

The New Genetic Information Non-Discrimination Act: Is Your Workplace Ready?

By Daniel Klein, Esq.

INTRODUCTION

In this age of medical advancement, it is becoming more and more common for individuals and their doctors to be able to predict and detect serious illnesses even before symptoms begin. The availability of genetic testing can allow individuals to take steps (e.g. preventative surgery, a course of drug therapy, etc.) to reduce the likelihood that they will contact a particular disorder.

But until recently, an employee's ability to discover his or her genetic propensity for illness also carried a risk. With the cost of health insurance rising to astronomical levels, what was to stop an employer from hiring or retaining only those employees with a positive health outlook? Could an employer fire or not hire an individual because the individual might potentially expose the company to high health insurance coverage costs down the road?

The concern that individuals might avoid undergoing beneficial health and genetic tests because they feared employer retribution led to the passage of the Genetic Information Non-Discrimination Act, or GINA. After languishing in Congress for more than 10 years, Congress passed GINA with overwhelming support from both parties, and President George W. Bush signed it into law on May 21. GINA, which amends the Health Insurance Portability and Accountability Act (HIPAA), the Employee Retirement Income Security Act (ERISA) and the Internal Revenue Code, is the first and only federal legislation that will provide protections against discrimination based on an individual's genetic information in employment and health insurance coverage.

GINA creates new prohibitions on employers regarding their use or consideration of employees' genetic information. GINA also prohibits group health insurance plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions based on an individual's genetic information, among other restrictions on health insurers. This article will discuss GINA's requirements directed at employers.

WHAT IS "GENETIC INFORMATION"?

Genetic information is information about:

- an individual's genetic tests;
- the genetic tests of family members of such individual; and
- the manifestation of a disease or disorder in family members of such individual.

The term "family member" includes dependents, and any other individual who is a first-, second-, third- or fourth-degree relative of the individual.

GINA requires that genetic information, as defined above, be treated as "protected health information" under HIPAA.

GINA'S NON-DISCRIMINATION REQUIREMENTS

Effective Nov. 21, 2009, employers, employment agencies and unions will be prohibited from:

- failing to hire an applicant or discharging any employee, or otherwise discriminating against any employee with respect to the compensation, terms, conditions or privileges of employment of the employee because of the genetic information of an appli-

cant or employee, or their family members; or

- limiting, segregating or classifying employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employment status of the employee because of the genetic information of the employee or his or her family members.

While GINA does not amend either Title VII of the Civil Rights Act of 1964 or the Americans with Disabilities Act (ADA), it could impact the way employers think about those laws in the workplace. For example, although the ADA does not necessarily prohibit discrimination on the basis of an employee's asymptomatic medical condition, GINA will bar an employer from discriminating against an employee based on genetic information revealing an asymptomatic medical condition or the potential for such condition in the future. Similarly, while Title VII does not prohibit discrimination on account of an employee's genetic information, an employee could contend that discrimination based on genetic characteristics linked to sex, such as one's susceptibility to ovarian or prostate cancer, violates Title VII in addition to GINA.

RESTRICTIONS ON EMPLOYERS' COLLECTION, POSSESSION AND DISCLOSURE OF GENETIC INFORMATION

GINA also places limitations on employers' collection, possession and disclosure of genetic information. These limitations are particularly important when considering issues such as requests for medical leave under the Family and Medical Leave Act (FMLA) or requests for reasonable accommodation under the ADA or state law.

COLLECTING GENETIC INFORMATION

Employers will not be permitted to collect genetic information except:

- if the employer inadvertently obtains genetic information;
- if genetic services are offered by the employer (e.g., in a wellness program), provided the employee provides prior written authorization, only the employee and health care professional receive individually identifiable information, and the information is not disclosed to the employer except in aggregate terms;
- if an employer requests or requires family medical history to comply with certification provisions of the FMLA or similar state law;
- if an employer purchases documents that are commercially and publicly available that include family medical history; or
- if the information is used for genetic monitoring of the biological effects of toxic substances in the workplace.

CONFIDENTIALITY

Even when employers have the need or right to collect and maintain genetic information, they will have to take steps to ensure that it remains confidential. An employer will be considered to be in compliance with GINA's confidentiality requirements if it treats genetic information as a confidential medical record under Section 102(d)(3)(B) of the ADA. Such procedures include keeping any genetic information about the employee or family member on separate forms and in separate confidential medical files apart from other employment and personnel records.

There are several exceptions to the confidentiality obligation. Specifically, disclosure will be permitted:

- to the employee if requested in writing;
- to an occupational or health researcher if the research is conducted in compliance with federal regulations;
- in response to a valid court order;
- to governmental officials who are investigating compliance with GINA;
- if the disclosure is made in connection with the employee's compliance with the certification provisions of the FMLA or similar state law; or
- to a public health agency if the information concerns a contagious disease

that presents an imminent hazard of death or life-threatening illness, following proper notice.

STATE LAWS

Even before GINA passed, 34 states and Washington, D.C., prohibited genetic information discrimination. Each of these laws contains different provisions and protections, and it is important to note that GINA does not pre-empt any of these state laws. Thus, any state protections or requirements that differ from GINA are not supplanted by the federal law. State genetic non-discrimination laws for each of the New England states are summarized as follows:

- **Prohibits genetic discrimination in hiring, firing, and/or terms, conditions or privileges of employment:** Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont (and 28 other states, plus D.C.);
- **Prohibits employers from requesting genetic information:** Connecticut, Massachusetts, New Hampshire, Rhode Island (and 15 other states);
- **Prohibits employers from requiring genetic information or testing:** Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont (and 20 other states);
- **Prohibits employers from performing genetic tests:** Massachusetts, New Hampshire, Rhode Island (and 13 other states);

- **Prohibits employers from obtaining genetic information/genetic test results:** Massachusetts (and 10 other states).

CONCLUSION

With the passage of GINA, lawmakers anticipate that individuals will be more willing to pursue potentially life-saving genetic testing and disease management and prevention, without fearing that their own genetic information will be used against them. Although, to date, there have been few lawsuits against employers for genetic information-based discrimination, this law aims to prevent any future incidents while encouraging the overall health and well-being of the workforce. While it may appear unlikely that the issues surrounding an employee's genetic information will affect your workplace in the near future, these issues are likely to surface as genetic testing becomes more prevalent. Employers, therefore, should audit their health data-collection policies to ensure compliance not only with GINA, but also with HIPAA and all applicable state laws. Employers should also review and revise their non-discrimination policies to include protections for employees' genetic information. ■

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