

HOUSE BILL No. 2442

By Representative Newton

2-7

AN ACT concerning genetic privacy.

Be it enacted by the Legislature of the State of Kansas:

Section 1. As used in this act, unless the context clearly shows otherwise:

(a) "Anonymous research" means:

(1) Scientific or medical research conducted in such a manner that the identity of an individual who has provided a sample, or the identity of an individual from whom genetic information has been obtained, cannot be determined; or

(2) scientific or medical research conducted in accordance with the federal policy for the protection of human subjects with the approval of an institutional review board established in accordance with that policy.

(b) "DNA" means deoxyribonucleic acid.

(c) "DNA sample" means any human biological specimen from which DNA was extracted, or any human biological specimen that is obtained or retained for the purpose of extracting and analyzing DNA to determine a genetic characteristic. "DNA sample" includes DNA extracted from the specimen.

(d) "Genetic characteristic" means any gene or chromosome, or alteration thereof, that is scientifically or medically believed to cause a disease, disorder or syndrome, or to be associated with statistically increased risk of development of a disease, disorder or syndrome.

(e) "Genetic information" is the information about an individual or family obtained from:

(1) A genetic test; or

(2) an individual's DNA sample.

(f) "Genetic test" means a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic.

(g) "Person" means an individual, partnership, corporation, association, joint stock company, trust or other association of people, including any official, employee or agent of the United States or any political subdivision thereof.

1 Sec. 2. (a) An individual's genetic information and DNA are uniquely
2 private and personal and are the property of that individual.

3 (b) No person shall obtain or retain genetic information from an in-
4 dividual or an individual's DNA without first obtaining the written in-
5 formed consent of the individual or individual's representative, except
6 where:

7 (1) The genetic testing, retention or inspection is necessary pursuant
8 to K.S.A. 21-2511, 22-4905 and 22-4907, and amendments thereto;

9 (2) the genetic testing, retention or inspection is necessary to deter-
10 mine paternity;

11 (3) the genetic testing is ordered by a court of competent jurisdiction;

12 (4) the genetic testing information is for anonymous research; or

13 (5) the genetic testing information is necessary to identify a deceased
14 person.

15 (c) An individual promptly upon request of such individual may in-
16 spect, request correction of and obtain genetic information from that
17 individual's records.

18 (d) Except for the purposes listed in subsection (b) or where the
19 information has been requested by the individual for such individual's
20 medical purposes, all genetic testing and DNA information shall be de-
21 stroyed promptly.

22 Sec. 3. (a) Regardless of the manner of receipt or the source of any
23 genetic information, including information received from an individual, a
24 person shall not, except for the exceptions in subsection (b) of section 2,
25 and amendments thereto, disclose, sell or unlawfully use or be compelled
26 by subpoena or any other means to disclose the identity of an individual
27 upon whom a genetic test has been performed or to disclose genetic
28 information about the individual in a manner that permits identification
29 of the individual.

30 (b) Any person who willfully discloses, sells or unlawfully uses an
31 individual's genetic information without such individual's consent or for
32 the exceptions listed in subsection (b) of section 2, and amendments
33 thereto, shall be liable to the individual for all actual damages including
34 damages for economic, bodily or emotional harm proximately caused by
35 the disclosure and shall be guilty of a misdemeanor.

36 (c) Any person who willfully discloses, sells or unlawfully uses an in-
37 dividual's genetic information without the individual's consent or for the
38 exceptions listed in subsection (b) of section 2, and amendments thereto,
39 shall be guilty of a misdemeanor and upon conviction shall be punished
40 by a fine of not less than \$25 and not more than \$10,000. Each day in
41 which the failure to cease such violations continues shall constitute a
42 separate offense.

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1 Sec. 4. This act shall take effect and be in force from and after its
2 publication in the statute book.
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