

MAINE STATE LEGISLATURE

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118th MAINE LEGISLATURE

FIRST REGULAR SESSION-1997

Legislative Document

No. 1243

S.P. 384

In Senate, February 25, 1997

An Act to Protect the Privacy of Genetic Information.

Reference to the Committee on Banking and Insurance suggested and ordered printed.

A handwritten signature in cursive script, reading "Joy J. O'Brien".

JOY J. O'BRIEN
Secretary of the Senate

Presented by Senator RAND of Cumberland.

Cosponsored by Senators: AMERO of Cumberland, JENKINS of Androscoggin, PARADIS of Aroostook, PINGREE of Knox, TREAT of Kennebec, Representatives: MITCHELL of Vassalboro, QUINT of Portland.

Be it enacted by the People of the State of Maine as follows:

2
4 **Sec. 1. 5 MRSA §4553, sub-§§5-B to 5-D** are enacted to read:

6 **5-B. Genetic characteristic.** "Genetic characteristic"
8 means any inherited gene or chromosome, or alteration of a gene
10 or chromosome, 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.

12 **5-C. Genetic information.** "Genetic information" means the
14 information concerning genes, gene products or inherited
characteristics that may derive from an individual or family
member.

16 **5-D. Genetic test.** "Genetic test" means a test for
18 determining the presence or absence of an inherited genetic
characteristic in an individual, including tests of nucleic acids
20 such as deoxyribonucleic acid, or DNA, ribonucleic acid, or RNA,
and mitochondrial DNA, chromosomes or proteins in order to
22 identify a predisposing genetic characteristic.

24 **Sec. 2. 5 MRSA §4572, sub-§1, §A,** as amended by PL 1991, c.
26 885, Pt. E, §7 and affected by §47, is further amended to read:

28 A. For any employer to fail or refuse to hire or otherwise
30 discriminate against any applicant for employment because of
32 race or color, sex, physical or mental disability, religion,
34 age, ancestry, genetic information or national origin,
36 because of the applicant's previous assertion of a claim or
38 right under former Title 39 or Title 39-A, or because of the
refusal to submit to a genetic test or make available the
results of a genetic test to an employer or because of
40 previous actions taken by the applicant that are protected
42 under Title 26, chapter 7, subchapter V-B; or, because of
44 those reasons, to discharge an employee or discriminate with
46 respect to hire, tenure, promotion, transfer, compensation,
48 terms, conditions or privileges of employment or any other
50 matter directly or indirectly related to employment; or, in
recruiting of individuals for employment or in hiring them,
to utilize any employment agency that the employer knows or
has reasonable cause to know discriminates against
individuals because of their race or color, sex, physical or
mental disability, religion, age, ancestry genetic
information or national origin, because of their previous
assertion of a claim or right under former Title 39 or Title
39-A or because of previous actions that are protected under
Title 26, chapter 7, subchapter V-B;

(1) This paragraph does not apply to discrimination governed by Title 39-A, section 353;

Sec. 3. 5 MRSA c. 503 is enacted to read:

CHAPTER 503

GENETIC INFORMATION

§19301. Definitions

As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings.

1. Genetic characteristic. "Genetic characteristic" means any inherited gene or chromosome, or alteration of a gene or chromosome, 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.

2. Genetic information. "Genetic information" means the information concerning genes, gene products or inherited characteristics that may derive from an individual or family member.

3. Genetic test. "Genetic test" means a test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as deoxyribonucleic acid, or DNA, ribonucleic acid, or RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic.

§19302. Informed consent

1. Informed consent required. A person may not 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 rules adopted by the Commissioner of Human Services, in consultation with the Superintendent of Insurance under section 19306.

2. Exception. Subsection 1 does not apply to genetic information obtained:

A. By a state, county, municipal or federal law enforcement agency for the purposes of establishing the identity of an individual in the course of a criminal investigation or prosecution;

2 B. To determine paternity in accordance with the provisions
3 of Title 19-A, chapter 53;

4 C. Pursuant to Title 25, chapter 194;

6 D. To determine the identity of deceased individuals;

8 E. For research if the identity of the subject will not be
9 released;

10 F. Pursuant to newborn screening requirements established
11 by state or federal law; or

14 G. As authorized by federal law for the identification of
15 individuals.

16 **§19303. Retention of genetic information**

18 **1. Informed consent required.** A person may not retain an
19 individual's genetic information without first obtaining
20 authorization under the informed consent requirement of section
21 19302 from the individual or the individual's representative,
22 unless:

24 A. Retention of the individual's genetic information is
25 necessary for the purposes of a criminal or death
26 investigation or a criminal or juvenile proceeding;

28 B. Retention of the individual's genetic information is
29 necessary to determine paternity in accordance with the
30 provisions of Title 19-A, chapter 53;

32 C. Retention of the individual's genetic information is
33 authorized by order of a court of competent jurisdiction;

36 D. Retention of the individual's genetic information is
37 necessary pursuant to the provisions of Title 25, chapter
38 194; or

40 E. Retention of the individual's genetic information is for
41 research if the identity of the subject will not be released.

42 **2. Destruction on request.** The DNA sample of an individual
43 from which genetic information has been obtained must be
44 destroyed promptly upon specific request of the individual or the
45 individual's representative unless:

48 A. Retention of the individual's DNA sample is necessary
49 for the purposes of a criminal or death investigation or a
50 criminal or juvenile proceeding; or

2 B. Retention of the individual's DNA sample is authorized
3 by order of a court of competent jurisdiction.

4
5 3. Research projects. A DNA sample from an individual who
6 is the subject of a research project must be destroyed promptly
7 upon completion of the project or withdrawal of the individual
8 from the project, whichever occurs first, unless the individual
9 or the individual's representative directs otherwise by informed
10 consent.

11 4. Insurance or employment purposes. A DNA sample from an
12 individual for insurance or employment purposes must be destroyed
13 promptly after the purpose for which the sample was obtained has
14 been accomplished unless retention is authorized by order of a
15 court of competent jurisdiction.

16 5. Right to obtain information. An individual or an
17 individual's representative, upon request, may inspect, request
18 correction of and obtain genetic information from the records of
19 the individual unless the individual directs otherwise by
20 informed consent pursuant to section 19302.

21 6. Application of this section. This section applies only
22 to genetic information that can be identified as belonging to an
23 individual or family. This section does not apply to any law,
24 contract or other arrangement that determines an individual's
25 rights to compensation relating to substances or information
26 derived from that individual's DNA sample.

27 §19304. Disclosure of genetic information

28 1. Authorized disclosure. Regardless of the manner of
29 receipt or the source of genetic information, including
30 information received from an individual, a person may not
31 disclose or be compelled, by subpoena or any other means, to
32 disclose the identity of an individual upon whom a genetic test
33 has been performed or to disclose genetic information about the
34 individual in a manner that permits identification of the
35 individual, unless:

36 A. Disclosure is necessary for the purposes of a criminal
37 or death investigation or a criminal or juvenile proceeding;

38 B. Disclosure is necessary to determine paternity in
39 accordance with the provisions of Title 19-A, chapter 53;

40 C. Disclosure is authorized by order of a court of
41 competent jurisdiction;

42

2 D. Disclosure is made pursuant to Title 25, chapter 194;

4 E. Disclosure is authorized by the tested individual or
6 the tested individual's representative by signing a consent
 that complies with the rules adopted by the Commissioner of
 Human Services;

8 F. Disclosure is for the purpose of furnishing genetic
10 information relating to a decedent for medical diagnosis or
 blood relatives of the decedent;

12 G. Disclosure is for the purpose of identifying a dead body;

14 H. Disclosure is pursuant to newborn screening requirements
 established by state or federal law; or

16 I. Disclosure is authorized by federal law for the
18 identification of individuals.

20 2. Subsequent disclosure. This section applies to a
22 subsequent disclosure by any person after another person has
 disclosed genetic information or the identity of an individual
24 upon whom a genetic test has been performed.

26 **§19305. Notice of genetic testing**

28 A person who requires or requests that genetic testing be
30 done or receives records, results or findings of genetic testing
32 shall provide notice to the individual tested that the test was
34 performed and that the records, results or findings were received
 unless otherwise directed by informed consent pursuant to section
 19302. The notice must state that the information may not be
 disclosed to any person without the written consent of the
 individual tested, unless disclosure is made pursuant to one of
 the exceptions in section 19302.

36 This section does not apply to newborn screening
38 requirements established by state or federal law.

40 **§19306. Rules for informed consent**

42 The Commissioner of Human Services, in consultation with the
44 Superintendent of Insurance, shall adopt rules pursuant to
46 chapter 375, subchapter II governing procedures for obtaining
48 informed written consent pursuant to this chapter, except when
 the procedures for obtaining informed written consent are
 governed by national standards for informed consent as designated
 by the Commissioner of Human Services, by rule, which may
 include, but are not limited to, guidelines from the Office of
50 Protection for Research Risk, the Food and Drug Administration or

2 other appropriate federal agencies. Rules adopted under this
3 section are routine technical rules under chapter 375, subchapter
4 II-A.

5 This section does not apply to newborn screening
6 requirements established by state or federal law.

7 **§19307. Penalties**

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10 **1. Unlawful disclosure.** A person who violates the
11 provisions of this chapter commits unlawful disclosure. Unlawful
12 disclosure is a Class E crime.

13
14 **2. Willful disclosure.** A person who willfully discloses an
15 individual's genetic information to a 3rd party in violation of
16 this chapter commits willful disclosure. Willful disclosure is a
17 Class D crime.

18
19 **3. Restitution.** A person who discloses an individual's
20 genetic information in violation of this chapter is liable to the
21 individual for all actual damages, including damages for
22 economic, bodily or emotional harm that is proximately caused by
23 the disclosure. Payment under this subsection may be ordered by
24 a criminal court in which the person has been found guilty of a
25 violation of this chapter or in a civil action brought by the
26 individual whose genetic information was disclosed.

27 **Sec. 4. 24-A MRSA §2159-C is enacted to read:**

28
29 **§2159-C. Discrimination on the basis of genetic information or**
30 **testing**

31
32
33 **1. Discrimination in health and hospital insurance.** An
34 insurer, nonprofit hospital and medical service organization or
35 health maintenance organization that issues group or individual
36 hospital, health or dental insurance may not discriminate
37 against an individual or eligible dependent on the basis of
38 genetic characteristics, genetic information or the refusal to
39 submit to a genetic test or make available the results of a
40 genetic test to the person in the issuance, withholding,
41 extension or renewal of any hospital confinement or other health
42 insurance, as defined by the superintendent, by rule, or in the
43 fixing of the rates, terms or conditions for that insurance, or
44 in the issuance or acceptance of any application for that
45 insurance.

46
47 **2. Discrimination in life and disability insurance.** A
48 person may not make or permit any unfair discrimination against
49 an individual in the application of the results of a genetic test
50 or genetic information in the issuance, withholding, extension or

2 renewal of an insurance policy covered by this Title, including
3 but not limited to, life insurance, including credit life
4 insurance, an annuity, disability income insurance contract or
5 credit accident insurance coverage. If the superintendent has
6 reason to believe that unfair discrimination has occurred,
7 including that the application of the results of a genetic test
8 is not reasonably related to anticipated claim experience and
9 that a proceeding by the superintendent is in the interest of the
10 public, the superintendent, in accordance with chapter 3, shall
11 serve upon the insurer a statement of the charges. Upon a
12 determination that the practice or act of the insurer is in
13 conflict with this section, the superintendent shall issue an
14 order requiring the insurer to cease and desist from engaging in
15 the practice or act and may order payment of a penalty consistent
16 with the provisions of section 12-A.

17 If, in the issuance, withholding, extension or renewal of a
18 policy of life insurance, including credit life insurance, an
19 annuity, disability income insurance contract or credit accident
20 insurance coverage, an insurer uses the results of a genetic test
21 in compliance with this subsection, the insurer shall notify the
22 individual who is the subject of the genetic test that such a
23 test is required and obtain the individual's written informed
24 consent for the test before the administration of the test in
25 accordance with Title 5, section 19306. The insurer shall ensure
26 that the physician, or other health care professional, designated
27 by the individual promptly receives a copy of the results of the
28 test, if required, an interpretation of the test results by a
29 qualified professional and that the individual states in writing
30 whether the individual wishes to be informed of the results of
31 the test.

32 **3. Definitions.** As used in this section, unless the
33 context otherwise indicates, the following terms have the
34 following meanings.

35 A. "Genetic characteristic" means any inherited gene or
36 chromosome, or alteration of a gene or chromosome, that is
37 scientifically or medically believed to predispose an
38 individual to a disease, disorder or syndrome or to be
39 associated with a statistically significant increased risk
40 of development of a disease, disorder or syndrome.

41 B. "Genetic information" means the information concerning
42 genes, gene products or inherited characteristics that may
43 be obtained from an individual or family member.

44 C. "Genetic test" means a test for determining the presence
45 or absence of an inherited genetic characteristic in an
46 individual, including tests of nucleic acids such as DNA,

2 RNA and mitochondrial DNA, chromosomes or proteins in order
3 to identify a predisposing genetic characteristic.

4
5 **SUMMARY**

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7 This bill provides measures for the protection of the
8 privacy of genetic information. It prohibits discrimination in
9 any form of insurance regulated by the Bureau of Insurance on the
10 basis of genetic information and requires informed consent for
11 obtaining genetic information. It also provides individuals who
12 are tested the right to inspect genetic information concerning
13 them and to be informed of the results of genetic tests. The
14 bill also prohibits discrimination in employment on the basis of
15 genetic information.
16