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Melissa E. Beyer*

The Genetic Information Nondiscrimination Act: Protecting Privacy and Ensuring Fairness in Health Insurance and Employment Practices

Almost two centuries ago, Thomas Jefferson, one of this country's foremost scientists and original thinkers, wrote, '[L]aws and institutions must go hand in hand with the progress of the human mind. As . . . new discoveries are made [and] new truths disclosed . . . institutions must advance also, and keep pace with the time.' In this age of genetic breakthroughs, it is essential that our laws catch up with science. We can't afford to take one step forward in science but two steps backward in civil rights. Our laws must specify, clearly and unambiguously, how genetic information may be used and how it may not be used.¹

Two fundamental ideals that Americans hold on the highest of pedestals are those of privacy and fairness. Indeed countless legislative actions have been taken to ensure the protection of Americans' rights to remain free from the overreaching ears and eyes of the government and private institutions, while those that threaten our privacy are scrutinized to the utmost extent.² Even the United States Constitution contemplates the notion that every citizen of our country should be extended the fair and equal protection of the laws.³ Legislation to protect groups that otherwise may not be afforded equal protection, such as the Americans with Disabilities Act and the Civil Rights Act of 1964, provides a means to prevent violations of those

* J.D. Candidate, University of Oregon School of Law, 2009. I would like to thank Professor Gabriel Eckstein, George W. McCleskey Professor of Water Law at Texas Tech Law, for the guidance and advice he provided me in writing this piece.

¹ Senator Thomas A. Daschle, 108 CONG. REC. S12498 (daily ed. Oct. 14, 2003).

² *See, e.g.*, Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (providing an example of a U.S. law protecting privacy); U.S. Patriot Act, Pub. L. No. 107-56 (2001) (providing an example of a U.S. law which arguably threatened American's rights to privacy).

³ U.S. CONST. amend. XIV, §1.

groups' rights, while also giving them a means to redress discriminatory treatment through civil actions.⁴

Embodying the fundamental ideals of privacy and fairness, the Genetic Information Non-discrimination Act of 2008 (GINA) comes at a time when our country is in dire need of such a law.⁵ With the advent of an era in which virtually all disease has a genetic component, access of scientists and medical professionals to genetic information has become a cornerstone to the advancement of research and the improvement of healthcare in our country.⁶ As the number and availability of various genetic tests have grown,⁷ so too has a fear among Americans that their genetic information may be used for purposes other than curing and preventing disease. In particular, many fear that their employers and health care insurers may use such information to their detriment.

For example, employers may use genetic testing as a cost-cutting tool to control expenses related to health care and reduce workers' compensation claims. Use of testing for these purposes would undeniably influence employers' decisions in promotion, hiring, and firing situations. Similarly, private health insurers and group health plans may employ genetic testing

⁴ See Americans with Disabilities Act, 42 U.S.C. § 12112 et seq. (1995); Civil Rights Act of 1964, 42 U.S.C.S. § 2000(e) et seq. (1964). The concept of fairness plays a large role in the motivation behind these laws, as well as GINA, with the idea being that people should not be punished for something completely beyond their control, such as their disability, the color of their skin, or their genetic makeup.

⁵ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (May 21, 2008) [hereinafter GINA].

⁶ Francis S. Collins and Victor A. McKusick, *Implications of the Human Genome Project for Medical Science*, 285 JAMA 5, 540, 540 (2001) (stating that virtually every disease has a "hereditary component" or important "hereditary influences").

⁷ See Dave Hansen, *After 13 Years, Congress OKs Genetic Bias Ban*, AMNEWS, May 19, 2008, at 4 tbl. 1 (illustrating how the number of diseases for which genetic tests are available has grown from 111 in 1993 to over 1,500 in May of 2008).

or attempt to acquire genetic information in order to determine rate structures or exclude individuals from coverage altogether.

Numerous surveys indicate that an overwhelming majority of Americans are strongly opposed to both their employers and health insurers gaining access to their genetic information for those very reasons.⁸ This has created a situation where many individuals are foregoing genetic testing for serious medical conditions and diseases altogether, even when their family medical history indicates that they are at risk.⁹

With the passage of GINA, those fears may now be allayed. The new law decrees that health insurers and group health plans may not refuse to cover and may not raise premiums on customers on the basis of their genetic information.¹⁰ Additionally, employers may not make hiring and firing decisions, or otherwise discriminate against workers based on their genetic information.¹¹ To add a further layer of protection, insurers and employers may not require applicants to submit to genetic tests.¹² In the event that discrimination does occur, GINA provides corrective and monetary penalties for such violations.¹³ The hope, therefore, is that

⁸ See, e.g., Survey, *Public Awareness and Attitudes About Genetic Technologies*, GENETICS AND PUBLIC POLICY CENTER (2004) (indicating that over 9 out of 10 individuals oppose allowing employers and 8 out of 10 oppose allowing insurers access to their genetic information); Survey, *U.S. Public Opinion of Uses of Genetic Information and Genetic Discrimination*, GENETICS AND PUBLIC POLICY CENTER 2 (2007), available at http://www.dnapolicy.org/resources/GINAPublic_Opinion_Genetic_Information_Discrimination.pdf (“The majority of Americans enthusiastically support genetic testing for research and health care, but a large majority (92%) also express concern that results of a genetic test that tells a patient whether he or she is at increased risk for a disease like cancer could be used in ways that are harmful to the person.”).

⁹ *Id.* at 1; see also *Faces of Discrimination: How Genetic Discrimination Affects Real People*, COALITION FOR GENETIC FAIRNESS (Nat’l Partnership for Women & Families, Wash. D.C.) 8-9, July 2004 http://www.geneticalliance.org/ksc_assets/documents/facesofgeneticdiscrimination.pdf [hereinafter *Faces of Discrimination*].

¹⁰ GINA, *supra* note 5, at §§ 101-106.

¹¹ *Id.* at §§ 201-213.

¹² See *infra*, notes 105-108 and accompanying text.

¹³ See *infra*, notes 111-116 and accompanying text.

GINA will encourage individuals to take advantage of the growing number of genetic tests available and realize the benefits of early detection and prevention, while still maintaining their genetic privacy.

At first glance, GINA appears to present little to argue about—what kind of American doesn't wish for increased privacy and fairness? However, many commentators are of the opinion that the consequences of the new legislation will be far from beneficial to Americans.¹⁴ Others suggest that GINA has made too much out of too little.¹⁵ While it is true that reported cases of genetic discrimination are scarce, they still exist and the potential for future genetic discrimination is huge. In that respect, GINA is forward-looking legislation—it anticipates the role that genetic testing will play in the future of Americans' health as the number and availability of genetic tests continue to rise. Despite critics' views that GINA will have adverse and unintended consequences, the legislation comes at an opportune time for our country and will preemptively protect many Americans from ever having to worry about genetic discrimination in the first place.

In this Comment, I begin with a brief look at the fundamental concepts of genetic testing and the trend toward personalized medicine that our country may look forward to in the future. Part II then discusses the legal background of GINA, beginning with a look at existing case law dealing with genetic discrimination in the context of employment, followed by an assessment of how existing federal and state laws apply to the new legislation. Part III provides an overview of GINA's provisions with regard to genetic nondiscrimination by health insurers and employers.

¹⁴ See *infra*, notes 121-124 and accompanying text, 131-136 and accompanying text.

¹⁵ For example, one critic, a management lawyer who testified before Congress on GINA for the Chamber of Commerce, suggested the new law remains a “solution in search of a problem.” Many critics of GINA insist that genetic testing in the workplace and in health insurance is a nonissue.

Next in Part IV, I explore the arguments on both sides of the debate over GINA and the implications the new law has for the health care and employment sectors. I then discuss certain protections that GINA fails to provide, but ultimately conclude that GINA is a crucial piece of legislation that will grow in value as genetic testing becomes more mainstream and, consequently, genetic discrimination becomes an increasingly viable threat.

I

GENETIC TESTING AND THE FUTURE OF PERSONALIZED MEDICINE

Given the growing role that genetic testing has come to play in health and health care, it is helpful to understand the basic fundamentals of genomic medicine before delving into any of its legal consequences.¹⁶ Human chromosomes contain approximately 20,000-25,000 genes, for which almost 3 billion base pairs of DNA provide the code.¹⁷ Each gene encompasses a section of that DNA and contains a sequence that corresponds to a specific protein. Changes or mutations to a DNA sequence may affect the function of a protein in the human body, which in turn could result or contribute to the development of a genetic disease.

Over the past two decades, advances in molecular biology techniques and the establishment of the Human Genome Project have led to the identification and sequencing of

¹⁶ “Genomic medicine refers to the application of the principles of genomics to the prevention, diagnosis, and treatment of disease, as well as to determining the probability of future disease.” NATIONAL INSTITUTES OF HEALTH, OFFICE OF BIOTECHNOLOGY ACTIVITIES, *The Study Priorities of the Secretary’s Advisory Committee on Genetics, Health, and Society, A Roadmap for the Integration of Genetics and Genomics into Health and Society* 2 (June 2004), available at <http://oba.od.nih.gov/oba/sacghs/reports/SACGHSPriorities.pdf>.

¹⁷ See generally, Amanda K. Sarata, *Genetic Testing: Scientific Background for Policymakers*, CRS REPORT FOR CONGRESS 3, January 26, 2007 [hereinafter *Background for Policymakers*] (citing National Research Council, *Reaping the Benefits of Genomic and Proteomic Research: Intellectual Property Rights, Innovation, and Public Health* 19 (Washington, DC: Nat’l Academics Press 2006)).

hundreds of genes.¹⁸ With the known sequence of a particular gene, it is relatively simple to identify specific changes in that sequence that can predispose an individual to common genetic diseases or indicate the presence of a disease. Genetic testing is a powerful technology in both diagnosing and predicting the likelihood that an individual either has or will develop a genetic disease.¹⁹ The term “genetic test” has been defined by one source as follows:

An analysis performed on human DNA, RNA, genes, and/or chromosomes to detect heritable or acquired genotypes, mutations, phenotypes, or karyotypes that cause or are likely to cause a specific disease or condition. A genetic test also is the analysis of human proteins and certain metabolites, which are predominantly used to detect heritable or acquired genotypes, mutations, or phenotypes.²⁰

Currently, genetic tests are available for 1,656 diseases, of which, 1,363 are available for clinical diagnosis of those diseases, with the remainder available solely for research purposes.²¹ Some of the most commonly known genetic disease include cancer, diabetes, Alzheimer’s disease, Huntington’s disease, and cystic fibrosis.

As the popularity of genetic testing continues to grow, distinct trends in health care have emerged. Specifically, health care providers and industry researchers alike have begun to shift their focus away from developing treatments and therapies that accommodate large numbers of

¹⁸ Sandy M. Thomas, *Society and Ethics – The Genetics of Disease*, 14 CURRENT OPINIONS IN GENETICS & DEVELOPMENT, 287, 287 (2004).

¹⁹ The two most common types of health-related genetic testing are diagnostic and predictive testing. Diagnostic testing is utilized in order to identify the presence or absence of a disease in an individual, while predictive testing is employed to predict whether an individual will unquestionably develop a disease in the future or to predict an individual’s risk of developing a disease in the future. *Background for Policymakers, supra* note 17, at 5.

²⁰ NATIONAL INSTITUTES OF HEALTH, OFFICE OF BIOTECHNOLOGY ACTIVITIES, Report of the Secretary’s Advisory Committee on Genetic Testing (SACGT), *Enhancing the Oversight of Genetic Tests: Recommendations of the SACGT*, available at <http://www4.od.nih.gov/oba/sacgt/sacgt.htm>.

²¹ See GeneTests Home Page, <http://www.genetests.org/> (last visited November 2, 2008). GeneTests is funded by the National Institutes of Health.

people toward the needs of the individual.²² This approach, termed “personalized medicine,” concentrates on developing pharmaceuticals and treatments that are tailored to the genotype and molecular profile of a specific individual and his or her disease.²³ Put in more simple terms, “Personalized medicine can be described as the right treatment at the right dose at the right time for the right patient with the right disease.”²⁴

The key to personalized medicine is the close link between therapeutics and diagnostics, termed “theranostics.”²⁵ Theranostics allows health care providers to use a patient’s genotypic information and to monitor that patient’s particular course of therapy and assess his or her response to it.²⁶ Currently, there are two major applications of personalized medicine.²⁷ The first, termed pharmacogenomic testing, deals with customizing drug treatments based on how a specific genetic profile metabolizes or responds to certain drugs as well as other agents—such as various foods or chemicals.²⁸ This method allows health care providers to administer the most appropriate treatment alternative or medication for patients in defined groups with a certain level of clinical predictability. The obvious benefit is medical efficiency—avoiding the waste of time and money by treating patients with drugs that are more effective for their genotype.

²² Gary E. Marchant, *Personalized Medicine and the Law*, 44 ARIZ. ATT’Y 12, 12 (October 2007).

²³ *Id.*

²⁴ *Id.*; see also *Background for Policymakers*, *supra* note 17, at 7 (“Personalized medicine is healthcare based on individualized diagnosis and treatment for each patient determined by information at the genomic level.”).

²⁵ See Lisa A. Haile, *Making Personalized Medicine a Reality*, 28 GENET. ENG. & BIOTECH. NEWS 1, (Jan. 1, 2008); see also Mary Ann Liebert, *New Developments in Medical Nanotechnology*, 27 *Biotechnology L. Rep.* 225, 226 (2008) (“The growing field of theranostics involves a search for nanomaterials that provide diagnosis and therapy in one treatment.”).

²⁶ *Id.*

²⁷ See Marchant, *supra* note 22, at 14.

²⁸ See Teresa Kelton, *Pharmacogenics: The Re-Discovery of the Concept of Tailored Drug Therapy and Personalized Medicine*, 19 *HEALTH LAW.* 3, 3 (Jan. 2007)

The second major application of personalized medicine is the subcategorizing of diseases based on specified genetic profiles.²⁹ This application has been developed mainly for use in the field of oncology, the branch of medicine that studies cancerous tumors. Recently developed technology, such as DNA microarrays or gene chips, is used to test for the expression of specific genes and other molecular attributes in cancer cells from specific patients to classify cancerous tumors into discrete categories with very different prognoses and treatment options.³⁰ This method may make it possible for health care providers to understand how cancer spreads and to determine the most effective therapeutic route for particular patients.

The potential benefits of personalized medicine include development of drugs and treatment methods that are safer and more effective for specific disease populations, a decrease in the overall cost of healthcare, and more accurate methods for determining drug and treatment dosages.³¹ While the future of personalized medicine appears bright, furthering this approach will require significant public policy reform and societal involvement to influence how genetic testing is integrated into our nation's health care system.³² Several barriers to the advancement of personalized medicine have been identified, one of which, of course, is the issue of genetic privacy.³³ The passage of GINA is certainly one step in the right direction to breaking down the privacy barrier—as fear of genetic discrimination and its actual practice are eliminated from our

²⁹ See Marchant, *supra* note 22, at 14.

³⁰ Gary E. Marchant, *Symposium: Law and the New Era of Personalized Medicine*, 48 *Jurimetrics J.* 131, 132 (2008).

³¹ See Sadaf Y. Qureshi and Nadeem Qureshi, 5 *PERSONALIZED MEDICINE* 4, 311, 312 Box 1 (2008)

³² See Kenneth Offit and Peter Thom, *Ethical and Legal Aspects of Cancer Genetic Testing*, 34 *J. SEMIN. ONCOL.*, 435, 436 (2007); *Personalized Medicine: Issues affecting adoption of personalized medicine*, *PERSONALIZED MEDICINE COALITION* (March 2007), <http://www.ashg.org/pdf/PMC%20%20Issues%20affecting%20adoption%20of%20personalized%20medicine.pdf>

³³ See Kelton, *supra* note 28, at 8; Marchant, *supra* note 30, at 133; Qureshi, *supra* note 31, at 313.

healthcare system, Americans will be more likely to participate in genetic testing and realize the progressive benefits available from the practice of personalized medicine.

II A LOOK AT CASE LAW, STATE AND FEDERAL LEGISLATION PRECEDING GINA

A. Case Law Preceding GINA

Genetic discrimination occurs when an individual with no symptoms or signs of a disease or medical condition receives less favorable or adverse treatment solely because of their genotype.³⁴ Generally, few cases of genetic-based employment discrimination have been documented, while even fewer cases of genetic-based insurance discrimination have been documented.³⁵ However, evidence exists which indicates that it is both a real and perceived threat in the employment and health insurance contexts. According to a survey taken by the American Management Association in 2004, employers reported genetically testing new hires and employees for breast and colon cancer, Huntington's disease, and sickle cell anemia.³⁶ Even more shocking is that over one half of those employers used the test results in decisions regarding the hiring, reassigning, or firing of those employees.³⁷ Additionally, one in six of the

³⁴ Marion Harris et al., *Controversies and Ethical Issues in Cancer-Genetics Clinic*, LANCET ONCOL 6, 301, 304 (2005); see also Paul Steven Miller, *Genetic Testing and the Future of Disability Insurance: Thinking About Discrimination in the Genetic Age*, 35 J.L. Med. & Ethics 47, 48 (2007) (defining genetic discrimination in the employment context as “an employer taking an adverse employment action based upon an asymptomatic, genetic predisposition to a disease or medical condition[.]”).

³⁵ Offit et al., *supra* note 32, at 435-36 (citing M.A. Hall and S.S. Rich, *Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination*, 66 AM. J. HUM. GENET., 293-307 (2000)).

³⁶ American Management Association, *AMA 2004 Workplace Testing Survey: Medical Testing 2* (2004), http://www.amanet.org/research/pdfs/Medical_testing_04.pdf.

³⁷ *Id.*

employers surveyed reported collecting family medical histories from employees and new hires.³⁸

In a 1992 survey of health care providers by the Congressional Office of Technology Assessment, seventeen out of twenty-nine individual commercial insurers and eleven out of twenty-five Blue Cross and Blue Shield plans reported that they would decline an individual applicant if presymptomatic testing revealed a likelihood of a serious disease or chronic future disease.³⁹ While the numbers were slightly more forgiving for applicants with a family history of genetic conditions, a few health insurers still reported that they would decline coverage.⁴⁰

The Council for Responsible Genetics estimates that up to 500 cases of genetic discrimination have been documented, in which individuals have been barred from either employment or health insurance coverage; although most of those cases have not been formally pursued in court.⁴¹ However, two landmark cases, in which formal court action *was* taken, serve as a demonstration of the dangerous potential of genetic discrimination through genetic testing in the employment context.

1. Norman-Bloodsaw v. Lawrence Berkeley Laboratory

The Ninth Circuit Court of Appeals' decision in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* was the first decision by a federal appellate court to recognize a constitutional right to genetic privacy in the workplace.⁴² In 1995, several employees of Lawrence Livermore

³⁸ *Id.*

³⁹ U.S. Congress, Office of Technology Assessment, *Genetic Tests and Health Insurance: Results of a Survey-Background Paper*, 14 (Washington, DC: U.S. Government Printing Office, October 1992).

⁴⁰ *Id.* at 20.

⁴¹ Council for Responsible Genetics, *Genetic Testing, Discrimination, and Privacy*, available at <http://www.gene-watch.org/programs/privacy.html>.

⁴² See Julie Gannon Shoop, *Workers are Entitled to Genetic Privacy at Work*, *Ninth Circuit Holds*, THE FREE LIBRARY, May 1, 1998, at 1; see also *infra* text accompanying notes 52-53.

National Laboratory in Berkeley, California, discovered that their employer secretly had been testing them for certain medical conditions, namely sickle-cell anemia, syphilis, and pregnancy, from approximately the 1960s to 1993.⁴³ Even more contemptible was that the employees neither consented to the tests, nor were they aware that they were being tested for those medical conditions.⁴⁴ Rather, the employees were under the impression that their blood and urine samples would be used for merely routine medical purposes, such as cholesterol screening.

The plaintiff employees brought claims against the defendant employer for violations of the ADA, Title VII of the Civil Rights Act, and the California and United States Constitutions.⁴⁵ They alleged that the defendant had violated Title VII by singling out African American and female employees for sickle cell trait testing and pregnancy testing, respectively.⁴⁶ They claimed that the defendant had violated the ADA by “requiring, encouraging, or assisting in medical testing that was neither job-related nor consistent with business necessity.”⁴⁷ Finally, the plaintiffs asserted that the defendants had violated both their state and federal right to privacy “by conducting the testing at issue, collecting and maintaining the results of the testing, and failing to provide adequate safeguards against disclosure of the results.”⁴⁸ Notably however, the plaintiffs did *not* claim that the defendants took any “employment-related action on the basis of the test results.”⁴⁹

⁴³ *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1264-65 (9th Cir.1998).

⁴⁴ *Id.* at 1265.

⁴⁵ *Id.* at 1265-66.

⁴⁶ *Id.* at 1266. “Sickle cell trait is a genetic condition in which an individual carries the gene that causes sickle cell anemia,” which is a condition present almost exclusively in the African-American population. *Id.* at 1265 n. 3.

⁴⁷ *Id.* at 1265.

⁴⁸ *Id.*

⁴⁹ *Id.*

The unanimous three-judge panel reversed the district court's grant of summary judgment for the defendant employer and upheld the plaintiffs' Title VII and privacy claims.⁵⁰ However, they denied their claims under the ADA, because neither the testing nor the retention of the medical records was prohibited under the ADA.⁵¹ The authoring judge, Judge Stephen Reinhardt, famously wrote, "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up. . . . [T]he conditions tested for were aspects of one's health in which one enjoys the highest expectations of privacy."⁵² Furthermore, the court recognized that "while the taking of a bodily fluid sample implicates one's privacy interests, '[t]he ensuing chemical analysis of the sample to obtain physiological data is a *further* intrusion of the test employee's privacy interests."⁵³

Concededly, *Norman-Bloodsaw* does not directly provide evidence of *genetic* discrimination in the workplace.⁵⁴ However, even the Congressional findings made in GINA, recognize this case as one that indicates the reality of genetic discrimination. Congress explicitly recognized that, because of examples of unauthorized genetic testing as in *Norman-Bloodsaw*, it "clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance."⁵⁵

⁵⁰ *Id.* at 1269-73.

⁵¹ *Id.* at 1273-74.

⁵² *Id.* at 1269-70.

⁵³ *Id.* at 1270 (quoting *Skinner v. Railway Labor Executives' Ass'n*, 489 U.S. 602, 616 (1989)) (emphasis in original).

⁵⁴ Rather, the defendant discriminated against the employees on the basis of race and sex by singling certain groups out for specific tests. *See supra*, text accompanying note 46.

⁵⁵ *See* GINA, *supra* note 5, at § 2 Findings ("Congress has been informed of examples of genetic discrimination in the workplace. These include the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1269 (9th Cir. 1998). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.").

2. *Equal Employment Opportunity v. Burlington Northern Santa Fe Railway Co.*

In the case of *Equal Employment Opportunity Commission v. Burlington Northern Santa Fe Railway Co.*, the Equal Employment Opportunity Commission (“EEOC”) brought its first ever case challenging the improper genetic testing of thirty-six employees by Burlington Northern Santa Fe Railway Company (“Burlington”).⁵⁶ The EEOC brought its claim under Title I of the ADA, alleging that the plaintiff employees, who had submitted work-related injury claims of developing carpal tunnel syndrome, were requested to submit to an improper medical examination.⁵⁷ The examination included a diagnostic blood test for a genetic marker, which, if present, indicated a predisposition to carpal tunnel syndrome.⁵⁸ The plaintiffs claimed that when they refused to submit to the genetic testing, Burlington threatened them with their jobs.⁵⁹

While the case never made it to trial, on May 8, 2002, the EEOC settled the case with Burlington and thirty-six employees received a settlement of \$2.2 million. Strangely, Burlington denied “that it or any of its agents engaged in any unlawful testing or other conduct, or violated any person's rights under the ADA” and that “it in any way . . . discriminated against any of its employees in violation of the ADA.”⁶⁰ The obvious question remains—then why did Burlington settle the case? The most logical reason, although only conjecture, is that Burlington settled to escape the expense and negative publicity associated with a full-blown trial, especially one in which it was accused of genetic discrimination.⁶¹ Whether or not Burlington was actually at fault, this case presents another documented example of genetic discrimination in the workplace.

⁵⁶ *EEOC v. Burlington Northern Santa Fe Railway Co.*, 2002 WL 32155386, 1 (E.D. Wis. 2002).

⁵⁷ *Id.*

⁵⁸ *Id.*

⁵⁹ *Id.*

⁶⁰ *Id.*

⁶¹ See Samantha French, *Genetic Testing in the Workplace: The Employer's Coin Toss*, 2002 DUKE L. & TECH. REV. 0015, 12 (2002).

It further demonstrates that GINA is a much-needed piece of legislation to protect the rights of employees, such as the thirty-six employees of Burlington.

B. Existing Federal Legislation

At first glance, it may appear that an employee or health insurance applicant has a variety of avenues through which to bring a claim of genetic discrimination. Couldn't an individual bring suit under the ADA, Title VII of the Civil Rights Act, or HIPAA? The answer is the ever-popular adage of the legal profession, "It depends." The fact is that, for various reasons, these pieces of federal legislation fall short when it comes to comprehensively protecting individuals from genetic discrimination. This is primarily because most of the applicable laws do not explicitly restrict the use of genetic testing in the employment or health insurance contexts, and if they do, gaping holes exist so that protection is limited to very narrow circumstances. Although other federal laws might be discussed here, I limit my discussion to three pieces of federal legislation that would appear to be the most applicable.

1. Americans With Disabilities Act of 1990

The Americans With Disabilities Act of 1990 (ADA) explicitly protects only those employees with a proven, qualifying "disability."⁶² The problem, therefore, lies in proving that an employee with a genetic disease, which displays no symptoms or a genetic predisposition, is disabled within the meaning of the ADA.⁶³ This is not a simple task, however. As one commentator points out, "Persons with mere predispositions to genetic disorders do not fall

⁶² Americans with Disabilities Act, 42 U.S.C. § 12112 et seq. (1995). The law does not contemplate individuals' rights in the context of health insurance.

⁶³ The ADA defines a "disability" as "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." *Id.* at §12102(2)(A)-(C).

within the ADA’s definition of disability because they display no present symptoms that substantially limit a major life activity.”⁶⁴

In 1995, the EEOC expanded the third prong in the definition of “disability”—“regarded as having a substantially limiting impairment”—to protect individuals who are subject to discrimination on the basis of genetic information relating to illness, disease, or other disorders.⁶⁵ An entity discriminating against an individual with a genetic predisposition, for example, would be treating that individual as having an impairment, and, thus, that individual would be protected under the ADA.⁶⁶

However, the guidance provided by this interpretation of the ADA is limited in scope and legal effect. First, the EEOC’s compliance manual does not have the binding effect of a court’s decision, a statute, or a regulation. Furthermore, to date, the EEOC’s interpretation has not been tested in court, aside from the *Burlington* case, which settled and therefore provides no guidance as to how a court would rule on the EEOC’s interpretation. Therefore, the limited protections offered by the ADA remain uncertain.

2. Health Insurance Portability and Accountability Act of 1996

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)⁶⁷ was the only federal law that directly addressed genetic discrimination before the passage of GINA. The law provides generally that individuals may not be excluded from coverage or charged higher rates in

⁶⁴ Kimberly A. Steinforth, *Bringing Your DNA to Work: Employers’ Use of Genetic Testing Under the Americans with Disabilities Act*, 43 ARIZ. L. REV. 965, 968-69 (2001).

⁶⁵ See EEOC COMPLIANCE MANUAL, § 902.8, Order 915.002, 902-45 (1995).

⁶⁶ NATIONAL INSTITUTES OF HEALTH, OFFICE OF BIOTECHNOLOGY ACTIVITIES, A Report Commissioned by the Secretary’s Advisory Committee on Genetics, Health, and Society, *An Analysis of the Adequacy of Current Law in Protecting Against Genetic Discrimination in Health Insurance and Employment*, i (May 2005), available at http://oba.od.nih.gov/oba/sacghs/reports/legal_analysis_May2005.pdf [hereinafter *Adequacy of Current Law*].

⁶⁷ Pub. L. No. 104191, 110 Stat. 1936 (codified as amended in scattered sections of 29 U.S.C.A. and 42 U.S.C.A.).

employer-based and commercially issued group health insurance plans on the basis of genetic information, unless the individual previously has been diagnosed with a condition related to the genetic information—referred to as a “preexisting condition exclusion.”⁶⁸

Even though HIPAA directly addresses the issue of genetic discrimination, it too has its own limitations. To start, it only applies to employer-based and commercially issued group health insurance plans; HIPAA offers no protection to individuals who are attempting to purchase health insurance coverage in the individual market.⁶⁹ Furthermore, HIPAA still allows health insurers to take genetic information into account and charge an entire employer group higher premiums for its coverage on the basis of one individual’s genetic information.⁷⁰ This may serve to deter employees from hiring or keeping certain individuals if they are suspicious of a predisposition to a genetic disease. Finally, although provisions of HIPAA provide some privacy protections for genetic information, it does not prohibit group health plans or issuers from requesting or purchasing genetic information, or requiring an individual to submit to a genetic test to obtain genetic information as a condition of coverage.⁷¹

3. *Title VII of the Civil Rights Act of 1964*

Under Title VII of the Civil Rights Act of 1964, employers are prohibited from discriminating against employees on the basis race, color, religion, sex, and national origin.⁷²

The statute does not, however, explicitly protect individuals from discrimination on the basis of

⁶⁸ HIPAA actually added section 701 of ERISA, 29 U.S.C. § 1181(a), section 2701 of the Public Health Service Act, 42 U.S.C. § 300gg(a), and section 9801 of the Internal Revenue Code, 26 U.S.C. § 9801(a), to provide these protections.

⁶⁹ *See Adequacy of Current Law, supra* note 66, at 13.

⁷⁰ *Id.* at 2.

⁷¹ *Id.* at i.

⁷² 42 U.S.C.S. § 2000(e) et seq. Title VII covers all private employers that have 15 or more employees, labors organizations, employment agencies, and Federal, State, and municipal government employers. *Id.* at § 2000(e)(b).

their genetic makeup. However, there may be some protection afforded from Title VII for racially- or ethnically-linked genetic diseases. The law may provide protection from genetic discrimination against an individual employee when such discrimination would disproportionately affect individuals belonging to one of the groups protected under Title VII.⁷³

An illustration of this can be seen in the *Norman-Bloodsaw* case, in which the employer was genetically testing African Americans for the Sickle Cell trait, which is very closely linked to that racial population.⁷⁴ If the African-American plaintiffs in *Norman-Bloodsaw* had been able to show that each employee had been given the same genetic test—the test for the Sickle Cell trait—and that test had had a discriminatory effect on their race, then, theoretically, they would have been protected from genetic discrimination under Title VII. The gap in protection afforded under Title VII is obvious—a strong relationship between race or national origin has been established for only a few diseases, and, therefore, only individuals with those few genetic diseases would be protected. Again, as with the ADA and HIPAA, it is clear that Title VII fails to provide the broad protection against genetic discrimination that Americans need.

C. Existing State Laws

Prior to the passage of GINA, forty-one states had passed genetic nondiscrimination laws related to health insurance and thirty-one had passed such laws relating to employment.⁷⁵ As can be expected, these laws vary widely in their scope, application, and the degree of protection they offer, principally due to their differing definitions of “genetic information.” For example, North

⁷³ See *Adequacy of Current Laws*, *supra* note 66, at 19.

⁷⁴ See *supra* note 46 and accompanying text.

⁷⁵ See Statement by Dr. Francis S. Collins, National Human Genome Research Institute, Fiscal Year 2005 Budget Request (April 1, 2004), available at <http://www.genome.gov/11511290>; see also Offit et al., *supra* note 32, at 437, tbl. 1 (demonstrating the variation in provisions of state law pertaining to the use of genetic information in health insurance and in genetic privacy protections of state laws).

Dakota has one of the broadest definitions of “protected health information,” which explicitly includes “genetic information”:

Any fluid or tissue samples collected from an individual, diagnostic and test results, whether oral or recorded in any form or medium, which... (1) relates to the past, present, or future physical or mental health or condition of an individual, including individual cells and their components; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual; and (2)(a) Identifies an individual; or (b) With respect to which there is a reasonable basis to believe that the information can be used to identify an individual.⁷⁶

Another example of an all-inclusive definition of genetic information exists in Virginia. The statute extends the definition to include family histories and inherited characteristics, but keeps the definition short and sweet, “‘Genetic information’ means information about genes, gene products, or inherited characteristics that may derive from an individual or a family member.”⁷⁷

In contrast, a narrow definition in a Texas statute limits the definition to include only the results of a genetic test. It defines “genetic information” as information that is “(A) obtained from or based on a scientific or medical determination of the presence or absence in an individual of a genetic characteristic; or (B) derived from the results of a genetic test performed on, or a family health history obtained from, an individual.”⁷⁸ Colorado, along with Georgia and Louisiana, even identify genetic information as an individual’s personal property: “Genetic information is the unique property of the individual to whom the information pertains.”⁷⁹

To compound the complications imposed by the varying applications and definitions in state nondiscrimination laws, the Employee Retirement Income Security Act (ERISA)⁸⁰ severely

⁷⁶ N.D.C.C. 23-01.3 Health Information Protection, at 01.

⁷⁷ Va. Code Ann. § 38.2-508.4(A).

⁷⁸ V.T.C.A., Labor Code § 21.401(4)(A)-(B).

⁷⁹ C.R.S.A. § 10-3-1104.7(1)(a). *See* Ga. Code Ann., § 33-54-1(1); LSA-R.S. 22 § 213.7(E) (“An insured’s or enrollee’s genetic information is the property of the insured or enrollee.”).

⁸⁰ Employee Retirement Income Security Act of 1974, 29 U.S.C.A. §§ 1101-1461 (1999).

limits the effect of those state laws on self-insured employee benefit plans commonly provided to employees as part of their employment benefits.⁸¹ Unfortunately, ERISA preempts state law and fails to provide protection against genetic discrimination.⁸² Therefore, state genetic nondiscrimination laws relating to the use of genetic information in health insurance are useless to individuals whose employers have a self-funded plan.

Supporters of GINA have coined the term “a patchwork of protection” to describe the various overlapping and intermingling federal and state laws that purport to protect individuals from genetic discrimination.⁸³ The clear advantage offered by GINA is that it sets a minimum standard of protection for all Americans that must be met in all states. GINA does not preempt state or federal laws that may provide equal or greater protection from genetic discrimination.⁸⁴ In other words, if a state has a less stringent standard than GINA, the federal law controls, but if a state has a more stringent standard than GINA, the state law controls. Some critics of GINA predict that the law’s failure to preempt state law will complicate compliance with genetic nondiscrimination laws for employers who do business in multiple states.⁸⁵ While it is important to consider all parties who will be affected by GINA, the inconvenience to employers in complying with various genetic nondiscrimination laws can hardly be seen to outweigh the need for a comprehensive law granting protection from genetic discrimination.

⁸¹ See *Adequacy of Current Laws*, *supra* note 66, at 10.

⁸² See ERISA at § 1140; *see also* Offit et al., *supra* note 32, at 437.

⁸³ *Adequacy of Current Laws*, *supra* note 66, at 11 (“The gaps in the protection of the confidentiality of genetic information under HIPAA, the HIPAA privacy regulations, State laws, and the often complex interaction of Federal and State law create a patchwork of protection for genetic information that may leave patients, health care providers, and health insurers in doubt about the viability and extent of that protection.”); *see* Hansen, *After 13 Years*, *supra* note 7, at 2.

⁸⁴ GINA, *supra* note 5, at § 206(a)(1).

⁸⁵ Kevin P. McGowan, *Employer Advocates Remain Wary of New Bias Law’s Potential Effects*, DAILY LABOR REPORT 99, May 22, 2008, <http://emlawcenter.bna.com/pic2/em.nsf/id/BNAP-7KMKU9?OpenDocument>.

III. AN IN DEPTH LOOK AT GINA

A. *GINA's Hard Fought Battle*

On May 21, 2008 the Genetic Information Nondiscrimination Act of 2008 was signed into law by President George W. Bush. GINA's passage through the 110th Congress was almost unanimous—the Senate approved the bill by a 95-0 vote and the House followed with a 414-1 vote. With such overwhelming support, it may surprise some to know that GINA fought a long battle through Congress of approximately thirteen years before finally being passed.⁸⁶ In fact, when Representative Louise Slaughter (D-NY) first introduced a bill addressing genetic discrimination in health insurance in the House in 1995 and Senator Olympia Snowe (R-ME) introduced similar legislation in the Senate,⁸⁷ both bills were more or less placed on the back burner primarily because few genetic tests existed at that time.⁸⁸ Neither bill passed in the 104th Congress, nor did similar bills pass when proposed to the 105th and 106th Congresses.⁸⁹

Early legislation was met with opposition from one from Senator in particular, Senator Tom Coburn of Oklahoma (R-OK). Senator Coburn feared that the bill would create a situation where self-insured employers could be sued twice for the same incidence of discrimination, once as the employer and again as the insurer.⁹⁰ The Senator also argued to include a "business necessity" exemption in the bill, similar to that in the ADA, for employers seeking to collect

⁸⁶ See *infra* notes 87-97 and accompanying text.

⁸⁷ See *What Does GINA Mean? A Guide to the Genetic Information Nondiscrimination Act*, COALITION FOR GENETIC FAIRNESS, 5 (November 10, 2008), http://www.geneticalliance.org/ksc_assets/publicpolicy/ginapublication111008.pdf [hereinafter *What Does GINA Mean?*].

⁸⁸ See Hansen, *supra* note 7, at 2. Approximately 300 diseases had genetic testing available at that time, compared to over 1,500 today. *Id.* at 4 tbl 1.

⁸⁹ See *What Does GINA Mean?*, *supra* note 87, at 5.

⁹⁰ See Hansen, *supra* note 7, at 2.

genetic information from employees.⁹¹ He finally agreed to a compromise when a "firewall," separating the employer and insurance sections of the bill to discourage inappropriate lawsuits, was negotiated.⁹² Senator Coburn never succeeded in negotiating his business necessity exemption, however.

Similar legislation were subsequently introduced in both the House and Senate in the 107th, 108th, and 109th Congresses, and while each year the bills continued to gain cosponsors in both chambers, each bill ultimately failed to pass.⁹³ Other strong opponents of the legislation leading up to GINA were lobbyists for employers and health insurance companies, as well as the U.S. Chamber of Commerce and the Society for Human Resource Management. Among their concerns were that the new legislation would invite frivolous litigation, alter employer use and processing of health care information, and that genetic discrimination was not even a current problem in either the health care or employment contexts.⁹⁴ The U.S. Chamber of Commerce opposed GINA until its passage in 2008. Michael Eastman, Executive Director of Labor Policy for the group, particularly opposed the allowance in the law for up to \$300,000 in punitive damages, declaring it as an excessive amount.⁹⁵

Finally, in the 110th Congress, the opponents of GINA lost their fervent battle. The bill first passed in the House on April 25, 2007,⁹⁶ and then, about one year later, it successfully passed in the Senate.⁹⁷ The provisions of Title I of GINA, relating to genetic nondiscrimination

⁹¹ Charles S. Plumb and Sam R. Fulkerson, *GINA: You've Come a Long Way Baby!*, 16 OKLAHOMA EMPLOYMENT LAW LETTER 7 (July 2008), <http://www.hrhero.com/hot/170562/>.

⁹² *Id.* Referring to § 209(2)(A)-(B) of GINA which dictates that nothing in Title II should be construed to provide for the enforcement of or penalties for Title I of GINA.

⁹³ See *What Does GINA Mean?*, *supra* note 87, at 5.

⁹⁴ See Plumb, *supra* note 91.

⁹⁵ See Hansen, *supra* note 7, at 2.

⁹⁶ Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. (2007).

⁹⁷ Genetic Information Nondiscrimination Act, S. 358, 110th Cong. (2007).

in health insurance, will take effect beginning in May of 2009, and Title II, relating to nondiscrimination in employment, in November of 2009.⁹⁸

B. GINA – What Does the Law Say?

GINA sets forth two sets of rules relating to an individual’s genetic information—Title I dictates the rules relating to genetic nondiscrimination in health insurance and Title II dictates the rules relating to genetic nondiscrimination in employment practice.⁹⁹ Before expanding upon those rules, it will be helpful to examine several definitions found in GINA. According to GINA, the “genetic information” of an individual is broadly defined as information about (1) the individual’s genetic tests, (2) the genetic tests of the individual’s family members, and (3) the manifestation of a disease or disorder in family members of the individual.¹⁰⁰ This means that if an individual carries a mutation of a gene that predisposes him or her to a genetic disease, or if a family member of that individual has or had a genetic disease, information of such is protected under GINA as “genetic information.” However, if an individual has been diagnosed with and currently has a genetic disease, that information does *not* fall within the definition of “genetic information,” despite the fact that the disease has a genetic component.

The definition of genetic information encompasses participation of an individual in clinical research and “genetic services,”¹⁰¹ which includes genetic tests, genetic counseling (including obtaining, interpreting, or assessing genetic information) or genetic education. GINA

⁹⁸ See Erin N. Miller, *The Genetic Information Nondiscrimination Act of 2008*, SP003 ALI-ABA 2031, 2017-18, July 24-26, 2008.

⁹⁹ See GINA, *supra* note 5, at §§ 101-106 (Title I), §§ 201-213 (Title II).

¹⁰⁰ GINA, *supra* note 5, Title II at §201(4). See also, GINA, *supra* note 5, Title I at §101-106 (the definition of “genetic information” is included in each section of code that Title I of GINA amends, namely, ERISA, 29 U.S.C.A. § 1181 et seq., the Public Health Services Act, 42 U.S.C.A. § 300gg-22(b), and the Internal Revenue Code, 26 U.S.C.A. § 9802 et seq.).

¹⁰¹ GINA, *supra* note 5, Title II at §201(4)(B) Inclusion of Genetic Services and Participation in Genetic Research.

defines a “genetic test” as an “analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.”¹⁰²

GINA makes certain exclusions from the definition of genetic information regarding an individual’s sex or age.¹⁰³ Notably, however, it does include (1) any genetic information of any fetus carried by the individual, and (2) any genetic information of any embryo legally held by the individual or family member.¹⁰⁴

Title I of GINA consists of amendments to certain provisions of ERISA, the Public Health Service Act, and the Tax Code. The new law applies to “group health plans” and “health insurance issuers” who offer coverage, and generally prohibits them from the following: (1) requesting or requiring genetic testing; (2) increasing group premiums or denying enrollment based on genetic information; (3) requesting, requiring, or purchasing genetic information for underwriting purposes or with respect to any individual prior to enrollment and in connection with enrollment; and (4) using or disclosing genetic information about an individual for underwriting purposes.¹⁰⁵

Also, Title I of GINA includes a section that requires the Secretary of Health and Human Services to revise HIPAA rules to indicate that (1) genetic information is “health information” for purposes of HIPAA privacy rules, and (2) the use or disclosure of genetic information for underwriting purposes is not a permitted use or disclosure under the privacy rules.¹⁰⁶

Title II of GINA applies to employers, employment agencies, labor organizations, and labor-management committees conducting apprenticeship or training programs, and generally

¹⁰² See GINA, *supra* note 5, Title I at § 101-106, Title II at § 201(7).

¹⁰³ See, e.g., ERISA, 29 U.S.C.A. § 733(d)(C) (“The term ‘genetic information’ does not include information about the sex or age of an individual.”).

¹⁰⁴ See, e.g., ERISA, 29 U.S.C.A. § 702(f)(1)-(2).

¹⁰⁵ See GINA, *supra* note 5, at Title I.

¹⁰⁶ *Id.* at § 105.

prohibits them from doing any of the following: (1) making employment decisions based on genetic information;¹⁰⁷ (2) retaliating against individuals who exercise their rights under GINA; (3) requesting or requiring genetic information; and (4) disclosing genetic information about an individual.¹⁰⁸

Title II also includes certain provisions which mandate that any genetic information that an employer might acquire, no matter how, must be maintained on separate forms and in separate files.¹⁰⁹ Furthermore, the employer must treat any such records containing genetic information as a confidential medical record under the ADA.¹¹⁰

The enforcement of GINA and the damages a claimant might expect differ with respect to Title I and Title II. To enforce violations of Title I, GINA amends the civil enforcement provision of ERISA and adds monetary penalties for violations of the law. The penalty amount imposed for noncompliance with GINA by a group health plan or health insurance issuer is \$100 for each day in the noncompliance period with respect to each participant to whom the noncompliance relates.¹¹¹ The statute further states that a de minimis violation will incur a

¹⁰⁷ *Id.* at § 202-206. The employment decisions of (1) include the following: failing to hire or discharging an employee or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of employment; for an employment agency, by failing or refusing to refer an individual for employment; for a labor organization, by excluding or expelling a member from the organization; for an employment agency, labor organization, or joint labor-management committee, by causing or attempting to cause an employer to discriminate against a member in violation of this Act; or for an employer, labor organization, or joint labor-management committee, by discriminating against an individual in admission to, or employment in, any program established to provide apprenticeships or other training or retraining.

¹⁰⁸ *Id.* at § 202-206. There are some limited exceptions for (3) and (4) which are discussed later in Part IV.

¹⁰⁹ *Id.* at § 206(a).

¹¹⁰ *Id.*

¹¹¹ *Id.* at § 101, amendments to ERISA at 29 U.S.C.A. §1132(3)(c)(9)(B)(i).

penalty of \$2,500¹¹² and any violation considered more than de minimis will incur a penalty of \$15,000.¹¹³ Interestingly, GINA provides limitations for violations of the law that were either unknown or undiscoverable by reasonable diligence of the insurer. In such cases, the usual penalties will either not be applied or will be limited in amount.¹¹⁴

In the employment context, Title II provides the same enforcement mechanisms and monetary penalties as those provided in Title VII of the Civil Rights Act and the ADA.¹¹⁵ The remedies through GINA are therefore determined by which of those two acts would otherwise cover the claimant. Additionally, the procedure employees must follow when filing a Title VII claim applies to employee claimants under GINA—claimants must file an EEOC charge before proceeding to court, the EEOC will then investigate the claim and attempt to settle it before either suing the employer or issuing a right to sue letter to the claimant. In cases under Title VII and the ADA compensatory and punitive damages are capped at \$300,000. Thus, the same cap would apply to an employee filing a genetic discrimination claim against his or her employer. Attorneys’ fees for the prevailing party are available under 42 U.S.C. § 1988, the fee-shifting statute for civil rights claims.¹¹⁶

IV

WHY SUCH A SENSITIVE SUBJECT? ARGUMENTS SURROUNDING AND IMPLICATIONS OF GINA

The potential for the use and misuse of genetic information carries with it exceptional social, economic, and psychological concerns. The idea of “genetic exceptionalism”—that genetic information is inherently unique and should be treated with special consideration by law and policy—sheds some light as to why a piece of legislation such as GINA was the source of

¹¹² *Id.* at (9)(C)(i).

¹¹³ *Id.* at (9)(C)(ii).

¹¹⁴ *Id.* at (9)(D)(i)-(iii).

¹¹⁵ *See id.* at § 207(a)-(b).

¹¹⁶ *Id.* at (a)(2).

such heated debate in Congress.¹¹⁷ As genetic testing eventually makes its way to becoming accepted as routine medical practice, access to the unique information contained within our DNA will only increase. In planning ahead for this phenomenon, our country's lawmakers were bombarded with conflicting opinions from hundreds of different interest groups regarding this sensitive subject, and after years of negotiation, GINA was the end result.

A. Arguments and Implications in Health Insurance

It is no secret that America's current health insurance system utilizes the practice of "underwriting," in which the insurer evaluates the potential risks and exposures of applicants and customers. The purpose of this system is to enable the insurer to employ "reasonable discrimination" and base premium rates on an individual's predicted costs to the company.¹¹⁸ While this process seems logical, issues obviously arise when it comes to genetic information, with the issue being whether a health insurer should be allowed to use genetic information as one of the factors it uses to determine an individual's statistical risk.

For advocates of GINA the answer to this question is a stern "no," especially when it comes to predictive genetic tests. Not only is it inherently unfair to penalize individuals for factual data beyond their control, but it is even more unjust to penalize them for a mere prediction, where the certainty of developing a disease is less than 100%.¹¹⁹ Moreover, the consequences of allowing such a practice are dangerous to the individual and potentially

¹¹⁷ See Offit et al., *supra* note 32, at 435 (discussing genetic exceptionalism); Michael Sharp, *The Effect of Genetic Determinism and Exceptionalism on Law and Policy*, HEALTH L. REV. Spring, 1, (2007) ("As a result of genetic exceptionalism, laws and policies around the world in the areas of informed consent, privacy, patenting and discrimination, have been influenced in different ways and at varying levels.").

¹¹⁸ Shannyn C. Riba, *The Use of Genetic Information in Health Insurance: Who Will Be Helped, Who Will Be Harmed and the Possible Long-Term Effects*, 16 S. Cal. Rev. L. & Soc. Just. 469, 476 (2007).

¹¹⁹ See *Faces of Discrimination*, *supra* note 9, at 1.

economically damaging to health insurers—individuals are dissuaded from being tested and may later develop a disease, for which the cost to treat would far exceed the screening test.¹²⁰

Opponents of GINA, on the other hand argue that genetic information should be an allowable factor in risk determination. After all, the entire industry is based on insuring against unknown risk.¹²¹ Some commentators argue that if insurance companies are restricted from using underwriting for high-risk individuals with predispositions to genetic diseases, average insurance rates will increase. That in turn might dissuade low-risk individuals from purchasing health insurance, leaving only the high-risk individuals with diagnosed illness or predispositions to disease to purchase insurance. Eventually, this could lead to the collapse of the entire health insurance industry as fewer low-risk policies are purchased, rates rise, and high-risk individuals are unable to afford to their increased rates.¹²² Many critics of GINA predict that the legislation is a huge step toward the institution of universal health care in America.¹²³

Other more middle-of-the-road opponents of GINA argue that the law should only protect testing done for predictive purposes, and not diagnostic purposes. They argue that diagnostic genetic testing utilized for individuals exhibiting symptoms should not be protected as genetic information, but should be considered “health status information” which is considered for underwriting purposes.¹²⁴

¹²⁰ See Riba, *supra* note 118, at 477.

¹²¹ See Michael Kinsley, *Genetic Discrimination: Unfair or Natural?*, TIME, May 08, 2008, at 45 (“The idea to insurance is to protect against the unexpected and the unlikely. Forbidding insurers to take predictable risks into account when choosing whom to insure and how much to charge is asking them to behave irrationally and make bets they are sure to lose.”).

¹²² See Riba, *supra* note 118, at 478-80; Amy Harmon, *Congress Passes Bill to Bar Bias Based on Genes*, N.Y. TIMES, May 2, 2008 (predicting that the health insurance industry may be upended).

¹²³ See Kinsley, *supra* note 121, at 45.

¹²⁴ National Association of Health Underwriters, *NAHU Position on Genetic Testing*, available at http://www.nahu.org/government/issues/genetic_discrimination/nahu_position.htm.

It is unclear what the future of our health insurance system holds after GINA goes into effect, but what is clear is that genetic discrimination in the health insurance market is a real threat. A 1992 survey of medical directors of life insurance companies indicated that over half of those asked held the opinion that a strong family history of breast cancer was a strong enough justification to deny coverage or substantially increase rates.¹²⁵ Granted that survey was taken almost seventeen years ago, but since then, the moneysaving potential for insurance companies has only increased due to the rising number of genetic tests.

GINA crafts a solution that accommodates both sides of the health insurance argument. First, it still allows health insurance groups to continue underwriting individuals with a previously diagnosed genetic disease, for example a woman diagnosed with breast cancer. However, GINA disallows underwriting an individual who tested positive for a predisposition to a disease or who has a family history of a genetic disease. Second, GINA has certain exceptions carved into it that cut health insurers some breaks. For example, GINA contains an exception for genetic information obtained by an insurer *incidentally* to a request, requirement, or purchase for other health related information. In such a case, the insurer would not be in violation of the law for obtaining such information, but is still prohibited from requesting, requiring, or purchasing such information prior to an individual's enrollment.¹²⁶ Third, GINA contains a research exception, in which an insurer "may request, but not require" that a customer undergo a genetic test, provided certain conditions are met, including that the request is in writing, compliance is voluntary, and non-compliance will not have an effect on the individual's enrollment status or

¹²⁵ See JE McEwan et al., *A Survey of State Insurance Commissioners Concerning Genetic Testing and Life Insurance*, AM. J. HUM. GENET. 51, 785-792 (1992).

¹²⁶ See GINA, *supra* note 5, at § 101, amendment to ERISA at § 702(d)(2)-(3).

rates.¹²⁷ Whether or not the accommodations made for the insurers in GINA will enable the law to provide adequate protection from genetic discrimination in the insurance market, only time will tell.

B. Arguments and Implications in Employment Practices

To many business owners and executives, it may seem like a rational business move to obtain medical information, including genetic information, about ones employees, especially when those employees are provided with health insurance on their employers' dime. GINA's advocates argue that if employers have unlimited access to their employee's genetic information, genetic discrimination will undeniably occur, and, in fact, it has. Instances of genetic discrimination in employment practices have been more prevalent than in the insurance context, examples of which are seen in the *Norman-Bloodsaw* and *Burlington Northern* cases discussed above.¹²⁸ The consequences resulting from employment discrimination are even more frightening than those resulting from insurance discrimination, because there is a potential that employees may lose their very livelihood, not just their insurance coverage. Just as in the insurance context, this fear factor may prevent those employees from taking preventative genetic tests with life-saving potential.¹²⁹

Moreover, the arguments of privacy and fairness again come into play—employees are entitled to the protection of their privacy, and genetic tests are not always certainties. Furthermore, many genetic tests develop slowly over time, allowing employees to continue working for years after diagnosis or prediction. If employers limit their employees due to the existence or prediction of a genetic disease, the employer risks missing out on the contributions

¹²⁷ *Id.* at § 101, amendments to ERISA at § 702(c)(4).

¹²⁸ *See infra* Part II.A.

¹²⁹ *See Faces of Discrimination, supra* note 9, at 1.

and innovations an employee could have made during the remaining useful years of his or her employment.¹³⁰

On the other side, employers arguing for access to the genetic information of their employees have a variety of reasons for doing so. For one, employers argue that such information is necessary to protect their employees, particularly in hazardous working environments.¹³¹ In such cases, employers may have a vested interest in monitoring the health of their employees to protect those particular employees with diseases or conditions, as well as those around them.

Furthermore, some commentators argue that GINA could potentially act as a Pandora's box, rife with opportunities for employees to initiate litigation against them.¹³² For example, the new law's definition of "genetic information" includes "the manifestation of a disease or disorder in family members" of individuals.¹³³ Under that broad definition, if an employee mentioned a family history of alcoholism to their employer or had to take leave to care for a bloodline family member with cancer, an employer could face a potential lawsuit from that employee if a detrimental employment decision was made.¹³⁴ As a consequence of employers' increased vulnerability to litigation, critics of GINA argue that the law may even backfire and make job candidates with genetic diseases more difficult to employ, because employers will fear lawsuits.¹³⁵

¹³⁰ See Susannah Carr, *Invisible Actors: Genetic Testing and Genetic Discrimination in the Workplace*, 30 U. ARK. LITTLE ROCK L. REV. 1, 4 (2007).

¹³¹ *Id.* at 2.

¹³² See McGowan, *supra* note 85.

¹³³ See *supra* notes 100-101 and accompanying text.

¹³⁴ See McGowan, *supra* note 85.

¹³⁵ Letter from the Genetic Information Nondiscrimination in Employment Coalition (GINE) to a Senator, January 23, 2007, available at http://www.nam.org/~media/Files/s_nam/docs/238200/238195.pdf.ashx.

Other concerns expressed by employers include the excessive compensatory and punitive damages available under GINA, the difficulty for employers in distinguishing between medical and genetic information records for recordkeeping purposes, and the fact that GINA does not create one federal standard by preempting state laws, making administration of the law complicated for multi-state employers.¹³⁶

Again, GINA's solution to solving genetic discrimination in the employment context made concessions for employers by including certain exceptions in Title II.¹³⁷ For example, GINA includes an exemption for genetic information obtained by employers under the Family and Medical Leave Act processes.¹³⁸ Additionally, there are exceptions for genetic information obtained inadvertently by the employer or where the employee provided prior, knowing, voluntary, and written authorization, among others.¹³⁹ As with Title I of GINA, only time will tell if GINA will provide adequate protection from genetic discrimination in the workplace, despite the exceptions made by its lawmakers, or if there are too many holes in the law for employers to navigate around. Regardless, the enactment of GINA is a huge step in the right direction to safeguarding our genetic information in both the employment and health insurance context. Most importantly, GINA came at the perfect time before genetic discrimination became routine practice in our society.

C. What's Missing From GINA?

Despite undergoing thirteen years of negotiations and amendments, GINA is still missing certain protections and, therefore, does not have the securities that many of the law's supporters had originally hoped for. Specifically, GINA does not apply to members of the military, nor

¹³⁶ *Id.* at 1-2.

¹³⁷ *See generally* GINA, *supra* note 5, at §202(b)(1)-(5).

¹³⁸ *Id.* at § 202(b)(3).

¹³⁹ *Id.* at §202(b)(1), (2).

does it apply to life, disability, and long-term care insurance. Commentators acknowledge that this was not merely a case of oversight;¹⁴⁰ rather, it is speculated that lawmakers made a strategic decision not to include those three insurance markets in GINA, as they are too distinct from the health insurance market.¹⁴¹

Another missing piece of the puzzle is that GINA does not mandate insurance coverage for any particular genetic test or treatment. A logical argument can be made that there are actually potential economic benefits for health insurers to cover the costs of preventative genetic tests because the cost of treating a disease later, if it goes undetected and manifests, would be much greater than the preemptive screening test.¹⁴²

Finally, many commentators are disappointed that GINA still allows health insurers to base coverage and rate determinations on an individual's current genetic health status—in other words, those that have been previously diagnosed with a genetic disease are not protected.¹⁴³ This extra degree of protection was not included in GINA for two reasons.¹⁴⁴ First, it is predicted that the addition of such a provision in GINA would have turned the current health insurance market upside-down. As discussed above, health insurance companies operate on their ability to underwrite according to the risk classifications, of which the existence of a previously diagnosed disease is certainly a factor.¹⁴⁵ Second, such a provision would raise an ethical

¹⁴⁰ See Kathy L. Hudson et al., *Keeping Pace with the Times – The Genetic Information Nondiscrimination Act of 2008*, 358 NEW ENG. J. OF MED. 25, 2661, 2663 (2008).

¹⁴¹ *Id.*

¹⁴² See Riba, *supra* note 118, at 477.

¹⁴³ See Hudson, *supra* note 140, at 2662-63.

¹⁴⁴ *Id.* at 2663

¹⁴⁵ *Id.*

question regarding whether those with genetic diseases should be given more protection than those with nongenetic diseases.¹⁴⁶

V CONCLUSION

Despite taking thirteen years to pass, the benefits and protections provided by GINA certainly were worth the wait. In fact, many of GINA's biggest supporters regard its long fought battle as a blessing in disguise because it educated both our nation's lawmakers and the public about the dangers of genetic discrimination.¹⁴⁷ Furthermore, it alerted them to the fact that genetic information requires special treatment if we are to continue using it to advance toward the goal of a more personalized health care system. While ultimately, GINA could not gratify every special interest, lawmakers were no doubt satisfied with the passage of a comprehensive federal standard that protects our valued privacy and restores the balance of fairness in the insurance and employment contexts for those that may not have inherited the perfect genes.

¹⁴⁶ *Id.*

¹⁴⁷ *Id.* at 2662.