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COMMERCE, REGULATION & LABOR

HOUSE FILE 378
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FOEGE

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

A BILL FOR

1 An Act relating to genetic information privacy, including the
2 requirement of informed consent to test and written
3 authorization prior to disclosure, prohibitions on certain
4 uses of genetic information, and creating a private cause of
5 action.

6 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

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1 Section 1. NEW SECTION. 729.7 GENETIC INFORMATION
2 PRIVACY -- INFORMED CONSENT TO TEST -- DISCLOSURE OF
3 INFORMATION LIMITED -- DISCRIMINATION PROHIBITED.

4 1. For purposes of this section, unless the context
5 otherwise requires:

6 a. "Genetic information" means information about genes,
7 gene product, or inherited characteristics that may derive
8 from the individual or a family member.

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

25 2. a. A person shall not obtain genetic information or
26 samples for genetic testing from an individual without first
27 obtaining informed and written consent from the individual or
28 the individual's authorized representative.

29 b. A person shall not perform genetic testing of an
30 individual or collect, retain, transmit, or use genetic
31 information without the informed and written consent of the
32 individual or the individual's authorized representative.

33 c. The following exceptions apply to the prohibitions in
34 paragraphs "a" and "b":

35 (1) To the extent that genetic information or the results

1 of genetic testing may be collected, retained, transmitted, or
2 used without the individual's written and informed consent
3 pursuant to federal or other state law.

4 (2) To identify an individual in the course of a criminal
5 investigation by a law enforcement agency.

6 (3) To identify deceased individuals.

7 (4) To establish parental identity.

8 (5) To screen newborns.

9 (6) By medical repositories or registries.

10 (7) For the purposes of medical or scientific research and
11 education.

12 3. a. Insurance administrators, health plans, and health
13 insurers shall not release genetic information without prior
14 written authorization of the individual. Written
15 authorization shall be required for each disclosure and shall
16 include the person to whom the disclosure is being made.

17 b. The following exceptions apply to the requirement in
18 paragraph "a":

19 (1) Those participating in research settings, including
20 those governed by the federal policy for the protection of
21 human research subjects.

22 (2) Tests conducted purely for research, tests for somatic
23 as opposed to heritable mutations, and testing for forensic
24 purposes.

25 (3) Newborn screening.

26 (4) Paternity testing.

27 (5) Criminal investigations.

28 4. a. An insurer shall not discriminate against an
29 individual or a member of the individual's family on the basis
30 of genetic information or genetic testing.

31 b. This section does not require a health insurer to
32 provide particular benefits other than those provided under
33 the terms of the insurer's plan or coverage. A health insurer
34 shall not consider a genetic propensity, susceptibility, or
35 carrier status as a preexisting condition for the purpose of

1 limiting or excluding benefits, establishing rates, or
2 providing coverage.

3 c. An insurer shall not use genetic information or genetic
4 testing for underwriting health insurance in the individual
5 and group markets.

6 5. a. Except as otherwise required by federal law, an
7 employer shall not do any of the following:

8 (1) Fail or refuse to hire, recruit, or promote an
9 individual because of genetic information that is unrelated to
10 the individual's ability to perform the duties of a particular
11 job or position.

12 (2) Discharge or otherwise discriminate against an
13 individual with respect to compensation or the terms,
14 conditions, or privileges of employment, because of genetic
15 information that is unrelated to the individual's ability to
16 perform the duties of a particular job or position.

17 (3) Limit, segregate, or classify an employee or applicant
18 for employment in a way that deprives or tends to deprive the
19 employee or applicant of employment opportunities or otherwise
20 adversely affects the status of an employee because of genetic
21 information that is unrelated to the employee's ability to
22 perform the duties of a particular job or position.

23 (4) Fail or refuse to hire, recruit, or promote an
24 individual on the basis of physical or mental examinations
25 that are not directly related to the requirements of a
26 particular job or position.

27 (5) Discharge or take other discriminatory action against
28 an individual on the basis of physical or mental examinations
29 that are not directly related to the requirements of a
30 particular job or position.

31 (6) Fail or refuse to hire, recruit, or promote an
32 individual when adaptive devices or aids may be utilized
33 thereby enabling that individual to perform the specific
34 requirements of a particular job or position.

35 (7) Discharge or take other discriminatory action against

1 an individual when adaptive devices or aids may be utilized
2 thereby enabling the individual to perform the specific
3 requirements of a particular job or position.

4 (8) Require an individual to submit to a genetic test or
5 to provide genetic information as a condition of obtaining or
6 maintaining employment, or of promotion.

7 b. Paragraph "a" does not prohibit the following:

8 (1) An employee may voluntarily provide to an employer
9 genetic information that is related to the employee's health
10 or safety in the workplace.

11 (2) An employer may use genetic information received from
12 an employee under this subsection to protect the employee's
13 health or safety.

14 c. Except as provided in subsection 2, an employer shall
15 not directly or indirectly acquire or have access to any
16 genetic information concerning an employee or applicant for
17 employment, or the genetic information of a member of the
18 employee's or applicant's family.

19 6. a. An individual whose rights under this section have
20 been violated may recover damages and be granted equitable
21 relief in a civil action according to this subsection.

22 b. An insurer or employer who violates the rights of an
23 individual under this section shall be liable to the
24 individual for all of the following, for each separate
25 violation as follows:

26 (1) Actual damages sustained as a result of the violation.

27 (2) Statutory or punitive damages according to the
28 following:

29 (a) One hundred thousand dollars if the violation is the
30 result of an intentional and willful act.

31 (b) Punitive damages if the violation is the result of a
32 malicious act.

33 (3) Reasonable attorney fees.

34 EXPLANATION

35 This bill adds a new section to Code chapter 729 regarding

1 individual rights. New Code section 729.7 addresses genetic
2 information privacy.

3 The new Code section defines genetic information and
4 genetic testing. The bill also requires informed consent of
5 an individual prior to genetic testing or retention of genetic
6 information, and written authorization prior to disclosure of
7 genetic information. Specific exceptions are granted for
8 circumstances such as newborn screening, research, paternity
9 testing, criminal investigations, and other exceptions
10 recognized under other federal and state laws.

11 The bill prohibits discrimination by insurers due to
12 genetic information or genetic testing, both against the
13 person or any member of the person's family. An insurer is
14 not permitted to use genetic information or genetic testing
15 for underwriting health insurance in the individual and group
16 markets.

17 Employers are prohibited from using genetic information or
18 genetic testing in employment decisions to avoid hiring,
19 recruiting, or promoting persons when the genetic information
20 is unrelated to the individual's ability to perform the duties
21 of a particular job or position. Discrimination in
22 compensation or employment opportunities, or discharging an
23 employee due to genetic information, is similarly prohibited.
24 An individual may not be required to submit to a genetic test
25 as a condition of obtaining employment or promotion.

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

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