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GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008: IT'S IN TITLE VII'S GENES

INTRODUCTION

As medical advances in the United States and throughout the world have progressed in regards to the human genome, individuals have become increasingly able to obtain new forms of personal information about themselves, most notably whether or not they possess genetic predispositions to certain diseases.¹ Tests to acquire this type of information have become less costly and more accessible to the general public and therefore individuals are more likely to undergo such testing.² In spite of the many benefits of having genetic testing done,³ the number of Americans taking advantage of such tests seems to have decreased in recent years.⁴ Health experts believe this may be due to public fear of genetic discrimination by employers and health insurance providers.⁵ Indeed, employers have a substantial interest in obtaining genetic information so that they can sort out individuals who are genetically predisposed to certain diseases, as employing such individuals would expose them to a higher risk of incurring high healthcare costs.⁶

1. James Sharpe, *Promises and Problems of Genetic Testing*, ROCK PRODUCTS (Apr. 1, 2007), <http://www.rockproducts.com/index.php/features/51-archives/6329.html> (“[T]oday there are genetic tests for almost 1,000 diseases and several hundred more are under development”).

2. See *Frequently Asked Questions About Genetic Testing*, NAT’L HUMAN GENOME RESEARCH INST., <http://www.genome.gov/19516567> (last visited Dec. 28, 2011) (noting that direct-to-consumer genetic tests are available that allow individuals to scrape a few cells from the inside of their cheeks and mail the samples to a laboratory that performs genetic testing to detect whether the individual is at risk of developing certain diseases).

3. See *What are the Benefits of Genetic Testing?*, GENETICS HOME REFERENCE (Dec. 27, 2011), <http://ghr.nlm.nih.gov/handbook/testing/benefits>. The benefits of genetic testing include providing people with a sense of release from uncertainty, helping people make informed decisions about their healthcare, identifying genetic disorders so that treatment can begin as early as possible, and helping people make decisions about having children. *Id.*

4. Catharine Paddock, *Fear Of Genetic Discrimination Fuelling Fall in DNA Testing*, MED. NEWS TODAY (Feb. 25, 2008), <http://www.medicalnewstoday.com/articles/98427.php>.

5. *Id.*

6. See Dep’t of Labor, *Genetic Information and the Workplace*, NAT’L HUMAN GENOME RESEARCH INST. (Jan. 20, 1998), <http://www.genome.gov/10001732> (“Based on genetic

Despite the lack of empirical evidence that a large number of employers are discriminating on the basis of genetic information, the United States has adopted new federal laws to protect this rapidly increasing range of private information.⁷ On May 21, 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act ("GINA") into law in an effort to protect employees from various forms of genetic discrimination by their employers.⁸

This note analyzes GINA, explains why such a law is necessary, and attempts to predict how the courts will handle claims of genetic discrimination brought under GINA. Part I provides background information on the legislative purpose behind GINA, discusses criticisms of the Act, describes the process of bringing a claim under GINA, and outlines remedies available to litigants. Part II examines the effect GINA will have on both employers and employees. This section explores avenues of litigation created by GINA, possible difficulties for employees in proving discrimination based on genetic information, and new measures that employers will have to take to avoid violating GINA. Part III surveys state laws designed to protect individuals from genetic discrimination and compares these laws to GINA. Part IV examines different international laws and agreements that are designed to prevent discrimination based on genetic information. The prevalence of such laws is a strong indication that GINA is necessary legislation. Part V analyzes a possible framework for the *prima facie* case and burden shifting structure for GINA claims, predicated upon Title VII of the Civil Rights Act of 1964 ("Title VII")⁹ and the Americans with Disabilities Act of 1990 ("ADA").¹⁰ The comparison to Title VII reviews the framework of discrimination claims premised on race, sex, religion, and national origin. The authors proffer a *prima facie* structure for cases brought under GINA. The ADA comparison argues that defendants (employers) under GINA ought to be afforded the ADA

information, employers may try to avoid hiring workers who they believe are likely to take sick leave, resign, or retire early for health reasons (creating extra costs in recruiting and training new staff), file for workers' compensation, or use healthcare benefits excessively").

7. See Pauline T. Kim, *Regulating the Use of Genetic Information: Perspectives From the U.S. Experience*, 31 COMP. LAB. L. & POL'Y J. 693, 696 (2010).

8. Dep't of Health & Human Servs., "GINA" *The Genetic Nondiscrimination Act of 2008: Information for Researchers and Health Care Professionals*, NAT'L HUMAN GENOME RESEARCH INST. (Apr. 6, 2009), <http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf>.

9. See generally Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e-2000e-17 (2006).

10. See generally Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12103, 12111-12117 (2006).

defense of “threat-to-self.”¹¹ Part VI concludes the note by applying the proposed GINA framework to a genetic discrimination complaint that was recently filed with the Equal Employment Opportunity Commission (“EEOC”).¹²

I. AN INTRODUCTION TO GINA: LEGISLATIVE PURPOSE, CRITICISMS, AND THE PROCESS OF BRINGING A CLAIM UNDER GINA

A “13-year odyssey” ended in May 2008 when Congress passed GINA, a bill that Congresswoman Louise Slaughter from New York’s 28th Congressional District first proposed in 1995.¹³ Congress passed GINA in an effort to establish a “national and uniform basic standard” of protection against occurrences of genetic discrimination by employers and health insurance providers.¹⁴ Because of the lack of evidence indicating a significant history of instances of genetic discrimination, GINA is predominately a preemptive form of protection intended to prevent a type of discrimination that may pose a greater threat in the future.¹⁵ This section of the note begins with a look at the legislative purpose behind GINA. Next, some of the criticisms of the young law are introduced. Finally, the process of bringing a claim under GINA is explained, along with the potential remedies available to prevailing plaintiffs.

A. Legislative Purpose

Genetic testing is a major advancement in health sciences and “is an invaluable tool because the information derived from these types of tests facilitates the diagnosis and confirmation of diseases.”¹⁶ If a genetic predisposition to a disease is discovered early enough, such

11. See 29 C.F.R. § 1630.15(b)(2) (2010).

12. See Steven Greenhouse, *Ex-Worker Says Her Firing Was Based on Genetic Test*, N.Y. TIMES, Apr. 30, 2010, <http://www.nytimes.com/2010/05/01/us/01gene.html>.

13. See Andrew Pollack, *Congress Near Deal on Genetic Test Bias Bill*, N.Y. TIMES, Apr. 23, 2008, <http://www.nytimes.com/2008/04/23/business/23gene.html?pagewanted=1>.

14. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, §2(5), 122 Stat. 881, 882-83 (2008).

15. Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 441 (2010).

16. See Amy Foster, Comment, *Critical Dilemmas in Genetic Testing: Why Regulations to Protect the Confidentiality of Genetic Information Should be Expanded*, 62 BAYLOR L. REV. 537, 540 (2010).

disease may be effectively managed or possibly even prevented.¹⁷ The first genetic test developed was designed to detect Huntington's Disease ("HD"), a severe genetic disorder that causes people to lose control over their mind and body as they grow older.¹⁸ Discovering that one carries the HD genetic mutation would be beneficial to the health of both the individual and their family, who may also have inherited the gene. But imagine that because a person carries this gene, he or she is fired from their job, or that his or her adult son or daughter is denied health insurance. This situation happened to Phil Hardt, a man who discovered that he carried the HD genetic mutation, and whose daughter was denied health insurance as a result of this discovery.¹⁹ Situations of genetic discrimination like this actually arise, and if such discrimination is not controlled, it may overshadow the benefits of having genetic testing done.

GINA was enacted to prevent occurrences of genetic discrimination and to encourage individuals to take advantage of genetic testing "without fearing that this information will be misused or abused."²⁰ Senator Edward M. Kennedy stated that GINA "opens [the] door to modern medical progress for millions and millions of Americans."²¹ The more people who take advantage of available genetic tests, the larger the data pool will be from which researchers can conduct studies and improve on the accuracy and other aspects of genetic testing.²² Under Title I, group health plans and health insurance issuers offering group health insurance coverage in connection with a group health plan may not establish rules of eligibility or adjust premium amounts for an individual on the basis of genetic information.²³ Under Title II, employers may not discharge, refuse to hire, or "otherwise . . .

17. See *id.*; cf. Allison Ito, *Privacy and Genetics: Protecting Genetic Test Results in Hawai'i*, 25 U. HAW. L. REV. 449, 455 (2003) ("Genetic testing is limited by the uncertainty of disease manifestation, misinterpretation, and low clinical sensitivity rates. These limitations mean that genetic test results cannot always provide a complete and accurate picture of an individual's future health").

18. Foster, *supra* note 16, at 537.

19. *Id.* at 537-38.

20. Press Release, U.S. Senate Comm. on Health, Educ., Labor, & Pensions, Kennedy, Enzi, Snowe Celebrate Passage of Genetic Information Nondiscrimination Act (Apr. 24, 2008), available at <http://help.senate.gov/newsroom/press/release/?id=313bfde8-f967-46b4-aa9d-11bc73728813&groups=Chair> (quoting a statement made by Senator Mike Enzi regarding the passage of GINA).

21. *Id.*

22. See Joanne Barken, *Judging GINA: Does the Genetic Nondiscrimination Act of 2008 Offer Adequate Protection?*, 75 BROOK. L. REV. 545, 546 (2009).

23. See Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. § 300gg-53(a)-(b) (Supp. II 2009).

discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee” based on the employee’s genetic information.²⁴ GINA also makes it unlawful for employers and health insurance providers to request or require that an individual or employee undergo a genetic test, and it further prohibits employers from purchasing genetic information about their employees.²⁵ “Genetic information” is defined under the Act as: (1) an “individual’s genetic tests,” (2) “the genetic tests of family members,” and (3) “the manifestation of a disease or disorder in family members.”²⁶

On November 9, 2010, the EEOC issued a final rule to implement Title II of GINA, which became effective on January 10, 2011.²⁷ The stated goal of the Commission in creating the rule was to “implement the various provisions of Title II consistent with Congress’s intent, to provide some additional clarification of those provisions, and to explain more fully those sections where Congress incorporated by reference provisions from other statutes.”²⁸ In addition, the EEOC recognized that GINA dealt with many scientifically technical terms that were “outside the areas of its expertise.”²⁹ For this reason, the EEOC obtained assistance from the National Human Genome Research Institute in developing definitions for such terms.³⁰

B. Criticisms of GINA

The passage of GINA has met mixed reviews regarding both whether there is a need for a law against genetic discrimination and whether GINA will adequately prevent genetic discrimination from occurring. Some groups representing businesses argue that GINA is an “unnecessary and costly burden on employers,” pointing to the lack of cases brought under state genetic discrimination laws to support their

24. *See id.* § 2000ff-1(a)(1).

25. *Id.* §§ 300gg-53(d)(1), 2000ff-1(b). There are certain exceptions where healthcare providers or employers may obtain genetic information about individuals or employees. *See* discussion *infra* Part II.B.

26. 42 U.S.C. § 2000ff(4)(A)(i)-(iii).

27. Regulations under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635).

28. *Id.* at 68,913. For example, the regulation expands on GINA section 201(2)(A)(i), which defines “employee” by referring the reader to Title VII of the Civil Rights Act of 1964, as well as to other statutes, by importing language from these documents into the text of the regulation so that individuals will not have to refer to other sources when reading the regulation. *Id.*

29. *Id.*

30. *Id.* at 68,913-14. Examples of scientifically technical terms used in GINA include “DNA,” “RNA,” and “chromosome.” *See id.* at 68,913.

argument.³¹ Michael J. Eastman, Executive Director for Labor Policy at the U.S. Chamber of Commerce, stated that the Act may be “a solution in search of a problem.”³² Many of GINA’s adversaries maintain that fear of genetic discrimination becoming a problem in the future does not justify the passage of an antidiscrimination statute because such fear is unfounded.³³ These critics support their argument by stating that there are no indications that employers and health insurers would discriminate on the basis of genetic information if presented with the opportunity.³⁴

Other opponents of GINA complain that its protections are applicable in too narrow a group of circumstances, thus leaving people unprotected in many situations in which genetic discrimination may occur.³⁵ For example, life and long-term care insurances are not covered under the Act.³⁶ Therefore, it seems that providers of these services are still free to require their current and prospective members to have genetic testing done and to discriminate against these individuals on the basis of genetic information.³⁷

GINA also does not protect members of the military.³⁸ Thus, military organizations are able to engage in potentially discriminatory practices, such as the practice contested in *Mayfield v. Dalton*.³⁹ The plaintiffs in *Mayfield* filed an action when they were on active duty in the Marine Corps.⁴⁰ Their claim challenged the constitutionality of a Department of Defense program that required all members of the armed forces to provide a DNA sample.⁴¹ In support of their claim, the plaintiffs expressed the fear “that information obtained from the repository samples, regarding the donors’ propensities for hereditary diseases and genetic disorders, might be used to discriminate against applicants for jobs, insurance or benefit programs.”⁴² The United States District Court for the District of Hawai’i granted summary judgment for the government in the suit, finding the plaintiffs’ fears to be too

31. Pollack, *supra* note 13.

32. *Id.*

33. Roberts, *supra* note 15, at 480.

34. *Id.*

35. See Barken, *supra* note 22, at 572-74.

36. Perry W. Payne, Jr., *Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination*, 5 SUFFOLK U. L. SCH. J. HEALTH & BIOMEDICAL L. 33, 58 (2009).

37. See Barken, *supra* note 22, at 573; Payne, *supra* note 36, at 58.

38. Barken, *supra* note 22, at 573.

39. 109 F.3d 1423 (9th Cir. 1997).

40. *Id.* at 1424.

41. See *id.*

42. *Id.*

hypothetical to present a judicable case or controversy.⁴³ Although this case was decided before the passage of GINA, the outcome would likely be the same today because the provisions of GINA do not apply to members of the military.⁴⁴

Other critics of GINA point out that the Act fails to protect individuals who express immutable characteristics “that may indicate a likelihood of developing an illness in the future.”⁴⁵ These immutable characteristics, such as abnormalities found during a colonoscopy or high cholesterol levels found during a cholesterol test, are not considered “genetic information” under GINA and thus may still be a basis for discrimination by employers or health insurance carriers.⁴⁶ Therefore, people who display manifestations of certain diseases or disorders but have not yet developed such diseases or disorders are in an unprotected limbo between the prohibition of genetic discrimination provided by GINA and the prohibition of discrimination against individuals with disabilities provided by the ADA.⁴⁷

C. The Process of Bringing a Claim and the Available Remedies under GINA

GINA's enforcement and damages provisions are mostly drawn from pre-existing federal employment laws including Title VII of the Civil Rights Act of 1964, the Government Employee Rights Act of 1991, and the Congressional Accountability Act of 1995.⁴⁸ Like in cases brought under Title VII and the ADA, a plaintiff who wishes to bring a suit under GINA is required to first “exhaust all administrative remedies.”⁴⁹ This involves filing a charge with the EEOC, which will investigate and either attempt to settle the charge before bringing an action on the aggrieved party's behalf or issue a right-to-sue letter that allows the individual to bring a private action.⁵⁰

43. *Mayfield v. Dalton*, 901 F. Supp. 300, 304 (D. Haw. 1995).

44. *See Barken*, *supra* note 22, at 573.

45. *Id.* at 573-74.

46. *Id.*; *see* Amy L. McGuire & Mary Anderlik Majumder, *Two Cheers for GINA?*, *GENOME MED.* (Jan. 20, 2009), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2651591/pdf/gm6.pdf>.

47. *See generally* Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12103, 12111-12117 (2006).

48. *See* Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. § 2000ff-6(a)-(e) (Supp. II 2009).

49. *Barken*, *supra* note 22, at 575.

50. Kevin P. McGowan, *Employer Advocates Remain Wary of New Bias Law's Potential Effects*, *BNA DAILY LAB. REP.* (May 22, 2008), <http://emlawcenter.bna.com/pic2/em.nsf/id/BNAP-7KMKU9?>.

Unlike under Title VII, there is no cause of action for “disparate impact” claims under GINA.⁵¹ As first explained by the Supreme Court in *Griggs v. Duke Power Co.*,⁵² a cause of action under the disparate impact provision of Title VII includes “not only overt discrimination but also practices that are fair in form, but discriminatory in operation.”⁵³ Therefore, proof that specific employer practices have a disparate impact on individuals with similar genetic information is not enough to establish a cause of action under GINA.⁵⁴ A plaintiff who wishes to bring a claim under GINA must allege specific instances where the employer intentionally discriminated against him or her on the basis of his or her genetic information.⁵⁵ If a plaintiff prevails, he or she may recover both compensatory and punitive damages under GINA. The total amount recoverable is capped based on the number of employees working for the defendant employer.⁵⁶ GINA also prohibits employer retaliation against any employee who “made a charge, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing under this chapter.”⁵⁷

II. APPLICATION OF GINA

GINA affords employees protection from any form of discrimination by employers on the basis of genetic information. To achieve this objective, GINA indirectly places additional burdens on employers. This section first addresses how employees can use GINA to

51. 42 U.S.C. § 2000ff-7(a).

52. 401 U.S. 424 (1971).

53. *Id.* at 431. The Court further noted that “good intent or absence of discriminatory intent does not redeem employment procedures or testing mechanisms that operate as ‘built-in headwinds’ for minority groups and are unrelated to measuring job capability.” *Id.* at 432.

54. See 42 U.S.C. § 2000ff-7(a). See also McGowan, *supra* note 50 (“Instead, the act provides that six years after enactment, Congress will appoint an eight-member commission to review the developing science of genetics and make recommendations on whether to add liability for neutral employment practices that may have an adverse impact against individuals based on genetic information”).

55. See 42 U.S.C. § 2000ff-1, 2000ff-7. See also discussion *infra* Part II.A.

56. See 42 U.S.C. § 2000ff-6(3); 42 U.S.C. § 1981a(b)(3). For example, if the employer has more than 500 employees, the complaining party can recover up to \$300,000; whereas if the employer has more than 200 but less than 501 employees, the complainant can only recover up to \$200,000. 42 U.S.C. § 1981a(b)(3). A plaintiff may also seek equitable relief in the form of future and back pay and, in addition, a successful plaintiff may obtain attorney’s fees. Erin Murphy Hillstrom, Comment, *May an Employer Require Employees to Wear “Genes” in the Workplace? An Exploration of Title II of the Genetic Information Nondiscrimination Act of 2008*, 26 J. MARSHALL J. COMPUTER & INFO. L. 501, 533 (2009); see also 42 U.S.C. § 1988(b) (2006).

57. 42 U.S.C. § 2000ff-6(f).

redress employer discrimination on the basis of genetic information. Then, we discuss the additional burdens that the provisions of GINA place on employers.

A. GINA's Effect on Employees in the Workplace

GINA resembles the seminal employment discrimination statutes in multiple ways. The statute extends protection not only to individuals currently employed, but also protects prospective employees and applicants.⁵⁸ Coverage and protection to applicants and prospective employees is in line with the Civil Rights Act of 1964,⁵⁹ the Age Discrimination in Employment Act of 1967 (ADEA),⁶⁰ and the Americans with Disabilities Act of 1990 (ADA).⁶¹ Thus, placing responsibility on employers to abide by federal provisions in regards to potential employees is nothing new, and is historically supported.

The largest effect on employees will likely come in the form of litigation; under GINA, litigants now have a statutory right against genetic discrimination.⁶² In the past, plaintiffs claiming employment discrimination based on genetic information would be forced to use an indirect line of legal argumentation. Litigants claiming discrimination based on genetic information were forced to make a Fourteenth Amendment due process argument.⁶³ A direct statutory claim could have been extremely advantageous to these plaintiffs. One example of such a situation arose in the case of *Fleming v. State University of New York*, in which an anesthesiologist who was suffering from sickle cell anemia was denied a job opportunity.⁶⁴ In *Fleming*, the reason for the rescission of the plaintiff's job offer was due entirely to an improper disclosure by a doctor at the State University of New York (SUNY) Health Science Center at Brooklyn.⁶⁵ The court ultimately agreed with the plaintiff, holding that the disclosure of his sickle cell anemia was in

58. 42 U.S.C. § 2000ff-4(a)(2).

59. Compare *id.* with Civil Rights Act of 1964, 42 U.S.C. § 2000e-2(a)(1) (2006).

60. Compare 42 U.S.C. § 2000ff-4(a)(2) with Age Discrimination in Employment Act of 1967, 29 U.S.C. § 623(a)(1) (2006).

61. Compare 42 U.S.C. § 2000ff-4(a)(2) with Americans with Disabilities Act of 1990, 42 U.S.C. § 12112(a) (2006).

62. 42 U.S.C. § 2000ff-1 (Supp. II 2009).

63. See, e.g., *Fleming v. State Univ. of N.Y.*, 502 F. Supp. 2d 324, 327 (E.D.N.Y. 2007).

64. See *id.*

65. *Id.* at 326-37. Although the exact factual situation in this case would not be covered by GINA, had the disclosure been of plaintiff's genetic predisposition to sickle cell anemia rather than his actual manifestation of the disease, the cause of action for his predisposition would have been protected.

violation of the Fourteenth Amendment's protection of medical confidentiality.⁶⁶ Though the issue was not novel to the court, it required the plaintiff to prove a constitutional protection rather than a direct statutory right.⁶⁷ Thus, in cases where no such constitutional violation is found, GINA is not a solution in search of a problem, but an effective form of redress for a harmed individual.⁶⁸ With the passage of GINA, litigants are now afforded a direct claim in combating employment and insurance discrimination based on genetic information.⁶⁹

The largest difference between GINA and the other employment discrimination statutes lies in the legal realm of disparate impact. GINA specifically states that a disparate impact cause of action does not exist within the statute.⁷⁰ Disparate impact under Title VII is an unlawful employment practice where:

[A] complaining party demonstrates that a respondent uses a particular employment practice that causes a disparate impact on the basis of race, color, religion, sex, or national origin and the respondent fails to demonstrate that the challenged practice is job related for the position in question and consistent with business necessity.⁷¹

The legal rationale behind disparate impact is that discrimination statutes were intended to protect individuals "not only [from] overt discrimination but also practices that are fair in form, but discriminatory in operation."⁷²

A disparate impact cause of action is available to plaintiffs trying to prove a systemic deficiency in a particular employment practice of the employer.⁷³ A disparate impact claim is made by a plaintiff upon a "showing that the employer 'uses a particular employment practice that causes a disparate impact' on one of the prohibited bases" provided by statute.⁷⁴ Thus the lack of a disparate impact cause of action under GINA forces plaintiffs to rely on the proof structure of disparate

66. *Id.* at 343.

67. *See id.* at 345.

68. *Contra* Pollack, *supra* note 13.

69. 42 U.S.C. § 2000ff-1(a) (Supp. II 2009).

70. *Id.* § 2000ff-7(a). The act does provide for the Genetic Nondiscrimination Study Commission to undergo a study as to whether or not the statute should be amended in the future to add disparate impact as a cause of action under the legislation. *Id.* § 2000ff-7(b).

71. *Id.* § 2000e-2(k).

72. *Griggs v. Duke Power Co.*, 401 U.S. 424, 431 (1971).

73. *See Lewis v. City of Chicago*, 130 S. Ct. 2191, 2197-98 (2010).

74. *Id.* (citing *Ricci v. DeStefano*, 129 S. Ct. 2658, 2672-73 (2009)).

treatment claims exclusively. The standard for proving disparate treatment is significantly different than the standard for proving disparate impact. To prove a *prima facie* case under a disparate treatment cause of action, a plaintiff must prove that:

- (1) he is a member of a protected class;
- (2) he was qualified for the position he held;
- (3) he suffered an adverse employment action; and
- (4) the adverse action took place under circumstances giving rise to the inference of discrimination.⁷⁵

If the plaintiff fulfills this four-element test, the burden is shifted to the defendant to rebut the presumption of discrimination by showing a legitimate nondiscriminatory reason for the adverse employment action.⁷⁶ If the defendant meets his burden, then the plaintiff must prove discrimination was the real reason for the adverse action.⁷⁷ Although no cases have been brought under GINA allowing courts to decide whether they will apply the same type of proof structure in genetic discrimination cases, we attempt to analyze what such a proof structure would look like in Part V of this note.⁷⁸

Many disparate impact claims are based on entire classes of plaintiffs claiming that particular employment practices produced discriminatory effects.⁷⁹ For example, under the disparate impact theory, an employer's application or promotion process, although it may be facially neutral, may be challenged as being discriminatory in practice.⁸⁰ Testing in and of itself is not illegal, so long as the test, as applied, does not produce discriminatory results.⁸¹ Legally, "[a] test has a disparate impact if it selects applicants in a . . . pattern significantly different from that of the pool of applicants."⁸² The lack of a disparate impact theory as a cause of action under GINA could potentially prevent

75. See *Ruiz v. Cnty. of Rockland*, 609 F.3d 486, 491-92 (2d Cir. 2010).

76. *Id.* at 492.

77. *Id.*

78. See discussion *infra* Part V.A.

79. See, e.g., *Lewis v. City of Chicago*, 130 S. Ct. 2191 (2010); *Wards Cove Packing Co. v. Antonio*, 490 U.S. 642 (1989); *Connecticut v. Teal*, 457 U.S. 440 (1982).

80. See, e.g., *Lewis*, 130 S. Ct. at 2193.

81. 14A C.J.S. *Civil Rights* § 240 (citing *Teal v. State of Conn.*, 645 F.2d 133 (2d Cir. 1981)).

82. *Id.* (citing *Albemarle Paper Co. v. Moody*, 422 U.S. 405 (1975)).

a class of individuals who were denied jobs based on their genetic information from litigating directly against the employer.

The concern about the lack of a disparate impact claim is only in regards to potential discrimination between employees and employers. GINA expressly disallows genetic testing by “[a] group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan.”⁸³ Thus, potential litigants arguing impropriety with genetic testing by insurance carriers have per se arguments rather than disparate impact arguments.

B. GINA’s Effect on Employers in the Workplace

The passage of GINA places additional burdens on employers in two ways: (1) employers now have increased confidentiality requirements and (2) they now must make hiring and termination decisions devoid of genetic discrimination.⁸⁴ GINA’s confidentiality protections dictate how medical information must be maintained and impose employers’ general duty not to disclose genetic information.⁸⁵ GINA mandates that if an employer “possesses genetic information about an employee or member, such information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member.”⁸⁶ Furthermore, an employer has a duty not to disclose the genetic information unless it falls under an enumerated exception.⁸⁷ The fact that GINA requires employers to keep such private data confidential should not be surprising. “DNA analysis provides unprecedented access into an individual’s future physical and psychological health, [and] the health of close relatives” and, therefore, is extremely worthy of protection with penalty for its disclosure.⁸⁸

Internally, employers will need to make changes in order to comply

83. 42 U.S.C. § 300gg-1(b)(1) (2006).

84. See 42 U.S.C. § 2000ff-1, 2000ff-5 (Supp. II 2009).

85. *Id.* § 2000ff-5(a)-(b).

86. *Id.* § 2000ff-5(a).

87. *Id.* § 2000ff-5(b). An employer is prohibited from disclosing genetic information concerning an employee except when it provides the information: (1) to the employee pursuant to the employee’s request; (2) to a health researcher conducting federally proper research; (3) in response to a court order; (4) to government officials investigating compliance with GINA; (5) to comply with the Family and Medical Leave Act or any similar state law; or (6) to any health agency that has concerns about a “contagious disease that presents an imminent hazard or life-threatening illness.” *Id.* § 2000ff-5(b)(1)-(6).

88. *Patterson v. State*, 742 N.E.2d 4, 10 n.3 (Ind. Ct. App. 2000).

with GINA's confidentiality requirements. These changes are minor and will likely not materially affect the economy in the aggregate or any specific sector of the economy.⁸⁹ The EEOC has deemed it unnecessary to perform a cost-benefit analysis of GINA's implementation because the total impact to the economy will be under \$100 million in the aggregate.⁹⁰ The costs to employers to implement changes in order to comply with GINA are inconsequential when compared to the importance of maintaining confidentiality with regard to the genetic information employers may possess.

Employers must also adapt to certain provisions that are unique to GINA and are not found in any of the other discrimination statutes. "Family medical history," "manifestation," "genetic information" and other terms are all unique to employers with regard to employment discrimination, and understanding these specific definitions is necessary in order to properly comply with the law.⁹¹ Employers are encouraged to create preventive policies to limit the risk of even coming into contact with genetic information.⁹² One such suggestion is that employers should modify any forms given to health care professionals to include a section that expressly states that family and medical history and other genetic information should not be given back to the employer.⁹³ Furthermore, employers that currently administer medical examinations related to employment may need to amend these procedures to make sure they maintain compliance with GINA.⁹⁴

A substantial issue that employers may face involves genetic information categorized as "inadvertent knowledge" under one of GINA's enumerated exceptions to the prohibition of the acquisition of genetic information.⁹⁵ The intention behind including this exception in

89. See Regulations under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,931 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635).

90. *Id.* The EEOC suggested that most human resource professionals will need three hours to become competent with their new responsibilities. Human resource professionals also have ample opportunity to go to EEOC sponsored events in order to receive proper training. *Id.*

91. See 29 C.F.R. § 1635.3(a)-(g) (2011).

92. See 29 C.F.R. § 1635.8; Regulations under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. at 68,920.

93. Regulations under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. at 68,926.

94. See 29 C.F.R. § 1635.8 (requiring employers to tell healthcare providers not to collect genetic information as part of an examination intended to determine if said employee can perform his or her job).

95. 42 U.S.C. § 2000ff-1(b)(1) (Supp. II 2009). The exceptions to the general prohibition of acquisition of genetic information include: (1) "where an employer inadvertently requests or requires family medical history of the employee or family member of the employee;" (2) "where . . . health or genetic services are offered by the employer," "the employee provides prior, knowing, voluntary, and written authorization," and the information gained by the services is only disclosed

the statute was to prevent liability through casual conversations or potential “water cooler problems.”⁹⁶ The mere utterance of one’s family history, employees consoling one another, or even errant emails should not place an increased burden on employers.⁹⁷ Although the inadvertent exception is clearly defined by the statute, “inadvertent” has no clear meaning and is without judicial interpretation. Therefore, it is likely that litigation may be heavily involved in determining the standard of “inadvertent” and the scope of its definition.

Employers will also have to adapt to litigation in other ways. Defenses once offered to employers may no longer be available because the use of such defenses may cause the defendant to violate GINA. For example, when responding to workers’ compensation claims, employers can no longer use the defense that the injuries allegedly caused on the job were actually the result of the plaintiff’s genetic predisposition to a certain disease or condition. An employer possessing genetic information about an employee is now unable to disclose this information under GINA, and is thus prevented from formulating this defense.⁹⁸ Lawyers for defendants may confront ethical issues in a situation where their best defense may require disclosure of the plaintiff’s genetic information. Thus, ethical problems may arise when employers are tempted to use employee information in order to promote the best possible defense.

Another exception to the duty to not disclose genetic information is when disclosure is requested via court order.⁹⁹ However, if an employer who possesses genetic or familial information about an employee is asked to release details of the specific information or documents containing such information during *traditional discovery*, the employer is prohibited from disclosing the information.¹⁰⁰ The EEOC

to the employer in aggregate terms that do not include the identity of the employee; (3) “where an employer requests or requires family medical history from the employee to comply with the certification provisions of section 2613 of title 29 or such requirements under State family and medical leave laws;” (4) “where an employer purchases documents that are commercially and publically available;” (5) “where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace” and the employee provides informed authorization after being properly notified of the genetic monitoring; and (6) “where the employer conducts DNA analysis for law enforcement purposes.” § 2000ff-1(b)(1)-(6).

96. 29 C.F.R. § 1635.8(b)(1)(ii)(B) (2011).

97. *See id.* § 1635.8(b)(1)(ii)(B)-(C).

98. *See* 42 U.S.C. § 2000ff-5(b).

99. 42 U.S.C. § 2000ff-5(b)(3).

100. *See* 42 U.S.C. § 2000ff-5(b). Traditional discovery is not included in the list of exceptions. *See* Regulations under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,928 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635).

recommends that employers deny discovery requests for employee information and that such information need only be disclosed in response to a court order.¹⁰¹ This is actually a sigh of relief for businesses because it offers a bright line rule and is thus easy to comply with. However, district court judges may have trouble in determining when to grant such court orders.

III. SURVEY OF STATE LEGISLATION PROTECTING EMPLOYEES FROM GENETIC INFORMATION ABUSES BY EMPLOYERS

As a response to discrimination against carriers of sickle cell anemia, state legislatures began enacting protections for genetic information as early as the 1970s.¹⁰² Eventually, the protections state legislatures afforded to those with debilitating genetic diseases expanded to the realm of employment law. As of January 2008, the National Conference of State Legislatures reported that thirty-four states and Washington, D.C. had enacted legislation regulating employers and their use of employees' genetic information.¹⁰³

A. State Legislation on the Use of Genetic Information in Employment

The most notable area where states have enacted legislation regulating the use of genetic information is with regard to employment discrimination. The earliest state laws prohibiting employers from discriminating based on genetic information only covered specific genetic disorders.¹⁰⁴ For example, New Jersey law only prohibited discrimination against carriers of sickle cell, hemoglobin C, thalassemia, Tay-Sachs and cystic fibrosis traits.¹⁰⁵ New York law similarly limited its protection to individuals with sickle cell, Tay-Sachs, and β -

101. See 29 C.F.R. § 1635.9(b)(3) (2011); Regulations under the Genetic Nondiscrimination Act of 2008, 75 Fed. Reg. at 68,928.

102. Samantha French, *Genetic Testing in the Workplace: The Employer's Coin Toss*, 2002 DUKE L. & TECH. REV. 0015 (2002), available at <http://www.law.duke.edu/journals/dltr/articles/2002dltr0015.html>.

103. *Genetic Employment Laws*, NAT'L CONF. OF ST. LEGISLATORS (Jan. 2008), <http://www.ncsl.org/default.aspx?tabid=14280> [hereinafter *Genetic Employment Laws*].

104. See, e.g., French, *supra* note 102 (noting the first such law that protected against discrimination of people with sickle cell anemia).

105. Steven G. Craig et al., *Protecting Genetic Privacy by Permitting Employer Access Only to Job-Related Employee Medical Information: Analysis of a Unique Minnesota law*, 24 AM. J.L. & MED. 399, 402 (1998) (citing N.J. STAT. ANN. § 10:5-5(y)-(cc) (West 1993)). New Jersey amended and broadened the statute in 1996. *Id.*

thalassemia traits.¹⁰⁶ The scope of diseases and conditions protected has recently been expanded by many states to include a broad definition of genetic information. This definition differs amongst the states.¹⁰⁷

While genetic information discrimination is defined differently among the states, all of these laws represent the ideal that employers ought not “discriminat[e] for any reason other than that of individual merit,” and are meant to protect employees from adverse employment decisions.¹⁰⁸ Protections afforded to employees are generally meant to prevent an employer from “discharg[ing], expel[ing] or otherwise discriminat[ing] against any person on the basis of genetic information.”¹⁰⁹ Frequently, “genetic information” is appended to the statutory language of the other protected employment classes such as sex, race, religion, and national origin. That is how Massachusetts,¹¹⁰ New Jersey,¹¹¹ and New York¹¹² have addressed genetic information discrimination by employers. South Dakota,¹¹³ Rhode Island,¹¹⁴ and Oregon¹¹⁵ have created separate sections for genetic information protection within the workplace.

When defining “employer,” Minnesota¹¹⁶ and North Carolina¹¹⁷ both explicitly include the state government as a covered entity. Nebraska has expanded the definition of employer to include “a person who has one or more employees,” granting widespread coverage to citizens.¹¹⁸ Most states, however, leave “employer” undefined in their

106. *Id.* (citing N.Y. CIV. RIGHTS LAW § 48 (McKinney 1992)). New York amended and broadened the statute in 1996. *Id.*

107. For example, Hawaii’s state discriminatory law defines genetic information as “information about genes, gene products, hereditary susceptibility to disease, or inherited characteristics that may derive from the individual or family member.” HAW. REV. STAT. § 378-1 (2007). Oklahoma has only enacted legislation that prevents an employer from obtaining or seeking a genetic test or genetic information, yet defines genetic information extremely narrowly as the results of a genetic test and that “[g]enetic information shall not include family history.” OKLA. STAT. ANN. tit. 36, § 3614.2-3614.3 (West 2011).

108. D.C. CODE § 2-1401.01 (2007).

109. CONN. GEN. STAT. ANN. § 46a-60(a)(11) (West 2009).

110. MASS. GEN. LAWS ANN. ch. 151B, § 4 (West 2004).

111. N.J. STAT. ANN. § 10:5-12 (West 2002).

112. N.Y. EXEC. LAW § 296 (McKinney 2010).

113. S.D. CODIFIED LAWS § 60-2-20 (2009).

114. R.I. GEN. LAWS § 28-6.7-1 (2003).

115. OR. REV. STAT. ANN. § 659A.303 (West 2003).

116. MINN. STAT. ANN. § 181.974(b) (West 2006) (“‘Employer’ means any person having one or more employees in Minnesota, and includes the state and any political subdivisions of the state . . .”).

117. N.C. GEN. STAT. § 95-28.1A (2009) (specifically defining employer to include a “State agency, unit of local government, or any public . . . entity”).

118. NEB. REV. STAT. ANN. § 48-236(1)(b) (LexisNexis 2007).

genetic information legislation, allowing it to be defined by other statutes or judicial interpretation.¹¹⁹

Although legislation differs from state to state, the majority of states have enacted legislation that mimics the same goals and purpose of GINA. Having a state venue for litigants offers further protection and alternatives when seeking remedies, ultimately making employers more aware and cautious.

B. State Legislation on Disclosing and Acquiring Genetic Information

State legislation regarding genetic information is not exclusively confined to the prohibition of its use in adverse employment decisions. There is also substantial legislation preventing employers from requesting, requiring, or obtaining genetic information.¹²⁰ In 1989, Oregon was the first state to enact legislation prohibiting employers from requiring a genetic test as a condition to employment or mobility within the organization.¹²¹ Legislation that prevents employers from requesting or obtaining genetic information is in addition to legislation prohibiting employment discrimination. No state that has regulated employers' possession of genetic information is without employment discrimination protections. Some states, such as Iowa, go a step further to protect employees by making employer genetic testing illegal.¹²² There, "[g]enetic testing does not mean routine physical measurement," and thus the law relates only to tests detecting the genetic code, prescribed by federal statute, as opposed to routine procedures like a urine analysis or a drug test.¹²³

Illinois¹²⁴ and Massachusetts¹²⁵ have expressly placed limitations

119. For example, Utah specifically references a section of a different statute in order to define "employer." UTAH CODE ANN. § 26-45-103 (LexisNexis 2007) (referencing section 34A-2-103).

120. See *Genetic Employment Laws*, *supra* note 103.

121. See Craig et al., *supra* note 105, at 402 (citing OR. REV. STAT. ANN. § 659.227 (West 1997)). Oregon's current statute reads "[e]xcept as provided in this section, it is an unlawful employment practice for any employer to subject, directly or indirectly, any employee or prospective employee to any breathalyzer test, polygraph examination, psychological stress test, genetic test or brain-wave test." OR. REV. STAT. ANN. § 659A.300(1).

122. See, e.g., IOWA CODE ANN. § 729.6(2)(a) (West 2011).

123. *Id.* § 729.6(1)(e).

124. 410 ILL. COMP. STAT. ANN. 513/25 (j) (West 2011) ("Despite lawful acquisition of genetic testing or genetic information . . . an employer, employment agency, labor organization, and licensing agency still may not use or disclose the genetic test or genetic information in violation of this Act").

125. MASS. GEN. LAWS ANN. ch. 151B, § 4(19)(a) ("It shall be unlawful discrimination for any employer, employment agency, labor organization, or licensing agency to . . . collect, solicit or require disclosure of genetic information from any person as a condition of employment, or

upon an employer's disclosure of genetic information. Vermont has even extended the limitation of disclosure to all citizens, not just employees.¹²⁶ In Vermont, it is a per se violation to disclose "to an employer, labor organization, employment agency . . . any genetic testing results or genetic information."¹²⁷ This provision may have unique consequences for the state of Vermont. By enacting such a law, Vermont has indirectly placed a larger confidentiality requirement on all health care professionals to ensure that genetic information never gets submitted to an employer or to a health insurance provider that may eventually share such information with an employer. Furthermore, such strong language has removed the "water cooler" problem that federal legislators sought to avoid through provisions regarding inadvertent knowledge.¹²⁸ Although this provision is presently unexamined by any tribunal in Vermont, it will be interesting to see how the federal and state laws will be interpreted due to the varying language.

C. States with Exclusive Federal Protection

Although state protection is extremely widespread, there are still sixteen states currently without genetic information discrimination statutes.¹²⁹ These are the jurisdictions where GINA will likely have a substantial impact, providing employees protections they had previously not enjoyed. Federal district courts will have jurisdiction over these cases under the "laws arising" doctrine.¹³⁰ In these states, federal judges will be the first interpreters of GINA for the state. States with legislative protections will have to balance both state and federal doctrine. GINA's application in both state and federal courts eventually should be strikingly similar, due to the fact that current Title VII state and federal court doctrines are practically identical.¹³¹

Despite widespread state protections against genetic information discrimination, little litigation has centered around the claim of genetic information misuse and discrimination. As critics have dubbed GINA "a

membership, or of obtaining a license . . .").

126. See VT. STAT. ANN. tit. 18, § 9333 (West 2007).

127. *Id.* § 9333(c).

128. See discussion *supra* pp. 241-42.

129. *Genetic Employment Laws*, *supra* note 103. Alabama, Alaska, Colorado, Florida, Georgia, Indiana, Kentucky, Mississippi, Montana, North Dakota, Ohio, Pennsylvania, South Carolina, Tennessee, West Virginia, and Wyoming are all without state statutes protecting genetic information discrimination. *Id.*

130. See 28 U.S.C. § 1331 (2006).

131. See, e.g., *Torres v. Pisano*, 116 F.3d 625, 629 n.1 (2d Cir. 1997).

solution in search of a problem,” they may have overlooked the power of deterrence that might already exist in the state jurisdictions that give protection to their citizens. Litigation and EEOC filings based on genetic information are miniscule compared to those of race, sex, national origin, age and disability. Genetic testing is not rampant, but at this juncture it is not uncommon either. Therefore, it may be safe to assume that employers were able to amend their current employment policies to confirm with state law protections of genetic information.

IV. INTERNATIONAL GENETIC DISCRIMINATION REGULATIONS

The United States is not the only country that has realized the threat genetic discrimination poses to the public. A number of international organizations and countries have issued various documents that express a desire for regulatory intervention that protects individuals from this form of discrimination. Many of these organizations and countries have even enacted some form of legislation to this pursuit.

One of the earliest organized international conferences to recognize the issue of genetic discrimination was the forty-fourth World Medical Assembly (“WMA”), held in Marbella, Spain in 1992.¹³² The WMA, in response to technological advances allowing individuals to obtain information about their genetic traits, recommended that “[i]t may be desirable, regarding genetic factors, to adopt the same tacit consensus which prohibits the use of race discrimination in employment or insurance.”¹³³ They feared that genetic testing could potentially become a source of “stigmatization and social discrimination” for those who possess a genetic predisposition to a certain disease or disorder.¹³⁴ While the WMA recognized the need to create “ethical and legal guidelines to prevent [genetic] discrimination and the genetic stigma” to the population at risk, it suggested a number of basic guidelines, but did

132. *WMA Declaration on the Human Genome Project*, WORLD MED. ASS'N, <http://www.wma.net/en/30publications/10policies/20archives/g6/index.html> (last visited Jan. 6, 2012) [hereinafter *Declaration of the Human Genome Project*]. The WMA is an international medical association founded in 1947, which represents physicians from different countries around the world. See *About the WMA*, WORLD MED. ASS'N, <http://www.wma.net/en/60about/index.html> (last visited Jan. 6, 2012). The purpose of the organization is “to serve humanity by endeavoring to achieve the highest international standards in Medical Education, Medical Science, Medical Art and Medical Ethics, and Health Care for all people in the world.” *Id.*

133. *Declaration of the Human Genome Project*, *supra* note 132.

134. *Id.*

not endeavor to make these guidelines binding.¹³⁵

In 1993, the International Bioethics Committee (“IBC”) of the United Nations Educational, Scientific and Cultural Organization (“UNESCO”) was charged with drafting an international bioethics instrument regarding human rights and genetics.¹³⁶ The efforts of the IBC led to the creation of the Universal Declaration on the Human Genome and Human Rights (“the 1997 Declaration”), which was adopted by the General Conference of UNESCO in 1997 and by the United Nations’ General Assembly in 1998.¹³⁷ The 1997 Declaration was the first universal instrument to establish ethical guidelines in the area of genetic discrimination.¹³⁸ Its goal was to convey the message to the international community that genetic information must be regulated in order to protect individuals from all forms of discrimination based on genetic characteristics.¹³⁹ Although the 1997 Declaration has no binding force on its member states, they are “expected to reflect its principles in their laws.”¹⁴⁰

The overarching theme of the 1997 Declaration is the protection of human dignity.¹⁴¹ Article 6 of the 1997 Declaration expressly prohibits discrimination based on genetic characteristics.¹⁴² The language of Article 6 is intentionally broad, stating that the types of genetic discrimination to be prohibited are those that “infringe or [have] the effect of infringing human rights, fundamental freedoms and human dignity.”¹⁴³ UNESCO likely used such broad language in an attempt to ensure that all types of genetic discrimination be prohibited, even types not yet envisioned. The 1997 Declaration further stressed the importance of confidentiality of genetic information in Article 7.¹⁴⁴

135. *See id.*

136. *See* Shawn H.E. Harmon, *The Significance of UNESCO’s Universal Declaration on the Human Genome & Human Rights*, 2 SCRIPT-ED 20, 24 (2005), available at <http://www.law.ed.ac.uk/ahrc/script-ed/vol2-1/harmon.asp#Introduction>.

137. *See id.* at 25.

138. *See* Noëlle Lenoir, Comment, *Universal Declaration on the Human Genome and Human Rights: The First Legal and Ethical Framework at the Global Level*, 30 COLUM. HUM. RTS. L. REV. 537, 538 (1999).

139. *See* U.N.E.S.C.O. Dec. 29/16, U.N. Doc. A/53/625/Add.2 (Nov. 11, 1997) [hereinafter *Universal Declaration on the Human Genome and Human Rights*], available at <http://unesdoc.unesco.org/images/0011/001102/110220e.pdf#page=47>.

140. *See* Lenoir, *supra* note 138, at 548.

141. *Id.* at 561.

142. *Universal Declaration on the Human Genome and Human Rights*, *supra* note 139, at art. 6.

143. *See id.*

144. *See id.* at art. 7 (“Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the

About two years after the 1997 Declaration was adopted, the UNESCO General Commission endorsed the Guidelines for the Implementation of the Universal Declaration on the Human Genome and Human Rights.¹⁴⁵ The Guidelines describe the actions that different states must take to implement the 1997 Declaration, and provide guidance on how to achieve these tasks.¹⁴⁶

UNESCO expanded on the 1997 Declaration through the 2003 International Declaration on Human Genetic Data (“the 2003 Declaration”), which was adopted by the thirty-second session of the General Conference of UNESCO on October 16, 2003.¹⁴⁷ The 2003 Declaration expresses goals similar to the 1997 Declaration; specifically to “ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data”¹⁴⁸ However, the provisions in the 2003 Declaration are more specific than those in the 1997 Declaration. For instance, Article 2 of the 2003 Declaration defines the term “human genetic data” as “[i]nformation about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis.”¹⁴⁹ In the 1997 Declaration, no terms were defined.¹⁵⁰ Article 7 of the 2003 Declaration states that:

Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities.¹⁵¹

The 2003 Declaration also covers informed consent in genetics¹⁵²

conditions set by law”).

145. Implementation of the Universal Declaration on the Human Genome and Human Rights, U.N.E.S.C.O., http://www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/SHS/pdf/Guidelines-Genome_EN.pdf (last visited Dec. 19, 2011).

146. *See id.*

147. United Nations Educational, Scientific and Cultural Organization [UNESCO], *International Declaration On Human Genetic Data*, at 1, SHS-2004/DECLAR.BIOETHIQUE CIB/4 (Oct. 16, 2003) [hereinafter *International Declaration on Human Genetic Data*], available at <http://unesdoc.unesco.org/images/0013/001342/134217e.pdf>.

148. *See id.* at art. 1.

149. *Id.* at art. 2. Many of the other scientific terms used within the 2003 Declaration are also defined in this section. *See id.*

150. *See* Universal Declaration on the Human Genome and Human Rights, *supra* note 139.

151. *International Declaration on Human Genetic Data*, *supra* note 147, at art. 7.

152. *See id.* at art. 8.

and confidentiality of genetic data.¹⁵³ Article 8 of the 2003 Declaration requires “[p]rior, free, informed and express consent” from an individual before the collection of his or her human genetic data.¹⁵⁴ This requirement is only excused for compelling reasons consistent with international law on human rights.¹⁵⁵ Article 14 states that human genetic data should not be made available to third parties, except where the person concerned gives prior consent or where there is an important public interest reason that is consistent with the international law of human rights.¹⁵⁶ In 2004, the UN Economic and Social Council (“EcoSoc”) reiterated the belief that the states need to protect and regulate human genetic data to prevent discrimination based on such information.¹⁵⁷ Although EcoSoc did not create its own guidelines, it urged the states to adopt legislation to accomplish this goal.¹⁵⁸

During the 1990s, many European nations also began to express the belief that they needed some form of protection against discrimination based on genetic data.¹⁵⁹ On November 19, 1996, the Council of Europe¹⁶⁰ adopted the Convention on Human Rights and Biomedicine (“the Convention”), and opened it up for signature by the Council’s members on April 4, 1997.¹⁶¹ The Convention urges the Council’s member states to deal with genetic discrimination through prohibitory legislative measures.¹⁶² It focuses on the protection of human dignity and identity, and on the guarantee that everyone shall receive respect for their integrity “with regard to the application of biology and

153. *Id.* at art. 14.

154. *Id.* at art. 8(a).

155. *See id.*

156. *See id.* at art. 14.

157. *See* E.S.C. Res. 2004/9, U.N. Doc. E/2004/INF/2/Add.2 (July 21, 2004), available at <http://www.un.org/en/ecosoc/docs/2004/resolution%202004-9.pdf>.

158. *See id.*

159. *See* Trudo Lemmens, *Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?*, 45 MCGILL L.J. 347, 356-57 (2000).

160. The Council of Europe was formed in 1949 by ten European countries, and now has forty-seven member countries. *Who We Are*, COUNCIL OF EUROPE, <http://www.coe.int/aboutcoe/index.asp?page=quisommesnous&l=en> (last visited Jan. 7, 2012). The goal of the council is to develop common principals throughout Europe based on the European Convention on Human Rights and other texts concerning the protection of individuals. *Id.*

161. Council of Europe, Directorate of Legal Affairs, *Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology & Medicine: Convention on Human Rights & Biomedicine*, at 4, DIR/JUR (97) 5 (May 1997) [hereinafter Council of Europe], available at <http://www.univie.ac.at/ierm/php/Dokumente/Oviedo-rap-E.pdf>.

162. *See id.* at ch. 1, art. 1.

medicine.”¹⁶³ Chapter IV of the Convention, which contains Articles 11-14, discusses the human genome.¹⁶⁴ Article 11 is a general prohibition against discrimination based on genetic information.¹⁶⁵ It states that “[a]ny form of discrimination against an individual on grounds of his or her genetic heritage is prohibited.”¹⁶⁶ Article 12 of the Convention explicitly prescribes that predictive genetic testing may only be performed for “health purposes for the individual” or for scientific research linked to health purposes.¹⁶⁷

The Council of Europe further defines genetic testing as “medical examinations aimed at detecting or ruling out the presence of hereditary illnesses or predisposition to such illnesses in a person by directly or indirectly analyzing [sic] their genetic heritage (chromosomes, genes).”¹⁶⁸ Furthermore, in the case of employers and private insurance contracts, Article 12 of the Convention prohibits genetic testing that does not have a health purpose, even with the assent of the person concerned.¹⁶⁹ As of February 13, 2011, twenty-seven of the member states of the Council of Europe have ratified the Convention, and seven member states have signed the Convention but have not yet ratified it.¹⁷⁰ The twenty-seven countries that have ratified the Convention are under an obligation to introduce legislation that gives effect to the provisions of the Convention, including a prohibition on the use of human genetic data for non-medical purposes.¹⁷¹

The United States legislature was likely influenced by the previously discussed international documents when it created GINA. Although it was not a party to any of the organizations that enacted these documents, there is evidence that the United States approved of their objectives and purposes. For example, the United States, although only an observer and not a member of UNESCO at the time the 1997 Declaration was adopted, approved of the 1997 Declaration.¹⁷²

163. *See id.*

164. *See id.* at ch. IV.

165. *Id.* at ch. IV, art. 11.

166. *Id.*

167. *Id.* at ch. IV, art. 12.

168. *Id.* at ch. IV.

169. *Id.* at ch. IV, art. 12.

170. *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, COUNCIL OF EUROPE (Feb. 13, 2011), <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=164&CM=8&DF=13/02/2011&CL=ENG> (showing which countries have signed and ratified the Convention).

171. *See Lemmens, supra* note 159, at 359.

172. *See Lenoir, supra* note 138, at 558.

Furthermore, the general purpose of GINA, which is to protect individuals from discrimination based on genetic information in employment and health insurance situations, is in harmony with the purposes of the aforementioned international documents. However, the provisions of GINA are more detailed and specific than most of the provisions in these international documents. For example, § 2000ff(4) provides a specific definition of “genetic information” and explicitly excludes certain features from such definition, namely the sex and age of an individual.¹⁷³ In contrast, most of the international documents simply use some form of the term “genetic information,” but fail to define what type of information the term includes.¹⁷⁴ GINA also includes a detailed list of exceptions from the general prohibition against collecting genetic information from individuals,¹⁷⁵ whereas the exceptions provided in the previously discussed international documents are very general.¹⁷⁶ For example, the 2003 Declaration provides only that consent for the disclosure of genetic information is not required when there are compelling reasons consistent with international law on human rights.¹⁷⁷ Another difference between GINA and the international documents is that GINA limits its prohibitions to employers and health insurance providers, while many of the international documents state a broad, general prohibition.¹⁷⁸

The prevalence of international documents aimed at prohibiting genetic discrimination is evidence that GINA is a necessary piece of legislation. Entities throughout the world concur that discrimination against individuals based on their genetic information is a new problem that must be addressed now so that it may be prevented.¹⁷⁹ GINA, as well as other legislation currently in effect throughout the world, is necessary to protect individuals from this new form of discrimination

173. See Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. § 2000ff(4)(a)-(c) (2006).

174. See, e.g., Universal Declaration on the Human Genome and Human Rights, *supra* note 139, at 42-43 (prohibiting discrimination based on “genetic characteristics,” but never defining “genetic characteristics”).

175. See 42 U.S.C. § 2000ff-2(b).

176. See, e.g., *International Declaration on Human Genetic Data*, *supra* note 147, at art. 8.

177. *Id.*

178. Compare 42 U.S.C. § 300gg-53 (prohibiting genetic information as a condition of eligibility for health insurance), and 42 U.S.C. § 2000ff-1 (protecting employees from discrimination on the basis of genetic information), with *International Declaration on Human Genetic Data*, *supra* note 147, at art. 8 (prohibiting disclosure of genetic information absent consent or a compelling reason), and Council of Europe, *supra* note 161 (generally prohibiting discrimination on the basis of genetic information).

179. See *supra* pp. 247-53.

that may very well occur more often in the near future. Additionally, if people fear that they may be discriminated against based on genetic information, they may be discouraged from taking the medical tests necessary to ascertain such information. Such a lack of genetic testing would hinder the medical community's ability to make advancements in deciphering the human genome, leaving individuals more susceptible to genetic-based diseases that may have been prevented if the individuals were aware of their genetic predispositions to such diseases.

V. THE PRIMA FACIE CASE AND BURDEN SHIFTING STRUCTURE FOR GINA PREDICATED UPON TITLE VII AND THE ADA

"Title VII was the first piece of legislation that prohibited employers from making decisions regarding their employees based on an employee's race, color, religion, sex, or national origin."¹⁸⁰ When the ADA was enacted in 1991, the list of protected classes was expanded to include persons with a recognized disease.¹⁸¹ Due to the flexibility of the general framework of a Title VII case, which was first enunciated by the Supreme Court in *McDonnell Douglas Corp. v. Green*,¹⁸² similar frameworks have been applied to cases under the other federal discrimination statutes with only minor deviations. In fact, the legislative history of the ADA shows that "several provisions of Title VII were copied or incorporated by reference into the ADA."¹⁸³ Due to GINA's express reference to Title VII's rights and remedies, GINA will no doubt grow upon existing Title VII prima facie structures.¹⁸⁴ Furthermore, because GINA deals with personal, specific and individualized medical concerns,¹⁸⁵ courts will likely adopt certain ADA jurisprudence. The following section will outline a proposed prima facie test for future plaintiffs bringing a claim under GINA, as well as a methodology for defendants to combat damages via a burden-shifting structure.

180. Leigh A. Van Ostrand, Note, *A Close Look at ADEA Mixed-Motives Claims and Gross v. FBL Financial Services, Inc.*, 78 FORDHAM L. REV. 399, 406 (2009).

181. See Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 (2006).

182. 411 U.S. 792, 802 (1973).

183. *U.S. Airways, Inc. v. Barnett*, 535 U.S. 391, 421 n.1 (2002) (Souter, J. dissenting).

184. See 42 U.S.C. § 2000ff-6(a).

185. See *supra* pp. 240-41.

A. GINA's Proof Structure as Compared to Title VII Actions

1. The Prima Facie Framework Under Title VII

Congress has specifically provided the potential remedies and causes of actions for plaintiffs when invoking the statutory protections of GINA.¹⁸⁶ An overt repudiation of disparate impact claims is in the statutory text,¹⁸⁷ as well as an endorsement of the current “powers, procedures and remedies provided” under Title VII.¹⁸⁸ Thus, GINA ought to make for a natural judicial transition to the already established proof structures under Title VII. In order to understand the current framework for plaintiffs, it is necessary to examine the evolution of the current Title VII jurisprudence to determine how GINA will fit into that structure.

Section 2000e-2(a) of Title VII states:

It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to his compensation, terms, conditions, or privileges of employment, because of such individual's race, color, religion, sex, or national origin.¹⁸⁹

In their broadest understanding, these statutory protections against discriminatory employment actions based on an “individual's race, color, religion, sex or national origin”¹⁹⁰ are meant to “eliminat[e] . . . discrimination in the workplace.”¹⁹¹ Prima facie causes of action for plaintiffs claiming discrimination were created because of how difficult it is to proffer direct evidence of racist, sexist or other discriminatory statements or actions of an employer.¹⁹² The famous and oft-cited Supreme Court case *McDonnell Douglas* initially clarified the prima facie case for Title VII disparate treatment claims.¹⁹³

The overall framework and burden-shifting method introduced by

186. 42 U.S.C. § 2000ff-6.

187. *Id.* § 2000ff-7(a).

188. *Id.* § 2000ff-6(a)(1).

189. 42 U.S.C. § 2000e-2(a)-(a)(1).

190. *Id.* § 2000e-2(a)(1).

191. *Oscar Mayer & Co. v. Evans*, 441 U.S. 750, 751 (1979).

192. *See Farm Labor Org. Comm. v. Ohio State Highway Patrol*, 95 F. Supp. 2d 723, 734 (N.D. Ohio 2000).

193. *McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 802 (1973).

the Supreme Court in *McDonnell Douglas* has remained intact with only minor variations since its inception. Although specified and enumerated factors suggest a rigid proof structure, it is important to point out that the original *McDonnell Douglas* ruling stated that factual situations may vary between different plaintiffs and that the prima facie case is not always necessary.¹⁹⁴ Thus, the Title VII framework is often flexible enough to fit the specific facts of different cases.¹⁹⁵ At its core, the prima facie case is meant to provide a presumption of discrimination.¹⁹⁶ Upon the defendant's failure to produce a legitimate, nondiscriminatory explanation for the adverse employment action at issue, a plaintiff who has proved a prima facie case is considered to have provided sufficient evidence to support a legal determination that the employment action was based on impermissible factors.¹⁹⁷ If the defendant offers evidence of a fair and proper reason for the adverse employment action, the plaintiff's only course of action is to prove that the stated reason was pretext for invidious discrimination.¹⁹⁸ This legal determination of employment discrimination may only be found after the employer has been given an opportunity to articulate some legitimate, nondiscriminatory reason for the employee's rejection, and the employee has sufficiently proved that those reasons were mere pretext for discrimination.¹⁹⁹ Since this prima facie framework has been applied and ordained by the Supreme Court for Title VII provisions, this same framework ought to achieve similar results in claims made under GINA.

The prima facie framework for race and sex discrimination works based on a built-in assumption. Membership in a protected class, based on either sex or race, is assumed because the physical aspects of the protected classes are noticeable to the eye.²⁰⁰ Genetic information, which is in the depths of one's genetic code, is entirely different. In fact, once a genetic disease begins to manifest itself, the affected individual is no longer under the auspices of GINA and, therefore, would need to bring a claim under the ADA instead.²⁰¹ An employer will be unable to identify genetic markers or recognize familial history with the naked

194. *Id.* at 802 n.13.

195. *See id.*

196. *See St. Mary's Honor Ctr. v. Hicks*, 509 U.S. 502, 506 (1993).

197. *Id.* at 506-07, 511.

198. *McDonnell Douglas*, 411 U.S. at 804.

199. *Id.*

200. Hannah Fleener, Note, *Looks Sell, But Are They Worth the Cost?: How Tolerating Looks-Based Discrimination Leads to Intolerable Discrimination*, 83 WASH. U.L.Q. 1295, 1302 (2005).

201. Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 839 (2008).

eye. This is by nature analogous to the protected classes of religion or national origin, membership in which may not be discernible by mere visual evidence. In instances where an employer is unaware of the religion of an employee, it is impossible for there to be discrimination based on religion.²⁰² Thus a knowledge requirement has been added by courts for religious discrimination actions under Title VII.²⁰³ This requirement ought to apply to GINA plaintiffs for similar reasons.

The religious protection afforded under Title VII has been broadly interpreted both by statute and judicial interpretation. The term “religion” includes all aspects of religious observance, practice and belief.²⁰⁴ Furthermore, courts have granted protection to “moral or ethical beliefs” and have specifically stated that “religious beliefs . . . need not be ‘acceptable, logical, consistent, or comprehensible to others.’”²⁰⁵ This broad definition of “religion” is analogous to the fact that “genetic information” can be construed equally as broad.²⁰⁶ If a similar interpretation is afforded to GINA claimants as is afforded to religious discrimination claimants under Title VII, then courts will take an inclusive rather than exclusive look at plaintiffs. Moreover, if this same wide deference given to religious beliefs is also given to genetic disease predispositions, then it will not force plaintiffs relying on GINA to have to substantiate their disease to the bench, which may be embarrassing or overly burdensome.

The general philosophy of broad statutory and judicial interpretation of “religion” requires a similar *prima facie* framework. In a religious discrimination action under Title VII, to prove a *prima facie* case, the plaintiff must show that the employment decision was made by an individual who had actual knowledge of the protected religion.²⁰⁷ The knowledge requirement already changes the *McDonnell Douglas* *prima facie* case, and not surprisingly a new framework is applied. A plaintiff must make a showing of the following elements:

- (1) he or she has a bona fide religious belief that conflicts with an employment requirement;

202. O'Connor v. Northshore Int'l Ins. Servs., 61 F. App'x 722, 724 (1st Cir. 2003).

203. See *id.*

204. Title VII of Civil Rights Act of 1964, 42 U.S.C. § 2000e(j) (2006).

205. EEOC v. Unión Independiente de la Autoridad de Acueductos y Alcantarillados de Puerto Rico, 279 F.3d 49, 56 (1st Cir. 2002) (citing *Thomas v. Review Bd. of Ind. Emp't Sec. Div.*, 450 U.S. 707, 714 (1981)).

206. See Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. § 2000ff(4)(A).

207. Lubetsky v. Applied Card Sys., Inc. 296 F.3d 1301, 1306 (11th Cir. 2002).

(2) he or she has informed the employer about this belief;

(3) he or she was disciplined for failure to comply with the conflicting employment requirement.²⁰⁸

This general framework is applied by a majority of Circuit Courts in religious discrimination cases.²⁰⁹ Although the three-step *prima facie* case will need to be altered when applied to GINA, the essential element of “knowledge” ought to remain.

2. Proposed *Prima Facie* Framework Under GINA

Ultimately, a GINA framework will likely combine *McDonnell Douglas* and religious discrimination *prima facie* proof structures.²¹⁰ The first prong will be a relatively easy pleading standard, reading for example: “(1) the employee must prove that he or she has had genetic testing done that indicated a genetic predisposition to a certain disease or condition, or that there is evidence of a familial genetic disease or condition.” Courts will probably interpret this gateway prong broadly. The second prong will resemble the *McDonnell Douglas* *prima facie* case, insuring that: “(2) the employee claiming genetic discrimination was qualified for the position in issue.” The third prong will likely combine an adverse employment action with the employer having knowledge of the alleged protected disease. An immediate distinction must be made with the religious framework, though. The religious framework presupposes that the employee has informed the employer.²¹¹ This immediately conflicts with the purpose and statutory provisions of GINA of preventing employer acquisition of genetic information.²¹² The only voluntary disclosure that employers can claim is disclosure in which “the employee provides prior, knowing, voluntary, and written authorization.”²¹³ Therefore, as long as the employee has given

208. *Id.* at 1306 n.2.

209. *See id.* (citing *Virts v. Consol. Freightways Corp. of Del.*, 285 F.3d 508, 516 (6th Cir. 2002); *Chalmers v. Tulon Co.*, 101 F.3d 1012, 1019 (4th Cir. 1996); *Protos v. Volkswagen of Am., Inc.*, 797 F.2d 129, 133-34 (3d Cir. 1986); *Philbrook v. Ansonia Bd. of Educ.*, 757 F.2d 476, 481 (2d Cir. 1985), *aff'd*, 479 U.S. 60 (1986); *Turpen v. Mo.-Kan.-Tex.R.R.*, 736 F.2d 1022, 1026 (5th Cir. 1984); *Anderson v. Gen. Dynamics Convair Aerospace Div.*, 589 F.2d 397, 401 (9th Cir. 1978)).

210. *See McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 802-11 (1973) (explaining the burden-shifting framework of Title VII); *Lubetsky*, 296 F.3d at 1306 n.2 (describing the requirements of a *prima facie* case of religious discrimination).

211. *See Lubetsky*, 296 F.3d at 1306.

212. *See* 42 U.S.C. § 2000ff-1(b).

213. *Id.* § 2000ff-1(b)(2)(B).

authorization for their genetic information to the employers, their claim ought to move forward.²¹⁴ If the employee has not given authorization, he or she must then produce evidence either that the employer wrongfully obtained genetic information, or that the employer obtained it through one of the other exceptions to the general prohibition against acquisition of genetic information. It should be noted that in order to prove the knowledge requirement, the employee does not have to prove that the employer wrongfully obtained his or her genetic information. However, proof of such is strong evidence that the employer used this information for discriminatory purposes. Thus, the third prong ought to read: “(3) the employee must produce evidence that the employer has knowledge of the genetic information.” Regardless of the factual circumstances regarding the acquisition of the genetic information, the *McDonnell Douglas* philosophy of flexibility allows for widespread application.²¹⁵

The final prong will be substantially different from the last prong in a *prima facie* case of religious discrimination. Under the religious discrimination *prima facie* case, a plaintiff is required to prove that an employer failed to comply with the employee’s request.²¹⁶ This is known as a “reasonable accommodation” and is prescribed by statute.²¹⁷ GINA, upon its enactment, has failed to statutorily require reasonable employer accommodation. This requirement should not be inferred by judicial interpretation and should remain as a purposeful and intentional omission by Congress. Therefore, the final prong should not resemble the religious accommodation requirement but should mimic a traditional *McDonnell Douglas* approach. Most likely the final prong will be: “(4) the alleged adverse action took place under circumstances giving rise to the inference of genetic information discrimination.” In summary, the four elements that should be required for a plaintiff to prove a *prima facie* case of genetic discrimination under GINA should read as follows:

The employee must prove that he or she has had genetic testing done that indicated a genetic predisposition to a certain disease or condition, or that there is evidence of a familial genetic disease or condition;

214. See *id.* Proof that the employee gave voluntary authorization to the employer to access his or her genetic information should be sufficient to meet the burden of proving that the employer had knowledge. However, this presumption of knowledge may be rebutted by the employer. See *supra* Part V.

215. See *McDonnell Douglas*, 411 U.S. at 802 n.13.

216. See *Lubetsky*, 296 F.3d at 1305.

217. See 42 U.S.C. § 2000e(j).

the employee claiming genetic discrimination was qualified for the position in issue;

the employee must produce evidence that the employer has knowledge of the genetic information; and

the alleged adverse action took place under circumstances giving rise to the inference of genetic information discrimination.

GINA must also be applied to defendants since Title VII *prima facie* cases are centered around burden shifting.²¹⁸ Once the plaintiff has proved his or her *prima facie* case of genetic discrimination, the burden then shifts to the defendant to rebut this claim. There are multiple defenses available to the defendant, most notably, a defense explaining a non-discriminatory, legitimate reason for the employer's adverse action against the employee.²¹⁹ If this defense is used by the employer, the case will resemble a race or sex discrimination case because the main argument will revolve around the issue of whether the non-discriminatory legitimate reason offered by the employer is merely a pretext for discrimination. In other words, if the employer can provide sufficient evidence that the adverse employment action was based on a non-discriminatory, legitimate reason, the burden will shift back to the employee to show that the employer is lying, and to provide further evidence of discrimination based on his or her genetic data.

GINA defendants may also argue on two separate theories in regards to the third prong of knowledge. Defendants may either argue that they were authorized to have the information under one of the exceptions provided in GINA, or that they did not have any knowledge of the claimant's genetic information.²²⁰ If the employer can prove that it did not have knowledge of the plaintiff employee's genetic information, the plaintiff's *prima facie* case would be destroyed in regards to his or her GINA claim. In the alternative, if the employer can prove that it had proper authorization to have access to the plaintiff's genetic data, or that it obtained the genetic data through one of the other exceptions provided under GINA, the plaintiff's *prima facie* case would likely be weakened in the eyes of the finder of fact.²²¹ It is important to note that this would not defeat the inference of discrimination, but only

218. See discussion *supra* Part V.

219. See *McDonnell Douglas*, 411 U.S. at 802.

220. See 42 U.S.C. § 2000ff-2(b).

221. See *id.*

weaken the plaintiff's argument. If the employer cannot prove that he obtained the genetic information under one of the exceptions listed in GINA, it can be inferred that he or she actively obtained the information in violation of GINA, thus supporting the inference of genetic discrimination.

Another defense that the courts could make available to defendants in GINA actions is one where the defendant is given the opportunity to admit that the plaintiff's genetic information was the basis for the adverse employment action, but then produce evidence that such action was taken because of a legitimate concern about the safety of the employee. To meet this burden, the employer would have to prove that it performed adequate research to determine that some aspect of the employee's genetic makeup makes him or her susceptible to developing a certain disease, and that some aspect of the particular work environment increases the employee's chance of developing such disease.

As an unrealistic example to explain this idea, imagine that Superman was working in a plant owned and operated by LexCorp that produces kryptonite. Unfortunately, being around kryptonite significantly increases Superman's chance of developing Super-Cancer, a disease to which he is genetically predisposed. The employer would have to produce sufficient medical statistics or testimony to prove that a person who is genetically predisposed to Super-Cancer has a significantly higher risk of developing such disease if he or she spends prolonged periods of time exposed to kryptonite. Obviously, there would need to be medical research done to make such a determination in real situations where a similar fact pattern may occur. The employer should also be required to prove that it was impossible to reasonably accommodate the employee instead of taking an adverse employment action against him or her, or that the accommodation would place an undue burden on the business of the employer. This "reasonable accommodation" requirement should be similar to the one found in the ADA.²²² If the employer proves a legitimate safety concern, it should not escape liability but rather the damages should be mitigated to some degree at the discretion of the court.

Courts may be unwilling to adopt such a defense because it is in conflict with a line of cases under Title VII concerning employers who take adverse employment actions based on benevolent purposes. In these cases, the courts have held that employees should have full discretion

222. See Americans with Disabilities Act of 1990, 42 U.S.C. § 12112(b)(5)(A).

regarding their safety and, therefore, employers cannot take adverse employment actions even when the employee's safety is the motivating factor.²²³ In *Johnson Controls, Inc.*, the plaintiff-employees alleged that the policy of their employer that excluded women who were pregnant or capable of bearing children from job positions involving lead exposure was in violation of Title VII because it was facially discriminatory against women.²²⁴ Johnson Controls argued that the policy fell under the safety exception to the "bona fide occupational qualification" ("BFOQ") and, therefore, was excluded from the scope of Title VII.²²⁵ The Supreme Court rejected this argument, holding that the safety of Johnson Controls' employees and their offspring was related neither to the "essence of the business" in which Johnson Controls was involved nor the employees' ability to perform their jobs.²²⁶

In *Dothard*, the Court indicated that discrimination on the basis of sex because of safety concerns is allowed only in narrow circumstances, such as where the safety of people other than the individual employee is involved.²²⁷ There, the Court upheld an Alabama State statute that required correctional counselors in Alabama prisons to be at least 5 feet 2 inches tall and to weigh at least 120 pounds, effectively excluding a disparate number of female applicants from employment.²²⁸ The Court reasoned that the statute was a BFOQ because it involved an employee's ability to maintain the safety of the inmates, which is an essential business function of a prison.²²⁹ However, it stressed that the argument that a particular job is too dangerous for a woman would usually not trigger the BFOQ exception because the purpose of Title VII is to allow the woman to make that decision for herself.²³⁰

Although the "legitimate safety concern" defense that we propose be offered to employers in GINA cases seems to fly in the face of the Supreme Court's holdings in cases like *Johnson Controls* and *Dothard*, we do not suggest that the defense allow a total escape from liability. Rather, the defense should only be a way for employers to mitigate the damages owed to the plaintiff-employees. The public policy supporting a defense based on a legitimate concern for the employee's safety is

223. See, e.g., *UAW v. Johnson Controls, Inc.*, 499 U.S. 187, 202-04 (1991); *Dothard v. Rawlinson*, 433 U.S. 321, 333, 335 (1977).

224. See 499 U.S. at 191-92.

225. *Id.* at 202.

226. *Id.* at 206.

227. See *Dothard*, 433 U.S. at 335-36.

228. See *id.* at 323-24, 336-37.

229. See *id.* at 335-36.

230. *Id.* at 335.

threefold. First, such a defense would potentially benefit employers because it allows them to reduce the risk that their health insurance costs will increase. If employees with genetic predispositions to certain diseases work in an environment which significantly increases the probability that they will develop such disease, there is a strong likelihood that the employee will develop the disease, thus driving up the price of health insurance for the employer. Although the employer will still be held liable for discriminating based on genetic factors, in some situations it may still be cost-effective to do so because the damages will be mitigated. Second, this defense will benefit employees because if an employer fires an employee based on the significantly high probability that the employee will develop a genetic disease by continuing to work at that job, the employee is removed from a harmful environment. Finally, employers are in a better position to determine whether an employee with a genetic predisposition to a certain disease has a significantly higher risk of developing that disease if he or she works in a certain environment. Genetic research is still a very new area of science, and employers have more access to certain resources and more money to fund the research necessary to determine the safety risks posed to their employees. Therefore, although courts have consistently held that employees should have discretion in making employment decisions regarding personal safety,²³¹ employees may not have the appropriate resources to make an informed decision where the risks involve the interaction between genetics and the work environment.

B. GINA's Proof Structure as Compared to ADA Actions

Although the "legitimate safety concern" defense for employers is in conflict with aspects of current Title VII analysis and may be seen as a significant departure from case law, the same cannot be said with ADA analysis. The statutory provisions, federal regulations, and subsequent judicial decisions carve out an explicit safety concern within the ADA that is not present in Title VII. It is the authors' contention that the ADA line of cases will provide a sufficient rationale for a tempered paternalistic undertaking in regards to GINA. Comparisons between GINA and the ADA are premised on the fact that their fundamental undertakings deal with protecting citizens in regards to their body, medical information, and role in the workplace. The two statutes also deal with specific individuals rather than an entire gender or racial

231. See *id.* at 335; *Johnson Controls*, 499 U.S. at 206.

classes.

1. The ADA's Direct Threat Doctrine

The explicit purpose of the ADA's enactment was "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."²³² Congress also found that "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination."²³³

Specifically in the area of employment law, Congress wanted to rectify persistent discrimination against disabled persons in the workplace through the passage of the ADA.²³⁴ The explicit language of the statute states that "no [employer] shall discriminate against a qualified individual on the basis of disability in regard to . . . [the] privileges of employment."²³⁵ Employers are further required to reasonably accommodate a qualified individual so long as the accommodations will not become an undue hardship.²³⁶ This requirement of a reasonable accommodation is not unique to the ADA since similar language can be found with regard to religious discrimination under Title VII.²³⁷

Congress has provided that an employer may make employment decisions based on religion only when "an employer demonstrates that he is unable to reasonably accommodate [an] employee's or prospective employee's religious observance or practice without undue hardship."²³⁸ Like in other Title VII proof structures, "[o]nce an employee has established a prima facie case, [the defendant] has the burden 'to show that it could not reasonably accommodate the employee without undue hardship.'"²³⁹ The ADA framework similarly includes a reasonable accommodation requirement.

To prove a prima facie case in an ADA claim, a plaintiff must

232. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(b)(1) (2006).

233. *Id.* § 12101(a)(1) (Supp. II 2009).

234. *See id.* § 12101(a)(3) ("discrimination against individuals with disabilities persists in such critical areas as employment . . .").

235. *Id.* § 12112(a) (Supp. II 2009).

236. *Id.* § 12112(b)(5)(A).

237. 42 U.S.C. § 2000e(j).

238. *Id.*

239. *Reed v. UAW*, 569 F.3d 576, 580 (6th Cir. 2009) (alteration in original) (quoting *Virts v. Consol. Freightways Corp.*, 285 F.3d 508, 516 (6th Cir. 2002)).

demonstrate that:

- (1) he was an “individual who has a disability” within the meaning of the statute;
- (2) the employer had notice of the disability;
- (3) he could perform the essential functions of the job with reasonable accommodation; and
- (4) the employer refused to make such accommodation.²⁴⁰

Once the plaintiff proves his prima facie case, the burden shifts to the defendant to prove that the “proposed accommodation would have resulted in undue hardship.”²⁴¹ However, this proof structure does not apply to all ADA claims or defenses.

The ADA has explicitly created a particular category of jobs that are outside the scope of protectable employment – jobs that are deemed to be a “direct threat.”²⁴² Federal regulations and judicial interpretation after the passage of the ADA shed light and further explanation as to the application and meaning of “direct threat.” The rationale for the “direct threat” language has been explained as “a very narrow permission to employers to exclude individuals with disabilities *not* for reasons related to their performance of their jobs, but because their mere presence could endanger others.”²⁴³ Relevant factors that employers may use to determine if an employee poses a “direct threat” include:

- (1) The duration of the risk;
- (2) The nature and severity of the potential harm;
- (3) The likelihood that the potential harm will occur; and

240. *Parker v. Columbia Pictures Indus.*, 204 F.3d 326, 332 (2d Cir. 2000).

241. *Id.*

242. See 42 U.S.C. § 12111(3). “The term ‘direct threat’ means a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation.” *Id.*

243. *Morton v. United Parcel Serv., Inc.*, 272 F.3d 1249, 1259 (9th Cir. 2001) (emphasis in original), *overruled by* *Bates v. United Parcel Serv., Inc.*, 511 F.3d 974, 982 (9th Cir. 2007). *Bates* only overrules “*Morton* to the extent that it imposes a [bona fide occupational qualification] standard under the ADA, as the plain language of the ADA does not support such a construction.” 511 F.3d at 982. Thus, it still upholds *Morton’s* rationale for a “direct threat.”

(4) The imminence of the potential harm.²⁴⁴

Furthermore, the determination of a direct threat must be uniformly applied to both prospective and current employees, and not just those who are entitled to ADA protection.²⁴⁵ To prove the existence of a direct threat, the employer must meet a higher evidentiary standard. Specifically, the “assessment . . . relies on the most current medical knowledge and/or on the best available objective evidence.”²⁴⁶

The only guidance the Supreme Court has given with regard to the direct threat exception is that “the ADA [does] not ask whether a risk exists, but whether it is significant.”²⁴⁷ The Court has not ruled as to the burden of proof required for a direct threat. There is some debate as to whether the burden is on the defendant to prove that a direct threat exists or on the plaintiff to demonstrate that they are not a direct threat.²⁴⁸ However, there is overwhelming support from multiple courts finding that the defendant bears the burden of proving a direct threat as an affirmative defense.²⁴⁹ Although this is the dominant jurisprudence, there is still significant criticism,²⁵⁰ and only some judicial support for the requirement that the direct threat be a necessary part of the plaintiff's prima facie case.²⁵¹

An illustrative case in which an employer was able to show that its refusal in hiring was based on the direct threat exception can be found in *Leverett v. City of Indianapolis*.²⁵² The plaintiff had applied and been denied a position as a firefighter for the City of Indianapolis due to his “total and permanent hearing loss in his left ear,” and sued under the

244. 29 C.F.R. § 1630.2(r) (2010).

245. 45A AM. JUR. 2D *Job Discrimination* § 303 (2010).

246. 29 C.F.R. § 1630.2(r).

247. *Bragdon v. Abbott*, 524 U.S. 624, 649 (1998).

248. *See Branham v. Snow*, 392 F.3d 896, 906 n.5 (7th Cir. 2004).

249. *See, e.g., Bates v. United Parcel Serv., Inc.*, 511 F.3d 974, 991 (9th Cir. 2007); *Hargrave v. Vermont*, 340 F.3d 27, 35 (2d Cir. 2003); *Rizzo v. Children's World Learning Ctrs., Inc.*, 213 F.3d 209, 212 (5th Cir. 2000); *EEOC v. Hussey Copper Ltd.*, 696 F. Supp. 2d 505, 520 (W.D. Pa. 2010); *EEOC v. Midwest Division-RMC, LLC*, No. 04-00883-CV-W-REL, 2006 WL 2164618, at *74 (W.D. Mo. July 31, 2006); *EEOC v. Overnite Transp. Co.*, No. 2:02CV591, 2006 WL 2594479, at *10 (S.D. Ohio July 5, 2006).

250. *See Jon L. Gillum, Tort Law and the Americans with Disabilities Act: Assessing the Need for a Realignment*, 39 IDAHO L. REV. 531, 566-67 (2003) (discussing the three existing judicial resolutions to the “Burden Problem”).

251. *See EEOC v. Amego, Inc.*, 110 F.3d 135, 144 (1st Cir. 1997) (“[I]n a Title I ADA case, it is the plaintiff's burden to show that he or she can perform the essential functions of the job, and is therefore ‘qualified.’ Where those essential job functions necessarily implicate the safety of others, plaintiff must demonstrate that she can perform those functions in a way that does not endanger others”).

252. 51 F. Supp. 2d 949 (S.D. Ind. 1999).

ADA.²⁵³ The City argued that their hearing test was meant to test one's ability to "localize sound," which is a critical aspect of the duties of a firefighter.²⁵⁴ The court agreed with the City, finding that the test was medically accurate, not created arbitrarily, and ultimately holding that, for a firefighter, a "hearing requirement [in both ears] is job-related and consistent with business necessity."²⁵⁵ Intuitively, this ruling seems to be in line with the ADA generally and with the statutory provision providing for a direct threat exception. There is little disagreement as to whether or not a firefighter poses a direct threat to others where any miscommunication could lead to potentially devastating harm to both fellow employees and the public at large.

In keeping with the discussion of our valued employee Superman,²⁵⁶ LexCorp is no better off with the direct threat exception to discrimination under the ADA. The reason for this is not legal but factual. A genetic predisposition to Super-Cancer only represents a potential direct threat to Superman himself, not to other employees or customers. Furthermore, upon the manifestation of Super-Cancer, GINA affords no protection and Superman then only falls under the auspices of the ADA. As outlined previously, a large number of courts have held that under Title VII, employer paternalism is not a defense to discriminatory employment actions.²⁵⁷ However, there is a line of ADA legal rationale that would grant LexCorp the ability to act paternally towards Superman – the "threat-to-self" doctrine.²⁵⁸ It is the authors' contention that employers in GINA claims should be afforded the possibility to mitigate damages using a "threat-to-self" defense.

2. The ADA's "Threat-to-Self" Doctrine

A circuit split between the Ninth and Eleventh Circuits in their interpretation of the Equal Employment Opportunity Commission's ("EEOC") regulations regarding the ADA "threat-to-self" doctrine was the primary reason for the *Echazabal* ruling.²⁵⁹ The Ninth Circuit

253. *Id.* at 950, 952.

254. *Id.* at 958.

255. *Id.* at 958-59.

256. See discussion *supra*, Part V.A.2.

257. See, e.g., *UAW v. Johnson Controls, Inc.*, 499 U.S. 187, 199-200 (1991) (rejecting the validity of an employer's paternalistic regulations in holding that fetal protection policies which prohibit women of child-bearing age from working in positions that are potentially harmful to their fetuses).

258. See *Chevron U.S.A. Inc., v. Echazabal*, 536 U.S. 73, 78 (2002).

259. See *id.* at 77-78.

refused to follow the EEOC's regulation in extending the scope of the "threat-to-self" doctrine.²⁶⁰ The EEOC regulation extends the "direct threat to others" exception of the ADA to include a direct threat to the health or safety of the individual as well.²⁶¹ The plaintiff in *Echazabal* had been working for an independent contractor at Chevron U.S.A. on an oil refinery.²⁶² Upon applying directly for a job with Chevron, he was required to take a physical, where it was found the plaintiff had liver abnormalities due to Hepatitis C.²⁶³ The plaintiff was denied the position because his condition would worsen upon "continued exposure to toxins at Chevron's refinery."²⁶⁴ Forced to decide the validity of the regulation, the opinion proclaimed the "threat-to-self" defense a valid action by the EEOC.²⁶⁵ Although predominantly an opinion on statutory interpretation,²⁶⁶ and the validity of Federal Regulations,²⁶⁷ the opinion makes some overtly intriguing claims in dictum.

The opinion fails to discredit Chevron's explanation for the "threat-to-self" defense, which included that the defendants "[wished] to avoid time lost to sickness, excessive turnover from medical retirement or death [and] litigation under state tort law."²⁶⁸ Without denouncing the arguments of Chevron, the Court seemed to take a different approach to discrimination law. This is verified when the opinion makes a distinction between Title VII business necessity cases like *Dothard* and the present ADA instance. The Court noted that cases such as *Dothard* and *Johnson Controls* "are beside the point, as they, like Title VII generally, were concerned with paternalistic judgments based on the broad category of gender, while the EEOC has required that judgments based on the direct threat provision be made on the basis of individualized risk assessments."²⁶⁹ The ADA "threat-to-self" regulation thus takes a completely different approach to judicial or statutory paternalism than Title VII does.

In a final analysis of our employee Superman, it seems that if the ADA "threat-to-self" defense is adopted, LexCorp may have the ability

260. See *id.* at 77.

261. 29 C.F.R. §§ 1630.2(r), 1630.15(b)(2) (2010).

262. *Echazabal*, 536 U.S. at 76.

263. *Id.*

264. *Id.*

265. *Id.* at 76.

266. See *id.* at 81, 84 (discussing "expressio unius exclusio alterius").

267. See *id.* at 79, 84-85 (applying the EEOC's regulations to *Chevron, U.S.A., Inc. v. Natural Res. Def. Council, Inc.*, 467 U.S. 837 (1984)).

268. *Id.* at 84.

269. *Id.* at 86 n.5.

to remove Superman. It should be noted that the legitimate safety concern and “threat-to-self” doctrines are virtually identical. Furthermore, the legitimate safety concern defense will not be an affirmative defense but instead a mitigation technique for employers to mitigate damages. Upon LexCorp’s heightened evidentiary standard of “the most current medical knowledge and/or on the best available objective evidence,”²⁷⁰ if an employer can show that there was a legitimate safety reason for its employment decision (that kryptonite will in fact lead to Superman’s demise), it is entitled to limited damages. The reason for limited damages and not an affirmative defense is because, ultimately, the employer still has made an adverse employment decision because of one’s genetic information. As the court in *Echazabal* failed to denounce the practical realities of termination decisions for both the employee and employer, the authors as well suggest that pragmatic concerns ought to dictate. If an employer acting responsibly, and with verifiable evidence and good reason, makes an employment decision it thinks will better its employee in the long run, it ought not be punished with excessive or punitive damages.

VI. CONCLUSION

GINA is not simply “a solution in search of a problem.” Rather, it is a preemptive law intended to prevent a form of discrimination that will likely become more of a problem in the near future. As genetic information continues to become increasingly available to employers, it is very likely that courts will see a rise in claims of genetic discrimination in the workplace. Many claims of genetic discrimination will probably be brought in conjunction with claims of discrimination based on race, sex, religion, and national origin. As stated by Elizabeth Pendo, Professor of Law at Saint Louis University School of Law, “the use of genetic information is not entirely separate from existing patterns of race and sex discrimination, rather these can be interlocking systems of classification and discrimination in the workplace.”²⁷¹

The case of *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*²⁷² provides an example of GINA’s relevance. Although decided ten years before the enactment of GINA, if the case were tried today the plaintiffs’

270. 29 C.F.R. § 1630.2(r) (2010).

271. Elizabeth Pendo, *Race, Sex, and Genes at Work: Uncovering the Lessons of Norman-Bloodsaw*, 10 HOUS. J. HEALTH L. & POL’Y 227, 250 (2010).

272. 135 F.3d 1260 (9th Cir. 1998).

claim would fall under the protections of GINA.²⁷³ In *Norman-Bloodsaw*, the plaintiffs were required to give blood and urine samples to the defendant employer in order to be considered for a position.²⁷⁴ These samples were tested for syphilis, sickle cell trait, and pregnancy.²⁷⁵ The plaintiffs contended that their employer violated the ADA, the right to privacy under both the United States Constitution and the California Constitution, and Title VII.²⁷⁶ Lawrence Berkeley Laboratory's mandatory sickle cell trait testing would be in violation of the prohibition against genetic testing under GINA if litigated today.²⁷⁷ Thus, GINA provides employees with an additional layer of protection against discrimination, with potentially larger settlements and jury awards.²⁷⁸

As of April 2010, only five months after GINA took effect, there had been approximately eighty claims filed with the EEOC alleging violations of GINA.²⁷⁹ The most notable of these claims is the complaint filed by Pamela Fink against her employer, MXenergy, in April 2010.²⁸⁰ After her two sisters were unfortunately diagnosed with breast cancer, Pamela decided to take advantage of the technological advances in genetic testing.²⁸¹ Through such tests, she was able to discover that she also carried a mutation in the BRCA2 gene, giving her an eighty-percent likelihood of developing breast cancer.²⁸² Electing to undergo preventive double mastectomy surgery, Pamela took a leave of absence from her job as Public Relations Director for MXenergy.²⁸³ Despite having an exemplary performance record before taking leave for the operation, upon her return to work she received a negative review

273. See 42 U.S.C. § 2000ff-1(b) (2006) (discussing GINA's prohibition on employer genetic testing).

274. 135 F.3d at 1264-65.

275. *Id.*

276. *Id.* at 1264. The case ultimately ended in a settlement agreement between the parties. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, No. C-95 3220 VRW, 2001 WL 764473, at *1 (N.D. Cal. June 22, 2001). However, even though the case settled, in reviewing the district court's rulings, the Court of Appeals for the Ninth Circuit found that the district court had erred in dismissing some of the plaintiffs' claims, but upheld the dismissal of the ADA claim. See *Norman-Bloodsaw*, 135 F.3d at 1264.

277. See § 2000ff-1(b).

278. See *Norman-Bloodsaw*, 135 F.3d at 1264 (showing that prior to the enactment of GINA, the claims and remedies for genetic discrimination were limited).

279. Greenhouse, *supra* note 12.

280. *Id.*

281. *Id.*

282. *Woman Says She Was Fired Because She Carries Gene for Breast Cancer* (Fox 61News television broadcast Apr. 28, 2010), available at <http://www.cancerandyourgenes.com/page/2/>.

283. *Id.*

and was subsequently fired.²⁸⁴ Pamela alleges that her termination was because of her genetic predisposition to breast cancer.²⁸⁵ If this case goes to trial, it will be interesting to see if the court adopts the prima facie structure proposed in this note.

Applying the facts of Pamela Fink's complaint to the GINA framework proposed in this note, a court would likely find that the defendant violated GINA. Under the first element of the four prong test, Pamela can likely prove that (1) she had genetic testing done and was positively identified with having a genetic predisposition to breast cancer. Because of her positive reviews, she will also likely be able to prove that (2) she was qualified for the position from which she was terminated. Pamela's request for leave to undergo a mastectomy infers that (3) the employer had knowledge of her genetic information. In response to the defendant's likely argument that Pamela's termination was due to structural changes of the company that eliminated the need for her position, Pamela will likely argue that this is mere pretext for discrimination. To support this claim she will presumably produce evidence that prior to her leave she had an outstanding performance record and that the employee who replaced her while she was on leave was still employed by the defendant.²⁸⁶ This evidence (4) gives rise to the inference of genetic discrimination. At this point, there is a sufficient question of fact as to whether Pamela has met her burden of persuasion.

The authors believe that their GINA prima facie structure and "legitimate safety concern" defense provide an adequate framework for cases alleging genetic discrimination under GINA.

284. 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#.Tw0iqNQS34s>.

285. *Woman Says She Was Fired Because She Carries Gene for Breast Cancer*, *supra* note 282.

286. *See id.*

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