



by Todd C. Myers

On November 21, 2009, the Genetic Information Nondiscrimination Act of 2008 (GINA) went into effect with the goal of preventing discrimination based on an individual's genetic information.¹ Prior federal anti-discrimination laws, including Title VII of the Civil Rights Act of 1964 (Title VII) and the Americans with Disabilities Act of 1990 (ADA), only prohibit discrimination based upon personal "traits" such as skin color, race, disability, or sex. Although Congress intended that the ADA would prohibit discrimination based upon both extant and inchoate disabilities, genetic abnormalities may never become disabling. Thus, the potential exists for discrimination to occur because someone might develop a disability. Moreover, genetic science was in its infancy when prior anti-discrimination laws were enacted. And far less was understood about how body chemistry dictates human traits, disease, and disabilities.

As genetics developed, Congress also recognized the privacy concerns associated with genetic information and the potential for its misuse. For instance, genetic tests could reveal an employee's (and his or her family member's) predisposition for Huntington's disease or cancer. Not only is this health information intensely private, but this information could be used by an employer to make employment decisions so as to avoid having an employee at a high risk for expensive future medical care. Congress

enacted GINA to protect the confidentiality of this information and to prevent its misuse.

The purpose of this article is to provide an overview of GINA as it applies to employers. The article will begin with a brief review of genetics. Then, the article will discuss the primary aspects of GINA, including a review of its prohibitions and enforcement. Finally, the article will discuss strategies employers must undertake to comply with GINA. Although the article is by no means comprehensive, it should serve to familiarize legal practitioners with GINA, which could enable one to better assist one's clients should an issue arise.

Genetics 101

A basic understanding of the developments in genetics is necessary to fully understand this area of law. To begin with, genetic material is stored in thread-like structures known as chromosomes, which are located in the nucleus of our cells. A human being has twenty-three pairs of chromosomes in every cell, for a total of forty-six chromosomes. These chromosomes hold our genes. Scientifically speaking, genes are units of deoxyribonucleic acid (DNA). A human is made up of an estimated 20,000 to 25,000 genes. Each gene is responsible for a particular trait or function, such as eye color or blood type. Collectively, all of an individual's genes are known as a genome. While genes are responsible for traits, they can also cause serious diseases or conditions when they are defective.²

In 1990, the National Institute of Health and the U.S. Department of Energy embarked on an ambitious effort known as the Human Genome Project (HGP).³ The goal of the HGP was to provide researchers with the ability to find genetic markers to diseases in human DNA, thus giving doctors and researchers the ability to make earlier diagnoses, develop cures, and even prevent certain diseases and conditions.⁴

By 2003, the HGP has fueled the discovery of more than 1,800 disease genes and paved the way for the development of more than 1,000 genetic tests for human conditions.⁵ The National Institute of Health believes that individualized analyses based on each person's genome will lead to powerful forms of preventive, personalized, and preemptive medicine. By tailoring recommendations to each person's DNA, healthcare professionals will be able to work with individuals to focus efforts on the specific strategies.⁶

While these breakthroughs in genetics present obvious opportunities to improve the length and quality of peoples' lives, genetic data also reveal very personal details about individuals, including personal information, biological relationships, and health factors. As a result, public concerns grew about the potential misuse of this information.⁷ To establish a national standard and ease concerns about discrimination that could prevent, or at least deter, individuals from obtaining important testing, Congress enacted GINA, which became effective on November 21, 2009.⁸

Genetic Discrimination

Several genetically related discrimination scenarios can arise that tend to expose an individual to discrimination: (1) abnormal physical traits – height, weight, and size; (2) symptomatic genetic disease; (3) asymptomatic, late-onset genetic disease; (4) asymptomatic genetic predisposition to disease; and (5) the unaffected carrying of the genetic disorder.⁹

Employers may attempt to use

genetic information to weed out applicants and employees with genetic disorders or those at a higher risk of developing certain diseases or conditions. For conditions and diseases that have become symptomatic, the ADA could likely protect them. On the other hand, asymptomatic genetic disorders that could develop later, or simply be passed on to offspring, are not likely covered by the ADA. Genetic testing can provide information to identify these individuals.

GINA

Like Title VII, GINA applies to employers with at least fifteen (15) employees (including state and local governments), labor unions, employment agencies, and training programs.¹⁰ In general, GINA prohibits: (1) discrimination based on employees' genetic information; (2) acquiring employees' genetic information; and (3) disseminating employees' genetic information.¹¹

A. "Genetic Information" Defined

GINA defines the term "genetic information" broadly to include "genetic test" results and "genetic services."¹² GINA defines "genetic test" as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes."¹³ As such, there are a myriad of medical tests that fall under this definition. The term "genetic information" also includes any "manifestation of a disease or disorder" in the employee's family members.¹⁴ Thus, information about an individual's family's medical history, frequently used to determine whether an individual is predisposed to developing a disease, disorder, or medical condition (such as Huntington's disease or Lou Gehrig's disease) is included. "Genetic services" are defined as "genetic tests, genetic counseling, or genetic education."¹⁵

GINA defines "family member" expansively, to include an individual's dependents and up to fourth-degree relatives.¹⁶ Information about a member's age or gender, however, is expressly excluded from the definition of "genetic

information" under GINA.¹⁷ The Equal Employment Opportunity Commission (EEOC) has stated in proposed regulations that routine tests, such as blood counts, cholesterol tests, and liver function tests, are not "genetic tests" under GINA.¹⁸ In addition, while testing an individual's *predisposition* for alcoholism or drug use constitutes a "genetic test," testing for the *presence* of drugs and alcohol does not constitute a "genetic test."¹⁹

In the proposed EEOC regulations, the EEOC has recognized that the subject-matter of GINA is beyond the scope of its expertise. As a result, the EEOC has invited comment by those with such expertise regarding the interpretation of these definitions.²⁰

B. Prohibited Conduct

1. Discrimination, Harassment, and Retaliation

As discussed above, GINA prohibits discrimination with respect to hiring, discharge, or with respect to compensation, terms, or privileges of employment based on genetic information, including testing, counseling, and services.²¹ Second, GINA makes it unlawful for employers to acquire genetic information about an employee or an employee's family member, except under limited circumstances.²² Third, employers who acquire or possess genetic information about an employee are required to treat the genetic information as part of a confidential medical record and maintain it separately, just as with medical records obtained under the ADA.²³ Employers may only disclose the information with the employee's written consent or in other limited circumstances.

The anti-discrimination provision prohibits the use of genetic information in making determinations as to the "terms, conditions, or privileges" of employment.²⁴ The prohibition prohibits treatment of employees motivated by their genetics, such as in terms of hiring, firing, job assignments, promotions, pay, fringe benefits, or any other terms.²⁵ Under GINA, this includes negatively limiting, segregating, or

classifying employees because of genetic information.²⁶ The prohibition extends beyond the results of genetic tests, and includes discrimination based on the fact that the employee has sought genetic counseling or services.²⁷ GINA likewise prohibits workplace harassment based upon genetic information of an employee or family member.²⁸ This could include hostile work environment claims in which employees are subjected to unwanted and offensive conduct by supervisors or other co-workers. Finally, GINA contains an anti-retaliation provision similar to Title VII.²⁹ The EEOC's proposed regulations state that retaliation claims under GINA will be analyzed under the same standard as Title VII retaliation claims.³⁰ Thus, *Burlington Northern & Santa Fe Railway Co. v. White*, 548 U.S. 53 (2006), will apply. In *Burlington*, the Court held that the anti-retaliation provision protects an individual from conduct, whether related to employment or not, that a reasonable person would find "materially adverse," meaning that the action "well might have 'dissuaded a reasonable worker from making or supporting a charge of discrimination.'"³¹

2. Acquisition of Genetic Information

GINA prohibits employers from acquiring genetic information about applicants, employees, or their family members.³² It prohibits employers from intentionally acquiring this information either by requesting or requiring genetic information from applicants, employees, or other individuals, or even by purchasing it from outside sources.³³ GINA has a few narrow exceptions to legal liability for employers.³⁴ These exceptions include requesting, requiring, or acquiring genetic information: (1) inadvertently; (2) through health or genetic services offered to employees as part of a wellness program; (3) in compliance with the Family and Medical Leave Act (FMLA) (or similar state law) certification requirements; (4) through commercially or publicly available sources; (5) through genetic monitoring

of the biological effects of toxic substances in the workplace; and (6) for law enforcement purposes.³⁵

One exception worthy of special attention is that for the inadvertent acquisition of genetic information.³⁶ According to the EEOC, this exception may be triggered, for example, when a supervisor overhears a casual conversation between co-workers in which family medical history is discussed or asks an employee a general question in a casual conversation about the health of a family member.³⁷ This exception also applies when genetic information is provided to the employer by the employee in support of a request for an accommodation under the ADA, or when an employer asks for medical information in response to an individual's request for leave pursuant to a leave policy independent of a state or federal leave or disability law, as long as the employer's request or requirement is reasonably tailored to the particular impairment for which leave has been requested.³⁸ Still, the information cannot be the basis for a decision and any decision made after the employer has certain genetic information may be questioned.³⁹

Another important point that should be made is that the EEOC is in the process of deciding whether personal websites and/or social networking sites fall within the scope of "publicly available information."⁴⁰ If these sites are not included in this exclusion, GINA could subject employers to liability for possessing information learned through these sites. This could be particularly difficult with respect to employees who "connect" with co-workers on social networking sites such as *Facebook* or *MySpace*. Care must also be exercised regarding background checks through the use of these types of sites. As genetic information could be potentially anywhere, any negative employment decisions made after learning of such information could call the motivation of the employer into question.

3. Confidentiality

GINA prohibits employers from disclosing any genetic information

obtained about applicants, employees, or family members once in the possession of the employer.⁴¹ There are limited exceptions for compliance with court orders or government investigations.⁴² Any genetic information must be treated like all medical information so as to be kept in a separate file limiting access to only essential employees with a need to have the information for clearly defined business purposes.⁴³

C. Enforcement

1. Administrative Enforcement

The EEOC is responsible for the enforcement of Title II of GINA.⁴⁴ Accordingly, employees who believe they have been subjected to genetic discrimination in violation of GINA must file a charge of discrimination with the EEOC within 180 days of the alleged discriminatory act as an initial step to obtaining relief.⁴⁵ The date of the alleged discriminatory act is generally held to be the date an employee is made aware of a decision involving the employee, and not when the decision

takes effect.⁴⁶ Like a Title VII claim, the EEOC will investigate and attempt to conciliate. If that does not work, the EEOC will issue a "right to sue" letter, giving the employee the right to file a private lawsuit.

2. Prima Facie Case

At this point, it has yet to be determined how courts would consider lawsuits from a proof standpoint. Most attorneys who practice in this area of law are well familiar with the *McDonnell Douglas Corp. v. Green* burden-shifting framework for bringing Title VII cases hinging on circumstantial or indirect evidence.⁴⁷ Under *McDonnell Douglas*, the plaintiff bears the initial burden of presenting a prima facie case. The burden then shifts to the employer to articulate a non-discriminatory reason for the adverse employment decision. Finally, the burden shifts back to the employee to prove that the employer's articulated reason was merely pretext.

The language of 42 U.S.C. § 2000e-

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2(m) in Title VII establishes that, in “mixed-motive” cases, consideration of the employee’s protected status need only be a “motivating factor” even if other non-discriminatory motivations played a role in the decision. The U.S. Supreme Court in *Desert Palace, Inc. v. Costa* abandoned the *McDonnell Douglas* framework in mixed-motive cases, based on the language of the statute.⁴⁸ However, the language found in 42 U.S.C. § 2000e-2(m) is not found in GINA. As a result, it is difficult to determine whether a mixed-motive GINA case would be viable and under what standard the Court would review it.

Next, it is possible that certain GINA claims based on family members’ genetic information would be more properly analyzed like association discrimination claims under the ADA.⁴⁹ It has been suggested that association claims under the ADA are not amenable to the *McDonnell Douglas* framework.⁵⁰

Finally, GINA specifically prohibits claims for discrimination based upon

disparate impact.⁵¹ Therefore, it appears that employees will only be able to bring claims for disparate treatment under GINA.

3. First GINA Claim

In late April 2010, a Fairfield, Connecticut woman, Pamela Fink, filed claims with the EEOC and the Connecticut Commission on Human Rights and Opportunities alleging that her employer violated GINA when it terminated her employment on March 25, 2010. According to ABC News, after genetic tests and family history indicated Ms. Fink was at risk for breast cancer, she underwent a preemptive double mastectomy.⁵² She alleges that her termination, which occurred approximately five months after her procedure, was the result of her informing her employer of her genetic test results that showed she carried the BRCA2 gene.

Her complaint is believed to be the first in the country brought under the employment provisions of GINA. It will

be watched closely as employers begin to understand the scope of protections for employees under this new law.

D. Available Relief

Reliefs for complainants include rehiring/reinstatement, or other equitable relief, as well as the issuance of injunctions preventing the employer from engaging in further discriminatory practices.⁵³ This relief includes the imposition of compensatory and punitive damages.⁵⁴ Compensatory damages for future pecuniary loss, emotional pain, suffering, inconvenience, mental anguish, and loss of enjoyment of life, as well as punitive damages, are limited to a fixed dollar amount based on the number of employees the employer has.⁵⁵ The maximum damages cap is \$300,000.⁵⁶ GINA also includes the right to a jury trial.⁵⁷

E. Employer Compliance

GINA is full of potential pitfalls for employers. It will be essential that employers train their administrative staff, hiring personnel, and benefits personnel regarding the obligations created by GINA. Employers that offer health insurance are likely to possess family history information in personnel records. Employers should review personnel files and purge them of all information that could be considered “genetic information.” Necessary medical records must be kept separate from personnel files. These would include medical records and family histories. All performance and conduct review procedures should be reviewed to ensure that genetic information is not requested or contained therein. This would include mention of family health problems that could be linked to genetic information. Finally, employers should update their policy manual records to ensure compliance with GINA.

Finally, GINA has a posting requirement. To comply with the law, employers may post the EEOC’s November 2009 version of the “EEO is the Law” poster, or, in the alternative, post the “EEO is the Law” supplement next to their current poster.⁵⁸

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Conclusion

GINA is an important new law of which employers must become familiar. As discussed above, GINA has many traps by which unwary employers can find themselves in difficult situations. Since the law and science upon which GINA is based are new, it will be essential for employers and their lawyers to stay abreast of developments to ensure compliance. ①

ENDNOTES

1. 42 U.S.C. §§ 2000ff *et seq.*
2. William J. McDavitt, *I Dream of GINA: Understanding the Employment Provisions of the Genetic Information Nondiscrimination Act of 2008*, 54 VILL. L. REV. 91 (2009).
3. NAT'L INST. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., HUMAN GENOME PROJECT: FACT SHEET.
4. *Id.*
5. *Id.*



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6. *Id.*
7. See S. Rep. No. 110-48 at 1, 6-8 (2007).
8. *Id.*
9. Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 39-52 (1992).
10. 42 U.S.C. §§ 2000ff(2)(B), 2000e(b), 2000e-16(a), 2000e-16c(a); 2 U.S.C. § 1301; 3 U.S.C. § 411.
11. 42 U.S.C. §§ 2000ff-1-2000ff-5.
12. *Id.* § 2000ff(4).
13. *Id.* § 2000ff(7).
14. *Id.* § 2000ff(4).
15. *Id.* § 2000ff(6).
16. *Id.* § 2000ff(3).
17. *Id.* § 2000ff(4)(C).
18. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9059 (proposed Mar. 2, 2009) (to be codified at 29 CFR § 1635).
19. *Id.*
20. *Id.* at 9056.
21. 42 U.S.C. §§ 2000ff-1-2000ff-4.
22. *Id.*
23. *Id.* § 2000ff-5.
24. *Id.* § 2000ff-1.
25. See *id.*
26. *Id.* § 2000ff-2.
27. *Id.* § 2000ff-1.
28. See EQUAL EMPLOYMENT OPPORTUNITY COMM'N, BACKGROUND INFORMATION FOR EEOC NOTICE OF PROPOSED RULEMAKING ON TITLE II OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 2 (2009), http://www.eeoc.gov/policy/docs/quanda_geneticinfo.html.
29. 42 U.S.C. § 2000ff-6(f).
30. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9060-61 (proposed Mar. 2, 2009) (to be codified at 29 CFR § 1635).
31. *Burlington Northern & Santa Fe Ry. Co. v. White*, 548 U.S. 53, 68 (2006) (quoting *Rochon v. Gonzales*, 438 F.3d 1211, 1219 (D.C. Cir. 2006)).
32. 42 U.S.C. § 2000ff-1-2000ff-4.
33. *Id.*
34. *Id.*
35. *Id.*
36. *Id.*
37. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9061 (proposed Mar. 2, 2009) (to be codified at 29 CFR § 1635).
38. *Id.* at 9061-64.
39. *Id.* at 9057, 9059, 9060.
40. *Id.* at 9063.
41. 42 U.S.C. § 2000ff-5.
42. *Id.* § 2000ff-5(b).
43. *Id.* § 2000ff-5(a).
44. *Id.* § 2000ff-6.
45. *Id.* (incorporating powers and remedies in Title VII).
46. See, e.g., *Mull v. ARCO Durethene Plastics, Inc.*, 784 F.2d 284 (7th Cir. 1986) (interpreting the Age Discrimination in Employment Act); *Stoller v. Marsh*, 682 F.2d 971 (D.C. Cir. 1982) (interpreting Title VII). It is quite reasonable to expect GINA to be interpreted in the same fashion as these other antidiscrimination statutes.
47. *McDonnell Douglas Corp. v. Green*, 411 U.S. 792 (1973).
48. *Desert Palace, Inc. v. Costa*, 539 U.S. 90 (2003).
49. 42 U.S.C. § 12112(b)(4).
50. See *Dewitt v. Proctor Hosp.*, 517 F.3d 944 (7th Cir. 2008) (suggesting the *McDonnell Douglas* framework should be tweaked to allow evidence of economic motive in plaintiff's prima facie case).
51. 42 U.S.C. § 2000ff-7.
52. Emily Friedman, *Pamela Fink Says She Was Fired After Getting a Double Mastectomy To Prevent Breast Cancer*, ABC NEWS, Apr. 30, 2010, <http://abcnews.go.com/Health/OnCallPlusBreastCancerNews/pamela-fink-fired-testing-positive-breast-cancer-gene/story?id=10510163>
53. 42 U.S.C. § 2000ff-6; *Id.* § 2000e *et seq.*
54. *Id.* § 2000ff-6; *Id.* § 1981a.
55. *Id.*
56. *Id.*
57. *Id.*
58. Both documents are available at <http://www1.eeoc.gov/employers/poster.cfm>.