

LC01614

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2003

A N A C T

RELATING TO GENETIC TESTING -- EMPLOYMENT DISCRIMINATION AND CONFIDENTIALITY

Introduced By: Representatives E Coderre, Lewiss, Ginaitt, Ajello, and Giannini

Date Introduced: February 11, 2003

Referred To: House Labor

It is enacted by the General Assembly as follows:

SECTION 1. Sections 28-6.7-1, 28-6.7-2.1, 28-6.7-3, 28-6.7-4 and 28-6.7-5 of the General Laws in Chapter 28-6.7 entitled "Genetic Testing as a Condition of Employment" are hereby repealed.

~~28-6.7-1. Genetic testing prohibited.~~ — (a) No employer, employment agency, or licensing agency shall directly or indirectly:

~~(1) Request, require or administer a genetic test to any employee, licensee, or applicant for employment or licensure;~~

~~(2) Affect the terms, conditions, or privileges of employment or licensure or terminate the employment or licensure of any person who obtains a genetic test;~~

~~(3) Deny employment or deny an application for an occupational license, or suspend, revoke, or refuse to renew an occupational license; or take any other action affecting the terms, conditions or privileges of employment against an employee or a license holder based directly or indirectly on the refusal of the employee, licensee or applicant for employment or licensure to:~~

~~(i) Submit to a genetic test;~~

~~(ii) Submit a family health history; or~~

~~(iii) Reveal:~~

~~(A) Whether the employee, applicant or holder has submitted to a genetic test; or~~

~~(B) The results of any genetic test to which the employee, applicant or holder has~~

submitted;

~~(4) Otherwise use genetic information to adversely affect the employment, licensure, or application for employment or licensure of any individual; or~~

~~(5) Reveal genetic information about employees, licensees, or applicants.~~

~~(b) No person may sell to or interpret for an employer, employment agency, or licensing agency a genetic test of a current or prospective employee or licensee.~~

28-6.7-2.1. Definitions. For the purposes of this chapter:

~~(1) "Employer" includes the state, and all political subdivisions of the state, and any person in this state employing individuals, and any person acting in the interest of an employer directly or indirectly.~~

~~(2) "Employment agency" includes any person undertaking with or without compensation to procure opportunities to work, or to procure, recruit, refer, or place employees.~~

~~(3) "Genetic information" means information about genes, gene product, or inherited characteristics that may derive from the individual or a family member and includes information concerning whether or not the individual or family member has sought or obtained a genetic test.~~

~~(4) "Genetic testing" means the analysis of an individual's DNA, RNA, chromosomes, proteins and certain metabolites in order to detect heritable disease related genotypes, mutations, phenotypes or karyotypes for clinical purposes. These purposes include predicting risk of disease, identifying carriers, establishing prenatal and clinical diagnosis or prognosis, prenatal newborn and carrier screening, as well as testing in high risk families. Tests for metabolites are covered only when they are undertaken with high probability that an excess or deficiency of the metabolite indicates the presence of heritable mutations in single genes. "Genetic testing" does not mean routine physical measurement, a routine chemical, blood, or urine analysis or a test for drugs or for infections; however, any genetic information, as defined in this section, revealed by the routine tests or examinations is subject to the provisions of this chapter.~~

~~(5) "Licensing agency" means a state agency or political subdivision that issues an occupational license.~~

~~(6) "Occupational license" means a license, certificate, registration, permit, or other form of authorization required by law or rule that must be obtained by an individual to engage in a particular business or occupation.~~

~~(7) "Person" includes one or more individuals, partnerships, associations, organizations, corporations, legal representatives, trustees, trustees in bankruptcy, or receivers.~~

~~(8) "Political subdivision" means a municipality, county, or special district or authority. The term includes a school district.~~

~~(9) "State agency" means a department, board, bureau, commission, committee, division, office, council, or agency of state government.~~

~~**28-6.7-3. Penalties for violations** -- In any civil action alleging a violation of this chapter, the court may:~~

~~(1) Award to a prevailing applicant or employee punitive damages in addition to any award of actual damages, and reasonable attorneys' fees and costs; and~~

~~(2) Afford injunctive relief against any employer who commits or proposes to commit a violation of this chapter.~~

~~**28-6.7-4. Severability** -- If any provision of this chapter or the application of any provision to any person or circumstances is held invalid, that invalidity shall not affect other provisions or applications of the chapter, which can be given effect without the invalid provision or application, and to this end the provisions of this chapter are severable.~~

~~**28-6.7-5. No waiver permitted.** -- Any contract or agreement, which purports to waive the provisions of this chapter, is declared null and void as against public policy.~~

SECTION 2. Chapter 28-6.7 of the General Laws entitled "Genetic Testing as a Condition of Employment" is hereby amended by adding thereto the following sections:

28-6.7-6. Definitions. -- For the purposes of this chapter:

(1) "DNA" means deoxyribonucleic acid, which is located in the cells of the body and provides an individual's personal genetic blue print. DNA encodes genetic information that is the basis of human hereditary and forensic identification;

(2) "Family health history" means a history taken by a physician or genetic professional to ascertain genetic or medical information about an individual's family;

(3) "Genetic characteristic" means a scientifically or medically identifiable genetic or chromosomal variation, composition, or alteration that:

(i) is scientifically or medically believed to:

(A) predispose an individual to a disease, disorder, or syndrome; or

(B) be associated with a statistically significant increased risk of development of a disease, disorder, or syndrome; and

(ii) may or may not be associated with any symptom of an ongoing disease, disorder, or syndrome affecting an individual on the date that genetic information is obtained regarding that individual:

(4) "Genetic information" means information that is:

(i) obtained from or based on a scientific or medical determination of the presence or absence in an individual of a genetic characteristic; or

1 (ii) derived from the results of a genetic test performed on, or a family health history
2 obtained from, that individual:

3 (5) “Genetic testing” means the analysis of an individual’s DNA, RNA, chromosomes,
4 proteins and certain metabolites in order to detect heritable disease-related genotypes, mutations,
5 phenotypes or karyotypes for clinical purposes. Such purposes include predicting risk of disease,
6 identifying carriers, establishing prenatal and clinical diagnosis or prognosis. Prenatal, newborn
7 and carrier screening, as well as testing in high risk families may be included provided there is an
8 approved release by a parent or guardian. Tests for metabolites are covered only when they are
9 undertaken with high probability that an excess of deficiency of the metabolite indicates the
10 presence of heritable mutations in single genes. “Genetic testing” does not mean routine physical
11 measurement, a routine chemical, blood, or urine analysis or a test for drugs or for HIV
12 infections;

13 (6) “Licensing agency” means a state agency or political subdivision that issued an
14 occupational license;

15 (7) “Occupational license” means a license, certificate, registration, permit, or other form
16 of authorization required by law or rule that must be obtained by an individual to engage in a
17 particular business or occupation;

18 (8) “Political subdivision” means a municipality, county, or special district or authority.
19 The term includes a school district;

20 (9) “RNA” means ribonucleic acid;

21 (10) “State agency” means a department, board, bureau, commission, committee,
22 division, office, council, or agency of state government.

23 **28-6.7-7. Prohibitions. - - No employer, employment agency may deny employment,**
24 **and no licensing agency may deny an application for an occupational license, or suspend, revoke,**
25 **or refuse to renew an occupational license; or take any other disciplinary action against an**
26 **employee or a license holder based directly or indirectly on the refusal or the employee of license**
27 **applicant or license holder to:**

28 (1) submit to a genetic test;

29 (2) submit a family health history; or

30 (3) reveal:

31 (i) whether the employee, applicant or holder has submitted to a genetic test; or

32 (ii) the results of any genetic test to which the employee, applicant or holder has
33 submitted.

34 **28-6.7-8. Genetic information confidential - Exceptions. - - (a) Except as provided by**

1 subsections (c) and (d) of this section, genetic information is confidential and privileged
2 regardless of the source of the information. A person or entity that holds that information may not
3 disclose or be compelled to disclose, by subpoena or otherwise, genetic information about an
4 individual unless the disclosure is specifically authorized by the individual as provided by
5 subsection (b) of this section. This subsection applies to a redisclosure of genetic information by a
6 secondary recipient of the information after disclosure of the information by an initial recipient.

7 (b) An individual or the legal representative of an individual may authorize the disclosure
8 of genetic information relating to that individual through a written authorization that includes:

9 (1) a description of the information to be disclosed;

10 (2) the name of the person or entity to whom the disclosure is made; and

11 (3) the purpose for the disclosure.

12 (c) Genetic information relating to an individual may be disclosed without the
13 authorization required under subsection (b) of this section if the disclosure is:

14 (1) authorized under a state or federal criminal law relating to:

15 (i) the identification of individuals; or

16 (ii) a criminal or juvenile proceeding, including, but not limited to, the provisions of
17 RIGL chapter 12-1.5.

18 (2) required under a specific order of a state or federal court;

19 (3) authorized under a state or federal law to establish paternity pursuant to RIGL chapter
20 15-8-71;

21 (4) made to furnish genetic information relating to a decedent to the blood relatives of the
22 decedent for the purpose of medical diagnosis; or

23 (5) made to identify a decedent.

24 (d) In addition to the exceptions under subsection (c) of this section, genetic information
25 relating to an individual may be disclosed without the authorization required under subsection (b)
26 of this section if:

27 (1) the disclosure is for information from a research study in which the procedure for
28 obtaining informed written consent and use of the information is governed by national standards
29 for protecting participants involved in research projects, including guidelines issued under 21
30 C.F.R. Part 50 and 45 C.F.R. Part 46; or

31 (2) the information does not identify a particular individual.

32 **28-6.7-9. Right to know test results. -** An individual who submits to a genetic test has
33 the right to know the results of that test. On the written request of the individual, the entity that
34 performed the test shall disclose the test results to the individual or to a physician designated by

1 the individual.

2 **28-6.7-10. Retention of sample. - -** A sample of genetic material taken for a genetic test
3 from an individual shall be destroyed promptly after the purpose for which the sample was
4 obtained is accomplished unless:

5 (1) the sample is retained under a court order;

6 (2) the individual tested authorizes retention of the sample for purposes of medical
7 treatment or scientific research;

8 (3) for a sample obtained for research that is cleared by an institutional review board, the
9 sample is retained under the requirements that the institutional review board imposes on a specific
10 research project or as authorized by the research participant with institutional review board
11 approval under federal law; or

12 (4) retention is otherwise authorized under a state or federal law.

13 **28-6.7-11. Severability. - -** If any provision of this chapter or the application of any
14 provision to any person or circumstances is held invalid, that invalidity shall not affect other
15 provisions or applications of the chapter, which can be given effect without the invalid provision
16 or application, and to this end the provisions of this chapter are declared to be severable.

17 SECTION 3. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF
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RELATING TO GENETIC TESTING -- EMPLOYMENT DISCRIMINATION AND
CONFIDENTIALITY

1 This act would prohibit employers and employment agencies from denying employment,
2 and would prohibit licensing agencies from denying occupational licenses based on a refusal to
3 submit to genetic testing by the employee or applicant. This act also would provide for
4 confidentiality of genetic information with certain exceptions.

5 This act would take effect upon passage.

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