

D R A F T

FOR DISCUSSION ONLY

MISUSE OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE ACT

NATIONAL CONFERENCE OF COMMISSIONERS

ON UNIFORM LAWS

For Drafting Committee Meeting April 20-22, 2007

WITH PREFATORY AND REPORTER'S NOTES

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NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM LAWS

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April 12, 2007

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UNIFORM MISUSE 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.

There are important policy issues concerning the appropriate form and scope of regulation of genetic information. Perhaps it would be possible to agree on several underlying policy goals as a starting point. One proposal for appropriate goals is 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).

Another commentator phrases these goals in a similar way, with a proposal that regulation is justified: (1) to protect the few people whose genetic inheritance puts them at risk for rational genetic discrimination; (2) to protect those who are at risk of irrational genetic discrimination; and (3) to allay public fears that could impede genetic research. Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1500 (2001). An additional important goal is to treat individuals with respect by maintaining the privacy of their genetic information.

The point about irrational discrimination needs elaboration. 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.

The genetic causation of most diseases 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.

Many of the existing state statutes on use of genetic information fall into three general categories: employment, health insurance, and other insurance, usually life, disability and long-term-care. There is some overlap, but often states treat each of these areas somewhat differently. Therefore, for ease of initial consideration, the draft is organized in separate articles corresponding to these topics.

It is important to remember, however, that some states have statutes that cut across all three areas and govern other topics as well. For example, statutes that concentrate on genetic testing or genetic privacy typically apply to issues of consent, disclosure, retention of samples, use of genetic material, and use of databases generally. These issues have applications beyond the context of employment and insurance, and will be relevant to the National Conference of Commissioners on Uniform State Law’s decisions on the eventual scope of the act.

Other issues also cut across the three main areas of state genetic legislation. There is 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 U.S. 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 the 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).

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. The drafting committee’s charge responds to the large number of states that have enacted legislation dealing with the threats associated with genetic information. That legislation is highly inconsistent and often deals only partially with the issues. 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.

Employment

General Policy Issues

Currently, there is no comprehensive legislation or regulation that declares genetic information confidential, restricts employer access, or requires employers to protect the privacy of their employees’ genetic information. 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 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.

Title VII 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 his or her disability, not its cause. Similarly, under the second prong the ADA covers individuals with a prior record 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 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 U.S. 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 access to 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. Employers also have the right at that point in the hiring process to require that individuals sign a blanket release disclosing all their medical records to the employer. Employers may also test existing employees if they can justify the testing as job-related. Thus, despite the ADA's protections against discrimination through its requirements for reasonable accommodations, the ease of employer access to medical information may deter individuals from obtaining testing.

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 have built on their statutes prohibiting 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 protections 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.

Health Insurance

General Policy Issues

As in the employment arena, the treatment of genetic information by health insurers raises concerns for individuals’ privacy and for how genetic information may be used by the industry. Privacy is a great concern because the health care system is where much genetic information is generated and stored.

Discrimination in health insurance is a uniquely American problem because the United States does not guarantee coverage of health care expenses for its citizens as other wealthy nations do. Legislation in this area responds to public perceptions that health insurers will deny coverage or increase premiums based on predictive genetic information. This may be irrational discrimination. In addition, individuals who fear reduced or more expensive health care

coverage may avoid genetic tests that could provide useful information for improving their health. The legislative restrictions are designed to avoid these outcomes.

The main argument against regulation in this market is that genetic information would allow insurers to decrease adverse selection. Adverse selection is the disproportionate purchase of insurance by individuals who have medical reasons to believe they will need to make claims. It leads to insurer losses when applicants fail to disclose the relevant health information and is a particular concern with individual health insurance policies. The industry and a number of scholars contend that avoiding losses due to adverse selection based on genetic information will lead to more affordable insurance.

In 1995, 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 health insurance. The recommendations apply to both group and individual health plans.

- Insurance providers should be prohibited from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment or contribution requirements.
- Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.
- Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.
- Insurance providers and other holders of genetic information 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 would be made.

Kathy Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 Science 392 (1995).

One study of state restrictions on the use of genetic information in health insurance concluded that there are almost no well-documented cases of insurers asking for genetic test results for pre-symptomatic conditions in either states with regulation or states without such regulation. The author argued that use of genetic information is not cost effective and is not seen by insurers as increasing the accuracy of their underwriting. Nonetheless, he believes that state laws will have an effect by making it less likely that insurers will use genetic information in the

future, because the laws have helped convince them that use of this information is not socially acceptable. Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 *Jurimetrics J.* 93 (1999).

The Federal Regulatory Context

As with employment, the states legislate against the background of federal statutes governing health insurance. The 1996 Health Insurance Portability and Accountability Act (HIPAA) partially addresses the treatment and use of genetic information in health insurance. Title I amends the Employee Retirement Income Security Act (ERISA) and the Public Health Service Act with regard to availability of health insurance. Title II 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.”

HIPAA’s Title I provisions on availability of health insurance cover employer-sponsored group health insurance plans for 50 or more individuals, including self-insured plans. A plan may not deny an applicant coverage as a result of a health-status related factor, including genetic information. Plans are specifically prohibited from using “genetic information” in establishing eligibility or benefit levels. The law also prohibits exclusions for pre-existing conditions on the basis of a genetic predisposition to a particular condition. Moreover, a plan may not restrict coverage, restrict benefits, or charge higher premiums based on the health status of an enrolled employee. This part of HIPAA regulates only a portion of the health insurance market. It does not apply to employees in small group health insurance plans or to individual health insurance coverage.

The Privacy Rule, which took effect in 2003, covers “health plans,” a category that includes both individual and group health insurers. It allows health insurers to disclose “protected health information,” i.e., “individually-identifiable health information” to facilitate treatment, payment, or health care operations. Otherwise, health insurers must first obtain authorization from the individual. 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. Insurers must notify individuals of uses of their protected health information and keep records of disclosures of that information. The Privacy Rule applies more widely than Title I, but there are some exceptions to its coverage. It does not apply to an employer-sponsored group health plan with less than 50 participants that is administered solely by the employer that established and maintains the plan. It also does not apply to two types of government-funded programs: programs such as the food stamps program whose principle purpose is not providing or paying the cost of health care and programs such as a community health center whose principle activity is to provide health care directly.

Current State Statutes

The law in 47 states restricts the use of genetic information by health insurers in some

way. Some states impose restrictions only on group health insurance (Ak, Iowa, SD, Wy), and some only on individual policies (Hawaii, Nebraska, WV), but most cover both group and individual health insurance and hence have a broader reach than HIPAA's coverage provisions.

There are five main types of state regulation of genetics in health insurance. First, many states prohibit insurers from requiring individuals to have genetic tests or to disclose genetic information to the insurer. (Ark, Cal, Col, Fla, Ga, Haw, Ill, Ind, Kan, Md, Mich, Minn, Mo, Montana, Neb, NH, NMex, NY, OH, OK, Or, RI, SD, Tenn, UT, Wis). In a few states (Mich, Neb) this restriction on access to information stands alone, but most states have additional measures.

Second, a number of states prohibit health insurers from disclosing genetic information without informed consent or authorization. (Ariz, Cal, Col, Del, Ga, Haw, Ill, Ky, La, Me, Md, Mass, Mich, Mo, Nev, NH, NJ, NMex, NY, Or, RI, SC, Tenn, Tex, Vt, Va, Wash).

In addition to these privacy-based protections, there are also restrictions on health insurers' use of genetic information. In a third category, a large number of statutes provide that insurers may not establish rules for eligibility, that is, deny coverage, based on genetic information. (Alaska, Ariz, Ark, Cal, Col, Conn, Del, Fla, Ga, Haw, Ill, Ind, Iowa, Kan, Ky, La, Me, Mass, Minn, Mo, Mont, Nev, NH, NJ, NMex, NY, NC, OH, OK, Or, RI, SC, SD, Tenn, Tex, UT, Va, WV, Wis, Wy).

Fourth, most of these same states impose some type of limit on the use of genetic information for risk selection or classification in health insurance, such as higher premiums, reduced coverage or reduced benefits. Many states simply prohibit insurers from considering genetic information for these purposes.

Fifth, some states do not permit health insurers to impose pre-existing condition exclusions based on predictive genetic information in the absence of a diagnosis based on symptoms of the disease or condition. (Alaska, Conn, Idaho, Iowa, Ky, others).

This draft does not consider the emerging health issue of access to genetic services and insurance coverage for their costs. Currently the states with laws in this area cover newborn screening and genetic childhood diseases. According to the National Conference of State Legislatures, no state currently requires coverage of testing for adult onset genetic disorders such as breast cancer, but bills are being introduced frequently.

Life, Disability, and Long-term-care Insurance

General Policy Issues

Life, disability, 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 can provide an accurate prediction of the likelihood of claims.

The argument for restricting access to 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 access to 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

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.

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.

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 feed 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. 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 further question is whether there is a sufficient scientific basis for assessing risk and how the sufficiency of that scientific basis should be determined .

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. 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); Mass. Gen. Laws Ann. Ch. 175, § 108I (disability-income and long-term-care).

Finally, 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); N.J. Stat. Ann. § 17B:30-12(f) (life & disability-income, with option for genetic counseling); N.Y. Ins. Law § 2615(e) (if adverse decision for life, disability-income or long-term-care).

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); Kan. Stat. Ann. § 40-2259(d) (disability-income & long-term-care). 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, either 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); Kan. Stat. Ann. § 40-2259(d) (life); 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); Mass. Gen. Laws Ann. Ch. 175, § 120E (life, disability-income & long-term-care); Mont. Code Ann. § 33-18-206 (life, disability-income & long-term-care); N.J. Stat. Ann. § 17B:30-12(f) (life & disability-income); N.M. Stat. Ann. § 24-21-4 (C) (life, disability-income & long-term-care); Vt. Stat. Ann. tit. 18, § 4724(3) (life, disability-income & long-term-care); Wis. Stat. Ann. § 631.89 (life & disability-income).

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

3 **ARTICLE 1**

4 **GENERAL PROVISIONS**

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

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

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

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

15 (3) “Employee” means an individual who is applying to work for hire or who works for
16 hire, including an independent contractor or an individual employed in a supervisory, managerial,
17 or confidential position.

18 (4) “Employer” means a person that has employed at least one employee for each working
19 day in each of 20 or more calendar weeks in the current or preceding calendar year.

20 (5) “Family medical history” means information about the occurrence of a disease or
21 disorder in a family member of an individual.

22 (6) “Family member” means an individual’s spouse or [partner], an individual’s child,

1 and all individuals related by blood within the fourth degree of consanguinity to the individual,
2 spouse or [partner], or child.

3 (7 Alternative A) “Genetic information” means information based on an individual’s
4 genetic tests, the genetic tests of an individual’s family member, or an individual’s family
5 member’s history of a genetic disease or disorder.

6 (7 Alternative B) “Genetic information” means information based on an individual’s
7 genetic tests or the genetic tests of an individual’s family member.

8 (8) “Genetic monitoring” means a periodic examination to evaluate acquired
9 modifications to genetic material, such as chromosomal damage or evidence of increased
10 occurrence of mutations, that may have developed due to exposure to toxic or hazardous
11 substances.

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

13 (10 Alternative A) “Genetic test” means an analysis of human genetic material that
14 detects a genotype or genetic marker.

15 (10 Alternative B) “Genetic test” means an analysis of human genetic material that is
16 intended to detect a genotype, genetic marker, mutation, or chromosomal change. Human
17 genetic material includes DNA, RNA, chromosomes, proteins, and metabolites. A genetic test
18 does not include an analysis of proteins or metabolites that is directly related to a manifested
19 disease, disorder, or condition that could reasonably be detected by a health care professional
20 with appropriate training and expertise in the relevant field of medicine.

21 (11) “Health insurance” means a health care arrangement that pays for, purchases, or
22 furnishes health care services to patients, insureds, or beneficiaries, including:

- 1 (A) insurance that covers hospital, medical, or health expenses;
- 2 (B) an employee welfare-benefit plan;
- 3 (C) a health maintenance organization;
- 4 (D) a preferred provider organization;
- 5 (E) a medical service organization;
- 6 (F) a physician-hospital organization;
- 7 (G) a self-insured health plan;
- 8 (H) a pre-paid health care service plan; or
- 9 (I) other health care arrangement in which risk is assumed.

10 (12) “Insured” means an individual who is covered or applying for coverage under a
11 policy of health, life, disability-income, or long-term-care insurance.

12 (13) “Insurer” means a person engaged in the business of health, life, disability-income,
13 or long-term-care insurance in this state regardless of where a contract of insurance is written or a
14 plan is administered. The term includes an insurance agent, broker, adjuster, underwriter, or
15 third-party administrator.

16 (14) “Life insurance” means insurance for the risk of death. The term includes
17 endowments and fixed and variable annuities.

18 (15) “Long-term-care insurance” means insurance that provides coverage for not less than
19 12 consecutive months on an expense-incurred, indemnity, prepaid, or other basis for one or
20 more necessary diagnostic, preventive, therapeutic, rehabilitative, maintenance, or personal care
21 services provided in a setting other than an acute care unit of a hospital. The term includes a
22 policy or rider that provides for payment of benefits based upon cognitive impairment or the loss

1 of functional capacity.

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

5 (17) “Predisposing genetic characteristic” means a gene or genetic marker that is
6 determined from genetic information and is associated with an individual’s statistically
7 significant increased risk of developing a disease or medical condition for which the individual is
8 presently asymptomatic.

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

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

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

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

15 **Legislative Note:** *In the definition of “family member,” states should insert for [partner] the*
16 *appropriate term for an unmarried partner who is eligible for coverage by health insurance,*
17 *such as “domestic partner,” “significant other,” “partner,” or a similar term.*

18 **Reporter’s Notes**

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

26
27 *Paragraph (2). (Disability-income insurance)* This definition of disability-income
28 insurance is used in several state statutes on genetic testing. *See, e.g.,* Cal. Ins. Code § 10147;
29 N.H. Rev. Stat. Ann. § 141-H:1.

1 *Paragraph (3). (Employee)* The definition of employee is adapted from the National
2 Conference of Commissioners on Uniform State Law’s Model Employment Termination Act.
3 The primary modification is that the definition includes rather than excludes independent
4 contractors. In addition, applicants for employment are also included within the definition of
5 employee. The drafting committee has not differentiated protections for applicants in the
6 substantive portions of the act from those that apply to employees.
7

8 *Paragraph (4). (Employer)* The definition of employer is also adapted from the National
9 Conference of Commissioners on Uniform State Law’s Model Employment Termination Act. It
10 is linked to the definition of “person” and therefore encompasses all types of entities, including
11 governmental and non-profit employers.
12

13 As the definition of employer is currently drafted, the act would cover all employers
14 regardless of size. One consideration is whether the requirements of the act would prove too
15 burdensome for small employers. Many statutes specify a minimum size using the number of
16 employees as a proxy for size. For example, Title VII of the Civil Rights Act of 1964 covers
17 employers who had 15 or more employees for each working day in 20 or more weeks over the
18 course of a year. The definition in the Uniform Law Commissioner’s Model Employment
19 Termination Act was modeled on Title VII, but it reduces the required number of employees to
20 five, and extends the qualifying period to two years.
21

22 Another way to limit the types of employers that are covered would be to exclude
23 immediate family members from the count of employees, as is done in the Fair Labor Standards
24 Act and the National Conference of Commissioners on Uniform State Law’s Model Employment
25 Termination Act. In addition, some state statutes exclude particular employee groups, such as
26 household workers or farm workers, in determining employer status.
27

28 *Paragraph (5). (Family medical history)* This term will become relevant if the drafting
29 committee decides to adopt Alternative B as the definition of “genetic information,” as explained
30 in the comments to Paragraph 7. The term is placed in brackets throughout this draft to indicate
31 where it would be appropriate in conjunction with Alternative B.
32

33 *Paragraph (6). (Family member)* A family member is defined broadly to encompass all
34 individuals whose own genotype could influence an employment or insurance decision. The
35 term includes (1) biological relations whose genetic information might provide information about
36 the genetic make-up of an individual employee, insured, or applicant for employment or
37 insurance, (2) dependants whose risk of future genetically-linked medical conditions could affect
38 employer health care costs or family insurance coverage and hence employment or insurance
39 decisions, and (3) dependants’ biological relations whose genetic information might provide
40 information about the genetic make-up of a dependant. The term “dependent child” is intended
41 to include both adopted and biologically-related children.
42

43 “Partner” or the equivalent term under state law is included in the definition of family

1 member because many employers provide health insurance for employees' unmarried partners.
2 Therefore, an unmarried partner can fall into the second category above. Because terminology
3 for this status varies among the states, each state should substitute its term for an unmarried
4 partner as described in the legislative note.

5
6 *Paragraph (7). (Genetic information)* The subcommittee on life, disability-income and
7 long-term-care insurance offers two alternative definitions of “genetic information” for
8 consideration by the drafting committee. Alternative A is the definition used in the draft for the
9 September 2006 drafting committee meeting. It is modeled on the type of definition that has
10 been chosen by the greatest number of states in that it includes information on genetic
11 characteristics broadly, whether it is obtained from tests or family medical history. (Cal, Conn,
12 Hawaii, LA, Maine, MD, Mass, Mich, NJ, NMex, NC, RI, SD, TX, WA).

13
14 Alternative A is also consistent with the definition of “genetic information” in H.R. 493,
15 the federal bill to prohibit discrimination on the basis of genetic information with respect to
16 health insurance and employment introduced in January 2007. The federal definition provides
17 that the term means “information about (i) an individual’s genetic tests; (ii) the genetic tests of
18 family members of the individual; or (iii) the occurrence of a disease of disorder in family
19 members of the individual.” Information about the sex or age of an individual is excluded from
20 this definition.

21
22 Alternative B was developed for potential use in Article 4 on life, disability-income, and
23 long-term-care insurance. It makes it easier to distinguish between genetic information based on
24 genetic testing only and genetic information considered more broadly to include family history.
25 This definition is modeled on those in states that limit protected genetic information to the results
26 of laboratory genetic testing only, either of the individual employee (Ark, Del, Neb, NH, NY,
27 OK, VT), or of the employee and blood relatives (LA, Minn, Or, UT).

28
29 The drafting committee has endorsed using the broader meaning of “genetic information”
30 signified by Alternative A for Articles 2 and 3 on employment and health insurance. It would be
31 possible to convey this meaning in those Articles by combining Alternative B’s more limited
32 definition of the term “genetic information” with the term “family medical history.”

33
34 *Paragraph (8). (Genetic monitoring)* The definition of “genetic monitoring” is drawn
35 from the description in Office of Technology Assessment, *Genetic Monitoring and Screening in*
36 *the Workplace* 4 (1990). The focus in monitoring is not on inherited characteristics, but on
37 genetic alterations in a group of exposed individuals over time. Genetic monitoring is typically
38 undertaken by employers to identify risks for groups of employees who have been exposed to
39 hazardous substances or to target work sites for safety and health measures.

40
41 *Paragraph (9). (Genetic service)* “Genetic service” is a broader category than genetic
42 testing. The term includes activities associated with obtaining genetic information that could
43 create assumptions about genetics even in the absence of a genetic test or genetic information.

1 “Counseling” implies a one-on-one consultation, so the definition also includes “genetic
2 education” in order to capture group information sessions on genetic conditions. Members of the
3 drafting committee have expressed concern, however, that “education” makes the definition too
4 broad.
5

6 In contrast, some states take a narrower approach that is limited to protecting requests for
7 genetic testing. For example, Rhode Island accomplishes this by including “request for genetic
8 testing” within its definition of “genetic information.”
9

10 *Paragraph (10). (Genetic test)* The subcommittee on life, disability-income and long-
11 term-care insurance offers two alternative definitions of “genetic test” for the drafting committee
12 to consider. Alternative A is the definition used in the draft for the September 2006 drafting
13 committee meeting. This definition of genetic test is not phrased in terms of particular types of
14 tests or specific substances that are used to provide information about a person’s genetic makeup,
15 as the substances used for this purpose may change or expand with scientific and medical
16 developments. “Human genetic material” is intended to include chromosomes, deoxyribonucleic
17 acid (DNA), ribonucleic acid (RNA), proteins, and metabolites that can detect or indicate
18 information about an individual’s genotype. It is also intended to prevent this list from becoming
19 unintentionally limiting and permit it to expand as scientific knowledge develops. See Henry T.
20 Greely, *Banning “Human Cloning:” A Study in the Difficulties of Defining Science*, 8 S. Cal.
21 Interdisciplinary L.J. 131 (1998).
22

23 Alternative B makes specific reference to the types of medical testing that currently
24 constitute genetic testing. A complication is that some testing to reveal a genotype is not done by
25 directly testing genetic material, but by testing proteins or metabolites associated with genetic
26 conditions. Testing of proteins and metabolites has many medical purposes other than
27 determining an individual’s genetic make-up. As a result, the concept of intent is included in the
28 definition, which may be a topic the committee wants to discuss.
29

30 The structure of Alternative B is similar to the definition of “genetic test” in the medical
31 insurance provisions of H.R. 493, the federal bill to prohibit discrimination on the basis of
32 genetic information with respect to health insurance and employment introduced in January
33 2007. The final sentence of the definition also serves to exclude testing for medical purposes
34 other than determining an individual’s genetic make-up. It does this by differentiating between
35 testing proteins and metabolites for genetic purposes and testing them to diagnose or treat an
36 expressed genetic condition. The incorporation of language about a manifest condition, however,
37 limits genetic testing based on measuring proteins and metabolites to predictive purposes only.
38 Based on the drafting committee’s previous deliberations, this concept of testing may not be
39 appropriate in the employment context and may necessitate a separate definition of “genetic test”
40 for Article 2.
41

42 Some states statutes limit their definition of “genetic test” to testing for disease-related
43 genes. (Ariz, Ark, Del, Ill, Iowa, Kan, LA, Maine, MD, Mich, Minn, Nev, MO, Neb, NJ, NM,

1 NY, NC, OK, OR, RI, TX, VT, VA, WI). Both of the draft’s alternatives follow the example of
2 other states, including some with newly enacted or amended statutes, that do not limit the
3 definition of genetic testing to genotypes associated with diseases or impairments. (Fla, Haw,
4 Mass, NH, Ore, UT). While most of the reasons that an employer or insurer might currently seek
5 or use genetic information probably involve a disease, disorder, or impairment, this may not
6 always be the case. One can imagine, for example, that the presence or absence of behavioral
7 traits might also be a criterion for selecting an employee. While the current evidence linking
8 behavior to genes is tenuous, this area continues to be the subject of investigation. Moreover, a
9 broad definition of “genetic test” would facilitate the eventual application of the statute to topics
10 outside employment and insurance, if that is the direction the National Conference of
11 Commissioners on Uniform State Laws takes. For example, provisions governing the retention
12 of samples used for research or identification would cover testing that is not necessarily linked to
13 disease.

14
15 Some of the state statutory definitions specifically include testing for the purpose of
16 monitoring for genetic damage through workplace exposure. (Ariz, Ill, N.Mex). Rather than
17 defining this as a “genetic test,” both definitions in the draft treat this as a permitted reason for
18 testing in section 203.

19
20 *Paragraph (11). (Health insurance)* The definition of “health insurance” is meant to be
21 broad. Definitions and terms of art vary greatly among the states. For example, a number of
22 states use the term “disability insurance” for what is commonly thought of as “health insurance.”
23 The definition is written in terms of functions and organizational structures and is intended to
24 capture the full range of health insurance without regard to specific state designations. It adopts
25 the broad framework used in Ala. Code § 27-53-1(3), supplemented with terms for health care
26 arrangements used in other states. In addition, the definition includes a “health care arrangement
27 in which risk is assumed,” which serves as a catch-all category. This concept is drawn from Fla.
28 Stat. § 627.4301.

29
30 *Paragraph (12). (Insured)* The definition of “insured” is intended to cover applicants for
31 insurance as well as those covered by insurance policies.

32
33 *Paragraph (13). (Insurer)* The definition of “insurer” is intended to cover broadly
34 insurance companies and other persons that issue health, life, disability-income, or long-term-
35 care insurance and all persons who might obtain, use, or disclose genetic information associated
36 with that process.

37
38 *Paragraph (14). (Life insurance)* “Life insurance” is intended to be defined broadly.
39 This definition is drawn from N.H. Rev. Stat. § 401:1(III).

40
41 *Paragraph (15). (Long-term-care insurance)* The definition of “long-term-care
42 insurance” is drawn from N.H. Rev. Stat. § 415-D:3(V). The definition could be made more
43 complex. For example, the New Hampshire provision also excludes a list of basic health care,

1 accident, and life insurance coverage. It further states that “any product advertised, marketed, or
2 offered as long-term-care insurance” is included in the definition.

3
4 *Paragraph (16). (Person)* This draft uses the broad version of the standard National
5 Conference of Commissioners on Uniform State Laws definition of “person.”
6

7 *Paragraph (17). (Predisposing genetic characteristic)* The definitions in the draft are
8 designed to allow tailoring of the scope of permitted uses of information. A “predisposing
9 genetic characteristic” refers to an genotype that signals an increased risk of a certain disease or
10 condition. The term does not include symptomatic diseases or conditions or genetic
11 characteristics that are manifest in a disease, medical condition, or disability. The broader terms
12 “genetic test” and “genetic information” include both predisposing and manifest genetic
13 characteristics as well as genetic information that does not necessarily pertain to health.
14

15 While the terms “propensity” or “susceptibility” are often used, the actual manifestation
16 of a disease or condition may depend on a complex chain of events and the degree to which risk
17 is elevated may be quite small. “Predisposing genetic characteristic” is meant to signal a more
18 tenuous connection between a genotype or marker and a physical manifestation.
19

20 *Paragraph (18). (Record)* The definition of “record” is the standard National Conference
21 of Commissioners on Uniform State Laws definition.
22

23 *Paragraph (19). (Sign)* The definition of “sign” is the standard National Conference of
24 Commissioners on Uniform State Laws definition.
25

26 **SECTION 103. AUTHORIZATION FOR ACCESS, RETENTION, OR**
27 **DISCLOSURE OF GENETIC INFORMATION [OR FAMILY MEDICAL HISTORY].**

28 (a) Except as otherwise provided in Sections 201, 301, or 401, or as authorized by an
29 employee or insured, an employer, employment agency, labor organization, licensing authority or
30 insurer may not access, retain, or disclose genetic information [or family medical history]. The
31 authorization must be knowing and voluntary and indicated by a record signed by the employee
32 or insured.

33 (b) An authorization by an employee or insured for disclosure of genetic information [or
34 family medical history] to an employer, employment agency, labor organization, licensing

1 authority, or insurer by another person shall include a description of the genetic information [or
2 family medical history] to be disclosed, its potential uses, and the person to whom it may be
3 disclosed.

4 (c) An authorization for an employer, employment agency, labor organization, or
5 licensing authority or insurer to retain genetic information [or family medical history] shall
6 include a description of the genetic information [or family medical history] to be retained, its
7 potential uses, limitations on its use, the person that will retain it, and the length of time it may
8 be retained. An employee or insured may revoke authorization for retention of genetic
9 information [or family medical history] at any time in a record signed by the employee or
10 insured.

11 (d) An authorization for an employer, employment agency, labor organization, or
12 licensing authority or insurer to disclose an employee's or insured's genetic information [or
13 family medical history] to another person shall include a description of the genetic information
14 [or family medical history] to be disclosed, its potential uses, limitations on its use, and the
15 person to which it may be disclosed.

16 **Reporter's Notes**

17
18 This draft groups authorization provisions for employment and insurance together in one
19 general section on the recommendation of the style committee. The provision on authorization
20 for genetic testing, however, is treated separately. It is located in Section 202 along with the
21 other provisions on employer-supplied genetic testing. The reason is that the draft does not
22 authorize insurers to supply genetic testing in connection with their insurance business, so the
23 provision is relevant only to employment.
24

25 The draft uses the term "authorization" to avoid confusion with the term "informed
26 consent," which has a specific meaning in the practice of medicine.
27

28 The draft does not disturb existing law that allows a minor to seek repudiation of consent

1 and expunge records when the minor reaches the age of majority.
2

3 The phrase “[or family medical history]” is included as a placeholder throughout the
4 section to indicate an addition if the drafting committee adopts Alternative B of the definition of
5 “genetic information.”
6

7 *Subsection (a) General requirements for authorization.* Under the draft, authorization is
8 required before an employer or insurer may access, retain, or disclose genetic information except
9 as provided elsewhere in the draft. In order to give a valid authorization, the employee or insured
10 must be informed as provided in the following subsections and must act voluntarily. This
11 subsection also includes requirements for the form of an authorization.
12

13 *Subsection (b) Authorization for access to genetic information.* This subsection states
14 requirements for the authorization that must be provided to a third party before it discloses
15 genetic information to an employer or insurer.
16

17 *Subsection (c) Authorization for retention of genetic information.* Authorization for
18 retention includes notice of the uses to which the genetic information may be put. Under the
19 current draft, an employee or insured may revoke authorization for retention at any time. If an
20 individual is deceased and unable to revoke authorization, the individual’s personal
21 representative may revoke the authorization. A drafting committee member has suggested that
22 revocations should apply only to future records.
23

24 *Subsection (d) Authorization for disclosure of genetic information.* If an individual is
25 deceased and unable to provide authorization for disclosure, the individual’s personal
26 representative may provide the authorization. This might be desirable if an individual’s relatives
27 seek genetic information that might be relevant to their genetic traits.

1 of a genetic service.

2 (c) If an employer, employment agency, labor organization, or licensing authority
3 supplies a genetic test as part of a genetic monitoring program, the employer, employment
4 agency, labor organization, or licensing authority shall receive the genetic test results in an
5 aggregate form that does not disclose individually-identifiable information.

6 (d) An employer, employment agency, labor organization, or licensing authority may
7 obtain genetic information [or family medical history] about an employee if:

8 (1) the employee has placed the employee's health at issue in a judicial, arbitral,
9 or administrative agency proceeding in which the employer, employment agency, labor
10 organization, or licensing authority is a defendant;

11 (2) the genetic information [or family medical history] is relevant to a claim or
12 defense in the proceeding; and

13 (3) on a motion by the employer, employment agency, labor organization, or
14 licensing authority a court, arbitral tribunal, or administrative agency orders the employee to
15 undergo genetic testing or provide genetic information [or family medical history] after finding
16 that the employer, employment agency, labor organization, or licensing authority has
17 demonstrated compelling need and that the information is otherwise unavailable.

18 **Reporter's Notes**

19
20 *Applicability.* This article is intended to apply broadly in the employment setting to an
21 employer, employment agency, labor organization, or licensing authority. Employment agencies,
22 labor organizations and licensing authorities are included because they control access to
23 employment through referrals or licensing.

24
25 *Existing state law.* An employer, employment agency, labor organization, or licensing
26 authority gets health information in a variety of ways including applications, interviews,

1 references, post-offer medical exams, post-offer releases of medical records, Family and Medical
2 Leave Act requests, worker’s compensation claims, health insurance claims to self-insured
3 employers, and voluntary disclosures by employees. Many states have tried to limit employer
4 access to genetic information. There are statutes that prohibit an employer from requiring,
5 requesting or administering genetic testing, obtaining genetic information, making inquiries
6 about genetic information, or some combination of these methods of accessing genetic
7 information. (Conn, Del, Iowa, Kan, MD, Mass, Mich, Minn, Neb, Nev, NH, NY, OR, RI, Tex,
8 UT, VT, VA, WA, WI).

9
10 *Privacy rationale.* One rationale for limiting employer access to genetic information is
11 the view that an employee should be able to keep genetic information private. At least one state
12 has a constitutional right of privacy that appears to be relevant to genetic information. (Alaska)
13 Another rationale is to make genetic discrimination less likely for, unlike discrimination based on
14 sex or race, an employer cannot discriminate on the basis of genetic characteristics unless it has
15 access to genetic information.

16
17 Scholars have argued that a privacy rationale makes more sense for protecting genetic
18 information in the employment context than an anti-discrimination rationale. Statutory
19 protections based on anti-discrimination rationales are designed for socially-recognized groups
20 that have been historically disadvantaged. Genetic variations do not fit especially well within
21 this paradigm. *See, e.g.,* Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking*
22 *Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

23
24 This draft of the act moves away from the approach used in statutes with an anti-
25 discrimination emphasis. Rather than broadly prohibiting employer testing and access to genetic
26 information subject to exceptions, the draft affirmatively permits access to genetic information
27 under certain circumstances.

28
29 *Subsection (a) Access to genetic information.* The draft permits an employer,
30 employment agency, labor organization, or licensing authority to access genetic information
31 about an employee at the employee’s instigation only. This follows the approach of a number of
32 states that restrict an employer’s ability to require or obtain genetic information. *See, e.g.,* Conn.
33 Stat. Ann. § 46a-60(11) (employer may not “request or require” genetic information from
34 employee); Kan. Stat. Ann. § 44-1009(a)(9) (employer may not seek to obtain, obtain, or use
35 testing information to distinguish employees or restrict a right or benefit); La. Rev. Stat. § 23:368
36 (employer may not “require, collect, or purchase” protected genetic information with respect to
37 an employee); Md. Code Art. 49B § 16(a) (employer may not “request or require” genetic
38 information as a condition for hiring or determining benefits); Mass. Gen. L. Art. 151B § 4(19)
39 (unlawful to “collect, solicit or require disclosure of genetic information” as a condition of
40 employment); Mich. Comp. Laws § 37.1202 (no employer may “directly or indirectly acquire or
41 have access to” an employee’s or family member’s genetic information unless an individual
42 provides it voluntarily); Minn. Stat. Ann. § 181.974(subd. 2) (employer may not “request,
43 require, or collect” protected genetic information as a condition of employment); Neb. Rev. Stat.

1 § 48-236 (employer may not require genetic information as a condition of employment or
2 promotion); Utah Code Ann. § 26-45-103 (employer may not “access or otherwise take into
3 consideration” private genetic information in connection with an employment decision); Wash.
4 Rev. Code Ann. § 49.44.180 (unlawful to require employee to submit genetic information as
5 condition of employment).
6

7 The draft’s approach is in contrast to that of anti-discrimination statutes, which typically
8 allow employers to compel testing or require employees to provide genetic information under
9 certain circumstances. Most of the states that rely on disability statutes to regulate genetic
10 information follow the ADA, which permits an employer to test an applicant and access an
11 applicant’s medical records after a conditional offer of employment. This approach opens the
12 door broadly to genetic information. (California and Minnesota are exceptions. They have
13 addressed this problem comprehensively by providing that employers may not have access to
14 non-job related medical information at any time.) In addition, under the ADA and most state
15 statutes modeled on it, an employer can obtain medical information about its employees if it has
16 a reasonable belief that (1) the employee will be unable to perform the essential functions of his
17 or her job due to the medical condition or (2) the employee will pose a direct threat to health or
18 safety because of the medical condition. Similarly, states that have amended their employment
19 discrimination statutes to include genetics usually follow the rubric of those statutes and permit
20 genetic testing or collection of genetic information when it is relevant to “job-related
21 qualifications” or justified by “business necessity.”
22

23 If an employee authorizes employer access to genetic information, the conditions under
24 which an employee grants that authorization are important. Some states permit employers to
25 request genetic information under the apparent assumption that an employee’s consent to an
26 employer’s request is voluntary. It is possible, however, to argue that in the context of at-will
27 employment, the need to retain one’s job may turn an employer’s request for genetic information
28 into a demand that an employee dare not refuse. Thus some statutes prohibit even requests or
29 inquiries. *See, e.g.*, Mass. Gen. L. Art. 151B § 4(19) (unlawful to “question a person about their
30 genetic information or genetic information concerning their family members”); Nev. Rev. Stat. §
31 613.345 (unlawful employment practice to “ask or encourage” an employee to submit to a
32 genetic test). This draft follows that approach.
33

34 A more stringent level of protection could protect workers from ever providing genetic
35 information or authorizing access, even on their own initiative. But a blanket prohibition on any
36 disclosure arguably goes too far. It would prevent an employee from sharing information that
37 could be used to protect the person from situations in which the employee is genetically
38 susceptible to harm. In addition, it would make it easy to violate the act inadvertently by
39 disclosing information an employee does not realize is genetic information. Instead, this draft
40 follows a middle approach that permits employees to volunteer genetic information, but does not
41 generally permit employers to require it.
42

43 Employees who provide genetic information voluntarily may do so directly, through oral

1 statements or by turning over reports of test results. They may also do so by permitting an
2 employer to see medical records held by a third party. In the case of disclosures made by a third
3 party to an employer, the draft requires prior authorization by the employee. The prohibition on
4 employer inquiries is intended to apply to inquires directed to other entities as well as to inquiries
5 directed to the employee.
6

7 A complication left unresolved in this draft is that employers who have access to medical
8 records will have access to genetic information because it is interspersed throughout medical
9 records. An employer that requests any medical information is likely to receive the entire file,
10 including genetic information. A solution would be to develop technologies that can limit the
11 scope of information disclosed by health care providers. Mark A. Rothstein & Meghan Talbott,
12 *Compelled Disclosure of health Information: Protecting Against the Greatest Potential Threat to*
13 *Privacy*, 295 JAMA 2882 (2006). Without improved technology to solve this probelm, the draft
14 could be interpreted to mean that employers may not ask for health records in general, because
15 they would likely contain genetic information. The drafting committee may not intend this broad
16 consequence, although there are those who maintain that legislation is needed to limit an
17 employer’s ability to obtain any non-job-related health information during the hiring process or
18 employment. See Mark A. Rothstien, *Genetic Exceptionalism and Legislative Pragmatism*, 35
19 Hastings Center Report No. 4 (2005), at 35.
20

21 Note that if the drafting committee adopts the more limited definition of genetic
22 information (Alternative B), the term “family medical history” will need to be added to make this
23 provision consistent with the meaning of genetic information previously endorsed by the drafting
24 committee in the context of employment.
25

26 *Subsection (b) Access to information about genetic services.* A number of state statutes
27 prohibit employers from accessing or using information about an employee’s request for or use
28 of genetic services. See, e.g., La. Rev. Stat. § 23:368 (employer may not “require, collect, or
29 purchase” information about an employee’s request for or use of genetic services); Maine Rev.
30 Stat. Ann. § 19302 (employer may not discriminate on basis that an individual received a genetic
31 test or genetic counseling except when based on a bona fide occupational qualification); N.C.
32 Gen. Stat. Ann. § 95-28.1A (unlawful to deny employment of account of request for genetic
33 testing or counseling services); Utah Code Ann. § 26-45-103 (employer may not inquire into
34 whether an individual or blood relative has taken or refused to take a genetic test); Vt. Stat. Ann.
35 § 9333 (employer may not use the fact that genetic counseling or tested services have been
36 requested or performed). This allows employees to keep private information that could lead to
37 discrimination based on assumptions about genetics, even in the absence of genetic information.
38 If an individual is unable to keep private his use of genetic services such as counseling, he may
39 be deterred from obtaining this service for fear that an employer or insurer will assume he has
40 reason to think he has a genetic disorder.
41

42 Alternatively, this subsection could be combined with subsection (a). It is separated here
43 for clarity of drafting.

1 *Subsection (c) Genetic monitoring programs.* Genetic monitoring programs are typically
2 undertaken by employers to identify risks for groups of employees who have been exposed to
3 hazardous substances or to target work sites for safety and health measures. Monitoring is testing
4 designed to detect whether the genetic material of a group of individuals has changed over time.
5 The premise is that such changes could indicate increased risk of future illness. Aggregated data
6 from tests for genetic damage is sufficient to allow an employer to reduce exposures to levels that
7 do not affect individuals' chromosome morphology or DNA. Office of Technology Assessment,
8 *Genetic Monitoring and Screening in the Workplace* 66 (1990). Moreover, while monitoring
9 may have predictive value for a group, the techniques that are used do not currently measure
10 increased individual health risks. The rationale for genetic monitoring programs is discussed in
11 more depth in the Reporter's notes to section 203.
12

13 *Subsection (d) Legal proceedings.* This draft provides for an employer to obtain an
14 employee's genetic information if the employee places his health at issue in a legal proceeding.
15 This right is limited in that it applies only if the employer has satisfied the burden of proof to
16 show compelling need and that the information is otherwise unavailable. Only that portion of an
17 employee's genetic information that is relevant to a claim or defense may be provided.
18

19 The form of the subsection follows Utah's statute, which authorizes genetic testing when
20 the employee has placed his or her health at issue in a proceeding, but only by order of a court or
21 administrative agency after finding compelling need and that the information is otherwise
22 unavailable. These procedures are consistent with Rule 35 of the Federal Rules of Civil
23 Procedure, which provides that a court may order a physical examination on motion for good
24 cause shown. Other states have more narrowly authorized employer testing to investigate a
25 worker's compensation claim. (NH, NY).
26

27 As in subsection (a), if the drafting committee adopts the more limited definition of
28 genetic information formulated by the subcommittee on life, disability-income, and long-term-
29 care insurance, the term "family medical history" will need to be added to make this provision
30 consistent with the meaning of genetic information previously endorsed by the drafting
31 committee in the context of employment.
32

33 **SECTION 202. EMPLOYER-, EMPLOYMENT AGENCY-, LABOR**
34 **ORGANIZATION-, OR LICENSING AUTHORITY-SUPPLIED GENETIC TESTING.**

35 (a) An employer, employment agency, labor organization, or licensing authority may
36 offer a genetic test and, with the prior authorization of the employee as required by subsection
37 (c), may supply a genetic test to an employee for one of the following purposes:

1 (1) to determine an employee's predisposing genetic characteristics that may
2 create susceptibility to harm to the employee from a workplace condition;

3 (2) to monitor the effects of employees' exposure to a workplace condition as
4 part of a genetic monitoring program;

5 (3) as part of a confidential preventative health program for employees.

6 (b) An employer, employment agency, labor organization, or licensing authority that
7 supplies a genetic test to an employee shall:

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

11 (2) provide for genetic counseling about the test result for the employee unless
12 the employee directs otherwise.

13 (3) require that the employee's biological sample obtained for a genetic test shall
14 be destroyed promptly following the completion of the testing unless the employee authorizes the
15 retention of the sample or an order of a court, arbitral tribunal, or administrative agency
16 authorizes or requires retention of the sample.

17 (c) Following genetic counseling about the risks and benefits of a genetic test, an
18 employee may authorize an employer, employment agency, labor organization, or licensing
19 authority to supply the genetic test for the employee if the test is permitted by subsection (a).

20 The authorization for the genetic test shall:

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

22 (2) inform the employee that the test result will be reported to the employee and a

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

2 (3) inform the employee that genetic counseling about the test result will be
3 provided to the employee unless the employee directs otherwise.

4 (d) An employee’s authorization for a genetic test shall be knowing and voluntary and
5 indicated by a record signed by the employee.

6 (e) If a court, administrative agency, or arbitral tribunal orders an employee to undergo a
7 genetic test under Section 201(d), the employer, employment agency, labor organization, or
8 licensing authority shall supply the genetic test for the employee.

9 **Reporter’s Notes**

10
11 Genetic testing is a means by which an employer can obtain genetic information, but it is
12 also possible for employers to supply testing without gaining access to individualized test results.
13 Therefore the draft separates provisions on employer access to genetic information, treated in
14 Section 201, from the provisions in this section on genetic testing.

15
16 Some states broadly prohibit employers from subjecting employees to genetic testing.
17 *See, e.g.*, Iowa Code Ann. § 729.6 (employer may not “solicit, require, or administer” a genetic
18 test as a condition of employment); Kan. Stat. Ann. § 44-1009(a)(9) (employer may not subject,
19 directly or indirectly, any employee to any genetic screening or test); Md. Code Art. 49B § 16(a)
20 (employer may not “request or require” genetic tests as a condition for hiring or determining
21 benefits); Mass. Gen. L. Art. 151B § 4(19) (unlawful to “solicit submission to, require, or
22 administer a genetic test” as a condition of employment); Mich. Comp. Laws § 37.1202 (no
23 employer may require a genetic test as a condition of employment); Minn. Stat. Ann. §
24 181.974(subd. 2) (employer may not “administer a genetic test” as a condition of employment);
25 Neb. Rev. Stat. § 48-236 (employer may not require a genetic test as a condition or employment
26 or promotion); Nev. Rev. Stat. § 613.345 (unlawful employment practice to “require or
27 administer” a genetic test as a condition of employment); N.H. Rev. Stat. § 141-H (may not
28 “solicit, require, or administer” genetic testing as a condition of employment); RI Stat. § 28-6.7-1
29 (employer may not “request, require, or administer” a genetic test); Utah Code Ann. § 26-45-103
30 (employer may not “request or require” an individual or blood relative to submit to a genetic test
31 in connection with an employment decision); Vt. Stat. Ann. § 9333 (may not require genetic
32 testing as a condition of employment); Va. Code Ann. § 40.1-28.7-1 (employer may not “request,
33 require, solicit, or administer” a genetic test as a condition of employment); Wash. Rev. Code
34 Ann. § 49.44.180 (unlawful to require employee to submit to genetic screening as condition of
35 employment); Wis. Stat. Ann. § 111.372 (employer may not “solicit, require, or administer” a

1 genetic test as a condition of employment unless employee requests test).
2

3 This draft focuses instead on the situations in which it is permissible for an employer to
4 offer or supply genetic testing without any necessary inference that the employer will have access
5 to the testing results. An employer should supply testing through an outside medical
6 organization. See Mark A. Rothstein, *Genetics and the Workforce of the Next Hundred Years*,
7 2000 Colum. Bus. L. Rev. 371 (2000).
8

9 *Subsection (a). Acceptable purposes for an employer to supply genetic tests.* The draft
10 permits employers to offer genetic testing for three purposes: to determine predisposing
11 characteristics that may create susceptibility for harm to the employee due to workplace
12 conditions, to monitor exposure to workplace conditions as part of an ongoing program, and as
13 part of an employee health program.
14

15 The drafting committee considered, but did not adopt, a provision that would permit
16 employees to supply genetic testing in order to protect the safety of other employees in the
17 workplace. It would be very rare for a genetic marker to indicate a safety threat to other
18 employees with sufficient certainty to justify a genetic test. The draft does not limit an
19 employer's ability to take an employee's manifested medical condition into account for safety
20 purposes, subject to the provisions of the Americans With Disabilities Act.
21

22 *Subsection (a)(1) Employee susceptibility.* Determining employee susceptibility to harm
23 from exposure to workplace substances is one situation in which some states have permitted
24 employers to test with the consent of the employee. Iowa, Louisiana, New Hampshire, New
25 York, and Wisconsin all have nearly identical provisions that permit genetic testing of an
26 employee to determine an employee's susceptibility to toxic substances if the employee requests
27 testing, provides informed consent or authorization, and the employer does not terminate the
28 employee or take other adverse action as a result of testing. Iowa Code Ann. § 729.6(7); N.H.
29 Rev. Stat. § 141-H:3; N.Y. Exec. Law § 296; Wis. Stat. Ann. § 111.372.
30

31 The utility of testing for susceptibility to workplace disclosures is illustrated by chronic
32 beryllium disease. Beryllium is a lightweight metal used in many industries that poses the threat
33 of this disease when dust or fumes are inhaled. Industry protections have greatly reduced
34 exposure, but a small portion of the population can contract the disease even after a very brief
35 exposure. A genetic marker has reportedly been identified for this extreme sensitivity that
36 purports to show with certainty which individuals will contract beryllium disease and die from
37 short exposure. Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in Employment*
38 *on the Basis of Genetics*, 6 Employee Rights & Employment Policy Journal 57, 63-64 (2002). If
39 so, testing could provide information that could define an individual's risk from workplace
40 exposure to beryllium.
41

42 The draft allows an employer to supply testing for such susceptibilities, but unless the
43 employee volunteers the test results under section 201(a), the employer is not authorized to

1 obtain them.
2

3 *Subsection (a)(2) Genetic monitoring program.* Monitoring for damage to employees'
4 genes from workplace exposure to harmful substances is another possible justification for testing.
5 The states that permit an employer to screen for genetic susceptibility to harmful workplace
6 substances also permit monitoring for exposure provided the employee requests testing, provides
7 informed consent or authorization, and the employer does not terminate the employee or take
8 other adverse action as a result of testing. Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-
9 H:3; N.Y. Exec. Law § 296; Wis. Stat. Ann. § 111.372. In addition, Louisiana authorizes
10 monitoring of biological effects of toxic substances in the workplace if the employee has
11 provided authorization and is notified of the results. La. Rev. Stat. § 23:368. More generally, the
12 definitions and prohibitions in many state's statutes do not appear to restrict monitoring for
13 genetic damage, or are ambiguous on this issue.
14

15 Genetic damage is caused by mutagens, that is, substances that are capable of triggering
16 change in the genetic material of a cell. Genetic damage appears in the form of recessive and
17 dominant mutations, large rearrangements of DNA, point mutations, or loss of genetic material.
18 Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* 71
19 (1990).
20

21 Not all mutations cause disease and the relationship between exposure and health effects
22 is not well understood. Mutagens are often, however, also carcinogens and so cancer is a
23 common result of high exposure levels. But because of the long latency period of cancer it is
24 difficult to establish causal relationships between a mutation and cancer. As a result, monitoring
25 can only provide a gross indication that there have been genetic changes and that disease could
26 follow. Despite this, measurements of genetic damage are used as indicators of exposure based
27 on the rationale that the genetic changes are part of a process that may ultimately produce
28 abnormal growth. *Id.* at 58, 71.
29

30 There are multiple genetic tests for exposure to mutagens at both the chromosomal and
31 molecular level. The most common indicators of chromosomal (cytogenic) damage are
32 chromosomal aberrations (CAs) and sister chromatid exchanges (SCEs). CAs are chromosomes
33 with breakage or rearrangements. *Id.* at 62. CAs are more likely to be induced by ionizing
34 radiation than chemical agents, but there are notable exceptions. For example, vinyl chloride
35 exposure results in increased CAs and places workers at risk of developing a form of liver
36 cancer. Workers exposed to benzene show elevated CAs and are at increased risk of leukemia.
37 *Id.* at 65. Sister chromatids are the two daughter strands of a duplicated chromosome. An
38 exchange results when apparently equivalent sections of the sister chromatids of the same
39 chromosome are switched during cell division. SCE is a sensitive marker for DNA damage and
40 repair that results only from chemical mutagens, not from radiation. *Id.* at 63.
41

42 As of 1990, no occupational studies had directly connected chromosomal abnormalities to
43 increased individual risk for disease. Thus, while CA and SCE monitoring may have predictive

1 value for a group, it is not a reliable way to predict health risks for an individual. *Id.* at 66.
2 Monitoring can, however, be used by employers to reduce exposures to known mutagens to a
3 level that does not affect individuals' chromosome morphology or DNA. Data on CAs are
4 routinely used by regulatory agencies in the process of setting exposure standards for industry.
5 *Id.*
6

7 New techniques that measure exposure to mutagens at the molecular level are being
8 refined. They include measuring the frequency of lymphocytes (T-cells) in which the HPRT
9 gene has been inactivated by mutation; detecting DNA "adducts" (an alteration in which
10 exogenous material is bound to DNA); determining DNA repair (which indicates excision
11 damage); measuring the DNA content of cells as a means to detect tumors (which contain cells
12 with elevated levels of chromosomes); and detecting oncogenes (cancer-causing genes), which
13 can be activated by damage such as translocations, breaks, and deletions of DNA. *Id.* at 66-69.
14 There is a potential that detecting activated oncogenes and DNA adducts may eventually provide
15 a method for predicting disease in asymptomatic individuals. *Id.* at 71.
16

17 This draft recognizes the utility of monitoring in the workplace using such tests, and
18 permits employers to supply genetic testing as part of a genetic monitoring program. Employers
19 may not, however, have access to test results except in the aggregate, non-individually
20 identifiable form prescribed in Section 201(c).
21

22 *Subsection (a)(3) Employee health plan.* An employer that provides preventative health
23 services to encourage a healthy workplace is not restricted from including genetic testing as part
24 of those services. The test results would not be available to the employer unless the employee
25 volunteers them under section 201(a).
26

27 *Subsection (b)(1) and (2) Reporting test results.* This subsection provides for reporting
28 genetic test results to the employee when an employer supplies testing. The reporting obligation
29 is incurred whether or not the employer may obtain the test results under Section 201. An
30 employer must be sensitive, however, to the fact that not all individuals wish to know their
31 genetic information. The draft recognizes an employee's right to decline to know the results of a
32 genetic test. An employee may not wish to be informed of the result because of the
33 psychological burdens that may accompany such knowledge.
34

35 The draft provides for reporting to a health care professional and mandates genetic
36 counseling so that the results can be interpreted for the employee. One unresolved problem is
37 that the term "genetic counseling" does not have the same meaning in all states. There is a legal
38 definition in states that license genetic counselors, but in other states individuals may hold
39 themselves out as providing this service without having to meet minimum standards for the
40 service they provide. The drafters anticipate that employer-provided genetic counseling would
41 be conducted by genetic counseling professionals from outside the employer organization.
42

43 *Subsection (b)(3) Destruction of the sample obtained for testing.* The provision for

1 prompt destruction of a sample obtained for genetic testing supplied by an employer protects the
2 employee’s privacy by preventing subsequent testing of the sample. It follows provisions
3 adopted in New Jersey and Oregon. Alternative approaches (1) put the burden on the employee
4 by requiring that the sample be destroyed promptly on the request of the individual tested or (2)
5 specify that a sample may be retained for a period of time. Some provisions combine elements of
6 more than one approach. In New York, for example, a sample may be retained for ten years if
7 authorized by the individual from whom the sample was obtained.
8

9 *Subsection (c). Authorization.* Under subsection (a), an employer may supply genetic
10 tests under certain circumstances but only with prior authorization of the employee. The term
11 “authorization” is used instead of “informed consent” to avoid confusion with medical practice.
12 Authorization for genetic testing is included in this section rather than with the general
13 provisions in Article 1 because providing testing is relevant only to the employment provisions
14 and the conditions for authorizing genetic testing differ from those in Section 103 for accessing,
15 retaining, or disclosing genetic information.
16

17 The authorization requirements are intended to ensure that employees who agree to
18 genetic tests have adequate information to make a knowing decision and are aware of their
19 options for reporting of test results and help in interpreting them through genetic counseling. As
20 noted above, however, the content and quality of pre-test genetic counseling may vary.
21

22 *Subsection (d) Court-ordered test.* This subsection requires an employer to supply the
23 genetic testing when a court has ordered that an employer may obtain genetic information
24 relevant to a claim or defense in a legal proceeding under Section 201(d).
25

26 **SECTION 203. EMPLOYER’S, EMPLOYMENT AGENCY’S, LABOR**
27 **ORGANIZATION’S, OR LICENSING AUTHORITY’S USE OF GENETIC**
28 **INFORMATION.**

29 (a) An employer, employment agency, labor organization, or licensing authority may use
30 genetic information [or family medical history] obtained in compliance with Sections 201 or 202
31 to:

32 (1) monitor the effects of employees’ exposure to a workplace condition as part
33 of a genetic monitoring program;

34 (2) defend a claim in a judicial, arbitral or administrative agency proceeding in

1 which an employee has placed the employee’s health at issue; or

2 (3) protect the health or safety of others in the workplace from a direct threat
3 indicated by an employee’s genetic information.

4 (b) An employer may use genetic information [or family medical history] obtained in
5 compliance with Section 201 about an employee’s predisposing genetic characteristic that may
6 create susceptibility to harm to the employee from a workplace condition in order to reduce the
7 employee’s exposure to that condition.

8 (c) An employer, employment agency, labor organization, or licensing authority may not
9 take an adverse employment action against an employee based on genetic information [or family
10 medical history] about the employee’s predisposing genetic characteristic that may create
11 susceptibility to harm to the employee from a workplace condition.

12 **Reporter’s Notes**

13
14 Many state statutes limit use of genetic information by prohibiting discrimination among
15 employees or applicants for employment on the basis of genetic information. (Ark, Ill, Kan, LA,
16 Maine, MD, Mass, Mich, MO, Neb, Nev, NJ, NY, NC, OK, OR, RI, SD, Tex). Others more
17 generally ban the use of genetic information in employment. For example, New Mexico’s 2005
18 statute provides simply that “[i]t is unlawful for a person to use genetic information in
19 employment, . . .” In Utah, employers may not take into account genetic information about an
20 individual in connection with an employment decision. Wisconsin and Minnesota prohibit
21 “adverse employment actions” based on genetic information. In Iowa, an employer may not use
22 genetic information to “affect the terms, conditions, or privileges of employment” of a person
23 who gets a genetic test. Iowa Code Ann. § 729.6(2).

24
25 Some states make exceptions to their discrimination prohibition for business necessity,
26 bona fide occupational qualifications (BFOQs) or inability to preform job duties. These are
27 primarily states that use disability or employment discrimination statutes as a vehicle for their
28 regulation of genetics in the workplace, but other states have made this exception as well. (Cal,
29 Hawaii, Maine, Mass, Mich, MO, Neb, NY). In addition, the ADA permits adverse employment
30 decisions against individuals with disabilities when employee safety is endangered. Some states
31 have restricted this exception when it is based on genetic information to the circumstance where
32 an employee voluntarily provides the genetic information. (Mich, Neb).

1 Instead of imposing a prohibition with exceptions that permit some use of genetic
2 information, the draft selectively authorizes ways that an employer may use genetic information
3 in employment decisions about individual employees.
4

5 Note that because the section uses the terms “genetic test” and “genetic information,” it
6 does not necessarily prevent an employer from making decisions based on an employee’s
7 condition or disease that is an expression of a genetic trait. Some employees with genetic
8 conditions would be covered under the ADA if the condition limits a major life activity, but there
9 is no comprehensive protection for individuals with medical conditions that result from genetic
10 traits. While some maintain that attempts to prevent genetic discrimination are mostly
11 meaningless without protection for people who have genetic diseases, *see* Mark A. Rothstein,
12 *Genetic Privacy and Confidentiality: Why They are so Hard to Protect*, 26 J. L. Med. & Ethics
13 181 (1998), others emphasize the difficulties with either policy choice, *see* Henry T. Greely,
14 *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L.
15 Rev. 1483, 1503 (2001).
16

17 *Subsection (a)*. Permitting an employer to use genetic information for a monitoring
18 program or defending a legal proceeding is consistent with the purposes for which an employer
19 may obtain genetic information under section 202. Subsection (a)(3) would permit an employer
20 to act on genetic information provided voluntarily by an employee when there is a direct threat to
21 the health or safety of others in the workplace. This provision is consistent with the ADA, which
22 allows an employer to establish qualification standards that include a requirement that employees
23 shall not pose a “direct threat to the health or safety of other individuals in the workplace.” 42
24 U.S.C. § 12113(b).
25

26 *Subsections (b) and (c) Susceptibility to harm in the workplace*. The current draft
27 follows the lead of the states that permit genetic testing to determine susceptibility only when an
28 employer does not use the information to terminate or take other adverse action against the
29 employee. Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-H:3; N.Y. Exec. Law § 296; Wis.
30 Stat. Ann. § 111.372. If an employee volunteers genetic information about susceptibility to
31 workplace exposures, the draft permits the employer to reduce the potentially harmful exposure,
32 but not to make an employment decision that would adversely affect the employee.
33

34 The way federal statutes would be applied to genetic information that predicts employee
35 susceptibility has not been directly tested in court and is not entirely clear. On one hand, in 1991
36 the United States Supreme Court held that a chemical company’s policy barring women of child-
37 bearing age from employment opportunities that involved exposure to lead violated Title VII
38 prohibitions on gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187
39 (1991). On the other hand, as discussed above, the ADA allows employers to act on health
40 information, even in the case of disability, when there is a direct threat to the health or safety of
41 others in the workplace. In a case that did not involve a genetic characteristic but rather a
42 worker’s liver damage due to exposure to workplace solvents, the United States Supreme Court
43 upheld the Equal Employment Opportunity Commission’s (EEOC’s) regulation interpreting this

1 ADA provision to apply when there is no risk to others but when an employer can show that an
2 individual's disability poses a significant risk of harm to the individual. *Chevron v. Echazabal*,
3 122 S. Ct. 2045 (2002). The implication of this case is that without specific state statutes, an
4 employer may make adverse employment decisions based on genetic screening or monitoring
5 requested by an employee.
6

7 The Brush-Wellman company in Cleveland, Ohio, developed a program (since
8 discontinued) that provides a model for permissible use of screening or monitoring information.
9 Brush-Wellman conducted genetic tests for its employees who work with beryllium, but the
10 testing was voluntary and confidential. Moreover, the test results were provided to the employee,
11 who made the decision on what action to take. The company took no action against the
12 employee as a result of the genetic testing. Cynthia Nance, Paul Miller, & Mark Rothstein,
13 *Discrimination in Employment on the Basis of Genetics*, 6 Employee Rights & Employment
14 Policy Journal 57, 64-65 (2002).
15

16 **SECTION 204. EMPLOYEE'S ACCESS TO GENETIC INFORMATION.** An
17 employee may inspect, request correction of, or obtain the employee's genetic information [or
18 family medical history] from any records of an employer, employment agency, labor
19 organization, or licensing authority that contain the information.

20 **Reporter's Notes**

21
22 This section is based on the conclusion that an employee ought to be able to find out what
23 genetic information an employer knows about an employee and to have the same information. It
24 is based on 16 Del. Code § 1223. It also provides a mechanism for an employee to correct
25 genetic information contained in employer records.
26

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

32 **SECTION 205. EMPLOYER'S, EMPLOYMENT AGENCY'S, LABOR**
33 **ORGANIZATION'S, OR LICENSING AUTHORITY'S RETENTION OF GENETIC**
34 **INFORMATION.**

1 (a) An employer, employment agency, labor organization, or licensing authority may
2 retain an employee's non-personally-identifiable genetic information to use in a genetic
3 monitoring program.

4 (b) Unless an employee authorizes otherwise, when the employee's employment ends the
5 employer, employment agency, labor organization, or licensing authority shall destroy a record of
6 the employee's authorization for the employer, employment agency, labor organization, or
7 licensing authority to supply genetic testing or to obtain, retain, or disclose genetic information.
8 The employee's authorization for the employer, employment agency, labor organization, or
9 licensing authority to supply genetic testing or to obtain, retain, or disclose genetic information is
10 a confidential medical record which the employer, employment agency, labor organization, or
11 licensing authority shall retain or require to be retained separately from the employee's personnel
12 records.

13 (c) An employer, employment agency, labor organization, or licensing authority may not
14 retain an employee's or employee's family member's individually-identifiable genetic
15 information [or family history information] or information about the employee's or employee's
16 family member's request for or receipt of genetic services without prior authorization by the
17 employee. Individually-identifiable genetic information and information about a request for or
18 receipt of genetic services are confidential medical records which the employer, employment
19 agency, labor organization, or licensing authority shall retain or require to be retained separately
20 from the employee's personnel records.

21 **Reporter's Notes**

22 *Subsections (a) Retention for genetic monitoring program.* An employer may retain
23

1 some information without an employee’s specific authorization. An employer may need to retain
2 the genetic information in order to make a monitoring program effective. Since an employer is
3 allowed access to this information only in a form that does not identify individual employees,
4 retention of monitoring information should not affect an employee’s privacy.
5

6 *Subsection (b) Retention of employee authorizations.* An employer may retain records of
7 an employee’s authorization for employer access to genetic information, genetic testing, retention
8 of information, or disclosure of information during the course of the employment relationship.
9 At the end of employment, the default rule is that the employer must destroy these records, unless
10 the employee authorizes the employer to continue to retain the records. Under Section 103, an
11 employee may revoke this authorization at any time.
12

13 *Subsection (c) Retention of individually-identifiable genetic information.* If an employer
14 obtains an employee’s individually-identifiable genetic information or information about use of
15 genetic services under Section 201, it needs the employee’s authorization under Section 103 to
16 retain that information. The separate storage requirement serves to protect the employee’s
17 privacy and is modeled on La. Rev. Stat. § 23:368(B).
18

19 Under Section 103, an employee may revoke this authorization at any time. An open
20 issue is whether an employee’s revocation should be effective for future records only. An
21 employer may need to retain records if there is an ongoing dispute with the employee.
22

23 **SECTION 206. EMPLOYER’S, EMPLOYMENT AGENCY’S, LABOR**
24 **ORGANIZATION’S, OR LICENSING AUTHORITY’S DISCLOSURE OF GENETIC**
25 **INFORMATION.** Except as necessary to defend a claim in a judicial, arbitral, or administrative
26 agency proceeding, an employer, employment agency, labor organization, or licensing authority
27 may not disclose an employee’s personally-identifiable genetic information to a person other than
28 the employee unless the employee authorizes the disclosure.

29 **Reporter’s Notes**
30

31 The draft is consistent with a number of states that have enacted (1) general privacy
32 protections for genetic information that prohibit disclosure without informed consent or
33 authorization (Alaska, Cal, Del, Fla, Maine, Mass, Nev, NH, NJ, NMex, NY, OR) or (2) specific
34 protections against the disclosure of genetic information by employers (Ariz, Fla, LA, Mass,
35 NH, NJ, Or, RI).
36

1 submit claims of unlawful employment discrimination based on use of genetic information to a
2 state agency or the federal Equal Opportunity Employment Commission. States otherwise rely
3 on a mixture of administrative and civil processes, although a few have enacted criminal
4 penalties. Using a state employment discrimination agency may make sense for enforcement of
5 provisions related to employment decisions because such agencies already have the apparatus in
6 place to enforce state civil rights and disability statutes. For privacy violations, however, such
7 agencies do not have expertise in controlling the flow of information and the typical remedies for
8 employment discrimination are not necessarily appropriate for a privacy violation. Enforcement
9 could be turned over to an agency with that expertise, but the drafters wish to avoid the cost of
10 creating and funding a new agency.

11
12 The draft provides alternative enforcement routes for the unauthorized use of genetic
13 information to make an employment determination. An aggrieved individual may elect to file a
14 claim with the state civil rights agency under subsection (b), but is not obligated to wait for a
15 right to sue letter in order to file a civil action under subsection (a). The remedy for a privacy
16 violation is limited to a private civil action.

17
18 Fee and cost shifting is included to compensate prevailing employees for their costs to
19 enforce the statute.

1 **ARTICLE 3**

2 **HEALTH INSURANCE**

3 **SECTION 301. HEALTH INSURER’S ACCESS TO GENETIC INFORMATION.**

4 (a) A health insurer that receives a claim for payment under a health-insurance policy
5 may request:

6 (1) genetic information and family medical history regarding the need for a
7 genetic test, but not the results of the test, if genetic testing or genetic counseling is the service
8 for which the claim is made; or

9 (2) the portion of genetic information [or family medical history] necessary to
10 determine the insurer’s obligation to pay for health-care services when the reason for rendering
11 the services is a genetic condition or predisposing genetic characteristic.

12 (b) In determining eligibility for health-insurance coverage and in setting rates, terms,
13 and conditions for a health-insurance policy, a health insurer may not:

14 (1) require or request an insured or an insured’s family member to take a genetic
15 test;

16 (2) require or request an insured’s or an insured’s family member’s genetic
17 information; or

18 (3) inquire whether an insured or an insured’s family member has taken or
19 refused to take a genetic test.

20 **Reporter’s Notes**

21
22 *Applicability.* The draft is meant to apply broadly to health insurance, whether issued on
23 an individual, group, or other basis. This article closes the gaps left by HIPAA, which applies
24 only to small group and individual coverage. In addition to individual and group health

1 insurance policies, some state statutes reference health insurance issued on a franchise or blanket
2 basis. These forms of health insurance are also subject to this article.

3
4 The drafting committee intends that this article also applies to employee welfare plans
5 unless there is a controlling judicial decision that the article is preempted by the Employee
6 Retirement Income Security Act of 1974 (ERISA), 29 U.S.C. § 1001 et seq. Federal preemption
7 is relevant because the United States Supreme Court has held that ERISA applies to employee
8 benefit plans such as health insurance as well as to pension plans. *Inter-Modal Rail Employees*
9 *Ass'n v. Atchison, Topeka and Santa Fe Ry. Co.*, 520 U.S. 510 (1997). The United States
10 Supreme Court has recognized three types of preemption under ERISA that are relevant to this
11 draft act: express, complete, and conflict preemption.

12
13 In order to simplify the administration of plans by ensuring that they are subject to only
14 one set of regulations, ERISA expressly preempts state regulation of the administration of
15 employee benefit plans to the extent those regulations “relate to” employee benefit plans. 29
16 U.S.C. § 1144(a). The statute contains a savings clause, however, that saves laws that regulate
17 insurance from ERISA preemption. 29 U.S.C. § 1144(b)(2)(A). The issue of whether state
18 regulations are preempted by ERISA has led to extensive litigation.

19
20 Recently, the United States Supreme Court clarified the application of the savings clause.
21 In order to fall under ERISA’s savings clause, a state law must first be “specifically directed
22 toward” the insurance industry. *Kentucky Ass’n of Health Plans, Inc. v. Miller*, 123 S. Ct. 1471,
23 1475 (2003). Laws of general application that merely have “some bearing on insurers” do not
24 fall under the clause. *Id.* Second, the ERISA provision saves state laws that regulate
25 “insurance,” not “insurers,” so a law must regulate insurers “with respect to their insurance
26 practices.” *Id.* A state law regulates an insurer with respect to insurance practices if it controls
27 the terms of insurance policies, *id.* at 1476, or if it “substantially affect[s] the risk pooling
28 arrangement between the insurer and the insured,” *id.* at 1477.

29
30 The preemption question is further complicated by that fact that ERISA also contains
31 what is referred to as the “deemer clause,” which creates an exception to the savings clause. It
32 provides that “neither an employee benefit plan . . . nor any trust established under such plan,
33 shall be deemed to be an insurance company or other insurer . . . for purposes of any law of any
34 State purporting to regulate insurance companies . . .” 29 U.S.C. § 1144(b)(2)(B). The United
35 States Supreme Court has interpreted the deemer clause to exempt self-funded (i.e. uninsured)
36 health plans from the savings clause. Thus the Court concluded that “self-funded ERISA plans
37 are exempt from state regulation insofar as that regulation ‘relate[s] to’ the plans.” *FMC Corp. v.*
38 *Holliday*, 498 U.S. 52, 61 (1990).

39
40 The distinction in *FCM Corp.* between insured and self-insured health plans has not been
41 overruled and continues to be applied by lower courts. *See, e.g., Daly v. Marriott International,*
42 *Inc.*, 415 F.3d 889 (8th Cir. 2005) (“deemer clause” of ERISA preemption provision exempted
43 employer funded health plan from application of state mental-health parity law); Blue Cross Blue

1 Shield of Alabama v. Sanders, 138 F.3d 1347 (11th Cir. 1998).

2
3 The second type of ERISA preemption may affect the draft’s enforcement provisions.
4 “Complete preemption” occurs when Congress has “so completely [preempted] a particular area
5 that any civil complaint raising this select group of claims is necessarily federal in character.”
6 *Metropolitan Life Ins. Corp. v. Taylor*, 481 U.S. 58, 63-64 (1987). In *Taylor*, the United States
7 Supreme Court held that the civil enforcement provision of ERISA, 29 U.S.C. § 1132(a),
8 completely preempts common law breach of contract and tort claims for wrongful termination of
9 disability benefits. See also *Prudential Ins. Co. of Amer. v. Nat’l Park Med. Center, Inc.*, 413
10 F.3d 897 (8th Cir. 2005) (with respect to suits that could be brought under ERISA, civil
11 enforcement provision preempts Arkansas Patient Protection Act civil penalties).

12
13 Third, “conflict preemption” also comes into play with civil remedies. The United States
14 Supreme Court has held that Congress intended to make the ERISA civil enforcement remedy
15 exclusive and that therefore a state-law cause of action that “duplicates, supplements, or
16 supplants” the ERISA civil remedy conflicts with congressional intent. *Aetna Health, Inc. v.*
17 *Davila*, 452 U.S. 200, 208 (2004) (Texas statute that created a cause of action against HMOs for
18 failure to exercise ordinary care in handling coverage decisions preempted). See also *Hawaii*
19 *Management Alliance v. Ins. Comm’n*, 100 P.3d 952 (Haw. 2004) (statute providing attorney’s
20 fees and costs for external review of insurer’s denial of coverage preempted by conflict with
21 ERISA).

22
23 *Subsection (a) Claims processing.* This subsection highlights the potential role for
24 genetic information in providing payment for genetic tests and health care services. First, genetic
25 information such as family history may be necessary for preauthorization for a genetic test or
26 service or for approval of payment for a genetic test or service. Second, health care services may
27 be medically justified by a predisposing genetic characteristic or a genetic condition. In this
28 context, genetic “condition” should be interpreted broadly to include the full range of health
29 effects influenced by a genotype, including a disease or disorder.

30
31 This subsection is modeled on a Utah provision.

32
33 *Subsection (b) Coverage decisions.* This subsection prohibits a health insurer from
34 requiring genetic tests or obtaining genetic information for uses associated with the issuance of
35 insurance, which in the current draft are prohibited in Section 302(c).

36
37 For health insurers such as HMOs, which also provide health care services, access to
38 genetic information for functions that involve determining eligibility and terms of insurance need
39 to be separated from access for health care provider functions. These insurers may provide
40 genetic tests to patients for therapeutic purposes as part of the practice of medicine, but not as
41 part of determining eligibility for insurance or for underwriting. Conditions for access to and use
42 of genetic information for diagnosis or treatment are not covered by this draft because those uses
43 constitute the practice of medicine.

1 There are many alternative approaches to regulating the use of genetic information in
2 health insurance. Some other states take an approach like that of HIPAA and use a non-
3 discrimination provision that prohibits higher premiums than those charged to similarly situated
4 individuals. (Alaska, Ark, Ill, Iowa). Yet other states prohibit the use of genetic information for
5 underwriting health insurance without actuarial justification. (Ariz, WVa). In some states, use
6 of genetic information for risk selection is permitted if an individual submits the information
7 voluntarily or if the information is favorable to the individual. (Ill, Ind, Mass, Mo, NY). Yet
8 other states regulate this use by prohibiting insurers from increasing policy rates based on genetic
9 information. (Md, Mont, Or, Tex).

10
11 This section illustrates some of the problems with treating genetic information as a
12 distinct category of medical information. First, the section offers less protection than HIPAA in
13 terms of eligibility decisions for individual and small group coverage because it regulates use of
14 genetic information only, not information on all medical conditions. Second, it is often
15 permissible for insurers to consider existing medical conditions in determining coverage and
16 premiums under other law so long as they treat like situations alike. This section would impose a
17 different standard by prohibiting consideration of conditions revealed by a genetic test, thus
18 raising the practical question of which conditions are “genetic.” Even conditions with a genetic
19 component are rarely entirely “genetic.”

20
21 A major policy question for the drafting committee is whether health care insurers should
22 be prohibited from denying coverage or offering less favorable terms based on an applicant’s
23 manifest genetic disease or only on an applicant’s predisposing genetic characteristics. An
24 argument can be made that protection for genetic information as defined in this draft is too wide.
25 As discussed above, the prohibition would create a different standard for genetic illnesses than
26 for other medical conditions. Some analysts maintain that attempts to prevent genetic
27 discrimination are mostly meaningless without protection for people who have genetic diseases.
28 *See* Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why They are so Hard to Protect*,
29 26 J. L. Med. & Ethics 181 (1998). Others think that this would place too great a burden on
30 insurers. *See, e.g.,* Henry T. Greely, *Genotype Discrimination: The Complex Case for Some*
31 *Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1503 (2001). An alternative consistent with the
32 latter position would be to limit the restrictions to predictive information by substituting
33 “predisposing genetic characteristic” for “genetic information” in subsection (c).

34
35 There is no separate section on retention of genetic information by health insurers. The
36 drafting committee endorsed the concept that genetic information retained by health insurers
37 should comply with the HIPAA requirements for retention of health care records. Because health
38 insurers are considered “health plans,” they are covered entities subject to the HIPAA
39 requirements, so a separate provision would be redundant.

40
41 **SECTION 303. HEALTH INSURER RETENTION OF GENETIC**

1 **INFORMATION.** A health insurer that retains genetic information shall comply with the terms
2 of the regulations issued by the United States Department of Health and Human Services
3 pursuant to the Health Insurance Portability and Accountability Act of 1996, 45 C.F.R. Part 160;
4 Part 164 Subparts A & E, as if the information were covered by that Act.

5 **Reporter's Notes**
6

7 This section extends the protections of HIPAA to all genetic information retained by
8 health insurers, whether covered by HIPAA or not. The health insurers that would be brought
9 under HIPAA's Privacy Rule by this provision are employer-sponsored group health plans with
10 less than 50 participants that are administered solely by the employer that established and
11 maintains the plan. The drafting committee noted that it would consider deleting this section.
12

13 **SECTION 304. HEALTH INSURER'S DISCLOSURE OF GENETIC**
14 **INFORMATION.**

15 (a) A health insurer may disclose an insured's genetic information to a person other than
16 the insured if the health insurer has obtained the insured's authorization.

17 **Reporter's Notes**
18

19 This section conditions the disclosure of an insured's genetic information on the
20 authorization of the insured. In some jurisdictions, however, health care providers may have a
21 common-law duty to inform others of a genetic disorder. This case law may require disclosure
22 by a health insurer without the insured's consent.
23

24 New Jersey's court has recognized a physician's duty to warn those "known to be at risk
25 of avoidable harm from a genetically transmissible condition." *Safer v. Pack*, 677 A.2d 1188
26 (N.J. Super. Ct. App. Div. 1996). The defendant in the case was the physician who had treated
27 the plaintiff's father for colorectal cancer that led to the father's death when the plaintiff was a
28 child. The plaintiff inherited multiple polyposis, an inherited condition that if undiscovered and
29 untreated, leads to metastatic colorectal cancer. The court found a duty to "take reasonable
30 steps" to warn that "extends beyond the patient to members of the immediate family of the
31 patient who may be adversely affected by a breach of that duty." It noted, but did not determine,
32 the issue that would arise if the father had instructed the doctor not to disclose details of the
33 illness or the genetic risk. In that event, it would be necessary to resolve the conflict between
34 physician-patient confidentiality and the duty to warn.

1 Minnesota has also recognized a duty regarding genetic testing and diagnosis that reaches
2 beyond the patient. The plaintiff alleged that her daughter’s physicians were negligent in failing
3 to diagnose a genetic disorder in the daughter that led the mother to conceive another child with
4 the same genetic disorder. *Molloy v. Meier*, 679 N.W.2d 711 (Minn. 2004). The court noted that
5 genetic testing and diagnosis affect not only the patient, but can benefit or harm both the patient
6 and her family. The Fragile X disorder is one that physicians ordinarily report to parents and it
7 was foreseeable that a negligent diagnosis of the disorder would cause harm to the family as well
8 as the patient. The court held that the duty to warn extends to “biological parents who
9 foreseeably may be harmed by a breach of that duty.” It did not consider whether it should
10 extend to additional family members.

11
12 The Florida Supreme Court has similarly held there is a duty to warn of the likelihood
13 that a condition was inherited by a patient’s children but, in contrast to the Minnesota and New
14 Jersey courts, it found that the duty is satisfied by warning the patient. *Pate v. Threlkel*, 661
15 So.2d 278 (Fla. 1995). The court observed that a patient can normally be relied upon to pass on
16 the warning and emphasized the heavy burden that would be entailed in seeking out and warning
17 family members.

18
19 Requirements for an authorization to disclose are contained in Section 103.
20

21 **SECTION 305. REMEDIES; ENFORCEMENT; LIMITATIONS OF ACTIONS.**

22 (a) No later than two years after an individual discovers an alleged violation of this
23 [article] or a person exercising reasonable care should have discovered an alleged violation of
24 this [article], an aggrieved individual may file a civil action with the court.

25 (b) A violation of this [article] shall constitute a violation of [the State unfair practices
26 insurance law]. An individual who is aggrieved by an alleged violation of this [article] may seek
27 enforcement by the [State Commissioner of Insurance].

28 (c) A court that finds a violation of this [article] may award compensatory damages,
29 injunctive relief, including expungement of records, or any other remedy the court finds
30 appropriate. The court shall award a prevailing insured reasonable attorneys fees and costs
31 unless justice requires otherwise.

1 **Legislative Note:** States should insert for [State Commissioner of Insurance] the appropriate
2 title of this department. [The State unfair practices insurance law] should be replaced with the
3 title of the relevant statute.
4

5 **Reporter's Notes**

6
7 Many state statutes that prohibit discrimination in health insurance based on genetic
8 testing or information declare that a violation is an unfair and deceptive insurance act or practice
9 under the state insurance code. They often provide that the State Commissioner of Insurance
10 shall enforce the prohibitions.
11

12 This draft concerns privacy as well as discrimination or misuse of genetic information in
13 insurance. It provides a private right of action for an aggrieved individual. Alternatively, an
14 aggrieved individual may seek enforcement through the State Commissioner of Insurance.
15

16 As in the case of the remedies for privacy violations in the employment context, the
17 drafting committee may want to consider whether statutory damages would be appropriate for a
18 violation of privacy interests.

1 **ARTICLE 4**

2 **LIFE, DISABILITY-INCOME, AND LONG-TERM-CARE INSURANCE**

3 **SECTION 401. INSURER’S ACCESS TO GENETIC INFORMATION.**

4 (a) An insurer may not request or require an insured or an insured’s family member to
5 take a genetic test in connection with the provision of life, disability-income, or long-term-care
6 insurance.

7 (b) An insurer may not request or require an insured or an insured’s family member to
8 provide genetic information or information about genetic services in connection with the
9 provision of life, disability-income, or long-term-care insurance.

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

12 (d) An insurer may access an insured’s genetic information in connection with the
13 provision of life, disability-income, or long-term-care insurance if the insured voluntarily submits
14 the genetic information to the insurer. If an insured voluntarily submits genetic information
15 retained by a source other than the insured, the insured shall authorize the disclosure as provided
16 in Section 103.

17 **Reporter’s Notes**

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

26
27 The justification for including life, disability-income, and long-term-care insurance in a

1 separate article from health insurance is that these insurance policies tend to be viewed as
2 financial products that are less necessary than health insurance. There are arguably, however,
3 policy rationales for treating each of the three types of insurance differently. Unlike life
4 insurance, disability-income and long-term-care insurance are increasingly viewed as a necessary
5 adjunct to health insurance and many states regulate disability-income and long-term-care
6 insurance as health insurance. In addition, underwriting principles differ among the three types
7 of insurance. Life insurance underwriting is concerned with mortality and uses life expectancy
8 tables. In contrast, disability-income underwriting is concerned with morbidity and long-term-
9 care underwriting is a hybrid process.

10
11 In general, this subsection limits access to genetic information by insurers that provide
12 life, disability-income, or long-term-care insurance. The limitations are based on the philosophy
13 that insurers may continue current information gathering practices, but may not at this time
14 expand their collection of genetic information. It is the drafting committee's understanding that
15 life, disability-income and long-term-care insurers do not at present require applicants to take
16 genetic tests, but do collect family history information for use in determining eligibility and in
17 underwriting.

18
19 The arguments for restricting access to genetic information by the insurance industry are
20 that this information is particularly private and its predictive power is easily exaggerated. There
21 are privacy concerns with commercial access to sensitive genetic information and predictions that
22 individuals will avoid genetic testing for fear of adverse effects on their insurability. There is
23 also a possibility that insurers may require applicants to take genetic tests and then deny
24 insurance or charge more based on genetic characteristics, unfairly making coverage unavailable
25 to people who are not sick and never will become sick. From the industry perspective, as with
26 health insurance, insurers worry about adverse selection. If applicants seek coverage because a
27 genetic characteristic exposes them to risk, but the insurer does not have this information, this
28 puts the insurer at a financial disadvantage. *See generally* Mark A. Rothstein, ed., *Genetics and*
29 *Life Insurance: Medical Underwriting and Social Policy* (2004).

30
31 A 1997 study by the Human Genetics Advisory Commission in the United Kingdom
32 concluded that it is unlikely that actuarially-sound genetic predictions of adult death will be
33 validated and available anytime in the near future. Genetic tests need to be connected to medical
34 and epidemiological research to establish what consequences for health and life-span can be
35 inferred from a given genetic test. The Commission concluded that a requirement to disclose
36 genetic tests as a condition of obtaining insurance would be acceptable only after research has
37 established an association between a given pattern of test results and life events that are relevant
38 for the insurance product. It recommended continuing a moratorium on requiring test results.
39 Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance*
40 (1997).

41
42 *Subsection (a) Genetic testing.* This subsection prohibits life, disability-income and
43 long-term-care insurers from requiring applicants to have genetic testing. It is consistent with the

1 moratorium recommended by the UK Human Genetics Advisory Commission because there is no
2 research establishing an association between a pattern of genetic test results and life events
3 relevant to insurance coverage. The subsection is also consistent with genetic testing
4 prohibitions in force in California, Massachusetts, and Vermont. *See* Cal. Ins. Code § 10233.1
5 (long-term-care insurance); Mass. Gen. L. Ann. 175 § 120E (life insurance); Mass. Gen. L. Ann.
6 175 § 108I (disability and long-term-care insurance); Vt. Stat. Ann. § 9334 (any insurance).

7
8 *Subsection (b) & (c) Genetic information and family history.* These subsections limit the
9 extent to which an insurance company may access genetic information or the results of genetic
10 testing through means other than requiring a test. If the drafting committee adopts Alternative B
11 for the definition of genetic information, subsection (b) prohibits insurers only from asking
12 applicants to provide information about genetic test results and access to genetic services.
13 Subsection (c), moreover, explicitly permits insurers to seek information about family medical
14 history, which they have traditionally used for underwriting. These provisions are is similar to
15 Kentucky’s regulation of disability-income insurers. Ky. Rev. Stat. Ann. § 304.12-085(3).

16
17 *Subsection (d) Voluntary disclosure.* Under this subsection, a life, disability-income or
18 long-term-care insurer does not violate the statute if an applicant for insurance reveals
19 information about genetic testing to the insurer.

20
21 Genetic testing data could be revealed directly by an applicant or could be contained in
22 the applicant’s medical records. The draft currently requires an applicant to authorize disclosure
23 by the custodian of the medical record and, under Section 103, the authorization must itemize the
24 genetic information, its potential uses and to whom it may be disclosed. This differs from the
25 current practice by which genetic information would become available to an insurer based on an
26 applicant’s standard authorization for access to medical information. In order for a separate
27 authorization to provide effective protection, genetic information would need to be segregated in
28 medical records, so that it could be withheld if its disclosure is not authorized. This is currently
29 done for mental health information, which is kept in separate files and may not be disclosed
30 without a special authorization. Medical records are not currently organized in a way that would
31 make it possible to segregate genetic data easily.

32 33 **SECTION 402. INSURER’S USE OF GENETIC INFORMATION.**

34 (a) An insurer may not use genetic information about an insured’s predisposing genetic
35 characteristics to determine eligibility or rates, terms, and conditions for disability-income or
36 long-term-care insurance.

37 (b) Except as otherwise provided in subsection (c) or prohibited by law, an insurer may

1 use genetic information about an insured's predisposing genetic characteristics to determine
2 eligibility, and rates, terms, and conditions for life insurance if the insured submits the genetic
3 information to the insurer. The insurer may not use a family member's genetic test for these
4 purposes.

5 (c Alternative A) Unless the [State Commissioner of Insurance] determines, in
6 consultation with the [State Department of Public Health], that research has established that
7 genetic information reliably relates to an insured's mortality, the use of a genetic information
8 about an insured's predisposing genetic characteristics to determine eligibility, and rates, terms,
9 and conditions for life insurance shall constitute unfair discrimination in violation of [State unfair
10 practices insurance law] . An insurer may petition for a determination under this subsection and
11 the [Commissioner] may, in consultation with the [State Department of Public Health], issue an
12 advisory opinion on whether a genetic test or pattern of test results provides reliable information
13 relating to an insured's mortality, based on sound actuarial principles or actual or reasonably
14 anticipated claim experience. An insurer may petition for a new hearing to update the advisory
15 opinion after two years from the date of the opinion.

16 (c Alternative B) Unless a geneticist or genetic counselor determines that a positive
17 genetic test or pattern of test results is reliably associated with an increased medical risk of
18 mortality and certifies the magnitude of the increase in risk, the use of a genetic information
19 about an insured's predisposing genetic characteristics to determine eligibility or rates, terms, or
20 conditions for life insurance shall constitute unfair discrimination in violation of [State unfair
21 practices insurance law].

22 ***Legislative Note:*** States should insert for [State Commissioner of Insurance] and [State

1 *Department of Public Health] the appropriate titles of these departments. [State unfair*
2 *practices insurance law] should be replaced with the title of the relevant statute.*

3 4 **Reporter's Notes**

5
6 The determination of eligibility for coverage includes decisions made in connection with
7 the offer, sale, continuation, or renewal of an insurance policy. The determination of rates,
8 terms, and conditions includes establishing premiums, limiting coverage, limiting or conditioning
9 benefits, or making any other underwriting decisions.

10
11 To illustrate two possible approaches, either of which would be consistent with Section
12 401, subsections (a) and (b) distinguish the use of genetic information for disability-income and
13 long-term-care insurance from its use for life insurance. The rationale for separating disability-
14 income and long-term-care insurance from life insurance is that while all three forms of
15 insurance are financial products, disability-income and long-term-care insurance are closer to the
16 purposes behind health-care insurance. Many states recognize this distinction in their structure
17 for insurance regulation by grouping income-disability and long-term-care insurance with health
18 insurance.

19
20 *Subsection (a). Disability-income and long-term-care insurance.* This subsection
21 prohibits the use of genetic information for determining eligibility or underwriting of disability-
22 income and long-term-care insurance. Traditional insurance underwriting has been based on
23 medical histories and tests that indicate existing medical conditions. It would be new to use
24 predictions based on predisposing genetic characteristics that have not been expressed as a
25 disease or condition.

26
27 The subsection is based on the treatment of these disability-income and long-term-care
28 insurance in Arizona, Colorado, and Kansas. Colo. Rev. Stat. § 10-3-1104.7(3)(b) (group
29 disability-income & long-term-care); Kan. Stat. Ann. § 40-2259(d) (disability-income & long-
30 term-care). Because the restriction on the use of genetic information includes information from
31 genetic testing of a blood relative, the subsection is also consistent with the law in Oregon and
32 Vermont, which prevent insurers from using any genetic information about a blood relative for
33 either eligibility or underwriting. Or. Rev. Stat. § 746.135; Vt. Stat. Ann. tit. 18, § 9334(a).
34 Arizona has restriction that is somewhat narrower than the draft in that it permits disability-
35 income and long-term-care insurers to use genetic information if there is an actual diagnosis of a
36 genetic condition. Ariz. Rev. Stat. Ann. § 20-448(F).

37
38 If the drafting committee adopts the Alternative B for the definition of “genetic
39 information,” an insurer would be able to use genetic information revealed by an individual’s
40 family medical history to determine eligibility or to underwrite. One member of the
41 subcommittee raised the question of whether there should be any limits on insurers’ use of family
42 medical history. The question was motivated by a concern that even if disclosures to insurers do
43 not change, insurers may be able to do more with those disclosures using ever more sophisticated

1 computer technology. The drafting committee may want to consider whether it is desirable to
2 prevent new uses of family history information that may become possible and if so, what limits
3 would be appropriate.
4

5 *Subsection (b). Life insurance.* This subsection permits life insurers' use of information
6 on an insured's predisposing genetic characteristics to predict risk if the information is obtained
7 in compliance with Section 401. This information must be used in accordance with other state
8 law, which usually prohibit discrimination among insureds as "unfair discrimination" unless it is
9 based on actuarial projections or actual or reasonably anticipated experience.
10

11 As with the disability-income, and long-term-care insurance decisions governed by
12 subsection (a), this subsection prohibits the use of genetic tests of family members as a basis for
13 life insurance determinations. The provision is based on an Oregon provision that prohibits
14 insurers from using genetic test results for a blood relative to deny insurance coverage, increase
15 rates, or affect terms and conditions. Or. Rev. Stat. § 746.135. Vermont has a similar restriction
16 prohibiting insurers from conditioning or underwriting a policy on the results of testing of a
17 family member, unless the test results are contained in the applicant's medical record. Vt. Stat.
18 Ann. §§ 4724(22), 9334(a).
19

20 *Subsection (c).* The subcommittee offers two alternatives to provide assurances that
21 insurance companies that are permitted to use genetic information do not misuse it. Both
22 alternatives are designed to protect against the premature or improper use of predictions based on
23 genetic information. The risk of misuse is increasing because of the explosion of genetic tests
24 available, the general lack of governmental oversight for these tests, and common misperceptions
25 about the extent to which a genetic test can predict a future medical disease or condition. In
26 addition, the pathways for gene expression remain uncertain. Links between most genetic
27 characteristics and the incidence of disease are extremely complex and depend on the
28 interrelation of many factors, both genetic and environmental.
29

30 Even with draft's restrictions on genetic testing by insurance companies, access to genetic
31 information in medical records will increase. More than 1,000 genetic tests are available
32 clinically as of early 2007; hundreds more are available to researchers. Some are marketed
33 directly to consumers with claims that they can be used to individually customize vitamins and
34 diet as well as test for disease. There is no government oversight of the validity of the tests used
35 for research or available through medical professionals.
36

37 The insurance industry has expressed a view that its use of genetic information must be
38 able to develop with the rapid development of knowledge in the genetic field. Both alternatives
39 provide a mechanism that will allow use of genetic information to evolve in response to new
40 scientific information that may justify the use of genetic information for eligibility and
41 underwriting determinations.
42

43 Alternative A provides a means for regulatory oversight of the use of genetic information

1 by insurers. Rather than allowing insurers to use genetic information subject to a challenge that
2 this use constitutes an unfair practice, Alternative A requires a threshold finding that there is a
3 reliable relationship between a predisposing genetic characteristic and the incidence of mortality.
4 It places the responsibility for assessment of scientific information about genetic risks on state
5 insurance regulators, but acknowledges their need for additional expertise by stipulating that they
6 must consult with experts in the department of public health. The process would allow an
7 insurer's use of genetic information to change as research develops reliable connections between
8 genetic characteristics and risk of mortality by permitting insurers to petition state regulators for
9 a determination or a new determination when they believe that use of genetic information can be
10 justified.

11
12 Alternative B leaves the determination that there is a reliable relationship between genetic
13 information and mortality to the insurance companies. A check is provided through the
14 requirement that a geneticist or genetic counselor must be involved in the process. This expert
15 would not make actuarial determinations, but would evaluate the medical literature to determine
16 the accuracy and completeness of the data an actuary proposes to use and the reliability of the
17 prediction possible with the genetic information.
18

19 **SECTION 403. INSURER'S RETENTION OF GENETIC INFORMATION.**

20 (a) A life, disability-income, or long-term-care insurer may retain a record of an insured's
21 authorization for the insurer to obtain, retain, or disclose genetic information.

22 (b) An insured's genetic information or information about an insured's request for or
23 receipt of genetic services is a confidential medical record that a life, disability-income, or long-
24 term-care insurer may retain only with prior authorization of the insured.

25 **Reporter's Notes**

26
27 This section permits insurers to retain genetic information under certain circumstances. It
28 follows the practice of the states with statutes that require authorization or informed consent for
29 the retention of genetic information which do not treat life, disability, or long-term-care insurers
30 differently than others who might retain such information. Other states, however, exempt these
31 insurers from their requirements for authorization or informed consent. (E.g., Mass., Nev., NH,
32 NMex, Ok)
33

34 There are arguments that insurers should not be limited in retaining genetic information.
35 They typically have two years to rescind a policy for misrepresentation, and may need the
36 information submitted with the application in order to show misrepresentation. In addition,

1 reinsurers may audit underwriting practices several years after a policy issues. Insurance industry
2 representatives state that under current practice, information is retained indefinitely because of
3 the risk of class action suits.
4

5 **SECTION 404. INSURER’S DISCLOSURE OF GENETIC INFORMATION.**

6 (a) A life, disability, or long-term-care insurer may disclose an insured’s genetic
7 information if the insurer has obtained the insured’s prior authorization for the disclosure.

8 (b) An insured may upon request inspect and obtain genetic information from the life,
9 disability, or long-term-care insurer’s records on the insured.

10 (c) If an insured’s genetic information is used to make an adverse determination
11 regarding eligibility or rates, terms, or conditions for life insurance, the insurer shall provide
12 notice to the insured. The insured may choose to repeat a genetic test to verify the analysis used
13 in the adverse determination. If the first analysis is found to be inaccurate, the insurer shall
14 reconsider the adverse determination.

15 **Reporter’s Notes**

16
17 *Subsection (a).* This subsection is drafted to allow the committee to consider whether the
18 ability of life, disability-income, and long-term-care insurers to disclose genetic information
19 should be restricted. The insurance industry argues that a special disclosure provision for genetic
20 information is unnecessary because of the number of states that have adopted statutes based on
21 National Association of Insurance Commissioners’ model laws dealing with general privacy of
22 information.
23

24 *Subsections (b) & (c).* Under these subsections, an insured is allowed to access his own
25 records and is provided an opportunity to correct mistakes in genetic information. The
26 subsections are modeled on Florida procedures which require the DNA analysis to be repeated in
27 the event of an adverse determination. Fla. Stat. § 760.40(3). Delaware also has a special
28 provision that allows an individual to access his genetic records and to correct those records. 16
29 Del. Code Ann. § 1223.
30

31 **SECTION 405. REMEDIES; ENFORCEMENT; LIMITATIONS OF ACTIONS.**

1 (a) No later than two years after an individual discovers an alleged violation of this
2 [article] or a person exercising reasonable care should have discovered an alleged violation of
3 this [article], an aggrieved individual may file a civil action with the court.

4 (b) A violation of this [article] shall constitute a violation of [the State unfair practices
5 insurance law]. An individual who is aggrieved by an alleged violation of this [article] may seek
6 enforcement by the [State Commissioner of Insurance].

7 (c) A court that finds a violation of this [article] may award compensatory damages,
8 injunctive relief, including expungement of records, or any other remedy the court finds
9 appropriate. The court shall award a prevailing insured reasonable attorneys fees and costs
10 unless justice requires otherwise.

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

14 **Reporter's Notes**

15 This section is identical to the enforcement provision for health insurance.
16
17

1 **ARTICLE 5**

2 **MISCELLANEOUS PROVISIONS**

3 **SECTION 501. 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 502. 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 503. EFFECTIVE DATE.** This [act] takes effect