

GINA Regulations Effective January 10, 2011: Be Prepared to Prevent Wrongful Acquisition and Disclosure of Genetic Information

Karen S. Aframe

On November 9, 2010, the Equal Employment Opportunity Commission published its final regulations implementing the portions of the Genetic Information Non-Discrimination Act of 2008 (GINA). GINA became effective in January 2009 and applies to private, state and local employers who employ fifteen or more employees. Like Title VII and the New Hampshire anti-discrimination law, which prohibit employment discrimination and harassment on the basis of protected characteristics including but not limited to race, sex, national origin, age, ethnicity, marital status, religion, disability and sexual orientation, GINA prohibits discrimination and harassment on the basis of *genetic information*. Also, like other anti-discrimination laws, it prohibits retaliation against an individual for participating in a discrimination investigation or suit, or otherwise opposing discrimination. However, GINA includes an additional prohibition -- *it prohibits employers from acquiring and/or disclosing genetic information*. The rules implementing this aspect of the law become effective January 10, 2011 and require immediate attention by employers.

While New Hampshire has had a genetic testing non-discrimination law on the books since 1996, GINA is much broader since it covers both genetic testing and "genetic information," which includes information regarding an employee's family members, and includes the prohibition against acquiring or disclosing "genetic information." In fact, the new regulations implementing GINA define "genetic information" beyond that which one might intuitively consider to be genetic information. Under GINA, genetic information includes, but is not limited to the following:

- Information about an individual's genetic tests;
- Information about the genetic tests of a family member;
- Family medical history;
- Requests for, and receipt of, genetic services by an individual or a family member; and
- Genetic information about a fetus carried by an individual or family member, or about an embryo legally held by the individual or family member using assisted reproductive technology.

Under GINA's final rules, the term "family members" is defined broadly to include spouse; children (natural and adopted); siblings and half-siblings; aunts, uncles, nieces and nephews; grandparents and grandchildren; great- and great-great-grandparents and grandchildren; and first cousins and first cousins once removed.

Employers Beware: Wrongful Acquisition of Genetic Information Is Easier Than You Think

As noted above, GINA generally prohibits an employer from acquiring genetic information. This means an employer may not request, require, or purchase genetic information of an individual or the individual's family member. Under GINA's regulations, a "request" may be as informal as "actively listening to third-party conversations for the purpose of obtaining genetic information" or "conducting an Internet search on an individual that is likely to yield a result containing genetic information." The final rules do provide exceptions to this broad prohibition. However, employers must be cautious because the final rules make it clear that

the exceptions are intended to be narrow. Discussions of some of the likely areas of concern follow:

1. **Inadvertent Acquisition.** The EEOC regulations provide an exception from the general prohibition of acquiring genetic information for an employer that inadvertently acquires genetic information by overhearing a conversation, receiving an unsolicited email about the health of an employee or the employee's family member, or receiving genetic information directly from an employee or third party in response to an expression of ordinary concern, such as "How are you?" or "Did they catch it early?" However, the EEOC clarifies that the inadvertent acquisition exception will *not* apply when a manager follows up a casual conversation about an employee's illness or the illness of an employee's family member with a question such as "Does cancer run in your family?" or "Has your cousin been tested for BRAC1?" This is because these sorts of probing questions, by their nature, will likely yield genetic information.
2. **Publicly Available Information.** GINA also provides an exception from its general prohibition of acquiring genetic information, if the employer acquires the genetic information from a publicly available source, such as a newspaper, television, or the Internet. However, the final rules specify that GINA prohibits conducting an Internet search on an individual in a way that that is *likely to result* in the employer obtaining genetic information. GINA also excludes from the "publicly available" exception information that an employer learns through a site such as Facebook or another social networking site, in which access has been restricted to those with permission. In some circumstances, the acquisition of genetic information through a social networking site will be covered by the inadvertent acquisition exception, such as where a manager is a "Facebook friend" of an employee and inadvertently learns of family medical history from the site. However, it is possible that where a site has ongoing conversations of health concerns, an employee could argue the acquisition by the manager was not "inadvertent." To limit potential liability, employers must consider GINA's implications on employee use of social media, and address these concerns in its social media policy.
3. **Requests for Medical Information.** Employers may also violate GINA if they receive genetic information from a health care provider in response to an otherwise lawful request for medical information, such as a fitness for duty verification or a leave request, including leaves under the FMLA and/or in connection with a request for a reasonable accommodation. However, the EEOC has created a safe harbor for employers who seek such medical information if the employer instructs the health care provider and/or individual from whom it requests the medical information not to provide genetic information. The final rule has set forth specific language that employers may use in connection with such requests for medical information:

The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and other entities covered by GINA Title II from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request for medical information. "Genetic information," as defined by GINA, includes an individual's family medical history, the results of an individual's or family member's genetic tests, the fact that an individual or an individual's family member sought or received genetic services, and genetic information of a fetus carried by an

individual or an individual's family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services.

4. **Wellness Programs.** Employers that offer voluntary wellness programs and/or health risk assessments must also consider GINA's restrictions. The employer must ensure that the employee provides knowing, voluntary and written authorization when providing any genetic information. The EEOC specifies that the authorization and program meet certain criteria in order to meet the standards of the exception. In addition, the final rules clarify that an employer may offer a financial inducement to participate in a health risk assessment only if the inducement is available irrespective of whether questions about family medical history/genetic information are answered.

Unlike the Title VII and state discrimination laws with which employers are familiar, GINA's prohibition on the acquisition or disclosure of genetic information creates liability even where there may not be an adverse employment action, such as firing, demotion, or denial of an employment benefit. Violations of GINA may result in costly damages. Remedies available for wrongful acquisition of genetic information include reinstatement, injunctive relief, backpay, compensatory and punitive damages, and attorney's fees and costs, as well as monetary fines of up to \$100 per day per individual.

To comply with GINA, employers must be sure that they post the revised version of the "EEO is the Law Poster" which is available at http://www.eeoc.gov/employers/upload/eeoc_self_print_poster.pdf. In addition, employers are encouraged to consult with legal advisers to review and revise their human resources practices and policies to ensure compliance with GINA, such as adding safe harbor language to FMLA and fitness-for-duty forms, making sure that social media policy is crafted in a way to limit potential liability under GINA, as well as training managers on the limits of permissible conduct under GINA.