

D R A F T

FOR APPROVAL

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

NATIONAL CONFERENCE OF COMMISSIONERS

ON UNIFORM STATE LAWS

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

WITH PREFATORY NOTE AND REPORTER'S NOTES

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By

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

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UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT ACT

TABLE OF CONTENTS

Prefatory Note 1

SECTION 1. SHORT TITLE 7

SECTION 2. DEFINITIONS 7

SECTION 3. APPLICABILITY. 20

SECTION 4. MEDICAL INFORMATION THAT IS NOT GENETIC INFORMATION. 20

SECTION 5. GENERAL PROHIBITION ON ACQUISITION OF GENETIC
INFORMATION. 21

SECTION 6. EXCEPTION FOR VOLUNTARY SUBMISSION OF GENETIC
INFORMATION BY EMPLOYEE. 26

SECTION 7. EXCEPTION FOR INFORMATION UNDER FAMILY MEDICAL LEAVE
ACT. 27

SECTION 8. EXCEPTION FOR INFORMATION IN PUBLIC DOCUMENTS. 27

SECTION 9. EXCEPTION FOR INFORMATION AND TESTING FOR VOLUNTARY
HEALTH OR GENETIC SERVICES. 29

SECTION 10. EXCEPTION FOR INFORMATION AND TESTING FOR GENETIC
MONITORING. 31

SECTION 11. EXCEPTION FOR CERTAIN EMPLOYERS THAT CONDUCT DNA
ANALYSIS. 34

[SECTION 12. EXCEPTION FOR CERTAIN LEGAL PROCEEDINGS. 34

SECTION 13. REQUIREMENTS FOR GENETIC TESTING. 35

SECTION 14. EMPLOYEE AUTHORIZATION FOR ACQUISITION OF GENETIC
INFORMATION AND GENETIC TESTING. 38

SECTION 15. FORM FOR AUTHORIZATION FOR ACQUISITION OF GENETIC
INFORMATION 42

SECTION 16. FORM FOR AUTHORIZATION OF GENETIC TESTING 45

SECTION 17. PROHIBITION OF USE OF GENETIC INFORMATION. 48

SECTION 18. EMPLOYEE ACCESS TO GENETIC INFORMATION. 51

SECTION 19. CONFIDENTIALITY AND RETENTION OF GENETIC INFORMATION. . 52

SECTION 20. DISCLOSURE OF GENETIC INFORMATION. 54

SECTION 21. FORM FOR AUTHORIZATION FOR DISCLOSURE OF GENETIC
INFORMATION 58

SECTION 22. RELATIONSHIP TO HEALTH REGULATIONS. 59

SECTION 23. REMEDIES; LIMITATION OF ACTIONS. 59

SECTION 24. UNIFORMITY OF APPLICATION AND CONSTRUCTION 64

SECTION 25. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL AND
NATIONAL COMMERCE ACT 64

SECTION 26. EFFECTIVE DATE 64

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 asymptomatic 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. There is a special concern about adverse employment actions based on predictive genetic information 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 publically-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 Uniform 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 Uniform 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. 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. The Act also regulates genetic testing by setting standards that require reporting the results to the employee, destroying the employee's biological sample, and expunging genetic information produced ancillary to the test.

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 prior to a private lawsuit. Unlike GINA, the Act does not prevent a state from enforcing the act or 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.

1 for a training, retraining, or apprenticeship program; or

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

3 (B) does not include an independent contractor.

4 (4) “Employer” means a person that compensated [five] or more individuals for each
5 working day in each of 20 or more calendar weeks in the current or preceding calendar year. The
6 term includes an agent of the person.

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

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

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

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

15 (A) related by blood to an employee as the employee’s child, parent, sibling, half-
16 sibling, niece, nephew, aunt, uncle, grandchild, grandparent, first cousin, great-grandchild, great-
17 grandparent, first cousin once-removed, great aunt, great uncle, great-great grandchild, or great-
18 great grandparent; or

19 (B) a dependent of the employee for purposes of an employment entity’s
20 employee insurance or other benefit program; and

21 (C) an individual who has one of the relationships to the dependent specified in
22 subparagraph (A).

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

1 (10) “Genetic counseling” includes:

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

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

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

9 (D) communicating and interpreting test results; and

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

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

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

18 (A) the individual’s genetic test;

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

20 (C) the individual’s family medical history;

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

23 (E) a genetic test of:

1 (i) a fetus carried by the individual or a family member of the individual;
2 or
3 (ii) an embryo legally held by the individual or a family member of the
4 individual.

5 (13) “Genetic monitoring” means a periodic examination of an employee to evaluate
6 acquired modification to the employee’s genetic material, such as chromosomal damage or
7 evidence of increased occurrence of mutations, which may have developed in the course of
8 employment due to exposure to workplace conditions, conducted to identify, evaluate, and
9 respond to the effects of or control adverse environmental exposures in the workplace.

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

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

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

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

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

1 includes an agent of the organization.

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

4 (20) “Manifested” means that an individual has been or could reasonably be diagnosed
5 with the disease, disorder, or pathological condition by a health-care professional with
6 appropriate training and expertise in the relevant field of medicine. The term does not include a
7 disease, disorder, or pathological condition if the diagnosis is based principally on genetic
8 information or on the results of one or more genetic tests.

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

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

15 (23) “RNA” means ribonucleic acid.

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

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

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

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

22 **Legislative Note:** *In the definition of “employer” states may replace [five] with a lesser number*
23 *of employees in order to extend the coverage of the act.*
24

Reporter's Notes

1
2
3 *Paragraph (1). (Credentialing authority)* Credentialing authorities are included in the
4 group of employment-related organizations labeled as “employment entities” and regulated in
5 this act. The act’s inclusion of credentialing authorities extends the coverage of GINA.
6

7 Credentialing authorities serve as gatekeepers to certain types of employment by
8 providing credentials that are required either under state law or by an employer. Examples
9 include state bar and medical examination boards, which control entry to the practice of law and
10 medicine, and state departments of motor vehicles, which issue commercial drivers licenses
11 necessary for some employment. Acquisition or use of genetic information by a credentialing
12 authority could have the same effects on employees and applicants for employment as acquisition
13 or use by an employer.
14

15 California’s state EEO statute similarly expands the protections of federal employment
16 law with regard to credentialing. It prohibits licensing boards from requiring an examination or
17 establishing any other qualification that has an adverse impact on a class by virtue of race, creed,
18 etc, unless the practice can be demonstrated to be job related. Cal. Gov’t Code § 12944 (West
19 2005).
20

21 Pursuant to Section 22, the act does not affect occupational medical certifications, such as
22 a medical examination required for a school bus driver, when the entity that certifies the medical
23 qualification of the employee is a covered entity under HIPAA.
24

25 *Paragraph (2). (DNA)* DNA is the commonly used abbreviation for deoxyribonucleic
26 acid. This is the chemical designation for a molecule that, in humans, codes genetic information
27 in chromosomes. The molecule is in the form of a double helix formed as two strands of DNA
28 spiral around each other. The code is determined by the sequence of nucleotides in the DNA
29 molecule.
30

31 *Paragraph (3). (Employee)* The definition of employee is adapted from the National
32 Conference of Commissioners on Uniform State Law’s Model Employment Termination Act. It
33 differs from GINA’s definition, 42 U.S.C. § 2000ff(2)(A) (Supp. II 2008), which defines an
34 employee by cross reference to Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e(f)
35 (2006). Title VII defines an employee as an individual employed by an employer.
36

37 For drafting ease, the term employee is used to also cover individuals who are labor
38 organization members, apprentices or trainees, or using employment agencies. Because GINA
39 combines its definitions of employee and applicant, the definition also includes applicants for
40 employment, labor organization membership, training or apprenticeship program, or an
41 employment credential. And because the proposed EEOC regulations implementing GINA
42 include former employees, etc., the definition includes them as well. The intent is to cover any
43 individual who is subject to collection of information or an employment decision by an
44 employment entity, which is defined as an employer, employment agency, labor organization,
45 credentialing authority, or joint labor management committee.
46

1 The definition is intended to encompass individuals who are employed in, applying for, or
2 formerly held a supervisory, managerial, or confidential position. The definition's requirement
3 for compensation is intended to exclude volunteers from the definition of employee. In addition,
4 the Drafting Committee decided to exclude independent contractors from the definition of
5 employee. This approach is not intended, however, to provide employers with an avenue to
6 evade their obligations by classifying employees as independent contractors. The definition does
7 not take a position on whether or not partners are considered employees, but leaves this to the
8 development of the law on the status of partners.
9

10 *Paragraph (4). (Employer)* GINA defines employer, 42 U.S.C. § 2000ff(2)(B) (Supp. II
11 2008), by reference to Title VII of the Civil Rights Act of 1964. This act uses language adapted
12 from Title VII, 42 U.S.C. § 2000e (b) (2006), to determine whether an employer has the
13 threshold number of employees based on the number of individuals employed for 20 or more
14 calendar weeks in the current or preceding calendar year. However, the definition in this act
15 differs from Title VII and GINA in two important ways – the definition of the employment
16 relationship and the threshold number of employees required for the employer to be covered by
17 the act.
18

19 *Employment relationship.* Title VII and the proposed regulations implementing GINA
20 define an employer as someone who has 15 employees. An employee, in turn is defined as an
21 individual employed by an employer. This act avoids this circularity by defining the employment
22 relationship in terms of compensation. In addition to avoiding circularity, this is also necessary
23 because the term employee is defined in this act to include applicants for employment, labor
24 organization members, apprentices or trainees, and individuals using employment agencies.
25

26 *Size of employers based on number of employees.* Both Title VII of the Civil Rights Act
27 of 1964 and GINA cover employers with 15 or more employees. Many state employment
28 discrimination statutes, however, expand the scope of their coverage beyond that provided by
29 Title VII by including employers with smaller workforces. And genetics statutes in several states
30 often apply all employers regardless of the threshold used in their employment discrimination
31 statute. The act follows this pattern by setting the threshold for coverage at five or more
32 employees. However, many states may want to reduce the number of employees required to
33 trigger the act's coverage and the legislative note gives them the option to do this.
34

35 In deciding whether to include smaller employers under the act's coverage, states should
36 consider the thresholds they have enacted in their existing genetics statute and other statutes,
37 such as their state employment discrimination statute and their workers compensation statute.
38 For example, 16 jurisdictions cover all employers (i.e., employers with one or more employees)
39 under their state employment discrimination acts. An additional 11 jurisdictions have set a
40 threshold below five, ranging from two to four employees. 6 Lex K. Larson, Employment
41 Discrimination § 114.02[2] (2d ed. 2005). Significantly, some states cover all employers with
42 even a single employee under their genetics statute even when the state's employment
43 discrimination statute sets a higher threshold for covering employers. See 410 Ill. Comp. Stat.
44 Ann. 513/10 (West 2005 & Supp. 2010); Iowa Code Ann. § 729.6 (West 2003 & Supp. 2010);
45 Neb. Rev. Stat. Ann. 48-236 (LexisNexis 2007); N.M. Stat. Ann. § 24-21-4 (LexisNexis 2007);
46 N.C. Gen. Stat. § 95-28.1A (2009); R.I. Gen. Laws § 28-6.7-2.1 (2003); Utah Code Ann. § 34A-

1 2-103 (2005 & Supp. 2009).

2
3 *Measurement of number of employees.* An individual is counted as an employee if they
4 have been employed for each working day in each of 20 or more weeks during the current or
5 preceding calendar year. This measurement should be applied according to the interpretation
6 given to the provision under Title VII and the other federal statutes that use this common
7 formula.

8
9 *Types of employers.* The act’s definition of employer is linked to the definition of
10 “person.” It therefore encompasses all types of entities, including governmental and non-profit
11 employers. This is consistent with the coverage specified by a number of states in their state
12 versions of Title VII of the Civil Rights Act of 1964 on employment discrimination. *See, e.g.,*
13 Haw. Rev. Stat. § 378-1 (2008); Iowa Code Ann. § 216.2 (West 2009 & Supp. 2010).

14
15 *Paragraph (5). (Employment agency)* This is the definition provided in Title VII, 42
16 U.S.C. § 2000e (c) (2006), which GINA incorporates by reference. 42 U.S.C. § 2000ff(2)(C)
17 (Supp. II 2008).

18
19 *Paragraph (6). (Employment entity)* Employment entity is the term used in the act to
20 collectively indicate an employer, an employment agency, a labor organization, a credentialing
21 authority, or a joint labor-management committee that offers training programs. The definition
22 expands GINA’s coverage by adding credentialing authorities.

23
24 The proposed regulations implementing GINA use the term “covered entity” to group the
25 organizations covered by the federal act. This term is not used in this act because of the potential
26 for confusion with the use of the term “covered entity” in HIPAA and because the act’s scope of
27 coverage is slightly different from GINA, which does not include credentialing authorities.

28
29 *Paragraph (7). (Family medical history)* Family medical history is often a source of
30 genetic information in that it is used to evaluate the likelihood that an individual carries an
31 inherited trait. The act follows GINA and includes family medical history within its definition of
32 “genetic information.” The term “family medical history” is not defined in GINA. This
33 definition follows the definition in the proposed regulations implementing GINA. 29 C.F.R. §
34 1635.3.

35
36 *Paragraph (8). (Family member)* The act defines family member to encompass all
37 individuals whose genotype could influence an employment decision. The term includes (1)
38 dependents of an employee whose risk of future genetically-linked medical conditions could
39 affect employer health care costs or the cost of family insurance coverage and hence affect
40 employment decisions, (2) biological relations of an employee whose genetic information might
41 provide information about the genetic make-up of the employee, and (3) biological relations of
42 an employee’s dependents, whose genetic information might provide information about the
43 genetic make-up of a dependent.

44
45 *Definition’s relationship to GINA.* The act adopts the definition of family member used
46 in GINA, 42 U.S.C. § 2000ff(3) (Supp. II 2008), which defines “family member” by using the

1 term “dependent” with reference to ERISA’s use of that term in its provisions on special
2 enrollment periods for group health plans, 29 U.S.C. § 1181(f)(2) (2006). As used in ERISA,
3 this status depends on the scope of health care coverage offered by the employer.
4

5 The Drafting Committee recognized the importance of defining family member to include
6 domestic partners when employers provide health insurance for employees’ unmarried partners
7 because in that situation an unmarried partner can be a dependent whose risk of a genetically-
8 linked medical condition could affect employment or insurance decisions. The Drafting
9 Committee did not include a provision explicitly covering domestic partners because an
10 unmarried partner is included in the term “family member” if the partner is covered by the
11 employee’s benefits.
12

13 *Degree of relationship to the individual or the individual’s dependents.* The definition
14 follows GINA and the proposed EEOC regulations by including relatives of an employee or the
15 employee’s dependents to the fourth degree of consanguinity. Genetic counselors typically
16 collect information on genetic diseases of family members related to the third degree of
17 consanguinity and often to the fourth degree. The family members listed in the definition are
18 identical to those listed in the proposed GINA regulations.
19

20 *Paragraph (9). (Genetic condition)* The term genetic condition is used in the definitions
21 of genetic counseling and genetic services. It is not defined in GINA. The definition is intended
22 to give the term a broad interpretation. A genetic condition includes a manifested genetic disease
23 or disorder as well as a genetic trait that may increase the likelihood of developing a disease or
24 disorder. However, the term may also refer to a positive or benign trait or characteristic that is
25 linked to a particular genotype.
26

27 *Paragraph (10). (Genetic counseling)* Genetic counseling is a key to an individual’s
28 informed decision making about getting a genetic test, understanding the result, and authorizing
29 its use, retention, or disclosure. GINA defines genetic counseling by inserting the following
30 parenthetical about genetic counseling into its definition of a genetic service: “(including
31 obtaining, interpreting, or assessing genetic information).” 42 U.S.C. § 2000ff(6) (Supp. II
32 2008). The Drafting Committee concluded that a more comprehensive definition is important
33 because genetic counseling is a relatively new profession and state regulation of genetic
34 counselors and genetic counseling is currently in flux. Some states license or certify genetic
35 counselors and they tend to have a definition of genetic counseling. But the majority of states do
36 not license genetic counselors or regulate genetic counseling and hence lack a definition.
37

38 It is important to note that the definition does not require that genetic counseling be
39 performed by a genetic counselor. Physicians, geneticists, and some nurse practitioners are also
40 qualified to provide genetic counseling.
41

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

1 the test. The functions in (D) and (E) take place after the test, if necessary.
2

3 One of the core principles of genetic counseling is “nondirective education,” a term of art
4 in genetic counseling. The concept involves explaining all the relevant considerations and
5 consequences without suggesting to the client what course to take. It is a particularly important
6 principle in genetic counseling because of the association in the early part of the twentieth
7 century between genetics and eugenics, which advocated the promotion of certain superior
8 genotypes and the reduction in the population of those judged to be inferior. The draft references
9 the concept of nondirective communication using the definition in Seymour Kessler,
10 *Psychological aspects of genetic counseling. XI. Nondirectiveness revisited.* 72 Am. J. Med.
11 Genet. 164, 166 (1997): “Non-directiveness describes procedures aimed at promoting the
12 autonomy and self-directedness of the client.”
13

14 *Paragraph (11). (Genetic education)* Genetic education is one element of genetic
15 services. It is typically less tailored to individual circumstances than a one-on-one genetic
16 counseling session. The definition is meant to be broad enough to include information provided
17 by support groups for genetic conditions to those who may have the condition. It is not meant to
18 encompass general genetic education such as that received in biology class or medical school.
19 This term is used in GINA’s definition of genetic services, 42 U.S.C. § 2000ff(6) (Supp. II 2008),
20 but is not itself not defined in GINA.
21

22 *Paragraph (12). (Genetic information)* This definition of “genetic information” follows
23 the definition in the employment title of GINA. 42 U.S.C. § 2000ff(4) (Supp. II 2008). It
24 includes a family member’s genetic tests and family medical history.
25

26 The definition also incorporates GINA’s provisions on the genetic information of fetuses,
27 which are found, not in GINA’s definitions, but in § 209, codified at 42 U.S.C. § 2000ff-8
28 (Supp. II 2008). Under GINA, if an employee or family member is a pregnant woman, references
29 to her genetic information include that of the fetus she is carrying. If an employee or family
30 member is using assisted reproductive technology, references to that individual’s genetic
31 information include the genetic information of any embryo held legally by that individual.
32

33 This definition of genetic information is consistent with many states that define “genetic
34 information” to include information on genetic characteristics broadly, whether obtained from
35 genetic tests or family medical history. *See* Cal. Gov’t Code § 12926 (West 2005); Conn. Gen.
36 Stat. Ann. § 46a-60 (West 2009); Haw. Rev. Stat. § 378-1 (2008); 410 Ill. Comp. Stat. Ann.
37 513/10 (West 2005 & Supp. 2010); La. Rev. Stat. Ann. § 23:302 (2010); Me. Rev. Stat. Ann. tit.
38 5, § 19301 (2002); Md. Code Ann., Ins. § 27-909 (LexisNexis 2009); Mass. Ann. Laws ch. 151B,
39 § 1 (LexisNexis 2008); Mich. Comp. Laws Ann. § 37.1201 (West 2001); N.J. Stat. Ann. § 10:5-5
40 (West 2002 & Supp. 2010); N.M. Stat. Ann. § 24-21-2 (LexisNexis 2007); N.C. Gen. Stat. § 95-
41 28.1A (2009); R.I. Gen. Laws § 28-6.7-2.1 (2003); S.D. Codified Laws § 60-2-21 (2009); Tex.
42 Lab. Code Ann. § 21.401 (Vernon 2006); Wash. Rev. Code Ann. § 49.44.180 (West, 2008).
43 States with definitions that do not include family medical history are less protective than GINA
44 and therefore preempted.
45

46 *Paragraph (13). (Genetic monitoring)* The definition of “genetic monitoring” follows

1 the definition in GINA. 42 U.S.C. § 2000ff(5) (Supp. II 2008). It is drawn from the description
2 in Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace 4*
3 (1990). The focus in monitoring is not on inherited characteristics, but on genetic alterations in a
4 group of exposed individuals over time. Genetic monitoring is typically undertaken by
5 employers to identify risks for groups of employees who have been exposed to hazardous
6 substances or to target work sites for safety and health measures. The definition in the act differs
7 slightly from that in GINA. GINA’s definition limits genetic monitoring to testing for mutations
8 due to exposure to toxic substances. In contrast the act’s definition uses the term “workplace
9 condition” and so mutations are not limited to those caused by toxic substances.

10
11 *Paragraph (14). (Genetic service)* This definition follows the definition of “genetic
12 services” in the employment title of GINA. 42 U.S.C. § 2000ff(6) (Supp. II 2008). “Genetic
13 service” is a broader category than genetic testing. The term includes activities associated with
14 obtaining genetic information that could create assumptions about an individual’s genetic status
15 even in the absence of information about genetic test results or medical history. “Counseling”
16 implies a one-on-one consultation, so the definition also includes “genetic education” in order to
17 capture group information sessions on genetic conditions. While the definition of a “genetic
18 service” does not separately define the term “genetic,” the term should be interpreted to be
19 consistent with the definitions of “genetic test” and “genetic information.”

20
21 *Paragraph (15). (Genetic test)* This is substantively identical to the definition of genetic
22 test used in GINA employment provisions. 42 U.S.C. § 2000ff(7) (Supp. II 2008). “Genetic
23 test” is defined in terms of both (1) the material that the test analyzes and (2) what the test
24 detects.

25
26 The first sentence makes specific reference to the types of biological material that are
27 currently analyzed in genetic tests. Note that genetic tests can be conducted not only on gene
28 sequences, but also on biological products such as proteins or metabolites that can indicate
29 genetic make-up. The first sentence also specifies that the test must function to determine an
30 individual’s genetic make-up, either through the identification of a genotype or by looking for a
31 mutation or chromosomal change.

32
33 Both components of the definition are equally important. Some of the materials listed in
34 the first clause, especially proteins and metabolites, are tested for many medical purposes. A test
35 of a protein or metabolite does not constitute a genetic test unless it is administered to determine
36 an individual’s genetic make-up as specified in the second clause. In addition, the second
37 sentence of the definition, although redundant, should reassure those who fear the definition will
38 be used to sweep in medical tests that are not given to detect genotypes, mutations, or
39 chromosomal changes.

40
41 *Existing state law.* Many states with genetic statutes define “genetic test” in a way that is
42 not as broad, and hence not as protective, as the definition in GINA. First, some statutes limit the
43 definition to testing of DNA or chromosomes and are therefore inconsistent with modern testing
44 practices. *E.g.*, Alaska Stat. § 18.13.100 (2008); Ark. Code Ann. § 11-5-402 (2002); Kan. Stat.
45 Ann. § 44-1002(m) (2008); Mo. Ann. Stat. § 375.1300(4) (West 2002); Okla. Stat. Ann. tit. 36, §
46 3614.2(B)(4) (West 1999); Utah Code Ann. § 26-45-102(4) (2007); Va. Code Ann. § 38.2-

1 508.4(A) (2007).
2

3 Second, many states statutes limit their definition of “genetic test” to testing for disease-
4 related genes. *E.g.*, Ariz. Rev. Stat. Ann. § 12-2801 (2003 & Supp. 2009); Ark. Code Ann. § 11-
5 5-402(4)(B) (2002); Del. Code Ann. tit. 18, § 2317(a)(3) (2005); D.C. Code § 2-1401.02(12B)
6 (2008); 410 Ill. Comp. Stat. Ann. 513/10 (West 2005 & Supp. 2010); Iowa Code Ann. § 729.6(c)
7 (West 2003 & Supp. 2010); Kan. Stat. Ann. § 44-1002(m) (2008); La. Rev. Stat. Ann. §
8 23:302(6) (2010); Me. Rev. Stat. Ann. tit. 5, § 19301 (2002); Md. Code Ann., Ins. § 27-909
9 (LexisNexis 2009); Mich. Comp. Laws Ann. § 37.1201(e) (West 2001); Minn. Stat. Ann. §
10 181.974(a) (West 2006); Mo. Ann. Stat. § 375.1300(4) (West 2002); Neb. Rev. Stat. Ann. § 77-
11 5519(d) (LexisNexis 2010); Nev. Rev. Stat. Ann. §§ 629.121, 613.345(2)(b) (LexisNexis 2008);
12 N.J. Stat. Ann. § 10:5-5(pp) (West 2002 & Supp. 2010); N.M. Stat. Ann. § 24-21-2(F)
13 (LexisNexis 2007); N.Y. Civ. Rights Law § 79-1 (21-a)-(21-b) (McKinney 2009); N.C. Gen. Stat.
14 § 95-28.1A(b) (2009); Okla. Stat. Ann. tit. 36, § 3614.2(B)(4) (West 1999); R.I. Gen. Laws § 28-
15 6.7-2.1(4) (2003); Tex. Lab. Code Ann. § 21.401(5) (Vernon 2006); Vt. Stat. Ann. tit. 18, §
16 9331(7) (2000); Va. Code Ann. § 38.2-508.4(A) (2007); Wis. Stat. Ann. § 49.44.180(7m) (West
17 2008). These definitions are not as protective as the definition in GINA, and thus these statutes
18 are likely preempted. While most of the reasons that an employer or insurer might currently seek
19 or use genetic information probably involve a disease, disorder, or impairment, this may not
20 always be the case. For example, an employer might attempt to use the presence or absence of a
21 behavioral trait as a criterion for selecting an employee. While the current evidence linking
22 behavior to genes is tenuous, this area continues to be the subject of investigation. The definition
23 in GINA and the act allows the law to adapt as scientific information develops. The act’s
24 definition is consistent with state definitions of genetic testing that are not limited to identifying
25 genotypes associated with diseases or impairments. *E.g.*, Fla. Stat. Ann. § 760.40 (West 2010);
26 Haw. Rev. Stat. § 378-1 (2008); Idaho Code Ann. § 39-8302 (Supp. 2009); Mass. Ann. Laws ch.
27 151B, § 1 (LexisNexis 2008); N.H. Rev. Stat. Ann. § 141-H:1(IV) (2005); Or. Rev. Stat. §
28 192.531 (2007); Utah Code Ann. § 26-45-102(4) (2007).
29

30 *Paragraph (16). (Individually identifiable genetic information)* This definition is
31 included because the concept is used in the provisions allowing employment entities to acquire
32 genetic information for the purpose of offering health and genetic services and conducting
33 genetic monitoring programs. The concept is also used, but not defined, in the proposed GINA
34 regulations and is drawn from the HIPAA Privacy Rule, which protects individually identifiable
35 health information. Under the Privacy Rule’s definition, individually identifiable health
36 information is health information that “identifies the individual[,] or [w]ith respect to which there
37 is a reasonable basis to believe the information can be used to identify the individual.” 45 C.F.R.
38 § 160.103 (2008).
39

40 The HIPAA Privacy Rule does not directly indicate what information triggers a
41 reasonable basis to believe that it could be used to identify an individual, but it does provide a
42 standard for “de-identification” of protected health information. Health information is not
43 individually identifiable if the following has been removed: names; all geographic subdivisions
44 smaller than a State, including street address, city, county, precinct, zip code, and their equivalent
45 geocodes (except for the initial three digits of a zip code if, according to the current publicly
46 available data from the Bureau of the Census, the geographic unit formed by combining all zip

1 codes with the same three initial digits contains more than 20,000 people); all elements of dates
2 (except year) for dates directly related to an individual, including birth date, admission date,
3 discharge date, date of death; all ages over 89 and all elements of dates (including year)
4 indicative of such age (except that such ages and elements may be aggregated into a single
5 category of age 90 or older); telephone numbers; fax numbers; electronic mail addresses; social
6 security numbers; medical record numbers; health plan beneficiary numbers; account numbers;
7 certificate/license numbers; vehicle identifiers and serial numbers, including license plate
8 numbers; device identifiers and serial numbers; web Universal Resource Locators (URLs);
9 internet Protocol (IP) address numbers; biometric identifiers, including finger and voice prints;
10 full face photographic images and any comparable images; and any other unique identifying
11 number, characteristic, or code. 45 C.F.R. § 164.514 (b) (2008).

12
13 *Paragraph (17). (Labor-management committee)* This definition is taken from the
14 definition of a joint labor-management committee in the proposed regulations implementing
15 GINA. 29 C.F.R. § 1635.2(g).

16
17 *Paragraph (18). (Labor organization)* This definition is derived from the definition of
18 labor organization in Title VII, 42 U.S.C. § 2000e (d) (2006), which GINA incorporates by
19 reference, 42 U.S.C. § 2000ff(2)(C) (Supp. II 2008). It omits, however, the federal statutes'
20 requirement that the organization be engaged in interstate commerce. It is similar to the
21 following definition, which is commonly used in state EEO acts: "Labor organization' means
22 any organization which exists and is constituted for the purpose, in whole or in part, of collective
23 bargaining or of dealing with employers concerning grievances, terms or conditions of
24 employment, or of other mutual aid or protection in connection with employment." *E.g.*, Cal.
25 Govt. Code § 12926 (West 2005); Haw. Rev. Stat. § 378-1 (2008); Iowa Code Ann. § 729.6
26 (West 2003 & Supp. 2010); N.Y. Exec. Law § 292 (McKinney 2010).

27
28 *Paragraph (19). (Labor-organization member)*. This definition is taken from GINA's
29 definition of "member." 42 U.S.C. § 2000ff(2)(D) (Supp. II 2008).

30
31 *Paragraph (20). (Manifested)*. This definition is taken from the proposed EEOC
32 regulations to implement GINA. 29 C.F.R. § 1635.3(g). It is relevant to the definition of family
33 medical history and genetic information in this section and to Section 3, which excludes from the
34 act's coverage medical information about a manifested disease, disorder or pathological
35 condition that is not genetic information.

36
37 *Paragraph (21). (Person)* The act uses the broad version of the standard National
38 Conference of Commissioners on Uniform State Laws definition of "person."

39
40 *Paragraph (22). (RNA)* RNA is the standard abbreviation for ribonucleic acid. This is
41 the chemical designation for several classes of molecules that, in humans, carry genetic
42 information based on a DNA template. They play important roles in protein synthesis and other
43 cell functions based on DNA sequences.

44
45 *Paragraph (23). (Record)* The definition of "record" is the standard National Conference
46 of Commissioners on Uniform State Laws definition.

1 *Paragraph (24). (Sign)* The definition of “sign” is the standard National Conference of
2 Commissioners on Uniform State Laws definition.

3
4 *Paragraph (25). (Tribunal)* The term “tribunal” refers collectively to the potential
5 decision-makers in a litigation or arbitration context.
6

7 **SECTION 3. APPLICABILITY.**

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

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

16 **Reporter’s Notes**

17
18 This section is designed to avoid litigation about retroactivity under the act. If an
19 employment entity has already obtained or used genetic information as of the effective date of the
20 act, the act requires the employment entity to store and disclose that information only in
21 compliance with the act. But acquisition and use of genetic information and genetic testing must
22 comply with the act only after the effective date. The Drafting Committee rejected a provision
23 that would have allowed an employment entity to disclose genetic information according to an
24 agreement, if any, that an employee signed prior to the effective date of the act. It decided that
25 any such agreements should be revisited and brought into compliance with the act.
26

27 **SECTION 4. MEDICAL INFORMATION THAT IS NOT GENETIC**

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

1 **Reporter's Notes**

2
3 *Exclusion of information that is not genetic information.* This section is a paraphrase of
4 section 210 of GINA, 42 U.S.C. § 2000ff-9 (Supp. II 2008). It is meant to signal that medical
5 information about a manifested disease is not covered by the act if it is not genetic information,
6 but that medical information is covered if it is genetic information. For example, an individual
7 with breast cancer diagnosed by a biopsy might learn from genetic testing that she is positive for
8 a BRCA mutation and thus has an increased risk of ovarian cancer. Under this section, the fact
9 that she has breast cancer is not protected information, but information about the genetic
10 mutation and her risk of ovarian cancer is protected.

11
12 Under this section an employment entity does not violate the act when it acquires, uses,
13 retains, or discloses medical information about a manifest disease that is not genetic information.
14 However, that information may be protected by HIPAA or the ADA.
15

16 **SECTION 5. GENERAL PROHIBITION ON ACQUISITION OF GENETIC**
17 **INFORMATION.**

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

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

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

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

25 **Reporter's Notes**

26
27 *Act's general approach to acquisition of genetic information.* This section imposes a
28 general prohibition on genetic testing of employees or employee's family members and on
29 acquisition of their genetic information. It should be read with the subsequent sections, which
30 establish a number of limited exceptions for situations in which genetic testing by employment
31 entities and/or their access to employee's genetic information is acceptable. The act permits
32 employment entities to acquire genetic information if they receive it from an employee who
33 provides it voluntarily, request it under the Family Medical Leave Act, obtain it in certain
34 publicly available documents, obtain it as part of offering a voluntary wellness program, use it for
35 genetic monitoring, use it for quality control in forensic testing laboratories, or pursuant to a
36 tribunal's order in litigation. An employment entity may provide genetic testing as part of a

1 wellness program and provide it or, when appropriate, require it for a genetic monitoring
2 program, for quality control use in forensic testing laboratories, or pursuant to a tribunal's order
3 in litigation.
4

5 There are two circumstances of note for which the act does not provide an exception for
6 genetic testing. The first is genetic testing for employee susceptibility to harm from a potential
7 exposure in the workplace. Several states currently allow employers to provide genetic tests,
8 with the consent of the employee, to screen for an employee's predisposing genetic
9 characteristics that may create susceptibility to harm to the employee from a workplace
10 condition. Iowa, Louisiana, New Hampshire, New York, and Wisconsin all have nearly identical
11 provisions that permit genetic testing of an employee to determine an employee's susceptibility
12 to toxic substances if the employee requests testing, provides informed consent or authorization,
13 and the employer does not terminate the employee or take other adverse action as a result of
14 testing. Iowa Code Ann. § 729.6(7) (West 2003 & Supp. 2010); N.H. Rev. Stat. Ann. § 141-H:3
15 (2005); N.Y. Exec. Law § 296 (McKinney 2010); Wis. Stat. Ann. § 111.372 (West 2002). This
16 exception for testing was not included in the act because the Drafting Committee believes that
17 allowing additional testing of employees could be interpreted as providing less protection to
18 employees than GINA, and the provision could thus be preempted by the federal statute. This
19 interpretation is not certain, however, because the purpose of the testing would be to provide an
20 employee with greater protection from harm in the workplace.
21

22 Second, the Drafting Committee also considered but decided not to include a second
23 exception that would permit employers to supply genetic testing in order to protect the safety of
24 other employees in the workplace. The Committee decided that it would be very rare for a
25 genetic marker to indicate a safety threat to other employees with sufficient certainty to justify a
26 genetic test. The act does not, however, limit an employer's ability to take an employee's
27 manifested medical condition into account for safety purposes, subject to the provisions of the
28 Americans With Disabilities Act.
29

30 *Rationale for prohibiting acquisition and testing.* One rationale for limiting employer
31 acquisition of genetic information is the view that an employee should be able to keep genetic
32 information private. Approximately 15 states have statutes that protect the privacy of genetic
33 information in general, without regard to employment or any other specific context. At least one
34 state has a constitutional right of privacy that appears to be relevant to genetic information.
35 Alaska Const. art. 1, § 22. Another rationale is to make genetic discrimination less likely.
36 Unlike discrimination based on sex or race, an employer cannot discriminate on the basis of
37 genetic characteristics unless it has access to genetic information.
38

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

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

14
15 While GINA prohibits certain uses of genetic information, it also places a value on
16 employee privacy and, subject to limited exceptions, prohibits the acquisition of genetic
17 information without regard to its use. 42 U.S.C. §§ 2000ff-1(b), 2000ff-2(b), 2000ff-3(b),
18 2000ff-4(b) (Supp. II 2008). This Uniform Act follows the same approach. Many state statutes
19 prohibit employers from obtaining information, and may also prohibit requests, but arguably they
20 are not as protective as GINA because they prohibit acquisition of genetic information only for
21 certain uses. *See, e.g.*, Idaho Code Ann. § 39-8303 (Supp. 2009) (employer may not “access or
22 otherwise take into consideration” private genetic information in connection with an employment
23 decision); Kan. Stat. Ann. § 44-1009(a)(9) (2008) (employer may not seek to obtain, obtain, or
24 use testing information to distinguish employees or restrict a right or benefit); Md. Code Ann.,
25 State Gov’t § 20-606(a)(3) (LexisNexis 2009) (employer may not “request or require” genetic
26 information as a condition for hiring or determining benefits); Mass. Ann. L. Art. 151B § 4(19)
27 (LexisNexis 2008) (unlawful to “collect, solicit or require disclosure of genetic information” as a
28 condition of employment or “question a person about their genetic information or genetic
29 information concerning their family members”); Minn. Stat. Ann. § 181.974(subd. 2) (West
30 2006) (employer may not “request, require, or collect” protected genetic information as a
31 condition of employment); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis 2007) (employer may not
32 require genetic information as a condition of employment or promotion); Utah Code Ann. § 26-
33 45-103 (2007) (employer may not “access or otherwise take into consideration” private genetic
34 information in connection with an employment decision); Wash. Rev. Code Ann. § 49.44.180
35 (West 2008) (unlawful to require employee to submit genetic information as condition of
36 employment).

37
38 Additionally, many states broadly prohibit employers from subjecting employees to
39 genetic testing. *See, e.g.*, Kan. Stat. Ann. § 44-1009(a)(9) (2008) (employer may not subject,
40 directly or indirectly, any employee to any genetic screening or test); R.I. Gen Laws § 28-6.7-1
41 (2003) (employer may not “request, require, or administer” a genetic test). Again, however,
42 many other states prohibit genetic testing only for certain uses or when it is a condition of
43 employment, which arguably is not as protective as GINA. *See, e.g.*, Idaho Code Ann. § 39-8303
44 (Supp. 2009) (employer may not “request or require” an individual or his blood relative to submit
45 to a genetic test in connection with an employment decision); Iowa Code Ann. § 729.6 (West
46 2003 & Supp. 2010) (employer may not “solicit, require, or administer” a genetic test as a

1 condition of employment); Md. Code Ann., State Gov't § 20-606(a)(3) (LexisNexis 2009)
2 (employer may not "request or require" genetic tests as a condition for hiring or determining
3 benefits); Mass. Ann. Laws ch. 151B, § 4(19) (LexisNexis 2008) (unlawful to "solicit
4 submission to, require, or administer a genetic test" as a condition of employment); Mich. Comp.
5 Laws Ann. § 37.1202 (West 2001) (no employer may require a genetic test as a condition of
6 employment); Minn. Stat. Ann. § 181.974(subd. 2) (West 2006) (employer may not "administer a
7 genetic test" as a condition of employment); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis 2007)
8 (employer may not require a genetic test as a condition or employment or promotion); Nev. Rev.
9 Stat. Ann. § 613.345 (LexisNexis 2006) (unlawful employment practice to "require or
10 administer" a genetic test as a condition of employment); N.H. Rev. Stat. Ann. § 141-H:3 (2005)
11 (may not "solicit, require, or administer" genetic testing as a condition of employment); Utah
12 Code Ann. § 26-45-103 (2007) (employer may not "request or require" an individual or blood
13 relative to submit to a genetic test in connection with an employment decision); Vt. Stat. Ann.
14 tit.18, § 9333 (2000) (may not require genetic testing as a condition of employment); Va. Code
15 Ann. § 40.1-28.7-1 (2002) (employer may not "request, require, solicit, or administer" a genetic
16 test as a condition of employment); Wash. Rev. Code Ann. § 49.44.180 (West 2008) (unlawful to
17 require employee to submit to genetic screening as condition of employment); Wis. Stat. Ann. §
18 111.372 (West 2002) (employer may not "solicit, require, or administer" a genetic test as a
19 condition of employment unless employee requests test). GINA does not contain prohibitions on
20 testing, which it regards as a form of acquiring genetic information that is covered by the
21 provisions limiting employer acquisition. The Uniform Act, in contrast, is more explicit. It
22 contains a general prohibition on genetic testing and, in the narrow circumstances singled out as
23 exceptions, provides employees with protections that relate specifically to testing.

24
25 Other states do not provide the protections required by GINA because they rely on state
26 anti-discrimination statutes, which typically allow employers to compel testing or to require
27 employees to provide genetic information under certain circumstances. Many of these states rely
28 on disability statutes to regulate genetic information, usually following the Americans with
29 Disabilities Act (ADA), which permits an employer to test an applicant and acquire an
30 applicant's medical records after a conditional offer of employment. 29 C.F.R. § 1630.14(b)
31 (2009). This approach opens the door broadly for employers to obtain genetic information once
32 an employer has made a conditional offer of employment. In addition, under the ADA and most
33 state statutes modeled on it, after an employee is hired, an employer can obtain medical
34 information if it has a reasonable belief that the employee is unable to perform the essential
35 functions of his or her job due to a medical condition. 29 C.F.R. § 1630.14(c) (2009). Some
36 states have amended their employment discrimination statutes to include genetics. Under the
37 rubric of these statutes, genetic testing or collection of genetic information is typically permitted
38 when it is relevant to "job-related qualifications" or justified by "business necessity." The
39 Drafting Committee considered and rejected these approaches because of a concern that tying the
40 Act's protections to the concept of "job-related" medical information would not provide adequate
41 protection for genetic information. In interpreting the ADA, some courts have interpreted the
42 category of "job-related" medical information broadly, thus permitting employers to access
43 medical information and narrowing the scope of protection.

44
45 The Act's approach also contrasts with California's and Minnesota's more
46 comprehensive limitations on employer access, which prohibit employers from accessing non-

1 job-related medical information at any time. Cal. Gov't Code § 12940 (West 2005); Minn. Stat.
2 Ann. § 181.974(subd. 2) (West 2006). An advantage of California's and Minnesota's approach
3 is that it does not depend on how "genetic information" is defined. In addition, it does not rely
4 on custodians of medical files to make a distinction between genetic information and medical
5 information more generally, which are often mixed in medical files. Practically speaking, when
6 an employee signs a release permitting employer access to medical records, everything in the
7 records is included. There are those who maintain that legislation is needed to limit an
8 employer's ability to obtain any non-job-related health information during the hiring process or
9 employment. See Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35
10 Hastings Center Report No. 4 (2005), at 35. The Drafting Committee discussed this approach,
11 but declined to adopt it because it extends beyond the scope granted to the Committee.
12

13 *Subsection (a) General prohibition on acquisition of genetic information and genetic*
14 *testing.* This section establishes a general prohibition on the acquisition of genetic information
15 by employment entities by prohibiting employment entities from "requesting, requiring, or
16 purchasing" an employee's genetic information. It also supplements GINA, which does not have
17 provisions that specifically cover genetic testing, by establishing a general rule that an
18 employment entity may not offer or provide genetic tests to employees.
19

20 The prohibition on acquisition uses the language of GINA by making it a violation for an
21 employer to "request, require, or purchase" genetic information. To avoid the possibility of a
22 restrictive interpretation of that language, the subsection additionally prohibits any other
23 acquisition of genetic information. The prohibition of requests is intended to apply to inquiries
24 directed to other entities as well as to inquiries directed to the employee or the employee's family
25 member. The prohibition on requesting genetic information is not, however, intended to prevent
26 an employer from informing an employee about the availability of a genetic test that is relevant to
27 conditions in the workplace or from informing an employee about a genetic monitoring program.
28

29 The general prohibitions are subject to specific exceptions found in subsequent sections.
30 Sections 6 to 12 establish limited exceptions to the prohibition on acquisition of genetic
31 information. Sections 9 to 12 establish limited exceptions to the prohibition on genetic testing.
32 Section 13 sets requirements for counseling and reporting that must be met if an employment
33 entity provides a genetic test as part of a voluntary wellness program or a genetic monitoring
34 program.
35

36 Because the definition of genetic information includes information about access to
37 genetic services, the limitations in the act, like those of GINA, allow employees to keep private
38 information that could lead to discrimination based on assumptions about genetics, even in the
39 absence of actual genetic test results. If an individual is unable to keep private his use of genetic
40 services such as counseling, the individual may be deterred from obtaining this service for fear
41 that an employer will assume the employee has reason to think he has a genetic disorder.
42 Protection of this information is consistent with provisions in a number of states that prohibit
43 employers from acquiring or using information about an employee's request for or use of genetic
44 services. See, e.g., La. Rev. Stat. Ann. § 23:368 (2010) (employer may not "require, collect, or
45 purchase" information about an employee's request for or use of genetic services); N.C. Gen.
46 Stat. § 95-28.1A (2009) (unlawful to deny employment of account of request for genetic testing

1 or counseling services); Utah Code Ann. § 26-45-103 (2007) (employer may not inquire into
2 whether an individual or blood relative has taken or refused to take a genetic test); Idaho Code
3 Ann. § 39-8303(1)(d) (Supp. 2009) (same); Vt. Stat. Ann. tit.18, § 9333 (2000) (employer may
4 not use the fact that genetic counseling or tested services have been requested or performed).
5

6 *Subsection (b) Inadvertent requests.* Congress included a provisions like this in GINA,
7 42 U.S.C. §§ 2000ff-1(b)(1), 2000ff-2(b)(1), 2000ff-3(b)(1), 2000ff-4(b)(1) (Supp. II 2008), to
8 address what it called the “water cooler problem” – when an employer unwittingly receives
9 information through casual conversation or by overhearing conversations. While GINA’s
10 provisions on inadvertent requests are expressly limited to requests for family medical history,
11 the proposed regulations expand it to include any genetic information on the theory that it should
12 not matter whether the employee is discussing a genetic test or a relative’s disease. 29 C.F.R. §
13 1635.8(b)(1). For consistency, the Uniform Act follows the approach in the regulations.
14

15 The proposed EEOC regulations include examples of circumstances in which the
16 acquisition of genetic information would be deemed inadvertent. 29 C.F.R. § 1635.8(b)(1)(i)-
17 (vi). These include overhearing conversations, receiving information that is not solicited, genetic
18 information submitted in response to a request for medical information, and information
19 submitted by an employee seeking an accommodation or leave.
20

21 Employment entities are urged, however, to take proactive measures and establish best
22 practices to avoid even inadvertent acquisition of genetic information. For example, if an
23 employer asks an employee to support a request for an accommodation by having a health-care
24 professional provide documentation about a disability, the request form should instruct the
25 health-care professional not to provide family medical history or other genetic information.
26

27 **SECTION 6. EXCEPTION FOR VOLUNTARY SUBMISSION OF GENETIC**
28 **INFORMATION BY EMPLOYEE.** An employment entity may acquire and use an
29 employee’s genetic information if

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

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

35 **Reporter’s Notes**

36 This section authorizes an employee to purposely provide an employer with genetic
37

1 information at the employee’s initiative. It recognizes employee autonomy and is designed to be
2 protective of an employee. For example, an employee might seek to submit information to
3 support a request for reassignment to avoid exposure to a chemical to which the employee has a
4 genetic susceptibility. The section limits use by the employment entity to the purposes specified
5 in the employee’s authorization.
6

7 This section also protects an employer from liability under the act if an employee submits
8 genetic information in a situation in which the employment entity’s acquisition is not inadvertent
9 and hence the employment entity is not protected under Section 5(b).
10

11 Employees who provide genetic information voluntarily may do so directly, through oral
12 statements or by turning over reports of test results. They may also do so indirectly by permitting
13 an employment entity to see medical records held by a third party. The authorization requirement
14 parallels GINA’s authorization requirements that apply when an employee provides genetic
15 information to an employment entity as part of a wellness program or for a genetic monitoring
16 program that is based on employee consent. When medical records are provided to an
17 employment entity by a third party, it is likely that the third party will be a covered entity under
18 HIPAA and the employee will need to authorize the disclosure.
19

20 **SECTION 7. EXCEPTION FOR INFORMATION UNDER FAMILY MEDICAL**

21 **LEAVE ACT.** An employment entity may request or require family medical history from an
22 employee to comply with the certification provisions of the Family Medical Leave Act, 29
23 U.S.C. Section 2613, or [state family and medical leave act].

24 *Legislative Note:* States should insert for [state family and medical leave act] the appropriate
25 name and citation for the state’s act.
26

27 **Reporter’s Notes**

28
29 This section parallels exceptions in GINA. 42 U.S.C. §§ 2000ff-1(b)(3), 2000ff-2(b)(3),
30 2000ff-3(b)(3), 2000ff-4(b)(3) (Supp. II 2008). The exception is limited to requests for family
31 medical history and does not cover genetic information more generally. The exception is
32 necessary because an employee seeking leave to care for an ill relative is asked about the
33 relative’s illness on Family Medical Leave Act certification forms and this information falls
34 within the act’s definition of family medical history.
35

36 **SECTION 8. EXCEPTION FOR INFORMATION IN PUBLIC DOCUMENTS.**

37 (a) Except as otherwise provided in subsection (b), an employment entity may obtain a
38 document, other than by purchasing medical or court record databases, that is publicly available,

1 including a newspaper, magazine, periodical, and book, even if it contains genetic information of
2 an employee or of a family member of an employee.

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

5 **Reporter's Notes**

6
7 This section is included in the act to maintain consistency with GINA. GINA has an
8 exception allowing employers to acquire family medical history when employers “purchase”
9 commercially available materials that may contain family medical history. *E.g.*, 42 U.S.C. §
10 2000ff-1(b)(4) (Supp. II 2008). While GINA’s exception is expressly limited to requests for
11 family medical history, the proposed regulations expand it to include any genetic information on
12 the theory that it should not matter whether a document reveals the results of a genetic test or a
13 relative’s disease. 29 C.F.R. § 1635.8(b)(4). The Drafting Committee follows the approach
14 taken in the proposed regulations because it sees no reason to limit the exception to family
15 medical history.

16
17 GINA explicitly lists newspapers, magazines, periodicals, and books as “excused” media.
18 The proposed EEOC regulations expand the list of excused media to include the internet,
19 television, and movies. The Drafting Committee considered the expanded list of excused media
20 contained in the proposed regulations and decided to follow the more limited list in GINA.
21 However, this list is not meant to be exclusive, as signaled by the introductory word “including.”
22 The Drafting Committee also considered removing the list from the black letter law and placing
23 it in the comments, but decided to leave list in the text for consistency with GINA and to provide
24 clear guidance.

25
26 The exception in this section differs from GINA and its implementing regulations in that
27 it is not limited to the *purchase* of media on the excused list. The Drafting Committee decided
28 that employment entities should not be in violation of the act if they obtain this material without
29 cost. The Committee regards the acquisitions covered in this section as examples of situations in
30 which an employment entity does not intend to acquire genetic information.

31
32 GINA explicitly excludes medical databases and court records from the list of media that
33 employers may consult even though they contain genetic information. The Drafting Committee
34 considered whether it is appropriate to restrict employer access to court records that contain
35 genetic information. One the one hand, court records are public records and the Drafting
36 Committee was concerned that statutorily prohibiting purchase of court records by employment
37 entities raises issues under the First Amendment and the principle of open courts. On the other
38 hand, the inclusion of genetic information in court records does pose a threat to employee’s
39 privacy in that data miners are obtaining information from court records to sell to employers,
40 landlords, and others and not all courts have adopted strong policies to redact genetic information
41 from court records. The Drafting Committee concluded that if the Uniform Act permits
42 employers to purchase court records containing genetic information by omitting GINA’s

1 exclusion for this category of information, then this provision would be less protective of
2 employees than GINA and preempted by the federal statute. Therefore, the exclusion for
3 purchase court records is included in the act. It is, however, narrowed to “court record
4 databases.” This protects against the potential harm to employees from data mining but clarifies
5 that the provision is not meant to prevent access to a single court record that is relevant for an
6 employer even though it happens to contain genetic information.
7

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

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

16 (2) individually identifiable genetic information of the employee or family member of the
17 employee is used only to provide health and genetic services to the employee or family member
18 of the employee;

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

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

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

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

26 (4) genetic information is not disclosed to the employment entity except in an aggregate

1 form under circumstances that do not disclose the identity of the individual employee or family
2 member of the employee.

3 **Reporter’s Notes**

4
5 This section permits an employer that provides preventative health services to encourage
6 a healthy workplace to include genetic testing and other genetic services as part of its program.
7 These provisions are intended to encourage employers to provide their employees access to
8 genetic services in this way. The employment entity must, however, meet the requirements listed
9 in the statute as a prerequisite to acquiring genetic information or providing genetic testing for
10 this purpose. The requirements in the section are similar to those in GINA. *E.g.*, 42 U.S.C. §
11 2000ff-1(b)(2) (Supp. II 2008).

12
13 GINA provides that an employment entity may offer health or genetic services as part of a
14 wellness program. This act follows the proposed EEOC regulations in limiting the application of
15 this section to wellness programs that are voluntary. 29 C.F.R. § 1635.8(b)(2). This is consistent
16 with a requirement set forth in the ADA. Under EEOC guidance, a wellness program is
17 voluntary “as long as an employer neither requires participation nor penalizes employees who do
18 not participate.” EEOC’s Enforcement Guidance on Disability-related Inquiries and Medical
19 Examinations of Employees under the Americans with Disabilities Act, 8 Fair Empl. Prac. Man.
20 (BNA) 405, Question 22 (July 27, 2000), available at [http://www.eeoc.gov/policy/docs/guidance-](http://www.eeoc.gov/policy/docs/guidance-inquiries.html)
21 [inquiries.html](http://www.eeoc.gov/policy/docs/guidance-inquiries.html).

22
23 As under GINA, the act requires employee authorization before genetic information can
24 be used in providing health or genetic services. Requirements for employee authorization for
25 genetic testing and for acquisition of genetic information are set forth in Section 14. The act also
26 provides additional protections not found in GINA. In Section 13, it requires employers to
27 provide genetic counseling about the risks and benefits of the test before an employee considers
28 signing the authorization for testing. The purpose of this counseling is so that the employee can
29 make an informed decision about whether or not to have the test. The Drafting Committee
30 decided that an employee may, however, decline the counseling. In addition, Section 13
31 mandates additional protections whenever an employment entity provides genetic testing. These
32 protections apply to both health or genetic services offered by an employment entity and to
33 genetic monitoring programs.

34
35 Prior ULC drafts provided that the employer must pay for the genetic testing and genetic
36 counseling. This differs from GINA. Because this testing is for the employee’s benefit and
37 might be covered by health insurance, the payment provision is dropped from the act.

38
39 The act includes GINA’s provision permitting access for a health-care professional
40 involved in providing the services for the employment entity. The Drafting Committee was
41 advised that employer-provided genetic services should ideally be conducted by professionals –
42 typically genetic counselors, geneticists, or physicians – from outside the employer organization.
43 This act is not intended, however, to regulate the practice of medicine, and so it does not directly
44 forbid an employer from using employees to provide these services. If an employer does use

1 employees, it would be necessary for the health-care professional providing genetic services to
2 obtain the genetic information of participating employees. The act specifies that this health-care
3 professional must be “a licensed health-care professional or board-certified genetic counselor”
4 because this is the language used in GINA. The Drafting Committee notes, however, that it
5 should be sufficient if a genetic counselor is board-eligible.
6

7 The intent of the act is to segregate individually identifiable genetic information so that it
8 is used only in providing genetic services and others in the employment entity do not have access
9 to it. Hence, any genetic information otherwise acquired by the employment entity must be in an
10 aggregate form that does not disclose the identity of the individual. However, employment
11 entities that obtain aggregate information may still violate the act if a small number of
12 participants or other factors make an individual’s genetic information readily identifiable from
13 the aggregate information.
14

15 In addition to this section and GINA’s employment provisions and implementing
16 regulations, Title I of GINA places restrictions on the genetic information that group health plans
17 may request or require from covered individuals. Employment entities that sponsor or maintain
18 group health plans that implement wellness programs should consult the regulations issued by the
19 Department of Labor, Health and Human Services, and the Department of the Treasury
20 concerning limitations on acquisition of genetic information by group health plans.
21

22 As provided in Section 22, the act is not intended to apply to uses of information covered
23 by the privacy regulations (Privacy Rule) that implement the 1996 Health Insurance Portability
24 and Accountability Act (HIPAA), which covers health insurers and other health practitioners.
25 Nothing in this section should be read to apply to or restrict the acquisition use, or disclosure of
26 genetic information that is subject to the HIPAA Privacy Rule. For example, if a university
27 employee becomes a patient in the university’s hospital, in that setting the individual’s genetic
28 information would be covered by the HIPAA Privacy Rule, not the provisions of this act.
29

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

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

36 (2) the genetic monitoring is:

37 (A) required by state or federal law; or

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

2 (3) the genetic monitoring is in compliance with:

3 (A) federal genetic monitoring law, including the Occupational Safety and Health
4 Act of 1970, 29 U.S.C. Section 651 et seq.[, as amended], the Federal Mine Safety and Health
5 Act of 1977, 30 U.S.C. Section 801 et seq.[, as amended], or the Atomic Energy Act of 1954, 42
6 U.S.C. Section 2011 et seq.[, as amended], and regulations adopted under those acts; or

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

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

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

12 (A) the employee;

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

14 (C) a licensed health-care professional or board-certified genetic counselor
15 involved in providing the employment entity’s monitoring program; and

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

18 **Legislative Note:** *In states in which incorporating future amendments to federal statutes is an*
19 *unconstitutional delegation of legislative power, “[, as amended]” should be deleted.*
20

21 **Reporter’s Notes**

22
23 Monitoring for damage to employees’ genes from workplace exposure to harmful
24 substances is an accepted reason for genetic testing in the workplace. Genetic monitoring
25 programs are typically undertaken by employers to identify risks for groups of employees who
26 have been exposed to hazardous substances or to target work sites for safety and health measures.
27 Monitoring is testing designed to detect whether the genetic material of a group of individuals
28 has changed over time. The premise is that such changes could indicate increased risk of future
29 illness. Aggregated data from tests for genetic damage is sufficient to allow an employer to

1 reduce exposures to levels that do not affect individuals' chromosome morphology or DNA.
2 Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* 66
3 (1990). However, while monitoring may have predictive value for a group, the techniques that
4 are used do not currently measure increased individual health risks.
5

6 The intent of the act is to segregate genetic information so that individually identifiable
7 information is used only in conducting monitoring and others in the employment entity do not
8 have access to it in an individually identifiable form. Hence, any genetic information otherwise
9 acquired by the employment entity must be in an aggregate form that does not disclose the
10 identity of the individual. However, employment entities that obtain aggregate information may
11 still violate the act if a small number of participants or other factors make an individual's genetic
12 information readily identifiable from the aggregate information.
13

14 *Relationship of this section to GINA.* This section is consistent with GINA's provisions
15 that permit employment entities to monitor genetic effects of workplace exposures. *E.g.*, 42
16 U.S.C. § 2000ff-1(b)(5) (Supp. II 2008). Both GINA and this act limit employer access to
17 aggregate genetic data, with an exception for health-care employees administering the
18 monitoring. The Drafting Committee has been advised that employer-provided genetic
19 monitoring should normally be conducted by professionals – typically genetic counselors,
20 geneticists, or physicians – from outside the employer organization. This act is not intended,
21 however, to regulate the practice of medicine, and so it does not directly forbid an employer from
22 using employees to conduct monitoring. If an employer does use employees, it would be
23 necessary for the health-care professional providing genetic services to obtain the genetic
24 information of participating employees. The act specifies that this health-care professional must
25 be “a licensed health-care professional or board-certified genetic counselor” because this is the
26 language used in GINA. The Drafting Committee notes, however, that it should be sufficient if a
27 genetic counselor is board-eligible.
28

29 Genetic testing by an employment entity is not explicitly authorized in GINA, but is a
30 form of acquisition of genetic information. This section provides that any testing for purposes of
31 genetic monitoring is to be performed in compliance with Section 13, which provides protections
32 for the employee that go beyond those in GINA.
33

34 *Reference to federal genetic monitoring regulations.* GINA, and this act, require that an
35 employment entity's genetic monitoring program must comply with federal regulations
36 governing genetic monitoring programs. The intent is to include future federal regulations and
37 amendments.
38

39 The Drafting Committee recognizes that in some states a provision that requires
40 compliance with future law or regulations constitutes an unconstitutional delegation of legislative
41 power. In these states, this problem can be avoided by omitting the term “as amended.”
42

43 *Existing State law and its relationship to GINA.* A number of states permit genetic
44 monitoring, provided that the employee requests testing, provides informed consent or
45 authorization, and the employer does not terminate the employee or take other adverse action as a
46 result of testing. Iowa Code Ann. § 729.6(7) (West 2003 & Supp. 2010); N.H. Rev. Stat. Ann. §

1 141-H:3 (2005); N.Y. Exec. Law § 296 (McKinney 2010); Wis. Stat. Ann. § 111.372 (West
2 2002). In addition, Louisiana authorizes monitoring of biological effects of toxic substances in
3 the workplace if the employee has provided authorization and is notified of the results. La. Rev.
4 Stat. Ann. § 23:368 (2010). More generally, the definitions and prohibitions in many states’
5 statutes do not appear to restrict monitoring for genetic damage, or are ambiguous on this issue.
6 Thus many state statutes do not appear to provide safeguards for employees consistent with
7 GINA.
8

9 **SECTION 11. EXCEPTION FOR CERTAIN EMPLOYERS THAT CONDUCT**

10 **DNA ANALYSIS.** An employer that conducts DNA analysis for law enforcement purposes at a
11 forensic laboratory or for purposes of identifying human remains may request or require genetic
12 information or genetic testing of an employee to the extent necessary to analyze DNA
13 identification markers for quality control to detect sample contamination by DNA of the
14 employee.

15 **Reporter’s Notes**

16
17 This section allows a limited subset of employers – those that perform genetic testing for
18 identification for law enforcement purposes or to identify human remains – to collect DNA
19 samples from employees in order to check for contamination of the forensic samples with the
20 employees’ DNA. The exception for this form of acquisition is limited to employers only and
21 does not include other employment entities. The section is consistent with GINA. 42 U.S.C. §
22 2000ff-1(b)(6) (Supp. II 2008).
23

24 Testing under this section is not subject to the protections in Section 13 because testing
25 for the purposes of quality control in an identification laboratory would be limited to specific
26 markers on the genome used for identification, which are not thought to have any medical or
27 predictive significance.
28

29 **[SECTION 12. EXCEPTION FOR CERTAIN LEGAL PROCEEDINGS.** If an
30 employee places the employee’s health at issue in a proceeding before a tribunal in which an
31 employment entity is a party, the employment entity may obtain genetic information about the
32 employee without the employee’s authorization only if:

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

1 (2) on a motion by the employment entity, a tribunal orders the employee to take a genetic
2 test or provide genetic information after finding that the genetic information is necessary in the
3 interest of justice to resolve the proceeding and that the information is otherwise unavailable;
4 (3) the employment entity pays for the genetic test if one is ordered under paragraph 2;
5 and
6 (4) the tribunal grants a protective order to protect the privacy of the genetic information.]

7 **Reporter’s Notes**
8

9 This bracketed section allows an employment entity to obtain an employee’s genetic
10 information that is relevant to a claim or defense in a legal proceeding, through testing if
11 necessary, if the employee places the employee’s health at issue in a legal proceeding. GINA
12 does not have a parallel provision. The section supplements GINA by providing standards that
13 give an employee greater protection than that afforded by civil litigation discovery standards for
14 medical testing.
15

16 The employer’s ability to acquire genetic information under this section is limited in that
17 it applies only if the employer has satisfied the burden of proof to show that the genetic
18 information is necessary in the interests of justice and that the information is otherwise
19 unavailable. Only that portion of an employee’s genetic information that is relevant to a claim or
20 defense may be provided. These procedures provide more protection than Rule 35 of the Federal
21 Rules of Civil Procedure or state equivalents, which provide that a court may order a physical
22 examination on motion for good cause shown. In addition, the genetic information must be
23 sealed or placed under a protective order.
24

25 The section requires the employer to pay for a genetic test if one is ordered when the test
26 is requested by motion of the employer. This provision is not intended to limit a tribunal’s
27 discretion to order payment for a genetic test if the test is ordered by the tribunal on its own
28 motion.
29

30 The substance of the section follows Utah’s statute, which authorizes genetic testing
31 when an employee has placed his or her health at issue in a proceeding, but only by order of a
32 court or administrative agency after finding compelling need and that the information is
33 otherwise unavailable. Utah Code Ann. § 26-45-103(2) (2007).
34

35 The section is placed in brackets because in some states the legislature may be limited in
36 its ability to alter state court rules of procedure. It should also be noted that the applicability of
37 the section in federal court might depend on application of the *Erie* doctrine by the federal courts.
38

39 **SECTION 13. REQUIREMENTS FOR GENETIC TESTING.** An employment

1 entity that provides a genetic test to an employee or family member of the employee as part of
2 health or genetic services offered under Section 9 or for a genetic monitoring program under
3 Section 10 shall:

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

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

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

11 (2) unless the individual directs otherwise, require the testing organization to report the
12 test result to the individual and any health-care professional designated by the individual;

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

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

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

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

20 (C) ordered by a tribunal; and

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

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

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

4 (C) ordered by a tribunal.

5 **Reporter's Notes**

6
7 This section provides the employee with protections in the event that an employment
8 entity provides testing as part of health or genetic services under Section 9 or a genetic
9 monitoring program under Section 10. These protections supplement GINA's provisions on on
10 acquisition of genetic information in conjunction with employee health programs and genetic
11 monitoring.
12

13 The Drafting Committee was informed that an employment entity that provides genetic
14 testing under one of these exceptions should supply it through an outside medical organization.
15 *See* Mark A. Rothstein, *Genetics and the Workforce of the Next Hundred Years*, 2000 Colum.
16 Bus. L. Rev. 371 (2000). This may not, however, be the case, which makes it particularly
17 important to protect employee privacy in wellness and monitoring programs.
18

19 Subparagraph (1) mandates genetic counseling and applies to employee wellness
20 programs and when genetic monitoring is conducted with an employee's authorization. It
21 provides that an employee must have genetic counseling prior to authorizing a test in order to be
22 able to make an informed decision about the risks and benefits of the test and the knowledge that
23 would result. This entails the counseling functions defined in subparagraphs (A)-(C) of the
24 definition of genetic counseling in Section 2(10). An employee has the right to refuse this
25 counseling, but only after being informed of the benefits of the counseling. Genetic counseling
26 may be provided by a genetic counselor, but may also be provided by a qualified physician or
27 geneticist.
28

29 Subparagraph (2) provides for reporting genetic test results to the employee when an
30 employment entity supplies testing. Not all individuals, however, wish to know their genetic
31 information; some may decide not to learn test results because of the psychological burdens that
32 may accompany such knowledge. So the act also recognizes an employee's right to decline to
33 know the results of a genetic test.
34

35 Subparagraph (3) mandates the availability of genetic counseling so that the test results
36 can be interpreted for the employee if the test result indicates a disease or disorder or an
37 increased risk for a disease or disorder. This entails the counseling functions defined in
38 subparagraphs (D)-(E) of the definition of genetic counseling in Section 2(10). Again, genetic
39 counseling may be provided by a genetic counselor, but may also be provided by a qualified
40 physician or geneticist.
41

42 Subparagraph (4) provides for destruction of the sample obtained for testing. The prompt

1 destruction of a sample obtained for genetic testing supplied by an employer protects the
2 employee's privacy by preventing subsequent testing of the sample. The subparagraph also
3 recognizes, however, that a testing laboratory is required to retain samples for certain time
4 periods for certification testing and other purposes. The provision follows statutes adopted in
5 New Jersey and Oregon. N.J. Stat. Ann. § 10:5-46 (West 2002); Or. Rev. Stat. § 192.537 (2007).
6

7 Possible alternative approaches (1) put the burden on the employee by requiring that the
8 sample be destroyed promptly on the request of the individual tested or (2) specify that a sample
9 may be retained for a period of time. Some provisions combine elements of more than one
10 approach. In New York, for example, a sample may be retained for ten years if authorized by the
11 individual from whom the sample was obtained. The Drafting Committee decided that the
12 placing the burden for destruction of the sample on the employment entity best protects an
13 employee's privacy.
14

15 Subparagraph (5) addresses advances in testing methodology, which now typically collect
16 information from multiple portions of the genome that can be analyzed to examine for a suite of
17 potential genetic traits. Before long, genetic testing may routinely involve a full genome scan.
18 This means that a machine has generated a great deal of genetic information, even if it is not all
19 analyzed by a bioinformatics system or used by the medical professional interpreting the tests
20 that were authorized by the individual. Under subparagraph (5), this information should be
21 destroyed along with the biological sample if it is not relevant to the authorized tests. Again, the
22 subparagraph also recognizes, however, that a testing laboratory may be required to retain this
23 information for a certain time period.
24

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

27 (a) Except as otherwise provided by law other than this [act], an authorization of an
28 employee or a family member of the employee for an employment entity to acquire the
29 individual's genetic information or provide a genetic test must be knowing and voluntary and
30 indicated in a record signed by the individual prior to the acquisition or test. An employment
31 entity that receives an authorization may use the genetic information or analyze a genetic test
32 only in accordance with the authorization. The authorization may not expand the authority of the
33 employment entity to acquire or use genetic information or to provide genetic testing beyond that
34 permitted by this [act]. The authorization may not waive any right of the employee or the family
35 member of the employee under federal law or the law of this state. The employment entity shall

1 provide a copy of the authorization to the employee or the family member of the employee who
2 signed the authorization.

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

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

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

- 11 (1) describe the test to be performed, its purpose, and the authorized uses of the
12 test result;
- 13 (2) inform the individual that the authorized test will be analyzed only for the
14 purposes specified in the authorization;
- 15 (3) explain the benefit of receiving genetic counseling about the risks and benefits
16 of the test before the individual authorizes the test;
- 17 (4) inform the individual that the employment entity is obligated to provide
18 genetic counseling before the individual authorizes the test, unless the individual waives genetic
19 counseling;
- 20 (5) if the test is part of a genetic monitoring program, inform the individual that
21 the employment entity is obligated to pay for genetic counseling before the individual authorizes
22 the test, unless the individual waives genetic counseling;
- 23 (6) inform the individual that the test result will be reported to the individual and a

1 health-care professional designated by the individual unless the individual directs otherwise;

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

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

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

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

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

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

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

21 **Reporter's Notes**

22
23 This section sets forth an authorization requirement for genetic testing and certain
24 acquisitions of genetic information by an employment entity and specifies the elements that must
25 be contained in an authorization form. It applies to the situations in which an employment entity
26 is permitted to acquire genetic information or conduct genetic testing with the consent of the

1 employee or family member of the employee: providing genetic services as part of a wellness
2 program, conducting a genetic monitoring program, and (for acquisition only) at the employee’s
3 behest. This authorization requirement, coupled with statutory limits and duties imposed on
4 employment entities by the act, is designed to maintain privacy for genetic testing and genetic
5 information. It does not, however, substitute for otherwise applicable authorization requirements
6 such as those mandated by HIPAA. The term “authorization” is used instead of “informed
7 consent” to avoid confusion with the use of that term in medical practice.
8

9 The Drafting Committee considered, but did not adopt, alternatives to authorization that
10 would (1) establish a general property right in a biological sample an individual provides for
11 genetic testing and in the resulting genetic information or (2) establish a limited property right in
12 genetic information applicable only to the context of employment.
13

14 *Relationship to GINA.* The section’s requirements for the content of an authorization
15 include the requirements in GINA and its proposed regulations, but also require a separate
16 authorization for genetic testing. GINA requires employee authorization when an employer
17 acquires genetic information in connection with providing health or genetic services and when an
18 employer conducts a monitoring program that is not required by law. In those circumstances,
19 GINA requires an employee authorization that is “prior, knowing, voluntary, and written.” *E.g.*,
20 42 U.S.C. § 2000ff-1(b)(2)(B), (b)(5)(B)(I) (Supp. II 2008). In addition, the proposed GINA
21 regulations also require that the authorization be written so that the person from whom the
22 genetic information is being obtained is reasonably likely to understand the form; that the form
23 describe the type of genetic information that will be obtained and the general purposes for which
24 it will be used; and that the form describe the restrictions on disclosure of genetic information.
25 29 C.F.R. § 1635.8(b)(2)(i), (b)(5)(i).
26

27 *Subsection (a) Requirement for authorization for acquisition of genetic information and*
28 *for genetic testing.* Subsection (a) sets forth the basic requirements that authorization must be
29 knowing and voluntary and memorialized in a record prior to the acquisition or testing. It limits
30 an employment entity’s use of genetic information and the tests it provides to those specified in
31 the authorization and makes clear that the authorization should not be interpreted to waive any of
32 the employee’s rights. An employment entity’s use of genetic information or analysis of a
33 genetic test is legal only if the employee’s authorization is valid and meet the requirements of
34 this section.
35

36 When an employee is considering authorizing genetic testing, the employee should have
37 genetic counseling before signing the authorization in order to meet the requirement of this
38 subsection that an authorization is knowing and voluntary. Genetic counseling provides
39 employees with adequate information to make an informed decision about genetic testing. It also
40 makes them aware of their options regarding reporting of test results and help in interpreting
41 them through genetic counseling. An employment entity that offers a genetic test as part of a
42 health program or genetic monitoring program has an obligation to provide genetic counseling
43 under Section 13. Genetic counseling may be provided by a genetic counselor, but may also be
44 provided by a qualified physician or geneticist. An employee may waive genetic counseling, but
45 must first be made aware of the benefits of genetic counseling.
46

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

3
4 The Drafting Committee anticipates that there might be circumstances in which an
5 individual is incapacitated or incapable of authorizing a genetic test. Other law of the state may
6 provide for a substitute decisionmaker or signer for the authorization if the employee is
7 incapacitated or incompetent. Revocation of an authorization by a substitute is similarly left to
8 existing law of the state that governs power of attorney, guardianship, or other substitute decision
9 makers.

10
11 *Subsection (b) Content of authorization for acquisition of genetic information.* This
12 subsection follows the GINA requirements for authorization for acquisition of genetic
13 information and is consistent with the proposed implementing regulations.

14
15 *Subsection (c) Content of authorization for genetic testing.* Before any genetic testing
16 can be performed, unless the testing is required by law, an employee must affirmatively authorize
17 the genetic testing and the employment entity's acquisition of the resulting genetic information.
18 Sections 9 and 10 provide for limited situations in which employment entities may request
19 authorization for testing from employees: an employment entity may supply genetic tests as part
20 of health or genetic services, but only with prior authorization from the employee, and as part of
21 a genetic monitoring program, but only if required by law or with prior authorization from the
22 employee.

23
24 This subsection builds on the GINA requirements for authorization for acquisition of
25 genetic information so that it applies to the situation when that acquisition involves offering a
26 genetic test. It draws on N.Y. Civ. Rights Law § 79-1 (McKinney 2009), which establishes
27 requirements for consent for a genetic test.

28
29 The requirements in subsection (c)(3), (4), (5), (7), and (8) reflect the obligations of the
30 employment entity to provide genetic counseling under Section 13.

31
32 The notification provisions regarding destruction of the sample and ancillary testing data
33 in (c)(10) and (11) are consistent with the employment entity's obligation to ensure that the
34 sample and this data are destroyed under Section 13, which recognizes that the testing laboratory
35 may be required to retain the sample or data for certification purposes.

36
37 **SECTION 15. FORM FOR AUTHORIZATION FOR ACQUISITION OF**
38 **GENETIC INFORMATION.** An authorization substantially in the following form, when
39 completed and signed, satisfies Section 14(b).

1 AUTHORIZATION FOR ACQUISITION OF GENETIC INFORMATION

2
3 I, _____, authorize _____ to acquire
4 Printed name Name of employment entity

5
6 my genetic information as checked below.

7
8 PURPOSE FOR PROVIDING GENETIC INFORMATION

9
10 _____ This genetic information is provided for a voluntary genetic monitoring program
11
12 conducted by _____. _____ may use
13 Name of employment entity Name of employment entity
14
15 this information only for the following purposes: _____.
16 Authorized uses

17
18 _____ This genetic information is provided for _____, a voluntary program
19 Name of program
20
21 offered by _____ to provide health and genetic services.
22 Name of employment entity

23
24 _____ may use this information only for the following purposes:
25 Name of employment entity
26
27 _____.
28 Authorized uses

29
30 _____ This genetic information is provided to _____ at my
31 Name of employment entity
32
33 initiative and by my voluntary submission for the following purpose: _____.
34 Authorized uses

35
36 TYPE OF GENETIC INFORMATION

37
38 _____ Family medical history
39
40 Family medical history is information concerning diseases and disorders of family
41
42 members and other relatives.

43
44 _____ My genetic test results: _____
45 Name of genetic test
46

1 Genetic tests are tests of DNA, RNA, chromosomes, or other material to determine your
2
3 genetic characteristics. If _____ will provide the genetic tests,
4 Name of employment entity
5
6 a separate authorization is necessary.

7
8 NOTICE CONCERNING DISCLOSURE OF YOUR GENETIC INFORMATION
9

10 If this genetic information is provided for a voluntary genetic monitoring program or a
11
12 voluntary program to that provides health and genetic services, only you, a health-care
13
14 professional whom you designate, and health-care professionals involved in providing the
15
16 program will have access to your individual genetic information. Otherwise,
17
18 _____ may not have access to your genetic information except in
19 Name of employment entity
20
21 an aggregate form that may not identify you. However, your genetic information may be
22
23 disclosed to (1) certain health researchers, (2) government officials investigating compliance with
24
25 laws protecting the privacy of genetic information or prohibiting genetic discrimination, (3) a
26
27 public health agency if the test result concerns a life-threatening contagious disease, (4) if
28
29 expressly ordered by a court, arbitral tribunal, or administrative agency, or (5) if you request and
30
31 authorize a disclosure.

32
33 YOUR LEGAL RIGHTS
34

35 By signing this authorization, you do not waive any legal rights to which you are entitled.
36
37 You are entitled to a copy of this authorization.

38
39 SIGNATURE OF INDIVIDUAL MAKING THIS AUTHORIZATION
40

41 _____
42 Signature

41 _____
42 Date

43
44 **Reporter's Notes**
45

46 This section provides guidance to employment entities on appropriate content for forms.

1 The use of a form following the pattern in this section, when properly completed and signed,
2 complies with the requirements of Section 14. The Drafting Committee decided that it prefers
3 having the forms in the black-letter law instead of in the comments. There is precedent for this
4 in other NCCUSL acts.
5

6 **SECTION 16. FORM FOR AUTHORIZATION OF GENETIC TESTING.** An
7 authorization substantially in the following form, when completed and signed, satisfies Section
8 14(c).

9 **AUTHORIZATION FOR GENETIC TESTING**

10 **LIMITED AUTHORIZATION**

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

13 **AVAILABILITY OF GENETIC COUNSELING BEFORE SIGNING THIS AUTHORIZATION**

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

19 _____ will provide [and pay for] this genetic counseling.
20
21 Name of employment entity

22 **PROPOSED GENETIC TESTS**

23 _____ proposes to provide the following genetic tests:
24
25 Name of employment entity

26 _____ . This test is provided as part of a genetic monitoring program. The
27
28 Name of test
29
30 purpose of this test is to monitor the effect of your exposure to _____ .
31
32 Workplace condition

1 The result of the test will be used only for the following purposes: _____.
2 Authorized uses
3

4 _____ . This test is provided by _____.
5 Name of test Name of health or genetic services program
6

7 The result will be used only for the following purposes: _____.
8 Authorized uses
9

10 REPORTING TEST RESULTS AND GENETIC COUNSELING

11 The test results will be reported to you and to a health-care professional whom you
12 designate unless you direct otherwise. It is recommended that you receive genetic counseling
13 about the test results. Genetic counseling is important for understanding the test results in the
14 context of your medical and family history. It can also provide you with support, informational
15 resources, and referrals, as appropriate, that can help you adapt to the implications of being at
16 risk of a genetic condition. _____ will provide and [pay for] genetic
17 Name of employment entity
18 counseling about the test results unless you decline genetic counseling.
19
20
21
22
23
24
25
26

27 NOTICE CONCERNING DISCLOSURE OF THE TEST RESULTS

28 Other than the medical professionals involved in providing this program,
29 _____ will not have access to the test results of the individuals who
30 Name of employment entity
31 authorize this test except in an aggregate form that will not identify you. However, the test
32 results may be disclosed to (1) certain health researchers, (2) government officials investigating
33 compliance with laws protecting the privacy of genetic information or prohibiting genetic
34 discrimination, (3) to a public health agency if the test result concerns a life-threatening
35 contagious disease, (4) if expressly ordered by a court, arbitral tribunal, or administrative agency,
36 or (5) if you request and authorize a disclosure.
37
38
39
40
41
42
43
44
45

46 DESTRUCTION OF YOUR BIOLOGICAL SAMPLE AND TESTING DATA

1 After the genetic test, your biological sample and data that is not necessary for the test
2
3 you authorized will be destroyed as soon as practicable unless you authorize otherwise in writing
4
5 or a court, arbitral tribunal, or administrative agency requires retention of the sample.
6

7 YOUR LEGAL RIGHTS
8

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

10
11 You are entitled to a copy of this authorization.
12

13 AUTHORIZATION
14

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

17
18 ___ I wish to receive test results.

19
20 ___ I do not wish to receive test results.

21
22 ___ Report test results to the following health-care professional:
23

24 Name: _____

25 Address: _____

26
27 Phone: _____
28
29

30 ___ Do not report test results to a health-care professional.
31

32 SIGNATURE OF INDIVIDUAL MAKING THIS AUTHORIZATION
33

34 _____
35 Signature

_____ Date

36
37 **Reporter's Notes**
38

39 This section provides guidance to employers on appropriate content for forms. The use of
40 a form following the pattern in this section, when properly completed and signed, complies with
41 the requirements of Section 14. The Drafting Committee decided that it prefers having the forms
42 in the black-letter law instead of in the comments. There is precedent for this in other NCCUSL
43 acts.
44

1 **SECTION 17. PROHIBITION OF USE OF GENETIC INFORMATION.**

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

6 (b) An employment agency may not take an adverse employment action against an
7 individual based on the individual's genetic information, including failing or refusing to refer the
8 individual for employment or discriminating against the individual.

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

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

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

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

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

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

7 (1) opposed an act or practice in violation of the federal Genetic Information
8 Nondiscrimination Act, 42 U.S.C. Section 2000ff et seq., or this [act]; or

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

12 **Reporter's Notes**

13
14 This section is based on the anti-discrimination provisions in GINA, supplemented to
15 prohibit employment entities from taking any adverse employment action based on genetic
16 information.

17
18 GINA has a separate statutory section defining unlawful employment practices for each
19 type of employment entity. 42 U.S.C. §§ 2000ff-1(a), 2000ff-2(a), 2000ff-3(a), 2000ff-4(a)
20 (Supp. II 2008). This section consolidates the provisions as much as possible while using the
21 terminology of GINA.

22
23 GINA does not contain the provision on retaliation in subsection (h), but the EEOC has
24 added it into the proposed regulations. 29 C.F.R. § 1635.7. This omission from the statute
25 illustrates the dangers of enumerating adverse employment actions and the importance of adding
26 the clauses that generally prohibit adverse employment actions. Subsection (e) governing
27 credentialing authorities is another departure from GINA. Both additional provisions provide
28 employees greater protection.

29
30 *Prohibition of adverse employment decisions.* GINA prohibits the actions listed in each
31 subsection. The uniform act also more generally prohibits adverse employment actions in order
32 to make sure that employee protections are not limited by omission of an employment actions
33 from the list in GINA. The lists of prohibited actions taken from GINA are not exclusive. The
34 word “including” should be read as “including, but not limited to.”
35

1 “Adverse employment decision” is a term of art in employment law that the Drafting
2 Committee decided does not need to be defined in this act. The term should be interpreted
3 broadly. One example of a broad statement of adverse employment actions can be found in the
4 District of Columbia Human Rights Act, which makes it a discriminatory practice for an
5 employer “[t]o fail or refuse to hire, or to discharge, any individual; or otherwise to discriminate
6 against any individual, with respect to his compensation, terms, conditions, or privileges of
7 employment, including promotion; or to limit, segregate, or classify his employees in any way
8 which would deprive or tend to deprive any individual of employment opportunities or otherwise
9 adversely affect his status as an employee.” D.C. Code § 2-1402.11 (2008).

10
11 *Rationale for limiting actions of employment entities.* The restrictions on employment
12 actions in GINA and this act are important because they will dispel uncertainty about how courts
13 would otherwise apply federal statutes to decisions based on genetic information that predicts
14 employee susceptibility to harm from workplace exposures. On one hand, in 1991 the United
15 States Supreme Court held that a chemical company’s policy barring women of child-bearing age
16 from employment opportunities that involved exposure to lead violated Title VII prohibitions on
17 gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187 (1991). On the
18 other hand, the ADA allows employers to act on health information, even in the case of
19 disability, when there is a direct threat to the health or safety of others in the workplace. The
20 Equal Employment Opportunity Commission (EEOC) has interpreted this ADA provision to
21 apply when there is no risk to others but when an employer can show that an individual’s
22 disability poses a significant risk of harm to the individual. The United States Supreme Court
23 upheld this interpretation. *Chevron v. Echazabal*, 122 S. Ct. 2045 (2002). Although the
24 *Echazabal* case did not involve a genetic characteristic, but rather a worker’s liver damage due to
25 exposure to workplace solvents, the implication of the case is that in the absence of a prohibition
26 in a state statute, an employer may make adverse employment decisions based on genetic
27 screening or monitoring requested by an employee even if there is no threat to others. This
28 section does not permit an employer to take an adverse employment action under these
29 circumstances. Harm to the employee or to others is not a justification. As a result, employers
30 would not be able to use an employee’s genetic information in the way the employee’s health
31 information was used in the *Echazabal* case.

32
33 Note that the section does not necessarily prevent an employer from making decisions
34 based on the effects of an employee’s manifest genetic condition or disease in the workplace.
35 This is because the protections in this section involve the use of “genetic information,” which is
36 defined with reference to a “genetic test.” In addition, Section 3 makes clear that employment
37 entities may acquire and use medical information about a manifested disease, even one with a
38 genetic basis, if that medical information is not genetic information. In addition to the
39 protections of this section, some employees with manifest genetic conditions would be covered
40 under the ADA if the condition limits a major life activity. But there is no comprehensive
41 protection for individuals with medical conditions that result from genetic traits. While some
42 maintain that attempts to prevent genetic discrimination are mostly meaningless without
43 protection for people who have genetic diseases, *see* Mark A. Rothstein, *Genetic Privacy and*
44 *Confidentiality: Why They are so Hard to Protect*, 26 J. L. Med. & Ethics 181 (1998), others
45 emphasize the difficulties with either policy choice, *see* Henry T. Greely, *Genotype*
46 *Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483,

1 1503 (2001).

2
3 *Existing state law.* Many state statutes limit use of genetic information by prohibiting
4 discrimination among employees or applicants for employment on the basis of genetic
5 information. Ark. Code Ann. § 11-5-403 (2002); 410 Ill. Comp. Stat. Ann. 513/25 (West 2005 &
6 Supp. 2010); Kan. Stat. Ann. § 44-1009 (2008); La. Rev. Stat. Ann. § 23:368 (2010); Me. Rev.
7 Stat. Ann. tit. 5, § 19302 (2002); Md. Code Ann., State Gov't § 20-606 (LexisNexis 2009);
8 Mass. Ann. Laws ch. 151B, § 4 (LexisNexis 2008); Mich. Comp. Laws Ann. § 37.1202 (West
9 2001); Mo. Ann. Stat. § 375.1306 (West 2002); Neb. Rev. Stat. Ann. § 48-236 (LexisNexis
10 2007); Nev. Rev. Stat. Ann. § 613.345 (LexisNexis 2006); N.J. Stat. Ann. § 10:5-12 (West 2002
11 & Supp. 2010); N.Y. Exec. Law § 296 (McKinney 2010); N.C. Gen. Stat. § 95-28.1A (2009);
12 Okla. Stat. Ann. tit. 36, § 3614.2 (West 1999); Or. Rev. Stat. § 659A.303 (2007); R.I. Gen. Laws
13 § 28-6.7-1 (2003); S.D. Codified Laws § 60-2-20 (2009); Tex. Lab. Code Ann. § 21.402 (Vernon
14 2006). However, these statutes do not all provide protections as comprehensive as those in
15 GINA and this act.

16
17 Other states more generally ban any use of genetic information in employment. For
18 example, New Mexico's 2005 statute provides simply that "[i]t is unlawful for a person to use
19 genetic information in employment," N.M. Stat. Ann. § 24-21-4 (LexisNexis 2007). In
20 Utah, employers may not take into account genetic information about an individual in connection
21 with an employment decision. Utah Code Ann. § 26-45-103 (2007). Similarly, in Iowa, an
22 employer may not use genetic information to "affect the terms, conditions, or privileges of
23 employment" of a person who gets a genetic test, Iowa Code Ann. § 729.6(2) (West 2003 &
24 Supp. 2010), and in Idaho an employer may not consider private genetic information "in
25 connection with a hiring, promotion, retention, or other related decision, Idaho Code Ann. § 39-
26 8303(1)(a) (Supp. 2009). Most comprehensively, Minnesota and Wisconsin prohibit any adverse
27 employment actions based on genetic information. Minn. Stat. Ann. § 181.974(subd. 2(a)(2))
28 (West 2006) (may not "affect the terms or conditions of employment or terminate the
29 employment of any person based on protected genetic information"); Wis. Stat. Ann. § 111.372
30 (West 2002) (may not "affect terms, conditions or privileges of employment, labor organization
31 membership or licensure or terminate the employment or labor organization membership or
32 licensure").
33

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

39 **Reporter's Notes**
40

1 This section supplements GINA and is more protective of the employee than the federal
2 statute. GINA allows employment entities to provide an employee’s genetic information to the
3 employee as an exception to its general prohibition on disclosure, 42 U.S.C. § 2000ff-5(b)(1)
4 (Supp. II 2008), but it does not give an employee a right to obtain this information. This section
5 is based on the conclusion that an employee ought to be able to find out what genetic information
6 an employer knows about an employee and to have the same information. It is modeled on Del.
7 Code Ann. tit. 16, § 1223 (2003).

8
9 This section also provides a mechanism for an employee to supplement or correct genetic
10 information contained in employer records. The right to correct genetic information also
11 includes expungement of information that should not be in a particular record. For example, an
12 employer may have incorrectly placed genetic information in an employee’s personnel file
13 instead of segregating it as required by Section 19.

14
15 If the employer supplied the genetic testing, information may also be kept in files at the
16 laboratory that performed the testing. The employer’s responsibility to correct errors does not
17 extend to the testing laboratory, which is regulated under the Clinical Laboratory Improvement
18 Amendments, (CLIA), 42 U.S.C. § 263a (2006).

19
20 The Drafting Committee considered but rejected an exception that would have prohibited
21 employee access to information an employment entity has compiled for litigation. This situation
22 will be governed by normal discovery rules, which are unaffected by this section.
23

24 **SECTION 19. CONFIDENTIALITY AND RETENTION OF GENETIC**

25 **INFORMATION.** Except for genetic information an employment entity obtains in aggregate
26 form under Section 9 for use in providing health or genetic services and under Section 10 for use
27 in conducting genetic monitoring:

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

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

33 (3) The requirement of subparagraph (2) is satisfied if an employment entity keeps the
34 genetic information in the record in which it maintains confidential medical information subject

1 to the Americans with Disabilities Act of 1990, Section 102(d)(3)(B), 42 U.S.C. Section
2 12112(d)(3)(B)[, as amended].

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

6 **Reporter’s Notes**

7
8 *Aggregate information for wellness or genetic monitoring programs.* Under Sections 9
9 and 10, an employment entity is allowed to acquire genetic information for the operation of a
10 wellness program or a genetic monitoring program, but only in an aggregate form that does not
11 identify individual employees. An employment entity may retain this aggregate information,
12 which would not be associated with any employee’s personnel file. Retention and disclosure of
13 aggregate information may be necessary in order to analyze trends or take action to reduce risk in
14 the workplace.

15
16 *Subparagraph (1) Confidentiality.* This subsection declares that genetic information,
17 which includes family medical history, is confidential in the employment context. “Genetic
18 information” is a category that includes information about use of or request for genetic services,
19 so this section also protects an employee’s authorizations concerning genetic tests or information.
20 This subsection is consistent with GINA, which provides that genetic information shall be treated
21 as a confidential medical record. 42 U.S.C. § 2000ff-5(a) (Supp. II 2008).

22
23 *Subparagraph (2) Retention of genetic information.* This provision follows the approach
24 of GINA and operates if an employer “possesses” genetic information. 42 U.S.C. § 2000ff-5(a)
25 (Supp. II 2008). It does not require an employee to authorize retention of the information. The
26 protections apply to any genetic information maintained by the employment entity. They are not
27 limited by the manner in which the employment entity obtained the genetic information and they
28 apply to any genetic information from any source, even if the acquisition was inadvertent.

29
30 Employment entities may retain genetic information without the burden of obtaining
31 employee authorization to maintain the information. They must protect the employee’s privacy,
32 however, by maintaining it as confidential information and by segregating this information from
33 the employee’s personnel file. The purpose of the segregation requirement is to protect
34 confidentiality and reduce the chance that the information will be inadvertently disclosed along
35 with other employee records. The segregation requirement applies generally to records. This
36 includes electronic files as well as paper documents.

37
38 *Subparagraph (3) Coordination with the Americans with Disability Act.* This provision
39 follows GINA. 42 U.S.C. § 2000ff-5(a) (Supp. II 2008). There is a need for coordination with
40 the ADA because many employers will acquire genetic information when they acquire an
41 employee’s medical records, which they may request under the ADA after a conditional offer of
42 employment or during employment for job-related purposes. Genetic information is likely to be
43 interspersed throughout medical records and an employer that requests medical information is
44 likely to receive an entire file, including genetic information. GINA addresses this by allowing

1 employers to keep genetic information with confidential medical information acquired under the
2 ADA so long as both types of information are retained as confidential records.

3
4 The cross-reference to the ADA as amended creates delegation issues in some states.
5 This reference should be deleted in states where the cross-reference would constitute an
6 unconstitutional delegation of legislative authority.
7

8 **SECTION 20. DISCLOSURE OF GENETIC INFORMATION.**

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

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

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

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

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

23 (4) to the extent ordered by a tribunal;

24 (5) in response to an official request from a government official who is
25 investigating compliance with this [act] or with the Genetic Information Nondiscrimination Act,
26 42 U.S.C. Section 2000ff through 2000ff-11, if the information is responsive to the government's

1 request;

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

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

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

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

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

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

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

9 10 **Reporter’s Notes**

11
12 This section follows the format of GINA, 42 U.S.C. § 2000ff-5(b) (Supp. II 2008), which
13 contains a general prohibition on disclosure of genetic information by employers coupled with
14 exceptions. It supplements GINA by permitting disclosures at the request of the employee and
15 by providing for authorization of those disclosures.

16
17 *Existing state law.* A number of states that have enacted general privacy protections for
18 genetic information that prohibit disclosure without informed consent or authorization. *E.g.*,
19 Alaska Stat. § 18.13.010 (2008); Cal. Civ. Code § 56.10 (West 2007 & Supp. 2010); Del. Code
20 Ann. tit. 16, § 1221 (2003); Fla. Stat. Ann. § 760.40 (West 2010); Me. Rev. Stat. Ann. tit. 22, §
21 1711-C (2004 & Supp. 2009); Mass. Ann. Laws ch. 111, § 70G (LexisNexis 2004); Minn. Stat.
22 Ann. § 13.386 (West Supp. 2010); N.H. Rev. Stat. Ann. § 141-C:10 (2005); N.M. Stat. Ann. §
23 24-21-3 (LexisNexis 2007); N.Y. Civ. Rights Law § 79-1 (McKinney 2009); Or. Rev. Stat. §
24 192.539 (2007). Other states have specific protections against the disclosure of genetic
25 information by employers. *E.g.*, Cal. Civ. Code § 56.20 (West 2007 & Supp. 2010); Ill. Comp.
26 Stat. Ann. 513/25 (West 2005 & Supp. 2010); La. Rev. Stat. Ann. § 23:368 (2010); Mass. Ann.
27 Laws ch. 151B, § 4 (LexisNexis 2008); R.I. Gen Laws § 28-6.7-1 (2003).

28
29 *Subsection (a) General prohibition on disclosure of genetic information.* This subsection
30 follows GINA and establishes a blanket rule that employment entities may not disclose
31 employee’s genetic information, subject to limited exceptions.

32
33 *Subsection (b) Permitted disclosures.* This subsection sets forth the circumstances under
34 which an employer may disclose an employee’s genetic information.

35
36 Subsection (b)(1) permits an employment entity to disclose genetic information to the
37 individual whom it concerns. This permission is consistent with the employee’s right of access
38 to the employee’s genetic information established by Section 18. GINA includes a parallel
39 provision. 42 U.S.C. § 2000ff-5(b)(1) (Supp. II 2008).

40
41 Subsection (b)(2) goes beyond GINA and respects employee autonomy by providing for
42 disclosures to third parties when an employee requests the disclosure and provides a knowing

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

3
4 Other law of the state may provide for a substitute decisionmaker or signer for the
5 authorization if the employee is incapacitated or incompetent. Revocation of an authorization by
6 a substitute is left to existing law of the state that governs power of attorney, guardianship, or
7 other substitute decision makers.

8
9 As a matter of good business practice, an employment entity should retain an employee's
10 authorization for disclosure of genetic information. An authorization for disclosure of genetic
11 information contains genetic information and so should be kept separately from the employee's
12 personnel file.

13
14 Subsection (b)(3) is parallel to GINA, 42 U.S.C. § 2000ff-5(b)(2) (Supp. II 2008), and
15 permits disclosures to occupational and health researchers so long as they comply with federal
16 policy for protection of human research subjects.

17
18 Subsection (b)(4) is parallel to GINA, 42 U.S.C. § 2000ff-5(b)(3) (Supp. II 2008), and
19 permits disclosures in response to an order from a court, arbitral tribunal, or administrative
20 agency. Disclosure of genetic information is limited to genetic information explicitly included in
21 the terms of the order. The provision does not authorize other disclosures in connection with
22 litigation such as in response to a discovery request, unless ordered by the tribunal. Subsection
23 (d) requires the employer to give the employee notice of this disclosure unless the employee has
24 otherwise received notice of the disclosure in the course of the legal proceedings.

25
26 Subsection (b)(5) is parallel to GINA, 42 U.S.C. § 2000ff-5(b)(4) (Supp. II 2008), and
27 permits disclosures to government officials investigating compliance with the act or with GINA.

28
29 Subsection (b)(6) is parallel to GINA, 42 U.S.C. § 2000ff-5(b)(5) (Supp. II 2008), and
30 permits disclosures made in conjunction with the Family Medical Leave Act or state or local
31 leave law.

32
33 Subsection (b)(7) is parallel to GINA, 42 U.S.C. § 2000ff-5(b)(6) (Supp. II 2008), and
34 permits disclosure of genetic information to public health authorities in connection with a
35 contagious disease that creates an imminent threat of death or life-threatening illness. If a
36 disclosure is made under this subsection without notice to the employee, the employer must
37 provide notice to the employee under subsection (c).

38
39 Under this subsection, there is no violation of the act if a public health office requests
40 medical information in connection with a serious contagious disease and the information
41 provided by the employer includes genetic information. In addition, disclosures of genetic
42 information may be directly relevant to the spread of a contagious disease if some individuals are
43 more susceptible to the disease because of their genetic make-up.

44
45 Subsection (b)(8) permits disclosures of aggregate genetic information obtained as part of
46 a health or genetic services program or a genetic monitoring program under Sections 9 or 10.

1 This provision supplements GINA.

2
3 *Subsection (c) Notice to employee of disclosures.* These limited requirements that an
4 employment entity provide notice to an employee of disclosure of genetic information are
5 parallel to GINA. 42 U.S.C. § 2000ff-5(b)(3)(B), (b)(6) (Supp. II 2008).

6
7 *Subsection (d) Authorization for disclosure of genetic information.* An employee or
8 employee’s family member may request and authorize disclosure of their genetic information.
9 This might happen, for example, if an employment entity possesses genetic information obtained
10 as part of operating an employee wellness program that the employee would like to submit to a
11 third party. The general requirements for a valid authorization are the same as those for
12 authorizations of acquisition of genetic information or genetic testing under Section 14. The
13 authorization is relatively simple, but must describe the genetic information to be disclosed,
14 identify the person to whom the genetic information is to be disclosed, indicate how long the
15 authorization is effective, and state that the individual is entitle to a copy of the authorization. If
16 the employment entity is a covered entity under HIPAA, however, it must comply with the
17 disclosure requirements of the HIPAA Privacy Rule.
18

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

22 AUTHORIZATION FOR DISCLOSURE OF GENETIC INFORMATION

23
24 I, _____, authorize _____ to disclose
25 Printed name Name of employment entity
26
27 my following genetic information _____ to
28 Specific description of genetic information
29

30 _____
31 Identity of person or entity to receive the disclosure

32
33 _____ This authorization is for one disclosure only.

34
35 _____ This authorization continues in effect until I revoke it.

36
37 _____ This authorization continues in effect until _____.
38 Date

39
40 _____
41 Signature

40 _____
41 Date

1 **Reporter's Notes**

2
3 Section 20(b) permits an employment entity to disclose genetic information to a third
4 person at the request of an employee or an employee's family member and Section 20(d)
5 describes the requirements for a valid authorization. This section provides guidance on the
6 appropriate content for an authorization form. The use of a form following the pattern of this
7 section, when properly completed and signed, complies with the requirements of Section 20(d).
8 As indicated in Section 22, employment entities that are covered entities under HIPAA are
9 subject to HIPAA requirements for use and disclosure of genetic information.
10

11 **SECTION 22. RELATIONSHIP TO HEALTH REGULATIONS.** This [act] does
12 not prevent a covered entity under the regulations issued by the Secretary of Health and Human
13 Services pursuant to Section 264(c) of the Health Insurance Portability and Accountability Act,
14 42 U.S.C. Section 1320d-2 note, from using or disclosing health information which is authorized
15 for a covered entity by the regulations.

16 **Reporter's Notes**

17
18 This section concerns the interaction of the act's provisions with HIPAA requirements
19 when an employment entity is also a covered entity under HIPAA. The section makes clear that
20 when a covered entity obtains information that is protected health information under the HIPAA
21 Privacy Rule, the entity is governed by the HIPAA rule. For example, if a hospital's employee
22 becomes a patient, the hospital's acquisition and use of that patient's genetic information is
23 governed by the HIPAA privacy rule, not GINA or this act.
24

25 The language of this section closely follows GINA section 206, 42 U.S.C. § 2000ff-5(c)
26 (Supp. II 2008). The proposed EEOC regulation implementing GINA, 29 CFR § 1635.11(d),
27 takes a slightly different approach. It provides that the employment provisions of GINA do not
28 apply to genetic information that is protected health information under the HIPAA Privacy Rule.
29 This has a broader meaning and the Drafting Committee decided to adhere to GINA's narrower
30 formulation.
31

32 **SECTION 23. REMEDIES; LIMITATION OF ACTIONS.**

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

35 [(b) An individual may seek remedies provided by law other than this [act]. Exhaustion

1 of administrative remedies is not required before seeking relief for a violation of this [act].]

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

4 **Reporter’s Notes**

5
6 For private employees, GINA adopts the enforcement and remedy structure of Title VII of
7 the Civil Rights Act of 1964, 42 U.S.C. § 2000e-4 et seq. (2006), incorporating it by reference.
8 42 U.S.C. § 2000ff-6(a) (Supp. II 2008). For the other employee groups it covers – state, federal,
9 and congressional employees – GINA incorporates the slightly different remedy provisions of the
10 other relevant federal EEO statutes. 42 U.S.C. § 2000ff-6(b) through 42 U.S.C. § 2000ff-6(e)
11 (Supp. II 2008). GINA explicitly excludes, however, claims for disparate impact, a cause of
12 action for unintentional discrimination that is available under Title VII. 42 U.S.C. § 2000ff-7
13 (Supp. II 2008).
14

15 This section follows the pattern of many of the state EEO statutes that supplement Title
16 VII and other federal civil rights statutes by providing a private cause of action. Because of the
17 variety of approaches taken by the states, the act allows a state some leeway to tailor remedies for
18 consistency with those in other state EEO statutes. The forms of available relief are to be
19 determined under state law. In addition, while the act includes a provision allowing a claimant to
20 file a private cause of action without exhausting administrative remedies under GINA and, if
21 applicable, under state administrative avenues, this provision is placed in brackets in order to
22 leave the exhaustion decision to the state. As in the federal EEO statutes, the section provides
23 for fee shifting for prevailing employees to compensate for their cost to enforce the statute.
24

25 *Background on GINA’s administrative procedures and the federal private cause of*
26 *action.* Under Title VII, and hence by reference under GINA, if there is a state or local fair
27 employment practices agency that is designated as a “deferral agency,” an individual seeking
28 relief from employment discrimination must first file a charge with that agency and the EEOC
29 must defer jurisdiction over the complaint for 60 days or until the state agency has terminated its
30 action. Almost all the states have created agencies that qualify as deferral agencies under Title
31 VII.
32

33 If there is no qualifying state fair employment practices agency, a complainant has 180
34 days from the violation to file a discrimination charge with the EEOC. When a state has a
35 deferral agency, then a complainant must meet the state filing deadline but has 300 days to file
36 with the EEOC, but a complainant must also meet the state’s time limitation for filing an
37 administrative claim. State time limitations range from 90 days (2 states) to one year (9 states),
38 with a majority of states (31) setting the time limit at 180 days or 6 months. The EEOC and state
39 fair employment agencies enter into annual work sharing agreements that provide that when a
40 charge is filed with either the EEOC or the state agency it is treated as dual filed with both of
41 them.
42

43 The EEOC serves a notice on the person named in the charge and investigates the charge.

1 If it finds reasonable cause to pursue the complaint, it must attempt to conciliate the matter. If
2 the EEOC dismisses the case, or if settlement is not reached within 180 days from the time the
3 charge was filed and the EEOC and Attorney General decide not to bring a court case, the EEOC
4 issues a “right to sue letter.” An employee may take court action only after the EEOC issues this
5 notice. The case must then be filed in court within 90 days.
6

7 Filing a timely administrative charge with the EEOC is a jurisdictional prerequisite to
8 filing a suit under Title VII, *McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 978 (1973), and
9 courts in a number of states have similarly interpreted statutes creating fair employment practice
10 agencies to require exhaustion of state administrative remedies before a plaintiff may bring a
11 private cause of action in state court. *See, e.g., Strauss v. A.L. Randall Corp.*, 194 Cal. Rptr. 520,
12 524 (Cal. Ct. App. 1983); *Melley v. Gillette Corp.*, 491 N.E.2d 252 (Mass. 1986); *Bonham v.*
13 *Dresser Indus.*, 569 F.2d 187 (3d Cir 1977) (construing Pennsylvania Human Rights Act).
14

15 *Background on GINA’s remedies and damages.* In general, GINA incorporates the
16 remedies and damages provisions of Title VII. These provisions authorize courts to issue
17 injunctive relief and to order affirmative action as appropriate. This may include, but is not
18 limited to, reinstatement or hiring of employees, with or without back pay, and any other
19 equitable relief the court finds appropriate, such as promotion and front pay. Back pay may not
20 extend for more than two years prior to the date the charge was filed with the EEOC, and it is
21 offset by interim earnings or amounts that were earnable with reasonable diligence by the
22 aggrieved individual. For intentional discrimination, the Civil Rights Act of 1991 added
23 compensatory and punitive damages to the remedies available under Title VII. Punitive damages
24 are available if the defendant acted with malice or reckless indifference to the employee’s
25 federally protected rights, but are not available against federal, state, or local government
26 employers. There is a cap on the total amount that may be awarded in punitive damages and
27 compensatory damages for nonpecuniary and future pecuniary losses. The cap is graduated
28 based on employer size as measured by the number of employees:
29

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

30
31
32
33
34
35
36 GINA differs from Title VII, however, in that it excludes remedies for claims of disparate
37 impact, subject to future study by a Commission.
38

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

1 *Background on state Fair Employment Practices Acts.* Most of the states provide
2 administrative remedies and have a state agency that qualifies as a “deferral agency” under
3 federal law. In addition most of the states provide a private cause of action for violations of EEO
4 laws. There is a great deal of variation, however, in the relationship between the availability of
5 administrative relief and private actions.
6

7 In 17 states (as of 2005) private EEO causes of action may be brought without first filing
8 a charge with an administrative agency (Alaska, Arkansas, District of Columbia, Idaho,
9 Kentucky, Louisiana, Maine, Minnesota, New Jersey, New York, North Dakota, Ohio, Oregon,
10 Tennessee, Vermont, Virginia, Washington). 6 Lex K. Larson, *Employment Discrimination* §
11 114.07[6] (2d ed. 2005). Other states that provide a private cause of action require exhaustion of
12 administrative remedies. Many of them follow a scheme patterned on the federal approach under
13 which the agency issues a “right to sue letter.” Others use other triggering mechanisms that
14 allow a claimant to file a private suit.
15

16 State statutes of limitations for fair employment actions range from six months
17 (Colorado) to six years (Ohio), with many states providing for two years (*e.g.* NJ) or three years
18 (*e.g.* Michigan, NY, Washington). 6 Lex K. Larson, *Employment Discrimination* § 114.07[3]
19 (2d ed. 2005).
20

21 State fair employment practices acts originally allowed more generous remedies than the
22 federal acts. Prior to the availability of compensatory and punitive damages under federal law
23 pursuant to the Civil Rights Act of 1991, many states provided for these damages either as
24 agency remedies, court remedies, or both. Compensatory damages have typically been defined to
25 include coverage for emotional distress, mental anguish, pain, suffering, humiliation, and the
26 like. When punitive damages are available under state law, the plaintiff usually must show that
27 the defendant acted with malicious or intentional disregard for statutory rights. With the
28 liberalization of damages permitted under the federal act, some state remedies may now be more
29 restrictive. If interpreted as less protective of employees, these provisions would be preempted
30 under GINA. Attorney’s fees and costs are generally available under state fair employment
31 practices acts.
32

33 *Remedies and damages under the Uniform Act.* The act is intended to provide remedies
34 for privacy violations, employment determinations based on misuse of genetic information, and
35 other harms. Privacy violations involve acquisition, retention, or disclosure of genetic
36 information that does not comply with the act. Employment determinations could include failure
37 to license, hire, refer for employment, promote, or decisions to terminate, demote, reduce pay,
38 reassign, or to take any other adverse action. Other harms could include torts such as intentional
39 infliction of emotional distress. The appropriate remedy will vary with the type of violation.
40

41 *Subsection (a) Private cause of action.* This subsection authorizes a private cause of
42 action for violation of the act. It specifies that the private cause of action is for “money damages
43 or other relief.” “Other relief” is understood to authorize injunctive remedies, but otherwise the
44 form of available relief is purposefully left to state law. Depending on the state, compensatory
45 damages, back pay, front pay, reassignment, reinstatement, injunctive relief, punitive damages,
46 and expungement of records may be available as remedies for a violation of the act. Unlike

1 GINA, the act does not exclude a remedy for a disparate impact claim, but instead leaves the
2 availability of this remedy to the development of state law. And unlike under GINA, damages
3 are not subject to the federal caps.
4

5 *Subsection (b) Exhaustion of administrative remedies.* Under this bracketed subsection,
6 an aggrieved person may choose to use GINA’s administrative remedies, including filing with a
7 state agency, but is not required to do so. This elimination of the requirement for exhaustion of
8 administrative remedies is consistent with statutory provisions in 17 states in which private EEO
9 causes of action may be brought without first filing a charge with an administrative agency. It
10 minimizes the increase in enforcement burden on state agencies by making a private civil action
11 the primary remedy for a violation of the act.
12

13 Given the privacy interests at stake with genetic information, there are special reasons for
14 allowing a private cause of action without requiring exhaustion of administrative procedures.
15 While state employment discrimination agencies have the expertise and the apparatus in place to
16 enforce state civil rights and disability statutes, discrimination agencies do not have expertise in
17 privacy violations and the typical remedies for employment discrimination are not necessarily
18 appropriate for a privacy violation. Enforcement could be turned over to an agency with that
19 expertise, but the Drafting Committee wish to avoid the cost of creating and funding a new
20 agency. Moreover, the Drafting Committee did not want to impose the delay associated with
21 administrative processes on an aggrieved employee.
22

23 Because, however, the states take many different approaches to exhaustion of
24 administrative remedies, the act leaves the decision to the legislature by placing this provision in
25 brackets. This gives states the freedom to make their approach to remedies under the act
26 consistent with the state’s other fair employment practices legislation.
27

28 *Subsection (c) Attorney’s fees.* Subsection (c) authorizes fee and cost shifting to
29 compensate prevailing employees for the cost of enforcing the statute. This fee and cost shifting
30 is discretionary, but is limited to providing expenses to employees.
31

32 *Statute of limitations and tolling.* The section does not establish a specific statute of
33 limitations or a tolling provision for administrative proceedings. This is left to the states so that
34 they can harmonize the provisions with their treatment of other fair employment practices acts.
35

36 *Statutory damages and civil penalties.* The act differs from provisions in several states
37 that specify statutory damages for privacy violations involving genetic information. A privacy
38 rights perspective assumes an intrinsic harm from the invasion of privacy, whether or not
39 consequential damages are incurred. Because of difficulties in measuring damage to privacy
40 interests, several states that provide a private right of action for privacy violations involving
41 genetic information also specify statutory damages, with higher amounts when the violation is
42 willful or leads to monetary gain for the violator. Alaska Stat. § 18.13.020 (2008) (actual
43 damages plus \$5,000, or plus \$1,000 if there is monetary gain); N.H. Rev. Stat. Ann. § 141-H:6
44 (2005) (not less than \$1,000 per violation); N.M. Stat. Ann. § 24-21-6 (LexisNexis 2007)
45 (economic loss plus damages of up to \$5,000 if the violation results from willful or grossly
46 negligent conduct). The Drafting Committee did not take this approach because statutory

1 damages often become a limit on the recovery available.
2

3 Several states also make civil penalties available to remedy unlawful discriminatory
4 practices. These penalties range from small (< \$1000) to significant amounts (up to \$50,000 or
5 \$100,000 per violation). Some states also authorize criminal penalties, although typically only
6 for willful violations of agency orders.
7

8 **SECTION 24. UNIFORMITY OF APPLICATION AND CONSTRUCTION.** In
9 applying and construing this uniform act, consideration must be given to the need to promote
10 uniformity of the law with respect to its subject matter among states that enact it.

11 **SECTION 25. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL AND**
12 **NATIONAL COMMERCE ACT.** This [act] modifies, limits, and supersedes the federal
13 Electronic Signatures in Global and National Commerce Act, 15 U.S.C. Section 7001, et seq.,
14 but does not modify, limit, or supersede Section 101(c) of that act, 15 U.S.C. Section 7001(c), or
15 authorize electronic delivery of any of the notices described in Section 103(b) of that act, 15
16 U.S.C. Section 7003(b).

17 **SECTION 26. EFFECTIVE DATE.** This [act] takes effect