

Chapter 192

GENETIC PRIVACY

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192.531 Definitions for ORS 192.531 to 192.549. 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 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 July 17, 2007.

(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, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose or determine a genetic characteristic.

(15) "Health care provider" has the meaning given that term in ORS 192.556.

(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 192.556.

(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. [Formerly 659.700; 2003 c.333 §1; 2005 c.678 §1; 2007 c.800 §6]

Note: 192.531 to 192.549 were enacted into law by the Legislative Assembly but were not added to or made a part of ORS chapter 192 or any series therein by legislative action. See Preface to Oregon Revised Statutes for further explanation.

192.533 Legislative findings; purposes. (1) The Legislative Assembly finds that:

(a) The DNA molecule contains information about the probable medical future of an individual and the individual's blood relatives. This information is written in a code that is rapidly being broken.

(b) Genetic information is uniquely private and personal information that generally should not be collected, retained or disclosed without the individual's authorization.

(c) The improper collection, retention or disclosure of genetic information can lead to significant harm to an individual and the individual's blood relatives, including stigmatization and discrimination in areas such as employment, education, health care and insurance.

(d) An analysis of an individual's DNA provides information not only about the individual, but also about blood relatives of the individual, with the potential for impacting family privacy, including reproductive decisions.

(e) Current legal protections for medical information, tissue samples and DNA samples are inadequate to protect genetic privacy.

(f) Laws for the collection, storage and use of identifiable DNA samples and private genetic information obtained from those samples are needed both to protect individual and family privacy and to permit and encourage legitimate scientific and medical research.

(2) The purposes of the genetic privacy statutes are as follows:

(a) To define the rights of individuals whose genetic information is collected, retained or disclosed and the rights of the individuals' blood relatives.

(b) To define the circumstances under which an individual may be subjected to genetic testing.

(c) To define the circumstances under which an individual's genetic information may be collected, retained or disclosed.

(d) To protect against discrimination by an insurer or employer based upon an individual's genetic characteristics.

(e) To define the circumstances under which a DNA sample or genetic information may be used for research. [Formerly 659.705; 2003 c.333 §2]

Note: See note under 192.531.

192.535 Informed consent for obtaining genetic information. (1) A person may not obtain genetic information from an individual, or from an individual's DNA sample, without first obtaining informed consent of the individual or the individual's representative, except:

(a) As authorized by ORS 181A.155 or comparable provisions of federal criminal law relating to the identification of persons, or for the purpose of establishing the identity of a person in the course of an investigation conducted by a law enforcement agency, a district attorney, a medical examiner or the Criminal Justice Division of the Department of Justice;

(b) For anonymous research or coded research conducted under conditions described in ORS 192.537 (2), after notification pursuant to ORS 192.538 or pursuant to ORS 192.547 (7)(b);

(c) As permitted by rules of the Oregon Health Authority for identification of deceased individuals;

(d) As permitted by rules of the Oregon Health Authority for newborn screening procedures;
(e) As authorized by statute for the purpose of establishing parentage; or
(f) For the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent.

(2) Except as provided in subsection (3) of this section, a physician licensed under ORS chapter 677 shall seek the informed consent of the individual or the individual's representative for the purposes of subsection (1) of this section in the manner provided by ORS 677.097. Except as provided in subsection (3) of this section, any other licensed health care provider or facility must seek the informed consent of the individual or the individual's representative for the purposes of subsection (1) of this section in a manner substantially similar to that provided by ORS 677.097 for physicians.

(3) A person conducting research shall seek the informed consent of the individual or the individual's representative for the purposes of subsection (1) of this section in the manner provided by ORS 192.547.

(4) Except as provided in ORS 746.135 (1), any person not described in subsection (2) or (3) of this section must seek the informed consent of the individual or the individual's representative for the purposes of subsection (1) of this section in the manner provided by rules adopted by the Oregon Health Authority.

(5) The Oregon Health Authority may not adopt rules under subsection (1)(d) of this section that would require the providing of a DNA sample for the purpose of obtaining complete genetic information used to screen all newborns. [Formerly 659.710; 2003 c.333 §3; 2005 c.678 §2; 2009 c.595 §168; 2017 c.651 §39]

Note: See note under 192.531.

192.537 Individual's rights in genetic information; retention of information; destruction of information. (1) Subject to the provisions of ORS 192.531 to 192.549, 659A.303 and 746.135, an individual's genetic information and DNA sample are private and must be protected, and an individual has a right to the protection of that privacy. Any person authorized by law or by an individual or an individual's representative to obtain, retain or use an individual's genetic information or any DNA sample must maintain the confidentiality of the information or sample and protect the information or sample from unauthorized disclosure or misuse.

(2)(a) A person may use an individual's DNA sample or genetic information that is derived from a biological specimen or clinical individually identifiable health information for anonymous research or coded research only if the individual:

(A) Has granted informed consent for the specific anonymous research or coded research project;

(B) Has granted consent for genetic research generally;

(C) Was notified in accordance with ORS 192.538 that the individual's biological specimen or clinical individually identifiable health information may be used for anonymous research or coded research and the individual did not, at the time of notification, request that the biological specimen or clinical individually identifiable health information not be used for anonymous research or coded research; or

(D) Was not notified, due to emergency circumstances, in accordance with ORS 192.538 that the individual's biological specimen or clinical individually identifiable health information may

be used for anonymous research or coded research and the individual died before receiving the notice.

(b) Paragraph (a) of this subsection does not apply to biological specimens or clinical individually identifiable health information obtained before July 29, 2005, if an institutional review board operating under ORS 192.547 (1)(b) meets the requirements described in ORS 192.547 (7)(b).

(3) A person may not retain another individual's genetic information or DNA sample without first obtaining authorization from the individual or the individual's representative, unless:

(a) Retention is authorized by ORS 181A.155 or comparable provisions of federal criminal law relating to identification of persons, or is necessary for the purpose of a criminal or death investigation, a criminal or juvenile proceeding, an inquest or a child fatality review by a county multidisciplinary child abuse team;

(b) Retention is authorized by specific court order pursuant to rules adopted by the Chief Justice of the Supreme Court for civil actions;

(c) Retention is permitted by rules of the Oregon Health Authority for identification of, or testing to benefit blood relatives of, deceased individuals;

(d) Retention is permitted by rules of the authority for newborn screening procedures; or

(e) Retention is for anonymous research or coded research conducted after notification or with consent pursuant to subsection (2) of this section or ORS 192.538.

(4) The DNA sample of an individual from which genetic information has been obtained shall be destroyed promptly upon the specific request of that individual or the individual's representative, unless:

(a) Retention is authorized by ORS 181A.155 or comparable provisions of federal criminal law relating to identification of persons, or is necessary for the purpose of a criminal or death investigation, a criminal or juvenile proceeding, an inquest or a child fatality review by a county multidisciplinary child abuse team;

(b) Retention is authorized by specific court order pursuant to rules adopted by the Chief Justice of the Supreme Court for civil actions; or

(c) Retention is for anonymous research or coded research conducted after notification or with consent pursuant to subsection (2) of this section or ORS 192.538.

(5) A DNA sample from an individual that is the subject of a research project, other than an anonymous research project, shall be destroyed promptly upon completion of the project or withdrawal of the individual from the project, whichever occurs first, unless the individual or the individual's representative directs otherwise by informed consent.

(6) A DNA sample from an individual for insurance or employment purposes shall be destroyed promptly after the purpose for which the sample was obtained has been accomplished unless retention is authorized by specific court order pursuant to rules adopted by the Chief Justice of the Supreme Court for civil, criminal and juvenile proceedings.

(7) An individual or an individual's representative, promptly upon request, may inspect, request correction of and obtain genetic information from the records of the individual.

(8) Subject to the provisions of ORS 192.531 to 192.549, and to policies adopted by the person in possession of a DNA sample, an individual or the individual's representative may request that the individual's DNA sample be made available for additional genetic testing for medical diagnostic purposes. If the individual is deceased and has not designated a representative to act on behalf of the individual after death, a request under this subsection may be made by the closest surviving blood relative of the decedent or, if there is more than one surviving blood

relative of the same degree of relationship to the decedent, by the majority of the surviving closest blood relatives of the decedent.

(9) The Oregon Health Authority shall coordinate the implementation of this section.

(10) Subsections (3) to (8) of this section apply only to a DNA sample or genetic information that is coded, identified or identifiable.

(11) This section does not apply to any law, contract or other arrangement that determines a person's rights to compensation relating to substances or information derived from an individual's DNA sample. [Formerly 659.715; 2003 c.333 §4; 2005 c.562 §21; 2005 c.678 §3; 2009 c.595 §169]

Note: Section 10, chapter 333, Oregon Laws 2003, provides:

Sec. 10. Notwithstanding ORS 192.537 (2)(a)(C), a person may use an individual's DNA sample or genetic information for anonymous research if the DNA sample or genetic information was obtained prior to the effective date of this 2003 Act [June 12, 2003] and the individual was not notified the sample or genetic information may be used for anonymous research. [2003 c.333 §10]

Note: See note under 192.531.

192.538 Notice by health care provider regarding anonymous or coded research. (1) A health care provider that is a covered entity as defined in ORS 192.556 (2)(c) and that obtains an individual's biological specimen or clinical individually identifiable health information shall notify the individual that the biological specimen or clinical individually identifiable health information may be disclosed or retained by the provider for anonymous research or coded research.

(2) A health care provider that is not a covered entity as defined in ORS 192.556 (2)(c) and that obtains an individual's biological specimen or clinical individually identifiable health information may notify the individual that the biological specimen or clinical individually identifiable health information may be disclosed or retained by the provider for anonymous research or coded research.

(3) A health care provider described in subsection (1) of this section shall provide a notice to the individual describing how the biological specimen or clinical individually identifiable health information may be used and allowing the individual to request that the specimen or information not be disclosed or retained for anonymous research or coded research. The notice must contain a place where the individual may mark the individual's request that the specimen or information not be disclosed or retained for anonymous research or coded research before returning the notice to the health care provider.

(4) The notice described in subsection (3) of this section:

(a) Must be given no later than when the provider obtains an individual's biological specimen or clinical individually identifiable health information; and

(b) May be given at the same time and in the same manner as the notice of privacy practices required under the federal Health Insurance Portability and Accountability Act privacy regulations, 45 C.F.R. parts 160 and 164. [2005 c.678 §5]

Note: See note under 192.531.

192.539 Disclosure of genetic information; exceptions. (1) Regardless of the manner of receipt or the source of genetic information, including information received from an individual or a blood relative of the individual, a person may not disclose or be compelled, by subpoena or any other means, to disclose the identity of an individual upon whom a genetic test has been performed or the identity of a blood relative of the individual, or to disclose genetic information about the individual or a blood relative of the individual in a manner that permits identification of the individual, unless:

(a) Disclosure is authorized by ORS 181A.155 or comparable provisions of federal criminal law relating to identification of persons, or is necessary for the purpose of a criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a child fatality review by a county multidisciplinary child abuse team;

(b) Disclosure is required by specific court order entered pursuant to rules adopted by the Chief Justice of the Supreme Court for civil actions;

(c) Disclosure is authorized by statute for the purpose of establishing parentage;

(d) Disclosure is specifically authorized by the tested individual or the tested individual's representative by signing a consent form prescribed by rules of the Oregon Health Authority;

(e) Disclosure is for the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent; or

(f) Disclosure is for the purpose of identifying bodies.

(2) The prohibitions of this section apply to any redisclosure by any person after another person has disclosed genetic information or the identity of an individual upon whom a genetic test has been performed, or has disclosed genetic information or the identity of a blood relative of the individual.

(3) A release or publication is not a disclosure if:

(a) It involves a good faith belief by the person who caused the release or publication that the person was not in violation of this section;

(b) It is not due to willful neglect;

(c) It is corrected in the manner described in ORS 192.541 (4);

(d) The correction with respect to genetic information is completed before the information is read or heard by a third party; and

(e) The correction with respect to DNA samples is completed before the sample is retained or genetically tested by a third party. [Formerly 659.720; 2005 c.562 §22; 2009 c.595 §170; 2017 c.651 §40]

Note: See note under 192.531.

192.540 Use of deceased individual's DNA sample or genetic information for research. Notwithstanding ORS 192.535 and 192.537 (2), a person may use an individual's DNA sample or genetic information that is derived from a biological specimen or clinical individually identifiable health information for anonymous research or coded research if the individual was deceased when the individual's biological specimen or clinical individually identifiable health information was obtained. [2005 c.678 §8]

Note: See note under 192.531.

192.541 Private right of action; remedies; affirmative defense; attorney fees. (1) An individual or an individual's blood relative, representative or estate may bring a civil action against any person who violates ORS 192.535, 192.537, 192.539 or 192.547.

(2) For a violation of ORS 192.537 or 192.547, the court shall award the greater of actual damages or:

(a) \$100, for an inadvertent violation that does not arise out of the negligence of the defendant;

(b) \$500, for a negligent violation;

(c) \$10,000, for a knowing or reckless violation;

(d) \$15,000, for a knowing violation based on a fraudulent misrepresentation; or

(e) \$25,000, for a knowing violation committed with intent to sell, transfer or use for commercial advantage, personal gain or malicious harm.

(3) For a violation of ORS 192.535 or 192.539, the court shall award the greater of actual damages or:

(a) \$1,000, for an inadvertent violation that does not arise out of the negligence of the defendant;

(b) \$5,000, for a negligent violation;

(c) \$100,000, for a knowing or reckless violation;

(d) \$150,000, for a knowing violation based on a fraudulent misrepresentation; or

(e) \$250,000, for a knowing violation committed with intent to sell, transfer or use for commercial advantage, personal gain or malicious harm.

(4) It is an affirmative defense to an action described in subsection (2)(a) or (b) or (3)(a) or (b) of this section that the defendant corrected the violation through destruction of illegally retained or obtained samples or information, or took other action to correct the violation, if the correction was completed within 120 days after the defendant knew or should have known that the violation occurred.

(5) The court may provide such equitable relief as it deems necessary or proper.

(6)(a) The court may award attorney fees to a defendant only if the court finds that the plaintiff had no objectively reasonable basis for asserting a claim or for appealing an adverse decision of the trial court.

(b) The court shall award attorney fees to a plaintiff if the court finds that the defendant committed a violation described in subsection (2)(c), (d) or (e) or (3)(c), (d) or (e) of this section.

(7) An action authorized by subsection (1) of this section must be commenced within three years after the date the plaintiff knew or should have known of the violation, but in no instance more than 10 years after the date of the violation.

(8) A plaintiff may recover damages provided by subsections (2) and (3) of this section for each violation by a defendant.

(9) ORS 31.725, 31.730, 31.735 and 31.740 do not apply to amounts awarded in actions under this section. [2001 c.588 §2]

Note: See note under 192.531.

192.543 Criminal penalty. (1) A person commits the crime of unlawfully obtaining, retaining or disclosing genetic information if the person knowingly, recklessly or with criminal negligence, as those terms are defined in ORS 161.085, obtains, retains or discloses genetic information in violation of ORS 192.531 to 192.549.

(2) Unlawfully obtaining, retaining or disclosing genetic information is a Class A misdemeanor. [2001 c.588 §3]

Note: See note under 192.531.

192.545 Enforcement; Attorney General or district attorney; intervention. (1) The Attorney General or a district attorney may bring an action against a person who violates ORS 192.535, 192.537, 192.539 or 192.547. In addition to remedies otherwise provided in ORS 192.541, the court shall award to the Attorney General or district attorney the costs of the investigation.

(2) The Attorney General may intervene in a civil action brought under ORS 192.541 if the Attorney General certifies that, in the opinion of the Attorney General, the action is of general public importance. In the action, the Attorney General shall be entitled to the same relief as if the Attorney General instituted the action under this section. [2001 c.588 §4]

Note: See note under 192.531.

192.547 Oregon Health Authority rules; procedures. (1)(a) The Oregon Health Authority shall adopt rules for conducting research using DNA samples, genetic testing and genetic information. Rules establishing minimum research standards shall conform to the Federal Policy for the Protection of Human Subjects, 45 C.F.R. 46, that is current at the time the rules are adopted. The rules may be changed from time to time as may be necessary.

(b) The rules adopted by the Oregon Health Authority shall address the operation and appointment of institutional review boards. The rules shall conform to the compositional and operational standards for such boards contained in the Federal Policy for the Protection of Human Subjects that is current at the time the rules are adopted. The rules must require that research conducted under paragraph (a) of this subsection be conducted with the approval of the institutional review board.

(c) Persons proposing to conduct anonymous research, coded research or genetic research that is otherwise thought to be exempt from review must obtain from an institutional review board prior to conducting such research a determination that the proposed research is exempt from review.

(2) A person proposing to conduct research under subsection (1) of this section, including anonymous research or coded research, must disclose to the institutional review board the proposed use of DNA samples, genetic testing or genetic information.

(3) The Oregon Health Authority shall adopt rules requiring that all institutional review boards operating under subsection (1)(b) of this section register with the department. The Advisory Committee on Genetic Privacy and Research shall use the registry to educate institutional review boards about the purposes and requirements of the genetic privacy statutes and administrative rules relating to genetic research.

(4) The Oregon Health Authority shall consult with the Advisory Committee on Genetic Privacy and Research before adopting the rules required under subsections (1) and (3) of this section, including rules identifying those parts of the Federal Policy for the Protection of Human Subjects that are applicable to this section.

(5) Genetic research in which the DNA sample or genetic information is coded shall satisfy the following requirements:

(a)(A) The subject has granted informed consent for the specific research project;
(B) The subject has consented to genetic research generally; or
(C) The DNA sample or genetic information is derived from a biological specimen or from clinical individually identifiable health information that was obtained or retained in compliance with ORS 192.537 (2).

(b) The research has been approved by an institutional review board after disclosure by the investigator to the board of risks associated with the coding.

(c) The code is:

(A) Not derived from individual identifiers;
(B) Kept securely and separately from the DNA samples and genetic information; and
(C) Not accessible to the investigator unless specifically approved by the institutional review board.

(d) Data is stored securely in password protected electronic files or by other means with access limited to necessary personnel.

(e) The data is limited to elements required for analysis and meets the criteria in 45 C.F.R. 164.514(e) for a limited data set.

(f) The investigator is a party to the data use agreement as provided by 45 C.F.R. 164.514(e) for limited data set recipients.

(6) Research conducted in accordance with this section is rebuttably presumed to comply with ORS 192.535 and 192.539.

(7)(a) Notwithstanding ORS 192.535, a person may use a DNA sample or genetic information obtained, with blanket informed consent, before June 25, 2001, for genetic research.

(b) Notwithstanding ORS 192.535, a person may use a DNA sample or genetic information obtained without specific informed consent and derived from a biological specimen or clinical individually identifiable health information for anonymous research or coded research if an institutional review board operating under subsection (1)(b) of this section:

(A) Waives or alters the consent requirements pursuant to the Federal Policy for the Protection of Human Subjects; and

(B) Waives authorization pursuant to the federal Health Insurance Portability and Accountability Act privacy regulations, 45 C.F.R. parts 160 and 164.

(c) Except as provided in subsection (5)(a) of this section or paragraph (b) of this subsection, a person must have specific informed consent from an individual to use a DNA sample or genetic information of the individual obtained on or after June 25, 2001, for genetic research.

(8) Except as otherwise allowed by rule of the Oregon Health Authority, if DNA samples or genetic information obtained for either clinical or research purposes is used in research, a person may not recontact the individual or the physician, physician assistant, naturopathic physician or nurse practitioner of the individual by using research information that is identifiable or coded. The Oregon Health Authority shall adopt by rule criteria for recontacting an individual or the physician, physician assistant, naturopathic physician or nurse practitioner of an individual. In adopting the criteria, the department shall consider the recommendations of national organizations such as those created by executive order by the President of the United States and the recommendations of the Advisory Committee on Genetic Privacy and Research.

(9) The requirements for consent to, or notification of, obtaining a DNA sample or genetic information for genetic research are governed by the provisions of ORS 192.531 to 192.549 and the administrative rules that were in effect on the effective date of the institutional review

board's most recent approval of the study. [2001 c.588 §6; 2003 c.333 §5; 2005 c.678 §6; 2009 c.595 §171; 2014 c.45 §33; 2017 c.356 §25]

Note: See note under 192.531.

192.549 Advisory Committee on Genetic Privacy and Research. (1) The Advisory Committee on Genetic Privacy and Research is established consisting of 15 members. The President of the Senate and the Speaker of the House of Representatives shall each appoint one member and one alternate. The Director of the Oregon Health Authority shall appoint one representative and one alternate from each of the following categories:

- (a) Academic institutions involved in genetic research;
- (b) Physicians licensed under ORS chapter 677;
- (c) Voluntary organizations involved in the development of public policy on issues related to genetic privacy;
- (d) Hospitals;
- (e) The Department of Consumer and Business Services;
- (f) The Oregon Health Authority;
- (g) Health care service contractors involved in genetic and health services research;
- (h) The biosciences industry;
- (i) The pharmaceutical industry;
- (j) Health care consumers;
- (k) Organizations advocating for privacy of medical information;
- (L) Public members of institutional review boards; and
- (m) Organizations or individuals promoting public education about genetic research and genetic privacy and public involvement in policymaking related to genetic research and genetic privacy.

(2) Organizations and individuals representing the categories listed in subsection (1) of this section may recommend nominees for membership on the advisory committee to the President, the Speaker and the director.

(3) Members and alternate members of the advisory committee serve two-year terms and may be reappointed.

(4) Members and alternate members of the advisory committee serve at the pleasure of the appointing entity.

(5) Notwithstanding ORS 171.072, members and alternate members of the advisory committee who are members of the Legislative Assembly are not entitled to mileage expenses or a per diem and serve as volunteers on the advisory committee. Other members and alternate members of the advisory committee are not entitled to compensation or reimbursement for expenses and serve as volunteers on the advisory committee.

(6) The Oregon Health Authority shall provide staff for the advisory committee.

(7) The advisory committee shall report biennially to the Legislative Assembly in the manner provided by ORS 192.245. The report shall include the activities and the results of any studies conducted by the advisory committee. The advisory committee may make any recommendations for legislative changes deemed necessary by the advisory committee.

(8) The advisory committee shall study the use and disclosure of genetic information and shall develop and refine a legal framework that defines the rights of individuals whose DNA samples and genetic information are collected, stored, analyzed and disclosed.

(9) The advisory committee shall create opportunities for public education on the scientific, legal and ethical development within the fields of genetic privacy and research. The advisory committee shall also elicit public input on these matters. The advisory committee shall make reasonable efforts to obtain public input that is representative of the diversity of opinion on this subject. The advisory committee's recommendations to the Legislative Assembly shall take into consideration public concerns and values related to these matters. [2001 c.588 §7; 2003 c.333 §6; 2009 c.595 §172; 2011 c.272 §4]

Note: See note under 192.531.

192.566 Authorization form. A health care provider may use an authorization that contains the following provisions in accordance with ORS 192.558:

AUTHORIZATION
TO USE AND DISCLOSE
PROTECTED HEALTH INFORMATION

I authorize: _____ (Name of person/entity disclosing information) to use and disclose a copy of the specific health information described below regarding: _____ (Name of individual) consisting of: (Describe information to be used/disclosed)

to: _____ (Name and address of recipient or recipients) for the purpose of: (Describe each purpose of disclosure or indicate that the disclosure is at the request of the individual)

If the information to be disclosed contains any of the types of records or information listed below, additional laws relating to the use and disclosure of the information may apply. I understand and agree that this information will be disclosed if I place my initials in the applicable space next to the type of information.

- _____ HIV/AIDS information
- _____ Mental health information
- _____ Genetic testing information
- _____ Drug/alcohol diagnosis, treatment, or referral information.

I understand that the information used or disclosed pursuant to this authorization may be subject to redisclosure and no longer be protected under federal law. However, I also understand that federal or state law may restrict redisclosure of HIV/AIDS information, mental health

information, genetic testing information and drug/alcohol diagnosis, treatment or referral information.

PROVIDER INFORMATION

You do not need to sign this authorization. Refusal to sign the authorization will not adversely affect your ability to receive health care services or reimbursement for services. The only circumstance when refusal to sign means you will not receive health care services is if the health care services are solely for the purpose of providing health information to someone else and the authorization is necessary to make that disclosure.

You may revoke this authorization in writing at any time. If you revoke your authorization, the information described above may no longer be used or disclosed for the purposes described in this written authorization. The only exception is when a covered entity has taken action in reliance on the authorization or the authorization was obtained as a condition of obtaining insurance coverage.

To revoke this authorization, please send a written statement to _____ (contact person) at _____ (address of person/entity disclosing information) and state that you are revoking this authorization.

SIGNATURE

I have read this authorization and I understand it. Unless revoked, this authorization expires _____ (insert either applicable date or event).

By: _____
(individual or personal representative)

Date: _____

Description of personal representative's authority: _____

[Formerly 192.522]

Note: See note under 192.553.

192.581 Allowed retention or disclosure of genetic information. (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 192.558 (3).

(3) As used in this section, “retain genetic information” has the meaning given that term in ORS 192.531. [Formerly 192.529]

Note: See note under 192.553.

Chapter 659A

MISCELLANEOUS UNLAWFUL EMPLOYMENT DISCRIMINATION

§ 659A.300 Requiring breathalyzer, polygraph, psychological stress or brain-wave test or genetic test prohibited

§ 659A.303 Employer prohibited from obtaining, seeking to obtain or using genetic information

659A.300 Requiring breathalyzer, polygraph, psychological stress or brain-wave test or genetic test prohibited (1) Except as provided in this section, it is an unlawful employment practice for any employer to subject, directly or indirectly, any employee or prospective employee to any breathalyzer test, polygraph examination, psychological stress test, genetic test or brain-wave test.

(2) As used in this section:

(a) “Breathalyzer test” means a test to detect the presence of alcohol in the body through the use of instrumentation or mechanical devices.

(b) “Genetic test” has the meaning given in ORS **192.531 (Definitions for ORS 192.531 to 192.549)**.

(c) “Polygraph examination or psychological stress test” means a test to detect deception or to verify the truth of statements through the use of instrumentation or mechanical devices.

(d) An individual is “under the influence of intoxicating liquor” when the individual’s blood alcohol content exceeds the amount prescribed in a collective bargaining agreement or the amount prescribed in the employer’s work rules if there is no applicable collective bargaining provision.

(3) Nothing in subsection (1) of this section shall be construed to prohibit the administration of a polygraph examination to an individual, if the individual consents to the examination, during the course of criminal or civil judicial proceedings in which the individual is a party or witness or during the course of a criminal investigation conducted by a law enforcement agency, as defined in ORS **181A.010 (Definitions for ORS 181A.010 to 181A.350)**, a district attorney or the Attorney General.

(4) Nothing in subsection (1) of this section shall be construed to prohibit the administration of a breathalyzer test to an individual if the individual consents to the test. If the employer has reasonable grounds to believe that the individual is under the influence of intoxicating liquor, the employer may require, as a condition for employment or continuation of employment, the administration of a blood alcohol content test by a third party or a breathalyzer test. The employer shall not require the employee to pay the cost of administering any such test.

(5) Subsection (1) of this section does not prohibit the administration of a genetic test to an individual if the individual or the individual’s representative grants informed consent in the manner provided by ORS **192.535 (Informed consent for obtaining genetic information)**, and the genetic test is administered solely to determine a bona fide occupational qualification.

[Formerly **659.227**]

659A.303 Employer prohibited from obtaining, seeking to obtain or using genetic information. (1) It is an unlawful employment practice for an employer to seek to obtain, to obtain or to use genetic information of an employee or a prospective employee, or of a blood relative of the employee or prospective employee, to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to an employee or a prospective employee.

(2) For purposes of this section, “blood relative,” “genetic information” and “obtain genetic information” have the meanings given those terms in ORS **192.531 (Definitions for ORS 192.531 to 192.549)**. [Formerly **659.036**; 2011 c.210 §4]

Chapter 746

GENERAL PROVISIONS

§ 746.135 Genetic tests and information

USE AND DISCLOSURE OF INSURANCE INFORMATION

§ 746.632 Genetic information used for treatment

746.135 Genetic tests and information. (1) If a person asks an applicant for insurance to take a genetic test in connection with an application for insurance, the use of the test shall be revealed to the applicant and the person shall obtain the specific authorization of the applicant using a form adopted by the Director of the Department of Consumer and Business Services by rule.

(2) A person may not use favorable genetic information to induce the purchase of insurance.

(3) A person may not use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy for hospital or medical expenses.

(4) A person may not use genetic information about a blood relative to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy of insurance.

(5) For purposes of this section, “blood relative,” “genetic information” and “genetic test” have the meanings given those terms in ORS **192.531 (Definitions for ORS 192.531 to 192.549)**. [1995 c.680 §8; 2001 c.588 §17]

746.632 Genetic information used for treatment. (1) Notwithstanding ORS **192.537 (Individual’s rights in genetic information)** (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 (Disclosure of genetic information)** (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 (Use and disclosure of personal information)** (3).

(3) As used in this section, “retain genetic information” has the meaning given that term in ORS **192.531 (Definitions for ORS 192.531 to 192.549)**.

(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 (Genetic tests and information)**. [2007 c.800 §8]