive genetic counseling about the test results. Genetic counseling is important for understanding the test results in the context of your medical and family history. It can also provide you with support, informational resources, and referrals, as appropriate, that can help you adapt to the implications of being at risk of a genetic condition. _____ will provide and [pay for] genetic
Name of employment entity
counseling about the test results unless you decline genetic counseling.

NOTICE CONCERNING DISCLOSURE OF THE TEST RESULTS

Other than the medical professionals involved in providing this program,
_____ will not have access to the test results of the individuals who
Name of employment entity
authorize this test except in an aggregate form that will not identify you. However, the test results may be disclosed to (1) certain health researchers, (2) government officials investigating compliance with laws protecting the privacy of genetic information or prohibiting genetic discrimination, (3) to a public health agency if the test result concerns a life-threatening contagious disease, (4) if expressly ordered by a court, arbitral tribunal, or administrative agency, or (5) if you request and authorize a disclosure.

DESTRUCTION OF YOUR BIOLOGICAL SAMPLE AND TESTING DATA

After the genetic test, your biological sample and data that is not necessary for the test

you authorized will be destroyed as soon as practicable unless you authorize otherwise in writing or a court, arbitral tribunal, or administrative agency requires retention of the sample.

YOUR LEGAL RIGHTS

By signing this authorization, you do not waive any legal rights to which you are entitled.

You are entitled to a copy of this authorization.

AUTHORIZATION

I, _____, authorize each genetic test that I have checked above.
Printed name

_____ I wish to receive test results.

_____ I do not wish to receive test results.

_____ Report test results to the following health-care professional:

Name: _____

Address: _____

Phone: _____

_____ Do not report test results to a health-care professional.

SIGNATURE OF INDIVIDUAL MAKING THIS AUTHORIZATION

Signature

Date

SECTION 17. PROHIBITION OF USE OF GENETIC INFORMATION.

(a) An employer may not take an adverse employment action against an employee as defined in Section 2(3)(A)(i) based on the employee’s genetic information, including failing or refusing to hire, discharging, or discriminating against an employee in regard to compensation or terms, conditions, or privileges of employment.

(b) An employment agency may not take an adverse employment action against an

individual based on the individual's genetic information, including failing or refusing to refer the individual for employment or discriminating against the individual.

(c) A labor organization may not take an adverse action against a labor-organization member based on the member's genetic information, including excluding or expelling the member from membership in the organization or discriminating against the member.

(d) An employer, labor organization, or labor-management committee controlling an apprenticeship or a training or retraining program may not take an adverse employment action against an individual based on the individual's genetic information, including discriminating against the individual in admission to or employment in the program.

(e) A credentialing authority may not take an adverse action against an individual based on the individual's genetic information, including discriminating against the individual in the provision of credentials.

(f) An employment entity may not limit, segregate, or classify an individual, or fail or refuse to refer the individual for employment based on the individual's genetic information in a way that would deprive or tend to deprive the individual of employment opportunities or otherwise adversely affect the status of the individual as an employee.

(g) An employment agency, labor organization, labor-management training or apprenticeship program, or credentialing authority may not cause or attempt to cause an employer to discriminate against an employee in violation of this [act].

(h) An employment entity may not discriminate against an employee because the employee:

(1) opposed an act or practice made unlawful by the federal Genetic Information Nondiscrimination Act, 42 U.S.C. Section 2000ff et seq., or this [act]; or

(2) made a charge, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing under the federal Genetic Information Nondiscrimination Act, 42 U.S.C. Section 2000ff et seq., or this [act].

SECTION 18. EMPLOYEE ACCESS TO GENETIC INFORMATION. An employee may inspect, request correction of, or obtain a copy of any record of an employment entity which contains genetic information of the employee. An employee must be permitted to provide genetic information in a signed record to supplement or correct genetic information in the employment entity's record.

SECTION 19. CONFIDENTIALITY AND RETENTION OF GENETIC INFORMATION. Except for genetic information an employment entity obtains in aggregate form under Section 9 for use in providing health or genetic services and under Section 10 for use in conducting genetic monitoring:

(1) An employment entity shall treat an employee's genetic information as a confidential record;

(2) If an employment entity possesses an employee's genetic information, the employment entity shall keep the genetic information in a record separate from the employee's personnel file; and

(3) The requirement of subparagraph (2) is satisfied if an employment entity keeps the genetic information in the record in which it maintains confidential medical information subject to the Americans with Disabilities Act of 1990, Section 102(d)(3)(B), 42 U.S.C. Section 12112(d)(3)(B)[, as amended].

Legislative note: *In States in which incorporating future amendments to federal statutes is an unconstitutional delegation of legislative power, "[, as amended]" should be deleted.*

SECTION 20. DISCLOSURE OF GENETIC INFORMATION.

(a) Except as otherwise permitted in this section, an employment entity may not disclose genetic information of an employee or a family member of the employee.

(b) An employment entity may disclose genetic information of an employee or a family member of the employee:

(1) to the employee or, if the genetic information is that of a family member of the employee, to the family member of the employee and, at the direction of the employee or family member of the employee, to a health-care professional designated by the employee or family member of the employee in a record signed by the employee or family member of the employee;

(2) to a person that the employee or, if the genetic information is that of a family member of the employee, the family member of the employee has designated in an authorization under subsection (d);

(3) to an occupational or other health researcher if the research is conducted in compliance with Department of Health and Human Services regulation on the protection of human research subjects, 45 C.F.R. Part 46[, as amended];

(4) to the extent ordered by a tribunal;

(5) in response to an official request from a government official who is investigating compliance with this [act] or with the Genetic Information Nondiscrimination Act, 42 U.S.C. Section 2000ff through 2000ff-11, if the information is responsive to the government's request;

(6) to the extent the disclosure is made to comply with the certification provisions of the Family Medical Leave Act, 29 U.S.C. Section 2613, or [state family and medical leave act];

(7) to a public health agency when the genetic information concerns the presence in an employee or an family member of the employee of a contagious disease that presents an imminent risk of death or life-threatening illness; or

(8) in aggregate form in connection with health or genetic services provided under Section 9 or genetic monitoring conducted under Section 10.

(c) Unless notice is otherwise given to an employee or, if the genetic information is that of a family member of the employee, to the family member of the employee, the employment entity of the employee shall provide notice in a record to the employee or the family member of the employee whose genetic information is disclosed if the disclosure is made under subsection (b)(4) or (b)(7).

(d) An authorization for an employment entity to disclose genetic information of an employee or the family member of an employee under subsection (b)(2) must be knowing and voluntary and indicated in a record signed by the individual. An employment entity that receives an authorization may disclose the genetic information only in accordance with the authorization. The authorization may not expand the authority of the employment entity to disclose genetic information beyond that permitted by this [act]. The authorization may not waive any right of the employee or the family member of the employee under federal law or the law of this state. The employment entity shall provide a copy of the authorization to the employee or the family member of the employee who signed the authorization. The authorization must:

- (1) describe the genetic information to be disclosed;
- (2) identify the person to whom the genetic information is to be disclosed;
- (3) indicate the duration of the authorization; and
- (4) state that the individual is entitle to a copy of the authorization.

Legislative Note: In subsection (b)(3), states in which incorporating future amendments to federal statutes is an unconstitutional delegation of legislative power should delete “[, as amended].” In subsection (b)(6), states should insert for [state family and medical leave act] the appropriate name and citation for the state’s act.

SECTION 21. FORM FOR AUTHORIZATION FOR DISCLOSURE OF GENETIC INFORMATION. An authorization substantially in the following form, when completed and signed, satisfies the authorization requirement in Section 20(d).

AUTHORIZATION FOR DISCLOSURE OF GENETIC INFORMATION

I, _____, authorize _____ to disclose
Printed name Name of employment entity
my following genetic information _____ to
Specific description of genetic information

Identity of person or entity to receive the disclosure

_____ This authorization is for one disclosure only.

_____ This authorization continues in effect until I revoke it.

_____ This authorization continues in effect until _____.
Date

Signature

Date

SECTION 22. RELATIONSHIP TO HEALTH REGULATIONS. This [act] does not prevent a covered entity under the regulations issued by the Secretary of Health and Human Services pursuant to Section 264(c) of the Health Insurance Portability and Accountability Act, 42 U.S.C. Section 1320d-2 note, from using or disclosing health information which is authorized for a covered entity by the regulations.

SECTION 23. REMEDIES.

(a) A person aggrieved by a violation of this [act] has a cause of action for money damages or other relief.

[(b) A person may seek remedies provided by law other than this [act]. Exhaustion of administrative remedies is not required before seeking relief for a violation of this [act].]

[(b)][(c)] A tribunal may allow a prevailing employee reasonable attorney’s fees and costs.

[SECTION 24. CAUSE OF ACTION FOR DISPARATE IMPACT.

Notwithstanding any other provision of this [act], “disparate impact”, as that term is used in 42 U.S.C. Section 2000e-2(k) does not establish a cause of action under this [act].]

SECTION 25. UNIFORMITY OF APPLICATION AND CONSTRUCTION. In applying and construing this uniform act, consideration must be given to the need to promote uniformity of the law with respect to its subject matter among states that enact it.

SECTION 26. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL AND NATIONAL COMMERCE ACT. This [act] modifies, limits, and supersedes the federal Electronic Signatures in Global and National Commerce Act, 15 U.S.C. Section 7001, et seq., but does not modify, limit, or supersede Section 101(c) of that act, 15 U.S.C. Section 7001(c), or authorize electronic delivery of any of the notices described in Section 103(b) of that act, 15 U.S.C. Section 7003(b).

SECTION 27. EFFECTIVE DATE. This [act] takes effect