

ASSEMBLY LABOR COMMITTEE

STATEMENT TO

ASSEMBLY COMMITTEE SUBSTITUTE FOR ASSEMBLY, Nos. 1499 and 1411

STATE OF NEW JERSEY

DATED: FEBRUARY 22, 1996

The Assembly Labor Committee reports favorably the Assembly Committee Substitute for Assembly bills, Nos. 1499 and 1411.

This substitute, entitled the "Law Against Genetic Discrimination," 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 discrimination against individuals on the basis of genetic information.

Progress in mapping the genes that cause breast cancer and other diseases has far outpaced the development of a legal and ethical context in which genetic information can be properly evaluated. Effective tests to determine the presence of genes that cause breast cancer and other diseases carry with them the devastating potential for discrimination against carriers of these genes. This substitute is intended to provide a legal and ethical context in which genetic information can be properly evaluated and to protect against genetic 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 an individual or to discharge or require the individual to retire because of information obtained from a genetic test or because the individual refuses to submit to a genetic test or provide information obtained from a genetic test.

The substitute prohibits life and health insurers from discriminating against any individual in the issuance, withholding, extension or renewal of any life or health insurance policy or annuity, or in the fixing of rates, terms or conditions of a life or health insurance policy, or in the issuance or acceptance of any life or health insurance application because of information obtained from a genetic test or because the individual refused to submit to a genetic test or provide information from a genetic test.

The substitute provides standards and procedures for obtaining, retaining and disclosing genetic information. The substitute prohibits any person from obtaining genetic information from an individual, or

from an individual's DNA sample without first obtaining informed consent from the individual or the individual's representative, except under certain limited circumstances set forth in the substitute.

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 set forth in the substitute. The substitute 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 set forth in the substitute.

The substitute 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 circumstances set forth in the substitute.

The substitute 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.

The substitute also 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.