

## **GINA (Genetic Information Nondiscrimination Act)**

<http://www.geneticalliance.org/advocacy/policyissues/geneticdiscrimination>

The benefits of integrating genetic information into health management are tremendous and include enabling an individual to make proactive and informed decisions. Knowledge about one's genes can be invaluable to healthcare delivery. However, that knowledge is also susceptible to misuse. Because no one is exempt from this harm—each of us carries a number of mutated genes—genetic discrimination and its related privacy concerns should be profoundly important to us all. The landmark bill, the Genetic Information Nondiscrimination Act (GINA), was passed in 2008, and revolutionized the way genetic information can be used. Genetic Alliance led the [Coalition for Genetic Fairness](#) which worked relentlessly for 12.5 years to pass the bill. Congresswoman Louise Slaughter (D-NY) was the staunchest champion of the Bill. Other champions included Senator Ted Kennedy (D-MA) and Judy Biggert (R-IL).

### **What is GINA?**

The Genetic Information Nondiscrimination Act (GINA) of 2008 was signed into law by President George W. Bush on May 21, 2008. GINA prohibits discrimination on the basis of genetic information with respect to health insurance and employment. It was passed to establish basic legal protections that will enable and encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies that will result from scientific advances in the field of genetics.

It also prevents health insurance companies from denying coverage or adjusting premiums based on an individual's predisposition to a genetic condition and prohibits employers from discriminating on the basis of predictive genetic information.

### **What does genetic discrimination look like?**

The following examples are not comprehensive but have been adapted from real examples of genetic discrimination from the Coalition for Genetic Fairness resource, in partnership with the National Partnership for Women & Families, entitled "Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People."

#### **Discrimination by Health Insurers:**

- Jacob, a boy who carries a gene for a disorder called Long QT Syndrome (LQTS), was denied coverage under his father's health insurance policy because of his pre-existing condition. LQTS is a rare and little-known genetic disorder that sometimes triggers sudden cardiac death. Those who carry the gene may be healthy until they suffer an attack without warning, but carriers can control their risk of cardiac arrest with preventive beta-blocker therapy. Jacob's father wanted Jacob to be insured, but even after their state enacted a law prohibiting genetic discrimination, Jacob's insurance company still refused to cover him.
- Last year, Jonathon's mother April was diagnosed with colon cancer. Because April's aunt died of colon cancer, and her sister was undergoing chemotherapy for the cancer, April decided to undergo genetic testing to determine if the cancer could be hereditary. She tested positive for a mutation in one of four genes regulating the replication of DNA in her cells, also known as Lynch syndrome. Last month, Jonathon's health insurance costs increased dramatically in response to the genetic test results of his mother.

## **Discrimination by Employers:**

- Kim was a social worker with a human services agency until she was fired because of her employer's fears about her family history of Huntington's disease. During a staff workshop on caring for people with chronic illnesses, Kim mentioned that she had been the primary caretaker for her mother, who died of Huntington's disease. Because of her family history, Kim had a 50 percent chance of developing the disease herself. One week later, despite outstanding performance reviews, Kim was fired from her job.
- Gary was diagnosed with Carpal Tunnel Syndrome (CTS) in 2000 and took leave from work to have surgery and recover. When he returned to work, Gary was told that he would have to undergo a mandatory medical examination. Gary was told that if he refused to submit to the examination he would be fired. He later learned that his employer was administering genetic tests to workers without their consent to identify a possible genetic predisposition to CTS as a defense to workers' compensation claims. Gary refused to take the exam, and soon after his employer began disciplinary proceedings to fire him.

## **When did GINA's provisions go into effect?**

As the first civil rights bill of the new century, GINA provides individuals with federal protections against genetic discrimination in health insurance and employment. The health insurance provisions of the bill, Title I, took effect on May 21, 2009. The protections in employment, Title II, took effect on November 21, 2009. All individuals residing within all 50 states and US territories benefit from these years of dedication and perseverance from the entire genetics community, led by the Coalition for Genetic Fairness, and more than 500 Congressional offices on Capitol Hill.

GINA is now in full effect, so every American is now protected against genetic discrimination in both health insurance and employment.

## **What does GINA *not* do?**

GINA does *not* cover an individual's manifested disease or condition—a condition from which an individual is experiencing, is being treated for, or that has been diagnosed.

## **Additionally GINA does not protect against the following:**

- The protections of GINA do not include protections from genetic discrimination in life, disability, or long-term care insurance.
- The health insurance provisions of GINA do not apply to members of the U.S. military, veterans obtaining healthcare through the Veteran's Administration, or the Indian Health Service. Furthermore, GINA does not apply to federal employees obtaining healthcare through the Federal Employees Health Benefits Plans.
- The employment provisions of GINA apply to those employers covered under the Americans with Disabilities Act (ADA) and Title VII of the Civil Rights Act of 1964; therefore, it does not cover employers with fewer than 15 employees. Furthermore, GINA does not apply to members of the U.S. military.
- The employment provisions of GINA do not cover an individual's manifested disease or condition—a condition from which an individual is experiencing symptoms, is being treated for, or that has been diagnosed. However, GINA does protect information about manifested disease in an individual's family members (for example, their family history of disease).

- The employment provisions of GINA do not interfere with an employee's ability to qualify for family or medical leave under state or federal Family and Medical Leave laws, nor to participate in an employer-sponsored wellness program or other genetic services offered by an employer. Furthermore, GINA does not interfere with an employer's ability to offer a safe and healthy work environment through federal or state required genetic monitoring of the biological effects on employees of toxic substances in the workplace.
- GINA does not restrict genetic services, the practice of medicine, or the authority of healthcare professionals, whether or not they are affiliated with a health plan or issuer or an employer. Clinicians and healthcare providers can recommend that an individual or an individual's family member undergo a genetic test for the purposes of that individual's medical benefit.
- GINA provides a baseline for protection against genetic discrimination for all Americans. GINA does not preempt state law; therefore, if a state's genetic discrimination law provides more extensive protections than GINA, GINA does not change it. However, no provision within GINA defines the strength of a law as based on the scope of the law or the penalties associated with the law. The regulations for enforcing GINA are currently being drafted, which will clarify this definition.