Protecting Genetic Data

A growing concern

By **Jeremy Gruber, JD**

As genetic testing and genetic information become increasingly available, it is critical that employers have a full understanding of current genetic privacy and nondiscrimination protections, to ensure their workplaces are in full compliance with federal and state laws. For example, the U.S. Genetic Information Nondiscrimination Act (GINA) took effect on November 21, 2009, yet many employers still are unfamiliar with its provisions. Many are even less familiar with applicable state genetic privacy laws, despite enhanced enforcement of both federal and state laws.

Federal law:
GINA and employment

Prohibitions

One section of GINA, called Title II, applies equally to employers, employment agencies, labor organizations, and joint labor-management committees that control job training. This section of the law makes it an unlawful employment practice for an employer to "fail or refuse to hire ... discharge ... or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment" because of an employee's genetic information. Generally, a person's genetic information is defined as information obtained from the individual's genetic tests, those of the individual's family members, or from the individual's family health history.

GINA applies only to individuals who are asymptomatic. Employees who do show symptoms, sometimes referred to as having a manifested health condition, are not protected. This is true even if an employee's manifested health condition has a genetic origin, such as Huntington's disease. The underlying genetic information, though, remains protected by GINA.

In addition to prohibiting discrimination, GINA makes it an unlawful practice for an employer to "request, require or purchase genetic information with respect to an employee or family member of an employee." GINA prohibits employers from requesting genetic information even in the rare case where it is arguably job related. An example of such a job-related situation would be one in which an employee makes a request for reasonable accommodation. Another example would be a medical examination that the employer authorizes following an offer of employment.

Workers' compensation laws are similarly affected by GINA. This means that an employer may not request or require genetic information from an employee who files a claim for workers' compensation.

Exceptions

However, GINA specifies exceptions to prohibitions on an employer's acquisition of genetic information. An employer may lawfully request such information:

1. Where an employer inadvertently requests or requires family medical history of the employee or family member of the employee. This exemption is limited to "water-cooler conversations" in which an employee voluntarily offers such information to the employer.
2. Where an employer offers health or genetic services, including a wellness program. In such situations, the statute requires the voluntary consent of the employee and limits access to the information obtained.
3. Where the employee voluntarily consents to genetic monitoring of the biological effects of toxic substances.

Additional exceptions include federal or state Family and Medical Leave Act (FMLA) compliance, commercially and publicly available records (but not medical databases and court records), and law enforcement purposes.

Confidentiality

GINA requires that genetic information be kept as part of the employee confidential medical record. Similar to other federal nondiscrimination laws, alleged violations of GINA must be filed with the Equal Employment Opportunity Commission (EEOC) before an individual can pursue a claim in federal court. Damages available to an individual who succeeds in a GINA-related charge or action include back pay, front pay, and compensatory and punitive damages, as well as attorneys' fees. ("Front pay" refers to money awarded for lost compensation during the period between the legal decision and the employee's reinstatement in his or her former job. It can also refer to money awarded if reinstatement is not feasible.)

EEOC and GINA

The EEOC has issued final regulations clarifying some of GINA's key provisions. The commission makes it clear that it is possible for an employer to violate GINA even if that employer does not intend to acquire genetic information. Further, the regulations broadly interpret the term "request" to include:

- Searching an individual's personal effects to obtain genetic information, or
- Requesting information about an individual's current health status in a manner likely to result in obtaining genetic information.

These regulations also make it clear that GINA's exception for commercially and publicly available information does not apply to materials made available to the public, or to some segment of the public, on a restricted basis. For example, this exception does not apply to Facebook pages and certain chat rooms. The exception also does not apply to publicly available materials accessed with the intent of obtaining genetic information, such as searching the Internet for information about someone in a manner likely to result in obtaining genetic information.

What this means for employers

- EEOC regulations make employers responsible for preventing employees' genetic information from being acquired. Employers are required under GINA to proactively inform health care providers not to collect genetic information as part of a medical examination intended to determine an individual's ability or fitness for work.

- These regulations include specific safe-harbor provision language that must be included on forms or questionnaires on which an employer makes a lawful request for medical information.

- EEOC regulations allow employers to offer financial incentives to encourage employee participation in a wellness program. However, if an employer offers an incentive for employees to complete a health-risk assessment that includes questions concerning the employee's medical history or the medical history of the employee's family members, the employer must identify such questions as optional. Specifically, the employer must indicate that the employee need not respond to them in order to receive the incentive.

Take note: The EEOC takes a vigorous role in enforcing GINA. In 2013, it successfully sued two employers for illegally asking about family medical histories such as heart disease, cancer, and mental disorders during required physical exams for employees or for people who had been offered jobs contingent on passing the exam.

GINA and group health plans

Another section of GINA, Title I, deals with genetic nondiscrimination in issuing health insurance. This has important practical implications for employers that sponsor group health plans.

Such employers and health plans are not allowed to ask employees about genetic information or to determine eligibility for coverage (including continued eligibility) based on genetic information. Employers and insurers also are not allowed to charge higher or lower premiums based on genetic information, or to consider genetic information as a preexisting condition. Requesting or requiring an individual or family member to offer genetic information or undergo genetic testing is prohibited, with certain exceptions. Exceptions include the right of a health plan to make payment for a medical service conditional on medical appropriateness, if the determination of medical appropriateness may require the insured person's genetic information. For example, let's say a health plan normally covers mammograms starting at age 40, but covers them at age 30 for individuals with a high risk of breast cancer. In order for the plan to cover the cost of mammograms before age 40, the plan is allowed to require that an individual under 40 submit genetic test results or family medical history as evidence of high risk of breast cancer.

State laws

Almost every state has genetic privacy and nondiscrimination statutes that mirror GINA, although these state laws tend to be more narrowly focused. Many only apply to genetic tests and do not cover family medical history. However, most state laws allow for a larger potential recovery. This may include up to three times the actual damages suffered due to the violation, as well as punitive damages.

A number of states also have statutes covering the misuse of genetic information in other areas that might involve employers. Sixteen states have laws protecting against discrimination in life

and disability insurance, and 10 states have protections in place covering long-term care insurance. Some require informed consent and actuarial justification for the use of genetic information. A handful of states, including Massachusetts and California, have laws covering all three types of insurance.

Employer action steps

In order to remain in compliance with GINA and state genetic privacy laws, employers should immediately:

- **Confirm** that any genetic information or test results currently in their possession are placed in a confidential medical file and kept separate from the employee's personnel file.
- **Review** all company applications to ensure they do not ask for genetic information, including family medical history.
- **Determine** they have an updated EEO poster and policy that addresses genetic information.
- **Assess** existing group health plan criteria to ensure premiums and contributions are not being adjusted based on health status and that genetic information is not collected at enrollment.
- **Ensure** that wellness programs that include health questionnaires make it clear that an employee does not need to provide genetic information. The employer should remove from such questionnaires any questions that relate to genetic information.

Be proactive

Years before GINA was enacted, IBM became the first U.S. corporation to establish a genetics privacy policy. This policy prohibits current or future employees' genetic information from being acquired or used in any context. As genetic information becomes a more common form of data, other employers may want to consider instituting a similar policy.

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