Policy – Genetic Discrimination

"In the coming years, the public will be offered more and more opportunities to take genetic tests and peer into their genetic destinies, but legislation must keep pace with the technology and help shape a fair and equitable society." *Sir Paul Nurse, chief executive of Cancer Research UK and 2001 Nobel Prize winner for Medicine, to CNSNews.com*

U.S. State Laws

In the United States, most of the legislative activity involving issues of genetic privacy and genetic discrimination here has occurred at the state level, not the federal level. Generally, 16 states require informed consent for a third party to perform or require a genetic test or obtain genetic information, while 23 require informed consent of the subject before disclosing genetic information to a third party.

Thirty-two states have passed laws concerning genetic discrimination in employment. While all of the laws in these states prohibit employers from discriminating against people on the basis of genetic tests, the specifics of what constitutes unlawful discrimination vary widely. Some definitions of genetic information only include the employed individual, while others include family members as well; some only protect information from genetic tests and others include family histories and other sources of genetic information. The laws vary as to whether employers may request or require genetic testing and how, if at all, that information may be disclosed or used. The penalties for discriminating against individuals based on genetic information also vary widely. The following link to the National Conference of State Legislatures contains a table that describes each state's laws: http://www.ncsl.org/programs/health/genetics/ndiscrim.htm.

At least thirty-four states prohibit the use of genetic information for certain health insurance purposes. Additionally, Arizona, Vermont, and West Virginia require actuarial justification for the use of genetic information. Texas bans the use of genetic information within group health plans, and Alabama prohibits discrimination based upon predisposition to cancer. Thirty states restrict employers from discriminating based on genetic information, but the laws are varied and contain different definitions and loopholes. Most of the state laws do not protect people from discrimination based on genetic information about their family members, thereby allowing insurers to easily circumvent the reach of the laws by basing their decisions on family histories. Few of the laws would prohibit an insurer from circumventing the law by discriminating against people based not on their test result, but on the fact that they previously requested genetic services.

In Illinois, health insurers may not "seek" genetic test results for a "nontherapeutic" purpose.[1] This could mean, though, that insurers could use results to discriminate if they obtained it in some way other than by 'seeking' it. There is also a paradoxical exception. If an individual voluntarily submits favorable results, those results can be used for non-therapeutic purposes.[2] This means that a man with the Huntington's disease mutation cannot be charged a higher rate for insurance. But his brother, who does not carry the mutation, can voluntarily submit his test results and be charged a *lower* rate. The net effect is the same, though, with people with the mutation being charged a higher rate.

There is another potential definitional loophole in some of the statutes. Wisconsin focuses only on tests of DNA and RNA[3] and the Indiana and Ohio statutes focus only on tests of genes or chromosomes.[4] These laws could be easily circumvented by undertaking tests of gene products such as proteins or enzymes (rather than on the RNA, DNA, gene, or chromosome itself). The most common Tay-Sachs test, for example, is of the gene products, not the genes. The following link to the National Conference of State Legislatures contains a table that describes each state's laws: http://www.ncsl.org/programs/health/genetics/ndishlth.htm

All of these laws, however, suffer from various loopholes. Some protect people from discrimination based only on genetic *test* results, but would not prohibit discrimination based on genetic information gathered by other means. Others define a "genetic test" too narrowly, as in Minnesota, where protections apply only to testing for the presence or absence of genes.[5] There are often reports of describing, for example, a "breast cancer gene," which makes it sound like you will get cancer if you have the gene and not get cancer if you don't. However, *everyone* has a breast cancer gene. It's just that some people have mutations in that gene which predispose to cancer. Thus, it would be extremely rare for a person's predisposition to disease to be due to the actual presence or absence of a gene.

U.S. Federal Law

At the federal level in the United States, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides some protection against genetic discrimination, such as barring the use of genetic information in denying or limiting health insurance coverage for members of a group plan. HIPAA provides certain protections so that people do not lose health insurance coverage if they change jobs. Under HIPAA, insurers providing health coverage for a group of 50 or more individuals may not deny an applicant as a result of a health status-related factor, nor establish eligibility for enrollment on the basis of health status, medical history or genetic information. A new employer cannot deny coverage or apply preexisting-condition exclusions for more than twelve months for any condition treated or diagnosed in the preceding twelve months. The law does not, however, prohibit genetic discrimination against people seeking insurance under individual plans, such as denial of coverage or charging exorbitant premiums for coverage, and it does not prohibit group insurers from charging higher rates to a whole group based on genetic information about a particular individual. HIPAA also does not prohibit employers from restricting benefits or coverage, or charging higher premiums. HIPAA also does not prohibit insurers from basing ratings on genetic information or prevent health insurers from disclosing or demanding access to such information.

In the employment context, in 1995 the Equal Employment Opportunity Commission (EEOC) interpreted the Americans with Disabilities Act (ADA) to protect a person's genetic predisposition to disease, but the interpretation did not address whether someone can be denied a job because he or she is a carrier of a recessive disorder (and the potential employer does not want to pay health costs associated with potential or actual affected children), nor did it prevent employers from requiring that potential employees undergo genetic testing. The EEOC interpretation was not binding for court decisions or other agencies. In 2000, President Clinton issued an executive order protecting federal employees from genetic discrimination.[6]

However, in 2002, in *Chevron USA, Inc. v. Echazabal*, the United States Supreme Court utilized in their decision an EEOC rule interpreting the ADA to permit employers to exclude an employee or job applicant from a position that would pose a direct threat to the employee's own health.[7] The Court found that predictive information contained in a worker's genome that indicated liver damage due to Hepatitis C could be used to support an argument that working with the employer would expose him to harmful toxins that would increase his liver damage, even though the worker was asymptomatic and may never be adversely affected by workplace environments.[8]

Pending Federal Legislation (108th Congress)

Unlike U.S. federal laws that protect against discrimination based on race, sex, or ethnicity, there is no existing federal law to protect one against discrimination based on predispositional, or other, genetic information.

Three genetic antidiscrimination bills are currently pending at the federal level: S. 1053, introduced by Senator Snowe, and H.R. 1910, introduced by Representative Slaughter, concerning health insurance and employment discrimination; H.R. 3636, introduced by Representative Stearns, concerning only health insurance discrimination.

International Policy

The Convention on Human Rights and Biomedicine was passed by the Council of Europe in 1997, and is a binding treaty that prohibits any form of genetic discrimination and allows predictive genetic tests only for health purposes or for scientific research linked to health purposes. It has been ratified by 18 nations and signed by 13 additional nations. The United States has not signed the treaty. The treaty, number 164, can be found at: http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm.

In Europe there are few national laws that specifically address genetic testing or privacy in the context of health insurance. This is due in large part to the lessened concern over insurance discrimination within countries that have national health care systems.

Belgium became the first country in the world to enact a law prohibiting the use of genetic information or data for insurance underwriting purposes. Denmark and France also now prohibit insurance companies from using genetic tests, whereas Sweden and the Netherlands authorize the use of genetic susceptibility tests with the consent of the individual tested where the insurance policy is above a certain financial level.[9] In France, Austria, Norway, the Netherlands, and Belgium, genetic testing for employment purposes is illegal.[10]

Britain has adopted a self-regulation approach on the use of genetic information. Britain's moratorium on the use of genetic information for underwriting applies to life insurance policies up to £500,000 and protection up to £300,000 for critical illness, long-term care insurance, and income-protection policies. Over those limits, Britain's insurance industry may consider genetic data, but only if the genetic tests used have been approved by the Genetics and Insurance Committee. British employers are not prohibited from using genetic data or testing, and a survey the Human Genetics Commission reports that: "There still does not seem to be any evidence that genetic test information is being used in employment, either during recruitment or as part of occupational health programmes. The Ministry of Defence has confirmed that they no longer screen aircrew recruits for sickle cell disease carrier status, although selective testing may be carried out where there is a clinical indication."[11]

---

[1] 410 ILCS 513/20(a).

[2] 410 ILCS 513/20(b).

[3] Wisc. Stat. § 631.89(1).

[4] Ind. Code Ann. § 27-8-26(2)(a); Ohio Rev. Code Ann. § 1751.64(A).

[5] Minn. Stat. Ann. § 72A-139(2)(b).

[6] *See* Executive Order No. 13145, February 8, 2000.

[7] *See* Chevron USA, Inc. v. Echazabal, 122 S.Ct. 2045 (2002).

[8] Chevron USA, Inc. v. Echazabal, 122 S.Ct. 2045, 2053 (2002).

[9] Herman Nys, et al., "Genetic Testing: Patients' Rights, Insurance and Employment, A Survey of Regulations in the European Union," at 141-142 (2002).

[10] *See* Opinion of the European Group on Ethics in Science and New Technologies to the European Comm'n, "Ethical Aspects of Genetic Testing in he Workplace," July 28, 2003, at 11.

[11] Human Genetics Comm'n, "Inside Information: Balancing Interests in the Use of Personal Genetic Data" at 8.8 (2002).