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Joanne Barken

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NOTES

Judging GINA

DOES THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 OFFER ADEQUATE PROTECTION?

INTRODUCTION

With the advancement of medicine and technology in genetics, new forms of discrimination have emerged in both the healthcare system and the workplace. In an attempt to minimize the costs associated with insurance premiums and sick leave, some employers have chosen to terminate employees who are genetically predisposed to certain conditions.¹ For example, Kim, a social worker, mentioned to her co-workers that she had cared for her mother who passed away from Huntington's disease.² Due to the genetic nature of the illness, this passing comment indicated that Kim had a 50% chance of also developing the debilitating disorder.³ Despite her record of strong job performance, Kim was discharged from her position only a week after her revelation.⁴ For Gary, his employer administered secret genetic testing in an attempt to determine which employees were genetically predisposed to developing Carpal Tunnel Syndrome.⁵ When Gary refused to partake in the genetic screening, his employer initiated disciplinary

¹ Rivka Jungreis, Note, *Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act of 2005 and Public Fears About Genetic Information*, 15 J.L. & POL'Y 211, 218 (2007).

² NAT'L P'SHIP FOR WOMEN & FAMILIES ON BEHALF OF THE COAL. FOR GENETIC FAIRNESS, *FACES OF GENETIC DISCRIMINATION: HOW DISCRIMINATION AFFECTS REAL PEOPLE* 5 (2004), available at <http://www.nationalpartnership.org/site/DocServer/FacesofGeneticDiscrimination.pdf>.

³ *Id.*

⁴ *Id.*

⁵ *Id.*

proceedings to terminate his employment.⁶ Likewise, though David has an approximately 16% chance of having a cancerous genetic mutation,⁷ he is waiting for discrimination protection before taking the necessary test.⁸ Not surprisingly, for many Americans, there is a growing wariness toward genetic screening out of fears of discrimination in the work place.

The nationwide fear of genetic testing has detrimental consequences not only for the physical health of individuals, but also for scientific development.⁹ Without participants to enroll in genetic studies, researchers cannot improve the accuracy of genetic screening, since large data pools are often required to link gene variants to health conditions.¹⁰ In addition, individuals put their physical well-being at risk by foregoing the opportunity to take additional measures to monitor or avoid conditions for which they are genetically predisposed.¹¹ In one frightening situation, the parents of a young girl learned that their family had a history of a Factor V Leiden mutation, a condition associated with a heightened risk for blood clots.¹² The family was advised to wait until Congress passed legislation protecting against genetic discrimination before testing their daughter for the mutation.¹³ As a result of waiting, their daughter nearly died after suffering a massive blood clot.¹⁴

In response to the growing concern about genetic discrimination in the workplace,¹⁵ Congress passed the Genetic Information Nondiscrimination Act of 2008 (“GINA”).¹⁶ Arguably, this new legislation will allow Americans to take greater advantage of genetic testing opportunities and to

⁶ *Id.*

⁷ Malorye Allison, *Industry Welcomes Genetic Information Nondiscrimination Act*, 26 NATURE BIOTECHNOLOGY 596, 597 (2008).

⁸ *Id.*

⁹ Susannah Baruch & Kathy Hudson, *Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World*, 83 AM. J. HUM. GENETICS 435, 436 (2008).

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ *Id.*

¹⁵ Kathy L. Hudson et al., *Keeping Pace with the Times—The Genetic Information Non-discrimination Act of 2008*, 358 NEW ENG. J. MED. 2661, 2661 (2008); Anne Bond Emrich, *New Law Will Protect Genetic Information*, GRAND RAPIDS BUS. J., Oct. 29, 2008, at S9.

¹⁶ IOMA, *Employer Advocates Remain Wary of Genetic Bias Law’s Potential Effects*, 8 MANAGING BENEFITS PLANS 1, 1 (2008) [hereinafter *Employer Advocates*].

receive more personalized medical care.¹⁷ For health insurance providers, GINA bars the use of an applicant's genetic information when making policy enrollment or coverage decisions.¹⁸ Furthermore, the Act addresses potential genetic discrimination in the workplace by prohibiting employers from using genetic information when making decisions related to the terms and conditions of employment.¹⁹

This Note argues that GINA was a necessary law in light of this country's history of discrimination on the basis of genetic information. Since prior federal laws, such as the Americans with Disabilities Act (the "ADA"), Title VII of the Civil Rights Act of 1964 (the "Civil Rights Act"), and the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") do not adequately protect employees from genetic discrimination, GINA now offers relief to employees who fall victim to discrimination based on a predisposition to a genetic disease. However, this legislation is only the first step in preventing discrimination by employers using genetic information. Indeed, the bill has not gone far enough to protect individuals and their families. Consequently, as science and technology continue to advance, amendments to GINA will be needed in order to provide full protection to affected individuals.

Part I of this Note presents a basic overview of genetic testing. Part II examines the historical background of GINA with specific instances of genetic discrimination as well as quantitative evidence of the current fear of discrimination based on genetic predisposition to an illness. In addition, Part II examines the gaps in federal legislation prior to GINA and argues that the ADA, Title VII, and HIPAA did not provide adequate protection from discrimination based on one's genes. Part III of this Note describes the scope of protection provided to employees by GINA. Finally, Part IV concludes that GINA fails to fully address the issue of genetic discrimination in the workplace, and, as such, additional protections are required.

¹⁷ Emrich, *supra* note 15.

¹⁸ COALITION FOR GENETIC FAIRNESS, WHAT DOES GINA MEAN?: A GUIDE TO THE GENETIC INFORMATION NONDISCRIMINATION ACT 3, 7 (2008), available at <http://www.geneticfairness.org/GINAPublication111008.pdf>.

¹⁹ *Id.* at 3, 9.

I. A BRIEF INTRODUCTION TO GENETIC TESTING

Genetic testing is an advanced method of diagnosis made available by the completion of the Human Genome Project.²⁰ Simply put, a gene is a segment of DNA that stores our hereditary information in cells.²¹ Through genes, parents pass biological information and physical traits such as hair color and height to their children.²² In particular, genes contain the “recipes” for protein creation and “supply the structural components of all our cells and tissues as well as specialized enzymes for all essential chemical reactions.”²³ These proteins enable genes to determine how well our bodies function and interact with the environment, for example, fighting infections and processing food.²⁴ It is estimated that each person has anywhere from 20,000-25,000 genes.²⁵

The unit of information in DNA is the “base,” which is composed of adenine, thymine, cytosine, or guanine—“A,” “T,” “C,” or “G,” respectively.²⁶ In any two individuals, the base sequence is estimated to be at least 99% identical.²⁷ Variation in DNA sequence accounts for some physical differences between people, and, in some cases, for differences in susceptibility to disease.²⁸ Rare sequence variations, called

²⁰ Hudson et al., *supra* note 15, at 2661. The Human Genome Project was completed in 2003. *Id.*

²¹ Denise Casey, *What Can the New Gene Tests Tell Us?* 36 JUDGES' J. 14, 14-15 (1997), available at http://www.ornl.gov/sci/techresources/Human_Genome/publicat/judges/judge.html (“In humans and other higher organisms, a DNA molecule consists of two ribbon-like strands that wrap around each other, resembling a twisted ladder. The ladder rungs are made up of chemicals called bases, abbreviated A, T, C, and G. Each rung consists of a pair of bases, either A and T or C and G. We have three billion base pairs (six billion bases) of DNA in most of our cells; this is our genome. With the exception of identical twins, the sequence of the bases—the order of As, Ts, Cs, and Gs—is different for everyone, which is what makes each of us unique. Variation in base sequence, along with environmental factors, accounts for all our diversity, including disease.”).

²² Paul Steven Miller, *Is There a Pink Slip in my Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 228 (2000).

²³ Casey, *supra* note 21, at 14.

²⁴ *Id.*

²⁵ Human Genome Program, U.S. Dep't Energy, Human Genome Project Information, http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml (last visited Jan. 16, 2010); Better Health Channel, Genes and Genetics, http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Genes_and_genetics (last visited Jan. 16, 2010).

²⁶ Genetics Home Reference, What is DNA?, <http://ghr.nlm.nih.gov/handbook/basics/dna> (last visited Jan. 16, 2010).

²⁷ *Id.*

²⁸ Casey, *supra* note 21, at 16.

mutations, can vastly increase the risk of certain diseases by producing “faulty proteins that function at less-than-normal levels or those that are completely nonfunctional”²⁹

The Human Genome Project enabled scientists to search for genes associated with diseases such as cystic fibrosis and Huntington’s disease.³⁰ By far, the most immediate and practical application to come out of the Project was the genetic test, which inspects “DNA sample[s] for mutated sequences.”³¹ Today, over 1,100 genetic tests are available which can be used for carrier testing, prenatal genetic testing, preimplantation genetic testing, newborn genetic screening, genome scanning,³² “presymptomatic testing for predicting adult-onset disorders such as Huntington’s disease, presymptomatic testing for estimating the risk of developing adult-onset cancers and Alzheimer’s disease, confirmational diagnosis of a symptomatic individuals, and forensic/ identity testing.”³³

Diagnostic testing explains why a person has symptoms of a disease and can also be used to confirm a diagnosis based on these symptoms.³⁴ Whereas presymptomatic testing can determine whether a person at risk for a disease such as Huntington’s has actually inherited the corresponding gene,³⁵ predictive testing can be used to determine whether a person not known to be at risk is in fact likely to develop a genetically based disease, such as particular forms of cancers.³⁶ For parents, carrier testing can determine whether a person carries

²⁹ *Id.* “Sometimes only a tiny change in DNA sequence will lead to a serious disease. The substitution of just a single base, for example, leads to sickle cell anemia. . . . Too many repetitions of a particular sequence of three DNA bases can doom a person to Huntington’s disease, a fatal neurological disorder; Fragile X syndrome, the most common form of inherited mental retardation; or myotonic dystrophy, a muscle-wasting disease.” *Id.*

³⁰ *Id.* at 18.

³¹ Human Genome Program, U.S. Dep’t Energy, Gene Testing, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml (last visited Jan. 16, 2010). “For some types of gene tests, researchers design short pieces of DNA called probes, whose sequences are complementary to the mutated sequences. These probes will seek their complement among three billion pairs of an individual’s genome. If the mutated sequence is present in the patient’s genome, the probe will bind to it and flag the mutation.” *Id.*

³² *Id.*

³³ Casey, *supra* note 21, at 17.

³⁴ NIH, U.S. Dep’t Health & Human Servs., Genetics Home Reference, What are the Types of Genetic Tests?, <http://ghr.nlm.nih.gov/handbook/testing/uses> (last visited Jan. 16, 2010).

³⁵ *Id.*

³⁶ *Id.*

a gene that, if passed to a child, will result in disease.³⁷ These tests can help people make informed choices about their personal health. However, evidence demonstrates that many Americans avoid taking advantage of these scientific developments for fear that non-favorable results could lead to discrimination by their employers, insurers, or healthcare providers.³⁸

II. LEGISLATIVE BACKGROUND OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

Senator Edward Kennedy of Massachusetts proclaimed that the Genetic Information Nondiscrimination Act of 2008 was “the first major new civil rights bill of the new century.”³⁹ Passage of this bill was no easy feat, and required thirteen years of congressional debate regarding the need for federal legislation to prevent abuse of individuals’ genetic information.⁴⁰ Throughout the debate, insurers and employers argued that existing laws provided adequate protection for individuals and that the passage of GINA would only create confusion and unnecessary costs.⁴¹ Furthermore, opponents expressed concern that the act was overly broad and that its definition of “genetic information” would require employers to provide health coverage for far too many genetic disorders.⁴² In addition, some challenged the bill on the basis that genetic discrimination did not occur in the workplace, as evidenced by the limited number of documented cases.⁴³ Likewise, employers maintained that in some situations access to genetic information is crucial to make important employment

³⁷ *Id.*

³⁸ Lauren J. Sismondo, *GINA, What Could You Do for Me One Day?: The Potential of the Genetic Information Nondiscrimination Act to Protect the American public*, 21 WASH. U. J.L. & POL’Y 459, 464 (2006); Ellen Wright Clayton, *Ethical, Legal, and Social Implications of Genome Medicine*, 349 NEW ENG. J. MED. 562, 562 (2003).

³⁹ Hudson et al., *supra* note 15, at 2662.

⁴⁰ *Id.* at 2661.

⁴¹ Lauren Elizabeth Nuffort, Note, *The Genetic Information Nondiscrimination Act of 2008: Raising a Shield to Genetic Discrimination in Employment and Health Insurance*, 21 HEALTH L. 1, 10-11 (2009).

⁴² Patricia Alten, Note, *GINA: A Genetic Information Nondiscrimination Solution in Search of a Problem*, 61 FLA. L. REV. 379, 389 (2009); Nuffort, *supra* note 41, at 11.

⁴³ Hon. Louise McIntosh Slaughter, *Genetic Testing and Discrimination: How Private is Your Information?*, 17 STAN. L. & POL’Y REV. 67, 78 (2006); Nuffort, *supra* note 41, at 11.

decisions.⁴⁴ These companies argued that access to such information allows them to both lower the potential costs associated with excessive sick leave as well as avoid the higher costs from potential increases in insurance claims from employees likely to become sick in the future.⁴⁵ However, these arguments were refuted by a long history of discrimination in the workplace made possible by employers' unregulated access to employees' genetic information. As a result, Congress determined that despite the potential for increases in litigation and employer costs, GINA was an absolutely necessary law.⁴⁶

A. *Genetic Discrimination of Racial and Ethnic Groups*

Long before the completion of the Human Genome Project and the resulting easy accessibility of genetic information, Americans still had reason to fear employment discrimination on the basis of their genes. In the early 1970s, scientists discovered a gene linked with sickle cell anemia—a blood disorder which is found in individuals of sub-Saharan African descent more commonly than other races.⁴⁷ In response to this discovery, many states mandated sickle cell anemia screening for African-Americans.⁴⁸ Later, researchers issued reports that those carrying the diseased gene might be more vulnerable to workplace toxins.⁴⁹ While the mandatory testing policies were originally intended to merely identify carriers and thus offer prenatal testing, the results were not kept confidential and were ultimately used in a discriminatory manner.⁵⁰ Healthy carriers of the gene suffered adverse employment actions, and a false stigma developed that African-Americans were inherently more susceptible to genetic disease than individuals of other races.⁵¹ In 1972, Congress responded by passing the National Sickle Cell Anemia Control Act, which

⁴⁴ Nuffort, *supra* note 41, at 11.

⁴⁵ *Id.*

⁴⁶ Daniel Schlein, *New Frontiers for Genetic Privacy Law: The Genetic Information Nondiscrimination Act of 2008*, 19 GEO. MASON U. CIV. RTS. L.J. 311, 351 (2009).

⁴⁷ Jungreis, *supra* note 1, at 228.

⁴⁸ Christine Formas Norris, Note, *The Genetic Information Nondiscrimination Act of 2008: History, Successes, and Future Considerations*, 7 U. MD. L.J. RACE, RELIGION, GENDER & CLASS 192, 201 (2007).

⁴⁹ Jungreis, *supra* note 1, at 228.

⁵⁰ *Id.* at 228-29.

⁵¹ Norris, *supra* note 48, at 201.

banned states from federal funds unless their mandated sickle cell screening programs were made voluntary.⁵²

Like African-Americans, people of Ashkenazi (Eastern European) Jewish descent have also feared discriminatory treatment for their susceptibility as a group to certain genetic characteristics such as Tay-Sachs disease, as well as breast, colon, and ovarian cancers.⁵³ As a result, in the 1980s, Rabbi Joseph Eckstein created an organization called Dor Yeshorim to prevent recessive genetic diseases from being passed from one generation to the next.⁵⁴ This program screens Hasidic youths and informs them of their genetic compatibility with potential partners to prevent marriage and procreation among individuals possessing the genes for various diseases.⁵⁵ In addition to preventing the tragedy of a child born with a life-threatening genetic disorder, the program is also designed to “avoid the risk of stigmatizing . . . young single[s] . . . [and] their family members.”⁵⁶ While this program may have sought to provide protection, in effect it has contributed to the stigmatization of individuals based on their genetic predispositions.

*B. Fears of Genetic Information in the Workplace—
Quantitative Evidence*

The most common concern among those who seek genetic testing is that the results will be used in some harmful way, typically either by denial of health insurance or by discrimination with regard to hiring or firing decisions.⁵⁷ In 1998, the federal government funded a national survey in conjunction with the National Center for Genome Resources to discern the public’s attitude regarding the emerging availability of genetic testing.⁵⁸ Of the 1,000 people polled, 85% indicated that they did not want employers to have access to test results, and 27% answered that they would not be willing

⁵² *Id.*

⁵³ Janet L. Dolgin, *Personhood, Discrimination, and the New Genetics*, 66 BROOK. L. REV. 755, 789 (2001).

⁵⁴ The Shidduch Site, Medical Issues (The Shidduch Site) Jewish Genetic Diseases, <http://www.shidduchim.info/medical.html> (last visited Jan. 16, 2010).

⁵⁵ Slaughter, *supra* note 43, at 69.

⁵⁶ The Shidduch Site, *supra* note 54.

⁵⁷ Clayton, *supra* note 38, at 562.

⁵⁸ Miller, *supra* note 22, at 232.

to take a genetic test if their employer could subsequently retrieve their results.⁵⁹

Although many people desire genetic testing for cancer, a large number clearly fear potential discrimination based on the outcome.⁶⁰ In 1999, the Yale Cancer Center surveyed 300 active cancer genetic counselors and found that 85% would test for the breast cancer gene mutation and 91% would test for the hereditary nonpolyposis colon cancer gene mutation.⁶¹ However, 68% of those surveyed indicated that they would not submit the charges of these screenings to their healthcare providers, and 26% claimed that they felt compelled to use a false name.⁶² Similarly, the U.S. Department of Labor also discovered that many women do not partake in breast cancer screening due to a fear of stigmatization if the results are made available to their employers.⁶³

Recently, the American Management Association (the “Association”) has found that employers have engaged in discriminatory practices toward healthy employees found to be genetically predisposed to certain diseases.⁶⁴ Importantly, the Association reported that employers have accessed their workers’ genetic information in the following ways: “one percent was conducting genetic tests for Sickle Cell Anemia, 0.4 percent was testing for Huntington’s disease . . . [f]ourteen percent were conducting workplace susceptibility testing which surveyors acknowledged might include genetic testing, . . . [and t]wenty percent were requesting family medical histories.”⁶⁵ In 2007, the American Journal of Human Genetics reported that three-quarters of their survey respondents desired a federal law that would thwart employers from making hiring and

⁵⁹ *Id.* at 232-33. A similar study was conducted by Georgetown University in 1995. Researchers discovered there that “[w]orker’s fears of workplace discrimination . . . have prevented one out of ten respondents from getting tested for genetic traits linked to breast cancer, cystic fibrosis, Huntington’s Disease, colon cancer, or other conditions, even though early detection and treatment could possibly improve their lives.” *Id.* at 234.

⁶⁰ *Yale Cancer Center Study Underscores Fear of Discrimination Over Genetic Testing*, SCI. DAILY, Oct. 25, 1999, <http://www.sciencedaily.com/releases/1999/10/991025075308.htm>.

⁶¹ *Id.*

⁶² *Id.* In addition, “82% of counselors said that if tested positive, they would share the results with their physicians, but many would not want their carrier status documented in their medical records.” *Id.*

⁶³ Miller, *supra* note 22, at 234.

⁶⁴ Norris, *supra* note 48, at, 197-98.

⁶⁵ *Id.*

firing decisions based on the respondents' genetic likelihood of developing a disease in the future.⁶⁶

From these survey results, it is clear that fear of discrimination flowing from genetic testing hinders the use of screening technologies. Consequently, this fear has serious implications for the overall health and well-being of individuals who avoid genetic screening programs that could be beneficial to their health.⁶⁷ In addition to individual concerns, the reluctance to utilize genetic testing raises serious social policy concerns. Most significantly, further scientific advancement relies on willing participants in clinical research.⁶⁸ If people are unwilling to partake in genetic studies, this may hinder the development of new genetic tests and may even inhibit the discovery of new treatments for genetic diseases.⁶⁹ This popular reluctance to genetic profiling creates difficulties for scientists who propose "massive population-based studies that will enable them to identify and distinguish genetic, environmental, and lifestyle-based contributors to disease."⁷⁰

C. *Judicial Application of Prior Legislation to Genetic Discrimination Cases*

Prior to the enactment of GINA, no federal law existed that specifically protected against workplace discrimination based on a genetic predisposition to certain diseases.⁷¹ Although minimal safeguards were given under the Americans with Disabilities Act and Title VII of the Civil Rights Act of 1964, these statutes were not extended to fully protect employees from discrimination based on their genetic profile.⁷² Further, some relief was made available to employees under federal privacy laws and via the Health Insurance Portability and Accountability Act of 1996.⁷³ A presidential executive order and many state laws were also put in place to protect employees

⁶⁶ Baruch & Hudson, *supra* note 9, at 437.

⁶⁷ Kathy L. Hudson, *Prohibiting Genetic Discrimination*, 356 NEW ENG. J. MED. 2021, 2021-23 (2007). "At a recent congressional hearing, legislatures heard testimony about a woman who underwent testing for the BRCA1 gene, using a false name to keep her results private. Ovarian cancer later developed and her diagnosis was delayed because her genetic-test result was not in her medical record." *Id.*

⁶⁸ Norris, *supra* note 48, at 200.

⁶⁹ *Id.*

⁷⁰ Hudson, *supra* note 67, at 2021-23.

⁷¹ Sismondo, *supra* note 38, at 466.

⁷² Slaughter, *supra* note 43, at 72.

⁷³ Miller, *supra* note 22, at 251-57.

from discrimination.⁷⁴ But significant gaps remained, indicating that American workers needed additional protection through the use of uniform federal regulation.⁷⁵

1. Americans with Disabilities Act

Prior to the passage of GINA, a worker experiencing genetic information discrimination usually sought relief under the Americans with Disabilities Act of 1990 (ADA). The ADA provides protection from employment discrimination for disabled employees that meet certain criteria.⁷⁶ In order for an employee to make a successful case under the ADA, the employee must show that he or she is a “qualified individual with a disability.”⁷⁷ The ADA defines a “qualified individual with a disability” as one who “with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires.”⁷⁸ The recently amended ADA also provides the courts with guidelines for determining whether an employee is disabled, defining “disability” as a “physical or mental impairment that substantially limits one or more major life activities⁷⁹ of such individual; a record of such impairment; or being regarded as having such an impairment.”⁸⁰

In addition, the ADA limits certain employers from requiring job candidates to provide medical information prior to the extension of a job offer.⁸¹ Once an offer of employment has

⁷⁴ *Id.* at 248-251, 259-263.

⁷⁵ *Id.*

⁷⁶ Americans with Disabilities Act, 42 U.S.C. §§ 12101-12117 (2006). “No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.” *Id.* § 12112(a).

⁷⁷ *Id.*

⁷⁸ *Id.* § 12111(8).

⁷⁹ *Id.* § 12102(2). A “major life activity” includes but is not limited to “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.” ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553, § 4(a)(3)(2)(A) (codified in scattered sections of 29 and 42 U.S.C.).

⁸⁰ ADA Amendments Act of 2008, § 4(a)(3). “An individual meets the requirement of ‘being regarded as having such an impairment’ if the individual establishes that he or she has been subjected to an action prohibited under this Act because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.” *Id.* § 4(a)(3)(A).

⁸¹ 42 U.S.C. § 12112(d)(2)(A).

been given, however, the employer can require that the employee undergo a medical examination.⁸² If an employer requires such an exam, the requirement must apply to all job applicants equally, and the medical “inquiries must be job-related and consistent with a business necessity.”⁸³

While the ADA will protect an employee who develops a genetically related illness when it begins to substantially limit a major life activity,⁸⁴ this standard can be difficult to prove and, in many situations, plaintiffs with genetic disorders will not fit within the ADA provisions.⁸⁵ For example, in *Murphy v. United Parcel Service*, the plaintiff suffered from hypertension, a condition which can be dependent both upon a person’s genetic makeup as well as the person’s lifestyle.⁸⁶ The Court found that the plaintiff could not assert a claim under the ADA because he was not “regarded as” disabled; although the plaintiff was found to be unqualified to work in one particular job (as a mechanic),⁸⁷ he was not substantially limited in the major life activity of working in a broad class of occupations.⁸⁸

In addition to difficulties of proof, the ADA does not address whether an employee’s genetic information, which indicates the likelihood of developing a future disease, can constitute a bona fide disability.⁸⁹ To clarify the position of the federal government, the United States Equal Employment Opportunity Commission (“EEOC”) published guidelines indicating that the government’s interpretation of the ADA prohibits employment discrimination based on an individual’s

⁸² *Id.* § 12112(d)(3).

⁸³ Jungreis, *supra* note 1, at 235 (citing 42 U.S.C. § 12112(d)(4)(A)).

⁸⁴ *Harris v. H & W Contracting Co.*, 102 F.3d 516, 524 (11th Cir. 1997). Plaintiff suffered from Graves’ Disease, an “endocrine disorder affecting the thyroid gland.” *Id.* at 517. Plaintiff suffered a panic attack and illness following an overdose of her medication. *Id.* at 518. The court held that this genetic disease is covered by the ADA. *Id.* at 524; *see also* *Arnold v. United Parcel Service, Inc.* 136 F.3d 854, 866 (1st Cir. 1998) (holding that a plaintiff may make out a discrimination claim under the ADA for diabetes mellitus).

⁸⁵ *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516, 525 (1999).

⁸⁶ *Id.* at 519.

⁸⁷ *Id.* “A person with a genetic predisposition may demonstrate that they are substantially limited in the major life activity of working if the individual can prove that their employer mistakenly believes that, due to the genetic anomaly, they are unable to work in either a class of jobs or a broad range of jobs in various classes as compared to the average person.” Miller, *supra* note 22, at 246.

⁸⁸ *Murphy*, 527 U.S. at 525.

⁸⁹ Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?*, 42 VILL. L. REV. 613, 620 (1997).

genetic makeup.⁹⁰ In particular, the EEOC's guidelines argue that discrimination resulting from genetic testing is covered by the disability definition prong of the ADA because it constitutes "being regarded as having an impairment."⁹¹ Along with the EEOC's interpretive guidance, several court decisions suggest that an "employer's concerns for an employee's future productivity, health insurance costs, and attendance fall within the 'regarded as' prong of the ADA."⁹² In its interpretive memoranda, the EEOC provides a hypothetical that describes an employer who retracts a job offer upon learning that the applicant is genetically predisposed to develop colon cancer in the future.⁹³ Under this scenario, the EEOC argues that the candidate should receive anti-discrimination protection under the ADA.⁹⁴ However, EEOC guidelines are merely persuasive and, in the past, the U.S. Supreme Court has not been swayed by the EEOC's recommendations.⁹⁵

Although the Supreme Court has never ruled on the specific issue of whether the ADA protects an employee from discrimination if genetic testing indicates a predisposition for disease, the holding in *Chevron U.S.A., Inc. v. Echazabal* suggests that such information does not fall under the ADA's disability provisions.⁹⁶ In *Echazabal*, the employer refused to hire the plaintiff because the company's required physical

⁹⁰ See U.S. EEOC, COMPLIANCE MANUAL, § 902 (1995).

⁹¹ *Id.*

⁹² Miller, *supra* note 22, at 240; see *Jones v. Inter-County Imaging Ctrs.*, 889 F. Supp. 741, 742, 745 (S.D.N.Y. 1995) (denying defendant employer's summary judgment motion to plaintiff's ADA claim alleging that he was terminated because defendant believed that his sickle-cell condition would adversely affect future work attendance). The sickle cell trait originates through inheritance of an unstable hemoglobin variant (Hb S). HARRISON'S PRINCIPLES OF INTERNAL MEDICINE 1518 (Anthony S. Fauci et al. eds., 17th ed. 2008). The abnormality occurs almost exclusively in persons of color. About eight percent of African-Americans are heterozygous for Hb S. *Id.* "Although the genetic abnormality may give rise to congenital hemolytic anemia, Hb S carriers generally have minimal clinical problems." Miller, *supra* note 22, at 225 n.121.

⁹³ U.S. EEOC, *supra* note 90, § 902.

⁹⁴ *Id.*

⁹⁵ *Sutton v. United Airlines*, 527 U.S. 471, 482 (1999). The Supreme Court disagreed with the EEOC interpretation of the ADA that employees are to be evaluated in their "hypothetical uncorrected state," and held that plaintiffs suffering correctable disabilities like vision impairment cannot make out a claim under the ADA. *Id.* The level of deference the Supreme Court will accord to EEOC guidelines "will depend upon the thoroughness evident in its consideration, the validity of its reasoning, its consistency with earlier and later pronouncements, and all those factors which give it power to persuade." *Gen. Elec. Co. v. Gilbert*, 429 U.S. 125, 141-42 (1976).

⁹⁶ *Chevron U.S.A. Inc., v. Echazabal*, 536 U.S. 73, 87 (2002); see Jungreis, *supra* note 1, at 238.

examination showed that the plaintiff had liver damage from Hepatitis C.⁹⁷ The employer's doctors said that the condition would be exacerbated by the exposure to toxins that were widespread at the employer's refinery.⁹⁸ Indeed, the employer "wish[ed] to avoid time lost to sickness, excessive turnover from medical retirement or death, litigation under state tort law, and the risk of violating the national Occupational Safety and Health Act of 1970."⁹⁹ To uphold the employer's policy, the Court broadened its interpretation of the "direct threat to others" defense and allowed this type of testing to continue if it prevents threats to the health of individual employees.¹⁰⁰ Arguably, this expanded reading of defenses to an ADA claim could also allow genetic test results to be used in employment decisions.¹⁰¹

The Seventh Circuit Court of Appeals has similarly indicated that the use of genetic information to withhold employment from applicants is permitted under the ADA.¹⁰² In *EEOC v. Rockwell International*, seventy-two job applicants were rejected by the employer based on their poor performance on nerve conduction tests administered as part of the application process.¹⁰³ Although the applicants did not suffer an impairment at the time of the examination, the employer believed that the results of the tests indicated that these applicants were likely to develop carpal tunnel syndrome in the future.¹⁰⁴ The court found that the ADA had not been violated since the job applicants were not currently disabled, nor were they mistakenly perceived to be currently disabled by the

⁹⁷ *Chevron*, 536 U.S. at 76.

⁹⁸ *Id.*

⁹⁹ *Id.* at 84.

¹⁰⁰ *Id.* at 78-79.

¹⁰¹ Jungreis, *supra* note 1, at 238.

¹⁰² *EEOC v. Rockwell Int'l Corp.*, 243 F.3d 1012, 1017 (7th Cir. 2001).

¹⁰³ *Id.* at 1014.

¹⁰⁴ *Id.* In *Rockwell*, the employer described the genetic testing as follows:

The tests were designed . . . to confirm the presence of neuropathy—a syndrome characterized by, among other things, sensory loss and muscle weakness. . . . Rockwell sent each applicant to a medical facility where the median nerves in his or her arms were stimulated with electric shocks and the travel time of the electrical impulse from the shock points to the muscles was recorded. The results of the test were given to Rockwell, which used them in making personnel decisions.

Id.

employer.¹⁰⁵ Consequently, this case indicates a likelihood that courts will not be afraid to dismiss discrimination claims brought under the ADA when employers use genetic information to predict the future health of job applicants.

In contrast to *Echazabal* and *Rockwell*, *Bragdon v. Abbott* suggests the possibility that the ADA could afford protection from discrimination based upon genetic predispositions for diseases.¹⁰⁶ In *Bragdon*, the Supreme Court found that the plaintiff's HIV infection, though asymptomatic, substantially limited the major life activity of reproduction because it would impose a serious risk of infection to her sexual partner and her future offspring.¹⁰⁷ Miller notes that "asymptomatic HIV is a physical impairment from the moment of infection due to 'the immediacy with which the virus begins to damage the infected person's blood cells and the severity of the disease.'"¹⁰⁸ While the Court recognized that an individual infected with HIV remained capable of reproduction, reproduction was regarded as dangerous to the public health, and "[w]hen significant limitations result from the impairment, the definition [of disability] is met even if the difficulties are not insurmountable."¹⁰⁹

A parallel can be drawn between individuals with a presently asymptomatic condition that will eventually progress to a serious deterioration of the immune system and those who are predisposed to a genetic disorder but currently show no evidence of the disease.¹¹⁰ The latter are therefore also arguably

¹⁰⁵ *Id.* at 1012. In a similar case decided that same year, the EEOC chose to settle. *EEOC v. Burlington N. Santa Fe R.R.*, No. 02-C-0456, 2002 WL 32155386, at *1 (E.D. Wis. May 8, 2002) (Agreed Order). Here the employer was also testing for a genetic condition that causes carpal tunnel syndrome. *Id.* The employer "additionally threatened one employee with termination when they refused to comply. According to the EEOC, the genetic tests were unlawful under the ADA because they were not job-related, and conditioning employment on genetic test results constituted disability discrimination." Norris, *supra* note 48, at 203-04.

¹⁰⁶ See *Bragdon v. Abbott*, 524 U.S. 624, 644-45 (1998).

¹⁰⁷ *Id.* at 639-40.

¹⁰⁸ Miller, *supra* note 22, at 242 (quoting *Bragdon*, 524 U.S. at 637).

¹⁰⁹ *Bragdon*, 524 U.S. at 641.

¹¹⁰ Miller, *supra* note 22, at 243. Miller noted:

Science may be able to demonstrate that many asymptomatic genetic disorders, while not resulting in any visible symptoms or characteristics, may create abnormalities in an individual's body systems or changes on a cellular level as was shown with asymptomatic HIV. . . . Should a plaintiff be able to demonstrate that the genetic condition causes some abnormality in the person's body, even on a molecular level, the condition would constitute a physical impairment for ADA purposes.

protected by the ADA under *Bragdon*. In addition, it could be argued that some genetic predispositions, although asymptomatic, limit a major life activity, as seen in *Bragdon*.¹¹¹ However, there is clearly disagreement and a lack of clarity between the outcome of *Bragdon* and the reasoning applied in cases such as *Chevron*, *Murphy*, and *Rockwell*.¹¹² As a result, federal legislation separate from the ADA that specifically addressed the growing field of genetic testing was necessary to provide adequate protection for employees in the workplace. As a practical matter, it had also been extremely difficult for plaintiffs to win ADA cases.¹¹³ In 1999, the American Bar Association Commission on Mental and Physical Disability Law reported that defendant employers won 291 cases in the federal court system, while only 13 plaintiff employees prevailed.¹¹⁴ Consequently, GINA was a necessary reform to give employees a chance to fight genetic information discrimination in the workplace.

2. Title VII of the Civil Rights Act of 1964

Like the ADA, Title VII of the Civil Rights Act of 1964 (“Title VII”) provides minimal relief to those suffering adverse employment actions because of their predisposition to genetic disease.¹¹⁵ Title VII is limited to barring employment discrimination on the basis of race, color, religion, sex, or national origin.¹¹⁶ While several genetic diseases do correlate with race, sex, and national origin, they are not solely dependent upon these characteristics.¹¹⁷

Under Title VII, employees can prevail on a claim if they establish that the employer singled out a specific

Id. at 243-44.

¹¹¹ See *Bragdon*, 524 U.S. at 637.

¹¹² See *Chevron U.S.A. Inc. v. Echazabel*, 536 U.S. 73 (2002); *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516 (1999); *EEOC v. Rockwell*, 243 F.3d 1012 (7th Cir. 2001).

¹¹³ Marisa Anne Pagnattaro, *Genetic Discrimination and the Workplace: Employee's Right to Privacy v. Employer's Need to Know*, 39 AM. BUS. L.J. 139, 165 (2001).

¹¹⁴ *Id.*; see also Claudia MacLachlan, *Employers Winning ADA Suits: ABA Study Shows Employees Won Only 13 Cases in 1999*, NAT'L L.J., July 31, 2000. “That means that ‘employers won 95.7% of the time,’ an increase over the 1998 survey results.” *Id.*

¹¹⁵ Jungreis, *supra* note 1, at 239.

¹¹⁶ 42 U.S.C. § 2000e-2(a) (2006).

¹¹⁷ Jungreis, *supra* note 1, at 239.

protected class for genetic testing.¹¹⁸ In *Norman-Bloodsaw v. Lawrence Berkely Laboratory*, the employer forced its black female employees to undergo genetic testing for sickle cell anemia, syphilis, and pregnancy.¹¹⁹ In that case, the plaintiffs' claims were deemed valid because the court found discrimination based on race and sex, both protected classes under Title VII.¹²⁰

However, if all employees of the lab had been required to undergo genetic testing, there would not have been a successful Title VII disparate treatment claim since each employee would have been treated equally.¹²¹ A disparate impact claim might be possible if, for example, a disproportionate number of black employees tested positive for sickle cell anemia and then suffered adverse employment actions.¹²² However, it is clear that Title VII can only be applied to genetic information discrimination under a very narrow set of circumstances.¹²³ As with the ADA, the scant coverage provided by Title VII indicated to Congress the need for separate federal legislation that would specifically target employment discrimination on the basis of genetic predisposition to disease.

3. Executive Order on Genetic Discrimination

Based on the inability of the ADA and Title VII to provide employees with protection from discrimination on the basis of their genetic information, President Clinton saw a need for increased safeguards against discriminatory behavior in the workplace.¹²⁴ On February 8, 2000, he issued Executive Order 13,145, To Prohibit Discrimination in Federal Employment Based on Genetic Information (the "Executive Order").¹²⁵ The

¹¹⁸ *Norman-Bloodsaw v. Lawrence Berkely Lab.*, 135 F.3d 1260, 1272 (9th Cir. 1998).

¹¹⁹ *Id.* at 1265.

¹²⁰ *Id.* at 1272.

¹²¹ See generally ROBERT BELTON ET AL., *EMPLOYMENT DISCRIMINATION LAW: CASES AND MATERIALS ON EQUALITY IN THE WORKPLACE* ch. 4 (7th ed. 2004).

¹²² See generally *id.*

¹²³ See generally *id.*

¹²⁴ Miller, *supra* note 22, at 248.

¹²⁵ Exec. Order No. 13,145, 65 Fed. Reg. 6,875 (Feb. 8, 2000) [hereinafter Exec. Order No. 13,145], available at <http://eeoc.gov/eeoc/history/35th/thelaw/13145.html>. The purpose of this Order is as follows:

Executive Order 13145 is intended to ensure that Executive branch applicants and employees are judged on their current ability to perform the

Executive Order targeted departments and agencies of the federal government by limiting their access to, and use of, their employees' genetic information.

The Executive Order prohibits federal departments and agencies from taking adverse employment actions based on an employee's "protected genetic information."¹²⁶ This "protected genetic information" is defined in the Executive Order as "(1) information about an individual's genetic tests; (2) information about the genetic tests of an individual's family members; or (3) information about the occurrence of a disease, or medical condition or disorder in family members of the individual."¹²⁷ The Executive Order makes clear that the federal government is barred from making employment decisions based upon a worker's predisposition to disease, medical condition, or other physical disorder that does not impact his or her ability to currently carry out the responsibilities of the position.¹²⁸ Likewise, under the Executive Order, federal employers are also prohibited from mandating genetic tests as a condition of employment,¹²⁹ including hiring and receiving benefits, evaluating ability to perform the job, and classifying employees in a discriminatory manner leading to lost job advancement opportunities.¹³⁰

In most instances, the Executive Order demands that genetic information be kept confidential and removed from

jobs they seek or hold, and not on the possibility that they might, some day, develop a disease or condition. Accordingly, the Executive Order places stringent limits on the collection, use, and disclosure of protected genetic information.

U.S. EEOC, POLICY GUIDANCE ON EXECUTIVE ORDER 13145: TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON GENETIC INFORMATION, <http://www.eeoc.gov/policy/docs/guidance-genetic.html>.

¹²⁶ Exec. Order No. 13,145, *supra* note 125, at 6877.

¹²⁷ *Id.* "Information about an 'individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses) is not protected genetic information' unless it falls within one of the above categories." Pagnattaro, *supra* note 113, at 157.

¹²⁸ Exec. Order No. 13,145, *supra* note 125, at 6877.

¹²⁹ *Id.*

¹³⁰ *Id.* Disclosure of such information is warranted only in the following circumstances:

(1) to the employee; (2) to a person conducting research that complies with 45 C.F.R. Part 46, which concerns research involving human subjects; (3) if required by federal law; (4) in response to a congressional subpoena or order from a court with competent jurisdiction; or (5) to Executive branch officials investigating compliance with the Executive Order.

Id.

personnel files that can be easily accessed. However, the Executive Order does provide federal employers some leeway to require family medical information from prospective employees who have already received conditional employment offers.¹³¹ Such information is only to be used for the purpose of determining whether an applicant needs additional testing to diagnose an *existing* disease or health condition that could prevent the individual from fulfilling his or her current job responsibilities.¹³² The results of these tests may only be viewed by medical personnel in charge of assessing whether the applicant must undergo additional medical testing.¹³³

Although the Executive Order expands the rights of federal employees beyond the ADA and Title VII, it leaves out the large number of Americans who are not employed by the federal government. Therefore, the vast majority of Americans still required legislation that prevented private employers from using their employees' genetic information as a means for discriminatory behavior.

4. Constitutional Privacy Rights and the Privacy Act of 1974

Another source of potential protection against genetic discrimination in the workplace is the Fourteenth Amendment of the U.S. Constitution. Indeed, some courts have held that an individual has the right to keep personal health information private and, therefore, employees should be protected against genetic information discrimination under the Fourteenth Amendment.¹³⁴ For example, in *United States v. Westinghouse Electric Corp.*, the Third Circuit Court of Appeals stated that there is "no question that an employee's medical records, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection."¹³⁵ The court held that "[g]enetic information should thus be protected pursuant to the right to privacy under the United States Constitution."¹³⁶

¹³¹ *Id.*

¹³² *Id.*

¹³³ *Id.* at 6879.

¹³⁴ This applies only to state actors (government employers). Miller, *supra* note 22, at 251.

¹³⁵ *U.S. v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980).

¹³⁶ Miller, *supra* note 22, at 251.

Similarly, the Supreme Court has found that, in certain situations, the government does have an obligation under the Fourteenth Amendment to avoid disclosing private information.¹³⁷ However, the Court has provided little guidance as to when such situations will arise. In *Whalen v. Roe*, patients requiring Schedule II drugs (the most dangerous of legitimate prescription medications) declined treatment due to their concern that the computerized records would stigmatize them as drug addicts.¹³⁸ Furthermore, doctors worried that they could not adequately treat their patients without privacy protection for their records.¹³⁹ While the Court was “not unaware of the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks,” it did not find a violation of “any right or liberty guaranteed” by the Fourteenth Amendment.¹⁴⁰

More pointedly, the Ninth Circuit Court of Appeals specifically addressed the issue of whether privacy rights apply to genetic information in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*.¹⁴¹ In *Norman-Bloodsaw*, the employer conducted genetic testing for syphilis, pregnancy, and sickle cell anemia during routine mandatory medical exams, but without the authorization of the employees.¹⁴² The plaintiffs challenged these practices as violations of both the ADA and Title VII and alleged that under the U.S. Constitution, their rights to privacy and due process had been denied.¹⁴³ The court determined that administering genetic tests without the consent of an employee was a clear violation of that employee’s right to privacy.¹⁴⁴ In addition, the court found that “the

¹³⁷ *Whalen v. Roe*, 429 U.S. 589, 605 (1977).

¹³⁸ *Id.* at 595.

¹³⁹ *Id.* at 604.

¹⁴⁰ *Id.* at 605-06.

¹⁴¹ *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998).

¹⁴² *Id.* at 1264-65.

¹⁴³ *Id.* at 1265. While granting relief on the constitutional claims, the court “dismiss[ed] . . . the ADA claims on the following grounds: (1) that no job related action was taken against the plaintiffs as a result of the testing; (2) the lack of evidence of inadequate safeguards to protect the confidentiality of the information; and (3) the scope of exams did not violate the statute.” Miller, *supra* note 22, at 253. For a discussion of the outcome of the Title VII claims see *supra* Part II(C)(2).

¹⁴⁴ Miller, *supra* note 22, at 253; see *Norman-Bloodsaw*, 135 F.3d at 1269.

performance of these tests, without explicit notice and informed consent, violates prevailing medical standards.”¹⁴⁵

Even if the Supreme Court eventually holds that genetic information testing requires protection under the Fourteenth Amendment, federal constitutional privacy interests can still be challenged. Under this analysis, privacy rights “must be balanced against the [federal and/or state] government employer’s legitimate interest in collecting the information.”¹⁴⁶ Thus, if a government employer can put forth a valid reason for requiring genetic information from their employees, the courts will not infringe upon these practices, even if they result in discriminatory behavior.¹⁴⁷

An additional modicum of protection for employees may be found in the Privacy Act of 1974 (the “Privacy Act”).¹⁴⁸ The Privacy Act regulates the collection and use of records by federal agencies and limits their access to information “relevant and necessary” to their purpose.¹⁴⁹ Under the Privacy Act, one is allowed to access his or her personal records on request and seek amendment to his or her file if it is inaccurate.¹⁵⁰ Finally, the Act limits disclosure of records to outside parties.¹⁵¹

The holdings of *Whalen* and *Norman-Bloodsaw* suggest that the Supreme Court is likely to find, in some situations, that employees’ genetic test results should be shielded from an employer.¹⁵² In these limited situations, employees would be protected from discrimination since their employer would not have access to genetic information indicating that they are predisposed to develop a disease in the future.¹⁵³ However, these rights can be limited if the government employer can show a legitimate interest in obtaining the information.¹⁵⁴

¹⁴⁵ Miller, *supra* note 22, at 253 (internal quotation marks omitted) (quoting *Norman-Bloodsaw*, 135 F.3d at 1267).

¹⁴⁶ *Id.* at 251.

¹⁴⁷ *Id.* at 253.

¹⁴⁸ 5 U.S.C. § 552(a) (2006). “Like the federal Constitution, however, it applies to only government action, particularly, the disclosure of information obtained by a government agency.” Miller, *supra* note 22, at 253; see *Norman-Bloodsaw*, 135 F.3d at 1269.

¹⁴⁹ Miller, *supra* note 22, at 253 (citation omitted) (internal quotation marks omitted).

¹⁵⁰ *Id.* at 253-54.

¹⁵¹ *Id.* at 254.

¹⁵² *Norman-Bloodsaw*, 135 F.3d at 1269.

¹⁵³ Miller, *supra* note 22, at 253.

¹⁵⁴ *Id.*

Furthermore, since these protections only apply to federal employees, those working in the private sector will be barred from making similar claims.¹⁵⁵ Consequently, GINA was required to provide a litigation outlet for the majority of employees.

5. The Health Insurance Portability and Accountability Act

Limited protection from genetic discrimination in health insurance access is also provided by the Health Insurance Portability and Accountability Act of 1996.¹⁵⁶ However, like the legislation previously discussed, HIPAA does not provide sufficient protection against genetic discrimination in the workplace. Since many Americans participate in group health insurance through their employers, HIPAA has become intertwined with workers' rights issues.¹⁵⁷ HIPAA bars group health insurance plans from abusing their access to participants' genetic information to deny continued eligibility in the plan.¹⁵⁸ In most cases, HIPAA enables individuals to receive insurance coverage even if they have prior or current medical conditions and it allows employees to retain coverage if they switch jobs or insurance providers.¹⁵⁹ Most significantly, under HIPAA, genetic information alone cannot constitute a preexisting condition or a means for excluding a covered employee.¹⁶⁰ Therefore, a member of a group health insurance plan who discovers that he has a gene that may predispose him to a disease will not be denied coverage if the plan is covered by HIPAA.¹⁶¹

Although HIPAA took the first steps toward directly targeting genetic discrimination, the statute is not sufficient.¹⁶² While HIPAA prevents health care providers from increasing the cost of an individual's insurance in a discriminatory manner, insurance companies are not barred from raising an

¹⁵⁵ *Id.*

¹⁵⁶ 29 U.S.C. § 1181 (2006).

¹⁵⁷ Miller, *supra* note 22, at 255.

¹⁵⁸ 29 U.S.C. § 1181(d)(1).

¹⁵⁹ Miller, *supra* note 22, at 255.

¹⁶⁰ *Id.*

¹⁶¹ Miller, *supra* note 22, at 255. "In addition, coverage cannot be denied for a newborn or newly adopted child's medical condition, as long as the child is enrolled within thirty days of birth or adoption, and benefits for the medical condition are otherwise available under the plan." *Id.*

¹⁶² Norris, *supra* note 48, at 204-05.

employer's group premium based on the genetic makeup of its employees.¹⁶³ Furthermore, HIPAA does not apply to individuals or the self-employed seeking health insurance independently; nor does it prohibit health care providers from denying coverage to these individuals outright.¹⁶⁴ This gap in HIPAA affects approximately 10-15% of people who purchase health insurance individually.¹⁶⁵ Finally, even though HIPAA bars insurers from rescinding policies to a small employer due to the genetic information of an enrollee, the same rule does not apply to larger employers.¹⁶⁶

Like prior attempts at regulation, the gaps in HIPAA, which allow for genetic information discrimination to occur, indicate that specific reform was needed to provide protection to employees.

6. State Law Protecting Against the Misuse of Genetic Information by Employers

The abuse of genetic information in employment was first addressed by state legislatures in the 1970s and 1980s through the creation of protective provisions for workers with the genetic marker for sickle cell anemia.¹⁶⁷ Some of the first states to enact such statutes were Florida, Louisiana, and North Carolina.¹⁶⁸ In 1981, New Jersey followed suit and banned employment discrimination based on a worker's genetic predisposition for "sickle cell anemia, hemoglobin C, thalassemia, Tay Sachs, or cystic fibrosis."¹⁶⁹ Currently, thirty-four states and the District of Columbia have enacted legislation barring genetic discrimination in decisions regarding hiring, firing, and/or determining the terms, conditions or privileges of employment.¹⁷⁰ However, there is great variation in the scope and application of these laws. For those that provide some level of protection for employees,

¹⁶³ *Id.* at 205.

¹⁶⁴ *See* 29 U.S.C. § 1181.

¹⁶⁵ Norris, *supra* note 48, at 205.

¹⁶⁶ *Id.*

¹⁶⁷ NAT'L CONFERENCE OF STATE LEGISLATURES, GENETIC EMPLOYMENT LAWS (2008) [hereinafter NAT'L CONFERENCE], *available at* <http://www.ncsl.org/IssuesResearch/Health/GeneticEmploymentLaws/tabid/14280/Default.aspx>.

¹⁶⁸ *Id.*

¹⁶⁹ Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 175 (2008).

¹⁷⁰ NAT'L CONFERENCE, *supra* note 167.

twenty-five states prohibit employers from requiring genetic testing, eighteen prohibit employers from requesting genetic test results, and sixteen prohibit employers from performing their own genetic testing in the workplace.¹⁷¹ Only eleven states outright ban employers from obtaining the genetic test results of their workers.¹⁷²

While it now appears that protections provided by states are on the rise, prior to the enactment of GINA, residents of fifteen states were left with only the bare-bones federal protection discussed earlier. Moreover, a system reliant solely on state law has proven difficult to administer since the various protections offered by each state unnecessarily burden multi-state employers with a grab-bag of state rules and regulations.¹⁷³ Furthermore, prior to uniform federal regulation, employees continued to fear genetic testing despite local protections.¹⁷⁴ If workers chose to relocate to a state that lacked similar legislation regarding genetic information, it would be too risky to have potentially harmful information in their medical records.¹⁷⁵

III. NEW PROTECTIONS PROVIDED BY GINA

After almost thirteen years of consideration by Congress, GINA passed, filling in the gaps in federal law and providing protection to the American workforce.¹⁷⁶ On May 21, 2008, President George W. Bush signed GINA into law,¹⁷⁷ and it went into effect on November 21, 2009.¹⁷⁸ As the first civil rights legislation of the twenty-first century,¹⁷⁹ “GINA represents significant progress in protecting civilians from genetic discrimination in employment and health insurance.”¹⁸⁰

¹⁷¹ *Id.*

¹⁷² *Id.* In addition, only fourteen states have created specific penalties for genetic discrimination in employment. *Id.*

¹⁷³ Jungreis, *supra* note 1, at 233.

¹⁷⁴ *Id.*

¹⁷⁵ *Id.*

¹⁷⁶ Baruch & Hudson, *supra* note 9, at 435.

¹⁷⁷ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

¹⁷⁸ *Id.* § 213.

¹⁷⁹ Hudson et al., *supra* note 15, at 2662.

¹⁸⁰ Baruch & Hudson, *supra* note 9, at 437. “[W]hen it finally overcame the opposition of a few members of Congress who controlled the rules of the House and Senate for many years, it passed almost unanimously, with strong bipartisan support.” *Id.* at 435.

Significantly, GINA was drafted to target both employers and health care providers. Title I targets genetic information discrimination in health insurance benefits and group health plans.¹⁸¹ In particular, it “prohibits the use of genetic information to set health insurance premiums, deny coverage, or affect employment.”¹⁸² More specifically, GINA “prohibits group and individual health insurers from using a person’s genetic information in determining eligibility or premiums; prohibits an insurer from requesting or requiring that a person undergo a genetic test; and prohibits employers from using a person’s genetic information about persons or their family members.”¹⁸³ Title I applies to all ERISA group health plans, group market insurers, individual market insurers, Medicare supplemental insurers, and non-federal governmental plans.¹⁸⁴

Title II of the Act applies specifically to genetic discrimination in employment.¹⁸⁵ This title pertains to employers, employment agencies, and labor organizations.¹⁸⁶ Under GINA, it is unlawful for employers to make hiring and firing decisions based on employees’ genetic information.¹⁸⁷ Furthermore, the statute prohibits employers from using genetic information to take discriminatory actions regarding compensation, benefits, or other terms and conditions of employment.¹⁸⁸ In addition, an employer is also barred from segregating or classifying employees in a manner that would deprive them of employment opportunities or adversely affect their employment status because of genetic data.¹⁸⁹

In addition to proscribing genetic discrimination, GINA also prohibits employers from requesting, requiring, or purchasing genetic information of an employee or from family members of the employee.¹⁹⁰ However, the Act does provide six

¹⁸¹ GINA, H.R. 493, 110th Cong. (2008).

¹⁸² Allison, *supra* note 7, at 596.

¹⁸³ Hudson et al., *supra* note 15, at 2662.

¹⁸⁴ Nuffort, *supra* note 41, at 12.

¹⁸⁵ GINA, H.R. 493.

¹⁸⁶ GINA, § 201(a)(2)(B); *id.* § 201(C). “Covered employees” (including an applicant) are those defined in section 701(f) of the Civil Rights Act of 1964 (42 U.S.C. § 2000e(f)). *Id.*

¹⁸⁷ *Id.* § 202(a)(1).

¹⁸⁸ *Id.*

¹⁸⁹ *Id.* § 202(a)(2).

¹⁹⁰ *Id.* § 202(b).

exceptions to this rule.¹⁹¹ First, there is no unlawful employment practice when an employer makes an inadvertent mistake requesting family medical history.¹⁹² Likewise, there is also no violation when an employee provides voluntary, written authorization for employers to obtain family genetic information.¹⁹³ In addition, employers may request family medical information in order to comply with the Family Medical Leave Act of 1993 or similar state laws.¹⁹⁴ Employers may also purchase commercially and publically available documents that contain family medical information of an employee.¹⁹⁵ An employer may also require genetic information if it is to be used for genetic monitoring of the biological effects of toxic substances in the workplace.¹⁹⁶ To fall within this exemption, the employer must provide written notice to the employee, obtain voluntary and written authorization from the employee, and keep the employee informed of individual monitoring results.¹⁹⁷ Such monitoring must also be required by Federal or State law, and must be in compliance with the Occupational Safety and Health Act of 1970.¹⁹⁸ Lastly, the genetic monitoring results must be received in the aggregate and cannot identify individual employees.¹⁹⁹ Finally, GINA also provides an exception when an employer must conduct DNA analysis for law enforcement purposes or when it is necessary to identify human remains.²⁰⁰

GINA provides definitions for key terms such as “genetic information,” “genetic services,” and “genetic test.”²⁰¹

¹⁹¹ *Id.* § 202(b)(1)-(6).

¹⁹² *Id.* § 202(b)(1).

¹⁹³ *Id.* § 202(b)(2).

¹⁹⁴ *Id.* § 202(b)(3).

¹⁹⁵ *Id.* § 202(b)(4). Employers may consult newspapers, magazines, periodicals, and books, but cannot use medical databases or court documents to obtain genetic information of an employee.

¹⁹⁶ *Id.* § 202(b)(5).

¹⁹⁷ *Id.* § 202(b)(5)(A); *id.* § 202(b)(5)(B)(i); *id.* § 202(b)(5)(C).

¹⁹⁸ *Id.* § 202(b)(5)(B)(ii); *id.* § 202(b)(5)(D).

¹⁹⁹ *Id.* § 202(b)(5)(E).

²⁰⁰ *Id.* § 202(b)(6).

²⁰¹ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881. “Genetic information” is:

information about genetic tests, the genetic tests of family members, and the manifestation of a disease or disorder in family members (a ‘family member’ is defined as a first-, second-, third-, or fourth-degree relative). It also includes any request for, or receipt of, genetic services, or participation in clinical research that includes genetic services, by an individual or his or her family members. ‘Genetic services’ may include a genetic test, genetic

Examples of genetic tests that will now be protected under GINA include, but are not limited to, the following: “tests for BRCA1/ BRCA2 (breast cancer) or HNPCC (colon cancer) mutations; classifications of genetic properties of an existing tumor to help determine therapy; tests for Huntington disease mutations; carrier screenings for disorders such as cystic fibrosis, sickle cell anemia, spinal muscular atrophy, and the fragile X syndrome.”²⁰²

Several federal agencies have been charged to enforce GINA, including the Department of Health and Human Services, the Department of Labor, and the Department of Treasury, along with the EEOC.²⁰³ In addition, GINA mandates that a Genetic Nondiscrimination Study Commission be formed by May 2015.²⁰⁴ This new Commission will review scientific advancements in genetics and advise Congress as to the potential need to amend GINA to include disparate impact causes of action.²⁰⁵ The Commission will be comprised of eight members and will be located in a facility within the EEOC.²⁰⁶

During deliberations, members of Congress determined that the imposition of harsher penalties for violations of GINA would be illogical and unreasonable if they exceeded the

counseling (including obtaining, interpreting, or assessing genetic information), or genetic education. The law states specifically that genetic information does not include information about sex or age. Further clarification about the scope of these definitions is expected through the federal regulatory process, currently under way. The definition of ‘genetic test’ is quite specific. Under GINA, genetic test means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites to detect genotypes, mutations, or chromosomal changes. However, according to the law, genetic test does not include ‘(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or (ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a healthcare professional with appropriate training and expertise in the field of medicine involved. It is important to note that (ii) does not appear in the employment section of the law- in the workplace, this exception to the definition of genetic test would not apply. In other words, GINA does not prohibit insurers from underwriting based on information that reveals information about current health status. However, employers may not use such information to make employment decisions.

Baruch & Hudson, *supra* note 9, at 438-39; Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

²⁰² Genetics & Pub. Policy Ctr., John Hopkins Univ., Information on the Genetic Information Nondiscrimination Act (GINA) [hereinafter Information on GINA], www.DNAPolicy.org.

²⁰³ Baruch & Hudson, *supra* note 9, at 439.

²⁰⁴ GINA, § 208(b).

²⁰⁵ *Id.*

²⁰⁶ *Id.* § 208(c). (d).

penalties for violating other employment laws such as the ADA, Title VII, and HIPPA.²⁰⁷ It was felt that consistency would ensure the bill's passage and avoid overloading the burden on health insurers and employers.²⁰⁸ However, remedies such as corrective action and monetary awards are available to harmed employees.²⁰⁹ In addition, citizens of states that have more encompassing protection under state law than under GINA will still be able to bring state law claims if they suffer genetic discrimination in the workplace.²¹⁰

With GINA in effect, workers who suffer from adverse employment action based on their employer's knowledge of their genetic predisposition to develop a disease will have a claim and remedy under federal law.²¹¹ Significantly, plaintiff employees no longer have to stretch the facts of their case to fit within the regulatory framework of the ADA and Title VII, which offer inadequate protection for genetic information discrimination.²¹²

IV. WHAT GINA LEFT OUT AND THE PROTECTIONS REQUIRED IN THE FUTURE

Despite the clear advantages that GINA provides to employees seeking relief from genetic information discrimination in the workplace, the Act fails to provide comprehensive protection. On the one hand, some remaining gaps in the legislation are due to the fact that GINA sponsors needed to make compromises for it to be passed.²¹³ Other weaknesses in the act are due to the rapid advancement of clinical medicine and biotechnology.²¹⁴

Critics of GINA argue that the act is too narrow and limited in scope.²¹⁵ For them, the Act "does not prevent health

²⁰⁷ Baruch & Hudson, *supra* note 9, at 439. *See generally* IOMA, *supra* note 16.

²⁰⁸ Baruch & Hudson, *supra* note 9, at 439.

²⁰⁹ *Employer Advocates*, *supra* note 16, at 1-6.

²¹⁰ Baruch & Hudson, *supra* note 9, at 439.

²¹¹ *Id.*

²¹² *See supra* Part II.(A), (B).

²¹³ Baruch & Hudson, *supra* note 9, at 435. "GINA is, like most enacted laws, a compromise and reflects a strategic and delicate balancing of interests of all key stakeholders including providers, patients, insurers, employers, researchers, and lawmakers." *Id.*

²¹⁴ J. M. Appel, *When the Boss Turns Pusher: A Proposal for Employee Protections in the Age of Cosmetic Neurology*, 34 J. MED. ETHICS 616, 618 (2008).

²¹⁵ Baruch & Hudson, *supra* note 9, at 435.

care providers from recommending genetic tests to their patients . . . , mandate coverage for any particular test or treatment . . . , prohibit medical underwriting based on current health status . . . , cover life, disability or long-term-care insurance, [and does not] apply to members of the military.”²¹⁶ With regard to employment issues in particular, GINA “does not prohibit workplace collection of genetic information for toxicity monitoring programs, employer-sponsored wellness programs, administration of federal and state Family and Medical Leave laws, and in certain cases of inadvertent acquisition of information.”²¹⁷

In the near future, courts may have to determine whether employers can require DNA testing for criminal background checks under GINA. Recently, the University of Akron implemented a policy reserving the right “to require any prospective faculty, staff, or contractor to submit a DNA sample.”²¹⁸ While employers typically conduct general background checks during the hiring process, the Ohio school is the first to take such extreme measures.²¹⁹ The school maintains that Akron’s goal is solely to sustain a safe environment for students and staff and that “DNA testing was included in the policy because there ha[s] been national discussion that indicate[s] that in the future, reliance on fingerprinting will diminish and DNA for criminal identification will be the prominent technology.”²²⁰ Arguably, GINA does not delineate a distinction between requiring genetic information for discriminatory versus legitimate purposes; likewise, the policy is not covered by one of the exceptions mentioned above.²²¹ Since one employee has already quit in response to the school’s policy,²²² this may lead to the first opportunity for the courts to evaluate GINA’s reach.

GINA also fails to protect those who suffer from other immutable characteristics that may indicate a likelihood of developing an illness in the future, such as abnormalities found

²¹⁶ Hudson et al., *supra* note 15, at 2662.

²¹⁷ Information on GINA, *supra* note 202.

²¹⁸ Declan McCullagh, *Want a Job in Akron? Hand Over Your DNA*, CBS NEWS, Oct. 28, 2009, http://www.cbsnews.com/blogs/2009/10/28/taking_liberties/entry5438012.shtml

²¹⁹ *Id.*

²²⁰ Scott Jaschik, *DNA Swabs for Your Job*, INSIDE HIGHER ED., Oct. 29, 2009, <http://www.insidehighered.com/news/2009/10/29/akron>.

²²¹ McCullagh, *supra* note 218.

²²² Jaschik, *supra* note 220.

on a screening colonoscopy.²²³ Thus, an insurance company can implement discriminatory coverage and pricing policies against these individuals, even though it could not do so to persons with a genetic predisposition for the condition.²²⁴

For many employees who believe that they should now be protected, GINA stands to cause confusion since many medical tests and examinations are not covered by the act.²²⁵ Routine screenings “such as complete blood counts (CBC, or blood panel), cholesterol tests, and liver-function tests are not protected under GINA.”²²⁶ This is problematic since cholesterol levels, for example, can depend on a person’s genetic makeup and thus cannot always be controlled by lifestyle choices.²²⁷ As a potentially immutable characteristic, these patients should also receive some form of protection against employer discrimination. Other areas of concern include: “DNA analysis of infectious agents such as bacteria, viruses, and fungi. An HIV test, for example, is not covered. Although it is a retrovirus that inserts itself into human DNA, HIV is not itself human DNA and measuring its presence does not constitute a genetic test under the law’s definition.”²²⁸ From these examples, it is clear that there is a fuzzy line as to what constitutes a genetic test. Arguably, GINA’s reach is too narrow and should be expanded to encompass additional borderline traits such as cholesterol.

²²³ Russell Korobkin & Rahul Rajkumar, *The Genetic Information Nondiscrimination Act—A Half-Step toward Risk Sharing*, 359 NEW ENG. J. MED. 335, 336 (2008).

²²⁴ *Id.* The authors argue that

GINA not only fails to protect the person with colonic polyps; it actually leaves him worse off than he would otherwise be. Because insurance companies may no longer make use of clearly relevant information such as family history in their risk assessment, they will rely even more heavily on current health status when setting rates, even when it has only slight value in predicting future illness. In a post-GINA world, not only will the very sick have even more trouble obtaining affordable insurance, but so will the mostly well. Second, while those who get bad news from genetic tests will rely on GINA to obtain health insurance at a subsidized rate, those whose genes put them at lower risk can opt out entirely or, more likely, purchase insurance with higher deductibles, greater cost sharing, and more exclusions.

Id.

²²⁵ Information on GINA, *supra* note 202.

²²⁶ *Id.*

²²⁷ *Lowering Your Cholesterol: Heart Attack Prevention Series*, MEDICINENET, <http://www.medicinenet.com/cholesterol/article.htm#tocb> (last visited Jan. 16, 2010).

²²⁸ Information on GINA, *supra* note 202.

Given the short period of time that a plaintiff has to file a complaint under GINA, many meritorious discrimination suits will likely be dismissed on procedural grounds. As in Title VII and ADA cases, employees have an obligation to exhaust all administrative remedies before they can bring suit under the act.²²⁹ Since the employment provisions of the legislation are regulated by the EEOC, employees must seek a right-to-sue letter from the agency within 90 days of the alleged discriminatory employment action or they will forfeit their right to bring a claim.²³⁰ Since a large number of eligible Title VII and ADA claims are dismissed each year for plaintiffs' failure to exhaust administrative remedies, typically because the plaintiffs were unaware of the strict and extremely short deadlines involved, it is likely that many legitimate allegations of genetic discrimination will be dismissed for the same procedural reasons.²³¹

In addition to the gaps mentioned above, it is likely that additional protective legislation for workers will be required as biotechnology and medicine progress.²³² Amendments to GINA likely will be necessary in the near future to accommodate rapid advancement in science. For example, many genetic tests currently require improvements in order to increase accuracy and effectiveness.²³³ While some tests are extremely precise, such as the screen for Huntington's disease,²³⁴ scientists are still looking to advance the predictive performance of the test for cardiovascular disease (CVD).²³⁵ While a gene variant has been identified for CVD, using this information has not helped geneticists to predict its occurrence.²³⁶ Out of a study of 22,129 women, "[a]dding the genotypic information to traditional risk factors—including family history—reclassified 2.6% of the women to different risk categories, but 63.4% of them were

²²⁹ BELTON ET AL., *supra* note 121, at 27; Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881.

²³⁰ Baruch & Hudson, *supra* note 9, at 439.

²³¹ BELTON ET AL., *supra* note 121, at 27-29.

²³² Appel, *supra* note 214, at 616.

²³³ John P.A. Loannidis, *Personalized Genetic Prediction: Too Limited, Too Expensive, or Too Soon?* 150 ANN INTERN MED. 139, 139-140 (2009).

²³⁴ See MARILYN J. WOLFF, HUNTINGTON'S DISEASE SOC'Y OF AM., GENETIC TESTING FOR HUNTINGTON'S DISEASE, <http://www.lkwdpl.org/hdsa/hdtest.htm> (last visited Jan. 16, 2010) (explaining that the gene for Huntington's Disease and the genetic predictor of trinucleotide repeats contained within the gene).

²³⁵ Loannidis, *supra* note 233, at 139-140.

²³⁶ *Id.* at 139.

incorrectly reclassified.”²³⁷ Similar problems have occurred in predictive studies for prostate cancer and Type 2 diabetes.²³⁸

However, research in this area is continuously evolving. While other problems such as cost-effectiveness²³⁹ exist, it is likely that these types of genetic tests will become more accurate and more available for a host of diseases that may or may not be covered by the current form of GINA.

Another example of an emerging scientific field with genetic discrimination potential is neuro-pharmacological enhancement, also referred to as “cosmetic neurology.”²⁴⁰ Potential developments in this field offer “the prospect of improving the learning, memory, and attention skills of healthy individuals, well beyond the normal human range.”²⁴¹ The field of cosmetic neurology is fraught with scientific, legal, and ethical concerns; yet, with regards to employment, new forms of coercion and discrimination are feared.²⁴² In particular, many are worried that the abuse will target behavioral traits such as limited attention span due to Attention Deficit Hyperactivity Disorder (“ADHD”). While ADHD can be caused by a range of factors including environmental agents, brain injury, food additives, and sugar, genetics plays a large role.²⁴³ Indeed, “[s]tudies indicate that 25% of the close relatives in the families of ADHD children also have ADHD, whereas the rate is about 5% in the general population.”²⁴⁴

Although ADHD has a strong link to genetics, GINA does not prevent employers from testing the memory skills or

²³⁷ *Id.*

²³⁸ *Id.* at 140.

²³⁹ *Id.*

²⁴⁰ Appel, *supra* note 214, at 616.

²⁴¹ *Id.*

²⁴² *Id.* at 617. Critics raise a variety of concerns:

First objectors argue that neurocognitive enhancement is anti-egalitarian because these technologies are expected to be costly and the wealthy will have significantly more access to them A second set of concerns about unlimited neurocognitive enhancement is advanced by objectors who assert that neurocognitive enhancements are both unnatural and a threat to good character A third group of critics resists neurocognitive enhancement on safety grounds.

Id. at 616-17.

²⁴³ Nat'l Inst. of Mental Health, What Causes ADHD?, <http://www.nimh.nih.gov/health/publications/attention-deficit-hyperactivity-disorder/what-causes-adhd.shtml> (last visited Jan. 16, 2010).

²⁴⁴ *Id.*

attention spans of their workers.²⁴⁵ Here, the danger stems from the naturally unbalanced relationship that exists in at-will employment situations: the employer enjoys a much better bargaining position than his or her employees. Thus, workers could feel compelled to consume enhancing drugs, such as Adderall, to retain their jobs or to keep pace with those in the workforce who choose to consume these pharmaceuticals.²⁴⁶ Eventually, this could result in discrimination, as separation forms between those who consume neurological enhancers and those who do not.²⁴⁷ While there certainly are situations where such skills are necessary to perform a job, as the science of pharmacology progresses, protections will be needed in the form of acts like GINA to guard employees from the pressure to medicate to maintain their positions.

CONCLUSION

Due to this country's history of genetic discrimination, the GINA was a necessary piece of legislation. Now that GINA is in effect, Americans no longer need to fear potential discrimination from their insurers and employers, and thus will be more willing to take advantage of existing opportunities for genetic testing.²⁴⁸ However, while GINA fills in some of the gaps of prior federal legislation, the compromises made in its passage leave unprotected many genetically-based categories of illness.²⁴⁹ Furthermore, as medicine and technology inexorably advance, it is also likely that amendments to GINA will be required to continue to provide adequate protection to individuals.²⁵⁰

Joanne Barken[†]

²⁴⁵ Appel, *supra* note 214, at 618.

²⁴⁶ *Id.* at 617.

²⁴⁷ *Id.* at 618.

²⁴⁸ Baruch & Hudson, *supra* note 9, at 436.

²⁴⁹ Miller, *supra* note 22, at 252-56.

²⁵⁰ See Appel, *supra* note 214, at 618.

[†] J.D. Candidate, Brooklyn Law School, 2010; B.S., Cornell University, 2005. I would like to thank the editors and staff of the *Brooklyn Law Review* for their time and assistance with this note. I would also like to give special thanks to Dr. Frederick Barken and Dr. Bruce Korf for their guidance and medical expertise.