


**Effective: [See Text Amendments]**

New Jersey Statutes Annotated [Currentness](#)

Title 10. Civil Rights

 [Chapter 5. Law Against Discrimination \(Refs & Annos\)](#)

**→ 10:5-43. Short title; Genetic Privacy Act**

Sections 1 through 10 of this act [\[FN1\]](#) shall be known and may be cited as the "Genetic Privacy Act."

CREDIT(S)

[L.1996, c. 126, § 1, eff. Nov. 19, 1996.](#)

[\[FN1\] N.J.S.A. §§ 10:5-5, 10:5-12, 10:5-43 to 10:5-49, 17B:30-12.](#)

GOVERNOR'S CONDITIONAL VETO MESSAGE

2002 Main Volume

**Senate Bill Nos. 695 and 854--L.1996, c.126**

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 obtaining, retaining, and disclosing genetic information, and specifies when genetic samples

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and DNA samples may be retained or must be destroyed.

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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:

\* \* \*

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Respectfully,

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/s/ Christine Todd Whitman  
Governor

#### HISTORICAL AND STATUTORY NOTES

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##### **Title of Act:**

An Act concerning genetic testing and privacy and medical underwriting, amending [N.J.S. 17B:30-12](#), amending and supplementing P.L.1945, c. 169 and supplementing Titles 17 and 26 of the Revised Statutes and Title 17B of the New Jersey Statutes. L.1996, c. 126.


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Age of new genetics tests, familiar legal concepts. James A. Robertson and Elizabeth D'Apolito, [166 N.J.L.J. 1024 \(2001\)](#).

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Constitutional Law  214, 274(5).

Health  642.

Westlaw Topic Nos. 78, 92, 198H.

[C.J.S. Civil Rights § § 2 to 10, 14 to 19, 21, 23, 24, 102 to 104, 107, 122, 143, 144, 146, 157, 160, 201 to 212, 214 to 217.](#)

[C.J.S. Constitutional Law § § 464, 717, 1248 to 1254.](#)

N. J. S. A. 10:5-43, NJ ST 10:5-43

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Title 10. Civil Rights

 [Chapter 5](#). Law Against Discrimination ([Refs & Annos](#))

**→ 10:5-44. Legislative findings and declaration**

The Legislature finds and declares:

- a. The DNA molecule contains information about an individual's probable medical future. This information is written in a code that is rapidly being broken.
- b. Genetic information is personal information that should not be collected, retained or disclosed without the individual's authorization.
- c. The improper collection, retention or disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance.
- d. An analysis of an individual's DNA provides information not only about an individual, but also about the individual's parents, siblings and children, thereby impacting family privacy, including reproductive decisions.
- e. Current legal protections for medical information, tissue samples and DNA samples are inadequate to protect genetic privacy.
- f. Laws for the collection, storage and use of identifiable DNA samples and private genetic information obtained from those samples are needed both to protect individual privacy and to permit legitimate genetic research.
- g. 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.
- h. 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.

CREDIT(S)

[L.1996, c. 126, § 2, eff. Nov. 19, 1996.](#)

**HISTORICAL AND STATUTORY NOTES**

2002 Main Volume

**Statement:** Governor's conditional Veto Message to Senate Bill Nos.695 and 854--L.1996, c.126, see§ 10:5-43.

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Westlaw Topic Nos. 78, 92, 198H.

[C.J.S. Civil Rights § § 2 to 10, 14 to 19, 21, 23, 24, 102 to 104, 107, 122, 143, 144, 146, 157, 160, 201 to 212, 214 to 217.](#)

[C.J.S. Constitutional Law § § 464, 717, 1248 to 1254.](#)

N. J. S. A. 10:5-44, NJ ST 10:5-44

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Title 10. Civil Rights

[Chapter 5.](#) Law Against Discrimination ([Refs & Annos](#))

**→ 10:5-45. Genetic information not to be obtained without prior informed consent; exceptions**

No person shall obtain 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 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.1996, c. 126 (C. 10:5-48).

a. The requirements of this section shall not apply to genetic information obtained:

- (1) By a State, county, municipal or federal law enforcement agency for the purposes of establishing the identity of a person in the course of a criminal investigation or prosecution;
- (2) To determine paternity in accordance with the provisions of section 11 of P.L.1983, c. 17 (C. 9:17-48);
- (3) Pursuant to the provisions of the "DNA Database and Databank Act of 1994," P.L.1994, c. 136 (C. 53:1-20.17 et seq.);
- (4) To determine the identity of deceased individuals;
- (5) For anonymous research where the identity of the subject will not be released;
- (6) Pursuant to newborn screening requirements established by State or federal law; or
- (7) As authorized by federal law for the identification of persons.

b. In the case of a policy of life insurance or a disability income insurance contract, informed consent shall be obtained pursuant to the provisions of P.L.1985, c. 179 (C. 17:23A-1 et seq.).

CREDIT(S)

[L.1996, c. 126, § 6.](#)

**HISTORICAL AND STATUTORY NOTES**

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L.1996, c. 126, § 17, approved Nov. 17, 1996, provided:

"This act shall take effect immediately [Nov. 19, 1996] and the provisions of sections 6 and 7 [§ § 10:5-45, 10:5-46] shall apply to genetic information obtained on or after the effective date of this act."


**Statement:** Governor's conditional Veto Message to Senate Bill Nos.695 and 854--L.1996, c.126, see§ 10:5-43.

Wearing your genes to work: Use of genetic information in hiring. E. David Krulewicz, 15 NJ Lawyer News. 603 (March 20, 2006).

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Constitutional Law  214, 274(5).

Criminal Law  1224(3).

Health  642.

Searches and Seizures  78.

Westlaw Topic Nos. 76H, 78, 92, 110, 198H, 349.

[C.J.S. Children Out-of-Wedlock § § 75, 76.](#)

[C.J.S. Civil Rights § § 2 to 10, 14 to 19, 21, 23, 24, 102 to 104, 107, 122, 143, 144, 146, 157, 160, 201 to 212, 214 to 217.](#)

[C.J.S. Constitutional Law § § 464, 717, 1248 to 1254.](#)

[C.J.S. Criminal Law § 1727.](#)

[C.J.S. Searches and Seizures § § 31, 103 to 107.](#)

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N. J. S. A. 10:5-45, NJ ST 10:5-45

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**Effective: [See Text Amendments]**

New Jersey Statutes Annotated [Currentness](#)

Title 10. Civil Rights

[Chapter 5. Law Against Discrimination \(Refs & Annos\)](#)

**→ 10:5-46. Prior informed consent required for retention of genetic information; exceptions**

a. No person shall retain an individual's genetic information without first obtaining authorization under the informed consent requirement of section 6 of P.L.1996, c. 126 (C. 10:5-45) from the individual or the individual's representative, unless:

- (1) Retention is necessary for the purposes of a criminal or death investigation or a criminal or juvenile proceeding;
- (2) Retention is necessary to determine paternity in accordance with the provisions of section 11 of P.L.1983, c. 17 (C. 9:17-48);
- (3) Retention is authorized by order of a court of competent jurisdiction;
- (4) Retention is made pursuant to the provisions of the "DNA Database and Databank Act of 1994," P.L.1994, c. 136 (C. 53:1-20.17 et seq.); or
- (5) Retention of information is for anonymous research where the identity of the subject will not be released.

b. The DNA sample of an individual from which genetic information has been obtained shall be destroyed promptly upon the specific request of that individual or the individual's representative, unless:

- (1) Retention is necessary for the purposes of a criminal or death investigation or a criminal or juvenile proceeding; or
- (2) Retention is authorized by order of a court of competent jurisdiction.

c. A DNA sample from an individual who is the subject of a research project shall be destroyed promptly upon completion of the project or withdrawal of the individual from the project, whichever occurs first, unless the individual or the individual's representative directs otherwise by informed consent.

d. A DNA sample from an individual for insurance or employment purposes shall be destroyed promptly after the purpose for which the sample was obtained has been accomplished unless retention is authorized by order of a court of competent jurisdiction.

e. An individual or an individual's representative, promptly upon request, may inspect, request correction of and obtain genetic information from the records of the individual unless the individual directs otherwise by informed consent pursuant to section 6 of P.L.1996, c. 126 (C. 10:5-45); except that, in the case of a policy of life insurance or a disability income insurance contract, the provisions of P.L.1985, c. 179 (C. 17:23A-1 et seq.) shall apply.

f. This section applies only to genetic information that can be identified as belonging to an individual or family. This section does not apply to any law, contract or other arrangement that determines a person's rights to compensation relating to substances or information derived from an individual's DNA sample.

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CREDIT(S)

[L.1996, c. 126, § 7.](#)

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L.1996, c. 126, § 17, approved Nov. 17, 1996, provided:

"This act shall take effect immediately [Nov. 19, 1996] and the provisions of sections 6 and 7 [§ § 10:5-45, 10:5-46] shall apply to genetic information obtained on or after the effective date of this act."

**Statement:** Governor's conditional Veto Message to Senate Bill Nos.695 and 854--L.1996, c.126, see§ 10:5-43.


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[C.J.S. Children Out-of-Wedlock § § 75, 76.](#)

[C.J.S. Constitutional Law § § 464, 1248 to 1254.](#)

[C.J.S. Criminal Law § 1727.](#)

[C.J.S. Searches and Seizures § § 31, 103 to 107.](#)

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Title 10. Civil Rights

[Chapter 5.](#) Law Against Discrimination ([Refs & Annos](#))

**→ 10:5-47. Disclosure of identity**

a. Regardless of the manner of receipt or the source of genetic information, including information received from an individual, a person may not disclose or be compelled, by subpoena or any other means, 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, unless:

- (1) Disclosure is necessary for the purposes of a criminal or death investigation or a criminal or juvenile proceeding;
- (2) Disclosure is necessary to determine paternity in accordance with the provisions of section 11 of P.L.1983, c. 17 (C. 9:17-48);
- (3) Disclosure is authorized by order of a court of competent jurisdiction;
- (4) Disclosure is made pursuant to the provisions of the "DNA Database and Databank Act of 1994," P.L.1994, c. 136 (C. 53:1-20.17 et seq.);
- (5) Disclosure is authorized by the tested individual or the tested individual's representative by signing a consent which complies with the requirements of the Department of Health and Senior Services;
- (6) Disclosure is for the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent;
- (7) Disclosure is for the purpose of identifying bodies;
- (8) Disclosure is pursuant to newborn screening requirements established by State or federal law;
- (9) Disclosure is authorized by federal law for the identification of persons; or
- (10) Disclosure is by an insurer pursuant to the requirements of P.L.1985, c. 179 (C. 17:23A-1 et seq.).

b. The provisions of this section apply to any subsequent disclosure by any person after another person has disclosed genetic information or the identity of an individual upon whom a genetic test has been performed.

CREDIT(S)

[L.1996, c. 126, § 8, eff. Nov. 19, 1996.](#)

**HISTORICAL AND STATUTORY NOTES**

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**Statement:** Governor's conditional Veto Message to Senate Bill Nos.695 and 854--L.1996, c.126, see§ 10:5-43.

N.J.S.A. 10:5-49






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[C.J.S. Children Out-of-Wedlock § § 75, 76.](#)  
[C.J.S. Constitutional Law § § 464, 1248 to 1254.](#)  
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[C.J.S. Searches and Seizures § § 31, 103 to 107.](#)

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Title 10. Civil Rights

 [Chapter 5. Law Against Discrimination \(Refs & Annos\)](#)

**→ 10:5-48. Notice to person tested; rules and regulations for obtaining informed consent**

a. A person who requires or requests that genetic testing be done or receives records, results or findings of genetic testing shall provide the person tested with notice that the test was performed and that the records, results or findings were received unless otherwise directed by informed consent pursuant to section 6 of P.L.1996, c. 126 (C. 10:5-45). The notice shall state that the information may not be disclosed to any person without the written consent of the person tested, unless disclosure is made pursuant to one of the exceptions provided for in section 8 of P.L.1996, c. 126 (C. 10:5-47).

b. The Commissioner of Health and Senior Services, in consultation with the Commissioner of Banking and Insurance, shall promulgate regulations pursuant to the provisions of the "Administrative Procedure Act," P.L.1968, c. 410 (C. 52:14B-1 et seq.) governing procedures for obtaining informed written consent pursuant to P.L.1996, c. 126, 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.

c. The provisions of this section shall not apply to newborn screening requirements established by State or federal law.

CREDIT(S)

[L.1996, c. 126, § 9, eff. Nov. 19, 1996.](#)

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Title 10. Civil Rights

 [Chapter 5.](#) Law Against Discrimination ([Refs & Annos](#))

**→ 10:5-49. Violations; penalties**

a. Any person violating the provisions of sections 6 through 9, inclusive, of P.L.1996, c. 126 (C. 10:5-45 through 10:5-48) shall be a disorderly person and shall be punished by a fine of \$1,000, a prison term of six months, or both.

b. Any person who willfully discloses an individual's genetic information to any third party in violation of P.L. 1996, c. 126 shall be punished by a fine of \$5,000, a prison term of one year, or both.

c. Any person who discloses an individual's genetic information in violation of P.L.1996, c. 126, 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.

CREDIT(S)

[L.1996, c. 126, § 10, eff. Nov. 19, 1996.](#)

HISTORICAL AND STATUTORY NOTES

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