

Senate Bill 99

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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

1
2 Relating to genetic information; creating new provisions; amending ORS 192.531; and declaring an
3 emergency.

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

5 **SECTION 1. Section 2 of this 2005 Act is added to and made a part of ORS 192.518 to**
6 **192.524.**

7 **SECTION 2. (1) Notwithstanding ORS 192.537 (3), a health care provider may retain ge-**
8 **netic information of an individual without obtaining an authorization from the individual or**
9 **a personal representative of the individual if the retention is for the provider's own treat-**
10 **ment, payment or health care operations.**

11 **(2) Notwithstanding ORS 192.539 (1), a health care provider may disclose genetic infor-**
12 **mation of an individual without obtaining an authorization from the individual or a personal**
13 **representative of the individual if the provider discloses the genetic information in accord-**
14 **ance with ORS 192.520 (3).**

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

17 **SECTION 3. ORS 192.531 is amended to read:**

18 192.531. As used in ORS 192.531 to 192.549:

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

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

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

26 (a) Related by blood to an individual; and

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

29 (4) "Clinical" means relating to or obtained through the actual observation, diagnosis or treat-
30 ment of patients and not through research.

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.

1 (5) "Coded" means identifiable only through the use of a system of encryption that links a DNA
2 sample or genetic information to an individual or the individual's blood relative. A coded DNA
3 sample or genetic information is supplied by a repository to an investigator with a system of en-
4 cryptation.

5 (6) "Deidentified" means lacking, or having had removed, the identifiers or system of encryption
6 that would make it possible for a person to link a DNA sample or genetic information to an indi-
7 vidual or the individual's blood relative, and neither the investigator nor the repository can recon-
8 struct the identity of the individual from whom the sample or information was obtained. Deidentified
9 DNA samples and genetic information must meet the standards provided in 45 C.F.R. 164.502(d) and
10 164.514(a) to (c), **as in effect on the effective date of this 2005 Act.**

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

13 (8) "DNA" means deoxyribonucleic acid.

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

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

22 (11) "Genetic information" means information about an individual or the individual's blood rel-
23 atives obtained from a genetic test.

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

26 (13) "Genetic research" means research using DNA samples, genetic testing or genetic infor-
27 mation.

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

32 (15) "Identifiable" means capable of being linked to the individual or a blood relative of the in-
33 dividual from whom the DNA sample or genetic information was obtained.

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

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

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

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

43 (20) "Research" means a systematic investigation, including research development, testing and
44 evaluation, designed to develop or contribute to generalized knowledge.

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

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

2 (23) "Unidentified" means deidentified or not identifiable.

3 **SECTION 4.** Section 5 of this 2005 Act is added to and made a part of ORS 746.600 to
4 **746.690.**

5 **SECTION 5.** (1) Notwithstanding ORS 192.537 (3), a health insurer may retain genetic in-
6 formation of an individual without obtaining an authorization from the individual or a per-
7 sonal representative of the individual if the retention is for the insurer's own treatment,
8 payment or health care operations.

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

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

15 **SECTION 6.** Sections 2 and 5 of this 2005 Act apply to genetic information obtained be-
16 fore, on or after the effective date of this 2005 Act.

17 **SECTION 7.** This 2005 Act being necessary for the immediate preservation of the public
18 peace, health and safety, an emergency is declared to exist, and this 2005 Act takes effect
19 on its passage.
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