

GeneScene

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The official newsletter of The Genomedical Connection

GINA takes away most concerns for Genetic Discrimination

Did you know...

- A recent survey found that 17% of Americans are afraid of unfair treatment as a result of getting a genetic test.
- Employees of the Burlington - Northern Railroad successfully sued the company for performing genetic testing without their knowledge when they applied for disability.
- 5% of the funding for the Human Genome Project went toward researching ethical, legal and social issues (ELSI).



The Genetic Information Non-discrimination Act, or GINA, was signed into law on May 21, 2008. This law protects Americans from

the unfair use of their genetic information by health insurers and employers. Genetic information includes genetic test results and family history.

When GINA goes into effect, it will **prevent Health Insurers** from:

- Using genetic information to decide who can get insurance,
- Using genetic information to charge more for group or private health insurance, and
- Making someone take a genetic test before insuring them.

It will also **prevent Employers** from:

- Using genetic information to make decisions about hiring, firing, and promotions, and
- Buying, asking, or making someone give them genetic information about themselves or a family member.

Americans can now feel at ease about:

- Sharing details about diseases that run in their families with a doctor,
- Taking part in research studies on diseases that run in their families,
- Talking with a genetic counselor about their risk for disease, and
- Taking a genetic test for a disease that runs in their family.

GINA was passed by Congress on May 1, 2008, and signed into law on May 21, 2008.

In the past, people were concerned that they could be treated unfairly as a result of taking a test for a disease they were more likely to get. This fear came at a cost. Patients often did not tell their doctor about diseases that ran in their families. Some patients paid out of pocket for a test to avoid having their health insurer find out their test results. Other patients chose not to have a test that would find a disease early since this information would be put into their medical record. GINA allows patients to share their family's health history with their doctor without these worries.

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GINA takes away most concerns for Genetic Discrimination (continued)

What GINA Doesn't Do

While GINA helps prevent unfair treatment by health insurers, it does not apply to life, disability or long-term care insurance. These types of policies can use genetic information to decide who to cover and what to charge.

GINA does not cover members of the military.

Other things that GINA does **not** do are:

- Ban health insurers from using a patient's current health status to set insurance costs,
- Make health insurers pay for tests or treatments that are not covered by a patient's insurance policy,
- Stop doctors from recommending that a patient think about having a genetic test, or
- Stop employers from collecting genetic information for special projects, such as wellness programs. However, employers cannot use this information or give it to others.

Health insurers have one year to change their policies. Employers have 18 months until this law will go into effect. This means that GINA will be fully in place by the end of 2009.

Until then, the current state and federal laws provide protection. Some of the federal laws that protect you from unfair treatment are:



- The **Americans with Disabilities Act (ADA)** protects people who are diagnosed with a disability from unfair treatment in the workplace,
- The **Health Insurance Portability and Accountability Act (HIPAA)** stops group health plans from deciding who can get health insurance. It also stops insurers from making people take genetic tests or increasing the cost of insurance if someone is more likely to get a disease,
- The **Executive order of 2000** protects against unfair treatment in the federal workplace.

The laws in each state are different. Some states are stricter than others. For information about the laws in your state that protect you from unfair treatment go to www.genomedical.com and click on Ethics and Law at the bottom of the page.



On the Web...

The Genomedical Connection

www.genomedical.com

The Genetic Information Non-Discrimination Act

www.Thomas.gov

The DNA Public Policy Center

www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf