

REVENUE: No revenue impact

FISCAL: Fiscal impact statement issued

Action:	Do Pass the A-Engrossed Measure
Vote:	10 - 0 - 1
Yeas:	Ackerman, Backlund, Dingfelder, Krieger, Lowe, Ringo, Shetterly, Walker C, Walker V, Williams
Nays:	0
Exc.:	Wilson
Prepared By:	Andrea Shartel, Counsel
Meeting Dates:	6/6

WHAT THE BILL DOES: Specifies that genetic information and DNA sample are private and that an individual has a right to protection of that privacy. Deletes provision providing that genetic information and DNA sample are the “property” of the individual. Establishes a civil cause of action to enforce the individual’s privacy interest by an individual, an individual’s blood relative, estate, or the Attorney General. Establishes minimum damages for specified violations from \$0 for inadvertent disclosure that is corrected before read by recipient to \$250,000 for a disclosure with the intent to use for commercial advantage. Creates criminal penalty for unlawfully obtaining, retaining or disclosing genetic information. Requires the Health Division to adopt rules consistent with Federal Policy for the Protection of Human Subjects (Common Rule) and to establish minimum research standards and institutional review boards to oversee testing of genetic information. Requires review by the institutional review board of all proposed anonymous research. Delegates rulemaking authority to Health Division to promulgate guidelines for genetic research in which the identity of the individual is encrypted. Requires Health Division to establish criteria for recontact of individuals when using research information with personal identifiers. Requires persons conducting research to obtain informed consent of the individual except where the individual’s identity is anonymous or encrypted. Limits the use of a blanket informed consent for further research. Requires notification to individual that individual’s DNA sample or genetic information may be used for anonymous research before any sample may be used for anonymous research. Establishes and specifies composition of Advisory Committee on Genetic Privacy and specifies issues for report to legislature. Prohibits an employer from obtaining or using genetic information to discriminate or restrict by adding use of genetic information of a blood relative of an employee or prospective employee. Clarifies insurance code provisions related to use of genetic information by insurer to affect terms or rate of insurance.

ISSUES DISCUSSED:

- Broad representation on Genetic Research Advisory Committee.
- Need for ongoing study because of rapidly evolving technology and public policy questions.
- Bill does not address question of royalties derived from DNA research.
- Nature of an individual’s rights with respect to his or her DNA.

EFFECT OF COMMITTEE AMENDMENTS: None.

BACKGROUND: The 1995 Legislative Assembly enacted legislation to protect the rights of an individual in the rapid expansion of genetic research and testing. The Legislative Assembly found that the improper collection, retention, or disclosure of genetic information could lead to significant harm to the individual, including stigmatization and discrimination in employment, education, health care and insurance and that current legal protections were inadequate (ORS 659.705(1)(d) and (e)). The Legislative Assembly declared genetic information to be the *property* of the individual and, as such, required law enforcement, district attorneys, and researchers to obtain informed consent before obtaining genetic information from an individual.

During the 1999 Legislative Assembly, SB 937 was introduced at the request of the Pharmaceutical Research and Manufacturers of America (PhRMA) to modify genetic privacy statutes. The goal was to balance the protection of patient confidentiality with the continuation of vital medical research in Oregon. PhRMA as well as the Oregon Medical

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This summary has not been adopted or officially endorsed by action of the committee.

Association and Oregon Health Sciences University testified that the complexity of the issues necessitated additional study and input from interested parties through an interim advisory committee. SB 937-B redefined “anonymous research” and required the Office for Oregon Health Plan Policy and Research to establish a Genetic Research Advisory Committee (GRAC) with specified membership to study the use and disclosure of genetic information. The GRAC was also charged with developing a legal framework defining the rights of individuals.

This bill comes to the Judiciary Committee as the consensus bill of the GRAC.