

SENATE HEALTH COMMITTEE

STATEMENT TO

SENATE COMMITTEE SUBSTITUTE FOR SENATE, Nos. 695 and 854

STATE OF NEW JERSEY

DATED: MARCH 14, 1996

The Senate Health Committee reports favorably a committee substitute for Senate Bill Nos. 695 and 859.

This committee substitute, the "Genetic Privacy Act," provides a comprehensive statutory framework for the regulation of genetic testing and the retention and disclosure of information obtained from genetic tests. The substitute provides protection from unauthorized genetic testing, the unauthorized use of genetic information, and from insurance and employment discrimination against individuals on the basis of genetic information.

The substitute prohibits all health insurers offering comprehensive health benefits plans in the State from excluding any eligible person or dependent in the issuance, withholding, extension or renewal of health insurance coverage and from establishing any rates or terms on the basis of an actual or expected health condition or on the basis of any genetic characteristics.

With respect to hospital confinement or other supplemental limited benefit health or credit life or credit accident insurance coverage, the substitute prohibits discrimination against any individual on the basis of genetic information or the refusal to submit to a genetic test or make available the results of a genetic test to the person in the issuance, withholding, extension or renewal of the coverage or in the fixing of the rates, terms or conditions therefor, or in the issuance or acceptance of any application therefor.

With respect to life and disability income insurance and annuities, the substitute prohibits any unfair discrimination against any individual in the application of the results of a genetic test or genetic information to underwriting or in determining insurability. (The application of the results of a genetic test or genetic information, if any, must be reasonably related to anticipated claims experience.) The substitute provides that if the Commissioner of Insurance determines that such unfair discrimination has occurred, the commissioner shall issue an order requiring the insurer to cease and desist from engaging in the discriminatory act or practice and may assess monetary penalties against the insurer.

Also the substitute provides that if a life, disability income or

annuity insurer intends to apply the results of a genetic test to its underwriting or in determining insurability for a policy or contract, the insurer shall notify the individual who is the subject of the genetic test that such a test shall be required and shall obtain the individual's written informed consent for the test prior to the administration of the test. The insurer shall also provide that the physician or other health care professional designated by the individual shall promptly receive a copy of the results of the test and, if required, an interpretation of the test results by a qualified professional and that the individual shall state in writing whether the individual elects to be informed of the results of the test.

With respect to employment discrimination, the substitute amends New Jersey's "Law Against Discrimination" to make it an unlawful employment practice for an employer to refuse to hire or refuse to employ a person or to discharge or require a person to retire on the basis of genetic information or because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer.

The substitute defines "genetic characteristic" to mean any inherited gene or chromosome, or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome. "Genetic information" is defined as the information about genes, gene products or inherited characteristics that may derive from an individual or family member. "Genetic test" is defined as a test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic.

The substitute provides standards and procedures for obtaining, retaining and disclosing genetic information. The substitute:

- declares that an individual's genetic information is the property of that individual, and prohibits any person from retaining an individual's genetic information without first obtaining specific authorization from the individual or the individual's representative, except under certain limited circumstances;

- requires that the DNA sample of an individual from which genetic information has been obtained shall be destroyed promptly upon the specific request of the individual, except under certain circumstances and for certain purposes;

- provides that no person may disclose or be compelled 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 of the individual, except under certain limited circumstances; and

- requires any person who performs genetic testing or receives genetic testing records to provide the person tested with notice that

the test was performed or that the information was received.

Finally, the substitute provides that any person violating its provisions shall be a disorderly person and shall be punished by a fine of \$1,000, a prison term of six months, or both. Any person who willfully discloses an individual's genetic information to any third party in violation of the substitute's provisions shall be punished by a fine of \$5,000, a prison term of one year, or both. Any person who discloses an individual's genetic information in violation of the substitute's provisions shall be liable to the individual for all actual damages, including damages for economic, bodily, or emotional harm which is proximately caused by the disclosure.