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On March 2, 2009, the EEOC issued proposed regulations interpreting the Genetic Information Nondiscrimination Act that is scheduled to be effective November 21, 2009, for employers with 15 or more employees. The proposed regulations attempt to clarify the definition of genetic information, provide guidance on the limitations on acquisition of genetic information and discuss how to limit disclosure of it.

Proposed Regulations Under Federal Genetic Information Nondiscrimination Act (GINA) Suggest Employer Action Now

By Margaret Hart Edwards

In May 2008, the Genetic Information Nondiscrimination Act of 2008 (GINA) became law. Congress enacted this law in recognition that advances in genetics and the development of genomic medicine could lead to discrimination against persons based on genetic information, not only with respect to the provision and underwriting of insurance, but also in employment.

GINA has two parts. Title I applies to group health plans sponsored by private employers, unions, and state and local government employers, issuers in the group and individual health insurance markets, and issuers of Medicare supplemental (Medigap) insurance. Title II applies to the same covered entities as Title VII of the Civil Rights Act of 1964. It prohibits the use of genetic information in employment, restricts the acquisition of genetic information, and strictly limits the disclosure of genetic information. The U.S. Equal Employment Opportunity Commission (EEOC) is empowered to issue regulations under Title II of GINA, and to enforce that title's provisions. Title II of GINA goes into effect for employers of 15 or more employees on November 21, 2009. For additional information about GINA see also Littler's National ASAP, *Genetic Antidiscrimination Law Creates New Compliance Challenges for Employers*.

On March 2, 2009, the EEOC issued its proposed regulations for public comment. The deadline to submit comments is May 1, 2009.

The proposed regulations attempt to clarify the definition of genetic information and provide guidance both on the limitations on acquisition of genetic information and ways to limit disclosure of genetic information acquired. As some of these regulations may change employers' practices, employers should make sure that human resources personnel and managers are familiar with the provisions of Title II of GINA before the effective date.

What Will GINA Prohibit?

GINA adds to the protections against discrimination based on genetic information

under the laws of 40 states. GINA prohibits all forms of disparate treatment employment discrimination against applicants, employees, and former employees based on genetic information.¹ This specifically includes limiting, classifying, or segregating employees based on genetic information. Thus, if an employee is known to have a genetic predisposition to heart disease, the employee could not be excluded from a position that might exacerbate his condition. GINA also prohibits retaliation against persons who oppose discrimination. The EEOC proposes that the definition of retaliatory conduct be that articulated by the U.S. Supreme Court in *Burlington Northern & Santa Fe Railway v. White*.²

GINA prohibits employers from acquiring genetic information about applicants or employees, except in very narrow circumstances: (1) inadvertently acquired information volunteered by employees, overheard, or received by accident; (2) aggregate information that is not individually identifiable acquired in the provision of voluntary wellness programs that provide genetic testing or counseling; (3) information provided to an employer in connection with the certification requirements for a leave request; (4) information from genetic monitoring either required by law (such as occupational safety and health laws) or specifically authorized in writing by an individual's knowing and voluntary agreement; (5) information obtained by law enforcement and the military, in limited circumstances, to assist with proper genetic identification; and (6) publicly available information. Even if genetic information is lawfully obtained under one of the exceptions, it may not be used to discriminate and must be kept confidential.

Like other individual medical data, genetic information may not be stored in a personnel file, but it may be kept in a separate confidential medical file (as required under the Americans with Disabilities Act). However, publicly available information need not be so stored.

Genetic information may not be disclosed to others, except: (1) to the person to whom the information relates; (2) to an occupational health researcher if the research is conducted under applicable federal regulations; (3) in response to a court order that specifically calls for the information (but not in response to discovery requests not governed by a court order); (4) to government officials investigating compliance with GINA; (5) disclosure in connection with a request for leave under federal, state or local law, and (6) disclosure to officials in connection with a contagious disease or imminent hazard of death or life-threatening illness.

The remedies for violations of GINA are those available under Title VII. GINA does not displace state or local laws that may provide greater protection. GINA's remedies are in addition to other remedies that may exist under federal law, such as under the Americans with Disabilities Act.

What is Genetic Information?

Genetic information is information about: (1) an individual's genetic tests; (2) genetic tests of the individual's family members (defined to include first through fourth degree³ relatives); (3) the manifestation of diseases or disorders in family members (e.g., family medical history); (4) an individual's request for or receipt of genetic services or participation in clinical research that includes genetic services; and (5) the genetic information of a fetus or any embryo legally held by an individual or family member using assisted reproductive technology. A *genetic test* is an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes. It does not include tests that reveal gender or age. It does not include tests for certain viruses or bacteria, alcohol or drug testing, or common medical tests such as complete blood counts, cholesterol tests, or liver-function tests. *Manifestation of disease or disorder* means that the person has been or could be reasonably diagnosed with the disease, disorder, or pathological condition by a health care professional with appropriate training and expertise. There is no *manifestation* if the individual simply tests positive for a genetic trait for a disease, even if the probability of manifestation at some point is 100%. This last provision is designed to avoid having a positive test be classified as a "pre-existing condition" under ERISA.

What Practical Steps Should Employers Prepare to Take?

1. Employers should revise EEO policies to include prohibitions against discrimination based on genetic information.

2. Employers must post a new nondiscrimination poster to be issued by the EEOC later in 2009 (before the November 21, 2009, effective date) prohibiting discrimination based on genetic information.
3. Employers should train human resources personnel and managers on the requirements of Title II of GINA and any applicable state or local laws.
4. If an employer requires post-offer, pre-employment medical examinations, the medical examinations may not include any inquiries about family medical history. As most physicians automatically ask for this information, physicians doing examinations for employers must be made aware of this restriction and the need to strictly avoid common questions about family medical history.
5. Employers who require a fitness-for-duty medical examination are similarly prohibited from having the physician ask for family medical history.
6. Employers may not seek genetic information in connection with any discussion of a reasonable accommodation of a disability.
7. Employers may not make overbroad requests for information in connection with requests for leave. The EEOC suggests as a “best practice” that employers who ask employees to have health care professional provide documentation of a disability to specifically state in the request that family medical history or other genetic information should not be provided.
8. Employers should not produce genetic information in response to a subpoena, unless the subpoena specifically calls for the production of this information.
9. The proposed regulations suggest that employers not use Internet resources, court records, or publicly available databases to acquire genetic information about applicants or employees. The EEOC asked for comments about whether this disfavored practice should extend to reviewing personal websites or social networking sites.
10. Employers should be very careful to avoid storing family medical history information in personnel files, as this is genetic information that must be stored in a separate medical file. As a practical matter, this means that documents associated with a leave to care for the serious illness of a family member may have to be kept apart from the personnel file.
11. Employers should train recruiters and hiring managers to avoid making a hiring (or other) decision based on personal knowledge of family history. Particularly in smaller towns, there may exist considerable knowledge (or lore, or mis-knowledge) of family medical history. A decision made with that data in mind, and its potential effect on the employer’s health care plan, would almost undoubtedly be illegal. Remember that 4th generational analysis goes back to one’s great-great grandparents.

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Margaret Hart Edwards is a Shareholder in Littler Mendelson’s San Francisco office. If you would like further information, please contact your Littler attorney at 1.888.Littler, info@littler.com, or Ms. Hart Edwards at mhedwards@littler.com.

¹ GINA does not create a claim for disparate impact discrimination.

² 548 U.S. 53 (2006).

³ Fourth degree relatives include an individual’s great-great grandparents, great-great grandchildren and first cousins once-removed (e.g., the children of the individual’s first cousins.)