



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

October 14, 2003
(Senate)

STATEMENT OF ADMINISTRATION POLICY

(THIS STATEMENT HAS BEEN COORDINATED BY OMB WITH THE CONCERNED AGENCIES.)

S. 1053 - Genetic Non-Discrimination Act of 2003

(Sen. Snowe (R) ME and seven cosponsors)

The Administration is committed to enactment of legislation to prohibit genetic discrimination in health insurance and employment. The Administration supports S. 1053, which would bar health insurers from denying coverage to a healthy individual or charging the person higher premiums based solely on a genetic predisposition to developing a disease in the future. The bill also would prohibit employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions.

The Administration wants to work with the Congress to ensure that individuals can be certain that they are protected against the improper use of genetic information. Unwarranted use of genetic information, and the fear of potential discrimination, threatens both society's ability to use new genetic technologies to improve human health and the ability to conduct the very research needed to understand, treat, and prevent diseases. Enactment of Federal legislation will help guarantee that the Nation fully realizes the potential of ongoing advances in genetic sciences.

"Genetic Information Nondiscrimination Act of 2003" Summary of Bipartisan Agreement

Goal: To fulfill the promise of the human genome project by establishing basic legal protections that will enable and encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies that will result from the scientific advances in the field of genetics.

Means: To prohibit discrimination in health insurance and employment on the basis of predictive genetic information and to fully protect the privacy of genetic information.

Title I - Health Insurance

Application: employer sponsored group health plans, health insurance issuers in the group and individual markets, Medigap insurance, and state and local non federal governmental plans.

Part I: Prohibits Discrimination in Health Insurance

Group market: Prohibits group health plans and health insurance issuers from 1) adjusting premium or contribution amounts, or 2) establishing enrollment restrictions for the group as a whole on the basis of genetic information.

Existing HIPAA protections in group market: Title I, Section 702 of HIPAA already prohibits group health plans and health insurance issuers from 1) adjusting premium or contribution amounts, or 2) establishing enrollment restrictions for individual members of a group on the basis of genetic information.

Individual market: Prohibits health insurance issuers in the individual market from using genetic information about enrollees or their family members to 1) adjust premium or contribution amounts, or 2) use as a condition of eligibility.

Genetic Services: Genetic information incorporates the request or receive of a genetic service by an individual or family member.

Part II: Protects the Privacy of Genetic Information

Privacy Regulations: The HHS HIPAA privacy regulations protect the use and disclosure of all individually identifiable health information, including genetic information. However, a permitted "use" of health information under the privacy rules (i.e., a specific item under 'health care operations') is underwriting, which is a practice that is contrary to insurance discrimination.

Ban on Underwriting: Therefore, this bill expressly bans the use or disclosure of genetic information for purposes of underwriting. In addition, this bill bans health plans and insurance issuers from collecting (i.e., requesting or requiring) genetic information in the first place for purposes of underwriting.

In addition, this bill further protections the privacy of genetic information by prohibiting plans and insurance issuers from collecting (i.e., requesting or requiring) genetic information prior to enrollment under the plan.

Title I Enforcement

By building these protections into existing statutes, this bill ensures that all health information, including genetic information, is afforded the same protections under the law. In addition this bill ensures that all individuals are provided the same protection under the law, regardless of whether they are currently sick or disabled, or currently healthy. All individuals (healthy and sick) have genetic information that could be used to discriminate against them.

- **Penalties/Remedies for Non Discrimination Provisions:** Same penalty/enforcement structure as Title I of HIPAA (existing portability, non discrimination provision). In general, under ERISA participants or DOL can sue for benefit recovery under ERISA. Agreement further clarifies right to seek injunctive relief and get coverage reinstated to date of violation. The appropriate Secretary may impose tax penalties of \$100 per day/per person, with a minimum penalty of \$2,500 - up to \$15,000 for multiple violations that are more than de minimis with an outside cap of up to \$500,000. For group health plan violations enforced under ERISA, the court may award the \$100/day penalty to the individual.
- **Penalties for Privacy Provisions:** Same enforcement structure and penalties as created by the Social Security Act for the HHS privacy standards. Enforced by the HHS Office of Civil Rights. Penalties are Civil monetary penalties of \$100 per violation - up to \$250,000 and 10 years in prison for egregious violations.

Title II: Employment Provisions

General: Treats genetic information in the same manner as other forms of employment discrimination, such as race under Title VII of the Civil Rights Act of 1964 or disability under the Americans with Disabilities Act.

Prohibition on Use: Strictly prohibits the use of genetic information in employment decisions, such as hiring, firing, job assignments, promotions, etc. This prohibition extends to employers, unions, employment agencies, and labor management training programs.

Limitation on Acquisition: An employer is prohibited from requesting, requiring, or purchasing genetic information about the employee or family member, except for certain legitimate reasons. An employer may request or require such information for certain legitimate reasons such as: (1) for genetic monitoring of biological effects of toxic substances in the workplace, (2) if the employer provides genetic services, such as through a wellness program, with the employee's prior consent, or (3) for compliance with the Family and Medical Leave Act or its state equivalent. The purchase of commercially and publicly available documents or the inadvertent acquisition of family medical history would not violate this title, but the information still could not be used or disclosed.

Confidentiality Protections: Safeguards the confidentiality of genetic information in the employment setting. If an employer (acting as an employer) acquires or comes into contact with genetic information, such information shall be treated and maintained as part of the employee's confidential medical records. Moreover, such information shall not be disclosed except in limited situations, such as to the individual or pursuant to a Federal or state family and medical leave laws, or court order.

Enforcement: (a) Consistent with the ADA and Title VII, a claimant is required to file a charge with the

EEOC, within a certain time period, prior to filing a suit in court. The bill imposes the same limits on compensatory and punitive damages applicable to the ADA and Title VII, which are progressive with the size of the employer and limited to cases of intentional discrimination.

Disparate Impact: The bill prohibits claims based on disparate impact (unintentional discrimination), and empowers a commission in six years to review the science and law of genetics.

Workers Compensation: Clarifies that the title shall not be construed to limit or expand the protections, rights or obligations of employees or employers under workers compensation laws.

Definitions - Applies to Title I and II

Genetic Information — information about an individual's genetic tests; the genetic tests of family members of the individual; or the occurrence of a disease or disorder in family members of the individual. Genetic information does not include information about the sex or age of an individual.

Genetic Test — DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

Exceptions* — Genetic test does not mean an analysis of 1) proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes or; 2) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

Genetic Services — a genetic test; genetic counseling, or genetic education.

* does not apply to Title II

MARY AS OF:

11/14/2003--Passed Senate, amended. (There are 2 other summaries)

Genetic Information Nondiscrimination Act of 2003 - Title I: Genetic Nondiscrimination in Health Insurance - (Sec. 101) Amends the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code to expand the prohibition on health plan or issuer discrimination on the basis of **genetic information** or services to prohibit: (1) enrollment discrimination based on **information** about a request for or receipt of **genetic** services by an individual or an individual's family member; (2) group premium discrimination based on the **genetic information** of an individual or an individual's family member; and (3) requiring **genetic** testing. Defines **genetic information** as **genetic** tests of an individual or family member or occurrence of a disease or disorder in family members. States that such term shall not include **information** about the sex or age of an individual. Defines **genetic** services as **genetic** tests, **genetic** counseling, or **genetic** education.

Amends the Public Health Service Act to prohibit such discrimination in coverage offered in the individual market.

Requires the Secretary of the Treasury, the Secretary of Labor, and the Secretary of Health and Human Services (HHS) to issue final regulations to carry out this title.

(Sec. 104) Amends title XVIII (Medicare) of the Social Security Act to prohibit an issuer of a Medicare supplemental policy from denying or conditioning the issuance or effectiveness of the policy, or from discriminating in the price of the policy of an eligible individual based on **genetic information**, on the receipt of **genetic** services or on a request for such services. Prohibits the issuer of such a policy from requesting or requiring a beneficiary to undergo a **genetic** test.

(Sec. 105) Applies the HHS medical privacy rules to the disclosure of **genetic information**. Prohibits a group health plan, a health insurance issuer, or an issuer of Medicare supplemental policies from using or disclosing **genetic information** for purposes of underwriting, determining eligibility to enroll, or premium rating. Prohibits such entities from using or disclosing **genetic information** for the creation, renewal, or replacement of a plan, contract, or coverage for health insurance or benefits. Prohibits such entities from requesting, requiring, or purchasing **genetic information** concerning a participant, beneficiary, or enrollee prior to the enrollment and in connection with such enrollment of such individual under the plan, coverage, or policy. Permits the incidental collection of such **genetic information** by such entities if the request, requirement, or purchase that brought the **information** was not made for certain purposes, including underwriting, and if the **information** is not used or disclosed in violation of the HHS medical privacy rules.

Makes the confidentiality standards inapplicable to group health plans, health insurance issuers, or issuers of Medicare supplemental policies that are not otherwise covered by regulations promulgated under part C of title XI of the Social Security Act and a health **information** privacy provision of the Health Insurance Portability and Accountability Act of 1996. Makes the prohibition on collection of **genetic information** inapplicable to **genetic information** that is not considered to be individually-identifiable health **information** under such regulations.

Title II: Prohibiting Employment Discrimination On the Basis of Genetic Information - (Sec. 202) Makes it an unlawful employment practice for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive such individual of employment opportunities because of **genetic information**. Prohibits the collection of **genetic information** except: (1) where health or **genetic** services are offered by the employer; (2) where an employer needs certain **information** to comply with the certification provisions of the Family and Medical Leave Act of 1993 or with State family and medical leave laws; (3) where an employer purchases documents that are commercially and publicly available that include family medical history; or (4) where necessary to monitor the effects of toxic substances in the workplace (when authorized by the employee or as required by law).

. 206) Requires **genetic information** to be treated as part of an individual's confidential medical record, limiting disclosure to certain parties, including the individual, the family, health researchers, or government officials investigating compliance with this title. Permits disclosure as required by court order or as made in order for an employee to comply with the certification provisions of the Family and Medical Leave Act of 1993 or with State family and medical leave laws.

(Sec. 207) Protects applicants or employees covered by: (1) title VII of the Civil Rights Act of 1964 (regarding the EEOC); (2) the Government Employee Rights Act of 1991; (3) the Congressional Accountability Act of 1995; (4) specified Federal law pertaining to the extension of certain rights and protections to presidential offices; and (5) the section of the Civil Rights Act of 1964 regarding employment by the Federal Government. Provides for the same compensatory and punitive damages available to prevailing plaintiffs under Federal law regarding damages in cases of intentional discrimination in employment.

(Sec. 208) Requires establishment of a **Genetic** Nondiscrimination Study Commission, which shall review the developing science of **genetics** and advise Congress on the advisability of providing for a disparate impact cause of action under this Act.

(Sec. 210) Declares that an employer, employment agency, labor organization, or joint labor-management committee shall not be considered to be in violation of this title based on the use, acquisition, or disclosure of medical **information** that is not **genetic information** about a manifested disease, disorder, or pathological condition of an employee or member.

(Sec. 211) Directs the EEOC to issue final regulations to carry out this title.

(Sec. 212) Authorizes appropriations to carry out this title.

Title III: Miscellaneous Provision - States that if any part of this Act is held to be unconstitutional, the remainder of this Act shall not be affected.

New Jersey outlaws genetic discrimination

Washington. The New Jersey state legislature last week gave near-unanimous approval to the most sweeping bill outlawing genetic discrimination yet passed in any of the 50 states.

But a controversial clause giving an individual property rights to genetic information was dropped after pressure from the biotechnology and pharmaceutical industries that are well represented in the state.

The bill is expected to be signed into law by New Jersey Governor Christine Todd Whitman (Republican) this week. It not only outlaws the use of genetic information to deny individuals jobs or health insurance, but also restricts how life and disability insurers may use such information.

In its revised form, the bill has received the backing of a wide range of interest groups, including the two industries involved, labour unions and the Roman Catholic church. The only obvious dissent has come from insurance groups, which testified against the bill last spring. They argue that insurers need all the information possible about applicants to accurately assess risk and avoid driving up rates on individual policies. They are said to have been "reluctantly coerced" into supporting the legislation.

Gene tests 'need research protocols'

Washington. An advisory committee to the National Institutes of Health (NIH) has recommended that genetic testing for breast and ovarian cancer be conducted only within strictly defined research protocols. This reverses an earlier position encouraging wider use of testing (see *Nature*, 380, 573; 1996).

Last week, the Advisory Committee on Research on Women's Health unanimously passed a resolution urging that genetic tests for breast and ovarian cancer be conducted only within "hypothesis-driven protocol studies" endorsed by NIH-approved institutional review bodies.

Typical studies, says the resolution, might address questions such as the positive predictive value of tests, and the appropriate medical management of those carrying mutations. The advice represents a refusal to endorse commercial genetic testing that does not incorporate hypothesis-driven research.

Last April, the committee refrained from calling for testing to be confined to research protocols. One dissenter at the time was Linda Burhansstipanov, director of the Native American Cancer Research Program at the AMC Cancer Research Center in Denver, Colorado, who called the resolution "paternalistic". But last week she supported the revised

Whitman had vetoed the bill in September, after both houses of the legislature had passed it unanimously (see *Nature* 383, 367; 1996). Her position reflected the concerns of the biotechnology and pharmaceutical industries, which had objected to a statement in the bill declaring genetic information to be an individual's private property.

The governor and the industries argued that this could have a 'chilling' effect on research, by exposing companies to law-suits for royalties by those whose DNA had been used to develop new products.

The property right declaration was subsequently removed from the bill. Supporters of the clause say that the political power of the pharmaceutical and biotechnology industries left them with little choice — but that the issue was a relatively minor concern when compared with the bill's broad anti-discrimination provisions.

Even in its modified form, the bill is "absolutely more far-reaching than any other", says Generosa Grana, a breast cancer specialist at Cooper Hospital in Camden, New Jersey, and an adviser to the New Jersey Cancer Commission, who helped draft the bill.

None of the advocacy groups fought

resolution, after the committee added a new, lengthy preamble. It includes a call for research on how poor, non-white and rural women can be guaranteed access to testing under research protocols.

Vivian W. Pinn, director of the NIH's Office of Research in Women's Health, says she agrees with the advisory committee. Access to genetics testing is important, but women "should know what it means", and such information is more likely to be both gathered and imparted in the research setting.

In adopting its position, the advisory committee joins the American Society of Human Genetics, the Advisory Council of the National Center for Human Genome Research, and the National Breast Cancer Coalition. In contrast, the American Society of Clinical Oncology has called for genetic testing to be made available outside research settings "as part of the preventive oncologic care of families".

The new recommendation comes two weeks after Myriad Genetics of Salt Lake City introduced a commercial full-sequence testing of *BRCA1* and *BRCA2* genes, mutations which can confer a predisposition to breast and ovarian cancers. The company is charging \$2,400 for initial testing, and \$395 for tests of additional family members. **M.W.**

Whitman's demanded change "because there was so much [else] to lose", adds Karen Rothenberg, director of the Law and Health Care Program at the University of Maryland School of Law, and an expert on state genetic discrimination laws.

Not everyone agrees. George Annas, a lawyer and professor of public health at Boston University School of Public Health, says that "gutting" the property right clause has turned the bill into "an anti-genetic privacy act". He called it "bizarre" that "other people can own your genetic information, but you can't". And State senator Robert Martin (Republican), a law professor who was the lone Senate opponent of the revised bill, argues that Whitman's concern to protect industry may not have given enough protection to ordinary citizens.

The strength of the bill lies in its prohibition of discrimination not only on the basis of genetic tests, but of genetic information — a far broader term which includes family history, and can include individual history, physical examination and the results of other tests.

The bill is also broad in scope. It imposes restraints on life and disability insurers, in addition to employers and health insurers. Laws in other states have been narrower.

Under the bill, neither genetic information, nor an individual's refusal to submit to a genetic test or provide test results, can be used in decisions on hiring, firing and health insurance. Life and disability insurers may demand and use genetic information in underwriting, but must not use it "unfairly".

A life insurer, for example, could not use the fact that a woman is carrying a *BRCA1* mutation to decide whether to issue a policy, or what rate to charge, because this fact is no guarantee that she will develop cancer.

But the same insurer could legally refuse cover or charge higher premiums to somebody who carries the gene for Huntington's disease, as that person has a 100 per cent chance of developing the disease. In such a case, the insurer would have to base rates on actuarial data for Huntington's patients.

Only one state — Oregon — of the 12 others that have passed laws dealing with genetic discrimination includes a property right. An official now implementing the Oregon law says that the property right does not seem to have had any immediate impact. Michael Skeels, director of the state's Public Health Laboratory, adds that its implications for research will "take years" to become clear.

Earlier this year, the US Congress passed a law merely forbidding health insurers from using genetic information to discriminate against people who change or lose jobs. Pressure is growing for a broader federal law, and the issue may be addressed in the next legislative session. **Meredith Wadman**





Genetic Technologies Project **Health Care Program**

Genetics Laws and Legislative Activity

Amendment X

"reserved for the States"

*promote general welfare
police powers*

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[Genetic Counselor Licensing](#)

[Health Insurance](#)

[Health Insurance Enforcement](#)

[Human Cloning](#)

[Life, Disability and Long-Term Care Insurance](#)

[Newborn Screening](#)

[Newborn Screening Privacy](#)

[Genetic Privacy](#)

[Use, Storage and Disposition of Frozen Embryos](#)



Source: U.S. Department of Energy Human Genome Program
<http://www.ornl.gov/hgmis>

2004 GENETICS LEGISLATIVE ACTIVITY

COMING SOON in a new, searchable format.

Please contact Alissa Johnson at alissa.johnson@ncsl.org with questions.

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NCSL Home > State & Federal Issues: Issue Areas > Health > State Genetics Employment Laws

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NCSL Genetics Tables**State Genetics Employment Laws**

Last updated: 2/3/03

Several states acted against employer use of genetic information in the 1970s and '80s to prohibit employer discrimination against applicants with the sickle cell trait. Wisconsin was the first state to ban genetic testing and discrimination in the workplace in 1991. With Hawaii, Utah and Virginia enacting measures in 2002, genetic nondiscrimination in employment laws are in place in 31 states. The scope and functions of these laws vary widely. All laws prohibit discrimination based on the results of genetic tests; many extend the protections to inherited characteristics, and some include test result of family members, family history and information about genetic testing, such as the receipt of genetic services. Most states also restrict employer access to genetic information, with some prohibiting employers from requesting, requiring and obtaining genetic information or genetic test results, or directly or indirectly performing or administering genetic tests.

On the federal level, the Equal Employment Opportunity Commission in 1995 interpreted "disability" in the Americans with Disabilities Act to include genetic predisposition to disease, but conflicting rulings raise questions whether the Supreme Court would accept the EEOC interpretation. President Clinton in February 2000 banned genetic discrimination in the federal workplace and called on Congress to pass a federal genetic information nondiscrimination law for private sector employment. The U.S. Senate debated the matter during the summer of 2000, but took no action.

State and Statute	Genetic Nondiscrimination Covers					Genetic discrimination prohibited in hiring, firing, and/or terms, conditions or privileges of employment	Prohibits Employer From				Specific Penalties for Genetic Discrimination in Employment
	Predictive Genetic Information Only	Genetic Test Results	Information About Genetic Testing	Family History	Inherited Characteristics		Requesting Genetic Information/ Genetic Test	Requiring Genetic Information/ Genetic Test	Performing Genetic Test	Obtaining Genetic Information/ Genetic Test Result	
Total	9	31	9	12	16	31	18	24	16	10	12
California Gov't. §12926, Gov't. §12940	✓	✓		✓	✓	✓			✓		



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State Genetic Nondiscrimination in Health Insurance Laws

Last updated: 8/7/02

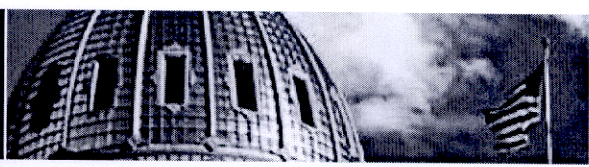
A patchwork of federal and state laws govern discrimination based on genetic information for health insurance. The 1945 McCarran-Ferguson Act explicitly endorses the primacy of state insurance regulation. The Employees Retirement Income Security Act of 1974 preempts state laws pertaining to self-funded employee benefits plans. The Health Insurance Portability and Accountability Act of 1996 became federal law to directly address genetic information. The law prohibits health insurance discrimination based on any "health status-related factor," including genetic information, for group health plans, u those with more than 50 individuals.

States have acted to fill in the gaps left by HIPAA. Laws in 34 states strictly prohibit the use of genetic information for risk selection and risk classification purposes. Additionally, Arizona, Vermont, and Virginia require actuarial justification for the use of genetic information. Texas bans use of genetic information in group health plans, and Alabama prohibits discrimination based upon predisposition to

State	Citation	Type of Insurance Policy	May not Establish Rules for Eligibility based on Genetic Information	May not Require Genetic Tests/ Genetic Information	May not Use Genetic Information for Risk Selection or Risk Classification Purposes	May not Disclose Information Without Informed Consent	Con of E Pro G Infr
California	Insurance Code: <u>§§742.405, 7, 10140, 3, 6 to 9, 9.1</u>	Individual and Group	√	√	√	√	GT

March 10, 2004

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State Genetic Nondiscrimination in Health Insurance Laws Enforcement Provisions

The majority of state legislatures have enacted measures to prohibit genetic discrimination in some or all forms of health insurance. Under state genetic nondiscrimination statutes, a state insurance commissioner's power to enforce the law ranges from the ability to suspend an insurer's license to the authority to impose heavy administrative fines. In addition, some state statutes specifically provide individuals who are damaged as a result of genetic discrimination the right to sue an insurer in civil court. Finally, penalty provisions in state genetic nondiscrimination laws often permit the insurance officials to promulgate additional regulations within the limits set forth by the statute.

State	License Revoked or Suspended	Private Right of Action	Authorizes Regulatory Penalties	Civil Liability, Criminal Penalties and Administrative Fines
California			√	Up to \$2,500 for the first unintentional violation and not more than \$5,000 for each

March 10, 2004

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Genetic Technologies Project

NCSL Genetics Laws and Legislative Activity

Genetics and Life, Disability and Long-term Care Insurance

Updated 10/03/03

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While a majority of states have enacted laws that strictly prohibit the use of genetic information for risk selection and risk classification in health insurance, fewer states restrict the use of genetic information in life, disability and long-term care insurance. Seven states prohibit genetic discrimination in life insurance without actuarial justification. Of these seven, Arizona, Maine, and New Jersey also prohibit genetic discrimination in disability insurance without actuarial justification, and Massachusetts, Montana and New Mexico extend their prohibitions to disability and long-term care insurance. Colorado, Massachusetts, Oregon and Vermont prohibit insurers from requiring applicants to undergo genetic testing for long-term care insurance but permit the use of test results. Some states mention life, disability or long-term care as exclusions to their genetic nondiscrimination legislation. For these states there are statute citations below but no columns are checked.

State and Statutes	Restricts Discrimination Based on Genetic Information in Life Insurance	Restricts Discrimination Based on Genetic Information in Disability Insurance	Restricts Discrimination Based on Genetic Information in Long-term Care Insurance	Requires Actuarial Justification to Use Genetic Information in Life Insurance	Requires Informed Consent to Use Genetic Information
California Insurance §§10146 to 10149.1	✓	✓	✓		✓ ¹

March 10, 2004

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NCSL Home > State & Federal Issues: Issue Areas > Health > Newborn Genetic and Metabolic Disease Screening

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Genetic Technologies Project Health Care Program

Newborn Genetic and Metabolic Disease Screening

Updated January 2003



Source:
kidshealth.org

State newborn screening systems were the first and remain the largest genetic programs for children. Nationwide, state public health programs screen an estimated 4 million infants annually for genetic disorders. Undetected and untreated abnormalities can result in severe problems, mental retardation or even death. Although funding newborn screening programs requires expenditures by the states, proactively treating congenital abnormalities may save states money by avoiding more financially burdensome medical costs and state institutional services. Comprehensive state newborn screening programs involve testing, follow-up, diagnosis, treatment and evaluation.

Even though newborn screening became available to infants through state programs in the 1960s and all states screen for some conditions, the extent of screening varies throughout the states. Some 700 genetic tests are available; however, not all the tests are recommended. For example, some conditions are so rare, testing is not cost-effective; in other cases no treatment exists for the conditions. State experiences vary regarding laws or regulations, specific tests, oversight responsibilities, state advisory boards, processes for informing parents, exemptions, storage policies and use of blood samples and payment for newborn screen procedures.

A Newborn Screening Task Force, co-sponsored by the American Academy of Pediatrics and the Maternal and Child Health Bureau, made a series of recommendations with regard to state newborn screening programs. Their report calls for states to: use a comprehensive systems approach; follow accepted national guidelines; coordinate infant programs and data; pilot new tests and technologies before adopting major policy changes and new mandates; monitor and evaluate program performance; involve and inform families; establish a state advisory group that has a diverse representation; set state-level policies for the use and storage of residual newborn screening blood samples; and assure adequate financing for a whole system using state newborn screening fees and other funds.

State laws on genetic screening relate to diseases and disorders such as adrenal hyperplasia, biotinidase deficiency, branched-chain ketonuria, cystic fibrosis, galactosemia, homocystinuria, hypothyroidism, maple syrup urine disease, phenylketonuria (PKU) and sickle cell anemia. Many state laws include exemptions for parents who object to genetic testing for religious or other reasons. During the 2002 legislative session, at least three states--**Mississippi, Nebraska** and **Virginia**--enacted laws related to newborn genetic screening. Other states have created laws related to newborn screening privacy issues.

California

Cal. Health & Safety Code § 1374.56 and Insurance Code § 10123.89 (1999) requires health plans to offer coverage for the testing and treatment of PKU. [Cal. Stats., Chap. 541 (SB 148)]

Cal. Health & Safety Code § 125000 and 125001 (1998) requires the Department of Health Services to establish a program to detect PKU and other preventable heritable or congenital disorders. The law requires the department to establish a genetic disease unit to promote a statewide program of information, testing, and counseling services. The law directs the department to charge a fee for tests. The law does not apply if a parent or guardian of the newborn objects to a test on religious grounds. [Cal. Stats., Chap. 1011 (S 537)]

Newborn Genetic Screening Privacy Laws

Health Programs

Updated July 2002

Currently, **28 states** require consent to either perform or require genetic testing or to obtain, retain or disclose genetic information through genetic-specific privacy laws. In addition, Washington includes genetic information in the definition of protected health information under the state's health privacy statute. Many of the states with genetic privacy laws exempt newborn screening from consent provisions, including Delaware, Illinois, Louisiana, Massachusetts, Michigan, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon and Vermont. The chart below does not address consent requirements or exemptions for newborn screening that may be found in state administrative codes.

At least **23 states** have laws that allow for an exemption to the newborn genetic screening requirements if parents object on religious grounds (Alabama, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Illinois, Indiana, Kentucky, Louisiana, Massachusetts, New Jersey, New York, North Dakota, Ohio, Rhode Island, South Carolina, Texas, Utah, Virginia, Washington and Wisconsin). Two states--Florida and Wyoming--allow for an exemption to the newborn genetic screening requirements if parents object on any grounds.

At least **12 states** have confidentiality requirements related to newborn screening laws (Arizona, Colorado, Florida, Hawaii, Iowa, Louisiana, New Jersey, North Dakota, Ohio, South Carolina, Virginia and Wisconsin).

At least **six states** and the District of Columbia have laws related to obtaining consent from the parents of children before performing genetic tests (Hawaii, Ohio, Nebraska, Texas, Wisconsin and Wyoming). Kansas requires informed consent in order to monitor infants with genetic disorders.

Many states have laws regulating newborn hearing screening, but these laws do not necessarily apply to newborn genetic screening.

State	Newborn Genetic Screening Privacy Laws	Law Allows for a Religious Exemption	Genetic Privacy Law Allows for an Exemption for Newborn Screening
California	<p><u>Cal. Health & Safety Code § 124975</u> clarifies that participation of people in hereditary disorders programs should be wholly voluntary, except for initial screening for phenylketonuria (PKU) and other genetic disorders treatable through the California newborn screening program. All information obtained from people involved in hereditary disorders programs in the state should be held strictly <u>confidential</u>.</p> <p><u>Cal. Health & Safety Code § 124980</u> prohibits tests from being performed on any minor over the objection of the minor's parents or guardian. Tests may not be performed unless the parent or guardian is fully <u>informed</u> of the purposes of testing for hereditary disorders and is given reasonable opportunity to object to the testing. No testing, except initial screening for phenylketonuria (PKU) and other diseases that may be added to the newborn screening program, shall require mandatory participation. The law requires all testing results and personal information generated from hereditary disorders programs to be made available to individuals over 18 years of age, or to the individual's parent or guardian. All testing results and personal information from hereditary disorders programs shall be held <u>confidential</u> and be considered a <u>confidential</u> medical record except for information that the individual, parent, or guardian <u>consents</u> to be released.</p>	<u>Cal. Health & Safety Code § 125000</u>	



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Last updated: 10/16/03

Medical information is often presumed confidential, but increasing capabilities to store and rapidly transfer data escalate the challenge of protecting privacy. Laws in all states restrict access to medical records. At issue is whether genetic information should be protected generally, as another component of health data, or by special genetic privacy laws.

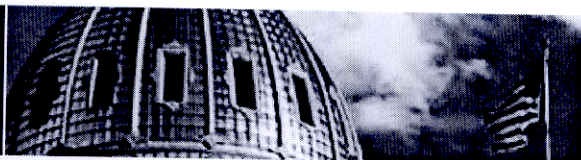
The case against "genetic exceptionalism" asserts that genetic information is fundamentally no different than other health data and special protections for one type of information could deny safeguards that should be established more generally. Proponents argue that the stability of genetic information and unique predictive - rather than merely historic - qualities warrant special consideration.

Laws in 16 states require informed consent for a third party either perform or require a genetic test or to obtain genetic information. Twenty-three states require informed consent to disclose genetic information. In addition, Rhode Island and Washington require written authorization to disclose genetic information. Colorado, Florida, Georgia, and Louisiana explicitly define genetic information as personal property. In 2001 Oregon repealed its property right to DNA samples and genetic information. Four states mandate individual access to personal genetic information, and 17 states have established specific penalties - civil or criminal - for violating genetic privacy laws.

The states with genetic privacy laws listed below also may have laws related to other issues, such as the use of genetic information in insurance and employment. The legislature may have addressed these issues in conjunction with genetic privacy. For a full understanding of genetics law in a particular state, please go back to the [Genetics Laws and Legislative Activity page](#) and click on the employment and insurance law tables. You also may want to view [maps](#) on state genetics laws created by Backbone Media for the PBS program [Bloodlines](#). NOTE: NCSL does not endorse any of the views expressed at the [Bloodlines](#) Web site or in the program.

State and Statute	Personal Access to Genetic Information Required	Informed Consent Required to				Define as Personal Property		Specific Penalties for Genetic Privacy Violations
		Perform/Require Genetic Test	Obtain/Access Genetic Information	Retain Genetic Information	Disclose Genetic Information	Genetic Information	DNA Samples	
California					✓			✓

<http://www.ncsl.org/programs/health/genetics/prt.htm>



[NCSL Genetics Tables](#)

State Embryonic and Fetal Research Laws

Updated January 27, 2004

NCSL magazine article on human cloning³⁴ [Attack of the Clones](#)³⁴ published in the April 2003 issue of *State Legislatures* magazine is now publicly available. NOTE: This article does not reflect 2003 changes to state human cloning or stem cell research laws. Please see NCSL [State Human Cloning Laws](#) page for current state laws.

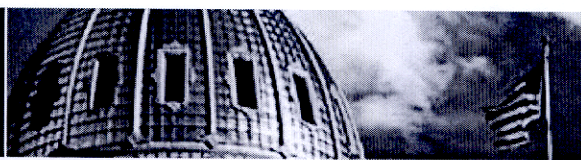
SEE NCSL'S [Genetics Legislative Activity](#) page for pending legislation.

There are four primary sources for embryonic stem cells: existing stem cell lines, aborted or miscarried fetuses/embryos, unused in vitro fertilized embryos, and cloned embryos. Current federal policy limits federally funded research to research conducted on embryonic stem cell lines created before August 2001. Federal funding of research involving cloning for the purpose of reproduction or research is prohibited. However, there is no federal law banning human cloning altogether. The Food and Drug Administration has claimed authority over the regulation of human cloning technology as an investigational new drug (IND) and stated that at this time, they would not approve any projects involving human cloning for safety reasons, but Congress has not passed legislation confirming the FDA's authority to prohibit cloning.

State laws may restrict some or all sources for embryonic stem cells or specifically permit certain activities. State laws on the issue vary widely. Approaches to stem cell research policy range from laws in California and New Jersey, which encourage embryonic stem cell research, including on cloned embryos, to South Dakota's law, which strictly forbids research on embryos regardless of the source. If, however, a fetus is aborted for the health of the mother in South Dakota, the fetus may be used for research purposes with maternal consent. Many states restrict research on aborted fetuses or embryos, but research is often permitted with consent of the patient. Almost half of the states also restrict the sale of fetuses or embryos. Louisiana is the only state that specifically prohibits research on IVF embryos. Illinois and Michigan also prohibit research on live embryos. Finally, Arkansas, Iowa, Michigan and North Dakota prohibit research on cloned embryos. Virginia's law also may ban research on cloned embryos, but the statute may leave room for interpretation because human being is not defined. Therefore, there may be disagreement about whether human being includes blastocysts, embryos or fetuses. California, New Jersey and Rhode Island also have human cloning laws, but these laws prohibit cloning only for the purpose of initiating a pregnancy, or reproductive cloning, but allow cloning for research. Missouri also forbids the use of state funds for reproductive cloning but not for cloning for the purpose of stem cell research, and Nebraska prohibits the use of state funds for embryonic stem cell research.

State/Jurisdiction Statute Section	Specifically permits research on embryos	Specifically prohibits research on aborted fetus/ embryo	Consent provisions to conduct research on fetus/embryo	Prohibits research on fetus or embryo resulting from sources other than abortion	Prohibits sale of fetus/ fetal tissue or embryo
California Health & Safety §§ 123440, 24185, 12115-7, 125300-320	Yes	Yes, prohibits research on aborted live fetus	Consent to donate IVF embryo to research	No	Yes, prohibits sale for the purpose of reproductive cloning or for stem cell research on cloned embryos

March 10, 2004

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State Human Cloning Laws

Updated: January 6, 2004

NCSL magazine article on human cloning³⁴ [Attack of the Clones](#)³⁴ published in the April 2003 issue of *State Legislatures* magazine is now publicly available. NOTE: This article does not reflect 2003 changes to state human cloning laws in Arkansas, Louisiana, New Jersey and North Dakota. Please see NCSL the table below for current state laws.

Nine states have laws pertaining to human cloning. The issue was first addressed by the state of California, which banned reproductive cloning, or cloning to initiate a pregnancy, in 1997. Since then, seven other states³⁴ Arkansas, Iowa, Michigan, Rhode Island, North Dakota, Virginia and most recently New Jersey³⁴ have enacted measures to prohibit reproductive cloning. Missouri forbids the use of public funds for human cloning research. Louisiana also enacted legislation that prohibited reproductive cloning, but the law expired in July 2003.

³ Arkansas, Iowa, Michigan and North Dakota laws extend their prohibitions to therapeutic cloning, or cloning for research purposes. Virginia's law also may ban human cloning for any purpose, but it may be unclear because the law does not define the term "human being," which is used in the definition of human cloning. Rhode Island law does not prohibit cloning for research, and California and New Jersey human cloning laws specifically permit cloning for the purpose of research.

State	Statute Citation	Summary	Prohibits Reproductive Cloning	Prohibits Therapeutic Cloning	Expiration
California	Business And Professions §16004 , §16105 , Health & Safety §24185 , §24187 , §24189 , §12115-7	Prohibits reproductive cloning; permits embryonic stem cell research, including the use of cloned embryos;	yes	no	

<http://www.ncsl.org/programs/health/genetics/rt-shcl.htm>

What Agencies & Laws Regulate Genetic Testing Products & Services?

Police Powers - "promote the general welfare"

① Test Products

Example: PATHWAY® - Her2 test for breast cancer

- The FDA regulates genetic testing kits, reagents, & machinery under the Medical Devices Act of 1976 & the Safe Medical Device Amendments of 1990.
- Intent is to provide safety & effectiveness - e.g., give proper results & distinguish between high risk, low risk, & false positives
- Premarket Approval (PMA) is required of all Medical devices marketed for in vitro diagnosis

② Laboratory Services

- Clinical Laboratory Improvement Act of 1967 (CLIA67) -
- Department of Human & Health Services (HHS)
- Clinical Laboratory Improvement Amendments of 1988 (CLIA88)
Materials from human body for purposes of diagnosis, prevention, or treatment of disease

WHAT LEGAL ISSUES ARE THERE in Genetic Testing?

- ① Health Care & Reproduction?
- ② Workplace?
- ③ Insurance?
- ④ Law Enforcement & Judicial Applications?

Legal Issues in Genetic Testing

J.A. Robertson

in

The Genome, Ethics, & the Law

MEDICAL CARE & HEALTH PROMOTION

NEW BORN SCREENING

1960s
Robert Guthrie
PKU Screening Test

- ① LAWS in Most States REQUIRE Mandatory new born screening IF disease CAN BE TREATED in new born baby to Prevent Disease or Mitigate More Serious Aspects of Disease — **MANDATORY PUBLIC HEALTH APPROACH!**
- ② PKU, Galactosemia, Primary Congenital Hypothyroidism, Sickle Cell and other Hemoglobin diseases (California Newborn Screening Program).
- ③ Only legal ground for refusal is religious beliefs & practices in CA. Ethical??
- ④ New Mass Spectroscopy Screening in CA and other States have added 20 more tests for Metabolic disorders voluntarily in a trial research period.
- ⑤ State pays although fee can be charged.
- ⑥ IF RISKS/BENEFITS OF TREATMENT NOT CLEAR, then CAN'T be MANDATORY & left to Parental discretion — OR NO TREATMENT

MANDATORY
Testing!

LAWS GOVERNING
— POLICE POWERS
"promote general welfare"
— "parens patriae"
authority to prevent person at risk from self-inflicting harm

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Genetic Technologies Project
Health Care Program

Newborn Genetic and Metabolic Disease Screening

Updated January 2003



Source:
kidshealth.org

State newborn screening systems were the first and remain the largest genetic programs for children. Nationwide, state public health programs screen an estimated 4 million infants annually for genetic disorders. Undetected and untreated abnormalities can result in severe problems, mental retardation or even death. Although funding newborn screening programs requires expenditures by the states, proactively treating congenital abnormalities may save states money by avoiding more financially burdensome medical costs and state institutional services. Comprehensive state newborn screening programs involve testing, follow-up, diagnosis, treatment and evaluation.

Even though newborn screening became available to infants through state programs in the 1960s and all states screen for some conditions, the extent of screening varies throughout the states. Some 700 genetic tests are available; however, not all the tests are recommended. For example, some conditions are so rare, testing is not cost-effective; in other cases no treatment exists for the conditions. State experiences vary regarding laws or regulations, specific tests, oversight responsibilities, state advisory boards, processes for informing parents, exemptions, storage policies and use of blood samples and payment for newborn screen procedures.

A Newborn Screening Task Force, co-sponsored by the American Academy of Pediatrics and the Maternal and Child Health Bureau, made a series of recommendations with regard to state newborn screening programs. Their report calls for states to: use a comprehensive systems approach; follow accepted national guidelines; coordinate infant programs and data; pilot new tests and technologies before adopting major policy changes and new mandates; monitor and evaluate program performance; involve and inform families; establish a state advisory group that has a diverse representation; set state-level policies for the use and storage of residual newborn screening blood samples; and assure adequate financing for a whole system using state newborn screening fees and other funds.

State laws on genetic screening relate to diseases and disorders such as adrenal hyperplasia, biotinidase deficiency, branched-chain ketonuria, cystic fibrosis, galactosemia, homocystinuria, hypothyroidism, maple syrup urine disease, phenylketonuria (PKU) and sickle cell anemia. Many state laws include exemptions for parents who object to genetic testing for religious or other reasons. During the 2002 legislative session, at least three states—Mississippi, Nebraska and Virginia—enacted laws related to newborn genetic screening. Other states have created laws related to newborn screening privacy issues.

California

Cal. Health & Safety Code § 1374.56 and Insurance Code § 10123.89 (1999) requires health plans to offer coverage for the testing and treatment of PKU. [Cal. Stats., Chap. 541 (SB 148)]

Cal. Health & Safety Code § 125000 and 125001 (1998) requires the Department of Health Services to establish a program to detect PKU and other preventable heritable or congenital disorders. The law requires the department to establish a genetic disease unit to promote a statewide program of information, testing, and counseling services. The law directs the department to charge a fee for tests. The law does not apply if a parent or guardian of the newborn objects to a test on religious grounds. [Cal. Stats., Chap. 1011 (S 537)]

Newborn Genetic Screening Privacy Laws

Health Programs

Updated July 2002

Currently, **28 states** require consent to either perform or require genetic testing or to obtain, retain or disclose genetic information through genetic-specific privacy laws. In addition, Washington includes genetic information in the definition of protected health information under the state's health privacy statute. Many of the states with genetic privacy laws exempt newborn screening from consent provisions, including Delaware, Illinois, Louisiana, Massachusetts, Michigan, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon and Vermont. The chart below does not address consent requirements or exemptions for newborn screening that may be found in state administrative codes.

At least **23 states** have laws that allow for an exemption to the newborn genetic screening requirements if parents object on religious grounds (Alabama, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Illinois, Indiana, Kentucky, Louisiana, Massachusetts, New Jersey, New York, North Dakota, Ohio, Rhode Island, South Carolina, Texas, Utah, Virginia, Washington and Wisconsin). Two states--Florida and Wyoming--allow for an exemption to the newborn genetic screening requirements if parents object on any grounds.

At least **12 states** have confidentiality requirements related to newborn screening laws (Arizona, Colorado, Florida, Hawaii, Iowa, Louisiana, New Jersey, North Dakota, Ohio, South Carolina, Virginia and Wisconsin).

At least **six states** and the District of Columbia have laws related to obtaining consent from the parents of children before performing genetic tests (Hawaii, Ohio, Nebraska, Texas, Wisconsin and Wyoming). Kansas requires informed consent in order to monitor infants with genetic disorders.

Many states have laws regulating newborn hearing screening, but these laws do not necessarily apply to newborn genetic screening.

State	Newborn Genetic Screening Privacy Laws	Law Allows for a Religious Exemption	Genetic Privacy Law Allows for an Exemption for Newborn Screening
California	<p>Cal. Health & Safety Code § 124975 clarifies that participation of people in hereditary disorders programs should be wholly voluntary, except for initial screening for phenylketonuria (PKU) and other genetic disorders treatable through the California newborn screening program. All information obtained from people involved in hereditary disorders programs in the state should be held strictly <u>confidential</u>.</p> <p>Cal. Health & Safety Code § 124980 prohibits tests from being performed on any minor over the objection of the minor's parents or guardian. Tests may not be performed unless the parent or guardian is fully <u>informed</u> of the purposes of testing for hereditary disorders and is given reasonable opportunity to object to the testing. No testing, except initial screening for phenylketonuria (PKU) and other diseases that may be added to the newborn screening program, shall require mandatory participation. The law requires all testing results and personal information generated from hereditary disorders programs to be made available to individuals over 18 years of age, or to the individual's parent or guardian. All testing results and personal information from hereditary disorders programs shall be held <u>confidential</u> and be considered a <u>confidential</u> medical record except for information that the individual, parent, or guardian <u>consents</u> to be released.</p>	Cal. Health & Safety Code § 125000	

The California Newborn Screening Program

The NBS Program has several mechanisms in place to ensure testing of all babies born in California. State NBS Regulations specify reporting requirements for both licensed perinatal health facilities and county registrars to ensure testing. **All newborns must be tested; the only legal ground for refusal is a conflict with religious beliefs and practices.** The following procedures and forms are utilized to ensure testing.

The NAPS laboratories enter demographic data and test results on terminals linked to a Genetic Disease Branch central computer in Berkeley. A computer-generated printed report of all test results, referred to as a "result mailer," is mailed to the hospital where the specimen was collected. Another copy is mailed to the physician of record as reported on the specimen collection form.

Perinatal facilities must review each newborn's medical record within 14 days from the date of discharge to determine that the NBS results are filed in it, or that a parent's or legal guardian's signed refusal is present. If it has been determined that a newborn was not tested, the facility must notify the infant's physician and the NBS Program. If a specimen was collected (as indicated by the presence of the goldenrod copy of the specimen collection form) but there is no NBS Results Mailer in the chart, the facility must complete a Missing Result Form (see below) and submit it to the State within five days. Most often the State has a record of the baby having been tested and a duplicate result mailer is forwarded to the hospital. Occasionally, a baby is not tested or the specimen is lost between the hospital and lab, and these are followed up. It is the responsibility of the pediatrician who provides comprehensive care for the child to ensure that a newborn screening test has been done and that the results have been reviewed and noted in the patient's chart. Pediatric care providers who do not have a copy of the NBS Result Mailer can request a duplicate from the State or regional ASC.

It is essential that the NBS-NO and NBS-OH forms be mailed promptly to the State NBS Program. The state follows up on each of these forms to make sure the baby has been tested. Unless there is a record of parent refusal on file, the State refers all untested babies under one year of age to the Newborn Screening Follow-Up Coordinators for assistance in obtaining the test. If you delay in sending us the forms, we are delayed in getting the babies tested, which in turn could delay treatment if a baby has one of the disorders for which the newborn screening panel tests.

Information for County Birth Registrars

County birth registrars are required to notify persons registering the birth of a baby born outside of licensed perinatal health facilities of newborn screening. The birth registrar must provide the person registering the birth with the pamphlet "Important Information for Parents About the Newborn Screening Test" and information about how to have the baby tested. The registrars are also required to notify the NBS Program of these births and must complete and send the NBS-OH form ("Notification of Registration of Birth Which Occurred Out of a Licensed Health Facility") to GDB.

Notification of Registration of Birth Which Occurred Outside of a Licensed Health Facility (NBS-OH)

Used by county birth registrars to report babies born outside of a licensed health facility

Important Information for Parents About the Newborn Screening Test (IIP):

Birth registrars are required to give this pamphlet to the person registering the birth of a baby born outside of a licensed health facility and not admitted to a hospital within 30 days of the birth.

To order these forms, please call (510) 540-3302.