Advancing Civil Rights, the Next Generation: the Genetic Information Nondiscrimination Act of 2007 and Beyond

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Abstract

On the leading edge of civil rights law and bioethics/healthcare law, this Article analyzes the Genetic Information Nondiscrimination Act (GINA) of 2007, which would extend important protection against discrimination in health insurance and employment. GINA would also bolster genetic research by freeing research subjects from the threat of genetic discrimination. This Article demonstrates how GINA would further protect this society against the rising dangers of genetic discrimination beyond already existing federal and state law.

Table of Contents

Introduction ..................................................................................................................2
Background .................................................................................................................10
Genetic Discrimination: Evidence of a Growing Problem ......................................15
Genetic Discrimination: Applicable Case Law .........................................................21
State Legislation .......................................................................................................36
GINA: Providing a Unifying National Standard without Uniformity .....................42
Preventing Genetic Discrimination in Health Insurance .........................................44
GINA’s Contribution: Creating Unified Protections in Health Insurance .........52
Preventing Genetic Discrimination in the Workplace ..........................................62
GINA: Providing New Protections in Employment Law ...........................................76
Financial Impact of GINA .......................................................................................80
Conclusion ...............................................................................................................81

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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.”2 If our particular glitches place us out of favor with the prevailing 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 “three generations of imbeciles are enough”3, 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.4 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.5 Accepting that “heredity plays an important part in the

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2 Collins’ official statement after the passage of GINA through the Senate in 2005
3 *Buck v. Bell*, 274 U.S. 200, 207 (1927)
4 *Id.* at 206.
5 *Id.*
transmission of insanity, imbecility, etc.”, the Supreme Court held that: “it 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.”

No less than thirty-two American states pushed through compulsory eugenic sterilization statutes from 1907 to 1937. 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. The complexities of genetic science and neuroscience mixed with strong ethical sensibilities pointed away from such crass eugenics. No additional state laws mandating eugenic sterilization prevailed afterwards, and the existing state laws increasingly fell into disuse and disfavor.

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, and scientists labor to understand

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6 Id. at 207.
8 Id. at 117.
9 Id.
how groups of genes interact. The ability to uncover more and more diseases with genetic etiologies has been expanding greatly. In a statistic that has most likely expanded substantially since publication, over 15,500 recognized genetic disorders affect 13 million Americans.\textsuperscript{10} Along these lines, consider that genetics cause around a quarter to a third of infant deaths,\textsuperscript{11} half of the instances of mental retardation,\textsuperscript{12} the inherited susceptibility of 15\% of cancers,\textsuperscript{13} and a component in a tenth of adult chronic diseases, including diabetes, rheumatoid arthritis and heart disease.\textsuperscript{14}

Francis Collins projects that a $1000 complete genetic screening for any person remains a realistic goal within the next decade.\textsuperscript{15} The challenge remains of how to reap the potentially immense benefits of genetic research and medical intervention in curing actual diseases, without re-opening up the Pandora’s Box of eugenics as well as genetic discrimination, and thereby trammeling civil rights.


\textsuperscript{13} K.A. Schneider, \textit{Counseling about Cancer: Strategies for Genetic Counselors} (Dennisport, MA: Graphic Illusion, 1994).


\textsuperscript{15} Francis S. Collins, \textit{NHGRI Policy Roundtable Summary: The Future of Genomic Medicine: Policy Implications for Research and Medicine}, Nov. 16, 2005, available at \url{http://www.genome.gov/17516574}. Collins is the current Director of the National Human Genome Research Institute (NHGRI). This roundtable discussion addressed policies to further the development of human genomics and the translation of this science into improved health care.
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:

- 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.¹⁶

- 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.¹⁷

- A 40-year old woman with an excellent employment record participated in a genetic survey, which revealed that she possessed the BRAC1 gene – a gene which 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.¹⁸

- 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.¹⁹

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¹⁶ Id. at 1351-1352.
¹⁷ Id.
¹⁸ Id.
In addition to those possessing genetic disorders, family members are at risk for 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.\(^{20}\)

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.\(^{21}\)

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

\(^{20}\) Id. at 566.

this information to employers— all for fear of facing genetic
discrimination. 22

- Many Americans are reluctant to take 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. 23

- 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. 24

- 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 BRAC1 gene, and therefore has a

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22 E. Virginia Lapham, Chahira Kozma & Joan O. Weiss, Genetic discrimination: perspectives of
23 Department of Labor, Department of Health and Human Services, Equal Employment
Opportunity Commission, Department of Justice, Genetic Information and the Workplace, Jan.
24 Id.
genetic predisposition to cancer, will not be able to provide advice about warning signs and preventative medicine.25

Serious concerns that employers have been 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 on 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.26

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 as preexisting conditions.27 A study conducted by Stephen Rich and Mark Hall in 2000 found almost no 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.28 Yet, merely

26 Id. at 7.
27 Id.
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.” 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.

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. 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 on to their medical records. 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.

Given the history of eugenics, the increasing potential for discrimination as genomic research moves forward, the actual instances of genetic discrimination,
and the continuing concerns of the populace, the case for national legislation in this important realm rises up. As of this scholarly contribution, the U.S. Senate still has before it the opportunity once again to pass such legislation that the House has already approved and the president said he would sign into law: it is called the Genetic Information Nondiscrimination Act (“GINA”) of 2007. The Genetic Information Nondiscrimination Act would advance civil rights by providing a consistent national standard that would remedy the patchwork quilt of inadequate state laws, fill gaps as well as clarify ambiguities in already existing federal law, and thus enhance protection against genetic discrimination in health insurance and employment, which in turn would advance genetic research by assuaging concerns that genetic information obtained in research would not be discriminatorily used against them.

**BACKGROUND**

**The Genetic Information Nondiscrimination Act of 2007**

Congress has made substantial attempts to pass comprehensive legislation prohibiting genetic discrimination since the 103rd Congress. The first legislation introduced was the Human Genome Privacy Act of 1990. 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

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34 [Id. at 5.]
insurance portability and continuity while including restrictions on the use of genetic information.36

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).37 This legislation is very similar to the current GINA in regards to the insurance provisions. Insurers would have been prohibited from discriminating in (1) individual enrollment; (2) group eligibility or group premium or contribution rates; (3) requesting or requiring genetic tests as a condition of employment or insurance; and (4) requesting, requiring, collecting, purchasing or disclosing genetic discrimination.38 These bills also incorporated definitions of genetic testing and information very similar to the current GINA. However, S.318 and H.R.602 did not prevail.

After S.318 and H.R. 602 failed to be ratified by Congress, Senator Snowe submitted the “Genetic Information Nondiscrimination Act of 2002.” 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. The other provisions of the legislation—including definitions and federal law to be amended

38 Id. at 54.
—remained primarily the same as it was in the Daschle bill. 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; its identical companion in the House of Representatives, H.R. 1910, did not come to a vote before the end of the legislative session. 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 House of Representatives by Representatives Biggert, Slaughter, Ney and Eshoo on March 10, 2005, but it did not come to a vote. 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) is currently pending legislation in Congress. It is sponsored by Senator Olympia Snowe, Representative Louise McIntosh Slaughter, and cosponsored by 258 senators and representatives. It passed the House with a vote of 420 to 3 on April 25, 2007 and was placed on the Senate legislative calendar under General Orders

39 Id. at 55.
41 Id.
on April 30, 2007. Although GINA differs little from its predecessor legislation, it represents the result of substantial debates and discussions.

The President intends to sign it into law if it receives congressional approval. President Bush mentioned the need for further legislation along these lines in his weekly radio address to the country on June 23, 2001. On February 16th, 2005, the White House issued a favorable statement regarding such legislation: “The Administration favors enactment of legislation to prohibit the improper use of genetic information in health insurance and employment. The Administration supports Senate passage of S. 306…The Administration wants to work with Congress to make genetic discrimination illegal and provide individuals with fair, reasonable protections against improper use of their genetic information.”

Francis Collins, in an official response to Senate passage in 2005, stated: “I am very hopeful that it will make it through the entire legislative process this year and the President, who has previously indicated his strong support, will be able to sign it into law. We need this legislation now more than ever.” Despite this legislation’s bipartisan appeal, its passage in the Senate in 2007 has stalled, albeit perhaps just temporarily. Senator Tom Coburn, a physician and Republican senator from Oklahoma, has placed a hold on GINA. Senator Coburn voted in favor of an almost identical bill during the last legislative session. Although he is not opposed to the general principles underpinning GINA, he is

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42 http://www.thomas.gov/cgi-bin/bdquery/z?d110:HR00493:@@@R; Senate Legislative Calendar No. 125.
43 Supra, footnote 2.
44 Bill block unwarranted; Senate’s ‘Dr. No’ unwisely puts a stop to law banning genetic discrimination, Buffalo News, Aug. 21, 2007 at A6.
concerned that the legislation would make it too easy for employees to sue employers, and that “genetic test” is defined differently for employers and insurers.\textsuperscript{45} Senator Coburn had recently urged amendments which would extend the protections afforded by GINA to fetuses and embryos.\textsuperscript{46} It is yet to be seen what will be the effect of this hold, which is based upon a little known rule of procedure.

Genetic nondiscrimination legislation is supported by consumer groups, members of the medical profession, researchers and the medical products industry.\textsuperscript{47} These groups asseverate that current laws are 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.\textsuperscript{48} Opponents to genetic nondiscrimination legislation include some members of the insurance industry and the US Chamber of Commerce.\textsuperscript{49} The members of the insurance industry argue that current laws provide sufficient protection, and that new legislation would create confusing, unnecessary, expensive regulations as well as increased opportunity for litigation.\textsuperscript{50} Moreover, insurance companies argue that GINA would be unfair, prohibiting the use of genetic information when they already use other health

\textsuperscript{48} Id.
\textsuperscript{49} Id.
\textsuperscript{50} Id. at 6.
Most opponents also point to how few documented cases of genetic discrimination have been recorded, and that GINA is an attempt to legislate based on fear rather than practice.

Some supporters, however, argue 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. 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 cannot be accomplished without the active participation of individuals who are willing to undergo genetic testing and research. And, overall public health will be best served if patients with genetic predispositions can confidently follow screening and preventative health care measures. The enactment of GINA, like preventative medicine, would help prohibit discrimination and lift patient fears at the same time.

**GENETIC DISCRIMINATION: EVIDENCE OF A GROWING PROBLEM**

**Genetic Discrimination: Examples**

*Accounts of Genetic Discrimination*

In the midst of what may seem 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

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51 Id.
52 Id. at 5-6.
Heidi Williams and her two children were victims of genetic discrimination in 2003. 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 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. 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.54

For Phaedra Malatek and her two sons, genetic testing presents a double-edged sword. 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 wellbeing of her children, wonders: “[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. […] It's troubling to me that as Americans we're placed in a position where we have to make such a terrible choice.” At the time of her testimony, Malatek’s sons still had not been tested for hemochromatosis for fear of discrimination.55

After a genetic test revealed a positive result for BRAC1, Tonia Phillips had to decide how to proceed with a 45% chance of developing breast cancer and an 80% chance of developing uterine cancer. 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." In the end, she did not switch insurance companies, but the office now requires employees to pay half of their insurance premiums.56

Phil Hardt has two genetic disorders, hemophilia B and Huntington’s Disease. 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 neither be 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.” 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.’” Although knowledge of genetic predispositions to disease opens the door to preventative medicine, the results are devastating to individuals and family members.57

Sports stars have been in the spotlight for genetic disorders in the recent years. In November 1991, Earvin “Magic” Johnson announced early retirement from professional basketball after testing positive for the human immunodeficiency virus (HIV). In the midst of the publicity, the process by which he learned of his disease was forgotten. Johnson did not decide to be directly tested for HIV. Rather, he consented to an AIDS test in correlation with a routine annual procedure for his health insurance coverage. Scholar Carol Lee observed that Johnson’s experience “reflects the growing use of diagnostic testing by

insurance companies to screen applicants for eligibility and rate-setting purposes. The majority of Americans does not enjoy the same economic or social status as Johnson, and find themselves vulnerable to potential abuse by health insurance companies. This situation requires but a small step to be extended to diagnostic genetic testing.

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. After becoming ill, with lightheadedness and dizziness, he was diagnosed with 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 which 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 mount a legal challenge under state and/or federal law to Curry’s refusal.

The Knicks also declined to bring suit under New York’s genetic discrimination statute. In fact, the Knicks were prevented from requiring Curry’s genetic information because of New York state law that prohibits genetic testing as a condition of employment. Instead, Curry submitted to various non-genetic

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59 Id.
61 Id. at 3-5.
62 Id. at 7-8.
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.63

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.

Even those who serve the military are not immune from the threat of genetic discrimination. Eric Miller, a 28 year old Army Ranger, suffered back pain during his tour in Afghanistan. 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 the Army in 2005 because of his illness, with no disability benefits or health insurance to help in his fight against cancer.64 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.65 The rule affords an exception if the individual has served more than eight years in the

63 Id. at 7.
65 Id.
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." 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.

**Genetic Discrimination: Applicable Case Law**

At the present, very few if any genetic discrimination cases—either in employment or health insurance—have been decided, either in the US Federal or state courts. Most cases referring to genetic discrimination concern the use of genetic information as evidence in criminal trials. Those cases which concern genetic discrimination focus either on privacy law or interpretations of the ADA. There have not been any cases concerning genetic discrimination in health insurance coverage. However, the dearth of current case law should not lull one

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66 *Id.*
67 *Id.*
to dismiss the prophylactic value of bills such as GINA, where the law has the opportunity to not lag so far behind technological and scientific advances, as it too often does.

_Norman-Bloodsaw v. Lawrence Berkeley Laboratory_

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 offer candidates employment, the offer conditioned on subsequent medical exams. 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. 69 Defendant employer stated that the tests were part of an overall occupational health program, 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. The plaintiffs’ constitutionally protected privacy rights were invaded

69 Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1264-1266 (9th Cir. 1998)
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.” Test results concerning syphilis, pregnancy and
the sickle cell trait contain information which may invite social stigma, and the
revelation of 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.” The court determined that answering a medical questionnaire, or
accepting to undergo a medical examination for employment, in no way puts the
employee on notice of the testing conditions, nor does it provide the employer
with consent.

Second, the Circuit Court reversed the dismissal of plaintiffs’ Title VII
discrimination claims. In its reasoning, the Court relied on Section 703(a) of Title
VII of the Civil Rights Act of 1964, prohibiting discrimination against individuals
with respect to terms and conditions of employment based upon race, color or
sex. 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.” In this case, the plaintiffs’ claim falls directly
under the protection of Title VII because African American and female employees

70 Id. at 1260, 1269
71 Id. at 1260, 1269 -1270
72 Id. at 1260, 1269 (9th Cir. 1998)
73 Id. at 1260, 1270-1271 (9th Cir. 1998)
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 than 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.\textsuperscript{74}

The holding in \textit{Norman-Bloodsaw} would protect individuals from genetic discrimination, so long as those individuals would be covered as a protected group under Title VII, or the violations of privacy in medical testing would rise to the gravity of the 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 not used by the employer in subsequent employment decisions. Thus, employers are still able to perform medical examinations designed to discover the employee’s genetic information. Second, the holding in \textit{Norman-Bloodsaw} would only apply to protected groups; those who are not part of protected groups, such as white males, could still be required to undergo nonconsensual genetic testing. The limitations of the \textit{Norman-Bloodsaw} case with respect to protection from genetic discrimination.

\textsuperscript{74} \textit{Id.} at 1260, 1272-1273 (9th Cir. 1998)
discrimination highlights accentuates the role that legislation like GINA could perform in enhancing protection.

Bragdon v. Abbott:

Although the courts have not yet decided whether individuals with presymptomatic genetic disorders or proclivities are protected by the ADA, the Supreme Court held in Bragdon v. Abbott that individuals with asymptomatic HIV are covered by the ADA.75 An asymptomatic HIV individual, Ms. Abbott, sought dental care from Dr. Bragdon. Dr. Bragdon agreed to perform the routine dental exam. But when the exam turned up a cavity, he explained that he would only fill cavities of HIV-infected patients in hospitals. Although he did not charge extra for the care, Ms. Abbott would have been responsible for hospital fees.76 She declined the dental care and sued Dr. Bragdon for discrimination under the ADA. The district court held in favor of Ms. Abbott, and the circuit court affirmed. On appeal, the Supreme Court granted certiorari.

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. The Supreme Court systematically reviewed the different aspects of this protection. 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.”77 Second, the Supreme Court determined that reproduction constitutes a major life activity.

76 Id. at 624, 628-629.
77 Id. at 637.
under the ADA. Third, HIV substantially limits an individual’s reproductive choices, as unprotected sex poses a threat to the sexual partner and unborn progeny. Since the anti-viral medications currently can only limit the risk of transmission of HIV by 8%, the risk is sufficient to prevent HIV-positive individuals from endangering those with whom they would engage in intercourse. Furthermore, the Court stated that its findings are supported by the many agency interpretations of the ADA statutes, as well as administrative guidance.

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, it left open whether HIV is universally a disability or if the holding includes women who are unable to reproduce because of menopause or sterility.

By analogy, this case would provide protection for individuals with genetic diseases under the ADA. However, it is unclear that the precedent set by

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78 Id. at 639.
79 Id. at 641-642.
81 Id. at 1, 40
Bragdon v. Abott 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.\textsuperscript{82} 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. This places a heavy burden because most genetic conditions first begin with the symptoms, and then are followed by the impairment.\textsuperscript{83} Additionally, the individual must prove that a major life activity has been limited. This is also a difficult burden to meet because genetic transmission differs substantially from HIV transmission.\textsuperscript{84} Genetically predisposed parents cannot transmit genetic disorders through sexual relations to a partner or through labor. And, 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. The individual must be able to demonstrate that either he or she had a physical or mental impairment which does not substantially limit the ability to perform major life activities, or that he or she did not suffer from an impairment.

\textsuperscript{82} Id. at 41; Anita Silvers & Michael Ashley Stein, An Equality Paradigm for Preventing Genetic Discrimination, 55 Vand. L. Rev. 1341, 1365 (2002)
\textsuperscript{84} Id.
listed as a disability under the ADA. Yet neither of these possibilities will cover all genetic discrimination claims.

There is another important concern which Jennifer Geeter 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 genetics. 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.” 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 future effects.” Indeed, the preamble to the ADA indicated that 43 million Americans had some form of physical or mental disability. 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

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85 Id. at 43.
86 Id. at 42.
limited group of individuals. 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. This would stretch the ADA beyond its original goal, and by protecting all Americans, it would effectively protect no one. Put another way, a genetic defect does not necessarily constitute a disability. Thus, this particular case and statute might not be the best possible vehicle to protect individuals from genetic discrimination.

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

In 2001, the EEOC v. Burlington Northern Santa Fe Railway case came closest to establishing court precedent for genetic nondiscrimination in employment. It constituted the first case raising 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. CTS is a painful hand and wrist condition caused by repetitive motions.

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Determining whether the injury was caused by a predisposition to CTS necessitated the testing, according to BNSF.\textsuperscript{93} 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.\textsuperscript{94} BSNF eliminated the genetic testing program as a condition of the settlement.\textsuperscript{95} Although the early settlement meant that the courts could not evaluate the legal principles involved in a genetic discrimination case,\textsuperscript{96} the idea of allowing nonconsensual genetic testing for employees did not find outspoken support.\textsuperscript{97}

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 they are sufficiently work-related, “any 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.”\textsuperscript{98}

However, the complexity of the ADA itself poses one of the main difficulties

\textsuperscript{93} Id.
\textsuperscript{96} Id.
\textsuperscript{97} Paul Steven Miller, Analyzing Genetic Discrimination in the Workplace, in \textit{RIGHTS AND LIBERTIES IN THE BIOTECH AGE} 173, 176-177 (Sheldon Krimsky & Peter Shorett eds., Rowman & Littlefield Publishers, Inc. 2005
facing the prohibition of discriminatory use of medical testing. Provisions which allow the 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.99

A similar case was filed by the EEOC in 2001 against Woodbridge Corporation concerning the screening of nineteen job applicants for CTS.100 This case is the only recorded federal decision deciding a genetic discrimination claim on the merits.101 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.102 Woodbridge responded that the testing was specifically designed and required for the repetitive motion required for a specific foam line in the one plant in Kansas City.103

The district court granted summary judgment to Woodbridge, holding that the employee’s argument failed to satisfy the “regarded as” prong of the ADA.104 The circuit court affirmed the decision on appeal. In order to prevail, the employer must have regarded the employee as disabled under the ADA, as “significantly restricted in the ability to perform either a class of jobs or a broad range of jobs in

100 E.E.O.C. v. Woodbridge Corp., 263 F.3d 812, 812 (8th Cir. 2001)
102 E.E.O.C. v. Woodbridge Corp., 263 F.3d 812, 813-814 (8th Cir. 2001)
103 Id.
104 Id.
various classes as compared to the average person.”105 The plaintiffs were unable to meet these requirements, especially considering 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 discriminatory hiring practices.106

**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.107 In correctly applying the ADA, the Court refused to apply the agency 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

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105 *E.E.O.C. v. Woodbridge Corp.*, 263 F.3d 812, 815 (8th Cir. 2001)
major life activity.\textsuperscript{108} Furthermore, the Court looked to the report prepared by the National Council on Disability, which was prepared for the creation of the ADA. This study stated that an overinclusive estimate of 160 million people with a disability would consider 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 the intent to limit the applicability of the ADA to those who meet a stricter definition of disability.\textsuperscript{109} Thus, those who are able to mitigate their impairments to the point of being able to function normally cannot be considered disabled.

In the second part of its analysis, the Court in \textit{Sutton} also held the myopic sisters did not meet the definition of being "regarded as", since it requires that the employer mistakenly believe that the individual actually has a limiting disability, or mistakenly believes that the actual impairment substantially limits one or more major life activities.\textsuperscript{110} 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.”\textsuperscript{111} 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.\textsuperscript{112} Thus, the Supreme Court affirmed the dismissal of both of the plaintiffs’ claims.

\textsuperscript{108} Id. at 482-483.
\textsuperscript{109} Id. at 484-485.
\textsuperscript{110} Id. at 489.
\textsuperscript{111} Anita Silvers & Michael Ashley Stein, An Equality Paradigm for Preventing Genetic Discrimination, 55 Vand. L. Rev. 1341, 1372 (2002).
These holdings guided the decisions in two other cases. In *Murphy v. United Parcel Service, Inc.*, UPS dismissed Murphy from his job as a mechanic. This 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 is a qualified mechanic and high blood pressure did not exclude Murphy from a broad array of jobs—only those jobs which would require driving commercial vehicles.¹¹³ *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.¹¹⁴

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 “disability”. Second, and more importantly for the genetic information nondiscrimination debate, the Supreme Court indicated in *Sutton* and *Albertson’s* that the court 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

¹¹⁴ Albertson’s, Inc v. Kirkingburg, 527 U.S. 555 (1999)
decide to extend deference to the EEOC’s regulations concerning genetic
discrimination protection under the ADA in future decisions.\footnote{Anita Silvers & Michael Ashley Stein, An Equality Paradigm for Preventing Genetic Discrimination, 55 Vand. L. Rev. 1341, 1365 (2002)}

However, in the \textit{Chevron U.S.A., Inc. v. Echazabal} case, 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 turned up a liver abnormality, which later was diagnosed as Hepatitis C, and 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.\footnote{Chevron U.S.A., Inc. v. Echazabal, 536 U.S. 73, 76-77 (2002)} Chevron defended its decision under an EEOC regulation which permitted the employer an affirmative defense if the worker’s disability posed a direct threat to others or his own health.

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.\footnote{Id. at 77-78.} This created a circuit split with the Eleventh Circuit, and the Supreme Court granted certiorari.
Unanimously, the Supreme Court held that the EEOC’s regulation that the “direct threat” affirmative defense included 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.”\textsuperscript{118} 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.\textsuperscript{119}

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.\textsuperscript{120}

\textbf{STATE LEGISLATION}

Given the inadequacies of federal protection against genetic nondiscrimination, 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 were less prevalent

\textsuperscript{118} Id. at 86.
\textsuperscript{119} Anita Silvers & Michael Ashley Stein, An Equality Paradigm for Preventing Genetic Discrimination, 55 Vand. L. Rev. 1341, 1369 (2002)
\textsuperscript{120} Id.
and very limited in scope. 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. Genetic information has found increasing protection against discrimination in both the health insurance and employment context. As of the fall of 2007, forty-nine states have some form of law that protects the misuse of genetic information--Pennsylvania alone lacks such legislation.

**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. The Colorado statute states: “Genetic information is the unique property of the individual to whom the information pertains.” 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

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124 Id. at 633.
125 Colo. Rev. Stat. Ann. § 10-3-1104.7(1)(a)
a privacy regime.”126 Moreover, a third approach to genetic information which emerges from state legislation is the direct nondiscrimination laws. Currently, the nondiscrimination approach appears to be the most common among states, as forty-six states prohibit health insurers from genetic discrimination and twenty-eight states prohibit employers from doing so.127

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.”128 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.129 Laws relating to use of genetic information by insurance companies has also expanded from applying only to specific genetic tests to broader legislation that forbids the use of genetic information regardless of the source.130

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126 Jeffrey Lawrence Weeden, Genetic Liberty, Genetic Property: Protecting Genetic Information, 4 Ave Maria L. Rev. 611, 633 (Summer 2006).
129 Id. at 375.
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; 3) and 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 state law categories.

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.131 In California, for example, both individual and group insurance policies are subject to the laws prohibiting genetic discrimination.132 Residents benefit from a generous definition of “genetic characteristics”, which includes “any scientifically or medically identifiable gene or chromosome, or combination or alteration

132 Cal Ins Code § 742.405, 7 (Jul. 30, 2007); Cal Ins Code § 10123.3 (Jul. 30, 2007).
thereof” and “inherited characteristics that may derive from the individual or family member” that “is determined to be associated with a statistically increased risk of development of a disease or disorder, and that is presently not associated with any symptoms of any disease or disorder.” California also is one of a minority of states which 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. At present, there are only two states which do not provide some form of statutory protection against genetic discrimination in health insurance, Pennsylvania and Mississippi.

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

133 Cal Ins Code § 10123.3 (Jul. 30, 2007).
135 Id.
137 Id.
138 Id.
139 Id.
outside of the therapeutic, research or investigatory context.” Other states “prohibit insurers from determining premiums based on genetic test results”, while still other states “prohibit insurers from determining premiums based on genetic traits.” Third, however, all state statutes governing genetic information by insurance companies are missing one important component. These statutes “offer no protection to people who have developed symptoms for genetically caused disorders.” 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.

**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-four states provide some form of genetic nondiscrimination law in the employment context. Those laws which currently exist “prohibit discrimination based on the results of genetic tests [and some] laws prohibit employers from both obtaining and using genetic information for employment decisions.” Some states’ protections extend more comprehensively than others. For example, only Minnesota, Oklahoma and South Dakota provide protections across the board in

140 [Id.](#)
141 [Id. at 53.](#)
142 [Id.](#)
employment, including prohibiting the employer from requesting genetic tests, 
requiring genetic tests, performing genetic tests or obtaining genetic testing 
results.145 Minnesota’s law on genetic testing in employment is brief, but 
complete.146 It provides a complete definition for 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.”147 Employers are prohibited from 
requesting, requiring, using or collecting genetic information. However, 
substantial loopholes 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.148

**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 or property rights. Effectively, substantial differences remain 
across state lines. Since the use of genetic information in both the employment 
and insurance contexts frequently traverses interstate, conflicting state laws will

147 *Id.*
148 *Id.*
present challenges for both individuals seeking protection and governments enforcing provisions.¹⁴⁹ 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 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 create unfair differences in the treatment of individuals. The myriad of state legislation elicits the concern of the bill’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.”¹⁵⁰

GINA’s enactment would directly address these problems by providing a national standard of genetic nondiscrimination protection. GINA’s provisions would be applied to states through preemption. The amendments brought to existing federal law—such as ERISA, SSA and HSA—will continue to preempt state law. New privacy and confidentiality sections will effectively “supersede any contrary provision of State law unless such provision […] imposes requirements,

¹⁵⁰ S. 358, 110th Cong. (2007)
standards, or implementation specifications that are more stringent than [those] imposed under” GINA. The employment provisions of GINA will be enforced through preexisting legislation that applies to private, federal, state and local employees. Once signed into law, the Department of Health and Human Services and the Department of Labor will have one year to promulgate appropriate regulations to assist with interpretation, coordination and enforcement. GINA would go into full effect 18 months after being signed into law. By the use of the preemption vehicle, it is possible for the federal government to create a unifying national standard for genetic information, without requiring uniformity, as long as the state law meets or exceeds the standard set in GINA.

PREVENTING GENETIC DISCRIMINATION IN HEALTH INSURANCE

Current Protections Against Discrimination in Health Insurance

Today, Americans derive protection from genetic discrimination by a veritable alphabet soup of legislation: ERISA, PHSA, SSA, and HIPPA. 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. Recipients of health insurance from smaller employers find themselves at risk because of the smaller

\[^{151}\text{Id.}\]
\[^{152}\text{Id.}\]
\[^{153}\text{Id.}\]
pool of beneficiaries (roughly 15% of people with private insurance). These federal laws only provide some 
form of protection against discrimination for some people some of the time.

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. 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 already prohibits discrimination based 
upon genetic information in the group health insurance market. GINA would bring identical amendments to the PHSA as in ERISA in regards to enrollment and premium nondiscrimination, as well as genetic testing limitations.

Title XVII of the Social Security Act (SSA) governs Medigap insurance 
coverage. Individuals who qualify for Medicare may purchase supplemental

\[\text{Id.} \]
\[\text{Id.} \]
\[\text{Id. at 24.} \]
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 will create a basic standard of nondiscrimination policies. States which provide lesser protection will be required to meet this floor in order to prevent preemption.

**HIPAA: Providing for Coverage, Privacy and Confidentiality**

Genetic information nondiscrimination provisions are already present in HIPAA legislation.\(^{159}\) The Health Insurance Portability and Accountability Act (HIPAA), signed into law in 1996, took effect on April 14, 2001. This act governs both the portability of group health insurance coverage for employees who transfer jobs, as well as protect 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 family member.”\(^{160}\) 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.

**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.\textsuperscript{161}

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.\textsuperscript{162} 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.\textsuperscript{163}

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 may not consider 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.\textsuperscript{164}

\begin{footnotesize}
\item[162] Health Insurance Portability and Accountability Act of 1996 (HIPAA) § 42 USCS § 300gg(b) (2007); 42 USCS § 300gg-1(a) (2007); Mary Crossley, Discrimination Against the Unhealthy in Health Insurance, 54 U. Kan. L. Rev. 73, 100 (2005)
\item[164] Robert F. Rich & Julian Ziegler, \textit{Genetic Discrimination in Health Insurance – Comprehensive Legal Solutions for a (Not So) Special Problem?}, 2 Ind. Health L. Rev. 5, 30-31 (2005); Mary
\end{footnotesize}
HIPAA provisions relating to the setting of premium rates also prohibit discrimination between members of the same group.\textsuperscript{165} Members may not have variable premiums based upon the member’s individual health status. Department of Health and Human Services regulations pertaining to HIPAA expressly prohibit the use of list-billing—or individualized premium rates. This particularly shields small groups of fewer than twenty-five employees and prevents the use of genetic information to determine individual premium rates.\textsuperscript{166} However, it fails to prevent insurers from charging an elevated premium to the entire group. It is thus still 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 such, they might cancel the plan entirely.\textsuperscript{167}

**Individual Health Insurance**

Concerning individual eligibility, those 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.\textsuperscript{168} They must offer eligible individuals coverage and enrollment in plans marketed on the individual health insurance

\textsuperscript{165} Mary Crossley, Discrimination Against the Unhealthy in Health Insurance, 54 U. Kan. L. Rev. 73, 115 (2005)


\textsuperscript{167} Id. at 32-33.

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.\footnote{Id. at 37.}

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.

**Privacy and Confidentiality**

The HIPAA privacy and confidentiality laws offer 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 regulations.” 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.\footnote{Joanne L. Hustead & Janlori Goldman, Genetics and Privacy, 28 Am. J.L. & Med. 285, 292-293 (2002)}

HIPAA legislation covers three main types of health care entities:

\footnote{Robert F. Rich & Julian Ziegler, Genetic Discrimination in Health Insurance – Comprehensive Legal Solutions for a (Not So) Special Problem?, 2 Ind. Health L. Rev. 5, 34-35 (2005)}
Health care providers who transmit health information electronically using a standard format. Health care providers consist of doctors, hospitals, clinics, pharmacists and laboratories;

Health plans, which include private insurers, employer-sponsored health insurance, HMOs and government-sponsored health insurance programs; and

Health care clearinghouses that process information that is transmitted between health plans and health care providers.\textsuperscript{172}

For genetic information to qualify for privacy and confidentiality protection, it must meet the definition of “protected health information” (PHI).\textsuperscript{173} PHI is individually identifiable health information which 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.\textsuperscript{174} 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 so long as 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

\textsuperscript{172} Id. at 289.
\textsuperscript{173} Id.
\textsuperscript{174} 45 CFR 160.103 (2007)
researcher also functions as a health care provider and whether the researcher bills insurance companies for health care services.\textsuperscript{175}

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 inappropriate uses by employers. For example, group health plans and insurers may share PHI with employers only if the information does not find use for employment-related purposes and that 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.\textsuperscript{176}

**Loopholes in HIPAA Protections**

HIPAA’s provisions do leave substantial loopholes which 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:

- HIPAA does not cover all entities which may come in contact with genetic information. For example, pharmaceutical companies, workers’ compensation insurers, employers and researchers—entities which may

\textsuperscript{176} *Id.* at 291.
not always receive the genetic information in the electronic format which would cause it to become protected health information (PHI).\textsuperscript{177}

- No statutorily established private right of action exists for people whose privacy rights have been violated.\textsuperscript{178}

- 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.\textsuperscript{179}

- Insurers may request, require, purchase and collect genetic information about applicants’ genetic information in both the group and individual insurance markets.\textsuperscript{180}

- Insurers in the individual market may deny coverage because of genetic information if the applicant does not meet the requirements for HIPAA protection, may consider genetic predisposition as a preexisting condition, and may set premiums based upon genetic information.\textsuperscript{181}

- Even if employers receive genetic information through health plans or issuers, HIPAA does prevent employers from using or disclosing the information to discriminate against employees.\textsuperscript{182}

**GINA’s Contribution: Creating Unified Protections in Health Insurance**

\textsuperscript{177} Id. at 288.
\textsuperscript{178} Id. at 291-292.
\textsuperscript{179} Id. at 292.
\textsuperscript{180} Id.; Mary Crossley, Discrimination Against the Unhealthy in Health Insurance, 54 U. Kan. L. Rev. 73, 100 (2005)
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 of genetic information prior to enrollment.

The bill specifies that all of 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 legislation does keep a health care professional from *requiring* that an individual undergo a genetic test.

*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 which apply to ERISA, PHSA, and SSA (Medigap).
• “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. 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.

• The term “genetic information” has the broad definition of information about an individual’s genetic tests, genetic tests of family members, or family medical history, or the occurrence of a disease or disorder in family members of an individual. However, genetic information in this context does not include information about the sex and age of the individual.

• “Genetic tests” include analyses of human DNA, RNA, chromosomes, proteins or metabolites that detect genotypes, mutations or chromosomal changes. However, this definition does not include other types of protein or metabolite tests which do not detect genotype, nor does it include testing which 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.

The interaction between “genetic information” and “genetic test” definitions insures that individuals gain refuge from presymptomatic discrimination, and still allows insurance issuers the ability to use the actuarial process to

183 S. 358, 110th Cong. (2007)
185 S. 358, 110th Cong. (2007)
186 S. 358, 110th Cong. (2007)
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 not genetic information which only provides a probability of developing a condition.

- “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 intends 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 provisions which define these terms in variegated ways, a set of uniform definitions will provide greater consistency and regularity.

*Amending ERISA, PHSA and SSA*

The amendments provided by GINA will clarify and expand the current nondiscrimination protections available under ERISA.\(^{187}\) ERISA already prohibits discrimination against participants and beneficiaries based on genetic information.

\(^{187}\) *Id.* at 18; S. 358, 110th Cong. (2007)
for enrollment or determination of premiums.188 The new protection provided by GINA is the requirement that insurance companies and issuers may not use genetic information to determine premiums for the entire group based upon one individual’s (or family member’s) genetic information.

Further, ERISA will be amended to prohibit group health plans and health insurance issuers from requesting or requiring that the individual undergo a genetic test.189 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.190

GINA’s amendments to the PHSA would provide new protection for the individual insurance market. GINA would add a new section prohibiting health discrimination on the basis of genetic information. Similar to the group health market regulations, insurance companies and issuers would no longer be able to use genetic information to determine eligibility for insurance or to calculate premium and contribution rates. Furthermore, amendments to the PHSA would prohibit insurance issuers from requesting or requiring genetic tests from individuals. As with amendments to ERISA, the limitations on genetic testing does not impede health care professionals, regardless of whether they are employed by or affiliated with the issuer, from recommending genetic tests for patients. GINA would also close a loophole in current PHSA legislation. Non-

189 Issues concerning the use, disclosure and gathering of existing genetic information is regulated by the HHS medical privacy rules.
federal government plans are currently exempted from genetic information
nondiscrimination. GINA would effectively eliminate this exception. All
government plans, both state as well as federal, would be required to desist from
genetic nondiscrimination.

Amendments to the SSA will 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. The limits on genetic testing again
do not restrain health care providers from requesting genetic tests or providing
genetic services to the covered individuals.

GINA – Closing the Gaps

GINA’s privacy and confidentiality provisions will be applicable 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 will also be prohibited for 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. \textsuperscript{191}

GINA’s privacy and confidentiality protections are subject to 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 (i.e. physical exams, blood or urine tests, etc.), they are not in violation of GINA so long as the information was not requested or required and is not used for any underwriting or eligibility purposes. Second, the confidentiality standard shall not apply to health care and insurance entities outside of current coverage by the SSA or HIPAA. Furthermore, the confidentiality standards do not apply to genetic information that is not individually identifiable. This would permit the collection and use of the genetic information in such situations as research and development of genetic science.\textsuperscript{192}

Once in effect, GINA would be applied in coordination with existing SSA and HIPAA provisions, and this coordination will be assured by the Department of Health and Human Services. HHS will also be responsible for the enforcement of these provisions, utilizing the remedies available under the SSA. As new federal law, GINA is designed to preempt current state laws, unless the state law imposes requirements or standards more stringent than this law.\textsuperscript{193}

GINA effectively closes one of the largest gaps left by HIPAA legislation. Insurance issuers may no longer require individuals to undergo genetic testing,

\textsuperscript{191} S. 358, 110th Cong. (2007)
\textsuperscript{192} S. 358, 110th Cong. (2007)
\textsuperscript{193} S. 358, 110th Cong. (2007)
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.\textsuperscript{194} Insurance issuers would still retain the ability to deny coverage to those individuals who are not considered eligible under HIPAA. Additionally, these prohibitions on the use and disclosure of genetic discrimination will also close the loopholes in the group health plan market as well.

\textit{Residual Concerns for Health Insurance Protection}

Although GINA closes some of the gaps in current legislation, it does not close all the potential loopholes. First, GINA expressly treats genetic information as protected health information (PHI), thereby eliminating potential loopholes where genetic information had not previously been protected. There is the possibility that GINA’s limited definition of genetic test – narrower than the medical or scientific definition that is both predictive and diagnostic – will leave the diagnostic genetic information unprotected.\textsuperscript{195} For example, information derived from the analysis of proteins or metabolites directly related to a manifested disease is not considered genetic information for the purposes of this section.\textsuperscript{196} This may lead to confusing situations—such as, for example, the instance of a woman diagnosed with cancer. If the tumor DNA 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 are not covered in the definition of “genetic testing”.

For yet another puzzling twist, if the tumor is removed, the information may be protected because it will no longer be a manifested disease. Nonetheless, this limited definition may constitute 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 which are subject to the confidentiality, disclosure and use prohibitions. Thus, pharmacists and laboratories still remain outside the reach of regulations, and the information must still be in the electronic insurance claims-type format to be protected.

Enforcement and Remedies: Are They Sufficient?

One of the largest concerns for 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, concerning Civil Enforcement, which adds the enforcement of genetic nondiscrimination requirements. Thus, all genetic nondiscrimination concerns benefit from the established remedies

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Id. at 35-36; 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.

200 S. 358, 110th Cong. (2007)
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 violation, the court has the discretion to reinstate coverage, 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 current law enforcement.

However, GINA provisions do not grant plan beneficiaries the right to sue for equitable relief under the PHSA, SSA and HIPPA. Rather, health insurance plans which fall under these laws are limited to the administrative relief already provided for under the SSA. For example, if an insurance company discriminates against an individual for coverage, and that individual complains to HHS, the Secretary has the discretion to impose a penalty on the insurer of $100 per violation—up to $25,000. 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 even increase to $250,000 and up to 10 years of prison if the offense accompanies intention to sell, transfer or use the information for commercial advantage, personal gain or malicious harm.

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Although GINA’s amendments to current legislation 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 the others not included in ERISA, the road of petitioning the Secretary of HHS to enforce the genetic nondiscrimination protections promised by GINA, with all its challenges, remains. This concern ought to reach equilibrium with the policy concern not to increase opportunistic and unnecessary litigation from disgruntled beneficiaries. Nonetheless, nondiscrimination legislation may not prove as successful as anticipated without adequate enforcement and remedies.

**PREVENTING GENETIC DISCRIMINATION IN THE WORKPLACE**

**Current Federal Prohibitions of Genetic Discrimination**

A motley assortment of federal legislation provides the current barriers against genetic discrimination. Federal employees have a fine legal bulwark against genetic discrimination in Executive Order 13145. All other employees depend upon the protections afforded by the Civil Rights Act of 1964 and the 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.

**Executive Order 13,145**

Executive Order 13,145 buffers federal employees from genetic discrimination. President Clinton signed Executive Order 13,415 on February 8, 2000, prohibiting discrimination against federal government employees based
upon genetic information or requests for genetic information. Through the interaction of its provisions, this executive order relates to genetic discrimination in both employment and health insurance. 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, they 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. Section 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. 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, do not fall under this definition.

**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. 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 must be disproportionately related to a protected group listed under the statute. For example, Tay-Sachs Disease appears more commonly among individuals of Eastern European Jewish descent, whereas sickle-cell anemia predominates in Africans. If the 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. GINA extends the civil rights protection of the Civil Rights Act in the important realm of genetic nondiscrimination.

The EEOC (the Equal Employment Opportunity Commission) 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

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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 also may 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. The size of the employer can cap certain damages.

**Americans with Disabilities Act**

The Americans with Disabilities Act (ADA) provides some, but insufficient, barriers against genetic discrimination. The ADA passed in 1990 to address employment discrimination against qualified individuals with disabilities. It operated based upon the animating principle that applicants and employees should be selected by their ability and willingness to do the job, not rejected based on their disabilities.\(^{209}\)

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.\(^{210}\) Specifically, the ADA has established human resources procedures for medical examinations, medical information requests and confidentiality.\(^{211}\)

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\(^{211}\) *Id.*
Currently, employers have the prerogative to request or require medical examinations of job applicants who have conditional offers of employment—so long as all similarly situated employees undergo the same examination.\textsuperscript{212} The ADA regulates the three times during employment that an employer may require medical tests from employees. First, employers may not require medical tests during the pre-employment phase.\textsuperscript{213} This includes medical questionnaires and exams, family history or genetic conditions. However, an employer may ask questions concerning the candidate’s ability to perform certain physical tasks.\textsuperscript{214} Second, employers may condition employment on the passage of medical examinations, so long as the examination: (a) applies to all employees in the same job category; (b) information collected must remain in separate, confidential medical files that may be consulted only for emergency situations, safety concerns or governmental investigations; and (c) if certain conditions emerge from the examination, the conditions must demonstrably render the individual unable to perform the specific job. Finally, any post-employment medical examinations must be voluntary or job-related.\textsuperscript{215}

\textsuperscript{212} Paul Steven Miller, \textit{Analyzing Genetic Discrimination in the Workplace, in RIGHTS AND LIBERTIES IN THE BIOTECH AGE} \textit{173, 175} (Sheldon Krimsy & Peter Shorett eds., Rowman & Littlefield Publishers, Inc. 2005)


Accordingly, employers may receive health information concerning applicants and employees only if it relates to the employee’s ability to perform the job.\textsuperscript{216} 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 promotion based upon that health information.\textsuperscript{217} Additionally, courts have held that benefits such as health insurance qualify as a condition or privilege of employment.\textsuperscript{218} 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 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.\textsuperscript{219} Employers can obtain genetic information only during the conditional offer phase of employment about an applicant or employee 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

\textsuperscript{217} Id.
the individual’s family history. However, the ADA limits the collection of this information through the comprehensive testing regulations mentioned above. Furthermore, employees receive additional privacy protections because employers do not have legal permission to request medical information which 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.

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. However, uncertainty remains whether an employee with a genetic condition has protection from discrimination based upon the ADA.

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 tests as being carriers of a

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220 Id. at 94; Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 50 (1992)
222 Id. at 129-130.
223 Anita Silvers & Michael Ashley Stein, An Equality Paradigm for Preventing Genetic Discrimination, 55 Vand. L. Rev. 1341, 1361 (2002); ADA 42 U.S.C. §12102(2)
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.  

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

Furthermore, the EEOC has stated its position that genetic discrimination falls within the scope the ADA. In 1995, the EEOC determined that the ADA covers genetic discrimination under the “regarded as” prong of the legislation. This position emerged again upon 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. Specifically, Commissioner Miller stated that a person is considered “regarded as having a disability” if a covered entity mistakenly believes an individual has a

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225 Id. at 1361-1362.  
227 Paul Steven Miller, Analyzing Genetic Discrimination in the Workplace, in RIGHTS AND LIBERTIES IN THE BIOTECH AGE 173, 174-175 (Sheldon Krimsky & Peter Shorett eds., Rowman & Littlefield Publishers, Inc. 2005  
228 Id. at 1361-1362.
substantially limiting impairment, when in fact the impairment does not so limit. Under such a theory, coverage for individuals with a genetic predisposition would generally rely on demonstrating a mistaken belief concerning the major life activity of working.\textsuperscript{230} Since the EEOC’s guidelines do not bind courts, concern persists that the ADA framework insufficiently covers individuals against genetic discrimination, as courts may disregard the EEOC guidelines.\textsuperscript{231}

Without Congressional action to amend the ADA, the courts will determine whether a particular genetic condition stays within the orbit of the ADA.\textsuperscript{232} The Supreme Court has not yet decided if the ADA covers genetic information, and recent decisions indicate that the Court tends towards limiting the application of the ADA, rather than expanding it.\textsuperscript{233}

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.\textsuperscript{234} However, genetic predispositions have not yet expressed, and may never express: thus, they do not substantially affect major life activities. Demonstrating that he or she is truly “regarded as”

\textsuperscript{230} Id. at, 1363 (2002); Paul S. Miller, \textit{Is there a Pink Slip in My Genes? Genetic Discrimination in the Workplace}, 3 J. Health Care L. & Pol'y 225, 246 (2000).
\textsuperscript{231} Paul Steven Miller, Analyzing Genetic Discrimination in the Workplace, in RIGHTS AND LIBERTIES IN THE BIOTECH AGE 173, 175 (Sheldon Krimsy & Peter Shoret ed., Rowman & Littlefield Publishers, Inc. 2005
having a disability, another prong under the ADA, is also fraught with difficulties.\textsuperscript{235}

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.\textsuperscript{236}

- **Already expressed genetic diseases** sort themselves under the ADA via the branch of those having impairment—so long as the disease substantially limits a major life activity. For example, substantially limiting diseases with a genetic component include muscular dystrophy (x-linked genetic disorder), multiple sclerosis, achondroplastic dwarfism, adult polycystic kidney disease, cystic fibrosis, hemophilia and diabetes mellitus.\textsuperscript{237}

- **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. Physical characteristics such as eye or hair color, height, and weight remain outside of the ADA’s shield. They do not limit major life activities, such as walking, talking, working or caring for oneself, nor do they substantially limit life activities. For example, some genetic conditions which do not meet the ADA’s standard for protection

\textsuperscript{235} *Id.* at 370.
\textsuperscript{236} Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 39 -52 (1992)
\textsuperscript{237} Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 39 -40 (1992)
include wearing eyeglasses, mild to moderate varicose veins, left
handedness, poor impulse control, strabismus or osteoarthritis.\textsuperscript{238}

- **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 communicate on this group, but legislative history and
case law seem to indicate that the ADA’s reach extends to this group.
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. Employers might want to exclude
the individual from employment because of the risk of steep, future health
care costs.\textsuperscript{239}

- **Genetic predisposition/increased risk** have been refused 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
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.\textsuperscript{240}

- **Unaffected carriers of recessive and X-linked disorders** retain the most
  risk for genetic discrimination because of their children who have, or who

\textsuperscript{238} \textit{Id.} at 40-43.
\textsuperscript{239} \textit{Id.} at 43-45.
\textsuperscript{240} \textit{Id.} at 45-47.
may have the genetic disorder. 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.” This section would extend protection to such diseases as AIDS, as well as Tay-Sachs and cystic fibrosis. However, this protection might 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, substantially limiting the major life activity of procreation (Bragdon v. Abbott). It remains unclear too whether the individual would be able to gain a buffer under the “regarded as” branch due to being regarded as carrying the disease.

- **Those having a record of a genetic disease** attain coverage under 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.

- **Those regarded as having a genetic disease** receive protection by the ADA in three specific situations: (1) the impairment does not substantially limit but the employer perceives it to do so; (2) the impairment substantially limits only because of the attitude of others; or (3) the

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242 Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 47-50 (1992)
243 *Id.* at 50.
individual does not have an impairment but is regarded as having a substantially limiting impairment. Some examples of such conditions with a genetic basis include neurofibromatosis, Tourette syndrome and Down syndrome.²⁴⁴

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.²⁴⁵ In the EEOC’s interpretation, employers and insurers must justify the costs and risks associated with coverage to comply with an overall actuarial fairness.²⁴⁶ 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.”²⁴⁷ This definition broadens the safe 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.²⁴⁸

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

²⁴⁴ ld. at 51-52.
²⁴⁶ ld. at 370-371.
²⁴⁷ ld. at 371
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.\textsuperscript{249}

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 \textit{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.\textsuperscript{250}

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. However, the ADA does not prevent employers from using

\textsuperscript{249} Id. at 1366-1367.

genetic information to discriminate against, and remove, an employee in order to avoid such responsibilities.\textsuperscript{251}

**GINA: Providing New Protections in Employment Law**

*Prohibition on Acquisition and Use of Genetic Information*

Title II of the Genetic Information Nondiscrimination Act (GINA) covers genetic nondiscrimination in employment. Employers may not use genetic information in employment decisions, including hiring, firing, job assignments and promotions.\textsuperscript{252} 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.\textsuperscript{253}

Just 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.\textsuperscript{254} This prohibition extends to family members, which not only include blood relatives, but spouses and even adopted children.

Five limited exceptions exist:\textsuperscript{255}

- Where the employer inadvertently requests or requires family medical history;

• Where the employee uses an employer-sponsored wellness program;

• Where the employer requests or requires family medical history to comply with federal and state family and medical leave laws;

• Where the employer purchases publicly available commercial documents (i.e. newspapers, magazines, etc.) which contain genetic information;

• Where the information is required for genetic monitoring of biological effects of toxic substances in the workplace, provided that the employee gives informed consent and the monitoring complies with federal and state law.²⁵⁶

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 care.²⁵⁷

**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 in separate forms and files, and treated as a confidential medical record. The employer may not disclose genetic information, unless the employer discloses it to the employee to whom it applies. Also, it must comply with

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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. The requirement of separate forms and files effectively creates an information firewall.

The bill forbids disclosure of genetic information except to the employee, health researchers, or in compliance with federal and state law. As to the research part, Francis Collins said: “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.”

One of the potential weaknesses of GINA 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 difficulties exists of the employer receiving genetic information in legal ways, using that information illegally, and then rationalizing it on legal grounds.

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258 For example, Section 103 of the Family and Medical Leave Act of 1993.
261 Supra, Statement at Note 2
Oversight and Enforcement

Rather than basing GINA legislation upon the Americans with Disabilities Act of 1992 (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, state and federal employees, congressional employees, and employees of the executive branch. 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. The Equal Employment Opportunity Commission (EEOC) would be charged with issuing regulations enforcing the employment title one year after enactment. The bill directs the Department of Labor to issue regulations enforcing the health insurance title of the law one year after enactment. The Secretary of Labor would enforce the employment related portions. Rules of construction in the legislation state that GINA does not limit an employee’s rights under the ADA, under the Rehabilitation Act of 1973 or any other federal or state statutes.

No Disparate Impact Cause of Action

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262 42 U.S.C. 2000e(f)
263 3 U.S.C. 411(c)
For claims brought under GINA, disparate impact does not constitute a valid 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. As the Commissioner for GINA, the EEOC is charged with establishing and funding a Commission, and charged with continued study of the genetic sciences. It will reconsider the disparate impact cause of action in six years from the adoption of GINA.\textsuperscript{266} 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.\textsuperscript{267}

**FINANCIAL IMPACT OF GINA**

The Congressional Budget Office (CBO) estimates an increase in 1000 people per year who would obtain insurance, 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 less than half a million dollars per year from 2006 through 2015.

CBO estimates that implementing S. 306 would cost less than half a million 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. Given how the current version of the bill is essentially identical to the S. 306 version, the projections made based on S. 306 would be closely comparable and without substantial difference.

The preemption and the limitations on state and local actions 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 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 UMRA ($123 million in 2005, adjusted annually for inflation) in any of the first five years in which the mandates would be effective.

**Conclusion**

The passage of the Genetic Information Nondiscrimination Act would advance civil rights in the 21st century by providing a national standard across states, and supplement already existing federal law with respect to health insurance and employment, which would 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, would 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 provides an opportunity to take 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 would help 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.