

September 19, 1996

**SENATE COMMITTEE SUBSTITUTE FOR
SENATE BILL NOS. 695 AND 854**

To the Senate:

Pursuant to Article V, Section I, Paragraph 14 of the New Jersey Constitution, I am returning Senate Committee Substitute for Senate Bill Nos. 695 and 854 with my recommendations for reconsideration.

A. Summary of the Bill

This bill, the Genetic Privacy Act, regulates genetic testing and the retention and disclosure of information obtained from genetic tests. The bill provides protection from insurance and employment discrimination on the basis of genetic information and from unauthorized genetic testing and the unauthorized use of genetic information.

The bill prohibits issuers of life insurance, annuities, or disability income insurance contracts from discriminating unfairly against insureds with regard to genetic information or to the insured's refusal to submit to a genetic test or to make available the results of a genetic test. It also requires that a life, disability-income, or annuity insurer that intends to apply the results of a genetic test to its underwriting or its determination of insurability must notify the subject of the genetic test that he or she may designate a physician or other health care professional to receive a copy of the test results and, if required, an interpretation of the results by a qualified professional. The person must state in writing whether he or she chooses to be given the test results.

The bill amends the Law Against Discrimination to make it an unlawful employment practice for an employer either to refuse to hire or to discharge a person on the basis of genetic information or because of the person's refusal to submit to a genetic test or to make available the results of a genetic test to an employer.

The bill declares that a person's genetic information is that person's property. It also provides standards and procedures for

obtaining, retaining, and disclosing genetic information, and specifies when genetic samples and DNA samples may be retained or must be destroyed.

The bill provides penalties for unauthorized and improper disclosure of genetic information.

B. Recommended Action

I commend the Legislature for passing this important legislation. Remarkable technological advances in the field of genetics have given us access to new information that will prove invaluable in assessing the risk of developing various diseases. As genetic testing becomes more widespread, however, so does the danger that the information will be used improperly to harm the very people it is intended to help. This bill is designed to avoid that danger by clarifying privacy rights and prohibiting discrimination based on information obtained through genetic testing. These are important goals, and I salute the Legislature for addressing them in such a timely and comprehensive fashion.

I am concerned, however, that the bill as drafted will result in unintended and harmful consequences. Specifically, the establishment of a new property right is a fundamental change from current practice that will have unintended but troubling consequences for research. A property right in genetic information is not needed to effectuate the bill's main purposes of protecting privacy and preventing discrimination. The provision may burden and eventually inhibit research, and it may cause some researchers to stop conducting clinical trials in New Jersey.

One consequence of creating a property right in genetic information is that a person could assert that right to seek royalties if genetic information from his or her tissue was used in the research that led to the development of drugs, diagnostic tests, or patents. Although participants in clinical trials and research are free to negotiate the terms of their participation in a study, including terms of

compensation, the creation of a new statutory property right could lead to a proliferation of litigation in New Jersey -- litigation that could have a chilling effect on scientific research. I am also advised that creating a property right would impose a de facto requirement that researchers notify anyone whose genetic information was used or is intended to be used in the course of research. That would further burden research, especially in cases where research is based on data from a stored sample. For researchers who use encrypted data, notification would actually have the effect of lessening the privacy protections that encryption provides.

In short, creating a property right could result in complicated social, legal, and policy consequences -- including some that no one can foresee at this time. Rather than create a new right that is not necessary to further the bill's goals and has the potential to create a wide range of problems, I propose deleting it from the bill.

In addition, the Commissioner of Health and Senior Services advises that the bill's informed consent guidelines may impede research and clinical trials because they do not take into account federal guidelines that researchers widely follow. I therefore propose to amend the bill to permit the Commissioner of Health and Senior Services to adopt federal guidelines when promulgating rules on informed consent.

In addition to addressing issues related to the property right and informed consent, I propose to amend the bill to eliminate disparate treatment of insurance companies. The Commissioner of Banking and Insurance advises me that in its current form the bill establishes separate standards for various types of insurance. To prevent any confusion that might undermine the effectiveness of those standards, I recommend that the unfair-discrimination standard in the bill, which applies to issuers of life insurance, annuities, and disability income insurance contracts, also apply to issuers of credit life insurance and credit accident insurance.

In summary, I recommend that the bill be amended as follows:

1. Delete the section of the bill that creates a property right in genetic information.
2. Permit the Commissioner of Health and Senior Services to adopt federal guidelines when promulgating rules on informed consent.
3. Amend the provision regarding the duty to provide notice to the tested person that genetic testing was performed. The bill requires any person who performs genetic testing to provide such notice. I recommend that the bill be amended to impose that requirement on a person who requires or requests the testing. That will ensure that the requirement falls only on an insurance company or employer who requests testing, not on a researcher or research laboratory.
4. Apply the unfair-discrimination standard to issuers of credit life insurance and credit accident insurance, in addition to issuers of life insurance, annuities, and disability income insurance contracts.

Therefore, I herewith return Senate Committee Substitute for Senate Bill Nos. 695 and 854 and recommend that it be amended as follows:

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| <u>Page 2, Section 3, Line 35:</u> | Delete "health or credit life or credit" |
| <u>Page 2, Section 3, Line 36:</u> | Delete "accident" and "coverage" |
| <u>Page 3, Section 3, Line 9:</u> | After "in the" insert "issuance, withholding, extension or renewal of"; delete "underwriting of or determining insurability" |
| <u>Page 3, Section 3, Line 10:</u> | Delete "for"; after "insurance," insert "including credit life insurance,"; after "annuity" insert "," and delete "or" |
| <u>Page 3, Section 3, Line 11:</u> | After "contract" insert "or credit accident insurance coverage" |
| <u>Page 3, Section 3, Line 23:</u> | After "insurance," insert "including credit life insurance,"; after "annuity" insert "," and delete "or"; after "contract" insert "or credit accident insurance coverage" |

- Page 16, Section 6, Line 39: After "representative" add "according to regulations promulgated by the Commissioner of Health and Senior Services, in consultation with the Commissioner of Banking and Insurance, pursuant to subsection b. of section 9 of P.L. , c. (now pending before the Legislature as this bill)"
- Page 17, Section 7, Line 13: Delete "An individual's genetic information is the"
- Page 17, Section 7, Line 14: Delete in its entirety.
- Page 17, Section 7, Line 15: Delete "b."
- Page 17, Section 7, Line 16: After "authorization" insert "under the informed consent requirement of section 6 of P.L. , c. (now pending before the Legislature as this bill)"
- Page 17, Section 7, Line 23: Delete "or"
- Page 17, Section 7, Line 26: Delete "." insert "; or (5) Retention of information is for anonymous research where the identity of the subject will not be released."
- Page 17, Section 7, Line 27: Delete "c." insert "b."
- Page 17, Section 7, Line 35: Delete "d." insert "c."
- Page 17, Section 7, Line 40: Delete "e." insert "d."
- Page 17, Section 7, Line 44: Delete "f." insert "e."
- Page 17, Section 7, Line 46: After "individual" insert "unless the individual directs otherwise by informed consent pursuant to section 6 of P.L. , c. (now pending before the Legislature as this bill)"
- Page 18, Section 7, Line 3: Delete "g." insert "f."
- Page 17, Section 8, Line 27: After "Health" insert "and Senior Services"
- Page 18, Section 9, Line 43: After "person" insert "who requires or requests"; delete "performs"
- Page 18, Section 9, Line 43: After "testing" insert "be done"
- Page 18, Section 9, Line 45: After "performed" delete "or" and insert "and"
- Page 18, Section 9, Line 46: Delete "information was" and insert "records, results or findings were"
- Page 18, Section 9, Line 46: After "received" insert "unless"

otherwise directed by informed consent pursuant to section 6 of P.L. , c. (now pending before the Legislature as this bill)"

Page 19, Section 9, Line 5:

After "Health" insert "and Senior Services, in consultation with the Commissioner of Banking and Insurance,"

Page 19, Section 9, Line 9:

Delete "which shall include a description of" insert "except where the procedures for obtaining informed written consent already are governed by national standards for informed consent as designated by the Commissioner of Health and Senior Services by regulation, which may include but need not be limited to guidelines from the Office of Protection for Research Risk, the Food and Drug Administration or other appropriate federal agencies."

Page 19, Section 9, Lines 10-13:

Delete in their entirety.

Respectfully,

/s/ Christine Todd Whitman

Governor

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Attest:

/s/ Michael P. Torpey

Chief Counsel to the Governor