APPENDIX E

CHARGE 2

States' Genetic Testing Laws

GENETIC TESTING LAWS

STATE	LAWS	SUMMARY
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 on a genetic condition. The exception is if claims experience or actuarial projections establish substantial differences in claims. The 1997 law defines procedures relating to the confidentiality, disclosure and handling of genetic tests. Requires informed consent.
	HB 2041 (2000)	Limits to whom genetic information may be released; genetic testing and information derived from genetic testing are confidential and considered privileged to the person tested.
	SB 1173 (2000)	Language included in the bill requires that an insurer not refuse to consider an application for life or disability insurance on the basis of a genetic condition, nor may insurers reject the application because of a genetic condition.
CA	Health and Safety Code: 1374.7; 1374.9	No plan shall refuse to enroll based on genetic characteristics. Cannot discriminate in rates, terms, conditions or benefits. Law effective until Jan. 1, 2002.
	Civil Code: 56.17; Insurance Code: 742.407	Creates penalties for negligently disclosing results of a genetic test.
	Insurance Code: 10123.3; 10123.31; 10123.35.	Restrictions to self-insured welfare benefit plan. Cannot refuse, increase rates, or provide different terms, conditions or benefits on the basis of a person's genetic characteristics.
	Insurance Code: 10146 through 10149-1	Establishes standards regarding unfair discrimination among individuals in the underwriting of life or disability income insurance on the basis of tests of a person's genetic characteristics. Cannot require test to determine insurability. Requires authorization for disclosure. Cannot limit benefits. Exempts life or disability income insurance. Establishes penalties for willful disclosure.
	Insurance Code: 10140 through 10145.3	Cannot refuse or change rates solely because the person carries a gene that may be associated with disability in that person or the person's offspring.

	Statutes: Chapter 532	Extends disclosure requirements to multiple employer welfare arrangements. Prohibits all health plans and insurers from obtaining, using or maintaining any genetic information for any non-therapeutic purpose. Revises the definition of genetic characteristics.
	Government Code: 12926	Prohibits discrimination in employment-related matters on the basis of genetic characteristics.
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.
	Public Act No. 97- 264	Creates a Huntington's disease clinic.
	Statutes: 46a-60	Employers, employment agencies and labor organizations may not request or require genetic information from an employee, person seeking employment or member, or 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.
	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 disclose the identity of an individual upon whom a genetic test has been performed or disclose genetic information about the individual in a manner that permits identification, except under certain circumstances.
FL	Statute: 760.40	Requires authorization for disclosure; privacy protection; provides mandatory reanalysis if use of genetic information results in a denial of insurance.
	Statute: 627.4301;	Prohibits insurers from requiring people to take genetic tests for "any insurance purpose"

	627.6419; 632.638; 636.0201 641.30; 641.438	and from soliciting information derivable from such tests from any other source. Requires an insurance company that has come into possession of genetic test results to maintain confidentiality. Provides civil and criminal penalties for violation of confidentiality requirements and for failure to obtain informed consent.
GA	Title 33, Ch. 54-1. through 54-8.	Prohibits use of genetic testing except to obtain information for therapeutic or diagnostic purposes. Requires authorization for disclosure and confidentiality protection. Prohibits health insurers from obtaining information derived from genetic testing.
НІ	Revised Statutes: 431:10A; 432:1; 432D	Prohibits the use of an individual's or a family member's genetic information and prohibits requesting test. An insurer cannot deny or limit any coverage or establish eligibility, continuations, enrollment or premium payments based on genetic information. Provides disclosure and informed consent provisions.
ID	ID Code 19: 5501- 551	8 All individuals found guilty of, or who plead guilty to, certain sexual and violent crimes must provide the department of law enforcement a DNA sample and a right thumbprint impression. The bureau of forensic services is authorized to analyze such samples for genetic markers, including DNA markers, and include the genetic profiles from such samples in the state's 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		
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.
	SR 292 (2000)	This law requires that the University of Illinois issue a report on human cloning containing aspects from the fields of medicine, religion, biotechnology, genetics, law, and bioethics; opinions of the general public; and a review and evaluation of current and past public policy and research related to human genetics.
IN		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		

KY		
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. Insurers may not make or permit any unfair discrimination against individuals in the issuance, withholding, extension or renewal of an insurance policy based on genetic information or the refusal to submit to a genetic test.
MD	Insurance Code: Art. 48A- 223 through 223.1 (recodified in 1997)	Cannot reject, deny, limit, cancel, refuse to renew, change rates or otherwise affect a health insurance policy or contract. Law in effect from Oct.1 until September 30, 2002.
	Health-Gen. Code: 19-706 (recodified in 1997)	Extends articles 48A-223 through 223.1 to be applicable to health maintenance organizations.
MI	SB 589 (2000)	Makes it illegal for state established health care providers to require members or applicants for coverage to take a genetic test before renewing, issuing or continuing a policy.
	SB 591 (2000)	Prohibits an HMO from requiring an enrollee or his or her dependent or an asymptomatic applicant for coverage of his or her asymptomatic dependent to take a genetic test or disclosing the results of the test.
	SB 593 (2000)	This version includes wording on genetic testing consent. The bill would provide for informing test subject of test results, risks, benefits and those with access to test results, among other things.
	SB 815 (2000)	Includes genetic information in the definition of discrimination in the hiring process, in segregation of the work place, or the termination of an employee due to genetic information. Prohibits an employer from requiring genetic testing or the submission of genetic information, but allows an employee to voluntarily submit genetic information to an employer.

MN	Statutes: 72A.139	Cannot require test; cannot consider results of a test in determining eligibility for health insurance coverage; cannot change rates, establish premiums or limit coverage; requires authorization for disclosure.
	SB 3138 (2000)	Creates the Agent Orange Information and Assistance Program. Requires the Commissioner of Health to provide genetic information and counseling to veterans who have concerns regarding the possible genetic effects which may be associated with exposure to chemical agents.
МО	RSMo 595.105	Insurers may not require or request a person or relative of that person to provide genetic information, take a genetic test, inquire whether they refused to take a genetic test or ask the result of a genetic test. The insurer must receive permission from the individual to consider relevant genetic testing information. Employers may not use genetic test results or genetic information of an employee or prospective employee to discriminate against or restrict any rights or benefits of an employee and prospective employee. The employment related provisions of this law do not apply to the use of genetic information when such information directly relates to a person's ability to perform job responsibilities.
MT	33-18-206	Cannot reject coverage or determine rates based on genetic conditions; violation considered unfair practice; 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.
	HB 1589 (2000)	Provides that life insurers who obtain the genetic testing information of an individual is prohibited from using that information in coverage except for life, disability and income insurance under certain circumstances.
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.
	Civil Rights Code:	Considers it unlawful practice to discriminate based on genetic characteristics regarding

	10:5-11	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 10.13-22.4.1 through 22.4.5	Under managed health care regulations 22.4, a plan, contract, policy or agreement is prohibited from requiring a test, taking into consideration the results of a test, making inquiry into results, making adverse decisions based on test; cannot develop or ask questions regarding medical history; cannot cancel or refuse; cannot deliver, issue or renew a plan that limits benefits based on the results of a test. Can consider results if favorable.
	NM H 331, 1998 Session	Prohibits discrimination by an insurer against a person or member of the person's family on the basis of genetic analysis, genetic information, genetic propensity or participation in genetic research or use of genetic services. Requires written consent from a person or a person's authorized representative for use of his or her genetic information, except under certain conditions.
NY	Civil Rights Law: 79-1	Confidentiality; requires authorization for disclosure; all samples are to be destroyed 60 days after the tests are made; all results are privileged and confidential.
	Executive Law: 292-21, 292-21a,b,c,d; 296-19.	; Unlawful discriminatory practice to require test or directly or indirectly inquire about results in employment; requires authorization for disclosure.
	Insurance Law: 2612	Requires authorization for disclosure; makes standards for consent form. Insurer may not infer applicability to another person genetically related to individual tested.
NY	Civil Rights Law: 79-1	Amends civil rights law regulating genetic testing, providing requirements governing genetic research without informed consent.
NC	58-58-25; 58-65-70; 58- 3-215	Cannot raise premium rates, refuse to issue or deliver policy, or charge a higher premium rate because of genetic information obtained.
ОН	through 1742.43,	Insurers and HMOs shall not consider any information obtained from genetic testing in processing individual or group health insurance application. Consideration of genetic testing is allowed if results are favorable to the 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	Н 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 prospective employee Employers may not require a genetic test or genetic information and provides penalties for violating these provisions.
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. A 1997 law creates provisions governing anonymous research.
RI		9; Prohibits insurers and health plans from: 7-Using a genetic test or the results of a genetic test to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect a health insurance policy or contract; Requesting or requiring a genetic test for the purpose of determining whether to issue or renew coverage; Releasing the results of a genetic test without the prior written authorization of the individual from whom the test was obtained, except in a format whereby individual identifiers are removed, encrypted or encoded so that the identity of the individual is not disclosed; Requesting or requiring information about whether an individual has ever had a genetic test, or participated in genetic testing of any kind, whether for clinical or research purposes.
	SR 2535	This resolution creates an eleven (11) member special senate commission to study confidentiality and proprietary rights regarding genetic testing.
	HB 7905	This resolution creates an eleven (11) member special house commission to study confidentiality and proprietary rights regarding genetic testing.

SC

Statutes:

Health insurers may not, on the basis of genetic information; terminate, restrict, limit or

	38-93-10, 20,30,40,50, 60 (SC S 535)	apply conditions to coverage of an individual or restrict the sale to an individual; cancel or refuse to renew the coverage of an individual; exclude an individual from coverage; impose a waiting period; exclude coverage for certain benefits and services; or establish differential in premium rates for coverage. Requires written authorization for disclosure of genetic information except under certain circumstances. Genetic tests may not be conducted on tissue, blood, urine, or other biological samples taken from an individual without prior consent from the individual, or a person legally authorized to consent on behalf of the individual, except under certain circumstances.
ΓN	TN H 413; 1997 legislative session	Cannot require; cannot request test; cannot deny, cancel coverage or vary premiums, terms or conditions for 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 eand research protocol. Allows individuals access to their test results.
UT		
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, and 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 for professional licensure. Also requires individuals convicted of violent crimes to submit a DNA sample. Provides procedures for the collection and analysis of samples.
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 expired July 1, 1998.
	Statutes: 38.2-613	Requires authorization for disclosure.
	Statutes: 38.2:-4214, 38.2-4319, 38.2-3543.2 through 38.2-3542.4	Genetic Information Privacy Act. Any insurer, corporation providing health coverage, or HMO cannot, on the basis of genetic information, obtain information concerning an individual or request genetic information; cannot terminate, restrict, limit or otherwise apply conditions to coverage of an individual or restrict an individual from purchasing coverage; cannot cancel or refuse, exclude, impose a waiting period or change rates

based on genetic information; information is privileged and confidential. Statute expired	
July 1, 1998.	

		July 1, 1776.
WA		 .
WI	Statutes: 631.89	Cannot require or request test. Cannot condition insurance coverage or health care benefits on whether a genetic test has been performed or regarding the results; cannot change rates. Statute does not apply to life or income continuation insurance. If they do obtain information, however, the same above restrictions apply as the above insurers.
	Statutes: 631.89(2) (bm) (A 157)	Expands the prohibition against insurers from inquiring about genetic tests to include health care providers. 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.
	S 494	Relates to genetic testing, paternity and child support.

Source: Health Policy Tracking Service, National Conference of State Legislatures, July 2000.