

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 September 8-10, 2006

WITH PREFATORY AND REPORTER'S NOTES

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August 15, 2006

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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). One might also add an additional goal 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 by an individual’s genetic sequence. These are the diseases that 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

genetics 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 toigmatize.

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 form 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

Many contend that genetic information has few appropriate uses in the workplace. The concern is that if employers are permitted 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 (HIPPA) protects employees against discrimination in group 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 the legislation 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.

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

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. The 1996 Health Insurance Portability and Accountability Act (HIPPA) partially addresses the use of genetic information in health insurance. It covers only insurers providing group health insurance for 50 or more individuals. Under HIPPA, an insurer may not deny an applicant coverage as a result of a health-status related factor, including genetic information. The law also prohibits exclusions for pre-existing conditions on the basis of a genetic predisposition to a particular condition. However, employers may restrict coverage, restrict benefits, or charge higher premiums so long as they treat like individuals alike.

The HIPPA 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. In addition, there is no federal provision on the use of genetic information in health insurance for employees covered by self-insured health plans, which are used by most large employers. These plans are subject to the federal Employee Retirement Income Security Act (ERISA), which preempts state regulation of employer sponsored welfare benefit plans.

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.

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. (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 because a smaller proportion of the market consists of group coverage for these types of insurance. This means that insurers take individual characteristics into account in determining risk and use this risk calculation in determining an individual's premium rates and terms and conditions for coverage and benefits. Individual underwriting could be done more accurately when an insurer has access to genetic information if that genetic information can be used to predict the likelihood of claims accurately.

The argument for restricting access to genetic information 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. On the other side, 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 solution adopted by many of the states that regulate in this area is to require an actuarial justification for the use of genetic information in determining eligibility and in underwriting. There are questions, however, about whether there is a sufficient scientific basis for assessing risk. 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 and 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 Statutes

Eighteen states have legislation regulating genetic testing or the use of genetic

information in life, disability or long-term care insurance. Of these 18 states, only eight have provisions that apply to all three types of coverage. Sixteen statutes that pertain to life insurance, 16 apply to disability insurance, and nine cover long-term care insurance. While many of the other states are silent on genetic information in the context of these types of insurance, some make clear that their restrictions on the use of genetics in health insurance do not apply to other insurance. (Ga, Ind, NH, OK, RI, Tex).

In the life insurance category, several of the states forbid insurers from requiring genetic tests and regulate the terms under which an insurer may disclose the results of voluntary tests. (Cal, Mass, Minn, NY, Or, Vt). Other states require an actuarial justification for using genetic information in denying coverage or underwriting, which means the insurer must be able to demonstrate a significant difference in claims due to a particular genetic condition. (Ariz, Kan, Maine, Md, Mass, Mont, NJ, Nmex, Vt, Wis). Florida and North Carolina prohibit discrimination based on the sickle cell trait.

Provisions are similar among the states that regulate disability insurance. States tend to prohibit insurers from requiring tests (Cal, Mass, Or), restrict use of information for eligibility and underwriting (Kan, Wy), or require actuarial justification for underwriting discrimination (Ariz, Maine, Mass). A few states impose conditions similar to those more commonly applicable to health insurance. They prohibit insurers from rejecting applicants for disability insurance (Arizona) or imposing limitations on coverage for pre-existing conditions (Idaho, Wyoming) on the basis of a genetic characteristic unless it has resulted in a diagnosed condition.

The pattern of regulation is similar, but less common, for long-term care insurance. Some states prohibit insurers from requiring genetic tests (Cal, Mass, Or, Vt) or require an actuarial justification for the use of genetic information in underwriting (Kan, Maine, Mass, Mont, NMex).

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

3
4 **ARTICLE 1**

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

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

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

12 (2) “Employee” means an individual who is applying to work for hire or who works for
13 hire, including an independent contractor or an individual employed in a supervisory, managerial,
14 or confidential position.

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

17 (4) “Family member” means an individual’s spouse or [partner], an individual’s
18 dependent child, and all individuals related by blood to the individual, spouse or [partner], or
19 dependent child.

20 (5) “Genetic information” means information based on an individual’s genetic tests, the
21 genetic tests of an individual’s family member, or an individual’s family member’s history of a
22 genetic disease or disorder.

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

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

6 (8) “Genetic test” means an analysis of human genetic material that detects a genotype or
7 genetic marker.

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

10 (A) insurance that covers hospital, medical, or health expenses;

11 (B) a self-insured health plan;

12 (C) a health maintenance organization;

13 (D) a preferred provider organization;

14 (E) a medical service organization;

15 (F) a physician-hospital organization;

16 (G) a pre-paid health care service plan; or

17 (H) other health care arrangement in which risk is assumed.

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

22 (11) “Life insurance” means insurance for the risk of death. The term includes

1 endowments and fixed and variable annuities.

2 (12) “Long-term care insurance” means insurance that provides coverage for not less than
3 12 consecutive months on an expense-incurred, indemnity, prepaid, or other basis for one or
4 more necessary diagnostic, preventive, therapeutic, rehabilitative, maintenance, or personal care
5 services provided in a setting other than an acute care unit of a hospital. The term includes a
6 policy or rider that provides for payment of benefits based upon cognitive impairment or the loss
7 of functional capacity.

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

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

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

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

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

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

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

Reporter's Notes

1
2
3 *Paragraph (1). (Disability income insurance)* This definition of disability income
4 insurance is used in several state statutes on genetic testing. *See, e.g.*, Cal. Ins. Code § 10147;
5 N.H. Rev. Stat. Ann. § 141-H:1.
6

7 *Paragraph (2). (Employee)* The definition of employee is adapted from the National
8 Conference of Commissioners on Uniform State Law's Model Employment Termination Act.
9 The primary modification is that the definition includes rather than excludes independent
10 contractors. In addition, applicants for employment are also included within the definition of
11 employee. The drafting committee has not differentiated protections for applicants in the
12 substantive portions of the act from those that apply to employees.
13

14 *Paragraph (3). (Employer)* The definition of employer is also adapted from the National
15 Conference of Commissioners on Uniform State Law's Model Employment Termination Act. It
16 is linked to the definition of "person" and therefore encompasses all types of entities, including
17 governmental and non-profit employers.
18

19 As the definition of employer is currently drafted, the act would cover all employers
20 regardless of size. One consideration is whether the requirements of the act would prove too
21 burdensome for small employers. Many statutes specify a minimum size using the number of
22 employees as a proxy for size. For example, Title VII of the Civil Rights Act of 1964 covers
23 employers who had 15 or more employees for each working day in 20 or more weeks over the
24 course of a year. The definition in the Uniform Law Commissioner's Model Employment
25 Termination Act was modeled on Title VII, but it reduces the required number of employees to
26 five, and extends the qualifying period to two years.
27

28 Another way to limit the types of employers that are covered would be to exclude
29 immediate family members from the count of employees, as is done in the Fair Labor Standards
30 Act and the National Conference of Commissioners on Uniform State Law's Model Employment
31 Termination Act. In addition, some state statutes exclude particular employee groups, such as
32 household workers or farm workers, in determining employer status.
33

34 *Paragraph (4). (Family member)* A family member is defined broadly to encompass all
35 individuals whose own genotype could influence an employment or insurance decision. The
36 term includes (1) biological relations whose genetic information might provide information about
37 the genetic make-up of an individual employee, insured, or applicant for employment or
38 insurance, (2) dependants whose risk of future genetically-linked medical conditions could affect
39 employer health care costs or family insurance coverage and hence employment or insurance
40 decisions, and (3) dependants' biological relations whose genetic information might provide
41 information about the genetic make-up of a dependant. The term "dependent child" is intended
42 to include both adopted and biologically-related children.
43

1 “Partner” is included in the definition of family member because many employers provide
2 health insurance for employees’ unmarried partners. Therefore, an unmarried partner can fall into
3 the second category above. Because terminology for this status varies among the states, each
4 state should substitute its term for an unmarried partner as described in the legislative note.
5

6 *Paragraph (5). (Genetic information)* The definition of “genetic information” is modeled
7 on the type of definition that has been chosen by the greatest number of states in that it includes
8 information on genetic characteristics broadly, whether it is obtained from tests or family medical
9 history. (Cal, Conn, Hawaii, LA, Maine, MD, Mass, Mich, NJ, NMex, NC, RI, SD, TX, WA).
10 A smaller number of states limit protected genetic information to the results of laboratory genetic
11 testing only, either of the individual employee (Ark, Del, Neb, NH, NY, OK, VT), or of the
12 employee and blood relatives (LA, Minn, Or, UT).
13

14 *Paragraph (6). (Genetic monitoring)* The definition of “genetic monitoring” is drawn
15 from the description in Office of Technology Assessment, *Genetic Monitoring and Screening in*
16 *the Workplace* 4 (1990). The focus in monitoring is not on inherited characteristics, but on
17 genetic alterations in a group of exposed individuals over time. Genetic monitoring is typically
18 undertaken by employers to identify risks for groups of employees who have been exposed to
19 hazardous substances or to target work sites for safety and health measures.
20

21 *Paragraph (7). (Genetic service)* “Genetic service” is a broader category than genetic
22 testing. The term includes activities associated with obtaining genetic information that could
23 create assumptions about genetics even in the absence of a genetic test or genetic information.
24 “Counseling” implies a one-on-one consultation, so the definition also includes “genetic
25 education” in order to capture group information sessions on genetic conditions. Members of the
26 drafting committee have expressed concern, however, that “education” makes the definition too
27 broad.
28

29 In contrast, some states take a narrower approach that is limited to protecting requests for
30 genetic testing. For example, Rhode Island accomplishes this by including “request for genetic
31 testing” within its definition of “genetic information.”
32

33 *Paragraph (8). (Genetic test)* One major concern is that the definitions in the act should
34 be crafted so that they do not become obsolete or unintentionally limited by advances in science.
35 See Henry T. Greely, *Banning “Human Cloning:” A Study in the Difficulties of Defining Science*,
36 8 S. Cal. Interdisciplinary L.J. 131 (1998). Therefore, the definition of genetic test is not phrased
37 in terms of particular types of tests or specific substances that are used to provide information
38 about a person’s genetic makeup, such as chromosomes or deoxyribonucleic acid (DNA), as
39 these may change with scientific and medical developments.
40

41 “Human genetic material” is a general term that is understood to include DNA,
42 ribonucleic acid (RNA), chromosomes, proteins, and metabolites that can detect or indicate
43 information about an individual’s genotype. As scientific knowledge develops, this list may

1 expand.
2

3 Some states statutes limit their definition of “genetic test” to testing for disease-related
4 genes. (Ariz, Ark, Del, Ill, Iowa, Kan, LA, Maine, MD, Mich, Minn, Nev, MO, Neb, NJ, NM,
5 NY, NC, OK, OR, RI, TX, VT, VA, WI). This draft follows the example of other states,
6 including some with newly enacted or amended statutes, that do not limit the definition of
7 genetic testing to genotypes associated with diseases or impairments. (Fla, Haw, Mass, NH, Ore,
8 UT). While most of the reasons that an employer or insurer might currently seek or use genetic
9 information probably involve a disease, disorder, or impairment, this may not always be the case.
10 One can imagine, for example, that the presence or absence of behavioral traits might also be a
11 criterion for selecting an employee. While the current evidence linking behavior to genes is
12 tenuous, this area continues to be the subject of investigation. Moreover, a broad definition of
13 “genetic test” would facilitate the eventual application of the statute to topics outside
14 employment and insurance, if that is the direction the National Conference of Commissioners on
15 Uniform State Laws takes. For example, provisions governing the retention of samples used for
16 research or identification would involve testing that is not necessarily linked to disease.
17

18 Some of the state statutory definitions specifically include testing for the purpose of
19 monitoring for genetic damage through workplace exposure. (Ariz, Ill, N.Mex). Rather than
20 defining this as a “genetic test,” the draft treats this as a permitted reason for testing in section
21 203.
22

23 *Paragraph (9). (Health insurance)* The definition of “health insurance” is meant to be
24 broad. Definitions and terms of art vary greatly among the states. This definition adopts the
25 broad framework used in Ala. Code § 27-53-1(3), supplemented with terms for health care
26 arrangements used in other states. The concept of a “health care arrangement in which risk is
27 assumed” is drawn from Fla. Stat. § 627.4301.
28

29 *Paragraph (10). (Insurer)* The definition of “insurer” is intended to cover broadly
30 insurance companies and other persons that issue health, life, disability income, or long-term care
31 insurance and all persons who might obtain, use, or disclose genetic information associated with
32 that process.
33

34 *Paragraph (11). (Life insurance)* “Life insurance” is intended to be defined broadly.
35 This definition is drawn from N.H. Rev. Stat. § 401:1(III).
36

37 *Paragraph (12). (Long-term care insurance)* The definition of “long-term care
38 insurance” is drawn from N.H. Rev. Stat. § 415-D:3(V). The definition could be made more
39 complex. For example, the New Hampshire provision also excludes a list of basic health care,
40 accident, and life insurance coverage. It further states that “any product advertised, marketed, or
41 offered as long-term care insurance” is included in the definition.
42

43 *Paragraph (13). (Person)* This draft uses the broad version of the standard National

1 Conference of Commissioners on Uniform State Laws definition of “person.”

2
3 *Paragraph (14). (Predisposing genetic characteristic)* The definitions in the draft are
4 designed to allow tailoring of the scope of permitted uses of information. A “predisposing
5 genetic characteristic” refers to an genotype that signals an increased risk of a certain disease or
6 condition. The term does not include symptomatic diseases or conditions or genetic
7 characteristics that are manifest in a disease, medical condition, or disability. The broader terms
8 “genetic test” and “genetic information” include both predisposing and manifest genetic
9 characteristics as well as genetic information that does not necessarily pertain to health.

10
11 While the terms “propensity” or “susceptibility” are often used, the actual manifestation
12 of a disease or condition may depend on a complex chain of events and the degree to which risk
13 is elevated may be quite small. “Predisposing genetic characteristic” is meant to signal a more
14 tenuous connection between a genotype or marker and a physical manifestation.

15
16 *Paragraph (15). (Record)* The definition of “record” is the standard National Conference
17 of Commissioners on Uniform State Laws definition.

18
19 *Paragraph (16). (Sign)* The definition of “sign” is the standard National Conference of
20 Commissioners on Uniform State Laws definition.

1 **ARTICLE 2**

2 **EMPLOYMENT**

3 **SECTION 201. APPLICABILITY.** This article applies to actions taken by an
4 employer, employment agency, labor organization, or licensing association.

5 **Reporter's Notes**

6
7 The article is meant to apply broadly in the employment setting although at this point the
8 provisions refer only to employers and employees.
9

10 **SECTION 202. EMPLOYER ACCESS TO GENETIC INFORMATION.**

11 (a) Except as provided in subsections (c) and (d), an employer may obtain genetic
12 information about an employee or an employee's family member only if the employee volunteers
13 the information to the employer. An employer may not inquire about an employee's or an
14 employee's family member's genetic information or request or require that this information be
15 provided. If an employee volunteers genetic information from a source other than the employee,
16 the employee shall provide informed consent for the disclosure to the employer. Informed
17 consent shall be indicated by a record signed by the employee that includes a description of the
18 genetic information to be disclosed, its potential uses, and the person to whom it may be
19 disclosed.

20 (b) An employer may obtain information about whether an employee or an employee's
21 family member has accessed or refused a genetic service only if the employee volunteers the
22 information to the employer. An employer may not inquire about an employee's or an
23 employee's family member's access or refusal of a genetic service and may not request or require
24 that this information be provided.

1 (c) If an employer provides a genetic test as part of a genetic monitoring program, the
2 employer may receive the genetic testing results in an aggregate form that does not disclose the
3 identity of specific employees.

4 (d) An employer may obtain genetic information about an employee if:

5 (1) the employee has placed the employee's health at issue in a court or
6 administrative agency proceeding;

7 (2) the genetic information is relevant to a claim or defense in the proceeding;
8 and

9 (3) on a motion by the employer a court or administrative agency orders the
10 employee to undergo genetic testing after finding that the employer has demonstrated compelling
11 need and that the information is otherwise unavailable.

12 **Reporter's Notes**

13
14 Employers get health information in a variety of ways including applications, interviews,
15 references, post-offer medical exams, post-offer releases of medical records, Family and Medical
16 Leave Act requests, worker's compensation claims, health insurance claims to self-insured
17 employers, and voluntary disclosures by employees. Many states have tried to limit employer
18 access to genetic information. There are statutes that prohibit an employer from requiring,
19 requesting or administering genetic testing, obtaining genetic information, making inquiries
20 about genetic information, or some combination of these methods of accessing genetic
21 information. (Conn, Del, Iowa, Kan, MD, Mass, Mich, Minn, Neb, Nev, NH, NY, OR, RI, Tex,
22 UT, VT, VA, WA, WI).

23
24 One rationale for limiting employer access to genetic information is the view that an
25 employee should be able to keep genetic information private. At least one state has a
26 constitutional right of privacy that appears to be relevant to genetic information. (Alaska)
27 Another rationale is to make genetic discrimination less likely for, unlike discrimination based on
28 sex or race, an employer cannot discriminate on the basis of genetic characteristics unless it has
29 access to genetic information.

30
31 Scholars have argued that a privacy rationale makes more sense for protecting genetic
32 information in the employment context than an anti-discrimination rationale. Statutory

1 protections based on anti-discrimination rationales are designed for socially-recognized groups
2 that have been historically disadvantaged. Genetic variations do not fit especially well within
3 this paradigm. *See, e.g.,* Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking*
4 *Employee Protections for a Brave New Workplace*, 96 NW U. L. Rev. 1497 (2002).

5
6 This draft of the act moves away from the approach used in statutes with an anti-
7 discrimination emphasis. Rather than broadly prohibiting employer testing and access to genetic
8 information subject to exceptions, the draft affirmatively permits access to genetic information
9 under certain circumstances.

10
11 *Subsection (a).* The draft permits employers to access genetic information about an
12 employee at the employee’s instigation only. This follows the approach of a number of states
13 that restrict an employer’s ability to require or obtain genetic information. *See, e.g.,* Conn. Stat.
14 Ann. § 46a-60(11) (employer may not “request or require” genetic information from employee);
15 Kan. Stat. Ann. § 44-1009(a)(9) (employer may not seek to obtain, obtain, or use testing
16 information to distinguish employees or restrict a right or benefit); La. Rev. Stat. § 23:368
17 (employer may not “require, collect, or purchase” protected genetic information with respect to
18 an employee); Md. Code Art. 49B § 16(a) (employer may not “request or require” genetic
19 information as a condition for hiring or determining benefits); Mass. Gen. L. Art. 151B § 4(19)
20 (unlawful to “collect, solicit or require disclosure of genetic information” as a condition of
21 employment); Mich. Comp. Laws § 37.1202 (no employer may “directly or indirectly acquire or
22 have access to” an employee’s or family member’s genetic information unless an individual
23 provides it voluntarily); Minn. Stat. Ann. § 181.974(subd. 2) (employer may not “request,
24 require, or collect” protected genetic information as a condition of employment); Neb. Rev. Stat.
25 § 48-236 (employer may not require genetic information as a condition or employment or
26 promotion); Utah Code Ann. § 26-45-103 (employer may not “access or otherwise take into
27 consideration” private genetic information in connection with an employment decision); Wash.
28 Rev. Code Ann. § 49.44.180 (unlawful to require employee to submit genetic information as
29 condition of employment).

30
31 The draft’s approach is in contrast to that of anti-discrimination statutes, which typically
32 allow employers to compel testing or require employees to provide genetic information under
33 certain circumstances. Most of the states that rely on disability statutes to regulate genetic
34 information follow the ADA, which permits an employer to test an applicant and access an
35 applicant’s medical records after a conditional offer of employment. This approach opens the
36 door broadly to genetic information. (California and Minnesota are exceptions. They have
37 addressed this problem comprehensively by providing that employers may not have access to
38 non-job related medical information at any time.) In addition, under the ADA and most state
39 statutes modeled on it, an employer can obtain medical information about its employees if it has
40 a reasonable belief that (1) the employee will be unable to perform the essential functions of his
41 or her job due to the medical condition or (2) the employee will pose a direct threat to health or
42 safety because of the medical condition. Similarly, states that have amended their employment
43 discrimination statutes to include genetics usually follow the rubric of those statutes and permit

1 genetic testing or collection of genetic information when it is relevant to “job-related
2 qualifications” or justified by “business necessity.”
3

4 An important issue in employer access to genetic information is the conditions under
5 which an employee consents to provide genetic information. Should employers be able to seek
6 out genetic information by asking employees to permit testing or access to existing data?
7 Statutes that permit employers to request genetic information appear to assume that an
8 employee’s consent to an employer’s request is voluntary. It is possible, however, to argue that
9 in the context of at-will employment, the need to retain one’s job may turn an employer’s request
10 for genetic information into a demand that an employee dare not refuse. Thus some statutes
11 prohibit even requests or inquiries. *See, e.g.*, Mass. Gen. L. Art. 151B § 4(19) (unlawful to
12 “question a person about their genetic information or genetic information concerning their family
13 members”); Nev. Rev. Stat. § 613.345 (unlawful employment practice to “ask or encourage” an
14 employee to submit to a genetic test). This draft follows that approach.
15

16 A more stringent level of protection could protect workers from ever providing genetic
17 information or authorizing access, even on their own initiative. But a blanket prohibition on any
18 disclosure arguably goes too far. It would prevent an employee from sharing information that
19 could be used to protect the person from situations in which the employee is genetically
20 susceptible to harm. In addition, it would make it easy to violate the act inadvertently by
21 disclosing information an employee does not realize is genetic information. Instead, this draft
22 follows a middle approach that permits employees to volunteer genetic information, but does not
23 generally permit employers to require it.
24

25 The prohibition on employer inquiries is intended to apply to inquires directed to other
26 persons as well as inquiries directed to the employee.
27

28 *Subsection (b).* A number of state statutes prohibit employers from accessing or using
29 information about an employee’s request for or use of genetic services. *See, e.g.*, La. Rev. Stat. §
30 23:368 (employer may not “require, collect, or purchase” information about an employee’s
31 request for or use of genetic services); Maine Rev. Stat. Ann. § 19302 (employer may not
32 discriminate on basis that an individual received a genetic test or genetic counseling except when
33 based on a bona fide occupational qualification); N.C. Gen. Stat. Ann. § 95-28.1A (unlawful to
34 deny employment of account of request for genetic testing or counseling services); Utah Code
35 Ann. § 26-45-103 (employer may not inquire into whether an individual or blood relative has
36 taken or refused to take a genetic test); Vt. Stat. Ann. § 9333 (employer may not use the fact that
37 genetic counseling or tested services have been requested or performed). This allows employees
38 to keep private information that could lead to discrimination based on assumptions about
39 genetics, even in the absence of genetic information. If an individual is unable to keep private his
40 use of genetic services such as counseling, he may be deterred from obtaining this service for fear
41 that an employer or insurer will assume he has reason to think he has a genetic disorder.
42

43 Alternatively, this subsection could be combined with subsection (a). It is separated here

1 for clarity of drafting.

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

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

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

28 29 **SECTION 203. EMPLOYER-PROVIDED GENETIC TESTING.**

30 (a) An employer may offer genetic testing and, with the prior informed consent of the
31 employee, may provide a genetic test to an employee for one of the following purposes:

32 (1) determining an employee's predisposing genetic characteristics that may
33 create susceptibility to harm from a workplace substance;

34 (2) monitoring the effects of employees' exposure to a harmful workplace
35 substance as part of a genetic monitoring program;

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

2 (b) An employee may provide informed consent for a genetic test following genetic
3 counseling concerning the test. Informed consent shall be indicated by a record signed by the
4 employee that

5 (1) includes a description of the genetic test to be performed, its purpose, and its
6 potential uses; and

7 (2) provides that the employee shall receive the result and genetic counseling
8 about the result unless the employee directs otherwise.

9 (c) An employer shall provide a genetic test for an employee if a court or administrative
10 agency orders the employee to provide genetic information under Section 202(d).

11 **Reporter's Notes**

12
13 Genetic testing is a means by which an employer can access genetic information, but it
14 can also be provided by employers who do not necessarily access individualized results of the
15 testing. Therefore the draft separates provisions on employer access to genetic information,
16 treated in Section 202, from the provisions in this section on genetic testing.

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

1 testing as a condition of employment); Va. Code Ann. § 40.1-28.7-1 (employer may not “request,
2 require, solicit, or administer” a genetic test as a condition of employment); Wash. Rev. Code
3 Ann. § 49.44.180 (unlawful to require employee to submit to genetic screening as condition of
4 employment); Wis. Stat. Ann. § 111.372 (employer may not “solicit, require, or administer” a
5 genetic test as a condition of employment unless employee requests test).
6

7 This draft focuses instead on the situations in which it is permissible for an employer to
8 offer or provide genetic testing without any necessary inference that the employer will have
9 access to the testing results. An employer may “provide” testing through an outside medical
10 organization or, if the employer has the capacity, it may do it in house.
11

12 *Subsection (a)(1).* Determining employee susceptibility to harm from exposure to
13 workplace substances is one situation in which some states have permitted employers to test with
14 the consent of the employee. Iowa, Louisiana, New Hampshire, New York, and Wisconsin all
15 have nearly identical provisions that permit genetic testing of an employee to determine an
16 employee’s susceptibility to toxic substances if the employee requests testing, provides informed
17 consent, and the employer does not terminate the employee or take other adverse action as a
18 result of testing. Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-H:3; N.Y. Exec. Law § 296;
19 Wis. Stat. Ann. § 111.372.
20

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

32 The draft allows an employer to provide testing for such susceptibilities, but unless the
33 employee volunteers the test results under section 202(a), the employer is not authorized to
34 obtain them.
35

36 *Subsection (a)(2).* Monitoring for damage to employees’ genes from workplace exposure
37 to harmful substances is another possible justification for testing. The states that permit an
38 employer to screen for genetic susceptibility to harmful workplace substances also permit
39 monitoring for exposure provided the employee requests testing, provides informed consent, and
40 the employer does not terminate the employee or take other adverse action as a result of testing.
41 Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-H:3; N.Y. Exec. Law § 296; Wis. Stat. Ann. §
42 111.372. In addition, Louisiana authorizes monitoring of biological effects of toxic substances in
43 the workplace if the employee has provided authorization and is notified of the results. La. Rev.

1 Stat. § 23:368. More generally, the definitions and prohibitions in many state’s statutes do not
2 appear to restrict monitoring for genetic damage, or are ambiguous on this issue.
3

4 Genetic damage is caused by mutagens, that is, substances that are capable of triggering
5 change in the genetic material of a cell. Genetic damage appears in the form of recessive and
6 dominant mutations, large rearrangements of DNA, point mutations, or loss of genetic material.
7 Occupational exposure to harmful substances is more likely to cause damage to somatic cells
8 than to germline cells that would lead to heritable damage. Office of Technology Assessment,
9 *Genetic Monitoring and Screening in the Workplace* 71 (1990).
10

11 Not all mutations cause disease and the relationship between exposure and health effects
12 is not well understood. Mutagens are often, however, also carcinogens and so cancer is a
13 common result of high exposure levels. But because of the long latency period of cancer it is
14 difficult to establish causal relationships between a mutation and cancer. As a result, monitoring
15 can only provide a gross indication that there have been genetic changes and that disease could
16 follow. Despite this, measurements of genetic damage are used as indicators of exposure based
17 on the rationale that the genetic changes are part of a process that may ultimately produce
18 abnormal growth. *Id.* at 58, 71. There are multiple genetic tests for exposure to mutagens at
19 both the chromosomal and molecular level.
20

21 The most common indicators of chromosomal (cytogenic) damage are chromosomal
22 aberrations (CAs) and sister chromatid exchanges (SCEs). CAs are chromosomes with breakage
23 or rearrangements. *Id.* at 62. CAs can be observed directly and, in addition, the previous
24 existence of CAs is indicated by the presence of micronuclei, which result when fragments of
25 chromosomes or whole chromosomes are excluded from nuclei formed during cell division. *Id.*
26 at 64. CAs are thought to be associated with cancer because they are found in lymph disorders
27 such as leukemia and in solid tumors, and some studies have found that cancer developed more
28 frequently among individuals with CAs. *Id.* at 62, 63. CAs are more likely to be induced by
29 ionizing radiation than chemical agents, but there are notable exceptions. For example, vinyl
30 chloride exposure results in increased CAs and places workers at risk of developing a form of
31 liver cancer. Workers exposed to benzene show elevated CAs and are at increased risk of
32 leukemia. *Id.* at 65.
33

34 Sister chromatids are the two daughter strands of a duplicated chromosome. An exchange
35 results when apparently equivalent sections of the sister chromatids of the same chromosome are
36 switched during cell division. SCE is a sensitive marker for DNA damage and repair that results
37 only from chemical mutagens, not from radiation. *Id.* at 63.
38

39 Based on over 100 studies of groups with occupational exposures, the following are the
40 most common occupational hazards that produce cytogenic abnormalities: alkylating anticancer
41 agents (CA, SCE), arsenic (CA), asbestos (CA, SCE), benzene (CA), benzidine (CA),
42 bis(chloromethyl)ether (CA), cadmium/lead/zinc (CA), coal gasification (CA), coal tars (CA),
43 coke products (SCE), diesel fumes (CA), dimethylformamide (CA), DDT (CA), epichlorohydrin

1 (CA), ethylene oxide (CA, SCE), mineral oils (CA), nickel refining (CA), organophosphorous
2 insecticides (CA, SCE), pentachlorophenol (CA, SCE), rubber industry (CA, SCE), shale oils
3 (SCE), styrene (CA), sulphite (wood pulp) (CA), trichloroethylene (CA, SCE), and vinyl
4 chloride (CA, SCE). *Id.* at 65.

5
6 As of 1990, no occupational studies had directly connected chromosomal abnormalities to
7 increased individual risk for disease. Thus, while CA and SCE monitoring may have predictive
8 value for a group, it is not a reliable way to predict health risks for an individual. *Id.* at 66.
9 Monitoring can, however, be used by employers to reduce exposures to known mutagens to a
10 level that does not affect individuals' chromosome morphology or DNA. Data on CAs are
11 routinely used by regulatory agencies in the process of setting exposure standards for industry.
12 *Id.*

13
14 At the molecular level, new techniques for documenting exposure to mutagens are being
15 refined and hold the promise of more clearly explaining the relationship between mutations and
16 disease. The most common molecular approaches to measuring mutagenesis include measuring
17 the frequency of lymphocytes (T-cells) in which the HPRT gene has been inactivated by
18 mutation; detecting DNA "adducts" (an alteration in which exogenous material is bound to
19 DNA); determining DNA repair (which indicates excision damage); measuring the DNA content
20 of cells to detect tumors (which contain cells with elevated levels of chromosomes); and
21 detecting oncogenes (cancer-causing genes), which can be activated by damage such as
22 translocations, breaks, and deletions of DNA. *Id.* at 66-69. There is a potential that detecting
23 activated oncogenes and DNA adducts may provide a method for predicting disease in
24 asymptomatic individuals. *Id.* at 71.

25
26 *Subsection (a)(3).* An employer that provides preventative health services to encourage a
27 healthy workplace is not restricted from including genetic testing as part of those services. The
28 test results would not be available to the employer unless the employee volunteers them under
29 section 202(a).

30
31 *Subsection (b).* The requirements for informed consent for testing are placed in this
32 section because they seem to be more substantive than definitional. In addition, the requirements
33 differ slightly for consent to testing, retention of information, and disclosure.

34
35 *Subsection (c).* This subsection requires an employer to provide the genetic testing when
36 a court has ordered that an employer may obtain genetic information relevant to a claim or
37 defense in a legal proceeding under Section 202(d).

38 39 **SECTION 204. EMPLOYER USE OF GENETIC INFORMATION.**

40 (a) An employer may use genetic information obtained in compliance with Section 202

1 for the following:

2 (1) monitoring the effects of employees' exposure to a harmful workplace
3 substance as part of a genetic monitoring program;

4 (2) defending a court or administrative agency proceeding in which an employee
5 has placed the employee's health at issue; or

6 (3) protecting the health or safety of others in the workplace from a direct threat
7 indicated by an employee's genetic information.

8 (b) An employer may use genetic information obtained in compliance with Section 202
9 about an employee's predisposing genetic characteristic that may create susceptibility to harm
10 from a workplace substance to reduce an employee's exposure to that substance, except that an
11 employer may not terminate an employee or take an adverse employment action based on this
12 genetic information.

13 **Reporter's Notes**

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

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

1 have restricted this exception when it is based on genetic information to the circumstance where
2 an employee voluntarily provides the genetic information. (Mich, Neb).
3

4 Instead of imposing a prohibition with exceptions that permit some use of genetic
5 information, the draft selectively authorizes ways that an employer may use genetic information
6 in employment decisions about individual employees.
7

8 *Subsection (a).* Permitting an employer to use genetic information for a monitoring
9 program or defending a legal proceeding is consistent with the purposes for which an employer
10 may obtain genetic information under section 202. Subsection (a)(3) would permit an employer
11 to act on genetic information provided voluntarily by an employee when there is a direct threat to
12 the health or safety of others in the workplace. This provision is consistent with the ADA, which
13 allows such action even in the case of a disability. 42 U.S.C. § 12113(b).
14

15 *Subsection (b).* Once an employee has volunteered genetic information about
16 susceptibility to workplace exposures to the employer, the question becomes the permissible use
17 of the data. To what extent should an employer be able to make employment decisions to
18 prevent potentially harmful employee exposure based on the information obtained from testing?
19

20 The way federal statutes would be applied to this genetic information has not been
21 directly tested in court and is not entirely clear. On one hand, in 1991 the United States Supreme
22 Court held that a chemical company's policy barring women of child-bearing age from
23 employment opportunities that involved exposure to lead violated Title VII prohibitions on
24 gender discrimination. *International Union v. Johnson Controls*, 499 U.S. 187 (1991). On the
25 other hand, as discussed above, the ADA allows employers to act on health information, even in
26 the case of disability, when there is a direct threat to the health or safety of others in the
27 workplace. In a case that did not involve a genetic characteristic but rather a worker's liver
28 damage due to exposure to workplace solvents, the United States Supreme Court upheld the
29 Equal Employment Opportunity Commission's (EEOC's) regulation interpreting this ADA
30 provision to apply when there is no risk to others but when an employer can show that an
31 individual's disability poses a significant risk of harm to the individual. *Chevron v. Echazabal*,
32 122 S. Ct. 2045 (2002). The implication of this case is that without specific state statutes, an
33 employer may make adverse employment decisions based on genetic screening or monitoring
34 requested by an employee.
35

36 The current draft follows the lead of the states that permit genetic testing to determine
37 susceptibility only when an employer does not use the information to terminate or take other
38 adverse action against the employee. Iowa Code Ann. § 729.6(7); N.H. Rev. Stat. § 141-H:3;
39 N.Y. Exec. Law § 296; Wis. Stat. Ann. § 111.372.
40

41 The Brush-Wellman company in Cleveland, Ohio, provides a model for the way in which
42 a company could be permitted to use screening or monitoring information. Brush-Wellman
43 conducts genetic tests for its employees who work with beryllium, but the testing is voluntary

1 and confidential. Moreover, the test results are provided to the employee, who makes the
2 decision on what action to take. The company takes no action against the employee as a result of
3 the genetic testing. Cynthia Nance, Paul Miller, & Mark Rothstein, *Discrimination in*
4 *Employment on the Basis of Genetics*, 6 Employee Rights & Employment Policy Journal 57, 64-
5 65 (2002).

6
7 An argument can be made that permissible uses for genetic information as defined in this
8 draft are too narrow in that they could be interpreted to exclude decisions an employer might
9 make based on an individual’s current medical condition. *See, e.g.*, Henry T. Greely, *Genotype*
10 *Discrimination: The Complex Case for Some Legislative Protection*, 149 U. Pa. L. Rev. 1483,
11 1503 (2001). An alternative would be to rely on existing law for protection of individuals with
12 genetic diseases that have become manifest and to frame the permissible uses of genetic
13 information in terms of predictive information using the concept of “predisposing genetic
14 characteristic.”
15

16 **SECTION 205. EMPLOYEE ACCESS TO GENETIC INFORMATION.**

17 (a) An employer that provides genetic testing under this article shall report or require
18 reporting of the results to the employee and a health care professional designated by the
19 employee unless otherwise requested by the employee.

20 (b) An employee may inspect, request correction of, or obtain genetic information from
21 an employer’s records on the employee.

22 **Reporter’s Notes**

23
24 *Subsection (a).* This subsection provides for reporting genetic test results to the employee
25 when an employer provides testing. This reporting obligation is incurred whether or not the
26 employer may obtain the test results under Section 202. There needs to be sensitivity, however,
27 to the fact that not all individuals wish to know their genetic information. So the draft leaves the
28 decision to the employee.
29

30 The draft provides for reporting to a health care professional so that the results can be
31 interpreted for the employee. But because the scope of the drafting committee’s mandate is
32 limited to use of genetic information in employment and insurance, the draft does not consider
33 standards for genetic counseling that should be associated with disclosures to an employee who
34 has been tested.
35

36 *Subsection (b).* This section is based on the conclusion that an employee ought to be able

1 to find out what genetic information an employer knows about an employee and to have the same
2 information. It is based on 16 Del. Code § 1223.
3

4 **SECTION 206. EMPLOYER RETENTION OF GENETIC INFORMATION.**

5 (a) An employer shall require that a sample obtained for genetic testing supplied by an
6 employer shall be destroyed promptly following the completion of the testing unless retention is
7 authorized by order of a court or administrative agency.

8 (b) An employer may retain genetic information about genetic monitoring that does not
9 disclose the identity of the employee.

10 (c) An employer may retain a record of an employee's informed consent for the employer
11 to obtain genetic information, for the employer to provide genetic testing, for the employer to
12 retain genetic information, or for the employer to disclose genetic information. The employer
13 shall treat a record of informed consent as a confidential medical record and store it separately
14 from the employee's personnel records.

15 (d) An employer may retain genetic information or information about a request for or
16 receipt of genetic services that identifies the employee only with prior informed consent of the
17 employee. The employer shall treat this information as a confidential medical record and store it
18 separately from the employee's personnel records.

19 (e) Informed consent for retention of genetic information is indicated by a record signed
20 by the employee that includes a description of the genetic information to be retained, its potential
21 uses, limitations on its use, and the person who shall retain it, and the length of time it may be
22 retained. An employee may revoke consent made under this subsection at any time.

23 **Reporter's Notes**

1 *Subsection (a).* The provision for prompt destruction of a sample obtained for genetic
2 testing provided by an employer follows provisions adopted in New Jersey and Oregon.
3 Alternative approaches include a requirement that the sample be destroyed promptly on the
4 request of the individual tested or that a sample may be retained for a period of time. In New
5 York, a sample may be retained for ten years if authorized by the individual from whom the
6 sample was obtained.

7
8 *Subsections (b)-(c).* An employer may retain some information without an employee’s
9 specific informed consent. An employer may need to retain the genetic information in order to
10 make a monitoring program effective. Since an employer is allowed access to this information
11 only in a form that does not identify individual employees, retention of monitoring information
12 should not affect an employee’s privacy. An employer may also retain records of an employee’s
13 informed consent with regard to employer access to genetic information, genetic testing,
14 retention of information, or disclosure of information.

15
16 *Subsection (d).* If an employer obtains an employee’s individually-identifiable genetic
17 information pursuant to Section 202, it needs informed consent to retain that information. The
18 separate storage requirement serves to protect the employee’s privacy and is modeled on La. Rev.
19 Stat. § 23:368(B).
20

21 **SECTION 207. EMPLOYER DISCLOSURE OF GENETIC INFORMATION.**

22 (a) An employer may disclose an employee’s genetic information to a person other than
23 the employee only if the employer has obtained the employee’s informed consent before the
24 disclosure is made.

25 (b) Informed consent for disclosure of genetic information is indicated by a record signed
26 by the employee that includes a description of the genetic information to be disclosed, its
27 potential uses, limitations on its use, and the person to whom it may be disclosed.

28 **Reporter’s Notes**

29
30 The draft is consistent with a number of states that have established general privacy
31 protections for genetic information that prohibit disclosure without informed consent (Alaska,
32 Cal, Del, Fla, Maine, Mass, Nev, NH, NJ, NMex, NY, OR) or that protect specifically against the
33 disclosure of genetic information by employers (Ariz, Fla, LA, Mass, NH, NJ, Or, RI).
34

1 **ARTICLE 3**

2 **HEALTH INSURANCE**

3 **SECTION 301. APPLICABILITY.**

4 (a) This article applies to health insurance issued on an individual, group, or other basis.

5 (b) This article applies to employee welfare plans in the absence of a controlling judicial
6 decision that it is preempted by the Employee Retirement Income Security Act of 1974, 29
7 U.S.C. § 1001 *et seq.*

8 **Reporter's Notes**

9
10 *Subsection (a).* The draft is meant to apply broadly to health insurance, and this section
11 closes the gaps left by HIPAA because it applies only to small group and individual coverage. In
12 addition to individual and group health insurance policies, some state statutes reference health
13 insurance issued on a franchise or blanket basis.

14
15 This article is not intended to apply to accident-only insurance, automobile medical
16 payment insurance, credit insurance, disability income insurance, life insurance, long-term care
17 insurance, worker's compensation insurance, or coverage issued as a supplement to liability
18 insurance.

19
20 *Subsection (b).* Federal preemption is relevant because the United States Supreme Court
21 has held that ERISA, 29 U.S.C. § 1001 *et seq.*, applies to employee benefit plans such as health
22 insurance as well as to pension plans. *Inter-Modal Rail Employees Ass'n v. Atchison, Topeka*
23 *and Santa Fe Ry. Co.*, 520 U.S. 510 (1997). The United States Supreme Court has recognized
24 three types of preemption under ERISA that are relevant to this draft act: express, complete, and
25 conflict preemption.

26
27 In order to simplify the administration of plans by ensuring that they are subject to only
28 one set of regulations, ERISA expressly preempts state regulation of the administration of
29 employee benefit plans to the extent those regulations "relate to" employee benefit plans. 29
30 U.S.C. § 1144(a). The statute contains a savings clause, however, that saves laws that regulate
31 insurance from ERISA preemption. 29 U.S.C. § 1144(b)(2)(A). The issue of whether state
32 regulations are preempted by ERISA has led to extensive litigation.

33
34 Recently, the United States Supreme Court clarified the application of the savings clause.
35 In order to fall under ERISA's savings clause, a state law must first be "specifically directed
36 toward" the insurance industry. *Kentucky Ass'n of Health Plans, Inc. v. Miller*, 123 S. Ct. 1471,

1 1475 (2003). Laws of general application that merely have “some bearing on insurers” do not
2 fall under the clause. *Id.* Second, the ERISA provision saves state laws that regulate
3 “insurance,” not “insurers,” so a law must regulate insurers “with respect to their insurance
4 practices.” *Id.* A state law regulates an insurer with respect to insurance practices if it controls
5 the terms of insurance policies, *id.* at 1476, or if it “substantially affect[s] the risk pooling
6 arrangement between the insurer and the insured,” *id.* at 1477.

7
8 The preemption question is further complicated by that fact that ERISA also contains
9 what is referred to as the “deemer clause,” which creates an exception to the savings clause. It
10 provides that “neither an employee benefit plan . . . nor any trust established under such plan,
11 shall be deemed to be an insurance company or other insurer . . . for purposes of any law of any
12 State purporting to regulate insurance companies . . .” 29 U.S.C. § 1144(b)(2)(B). The United
13 States Supreme Court has interpreted the deemer clause to exempt self-funded (i.e. uninsured)
14 health plans from the savings clause. Thus the Court concluded that “self-funded ERISA plans
15 are exempt from state regulation insofar as that regulation ‘relate[s] to’ the plans.” *FMC Corp. v.*
16 *Holliday*, 498 U.S. 52, 61 (1990).

17
18 *FCM Corp.* and its distinction between insured and self-insured health plans has not been
19 overruled and continues to be applied by lower courts. *See, e.g., Daly v. Marriott International,*
20 *Inc.*, 415 F.3d 889 (8th Cir. 2005) (“deemer clause” of ERISA preemption provision exempted
21 employer funded health plan from application of state mental-health parity law); *Blue Cross Blue*
22 *Shield of Alabama v. Sanders*, 138 F.3d 1347 (11th Cir. 1998).

23
24 The second type of ERISA preemption may affect the draft’s enforcement provisions.
25 “Complete preemption” occurs when Congress has “so completely [preempted] a particular area
26 that any civil complaint raising this select group of claims is necessarily federal in character.”
27 *Metropolitan Life Ins. Corp. v. Taylor*, 481 U.S. 58, 63-64 (1987). In *Taylor*, the United States
28 Supreme Court held that the civil enforcement provision of ERISA, 29 U.S.C. § 1132(a),
29 completely preempts common law breach of contract and tort claims for wrongful termination of
30 disability benefits. *See also Prudential Ins. Co. of Amer. v. Nat’l Park Med. Center, Inc.*, 413
31 F.3d 897 (8th Cir. 2005) (with respect to suits that could be brought under ERISA, civil
32 enforcement provision preempts Arkansas Patient Protection Act civil penalties).

33
34 Third, “conflict preemption” also comes into play with civil remedies. The United States
35 Supreme Court has held that Congress intended to make the ERISA civil enforcement remedy
36 exclusive and that therefore a state-law cause of action that “duplicates, supplements, or
37 supplants” the ERISA civil remedy conflicts with congressional intent. *Aetna Health, Inc. v.*
38 *Davila*, 452 U.S. 200, 208 (2004) (Texas statute that created a cause of action against HMOs for
39 failure to exercise ordinary care in handling coverage decisions preempted). *See also Hawaii*
40 *Management Alliance v. Ins. Comm’n*, 100 P.3d 952 (Haw. 2004) (statute providing attorney’s
41 fees and costs for external review of insurer’s denial of coverage preempted by conflict with
42 ERISA).

1 **SECTION 302. HEALTH INSURER ACCESS TO GENETIC INFORMATION.**

2 (a) An insurer that receives a claim for payment under a health insurance policy may
3 request:

4 (1) information regarding the need for a genetic test, but not the results of the test,
5 when the service rendered is a genetic test or genetic counseling;

6 (2) the portion of genetic information necessary to determine the insurer’s
7 obligation to pay for health care services when the reason for rendering the services is a genetic
8 disorder or predisposing genetic characteristic.

9 (b) In determining eligibility for health insurance coverage and in setting rates, terms,
10 and conditions for a health insurance policy, an insurer may not:

11 (1) request an individual’s genetic information; or

12 (2) inquire whether an individual or an individual’s family member has taken or
13 refused to take a genetic test.

14 **Reporter’s Notes**

15
16 *Subsection (a).* This subsection highlights the potential role for genetic information in
17 providing payment for genetic tests and health care services. First, genetic information such as
18 family history may be necessary for preauthorization for a genetic test or service or for approval
19 of payment for a genetic test or service. Second, health care services may be medically justified
20 by a predisposing genetic characteristic or a genetic condition. In this context, genetic “disorder”
21 should be interpreted broadly to include the full range of health effects influenced by a genotype,
22 including a disease or condition.

23
24 This subsection is modeled on a Utah provision.

25
26 *Subsection (b).* This subsection prohibits a health insurer from obtaining genetic
27 information for the uses prohibited in Section 304.
28

1 **SECTION 303. GENETIC TESTING.**

2 (a) Following genetic counseling, a health insurer may provide a genetic test for
3 therapeutic purposes with the informed consent of the individual tested or the individual’s
4 representative before the genetic test is provided.

5 (b) Informed consent shall be indicated by a record signed by the individual to be tested
6 or the individual’s representative that includes a description of the genetic test to be performed,
7 its purpose, its potential uses, and provides that the individual shall receive the result and genetic
8 counseling about the result unless the individual directs otherwise.

9 **Reporter’s Notes**

10 This Section follows the privacy protections of states that require informed consent for
11 most genetic testing. (E.g., Alaska, Arizona, Delaware, Florida, Mass, Nevada, NH, NJ, NMex,
12 NY OR, SD.)
13

14 The draft does not disturb existing law that allows a minor to seek repudiation of consent
15 and expunge records when the minor reaches the age of majority.
16
17

18 **SECTION 304. HEALTH INSURER USE OF GENETIC INFORMATION.**

19 (a) A health insurer may use an individual’s genetic information for therapeutic purposes
20 for the individual.

21 (b) An insurer that receives a claim for payment under a health insurance policy may use
22 information requested under section 302(a) for purposes of determining a payment obligation.

23 (c) An insurer may not consider an individual’s genetic information in determining
24 eligibility for health insurance coverage or in setting rates, terms, and conditions for a health
25 insurance policy.

26 **Reporter’s Notes**

1 This section reflects and combines the approaches of many states that prohibit the use of
2 genetic information for setting eligibility requirements and for underwriting in health insurance.
3 It partially closes the gaps left by HIPPA in that it extends beyond merely prohibiting complete
4 denial of coverage; the section also prohibits use of genetic information in determining rates
5 terms and conditions.
6

7 A determination of eligibility for coverage is meant to include decisions made in
8 connection with the offer, sale, continuation, or renewal of a health insurance policy. A
9 determination of rates, terms, and conditions includes establishing premiums, limiting coverage,
10 limiting or conditioning benefits, or making any other underwriting decisions. The prohibition
11 on using genetic information for these purposes also precludes an insurer from treating a
12 predisposing genetic characteristic as a preexisting condition for purposes of limiting or
13 excluding benefits or coverage. This is consistent with statutes in several states that do not
14 permit health insurers to impose preexisting condition exclusions based on predictive genetic
15 information in the absence of a diagnosis based on symptoms of the disease or condition.
16 (Alaska, Conn, Idaho, Iowa, Ky, OR).
17

18 There are many alternative approaches to regulating the use of genetic information in
19 health insurance. Some other states take an approach like that of HIPPA and use a non-
20 discrimination provision that prohibits higher premiums than those charged to similarly situated
21 individuals. (Alaska, Ark, Ill, Iowa). Yet other states prohibit the use of genetic information for
22 underwriting health insurance without actuarial justification. (Ariz, WV). In some states, use
23 of genetic information for risk selection is permitted if an individual submits the information
24 voluntarily or if the information is favorable to the individual. (Ill, Ind, Mass, Mo, NY). Yet
25 other states regulate this use by prohibiting insurers from increasing policy rates based on genetic
26 information. (Md, Mont, Or, Tex).
27

28 This section illustrates some of the problems with treating genetic information as a
29 distinct category of medical information. First, the section offers less protection than HIPPA in
30 terms of eligibility decisions for individual and small group coverage because it regulates use of
31 genetic information only, not information on all medical conditions. Second, it is often
32 permissible for insurers to consider existing medical conditions in determining coverage and
33 premiums under other law so long as they treat like situations alike. This section would impose a
34 different standard with regard to conditions predicted by genetic information, thus raising the
35 practical question of which conditions are “genetic.” Even conditions with a genetic component
36 are rarely entirely “genetic.”
37

38 The prohibition on considering an individual’s genetic information in this section is
39 consistent with the draft’s policy treatment of use of information in the employment context.
40 However, again an argument can be made that protection for genetic information as defined in
41 this draft is too wide. As discussed above, the prohibition would create a different standard for
42 genetic illnesses than for other medical conditions. Many think that this would place too great a
43 burden on insurers. See, e.g., Henry T. Greely, *Genotype Discrimination: The Complex Case for*

1 *Some Legislative Protection*, 149 U. Pa. L. Rev. 1483, 1503 (2001). An alternative would be to
2 limit the restrictions to predictive information by substituting “predisposing genetic
3 characteristic” for “genetic information” in subsection (b).
4

5 **SECTION 305. HEALTH INSURER RETENTION OF GENETIC**

6 **INFORMATION.** An insurer that retains genetic information shall comply with the terms of
7 the Health Insurance Portability and Accountability Act of 1996 as if the information is covered
8 by that Act.

9 **Reporter’s Notes**

10
11 This section extends the protections of HIPAA to all genetic information retained by
12 health insurers, whether covered by HIPAA or not.
13

14 **SECTION 306. HEALTH INSURER DISCLOSURE OF GENETIC**

15 **INFORMATION.**

16 (a) A health insurer may disclose an individual’s genetic information to a person other
17 than the individual if it has obtained the individual’s informed consent.

18 (b) Informed consent for disclosure of genetic information shall be indicated by a record
19 signed by the individual that includes a description of the genetic information to be disclosed, its
20 potential uses, limitations on its use, and the person to whom it may be disclosed.

21 **Reporter’s Notes**

22
23 This section conditions the disclosure of an individual’s genetic information on the
24 informed consent of the individual. An important issue to consider is whether there are
25 circumstances in which disclosures should be made absent such consent. In some jurisdictions,
26 health care providers may have a common-law duty to inform others of a genetic disorder.
27

28 New Jersey’s court has recognized a physician’s duty to warn those “known to be at risk
29 of avoidable harm from a genetically transmissible condition.” *Safer v. Pack*, 677 A.2d 1188
30 (N.J. Super. Ct. App. Div. 1996). The defendant in the case was the physician who had treated

1 the plaintiff's father for colorectal cancer that led to the father's death when the plaintiff was a
2 child. The plaintiff inherited multiple polyposis, an inherited condition that if undiscovered and
3 untreated, leads to metastatic colorectal cancer. The court found a duty to "take reasonable
4 steps" to warn that "extends beyond the patient to members of the immediate family of the
5 patient who may be adversely affected by a breach of that duty." It noted, but did not determine,
6 the issue that would arise if the father had instructed the doctor not to disclose details of the
7 illness or the genetic risk. In that event, it would be necessary to resolve the conflict between
8 physician-patient confidentiality and the duty to warn.
9

10 Minnesota has also recognized a duty regarding genetic testing and diagnosis that reaches
11 beyond the patient. The plaintiff alleged that her daughter's physicians were negligent in failing
12 to diagnose a genetic disorder in the daughter that led the mother to conceive another child with
13 the same genetic disorder. *Molloy v. Meier*, 679 N.W.2d 711 (Minn. 2004). The court noted that
14 genetic testing and diagnosis affect not only the patient, but can benefit or harm both the patient
15 and her family. The Fragile X disorder is one that physicians ordinarily report to parents and it
16 was foreseeable that a negligent diagnosis of the disorder would cause harm to the family as well
17 as the patient. The court held that the duty to warn extends to "biological parents who
18 foreseeably may be harmed by a breach of that duty." It did not consider whether it should
19 extend to additional family members.
20

21 In contrast, the Florida Supreme Court has held that a duty to warn of the likelihood that a
22 condition was inherited by a patient's children is satisfied by warning the patient. *Pate v.*
23 *Threlkel*, 661 So.2d 278 (Fla. 1995). The court observed that a patient can normally be relied
24 upon to pass on the warning and emphasized the heavy burden that would be entailed in seeking
25 out and warning family members.
26

27 Because the scope of the drafting committee's mandate is limited to use of genetic
28 information in employment and insurance, the draft does not consider standards for genetic
29 counseling that should be associated with disclosures to an individual who has been tested or to
30 family members.
31

32 **SECTION 307. ENFORCEMENT AND REMEDIES.**

33 (a) On or before two years of the date of the occurrence of an alleged violation of this
34 article, an aggrieved individual may file a civil action or a claim with the [State Commissioner of
35 Insurance], which may seek all available remedies, including those provided under this Act.

36 (b) A civil action for a violation of this article may seek compensatory damages or
37 injunctive relief, including expungement of records. A court shall award a prevailing plaintiff

1 costs and reasonable attorneys fees unless justice requires otherwise.

2 **Reporter's Notes**

3
4 Many state statutes that prohibit discrimination in health insurance based on genetic
5 testing or information declare that a violation is an unfair and deceptive insurance act or practice
6 under the state insurance code. They often provide that the State Commissioner of Insurance
7 shall enforce the prohibitions.

8
9 This draft reaches more broadly than discrimination in insurance and provides a private
10 right of action for an individual whose genetic information is misused. Alternatively, an
11 aggrieved individual may seek enforcement through the State Commissioner of Insurance.

1 **ARTICLE 4**

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

3 **SECTION 401. APPLICABILITY.** This article applies to life insurance, disability
4 income insurance, and long-term care insurance issued on an individual, group, or other basis.

5 **Reporter's Notes**

6
7 This draft includes a broad applicability provision that includes individual insurance as
8 well as group-based insurance. Regulation of the use of information for individual insurance
9 policies is a major issue because individual policies are subject to underwriting. Life, disability
10 income and long-term care insurance can be distinguished from health insurance in that a greater
11 proportion of the market consists of individual policies rather than group coverage. According to
12 the National Conference of State Legislatures, approximately 60 percent of life insurance, 40
13 percent of disability income insurance, and almost all of long-term care insurance is underwritten
14 individually, compared to only about 10 percent of health insurance. Individual underwriting
15 decisions are based on an individual's characteristics rather than broader group characteristics, so
16 there would be more value in knowing individual genetic information if it could accurately
17 predict the likelihood of claims.

18
19 The draft does not distinguish between individual and group insurance because most of
20 the states that regulate the use of genetic information or testing for life, disability income, or
21 long-term care insurance treat both categories identically.
22

23 **SECTION 402. INSURER ACCESS TO GENETIC INFORMATION.**

24 (a) An insurer may not require an applicant for insurance or an applicant's family
25 member to take a genetic test as a condition of the issuance or renewal of a policy for life
26 insurance, disability income insurance, or long-term care insurance.

27 (b) An insurer may ask on an application for insurance whether or not an applicant has
28 taken a genetic test. The applicant is not required to answer any questions concerning genetic
29 testing or genetic information. An application requesting this information must inform the
30 applicant that the applicant is not required to answer any question in connection with genetic

1 testing or information.

2 (c) An application for life insurance must provide notice to the applicant if failure to
3 answer questions concerning genetic information of testing may result in an increased rate or
4 denial of coverage.

5 **Reporter's Notes**

6
7 The argument for restricting access to genetic information is that its predictive power is
8 easily exaggerated and insurers may force applicants to take genetic tests and then deny insurance
9 or charge more based on genetic characteristics. This raises the possibility that a large class of
10 people will lack coverage even though they are not sick. On the other side, as with health
11 insurance, insurers worry about adverse selection. If applicants seek coverage because a genetic
12 characteristic exposes them to risk, but the insurer does not have this information, this puts the
13 insurer at a financial disadvantage. *See generally* Mark A. Rothstein, ed., *Genetics and Life*
14 *Insurance: Medical Underwriting and Social Policy* (2004).

15
16 A 1997 study by the Human Genetics Advisory Commission in the United Kingdom
17 concluded that it is unlikely that actuarially-sound genetic predictions of adult death will be
18 validated and available anytime in the near future. Genetic tests need to be connected to medical
19 and epidemiological research to establish what consequences for health and life-span can be
20 inferred from a given genetic test. The Commission concluded that a requirement to disclose
21 genetic tests as a condition of obtaining insurance would be acceptable only after research has
22 established an association between a given pattern of test results and life events that are relevant
23 for the insurance product. It recommended continuing a moratorium on requiring test results and
24 predicted that the life insurance industry could withstand the limited adverse selection that might
25 result from non-disclosure. Human Genetics Advisory Commission, *The Implications of Genetic*
26 *Testing for Insurance* (1997).

27
28 *Subsection (a).* Many of the states that regulate genetic testing in the context of life
29 insurance, disability income insurance, and long-term care insurance prohibit insurers from
30 requiring genetic tests for one or more of these categories of insurance. Cal. Ins. Code § 10233.1
31 (long-term care insurance); Colo. Rev. Stat. Ann. § 10-3-1104.7 (group disability and long-term
32 care insurance); Kan. Stat. Ann. § 40-2259 (disability and long-term care insurance); Mass. Gen.
33 L. Ann. 175 § 120E (life insurance); Mass. Gen. L. Ann. 175 § 108I (disability and long-term
34 care insurance); Mich. Comp. L. Ann. § 500.3407b (disability insurance); Vt. Stat. Ann. § 9334
35 (any insurance). This draft is drawn from these examples.

36
37 Alternatively, some states do not prohibit testing, but restrict it in other ways for
38 particular types of insurance. In California, for example, insurers may not require applicants for
39 life or disability income insurance to take a genetic test for a pre-disposing characteristic unless

1 the policy is contingent on review or testing for other diseases or medical conditions. Cal. Ins.
2 Code § 10148.

3
4 *Subsection (b).* This provision is included for the drafting committee to consider the
5 extent to which an insurance company should have access to genetic information or the results of
6 genetic testing through means other than requiring a test. In the current draft, genetic information
7 may be used by a life insurance company under certain circumstances, but only if submitted by
8 the applicant. This provision permits applicants to maintain the privacy of their genetic
9 information. It is adapted from the Massachusetts Act on Insurance and Genetic Testing and
10 Privacy Protection. Mass. Gen. L. Ann. 175 § 120E (life insurance); Mass. Gen. L. Ann. 175 §
11 108I (disability and long-term care insurance).
12

13 **SECTION 403. INSURER USE OF GENETIC INFORMATION.**

14 (a) Except as provided in subsections (c) and (d), an insurer may use information about
15 an applicant's symptomatic genetic disorder to determine eligibility or rates, terms, and
16 conditions for life, disability income, and long-term care insurance unless otherwise prohibited
17 by law.

18 (b) An insurer may use genetic information about an individual's predisposing genetic
19 characteristics in determining eligibility, or rates, terms, and conditions for life insurance
20 coverage if:

- 21 (1) an applicant for insurance submits the genetic information to an insurer; and
22 (2) the applicant's medical condition and history and the insurer's claims
23 experience or actuarial projections establish that substantial differences in claims are likely to
24 result from the applicant's predisposing genetic characteristics.

25 (c) If the individual who determines the actuarial projection is a qualified geneticist or
26 genetic counselor, the determination is presumed correct.

27 (d) An insurer may not determine eligibility for insurance coverage or affect rates, terms

1 and conditions of life, disability income, and long-term care insurance based on the results of a
2 genetic test of a family member.

3 (e) An insurer may not use favorable genetic information to induce a purchase of life,
4 disability income, and long-term care insurance.

5 **Reporter's Notes**

6
7 The extent to which states regulate the use of genetic information in life, disability
8 income, and long-term care insurance varies. The draft makes a distinction between an existing
9 disorder with a genetic cause or contribution (subsection (a)) and predisposing genetic
10 characteristics that are not symptomatic (subsection (b)). The term “disorder” includes the
11 concepts of disease or condition and should be interpreted broadly.
12

13 The determination of eligibility for coverage includes decisions made in connection with
14 the offer, sale, continuation, or renewal of an insurance policy. The determination of rates,
15 terms, and conditions includes establishing premiums, limiting coverage, limiting or conditioning
16 benefits, or making any other underwriting decisions.
17

18 *Subsection (a).* This subsection permits an insurer to use information about phenotypic
19 symptoms that indicate a disorder. This is distinguished from using predictive genetic
20 information, which is covered in subsection (b).
21

22 Some of these states that require actuarial justification apply this requirement to the use
23 of genetic tests or information about a predisposing genetic characteristic, but do not condition
24 availability of insurance or prohibit underwriting based on a diagnosed genetic disease or
25 condition. *E.g.*, Cal. Ins. Code § 10147(b); Kan. Stat. Ann. § 2259; Md. Code Ann. Ins. § 27-
26 208. Others are more restrictive and use definitions that appear to prohibit underwriting on
27 either grounds. *E.g.*, 24-A Maine Rev. Stat. § 2159-C (no discrimination on the basis of “genetic
28 information,” which includes family history); Vt. Stat. Ann. § 9331(7) (“genetic testing” can be
29 diagnostic or predictive). Arizona takes an intermediate position. It does not permit
30 underwriting for disability income insurance based on a predisposing genetic characteristic,
31 although underwriting based on actuarial projections are acceptable for diagnosed genetic
32 conditions. Underwriting life insurance appears to be permitted on both grounds. Ariz. Rev. Stat.
33 § 20-448.
34

35 *Subsection (b).* This subsection regulates insurers’ use of information on an individual’s
36 predisposing genetic characteristics to predict risk.
37

38 Many states require an actuarial justification for using results of genetic tests to deny
39 coverage or in underwriting for one or more of the types of coverage in regulated in this article.

1 E.g., Ariz. Rev. Stat. § 20-448 (life and disability income insurance); Cal. Ins. Code § 10148 (life
2 and disability income insurance); Kan. Stat. Ann. § 2259 (life); 24-A Maine Rev. Stat. § 2159-C
3 (life, disability income, and long-term care insurance); Md. Code Ann. Ins. § 27-208 (life
4 insurance); Mass. Gen. L. Ann. 175 §§ 120E, 108I (life, disability income, and long-term care
5 insurance); Mont. Code Ann. § 33-18-206 (life and disability income insurance); 8 N.M. Stat.
6 Ann. § 24-21-4 (life, disability income, and long-term care insurance); N.J. Stat. Ann. § 17B:30-
7 12(f) (life and disability income insurance); Vt. Stat. Ann. § 4724(7)(D) (life, disability income,
8 and long-term care insurance).

9
10 Some states place greater restrictions on the use of genetic information for disability
11 income or long-term care insurance. In Colorado, an insurer may not use information from
12 genetic testing for underwriting group disability or long-term care insurance. Colo. Rev. Stat. §
13 10-3-1104.7(3)(b). In Kansas, the availability of disability income and long-term care insurance
14 may not be conditioned on getting a genetic test or on the results of the test. Similarly, testing
15 and test results may not be considered in underwriting. Kan. Stat. Ann. § 2259.

16
17 For life insurance, this draft requires an actuarial justification for the use of information
18 on predisposing genetic characteristics. Genetic diseases or conditions for which an applicant is
19 symptomatic are not subject to this requirement under subsection (a). The draft differentiates
20 disability income and long-term care insurance from life insurance, adopting the more restrictive
21 Colorado and Kansas approach by not authorizing use of predisposing characteristics for
22 underwriting.

23
24 *Subsection (c).* This provision addresses concerns about misinterpretation of genetic
25 testing results by persons without adequate training in genetics. It does not require that actuarial
26 projections are made by a person with genetic training, but provides a presumption of correctness
27 if they are. This presumes that there is some means to challenge an actuarial determination made
28 by a life insurance company.

29
30 *Subsection (d).* This provision excludes genetic testing of family members as a basis for
31 life, disability income, and long-term care insurance decisions. It is based on an Oregon
32 provision that prohibits insurers from using genetic test results for a blood relative to deny
33 insurance coverage, increase rates, or affect terms and conditions. Or. Rev. Stat. § 746.135.
34 Vermont has a similar restriction prohibiting insurers from conditioning or underwriting a policy
35 on the results of testing of a family member, unless the test results are contained in the
36 applicant's medical record. Vt. Stat. Ann. §§ 4724(22), 9334(a).

37
38 *Subsection (e).* This subsection is drawn from an Oregon provision. Or. Rev. Stat. §
39 746.135.

1 (b) Informed consent for disclosure of genetic information is indicated by a record signed
2 by the individual that includes a description of the genetic information to be disclosed, its
3 potential uses, limitations on its use, and the person to whom it may be disclosed.

4 **Reporter's Notes**

5 This section is identical to the disclosure provision for health insurance.
6
7

8 **SECTION 406. ENFORCEMENT AND REMEDIES.**

9 (a) On or before two years from the date of the occurrence of an alleged violation of this
10 article, an aggrieved individual may file a civil action or a claim with the [State Commissioner of
11 Insurance], which may seek all available remedies, including those provided under this Act.

12 (b) A civil action for a violation of this article may seek compensatory damages or
13 injunctive relief, including expungement of records. A court shall award a prevailing plaintiff
14 costs and reasonable attorneys fees unless justice requires otherwise.

15 **Reporter's Notes**

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

1 **ARTICLE 5**

2 **SECTION 501. UNIFORMITY OF APPLICATION AND CONSTRUCTION.** In

3 applying and construing this uniform act, consideration must be given to the need to promote
4 uniformity of the law with respect to its subject matter among states that enact it.

5 **SECTION 502. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL
6 AND NATIONAL COMMERCE ACT.** This [act] modifies, limits, and supersedes the federal
7 Electronic Signatures in Global and National Commerce Act (15 U.S.C. Section 7001, et seq.)
8 but does not modify, limit, or supersede Section 101(c) of that act (15 U.S.C. Section 7001(c)) or
9 authorize electronic delivery of any of the notices described in Section 103(b) of that act (15
10 U.S.C. Section 7003(b)).

11 **SECTION 503. SAVINGS AND TRANSITIONAL PROVISIONS.**

12 **[SECTION 504. SEVERABILITY.** If any provision of this [act] or its application to
13 any person or circumstance is held invalid, the invalidity does not affect other provisions or
14 applications of this [act] which can be given effect without the invalid provision or application,
15 and to this end the provisions of this [act] are severable.]

16 *Legislative Note: Include this section only if this state lacks a general severability statute or a*
17 *decision by the highest court of this state stating a general rule of severability.*
18

19 **[SECTION 505. REPEALS.** The following acts and parts of acts are repealed:

20 (1)

21 (2)

22 (3)]

23 **SECTION 506. EFFECTIVE DATE.** This [act] takes effect