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Genetic Information Non Discrimination Act ("GINA")

The Genetic Information Non-Discrimination Act (the "Act" or "GINA") becomes effective on November 21, 2009, and employers should be aware of provisions related to employment practices. The Act, which the late Senator Edward Kennedy called the "first major new civil rights bill of the new century," was designed with two purposes in mind: (1) to protect the public from potential discrimination; and (2) to allay the public's concerns about potential discrimination, so that individuals would be more comfortable taking advantage of genetic testing, technologies, research and new therapies.

For purposes of the Act, "genetic information" includes: (a) information about an individual's genetic tests; (b) information about the genetic tests of family members of the individual; and (c) information about the manifestation of a disease or disorder in family members of individuals (in other words information about family histories regarding various diseases or disorders). "Genetic tests" are any "analysis of human DNA/RNA/chromosomes that detect genotypes, mutations or chromosomal changes." Examples of genetic tests include carrier screening tests for conditions such as cystic fibrosis or sickle cell anemia. The regulations specifically exclude from the definition cholesterol tests, liver function tests, HIV tests, and tests for drugs or alcohol.

GINA contains three main prohibitions employers should be aware of. First, the Act prohibits employment discrimination based on genetic information. Second, GINA prohibits an employer from requesting, requiring, or purchasing genetic information about employees (including applicants). Finally, the Act prohibits employers from disclosing any genetic information that is obtained.

The non-discrimination provisions of GINA are similar to those in Title VII of the Civil Rights Act of 1964. The Act prohibits discrimination at all stages of the employment process, including hiring, firing, job assignments, and privileges of employment. As is the case with other discrimination claims, before filing a lawsuit, the individual employee must first exhaust available administrative remedies. The major difference between GINA and Title VII Claims is that there are no disparate impact claims under GINA. Thus, neutral and non-discriminatory actions by an employer that disproportionately affect individuals because of genetic information, are not covered by the Act. GINA does require the creation of a bipartisan committee in six years to study whether disparate impact claims are necessary.

The general prohibition on employers acquiring genetic information about employees (or applicants) has several exceptions, or circumstances under which acquisition of such information is allowed.

Water cooler exception. Congress has allowed for the "water cooler" exception, under which employees themselves might reveal information about their family history. For instance, an employer might casually ask an

October 2009

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employee, "How are you doing?" and the employee could respond by saying he/she is upset because a relative had been diagnosed with a form of cancer. Although this would technically represent the acquisition of genetic information by the employer, this type of scenario is excluded from the general prohibition.

Purchasing documents. Employers are allowed to purchase documents containing genetic information that are commercially available. For instance, if a newspaper article quoted an employee talking about his/her family's history of a disease, the employer would not violate GINA by purchasing and reading that article. This exception does not apply to information found in medical databases or court records.

FMLA. The acquisition of genetic information provided in an FMLA certification is an exception to the general prohibition found in the GINA.

Other. Exceptions are made for information acquired in connection with employer-run wellness programs and genetic monitoring used to assess the effects of toxic substances in the workplace. For these exceptions to apply, employers must follow a strict protocol.

Where employers have obtained knowledge of genetic information regarding an employee, they have a duty to maintain the confidentiality of the information. GINA requires employers to maintain the information on separate forms and in separate medical files. Additionally, employers must treat the information as a confidential medical record of the employer. Employers are prohibited from disclosing any genetic information except in six limited circumstances.

1. Genetic information may be disclosed at the written request of the employee.

2. Disclosure is permitted by court order. This exception does not include subpoenas or discovery requests absent a court order.

3. Disclosure is permitted when made in connection with compliance investigations conducted by government officials.

4. Just as employers are permitted to acquire information necessary for FMLA certifications, they may disclose genetic information as is necessary to comply with their FMLA obligations.

5. Disclosures to health agencies concerning contagious diseases that present an imminent hazard of death or life-threatening illness. When this exception applies, the employee that is the subject of the disclosure must be notified.

6. Disclosures made to certain types of health researchers. These types of disclosures must follow a strict protocol under various federal regulations.

While the prohibitions found in GINA only apply to employers with 15 or more employees, Delaware employers should be aware that Delaware law also prohibits employers from discriminating against employees on the basis of genetic information. These prohibitions are found in Title 19 of the Delaware Code, and apply to employers with 4 or more employees.