

Senate File 2068 - Introduced

SENATE FILE 2068
BY JOCHUM

A BILL FOR

1 An Act relating to the use of genetic information and samples
2 for genetic testing and providing for civil enforcement.
3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

1 Section 1. Section 729.6, subsection 1, Code 2009, is
2 amended by adding the following new paragraph:

3 NEW PARAGRAPH. *bb.* "Genetic information" means information
4 about genes, gene products, or inherited characteristics that
5 may derive from an individual or an individual's family member.

6 Sec. 2. Section 729.6, subsection 1, paragraph c, Code 2009,
7 is amended by striking the paragraph and inserting in lieu
8 thereof the following:

9 *c.* "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 karyotypes
13 for clinical purposes, including predicting risk of disease,
14 identifying carriers, and establishing prenatal and clinical
15 diagnosis or prognosis. "Genetic testing" includes prenatal,
16 newborn, and carrier screening, and testing in high-risk
17 families if a parent or guardian approves a release for such
18 screening or testing. "Genetic testing" includes tests for
19 metabolites if the tests are undertaken with high probability
20 that an excess or deficiency of the metabolite indicates the
21 presence of heritable mutations in single genes. "Genetic
22 testing" does not mean routine physical measurement, a routine
23 chemical, blood, or urine analysis, or a test for drugs or for
24 human immunodeficiency virus infections.

25 Sec. 3. Section 729.6, Code 2009, is amended by adding the
26 following new subsections:

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

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

35 *c.* The following exceptions apply to the prohibitions in

1 paragraphs "a" and "b":

2 (1) To the extent that genetic information or the results
3 of genetic testing may be collected, retained, transmitted,
4 or used without the individual's written and informed consent
5 pursuant to federal or other state law.

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

8 (3) To identify deceased individuals.

9 (4) To establish parental identity.

10 (5) To screen newborns.

11 (6) By medical repositories or registries.

12 (7) For the purposes of medical or scientific research and
13 education.

14 NEW SUBSECTION. 2B. a. (1) An insurance administrator,
15 health plan, or health insurer shall not release genetic
16 information pertaining to an individual without prior written
17 authorization of the individual. Written authorization shall
18 be required for each disclosure and shall include the person to
19 whom the disclosure is being made.

20 (2) The following exceptions apply to the requirement in
21 subparagraph (1):

22 (a) Individuals participating in research settings,
23 including individuals governed by the federal policy for the
24 protection of human research subjects.

25 (b) Tests conducted purely for research, tests for somatic
26 as opposed to heritable mutations, and testing for forensic
27 purposes.

28 (c) Newborn screening.

29 (d) Paternity testing.

30 (e) Criminal investigations.

31 b. (1) An insurer shall not discriminate against an
32 individual or a member of the individual's family on the basis
33 of genetic information or genetic testing.

34 (2) This section shall not require a health insurer to
35 provide particular benefits other than those provided under

1 the terms of the insurer's plan or coverage. A health insurer
2 shall not consider a genetic propensity, susceptibility, or
3 carrier status as a preexisting condition for the purpose
4 of limiting or excluding benefits, establishing rates, or
5 providing coverage.

6 (3) An insurer shall not use genetic information or genetic
7 testing for underwriting health insurance in the individual and
8 group markets.

9 Sec. 4. Section 729.6, subsection 6, Code 2009, is amended
10 to read as follows:

11 6. This section may be enforced through a civil action.

12 a. A person who violates this section or who aids in
13 the violation of this section is liable to an aggrieved
14 insured, employee, labor organization member, or licensee, or
15 aggrieved prospective insured, employee, member, or licensee,
16 for affirmative relief including reinstatement or hiring,
17 with or without back pay, membership, licensing, or any other
18 equitable relief as the court deems appropriate including
19 attorney fees and court costs.

20 b. If a person commits, is committing, or proposes to
21 commit, an act in violation of this section, an injunction may
22 be granted through an action in district court to prohibit the
23 person from continuing such acts. The action for injunctive
24 relief may be brought by an aggrieved insured, employee, labor
25 organization member, or licensee, or aggrieved prospective
26 insured, employee, member, or licensee, the county attorney,
27 or the attorney general.

28 c. A person who in good faith brings an action under
29 this subsection alleging that an employer, employment agency,
30 labor organization, insurance administrator, health plan,
31 health insurer, or licensing agency has required or requested
32 a genetic test in violation of this section, obtained genetic
33 information or samples for genetic testing in violation of this
34 section, performed genetic testing or collected, retained,
35 transmitted, or used genetic information in violation of this

1 section, or released genetic information in violation of this
2 section, shall establish that sufficient evidence exists upon
3 which a reasonable person could find that a violation has
4 occurred. Upon proof that sufficient evidence exists upon
5 which a finding could be made that a violation has occurred as
6 required under this paragraph, the employer, employment agency,
7 labor organization, insurance administrator, health plan,
8 health insurer, or licensing agency has the burden of proving
9 that the requirements of this section were met.

10

EXPLANATION

11 This bill amends Code section 729.6 concerning genetic
12 testing by adding a definition of "genetic information" and
13 revising the definition of what constitutes "genetic testing".

14 New Code section 729.6(2A) prohibits a person from obtaining
15 genetic information or samples for genetic testing from
16 an individual without first obtaining that individual's
17 informed and written consent. Exceptions to the consent
18 requirement are where federal or other state law provides
19 otherwise; to identify an individual in the course of a
20 criminal investigation by a law enforcement agency; to identify
21 deceased individuals; to establish parental identity; to screen
22 newborns; for medical repositories or registries; and for the
23 purposes of medical or scientific research and education.

24 New Code section 729.6(2B) prohibits insurance
25 administrators, health plans, and health insurers from
26 releasing genetic information without prior written
27 authorization or discriminating against an individual or a
28 member of an individual's family on the basis of genetic
29 information or genetic testing.

30 The provisions of the bill are enforceable through a civil
31 action brought by an aggrieved individual. Such an individual
32 may seek equitable and injunctive relief as well as attorney
33 fees and costs.