Approved: February 2, 1999
Date

MINUTES OF THE SENATE COMMERCE COMMITTEE.

The meeting was called to order by Chairperson Alicia Salisbury at 8:00 a.m. on January 29,, 1999 in Room 123-S of the Capitol.

All members were present except: Senator Steineger

Committee staff present: Jerry Donaldson, Legislative Research Department
Lynne Holt, Legislative Research Department
Betty Bomar, Committee Secretary

Conferees appearing before the committee:
Raney Gilliland, Legislative Research Department
Representative Phill Kline
Representative Jim Gardner
William V. Minner, Executive Director, Kansas Human Rights Commission
James D. Hall, Senior Counsel, American Council of Life Insurance

Others attending: See attached list

Upon motion by Senator Steffes, seconded by Senator Donovan, the Minutes of the January 27, and January 28, 1999 Meetings were unanimously approved.

Sherry Brown, Department of Commerce and Housing, requested the Committee introduce a bill relating to the SIC code qualifications for the High Performance Incentive Program.

Senator Steffes moved, seconded by Senator Ranson, that a Committee bill be introduced to include distribution center in the qualifications for High Performance Incentive Program. The voice vote was unanimous in favor of the motion.

Philip Harness, Director, Workers Compensation Division, requested the Committee introduce a bill amending sections of the Workers Compensation Act.

Senator Donovan moved, seconded by Senator Barone, that a Committee bill be introduced amending the Workers Compensation Act. The voice vote was unanimous in favor of the motion.

SB 22 - Unlawful employment practices, genetic testing

Representative Phill Kline, appeared before the Committee in support of **SB 22**, stating the bill is a recommendation of the Special Committee on Information Management. Representative Kline stated when our founding fathers declared that all men are created equal, the fullness nor power of the idea they articulated was not fully understood. Two centuries later the call for equality is yet to be a reality, yet this bill is another step toward that goal. The genetic proclivity toward disease is not the manifestation of a disease, and the potential of infirmity is not the inability to perform a job. The physical forces discovered in a gene are neither definable nor controllable by their bearer. (Attachment 1)

Raney Gilliland, stated the amendments to the unlawful employment practices law are on Page 3 in the definition of "genetic screening or testing"; and on Page 5, enlarging the unlawful employment practice to include the use of genetic screening or testing information of an employee or a prospective employee to discriminate against or restrict the rights of an employee in his/her employment. Mr. Gilliland submitted a copy of the Special Committee on Information Management Conclusions and Recommendations, (Attachment 2) and a Issue Brief on Genetic Testing. (Attachment 3)

CONTINUATION SHEET

Representative Jim Garner testified in support of **SB 22**, stating it makes it an unlawful employment practice for an employer to subject an employee or prospective employee to genetic testing or to use preexisting genetic screening to discriminate against or make distinctions between an employee or prospective employee. A 1997 study by the American Management Association found that over 5% of its members currently conducted genetic tests on employees or prospective employees. This number will only increase in the coming years as the federally-funded Human Genome Project continues. Allowing employers to genetically screen employees can result in workers being fired or not employed due to a genetic risk which may never manifest itself; there is also a question of privacy. Representative Garner stated the use of genetic screening information should be unlawful, as is provided in **SB 22**. (Attachment 4)

Senator Barone asked whether the language in **SB 22** would prohibit a person from gaining employment where such testing was the basis for employment. Representatives Kline and Garner replied they did not believe science projects or research projects would meet the employment definition.

William V. Minner, Executive Director, Kansas Human Rights Commission, submitted written testimony stating the Commission's position. (Attachment 5) Mr. Minner stated the Commission would enforce the provisions of **SB 22**. There is a fiscal note of $750.

Jim Hall, Senior Counsel, American Council of Life Insurance, testified on **SB 22**. Mr. Hall submitted an amendment to **SB 22** on Page 5, line 21 by inserting the following: **(C) The provisions of subsections (A) and (B) shall not prohibit or limit the ue of genetic screening or testing allowed pursuant to the provisions of K.S.A. 40-2259**. Mr. Hall stated this amendment would ensure that employers would be subject to prohibition in making employment related decisions, but insurers providing insurance to the employer's employees, would still be subject to the prohibited and permitted activities in KSA 40-2259 in conducting their insurance risk classification, underwriting and claims administration. (Attachment 6)

Mr. Hall, in response to questions from the Committee, stated the Legislature passed legislation making it unlawful for an insurance company, health maintenance organization, nonprofit medical and hospital to require or request genetic screening or testing, but excluded an insurer writing life insurance, disability income insurance or long-term care insurance.

The hearing on **SB 22** was concluded.

Senator Ranson moved, seconded by Senator Jordan, that SB 22 be passed. The recorded vote was Yes - 8; No - 1.

The Committee considered **SB 63 - Emergency phone tax imposed on wireless service**

Senator Brownlee moved, seconded by Senator Gooch, that the Committee request a Legislative Post Audit Report on emergency 911. The voice vote was in favor of the motion.

The meeting adjourned at 9:00 a.m.

The next meeting is scheduled for February 2, 1999.

SENATE COMMERCE COMMITTEE GUEST LIST

DATE: January 29, 1999

NAME	REPRESENTING
Bill Minner	KS. Human Rights Commission
Mike Hollar	" " "
Sherry Brown	Commerce & Housing
Trish Heim	SBG
Virginea Starr	Federico Consulting
KEITH K LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS
Susan Duran	Issues Management Group
Sharon Hoffman	KCDC
Bill Sneed	Da Vest
David Hanson	Ks Insur Assn

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Sharon Hoffman	KCDC
Bill Sneed	Ad-Vest
David Hanson	Ks Insur Assn

PHILL KLINE

REPRESENTATIVE, 18TH DISTRICT

LEGISLATIVE HOTLINE
1-800-432-3924

CHAIRMAN,
HOUSE APPROPRIATIONS COMMITTEE

STATE OF KANSAS
HOUSE OF REPRESENTATIVES

Friday, January 29, 1999

Dear Madame Chair and members of the committee:

Thank you for the opportunity to speak to you today regarding the reasons I believe Senate Bill 22 should become law. When our founding fathers first articulated the resounding truth that all men are created equal they set the world on its head. For in that day, the commonly held belief granted the authority of any declaration of rights to be made by government, not any self-evident truth.

Yet, many of the framers of the Declaration did not know the fullness nor power of the idea they articulated. Many were slaveholders and women were denied participation in their deliberations. Some would be surprised today of the breadth of humanity which falls within reach of their bold declaration. Others, I am certain, would rejoice at the present day. They knew that what they could not then do politically, the progressive march of truth would eventually gain, though at great cost with bloodshed, turmoil and conflict.

The authors of the Declaration of Independence were not making a statement of the physical conformity of human beings. Their intent was not to claim that all of us have the same capabilities, intellectual capacity or physical strength and stamina. Rather, the Declaration is a celebration of the immeasurable qualities and capacity of the human spirit. The founding fathers were declaring to the world that no power of government has the right or privilege to impede the divine grant of authority for any human spirit to find full expression, as long as that expression does not harm the rights of others.

Over two centuries later the fullness and richness of this call for equality is yet to reach its full bloom in this nation. There are still many who are wrongfully denied opportunity for circumstances beyond their capacity to control. Yet we strive forward, and this bill is a step forward.

STATE CAPITOL BLDG., SUITE 514-S
TOPEKA, KS 66612-1504
(785) 296-7693 FAX: (785) 291-3446

pkline@ink.org
http://www.woodsland.com/kline

Senate Commerce Committee
Date: 1-29-99
Attachment # 1-1 thru 1-2

The genetic proclivity towards disease is not the manifestation of disease. The potential of infirmity is not the inability to perform a job. The physical forces discovered in a gene are neither definable nor controllable by their bearer. Do we really desire to limit human potential to an actuarial table?

There are many that will say to deny this form of discrimination is to foist the cost of one person's frailty on another. They are correct in that our nation, beyond the bounds of human compassion, does not support the forced payment of one, for another's failing. To do so is unjust confiscation. The proclivity to a disease, however, is not a certainty.

The day is soon coming when I can pluck a hair from your head, plug the results into a table and inform you of the likelihood of illness in 30 years. Yet, this projection ignores the potential of cure, the advance of science, the impact of environment and the possibilities of the human spirit.

There are others who will say that it is unjust for those with full genetic health to pay for the defective health of another through higher premiums, or health care costs. I would ask: what damage to the concept of freedom for certain individuals to potentially be stamped as defective, with lesser opportunity and rights at the moment of birth?

Yet, our founding fathers had an even more radical notion than the belief that society is best served by the protection of freedom. Our founding fathers firmly believed that freedom, and inherent rights, and equality before the law, were concepts of truth, which held their own power. That the march of these truths would destroy any culture, which denied their existence. You see, our founding fathers mutually pledged to each other their very lives in order to allow the full expression of potential by their neighbor.

Did they recognize their pledge had a cost? Yes, they fought a war. But they believed in doing that which is right, regardless of the cost. They were radical in their protection of human freedom.

Do not let the march of science, which has unleashed human potential in so many ways, be an instrument to define that capacity by the vagaries and expressionless numbers contained in an actuarial table.

SPECIAL COMMITTEE ON INFORMATION MANAGEMENT

VARIOUS PRIVACY OF INFORMATION ISSUES AFFECTING CITIZENS*

CONCLUSIONS AND RECOMMENDATIONS

The Special Committee on Information Management recommends the following legislation:

- a concurrent resolution urging Congress to enact legislation which would prohibit the establishment of a system of national identification numbers and national identification cards for medical purposes and urging Congress to prohibit the use of Social Security numbers as a basis for establishing any such system;
- a concurrent resolution memorializing Congress to pass legislation which would eliminate the requirement that state issued drivers' licenses and nondriver identification cards contain the holder's Social Security number or that the state verify the number with the Social Security Administration;
- House and Senate resolutions, each requiring the Kansas Attorney General to file and prosecute an action challenging the legality of a provision of the 1996 federal Immigration Reform Act which requires that state issued drivers' licenses and nondriver identification cards contain the holder's Social Security number and that the state verify the number;
- a bill which would prohibit state agencies from accepting for any identification-related purpose any identification number which another state agency already accepts (this would apply to all branches of government);
- the reintroduction of 1998 H.B. 2648 which would close Kansas motor vehicle records, with the exceptions provided by federal law and with an additional new state exception that would allow disclosure of motor vehicle title information relating to a previous owner of a motor vehicle after transfer of title;
- a bill to update the present criminal statute on eavesdropping and rename it "invasion of privacy," and to repeal the crime of breach of privacy and incorporate it into the crime of invasion of privacy (the crime of "invasion of privacy" would be made a level 8, person felony);
- a bill which would prohibit a person from selling, distributing, disclosing, or using any information contained in or obtained from any record pertaining to the health care of an individual without first having obtained the consent of the individual, with certain exceptions; and
- a bill which would amend the employment discrimination law to make it unlawful for any employer to seek, to obtain, or to use genetic screening or testing information of an employee or a prospective employee to distinguish between or discriminate against or restrict any right or benefit otherwise due or available, or subject any employee or prospective employee to any genetic screening or test.

The Committee makes no recommendation with respect to the Health Information Privacy Model Act of the National Association of Insurance Commissioners (NAIC), but the members of the Committee believe that the proposed measure is worthy of further consideration by the 1999 Legislature.

The Committee recommends that each computer system in the state system be audited for security once Y2K implementation has been completed. The Chairperson, Vice Chairperson, and the Ranking Minority Member intend to work with the Legislative Post Auditor on a scope statement.

Of concern to the Committee is the potential monitoring of electronic communications and Internet usage of members of the Legislature, their staff, and employees by system administrators not in the Legislative Branch. The Chairperson, Vice Chairperson, and Ranking Minority member intend to express this concern to the LCC.

The members of the Committee also discussed the issue of governmental monitoring or surveillance. The members of the Committee believe that monitoring or surveillance should occur only after public notice and public hearing. The Committee believes that the public notice should indicate where the monitoring or surveillance is going to take place, when it is to occur, and the reason it is necessary. The members of the Committee wish to express their concern with this issue and believe that additional study of the issue is needed.

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* S.B. 20, S.B. 21, S.B. 22, S.C.R. 1603, S.R. 1803, H.B. 2018, H.B. 2019, H.C.P. 5006, and H.B. 6004 introduced by this Committee.

BACKGROUND

The Special Committee on Information Management was directed to study various issues concerning privacy of citizens and governmental action in relationship to privacy considerations. One example of the types of personal information that may be considered in making employment decisions and determining health insurance coverage is genetic history. The Committee was also asked to review the use of monitoring or surveillance devices that chronicle activities of individuals without their knowledge (such as through video recording) in employment settings, as business patrons, or as private individuals otherwise engaged in routine daily activities. Finally, the Committee was to review the compilation of personal information databases, such as a national medical records database, that may violate traditional privacy expectations.

As a part of the background review on the various issues with respect to privacy, the members of the Special Committee on Information Management heard from a nationally known expert on the issue of privacy. In this regard, the members of the Committee heard a presentation from Robert Ellis Smith, the Editor and Publisher of the *Privacy Journal.*

Mr. Smith's presentation included information on a wide variety of topics with respect to the issue of privacy. According to Mr. Smith, the issue of privacy is not new, but has recently come to the forefront of consideration because of new capabilities that allow manipulation of increasing amounts of private information about individuals. According to a recent publication of Mr. Smith's, concern with the issue of privacy began late in the 1800s. Mr. Smith states that in 1890, Mrs. Samuel D. Warren of Boston was outraged at the press coverage of her parties. According to the publication, this situation prompted her husband to team with a fellow law professor, Louis D. Brandeis, to devise "the right of the individual to be let alone." He noted that the Warren-Brandeis Harvard Law Review article on the right to privacy became the fountainhead for later law and social policy in the United States, a relatively new and spacious nation where privacy had not previously been a prime concern.

Mr. Smith states in the publication that later, after becoming a U.S. Supreme Court justice, Mr. Brandeis called the right to be let alone "the most comprehensive of rights and the right most valued by civilized men," *Olmstead v. U.S.,* 277 U.S. 438 (1928), in a dissent to the Court's holding that wiretaps were not prohibited by the Fourth Amendment, which was overturned in a later decision.

Mr. Smith stated that courts came to recognize the right of the individual to recover damages when privacy was invaded because of:

- intrusion upon solitude,
- public disclosure of private facts,
- casting one in a false light, or
- using another person's name or image for one's profit.

Mr. Smith's publication cites several cases which recognized an individual's right to privacy.

Mr. Smith stated in the publication that concern about personal privacy perhaps stems from the Roosevelt Administration's New Deal programs, which required large-scale government collection of personal data to determine eligibility (for such things as Social Security and veterans benefits). He noted that various levels of government began to collect even more personal information in the 1960s to evaluate effectiveness of programs.

According to Mr. Smith, private business increased its data collection in the mid-20th Century as well, in a population relying on credit purchases (an estimated 55 percent of retail sales are made on credit), insurance (78 percent of all Americans now carry health insurance), and mobility (35 percent of all Americans no longer live in the community where they were born and thus are not known to merchants).

Computers, according to Mr. Smith, have made it easier to gather, store, and organize personal information. He noted in the publica-

tion that the information once kept in a manila folder now can be transferred great distances, analyzed cheaply, stored in a fraction of the space, and retrieved instantaneously. Mr. Smith concluded that a computer record also can appear accurate or current when it really is not and can be used for decisions about a person without any human intervention.

Mr. Smith wrote in his publication that the number of computer data banks has increased dramatically and include: the Social Security Administration, Federal Bureau of Investigation, Internal Revenue Service, state motor vehicle departments, National Driver Registry, "drug abuse data acquisition projects," Retail Credit Company (now Equifax), the Medical Information Bureau, TRW Credit Data (now Experian), the Educational Testing Service, state criminal justice information systems, municipal data systems, Veterans Administration, military, state welfare departments, corporate personnel offices, programs for the handicapped, regional mental health programs, professional standards review organizations for health care evaluation, the National Parent Locator, child abuse prevention projects, national church organizations, credit card companies, telephone companies, the Passport Office, the Immigration and Naturalization Service, state university systems, Medicaid, and many more.

In his publication, Mr. Smith noted that citizens demand protection. He wrote that they call it privacy, but what they really want is minimal data collection, accuracy, the right to see and correct their own records, notice before their data is shared with others, and the right to know which data banks exist.

COMMITTEE ACTIVITIES

The Special Committee on Information Management held meetings on September 25, October 21-22, November 5, November 23-24, and December 15-16. Many conferees were heard and various topics involving privacy were discussed.

The Committee began its review of the various privacy issues by hearing from Mr. Smith. His presentation focused on federal enactments in the following areas: bank records, cable TV, computer crime, credit reporting, criminal justice information systems, electronic surveillance, employment records, employment testing, government information, insurance, library records, mailing lists, medical records, school records, Social Security numbers, telephone sales, encryption, Internet, press, and theft-of-identity. In some instances, the federal government has acted to provide protections, but in some other cases no laws have been enacted. In the opinion of some, the actions of the federal government do not protect the privacy of individuals in some instances, Mr. Smith noted. The conferee also discussed Kansas law with respect to its provisions or lack thereof regarding bank records; cable TV; computer crime; credit reporting; criminal justice information systems; electronic surveillance; employment records; employment testing; government information; insurance; library records; mailing lists; medical records; school records; Social Security numbers; and telephone sales.

In addition to the testimony provided by Mr. Smith of the *Privacy Journal*, the members of the Committee heard an update on recently enacted state privacy measures by staff of the National Conference of State Legislatures (NCSL). The presentation by the NCSL staff contained a brief review of selected bills from the hundreds which were introduced and the significant number which were enacted. Also, the Committee heard from NCSL staff on the issues of genetic privacy, cloning, and medical records. This staff person noted that state legislatures considered hundreds of bills relating to genetic testing in 1997 and logged hundreds of requests for information from NCSL in 1997 through January of 1998. Members of the Committee learned that because of the intensity of the concern among other state legislators NCSL created a special task force to consider the issues surrounding genetic technologies. The presentation by NCSL staff indicated that at least 27 states had enacted some sort of legislation to deal with the privacy and use of genetic information. Committee members

learned that legislatures across the country addressed the initial emergence of genetic issues in the form of antidiscrimination laws to prevent the use of genetic testing in job applications and in securing health insurance. The Committee was told that it was difficult to adopt public policies in this area because technology is advancing at such great speed.

One area of concern to some members of the Committee was the privacy policy of various state agencies with respect to the information collected and maintained by them. The members of the Committee determined that there were five principal state agencies which collect considerable amounts of personal information on the citizens of the state. Officials with the Department of Health and Environment, the Kansas Board of Healing Arts, the Department of Revenue, the Department of Social and Rehabilitation Services, and the Department of Human Resources were asked to appear before the Committee and answer specific questions with respect to the privacy of personal information which they collect. Also asked to testify was a spokesperson representing the State Archivist.

The District Attorney of Johnson County testified with respect to his experiences with state laws on eavesdropping and illegal surveillance. He cited examples of cases that could be prosecuted under current Kansas law and other cases where new laws are needed. As a follow up to the presentation, the members of the Committee met at the Kansas Bureau of Investigation (KBI) headquarters to hear comments from various KBI agents with respect to electronic surveillance, wiretapping, and computer crime. A spokesperson for the KBI provided recommendations for updates in Kansas privacy law particularly to reflect changes in technology.

Another area of concern with respect to privacy which the members of the Committee addressed was that of medical records and the use of the results of genetic testing for employment purposes or for insurance. A number of conferees came before the Committee to discuss the impact of information technology on the use of medical information, the policy implications for genetic testing, the legal implications relating to the privacy and confidentiality of medical records, the perspective of the life insurance industry with respect to the use of medical records, and the ethical issues relating to privacy of confidential medical information. At one particular hearing, the Insurance Commissioner discussed and distributed to the members of the Committee a copy of the Model National Association of Insurance Commissioners' Act on Health Information Privacy. The Special Committee held hearings on the Model Act at a later date where several conferees made comments on the proposed model legislation.

The members of the Committee also heard from a spokesperson from the Department of Revenue, Division of Vehicles, with respect to certain requirements under the federal Immigration Reform Act of 1996. The members heard that a provision in the Act requires that drivers' licenses or identification cards contain an individual's Social Security number which can be read visually, or by electronic means. The conferee said that the states must implement this by October 1, 2000. The members of the Committee were told that the federal enactment requires that all states verify each applicant's Social Security number with the Social Security Administration prior to issuance of the driver's license. The members heard from the conferee that there is concern about being able to verify, on a timely basis, an applicant's Social Security number while the applicant is at the driver's license station. The conferee noted that this legislation had created concerns in all states and that some of those concerns include: the requirement is an unfunded mandate and that it will cost millions of dollars nationally to implement; that it violates the 10th Amendment of the *U.S. Constitution*; that it is a violation of the federal privacy acts; that it might be considered to be a national identification card; and that biological information might be added to this information at a later date.

Another issue of concern to several members of the Committee is the issue of the security of phone calls, e-mail, and Internet usage by members of the Legislature and their staff. Concern

was expressed about the monitoring or potential monitoring of phone calls and access to e-mails by the legislative computer system administrator, but also by persons in the Department of Administration. To gather information on this issue, the Committee heard testimony from the Director of the Division of Information Systems and Communications. Testimony indicated that the recent computer installation of specialized computer hardware has built a system which blocks access by outside individuals and therefore protects the communications and files contained in the computers operated by members of the Legislature and their staff. This system is intended to protect internal communications and documents including information relating the web pages being accessed by members of the Legislature and their staff. Several members of the Committee noted that it may be possible to circumvent this protection regardless of the measures taken to protect its privacy.

CONCLUSIONS AND RECOMMENDATIONS

The members of the Special Committee on Information Management make several recommendations for consideration by the 1999 Legislature.

Throughout the interim Committee members expressed concern with the use of Social Security numbers as personal identifiers. The members of the Committee learned that two provisions of the Social Security Act allow federal agencies to construe federal law as authorizing the establishment of a system of national identification numbers and national identification cards for medical purposes. In this regard, the Committee recommends a concurrent resolution strongly urging the U.S. Congress to enact specific legislation which would prohibit the establishment of a system of national identification numbers and national identification cards for medical purposes. The resolution also urges Congress to prohibit the use of the Social Security number as a basis for establishing the system.

Another issue which the members of the Committee discussed was a provision in the federal Immigration Reform Act of 1996. This provision requires that state issued drivers' licenses and nondriver identification cards contain the holder's Social Security number or that the state verify with the Social Security Administration the Social Security number of each applicant for a driver's license or identification card. The members of the Committee were informed federal dollars were not appropriated to implement this costly requirement. Committee members expressed concern that this requirement would establish a system of national identification numbers and national identification cards. The Committee recommends a concurrent resolution memorializing Congress to pass the Freedom and Privacy Restoration Act of 1998, which would eliminate this requirement.

With respect to the concern expressed in the preceding paragraph regarding the requirements in the federal Immigration Reform Act of 1996, the Committee recommends House and Senate resolutions, each requiring the Kansas Attorney General to file and prosecute an action challenging the legality of the provisions of the federal Act which requires that state issued drivers' licenses and nondriver identification cards contain the holder's Social Security number or that the state verify the number of the applicant with the Social Security Administration.

Committee members discussed the issue of unique identifying numbers being used by various agencies of state government to identify individuals, corporations, partnerships, limited partnerships, associations, or other entities. The members of the Committee believe that the same unique identifying number should not be used by different agencies of state government for identification purposes. Therefore, the Committee recommends legislation which would prohibit state agencies from accepting for any identification-related purpose any identification number which another state agency already accepts for an identification-related purpose. The proposed legislation would apply to the legislative, executive, and judicial branches of the state.

Current Kansas law makes most motor vehicle records "open" to the public but federal law requires that individuals be able to close their vehicle records, subject to limited exceptions. The Committee discussed 1998 H.B. 2648, which would have closed all Division of Vehicles' records, subject to the exceptions allowed by federal law. The Director of Vehicles of the Department of Revenue had opposed 1998 H.B. 2648 because it would have closed records about previous ownership of a vehicle, even after title to the vehicle had transferred, unless a waiver were obtained from the previous owner. There was concern that this would hamper a consumer's ability to obtain information regarding the condition of a used motor vehicle. The Committee recommends the reintroduction of 1998 H.B. 2648 with an additional exception to address this concern. The proposed legislation would close Kansas motor vehicle records, with the exceptions provided by federal law and an additional state exception that would allow disclosure of motor vehicle title information relating to a previous owner of a motor vehicle after the owner has transferred title to the motor vehicle.

Other issues which the members of the Committee discussed were eavesdropping and other breaches of privacy. The Committee heard comments from an assistant Attorney General with the KBI who made suggested changes in the current law to deter technological trespass. The Committee recommends legislation to amend the current criminal statute on eavesdropping and to rename the crime "invasion of privacy." Other provisions of current law would be modified to reflect current technological capabilities. The legislation also would repeal the crime of breach of privacy and incorporate it into the crime of invasion of privacy. The crime of "invasion of privacy" would be made a level 8, person felony. The violation would not apply to communications overheard through a regularly installed instrument on a telephone party line or on an extension.

With respect to the issue of the privacy of medical records, the members of the Special Committee on Information Management wish to note that they spent a considerable amount of time reviewing and having hearings on the Health Information Privacy Model Act of the NAIC. The Committee makes no recommendation with respect to this legislation, but the members of the Committee believe that the proposed measure is worthy of further consideration by the 1999 Legislature.

Although the Committee does not make any recommendation with respect to the NAIC legislation, the Committee does recommend legislation which would prohibit a person from selling, distributing, disclosing, or using any health care information contained in or obtained from any record pertaining to the health care of an individual without first having obtained the consent of the individual to whom the health care information pertains. The bill would define "health care information" to include any recorded information, regardless of form or characteristics, which pertains to the health or medical treatment of an individual. The bill outlines certain exceptions to the requirement of consent such as when the information is used for the purpose of providing medical treatment or health care to the individual to whom the health care information pertains; if it is used or required for the purposes of paying or processing insurance claims for the individual to whom the health care information pertains; or if it is used under circumstances whereby the individual to whom the health care information pertains can not be reasonably identified. Provisions of the bill would allow a parent or legal guardian to consent to the release of health care information under certain circumstances. A person who violates these provisions would be guilty of a class A misdemeanor.

Another issue on which the members of the Committee spent a considerable amount of time hearing testimony and discussing was the issue of the use of genetic information about individuals. The Committee members are concerned that the use of this information may discriminate against individuals in a variety of ways such as employment or health and life insurance. Therefore, the members of the Committee are recommending legislation which would amend the employment

discrimination law to make it unlawful for any employer to seek, obtain, or use genetic screening or testing information of an employee or a prospective employee to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to an employee or a prospective employee; or subject directly or indirectly, any employee or prospective employee to any genetic screening or testing. The recommended legislation would define "genetic screening or testing" to mean 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 a direct manifestation of genetic disorders.

One item of consideration by the members of the Committee was the issue of the security of the computer systems operated by the many agencies of the state. The members of the Committee were provided information regarding the concern at the federal level with the computer systems of certain agencies of the federal government. A part of this information was a copy of a General Accounting Office Report entitled, "Information Security." The report indicated areas of security weaknesses and states that there are potential security breaches in critical federal agencies. The members of the Committee recommend that each computer system in the state system be audited for security once Y2K implementation has been completed. The Chairperson, Vice Chairperson, and the Ranking Minority Member intend to work with the Director of the Division of Post Audit on a scope statement. It is the desire of the members of the Committee that this audit not begin for some time because state agencies are consumed with the effort to become Y2K compliant.

Of great concern to the members of the Committee is the potential monitoring of telephone conversations, e-mail communications, and Internet usage of the members of the Legislature, their staff, and employees of the legislative agencies by system administrators or state employees not in the Legislative Branch. The Chairperson, Vice Chairperson, and Ranking Minority Member of the Committee intend to express this concern to the members of the Legislative Coordinating Council in a written communication. Some members of the Committee had no knowledge that these forms of communications may be monitored or accessed by others without one's knowledge.

The members of the Committee also discussed the issue of the monitoring or surveillance (either video or audio) that may occur by governmental units. The members of the Committee believe that this monitoring or surveillance should occur only after public notice and public hearing. The Committee believes that the public notice should indicate where the monitoring or surveillance is going to take place, when it is to occur, and the reason the monitoring or surveillance is necessary. The members of the Committee wish to express their concern with this issue and believe that additional study of the issue is needed.

ISSUE BRIEF

HEALTH POLICY TRACKING SERVICE

Subject: Finance Title: Genetic Testing	Date: 12/31/98

By: Andrew Zebrak

States have enacted genetic testing laws to address the contentious privacy, consent, research, discrimination, insurance and employment issues surrounding genetic information. These genetic testing laws attempt to strike a balance between the concerns of the consumer, research, insurance and business communities.

OVERVIEW

The evolution of science has advanced the capabilities and uses of genetic testing. The potential applications of the information made available through genetic testing causes a passionate conflict. Genetic information may reveal an individual's susceptibility to specific diseases because individuals possess genes that predispose them to certain diseases. This information may allow: people to take preventive measures to reduce their risk of certain illnesses, the detection of diseases at an earlier stage than previously possible, more time to take medical action and further research in genetics may even lead to cures. However, individuals often fear genetic testing and information because of the potential for discrimination in employment and health insurance coverage. Therefore individuals demand control of their genetic information and may not wish to share information about their genetic status. Insurers argue that private medical data, including genetic information, is vital to health insurance carriers because it enables them to identify individuals who are likely to develop serious illnesses or disease.

Many states have enacted laws to protect citizens from discrimination based on genetic testing and information by prohibiting insurers and/or employers from mandating testing, inquiring about test results and using genetic information to determine rates. Furthermore, some of these laws require informed consent for use of an individual's genetic information. In 1998, six states amended their existing genetic testing laws and seven more states enacted their first laws to address genetic testing and information. Currently, 34 states have passed laws governing genetic testing and information

DEFINITION

A basic definition of **genetic information** is information about genes, gene products or inherited characteristics that may derive from an individual or a family member. **Genetic testing** refers to a microbiological or molecular testing mechanism, the purpose of which is to determine the genetic makeup of an individual.

TYPES OF TESTS

Three testing methods are used to obtain an individual's genetic information. Carrier testing is performed on individuals who may be at risk for producing a child with a genetically transmitted disease. Carrier tests are available for diseases such as Tay-Sachs and sickle cell anemia.

Another form of genetic tests is prenatal and postnatal testing. These procedures involve the testing of the embryo or fetus through amniocentesis, chorion villi sampling or in vitro fertilization.

For more than 30 years newborns have received genetic tests. All states test for phenylketonuria (a metabolism disorder commonly known as PKU) and most states test for hypothyroidism, galactosemia and cystic fibrosis. Thirty states test for sickle cell anemia and a few states test for congenital adrenal hyperplasis, an adrenal disorder affecting sexual development. Tests for hemoglobin deficiencies also are conducted. Infant genetic testing often is performed within the first 24 hours after birth. A second screening is recommended within the first seven days of life to ensure conclusive results.

The third type of genetic test is adult presymptomatic testing. This test causes fi

develop serious illnesses or disease. However, no HIAA members require applicants to submit to a genetic test in order to receive major medical coverage.

GENETIC TESTING LAWS

Currently, 34 states--**Alabama, Arizona, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Louisiana, Maine, Maryland, Minnesota, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Texas, Vermont, Virginia** and **Wisconsin**--have passed laws governing genetic testing and information. The laws in 33 of these 34 states--all of the states listed above except for **Idaho**--generally prohibit insurers from discriminating on the bases of genetic testing and information. Furthermore, nine of these 33 states--**California**, **Connecticut**, **Delaware, Maine**, **Missouri**, **New Jersey**, **New York**, **Oklahoma** and **Vermont**--prohibit discrimination by employers on the basis of genetic testing and information.

1998 LEGISLATION

Genetic testing remains a contentious issue in the states this year. The 1998 state legislative sessions resulted in ten states enacted genetic testing and information laws. A total of twenty-five states moved 39 genetic testing bills in 1998. This year six states--**California, Connecticut, Idaho, New Mexico, Ohio** and **Wisconsin**--supplemented their existing genetic testing laws with additional genetic testing measures. Current law in **California** prohibits discrimination in employment- related matters on the basis of certain factors, including an employee's medical condition. A new law adds "genetic characteristics" to the definition of medical condition. A second law enacted in **California** broadens the prohibition against insurers from requiring a test for the presence of a genetic characteristic for the purpose of determining insurability. Lawmakers in **Connecticut** established a measure that prohibits employers from discriminating against employees or individuals seeking employment on the basis of genetic information. The measure passed in **Idaho** changes terminology in existing laws concerning a state DNA database. The **New Mexico** law prohibits genetic discrimination and requires written consent from a person for use of their genetic information, except under certain conditions. The law in **Ohio** relates to DNA use in identifying missing persons and unidentified dead persons. The superintendent of the Bureau of Criminal Identification may compare DNA records from two state databases to match identities of unidentified persons. Lawmakers in **Wisconsin** enacted a measure that expands the prohibition against insurers from making inquiries about genetic tests. Insurers may not require or request a health care provider to reveal whether an individual or a member of the individual's family has obtained a genetic test or indicate the results of the test.

Seven states that previously had no genetic testing laws--**Delaware, Maine, Missouri, Oklahoma, Rhode Island, South Carolina** and **Vermont**--addressed this issue by enacting new laws in 1998. On July 17 lawmakers in **Delaware** enacted a policy that disallows discrimination in insurance and employment based on genetic information. No person shall discriminate against any individual in the issuance, denial, or renewal of or in the fixing of the rates, terms or conditions for insurance. This provision does not apply to disability insurance or long term care insurance. Additionally, this law declares that it is an unlawful employment practice to intentionally collect, directly or indirectly, any genetic information concerning any employee or applicant for employment, or any member of their family. This policy allows exceptions if (1) it can be demonstrated that the information is job related and consistent with business necessity; or (2) the information is sought in connection with the retirement policy or system of any employer or the underwriting or administration of a bona fide employee welfare benefit plan.

In **Delaware** a second genetic testing measure, Senate Bill 153, was passed on July 17. This law prevents disclosure of an individual's genetic information without that individual's consent, except in certain circumstances. The bill declares that no person shall obtain or retain genetic information about an individual without first obtaining informed consent from the individual. These provisions do not apply to genetic information obtained for anonymous research where the identity of the subject will not be released and also to certain other conditions. This law states that a person does not have to disclose the identity of an individual upon whom a genetic test has been performed or to disclose genetic information about the individual in a manner that permits identification, except under certain circumstances.

Maine passed a broad genetic testing law that prohibits discrimination in employment and insurance on the basis of genetic information. Insurers may not conduct or permit any unfair discrimination against individuals based on genetic information or the refusal to submit to a genetic test. Policies for life, credit life, disability, long-term care, accidental injury, specified disease, hospital indemnity and credit accident insurance may not conduct or permit unfair discrimination against individuals in the application of genetic information or the results of a genetic test. For these life, disability and long-term care policies, "unfair discrimination" includes the application of results of a genetic

insured, or his or her family member, disclose genetic information. The Assembly passed this bill on June 18 and sent it to the Senate.

Assembly Bill 8412 would prevent an issuer of health insurance from requiring or utilizing genetic information about an individual as part of the process of underwriting. The bill also stipulates that a health condition or expected health condition that is initially identified from genetic tests or genetic information rather than direct diagnosis shall not be deemed a pre-existing condition. On June 11 the Assembly passed this bill and sent it to the Senate.

1997 LEGISLATION

Overview

In 1997, legislators in 45 states introduced 155 bills relating to genetic testing. These bills address a wide range of genetic testing topics, including compliance with genetic testing provisions of the Health Insurance Portability and Accountability Act (HIPAA). Although this analysis discusses HIPAA measures, the main focus of this issue brief are the more broad genetic testing bills related to insurance.

At the start of the 1997 legislative session, 20 states had laws or regulations concerning genetic testing. Eighteen of these states introduced legislation in 1997 to amend existing genetic testing laws. Disregarding the 32 enacted HIPAA compliance measures, at the close of 1997, six states that previously had no genetic testing laws enacted legislation, nine states revised or added to their current genetic testing laws, three states adopted commissions to examine genetic testing issues, one law created a Huntington's disease clinic, and one law recodified statutes, thereby affecting that state's genetic testing laws.

New Laws in 1997

Six states--**Connecticut, Hawaii, Illinois, Indiana, Nevada** and **Texas**--that did not previously have genetic testing laws enacted measures in 1997.

Connecticut's law provides restrictions to health coverage in that an insurer cannot refuse to insure, cancel, or limit the amount, extent, or kind of coverage available to an individual. The law also prohibits charging an individual a different rate for the same coverage because of genetic information about the individual. This measure includes provisions relating to preexisting conditions and unfair methods of practice.

Hawaii's law is slightly more comprehensive than Connecticut's because it also includes provisions related to disclosure and informed consent.

Illinois and **Indiana** enacted laws similar to each other, but different than other measures. Both new laws allow insurers to consider the results of genetic tests if the individual voluntarily submits the results and the results are favorable. The **Illinois** law contains a provision that allows one who is aggrieved by a violation to take action in court and recover certain financial awards for compensation.

The new laws in **Nevada** and **Texas** are the most comprehensive enacted this year. The laws include provisions that restrict insurers, mandate informed consent and disclosure, and establish liability for violations. These measures also allow civil actions for the recovery of damages associated with unlawful disclosure of genetic information. The **Texas** law provides an individual access to genetic test results. It also has a "cease and desist" provision that authorizes the commissioner to revoke or suspend the issuer's certificate of authority when violations occur.

Broadened Laws in 1997

Before 1997, **Alabama, Florida, Louisiana, North Carolina** and **Tennessee** had disease-specific laws that prohibit discrimination against those with certain traits, such as sickle cell. These five states changed their statutes, in varying degrees, to create more comprehensive genetic testing laws.

Revised Laws in 1997

Four states that already had comprehensive genetic testing legislation revised their laws in 1997.

Arizona's efforts to revise its genetic testing laws faced significant controversy and publicity. According to news articles, two large insurance companies threatened to discontinue coverage of long-term health care and disability insurance in the state if the governor approved the proposed genetic testing measure. However, the bill became law and these insurance companies continue to operate in Arizona.

Connecticut enacted a law that establishes and administers a program of services for those suffering from Huntington's disease. The state also enacted a law that adds using genetic information to determine coverage or insurability to the list of acts that are considered and defined as unfair methods of competition and unfair and deceptive acts of practice.

LEGISLATIVE HISTORY

State legislation on genetic testing has progressed slowly. In the 1970s and 1980s, the majority of legislation focused solely on specific (and sometimes rare) traits, such as sickle cell trait, Tay-Sachs trait, or hemoglobin C trait. The first genetic testing law was passed in **North Carolina.** This law prohibits health insurers from refusing to issue coverage or from charging higher rates based on sickle cell trait or hemoglobin C trait. **Florida** enacted a similar measure that prohibits discrimination only against those who possess the sickle cell trait.

In 1986, **Maryland** passed a law with the widest range of traits that could not be discriminated against: sickle cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, "or any trait which is harmless within itself." However, the bill allows insurers to continue to use genetic information to determine insurability, but only if "actuarial justification" exists.

A decisive event in the course of genetic testing legislation occurred in 1991 when **Wisconsin** passed a law that prohibited health insurers from using genetic information when establishing coverage. This measure was considered very broad and radical. The Wisconsin law changed the focus of genetic testing legislation because it prohibited the use of genetic tests in four ways, leaving little flexibility for insurers to find loopholes. First, the law prohibits health insurers from requiring or requesting an individual or a member of that individual's family to obtain a genetic test. Second, it prohibits an insurer from requiring or requesting, either directly or indirectly, the results of a genetic test. Third, it prohibits insurers from conditioning the provisions of insurance coverage or benefits on genetic testing information. Fourth, it places restrictions on consideration of genetic testing when determining health insurance rates. Many states–**California, Colorado, Georgia, Maine, Minnesota, New Hampshire, Ohio** and **Oregon**–have followed **Wisconsin's** example and enacted similar laws.

By the end of 1996, 20 states had established laws or regulations regarding genetic testing and information.

GENETIC TESTING LAWS AND BILLS

*Bills included in this chart were introduced or acted upon in the 1998 legislative session.

STATE	LAWS	SUMMARY	BILLS (1998)	STATUS
AL	AL S 113, 1997 legislative session	Cannot require as a condition of insurability that a person take a genetic test that may show the predisposition of a person for cancer to determine insurability or to otherwise discriminate against the person in rates or benefits based on the genetic test result.	--	--
	27-5-13	Prohibits insurers from denying coverage to an applicant because the applicant has been diagnosed with sickle-cell anemia.	--	--
AZ	Statutes: 20-448; 41-1463	Labels as an unfair practice the consideration of a genetic condition in determining rates, terms or conditions of a health or life insurance policy or to reject an application for coverage based	--	--

CO	Title 10; article 3, part II: 10-3-1104.7	Prohibits obtaining or using genetic information to deny health, group disability or long-term care insurance.	--	--
CT	Statutes: 38a-816	Cannot refuse to insure, refuse to continue to insure, or limit the amount, extent, or kind of coverage available to an individual or charge an individual a different rate for the same coverage because of genetic information. Violation is considered an unfair method of competition.	H 5471 S 85 S 80	Died Died Enacted
	Public Act No. 97- 264	Creates a Huntington's disease clinic.		
	Statutes: 46a-60	Employers, employment agencies, and labor organizations may not: (A) request or require genetic information from an employee, person seeking employment or member, or (B) discharge, expel or otherwise discriminate against any person on the basis of genetic information.	--	--
DE	DE Code Ch. 23, Title 18, Sec. 2317; Title 19, Sec. 710- 711.	No person shall discriminate against any individual in the issuance, denial, or renewal of or in the fixing of the rates, terms or conditions for insurance. This provision does not apply to disability insurance or long term care insurance. Declares that it is an unlawful employment practice to intentionally collect, directly or indirectly, any genetic information concerning any employee or applicant for employment, or any member of their family. Allows certain exceptions.	S 337 S 153	Enacted Enacted
	DE Code Ch. 12, Title 16, Sec. 1220- 1227.	Prevents disclosure of an individual's genetic information without that individual's consent, except in certain circumstances. Declares that no person shall obtain or retain genetic information about an individual without first obtaining informed consent from the individual. These provisions do not apply to genetic information obtained for anonymous research where the identity of the subject will not be released and also to certain other conditions. A person does not have to	--	--

		convicted felon DNA databank and databases. The statistical and research information obtained from the databank and database may be disseminated provided that the subject of the file is not identified from the information disclosed.		
	ID Code 19: 5505, 5507,5509, 5511,5514, 5517	Provides correct terminology and deletes incorrect terminology in the Idaho DNA Database Act of 1996.	--	--
IA	--	--	S 2258	Died
IL	410 ILCS 513/	Cannot seek information for use in connection with a policy. Can consider the results if the individual voluntarily submits the results and the results are favorable. Establishes disclosure and confidentiality provisions. Person aggrieved by a violation may seek financial compensation.	--	--
IN	IC 16-39-5-2; 27-4-1-4 27-8-5-26; 27-8-26; 27-13-7-14	Cannot require test; cannot use information in an adverse manner; cannot inquire into the results; can consider results if voluntarily submitted and are favorable.	--	--
KS	--	--	H 2734	Died
KY	--	--	S 334	Died
LA	R.S. 22: 2002(7); 22:213.6, 213.7; 22: 1214(22) (23); 40: 2207	Cannot request or require test; cannot terminate, restrict, limit, cancel, refuse to renew, deny coverage, establish differentials in premium rates, etc., based on the results of test or the refusal to submit to a genetic test. Provides provisions governing informed consent, research and property rights. Violation is unfair method of competition.	--	--
ME	5 MRSA c. 503; 24-A MRSA sec. 2159- C, and c.24 and sec. 4222- B.	Prohibits discrimination in employment and insurance on the basis of genetic information. Employers may not refuse to hire, discharge or otherwise discriminate against an employee or applicant for employment on the basis of genetic information concerning that individual or that individual's refusal to submit to a genetic test or make available the results of a genetic test.	S 384	Enacted

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		exception provided if history and claims experience (or actuarial projections) establish that substantial differences in claims are likely to result from the genetic condition.		
NV	NRS 689A	Cannot require test; cannot require disclosure; cannot determine rates or any other coverage or benefit or benefits for health care based on genetic information or whether test has been taken. Provides provisions governing informed consent, disclosure and research. A person who takes a genetic test may inspect or obtain any genetic information included in the records of test.	--	--
NH	RSA 141-H:1 through 141-H:6	Cannot condition provisions, determine rates or determine benefits based on the result of genetic tests; cannot require test or inquire regarding test.	--	--
NJ	Insurance Code: 17B:30-12	May not discriminate on the basis of genetic information or refuse to submit to a genetic test or make available the results of a genetic test in the issuance, withholding, extension or renewal of any hospital confinement or other supplemental limited benefit insurance; cannot change rates, terms or conditions.	A 329	Carried over to 1999
	Civil Rights Code: 10:5-11	Considers it unlawful practice to discriminate based on genetic characteristics regarding employment related situations.		
	Insurance Code: 17:48-6:18; 17:48A-6.11; 17:48E-15.2; 17B:26-3.2; 17B:27-36.2	Cannot exclude or change rates on the basis of any genetic characteristic related to hospital and medical service corporations, individual and group health.		
	Health and Vital Statistics: 26:2J-15.1	Any health care services cannot exclude any person or eligible dependent or change rates or terms on the basis of an actual or expected health condition or on the basis of any genetic characteristic.		
NM	Regulations: 13 NMAC	Under managed health care regulations 22.4, a plan, contract, policy or	H 331	Enacted

	3901.501	application and voluntarily submitted. Cannot cancel, refuse, renew or limit benefits. Cannot require test or inquire about results from genetic test. Statute expires 2004. The 1997 law extended current law to "health insuring corporations", which include all forms of managed care.		
	Statutes: 109.573, 313.08 (S 140)	Provides the Bureau of Criminal Identification and Investigation authority to establish a relatives of missing persons database to be used in comparison with the unidentified person database to aid in the establishment of the identity of unknown human corpses, remains and living individuals. Persons related to a missing person may submit a DNA specimen to the bureau. The superintendent of the bureau may compare DNA records from the databases to match identities of unidentified persons.		
OK	H 3169	Prohibits insurers from requiring or requesting any individual or family member to undergo a genetic test. Insurers may not condition the provision of a policy on a genetic test requirement. Employers may not seek to obtain or use a genetic test or genetic information from an employee or perspective employee. Employers may not require a genetic test or genetic information and provides penalties for violating these provisions.	H 3169	Enacted
OR	Statutes: 746.135	Cannot use a favorable genetic test as an inducement to purchase insurance. Cannot 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. Requires authorization for disclosure.	--	--
	659.700 through 659-720	Requires authorization for disclosure; genetic information is property of the individual; provides exception for criminal matters. 1997 law creates provisions governing anonymous research.		

	session	health insurance solely on the basis of genetic information or on the basis that the individual has requested or received genetic services. Requires prior written authorization for disclosure.		
TX	Labor Code ch. 21, sub.ch. H; ch.20, Title 132, art.9031; Ins. Code 21.73	Cannot use genetic information to reject, deny, limit, cancel, refuse to renew, increase the premiums for, or otherwise adversely affect eligibility. Provisions govern disclosure and research protocol. Allows individuals access to their test results.	--	--
UT	--	--	H 271	Died
VT	20 VSA ch.113, sub.ch.4; 18 VSA ch.217; 8 VSA sec. 4724 (VT H 89)	An individual may be required to undergo genetic testing to establish parentage, to determine the presence of disorders in newborns, for a criminal investigation or prosecution, for identification of remains, for purposes of the state DNA databank and database. Except for the conditions listed and for anonymous medical research, no individual may be required to undergo genetic testing without the individual's prior written authorization and informed consent. Prohibits discrimination based on genetic testing in insurance, employment, membership in a labor organization, and professional licensure. Also requires individuals convicted of violent crimes to submit a DNA sample. Provides procedures for the collection and analysis of samples.	H 89	Enacted
VA	Statutes: 38.2-508.4	Cannot terminate, restrict, limit or otherwise apply conditions on coverage of an individual; cannot cancel or refuse to renew, or exclude, impose a waiting period, or change rates on the basis of the results of genetic information; genetic tests results are privileged and confidential. Statute expires July 1, 1998.	S 652	Carried over to 1999
	Statutes: 38.2-613	Requires authorization for disclosure.		
	Statutes: 38.2:-4214, 38.2-4319, 38.2-3543.2	Genetic Information Privacy Act. Any insurer, corporation providing health coverage, or HMO cannot, on the basis of genetic information, obtain		

The purpose of including genetic testing as a preexisting condition is to prevent insurers from denying or eliminating coverage to individuals who are shown to be susceptible to certain serious conditions through genetic testing. It also prohibits employers from gaining access to test results.

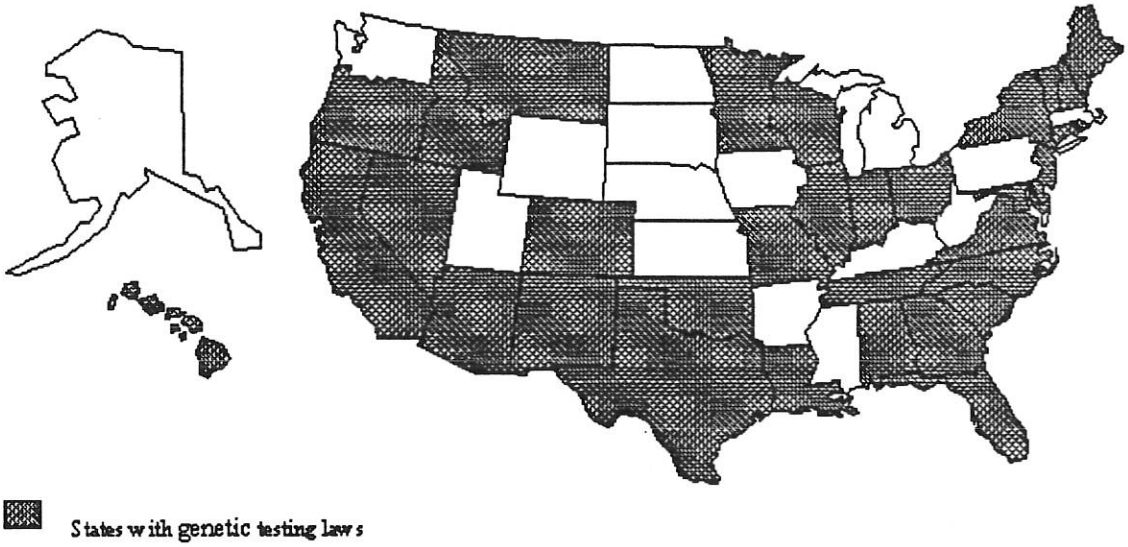
The Health Insurance Portability and Accountability Act requires compliance by the end of 1997. All states are in compliance with HIPAA except **California, Michigan, Missouri** and **Rhode Island. Kentucky** was granted extra time to comply because it was not in a regular legislative session.

1997 HIPAA COMPLIANCE

STATES	1997 BILLS	LAW DATE
ALASKA	S 104	6/13/97
ARIZONA	S 1321	4/29/97
ARKANSAS	H 1715	4/01/97
COLORADO	S 54	5/01/97
CONNECTICUT	H 8007 b	7/01/97
DELAWARE	S 166	7/03/97
FLORIDA	S 1682	5/30/97
IDAHO	S 1249	3/24/97
ILLINOIS	S 802	6/26/97
IOWA	H 701	5/01/97
KANSAS	S 204	5/15/97
LOUISIANA	S 1309	7/14/97
MAINE	H 1278 a	6/10/97
MARYLAND	H 1358	4/29/97
MONTANA	S 378	4/28/97
NEBRASKA	L 55	6/11/97
NEBRASKA	L 862	4/02/97
NEVADA	A 521	7/16/97
NEW HAMPSHIRE	S 130	6/23/97
NEW JERSEY	S 2192	6/26/97
NEW MEXICO	H 832	4/11/97
NEW YORK	S 5452	9/24/97
NORTH CAROLINA	H 434	7/01/97
NORTH DAKOTA	H 1168	4/11/97
OHIO	H 374	6/26/97
SOUTH CAROLINA	S 288	3/31/97
SOUTH DAKOTA	S 208	3/11/97
TENNESSEE	S 1699	4/30/97
VIRGINIA	H 2887	4/02/97
VIRGINIA	S 1112	4/02/97
WEST VIRGINIA	H 2667	5/07/97

Wisconsin supplemented their existing genetic testing laws with additional genetic testing provisions. **Idaho** adjusted terminology in laws concerning a state DNA database. **Delaware, Maine** and **Oklahoma** enacted comprehensive genetic testing measures that prohibit discrimination in employment and insurance based on genetic testing. **Missouri** established a law that prohibits insurers and employers from using genetic testing and genetic information in decision making unless the individual approves the use of this information. **Rhode Island** established a law that prohibits insurers from using genetic testing in any aspect of coverage under its policies or contracts. Lawmakers in **Vermont** passed a measure that bans discrimination based on genetic testing in insurance, employment, membership in a labor organization, and professional licensure. **South Carolina** enacted a law that prevents health insurance discrimination on the basis of genetic information. Currently 34 states have laws governing genetic testing and information.

Genetic Testing Laws



States with genetic testing laws

In conclusion, the significance of genetic testing legislation continues to escalate because of the sensitive nature of this information and its potential applications. States continue to address the complex scientific, ethical, legal and social questions concerning genetic testing and information.

Although states may not have settled all the conflicts relating to genetic testing, they have learned that solutions require a balance between the research communities, the insurance industry and individual rights.

References:

[1] Health Insurance in the Age of Genetics, *Department of Health and Human Services*, July 1997.

[2] Genetic Information and the Workplace, *Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice*, January 20, 1998.

[3] Benjamin Wilfond, et al, "Cancer Genetic Susceptibility Testing: Ethical and Policy Implications for Future Research and Clinical Practice", *Journal of Law, Medicine and Ethics*, 25 (1997).

[4] Benjamin Wilfond, et al, "Cancer Genetic Susceptibility Testing: Ethical and Policy Implications for Future Research and Clinical Practice", *Journal of Law, Medicine and Ethics*, 25 (1997).

[5] H.R. 306, The Genetic Information Non-discrimination in Health Insurance Act of 1997, Congress of the United

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STATE OF KANSAS
HOUSE OF REPRESENTATIVES

TOPEKA ADDRESS
STATE CAPITOL, ROOM 327-S
TOPEKA, KANSAS 66612-1504
(785) 296-7630
REPRESENTATIVE, ELEVENTH DISTRICT

COFFEYVILLE ADDRESS
601 EAST 12TH, P.O. BOX 538
COFFEYVILLE, KS 67337
(316) 251-1900 (OFFICE)
(316) 251-1864 (HOME)

JIM GARNER
HOUSE DEMOCRATIC LEADER

Madame Chair and members of committee:

Thank you for the opportunity to appear and testify in support of S. B. 22. Senate Bill 22 makes it an "unlawful employment practice" for an employer to subject an employee or prospective employee to genetic testing or to use preexisting genetic screening to discriminate against or make distinctions between an employee or prospective employee.

At first glance, debating the issue of genetic screening may seem premature and abstract, but this issue has already had very real consequences and will, without question, become increasingly relevant to our daily lives. A 1997 study by the American Management Association found that over 5 percent of its members currently conducted genetic tests on employees or prospective employees. The number of employers using genetic testing will only increase in the coming years as the federally-funded Human Genome Project continues making advancements in genetic knowledge and health care costs resume their rapid rise.

The problems with allowing employers to genetically screen their employees are not difficult to envision. There are already cases of workers being fired because genetic testing reveals they are higher risks for contracting certain illnesses. Please note I say *higher risks*, these employees were not sick, and might never contract the illnesses in question. As genetic testing becomes more prevalent, imagine the possibilities. Able-bodied, qualified workers unable to obtain jobs, or if they do obtain jobs they could be denied health care benefits.

There is also the question of privacy. Why does an employer have the right to obtain information on an individual's genetic make-up? Job applicants should submit resumes detailing abilities and work experience, not resumes outlining the odds of contracting certain diseases and afflictions. The state of Kansas needs to be proactive in preventing such invasive actions.

Fortunately, we can take steps to stop the growing trend of genetic screening and genetic discrimination. Attached is a list of states that have recently considered this issue.

I urge you to support making the use of genetic screening information an unlawful employment practice. We must begin making policy to address the new advances in genetic testing and their implications in our daily lives.

Thank you for your time and I urge your support for this bill.

Senate Comm Senate Commerce Committee
Date: 1-29-99
Attachment # 4-1 thru 4-4

Table 8-1.
State Genetic Employment Legislation Introduced in 1997

STATE	HOUSE BILL	SENATE BILL	SUMMARY	STATUS
California		SB 654	Relates to the prohibition against discrimination in employment-related matters on the basis of, among other things, medical condition; the bill provides that "medical condition" includes genetic characteristics, as defined.	9/9/97 – Placed in inactive file
Connecticut		SB 45	Prohibits the use of genetic information in employment decisions.	5/1/97 – To Joint Committee on Judiciary
Hawaii	HB 1566		Prohibits genetic testing as a prerequisite for employment or membership; prohibits unlawful discriminatory practices; prohibits insurers to require genetic testing to obtain benefits, coverage, or renewed coverage under a policy.	1/24/97 – To House Committee on Labor and Public Employment
Hawaii		SB 112	Relates to genetic testing; prohibits use of genetic testing by employers; prohibits insurer to require an individual to undergo any genetic testing or to present the results of such tests in order to obtain benefits.	1/17/97 – To Senate Committee on Human Resources
Illinois	HB 8		Creates the Genetic Information Privacy Act. Provides that information derived from genetic testing is confidential. Limits the use of genetic information by insurers and employers. Provides exceptions to the confidentiality of genetic information with respect to certain disclosures by medical personnel. Provides that persons aggrieved by a violation of the act have a right of action. Excludes chemical, blood and urine analyses, drug testing and HIV testing.	6/23/97 – Signed by governor
Illinois		SB 672	Creates the Genetic Information Privacy Act. Provides that information derived from genetic testing is confidential. Limits the use of genetic information by insurers and employers. Excludes chemical, blood and urine analyses, drug testing and HIV testing from the scope of the bill; provides that samples obtained by peace officers may be used for identification purposes; authorizes expungement of court records only; limits remedies against insurers that violate the act.	5/8/97 – Referred to House Committee on Rules
Maine		SB 384	Protects the privacy of genetic information. Prohibits discrimination in any form of insurance regulated by the Bureau of Insurance on the basis of genetic information and requires informed consent for obtaining genetic information. Prohibits discrimination in employment on the basis of genetic information.	10/22/97 – Carried over to 1998 regular session

Table 8-1.
State Genetic Employment Legislation Introduced in 1997
(continued)

STATE	HOUSE BILL	SENATE BILL	SUMMARY	STATUS
Maryland	HB 776		Makes it unlawful to fail or refuse to hire, to discharge, or to discriminate against an individual due to the individual's genetic information or refusal to submit to a genetic test or to provide genetic test results; prohibits an insurer, nonprofit health service plan or health maintenance organization from requesting or requiring a genetic test in regard to a life insurance policy or contract or annuity contract.	4/5/97 - Referred to interim study by Committee on Environmental Matters
Maryland	HB 920		Makes it an unlawful employment practice for an employer to fail or refuse to hire or to discharge an individual or otherwise discriminate against an individual because of the individual's genetic information or refusal to submit to a genetic test or make available the results of a genetic test; prohibits an insurer from making certain differentials in rating, premium payments or dividends in life insurance, annuity contracts, credit life or disability insurance policies; etc.	4/5/97 - Referred to interim study by Committee on Environmental Matters
New York	AB 4512		Makes technical corrections regarding employment discrimination based on genetic characteristics and information realized from genetic testing.	3/5/97 - To Senate Committee on Investigation and Taxation
New York		SB 3284	Makes technical corrections regarding employment discrimination based on genetic characteristics and information realized from genetic testing.	6/4/97 - Amended in Senate Committee on Investigation and Taxation
North Carolina	HB 350		Prohibits discrimination in health insurance and employment based on genetic information.	8/28/97 – Not carried over
North Carolina		SB 254	Prohibits discrimination in health insurance and employment based on genetic information.	8/4/97 - Signed by governor
Pennsylvania	HB 771		Amends the Pennsylvania Labor Relations Act. Restricts the use of genetic test results	3/12/97 - To House Committee on Labor Relations
Texas	HB 39		Relates to prohibition of discrimination in the determination of eligibility for employment, occupational licenses, and health insurance coverage based on the use of genetic tests.	6/20/97 - Signed by governor
Texas		SB 98	Relates to a prohibition of discrimination in the determination of eligibility for employment and insurance coverage based on the use of certain genetic tests and to limitations on the use of information derived from those tests.	4/4/97 - Withdrawn from calendar

Table 8-1.
State Genetic Employment Legislation Introduced in 1997
(continued)

STATE	HOUSE BILL	SENATE BILL	SUMMARY	STATUS
Vermont	HB 191		Restricts the use of genetic testing for employment membership in a labor organization, professional licensing or insurability and provides safeguards for confidentiality of genetic testing information.	2/28/97 - To House Committee on Judiciary
Wisconsin	AB 69		Relates to remedies under the fair employment law for a complainant who quits his or her employment, membership or licensure voluntarily.	2/10/97 - To Assembly Committee on Labor and Employment

Source: Compiled by Kelly Fox, NCSL, October 1997.

TESTIMONY OF KANSAS HUMAN RIGHTS COMMISSION
BEFORE THE SENATE COMMERCE COMMITTEE
REGARDING S.B. 22, JANUARY 29, 1999
WILLIAM V. MINNER, EXECUTIVE DIRECTOR
ROBERT M. HOLLAR, ASSISTANT DIRECTOR
BRANDON L. MYERS, CHIEF LEGAL COUNSEL

The Kansas Human Rights Commission requests that it be allowed to provide the following written testimony before the Committee, but does not request to address the committee as a conferee during the hearing on this bill.

S.B. 22 proposes to amend the Kansas Act Against Discrimination (K.S.A. 44-1001, et seq., hereinafter "KAAD") to prohibit the use of genetic testing or the results of genetic screening as an employment technique, thereby making such procedures unlawful discriminatory employment practices under KAAD. KHRC enforces and administers the KAAD and the Kansas Age Discrimination in Employment Act. S.B. 22 would add this as a basis upon which to file an employment discrimination complaint with KHRC. KHRC investigates such complaints, provides opportunities for mediation and conciliation of the complaint controversies, and holds public hearings proceedings as to complaints found to have probable cause that are not resolved by settlement. Final orders of the Commission resulting from the public hearing process are appealable to State District Court and the Kansas appellate court system.

The Commission has received no inquiries or information which leads it to believe that genetic testing/screening is being used by employers within the State of Kansas in the manner proposed for prohibition by S.B. 22. However, when a similar bill was proposed to the Legislature in 1995, our staff was informed by its proponent that the purpose was to establish a statement of public policy within Kansas statutes against such procedures to assure employers did not begin to use them. The purpose was to stop it before it started. We presume that is the intent of the

current proposal. Although KHRC has not requested this amendment, the agency does not oppose it.

When the previous bill was proposed, the KHRC was still in the midst of trying to deal with a crisis of burgeoning caseload, case processing delays and a backlog of complaints awaiting investigation. The Commission has successfully dealt with those problems. Attached hereto is a graph which charts the progress the Commission has made on these issues. While the Commission wishes never to return to a time when it was as overburdened as it previously was, the possibility of additional responsibilities and cases due to an expansion of KAAD is not as significant an issue as it has been.

In addition, it is possible that complaints about genetic testing/screening could arise under the existing statutory form of the KAAD and the Commission could be construed to already have some such responsibilities. It is therefore difficult to contend that the new provisions would necessarily prompt more work for the Commission. When the previous bill was proposed, we reviewed the position of the United States Equal Employment Opportunity Commission, (which enforces employment discrimination laws at the Federal level which have provisions similar to those of the KAAD) as to whether such practices violated the Americans with Disability Act. The disability discrimination provisions of the KAAD are patterned upon the Federal ADA, Title I of which is enforced by EEOC. As can be seen by the attachment hereto, EEOC took the position that using genetic screening/testing results could violate the provisions of ADA in that an otherwise qualified person could be denied employment or have an adverse employment decision taken toward them because they were "regarded" by an employer as having a disability.

Since KAAD provisions parallel those upon which the EEOC's ADA analysis is based, it is arguable that genetic screening/testing provisions addressed by S.B. 22 are already covered and prohibited by KAAD as a volition of its disability discrimination provisions. Similarly, it could be argued that if an employer screened out individuals for certain conditions that could be proven to impact a particular race more than others (for example, if all with a propensity for sickle-cell anemia were screened out, that arguably might have an adverse discriminatory impact upon African-Americans), or if screening, say, for certain cancers might impact along gender lines, etc., there could be a violation of Federal Title VII or KAAD provisions prohibiting discrimination on the basis of race, ancestry, sex, etc. using a disparate impact theory of discrimination. In short, KAAD may have provisions that could be used to challenge genetic screening/testing employment decisions as discriminatory. However, there is not precedent based upon caselaw resulting from the investigation and litigation of any KAAD cases on this point, so it is open to interpretation. If the Legislature wishes to clarify that this is a prohibited discriminatory practice under the KAAD, S.B. 22 would accomplish that, even if it might be arguably also be prohibited under other interpretations of the existing KAAD. Arguably the prohibitions within S.B. 22 support existing provisions and intent of the KAAD. That is, an employer who wished not to hire someone who is black might claim they were not hiring instead because of the person's genetic propensity to get sickle-cell anemia, and attempt to use that pretext to cover up a racially-discriminatory motive underlying the employment decision. There may well be good reason to add the proposed provisions to KAAD.

Whether or not interpretations of existing law might already prohibit genetic testing/screening, there appears to be a national trend to amend state antidiscrimination law to clarify or add

provisions to assure it is prohibited in a manner similar to that proposed by S.B. 22. Attached is a publication from a legal service KHRC subscribes to which mentions several states having adopted such provisions last year, including Oklahoma and Missouri. When we reviewed the situation in response to the previous bill, we found at that time that Oregon had such a law. Officials in Oregon indicated they had received no inquiries or complaints regarding any employer using genetic testing/screening.

Attached hereto is the Fiscal Note requested of the Commission. Basically, we would see the fiscal expense of adding this to KAAD as being negligible, unless there is a reason to believe that we do not currently know of, that a number of complaints will be forthcoming.

If the Legislature chooses not to add this to the KAAD, but wishes to nevertheless make a statutory prohibition against employment practices based upon genetic testing/screening, it could adopt provisions similar to those which prohibit discrimination based upon military status. That was originally proposed as an amendment to KAAD, but there was concern about adding to KHRC's responsibilities at a time the agency was overburdened with cases. There was also consideration as to whether it was necessary to have an administrative agency proceeding available to address the issues. Instead, it was decided to just give victims of such practices the right to bring a private lawsuit in State District Court and seek damages. That might be an option as to this issue. However, given the argument that such practices might be discriminatory under the KAAD in some regards already, if a direct lawsuit action was established by statute, the Legislature might wish to consider amending KAAD to clarify that the same things are not also prohibited under the KAAD. Otherwise, there might confusingly end up to be two different

means of redress. Perhaps that would be seen as good, but it is an issue to consider. If clarification that KAAD did not cover this and that such matters should proceed under court action authorized by another statute, an amendment to K.S.A. 44-1006 would probably be the way to do that. In that section it is clarified that KAAD does not prohibit or mandate certain matters, and it could be added therein to state that nothing within the KAAD shall be interpreted as prohibiting genetic screening/testing as an unlawful discriminatory practice.

Memorandum

To: Rep. Garner

From: Brandon L. Myers, Chief Legal Counsel, Ks. Human Rights Commission

Re: H.B. 2250; KAAD amendments to prohibit employment practices based upon genetic testing

Date: Feb. 13, 1995

Per our discussion, you indicated that this bill was based upon and Oregon statute. I contacted the Oregon agency (counterpart to KHRC) and spoke to Sue Jordan one of their agency officers and the agency person who was the agency's legislative liasion on the amendment to the Oregon statute. I attach a copy of the Oregon statute. She told me that there was legislative interest in the issue and it was amended into the Oregon antidiscrimination in employment statutes two years ago. She said that presently, and at the time the amendment was made, there has not been any indication that this practice is occurring in Oregon. She said that since they have had the law on the books, they have had no inquiries from anyone wishing to file a complaint over this, and have had no complaints filed over it. (She says that in this regard the genetic testing prohibition of the statute is similar to another section of the statute which prohibits employment screening based upon brain wave testing: neither have had any inquiries or complaints, but are more preventive than reactive, as you described the 2250 proposal). She also indicated that Oregon prohibits employment discrimination on the basis of disability with ADA-type language similar to that in the KAAD, and that she agrees that genetic testing/screening in employment based upon regarding a person as having a disability if they have certain genetic makeups might be already prohibited under the disability provisions of the statute. She also agreed that screening on certain bases for conditions which impact females more than men and vice versa, or impact certain races more than others, might already be prohibited as disparate impact discrimination under existing race, sex, etc. provisions of the employment discrimination laws.

Please keep us apprised of this bill. While I don't believe KHRC has any major opposition to the proposal, with our backlog, adding new KAAD provisions is difficult. We would probably ask for more resources to enforce these proposed new provisions, although it is hard to calculate the impact; there might be no increase in complaints filed with us if Oregon is an example. Still, we remain concerned about adverse amnedments to the KAAD being tacked onto the bill which we would have to oppose. I hope this information is helpful.

cc: Michael J. Brungardt, Executive Director
Robert Lay, Assistant Director

ion or employment agency alleged to e committed the unlawful employment ctice complained of and which complaint ll set forth the particulars thereof. The plainant may be required to set forth in the complaint such other information as the commissioner may deem pertinent. A complaint filed pursuant to this section shall be filed no later than one year after the alleged unlawful employment practice.

(2) Whenever the Attorney General or commissioner has reason to believe that any person, employer, labor organization or employment agency has committed an unlawful employment practice, the Attorney General or the commissioner may make, sign and file a complaint in the same manner as a complaint is filed under subsection (1) of this section.

(3) Any employer whose employees, or any of them, refuse or threaten to refuse to abide by ORS 659.010 to 659.110, 659.400 to 659.460 and 659.505 to 659.545 or to cooperate in carrying out the purposes of said statutes may file with the commissioner a verified complaint requesting assistance by conciliation or other remedial action.

(4) The commissioner shall notify the person against whom a complaint is made within 30 days of the filing of the charge. The notice shall include the date, place and circumstances of the alleged unlawful employment practice. [Amended by 1957 c.724 §13; 1971 c.723 §1; 1977 c.453 §2; 1977 c.770 §3]

659.045 Complaints of discrimination in housing or in place of public accommodation or in private vocational, professional or trade school. (1) Any person claiming to be aggrieved by an alleged distinction, discrimination or restriction on account of race, religion, sex, marital status, color, national origin or age if the individual is 18 years of age or older made by any place of public accommodation as defined in ORS 30.675 or by any person acting on behalf of such place or in violation of ORS 30.685 or any person claiming to be aggrieved by a violation of ORS 345.240 or any person claiming to be aggrieved by a violation of ORS 659.033 may, or the attorney of the person may, make, sign and file with the Commissioner of the Bureau of Labor and Industries a verified complaint in writing which shall state the name and address of the person, the place of accommodation or the vocational, professional or trade school alleged to have committed the act complained of and which complaint shall set forth the particulars thereof. The complainant may be required to set forth in the complaint such other information as the commissioner may deem pertinent. A complaint filed pursuant to this section shall be filed no later than one year

subsection (2) of this section, any person aggrieved by an unlawful employment practice prohibited by subsection (1)(b) of this section may seek compensatory damages or $250, whichever is greater. [1981 c.470 §5; 1985 c.404 §3; 1989 c.890 §10]

659.036 Employer prohibited from obtaining, seeking to obtain or using genetic screening information; remedies. (1) It shall be an unlawful employment practice for an employer to seek to obtain, to obtain, or to use genetic screening information of an employee or a prospective employee to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to an employee or a prospective employee.

(2) If an employee or a prospective employee files a complaint with the Bureau of Labor and Industries alleging violation of subsection (1) of this section, the bureau shall cause any necessary investigation to be made and shall enforce subsection (1) of this section in the manner provided in ORS 659.010 to 659.110 and 659.121. [1993 c.719 §2]

659.037 Notice that discrimination will be made in place of public accommodation prohibited; age exceptions. Except as provided by laws governing the consumption of alcoholic beverages by minors and the frequenting of minors in places of public accommodation where alcoholic beverages are served, and except for special rates or services offered to persons 55 years old and older, no person acting on behalf of any place of public accommodation as defined in ORS 30.675 shall publish, circulate, issue or display, or cause to be published, circulated, issued or displayed, any communication, notice, advertisement or sign of any kind to the effect that any of the accommodations, advantages, facilities, services or privileges of such place of public accommodation will be refused, withheld from or denied to, or that any discrimination will be made against, any person on account of race, religion, sex, marital status, color, national origin or age if the individual is 18 years of age and older. [1957 c.724 §10; 1973 c.714 §8; 1977 c.770 §2]

659.040 Complaints of unlawful employment practices. (1) Any person claiming to be aggrieved by an alleged unlawful employment practice, may, or the attorney of the person may, make, sign and file with the commissioner a verified complaint in writing which shall state the name and address of the person, employer, labor organ-

KANSAS HUMAN RIGHTS COMMISSION

Date 4/28/95

To Rep. Garner

From Brandon Myers

____ Ready for finding

____ For your approval

____ Please take necessary action

____ Please prepare reply for my signature

____ For your comment

____ Please note and return

____ For your signature

____ Please confer with me

____ As you requested

____ Per our telephone conversation

✓ For your information RE: HB2250 issues

____ File

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Fair Employment Practices
SUMMARY OF LATEST DEVELOPMENTS

April 24, 1995

Route to... / / /

Retain this issue in the Current Reports binder.

Highlights . . .

Non-harassment v. freedom of speech. See conference report, page 45.

Pay equity initiatives proposed, see special report, page 46.

Military policy on gays no good, page 44.

In the Binders . . .

North Dakota amends Human Rights Act and Equal Pay Act, effective July 1, 1995, at 457:11 and 457:161, respectively.

Genetic Information Bias and ADA

Characterizing discrimination on the basis of genetic information as unlawful under the Americans With Disabilities Act is a "natural extension" of all that EEOC has already said on the subject, says Peggy Mastroianni, assistant legal counsel of EEOC's ADA policy division.

EEOC's recent *Guidance on the Definition of the Term "Disability" Under ADA* is an "interpretation of the law that's already there," Mastroianni says at a Washington, D.C. seminar co-sponsored by the D.C. Bar and George Washington University's National Law Center.

An individual who is "regarded as" having an impairment that substantially limits a major life activity is covered under the third prong of ADA's definition of disability. An employer that discriminates on the basis of genetic information is treating or "regarding" an applicant or employee as if he or she has a disability, Mastroianni explains.

The Guidance gives an example of a job applicant whose genetic profile reveals an increased susceptibility to colon cancer, although the applicant has no symptoms and may never develop the disease. (See *FEP Binder* at 405:7280.) After making a conditional job offer, the employer learns about the applicant's susceptibility. It then withdraws the job offer because of concerns about productivity, insurance costs, and attendance. Because the employer is treating the applicant as having an impairment that substantially limits a major life activity, the applicant is covered under the definition of disability, says the Guidance, which the commissioners unanimously approve.

What's New With FMLA?

The Labor Department's Wage and Hour Division received 2,065 complaints under the Family and Medical Leave Act and completed action on 1,967 of them as of Dec. 31, 1994, the agency says. The Commission on Family and Medical Leave schedules a hearing in Chicago for May 8, while 35 percent of respondents to a Hewitt Associates study provide greater benefits than the FMLA requires.

Of the 61 percent of FMLA complaints found to be valid, 63 percent involve refusal to reinstate an employee following FMLA leave, 20 percent involve a refusal to grant leave, 8 percent involve a refusal to maintain group health benefits, and 8 percent involve discrimination against an employee using leave, according to the latest DOL statistics.

Hearing Scheduled in May

The Labor Department's Commission on Family and Medical Leave will conduct a hearing in Chicago May 8 to examine the costs and benefits of the Family and Medical Leave Act.

The commission will examine existing policies relating to family and temporary medical leave, including employer policies not covered under the Act and policies that have provided temporary wage replacement during periods of family and medical leave. It also will look at alternative and equivalent state enforcement, methods used to reduce administrative costs, and the ability of employers to recover premiums. (Contact Susan King, executive director, Commission on Family and Medical Leave, U.S. Department of Labor, 200 Constitution Ave. N.W., Room S-3002, Washington D.C. 20210, (202) 219-4526, Ext. 102.)

Hewitt Associates Study

Only 876 of the 1,035 respondents to its survey on employer benefits provided information on their family and medical leave policies, according to Hewitt Associates, Lincolnshire, Ill. Sixty-five per-

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Special Report

Changes to State Job Discrimination Laws Made in 1998

The most dramatic change to state fair employment practice laws and regulations made in 1998 was more new laws regulating genetic testing and protecting the privacy of genetic information. Nine states enacted laws protecting the confidentiality of genetic test results; some of these laws also prohibit discrimination in employment based on genetic information. These and other significant changes to state job discrimination laws made in 1998 are outlined below.

■ *Arizona* amended its AIDS Testing and Confidentiality Act to add a definition of "significant exposure risk," effective Aug. 21 (453:1151).

■ *California* amended its Fair Employment and Housing Act to prohibit employers from discriminating against employees who are predisposed to a hereditary disease and to add genetic characteristics to the definition of "medical condition" (453:2711)and amended the Unruh Act, which prohibits discrimination in business transactions, to add a section specifying that actions can be brought in any court of competent jurisdiction, including small claims court if the amount of the damages sought does not exceed $5,000, effective Jan. 1, 1999 (453:3001).

California also amended its Discrimination in Public Employment law to provide that discrimination complaints must be filed within one year of the alleged act (453:3161) and its State Civil Service Affirmative Action law to except bargaining units 5, 6, 16, and 19 from the requirement to maintain the same composition of the workforce after a layoff (453:3175), effective July 3.

■ *Colorado* amended its Discrimination in State Employment law to include the "performance management review process" as another option for review, allow employees who are not under the Colorado Peak Performance to file formal grievances and also prohibit certain issues from being grievable, and allow any person to petition the director to review and investigate matters involving the administration of the State Personnel System, effective July 2 (453:4511).

■ *Connecticut* amended its Human Rights and Opportunities law to provide that a written finding of reasonable cause or no reasonable cause must be made within 190 days of the initial determination, which must be made within 90 days of the filing of the answer, and to provide an additional 50 days for attempted conciliation before the complaint is certified for hearing; to require that the commission report annually to the judiciary committee the number of cases that have not met the law's time requirements; and to allow a complainant to ask the court for an order requiring the issuance of a reasonable cause finding for a complaint pending for more than 2 years, effective July 1.

Another amendment to the Connecticut Human Rights and Opportunities law prohibits discrimination against individuals on the basis of genetic information, effective Oct. 1 (453:4611).

■ *Delaware* amended its Fair Employment Practices Act to add a prohibition against employment discrimination based on "genetic information" (453:7011) and recodified its AIDS Testing Confidentiality law (453:7111), effective July 17.

■ *Florida* amended its AIDS Act to require informed consent before an HIV test may be ordered and to provide for the confidentiality of test results, except under certain circumstances, effective July 1 (454:111).

■ *Hawaii* amended its Fair Employment Practice Law to allow employers to inquire about and consider a prospective employee's conviction records if they bear a rational relationship to the duties and responsibilities of the position sought, effective July 15 (454:1871).

■ *Idaho* amended its Commission Rules to provide that the staff director may close a case for administrative reasons and to add a notice-of-right-to-sue provision requiring that a suit be filed within 90 days of the notice, effective July 1 (454:3901).

■ *Illinois* amended its Hum Rights Commission Procedural Rul to specify that a motion to compel department employee to testify mu be served on the Department of H man Rights chief legal counsel, effe tive Jan. 1 (454:5011).

■ *Indiana* amended its State E ployee's Family Leave Rules to pr vide that sick leave accrues to fu time employees at the rate of 7 hours for every two months of e ployment and an additional 7.5 hou for every four months and to pa time employees at 3.75 hours for e ery two months of employment a an additional 3.75 hours for eve four months, effective Jan. (454:5745).

The state also amended its Equ Pay Act to include "quality of produ tion" as an exception for whi wages can be paid differently to ea sex, effective July 1 (454:5571).

■ *Iowa* amended its Civil Rig Act to protect the confidentiality mediation communications and doc ments and to prevent their disclosur except in specified circumstances, e fective July 1, and to specify that a ministrative law judges must be en ployed by either the Civil Righ Commission or the Division of A ministrative Hearings to issue a d termination of probable cause or n probable cause for complaints, effe tive July 1, 1999 (454:6311).

■ *Maine* enacted a new Genetic I formation Privacy Act to prohibit em ployers and insurers from discrim nating based on genetic informatio a refusal to submit to a genetic tes or the results of a genetic test, effe tive June 30 (455:2231).

The state's prohibition against dis crimination based on sexual orienta tion, contained in the Human Right Act, was repealed by voters Feb. 1 (455:2011).

■ *Maryland* amended its State Em ployees' Family and Medical Leav Law to allow, not require, regulation providing that eligible employee may use other available accrue leave concurrently with family an medical leave, effective Oct. (455:3851).

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The state also amended its Commission on Human Relations Rules of Procedure to provide more flexibility to the general counsel in drafting statements of charges, broaden the standard of review of agency decisions, and provide notice of the commission's procedures for retaining and disclosing investigative case files, effective Oct. 19 (455:4071).

■ *Massachusetts* enacted a law requiring state officials to develop goals for employing women in building trades on state construction projects, effective Aug. 10 (455:4915).

The state also enacted a new Family, Medical and School Leave law that allows eligible employees to take up to 24 hours of unpaid leave, in addition to leave granted under the federal FMLA, to participate in school activities and to attend medical appointments with their children or elderly relatives, effective Aug. 4 (455:4801).

Massachusetts overhauled its Discrimination Commission Regulations to address a state court ruling guaranteeing employers a jury trial in discrimination cases, include a requirement that the commission complete its processing within 18 months, provide that the commission review each complaint before investigating, allow the parties to attempt mediation before filing a complaint, allow the use of pseudonym, authorize the commission to issue subpoenas, streamline procedures for commission-initiated complaints, incorporate a presumption that all materials held by the commission are not subject to public disclosure, and clarify the commission's position that no waiver agreement between parties can prevent the commission's processing of complaints, effective Jan. 1, 1999. (455:5061).

■ *Michigan* enacted a new State Business Contracts for Persons With Disabilities law to provide that persons with disabilities be awarded a percentage of total expenditures from executive branch departments to promote business opportunities for such persons, effective May 5 (455:5771).

Michigan also amended its Bias Against Persons With Disabilities law to change "handicap" and "handicapper" to" disability" and "person with a disability," effective March 17 (455:5581).

■ *Minnesota* enacted a new Breast-Feeding Rights in Employment Law that requires employers to provide reasonable unpaid break time for a nursing mother to express breast milk for her child, effective Aug. 1 (455:6267).

The state also amended its Affirmative Action in Metropolitan Government law to raise the threshold for government contractors required to have affirmative action plans to contractors with contracts in excess of $100,000 and with more than 40 full-time employees, effective April 21 (455:6673).

■ *Mississippi* amended its Discrimination in State Employment law to cover all, not just physical, disabilities, effective July 1 (455:7271).

■ *Missouri* enacted a new Genetic Testing Information Bias law prohibiting employers from discriminating against employees based on genetic testing information, except when related to job responsibilities, and making such information confidential and providing penalties, effective Jan. 1, 1999 (455:7701).

The state also amended its Human Rights Law to change "handicap" to "disability" and to make more specific the references to sections in the law where, when the administrative processing of complaints has not been completed, the commission must issue a right-to-sue letter on request, effective Aug. 28 (455:7511).

■ *New Hampshire* revised its Commission on Human Rights Rules, effective Feb. 5 (456:3713).

■ *New Mexico* enacted a new Genetic Information Privacy Act that prohibits the collection or retention of genetic information without the informed, written consent of the subject or an authorized representative, makes exceptions for the release of information under certain circumstances, and provides penalties, effective May 20 (456:5661).

The New Mexico Human Rights Division/Commission Rules of Procedure also were revamped to implement changes in the Human Rights Act, effective Sept. 1 (456:5991).

■ *North Carolina* amended its Contested Cases and Alternative Dispute Resolution law to provide that a state department or agency has 60 days to take remedial action after receiving a discrimination complaint from a state employee and to authorize state employees to appeal directly to the State Personnel Commission if they think they have been discriminated or retaliated against or harassed, effective Aug. 15 (456:8361).

■ *Ohio* amended its Procedural and Substantive Civil Rights Commission Rules to repeal a section on testing and selection procedures, revise some definitions, and replace "handicap" with "disability," effective Jan. 11 (457:1651).

■ *Oklahoma* enacted a new Genetic Nondiscrimination in Employment law that prohibits discrimination based on genetic information and provides penalties, effective July 1 (457:2301).

■ *Oregon* amended its Civil Rights Rules to give the Civil Rights Division subpoena power in investigations of unlawful discrimination, require that at the end of an investigation the division dismiss the complaint or issue a Substantial Evidence Determination, and allow the informal disposition of contested cases, effective Feb. 11 (457:4811).

The state also amended its Sex Discrimination Rules to delete a provision that allowed an employer to request a medical verification of a pregnant employee's ability to do her job (457:4881) and its Handicapped Employment Rules to define "otherwise qualified disabled person" and "essential functions," among other changes, effective Feb. 3 (457:4981).

■ *Rhode Island* amended its Fair Employment Practices Act to add a section allowing the Rhode Island Commission to investigate, take evidence, consider claims, or issue findings on matters that could have been brought before any other state administrative agency, but were not, and to allow the commission to grant relief on matters decided by another state administrative agency, effective July 9 (457:7461).

The state also amended its Domestic Abuse Bias in Employment law to prohibit discrimination against an employee who refuses to seek or obtain a protective order because of domestic abuse and to provide that courts cannot award punitive damages against the state or its political subdivision, effective July 22 (457:8075).

■ *South Carolina* enacted a new Genetic Information Privacy Act to protect the privacy of genetic information under specified conditions and to provide the means by which genetic information may be used and disclosed, effective Nov. 26 (458:101).

■ *Tennessee* amended its Human Rights Commission Rules and Regulations to authorize a subordinate supervisor, chosen by the commission's executive director, to designate an investigator from a group of contract investigators or from the commission

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to investigate a complaint, effective June 26 (458:2411).

■ *Utah* amended its Antidiscrimination Act to make the commissioner responsible for the membership, appointments, and terms of the members of the Antidiscrimination Advisory Counsel, effective May 4 (458:3561).

The state also amended its State Employees' Rules on Discrimination, Sexual Harassment to redefine "sexual harassment" to include unwelcome and pervasive behavior of a sexual nature and to provide that quid pro quo behavior is sexual harassment, effective Sept. 15 (458:4351).

■ *Vermont* enacted a new Genetic Testing in Employment law that prohibits discrimination based on genetic testing or test results, prohibits requiring genetic information as a condition of employment, provides penalties, and allows civil actions, effective Jan. 1, 1999 (458:4621).

■ *Virginia* amended its Handicapped Discrimination law to insert the word "conservator" in the definition of "consumer," effective Jan. 1 (458:5271).

■ *Washington* amended its Law Against Discrimination in Employment to incorporate the Washington State Civil Rights Act, which prohibits the government from discriminating against or granting preferential treatment to individuals or groups based on race, sex, color, ethnicity, or national origin, effective Dec. 3 (458:6241).

The state also amended its Disability Regulations to define "dog guide" and "service animal" and to prohibit discrimination against an individual who uses a dog guide or service animal, effective April 24 (458:7311).

■ *West Virginia* amended its Human Rights Act by adding a section that establishes a civil action by the attorney general for violence and threats of violence motivated by race, color, religion, sex, ancestry, national origin, political affiliation, or disability, effective June 12 (458:7741).

The state enacted an Equal Pay for State Employees law to protect state workers from gender discrimination in wages paid for comparable work, effective June 11 (458:7947). West Virginia also extended the existence of its Human Rights Commission by amendment to its Human Rights Act, effective June 12 (458:7741), and extended the existence of its Women's Commission by amendment to its Women's Commission law, effective June 2 (458:7991).

■ *Wisconsin* amended its Fair Employment Act to change the terms "handicapped individual" to "individual with a disability" and "handicap" to "disability," effective April 30 (458:8661).

The state also amended its Family Leave Act to empower the State Personnel Commission to handle complaints related to state employees' family or medical leave, effective May 13 (458:9001), and its Discrimination by State Contractors law to add "Prader-Willi syndrome" to the definition of "developmental disability," effective Jan. 3 (458:9251).

Affirmative Action

Court Approves Remedial Relief for Whites in Reverse Bias Suit

A long-running challenge to an affirmative action program at Illinois State University is winding down with a federal district court's approval of remedial relief for 46 white male applicants who were unlawfully denied an opportunity to access janitorial positions.

The public university agreed to settle the reverse discrimination claims for $113,000 soon after the court ruled in 1996 that a short-term apprenticeship program for women and minorities violated Title VII because it excluded white men (72 FEP Cases 382).

The Justice Department's Civil Rights Division and the university spent the last two years identifying claimants and determining how they would be compensated, according to the university's attorney, Carol J. Posegate.

With the court's entry of the final order, "I don't anticipate any further involvement by the court unless there is a problem with implementation," said Posegate, of Giffin, Winning, Cohen & Bodewes in Springfield, Ill.

$110,000 Goes to 31 Claimants

Of the $113,000 settlement fund, $3,000 was initially set aside for the single named plaintiff, leaving $110,000 and accumulated interest to be distributed to 31 claimants who are entitled to monetary relief under the court order. The parties agreed to prorated individual back pay awards ranging from about $500 to about $4,700.

Most of the claimants who are not already employed by the university in building service worker positions can elect to be placed on a priority hiring list for vacancies. Those who accept priority hire offers and the 10 claimants already employed in these positions will be given retroactive seniority for calculation of pay and benefits and determination of job assignments.

Between 1982 and 1991, the university operated a "learner program" for female and minority building service workers. The program was ostensibly created out of concern that most positions were being taken by military veterans, most of whom were white men, whose score on the civil service exam was enhanced by their veteran status. The program allowed participants to bypass the exam.

The court found that none of the 127 participants hired by the university into building service worker jobs between 1982 and 1991 were white males, despite "the fact that nearly half of the local labor pool were white men." The program was discontinued in 1991 after a reverse discrimination charge was filed with the EEOC, but revived again in 1992 without exclusions on participants (*U.S. v. Board of Trustees of Illinois State University*, C.D. Ill., No. 95-3067, 12/22/98).

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FISCAL NOTE

Agency: Kansas Human Rights Commission (05800) Date: January 15, 1999

Bill Number : SB 22

Analysis: The Agency can not at this time estimate the number of additional cases, if any, that SB 22 would generate. One time additional printing cost would be required to update manuals and brocures. One time additional training costs would be required to train investigative staff on genetic testing.

Expenditures

		FY 2000	FY 2001	FY 2002
Salaries and Wages	100	0	0	0
Communication	200			
Freight & Express	210			
Printing & Advertising*	220	600	0	0
Rents	230			
Repairing & Servicing	240			
Travel & Subsistance	250			
Fee - Other Services*	260	150	0	0
Fees - Pro. Services	270			
Other Contractual Services	290			
Total Contractual Services		750	0	0
Food For Human Cons.	320			
Professional Supplies	360			
Stationery & Office Supp.	370			
Other Supplies	390			
Total Commodities		0	0	0
Total Capital Outlay	400	0	0	0
TAL		$750	$0	$0

Financing

	FY 2000	FY 2001	FY 2002
State General Fund			
1000-03	750	0	0
Total State General Fund	750	0	0
Fee Funds			
2282-00			
2404-00			
Total Fee Funds	0	0	0
Federal Funds			
3016-00			
Total Federal Funds	0	0	0
TOTAL	$750	$0	$0

* 50 copies of the KHRC Rules and Regulations at $5.00 per copy and 100 copies of the KAAD at $3.50 per copy. Training cost for investigators - 1 class.

BILL GRAVES, GOVERNOR
STATE OF KANSAS

KANSAS HUMAN RIGHTS COMMISSION
LANDON STATE OFFICE BLDG. - 8TH FLOOR
900 S.W. JACKSON ST. - SUITE 851-SOUTH
TOPEKA, KANSAS 66612-1258
(785) 296-3206

January 15, 1999

Mr. Duane A. Goossen
Director of the Budget
Division of the Budget
Capitol Building 1st Floor
Topeka, Kansas 66612

Dear Mr. Goossen:

In accordance with K.S.A. 75-3715(a), please find attached our analysis, projections and long-range effects of Senate Bill 22. If there are any questions regarding this Fiscal Note, please do not hesitate to contact either myself or Mike Hollar, my Assistant Director, at 296-3206.

Sincerely,

William V. Minner

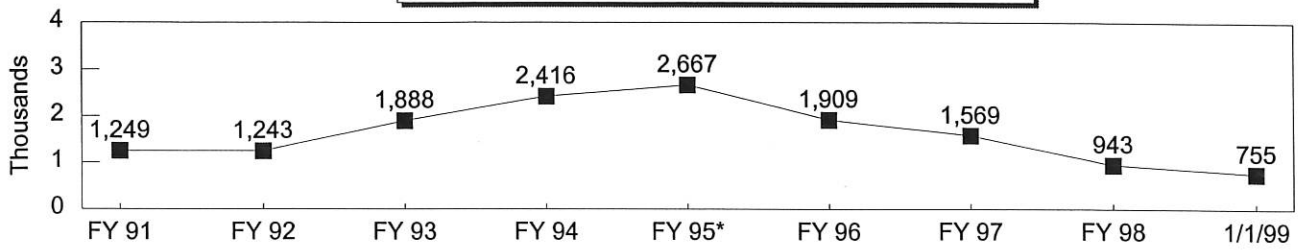
William V. Minner
Executive Director

WVM:ch

5-14

Open Cases

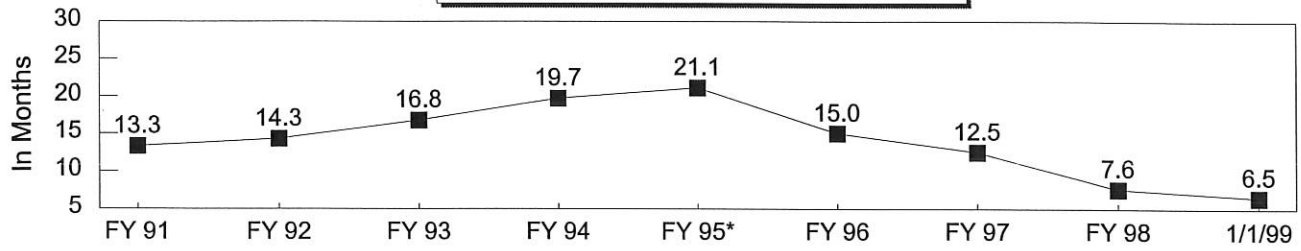
As of June 30



*The total on March 27, 1995 was 2,768 open cases, the highest total ever.

Processing Time

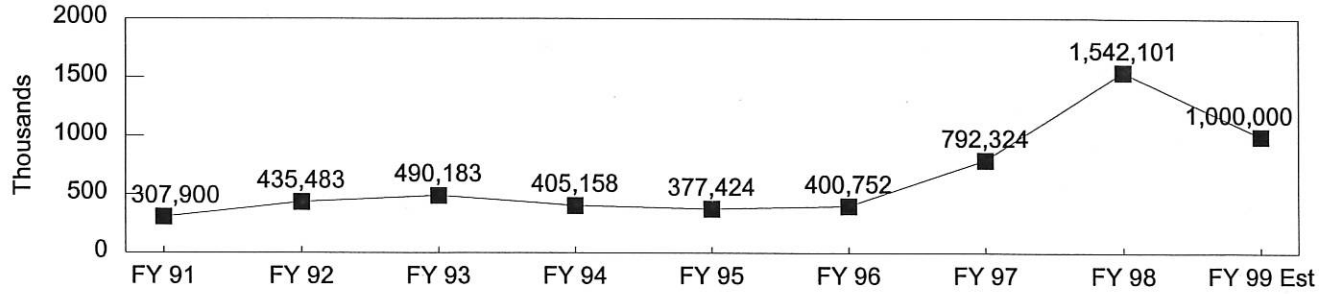
As of June 30



*The longest processing time was approximately 22 months in March, 1995.

Total Annual Recovery

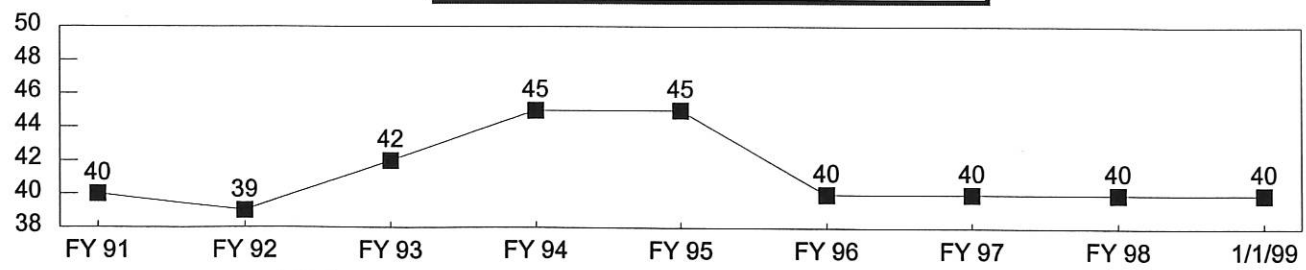
As of June 30



Of the $4.75 million collected from FY 91 to FY 98, nearly half was collected in FY 97 & FY 98.

Authorized Positions

As of June 30



Currently authorized 37 FTE and 3 Unclassified Temporary positions

American Council of Life Insurance

James D. Hall
Senior Counsel

January 29, 1999

TO: KANSAS STATE SENATE COMMERCE COMMITTEE

RE: SENATE BILL 22 - UNLAWFUL EMPLOYMENT PRACTICES; GENETIC TESTING

Members of the Committee:

I am appearing on behalf of the American Council of Life Insurance (ACLI) whose 532 member companies hold 88.7 percent of the legal reserve life insurance in force in the United States. We have 402 member companies licensed in Kansas holding approximately 90.7 percent of the life insurance in force in the state. Many of our members also sell disability income and long-term care insurance in Kansas. Thank you for the opportunity to appear before the committee to offer our comments.

I appear before the Committee today for the purpose of offering a clarifying amendment to Senate Bill 22. In its current form, SB 22 would make it unlawful for employers to "(A) Seek to obtain, to obtain or to use genetic screening or testing information of an employee or prospective employee to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to an employee or a prospective employee; or (B) subject directly or indirectly, any employee or prospective employee to any genetic screening or test."

The Insurance Code sets forth at K.S.A. 40-2259 the prohibited and permitted activities regarding insurers and genetic screening, genetic testing and use of genetic information. Our proposed amendment would simply make it clear that the prohibition placed on employers by SB 22 would neither restrict nor liberalize the current prohibited and permitted activities of insurers set forth in K.S.A. 40-2259. Employers would be subject to SB 22's prohibitions in making employment related decisions but insurers providing insurance to the employer's employees would still be subject to the prohibited and permitted activities in K.S.A. 40-2259 in conducting their insurance risk classification, underwriting and claims administration.

Thank you for the opportunity to appear before the Committee.

Senate Commerce Committee

Date 1-29-99

Attachment # 6-1 thru 6-2

1001 PENNSYLVANIA AVENUE, N.W.
WASHINGTON, D.C. 20004-2599
202/624-2000
FACSIMILE 202/624-2319

qualification standards, employment tests or other selection criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities unless the standard, test or other selection criteria, as used, is shown to be job-related for the position in question and is consistent with business necessity; or (H) fail to select and administer tests concerning employment in the most effective manner to ensure that, when such test is administered to a job applicant or employee who has a disability that impairs sensory, manual or speaking skills, the test results accurately reflect the skills, aptitude or whatever other factor of such applicant or employee that such test purports to measure, rather than reflecting the impaired sensory, manual or speaking skills of such employee or applicant (except where such skills are the factors that the test purports to measure).

(9) For any employer to:

(A) Seek to obtain, to obtain or to use genetic screening or testing information of an employee or a prospective employee to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to an employee or a prospective employee; or

(B) subject, directly or indirectly, any employee or prospective employee to any genetic screening or test.

(b) It shall not be an unlawful employment practice to fill vacancies in such way as to eliminate or reduce imbalance with respect to race, religion, color, sex, disability, national origin or ancestry.

(c) It shall be an unlawful discriminatory practice:

(1) For any person, as defined herein being the owner, operator, lessee, manager, agent or employee of any place of public accommodation to refuse, deny or make a distinction, directly or indirectly, in offering its goods, services, facilities, and accommodations to any person as covered by this act because of race, religion, color, sex, disability, national origin or ancestry, except where a distinction because of sex is necessary because of the intrinsic nature of such accommodation.

(2) For any person, whether or not specifically enjoined from discriminating under any provisions of this act, to aid, abet, incite, compel or coerce the doing of any of the acts forbidden under this act, or to attempt to do so.

(3) For any person, to refuse, deny, make a distinction, directly or indirectly, or discriminate in any way against persons because of the race, religion, color, sex, disability, national origin or ancestry of such persons in the full and equal use and enjoyment of the services, facilities, privileges and advantages of any institution, department or agency of the state of Kansas or any political subdivision or municipality thereof.

Sec. 3. K.S.A. 44-1002 and 44-1009 are hereby repealed.

(C) The provisions of subsections (A) and (B) shall not prohibit or limit the use of genetic screening or testing allowed pursuant to the provisions of K.S.A. 40-2259.