

Many Americans wonder if participating in genetics research or undergoing genetic testing will lead to being discriminated against based on their genetics. These questions may be the basis for why or why not patients decide to take genetics-based clinical tests or volunteer to participate in the research needed for the development of new tests, therapies, and cures. This page provides an overview of the Genetic Information Nondiscrimination Act (GINA) and describes what protections GINA **does** and **does not** offer.

## Genetic Information Nondiscrimination Act of 2008

The Genetic Information Nondiscrimination Act (GINA) of 2008 protects Americans from discrimination based on their genetic information in both health insurance (Title I) and employment (Title II). Title I amends the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code (IRC), through the Health Insurance Portability and Accountability Act of 1996 (HIPAA), as well as the Social Security Act, to prohibit health insurers from engaging in genetic discrimination. Title II of GINA is implemented by the Equal Employment Opportunity Commission (EEOC) and prevents employers from using genetic information in employment decisions and prevents employers from requesting and requiring genetic information from employees or those applying for jobs.

### Health Insurance (Title I)

GINA prohibits health insurers from discrimination based on the genetic information of enrollees. Specifically, health insurers may not use genetic information to determine if someone is eligible for insurance or to make **coverage, underwriting** or **premium**-setting decisions. Furthermore, health insurers may not request or require individuals or their family members to undergo genetic testing or to provide genetic information. As defined in the law, genetic information includes family medical history, manifest disease in family members, and information regarding individuals' and family members' genetic tests. The **health insurance** protections of GINA extend to private health insurers, Medicare, Medicaid, Federal Employees Health Benefits, and the Veterans Health Administration. For the U.S. Military's TRICARE insurance program, GINA offers more limited protection. TRICARE may not use genetic information for coverage, underwriting, or premium-setting, but eligibility for TRICARE insurance is contingent upon employment by the U.S. Military, and GINA's employment protections do not apply to the U.S. Military. The U.S. military **is** permitted to use genetic and medical information to make employment decisions (see next section on "Employment (Title II)" for more information).

GINA's health insurance protections **do not** cover long-term care insurance, life insurance, or disability insurance, though some states have state laws that offer additional protections

against genetic discrimination in these lines of insurance. Visit the [Genome Statute and Legislation Database](#) to search for relevant state laws.

[The regulations governing the implementation of GINA in health insurance](#) took effect on December 7, 2009 and are implemented by the Internal Revenue Service, Department of Labor, and Department of Health and Human Services (HHS). GINA amends HIPAA to clarify that genetic information is health information and provides a [finalized](#) rule that went into effect March 26, 2013.

## Employment (Title II)

Title II of GINA is implemented by the Equal Employment Opportunity Commission (EEOC) and prevents employers from using genetic information in employment decisions such as hiring, firing, promotions, pay, and job assignments. Furthermore, GINA prohibits employers or other covered entities (employment agencies, labor organizations, joint labor-management training programs, and apprenticeship programs) from requiring or requesting genetic information and/or genetic tests as a condition of employment. The [regulations](#) governing implementation of GINA in employment took effect on January 10, 2011.

An important exception to Title II of GINA involves the U.S. Military. The military **is** permitted to use genetic information to make employment decisions. Note that eligibility for TRICARE insurance is contingent upon employment by the military, and so genetic test results may affect one's ability to access TRICARE insurance.

Also, importantly, GINA does not apply to employers with fewer than 15 employees.

View the full text of [The Genetic Information Nondiscrimination Act of 2008, Public Law 110-223](#).

# Implications of GINA

## GINA and Clinical Research

GINA has implications for individuals participating in research studies. The Office for Human Research Protections (OHRP) within HHS has issued [guidance on integrating GINA into clinical research](#), including information on GINA's research exemption, considerations for Institutional Review Boards, and integrating information on GINA into informed consent forms. To comply with GINA, informed consent forms should include information on any risks associated with participation in the research project and a statement describing how the confidentiality of records will be maintained. NHGRI has developed an [informed consent resource](#) for participants in genomics research.

## Employee Wellness Programs

Some workplaces implement wellness programs aiming to promote good health and disease prevention among employees. In exchange for participating in these wellness programs, employees may receive inducements in the form of discounts on employer-provided health insurance or extra paid leave, for example. An inducement may also be considered a penalty in certain circumstances; if employees participating in a wellness program do not provide certain types of information, they could see the cost of health insurance increase. Typically, wellness programs are run by third-party companies that collect employees' biometric data (e.g. weight, blood pressure, cholesterol levels) and use this information to design workplace interventions to improve health. Wellness programs might provide smokers with smoking cessation resources or recommend diet and exercise plans for individuals seeking to lose weight.

Since wellness programs involve the exchange of health information between employees and their employers, they are relevant to the enforcement of GINA in cases where wellness programs request genetic information from employees. Under GINA it is permissible for employers to request employees' genetic information for the purposes of voluntary wellness programs. However, employers cannot induce employees to provide their genetic information; this means that if an employee chooses to give genetic information to the wellness program, they cannot receive an additional reward for doing so. Conversely, if an employee chooses to withhold genetic information, they cannot be penalized.

Some interpreted GINA to be unclear about whether or not it is permissible to request the genetic information of employees' spouses and if employers may offer inducements in exchange for spouses' genetic information. According to GINA, the definition of "genetic information" includes health information of family members, which includes spouses.

On May 16, 2016, EEOC **amended** GINA regulations to provide clarification on the issue of spouses' genetic information. This amended rule states that it is permissible for wellness programs to offer limited inducements, in the form of a reward or penalty, in exchange for information about the manifestation of disease or disorders in spouses. Some argue that EEOC's ruling conflicts with GINA's definition of "genetic information" and that under GINA, should not be permissible for wellness programs to offer inducements for spouses' health information.

The maximum inducement that wellness programs may offer in exchange for employees' or their spouses' health information is 30 percent the cost of a self-only insurance plan (a plan that covers only one person). If both the employee and the spouse do not volunteer their health information, they could pay a combined 60 percent the cost of a self-only insurance plan on top of their current premium.

While EEOC's ruling amended GINA's treatment of wellness programs, it does not alter GINA's fundamental prohibition of employment discrimination based upon genetic information.

## Other Laws

## **The Health Insurance Portability and Accountability Act**

One part of Title I of GINA required HHS to amend the Health Insurance Portability and Accountability Act (HIPAA), which lays out privacy requirements for health information. The modification to HIPAA, made in 2013, states that genetic information is considered to be health information; therefore, it cannot be used by health insurers to make any decisions about health insurance benefits, eligibility for benefits, or the calculation of premiums under a health plan.

## **The Affordable Care Act**

A major provision of **The Affordable Care Act of 2010 (ACA)** is to establish 'guaranteed issue'; issuers offering insurance in either the group or individual market must provide coverage for all individuals who request it. The law therefore prohibits issuers of health insurance from discriminating against patients with genetic diseases by refusing coverage because of 'pre-existing conditions'. ACA further provides additional protections for patients with genetic diseases by establishing that certain health insurers may only vary premiums based on a few specified factors such as age or geographic area, thereby prohibiting the adjustment of premiums because of medical conditions.

## **The Americans with Disabilities Act**

**The Americans with Disabilities Act (ADA)** prohibits discrimination in employment, public services, accommodations, and communications based on a disability. In 1995, EEOC issued an interpretation that discrimination based on genetic information relating to illness, disease, or other disorders is prohibited by the ADA. In a subsequent Senate hearing in 2000, EEOC Commissioner Paul Miller further affirmed that the ADA "can be interpreted to prohibit employment discrimination based on genetic information." However, these EEOC opinions are not legally binding, and whether the ADA protects against genetic discrimination in the workplace has never been tested in court.

On May 17, 2016, in conjunction with releasing amended regulations on GINA and wellness programs (see "**Employee Wellness Programs**"), EEOC amended ADA regulations to permit employers to offer inducements to employees who volunteer disability-related health information for the purposes of wellness programs. The amended ADA regulations also say that wellness programs may request medical examinations of participating employees. EEOC further stated that collecting disability-related information and requesting medical examinations for wellness programs would only be permissible provided that employers comply with existing nondiscrimination and nondisclosure protections dictated by ERISA and HIPAA. The permissibility of offering inducements in exchange for employees' health information is contingent upon the voluntary nature of wellness programs.

The ADA has been used to challenge genetic testing practices by an employer. In 2001, EEOC filed a suit against the Burlington Northern Santa Fe (BNSF) Railroad for secretly testing its

employees for a rare genetic condition (hereditary neuropathy with liability to pressure palsies - HNPP) that causes carpal tunnel syndrome as one of its many symptoms. BNSF claimed that the testing was a way of determining whether the high incidence of repetitive-stress injuries among its employees was work-related. Besides testing for HNPP, company-paid doctors also were instructed to screen for several other medical conditions such as diabetes and alcoholism. EEOC and BNSF **announced a mediated settlement** in 2002.

## State Laws

A patchwork of state laws exists to protect Americans from genetic discrimination, although these laws vary widely in the scope, applicability, and amount of protection provided. GINA sets a floor of minimum protection against genetic discrimination and does not preempt state laws with stricter protections.

The earliest state laws focused on particular genetic conditions. For example, North Carolina was the first state to prohibit discrimination based on the presence of the sickle cell trait. In 1991, Wisconsin was the first state to prevent whole-sale discrimination based on genetic tests.

Some states have passed laws that go beyond the scope of GINA to prohibit genetic discrimination for "other insurances", including life insurance, disability insurance, and long-term care insurance. In 2011, California passed the "California Genetic Information Nondiscrimination Act" (CalGINA), which extended protections even further to prohibit genetic discrimination in emergency medical services, housing, mortgage lending, education, and other state-funded programs. You may visit the **Genome Statute and Legislation Database** to search for relevant state laws.