

Overview of GINA (Genetic Information Nondiscrimination Act)

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GINA, the Genetic Information Nondiscrimination Act, was signed into law May, 2008 and took effect November, 2009. The promise of the legislation was to make genetic discrimination regarding employment or health insurance illegal in the United States. One of the intents of the legislation was to remove barriers, perceived by patients themselves, to getting needed genetic testing. Here is an overview of what GINA was intended to accomplish and some already identified limitations:

The law prohibits insurance companies from:

1. Establishing rules for eligibility of adjustment of premiums based on genetic information.
2. Requesting or requiring a genetic test from an individual or family member, although an exception exists for making a written request for a genetic test if an individual is voluntarily participating in federally approved research.
3. Requesting, requiring or purchasing genetic information before or after enrollment in a health insurance plan.
4. Exercising any pre-existing condition clause unless and until the disease has manifested clinically.
5. Determining the rules for the creation, renewal or replacement of a health insurance contract.

The law allows:

1. Receiving genetic test results for documentation that a test has been performed for insurance payment purposes; only the minimum necessary information can be requested.

The law prohibits employers from:

1. Failing or refusing to hire, discharging or otherwise discriminating against an employee based on their genetic information.
2. Segregating or classifying employees or in any way depriving them of employment opportunities based on their genetic information; this includes employment in apprenticeship, training and re-training programs.
3. Requesting, requiring or purchasing genetic information on any employee or employee family member.

The law allows:

1. An employer to possess genetic information if the employee volunteers the information. At this point, the information must be held as any other confidential medical record subject to HIPPA guidelines.
2. an employer to conduct genetic monitoring of individuals to determine the effect of workplace conditions on employees, which may include monitoring for acquired modifications to their genetic material (environmental DNA mutations).

Some of the weaknesses of the law, after legal review, include the following:

1. The fact that it does not extend to life, disability and long-term care insurances.
2. The law does not mandate coverage for any particular tests or treatments.
3. The protections the law offers for health insurance do not extend to other medical conditions or manifest conditions of genetic origin.
4. The limit set on monetary sanctions may result in it being more cost effective for the insurer to violate the law and pay the statutory fine than to comply.
5. The law does allow a number of legal ways for employers to obtain employee genetic information; this includes enrollment in employee wellness programs or family medical leave.
6. The law doesn't address the provision of pre-employment medical records, which may include genetic information, to prospective employers.
7. Enforcement of damages is the same as those associated with Title VII of the Civil Rights Act of 1964 (prohibiting race and gender discrimination); filing a lawsuit has proven arduous and expensive to the plaintiffs.