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Background Brief on...

# Genetic Privacy

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## Background

An individual's DNA molecules contain genetic information that includes the individual's probable medical future. This is important and sensitive information and could be used to benefit or harm the individual. Oregon, like many other states, has adopted genetic privacy laws to protect the public from the abusive use of DNA information.<sup>1</sup> In doing so, the Legislature found that genetic information is uniquely private and personal and should not be collected, retained or disclosed without the individual's authorization.

In Oregon, it is a Class A misdemeanor to unlawfully obtain or disclose genetic information. Also, Oregon law creates a civil cause of action against anyone who unlawfully obtains or discloses genetic information, and allows an individual whose DNA is illegally used to obtain the greater of actual damages or set statutory damages that range from \$100 for negligent violations up to \$250,000 for knowing violations committed with the intent to sell or use a person's DNA for commercial purposes.

Oregon law allows the use of DNA without an individual's consent for the following reasons:

- Identification of deceased individuals
- Paternity
- Newborn screening
- Genetic information from a decedent for medical diagnoses of blood relatives
- Court order
- Anonymous research conducted after proper notification

Oregon law requires the Health Division to adopt rules establishing minimum research standards for the collecting and testing of genetic information. The law also requires that individuals be notified if their DNA sample or genetic information is being used for anonymous research before it is used. However, the researcher does not need the individual's consent to use the individual's DNA in the research if the individual's identity is anonymous and the information is encrypted.

Oregon law requires the Department of Human Services to establish institutional review boards to review and approve a

<sup>1</sup> See ORS 192.531 to 192.549.

researcher's request to conduct anonymous research. A researcher cannot conduct genetic research in Oregon without approval by an institutional review board.

Oregon law prohibits an employer from obtaining or using genetic information to discriminate against an employee or prospective employee or a blood relative of an employee or prospective employee. The law also clarifies that an insurance company may use genetic information to encourage an individual to obtain insurance, but may not use the results to reject an application or to increase the rates of a policy.<sup>2</sup>

## History

Oregon's first genetic privacy law was enacted in 1995. Legislators expressed concern 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. The 1995 law established genetic information as 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. This particular provision caused problems for both the law enforcement and medical research community.

During the 1999 legislative session, the Pharmaceutical Research and Manufacturers of America asked the 1999 Legislative Assembly to modify Oregon's existing genetic privacy laws. The goal was to balance the protection of patient confidentiality with the continuation of vital medical research in Oregon. In addition to the pharmaceutical research industry, the Oregon Medical Association and Oregon Health Sciences University testified that the complexity of the issue necessitated additional study and requested an interim advisory committee. In response, the Legislature created the Genetic Research Advisory Committee (**GRAC**) to study the use and disclosure of genetic information and to report back to the 2001 Legislative Assembly.

GRAC did so, and produced Senate Bill 114 (2001), a bill that the Legislature adopted in modified form.<sup>3</sup> The most significant change contained in the bill was that it replaced the provision making DNA property of

the individual with a privacy right. In addition, the bill continued GRAC and required it to report biennially to the Legislature.<sup>4</sup>

## Federal Law

The federal government regulates research involving human subjects conducted, supported or otherwise regulated by any federal department or agency.<sup>5</sup> These regulations are known as the Common Rule because 15 federal agencies adopted them simultaneously. These regulations reach genetic testing involving humans. These regulations do not affect state laws or regulations which provide additional protections for human subjects. Senate Bill 114 (2001), made the Common Rule applicable to nonfederal research conducted in Oregon.

The Health Insurance Portability and Accountability Act of 1996 (**HIPAA**) establishes a basic threshold for the protection of health care data. Health care data includes the genetic information of individual patients. These regulations set limitations on the release of health records and provide individuals with more control over his or her personal health information.

## Other States

Twenty-nine states have laws that pertain directly to genetic privacy. Of these states, sixteen require informed consent for a third party to either perform or require a genetic test or to obtain genetic information. Twenty-three states require informed consent to disclose genetic information. Rhode Island and Washington require written authorization to disclose genetic information. Four states explicitly define genetic information as the personal property of the individual. One state, Oregon, repealed its property right to genetic information and replaced it with a privacy right.<sup>6</sup>

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<sup>4</sup> Chapter 333, Oregon Laws 2003 made changes to Oregon's genetic privacy laws that clarified certain definitions and statutory requirements

<sup>5</sup> 56 FR 28003, Revised November 13, 2001; 45 CFR 46

<sup>6</sup> Source: National Conference of State Legislatures

<sup>2</sup> ORS 659A.303

<sup>3</sup> Chapter 588, Oregon Laws 2001