The Genetic Information Nondiscrimination Act (GINA): Final Employment Regulations

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Summary

The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits discrimination based on genetic information by health insurers and employers. GINA is divided into two main parts: Title I, which prohibits discrimination based on genetic information by health insurers; and Title II, which prohibits discrimination in employment based on genetic information. Title II of GINA prohibits discrimination in employment because of genetic information and, with certain exceptions, prohibits an employer from requesting, requiring, or purchasing genetic information. The law prohibits the use of genetic information in employment decisions—including hiring, firing, job assignments, and promotions—by employers, unions, employment agencies, and labor management training programs and mandates confidential treatment of any genetic information that is obtained.

The Equal Employment Opportunity Commission (EEOC) promulgated final regulations under Title II of GINA on November 9, 2010. The EEOC noted that the regulations closely track the statutory language but they do provide clarification regarding definitions in GINA; provide guidance regarding the exceptions in GINA to employer liability for acquiring genetic information; discuss the application of GINA to wellness programs; and discuss the interplay between GINA and other statutes. The regulations also provide specific examples to help clarify the requirements of the statute and regulations. For instance, the regulations clarify that a genetic test includes a test to determine whether an individual has a BRCA1 or BRCA2 variant which would indicate a predisposition to breast cancer, and would include preimplantation genetic diagnosis in embryos. The regulations also specifically state that a test for cholesterol levels is not a genetic test. Similarly, the regulations provide a definition of manifested disease, and note that when the diagnosis of a disease depends on both signs and symptoms and genetic information, the disease will be considered manifested. It was emphasized, however, that medical information is still subject to other laws, such as Title I of the Americans with Disabilities Act (ADA), which regulates the acquisition and use of medical information.

GINA and its regulations prohibit the collection of genetic information by employers but do provide some exceptions. The question of how the EEOC would interpret GINA's application to employer-run wellness programs was highly anticipated. In the final regulations, the EEOC concluded that inducements may be offered to encourage individuals to participate in wellness programs, but inducements may not be offered to provide genetic information. However, the EEOC does not permit a covered entity to request genetic information in order to evaluate whether an employee or applicant is able to safely and effectively perform the job. This is in contrast to the ADA as interpreted by the Supreme Court in *Chevron v. Echazabal*, where the Court found no violation of the ADA when an employer refused to hire an individual whose health would be endangered by the job. This issue may become more problematic as genetic information becomes more widely used.

Generally, the EEOC GINA regulations provide significant guidance to employers, especially in the use of examples, and in the clarification of GINA's applicability to wellness programs. However, due to the lack of decided cases and the ever-changing science, there is still some uncertainty concerning GINA's exact parameters.

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Introduction

The Genetic Information Nondiscrimination Act of 2008 (GINA),[1] referred to by its sponsors as the first civil rights act of the 21st century, was enacted on May 21, 2008.[2] GINA, P.L. 110-233, prohibits discrimination based on genetic information by health insurers and employers. The sequencing of the human genome and subsequent advances raise hope for genetic therapies to cure disease, but this scientific accomplishment is not without potential problems.[3] An employer or health insurer could decide to take adverse action based on a genetic predisposition to disease, and situations have arisen where discriminatory action based on genetic information may have occurred.[4] In addition, there is evidence that the fear of genetic discrimination has an adverse effect on those seeking genetic testing, as well as on participation in genetic research.[5] GINA was enacted to remedy these situations.

GINA is divided into two main parts: Title I, which prohibits discrimination based on genetic information by health insurers; and Title II, which prohibits discrimination in employment based on genetic information. Title I of GINA amends the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code (IRC), through the Health Insurance Portability and Accountability Act of 1996 (HIPAA), as well as the Social Security Act, to prohibit health insurers from engaging in genetic discrimination.[6] Title II of GINA prohibits discrimination in employment because of genetic information and, with certain exceptions, prohibits an employer from requesting, requiring, or purchasing genetic information. The law prohibits the use of genetic information in employment decisions—including hiring, firing, job assignments, and promotions—by employers, unions, employment agencies, and labor management training programs.

The Equal Employment Opportunity Commission (EEOC) promulgated final regulations under Title II of GINA on November 9, 2010. These regulations take effect on January 10, 2011, 60 days after publication in the Federal Register.[7] The EEOC noted that the regulations closely track the statutory language. However, they do provide clarification regarding definitions in GINA; provide guidance regarding the exceptions in GINA to employer liability for acquiring genetic information; discuss the application of GINA to wellness programs; and discuss the interplay

[1] 42 U.S.C. §2000ff *et seq.*

[2] For a discussion of the statutory provisions of GINA see CRS Report RL34584, *The Genetic Information Nondiscrimination Act of 2008 (GINA)*, by (name redacted) and (name redacted).

[3] GINA is a rarity among civil rights statutes since it does not address a long history of discrimination but rather attempts to ensure that new technologies do not give rise to discriminatory actions. For a discussion of the uniqueness of genetic information see CRS Report RL34376, *Genetic Exceptionalism: Genetic Information and Public Policy*, by (name redacted).

[4] According to Peggy Mastroianni, EEOC's associate legal counsel, EEOC has received about 200 charges alleging GINA violations since the act took effect last year although EEOC has not yet issued a complaint under GINA. BNA's Health Care Daily, http://news.bna.com/hdln/HDLNWB/split_display.adp?fedfid=18392162&vname=hcenotallissues&wsn=496967000&fn=18392162&split=0. Prior to the enactment of GINA, the EEOC filed a complaint regarding genetic discrimination under the Americans with Disabilities Act (ADA), 42 U.S.C. §12101 et seq., which was ultimately settled. http://www.eeoc.gov/eeoc/newsroom/release/2-9-01-c.cfm

[5] See CRS Report RL34376, *Genetic Exceptionalism: Genetic Information and Public Policy*, by (name redacted).

[6] Interim final regulations have been issued under Title I. See 29 C.F.R. §2590.702, 74 FED. REG. 51683 (October 7, 2009). A discussion of Title I of GINA is beyond the scope of this report.

[7] 75 FED. REG. 68912 (November 9, 2010).

between GINA and other statutes. The regulations also provide specific examples to help clarify the requirements of the statute and regulations. This report examines the final EEOC Title II regulations with an emphasis on areas where the regulations elaborate upon the statutory requirements.

Definitions

Overview

Generally, the definitions in the final regulations track the statutory definitions although where the statute incorporates the provisions of other statutes, such as Title VII of the Civil Rights Act, the final GINA regulations specifically describe the provisions incorporated. In addition, the regulations include a definition of "covered entity," which the EEOC describes as "a simplifying shorthand to aid in the readability of the final regulation…."[8] Title II of GINA covers employers, unions, employment agencies, and labor management training programs, and rather than reiterating this coverage, where appropriate the regulations refer to "covered entity." Although the use of "covered entity" was criticized in the proposed regulations because of possible confusion with the Health Insurance Portability and Accountability Act (HIPPA), the EEOC kept the term in the final regulations noting that, since most of the entities subject to Title II of GINA are not HIPAA covered entities, there should be no confusion.[9] The following discussion covers several of the most significant regulatory definitions, and does not discuss those that largely track the statutory language.

Employee

An employee is defined in the regulations, in part, as "an individual employed by a covered entity, as well as an applicant for employment and a former employee."[10] The inclusion of former employees in the proposed regulations was controversial,[11] but the EEOC kept the language, noting that the Supreme Court in *Robinson v. Shell Oil Company*[12] stated that the definition of employee in Title VII of the Civil Rights Act "is consistent with either current or past employment."[13]

Employer

The EEOC regulations do not reiterate the statutory definition of employer which provides citations to the definitions used in other laws; rather, the final regulations provide a more concise definition drawn from the statutory references. Employer is defined as

[8] 75 FED. REG. 68914 (November 9, 2010).

[9] *Id.*

[10] 29 C.F.R. §1635.2(c); 75 FED. REG. 68932 (November 9, 2010).

[11] See 75 FED. REG. 68914 (November 9, 2010).

[12] 519 U.S. 337 (1997).

[13] *Id.* at 342.

> any person that employs an employee defined in §1635.2(c) of this part, and any agent of such person, except that, as limited by section 701(b)(1) and (2) of the Civil Rights Act of 1964 …, an employer does not include an Indian tribe, or a bona fide private club (other than a labor organization) that is exempt from taxation under section 501(c) of the Internal Revenue Code of 1986.[14]

The definition does not specifically state that there is no individual liability for violations of GINA, as one commenter on the proposed regulations had suggested. The EEOC determined that it was not necessary to specifically include such a statement in the definition of employee.[15] In making this determination, the EEOC observed that GINA references the definition of employer used by Title VII of the Civil Right Act of 1964 and numerous courts have held that this definition does not allow for individual liability.[16]

Family Member

GINA's statutory definition of family member references ERISA Section 701(f)(2),[17] and also includes other individuals who are in first-, second-, third-, or fourth-degree relationships. The EEOC's final regulations provide that a family member with respect to an individual is "a person who is a dependent of that individual as a result of marriage, birth, adoption, or placement for adoption."[18] Although some commenters to the proposed regulations argued that dependents by adoption or placement by adoption should not be included since they did not share the same genetics as the adoptive parents, the EEOC rejected this argument, noting that Section 701(f)(2) of ERISA specifically referred to adoption, and that the acquisition of genetic information about an adoptive child could result in genetic discrimination.[19]

Family Medical History

Family medical history is not defined in the statute, but is used in the statutory prohibition on the acquisition of genetic information.[20] The EEOC final regulations define the term as meaning "information about the manifestation of disease or disorder in family members of the individual."[21]

Genetic Test

GINA's statutory language defines genetic test as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes," but contains an exception for "an analysis of proteins or metabolites that does not

[14] 29 C.F.R. §1635.2(d); 75 FED. REG. 68932 (November 9, 2010).

[15] 75 FED. REG. 68914 (November 9, 2010).

[16] *Id.*

[17] 29 U.S.C. §1181(f)(2). This subsection provides that a person may become a dependent "through marriage, birth, or adoption or placement for adoption…."

[18] 29 C.F.R. § 1635.3(a); 75 FED. REG. 68933 (November 9, 2010).

[19] 75 FED. REG. 68915 (November 9, 2010).

[20] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4.

[21] 29 C.F.R. § 1635.3(b); 75 FED. REG. 68933 (November 9, 2010).

detect genotypes, mutations, or chromosomal changes."[22] The EEOC's final regulations mirror the statutory language except that the regulations provide specific examples of genetic tests and of tests or procedures that are not genetic tests. For example, a genetic test includes a test to determine whether an individual has a BRCA1 or BRCA2 variant which would indicate a predisposition to breast cancer, and would include preimplantation genetic diagnosis on embryos.[23] One of the examples given in the regulations of a test that is not a genetic test is a test for cholesterol levels, since a cholesterol test does not detect mutations.[24] Similarly, testing for the presence of alcohol or illegal drugs is also not considered a genetic test since it is not an analysis of DNA or RNA, but a test to determine whether an individual has a genetic predisposition for alcoholism or drug use is a genetic test.[25]

Manifestation or Manifested

Since the statutory language of GINA refers to the manifestation of a disease,[26] the EEOC includes a definition of the term in final regulations. Manifestation or manifested is defined in the final regulations as meaning,

> with respect to a disease, disorder, or pathological condition, that an individual has been or could reasonably be diagnosed with the disease, disorder, or pathological condition by a health care professional with appropriate training and expertise in the field of medicine involved. For the purposes of this part, a disease, disorder, or pathological condition is not manifested if the diagnosis is based principally on genetic information.[27]

In its comments on this definition, the EEOC notes that when the diagnosis of a disease depends on both signs and symptoms and genetic information, the disease will be considered manifested.[28] It was emphasized, however, that such information is still subject to other laws, such as Title I of the ADA which regulates the acquisition and use of medical information.[29]

Prohibited Practices in GINA Final Regulations

The EEOC final regulations echo the statutory language regarding prohibitions against discrimination. The statute and regulations provide that it is unlawful

- for an employer to discriminate against an individual on the basis of genetic information in regard to hiring, discharge, compensation, terms, conditions, or privileges of employment;[30]

[22] 42 U.S.C. §2000ff(7).

[23] 29 C.F.R. § 1635.3(f)(2); 75 FED. REG. 68933 (November 9, 2010).

[24] 29 C.F.R. § 1635.3(f)(3); 75 FED. REG. 68933 (November 9, 2010).

[25] 29 C.F.R. § 1635.3(f)(4); 75 FED. REG. 68933 (November 9, 2010).

[26] 42 U.S.C. §2000ff(4)(A)(iii); 42 U.S.C. §2000ff-9.

[27] 29 C.F.R. § 1635.3(g); 75 FED. REG. 68933-68934 (November 9, 2010).

[28] 75 FED. REG. 68917 (November 9, 2010).

[29] 42 U.S.C. §12112(d). For a general discussion of the ADA, including these provisions, see CRS Report 98-921, *The Americans with Disabilities Act (ADA): Statutory Language and Recent Issues*, by (name redacted).

[30] 42 U.S.C. §2000ff-1; 29 C.F.R. §1635.4(a).

- for an employment agency to fail or refuse to refer any individual for employment or otherwise discriminate against any individual because of genetic information of the individual;[31]
- for a labor organization to exclude or to expel from the membership of the organization, or otherwise discriminate against, any member because of genetic information;[32] and
- for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training programs to discriminate against an individual because of genetic information of the individual.[33]

The EEOC observes in its comments on the regulations that claims of harassment on the basis of genetic information may also be brought.[34]

The final regulations also reiterate the statutory language prohibiting actions that may limit, segregate, or classify employees because of genetic information.[35] A clarifying statement provides that a covered entity is not in violation of the prohibition on actions that limit, segregate, or classify employees due to genetic information if the action was required by a law or regulation mandating genetic monitoring.[36] The GINA regulations echo the statutory language prohibiting actions that cause a covered entity to discriminate,[37] but also include employers in this prohibition. The EEOC reasoned that although the GINA statutory language regarding employers does not include this prohibition, jurisprudence under Title VII of the Civil Rights Act includes employers' agents in the definition of employer. Thus, GINA would prohibit an employer from engaging in actions that would cause another covered entity acting as its agent to discriminate. To illustrate this, the EEOC gave an example of an employer who directed an employment agency to ask applicants for genetic information, thereby causing the employment agency, if they complied with the request, to be in violation of GINA.[38]

Retaliation

GINA prohibits retaliation against an individual because the individual has opposed any act or practice that is unlawful under GINA or participated in an investigation, proceeding, or hearing concerning GINA.[39] The final regulations track this statutory language. In its comments, the EEOC notes that it believes the standard for retaliation under GINA was intended to be the same as that under Title VII as described in *Burlington Northern & Santa Fe Ry. v. White*.[40] In

[31] 42 U.S.C. §2000ff-2; 29 C.F.R. §1635.4(b).

[32] 42 U.S.C. §2000ff-3; 29 C.F.R. §1635.4(c).

[33] 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.4(d).

[34] 75 FED. REG. 68918 (November 9, 2010).

[35] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.5, 75 FED. REG. 68934 (November 9, 2010).

[36] 29 C.F.R. §1635.5(a), 75 FED. REG. 68934 (November 9, 2010).

[37] 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.6, 75 FED. REG. 68934 (November 9, 2010).

[38] 75 FED. REG. 68918 (November 9, 2010).

[39] 42 U.S.C. §2000ff-6(f).

[40] 548 U.S. 53 (2006). The EEOC discussion of this issue is at 75 FED. REG. 68918 (November 9, 2010).

Burlington, the Supreme Court found that an anti-retaliation provision protects an individual if the action might have dissuaded a reasonable worker from making a discrimination claim.

Acquisition of Genetic Information

General Prohibitions

Providing nondiscrimination protections is a three-part process in GINA, as it is in the ADA. First, there is a general prohibition against discrimination;[41] second, there are prohibitions on the acquisition of information about the covered class that could result in discrimination; and third, there are confidentiality provisions.[42] GINA's statutory language left some ambiguity concerning when the "passive acquisition" of information was covered.[43] The EEOC resolved this issue by adding regulatory language defining "request" as including conducting an Internet search on an individual in such a way as is likely to result in obtaining genetic information; actively listening to third-party conversations; searching an individual's personal effects for the purpose of obtaining genetic information; and making requests for information about an individual's health status in a way that is likely to result in obtaining genetic information.[44]

Exceptions

The prohibition on the acquisition of information also contains exceptions, and the EEOC final regulations provide clarifying examples concerning these exceptions.

Inadvertent Requests or Acquisitions

The statutory language of GINA provides for an exception to the prohibition on the acquisition of information when a covered entity inadvertently requests or requires family medical history of the employee, individual, union member, or a family member.[45] The House Education and Labor Report noted that this exception "addresses the so-called 'water cooler' problem, in which an employer unwittingly receives otherwise protected genetic information in the form of family medical history through casual conversations with a worker."[46] The final regulations provide that if a covered entity inadvertently requests or requires genetic information relating to an individual or family member, the general prohibition does not apply. In its discussion of the final regulations, the EEOC notes that the statute only refers to family medical history, but states that it

[41] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.4, 75 FED. REG. 68934 (November 9, 2010).

[42] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.8, 75 FED. REG. 68934 (November 9, 2010).

[43] 75 FED. REG. 68919 (November 9, 2010).

[44] 29 C.F.R. §1635.8(a), 75 FED. REG. 68934 (November 9, 2010).

[45] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4; 29 C.F.R. §1635.8(b)(1), 75 FED. REG. 68934 (November 9, 2010).

[46] H.Rept. 110-28, Part 1 at 37 (March 5, 2007).

believes that "it is consistent with Congress's intent to extend the exception to any genetic information that an employer inadvertently acquires."[47]

When a covered entity requests medical information, the final regulations provide that, if a statement is provided warning individuals not to provide medical information, any information obtained is considered inadvertent. There would be no violation of GINA for obtaining information in this manner. However, even if a written notice is not provided, a covered entity may still be able to establish that information was obtained inadvertently.[48]

Wellness Programs

The second exception provided in GINA is for health or genetic services offered by the entity as part of a health or genetic services, including a wellness program.[49] To qualify for the exemption,

- the employee, individual, or union member must provide prior, knowing, voluntary, and written authorization;
- only the employee, individual, union member, or family member and the licensed health care profession or board certified genetic counselor involved in providing such services can receive individually identifiable information concerning the results of the services; and
- any individually identifiable genetic information is only available for such services and shall not be disclosed to the employer except in aggregate terms that do not identify individuals.[50]

The EEOC regulations reiterate the exception and its requirements.[51] In the proposed regulations, EEOC emphasized that such programs must be voluntary, and asked for comments concerning the appropriate level of inducement offered for participation in a wellness program. In the final regulations, the EEOC concluded that inducements may be offered to encourage individuals to participate in wellness programs, but inducements may not be offered to provide genetic information. The EEOC provides the following example in the regulations as a situation that does not violate GINA:

> A covered entity offers $150 to employees who complete a health risk assessment with 100 questions, the last 20 of them concerning family medical history and other genetic information. The instructions for completing the health risk assessment make clear that the inducement will be provided to all employees who respond to the first 80 questions, whether or not the remaining 20 questions concerning family medical history and other genetic information are answered.[52]

[47] 75 FED. REG. 68919 (November 9, 2010).

[48] 29 C.F.R. §1635.8(b)(1)(i), 75 FED. REG. 68934 (November 9, 2010).

[49] For a discussion of the legal issues involving wellness programs generally, see CRS Report R40661, *Wellness Programs: Selected Legal Issues*, coordinated by (name redacted).

[50] 42 U.S.C. §2000ff-1; 42 U.S.C. §2000ff-2; 42 U.S.C. §2000ff-3; 42 U.S.C. §2000ff-4.

[51] 29 C.F.R. §1635.8(b)(2), 75 FED. REG. 68935 (November 9, 2010).

[52] 29 C.F.R. §1635.8(b)(2)(ii)(A), 75 FED. REG. 68935 (November 9, 2010).

However, if the health risk assessment does not make clear which questions must be answered, it would violate GINA.[53]

Similarly, financial inducements may be offered to encourage participation in wellness programs for individuals who have voluntarily provided genetic information. In order to comply with GINA, these programs must also be offered to individuals with health conditions or life style choices that put them at an increased risk of developing a condition. For example, it would not violate GINA to offer $150 for participation in a weight loss program to employees who voluntarily disclose a family history of diabetes, heart disease, or high blood pressure, and to employees who have a current diagnosis of one of these conditions. [54]

The regulations also provide that they do not limit the rights or protections available under the ADA, other civil rights laws, or the Health Insurance Portability and Accountability Act (HIPAA). For example, an employer must make reasonable accommodations, as required under the ADA to enable a person with a disability to participate in a wellness program.[55]

Information Necessary for Certification Provisions

GINA provides an exception for information necessary for certification procedures under federal and state family and medical leave laws. This exception was described in the House report as "eliminat[ing] the potential for conflict with existing laws."[56] EEOC's final regulations track the statutory provision.[57]

Obtaining Genetic Information from Commercially and Publicly Available Sites

The fourth exception under GINA, like the first, concerns the inadvertent acquisition of genetic information by the purchase of documents, such as newspapers, that are commercially and publicly available and that include family medical history. This exception was intended to address the concern that GINA could be violated by such actions as the purchase of a newspaper "containing the obituary of an employee's parent who died of breast cancer."[58] The EEOC's regulations include electronic media, such as the Internet, television, and movies, as potential sources of genetic information.[59] In its discussion of this exception, the EEOC examines the factors used in deciding whether a document is commercially or publicly available and determines that the key criteria is "whether access requires permission of an individual or is limited to individuals in a particular group, not whether the source is categorized as a social networking site, personal Web site, or blog."[60] The EEOC also notes that the exception does not apply to genetic information gathered by actively searching for genetic information from

[53] 29 C.F.R. §1635.8(b)(2)(ii)(B), 75 FED. REG. 68935 (November 9, 2010).

[54] 29 C.F.R. §1635.8(b)(2)(iii), 75 FED. REG. 68935 (November 9, 2010).

[55] 29 C.F.R. §1635.8(b)(2)(iv), 75 FED. REG. 68936 (November 9, 2010).

[56] H.Rept. 110-28, Part 1 at 38 (March 5, 2007).

[57] 29 C.F.R. §1635.8(b)(3), 75 FED. REG. 68936 (November 9, 2010).

[58] H.Rept. 110-28, Part 1 at 38 (March 5, 2007).

[59] 29 C.F.R. §1635.8(b)(4), 75 FED. REG. 68936 (November 9, 2010).

[60] 75 FED. REG. 68925 (November 9, 2010).

commercially and publicly available sources, or to the acquisition of genetic information from a source likely to contain such information, such as a website that focuses on genetic testing.[61]

Genetic Monitoring of Biological Effects of Toxic Substances

The fifth exception applies when the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace. There are several conditions that must be met prior to applying this exception, including written notice of the monitoring, and knowing and voluntary authorization.[62] At the suggestion of several commenters to the proposed regulation, the EEOC added a provision to the final regulations stating that the covered entity may not retaliate or otherwise discriminate against an individual due to his or her refusal to participate in genetic monitoring that is not required by federal or state law.[63]

DNA Analysis for Law Enforcement Purposes

GINA contains a limited exception which allows employers and training programs that conduct DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification to request or require genetic information from their employees, but only when it is used for analysis of DNA identification markers for quality control to detect sample contamination. The EEOC in its comments to the final regulations notes that this exception is "very limited" and that "if the analysis is properly conducted, an employer or training program would not obtain health-related genetic information."[64]

Inquiries Made of Family Members

The EEOC final regulations provide that a covered entity does not violate GINA or the regulations when it requests or obtains information about a manifested disease of an employee whose family member is an employee for the same employer. The final regulations give the following example: "an employer will not violate this section by asking someone whose sister also works for the employer to take a post-offer medical examination that does not include requests for genetic information."[65]

Medical Examinations Relating to Employment

The prohibition on the acquisition of genetic information also applies to medical examinations relating to employment. The final regulations specifically provide that a covered entity must tell health care providers not to collect genetic information, including family history, during a medical examination relating to employment, and take appropriate action if it learns that genetic

[61] *Id.*

[62] 29 C.F.R. §1635.8(b)(5), 75 FED. REG. 68936 (November 9, 2010).

[63] *Id.*

[64] 75 FED. REG. 68926 (November 9, 2010).

[65] 29 C.F.R. §1635.8(c), 75 FED. REG. 68936 (November 9, 2010).

information is being collected. This action may include no longer using the services of a health care provider.[66]

The EEOC specifically declined to include an exemption that would permit a covered entity to request genetic information in order to evaluate whether an employee or applicant is able to safely and effectively perform the job. The EEOC's discussion of this section observes that the U.S. Customs and Immigration Services asked if there would be an exception allowing a covered entity to collect family medical history, such as a history of psychiatric disability, as part of determining whether to grant or deny a security clearance. The EEOC declined to provide such an exception, noting that there was no such exception in the statutory language or discussed in the legislative history.[67] The lack of a safety exemption may apply to situations such as that reportedly involving professional basketball player Eddy Curry. Mr. Curry was reportedly asked by the Chicago Bulls to take a genetic test to determine if he had hypertropic cardiomyopathy, a condition that can lead to sudden heart failure during exertion.[68] This is in contrast to the ADA as interpreted by the Supreme Court in *Chevron v. Echazabal*,[69] where the Court found no violation of the ADA when an employer refused to hire an individual whose health would be endangered by the job. This issue may become more problematic as genetic information becomes more precise.

Confidentiality

Generally, Title II of GINA requires that genetic information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record, and prohibits a covered entity from disclosing genetic information. These entities are considered to be in compliance with the maintenance of information requirements if the genetic information is treated as a confidential record under §102(d)(3)(B) of the Americans with Disabilities Act. However, the general prohibition on disclosure in GINA is subject to six exceptions, including disclosure to the employee.[70] GINA also contains a provision concerning the relationship of the confidentiality provisions with the HIPAA privacy rule. GINA does not prohibit an entity covered under HIPAA "from any use or disclosure of health information that is authorized for the covered entity under such regulations."[71]

[66] 29 C.F.R. §1635.8(d), 75 FED. REG. 68937 (November 9, 2010).

[67] 75 FED. REG. 68926 (November 9, 2010).

[68] For a discussion of this situation and the use by Major League Baseball of genetic testing to determine the age of potential players see, Rhonda B. Evans, "`Striking Out': The Genetic Information Nondiscrimination Act of 2008 and Title II's Impact on Professional Sports Employers," 11 N. C. J. of Law and Technology 205 (Fall 2009) available at http://jolt.unc.edu/sites/default/files/Evans_Rhonda_v11i1_205_221.pdf. The application of GINA in this situation may turn on whether the condition is considered "manifested." See supra p. 4.

[69] 536 U.S. 73 (2002). But see UAW v. Johnson Controls, Inc., 499 U.S. 187 (1991), where the Court held that under the Civil Rights Act of 1964 employers could not enforce "fetal protection" policies that kept women, whether pregnant or with the potential to become pregnant, from jobs that might endanger a developing fetus. For a more detailed discussion of these cases see CRS Report RL31401, *The Americans with Disabilities Act: Supreme Court Decisions*, by (name redacted).

[70] 42 U.S.C. §12112(d)(3)(B).

[71] *Id.*

The EEOC final regulations track the legislative language.[72] The EEOC in its discussion of the final regulations addresses several concerns raised by commenters. For example, the EEOC states that genetic information that had been placed in a personnel file prior to the effective date of GINA, need not be removed and its existence does not create a violation of GINA. However, disclosing such information to a third party would violate the law.[73]

Enforcement and Remedies

Generally, GINA uses the remedies and enforcement mechanisms available in Title VII of the Civil Rights Act of 1964,[74] although for employees covered by the Government Employee Rights Act of 1991,[75] the Congressional Accountability Act of 1995,[76] chapter 5 of Title 3 of the U.S. Code,[77] or Section 717 of the Civil Rights Act of 1964,[78] the remedies and procedures track those acts and statutory provisions. The final regulations mirror the statutory provisions, and add a specific subsection referencing the remedies applicable to GINA. These include compensatory and punitive damages, reasonable attorneys' fees, and injunctive relief.[79]

Construction

Section 209 of GINA contains several rules of construction, including a provision concerning the relationship between Title I and Title II of the act.[80] GINA provides that nothing in Title II is to be construed to limit the rights or protections of an individual under any federal or state statute that provides equal or greater protection. In addition, nothing in Title II is to limit the rights or protections of an individual to bring an action, or provide for enforcement of, or penalties for, any violation under Title I of GINA, certain sections of ERISA, the Public Health Service Act, and the Internal Revenue Code. This provision has been referred to as a "firewall" between Titles I and II, and has been described as clarifying "that employers are not liable for health insurance violations under civil rights laws unless the employer has separately violated a provision of Title II governing employers."[81]

The final regulations mirror the statutory language and elaborate on the firewall provision. The regulations note that,

> [t]he firewall seeks to ensure that health plan or issuer provisions or actions are addressed and remedied through ERISA, the Public Health Service Act, or the Internal Revenue Code, while actions taken by employers and other GINA Title II covered entities are remedied

[72] 29 C.F.R. §1635.9, 75 FED. REG. 68937 (November 9, 2010).

[73] 75 FED. REG. 68927 (November 9, 2010).

[74] 42 U.S.C. §2000e-4 et seq.

[75] 42 U.S.C. §2000e-16(b) and (c).

[76] 2 U.S.C. §1301 et seq.

[77] 3 U.S.C. §451-454.

[78] 42 U.S.C. § 2000e-16.

[79] 29 C.F.R. §1635.10(b), 75 FED. REG. 68937-68938 (November 9, 2010).

[80] 42 U.S.C. §2000ff-8.

[81] 154 Cong. Rec. H2972 (daily ed. May 1, 2008)(statement of Rep. Dingell).

> through GINA Title II. Employers and other GINA Title II covered entities would remain liable for any of their actions that violate Title II, even where those actions involve access to health benefits, because such benefits are within the definition of compensation, terms, conditions, or privileges of employment. For example, an employer that fires an employee because of anticipated high health claims based on genetic information remains subject to liability under Title II.[82]

The EEOC's discussion of the final regulations also notes that over 30 states have laws concerning genetic discrimination. The EEOC states that it will provide information on these state and local laws on its website.[83]

Medical Information that is not Genetic Information

Section 210 of GINA clarifies that the act does not cover medical information that is not genetic information about a manifested disease, disorder, or pathological condition, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.[84] The final regulations elaborate on the statutory language specifically stating that "the acquisition, use, and disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition is subject to applicable limitations under sections 103(d)(1)-(4) of the Americans with Disabilities Act (42 U.S.C. 12112(d)(1)-(4)), and regulations at 29 CFR 1630.13, 1630.14, and 1630.16."[85]

In its discussion of the final regulations, the EEOC notes that one commenter had expressed concern that individuals who have a manifested genetic disease that is not yet substantially limiting may not be covered under either law. The EEOC declined to address this issue, stating that it had no authority to expand the coverage of GINA. However, the EEOC observed that with the enactment of the ADA Amendments Act (ADAAA),[86] which expanded the definition of disability under the ADA, it is less likely that there would be a significant number of individuals who would not be covered by either act.[87]

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[82] 29 C.F.R. §1635.11(b)(2), 75 FED. REG. 68938 (November 9, 2010).

[83] 75 FED. REG. 68929 (November 9, 2010).

[84] 42 U.S.C. §2000ff-9.

[85] 29 C.F.R. §1635.12, 75 FED. REG. 68939 (November 9, 2010).

[86] P.L. 110-325. For a discussion of the ADAAA see CRS Report RL34691, *The ADA Amendments Act: P.L. 110-325*, by (name redacted).

[87] 75 FED. REG. 68931 (November 9, 2010).

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This report was initially authored by (name redacted)