



## **Federal Legislative Alert!**

On Wednesday, May 21, 2008, President Bush signed into law the Genetic Information Nondiscrimination Act (GINA). The new law, which has been called “*the first civil rights law of the 21<sup>st</sup> Century*,” would prohibit discrimination against individuals on the basis of their genetic information in both employment and health care.

The employment provisions of GINA become effective in November 2009, or 18 months after the President signed the bill, and the provisions pertaining to group health plans become effective in May 2009, or one year after the date of enactment.

To watch the signing ceremony in the Oval Office, click [here](#):

Relevant to HR professionals, the legislation contains the following provisions:

**State Genetic law Preemption** – GINA will allow state laws that are more stringent in the requirements, standards, or implementations than those contained in GINA to supersede the new federal law.

**Nondiscrimination in Employment** – GINA will prohibit an employer from discriminating against an individual in the hiring, firing, compensation, terms, or privileges of employment on the basis of genetic information of the individual or family member of the individual.

**Definition of Family Member** – GINA defines a family member as the:

- (1) spouse of the individual;
- (2) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; or
- (3) parent, grandparent, or great-grandparent.

**Restrictions on Collecting Genetic Information** – GINA forbids an employer from requesting, requiring, or purchasing genetic information of the individual or family member except (1) where the employer inadvertently requests or requires

the information, (2) for genetic services offered by the employer (including wellness programs), (3) for purposes of complying with the Family and Medical Leave Act, and (4) where the employer purchases documents that are commercially available.

**Genetic Monitoring in the Workplace Exception** – GINA does allow for genetic monitoring of biological effects of toxic substances in the workplace, but only if (1) the employer provides written notice of the monitoring to the employee; (2) the employee agrees to the monitoring in writing or the monitoring is required by federal, state, or local law; (3) the employee is informed of the results of the test; (4) the monitoring conforms to any federal or state law, including rules promulgated by OSHA; and (5) the employer receives the results of the tests in aggregate terms.

**Health Care Coverage Protections** – GINA will prohibit an insured or self-insured health care plan, from denying eligibility to enroll for health care coverage or from adjusting premium or contribution rates under a plan based on an individual or family member's genetic information. Health care plans would also be prevented from requiring a plan participant to undergo a genetic test to be eligible for coverage under a health care plan.

**Exceptions for Genetic Testing for Health Care Treatment** – GINA will allow a health care professional to request that a patient undergo a genetic test or advise a patient on the provision of genetic test or services through a wellness program.

**Remedies for Violations of the Health Care Coverage Provisions** – GINA will allow plan participants to receive injunctive relief under the Employee Retirement Income Security Act (ERISA) and have health care coverage reinstated back to the date of loss of coverage. Plan administrators could be personally liable for discriminating in coverage decisions and be assessed a penalty of \$100 per day for the period of noncompliance. Plans could be fined a minimum penalty of \$2,500 to \$15,000 for more than de minimis violations up to a total of \$500,000 for multiple violations.

**Confidentiality of Genetic Health Care Information** – GINA requires that the disclosure of protected genetic health care information would be governed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The law would also provide participants with injunctive and equitable relief for violations of the confidentiality provisions of GINA. For violations of the privacy provisions of the law, civil monetary penalties of \$100 per day up to \$250,000 and 10 years in provision for egregious violations.

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*A personal message from*



Andrea Levario, Executive Director  
American Celiac Disease Alliance

This landmark law, which I personally worked on when it was first introduced in 1995, BARS insurance companies from requiring individuals to undergo genetic testing and BARS insurance companies from using an individual's genetic information in setting insurance premiums for a group plan or an individual health insurance plan.

It is very important to note that the new law does not prevent insurers from declining to offer coverage, based on an individual's current health status. Meaning, if you currently know you have celiac disease, even though this is a genetic condition, an insurance company can refuse to offer you insurance. It also does not require an insurance plan to pay for genetic tests.

A chart detailing what the new law does and does not do, has been prepared by the Genetics & Public Policy Center at Johns Hopkins University

<http://www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf>

The American Celiac Disease Alliance (and its predecessor the American Celiac Task Force) has been a supporter of this legislation since 2003.

Additional information about the new law and a Q & A with medical experts will be posted to our website in the next few days at [www.americanceliac.org](http://www.americanceliac.org)