

Understanding GINA:

How the Genetic Information Nondiscrimination Act Protects Our Community



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Consider the Following...

A woman has a family history of a genetic condition and is interested in genetic testing. She asks her healthcare provider whether a positive test result could be used to deny her health insurance or employment.

These practices are examples of genetic discrimination, the misuse of genetic information

What is GINA?

The Genetic Information Nondiscrimination Act of 2008 is a federal law that protects individuals from genetic discrimination in health insurance & employment.

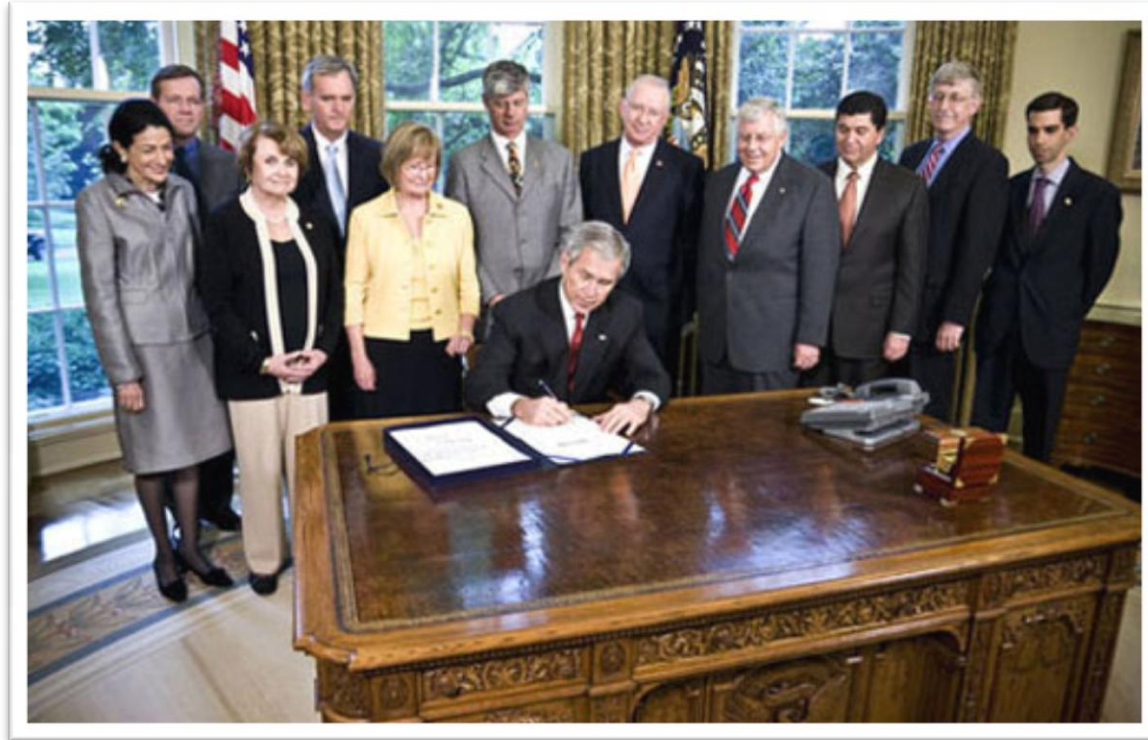
This presentation includes:

- Basic information about GINA
- Examples to demonstrate how the law applies
- Resources for more information

Why GINA?

- Genetics continues to transform how we understand health and disease
- Integrating genetic information into healthcare enables proactive and informed decision-making
- Fear of genetic discrimination has been a barrier to utilization of genetic services and participation in research

President Bush signed GINA into law May 21, 2008
Law in effect since November 21, 2009



GINA represents the culmination of thirteen years of perseverance from the entire genetics community and more than 500 Congressional offices on Capitol Hill

What does GINA do?

- Protects individuals from genetic discrimination in health insurance and employment
- Illegal for a health insurer to use family health history and genetic test results as a reason to deny health insurance or determine cost of coverage
- Illegal for an employer to use family health history and genetic test results in making decisions related to employment

Genetic Tests Covered by GINA

Examples of tests covered by GINA:

- BRCA1/BRCA2 or HNPCC mutations for hereditary cancers
- Carrier screening for disorders such as cystic fibrosis and fragile X syndrome
- Newborn screening for genetic conditions
- Classifications of genetic properties of tumors to help determine therapy

Examples of tests NOT covered by GINA: routine tests such as blood counts, cholesterol tests, liver-function tests

What does GINA not do?

- Diagnosed conditions
- Life, disability, or long-term-care insurance
- Employers with fewer than 15 employees
- Certain groups:
 - Members of the US Military
 - Veterans receiving care through the VA
 - Federal employees enrolled in the FEHB
 - Individuals using the Indian Health Service

The following case examples will help you understand more about GINA and how it applies...

Example 1: GINA, existing conditions & risk for new conditions



A 39-year-old woman finds a lump in her right breast and a biopsy indicates she has breast cancer. Because of her young age, she is referred for genetic counseling and testing, and learns that she has a BRCA1 mutation that shows high risk for breast and ovarian cancer. She reviews her treatment options and risks for other cancers, and chooses to have bilateral mastectomy.

Questions:

1. Is the breast cancer diagnosis protected under GINA?
2. Is the BRCA1 test result protected under GINA?
3. Is her risk for ovarian cancer protected under GINA?
4. Does GINA require the health insurer to cover costs for ovarian cancer screening?

Example 1 continued: the woman's sister



The woman decides to tell her 32-year old sister that she may be at risk to carry a BRCA1 mutation and develop breast and ovarian cancer at an early age. The sister now wants a genetic test.

Questions:

1. If this sister shares this information with her doctor, can her insurance company use that information against her?
2. If this sister has genetic testing and is found to have a BRCA1 mutation, can her insurance company deny her treatment if she develops breast or ovarian cancer because she had an increased risk?

Example 1: Key Points

- The woman with breast cancer:
 - GINA does not prevent a health insurer from using information about an existing condition, even if that condition has a genetic basis (breast cancer diagnosis)
 - The increased risk of other cancers based on the BRCA1 mutation (ovarian cancer) is protected
- The sister:
 - GINA protects against misuse of information about a family history of hereditary breast cancer
 - Her insurer may need family history to approve BRCA testing, but the information cannot be used against her once the insurer has it

Example 2: GINA & Work Setting



A woman is on her break at work and is talking with her co-worker about her mother's battle with Huntington's disease, a genetic condition that she is at risk for as well. Her supervisor overhears the conversation, and the woman becomes concerned that she will be fired due to her risk for developing the condition.

Questions:

1. Can the woman be fired or denied a promotion due to her risk?
2. If she needs to take leave from work under the Family and Medical Leave Act (FMLA) to care for her mother, can her employer use the information on the forms to discriminate against her?

Example 2: GINA & Work Place

Key Points

- GINA indicates when an employer can legally have genetic information about an employee, two examples:
 - An employer accidentally becomes aware (overhearing a conversation)
 - When an employee provides information for family and medical leave
- When an employer has genetic information
 - They cannot use it to discriminate against an employee
 - The information must be kept in a separate and confidential file

GINA's Protections: Summary

- GINA protects individuals from genetic discrimination in health insurance and employment
- It is illegal for a health insurer to use genetic information as a reason to deny health insurance or determine the cost of insurance
- It is illegal for an employer to use genetic information in making decisions related to employment

With GINA's protections individuals can feel comfortable talking about family health history with their family and doctor, and using genetic testing and other services to learn about health risks without fears of genetic discrimination

GINA Resources



GINA Materials for the Public & Healthcare Providers

<http://www.GINAhelp.org>

Guide to the Genetic Information Nondiscrimination Act

<http://www.geneticfairness.org/ginaresource.html>

Frequently Asked Questions from Genetics and Public Policy Center

<http://www.dnapolicy.org/gina/>

Human Genome Research Institute & Genetic Discrimination Fact Sheet

<http://www.genome.gov/10002328>

Organizations Involved With Development of This Resource

www.geneticalliance.org / www.dnapolicy.org / www.nchpeg.org