Oregon Genetic Privacy Statutes
Compared with Genetic Information Nondiscrimination Act of 2008

Oregon Revised Statutes	Genetic Information Nondiscrimination Act of 2008 (GINA) (Congressional Research Service summary, or bill text)
CONFIDENTIALITY	
ORS 192.529 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 192.520 (3). (3) As used in this section, “retain genetic information” has the meaning given that term in ORS 192.531. [2007 c.800 §5]	(Sec. 105) Amends title XI (General Provisions, Peer Review, and Administrative Simplification) of SSA [Social Security Act] to require the Secretary of Health and Human Services to revise Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy regulations to: (1) treat genetic information as health information; and (2) prohibit the use or disclosure by a group health plan, health insurance coverage, or Medicare supplemental policy of genetic information about an individual for underwriting purposes.
DEFINITIONS	
ORS 192.531 Definitions for ORS 192.531 to 192.549. As used in ORS 192.531 to 192.549:	[Substantially parallel definitions are found in sections 101, 102, 103, 104, and 201.]
(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.	(3) FAMILY MEMBER- The term `family member' means, with respect to an individual-- (A) a dependent (as such term is used for purposes of section 701(f)(2) of the Employee Retirement Income Security Act of 1974) of such

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	individual, and (B) any other individual who is a first-degree, second-degree, third-degree, or fourth-degree relative of such individual or of an individual described in subparagraph (A).
(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. (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.	(4) GENETIC INFORMATION- (A) IN GENERAL- The term `genetic information' means, with respect to any individual, information about-- (i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual. (B) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH- Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual. (C) EXCLUSIONS- The term `genetic information' shall not include information about the sex or age of any individual. (6) GENETIC SERVICES- The term `genetic services' means-- (A) a genetic test; (B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or (C) genetic education. (7) GENETIC TEST-

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	(A) IN GENERAL- The term `genetic test' means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes. (B) EXCEPTIONS- The term `genetic test' does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes. 209(b) Genetic Information of a Fetus or Embryo- Any reference in this title to genetic information concerning an individual or family member of an individual shall-- (1) with respect to such an individual or family member of an individual who is a pregnant woman, include genetic information of any fetus carried by such pregnant woman; and (2) with respect to an individual or family member utilizing an assisted reproductive technology, include genetic information of any embryo legally held by the individual or family member.
FINDINGS	
ORS 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.	**SEC. 2. FINDINGS.** Congress makes the following findings: (1) Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract a particular disorder. New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current

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(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.	treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment. (2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic `defects' such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to `correct' apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area. (3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary. (4) Congress has been informed of examples of genetic discrimination

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(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]	in the workplace. These include the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case Norman-Bloodsaw v. Lawrence Berkeley Laboratory (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance. (5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections. Moreover, while many States have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.

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EMPLOYMENT	
ORS 659A.300 Requiring … genetic test prohibited; exceptions. (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 … genetic test … . (2) As used in this section:… (b) "Genetic test" has the meaning given in ORS 192.531. (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, and the genetic test is administered solely to determine a bona fide occupational qualification. [Formerly 659.227]	**Title II: Prohibiting Employment Discrimination on the Basis of Genetic Information** - (Sec. 202) Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from discriminating against an employee, individual, or member because of genetic information, including: (1) for an employer, by failing to hire or discharging an employee or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of employment; (2) for an employment agency, by failing or refusing to refer an individual for employment; (3) for a labor organization, by excluding or expelling a member from the organization; (4) for an employment agency, labor organization, or joint labor-management committee, by causing or attempting to cause an employer to discriminate against a member in violation of this Act; or (5) for an employer, labor organization, or joint labor-management committee, by discriminating against an individual in admission to, or employment in, any program established to provide apprenticeships or other training or retraining. Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from limiting, segregating, or classifying employees, individuals, or members because of genetic information in any way that would deprive or tend to deprive such individuals of employment opportunities or otherwise adversely affect their status as employees.

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ORS 659A.303 Employer prohibited from obtaining, seeking to obtain or using genetic information; remedies. (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) An employee or prospective employee may bring a civil action under ORS 659A.885 for a violation of this section. (3) For purposes of this section, “blood relative,” “genetic information” and “obtain genetic information” have the meanings given those terms in ORS 192.531.	Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from requesting, requiring, or purchasing an employee's genetic information, except for certain purposes, which include where: (1) such information is requested or required to comply with certification requirements of family and medical leave laws; (2) the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace; and (3) the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory. (Sec. 206) Requires an employer, employment agency, labor organization, or joint labor-management committee that possesses any genetic information about an employee or member to maintain such information in separate files and treat such information as a confidential medical record. Prohibits an employer, employment agency, labor organization, or joint labor-management committee from disclosing such genetic information, except: (1) to the employee or member upon request; (2) to an occupational or other health researcher; (3) in response to a court order; (4) to a government official investigating compliance with this Act if the information is relevant to the investigation; (5) in connection with the employee's compliance with the certification provisions of the Family and Medical Leave Act of 1993 or such requirements under state family and medical leave laws; or (6) to a public health agency.. (Sec. 208) Provides that disparate impact on the basis of genetic information does not establish a cause of action under this Act.

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INSURANCE	
ORS 743.730 Definitions for ORS 743.730 to 743.773. For purposes of ORS 743.730 to 743.773 [relating to Small Employer, Group, Individual and Portability Health Insurance]: (27) “Preexisting conditions provision” means a health benefit plan provision applicable to an enrollee or late enrollee that excludes coverage for services, charges or expenses incurred during a specified period immediately following enrollment for a condition for which medical advice, diagnosis, care or treatment was recommended or received during a specified period immediately preceding enrollment. For purposes of ORS 743.730 to 743.773: … (b) Genetic information does not constitute a preexisting condition in the absence of a diagnosis of the condition related to such information… . **ORS 746.135 Genetic tests and information; rules.** (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	**Title I: Genetic Nondiscrimination in Health Insurance** - (Sec. 101) Amends the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code to prohibit a group health plan from adjusting premium or contribution amounts for a group on the basis of genetic information. Prohibits a group health plan from requesting or requiring an individual or family member of an individual from undergoing a genetic test. Provides that such prohibition does not: (1) limit the authority of a health care professional to request an individual to undergo a genetic test; or (2) preclude a group health plan from obtaining or using the results of a genetic test in making a determination regarding payment. Requires the plan to request only the minimum amount of information necessary to accomplish the intended purpose. Allows a group health plan to request, but not require, a participant or beneficiary to undergo a genetic test for research purposes if certain requirements are met, including: (1) the plan clearly indicates that compliance is voluntary and that noncompliance will have no effect on enrollment status or premium or contribution amounts; (2) no genetic information collected or acquired is used for underwriting purposes; and (3) the plan notifies the Secretary of Health and Human Services that it is conducting activities pursuant to this exception and includes a description of the activities. Prohibits a group health plan from requesting, requiring, or purchasing genetic information: (1) for underwriting purposes; or (2) with respect

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expenses.	to any individual prior to such individual's enrollment in connection with such enrollment (provides that incidentally obtains such information is not a violation).
(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. [1995 c.680 §8; 2001 c.588 §17] **ORS 746.632 Genetic information used for treatment; authorization; disclosure.** (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.	Applies such prohibitions to all group health plans, including small group health plans. Provides that any reference to genetic information concerning an individual or family member includes genetic information of: (1) a fetus carried by a pregnant woman; and (2) an embryo legally held by an individual or family member utilizing an assisted reproductive technology. Authorizes a penalty against any sponsor of a group health plan for any failure to meet requirements of this Act. Allows a waiver or limitation on such penalty if the failure was not discovered after exercising reasonable diligence or was due to reasonable cause. (Sec. 102) Amends the PHSA to prohibit: (1) a health insurance issuer offering health insurance coverage in the individual market from establishing eligibility rules for enrollment based on genetic information; (2) discrimination on the basis of genetic information for health insurance offered in the individual market in the same manner as such discrimination is prohibited for group coverage; and (3) the imposition by a health insurance issuer offering health insurance coverage in the individual market of a preexisting condition exclusion on the basis of genetic information. `(9) UNDERWRITING PURPOSES- The term `underwriting purposes' means, with respect to any group health plan, or health

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(5) Nothing in this section shall be construed to interfere with or limit the requirements of ORS 746.135. [2007 c.800 §8]	insurance coverage offered in connection with a group health plan-- `(A) rules for, or determination of, eligibility (including enrollment and continued eligibility) for benefits under the plan or coverage; `(B) the computation of premium or contribution amounts under the plan or coverage; `(C) the application of any pre-existing condition exclusion under the plan or coverage; and `(D) other activities related to the creation, renewal, or replacement of a contract of health insurance or health benefits.'.