



legislative update

The Genetic Information Nondiscrimination Act of 2008

October, 2009

On May 21, 2008, President Bush signed into law the Genetic Information Nondiscrimination Act of 2008 (“GINA”). GINA provides broad protections in employment and health benefits against the improper collection, use or disclosure of employees’ genetic information, in part by amending a number of major laws such as ERISA, HIPAA and the IRC. The employment provisions of GINA become effective 18 months after the date of enactment (i.e., November 21, 2009), while the provisions targeted at insurers go into effect for plan years beginning one year after the date of enactment (i.e., May 21, 2009, but the effective date for calendar year plans is January 1, 2010). The EEOC and other applicable federal agencies must issue final clarifying regulations. The EEOC issued proposed regulations regarding the employment provisions of GINA on March 2, 2009. This Legislative Update provides a brief overview of GINA.

What is Genetic Information?

GINA defines “genetic information” to mean information about:

- an individual’s genetic tests,
- the genetic tests of family members of the individual, and
- the manifestation of a disease or disorder in family members of the individual.

Genetic information also includes any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by the individual or any family member of the individual. The genetic information of any fetus carried by a pregnant woman and the genetic information of any embryo legally held by an individual or family member using assisted reproductive technology are also considered genetic information protected by GINA. The term does not include information about the sex or age of any individual.

Impact on Health Plans (Title I of GINA)

Title I of GINA deals with genetic nondiscrimination in health insurance. Title I regulates group health plans, including small group health

plans, health insurance issuers offering health insurance coverage in the individual market, non-federal governmental plans and issuers of Medicare supplemental policies. Generally, Title I amends a number of major laws to prohibit a group health plan from adjusting premium or contribution amounts for a group on the basis of genetic information. A group health plan is also prohibited from requesting or requiring individuals (or their family members) to undergo a genetic test. Further, GINA makes changes to the HIPAA portability rules in ERISA, the PHSA and the IRC, adding new provisions regarding genetic information, as well as provisions for insurance issuers in the individual market. Health insurance issuers in the individual market, as well as issuers of Medicare supplemental policies, are prohibited from establishing eligibility rules based on genetic information, and from imposing a pre-existing condition exclusion on the basis of genetic information. A group health plan is also prohibited from requesting or requiring

individuals (or their family members) to undergo a genetic test. Further, GINA makes changes to the HIPAA portability rules in ERISA, the PHSA and the IRC, adding new provisions regarding genetic information, as well as provisions for insurance issuers in the individual market. Health insurance issuers in the individual market, as well as issuers of Medicare supplemental policies, are prohibited from establishing eligibility rules based on genetic information, and from imposing a pre-existing condition exclusion on the basis of genetic information. GINA requires amendments to the HIPAA privacy regulations by prohibiting the use or disclosure by a group health plan, health insurance issuer or issuer of a Medicare supplemental policy of genetic information about an individual for underwriting purposes. For purposes of HIPAA, genetic information must be treated as health information.

Impact on Employers (Title II of GINA)

Title II of GINA outlines the prohibition of employment discrimination on the basis of genetic information. Employers, employment agencies, labor organizations and joint labor-management committees are prohibited from discriminating against an employee, individual or member based on genetic information. Employers may not fail or refuse to hire, or discharge, any employee, or otherwise discriminate against any employee with respect to the compensation, terms, conditions or privileges of employment because of genetic information. Employment agencies may not fail or refuse

to refer for employment, or otherwise discriminate against any individual because of genetic information. A labor organization may not exclude or expel from membership, or otherwise discriminate against, any member because of genetic information. Individuals also may not be discriminated against because of genetic information with respect to admission or employment in any program established to provide training or apprenticeship.

Employers, employment agencies, labor organizations and joint labor-management committees are also prohibited from requesting, requiring or purchasing genetic information about an individual or family member except where the entity:

- inadvertently requests or requires family medical history of the individual or family member,
- offers health or genetic services, the individual provides specific authorization and individual information is not released to others,
- requests or requires family medical history to comply with the federal FMLA or state family and medical leave laws,
- purchases documents that are commercially and publicly available that include family medical history,
- uses the information for genetic monitoring of the biological effects of toxic substances in the workplace if certain detailed conditions are met, or
- conducts DNA analysis for law enforcement purposes as a fo-

rensic laboratory and requires such analysis for quality control.

Finally, genetic information about an individual must be maintained separately and treated as a confidential medical record. Genetic information about an individual may be disclosed to the individual, an occupational or other health researcher, in response to a court order, to government officials investigating compliance, for FMLA leave purposes, or to a public health agency regarding a contagious disease presenting an imminent hazard only when certain specifically outlined conditions are met.

Actions to Take Now

Entities subject to GINA should become familiar with the law, the proposed EEOC regulations, and any specific requirements. They should also evaluate how related state laws may interact with GINA, review applicable employment policies, practices and paperwork to be sure the genetic information issue is properly addressed, review any health plan to be sure it is not inappropriately requesting or receiving genetic information, and evaluate whether any changes are necessary regarding the administration of benefits. Entities subject to GINA should also take steps to ensure that any genetic information is treated with strict confidentiality, as under HIPAA. Further, they should train managers and supervisors so that they do not unwittingly violate GINA by, for example, using genetic information in employment-related decisions. Finally, entities subject to GINA should watch for the issuance of upcoming final regulations.

For a copy of GINA, see: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:h493enr.txt.pdf. If you have questions regarding this important and emerging area, please contact your EPIC Employee Benefits representative. This EPIC Legislative Update is not intended to be exhaustive nor should any discussion or opinions be construed as legal advice. Readers should contact legal counsel for legal advice.