Protection of Genetic Information
You Are Protected Against Genetic Discrimination

Genetic information can be used to improve your health and make medical treatment decisions. Some people may have concerns that genetic information could also be used to deny, limit, or cancel health insurance. In recent years, laws have been passed that prohibit discrimination by health insurers and employers based on genetic information.

What is genetic information?
The term "genetic information" means information about your genetic tests, the genetic tests of a family member, embryo, or fetus, and the diagnosis of a disease or disorder in your family members (also referred to as "family history"). It includes any analysis of DNA, RNA, chromosomes, proteins, or metabolic compounds that detect genetic mutations or chromosomal changes. It also includes any request for, or receipt of, genetic services, or participation in research that includes genetic services, by you or your family members.

What is genetic discrimination?
Genetic discrimination happens when an individual is treated differently because of genetic information that may indicate an increased risk of getting a certain disease or condition.

What are the laws that protect you from genetic discrimination?
First there are Federal laws, which provide protection for all Americans:

HIPAA – Health Insurance Portability and Accountability Act of 1996
In general, HIPAA does not allow group health plans and group health insurance issuers to establish any rule of eligibility for a person or his/her dependents that discriminates against that person based on any health factor. The term "health factor" includes genetic information.

Under HIPAA:
- You cannot be excluded from or denied enrollment into a group health plan based on your genetic information.
- Your group health plan cannot be cancelled based on your genetic information.
- You cannot be charged premiums higher than others in your group health plan based on your genetic information.
- Your genetic information cannot be used to determine your eligibility for group health plan nor can it be viewed as a pre-existing condition (a medical problem or illness you have at the time you enroll in or purchase your health insurance).

HIPAA only applies to group health coverage. It does not apply to individually purchased health insurance, to life insurance, or to employment.

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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.

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GINA - Genetic Information Nondiscrimination Act of 2008

Under GINA, health insurers are not allowed to reject coverage or raise premiums for individuals based on genetic information alone. The health insurance protections written into GINA cover genetic information of an individual and the genetic information of family members (for example, in determining family health history of disease). GINA does not provide protection for an individual experiencing symptoms from, being treated for, or diagnosed with a genetic disorder.

GINA strictly prohibits the following:
- Health insurers may not require individuals to provide their genetic information or the genetic information of a family member to the insurer for eligibility, coverage, underwriting, or premium-setting decisions.
- Health insurers may not use genetic information to make enrollment or coverage decisions.
- Health insurers may not request or require that an individual or an individual's family member undergo a genetic test; and
- In the Medicare supplemental policy and individual health insurance markets, genetic information cannot be used as a preexisting condition.

A provider may request or recommend genetic testing in the course of treatment. Health insurers may request voluntary genetic testing or information for research purposes as permitted by law. GINA also includes genetic information protection from employment discrimination. GINA does not include protection from genetic discrimination in life insurance, disability insurance, or long-term care insurance.

CALIFORNIA LAWS

In addition to the Federal laws, California has established many state laws to provide protection for California residents against genetic discrimination based on an individual’s genetic characteristics.

California law defines "genetic characteristics" to mean any identifiable gene or inherited characteristic that is statistically related to risk of a disorder but with no symptoms present.

California Health and Safety Code Section 1374.7 (1994) - Addendum to the Knox-Keene Health Care Service Plan Act of 1975

Prohibits health care service plans from refusing to enroll an individual, or discriminating in price or other terms, on the basis of a person's genetic characteristics alone.

California Insurance Code Sections 10140, 10143 and 10146-10149.1

These provisions prohibit disability insurers from discriminating against subscribers or prospective subscribers in either enrollment or premiums based on genetic characteristics that may be associated with a future disability in the subscriber or the subscriber's children. Both life and disability insurers are prohibited from discrimination based solely on carrier status for recessive disorders. The insurance codes also limit (but do not prohibit) when life and disability insurers can require genetic testing as a condition of eligibility for enrollment.

California Civil Code Section 56.17 (2003)

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

Who has access to your genetic information?

Like all medical information, your genetic information is part of your medical record (paper and/or electronic). As such, the privacy and confidentiality of your genetic information is protected by the same laws that safeguard the rest of your personal medical information.

Under HIPAA privacy rules your medical information can only be accessed by people who need the information for the purposes of your treatment, payment of services, and health care operations. Any other use or disclosure of your medical information requires your written authorization, with the exception of legally permitted or required disclosures (such as reporting a contagious disease to the State Public Health Department).
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 for more complete coverage of laws that protect your genetic information:

Genetics and Public Policy Center – Detailed information about GINA
http://www.dnapolicy.org/gina

National Human Genome Research Institute
Genetic discrimination and GINA
http://www.genome.gov/10002328

Database of Federal and State laws/statutes related to genetics
http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm

Genetic Home Reference – Overview of genetic discrimination; links to additional resources

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

Council for Responsible Genetics – A non-profit, non-governmental organization that fosters public debate about the social, ethical and environmental implications of genetic technologies.
http://www.councilforresponsiblegenetics.org

http://www.hhs.gov/ocr

http://www.ca.gov/Health/LawsAndRegs.html

State of California: Department of Managed Health Care - Knox-Keene Health Care Service Plan Act of 1975 - The Knox-Keene Act is the set of laws passed by the State Legislature to regulate HMOs within the State of California. This link opens a quick reference guide covering the Knox-Keene protections (PDF file).
http://www.healthconsumer.org/cs016knoxkeene.pdf

California Insurance Code – A listing of all California insurance codes. Information about genetic discrimination can be found under: Code Sections 10140, 10143, 10146- 10149.1.
http://www.leginfo.ca.gov/ins_table_of_contents.html

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.
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