

PRESS RELEASE

THE GENETIC INFORMATION NONDISCRIMINATION ACT: THE DISABILITY COMMUNITY AND BUSINESSES

*(Summary briefing memo on the Genetic Information Nondiscrimination Act (GINA) prepared by **John D. Kemp**, Executive Director & General Counsel for the US Business Leadership Network (USBLN).*

After a decade of work by Congress and an EEOC lawsuit ending genetic testing by a major employer, the Genetic Information Nondiscrimination Act of 2008 ("GINA") was signed into law by President George W. Bush on May 21, 2008. GINA protects individuals from genetic discrimination by health insurers or employers. With the GINA signed into law, various questions and concerns on how this new law affects a range of people and business entities have surfaced.

WHY IS GINA NECESSARY?

Each of us carries a handful of genetic anomalies. Some of those might cause us to be affected by genetic conditions. Some of those will not affect our health, but may affect the health of our children.

- Genetic information is invaluable. It provides a key to our makeup that we can use to proactively manage our health. However, this same information may also be misused and put us at risk for genetic discrimination.
- Fear of misuse of genetic information prevents people from getting genetic tests done. Individuals' lack of testing denies them important medical information that they could otherwise use to proactively manage their health. The information garnered by genetic tests also helps doctors to prescribe treatments and lifestyle changes with increased success. The same information can be used by researchers to effectively create targeted drugs and develop treatments. In addition, companies developing these important tests cannot recoup research costs, and therefore, are unable to invest in further development.
- Fear of discrimination has caused a large number of people to opt out of clinical trials. Fewer participants in clinical trials leads to slower development of treatments and beneficial drugs.

WHAT IS GINA?

- Prohibits group health insurance plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of an individual's genetic information. Insurance companies cannot request, require or purchase the results of genetic tests, and they are prohibited from disclosing personal genetic information.

- Prohibits issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. Issuers cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibits employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and they are also prohibited from disclosing personal genetic information. Similar provisions apply to employment agencies and labor organizations.

GINA AND THE DISABILITY COMMUNITY

The U.S. disability community has been deeply concerned about employers' use of genetic information for more than ten years. In late 2001, the Equal Employment Opportunity Commission (EEOC) settled its first court action challenging the use of workplace genetic testing under the Americans with Disabilities Act of 1990 (ADA). The EEOC was suing Burlington Northern Santa Fe Railway (BNSF) to end genetic testing of employees who filed claims for work-related injuries based on carpal tunnel syndrome.

"EEOC sought the preliminary injunction to prevent irreparable harm to employees who faced the impossible choice of potentially losing their jobs or revealing their genetic makeup," said Ida Castro, then EEOC chairwoman, "Our swift action in this case allows BNSF employees subjected to genetic testing to continue work free of retaliation and future invasions of privacy in violation of the ADA."

According to the lawsuit, BNSF's genetic testing program was carried out without the knowledge or consent of its employees, and at least one worker was threatened with termination for failing to submit a blood sample for a genetic test. Under the terms of the settlement, BNSF admits it tested certain employees for a genetic marker, and the company "agrees it will not request employees to undergo genetic test, will not discipline any employees for refusal to submit to genetic test and will preserve all records in its control."

A survey of 2,133 employers last year by the American Management Association found that seven use genetic testing for either job applicants or employees.

GINA is a direct outcome of the EEOC's findings of ADA violations in this area of genetic information discrimination but also its and Congress's determination that further legislative remedies were needed to assure prospective and current workers that their genetic information would not be used inappropriately and without their knowledge and consent.

GINA AND THE BUSINESS COMMUNITY

While GINA does not go into effect for employers until 18 months from May 21, 2008, this time prior to the effective date can enable employers to ensure they are GINA-compliant.

- Like Title VII, GINA requires people to file with the Equal Employment Opportunity Commission (EEOC) and uses the same language to detail what qualifies as a prohibited employee practice.
- Employers should review employee family history, background and health forms to ensure they are not inadvertently acquiring information protected under GINA.
- This is an opportunity for employers and their respective health insurance providers to review their processes and documentation.
- Should an employer be found to be noncompliant with GINA, penalties can carry punitive damages and a jury trial.

Sources: Coalition for Genetic Fairness Retrieved July 25, 2008 from www.geneticfairness.org/index.html. Diversity Executive. Retrieved July 25, 2008 from http://diversity-executive.com/article/Employers_on_a_Clock_to_Comply_With_Genetics_Legislation.php.

For further information contact:
US Business Leadership Network
Phone: 866-624-3502
Email: bln@suntrust.com
Web: <http://www.usbln.org>