

Genetic Discrimination and Health Insurance: An Urgent Need for Reform

Kathy L. Hudson, Karen H. Rothenberg, Lori B. Andrews, Mary J₀ Ellis Kahn, Francis S. Collins

The accelerated pace of gene discovery and molecular medicine portend a future in which information about a plethora of disease genes can be readily obtained. As at-risk populations are identified, research can be done to determine effective prevention and treatment strategies that will lower the personal, social, and perhaps the financial costs of disease in the future. We all carry genes that predispose to common illnesses. In many circumstances knowing this information can be beneficial, as it allows individualized strategies to be designed to reduce the risk of illness. But, as knowledge about the genetic basis of common disorders grows, so does the potential for discrimination in health insurance coverage for an ever increasing number of Americans.

The use of genetic information to exclude high-risk people from health care by denying coverage or charging prohibitive rates will limit or nullify the anticipated benefits of genetic research. In addition to the real and potentially devastating consequences of being denied health insurance, the fear of discrimination has other undesirable effects. People may be unwilling to participate in research and to share information about their genetic status with their health care providers or family members because of concern about misuse of this information. As genetic research progresses, and preventive and treatment strategies are developed, it will be increasingly important that discrimination and the fear of discrimination not be a roadblock to reaping the benefits. To address these issues, the National Institutes of Health—Department of Energy (NIH-DOE) Working Group on Ethical, Legal, and Social Implications (ELSI) of the Human Genome

K.L. Hudson is assistant director for Policy Coordination, National Center for Human Genome Research, National Institutes of Health (NIH). K. H. Rothenberg is Marjorie Cook Professor of Law and director of the Law and Health Care Program, University of Maryland School of Law, and member of the National Action Plan on Breast (NAPBC). L. B. Andrews is chair of The NIH-DOE Energy Working Group on Ethical, Legal, and Implications and professor at Chicago-Kent of Law. M. J. Ellis Kahn represents the Virginia cancer Foundation and the National Breast Coalition and is co-chair of the Hereditary Susceptibility Working Group, NAPBC. F. S.

Project and the National Action Plan on Breast Cancer

have jointly developed a series of recommendations for state and federal policy-makers which are presented below.

In the past, genetic information has been used by insurers to discriminate against people. In the early 1970s, some insurance companies denied coverage and charged higher rates to African Americans who were carriers of the gene for sickle cell anemia (1). Contemporary studies have documented cases of genetic discrimination against people who are healthy themselves but who have a gene that predisposes them or their children to a later illness such as Huntington's disease (2). In a recent survey of people with a known genetic condition in the family, 22% indicated that they had been refused health insurance coverage because of their genetic status, whether they were sick or not (3).

As a case example, Paul (not his real name) is a healthy, active 4-year-old, but he has been twice denied health insurance. Paul's mother died in her sleep of sudden cardiac arrest when Paul was only 5 months old. Paul's maternal uncle also died of sudden cardiac arrest when he was in his twenties. After these sudden and unexpected deaths, Paul's family began a hunt to discover the cause. Their search finally led to a research geneticist who was able to determine that several family members, including Paul and his mother, carried an alteration in a gene on chromosome 7. This gene is one of several genes that causes the long QT syndrome, so-called because of the distinctive diagnostic pattern on an electrocardiogram.

Several years ago, Paul's father, Bob, lost his job and with it the group policy that provided health insurance coverage for Paul and him. Paul's father has repeatedly applied for a family health insurance policy with a major insurance company. The company agreed to cover Bob but refused to issue a family policy that would cover Paul because he has inherited the altered gene for the long QT syndrome from his mother.

The story of Jackie and Emma further illustrates the social, ethical, and legal dilemmas presented by the revelation of genetic information. Sisters Jackie and Emma,

along with many other members of their family, have been tested as part of a research protocol for alterations in the gene, BRCA1, that confers hereditary susceptibility to breast and ovarian cancer. Both were offered an opportunity to learn the results of their genetic tests and both accepted. They each learned they carry an altered form of the gene, putting them at increased risk for breast and ovarian cancer.

After finding out the results of her genetic test, Emma had a mammogram that showed a very small lesion in her breast. A subsequent biopsy revealed carcinoma, and Emma decided to proceed with a bilateral mastectomy because of the substantial risk of cancer arising in the opposite breast. Her lymph nodes were negative for cancer, so her prognosis for cure is very good.

Emma's sister Jackie also tested positive for the same alteration in the BRCA1 gene, though no cancer was detected. Although the benefit of prophylactic mastectomy in reducing the risk for breast cancer is not yet known, she decided to have a bilateral prophylactic mastectomy. Emma and Jackie feel strongly that they have benefited from knowing this genetic information but are fearful that it will be used against them and their family by insurers and employers. They both keep their genetic status secret and are so fearful of losing their health insurance that they used assumed names when sharing their story at a recent workshop on genetic discrimination (4).

Emma and Jackie's story is not unique. An estimated 1 in 500 women carry a mutation in the BRCA1 gene that may confer as much as an 85% chance of breast cancer and a 50% chance of ovarian cancer (5). Although substantial uncertainty exists about the relative value of the available options (surgery compared with intensive surveillance) for a woman with a BRCA1 mutation, it is likely that ultimately this information will be medically useful.

Health Insurance in the United States

Because of high costs, insurance is essentially required to have access to health care in the United States. Over 40 million people in the United States are uninsured (6). Group insurance, individual insurance, self-insurance, and publicly financed insurance (for example, Medicare and Medicaid) are the principal forms of health insurance in the United States for the —240 million Americans with coverage. Most people get their health insurance through their employer. Many employers provide health insurance coverage through self-funded plans in which the employer, either directly or

policies related to human genome research and its applications. The ELSI Working Group has long been involved in discussions about the fair use of genetic information. In a 1993 report, "Genetic Information and Health Insurance" (11), the ELSI Working Group recommended a return to the risk-spreading goal of insurance. The Working Group suggested that individuals be given access to health care insurance irrespective of information, including genetic information about their past, current, or future health status. Because denial of insurance coverage for a costly disease such as breast cancer may prove to be a death sentence for many women, the National Action Plan on Breast Cancer (NAPBC), a public-private partnership designed to eradicate breast cancer as a threat to the lives of American women, has identified genetic discrimination in health insurance as a high priority (12).

Building on their shared concerns, the f NAPBC (13) and the ELSI Working Group (14) recently cosponsored a workshop on genetic discrimination and health insurance a (4). Scientists, representatives from the insurance industry, and members of the ELSI Working Group and the NAPBC participated in the 1-day session. On the basis of the information presented at the workshop, the ELSI Working Group and the NAPBC developed the following recommendations and definitions for state and federal policymakers to protect against genetic discrimination.

- 1) 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.
- 2) Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.
- 3) Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.
- 4) 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 set disclosure would be made.

The definitions are as follows. Genetic information is information about genes, gene products, or inherited characteristics that may derive from the individual or a family member. Insurance provider means an insurance company, employer, or any other entity providing a plan of health insurance or health benefits including group and individual health plans whether fully insured or self-funded.

These recommendations have been endorsed by the National Advisory Council for Human Genome Research (NACHGR) (15). The NACHGR

stresses the positive value of genetic information for improving the medical care of individual patients and the need to ensure the freedom of patients and their health care providers to use genetic information for patient care. The NACHGR views the elimination of the use of genetic information to discriminate against individuals in their access to health insurance as a critical step toward these goals.

The ability to obtain sensitive genetic information about individuals, families, and even populations raises profound and troubling questions about who will have access to this information and how it will be used. The recommendations presented here for state and federal policy-makers are intended to help ensure that our current social, economic, and health care policies keep pace with both the opportunities and challenges that the new genetics present for understanding the causes of disease and developing new treatment and preventive strategies.

REFERENCES AND NOTES

1. L. Andrews, *Medical Genetics: A Legal Frontier* (American Bar Foundation, Chicago, IL 1987).
2. P. R. Billings *et al*, *Am. J Hum. Genet.* 50, 476 (1992).
3. E. V. Lapham (Georgetown University) and J. O. Weiss, *The Alliance of Genetic Support Groups*. Human Genome Model Project, preliminary results of a survey of persons with a genetic disorder in the family.
4. "Genetic discrimination and health insurance: A case study on breast cancer," Bethesda, MD, 11 July 1995. workshop sponsored by the National Action Plan on Breast Cancer (NAPBC) and the NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.
5. D. F. Easton *et al*, *Am. J Hum. Genet.* 52, 678 (1993); D. Ford *et al.*, *Lancet* 34.3, 692 (1994).
6. *Employee Benefit Research Institute Special Report SR-28*, issue brief number 158, February 1995.
7. K. H. Rothenberg, *1 Law Med. Ethics*, in press.
8. North Carolina, NC ST: 58-65-70 (1975), Florida, FL ST: 626.9707 (1978), Alabama, AL ST: 27-5-13 (1982). In 1987, Maryland passed a law, Art. 48A, 223(b)(4), prohibiting health insurers from discrimination in rates based on genetic traits unless there was

9. 'actuarial (justification)'. In March 1995, the U.S. Equal Employment Opportunity Commission (EEOC) released official guidance on the definition of the term "disability." The EEOC's guidance clarifies that protection under the Americans with Disabilities Act (ADA) extends to individuals who are discriminated against in employment decisions solely on the basis of genetic information about an individual. For example, an employer who makes an adverse employment decision on the basis of an individual's genetic predisposition to disease, whether because of concerns about insurance costs, productivity, or attendance, is in violation of the ADA because that employer is regarding the individual as disabled. Issuance of the EEOC's guidance is precedent setting; it is the first broad federal protection against the unfair use of genetic information.
10. *Health Security Act*, Section 516, S. 1757/HR 3600.
11. "Genetic information and health insurance: Report of the task force on genetic information and insurance" (NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research, 10 May 1993).
12. The NAPBC has as its mission to reduce the morbidity and mortality from breast cancer and to prevent the disease. Specific goals include the following: (i) to promote a national effort to establish and address priority issues related to breast cancer etiology, early detection, treatment, and prevention; (ii) to promote and foster communication, collaboration, and cooperation among diverse public and private partners; and (iii) to develop strategies, actions, and policies to improve breast cancer awareness, services, and research.
13. NAPBC steering committee: Susan J. Blumenthal (co-chair), Zora Kramer Brown, Doris Browne, Anna K. Chacko, Francis S. Collins, Nancy W. Con-nell, Kay Dickerson, Arlyne Draper, Nancy Evans, Harmon Eyre, Leslie Ford, Janyce N. Hedetniemi, Mary Jo Ellis Kahn, Amy S. Langer, Susan M. Love, Alan Rabson, Jane Reese-Coulbourne, Irene M. Rich, Barbara K. Rirrier, Susan Sieber, Edward Sondik, and Frances M. Visco (co-chair). NAPBC hereditary susceptibility working group: Kathleen A. Caizone, Francis S. Collins (co-chair), Sherman Elias, Linda Finney, Judy E. Garber, Ruthann M. Giusti, Jay R. Harris, Joseph K. Hurd Jr., Mary Jo Ellis Kahn (co-chair), Mary-Claire King, Caryn Lerman, Mary Jane Massie, Paul G. McDonough, Patricia D. Murphy, Philip D. Nouguchi, Barbara K. Rimer, Karen H. Rothenberg, Karen K. Steinberg, and Jill Stopfer.
14. ELSI working group: Betsy Anderson, Lcd Andrews (chair), James Bowman (dissenting), David Ccx, Troy Duster, (vice chair), Rebecca Eisenberg, Beth Fine, Neil Holtzman, Philip Kitcher, Joseph McInerney, Jeffrey Murray, Dorothy Nelkin, Rayna Rapp, Marsha Saxton, and Nancy Wexler.
15. NCHGR council members: Anita Allen, Lenette J. Benjamin; David Botstein, R. Daniel Camerini-Otero (dissent with recommendation 3), Ellen W. Clayton, Troy Duster, Leroy E. Hoed, David E. Housman,

known as underwriting. Insurers argue that underwriting is essential in a voluntary market to prevent “adverse selection,” in which individuals elect not to purchase insurance until they are already ill or anticipate a future need for health care. Insurers fear that individuals will remain uninsured until, for example, they receive a genetic test result indicating a predisposition to some disease such as breast or colon cancer.

In the absence of the ability to detect hereditary susceptibility to disease, the costs of medical treatment have been absorbed under the current health insurance system of shared risk and shared costs. Today, our understanding of the relation between a misspelling in a gene and future health is still incomplete, thus limiting the ability of insurers to incorporate genetic risks into actuarial calculations on a large scale. As genetic research enhances the ability to predict individuals’ future risk of diseases, many Americans may become uninsurable on the basis of genetic information.

State and Federal Initiatives

A recent survey has shown that a number of states have enacted laws to protect individuals from being denied health insurance on the basis of genetic information (Fig. 1) (7). The first laws addressing genetic discrimination were quite limited in scope and focused exclusively on discrimination against people with a single genetic trait such as sickle cell trait (8). Since the Human Genome Project was launched in 1990, eight states have enacted some form of protection against genetic discrimination in health insurance. The recently enacted state laws are not limited to a specific genetic trait but apply potentially to an unlimited number of

genetic conditions. These state laws prohibit insurers from denying coverage on the basis of genetic test results, and prohibit the use of this information to establish premiums, charge differential rates, or limit benefits. A few of these states, including Oregon and California, integrate protection against discrimination in insurance practices with privacy protections that prohibit insurers from requesting genetic information and from disclosing genetic information without authorization.

Two factors limit the protection against discrimination afforded by current state laws. First, the federal Employee Retirement Income Security Act exempts self-funded plans from state insurance laws. Nationwide, over one-third of the nonelderly insured population obtains health insurance coverage through a self-funded plan. Second, nearly all of the state laws focus narrowly on genetic tests, rather than more broadly on genetic information generated by family history, physical examination, or the medical record (7). Limiting the scope of protection to results of genetic tests means that insurers are only prohibited from using the results of a chemical test of DNA, or in some cases, the protein product of a gene. But insurers can use other phenotypic indicators, patterns of inheritance of genetic characteristic, or even requests for genetic testing as the basis of discrimination. Meaningful protection against genetic discrimination requires that insurers be prohibited from using all information about genes, gene products, or inherited characteristics to deny or limit health insurance coverage.

No federal laws are currently in place to prohibit genetic discrimination in health insurance (9), The Clinton Administra-

tion’s proposal to reform the health care system and provide health insurance for all Americans did prohibit limiting access or coverage on the basis of “existing medical conditions or genetic predisposition to medical conditions” (10).

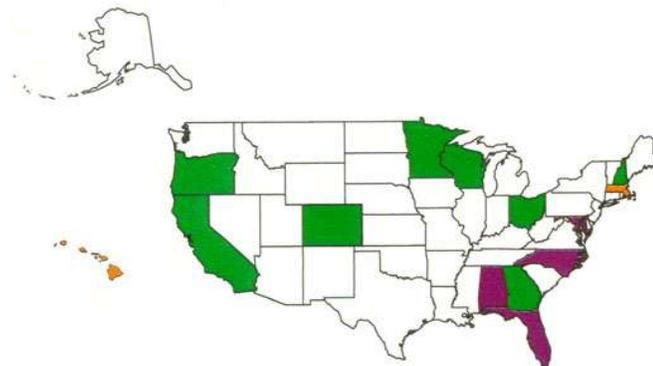
Congressional efforts to reform the health care system in 1995 have been much more modest and are targeted at guaranteeing access, portability, and renewability of coverage and at leveling the playing field in the insurance market so that the same rules apply to insured and self-funded plans. Recent federal health insurance reform proposals attempt to guarantee the availability of health care by prohibiting insurers from denying coverage on the basis of health status, medical condition, claims experience, or medical history of a participant. Most of the proposals permit exclusions for pre-existing conditions, but these are time limited.

It is not clear if the current health insurance reform proposals would prohibit insurers from denying coverage on the basis of genetic information. Genetic information is distinct from other types of medical information because it provides information about an individual’s predisposition to future disease. In addition, genetic information can provide clues to the future health risks for an individual’s family members. If enacted, current health reform proposals would prohibit denying insurance to those currently suffering from disease or with a past history of disease. But these proposals may not protect people like Paul, who are healthy but have a genetic predisposition to disease, from being refused insurance coverage. Current proposals also may fail to protect couples who, although healthy themselves, carry the gene for a recessive disorder such as cystic fibrosis that might affect their children or future children.

Recommendations

Planners of the Human Genome Project recognized from the beginning that maximizing the medical benefits of genome research would require a social environment in which health care consumers were protected from discrimination and stigmatization based on their genetic makeup. Genome programs at both the DOE and the National Center for Human Genome Research, a component of NIH, have each set aside a portion of their research budget to anticipate, analyze, and address the ELSI of new advances in human genetics. The original planners also created the NIH-DOE ELSI Working Group, which has a broad and diverse membership including genome scientists; medical geneticists; experts in law, ethics, and philosophy; and consumers, to explore and propose options for the development of sound professional and public

Fig. 1. State laws on the use of genetic information in health insurance (7). States shown in purple were the first states—to enact legislation addressing genetic issues in insurance. Florida and Alabama laws prohibit insurers from denying coverage on the basis of the sickle cell trait. North Carolina prohibits insurers from denying coverage because the applicant has the hemoglobin C or sickle cell trait.



Maryland prohibits discrimination in rates based on any genetic trait unless there is actuarial justification. States shown in green (California, Oregon, Colorado, Minnesota, Wisconsin, Ohio, Georgia, and New Hampshire) prohibit insurers, to varying degrees, from requiring or requesting genetic tests or their results, from denying coverage on the basis of genetic tests, and from using tests to determine rates

and benefits. California, Colorado, Oregon, and Wisconsin laws include provisions to protect the privacy of genetic information. States shown in orange (Massachusetts and Hawaii) have related bills pending.

Health Insurance Portability and Accountability Act, 104 Public Law No. 104-191, 701, 110 Stat 1936 (1996).

National Partnership for Women & Families, Guide to HIPAA: What the Health Insurance Reform Law Means for Women & Families (1998).

U.S. Department of Health and Human Services, HHS Fact Sheet: Health Insurance Portability and Accountability Act of 1996 (August 21, 1996).

Health Insurance Issue Update:

http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/99upins21.htm

NATIONAL HUMAN GENOME RESEARCH
INSTITUTE

ISSUE UPDATE

October 1999

HEALTH INSURANCE DISCRIMINATION

The public is concerned that genetic information will be used by insurers to deny, limit or cancel their health insurance. This concern is affecting the choices individuals make about their own health care and their decisions whether to participate in research. Survey results released in March of 1998 found that 69 percent of Americans thought health insurers should be barred from accessing genetic information. (1) A majority of respondents (63 percent) said they probably or definitely would not take a genetic test if insurers or employers would have access to the results. In genetic testing studies at the NIH, nearly 32 percent of eligible people recently offered a test for breast cancer risk declined to take it, most citing concerns about health insurance discrimination and loss of privacy.

Recommendations for Action

On July 11, 1995, the NIH-DOE Ethical, Legal and Social Implications (ELSI) Working Group and the National Action Plan on Breast Cancer (NAPBC) cosponsored a workshop on genetic discrimination and health insurance to develop recommendations for action. (2) The findings and recommendations of the workshop were subsequently endorsed by the NHGRI Council and published in the October 20 issue of Science. (3) It is important to note that the Workshop recommendations focus on health insurance. The characteristics and social purpose of life and disability insurance were viewed as sufficiently different to warrant separate consideration.

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPAA was the first step toward implementation of the NIH-DOE ELSI Working Group and NAPBC recommendations and provided some protection from discrimination, but loopholes remain.

HIPAA did:

- Prohibit excluding an individual from group coverage because of past or present medical problems, including genetic information.
- Prohibit charging a higher premium to an individual than to others in the group.
- Limit exclusions in group health plans for preexisting conditions to 12 months, and prohibits such exclusions if

the individual has been previously covered for that condition for 12 months or more.
State explicitly that genetic information in the absence of a current diagnosis of illness shall not be considered a preexisting condition.

HIPAA did not:

Prohibit an insurer from denying coverage to individuals seeking health insurance in the individual market based upon genetic information.
Prohibit the use of genetic information as a basis for charging exorbitant premiums for health insurance.
Limit the collection of genetic information by insurers and prohibit insurers from requiring an individual to take a genetic test.
Limit the disclosure of genetic information by insurers.

Administration Response:

On May 18, 1997, the President, speaking at Morgan State University, urged passage of "bipartisan legislation to prohibit insurance companies from using genetic information to determine the premium rate or eligibility of Americans for health insurance." The recommendations endorsed by the President are included in a July 1997 report issued by the Department of Health and Human Services. (4)

Key Principles for Legislation

Definition of Predictive Genetic Information

To provide protection, the definition of predictive genetic information in the legislation must include family history. It is not sufficient to limit the definition to information derived from a genetic test, as many of the states have done. Failing to protect information about family medical history would allow insurers in the individual market to use predictive genetic information, such as cause of death and/or a history of disease in parents or siblings, to deny coverage or charge exorbitant premiums. The elements of the definition of predictive genetic information include:

1. An individual's request for or receipt of genetic services;
2. The results of an individual's genetic test or tests;
3. The results of genetic tests of family members of an individual; and
4. An individual's family medical history.

Closing HIPAA Loopholes

Currently healthy individuals, seeking health insurance in the individual market, should be protected from insurers using predictive genetic information in decisions about coverage, enrollment, or premiums.
Individuals enrolled in a group health plan should be protected from insurers increasing the premiums of the whole group based on predictive genetic information of one or more individuals in the group.
Individuals should be protected from being required to take a genetic test.
Individuals should be protected from the disclosure of genetic information to insurers, plan sponsors (employers), and medical information bureaus, without their consent.
In order to assure individuals that the protections afforded by the legislation will deter violations by insurers, penalties in HIPAA for a violation of the discrimination and disclosure provisions should be strengthened.

Congressional Activity

Nine bills were introduced in the 105th Congress to address the "holes" in HIPAA, but none received final action. The following bills have been introduced in the 106th Congress:

H.R. 293

Genetic Information Health Insurance Nondiscrimination Act of 1999;
(Representative Sweeney, R-NY)

H.R. 306

Genetic Information Nondiscrimination in Health Insurance Act of 1999;
(Representative Slaughter, D-NY, 191 cosponsors as of 6/99)

H.R. 2457

Genetic Nondiscrimination in Health Insurance and Employment Act of 1999;
(Representative Slaughter, D-NY, 17 cosponsors; companion to S. 1322)

H.R. 2555

- Genetic Privacy and Nondiscrimination Act of 1999
(Representative Stearns, R-FL, 16 cosponsors)
- S. 300
Genetic Information Nondiscrimination in Health Insurance Act of 1999;
(Title II of S. 300, Patients' Bill of Rights Act, Senator Lott, R-MS)
- S. 326
Genetic Information Nondiscrimination in Health Insurance Act of 1999;
(Title II of S. 326, Patients' Bill of Rights Act, Senator Jeffords, R-VT)
- S. 543
Genetic Information Nondiscrimination in Health Insurance Act of 1999;
(Senator Snowe, R-ME)
- S. 1322
Genetic Nondiscrimination in Health Insurance and Employment Act of 1999;
(Senator Daschle, D-SD, 3 Cosponsors)
- S. 1344
(Genetic Information Nondiscrimination in Health Insurance Act of 1999;
(Title II of S. 1344, Patients' Bill of Rights Act, passed Senate 7-15-99)

Current Status - States

Most states have now enacted HIPAA-conforming legislation. In addition, thirty five states have enacted legislation regarding genetic discrimination and health insurance, and there continues to be a high degree of interest in this topic in the state legislatures. In the 1999 state legislative sessions, there have been over 100 bills introduced regarding genetic discrimination in the workplace and/or genetic discrimination by insurers. Some of these state bills would inaugurate genetic antidiscrimination protection, while other bills would modify or clarify existing antidiscrimination legislation.

ENDNOTES

1. National Center for Genome Resources survey, "Attitudes Toward Genetic Testing", March 4, 1998.
2. "Genetic discrimination and health insurance: A case study on breast cancer," Bethesda, MD, 11 July 1995, workshop sponsored by the National Action Plan on Breast Cancer (NAPBC) and the NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.
3. Hudson, Kathy et al, "Genetic Discrimination and Health Insurance: An Urgent Need for Reform," Science, Vol. 270, 391-93, 20 October, 1995.
4. "Health Insurance in the Age of Genetics," Department of Health and Human Services, July 1997 (www.nhgri.nih.gov:80/NEWS/Insurance).

Genetic Information and Health Insurance: Enacted Legislation.

http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm

<http://www.ornl.gov/hgmis/publicat/hgn/v8n3/01fear.html>

Protection under HIPAA

NATIONAL HUMAN GENOME RESEARCH INSTITUTE

ISSUE UPDATE

October 1999

HEALTH INSURANCE DISCRIMINATION

The public is concerned that genetic information will be used by insurers to deny, limit or cancel their health insurance. This concern is affecting the choices individuals make about their own health care and their decisions whether to participate in research. Survey results released in March of 1998 found that 69 percent of Americans thought health insurers should be barred from accessing genetic information.⁽¹⁾ A majority of respondents (63 percent) said they probably or definitely would not take a genetic test if insurers or employers would have access to the results. In genetic testing studies at the NIH, nearly 32 percent of eligible people recently offered a test for breast cancer risk declined to take it, most citing concerns about health insurance discrimination and loss of privacy.

Recommendations for Action

On July 11, 1995, the NIH-DOE Ethical, Legal and Social Implications (ELSI) Working Group and the National Action Plan on Breast Cancer (NAPBC) cosponsored a workshop on genetic discrimination and health insurance to develop recommendations for action.⁽²⁾ The findings and recommendations of the workshop were subsequently endorsed by the NHGRI Council and published in the October 20 issue of *Science*.⁽³⁾ It is important to note that the Workshop recommendations focus on health insurance. The characteristics and social purpose of life and disability insurance were viewed as sufficiently different to warrant separate consideration.

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPAA was the first step toward implementation of the NIH-DOE ELSI Working Group and NAPBC recommendations and provided some protection from discrimination, but loopholes remain.

HIPAA did:

- Prohibit excluding an individual from group coverage because of past or present medical problems, including genetic information.
- Prohibit charging a higher premium to an individual than to others in the group.

- Limit exclusions in group health plans for preexisting conditions to 12 months, and prohibits such exclusions if the individual has been previously covered for that condition for 12 months or more.
- State explicitly that genetic information in the absence of a current diagnosis of illness shall not be considered a preexisting condition.

HIPAA did not:

- Prohibit an insurer from denying coverage to individuals seeking health insurance in the individual market based upon genetic information.
- Prohibit the use of genetic information as a basis for charging exorbitant premiums for health insurance.
- Limit the collection of genetic information by insurers and prohibit insurers from requiring an individual to take a genetic test.
- Limit the disclosure of genetic information by insurers.

Administration Response:

On May 18, 1997, the President, speaking at Morgan State University, urged passage of "bipartisan legislation to prohibit insurance companies from using genetic information to determine the premium rate or eligibility of Americans for health insurance." The recommendations endorsed by the President are included in a July 1997 report issued by the Department of Health and Human Services. [\(4\)](#)

Key Principles for Legislation

Definition of Predictive Genetic Information

To provide protection, the definition of predictive genetic information in the legislation must include family history. It is not sufficient to limit the definition to information derived from a genetic test, as many of the states have done. Failing to protect information about family medical history would allow insurers in the individual market to use predictive genetic information, such as cause of death and/or a history of disease in parents or siblings, to deny coverage or charge exorbitant premiums. The elements of the definition of predictive genetic information include:

1. An individual's request for or receipt of genetic services;
2. The results of an individual's genetic test or tests;
3. The results of genetic tests of family members of an individual; and
4. An individual's family medical history.

Closing HIPAA Loopholes

- Currently healthy individuals, seeking health insurance in the individual market, should be protected from insurers using predictive genetic information in decisions about coverage, enrollment, or premiums.
- Individuals enrolled in a group health plan should be protected from insurers increasing the premiums of the whole group based on predictive genetic information of one or more

individuals in the group.

- Individuals should be protected from being required to take a genetic test.
- Individuals should be protected from the disclosure of genetic information to insurers, plan sponsors (employers), and medical information bureaus, without their consent.
- In order to assure individuals that the protections afforded by the legislation will deter violations by insurers, penalties in HIPAA for a violation of the discrimination and disclosure provisions should be strengthened.

Congressional Activity

Nine bills were introduced in the 105th Congress to address the "holes" in HIPAA, but none received final action. The following bills have been introduced in the 106th Congress:

- H.R. 293 *Genetic Information Health Insurance Nondiscrimination Act of 1999*;
(Representative Sweeney, R-NY)
- H.R. 306 *Genetic Information Nondiscrimination in Health Insurance Act of 1999*;
(Representative Slaughter, D-NY, 191 cosponsors as of 6/99)
- H.R. 2457 *Genetic Nondiscrimination in Health Insurance and Employment Act of 1999*;
(Representative Slaughter, D-NY, 17 cosponsors; companion to S. 1322)
- H.R. 2555 *Genetic Privacy and Nondiscrimination Act of 1999*
(Representative Stearns, R-FL, 16 cosponsors)
- S. 300 *Genetic Information Nondiscrimination in Health Insurance Act of 1999*;
(Title II of S. 300, Patients' Bill of Rights Act, Senator Lott, R-MS)
- S. 326 *Genetic Information Nondiscrimination in Health Insurance Act of 1999*;
(Title II of S. 326, Patients' Bill of Rights Act, Senator Jeffords, R-VT)
- S. 543 *Genetic Information Nondiscrimination in Health Insurance Act of 1999*;
(Senator Snowe, R-ME)
- S. 1322 *Genetic Nondiscrimination in Health Insurance and Employment Act of 1999*;
(Senator Daschle, D-SD, 3 Cosponsors)
- S. 1344 (*Genetic Information Nondiscrimination in Health Insurance Act of 1999*;
(Title II of S. 1344, Patients' Bill of Rights Act, passed Senate 7-15-99)

Current Status - States

Most states have now enacted HIPAA-conforming legislation. In addition, thirty five states have enacted legislation regarding genetic discrimination and health insurance, and there continues to be a high degree of interest in this topic in the state legislatures. In the 1999 state legislative sessions, there have been over 100 bills introduced regarding genetic discrimination in the workplace and/or genetic discrimination by insurers. Some of these state bills would inaugurate genetic antidiscrimination protection, while other bills would modify or clarify existing

antidiscrimination legislation.

ENDNOTES

1. National Center for Genome Resources survey, "Attitudes Toward Genetic Testing", March 4, 1998.
2. "Genetic discrimination and health insurance: A case study on breast cancer," Bethesda, MD, 11 July 1995, workshop sponsored by the National Action Plan on Breast Cancer (NAPBC) and the NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.
3. Hudson, Kathy et al, "Genetic Discrimination and Health Insurance: An Urgent Need for Reform," *Science*, Vol. 270, 391-93, 20 October, 1995.
4. "Health Insurance in the Age of Genetics," Department of Health and Human Services, July 1997 (www.nhgri.nih.gov:80/NEWS/Insurance).

GENETIC INFORMATION AND HEALTH INSURANCE

ENACTED LEGISLATION

This chart reflects legislation enacted as of August, 1999.

State	Citation	Description
Alabama (1982)	AL ST: 27-5-13	Prohibits health insurers from denying coverage because applicant has sickle cell anemia.
Alabama (1997)	H 113	<p>Prohibits health insurers from requiring genetic testing to determine a predisposition for cancer.</p> <p>Prohibits health insurers from using genetic testing for a predisposition for cancer to determine insurability or to determine rates or benefits.</p> <p>Genetic test: A pre-symptomatic laboratory test which is generally accepted in the scientific and medical communities for the determination of the presence or absence of the genetic characteristics that cause or are associated with risk of a disease or disorder.</p> <p>Genetic characteristics: A scientifically or medically identifiable gene or chromosome, or alteration thereof, that is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder.</p>
Arizona (1997)	H 2144	<p>Prohibits disability insurers (includes health insurers) from rejecting an application or determining rates, terms or conditions on the basis of a genetic condition - in the absence of a diagnosis of the condition.</p> <p>Prohibits a person from requiring the performance of or performing a genetic test without written informed consent.</p> <p>Prohibits the release of the results of a genetic test without consent.</p> <p>Prohibits employers from failing or refusing to hire, from discharging or from otherwise discriminating on the basis of the results of a genetic test.</p> <p>Genetic test: An analysis of an individual's DNA, gene products or chromosomes that indicates a propensity for or susceptibility to illness, disease, impairment or other disorders, whether physical or mental, or that demonstrates genetic or chromosomal damage due to environmental factors, or carrier status for disease or disorder.</p>

		Genetic condition: A specific chromosomal or single-gene genetic condition.
Arizona (2000)	HB 2041	<p>Provides that genetic testing and information derived from genetic testing are confidential and considered privileged to the person tested and shall be released only to:</p> <ol style="list-style-type: none"> 1. The person tested 2. Any person who is specifically authorized in writing by the person tested or by that person's authorized representative to receive this information. 3. The authorized representative of the person tested 4. A researcher for medical research or public health purposes 5. A third person if approved by a human subjects review committee or a human ethics committee, with respect to persons who are subject to an Arizona cancer registry. 6. An authorized agent or employee of a health care provider if <ol style="list-style-type: none"> a. The health care provider performs the test or is authorized to obtain the test results by the person tested for the purposes of genetic counseling or treatment. b. The agent or employee provides patient care, treatment or counseling. c. The agent or employee needs to know the information in order to conduct the test or provide patient care, treatment or counseling. 7. A health care provider that procures, processes, distributes or uses: <ol style="list-style-type: none"> a. A human body part from a deceased person with respect to medical information regarding that person b. Semen or ova for the purpose of artificial insemination 8. A health care provider to conduct utilization review, peer review and quality assurance 9. Authorized agent of a federal, state or county health department to conduct activities specifically authorized pursuant to the laws of this state for the birth defects registry, children's rehabilitative services, newborn screening and sickle cell diagnosis and treatment programs and chronic, environmentally-provoked and infectious disease programs. 10. The legal representative of a health care provider that is in possession of the medical record. 11. A health care provider that assumes the responsibility to provide care for, or consultation to, the patient from another health care provider that had access to the patient's genetic records.

Provides that the court, in the instance that genetic testing information is subpoenaed or obtained pursuant to court order, shall take all steps necessary to prevent the disclosure or dissemination of that information.

Prohibits a person to whom test results have been disclosed pursuant to this article, other than the person tested, from disclosing the test results to any other person, except as specifically provided in this article.

Prohibits a genetic test from being conducted on an unemancipated minor without the consent of the parent or legal guardian of the minor.

Provides that the physician who orders the genetic testing of an unemancipated minor shall notify the child's parent or legal guardian of the results of the test.

Prohibits a health care provider from conducting a genetic test on a person unless the health care provider first obtains written informed consent from the person to be tested or from the person's authorized representative.

Provides that information and records held by a state agency or a local health authority relating to genetic testing information are confidential and are exempt from the public copying and inspection requirements.

Prohibits a state agency or local health authority from releasing or making available to the public genetic testing information and records.

Genetic test/genetic testing: A test of a person's genes, genetic sequence, gene products or chromosomes for abnormalities or deficiencies, including carrier status, that:

- a. Are linked to physical or mental disorders or impairments
- b. Indicate a susceptibility to any illness, disease, impairment or other disorder, whether physical or mental
- c. Demonstrate genetic or chromosomal damage due to any environmental factor

Does not include:

- a. Chemical, blood and urine analyses that are widely accepted and used in clinical practice and that are not used to determine genetic traits.
- b. Tests used in a criminal investigation or prosecution or as a result of a criminal conviction.
- c. Tests for the presence of the human immunodeficiency virus.
- d. Tests to determine paternity
- e. Tests given for use in biomedical research that is conducted to

		generate scientific knowledge about genes or to learn about the genetic basis of disease or for developing pharmaceutical and other treatment of disease.
California (1994)	<p>Insurance Code: §10123.3; §10140; §10148; §10149; §10149.1; §11512.95</p> <p>Health & Safety Code: §1374.7</p>	<p>Prohibits health insurance plans from refusing to enroll or accept persons based on genetic characteristics;</p> <p>Prohibits health insurers from requiring a higher rate or charge on the basis of genetic characteristics;</p> <p>Provides for privacy protection of genetic information.</p>
California (1995)	<p>Insurance Code: §10123.3; §10140; §10147; §11512.95; §10123.31; §10123.35; §10140.1; §10140.5; §11512.96; §11512.965</p> <p>Health & Safety Code: §1374.7; §1374.9</p>	<p>Prohibits health insurance plans from offering or providing different terms, conditions or benefits on the basis of genetic characteristics.</p>

California (1996)	<p>Civil Code: §56.17</p> <p>Health & Safety Code: §1374.7</p> <p>Insurance Code: §742.24; §742.405; §742.407; § 10123.3; §10123.35; §10140; §10140.1</p>	<p>Prohibits health insurers from seeking, using or maintaining genetic information for any nontherapeutic purposes.</p> <p>Prohibits health insurers from discriminating in the renewal of policies on the basis of genetic characteristics.</p> <p>Revises the definition of genetic characteristics to include family history.</p> <p>Applies prohibitions on genetic discrimination by health insurers to "multiple employer welfare arrangements."</p>
California (1998)	<p>Health & Safety Code: §1374.7</p> <p>Insurance Code: §742.405 & §10148 (§ 10123.3 & §10140 repealed)</p>	<p>Removes the sunset clause and indefinitely extends the prohibition on health insurers from seeking information about a person's genetic characteristics for any nontherapeutic purpose.</p> <p>Revises the definition of genetic characteristics to include genes or chromosomes that are known to be a cause of a disease or disorder in a person or his or her offspring.</p> <p>Prohibits an insurer from requiring a test for the presence of a genetic characteristic for the purpose of determining insurability except with respect to those policies that are contingent on review or testing for other diseases or medical conditions. In these cases, the test shall be done in accordance with informed consent and privacy protection provisions.</p> <p>Genetic characteristic: Any scientifically or medically identifiable gene or chromosome, or combination or alteration thereof, that is known to be a cause of a disease or disorder in a person or his or her offspring, or that is determined to be associated with a statistically increased risk of development of a disease or disorder, or inherited characteristics that may derive from the individual or family member, that is presently not associated with any symptoms of any disease or disorder.</p>

Colorado (1994)	Title 10, Art. 3, Part II: §10-3-1104.7	<p>Prohibits the utilization of information derived from genetic testing from being used to deny access to health care insurance.</p> <p>Provides for privacy protection of genetic information.</p> <p>Genetic test: Any laboratory test of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness. Genetic testing includes only such tests as are direct measures of such alterations rather than indirect manifestations thereof.</p>
Connecticut (1997)	H 6527	<p>Prohibits health insurers from refusing to insure, refusing to continue to insure or limiting the amount, extent or kind of coverage available to an individual because of genetic information.</p> <p>Prohibits health insurers from charging an individual a different rate for the same coverage because of genetic information.</p> <p>Genetic information: The information about genes, gene products or inherited characteristics that may derive from an individual or family member.</p>
Delaware (1998)	S 337	<p>Prohibits health insurance discrimination against any individual in rates, terms or conditions. (Title of legislation is "Genetics Based Discrimination, but discrimination prohibition language is not specific to genetics.)</p> <p>Prohibits a cause of action in the nature of defamation, invasion of privacy or negligence for disclosing personal or privileged information in accordance with this Act. However, it does not provide immunity for disclosing or furnishing false information with malice or willful intent to injure.</p> <p>Prohibits a cause of action in the nature of defamation, invasion of privacy or negligence for disclosing personal or privileged information to an insurance institution, agent or insurance support organization. However, it does not provide immunity for disclosing or furnishing false information with malice or willful intent to injure.</p> <p>Definition of genetic characteristic in <i>discrimination</i> legislation: <i>Note: This definition varies from the definition contained in separate confidentiality legislation.</i> Any inherited gene or chromosome or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.</p> <p>Definition of genetic information in discrimination legislation: <i>Note: This definition varies from the definition contained in separate</i></p>

		<p><i>confidentiality legislation.</i> Information about inherited genes or chromosomes, and of alterations thereof, whether obtained from an individual or family member, that is scientifically or medically believed to predispose an individual to disease, disorder or syndrome, or believed to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome. This includes, but is not limited to, information regarding carrier status, information regarding an increased likelihood of future disease or increased sensitivity to any substance, information derived from laboratory tests that identify mutations in specific genes or chromosomes, requests for genetic services or counseling, tests of gene products, and direct analysis of genes or chromosomes.</p> <p>Definition of genetic test: A test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic associated with disease, disorder or syndrome.</p>
Delaware (1998)	S 153	<p>Prohibits the obtaining of genetic information about an individual without first obtaining informed consent. Provides exceptions.</p> <p>Prohibits the retaining of genetic information without first obtaining informed consent. Provides exceptions.</p> <p>Provides that an individual, promptly upon request, may inspect, request correction of and obtain genetic information from the records of that individual.</p> <p>Prohibits a person from disclosing or being compelled to disclose, by subpoena or any other means, the identity of an individual upon whom a genetic test has been performed or from disclosing genetic information about the individual in a manner that permits identification of the individual. Provides exceptions.</p> <p>Provides penalties for unlawful disclosure of genetic information.</p> <p>Definition of genetic characteristic: <i>Note: This definition varies from the definition contained in separate discrimination legislation.</i> Any inherited gene or chromosome, or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome. This includes, but is not limited to, information regarding carrier status, information regarding an increased likelihood of future disease or increased sensitivity to any substance, information derived from laboratory tests that identify mutations in specific genes or chromosomes, requests for genetic services or counseling, tests of gene</p>

		<p>products, and direct analysis of genes or chromosomes.</p> <p>Definition of genetic information in <i>confidentiality</i> legislation: <i>Note: This definition varies from the definition contained in separate discrimination legislation.</i> Information about inherited genes or chromosomes, and of alterations thereof, whether obtained from an individual or family member, that is scientifically or medically believed to predispose an individual to disease, disorder or syndrome, or believed to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.</p> <p>Definition of genetic test: A test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic associated with disease, disorder or syndrome.</p>
Florida (1978)	FL ST: 626.9707	<p>Prohibits insurers from refusing to issue and deliver any policy of "disability" insurance, which "affords benefits and coverage for any medical treatment or service," solely because a person has the sickle cell trait.</p> <p>Prohibits a "disability" insurance policy from charging a higher rate solely because a person has the sickle cell trait.</p>
Florida (1992)	FL ST: 760.40	Provides for informed consent and privacy protection of genetic information.
Florida (1997)	H 37	<p>Prohibits health insurers from cancelling, limiting, denying or establishing differentials in premium rates based on genetic test results.</p> <p>Prohibits health insurers from requiring or soliciting genetic information or from using genetic test results or considering a person's decisions related to genetic testing.</p> <p>Genetic information: Information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder, or syndrome, or are associated with a statistically increased risk of developing a disease, disorder, or syndrome, which is asymptomatic at the time of testing. Such testing does not include routine physical examinations or chemical, blood, or urine analysis, unless conducted purposefully to obtain genetic information, or questions regarding family history.</p>

Georgia (1995)	Title 33, Chapter 54	<p>Prohibits the use of genetic testing except to obtain information for therapeutic or diagnostic purposes.</p> <p>Provides for written consent prior to genetic testing.</p> <p>Provides for privacy protection of genetic information.</p> <p>Prohibits health insurers from seeking information derived from genetic testing.</p> <p>Genetic test: Laboratory tests of human DNA or chromosomes for the purpose of identifying the presence or absence of inherited alterations in genetic material or genes which are associated with a disease or illness that is asymptomatic at the time of testing and that arises solely as a result of such abnormality in genes or genetic material. For purposes of this chapter, genetic testing shall not include routine physical measurements; chemical, blood, and urine analysis; tests for abuse of drugs; and tests for the presence of the human immunodeficiency virus.</p>
Hawaii (1997)	S 1565	<p>Prohibits health insurers from using an individual's or a family member's genetic information, or request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment, or premium payments.</p> <p>Prohibits health insurers from requesting or requiring the collection or disclosure of an individual's or a family member's genetic information.</p> <p>Prohibits a health insurer from disclosing an individual's or a family member's genetic information without the written consent of the person affected.</p> <p>Genetic information: Information about genes, gene products, hereditary susceptibility to disease, or inherited characteristics that may derive from the individual or family member.</p>
Illinois (1997)	H 008	<p>Provides that genetic testing and information derived from genetic testing is confidential and privileged and may be released only to the individual tested and to persons specifically authorized in writing by that individual.</p> <p>Provides that genetic testing and information derived from genetic testing shall not be admissible as evidence, nor discoverable in any action of any kind in any court, or before any tribunal, board, agency or person pursuant to the Code of Civil Procedure except when legally obtained by a peace officer for use in a criminal investigation or prosecution.</p> <p>Prohibits health insurers from seeking information derived from genetic testing for use in connection with a policy.</p>

		<p>Provides that health insurers may consider the results of genetic testing if the individual voluntarily submits the results and the results are favorable to the individual.</p> <p>Prohibits health insurers from releasing the information from genetic testing to a third party.</p> <p>Provides that no person may disclose or be compelled to disclose the identity of any person upon whom a genetic test is performed or the results of a genetic test in a manner that permits identification of the subject of the test, except as provided by law.</p> <p>Provides for private right of action.</p> <p>Genetic test: A test of a person's genes, gene products or chromosomes for abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, indicate a susceptibility to illness, disease, impairment, or other disorders, whether physical or mental, or demonstrate genetic or chromosomal damage due to environmental factors. Genetic testing does not include routine physical measurements; chemical, blood and urine analyses that are widely accepted and in use in clinical practice, tests for use of drugs, and tests for the presence of the human immunodeficiency virus.</p>
Indiana (1997)	H 1684	<p>Prohibits insurers, other than life insurers, from obtaining the results of any genetic screening or testing without a separate written consent.</p> <p>Provides that an insurer is not liable if they inadvertently receive the results of genetic testing or screening.</p> <p>Provides that an insurer that inadvertently receives testing or screening results may not use the genetic testing or screening results in violation of other sections of the law.</p> <p>Prohibits health insurers from requiring an individual to submit to genetic screening or testing when processing an application for coverage or in determining insurability.</p> <p>Prohibits health insurers from considering any information obtained from genetic screening or testing in a manner adverse to the applicant or an individual already covered.</p> <p>Prohibits health insurers from inquiring, directly or indirectly, into the results of genetic screening or testing, or from using such information to cancel, refuse to issue or renew, or limit benefits.</p> <p>Prohibits health insurers from making a decision adverse to an applicant based on entries related to the results of genetic testing or screening in medical records or other reports of genetic screening or</p>

testing.

Prohibits health insurers from developing and asking questions regarding the medical history of an applicant that reflect the results of or are questions designed to ascertain the results of genetic screening or testing.

Prohibits health insurers from canceling, refusing to issue, refusing to renew, or refusing to enter into a contract based on the results of genetic screening or testing.

Prohibits health insurers from delivering, issuing for delivery, renewing or executing a contract that limits benefits or establishes premiums based on the results of genetic screening or testing.

Provides for health insurers to consider the results of genetic screening or testing if the results are voluntarily submitted by the applicant seeking renewal of coverage AND if the results are favorable to the applicant.

Genetic test: A laboratory test:

1. of an individual's genes or chromosomes for abnormalities, defects, or deficiencies, including changes in the number, structure, or integrity of an individual's chromosomes or carrier status, that: (A) are linked to physical or mental disorders or impairments; (B) indicate a susceptibility to illness, disease, or other disorders, whether physical or mental; or (C) demonstrate genetic or chromosomal damage due to environmental factors; AND
2. that is a direct test for abnormalities, defects, or deficiencies in an individual's genes or chromosomes. The term does not include the detection of a genetic disorder through the manifestation of the genetic disorder.

Kansas (1997)

HB 2417

Prohibits health insurers from requiring or requesting directly or indirectly any individual or a member of the individual's family to obtain a genetic test.

Prohibits health insurers from requiring or requesting directly or indirectly any individual to reveal whether the individual or a member of the individual's family has obtained a genetic test or the results of the test, if obtained by the individual or a member of the individual's family.

Prohibits health insurers from conditioning the provision of insurance coverage or health care benefits on whether the individual or a member of the individual's family has obtained a genetic test or the results of the test, if obtained by the individual or a member of the individual's

		<p>family.</p> <p>Prohibits health insurers from considering in the determination of rates or any other aspect of insurance coverage or health care benefits provided to an individual whether an individual or a member of the individual's family has obtained a genetic test or the results of the test, if obtained by the individual or a member of the individual's family.</p> <p>Prohibits insurers from writing life insurance, disability income insurance or long-term care insurance coverage to provide for rates or any other aspect of coverage that is not reasonably related to the risk involved.</p> <p>Genetic screening or testing: A laboratory test of a person's genes or chromosomes for abnormalities, defects or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects or deficiencies, and not an indirect manifestation of genetic disorders.</p>
Kentucky (1998)	SR 161	Authorizes the Legislative Research Commission to study the impact of genetic testing on health, life and disability income insurance. The results of the study are to be reported to the year 2000 Regular Session of the General Assembly.
Louisiana (1997)	22:213.6	<p>Prohibits hospital, health, or medical expense insurance policies, hospital or medical service contracts, employee welfare benefit plans, health and accident insurance policies, or any other insurance contract of this type, including a group insurance plan, or any policy of group, family group, blanket, or franchise health and accident insurance, a self-insurance plan, health maintenance organization, and preferred provider organization, which delivers or issues for delivery in this state an insurance policy or plan shall, on the basis of any prenatal test result from:</p> <ol style="list-style-type: none"> 1. Terminating, restricting, limiting, or otherwise applying conditions to the coverage under the policy or plan, or restrict the sale of the policy or plan in force. 2. Canceling or refusing to renew the coverage under the policy or plan in force. 3. Denying coverage or excluding an individual or family member from coverage under the policy or plan in force. 4. Imposing a rider that excludes coverage for certain benefits or services under the policy or plan in force. 5. Establishing differentials in premium rates or cost sharing for coverage under the policy or plan in force.

		6. Otherwise discriminating against an individual or family member in the provision of insurance.
Louisiana (1997)	22:213.7	<p>Prohibits health insurers from terminating, restricting, limiting, or otherwise applying conditions to the coverage of an individual or family member under the policy or plan, or restrict the sale of the policy or plan to an individual or family member on the basis of genetic information.</p> <p>Prohibits health insurers from canceling or refusing to renew the coverage of an individual or family member under the policy or plan.</p> <p>Prohibits health insurers from denying coverage or excluding an individual or family member from coverage under the policy or plan.</p> <p>Prohibits health insurers from imposing a rider that excludes coverage for certain benefits or services under the policy or plan.</p> <p>Prohibits health insurers from establishing differentials in premium rates or cost sharing for coverage under the policy or plan.</p> <p>Prohibits health insurers from otherwise discriminating against an individual or family member in the provision of insurance.</p> <p>Prohibits health insurers from requiring an applicant for coverage under the policy or plan, or an individual or family member who is presently covered under a policy or plan, to be the subject of a genetic test or to be subjected to questions relating to genetic information.</p> <p>Requires insurers to provide an applicant or enrollee with a written statement disclosing the rights of the applicant or enrollee under this section. Such statement shall be in a form and manner that is noticeable to and understandable by an average applicant or enrollee.</p> <p>Prohibits health insurers from obtaining genetic information from an insured or enrollee, or from their DNA sample, without first obtaining written informed consent from the insured, enrollee, or their representative.</p> <p>Provides that an insured's or enrollee's genetic information is the property of the insured or enrollee. No person shall retain an insured's or enrollee's genetic information without first obtaining authorization from the insured, enrollee, or their representative.</p> <p>Genetic characteristic: Any gene or chromosome, or alteration thereof, that is scientifically or medically believed to cause a disease, disorder, or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder, or syndrome.</p> <p>Genetic analysis: The process of characterizing genetic information</p>

		<p>from a human tissue sample.</p> <p>Genetic information: All information about genes, gene products, inherited characteristics, or family history/pedigree that is expressed in common language.</p> <p>Genetic test: Any test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids, such as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins in order to diagnose or identify a genetic characteristic.</p>
Maine (1997)	24-A 2159-C	<p>Prohibits health insurers from discriminating against an individual or eligible dependent on the basis of genetic information or the refusal to submit to a genetic test or make available the results of a genetic test or on the basis that the individual or eligible dependent received a genetic test or genetic counseling in the issuance, withholding, extension or renewal of any hospital confinement or other health insurance, as defined by the superintendent, by rule, or in the fixing of the rates, terms or conditions for insurance, or in the issuance or acceptance of any application for insurance. This does not apply to accidental injury, specified disease, hospital indemnity, disability, long-term care and other limited benefit health insurance policies and contracts.</p> <p>Prohibits health insurers from making or permitting any unfair discrimination against an individual in the application of genetic information or the results of a genetic test in the issuance, withholding, extension or renewal of an insurance policy for life, credit life, disability, long-term care, accidental injury, specified disease, hospital indemnity or credit accident insurance or an annuity.</p> <p>Genetic characteristic: Any inherited gene or chromosome, or alteration of a gene or chromosome, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.</p> <p>Genetic information: The information concerning genes, gene products or inherited characteristics that may be obtained from an individual or family member.</p> <p>Genetic test: A test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids, such as deoxyribonucleic acid, or DNA, ribonucleic acid, or RNA, or mitochondrial DNA, and tests of chromosomes or proteins in order to identify a predisposing genetic characteristic.</p>

Maine (1998)	SP 384	<p>Prohibits insurers from discriminating on the basis of genetic information or the refusal to submit to a genetic test or make available the results of a genetic test or on the basis that the individual or eligible dependent received a genetic test or genetic counseling in the issuance, withholding, extension, renewal, fixing of rates, terms or conditions or in the issuance or acceptance of insurance.</p> <p>Prohibits life, disability and long-term care insurers from making or permitting any unfair discrimination against an individual in the application of genetic information or the results of a genetic test in the issuance, withholding, extension or renewal of any insurance policy for life, credit life, disability, long-term care, accidental injury, specified disease, hospital indemnity or credit accident insurance or an annuity.</p> <p>Genetic characteristic: Any inherited gene or chromosome, or alteration of a gene or chromosome, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.</p> <p>Genetic information: The information concerning genes, gene products or inherited characteristics that may be obtained from an individual or family member.</p> <p>Genetic test: A test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as deoxyribonucleic acid, or DNA, ribonucleic acid, or RNA, or mitochondrial DNA, and tests of chromosomes or proteins in order to identify a predisposing genetic characteristic.</p> <p>Unfair discrimination: Unfair discrimination includes, but is not limited to, the application of the results of a genetic test in a manner that is not reasonably related to anticipated claims experience.</p>
Maryland (1986)	<p>Insurance Code:</p> <p>Art. 48A, §223(b)(4)</p>	<p>Prohibits health insurers from making or permitting differentials in rates based on any genetic trait, unless there is actuarial justification.</p>

Maryland (1996)	S 276 (Ch. 24)	<p>Prohibits health insurers from using a genetic test or the results of a test to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect a health insurance policy or contract.</p> <p>Prohibits health insurers from requesting or requiring a genetic test for the purpose of determining whether or not to issue or renew health benefits coverage.</p> <p>Prohibits the release of the results of a genetic test without the prior written authorization of the individual.</p> <p>Genetic test: A laboratory test of human chromosomes or DNA that is used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness.</p>
Maryland (1999)	S 774	<p>Prohibits health insurers from using a genetic test, the results of a genetic test, genetic information, or a request for genetic services, to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect a health insurance policy or contract.</p> <p>Prohibits health insurers from requesting or requiring a genetic test, the results of a genetic test, or genetic information for the purpose of determining whether or not to issue or renew health benefits coverage.</p> <p>Prohibits health insurers from releasing identifiable genetic information or the results of a genetic test to any person who is not an employee of the insurer, nonprofit health service plan, or health maintenance organization or a participating health care provider who provides medical services to insureds or enrollees without the prior written authorization of the individual from who the test results or genetic information was obtained.</p> <p>Limits the disclosure of identifiable genetic information to an employee or health care provider only for the purpose of:</p> <ol style="list-style-type: none"> 1. providing medical care to patients; or 2. conducting research that has been approved by an institutional review board. <p>Requires an authorization for each disclosure of identifiable genetic information or the results of a genetic test. Requires the authorization to describe the individual or entities making the disclosure, to whom the disclosure is to be made and the information to be disclosed.</p> <p>Definition of gene product: The biochemical material, either RNA or protein, made by a gene.</p>

		<p>Definition of genetic information: Genetic information means information: 1. About chromosomes, genes, gene products, or inherited characteristics that may derive from an individual or a family member; 2. Obtained for diagnostic and therapeutic purposes; and 3. Obtained at a time when the individual to whom the information relates is asymptomatic for the disease. Genetic information does not include: 1. Routine physical measurements; 2. Chemical, blood, and urine analyses that are widely accepted and in use in clinical practice; 3. Tests for use of drugs; or 4. Tests for the presence of the human immunodeficiency virus.</p> <p>Definition of genetic services: Health services that are provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes and for genetic education and counseling.</p>
Michigan (1997)	E.O. 9714	<p>Establishes the Michigan Commission on Genetic Privacy and Progress.</p> <p>Provides that the Commission shall recommend model state statutory and administrative policies which protect the privacy of genetic information, prevent discrimination based upon such genetic information in the areas of employment, health care, health care insurance.</p> <p>Provides that no later than November 15, 1998, the Commission shall issue a final report to the Governor and the legislature.</p>
Michigan (2000)	SB 590	<p>Prohibits health insurers from requiring an insured or his or her dependent or an asymptomatic applicant for insurance or his or her asymptomatic dependent to:</p> <ol style="list-style-type: none"> 1. Undergo genetic testing before issuing, renewing, or continuing the policy or certificate in Michigan. 2. Disclose whether genetic testing has been conducted or the results of genetic testing or genetic information. <p>Genetic information: Information about a gene, gene product, or inherited characteristic derived from a genetic test.</p> <p>Genetic test: The analysis of human DNA, RNA, chromosomes, and those proteins and metabolites used to detect heritable or somatic disease - related genotypes or karyotypes for clinical purposes. A genetic test must be generally accepted in the scientific and medical communities as being specifically determinative for the presence, absence, or mutation of a gene or chromosome in order to qualify under this definition. Genetic test does not include a routine physical examination or a routine analysis, including, but not limited to, a chemical analysis, of body fluids, unless conducted specially to determine the presence, absence, or mutation of a gene or</p>

		chromosome.
Michigan (2000)	SB 593	<p>Prohibits a physician or an individual to whom the physician has delegated authority to perform a selected act, task, or function under section 16215 from ordering a presymptomatic or predictive genetic test without first obtaining the written, informed consent of the test subject.</p> <p>For purposes of this subsection, written, informed consent consists of a signed writing executed by the test subject or the legally authorized representative of the test subject that confirms that the physician or the individual acting under the delegatory authority of the physician has explained, and the test subject or the legally authorized representative of the test subject understands, at a minimum, all of the following:</p> <ol style="list-style-type: none"> 1. The nature and purpose of the presymptomatic or predictive genetic test. 2. The effectiveness and limitations of the presymptomatic or predictive genetic test. 3. The implications of taking the presymptomatic or predictive genetic test, including, but not limited to, the medical risks and benefits. 4. The future uses of the sample taken from the test subject in order to conduct the presymptomatic or predictive genetic test and the information obtained from the presymptomatic or predictive genetic test. 5. The meaning of the presymptomatic or predictive genetic test results and the procedure for providing notice of the results to the test subject. 6. Who will have access to the sample taken from the test subject in order to conduct the presymptomatic or predictive genetic test and the information obtained from the presymptomatic or predictive genetic test, and the test subject's right to confidential treatment of the sample and the information. <p>Predictive genetic test: A genetic test performed for the purpose of predicting the future probability that the test subject will develop a genetically related disease or disability.</p> <p>Presymptomatic genetic test: A genetic test performed before the onset of clinical symptoms or indications of disease.</p>

Minnesota (1995)	S.F. No. 259	<p>Prohibits health insurers from utilizing information from genetic testing to determine eligibility, establish premiums, limit coverage, or renew coverage.</p> <p>Prohibits health insurers from requiring a genetic test and from inquiring or determining whether or not an individual has had a genetic test.</p> <p>Genetic test: A presymptomatic test of a person's genes, gene products or chromosomes for the purpose of determining the presence or absence of a gene or genes that exhibit abnormalities, defects, or deficiencies, including carrier status, that are known to be the cause of a disease or disorder, or are determined to be associated with a statistically increased risk of development of a disease or disorder. Genetic test does not include a cholesterol test or other test not conducted for the purpose of determining the presence or absence of a person's gene or genes.</p>
Missouri (1998)	MO ST: 375.1303	<p>Prohibits health insurers from requiring or requesting genetic information or a genetic test. Prohibits health insurers from inquiring whether a person has taken or refused a genetic test or inquiring about the results of a genetic test. Prohibits health insurers from considering without approval the fact that genetic information or a genetic test was taken or refused. Prohibits health insurers from considering without approval genetic information or the results of any genetic test. Genetic information: The results of a genetic test. Genetic information shall not include family history, the results of routine physical measurements, or the results of chemical, blood, urine analysis, or the results of tests for drugs or the presence of the human immunodeficiency virus, or from results of any other tests commonly accepted in clinical practice at the time. Genetic test: A laboratory test of human deoxyribonucleic acid (DNA) or ribonucleic acid (RNA) used to identify the presence or absence of inherited alterations in the DNA or RNA which cause predisposition to disease or illness. The term does not include routine physical measurements and examinations, routine tests performed as a part of a physical examination, chemical, blood or urine analysis, cholesterol tests, tests for the presence of the human immunodeficiency virus, a test for drugs, or tests commonly accepted in clinical practice at the time.</p>

<p>Montana (1999)</p>	<p>H 111</p>	<p>Prohibits health insurers from requiring an individual to obtain a genetic test unless the test is otherwise required by law.</p> <p>On the basis of a genetic test, prohibits health insurers from:</p> <ol style="list-style-type: none"> 1. failing or refusing to accept an application for a policy or certificate of insurance; 2. failing or refusing to issue a policy or certificate of insurance to an applicant; 3. canceling a policy or certificate of insurance; 4. refusing to renew a policy or certificate of insurance; 5. charging a higher rate or premium for a policy or certificate of insurance; or 6. offering or providing different terms, conditions, or benefits or placing a limitation on coverage under a policy or certificate of insurance. <p>Prohibits health insurers from underwriting or conditioning coverage on the basis of:</p> <ol style="list-style-type: none"> 1. a requirement or agreement that the individual undergo genetic testing; or 2. genetic information about a member of the individual's family. <p>Prohibits discrimination in the fees or commissions of agents or brokers for writing or renewing an individual or group policy of insurance on the basis of an individual's genetic traits.</p> <p>Provides that this law does not apply to life, disability income or long-term care insurance.</p> <p>Provides that health insurers can discriminate as otherwise allowed by law on the basis of other factors unrelated to genetic traits.</p> <p>Prohibits health insurers from seeking genetic information about an individual for a purpose that is:</p> <ol style="list-style-type: none"> 1. unrelated to assessing or managing the individual's current health; 2. inappropriate in an asymptomatic individual; or 3. unrelated to research in which a subject is not personally identifiable.
---------------------------	--------------	--

Nebraska (1997)	L.B. 111	<p>Establishes the Nebraska Commission on Human Genetic Technologies.</p> <p>Provides that the Commission shall gather data about the impact of human genetic conditions and technologies in Nebraska. The data shall be gathered by requesting information from public and private sources, holding public hearings and other methods adopted by the Commission.</p> <p>Provides that the Commission shall study laws and other public initiatives in other states, including any information available about the impact and effectiveness of such laws and initiatives, and shall make specific recommendations to the Legislature regarding legislation.</p> <p>Provides that the Commission shall encourage improvements in the education available in Nebraska at all levels about human genetics, genetic tests and their meanings, causes and prevention of genetic discrimination, the positive value of human genetic diversity, the quality and availability of support services for persons with human genetic conditions, including counseling and peer support, and the effective use of human genetic information in the criminal justice system in a way that fully protects an individual's civil rights and privacy.</p> <p>Provides for the cessation of the Commission on January 1, 1999.</p>
Nevada (1997)	A.B. 549	<p>Prohibits health insurers from requiring an insured person to take a genetic test or to disclose whether he has taken a genetic test or to disclose genetic information of the insured person or a member of his family.</p> <p>Prohibits health insurers from determining the rates or any other aspect of the coverage or benefits for health care provided to an insured person based on whether the insured person has taken a genetic test or on any genetic information of the insured person or any member of his family.</p> <p>Genetic information: Genetic information means any information that is obtained from a genetic test.</p> <p>Genetic test: Genetic test means a test, including a laboratory test that uses deoxyribonucleic acid extracted from the cells of a person or a diagnostic test, to determine the presence of abnormalities or deficiencies, including carrier status, that: 1. Are linked to physical or mental disorders or impairments; or 2. Indicate a susceptibility to illness, disease, impairment or any other disorder, whether physical or mental.</p>

New Hampshire (1995)	NH ST: Chapter 141-H	<p>Prohibits health insurers from conditioning the provision of health insurance coverage on the results of genetic testing.</p> <p>Prohibits health insurers from considering genetic testing in the determination of rates or benefits.</p> <p>Prohibits health insurers from requiring a genetic test and from inquiring or determining whether or not an individual has had a genetic test.</p> <p>Genetic test: A test, examination or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence or alteration of any gene or chromosome, and any report, interpretation or evaluation of such a test, examination or analysis, but excludes any otherwise lawful test, examination or analysis that is undertaken for the purpose of determining whether an individual meets reasonable functional standards for a specific job or task.</p>
New Jersey (1996)	S 695 A 1411	<p>Prohibits health insurers from discriminating in the issuance, withholding, extension, renewal, or establishment of rates, terms or conditions on the basis of genetic information.</p> <p>Prohibits any person from obtaining or retaining an individual's genetic information without first obtaining authorization from the individual.</p> <p>Prohibits the disclosure of genetic information in a manner that permits identification of the individual without the authorization of the individual.</p> <p>Genetic characteristic: Any inherited gene or chromosome, or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.</p> <p>Genetic information: The information about genes, gene products or inherited characteristics that may derive from an individual or family member.</p> <p>Genetic test: A test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic.</p>

<p>New Mexico (1998)</p>	<p>H.B. 331</p>	<p>Prohibits persons from obtaining genetic information or samples for genetic analysis without first obtaining informed and written consent.</p> <p>Prohibits the genetic analysis of a person or collection, retention, transmission or use of genetic information without written and informed consent.</p> <p>Prohibits discrimination by an insurer on the basis of genetic analysis, genetic information or genetic propensity.</p> <p>Prohibits a health insurer from considering a genetic propensity, susceptibility or carrier status as a preexisting condition for the purpose of limiting or excluding benefits, establishing rates or providing coverage.</p> <p>Provides for life, disability income or long-term care insurers to use genetic analysis, genetic propensity or genetic information in underwriting if based on sound actuarial principles or related to actual or reasonably anticipated experience.</p> <p>Provides for penalties for violation of these provisions.</p> <p>Genetic analysis: A test of a person's DNA, gene products or chromosomes that indicates a propensity for or susceptibility to illness, disease, impairment or other disorders, whether physical or mental; that demonstrates genetic or chromosomal damage due to environmental factors; or that indicates carrier status for disease or disorder; excluded, however, are routine physical measurements, chemical, blood and urine analysis, tests for drugs and tests for the presence of HIV virus and any other tests or analyses commonly accepted in clinical practice at the time ordered.</p> <p>Genetic information: Information about the genetic makeup of a person or members of a person's family, including information resulting from genetic analysis, DNA composition, participation in genetic research or use of genetic services.</p> <p>Genetic propensity: The presence in a person or members of a person's family of real or perceived variations in DNA or other genetic material from that of the normal genome that do not represent the outward physical or medical signs of a genetic disease at the time of consideration.</p>
------------------------------	-----------------	---

New Mexico (1999)	S 570	<p>Establishes May 20, 1998 as the effective date of the Genetic Information Privacy Act.</p> <p>Provides that the section of the Act prohibiting genetic discrimination and proceedings brought alleging violations of that section shall apply to genetic analysis whenever performed and genetic information and gene products whenever obtained.</p>
New York (1996)	S 4293-D A 5796-C	<p>Prohibits authorized insurers from requesting or requiring an individual proposed for insurance coverage to be the subject of a genetic test without receiving the written informed consent of such individual prior to such testing.</p> <p>Genetic anomaly: Any variation in an individual's DNA which has been shown to confer a genetically influenced disease or predisposition to a genetically influenced disease or makes the individual a carrier of such variation.</p> <p>Genetic predisposition: The presence of a variation in the composition of the genes of an individual which is scientifically or medically identifiable and which is determined to be associated with an increased statistical risk of being expressed as a physical or mental disease or disability in the individual but which has not resulted in any symptoms of such disease or disorder.</p> <p>Genetic test: An assay employing DNA, constituent genes, or gene products to diagnose or predict the presence of a genetic anomaly that is linked to a physical or mental disease or disability in the individual or the individual's offspring, or susceptibility to or predisposition for a genetically influenced disease or disability.</p>
North Carolina (1975)	NC ST: §58-65-70	<p>Prohibits health insurers from refusing to issue health insurance because an individual has sickle cell trait or hemoglobin C trait.</p> <p>Prohibits health insurers from charging higher premiums based on sickle cell trait or hemoglobin C trait.</p>

North Carolina (1997)	S 254	<p>Prohibits health insurers from refusing to issue or deliver any policy based on genetic information obtained about the person to be insured.</p> <p>Prohibits health insurers from charging a higher premium rate by reason of genetic information.</p> <p>Genetic information: Information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.</p> <p>Genetic test: A test for determining the presence or absence of genetic characteristics in an individual or a member of the individual's family in order to diagnose a genetic condition or characteristic or ascertain susceptibility to a genetic condition.</p> <p>Genetic characteristic: Any scientifically or medically identifiable genes or chromosomes, or alterations or products thereof, which are known individually or in combination with other characteristics to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder and which are asymptomatic of any disease or disorder.</p>
Ohio (1993)	OH ST: §1742.42; §1742.43; §3901.49; §3901.491; §3901.50; §3901.501	<p>Prohibits health insurers from canceling, refusing to issue, or renewing coverage or limiting benefits based on genetic screening or testing.</p> <p>Prohibits health insurers from requiring a genetic test or making an inquiry as to the results of genetic screening or testing.</p> <p>Provides for consideration of genetic testing if the results are favorable to the applicant and voluntarily submitted.</p> <p>Establishes the Task Force on Genetic Testing in Health Insurance.</p> <p>Genetic screening or testing: A laboratory test of a person's genes or chromosomes for abnormalities, defects or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.</p>

Ohio (1997)	OH ST: §1751.64	<p>Prohibits health insurers from requiring an individual seeking coverage to submit to genetic screening or testing.</p> <p>Prohibits health insurers from taking into consideration the results of genetic screening or testing.</p> <p>Prohibits health insurers from making any inquiry to determine the results of genetic screening or testing.</p> <p>Prohibits health insurers from making a decision adverse to the applicant based on entries in medical records or other reports of genetic screening or testing.</p> <p>Prohibits health insurers from asking for the results of genetic screening or testing or asking questions designed to ascertain the results of genetic screening or testing.</p> <p>Prohibits health insurers from canceling or refusing to issue or renew coverage for health care services based on the results of genetic screening or testing.</p> <p>Prohibits health insurers from delivering, issuing for delivery, or renewing an individual or group policy, contract, or agreement in this state that limits benefits based on the results of genetic screening or testing.</p> <p>Genetic screening or testing: A laboratory test of a person's genes or chromosomes for abnormalities, defects or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.</p>
Oklahoma (1996)	HCR 1113	<p>Creates the Task Force on Prevention of Genetic Discrimination. The duties of the Task Force include: reviewing House Bill 2478; reviewing legislation from other states and any model legislation related to genetic discrimination; and, making recommendations to the legislature by January 1, 1997 concerning proposed legislation which the Task Force deems necessary to prevent genetic discrimination particularly with regard to insurance and employment.</p>

Oklahoma (1997)	HCR 1012	<p>Creates the Task Force on Prevention of Genetic Discrimination. The duties of the Task Force include:</p> <ul style="list-style-type: none"> ● reviewing H.B. 2478 of the 2nd Session of the 45th Oklahoma Legislature which proposes the creation of a Genetic Nondiscrimination Act for the State of Oklahoma ● reviewing legislation from other states and any model legislation related to genetic discrimination; and - making recommendations to the Legislature by January 1, 1998, concerning proposed legislation which the Task Force deems necessary to prevent genetic discrimination, particularly with regard to insurance and employment.
Oklahoma (1998)	HB 3169	<p>Prohibits health insurers, for the purpose of determining eligibility, establishing premiums, limiting coverage, renewing coverage, terminating coverage or any other underwriting decision in connection with the offer, sale or renewal or continuation of a policy, except to the extent and in the same fashion as an insurer limits coverage, or increases premiums for loss caused or contributed to by other medical conditions presenting an increased degree of risk:</p> <ol style="list-style-type: none"> 1. requiring or requesting any individual to obtain a genetic test; and 2. conditioning the provision of the policy upon a requirement that an individual take a genetic test. <p>For purposes of distinguishing between or discriminating against or restricting any right or benefit otherwise due or available to an employee or prospective employee, other than in connection with the determination of insurance coverage or benefits, no employer shall:</p> <ol style="list-style-type: none"> 1. seek to obtain, or use a genetic test or genetic information of the employee or the prospective employee; or 2. require a genetic test of or require genetic information from the employee or prospective employee. <p>Definition of genetic information: Information derived from the results of a genetic test. Genetic information shall not include family history, the results of a routine physical examination or test, the results of a chemical, blood or urine analysis, the results of a test to determine drug use, the results of a test for the presence of the human immunodeficiency virus, or the results of any other test commonly accepted in clinical practice at the time it is ordered by the insurer.</p> <p>Definition of genetic test: A laboratory test of the DNA, RNA, or chromosomes of an individual for the purpose of identifying the presence or absence of inherited alterations in the DNA, RNA, or</p>

		<p>chromosomes that cause a predisposition for a clinically recognized disease or disorder. Genetic test does not include: (A) a routine physical examination or a routine test performed as a part of a physical examination; (B) a chemical, blood, or urine analysis; (C) a test to determine drug use; (D) a test for the presence of the human immunodeficiency virus; or (E) any other test commonly accepted in clinical practice at the time it is ordered by the insurer.</p>
Oklahoma (1999)	HB 1368	<p>Provides that all research records of individual subjects in genetic research studies shall be confidential and not subject to subpoena or discovery in civil suits, except where the information in the records is the basis of the suit.</p> <p>Provides that the confidentiality provisions of the bill shall not apply to an insurer or to an individual or third party dealing with an insurer in the ordinary course of underwriting, conducting or administering the business of life, disability income or long-term care insurance.</p> <p>Provides that stored tissues can be used for genetic research studies if informed consent has been obtained.</p> <p>Provides for the publishing or use of results of genetic research studies for research or educational purposes if no individual subject is identified or if specific informed consent from the individual has been obtained.</p> <p>Definition of Genetic Research Studies: Those genetic research studies approved by an institutional review board as defined by 21 CFR, Section 50 or conducted subject to the requirements of the federal common rule at 21 CFR, Section 50 and Section 56, and 45 CFR, Section 46.</p>
Oregon (1995)	OR ST: 659.036; 659.227	<p>Prohibits health insurers from utilizing genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, or affect the terms and conditions of health insurance policies.</p> <p>Provides for informed consent and privacy protection of genetic information.</p> <p>Genetic test: A test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic.</p> <p>Genetic information: The information about an individual or family obtained from a genetic test or an individual's DNA sample.</p>

Rhode Island (1998)	H 7590	<p>Prohibits health insurers from using a genetic test or the results of a genetic test to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of or otherwise affect a health insurance policy or contract.</p> <p>Prohibits health insurers from requesting or requiring a genetic test for the purpose of determining whether or not to issue or renew health benefits coverage.</p> <p>Prohibits the release of results of a genetic test without the prior written authorization of the individual, except where the individual is not identified.</p> <p>Prohibits health insurers from requesting or requiring information as to whether an individual has ever had a genetic test.</p> <p>Definition of genetic test: A test of an individual's DNA, RNA, chromosomes or proteins for inherited abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate the predisposition or susceptibility to illness, disease, impairment, or other disorders, whether physical or mental. Provided further, that "genetic testing" shall not mean routine physical measurement, a routine chemical, blood or urine analysis, or a test for drugs or for HIV infection.</p>
South Carolina(1998)	S 535	<p>Prohibits insurers from discriminating on the basis of genetic information by: terminating, restricting, limiting or otherwise applying conditions to coverage of any individual or restricting the sale to an individual; canceling or refusing to renew coverage; excluding from coverage; imposing a waiting period; requiring inclusion of a rider; or, establishing a differential in premium rates.</p> <ul style="list-style-type: none"> ● Prohibits the disclosure of genetic information to a third party without written informed consent. ● Prohibits insurers from requiring a person to consent to disclosure of genetic information as a condition for obtaining insurance. ● Prohibits the performance of a genetic test without informed consent. <p>Genetic characteristic: Any scientifically or medically identifiable gene or chromosome, or alteration thereof, which is known to be a cause of disease or disorder or determined to be associated with a statistically increased risk of development of a disease or disorder and which is asymptomatic of any disease or disorder.</p> <p>Genetic information: Information about genes, gene products, or</p>

		<p>genetic characteristics derived from an individual or a family member of the individual. "Gene product" is a scientific term that means messenger RNA and translated protein. For purposes of this chapter, genetic information shall not include routine physical measurements; chemical, blood and urine analysis, unless conducted purposely to diagnose a genetic characteristic; tests for abuse of drugs; and tests for the presence of the human immunodeficiency virus.</p> <p>Genetic test: A laboratory test or other scientifically or medically accepted procedure for determining the presence or absence of genetic characteristics in an individual.</p>
Tennessee (1997)	H 413	<p>Prohibits insurers from denying or canceling health insurance coverage on the basis of genetic information or on the basis that the individual or a family member of an individual has requested or received genetic services.</p> <p>Prohibits insurers from varying the premiums, terms or conditions for health insurance on the basis of genetic information or on the basis that the individual or a family member of an individual has requested or received genetic services.</p> <p>Prohibits insurers from requesting or requiring the disclosure of genetic information.</p> <p>Prohibits insurers from disclosing genetic information without prior written authorization.</p> <p>Genetic information: Information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder or syndrome, or are associated with a statistically increased risk of developing a disease, disorder or syndrome, which is asymptomatic at the time of testing. Such testing does not include either routine physical examinations or chemical, blood or urine analysis unless conducted purposefully to obtain genetic information or questions regarding family history.</p>

Texas (1997)	H 39	<p>Provides that genetic information is confidential and that persons may not disclose or be compelled to disclose, by subpoena or otherwise, genetic information about an individual unless the disclosure is specifically authorized by the individual.</p> <p>Provides that a written authorization for release of genetic information should include: (1) a description of the information to be disclosed; (2) the name of the person to whom the disclosure is made; and (3) the purpose for the disclosure.</p> <p>Prohibits health insurers from using genetic information or the refusal to submit to a genetic test to reject, deny, limit, cancel, refuse to renew, increase the premiums for, or otherwise adversely affect eligibility for coverage.</p> <p>Provides that health insurers requesting a genetic test in connection with the application for coverage for a purpose other than those prohibited, must notify the applicant that the test is required, disclose to the applicant the proposed use of the test results and obtain the applicant's written informed consent for the test. The health insurer may not use the results of a genetic test obtained under these conditions as an inducement for the purchase of coverage.</p> <p>Provides that an individual who submits to a genetic test has the right to know the results of that test.</p> <p>Genetic information: Information derived from the results of a genetic test.</p> <p>Genetic test: A laboratory test of an individual's DNA, RNA, proteins, or chromosomes to identify by analysis of the DNA, RNA, proteins, or chromosomes the genetic mutations or alterations in the DNA, RNA, proteins, or chromosomes that are associated with a predisposition for a clinically recognized disease or disorder. The term does not include: (A) a routine physical examination or a routine test performed as a part of a physical examination; (B) a chemical, blood or urine analysis; (C) a test to determine drug use; or (D) a test for the presence of the human immunodeficiency virus.</p>
--------------	------	---

Vermont (1998)	H 89	<p>Prohibits persons from being required to undergo genetic testing except as provided by this law.</p> <p>Prohibits genetic testing or disclosure of genetic test results without the prior written authorization and informed consent of the individual, except as provided by this law.</p> <p>Provides that individuals be told that genetic test results may become part of their permanent medical record and that the test results may affect their ability to obtain insurance benefits.</p> <p>Provides for the use of genetic testing results or genetic information in connection with life, disability income or long-term care insurance provided under an employee benefit plan.</p> <p>Prohibits insurance to be underwritten or conditioned on the basis of any requirement or agreement of the individual to undergo genetic testing or the results of genetic testing of a member of the individual's family.</p> <p>Genetic information: The results of genetic testing contained in any report, interpretation, evaluation, or other record thereof.</p> <p>Genetic testing: A test, examination or analysis that is diagnostic or predictive of a particular heritable disease or disorder and is of: (i) a human chromosome or gene; (ii) human DNA or RNA; or (iii) a human genetically encoded protein. Genetic testing does not include: (i) a test, examination or analysis which reports on an individual's current condition unless such a test, examination or analysis is designed or intended to be specifically determinative for the presence or absence of a mutation, alteration, or deletion of a gene or chromosome; or (ii) a test, examination or analysis of a human chromosome or gene, of human DNA or RNA, or of a human genetically encoded protein that is diagnostic or predictive of a particular heritable disease or disorder, if, in accordance with generally accepted standards in the medical community, the potential presence or absence of a mutation, alteration or deletion of a gene or chromosome has already manifested itself by causing a disease, disorder or medical condition or by symptoms highly predictive of the disease, disorder or medical condition.</p>
Virginia (1995)	S.J.R. 372	Establishes a subcommittee to study the legal and policy ramifications of breast cancer susceptibility gene research, including the ethical and legal issues of health insurance coverage and reimbursement.
Virginia (1996)	S.J.R. 50	Continues the subcommittee established in 1995 to study the legal and policy ramifications of breast cancer susceptibility gene research, including the ethical and legal issues of health insurance coverage and reimbursement.

Virginia (1996)	S 335 (Ch. 704)	<p>Prohibits health insurers from terminating, restricting or limiting coverage or sale, canceling or refusing to renew coverage, excluding from coverage, imposing a waiting period, requiring a rider or establishing differentials in premium rates based on any genetic information.</p> <p>Establishes that information obtained from genetic screening or testing shall be confidential and shall not be made public or used in any way, in whole or in part, to cancel, refuse to issue or renew, or limit benefits under any policy, contract or plan.</p> <p>Genetic characteristic: Any scientifically or medically identifiable gene or chromosome, or alteration thereof, which is known to be a cause of disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder, and which is asymptomatic of any disease or disorder.</p> <p>Genetic information: Information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.</p> <p>Genetic test: A test for determining the presence or absence of genetic characteristics in an individual in order to diagnose a genetic characteristic.</p>
Washington (1999)	HCR 4412	<p>Establishes the joint select committee on DNA identification to review the following:</p> <ol style="list-style-type: none"> 1. DNA use; 2. DNA identification; 3. DNA testing; 4. DNA data banking; 5. DNA technology; 6. DNA research; and 7. DNA privacy issues. <p>Committee to report its findings to the appropriate committees of the legislature by December 1, 1999.</p>

Wisconsin (1991)	WI SC: §631.89	<p>Prohibits health insurers from conditioning the provision of insurance coverage or benefits on genetic testing.</p> <p>Prohibits use of genetic testing information in determining rates.</p> <p>Prohibits health insurers from requiring an individual to obtain a genetic test.</p> <p>Prohibits health insurers from requiring an individual to reveal whether or not a genetic test has been obtained, or, if a genetic test has been obtained, the results of the test.</p> <p>Genetic testing: A test of a person's genes, gene products or chromosomes, for abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, impairment or other disorders, whether physical or mental or that demonstrate genetic or chromosomal damage due to environmental factors.</p>
Wisconsin (1998)	AB 157	<p>Expands the prohibition against insurers inquiring about genetic tests. Prohibits insurers from requiring or requesting directly or indirectly a health care provider to reveal whether an individual has obtained a genetic test or what the results of the test, if obtained, were.</p>



Sponsored by the [U.S. Department of Energy Human Genome Program](#)

Human Genome News, January-June 1997; 8:(3 & 4)

Fear of Genetic Discrimination Drives Legislative Interest

Ownership, Predisposition Major Issues

by Philip R. Reilly, Shriver Center

Legislative interest in regulating the uses of genetic information is at an all-time high, after decades in which not one legislator at either the congressional or state level introduced a bill to control the use of genetic information. Since 1989, however, the number of such proposals, as well as the territory they seek to cover, has expanded steadily as genetic data has proliferated.

In the early 1990s, legislation focused almost exclusively on attempting to forbid insurers from using genetic information in health-insurance underwriting decisions. Currently, the social concern driving legislative interest is fear of genetic discrimination, defined here as discrimination against otherwise-healthy individuals on the basis of a genotypic variation. As of April 1997, at least 15 states had enacted genetic privacy laws. More than 75 similar bills are pending in more than 30 states, according to a survey by the Biotechnology Industrial Organization, and several federal bills have been introduced into the 105th Congress.

Protection Under HIPAA

Significant legislation at the state level has been more than eclipsed by a new federal law, "The Health Insurance Portability and Accountability Act of 1996" (PL-104-191), which takes effect this year. HIPAA provides an important new protection for people who want to undergo genetic testing but fear discrimination by health insurers if their test results indicate an increased risk for developing a serious disease. Section 101 of HIPAA sharply curtails the right of group health insurers to limit coverage of new employees because of "preexisting conditions." As of August 1997, group health insurance plans may impose a preexisting-condition exclusion only when medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period before enrollment.

The new law also forbids group health insurance plans to apply the preexisting-condition rule to genetic

information unless the person has been diagnosed with the illness predicted by the genetic test. For example, a woman who does not have cancer may not be denied coverage even if her test results indicate a predisposing mutation for breast or ovarian cancer.

Given the scope of HIPAA, rapid proliferation of similar state laws, steady growth of managed care, and public mood, individuals who decide to undergo DNA-based predispositional testing may face relatively little risk of discrimination in health insurance. Nevertheless, a widespread concern stimulated in part by the emergence of tests to identify persons at increased risk for cancer is that test results can and will be used against people. Some are so concerned that even protective legislation is unlikely to reassure them.

The vast number of genetic privacy bills circulating in state legislatures has generated many questions. Four of the most important are (1) What is meant by a genetic test? (2) Is genetic information distinct from or merely one form of medical information? (3) Should a tissue sample and data derived from it be the property of the person from whom it was taken? (4) Do we need more stringent oversight of human genetic research?

Defining "Genetic Test"

Deciding what constitutes a genetic test is not so easy, and definitions vary widely. A current Texas bill (TX75RSB98) defines it as a test of an "individual's DNA, RNA, or chromosomes...associated with a predisposition for a clinically recognized disease or disorder." Note that this definition does not include proteins, so it excludes some newborn screening, prenatal tests for neural tube defects, and many tests currently used by geneticists to make diagnoses. A more-inclusive Vermont bill (H.89), on the other hand, defines genetic testing as analysis of a chromosome, a gene, DNA, RNA, or protein encoded by a gene...." Both bills also exclude certain standard medical tests from their reach. If each state bill has its own particular definition and many become law, these variations may someday haunt insurers, employers, and testing laboratories that seek to comply with laws in the individual states.

Protection for Other Clinical Data

Is genetic information so different from other clinical data that it deserves special protection? There is, admittedly, precedent for this. Our society traditionally accords a special level of protection to psychiatric records, and, to some extent, we have condoned a higher degree of protection to HIV test results. In essence, the argument that genetic data is different from regular medical information and deserves special protection is two pronged:

- genetic tests may predict future risks for healthy persons, and
- these tests may infer risk about relatives.

True enough but the ability to treat genetic information with special care depends on how well it can be separated from other clinical information. If genetic testing permeates medical care, as it almost certainly will within the next 20 years, it will be very difficult to implement a law that requires separate treatment of portions of many people's medical records. Few bills have confronted this issue; in those that have sought to deal with it, genetic information is defined so narrowly that, if enacted, the bills would protect very little information about very few people. Too often lost in the discussion about genetic privacy is the point that nearly everyone would benefit from enactment of a general medical privacy law covering access to and use of all health information.

Individual Property Rights

In 1995, bills began to appear that were partly influenced by a model "Genetic Privacy Act" drafted by DOE ELSI grantee George Annas and his colleagues at Boston University. These bills asserted that tissue taken for genetic testing, as well as the test results, should remain the property of the individual tested. This principle challenges a century of practice in which discarded tissue samples have been used routinely by pathologists for research and teaching in a manner that respects the donor's privacy.

In 1995, Oregon enacted a law based on Annas's model, and the property proposal has since popped up in many other bills. In 1996, the New Jersey legislature passed a similar bill that was vetoed by Governor Whitman after 11th-hour protests from the pharmaceutical industry. Citing the bill's possible chilling effect on research, Whitman later signed an amended version that deleted the property provision but required that all genetic testing be preceded by written informed consent. A bill now before the New Jersey legislature seeks to reintroduce the property concept.

Bills that include provisions forever tying up tissue samples as property of persons from whom they were taken do raise questions about uses to which the academic and research community may put the DNA. Like it or not, given the importance of intellectual property concerns, scientists might not go forward with research if they don't have a clear right to use the samples.

IRB Oversight

The most recent trend in genetic privacy bills is the notion that genetic information is so sensitive and the threat of genetic discrimination so significant that our society needs a new level of oversight for research involving human genetics. Proponents of these provisions offer few concrete examples of studies in which genetic research has harmed human subjects; rather, they assert a potential future risk. Nevertheless, it would not be surprising to see state laws that define all research involving human gene mapping as constituting significant social risk to subjects. Any such research, regardless of its funding, thus would require the equivalent of an independent review by an institutional review board (IRB) or its equivalent. Although unlikely to become law this year, "The Human Research Subjects Protection Act of 1997" (S.193), introduced by Senator John Glenn (D-OH), proposes to extend IRB oversight to all U.S. research involving human subjects.

Federal Control

If the federal government decides to broaden its level of control over research, a comprehensive federal law could be enacted to preempt individual state regulations. Monitoring and abiding by a potpourri of varying state rules might be exceedingly expensive and time consuming for multicenter investigations.

See also:

- [*Pending Legislation Could Impact Research*](#)
- [*Genetic Testing Report*](#)
- [*President's Bill Would Prohibit Human Cloning*](#)

[Back to Home Page](#)

[Back to Table of Contents](#)