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Morse Hyun-Myung Tan

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ADVANCING CIVIL RIGHTS, THE NEXT GENERATION: THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 AND BEYOND

Morse Hyun-Myung Tan[†]

ABSTRACT

On the leading edge of civil rights law and bioethics/healthcare law, this Article provides the first law review analysis of the recently passed Genetic Information Nondiscrimination Act (GINA) of 2008, which extends important protection against discrimination in health insurance and employment. GINA also bolsters genetic research by freeing research subjects from the threat of genetic discrimination. This Article demonstrates how GINA further protects this society against the rising dangers of genetic discrimination beyond previously existing federal and state law.

[†] Professor Tan would like to thank Dr. Francis Collins, Director of the Human Genome Project, for personally providing his input, encouragement and the chief inspiration behind this Article. The author also thanks Professor John Kilner for his suggestions, and for providing a national conference opportunity to present a portion of these materials. Thanks to Stanford Law Professor Hank Greely for his correspondence regarding this article. Anna Sabayrac provided excellent research assistance for me at the University of Texas School of Law. Fabio Moon and Brianna Zuber added their research assistance as well. Holly Fistler deserves special recognition for her particularly stellar research assistance, truly outstanding in its diligence and singular in its scope. Finally, I would like to dedicate this work of scholarship to my baby daughter Hope and infant Enoch (born just 3 days before GINA became law!), whose generation will see more of genetic science's promise fulfilled, ideally in a society whose laws sufficiently protect against genetic discrimination.

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I. INTRODUCTION

Civil rights in the 21st century and beyond encounter an increasingly serious challenge in genetic discrimination as the march of genetic technologies continues forward. Dr. Francis Collins, the head of the Human Genome project admonishes: "Since all of us have dozens of genetic glitches that put us at risk for disease, we all have a reason to be concerned about the possible misuse of genetic information."¹ If our particular glitches place us out of favor with the prevail-

¹ Francis S. Collins, Dir., Nat'l Human Genome Research Inst., Regarding

ing legal/political winds, then any one of us can find ourselves without health insurance, employment – or worse. So none of us find ourselves immune to the possibility of having our civil rights violated – due to nothing more than the particular genomic hand dealt to us.

One need look no further than our country's own eugenic past to see not only what can happen, but what did actually happen already in violation of civil rights. In 1927, the famous Supreme Court Justice Oliver Wendell Holmes handed down his opinion in *Buck v. Bell*, in which he opined that “[t]hree generations of imbeciles are enough”² and thus stamped the approval of the highest court in our land on forced sterilization. In this case, Carrie Buck was the daughter of a “feeble minded” mother, as well as the mother of a “feeble minded” child.³ The Virginia statute in question determined that the sterilization of mentally impaired individuals would promote the health of the patient and the health of society.⁴ Accepting that “heredity plays an important part in the transmission of insanity, imbecility, etc.,” the Supreme Court held that: “[i]t is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.”⁵

No less than thirty-two American states pushed through compulsory eugenic sterilization statutes from 1907 to 1937.⁶ These statutes forced the removal of reproductive capacities in genetically “undesirable” groups of people, such as the “feeble-minded.”

However, leading historians of the eugenics movement point to a 1936 report from the American Neurological Association that expressed disapprobation for eugenic, forced sterilization as a turning point that, together with a 1939 declaration by the International Genetics Congress attacking Nazi eugenic theories, decisively influenced the America of that era against eugenics.⁷ The complexities of genetic science and neuroscience mixed with strong ethical sensibilities pointed away from such crass eugenics. No additional state laws

the Passage of Genetic Information Nondiscrimination Act of 2005 (S. 306) (Feb. 17, 2005), <http://www.genome.gov/13014311> (last visited Jan. 9, 2009).

² *Buck v. Bell*, 274 U.S. 200, 207 (1927).

³ *Id.* at 205.

⁴ *Id.*

⁵ *Id.* at 206-07.

⁶ Edward J. Larson, *Confronting Scientific Authority with Religious Values: Eugenics in American History*, in “GENETIC ENGINEERING: A CHRISTIAN RESPONSE – CRUCIAL CONSIDERATIONS IN SHAPING LIFE” 105, 106 (Timothy J. Demy & Gary P. Stewart eds., 1999).

⁷ *Id.* at 117.

mandating eugenic sterilization prevailed afterwards, and the existing state laws increasingly fell into disuse and disfavor.⁸

Through the discoveries of genetic science in the Human Genome Project and beyond, the dangers of a new eugenics and genetic discrimination have taken on ever more sophisticated and potentially deleterious forms. The Human Genome Project is now essentially complete, with scientists laboring currently to further understand how groups of genes interact. The ability to uncover more and more diseases with genetic etiologies has been expanding greatly. In a statistic that will have most likely expanded substantially when this article prints, "over 15,500 recognized genetic disorders affect 13 million Americans."⁹ Along these lines, consider that genetics cause around a quarter of infant deaths,¹⁰ half of the instances of mental retardation,¹¹ the inherited susceptibility of 5-10% of cancers,¹² and a component in a tenth of adult chronic diseases, including diabetes, rheumatoid arthritis and heart disease.¹³

Francis Collins projects that a \$1,000 complete genetic screening for any person remains a realistic goal within the next decade.¹⁴ The challenge remains of how to reap the potentially immense benefits of genetic research and medical intervention in curing actual diseases, without re-opening the Pandora's Box of eugenics as well as genetic discrimination, and thereby trammeling civil rights.

There exists a mounting body of reports from individuals who have been, or who believe they have been, discriminated against based upon their genetic information:

⁸ *Id.*

⁹ Victor A. McKusick, *MENDELIAN INHERITANCE IN MAN: A CATALOG OF HUMAN GENES AND GENETIC DISORDERS* (11th ed. 1994); *See generally* DIGAMBER S. BORGAONKAR, *CHROMOSOMAL VARIATION IN MAN* (7th ed., 1994) (cataloging over 7000 reports of structural aberrations, polymorphisms and fragile sites).

¹⁰ R. J. Berry et al., *Birth Weight-Specific Infant Mortality Due to Congenital Anomalies, 1960 and 1980*, 102 *PUB. HEALTH REP.* 171, 172 (1987).

¹¹ A.W.H. Emery, and D.L. Rimoim, eds., *Principles and Practice of Medical Genetics*, 2nd edition (Edinburgh and New York: Churchill Livingstone, 1990).

¹² KATHERINE SCHNEIDER, *COUNSELING ABOUT CANCER: STRATEGIES FOR GENETIC COUNSELING* 9 (2d ed., 2002).

¹³ *See* D.J. WEATHERALL, *THE NEW GENETICS AND CLINICAL PRACTICE* 193 (3d ed. 1991).

¹⁴ Nat'l Human Genome Research Inst., *NHGRI Policy Roundtable Summary: The Future of Genomic Medicine: Policy Implications for Research and Medicine*, Nov. 16, 2005, <http://www.genome.gov/17516574>. Francis Collins is the current Director of the National Human Genome Research Institute (NHGRI). *Id.* This roundtable discussion addressed policies to further the development of human genomics and the translation of this science into improved health care. *Id.*

- A recent survey conducted by the Eunice Kennedy Shriver Center discovered almost 600 cases where individuals lost employment because of their predispositions to genetic diseases.¹⁵
- For example, a young social worker mentioned that her mother had died of Huntington's Disease. Because of the 50% chance of developing the disease, she was denied her position.¹⁶
- A 40-year old woman with an excellent employment record participated in a genetic survey, which revealed that she possessed the BRCA1 gene – a gene that is linked to some forms of breast and ovarian cancers. In prophylactic surgery to reduce her chances of developing this form of cancer, she had her breasts, ovaries and uterus removed. Nevertheless, despite her efforts to reduce her chances, she was still fired.¹⁷
- After suffering a heart attack, one man's insurer "refused to pay the hospital bills or cover future treatment for cardiovascular disease" because a genetic test revealed that he possessed a genetic predisposition to high cholesterol. The insurer determined that the genetic condition, being present since birth, constituted a preexisting condition.¹⁸
- In addition to those possessing genetic disorders, family members are at risk of genetic discrimination. For example, those with a family history of Huntington's Disease will face discrimination, even though the disease is rather rare, affecting one in 10,000. Based on calculations, there are 150,000 relatives of Huntington's disease patients at risk in the United States. In Boston, a woman with a family history of the disease applied thirteen times for health insurance – and was turned down by every company until she took a genetic test to prove she had not inherited the disease. She was even unable to obtain health insurance for her children.¹⁹

¹⁵ Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1351-52 (2002).

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ Richard A. Bornstein, *Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes*, 4 J. L. & POL'Y 551, 566-568 (1996) (quoting Susan Ince, *Predictive Testing: A Bite of the Apple*, HARV. HEALTH LETTER, June, 1995, note 5, at 4).

¹⁹ *Id.* at 566.

Many statistics, numbers and reports document possible instances of genetic discrimination. Most of these studies document a continuing trepidation about the misuse of genetic information by third parties, most notably employers and insurance companies.²⁰

- A 1996 study of the perceptions of 332 members of genetic disorder support groups revealed that, as a result of testing positive for one or more of 101 different genetic disorders, 25% of respondents believed they were refused life insurance, 22% believed they were denied health insurance, and 13% believed that they were denied or fired from a job. Concerning genetic testing, 9% refused to be tested for genetic conditions, 18% did not reveal genetic information to insurers, and 17% did not reveal this information to employers – all for fear of facing genetic discrimination.²¹
- Many Americans charily avoid taking advantage of new breakthroughs in genetic testing for fear that the results will not be used to improve their health, but rather to deny them jobs or health insurance.
- In 1995, a Harris poll of the general public revealed that 85% of those surveyed were very concerned or somewhat concerned that insurers or employers might have access to and use their genetic information.²²
- A 1997 telephone survey found that 63% of respondents would not submit to genetic testing if health insurers or employers could gain access to the results. Moreover, 85% of respondents felt that employers should be prohibited from obtaining genetic information about prospective and current employees.²³
- Genetic counselors report that many of their patients are concerned about the misuse and abuse of genetic information – to the point that patients conceal the information even from their doctors. This secrecy may have disastrous results for a patient's health. For example, a woman whose doctor is unaware that she has the BRCA1 gene, and therefore has a genetic predisposition to cancer, will not receive

²⁰ S. REP. NO. 110-48, at 6 (2007).

²¹ E. Virginia Lapham, Chahira Kozma & Joan O. Weiss, *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621 (1996).

²² DEP'T OF LABOR, DEP'T OF HEALTH AND HUMAN SERV., EQUAL EMP. OPPORTUNITY COMM'N, DEP'T OF JUSTICE, GENETIC INFORMATION AND THE WORKPLACE (1998), available at <http://www.genome.gov/pfv.cfm?pageID=10001732>.

²³ *Id.*

a proper warning or be aware of necessary preventative medicine alternatives.²⁴

Serious concerns of employers engaging in unwanted or covert genetic testing of employees not only have a current basis, but the potential for extensive expansion in the future. In 2000, the American Management Association conducted a "Workplace Testing Survey." Of 2,133 employers surveyed, seven responded that their company performed genetic testing of employees. Of the seven, four reported genetic testing of job applicants, and six reported genetic testing of employees. An earlier study of Fortune 500 companies in 1989 conducted by the U.S. Congress Office of Technology Assessment (OTA) found that out of 330 respondents, 12 admitted to genetic testing of employees.²⁵

According to the American Academy of Actuaries, private insurers do not require applicants to undergo genetic testing, nor do they use genetic information to limit coverage by considering genetic proclivities as preexisting conditions.²⁶ A 2000 study conducted by Stephen Rich and Mark Hall found few well-documented cases of health insurers asking for or using genetic test results in underwriting decisions. Although some insurers use family history for common diseases such as heart disease, cancer and diabetes, the insurance industry reported that this practice is used to evaluate preexisting conditions and not to predict future illness.²⁷ Yet, merely because the insurance industry states that it does not consider genetic information in its current decisions, "[t]his does not mean that health insurers never have and never will engage in genetic discrimination."²⁸ Furthermore, indications exist that insurance companies seek to discern future illness through current genetic predispositions for breast cancer (BRCA 1 and 2), high cholesterol and high blood pressure.²⁹

Incidents of genetic discrimination have been an ongoing concern of the Department of Health and Human Services. In January 2000, the Secretary's Advisory Committee on Genetic Testing (SACGT) gathered perspectives on genetic testing through a public forum.³⁰

²⁴ S. REP. NO. 110-48, at 6.

²⁵ *Id.* at 7.

²⁶ *Id.*

²⁷ *Id.* at 8 (citation omitted); *See generally* Mark A. Hall & Steven S. Rich, *Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination*, 66 AM. J. HUM. GENETICS 293-94 (2000) ("Information from genetic tests is the sensible point of concern because that is where the fear of insurance discrimination has the greatest discernible impact.").

²⁸ *Id.* at 303.

²⁹ *See Id.* at 297.

³⁰ MICHELE SCHOONMAKER & ERIN D. WILLIAMS, CSR REPORT FOR

The testimonies revealed several cases of genetic discrimination. During these consultations, the SACGT heard from individuals who were concerned about the abuse of genetic information by health insurers and employers, whose fears of genetic discrimination dissuaded them from undergoing genetic tests, and who would consider paying out of pocket for genetic tests to prevent the results from posting onto their medical records.³¹ This trepidation in the face of genetic testing may be a deterrent to the development of genetic tests and preclude individuals from benefiting from the information these tests provide.³²

Given the history of eugenics, the increasing potential for discrimination as genomic research moves forward, actual instances of genetic discrimination, and the continuing concerns of the populace, Congress took a vital step in this important realm by passing the Genetic Information Nondiscrimination Act (“GINA”) of 2008, which was signed into law in the summer of 2008. The Genetic Information Nondiscrimination Act advances civil rights by providing a consistent national standard that would remedy the patchwork quilt of inadequate state laws, and fill gaps as well as clarify ambiguities in already existing federal law. Thus, GINA enhances protection against genetic discrimination in health insurance and employment, which in turn should advance genetic research by assuaging concerns that genetic information obtained in research might be discriminatorily used against the subjects of genetic research.

II. BACKGROUND: THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

Congress had made substantial attempts to pass comprehensive legislation prohibiting genetic discrimination since the 103rd Congress.³³ The first legislation introduced was the Human Genome Privacy Act of 1990.³⁴ In the mid 1990’s, there was a flurry of six different bills proposed within a five month time period. Three of these bills addressed the protection of individuals against genetic discrimination, while the other three were proposed to improve health

CONGRESS, GENETIC TESTING: SCIENTIFIC BACKGROUND AND NONDISCRIMINATION LEGISLATION 24 (2005), available at <http://ncseonline.org/NLE/CRSreports/05mar/RL32478.pdf>.

³¹ *Id.*

³² *Id.*

³³ *Id.* at 1.

³⁴ Bornstein, *supra* note 18, at 579.

insurance portability and continuity while including restrictions on the use of genetic information.³⁵

Senator Daschle and Congresswoman Slaughter concurrently introduced Senate Bill S.318 and House Bill H.R. 602 on February 13, 2001. The bill, called the “Genetic Nondiscrimination in Health Insurance and Employment Act,” would have amended ERISA, the Public Health Service Act (PHSA) and the Internal Revenue Code (IRC).³⁶ This legislation is very similar to the current GINA in regards to the insurance provisions. Insurers would have been prohibited from: (1) discriminating in “individual enrollment”; (2) discriminating in “group eligibility or group premium or contribution rates”; (3) “requesting or requiring [genetic] test[s] . . . as a condition of employment or insurance”; and (4) “requesting, requiring, collecting, purchasing, or disclosing [genetic] information, unless authorized by the individual.”³⁷ These bills also incorporated definitions of genetic testing and information very similar to GINA. However, S.318 and H.R.602 did not prevail.

After S.318 and H.R. 602 failed passage in Congress, Senator Snowe submitted the “Genetic Information Nondiscrimination Act of 2002.”³⁸ This piece of legislation marked a departure from previous bills, as it added prohibitions of genetic discrimination based upon the Civil Rights Act of 1964.³⁹ The other provisions of the legislation – including definitions and federal law to be amended – remained primarily the same as they appeared in the Daschle bill.⁴⁰ As before, this legislative initiative was not approved by both houses of Congress.

In the coming years, there would be many more attempts to pass comprehensive nondiscrimination legislation. In 2003, the Senate introduced S. 1053, the Genetic Information Nondiscrimination Act, which passed the Senate on October 14 by a vote of 95-0; however, its identical companion in the House of Representatives, H.R. 1910, did not come to a vote before the end of the legislative session.⁴¹ On February 7, 2005, Senator Snowe introduced S. 306, the Genetic Information Nondiscrimination Act of 2005. It was passed by the Senate by a vote of 98-0. An identical bill, H.R. 1227, was introduced in the

³⁵ *Id.* at 579.

³⁶ Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 53-54 (2002).

³⁷ *Id.* at 54 (citation omitted).

³⁸ *Id.* at 55.

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ SCHOONMAKER & WILLIAMS, *supra* note 30, at 1.

House of Representatives by Representatives Biggert, Slaughter, Ney and Eshoo on March 10, 2005, but it did not come to a vote.⁴² The only change made by S. 306 was the deletion of one tax related provision from Section 103 of the legislation.

The Genetic Information Nondiscrimination Act of 2007 (GINA), sponsored by Senator Olympia Snowe and Representative Louise McIntosh Slaughter, and co-sponsored by 258 senators and representatives, passed the House with a vote of 420 to 3 on April 25, 2007, and passed the Senate with a vote of 95 to 0 on April 24, 2008.⁴³ On May 1, 2008, the GINA of 2008 was re-introduced in the House, which passed it that same day, 414 to 1 on motion to suspend the rules and agree to the resolution. Despite the repeated history of one chamber passing it and the other chamber failing to do so, GINA of 2008 finally passed without amendment by Unanimous Consent in the Senate. On May 21, 2008, President Bush signed H.R. 493, the Genetic Information Nondiscrimination Act of 2008 into federal law. Civil rights thus took a quantum leap into the 21st century!

Genetic nondiscrimination legislation such as GINA of 2008 had the support of consumer groups, members of the medical profession, researchers and the medical products industry.⁴⁴ These groups asseverated that prior laws were insufficient to protect individuals from genetic discrimination. Without protection, these individuals will not seek out genetic testing and preventative treatment for fear of reprisals from employers and insurance companies.⁴⁵ Opponents to genetic nondiscrimination legislation included some members of the insurance industry and the US Chamber of Commerce.⁴⁶ The insurance industry representatives argued that current laws provide sufficient protection, and that new legislation would create confusing, unnecessary, expensive regulations as well as increased opportunity for litigation.⁴⁷ Moreover, insurance companies claimed that GINA would be unfair, prohibiting the use of genetic information when they already use other health information.⁴⁸ Most opponents also pointed to how few documented cases of genetic discrimination have been recorded,

⁴² *Id.*

⁴³ GovTrack.us, H.R. 493: Genetic Information Nondiscrimination Act of 2008, <http://www.govtrack.us/congress/bill.xpd?bill=h110-493> (last visited Nov. 3, 2008).

⁴⁴ SCHOONMAKER & WILLIAMS, *supra* note 30, at 1-2.

⁴⁵ *Id.* at 24.

⁴⁶ *Id.* at 2.

⁴⁷ *See id.*

⁴⁸ *Id.*

and claimed that GINA was an attempt to legislate based on fear rather than practice.

Some supporters of GINA, however, argued that these fears of genetic discrimination must be addressed. If the fears of genetic discrimination are allayed, supporters believe that individuals will be more apt to seek out health care service, participate in clinical research, and benefit from the advances of the Human Genome Project.⁴⁹ With the technological advances in genetics, scientists are continuing to decipher the sequence of the human genome and develop tests to detect diseases and disorders. This endeavor cannot be accomplished without the active participation of individuals who are willing to undergo genetic testing and research. Furthermore, public health will best be served if patients with genetic predispositions can confidently pursue screening and preventative health care measures. The enactment of GINA, like preventative medicine, helps prohibit discrimination and lift fears at the same time.

III. GENETIC DISCRIMINATION: EVIDENCE OF A GROWING PROBLEM

A. Accounts of Genetic Discrimination

In the midst of what may seem to be impersonal and desiccated statistics and reports, it is important to remember that behind every number and incident, there are individuals who have undergone difficult situations brought on by genetic discrimination. Some of these individuals provided testimony to the Secretary of Health and Human Service's Advisory Committee on Genetics, Health and Society on October 18, 2004.⁵⁰ Their narratives painted persuasive portraits for the passage of GINA.

Heidi Williams and her two children were victims of genetic discrimination in 2003.⁵¹ When she applied for health insurance for her children, she was asked whether her children had any pre-existing conditions. “[U]nder a threat of a fine and incarceration for falsifying

⁴⁹ *Id.*

⁵⁰ The Agenda and testimony from the meeting is available at Nat'l Institutes of Health, Secretary's Advisory Committee on Genetics, Health, and Society, <http://www.webconferences.com/nih/acghs/18oct2004.html> (last visited Nov. 3, 2008); SCHOONMAKER & WILLIAMS, *supra* note 30, at 25.

⁵¹ Heidi Williams, Testimony before the Secretary's Advisory Committee on Genetics, Health, and Society (Oct. 18-19, 2004), http://oba.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Williams_trans.pdf (last visited Jan. 7, 2009).

information” she told the insurance representative that her children are carriers of the alpha-1 antitrypsin deficiency, or AAT, a genetic liver deficiency that can progressively affect the lungs, the liver, or both.⁵² However, being only carriers of the gene, they would not develop the disease. Williams was denied coverage by the insurer twice, even after submitting letters from the National Institutes of Health and the Alpha-1 Foundation affirming that her children would not develop the disease. The treatment that Williams received from the insurance company made her feel guilty, ashamed and angry:

We are all viable members of a community with contributions to make and shouldn't have to be afraid that our genetic anomalies, in whatever form they arise, will be held against us. I should not have had to spend the better part of six months wondering if the decision to have my children's genetic status verified by their pediatrician was a huge mistake. I should not have to wonder if my children's genetic status is going to follow them into the workforce and render them unable to become employed in their chosen fields. And I certainly should not have to feel guilty for unknowingly passing this genetic anomaly on to my children.⁵³

For Phaedra Malatek and her two sons, genetic testing presents a double-edged sword.⁵⁴ In 1991, her father was diagnosed with hemochromatosis – a commonly inherited genetic disorder which causes iron overload in the blood – and subsequently passed away from the damage caused to his liver and heart. Malatek, out of concern for the well being of her children, wondered: “[I]f my children undergo genetic testing for hemochromatosis, they risk not being able to obtain health insurance when they're no longer covered under my husband's policy and possible discrimination when they seek employment.”⁵⁵ Furthermore, Malatek explained that “[i]t's troubling to me that as Americans we're placed in a position where we have to make such a terrible choice.”⁵⁶ At the time of her testimony, Malatek's sons still had not been tested for hemochromatosis for fear of discrimination.⁵⁷

⁵² *Id.*

⁵³ *Id.*

⁵⁴ Phaedra Malatek, Testimony before the Secretary's Advisory Committee on Genetics, Health, and Society (Oct. 18-19, 2004), http://oba.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Malatek_trans.pdf (last visited Jan. 7, 2009).

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ *Id.*

After a genetic test revealed a positive result for BRCA1, Tonia Phillips had to decide how to proceed with a 45% chance of developing breast cancer and an 80% chance of developing uterine cancer.⁵⁸ After undergoing a hysterectomy and a prophylactic double mastectomy, the insurance rates in her four-person office rose by \$13,000 per person. Her boss asked her to switch to her husband's insurance policy, even offering her a pay raise to do so. For Phillips, "[i]t seems unfair to me that I am taking steps to keep myself healthy and to prevent cancer in the future, and I am being singled out and made to feel I am a liability."⁵⁹ In the end, she did not switch insurance companies, but the office now requires employees to pay half of their insurance premiums.⁶⁰

Phil Hardt has two genetic disorders: hemophilia B and Huntington's Disease.⁶¹ Upon the diagnosis of Hardt's hemophilia in the early 1990s, his HR director recommended that he not reveal his disease to his boss; otherwise, he would be neither trained nor promoted. He was denied credit insurance for his car purchase when it was discovered that he had Huntington's Disease (HD). Hardt described the affliction of HD as being "like living with Alzheimer's, Parkinson's, MS, and going insane all at the same time."⁶² However, the effects of his genetic diseases reach farther than his own health. His children and grandchildren are routinely denied life insurance unless they are tested for HD and the test result is negative. His grandchildren have been denied health insurance because of the hemophilia and are left with an option: either earn very little money to qualify for state welfare, or pay their own health costs. Hardt likened the current state of genetic testing in the US to the Tiresias complex. "If you remember, the blind seer Tiresias confronted Oedipus with the dilemma, 'it is but sorrow to be wise when wisdom profits not.'"⁶³ Although knowledge of genetic predispositions to disease opens the door to preventative medicine, the results are devastating to individuals and family members.

⁵⁸ Tonia Phillips, Testimony before the Secretary's Advisory Committee on Genetics, Health, and Society (Oct. 18-19, 2004), http://oba.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Phillips_trans.pdf (last visited Jan. 9, 2009).

⁵⁹ *Id.*

⁶⁰ *Id.*

⁶¹ See Phil Hardt, Testimony before the Secretary's Advisory Committee on Genetics, Health, and Society (Oct. 18-19, 2004), http://oba.od.nih.gov/oba/SACGHS/meetings/October2004/transcript/Hardt_trans.pdf (last visited Jan. 7, 2009).

⁶² *Id.*

⁶³ *Id.*

In one particularly well known example that transpired in October of 2005, the Chicago Bulls requested that a player named Eddie Curry receive genetic testing to diagnose a possible heart arrhythmia.⁶⁴ After becoming ill with lightheadedness and dizziness, he was diagnosed with an irregular heartbeat and benched for the rest of the season. The Bulls thought that Curry might have a predisposition to Hypertrophic Cardiomyopathy (HCM), which had resulted in the early demise of other NBA basketball players. HCM is a genetic disorder that affects the heart, causing it to enlarge and weaken. Curry declined the genetic testing on the basis of what he considered federal constitutional grounds. The Bulls, in response, traded Curry to the New York Knicks rather than mounting a legal challenge to Curry's refusal under state and/or federal law.

The Knicks also declined to bring suit under New York's genetic discrimination statute. In fact, New York state law, prohibiting genetic testing as a condition of employment, prevented the Knicks from requiring Curry's genetic information.⁶⁵ Instead, Curry submitted to various non-genetic physical examinations, which all established Curry's then current condition of health. Moreover, the Knicks' team doctor decided that a genetic test was not necessary because DNA testing was still too new and inconclusive.⁶⁶

The insurance carrier for the NBA balked at indemnifying Curry's contract due to his history of prior heart issues. The Knicks then sought to find an alternative insurer. The New York franchise also made Curry's contract partially contingent upon his health. The Knicks would not retain liability for his full contract if Curry could not play because of coronary difficulties. This case demonstrates not only potential sources of genetic discrimination, but also the differing levels of protection offered by the states' privacy and discrimination laws, thus illustrating the benefit of GINA's laying a consistent floor below the patchwork quilt of state laws.

Those who serve in the military also did not find themselves immune from the threat of genetic discrimination. Eric Miller, a 28 year old Army Ranger, suffered back pain during his tour in Afghanistan.⁶⁷ It took three surgeries to remove the tumors in his back and brain. A genetic test, however, discovered a genetic mutation which facilitated uncontrollable tumor growth. Miller was discharged from

⁶⁴ Andrew E. Rice, *Eddy Curry and the Case for Genetic Privacy in Professional Sports*, 6 VA. SPORTS & ENT. L.J. 1, 2-3 (2006).

⁶⁵ *Id.* at 7-8.

⁶⁶ *Id.* at 7.

⁶⁷ Karen Kaplan, *U.S. Military Practices Genetic Discrimination in Denying Benefits*, L.A. TIMES, Aug. 18, 2007, at A1.

the Army in 2005 because of his illness, with no disability benefits or health insurance to help in his fight against cancer. For the last 20 years, it has been military policy to deny disability benefits to service men and women for congenital disorders in an effort to prevent individuals from choosing a military career for the benefits.⁶⁸ The rule affords an exception if the individual has served more than eight years in the military. It has been argued that some genetic discrimination is necessary for the strength and efficacy of the military, such as refusing to accept those who have achondroplasia (dwarfism), color blindness, or hereditary hearing loss. However, refusing benefits goes beyond mere selection of service men and women. As Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University stated bluntly: "You could be in the military and be a six-pack-a-day smoker, and if you come down with emphysema, 'That's OK. We've got you covered.' . . . But if you happen to have a disease where there is an identified genetic contribution, you are screwed."⁶⁹ This practice is even causing military doctors to recommend that service men and women not submit to genetic testing. By refusing genetic tests, these individuals lose the chance to learn from potentially life-saving diagnoses and treatments. Miller lost his case on appeal and received no benefits or insurance.⁷⁰

B. Applicable Case Law

At present, the US Federal or state courts have decided very few if any genetic discrimination cases in the scope of either in employment or health insurance.⁷¹ Most cases referring to genetic discrimination concern the use of genetic information as evidence in criminal trials. Those cases that have related to genetic discrimination focused either on privacy law or interpretations of the ADA. There have not been any published cases concerning genetic discrimination in health insurance coverage. However, the dearth of current case law should not lull one to dismiss the prophylactic value of GINA, where the law does not lag as far behind technological and scientific advances than it formerly did.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ Paul Steven Miller, *Analyzing Genetic Discrimination in the Workplace*, in RIGHTS AND LIBERTIES IN THE BIOTECH AGE 173, 176 (Sheldon Krinsky & Peter Shorett eds., 2005).

*Norman-Bloodsaw v. Lawrence Berkeley Laboratory*⁷²

Although not expressly concerning genetic discrimination, the *Norman-Bloodsaw* case contributes to this debate because it concerns an employer's invasions of privacy through medical examinations. Genetic tests constitute a type of medical examination.

In its hiring process, the Lawrence Berkeley Laboratory would conditionally offer candidates employment subject to subsequent medical exams.⁷³ The plaintiffs in this case, seven present and former employees, accepted the condition of undergoing the medical examinations, including blood and urine samples. In addition, the employees answered health information questionnaires, including questions regarding sickle cell anemia (a genetically linked condition), venereal disease, and female menstrual disorders. Without knowledge or consent, African-American employees were tested for the sickle cell trait, women were tested for pregnancy, and all were tested for syphilis. Defendant employer stated that the tests were part of an overall occupational health program (permissible under GINA, too), and regardless, the questioned testing had been terminated as of 1995. After the district court dismissed the plaintiffs' allegations, the Ninth Circuit Court of Appeals reviewed the decision on appeal.

First, the Court reversed the District Court's dismissal on the invasion of privacy claim.⁷⁴ According to the Court, the plaintiffs' constitutionally protected privacy rights were invaded by the medical examinations. In invasion of privacy cases, "the *most basic* violation possible involves the performance of unauthorized tests – that is, the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiffs."⁷⁵ Test results concerning syphilis, pregnancy and the sickle cell trait contain information which may invite social stigma, and reveal sensitive personal information about family history and reproductive choices. With respect to the testing for syphilis and pregnancy, the Ninth Circuit has established "that the Constitution prohibits unregulated, unrestrained employer inquiries into personal sexual matters that have no bearing on job performance."⁷⁶ The court determined that answering a medical questionnaire or agreeing to undergo a medical examination for

⁷² 135 F.3d 1260 (9th Cir. 1998).

⁷³ *Id.* at 1264-66.

⁷⁴ *Id.* at 1268-70.

⁷⁵ *Id.* at 1269.

⁷⁶ *Id.* (citations omitted).

employment in no way puts the employee on notice of the testing conditions, nor does it provide the employer with consent.⁷⁷

Second, the Circuit Court reversed the dismissal of plaintiffs' Title VII discrimination claims.⁷⁸ In its reasoning, the Court relied on Section 703(a) of Title VII of the Civil Rights Act of 1964, which prohibits discrimination against individuals with respect to terms and conditions of employment based upon race, color or sex.⁷⁹ It also relied on the Pregnancy Discrimination Act, which defines "sex" discrimination to include discrimination on the basis of pregnancy, childbirth or other related medical conditions.⁸⁰ In this case, the plaintiffs' claim fell directly under the protection of Title VII because African-American and female employees were singled out for additional nonconsensual medical examinations. Because the medical examinations were an explicit condition of employment, these additional tests in effect created different terms and conditions of employment for the plaintiffs than for other job applicants. Furthermore, the process of obtaining such medical information based upon sex, color or race constitutes a statutory "adverse effect" under Title VII.⁸¹

The holding in *Norman-Bloodsaw ipso facto* would only protect individuals from genetic discrimination so long as they are covered as a protected group under Title VII, or the violations of privacy in medical testing rise to the gravity of nonconsensual testing conducted by the employer into the employee's sensitive personal information. Yet, this holding is not broad enough to provide protection to all individuals who would bring forth a claim of genetic discrimination. First, the Court affirmed the dismissal of the claim brought under the ADA, because the ADA does not limit the scope of the medical examinations made after a conditional offer of employment. These examinations are not required to be solely job-related or consistent with business necessity. The only requirement is that this information must be kept confidential, and must not be used by the employer in subsequent employment decisions. Thus, under this holding alone, employers are still able to perform medical examinations designed to discover the employee's genetic information. Second, the holding in *Norman-Bloodsaw* only applies to protected groups; those who are not part of protected groups, such as white males, for example, could still be required to undergo nonconsensual genetic testing. The limitations of the *Norman-Bloodsaw* case with respect to protection from genetic

⁷⁷ *Id.*

⁷⁸ *Id.* at 1271-73.

⁷⁹ *Id.*

⁸⁰ *Id.*

⁸¹ *Id.* at 1272.

discrimination highlights the role that GINA performs in enhancing protection.

*Bragdon v. Abbott*⁸²

Although the courts have not yet decided whether individuals with presymptomatic genetic disorders or proclivities are protected by the ADA (now they are clearly protected through GINA), the Supreme Court held in *Bragdon v. Abbott* that individuals with asymptomatic HIV are covered by the ADA.⁸³ An asymptomatic HIV individual, Ms. Abbott, sought dental care from Dr. Bragdon. Dr. Bragdon agreed to perform the routine dental exam.⁸⁴ But when the exam turned up a cavity, he explained that he would only fill cavities of HIV-infected patients in hospitals.⁸⁵ Although he did not charge extra for the care, Ms. Abbott would have been responsible for hospital fees.⁸⁶ She declined the dental care and sued Dr. Bragdon for discrimination under the ADA.⁸⁷ The district court held in favor of Ms. Abbott, and the circuit court affirmed. On appeal, the Supreme Court granted certiorari.⁸⁸

The Supreme Court held that Ms. Abbott is disabled under the ADA because asymptomatic HIV constitutes a physical impairment that substantially limits one or more of the major life activities of the individual.⁸⁹ The Supreme Court systematically reviewed the different aspects of this protection.⁹⁰ First, the court held that HIV meets the statutory definition of disability because it is a "physiological disorder with a constant and detrimental effect in the infected person's hemic and lymphatic systems from the moment of infection."⁹¹ Second, the Supreme Court determined that reproduction constitutes a major life activity under the ADA.⁹² Third, HIV substantially limits an individual's reproductive choices, as unprotected intercourse poses a threat to the sexual partner and progeny.⁹³ Since current anti-viral medications can only reduce the risk of transmission of HIV by 8%,

⁸² 524 U.S. 624 (1998).

⁸³ *Id.* at 647.

⁸⁴ *Id.* at 628-30.

⁸⁵ *Id.*

⁸⁶ *Id.*

⁸⁷ *Id.*

⁸⁸ *Id.*

⁸⁹ *Id.* at 641-42.

⁹⁰ *Id.* at 637-42.

⁹¹ *Id.* at 637.

⁹² *Id.* at 639.

⁹³ *Id.* at 641.

the risk of transmission is sufficient to prevent HIV-positive individuals from endangering those with whom they would engage in intercourse.⁹⁴ Furthermore, the Court stated that its findings are supported by the many agency interpretations of the ADA statutes, as well as administrative guidance.⁹⁵

As some scholars have observed, this holding vastly expands the existing ADA interpretations. First, the Supreme Court determined that asymptomatic HIV qualified as a disability under the ADA, although its effects of physical impairment are relatively minor in comparison with other disabilities. Second, reproduction, although important to many, is not the same type of major life activity as walking, talking, seeing, hearing or working. Third, the application of protection under the ADA is intended to be determined upon inquiry into individual cases. In this case, Ms. Abbott had no interest in having children. Finally, the holding was not limited to Ms. Abbott; rather, the Court left open whether HIV is universally a disability and whether the holding includes women who are unable to reproduce because of menopause or sterility.⁹⁶

By analogy, this case would provide protection for individuals with genetic diseases under the ADA. However, it is unclear that the precedent set by *Bragdon v. Abbott* will provide protection for individuals with genetic predispositions to specific diseases. Those with monogenetic predispositions with almost categorical expectations of eventual disease onset, such as those with the gene for Huntington's Disease, may find aegis under *Bragdon's* interpretation of the ADA.⁹⁷ Those with less certain genetic predispositions face a heavy dual burden of proof to qualify under the ADA. First, the individual will have to prove that he or she "suffered from physical impairment" before the symptoms occurred.⁹⁸ This creates a heavy burden because most genetic conditions first begin with the symptoms, and then are followed by the impairment.⁹⁹ Additionally, the individual must prove that a major life activity has been limited.¹⁰⁰ This is also a difficult burden to meet because genetic transmission differs substantially from HIV transmission.¹⁰¹ Genetically predisposed parents cannot transmit genetic disorders through sexual relations to a partner or through

⁹⁴ *Id.* at 640-41; Geetter, *supra* note 36, at 40.

⁹⁵ *Bragdon*, 524 U.S. at 642.

⁹⁶ *Id.*; Geetter, *supra* note 36, at 40.

⁹⁷ See Geetter, *supra* note 36, at 41; Silvers & Stein, *supra* note 15, at 1365.

⁹⁸ Geetter, *supra* note 36, at 42.

⁹⁹ *Id.*

¹⁰⁰ *Id.*

¹⁰¹ See *id.*

labor. Even if the child actually inherits the unfortunate genetic sequence, it remains uncertain whether the child will even develop the disease. Genetically presymptomatic individuals could also bring suit under the “regarded as” prong of the ADA.¹⁰² The individual must be able to demonstrate that either he or she had a physical or mental impairment that does not substantially limit the ability to perform major life activities, or that he or she did not suffer from an impairment listed as a disability under the ADA.¹⁰³ Yet neither of these possibilities will cover all genetic discrimination claims.

There is another important concern that Jennifer Geetter points out in her research concerning the difference between HIV transmission and genetic transmission. With our nation’s history of eugenics, it is important not to attach stigmas to certain genotypes or phenotypes. In effect, “[b]y considering someone disabled because she may pass along a genotype that departs in one way from the healthy norm, we have created something akin to benign eugenics.”¹⁰⁴ It is inadvisable to create a legal standard that some people are limited in their ability to have children because of genotype or phenotype, as most of our states did earlier in our history.

Moreover, this holding has been criticized as overly broad. In the dissent, Justices Scalia, Thomas and Rehnquist noted that this holding “taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease ‘disabled’ here and now because of some possible future effects.”¹⁰⁵ The preamble to the ADA indicated that 43 million Americans had some form of physical or mental disability.¹⁰⁶ The majority in this case determined that this decision would expand coverage to 160 million Americans. It has been posited that the “43 million” statistic demonstrates legislative intent to protect a limited group of individuals.¹⁰⁷ Furthermore, an expansion of the ADA’s coverage to genetically predisposed individuals would effectively cause all Americans to be protected under the ADA “because all [individuals] . . . have identifiable genetic abnormalities.”¹⁰⁸ This would stretch the ADA beyond its original goal and, by protecting all Americans, it would effectively protect no

¹⁰² *Id.* at 43.

¹⁰³ *Id.*

¹⁰⁴ *Id.* at 42.

¹⁰⁵ *Bragdon v. Abbott*, 524 U.S. 624, 661 (1998) (Rehnquist, J., dissenting).

¹⁰⁶ Geetter, *supra* note 36, at 41; Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12101 (2007) (this section contains the Congressional findings and purposes for enacting the ADA).

¹⁰⁷ Geetter, *supra* note 36, at 41.

¹⁰⁸ *Id.*

one. Put another way, a genetic defect does not necessarily constitute a disability. Thus, *Bragdon* and the ADA might not be the best possible vehicle to protect individuals from genetic discrimination. GINA has more sensibly done so.

*EEOC v. Burlington Northern and Santa Fe Railway*¹⁰⁹

In 2001, *EEOC v. Burlington Northern Santa Fe Railway* came closest to establishing court precedent for genetic nondiscrimination in employment. It constituted the first case involving a claim of genetic discrimination under the Americans with Disabilities Act (ADA).

Burlington Northern and Santa Fe Railway (BNSF) required union employees who claimed to suffer from carpal tunnel syndrome (CTS) to undergo blood tests. BNSF then used these blood samples to conduct genetic testing for CTS predisposition without the express consent of the employees. At least one employee complained that BNSF threatened to fire him if he refused the blood test.¹¹⁰ “CTS is a painful hand and wrist condition often caused by repetitive motion.”¹¹¹ Determining whether the injury was caused by a predisposition to CTS necessitated the testing, according to BNSF.¹¹² The Equal Employment Opportunity Commission (EEOC) and the affected labor union responded by filing lawsuits. The lawsuit was settled in 2002 for \$2.2 million before it went to trial, possibly due to the publicity surrounding it.¹¹³ BSNF eliminated the genetic testing program as a condition of the settlement.¹¹⁴ Although the early settlement meant that the courts could not evaluate the legal principles involved in a genetic discrimination case,¹¹⁵ the idea of allowing non-consensual genetic testing for employees did not find outspoken support.¹¹⁶

This case came as the EEOC’s first concerning genetic discrimination. In a statement to the press, EEOC Commissioner Paul Steven Miller averred that discriminatory employment practices based on genetic testing violated the ADA. Although employers are permitted to require employees to undergo medical examinations provided that

¹⁰⁹ No. C01-4013 (N.D. Iowa Feb. 9, 2001).

¹¹⁰ Silvers & Stein, *supra* note 15, at 1350.

¹¹¹ SCHOONMAKER & WILLIAMS, *supra* note 30, at 22.

¹¹² *Id.*

¹¹³ Joanne L. Husted & Janlori Goldman, *Genetics and Privacy*, 28 AM. J.L. & MED. 285, 295 & n.55 (2002); SCHOONMAKER & WILLIAMS, *supra* note 30, at 22.

¹¹⁴ Husted & Goldman, *supra* note 113, at 295 n.55.

¹¹⁵ *Id.* at 295.

¹¹⁶ Miller, *supra* note 71, at 176-177.

they are sufficiently work-related, “[a]ny test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee’s present ability to perform his or her job.”¹¹⁷ However, the complexity of the ADA itself poses one of the main difficulties facing the prohibition of discriminatory use of medical testing. Provisions that allow for differential treatment of prospective and existing employees, as well as the difficulties in defining the concept of “disability,” make it hard for courts and employers to determine the precise contours of the ADA protections.¹¹⁸

A similar case was filed by the EEOC in 2001 against Woodbridge Corporation concerning the screening of nineteen job applicants for CTS.¹¹⁹ This case is the only recorded federal decision deciding a genetic discrimination claim on the merits.¹²⁰ These applicants were tested for abnormal wrist neurometric readings in order to determine whether the applicant would be predisposed to developing CTS. The EEOC argued that Woodbridge used the tests to discriminate against the nineteen applicants because of a perceived disability that would substantially limit their ability to work.¹²¹ Woodbridge responded that the testing was specifically designed and required for the repetitive motion necessary for a specific foam line in the one plant in Kansas City.¹²²

The district court granted summary judgment to Woodbridge, holding that the employee’s argument failed to satisfy the “regarded as” prong of the ADA.¹²³ The circuit court affirmed the decision on appeal. In order to prevail, the employer must have regarded the employee as disabled under the ADA, which means “significantly restricted in the ability to perform either a class of jobs or a broad range of jobs in various classes as compared to the average person.”¹²⁴ The plaintiffs were unable to meet these requirements, especially con-

¹¹⁷ Press Release, Equal Employment Opportunity Comm’n, EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act (Feb. 9, 2001), *available at* <http://www.eeoc.gov/press/2-9-01-c.html>.

¹¹⁸ Husted & Goldman, *supra* note 113, at 295.

¹¹⁹ Equal Emp. Opp. Comm’n v. Woodbridge Corp., 263 F.3d 812 (8th Cir. 2001).

¹²⁰ Silvers & Stein, *supra* note 15, at 1363-64 (discussing that “only a handful of cases clearly charging genetic discrimination have been filed by the EEOC.”).

¹²¹ *Woodbridge Corp.*, 263 F.3d at 813-14.

¹²² *Id.*

¹²³ Silvers & Stein, *supra* note 15, at 1373 (providing background information on the *Woodbridge* case).

¹²⁴ *Woodbridge Corp.*, 263 F.3d at 815 (quoting 29 C.F.R. § 1630.2(j)(3)(i) (1991)).

sidering that Woodbridge hired some of the nineteen applicants for other positions in the corporation and the limited nature of the testing. Despite this case's similarity to the recently settled *EEOC v. Burlington Northern and Santa Fe Railway* case, the court did not find that this situation qualified as a discriminatory hiring practice.¹²⁵

Cases effectively limiting the protections available under the ADA

Despite the broad holding in *Bragdon v. Abbott* and the recent EEOC victory against genetic testing in *EEOC v. Burlington Northern and Santa Fe Railway*, the most recent Supreme Court cases interpreting the ADA have tended to limit, rather than expand, the application of the ADA.

In a recent trio of decisions, the Supreme Court has limited the interpretation of disability under the ADA. In *Sutton v. United Airlines, Inc.*, twin sisters with severe myopia were denied employment as airline pilots because their uncorrected vision did not meet company standards.¹²⁶ In interpreting the ADA, the Court refused to employ the EEOC guidelines that directed people to be judged in their uncorrected state. Rather, employers must judge prospective or current employees by their condition together with mitigating factors. If an individual has an impairment that can be fully corrected by medication or other measures, then that individual cannot be said to be substantially limited in a major life activity.¹²⁷ Furthermore, the Court looked to the report prepared by the National Council on Disability, which the Council wrote to play a pivotal role in the creation of the ADA. This study stated that an overinclusive estimate of 160 million people with a disability would encompass people with all conditions that affect health or normal functions, and an underinclusive estimate of 22.7 million would consider only those with work-related disabilities. Instead, the 43 million number demonstrates an intent to limit the applicability of the ADA to those who meet a stricter definition of disability.¹²⁸ Thus, those who are able to mitigate their impairments to the point of being able to function normally would not be considered disabled.

In the second part of its analysis, the Court in *Sutton* also held that the myopic sisters did not meet the definition of being "regarded as disabled," since it requires that the employer mistakenly believe that the individual actually has a limiting disability, or mistakenly believe

¹²⁵ Silvers & Stein, *supra* note 15, at 1373-74.

¹²⁶ *Sutton v. United Airlines, Inc.*, 527 U.S. 471, 475-76 (1999).

¹²⁷ *Id.* at 482-83.

¹²⁸ *Id.* at 487.

that the actual impairment substantially limits one or more major life activities.¹²⁹ Or, more specifically, “an employer has to believe that the individual is ecumenically disabled—that she cannot perform an entire range of jobs in addition to the one from which she claims she has been unjustly excluded.”¹³⁰ In this case, the myopic twins were excluded from one type of employment only – global airline pilot – but would have been able to qualify as a co-pilot or pilot for a courier service.¹³¹ Thus, the Supreme Court affirmed the dismissal of both plaintiffs’ claims.

These holdings guided the decisions in two other cases. In *Murphy v. United Parcel Service, Inc.*, UPS dismissed the plaintiff Murphy from his job as a mechanic. The job required driving commercial vehicles; his high blood pressure would prevent him from receiving the necessary Department of Transportation certification. Although high blood pressure constitutes a medical condition, medicine can diminish it. Murphy was a qualified mechanic and high blood pressure did not exclude him from a broad array of jobs, but it did exclude him from jobs that would require driving commercial vehicles.¹³² *Albertson’s, Inc. v. Kirkingburg* involved the firing of an employee from his position as truck driver because of monocular vision problems. Although the Department of Transportation established an experimental waiver program, the Supreme Court determined that an employer does not violate the ADA by enforcing the standard statutory requirements for commercial trucking vision requirements.¹³³

This trio of cases limits the interpretation of the ADA in two major ways. First, the Supreme Court held in *Sutton* that mitigating factors must be taken into account when determining the existence of a “disability.” Second, and more importantly for the genetic information nondiscrimination debate, the Supreme Court indicated in *Sutton* and *Albertson’s* that it would not always extend to the EEOC guidelines the deference traditionally granted to federal regulatory agencies. Depending upon judicial interpretation and analysis, courts may or may not decide to extend deference to the EEOC’s regulations concerning genetic discrimination protection under the ADA in future decisions.¹³⁴ GINA decisively fills the gap not covered by the ADA.

¹²⁹ *Id.* at 489.

¹³⁰ Silvers & Stein, *supra* note 15, at 1372.

¹³¹ *Sutton*, 527 U.S. at 493.

¹³² *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516 (1999).

¹³³ *Albertson’s, Inc v. Kirkingburg*, 527 U.S. 555 (1999).

¹³⁴ Silvers & Stein, *supra* note 15, at 1365-66.

However, in *Chevron U.S.A., Inc. v. Echazabal*, the Supreme Court expanded the affirmative defense of “direct threat” available to employers under the ADA by adopting an EEOC regulation. Echazabal worked for independent contractors at a Chevron-operated refinery and had twice applied to work directly for Chevron. Each time, post-offer conditional medical exams revealed a liver abnormality, which later was diagnosed as Hepatitis C. Echazabal was refused employment because the condition would be aggravated by exposure to toxins at the refinery. Additionally, Chevron asked the independent contractors to reassign Echazabal to a job without exposure to harmful chemicals or remove him from the refinery position. After Echazabal was laid off by the independent contractors, he sued Chevron for violating the ADA.¹³⁵ Chevron defended its decision under an EEOC regulation that permitted the employer an affirmative defense if the worker’s disability posed a direct threat to his or her own health or the health of others.

When the district court granted summary judgment in favor of Chevron, Echazabal appealed. The Ninth Circuit reversed, holding that the employer erred in its interpretation of “direct threat” by including threats to the individual himself in the scope of the defense.¹³⁶ This created a circuit split with the Eleventh Circuit, and the Supreme Court granted certiorari.

Unanimously, the Supreme Court held that the “direct threat” affirmative defense included consideration of whether the disability would pose a threat to the individual’s own health. “Direct threat” must be demonstrated by “reasonable medical judgment,” an “individualized assessment of the individual’s present ability to safely perform the essential functions of the job,” and a consideration of “the imminence of the risk and the severity of the harm portended.”¹³⁷ The Court did not, however, explain the specific standards for the application of the newly expanded “direct threat” defense. Nor did the Court determine whether Chevron correctly applied the defense; rather, it remanded the case to the Ninth Circuit for further proceedings.¹³⁸

Given the unanimous acceptance of this decision, perhaps the holding could extend to individuals with genetic conditions. Employers would be permitted to decide whether the genetic condition of an employee would currently, or in the near future, be aggravated and pose a direct threat to the employee’s health.¹³⁹ GINA defuses the

¹³⁵ *Chevron U.S.A., Inc. v. Echazabal*, 536 U.S. 73, 76 (2002).

¹³⁶ *Id.* at 77-78.

¹³⁷ *Id.* at 86.

¹³⁸ Silvers & Stein, *supra* note 15, at 1369.

¹³⁹ *Id.*

threat of the “direct threat” affirmative defense of the ADA by affording protection that the ADA does not.

IV. STATE LEGISLATION

Given the inadequacies of federal protection against genetic non-discrimination, states have largely governed the realm of genetic discrimination. This state of affairs sharply contrasts the virtual federal monopoly over other forms of discrimination. Prior to 1986, state laws addressing genetic discrimination were less prevalent and very limited in scope.¹⁴⁰ However, following the development of the Human Genome Project and increased academic and media attention, state protection of genetic information has greatly expanded and changed in both the health insurance and employment contexts.¹⁴¹ As of the fall of 2006, forty-nine states have some form of law that protects the misuse of genetic information – Pennsylvania alone lacks such legislation.¹⁴²

A. Predominant State Approaches to Genetic Information

Currently, there are two predominant approaches for the protection of genetic information: protection based on property law, or protection based on privacy law. The majority of states justify protection on privacy grounds, equating genetic information to other sensitive medical information that is currently protected. A small minority of states – including Colorado, Georgia and Louisiana – protect genetic information as property.¹⁴³ The Colorado statute states: “Genetic information is the unique property of the individual to whom the information pertains.”¹⁴⁴ The adoption of the property model, as stated by scholars like Weeden, “would allow these states the future flexibility to better regulate even the possession of someone else’s genetic information, an option not available under a privacy regime.”¹⁴⁵ Moreover, a third approach to handling genetic information that emerges from state legislation is to employ direct nondiscrimination laws. Currently, the nondiscrimination approach appears to be the

¹⁴⁰ Bornstein, *supra* note 18, at 588.

¹⁴¹ Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 690 (2001); Bornstein, *supra* note 18, at 589.

¹⁴² Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611, 632 (2006).

¹⁴³ *Id.* at 633.

¹⁴⁴ COLO. REV. STAT. § 10-3-1104.7(1)(a) (2008).

¹⁴⁵ Weeden, *supra* note 142, at 633.

most common among states, as forty-six states prohibit health insurers from genetic discrimination and twenty-eight states prohibit employers from doing so.¹⁴⁶

B. State Laws Concerning Health Insurance

State statutes governing the use of genetic information in health insurance have shifted from very limited protection against unfair trade practices to “more intrusive regulation imposing restrictions on insurance practices for the purpose of advancing social goals.”¹⁴⁷ Initially, state laws were aimed at preventing insurance companies from discriminating against individuals absent an actuarial finding serving as the basis for discrimination. Current laws protecting genetic information prevent insurance companies from discriminating despite actuarial genetic differences, thus barring use of genetic information even if it is relevant to assessing risk.¹⁴⁸ Laws relating to use of genetic information by insurance companies have also expanded from applying only to specific genetic tests to broader legislation that forbids the use of genetic information regardless of the source.¹⁴⁹

The protections afforded by state law vary widely from state to state. Broadly speaking, state laws largely separate themselves into three categories of progressively increasing protection: (1) trait protection; (2) prohibition of discrimination from the results of genetic testing; and (3) forbidding discrimination in regards to genetic information. Trait protection seeks to prevent discrimination based on particular, genetically related traits. The first state to afford such protection was North Carolina in 1975. States that prohibit discrimination based on the results of genetic testing, such as Texas, afford a higher level of protection. States such as New York provide protection in the highest category among states, forbidding discrimination relating to genetic information, which may or may not have been obtained through the genetic tests referred to in level two protections. Even the highest two levels of state protection do not address the issue of the *collection* of genetic information. GINA does address the collection of genetic information, and thereby provides greater protection than all three general categories of state law.

¹⁴⁶ Suter, *supra* note 141, at 692.

¹⁴⁷ John V. Jacobi, *Genetic Discrimination in a Time of False Hopes*, 30 FLA. ST. U. L. REV. 363, 373 (2003); Geetter, *supra* note 36, at 51-52.

¹⁴⁸ Jacobi, *supra* note 147, at 375.

¹⁴⁹ Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73, 99 (2005).

Some of the more comprehensive legislative protections have been passed in states like California, Colorado, Georgia, Illinois, Maryland, New Hampshire, New Mexico, New York, Oregon, Rhode Island and Tennessee.¹⁵⁰ In California, for example, both individual and group insurance policies are subject to the laws prohibiting genetic discrimination.¹⁵¹ Residents benefit from a generous definition of “[g]enetic characteristics,” which includes “[a]ny scientifically or medically identifiable gene or chromosome, or combination or alteration thereof” and “[i]nherited characteristics that may derive from the individual or family member . . . that are determined to be associated with a statistically increased risk of development of a disease or disorder, and that are presently not associated with any symptoms of any disease or disorder.”¹⁵² California is also one of a minority of states that provides relatively comprehensive protection against genetic discrimination, as it prohibits establishing rules for eligibility based on genetic information, requiring genetic tests, using genetic information for selection and risk classification, and disclosing information without informed consent.¹⁵³ At present, there are only two states that do not provide some form of statutory protection against genetic discrimination in health insurance: Pennsylvania and Mississippi.¹⁵⁴

There are several observable trends in these state laws.¹⁵⁵ First, all of the prohibitions generally do two things: “define the types of information . . . regulated” and “proscribe how [the] regulated information can be used.”¹⁵⁶ “Several states try to distinguish between genetic and non-genetic information” by how they define “genetic information.”¹⁵⁷ Other states attempt to define “genetic characteristics.”¹⁵⁸ These definitions vary greatly among states. Second, states also vary in their prohibitions regarding the use of genetic information. For instance, “[s]everal states prohibit the use of a patient’s genetic information outside of the therapeutic, research or investiga-

¹⁵⁰ National Conference of State Legislatures (NCSL), State Genetic Discrimination in Health Insurance Laws, <http://www.ncsl.org/programs/health/genetics/ndishlth.htm> (last visited Oct. 29, 2008).

¹⁵¹ CAL. INS. CODE §§ 742.405, 10123.3 (West 2007).

¹⁵² § 10123.3(d)(1)-(2).

¹⁵³ NCSL, State Genetic Discrimination in Health Insurance Laws, *supra* note 150.

¹⁵⁴ *Id.*

¹⁵⁵ Geetter, *supra* note 36, at 52.

¹⁵⁶ *Id.*

¹⁵⁷ *Id.*

¹⁵⁸ *Id.*

tory context.”¹⁵⁹ Other states “prohibit an insurer from denying issuance or renewal based on genetic test results,” while still “other states . . . prohibit insurers from determining premiums based on genetic traits.”¹⁶⁰ Third, however, all state statutes governing the use of genetic information by insurance companies are missing one important component. These statutes “offer no protection to people who are symptomatic for genetically caused disorders.”¹⁶¹ Consequently, a person with a family history of breast cancer may not be discriminated against, but a person who has had breast cancer may be charged expensive premiums or even denied health insurance.

C. State Laws Concerning Employment Discrimination

Legislation governing the use of genetic information by employers also varies substantially. Compared to the state protections afforded in the health insurance sector, there are fewer provided in employment. Currently, only thirty-five states provide some form of genetic nondiscrimination law in the employment context.¹⁶² Those laws that currently exist “prohibit discrimination based on the results of genetic tests” and “[s]ome [laws] prohibit employers from both obtaining and using genetic information for employment decisions.”¹⁶³ Some states’ protections extend more comprehensively than others. For example, only Minnesota, Oklahoma and South Dakota provide protections across the board in employment, including prohibiting the employer from requesting genetic tests, requiring genetic tests, performing genetic tests or obtaining genetic testing results.¹⁶⁴ Minnesota’s law on genetic testing in employment is brief but complete.¹⁶⁵ It provides a complete definition of genetic testing, which includes “analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations [and] [t]ests for metabolites . . . when an excess or deficiency of the metabolites indicates the presence of a mutation or mutations.”¹⁶⁶ Employers are prohibited from requesting, requiring, using or collecting genetic information. However, substantial loop-

¹⁵⁹ *Id.* at 53.

¹⁶⁰ *Id.*

¹⁶¹ *Id.*

¹⁶² National Conference of State Legislatures (NCSL), State Genetics Employment Laws, <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last visited Oct. 29, 2008).

¹⁶³ Suter, *supra* note 141, at 693 (footnote omitted).

¹⁶⁴ NCSL, State Genetics Employment Laws, *supra* note 162.

¹⁶⁵ MINN. STAT. ANN. § 181.974 (West 2006).

¹⁶⁶ *Id.*

holes remain even in a statute as far-reaching as Minnesota's: protection does not extend to independent contractors and the only penalties available come through civil actions, which place the burden on the aggrieved employee to prove discrimination.¹⁶⁷

D. GINA: Providing a Unifying National Standard without Uniformity

Despite the prevalence of state legislation, the myriad of statutes and protections available resemble a hole-riddled patchwork quilt. Each state provides its own mix of nondiscrimination statutes in regards to health insurance, employment, privacy and property rights and substantial differences remain across state lines. Since genetic information in both the employment and insurance contexts frequently traverses interstate lines, if not for GINA, conflicting state laws would have continued to present challenges for both individuals seeking protection and governments enforcing provisions.¹⁶⁸ For example, consider an individual who lives in Pennsylvania, who commutes to New York to work, receives medical treatment in New Jersey, and whose insurance company has its corporate headquarters in Delaware. The choice of law questions would become exceedingly complex and their outcome would be important for the individual. In fact, this scenario puts a double burden on the individual: first, to establish which jurisdiction's laws apply, and second, to meet the appropriate burden of proof. Another example would be that of Eddy Curry, the NBA basketball player discussed above who would have been required by the Chicago Bulls to undergo genetic testing, but not by the New York Knicks based on different state laws. The varying state protections also created unfair differences in the treatment of individuals. The myriad of state legislation elicited the concern of GINA's authors, who stated that there is "substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination."¹⁶⁹

GINA's enactment directly addresses these problems by providing a national standard of genetic nondiscrimination protection. GINA's provisions are applied to states through preemption. Thus, the amendments brought to existing federal law – such as ERISA, SSA and HAS – continue to preempt state law. New privacy and confiden-

¹⁶⁷ *Id.*

¹⁶⁸ Weeden, *supra* note 142, at 633.; 43 Am. Bus. L.J. 79, 137 (2006).

¹⁶⁹ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2, 122 Stat. 881, 882 (2008).

tiality sections effectively “supersede any contrary provision of State law unless such provision . . . imposes requirements, standards, or implementation specifications that are more stringent than [those] imposed under” GINA.¹⁷⁰ The employment provisions of GINA are enforced through preexisting legislation that applies to private, federal, state and local employees.¹⁷¹ From the time GINA became law, the Department of Health and Human Services and the Department of Labor has had one year to promulgate appropriate regulations to assist with interpretation, coordination and enforcement. GINA will go into full effect 12 months after it was signed into law.¹⁷² Through preemption, it is possible for the federal government to create a unifying national floor for genetic information, without requiring uniformity, as long as the state law in question meets or exceeds the standard set in GINA.

V. PREVENTING GENETIC DISCRIMINATION IN HEALTH INSURANCE

A. Current Protections Against Discrimination in Health Insurance

Before GINA, Americans derived protection from genetic discrimination by a veritable alphabet soup of legislation: ERISA, PHSA, SSA, and HIPAA. For the majority of Americans covered by government programs or medium-to-large employers (20+ employees), federal law requires that coverage be issued to everyone who is eligible and that rates are the same across the board. This accounts for roughly 80% of the people in the US.¹⁷³ Recipients of health insurance from smaller employers find themselves at risk because of the smaller pool of beneficiaries (roughly 15% of people with private insurance).¹⁷⁴ People who purchase their own health insurance policies experience the greatest risk. They undergo the greatest scrutiny for health records, coverage and rates (about 10% of people with private insurance).¹⁷⁵ These federal laws only provide some form of protection against discrimination for some people some of the time.

¹⁷⁰ S. 358, 110th Cong. § 104 (2007).

¹⁷¹ Genetic Information Nondiscrimination Act §§ 201-13.

¹⁷² § 101, 122 Stat. at 888.

¹⁷³ MARK A. HALL, NORTH CAROLINA GENOMICS BIOINFORMATICS CONSORTIUM, GENETIC DISCRIMINATION 3 (2001), available at http://www.ncbiotech.org/services_and_programs/genomics_consortium/consortium_projects_and_events/geneticdiscrimination.pdf.

¹⁷⁴ *Id.*

¹⁷⁵ *Id.*

1. ERISA, PHSa and SSA: Protections for Governmental and Group Health Insurance Plans

The Employee Retirement Income Security Act of 1974 (ERISA) federally preempts state law in regards to employer-provided health insurance benefits. Currently, ERISA prohibits group health plans and health insurance issuers from discriminating against participants and beneficiaries based on the individual's genetic information. ERISA's nondiscrimination provisions apply to eligibility for enrollment as well as group premiums.¹⁷⁶

The Public Health Service Act (PHSA) governs both the group and individual insurance market. With the exception of the enforcement provisions, PHSA provisions concerning the group insurance market trace those contained in ERISA legislation. As such, the PHSA prohibits discrimination based upon genetic information in the group health insurance market. GINA brings identical amendments to the PHSA as in ERISA in regards to enrollment and premium nondiscrimination, as well as genetic testing limitations.¹⁷⁷

Title XVII of the Social Security Act (SSA) governs Medigap insurance coverage. Individuals who qualify for Medicare may purchase supplemental health insurance to cover the "gap" between costs covered by Medicare and the remaining balance. This supplemental private insurance presently remains under state law. GINA's amendments to the SSA create a basic standard of nondiscrimination policies. States that provide lesser protection are required to meet this floor in order to prevent preemption.

2. HIPAA: Providing for Coverage, Privacy and Confidentiality

Genetic information nondiscrimination provisions are already present in the Health Insurance Portability and Accountability Act (HIPAA).¹⁷⁸ HIPAA, signed into law in 1996, took effect on April 14, 2001. This act both governs the portability of group health insurance coverage for employees who transfer jobs, and safeguards the privacy and confidentiality of protected health information (PHI). HIPAA does not define the term "genetic information." However, the Department of Health and Human Services determined that genetic information, as it applies to HIPAA, includes "genes, gene products, and inherited characteristics that may derive from the individual or a

¹⁷⁶ S. REP. NO. 110-48, at 2 (2007).

¹⁷⁷ *Id.* at 24.

¹⁷⁸ Jacobi, *supra* note 147, at 372.

family member.”¹⁷⁹ This definition also includes carrier status, information from laboratory tests that identify genetic and chromosomal mutations, physical examinations, family history and direct genetic and chromosomal analysis.

3. Group Health Insurance

HIPAA regulations insure the “portability” of health care coverage for employees who change jobs. Group health plans, for example, must limit periods of exclusion from coverage for preexisting conditions (usually twelve months). This provision functions to permit workers to change jobs without fear of losing their health coverage due to ongoing conditions.¹⁸⁰

Health insurance issuers may not consider genetic information in coverage limitations and in the determination of membership eligibility because genetic predisposition to a disease does not count as a preexisting condition.¹⁸¹ Yet, this does not guarantee that the issuer is prohibited from genetic discrimination. Issuers may exclude the coverage of certain diseases as long as the exclusion applies equally to the entire insured group.¹⁸²

In the determination of group eligibility, insurers must have uniform eligibility rules for the plan members. HIPAA prevents issuers from establishing groups of high-risk individuals based on health information and from considering genetic predispositions as preexisting conditions. So long as similarly situated individuals receive uniform treatment, these eligibility rules do not prevent the issuer from restricting the amounts of benefits or eliminating coverage for certain medical conditions. In effect, HIPAA does not guarantee a mandatory minimum coverage or benefits package. Thus, an issuer may cap benefits or coverage for genetically identifiable diseases so long as the cap applies uniformly across the entire group.¹⁸³

HIPAA provisions relating to the setting of premium rates also prohibit discrimination between members of the same group.¹⁸⁴ Members may not have variable premiums based upon their individ-

¹⁷⁹ Requirements Relating to Health Insurance Coverage, 45 C.F.R. § 144.103 (2007).

¹⁸⁰ Jacobi, *supra* note 147, at 372.

¹⁸¹ See, e.g., Health Insurance Portability and Accountability Act of 1996 (HIPAA), 42 U.S.C. § 300gg(b) (2007); Crossley, *supra* note 149, at 100.

¹⁸² Robert F. Rich & Julian Ziegler, *Genetic Discrimination in Health Insurance – Comprehensive Legal Solutions for a (Not So) Special Problem?*, 2 *IND. HEALTH L. REV.* 1, 31 (2005).

¹⁸³ *Id.* at 30-31; Crossley, *supra* note 149, at 115.

¹⁸⁴ Crossley, *supra* note 149, at 100.

ual health status. Department of Health and Human Services regulations pertaining to HIPAA expressly prohibit the use of list-billing, which is the use of individualized premium rates deducted from employee payrolls and paid to the insurance company by the employer through a single bill. This practice particularly shields small groups of fewer than twenty-five employees and prevents the use of genetic information to determine individual premium rates.¹⁸⁵ However, it fails to prevent insurers from charging an elevated premium to the entire group. Before GINA, it thus was possible for issuers to recuperate the costs from one individual by applying a higher premium rate to the entire group. Small group insurance plans would find this practice particularly burdensome since they may not have the capacity to absorb the increased costs. As a result, these plans might cancel coverage entirely.¹⁸⁶

4. Individual Health Insurance

Concerning individual eligibility, workers with a sufficiently long period of continuous coverage will receive continued coverage and a guaranteed renewal from insurance issuers. Insurance issuers cannot legally use genetic information to avoid these requirements.¹⁸⁷ They must offer eligible individuals coverage and allow them to enroll in plans marketed on the individual health insurance market.¹⁸⁸ Furthermore, the insurance issuers have to renew the individual health insurance policies and genetic information may not be taken into account in the decision. However, the issuer may alter the coverage and benefits based on genetic information, so long as the changes uniformly apply to all individuals in the same policy and the changes comply with state law.¹⁸⁹

Despite protections for eligibility and enrollment, HIPAA regulations do not constrain insurance issuers from setting premiums for eligible individuals. HIPAA also does not prohibit health plans or issuers from requesting, requiring or compiling genetic information. Issuers may base premium rates for insurance on the individual risk, and may take into account the genetic information provided by the individual. However, states have the discretion to regulate the premium determination policies. GINA compensates for HIPAA's deficiencies.

¹⁸⁵ Rich & Ziegler, *supra* note 182, at 32.

¹⁸⁶ *Id.*

¹⁸⁷ Jacobi, *supra* note 147, at 373.

¹⁸⁸ Rich & Ziegler, *supra* note 182, at 34-35.

¹⁸⁹ *Id.* at 37.

5. Privacy and Confidentiality

The HIPAA privacy and confidentiality laws constitute the first federal laws to protect health information within the context of health care providers and health insurance plans. HIPAA does not completely preempt state privacy laws. Rather, it creates “a federal floor of privacy protections.” It preempts state law to the extent necessary to meet the federal floor requirement. HIPAA does not change state law that provides greater privacy protections to its citizens.¹⁹⁰

HIPAA legislation covers three main types of health care entities:

1. health care providers who transmit health information electronically using a standard format (health care providers consist of doctors, hospitals, clinics, pharmacists and laboratories);
2. health plans, including private insurers, employer-sponsored health insurance, HMOs and government-sponsored health insurance programs; and
3. health care clearinghouses that process information that is transmitted between health plans and health care providers.¹⁹¹

For genetic information to qualify for privacy and confidentiality protection, it must meet the definition of “protected health information” (PHI).¹⁹² PHI is individually identifiable health information that may be transmitted or maintained electronically or in any other form or medium. This definition excludes employment records held by health care providers, health plans or health care clearinghouses, when acting in the role of employer.¹⁹³ In order to disclose PHI to other parties, the covered entity must first obtain the patient’s consent.

HIPAA shields information derived from genetic tests, services and counseling, as well as family history. Health care providers that provide general medical services, as well as specialists, should comply with HIPAA regulations if they maintain and transmit health information electronically in standard, claims-type format. Thus, genetic information compiled in research programs might remain outside the aegis of HIPAA, depending on whether the researcher also functions as a health care provider and whether the researcher bills insurance companies for health care services.¹⁹⁴

¹⁹⁰ Husted & Goldman, *supra* note 113, at 292-293.

¹⁹¹ *Id.* at 289.

¹⁹² *Id.*

¹⁹³ 45 C.F.R. § 160.103 (2007).

¹⁹⁴ Husted & Goldman, *supra* note 113, at 289-90.

HIPAA protects workers by limiting disclosures of PHI, including genetic information, by group health plans to insurers and employers. HIPAA provisions attempt to prevent disclosures to employers and to prohibit the inappropriate use of PHI by employers. For example, group health plans and insurers may share PHI with employers only if the information cannot be used for employment-related purposes and even then only those employees involved in plan administration have access. Another complicated situation arises when the employer provides health care services. If the information gathered is stored in the claim-type format and maintained in electronic format, HIPAA regulations apply. Nonetheless, it remains difficult to limit the flow of all information once the employer has set up the health plan.¹⁹⁵

6. Loopholes in HIPAA Protections

HIPAA's provisions do leave substantial loopholes that would allow group health plans and insurance issuers to discriminate against people because of their genetics. These loopholes leave open the possibility for breaches of confidentiality and privacy, as well as permit discrimination in eligibility and enrollment. They include the following:

- HIPAA does not cover all entities that may come in contact with genetic information. For example, pharmaceutical companies, workers' compensation insurers, employers and researchers – entities that may not always receive the genetic information in the electronic, claims-type format that would cause it to become protected health information (PHI).¹⁹⁶
- No statutorily established private right of action exists for people whose privacy rights have been violated.¹⁹⁷
- Insurers in group markets may charge an entire group higher premiums, or even refuse to cover entire groups because of the genetic information of one individual.¹⁹⁸
- Insurers may request, require, purchase and collect genetic information about applicants in both the group and individual insurance markets.¹⁹⁹
- Insurers in the individual market may deny coverage because of genetic information if the applicant does not meet

¹⁹⁵ *Id.* at 291.

¹⁹⁶ *See id.* at 288.

¹⁹⁷ *Id.* at 291-92.

¹⁹⁸ *Id.* at 292.

¹⁹⁹ *Id.*; *See Crossley, supra* note 149, at 100.

the requirements for HIPAA protection, may consider genetic predisposition as a preexisting condition, and may set premiums based upon genetic information.²⁰⁰

- Even if employers receive genetic information through health plans or issuers, HIPAA does not prevent employers from using or disclosing the information to discriminate against employees.²⁰¹

B. GINA's Contribution: Creating Unified Protections in Health Insurance

GINA fills in the gaps of current federal law such that all health insurers – whether governmental, private, group or individual—would be forbidden to discriminate on the basis of genetic information. Health insurers may not use genetic information to determine eligibility or set premiums. They cannot use genetic information to impose enrollment restrictions or adjust premium or contribution amounts. Health insurers may not require or even request genetic testing or test results, except as necessary for treatment, payment or health care operations. This includes requesting, requiring or purchasing genetic information prior to enrollment.

The bill also specifies that these prohibitions shall not interfere with the delivery of health care services. For instance, it does not limit the authority of the treating health care professional to request that an individual or family member undergo a genetic test. Nor does it limit the authority of a health care professional employed by or affiliated with a health plan or issuer from notifying an individual about genetic tests or providing information about a genetic test if it constitutes part of a *bona fide* wellness program. However, the law does prohibit a health care professional from *requiring* that an individual undergo a genetic test.

1. Uniform Definitions for the Health Insurance Provisions of GINA

The Genetic Information Nondiscrimination Act of 2007 has the advantage of uniformity of definitions. Title I of GINA, concerning health insurance practices and policies, provides definitions that apply to ERISA, PHSA, and SSA (Medigap).

²⁰⁰ Hustead & Goldman, *supra* note 113, at 292.

²⁰¹ Nancy J. King, Sukanya Pillay & Gail A. Lasprogata, *Workplace Privacy and Discrimination Issues Related to Genetic Data: A Comparative Law Study of the European Union and the United States*, 43 AM. BUS. L.J. 79, 135 (2006).

- “Family member” means the spouse of the individual, dependent children including both biological and adoptive children, and all other individuals related by blood to the individual or individual’s spouse.²⁰² The committee determined that this broad definition of family member would prevent issuers and plans from using family history as a surrogate for genetic information.²⁰³
- The term “genetic information” has the broad definition of information about an individual’s genetic tests, genetic tests of family members, or the occurrence of a disease or disorder in family members of an individual.²⁰⁴ However, genetic information in this context does not include information about the sex and age of the individual.²⁰⁵
- “Genetic test” includes “analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.”²⁰⁶ However, this definition does not include other types of protein or metabolite tests that do not detect genotype, nor does it include an analysis of protein or metabolite testing that directly relates to a “manifested disease [or] disorder . . . that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.”²⁰⁷ The interaction between “genetic information” and “genetic test” definitions ensures that individuals gain refuge from presymptomatic discrimination, and still allows insurance issuers the ability to use the actuarial process to underwrite insurance policies. In this case, GINA precludes insurance companies from considering genetic information, including family history, as well as the results from genetic testing, both predictive in nature. If an individual goes in for a thorough check up and genetic screening, the insurance companies may only consider the information pertaining to already manifested, preexisting medical conditions – and may not consider genetic information which only provides a probability of developing a condition.

²⁰² Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 101, 122 Stat. 881, 885 (2008).

²⁰³ S. REP. NO. 110-48, at 16 (2007).

²⁰⁴ Genetic Information Nondiscrimination Act § 101, 122 Stat. at 885.

²⁰⁵ *Id.*

²⁰⁶ § 101, 122 Stat. at 885.

²⁰⁷ § 101, 122 Stat. at 885-86.

- “Genetic services” is a new term, created to encompass genetic tests, genetic counseling and genetic education. In addition to protecting individuals from discrimination when applying for insurance, Congress intended to provide additional incentive for individuals to participate in and support the development of genetic sciences. Genetic research and education relies upon the voluntary participation of individuals. Without this added protection, individuals may refuse to participate or seek genetic counseling for fear of discrimination.

With the great variety of state law and federal law that define these terms in variegated ways, this set of uniform definitions creates greater consistency and regularity across the country.

2. Amending ERISA, PHSa and SSA

The amendments provided by GINA clarify and expand the non-discrimination protections available under ERISA.²⁰⁸ ERISA already prohibits discrimination against participants and beneficiaries based on genetic information for enrollment or determination of premiums.²⁰⁹ GINA provides new protection by preventing insurance companies and issuers from using genetic information to determine premiums *for the entire group* based upon one individual’s (or family member’s) genetic information.

Further, GINA amends ERISA to prohibit group health plans and health insurance issuers from requesting or requiring that the individual undergo a genetic test.²¹⁰ However, this prohibition pertains only to the issuer or group health plan. Congress did not intend to prevent health care providers from being able to recommend genetic tests. With the development of genetic testing, this information may become essential for treatment and preventative medicine.²¹¹

Moreover, GINA’s amendments to the PHSa provide new protection for the individual insurance market. GINA adds a new section prohibiting health discrimination on the basis of genetic information. Similar to the group health market regulations, insurance companies and issuers may no longer use genetic information to determine eligibility for insurance or to calculate premium and contribution rates.

²⁰⁸ See § 101, 122 Stat. at 886.

²⁰⁹ Employee Retirement Income Security Act of 1974 § 702, 29 U.S.C. § 1182(a)(1)(F) (2008).

²¹⁰ HHS medical privacy rules regulate issues concerning the use, disclosure, and gathering of existing genetic information.

²¹¹ S. REP. NO. 110-48, at 19-20 (2007).

Furthermore, amendments to the PHSA prohibit insurance issuers from requesting or requiring genetic tests from individuals. As with amendments to ERISA, the limitations on genetic testing do not impede health care professionals, regardless of whether they are employed by or affiliated with the issuer, from recommending genetic tests for patients. GINA also closes a loophole in current PHSA legislation. Non-federal government plans are currently exempt from this genetic information nondiscrimination duty. GINA effectively eliminates this exception. All government plans, both state as well as federal, are now required to desist from genetic discrimination because of GINA.

Finally, GINA's amendments to the SSA prohibit issuers of Medicare supplemental policies from conditioning eligibility or setting premiums on the basis of genetic information from the individual. Also, genetic testing may not be requested or required as a condition of insurance coverage. Again, these limits on genetic testing do not restrain health care providers from requesting genetic tests or providing genetic services to covered individuals.

3. GINA – Closing the Gaps

GINA's privacy and confidentiality provisions apply to ERISA, the PHSA and to the Internal Revenue Code § 9831(a)(2) concerning group health plans. GINA bases its protection of genetic information on the existing SSA and HIPAA regulations. Notwithstanding these current regulations, GINA will prohibit group health plans, health insurance issuers and issuers of Medicare supplemental policies from disclosing or using genetic information for purposes of underwriting, eligibility determinations, premium ratings, creation and renewal of policies, as well as coverage and benefits. It also prohibits group health plans, health insurance issuers, and issuers of Medicare supplemental policies from requesting, requiring, buying or collecting genetic information for purposes of underwriting, eligibility determinations, premium ratings, creation and renewal of policies, as well as coverage and benefits.²¹²

GINA's privacy and confidentiality protections do contain some limitations. First, collection of genetic information is permitted in the limited situation of "incidental collection". If a plan or issuer receives genetic information incidental to other health information requests (e.g., physical exams, or blood or urine tests), it is not in violation of GINA so long as the information was not requested or required and is

²¹² Genetic Information Nondiscrimination Act § 105, 122 Stat. at 903-05.

not used for any underwriting or eligibility purposes. Second, the confidentiality standard does not extend to health care and insurance entities not covered by the SSA or HIPAA. Furthermore, the confidentiality standards do not apply to genetic information that is not individually identifiable. This permits the collection and use of genetic information in such situations as research and development of genetic science.²¹³

GINA must coordinate with existing SSA and HIPAA provisions under the auspices of the Department of Health and Human Services (HHS). HHS bears responsibility for the enforcement of these provisions, utilizing the remedies available under the SSA. As new federal law, GINA preempts current state laws, unless the state law imposes requirements or standards more stringent than GINA does.²¹⁴

GINA effectively closes one of the largest gaps left by HIPAA legislation. Insurance issuers may no longer require individuals to undergo genetic testing and may no longer establish eligibility rules, premium levels or coverage based upon an individual's genetic information. As long as the individual meets the eligibility standard created by HIPAA, the individual will have guaranteed access to health insurance.²¹⁵ Insurance issuers still retain the ability to deny coverage to those individuals ineligible under HIPAA. Additionally, these prohibitions on the use and disclosure of genetic information will close the loopholes in the group health plan market.

4. Residual Concerns for Health Insurance Protection

Although GINA closes some of the gaps in current legislation, it does not close all of the potential loopholes. On the positive side of the ledger, GINA expressly treats genetic information as protected health information (PHI), thereby eliminating potential loopholes where genetic information had not previously been protected. However, GINA's limited definition of genetic test – narrower than the medical or scientific definition that is both predictive and diagnostic – may leave diagnostic genetic information unprotected.²¹⁶ For example, information derived from the analysis of proteins or metabolites directly related to a manifested disease does not constitute genetic

²¹³ *Id.*

²¹⁴ See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

²¹⁵ Rich & Ziegler, *supra* note 182, at 37.

²¹⁶ Husted & Goldman, *supra* note 113, at 301; SCHOONMAKER & WILLIAMS, *supra* note 30, at 29-30.

information for the purposes of this section.²¹⁷ This may lead to confusing situations. For example, consider a woman diagnosed with cancer. If the DNA from her tumor is tested and the tumor has not yet been removed, the information is protected. However, if the tumor proteins are analyzed, the information may or may not be protected because protein tests of tumors are not covered in the definition of “genetic testing” if the tumor does not qualify as part of that person. For yet another puzzling twist, the information regarding a removed tumor may be protected because it will no longer be a manifested disease.²¹⁸ Nonetheless, this limited definition may represent an attempt to strike a balance between genetic nondiscrimination and the correct functioning of the actuarial process in health insurance. Second, because GINA is based upon HIPAA provisions, it does not redefine or enlarge the types of entities or information that are subject to the confidentiality, disclosure and use prohibitions. Thus, pharmaceutical companies and laboratories still remain outside the reach of regulations, and the information must still be in the insurance claims-type format to garner protection.

5. Enforcement and Remedies: Are They Sufficient?

One of the largest concerns about the effectiveness of GINA regards the remedies and enforcement provisions. Unlike the employment title of GINA, the health insurance provisions do not provide a unitary standard for remedies and enforcement.

GINA adds a provision to ERISA, § 502,²¹⁹ concerning Civil Enforcement, which adds the enforcement of genetic nondiscrimination requirements.²²⁰ Thus, all proven genetic nondiscrimination concerns benefit from the established remedies under ERISA. ERISA lets group health plan participants or the Department of Labor sue for equitable relief. With respect to a group health plan, a participant or beneficiary may seek injunctive relief before exhausting administrative remedies if taking time to pursue administrative remedies would cause irreparable harm to the participant’s health. Where a participant or beneficiary obtains equitable relief under ERISA for a genetic discrimination claim, the court has the discretion to reinstate coverage

²¹⁷ SCHOONMAKER & WILLIAMS, *supra* note 30, at 30.

²¹⁸ *Id.* at 31-32. Please refer to Table 2, Examples of Genetic Testing Scenarios and Protected Information Under S. 306 and H.R. 1227, for a detailed study of which situations would be covered.

²¹⁹ Employment Retirement Income Security Act of 1974 § 502, 29 U.S.C. § 1132 (2008).

²²⁰ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 101, 122 Stat. 881, 886 (2008).

retroactive to the date of violation and can award a penalty to the participant. The penalty amount payable to the individual is the same as the primary penalty that may be assessed by the Secretary under the prior law enforcement regime.

However, GINA does not grant plan beneficiaries the right to sue for equitable relief under the PHSA,²²¹ SSA and HIPPA. Rather, health insurance plans covered by these laws restrict themselves to the administrative relief already provided for by the SSA. For example, if an insurance company discriminates against an individual when making a coverage decision and that individual complains to HHS, the Secretary has the discretion to impose a penalty on the insurer ranging from \$100 to \$25,000 per violation.²²² Should the insurer wrongfully disclose individually identifiable genetic information, the Secretary has the discretion to impose a penalty of up to \$50,000; this penalty may increase to \$250,000 and up to 10 years in prison if done with the intention to sell, transfer or use the information for commercial advantage, personal gain or malicious harm.²²³

Although GINA's amendments to pre-existing law raise the bar for genetic nondiscrimination, they may not provide adequate remedies for the individual. As it stands, only those individuals covered by ERISA insurance plans qualify for equitable relief. For those not covered under ERISA, the road of petitioning the Secretary of HHS to enforce the genetic nondiscrimination protections promised by GINA, with all its challenges, remains before them. Further, lawmakers must reconcile equitable relief with a potential increase in opportunistic and unnecessary litigation from disgruntled beneficiaries. Nonetheless, nondiscrimination legislation may not prove as successful as anticipated without adequate enforcement and remedies.

VI. PREVENTING GENETIC DISCRIMINATION IN THE WORKPLACE

A. Current Federal Prohibitions of Genetic Discrimination

Before GINA, a motley assortment of federal legislation provided the barriers against genetic discrimination in employment. Federal employees have a legal bulwark against genetic discrimination in Executive Order 13,145. All other employees depend upon the protections afforded by the Civil Rights Act of 1964 and the

²²¹ Public Health Service Act, 42 U.S.C. §§ 201 to 300ii-4 (2000).

²²² 42 U.S.C. § 1320d-5 (2000).

²²³ 42 U.S.C. § 1320d-6 (2000).

Americans with Disabilities Act of 1992. As discussed below, these federal protections do not provide integrated, equal protection. GINA's employment provisions extend refuge for all employees based on a civil rights model.

1. Executive Order 13,145

Executive Order 13,145 buffers federal employees from genetic discrimination. President Clinton signed Executive Order 13,145 on February 8, 2000, prohibiting discrimination against federal government employees based upon genetic information or requests for genetic information.²²⁴ Through the interaction of its provisions, this executive order relates to genetic discrimination in both employment and health insurance contexts. Section 2-202 forbids employing departments and agencies from discharging, failing to hire, segregating or depriving employees of compensation, privileges or opportunities based upon the employee's protected genetic information. The employing department or agency may not request, require, collect or purchase genetic information. Furthermore, it may not disclose genetic information unless requested by the concerned employee or required by court order. Genetic information obtained through employee consent or genetic monitoring for toxic substances must stay in files separate from general personnel files. Sections 1-202(c), 1-301(b)(4), and 2-202(a) and (b) additionally act together to prohibit the improper use of genetic information with respect to government-provided health insurance.²²⁵ Employing departments and agencies may not legally use genetic information in all contexts, with the exception of medical treatment. Health insurance coverage, a part of employee compensation and benefits, also gains aegis from discrimination based on genetic information.

Additionally, this executive order uses a broad definition of the term "genetic information". Section 1-201(e) defines genetic information as any information about an employee's genetic tests, genetic tests of the employee's family members, and family history. Information obtained concerning current health conditions, such as blood and urine samples, sex, age or physical exams, does not fall under this definition.

²²⁴ Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 10, 2000).

²²⁵ Rich & Ziegler, *supra* note 182, at 26.

2. The Civil Rights Act of 1964

Title VII of the Civil Rights Act of 1964 makes it illegal for employers to discriminate against any individual based upon race, color, sex, nationality, or religion.²²⁶ However, the plain language of the statute does not mention genetic information. For an individual to qualify indirectly for protection under the Civil Rights Act, the genetic discrimination alleged must be disproportionately related to a protected group listed under the statute.²²⁷ For example, Tay-Sachs Disease appears more commonly among individuals of Eastern European Jewish descent, whereas sickle-cell anemia predominates in Africans. If an employer discriminates against individuals based upon these or similar genetic conditions, then the employee may qualify for protection under the Civil Rights Act. If the genetic information does not disparately impact a protected group, then the individual has no cause of action.²²⁸ GINA extends the civil rights protection of the Civil Rights Act into the important realm of genetic non-discrimination.

The Equal Employment Opportunity Commission (EEOC) has enforcement powers under Title VII of the Civil Rights Act, which prohibits employment discrimination based on race, color, religion, sex, or national origin. The procedures and remedies under GINA mirror current law. Employees who believe they have a claim must file a charge with the EEOC or the appropriate state agency. The EEOC will investigate the claim and bring suit on behalf of the employee if evidence of a violation is found. The EEOC may also pursue mediation if the employer and employee agree to that option. In cases in which the EEOC chooses not to bring suit, the employee may bring suit independently. Penalties for Title VII violations include reinstatement, back pay, injunctive relief, equitable relief, and attorney's and expert witness fees. Certain caps on damages may apply depending on the size of the employer.

3. Americans with Disabilities Act

The Americans with Disabilities Act (ADA) provides some, albeit insufficient, barriers against genetic discrimination. The ADA, passed in 1990, addresses employment discrimination against qualified individuals with disabilities. It operated based upon the animating princi-

²²⁶ S. REP. NO. 110-48, at 11 (2007); Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e to 2000e-16 (2000 & Supp. V 2007).

²²⁷ S. REP. NO. 110-48, at 11.

²²⁸ S. REP. NO. 110-48, at 11.

ple that applicants and employees should be selected by their ability and willingness to do the job, not rejected based on their disabilities.²²⁹

All private-sector employers with at least fifteen employees must comply with ADA regulations. These regulations influence employment policies and practices, as well as establish privacy standards for employees' medical information.²³⁰ Specifically, the ADA has established human resources procedures for medical examinations, medical information requests and confidentiality.²³¹

Employers have the prerogative to request or require medical examinations of job applicants who have conditional offers of employment, but only if all similarly situated employees undergo the same examination. The ADA regulates the three instances during employment in which an employer may require medical tests from employees. First, employers may not require medical tests during the pre-employment phase.²³² This includes medical questionnaires and exams, family history and tests for genetic conditions. However, an employer may ask questions concerning the candidate's ability to perform certain physical tasks.²³³ Second, employers may condition employment on the passage of medical examinations, so long as: (a) the examination applies to all employees in the same job category; (b) information collected remains in separate, confidential medical files that may be consulted only for emergency situations, safety concerns or governmental investigations; and (c) any conditions revealed by the examination demonstrably render the individual unable to perform the specific job. Finally, any post-employment medical examinations must be voluntary or job-related.²³⁴

Accordingly, employers may receive health information concerning applicants and employees only if it relates to the employee's ability to perform the job.²³⁵ However, employers may not discriminate against disabled-but-qualified individuals when making employment decisions or choices relating to conditions and privileges of employment. They cannot revoke offers or make decisions regarding promo-

²²⁹ Miller, *supra* note 71, at 174.

²³⁰ King et al., *supra* note 201, at 122-23.

²³¹ *Id.* at 122.

²³² Americans with Disabilities Act (ADA) of 1990 (ADA), 42 U.S.C. § 12112 (d) (2)(A) (2007); King et al., *supra* note 201, at 127.

²³³ 42 U.S.C. § 12112(d)(4)(B).

²³⁴ Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 Hous. L. Rev. 23, 55 (1992); 42 U.S.C. § 12112(d)(4)(B); King et al., *supra* note 201, at 127-28.

²³⁵ SCHOONMAKER & WILLIAMS, *supra* note 30, at 13.

tions based upon that health information.²³⁶ Thus, individuals protected by the ADA for hiring and firing decisions should also receive the same health insurance coverage granted to similarly situated employees.

In addition to addressing medical testing and information, the ADA protects applicants' and employees' medical information. Employers must treat this information as confidential, maintain the information in separate files, and may not disclose the information, except in specific circumstances.²³⁷ Employers can obtain genetic information about an applicant or employee only during the conditional offer phase of employment in four ways: (1) perform a genetic test; (2) require the release of medical records or history which contains genetic information; (3) use available genetic information stored in computerized databases; and (4) obtain the individual's family history.²³⁸ However, the ADA limits the collection of this information through the comprehensive testing regulations mentioned above.²³⁹ Furthermore, employees receive additional privacy protections because employers do not have legal permission to request medical information that does not assess ability to perform the job or relate to accommodation or business necessity. Family leave laws also limited employers by restricting the medical information employers may request when granting leave.²⁴⁰

To qualify for protection under the ADA, individuals must meet one of the three prongs of the statute: (1) the individual currently has a disability; (2) the individual has a medical record of having had a disability; or (3) the individual is regarded as having a disability.²⁴¹ However, uncertainty remains whether an employee with a genetic condition has protection from discrimination based upon the ADA alone.

4. Is the ADA Sufficiently Broad?

Indications of legislative intent to cover genetic discrimination appear in the congressional record. Congressman Major Owens and his colleagues expressed the aspiration that "[t]hese protections of the ADA will also benefit individuals who are identified through genetic

²³⁶ *Id.*

²³⁷ King et al., *supra* note 201, at 125.

²³⁸ *Id.* at 94.

²³⁹ *Id.* at 125.

²⁴⁰ *Id.* at 129-30.

²⁴¹ Silvers & Stein, *supra* note 15, at 1361; Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. §12102(2) (2007).

tests as being carriers of a disease-associated gene."²⁴² People with genetic diseases, like those with other disabilities, may find themselves discriminated against because of the social stigmas that may attach to these undesirable differences.²⁴³

Certain gene-associated diseases clearly come under the ADA, such as muscular dystrophy, Williams syndrome, retinitis pigmentosa, osteogenesis imperfecta, and multiple sclerosis. Some of these diseases move through stages, potentially causing the employee to have certain limitations in the future and to be regarded as having a particular disability.²⁴⁴

Furthermore, the EEOC has stated its position that genetic discrimination falls within the scope the ADA.²⁴⁵ In 1995, the EEOC determined that the ADA covers genetic discrimination under the "regarded as" prong of the legislation.²⁴⁶ This position emerged again upon the ADA's tenth anniversary in 2000, and expanded further when the EEOC stated that blood tests detecting genetic markers or diseases constitute medical examinations covered by the ADA.²⁴⁷ Specifically, Commissioner Miller stated that a person is "regarded as having a disability" if a covered entity mistakenly believes an individual has a substantially limiting impairment, when in fact the impairment does not so limit. "Under such a theory, [obtaining] coverage for individuals with a genetic predisposition would generally rely on demonstrating a mistaken belief concerning the major life activity of working."²⁴⁸ Since the EEOC's guidelines do not bind courts, concern persists that the ADA framework insufficiently protects individuals from genetic discrimination, as courts may disregard the EEOC guidelines.²⁴⁹

Without GINA, the courts would have determined whether a particular genetic condition stays within the orbit of the ADA.²⁵⁰ The Supreme Court has not yet decided if the ADA covers genetic infor-

²⁴² Silvers & Stein, *supra* note 15, at 1361; 136 CONG. REC. H4614-02 (1990), available at 1990 WL 97270, at H4623.

²⁴³ Silvers & Stein, *supra* note 15, at 1361.

²⁴⁴ *Id.* at 1361-62.

²⁴⁵ *Id.* at 1362-63; Jacobi, *supra* note 147, at 369; SCHOONMAKER & WILLIAMS, *supra* note 30, at 13.

²⁴⁶ Miller, *supra* note 71, at 174-75.

²⁴⁷ Silvers & Stein, *supra* note 15, at 1362-63.

²⁴⁸ Paul S. Miller, *Is there a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 246 (1999-2000); see Silvers & Stein, *supra* note 15, at 1363.

²⁴⁹ Miller, *supra* note 71, at 175.

²⁵⁰ See King et al., *supra* note 201, at 130.

mation, and recent decisions indicate that the Court tends towards limiting the application of the ADA, rather than expanding it.²⁵¹

The Supreme Court determined that the ADA sets a “demanding standard” for disability. The term “major life activity” must be an activity of central importance in that person’s life. Moreover, the disability must currently present substantial limitations; a past condition or a future condition is not sufficient to warrant ADA protection under this prong.²⁵² However, by definition, genetic predispositions have not yet expressed and may never do so. Thus, they do not substantially affect major life activities. Demonstrating that a person is truly “regarded as” having a disability, another prong under the ADA, is also fraught with difficulties.²⁵³

Furthermore, the ADA does not provide consistent coverage for genetic conditions. Genetic law scholar Mark Rothstein broke down the broader category of genetic conditions into seven different groups and analyzed each group’s potential coverage by the ADA:²⁵⁴

- Already expressed genetic diseases fall under the ADA category of those having impairment – so long as the disease substantially limits a major life activity.²⁵⁵ For example, substantially limiting diseases with a genetic component include muscular dystrophy (an x-linked genetic disorder), multiple sclerosis, achondroplastic dwarfism, adult polycystic kidney disease, cystic fibrosis, hemophilia and diabetes mellitus.²⁵⁶
- Already expressed minor genetic conditions, although expressed, do not rise to the level of ADA coverage because these conditions do not substantially limit a major life activity.²⁵⁷ Physical characteristics such as eye or hair color, height, and weight remain outside of the ADA’s shield.²⁵⁸ They do not substantially limit major life activities, such as walking, talking, working or caring for oneself.²⁵⁹ For example, some genetic conditions which do not meet the ADA’s standard for protection include wearing eyeglasses,

²⁵¹ Jacobi, *supra* note 147, at 369.

²⁵² *Id.*

²⁵³ *Id.* at 370.

²⁵⁴ Rothstein, *supra* note 234, at 39-52.

²⁵⁵ *Id.* at 39.

²⁵⁶ *Id.* at 40.

²⁵⁷ *Id.* at 41.

²⁵⁸ *Id.*

²⁵⁹ *Id.*

mild to moderate varicose veins, left handedness, poor impulse control, strabismus or osteoarthritis.²⁶⁰

- Unexpressed late-onset genetic diseases should be protected under the ADA under either the current disability strand or the “regarded as” strand. The ADA does not address this group, but legislative history and case law seem to indicate that the ADA’s reach extends to this group.²⁶¹ Late-onset genetic diseases also place themselves under the “regarded as” prong because of the future health risks associated with the genetic condition. For example, if a parent has adult polycystic kidney disease (APKD), an autosomal dominant disorder, a fifty percent chance exists that the child will develop the disease.²⁶² Employers might want to exclude the individual from employment because of the risk of steep, future health care costs.²⁶³
- Genetic predisposition/increased risk have been rejected by the EEOC as genetic conditions which merit ADA protection. All individuals – healthy or otherwise – have inherited genetic predispositions. If an individual’s father had cancer or mother had diabetes, the individual may inherit proclivities to developing either or both conditions. However, the EEOC determined that such a family history does not find refuge in the ADA because that person may not already have the disease and may never suffer from it.²⁶⁴
- Unaffected carriers of recessive and X-linked disorders retain the most risk for genetic discrimination because of their children who have or who may have the genetic disorder.²⁶⁵ ADA §102(b)(4) defines “discriminate” to include “excluding or otherwise denying equal jobs or benefits to a qualified individual because of the known disability of an individual with whom the qualified individual is known to have a relationship or association.”²⁶⁶ This section would extend protection to individuals with diseases such as AIDS, Tay-Sachs and cystic fibrosis.²⁶⁷ However, this protection might

²⁶⁰ *Id.* at 42.

²⁶¹ *Id.* at 43.

²⁶² *Id.* at 45.

²⁶³ *Id.*

²⁶⁴ *Id.* at 46-47.

²⁶⁵ *Id.* at 47.

²⁶⁶ Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12112(b)(4)

(2007).

²⁶⁷ Rothstein, *supra* note 234, at 47.

not extend to employees who have not yet had children. Furthermore, it is unclear whether the individual would be protected as already having the disease because of the substantial limitation on the major life activity of procreation.²⁶⁸ It also remains unclear whether the individual would be able to gain a buffer under the “regarded as” branch due to being regarded as carrying the disease.²⁶⁹

- Those having a record of a genetic disease attain coverage under the EEOC guidelines of the ADA, similar to those who already had an impairment that substantially limits a major life activity such as cancer or heart disease, both prevalent in this country. The ADA protects these individuals because of the discrimination faced long after recovery.²⁷⁰
- Those regarded as having a genetic disease receive protection by the ADA in three specific situations: (1) the impairment does not substantially limit the employee, but the employer perceives it to do so; (2) the impairment substantially limits the employee only because of the attitude of others; or (3) the individual does not have an impairment but is regarded as having a substantially limiting impairment.²⁷¹ Some examples of such conditions with a genetic basis include neurofibromatosis, Tourette syndrome and Down syndrome.²⁷²

The ADA’s “safe harbor” provision in §501(c) permits insurers and employers providing insured or self-insured plans to conduct actuarial risk analysis when determining coverage for employees. This safe harbor protects these actions so long as the risk analysis does not consist of a “subterfuge” for illegal discrimination.²⁷³ In the EEOC’s interpretation, employers and insurers must justify the costs and risks associated with coverage to comply with an overall actuarial fairness.²⁷⁴ However, the majority of courts have adopted the Supreme Court’s interpretation of “subterfuge” contained in the Age Discrimination in Employment Act (ADEA), meaning “a scheme, plan, stratagem, or artifice of evasion.”²⁷⁵ This definition broadens the safe

²⁶⁸ *Bragdon*, 524 U.S. 624.

²⁶⁹ Rothstein, *supra* note 234, at 48-49.

²⁷⁰ *Id.* at 50.

²⁷¹ *Id.* at 51.

²⁷² *Id.* at 51-52.

²⁷³ Jacobi, *supra* note 147, at 370.

²⁷⁴ *Id.* at 370-71.

²⁷⁵ *Id.* at 371.

harbor contained in the ADA and substantially increases the plaintiff's burden. Instead of providing a prima facie case of poor business judgment, the employee would need to prove a clear discriminatory motive based on the employee's genetic condition.²⁷⁶

Furthermore, the majority of courts will defer to employers' determinations as to whether an individual's condition would prevent them from doing their job. Employers must determine whether or not the individual qualifies for that job, and if the individual cannot perform those functions, the ADA does not require their retention. The vast majority of courts have deferred to employers' decisions for what constitute essential tasks for a specific job, and have ruled as a matter of law in favor of the employers.²⁷⁷

Similarly, employers benefit from the "direct threat" affirmative defense. In the event that an employee's disability – whether it is the disease itself or the individual's ability to perform the job in a safe manner – creates a public health risk or endangers fellow employees, the employer may treat the employee differently from others. Furthermore, the "direct threat" defense has expanded after a recent Supreme Court decision. In *Chevron v. Echazabal*, the Supreme Court ruled upon the EEOC's regulation and held that employers may treat currently or potentially disabled employees differently if they pose a direct threat to themselves, as well as to other employees or the public.²⁷⁸

The ADA does not prohibit employers from obtaining medical information about the employee once hired. ADA regulations permit employers to conduct ongoing medical examinations, provided that the examinations relate to the job or the employee voluntarily undergoes the examinations. On the one hand, this approach may help employers accommodate employees with disabilities and comply with OSHA regulations which authorize testing for individuals who work with toxic agents. On the other hand, the ADA does not prevent employers from using genetic information to discriminate against and remove an employee in order to avoid such responsibilities.²⁷⁹

²⁷⁶ *Id.* at 372; See Silvers & Stein, *supra* note 15, at 1369-70.

²⁷⁷ Silvers & Stein, *supra* note 15, at 1366-67 (footnote omitted).

²⁷⁸ *Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73, 86-87 (2002).

²⁷⁹ Silvers & Stein, *supra* note 15, at 1366.

B. GINA: Providing New Protections in Employment Law

1. Prohibition of Acquisition and Use of Genetic Information

Title II of GINA covers genetic nondiscrimination in employment. Employers may not use genetic information in employment decisions, including hiring, firing, job assignments and promotions.²⁸⁰ This prohibition extends to employment agencies in regards to employee referrals, labor organizations in regards to membership in the organization, and labor-management training programs.²⁸¹

As for insurers, GINA also makes it unlawful for these employer entities to request, require or purchase genetic information. It also eliminates the options of requesting or requiring genetic testing as a condition of employment.²⁸² This prohibition extends to family members, which not only include blood relatives, but also spouses and even adopted children.

However, five limited exceptions to the ban on requesting, requiring or purchasing genetic information exist:²⁸³

1. where the employer inadvertently requests or requires family medical history
2. where the employee uses an employer-sponsored wellness program
3. where the employer requests or requires family medical history to comply with federal and state family and medical leave laws
4. where the employer purchases publicly available commercial documents (e.g., newspapers or magazines) that contain genetic information
5. where the information is required for genetic monitoring of the biological effects of toxic substances in the workplace, provided that the employee gives informed consent and the monitoring complies with federal and state law.²⁸⁴

²⁸⁰ S. REP. NO. 110-48, at 4 (2007); Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 202, 122 Stat. 881, 907 (2008).

²⁸¹ S. REP. NO. 110-48, at 4; Genetic Information Nondiscrimination Act §§ 203-205, 122 Stat. at 908-13.

²⁸² SCHOONMAKER & WILLIAMS, *supra* note 30, at 36.

²⁸³ S. REP. NO. 110-48, at 4; Genetic Information Nondiscrimination Act § 204, 122 Stat. at 910-11; King et al., *supra* note 201, at 140.

²⁸⁴ *See, e.g.*, Occupational Safety and Health Act of 1970, 29 U.S.C. §§ 651-78 (2000); Federal Mine Safety and Health Act of 1977, 30 U.S.C. § 801 (1977); Atomic Energy Act of 1954, 42 U.S.C. §§ 2011-2296b (2000).

However, nothing in these provisions would prevent health care professionals from requesting or recommending that an employee or family member undergo genetic testing within the context of providing medical care.²⁸⁵

2. Confidentiality and Disclosure

Should an employer, employment agency, labor organization or labor-management training program obtain access to genetic information, it must comply with GINA confidentiality provisions. Such genetic information must be kept on separate forms and in separate files, which must be treated as confidential medical records. The employer may not disclose genetic information unless the employer also discloses it to the employee to whom it applies. Also, the employer must comply with federal²⁸⁶ and state family leave laws or a court order.²⁸⁷ This section provides more protection for the employee's genetic information than exists under the ADA. GINA provisions prohibit supervisors from gaining access to the employee's medical information.²⁸⁸ The requirement of separate forms and files effectively creates an information firewall.

GINA also forbids disclosure of genetic information, except to the employee, health researchers, or in compliance with federal and state law. As to the research related dimension of GINA, Francis Collins stated prior to the passage of GINA: "We know that many people have refused to participate in research for fear of genetic discrimination. This means that without the kind of legal protections offered by this bill, our clinical research protocols will lack participants, and those who do participate will represent a self-selected group, thus further compromising research."²⁸⁹

One of the potential weaknesses of GINA, however, concerns the protection of genetic information obtained indirectly. Employers who obtain genetic information about their employees indirectly but legally through compliance with other laws (such as the Family and Medical Leave Act) or through certain efforts to preserve employee health would not be penalized unless they used such information to discriminate against the employee. A real danger fraught with evidentiary

²⁸⁵ SCHOONMAKER & WILLIAMS, *supra* note 30, at 36.

²⁸⁶ See generally The Family and Medical Leave Act of 1993 § 103, 29 U.S.C. 2613 (1993) ("An employer may require that a request for leave . . . be supported by a certification issued by the health care provider. . .").

²⁸⁷ S. REP. NO. 110-48, at 4.

²⁸⁸ King et al., *supra* note 201, at 142.

²⁸⁹ Collins, *supra* note 1.

difficulties exists of the employer receiving genetic information in legal ways, using that information illegally, and then rationalizing such use on legal grounds.

3. Oversight and Enforcement

Rather than basing GINA legislation upon the ADA, the remedies and enforcement provisions of GINA stem from the Civil Rights Act of 1964 and other statutes governing federal, state and congressional employees. GINA protects employees and applicants as defined under the Civil Rights Act of 1964,²⁹⁰ state and federal employees, congressional employees, and employees of the executive branch.²⁹¹ Employees alleging genetic discrimination must bring a claim before the proper enforcement agency within the applicable statute of limitations before filing suit in court. The compensatory and punitive damages are proportionate to the size of the employer.²⁹² The EEOC would be charged with issuing regulations enforcing the employment title one year after enactment. The Secretary of Labor would enforce the employment related portions. Rules of construction in the legislation indicate that GINA does not limit an employee's rights under the ADA, under the Rehabilitation Act of 1973, or under any other federal or state statutes.²⁹³

4. No Disparate Impact Cause of Action

"Disparate impact" discrimination, while not an intentional adverse employment action, produces a discriminatory effect on a protected class caused by an employment practice or policy that appears to be nondiscriminatory on its face. For claims brought under GINA, disparate impact does not constitute a valid cause of action. As the Commissioner for GINA, the EEOC is charged with establishing and funding a Commission, and with continuing the study of the genetic sciences. It will reconsider the disparate impact cause of action six years after the adoption of GINA.²⁹⁴ The Commission would determine whether GINA would benefit from a "disparate impact" provision that would protect employees in situations where the employer's actions inadvertently have a disproportionate adverse effect on individuals with certain genetic traits.²⁹⁵

²⁹⁰ 42 U.S.C. § 2000e(f).

²⁹¹ 3 U.S.C. § 411(c).

²⁹² S. REP. NO. 110-48, at 4.

²⁹³ SCHOONMAKER & WILLIAMS, *supra* note 30, at 37.

²⁹⁴ S. REP. NO. 110-48, at 4.

²⁹⁵ SCHOONMAKER & WILLIAMS, *supra* note 30, at 37.

VII. FINANCIAL IMPACT OF GINA

The Congressional Budget Office (CBO) estimated an increase in 1000 people per year who would obtain insurance as a result of the enactment of GINA, nearly all of whom would do so in the individual market. Some of these premiums would be tax-deductible, decreasing tax revenue for the U.S. government by less than half a million dollars per year from 2006 (when this estimate was made) through 2015.

CBO estimated that implementing GINA would cost less than half a million dollars in 2007 and about two million dollars over the 2006-2015 period. By federal government standards, the bill would have no significant effect on direct spending.

The preemption of and limitations on state and local actions as a result of the enactment of GINA would be intergovernmental mandates as defined in the Unfunded Mandates Reform Act (UMRA), but there is little indication that state, local, or tribal governments currently engage in or are likely to engage in the activities that the bill would prohibit. Consequently, CBO estimates that the costs of the mandates would not be significant, and would not exceed the threshold established in the UMRA (\$72 million in 2005, adjusted annually for inflation).

CBO estimates that the direct costs of private-sector mandates on health insurers, health plans, employers, labor unions, and other organizations would not exceed the annual threshold specified in the UMRA (\$123 million in 2005, adjusted annually for inflation) in any of the first five years in which the mandates would be effective.

VIII. CONCLUSION

The passage of the Genetic Information Nondiscrimination Act advances civil rights in the 21st century by providing a national standard across states, and supplements already existing federal law with respect to health insurance and employment. This should boost genetic research by mitigating the reluctance of potential genetic research subjects due to possible genetic discrimination. The protections provided by GINA, while not a panacea, move substantially in the direction of preventing genetic discrimination in two important areas. Other areas, such as the educational sphere for example, could benefit from similar protection.

The history of discrimination and eugenics in our society invite us to learn critical lessons and apply them well in the midst of the

Genetic Revolution – concomitantly replete with promise as well as pitfalls. Although the law has generally lagged behind new developments in science and technology, GINA takes that rare step of anticipating, preventing and giving remedies for a wave of problems to come as genetic science continues to forge forward. Indeed, GINA helps to accelerate the rate of development of genetic science, while helping to ensure that the wonders it brings do not also invite the nightmares of genetic discrimination in the critical areas of employment and healthcare insurance. Its passage shines an auspicious light for high-tech civil rights in the 21st century and beyond.

