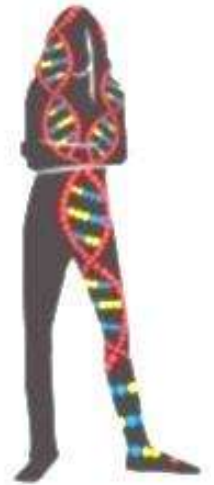


Stay Out of My Genes

Know Your Rights to Genetic Privacy in Oregon

Why do many people desire genetic privacy?

Although genetic research can lead to important medical discoveries and treatments for disease, many people wish to keep their genetic information private. The reason for their concern is that genetic material holds personal information about an individual's traits, disease profile, and family medical history. Tissue samples taken during a medical examination contain information not only about the patient but also about his or her blood relatives. A number of public opinion studies have found that people are particularly concerned that their genetic information might lead to discrimination by insurance companies and employers if that information were available to them.



What laws address this concern?

Both federal and state laws have been passed in the last 20 years to address the need to balance the potential benefits of making genetic information readily available to researchers against the interests of people who might wish to keep their genetic information private. For example, the Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects people from genetic discrimination in health insurance and employment. Oregon's Genetic Privacy Law (OGPL), which was first passed in 1995, requires researchers to obtain your express permission before using specimens collected from you that are identified (with your name or address, or birth date) in genetic research. Even when the specimen has been "de-identified" (it has been given a code that cannot be easily linked to you) Oregon's law requires that you be given an opportunity to prevent its use in genetic research if that is your wish by an opt-out form supplied by a doctor or health care provider.

What has the ACLU of Oregon done to promote genetic privacy?

It is the position of the ACLU of Oregon that genetic information is uniquely private and generally should not be collected, retained, or disclosed without the individual's permission. Even de-identified tissue and blood samples (used in anonymous or coded research) could be linked to the donor according to some recent scientific studies because the DNA itself contains identifying information. For these reasons the ACLU of Oregon was involved in the process of drafting Oregon's genetic privacy law and has participated in subsequent efforts to modify and refine the original law. The basic principle guiding the ACLU's work on genetic privacy is that if a person is concerned about use of their genetic information in research they must be given a meaningful opportunity to deny its use.



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