

FEB 4 2005
HUMAN RESOURCES

HOUSE FILE 214
BY JOCHUM

Passed House, Date _____ Passed Senate, Date _____
Vote: Ayes _____ Nays _____ Vote: Ayes _____ Nays _____
Approved _____

A BILL FOR

1 An Act relating to genetic testing, by regulating genetic testing
2 and information, prohibiting certain uses by employers,
3 insurers, and others, and providing exceptions and remedies.
4 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

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1 Section 1. Section 729.6, Code 2005, is amended by
2 striking the section and inserting in lieu thereof the
3 following:

4 729.6 TITLE OF ACT.

5 This subchapter shall be known and may be cited as the
6 "Genetic Testing Act".

7 Sec. 2. NEW SECTION. 729.7 DEFINITIONS.

8 As used in this subchapter, unless the context otherwise
9 requires:

10 1. "Employer" means the same as defined in section 216.2.

11 2. "Employment agency" means the same as defined in
12 section 94A.1.

13 3. "Genetic information" means information about genes,
14 gene product, or inherited characteristics that may derive
15 from an individual or an individual's family member.

16 4. "Genetic testing" means the analysis of an individual's
17 deoxyribonucleic acid, ribonucleic acid, chromosomes,
18 proteins, and certain metabolites in order to detect heritable
19 disease-related genotypes, mutations, phenotypes, or
20 karyotypes for clinical purposes, including predicting risk of
21 disease, identifying carriers, and establishing prenatal and
22 clinical diagnosis or prognosis. "Genetic testing" includes
23 prenatal, newborn, and carrier screening, and testing in high-
24 risk families if a parent or guardian approves a release for
25 such screening or testing. "Genetic testing" includes tests
26 for metabolites if the tests are undertaken with high
27 probability that an excess of deficiency of the metabolite
28 indicates the presence of heritable mutations in single genes.
29 "Genetic testing" does not mean routine physical measurement,
30 a routine chemical, blood, or urine analysis, or a test for
31 drugs or for human immunodeficiency virus infections.

32 5. "Labor organization" means the same as defined in
33 section 216.2.

34 6. "Licensing agency" means a board, commission,
35 committee, council, department, examining board, or officer,

1 except a judicial officer, in the state, or in a city, county,
2 township, or local government, authorized to grant, deny,
3 renew, revoke, suspend, annul, withdraw, or amend a license or
4 certificate of registration.

5 Sec. 3. NEW SECTION. 729.8 CONSENT FOR GENETIC TESTING
6 -- EXCEPTIONS.

7 1. A person shall not obtain genetic information or
8 samples for genetic testing from an individual without first
9 obtaining informed and written consent from the individual or
10 the individual's authorized representative.

11 2. A person shall not perform genetic testing of an
12 individual or collect, retain, transmit, or use genetic
13 information without the informed and written consent of the
14 individual or the individual's authorized representative.

15 3. The following exceptions apply to the prohibitions in
16 subsections 1 and 2:

17 a. To the extent that genetic information or the results
18 of genetic testing may be collected, retained, transmitted, or
19 used without the individual's written and informed consent
20 pursuant to federal or other state law.

21 b. To identify an individual in the course of a criminal
22 investigation by a law enforcement agency.

23 c. To identify deceased individuals.

24 d. To establish parental identity.

25 e. To screen newborns.

26 f. By medical repositories or registries.

27 g. For the purposes of medical or scientific research and
28 education.

29 Sec. 4. NEW SECTION. 729.9 PROHIBITED USE BY INSURER.

30 1. a. Insurance administrators, health plans, and health
31 insurers shall not release genetic information without prior
32 written authorization of the individual. Written
33 authorization shall be required for each disclosure and shall
34 include the person to whom the disclosure is being made.

35 b. The following exceptions apply to the requirement in

1 paragraph "a":

2 (1) Those participating in research settings, including
3 those governed by the federal policy for the protection of
4 human research subjects.

5 (2) Tests conducted purely for research, tests for somatic
6 as opposed to heritable mutations, and testing for forensic
7 purposes.

8 (3) Newborn screening.

9 (4) Paternity testing.

10 (5) Criminal investigations.

11 2. a. An insurer shall not discriminate against an
12 individual or a member of the individual's family on the basis
13 of genetic information or genetic testing.

14 b. This section does not require a health insurer to
15 provide particular benefits other than those provided under
16 the terms of the insurer's plan or coverage. A health insurer
17 shall not consider a genetic propensity, susceptibility, or
18 carrier status as a preexisting condition for the purpose of
19 limiting or excluding benefits, establishing rates, or
20 providing coverage.

21 c. An insurer shall not use genetic information or genetic
22 testing for underwriting health insurance in the individual
23 and group markets.

24 Sec. 5. NEW SECTION. 729.10 PROHIBITED USE BY EMPLOYER.

25 Except as otherwise required by federal law, an employer
26 shall not do any of the following:

27 1. Except as provided in section 729.8, directly or
28 indirectly acquire or have access to any genetic information
29 concerning an employee or applicant for employment, or the
30 genetic information of a member of the employee's or
31 applicant's family.

32 2. Fail or refuse to hire, recruit, or promote an
33 individual because of genetic information that is unrelated to
34 the individual's ability to perform the duties of a particular
35 job or position.

1 3. Discharge or otherwise discriminate against an
2 individual with respect to compensation or the terms,
3 conditions, or privileges of employment, because of genetic
4 information that is unrelated to the individual's ability to
5 perform the duties of a particular job or position.

6 4. Limit, segregate, or classify an employee or applicant
7 for employment in a way that deprives or tends to deprive the
8 employee or applicant of employment opportunities or otherwise
9 adversely affects the status of an employee because of genetic
10 information that is unrelated to the employee's ability to
11 perform the duties of a particular job or position.

12 5. Fail or refuse to hire, recruit, or promote an
13 individual on the basis of physical or mental examinations
14 that are not directly related to the requirements of a
15 particular job or position.

16 6. Discharge or take other discriminatory action against
17 an individual on the basis of physical or mental examinations
18 that are not directly related to the requirements of a
19 particular job or position.

20 7. Fail or refuse to hire, recruit, or promote an
21 individual when adaptive devices or aids may be utilized
22 thereby enabling that individual to perform the specific
23 requirements of a particular job or position.

24 8. Discharge or take other discriminatory action against
25 an individual when adaptive devices or aids may be utilized
26 thereby enabling the individual to perform the specific
27 requirements of a particular job or position.

28 9. Require an individual to submit to a genetic test or to
29 provide genetic information as a condition of obtaining or
30 maintaining employment, or of promotion.

31 Sec. 6. NEW SECTION. 729.11 VOLUNTARY GENETIC TESTING.

32 1. Section 729.10 does not prohibit the genetic testing of
33 an employee who requests a genetic test and provides written
34 and informed consent pursuant to section 729.8 for the
35 following purposes:

1 a. Investigating a workers' compensation claim under
2 chapter 85, 85A, 85B, or 86.

3 b. Determining the employee's susceptibility or level of
4 exposure to potentially toxic chemicals or potentially toxic
5 substances in the workplace. However, the employer shall not
6 terminate the employee, or take any other action that
7 adversely affects any term, condition, or privilege of the
8 employee's employment as a result of the genetic test.

9 2. An employee may voluntarily provide to an employer
10 genetic information that is related to the employee's health
11 or safety in the workplace. An employer may use genetic
12 information received from an employee under this subsection to
13 protect the employee's health or safety.

14 Sec. 7. NEW SECTION. 729.12 PROHIBITED USE BY EMPLOYMENT
15 AGENCY, LABOR ORGANIZATION, OR LICENSING AGENCY.

16 An employment agency, labor organization, or licensing
17 agency, or its employees, agents, or members shall not
18 directly or indirectly do any of the following:

19 1. Solicit, require, or administer a genetic test to a
20 person as a condition of preemployment application, labor
21 organization membership, or licensure.

22 2. Affect the terms, conditions, or privileges of
23 preemployment application, labor organization membership, or
24 licensure, or terminate the labor organization membership, or
25 licensure of any person who obtains a genetic test.

26 Sec. 8. NEW SECTION. 729.13 ADDITIONAL PROHIBITIONS.

27 1. Except as provided in section 729.11, a person shall
28 not sell to or interpret for an employer, employment agency,
29 labor organization, or licensing agency, or its employees,
30 agents, or members, a genetic test of an employee, labor
31 organization member, or licensee, or of a prospective
32 employee, member, or licensee.

33 2. An agreement between a person and an employer,
34 prospective employer, employment agency, labor organization,
35 or licensing agency, or its employees, agents, or members

1 offering the person employment, labor organization membership,
2 licensure, or any pay or benefit in return for taking a
3 genetic test is prohibited.

4 Sec. 9. NEW SECTION. 729.14 FILING A COMPLAINT --
5 DISCRIMINATION.

6 An employee, labor organization member, or licensee, or
7 prospective employee, member, or licensee who acted in good
8 faith shall not be discharged, disciplined, or discriminated
9 against in any manner for filing a complaint or testifying in
10 any proceeding or action involving a violation of this
11 subchapter. An employee, labor organization member, or
12 licensee, or prospective employee, member, or licensee who is
13 discharged, disciplined, or otherwise discriminated against in
14 violation of this section shall be compensated by the
15 employer, employment agency, labor organization, or licensing
16 agency in the amount of any loss of wages and benefits arising
17 out of the discrimination.

18 Sec. 10. NEW SECTION. 729.15 CIVIL ACTION.

19 1. This subchapter may be enforced through a civil action.
20 An individual whose rights under this subchapter have been
21 violated may recover damages and be granted equitable relief
22 in a civil action according to this subsection.

23 a. A person who violates this subchapter or who aids in
24 the violation of this subchapter is liable to an aggrieved
25 employee, labor organization member, or licensee, or an
26 aggrieved prospective employee, member, or licensee, for
27 affirmative relief including reinstatement or hiring, with or
28 without back pay, membership, licensing, or any other
29 equitable relief as the court deems appropriate including
30 attorney fees and court costs.

31 b. If a person commits, is committing, or proposes to
32 commit an act in violation of this subchapter, an injunction
33 may be granted through an action in district court to prohibit
34 the person from continuing such acts. The action for
35 injunctive relief may be brought by an aggrieved employee,

1 labor organization member, or licensee, or an aggrieved
2 prospective employee, member, or licensee, an aggrieved
3 insured, the county attorney, or the attorney general.

4 A person who in good faith brings an action under this
5 subsection alleging that an employer, employment agency, labor
6 organization, or licensing agency has required or requested a
7 genetic test in violation of this subchapter shall establish
8 that sufficient evidence exists upon which a reasonable person
9 could find that a violation has occurred. Upon proof that
10 sufficient evidence exists upon which a finding could be made
11 that a violation has occurred, the employer, employment
12 agency, labor organization, or licensing agency has the burden
13 of proving that the requirements of this subchapter were met.

14 2. An insurer or employer, employment agency, labor
15 organization, or licensing agency who violates the rights of
16 an individual under this subchapter shall be liable to the
17 individual for all of the following, for each separate
18 violation as follows:

19 a. Actual damages sustained as a result of the violation.

20 b. Statutory or punitive damages according to the
21 following:

22 (1) One hundred thousand dollars if the violation is the
23 result of an intentional and willful act.

24 (2) Punitive damages if the violation is the result of a
25 malicious act.

26 (3) Reasonable attorney fees.

27 EXPLANATION

28 This bill creates a new subchapter in Code chapter 729, to
29 be known as the "Genetic Testing Act".

30 The bill defines genetic information and genetic testing.
31 The bill also requires informed consent of an individual prior
32 to genetic testing or retention of genetic information, and
33 written authorization prior to disclosure of genetic
34 information. Specific exceptions are granted for
35 circumstances such as newborn screening, research, paternity

1 testing, criminal investigations, and other exceptions
2 recognized under other federal and state laws.

3 The bill prohibits discrimination by insurers due to
4 genetic information or genetic testing, both against the
5 person or any member of the person's family. An insurer is
6 not permitted to use genetic information or genetic testing
7 for underwriting health insurance in the individual and group
8 markets.

9 Employers are prohibited from using genetic information or
10 genetic testing in employment decisions to avoid hiring,
11 recruiting, or promoting persons when the genetic information
12 is unrelated to the individual's ability to perform the duties
13 of a particular job or position. Discrimination in
14 compensation or employment opportunities, or discharging an
15 employee due to genetic information, is similarly prohibited.
16 An individual may not be required to submit to a genetic test
17 as a condition of obtaining employment or promotion.

18 Employment agencies, labor organizations, and licensing
19 agencies are similarly prohibited from obtaining and using
20 genetic testing information to discriminate against a person.

21 The bill provides a private cause of action for persons
22 whose rights are violated by insurers, employers, and others.
23 A person may seek injunctive relief, actual damages, and
24 attorney fees. In addition, the person is entitled to
25 statutory damages of \$100,000 if the violation was an
26 intentional and willful act, or is entitled to punitive
27 damages if the act was malicious.

28 The bill includes provisions previously contained in Code
29 section 729.6 pertaining to genetic testing.

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