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Genetic Information in the Workplace: The EEOC's New Regulations

On May 21, 2008, Congress enacted the Genetic Information Nondiscrimination Act of 2008 (GINA) in order to prevent discrimination on the basis of genetic information in health insurance and employment. This discussion focuses on Title II of GINA, which concerns discrimination in employment.¹ Title II of GINA, which went into effect 18 months after passage of the act (on Nov. 21, 2009), dealt with discrimination in employment.

This discussion focuses on Title II and offers some guidance to employers on how to best comply with the changes under the EEOC regulations.

GINA's nondiscrimination provisions prohibit employers from using genetic information in making decisions related to an individual's employment. Specifically, GINA prohibits employers from considering an individual's genetic information when making decisions about hiring, discharge, compensation, terms, conditions, and privileges of employment. Employers are also barred from actions that may limit, segregate, or classify individuals because of genetic information in a way that might deprive them of employment opportunities.²

In passing GINA, proponents argued that the law encourages individuals to screen for those conditions to which they are genetically predisposed by protecting them from any

adverse employment actions relating to the results of that screening. The hope was that GINA would give workers the freedom to pursue genetic testing for diseases such as cancer, heart disease,

diabetes, and Alzheimer's disease without being concerned about losing their jobs or health insurance.

Congressional findings further acknowledged that, with advancements in medical techniques and technology, an increase in genetic

testing increases the likelihood that researchers will come up with early lifesaving therapy for a wide range of hereditary diseases.

GINA requires the Equal Employment Opportunity Commission to issue regulations regarding

enforcement of the law within one year of its enactment. On March 2, 2009, the EEOC released its proposed regulations for GINA, which included regulations that are specific to GINA's nondiscrimination requirements in the employment context under Title II of the act.³ The EEOC had hoped that the regulations would bring sorely needed clarification about the application and enforcement of GINA, but the initial reaction was one of concern and further confusion about the impact the law might have on employers.⁴ The following discussion highlights the most relevant changes to the regulations and explains the impact they may have on employers' current obligations, policies, and practices.

GINA's Broad Definitions

One topic of concern remains GINA's broad definitions. GINA's definition of "genetic information" not only includes the individual employee's genetic information but also extends the amount of the information to include the medical history of that employee's family. The EEOC's regulations clarify that an individual's genetic information includes information about the individual's genetic tests or the genetic tests of that individual's family members, the manifestation of a disease or disorder in that individual's family medical history, or any request for or receipt of genetic services by that individual or that individual's family members.⁵

In addition, the act defines "family members" broadly to include dependents under the employer's group health insurance plan and fourth-degree relatives of the employee or the employee's dependents. The regulations clarify that prohibited genetic information of an employee's family members includes current medical information about that employee's children, spouse, parents, grandparents, great-grandparents, aunts, uncles, and first cousins.⁶

Exceptions to GINA's Ban on Acquiring Genetic Information

Generally, GINA imposes strict restrictions on the deliberate acquisition of genetic information. However, the EEOC has carved out specific exceptions that the regulations address:⁷

- inadvertent request or requirement for genetic information—This exception applies when an



employer unwittingly receives genetic information from an employee's family medical history through casual conversations with an employee or by overhearing conversations between employees. The regulations extend this exception to apply "in any situation in which an employer might inadvertently acquire genetic information, not just situations involving conversations between co-workers that are overheard," and provide a list of possible situations the EEOC believes to be within congressional intent.⁸

- health care or genetic services—GINA allows employers to offer health care or genetic services as a part of a wellness program. The regulations clarify that the wellness program must be "voluntary," and they define "voluntary" as a wellness program offered by an employer that "neither requires participation nor penalizes employees who do not participate."⁹
- Family and Medical Leave Act—The GINA regulations clarify that employees requesting leave under the FMLA may provide their family's medical information to employers. However, employers must keep such information in a separate medical file and treat that information as a confidential medical record.
- genetic information that is available commercially and publicly—The regulations also provide an exception for employers that acquire genetic information from commercially and publicly available sources such as newspapers, magazines, and information communicated through electronic media. However, the regulations clearly state that this exception excludes information found in court records and medical databases.
- genetic monitoring—This exception allows employers to perform genetic monitoring of the biological effects of toxic substances in the workplace as long as these employers comply with the requirements set forth in the regulations.¹⁰
- DNA testing for purposes of law enforcement or identification of human remains—This narrow exception applies only to employers engaging in DNA testing needed by law enforcement or for the identification of human remains. The regulations permit employers to request genetic information from their employees in such very limited circumstances.

Interplay with Other Laws

Because GINA is one of several anti-discrimination laws that the EEOC has the duty to enforce, some commentators have questioned the potential impact the new GINA regulations may have on the requirements set forth in other state and federal statutes. The regulations offer some clarification on this statutory interplay. For example, the regulations state that GINA does not pre-empt or limit any state or local laws that provide equal or greater protec-

tion from genetic discrimination.

Nor does GINA pre-empt any pre-existing federal laws that prohibit discrimination against individuals based on a disability. The EEOC suggests, for example, that an individual could challenge the disclosure of genetic information under the Americans with Disabilities Act (ADA) when the information is also considered medical information subject to that law. In addition, even if that information—that an employee currently has a disease—is not subject to GINA's confidentiality requirement, the information would be protected under the ADA, and an employer could be found liable under the ADA for disclosing the information.

The regulations clarify that GINA limits an employer's ability to obtain genetic information as a part of an inquiry or medical examination related to an employee's disability. For example, an employer can no longer obtain the family medical history or conduct genetic tests of applicants who have been offered a job with the employer, as is currently permitted under the ADA. However, the regulations make it clear that genetic information that is obtained to support an employee's request for a reasonable accommodation under the ADA will be considered an inadvertent disclosure.¹¹

The regulations further clarify that Title II is not meant to interfere with—or apply to—uses and disclosures of protected health information under HIPAA.¹² An employer who is subject to the HIPAA requirements must continue to abide by those requirements when obtaining genetic information—not the requirements set forth under GINA. For example, if a hospital is subject to the HIPAA privacy rule and treats a patient who is also an employee of the hospital, any genetic information obtained or created by the hospital in its role as a health care provider is protected health information and is subject to the requirements of the HIPAA, not those of GINA. However, any genetic information obtained by the hospital in its role as an employer is subject to GINA.

Suggested Actions for Employers

In light of GINA's expansive definitions and express prohibition against using genetic information when making decisions related to a person's employment, employers need to be aware of the information they have collected from their employees and job applicants and whether that information will create a GINA violation. In addition to updating their EEOC postings, we suggest, as others have, that employers consider the following ways to comply with GINA and the regulations:¹³

- updating employee handbooks and/or workplace policies to specifically prohibit discrimination

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and harassment based on “genetic information”— something that should be done even though most harassment and discrimination policies contain a catch-all provision that covers “any other bases protected by applicable law”;

- discussing “genetic information” in any training seminars about preventing harassment and discrimination in the workplace;
- reviewing record keeping procedures and ensuring that any genetic information is kept in a separate medical file and treated in the same manner as medical records are treated under the ADA;
- examining and revising employment forms, especially any requests for medical records or information, to be certain that those forms do not request genetic information and taking proactive measures to avoid receiving genetic information, even through inadvertent disclosure; and
- reviewing any wellness programs to ensure they are in compliance with GINA and considering providing training for employees who may come across genetic information.

Conclusion

The Equal Employment Opportunity Commission is expected to finalize its GINA regulations by November 2010. Employers should be mindful of the potential compliance issues raised by GINA as well as the increased burdens they now face and should strive to be proactive in complying with GINA and its regulations. **TFL**

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Endnotes

¹Pub. L. 110-233, H.R. 493, 122 Stat. 881, 881-882 (May 21, 2008). Title I of GINA deals with group health plans and health information.

²However, a cause of action for disparate impact (when a practice is neutral on its face, but an individual alleges that the practice disproportionately affects a protected group of workers to their detriment) is not available under GINA. 42 U.S.C. § 2000ff-6.

³To view the proposed EEOC regulations in their entirety, please visit FR Doc. E9-4221, available at edocket.access.gpo.gov/2009/E9-4221.htm. While the proposed regulations also address Title II of the Act,

Title II was not enacted until Nov. 21, 2009. Without further amendment, these regulations will become final by Nov. 21, 2010. 42 U.S.C. § 2000ff-10.

⁴Prop. 29 C.F.R. Part 1635.3(a), 74 Fed. Reg. 9056 (Mar. 2, 2009).

⁵Prop. 29 C.F.R. Part 1635.3(c), 74 Fed. Reg. 9056, 9059 (Mar. 2, 2009).

⁶Prop. 29 C.F.R. Part 1635.3(a), 74 Fed. Reg. 9056, 9058-9059 (Mar. 2, 2009).

⁷42 U.S.C. § 2000ff-1(b)(1-6); Prop. 29 C.F.R. Part 1635.8, 74 Fed. Reg. 9056, 9061-9063 (Mar. 2, 2009). The EEOC cautions employers that, despite the recognized exceptions, “the use of genetic information to discriminate, no matter how that information may have been acquired, is prohibited.” Prop. 29 C.F.R. Part 1635.8, 74 Fed. Reg. 9056, 9061-9063 (Mar. 2, 2009).

⁸See Prop. 29 C.F.R. Part 1635.3(a), 74 Fed. Reg. 9056, 9061 (Mar. 2, 2009).

⁹Prop. 29 C.F.R. Part 1635.8, 74 Fed. Reg. 9056, 9062 (Mar. 2, 2009).

¹⁰See *id.* at 9063.

¹¹Prop. 29 C.F.R. Part 1635.8, 74 Fed. Reg. 9056, 9061-9062 (Mar. 2, 2009).

¹²Prop. 29 C.F.R. Part 1635.11(d), 74 Fed. Reg. 9056, 9064-9065 (Mar. 2, 2009).

¹³See *e.g.*, New Jersey Employment Law Letter, *Proposed GINA Regulations for Federal Genetic Discrimination Law*, available at www.hrhero.com/hl/052209-tip-gina.html?TOPIC (last visited Dec. 31, 2009). For more suggestions on preparing for the changes imposed by the EEOC's GINA regulations, see www.eeoc.gov/laws/types/genetic.cfm.