

D R A F T

FOR DISCUSSION ONLY

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

NATIONAL CONFERENCE OF COMMISSIONERS

ON UNIFORM LAWS

For October 23 - 24, 2009 Drafting Committee Meeting

With Prefatory and Reporter's Notes

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October 5, 2009

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UNIFORM PROTECTION OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE ACT

Prefatory Note

The scientific developments in the field of genetics are often characterized as a “revolution.” This revolution is ushering in a new era of greater understanding of human biological processes and the promise of new approaches to medicine that can tailor medical treatments to individuals’ genetic traits. Genetic tests also offer the possibility of identifying individuals who are at risk of developing certain diseases in the future. Unfortunately, while risk information has the potential to improve preventative medicine, it is also subject to misunderstanding and misuse. This Act strikes a balance between making genetic information available for beneficial uses and preventing acquisition of information that creates a risk of misuse.

There are important policy issues concerning the appropriate form and scope of regulation of genetic information. Appropriate goals for regulation include that (1) individuals should not be coerced into having genetic tests; (2) individuals who want to be tested should not be discouraged through fear of how the results will be used; (3) genetic information should not be used for irrational discrimination, that is, where there is no scientific basis for discrimination; and (4) even “rational” discrimination should be prohibited when it violates public policy, including the policy of preventing discrimination on the basis of disability. Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in Employment on the Basis of Genetics*, 6 Employee Rights & Employment Policy Journal 57, 79 (2002). See also Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1500 (2001).

The Drafting Committee has articulated four concepts that support the goals of protecting privacy and encouraging testing: control, confidentiality, consent, and counseling. The principle of knowing and voluntary consent can allow an individual to control genetic testing by vesting the decision in the individual to be tested. A baseline rule of confidentiality, coupled with the individual’s capability to consent to exceptions, can allow an individual to control how others acquire, use, retain, or disclose the individual’s genetic information. Finally, given the complexities and uncertainties of genetic science, genetic counseling is necessary if these decisions about consent are to be knowing and informed.

The Drafting Committee has identified reasons why it is important to regulate genetic testing and acquisition, use, retention, and disclosure of genetic information by employers and insurers. These include the need to prevent fears of adverse consequences associated with genetic testing; the tendency to overstate the predictive power of genetic information, which can lead to actions that are not justified by that information; and the growing availability of genetic information.

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. Currently, 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. There is more than anecdotal evidence that these fears are widespread. In a 1997 national survey, 63% 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>). In an actual genetic study of individuals at risk for hereditary colon cancer, only 43% of those eligible participated. Of those who declined, 39% said the primary reason was fear that the test results would affect their medical insurance coverage. D. Hadley, et al, *Genetic Counseling and testing in families with hereditary nonpolyposis colorectal cancer*, *Archives of Internal Medicine* 163: 573-582 (2003). These examples illustrate that individuals must have control not only over whether or not to undergo a test, but also over the information that results from genetic testing.

Exaggerated predictive power of genetic information. Because the human genome has been portrayed with images such as “blueprint,” “code,” and “future diary,” public misunderstandings of the role of genetics are common. Employers and insurers cannot be expected to be exempt from such misunderstandings, 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 that can be predicted with certainty from an individual’s genetic sequence. These diseases may arguably justify “rational” discrimination. But such monogenetic diseases are the exception. They have received much attention as the first diseases for which researchers established a genetic link, but they afflict relatively few individuals. And even with such 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. It is more common for medical conditions to result from interactions among multiple genes and with the environment. Most of the diseases that are linked to a genetic variation do not appear in all of the individuals with that genotype. This is termed “incomplete penetrance.” 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 their degree of penetrance 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. More than 180 different sequences of beta-globin genes are associated with the blood disease beta-thalassemia. And the severity of the symptoms of patients with this disease vary dramatically. Similarly, there are more than 300 forms of the gene responsible for cystic fibrosis. Unfortunately, identifying the variant of the gene does not explain the variation in symptoms.

Low penetrance, multiple genetic variations that may cause a single disease, and other sources of complications diminish the predictive value of genetic testing. In addition to the over-

inclusiveness of many medical predictions based on genetic tests (in that a person with a predisposing genotype may never have symptoms of the disease), genetic predictions are also often extremely under-inclusive. For example, the predisposing variants of the BRCA 1 and BRCA 2 genes are present in only 5 to 10 percent of breast cancer patients. Thus, genetic data often do not provide an accurate individualized prediction. This is a major justification for the regulation of genetic information.

Increased Availability of Genetic Information. Scientific advances in genetics mean that a very large amount of information can be obtained from one small sample that is easily obtained and analyzed, yielding data that is easily stored and disseminated. This is not unique, but the concentration of information makes genetic information, which combines the power of many other types of medical information, seem particularly threatening.

Recent developments are making genetic information far more available and increasing the risk that it can be misused. One development is in 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 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. In 2005, the Secretary of Health and Human Services, Michael Leavitt, established the American Health Information Community, a federal advisory committee, to make recommendations on how to accelerate a shift to electronic records with the goal of reducing costs and improving medical care. Genetic information is typically contained in a standard medical record. Such records could be linked to each other and available electronically.

Scope of Regulation. Proposals to regulate genetic information, however, have provoked a major policy debate over the wisdom of “genetic exceptionalism,” that is, the regulation of genetic testing and information as a special category rather than as part of more comprehensive regulation of medical testing and information. *See generally* T.H. Murray, *Genetic Exceptionalism and Future Diaries: Is Genetic Information Different from other Information*, in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (Mark A. Rothstein ed. 1977); Sonia M. Sutter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 Wash U. L.Q. 669 (2001).

In the course of this debate, many arguments for singling out genetics for special attention have been raised and rejected. In the early 1990s, the Task Force on Genetic Information and Insurance, a joint working group of the National Institutes of Health and the United States Department of Energy, considered and rejected three justifications for such a policy: (1) They decided that genetic information is not sufficiently distinct from other health information on the basis of its prophetic potential. Genetic predispositions can be affected by many factors and information on non-genetic characteristics, such as lifestyle, may be better health predictors; (2) Genetic information is also not unique in its implications for family members; and (3) Genetic information is not the only type of health information with the ability

to stigmatize.

Other arguments for exceptionalism include that genetic information is particularly sensitive in that it identifies normal variations that fuel discrimination despite their lack of clinical significance. Genetic codes are also viewed as immutable, so that one test can follow a person forever, and genetic information is more probabilistic than other types of medical information. These arguments can also be refuted as a basis for exceptionalism on the ground that they apply as well to other types of health information. Laine Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons from HIV*, 29 J. L. Med. & Ethics 141 (2001).

There are also objections to treating genetic information separately on practical grounds. The distinction between genetic and non-genetic disorders is increasingly difficult to draw; most conditions have both a genetic and non-genetic component. Opponents of exceptionalism also contend that it is unrealistic to separate genetic information in medical records, so that it would be impossible to comply with restrictions on disclosing genetic information to employers or insurers. L.O. Gostin & J.G. Hodge, *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 Jurimetrics 21 (1999). Also, there is a social argument that it is unwise to enact laws that treat genetic conditions as if there is a stigma attached to them because that reinforces such attitudes and becomes a self-fulfilling prophecy. Moreover, treating genetics as unique only encourages the public view that genetics exert a special control over our lives, a view termed “genetic essentialism.” See, e.g., Rochelle Cooper Dreyfus & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 Vand. L. Rev. 313 (1992).

Most of the opponents of genetic exceptionalism do not oppose privacy protections, rather they advocate more holistic approaches to health information and its use in employment and insurance. The larger debate is about how to protect medical data from harmful uses while providing access for uses that individuals, clinicians, and society regard as beneficial. Genetic information is one part of the problem posed by the ease of collecting, storing, and disseminating personal information. Thus it is possible to argue that the exceptionalism debate is a distraction from more important questions about how regulations should be adapted to new scientific developments. Zita Lazzarini, *What Lessons Can We Learn from the Exceptionalism Debate (Finally)?*, 29 J. L. Med. & Policy 149 (2001). In the context of health insurance, one commentator maintains that “[g]enetic equity should be regarded not as an exceptional goal, but as an aim consistent with a broader movement toward equitable access to health care in a time of scarcity.” John V. Jacobi, *Genetic Discrimination in a Time of False Hopes*, 30 Fla. St. U. L. Rev. 363, 364 (2003).

The Drafting Committee’s charge, which covers the misuse of genetic information in employment and insurance, responds to the large number of states that have enacted legislation. That legislation is highly inconsistent and often deals only partially with the issues associated with genetic information. The charge does contemplate genetic exceptionalism by focusing on use of genetic information rather than on health information or privacy more generally. Broader measures for all medical information may not be practical at this time. Nonetheless, it is still important to respond to problems with the use of genetic information. Perhaps regulation of the use of genetic information can serve as an example for policies that need to be developed for the treatment of medical information more generally.

Privacy Protections in General

General Policy Issues

The genetic revolution has raised challenges for several different aspects of privacy: informational privacy, physical privacy, decisional privacy, and proprietary privacy. *See* Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* 31 (Mark A. Rothstein, ed. 1997).

Informational privacy can be thought of as an individual's ability to determine what information about that individual should be available to others. "By controlling personal information, individuals can control the extent to which other people can participate in their lives." David Orentlicher, *Genetic Privacy in the Patient-Physician Relationship*, in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* 77 (Mark A. Rothstein, ed. 1997). Informational privacy of any type is challenging given advances in information technology that greatly increase the potential for others to acquire or disclose one's personal information.

In the genetic context, an individual's primary informational concern is the confidentiality or anonymity of the results of genetic testing. This privacy interest extends beyond the results of one's personal genetic testing to genetic testing of blood relatives, which can also provide information about the individual. The desire to maintain the privacy of this genetic information often has a consequential motivation: people are concerned about others using their genetic information to their detriment. It also springs from a sense of the intrinsic value of keeping such personal information private whether or not the release of genetic information could lead to adverse consequences. The understanding that one's characteristics, and even one's personality, are strongly linked to one's genetic composition heightens the sense that this information is a reflection of personal identity, and thus has inherent personal value.

The other forms of privacy are also important in the context of genetics. Physical privacy, the protection of bodily and personal space, is implicated by genetic testing or treatment. The importance of this form of privacy is recognized in concern for informed, voluntary consent for genetic testing. Decisional privacy, the freedom to make choices without interference by others, is implicated by the need to make decisions about using genetic services. Decisional privacy is an important tenet of genetic counseling, which supports autonomous decisionmaking about having genetic testing and learning the results of the testing. Proprietary privacy, control over possessions and economic interests, is implicated by the value of some individuals' samples or genetic information and by a sense of ownership of one's own identity. *See* Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* 31 (Mark A. Rothstein, ed. 1997).

Privacy is valued in society and law, but not absolutely. The important interest in genetic privacy and confidentiality must be balanced against competing values, including facilitating medical research, improving medical care, protecting public health, enforcing the law, and controlling costs.

The Federal Regulatory Context

State legislation on privacy of medical information is set against the background of the 1996 Health Insurance Portability and Accountability Act (HIPAA), which covers health insurers and other health practitioners, and the recently enacted Genetic Information Nondiscrimination Act of 2008 (GINA), Pub. L. 110-233, which covers health insurers and employers.

Title II of HIPAA required the Department of Health and Human Services to promulgate rules that created standards for the use and dissemination of health care information, including what is now called “The Privacy Rule.” The Privacy Rule, which took effect in 2003, regulates those who create and disclose health information – individual practitioners, multi-national health plans, pharmacies, and information clearinghouses – but not many of the key recipients of this information. “Covered entities,” which include most health insurers, may disclose “protected health information,” i.e., “individually identifiable health information” to facilitate treatment, payment, or health care operations. For other disclosures, with some exceptions, they must first obtain “consent,” “authorization,” or “agreement” from the individual, depending on the circumstances of the disclosure. The Privacy Rule also allows individuals access to their own health information and gives them the right to request a correction of any inaccurate data. Covered entities must notify individuals of uses of their protected health information and keep records of disclosures.

Health insurers who are covered entities must follow these rules when they disclose health information to employers or life, disability-income, or long-term-care insurers, but employers and these insurers are not directly subject to the HIPAA regulations and so do not need to follow these rules in their own treatment of the information.

Although HIPAA does include general preemption provisions, they do not apply to state laws that relate to the privacy of individually identifiable health information that are contrary to and more stringent than the federal requirements. Thus HIPAA provides a floor, not a ceiling, for privacy protections and would not preempt the privacy provisions of the Act.

Recent federal legislation has established specific privacy requirements for genetic information. GINA supplements privacy regulations for group, individual and medigap health insurers already covered by the HIPAA privacy regulations. It prohibits these health insurers from requesting, requiring or purchasing genetic information before an individual’s enrollment and from using genetic information in underwriting or determining eligibility.

The legislation also limits acquisition, use, and disclosure of genetic information by employers, labor organizations, employment agencies, and joint labor-management committees. Its provisions do not apply to life, disability-income, and long-term-care insurers. Like HIPAA, the GINA employment provisions do not preempt state legislation that provides equal or greater privacy protection to individuals.

Current State Statutes

Approximately 15 states have statutes that protect the privacy of genetic information in general, without regard to employment or insurance or any other specific context. Most of these statutes are tailored to cover information derived from genetic testing, although some establish a

principle of confidentiality for medical information more generally. (Cal, Maine, ND) Many of these statutes declare that genetic testing and test results are confidential. *See, e.g.*, Ariz. (confidential and privileged), Cal, Maine, New York, Oregon. A few states have established a property right in genetic test results. Alaska Stat. § 18.13.010 (exclusive property right in DNA sample and results of analysis performed on sample); Fla. Stat. § 760.40 (results of DNA analysis are the exclusive property of the person tested); OR (repealed)).

Most of these generally-applicable statutes prohibit obtaining, analyzing, retaining, or disclosing genetic test results without the informed consent or specific authorization of the tested individual. All these statutes also define exceptions where genetic information may be obtained or disclosures may be made without authorization. Typical exceptions include law enforcement purposes and paternity determinations. Some states also exempt certain forms of insurance. *See, e.g.*, Mass. (disability-income and long-term-care insurance); NH (life, disability-income, and long-term-care insurance); NMex (life, disability-income, and long-term-care insurance if underwriting based on sound actuarial principles); OK (life, disability-income, and long-term-care insurance). Others make special provisions for research. *See, e.g.*, NY; OR (repealed).

The NCCUSL Draft

This draft protects privacy through limitations on the ability of employers and insurers to require genetic tests and to acquire, use, retain, and disclose genetic information. These limitations are coupled with requirements that employees and insureds authorize testing and acquisition, use, retention, and disclosure of their genetic information. In the section of the draft on employment, the privacy provisions are presented with information on GINA to enable the Committee to make policy decisions about the extent to which the Uniform Act should supplement the federal statute.

The Drafting Committee considered adopting a property right as a means to protect privacy of genetic information, but decided against this approach. While it might make sense to recognize a property right in genetic information in general, it is difficult to do only in the context of employment and insurance. Moreover, a majority of the Committee felt that a system of limitations on testing, acquisition, use, retention, and disclosure would be as effective as a property right in providing control over genetic information.

Employment

General Policy Issues

Many contend that employers' ability to obtain genetic information should be limited because it has few appropriate uses in the workplace. The concern is that if employers are permitted to consider genetic information in making personnel decisions, individuals may be unfairly barred or dismissed from employment for reasons that are not related to their ability to do the job. This is an especially high risk with 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.

Employers arguably 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. Somewhat perversely, because the federal Health Insurance Portability and Accountability Act (HIPAA) protects employees against discrimination in health insurance based on medical conditions, including genetic characteristics, the most effective way for employers to avoid high insurance costs is to screen applicants and avoid hiring high-risk individuals. Nonetheless, there are few well-documented cases of genetic discrimination in employment.

In 1996, the NIH-DOE Joint Working Group on Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group) and the National Action Plan of Breast Cancer developed and issued the following recommendations for state and federal policy makers to protect against genetic discrimination in employment. To a large extent, these recommendations mirror the approach of the Americans With Disabilities Act, described below.

- Employment organizations should be prohibited from using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits or termination of employment unless the employment organization can prove this information is job related and consistent with business activity.
- Employment organizations should be prohibited from requesting or requiring collection or disclosure of genetic information prior to a conditional offer of employment, and under all circumstances, employment organizations should be prohibited from requesting or requiring collection or disclosure of genetic information unless the employment organization can prove this information is job related and consistent with business necessity, or otherwise mandated by law. Written and informed consent should be required for each request, collection or disclosure.
- Employment organizations should be restricted from access to genetic information contained in medical records released by individuals as a condition of employment, in claims filed for reimbursement of health care costs and other sources.
- Employment organizations should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure will be made.
- Violators of these provisions should be subject to strong enforcement mechanisms, including private right of action.

Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 Science 1755 (1996).

The Federal Regulatory Context

The states are legislating in a regulatory environment in which recent federal legislation, the Genetic Information Nondiscrimination Act of 2008 (GINA), has increased the role of the federal government in regulating genetic testing and genetic information in employment. The employment provisions of this act do not, however, preempt state legislation that provides equal or greater protection to individuals. 42 U.S.C. § 2000ff-8(a)(1). In addition, two federal statutes provide modest legal protections against discrimination in employment on a genetic basis: Title VII of the Civil Rights Act of 1964 (Title VII) and the Americans with Disabilities Act (ADA). These statutes are also important because many states have their own version of these statutes which they have modified to incorporate genetic protections.

Recent federal legislation now specifically regulates acquisition of genetic information and its use by employers. 42 U.S.C. §§ 2000ff to 2000ff-11. GINA applies to employers, employment agencies, labor organizations, and training programs. These entities are prohibited from discriminating on the basis of genetic information. They are also prohibited from acquiring genetic information, with exceptions that include offering genetic services as part of an employer wellness program and genetic monitoring that is required by federal or state law. Employees may bring claims for disparate treatment based on genetic information, but not for disparate impact. In six years, a study group will make recommendations regarding whether or not to add a cause of action for disparate treatment. Remedies and enforcement are generally limited to those available under Title VII of the Civil Rights Act of 1964, which requires filing a claim with the Equal Employment Opportunity Commission.

GINA is supplemented by Title VII, which prohibits employer discrimination on the basis of race, sex, color, national origin, and religion. It is applicable to genetic discrimination if an employer tests a group of employees in one of the protected classes. For example, the court in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998), held that testing only black employees for the sickle cell trait violated Title VII by imposing a condition of employment on the basis of race. It is also possible that testing all employees could violate the Act if the test were for a trait closely associated with a protected group, such as sickle cell trait (which is more prevalent among African-Americans) or Tay-Sachs disease (associated with Ashkenazi Jewish ancestry). However, in these circumstances the statute would require the difficult showing that the testing was a pretext for intentional discrimination against the group or that it had a statistically significant disparate impact on employment opportunities of members of the group. Most importantly, the narrow focus on employers' actions with respect to certain groups means that Title VII would certainly not apply if an employer instituted a screening program for traits that are not strongly associated with a protected group. See Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

The ADA could provide some protections against genetic discrimination through its regulation of disability discrimination, although this potential is limited by the United States Supreme Court's narrow interpretation of the statute. See, e.g., *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 484-85 (1999) (stating ADA is intended to have limited coverage). "Disability" is defined under the ADA as (1) a physical or mental impairment that substantially limits one or more of the major life activities of an individual; (2) a record of such impairment; or (3) being

regarded as having such an impairment. 42 U.S.C. § 12112(d)(2). If a genetically-caused disease results in a disability under the first prong of the definition, the ADA's protections will apply. The genetic connection is irrelevant; the statute protects the person because of the person's disability, not its cause. Similarly, under the second prong the ADA covers individuals with a prior history of a genetically-related disability, such as a person recovering from a cancer. Of course, if these genetic conditions do not qualify under the definition of "disability" by substantially limiting a major life activity, the individual is not covered by the ADA.

The application of the ADA to discrimination based on a genetic trait that is not manifested in symptomatic disease is a more difficult question. In 1995 the Equal Employment Opportunity Commission (EEOC) issued a policy statement that an individual should be "regarded as" having a disability under the statute's third prong if the employer discriminates on the basis of "genetic information relating to illness, disease, or other disorders." EEOC Order No. 915.002 § 902 (1995). This interpretation of the statute has not been considered by the courts, although several United States Supreme Court justices have expressed their disapproval in dicta. *See, e.g., Bragdon v. Abbott*, 524 U.S. 624, 661 (1998) (Rehnquist, J., joined by Scalia, J. & Thomas, J., concurring in part & dissenting in part). Moreover, the EEOC's position has been criticized in both conceptual and practical terms. *See, e.g., Pauline T. Kim, Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

The ADA protects a disabled job applicant or employee from discrimination in the workplace. This includes a duty to provide reasonable accommodations to a qualified individual with a disability unless the accommodation would impose an undue hardship on the operation of the business. The ADA also regulates testing and acquisition of information by prohibiting medical examinations or testing before a job offer. However, after making a "conditional offer," an employer may require an applicant to take a medical exam. After making a conditional offer employers also have the right to require that individuals sign a blanket release disclosing all their medical records to the employer. Furthermore, once an individual is hired, an employer may test the employee if it can justify the testing as job-related.

Current State Statutes

Concern about economic incentives for employers has led 34 states, as of January 2006, to enact statutes that regulate the use of genetic information or genetic testing by employers. One group of states has used an existing state statute as a platform, amending it to apply to genetic testing or information. A second, larger, group has enacted statutes that are specifically tailored for genetic issues. This diversity of approaches has led to much inconsistency in state law.

In the first group, some states have extended their disability statutes to prohibit discrimination by employers based on genetic information under the rubric of disability. *See, e.g., Hawaii RS §§ 378-1 to 378-6; Illinois, 410 ILCS 513/5 to 513/30 (tied to federal Americans with Disability Act); Mich Comp Laws Ann §§ 37.1201-37.1202; NY Exec Law §§ 292, 296 (adds genetic conditions to the definition of protected disability).*

Other states in the group that has adapted existing statutes have built on their statutes that

prohibit discrimination in employment, expanding them from race, sex, national origin, and other protected classes, to include discrimination based on genetic information. *See, e.g.*, Ariz Rev Stat Ann § 41-1463; Cal Govt Code §§ 12926, 12940; Conn Gen Stat Ann § 46a-60; Mass Gen L ch 151B; Nev Stat § 613.345; NJ Stat Ann §§ 10:5-5, 10.5-12.

Wisconsin has used its Fair Employment Act as its vehicle, amending it to restrict the ability of employers to conduct genetic testing and use genetic information. Wis Stat § 111.372.

States in the second group have enacted special statutes that regulate genetic testing or the use of genetic information. This is the largest group of states, but the extent to which they concentrate on the context of employment varies to some extent. Most commonly, the provisions are tailored specifically for employment. *See, e.g.*, Ark Code Ann §§ 11-5-401 to 11-5-405; Del Code Ann § 710; Kan Stat Ann §§ 44-1002(m), 44-1009(a)(9); La Rev Stat Ann §§ 23.302, 23.368-369; Iowa Code § 729.6; Me Rev Stat Ann tit 5, § 19301; Md Code Ann art. 49B §§ 15,16; Minn Stat § 181.974; Neb Rev Stat § 48-236; NH Rev Stat Ann §§ 141-H:1 to 141-H:5; NC Gen Stat § 95-28.1A; Okla Stat tit 36, § 3614.2; Or Rev Stat § 659A.300; RI Gen Laws §§ 28-6.7-1 to 28-6.7-4; S.D. codified laws §§ 60-2-20 to 60-2-21; Tex Lab Code Ann § 21.401; Utah Code Ann §§ 26-45-101 to 26-45-106; Vt Stat Ann tit 18, §§ 9331-9335; Va Code Ann § 40.1-28.7:1(A); Wash Rev Code Ann § 49.44.180. Some statutes cover genetic information more broadly, regulating its use in employment along with insurance and other activities. *See, e.g.*, N Mex Stat Ann § 24-21-2. For other statutes, the focus is on broad regulation of genetic testing and information, with coverage that applies to employers along with others who might use the information. *See, e.g.*, Fla Stat § 760.4; NJ Stat Ann § 10:5-44, Or Rev Stat § 192.537.

The states that have special statutes limiting genetic testing or the use of genetic information in the employment setting have obviously embraced exceptionalism. But so, for the most part, have the states that have added discrimination based on genetic information to their employment discrimination statutes. This is the case because genetic characteristics are singled out and treated differently from other medical conditions under these statutes. An exception is California, whose statute prohibits employment discrimination on the basis of medical conditions in addition to the more traditional categories of race, sex, and national origin. Under this statutory scheme, a genetic characteristic is treated as a medical condition and receives the same protection as other health problems. Finally, disability statutes by definition single out certain types of medical conditions for special protection: those that are disabling because they limit a major life activity. When genetic predispositions or conditions are defined as disabilities, they are treated similarly to this class of medical conditions. However, to the extent that a genetic condition does not fit within the rubric of “limiting a major life activity,” it is being treated differently from other non-disabling medical conditions under these statutes.

The NCCUSL Draft

The draft presents a framework for the Drafting Committee to consider in structuring a state version of GINA, following the example of the state EEO statutes that supplement federal EEO law. It variously incorporates language from GINA, retains provisions from the prior NCCUSL draft, combines provisions, or offers alternative formulations. The goal is to present the Committee with a tool it can use to balance the goal of consistency with GINA with the policy decisions it has previously made to protect employees’ genetic information.

Life Insurance, Disability-income Insurance, and Long-term-care Insurance

General Policy Issues

Life, disability-income, and long-term-care insurance can be distinguished from health insurance in that individual underwriting of policies is more common. This is because a larger proportion of the market for these insurance products consists of individual coverage than group coverage. According to the National Conference of State Legislatures, approximately 60 percent of life insurance, 40 percent of disability-income insurance, and almost all of long-term-care insurance is underwritten individually, compared to only about 10 percent of health insurance. Individual underwriting decisions take individual characteristics into account in determining risk and use this risk calculation in determining an individual's premium rates and the terms and conditions for coverage and benefits. Individual underwriting could be done more accurately with access to genetic information if that genetic information provides an accurate prediction of the likelihood of claims.

The argument for restricting acquisition of genetic information by the insurance industry is that its predictive power is easily exaggerated and insurers may force applicants to take genetic tests and then deny insurance or charge more based on genetic characteristics. This raises the possibility that a large class of people will lack coverage even though they are not sick and never will become sick. There are also privacy concerns with commercial acquisition of sensitive genetic information and predictions that individuals will avoid genetic testing for fear of adverse effects on their insurability. From the industry perspective, as with health insurance, insurers worry about adverse selection. If applicants seek coverage because a genetic characteristic exposes them to risk, but the insurer does not have this information, this puts the insurer at a financial disadvantage. *See generally* Mark A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (2004).

The Federal Regulatory Context

Life, disability-income, and long-term-care insurance are not covered by the recent federal Genetic Information Nondiscrimination Act of 2008.

Obtaining, retaining, and disclosing information. The insurance industry is primarily regulated by the states, but there are federal laws that affect privacy procedures for some aspects of obtaining, retaining, or disclosing medical information. First, HIPAA is the primary source of privacy rules in the medical context. Long-term-care insurers, like health-care insurers, are directly subject to the privacy rules in HIPAA.

Life and disability-income insurers are not directly subject to HIPAA, but their methods of obtaining medical information are affected indirectly because HIPAA controls the way in which health care providers can furnish them with medical information. Under HIPAA, the consumer must first provide an authorization for disclosure by the health care provider. Therefore, in order to obtain medical information from a health care provider to underwrite new coverage or evaluate a claim, an insurer's forms must meet HIPAA requirements for consumer authorization. HIPAA does not apply, however, to other forms of access, (such as genetic testing by a life or disability-income insurance company) or to the use, retention, or disclosure of

genetic information by life or disability-income insurers.

Second, the Fair Credit Reporting Act affects insurers' ability to disclose as well as obtain medical information (including genetic information). It imposes requirements on obtaining, using, and disclosing "consumer reports." The term consumer report may include medical information, including genetic information, that is used as a factor in establishing eligibility for insurance. It does not, however, include medical information disclosed to an affiliate in connection with the business of insurance or annuities and hence such disclosures are not regulated by the act.

The Fair Credit Reporting Act was amended in 2003 by the Fair and Accurate Credit Transactions Act (FACT Act) in response to concerns about the use of medical information in determinations of eligibility for credit. Under the FACT Act, consumer reporting agencies may furnish a consumer report containing medical information in connection with an insurance transaction only with consumer consent. In addition, an insurer or other third party who receives medical information from an insurer in connection with the business of insurance may not re-disclose that information except as necessary to carry out the purpose for which the information was initially disclosed or as otherwise permitted by law.

Third, the Gramm-Leach-Bliley Act (GLBA) protects consumers from certain disclosures of their "nonpublic personal information." In general, this information may not be shared by a financial institution (including insurers) with an unaffiliated third party unless the consumer has been given notice and an opportunity to opt-out of such sharing. However, sharing without an opt-out opportunity is permitted if it is in connection with the performance of business activities or a joint marketing agreement between financial institutions. The GLBA requires state insurance regulators to adopt rules to implement and enforce its provisions. In doing so, many states have gone further in protecting medical information by requiring an authorization from the consumer (opt-in) before medical information may be shared, as described below.

The State Regulatory Context

Obtaining, retaining, and disclosing information. Disclosure of genetic information by insurers is covered under state provisions on general information practices in the insurance industry. First, about 18 states have adopted provisions based on the National Association of Insurance Commissioners' Insurance Information and Privacy Protection Model Act. These provisions require written authorization from a consumer before an insurer may share personal consumer information, except as needed to perform basic insurance functions. *See, e.g.,* Ariz. Rev. Stat. §§ 20-2101 to 20-2102; Cal. Ins. Code §§ 791.01 to 791.23; Conn. Gen. Stat. §§ 38a-975 to 38a-999a; Ga. Code Ann. §§ 33-39-1 to 33-39-23; 215 Ill. Comp. Stat. Ann. 5/1001 to 5/1024; Me. Rev. Stat. Ann. tit. 24-A §§ 2201 to 2220; Mass. Gen. Laws ch 175I §§ 1 to 22; Minn. Stat. Ann. §§ 72A.49 to 72A.505; Mont. Code Ann. §§ 33-19-101 to 33-19-409; Nev. Admin Code §§ 679B.560 to 679B.750; N.J. Stat. Ann. §§ 17:23A-1 to 17:23A-22; N.C. Gen. Stat. §§ 58-39-1 to 58-39-125; Ohio Rev. Code Ann. §§ 3904.1 to 3904.22; Or. Rev. Stat. §§ 746.600 to 740.690; Va. Code Ann. §§ 38.2-600 to 38.2-620.

Second, in implementing the GLBA, 27 states have adopted provisions specifically protecting medical information from disclosure by insurance companies. These provisions are

based on the National Association of Insurance Commissioners' Privacy of Consumer Financial and Health Information Model Regulation. It provides that an insurer may not disclose nonpublic personal health information unless the consumer has provided authorization or unless the disclosure is made in connection with insurance business functions. *See* Alaska Admin. Code tit. 3 §§ 26.605 to 26.749; Ark. Ins. Rule & Reg. 74; Cal. Fin. Code §§ 4050 to 4060; Colo. Admin. Ins. Reg 6-4-1; Conn. Admin. Code tit. 38a §§ 8-105 to 8-123; Fla. Admin. Code §§ 69O-128.001 to 69O-128.025; Iowa Admin. Code §§ 191-90.1 to 191-90.26; Kan. Admin. Regs. § 40-1-46; 806 Ky Admin. Regs. 3:210-3:220; Md. Admin. Code §§ 31.16.08.01 to 31.16.08.24; Neb. Rev. Stat. § 44-901 to 44-925; N.H. Admin. Code Ins. §§ 3001.01 to 3006.05; N.Y. Comp. Code R. & Regs. tit 11, §§ 420.0 to 420.24 (Reg. 169); N.D. Admin. Code §§ 45-14-01-01 to 45-14-01-25; Okla. Admin. Code §§ 365:35-1-1 to 365:35-1-54; Or. Admin. R. 836-080-0501 to 836-080-0551 & 836-080-0600 to 836-080-0700; 31 Pa.Code §§ 146a.1 to 146a.44 & 146b.1 to 146b.24; R.I. Code Regulation 100; S.C. Code Ann. Regs. 69-58; S.D. Admin R. 20:06:45:01 to 20:06:45:31; Tex. Admin Code §§ 22.1 to 22.67; Utah Admin Code 590-206; Vt. Code R. IH-2001-1; Wash. Admin Code §§ 284-04-120 to 284-04-260; W. Va. Code St. R. §§ 114-57-1 to 114-57-22; Wis. Admin. Code § § 25.01 to 25.95; Wyo Ins. Regs. ch. 54 §§ 1 to 26.

Use of Information. General limitations on the use of information in insurance underwriting are included in the Unfair Trade Practices Acts in effect in almost every state. These limitations apply to genetic information as well as to other information. Typically, these provisions prohibit “making or permitting any unfair discrimination between individuals of the same class and equal expectation of life in the rates charged for any life insurance policy or annuity . . . or in any other terms and conditions of such policy.” National Association of Insurance Commissioners Model Unfair Trade Practices Act § 4(G)(1). In many states, disability-income and long-term-care insurance are regulated as health insurance. For health insurance, a typical provision prohibits “unfair discrimination between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees or rates charged for any accident or health insurance policy or in the benefits payable thereunder, or in any of the terms and conditions of such policy, or in any other manner.” § 4(G)(2).

In both life and health insurance, practices that constitute “unfair discrimination” between individuals of the same class are identified as “refusing to insure, refusing to continue to insure, or limiting the amount, extent, or kind of coverage available to an individual or charging a different rate for the same coverage solely because of a physical or mental impairment, except where the refusal, limitation or rate differential is based on sound actuarial principles or is related to actual or reasonably anticipated experience.” National Association of Insurance Commissioners Model Regulation on Unfair Discrimination in Life and Health Insurance on the Basis of Physical or Mental Impairment § 3.

Some states also specifically regulate the use of genetic information in life, disability-income, or long-term-care insurance. Many of them reiterate their Unfair Trade Practices Act by requiring an actuarial justification for the use of genetic information in determining eligibility and in underwriting. This does not address, however, the important question of whether there is a sufficient scientific basis for assessing risk and how the sufficiency of that scientific basis should be determined. Moreover, an additional question in the genetic context is whether or not there are conditions that should be excluded from consideration even if there is an actuarial justification for different treatment.

A 1997 study by the Human Genetics Advisory Commission in the United Kingdom concluded that it is unlikely that actuarially-sound genetic predictions of adult death will be validated and available anytime in the near future. Genetic tests need to be connected to medical and epidemiological research to establish what consequences for health and life-span can be inferred from a given genetic test. The Commission concluded that a requirement to disclose genetic tests as a condition of obtaining insurance would be acceptable only after research has established an association between a given pattern of test results and life events that are relevant for the insurance product. They recommended continuing a moratorium on requiring test results. They also predicted that the life insurance industry could withstand the limited adverse selection that might result from non-disclosure. Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance* (1997).

Current State Genetic Statutes

At least twenty-three states have legislation that regulates genetic testing or the use of genetic information in life, disability, or long-term-care insurance. Twenty-two states have statutes that pertain to life insurance, nineteen apply to disability insurance, and fifteen cover long-term-care insurance.

Obtaining and disclosing genetic information. The most common privacy protection in state law is a requirement for informed consent or authorization for genetic testing by the individual to be tested. Several states have general provisions requiring informed consent to obtain genetic information that are applicable to insurers. *See, e.g.*, Alaska Stat. §§ 18.13.010 (informed and written consent needed for DNA collection, analysis, retention, & disclosure); Del. Code Ann. § 1221(a) (same); Fla. Stat. Ann. § 760.40(2)(a) (informed consent necessary to perform DNA analysis). A larger number of states specifically require an individual's informed consent or authorization for genetic testing for life, disability-income, or long-term-care insurance. *See* Ariz. Rev. Stat. Ann. § 20-448.02(A) (life, disability-income, long-term-care); Cal. Ins. Code § 10148 (life, disability-income); Colo. Rev. State § 10-3-1104.7(10)(a) (life, individual disability-income); Minn. Stat. Ann. § 72A.139 (life); Nev. Rev. Stat. Ann. § 629.151 (life); N.J. Stat. Ann. § 17B:30-12(f) (life, disability-income); N.Y. Ins. Law § 2615(a) (life, disability-income, long-term-care); Or. Rev. Stat. § 192.535 (life, disability-income, long-term-care); Vt. Stat. Ann. tit. 18, § 9332(d) (life, disability-income, long-term-care). In a couple of states, insurers that require genetic tests must pay the cost of the test. Cal. Ins. Code § 10148 (life and disability-income); Minn. Stat. Ann. § 72A.139 (life).

Other states prohibit insurance companies from requiring genetic testing as a condition of obtaining insurance. For all three types of insurance, insurers may not require applicants in Massachusetts or Vermont to undergo a genetic test as a condition of issuing or renewing a policy. Mass. Gen. Laws Ann. Ch. 175, § 120E (life); Mass. Gen. Laws Ann. Ch. 175, § 108I (disability-income, long-term-care); Vt. Stat. Ann. tit. 18, § 9334(a). In California, there is a special provision for long-term-care insurance that prohibits insurers from requiring genetic testing to determine insurability or for underwriting. Cal. Ins. Code § 10233.1.

A couple of states impose restrictions on asking applicants for genetic information. In Kentucky, disability-income insurers may not request or require an applicant to disclose a genetic test. Ky. Rev. Stat. Ann. § 304.12-085(3). In contrast, in Massachusetts, all three types

of insurers may ask if an applicant has taken a genetic test. The application form must indicate, however, that the applicant is not required to answer questions about genetic testing or genetic information, but that failure to answer may result in denial of coverage or an increased rate. Mass. Gen. Laws Ann. Ch. 175, § 120E (life insurance); Mass. Gen. Laws Ann. Ch. 175, § 108I (disability-income and long-term-care insurance).

Finally, some states also regulate disclosure of genetic information, requiring either informed consent or authorization of the individual tested. *See, e.g.*, Alaska Stat. §§ 18.13.010; Cal. Ins. Code § 10149.1. Another approach classifies genetic information with mental health information and HIV status as “sensitive health information” that requires protections against disclosure beyond that required for medical information. *See, e.g.*, Conn. Gen. Stat. § 38a-999. In terms of access to test results by the individual tested, some states require insurers to provide test results to the individual or the individual’s designated physician. *See, e.g.*, Fla. Stat. § 760.40(3) (general); Minn. Stat. Ann. § 72A.139 (life insurance); N.J. Stat. Ann. § 17B:30-12(f) (life & disability-income insurance, with option for genetic counseling); N.Y. Ins. Law § 2615(e) (if adverse decision for life, disability-income, or long-term-care insurance).

Use of genetic information. The broadest restrictions on use of genetic information prohibit insurers from using genetic testing results or genetic information to determine eligibility or for underwriting. *See* Colo. Rev. Stat. § 10-3-1104.7(3)(b) (group disability-income & long-term-care insurance); Kan. Stat. Ann. § 40-2259(d) (disability-income & long-term-care insurance). Arizona prevents disability-income and long-term-care insurers from using information about a genetic predisposition in underwriting by permitting those insurers to use genetic test results only if there is an actual diagnosis of a genetic condition. Ariz. Rev. Stat. Ann. § 20-448(F). Both Oregon and Vermont prevent all three types of insurers from using any genetic information about a blood relative for either eligibility or underwriting. Or. Rev. Stat. § 746.135; Vt. Stat. Ann. tit. 18, § 9334(a).

Other states restrict use of genetic information by prohibiting insurers from denying coverage or underwriting based on the applicant’s status as a carrier of a genetic disease. California specifies that life and disability-income insurers may not rely on information about an applicant’s genetic characteristic that causes no adverse effects on the carrier, even though it might be associated with disability in the applicant’s offspring. Cal. Ins. Code § 10143. These traits include, but are not limited to, Tay Sachs trait, sickle cell trait, thalassemia trait, and X-linked hemophilia A. Other states similarly prohibit insurance decisions based on specific genetic traits. *See* Fla. Stat. Ann. § 626.9706 (sickle-cell trait) (life); La. Rev. Stat. Ann. § 22:652.1(A), (D) (sickle-cell trait & severe disability) (life and disability-income); N.C. Gen. Stat. § 58-58-25 (sickle-cell trait & hemoglobin C trait) (life); Tenn. Code Ann. § 56-7-207 (sickle-cell trait & hemoglobin C trait) (life).

Finally, a number of state genetic statutes reiterate standards for underwriting that duplicate provisions of most state Unfair Practices Act, stating that the use of genetic information in underwriting must be based on an actuarial justification, may not be used for unfair discrimination, or must be reasonably related to risk. *See* Ariz. Rev. Stat. Ann. § 20-448(E) (life, disability-income, & long-term-care insurance); Kan. Stat. Ann. § 40-2259(d) (life insurance); 24A Me. Rev. Stat. Ann. § 2159-C(3) (life, disability-income, & long-term-care); Md. Code Ann., Ins. § 27-208(a)(3) (life, disability-income, & long-term-care insurance); Mass.

Gen. Laws Ann. Ch. 175, § 120E (life, disability-income, & long-term-care insurance); Mont. Code Ann. § 33-18-206 (life, disability-income, & long-term-care insurance); N.J. Stat. Ann. § 17B:30-12(f) (life & disability-income insurance); N.M. Stat. Ann. § 24-21-4 (C) (life, disability-income, & long-term-care insurance); Vt. Stat. Ann. tit. 18, § 4724(3) (life, disability-income, & long-term-care insurance); Wis. Stat. Ann. § 631.89 (life & disability-income insurance).

The NCCUSL Draft

The draft allows life insurers, disability-income insurers, and long-term-care insurers to require genetic tests and use genetic information for coverage and underwriting decisions only as scientific developments justify that use. The draft places a burden on insurers to show that a positive genetic test is reliably associated with increased medical risk of mortality or morbidity. If an insurer can demonstrate that to a reasonable degree of scientific certainty, it can use the information. If the available scientific evidence does not meet this standard, use of the genetic information would be a violation of state unfair practices insurance law.

1 **UNIFORM PROTECTION OF GENETIC INFORMATION**
2 **IN EMPLOYMENT AND INSURANCE ACT**

3 **[ARTICLE] 1**

4 **GENERAL PROVISIONS**

5 **SECTION 101. SHORT TITLE.** This [act] may be cited as the Protection of Genetic
6 Information in Employment and Insurance Act.

7 **Reporter’s Notes**

8
9 In the early stages of drafting, the act was named “Misuse of Genetic Information in
10 Employment and Insurance Act.” In 2008, the ULC Executive Committee authorized changing
11 the name of the act to “Protection of Genetic Information in Employment and Insurance,” which
12 better reflects the scope of the act. The act deals not only with misuse, but also use, acquisition,
13 retention, and disclosure of genetic information, setting a balance that provides appropriate
14 protection for genetic information in all these contexts.
15

16 **SECTION 102. DEFINITIONS.** In this [act]:

17 (1) “Child” means a son or daughter of an individual, whether related by whole or half
18 blood, affinity, adoption, or born as the result of assisted reproduction technology, who is
19 deemed to be a child of the individual under law other than this [act].

20 (2) “Family medical history” means information about a current or past medical
21 condition of a family member of an individual.

22 (3) “Family member” means an individual’s spouse or [domestic partner], child, and all
23 individuals related by whole or half blood within the fourth degree of consanguinity measured
24 using the civil law method to the individual, the individual’s spouse or [domestic partner], or the
25 individual’s child.

26 (4) “Genetic counseling” includes:

27 (A) assessing an individual’s genetic risk for an inherited condition by

1 interpreting family medical histories;

2 (B) providing nondirective education about the inheritance, testing, management,
3 and prevention of a genetic condition;

4 (C) helping an individual to understand the risks and benefits of testing for a
5 genetic trait to promote informed decision-making about whether or not to undergo genetic
6 testing;

7 (D) communicating and interpreting test results; and

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

11 (5) “Genetic education” means the process by which an individual acquires information
12 about the individual’s or the individual’s family member’s existing or suspected genetic
13 condition.

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

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

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

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

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

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

24 (10) “Tribunal” means a court, arbitral tribunal, or administrative agency.

1 **Legislative Note:** In the definition of “family member” states should insert for [domestic
2 partner] the appropriate term for an unmarried partner who is eligible for benefit coverage such
3 as health insurance in the workplace, such as “partner,” “significant other,” “domestic
4 partner” or other term.
5

6 **Reporter’s Notes**

7
8 *Paragraph (1). (Child)* The term “child” is defined because an individual’s child is
9 included in the definition of “family member.” This definition acknowledges the many ways in
10 which the relationship of parent-child is created, including by adoption and assisted reproductive
11 techniques. This relationship is governed by other law, such as the Uniform Parentage Act. This
12 broad definition is necessary because even nonbiologically-related children can affect health-
13 care costs that may affect an employer’s costs for insurance coverage.
14

15 This definition is not found in GINA. It is included in this draft because of the approach
16 the Committee has taken to defining “family member.” The decision to retain this definition of
17 “child” will depend on the Committee’s decision about retaining its approach to defining “family
18 member.”
19

20 *Paragraph (2). (Family medical history)* Family medical history is often a source of
21 genetic information in that it is used to evaluate the likelihood that an individual carries an
22 inherited trait. The act’s employment article follows GINA and includes family medical history
23 within its definition of “genetic information.” The definition of “genetic information” in the
24 act’s insurance article, however, does not encompass family medical history, which is treated
25 differently under that article.
26

27 *Paragraph (3). (Family member)* The draft defines family member to encompass all
28 individuals whose genotype could influence an employment or insurance decision. The term
29 includes (1) biological relations whose genetic information might provide information about the
30 genetic make-up of an individual employee or insured, (2) dependants whose risk of future
31 genetically-linked medical conditions could affect employer health care costs or family
32 insurance coverage and hence affect employment or insurance decisions, and (3) those
33 dependants’ biological relations whose genetic information might provide information about the
34 genetic make-up of a dependant. The separately-defined term “child” includes both adopted and
35 biologically-related children because either can affect health-care costs or family insurance
36 coverage.
37

38 *Dependents.* Many employers provide health insurance for employees’ unmarried
39 partners. Therefore, an unmarried partner can be a dependent whose risk of a genetically-linked
40 medical condition could affect employment or insurance decisions. As a result, “domestic
41 partner” is included in the definition of family member for purposes of obtaining, retaining,
42 using, and disclosing genetic information. The brackets around this term are not meant to
43 indicate that a state may drop the concept, but only that a state should substitute the term it uses
44 for a person in this relationship. This definition is not meant to affect other state law definitions
45 of marriage or family.
46

47 *Relationship to GINA.* The draft retains the prior draft’s definition, which differs

1 somewhat from GINA’s in that the draft specifies the persons who may be dependents (spouse,
2 child, domestic partner), and covers all of them. In contrast, GINA defines “family member” by
3 using the term “dependent” with reference to ERISA’s use of that term in its provisions on
4 special enrollment periods for group health plans, 29 U.S.C. § 1181(f)(2). As used in ERISA,
5 this status depends on the scope of health care coverage offered by the employer. A person can
6 be a “dependent” only if a group health plan makes coverage available for them and the person
7 they are dependent on is enrolled in the plan. In addition, regardless of the scope of the
8 employer’s health plan, “dependents” are limited to those who are dependent through marriage,
9 birth, or adoption, or placement for adoption.

10
11 The draft did not adopt GINA’s approach for several reasons. First, state legislation
12 usually does not define its terms through cross references to federal statutes. Second, GINA’s
13 definition does not include family members who are not *currently* eligible for employer-provided
14 health benefits or dependent on an individual who is not *currently* enrolled in those benefits,
15 even if they might be eligible or enrolled later. Third, in the past the Drafting Committee has
16 decided it was important to include domestic partners within the definition because many
17 companies offer this coverage.

18
19 The Committee will need to decide whether to retain its prior approach or adopt that of
20 GINA.

21
22 *Degree of relationship to the individual or the individual’s dependents.* Genetic
23 counselors typically collect information on genetic diseases of family members related to the
24 third degree of consanguinity and often to the fourth degree. The Drafting Committee specified
25 collateral consanguinity to the fourth degree using the civil law method of calculation, which is
26 reportedly the method most commonly used by the states. The Drafting Committee considered a
27 provision that would replace the designation “fourth degree of consanguinity” with a list of
28 family members, but decided instead to include information in the notes that designates which
29 family members are included within the fourth degree of consanguinity. This information is
30 included below.

31
32 The current draft is consistent with GINA, which also defines a family member as
33 including first- to fourth-degree relatives. The proposed EEOC implementing regulations list
34 these family members. The method the EEOC used is not identified, but unfortunately the list
35 does not correspond to the method specified by the Drafting Committee. The practical outcome
36 is, however, only slightly different, with grandnieces and grandnephews omitted from the EEOC
37 list and first cousins once removed included on that list when they would not be included under
38 the current draft. Hence at present, the draft is consistent with GINA but slightly inconsistent
39 with the proposed implementing regulations. This inconsistency could be removed in the future
40 if the final regulations do not change.

41
42 Lineal consanguinity is the relationship between persons when one is directly descended
43 from the other. Each generation in this direct line constitutes a degree. Collateral consanguinity
44 refers to the relationship between persons who descend from the same common ancestor, but not
45 from each other. The civil law method of calculating degree of collateral consanguinity, used in
46 most states, is to count the number of generations from one person up to the common ancestor
47 and then down to the other person. The following table identifies the relatives within four

degrees of collateral consanguinity from an individual, using the civil law method, with each row representing a generation.

				Great-great-grandparents (4)
			Great-grandparents (3)	
		Grandparents (2)	Grand Aunts and Grand Uncles (4)	
	Parents (1)	Aunts and Uncles (3)		
Individual	Sisters and Brothers (2)	First Cousins (4)		
Children (1)	Nieces and Nephews (3)			
Grandchildren (2)	Grandnieces and Grandnephews (4)			
Great-grandchildren (3)				
Great-great-grandchildren (4)				

Paragraph (4). (Genetic counseling) This definition is retained from the prior ULC draft. It is more comprehensive than the treatment in GINA, which lists genetic counseling as a genetic service with the following parenthetical: “(including obtaining, interpreting, or assessing genetic information),” but does not otherwise define the term.

Genetic counseling is a key to an individual’s informed decision making about getting a genetic test, understanding the result, and authorizing its use, retention, or disclosure. Most states that license genetic counselors have a definition of genetic counseling, but the majority of states do not license genetic counselors or regulate genetic counseling. Note that the definition does not require that genetic counseling be performed by a genetic counselor. Physicians and geneticists are also qualified to provide genetic counseling.

The definition uses the term genetic “condition,” which is intended to have a broad interpretation. Genetic condition includes the concepts of genetic disease and disorder, but in some circumstances it may also refer to a positive or benign trait or characteristic that is linked

1 to a particular genotype.
2

3 Genetic counseling is usually a two-step process consisting of 1) counseling before a test
4 about the decision whether or not to have the test and 2) counseling after the test if the test
5 indicates the individual is at risk. In addition, for some conditions counseling may also be
6 appropriate if the test indicates the individual is not at risk. The functions listed in (A)-(C) of the
7 definition of genetic counseling take place before an individual decides whether or not to have
8 the test. The functions in (D) and (E) take place after the test, if necessary.
9

10 *Paragraph (5). (Genetic education)* Genetic education is one element of genetic
11 services. It is typically less tailored to individual circumstances than a one-on-one genetic
12 counseling session. The definition is meant to be broad enough to include information provided
13 by support groups for genetic conditions to those who may have the condition. It is not meant to
14 encompass general genetic education such as that received in biology class or medical school.
15

16
17 This term is used, but not defined, in GINA.
18

19 *Paragraph (6). (Genetic service)* “Genetic service” is a broader category than genetic
20 testing. The term includes activities associated with obtaining genetic information that could
21 create assumptions about an individual’s genetic status even in the absence of information about
22 genetic test results or medical history. “Counseling” implies a one-on-one consultation, so the
23 definition also includes “genetic education” in order to capture group information sessions on
24 genetic conditions. While the definition of a “genetic service” does not separately define the
25 term “genetic,” the term should be interpreted to be consistent with the definitions of “genetic
26 test” and “genetic information.”
27

28 This definition follows the definition of “genetic services” in the employment title of
29 GINA, except that the GINA definition expands on the term “genetic counseling” by noting
30 parenthetically that it “includ[es] obtaining, interpreting, or assessing genetic information.” The
31 draft has an independent, more comprehensive definition of genetic counseling and requirements
32 for employers and insurers to provide genetic counseling that exceed the protections of GINA.
33

34 *Paragraph (7). (Person)* This draft uses the broad version of the standard National
35 Conference of Commissioners on Uniform State Laws definition of “person.”
36

37 *Paragraph (8). (Record)* The definition of “record” is the standard National Conference
38 of Commissioners on Uniform State Laws definition.
39

40 *Paragraph (9). (Sign)* The definition of “sign” is the standard National Conference of
41 Commissioners on Uniform State Laws definition.
42

43 *Paragraph (10). (Tribunal)* The term “tribunal” refers collectively to the potential
44 decision-makers in a litigation or arbitration context.
45

1 [ARTICLE] 2

2 EMPLOYMENT

3 SECTION 201. DEFINITIONS. In this [article]:

4 (1) “Credentialing authority” means a governmental or private entity that provides a
5 license, registration, or credential or certifies competence that is necessary for an individual to
6 qualify for employment or to participate in an occupation or profession.

7 (2) “Employee” means an individual who works for, or applies to work for,
8 compensation, a member or applicant for membership in a labor organization, an apprentice,
9 trainee or applicant for a training or retraining program, or an individual considered by a
10 credentialing authority. The term includes an individual employed in, or applying for
11 employment in, a supervisory, managerial, or confidential position. The term does not include an
12 independent contractor.

13 [[(2) “Employee” means an individual, including an applicant, employed by an
14 employer.]]

15 (3) “Employer” means a person, including an agent of that person, that has one or more
16 employees.

17 [[(3) “Employer” means a person, including an agent of that person, that has fifteen or
18 more employees for each working day in each of twenty or more calendar weeks in the current or
19 preceding calendar year.]]

20 (4) “Employment agency” means a person, including an agent of that person, that
21 regularly undertakes, with or without compensation, to procure employees for an employer or to
22 procure for employees opportunities to work for an employer.

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

1 (6) “Genetic information” means, with respect to an individual, information about:

2 (A) the individual’s genetic test;

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

4 (C) a manifested disease or disorder in family members of the individual;

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

7 or

8 (E) the genetic test of a fetus carried by the individual or a family member of the
9 individual or an embryo legally held by the individual or a family member of the individual.

10 The term shall not include information about the sex or age of any individual.

11 (7) “Genetic monitoring” means a periodic examination of an employee to evaluate
12 acquired modification to the employee’s genetic material, such as chromosomal damage or
13 evidence of increased occurrence of mutations, that may have developed in the course of
14 employment due to exposure to toxic substances in the workplace, in order to identify, evaluate,
15 and respond to the effects of or control adverse environmental exposures in the workplace.

16 (8) “Genetic test” means an analysis of human deoxyribonucleic acid (DNA), ribonucleic
17 acid (RNA), chromosomes, proteins, or metabolites, that detects genotypes, mutations, or
18 chromosomal changes. The term does not mean an analysis of proteins or metabolites that does
19 not detect genotypes, mutations, or chromosomal changes.

20 (9) “Joint labor-management committee” means an entity that establishes, offers, or
21 controls apprenticeship or other training or retraining programs, including on-the-job training
22 programs.

23 (10) “Labor organization” means an organization in which employees participate that
24 exists for the purpose, in whole or in part, of dealing with employers concerning grievances,

1 labor disputes, wages, rates of pay, hours, or other terms or conditions of employment, including
2 an agent of the labor organization.

3 (11) “Labor organization member” means a member in a labor organization or an
4 applicant for membership.

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

9 **Reporter’s Notes**

10
11 *Paragraph (1). (Credentialing authority)* This is a concept included in the draft act that
12 is not part of GINA. Credentialing authorities are included in the group of employment-related
13 organizations labeled as “employment entities” and regulated in this article. This draft keeps this
14 concept to enable the Committee to decide if it should be retained.
15

16 Credentialing authorities serve as gatekeepers to certain types of employment by
17 providing credentials that are required either under state law or by an employer. Examples
18 include state bar and medical examination boards, which control entry to the practice of law and
19 medicine, and state departments of motor vehicles, which issue commercial drivers licenses
20 necessary for some employment. Acquisition or use of genetic information by a credentialing
21 authority could have the same effects on employees and applicants for employment as
22 acquisition or use by an employer.
23

24 California’s state EEO statute similarly expands the protections of federal employment
25 law with regard to credentialing. It prohibits licensing boards from requiring an examination or
26 establishing any other qualification that has an adverse impact on a class by virtue of race, creed,
27 etc, unless the practice can be demonstrated to be job related. Cal. Gov. Code § 12944.
28

29 *Paragraph (2). (Employee)* There are two alternatives for the Committee’s
30 consideration.

31 GINA’s definition of employee is based on the definition in Title VII, which GINA
32 supplements to include applicants for employment and state employees, Congressional
33 employees, executive branch employees, and other federal employees. A version of GINA’s
34 definition adapted from Title VII (42 U.S.C. § 2000e (f)) appears in double brackets . It defines
35 an employee as an individual employed by an employer.
36

37 The definition of employee taken from the prior draft avoids this circularity. It is adapted
38 from the National Conference of Commissioners on Uniform State Law’s Model Employment
39 Termination Act. The definition’s requirement for compensation is intended to exclude

1 volunteers from the definition of employee.
2

3 In addition, for drafting ease, the term employee is used to also cover individuals who are
4 labor organization members, apprentices and trainees, and applicants for employment, labor
5 organization membership, or an employment credential. The intent is to cover any individual
6 who is subject to collection of information or an employment decision by an employment entity,
7 which is defined as an employer, employment agency, labor organization, credentialing
8 authority, or joint labor management committee.
9

10 The Drafting Committee considered including independent contractors in the definition
11 of employees, but decided to exclude this category of workers. This approach is not intended,
12 however, to provide employers with an avenue to evade their obligations by classifying
13 employees as independent contractors.
14

15 The prior draft defined “applicant for employment” separately. Because GINA combines
16 the definitions of applicant and employee, they have been consolidated in this draft.
17

18 *Paragraph (3). (Employer)* The draft’s definition of employer is linked to the broad
19 definition of “employee” in paragraph 7 and to the definition of “person” in paragraph 16. It
20 therefore encompasses all types of entities, including governmental and non-profit employers.
21 This is consistent with the coverage specified by a number of states in their state versions of
22 Title VII of the Civil Rights Act of 1964 on employment discrimination. (See, e.g., Hawaii,
23 Iowa.)
24

25 As the definition of employer is currently drafted, the act would cover all employers
26 regardless of size. One consideration is whether the requirements of the act would prove too
27 burdensome for small employers. Many statutes specify a minimum sized employer using the
28 number of employees as a proxy for size. GINA sets the lower limit at 15 employees. It defines
29 “employer” by a cross reference to Title VII of the Civil Rights Act of 1964, supplemented to
30 include federal and state government employers. Title VII’s definition covers employers who
31 had 15 or more employees for each working day in 20 or more weeks over the course of a year.
32 The double bracketed language duplicates this policy choice, using language adapted from Title
33 VII (42 U.S.C. § 2000e (b)).
34

35 This is an area in which many state employment discrimination statutes expand the scope
36 of coverage beyond that provided by federal statute. State employment discrimination acts set
37 varying thresholds for coverage, ranging from a requirement of only one employee (16 states) up
38 to fifteen employees (13 states). The definition in the Uniform Law Commission’s Model
39 Employment Termination Act requires five employees, measured over a period of two years.
40

41 Another way to limit the types of employers that are covered would be to exclude
42 immediate family members from the count of employees, as is done in the Fair Labor Standards
43 Act and the National Conference of Commissioners on Uniform State Law’s Model Employment
44 Termination Act. In addition, some state statutes exclude particular employee groups, such as
45 household workers or farm workers, in determining employer status.
46

47 *Paragraph (4). (Employment agency)* This is the definition provided in GINA.

1 *Paragraph (5). (Employment entity)* Employment entity is the term used in the act to
2 collectively indicate an employer, an employment agency, a labor organization, a credentialing
3 authority, or a joint labor-management committee that offers training programs. The definition
4 expands GINA’s coverage by adding credentialing authorities.
5

6 The regulations implementing GINA use the term “covered entity” to group the
7 organizations it covers. This term is not used in the draft because the scope of coverage is
8 slightly different from GINA, which does not include credentialing authorities, and because of
9 the potential for confusion with the use of the term “covered entity” in HIPAA.
10

11 *Paragraph (6). (Genetic information)* This definition of “genetic information” follows
12 the definition in the employment title of GINA. It includes family medical history through the
13 reference to the occurrence of a disease or disorder in family members of the individual. It also
14 incorporates GINA’s provisions on the genetic information of fetuses, although they are not
15 found in GINA’s definitions, but in § 209, codified at 42 U.S.C. § 2000ff-8. Under GINA, if an
16 employee or family member is a pregnant woman, references to her genetic information includes
17 that of the fetus she is carrying. If an employee or family member is using assisted reproductive
18 technology, references to that individual’s genetic information include the genetic information of
19 any embryo held legally by that individual.
20

21 This definition is consistent with many states that define “genetic information” to include
22 information on genetic characteristics broadly, whether obtained from genetic tests or family
23 medical history. (Cal, Conn, Hawaii, LA, Maine, MD, Mass, Mich, NJ, NMex, NC, RI, SD, TX,
24 WA).
25

26 This definition now differs from the definition of genetic information used in Article 3 on
27 life, disability-income, and long-term-care insurance. That article allows these insurers to
28 continue to collect information on family history, even though family history is a major source of
29 information to evaluate an individual’s genetic risks.
30

31 *Paragraph (7). (Genetic monitoring)* The definition of “genetic monitoring” follows the
32 federal definition in GINA. It is drawn from the description in Office of Technology
33 Assessment, *Genetic Monitoring and Screening in the Workplace* 4 (1990). The focus in
34 monitoring is not on inherited characteristics, but on genetic alterations in a group of exposed
35 individuals over time. Genetic monitoring is typically undertaken by employers to identify risks
36 for groups of employees who have been exposed to hazardous substances or to target work sites
37 for safety and health measures. Testing for this purpose is permitted in Section 202.
38

39 *Paragraph (8). (Genetic test)* This is identical to the definition of genetic test used in
40 GINA employment provisions. “Genetic test” is defined in terms of (1) the material that the test
41 analyzes and (2) what the test detects.
42

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

1 mutation or chromosomal change.

2
3 Both clauses are equally important to the definition. First, some of the materials listed in
4 the first clause, especially proteins and metabolites, are tested for many medical purposes. A test
5 of a protein or metabolite does not constitute a genetic test unless it is administered to determine
6 an individual's genetic make-up as specified in the second clause.

7
8 Insurance industry representatives have expressed the fear that this definition is so broad
9 that it will sweep in routine medical tests such as blood tests of lipoproteins to measure
10 cholesterol levels. It is true that a cholesterol test analyzes proteins. A cholesterol test is not,
11 however, given specifically to detect a genotype, genetic marker, mutation, or chromosomal
12 change, so it would not be considered a genetic test under the draft. Instead, a high cholesterol
13 reading may indicate a number of causal factors, including inappropriate diet, lack of exercise,
14 and/or a condition called inherited familial high cholesterol. If the measurement of cholesterol
15 leads a doctor or insurance company to do further testing to see if an individual has a specific
16 genotype, then that would be a genetic test under the draft's definition. Other common medical
17 tests of proteins or metabolites that would not fall under the definition of "genetic test" include
18 urine tests for kidney disease, blood protein and creatinin tests for diabetes, blood tests of liver
19 enzyme proteins for liver function, urine tests measuring glucose to diagnose diabetes, blood
20 tests measuring serum blood glucose for diabetes, and triglycerides for heart disease. The
21 second sentence of the definition, although redundant, should reassure those who fear the
22 definition will be used to sweep in medical tests that are not given to detect genotypes,
23 mutations, or chromosomal changes.

24
25 The primary difference between this definition, which tracks the federal statute almost
26 exactly, and the prior draft is that the definition in the prior draft included the concept of intent.
27 It required that the test be given with the intent to detect a genotype, mutation, or chromosomal
28 change. This requirement had been included to help assure insurance company representatives
29 that the test would not be misused, as discussed in the prior paragraph. In addition, the prior
30 draft did not include the second sentence because it was deemed redundant.

31
32 The draft is consistent with states with definitions of genetic testing that are not limited to
33 identifying genotypes associated with diseases or impairments. (Fla, Haw, Mass, NH, Ore, UT).
34 In contrast, many other states statutes limit their definition of "genetic test" to testing for
35 disease-related genes. (Ariz, Ark, Del, Ill, Iowa, Kan, LA, Maine, MD, Mich, Minn, Nev, MO,
36 Neb, NJ, NM, NY, NC, OK, OR, RI, TX, VT, VA, WI). While most of the reasons that an
37 employer or insurer might currently seek or use genetic information probably involve a disease,
38 disorder, or impairment, this may not always be the case. One can imagine, for example, that the
39 presence or absence of behavioral traits might also be a criterion for selecting an employee.
40 While the current evidence linking behavior to genes is tenuous, this area continues to be the
41 subject of investigation.

42
43 *Paragraph (9). (Joint labor-management committee)* This definition is taken from the
44 proposed regulations implementing GINA.

45
46 *Paragraph (10). (Labor organization)* This definition is the one used in the proposed
47 regulations implementing GINA, omitting GINA's requirement that the organization be engaged

1 in interstate commerce. It is similar to the following definition, which is commonly used in state
2 EEO acts: “‘Labor organization’ means any organization which exists and is constituted for the
3 purpose, in whole or in part, of collective bargaining or of dealing with employers concerning
4 grievances, terms or conditions of employment, or of other mutual aid or protection in
5 connection with employment.” (e.g., Cal., Colo., Hawai’i, Iowa, Minn, NY)

6
7 *Paragraph (11). (Labor organization member).* This definition is taken from GINA for
8 the purpose of including applicants within the scope of the definition.

9
10 *Paragraph (12). (Manifested disease or disorder).* This definition is taken from the
11 proposed EEOC regulations to implement GINA. It is relevant to the definition of genetic
12 information in this article and to Section 213, which excludes from coverage medical
13 information about a manifested disease or disorder that is not genetic information.
14

15 **SECTION 202. ACQUISITION OF GENETIC INFORMATION.**

16 (a) Except as otherwise provided in this section, an employment entity may not request,
17 require, or purchase genetic information of an employee or an employee’s family member.

18 (b) Except as otherwise provided in this section or by law other than this [act], an
19 employment entity may not require, offer, or provide a genetic test to an employee or an
20 employee’s family member.

21 (c) It shall not be an unlawful employment practice if an employment entity inadvertently
22 requests or requires [[family medical history]] [[genetic information]] from an employee or an
23 employee’s family member.

24 (d) An employment entity may acquire an employee’s genetic information if the
25 employee voluntarily submits the genetic information to the employment entity. If an employee
26 voluntarily submits genetic information retained by a source other than the employee, the
27 employee must authorize the employment entity’s acquisition in accordance with Section 209.

28 (e) An employment entity may request or require family medical history from an
29 employee to comply with the certification procedures of the Family Medical Leave Act, 29
30 U.S.C. § 2613, or certification requirements under the [state family and medical leave act].

1 (f) An employment entity may purchase documents that are commercially and publicly
2 available, including newspapers, magazines, periodicals, and books, even if they contain [[family
3 medical history]] [[genetic information]]. This exception does not include the purchase of
4 medical databases or court records.

5 (g) An employment entity that offers health or genetic services, including as part of a
6 wellness program, may offer and provide genetic testing to an employee in accordance with
7 subsection (i) and may acquire the employee's information if:

8 (1) the employment entity provides genetic counseling about the risks and
9 benefits of a genetic test before the employee considers authorizing the test unless the employee
10 knowingly and voluntarily waives counseling before the test in a signed record that contains
11 information about the benefits of genetic counseling;

12 (2) the employee authorizes the genetic testing in accordance with section 203
13 and authorizes the acquisition of genetic information in accordance with section 209; and

14 (3) genetic information acquired by the employment entity is available only to a
15 licensed health care professional or board certified genetic counselor involved in providing the
16 employment entity's genetic services.

17 (h) An employment entity that conducts genetic monitoring of the biological effects of
18 toxic substances in the workplace may offer and provide genetic testing to an employee and
19 acquire an employee's genetic information if:

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

22 (2) the genetic monitoring is

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

24 (B) authorized by the employee in accordance with sections 203 and 209

1 after the employment entity provides and pays for genetic counseling for the employee about the
2 risks and benefits of the genetic test, unless the employee knowingly and voluntarily waives
3 counseling in a signed record that contains information about the benefits of genetic counseling;

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

5 (A) federal genetic monitoring regulations, including regulations that may
6 be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of
7 1970, 29 U.S.C. 651 et seq., the Federal Mine Safety and Health Act of 1977, 30 U.S.C. 801 et
8 seq., or the Atomic Energy Act of 1954, 42 U.S.C. 2011 et seq.; or

9 (B) state genetic monitoring regulations if a State implements genetic
10 monitoring regulations under the authority of the Occupational Safety and Health Act of 1970;
11 29 U.S.C. 651 et seq.;

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

14 (5) genetic information disclosed to the employment entity, excluding a licensed
15 health care professional or board certified genetic counselor involved in providing the
16 monitoring program, is in an aggregate form that does not disclose the identity of the individual
17 employee.

18 (i) An employment entity that provides a genetic test as part of health or genetic services
19 offered under subsection (g) or a genetic monitoring program under subsection (h) must:

20 (1) require the testing organization to report the test result to the employee and a
21 health-care professional designated by the employee unless the employee directs otherwise;

22 (2) provide genetic counseling for the employee about a positive test result;

23 (3) require the destruction of the employee's biological sample obtained for a
24 genetic test as soon as permitted by law after the test is completed unless retention of the sample

1 is authorized by the employee, permitted by law other than this [act], or ordered by a tribunal.

2 (j) An employer that conducts DNA analysis for law enforcement purposes as a forensic
3 laboratory or for purposes of identifying human remains may request or require genetic
4 information or genetic testing of its employees to the extent necessary to analyze DNA
5 identification markers for quality control to detect sample contamination.

6 (k) When an employee has placed the employee's health at issue in a proceeding before a
7 tribunal in which an employment entity is a party, the employment entity may obtain genetic
8 information about the employee without the employee's authorization only if:

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

10 (2) on a motion by the employment entity a tribunal orders the employee to take a
11 genetic test or provide genetic information after finding that the employment entity has
12 demonstrated a compelling need and that the information is otherwise unavailable; and

13 (3) the employment entity pays for the genetic test if one is ordered by the
14 tribunal.

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

17 **Reporter's Notes**

18
19
20 *Applicability of Article 2.* This article is intended to apply broadly in the employment
21 setting to any employment entity. Employment agencies, labor organizations, credentialing
22 authorities, and joint labor-management committees offering training programs are included
23 within the scope of the article in addition to employers because they control access to
24 employment through referrals or licensing.

25
26 As explained in the Reporter's Notes in section 201, the article expands the scope of
27 GINA and makes it more protective of employees. It does this by 1) covering all employers, not
28 only those with more than 15 employees and 2) by regulating credentialing authorities along
29 with the other employment entities.

30
31 *Rationale for prohibiting acquisition and testing.* One rationale for limiting employer
32 acquisition of genetic information is the view that an employee should be able to keep genetic
33 information private. At least one state has a constitutional right of privacy that appears to be

1 relevant to genetic information. (Alaska) Another rationale is to make genetic discrimination
2 less likely. Unlike discrimination based on sex or race, an employer cannot discriminate on the
3 basis of genetic characteristics unless it has access to genetic information.
4

5 *Existing state law.* There are many avenues by which employment entities obtain health
6 information, which may include genetic information. These include employment applications,
7 interviews, references, post-offer medical exams, post-offer releases of medical records, Family
8 and Medical Leave Act requests, workers' compensation claims, health insurance claims to self-
9 insured employers, and voluntary disclosures by employees. Many states have tried to limit
10 employer acquisition of genetic information.
11

12 First, many states have statutes that prohibit an employer from obtaining genetic
13 information. Some even prohibit making inquiries about genetic information, for in the context
14 of at-will employment, the need to retain one's job may turn an employer's request for genetic
15 information into a demand that an employee dare not refuse. *See, e.g.,* Conn. Stat. Ann. § 46a-
16 60(11) (employer may not "request or require" genetic information from employee); Kan. Stat.
17 Ann. § 44-1009(a)(9) (employer may not seek to obtain, obtain, or use testing information to
18 distinguish employees or restrict a right or benefit); La. Rev. Stat. § 23:368 (employer may not
19 "require, collect, or purchase" protected genetic information with respect to an employee); Md.
20 Code Art. 49B § 16(a) (employer may not "request or require" genetic information as a condition
21 for hiring or determining benefits); Mass. Gen. L. Art. 151B § 4(19) (unlawful to "collect, solicit
22 or require disclosure of genetic information" as a condition of employment or "question a person
23 about their genetic information or genetic information concerning their family members"); Mich.
24 Comp. Laws § 37.1202 (no employer may "directly or indirectly acquire or have access to" an
25 employee's or family member's genetic information unless an individual provides it voluntarily);
26 Minn. Stat. Ann. § 181.974(subd. 2) (employer may not "request, require, or collect" protected
27 genetic information as a condition of employment); Neb. Rev. Stat. § 48-236 (employer may not
28 require genetic information as a condition of employment or promotion); Nev. Rev. Stat. §
29 613.345 (unlawful employment practice to "ask or encourage" an employee to submit to a
30 genetic test); Utah Code Ann. § 26-45-103 (employer may not "access or otherwise take into
31 consideration" private genetic information in connection with an employment decision); Wash.
32 Rev. Code Ann. § 49.44.180 (unlawful to require employee to submit genetic information as
33 condition of employment).
34

35 Second, many states broadly prohibit employers from subjecting employees to genetic
36 testing. *See, e.g.,* Iowa Code Ann. § 729.6 (employer may not "solicit, require, or administer" a
37 genetic test as a condition of employment); Kan. Stat. Ann. § 44-1009(a)(9) (employer may not
38 subject, directly or indirectly, any employee to any genetic screening or test); Md. Code Art. 49B
39 § 16(a) (employer may not "request or require" genetic tests as a condition for hiring or
40 determining benefits); Mass. Gen. L. Art. 151B § 4(19) (unlawful to "solicit submission to,
41 require, or administer a genetic test" as a condition of employment); Mich. Comp. Laws §
42 37.1202 (no employer may require a genetic test as a condition of employment); Minn. Stat.
43 Ann. § 181.974(subd. 2) (employer may not "administer a genetic test" as a condition of
44 employment); Neb. Rev. Stat. § 48-236 (employer may not require a genetic test as a condition
45 or employment or promotion); Nev. Rev. Stat. § 613.345 (unlawful employment practice to
46 "require or administer" a genetic test as a condition of employment); N.H. Rev. Stat. § 141-H
47 (may not "solicit, require, or administer" genetic testing as a condition of employment); RI Stat.

1 § 28-6.7-1 (employer may not “request, require, or administer” a genetic test); Utah Code Ann. §
2 26-45-103 (employer may not “request or require” an individual or blood relative to submit to a
3 genetic test in connection with an employment decision); Vt. Stat. Ann. § 9333 (may not require
4 genetic testing as a condition of employment); Va. Code Ann. § 40.1-28.7-1 (employer may not
5 “request, require, solicit, or administer” a genetic test as a condition of employment); Wash.
6 Rev. Code Ann. § 49.44.180 (unlawful to require employee to submit to genetic screening as
7 condition of employment); Wis. Stat. Ann. § 111.372 (employer may not “solicit, require, or
8 administer” a genetic test as a condition of employment unless employee requests test).

9
10 The draft combines limits on acquisition and testing similar to these state provisions with
11 a set of exceptions taken from GINA that are modified in some instances and supplemented to
12 provide greater protection for employees.

13
14 An alternative approach taken by some states is to rely on state anti-discrimination
15 statutes, which typically allow employers to compel testing or to require employees to provide
16 genetic information under certain circumstances. Most of the states that rely on disability
17 statutes to regulate genetic information follow the Americans with Disabilities Act (ADA),
18 which permits an employer to test an applicant and acquire an applicant’s medical records after a
19 conditional offer of employment. 29 C.F.R. § 1630.14(b). This approach opens the door broadly
20 to genetic information once an employer has made a conditional offer of employment. In
21 addition, under the ADA and most state statutes modeled on it, after an employee is hired, an
22 employer can obtain medical information if it has a reasonable belief that the employee is unable
23 to perform the essential functions of his or her job due to a medical condition. 29 C.F.R. §
24 1630.14(c). States that have amended their employment discrimination statutes to include
25 genetics usually follow the rubric of these statutes and permit genetic testing or collection of
26 genetic information when it is relevant to “job-related qualifications” or justified by “business
27 necessity.” However, members of the Drafting Committee were concerned that tying the Act’s
28 protections to the concept of “job-related” medical information would not provide adequate
29 protection for genetic information. In interpreting the ADA, some courts have interpreted that
30 category broadly to permit employers to access medical information, thus narrowing the scope of
31 protection. The draft does not adopt this approach.

32
33 The draft’s approach also contrasts with California’s and Minnesota’s more
34 comprehensive limitations on employer access, which prohibit employers from accessing non-
35 job-related medical information at any time. An advantage of California’s and Minnesota’s
36 approach is that it does not depend on how “genetic information” is defined. In addition, it does
37 not rely on custodians of medical files to make a distinction between genetic information and
38 medical information more generally, which are usually mixed in medical files. Practically
39 speaking, when an employee signs a release permitting employer access to medical records,
40 everything in the records is included. There are those who maintain that legislation is needed to
41 limit an employer’s ability to obtain any non-job-related health information during the hiring
42 process or employment. See Mark A. Rothstein, *Genetic Exceptionalism and Legislative*
43 *Pragmatism*, 35 Hastings Center Report No. 4 (2005), at 35. The Drafting Committee discussed
44 this approach, but declined to adopt it because it extends beyond the scope granted to the
45 Committee.

46
47 *Subsection (a) General prohibition on acquisition of genetic information.* This

1 subsection establishes a general prohibition on acquisition of genetic information by
2 employment entities by prohibiting employment entities from “requesting, requiring, or
3 purchasing” an employee’s genetic information. Subsections (c)-(k) establish limited exceptions
4 to the prohibition.
5

6 This draft uses the language of GINA. It is now narrower than the prohibition in the
7 prior draft, which provided more comprehensively that an employment entity may not
8 “knowingly obtain or directly or indirectly inquire about, request, or require” an employee to
9 provide genetic information.
10

11 In addition to limiting acquisition of test results and information about testing, the draft
12 allows employees to keep private information that could lead to discrimination based on
13 assumptions about genetics, even in the absence of actual genetic testing. If an individual is
14 unable to keep private his use of genetic services such as counseling, the individual may be
15 deterred from obtaining this service for fear that an employer will assume the employee has
16 reason to think he has a genetic disorder. This draft follows GINA and a number of state statutes
17 that prohibit employers from acquiring or using information about an employee’s request for or
18 use of genetic services. *See, e.g.*, La. Rev. Stat. § 23:368 (employer may not “require, collect, or
19 purchase” information about an employee’s request for or use of genetic services); Maine Rev.
20 Stat. Ann. § 19302 (employer may not discriminate on basis that an individual received a genetic
21 test or genetic counseling except when based on a bona fide occupational qualification); N.C.
22 Gen. Stat. Ann. § 95-28.1A (unlawful to deny employment of account of request for genetic
23 testing or counseling services); Utah Code Ann. § 26-45-103 (employer may not inquire into
24 whether an individual or blood relative has taken or refused to take a genetic test); Vt. Stat. Ann.
25 § 9333 (employer may not use the fact that genetic counseling or tested services have been
26 requested or performed). The draft accomplishes this by defining “genetic information” to
27 include information about requests for or receipt of genetic services in the definition of genetic
28 information.
29

30 The prohibition on requesting genetic information is not intended to prevent an employer
31 from informing an employee about the availability of a genetic test that is relevant to conditions
32 in the workplace or from informing an employee about a genetic monitoring program.
33

34 *Subsection (b) General prohibition on genetic testing.* This subsection is a supplement to
35 GINA, which does not have provisions that specifically cover genetic testing. It establishes a
36 general rule that an employment entity may not offer or provide genetic tests to employees.
37 Subsections (g)-(k) establish limited exceptions and set requirements for counseling and
38 reporting that must be met if an employer provides a genetic test. An employment entity that
39 provides genetic testing under one of these exceptions should supply it through an outside
40 medical organization. *See* Mark A. Rothstein, *Genetics and the Workforce of the Next Hundred*
41 *Years*, 2000 Colum. Bus. L. Rev. 371 (2000).
42

43 *Exceptions to the general prohibitions on acquisition and testing.* Subsections (c)-(k),
44 described individually below, provide situations in which employment entities’ access to genetic
45 information and/or genetic testing is acceptable. The draft permits employment entities to
46 acquire genetic information if they request it inadvertently, receive it from an employee who
47 provides it voluntarily, request it under the Family Medical Leave Act, obtain it by purchasing

1 certain publicly available documents, obtain it under certain conditions as part of offering a
2 wellness program, use it for genetic monitoring, use it for quality control in forensic testing
3 laboratories, or pursuant to a court order in litigation. An employment entity may variously
4 provide or require genetic testing as part of a wellness program or genetic monitoring program,
5 for quality control use in forensic testing laboratories, or pursuant to a court order in litigation.
6

7 *Subsection (c) Inadvertent requests.* This subsection was added for consistency with
8 GINA. Congress included this provision to address the “water cooler problem” – when an
9 employer unwittingly receives information through casual conversation or by overhearing
10 conversations. While GINA’s exception is expressly limited to requests for family medical
11 history, the proposed regulations expand it to include any genetic information on the theory that
12 it should not matter whether the employee is discussing a genetic test or a relative’s disease. The
13 proposed EEOC regulations include examples of circumstances in which the acquisition of
14 genetic information would be deemed inadvertent. These include overhearing conversations,
15 receiving information that is not solicited, genetic information submitted in response to a request
16 for medical information, and information submitted by an employee seeking an accommodation
17 or leave.
18

19 *Subsection (d) Information voluntarily provided by employee.* This section is not found
20 in GINA. It is retained from the prior ULC draft. There is a question as to whether it is more
21 protective of the employee, in that it provides an additional avenue for an employer to obtain
22 genetic information. It may be somewhat duplicative of the idea behind GINA’s exception for
23 information an employer obtains inadvertently. However, it also would allow an employee
24 purposely to provide an employer with genetic information at the employee’s initiative. This
25 would be protective of an employee if, for example, the employee sought reassignment to avoid
26 exposure to a chemical which the employee might have a genetic susceptibility. And, when
27 coupled with the authorization in section 209, it allows the employee to control the privacy of
28 this information. This provision would also protect an employer from liability under the act if an
29 employee submits genetic information without any request from the employer.
30

31 Employees who provide genetic information voluntarily may do so directly, through oral
32 statements or by turning over reports of test results. They may also do so by permitting an
33 employment entity to see medical records held by a third party. In the case of disclosures made
34 by a third party to an employer, the draft requires prior authorization by the employee. The
35 prohibition on employer inquiries is intended to apply to inquires directed to other entities as
36 well as to inquiries directed to the employee.
37

38 *Subsection (e) Family Medical Leave Act.* This subsection was added for consistency
39 with GINA. The exception is limited to requests for family medical history. An employee
40 seeking leave to care for an ill relative is asked about the relative’s illness on FLMA certification
41 forms.
42

43 *Subsection (f) Purchased documents.* This subsection was added for consistency with
44 GINA. GINA has an exception when employers purchase commercially available materials that
45 may contain family medical history. The proposed EEOC regulations expand the scope of this
46 provision to include any genetic information.
47

1 GINA explicitly includes newspapers, magazines, periodicals, and books as “excused”
2 media and excludes medical databases and court records. The proposed EEOC regulations
3 expands the list of excused media to include the internet, television, and movies.
4

5 *Subsection (g) Employee health or genetic services.* This subsection permits an
6 employer that provides preventative health services to encourage a healthy workplace to include
7 genetic testing as part of those services. Both GINA and the prior ULC draft include provisions
8 to encourage employers to provide their employees access to genetic information in this way.
9 Both required employee authorization for this service. The ULC draft contemplated that while
10 the employer might provide testing, it could not receive any resulting genetic information unless
11 the employee voluntarily submitted it to the employer. In contrast, GINA allows the employer to
12 receive genetic information in an aggregate form and a health care professional involved in
13 providing the services for the employer to receive individualized genetic information.
14

15 This draft combines acquisition provisions from both the prior ULC draft and from
16 GINA. It permits an employer to offer genetic testing, but it differs from GINA in that it does
17 not permit the employer to acquire the resulting information, even in aggregate form. The
18 Committee needs to decide if it is appropriate to retain this extra protection for employees. The
19 current draft does adopt GINA’s provision permitting access for a health care professional
20 involved in providing the services for the employer. The Drafting Committee has been advised
21 that employer-provided genetic counseling should normally be conducted by professionals –
22 typically genetic counselors, geneticists, or physicians – from outside the employer organization.
23 This act is not intended, however, to regulate the practice of medicine, and so it does not directly
24 forbid an employer from using employees to provide these services. If an employer does use
25 employees, it would be necessary for the health care professional providing genetic services to
26 obtain the genetic information of participating employees. The intent of the current draft is to
27 segregate that information so that others in the employment entity do not have access to the
28 information.
29

30 The draft also follows the prior ULC draft by providing additional protections not found
31 in GINA. In this subsection it requires employers to provide genetic counseling about the risks
32 and benefits of the test before an employee considers signing the authorization for testing. The
33 purpose of this counseling is so that the employee can make an informed decision about whether
34 or not to have the test. The Committee decided that an employee may, however, decline the
35 counseling. In addition, in subsection (i), the draft mandates additional protections when an
36 employer does provide genetic testing. These protections apply to both health or genetic
37 services offered by an employer and to genetic monitoring programs.
38

39 The prior ULC draft provided that the employer must pay for the genetic testing and
40 genetic counseling. This differs from GINA. Because this testing is for the employee’s benefit
41 and might be covered by health insurance, the payment provision is dropped from the current
42 draft.
43

44 *Subsection (h) Genetic monitoring program.* Monitoring for damage to employees’
45 genes from workplace exposure to harmful substances is another possible justification for
46 testing. Genetic monitoring programs are typically undertaken by employers to identify risks for
47 groups of employees who have been exposed to hazardous substances or to target work sites for

1 safety and health measures. Monitoring is testing designed to detect whether the genetic
2 material of a group of individuals has changed over time. The premise is that such changes
3 could indicate increased risk of future illness. Aggregated data from tests for genetic damage is
4 sufficient to allow an employer to reduce exposures to levels that do not affect individuals'
5 chromosome morphology or DNA. Office of Technology Assessment, *Genetic Monitoring and*
6 *Screening in the Workplace* 66 (1990). However, while monitoring may have predictive value
7 for a group, the techniques that are used do not currently measure increased individual health
8 risks.

9
10 *Existing State law.* A number of states permit genetic monitoring, provided that the
11 employee requests testing, provides informed consent or authorization, and the employer does
12 not terminate the employee or take other adverse action as a result of testing. Iowa Code Ann. §
13 729.6(7); N.H. Rev. Stat. § 141-H:3; N.Y. Exec. Law § 296; Wis. Stat. Ann. § 111.372. In
14 addition, Louisiana authorizes monitoring of biological effects of toxic substances in the
15 workplace if the employee has provided authorization and is notified of the results. La. Rev.
16 Stat. § 23:368. More generally, the definitions and prohibitions in many state's statutes do not
17 appear to restrict monitoring for genetic damage, or are ambiguous on this issue.

18
19 *Relationship to GINA.* The prior ULC draft permitted testing in conjunction with a
20 genetic monitoring program only with the authorization of the employee. This draft follows
21 GINA by also permitting testing, without employee authorization, when required by federal or
22 state law. It expands GINA's protections by including the provision from the prior ULC draft
23 for genetic counseling when the testing is conducted pursuant to an employee's authorization.
24 Both GINA and the prior draft limited employer access to aggregate genetic data. This provision
25 is retained with an exception for employees administering the monitoring.

26
27 When an employer provides genetic testing as part of a genetic monitoring program, this
28 draft provides protections for the employee in subsection (i) that go beyond GINA.

29
30 *Subsection (i) Protections in conjunction with genetic testing.* This subsection provides
31 the employee with protections in the event that an employment entity provides testing as part of
32 health or genetic services under subsection (g) or a genetic monitoring program under subsection
33 (h). These protections supplement GINA's provisions on health plans and monitoring.

34
35 *Subsection (i)(1) Reporting test results.* This subsection provides for reporting genetic
36 test results to the employee when an employment entity supplies testing. An employer must be
37 sensitive, however, to the fact that not all individuals wish to know their genetic information.
38 The draft recognizes an employee's right to decline to know the results of a genetic test. An
39 employee may not wish to be informed of the result because of the psychological burdens that
40 may accompany such knowledge.

41
42 *Subsection (i)(2) Genetic counseling.* Along with reporting test results to a health care
43 professional, the draft mandates the availability of genetic counseling so that the results can be
44 interpreted for the employee if the result is positive.

45
46 *Subsection (i)(3) Destruction of the sample obtained for testing.* The provision for
47 prompt destruction of a sample obtained for genetic testing supplied by an employer protects the

1 employee’s privacy by preventing subsequent testing of the sample. It also recognizes, however,
2 that a testing laboratory is required to retain samples for certain time periods for certification
3 testing and other purposes. The provision follows statutes adopted in New Jersey and Oregon.
4

5 Possible alternative approaches (1) put the burden on the employee by requiring that the
6 sample be destroyed promptly on the request of the individual tested or (2) specify that a sample
7 may be retained for a period of time. Some provisions combine elements of more than one
8 approach. In New York, for example, a sample may be retained for ten years if authorized by the
9 individual from whom the sample was obtained.
10

11 *Subsection (j) Forensic testing laboratories.* This subsection was added for consistency
12 with GINA. It allows a limited subset of employers – those that perform genetic testing for
13 identification for law enforcement purposes or to identify human remains – to collect DNA
14 samples from employees in order to check for contamination of samples with the employees’
15 DNA.
16

17 Testing under this subsection is not subject to the protections in subsection (i) because
18 testing for the purposes of quality control in an identification laboratory would be limited to the
19 sections of the genome used for identification, which are not thought to have any medical or
20 predictive significance.
21

22 *Subsection (k) Legal proceedings.* This subsection allows an employer to obtain an
23 employee’s genetic information that is relevant to a claim or defense in a legal proceeding,
24 through testing if necessary, if the employee places the employee’s health at issue in a legal
25 proceeding. It supplements GINA and provides standards that give an employee greater
26 protection than that afforded by civil litigation discovery standards for medical testing.
27

28 The employer’s ability to acquire genetic information is limited in that it applies only if
29 the employer has satisfied the burden of proof to show compelling need and that the information
30 is otherwise unavailable. Only that portion of an employee’s genetic information that is relevant
31 to a claim or defense may be provided. These procedures provide more protection than Rule 35
32 of the Federal Rules of Civil Procedure or state equivalents, which provide that a court may
33 order a physical examination on motion for good cause shown. The Drafting Committee
34 considered a requirement that the genetic test results be sealed or placed under a protective
35 order, but decided to leave this to existing law.
36

37 The substance of the subsection follows Utah’s statute, which authorizes genetic testing
38 when an employee has placed his or her health at issue in a proceeding, but only by order of a
39 court or administrative agency after finding compelling need and that the information is
40 otherwise unavailable. Utah Code Ann. § 26-45-103(2). Other states have more narrowly
41 authorized employer testing to investigate a workers’ compensation claim. (NH, NY).
42

43 *Employee susceptibility.* One circumstance in which the prior draft allowed genetic
44 testing is now omitted – genetic screening to determine the employee’s predisposing genetic
45 characteristics that may create susceptibility to harm to the employee from a workplace
46 condition. This was done based on the judgment that this provision would not provide greater
47 protection to employees than GINA, and would thus be preempted. This note is retained to alert

1 the Drafting Committee to this omission and to allow discussion, if desired, of the preemption
2 issue and the desirability of retaining this exception.

3
4 Several states currently allow to test for screening purposes, with the consent of the
5 employee. Iowa, Louisiana, New Hampshire, New York, and Wisconsin all have nearly
6 identical provisions that permit genetic testing of an employee to determine an employee's
7 susceptibility to toxic substances if the employee requests testing, provides informed consent or
8 authorization, and the employer does not terminate the employee or take other adverse action as
9 a result of testing. Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-H:3; N.Y. Exec. Law §
10 296; Wis. Stat. Ann. § 111.372.

11
12 The utility of testing for susceptibility to workplace exposures is illustrated by chronic
13 beryllium disease. Beryllium is a lightweight metal used in many industries that poses the threat
14 of this disease when dust or fumes are inhaled. Industry protections have greatly reduced
15 exposure, but a small portion of the population can contract the disease even after a very brief
16 exposure. A genetic marker has reportedly been identified for this extreme sensitivity that
17 purports to show with certainty which individuals will contract beryllium disease and die from
18 short exposure. Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in Employment*
19 *on the Basis of Genetics*, 6 Employee Rights & Employment Policy Journal 57, 63-64 (2002). If
20 so, testing could provide information that could define an individual's risk from workplace
21 exposure to beryllium.

22
23 The prior draft allowed an employment entity to supply testing for such susceptibilities,
24 but unless the employee volunteers the test results, the employment entity was not authorized to
25 obtain them.

26
27 *Safety of other employees.* The Drafting Committee considered, but did not adopt, a
28 provision that would permit employers to supply genetic testing in order to protect the safety of
29 other employees in the workplace. It would be very rare for a genetic marker to indicate a safety
30 threat to other employees with sufficient certainty to justify a genetic test. The draft does not
31 limit an employer's ability to take an employee's manifested medical condition into account for
32 safety purposes, subject to the provisions of the Americans With Disabilities Act.

33
34 **SECTION 203. EMPLOYEE AUTHORIZATION FOR A GENETIC TEST.**

35 (a) Except as otherwise provided by law other than this [act], an employee's
36 authorization for a genetic test must be knowing and voluntary and indicated in a record signed
37 by the employee that complies with subsection (b) of this section. An employment entity that
38 receives a valid authorization for genetic testing may provide a test only in accordance with the
39 authorization. An authorization may not expand the genetic testing permitted by this [article]
40 and may not include exculpatory language waiving any of the employee's legal rights.

1 (b) An authorization for a genetic test for employment must:

2 (1) describe the genetic test to be performed, its purpose, and its permitted uses;

3 (2) inform the employee that only the authorized genetic test will be performed on
4 the employee's biological sample;

5 (3) inform the employee that the employment entity is obligated to provide and
6 pay for genetic counseling about the risks and benefits of the test before the employee decides to
7 authorize the test;

8 (4) inform the employee that the employment entity is obligated to provide and, if
9 applicable, pay for genetic counseling about the test result unless the employee waives genetic
10 counseling;

11 (5) inform the employee that the test result will be reported to the employee and a
12 health-care professional designated by the employee unless the employee directs otherwise;

13 (6) include an opportunity for the employee to provide directions about reporting
14 test results and genetic counseling;

15 (7) inform the employee that the employee's biological sample will be destroyed
16 as soon as permitted by law after the test is completed unless the employee authorizes retention
17 of the sample or unless otherwise ordered by a tribunal; and

18 (8) state that the employee is entitled to a copy of the authorization.

19 (c) The use of the following form complies with this section.

20 **AUTHORIZATION FOR GENETIC TESTING**

21 Limited Authorization. Only the genetic tests that you authorize on this form will be
22 performed on your biological sample. These tests are voluntary.
23

24
25
26
27 Availability of Genetic Counseling. Before you complete this authorization, it is highly
28

1 recommended that you meet with a genetic counselor who will help you understand and evaluate
2
3 the risks, benefits, and consequences for you and your family of having the tests listed below.

4
5 (Only if applicable:) _____ will provide and pay for this genetic
6 [Name of employment entity]
7 counseling.

8
9
10 Proposed Genetic Tests. _____ proposes to provide the following
11 [Name of employment entity]
12 genetic tests:

13
14
15 _____
16 [Name of test]

17
18 This test is provided as part of a genetic monitoring program. The purpose of this test is
19
20 to monitor the effect of your exposure to _____. The result of the test will be
21 [workplace condition]
22 used only for the following purposes: _____. _____
23 [Name of employment entity]
24 will have access to the test results of all employees who authorize this test only in an
25
26 aggregate form that does not include individually identifiable information.

27
28
29 _____
30 [Name of test]

31
32 This test is provided through _____. The
33 [name of health plan or genetic services program]
34 purpose of the test is _____. _____ may
35 [Name of employment entity]
36 not request or require you to disclose this test result and it will not have access to
37 the test
38
39 result unless you authorize it. If you authorize acquisition of the test result, it will be
40 used
41
42 only for the following purposes: _____.

43
44
45 Reporting Test Results and Genetic Counseling. The test results will be reported to you and
46
47 to a health-care professional whom you designate unless you direct otherwise. It is

1 recommended that you receive genetic counseling about the test results. _____
2 [Name of employment entity]
3 will provide and (if applicable) pay for genetic counseling about the test results unless you
4 decline genetic counseling. Genetic counseling is important for understanding the test results in
5 the context of your medical and family history. It can also provide you with support,
6 informational resources, and referrals, as appropriate, that can help you adapt to the implications
7 of being at risk of a genetic condition.
8
9
10
11
12

13
14 Destruction of your Biological Sample. After the genetic test, your biological sample will be
15 destroyed as soon as permitted by law unless you agree to authorize otherwise in writing or a
16 court, arbitral tribunal, or administrative agency requires retention of the sample.
17
18
19

20
21 By signing this authorization, you do not lose any legal rights to which you are entitled. You are
22 entitled to a copy of this authorization.
23
24
25

26 I, _____, authorize the genetic test(s) I have checked above.
27 [print name]

- 28
29 I wish to receive test results.
30 I do not wish to receive test results.
31
32 Report test results to the following health care professional:
33 Name: _____
34 Address: _____
35 Do not report test results to a health care professional.
36
37
38

39 _____
Signature Date

40 41 **Reporter's Notes**

42
43 This section sets forth an authorization requirement for genetic testing and the elements
44 that must be contained in an authorization form. The term "authorization" is used instead of
45 "informed consent" to avoid confusion with the use of that term in medical practice. The
46 requirement in this draft is more detailed and comprehensive than GINA. GINA requires

1 employee authorization when an employer acquires genetic information in connection with
2 providing health or genetic services and when an employer conducts a monitoring program that
3 is not required by law. In those circumstances, GINA requires an employee authorization that is
4 “prior, knowing, voluntary, and written.”
5

6 The draft’s authorization requirement, coupled with statutory limits and duties imposed
7 on employers, employment agencies, labor organizations, and credentialing authorities, is
8 designed to maintain privacy for genetic testing and genetic information. Under this approach,
9 before any genetic testing can be performed, unless the testing is required by law, an employee
10 must affirmatively authorize any genetic testing and acquisition, use, retention, or disclosure of
11 the resulting genetic information. The authorization requirement is not simply a procedural step
12 because Section 202 establishes limitations on the situations in which employment entities may
13 request authorization from employees.
14

15 The Committee needs to decide whether to adopt GINA’s simple provision on
16 authorization or retain the current details and form.
17

18 The Drafting Committee considered, but did not adopt alternatives that would (1)
19 establish a general property right in a biological sample an individual provides for genetic testing
20 and in the resulting genetic information or (2) establish a limited property right applicable only
21 to the context of employment.
22

23 *Subsection (a) Requirement for authorization for genetic testing.* Under Section 202, an
24 employment entity may supply genetic tests as part of health or genetic services, but only with
25 prior authorization from the employee, and as part of a genetic monitoring program, but only if
26 required by law or with prior authorization from the employee.
27

28 In order to meet the requirement of this subsection that an authorization be knowing and
29 voluntary, an employee or insured should have genetic counseling before signing the
30 authorization. Genetic counseling provides employees or insureds with adequate information to
31 make an informed decision about genetic testing. It also makes them aware of their options
32 regarding reporting of test results and help in interpreting them through genetic counseling. An
33 employment entity that offers a genetic test as part of a health program or genetic monitoring
34 program has an obligation to provide genetic counseling. Genetic counseling may be provided
35 by a genetic counselor, but may also be provided by a qualified physician or geneticist. An
36 employee may waive genetic counseling, but must first be made aware of the benefits of genetic
37 counseling.
38

39 The Drafting Committee anticipated that there might be circumstances in which an
40 individual is incapacitated or incapable of authorizing a genetic test. This situation is left to
41 existing law of the state that provides for power of attorney, guardianship, or other substitute
42 decision makers.
43

44 *Subsection (b) Content of authorization for testing.* The section draws on N.Y. Civ.
45 Rights Law § 79-1 (McKinney), which establishes requirements for consent for a genetic test.
46

47 The limitation in (b)(2) to the authorized test is consistent with the requirements for prior

1 authorization in Section 202.
2

3 The requirements in subsection (b)(3)-(6) reflect the obligations of the employment entity
4 to provide genetic counseling under Section 202(g), (h), and (i).
5

6 The notification provision for retention of the sample in (b)(7) is consistent with the
7 employment entity's obligation to ensure that the sample is destroyed under Section 202(h),
8 which recognizes that the testing laboratory may be required to retain the sample for certification
9 purposes.
10

11 *Subsection (c) Authorization form.* The use of a form following the pattern in this
12 subsection would comply with the requirements of the section.
13

14 **SECTION 204. PROHIBITION ON USE OF GENETIC INFORMATION.** An
15 employment entity may not take an adverse employment action against an employee based on
16 the employee's genetic information.

17 **[[SECTION 204. PROHIBITION ON USE OF GENETIC INFORMATION.**

18 (a) An employer shall not fail or refuse to hire, discharge, or discriminate against an
19 employee in regard to compensation, terms, conditions, or privileges of employment because of
20 genetic information with respect to the employee.

21 (b) An employment agency shall not fail or refuse to refer an individual for employment
22 or discriminate against an individual because of genetic information with respect to the
23 individual.

24 (c) A labor organization shall not exclude a labor organization member from membership
25 in the organization or discriminate against any labor organization member because of genetic
26 information with respect to the member.

27 (d) An employer, labor organization, or joint-labor management committee controlling an
28 apprenticeship or a training or retraining program shall not discriminate against an individual
29 because of genetic information with respect to the individual in admission to or employment in
30 the program.

1 (e) A credentialing authority shall not discriminate against an individual because of
2 genetic information with respect to the individual.

3 (f) An employment entity shall not limit, segregate, or classify an individual, or fail or
4 refuse to refer for employment an individual, in a way that would deprive or tend to deprive the
5 individual of employment opportunities or otherwise adversely affect the status of the individual
6 as an employee, because of genetic information with respect to the individual.

7 (g) An employment agency, labor organization, or joint labor-management training or
8 apprenticeship program shall not cause or attempt to cause an employer to discriminate against
9 an employee in violation of this [article].

10 (h) An employment entity shall not discriminate against an employee because the
11 employee has opposed an act or practice made unlawful by this [article] or because the employee
12 made a charge, testified, assisted, or participated in any manner in an investigation, proceeding,
13 or hearing under this [article].]]

14
15
16 **Reporter's Notes**
17

18 This section presents alternative formulations to restrict use of genetic information by
19 employment entities. The first version of the section is based on the prior ULC draft. The
20 version in double brackets is drawn from the language in GINA.

21
22 *Existing state law.* Many state statutes limit use of genetic information by prohibiting
23 discrimination among employees or applicants for employment on the basis of genetic
24 information. (Ark, Ill, Kan, LA, Maine, MD, Mass, Mich, MO, Neb, Nev, NJ, NY, NC, OK,
25 OR, RI, SD, Tex). Others more generally ban any use of genetic information in employment.
26 For example, New Mexico's 2005 statute provides simply that "[i]t is unlawful for a person to
27 use genetic information in employment," In Utah, employers may not take into account
28 genetic information about an individual in connection with an employment decision. Similarly,
29 in Iowa, an employer may not use genetic information to "affect the terms, conditions, or
30 privileges of employment" of a person who gets a genetic test. Iowa Code Ann. § 729.6(2).
31 Minnesota and Wisconsin prohibit adverse employment actions based on genetic information.
32 Minn. Stat. § 181.974 subd. 2(a)(2) (may not "affect the terms or conditions of employment or
33 terminate the employment of any person based on protected genetic information"); Wis. Stat. §
34 111.375 (may not "affect terms, conditions or privileges of employment, labor organization

1 membership or licensure or terminate the employment labor organization membership or
2 licensure”).

3
4 *Provision from the prior draft.* The prior ULC draft used the term “adverse employment
5 decision.” The Drafting Committee regarded this as a term of art in employment law that does
6 not need to be defined in this act. The Drafting Committee decided not to list adverse
7 employment actions in the black letter law because of the risk that something would be left off
8 the list and the list would be treated as limiting. The Committee intends, however, for the term
9 to be interpreted broadly. One example of a broad statement of adverse employment actions can
10 be found in the District of Columbia Human Rights Act, which makes it a discriminatory
11 practice for an employer “[t]o fail or refuse to hire, or to discharge, any individual; or otherwise
12 to discriminate against any individual, with respect to his compensation, terms, conditions, or
13 privileges of employment, including promotion; or to limit, segregate, or classify his employees
14 in any way which would deprive or tend to deprive any individual of employment opportunities
15 or otherwise adversely affect his status as an employee.” D.C. Code § 2-1402.11.

16
17 The term “adverse employment action” is consistent with and intended to include the
18 actions listed in the federal Genetic Information Nondiscrimination Act of 2008, which makes it
19 an unfair employment practice for an employer “(1) to fail to hire, or to discharge, any employee,
20 or otherwise to discriminate against any employee with respect to the compensation, terms,
21 conditions, or privileges of employment of the employee, because of genetic information with
22 respect to the employee; or (2) to limit, segregate, or classify the employees of the employer in
23 any way that would deprive or tend to deprive any employee of employment opportunities or
24 otherwise adversely affect the status of the employee as an employee, because of genetic
25 information with respect to the employee.” 42 U.S.C. § 2000ff-1(a).

26
27 *Provision based on GINA.* GINA has a separate statutory section defining unlawful
28 employment practices for each type of employment entity. This version follows the proposed
29 EEOC regulations, which consolidate the provisions as much as possible, using the terminology
30 of GINA.

31
32 GINA does not contain the provision on retaliation in subsection (h), but the EEOC has
33 added it into the regulations. This omission from the statute illustrates the dangers of
34 enumerating adverse employment actions. Subsection (e) governing credentialing authorities is
35 another departure from GINA. Both additional provisions provide employees greater protection.

36
37
38 *Rationale for limiting actions of employment entities.* The restrictions on employment
39 actions in GINA and this draft are important because they will dispel uncertainty about how
40 courts would otherwise apply federal statutes to decisions based on genetic information that
41 predicts employee susceptibility to harm from workplace exposures. On one hand, in 1991 the
42 United States Supreme Court held that a chemical company’s policy barring women of child-
43 bearing age from employment opportunities that involved exposure to lead violated Title VII
44 prohibitions on gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187
45 (1991). On the other hand, the ADA allows employers to act on health information, even in the
46 case of disability, when there is a direct threat to the health or safety of others in the workplace.
47 The Equal Employment Opportunity Commission (EEOC) has interpreted this ADA provision to

1 apply when there is no risk to others but when an employer can show that an individual's
2 disability poses a significant risk of harm to the individual. The United States Supreme Court
3 upheld this interpretation. *Chevron v. Echazabal*, 122 S. Ct. 2045 (2002). Although the
4 *Echazabal* case did not involve a genetic characteristic, but rather a worker's liver damage due to
5 exposure to workplace solvents, the implication of the case is that in the absence of a prohibition
6 in a state statute, an employer may make adverse employment decisions based on genetic
7 screening or monitoring requested by an employee even if there is no threat to others. Section
8 204 does not permit an employer to take an adverse employment action under these
9 circumstances. Harm to the employee or to others is not a justification. As a result, employers
10 would not be able to use an employee's genetic information in the way the employee's health
11 information was used in the *Echazabal* case.

12
13 Note that the section does not necessarily prevent an employer from making decisions
14 based on the effects of an employee's manifest genetic condition or disease in the workplace.
15 This is because the section uses the term "genetic information," which is defined with reference
16 to a "genetic test." Some employees with manifest genetic conditions would be covered under
17 the ADA if the condition limits a major life activity, but there is no comprehensive protection for
18 individuals with medical conditions that result from genetic traits. While some maintain that
19 attempts to prevent genetic discrimination are mostly meaningless without protection for people
20 who have genetic diseases, see Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why*
21 *They are so Hard to Protect*, 26 J. L. Med. & Ethics 181 (1998), others emphasize the
22 difficulties with either policy choice, see Henry T. Greely, *Genotype Discrimination: The*
23 *Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1503 (2001).

24 **SECTION 205. AUTHORIZED USE OF GENETIC INFORMATION.** An

25 employment entity that obtains genetic information as permitted by Section 202 may use the
26 genetic information:

27 (a) to monitor the effects of an employee's exposure to a workplace condition as part of a
28 genetic monitoring program;

29 (b) for purposes of quality control if the employer conducts DNA analysis for law
30 enforcement purposes as a forensic laboratory or for purposes of identifying human remains; or

31 (c) to defend a claim in a proceeding before a tribunal in which an employee has placed
32 the employee's health at issue.

33 **Reporter's Notes**

34
35 The draft selectively authorizes ways that an employment entity may use genetic
36 information. It is taken from the prior draft and clarifies GINA, which permits employers to
37 acquire information for certain purposes, but fails to authorize those uses.

1 The Drafting Committee considered a provision that would have allowed adverse
2 employment actions in the case of an employee with a predisposing genetic characteristic that
3 poses a direct threat of harm to others. It decided not to include this provision because the
4 Drafting Committee was unable to identify any known genetic trait that would qualify and if
5 testing is permitted for this purpose it could be abused. In addition, such a provision would
6 probably be preempted by GINA, which permits states to depart from federal law only to provide
7 greater protections for employees.
8

9 Because of concerns about preemption, this draft drops a provision from the prior draft
10 that would have permitted an employer to use genetic information on employee susceptibility to
11 harm in the workplace to reduce the potentially harmful exposure, but not to make an
12 employment decision that would adversely affect the employee. The utility of this form of
13 genetic information is described in the Reporter's Notes to section 202.
14

15 **SECTION 206. ACCESS TO GENETIC INFORMATION BY EMPLOYEE.** An
16 employee may inspect, request correction of, or obtain a copy of the employee's genetic
17 information in any record of an employment entity which contains the information. If an
18 employee requests correction of genetic information in a signed record, the employment entity
19 shall include the request for correction, and supporting data, in the employee's record.

20 **Reporter's Notes**

21
22 This section supplements GINA and is more protective of the employee than the federal
23 statute. GINA allows employment entities to provide an employee's genetic information to the
24 employee as an exception to its general prohibition on disclosure, but it does not give an
25 employee a right to obtain this information. This section follows the prior ULC draft. It is based
26 on the conclusion that an employee ought to be able to find out what genetic information an
27 employer knows about an employee and to have the same information. It is modeled on 16 Del.
28 Code § 1223. It also provides a mechanism for an employee to correct genetic information
29 contained in employer records.
30

31 If the employer supplied the genetic testing, information may also be kept in files at the
32 laboratory that performed the testing. The employer's responsibility to correct errors does not
33 extend to the testing laboratory, which is regulated under the Clinical Laboratory Improvement
34 Amendments, (CLIA), 42 U.S.C. § 263a.
35

36 The Drafting Committee considered but rejected an exception that would have prohibited
37 employee access to information an employment entity has compiled for litigation. This situation
38 will be governed by normal discovery rules, which are unaffected by this section.
39

40 **SECTION 207. CONFIDENTIALITY AND RETENTION OF GENETIC**

1 **INFORMATION.**

2 (a) An employment entity shall treat genetic information about an employee or an
3 employee’s family member as a confidential record.

4 (b) If an employee authorizes an employment entity to keep a record of an employee’s
5 genetic information, the employment entity shall keep the record separately from the employee’s
6 personnel file.

7 [[b) If an employment entity possesses genetic information about an employee or an
8 employee’s family member, the employment entity shall keep the genetic information on a
9 separate form in a separate medical file that is kept separately from the employee’s personnel
10 file.]]

11 (c) The requirements of subsection (b) are satisfied if the employment entity maintains
12 the genetic information in a separate medical file with information regarding the employee’s
13 medical condition or history that the employment entity obtained from a medical examination
14 after an offer of employment had been extended, and treats the information as a confidential
15 medical record pursuant to the Americans with Disabilities Act, 42 U.S.C. § 12112(d)(3)(B).

16 (d) Notwithstanding this section, an employment entity may keep genetic information
17 obtained in aggregate form pursuant to Section 202(h) for use in a genetic monitoring program.

18 **Reporter’s Notes**

19
20 *Subsection (a) Confidentiality.* This subsection declares that genetic information, which
21 includes family medical history, is confidential in the employment context. “Genetic
22 information” is a category that includes information about use of or request for genetic services,
23 so it also includes an employee’s authorizations concerning genetic tests or information.
24

25 Starting the section with a declaration of confidentiality is the approach used in the prior
26 ULC draft. It is consistent with GINA, which provides that genetic information shall be treated
27 as a confidential medical record, but it gives greater emphasis to the principle.
28

29 *Subsection (b) Retention of genetic information.* The alternative versions of this
30 subsection present two different approaches to regulating the retention of information. Under the

1 prior draft, if an employment entity obtains any genetic information, it needs the employee's
2 authorization to retain the information. This was consistent with the prior draft's provisions on
3 acquisition of information, which did not include the range of possibilities for acquisition of
4 genetic information that are included in GINA and which contemplated that genetic information
5 the employer received would be authorized by the employee .
6

7 GINA's provision operates if an employer "possesses" genetic information. It does not
8 require an employee to authorize retention of the information. This is consistent with the
9 avenues by which an employer might inadvertently obtain genetic information, as recognized in
10 GINA. The Drafting Committee will need to decide the extent to which an authorization
11 requirement should be required before employers may legally retain genetic information in their
12 files.
13

14 Both versions include a separate storage requirement that serves to protect the
15 employee's privacy.
16

17 *Subsection (c) Coordination with the Americans with Disability Act.* This provision
18 follows GINA. There is a need for coordination because many employers will acquire genetic
19 information when they acquire an employee's medical records (which they may request under
20 the ADA after a conditional offer of employment or during employment for job-related
21 purposes). Genetic information is likely to be interspersed throughout medical records and an
22 employer that requests medical information is likely to receive the entire file, including genetic
23 information. GINA addresses this by allowing employers to keep genetic information with
24 confidential medical information acquired under the ADA so long as both types of information
25 are retained as confidential records separate from an employee's personnel file.
26

27 This approach is not inconsistent with prior Committee deliberations in which the
28 Committee considered, but rejected, requiring genetic tests to be kept in a record separate from
29 other medical information. The Committee considered the fact that mental health records are
30 kept separate from medical records and HIPAA requires a separate authorization before they can
31 be disclosed. However, mental health records are not determined by the content of the record,
32 but as those kept by a psychologist or psychiatrist. An alternative solution would be to develop
33 technologies that can limit the scope of information disclosed by health care providers. Mark A.
34 Rothstein & Meghan Talbott, *Compelled Disclosure of Health Information: Protecting Against*
35 *the Greatest Potential Threat to Privacy*, 295 JAMA 2882 (2006).
36

37 *Subsection (d) Genetic monitoring program.* An employer may retain and disclose
38 genetic information without an employee's specific authorization for a genetic monitoring
39 program. An employer is allowed access to this information only in an aggregate form that does
40 not identify individual employees, which should minimize the effects of retaining monitoring
41 information for an employee's privacy. An employer may need to disclose aggregate monitoring
42 information in order to analyze trends or take action to reduce risk in the workplace.
43

44 **SECTION 208. DISCLOSURE OF GENETIC INFORMATION.**

45 (a) Except as otherwise permitted in this section or as authorized by the employee, an

1 employment entity may not disclose an employee’s individually identifiable genetic information
2 to a person other than the employee and a health-care professional designated by the employee.

3 (b) An employment entity may disclose an employee’s genetic information:

4 (1) to an occupational or other health researcher if the research is conducted in
5 compliance with the regulations and protections provided for under part 46 of title 45, Code of
6 Federal Regulations;

7 (2) in response to an order by a tribunal, if the genetic information is expressly
8 authorized by the order;

9 (3) to government officials who are investigating compliance with this [act] or
10 with the Genetic Information Nondiscrimination Act, 42 U.S.C. § 2000ff to 2000ff-11, if the
11 information is relevant to the investigation;

12 (4) to the extent the disclosure is made to comply with the certification
13 requirements of the Family Medical Leave Act, 29 U.S.C. § 2613, or certification requirements
14 under the [state family and medical leave act]; or

15 (5) to a public health agency when the genetic information concerns the
16 manifestation in an employee or an employee’s family member of a contagious disease that
17 presents an imminent hazard of death or life-threatening illness.

18 (6) in aggregate form in connection with a genetic monitoring program operated
19 pursuant to Section 202(h).

20 (c) The employment entity shall provide notice in a record to the employee whose genetic
21 information is disclosed if:

22 (1) the disclosure is made under subsection (b)(2) of this section and the court
23 order was secured without the knowledge of the employee; or

24 (2) the disclosure is made under subsection (b)(5) of this section.

1 **Legislative Note:** In subsection (b)(4), states should insert for [state family and medical leave
2 act] the appropriate name for the state's act.
3

4 **Reporter's Notes**

5
6 This subsection has been redrafted to follow GINA, which contains a general prohibition
7 on disclosure of genetic information by employers coupled with exceptions. This is a different
8 approach from the prior draft, which prohibited any disclosures unless authorized by the
9 employee or ordered by a tribunal.
10

11 *Existing state law.* A number of states that have enacted (1) general privacy protections
12 for genetic information that prohibit disclosure without informed consent or authorization
13 (Alaska, Cal, Del, Fla, Maine, Mass, Nev, NH, NJ, NMex, NY, OR) or (2) specific protections
14 against the disclosure of genetic information by employers (Ariz, Fla, LA, Mass, NH, NJ, Or,
15 RI).
16

17 *Subsection (a) General prohibition on disclosure of genetic information.* This section
18 follows GINA except for the clause that permits disclosure if authorized by an employee. This
19 addition is included to respect employee autonomy.
20

21 *Subsection (b) Permitted disclosures.* These provisions are taken from and consistent
22 with GINA except for (b)(6) on genetic monitoring programs. This exception is retained from
23 the prior draft.
24

25 *Subsection (c) Notice to employee of disclosures.* These limited requirements for notice
26 are taken from GINA.
27

28 **SECTION 209. AUTHORIZATION FOR ACQUISITION, USE, RETENTION,** 29 **OR DISCLOSURE OF GENETIC INFORMATION.**

30 (a) Except as otherwise provided by this [act] or by law other than this [act], an
31 employment entity may not acquire, use, keep or disclose an employee's genetic information
32 without the employee's knowing and voluntary authorization indicated in a record signed by the
33 employee that complies with subsection (c). An employment entity that receives a valid
34 authorization may acquire, use, keep or disclose genetic information only in accordance with the
35 authorization. An authorization may not expand the acquisition, use, retention, or disclosure of
36 genetic information permitted by this [article] and may not include exculpatory language
37 waiving any of the employee's legal rights.

1 (b) Except as otherwise provided by this [act] or law other than this [act], a person who
2 receives genetic information disclosed by an employment entity must maintain the
3 confidentiality of the employee's genetic information and may not disclose the information
4 without the employee's knowing and voluntary authorization indicated by a record signed by the
5 employee that complies with subsection (c). A recipient that receives the employee's valid
6 authorization to disclose genetic information may disclose the information only in accordance
7 with the authorization. An authorization may not expand the disclosure of genetic information
8 permitted by this [article] and may not include exculpatory language waiving any of the
9 employee's legal rights. When an employment entity discloses an employee's genetic
10 information, it must notify the recipient of the information about these obligations.

11 (c) An authorization to acquire, use, keep, or disclose an employee's genetic information
12 must:

13 (1) describe the genetic information to be acquired, used, retained, or disclosed in
14 a specific and meaningful fashion;

15 (2) identify or describe the person that is authorized to acquire, use, keep, or
16 disclose the genetic information;

17 (3) if the authorization is for acquisition of genetic information through disclosure
18 by another person to an employment entity, identify or describe the person authorized to make
19 the disclosure;

20 (4) if the authorization is for use of genetic information, describe the permitted
21 uses;

22 (5) if the authorization is for retention of genetic information, describe where the
23 information will be retained and identify or describe the custodian of the information;

24 (6) if the authorization is for disclosure to a third person, identify or describe the

1 third person to which the authorized person may disclose the genetic information;

2 (7) indicate the duration of the authorization with an expiration date if any or
3 expiration event that relates to the employee or to the purpose of the acquisition, use, retention,
4 or disclosure;

5 (8) state that the employee may revoke the authorization at any time in a signed
6 record, subject to the right of a person that acted in reliance on the authorization before receiving
7 notice of revocation, and provide instructions on how to revoke an authorization; and

8 (9) state that the employee is entitled to a copy of the authorization.

9 (d) The use of the following forms comply with this section:

10 Authorization for Acquisition and Use

11
12 _____ seeks your authorization to acquire the following genetic test
13 [Name of employment entity]
14 results and use it for the purposes identified:

15
16
17 Family medical history information about _____. _____
18 [name of medical condition] [Name of
19 _____ will use this information only for the following purposes: _____.
20 employment entity]

21
22
23 Disclosure by _____ of genetic information about _____
24 [name of person to disclose] [name of test and
25 _____ will use this information only for the following
26 condition] [Name of employment entity]
27 purposes: _____.

28
29 You may revoke this authorization for acquisition and use at any time by sending a letter to
30 _____ unless _____ has _____
31 [name and address] [name of employment entity] [description of action that
32 _____
33 would be taken based on the information]

34
35
36 You are entitled to a copy of this authorization. By signing this authorization, you do not lose
37 any legal rights to which you are entitled.
38

1 This authorization is valid until _____.
2 [date or event]

3
4 I, _____, authorize _____ to acquire the genetic information
5 [print name] [name of employment entity]
6 checked above for use for the purposes indicated.
7

8 _____
9 Signature

_____ Date

10
11
12 Authorization for Retention of Genetic Information

13
14 _____ seeks your authorization to keep the following genetic
15 [Name of employment entity]
16 information history to which you have granted _____
17 [name of employment entity]
18 access. This information will be treated as a confidential record and kept separately from the
19 rest
20
21 of your personnel records.

22
23 _____
24 [Name of test and condition tested for]

25
26 Family medical history information about _____
27 [name of medical condition]

28
29 The purpose for keeping this information is _____.

30
31 You may revoke this authorization for retention at any time by sending a letter to
32 _____ unless _____ has _____
33 [name and address] [name of employment entity] [description of action that
34 _____
35 would be taken based on the information]

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

39
40 This authorization is valid until _____.
41 [date or event]

42
43 I, _____, authorize _____ to keep the information checked
44 [print name] [name of employment entity]
45 above.
46
47 _____

1 Signature

Date

4 Authorization for Disclosure of Genetic Information

6 _____ seeks your authorization to disclose the following genetic
7 [Name of employment entity]
8 information to _____.

9 [name of recipient of the information]

10 _____ will notify _____ that
11 [Name of employment entity] [name of recipient of the information]
12 _____ is legally obligated to maintain the confidentiality

13 [name of recipient of the information]
14 of this information and that it may not make further disclosures without your authorization.

17 _____
18 [Name of test and condition tested for]

20 Family medical history information about _____
21 [name of medical condition]

23 You may revoke this authorization for disclosure at any time by sending a letter to _____
24 [name and
25 _____ unless _____ has already disclosed the information.
26 address] [name of employment entity]

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

33 This authorization is valid until _____.
34 [date or event]

36 I, _____, authorize _____
37 [print name] [name of person authorized to make disclosure]
38 to make the disclosures checked above.

41 Signature

Date

43 **Reporter's Notes**

45 This section was drafted to require an employee to provide an authorization before an
46 employment entity could acquire, use, keep or disclose genetic information or family medical
47 history and to provide forms for this purpose. There is no parallel provision in GINA. The

1 Committee needs to decide if this requirement should be retained given the more limited role for
2 employee authorization under GINA.

3
4 The draft does not disturb existing law that allows a minor to seek repudiation of consent
5 and expunge records when the minor reaches the age of majority.

6
7 *Subsection (a) General requirement for authorization.* This subsection would establish a
8 requirement that an employment entity must be authorized by the employee before it may
9 acquire, keep, or disclose genetic information, except as provided elsewhere in the act. In order
10 to give a valid authorization, the employee must be informed as provided in the following
11 subsections and must act voluntarily. This subsection also includes a requirement that an
12 authorization must be indicated by a signed record. This authorization requirement is coupled
13 with limitations on acquisition, use, retention, and disclosure in Sections 204, 205, 207, and 208.

14
15 Other law of the state may provide for a substitute decisionmaker or signer if the
16 employee is incapacitated or incompetent. This situation is left to existing law of the state that
17 governs power of attorney, guardianship, or other substitute decision makers.

18
19 *Subsection (b) Obligation of recipient of authorized disclosure.* One of the difficulties in
20 authorizing disclosure is control over the information once it has been disclosed. The Drafting
21 Committee decided that regulation of the initial disclosure is ineffective without a continuing
22 obligation of confidentiality that is binding on the recipient. Hence under this subsection a
23 recipient may not redisclose the genetic information without the insured's authorization. This
24 provision extends beyond the privacy protections provided by HIPAA. States are permitted to
25 depart from HIPAA privacy provisions if they impose more stringent protections. 45 C.F.R. §
26 160.203(b).

27
28 The Committee considered and rejected several approaches to the issue of redisclosures,
29 including 1) a notice to the insured that the genetic information disclosed by the authorized
30 person may be subject to redisclosure by the recipient and not longer protected, and 2) a
31 provision that an insured could enter into a confidentiality agreement with recipients of their
32 genetic information.

33
34 *Subsection (c) Content of authorization.* The provision on authorization for acquisition,
35 use, retention, or disclosure of genetic information or family medical history is adapted from the
36 HIPAA Privacy Rule regulations for "uses and disclosures for which an authorization is
37 required." 45 C.F.R. §§ 164.508 (a) and (c), 164.512(a). The subsection adapts these
38 regulations to apply to genetic information and family medical history, and expands them to
39 include authorization for acquisition and retention as well as for use and disclosure.

40
41 An advantage of using the HIPAA regulations as the foundation for the authorization
42 requirements is that the requirements to authorize a disclosure by a health care provider to an
43 employer, employment agency, labor organization, or credentialing authority would be similar to
44 the requirements that health care provider must follow as a covered entity under HIPAA. The
45 context of the HIPAA regulations is different enough, however, that they cannot be transported
46 directly into the Act without modification. Moreover, under HIPAA, states are permitted to
47 impose their own, more stringent, privacy requirements. 45 C.F.R. § 160.203(b). Some have

1 enacted statutes with different requirements for disclosing health care information, which
2 reduces the uniformity that would theoretically be achieved by using the HIPAA format.
3 Therefore, while the structure of this subsection is modeled on the HIPAA regulations, it
4 includes some additional provisions from various state statutes. *See, e.g.,* Me. Rev. Stat. Ann.
5 tit. 22 § 1711-C.
6

7 *Subsection (d) Authorization forms.* The subsection includes forms that could be used for
8 an employee to authorize an employment entity to acquire and use genetic information, to keep
9 genetic information, or to disclose genetic information. The use of a form following this pattern
10 would comply with the requirements of the section.
11

12 **SECTION 210. REVOCATION OF AUTHORIZATION.**

13 (a) Except as otherwise provided in subsection (b) or by law other than this [act], an
14 employee may revoke an authorization provided under this [article] at any time in a signed
15 record.

16 (b) An employee's revocation of an authorization under subsection (a) has no effect to
17 the extent that an employment entity has taken action in reliance on the authorization.

18 **Reporter's Notes**

19
20 This section is adapted from the HIPAA regulation that governs revocation of an
21 authorization. 45 C.F.R. § 164.508(b)(5). It is similar to provisions governing health care
22 information that have been adopted by some of the states.
23

24 There is no parallel provision under GINA. The Committee should consider whether or
25 not to retain this section when it reconsiders the authorization provision.
26

27 The Drafting Committee considered expanding this section to give employees the ability
28 to amend their authorizations short of revoking them, but decided that it would be preferable for
29 employees to revoke one authorization and execute a new one.
30

31 Other law of the state may provide for a substitute decisionmaker or signer if the
32 employee is incapacitated or incompetent. Revocation by a substitute is left to existing law of
33 the state that governs power of attorney, guardianship, or other substitute decision makers.
34

35 **SECTION 211. RETENTION OF AUTHORIZATION.** An employment entity that
36 receives an employee's authorization under this [article] shall treat the authorization as a
37 confidential record and keep the authorization or require the authorization to be kept separately

1 from the employee’s personnel records. The employment entity shall keep a record of the
2 authorization for six years from the expiration date of the authorization or, if the authorization
3 does not have an expiration date, for six years from the date the authorization was created.

4 **Reporter’s Notes**

5
6 An employee’s authorization for genetic testing or employer acquisition, retention, or
7 disclosure of genetic information under Sections 203 or 209 is a confidential record that must be
8 kept separate from the employee’s personnel files. The provision that the authorization must be
9 retained for six years is adapted from the HIPAA regulations that govern documentation and
10 retention of a signed authorization. 45 C.F.R. § 164.508 (b) (6), § 164.530(j).

11
12 There is no parallel provision in GINA. The Committee needs to decide if this section
13 should be retained.
14

15 **SECTION 212. MEDICAL INFORMATION THAT IS NOT GENETIC**

16 **INFORMATION.** An employment entity’s acquisition, use, retention, or disclosure of medical
17 information that is not genetic information about a manifested disease, disorder, or pathological
18 condition does not violate this [article] even if the manifested disease, disorder, or pathological
19 condition has or may have a genetic basis.

20 **Reporter’s Notes**

21
22 This section is a paraphrase of section 210 of GINA, 42 U.S.C. § 2000ff-9. It is meant to
23 signal that medical information about a manifested disease is not covered by the act if it is not
24 genetic information, but that medical information is covered if it is genetic information. For
25 example, an individual with breast cancer might learn from genetic testing that she is positive for
26 a BRACA mutation and thus has an increased risk of ovarian cancer. Under this section, the fact
27 that she has breast cancer is not protected, but information about the genetic mutation is
28 protected.
29

30 Although under this section an employment entity does not violate the act when it
31 acquires, uses, retains, or discloses medical information about a manifest disease that is not
32 genetic information, that information may be protected by HIPAA or the ADA.
33

34 **SECTION 213. REMEDIES; LIMITATION OF ACTIONS.**

35 (a) n individual aggrieved by a violation of this [article] may file a civil action without

1 exhausting arbitral procedures or administrative remedies provided by an agreement of the
2 parties or by law other than this [act]. This section does not prohibit an employee from pursuing
3 administrative remedies or other remedies available under law other than this [act].

4 (b) All remedies at law and in equity are available to enforce this [article], including
5 compensatory damages, back pay, front pay, reassignment, reinstatement, injunctive relief,
6 punitive damages, expungement of records, and the right to a jury trial.

7 (c) A court shall award a prevailing employee reasonable attorney’s fees and costs unless
8 justice requires otherwise.

9 (d) An individual may file the civil action authorized in subsection (a) not later than two
10 years after the individual discovers the violation of this [article] or an individual exercising
11 reasonable care should have discovered the violation.

12 **Reporter’s Notes**

13
14 *GINA’s remedy and enforcement provisions.* For private employees, GINA adopts the
15 enforcement and remedy structure of Title VII of the Civil Rights Act of 1964, incorporating it
16 by reference. For the other employee groups it covers – state, federal, and congressional
17 employees – GINA incorporates the slightly different remedy provisions of the other relevant
18 federal EEO statutes. GINA explicitly excludes, however, claims for disparate impact, a cause
19 of action for unintentional discrimination that is available under Title VII.

20
21 *Administrative procedures.* Under Title VII, an individual seeking relief from
22 employment discrimination must first file a charge with a state or local agency if there is one that
23 is charged with enforcing a law that bans the alleged discriminatory act. If the state or locale
24 does not have its own law that covers the discriminatory act, an employee has 180 days from the
25 violation to file a discrimination charge with the EEOC. When state law has coverage similar to
26 Title VII, the charge must be filed with the EEOC within 300 days of the violation or within 30
27 days after the state terminates its own proceedings.

28
29 The EEOC serves a notice on the person named in the charge and investigates the charge.
30 If it finds reasonable cause to pursue the complaint, it must attempt to conciliate the matter. If
31 the EEOC dismisses the case or if settlement is not reached within 180 days from the time the
32 charge was filed and the EEOC and Attorney General decide not to bring a court case, the EEOC
33 issues a “right to sue letter.” The employee may take court action only after the EEOC issues
34 this notice. The case must be filed in court within 90 days.

35
36 *Remedies and damages.* Title VII authorizes courts to issue injunctive relief and to order

1 affirmative action as appropriate. This may include, but is not limited to, reinstatement or hiring
2 of employees, with or without back pay, and any other equitable relief the court finds
3 appropriate, such as promotion and front pay. Back pay may not extend for more than two years
4 prior to the date the charge was filed with the EEOC, and it is offset by interim earnings or
5 amounts that were earnable with reasonable diligence by the aggrieved individual. The Civil
6 Rights Act of 1991 added compensatory and punitive damages for intentional discrimination to
7 the remedies available under Title VII. Punitive damages are available if the defendant acted
8 with malice or reckless indifference to the employee's federally protected rights, but not against
9 federal, state, or local government employers. There is a cap on the total amount that may be
10 awarded in compensatory damages for nonpecuniary and future pecuniary losses and punitive
11 damages. The cap is graduated based on employer size as measured by the number of
12 employees:
13

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

14
15
16
17
18
19
20 Prevailing parties may be awarded a reasonable attorney's fee as part of litigation costs.
21

22 *Remedy and enforcement provisions of the prior ULC draft.* To enable the Committee to
23 make decisions on the extent to which the draft will supplement GINA, the remedy provisions of
24 the current draft remain identical to the prior draft, which provided a private cause of action that
25 could be filed without pursuing administrative avenues or arbitration under an employment
26 contract.
27

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

36 The draft provides for a civil cause of action that will supercede limitations in union
37 contracts, arbitration agreements, and administrative processes that otherwise apply in the
38 employment context. At the same time, the draft preserves existing remedies. The cause of
39 action created by the statute is cumulative and available in addition to existing remedies.
40

41 The section does not increase the enforcement burden on state agencies. The primary
42 remedy for a violation of the article is a private civil action. Fee and cost shifting are included to

1 compensate prevailing employees for their costs to enforce the statute.
2

3 The Drafting Committee considered a tolling provision, but rejected this approach
4 because they did not want to impose a long period of potential liability on employment entities.
5

6 States with genetic statutes tend to provide relief for violations using a mixture of
7 administrative and civil processes, and a few have even enacted criminal penalties. Many state
8 statutes that emphasize discrimination require employees to submit claims of unlawful
9 employment discrimination based on use of genetic information to a state agency or the federal
10 Equal Opportunity Employment Commission. The Committee felt that using a state employment
11 discrimination agency makes sense for enforcement of provisions related to employment
12 decisions because such agencies already have the apparatus in place to enforce state civil rights
13 and disability statutes, and the draft does not prevent that avenue of enforcement. For privacy
14 violations, however, other avenues are desirable. Discrimination agencies do not have expertise
15 in privacy violations and the typical remedies for employment discrimination are not necessarily
16 appropriate for a privacy violation. Enforcement could be turned over to an agency with that
17 expertise, but the Drafting Committee wish to avoid the cost of creating and funding a new
18 agency. Moreover, the Drafting Committee did not want to impose the delay associated with
19 administrative processes on an aggrieved employee.
20

21 A privacy rights perspective assumes an intrinsic harm from the invasion of privacy,
22 whether or not consequential damages are incurred. Because of difficulties in measuring damage
23 to privacy interests, several states that provide a private right of action for privacy violations
24 involving genetic information also specify statutory damages, with higher amounts when the
25 violation is willful or leads to monetary gain for the violator. Alaska Stat. § 18.13.020 (actual
26 damages plus \$5,000, or plus \$1,000 if there is monetary gain); N.H. Rev. Stat. § 141-H:6 (not
27 less than \$1,000 per violation); NM Stat. Ann. § 24-21-6 (economic loss plus damages of up to
28 \$5,000 if the violation results from willful or grossly negligent conduct). The Drafting
29 Committee did not take this approach because statutory damages often become a limit on the
30 recovery available.
31

1 [ARTICLE] 3

2 LIFE INSURANCE, DISABILITY-INCOME INSURANCE,

3 AND LONG-TERM-CARE INSURANCE

4 SECTION 301. DEFINITIONS. In this [article]:

5 (1) “Adverse insurance determination” means a denial of coverage or the offering of less
6 favorable rates, terms, or conditions for insurance than would be available if the insurer did not
7 use genetic information in making the determination.

8 (2) “Disability-income insurance” means insurance intended to protect against loss of
9 occupational or professional earning capacity arising from injury, sickness, or disablement. The
10 term includes insurance that provides benefits for overhead expenses of a business, occupation,
11 or profession when the insured becomes disabled.

12 (3) “Genetic information” means:

13 (A) the results of a genetic test;

14 (B) information based on the genetic test of an individual or an individual’s
15 family member; or

16 (C) information that an individual or an individual’s family member requested or
17 received genetic services.

18 (4) “Genetic test” means an analysis of human genetic material, including
19 deoxyribonucleic acid, ribonucleic acid, chromosomes, proteins, and metabolites, that is
20 intended to detect:

21 (A) a genotype or genetic marker; or

22 (B) a mutation or chromosomal change.

23 (5) “Insured” means an individual who is covered by or applying to be covered by life,
24 disability-income, or long-term-care insurance.

1 (6) “Insurer” means a person engaged in the business of life, disability-income, or long-
2 term-care insurance in this state, regardless of where a contract of insurance is entered into or
3 issued or a plan is administered. The term includes an insurance agent, broker, underwriter, and
4 third-party administrator.

5 (7) “Life insurance” means insurance against the financial risk of death.

6 (8) “Long-term-care insurance” means insurance that provides coverage for not less than
7 12 consecutive months for one or more necessary diagnostic, preventive, therapeutic,
8 rehabilitative, maintenance, or personal-care services provided in a setting other than an acute
9 care unit of a hospital. The term includes a policy or rider that provides for payment of benefits
10 based upon cognitive impairment or inability to perform the activities of daily living.

11 (9) “Predisposing genetic characteristic” means a gene variant or genetic marker that is
12 determined from genetic information and is associated with an individual’s increased risk of
13 developing a disease or medical condition for which the individual is presently asymptomatic.

14 **Reporter’s Notes**

15
16 *Paragraph (1). (Adverse insurance determination)* The use of genetic information makes
17 an insurance determination adverse if it leads to denial of coverage or coverage on less favorable
18 terms than would have been available absent the insurer’s consideration of the information. This
19 definition is relevant to an individual’s ability to correct a faulty genetic test that has
20 consequences for insurance eligibility or terms and conditions for issuance of insurance.

21
22 *Paragraph (2). (Disability-income insurance)* This definition of disability-income
23 insurance is used in several state statutes on genetic testing. *See, e.g.*, Cal. Ins. Code § 10147;
24 N.H. Rev. Stat. Ann. § 141-H:1. The Committee discussed substituting the term “income” for
25 “earning capacity,” but decided not to make this substitution.

26
27 *Paragraph (3). (Genetic information)* This definition of “genetic information” differs
28 from the definition in the employment article of the draft in that it excludes family medical
29 history. Even though family history is a major source of information to evaluate an individual’s
30 genetic risks, Article 3 does not change the practices of life, disability-income, and long-term-
31 care insurers, which traditionally have collected information on family history.

32
33 *Paragraph (4). (Genetic test)* “Genetic test” is defined in terms of (1) the material that
34 the test analyzes and (2) the purpose of the test. This draft retains the definition used in the prior

1 draft. It now differs slightly from the definition in the employment article, which was changed
2 to follow the wording of GINA. The primary difference between the definitions is that the one
3 used in this article includes the concept of intent. It requires that the test be given with the intent
4 to detect a genotype, mutation, or chromosomal change. This requirement is included to help
5 assure insurance company representatives that the test will not be misused, as discussed below.
6

7 The first clause makes specific reference to the types of biological material that are
8 currently analyzed in genetic tests. Note that genetic tests can be conducted not only on gene
9 sequences, but also on biological products such as proteins or metabolites that can indicate
10 genetic make-up. The second clause specifies that the test must be for the purpose of
11 determining an individual's genetic make-up, either through the identification of a genotype or
12 genetic marker or by looking for a mutation or chromosomal change.
13

14 Both clauses are equally important to the definition. First, some of the materials listed in
15 the first clause, especially proteins and metabolites, are tested for many medical purposes. A test
16 of a protein or metabolite does not constitute a genetic test unless it is administered for the
17 purpose of determining individual's genetic make-up as specified in the second clause.
18

19 Second, some genetic diagnoses are made without laboratory tests of the type listed in the
20 first clause. For example, a doctor may identify a genetic condition based on specific physical
21 features occurring in combination, or "dismorphology." This physical diagnosis of an
22 individual's genetic-make-up does not constitute a genetic test under the draft because it is not a
23 test of "genetic material."
24

25 Insurance industry representatives have expressed the fear that this definition is so broad
26 that it will sweep in routine medical tests such as blood tests of lipoproteins to measure
27 cholesterol levels. It is true that a cholesterol test analyzes proteins. A cholesterol test is not,
28 however, given specifically to detect a genotype, genetic marker, mutation, or chromosomal
29 change, so it would not be considered a genetic test under the draft. Instead, a high cholesterol
30 reading may indicate a number of causal factors, including inappropriate diet, lack of exercise,
31 and/or a condition called inherited familial high cholesterol. If the measurement of cholesterol
32 leads a doctor or insurance company to do further testing to see if an individual has a specific
33 genotype, then that would be a genetic test under the draft's definition. Other common medical
34 tests of proteins or metabolites that would not fall under the definition of "genetic test" include
35 urine tests for kidney disease, blood protein and creatinin tests for diabetes, blood tests of liver
36 enzyme proteins for liver function, urine tests measuring glucose to diagnose diabetes, blood
37 tests measuring serum blood glucose for diabetes, and triglycerides for heart disease.
38

39 The draft follows the example of states with definitions of genetic testing that are not
40 limited to identifying genotypes associated with diseases or impairments. (Fla, Haw, Mass, NH,
41 Ore, UT). In contrast, many other states statutes limit their definition of "genetic test" to testing
42 for disease-related genes. (Ariz, Ark, Del, Ill, Iowa, Kan, LA, Maine, MD, Mich, Minn, Nev,
43 MO, Neb, NJ, NM, NY, NC, OK, OR, RI, TX, VT, VA, WI). While most of the reasons that an
44 insurer might currently seek or use genetic information probably involve a disease, disorder, or
45 impairment, this may not always be the case. For example, an insurer could be interested in
46 reliable predictions of addictive behavior. While the current evidence linking behavior to genes
47 is tenuous, this area continues to be the subject of investigation.

1 *Paragraph (5). (Insured)* The definition of “insured” includes applicants. It
2 encompasses individuals with the types of insurance policies covered by the act.
3

4 *Paragraph (6). (Insurer)* The definition of “insurer” is intended to cover broadly
5 insurance companies and other persons and individuals that issue life, disability-income, or long-
6 term-care insurance and all persons who might obtain, use, or disclose genetic information
7 associated with that process. Nothing in this definition is intended to subject insurance agents,
8 brokers, underwriters, or third-party administrators to insurance regulations to which they are not
9 already subject.
10

11 *Paragraph (7). (Life insurance)* “Life insurance” is intended to be defined broadly.
12 This definition is drawn from N.H. Rev. Stat. § 401:1(III).
13

14 *Paragraph (8). (Long-term-care insurance)* The starting point for the definition of
15 “long-term-care insurance” is N.H. Rev. Stat. § 415-D:3(V). The definition is intended to
16 include all coverage of this nature whether it is provided on an expense-incurred, indemnity,
17 prepaid, or other basis.
18

19 *Paragraph (9). (Predisposing genetic characteristic)* A “predisposing genetic
20 characteristic” refers to a genotype that signals an increased risk of a certain disease or
21 condition. The term does not include symptomatic diseases or conditions or genetic
22 characteristics that are manifest in a disease, medical condition, or disability. The broader terms
23 “genetic test” and “genetic information” may include both predisposing and manifest genetic
24 characteristics as well as genetic information that does not necessarily pertain to health.
25

26 While the terms “propensity” or “susceptibility” are often used, the actual manifestation
27 of a disease or condition may depend on a complex chain of events and the degree to which risk
28 is elevated may be quite small. The use of the term “predisposing” is meant to signal the tenuous
29 connection between a genotype or marker and a physical manifestation.
30

31 **SECTION 302. GENETIC TESTING.**

32 (a) If an insurer files information on a genetic test that meets the standards of Section
33 306, an insurer may request or require an insured to take the genetic test in connection with the
34 provision of life insurance, disability-income insurance, or long-term-care insurance and, with
35 prior authorization of the insured that meets the requirements of Section 303, may provide the
36 test to the insured.

37 (b) An insurer that requests or requires a genetic test in connection with the provision of
38 life insurance, disability-income insurance, or long-term-care insurance shall provide and pay for

1 genetic counseling for the insured about the risks and benefits of the genetic test before the
2 insured decides to authorize the test. The insured may knowingly and voluntarily waive
3 counseling in a signed record that informs the insured of the benefits of genetic counseling.

4 (c) An insurer that provides a genetic test to an insured in connection with the provision
5 of life insurance, disability-income insurance, or long-term-care insurance shall:

6 (1) pay for the genetic test;

7 (2) require the testing organization to make a report of the test result to the
8 insured and a health-care professional designated by the insured unless the insured directs
9 otherwise;

10 (3) provide and pay for genetic counseling for the insured about a test result
11 unless the insured knowingly and voluntarily waives counseling in a signed record that informs
12 the insured of the benefits of genetic counseling; and

13 (4) require the destruction of the insured's biological sample obtained for a
14 genetic test as soon as permitted by law after the test is completed unless retention of the sample
15 is authorized by the insured, permitted by law other than this [act], or ordered by a tribunal.

16 **Reporter's Notes**

17
18 *Applicability of Article 3.* This article applies to life insurance, disability-income
19 insurance, and long-term-care insurance issued on an individual, group, or other basis. Including
20 individual policies is significant because individual insurance policies are subject to
21 underwriting and many life, disability-income, or long-term-care insurance policies are issued on
22 an individual basis. The draft does not distinguish between individual and group insurance,
23 however, because most of the states that regulate genetic testing or the use of genetic information
24 for issuing life, disability-income, or long-term-care insurance treat both individual and group
25 insurance identically.

26
27 GINA, ERISA, and HIPAA regulate acquisition, use, retention, and disclosure of genetic
28 information by health insurers. These statutes broadly preempt state regulation. There is,
29 however, no federal regulation or preemption of acquisition and use of genetic information by
30 life, disability-income, and long-term-care insurers. State regulation is important because life
31 insurance plays a central role in the financial lives of many individuals and families. Disability-
32 income and long-term-care insurance are increasingly viewed as a necessary adjunct to health

1 insurance and many states regulate disability-income and long-term-care insurance as health
2 insurance.

3
4 This draft treats life, disability-income, and long-term-care insurance identically in one
5 article. There are, however, differences in underwriting principles among the three types of
6 insurance. Life insurance underwriting is concerned with mortality and uses life expectancy
7 tables. In contrast, disability-income underwriting is concerned with morbidity and long-term-
8 care underwriting is a hybrid process.

9
10 *Genetic testing and genetic information.* This section and the section 304 limit
11 acquisition of genetic information by insurers that provide life, disability-income, or long-term-
12 care insurance. This section limits genetic testing and section 304 limits acquisition of genetic
13 information in general. The limitations are based on the philosophy that insurers may continue
14 current information gathering practices, but may not expand their collection of genetic
15 information unless and until there is a strong scientific basis for its use to predict mortality and
16 morbidity. It is the Drafting Committee's understanding that life, disability-income and long-
17 term-care insurers do not at present require applicants to take genetic tests, but do collect family
18 history information for use in determining eligibility and in underwriting.

19
20 The Drafting Committee considered, but did not adopt, an approach to regulating genetic
21 information for life, disability-income or long-term-care insurance based on the amount of the
22 insurance policy. The suggestion was to prohibit genetic testing and consideration of genetic
23 information for policies worth less than a specified monetary threshold. Above that value,
24 insurers would be permitted to consider genetic information freely.

25
26 The arguments for restricting acquisition of genetic information by the insurance industry
27 are that this information is particularly private and its predictive power is easily exaggerated.
28 There are privacy concerns with commercial acquisition of sensitive genetic information and
29 predictions that individuals will avoid genetic testing for fear of adverse effects on their
30 insurability. There is also a possibility that insurers may require applicants to take genetic tests
31 and then deny insurance or charge more based on genetic characteristics, unfairly making
32 coverage unavailable to people who are not sick from the genetic condition and never will
33 become sick from that condition. From the industry perspective, as with health insurance,
34 insurers worry about adverse selection. If applicants seek coverage because a genetic
35 characteristic exposes them to risk, but the insurer does not have this information, this puts the
36 insurer at a financial disadvantage. *See generally* Mark A. Rothstein, ed., *Genetics and Life*
37 *Insurance: Medical Underwriting and Social Policy* (2004).

38
39 A 1997 study by the Human Genetics Advisory Commission in the United Kingdom
40 concluded that it is unlikely that actuarially-sound genetic predictions of adult death will be
41 validated and available anytime in the near future. Genetic tests need to be connected to medical
42 and epidemiological research to establish what consequences for health and life-span can be
43 inferred from a given genetic test. The Commission concluded that a requirement to disclose
44 genetic tests as a condition of obtaining insurance would be acceptable only after research has
45 established an association between a given pattern of test results and life events that are relevant
46 for the insurance product. It recommended continuing a moratorium on requiring test results.
47 Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance*

1 (1997).
2

3 *Genetic testing.* This section prohibits insurers from requiring applicants to have genetic
4 testing as a condition of obtaining life, disability-income or long-term-care insurance unless
5 scientific developments support a conclusion that a test provides a relevant prediction. The
6 section is consistent with genetic testing prohibitions in force in California, Massachusetts, and
7 Vermont, except that it allows the prohibition to be modified as justified by scientific
8 developments. Vermont and Massachusetts prohibit insurers from requiring applicants to take a
9 genetic test as a condition of obtaining or renewing a policy. California prohibits long-term-care
10 insurers from requiring genetic testing for use in determining insurability or in underwriting. *See*
11 Cal. Ins. Code § 10233.1 (long-term-care insurance); Mass. Gen. L. Ann. 175 § 120E (life
12 insurance); Mass. Gen. L. Ann. 175 § 108I (disability and long-term-care insurance); Vt. Stat.
13 Ann. § 9334 (any insurance).
14

15 The section also sets forth requirements similar to those imposed on employers who
16 provide genetic tests.
17

18 *Genetic Counseling.* This section requires insurers who have applicants take genetic tests
19 to provide genetic counseling. The counseling occurs in two stages: before the test to assist in
20 the decision to take the genetic test and after the test to interpret results if the test indicates the
21 individual is at risk. Counseling is an important component of the testing process in the field of
22 genetics for several reasons. Tests may indicate a risk of a condition for which there is no
23 treatment and the information may have implications for family members who are not tested
24 directly. The outcomes require interpretation of complex probabilities which can be easily
25 misunderstood. The genetic counseling that is required before the test is covered in subsection
26 (b) and the counseling that is appropriate after a test is covered in subsection (c).
27

28 The Committee received differing opinions from industry participants on this issue which
29 ranged from opposition to any obligation to provide counseling to a view that if insurance
30 companies request the tests they should provide and pay for counseling in conjunction with the
31 test.
32

33 **SECTION 303. AUTHORIZATION FOR GENETIC TEST.**

34 (a) An insured's authorization for the genetic test requested or required under Section
35 302 must be knowing and voluntary and indicated in a record signed by the insured that complies
36 with subsection (b) of this section. An insurer that receives a valid authorization for genetic
37 testing may provide a test only in accordance with the authorization. An authorization may not
38 expand the genetic testing permitted by this [act] and may not include exculpatory language
39 waiving any of the insured's legal rights.

1 (b) An authorization for a genetic test for life insurance, disability-income insurance, or
2 long-term-care insurance must:

3 (1) describe the genetic test to be performed, its purpose, and its permitted uses;

4 (2) state that only the authorized genetic test will be performed on the insured's
5 biological sample;

6 (3) inform the insured that the insurer is obligated to provide and pay for genetic
7 counseling about the risks and benefits of the test before the insured decides to authorize the test;

8 (4) inform the insured that the insurer is obligated to provide and pay for genetic
9 counseling about the test result unless the insured waives genetic counseling;

10 (5) state that the test result will be reported to the insured and a health-care
11 professional designated by the insured, unless the insured directs otherwise;

12 (6) include an opportunity for the insured to provide directions about reporting
13 test results;

14 (7) inform the insured that the insured's biological sample will be destroyed as
15 soon as permitted by law after the test is completed unless the insured authorizes retention of the
16 sample or unless otherwise ordered by a tribunal; and

17 (8) state that the insured is entitled to a copy of the authorization.

18 (c) The use of the following form complies with this section.

19 Authorization for Genetic Testing

20 Limited Authorization. Only the genetic tests that you authorize on this form will be performed
21 on your biological sample. These tests are voluntary, but refusing a test requested by
22

23 _____ may mean that your application for insurance will be denied.
24 [name of insurer]
25

26
27
28 Availability of Genetic Counseling. Before you complete this authorization, it is highly
29

1 recommended that you meet with a genetic counselor who will help you understand and evaluate
2
3 the risks, benefits, and consequences for you and your family of having the tests listed below.

4 _____ will provide and pay for this genetic counseling.
5
6 [Name of insurer]

7
8
9 Proposed Genetic Tests. Based on a review of your family medical history, _____
10 [name of insurer]
11 requests the following genetic test:

12
13
14 _____
15 [Name of test]

16
17 The purpose of this test is to determine if you have a predisposition for _____ .
18 [genetic condition]

19 If you authorize _____ to have access to the test result, it will be used only for the
20 [insurer]
21 following purposes: _____.

22
23
24 Reporting Test Results and Genetic Counseling. The test results will be reported to you and to a
25 health-care professional whom you designate unless you direct otherwise. It is recommended
26 that

27
28 you receive genetic counseling about the test results. Genetic counseling is important for
29 understanding the test results in the context of your medical and family history. It can also
30 provide you with support, informational resources, and referrals, as appropriate, that can help
31 you

32
33 adapt to the implications of being at risk of a genetic condition. _____
34 [Name of insurer]
35 will provide and pay for genetic counseling about the test results unless you decline genetic
36 counseling.

37
38
39 Destruction of your Biological Sample. After the genetic test, your biological sample will be
40 destroyed as soon as permitted by law unless or a court, arbitral tribunal, or administrative
41 agency requires retention of the sample or you sign a written authorization for
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[name of insurer]

to keep the sample.

Retention of Legal Rights. By signing this authorization, you do not lose any legal rights to which you are entitled.

Copy of this form. You are entitled to a copy of this authorization.

I, _____, authorize the genetic test(s) I have checked above.
[print name]

- I wish to receive test results.
- I do not wish to receive test results.
- Report test results to the following health care professional:
Name: _____
Address: _____
- Do not report test results to a health care professional.

Signature

Date

Reporter’s Notes

This section sets forth an authorization requirement for genetic testing and the elements that must be contained in an authorization form. The term “authorization” is used instead of “informed consent” to avoid confusion with the use of that term in medical practice.

The Drafting Committee decided that the best method to protect privacy for genetic testing and genetic information is to establish an authorization requirement that is coupled with statutory limits and duties imposed on insurers. Under this approach, an insured must affirmatively authorize any genetic testing or acquisition, use, retention, or disclosure of genetic information. The authorization requirement is not simply a procedural step because Article 3 establishes limitations on the situations in which insurers may request authorization from insureds.

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

Subsection (a) Requirement for authorization for genetic testing. Under Section 302, an insurer may require a genetic test as a condition of obtaining life, disability-income, or long-

1 term-care insurance if the test has been filed and meets the standards of Section 306. This
2 subsection adds an additional requirement that genetic testing is permitted only with the prior
3 authorization of the insured.
4

5 In order to meet the requirement that an authorization be knowing and voluntary, an
6 employee or insured should have genetic counseling before signing the authorization. Genetic
7 counseling provides insureds with adequate information to make an informed decision about
8 genetic testing. It also makes them aware of their options regarding reporting of test results and
9 help in interpreting them through genetic counseling. Genetic counseling may be provided by a
10 genetic counselor, but may also be provided by a qualified physician or geneticist.
11

12 Other law of the state may provide for a substitute decisionmaker or signer if the
13 employee is incapacitated or incompetent. This situation is left to existing law of the state that
14 governs power of attorney, guardianship, or other substitute decision makers.
15

16 *Subsection (b) Content of authorization for testing.* The section draws on N.Y. Civ.
17 Rights Law § 79-1 (McKinney), which establishes requirements for consent for a genetic test.
18

19 The limitation in (b)(2) to the authorized test is consistent with the requirements for prior
20 authorization in Section 302.
21

22 The notification provision regarding destruction of the sample in subsection (b)(7) is
23 consistent with the insurer's obligation to ensure the sample is destroyed under Section
24 302(c)(4), which recognizes that the testing laboratory may be required to retain the sample for
25 certification purposes.
26

27 *Subsection (c). Authorization form.* The subsection provides a form that may be used to
28 authorize an insurance company to provide a genetic test. The use of a form following this
29 pattern would comply with the requirements of the section.
30

31 **SECTION 304. ACQUISITION OF GENETIC INFORMATION.**

32 (a) Unless an insurer has filed information on a genetic test that meets the standards of
33 Section 306, an insurer may not knowingly obtain or directly or indirectly inquire about, request,
34 or require an insured to provide the insured's genetic information based on a genetic test in
35 connection with the provision of life insurance, disability-income insurance, or long-term-care
36 insurance.

37 (b) Nothing in this [article] prohibits an insurer from obtaining medical records of an
38 applicant for insurance that contain genetic information in connection with the provision of life

1 insurance, disability-income insurance, or long-term-care insurance.

2 (c) An insurer may request or require an insured to provide family medical history in
3 connection with the provision of life insurance, disability-income insurance, or long-term-care
4 insurance.

5 **Reporter's Notes**
6

7 This section limits the extent to which an insurance company may acquire genetic
8 information or the results of genetic testing based on the rationale discussed in the reporter's
9 notes to Section 302. Subsection (a) permits acquisition of genetic information if it is based on a
10 genetic test that meets the standards set forth in Section 306.
11

12 Subsection (b) is included to reassure the industry that its traditional access to medical
13 records is preserved, despite the fact that medical records may contain genetic information.
14

15 The prohibition on acquisition of genetic information does not apply to family medical
16 history, which is not included in the definition of "genetic information." Subsection (c),
17 moreover, explicitly permits insurers to seek information about family medical history, which
18 they have traditionally used for underwriting.
19

20 **SECTION 305. PROHIBITION ON USE OF GENETIC INFORMATION.** Unless
21 genetic information is based on a genetic test that has been filed and meets the standards
22 provided in Section 306, an insurer may not use the genetic information about an insured's
23 predisposing genetic characteristics to determine eligibility for or rates, terms, and conditions of
24 life insurance, disability-income insurance, or long-term-care insurance.

25 **Reporter's Notes**
26

27 The determination of eligibility for coverage includes decisions made in connection with
28 the offer, sale, continuation, or renewal of an insurance policy. The determination of rates,
29 terms, and conditions includes establishing premiums, limiting coverage, limiting or
30 conditioning benefits, or making any other underwriting decisions.
31

32 This section prohibits the use of genetic information for determining eligibility or
33 underwriting of life, disability-income, and long-term-care insurance unless the genetic test has
34 been filed and meets that standards provided in Section 306. Traditional insurance underwriting
35 has been based on medical histories and tests that indicate existing medical conditions. The draft
36 permits those practices to continue. Using predictions based on predisposing genetic
37 characteristics that have not been expressed as a disease or condition would be a new step,

1 however, and there is a great risk that such predictions would not be reliable in the context of
2 insurance.

3
4 The restriction on use of genetic information in life, disability-income & long-term-care
5 insurance applies only to predisposing genetic characteristics. Therefore, insurers are not
6 restricted from using genetic information with regard to a medical condition that has been
7 diagnosed as manifest in an individual.

8
9 The section ties use of genetic information about predisposing characteristics to the
10 process in Section 306 for ensuring that the genetic test provides a reliable prediction of
11 individual mortality or morbidity. If an insurer has filed information to show that a genetic test
12 is valid, it may use the results of that test in underwriting. Otherwise, life, disability-income and
13 long-term-care insurers may not use genetic information about predisposing characteristics for
14 determining eligibility or in underwriting.

15
16 This prohibition is consistent with regulation in a number of states. Because genetic tests
17 are not yet routine in medical care and few individuals have previously taken genetic tests when
18 they apply for insurance, the prohibitions on requiring tests in California, Massachusetts, and
19 Vermont have the effect of preventing the use of genetic information in insurance
20 determinations. In addition, a number of states directly prohibit insurers from using genetic
21 information to determine eligibility or in underwriting. *See* Colo. Rev. Stat. § 10-3-1104.7(3)(b)
22 (group disability-income & long-term-care); Kan. Stat. Ann. § 40-2259(d) (disability-income &
23 long-term-care); Or. Rev. Stat. § 746.135 (genetic information from a blood relative for life,
24 disability-income & long-term-care insurance); Vt. Stat. Ann. tit. 18, § 9334(a) (same). *See also*
25 Ariz. Rev. Stat. Ann. § 20-448(F) (permitting disability-income and long-term-care insurers to
26 use genetic information only if there is an actual diagnosis of a genetic condition).

27
28 The insurance industry maintains that any restrictions on their ability to use genetic
29 information will undermine the availability and pricing structure of life, disability-income &
30 long-term-care insurance. However, there is broad international consensus that the use of
31 genetic information in life insurance should be restricted. Numerous countries have enacted
32 restrictions, as have the states noted above. There is no evidence, moreover, that these
33 restrictions have been associated with adverse selection, increased pricing, reduced availability
34 of policies, or decreased profitability of the insurance industry. Without some supporting
35 evidence, these industry concerns do not outweigh the importance of protecting against new uses
36 of information that would diminish privacy and that carry a high risk of irrational discrimination.

37
38
39 With the draft's narrow definition of "genetic information," an insurer would be able to
40 use genetic data revealed by an individual's family medical history to determine eligibility or to
41 underwrite without restriction. One member of the Committee raised the question of whether
42 there should be any limits on insurers' use of family medical history. The question was
43 motivated by a concern that even if disclosures to insurers do not change, insurers may be able to
44 do more with those disclosures using ever more sophisticated computer technology. The
45 Drafting Committee did not consider if it would be desirable to prevent new uses of family
46 history information or what limits would be appropriate.

1 section provides a mechanism that will allow use of genetic information to evolve, in response to
2 new scientific information that may justify the use of genetic information for eligibility and
3 underwriting determinations as determined by an evidence-based review process.
4

5 The Drafting Committee considered and rejected an approach that would have
6 established regulatory oversight of the use of genetic information by insurers by requiring a prior
7 finding of an association with mortality or morbidity by state insurance regulators in consultation
8 with state public health authorities. The Committee also considered and rejected an approach
9 that would have required that the appropriate finding be made by a geneticist or genetic
10 counselor. Instead, the Drafting Committee decided that the insurance industry should be
11 responsible for determining the accuracy and completeness of the data on a genetic test and the
12 reliability of the prediction possible with the genetic information.
13

14 The approach selected by the Committee requires an insurance company to identify
15 genetic tests that it plans to use and to file documentation supporting the validity of the test with
16 the state insurance commissioner. This documentation would then be open to public scrutiny,
17 creating transparency that can provide a check on a company's determination. This process will
18 allow an insurer's use of genetic information to change as research develops reliable connections
19 between genetic characteristics and risk of mortality or morbidity.
20

21 The process required here contemplates the type of evidence-based review of genetic
22 tests conducted by the Evaluation of Genomic Applications in Practice and Prevention (EGAPP)
23 Working Group formed under the auspices of the Centers for Disease Control National Office of
24 Public Health Genomics. See <http://www.cdc.gov/genomics/gtesting/EGAPP/about.htm>.
25

26 As explained in the following excerpt from the Final Report of the Task Force on Genetic
27 Testing, Promoting Safe and Effective Genetic Testing in the United States (1997) (available at
28 <http://www.genome.gov/10001733>), before relying on a genetic test, there must be scientific
29 evidence to (1) establish a reliable relationship between a disease, genes, and inherited
30 mutations; (2) establish the analytical validity of the test; and (3) establish the clinical validity of
31 the test.
32

33 Establishing Associations Between a Disease, Genes, and Inherited Mutations 34

35 In developing genetic tests, scientists must first be confident that the DNA
36 segments under investigation play a role in the disease in question. These
37 segments might be apparently functionless markers that appear to be spatially
38 linked on a chromosome to a disease-related gene. Linkage is demonstrated
39 when, within families, one form of the marker is found in those with the disease
40 more often than in blood relatives in whom the disease is absent. Because such
41 associations might be due to chance, as was the case for the linkage claimed
42 between bipolar affective disorder and markers on chromosome 11, and between
43 schizophrenia and markers on chromosome 5, stringent statistical standards must
44 be satisfied before accepting linkage, and the findings must be confirmed in
45 additional families with the disease. . . .
46

47 Further research leads scientists from the linked, functionless marker to a nearby

1 gene suspected of being casually related to the diseases in question. The proof
2 depends on finding mutations in the gene that are only present (in gene dosage
3 sufficient to cause disease) in family members with disease. Further proof that a
4 gene is causally related to disease comes from demonstrating that the protein
5 encoded by the gene is absent, not synthesized in adequate amounts, or manifests
6 a structural or functional aberration that plausibly accounts for symptoms and
7 signs of the disease.
8

9 Another approach to identifying a disease-related gene does not depend on
10 linkage but on suspecting that a gene that has been previously identified
11 (“candidate gene”) plays a role in a specific disease. Here too, mutations must be
12 found only in those with the disease.
13

14 The DNA segments associated with a disease might be functional, common,
15 polymorphic gene variants. Recently, attention has been given to the association
16 between the apolipoprotein E polymorphism and Alzheimer disease (AD). A
17 higher proportion of people with apoE4 will develop AD than those with other
18 forms of the polymorphism. Some people with AD, however, will not inherit
19 apoE4 and other with apoE4 will never develop AD; the polymorphism is neither
20 a necessary nor sufficient cause for the disease. It is not clear whether
21 polymorphic variants themselves predispose to the disease, whether the
22 association is spurious (unlikely in the case of apoe4 and AD), or whether a
23 marker linked to both the polymorphic gene and the disease-related gene is
24 responsible. The following criterion must be satisfied before either linked
25 markers or putative disease-related mutations are used as the basis of a genetic
26 test. **The genotypes to be detected by a genetic test must be shown by**
27 **scientifically valid methods to be associated with the occurrence of a disease.**
28 **The observations must be independently replicated and subject to peer**
29 **review.**
30

31 Analytical Validity 32

33 For DNA-based tests, analytical validity requires establishing the probability that
34 a test will be positive when a particular sequence (analyte) is present (analytical
35 sensitivity) and the probability that the test will be negative when the sequence is
36 absent (analytical specificity). In contrast to DNA-based tests, enzyme and
37 metabolite assays measure continuous variables (enzyme activity or metabolic
38 concentration). One key measure of their analytical validity is accuracy, or the
39 probability that the measured value will be within a predefined range of the true
40 activity or concentration. Another measure of analytical validity is reliability, or
41 the probability of repeatedly getting the same result.
42

43 [V]alidation includes performing replicate determinations to ensure that a single
44 observation is not spurious, and “blind” testing of coded positive samples (from
45 patients with the disease in whom the alteration is known to be present) and
46 negative samples (from controls). Organizations engaged in new test
47 development should have access to a sufficient number of patient samples to have

1 statistical confidence in the validation. In validating a new test analytically, the
2 laboratory techniques should be as similar as possible to those used when the test
3 will be performed clinically once it is validated.
4

5 **Analytical sensitivity and specificity of a genetic test must be determined**
6 **before it is made available in clinical practice.**

7
8 Clinical Validity
9

10 Clinical validity involves establishing several measures of clinical performance
11 including (1) the probability that the test will be positive in people with the
12 disease (clinical sensitivity), (2) the probability that the test will be negative in
13 people without the disease (clinical specificity), and (3) the probability that
14 people with positive test results will get the disease (positive predictive value
15 (PPV)) and that people with negative results will not get the disease (negative
16 predictive value.) Predictive value depends on the prevalence of the disease in
17 the group or populations being studied, as well as on the clinical sensitivity and
18 specificity of the test.
19

20 Two intrinsic features of genetic diseases, heterogeneity and penetrance, affect
21 clinical validity.
22

23 *Heterogeneity.* The same genetic disease might result from the presence (in the
24 necessary gene dosage) of any of several different variants (alleles) of the same
25 gene (allelic diversity) or of different genes (locus heterogeneity). With current
26 technology, all disease-related alleles cannot always be identified, particularly
27 when there are many of them, which is often the case. This failure to detect all
28 disease-related mutations reduces a test's clinical sensitivity.
29

30 *Penetrance.* The probability that disease will appear when a disease-related
31 genotype is present is the penetrance of the genotype. When penetrance is
32 incomplete, PPV is reduced. Penetrance is incomplete when other genetic or
33 environmental factors must be present. In high-risk breast cancer families, 10 to
34 15 percent of women with inherited susceptibility mutations of the BRCA1 gene
35 will never develop breast cancer. Environmental factors and possibly other
36 inherited factors are required as well. In women without a family history of
37 breast cancer, the penetrance of a BRCA1 or BRCA2 is even lower. Alleles at
38 other gene loci and similar environments are more likely to be shared by relatives
39 than by people in the general population.
40

41 * * *

42
43 Parameters of clinical validity will depend in part on the group or population in
44 which the test will be used. For instance, the frequency of disease-related alleles
45 might differ between ethnic groups, making it difficult if not impossible to
46 extrapolate the test sensitivity from one group to another. This is the case for
47 cystic fibrosis and breast cancer in which certain alleles can predominate in one

1 ethnic group or geographical area but not in others. Penetrance can also differ
2 among ethnic groups. The prevalence of allele frequencies will have a marked
3 effect on PPV; the greater the prevalence, the higher the PPV. Age will also
4 affect allele prevalence; in a population older than the age at which the disease
5 usually causes death, the allele frequency will be lower than in a younger
6 population. For all these reasons, validation studies should be conducted in a
7 group representative of the one in which the test is intended for clinical use.
8

9 When tests are developed for one purpose are used for another, there is no
10 assurance that the sensitivity or PPV will be the same. . . .
11

12 The three following criteria help ensure that appropriate data on the clinical
13 validity of genetic tests will be collected during the developmental stages.
14

- 15 • **Data to establish the clinical validity of genetic tests (clinical**
16 **sensitivity, specificity, and predictive value) must be collected under**
17 **investigative protocols.**
- 18 • **In clinical validation, the study sample must be drawn from a group**
19 **of subjects representative of the population for whom the test is**
20 **intended.**
- 21 • **Formal validation for each intended use of a genetic test is needed.**
22

23 (emphasis in original, citations omitted)
24

25 **SECTION 307. CORRECTION OPTION FOR GENETIC INFORMATION.** If an
26 insurer uses an insured's genetic information to make an adverse determination regarding
27 eligibility or rates, terms, or conditions for life insurance, disability-income insurance, or long-
28 term-care insurance, the insurer shall provide notice of that use to the insured. The insured may
29 choose to repeat a genetic test to verify the analysis used in the adverse determination. If the
30 initial test was performed at the request of the insurer, the insurer shall pay for a repeat test
31 requested by the insured. If the first analysis is found to be inaccurate, the insurer shall
32 reconsider the adverse determination.

33 **Reporter's Notes** 34

35 Under this section, an insured is provided an opportunity to correct mistakes in genetic
36 information. The section is modeled on Florida procedures which require the DNA analysis to
37 be repeated in the event of an adverse determination. Fla. Stat. § 760.40(3). Delaware also has a
38 special provision that allows an individual to access his genetic records and to correct those

1 records. 16 Del. Code Ann. § 1223.
2

3 **SECTION 308. CONFIDENTIALITY; RETENTION OF GENETIC**

4 **INFORMATION.** An insured's genetic information is a confidential medical record. Except as
5 otherwise provided by law other than this [act], a life insurer, disability-income insurer, or long-
6 term-care insurer may keep an insured's genetic information only with authorization of the
7 insured in accordance with Section 310.

8 **Reporter's Notes**
9

10 This section permits insurers to retain genetic information under certain circumstances.
11 It follows the practice of the states with statutes that require authorization or informed consent
12 for the retention of genetic information and do not treat life, disability-income, or long-term-care
13 insurers differently than others who might retain such information. It departs from the approach
14 of some other states, however, that exempt these insurers from their requirements for
15 authorization or informed consent. (E.g., Mass., Nev., NH, NMex, Ok)
16

17 There are arguments that insurers should not be limited in retaining genetic information.
18 They typically have two years to rescind a policy for misrepresentation, and may need the
19 information submitted with the application in order to show misrepresentation. In addition,
20 reinsurers may audit underwriting practices several years after a policy issues. Insurance
21 industry representatives state that under current practice, information is retained indefinitely
22 because of the risk of class action suits.
23

24 **SECTION 309. DISCLOSURE OF GENETIC INFORMATION.**

25 (a) Except as otherwise provided in Section 310, a life insurer, disability-income insurer,
26 or long-term-care insurer may disclose an insured's genetic information to a person other than
27 the insured only if the insurer has obtained the insured's prior authorization for the disclosure in
28 accordance with Section 310.

29 (b) An insured, upon request, may inspect and obtain a copy of genetic information from
30 the insurer's files on the insured.

31 **Reporter's Notes**
32

33 *Subsection (a).* This subsection restricts the ability of life, disability-income, and long-

1 term-care insurers to disclose genetic information without authorization of the insured.
2

3 The insurance industry argues that disclosures are necessary for business purposes and
4 that a special disclosure provision for genetic information is unnecessary because a number of
5 states have adopted statutes based on National Association of Insurance Commissioners' model
6 laws dealing with general privacy of information. In the Drafting Committee's view, disclosures
7 of genetic information are not protected adequately when there are broad exceptions that allow
8 this information to be shared for business purposes.
9

10 *Subsection (b).* Under this subsection, an insured is allowed to access an insurer's
11 records of his genetic information. In combination with the procedure in Section 307, this
12 enables an insured to correct those records.
13

14 **SECTION 310. AUTHORIZATION FOR ACQUISITION, USE, RETENTION,**
15 **OR DISCLOSURE OF GENETIC INFORMATION.**

16 (a) Except as otherwise provided by this [act] or law other than this [act], an insurer may
17 not acquire, use, keep, or disclose an insured's genetic information without the insured's
18 knowing and voluntary authorization indicated by a record signed by the insured that complies
19 with subsection (c) of this section. An insurer that receives a valid authorization may acquire,
20 use, keep, or disclose genetic information only in accordance with the authorization. An
21 authorization shall not expand the acquisition, use, retention, or disclosure of genetic information
22 permitted by this [article] and may not include exculpatory language waiving any of the
23 insured's legal rights.

24 (b) Except as otherwise provided by this [act] or law other than this [act], a person who
25 receives genetic information disclosed by an insurer must maintain the confidentiality of the
26 insured's genetic information and may not disclose the information without the insured's
27 knowing and voluntary authorization indicated by a record signed by the insured that complies
28 with subsection (c) of this section. A recipient that receives the insured's valid authorization to
29 disclose genetic information may disclose the information only in accordance with the
30 authorization. An authorization may not expand the disclosure of genetic information permitted

1 by this [article] and may not include exculpatory language waiving any of the insured's legal
2 rights. When an insurer discloses an insured's genetic information, it must notify the recipient of
3 the information about these obligations.

4 (c) An authorization to acquire, use, keep, or disclose an insured's genetic information
5 must:

6 (1) describe the genetic information to be acquired, used, kept, or disclosed in a
7 specific and meaningful fashion;

8 (2) identify or describe the person that is authorized to acquire, use, keep, or
9 disclose the genetic information;

10 (3) if the authorization is for acquisition of genetic information through disclosure
11 by another person to an insurer, identify or describe the person authorized to make the
12 disclosure;

13 (4) if the authorization is for use of genetic information, describe the permitted
14 uses;

15 (5) if the authorization is for retention of genetic information, describe where the
16 information will be kept and identify or describe the custodian of the information;

17 (6) if the authorization is for disclosure to a third person, identify or describe the
18 third person to which the authorized person may disclose the genetic information;

19 (7) indicate the duration of the authorization with an expiration date if any or
20 expiration event that relates to the insured or to the purpose of the acquisition, use, retention, or
21 disclosure;

22 (8) state that the insured may revoke the authorization at any time in a signed
23 record, subject to the right of an insurer or other person that acted in reliance on the
24 authorization before receiving notice of revocation, and provide instructions on how to revoke an

1 authorization; and

2 (9) state that the insured is entitled to a copy of the authorization.

3 (d) The use of the following forms complies with this section.

4 Authorization for Acquisition and Use of Genetic Information

5
6 _____ requests your authorization to acquire the following genetic test results
7 and

8 [Name of insurer]
9 use them for the purposes identified:

10
11
12 Access to the results of the test for _____. The purpose
13 [name of test and condition tested for]
14 of this test is to determine if you have a genetic characteristic that predisposes you towards the
15 following medical condition: _____. _____ will use this information
16 [Name of insurer]
17 only for the following purposes: _____.

18
19
20
21 Disclosure by _____ of genetic information about _____
22 [name of person to disclose] [name of test
23 _____ to _____. _____ will use this information
24 and condition] [name of insurer] [Name of insurer]
25 only for the following purposes: _____.

26
27
28 You may revoke this authorization for acquisition and use at any time by sending a letter to
29 _____ unless _____ has _____
30 [name and address] [name of insurer] [description of action that would
31 _____
32 be taken based on the information]

33
34
35
36 You are entitled to a copy of this authorization. By signing this authorization, you do not lose
37 any legal rights to which you are entitled. This authorization is valid until _____.
38 [date or event]

39
40
41
42
43 I, _____, authorize _____ to acquire and use my genetic
44 [print name] [name of insurer]

1 information as checked above.

2
3
4
5 _____
Signature

_____ Date

6
7
8 Authorization for Retention of Genetic Information

9
10 _____ requests your authorization to keep the following genetic information:
11 [Name of insurer]

12
13
14 _____
15 [Name of test and condition tested for]

16
17
18 You may revoke this authorization for _____ to keep your genetic information at
19 [name of insurer]
20 any time by sending a letter to _____ unless _____
21 [name and address] [name of insurer]
22 has _____.
23 [description of action that would be taken based on the information]

24
25
26 You are entitled to a copy of this authorization. By signing this authorization, you do not lose
27
28 any legal rights to which you are entitled. This authorization is valid until _____.
29 [date or event]

30
31
32 I, _____, authorize _____ to keep the genetic information
33 [print name] [name of insurer]
34 checked above.

35
36
37 _____
Signature

_____ Date

38
39
40
41 Authorization for Disclosure of Genetic Information

42
43 _____ seeks your authorization to disclose the following genetic information to
44 [Name of insurer]

45 _____ will notify _____
46 [name of recipient of the information] [Name of insurer] [name of recipient]

1 _____ that _____ is legally obligated
2 of the information] [name of recipient of the information]
3 to maintain the confidentiality of this information and that if may not make further disclosures
4
5 without your authorization.
6

7
8 _____
9 [Name of test and condition tested for]
10

11
12 You may revoke this authorization for disclosure at any time by sending a letter to
13
14 _____ unless _____ has already disclosed the information.
15 [name and address] [name of insurer]
16

17
18 You are entitled to a copy of this authorization. By signing this authorization, you do not lose
19
20 any legal rights to which you are entitled. This authorization is valid until _____.
21 [date or event]
22

23
24 I, _____, authorize _____ to
25 [print name] [name of person authorized to make disclosure]
26 disclose my genetic information checked above to _____.
27 [name of recipient of the information]
28

29
30 _____
31 Signature Date

32
33 **Reporter's Notes**
34

35 This section requires an insured to provide an authorization before an insurer may
36 acquire, use, keep, or disclose genetic information. The provisions differ from those in the
37 employment context in that insurers are permitted to continue their traditional use of family
38 medical history without special authorization requirements.
39

40 The draft does not disturb existing law that allows a minor to seek repudiation of consent
41 and expunge records when the minor reaches the age of majority.
42

43 *Subsection (a) General requirement for authorization.* This subsection would establish a
44 requirement that an insurer must be authorized by the insured before it may acquire, keep, or
45 disclose genetic information, except as provided elsewhere in the act. In order to give a valid
46 authorization, the insured must be informed as provided in the subsection (b) and must act
47 voluntarily. Subsection (a) also includes a requirement that an authorization must be indicated

1 by a signed record. The authorization requirement is coupled with limitations on acquisition,
2 use, retention, and disclosure in Sections 304, 305, 306, 308, and 309.
3

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

8 *Subsection (b) Obligation of recipient of authorized disclosure.* One of the difficulties in
9 authorizing disclosure is control over the information once it has been disclosed. The Drafting
10 Committee decided that regulation over the initial disclosure is ineffective without a continuing
11 obligation of confidentiality that is binding on the recipient. Hence under this subsection a
12 recipient may not redisclose the genetic information without the insured's authorization. This
13 provision extends beyond the privacy protections provided by HIPAA. States are permitted to
14 depart from HIPAA privacy provisions if they impose more stringent protections. 45 C.F.R. §
15 160.203(b).
16

17 The Committee considered and rejected several approaches to the issue, including 1) a
18 notice to the insured that the genetic information disclosed by the authorized person may be
19 subject to redisclosure by the recipient and not longer protected, and 2) a provision that an
20 insured could enter into a confidentiality agreement with recipients of their genetic information.
21

22 *Subsection (c) Content of authorization.* The provision on authorization for acquisition,
23 use, retention, or disclosure of genetic information is adapted from the HIPAA Privacy Rule
24 regulations for "uses and disclosures for which an authorization is required." 45 C.F.R. §§
25 164.508 (a) and (c), 164.512(a). The subsection adapts these regulations to apply to genetic
26 information and expands them to include authorization for acquisition and retention as well as
27 for use and disclosure.
28

29 An advantage of using the HIPAA regulations as the foundation for the authorization
30 requirements is that the requirements to authorize a disclosure by a health care provider to an
31 insurer would be similar to the requirements that health care provider must follow as a covered
32 entity under HIPAA. The context of the HIPAA regulations is different enough, however, that
33 they cannot be transported directly into the Act without modification. Moreover, states are
34 permitted to impose their own, more stringent, privacy requirements. 45 C.F.R. § 160.203(b).
35 Some have enacted statutes with different requirements for disclosing health care information,
36 which reduces the uniformity that would theoretically be achieved by using the HIPAA format.
37 Therefore, while the structure of this subsection is modeled on the HIPAA regulations, it
38 includes some additional provisions from various state statutes. *See, e.g.,* Me. Rev. Stat. Ann.
39 tit. 22 § 1711-C.
40

41 *Subsection (d). Authorization form.* This subsection provides forms that may be used for
42 an insured to provide authorization for use, retention or disclosure of genetic information. Forms
43 following these examples would comply with this section.
44

45 SECTION 311. REVOCATION OF AUTHORIZATION.

1 (a) Except as otherwise provided in subsection (b) or by law other than this [act], an
2 insured may revoke an authorization provided under this [article] at any time in a signed record.

3 (b) An insured may not revoke an authorization provided under this [article]:

4 (1) to the extent that an insurer or other person has taken action in reliance on the
5 authorization; or

6 (2) if the authorization was granted as a condition of obtaining insurance and
7 other law provides the insurer with a right to contest a claim under, or the validity of, the policy.

8 **Reporter's Notes**
9

10 This section is adapted from the HIPAA regulation that governs revocation of an
11 authorization. 45 C.F.R. § 164.508 (b) (5). It is similar to provisions governing health care
12 information that have been adopted by some of the states. Long-term-care insurers are subject to
13 HIPAA, but life insurers and disability-income insurers are not, so this section extends the law in
14 order to give an insured greater control over his genetic information.
15

16 Other law of the state may provide for a substitute decisionmaker or signer if the
17 employee is incapacitated or incompetent. This situation is left to existing law of the state that
18 governs power of attorney, guardianship, or other substitute decision makers.
19

20 Subsection (b)(2) is included because Section 302 permits an insurer to condition the
21 availability of life, disability-income, or long-term-care insurance on an applicant's authorization
22 for a genetic test or access to genetic information about the test, if the test meets the standards of
23 Section 306 for providing a reliable prediction of mortality or morbidity. An insurer needs to
24 continue to access this information in order to protect against fraud or misrepresentation in an
25 insurance application; it has two years in which to contest the validity of the insurance contract.
26 Records are also kept for reinsurance purposes and for reapplications by the insured.
27

28 **SECTION 312. RETENTION OF AUTHORIZATION.** An insurer that receives an
29 authorization under this [article] shall keep a record of the authorization for six years after the
30 expiration date of the authorization or, if the authorization has no expiration date, for six years
31 from the date the authorization was created.

32 **Reporter's Notes**
33

34 This section on the length of the obligation to keep an authorization is adapted from the
35 HIPAA regulations that govern documentation and retention of a signed authorization. 45

1 C.F.R. §§ 164.508 (b) (6), § 164.530(j).
2

3 **SECTION 313. REMEDIES; ENFORCEMENT; LIMITATION OF ACTIONS.**

4 (a) An individual aggrieved by a violation of this [article] may initiate an appropriate
5 proceeding with the [state commissioner of insurance] for whatever action the [commissioner]
6 may be authorized to take under the [state unfair practice insurance law].

7 (b) An individual may initiate the administrative action authorized in subsection (a) not
8 later than two years after the individual discovers the violation of this [article] or an individual
9 exercising reasonable care should have discovered the violation.

10 *Legislative Note: States should insert for [state commissioner of insurance] the appropriate*
11 *title of this department. [The state unfair practices insurance law] should be replaced with the*
12 *title of the relevant statute.*
13

14 **Reporter's Notes**

15
16 The draft's remedy section is written to respond to privacy violations as well as
17 discrimination or misuse of genetic information in insurance. It has been rewritten to eliminate a
18 private right of action for an individual. An aggrieved individual may seek enforcement through
19 the State Commissioner of Insurance. An administrative remedy such as this is typical in state
20 statutes that prohibit discrimination in health insurance based on genetic testing or information.
21 These statutes declare that a violation is an unfair and deceptive insurance act or practice under
22 the state insurance code. They often provide that the State Commissioner of Insurance shall
23 enforce the prohibitions.
24

25 The Committee considered and rejected statutory damages as a remedy for a privacy
26 violation for the reason that statutory damages often serve primarily to limit recovery.

1 [ARTICLE] 4

2 MISCELLANEOUS PROVISIONS

3 SECTION 401. UNIFORMITY OF APPLICATION AND CONSTRUCTION. In
4 applying and construing this uniform act, consideration must be given to the need to promote
5 uniformity of the law with respect to its subject matter among states that enact it.

6 SECTION 402. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL
7 AND NATIONAL COMMERCE ACT. This [act] modifies, limits, and supersedes the federal
8 Electronic Signatures in Global and National Commerce Act, 15 U.S.C. Section 7001, et seq.,
9 but does not modify, limit, or supersede Section 101(c) of that act, 15 U.S.C. Section 7001(c), or
10 authorize electronic delivery of any of the notices described in Section 103(b) of that act, 15
11 U.S.C. Section 7003(b).

12 SECTION 403. EFFECTIVE DATE. This [act] takes effect