

Protection of Genetic Information

You Are Protected Against Genetic Discrimination



Genetic information can be used to improve your health and make medical treatment decisions. However, you may worry that your genetic information could be used against you. It can help to know that there are laws in place to protect you from genetic discrimination.

What is genetic information?

The term "genetic information" includes:

- **Your genetic tests** –This is any test that can diagnose a genetic disorder or genetic risk. Genetic testing might be done by looking at a person’s DNA, RNA, chromosomes, proteins, or metabolic compounds.
- **Genetic tests of a family member, embryo, or fetus**
- **Your family history** (the diagnosis of a disease or disorder in your family members)
- **Use of genetic services** by you or your family members
- **Participation in genetic research** by you or your family members

What is genetic discrimination?

Genetic discrimination is when a person is treated unfairly due to genetic information that shows a higher risk of getting a certain disease or condition.

What laws protect you from genetic discrimination?

FEDERAL LAWS - Federal laws provide genetic protection for all Americans

HIPAA – Health Insurance Portability and Accountability Act of 1996 (amended in 2013)

HIPAA states that your genetic information is part of your health information and must be protected in the same way. This law also ensures that health plans cannot use your genetic information to decide whether or not you can get health insurance, how much you should pay for it, or how much coverage you can get.

HIPAA

Under HIPAA, your genetic information CANNOT be used by a health plan to:

- Deny coverage or cancel your existing coverage
- Charge higher premiums
- Determine your eligibility for health insurance
- Qualify as a pre-existing condition (a medical problem or illness you have at the time you start your health insurance)

“Health plans” include health maintenance organizations (HMOs), group plans, health insurance issuers, and issuers of Medicare policies

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This information is not intended in any way to provide legal advice on any matter, including the matter of genetic discrimination. This document is merely intended to be a general description of the law related to genetic discrimination as of the date of this document and should not be relied upon to make decisions about your particular situation related to genetic information or genetic discrimination. If you want to understand the current state of the law related to these matters, please consult your own legal advisor.



GINA - Genetic Information Nondiscrimination Act of 2008

GINA protects genetic information for individuals and their family members. GINA makes sure health insurers do not deny individual coverage or raise premiums based on genetic information alone. GINA also provides protection from genetic discrimination at work.

GINA

Under GINA, your health insurer CANNOT:

- Require that you share genetic information to get coverage or keep coverage
- Use genetic information to deny you coverage or decide how much you pay for insurance
- Require you or a family member to have a genetic test to decide if you can have insurance
- Use genetic information as a pre-existing condition

This law allows your genetic information to be used in ways that do not discriminate.

- Your doctor can ask about your family history and recommend genetic testing as part of your medical care.
- Health insurers are allowed to ask for genetic information or offer genetic testing as part of a voluntary research program.

However, GINA does not provide protection for a person who already has symptoms of a genetic disease. GINA also does not include protection from genetic discrimination in life insurance, disability insurance, or long-term care insurance.

ACA

ACA - Affordable Care Act (“Obamacare”)

Ensures that health insurance companies cannot refuse to cover you or charge you more if you have a pre-existing condition. This provides protection if you have already been diagnosed or are being treated for a genetic disorder.

CALIFORNIA LAWS - California provides additional genetic protection for those who live in the state.

CALIFORNIA LAWS

CalGINA: California Genetic Nondiscrimination Act of 2011

CalGINA added “genetic information” to the list of protected classes in California law. This increased genetic protection to areas beyond health insurance and employment. Some examples include:

- Mortgage lending
- Education
- Public accommodations
- Emergency medical services
- Participation in State programs or activities

California Insurance Codes (Sections 10140, 10143 and 10146-10149.1)

Provides some protection from genetic discrimination in life and disability insurance.

California Civil Code (Section 56.17)

Prohibits a health care service plan from disclosing your genetic test results without your permission.

Who can access your genetic information?

Your genetic information is part of your medical record (paper and electronic). Privacy laws protect your genetic information in the same way other personal medical information is protected.

Under HIPAA privacy rules your genetic information can only be accessed for medical care, payment, and health care operations, and other defined purposes. The KP notice of Privacy Practices describes more details about how your privacy is protected.

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Resources on Genetic Discrimination

For more information about Kaiser Permanente's privacy practices, please visit our members' website at: www.kp.org and use the word "privacy" in the search menu.

Visit the following websites to learn more about genetic discrimination and the laws that protect your genetic information:

GINA: Genetic Information and Nondiscrimination Act – Detailed information about GINA
<http://ginahelp.org/>

Medline Plus – Overview of genetic discrimination; links to additional resources
<https://medlineplus.gov/genetics/understanding/testing/discrimination/>

National Institute of Health – Office of Legislative Policy and Analysis
<http://olpa.od.nih.gov>

Department of Health and Human Service – Office of Civil Rights - Information on Federal civil rights laws and the HIPAA Privacy Rule.
<http://www.hhs.gov/ocr>

Genetic Privacy Network – Educational website for California consumers and the broader public about genetic privacy rights under California and federal law
<https://geneticprivacynetwork.wordpress.com/>

Justia - Justia is a Silicon-Valley based company that provides Internet users with free case law, codes, regulations, legal articles and legal blog databases, as well as community resources.
<http://www.justia.com/>