



The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information. This resource provides an introduction to GINA and its protections in health insurance and employment. It includes answers to common questions and examples to help you learn.

This online resource was created by Genetic Alliance, the Genetics and Public Policy Center at Johns Hopkins University, and the National Coalition for Health Professional Education in Genetics through funding by The Pew Charitable Trusts. May 2010.

Genetic Information

What is genetic information and why is it important?

The genetic information protected by the law includes family health history, the results of genetic tests, the use of genetic counseling and other genetic services, and participation in genetic research.

Why is genetic information important to me?

Genetic information helps you know and understand health conditions that run in your family, as well as your risk for developing certain health conditions or having a child with certain conditions. This information can help you make healthy lifestyle choices and important life and medical decisions. It also helps your doctor in providing you the best care possible.

How does GINA help me?

With GINA's protections, you can feel comfortable talking about family health history with your family and healthcare providers. You may choose to use genetic testing and other services to learn about health risks without fear of genetic discrimination.

GINA & Your Health Insurance

GINA makes it against the law for health insurers to request, require, or use genetic information to make decisions about:

- Your eligibility for health insurance
- Your health insurance premium, contribution amounts, or coverage terms

This means it is against the law for your health insurer to use a genetic test result or family health history as a reason to deny you health insurance, or decide how much you pay for your health insurance.

In addition, GINA makes it against the law for your health insurer to:

- Consider family health history or a genetic test result as a pre-existing condition
- Ask or require that you have a genetic test
- Use any genetic information they do have to discriminate against you, even if they did not mean to collect it

GINA & My Health Insurance (questions and examples)

Does GINA apply to my health insurer?

GINA's protections apply to *most* health insurers. GINA applies to the health insurance plan you receive through your employer (a group plan) as well as health insurance you purchase on your own (an individual plan) for you and your family. GINA also applies to Medicare supplemental policies for individuals who have insurance through Medicare.

The health insurance protections of GINA *do not* apply to

- Members of the US military who receive their care through the Tricare military health system
- Veterans who receive their care through the Veteran's Administration
- The Indian Health Service
- Federal employees who get care through the Federal Employees Health Benefits Plans

These groups have policies in place that provide discrimination protections similar to GINA.

Does GINA mean that a health insurer can't raise my premiums or deny me coverage if I have already been diagnosed with a genetic condition?

No. GINA does not stop health insurers from basing their decisions about eligibility, coverage, or premiums on current symptoms or diagnosis of a health condition (also known as "current health status" or "manifest disease"). This is true even if the condition is a genetic disease or was diagnosed in part by a genetic test.

The March 2010 Health Reform law will help individuals, including those diagnosed with conditions, get access to insurance coverage for healthcare.

Example:

Huntington disease provides a good example for understanding how GINA applies to those at risk to develop a condition, but not those who are diagnosed with a condition. Huntington disease affects the brain and results in uncontrolled movements, as well as emotional (mood) and thinking (cognition) problems. If a person inherits a mutation in the Huntington disease gene, they will develop the disease sometime in their life (usually by age 30 or 40). Until age 30 or 40, they may have no signs of the disease.

There is a genetic test that can tell a person if they inherited a gene mutation that causes Huntington disease. A person can have this test before he or she has symptoms of the condition, and if they do, their insurer cannot use the information to make decisions about their eligibility, coverage, or premiums for health insurance. The genetic test result is protected by GINA. However, when a person begins to show signs and symptoms of Huntington disease and is diagnosed with the disease, GINA does not stop health insurers from using that information to make decisions about the person's eligibility or rates for health insurance.

I just had (or I am considering) a genetic test. Can my health insurer deny me health insurance or raise my premiums because of the results?

No. Under GINA, health insurers *cannot* use genetic information, including results of predictive genetic tests, to make eligibility and coverage decisions. Predictive genetic test results cannot be considered a pre-existing condition.

Example:

A woman has a family history of breast and ovarian cancer. She talks with her doctor about a genetic test to determine if she has a gene mutation that increases her risk of breast and ovarian cancer. She has testing and learns she has a mutation in the BRCA1 gene, confirming her increased risk to develop those cancers.

Her health insurer cannot request, require, or use her genetic test results to make decisions about her eligibility for coverage or the amount she pays for her health insurance.

Can health insurance companies discriminate against me if a family member has been diagnosed with a health condition?

No. GINA makes it against the law for health insurers to use information about diagnosed conditions in an individual's family members.

GINA defines family member as a first- (child, sibling, parent), second- (grandchild, uncle or aunt, niece or nephew, grandparent), third- (cousin, great grandparents, great grandchildren), or fourth-degree (second cousin, great-great grandparents, great-great grandchildren) relative.

Example:

Your doctor asks you about health conditions in your family. You share that your mother's mother (maternal grandmother) died of colon cancer, your mother has heart disease, your father and his father have high cholesterol, and your brother has hypothyroidism. Your doctor will use this information to help understand and talk with you about what conditions you may be at increased risk to develop, and what to do about those risks. This information cannot be used by your health insurer to discriminate against you.

Does GINA apply to other types of insurance?

As of the date this resource was written (May 2010), GINA's protections for insurance apply only to health insurance. They *do not* apply to life, long-term care, or disability insurance. Some state laws may apply to these types of coverage. Check with your state insurance commissioner's office for more information.

GINA & My Genetic Services (questions and examples)

Does GINA mean that my health insurer has to pay for my genetic test or genetic counseling?

No. Health insurers can still make decisions about whether or not they will pay for services based upon your medical need for those services.

Can my health insurance company ask me to have a genetic test or ask to see my genetic test results?

In general, it is against the law for health insurers to ask for, require, or obtain genetic information about applicants or the individuals that they cover. An exception is that your health insurer can ask for genetic information to make a decision about whether or not they will pay for a requested test, treatment, or procedure, in order to determine the medical need for the service. In these situations, GINA only allows the insurer to ask for the minimum amount of information they need to make a decision. Once they have the information, GINA prevents them from using the information to discriminate against you.

Example:

If you decide to have a genetic test because you have a family history of colon cancer, your health insurer may need to know that your family history meets certain criteria in order to pay for your test.

If you have the test and are found to have a mutation that increases your risk, and you need a treatment or procedure based on the test result, your insurer may ask for information about why you need the treatment.

In these examples, according to GINA, the insurer may ask for only the minimum amount of information required to determine if the test or treatment are medically necessary.

GINA & Your Job

GINA makes it against the law for employers to use your genetic information in the following ways:

- To make decisions about hiring, firing, promotion, pay, privileges or terms
- To limit, segregate, classify, or otherwise mistreat an employee

This means it is against the law for your employer to use family health history and genetic test results in making decisions about your employment.

It is also against the law for an employer to request, require, or purchase the genetic information of a potential or current employee, or his or her family members. There are a few exceptions to when an employer can legally have your genetic information. If an employer does have the genetic information of an employee, the employer must keep it confidential and in a separate medical file.

Common Questions About GINA and Employment

Does my employer have to comply with GINA?

GINA applies to all employers with 15 or more employees, regardless if it is a not-for-profit organization or a corporation.

GINA's protections in employment do not extend to the US military or employees of the federal government. In 2000, President Bill Clinton signed Executive Order 13145 into law, which protects federal employees from genetic discrimination in employment. The US military has its own policies in place that may protect members of the military from genetic discrimination.

When is it legal for my employer to know my genetic information?

There are some exceptions to GINA that determine when an employer can legally have your genetic information. Some of the more common situations may include:

- **Inadvertent knowledge:** In some cases an employer may learn about an employee's genetic information accidentally. If he or she overhears a conversation about an employee's sick parent, for example, the employer has not violated GINA.
- **Publicly available information:** An employer may learn the genetic information of an employee or the employee's family members if it is available in the newspaper or other publicly available information sources. If the employer learns of an employee's genetic information this way, the employer has not violated GINA.
- **Voluntary health services:** Some employers offer voluntary health or genetic services, including employee wellness programs. If specific requirements are met and participation in the service is voluntary, then forms, questionnaires, or health care

professionals treating employees as part of the service may request family health history or other genetic information.

- **Family and Medical Leave Act (FMLA):** Forms that employees must fill out as part of asking for time off from work to care for a sick family member may include questions about genetic information. Employees may need to provide this information for extended leave to be approved.

In all the above instances, it is against the law for employers to use the genetic information collected to discriminate against employees.

If my employer finds or collects my genetic information legally, what measures must she take to ensure my information is kept private?

Under GINA and the Health Insurance Portability and Accountability Act (HIPAA), all medical information collected by an employer, including genetic information, must be kept in a confidential, separate medical record.

How GINA Works

GINA was signed into law on May 21, 2008 by President George W. Bush. It is now in effect. At the time this resource was written (April 2010), the federal agencies responsible for enforcing the law are finalizing the regulations that specify how the law will be enforced.

How will GINA be enforced?

The Department of Labor, the Department of the Treasury, and the Department of Health and Human Services all have specific responsibilities in enforcing the health insurance protections of GINA. The Equal Employment Opportunity Commission (EEOC) is responsible for enforcing the employment protections of GINA.

Remedies for individuals who feel they have been discriminated against in either health insurance or employment include corrective action and monetary penalties. Under Title II of GINA, individuals may also have the right to pursue private litigation.

How does GINA interact with state law?

GINA provides a “floor” or minimum level of protection against genetic discrimination. If a state has a law against discrimination that is stronger than GINA, the state law applies. For example, some states don’t allow health insurers to make decisions about whether or not a person qualifies for health insurance or how much they should pay for health insurance based upon current health status. Check with your state health insurance commissioner to learn about your state’s protections against health insurance discrimination.

GINA requires that state health insurance regulations match GINA’s protections as of May 21, 2009. If states do not offer GINA’s level of protections, the federal government can step in and enforce GINA.

What if I got a genetic test before GINA was signed into law, or before it went into effect? Is that genetic information protected by GINA?

GINA protects you from genetic discrimination in employment and health insurance regardless of when you had a genetic test done, when you received the results, or when you used genetic counseling or other genetic services.

However, GINA is not retroactive. This means that GINA does not apply to acts of discrimination that occurred before GINA went into effect.

Example:

A woman had a genetic test that determined she has a mutation increasing her risk for breast and ovarian cancer. Regardless of when she had the test, if she were discriminated against by her health insurer or employer before GINA went into effect, GINA’s protections would not



apply. However if the discrimination occurred after the law was in effect, the protections would apply.

Who should I contact if I feel I have been discriminated against?

Health insurance discrimination: Start with your state insurance commissioner’s office. GINA requires that state health insurance regulations match GINA’s protections as of May 21, 2009 and that they enforce the law themselves. If states fail to provide GINA-level protections, the federal government will enforce these protections and fine the health insurer.

Employment discrimination: Individuals first must file a claim with the Equal Employment Opportunity Commission (EEOC) in order to later file a claim in state or federal court. The EEOC will assign an investigator to your case, contact your employer, and attempt to resolve the situation through mediation. If the EEOC finds reasonable cause for discrimination, it will attempt to resolve the matter through informal conciliation. If at the end of the process a meritorious claim is found to exist, the EEOC will give you a notice of Right to Sue or may actually file a civil suit on your behalf. Visit eoc.gov for more information.

GINA Terms and Definitions

Family Member

GINA defines family member as a first- (child, sibling, parent), second- (grandchild, uncle or aunt, niece or nephew, grandparent), third- (cousin, great grandparents, great grandchildren), or fourth-degree (second cousin, great-great grandparents, great-great grandchildren) relative.

Genetic Information

GINA defines genetic information as including the following:

- An individual's genetic tests or the genetic tests of the individual's family members, and the manifestation of a disease or disorder in the individual's family members
- Genetic information also includes the request or receipt of genetic services or participation in clinical research that includes genetic services, for both the individual and the individual's family members

Information regarding an individual's sex or age is NOT protected genetic information under GINA

Genetic Services

GINA defines genetic services as receipt of genetic testing, genetic counseling, genetic education, or participation in a research study.

Genetic Test

GINA defines a genetic test as the analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.

Under GINA, a genetic test does not include the analysis of proteins or metabolites directly related to the manifestation of a disease that could reasonably be detected by a healthcare professional with appropriate training and expertise in the field of medicine involved.

Examples of tests covered by GINA:

- Tests for BRCA1/BRCA2 (breast cancer) or HNPCC (colon cancer) mutations; tests for Huntington's disease mutations, carrier screening for conditions such as cystic fibrosis and fragile X syndrome, and classifications of genetic properties of an existing tumor to help determine treatment. Newborn screening tests for genetic conditions are covered by GINA, however the diagnosis of the genetic condition following confirmatory testing is not covered by GINA.

Examples of tests NOT covered by GINA:

- Routine tests such as routine blood counts, cholesterol tests, and liver-function tests

Manifest Disease

In GINA, the term “manifest disease” means that an individual has been or could reasonably be diagnosed with a disease, disorder, or pathological condition by a health care professional not based mainly on genetic information (for example, the results of a diagnostic test). More specifically, a disease is “manifest” when an individual is experiencing signs or symptoms of the condition.

Additional Resources

About GINA

GINA & You Information Sheet developed by Genetic Alliance, National Coalition for Health Professional Education in Genetics, and The Genetics and Public Policy Center at Johns Hopkins University, PDF available on www.GINAHelp.org at bottom of the homepage

A Guide to the Genetic Information Nondiscrimination Act
<http://www.geneticfairness.org/ginaresource.html>

Genetics and Public Policy Center GINA Resources
<http://www.dnapolicy.org/gina/>

Equal Employment Opportunity Commission (EEOC) GINA Fact Sheet
<http://www.eeoc.gov/laws/types/genetic.cfm>

National Human Genome Research Institute (NHGRI) Genetic Discrimination Fact Sheet
<http://www.genome.gov/10002328>

GINA Resources for Healthcare Providers
http://www.nchpeg.org/index.php?option=com_content&view=article&id=97&Itemid=120

State Resources

National Conference of State Legislatures (NCSL)
<http://www.ncsl.org/>

National Association of Insurance Commissioners
http://www.naic.org/state_web_map.htm

The GINA Legislation and Regulations

The Genetic Information Nondiscrimination Act of 2008

<http://www.gpo.gov/fdsys/pkg/PLAW-110publ233/pdf/PLAW-110publ233.pdf>

Title I: Document for Federal Regulations Regarding Insurance

<http://edocket.access.gpo.gov/2009/pdf/E9-22504.pdf>

The Departments of Health and Human Services, Labor, and the Treasury have published in the Federal Register its proposed regulations for Title I of the Genetic Information Non-Discrimination Act (GINA).

Title II: Document for Federal Regulations Regarding Employment

<http://edocket.access.gpo.gov/2009/pdf/E9-4221.pdf>

The Equal Employment Opportunity Commission (EEOC) has published in the Federal Register its proposed regulations for Title II of the Genetic Information Non-Discrimination Act (GINA).

About This Resource

This online resource was created by Genetic Alliance, the Genetics and Public Policy Center at Johns Hopkins University, and the National Coalition for Health Professional Education in Genetics through funding by The Pew Charitable Trusts. May 2010.

Organizational Websites:

Genetic Alliance

<http://www.geneticalliance.org>

Genetics and Public Policy Center

<http://www.dnapolicy.org>

National Coalition for Health Professional Education in Genetics

<http://www.nchpeg.org>

