74th OREGON LEGISLATIVE ASSEMBLY--2007 Regular Session

Senate Bill 759

Sponsored by COMMITTEE ON RULES

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced.**

Modifies requirements for retention and disclosure of genetic information.
Declares emergency, effective on passage.

A BILL FOR AN ACT

Relating to genetic information; creating new provisions; amending ORS 192.531; and declaring an emergency.

Be It Enacted by the People of the State of Oregon:

SECTION 1. Section 2 of this 2007 Act is added to and made a part of ORS 192.518 to 192.526.

SECTION 2. (1) Notwithstanding ORS 192.537 (3), a health care provider may retain genetic information of an individual without obtaining an authorization from the individual or a personal representative of the individual if the retention is for treatment, payment or health care operations by the provider.

(2) Notwithstanding ORS 192.539 (1), a health care provider may disclose genetic information of an individual without obtaining an authorization from the individual or a personal representative of the individual if the provider discloses the genetic information in accordance with ORS 192.520 (3).

(3) As used in this section, "retain genetic information" has the meaning given that term in ORS 192.531.

SECTION 3. ORS 192.531 is amended to read:

192.531. As used in ORS 192.531 to 192.549:

(1) "Anonymous research" means scientific or medical genetic research conducted in such a manner that any DNA sample or genetic information used in the research is unidentified.

(2) "Blanket informed consent" means that the individual has consented to the use of the individual's DNA sample or health information for any future research, but has not been provided with a description of or consented to the use of the sample in genetic research or any specific genetic research project.

(3) "Blood relative" means a person who is:

(a) Related by blood to an individual; and

(b) A parent, sibling, son, daughter, grandparent, grandchild, aunt, uncle, first cousin, niece or nephew of the individual.

(4) "Clinical" means relating to or obtained through the actual observation, diagnosis or treatment of patients and not through research.

(5) "Coded" means identifiable only through the use of a system of encryption that links a DNA

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

sample or genetic information to an individual or the individual's blood relative. A coded DNA sample or genetic information is supplied by a repository to an investigator with a system of encryption.

(6) "Deidentified" means lacking, or having had removed, the identifiers or system of encryption that would make it possible for a person to link a DNA sample or genetic information to an individual or the individual's blood relative, and neither the investigator nor the repository can reconstruct the identity of the individual from whom the sample or information was obtained. Deidentified DNA samples and genetic information must meet the standards provided in 45 C.F.R. 164.502(d) and 164.514(a) to (c)**, as in effect on the effective date of this 2007 Act**.

(7) "Disclose" means to release, publish or otherwise make known to a third party a DNA sample or genetic information.

(8) "DNA" means deoxyribonucleic acid.

(9) "DNA sample" means any human biological specimen that is obtained or retained for the purpose of extracting and analyzing DNA to perform a genetic test. "DNA sample" includes DNA extracted from the specimen.

(10) "Genetic characteristic" includes a gene, chromosome or alteration thereof that may be tested to determine the existence or risk of a disease, disorder, trait, propensity or syndrome, or to identify an individual or a blood relative. "Genetic characteristic" does not include family history or a genetically transmitted characteristic whose existence or identity is determined other than through a genetic test.

(11) "Genetic information" means information about an individual or the individual's blood relatives obtained from a genetic test.

(12) "Genetic privacy statutes" means ORS 192.531 to 192.549, 659A.303 and 746.135 and the provisions of ORS 659A.300 relating to genetic testing.

(13) "Genetic research" means research using DNA samples, genetic testing or genetic information.

(14) "Genetic test" means a test for determining the presence or absence of genetic characteristics in an individual or the individual's blood relatives, including tests of nucleic acids such as DNA[*,*] **and** RNA [*and mitochondrial DNA*], chromosomes or [*proteins*] **metabolites** in order to diagnose or determine a genetic characteristic.

(15) "Health care provider" has the meaning given that term in ORS 192.519.

(16) "Identifiable" means capable of being linked to the individual or a blood relative of the individual from whom the DNA sample or genetic information was obtained.

(17) "Identified" means having an identifier that links, or that could readily allow the recipient to link, a DNA sample or genetic information directly to the individual or a blood relative of the individual from whom the sample or information was obtained.

(18) "Identifier" means data elements that directly link a DNA sample or genetic information to the individual or a blood relative of the individual from whom the sample or information was obtained. Identifiers include, but are not limited to, names, telephone numbers, electronic mail addresses, Social Security numbers, driver license numbers and fingerprints.

(19) "Individually identifiable health information" has the meaning given that term in ORS 192.519.

(20) "Obtain genetic information" means performing or getting the results of a genetic test.

(21) "Person" has the meaning given in ORS 433.045.

(22) "Research" means a systematic investigation, including research development, testing and

evaluation, designed to develop or contribute to generalized knowledge.

(23) "Retain a DNA sample" means the act of storing the DNA sample.

(24) "Retain genetic information" means making a record of the genetic information.

(25) "Unidentified" means deidentified or not identifiable.

SECTION 4. Section 5 of this 2007 Act is added to and made a part of ORS 746.600 to 746.690.

SECTION 5. (1) Notwithstanding ORS 192.537 (3), a health insurer may retain genetic information of an individual without obtaining an authorization from the individual or a personal representative of the individual if the retention is for treatment, payment or health care operations by the insurer.

(2) Notwithstanding ORS 192.539 (1), a health insurer may disclose genetic information of an individual without obtaining an authorization from the individual or a personal representative of the individual if the insurer discloses the genetic information in accordance with ORS 746.607 (3).

(3) As used in this section, "retain genetic information" has the meaning given that term in ORS 192.531.

(4) As used in this section, "health care operations" does not include underwriting activities.

(5) Nothing in this section shall be construed to interfere with or limit the requirements of ORS 746.135.

SECTION 6. Sections 2 and 5 of this 2007 Act apply to genetic information obtained before, on or after the effective date of this 2007 Act.

SECTION 7. This 2007 Act being necessary for the immediate preservation of the public peace, health and safety, an emergency is declared to exist, and this 2007 Act takes effect on its passage.