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## COMMENTS

# MAY AN EMPLOYER REQUIRE EMPLOYEES TO WEAR “GENES” IN THE WORKPLACE? AN EXPLORATION OF TITLE II OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

ERIN MURPHY HILLSTROM\*

### I. INTRODUCTION

On May 21, 2008, President George W. Bush signed into law the Genetic Information Nondiscrimination Act of 2008 (“GINA”).<sup>1</sup> This law became effective almost seven years after President Bush stated, before the nation, that genetic discrimination is “unfair to workers” and it “violates our country’s belief in equal treatment.”<sup>2</sup> GINA is federal legislation that was enacted to address genetic discrimination<sup>3</sup> by preventing

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\* I want to thank all of the members of The Journal of Computer and Information Law for assisting me with the editing process, especially Erica Bertini. I would also like to thank my family for supporting and encouraging me, especially my sister Ellen Murphy. Finally, I would like to dedicate this comment to my husband Eric.

1. Coalition for Genetic Fairness, *President Bush Signs Landmark Genetic Nondiscrimination Information Act Into Law*, [http://www.geneticfairness.org/action\\_alert11.html](http://www.geneticfairness.org/action_alert11.html) (last visited Sept. 30, 2008) [hereinafter *President Signs GINA*].

2. President George W. Bush, Presidential Radio Address to the Nation (June 23, 2001), available at <http://www.whitehouse.gov/news/releases/2001/06/20010623.html>. In his radio address to the nation, President Bush stated:

[g]enetic discrimination is unfair to workers and their families. It is unjustified—among other reasons, because it involves little more than medical speculation. A genetic predisposition toward cancer or heart disease does not mean the condition will develop. To deny employment or insurance to a healthy person based only on a predisposition violates our country’s belief in equal treatment and individual merit. *Id.*

3. *President Signs GINA*, *supra* note 1; but see The Equal Employment Opportunity Commission (“EEOC”), *Facts About the ADA: Americans with Disabilities Act*, <http://www.eeoc.gov/facts/fs-ada.html> (last visited Nov. 26, 2008) [hereinafter *Facts About the ADA*]

health insurance providers and employers from discriminating against individuals based on genetic information.<sup>4</sup> Title I of GINA, which addresses health insurance providers, went into effect May 2008 and Title II, which addresses employers, went into effect November 2009.<sup>5</sup>

GINA protects the health of individuals by ensuring that those who take genetic tests will not be discriminated against by employers and health care providers.<sup>6</sup> GINA makes it illegal for health care providers and employers to discriminate against individuals based on their genetic information.<sup>7</sup> More specifically, under Title I of GINA, group health plan and health insurance issuers “shall not request, require, or purchase genetic information with respect to any individual prior to such individual’s enrollment under the plan or coverage in connection with such enrollment.”<sup>8</sup> Title II of GINA prohibits an employer from requesting that either prospective or current employees undergo genetic testing and prohibits an employer from using genetic test results in making promotional or hiring decisions.<sup>9</sup>

This comment will focus on the employer provisions of GINA, as set forth under Title II of the act.<sup>10</sup> Congress’ purpose in enacting GINA

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(discussing the proper use of medical examinations offering an inference that genetic testing is a type of medical examination, and therefore covered under the Americans with Disabilities Act of 1990 (“ADA”)); National Human Genome Research Inst., *Existing Federal Anti-Discrimination Laws and How They Apply to Genetics*, <http://www.genome.gov/12513979> (last visited Nov. 26, 2008) [hereinafter *Existing Federal Laws*] (noting that an argument can be made that genetic discrimination is prevented under Title VII of the Civil Rights Act of 1964 (“Title VII”) where an employer discriminates against an employee based on a genetic trait that is substantially linked to a race or ethnic group).

4. H.R. 493, 110th Cong. § 2 (2008); see also *President Signs GINA*, *supra* note 1.

5. *Id.*

6. Coalition for Genetic Fairness, *Current Status of GINA*, [http://www.geneticfairness.org/ginaresource\\_history.html#2](http://www.geneticfairness.org/ginaresource_history.html#2) (last visited Oct. 5, 2008) [hereinafter *Current Status of GINA*].

7. *Id.*

8. H.R. 493, 110th Cong. § 101(d)(2) (2008); see also Genetic Alliance, *How Does GINA Impact Me?*, <http://www.geneticalliance.org/ginaresource.impact> (last visited Oct. 29, 2008) [hereinafter *How Does Gina Impact Me?*] (noting that The Genetic Information Nondiscrimination Act of 2008 (“GINA”) prohibits both group and individual health insurance companies from “requesting or requiring” genetic testing of an individual or her family members or relying on genetic information to determine eligibility for coverage or setting premiums).

9. H.R. 493, 110th Cong. § 202 (2008) (citing those employer practices that are prohibited under Title II of GINA); see also *How Does GINA Impact Me?*, *supra* note 8. GINA prevents labor organizations and employment agencies from discriminating against individuals based on their genetic makeup. *Id.* Additionally, employers cannot make decisions regarding an individual’s acceptance into an employee training program based on the individual’s genetic makeup. *Id.*

10. This comment focuses solely on the employer provisions of GINA. While GINA prevents genetic discrimination in general, there are two distinct areas of application: employer provisions and health insurance provisions. The health insurance provisions are

was to eliminate an individual's fear of genetic discrimination and to encourage individuals to undergo genetic testing.<sup>11</sup> While there is a legitimate purpose for Congress to encourage individuals to undergo genetic testing, Congress acted prematurely by passing a statute directly focusing on genetic discrimination before a court had an opportunity to interpret whether current federal law would have adequately prevented genetic discrimination.

As an illustration of how genetic discrimination may occur in the workplace, consider the following hypothetical. Jean, a thirty-year-old woman revealed to a fellow employee that she had a family history of Huntington's disease.<sup>12</sup> Soon after her employer discovered this information, Jean received a series of negative job reviews, despite a history

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outside the scope of this comment. See Coalition for Genetic Fairness, *Current Status of GINA*, <http://www.geneticfairness.org/act.html> (last visited Oct. 5, 2008) (noting that there were two purposes for enacting GINA; first, to prevent health insurance providers from discriminating against an individual based on genetic information and second, to prevent employers from discriminating against employees in regards to their terms of employment based on genetic information).

11. See The Library of Congress, *Summary of the Genetic Nondiscrimination Act of 2008*, <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@L&summ2=M&> (last visited Nov. 5, 2008); see also Exec. Order No. 13,145, 65 Fed. Reg. 6877 (2000) (noting that there are limitations on the federal government prohibiting disability-related inquiries and medical examinations of government employees under the ADA); see also H.R. 493, 110th Cong. § 2 (2008) (citing findings and purposes for enacting GINA).

12. See Council for Responsible Genetics, *Genetic Discrimination: A Position Paper*, available at <http://www.councilforresponsiblegenetics.org/ViewPage.aspx?pageId=85> [hereinafter Council for Responsible Genetics]; see also National Nat'l Institute Inst. of Neurological Disorders and Stroke ("NINDS"), *Huntington Disease Information Page*, available at <http://www.ninds.nih.gov/disorders/huntington/huntington.htm> [hereinafter Huntington's Disease].

Huntington's disease ("HD") is a result of, "genetically programmed degeneration of brain cells, called neurons, in certain areas of the brain." *Id.* This degeneration can cause, "uncontrolled movements, loss of intellectual faculties, and emotional disturbance." *Id.* HD is a disease passed down to a child from his parents through a mutated gene. *Id.* Every child that has an HD parent has a fifty percent (50%) likelihood of inheriting this gene. *Id.* If a child with an HD parent does not inherit the mutated gene linked to HD, she will not develop HD and will not pass the defective gene on to one of her children or any subsequent generations. *Id.* Additionally, "whether one child inherits the gene has no bearing on whether others will or will not inherit the gene." *Id.* Every single person with the mutated HD gene will develop HD sooner or later. *Id.* Early symptoms of HD include, "mood swings, depression, irritability or trouble driving, learning new things, remembering a fact, or making a decision." *Id.* HD is diagnosed by a conducting a genetic test, laboratory and neurological tests, and family medical history. *Id.* There is no way to reverse the effects of HD once the disease has manifested. *Id.* See also J.F. Gusella et al., *A Polymorphic DNA Marker Genetically Linked to Huntington's Disease*, 306 NATURE 234, 234-38 (1983) (noting that the gene mutation that causes Huntington's disease is located in the tip of chromosome four); see also Brian R. Gin, *Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act*, 97 COLUM L. REV. 1406, 1414 (1997) (noting that the discovery of the genetic mutation that causes Huntington's disease was hailed as one of the

of good performance evaluations and promotions.<sup>13</sup> Jean was later fired, and subsequently learned that she had been fired because her employer expressed concerns about Jean developing Huntington's disease.<sup>14</sup> The employer did not want to continue to train Jean as an employee if she would leave the workforce prematurely because of her predisposition for developing Huntington's disease.<sup>15</sup>

This hypothetical illustrates one way an employer could discriminate against an employee based on her genetic information. There is a real threat that an employer may use an individual's genetic test results against an employee.<sup>16</sup> Therefore, Congress enacted GINA with the intention of providing individuals with a minimum level of protection from their employers' misuse of their genetic information.<sup>17</sup> Because the provisions of GINA are confusing, however, GINA will not have the intended effect of sufficiently preventing genetic discrimination. GINA's broad definitions and provisions frustrate compliance, and will cause a surge in litigation.<sup>18</sup>

It is important for employers to note that the employer provisions of GINA took effect on November 21, 2009. Taking the mandatory steps to ensure that employers are in compliance will reduce an employer's exposure to potential litigation by employees for violations of GINA. Additionally, ensuring that an employer is in compliance with the law could afford the employer a good faith argument if an employee files a claim against the employer for violating GINA.

As previously stated, GINA was enacted prematurely. GINA is problematic because Congress enacted GINA before a court was afforded an opportunity to decide whether employees asserting claims of genetic

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very first successes in the process of mapping the human genome, and led to an expansion in genetic research).

13. See Tara L Rachinsky, *Genetic Testing Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace*, 2 U. PA. J. LAB. & EMP. L. 575, 576 (2000).

14. *Id.*

15. *Id.*; see also Nat'l Partnership for Women & Families, *Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People* (July 2004), available at [http://www.geneticalliance.org/ksc\\_assets/documents/facesofgeneticdiscrimination.pdf](http://www.geneticalliance.org/ksc_assets/documents/facesofgeneticdiscrimination.pdf) (noting that many employees potentially lost out on the benefits of early detection and preventative health care measures because of their fear of genetic discrimination) [hereinafter *Faces of Genetic Discrimination*].

16. See Rachinsky, *supra* note 13 at 582 (noting, for example, an employer could research genetic diseases, make a determination on which diseases cost the most in terms of health coverage and time away from the job, screen applicants for a predisposition for the disease, and refuse to hire those individuals with a higher predisposition); see also *Faces of Genetic Discrimination*, *supra* note 15.

17. See The Library of Congress, *supra* note 11.

18. See Kevin P. McGowan, *Employer Advocates Remain Wary of New Bias Law's Potential Effects*, [May] Daily Lab. Rep., (BNA) at C-1 (May 22, 2008), available at <http://elawcenter.bna.com/pic2/em.nsf/id/BNAP-7KMKU9?OpenDocument>.

discrimination could have been afforded redress under other federal laws. Other federal laws, such as Title VII of the Civil Rights Act of 1964 (“Title VII”) and the American’s With Disabilities Act of 1990 (“ADA”), could have been relied upon by the courts to redress cases in which employees alleged genetic discrimination.<sup>19</sup> Because these statutes already afforded adequate protection, GINA will cause compliance issues for employers and because GINA affords an employee a new right of action, GINA will also increase litigation.<sup>20</sup> Therefore, it is important to note that this comment should not be construed as adopting an opinion counter to the realization of the important policy goals of protecting individuals from discrimination based on their genetic information, and affording redress to those who have been discriminated against. However, GINA is both premature and insufficient to adequately ensure that these goals are met.

In terms of realizing human longevity, genetic testing is one of the greatest accomplishments of the new century.<sup>21</sup> This comment will first provide a brief discussion of genetics and genetic testing. Section II of this comment will provide a basic introduction on genetics, genetic testing, and genetic discrimination. Additionally, Section II will provide a brief overview of current federal laws that address genetic discrimination in the workplace. Finally, Section II will examine the major employment provisions of GINA.

Section III of this comment will examine whether there was a need for GINA, and will argue that GINA will not have the full effect intended by Congress. The major sources of litigation under GINA will then be reviewed based on the articulated issues. With these potential sources of litigation in mind, Section III will suggest to employers necessary steps that should be taken to ensure that the employer is in compliance with the provisions of GINA. Finally, Section III will examine some of the public-policy concerns legislators should keep in mind when they revisit and amend GINA in the future. Section IV will provide a brief conclusion.

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19. See 42 U.S.C. § 2000(e)(2) (1990); *Facts About the ADA*, *supra* note 3; see generally 42 U.S.C. § 12101 (2008).

20. See McGowan, *supra* note 18.

21. See Press Release, Snowe Calls for Passage of Genetics Nondiscrimination Bill: Gina is the “first civil rights act of the 21st century” (April 22, 2008), available at [http://snowe.senate.gov/public/index.cfm?FuseAction=PressRoom.PressReleases&ContentRecord\\_id=77c1bf5a-802a-23ad-4efb-6f1fbc897ab0&IsPrint=true](http://snowe.senate.gov/public/index.cfm?FuseAction=PressRoom.PressReleases&ContentRecord_id=77c1bf5a-802a-23ad-4efb-6f1fbc897ab0&IsPrint=true) [hereinafter *Snowe*]. It is important to note that this comment should not be construed as adopting an opinion counter to the realization of the important policy goals of protecting individuals from discrimination based on their genetic information and affording those who have been discriminated against with redress.

## II. BACKGROUND

To understand GINA, it is important to have some background knowledge on genetics. Therefore, the first part of this section provides basic information on genetics, genetic testing, and genetic discrimination. The second part of this section explores the specific provisions of GINA and Congress' intent in enacting the legislation. The third part of this section lists current federal laws that have been enacted to address workplace discrimination. The final part of this section outlines the employer provisions of GINA, as set forth under Title II.

### A. PRIMER ON GENETICS

Genes are the building blocks of human beings, and function as the human body's blueprint.<sup>22</sup> This blueprint is designed by the unique set of genes each individual inherits from their mother and father.<sup>23</sup> These genes determine an individual's physical characteristics, such as eye and hair color. However, genes also determine characteristics which cannot be seen with the human eye, such as whether an individual is susceptible to developing a certain genetic disease later in life, including heart disease or cancer.<sup>24</sup> Every human being has a unique genetic code; no two people have the same genetic information.<sup>25</sup>

#### 1. *Genetic Information*

To understand what a genetic test is, it is helpful to understand the basics of genetic information. "Genetic information is contained in the DNA of every living organism."<sup>26</sup> According to Microsoft Encarta:

Genes are composed of segments of deoxyribonucleic acid ["DNA"], a molecule that forms the long, threadlike structures called chromosomes. The information encoded within the DNA structure of a gene directs the manufacture of proteins, molecular workhorses that carry

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22. Christine Formas Norris, *The Genetic Information Nondiscrimination Act of 2008: History, Successes and Future Considerations*, 7 U. MD. L.J. RACE, RELIGION, GENDER & CLASS 192, 193 (2007).

23. See Kids Health, *What is a Gene?*, [http://kidshealth.org/kid/talk/qa/what\\_is\\_gene.html](http://kidshealth.org/kid/talk/qa/what_is_gene.html) (last visited Nov. 1, 2008).

24. Anthro Limited, *Inheriting Eye Color*, <http://www.athro.com/evo/gen/genefr2.html> (last visited Oct. 30, 2008); see also *Faces of Genetic Discrimination*, *supra* note 15 (stating that, "a genetic predisposition to heart disease or cancer does not mean that the condition will develop").

25. KRISTINE BARLOW-STEWART, *THE AUSTRALASIAN GENETICS RESOURCE BOOK 1-4* (6th ed. 2007), available at [http://www.whoisyourcreator.com/assets/PDF%27s/Changes-ToTheGenetic\\_Code.pdf](http://www.whoisyourcreator.com/assets/PDF%27s/Changes-ToTheGenetic_Code.pdf).

26. See Rivka Jungreis, *Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act of 2005 and Public Fears About Genetic Information*, 15 J.L. & POL'Y 211, 213 (2007) (stating each strand of DNA is composed of two- paired strands of nucleotides which are twisted together into a double- helical structure).

out all life-supporting activities within a cell. DNA is the genetic material of all cellular organisms and most viruses. A molecule of DNA consists of two *chains*, strands composed of a large number of chemical compounds, called nucleotides, linked together to form a chain. These chains are arranged like a ladder that has been twisted into the shape of a winding staircase, called a double helix. Human genes reside on 23 pairs of chromosomes found in the nucleus of every cell in the body except gamete cells called genomes.<sup>27</sup>

Human DNA is sorted into twenty-three matched sets of chromosomes that direct the cell to perform a specific function.<sup>28</sup> It is estimated that humans have between thirty-two and thirty-five thousand genes.<sup>29</sup> Ninety-nine point nine percent (99.9%) of the human genome is exactly the same in all human beings.<sup>30</sup> The remaining one-tenth of a percent (.1%) is what makes each individual unique.<sup>31</sup> The genes that differ between each human being help to account for the various ways an individual will respond to an infection, disease, toxins, chemicals, and drug therapies.<sup>32</sup>

## 2. Genetic Testing

An individual's unique genes are important to geneticists who rely on large genetic databases for their research.<sup>33</sup> In order for geneticists to collect genetic information, an individual must undergo a genetic test.<sup>34</sup> Genetic testing involves any technique that analyzes human DNA or proteins.<sup>35</sup> Healthcare providers have historically used genetic tests as a

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27. Microsoft Encarta Online Encyclopedia, *Deoxyribonucleic Acid*, [http://encarta.msn.com/encyclopedia\\_761561874/Deoxyribonucleic\\_Acid.html](http://encarta.msn.com/encyclopedia_761561874/Deoxyribonucleic_Acid.html) (last visited Sept. 9, 2009).

28. Jungreis, *supra* note 26 at 213.

29. Electronic Privacy Information Center, *Genetic Privacy*, <http://epic.org/privacy/genetic> (last visited Oct. 20, 2008) [hereinafter *Genetic Privacy*].

30. *Id.*

31. *Id.*; see also BARLOW-STEWART, *supra* note 25 (explaining that a genetic test is used in order to determine what small variants make an individual unique).

32. *Genetic Privacy*, *supra* note 29 (explaining only identical twins, triplets, etc. have identical DNA).

33. See Council for Responsible Genetics, *supra* note 12.

34. See Genetics Home Reference, *What is a genetic testing?*, <http://ghr.nlm.nih.gov/handbook/testing/geneticstesting> (last visited Sept. 9, 2009).

35. Genetics Home Reference, *What is DNA?*, <http://ghr.nlm.nih.gov/handbook/basics/dna> (last visited Oct. 29, 2008); Genetics Home Reference, *What are Proteins?*, <http://ghr.nlm.nih.gov/handbook/howgeneswork/protein> (last visited Oct. 29, 2008). Proteins are large complex molecules that perform critical roles in the body. *Id.* Proteins perform the majority of the work in a cell and "are required for the structure, function, and regulation of the body's tissues and organs." *Id.* Proteins are composed of "hundreds or thousands of smaller units called amino acids, which are attached to one another in long chains." *Id.* There are, "twenty different types of amino acids that can be combined to make a protein. *Id.* The sequence of amino acids determines each protein's unique three-dimensional structure and its specific function." *Id.*; See also National Institute of Health, *Promoting Safe*

tool to detect gene variations associated with a specific disease or health condition, and for non-diagnostic matters such as paternity testing and forensic science.<sup>36</sup> Uses of genetic tests include: early detection of genetic diseases in fetuses; determining whether parents pose a risk of passing a mutated gene to their child; discovery of genetic diseases before symptoms of the disease develop; or confirmation of a doctor's diagnosis of a genetic disease before an individual has developed symptoms.<sup>37</sup>

A genetic test encapsulates any alterations in an individual's genes by looking at changes in the level of key proteins coded for by specific genes.<sup>38</sup> If an abnormality is detected, the gene is flagged, and could be evidence that an individual has an inherited disorder.<sup>39</sup> Currently, there are tests available to diagnose thousands of different diseases.<sup>40</sup> Three main types of genetic tests currently relied upon by geneticists are

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*and Effective Genetic Testing in the United States: Final Report of the Task Force on Genetic Testing*, <http://www.genome.gov/10002393> (last visited Sept. 9, 2009) [hereinafter *Safe and Effective Testing*]. The analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect inheritable disease-related genotypes, mutations, phenotypes, or karyotypes for clinical purposes. *Id.* Such purposes include predicting risk of disease, identifying carriers, and establishing prenatal and clinical diagnosis or prognosis. *Id.* Prenatal, newborn, and carrier screening, as well as testing in high risk families, are included. *Id.*

36. National Human Genome Research Institute, *Genetic Testing*, <http://www.genome.gov/10002335> (last visited Oct. 29, 2008) [hereinafter *NHGRI Genetic Testing*].

37. Medline Plus, *Genetic Testing*, <http://www.nlm.nih.gov/medlineplus/genetictesting.html> (last visited Sept. 24, 2008).

38. National Human Genome Research Institute, *A Brief Primer on Genetic Testing*, <http://www.genome.gov/10506784> (last visited Sept. 9, 2009). There are three different types of genetic tests gene tests, chromosomal test, and biochemical tests. *Id.* A gene test looks at a DNA sample from an individual's blood, bodily fluid, or tissues, and assesses the sample for any large changes such as a missing section, a gene with too many copies, an overactive gene, or an altered chemical base. *Id.* A chromosomal test centers on the structure of the nucleus of a cell containing DNA. *Id.* This test looks for any chromosomes that have been switched or that are located in the wrong position. *Id.* Finally, a biochemical test looks at the level of key proteins to determine whether or not a gene is functioning properly. *Id.*

39. National Human Genome Research Institute, *Frequently Asked Questions About Genetic Testing*, <http://www.genome.gov/19516567> (last visited Sept. 9, 2009).

40. *Faces of Genetic Discrimination*, *supra* note 15 (stating scientists have identified genetic markers for cancer, diabetes, Alzheimer's disease, Huntington's disease, cystic fibrosis, and thousands of others); *See also The Potential for Discrimination in Health Insurance Based on Predictive Genetic Test: Hearing Before the Subcomm. on Commerce, Trade and Consumer Protection of the H. Comm. on Energy and Commerce*, 107th Cong. (2001), available at <http://www.geneticalliance.org/PDF/GAtestimony.pdf> (publishing the testimony of Mary E. Davidson, Executive Director, Genetic Alliance); National Institute of Health Consensus Development Program, *Genetic Testing For Cystic Fibrosis*, <http://www.nih.gov/news/pr/apr97/nihod-09.htm> (last visited Nov. 8, 2008); Associated Press, *Discovery Could ID Diabetes-Risk Kids*, <http://www.khccgroup.com/item.php?IID=16> (last visited Sept. 8, 2009).

diagnostic, predictive, and carrier tests.<sup>41</sup>

A person, who shows signs or symptoms of a genetic disease, can undergo a diagnostic test in order to confirm a diagnosis of a particular disease.<sup>42</sup> Diagnostic tests can be performed before birth or at any time during an individual's life.<sup>43</sup> Likewise, a predictive test determines if an individual has a higher probability of developing a disease before symptoms of a disease are present.<sup>44</sup> A predictive test reveals diseases such as breast cancer, colorectal cancer, and polyps.<sup>45</sup> If parents are concerned about passing on inherited disorders, they could undergo a carrier test.<sup>46</sup> A carrier test can determine whether an individual is a carrier of certain defective genes that could be passed on to their children.<sup>47</sup> Diseases such as Huntington's disease, Tay-Sachs, and Cystic Fibrosis can be detected by carrier tests.<sup>48</sup>

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41. *NHGRI Genetic Testing*, *supra* note 36.

42. *Id.*

43. Genetics Home Reference, *What are the Types of Genetic Tests?*, <http://ghr.nlm.nih.gov/handbook/testing/uses> (last visited Nov. 21, 2008).

44. *NHGRI Genetic Testing*, *supra* note 36.

45. Myriad, *Understanding Inherited Breast and Ovarian Cancer*, <http://www.myriadtests.com/brac.htm> (last visited Sept. 29, 2008). Each year approximately 200,000 women are diagnosed with breast cancer and 25,000 women with ovarian cancer. *Id.* Of these cases, approximately ten percent (10%) are due to hereditary genetic predispositions. *Id.* Women of the Ashkenazi or Eastern European Jewish ancestry are at higher risk of carrying this genetic mutation. *Id.* Of the 30,000 genes that we inherit from our parents, the BRCA-1 and BRCA-2 genes prevent a woman from developing breast cancer. *Id.* In some cases, a mutation or alteration occurs to this gene causing an individual to be more susceptible to developing breast cancer. *Id.*

46. *NHGRI Genetic Testing*, *supra* note 36.

47. *Id.*

48. Huntington's Disease, *supra* note 12; National Institute of Neurological Disorders and Stroke ("NINDS"), *Tay-Sachs Disease Information Page*, <http://www.ninds.nih.gov/disorders/taysachs/taysachs.htm> (last visited Nov. 16, 2008) [hereinafter *Tay-Sachs*]. Tay-Sachs disease is a "fatal genetic lipid storage disorder in which harmful quantities of a fatty substance called *ganglioside* G<sub>M2</sub> build up in tissues and nerve cells in the brain." *Id.* This process is caused by "insufficient activity of an enzyme called *beta-hexosaminidase A* that catalyzes the biodegradation of acidic fatty materials known as *gangliosides*." *Id.* Gangliosides are "made and biodegraded rapidly in early life as the brain develops." *Id.* An infant that has Tay-Sachs disease will appear normal in the beginning of his developmental stage. *Id.* However, "as nerve cells become distended with fatty material, a relentless deterioration of mental and physical abilities occurs including deafness, blindness, and an inability to swallow." *Id.* Tay-Sachs also causes muscles to atrophy, causing the infant to become paralyzed. *Id.* Tay-Sachs can also develop later on in life in patients in their early twenties and thirties. *Id.* Patients developing Tay-Sachs later in life often experience gait and neurological deterioration. Additionally, individuals with Tay-Sachs usually have "cherry-red" spots in their eyes. *Id.* Tay-Sachs can be identified by a blood test that measures an individual's level of beta-hexosaminidase A activity. *Id.* In order for an individual to have Tay-Sachs disease, both of her parents must carry the mutated gene. *Id.* If both parents are carriers of the mutated gene, there is a twenty-five percent (25%) chance that their child will have Tay-Sachs. *Id.* There is currently no treatment for Tay-Sachs.

The results of genetic tests are also utilized by geneticists to develop the individualized medicine industry.<sup>49</sup> The development of the individual medicine industry is made possible by the newest form of genetic testing: *pharmacogenomic testing*.<sup>50</sup> This type of test determines how drugs move through the body and are broken down into particles that the body can absorb.<sup>51</sup> In the future, genetic testing could be used to specifically tailor drug treatments to each individual person, ensuring each individual receives the right amount of medicine to treat a disease.<sup>52</sup>

With advancements in genetic testing over the past few years, the price of undergoing a genetic test has fallen dramatically.<sup>53</sup> There are now direct-to-consumer kits that will scrutinize over six billion points of your genetic makeup for around \$1,000.<sup>54</sup> If more than one family member participates, the genetic test could show inherited traits such as athletic endurance or bitter taste blindness.<sup>55</sup>

### 3. Genetic Discrimination

Since the completion of the Human Genome Project in 2000, researchers have been concerned about genetic discrimination.<sup>56</sup> An individual who chooses to undergo genetic testing makes a decision not only to dis-

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*Id.* Even with current medical advancements, children diagnosed with Tay-Sachs usually die by age four as a result of recurring infection. *Id.*; see also The American College of Obstetricians and Gynecology, *Cystic Fibrosis Carrier Testing: The Decision is Yours*, [http://www.acog.org/from\\_home/wellness/cf001.htm](http://www.acog.org/from_home/wellness/cf001.htm) (last visited Nov. 8, 2008) [hereinafter *Cystic Fibrosis*]. The purpose of carrier testing for cystic fibrosis is to allow a couple to determine whether they have an increased chance of giving birth to a child who will suffer from this disease. *Id.* Cystic fibrosis is a double-impaired genetic disease. *Id.* This means that in order for a child to inherit the genetic disorder, both parents have to be a carrier of a mutated or altered gene. *Id.* Carrier testing for cystic fibrosis is conducted on a sample of either saliva or blood from the couple. *Id.* While there is nothing that can be done in the prenatal stage to treat or cure this disease in the fetus, and later the child, the purpose of the test is to prepare couples to care for a child who will require special health care needs. *Id.*

49. Council for Responsible Genetics, *supra* note 12.

50. National Institute of Health: Department of Health and Human Services NIH Publication # 07- 6283 (Aug. 2007), available at <http://www.genome.gov/Pages/Health/PatientsPublicInfo/GeneticTestingWhatItMeansForYourHealth.pdf> [hereinafter *NIH Publication*].

51. *Id.*

52. *Id.*

53. Matt Ransford, *Genetic Testing: Cheaper, Easier* (Apr. 24, 2004), available at <http://www.popsci.com/scitech/article/2008-04/genetic-testing-cheaper-easier>.

54. Thomas Goetz, *23AndMe Will Decode Your DNA for \$1,000. Welcome to the Age of Genomics*, *WIRED*, Nov. 17, 2007, at 256, available at [http://www.wired.com/medtech/genetics/magazine/15-12/ff\\_genomics](http://www.wired.com/medtech/genetics/magazine/15-12/ff_genomics).

55. *Id.*

56. See Genetic Discrimination in Health Insurance, *What is the Issue?*, <http://www.genome.gov/10002328> (last visited Oct. 28, 2008).

close private medical information about himself, but also about every other person who shares his genetic makeup.<sup>57</sup> This fear has led some individuals to forgo genetic testing in order to prevent being discriminated against by their health insurance provider and employer.<sup>58</sup> A 2007 survey, conducted by the Genetics and Public Policy Center, found that ninety-two percent (92%) of the respondents were concerned that genetic tests that revealed a risk of developing future disease could be used against them by their employers and health care providers.<sup>59</sup> The survey reported that most respondents were concerned that their genetic information would be used to deny them employment.<sup>60</sup>

If individuals are concerned about genetic discrimination, they can meet with a genetic counselor who will discuss with them the benefits and drawbacks of undergoing genetic testing.<sup>61</sup> Genetic counseling, a service that usually accompanies a genetic test, involves a genetic counselor who informs an individual of the risks associated with undergoing a genetic test.<sup>62</sup> A genetic counselor's role is to provide an individual with the realistic outcomes of receiving a positive test result for a specific disease to provide the individual with realistic expectations for treatment options and to inform an individual about current legal safeguards regarding their genetic information.<sup>63</sup>

#### B. CURRENT FEDERAL LAWS ENACTED TO PREVENT EMPLOYMENT DISCRIMINATION

Genetic discrimination can be in the form of employment discrimination.<sup>64</sup> Two federal acts that cover employment discrimination are Title VII and the ADA.<sup>65</sup> Title VII was enacted by Congress in order to pre-

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57. *Id.*

58. Genetics and Public Policy Center, *US Public Opinion on Uses of Genetic Information and Genetic Discrimination*, [http://www.dnapolicy.org/resources/GINAPublic\\_Opinion\\_Genetic\\_Information\\_Discrimination.pdf](http://www.dnapolicy.org/resources/GINAPublic_Opinion_Genetic_Information_Discrimination.pdf). See also *Faces of Genetic Discrimination*, *supra* note 15. Kim was a social worker with a human services agency. *Id.* She was fired by her employer after she disclosed during a staff workshop on caring for people with chronic illness that her mother had died of Huntington's disease. *Id.* Based on her genetics, Kim had a 50% of developing Huntington's herself. *Id.* One week later Kim was fired despite outstanding performance reviews. *Id.*

59. Genetics and Public Policy Center, *supra* note 58 (reporting while eighty-six percent (86%) of respondents reported that they would trust health care providers not to misuse the information, over ninety-three percent (93%) replied that this information should not be used by employers in hiring and promotion related decisions).

60. *Id.*

61. Amy Adams, *What is Genetic Counseling?*, Genetic Health, Dec. 4, 2003, available at [http://www.genetichealth.com/Resources\\_What\\_Is\\_Genetic\\_Counseling.shtml](http://www.genetichealth.com/Resources_What_Is_Genetic_Counseling.shtml).

62. *Id.*

63. *Id.*

64. See H.R. 493 110th Cong. § 2 (2008).

65. See 42 U.S.C. § 2000(e)(2) (1990); *Facts About the ADA*, *supra* note 3.

vent an employer from discriminating against employees or potential employees on the basis of race, color, religion, sex, or national origin.<sup>66</sup> The ADA was enacted in 1990 to prevent employers from discriminating against individuals with disabilities.<sup>67</sup> The ADA imposes legal consequences upon employers who wrongly correlate an individual's disability with an inability to perform a particular job or job function.<sup>68</sup> Under both Title VII and the ADA, an employer may not discriminate against any individual on the basis of one of the above mentioned protected classes with regard to the terms of employment.<sup>69</sup>

### 1. *Title VII of the Civil Rights Act of 1964*

Title VII prohibits discrimination based on an individual's race, color, religion, sex, or national origin.<sup>70</sup> As set forth in Title VII, if an individ-

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66. U.S. EEOC, *Federal Laws Preventing Job Discrimination: Questions and Answers*, <http://www.eeoc.gov/facts/qanda.html> (last visited Nov. 15, 2008) [hereinafter *Federal Laws*].

67. Education for Disability and Gender ("EDGE"), *Why Did the Government Need to Enact the American's With Disabilities Act (ADA)?*, [http://www.disabilityhistory.org/dwa/edge/curriculum/gov\\_contenta2.htm](http://www.disabilityhistory.org/dwa/edge/curriculum/gov_contenta2.htm) (last visited Nov. 15, 2008); Education for Disability and Gender ("EDGE"), *What Does the ADA Do?*, [http://www.disabilityhistory.org/dwa/edge/curriculum/gov\\_contenta3.htm](http://www.disabilityhistory.org/dwa/edge/curriculum/gov_contenta3.htm) (last visited Nov. 15, 2008).

68. *Id.*

69. *Federal Laws*, *supra* note 66. Under federal law it is illegal for an employer to discriminate against an individual regarding any aspect of employment including: hiring and firing; compensation, assignment or classification of employees; transfer, promotion, layoff, or recall; job advertisements; recruitment; testing; use of company facilities; training and apprenticeship programs; fringe benefits; pay, retirement plans, and disability leave; or other terms or conditions of employment. *Id.* Discrimination under both the ADA and Title VII includes: harassment on the basis of race, sex, color, religion, national origin, disability or age; retaliation against an individual for filing a charge of discrimination, participating in an investigation, or opposing a discriminatory practice; employment decisions based on stereotypes or assumptions about the abilities, traits or performance of individuals of certain sex, race, age, religion, or ethnic group or individuals with disabilities; or denying employment opportunities to an individual because of marriage to or association with an individual of a particular race, religion, national origin, or an individual with a disability. *Id.* Also, Title VII prohibits discrimination because of participation in schools or places of worship associated with a particular race, ethnic, or religious group. *Id.*

70. GEORGE RUTHERGLEN, *EMPLOYMENT DISCRIMINATION LAW: VISIONS OF EQUALITY IN THEORY AND DOCTRINE* 6-8, (Foundation Press 2d ed. 2007). The provisions of Title VII set forth the "most important of the statutory prohibitions against employment discrimination and the one that most clearly expanded upon the protection offered by the Constitution." *Id.* Title VII expanded the protection of employees from discrimination by private entities (i.e. employers), which are beyond the scope and force of the Fifth and Fourteenth Amendments. *Id.* Title VII incorporated the fair employment practices set forth in state law into federal law. *Id.* The provisions incorporated from state law into Title VII were "exceedingly broad, covering all aspects of employment: hiring, discharge, compensation, fringe benefits, conditions of work, and anything else connected with employment." *Id.* Title VII also expanded the grounds for impermissible discrimination to add additional characteristics besides racial discrimination, including discrimination based upon national origin, re-

ual believes he or she has been the victim of discrimination, the individual first files a claim with the Equal Employment Opportunity Commission ("EEOC").<sup>71</sup> The EEOC then conducts an investigation to determine whether the individual's claim has merit.<sup>72</sup> Upon determining that an individual's claim has merit, the EEOC has three courses of action: attempt to settle the matter with the employer on behalf of the employee; filing suit on behalf of the employee; or issue the individual a right-to-sue letter.<sup>73</sup>

To bring a Title VII claim for genetic discrimination, an individual must have a predisposition to a disease that is specific to his race or ethnic category.<sup>74</sup> Protection under Title VII is only available if an employer engaged in discriminatory practices based on a genetic trait *substantially related* to a specific race or ethnic group.<sup>75</sup> An individual's claim for redress under Title VII may rely on either of two theories: disparate treatment or disparate impact.<sup>76</sup> In order to rely upon a disparate treatment theory, a plaintiff must prove by direct and circumstantial evidence that his employer intentionally discriminated against him because of his membership in a Title VII protected class.<sup>77</sup> Alternatively, under a disparate impact claim, a plaintiff must prove that a facially neutral policy (in this case genetic testing) is discriminatory in effect.<sup>78</sup> If a plaintiff is successful in establishing a *prima facie* case, then the burden shifts to the employer to show that the genetic test

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ligion, and sex. *Id.* Race and national origin are protected under the Fifth and Fourteenth Amendments; religion is protected under the religious clause of the First Amendment; sex was expressly protected by Supreme Court interpretation. *Id.*; 42 U.S.C. § 2000(e)(2) (1990). Title VII prohibits employment discrimination based on race, color, religion, sex, or national origin. *Id.* Section 2000(e)(2) provides that:

it shall be unlawful employment practice for an employer to fail or refuse to hire or to discharge any individual or otherwise to discriminate against any individual with respect to his compensation, terms, conditions, or privileges or employment, because of such individual's race, color, religion, sex, or national origin; or to limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee, because of such individual's race, color, religion, sex, or national origin. *Id.*

71. H.R. 483, 110th Cong. § 207(a)(1) (2008); *see also* 42 U.S.C. § 2000(e)(2) (1990).

72. 42 U.S.C. § 2000(e)-5(b) (2007).

73. McGowan, *supra* note 18.

74. Existing Federal Laws, *supra* note 3.

75. *Id.*

76. Melinda B. Kaufmann, *Genetic Discrimination in the Workplace: An Overview of Existing Protections*, 30 LOY. U. CHI. L.J. 393, 419 (1999).

77. Jared A. Feldman & Richard J. Katz, *Genetic Testing & Discrimination In Employment: Recommending A Uniform Statutory Approach*, HOFSTRA LAB. & EMP. L. J. 389, 401 (2002).

78. *Id.* at 405.

is job-related or a matter of business necessity.<sup>79</sup> To bring a Title VII claim for genetic discrimination, an individual has to be predetermined to have a disease linked to a specific racial or ethnic category.<sup>80</sup> Protection under Title VII is only available if an employer engaged in discriminatory practices based on a genetic trait *substantially related* to a specific race or ethnic group.<sup>81</sup>

## 2. *The Americans with Disabilities Act*

The ADA is another federal act to ban employment discrimination.<sup>82</sup> The ADA prevents an employer from discriminating against an individual based on a real or perceived disability.<sup>83</sup> The *regarded as* prong (perceived disability) directly relates to discrimination of an employee by an employer.<sup>84</sup> The *regarded as* prong of the ADA was enacted to prevent discrimination where an employer *erroneously* believed an employee or prospective employee was disabled and treated the employee differently because of that erroneous belief.<sup>85</sup>

Additionally, under Title I of the ADA, an employer may not ask a job applicant or employee about the existence, nature, or severity of a real or perceived disability.<sup>86</sup> In the pre-employment stage, an employer cannot require an individual to undergo a medical examination.<sup>87</sup> Once an offer has been extended, and before the individual is hired as an employee, the ADA sets forth, “a covered entity may require a medical examination after an offer of employment has been made to a job applicant, and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of such

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79. Kaufmann, *supra* note 76. “Business necessity” is defined as relating to an employment practice and an individual employee’s ability to perform requisite job functions. *Id.* “Job-relatedness” is applicable when an employer proves that the criteria it relies upon to select employees for a specific job fit within the demands of the job. *Id.* A court will usually rely upon a balancing test to determine whether genetic testing is permissible and in line with the employer’s ultimate objective. *Id.*

80. *Existing Federal Laws, supra* note 3.

81. *Id.*

82. *Facts About the ADA, supra* note 3.

83. *Id.*

84. *Id.*

85. The National Workrights Institute (“NWI”), *Genetic Discrimination and the Americans with Disabilities Act: An Unlikely Fit*, [http://www.workrights.org/issue\\_genetic/gd\\_ada.html](http://www.workrights.org/issue_genetic/gd_ada.html) (last visited Nov. 1, 2008) (emphasis added).

86. *Facts About the ADA, supra* note 3.

87. 42 U.S.C. § 12112(d)(2)(A), (3), (4)(B) (1994) (noting that an employer may notify an applicant that a job offer will be contingent upon that individual’s consent to undergoing a routine medical examination, and passing that exam, as long as it is required of all applicants).

examination.”<sup>88</sup> Once an employee is hired, an employer cannot require that the employee undergo medical testing to determine whether or not the employee suffers from a disability.<sup>89</sup> In fact, employers may only require an employee undergo job-related examinations that are consistent with business necessity.<sup>90</sup>

In addition to preventing an employer from requesting medical information or testing, Title I of the ADA requires any medical records obtained by an employer regarding an employee, be kept confidential.<sup>91</sup> Furthermore, information can be classified as confidential even if there is no medical diagnosis or treatment listed on the document.<sup>92</sup> A document may be confidential under the ADA even if it is not created by a health care professional.<sup>93</sup> Under Title I of the ADA, however, there are a few limited situations where an employer may disclose an employee’s

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88. 42 U.S.C. § 12112(d)(3) (1994). In order for an employer to utilize these tests in his employment process there is a three-prong test that must be satisfied to ensure that his use does not violate the provisions of the ADA. *Id.* First, the employer must test all employees applying for employment, regardless of whether or not there is a disability. *Id.* Second, the information collected from these exams must be maintained on separate forms and in a separate medical file and treated as confidential information. *Id.* Third, the employer must ensure that any results from the medical examination are used only in accordance with the provisions of the sub-chapter. *Id.* See also U.S. EEOC, *Questions and Answers About Cancer in the Workplace and the Americans with Disabilities Act (ADA): Notice Concerning the Americans With Disabilities Act Amendments Act of 2008*, <http://www.eeoc.gov/facts/cancer.html> (last visited Oct. 29, 2008) [hereinafter *Cancer in the Workplace*]. Once an employer has extended a position to an individual applicant, it may ask questions about an applicant’s current health status and could require a medical examination so long as all other applicants are subjected to that same test. *Id.* This request for medical information regarding an applicant may only occur once the employer has obtained, reviewed, and evaluated all other non-medical application information, and made the job offer “real” pending a medical examination. *Id.*

89. Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 132 (1991).

90. *Id.* (stating medical tests for non-job-related purposes are impermissible because they could not yield any legitimate employer purpose).

91. *Facts About the ADA*, *supra* note 3.

92. *Id.*

93. *Id.* See also Arizona Center for Disability law, *The Americans with Disabilities Act (ADA) and Confidentiality of Medical Information*, Oct. 10, 2001, at 8, available at <http://www.acdl.com/pdfs/E7.pdf>. Any medical information obtained through an employer requested medical examination, or test result obtained regarding an employee, is clearly covered by the confidentiality provisions of the ADA. *Id.* Additionally, if an employer obtains medical information during the course of employment regarding any employee from any other source, that information would also be subject to the confidentiality provisions under the ADA. *Id.* See also 42 U.S.C. § 12112(d)(3)(A)-(C) (1994). For an employer to give a “conditional examination” to prospective employees, three elements must be satisfied: first, the examination must be given to all entering employees regardless of disability. *Id.* Second, the information obtained must be collected and maintained in a confidential manner. *Id.* Third, the statute requires that the results of any medical examination may be used only in accordance with the non-discrimination requirements of the statute. *Id.*

confidential medical information.<sup>94</sup>

### C. THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

GINA was enacted into law in May 2008, after thirteen years of debate before Congress.<sup>95</sup> Previous drafts of GINA were before the House of Representatives since 1995, and the Senate since 1996.<sup>96</sup> Congress decided to enact GINA to provide clear and consistent protections over genetic information, replace inadequate state laws, and provide a uniform federal standard preventing genetic discrimination.<sup>97</sup>

GINA assures, as a matter of law, that neither health insurers nor employers can use employees' genetic information to discriminate.<sup>98</sup> Under Title I of GINA, health insurance providers cannot require an individual to provide genetic information or family genetic information when making a determination about eligibility, coverage, underwriting, or premiums.<sup>99</sup> Additionally, health insurance providers may not use genetic information collected from an individual, intentionally or incidentally, to determine whether or not to provide that individual with coverage.<sup>100</sup> Under Title I, healthcare providers may not require an individual or an individual's family members to undergo genetic testing as a condition of extending coverage.<sup>101</sup> GINA ensures that an individual who voluntarily chooses to undergo genetic testing will not face any discrimination.<sup>102</sup>

GINA, however, does not prevent discrimination in life, disability, or

94. 42 U.S.C. §12112(d)(3)(A)-(C) (1994).

95. *President Signs GINA*, *supra* note 1.

96. *Current Status of GINA*, *supra* note 6. Both the 1995 and 1996 bills addressed genetic discrimination in the health insurance industry, however, neither bill was passed by the 104th Congress. *Id.* A second attempt was made in 2002 before the 107th Congress, which addressed genetic discrimination by both health insurance providers and employers but also failed. *Id.* Legislation was introduced again before the 108th Congress in the House of Representative as H.R. 1910 and gained 242 co-sponsors. *Id.* Identical legislation was introduced in the Senate as S. 1053 and gained 23 co-sponsors. *Id.* The legislation passed in the Senate by a vote of 95-0; however the legislation failed in the House. *Id.* Legislation again was introduced before the 109th Congress. *Id.* The genetic discrimination bill was introduced in the House as H.R. 1227 and gained 244 co-sponsors. *Id.* The bill was introduced in the Senate as S. 306. *Id.* The bill passed once again in the Senate by a vote of 98-0, however failed in the House once again. *Id.*

97. Genetics and Public Policy Center, *supra* note 58; *Current Status of GINA*, *supra* note 6 (noting GINA was introduced on January 16, 2007, by bipartisan team Representatives Slaughter, Biggert, Eshoo, and Walden).

98. Kathy L. Hudson, *Prohibiting Genetic Discrimination*, 365 NEW ENG. J. MED. 2021, 2021-22 (2007) available at <http://dceg.cancer.gov/files/genomicscourse/hudson072607.pdf>.

99. *How Does GINA Impact Me?*, *supra* note 8.

100. H.R. 493, 110th Cong. § 101 (2008).

101. *How Does GINA Impact Me?*, *supra* note 8.

102. *Id.*

long-term-care insurance markets.<sup>103</sup> Nor does GINA prevent disclosure of an individual or family member's already diagnosed genetic disease.<sup>104</sup> Also, GINA does not preempt more extensive protections afforded under state law.<sup>105</sup>

Under Title II, an employer may not use genetic information for hiring, promotional decisions, conditions of employment, privileges of employment, compensation, or in making termination decisions.<sup>106</sup> Employers may neither require individuals to undergo genetic testing, nor fail to refer an individual for employment based on their genetic information.<sup>107</sup> An employer may only have access to an employee's genetic information if the information is provided inadvertently, through publicly available sources, or with the written authorization of the individual.<sup>108</sup>

Furthermore, an individual's genetic information may not be disclosed except with the individual's written express consent, court order, or ordered under existing laws to federal, state, or local authorities.<sup>109</sup> Title II of GINA applies to those employers covered under Title VII.<sup>110</sup> This means employers with fewer than fifteen employees are exempt from GINA's provisions.<sup>111</sup>

Title II of GINA was enacted to prevent "workplace discrimination based upon an individual's genetic information."<sup>112</sup> GINA is the first federal legislation specifically targeted at preventing genetic discrimination.<sup>113</sup> According to the provisions of GINA, "genetic information includes information regarding: (i) an individual's genetic tests; (ii) genetic test of the individual's family members; as well as (iii) the manifestation of a disease or disorder in an individual's family members."<sup>114</sup> Genetic information also covers an employee's request for genetic services.<sup>115</sup> Genetic services incorporate genetic tests, genetic counseling, and ge-

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103. *Id.*

104. *Id.*

105. *Id.*

106. Genetics & Public Policy Center, *Information on the Genetic Information Nondiscrimination Act*, <http://www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf> [hereinafter *Information on GINA*].

107. *Id.*

108. *Id.*

109. *Id.*

110. *Id.*

111. *Id.*

112. Eric N. Miller, *The Genetic Information Nondiscrimination Act of 2008*, ALI-ABA 2013, 2015 (2008).

113. *Id.*

114. *Id.*

115. *Id.*

netic education.<sup>116</sup>

Employer is defined the same under Title II of GINA and Title VII.<sup>117</sup> Thus, the term employer includes some government agencies.<sup>118</sup> GINA broadly sets forth a general rule whereby:

[I]t is unlawful for an employer, because of an employee's genetic information, to: (i) fail or refuse to hire, or to discharge the employee; (ii) otherwise discriminate against the employee with respect to the compensation, terms, conditions, or privileges of the employment of the employee; or (iii) limit, segregate, or classify the employee in any way that would deprive (or tend to deprive) the employee of employment opportunities or adversely affect the status of the employee.<sup>119</sup>

Under Title II, an employer may not request, require, or purchase genetic information regarding an employee or an employee's family member.<sup>120</sup> There are, however, a number of limited exceptions when an employer may obtain genetic information about an employee or employee's family member.<sup>121</sup> For instance, an employer may obtain genetic information if related to a request for time off under the Family Medical Leave Act ("FMLA").<sup>122</sup>

Title II provides limited situations where an employer may disclose genetic information regarding an employee.<sup>123</sup> An employer may only disclose information:

(i) to the employee at his or her written request, (ii) in connection with certain research activities, (iii) in response to a court order, (iv) to government officials who are investigating compliance with Title II of GINA, if the genetic information is relevant to the investigation, (v) to the extent necessary in connection with the employee's certification requirements under the FMLA, or (vi) to a Federal, State or local public health agency that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness.<sup>124</sup>

Congress enacted GINA to prevent genetic discrimination in the workplace by setting forth a number of safeguards for an employee's genetic information under Title II.<sup>125</sup> According to GINA, employers may not request genetic information from an employee or employee's family

116. *Id.*

117. *Id.* at 2017(stating that employers subject to Title VII of the Civil Rights Act of 1964 includes any employer that employs fifteen or more employees); *see also* H.R. 493, 110th Cong. §201(B) (2008).

118. Miller, *supra* note 112.

119. H.R. 493 110th Cong. § 202(a)(1)-(2) (2008).

120. Miller, *supra* note 112.

121. *Id.* at 2015.

122. Miller, *supra* note 112.

123. H.R. 493, 110th Cong. § 202(b) (2008); *see also* Miller, *supra* note 112.

124. Miller, *supra* note 112; *see also* H.R. 493, 110th Cong. § 202(b) (2008).

125. H.R. 493, 110th Cong. § 201 (b) (2008).

members.<sup>126</sup> Disclosure of an employee's genetic information is permissible under a few limited circumstances.<sup>127</sup>

Additionally, an employer has a duty to ensure a minimum level of confidentiality regarding the genetic information of an employee.<sup>128</sup> Title II sets forth a minimum level of confidentiality required for employers who have, or will, obtain genetic information about its employees. Title II requires an employer to keep its employee's genetic information separate from other medical information.<sup>129</sup> This is similar to the current requirement that employers keep an employee's medical information separate from the employee's personnel information on file with the employer.<sup>130</sup> Maintaining genetic information separately from other medical information reduces the risk of the genetic information being improperly accessed or disclosed by employers.<sup>131</sup>

### III. ANALYSIS

GINA is a federal law that specifically addresses the issue of genetic discrimination, and was enacted after Congress concluded that Title VII and the ADA were insufficient to remedy employment discrimination based on a genetic predisposition to developing a disease. A genetic test merely reports the *likelihood* that an individual could one day suffer from a potentially life-threatening disease, and does not guarantee that an individual will develop the disease.<sup>132</sup> Therefore, Congress argued that specific legislation was warranted to address this form of employment discrimination. However, GINA is duplicative and will not have the effect Congress intended.

#### A. GINA IS DUPLICATIVE AND PREMATURE

While GINA has been hailed as the first piece of civil rights legislation in the twenty-first century, there is much debate as to whether GINA is necessary.<sup>133</sup> Some critics of GINA argue that current federal law could have prevented genetic discrimination, making GINA duplicative and

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126. *Id.*

127. H.R. 493 110th Cong. § 206(b) (2008). For example, an employer may be required to disclose an employee's genetic information in response to a court order. *Id.*

128. H.R. 493, 110th Cong. § 206(a) (2008).

129. Miller, *supra* note 112.

130. *Id.*

131. *Id.*

132. See NATIONAL HUMAN GENOME RESEARCH INSTITUTE, FINAL REPORT OF THE TASK FORCE ON GENETIC TESTING Ch. 1 (1997) available at <http://www.genome.gov/10002405>.

133. Snowe, *supra* note 21.

unnecessary.<sup>134</sup> Based on the current broad protections set forth under the ADA and Title VII, it is arguable that employees were adequately protected from genetic discrimination under current federal laws.

Additionally, GINA is premature because Congress enacted GINA before a court decision was handed down addressing whether current federal law was sufficient to prevent genetic discrimination. First, there have only been two cases of genetic discrimination filed in federal courts, evidencing that this is not a common issue for employees. Second, a court has never been afforded an opportunity to apply current federal discrimination laws to an employee's complaint of genetic discrimination.

### 1. *Genetic Discrimination Is Protected by the ADA*

The ADA is the federal law most often cited by critics as sufficient for preventing genetic discrimination.<sup>135</sup> There are two main provisions set forth under the ADA that could have been used for genetic discrimination.<sup>136</sup> First, as previously discussed, the *regarded as* prong of the ADA adequately protected employees from discrimination based on their genetic information.<sup>137</sup> Second, the ADA's limitations on employee examinations, and the confidentiality requirement regarding an employee's medical records could have prevented genetic discrimination in the workplace.<sup>138</sup>

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134. See Ron Zapata, *Genetic Anti-Bias Bill Rouses Litigation Fears*, EMPLOYMENT LAW 360, May 21, 2008 at 5. L Lawrence Z. Lorber commenting, "If there is no problem to deal with, why are we passing a law?" *Id.* In reference to the fact that over thirty states have laws preventing genetic discrimination and that no claims have been filed on the violation of those laws. *Id.* Additionally, a survey of Chamber members reported that "many businesses were unaware of genetic testing and would never pay for it." *Id.* The case that was filed against Burlington Northern for its non-consensual testing of its employers for a genetic predisposition for carpal tunnel syndrome is an exceptional case and should not be deemed as evidencing that there is a larger problem of genetic discrimination generally in the employment setting. *Id.* Burlington Northern as an outlier occurrence is further evidenced by the lack of litigation in the area, which could imply that there is a lack of employers requiring that employees undergo genetic testing. *Id.*

135. *Facts About the ADA*, *supra* note 3. Title I of the ADA prohibits, "private employer, state and local government, employment agencies, and labor unions from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment." *Id.* The act, "covers employers with 15 or more employees, including state and local governments, and also applies to employment agencies and to labor organizations." *Id.*

136. *Cancer in the Workplace*, *supra* note 88 (stating that the EEOC has made a determination that an asymptomatic genetic condition is considered a disability under the ADA).

137. *Id.* (emphasis added).

138. *Id.*; see also Committee on Education and Labor, *ADA Amendments Act of 2008*, <http://edlabor.house.gov/ada-amendments-act-of-2008/index.shtml> (last visited Nov. 2,

Proponents of GINA argue that neither of the provisions under the ADA are sufficient combat genetic discrimination. First, there is no clear legislative history evidencing that Congress intended to include asymptomatic genetic conditions under the *regarded as* prong of the ADA.<sup>139</sup> An individual who is asymptomatic is a carrier of a mutated gene that could cause a genetic disease to manifest later in life.<sup>140</sup> This means an individual who has a likelihood of manifesting a disease later in life would not be considered currently *disabled* under the ADA.<sup>141</sup> Additionally, because an individual may never develop a genetic disease, additional safeguards are needed for medical testing of employees.<sup>142</sup>

However, it takes an extremely broad interpretation of the ADA to cover genetic discrimination.<sup>143</sup> Under the *regarded as* prong, any indi-

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2008). The ADA Amendments Act of 2008 was signed into law on September 25, 2008. *Id.* The Act overturns the, “erroneous Supreme Court decisions that have eroded the protections for people with disabilities under the ADA, restoring original Congressional intent.” *Id.* The Act affirmatively rejects the Court’s prior “strict interpretation of the definition of disability, and makes it absolutely clear that the ADA is intended to provide broad coverage to protect anyone who faces discrimination on the basis of disability.” *Id.* The amendments also seek to reach a “balance between employer and employee interests.” *Id.* The amendments also “cover[s] people who experience discrimination based on a perception of impairment regardless of whether the individual experiences a disability.” *Id.* Additionally, the Act also sets forth, “reasonable accommodations are only required for individuals who can demonstrate they have an impairment that substantially limits a major life activity, or a record of such impairment; accommodations need not be provided to an individual who is only ‘regarded as’ having an impairment.” *Id.* See also Tiffany Hildreth, *2008 ADA Amendments Act*, Sept. 23, 2008, <http://www.strasburger.com/calendar/news/labor/ADA-Amendments-Act-of-2008.htm>.

139. E-medicine Health, *Practical Guide to Health: Definition Asymptomatic*, <http://www.emedicinehealth.com/script/main/art.asp?articlekey=9790> (last visited Nov. 1, 2008) (defining asymptomatic as “without symptoms”; for example an asymptomatic infection is an infection without symptoms); Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J.L. MED. & ETH. 189, 190 (1998).

140. NWI, *supra* note 85. Coverage under the ADA requires that a person have a current disability. *Id.* According to the NWI, it is “clear that the ADA would potentially cover genetic discrimination in employment after a disease with genetic origins has left its host disabled.” *Id.* However, because an individual who has been diagnosed through a genetic test only potentially could develop the disease later in life, their symptoms or condition is asymptomatic. *Id.* Since the conditions and symptoms have not yet manifested in an individual they could not currently be classified as disabled, and therefore are, “unlikely to be impaired in a major life activity,” a condition required for relief under the ADA. *Id.*

141. *Id.* (emphasis added).

142. 42 U.S.C. § 12112(a) (1994); see also Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTHCARE L. & POL’Y 225, 238 (2000).

143. Zapata, *supra* note 134, at 4. Genetic discrimination actions, before GINA’s passage and implementation, could have been brought under the “regarded as” prong of the ADA because genetic discrimination could be categorized as a perceived physical or mental impairment. *Id.* Lawrence Z. Lorber states, “[i]f you lost your job because you are presumed to have a physical condition, than you have an ADA action. . .therefore why pass a

vidual who is assumed to have a *major life impairment* is considered to be disabled.<sup>144</sup> The *regarded as* standard is subjective, reflecting the mindset of each individual employer regarding its determination of whether an employee is *disabled*.<sup>145</sup> The definition of *disability* also incorporates an individual with a disability that is not immediately known by an employer.<sup>146</sup> Likewise, the *regarded as* prong of the ADA prevents an employer from discriminating against an employee based on preconceived notions of any of the individual's limitations.<sup>147</sup> The ADA can protect genetic information, because it extensively limits an employer's ability to collect, use, and disclose medical information.<sup>148</sup> Therefore, the ADA protects genetic information, because it prohibits an employer

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law when you're already covered?" *Id.* Additionally, Reed Russel, legal counsel for the EEOC, states, "GINA makes it easier to frame a complaint because of GINA's broader basis of coverage." *See also Cancer in the Workplace*, *supra* note 88.

144. *See Cancer in the Workplace*, *supra* note 88 (emphasis added).

145. *NWI*, *supra* note 85 (emphasis added).

146. *Cancer in the Workplace*, *supra* note 88 (emphasis added). An applicant is not required under the ADA to disclose to his employer information regarding a disability, such as whether the individual has cancer, unless he will need a reasonable accommodation during the application process. *Id.* An individual may also request a reasonable accommodation for a disability after becoming an employee, even if she did not ask for the reasonable accommodation during the application stage. *Id.*

147. *Id.* "Cancer is a disability under the ADA if it, or a side effect, substantially limit(s) one or more of a person's major life activities." *Id.* For example:

following a lumpectomy and radiation for aggressive breast cancer, a computer sales representative experienced extreme nausea and constant fatigue for six months. She continued to work during her treatment, although she frequently had to come in later in the morning, work later in the evening to make up the time, and take breaks when she experienced nausea and vomiting. She was too exhausted when she came home to cook, shop, or do household chores, and had to rely almost exclusively on her husband and children to do these tasks. This individual's cancer is a disability because it substantially limits her ability to care for herself. *Id.*

Cancer may also be considered a disability because it has "substantially limited an individual to perform a major life activity sometime in the past." *Id.* For example:

a company president was hospitalized for 30 days immediately following his diagnosis of blood cancer. Because his treatment, which included chemotherapy and a bone marrow transplant, weakened his immune system, he was unable to care for himself for six months and had to avoid interactions with almost everyone except his doctors, nurses, and immediate family members. *Id.*

This individual would be regarded as having a, "record of disability." *Id.* Finally, cancer is regarded as a disability even if it does not affect a person's major life activities, but the employer treats the individual as if it does. *Id.* For example:

an individual with a facial scar from surgery to treat skin cancer applies to be an airline customer service representative. The interviewer refuses to consider him for the position because she fears that his scar will make customers uncomfortable. In basing her decision not to hire on the presumed negative reactions of the customers, the interviewer is regarding the applicant as substantially limited in working in any job that involves interacting with the public. The employer is treating the applicant as if he has a disability. *Id.*

148. *Id.*

from discriminating against individuals based on their medical information.<sup>149</sup>

Additionally, genetic testing could have been covered as a *medical examination* under the ADA.<sup>150</sup> A *genetic test* could be considered a *medical examination*, thereby subjecting the use of genetic information by employers to the same use requirements as other medical examinations.<sup>151</sup>

Finally, the current judicial trend further evidences a broad interpretation of the *regarded as* prong of the ADA. This current trend has allowed individuals who do not fit within the traditional definition of *disabled* under the ADA to enforce the ADA's restrictions on medical testing under the statute.<sup>152</sup> Therefore, even if a genetic defect was not considered a *disability* under the ADA, the statute would still prevent an employer from requiring that an employee undergo a genetic test.<sup>153</sup> Both the historically broad application of the *regarded as* prong as well as the current judicial trend evidences that GINA is duplicative, because the ADA adequately prevents genetic discrimination.

In addition to the historical and current interpretation of the courts, the EEOC has interpreted the ADA to prevent genetic discrimination.<sup>154</sup>

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149. Philip L. Gordon & Jennifer L. Mora, *Genetic Antidiscrimination Law Creates New Compliance Challenges for Employers*, ASAP May 2008, available at <http://www.jdsupra.com/post/documentViewer.aspx?fid=2711c1fd-da19-408c-b8ee-04e4b1330648>.

150. *The Genetic Discrimination Nondiscrimination Act: Hearing Before the Subcomm. on Health of the H. Comm. on Energy and Commerce*, 110th Cong. (2007) (statement of Burton J. Fishman, on behalf of the Genetic Information Nondiscrimination in Employment Coalition) (emphasis added) [hereinafter *Energy and Commerce Hearing*]. The Genetic Information Nondiscrimination in Employment Coalition ("GINE") is a business association comprised of trade associations, professional organization, and individual companies. *Id.* GINE's main focus is addressing the, "prevention of genetic non-discrimination in employment." *Id.* GINE's major issue with GINA is the fact that the bill focuses as written on the "flow" of genetic information instead of focusing on the potential, "discriminatory misuses" of genetic tests and information. *Id.* Because GINA focuses on the "flow," and not on discrimination, according to GINE, "the bill will inevitably be plagued by serious, negative, albeit unintended consequences." *Id.*

151. *Id.*

152. *Id.*; see also Griffin v. Steel Tech, Inc., 160 F.3d 591, 594 (10th Cir. 1998); Fredenburg v. Contra Costa County Dept. of Health Services, 172 F.3d 1176, 1182 (9th Cir. 1999).

153. *Energy and Commerce Hearing*, *supra* note 151.

154. Press Release, The United States Equal Employment Opportunity Commission, EEOC Settles ADA Suit Against BNSF For Genetic Bias (Apr. 18, 2001) available at <http://www.eeoc.gov/eeoc/newsroom/release/archive/4-18-01.html> (last visited Sept. 23, 2008) [hereinafter EEOC Settles ADA Suit]. The press release provides:

EEOC is a federal agency responsible for enforcing Title I of the ADA, which prohibits discrimination against qualified individuals with disabilities, including prohibiting an employer from seeking disability related information not related to an employee's ability to perform his or her job. In addition, EEOC enforces Title VII of the Civil Rights Act of 1964, which prohibits discrimination on the bases of race, color, religion, sex, or national origin; the Age Discrimination in Employment

The EEOC has interpreted the ADA's *regarded as* prong to prevent an employer from discriminating against an individual based on her genetic information.<sup>155</sup> If an employer has genetic information regarding an individual and uses this information to discriminate against the employee, the employee would have an actionable claim under the ADA.<sup>156</sup> However, because a court has never been afforded an opportunity to uphold the EEOC's interpretation of the ADA as applying to genetic information, it lacks the full force and effect of a law.<sup>157</sup>

In *EEOC v. Burlington Northern Santa Fe Railway Company*, the EEOC interpreted the ADA as covering genetic testing.<sup>158</sup> Burlington Northern conducted genetic testing on its employees without their consent or knowledge.<sup>159</sup> Burlington Northern conducted genetic testing in

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Act, which protects workers 40 and older; and the Equal Pay Act which prohibits sex-based differences in compensation. *Id.*

In the case between the EEOC and Burlington Northern Santa Fe Railroad ("BNSF"), the EEOC filed a preliminary injunction against BNSF to prevent irreparable harm to the employees of the company who could potentially lose their jobs based on their genetic makeup. *Id.* By settling the suit, the EEOC ensured that employees would not be subject to retaliation or future privacy invasions in violation of the American's with Disabilities Act. *Id.* According to the petition filed by the EEOC on behalf of BNSF employees, genetic tests were being performed on employees without their knowledge or consent. *Id.* See also *Cancer in the Workplace*, *supra* note 88; *Genetic Non-Discrimination: Implications for Employers and Employees: Hearing before the Subcomm. on Employer-Employee Relations of the H. Comm. on Education and the Workforce*, 107th Cong. (2001) (statement of Mr. Gary Avary, Member of the Brotherhood of Maintenance and Way Employees and Employee of Burlington Northern Santa Fe Railroad Company), available at <http://www.edworkforce.house.gov/hearings/107th/eeer/genetic72401/avary.htm>.

What happened to me should not happen to anyone especially in the United States. It is a direct infringement on our fundamental right to be who we are. No one can help how they are put together, only God knows that—your employer, insurance companies or anyone else has no business of that knowledge. That information. . . should not be used against you and your family for hiring and firing practices, or acceptance and/or denial into insurance programs. *Id.*

155. EEOC Settles ADA Suit, *supra* note 155 (emphasis added).

156. *Id.*

157. Agreed Order at *EEOC v. Burlington N. Santa Fe R.R. Co.*, No. 01-4013 MWB (N.D.L.A. Apr. 23, 2001) [hereinafter Agreed Order]; see also Press Release, The United States Equal Employment Opportunity Commission, EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans With Disabilities Act (Feb. 9, 2001) available at <http://www.eeoc.gov/press/2-9-01-c.html>.

158. *EEOC v. Burlington N. Santa Fe R.R. Co.*, Civ. No. 01-4013 MWB (N.D. Iowa Apr. 18, 2001) (granting preliminary settlement agreement); see also Agreed Order, *supra* note 158.

159. EEOC Settles ADA Suit, *supra* note 155. In *Burlington Northern Santa Fe v. EEOC*, the EEOC filed a charge on behalf of BNSF's employees who had been tested, without their consent or knowledge, for genetic predisposition for carpal tunnel syndrome. *Id.* The group of employees had filed a worker's compensation claim with the company for developing carpal tunnel syndrome as a result of their employment duties. *Id.* BNSF had also threatened one of its workers with termination if he failed to comply with the medical

order to determine whether its employees had developed carpal tunnel syndrome as a result of work conditions, or whether the employees had a genetic predisposition to develop the disease.<sup>160</sup> The EEOC relied on the legal argument that the Burlington Northern had violated the ADA by requiring employees to undergo testing that was neither job-related nor consistent with business necessity.<sup>161</sup> The court was not afforded an opportunity to determine whether or not genetic testing could have been prevented under the ADA because the case settled out of court.<sup>162</sup>

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test. *Id.* The EEOC determined that the non-consensual genetic testing of employees violated the ADA because the test was not job-related. *Id.* The EEOC deemed that a predisposition to developing a disease in the future had absolutely no correlation to an individual's current ability to perform his job, and therefore conditioning the terms of an individual's employment based on the likelihood that he could later develop a disease was actionable as discrimination founded on a disability. *Id.* See also, Robert B. Lanman, *An Analysis of the Adequacy of Current Law in Protecting Against Genetic Discrimination in Health Insurance and Employment*, at 17 (May 2005), available at [http://www4.od.nih.gov/oba/SACHGS/reports/legal\\_analysis\\_May2005.pdf](http://www4.od.nih.gov/oba/SACHGS/reports/legal_analysis_May2005.pdf). The Health and Human Services Secretary's Advisory Committee on Genetic, Health, and Society commissioned a study in 2005 on whether current laws could adequately protect an individual from employers and health insurance providers from discriminating against him. *Id.* The study was assisted by the contributions of the Department of Labor, Department of Justice, EEOC, Centers for Medicare & Medicaid Services and Office for Civil Rights. *Id.* This study was used as a basis for drafting the new GINA which was enacted into law in May, 2008. *Id.*; see also Interview with Jean Kamp, Associate Regional Attorney, U.S. Equal Employment Opportunity Commission, in Chicago, Ill. (Oct. 7, 2008) (on file with author) [hereinafter Kamp Interview].

160. EEOC Settles ADA Suit, *supra* note 155; see also Kamp Interview, *supra* note 160.

161. Kamp Interview, *supra* note 160; see also Medline Plus, *Carpal Tunnel Syndrome*, <http://www.nlm.nih.gov/medlineplus/carpaltunnelsyndrome.html> (last visited Nov. 15, 2008) [hereinafter *Carpal Tunnel Syndrome*]. The carpal tunnel is a narrow passageway of ligaments and bones at the base of an individual's hand. *Id.* The passageway contains both nerves and tendons. *Id.* Sometimes, thickening from irritated tendons or other swelling narrows the tunnel and causes the nerve to be compressed. *Id.* Carpal tunnel syndrome is usually caused by one of two problems; an individual may inherit narrow carpal tunnels, and therefore have a genetic predisposition to develop the disease, or an individual may develop the disease from assembly line work, wrist injury or other disease such as rheumatoid arthritis. *Id.* Women are three times more likely than men to develop carpal tunnel syndrome. *Id.* Treatments of the disease include resting, splints, pain and anti-inflammatory medicines and surgery. *Id.*

162. Brief of Plaintiff at 1, U.S. EEOC v. Burlington N. Santa Fe R.R. Co., No.06-6074 (E.D. Wis. 2002). The EEOC filed suit on behalf of BNSF employees who were required to undergo genetic testing in response to a company policy mandating genetic testing of all individuals who claimed to have developed carpal tunnel syndrome. *Id.* The EEOC stated that while BNSF employees were told that they would undergo, "laboratory testing," at no time did BNSF disclose that blood samples would be taken and sent to a genetic testing facility and analyzed. *Id.* Instead of informing its employees about the genetic testing, it was the wife of one employee who was a nurse that inquired as to why her husband was required to undergo blood work as, "part of a purported 'medical examination' of whether his carpal tunnel syndrome was work-related." *Id.* It was in response to the nurse's inquiry on behalf of her husband that she learned that the tests being performed by BNSF were genetic tests. *Id.* See also Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d

## 2. Title VII Additionally Prevents Genetic Discrimination

Title VII also prevents employers from discriminating against individuals based on their genetic makeup. In order to bring a Title VII claim for genetic discrimination, an individual must be predisposed to a genetically linked disease specific to a racial or ethnic category.<sup>163</sup> Protection under Title VII is only available if an employer engaged in discriminatory practices based on a genetic trait *substantially related* to a specific race or ethnic group.<sup>164</sup> Only a few genetic diseases, however, have been scientifically linked to race, or ethnicity. For example, discrimination based on Tay-Sachs, which has a high incidence among Eastern Europeans and Ashkenazi Jews, would be actionable because the disease is linked to a protected category of religion or national origin.<sup>165</sup> Therefore, only a few genetic diseases would be actionable on the basis of a Title VII claim.<sup>166</sup>

There are only a few types of genetic diseases that may only be developed by males or females. For example, only men can develop prostate cancer.<sup>167</sup> Therefore, in regards to the protected class of sex, if an employer were to discriminate on the basis of prostate cancer, this discrimination would be actionable under Title VII because this type of disease is linked to a particular gender.<sup>168</sup>

Proponents of GINA point out that this legislation was needed based on a shortfall in coverage under Title VII.<sup>169</sup> This argument lacks merit, because Title VII should not be interpreted as being limited in its cover-

1260, 1273 (9th Cir. 1998) (applying the ADA to plaintiffs' genetic claim holding that the ADA was not violated because the plaintiffs merely challenged the scope of the medical testing examinations which is not protected under the ADA).

163. Susan M. Wolf & Jeffery P. Kahn, *Genetic Testing and the Future of Disability Insurance: Ethics, Law & Policy*, 35 J. L. MED. & ETHICS 6, 8 (2007). The case was settled out of court for \$2.2 million. *Id.*

164. *Existing Federal Laws*, *supra* note 3.

165. *Id.*

166. *Id.*

167. National Cancer Institute, *What You Need to Know About Prostate Cancer*, <http://www.cancer.gov/cancertopics/wyntk/prostate/page2> (last visited Nov. 23 2009).

168. *Tay-Sachs*, *supra* note 48.

169. Phoenix5, *Where Is Your Prostate and What Does It Do?*, <http://www.phoenix5.org/Infolink/Physiology.html> (last visited Nov. 16, 2008). Only men have prostates, therefore only men may develop prostate cancer. *Id.* A man's prostate is a solid organ located immediately below his bladder. *Id.* The prostate controls both bladder and sexual functions. *Id.*; see also Tirgan Oncology Associates, *Prostate Cancer*, <http://www.tirgan.com/genetics/genprostate.htm> (last visited Nov. 16, 2008). The most prevalent cancer among American men is prostate cancer. *Id.* Annually, approximately 250,000 American men are diagnosed with prostate cancer. *Id.* The risk of developing prostate cancer increases as a man gets older. *Id.* Most men are diagnosed with prostate cancer over the age of sixty. *Id.* African-American men carry an increased risk of approximately ten percent of developing the disease during their life. *Id.*

age, rather it should be viewed as providing additional coverage to individuals. If an employee was discriminated against not only because of results of a genetic test, but also for being a member of a protected category, he could bring a Title VII claim as well as an ADA claim.<sup>170</sup> Therefore, Title VII should not be regarded as limiting, rather, it should be considered as providing additional protections against genetic discrimination.

A Title VII violation for genetic discrimination was brought before the Ninth Circuit in *Norman Bloodsaw v. Lawrence Berkeley Laboratory*.<sup>171</sup> In that case, the plaintiffs were former employees of a research institute operated by state and federal agencies in California.<sup>172</sup> The plaintiffs alleged that during a mandatory employment entrance exam, their employer tested their blood and urine for private medical conditions without their knowledge or consent. Specifically, the plaintiffs alleged that the blood samples of African-Americans were screened for sickle-cell anemia and syphilis, and the urine samples of female applicants were tested for pregnancy.<sup>173</sup> The district court dismissed the plaintiffs' claims and entered judgment for the defendant.<sup>174</sup>

On appeal, the Ninth Circuit held that the employer violated Title VII by making these testing distinctions based on the *alleged classification* of race and sex, and that the employees had demonstrated an ad-

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170. See *Existing Federal Laws*, *supra* note 3 (noting to rely on Title VII for a genetic discrimination claim there must be a strong relationship between race or national origin which has only been established for a few diseases).

171. *Norman-Bloodsaw*, 135 F.3d at 1260.

172. *Id.* at 1273. Plaintiffs, African-American former employees, brought both a Title VII claim and ADA claim against defendants alleging non-consensual genetic testing.

173. *Id.* at 1264.

174. *Id.* at 1265; see also Medline Plus, *Sickle Anemia*, <http://www.nlm.nih.gov/medlineplus/ency/article/000527.htm>. Sickle cell anemia is also referred to as Hemoglobin SS disease. *Id.* Sickle cell anemia is a disease in which an individual produces abnormally shaped red blood cells. *Id.* The cells are misshapen like a crescent or a sickle as opposed to normal round blood cells. *Id.* Since the cells are misshapen, they do not last as long as normal blood cells which leads to anemia. *Id.* Another problem with sickle shaped cells is that they get caught in blood vessels, restricting the flow of blood. *Id.* A genetic abnormality causes sickle cell anemia. *Id.* Individuals who have the disease receive defective genes from both of their parents who are carriers of the defective gene. *Id.* Approximately one in every twelve African-Americans has sickle cell anemia. *Id.* A blood test can determine whether or not an individual has the disease. *Id.* Therefore, most babies of African-American decent are tested for sickle cell anemia. *Id.* See also The Sickle Cell Anemia Center, *Frequently Asked Questions (FAQ): Sickle Trait and Malaria Protection*, <http://www.scinfo.org/faqtrait.htm> (last visited Nov. 15, 2008). The highest prevalence of sickle cell anemia occurs in individuals of African and Mediterranean descent. *Id.* The high correlation between ethnicity and the disease has been linked to a reduced mortality rate in those areas from malaria infection compared to other ethnicities that do not carry this mutated gene. *Id.*

verse employment effect based on this classification.<sup>175</sup> First, the plaintiffs alleged that African-American and female employees had been singled out for the nonconsensual genetic testing.<sup>176</sup> Therefore, the employer had selectively invaded the private medical information of a specific group of employees on the basis of race, and sex.<sup>177</sup> Second, the Ninth Circuit relied on past precedent that provides that Title VII prevents discrimination on the *terms and conditions* of employment.<sup>178</sup> In this case, the employer imposed a condition of employment on African-Americans and females that it did not impose on all of its employees collectively.<sup>179</sup> Finally, the Ninth Circuit remanded the case on the grounds that the employer's invasion into the private and sensitive medical information of its employees without their consent was sufficient to constitute an adverse effect under Title VII.<sup>180</sup>

Based on language and interpretations, both the ADA and Title VII adequately prevents employers from discriminating against employees on a wide variety of characteristics. The Ninth Circuit has interpreted genetic discrimination founded on a protected category as actionable under Title VII. Additionally, the EEOC has interpreted the ADA as covering genetic discrimination without a protected class category.<sup>181</sup>

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175. *Norman-Bloodsaw*, 135 F.3d at 1265 (emphasis added).

176. *Id.* at 1271 (stating that the claim falls "neatly" within the framework of Title VII).

177. *Id.* at 1272.

178. *Id.* referencing *Griggs v. Duke Power Co.*, 401 U.S. 424, 432-37 (1971); *Hashimoto v. Dalton*, 118 F.3d 671, 676 (9th Cir. 1997); *EEOC v. Hacienda Hotel*, 881 F.2d 1504 (9th Cir. 1989).

179. *Id.* at 1272.

180. *Id.*

181. *Id.* at 1269, 1272-73. The Ninth Circuit deemed that the unauthorized intrusion into the private medical information regarding an employee was the, "most basic violation possible." *Id.* Additionally, a requirement of pre-employment health tests only administered to female employees or black employees would surely violate Title VII. *Id.* Plaintiff's brought an ADA violation against their employer and the Ninth Circuit dismissed the plaintiff's ADA claim holding that a because their employer had required the test after an offer of employment had been made, but prior to the employer's working as an employee, the only restrictions the ADA places on an entrance exam are confidentiality requirements. The Ninth Circuit reasoned that in this case the plaintiffs had not raised a claim relating to their employer violating the confidentiality requirements under the ADA, and therefore did not assert a claim upon which relief could be granted. *Id.* The plaintiff's claim focused on the scope of the examination, and because the ADA does not regulate the scope of a pre-employment examination, the Ninth Circuit could not redress their claim. *Id.* See also, Reginald C. Govan & Freddie Mac, *Personnel, Investigative and Health Records*, 763 PLI/LIT 409, 582 (2007). The case was ultimately settled between the plaintiffs and the University of California for \$2.2 million. *Id.* The settlement incorporated three, "subclasses of employees—women who were tested for pregnancy, African-Americans who were tested for sickle cell traits, and workers at the lab from January 1, 1981, and April 12, 1993, who were tested for syphilis." The affected class of persons included approximately 3,000 women who were tested for pregnancy and 900 African-American employees were tested for sickle cell traits between 1972 and 1994 and between 1972 and 1995, respectively." *Id.*; see

Therefore, because no court has been afforded an opportunity to review the EEOC's interpretations, the enactment of GINA was premature. Additionally, it is inferable that a lack of genetic discrimination cases brought by employees is evidence that genetic discrimination may not be as great of a problem as Congress believed. The lack of litigation also supports the conclusion that GINA was prematurely enacted.

#### B. ISSUES WITH TITLE II OF GINA AS ENACTED

The legislative history of GINA suggests that GINA was necessary to ensure greater protection of an individual's genetic information.<sup>182</sup> Congress found that less than one percent (1%) of Americans have undergone genetic testing because they fear employers and health insurance providers would use their genetic information for discriminatory purposes.<sup>183</sup> However, as written, the provisions of Title II of GINA do not prevent genetic discrimination in the workplace. Thus, Title II is problematic because it fails to fulfill the purpose of enacting the statute: to provide a uniform standard of protection to employees' nation-wide.

Additionally, GINA is confusing. GINA relies upon both broad provisions and definitions that raise potential compliance issues for employers and employees.<sup>184</sup> Specifically, these broad provisions make it unclear what is, and is not, covered under GINA. As a result, GINA will merely be another federal employment law that was enacted with good intentions that inevitably increases litigation, similar to the FMLA.<sup>185</sup>

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*also Griggs*, 401 U.S. at 432-36 (noting that even if testing requirements appear facially neutral, if they do not reasonably measure job performance and have a disparate impact by preventing minorities from obtaining jobs, then the test violates Title VII).

182. Nancy Lee Jones, CRS REPORT FOR CONGRESS, *GENETIC INFORMATION: LEGAL ISSUES RELATING TO DISCRIMINATION AND PRIVACY*, at 15, available at <http://www.ncseonline.org/nle/crsreports/science/st-55.pdf>.

183. See The Library of Congress, *supra* note 11; see also H.R. 493 110th Cong. § 2 (2008).

184. See generally *Energy and Commerce Hearing*, *supra* note 151.

185. Derrick Kain, *Discrimination-Legislation to Ban Genetic Discrimination in Workplace Clears House; Bush to Sign*, [May] Daily Lab. Rep., at AA-1 (May 2, 2008), available at <http://pubs.bna.com/ip/bna/dlr.nsf/eh/a0b6k4p8r5>. But see *Energy and Commerce Hearing*, *supra* note 151. While Fishman acknowledges that some people believe that their genetic information could be used against them regarding employment opportunities, that fear is unfounded and misguided. *Id.* Fishman argues that this fear is, "fed by apocryphal stories and, of course, on the rare but highly publicized cases involving Burlington Northern-Santa Fe Railroad, from nearly a decade ago." *Id.* See also Linn F. Freedman, *Privacy of Genetic Info and Gina in An Electric Age*, EMP. L. 360, Sept. 18, 2008, at 4; see also Tresa Baldas, *FMLA an Increasing Source of Litigation, Say Employment Lawyers*, Jan. 1, 2007, available at <http://www.law.com/jsp/article.jsp?id=1168509734039>.

### 1. *Non-preemption Contradicts Need for Uniform Protection*

To adequately protect individuals, proponents of GINA argue that there needed to be a uniform federal statute addressing genetic discrimination and enacted GINA in order to accomplish that goal.<sup>186</sup> While proponents believe that GINA provides the necessary uniformity, GINA does not preempt state law,<sup>187</sup> therefore, it fails to provide a uniform floor. GINA does nothing to remedy the state standards that impose inconsistent requirements because each state is allowed to retain its own provisions on genetic testing so long as the laws are more comprehensive than GINA. By not preempting state law, Congress' intention of providing a uniform set of protections is undermined.<sup>188</sup> If Congress wanted to ensure uniform protection, it should have enacted legislation that imposes only one standard regarding genetic discrimination.<sup>189</sup> Instead, Congress has complicated compliance by allowing varying laws among the several states.<sup>190</sup>

There is also a question of whether a real need for federal legislation, such as GINA, existed, or whether the individual states' statutes would have been sufficient. At the time GINA was signed into law, thirty-four states had laws preventing employers from using genetic information to make employment decisions.<sup>191</sup> Additionally, the states that had genetic discrimination laws had yet to see litigation regarding genetic discrimination in violation of these laws.<sup>192</sup>

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186. See The Library of Congress, *supra* note 11.

187. See *Id.*; see also HR 493, 110th Cong. § 201(3)(b) (2008) (stating "nothing under Title II of GINA shall be construed to limit the rights to an individual than the rights or protections provided for under this title, including the protections of an individual under the Americans with Disabilities Act of 1990 (42 U.S.C. § 12101 (1994)) including coverage afforded to individuals under section 102 of such Act (42 U.S.C. § 12112 (1994)) or under the Rehabilitation Act of 1973 (29 U.S.C. § 701 (1973))").

188. Marian Waldmann, Timothy Verrall, & Christine Lyon, *New Federal Law Regulates Collection and Use of Genetic Information By Employers and Group Health Plans*, BUREAU OF NAT'L AFFAIRS PRIVACY & SEC. LAW, May 19, 2008 at 764, available at [http://www.mofo.com/docs/pdf/BNA\\_GINA\\_May2008.pdf](http://www.mofo.com/docs/pdf/BNA_GINA_May2008.pdf).

189. *Id.*

190. McGowan, *supra* note 18; see also *Energy and Commerce Hearing*, *supra* note 151 (stating that if Congress intends to enact a uniform statute it should include a "safe-harbor" provision that any employer in compliance with federal standards cannot be liable under state or local laws banning such discrimination because there should be only one standard, the federal standard).

191. National Conference of State Legislatures, *State Genetics Employment Laws*, available at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>.

192. Human Genome Project Information, *Breaking News: GINA Becomes Law May 2008*, [http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/legislat.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml) (last visited Oct. 29, 2008).

## 2. *Broad Definitions Will Cause Confusion Regarding GINA's Application*

Another issue is Congress' use of broad definitions of *family member* and *genetic information*.<sup>193</sup> Congress expanded the definition of *family member* to include information regarding the fourth-degree relative of an individual.<sup>194</sup> Under this provision, genetic information regarding an employee's mother, grandmother, great-grandmother, and great-great-grandmother would be protected by GINA.<sup>195</sup> While proponents of GINA argue these broad definitions are needed to adequately protect highly private and sensitive information, though Congress' failure to narrow the scope of these definitions could be problematic in application.<sup>196</sup>

Additionally, every type of genetic research is classified under a broad heading of genetic information. However, because of the numerous types of genetic research and tests currently being preformed, experts have not reached a consensus on a precise definition of genetic information.<sup>197</sup> The lack of a formal definition is problematic because it is not readily apparent what types of genetic information are precisely referred to when the term is used.<sup>198</sup>

Genetic information not only includes the genetic information of individual employees and their family members, but also prevents discrimination based upon any *manifestations* of a genetic disorder in employees' family members.<sup>199</sup> This provision was adopted to ensure that an employer did not erroneously rely upon an individual's genetic predisposition of developing a disease based on the genetic tests of family members in making its employment decisions regarding a current or prospective employee.<sup>200</sup>

While extending protection far into a family's medical history is one way to ensure genetic information remains confidential, it can also be problematic. For example, extending protection under GINA to cover family medical history presents a dilemma because medical histories do

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193. *Energy and Commerce Hearing*, *supra* note 151. Fishman argues that "genetic information" under GINA should be defined with limitation regarding only a "genetic predisposition to develop a disease in the future." *Id.* With the broad definition of genetic information under the Act, the term could include the occurrence of a disease or disorder in family members of the individual without any limitation." *Id.* Fishman argues that based on this usage, Congressional intent could be interpreted to include minor ailments such as the cold, flu, and chicken pox under its provisions. *Id.*

194. H.R. 493, 110th Cong. § 201(3)(b) (2008).

195. Gordon, *supra* note 150.

196. *Energy and Commerce Hearing*, *supra* note 151.

197. *Id.*

198. See Electronic Privacy Information Center, *Genetic Privacy*, <http://epic.org/privacy/genetic> (last visited Oct. 20, 2008).

199. Gordon, *supra* note 150.

200. *Id.*

not provide the same information as a genetic test.<sup>201</sup> This is problematic because the definitions are not clear or concise, causing confusion for both employers and employees as to what is covered under the act, when there is a lack of agreed interpretation issues arise.<sup>202</sup>

Also problematic is the broad definition of genetic information.<sup>203</sup> Under GINA, genetic information covers information regarding an individual's genetic tests, family member's genetic tests, and the manifestation of a disease or disorder in an individual and the individual's family members.<sup>204</sup> This definition is confusing, and will lead to numerous questions by employers and employees as to what is covered under Title II of GINA.<sup>205</sup> Additionally, the definition of genetic information causes difficulties because it may encompass family medical histories that are used by an employer in reviewing an employee's FMLA request.<sup>206</sup> An employer may require medical history as a requirement of granting an employee's FMLA request.<sup>207</sup> If this information is used, however, it could qualify as genetic information.<sup>208</sup> Then, if an employer later took an adverse disciplinary action against the employee, the employer could subject itself to liability for genetic discrimination.<sup>209</sup>

As written, Title II is at odds with Congress' intent for enacting GINA because its provisions are vague. The need for a uniform statute has not been established. Moreover, by enacting broad provisions, it remains unclear what is covered under GINA. Therefore, employees are still not afforded clear assurance that genetic discrimination will be prevented by GINA. Analyzing these issues, it is apparent there are potential conflicts between GINA as written, and the potential outcomes of enforcement.

### C. POTENTIAL SOURCES OF LITIGATION UNDER TITLE II OF GINA

Historically, litigation increases when new legislation is enacted affording a private right of action.<sup>210</sup> While it is conceivable that employers will not face an increase in litigation under GINA, it is likely that

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201. Letter from the Genetic Information Nondiscrimination in Employment Coalition, to Congress, (Jan. 23, 2007) available at [http://www.nam.org/~media/Files/s\\_nam/docs/238200/238195.pdf.ashx](http://www.nam.org/~media/Files/s_nam/docs/238200/238195.pdf.ashx) [hereinafter Employment Coalition Letter].

202. Baldas, *supra* note 186.

203. *Energy and Commerce Hearing*, *supra* note 151, at 10.

204. H.R. 493, 110th Cong. § 201(4)(A) (2008).

205. Jo-el J. Meyer, *Employee Benefits, Genetic and Disability Discrimination Laws Play Role in Wellness Plans, Attorney Says*, [Oct.] Daily Lab. Rep., (BNA) Oct. 7, 2008.

206. *Id.*

207. *Id.*

208. *Id.*

209. *Id.*

210. McGowan, *supra* note 18.

litigation is inevitable.<sup>211</sup> Not only is litigation likely to ensue, but there will also be an increase in meritless claims under GINA. This is reflected in the EEOC's 2006 finding that sixty-two percent (62%) of the claims filed alleging workplace discrimination were deemed meritless.<sup>212</sup>

Additionally, there are provisions under GINA which will lead to subsequent litigation once it takes effect. GINA affords a plaintiff a private right of action, entitling a plaintiff to compensatory and punitive damages as well as equitable relief.<sup>213</sup> With these kinds of damages and remedies available to litigants, frivolous litigation is inevitable.<sup>214</sup>

While GINA sets forth new requirements and compliance demands for employers, the damages scheme and enforcement provisions rely upon Title VII.<sup>215</sup> Under the provisions of GINA, damages cannot exceed \$300,000, and the court will consider the size of the employer in awarding an employee damages.<sup>216</sup> In addition, a plaintiff may seek equitable relief in the form of future pay and back pay.<sup>217</sup> It is the private right of action provided through Title VII, and now GINA, that poses the greatest likelihood of ensuing expensive and time-consuming trials and resulting money damages under GINA.<sup>218</sup>

Unlike Title VII and the ADA, GINA differs in its enforcement provisions. There is no *disparate impact* clause provided under GINA, which means a plaintiff cannot bring a claim alleging that a facially neutral genetic policy is discriminatory.<sup>219</sup> Additionally, a plaintiff who brings a successful claim under GINA may obtain attorney's fees.<sup>220</sup> This is counter to the American Rule, which usually requires a party to pay for their own litigation expenses.<sup>221</sup>

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211. Freedman, *supra* note 186 at 3. Reed Russell, legal counsel of the EEOC, predicts that genetic discrimination claims are "reasonably rare." *Id.* In response to whether GINA is likely to cause an increase in litigation, Russell commented that "I don't expect the statute to overwhelm us, though there may be some uptick in cases." *Id.* Additionally, experts in employment discrimination law do not believe that genetic discrimination cases will become as large of a basis for lawsuits as traditional protected classes such as race, gender, and age. *Id.* No suits have been brought under state statute as well as federal statutes as of the publication of this article. *Id.*

212. Employment Coalition Letter, *supra* note 202.

213. Freedman, *supra* note 186, at 4.

214. Agreed Order, *supra* note 158; *see also Norman-Bloodsaw*, 135 F.3d at 1273.

215. H.R. 493, 110th Cong. § 207(a) (2008).

216. McGowan, *supra* note 18.

217. *Id.*

218. *Id.*

219. McGowan, *supra* note 18.

220. 42 U.S.C. § 1988 (2006). A general attorney's fees statute that provides for fee-shifting in a cause of action for federal civil rights.

221. Title 4 Civil Resources Manual § 220 Attorney's Fees, [http://www.usdoj.gov/usao/eousa/foia\\_reading\\_room/usam/title4/civ00220.htm](http://www.usdoj.gov/usao/eousa/foia_reading_room/usam/title4/civ00220.htm) [hereinafter Title 4 Manual]. The general rule in the United States is that each litigant is responsible for his own attorney's fees.

There are also serious penalties for relying on Title VII to enforce the provisions of GINA because an employer who inadvertently discloses genetic information may be held liable for both compensatory and punitive damages. Such damages awards by a court could be substantial.<sup>222</sup> For instance, under the caps set forth in GINA, a large employer with more than 500 employees could be held liable for \$300,000 in compensatory damages and \$300,000 in punitive damages.<sup>223</sup> Furthermore, an employee may bring suit under additional federal statutes, such as the ADA or Title VII, in addition to GINA to obtain relief for genetic discrimination. GINA could end up being another act passed by Congress with good intentions that leads to endless litigation for employers.<sup>224</sup>

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*Id.* This common practice and knowledge has been dubbed the, "American Rule." *Id.* See also *Alyeska Pipeline Serv. Co. v. Wilderness Soc'y*, 421 U.S. 240 (1975). *But see* *F.D. Rich Co. v. Indus. Lumber Co.*, 417 U.S. 116, 129 (1974) (holding that proof of a party's "bad faith" such as willfully disobeying a court order or acting vexatiously, wantonly, or oppressively could warrant a court to award attorney's fees to the opposing party).

222. *Workplace Fairness, Damages*, <http://www.workplacefairness.org/damages#maincontent> (last visited Nov. 15, 2008) [hereinafter *Damages*]. The purpose of compensatory damages is to make an employee who has been discriminated against by his employer "whole." *Id.* Compensatory damages are also referred to as "actual damages." *Id.* A court may award any of the following as part of compensatory damages: emotional distress, pain and suffering, permanent disability, mental impairment, or medical bills. Under Title VII, the amount of compensatory damages awarded to an employee is capped based on the size of his employer. *Id.* If an employer has between fifteen and one hundred (15-100) employees, compensatory damages are capped at \$50,000. Between 101-200 employees, the cap is \$100,000. *Id.* Between 201-500 employees, the cap is \$200,000. *Id.* In excess of 500 employees, the cap is \$300,000. *Id.* Likewise, punitive damages are damages awarded to an individual in cases where an employer has acted maliciously. *Id.* In employment cases, punitive damages are used to punish an employer and to set an example that a specific type of conduct will not be tolerated by the courts. *Id.* In order to award punitive damages, an employee must establish that an employer discriminated with reckless indifference. *Id.* However, the court does not consider the seriousness of the employer's conduct in making its determination whether to award punitive damages. *Id.* Instead, the court focuses on the employer's intent. *Id.* In other words, did the employer know that a particular action was unlawful discrimination and still choose to engage in that conduct anyway? *Id.* An employer who adopts an anti-discrimination policy, effectively enforces that policy, and thoroughly adopts that policy may rely upon good faith as a defense against punitive damages awards and rely on the policy as evidence that the discriminatory practice did not occur in the first place. *Id.* Punitive damages are only available against private employers. *Id.* Punitive damages are also very rarely awarded to an employee. *Id.* This is in part because if an employer expects that it will be liable for a large punitive damages award, it will usually choose to settle the case out of court with an employee. *Id.* This is done to avoid both large financial liability and prevent negative publicity. *Id.* When punitive damages are awarded by a court they can be substantial and are capped at the same amounts as compensatory damages stated above. *Id.*

223. H.R. 493, 110th Cong. § 207(3) (2008); *see also* 42 U.S.C. § 1981(a) (1981).

224. Freedman, *supra* note 186 at 4. Michael J. Ossip compares "the good intentions behind GINA to those underlying the factors that led to the passage of the Family Medical Leave Act, which mandates unpaid leave for employees due to health reasons and other

The FMLA is one example of how broad provisions lead to increased litigation. The FMLA, enacted twelve years ago, caused an increase in employees erroneously holding their employers liable for not granting leave the employee was entitled to under the Act.<sup>225</sup> Conversely, employers have claimed that their employees abused the FMLA by requesting time off for uses not covered under the statute.<sup>226</sup> While most claims under the FMLA are settled through administrative proceedings, there has been an increase in employees relying on their private right to bring suit in court.<sup>227</sup>

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conditions.” *Id.* Regarding the FMLA, Ossip commented, “[w]hat was a deceptively simple statute has turned into a decade plus of litigation, which doesn’t seem to be ending anytime soon.” *Id.* However, Karen Rothenberg, dean of the University of Maryland School of Law in Baltimore commented, “the law makes a ‘statement of social policy’ that genetic rights are like traditional civil rights.” *Id.* Rothenberg disregards the argument that GINA will, “open the floodgates to suit because of the difficulty in winning such cases and the toll it may take on plaintiffs.” *Id.* See also Baldas, *supra* note 186.

225. Baldas, *supra* note 186. The Department of Labor reports that the number of FMLA-related complaints has averaged around 3,000 per year for the last five years. *Id.* Most of these complaints are settled out of court at the administrative level. *Id.*

226. *Id.* One major area of dispute between employees and employers under the FMLA is whether stress-related illnesses constitute a “serious health condition” covered under the act. *Id.* Employers have reported that employees are abusing the intended purpose of the FMLA, by claiming that the flu or a headache entitles them to leave under the FMLA. *Id.* Because tensions have risen in the past few years, the Department of Labor has launched a public inquiry regarding whether the FMLA is serving its intended purpose of providing twelve weeks of unpaid leave for a variety of health-related reasons. *Id.* The two most litigated areas under the FMLA are the definitions of “serious health condition,” and when an employee may request an unscheduled intermittent leave. *Id.* Intermittent leave permits an employee with a “chronic condition,” to take leaves of absences occasionally. *Id.* The courts have not provided any serious guidance in this area, yielding conflicting interpretations that have only added to the confusion of employers, employees, and the Labor Department. *Id.* Defense attorneys for employers maintain that this is a serious problem that has become unmanageable, stating that employers have become “frustrated” with employee abuse of the FMLA. *Id.* Plaintiffs’ attorneys argue that litigation under the FMLA is a result of employers refusing to grant employees leave under the FMLA. *Id.* The Plaintiffs’ claim is directly supported by the 2002 victory for an employee who was retaliated against by his employer for taking FMLA leave to care for his “aging parents.” *Id.* The jury verdict in that case was the largest FMLA award of \$11.65 million, and the case was settled on appeal for an undisclosed amount. *Id.* There is also a FMLA class action filed in the Northern District of Illinois against AT&T alleging that the company visited the homes of its employees to make sure that they were at home, monitored the employees’ “comings and goings from their houses,” and notified certain employees that while under FMLA leave they could only leave their homes to attend doctor’s appointments or to visit the drug store. *Id.* Conversely, defense attorneys state that if employers are worried about litigation under FMLA being brought against them, if they are unclear about whether to grant leave for an employee’s specific condition, they should err on the side of caution and “nine out of ten times” grant the request. *Id.*; see also *Butler v. Illinois Bell Telephone*, No. 06 C 5400, 2008 U.S. Dist. LEXIS 11901 (N.D. Ill. Feb. 14, 2008).

227. See Baldas, *supra* note 186.

The increased amount of litigation under the FMLA is a prediction of the future legislative trend under GINA. Like the FMLA, GINA's provisions are not clear to employers. Therefore, similar to the FMLA, employees can increasingly file complaints that genetic information is being mishandled by their employer because they do not understand the provisions of GINA. On the other hand, the confusing terms under GINA could also cause an employer to complain that employees are abusing the provisions of GINA, because the company does not understand what information is protected. Moreover, like the FMLA, GINA affords employees a private right of action to bring suit in court if they are not satisfied with the outcome of their administrative proceeding. Employees will increasingly rely on that right to bring litigation against employers.

Historically whenever Congress has relied upon broad provisions to ensure wide coverage there have been enforcement problems. For instance, GINA's broad definition of "genetic information" is similar to the FMLA's definition of "serious condition."<sup>228</sup> When the FMLA was first enacted, there appeared to be a clear understanding between both employees and employers that a "serious condition" meant an illness that was narrowly defined as potentially life threatening.<sup>229</sup> In recent years, there has been movement away from this strict interpretation to a more liberal construction.<sup>230</sup> The employers' reliance on the broad use of "serious condition" led employers to grant leaves for conditions not originally intended by Congress to be covered under the FMLA.<sup>231</sup> Similarly, because GINA relies on broad definitions of "genetic information" and "family members," GINA will also cause confusion for employers and misuse by employees.

Finally, the lack of litigation regarding genetic discrimination under state statutes, the executive order, and federal law should not be interpreted as evidence that litigation will not occur under GINA.<sup>232</sup> As tech-

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228. *See Id.*

229. *Id.*

230. *Id.*

231. *Id.* When the FMLA was first passed, employers granted requests under FLMA that were not "serious health condition(s)." *Id.* Employers have a duty to be compassionate and understanding, but at the same time make sure that granting leave does not begin to negatively impact the company. *Id.* These two goals are at odds with one another. Therefore, an employer must find a balance between compassion and doing those actions which are in the best interest of the company. *Id.* This problem is furthered not only by frivolous claims, but for those individuals who have conditions that should be protected under the FMLA and do not fall into one specific category under the Act. *Id.* Further, some employers have chosen to ignore the law entirely even though the FMLA act has been on the books for twelve years. *Id.*

232. Audio tape: Webinar Conference on GINA and the 2008 ADA Amendment, held by Seyfarth Shaw LLP (Sept. 2008) (on file with author) [hereinafter Seyfarth Shaw Webinar]. Another important factor to consider in predicting whether litigation will occur under GINA is to examine the number of genetic suits that have currently been brought under

nology improves and the cost of genetic testing declines, health care providers will rely more and more upon genetic testing as a healthcare tool.<sup>233</sup> As genetic testing becomes more predominant, the risk of genetic discrimination likewise grows exponentially. Therefore, as more individuals undergo genetic testing, the pool of potential litigants increases as well.<sup>234</sup>

Now that GINA has taken effect, litigation is likely to ensue. Employees not only have a channel for relief expressly provided under GINA, they may also rely on other federal statutes to bring suit. Past genetic discrimination claims have been redressed by substantial amounts, even though a plaintiff could not recover punitive damages.<sup>235</sup> GINA, however, entitles a plaintiff to recover compensatory, as well as punitive, and equitable relief. Therefore, even though damages are capped, an award can still be substantial under GINA.<sup>236</sup>

#### D. STEPS EMPLOYERS SHOULD TAKE TO LIMIT LIABILITY UNDER GINA

To help prevent and limit liability, an employer must ensure that it is in compliance with GINA's Title II provisions.<sup>237</sup> It is important to remember that GINA does not preempt more inclusive state statutes, and there is no safe harbor provision under GINA; therefore, an employer must also comply with state regulations.<sup>238</sup>

In order for an employer to ensure its compliance with GINA an employer must examine its current employment practices. In order to determine whether or not an employer's current employment practices are sufficient to comply with GINA, an employer should examine its nondiscrimination policies, current policies on the retention and disclosure of employee medical information, benefit and wellness plans offered by the employer, and electronic privacy practices. Most importantly, it is the

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current state law. *Id.* Thirty-four states have statutes that prohibit employers from discriminating against employees on the basis of genetic information. *Id.* Additionally, Executive Order 13145 prohibits the government from discriminating against its employees on the basis of genetic information. *Id.*

233. *See Safe and Effective Testing, supra* note 35.

234. *Id.*

235. Press Release, The United States Equal Employment Opportunity Commission, EEOC and BNSF Settle Genetic Testing Case Under Americans With Disabilities Act (May 8, 2002), available at <http://www.eeoc.gov/press/5-8-02.html> (stating that the case was settled for \$2.2 million).

236. H.R. 493, 110th Cong. § 207(a)(3) (2008).

237. Employment Coalition Letter, *supra* note 202 (noting a safe harbor provision would make an employer who is currently in compliance with the provisions of a federal statute immune from liability under state laws regarding that same form of discrimination).

238. *Id.* Discussions of the individual states' laws on genetic discrimination are outside of the scope and purposes of this comment.

employer's duty to ensure that its employees' genetic information remains confidential.

1. *Expand Current Nondiscrimination Practices to Include Genetic Discrimination*

GINA's purpose is to prevent discrimination and should be complied with in the same manner as other federal laws addressing discrimination. If an employer has an employment statement, it must amend such statements to include language stating that the employer "will not discriminate against an individual in hiring, promotion, pay, fringe benefits, job training, classification, referral, and other aspects of employment based on an individual's genetic information."<sup>239</sup>

In order to safeguard themselves from potential litigation, employers must also immediately stop any current practice of asking employees for genetic information. Even if an employer believes it will not rely upon genetic information in any discriminatory way, employers should not ask employees for this information.<sup>240</sup> In addition, an employer should also no longer ask for an employee or applicant's family medical history.<sup>241</sup>

Requesting information regarding a family member's medical condition to evaluate a leave request under the FMLA could subject an employer to liability.<sup>242</sup> Thus, another safeguard employers must implement is a policy, which avoids inadvertent disclosure of genetic information when requesting documentation to grant an FMLA request. FMLA requests have the potential to disclose genetic information about an employee's family members' genetic conditions.<sup>243</sup> Even though this practice is permissible under GINA, an employer should not engage in this act in order to protect it from future litigation.<sup>244</sup>

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239. DEP'T OF LABOR, EQUAL EMPLOYMENT OPPORTUNITY IS THE LAW, available at <http://www.dol.gov/ofccp/regs/compliance/posters/pdf/eeopost.pdf> (noting equal employment opportunity statement should afford that an employer does not discriminate in hiring, promotion, discharge, pay, fringe benefits, job training, classification, referral, and other aspects of employment on the basis of race, color, religion, sex (including pregnancy and sexual orientation), or national origin).

240. Meyer, *supra* note 206.

241. Seyfarth Shaw Webinar, *supra* note 233.

242. McGowan, *supra* note 18. For example, an individual who reported on an FMLA application that she needed time off to care for her mother who is suffering from breast cancer has inadvertently disclosed the manifestation of a genetic condition to her employer. *Id.* The employee could later use that incident to argue that the employer discriminated against her if she was passed up for a promotion. *Id.*

243. Gordon, *supra* note 150.

244. *Id.*

## 2. *Minimize Risk of Inadvertent Collection*

Litigation under GINA will most likely result from an employer's *inadvertent collection* of genetic information.<sup>245</sup> Employers' inadvertent collection is often referred to as the water-cooler collection of employee information.<sup>246</sup> For example, suppose an employee disclosed to one of his co-workers that there was a history of colon cancer in his family. If his co-worker informed their employer, the employer would have inadvertently acquired genetic information about an employee. If the employee knew that his employer had this information, and later took an adverse employment action against him, the employee could argue that the action was a result of genetic discrimination.<sup>247</sup>

Additionally, while GINA prevents an employer from acquiring and collecting genetic information from commercially and publicly available sources such as newspapers, magazines, periodicals, and books that include family medical history, it does not specifically prevent the employer from using medical databases or court records.<sup>248</sup> Therefore, an employer should take extra precaution and assume there is a risk of inadvertent collection if genetic information is retained from medical databases and court records. Court records and medical databases are not expressly prohibited as sources of genetic information.<sup>249</sup> Thus, to minimize potential liability for inadvertent collection an employer should implement a policy prohibiting the collection of any medical information from court records or medical databases.<sup>250</sup>

Moreover, GINA does not provide for the situation where an employer visits an employee at the hospital.<sup>251</sup> During such a visit, there is a possibility the employer could obtain information regarding an individual's genetic information.<sup>252</sup> If the employer were to take an adverse action against the employee after such a visit, it is possible that the employee could file a claim alleging the action was based on the employer's discrimination of genetic information.<sup>253</sup>

Every person who undergoes a genetic test or has a known manifested disease in his family is a member of a protected class under

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245. Interview with Steve Pearlman, Senior Associate, Seyfarth Shaw LLP, in Chicago, Ill. (Oct. 9, 2008); Steve Pearlman, Senior Associate, Address on GINA at the Labor and Employment Relations Association Lunch (Oct. 2, 2008) [hereinafter LERA].

246. LERA, *supra* note 246.

247. *Id.*

248. H.R. 493, 110th Cong. § 202(4) (2008).

249. H.R. 493, 110th Cong. § 206(b)(3) (2008).

250. H.R. 493, 110th Cong. § 206(b)(3)(B), (2008); *see also* Seyfarth Shaw Webinar, *supra* note 233.

251. LERA, *supra* note 246; Seyfarth Shaw Webinar, *supra* note 233.

252. *Id.*

253. *Id.*

GINA.<sup>254</sup> It is argued that GINA has, in a sense, opened Pandora's Box for employers. Not a single human being has perfect genes.<sup>255</sup> Therefore, because every individual has a predisposition to develop genetically linked diseases in the future, every person has a basis for filing a claim founded on genetic discrimination.<sup>256</sup> Because the ramifications for inadvertent collection are substantial an employer must ensure that all measures are taken to prevent inadvertent collection of genetic information.<sup>257</sup>

### 3. *Employment Benefits and Wellness Plans*

GINA will play a major role in the future development of employee benefits and wellness plans.<sup>258</sup> As genetic testing becomes more common in future healthcare, it is realistic that an employer will offer genetic services as part of an employee benefit or wellness program.<sup>259</sup> One of the new features employers are offering as part of their wellness plans are health risk assessments ("HRAs").<sup>260</sup> An employer currently offering HRAs as part of their wellness plans must ensure the medical information collected does not violate the provisions of GINA.<sup>261</sup> If an HRA currently in place affects the ability of an employee to participate in

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254. McGowan, *supra* note 18 (citing according to Rebecca Springer of Crowell & Moring, "the act is broadly written and creates an opportunity for an employee who has told his employer of family history of alcoholism, for example, to claim genetic bias if he is subsequently fired").

255. Ricardo Alonso-Zaldivar, *Senate backs privacy for genetic data*, L.A. TIMES, April 25, 2008 available at <http://articles.latimes.com/2008/apr/25/nation/na-genes25>.

256. *Id.*

257. See Agreed Order, *supra* note 158; see also May 8, 2002 Press Release, *supra* 236; see also H.R. 493, 110th Cong. §207(a)(3) (2008) (providing compensatory and punitive damages as well as other equitable relief).

258. Meyer, *supra* note 206. As employers continue to develop their wellness programs that are centered on improving the health of their employees, they must take GINA into consideration along with the Health Insurance Portability and Accountability Act, the ADA, and Title VII. *Id.* A major trend among employers that provided wellness plans is to offer employees two different plans, one for health and one for wellness. *Id.*

259. Gordon, *supra* note 150 (noting genetic counseling could be offered currently or in the near future by employers as part of an employee benefit or wellness program); see also National Society of Genetic Counselors, *Genetic Counseling as a Profession*, <http://www.nsgc.org/about/definition.cfm>.

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates: interpretation of family and medical histories to assess the chance of disease occurrence or recurrence, education about inheritance, testing, management, prevention, resources and research, and counseling to promote informed choices and adaptation to the risk or condition. *Id.*

See also Human Genome Project, *Genetic Counseling*, [http://www.ornl.gov/sci/techresources/Human\\_Genome/medicine/genecounseling.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genecounseling.shtml).

260. Meyer, *supra* note 206.

261. *Id.*

a health plan, this would be a violation of GINA.<sup>262</sup>

Another facet of employer-provided wellness plans that must be reviewed are those plans that pay cash bonuses to employees for maintaining a certain level of health.<sup>263</sup> A predisposition or diagnosis of a genetic disease could prevent an employee from attaining a level of health that would entitle him to a cash bonus. If an employee was denied a cash bonus based on his genetic information, he could bring suit under GINA.<sup>264</sup> An employer need not sacrifice compensating employees all together in an effort to take proactive steps to improve the health of its own employees.<sup>265</sup> Rather, there are other ways to encourage and award employees who take an active role in improving their health such as bonuses for participation in fitness events or participation in stress-management classes.<sup>266</sup>

Under GINA, there is an exception for the acquisition of genetic information in accordance with employer-provided group-health and wellness plans.<sup>267</sup> If genetic information is made available under this exception, the information may not have any individual identifying characteristics, and must be provided to the employer in aggregate terms.<sup>268</sup> GINA expressly states that information regarding an individual's sex or age cannot be disclosed to an employer.<sup>269</sup> GINA, however, does not mention disclosing information based on race or national origin. If an employer lacks diversity among its employees, race or national origin could be used to single out an employee if the genetic disease is associated with only one race or national origin. Thus, GINA makes it advisable for an employer to limit access to genetic information in making a contribution or paying for genetic services.<sup>270</sup>

#### 4. *Duty to Maintain Confidentiality*

An individual's genetic makeup is extremely private information due to its sensitive nature. Congress took this into consideration when drafting GINA because it imposed a strict standard of confidentiality. GINA requires employers to treat an employee's genetic information similarly to any other medical information an employer keeps on file.<sup>271</sup> Genetic in-

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262. *Id.*

263. *Id.*

264. *Id.* (stating an example of current cash bonuses offered to employees include employees who reach certain blood pressure, cholesterol, and body mass targets).

265. *Id.*

266. Meyer, *supra* note 206.

267. H.R. 493, 110th Cong. § 202(b)(1)(A) (2008).

268. H.R. 493, 110th Cong. § 202(b)(1)(D) (2008).

269. H.R. 493, 110th Cong. § 201(4)(C) (2008).

270. Gordon, *supra* note 150.

271. *Id.*

formation, therefore, should be afforded the same protection as medical information under the ADA.<sup>272</sup> This means that genetic information must be labeled as confidential and preserved on separate forms in a separate medical file. As an added precaution, accessibility must be limited on a strict need-to-know basis.<sup>273</sup>

Under the heightened confidentiality provisions of GINA, employers must ensure that if they currently have, or obtain genetic information regarding an employee, that the information is adequately protected. Employers must review their current system regarding the storage of medical files to see whether there are changes that must be made to accommodate the specific confidentiality provisions set forth under GINA. One measure that should be incorporated is the training of individuals who will have access to genetic information on how to determine whether medical information constitutes genetic information under GINA.<sup>274</sup> Additionally, an employer should require that genetic information be placed into a separate file upon receipt to ensure that it is kept confidential.<sup>275</sup> An employer should go as far as clearly labeling the information as genetic information, placing the information into a locked filing cabinet, and even placing a note on the file that the information should not be disclosed except through a court order.<sup>276</sup>

Moreover, GINA specifically affords very narrow circumstances in which an employer can disclose an employee's genetic information. GINA, however, does not provide an exception for responding to a subpoena or civil discovery request.<sup>277</sup> This is problematic because:

employment litigators, particularly on the defense side, commonly subpoena personnel files, including all medical information—for example, to test a plaintiff's allegations that the current employer's alleged actions caused emotional distress. An employer that inadvertently produces genetic information in response to such a subpoena would violate GINA because the act does not require a knowing disclosure to support a claim.<sup>278</sup>

### 5. *Compliance Could Evidence Good Faith Effort*

Even if an employer takes every conceivable step possible to ensure compliance with the provisions of GINA, litigation still may be inevitable

272. *Id.*

273. *Id.*; see also U.S. Navy, *HIPPA Frequently Asked Questions*, <http://www.bethesda.med.navy.mil/patient/hipaa/faqs.asp> (last visited Nov. 27, 2008) (defining *need-to-know* basis as minimum necessary protections under the rule).

274. Gordon, *supra* note 150.

275. *Id.*

276. McGowan, *supra* note 18.

277. *Id.*

278. *Id.*; see also Employment Coalition Letter, *supra* note 202.

as attorneys push the envelope as to what claims may be brought under GINA. Litigation may be inevitable against an employer even if all measures provided for in this comment and beyond are implemented.

One incentive to employers to undertake immediate compliance measures is that if an employer is sued it could rely on the compliance steps previously taken to evidence of good faith.<sup>279</sup> Because an employer can be held liable for compensatory and punitive damages under GINA,<sup>280</sup> an ongoing commitment to compliance may show good faith, thereby dissuading a court from awarding punitive damages.<sup>281</sup>

## E. THE IMPORTANT PUBLIC POLICY CONCERNS UNDER GINA

GINA has been hailed as an important step in the movement from a health care system focused on treating the sick, to a system focused on prevention.<sup>282</sup> Under GINA there is a sunset provision that will allow Congress to revisit GINA in six years and make amendments.<sup>283</sup> At that time, there are three important policy concerns that must be considered by Congress in order to ensure that GINA will prevent genetic discrimination. First, GINA must prevent employers from discriminating against employees based on a likelihood of developing a disease in the future. Second, GINA must afford adequate protection so that individuals will accept genetic testing as a part of the future of healthcare. Third, the provisions of GINA should clearly reflect congressional intent and yield uniform interpretations by the courts to limit potential confusion.

### 1. *Reduce Discrimination*

Reducing the potential for discrimination is a major goal and value in society today. There have been numerous cases litigated on behalf of individuals who have been historically discriminated against in order to provide an equal opportunity for everyone regardless of individual characteristics.<sup>284</sup> Discriminating factors have evolved over time from sex and race to current issues of alien status and genetics.<sup>285</sup> As technology

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279. LERA, *supra* note 246.

280. H.R. 493, 110th Cong. § 207(a)(1) (2008).

281. *See Alvarez v. IBP, Inc.*, 339 F.3d 894 (9th Cir. 2003) (rejecting employer's good faith argument where employer was on notice for three years to comply with the FMLA and failed to do so). *See also Damages, supra* note 223.

282. *See Zapata, supra* note 134 at 5.

283. H.R. 493 110th Cong. § 208(b) (2008).

284. *See* GEORGE RUTHERGLEN, *EMPLOYMENT DISCRIMINATION LAW: VISIONS OF EQUALITY IN THEORY AND DOCTRINE* 6-8 (Foundation Press 2d ed. 2007) (2001).

285. *Id.*; Howard F. Chang, *Immigration and the Workplace: Immigration Restrictions as Employment Discrimination*, 78 CHI-KENT L. REV. 291 (2003); John C. Hendrickson, *Selected Materials on Emerging Employment Discrimination Claims*, 782 P.L.I./LIT. 403 (2008).

progresses, the potential for discrimination based on internal genetic differences increases. One major concern about relying upon genetic information is that having the potential to develop a disease in the future does not ensure the disease will manifest itself. Therefore, relying on genetic information for discriminatory purposes places different treatment based on an individual's characteristic that may not exist.

## 2. *Encourage Genetic Testing*

The ability to predict a predisposition of developing any genetic disease is becoming more of a reality every day. The ability of a nation to adopt and incorporate advancements in technology creates vast improvements in the lives of its citizens, and can lead to an improvement in utility.<sup>286</sup> Such an improvement in utility can be translated into a more productive workforce, and therefore a more productive economy.<sup>287</sup>

There are numerous benefits provided by genetic testing. One of the most beneficial is that genetic testing will shift the focus of the health care industry in the United States away from a system focused on treatment, to a system focused on prevention. If an individual undergoes a genetic test and finds out that he is predisposed to developing a particular disease, healthcare providers will be able to take steps to prevent the disease from developing, instead of treating a disease after it has fully developed.<sup>288</sup> Moreover, a genetic test confirming that an individual is predisposed to developing a disease in the future could encourage the individual to make lifestyle changes. Immediate lifestyle changes could prevent a disease from developing.<sup>289</sup>

Genetic testing will afford individuals the ability to learn about predispositions to genetic conditions and therefore take preventative measures to reduce the risk of a genetic disease manifesting later. Additionally, as more genetic information becomes available, geneticists will be able to develop individualized medicine to treat patients. This has a dual benefit to employers. First, with individual tailoring of medicine, an employee's recovery time for serious diseases could be greatly reduced.<sup>290</sup> Thus, the potential loss in time for trial and error treatments will reduce the length of time an employee is off work and

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286. Dictionary.com, *Utility*, <http://dictionary.reference.com/browse/utility> (last visited Nov. 30, 2008) (defining utility as that which is conducive to the happiness and well-being of the greatest number).

287. *Id.*

288. NATIONAL HUMAN GENOME RESEARCH INSTITUTE, FINAL REPORT OF THE TASK FORCE ON GENETIC TESTING (Sept. 1997), available at <http://www.genome.gov/10001733>.

289. *Id.*

290. See Monica G. Marcu, *Personalized Medicine: Sweet or Bitter Pill?*, THE SCI. ADVISORY BOARD, available at <http://www.scienceboard.net/community/perspectives.107.html>.

will also reduce the amount an employer will spend on healthcare.<sup>291</sup> Employer expenditures for healthcare will be reduced not only because the disease will not be treated for as long, but also because employees would not be undergoing unnecessary procedures.

### 3. *Reduce the Potential for Excessive Litigation*

In addition, there is a real potential threat of excessive litigation costs for suits brought under GINA. Not only will excessive litigation tie up the limited resources of the courts, but such litigation will require large expenditures by employers to defend themselves.<sup>292</sup> Moreover, the time and expense associated with frivolous lawsuits could deter individuals who have merit based claims from filing their own suits. Therefore, there is a real need for measures to reduce the amount of litigation brought under GINA and to ensure those claims brought in good faith can be adequately investigated, pursued, and remedied.

These three policy goals must be kept in mind when GINA is revisited in the future, since the purpose of GINA was to reduce genetic discrimination. Therefore, Congress and the appointed taskforce must ensure that GINA prevents genetic discrimination. Additionally, based on the tremendous advantages of genetic testing, individuals must be encouraged by GINA to undergo genetic tests. Finally, Congress and the taskforce must prevent frivolous litigation under GINA. There must be a balancing of these goals if GINA is to do all that it is intended to do.

## IV. CONCLUSION

GINA was enacted by Congress with good intentions. Congress sought to limit discrimination based on genetic information by employers and health care providers; however, GINA, as currently enacted, is problematic. Current federal laws could have prevented genetic discrimination making GINA duplicative. Additionally, because GINA was enacted before a court interpreted genetic discrimination as not being protected under current federal laws, it is also premature.

Until litigation arises under GINA, it remains unclear whether GINA will live up to Congress' expectations. However, as enacted, there are issues under GINA that conflict with Congress' intentions. The mandate for a uniform federal law is weakened by not preempting state laws. The intentionally broad definitions relied upon in the legislation could lead to a surge in litigation due to confusion by both employers and employees on how to interpret GINA. The reliance of GINA on a Title VII enforcement scheme is also unduly harsh on employers who could be lia-

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291. *See Id.*

292. *See* John Phillips, *GINA: Goddess of Genes*, <http://employmentlawpost.com/the-word/2008/05/28/gina-goddess-of-genes/> (May 28, 2008, GMT 9:20).

ble under its provisions for non-intentional disclosures of genetic information. These issues with the provisions of GINA will lead to litigation.

Historically, where a new private right of action is afforded to individuals, this right of action always leads to an increase in litigation. Therefore, employers need to ensure that they are implementing practices now that will comply with the new regulations under GINA. An employer must make clear that it does not discriminate against employees based on genetic information, minimize its ability to inadvertently collect genetic information, examine current practices and remedy any defects, ensure any genetic information it has is confidentially stored, and realize the movement toward electronic storage of health information to ensure that their measures are current. Finally there are three public policy goals that must be adequately promoted by GINA and subsequent legislation. Employees must be assured that their genetic predispositions will not be used adversely against them in employment decisions. Employees also should feel free to undergo genetic testing not only for personal benefits, but indirect benefits that could be realized by the employer. Finally, with this expanded protection to employees, there must be some type of control put forward to limit the number of frivolous lawsuits brought against employers.