



"GINA" Comes of Age: New Regulations Clarify (and Expand on) the Requirements of The Genetic Information Non-Discrimination Act

By Jillian Barron

More than two years after enactment of the Genetic Information Non-Discrimination Act ("GINA" or "Act"), the Act's impact is still not widely understood. Passed in May 2008 and effective with respect to employment practices in November 2009, GINA prohibits employers, employment agencies, and labor organizations from acquiring employees' "genetic information," except under limited circumstances, and from discriminating based on such information in general. Complying with those restrictions may sound simple. Without delving into GINA's specifics, however, it would be easy to miss the full scope of the Act's requirements.

On November 9, 2010, the Equal Employment Opportunity Commission issued regulations that implement and in some cases expand on GINA's provisions as they apply to employment practices. A review of the regulations, which take effect on January 11, 2011, provides a better understanding of the steps employers need to take to ensure compliance with the Act's obligations. Following are some points to keep in mind.

GINA does not apply to some information of a medical nature. The Act does *not* cover information about: (1) the sex, age, race, or ethnicity of an employee or his/her family members (except when such information is derived from a genetic test); (2) drug and alcohol tests; or (3) *manifested* diseases or disorders *of an employee*, where such information is not otherwise genetic information. (Information about the diseases and disorders of an employee's *family member* is genetic information.) Such information may be protected by other laws, however; for example, acquisition, use, and disclosure of non-genetic medical information about an employee is subject to protection under the Americans with Disabilities Act.

GINA's protections reach beyond current employees. Individuals whose genetic information is protected by GINA include not only current employees, but also job applicants and former employees (all considered "employees" under the new regulations), and those individuals' family members.

"Family members" of employees, whose genetic information is also protected, are extensive, including: relatives to the fourth degree (*e.g.*, great-great-grandparents and first cousins); dependents as a result of marriage, birth, adoption, and placement for adoption; and relatives of those dependents.

Intentional acquisition of genetic information is generally prohibited. GINA forbids requesting, requiring, or purchasing genetic information, with limited exceptions. "Requesting" information includes doing Internet searches, actively listening to third-party conversations, searching personal effects, or otherwise seeking information about an individual's health status in a way likely to result in the acquisition of genetic information. Among the exceptions to the general rule, employers may request family medical information in compliance with federal or state law allowing leave to care for an ill or disabled family member. Employers may also request genetic information as part of a voluntary wellness program, but only when provision of the information is voluntary, and any individually identifiable genetic information is not provided or accessible to managers, supervisors, or anyone else in the workplace other than the employee. Several other exceptions also apply.

Warnings should now be given when lawfully requesting medical information. Inadvertent receipt of genetic information generally is not a violation of GINA. The new regulations cite examples of inadvertent receipt, such as overhearing conversations among employees, and receipt of information in response to casual questions about an employee's family member's wellbeing. The regulations also state, however, that receipt of genetic information in response to a lawful request for medical information—for example medical information sought in connection with an employee's request for family medical leave or accommodation of a disability, or upon the employee's return to work following medical leave—generally will *not* be considered inadvertent unless the employer specifically instructs the employee and/or medical provider *not to provide genetic information*, including family medical history. When requiring medical examinations intended to determine an individual's ability to perform a job, for example post-offer and fitness-for-duty exams, employers must go further and advise the health care provider *not to even collect genetic information*, including family history.

Genetic information must be kept confidential. Any written genetic information an employer does possess, including information in electronic form, must be treated as a confidential medical record maintained separately from general personnel files, and not be disclosed except under limited, specified circumstances.

General advice for employers. Employers need to be aware that GINA's protections extend beyond what is commonly thought of as genetic information to encompass family medical history—information that is often shared in the workplace, such as when an employee mentions a relative suffering from cancer, Alzheimer's disease, or other health conditions. While inadvertent receipt of such information through "water cooler" conversations or sympathetic inquiries about an employee's health does not violate GINA, supervisors and managers should be advised to avoid probing questions likely to result in the acquisition of specific information about employees' family members' medical history or whether an employee or his/her family member has been tested for a genetic condition. In addition, employers should adopt procedures for warning employees and health care providers that when obtaining and submitting medical information to the employer, genetic information should not be included. To help ensure compliance with GINA, nondiscrimination policies and training should be modified to recognize genetic information as a protected factor.

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