UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT*

Drafted by the

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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WITH PREFATORY NOTE AND COMMENTS

May 24, 2011

*The Conference changed the designation of the Protection of Genetic Information in Employment Act from Uniform to Model as approved by the Executive Committee on July 11, 2016.

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UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT

TABLE OF CONTENTS

UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT

Prefatory Note

Background

Approximately 37 states have statutes that regulate how employment entities collect, use, retain, or disclose employees' genetic information. State policy decisions to legislate in this area reflect the need to encourage beneficial uses of genetic information while protecting individuals' privacy and preventing misuse of that information. Scientific developments in the field of genetics bring with them the promise of a new era in understanding human biology and new approaches to medicine that offer individual treatments tailored to one's genetic characteristics. For these promises to become reality, however, individuals must be willing to take genetic tests. For that, individuals must have confidence that they can control the privacy of their genetic information and that it will not be used to harm them in the workplace for reasons that are not related to their ability to do the job.

This need for regulation of genetic information and the desirability of uniformity in the area was recognized at the federal level with the enactment of the Genetic Information Nondiscrimination Act (GINA) of 2008. 42 U.S.C. §§ 2000ff to 2000ff-11 **(**Supp. II 2008). However, much in the same way that states have supplemented federal employment nondiscrimination acts with their own fair employment acts, there is a role for states in the regulation of genetic information in the workplace. This role is explicitly contemplated by GINA; its employment provisions do not preempt state legislation that provides equal or greater protection to individuals. 42 U.S.C. § 2000ff-8(a)(1) (Supp. II 2008).

Preemption of existing state statutes. GINA has created general uncertainty about the enforceability of state genetic statutes in the context of employment. Most of the state statutes have definitions of genetic information or genetic testing that are more limited than those in GINA. Many also have coverage that is less comprehensive than GINA. For example, many statutes prohibit discriminatory uses of genetic information, but do not restrict acquisition, retention, or disclosure of that information. Others are concerned primarily with privacy, but do not address discrimination. Some do not provide a private cause of action as an enforcement mechanism. As a result, GINA currently preempts most of the state statutes that protect genetic information in employment because they fail to provide protection equal to or greater than the federal statute.

Lack of uniformity among existing state statutes. To the extent that the state statutes remain enforceable in the wake of GINA, there is a lack of uniformity among the states. They have experimented with many different approaches to regulating genetic information in the employment setting. Some states have extended their disability or employment discrimination statutes to cover discrimination based on genetic information. Some have instead enacted specific statutes to regulate genetic testing or the use of genetic information. Yet others have statutes that focus on privacy of genetic test results. Some of the specific genetic statutes and privacy statutes are general provisions that apply to many types of entities; others are tailored for the employment setting. These different approaches have resulted in great variation in state

regulation. Only a few states comprehensively cover acquisition, use, retention, *and* disclosure of genetic information by employers and other employment entities. There are also differences in key definitions that result in significant variation in the scope of state regulation of genetic information. These inconsistent frameworks and requirements create burdens on employers that operate in more than one jurisdiction.

Need for Regulation of Genetic Information in Employment

Fear as a deterrent to genetic testing. To encourage individuals to undergo testing that can lead to advances in genetics and improved medical care, it is important to prevent fears that their privacy may be invaded or that testing may lead to detrimental treatment by employers or insurers. Without protection, a substantial portion of the public is afraid of taking advantage of genetic testing. *See, e.g.,* Amy Harmon, *Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests,* N.Y. Times, Feb. 24, 2008, at A1. In a 1997 national survey, 63 percent of the respondents reported that they would not take genetic tests if employers or insurers could obtain access to the results. Department of Labor, Department of Health & Human Services, Equal Employment Opportunity Commission, & Department of Justice, *Genetic Information and the Workplace* (Jan. 20, 1998) (available at http://www.genome.gov/10001732).

Exaggerated predictive power of genetic information. Partly because the human genome has been portrayed with images such as "blueprint," "code," and "future diary," the public commonly misunderstands genetics and thinks of an individual's genome as determinative. Employers cannot be expected to be exempt from such misunderstanding, which may cause them to exaggerate the predictive potential of genetic information.

There are some rare genetic diseases, such as Huntington's disease, that are caused by a single gene and can be predicted with near certainty from an individual's genetic sequence. But such diseases are the exception and afflict relatively few individuals. And even with these diseases, there is usually variation in the age that symptoms appear and in their severity that lessens predictability.

The genetic causation of most diseases, and hence their predictability, is far more complex. Typically, medical conditions result from interactions among multiple genes and with the environment. As a result, many individuals who have a genotype that is linked to a disease never develop the condition. While a particular genotype may be a sign of increased risk, it is not predictive of disease. For example, certain forms of the BRCA 1 gene are strongly associated with susceptibility to breast cancer. But only 50 to 85 percent of women who have this form of the gene will ever develop the disease. Moreover, the frequency of particular gene variants and the degree to which they are associated with disease often differ among ethnic groups, which also complicates the clinical sensitivity of genetic tests and their predictive capabilities. Another complicating factor for accurate prediction is that often a large number of genetic variations can cause the same disease.

Contrary to the common understanding of genetics, genes do not provide a sure prediction. Unfortunately they are often treated as if they do, resulting in the misunderstanding and misuse of genetic information.

Increased Availability of Genetic Information. Recent developments are making genetic information far more available and hence increasing the risk that it can be misused. One development is genetic testing offered directly to consumers. Companies such as 23andMe and Navigenics offer a genome scan of a saliva sample for as little as $1,000. There are even companies that purport to help clients find DNA-compatible mates based on differences in immune systems or use DNA samples to identify nutritional needs that can be met by purchases of dietary supplements. *See generally* Rick Weiss, *Genetic Testing Gets Personal: Firms Sell Answers on Health, Even Love,* Wash. Post, Mar. 25, 2008. A second development that will vastly increase the amount of readily available genetic information is the ongoing transition within the practice of medicine to electronic medical records. Sharona Hoffman, *Employing E-Health: The Impact of Electronic Health Records on the Workplace,* 19 Kan. J.L & Pub. Pol'y 409 (2010). The increase in genetic information about individuals and the ease of transmitting genetic information increase the likelihood that employers will acquire and use this information.

Abuse in the Employment Setting. Employers have an economic incentive to use genetic information to avoid hiring employees with higher medical insurance claims, higher absenteeism, or lower productivity. They may also wish to avoid the effect of high health care costs incurred by employees' dependents. As a result, if employers are permitted to consider genetic information in making personnel decisions, they may use it to bar or dismiss unsymptomatic individuals from employment. This discrimination would be unfair because, in the absence of a manifested condition, genetic information is predictive only in terms of risk and is not related to an individual's present ability to do a job. The potential for such adverse employment actions based on predictive genetic information is a special concern because so many persons tend to exaggerate the role of genes in disease and mistakenly regard an increased risk of an illness as a certainty that it will occur.

According to a 2004 survey of more than 500 companies by the American Management Association, some companies routinely require prospective and existing employees to submit genetic information and take genetic tests. A significant proportion of these companies stated that they used this information in making hiring, retention, and assignment decisions. American Management Association, AMA 2004 Workplace Testing Survey: Medical Testing, available at http://www.amanet.org/research/pdfs/Medical_testing_ 04.pdf. Moreover, two high-profile lawsuits have confirmed the existence, in some companies, of genetic testing of employees without their knowledge. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory,* 135 F.3d 1260 (9th Cir. 1998); *EEOC v. Burlington Northern Santa Fe Railway,* No. C 01-4013-MWB (N.D. Iowa Apr. 18, 2001).

While there is little evidence of widespread abuse of genetic information in the employment setting, that does not diminish the need for legislation. The technologies are new and the potential for using them is rapidly growing. Furthermore, credit should be given to the role of existing state statutes, most of which predate GINA, in preventing serious problems from arising. State statutes need to be updated for consistency with GINA in order to continue to play this important role.

The Federal Regulatory Context of GINA

GINA prohibits genetic discrimination in both health insurance and employment. However, its scope extends beyond the reference to nondiscrimination in its title; it also contains provisions designed to protect privacy. Title II of GINA, which applies specifically to employment, covers employers with 15 or more employees, labor unions, employment agencies, and joint labor-management training programs. It restricts intentional acquisition of genetic information about applicants or employees, prohibits employment decisions based on genetic information, and imposes confidentiality requirements for the retention and disclosure of genetic information.

GINA uses a broad definition of genetic information. It includes both the results of genetic tests and information about diseases or disorders in family members, commonly known as family medical history. The definition of genetic test is carefully limited with dual requirements designed to exclude common non-genetic medical tests such as cholesterol. A genetic test is defined in terms of both the materials that are tested – human DNA, RNA, chromosomes, proteins, or metabolites – and the purpose of the test – to detect genotypes, mutations, or chromosomal changes. Unlike many existing state statutes, GINA's definition is not restricted to genetic tests for disease.

GINA generally prohibits employers, unions, employment agencies, and training programs from requesting, requiring, or purchasing genetic information of employees or their family members. There are limited exceptions. Employers are excused from liability for inadvertent acquisition, such as in response to a casual conversation about an employee's family. Other exceptions allow for information to process Family Medical Leave Act requests, protect an employer who obtains genetic information in a publicly-available document, allow an employer to offer genetic services as part of a wellness program, permit employers to monitor the genetic effects of workplace conditions, and allow certain employers involved in DNA testing to conduct quality control to detect contamination by employees' DNA.

GINA prohibits employers, unions, employment agencies and training programs from discriminating based on genetic information, regardless of how that information was obtained. It does not, however, affect employment decisions that take into account a manifested disease or condition. Those decisions are regulated by the Americans with Disabilities Act.

GINA declares that genetic information is confidential and requires that an employer that retains this information must segregate it from employees' personnel files. It also imposes limits on disclosures of genetic information by employers to other entities, with exceptions for research, court orders, the Family Medical Leave Act, and public health agencies under certain circumstances.

GINA's enforcement and remedy provisions incorporate the provisions of Title VII of the Civil Rights Act of 1964, so it offers dual enforcement by the Equal Employment Opportunity Commission and private civil suits that may follow exhaustion of administrative remedies. Unlike Title VII, however, it does not permit disparate impact claims at this time. Instead, it authorizes the formation of a committee to study whether this cause of action is desirable.

Highlights of the Act

The uniform act is designed to eliminate the preemption problems created by GINA for existing state statutes. It thus incorporates the key definitions and concepts of GINA. It also complements and supplements GINA with additional provisions that are more protective of employees, following the pattern of many state fair employment laws that supplement Title VII and other federal statutes. The act comprehensively regulates acquisition, use, retention, and disclosure of genetic information in the employment setting.

The act expands coverage beyond that of GINA in two principal ways. First, in addition to covering employers, unions, employment agencies, and training programs, it closes a gap in GINA by extending coverage to entities that license or provide credentials for workers. Second, it includes employers with five or more employees, while giving states an option to extend coverage to smaller employers. This follows the pattern of state fair employment statutes, many of which cover smaller employers than Title VII, and of existing state genetics statutes, which often cover all employers regardless of size.

The act protects employees by requiring them to authorize employer acquisition of their genetic information and voluntary genetic testing as part of an employee wellness program or a genetic monitoring program. These authorization requirements are consistent with GINA, but more specific. The act sets forth the desirable content for authorization forms to give employers guidance and the assurance that they are following the law. It also allows employees to submit genetic information voluntarily so that it can be used for their protection, for example, in support of a request for reassignment to avoid a workplace substance to which a worker has a genetic susceptibility.

The act supplements GINA with specific provisions on genetic testing, which is treated in GINA as part of the general category of acquisition of genetic information. The act allows an employer to offer genetic testing only as part of a voluntary employee wellness program or a genetic monitoring program. It recognizes the importance of genetic counseling for employees' decisions to have a genetic test and in interpreting the results. Unlike GINA, the act thus requires genetic counseling before an employee or family member authorizes a genetic test and when a test predicts a disease or disorder unless the individual waives genetic counseling in writing. The act also sets standards for genetic testing that require reporting the results to the employee, destroying the employee's biological sample, and expunging genetic information produced ancillary to the test. At the same time, the act recognizes that genetic counseling is an emerging profession that is not regulated in many states and so it does not impose requirements on who may provide counseling. Therefore, unless there is state law to the contrary, counseling may be provided by physicians, geneticists, and nurse practitioners in addition to trained genetic counselors.

In order to prevent employment discrimination based on genetic information, the act follows GINA by prohibiting specific actions based on genetic information, such as failure to hire, discharge, or discriminate in compensation or terms and conditions of employment. It also more comprehensively prohibits *any* adverse employment action against an employee based on the employee's genetic information.

The act incorporates GINA's provisions that make genetic information confidential and limit disclosures of that information. It supplements GINA by allowing employees to direct disclosures to third parties and by giving employees a specific right to inspect and copy genetic information in the employer's possession and to submit corrected information.

The enforcement and remedies section establishes a state-law private cause of action for violations of the act. It contains an option that allows a state to use its fair employment enforcement apparatus and an option to make exhaustion of administrative remedies optional before a private lawsuit. Unlike GINA, the act leaves it optional as to whether or not a state will prevent an employee from filing a cause of action on a theory of disparate impact. Remedies are not limited to those authorized for Title VII, and thus the federal caps on damages do not apply. Awards of attorney's fees generally follow federal law and are discretionary. They are authorized only for prevailing employees in order to cover the cost of enforcing the act.

In sum, the act provides for counseling, consent, and confidentiality and, through these mechanisms, gives employees control over their genetic information in the workplace. It allows states to use the enforcement mechanisms they have in place under their fair employment statutes. It eliminates preemption of state law under GINA and fosters uniformity among the states.

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 that 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 an apprenticeship or other training or retraining 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 as described 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, labor-management committee, or credentialing authority.

(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 described in subparagraph (B).

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

(10) “Genetic counseling” includes:

(A) providing an individual with an assessment of the individual’s genetic risk for an inherited genetic condition by interpreting family medical histories;

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

(C) helping an individual 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 or a family member of the individual, about:

(A) the individual's genetic test;

(B) a genetic test of the family member;

(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 the family member; or

(E) a genetic test of:

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

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

(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. The term includes an agent of the committee.

(18) “Labor organization” means an organization in which employees participate that 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 reasonably could 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.

(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: *States may replace [five] with a lesser number of employees in the definition of "employee" in order to extend the coverage of the [act].*

Comment

Paragraph (1). (Credentialing authority) Credentialing authorities are included in the group of employment-related organizations labeled as "employment entities" and regulated in this act. The act's inclusion of credentialing authorities extends the coverage of GINA.

Credentialing authorities serve as gatekeepers to certain types of employment by providing credentials that are required either under state law or by an employer. Examples include state bar and medical examination boards, which control entry to the practice of law and medicine, and state departments of motor vehicles, which issue commercial drivers' licenses necessary for some employment. Acquisition or use of genetic information by a credentialing authority could have the same effects on employees and applicants for employment as acquisition or use by an employer.

California's state equal employment opportunity statute similarly expands the protections of federal employment law with regard to credentialing. It prohibits licensing boards from requiring an examination or establishing any other qualification that has an adverse impact on a

class by virtue of race, creed, etc., unless the practice can be demonstrated to be job related. Cal. Gov't Code § 12944 (West 2005).

Paragraph (2). (DNA) DNA is the commonly used abbreviation for deoxyribonucleic acid. This is the chemical designation for a molecule that, in humans, codes genetic information in chromosomes. The molecule is in the form of a double helix formed as two strands of DNA spiral around each other. The code is determined by the sequence of nucleotides in the DNA molecule.

Paragraph (3). (Employee) For drafting ease, the term employee is used to cover not only traditional employees, but also individuals who are labor organization members, apprentices, trainees, or using employment agencies. Like GINA, which includes both applicants with employees in its definition, this act's definition of employee also includes applicants for employment, labor organization membership, training or apprenticeship program, or an employment credential. Also, like the EEOC regulations implementing GINA, which include former employees, etc., the definition includes them as well. The intent is to cover any individual who is subject to collection of information or an employment decision by an employment entity, which is defined as an employer, employment agency, labor organization, credentialing authority, or joint labor management committee.

The traditional definition of employee in subparagraph 3(A)(i) is based on the definition in the regulations implementing GINA. 29 C.F.R. § 1635.2(c). GINA's definition of employee is a cross reference to Title VII of the Civil Rights Act of 1964. 42 U.S.C. § 2000ff(2)(A) (Supp. II 2008), 42 U.S.C. § 2000e(f) (2006). In interpreting the act's definition, a tribunal should act consistently with interpretations of the federal term.

Independent contractors are explicitly excluded from the act's definition of employee. This approach is not intended, however, to provide employers with an avenue to evade their obligations by classifying employees as independent contractors. The definition does not take a position on whether or not partners are considered employees, but leaves this to the development of the law on the status of partners.

Size of employers based on number of employees. Both Title VII of the Civil Rights Act of 1964 and GINA cover employers with 15 or more employees. Many state employment discrimination statutes, however, expand the scope of their coverage beyond that provided by Title VII by including employers with smaller workforces. Furthermore, genetics statutes in several states often apply to *all* employers regardless of the threshold used in their employment discrimination statute. The act follows this pattern of expanded coverage under existing state statutes by setting the threshold for coverage at five or more employees. However, many states may want to reduce further the number of employees required to trigger the act's coverage and the legislative note gives them the option to do this.

In deciding whether to include employers with fewer than five employees under the act's coverage, states should consider the thresholds they have enacted in their existing genetics statute and other statutes, such as their state employment discrimination statute and their workers compensation statute. For example, 16 jurisdictions cover all employers (i.e., employers with

one or more employees) under their state employment discrimination acts. An additional 11 jurisdictions have set a threshold below five, ranging from two to four employees. 6 Lex K. Larson, Employment Discrimination § 114.02[2] (2d ed. 2005). Significantly, some states cover all employers with even a single employee under their genetics statute even when the state's employment discrimination statute sets a higher threshold for covering employers. *See* 410 Ill. Comp. Stat. Ann. 513/10 (West 2005 & Supp. 2010); Iowa Code Ann. § 729.6 (West 2003 & Supp. 2010); Neb. Rev. Stat. Ann. 48-236 (LexisNexis 2007); N.M. Stat. Ann. § 24-21-4 (LexisNexis 2007); N.C. Gen. Stat. § 95-28.1A (2009); R.I. Gen. Laws § 28-6.7-2.1 (2003); Utah Code Ann. § 34A-2-103 (2005 & Supp. 2009).

Measurement of number of employees. An individual is counted as an employee if they have been employed for each working day in each of 20 or more weeks during the current or preceding calendar year. This measurement should be applied according to the interpretation given to the provision under Title VII and the other federal statutes that use this common formula.

Paragraph (4). (Employer) GINA defines employer by reference to Title VII of the Civil Rights Act of 1964. 42 U.S.C. § 2000ff(2)(B) (Supp. II 2008). This act follows the definition in the regulation implementing GINA. 29 C.F.R. § 1635.2(d).

This act's definition of employer is linked to the definition of "person." It therefore encompasses all types of entities, including governmental and non-profit employers. This is consistent with the coverage specified by a number of states in their state versions of Title VII of the Civil Rights Act of 1964 on employment discrimination. *See, e.g.,* Haw. Rev. Stat. § 378-1 (2008); Iowa Code Ann. § 216.2 (West 2009 & Supp. 2010).

Paragraph (5). (Employment agency) This is the definition provided in Title VII, 42 U.S.C. Section 2000e (c) (2006), which GINA incorporates by reference, 42 U.S.C. Section 2000ff(2)(C) (Supp. II 2008).

Paragraph (6). (Employment entity) Employment entity is the term used in this act to collectively indicate an employer, an employment agency, a labor organization, a credentialing authority, or a joint labor-management committee that offers training programs. The definition expands GINA's coverage by adding credentialing authorities.

The regulations implementing GINA use the term "covered entity" to group the organizations covered by the federal act. 29 C.F.R. § 1635.2(b). This term is not used in this act because of the potential for confusion with the use of the term "covered entity" in HIPAA and because this act's scope of coverage is slightly different from GINA, which does not include credentialing authorities.

Paragraph (7). (Family medical history) Family medical history is often a source of genetic information in that it is used to evaluate the likelihood that an individual carries an inherited trait. The act follows GINA and includes family medical history within its definition of "genetic information." The term "family medical history" is not defined in GINA. This definition follows the definition in the regulation implementing GINA. 29 C.F.R. § 1635.3(b).

Paragraph (8). (Family member) This act defines family member to encompass all individuals whose genotype could influence an employment decision. The term includes (1) biological relations of an employee whose genetic information might provide information about the genetic make-up of the employee, (2) individuals who are covered, or eligible for coverage, under a benefit program provided through the employer, whose risk of future genetically-linked medical conditions could therefore affect employer health care costs or the cost of family insurance coverage and hence affect employment decisions, and (3) biological relations of an individual covered by or eligible for a benefit program, whose genetic information might provide information about the genetic make-up of the covered or eligible individual. The definition is based on the definition of family member used in GINA. 42 U.S.C. § 2000ff(3) (Supp. II 2008).

Degree of biological relationship to the employee. The first part of the definition, found in subparagraph (A), follows GINA and the proposed EEOC regulations by including blood relatives to the fourth degree of consanguinity. Genetic counselors typically collect information on genetic diseases of family members related to the third degree of consanguinity and often to the fourth degree. The family members listed in the definition are identical to those listed in the GINA regulation. 29 C.F.R. § 1635.3(a)(2).

Individuals covered under a benefit program. The second part of the definition, found in subparagraph (B), applies to individuals such as a spouse, adopted child, child placed for adoption, or domestic partner if the individual is covered or eligible to be covered under a benefit plan the employer provides to the employee. The reason for including these individuals is that although they are not blood relatives, their genetic information might influence an employment decision about the employee if an employer thought that covering the family member could increase the cost of health insurance or other benefits. In this context GINA defines "family member" by using the term "dependent" with reference to ERISA's use of that term in its provisions on special enrollment periods for group health plans. *See* 29 U.S.C. § 1181(f)(2) (2006). As used in ERISA, this status depends on the scope of health care coverage offered by the employer. This act avoids the use of the term "dependent" because its meaning under state law may be linked to tax laws or other state provisions.

Biological relations of an individual covered by a benefit plan. Genetic information about a biological relation of a spouse or other individual covered under a benefit plan reveals things about the individual's genetic traits, just as genetic information about a biological relation of an employee sheds light on the employee's genetic make-up. For that reason, both GINA and subparagraph (8)(C) of this act cover these blood relatives in the definition of family member.

Paragraph (9). (Genetic condition) The term genetic condition is used in the definitions of genetic counseling and genetic services. It is not defined in GINA. The act's definition is intended to give the term a broad interpretation. A genetic condition includes a manifested genetic disease or disorder as well as a genetic trait that may increase the likelihood of developing a disease or disorder. In addition, the term may also refer to a positive or benign trait or characteristic that is linked to a particular genotype. Positive and benign traits are included because genetic counseling can include discussion of these genetic characteristics. For example, a person may carry a form of a gene that could reduce, rather than increase, the risk of developing a particular disease or disorder.

Paragraph (10). (Genetic counseling) Genetic counseling is a key to an individual's informed decision making about getting a genetic test, understanding the result, and authorizing its use, retention, or disclosure. GINA defines genetic counseling by inserting a parenthetical about genetic counseling into its definition of a genetic service. The parenthetical refers to genetic counseling as "(including obtaining, interpreting, or assessing genetic information)." 42 U.S.C. § 2000ff(6) (Supp. II 2008); *see also* 29 C.F.R. § 1635.3(e). The Drafting Committee rejected this approach and concluded that a more comprehensive definition is important because genetic counseling is a relatively new profession and state regulation of genetic counselors and genetic counseling is currently in flux. Some states license or certify genetic counselors and they tend to have a definition of genetic counseling. But the majority of states do not license genetic counselors or regulate genetic counseling and hence lack a definition.

It is important to note that the definition does not require that genetic counseling be performed by a genetic counselor. Physicians, geneticists, and some nurse practitioners are also qualified to provide genetic counseling.

Genetic counseling is usually a two-step process consisting of 1) counseling before a test about the decision whether or not to have the test and 2) counseling after the test if the test indicates the individual is at risk. In addition, for some conditions counseling may also be appropriate if the test indicates the individual is not at risk. The functions listed in (A) through (C) of the definition of genetic counseling take place before an individual decides whether or not to have the test. The functions in (D) and (E) take place after the test, if necessary.

One of the core principles of genetic counseling is "nondirective education," a term of art in genetic counseling. The concept involves explaining all the relevant considerations and consequences without suggesting to the client what course to take. It is a particularly important principle in genetic counseling because of the association in the early part of the twentieth century between genetics and eugenics, which advocated the promotion of certain superior genotypes and the reduction in the population of those judged to be inferior. The act references the concept of nondirective communication using the definition in Seymour Kessler, *Psychological aspects of genetic counseling. XI. Nondirectiveness revisited,* 72 Am. J. Med. Genet. 164, 166 (1997): "Non-directiveness describes procedures aimed at promoting the autonomy and self-directedness of the client."

Paragraph (11). (Genetic education) Genetic education is one element of genetic services. The term "genetic education" is used in the definition of genetic services in GINA, 42 U.S.C. Section 2000ff(6) (Supp. II 2008), and the regulations implementing GINA, 29 C.F.R. Section 1635.3(e), but it is not defined.

Genetic education is typically less tailored to individual circumstances then a one-on-one genetic counseling session and may be delivered by individuals who would not necessarily be qualified to conduct genetic counseling. The act's definition is meant to be broad enough to include information provided by support groups to groups or individuals who are concerned about a genetic condition. It is not meant to encompass general genetic education such as that received in biology class or medical school.

Paragraph (12). (Genetic information) The act's definition of "genetic information" follows the definition in the employment title of GINA. 42 U.S.C. § 2000ff(4) (Supp. II 2008). It includes a family member's genetic tests and family medical history.

The definition also incorporates GINA's provisions on the genetic information of fetuses, which are found, not in GINA's definitions, but in Section 209, codified at 42 U.S.C. Section 2000ff-8 (Supp. II 2008). Under GINA, if an employee or family member is a pregnant woman, references to her genetic information include that of the fetus she is carrying. If an employee or family member is using assisted reproductive technology, references to that individual's genetic information include the genetic information of any embryo held legally by that individual.

The act's definition of genetic information is consistent with many states that define "genetic information" to include information on genetic characteristics broadly, whether obtained from genetic tests or family medical history. *See* Cal. Gov't Code § 12926 (West 2005); Conn. Gen. Stat. Ann. § 46a-60 (West 2009); Haw. Rev. Stat. § 378-1 (2008); 410 Ill. Comp. Stat. Ann. 513/10 (West 2005 & Supp. 2010); La. Rev. Stat. Ann. § 23:302 (2010); Me. Rev. Stat. Ann. tit. 5, § 19301 (2002); Md. Code Ann., Ins. § 27-909 (LexisNexis 2009); Mass. Ann. Laws ch. 151B, § 1 (LexisNexis 2008); Mich. Comp. Laws Ann. § 37.1201 (West 2001); N.J. Stat. Ann. § 10:5-5 (West 2002 & Supp. 2010); N.M. Stat. Ann. § 24-21-2 (LexisNexis 2007); N.C. Gen. Stat. § 95-28.1A (2009); R.I. Gen. Laws § 28-6.7-2.1 (2003); S.D. Codified Laws § 60-2-21 (2009); Tex. Lab. Code Ann. § 21.401 (Vernon 2006); Wash. Rev. Code Ann. § 49.44.180 (West, 2008). States with definitions that do not include family medical history are less protective than GINA and therefore preempted.

Paragraph (13). (Genetic monitoring) The act's definition of "genetic monitoring" follows the definition in GINA. 42 U.S.C. § 2000ff(5) (Supp. II 2008). It is drawn from the description in Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* 4 (1990). The focus of monitoring is not on inherited characteristics, but on genetic alterations in a group of exposed individuals over time. Genetic monitoring is typically undertaken by employers to identify risks for groups of employees who have been exposed to hazardous substances or to target work sites for safety and health measures. The definition in the act differs slightly from that in GINA. GINA's definition limits genetic monitoring to testing for mutations due to exposure to toxic substances. In contrast, the act's definition uses the term "workplace condition" so that it can include any appropriate testing for mutations linked to employment.

Paragraph (14). (Genetic service) This definition follows the definition of "genetic services" in the employment title of GINA. 42 U.S.C. § 2000ff(6) (Supp. II 2008). "Genetic service" is a broader category than genetic testing. The term includes activities associated with obtaining genetic information that could create assumptions about an individual's genetic status even in the absence of information about genetic test results or medical history. "Counseling" implies an individual consultation, so the definition also includes "genetic education" in order to capture group information sessions on genetic conditions. While the definition of a "genetic service" does not separately define the term "genetic," the term should be interpreted to be consistent with the definitions of "genetic test" and "genetic information."

Paragraph (15). (Genetic test) The act's definition is substantively identical to the definition of genetic test used in GINA employment provisions. 42 U.S.C. § 2000ff(7) (Supp. II 2008). "Genetic test" is defined in terms of both (1) the material that the test analyzes and (2) what the test detects.

The first clause of the first sentence of the definition makes specific reference to the types of biological material that are currently analyzed in genetic tests. Note that genetic tests can be conducted not only on gene sequences, but also on biological substances such as proteins or metabolites that can indicate an individual's genetic make-up. The second clause of the first sentence specifies that the test must function to determine an individual's genetic make-up, either through the identification of a genotype or by looking for a mutation or chromosomal change.

Both components of the definition are equally important. Some of the materials listed in the first clause, especially proteins and metabolites, are tested for many medical purposes. A test of a protein or metabolite does not constitute a genetic test unless it is administered to determine an individual's genetic make-up as specified in the second clause. In addition, the second sentence of the definition, although redundant, should reassure those who fear the definition will be used to sweep in medical tests that are not given to detect genotypes, mutations, or chromosomal changes. Examples of medical tests that do not fall within the definition include complete blood counts; cholesterol tests; liver-function tests; tests for a virus not composed of human DNA, RNA, chromosomes, proteins, or metabolites; tests for infectious and communicable disease that may be transmitted by food handling; and tests for the presence of alcohol or illegal drugs.

Existing state law. Many states with genetic statutes define "genetic test" in a way that is not as broad, and hence not as protective, as the definition in GINA. First, some statutes limit the definition to testing of DNA or chromosomes and are therefore inconsistent with modern testing practices. *E.g.,* Alaska Stat. § 18.13.100 (2008); Ark. Code Ann. § 11-5-402 (2002); Kan. Stat. Ann. § 44-1002(m) (2008); Mo. Ann. Stat. § 375.1300(4) (West 2002); Okla. Stat. Ann. tit. 36, § 3614.2(B)(4) (West 1999); Utah Code Ann. § 26-45-102(4) (2007); Va. Code Ann. § 38.2-508.4(A) (2007).

Second, many states statutes limit their definition of "genetic test" to testing for disease-related genes. *E.g.,* Ariz. Rev. Stat. Ann. § 12-2801 (2003 & Supp. 2009); Ark. Code Ann. § 11-5-402(4)(B) (2002); Del. Code Ann. tit. 18, § 2317(a)(3) (2005); D.C. Code § 2-1401.02(12B) (2008); 410 Ill. Comp. Stat. Ann. 513/10 (West 2005 & Supp. 2010); Iowa Code Ann. § 729.6(c) (West 2003 & Supp. 2010); Kan. Stat. Ann. § 44-1002(m) (2008); La. Rev. Stat. Ann. § 23:302(6) (2010); Me. Rev. Stat. Ann. tit. 5, § 19301 (2002); Md. Code Ann., Ins. § 27-909 (LexisNexis 2009); Mich. Comp. Laws Ann. § 37.1201(e) (West 2001); Minn. Stat. Ann. § 181.974(a) (West 2006); Mo. Ann. Stat. § 375.1300(4) (West 2002); Neb. Rev. Stat. Ann. § 77-5519(d) (LexisNexis 2010); Nev. Rev. Stat. Ann. §§ 629.121, 613.345(2)(b) (LexisNexis 2008); N.J. Stat. Ann. § 10:5-5(pp) (West 2002 & Supp. 2010); N.M. Stat. Ann. § 24-21-2(F) (LexisNexis 2007); N.Y. Civ. Rights Law § 79-l (21-a)-(21-b) (McKinney 2009); N.C. Gen. Stat. § 95-28.1A(b) (2009); Okla. Stat. Ann. tit. 36, § 3614.2(B)(4) (West 1999); R.I. Gen. Laws § 28-6.7-2.1(4) (2003); Tex. Lab. Code Ann. § 21.401(5) (Vernon 2006); Vt. Stat. Ann. tit. 18, § 9331(7) (2000); Va. Code Ann. § 38.2-508.4(A) (2007); Wis. Stat. Ann. § 49.44.180(7m) (West

2008). These definitions are not as protective as the definition in GINA, and thus these statutes are likely preempted. While most of the reasons that an employer or insurer might currently seek or use genetic information probably involve a disease, disorder, or impairment, this may not always be the case. For example, an employer might attempt to use the presence or absence of a behavioral trait as a criterion for selecting an employee. While the current evidence linking behavior to genes is tenuous, this area continues to be the subject of investigation. The definition in GINA and the act allows the law to adapt as scientific information develops. The act's definition is consistent with state definitions of genetic testing that are not limited to identifying genotypes associated with diseases or impairments. *E.g.,* Fla. Stat. Ann. § 760.40 (West 2010); Haw. Rev. Stat. § 378-1 (2008); Idaho Code Ann. § 39-8302 (Supp. 2009); Mass. Ann. Laws ch. 151B, § 1 (LexisNexis 2008); N.H. Rev. Stat. Ann. § 141-H:1(IV) (2005); Or. Rev. Stat. § 192.531 (2007); Utah Code Ann. § 26-45-102(4) (2007).

Paragraph (16). (Individually identifiable genetic information) The act includes this definition because the concept is used in the provisions allowing employment entities to acquire genetic information for the purpose of offering health and genetic services and conducting genetic monitoring programs. The concept is also used, but not defined, in the GINA regulations. The act's definition is drawn from the HIPAA Privacy Rule, which protects individually identifiable health information. Under the Privacy Rule's definition, individually identifiable health information is health information that "identifies the individual[,] or [w]ith respect to which there is a reasonable basis to believe the information can be used to identify the individual." 45 C.F.R. § 160.103 (2009).

The HIPAA Privacy Rule does not directly indicate what information triggers a reasonable basis to believe that it could be used to identify an individual, but it does provide a standard for "de-identification" of protected health information. Health information is not individually identifiable if the following has been removed: names; all geographic subdivisions smaller than a state, including street address, city, county, precinct, zip code, and their equivalent geocodes (except for the initial three digits of a zip code if, according to the current publicly available data from the Bureau of the Census, the geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people); all elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; all ages over 89 and all elements of dates (including year) indicative of such age (except that such ages and elements may be aggregated into a single category of age 90 or older); telephone numbers; fax numbers; electronic mail addresses; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; web Universal Resource Locators (URLs); internet Protocol (IP) address numbers; biometric identifiers, including finger and voice prints; full face photographic images and any comparable images; and any other unique identifying number, characteristic, or code. 45 C.F.R. § 164.514(b) (2009).

Paragraph (17). (Labor-management committee) This definition is taken from the definition of a joint labor-management committee in the regulations implementing GINA. 29 C.F.R. § 1635.2(g). The training programs should be understood to include on-the-job training programs.

Paragraph (18). (Labor organization) This definition is derived from the definition of labor organization in Title VII, 42 U.S.C. Section 2000e (d) (2006), which GINA incorporates by reference, 42 U.S.C. Section 2000ff(2)(C) (Supp. II 2008). *See* 29 C.F.R. § 1635.2(h). The act's definition omits, however, the federal statutes' requirement that the organization be engaged in interstate commerce. It is similar to the following definition, which is commonly used in state EEO acts: "'Labor organization' means any organization which exists and is constituted for the purpose, in whole or in part, of collective bargaining or of dealing with employers concerning grievances, terms or conditions of employment, or of other mutual aid or protection in connection with employment." *E.g.,* Cal. Govt. Code § 12926 (West 2005); Haw. Rev. Stat. § 378-1 (2008); Iowa Code Ann. § 729.6 (West 2003 & Supp. 2010); N.Y. Exec. Law § 292 (McKinney 2010).

Paragraph (19). (Labor-organization member). This definition is taken from GINA's definition of "member." 42 U.S.C. § 2000ff(2)(D) (Supp. II 2008); 29 C.F.R. § 1635.2(i). For drafting convenience, labor-organization members are grouped with the traditional definition of employee and individuals using an employment agency, training program, or credentialing authority under the term "employee." To be parallel to the act's other components of the term employee, the definition includes former labor-organization members and applicants.

Paragraph (20). (Manifested). This definition is taken from the EEOC regulations implementing GINA. 29 C.F.R. § 1635.3(g). It is relevant to the definitions of family medical history and genetic information in this section and to Section 4, which excludes from the act's coverage medical information about a manifested disease, disorder or pathological condition that is not genetic information.

The concept of a manifested disease, disorder, or pathological condition is important because the mere presence of a genetic variant does not mean that an individual has any disease, disorder, or pathological condition. The genetic trait alone is not a diagnosis. A genetic variant may indicate an increased or decreased risk of disease, but a diagnosis requires other medical indications or symptoms.

When a diagnosis is based on the presence of both genetic information and other medical indications or symptoms, the disease, disorder, or pathological condition will be considered manifest. The fact that an individual has the manifested disease, disorder, or manifested condition is not protected by this act as genetic information. The individual's symptoms used for the diagnosis are similarly not genetic information. But information about any family medical history or genetic tests that was used along with the symptoms as the basis of the diagnosis is genetic information protected by this act. In addition, note that the other laws regulate the acquisition and use of medical information, including the Americans with Disabilities Act (ADA). *See* 42 U.S.C. § 12112(d) (2006).

Paragraph (21). (Person) The act uses the broad version of the standard National Conference of Commissioners on Uniform State Laws definition of "person."

Paragraph (22). (RNA) RNA is the standard abbreviation for ribonucleic acid. This is the chemical designation for several classes of molecules that, in humans, carry genetic

information based on a DNA template. They play important roles in protein synthesis and other cell functions based on DNA sequences.

Paragraph (23). (Record) The definition of "record" is the standard National Conference of Commissioners on Uniform State Laws definition.

Paragraph (24). (Sign) The definition of "sign" is the standard National Conference of Commissioners on Uniform State Laws definition.

Paragraph (25). (Tribunal) The term "tribunal" refers collectively to the potential decision-makers in a litigation or arbitration context.

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 regardless of when the information was acquired.

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

Comment

This section is designed to avoid litigation about retroactivity under the act. Under subsection (a), if an employment entity has already obtained or used genetic information as of the effective date of the act, the act requires the employment entity to store and disclose that information only in compliance with the act. The application of the confidentiality and retention provisions in Section 19 to genetic information acquired before the effective date of this act differs from the treatment under GINA. In contrast to this act, the implementing EEOC regulations do not require employment entities to segregate genetic information acquired before GINA's effective date. But the regulations do require employment entities to apply GINA's restrictions on use and disclosure to genetic information regardless of the date the employment entity acquired the genetic information. 29 C.F.R. § 1635.9(a)(5). Similarly, the Drafting Committee considered and rejected a provision that would have allowed an employment entity to

disclose genetic information according to an agreement, if any, that an employee signed prior to the effective date of the act. Any such agreements should be revisited and brought into compliance with the act.

Under subsection (b), actions taken by an employment entity with regard to acquisition and use of genetic information and genetic testing must comply with the act only after the effective date.

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 or a family member of an employee does not violate this [act] even if the manifested disease, disorder, or pathological condition has or may have a genetic basis.

Comment

Exclusion of information that is not genetic information. This section is a paraphrase of Section 210 of GINA, 42 U.S.C. Section 2000ff-9 (Supp. II 2008). It is meant to signal that medical information about a manifested disease is not covered by the act if it is not genetic information. But medical information about a manifested disease is covered by the act if it is genetic information. For example, an individual with breast cancer diagnosed by a biopsy has a manifested disease. In addition, she might learn from genetic testing that she is positive for a BRCA mutation, which indicates an increased risk of both breast and ovarian cancer. Under this section, the fact that she has breast cancer is not protected information under the act because the breast cancer is a manifested disease, even though it may have a genetic basis. But information about the genetic mutation and her risk of ovarian cancer is protected by the act because it is genetic information obtained from a genetic test.

Under this section an employment entity does not violate the act when it acquires, uses, retains, or discloses medical information about a manifest disease that is not genetic information. However, that information may be protected by the ADA. *See* 42 U.S.C. § 12112(d) (2006).

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 a 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.

Comment

Act's general approach to acquisition of genetic information. This section imposes a general prohibition on genetic testing of employees or employee's family members and on acquisition of their genetic information. The general prohibition should be read with the subsequent sections, which establish a number of specific exceptions for situations in which genetic testing by employment entities is permissible and conditions under which their access to employee's genetic information is acceptable.

Sections 6 through 12 establish limited exceptions to the prohibition on acquisition of genetic information. The act permits employment entities to acquire genetic information if they receive it from an employee who provides it voluntarily, request it under the Family Medical Leave Act, obtain it in certain publicly available documents, obtain it as part of offering a voluntary wellness program, use it for genetic monitoring, use it for quality control in forensic testing laboratories, or obtain it pursuant to a tribunal's order in litigation.

Sections 9 through 12 establish limited exceptions to the prohibition on genetic testing. An employment entity may provide genetic testing as part of a wellness program and provide it or, when appropriate, require it for a genetic monitoring program, for quality control use in forensic testing laboratories, or pursuant to a tribunal's order in litigation. Section 13 sets requirements for counseling and reporting that must be met if an employment entity provides a genetic test as part of a voluntary wellness program or a genetic monitoring program.

Rationale for prohibiting acquisition and testing. One rationale for limiting employer acquisition of genetic information is the view that an employee should be able to keep genetic information private. Approximately 15 states have statutes that protect the privacy of genetic information in general, without regard to employment or any other specific context. At least one state has a constitutional right of privacy that appears to be relevant to genetic information. Alaska Const. art. 1, § 22. Another rationale for limiting acquisition is to make genetic discrimination less likely. Unlike discrimination based on sex or race, an employer cannot discriminate on the basis of genetic characteristics unless it has access to genetic information.

Subsection (a) General prohibition on acquisition of genetic information and genetic testing. This section establishes a general prohibition on the acquisition of genetic information by employment entities by prohibiting employment entities from requesting, requiring, or purchasing an employee's genetic information. It also supplements GINA, which does not have

provisions that specifically cover genetic testing, by establishing a general rule that an employment entity may not offer or provide genetic tests to employees.

The act's prohibition on acquisition incorporates the language of GINA by making it a violation for an employer to "request, require, or purchase" genetic information. 42 U.S.C. §§ 2000ff-1(b), 2000ff-2(b), 2000ff-3(b), 2000ff-4(b) (Supp. II 2008). To avoid the possibility of a restrictive interpretation of that language, the subsection additionally prohibits any other acquisition of genetic information except as otherwise permitted in the act. The prohibition of "requests" is intended to apply to inquiries directed to other entities as well as to inquiries directed to the employee or the employee's family member. The prohibition on requesting genetic information is not, however, intended to prevent an employer from informing an employee about the availability of a genetic test that is relevant to conditions in the workplace or from informing an employee about a genetic monitoring program.

GINA does not contain prohibitions on testing, which it regards as a form of acquiring genetic information that is covered by the provisions limiting employer acquisition. This act, in contrast, is more explicit. It contains a general prohibition on genetic testing and, in the narrow circumstances singled out as exceptions, provides employees with protections that relate specifically to testing.

Subsection (b) Inadvertent requests. GINA makes an exception to its prohibition on acquisition of genetic information when an employment entity "inadvertently"requests or requires family medical history. 42 U.S.C. §§ 2000ff-1(b)(1), 2000ff-2(b)(1), 2000ff-3(b)(1), 2000ff-4(b)(1) (Supp. II 2008). The purpose of the exception is to address the "water cooler problem" – when an employer unwittingly receives information through casual conversation or by overhearing conversations. While GINA's provision on inadvertent requests is limited to requests for family medical history, the implementing regulations expand it to include any genetic information on the theory that if the acquisition is inadvertent it should not matter whether the information concerns a genetic test or a relative's disease. 75 Fed. Reg. 68912, 68919 (Nov. 9, 2010). This act follows the approach in the regulations. 29 C.F.R. § 1635.8(b)(1).

The EEOC regulations include examples of circumstances in which the acquisition of genetic information would be deemed inadvertent. 29 C.F.R. § 1635.8(b)(1)(ii). These include overhearing conversations, responses to ordinary expressions of concern such as asking, "How are you?", receiving information that is not solicited, or finding information on a social media platform when it is accessed with the permission of the creator.

A response to an employment entity's lawful request for medical information that contains genetic information can also be an instance of inadvertent acquisition, under certain circumstances. The employment entity must be proactive in preventing acquisition of genetic information in response to requests for health information. The acquisition qualifies as inadvertent if the employment entity directed the individual or health care entity to whom the request was made not to provide genetic information. 29 C.F.R. § 1635.8(b)(1)(i)(A). It also qualifies as inadvertent if the request was not likely to result in an employment entity obtaining genetic information, such as a tailored request for specific health information. 29 C.F.R. §

1635.8(b)(1)(i)(C).

An employment entity must also be proactive in the context of ordering a medical examination for the purpose of determining an individual's ability to perform a job, such as in a fitness for duty examination or a post-offer examination. The prohibition on acquiring genetic information, including family medical history, applies to these examinations. The EEOC regulations implementing GINA require an employment entity to tell the health-care professional conducting the examination not to collect genetic information as part of the examination. The employment entity must also take reasonable measures if it learns that a health-care provider is collecting genetic information, such as changing health-care providers. 29 C.F.R. § 1635.8(d).

Relationship of existing state law to GINA and this act. There are many avenues by which employment entities obtain health information, which may include genetic information. These include employment applications, interviews, references, post-offer medical exams, post-offer releases of medical records, Family and Medical Leave Act requests, workers' compensation claims, health insurance claims to self-insured employers, and voluntary disclosures by employees. Many states have tried to limit employer acquisition of genetic information or employer-sponsored genetic testing. They have used a variety of approaches. Some statutes are consistent with GINA in some respects but are less protective in others and are thus preempted by the federal law.

Many states have statutes that prohibit an employer from obtaining genetic information. *See, e.g.,* La. Rev. Stat. Ann. § 23:368 (2010) (employer may not "require, collect, or purchase" protected genetic information with respect to an employee); Mich. Comp. Laws Ann. § 37.1202 (West 2001) (no employer may "directly or indirectly acquire or have access to" an employee's or family member's genetic information unless an individual provides it voluntarily). These statutes do not, however, provide as extensive protection as GINA, which additionally prohibits employers from *asking* for genetic information. The rationale for this protection is that in the context of at-will employment the need to retain one's job may turn an employer's request for genetic information into a demand that an employee dare not refuse. There are some state statutes that, like GINA, do prohibit such requests. *See, e.g.,* Conn. Gen. Stat. Ann. § 46a-60(11) (West 2009) (employer may not "request or require" genetic information from employee); Nev. Rev. Stat. Ann. § 613.345 (LexisNexis 2006) (unlawful employment practice to "ask or encourage" an employee to submit to a genetic test).

While GINA prohibits certain uses of genetic information, it also places a value on employee privacy and, subject to limited exceptions, prohibits the acquisition of genetic information without regard to its use. 42 U.S.C. §§ 2000ff-1(b), 2000ff-2(b), 2000ff-3(b), 2000ff-4(b) (Supp. II 2008). This act follows the same approach. Many state statutes prohibit employers from obtaining information, and may also prohibit requests, but arguably they are not as protective as GINA because they prohibit employers from acquiring genetic information only in the context of certain uses. *See, e.g.,* Idaho Code Ann. § 39-8303 (Supp. 2009) (employer may not "access or otherwise take into consideration" private genetic information in connection with an employment decision); Kan. Stat. Ann. § 44-1009(a)(9) (2008) (employer may not seek to obtain, obtain, or use testing information to distinguish employees or restrict a right or benefit); Md. Code Ann., State Gov't § 20-606(a)(3) (LexisNexis 2009) (employer may not "request or

require" genetic information as a condition for hiring or determining benefits); Mass. Ann. L. Art. 151B § 4(19) (LexisNexis 2008) (unlawful to "collect, solicit or require disclosure of genetic information" as a condition of employment or "question a person about their genetic information or genetic information concerning their family members"); Minn. Stat. Ann. § 181.974(subd. 2) (West 2006) (employer may not "request, require, or collect" protected genetic information as a condition of employment); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis 2007) (employer may not require genetic information as a condition of employment or promotion); Utah Code Ann. § 26-45-103 (2007) (employer may not "access or otherwise take into consideration" private genetic information in connection with an employment decision); Wash. Rev. Code Ann. § 49.44.180 (West 2008) (unlawful to require employee to submit genetic information as condition of employment).

Unlike GINA, however, many states broadly prohibit employers from subjecting employees to genetic testing. *See, e.g.*, Kan. Stat. Ann. § 44-1009(a)(9) (2008) (employer may not subject, directly or indirectly, any employee to any genetic screening or test); R.I. Gen Laws § 28-6.7-1 (2003) (employer may not "request, require, or administer" a genetic test). Again, however, many other states prohibit genetic testing only for certain uses or when it is a condition of employment, which arguably is not as protective as GINA. *See, e.g.*, Idaho Code Ann. § 39-8303 (Supp. 2009) (employer may not "request or require" an individual or the individual's blood relative to submit to a genetic test in connection with an employment decision); Iowa Code Ann. § 729.6 (West 2003 & Supp. 2010) (employer may not "solicit, require, or administer" a genetic test as a condition of employment); Md. Code Ann., State Gov't § 20-606(a)(3) (LexisNexis 2009) (employer may not "request or require" genetic tests as a condition for hiring or determining benefits); Mass. Ann. Laws ch. 151B, § 4(19) (LexisNexis 2008) (unlawful to "solicit submission to, require, or administer a genetic test" as a condition of employment); Mich. Comp. Laws Ann. § 37.1202 (West 2001) (no employer may require a genetic test as a condition of employment); Minn. Stat. Ann. § 181.974(subd. 2) (West 2006) (employer may not "administer a genetic test" as a condition of employment); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis 2007) (employer may not require a genetic test as a condition or employment or promotion); Nev. Rev. Stat. Ann. § 613.345 (LexisNexis 2006) (unlawful employment practice to "require or administer" a genetic test as a condition of employment); N.H. Rev. Stat. Ann. § 141-H:3 (2005) (may not "solicit, require, or administer" genetic testing as a condition of employment); Utah Code Ann. § 26-45-103 (2007) (employer may not "request or require" an individual or blood relative to submit to a genetic test in connection with an employment decision); Vt. Stat. Ann. tit.18, § 9333 (2000) (may not require genetic testing as a condition of employment); Va. Code Ann. § 40.1-28.7-1 (2002) (employer may not "request, require, solicit, or administer" a genetic test as a condition of employment); Wash. Rev. Code Ann. § 49.44.180 (West 2008) (unlawful to require employee to submit to genetic screening as condition of employment); Wis. Stat. Ann. § 111.372 (West 2002) (employer may not "solicit, require, or administer" a genetic test as a condition of employment unless employee requests test).

Through their definitions of genetic information, which include information about access to genetic services, both GINA and this act allow employees to keep private information that could lead to discrimination based on assumptions about genetics, even in the absence of actual genetic test results. If an individual is unable to keep private his use of genetic services such as counseling, the individual may be deterred from obtaining this service for fear that an employer

will assume the employee has reason to think he has a genetic disorder. Protection of this information is consistent with existing provisions in a number of states that prohibit employers from acquiring or using information about an employee's request for or use of genetic services. *See, e.g.,* La. Rev. Stat. Ann. § 23:368 (2010) (employer may not "require, collect, or purchase" information about an employee's request for or use of genetic services); N.C. Gen. Stat. § 95-28.1A (2009) (unlawful to deny employment of account of request for genetic testing or counseling services); Utah Code Ann. § 26-45-103 (2007) (employer may not inquire into whether an individual or blood relative has taken or refused to take a genetic test); Idaho Code Ann. § 39-8303(1)(d) (Supp. 2009) (same); Vt. Stat. Ann. tit.18, § 9333 (2000) (employer may not use the fact that genetic counseling or tested services have been requested or performed).

Other states do not provide the protections required by GINA because they rely on state anti-discrimination statutes, which typically allow employers to compel testing or to require employees to provide genetic information under certain circumstances. Many of these states rely on disability statutes to regulate genetic information, usually following the ADA, which permits an employer to test an applicant and acquire an applicant's medical records after a conditional offer of employment. 29 C.F.R. § 1630.14(b) (2010). This approach opens the door broadly for employers to obtain genetic information once an employer has made a conditional offer of employment. In addition, under the ADA and most state statutes modeled on it, after an employee is hired, an employer can obtain medical information if it has a reasonable belief that the employee is unable to perform the essential functions of his or her job due to a medical condition. 29 C.F.R. § 1630.14(c) (2010). Some states have amended their employment discrimination statutes to include genetics. Under the rubric of these statutes, genetic testing or collection of genetic information is typically permitted when it is relevant to "job-related qualifications" or justified by "business necessity." The Drafting Committee considered and rejected these approaches because of a concern that tying the Act's protections to the concept of "job-related" medical information would not provide adequate protection for genetic information. In interpreting the ADA, some courts have interpreted the category of "job-related" medical information broadly, thus permitting employers to access medical information and narrowing the scope of protection.

The act's approach also contrasts with California's and Minnesota's more comprehensive limitations on employer access, which prohibit employers from accessing non-job-related medical information at any time. Cal. Gov't Code § 12940 (West 2005); Minn. Stat. Ann. § 181.974(subd. 2) (West 2006). An advantage of California's and Minnesota's approach is that it does not depend on how "genetic information" is defined. In addition, it does not rely on custodians of medical files to make a distinction between genetic information and medical information more generally, which are often mixed in medical files. Practically speaking, when an employee signs a release permitting employer access to medical records, everything in the records is included. There are those who maintain that legislation is needed to limit an employer's ability to obtain any non-job-related health information during the hiring process or employment. *See* Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 Hastings Center Report No. 4 (2005), at 35. The Drafting Committee discussed this approach, but declined to adopt it because it extends beyond the scope granted to the Committee.

Exceptions for genetic testing not incorporated into the act. There are two circumstances

of note for which the act does not provide an exception for genetic testing. The first is genetic testing for employee susceptibility to harm from a potential exposure in the workplace. Several states currently allow employers to provide genetic tests, with the consent of the employee, to screen for an employee's predisposing genetic characteristics that may create susceptibility to harm to the employee from a workplace condition. Iowa, Louisiana, New Hampshire, New York, and Wisconsin all have nearly identical provisions that permit genetic testing of an employee to determine an employee's susceptibility to toxic substances if the employee requests testing, provides informed consent or authorization, and the employer does not terminate the employee or take other adverse action as a result of testing. Iowa Code Ann. § 729.6(7) (West 2003 & Supp. 2010); N.H. Rev. Stat. Ann. § 141-H:3 (2005); N.Y. Exec. Law § 296 (McKinney 2010); Wis. Stat. Ann. § 111.372 (West 2002). This exception for testing was not included in the act because allowing additional testing of employees could be interpreted as providing less protection to employees than GINA, and the provision could thus be preempted by the federal statute. This interpretation is not certain, however, because the purpose of the testing would be to provide an employee with greater protection from harm in the workplace.

Second, the Drafting Committee also considered but decided not to include an exception that would permit employers to supply genetic testing in order to protect the safety of other employees in the workplace. The Committee's reasoning was that it would be very rare for a genetic variant to indicate a safety threat to other employees with sufficient certainty to justify a genetic test for that variant. The act does not, however, limit an employer's ability to take an employee's manifested medical condition into account for safety purposes, subject to the provisions of the ADA.

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.

Comment

This section authorizes an employee to purposely provide an employer with genetic information at the employee's initiative. It recognizes employee autonomy and is designed to be protective of an employee. For example, an employee might seek to submit information to

support a request for reassignment to avoid exposure to a chemical to which the employee has a genetic susceptibility. The section limits use by the employment entity to the purposes specified in the employee's authorization.

Some voluntary submissions of genetic information by an employee might qualify as an inadvertent submission under Section 5(b). This section, however, eliminates any doubt about the employer's liability when an employee submits genetic information at the employee's own initiative.

Employees who provide genetic information voluntarily may do so directly, through oral statements or by turning over reports of test results. They may also do so indirectly by permitting an employment entity to obtain medical records held by a third party. The authorization required in this section parallels the authorization requirements that apply under GINA when an employee provides genetic information to an employment entity as part of a wellness program or for a genetic monitoring program that is based on employee consent. In addition, when medical records are provided to an employment entity by a third party, it is likely that the third party will be a covered entity under HIPAA and the employee will need to authorize the disclosure under HIPAA privacy regulations.

SECTION 7. EXCEPTION FOR INFORMATION UNDER FAMILY MEDICAL LEAVE ACT. An employment entity may request or require relevant family medical history from an employee:

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

(2) under a policy of the employment entity that is applicable to all employees and that permits an employee to use leave to care for a sick family member and requires an employee to substantiate the need for leave by providing information about the health condition of the family member.

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

Comment

This section parallels an acquisition exception in GINA. 42 U.S.C. §§ 2000ff-1(b)(3), 2000ff-2(b)(3), 2000ff-3(b)(3), 2000ff-4(b)(3) (Supp. II 2008). The exception is necessary because an employee seeking leave to care for an ill relative is asked about the relative's illness

on Family Medical Leave Act (FMLA) certification forms and this information falls within the act's definition of family medical history. The exception is limited to requests for family medical history and does not cover other types of genetic information such as genetic tests.

Some small employers may not be covered by the FMLA or a state equivalent. Under the regulations implementing GINA, these employers may request genetic information pursuant to a voluntary leave policy that allows for care of a sick family member if the voluntary policy qualifies for this exception. The employment entity's policy must require all employees to provide information about the health condition of the family member in order to substantiate the need for leave. 29 C.F.R. § 1635.8(b)(3).

SECTION 8. EXCEPTION FOR INFORMATION IN PUBLIC DOCUMENT.

(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 family member of an employee.

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

Comment

This section parallels an acquisition exception in GINA, which allows employers to acquire family medical history when employers "purchase" commercially available materials that may contain family medical history. 42 U.S.C. §§ 2000ff-1(b)(4), 2000ff-2(b)(4), 2000ff-3(b)(4), 2000ff-4(b)(4) (Supp. II 2008). While GINA's exception is expressly limited to requests for family medical history, the implementing regulations expand it to include any genetic information on the theory that it should not matter whether a document reveals the results of a genetic test or a relative's disease. 75 Fed. Reg. 68912, 68924 (Nov. 9, 2010). This section follows the approach in the regulations. 29 C.F.R. § 1635.8(b)(4).

GINA explicitly lists newspapers, magazines, periodicals, and books as "excused" media. The regulations expand the list of excused media to include electronic media such as the internet, television, and movies. 29 C.F.R. § 1635.8(b)(4). The Drafting Committee considered the expanded list of excused media contained in the proposed regulations and decided to follow the more limited list specified in GINA. However, this list is not meant to be exclusive, as signaled by the introductory word "including."

The exception in this section differs from GINA in that it is not limited to the *purchase* of media on the excused list. If an employment entity reads about an employee in a newspaper, it should not matter whether the newspaper was purchased, free, or available in a waiting room. Therefore, employment entities are not in violation of the act if they obtain this material without

cost. The implementing regulations similarly do not require an employment entity to purchase the material.

The exception in this section is not, however, intended to protect an employment entity that is searching for genetic information. Thus it does not apply when an employment entity consults a media source with the intention of learning genetic information. It also does not apply if an employment entity is likely to acquire genetic information by consulting a particular media source, such as a web site or discussion group that focuses on issues such as genetic testing of individuals.

GINA explicitly excludes medical databases and court records from the list of media that employers may consult even though they contain genetic information. The Drafting Committee considered whether it is appropriate to restrict employer access to court records that contain genetic information. One the one hand, court records are public records and the Drafting Committee was concerned that statutorily prohibiting purchase of court records by employment entities raises issues under the First Amendment and the principle of open courts. On the other hand, the inclusion of genetic information in court records does pose a threat to employee's privacy in that data miners obtain information from court records to sell to employers, landlords, and others, and not all courts have adopted strong policies to redact genetic information from court records. The Drafting Committee concluded that if this act omitted GINA's exclusion for purchasing court records, then this provision would be less protective of employees than GINA and preempted by the federal statute. Therefore, this act prohibits employment entities from acquiring genetic information by purchasing "court record databases." By narrowing the exclusion for court records to databases, this section protects against the potential harm to employees from data mining but clarifies that the provision is not meant to prevent access to a single court record that is relevant for an employer even thought it happens to contain genetic information.

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 in accordance with Section 13 for use in providing voluntary health or genetic services to the employee or family member, 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 is

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

(3) individually identifiable genetic information is provided only to one or more of the following:

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

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

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

(4) except for a disclosure under paragraph 3(C), genetic information may not be disclosed to the employment entity except in an aggregate form that does not disclose the identity of the individual employee or family member.

Comment

This section permits an employer that provides preventative health services to encourage a healthy workplace to include genetic testing and other genetic services as part of its program. These provisions are intended to encourage employers to provide their employees access to genetic services in this way. The employment entity must, however, meet the requirements listed in the statute as a prerequisite to acquiring genetic information or providing genetic testing for this purpose. The requirements in the section are similar to those in GINA. 42 U.S.C. §§ 2000ff-1(b)(2), 2000ff-2(b)(2), 2000ff-3(b)(2), 2000ff-4(b)(2) (Supp. II 2008).

GINA provides that an employment entity may offer health or genetic services as part of a wellness program. This act follows the implementing EEOC regulations by limiting the application of this section to wellness programs that are voluntary. 29 C.F.R. § 1635.8(b)(2). The EEOC interprets "voluntary" to mean that an employment entity may offer certain inducements, including certain financial inducements, to encourage individuals to participate in health or genetic services. But they may not offer an inducement to provide genetic information. Thus a health risk assessment that asks for family medical history, must make clear that the inducement is available without answering these questions. *See* 29 C.F.R. § 1635.8(b)(2)(ii). In addition, employment entities may offer a program or inducement designed to encourage an individual to meet health goals (such as a weight, blood pressure level, or cholesterol level). But they may not offer this program based on genetic information voluntarily provided by an employee unless they also offer it to individuals with current health conditions and those whose

lifestyle puts them at risk of acquiring a condition. *See* 29 C.F.R. § 1635.8(b)(2)(iii).

As under GINA, the act requires employee authorization before genetic information can be used in providing health or genetic services. Requirements for employee authorization for genetic testing and for acquisition of genetic information are set forth in Section 14. The act also provides additional protections not found in GINA. In Section 13, it requires employers to provide genetic counseling about the risks and benefits of the test before an employee considers signing the authorization for testing. The purpose of this counseling is so that the employee can make an informed decision about whether or not to have the test. An employee may, however, decline the counseling. In addition, Section 13 mandates additional protections whenever an employment entity provides genetic testing. These protections apply to both health or genetic services offered by an employment entity and to genetic monitoring programs.

In subsection 3(C), the act includes GINA's provision permitting access for a health-care professional involved in providing the services for the employment entity. Employer-provided genetic services should ideally be conducted by professionals (typically genetic counselors, geneticists, or physicians) from outside the employer organization. This act is not intended, however, to regulate the practice of medicine, and so it does not directly forbid an employer from using employees to provide these services. This subsection covers the situation in which employees provide these services by permitting a health-care professional providing genetic services for the employment entity to obtain the genetic information of participating employees.

The intent of the act is to segregate individually identifiable genetic information so that it is used only in providing genetic services and so that others in the employment entity do not have access to it. Hence, any genetic information otherwise acquired by the employment entity must be in an aggregate form that does not disclose the identity of the individual.

In addition to this section and GINA's employment provisions and implementing regulations, Title I of GINA places restrictions on the genetic information that group health plans may request or require from covered individuals. Employment entities that sponsor or maintain group health plans that implement wellness programs should consult the regulations issued by the Department of Labor, the Department of Health and Human Services, and the Department of the Treasury concerning limitations on acquisition of genetic information by group health plans.

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 notice in a record 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) [this state's genetic monitoring law], including state rules required by 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 one or more of 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) except for a disclosure under paragraph 5(C), genetic information may not be disclosed to the employment entity except in an aggregate form that does not disclose the identity of the employee.

Comment

Monitoring for damage to employees' genes from workplace exposure to harmful substances is an accepted reason for genetic testing in the workplace. Genetic monitoring

programs are typically undertaken by employers to identify risks for groups of employees who have been exposed to hazardous substances or to target work sites for safety and health measures. Monitoring is testing designed to detect whether the genetic material of a group of individuals has changed over time. The premise is that such changes could indicate increased risk of future illness. Aggregated data from tests for genetic damage is sufficient to allow an employer to reduce exposures to levels that do not affect individuals' chromosome morphology or DNA. Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* 66 (1990). However, while monitoring may have predictive value for a group, the techniques that are used do not currently measure increased individual health risks.

The intent of the act is to segregate genetic information so that individually identifiable information is used only in conducting monitoring and others in the employment entity do not have access to it in an individually identifiable form. Hence, any genetic information acquired by the employment entity (other than by a medical professional who is involved in the monitoring) must be in an aggregate form that does not disclose the identity of the individual.

Relationship of this section to GINA. This section is consistent with GINA's provisions that permit employment entities to monitor genetic effects of workplace exposures. 42 U.S.C. §§ 2000ff-1(b)(5), 2000ff-2(b)(5), 2000ff-3(b)(5), 2000ff-4(b)(5) (Supp. II 2008). Both GINA and this act permit employer access only to aggregate genetic data, with an exception for health-care employees administering the monitoring. Employer-provided genetic monitoring should normally be conducted by professionals (typically genetic counselors, geneticists, or physicians) from outside the employer organization. However, because the act does not directly forbid an employer from using employees to conduct monitoring it contains an exception allowing the health-care professional providing genetic monitoring to obtain the genetic information of participating employees.

Genetic testing by an employment entity is not explicitly authorized in GINA, but is a form of acquisition of genetic information. This section provides that any testing for purposes of genetic monitoring is to be performed in compliance with Section 13, which provides protections for the employee that go beyond those in GINA.

Reference to federal genetic monitoring regulations. GINA, and this act, require that an employment entity's genetic monitoring program must comply with federal regulations governing genetic monitoring programs. The intent is to include future federal regulations and amendments. In some states a provision that requires compliance with future law or regulations constitutes an unconstitutional delegation of legislative power. In these states, this problem can be avoided by omitting the term "as amended."

Existing State law and its relationship to GINA. A number of states permit genetic monitoring, provided that the employee requests testing, provides informed consent or authorization, and the employer does not terminate the employee or take other adverse action as a result of testing. Iowa Code Ann. § 729.6(7) (West 2003 & Supp. 2010); N.H. Rev. Stat. Ann. § 141-H:3 (2005); N.Y. Exec. Law § 296 (McKinney 2010); Wis. Stat. Ann. § 111.372 (West 2002). In addition, Louisiana authorizes monitoring of biological effects of toxic substances in the workplace if the employee has provided authorization and is notified of the results. La. Rev.

Stat. Ann. § 23:368 (2010). More generally, the definitions and prohibitions in many states' statutes do not appear to restrict monitoring for genetic damage, or are ambiguous on this issue. Thus currently many state statutes do not appear to provide safeguards for employees consistent with GINA.

SECTION 11. EXCEPTION FOR CERTAIN EMPLOYERS THAT CONDUCT DNA ANALYSES. An employer that conducts DNA analyses for law enforcement purposes at a forensic laboratory or for the purpose 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.

Comment

This section allows a limited subset of employers – those that perform genetic testing for identification for law enforcement purposes or to identify human remains – to collect DNA samples from employees in order to check for contamination of the forensic samples with the employees' DNA. This is a narrow exception: testing for the purposes of quality control in an identification laboratory should be limited to specific markers on the genome used for identification, which are not thought to have any medical or predictive significance. The types of employees affected by this exception are those described in Section 2(3)(a)(i) and (iv): traditional employees and trainees. The section is consistent with GINA. 42 U.S.C. §§ 2000ff-1(b)(6), 2000ff-4(b)(6) (Supp. II 2008).

[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 in the proceeding 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 is otherwise unavailable;

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

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

Comment

This bracketed section allows an employment entity to obtain an employee's genetic information that is relevant to a claim or defense in a legal proceeding, through testing if necessary, if the employee places the employee's health at issue in a legal proceeding. GINA does not have a parallel provision. The section supplements GINA by providing standards that give an employee greater protection than that afforded by civil litigation discovery standards for medical testing.

The employer's ability to acquire genetic information under this section is limited in that it applies only if the employer has satisfied the burden of proof to show that the genetic information is necessary in the interests of justice and that the information is otherwise unavailable. Only that portion of an employee's genetic information that is relevant to a claim or defense may be provided. These procedures provide more protection than Rule 35 of the Federal Rules of Civil Procedure or state equivalents, which provide that a court may order a physical examination on motion for good cause shown. In addition, the genetic information must be sealed or placed under a protective order.

The section requires the employer to pay for a genetic test if one is ordered when the test is requested by motion of the employer. This provision is not intended to limit a tribunal's discretion to order payment for a genetic test if the test is ordered by the tribunal on its own motion.

The substance of the section follows Utah's statute, which authorizes genetic testing when an employee has placed the employee's health at issue in a proceeding, but only by order of a court or administrative agency after finding compelling need and that the information is otherwise unavailable. Utah Code Ann. § 26-45-103(2) (2007).

The section is placed in brackets because in some states the legislature may be limited in its ability to alter state court rules of procedure. It should also be noted that the applicability of the section in federal court might depend on application of the *Erie* doctrine by the federal courts.

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 under Section 9 or for genetic monitoring under Section 10 shall:

(1) provide genetic counseling about the risks and benefits of a genetic test before the

individual 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 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 the 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.

Comment

This section provides the employee with protections in the event that an employment entity provides testing as part of health or genetic services under Section 9 or a genetic monitoring program under Section 10. These protections supplement GINA's provisions on acquisition of genetic information in conjunction with employee health programs and genetic monitoring.

An employment entity that provides genetic testing under one of these exceptions should supply it through an outside medical organization. *See* Mark A. Rothstein, *Genetics and the Workforce of the Next Hundred Years*, 2000 Colum. Bus. L. Rev. 371 (2000). This may not, however, always be the case, which makes it particularly important to protect employee privacy in wellness and monitoring programs.

Paragraph (1) mandates genetic counseling before genetic testing as part of an employee wellness program and before genetic monitoring is conducted with an employee's authorization. It provides that an employee must have genetic counseling prior to authorizing a genetic test in order to be able to make an informed decision about the risks and benefits of the test and the knowledge that would result. This entails the counseling functions defined in subparagraphs (A) through (C) of the definition of genetic counseling in Section 2(10). An employee has the right to refuse this counseling, but only after being informed of the benefits of the counseling. Genetic counseling may be provided by a genetic counselor, but may also be provided by a qualified physician or geneticist.

Paragraph (2) provides for reporting genetic test results to the employee when an employment entity supplies testing. Not all individuals, however, wish to know their genetic information; some may decide not to learn test results because of the psychological burdens that may accompany such knowledge. So the act also recognizes an employee's right to decline to know the results of a genetic test.

Paragraph (3) mandates the availability of genetic counseling so that the test results can be interpreted for the employee if the test result indicates a disease or disorder or an increased risk for a disease or disorder. This entails the counseling functions defined in subparagraphs (D) and (E) of the definition of genetic counseling in Section 2(10). Again, genetic counseling may be provided by a genetic counselor, but may also be provided by a qualified physician or geneticist.

Paragraph (4) provides for destruction of the sample obtained for testing. The prompt destruction of a sample obtained for genetic testing supplied by an employer protects the employee's privacy by preventing subsequent testing of the sample. The subparagraphs recognize exceptions. For example, a testing laboratory is required to retain samples for certain time periods for certification testing and other purposes. The provision follows statutes adopted in New Jersey and Oregon. N.J. Stat. Ann. § 10:5-46 (West 2002); Or. Rev. Stat. § 192.537 (2007).

The Drafting Committee considered and rejected alternative approaches that (1) put the burden on the employee by requiring that the sample be destroyed promptly on the request of the

individual tested or (2) specify that a sample may be retained for a period of time. Some current state provisions combine elements of more than one approach. In New York, for example, a sample may be retained for ten years if authorized by the individual from whom the sample was obtained. The Drafting Committee decided that the placing the burden for destruction of the sample on the employment entity best protects an employee's privacy.

Paragraph (5) addresses advances in testing methodology. Current technology using "chips" now typically collect information from multiple portions of the genome that can be analyzed to examine for a suite of potential genetic traits. Before long, it may be economically feasible for genetic testing to routinely involve a full genome scan. This means that a machine has generated a great deal of genetic information, even if it is not all analyzed by a bioinformatics system or used by the medical professional interpreting the tests that were authorized by the individual. Under paragraph (5), this information should be destroyed along with the biological sample if it is not relevant to the authorized tests. Again, the paragraph also recognizes, however, that the individual tested may want this information retained or that a testing laboratory may be required to retain this information for a certain time period.

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 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 before 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 individual under federal law or the law of this state. The employment entity shall provide a copy of the authorization to the individual who signed the authorization.

(b) An authorization for an employment entity to acquire genetic information of an employee or family member of the 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 of an employee or family member of the employee 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 retention is permitted by law other than this [act] or 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 retention is permitted by law other than this [act] or 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.

Comment

This section sets forth an authorization requirement for genetic testing and certain acquisitions of genetic information by an employment entity and specifies the elements that must be contained in an authorization form. It applies to the situations in which an employment entity is permitted to acquire genetic information or conduct genetic testing with the consent of the employee or family member of the employee: providing genetic services as part of a wellness program, conducting a genetic monitoring program, and (for acquisition only) at the employee's behest. This authorization requirement, coupled with statutory limits and duties imposed on employment entities by the act, is designed to maintain privacy for genetic testing and genetic information. It does not, however, substitute for otherwise applicable authorization requirements such as those mandated by HIPAA for covered entities under that statute. The term

"authorization" is used instead of "informed consent" to avoid confusion with the use of that term in medical practice.

The Drafting Committee considered, but did not adopt, alternatives to authorization that would (1) establish a general property right in a biological sample an individual provides for genetic testing and in the resulting genetic information or (2) establish a limited property right in genetic information applicable only to the context of employment.

Relationship to GINA. GINA requires employee authorization when an employer acquires genetic information in connection with providing health or genetic services and when an employer conducts a monitoring program that is not required by law. This section requires employee authorization in the same circumstances, and also when an employee voluntarily provides genetic information under Section 6. In addition, this section is more protective than GINA's requirements for authorization in that it also requires a separate authorization for genetic testing.

The requirements in this section for the content of an employee's authorization are consistent with the requirements in GINA and its implementing regulations. GINA requires an employee authorization that is "prior, knowing, voluntary, and written." 42 U.S.C. §§ 2000ff-1(b)(2)(B), 2000ff-1(b)(5)(B)(i), 2000ff-2(b)(2)(B), 2000ff-2(b)(5)(B)(i), 2000ff-3(b)(2)(B), 2000ff-3(b)(5)(B)(i), 2000ff-4(b)(2)(B), 2000ff-4(b)(5)(B)(i) (Supp. II 2008). The GINA regulations further require that the authorization be written so that the person from whom the genetic information is being obtained is reasonably likely to understand the form; that the form describe the type of genetic information that will be obtained and the general purposes for which it will be used; and that the form describe the restrictions on disclosure of genetic information. 29 C.F.R. § 1635.8(b)(2)(i), (b)(5)(i).

Subsection (a) Requirement for authorization for acquisition of genetic information and for genetic testing. Subsection (a) sets forth the basic requirements that authorization must be knowing and voluntary and memorialized in a record before the acquisition or testing. It limits an employment entity's use of genetic information and the tests it provides to those specified in the authorization and makes clear that the authorization should not be interpreted to waive any of the employee's rights. An employment entity's use of genetic information or analysis of a genetic test is legal only if the employee's authorization is valid and meets the requirements of this section.

When an employee is considering authorizing genetic testing, the employee should have genetic counseling before signing the authorization in order to meet the requirement of this subsection that an authorization is knowing and voluntary. Genetic counseling provides employees with adequate information to make an informed decision about genetic testing. It also makes them aware of their options regarding reporting of test results and help in interpreting them through genetic counseling. An employment entity that offers a genetic test as part of a health program or genetic monitoring program has an obligation under Section 13 to provide genetic counseling. Genetic counseling may be provided by a genetic counselor, but may also be provided by a qualified physician or geneticist. An employee may waive genetic counseling, but must first be made aware of the benefits of genetic counseling.

The power to authorize inherently and of necessity includes to power to revoke and the employee may revoke this authorization at any time.

There might be circumstances in which an individual is incapacitated or incapable of authorizing a genetic test. Other law of the state may provide for a substitute decisionmaker or signer for the authorization if the employee is incapacitated or incompetent. Revocation of an authorization by a substitute is similarly left to existing law of the state that governs power of attorney, guardianship, or other substitute decision makers.

Subsection (b) Content of authorization for acquisition of genetic information. This subsection follows the GINA requirements for authorization for acquisition of genetic information and is consistent with the implementing regulations.

Subsection (c) Content of authorization for genetic testing. Before any genetic testing can be performed, unless the testing is required by law, an employee must affirmatively authorize the genetic testing and the employment entity's acquisition of the resulting genetic information. Sections 9 and 10 provide for limited situations in which employment entities may request authorization for testing from employees: an employment entity may supply genetic tests as part of health or genetic services, but only with prior authorization from the employee, and as part of a genetic monitoring program, but only if required by law or with prior authorization from the employee.

This subsection builds on the GINA requirements for authorization for acquisition of genetic information so that it applies to the situation when that acquisition involves offering a genetic test. It draws on New York law that establishes requirements for consent for a genetic test. N.Y. Civ. Rights Law § 79-*l* (McKinney 2009).

The requirements in subsection (c)(3), (4), (5), (7), and (8) reflect the obligations of the employment entity to provide genetic counseling under Section 13.

The notification provisions regarding destruction of the sample and ancillary testing data in subsections (c)(10) and (11) are consistent with the employment entity's obligation to ensure that the sample and this data are destroyed under Section 13, which recognizes that the testing laboratory may be required to retain the sample or data for certification purposes.

SECTION 15. FORM FOR AUTHORIZATION FOR ACQUISITION OF GENETIC INFORMATION. A completed and signed authorization substantially in the following form 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: _____.
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:
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: _____.
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 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 (1) to certain health researchers, (2) to government officials investigating compliance with laws protecting the privacy of genetic information or prohibiting genetic discrimination, (3) to a public health agency if the information 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

Comment

This section provides guidance to employment entities on appropriate content for forms. The use of a form following the pattern in this section, when properly completed and signed, complies with the requirements of Section 14. The form is consistent with the requirements of the GINA regulations that the authorization be written so that the person from whom the genetic information is being obtained is reasonably likely to understand the form; that the form describe the type of genetic information that will be obtained and the general purposes for which it will be

used; and that the form describe the restrictions on disclosure of genetic information. 29 C.F.R. § 1635.8(b)(2)(i), (b)(5)(i).

SECTION 16. FORM FOR AUTHORIZATION OF GENETIC TESTING. A completed and signed authorization substantially in the following form 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: _____.
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: _____.
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 highly 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]
Name of employment entity

genetic 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 (1) to certain health researchers, (2) to government officials investigating compliance with laws protecting the privacy of genetic information or prohibiting genetic discrimination, (3) if expressly ordered by a court, arbitral tribunal, or administrative agency, or (4) 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

CHOOSE ONE:

____ I wish to receive test results.

____ I do not wish to receive test results.

CHOOSE ONE:

____ 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

Comment

This section provides guidance to employers on appropriate content for forms. The use of a form following the pattern in this section, when properly completed and signed, complies with the requirements of Section 14. The form is consistent with the requirements of the GINA regulations that the authorization be written so that the person from whom the genetic information is being obtained is reasonably likely to understand the form; that the form describe the type of genetic information that will be obtained and the general purposes for which it will be used; and that the form describe the restrictions on disclosure of genetic information. 29 C.F.R. § 1635.8(b)(2)(i), (b)(5)(i).

SECTION 17. PROHIBITION OF USE OF GENETIC INFORMATION.

(a) An employer may not take an adverse employment action against an employee as described in Section 2(3)(A)(i) based on the employee's genetic information, including failing or refusing to hire, discharging, or discriminating against the 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 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 an investigation, proceeding, or hearing under the Genetic Information Nondiscrimination Act, 42 U.S.C. Section 2000ff et seq., or this [act].

Comment

This section is based on the anti-discrimination provisions in GINA, supplemented to prohibit employment entities from taking any adverse employment action based on genetic information.

GINA has a separate statutory section defining unlawful employment practices for each type of employment entity. 42 U.S.C. §§ 2000ff-1(a), 2000ff-2(a), 2000ff-3(a), 2000ff-4(a) (Supp. II 2008). This section consolidates the provisions as much as possible while using the terminology of GINA.

Subsections (a) through (d) Prohibition of adverse employment decisions. Both GINA and this act prohibit the specific actions listed in each subsection. In addition, this act also more generally prohibits adverse employment actions in order to make sure that employee protections are not limited by omission of an employment action from the list in GINA. The lists of prohibited actions taken from GINA are not exclusive. The word "including" should be read as "including, but not limited to."

"Adverse employment decision" is a term of art in employment law. The term should be interpreted broadly. One example of a broad statement of adverse employment actions can be found in the District of Columbia Human Rights Act, which makes it a discriminatory practice for an employer "[t]o fail or refuse to hire, or to discharge, any individual; or otherwise to discriminate against any individual, with respect to his compensation, terms, conditions, or privileges of employment, including promotion; or to limit, segregate, or classify his employees in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee." D.C. Code § 2-1402.11 (2008).

Subsection (e) Credentialing authorities. Subsection (e) governing credentialing authorities is a supplement to GINA. The provision provides employees greater protection.

Subsection (f) Limiting, segregating, or classifying. Subsection (f) is drawn from the language in GINA that bars employment entities from taking action that may limit, segregate, or classify employees because of genetic information. 42 U.S.C. §§ 2000ff-1(a)(2), 2000ff-2(a)(2), 2000ff-3(a)(2), 2000ff-4(a)(2) (Supp. II 2008). These actions are prohibited if they adversely affect the status of an employee regardless of the intent of the employment entity. If a state enacts bracketed Section 24, however, an employee will have no private right of action as a remedy for disparate impact, which would be a way of enforcing this subsection.

Subsection (g) Causing an employer to discriminate. Subsection (g) is drawn from language in GINA that prohibits employment entities from causing an employer to discriminate on the basis of genetic information. 42 U.S.C. §§ 2000ff-2(a)(3), 2000ff-3(a)(3), 2000ff-4(a)(3) (Supp. II 2008).

Subsection (h) Retaliation. GINA does not contain the prohibition on retaliation in subsection (h), but the EEOC has added the concept in the implementing regulations. 29 C.F.R. § 1635.7. This omission from the statute illustrates the dangers of enumerating adverse employment actions and the importance of adding the clauses in this section that generally prohibit adverse employment actions. This act's prohibition on retaliation provides employees greater protection than GINA and is consistent with other federal law. The federal standard for protection against retaliation under Title VII was established in *Burlington Northern & Santa Fe Ry. V. White,* 548 U.S. 53 (2006), which held that an individual is protected from conduct, related to employment or not, that "well might have 'dissuaded a reasonable worker from making or supporting a charge of discrimination.'" *Id.* At 57-58 (citations omitted).

Susceptibility to workplace exposures. The restrictions on employment actions in GINA and this act will dispel uncertainty about how courts would otherwise apply federal statutes to employment decisions based on genetic information that predicts employee susceptibility to harm from workplace exposures. On one hand, in 1991 the United States Supreme Court held that a chemical company's policy barring women of child-bearing age from employment opportunities that involved exposure to lead violated Title VII prohibitions on gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187 (1991). On the other hand, the ADA allows employers to act on health information, even in the case of disability, when there is a direct threat to the health or safety of others in the workplace. The Equal Employment Opportunity Commission (EEOC) has interpreted this ADA provision to apply when there is no risk to others but when an employer can show that an individual's disability poses a significant risk of harm to the individual. The United States Supreme Court upheld this interpretation. *Chevron v. Echazabal*, 122 S. Ct. 2045 (2002). Although the *Echazabal* case did not involve a genetic characteristic, but rather a worker's liver damage due to exposure to workplace solvents, the implication of the case is that in the absence of a prohibition in a state statute, an employer may make adverse employment decisions based on genetic information if there is risk to the employee even if there is no threat to others. This section does not permit an employer to take an adverse employment action under these circumstances. Harm to the employee or to others is not a justification. As a result, employers would not be able to use an employee's genetic

information in the way the employee's health information was used in the *Echazabal* case.

Manifested disease or condition. The section does not necessarily prevent an employer from making decisions based on the effects of an employee's manifest genetic condition or disease in the workplace. Section 4 provides that employment entities may acquire and use medical information about a manifested disease, even one with a genetic basis, if that medical information is not genetic information. In addition to the protections of this act, some employees with manifest genetic conditions would be covered under the protections of the ADA. But there is no comprehensive protection for individuals with medical conditions that result from genetic traits. While some maintain that attempts to prevent genetic discrimination are mostly meaningless without protection for people who have genetic diseases, *see* Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why They are so Hard to Protect,* 26 J. L. Med. & Ethics 181 (1998), others emphasize the difficulties with either policy choice, *see* Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1503 (2001).

Existing state law. Many state statutes limit use of genetic information by prohibiting discrimination among employees or applicants for employment on the basis of genetic information. Ark. Code Ann. § 11-5-403 (2002); 410 Ill. Comp. Stat. Ann. 513/25 (West 2005 & Supp. 2010); Kan. Stat. Ann. § 44-1009 (2008); La. Rev. Stat. Ann. § 23:368 (2010); Me. Rev. Stat. Ann. tit. 5, § 19302 (2002); Md. Code Ann., State Gov't § 20-606 (LexisNexis 2009); Mass. Ann. Laws ch. 151B, § 4 (LexisNexis 2008); Mich. Comp. Laws Ann. § 37.1202 (West 2001); Mo. Ann. Stat. § 375.1306 (West 2002); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis 2007); Nev. Rev. Stat. Ann. § 613.345 (LexisNexis 2006); N.J. Stat. Ann. § 10:5-12 (West 2002 & Supp. 2010); N.Y. Exec. Law § 296 (McKinney 2010); N.C. Gen. Stat. § 95-28.1A (2009); Okla. Stat. Ann. tit. 36, § 3614.2 (West 1999); Or. Rev. Stat. § 659A.303 (2007); R.I. Gen. Laws § 28-6.7-1 (2003); S.D. Codified Laws § 60-2-20 (2009); Tex. Lab. Code Ann. § 21.402 (Vernon 2006). However, these statutes do not all provide protections as comprehensive as those in GINA and this act.

Other states do not limit their prohibitions to discrimination and more generally ban the use of genetic information in employment. Idaho Code Ann. § 39-8303(1)(a) (Supp. 2009) (employer may not consider private genetic information in connection with a hiring, promotion, retention, or other related decision); Iowa Code Ann. § 729.6(2) (West 2003 & Supp. 2010) (employer may not use genetic information to "affect the terms, conditions, or privileges of employment" of a person who gets a genetic test); Minn. Stat. Ann. § 181.974(subd. 2(a)(2)) (West 2006) (may not "affect the terms or conditions of employment or terminate the employment of any person based on protected genetic information"); N.M. Stat. Ann. § 24-21-4 (LexisNexis 2007) (unlawful for a person to use genetic information in employment); Utah Code Ann. § 26-45-103 (2007) (employers may not take into account genetic information about an individual in connection with an employment decision); Wis. Stat. Ann. § 111.372 (West 2002) (may not "affect terms, conditions or privileges of employment, labor organization membership or licensure or terminate the employment or labor organization membership or licensure"). The coverage of this section is similar to these statutes because it prohibits adverse employment decisions.

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. The employment entity shall permit the employee to provide genetic information in a signed record to supplement or correct genetic information in the employment entity's record.

Comment

This section supplements GINA and is more protective of the employee than the federal statute. GINA allows employment entities to provide an employee's genetic information to the employee as an exception to its general prohibition on disclosure. 42 U.S.C. § 2000ff-5(b)(1) (Supp. II 2008). This section gives an employee a right to obtain this information. It is based on the rationale that an employee ought to be able to find out what genetic information an employer knows about an employee and to have the same information. It is modeled on Del. Code Ann. tit. 16, Section 1223 (2003).

This section also provides a mechanism for an employee to supplement or correct genetic information contained in employer records. The right to correct genetic information should be interpreted to include expungement of information that should not be in a particular record. For example, an employer may have incorrectly placed genetic information in an employee's personnel file instead of segregating it as required by Section 19.

If the employer supplied the genetic testing, information may also be kept in files at the laboratory that performed the testing. The employer's responsibility to correct errors does not extend to the testing laboratory, which is regulated under the Clinical Laboratory Improvement Amendments (CLIA). 42 U.S.C.§ 263a (2006).

The Drafting Committee considered but rejected an exception that would have prohibited employee access to information an employment entity has compiled for litigation. This situation will be governed by normal discovery rules, which are unaffected by this section.

SECTION 19. CONFIDENTIALITY AND RETENTION OF GENETIC INFORMATION. Except for genetic information an employment entity obtains in aggregate form under Section 9 or Section 10, the following rules apply:

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

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

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

Comment

Aggregate information for wellness or genetic monitoring programs. Under Sections 9 and 10, an employment entity is allowed to acquire genetic information for the operation of a wellness program or a genetic monitoring program, but only in an aggregate form that does not identify individual employees. An employment entity may retain this aggregate information, which would not be associated with any employee's personnel file. Retention and disclosure of aggregate information may be necessary in order to analyze trends or take action to reduce risk in the workplace.

Paragraph (1) Confidentiality. This paragraph declares that genetic information, which includes family medical history, is confidential in the employment context. "Genetic information" is a category that includes information about use of or request for genetic services, so this section also protects an employee's authorizations concerning genetic tests or genetic information. This paragraph is consistent with GINA, which provides that genetic information shall be treated as a confidential medical record. 42 U.S.C. § 2000ff-5(a) (Supp. II 2008).

Paragraph (2) Retention of genetic information. This provision follows the approach of GINA and operates if an employer "possesses" of an employee's genetic information. 42 U.S.C. § 2000ff-5(a) (Supp. II 2008). The paragraph does not require an employee to authorize retention of the information. The protections apply to any record of an employee's genetic information maintained by the employment entity. They are not limited by the manner in which the employment entity obtained the genetic information and they apply to any genetic information from any source, even if the acquisition was inadvertent.

Employment entities may retain genetic information without the burden of obtaining employee authorization to maintain the information. They must protect the employee's privacy, however, by maintaining it as confidential information and by segregating this information from the employee's personnel file. The purpose of the segregation requirement is to protect confidentiality and reduce the chance that the information will be inadvertently disclosed along with other employee records. The segregation requirement applies to all records, which include electronic files as well as paper documents.

Paragraph (3) Coordination with the Americans with Disabilities Act. This provision follows GINA. 42 U.S.C. § 2000ff-5(a) (Supp. II 2008). There is a need for coordination with the ADA because many employers will acquire genetic information when they acquire an

employee's medical records, which they may request under the ADA after a conditional offer of employment or for job-related purposes during employment. Genetic information is likely to be interspersed throughout medical records and an employer that requests medical information is likely to receive an entire file, including genetic information. GINA addresses this by allowing employers to keep genetic information with confidential medical information acquired under the ADA so long as both types of information are retained as confidential records.

The cross-reference to the ADA as amended creates delegation issues in some states. The reference to amendments should be deleted in states where the cross-reference would constitute an unconstitutional delegation of legislative authority.

SECTION 20. DISCLOSURE OF GENETIC INFORMATION.

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

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

(1) to the employee or, if the genetic information is that of a family member, to the family member when authorized in a record signed by the employee or family member;

(2) to a person that the employee or, if the genetic information is that of a family member, 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 regulations 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 et seq., if the information is responsive to the official's request;

(6) to the extent the disclosure is made to comply with the certification provisions of Section 103 of the Family Medical Leave Act, 29 U.S.C. Section 2613[, or state family medical leave act];

(7) to a public health agency when the genetic information is family medical history that concerns 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 under Section 9 or genetic monitoring 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, an employment entity of the employee shall provide notice in a record to the employee or family member whose genetic information is disclosed if the disclosure is made under subsection (b)(4) or (7).

(d) An authorization for an employment entity to disclose genetic information of an employee or a family member of an employee must be knowing and voluntary and in a record signed by the individual. The authorization must:

(1) describe the genetic information to be disclosed;

(2) identify the person to which the genetic information is to be disclosed;

(3) indicate the duration of the authorization; and

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

(e) 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 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 family member who signed the authorization.

Legislative Note: *In subsection (b)(6), states should insert for [state family medical leave act] the appropriate name and citation for the state's act.*

Comment

This section follows the format of GINA, which contains a general prohibition on disclosure of genetic information by employers coupled with exceptions. 42 U.S.C. § 2000ff-5(b) (Supp. II 2008). It supplements GINA by permitting disclosures at the request of the employee and by providing for authorization of those disclosures.

Existing state law. A number of states that have enacted general privacy protections for genetic information that prohibit disclosure without informed consent or authorization. *E.g.,* Alaska Stat. § 18.13.010 (2008); Cal. Civ. Code § 56.10 (West 2007 & Supp. 2010); Del. Code Ann. tit. 16, § 1221 (2003); Fla. Stat. Ann. § 760.40 (West 2010); Me. Rev. Stat. Ann. tit. 22, § 1711-C (2004 & Supp. 2009); Mass. Ann. Laws ch. 111, § 70G (LexisNexis 2004); Minn. Stat. Ann. § 13.386 (West Supp. 2010); N.H. Rev. Stat. Ann. § 141-C:10 (2005); N.M. Stat. Ann. § 24-21-3 (LexisNexis 2007); N.Y. Civ. Rights Law § 79-*l* (McKinney 2009); Or. Rev. Stat. § 192.539 (2007).

Other states have specific protections against the disclosure of genetic information by employers. *E.g.,* Cal. Civ. Code § 56.20 (West 2007 & Supp. 2010); Ill. Comp. Stat. Ann. 513/25 (West 2005 & Supp. 2010); La. Rev. Stat. Ann. § 23:368 (2010); Mass. Ann. Laws ch. 151B, § 4 (LexisNexis 2008); R.I. Gen Laws § 28-6.7-1 (2003).

Subsection (a) General prohibition on disclosure of genetic information. This subsection follows GINA and establishes a blanket rule that employment entities may not disclose employee's genetic information, subject to limited exceptions.

Subsection (b) Permitted disclosures. This subsection sets forth the circumstances under which an employer may disclose an employee's genetic information.

Subsection (b)(1) permits an employment entity to disclose genetic information to the individual whom it concerns. This permission is consistent with the employee's right of access to the employee's genetic information established by Section 18. GINA includes a parallel provision. 42 U.S.C. § 2000ff-5(b)(1) (Supp. II 2008).

Subsection (b)(2) goes beyond GINA and respects employee autonomy by providing for disclosures to third parties when an employee requests the disclosure and provides a knowing and voluntary authorization.

The power to authorize inherently and necessarily includes the power to revoke and the employee may revoke this authorization at any time. Other law of the state may provide for a

substitute decisionmaker or signer for the authorization if the employee is incapacitated or incompetent. Revocation of an authorization by a substitute is left to existing law of the state that governs power of attorney, guardianship, or other substitute decision makers.

As a matter of good business practice, an employment entity should retain an employee's authorization for disclosure of genetic information. An authorization for disclosure of genetic information contains genetic information and so should be kept separately from the employee's personnel file.

Subsection (b)(3) is parallel to GINA, 42 U.S.C. Section 2000ff-5(b)(2) (Supp. II 2008), and permits disclosures to occupational and other health researchers so long as they comply with federal policy for protection of human research subjects.

Subsection (b)(4) is parallel to GINA, 42 U.S.C. Section 2000ff-5(b)(3) (Supp. II 2008), and permits disclosures to the extent ordered by a court, arbitral tribunal, or administrative agency. Disclosure of genetic information is limited to genetic information explicitly included in the terms of the order. The provision does not authorize other disclosures in connection with litigation such as in response to a discovery request, unless ordered by the tribunal. Subsection (c) requires the employer to give the employee notice of this disclosure unless the employee has otherwise received notice of the disclosure in the course of the legal proceedings.

Subsection (b)(5) is parallel to GINA, 42 U.S.C. Section 2000ff-5(b)(4) (Supp. II 2008), and permits disclosures to government officials investigating compliance with the act or with GINA.

Subsection (b)(6) is parallel to GINA, 42 U.S.C. Section 2000ff-5(b)(5) (Supp. II 2008), and permits disclosures made in conjunction with the Family Medical Leave Act or state or local leave law.

Subsection (b)(7) is parallel to GINA, 42 U.S.C. Section 2000ff-5(b)(6) (Supp. II 2008), and permits disclosure of family medical history to public health authorities in connection with a contagious disease that creates an imminent threat of death or life-threatening illness. This permits an employment entity to respond to a request from a public health office for medical information about the manifestation of a disease in an employee's family member in connection with a serious contagious disease. Without this provision, an employer would be barred from disclosing this information because it is family medical history and hence genetic information. If a disclosure is made under this subsection without other notice to the employee, the employer must provide notice to the employee under subsection (c).

Subsection (b)(8) permits disclosures of aggregate genetic information obtained as part of a health or genetic services program or a genetic monitoring program under Sections 9 or 10. This provision supplements GINA.

Subsection (c) Notice to employee of disclosures. This provision requires an employment entity to provide notice to an employee of disclosure of genetic information under limited circumstances when the employee or family member has not otherwise been notified. The

subsection is parallel to GINA. 42 U.S.C. § 2000ff-5(b)(3)(B), (b)(6) (Supp. II 2008).

Subsection (d) Authorization for disclosure of genetic information. An employee or employee's family member may request and authorize disclosure of their genetic information. This might happen, for example, if an employment entity possesses genetic information obtained as part of operating an employee wellness program and the employee would like to submit it to a third party. The general requirements for a valid authorization are the same as those for authorizations of acquisition of genetic information or genetic testing under Section 14. The authorization is relatively simple, but must describe the genetic information to be disclosed, identify the person to whom the genetic information is to be disclosed, indicate how long the authorization is effective, and state that the individual is entitle to a copy of the authorization. If the employment entity is a covered entity under HIPAA, however, it must comply with the disclosure requirements of the HIPAA Privacy Rule.

Subsection (e) Protections associated with authorization. An employment entity may not use the authorization process to expand its authority to disclose genetic information beyond that permitted by this act. An authorization for a disclosure shall not be interpreted to waive any rights held by the employee or family member.

SECTION 21. FORM FOR AUTHORIZATION FOR DISCLOSURE OF GENETIC INFORMATION. A completed and signed authorization substantially in the following form 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

CHOOSE ONE:

_____ 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

Comment

Section 20(b) permits an employment entity to disclose genetic information to a third person at the request of an employee or an employee's family member and Section 20(d) describes the requirements for a valid authorization. This section provides guidance on the appropriate content for an authorization form. The use of a form following the pattern of this section, when properly completed and signed, complies with the requirements of Section 20(d). As indicated in Section 22, employment entities that are covered entities under HIPAA are subject to HIPAA requirements for use and disclosure of genetic information.

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, Pub. Law 104-191 (1996) (110 Stat. 2033), from using or disclosing health information as authorized for a covered entity by the regulations.

Comment

This section concerns the interaction of the act's provisions with HIPAA requirements when an employment entity is also a covered entity under HIPAA. As provided in GINA, covered entities under HIPAA must continue to apply the HIPAA Privacy Rule to protected health information. However, an employment entity covered by this act, whether or not it is a covered entity under HIPAA, must follow this act when it is acting as an employer. For example, if a hospital's employee becomes a patient, the hospital's acquisition and use of that patient's genetic information in its role as a health care provider is governed by the HIPAA Privacy Rule, not this act. In contrast, if the hospital obtains genetic information in its role as an employer, such as by a request for family medical leave, the information is subject to this act.

The language of this section follows GINA Section 206, 42 U.S.C. Section 2000ff-5(c) (Supp. II 2008). The EEOC regulation implementing GINA provides that the employment provisions of GINA do not apply to genetic information that is protected health information under the HIPAA Privacy Rule. 29 CFR § 1635.11(d). This section adheres to GINA's formulation.

SECTION 23. REMEDIES.

(a) A person aggrieved by a violation of this [act] has a right of action for damages or

other relief. A court or arbitral tribunal may award reasonable attorney's fees and costs to an employee who prevails in an action under this subsection.

[(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].]

Comment

For private employees, GINA adopts the enforcement and remedy structure of Title VII of the Civil Rights Act of 1964, 42 U.S.C. Section 2000e-4 et seq. (2006), incorporating it by reference. 42 U.S.C. § 2000ff-6(a) (Supp. II 2008). For the other employee groups it covers (state, federal, and congressional employees), GINA incorporates the remedy provisions of the other relevant federal EEO statutes. 42 U.S.C. § 2000ff-6(b) through(e) (Supp. II 2008). GINA explicitly excludes, however, claims for disparate impact, a cause of action for unintentional discrimination that is available under Title VII. 42 U.S.C. § 2000ff-7 (Supp. II 2008).

Subsection (a) follows the pattern of many of the state employment discrimination statutes that supplement Title VII and other federal civil rights statutes by providing a private right of action. Because of the variety of approaches taken by the states, the act allows a state leeway to tailor remedies for consistency with those in other state employment discrimination statutes. The forms of available relief are to be determined under state law. Consistent with GINA, the section provides for fee shifting for prevailing employees.

Subsection (b) is a provision allowing a claimant to file a private cause of action without exhausting administrative remedies under GINA and, if applicable, under state administrative avenues. This provision is placed in brackets in order to leave the exhaustion decision to the state.

Background on GINA's administrative procedures. Under Title VII, and hence by reference under GINA, if there is a state or local fair employment practices agency that the EEOC has designated as a "deferral agency," an individual seeking relief from employment discrimination must first file a charge with that agency. The EEOC must defer jurisdiction over the complaint for 60 days or until the state agency has terminated its action. Almost all the states have created agencies that qualify as deferral agencies under Title VII.

If there is no qualifying state fair employment practices agency, a complainant has 180 days from the violation to file a discrimination charge with the EEOC. When a state has a deferral agency, then a complainant has 300 days to file with the EEOC, but must also meet the state's time limitation for filing an administrative claim. State time limitations range from 90 days (2 states) to one year (9 states), with a majority of states (31) setting the time limit at 180 days or 6 months. The EEOC and state fair employment agencies enter into annual work sharing agreements that provide that when a charge is filed with either the EEOC or the state agency it is treated as filed with both of them.

The EEOC serves a notice on the person named in the charge and investigates the charge. If it finds reasonable cause to pursue the complaint, it must attempt to conciliate the matter. If the EEOC dismisses the case, or if settlement is not reached within 180 days from the time the charge was filed and the EEOC and Attorney General decide not to bring a court case, the EEOC issues a "right to sue letter." An employee may take federal court action only after the EEOC issues this notice. The case must then be filed in federal court within 90 days.

Background on GINA's remedies and damages. In general, GINA incorporates the remedies and damages provisions of Title VII. These provisions authorize courts to issue injunctive relief and to order affirmative action as appropriate. This may include, but is not limited to, reinstatement or hiring of employees, with or without back pay, and any other equitable relief the court finds appropriate, such as promotion and front pay. Back pay may not extend for more than two years before the date the charge was filed with the EEOC, and it is offset by interim earnings or amounts that were earnable with reasonable diligence by the aggrieved individual. For intentional discrimination, the Civil Rights Act of 1991 added compensatory and punitive damages to the remedies available under Title VII. Punitive damages are available if the defendant acted with malice or reckless indifference to the employee's federally protected rights, but are not available against federal, state, or local government employers. There is a cap on the total amount that may be awarded in punitive damages and compensatory damages for nonpecuniary and future pecuniary losses. The cap is graduated based on employer size as measured by the number of employees:

Number of employees	Cap on compensatory and punitive damages
more than 14 & less than 101	$ 50,000
more than 100 & less than 201	$ 100,000
more than 200 & less than 501	$ 200,000
more than 500	$ 300,000

GINA differs from Title VII, however, in that it excludes remedies for claims of disparate impact, subject to future study by a Commission.

For attorney's fees, GINA incorporates 42 U.S.C. Section 1988 (2006), the attorney's fee provision for the federal civil rights acts. 42 U.S.C. § 2000ff-6(a)(2) (Supp. II 2008). It provides that prevailing parties may be awarded a reasonable attorney's fee as part of litigation costs.

Background on state Fair Employment Practices Acts. Most of the states provide administrative remedies and have a state agency that qualifies as a "deferral agency" under federal law. In addition most of the states provide a private cause of action for violations of EEO laws. There is a great deal of variation, however, in the relationship between the availability of administrative relief and private actions.

In 17 states (as of 2005) private EEO causes of action may be brought without first filing

a charge with an administrative agency (Alaska, Arkansas, District of Columbia, Idaho, Kentucky, Louisiana, Maine, Minnesota, New Jersey, New York, North Dakota, Ohio, Oregon, Tennessee, Vermont, Virginia, Washington). 6 Lex K. Larson, Employment Discrimination § 114.07[6] (2d ed. 2005). Other states that provide a private cause of action require exhaustion of administrative remedies. Many of them follow a scheme patterned on the federal approach under which the agency issues a "right to sue letter." Other states use other triggering mechanisms that allow a claimant to file a private suit.

State statutes of limitations for fair employment actions range from six months (Colorado) to six years (Ohio), with many states providing for two years (*e.g.* New Jersey) or three years (*e.g.* Michigan, New York, Washington). 6 Lex K. Larson, Employment Discrimination § 114.07[3] (2d ed. 2005).

State fair employment practices acts originally allowed more generous remedies than the federal acts. Before the availability of compensatory and punitive damages under federal law pursuant to the Civil Rights Act of 1991, many states provided for these damages either as agency remedies, court remedies, or both. Compensatory damages have typically been defined to include coverage for emotional distress, mental anguish, pain, suffering, humiliation, and the like. When punitive damages are available under state law, the plaintiff usually must show that the defendant acted with malicious or intentional disregard for statutory rights. With the liberalization of damages permitted under the federal act, some state remedies may now be more restrictive then the federal counterpart. If interpreted as less protective of employees, these provisions would be preempted under GINA. Attorney's fees and costs are generally available under state fair employment practices acts.

Remedies and damages under the Act. The act is intended to provide remedies for privacy violations, employment determinations based on misuse of genetic information, and other harms. Privacy violations involve acquisition, retention, or disclosure of genetic information that does not comply with the act. Employment determinations could include failure to license, hire, refer for employment, promote, or decisions to terminate, demote, reduce pay, reassign, or to take any other adverse action. Other harms could include torts such as intentional infliction of emotional distress. The appropriate remedy will vary with the type of violation.

Subsection (a) Private right of action. This subsection authorizes a private right of action for violation of the act. It specifies that the private cause of action is for "damages or other relief." "Other relief" is understood to authorize injunctive remedies, but otherwise the form of available relief is purposefully left to state law. Depending on the state, compensatory damages, back pay, front pay, reassignment, reinstatement, injunctive relief, punitive damages, and expungement of records may be available as remedies for a violation of the act. Unlike under GINA, damages are not subject to the federal caps. States should ensure, however, that their remedies are at least as protective as those available under GINA, or they will be preempted by the federal act. States have the option to follow GINA and exclude a remedy for a disparate impact claim, or they may omit Section 24 and leave the availability of this remedy to the development of state law.

Subsection (a) also authorizes fee and cost shifting to provide an incentive for employees

to act as private attorneys general and to compensate for the cost of enforcing the statute. This fee and cost shifting is discretionary, but is limited to awards to employees.

Subsection (b) Exhaustion of administrative remedies. Under this bracketed subsection, an aggrieved person may choose to use GINA's administrative remedies, including filing with a state agency, but is not required to do so. This elimination of the requirement for exhaustion of administrative remedies is consistent with statutory provisions in 17 states in which private EEO causes of action may be brought without first filing a charge with an administrative agency. It minimizes the increase in enforcement burden on state agencies by making a private civil action the primary remedy for a violation of the act.

Given the privacy interests at stake with genetic information, there are special reasons for allowing a private cause of action without requiring exhaustion of administrative procedures. While state employment discrimination agencies have the expertise and the apparatus in place to enforce state civil rights and disability statutes, discrimination agencies do not have expertise in privacy violations. In addition, the typical remedies for employment discrimination are not necessarily appropriate for a privacy violation. Enforcement could be turned over to an agency with that expertise, but relying on a private right of action avoids the cost of creating and funding a new agency. Moreover, it avoids imposing on an aggrieved employee the delay associated with administrative processes.

However, because the states take many different approaches to exhaustion of administrative remedies, the act leaves the decision to the legislature by placing this provision in brackets. This gives states the freedom to make their approach to remedies under the act consistent with the state's other fair employment practices legislation.

Statute of limitations and tolling. The section does not establish a specific statute of limitations or a tolling provision for administrative proceedings. This is left to the states so that they can harmonize the provisions with the treatment in other fair employment practices acts.

Statutory damages and civil penalties. The act differs from provisions in several states that specify statutory damages for privacy violations involving genetic information. A privacy rights perspective assumes an intrinsic harm from the invasion of privacy, whether or not consequential damages are incurred. Because of difficulties in measuring damage to privacy interests, several states that provide a private right of action for privacy violations involving genetic information also specify statutory damages, with higher amounts when the violation is willful or leads to monetary gain for the violator. Alaska Stat. § 18.13.020 (2008) (actual damages plus $5,000, or plus $1,000 if there is monetary gain); N.H. Rev. Stat. Ann. § 141-H:6 (2005) (not less than $1,000 per violation); N.M. Stat. Ann. § 24-21-6 (LexisNexis 2007) (economic loss plus damages of up to $5,000 if the violation results from willful or grossly negligent conduct). The Drafting Committee did not take this approach because statutory damages often become a limit on the recovery available.

Several states also make civil penalties available to remedy unlawful discriminatory practices. These penalties range from small (< $1000) to significant amounts (up to $50,000 or $100,000 per violation). Some states also authorize criminal penalties, although typically only

for willful violations of agency orders.

[SECTION 24. NO RIGHT 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 right of action under this [act].]

Comment

GINA provides that disparate impact does not establish a cause of action under the federal act. Instead, it provides for a study commission to be established in 2014 to make recommendations to Congress regarding whether to provide a disparate impact cause of action. 42 U.S.C. § 2000ff-7 (Supp. II 2008). This bracketed section is included so that states may limit remedies to those currently available under GINA or, by eliminating this section, may choose to provide a right of action based on disparate impact at this time. If a cause of action for disparate impact is eventually authorized by GINA, then states that have enacted this section will need to take action to avoid preemption by the federal statute.

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 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 . . . .