

ASSURING GENETIC PRIVACY IN OREGON

*THE REPORT OF THE
GENETIC RESEARCH ADVISORY COMMITTEE*

November 15, 2000

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EXECUTIVE SUMMARY

Remedies for violations of genetic privacy requirements

The Genetic Research Advisory Committee recommends the adoption of both civil and criminal penalties for violation of Oregon's genetic privacy statutes. Minimum civil damages would be \$1,000 for inadvertent violations involving obtaining or disclosing genetic information or material, and \$100 for inadvertently retaining genetic information or material. Penalties for inadvertent violations could be avoided altogether by correcting breaches of genetic privacy starting within 60 days of their discovery. For knowing violations of genetic privacy, the committee recommends much more stringent minimum penalties, between \$100,000 and \$250,000 per violation (depending on the nature of the violation) for knowingly obtaining or disclosing in violation of the law, and between \$10,000 and \$25,000 for knowingly retaining genetic information in violation of the law. Violations which are not shown to be either inadvertent or knowing will be subject to minimum damages of \$500 for illegal retention and \$5,000 for illegal obtaining or disclosing of genetic information or material. In all cases, actual damages will be awarded if the actual damages are greater than the minimum damages cited above. Violations which occur knowingly, recklessly, or with criminal negligence would be a Class A misdemeanor.

Family issues

The committee recommends that the statute be amended to include privacy protections for blood relatives of persons who have been the subject of genetic testing. We also propose that a new Advisory Committee on Genetic Privacy and Research study the issue of discrimination based on the family medical history.

Informed consent

The committee recommends that research with identifiable genetic information should be conducted under the federal "Common Rule" for "Protection of Human Subjects." Oregon statute should be revised to provide the Health Division with rulemaking authority in this regard. The Health Division should also adopt standards for recontacting patients for new research on genetic material that had been provided at an earlier date. And the Health Division should promulgate advisory guidelines for research using encoded or encrypted patient identifiers.

Rulemaking authority related to informed consent for genetic testing for insurance purposes should be transferred from the Health Division to the Department of Consumer and Business Services.

Property

Oregon statute currently provides that an individual's genetic information is the property of the individual. The Genetic Research Advisory Committee believes that it is not essential to retain the property clause, but it is critically important that the purposes intended to be served by the property clause be accomplished. These include standing for individuals to pursue violations of the genetic privacy rights, mechanisms for families to obtain genetic information regarding a deceased family member, and protection of family members from discrimination based on genetic information. The committee believes that these purposes can be accomplished through the recommendations outlined above concerning remedies, family issues, and informed consent. We therefore recommend that the property clause be deleted in conjunction with the other changes recommended in this report, and that a privacy right be adopted in its stead.

The committee is also concerned about intellectual property issues related to genetic information. Many committee members are especially concerned about the current federal policy that allows human gene sequences to be patented. We recommend that the proposed new Advisory Committee on Genetic Privacy and Research should study this issue in depth starting next year.

Continued study and oversight

Genetic privacy and research are perennial topics for legislative consideration, and this is likely to continue. The issues are technical and complex, and are ever-changing due to rapid scientific, legal, and ethical developments in the field. The Genetic Research Advisory Committee therefore recommends that an ongoing advisory committee be established to monitor these issues and make recommendations to the legislature. The new body should be called the Advisory Committee on Genetic Privacy and Research. We recommend that the Health Division staff this advisory committee. This new committee should create opportunities to educate the public about issues related to genetic privacy and genetic research, and should solicit and consider public input in developing its recommendations.

RECOMMENDATIONS FOR STATUTORY REVISIONS *Genetic Research Advisory Committee*

Remedies for violations of genetic privacy requirements

The committee recommends the adoption of both civil and criminal penalties for violation of Oregon’s genetic privacy statutes. These proposed provisions are found in sections 2-4 of the attached bill draft, and are summarized below.

1. Private Action.

Recommended Minimum Damages (per violation)		
	<i>Illegal retention</i>	<i>Illegal obtaining or disclosing</i>
Inadvertent violations		
Corrected	\$0	\$0
Not corrected	\$100	\$1,000
Violations	\$500	\$5,000
Knowing or reckless violations	\$10,000	\$100,000
Knowing violations committed under false pretenses	\$15,000	\$150,000
Knowing violations committed with intent to make monetary gain or with malicious intent	\$25,000	\$250,000

- For inadvertent violations, damages would be \$100 or actual damages, whichever is greater, for retaining genetic information or material and \$1,000 or actual damages, whichever is greater, for obtaining or disclosing genetic information or material.
- Penalties for inadvertent violations could be avoided altogether by correcting breaches of genetic privacy starting within 60 days of their discovery. Defendants would have the opportunity to complete correction of violations within 60 days after a complaint is filed or within 60 days of receiving notice of intent to file a complaint.
- \$10,000 or actual damages, whichever is greater, for knowingly or recklessly retaining in violation of the law; and \$100,000 or actual damages, whichever is greater, for knowingly or recklessly obtaining or disclosing in violation of the law.
- \$15,000 or actual damages, whichever is greater, for knowing retaining violations committed under false pretenses; and \$150,000 or actual damages, whichever is greater, for knowingly obtaining or disclosing under false pretenses.
- \$25,000 or actual damages, whichever is greater, for knowing retaining violations committed with intent to make monetary gain or with malicious intent; and \$250,000 or actual damages, whichever is greater, for knowingly obtaining or disclosing with intent to make monetary gain or with malicious intent.
- Damages are for each violation, and in all cases actual damages will be awarded if actual damages are greater than the minimum dollar amounts cited above.
- Equitable relief, including court orders to destroy genetic material, available.

- Standing available to individual and to any blood relative.
 - In order to clarify when a violation occurs, new definitions of “disclose,” “obtain,” and “retain” would be added to ORS 659.700.
2. Action by Prosecuting Attorney.
 - Prosecuting attorney (AG or relevant DA) may bring action for damages equal to damages set forth above to any Oregon residents.
 - Prosecuting attorney may bring action using procedures similar to those in ORS 124.125.
 3. Criminal Penalties.
 - Class A misdemeanor (up to 1 year in prison and/or \$5,000 fine) if violation occurs knowingly, recklessly, or with criminal negligence.
 4. Attorney Fees.

Attorney fees may be awarded to the prevailing party, upon application to the court, subject to the following conditions:

- A plaintiff would only have to pay the attorney fees of a defendant if the court finds that the plaintiff’s claim was frivolous or harassing or presented for some other improper purpose.
- The court *must* award attorney fees to a plaintiff if the defendant is found to have committed a knowing violation.
- No attorney fees shall be awarded if the violation was inadvertent and has been corrected.
- In situations in which none of the three circumstances bulleted above apply, the court will have discretion regarding the awarding of attorney fees. If the award of attorney’s fees is discretionary, the amount of the award is also discretionary. Judges can award less than full attorney fees in such cases.

Family issues

The committee recommends that the statute be amended to include privacy protections for blood relatives of persons who have been the subject of genetic testing. The attached bill draft adds references to blood relatives at a number of points where the existing statute refers only to the individual. It also provides a definition of “blood relative” in a proposed new ORS 659.700(3). In addition, there are four new substantive provisions proposed to be added because of their importance to blood relatives. The first three of these were initially proposed (but not enacted) in SB 1008 in the 1999 legislative session.

1. Authority to obtain genetic information about a decedent for medical diagnosis of blood relatives. New ORS 659.710(1)(f). This corresponds to existing ORS 659.720(1)(e), which allows *disclosing* genetic information about a decedent for medical diagnosis of blood relatives.
2. Authority to request additional diagnostic testing of retained DNA samples. New ORS 659.715(8). This right would be created for the tested individual as well.

3. Standing for a blood relative or the estate of an individual to bring an action for violation. Included in new section 2, subsection (1), of the bill draft.
4. Protection of blood relatives against discrimination by employers or insurers. Revised ORS 659.036(1) and new ORS 746.135(4).

GRAC recognizes the potential to violate an individual's genetic privacy through inappropriate use of family history, genetic testing of blood relatives, and determining genetic characteristics through non-genetic evidence. A new Advisory Committee on Genetic Privacy and Research should study this issue next year. This proposed new advisory committee is described later in this report, and in section 6 of the committee's draft legislation.

Informed consent

The committee identified four main settings in which informed consent for genetic testing should be considered, and recommended statutory revisions related to these settings.

1. Clinical Health Care.

- ORS 677.097 currently governs informed consent in the doctor's office. The committee recommends *no change* to this statute. We note that current voluntary standards of informed consent for genetic testing used by major health care institutions, geneticists, and genetic counselors exceed requirements of ORS 677.097.
- Proposed federal regulations for genetic testing under the Clinical Laboratory Improvement Amendments (CLIA)¹ would require that any sample submitted to a lab for genetic testing must have been obtained through informed consent. Medical practitioners would have to comply with these rules in order to have genetic tests conducted by a regulated laboratory. This would effectively establish informed consent and privacy standards in the clinical setting that exceed state standards.
- Currently, Oregon statute protects the privacy of information resulting from genetic testing, but does not address situations in which a person *seeks* genetic counseling or a genetic test. It is possible that people could be discriminated against simply because they have sought genetic counseling. The proposed new Advisory Committee on Genetic Privacy and Research should study the need for legal privacy protections in such circumstances. Subsection (6) of section 6 of the draft legislation.

2. Research.

- Research with identifiable genetic information should be conducted under Health Division rules which would incorporate the federal "Common Rule" for "Protection of Human Subjects" (45 CFR 46 and *Federal Register*, 56:117, pages 28002-28032, June 18, 1991). Oregon statute should be revised to provide the Health Division with rulemaking authority in this regard. Research conducted in conformance with these provisions would be presumed to comply with the informed consent and confidentiality

¹ *Federal Register*, May 4, 2000, pages 25928-25934.

provisions of Oregon's genetic privacy statutes. Research that fails to comply with the Common Rule requirements, however, would be subject to the damage awards and other remedies outlined in the committee's draft bill. Subsections (1), (4), and (6) of section 5 of the attached draft legislation.

- Under the Common Rule, institutional review boards (IRBs) supervise research on human subjects. The committee recommends that Oregon statute authorize the Health Division to establish a registry of all IRBs overseeing research in Oregon. Subsections (3) and (4) of section 5 of the attached draft legislation.
- Anonymous research (that is, research in which the identity of the person providing the DNA sample is not known) is exempt from the provisions of Oregon's genetic privacy law, and may also be exempt from IRB review under the provisions of the federal Common Rule. The committee proposes that Oregon researchers proposing to conduct anonymous research or research which is otherwise thought to be exempt from IRB review should first obtain a determination from an IRB that the proposed research is, in fact, exempt. Paragraph (1)(c) of section 5 of the draft legislation.
- ORS 659.700(1)(b) currently defines research conducted under the Common Rule as "anonymous research," thereby exempting Common Rule research from the requirements of Oregon's genetic privacy law, and from state regulation generally. As detailed above, the committee's recommendations would insert a new section into Oregon's genetic privacy statutes that would require genetic research in Oregon to conform to the Common Rule. Inclusion of Common Rule research under the definition of "anonymous research" is therefore no longer necessary. And because research under the Common Rule is *not* necessarily anonymous research, this definition doesn't entirely make sense. Therefore, the committee's draft legislation proposes to delete ORS 659.700(1)(b).
- Samples already collected with blanket informed consent for research (*i.e.*, informed consent for any type of research) could be used for genetic research without specific consent, but samples obtained after the effective date of the legislation should require specific consent for genetic research. That is, the patient would need to be informed that genetic research might be done on the sample, and must consent to such research. Subsection (7) of section 5 of the draft legislation. We also propose to add a definition of "Blanket informed consent" in new subsection ORS 659.700(2).
- If clinical DNA samples or clinical genetic information are used in research, a firewall should disallow recontacting the patient or patient's physician using personal identifiers unless defined criteria are satisfied. Such criteria should be promulgated by the Health Division based on recommendations of national organizations such as the National Bioethics Advisory Commission and on recommendations of the proposed new Advisory Committee on Genetic Privacy and Research. The Genetic Research Advisory Committee believes that these criteria should establish, as a general rule, that there should be no disclosure of genetic information from a researcher to a patient or the patient's physician. Exceptions to this general rule could include cases in which the patient has requested such data, or situations in which disclosure of the research data would be to the clear and overwhelming benefit of the patient. The firewall criteria should not preclude the researcher from having coded or encrypted genetic information momentarily decoded or de-encrypted for purposes of linking the information to additional demographic, family history or medical record information, provided that the confidentiality of the patient's identity to the researcher to is maintained during the decoding or de-encryption process

Proposed Policy Matrix Relating to Legal Requirements for Informed Consent for Genetic Research			
<i>Sample/Genetic Information Obtained</i>	<i>1. Anonymous</i>	<i>2. Encoded/Encrypted</i>	<i>3. Identifiable</i>
After effective date of 2001 legislation	a. IC/G-B not required b. IC/SGR not required IRB must determine that research is truly “anonymous.”	a. IC/G-B not required b. IC/SGR not required IC/SGR required in cases where an IRB finds greater than minimal risk to research subjects. “Firewall” restricts use of genetic information without informed consent. “Firewall” may be breached if IRB/OHD conditions & standards are met.	a. IC/SGR required “Firewall” may be breached if IRB/OHD conditions & standards are met.
Before effective date of 2001 legislation	c. IC/G-B not required d. IC/SGR not required	c. IC/G-B not required d. IC/SGR not required IC/G-B required in cases where an IRB finds greater than minimal risk to research subjects. “Firewall” can be breached only if, at minimum, IC/GB has been obtained. IRB/OHD conditions & standards must also be met.	b. IC/G-B required “Firewall” may be breached if IRB/OHD conditions & standards are met.

Key:

- IC/G-B A general or blanket informed consent for research generally (genetic research and other forms of scientific research on human subjects).
- IC/SGR A specific informed consent for genetic research on human subjects.
- Firewall A legal prohibition on contacting a research subject or the research subject’s treating physician by the researcher unless certain conditions exist and them only in accordance with standards governing the manner and form of recontact of the research subject by the researcher.
- IRB/OHD The institutional review board responsible for review of the research protocol and the Oregon Health Division.

and after completion of such process. Subsection (8) of section 5 and subsection (6) of section 6 of the draft legislation. In addition, a definition of “clinical” would be added in new ORS 659.700(4).

- Oregon should require that researchers affirmatively disclose to IRBs the genetic privacy aspects of proposed research. Subsection (2) of section 5 of the draft legislation.

NOTE: The matrix above summarizes the legal requirements for informed consent that are listed above.

- Research using encoded information may be carried out under a waiver of consent if approved by an IRB. In addition to the legal requirements outlined above, the committee recommends that Oregon statute authorize the Health Division to adopt advisory

guidelines for research using encoded information based on current national practice standards, such as Section 12 of the National Association of Insurance Commissioners' 1998 "Health Information Privacy Model Act" and the recommendations of the National Bioethics Advisory Commission in "Research Involving Human Biological Materials: Ethical Issues and Policy Guidance," Volume 1, August 1999. Subsection (5) of section 5 of the draft legislation.

- Some committee members believe that informed consent should always be required prior to conducting research on a DNA sample, even if identifying information is encoded or encrypted. Possible expansion of informed consent requirements should be studied by the new Advisory Committee on Genetic Privacy and Research. Subsection (6) of section 6 of the draft legislation.

3. Insurance.

- Rulemaking authority related to informed consent for genetic testing for insurance purposes should be transferred from the Health Division to the Department of Consumer and Business Services. ORS 746.135(1).

4. Employment.

- ORS 659.036 prohibits employers from discriminating against employees on the basis of genetic information. The committee proposes to retain this prohibition. However, this statute currently allows employers, "with specific authorization of the employee," to use genetic information to "determine a bona fide occupational qualification." We propose to delete this provision, because we believe that it is inappropriate for employers to determine occupational qualifications on the basis of genetic information. Section 7 of the draft legislation.
- In addition, we are aware that the Civil Rights Work Group of the Oregon Law Commission recently found that ORS 659.036(2) is unclear in regard to the remedies that would be available for employment discrimination based on genetic information. The Genetic Research Advisory Committee believes that victims of employment discrimination on the basis of genetic information should have a clear and stringent remedy available to them. We therefore recommend that a reference to ORS 659.036 be added to ORS 659.121(2). This would mean that victims of employment discrimination on the basis of genetic information could seek compensatory damages, punitive damages, and equitable relief through the courts. Sections 7 and 8 of the draft legislation.

Property

ORS 659.715(1) currently provides that "an individual's genetic information and DNA sample are the property of the individual except when the information or sample is used in anonymous research." The committee has been told by the drafters of this provision that the property clause was intended to provide a way for individuals and their families to retain some control over their genetic information. It was also expected that individuals and their families could enforce the privacy rights provided in the statute through court action based on their property rights. The reasons that a property right was created as the mechanism for these purposes were:

- It's a simple concept.
- It gives families ownership of the genetic material of a decedent.
- It provides families with protection from discrimination by providing them with standing for legal action.

Other committee members pointed out, however, that there have been no attempts to date to use the property clause in a court action to enforce genetic privacy rights, and it might be difficult to do so in practice. In addition, the property clause makes genetic privacy an alienable right. Under current Oregon statute, when one signs away one's property rights to a DNA sample, as many patients do when the sample is obtained, a person also signs away his or her privacy rights. Concern has also been expressed that the property clause may inhibit genetic research and the development of the biotechnology industry in Oregon.

The consensus of the Genetic Research Advisory Committee is that it is not essential to retain the property clause, but it is critically important that the purposes intended to be served by the property clause be accomplished. These include standing for individuals to pursue violations of the genetic privacy rights, mechanisms for families to obtain genetic information regarding a deceased family member, and protection of family members from discrimination based on genetic information. The committee believes that these purposes can be accomplished through the statutory changes outlined under the "Remedies..." and "Family issues" headings, above.

We therefore recommend that the property clause in ORS 659.715(1) be deleted in conjunction with the other changes recommended in this report. In the attached bill draft, the property clause would be replaced by language stating that individuals have a right to the privacy of their genetic information, and the confidentiality of such information must be protected.

The committee is also concerned about intellectual property issues related to genetic information. Many committee members are especially concerned about the current federal policy that allows human gene sequences to be patented. We recognize that this is a national policy issue, but because of the implications of this policy for Oregonians, we recommend that the proposed new Advisory Committee on Genetic Privacy and Research should study this issue in depth starting next year. Subsection (6) of section 6 of the draft legislation.

Continued study and oversight

Genetic privacy and research have been considered in every legislative session since 1993. The issues are technical and complex, and are ever-changing due to rapid scientific, legal, and ethical developments in the field. The Genetic Research Advisory Committee therefore recommends that an ongoing advisory committee be established to monitor these issues and make recommendations to the legislature. The new body should be called the Advisory Committee on Genetic Privacy and Research. Because the Health Division would have responsibility for genetic research rulemaking and issuance of guidelines under these recommendations, we recommend that the Health Division also staff this advisory committee. The membership of the advisory committee should represent the same constituencies as the Genetic Research Advisory Committee. Section 6 of the draft legislation.

During the course of its deliberations over the past year, the committee had the benefit of responses from Oregonians around the state generated from focus groups and an Internet web site organized by Geneforum.org, whose Executive Director served as the consumer representative on the Genetic Research Advisory Committee. The input we received reflected a citizenry generally supportive of genetic research but equally concerned about the protection of their privacy. In addition, Geneforum.org's findings showed that Oregonians share with citizens throughout the country a high degree of confusion, misunderstanding and misinformation about all aspects of genetic research and genetic privacy. The committee therefore recommends that continuing efforts be made to gather public input on genetic privacy issues, to inform and educate the public about genetic research, and to promote public dialogue on these issues. The committee believes that the Health Division, in staffing the new committee, can provide for these activities by partnering with community organizations with an interest and involvement in genetic privacy and health care consumer concerns. It is our intent that these activities should not result in any fiscal impact on the Health Division. Section 6 of the draft legislation instructs the new Advisory Committee on Genetic Privacy and Research to create opportunities for such dialogue, and to consider public concerns and values in developing its recommendations. The committee should make reasonable efforts to insure that this public input is representative of the diversity of opinion in the Oregon population.

Housekeeping revisions

- The committee believes that one of its purposes is to lay a foundation for expanded genetic research efforts in Oregon, through developing clear standards for genetic privacy and informed consent. We therefore propose to amend the legislative findings in ORS 659.705(1)(f) to state that one purpose of these legal standards is to *encourage* research.
- The committee proposes to replace “insurance provider” with “person” throughout the statute. This will make genetic private statutes consistent with the terminology used in Oregon’s insurance laws. These proposed changes are found in deleted ORS 659.700(7) and ORS 746.135 of the attached draft legislation.
- In addition to the substantive changes to definitions noted earlier, the committee proposes several definitional changes for purposes of clarification. These include changes to the definitions of “DNA sample” (renumbered ORS 659.700(7) in the attached draft), “Genetic characteristic” (renumbered ORS 659.700(8)), “Genetic information” (renumbered ORS 659.700(9)), “Genetic test” (renumbered ORS 659.700(11)), and a proposed new definition of “Research” (new ORS 659.700(14)). The new definition of “research” is drawn verbatim from the Common Rule. The committee intends that the term “research” will be interpreted as parallel to the Common Rule.
- Section 3, chapter 921, Oregon Laws 1999 (SB 937-B, enacted by the 1999 legislature), provides that as of January 1, 2002, the definitions in ORS 659.700 will revert to the version of these definitions that existed prior to 1999. The purpose of this provision was to provide a time limit on the definition of “Anonymous research,” which currently includes research conducted under the federal Common Rule. As noted above, the committee proposes to delete this portion of the “Anonymous research” definition, and make changes to several other definitions. Therefore, reversion to the old definitions as they existed prior to 1999 is

neither necessary nor appropriate. Section 3, chapter 921, OL 1999, therefore needs to be repealed. This repeal is contained in section 15 of the attached draft.

- The committee proposes to revise ORS 659.710(1)(b). This subparagraph is part of a list of exceptions to the general requirement that “No person shall obtain genetic information from an individual... without first obtaining informed consent...” The current exemption from this requirement is for “Anonymous research where the identity of the subject will not be revealed.” We would change this to simply read “Anonymous research.” Our purpose in proposing this change is to clarify and simplify the language of this subparagraph, without changing its meaning. The current language dates to the original enactment of the statute in 1995. In 1997, a definition of “anonymous research” was added to the statute. Because this definition is in statute and, as noted above, would be returned to its original meaning by our recommendations, the explanatory clause in ORS 659.710(1)(b) is no longer needed.

**POSSIBLE BILL LANGUAGE TO IMPLEMENT
GENETIC RESEARCH ADVISORY COMMITTEE RECOMMENDATIONS**

SECTION 1. Sections 2 through 6 are added to and made a part of ORS 659.700 to 659.720.

SECTION 2.

- (1) An individual or the individual's blood relative, representative, or estate may bring a civil action against any person who violates ORS 659.700 to 659.720.**
- (2) The court shall award the following to a plaintiff who prevails in an action under this section:**
 - (a) For any violation that involves unlawfully retaining genetic information or a DNA sample, the unlawful failure to destroy a DNA sample, or any other violation of ORS 659.700 to 659.720 not described in paragraph (b) of this subsection,**
 - (i) \$100, for a violation that:**
 - (A) Resulted from a good faith belief by the person claimed to be in violation of ORS 659.700 to 659.720, that such person was not acting contrary to said statutory provisions; and**
 - (B) Was not due to willful neglect;**
 - (ii) \$500, for a violation not described in subparagraphs (i), (iii), (iv), or (v) of this paragraph;**
 - (iii) \$10,000, for a knowing or reckless violation not described in subparagraphs (iv) or (v) of this paragraph;**
 - (iv) \$15,000, for a knowing violation committed under false pretenses, except as provided in subparagraph (v) of this paragraph; or**
 - (v) \$25,000, for a knowing violation committed with intent to sell, transfer, or use for commercial advantage, personal gain, or malicious harm.**
 - (b) For any violation that involves the unlawful obtaining or disclosure of genetic information or a DNA sample,**
 - (i) \$1,000, for a violation that:**
 - (A) Resulted from a good faith belief by the person claimed to be in violation of ORS 659.700 to 659.720, that such person was not acting contrary to said statutory provisions; and**
 - (B) Was not due to willful neglect;**
 - (ii) \$5,000, for a violation not described in subparagraphs (i), (iii), (iv), or (v) of this paragraph;**
 - (iii) \$100,000, for a knowing or reckless violation not described in subparagraphs (iv) or (v) or this paragraph;**
 - (iv) \$150,000, for a knowing violation committed under false pretenses, except as provided in subparagraph (v) of this paragraph; or**

NOTE: Material in **boldfaced** type is proposed new law. Material [*italic and bracketed*] is existing law to be omitted. Material in an amended section which is neither in boldfaced type nor italic and bracketed is existing law which is not proposed to be changed. This draft was produced by GRAC staff. Most of this bill language has *not* been produced or reviewed by Legislative Counsel.

- (v) \$250,000, for a knowing violation committed with intent to sell, transfer, or use for commercial advantage, personal gain, or malicious harm.
- (c) All economic damages, as defined in ORS 18.560, if greater than the amounts described in paragraphs (a) and (b) of this subsection.
- (3) Correcting a violation through destruction of illegally retained or obtained samples or information, or other effective means, shall be an affirmative defense against a complaint under subparagraphs (2)(a)(i) or (2)(b)(i) of this section, if the correction:
 - (a) Was diligently initiated during the 60-day period beginning on the first date the defendant knew, or by exercising reasonable diligence would have known, that the violation occurred; and
 - (b) Was completed by the later of the filing of a complaint or 60 days after written notice to the person claimed to be in violation of intent to file a complaint.
- (4) The court may provide such equitable relief as it deems necessary or proper.
- (5) The court may award attorney fees to the prevailing party as provided in ORCP 68, subject to the following conditions:
 - (a) Attorney fees may be awarded to a defendant only if the court finds that the plaintiff has made or is responsible for a false certification to the court, as defined in ORCP 17 C, or had no objectively reasonable basis for asserting a claim or no reasonable basis for appealing an adverse decision of the trial court.
 - (b) The award of attorney fees to a plaintiff shall be mandatory if the defendant is found to have committed a violation described in subparagraphs (2)(a)(iii), (iv) or (v) or subparagraphs (2)(b)(iii), (iv), or (v) of this section.
 - (c) The court shall not award attorneys fees to a plaintiff if the defendant is found to have committed a violation that is described in subparagraph (2)(a)(i) or subparagraph (2)(b)(i) of this section and that has been corrected as described in subsection (3) of this section.
 - (d) If the award of attorney fees under this subsection is at the discretion of the court, the amount of attorney fees shall be determined after taking into account the factors in ORS 20.075.
- (6) The actions authorized by subsection (1) of this section must be filed within three years of the date the plaintiff knew or should have known of the violation, but in any case no more than ten years after the date of the injury.
- (7) A plaintiff may recover damages provided by subsection (2) of this section for each violation by a defendant.
- (8) A person who knowingly, recklessly or with criminal negligence obtains, retains, or discloses genetic information in violation of ORS 659.700 to 659.720 is guilty of a Class A misdemeanor.

SECTION 3.

- (1) The Attorney General or any district attorney may bring an action against any person who violates ORS 659.700 to 659.720. In addition to remedies otherwise provided in section 2 of this 2001 Act, upon prevailing in the action, the court shall award to the Attorney General or district attorney costs of investigation.
- (2) The Attorney General may intervene in any civil action brought under section 2 of this 2001 Act if the Attorney General certifies that, in the opinion of the Attorney General, the action is of general public importance. In the action, the State shall be entitled to the

same relief as if the Attorney General instituted the action under the provisions of this section.

SECTION 4. Sections 2 and 3 of this 2001 Act apply only to causes of action that arise on or after the effective date of this 2001 Act.

SECTION 5.

- (1) (a) Research using DNA samples, genetic testing, or genetic information shall be conducted in accordance with the Federal Policy for the Protection of Human Subjects.**
- (b) Such research shall be conducted with the approval of an institutional review board which complies with the compositional and operational standards for such boards contained in the Federal Policy for the Protection of Human Subjects.**
- (c) Persons proposing to conduct anonymous research, as defined in ORS 659.700(1), or genetic research which is otherwise thought to be exempt from review by an institutional review board under the provisions of the Federal Policy for the Protection of Human Subjects, shall obtain a determination from an institutional review board that such research is, in fact, exempt from review prior to conducting such research.**
- (2) A person proposing to conduct research under subsection (1) of this section, including anonymous research, shall disclose to the institutional review board the proposed use of DNA samples, genetic testing, or genetic information.**
- (3) All institutional review boards established in accordance with paragraph (1)(b) of this section shall register with the Health Division.**
- (4) In consultation with the Advisory Committee on Genetic Privacy and Research, the Health Division shall adopt any rules necessary to carry out subsections (1) and (3) of this section, including rules identifying those parts and versions of the Federal Policy for the Protection of Human Subjects which are applicable to this section.**
- (5) In consultation with the Advisory Committee on Genetic Privacy and Research, the Health Division shall promulgate advisory guidelines for genetic research in which the identity of the individual providing a DNA sample is protected by an encryption or coding system. Such guidelines shall be based on recommendations of credible national and state organizations.**
- (6) Research conducted in accordance with this section will be rebuttably presumed to comply with ORS 659.710 and 659.720.**
- (7) In cases where informed consent is required by either ORS 659.710 or the Federal Policy for the Protection of Human Subjects, samples collected before the effective date of this 2001 Act with blanket informed consent for research may be used for genetic research without specific informed consent, but samples obtained after the effective date of this 2001 Act shall have informed consent from the patient for genetic research.**
- (8) If DNA samples or genetic information obtained for either clinical or research purposes are used in research, no person may recontact the patient or patient's physician using research information with personal identifiers unless defined criteria are satisfied. The Health Division shall adopt such criteria in rule based on recommendations of national organizations such as the National Bioethics Advisory Commission and from recommendations of the Advisory Committee on Genetic Privacy and Research.**

SECTION 6.

- (1) The Health Division shall establish an Advisory Committee on Genetic Privacy and Research. 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.**
- (2) The Advisory Committee on Genetic Privacy and Research shall consist of one representative and one alternate from each of the following constituencies:**
 - (a) One representative and one alternate appointed by the President of the Senate;**
 - (b) One representative and one alternate appointed by the Speaker of the House of Representatives;**
 - (c) Academic institutions involved in genetic research;**
 - (d) Voluntary organizations involved in the development of public policy on issues related to genetic privacy;**
 - (e) Physicians licensed under ORS chapter 677;**
 - (f) Hospitals;**
 - (g) Health Division;**
 - (h) Department of Consumer and Business Services;**
 - (i) Health care service contractors involved in genetic and health services research;**
 - (j) The biosciences industry;**
 - (k) The pharmaceutical industry; and**
 - (L) Health care consumers.**
- (3) Members and alternates representing the constituencies identified in paragraphs (2)(c) through (2)(L) of this section shall be appointed by the Assistant Director for Health of the Department of Human Services from nominations submitted by organizations and individuals representing these constituencies.**
- (4) Members and alternate members of the advisory committee shall serve two-year terms, and may be reappointed at the completion of each term.**
- (5) The Health Division shall provide staff for the Advisory Committee on Genetic Privacy and Research.**
- (6) The Advisory Committee on Genetic Privacy and Research shall make its report by the start of each regular session of the Legislative Assembly in the manner provided by ORS 192.245. The advisory committee's report shall include the results of its studies and shall make any recommendations for legislative changes deemed necessary for the implementation of the recommendations of the committee. In its report to the Seventy-second Legislative Assembly, the advisory committee shall include recommendations relating to:**
 - (a) Patenting of human genes,**
 - (b) Standards for recontact with patients who have provided samples for genetic research,**
 - (c) The privacy of information about genetic conditions obtained other than through a genetic test,**
 - (d) The privacy of persons who seek genetic counseling or genetic testing, and**
 - (e) Whether to modify or expand current statutory provisions requiring informed consent for genetic research.**

- (7) **As part of its regular activities, the Advisory Committee on Genetic Privacy and Research shall create opportunities for public education on the scientific, legal, and ethical development within the fields of genetic privacy and research. The committee shall also elicit public input on these matters. The committee’s recommendations shall take into consideration public concerns and values related to these matters. The committee should make reasonable efforts to insure that this public input is representative of the diversity of opinion in the Oregon population.**

SECTION 7. ORS 659.036 is amended to read:

659.036. (1) It shall be an unlawful employment practice for an employer to seek to obtain, to obtain, or to use genetic information, [*as defined in ORS 659.700,*] 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. [*This subsection does not prohibit an employer from seeking, obtaining or using genetic information with specific authorization of the employee or prospective employee solely to determine a bona fide occupational qualification, as may be defined by rules adopted by the Commissioner of the Bureau of Labor and Industries.*]

(2) If an employee or a prospective employee files a complaint with the Bureau of Labor and Industries alleging violation of subsection (1) of this section, the bureau shall cause any necessary investigation to be made and shall enforce subsection (1) of this section in the manner provided in ORS 659.010 to 659.110 [*and 659.12.*]. **A civil action may be brought under ORS 659.121 for violation of this section.**

(3) **For purposes of this section, “blood relative,” “genetic information,” and “obtain” have those meanings given in ORS 659.700.**

SECTION 8. ORS 659.121 is amended to read:

659.121 (1) Any person claiming to be aggrieved by an unlawful employment practice prohibited by ORS 25.424, 399.235, 659.030, 659.035, 659.227, 659.270, 659.295, 659.330, 659.340 or 659.400 to 659.494 may file a civil suit in circuit court for injunctive relief and the court may order such other equitable relief as may be appropriate, including but not limited to reinstatement or the hiring of employees with or without back pay. Back pay liability shall not accrue from a date more than two years prior to the filing of a complaint with the Commissioner of the Bureau of Labor and Industries, pursuant to ORS 659.040, or if no such complaint has first been filed, then, more than two years prior to the filing of the civil suit provided for in ORS 659.040, 659.045, 659.095 and this section. In any suit brought under this subsection, the court may allow the prevailing party costs and reasonable attorney fees at trial and on appeal.

(2) Any person claiming to be aggrieved by alleged violations of ORS 659.033 (1) or (3), **659.036**, 659.295, 659.400 to 659.449 or 659.550 may file a civil action in circuit court to recover compensatory damages or \$200, whichever is greater, and punitive damages. In addition, the court may award relief authorized under subsection (1) of this section and such equitable relief as it considers appropriate. At the request of any party, the trial of such case shall be by jury. In any action brought under this subsection, the court may allow the prevailing party costs and reasonable attorney fees at trial and on appeal. Any attorney fee agreement shall be subject to approval by the court.

- (3) Where no complaint has been filed pursuant to ORS 659.040 (1) or 659.045 (1) and except as otherwise provided herein, the civil suit or action shall be commenced within one year of the occurrence of the alleged unlawful employment practice. Where a complaint has been filed pursuant to ORS 659.040 (1) or 659.045 (1) the civil suit or action provided for herein shall be commenced only in accordance with the time limitations provided for in ORS 659.095. The filing of a complaint with the commissioner under ORS 659.040 (1) or 659.045 (1) shall not be a condition precedent to the filing of civil suit or action under this section.
- (4) This section shall not be construed to limit or alter in any way the authority or power of the commissioner or to limit or alter in any way any of the rights of an individual complainant until and unless the complainant commences civil suit or action. Except as provided in subsection (5) of this section, the filing of a civil suit or action in either circuit court pursuant to subsection (1) of this section or federal district court under applicable federal law shall constitute both an election of remedies as to the rights of that individual with respect to those matters alleged in the complaint filed with the commissioner, and a waiver with respect to the right to file a complaint with the commissioner pursuant to ORS 659.040 (1) or 659.045 (1).
- (5) (a) Where a person claiming to be aggrieved by alleged violations of ORS 659.033 or 659.430 or applicable federal law files a civil suit or action in circuit court or in federal district court, that filing does not constitute an election of remedies until such time as the trial commences.
(b) An aggrieved person may not commence a civil action under this subsection with respect to an alleged discriminatory housing practice which forms the basis of specific charges issued by the commissioner if a hearings referee has commenced a hearing on the record under this chapter with respect to such charge.
- (6) Notwithstanding any other provision of ORS 659.010 to 659.121 and 659.470 to 659.545, a civil complaint alleging violations of ORS 659.033 or 659.430 may be filed not later than two years after the occurrence or the termination of an alleged discriminatory housing practice, or the breach of a conciliation agreement entered into under ORS 659.010 to 659.121 and 659.470 to 659.545, whichever occurs last. The two-year period shall not include any time during which an administrative proceeding was pending with respect to the housing practice or breach.

SECTION 9. ORS 659.700 is amended to read:

659.700 As used in ORS 659.700 to 659.720:

- (1) “Anonymous research” means[:]
[(a) S] 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, **or the identity of the individual’s blood relatives,** cannot be determined.[: or]
[(b) *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.*]
- (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) **“Disclose” means to release or publish a DNA sample or genetic information to a third party. A release or publication shall not be a disclosure if it:**
- (a) **Involves a good faith belief by the person who caused the release or publication that such person was not in violation of ORS 659.700 to 659.720;**
 - (b) **Is not due to willful neglect;**
 - (c) **Is corrected in the manner described in subsection (3) of section 2 of this 2001 Act;**
 - (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.**
- [(2)] (6) **“DNA” means deoxyribonucleic acid.**
- [(3)] (7) **“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] perform a genetic test. “DNA sample” includes DNA extracted from the specimen.**
- [(4)] (8) **“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.] “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 blood relatives. “Genetic characteristic” does not include family history or a genetically transmitted characteristic whose existence or identity is determined other than through a genetic test.**
- [(5)] (9) **“Genetic information” [is the] means information about an individual or [family] the individual’s blood relatives obtained from[:]**
- [(a)] **A a genetic test.[: or]**
 - [(b)] **An individual’s DNA sample.]**
- (10) **“Genetic research” means research using DNA samples, genetic testing, or genetic information.**
- [(6)] (11) **“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.**
- [(7)] **“Insurance provider” means an insurance company, health care service contractor, fraternal benefit organization, insurance agent, third party administrator, insurance support organization or other person subject to regulation by the Insurance Code.]**
- (12) **“Obtain” genetic information means to perform or get the results of a genetic test.**

[(8)] (13) “Person” has the meaning given in ORS 433.045.

(14) “Research” means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

(15) “Retain” genetic information means to make a record of the genetic information.
“Retain” a DNA sample means the act of storing the sample.

SECTION 10. ORS 659.705 is amended to read:

659.705. (1) The Legislative Assembly finds that:

- (a) The DNA molecule contains information about [*an individual's*] **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 the 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 an 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 ORS 659.700 to 659.720 and 746.135 and the provisions of ORS 659.036, 659.227 and 746.015 relating to genetic characteristics, information and testing 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.

SECTION 11. ORS 659.710 is amended to read:

659.710. (1) No person shall 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 181.085 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 [*where the identity of the subject will not be revealed*];
- (c) As permitted by rules of the Health Division for identification of deceased individuals;
- (d) As permitted by rules of the Health Division for newborn screening procedures; or
- (e) As authorized by statute for the purpose of establishing paternity[.] **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] 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, [A]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 section 5 of this 2001 Act.**

[(3)] (4) [*An insurance provider 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 rules adopted by the Department of Consumer and Business Services.*] **Except as provided in ORS 746.135(1), any other person 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 Health Division.**

[(4)] (5) The Health Division 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.

SECTION 12. ORS 659.715 is amended to read:

659.715. (1) Subject to the provisions of ORS 659.036, 659.700 to 659.720 and 746.135, an individual's genetic information and DNA sample are [*the property of the individual except when the information or sample is used in anonymous research.*] **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 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 person does not [*interfere with, infringe upon, misappropriate or otherwise damage an individual's property*] **violate or otherwise interfere with the confidentiality of an individual's genetic information or DNA sample** by obtaining, testing, retaining, disclosing or providing an individual's genetic information or DNA sample solely for anonymous research.

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

- (a) Retention is authorized by ORS 181.085 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 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 Health Division for identification of, or testing to benefit blood relatives of, deceased individuals;
 - (d) Retention is permitted by rules of the Health Division for newborn screening procedures; or
 - (e) Retention is for anonymous research.
- (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 181.085 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 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.
- (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 of 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, unless the genetic information has been made anonymous by destruction of all information that could allow disclosure of the identity of the individual who provided the sample **or of the individual's blood relatives.**
- (8) Subject to all other provisions of ORS 659.700 to 659.720, and to all reasonable 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.**
- [(8)] **(9)** The Health Division shall coordinate the implementation of this section.
- [(9)] **(10)** This section applies only to genetic information that can be identified as belonging to an individual or *[family]* **the individual's blood relative.** 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.

SECTION 13. ORS 659.720 is amended to read:

659.720. (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 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 181.085 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 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 paternity;
 - (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 Health Division;
 - (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 a blood relative of the individual**.

SECTION 14. ORS 746.135 is amended to read:

746.135. (1) If [*an insurance provider*] **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 [*provider*] **person** shall obtain the specific authorization of the applicant using a form [*prescribed by rules of the Health Division*] **adopted by the Director of the Department of Consumer and Business Services by rule.**

- (2) [*An insurance provider*] **A person** may not use [*a favorable genetic test as an inducement to purchase insurance.*] **favorable genetic information to induce the purchase of insurance.**
- (3) [*An insurance provider*] **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.**

[(4)] (5) For purposes of this section, **“blood relative,” “genetic information,” and “genetic test”** [*and “insurance provider”*] have those meanings given in ORS 659.700

SECTION 15. Section 3, chapter 921, Oregon Laws 1999, is repealed.

SECTION 16. This 2001 Act being necessary for the immediate preservation of the public peace, health and safety, an emergency is declared to exist, and this 2001 Act takes effect on its passage.