Report of the NAIC Genetic Testing Working Group
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The National Association of Insurance Commissioners is celebrating its 125th anniversary in 1996. On May 24, 1871, state insurance regulators met for the first time to work together on common goals, resulting in the formation of the NAIC.

Eighteen commissioners attended the first National Insurance Convention of the United States, as it was then called. This step marked the beginning of a new era of cooperation in state insurance regulation that continues today.

For 125 years state regulators, through the NAIC, have proven that state insurance regulation works, aiming for the best in consumer protection and a thriving marketplace.
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The NAIC Life Insurance (A) Committee created Genetic Testing Working Group following the national meeting in Denver in 1994. The charge to the working group was to analyze the appropriateness of insurers using genetic testing in applications for insurance coverage. The working group conducted open hearings on genetic testing at the national NAIC meetings held in Baltimore, Minneapolis and New Orleans in 1994 and in Miami, San Antonio, St. Louis, and Philadelphia in 1995. In addition members of the working group participated in various seminars specifically addressing genetic testing held across the country. Also, the states have held hearings and developed various model laws. This paper is designed to provide a brief, easily understood, primer on genetic testing, its status and issues raised by its use; an overview of actions taken by the various states; suggestions as to possible regulatory options; and finally a compilation of the statutes enacted by the states.

Introduction

Each person has his or her own unique combination of twenty-three pairs of genes or chromosomes, the basic units of human heredity. These genes form the human genome. The human genome is the genetic blueprint of the human body. The code is made up of about three billion chemical “letters” or nucleotides, the chemical units that create each person’s chromosomes. The genetic code is formed by combinations of only four amino acids, cytosine, tyrosine, guanine and adenine, in various combinations. These nucleotides are arranged in pairs, forming a twisting, ladderlike structure, known as a double helix, called deoxyribonucleic acid (DNA). If stretched out, each cell’s genetic code would be about three feet in length.

Each cell of the human body contains the entire genetic code for an individual, consisting of about one hundred thousand genes. Genes order the production of proteins and other chemicals that go into making up the human body. When a gene is altered or mutated, the wrong message is sent to the production mechanism of the cell, which can, in turn, cause the body to malfunction, creating genetic disease. Genetic disease may be either inherited or acquired. Inherited disease arises from the chromosomes received directly from parents, as in cystic fibrosis. These diseases may be from dominant genes, requiring only a single gene from one parent. Or they may be from recessive genes, requiring a gene from each parent. Genetic disease may also arise from alteration of the genetic code after birth, an acquired disorder. Certain forms of cancer are most likely this type of disease, since the gene which controls the growth of a specific cell appears to be damaged so that the normal cell loses control, expanding locally and spreading distantly, ultimately killing the patient. Alterations to genes may also increase the likelihood of an individual developing a disease, though the disease itself is not genetic in origin.

Definition of Genetic Testing

No generally accepted term precisely defines “genetic testing.” The term implies that a piece of the human genetic code is examined to determine if the chemical sequence is proper. However, this is not currently possible except in the most sophisticated laboratories. Rather, the underlying genetic code must be deciphered through indirect evidence.

In those states where legislation has been adopted addressing genetic testing, the definition has been relatively restrictive, limiting the definition to those tests which examine the genetic code or direct gene products. In addressing the issue of defining genetic testing, insurers have advocated
extremely tight restrictions, limiting such testing to laboratory testing of human DNA or chromosomes. On the other side of the issue, some advocacy groups have advocated much broader definitions, including a prohibition against inquiring into the applicant’s family history or even the ages or health of one’s parents as a form of a genetic test.

The Task Force on Genetic Testing of the Working Group on the Ethical, Legal and Social Implications of the Human Genome Project:

“Genetic tests” - The analysis of human DNA, chromosomes, proteins or other gene products to determine the presence of disease-related genotypes, mutations, phenotypes or karyotypes for clinical purposes. Such purposes include prediction of disease risks, identification of carriers, monitoring, diagnosis or prognosis, but do not include tests conducted purely for research.

The Working Group suggests the working definition be:

“Genetic screening or testing” means 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 indicates 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.

CURRENT STATE OF GENETIC TESTING

Perhaps the most famous genetic project currently is the Human Genome Project. The Human Genome project is a worldwide project initiated approximately five years ago in an attempt to analyze the human genetic code. It is anticipated that the Project will take about fifteen years and cost about $3 billion. Presently, scientists estimate that they have identified genes responsible for about one half the 6,500 known inherited diseases caused by a single defective gene, including the genes responsible for cystic fibrosis and neurofibromatosis. In addition, certain genetic abnormalities have been discovered which predispose individuals to certain diseases, such as breast cancer in women who inherit the BRCA-1 abnormality or indicate a high probability of cancer in families who have a history of hereditary non-polyposis colon cancer.

The project hopes to accomplish two goals. First is to map the genome, to determine the location of each of the thousands of genes. Second is to sequence the genome, to determine the order of each of the chemical letters making up the genetic code. By achieving this, scientists hope to be able to examine an individual’s genetic code to identify any abnormality that might exist in the sequence of the code and then determine how that abnormality might affect the individual by ascertaining which structure or function might be changed by the location of the abnormality on the map of the genome. To date less than one percent of the genome’s three billion units has been sequenced or deciphered.

Most current “genetic tests” examine either gene products or macroscopic structures resulting from the action of a specific gene. Many genetic syndromes are diagnosed solely through the physical examination of the patient. Other genetic tests examine the chemicals created by the body from the genetic code, for example testing of newborns for treatable metabolic diseases
such as phenylketonuria (PKU). Many states mandate such neonatal testing. Still other diseases are diagnosed by a combination of these two methods.

On a microscopic basis, chromosomes themselves may be examined to determine if there is a cellular chromosomal abnormality, as when an amniocentesis is performed on a pregnant woman looking for Down Syndrome connected with trisomy.

Genetic testing is of variable utility. This is particularly evident in autosomal regressive conditions, where the genetic abnormality must be inherited from both parents. For example, with cystic fibrosis two individuals who carry the single abnormal gene will not develop the disease. However, should those individuals have children together, those children carry a twenty-five percent risk of inheriting both abnormal genes and will then certainly develop the disease. Therefore carrier status is not predictive of future disability for those individuals. In autosomal dominant conditions such as Huntington’s Chorea, the presence of a single gene means those individuals will develop the disease if they live long enough. These individuals are essential presymptomatic with the disease process, since the only condition under which the disease will not develop is an early death. The identification of the gene is therefore highly predictive of future disability. Intermediate between these two conditions are the complex gene-influenced conditions which have a predisposition toward the development of a disease. For example a woman who inherits the BRCA-1 abnormality has a high probability of developing breast cancer. However, about fifteen percent will not develop the disease. Therefore, the predictive value of the genetic abnormality is of significance, but places the individual in an intermediate risk exposure, lying between the recessive and dominant genetic disorders.

The working group sought responses to several questions regarding the status of genetic testing. The first was whether insurers were currently requiring applicants to submit to genetic testing. We found that, now, insurers are not requiring genetic testing as a prerequisite to coverage. Second was whether insurers were using genetic test results from any source in underwriting. It was found that, although no insurers are now requiring genetic testing, if the results of genetic testing are in an applicant’s medical record and are relevant, insurers are likely to include such results in the underwriting process.

**GENETIC TESTING ISSUES**

**LIFE AND DISABILITY INCOME INSURANCE**

Life and disability income insurance policies provide financial security to the policyholder’s beneficiaries and for the benefit of the insured. By contrast, health insurance contracts provide indemnification for the cost of medical services rendered the insured.

Life and disability income insurance may be underwritten either individually or on a group basis. Both the underwriting and pricing of these policies are performed at the inception of these contracts. Usually once issued, neither the terms of nor the premiums for these individual policies can be changed regardless of changes in the nature of the insured risk or the length of time the contract is in effect. These policies also cannot generally be terminated except for nonpayment of premium. Most life insurance policies are individual in nature. By contrast, most health insurance is provided by employer group contracts and hence, re-priced annually and can be canceled under certain circumstances.
Some group life and disability income policies have provisions allowing the modification of premiums for groups as a whole. However, an individual may not be singled out for premium increases based on health factors. Also, while policies cannot be terminated except for nonpayment of premiums, some policies do expire after a stated period.

At the end of 1993, the most recent year for which there are published statistics, life insurance in force in the United States amounted to $11,105 billion. Seventy-eight percent of all American households and 154 million Americans owned life insurance at the end of 1993. Life insurance purchases during the year totaled $1.7 trillion. Two thirds of that amount were for individual ordinary life insurance.

Of the $11,105 billion of life insurance in force at the end of 1993, 57.9 percent ($6,428.4 billion) was ordinary individual life insurance which continues to be the principal type of life insurance protection for Americans. This type of insurance is purchased by individuals to meet individual needs. Group life insurance in force at the end of 1993 totaled $4,456.3 billion and represented 40.1% of the life insurance in force in the United States.

The process of risk classification is used primarily in underwriting individual life and disability income insurance. Through the process of risk classification and underwriting, insurance companies place applicants for coverage into groups or classes. Each class is comprised of individuals who pose the same or comparable levels of risk. All the members of the class pay the same premiums. This is how insurers attempt to achieve fairness among insureds by matching premiums to the risks presented so that all those who present the same level of risk pay the same premiums.

On one side, individuals with any type of genetic abnormality, even if that abnormality is not predictive of any increased morbidity or mortality, are concerned that they will not be able to get insurance. On the other, life and disability insurers are concerned that, if an individual has knowledge of a genetic condition which is either presymptomatic or highly dispositive to developing a disease, that individual has an increased incentive to obtain higher levels of insurance without disclosing what may be a highly predictive risk underwriting factor.

Health Insurance

Health insurance is sold on a group and individual basis. Most major medical insurance coverage is provided on a group basis by an employer. Insurers classify risk for health insurance for groups either by the group’s own claims experience, or by data from the claims experience of other similar groups in the same industry. The premium rates are also set according to these factors. Major medical coverage pays for most medical expenses incurred for hospital and physician services at a percentage of the amount billed, after a deductible has been satisfied. Many policies limit coverage to a lifetime maximum, which is rarely exhausted.

The smaller the group, the fewer people there are to spread the expense of high cost claims; therefore, insurers may medically underwrite smaller groups on an individual basis. Many states have enacted small employer laws that require insurers to accept all employees of a small employer so underwriting does not result in exclusion from the group. Some states have laws or regulations that limit or prohibit medical underwriting, impose rating restrictions which prohibit an insurer from varying rates for small groups beyond certain thresholds or limit the degree to
which an insurer can vary a group’s rates based upon an individual’s medical history or claims experience.

Sole proprietors, small employers, and individuals applying for major medical coverage experience medical underwriting. If a person has a medical condition that the insurer determines is unacceptable because of potential high medical expenses, in most states the insurer may reject the applicant, or issue a policy that excludes the preexisting condition for some period, or may never cover the condition. For this reason many states have laws that provide major medical coverage to individuals through a state high risk pool, while a few states require an insurer, such as Blue Cross Blue Shield, to accept these individuals. Insurers reject or limit coverage according to data that demonstrates that certain medical conditions, such as diabetes and cancer, will result in medical expenses. Other types of health insurance such as long-term care insurance, Medicare Supplement insurance and limited indemnity coverage are also medically underwritten. However, federal and state laws require insurers to issue Medicare Supplement insurance policies to applicants the first six months they receive Medicare Part B and reach 65 years of age, regardless of individual health conditions.

Premiums for individual insurance coverage are set according to the individual’s age, sex, and geographic residence because these are reliable factors that indicate claims experience and medical expenses in the area where a person resides.

With the increasing adoption of open enrollment requirements among the states, the utility of genetic information in underwriting health insurance is rapidly disappearing, since open enrollment requires the insurer to accept all applicants, regardless of health status. Despite these changes, several legislators have recently introduced legislation at the federal level to prohibit the use of genetic information in the health insurance area and to restrict the use in other insurance lines. Copies of bills currently before the Congress are attached to his paper.

**AVAILABILITY OF INSURANCE COVERAGE**

Health insurance is the fundamental means to health care for many people. Life insurance is a primary means to future financial security. If an individual’s genetic information indicates a potentially adverse genetic condition, genetic testing could threaten the individual’s ability to obtain either coverage. In response to test results, an insurer may increase premiums, exclude coverage for a condition from coverage even if the individual is healthy, or deny insurance altogether. An individual’s access to health care and future financial security may be threatened or closed.

**RISK CLASSIFICATION**

Risk classification is a critical element for any insurance system. It is one step in the process insurers use to classify and divide individuals into groups with similar claims experience, and to thereby gain an estimate of expected costs. By classifying the risk associated with projected claims, this procedure protects the insurer’s solvency and allows individuals in the class to pay the lowest price compatible with projected costs.

Risk classification also attempts to offset the negative impact of adverse selection. Adverse selection describes a situation in which the individuals most likely to purchase insurance are those with the highest risk of incurring losses. A case study on adverse selection (also known as
antiselection) appears in the March/April 1996 issue of the American Academy of Actuaries’ publication, *Contingencies*.

The viability of a voluntary insurance system is dependent upon insurers’ capacity to avoid or limit the impacts of adverse selection through risk classification. To do this, insurers must have access to the same material knowledge as the insurance applicant. Risk classification also promotes equity among consumers, whereby each person pays a premium commensurate with the individual’s risk. For example, nonsmokers pay less in insurance premiums than smokers.

**CONFIDENTIALITY**

As a medical test, a genetic test becomes part of an individual’s medical record. Consumers have justifiable concerns that private medical information will be circulated to persons other than the individual or his or her medical practitioner.

**BURDEN OF KNOWLEDGE**

Learning about a genetic condition may create a serious mental and emotional burden for an individual, depending on the condition and its likelihood or potential for injuring the individual’s health. An individual has no control over the condition. Depression, hopelessness and psychological trauma are obvious concerns. Family discord arising from unknown or undiscovered hereditary conditions are possible. Finally, the knowledge may have no therapeutic value for an individual if nothing can be done to prevent or deal with the condition. The lack of therapeutic value of the testing itself, as well as of the test results, is especially troubling because the testing at the outset was not done for the individual’s medical benefit or by the individual’s choice, but for the economic interest of a third party, the insurer. However, it is important to note that requiring an individual to disclose genetic results from a test previously performed does not raise the burden of knowledge issue. The burden of knowledge also varies by the type of test performed. For example, informing an individual of a high cholesterol level associated with a familial syndrome is different from revealing that an individual may be at risk for developing a life-threatening condition later in life.

**DISCRIMINATION**

A perfectly healthy individual who has a potentially adverse genetic condition (if such an individual may be properly described as “perfectly healthy”) may be the object of discrimination by insurers, employers and others if these parties know about the genetic condition before taking some specified action. Similarly, an individual who has this knowledge, while others do not, may behave differently when buying insurance or taking other actions. Essentially, the individual runs the risk of being negatively stereotyped or categorized regardless of the individual’s current health, though insurance involves, by its very nature, the sorting of individuals into risk classes. In any case, the question arises about whether or not knowledge of a genetic condition will result in unfair categorization.
EFFECT ON CURRENT POLICYHOLDERS

A policyholder who learns of a genetic condition will recognize that a change in employment may threaten health care and future economic security. The individual’s freedom to move from one job to another and the freedom to move from one type of coverage to another may be circumscribed. The individual’s employment may even be threatened. Finally, a healthy person with a potentially serious genetic condition may be treated unnecessarily as having a chronic, fatal disease.

Regulatory Options

When the working group originally met, there was substantial discussion over the possible development of a model act or regulation. This substantial discussion resulted in substantial disagreement regarding the advisability, necessity and even the capability of the working group to come to agreement on such a model.
## Appendix

### Survey of State Legislation

**STATE POSITIONS ON THE ISSUE OF GENETIC TESTING FOR INSURANCE COVERAGE**

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<thead>
<tr>
<th>STATE</th>
<th>CITATION</th>
<th>COVERAGE</th>
<th>PROVISIONS</th>
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<tbody>
<tr>
<td>Arizona</td>
<td>§ 20-448</td>
<td>Life and Health</td>
<td>It is an unfair trade practice to consider a genetic condition in determining rates, terms or conditions of a life or health insurance policy or to reject an application for coverage based on a genetic condition unless claims experience or actuarial projections establish substantial differences in claims are likely to result from the genetic condition.</td>
</tr>
<tr>
<td>California</td>
<td>Ins. § 10140</td>
<td>Health</td>
<td>No insurer shall refuse to issue or sell or renew any policy of health insurance or charge a higher premium solely because the person carries a gene which may be associated with disability in that person or the person’s offspring. Establishes standards for underwriting life and health insurance on the basis of genetic characteristics. Additional penalties and remedies with respect to violation of provisions relating to discrimination on basis of genetic characteristics apply to self-insured welfare benefit plan.</td>
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<tr>
<td></td>
<td>§§ 10146 to 10149.1</td>
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<td>§ 10123.35</td>
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</tr>
<tr>
<td>Colorado</td>
<td>§ 10-3-1104.7</td>
<td>Health, disability income, long-term care</td>
<td>Prohibits health and disability underwriters from seeking genetic information or using it to deny health insurance, group disability or long-term care insurance.</td>
</tr>
<tr>
<td>Florida</td>
<td>§§ 626.9706, 626.9707</td>
<td>Life and health; sickle-cell trait</td>
<td>No life or health insurer shall refuse to issue and deliver any policy of insurance solely because the person has sickle-cell trait.</td>
</tr>
<tr>
<td>Georgia</td>
<td>§§ 33-54-1 to 33-54-8</td>
<td>Health</td>
<td>Prohibits use of any information obtained from genetic testing to deny access to health insurance.</td>
</tr>
<tr>
<td>Hawaii</td>
<td>SB 299 pending (1995)</td>
<td>Health</td>
<td>May not use results of genetic test to decide whether to insure for health insurance or in determination of rates or any other aspect of health insurance. Does not apply to life insurance, as long as rates are reasonably related to risk involved.</td>
</tr>
<tr>
<td>Louisiana</td>
<td>R.S. 22:652.1</td>
<td>Life and health; sickle-cell trait</td>
<td>No insurer shall refuse to provide a policy of life insurance or health insurance solely because the applicant has sickle-cell trait.</td>
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<td>STATE</td>
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<tr>
<td>Maryland</td>
<td>48A § 223</td>
<td>Genetic discrimination; life</td>
<td>Insurer may not refuse to insure or make or permit any differential in ratings for life insurance solely because the applicant has a genetic trait which is harmless within itself unless there is actuarial justification for it.</td>
</tr>
<tr>
<td>Minnesota</td>
<td>§ 72A.139</td>
<td>Health</td>
<td>May not require a genetic test or consider results of a test in determining eligibility for health insurance coverage, establishing premiums, or limiting coverage. Life insurers should obtain informed consent before testing and should recommend counseling.</td>
</tr>
<tr>
<td>Montana</td>
<td>§ 33-18-206</td>
<td>Genetic discrimination; all lines</td>
<td>The rejection of an application or determination of rates based on a genetic condition is unfair discrimination unless the applicant’s medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition.</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>§§ 141-H:1 to 141-H:6</td>
<td>Health</td>
<td>Health insurer may not require genetic testing or condition provision of health insurance on results of a genetic test. May not consider in determination of rates. Does not apply to life, disability income or long-term care insurance.</td>
</tr>
<tr>
<td>North Carolina</td>
<td>§ 58-58-25</td>
<td>Life; sickle-cell trait</td>
<td>Insurer shall not refuse to issue or deliver any policy of life insurance solely by reason of the fact that their person possesses sickle cell trait or hemoglobin C trait, nor shall the policy carry a higher premium rate or charge by reason of the fact of the insured possesses the trait.</td>
</tr>
<tr>
<td>Ohio</td>
<td>§§ 1742.42 to 1742.43, 3901.491 to 3901.501</td>
<td>Health</td>
<td>Insurers and HMOs shall not consider any information obtained from genetic testing in processing individual or group health insurance applications. Statute effective until the year 2004.</td>
</tr>
<tr>
<td>Oregon</td>
<td>§ 746.135</td>
<td>Hospital or medical expense coverage</td>
<td>Requires informed consent before testing DNA. May not use results of testing to reject, deny, limit, cancel, refuse to renew, increase the rates, or otherwise affect any policy covering hospital or medical expenses.</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>Senate Resolution 6 pending (1995)</td>
<td>Health</td>
<td>Encourages insurers to place a two-year moratorium on the practice of denying individuals insurance coverage due to genetic abnormalities while Dept. of Health conducts a study.</td>
</tr>
<tr>
<td>Tennessee</td>
<td>§ 56-7-207</td>
<td>Life; sickle-cell trait</td>
<td>Insurer shall not refuse to issue or deliver any policy of life insurance solely by reason of the fact that the person to be insured possesses sickle cell trait or hemoglobin C trait.</td>
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<tbody>
<tr>
<td>Virginia</td>
<td>§ 38.2-508.4</td>
<td>Health</td>
<td>Insurer may not terminate, restrict, limit or otherwise apply conditions on coverage of an individual; cancel or refuse to renew; exclude; impose a waiting period; or establish a different rate for coverage on the basis of the results of genetic information. Information obtained from genetic screening or testing is confidential. Statute expires on July 1, 1998.</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>§ 631.89</td>
<td>Health</td>
<td>Insurer may not require or request any individual or a member of the individual’s family to obtain a genetic test. Shall not condition the provision of insurance coverage or health care benefits on whether a genetic test has been performed or on what the test results are. Does not apply to life insurance or income continuation insurance. If life or income continuation insurers do obtain genetic testing information, they are under the same information use restrictions as the insurers mentioned above.</td>
</tr>
</tbody>
</table>

Note: Every effort has been made to provide correct and complete information. For further information, consult the statutes listed.
§ 20-448 Unfair discrimination

A. No person shall make or permit any unfair discrimination between individuals of the same class and equal expectation of life in the rates charged for any contract of life insurance or of life annuity or in the dividends or other benefits payable thereon, or in any other of the terms and conditions of the contract.

B. No person shall make or permit any unfair discrimination respecting hemophiliacs or between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees or rates charged for any policy or contract of disability insurance or in the benefits payable thereunder, or in any of the terms or conditions of the contract, or in any other manner whatever. The provisions of this subsection regarding hemophiliacs shall not apply to any policy or subscription contract which provides only benefits for specific diseases or for accidental injuries or which provides only indemnity for blood transfusion services or replacement of whole blood products, fractions or derivatives.

C. As to kinds of insurance other than life and disability, no person shall make or permit any unfair discrimination in favor of particular persons, or between insureds or subjects of insurance having substantially like insuring, risk and exposure factors, or expense elements, in the terms or conditions of any insurance contract, or in the rate or amount of premium charged therefor. This subsection shall not apply as to any premium or premium rate in effect pursuant to chapter 2, article 4 of this title (rate laws, fire and casualty).

D. No insurer shall refuse to consider an application for life or disability insurance on the basis of a genetic condition, developmental delay or developmental disability.

E. The rejection of an application or the determining of rates, terms or conditions of a life or disability insurance contract on the basis of a genetic condition, developmental delay or developmental disability constitutes unfair discrimination, unless the applicant’s medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition, developmental delay or developmental disability.

F. As used in this section:

1. “Developmental delay” means a delay of at least one and one-half standard deviations from the norm.

2. “Developmental disability” is as defined in section 36-551.

3. “Genetic condition” means a specific chromosomal or single-gene genetic condition.
CALIFORNIA

Ins § 10140 Discrimination prohibited; violations

Text of section operative until January 1, 2002

(a) No admitted insurer, licensed to issue life or disability insurance, shall fail or refuse to accept an application for that insurance, to issue that insurance to an applicant therefor, or issue or cancel that insurance, under conditions less favorable to the insured than in other comparable cases, except for reasons applicable alike to persons of every race, color, religion, national origin, ancestry, or sexual orientation. Race, color, religion, national origin, ancestry, or sexual orientation shall not, of itself, constitute a condition or risk for which a higher rate, premium, or charge may be required of the insured for that insurance.

(b) Except as otherwise permitted by law, no admitted insurer, licensed to issue disability insurance policies for hospital, medical, and surgical expenses, shall fail or refuse to accept an application for that insurance, fail or refuse to issue that insurance to an applicant therefor, cancel that insurance, charge a higher rate or premium for that insurance, or offer or provide different terms, conditions, or benefits, or place a limitation on coverage under that insurance, on the basis of a person’s genetic characteristics that may, under some circumstances, be associated with disability in that person or that person’s offspring. This subdivision shall not apply to life and disability income policies issued or delivered on or after January 1, 1995, that are contingent upon review or testing for other diseases or medical conditions.

(c) No discrimination shall be made in the fees or commissions of agents or brokers for writing or renewing a policy of disability insurance, other than disability income, on the basis of a person’s genetic characteristics that may, under some circumstances, be associated with disability in that person or that person’s offspring.

(d) It shall be deemed a violation of subdivision (a) for any insurer to consider sexual orientation in its underwriting criteria or to utilize marital status, living arrangements, occupation, gender, beneficiary designation, zip codes or other territorial classification within this state, or any combination thereof for the purpose of establishing sexual orientation or determining whether to require a test for the presence of the human immunodeficiency virus or antibodies to that virus, where that testing is otherwise permitted by law. Nothing in this section shall be construed to alter, expand, or limit in any manner the existing law respecting the authority of insurers to conduct tests for the presence of human immunodeficiency virus or evidence thereof.

(e) This section shall not be construed to limit the authority of the commissioner to adopt regulations prohibiting discrimination because of sex, marital status, or sexual orientation or to enforce these regulations, whether adopted before or on or after January 1, 1991.

(f) “Genetic characteristics” as used in this section shall have the same meaning as defined in Section 10147.
This section shall remain in effect only until January 1, 2002, and as of that date is repealed, unless a later enacted statute, that is enacted before January 1, 2002, deletes or extends that date.

**Ins § 10140.1 Disclosure of genetic test results: violations**

(a) This section shall apply to the disclosure of genetic test results contained in an applicant or enrollee’s medical records by an admitted insurer licensed to issue life or disability insurance, except life and disability income policies issued or delivered on or after January 1, 1995, that are contingent upon review or testing for other diseases or medical conditions.

(b) Any person who negligently discloses results of a test for a genetic characteristic to any third party, in a manner that identifies or provides identifying characteristics, of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), this shall be assessed a civil penalty in an amount not to exceed one thousand dollars ($1,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(c) Any person who willfully discloses the results of a test for a genetic characteristic to any third party, in a manner that identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), shall be assessed a civil penalty in an amount not less than one thousand dollars ($1,000) and no more than five thousand dollars ($5,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(d) Any person who willfully or negligently discloses the results of a test for a genetic characteristic to a third party, in a manner that identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), that results in economic, bodily, or emotional harm to the subject of the test, is guilty of a misdemeanor punishable by a fine not to exceed ten thousand dollars ($10,000).

(e) In addition to the penalties listed in subdivisions (b) and (c), any person who commits any act described in subdivision (b) or (c) shall be liable to the subject for all actual damages, including damages for economic, bodily, or emotional harm which is proximately caused by the act.

(f) Each disclosure made in violation of this section is a separate and actionable offense.

(g) The applicant’s “written authorization,” as used in this section, shall satisfy the following requirements:

1. Is written in plain language.
2. Is dated and signed by the individual or a person authorized to act on behalf of the individual.
(3) Specifies the types of persons authorized to disclose information about the individual.

(4) Specifies the nature of the information authorized to be disclosed.

(5) States the name or functions of the persons or entities authorized to receive the information.

(6) Specifies the purposes for which the information is collected.

(7) Specifies the length of time the authorization shall remain valid.

(8) Advises the person signing the authorization of the right to receive a copy of the authorization. Written authorization is required for each separate disclosure of the test results, and the authorization shall set forth the person or entity to whom the disclosure would be made.

(h) This section shall not apply to disclosures required by the Department of Health Services necessary to monitor compliance with Chapter 1.5 (commencing with Section 150) of Part 1 of Division 1 of, and Sections 289.7 and 309 of, the Health and Safety Code, nor to disclosures required by the Department of Corporations necessary to administer and enforce compliance with Section 1374.7 of the Health and Safety Code.

Ins § 10140.5 Penalties for violations

(a) In addition to any other remedy permitted by law, the commissioner shall have the administrative authority to assess penalties specified in this section against life or disability insurers for violations of Section 10140.

(b) Any life or disability insurer that violates Section 10140 is liable for administrative penalties of not more than two thousand five hundred dollars ($2,500) for the first violation and not more than five thousand dollars ($5,000) for each subsequent violation.

(c) Any life or disability insurer that violates Section 10140 with a frequency that indicates a general business practice or commits a knowing violation of that section, is liable for administrative penalties of not less than fifteen thousand dollars ($15,000) and not more than one hundred thousand dollars ($100,000) for each violation.

(d) An act or omission that is inadvertent and that results in incorrect premium rates being charged to more than one subscriber shall be a single violation for the purpose of this section.

Ins § 10146 Purpose

The purposes of this article are to establish standards regarding unfair discrimination among individuals of the same class in the underwriting of life or disability income insurance on the basis of tests of a person's genetic characteristics; to establish minimum standards for determining insurability which are sufficiently reliable to be used for life and disability income insurance risk classification and underwriting purposes; to require the maintenance of strict
confidentiality of personal information obtained through a test of a person’s genetic characteristics; and to require informed consent before insurers underwrite on the basis of a test of a person’s genetic characteristics. This article and Sections 10140 and 10143 shall constitute the exclusive requirements for insurers’ practices relating to genetic characteristics or to tests thereof.

Ins § 10147 Definitions

As used in this article:

(a) “Disability income insurance” means insurance against loss of occupational earning capacity arising from injury, sickness, or disablement, and includes insurance which provides benefits for overhead expenses of a business or profession when the insured becomes disabled.

(b) “Genetic characteristics” means any scientifically or medically identifiable gene or chromosome, or alteration thereof, which 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 that is presently not associated with any symptoms of any disease or disorder.

(c) “Life or disability income insurer” means an insurer licensed to transact life insurance or disability income insurance in this state or a fraternal benefit society licensed in this state.

(d) “Policy” means (1) a life insurance policy or a disability income insurance policy delivered in this state, or (2) a certificate of life insurance benefits or disability income insurance benefits, issued under a group life or disability income insurance policy and delivered in this state by a life or disability income insurer or a fraternal benefits society, regardless of the location of the group master policy.

(e) “Test of a person’s genetic characteristics” means a laboratory test which is generally accepted in the scientific and medical communities for the determination of the presence or absence of genetic characteristics.

Ins § 10148 Written consent

No insurer shall require a test for the presence of a genetic characteristic for the purpose of determining insurability other than in accordance with the informed consent, and privacy protection provisions of this article and Article 6.6 (commencing with Section 791) of Chapter 1 of Part 2 of Division 1. Notwithstanding any other provision of law, this constitutes the exclusive requirements for informed consent, and privacy protection for that testing.

(a) An insurer that requests an applicant to take a genetic characteristic test shall obtain the applicant’s written informed consent for the test. Written informed consent shall include a description of the test to be performed, including its purpose, potential uses, and limitations, the meaning of its results, procedures for notifying the applicant of the results, and the right to confidential treatment of the results.
(b) The insurer shall notify an applicant of a test result by notifying the applicant or the applicant’s designated physician. If the applicant tested has not given written consent authorizing a physician to receive the test results, the applicant shall be urged, at the time the applicant is informed of the test results, to contact a health care professional.

(c) The commissioner shall develop and adopt standardized language for the informed consent disclosure form required by this section to be given to any applicant for life or disability income insurance who takes a test for a genetic characteristic.

(d) A life or disability income insurer shall not require a person to undergo a test of the person’s genetic characteristics unless the cost of the test is paid by the insurer.

(e) No policy shall limit benefits otherwise payable if loss is caused or contributed to by the presence or absence of genetic characteristics, except to the extent and in the same fashion as the insurer limits coverage for loss caused or contributed to by other medical conditions presenting an increased degree of risk.

(f) Nothing in this chapter shall limit an insurer’s right to decline an application or enrollment request for a life or disability income insurance policy, charge a higher rate or premium for such a policy, or place a limitation on coverage under such a policy, on the basis of manifestations of any disease or disorder.

(g) No discrimination shall be made in the fees or commissions of agents or brokers writing or renewing a life or disability income policy on the basis of a test of that person’s genetic characteristics.

Ins § 10149.1 Disclosure of test results

(a) This section shall apply to the disclosure of the results of a test for a genetic characteristic requested by an insurer pursuant to this article.

(b) Any person who negligently discloses results of a test for a genetic characteristic to any third party, in a manner which identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), or except as provided in this article or in Sections 1603.1 and 1603.3 of the Health and Safety Code, shall be assessed a civil penalty in an amount not to exceed one thousand dollars ($1,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(c) Any person who willfully discloses the results of a test for a genetic characteristic to any third party, in a manner which identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), or except as provided in this article or in Sections 1603.1 and 1603.3 of the Health and Safety Code, shall be assessed a civil penalty in an amount not less than one thousand dollars ($1,000) and no more than five thousand dollars ($5,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.
(d) Any person who willfully or negligently discloses the results of a test for a genetic characteristic to a third party, in a manner which identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), or except as provided in this article or in Sections 1603.1 and 1603.3 of the Health and Safety Code, which results in economic, bodily, or emotional harm to the subject of the test, is guilty of a misdemeanor punishable by imprisonment in a county jail for a period not to exceed one year, by a fine of not to exceed ten thousand dollars ($10,000), or by both that fine and imprisonment.

(e) Any person who commits any act described in subdivision (b) or (c) shall be liable to the subject for all actual damages, including damages for economic, bodily, or emotional harm which is proximately caused by the act.

(f) Each disclosure made in violation of this section is a separate and actionable offense.

(g) The applicant's "written authorization," as used in this section, applies only to the disclosure of test results by a person responsible for the care and treatment of the person subject to the test. Written authorization is required for each separate disclosure of the test results, and shall include to whom the disclosure would be made.

Ins § 10123.35 Disclosure of genetic test results: violations

(a) This section shall apply to the disclosure of genetic test results contained in an applicant or enrollee's medical records by a self-insured welfare benefit plan.

(b) Any person who negligently discloses results of a test for a genetic characteristic to any third party, in a manner that identifies or provides identifying characteristics, of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), shall be assessed a civil penalty in an amount not to exceed one thousand dollars ($1,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(c) Any person who willfully discloses the results of a test for a genetic characteristic to any third party, in a manner that identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), shall be assessed a civil penalty in an amount not less than one thousand dollars ($1,000) and no more than five thousand dollars ($5,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(d) Any person who willfully or negligently discloses the results of a test for a genetic characteristic to a third party, in a manner that identifies or provides identifying characteristics of the person to whom the test results apply, except pursuant to a written authorization, as described in subdivision (g), that results in economic, bodily, or emotional harm to the subject of the test, is guilty of a misdemeanor punishable by a fine not to exceed ten thousand dollars ($10,000).

(e) In addition to the penalties listed in subdivisions (b) and (c), any person who commits any act described in subdivision (b) or (c) shall be liable to the subject for all actual damages,
including damages for economic, bodily, or emotional harm which is proximately caused by the act.

(f) Each disclosure made in violation of this section is a separate and actionable offense.

(g) The applicant’s “written authorization,” as used in this section, shall satisfy the following requirements:

1. Is written in plain language.

2. Is dated and signed by the individual or a person authorized to act on behalf of the individual.

3. Specifies the types of persons authorized to disclose information about the individual.

4. Specifies the nature of the information authorized to be disclosed.

5. States the name or functions of the persons or entities authorized to receive the information.

6. Specifies the purposes for which the information is collected.

7. Specifies the length of time the authorization shall remain valid.

8. Advises the person signing the authorization of the right to receive a copy of the authorization. Written authorization is required for each separate disclosure of the test results, and the authorization shall set forth the person or entity to whom the disclosure would be made.

(h) This section shall not apply to disclosures required by the Department of Health Services necessary to monitor compliance with Chapter 1.5 (commencing with Section 150) of Part 1 of Division 1 of, and Sections 289.7 and 309 of, the Health and Safety Code, nor to disclosures required by the Department of Corporations necessary to administer and enforce compliance with Section 1374.7 of the Health and Safety Code.

COLORADO

§ 10-3-1104.7 Genetic testing—declaration—definitions—limitations—on disclosure of information—liability—legislative—declaration

(1) The general assembly hereby finds and determines that recent advances in genetic science have led to improvements in the diagnosis, treatment, and understanding of a significant number of human diseases. The general assembly further declares that:

(a) Genetic information is the unique property of the individual to whom the information pertains;
(b) Any information concerning an individual obtained through the use of genetic techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual to whom the information pertains;

(c) To protect individual privacy and to preserve individual autonomy with regard to the individual’s genetic information, it is appropriate to limit the use and availability of genetic information;

(d) The intent of this statute is to prevent information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage.

(2) For the purposes of this section:

(a) “Entity” means any sickness and accident insurance company, health maintenance organization, nonprofit hospital, medical-surgical and health service corporation, or other entity that provides health care insurance, group disability insurance, or long-term care insurance coverage and is subject to the jurisdiction of the commissioner of insurance.

(b) “Genetic testing” means 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.

(3) (a) Information derived from genetic testing shall be confidential and privileged. Any release, for purposes other than diagnosis, treatment, or therapy, of genetic testing information that identifies the person tested with the test results released requires specific written consent by the person tested.

(b) Any entity that receives information derived from genetic testing may not seek, use, or keep the information for any nontherapeutic purpose or for any underwriting purpose connected with the provision of health care insurance, group disability insurance, or long-term care insurance coverage.

(4) Notwithstanding the provisions of subsection (3) of this section, in the course of a criminal investigation or a criminal prosecution, and to the extent allowed under the federal or state constitution, any peace officer, district attorney, or assistant attorney general, or a designee thereof, may obtain information derived from genetic testing regarding the identity of any individual who is the subject of the criminal investigation or prosecution for use exclusively in the criminal investigation or prosecution without the consent of the individual being tested.

(5) Notwithstanding the provisions of subsection (3) of this section, any research facility may use the information derived from genetic testing for scientific research purposes so long as the identity of any individual to whom the information pertains is not disclosed to any third party; except that the individual’s identity may be disclosed to the individual’s physician if the individual consents to such disclosure in writing.
(6) This section does not limit the authority of a court or any party to a parentage proceeding to use information obtained from genetic testing for purposes of determining parentage pursuant to section 13-25-126, C.R.S.

(7) This section does not limit the authority of a court or any party to a proceeding that is subject to the limitations of part 5 of article 64 of title 13, C.R.S., to use information obtained from genetic testing for purposes of determining the cause of damage or injury.

(8) This section does not limit the authority of the state board of parole to require any offender who is involved in a sexual assault to submit to blood tests and to retain the results of such tests on file as authorized under section 17-2-201(5)(g), C.R.S.

(9) This section does not limit the authority granted the state department of public health and environment, the state board of health, or local departments of health pursuant to section 25-1-122, C.R.S.

(10) This section does not apply to the provision of life insurance or individual disability insurance.

(11) Any violation of this section is an “unfair practice,” as defined in section 10-3-1104(1), and is subject to the provisions of sections 10-3-1106 to 10-3-1113.

(12) Any individual who is injured by an entity’s violation of this section may recover in a court of competent jurisdiction the following remedies:

(a) Equitable relief, which may include a retroactive order, directing the entity to provide health insurance, group disability insurance, or long-term care insurance coverage, whichever is appropriate, to the injured individual under the same terms and conditions as would have applied had the violation not occurred; and

(b) An amount equal to any actual damages suffered by the individual as a result of the violation.

(13) The prevailing party in an action under this section may recover costs and reasonable attorney fees.

FLORIDA

§ 626.9706 Life insurance discrimination based on sickle-cell trait

(1) No insurer authorized to transact insurance in this state shall refuse to issue and deliver any policy of life insurance solely because the person to be insured has the sickle-cell trait.

(2) No life insurance policy issued and delivered in this state shall carry a higher premium rate or charge solely because the person to be insured has the sickle-cell trait.

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§ 626.9707 Disability insurance discrimination based on sickle-cell trait

(1) No insurer authorized to transact insurance in this state shall refuse to issue and deliver in this state any policy of disability insurance, whether such policy is defined as individual, group, blanket, franchise, industrial, or otherwise, which is currently being issued for delivery in this state and which affords benefits and coverage for any medical treatment or service authorized and permitted to be furnished by a hospital, clinic, health clinic, neighborhood health clinic, health maintenance organization, physician, physician’s assistant, nurse practitioner, or medical service facility or personnel solely because the person to be insured has the sickle-cell trait.

(2) No disability insurance policy issued or delivered in this state shall carry a higher premium rate or charge solely because the person to be insured has the sickle-cell trait.

GEORGIA

§ 33-54-1 Purpose of provisions

The General Assembly finds and determines that recent advances in genetic science have led to improvements in the diagnosis, treatment, and understanding of a significant number of human diseases. The General Assembly further finds and declares that:

(1) Genetic information is the unique property of the individual tested;

(2) The use and availability of information concerning an individual obtained through the use of genetic testing techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual tested;

(3) To protect individual privacy and to preserve individual autonomy with regard to an individual’s genetic information, it is appropriate to limit the use and availability of genetic information; and

(4) The intent of this chapter is to prevent accident and sickness insurance companies, health maintenance organizations, managed care organizations, and other payors from using information derived from genetic testing to deny access to accident and sickness insurance.

§ 33-54-2 “Genetic testing”; “insurer”

As used in this chapter, the term:

(1) “Genetic testing” means 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.

§ 33-54-3 Written consent for testing and disclosure of results

(a) Except as otherwise provided in this chapter, genetic testing may only be conducted to obtain information for therapeutic or diagnostic purposes. Genetic testing may not be conducted without the prior written consent of the person to be tested.

(b) Information derived from genetic testing shall be confidential and privileged and may be released only to the individual tested and to persons specifically authorized by such individual to receive the information. Any insurer that possesses information derived from genetic testing may not release the information to any third party without the explicit written consent of the individual tested. Information derived from genetic testing may not be sought by any insurer as defined in Code Section 33-54-2.

§ 33-54-4 Utilization of test results

Any insurer that receives information derived from genetic testing may not use the information for any nontherapeutic purpose.

§ 33-54-5 Use of results in legal proceedings

Notwithstanding the provisions of Code Sections 33-54-3 and 33-54-4, information derived from genetic testing regarding the identity of any individual who is the subject of a criminal investigation or a criminal prosecution may be disclosed to appropriate legal authorities conducting the investigation or prosecution. The information may be used during the course of the investigation or prosecution with respect to the individual tested without the consent of such individual.

§ 33-54-6 Testing for research purposes; information disclosure

Notwithstanding the provisions of Code Sections 33-54-3 and 33-54-4, any research facility may conduct genetic testing and may use the information derived from genetic testing for scientific research purposes so long as the identity of any individual tested is not disclosed to any third party, except that the individual’s identity may be disclosed to the individual’s physician with the consent of the individual.

§ 33-54-7 Applicability of provisions

This chapter shall not apply to a life insurance policy, disability income policy, accidental death or dismemberment policy, Medicare supplement policy, long-term care insurance policy, credit insurance policy, specified disease policy, hospital indemnity policy, blanket accident and sickness policy, franchise policy issued on an individual basis to members of an association, limited accident policy, health insurance policy written as a part of workers’ compensation equivalent coverage, or other similar limited accident and sickness policy.
§ 33-54-8 Legal procedure; violation of genetic testing laws

(a) Any violation of this chapter by an insurer shall be unfair trade practice subject to the provisions of Article 1 of Chapter 6 of this title, and a violation of this chapter by any other person shall be an unfair practice and shall be subject to the provisions of Part 2 of Article 15 of Chapter 1 of Title 10, the “Fair Business Practices Act of 1975.” In addition, any individual who is harmed as a result of a violation of this chapter shall have a cause of action against the person whose violation caused the harm.

(b) Any insurer that is found in violation of the provisions of this chapter by a court of competent jurisdiction is liable to the individual injured by the violation in an amount equal to any actual damages suffered by the individual. In the alternative, the court may issue an order directing the insurer to provide accident and sickness insurance to the injured individual under the same terms and conditions as would have applied had the violation not occurred.

(c) The court shall award costs and reasonable attorney’s fees to any individual who is successful in enforcing the provision of this chapter.

LOUISIANA

R.S. 22:652.1 Life or disability insurance; discrimination based on “severe disability” or sickle cell trait prohibited

A. No insurance company shall charge unfair discriminatory premiums, policy fees or rates for, or refuse to provide any policy or contract of life insurance, life annuity, or policy containing disability coverage for a person solely because the applicant therefor has a severe disability, unless the rate differential is based on sound actuarial principles or is related to actual experience. No insurance company shall unfairly discriminate in the payments of dividends, other benefits payable under a policy, or in any of the terms and conditions of such policy or contract solely because the owner of the policy or contract has a severe disability.

B. “Severe disability,” as used in this Section, means any disease of, or injury to, the spinal cord resulting in permanent and total disability, amputation of any extremity that requires prosthesis, permanent visual acuity of twenty/two hundred or worse in the better eye with the best correction, or a peripheral field so contracted that the widest diameter of such field subtends an angular distance no greater than twenty degrees, total deafness, inability to hear a normal conversation or use a telephone without the aid of an assertive device, or persons who have developmental disabilities, including but not limited to autism, cerebral palsy, epilepsy, mental retardation, and other neurological impairments.

C. Nothing in this Section shall be construed as requiring an insurance company to provide insurance coverage against a severe disability which the applicant or policyholder has already sustained.

D. No insurance company shall charge unfair discriminatory premiums, policy fees or rates for, or refuse to provide any policy or contract of life insurance, life annuity, or policy containing disability coverage for a person solely because the applicant therefor has sickle
cell trait. No insurance company shall unfairly discriminate in the payments of dividends, other benefits payable under a policy, or in any of the terms and conditions of such policy or contract solely because the insured of the policy or contract has sickle cell trait. Nothing in this Subsection shall prohibit waiting periods, preexisting conditions, or dreaded disease rider exclusions, or any combination thereof, if they do not unfairly discriminate.

MARYLAND

§ 48A § 223 Unfair discrimination: life, health, and annuity contracts

(a)  

(1) No person shall make or permit any unfair discrimination between individuals of the same class and equal expectation of life in the rates charged for any contract of life insurance or of life annuity or in the dividends or other benefits payable thereon, or in any other of the terms and conditions of such contract.

(2)  

(i) Notwithstanding any other provisions in this section, an insurer may not make or permit any differential in ratings, premium payments or dividends for life insurance and annuity contracts for any reason based on the blindness or other physical handicap or disability of an applicant or policyholder.

(ii) Actuarial justification for the differential may be considered for a physical handicap or disability other than blindness or hearing impairment.

(3) An insurer may not refuse to insure or make or permit any differential in ratings, premium payments, or dividends in connection with life insurance and life annuity contracts solely because the applicant or policyholder has the sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or any genetic trait which is harmless within itself, unless there is actuarial justification for it.

(b)  

(1) No person shall make or permit any unfair discrimination between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees, or rates charged for any policy or contract of health insurance or in the benefits payable thereunder, or in any of the terms, or conditions of such contract, or in any other manner whatever.

(2) Notwithstanding any other provisions in this section, an insurer may not make or permit any differential in ratings, premium payments or dividends for any reason based on the sex of an applicant or policyholder unless there is actuarial justification for the differential.

(3)  

(i) Notwithstanding any other provisions in this section, an insurer may not make or permit any differential in ratings, premium payments or dividends for health insurance contracts for any reason based on the blindness or other physical handicap or disability of an applicant or policyholder.

(ii) Actuarial justification for the differential may be considered for a physical handicap or disability other than blindness or hearing impairment.
(4) An insurer may not make or permit any differential in ratings, premium payments, or dividends in connection with a health insurance contract solely because the applicant or policyholder has the sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or any genetic trait which is harmless within itself, unless there is actuarial justification for it.

MINNESOTA

§ 72A.139 Genetic discrimination act

Subdivision 1. Name and citation. This section shall be known and may be cited as the “genetic discrimination act.”

Subdivision 2. Definitions.

(a) As used in this section, “commissioner” means the commissioner of commerce for health plan companies and other insurers regulated by that commissioner and the commissioner of health for health plan companies regulated by that commissioner.

(b) As used in this section, a “genetic test” means 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.

(c) As used in this section, “health plan” has the meaning given in section 62Q.01, subdivision 3.

(d) As used in this section, “health plan company” has the meaning given in section 62Q.01, subdivision 4.

(e) As used in this section, “individual” means an applicant for coverage or a person already covered by the health plan company or other insurer.

Subdivision 3. Prohibited acts; health plan companies. A health plan company, in determining eligibility for coverage, establishing premiums, limiting coverage, renewing coverage, or any other underwriting decision, shall not, in connection with the offer, sale, or renewal of a health plan:

(1) require or request an individual or a blood relative of the individual to take a genetic test;

(2) make any inquiry to determine whether an individual or a blood relative of the individual has taken or refused a genetic test, or what the results of any such test were;

(3) take into consideration the fact that a genetic test was taken or refused by an individual or blood relative of the individual; or
take into consideration the results of a genetic test taken by an individual or a blood relative of the individual.

Subdivision 4. Application. Subdivisions 5, 6, and 7 apply only to a life insurance company or fraternal benefit society requiring a genetic test for the purpose of determining insurability under a policy of life insurance.

Subdivision 5. Informed consent. If an individual agrees to take a genetic test, the life insurance company or fraternal benefit society shall obtain the individual’s written informed consent for the test. Written informed consent must include, at a minimum, a description of the specific test to be performed; its purpose, potential uses, and limitations; the meaning of its results; and the right to confidential treatment of the results. The written informed consent must inform the individual that the individual should consider consulting with a genetic counselor prior to taking the test and must state whether the insurer will pay for any such consultation. An informed consent disclosure form must be approved by the commissioner prior to its use.

Subdivision 6. Notification. The life insurance company or fraternal benefit society shall notify an individual of a genetic test result by notifying the individual or the individual’s designated physician. If the individual tested has not given written consent authorizing a physician to receive the test results, the individual must be urged, at the time that the individual is informed of the genetic test result described in this subdivision, to contact a genetic counselor or other health care professional.

Subdivision 7. Payment for test. A life insurance company or fraternal benefit society shall not require an individual to submit to a genetic test unless the cost of the test is paid by the life insurance company or fraternal benefit society.

Subdivision 8. Enforcement. A violation of this section is subject to the investigative and enforcement authority of the commissioner, who shall enforce this section.

MONTANA

§ 33-18-206 Unfair discrimination

(1) No person shall make or permit any unfair discrimination between individuals of the same class and equal expectation of life in the rates charged for any contract of life insurance or of life annuity or in the dividends or other benefits payable thereon or in any other of the terms and conditions of such contract.

(2) No person shall make or permit any unfair discrimination between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees, or rates charged for any policy or contract of disability insurance or in the benefits payable thereunder or in any of the terms or conditions of such contract or in any other manner whatever.

(3) An insurer may not refuse to consider an application for life or disability insurance on the basis of a genetic condition, developmental delay, or developmental disability.
(4) The rejection of an application or the determining of rates, terms, or conditions of a life or
disability insurance contract on the basis of genetic condition, developmental delay, or
developmental disability constitutes unfair discrimination unless the applicant’s medical
condition and history and either claims experience or actuarial projections establish that
substantial differences in claims are likely to result from the genetic condition, developmental delay, or developmental disability.

(5) As used in this section, the following definitions apply:

(a) “Developmental delay” means a delay of at least 1 1/2 standard deviations from
the norm.

(b) “Developmental disability” means the singular of developmental disabilities as
defined in 53-20-202.

(c) “Genetic condition” means a specific chromosomal or single-gene genetic
condition.

NEW HAMPSHIRE

§ 141-H:1 Definitions In this chapter:

I. “Disability income insurance” means insurance intended to protect against loss of
occupational earning capacity arising from injury, sickness or disablement, including
insurance that provides benefits for overhead expenses or purchase of a business or
profession when the insured becomes disabled.

II. “Employment” means work performed by an employee for an employer for remuneration.

III. “Employment agency” has the meaning given in RSA 354-A:2, VIII.

IV. “Genetic testing” means 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.

V. “Health insurance” means any arrangement with any entity which pays medical claims on
behalf of an individual, an employee or dependents, including any such arrangement
evidenced by a hospital or medical policy or certificate, hospital or medical service plan
or contract, or health maintenance organization group or individual subscriber contract, or
self insurance plan or contract, or other evidence of coverage, except for the purposes of
this chapter, “health insurance” shall not mean life, disability income, or long-term care
insurance.

VI. “Individual” means a human being.

VII. “Labor organization” has the meaning given in RSA 354-A:2, X.
VIII. "Licensing agency" means a unit of government which is authorized to grant, deny, renew, revoke, suspend, annul, withdraw, or amend an occupation license.

IX. "Life insurance" means insurance in which the risk contemplated is the death of a particular individual upon which event the insurer pays a stipulated sum, or the type of insurance defined in RSA 401:1, III.

X. "Long-term care insurance" means the types of insurance defined in RSA 415-D:3, V.

XI. "Person" includes a human being, an association or organization, a trust, corporation and partnership.

§ 141-H:2 Standards; permissible disclosure

I. Except as otherwise provided in this chapter, no individual or member of the individual's family shall be required to undergo genetic testing as a condition of doing business with another person.

II. Except as required to establish paternity under RSA 522, or as required to test newborns for metabolic disorders under RSA 132:10-a, or as required for purposes of criminal investigations and prosecutions, or as is necessary to the functions of the office of chief medical examiner, no genetic testing shall be done in this state on any individual or anywhere on any resident of this state based on bodily materials obtained within this state, without the prior written and informed consent of the individual to be tested. The results of any such test shall be provided only to those persons approved in writing by the individual. No person shall refuse to perform genetic testing, or to arrange for genetic testing to be performed, or to do business with an individual, solely because the individual to be tested refuses to consent to providing the test results to some or all persons.

III. Except as provided in paragraph II, no person shall disclose to any other person that an individual has undergone genetic testing, and no person shall disclose the results of such testing to any other person, without the prior written and informed consent of the individual.

§ 141-H:3 Use in employment situations

I. No employer, labor organization, employment agency or licensing agency shall directly or indirectly:

(a) Solicit, require or administer genetic testing relating to any individual as a condition of employment, labor organization membership or licensure.

(b) Affect the terms, conditions or privileges of employment, labor organization membership or licensure or terminate the employment, labor organization membership or licensure of any individual based on genetic testing.

II. Except as provided in paragraph IV of this section, no person shall sell or otherwise provide to an employer, labor organization, employment agency or licensing agency any
genetic testing relating to an employee, labor organization member or licensee or to a prospective employee, labor organization member or licensee.

III. Any agreement between an employer, labor organization, employment agency or licensing agency and an individual offering employment, labor organization membership, licensure or any pay or benefit to that individual in return for taking a genetic test is prohibited.

IV. This section shall not prohibit the genetic testing of an employee who requests to undergo genetic testing and who provides written and informed consent to genetic testing for any of the following purposes:

(a) Investigating a worker’s compensation claim under RSA 281-A.

(b) Determining the employee’s susceptibility or level of exposure to potentially toxic chemicals or potentially toxic substances in the workplace, if the employer does not terminate the employee, or take any other action that adversely affects any term, condition or privilege of the employee’s employment, as a result of genetic testing.

V. This section shall not prohibit or limit genetic testing for evidence of insurability with respect to life, disability income, or long-term care insurance under the terms of an employee benefit plan.

§ 141-H:4 Health insurance prohibitions

A health insurer in connection with providing health insurance shall not:

I. Require or request directly or indirectly any individual or a member of the individual’s family to undergo genetic testing.

II. Require or request directly or indirectly any individual to reveal whether the individual or a member of the individual’s family has undergone genetic testing or the results of the testing, if undergone by the individual or a member of the individual’s family.

III. Condition the provision of health insurance coverage or health care benefits on whether an individual or a member of the individual’s family has undergone genetic testing or the results of the testing, if undergone by the individual or a member of the individual’s family.

IV. Consider in the determination of rates or any other aspect of health insurance coverage or health care benefits provided to an individual whether an individual or a member of the individual’s family has undergone genetic testing or the results of the testing, if undergone by the individual or a member of the individual’s family.
§ 141-H:5 Prohibited use by certain insurers

I. Except as provided in paragraph II of this section, the provisions of this chapter shall not apply to the provision of life insurance, disability income insurance, or long-term care insurance.

II. A person in the business of providing life, disability income, or long-term care insurance who obtains information with respect to any genetic testing of an individual or a member of the individual’s family shall not use that information in writing a type of insurance coverage other than life, disability income, or long-term care insurance.

§ 141-H:6 Civil actions

An aggrieved individual may bring a civil action under this chapter and, if successful, shall be awarded special or general damages of not less than $1,000 for each violation, and costs and reasonable legal fees.

NORTH CAROLINA

§ 58-58-25 Discrimination against sickle cell trait or hemoglobin C trait prohibited

No insurance company licensed in this State pursuant to the provisions of Articles 1 through 64 of this Chapter shall refuse to issue or deliver any policy of life insurance authorized thereunder solely by reason of the fact that the person to be insured possesses sickle cell trait or hemoglobin C trait; nor shall any such policy issued and delivered in this State carry a higher premium rate or charge by reason of the fact that the person to be insured possesses said traits. The term “sickle cell trait” is defined as the condition wherein the major natural hemoglobin components present in the blood of the individual are hemoglobin A (normal) and hemoglobin S (sickle hemoglobin) as defined by standard chemical and physical analytic techniques, including electrophoresis, and the proportion of hemoglobin A is greater than the proportion of hemoglobin S or one natural parent of the individual is shown to have only normal hemoglobin components (hemoglobin A, hemoglobin A2, hemoglobin F) in the normal proportions by standard chemical and physical analytic tests. The term “hemoglobin C trait” is defined as the condition wherein the major natural hemoglobin components present in the blood of the individual are hemoglobin A (normal) and hemoglobin C as defined by standard chemical and physical analytic techniques, including electrophoresis, and the proportion of hemoglobin A is greater than the proportion of hemoglobin C or one natural parent of the individual is shown to have only normal hemoglobin components (hemoglobin A, hemoglobin A2, hemoglobin F) in the normal proportions by standard chemical and physical analytic tests.

OHIO

§ 3901.491 Use of genetic screening information prohibited

(A) As used in this section:

(1) “Genetic screening or testing” means 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.

(2) “Insurer” means any person authorized under Title XXXIX of the Revised Code to engage in the business of sickness and accident insurance.

(3) “Sickness and accident insurance” means sickness and accident insurance under Chapter 3923. of the Revised Code excluding disability income insurance and excluding supplemental policies of sickness and accident insurance.

(B) Upon the repeal of section 3901.49 of the Revised Code by Sub. H.B. No. 71 of the 120th General Assembly, no insurer shall do either of the following:

(1) Consider, in a manner adverse to an applicant or insured, any information obtained from genetic screening or testing conducted prior to the repeal of section 3901.49 of the Revised Code in processing an application for an individual or group policy of sickness and accident insurance, or in determining insurability under such a policy;

(2) Inquire, directly or indirectly, into the results of genetic screening or testing conducted prior to the repeal of section 3901.49 of the Revised Code, or use such information, in whole or in part, to cancel, refuse to issue or renew, or limit benefits under, a sickness and accident insurance policy.

(C) Any insurer that has engaged in, is engaged in, or is about to engage in a violation of division (B) of this section is subject to the jurisdiction of the superintendent of insurance under section 3901.04 of the Revised Code.

§ 3901.50 Self insurers prohibited from using genetic screening

Text of section repealed effective February 9, 2004

(A) As used in this section:

(1) “Genetic screening or testing” means 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.

(2) “Self-insurer” means any government entity providing coverage for health care services on a self-insurance basis.

(B) No self-insurer, in processing an application for coverage under a plan of self-insurance or in determining insurability under such a plan, shall do any of the following:

(1) Require an individual seeking coverage to submit to genetic screening or testing;
(2) Take into consideration, other than in accordance with division (F) of this section, the results of genetic screening or testing;

(3) Make any inquiry to determine the results of genetic screening or testing;

(4) Make a decision adverse to the applicant based on entries in medical records or other reports of genetic screening or testing.

(C) In developing and asking questions regarding medical histories of applicants for coverage under a plan of self-insurance, no self-insurer shall ask for the results of genetic screening or testing or ask questions designed to ascertain the results of genetic screening or testing.

(D) No self-insurer shall cancel or refuse to provide or renew coverage for health care services based on the results of genetic screening or testing.

(E) No self-insurer shall establish or modify a plan of self-insurance in this state that limits benefits based on the results of genetic screening or testing.

(F) A self-insurer may consider the results of genetic screening or testing if the results are voluntarily submitted by an applicant for coverage or renewal of coverage and the results are favorable to the applicant.

(G) A violation of this section is an unfair and deceptive act or practice in the business of insurance under sections 3901.19 to 3901.26 of the Revised Code.

§ 3901.501 Use of genetic screening information prohibited

(A) As used in this section:

(1) "Genetic screening or testing" means 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.

(2) "Self-insurer" means any government entity providing coverage for health care services on a self-insurance basis.

(B) Upon the repeal of section 3901.50 of the Revised Code by Sub. H.B. No. 71 of the 120th general assembly, no self-insurer shall do either of the following:

(1) Consider, in a manner adverse to an applicant or insured, any information obtained from genetic screening or testing conducted prior to the repeal of section 3901.50 of the Revised Code in processing an application for coverage under a plan of self-insurance or in determining insurability under such a plan;

(2) Inquire, directly or indirectly, into the results of genetic screening or testing conducted prior to the repeal of section 3901.50 of the Revised Code, or use such
information, in whole or in part, to cancel, refuse to provide or renew, or limit benefits under, a plan of self-insurance.

(C) Any self-insurer that has engaged in, is engaged in, or is about to engage in a violation of division (B) of this section is subject to the jurisdiction of the superintendent of insurance under section 3901.04 of the Revised Code.

§ 1742.42 Prohibition from using genetic screening

Text of section effective until February 9, 2004

(A) As used in this section, “genetic screening or testing” means 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.

(B) No health maintenance organization, in processing an application for coverage for health care services under an individual or group health maintenance organization contract or in determining insurability under such a contract, shall do any of the following:

(1) Require an individual seeking coverage to submit to genetic screening or testing;

(2) Take into consideration, other than in accordance with division (F) of this section, the results of genetic screening or testing;

(3) Make any inquiry to determine the results of genetic screening or testing;

(4) Make a decision adverse to the applicant based on entries in medical records or other reports of genetic screening or testing.

(C) In developing and asking questions regarding medical histories of applicants for coverage under an individual or group health maintenance organization contract, no health maintenance organization shall ask for the results of genetic screening or testing or ask questions designed to ascertain the results of genetic screening or testing.

(D) No health maintenance organization shall cancel or refuse to issue or renew coverage for health care services based on the results of genetic screening or testing.

(E) No health maintenance organization shall deliver, issue for delivery, or renew an individual or group contract in this state that limits benefits based on the results of genetic screening or testing.

(F) A health maintenance organization may consider the results of genetic screening or testing if the results are voluntarily submitted by an applicant for coverage or renewal of coverage and the results are favorable to the applicant.
(G) A violation of this section is an unfair and deceptive act or practice in the business of insurance under sections 3901.19 to 3901.26 of the Revised Code.

Note—Section three of 1993 H 71, eff. 2-9-94, reads:

(A) There is hereby created the Task Force on Genetic Testing in Health Insurance.

(B) The Task Force shall be composed of the following:

(1) The Superintendent of Insurance or his representative

(2) The Director of Health or his representative

(3) Two members of the Senate appointed by the President of the Senate

(4) Two members of the House of Representatives appointed by the Speaker of the House of Representatives

(5) Six members appointed by the Speaker of the House of Representatives, one of whom shall be a consumer representative, one of whom shall be a representative of an Ohio health care advocacy organization that is exempt from taxation under section 501(c)(3) of the “Internal Revenue Code of 1986,” 100 Stat. 2085, 26 U.S.C.A. 501, as amended, one of whom shall be a hospital representative, one of whom shall be an insurance underwriter, one of whom shall be an insurance medical director, and one of whom shall be a geneticist. The geneticist shall be appointed from a list of five names submitted by insurers doing business in Ohio. If the Speaker of the House is not satisfied with the names submitted, the insurers shall submit additional names until he makes the appointment.

(6) Six members appointed by the President of the Senate, one of whom shall be a consumer representative, one of whom shall be a representative of an Ohio health care advocacy organization that is exempt from taxation under section 501(c)(3) of the “Internal Revenue Code of 1986,” 100 Stat. 2085, 26 U.S.C.A. 501, as amended, one of whom shall be a hospital representative, one of whom shall be an insurance underwriter, one of whom shall be an insurance medical director, and one of whom shall be a geneticist. The geneticist shall be appointed from a list of five names submitted by the Ohio health care advocacy organizations described in division (B)(6) of this section. If the President of the Senate is not satisfied with the names submitted, the organizations shall submit additional names until he makes the appointment.

Vacancies shall be filled in the same manner as original appointments.

(C) Within thirty days after the effective date of this act, the Speaker of the House of Representatives and the President of the Senate shall make their respective appointments to the Task Force.

(D) The Superintendent of Insurance shall serve as chairman, and in his absence his representative shall serve as chairman. He shall also designate a person from his staff to serve as secretary.
The Task Force shall conduct a comprehensive study of genetic screening and testing as they relate to the medical underwriting of health benefit plans, including sickness and accident insurance, other than disability income insurance, health maintenance organization benefit plans, and other health benefit plans and programs in Ohio. The study shall include, but is not limited to, the following:

(1) A review of all complaints filed with the Department of Insurance regarding substandard rating or rejections, or both, by such health benefit plans based on genetic screening or testing results.

(2) A review of the use of genetic screening or testing required to be taken by applicants residing in Ohio during calendar years 1992 and 1993 as part of the medical underwriting processes of health benefit plan providers, including insurers doing the business of sickness and accident insurance, other than disability income insurance, health maintenance organizations, and other health benefit plan and program providers in Ohio.

(3) A review of the health benefit plan provider use of results of genetic screening or testing previously administered to applicants, including how health benefit plan providers use the results of previously administered genetic screenings or testings as part of the application process.

(4) A review of the impact that increasingly sophisticated and reliable medical screenings and testings, including genetic screening and testing, have had on the proportion of applications for health benefit plans that have been accepted on a standard basis, rated on a substandard basis, or rejected.

(5) A review of the alternative sources of health benefit plan coverage for persons residing in Ohio who are denied access to conventional health benefit plans due to their high risk health conditions, including a survey of sickness and accident insurers to determine the number of persons accepted for health benefit plan coverage under the open enrollment provisions of Am. Sub. H.B. 478 of the 119th General Assembly, a survey of health maintenance organizations to determine the number of persons accepted for health benefit plan coverage under the open enrollment provisions of Chapter 1742 of the Revised Code, a survey of every mutual insurance company that merged or consolidated with a hospital service association to determine the number of persons accepted for health benefit plan coverage under the open enrollment provisions of section 3941.53 of the Revised Code, and a determination of the number of Ohio residents who are covered by health benefit plans that require no medical underwriting in the application process, including, but not limited to, group sickness and accident insurance, other than disability income insurance, health maintenance organization plans, multiple employer welfare arrangements, self-funded plans, Medicare, and Medicaid.

(6) A review of genetic screenings or testings conducted annually by medical care providers in Ohio, including, with respect to calendar years 1993 and 1994, the identification of the genetic screenings or testings available that are reliable predictors of adverse health conditions and the approximate cost range for each, the number of genetic screenings or testings administered in Ohio, the types of
genetic screenings or testings administered in Ohio, and the percentage of each type of screening or testing that produced adverse results.

(F) The Superintendent of Insurance shall provide all research, technical, clerical, and other staff assistance needed by the Task Force in carrying out its duties. To help defray the costs incurred by the Superintendent, in providing such assistance, assessments, totaling in the aggregate not more than two hundred fifty thousand dollars, may be levied by and at the discretion of the Superintendent of Insurance on the health benefit plan providers described in division (E)(2) of this section. All assessments levied under this division shall be paid into the state treasury to the credit of the Department of Insurance Operating Fund created under section 3901.021 of the Revised Code. In addition, the departments, universities, agencies, and officers of this state shall cooperate with the Task Force to the fullest possible extent, including providing such facilities or data as may be available.

(G) The Task Force shall issue a final report to the Governor and the General Assembly, including any recommendations, not later than December 31, 1995. Upon issuance of the final report, the Task Force shall cease to exist.

§ 1742.43 Use of genetic screening information prohibited

(A) As used in this section, "genetic screening or testing" means 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.

(B) Upon the repeal of section 1742.42 of the Revised Code by Sub. H.B. No. 71 of the 120th General Assembly, no health maintenance organization shall do either of the following:

(1) Consider, in a manner adverse to an applicant or insured, any information obtained from genetic screening or testing conducted prior to the repeal of section 1742.42 of the Revised Code in processing an application for coverage for health care services under an individual or group contract or in determining insurability under such a contract;

(2) Inquire, directly or indirectly, into the results of genetic screening or testing conducted prior to the repeal of section 1742.42 of the Revised Code, or use such information, in whole or in part, to cancel, refuse to issue or renew, or limit benefits under, an individual or group contract.

(C) Any health maintenance organization that has engaged in, is engaged in, or is about to engage in a violation of division (B) of this section is subject to the jurisdiction of the superintendent of insurance under section 3901.04 of the Revised Code.
OREGON

§746.135 Genetic testing

(1) If an insurance provider asks an applicant for insurance to take a genetic test in connection with an application for insurance, the use of the test shall be revealed to the applicant and the provider shall obtain the specific authorization of the applicant using a form prescribed by rules of the Health Division.

(2) An insurance provider may not use a favorable genetic test as an inducement to purchase insurance.

(3) An insurance provider may not use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy for hospital or medical expenses.

(4) For purposes of this section, “genetic information,” “genetic test” and “insurance provider” have those meanings given in ORS 659.700.

TENNESSEE

56-7-207 Sickle cell and hemoglobin C

(a) No insurance company which has been qualified and authorized to do business in this state pursuant to the provisions of chapter 2 of this title shall refuse to issue or deliver any policy of life insurance authorized thereunder solely by reason of the fact that the person to be insured possesses sickle cell trait or hemoglobin C trait.

(b) As used in this section:

(1) “Hemoglobin C trait” means the condition wherein the major natural hemoglobin components present in the blood of the individual are hemoglobin A (normal) and hemoglobin C as defined by standard chemical and physical analytic techniques, including electrophoresis; and the proportion of hemoglobin A is greater than the protection of hemoglobin C or one (1) natural parent of the individual is shown to have only normal hemoglobin components (hemoglobin A, hemoglobin A2, hemoglobin F) in the normal proportions by standard chemical and physical analytic tests; and

(2) “Sickle cell trait” means the condition wherein the major natural hemoglobin components present in the blood of the individual are hemoglobin A (normal) and hemoglobin S (sickle hemoglobin) as defined by standard chemical and physical analytic techniques, including electrophoresis; and the proportion of hemoglobin A is greater than the proportion of hemoglobin S or one (1) natural parent of the individual is shown to have only normal hemoglobin components (hemoglobin A, hemoglobin A2, hemoglobin F) in the normal proportions by standard chemical and physical analytic tests.
VIRGINIA

§ 38.2-508.4. Genetic information privacy.

A. As used in this section:

“Genetic characteristic” means any scientifically or medically identifiable gene or chromosome, or alteration thereof, which 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, and which is asymptomatic of any disease or disorder.

“Genetic information” means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.

B. No person proposing to issue, re-issue, or renew any policy, contract, or plan of accident and sickness insurance defined in Section 38.2-109, but excluding disability income insurance, issued by any (i) insurer providing hospital, medical and surgical or major medical coverage on an expense incurred basis, (ii) corporation providing a health services plan, or (iii) health maintenance organization providing a health care plan for health care services shall, on the basis of any genetic information obtained concerning an individual or on the individual’s request for genetic services, with respect to such policy, contract, or plan:

1. Terminate, restrict, limit, or otherwise apply conditions to coverage of an individual or restrict the sale to an individual;

2. Cancel or refuse to renew the coverage of an individual;

3. Exclude an individual from coverage;

4. Impose a waiting period prior to commencement of coverage of an individual;

5. Require inclusion of a rider that excludes coverage for certain benefits and services; or

6. Establish differentials in premium rates for coverage.

In addition, no discrimination shall be made in the fees or commissions of an agent or agency for an enrollment, a subscription, or the renewal of an enrollment or subscription of any person on the basis of a person’s genetic characteristics which may, under some circumstances, be associated with disability in that person or that person’s offspring.

C. Notwithstanding any other provisions of law, all information obtained from genetic screening or testing conducted prior to the repeal of this section shall be confidential and shall not be made public nor 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 subject to the provisions of this section.
§ 38.2-613. Disclosure limitations and conditions.

A. An insurance institution, agent, or insurance-support organization shall not disclose any personal or privileged information about an individual collected or received in connection with an insurance transaction unless the disclosure is:

1. With the written authorization of the individual, provided:

   a. If the authorization is submitted by another institution, agent, or insurance-support organization, the authorization meets the requirements of § 38.2-606; or

   b. If the authorization is submitted by a person other than an insurance institution, agent, or insurance-support organization, the authorization is:

      (1) Dated,

      (2) Signed by the individual; or

      (3) Obtained one year or less prior to the date a disclosure is sought pursuant to this subdivision; or

2. To a person other than an insurance institution, agent, or insurance-support organization, provided the disclosure is reasonably necessary:

   a. To enable that person to perform a business, professional or insurance function for the disclosing insurance institution, agent, or insurance-support organization, and that person agrees not to disclose the information further without the individual’s written authorization unless the further disclosure:

      (1) Would otherwise be permitted by this section if made by an insurance institution, agent, or insurance-support organization; or

      (2) Is reasonably necessary for that person to perform its function for the disclosing insurance institution, agent, or insurance-support organization; or

   b. To enable that person to provide information to the disclosing insurance institution, agent, or insurance-support organization for the purpose of:

      (1) Determining an individual’s eligibility for an insurance benefit or payment; or

      (2) Detecting or preventing criminal activity, fraud, material misrepresentation, or material nondisclosure in connection with an insurance transaction; or
3. To an insurance institution, agent, or insurance-support organization, or self-insurer, provided the information disclosed is limited to that which is reasonably necessary:

a. To detect or prevent criminal activity, fraud, material misrepresentation, or material nondisclosure in connection with insurance transactions; or

b. For either the disclosing or receiving insurance institution, agent or insurance-support organization to perform its function in connection with an insurance transaction involving the individual; or

4. To a medical-care institution or medical professional for the purpose of (i) verifying insurance coverage or benefits, (ii) informing an individual of a medical problem of which the individual may not be aware or (iii) conducting an operations or services audit, provided only that information is disclosed as is reasonably necessary to accomplish the foregoing purposes; or

5. To an insurance regulatory authority; or

6. To a law-enforcement or other government authority:

a. To protect the interests of the insurance institution, agent or insurance-support organization in preventing or prosecuting the perpetration of fraud upon it; or

b. If the insurance institution, agent, or insurance-support organization reasonably believes that illegal activities have been conducted by the individual; or

c. Upon written request of any law-enforcement agency, for all insured or claimant information in the possession of an insurance institution, agent, or insurance-support organization which relates an ongoing criminal investigation, such insurance institution, agent, or insurance-support organization shall release such information, including, but not limited to, policy information, premium payment records, record of prior claims by the insured or by another claimant, and information collected in connection with an insurance company’s investigation of an application or claim. Any information released to a law-enforcement agency pursuant to such request shall be treated as confidential criminal investigation information and not be disclosed further except as provided by law. Notwithstanding any provision in this chapter, no insurance institution, agent, or insurance-support organization shall notify any insured or claimant that information has been requested or supplied pursuant to this section prior to notification from the requesting law-enforcement agency that its criminal investigation is completed. Within ninety days following completion of any such criminal investigation, the law-enforcement agency making such a request for information shall notify any insurance institution, agent, or insurance-support organization from whom
information was requested that the criminal investigation has been completed.

7. Otherwise permitted or required by law; or

8. In response to a facially valid administrative or judicial order, including a search warrant or subpoena; or

9. Made for the purpose of conducting actuarial or research studies, provided:
   a. No individual may be identified in any actuarial or research report; and
   b. Materials allowing the individual to be identified are returned or destroyed as soon as they are no longer needed, and
   c. The actuarial or research organization agrees not to disclose the information unless the disclosure would otherwise be permitted by this section if made by an insurance institution, agent, or insurance-support organization; or

10. To a party or a representative of a party to a proposed or consummated sale, transfer, merger, or consolidation of all or part of the business of the insurance institution, agent, or insurance-support organization, provided:
   a. Prior to the consummation of the sale, transfer, merger, or consolidation only such information is disclosed as is reasonably necessary to enable the recipient to make business decisions about the purchase, transfer, merger, or consolidation, and
   b. The recipient agrees not to disclose the information unless the disclosure would otherwise be permitted by this section if made by an insurance institution, agent, or insurance-support organization; or

11. To a person whose only use of such information will be in connection with the marketing of a product or service, provided:
   a. No medical-record information, privileged information, or personal information relating to an individual’s character, personal habits, mode of living, or general reputation is disclosed, and no classification derived from the information is disclosed,
   b. The individual has been given an opportunity to indicate that he does not want personal information disclosed for marketing purposes and has given no indication that he does not want the information disclosed, and
c. The person receiving such information agrees not to use it except in connection with the marketing of a product or service; or

12. To an affiliate whose only use of the information will be in connection with an audit of the insurance institution or agent or the marketing of an insurance product or service, provided the affiliate agrees not to disclose the information for any other purpose or to unaffiliated persons; or

13. By a consumer reporting agency, provided the disclosure is to a person other than an insurance institution or agent; or

14. To a group policyholder for the purpose of reporting claims experience or conducting an audit of the insurance institution’s or agent’s operations or services, provided the information disclosed is reasonably necessary for the group policyholder to conduct the review or audit; or

15. To a professional peer review organization for the purpose of reviewing the service or conduct of a medical-care institution or medical professional; or

16. To a governmental authority for the purpose of determining the individual’s eligibility for health benefits for which the governmental authority may be liable; or

17. To a certificate holder or policyholder for the purpose of providing information regarding the status of an insurance transaction; or

18. To a lienholder, mortgagee, assignee, lessor or other person shown on the records of an insurance institution or agent as having a legal or beneficial interest in a policy of insurance, provided that:

a. No medical record information is disclosed unless the disclosure would be permitted by this section; and

b. The information disclosed is limited to that which is reasonably necessary to permit such person to protect his interest in the policy.

B. 1. No person proposing to issue, re-issue, or renew any policy, contract, or plan of accident and sickness insurance defined in Section 38.2-109, but excluding disability income insurance, issued by any (i) insurer providing hospital, medical and surgical or major medical coverage on an expense incurred basis, (ii) corporation providing a health services plan, or (iii) health maintenance organization providing a health care plan for health care services shall disclose any genetic information about an individual or a member of such individual’s family collected or received in connection with any insurance transaction unless the disclosure is made with the written authorization of the individual.
2. For the purpose of this subsection, "genetic information" means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.

3. Agents and insurance support organizations shall be subject to the provisions of this subsection to the extent of their participation in the issue, re-issue, or renewal of any policy, contract, or plan of accident and sickness insurance defined in Section 38.2-109, but excluding disability income insurance.

Section 2. That the provisions of Section 38.2-508.4 shall expire on July 1, 1998.

**WISCONSIN**

§ 631.89 Genetic tests

(1) In this section, "genetic test" means a test using deoxyribonucleic acid extracted from an individual’s cells in order to determine the presence of a genetic disease or disorder or the individual’s predisposition for a particular genetic disease or disorder.

(2) An insurer, or a county, city, village or school board that provides health care services for individuals on a self-insured basis, may not do any of the following:

(a) Require or request directly or indirectly any individual or a member of the individual’s family to obtain a genetic test.

(b) Require or request directly or indirectly any individual to reveal whether the individual or a member of the individual’s family has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual’s family, were.

(c) Condition the provision of insurance coverage or health care benefits on whether an individual or a member of the individual’s family has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual’s family, were.

(d) Consider 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 what the results of the test, if obtained by the individual or a member of the individual’s family, were.

(3) (a) Subsection (2) does not apply to an insurer writing life insurance coverage or income continuation insurance coverage.

(b) An insurer writing life insurance coverage or income continuation insurance coverage that obtains information under sub. (2)(a) or (b) may not do any of the following:
1. Use the information contrary to sub. (2)(c) or (d) in writing a type of insurance coverage other than life or income continuation for the individual or a member of the individual’s family.

2. Provide for rates or any other aspect of coverage that is not reasonably related to the risk involved.
Federal Proposals

Several proposals are pending before Congress. Sections of two bills to be considered by a joint conference committee (H.R. 3160 and S. 1028) deal with genetic testing and health insurance. In addition, S. 1416, H.R. 2748 and S. 1600 are bills introduced to limit the use of genetic testing.

104th CONGRESS
2D SESSION

H.R. 3160

To amend the Internal Revenue Code of 1986 to improve portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in health insurance and health care delivery, to promote the use of medical savings accounts, to improve access to long-term care services and coverage, to simplify the administration of health insurance, to reform medical liability, and for other purposes.

SECTION 101. PORTABILITY OF COVERAGE FOR PREVIOUSLY COVERED INDIVIDUALS.

(a) CREDITING PERIODS OF PREVIOUS COVERAGE TOWARD PREEXISTING CONDITION RESTRICTIONS. Subject to the succeeding provisions of this section, a group health plan, and an insurer or health maintenance organization offering health insurance coverage in connection with a group health plan, shall provide that any preexisting condition limitation period (as defined in subsection (b)(2)) is reduced by the length of the aggregate period of qualified prior-coverage (if any, as defined in subsection (b)(3)) applicable to the participant or beneficiary as of the date of commencement of coverage under the plan.

(b) DEFINITIONS AND OTHER PROVISIONS RELATING TO PREEXISTING CONDITIONS.

(1) PREEXISTING CONDITION.

(A) IN GENERAL. For purposes of this subtitle, subject to subparagraph (B), the term “preexisting condition” means a condition, for which medical advice, diagnosis, care, or treatment was recommended or received with the 6-month period ending on the day before—

(i) the effective date of the coverage of such participant or beneficiary, or

(ii) the earliest date upon which such coverage could have been effective if there were no waiting period applicable,

which ever is earlier.

* * *

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(B) TREATMENT OF GENETIC INFORMATION. For purposes of this section, genetic information shall not be considered to be a preexisting condition, so long as treatment of the condition to which the information is applicable has not been sought during the 6-month period described in subparagraph (A).

***

SECTION 103. PROHIBITING EXCLUSIONS BASED ON HEALTH STATUS AND PROVIDING FOR ENROLLMENT PERIODS.

(a) PROHIBITION OF EXCLUSION OF PARTICIPANTS OR BENEFICIARIES BASED ON HEALTH STATUS.

(1) IN GENERAL. A group health plan, and an insurer or HMO offering health insurance coverage in connection with a group health plan, may not exclude an employee or his or her beneficiary from being (or continuing to be) enrolled as a participant or beneficiary under the terms of such plan or coverage based on health status (as defined in section 191(c)(6)).

(2) CONSTRUCTION. Nothing in this subsection shall be construed as preventing the establishment of preexisting condition limitations and restrictions to the extent consistent with the provisions of this subtitle.

(b) PROHIBITION OF DISCRIMINATION IN PREMIUM CONTRIBUTIONS OF INDIVIDUAL PARTICIPANTS OR BENEFICIARIES BASED ON HEALTH STATUS.

(1) IN GENERAL. A group health plan, and an insurer or HMO offering health insurance coverage in connection with a group health plan, may not require a participant or beneficiary to pay a premium or contribution which is greater than such premium or contribution for a similarly situated participant or beneficiary solely on the basis of the health status of the participant or beneficiary.

***

(6) HEALTH STATUS. The term “health status” includes, with respect to an individual, medical condition, claims experience, receipt of health care, medical history, genetic information, evidence of insurability (including conditions arising out of acts of domestic violence), or disability.
IN THE SENATE OF THE UNITED STATES—104th Cong., 1st Sess.

S.1028

To provide increased access to health care benefits, to provide increased portability of health care benefits, to provide increased security of health care benefits, to increase the purchasing power of individuals and small employers, and for other purposes.

***

(A) A health plan issuer offering a group health plan may not decline to offer whole group coverage to a group purchaser desiring to purchase such coverage; and

(B) An employee health benefit plan or a health plan issuer offering a group health plan may establish, under the terms of such plan, eligibility, enrollment, or premium contribution requirements for individual participants or beneficiaries, except that such requirements shall not be based on health status, medical condition, claims experience, receipt of health care, medical history, evidence of insurability, genetic information, or disability.

***

(f) LIMITATIONS ON COOPERATIVE ACTIVITIES. A health plan purchasing cooperative shall not—

(1) Perform any activity relating to the licensing of health plan issuers.

(2) Assume financial risk directly or indirectly on behalf of members of a health plan purchasing cooperative relating to any group health plan or individual health plan.

(3) Establish eligibility, enrollment, or premium contribution requirements for individual participants or beneficiaries based on health status, medical condition, claims experience, receipt of health care, medical history, evidence of insurability, genetic information, or disability.

***
S. 1416

A BILL

To establish limitation with respect to the disclosure and use of genetic information, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Genetic Privacy and Nondiscrimination Act of 1995”.

SECTION 1. FINDINGS AND PURPOSES.

(a) FINDINGS. Congress finds the following:

(1) The DNA molecule contains information about an individual’s probable medical future.

(2) Genetic information is uniquely private and personal information that should not be disclosed without the authorization of the individual.

(3) The improper disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such employment, education, health care and insurance.

(4) An analysis of an individual’s DNA provides information not only about an individual, but also about the individual’s parents, siblings and children.

(5) Current legal protections for genetic information, tissue samples and DNA samples are inadequate to protect genetic privacy, and require further attention.

(6) Laws for the collection, storage and use of identifiable DNA samples and private genetic information obtained from those samples are needed both to protect individual privacy and to permit legitimate genetic research.

(b) PURPOSES. It is the purpose of this Act to—

(1) define the rights of individuals whose genetic information is disclosed;
(2) define the circumstances under which an individual’s genetic information may be disclosed; and

(3) protect against discrimination by an insurer or employer based upon an individual’s genetic information.

SECTION 3. DEFINITIONS.

As used in this Act:

(1) DNA. The term “DNA” means deoxyribonucleic acid.

(2) DNA SAMPLE. The term “DNA sample” means any human biological specimen from which DNA can be extracted, or the DNA extracted from such specimen.

(3) EMPLOYER. The term “employer” has the same meaning given such term in section 3(d) of the Fair Labor Standards Act of 1938 (29 U.S.C. 203(d)).

(4) GENETIC INFORMATION. The term “genetic information” means the information about genes, gene products or inherited characteristics that may derive from an individual or a family member.

(5) GENETIC TEST. The term “genetic test” means a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondria DNA, chromosomes or proteins in order to diagnose a genetic characteristic.

(6) INSURER. The term “insurer” means an insurance company, health care service contractor, fraternal benefit organization, insurance agent, third party administrator, insurance support organization or other person subject to regulation under State insurance laws. Such term includes self-funded health plans and health plans regulated under the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1001 et seq.).

(7) SECRETARY. The term “Secretary” means the Secretary of Health and Human Services.

SECTION 4. REQUIREMENTS FOR DISCLOSURE OF GENETIC INFORMATION.

(a) PROHIBITION.

(1) IN GENERAL. Except as provided in paragraph (2), regardless of the manner in which genetic information was received, or of the source of such information, including information received from an individual, an entity may not disclose or be compelled (by subpoena or any other means) to disclose genetic information about an individual unless such disclosure is specifically authorized by the individual involved or the legal representative of the individual through a written authorization which includes a description of the information being disclosed, the name of the
individual or entity to whom the disclosure is being made, and the purpose of the disclosure.

(2) EXCEPTIONS. Notwithstanding paragraph (1), genetic information concerning an individual may be disclosed if such disclosure—

(A) is authorized under Federal or State criminal laws relating to identification of individuals, or as is necessary for the purpose of a criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a child fatality review by a multidisciplinary child abuse team;

(B) is required under the specific order of a Federal or State court;

(C) is authorized under Federal or State law for the purpose of establishing paternity;

(D) is for the purpose of furnishing genetic information relating to a decedent to the blood relatives of the decedent for the purpose of medical diagnosis; or

(E) is for the purpose of identifying bodies.

(b) APPLICATION OF SECTION. The prohibitions of this section shall apply to any redisclosure by any entity after another entity has disclosed the genetic information.

SECTION 5. PROHIBITION ON CERTAIN EMPLOYMENT PRACTICES.

(a) DISCRIMINATION AS TO RIGHTS OR BENEFITS. No employer may seek to obtain, obtain, or use the genetic information of an employee or a prospective employee, or require a genetic test of an employee or prospective employee, to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to the employee or prospective employee.

(b) ENFORCEMENT. The powers, remedies, and procedures set forth in sections 705 through 709 of the Civil Rights Act of 1964 shall by the powers, remedies, and procedures this section provides to any person alleging a violation of this section.

SECTION 6. REQUIREMENTS RELATING TO INSURERS

(a) GENERAL PROHIBITION. An insurer offering health insurance may not use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, or otherwise affect health insurance.

(b) PROHIBITION ON INDUCEMENT. With respect to a genetic test conducted in accordance with subsection (c), an insurer may not use such a genetic test as an inducement for the purchase of insurance.
PERMISSIBILITY OF TESTS. If an insurer requests that an applicant for insurance (other than an applicant for health insurance) take a genetic test in connection with an application for insurance, the use of the results of such test shall be disclosed to the applicant and the insurer shall obtain the specific written authorization of the applicant for such disclosure.

APPLICATION. This section shall apply only to insurance policies issued on or after the date of enactment of this Act, and to the renewal of policies issued before, on, or after such date of enactment.

SECTION 7. FURTHER RECOMMENDATION BY THE NATIONAL BIOETHICS ADVISORY COMMISSION.

Not later than August 31, 1996, the National Bioethics Advisory Commission shall prepare and submit to the appropriate committees of Congress a report containing recommendations on—

(1) the development and implementation of standards to provide increased protection for the collection, storage, and use of identifiable DNA samples and genetic information obtained from those samples; and

(2) the development and implementation of appropriate standards for the acquisition and retention of genetic information in all settings, including appropriate exceptions.

H.R. 2748

A BILL

To prohibit insurance providers from denying or canceling health insurance coverage, or varying the premiums, terms, or conditions for health insurance coverage on the basis of genetic information or a request for genetic services, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Genetic Information Nondiscrimination in Health Insurance Act of 1995”.

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SECTION 2. PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION.

(a) IN GENERAL. An insurance provider may not deny or cancel health insurance coverage, or vary the premiums, terms, or conditions for health insurance coverage, for an individual or a family member of an individual—

(1) on the basis of genetic information; or

(2) on the basis that the individual or family member of an individual has requested or received genetic services.

(b) LIMITATION ON COLLECTION AND DISCLOSURE OF INFORMATION—

(1) IN GENERAL. An insurance provider may not request or require an individual to whom the provider provides health insurance coverage, or an individual who desires the provider to provide health insurance coverage, to disclose to the provider genetic information about the individual or family member of the individual.

(2) REQUIREMENT OF PRIOR AUTHORIZATION. An insurance provider may not disclose genetic information about an individual without the prior written authorization of the individual or legal representative of the individual. Such authorization is required for each disclosure and shall include an identification of the person to whom the disclosure would be made.

(c) ENFORCEMENT.

(1) PLANS OTHER THAN EMPLOYEE HEALTH BENEFIT PLANS. The requirements established under subsections (a) and (b) shall be enforced by the State insurance commissioner for the State involved or the official or officials designated by the State, except that in no case shall a State enforce such requirements as they relate to employee health benefit plans.

(2) EMPLOYEE HEALTH BENEFIT PLANS. With respect to employee health benefit plans, the Secretary shall enforce the requirements established under subsections (a) and (b) in the same manner as provided for under sections 502, 504, 506, and 510 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1132, 1134, 1136, and 1140).

(3) PRIVATE RIGHT OF ACTION. A person may bring a civil action.

(A) to enjoin any act or practice which violates subsection (a) or (b),

(B) to obtain other appropriate equitable relief (i) to redress such violations, or (ii) to enforce any such subsections, or

(C) to obtain other legal relief, including monetary damages.
(4) JURISDICTION. State courts of competent jurisdiction and district courts of the United States have concurrent jurisdiction of actions under this subsection. The district courts of the United States shall have jurisdiction, without respect to the amount in controversy or the citizenship of the parties, to grant the relief provided for in paragraph (3) in any action.

(5) VENUE. For purposes of this subsection the venue provisions of section 1391 of title 28, United States Code, shall apply.

(6) REGULATIONS. The Secretary may promulgate such regulations as may be necessary or appropriate to carry out this section.

(d) APPLICABILITY.

(1) PREEMPTION OF STATE LAW. A State may establish or enforce requirements for insurance providers or health insurance coverage with respect to the subject matter of this section, but only if such requirements are more restrictive than the requirements established under subsections (a) and (b).

(2) RULE OF CONSTRUCTION. Nothing in this section shall be construed to affect or modify the provisions of section 514 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1144).

(3) CONTINUATION. Nothing in this section shall be construed as requiring a group health plan or an employee health benefit plan to provide benefits to a particular participant or beneficiary.

(e) DEFINITIONS. For purposes of this Act:

(1) EMPLOYEE HEALTH BENEFIT PLAN. The term “employee health benefit plan” means any employee welfare benefit plan, governmental plan, or church plan (as defined under paragraphs (1), (32), and (33) of section 3 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1002)) that provides or pays for health insurance coverage (such as provider and hospital benefits) whether—

(A) directly;

(B) through a group health plan; or

(C) otherwise.

(2) FAMILY MEMBER. The term “family member” means, with respect to an individual, another individual related by blood to that individual.

(3) GENETIC INFORMATION. The term “genetic information” means information about genes, gene products, or inherited characteristics.
(4) GENETIC SERVICES. The term “genetic services” means health services to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling.

(5) GROUP HEATH PLAN. The term “group health plan” has the meaning given such term in section 607 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1167), and includes a multiple employer welfare arrangement (as defined in section 3 (40) of such Act) that provides health insurance coverage.

(6) HEALTH INSURANCE COVERAGE. The term “health insurance coverage” means a contractual arrangement for the provision of a payment of health care, including—

(A) a group health plan; and

(B) any other health insurance arrangement, including any arrangement consisting of a hospital or medical expense incurred policy or certificate, hospital or medical service plan contract, or health maintenance organization subscriber contract.

(7) INDIVIDUAL HEALTH PLAN. The term “individual health plan” means any health insurance coverage offered to individuals that is not a group health plan.

(8) INSURANCE PROVIDER. The term “insurance provider” means an insurer or other entity providing health insurance coverage.

(9) PERSON. The term “person” includes corporations, companies, associations, firms, partnerships, societies, and joint stock companies, as well as individuals.

(10) SECRETARY. The term “Secretary” means the Secretary of Labor.

(11) STATE. The term “State” means any of the 50 States, the District of Columbia, Puerto Rico, the Northern Mariana Islands, the Virgin Islands, American Samoa, and Guam.


(g) EFFECTIVE DATE. This section shall apply to health insurance coverage offered or renewed on or after the end of the 90-day period beginning on the date of the enactment of this Act.
A BILL

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Genetic Fairness Act of 1996”.

SECTION 2. DEFINITIONS.

As used in this Act:

(1) FAMILY MEMBER. The term “family member” means, with respect to an individual, another individual related by blood to that individual or an spouse or adopted child of the individual or a spouse or adopted child of the individual.

(2) GENETIC INFORMATION. The term “genetic information” means the information about genes, gene products or inherited characteristics that may be derived from an individual or a family member.

(3) GENETIC SERVICES. The term “genetic services” means health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling.

(4) GENETIC TEST. The term “genetic test” means a procedure that is generally accepted in the scientific and medical communities and that is performed for the purposes of identifying the presence, absence, or alternation of any gene or chromosome.

(5) HEALTH PLAN. The term “health plan” means—

(A) a group health plan (as such term is defined in section 607 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1167), and a multiple employer welfare arrangement (as defined in section 3(40) of such Act) that provides health insurance coverage; or

(B) any contractual arrangement for the provision of a payment for health care, including any health insurance arrangement or any arrangement consisting of a hospital or medical expense incurred policy or certificate, hospital or medical service plan contract, or health maintenance organization subscriber contract.

(6) INSURER. The term “insurer” means
(A) an insurance company, health care service contractor, fraternal benefit organization, insurance agent, third party administrator, insurance support organization or other person subject to regulation under State health insurance laws;

(B) a managed care organization; or

(C) an employee welfare benefit plan regulated under the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1001 et seq.).

(7) SECRETARY. The term “Secretary” means the Secretary of Health and Human Services.

SECTION 3. PROHIBITIONS

(a) GENETIC INFORMATION. An insurer offering a health plan may not—

(1) terminate, restrict, limit, or otherwise apply conditions to coverage of an individual or family member under the plan, or restrict the sale of the plan to an individual or family member;

(2) cancel or refuse to renew the coverage of an individual or family member under the plan;

(3) deny coverage or exclude an individual or family member from coverage under the plan;

(4) impose a rider that excludes coverage for certain benefits and services under the plan;

(5) establish differentials in premium rates or cost sharing for coverage under the plan; or

(6) otherwise discriminate against an individual or family member in the provision of health care;

on the basis of any genetic information concerning and individual or family member or on the basis of an individual’s or family member’s request for or receipt of genetic services.

(b) GENETIC TESTS. An insurer offering a health plan may not require an applicant for coverage under the plan, or an individual or family member who is presently covered under the plan, to be the subject of a genetic test or to be subjected to questions relating to genetic information.

(c) NOTICE OF RIGHTS. An insurer offering a health plan shall, in the enrollment information provided by the insurer concerning such plan, provide an enrollee with a written statement disclosing the rights of the enrollee under this Act. Such statement shall be in a form and manner that is noticeable to and understandable by an average enrollee.
ENFORCEMENT.

(1) PLANS OTHER THAN EMPLOYEE WELFARE BENEFIT PLANS. The requirements established under subsections (a), (b), and (c) shall be enforced by the State insurance commissioner for the State involved or the official or officials designated by the State, except that in no case shall a State enforce such requirements as they relate to employee welfare benefit plans.

(2) EMPLOYEE WELFARE BENEFIT PLANS. With respect to employee welfare benefit plans, the Secretary shall enforce the requirements established under subsections (a), (b) and (c) in the same manner as provided for under sections 502, 504, 506, and 510 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1132, 1134, 1136, and 1140).

(3) PRIVATE RIGHT OF ACTION. A person may, after that person has exhausted all available administrative remedies, bring a civil action—

(A) to enjoin any act or practice which violates subsection (a), (b), or (c);

(B) to obtain other appropriate equitable relief—

(i) to redress such violations; or

(ii) to require the Secretary of Health and Human Services to enforce any such subsections, or

(C) to obtain other legal relief, including monetary damages.

(4) JURISDICTION. State courts of competent jurisdiction and district courts of the United States have concurrent jurisdiction of actions under this subsection. The district courts of the United States shall have jurisdiction, without respect to the amount in controversy or the citizenship of the parties, to grant the relief provided for in paragraph (3) in any action.

(5) VENUE. For purposes of this subsection the venue provisions of section 1391 of title 28, United States Code, shall apply.

(6) REGULATIONS. The Secretary may promulgate such regulations as may be necessary or appropriate to carry out this section.

SECTION 4. EFFECTIVE DATE

This Act shall apply to any health plan offered or renewed on or after the end of the 90-day period beginning on the date of the enactment of this Act.
Consumer Position Paper

Genetic Testing: A Tool for Doctors, Not For Insurers

Council for Responsible Genetics

The science of genetics holds great promise. New genetic discoveries have the potential to improve medical care for millions of Americans. Legitimate medical uses of genetic testing are beneficial and should be encouraged. But there is no role for genetic testing—or the use of predictive genetic information—in the insurance context.

Life, health, and disability insurers should not be permitted to require or request that applicants undergo genetic testing as a condition of obtaining or retaining insurance.

Life, health, and disability insurers should not be permitted to use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect an insurance policy or contract.

Scientists working with the Council for Responsible Genetics have identified over 200 cases in which healthy individuals were denied insurance or employment on the basis of predictive genetic information. Unfortunately, the same technology that can be used to help doctors identify and treat illness is also being misused to discriminate against people perceived to be at risk for future ill health.

Genetic Tests Are Of Limited Predictive Ability

Genetic tests do not function as the proverbial crystal ball, enabling their users to look into the future. Genes can tell us only part of the story about why some people get sick and others do not. Many genetic tests predict, with limited accuracy, that a disease will become manifest at an undetermined time in the future. In some cases, individuals who carry copies of a disease-linked gene never develop any symptoms of the disease. In other cases, the severity of the individual’s experience of the disease varies widely. Individuals with sickle cell anemia and cystic fibrosis, for example, may have debilitating cases of these conditions, or may have relatively mild forms with few medical complications. Unfortunately, these relatively healthy individuals are often treated by insurers as if they had a chronic, fatal and costly illness. While these individuals may not feel ill or impaired, they face discrimination and stigmas associated with illness in our society.

The Threat of Genetic Discrimination Compromises Quality Medical Care

Fear of genetic discrimination can undermine whatever benefits might be derived from new developments in genetic testing technology. Already, some consumers are avoiding genetic testing for fear that the test results will be used against them. The threat of discrimination compromises their ability to take full advantage of their medical options. In some cases, this means that they will miss out on early diagnosis, treatment or even prevention. In many cases, an early diagnosis of a genetic condition can lead to treatments which can delay the onset of symptoms and minimize those symptoms when they do appear. If consumers avoid taking advantage of available medical options out of fear of discrimination, they are likely to suffer more serious—and more expensive—health problems in the long run.

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Genetic Conditions are Already Reflected in Actuarial Tables

Insurance companies claim they will go bankrupt if forced to insure people at risk for genetic diseases. This claim is hard to take seriously. Unlike infectious diseases, genetic conditions exist at a fairly stable incidence in our society. There is no epidemic of genetic conditions. Thus, they are already reflected in the actuarial tables used by insurers to establish rates. It is misleading for insurers to suggest that their financial solvency will be jeopardized if they are obligated to insure people at risk for genetic conditions. In fact, insurers have always insured people at risk for genetic conditions. Previously, however, it was not possible to identify those people at risk for genetic conditions before they became ill with the disorder. There is no reason for insurers to begin to use this new predictive information now, merely because it is available. Early identification of risk status may actually lead to insurer cost savings as a result of preventative care and longer life spans during which premiums can be collected.

Genetic Testing Creates a Burden of Knowledge

If insurance applicants are required to undergo genetic testing as a condition of obtaining insurance, consumers will be obliged to obtain unwanted information about their genetic inheritance. This “burden of knowledge” in turn may create feelings of hopelessness and may lead to serious psychological traumas. In many cases, the identification of a gene associated with a particular disease is of no therapeutic value to the consumer. There is a general consensus in the medical community that coercive medical interventions represent a gross violation of medical ethics. This is doubly true when the medical intervention offers no benefit to the patient, and merely serves the interests of some third party such as an insurance company. The decision to undergo testing for highly sensitive genetic information must be entirely in the hands of the consumer, and should never enter into the application requirements for obtaining insurance.

Genetic Discrimination Undermines the Social Goal of Insurance

Insurance is a publicly regulated activity designed to meet broad community goals. In the case of health insurance, the goal is to ensure access to health care by providing adequate financing mechanisms. In the case of life and disability insurance, the goal is to provide families some measure of economic security following a tragic death or disability. Underwriting practices for all three types of insurance are becoming increasingly stringent: they violate individual privacy and seem geared to identify and insure only the healthy and long-lived. This trend undermines the social goal of insurance, which is to spread the risk across communities. The number of individuals stigmatized as “substandard” risks or as “ uninsurable,” has increased. This stratification of our community into “haves” and “have nots” is not consistent with the public interest.
GENERAL POSITION OF THE
AMERICAN COUNCIL OF LIFE INSURANCE
ON GENETIC INFORMATION AND GENETIC TESTS
AND LIFE AND DISABILITY INCOME INSURANCE

ACLl Position Paper

It is becoming increasingly difficult, if not impossible, to distinguish genetic conditions from other medical conditions and genetic tests from other medical tests. Increasing numbers of common diseases, such as various forms of cancer and heart disease, not previously considered genetic, are being found to have a genetic component. Also, DNA-based tests are widely expected to become the standard of practice in clinical medicine in connection with common conditions many of which have significant mortality and morbidity implications.

Genetic information and genetic tests include information and tests which have been used in and are essential to the underwriting process for a long time, such as height and weight and tests for high blood pressure and cholesterol. Also, if, as expected, DNA-based tests become as common as today’s blood or urinalysis tests, it is likely that life and disability income insurers will wish and in some cases need to use some of these tests in underwriting. As a result, any inquiry into life and disability income insurers’ use of genetic information and tests is more appropriately characterized as an inquiry into their continued use of all medical information. Fundamentally, it is an inquiry into the appropriateness of the risk classification process and the continued existence of the current private system of life and disability income insurance.

Risk classification is the cornerstone of the existing private life and disability income insurance market. It is the mechanism used to insure that premiums are fair in relation to each insured’s risk and that premiums are adequate for the insurer to meet its future claims obligations. Elimination or significant restriction of risk classification would make it likely that prices for consumers would increase in order to compensate for losses arising from unknown risks. It would jeopardize insurers’ ability to fulfill their existing contractual obligations to consumers because of insurers’ resulting vulnerability to claims for which inappropriately low premiums were charged as a result of ignorance of the full extent of assumed risks. Ultimately, elimination or significant restriction of risk classification would result in some form of socialized risk or public insurance program to satisfy insurance needs now handled privately.

The private life and disability income insurance industry serves a vital role in our society through its provision of financial security to millions of Americans. This role will undoubtedly increase in importance as the federal and state governments become less willing and able to provide this security. The life and disability income insurance industry does not believe that insurance consumers desire a fundamental restructuring of the current life and disability income insurance marketplace or that the federal or state governments are able or willing to assume this role. Consequently, the life and disability income insurance industry would vigorously oppose any proposed limitation of their right to use relevant medical information and tests, including genetic information and tests, which would ultimately jeopardize the current life and disability income insurance marketplace.

These comments focus exclusively on underwriting for life and disability income insurance. Most life and much disability income insurance is individually underwritten. Individual life and disability income insurance policies cannot be canceled except for nonpayment of premiums.
Once issued, neither the original terms of nor premiums for these policies can be changed except in the event of improvement in the insured’s health in which cases premiums may be decreased. Consequently, careful risk assessment at the time of issue of life and disability income insurance policies is vital.

Proponents of limitations on insurer’s use of genetic information or tests maintain that this legislation is necessary in order to prevent the creation of a “genetic underclass.” They seem to believe that without such restrictions insurers will use genetic information or test results to refuse coverage to as many people as they can. This concern reflects a lack of awareness of certain important points.

First, life and disability income insurers have no desire to turn away business. They seek to offer coverage to as many people as possible while assuring themselves that their prices are both fair and adequate. After all, a fundamental purpose of life and disability income insurance companies is to provide financial security through the sale of insurance. The life and disability income insurance industry has every reason to seek to be inclusive, not exclusive.

Second, the life and disability income insurance industry is very competitive. Each company underwrites risks differently. If an applicant is turned down by one insurer, it is very possible that he or she may be able to receive coverage from another. Some insures specialize in substandard risks.

Third, because life and disability income insurers’ prices are affordable, their products are widely available. The vast majority of life and disability income insurance applicants are issued standard coverage at standard rates. This is particularly true with respect to life insurance. Industry statistics indicate that 96% of those who apply for individual ordinary life insurance are provided coverage. Ninety-one percent of these individuals are covered at standard or better rates.

Fourth, historically, improved technology and scientific and medical advances have increased the availability and affordability of life and disability income insurance. They have made it possible for many people to obtain coverage who were unable to obtain any coverage before and have made it possible for many to purchase coverage at cheaper rates than they could have otherwise. For example, in 1952, 55% of the applications of persons with cardiovascular problems were declined. In 1992, only 25% of such individuals’ applications were declined. In 1958, only 2% of the ordinary individual life insurance policies issued insured individuals 55 years old or older. In 1993, 11% of the ordinary individual life insurance policies issued insured individuals 55 years old or older. Moreover, life insurance is one of the few consumer products to enjoy a steady drop in cost. Today an average 25 year old working man can buy life insurance, equal to five times his income, for less than half the money his counterpart paid in 1960 (after adjusting for inflation).

Fifth, when people hear the term “genetic tests” they are prone to think of abnormal results and unfavorable consequences. Such a focus is unfortunate. The fact is that most tests, and DNA-based tests will be no exception, yield a vast preponderance of normal results and just a small minority of abnormal results. If it proves to be true, as many now are predicting, that genetic tests for common conditions become the standard of practice in clinical medicine, millions of Americans will receive reports from their doctors that they are not at increased risk for a number of diseases. Also, many individuals who learn that they are predisposed to certain conditions may be able to avoid or ameliorate those conditions through changes in lifestyle or diet. As a result, it
is very possible that genetic tests, like past medical and technological advances, may make otherwise uninsurable individuals insurable or make it possible for many individuals to obtain insurance at cheaper rates than otherwise would have been possible.

The blurring of the distinctions between genetic conditions and other medical conditions and genetic tests and other medical tests has caused the question of life and disability income insurers’ use of genetic information and genetic tests to become fundamental questions relating to the use of all medical information, the appropriateness of the process of risk classification and the continuation of the existing private system of life and disability income insurance, under which life and disability insurance are widely available at increasingly lower prices. There is no evidence that the federal or state governments are willing or able to assume responsibility for the financial security of the millions of Americans currently privately insured by life and disability income insurance policies. There is no evidence that American consumers desire a fundamental restructuring of the exiting life and disability income insurance marketplace. Consequently, the life and disability income insurance industry would vigorously oppose any proposed limitation of their ability to use relevant medical information and tests, including genetic information and tests, which limitation necessarily would ultimately jeopardize the current private marketplace.
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