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# Genetic Discrimination in the Workplace: An Overview of Existing Protections

*Melinda B. Kaufmann\**

Our fate is in our genes.<sup>1</sup>

## I. INTRODUCTION

The sophistication of genetic technology has grown at an amazing rate. As this technology improves, scientists can predict more genetic markers and traits than ever before.<sup>2</sup> Genetic information can potentially benefit society because it is likely to lead to cures and treatments for currently incurable genetic disorders. This knowledge, however, also has the potential to create a biological underclass of people based on their latent genetic disorders. Some critics have gone so far as to suggest that knowledge of genetic fitness could be used to choose between parents in custody battles, or to determine whether potential adoptive parents are suitable.<sup>3</sup> More commonly, however, genetic technology can be used to screen applicants for both employment and health insurance.

Several studies have noted a significant trend in the use of genetic testing in employment. For example, a 1989 study conducted by the United States Congress Office of Technology Assessment (“OTA”) that surveyed Fortune 500 companies,<sup>4</sup> discovered that of the 330

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1. Leon Jaroff, *The Gene Hunt*, TIME, Mar. 20, 1989, at 62, 67 (quoting James Watson, Director of the Human Genome Project).

2. For example, genetic tests currently available include identification of adult polycystic kidney disease, fragile X syndrome, sickle cell anemia, Duchenne muscular dystrophy, cystic fibrosis, Huntington’s disease, hemophilia, phenylketonuria, and retinoblastoma. See OFFICE OF TECH. ASSESSMENT, U.S. CONGRESS, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 15, tbls.1-2 (1990) [hereinafter GENETIC MONITORING SURVEY].

3. See Brian R. Gin, *Genetic Discrimination: Huntington’s Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406, 1411 (1997) (suggesting that in the future adoption agencies may choose suitable parents based on their genetic potential and that the same information may be used by courts in determining who should receive custody of children in divorce settlements).

4. See GENETIC MONITORING SURVEY, *supra* note 2, at 21 tbls.1-5 (asking each company if it was conducting either “biochemical genetic screening” or “direct DNA screening” on its employees or potential employees).

companies responding, twelve companies admitted to currently conducting genetic tests on employees.<sup>5</sup> In a follow-up survey, the OTA reported that almost half of the health officers and personnel officers surveyed said their companies would approve of pre-employment exams to screen applicants for genetic susceptibility to workplace toxins.<sup>6</sup> These numbers are projected to increase as another survey revealed that fifteen percent of responding companies plan to use genetic testing as a condition to employment by the year 2000.<sup>7</sup> In addition, some companies indicated that their future use of genetic testing could depend upon its cost-effectiveness.<sup>8</sup> At the time of the survey, however, few of these surveyed companies felt that genetic testing was cost-effective.<sup>9</sup>

Currently, some employers already use the results of medical tests as a hiring criterion before extending a final job offer.<sup>10</sup> While the practice of genetically testing employment applicants is not widespread, its expansion seems inevitable as the tests become cheaper and easier for employers to use. Support for this proposition comes

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5. See Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 115 (1991). Further, eight companies admitted to utilizing genetic testing in the past. See *id.*

6. See OFFICE OF TECH. ASSESSMENT, U.S. CONGRESS, MEDICAL MONITORING AND SCREENING IN THE WORKPLACE: RESULTS OF A SURVEY-BACKGROUND PAPER 4 (1991) [hereinafter MEDICAL MONITORING SURVEY]. Congress initially became interested in the issue of genetic monitoring and screening in the workplace in the late 1970s and early 1980s. See *id.* at 16. This interest led to hearings by the House Committee on Science and Technology and an OTA assessment formally labeled *The Role of Genetic Testing in the Prevention of Occupational Diseases in 1983*. See *id.*

7. See Gostin, *supra* note 5, at 115 (discussing the Northwestern National Life Insurance Company survey conducted in 1989). Further studies have uncovered anecdotal information about genetic discrimination in employment. See Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476 (1992). Billings reported 42 incidents of genetic discrimination, 39 of which involved insurance or employment. See *id.* at 478. For example, one insurance company denied an individual coverage due to his hereditary hemochromatosis, a condition resulting in excessive iron storage. See *id.* The insurance company refused coverage despite the fact that the individual never had even the slightest symptom and underwent preventative treatment. See *id.* Another case involved an individual whose brother was diagnosed with Gaucher Disease. See *id.* When the individual applied for a governmental job, the government agency denied him employment because he was a "carrier, like sickle cell." See *id.*

8. See MEDICAL MONITORING SURVEY, *supra* note 6, at 5.

9. See *id.* at 38.

10. See *id.* at 44. Specifically, 36% of the companies surveyed admitted to periodically engaging in health insurance risk assessments of prospective employees. See *id.*

from the Ethical, Legal and Social Implications research component of the Human Genome Project,<sup>11</sup> which has identified the possibility of employers using the new genetic information for discrimination as one of the major concerns of increased genetic knowledge.<sup>12</sup> Yet, thus far no court has directly addressed the issue of genetic testing.<sup>13</sup>

This Article discusses the legal and ethical ramifications of using genetic screening to select job applicants and genetic monitoring of employees. This Article begins by explaining how genetic testing is used as a screening and monitoring tool.<sup>14</sup> In doing so, it also traces the history of discrimination based on genetic testing in the United States.<sup>15</sup> This Article then addresses an individual's potential protections under the Americans with Disabilities Act ("ADA") including individuals protected by the ADA, the impact of testing on job applicants, the requirements of an ADA action, and the Equal Employment Opportunity Commission's ("EEOC") interpretation of

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11. The Human Genome Project is a collection of related, independent research projects with the ultimate goal of analyzing the structure of human DNA, and mapping and sequencing the estimated 100,000 human genes. The project began in 1990 and its estimated completion date is 2005. See Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 24-25 (1992) (discussing the impact of the Human Genome Project on the operation of the ADA and the inadequacies of the ADA to protect against genetic based discrimination).

12. See Lynda M. Fox & Sherman G. Finesilver, *Genetics and the Workplace: ADA Applicability to Genetic Information*, 26 COLO. LAW. 75, 75 (1997) (citing *Using Gene Tests to Deny Jobs is Ruled Illegal*, N.Y. TIMES, Apr. 8, 1995, at A12) (reporting that the Equal Employment Opportunity Commission considers the use of genetic tests discriminatory if used to deny employment)).

13. Recently, both current and former employees of a state and federally funded laboratory filed a claim in the Northern District of California. The claim alleged that the laboratory performed genetic and other medical tests (specifically for syphilis, sickle cell, and pregnancy) without informing the applicants of the tests. Further, the claims alleged violations of the Americans with Disabilities Act ("ADA"), Title VII, and the right to privacy under both the United States and California Constitutions. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, No. 95-03220 (N.D. Cal. Sept. 3, 1995). The District Court dismissed all the employees' charges based on motions for dismissal, improper pleadings, and summary judgment. On appeal, the Ninth Circuit reversed all but the district court's dismissal of the ADA claims. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1275 (9th Cir. 1998). The Court of Appeals found that the plaintiffs stated a claim based on violations of Title VII (the plaintiffs' complaint alleged that the tests for sickle cell were only given to African Americans, and the pregnancy tests were only given to women), as well as privacy claims based on violations of both the United States Constitution and the California Constitution. See *id.* at 1269-73. Thus, while the merits of the claims are pending, at least one circuit has recognized that genetic testing implicates Title VII and privacy claims.

14. See *infra* Part II.

15. See *infra* Part II.B.

the ADA.<sup>16</sup> Further, this Article discusses potential claims based on Title VII of the Civil Rights Act.<sup>17</sup> Next, this Article addresses the effect of the Occupational Health and Safety Act ("OSHA") on genetic testing.<sup>18</sup> It follows with a discussion of the constitutional ramifications based on privacy rights that arise from genetic testing.<sup>19</sup> It then chronicles several state efforts to control genetic testing within their borders.<sup>20</sup> Finally, this Article concludes that current jurisprudence provides adequate protection against genetic discrimination based on genetic testing in the employment arena.<sup>21</sup> It suggests, however, that Congress needs to specifically include genetic testing within the protections of the ADA, in order to stem the present confusion that has spurred so many states to pass their own genetic protection laws.

## II. GENETIC TESTING—AN OVERVIEW

Every person is genetically unique. An individual's genetic structure is the blueprint to his or her personal characteristics. A basic understanding of genetics begins with a discussion of deoxyribonucleic acid ("DNA"), which is the building block of an individual's genes.<sup>22</sup> These genes link together to make up chromosomes. Each individual has 23 pairs of chromosomes that ultimately determine the individual's genetic traits. Scientists estimate "that there are over 3 billion base pairs of DNA in the human genome."<sup>23</sup> The Human Genome Project began in 1990.<sup>24</sup> It is a collection of related, independent research projects with the ultimate goal of analyzing the structure of human DNA by mapping and sequencing the estimated 100,000 human genes.<sup>25</sup> Although its

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16. See *infra* Part III.

17. See *infra* Part IV.

18. See *infra* Part V.

19. See *infra* Part VI.

20. See *infra* Part VII.

21. See *infra* Part VIII.

22. See ALTON BIGGS ET AL., *BIOLOGY: THE DYNAMICS OF LIFE* 312 (1995) (noting that organisms differ due to variations in the nucleotides of DNA).

23. *Id.* at 386. The human genome is the approximately 100,000 genes in the 46 human chromosomes. See *id.*

24. See Rothstein, *supra* note 11, at 24 (noting that the Human Genome Project is widely considered to be one of the most significant scientific projects ever conducted).

25. See *id.* at 24 (citing OFFICE OF TECH. ASSESSMENT, U.S. CONGRESS, *MAPPING OUR GENES—THE GENOME PROJECTS: HOW BIG, HOW FAST?* 4 (1988)).

estimated completion date is 2005,<sup>26</sup> only a few thousand of the known genes have been mapped on particular chromosomes to date.<sup>27</sup>

Some genetic traits can be linked to a single, identifiable gene. Geneticists have been able to identify over 200 human traits that are coded by a single, dominant allele or contrasting gene.<sup>28</sup> About 250 other traits have been traced to homozygous recessive genes.<sup>29</sup> Other genetic traits, however, are controlled by multiple genes.<sup>30</sup> As scientists learn more about genetics, it will become possible to determine an individual's genetic susceptibility to different conditions based on an examination of the individual's genetic make-up. Genetic testing allows doctors to predict a person's potential for future health problems and behavior disorders.<sup>31</sup> Testing to identify genetic disorders can occur through two processes: genetic screening and genetic monitoring.

#### A. *The Types of Testing—Tools For the Employer*

Genetic screening is a one-time test performed on job applicants in order to determine their current genetic predisposition.<sup>32</sup> Employers may genetically screen applicants using two methods—each can be used to identify the presence of genetic traits that render a person hypersusceptible to certain toxins<sup>33</sup> or detect general genetic conditions that are not necessarily associated with occupational diseases.<sup>34</sup> The first

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26. *See id.*

27. *See* BIGGS, *supra* note 22, at 386.

28. *See* ALBERT TOWLE, *MODERN BIOLOGY* 171 (1993). Huntington's disease is an example of a trait linked to a single allele or dominant contrasting gene. *See id.* This disease causes "loss of muscle control, uncontrollable physical spasms, severe mental illness, and eventual death." *Id.* at 172.

29. *See id.* at 171. A homozygous recessive gene is a gene that is directly linked to a single genetic trait. For example, cystic fibrosis and phenylketonuria (PKU) are two genetic diseases linked to a single, recessive gene. *See* BIGGS, *supra* note 22, at 358-59.

30. *See* Towle *supra* note 28, at 173. Thus, in order for an individual to manifest such a trait, he or she would have to possess a certain combination of genes.

31. *See* Kristie A. Deyerle, Comment, *Genetic Testing in the Workplace: Employer Dream, Employee Nightmare—Legislative Regulation in the United States and the Federal Republic of Germany*, 18 *COMP. LAB. L.J.* 547, 549 (1997) (noting the implications of genetic information for family members and its potential to stigmatize individuals).

32. *See* GENETIC MONITORING SURVEY, *supra* note 2, at 5 (noting that the focus of genetic screening is the "preexisting genetic makeup" that workers bring to the job).

33. *See id.* For example, an employer may screen applicants for susceptibility to benzene before beginning work when large amounts of benzene will be present in the workplace.

34. *See id.* For example, an employee could be tested for sickle cell trait, or

method, and the one most often used in the employment setting, is biochemical genetic screening.<sup>35</sup> This method consists of the analysis of mutant genes based on altered proteins or enzymes in the individual's bloodstream.<sup>36</sup> Biochemical genetic screening may be accomplished through either a simple blood test or the collection of a tissue sample. The second method is direct-DNA screening.<sup>37</sup> This method involves the direct examination of the individual's DNA.

Several reasons may motivate employers to conduct these or similar medical tests. For example, some employers simply may be complying with OSHA guidelines that require medical testing.<sup>38</sup> Alternatively, employers may be paternalistically shielding susceptible workers from known toxins. The employer's rationale, however, may also be self-serving. For instance, as employers increasingly provide health benefits to workers, genetic and medical screening may be used to weed out job applicants or workers who are likely to have higher insurance costs.<sup>39</sup> In addition, employers may be interested in decreasing the costs associated with occupational illnesses by eliminating workers with a genetic predisposition to those diseases.<sup>40</sup>

The second type of genetic testing is genetic monitoring. These tests involve periodic testing of individuals to evaluate any modifications that may have occurred in their genetic material.<sup>41</sup> These tests help determine the effect of workplace toxins on an employee's

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Huntington's disease, neither of which is triggered by workplace toxins.

35. *See id.*, at 21 tbls.1-5 (tracking Fortune 500 companies' use of genetic screening).

36. *See id.* at 10 (noting that the strides in DNA technology have increased our capability to examine the genetic basis for disease and to protect and to diagnose such diseases in large population groups).

37. *See id.* at 21 tbls.1-5. At the time of the survey, no employers reported current use of direct DNA-screening or monitoring of employees or applicants. *See id.*

38. *See infra* Part V (discussing OSHA and genetic testing).

39. *See Rothstein, supra* note 11, at 27 (pointing out that 42% of the companies questioned in an OTA survey used a job applicant's health insurance risk as a factor in deciding employability). This will unlikely serve as a successful argument for employers because of legislation, such as the Americans with Disabilities Act, that limit the type of medical testing employers are allowed to conduct on job applicants. *See id.* at 39-62 (discussing the ADA and its effect on genetic testing).

40. *See id.* at 73 (noting that concern over this type of screening surfaced in the 1980s when it was documented that some employers were investigating genetic traits for a link to occupational exposure).

41. *See GENETIC MONITORING SURVEY, supra* note 2, at 4 (listing "chromosomal damage" or "increased molecular mutations" during employment as examples of genetic material modifications).

genetic make-up.<sup>42</sup> Reasons given to conduct genetic monitoring include: identifying risks associated with certain toxins, targeting work areas for increased safety, and identifying previously unknown workplace toxins.<sup>43</sup>

Experts estimate that approximately three or four percent of all newborns, and approximately fifteen to twenty percent of adults, have congenital defects.<sup>44</sup> Additionally, each individual, regardless of any visible signs of a genetic defect, carries approximately five to seven lethal recessive genes.<sup>45</sup> Some of these defects will have immediate ramifications, while others only have future consequences or may have no impact on the individual's health.<sup>46</sup>

Various illnesses, mental traits, and personality characteristics have been linked to genetics.<sup>47</sup> At present, however, most of the genetic

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42. *See id.* It should also be noted that genetic monitoring can ascertain changes in genetic material due to factors outside the workplace such as habits, age, and lifestyle. *See id.*

43. *See id.*

44. *See Deyerle, supra* note 31, at 551 (noting that approximately one third of these adults have defects that involve either a major medical or major cosmetic impact).

45. *See id.* The consequence of carrying a lethal recessive gene is that while the individual himself will show no evidence of the defect, it is potentially hazardous for the individual's offspring if he should mate with another person carrying the same recessive gene. *See* RAYMOND F. ORAM, *BIOLOGY LIVING SYSTEMS* 144 (1983) (listing examples of diseases caused by gene defects such as sickle cell anemia, which blocks the normal transportation of oxygen to cells, and galactosemia, which may cause damage to the nervous system).

46. *See* ORAM, *supra* note 45, at 144. For example, carriers of one Tay Sachs gene will have no present symptoms. *See* BIGGS, *supra* note 22, at 344. The disease could potentially manifest itself in the individual's offspring if he or she mated with another Tay Sachs carrier. Someone carrying the gene for Huntington's disease, however, will eventually develop the symptoms of this degenerative disease. It is not certain, however, when the symptoms will appear. *See id.* at 37, 161. Other diseases, such as phenylketonuria (PKU) and galactosemia can be treated successfully and will have little or no impact on an individual's ability to work productively. *See* ORAM, *supra* note 45, at 145.

47. *See* Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 *VAND. L. REV.* 313, 320 (1992). Some personality traits thought to be linked to genetics include: mental illness, homosexuality, aggressive personality, job and educational success, exhibitionism, stress, risk-taking behaviors, and shyness. *See id.* Some examples of diseases linked to genetics include: sickle cell anemia, Bloom's Syndrome, Tay-Sachs disease, breast cancer, cystic fibrosis, Huntington's disease, and thalassemia. *See generally* Gostin, *supra* note 5, at 111 nn.9-11 (pointing out the fact that specific genetic diseases are sometimes closely linked to particular ethnic or racial groups such as African Americans, Ashkenazi Jews and Armenians); Karen H. Rothenberg, *Breast Cancer, The Genetic "Quick Fix" and the Jewish Community*, 7 *HEALTH MATRIX* 97, 98 (1997) (noting that nearly one percent of sampled Eastern European Jews contain a gene mutation that predisposes them to breast and ovarian cancer); Katherine Brokaw, Comment, *Genetic Screening in the Workplace and*



tests available are unreliable and often inconclusive.<sup>48</sup> Often a genetic test can only reveal the possibility that a person may develop a certain disease in the future, but cannot tell whether the individual will actually get the disease.<sup>49</sup> This is true because genetic tests are limited to known genetic mutations associated with known diseases.<sup>50</sup> Even tests with high reliability cannot predict the time frame of disease onset and eventual prognosis.<sup>51</sup> The uncertainty associated with genetic tests makes their use in employment decisions risky. Specifically, even though individuals may never manifest symptoms during their lifetime, mere *possibilities* of disease or a future genetic condition may cause discrimination. The use of genetic testing is more frightening when considering the history of genetic discrimination in the United States.<sup>52</sup>

### B. *The History of Genetic Discrimination in America*

Genetic discrimination is defined as “discrimination against an

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*Employers’ Liability*, 23 COLUM. J.L. & SOC. PROBS., 317, 324 n.33 (1990) (charting genetic traits and the primary group of people affected).

48. See Gostin, *supra* note 5, at 113 (explaining that medical technology does not always provide an accurate assessment); Brokaw, *supra* note 47, at 325-26 (discussing the inconclusive nature of scientific data linking traits to occupational disease).

49. See Gostin, *supra* note 5, at 114. For example, new genetic studies have linked the gene BRCA1 to breast and ovarian cancer. See Rothenberg, *supra* note 47, at 98 (noting that this finding has prompted a clinical study to evaluate cancer risk in Eastern Europe). Only about 5 to 10% of breast cancer cases, however, are linked to this gene. See *id.* at 98-99. It is estimated that a woman from a high-risk family with the BRCA1 gene has an 85% chance of getting breast cancer. See *id.* at 99. This means that while many women with the BRCA1 gene will develop breast cancer, many others will not. An employer who does not wish to employ women who will contract breast cancer may screen employees for BRCA1, but only at the cost of excluding many workers who may never develop the disease.

50. See Gostin, *supra* note 5, at 113 (noting that, at present, genetic screening can only detect 75% of cystic fibrosis chromosomes in the white population in the United States).

51. See *id.* at 113-14. For example, the presence of Huntington’s disease can be detected with 99% accuracy. See Gin, *supra* note 3, at 1415 (pointing out that a test to diagnose Huntington’s disease may be administered at any time in a person’s life and will have no bearing in the accuracy of the diagnosis). While a positive test result signals that an individual ultimately will get Huntington’s disease, it is impossible to predict when the disease will manifest itself and how quickly the person will become debilitated. See Gostin, *supra* note 5, at 114 (attributing this inability to Huntington disease’s “multi-factorial” nature and to the fact that it is caused by a specific gene mutation or marker). Thus, an individual with the genetic markers for Huntington’s disease may lead a long, productive life before the onset of the debilitating symptoms. See Gin, *supra* note 3, at 1414-15 (estimating that the disease begins to surface at age 35).

52. History has shown that we are apt to overreact to small steps in genetic understanding, often with the result of discrimination against healthy, productive individuals.

individual or a member of an individual's family solely on the basis of that individual's genotype."<sup>53</sup> The first known use of genetic discrimination occurred in the 1800s when Francis Galton published his theory of eugenics.<sup>54</sup> Eugenists generally exaggerated the extent to which human behavior and other traits could be traced to biology, including the supposed connections between genetics and disease.<sup>55</sup> As early as 1938, J. B. S. Haldane introduced the idea of classifying workers based on their genetic susceptibilities to disease.<sup>56</sup> One of the first reported cases of genetic susceptibility to a chemical agent or drug was in the 1950s when some American soldiers in Korea experienced hemolysis, (the destruction of red blood cells), after receiving the anti-malaria drug primaquine.<sup>57</sup> The hemolysis was attributed to the soldiers' carrier status for glucose-6-phosphate dehydrogenase ("G-6-PD") deficiency.<sup>58</sup>

History most vividly illustrates discrimination "based on genotype" through an examination of sterilization laws. During the early twentieth century many states enacted immigration laws aimed at "purifying and keeping pure blood in America."<sup>59</sup> In 1907, Indiana passed the United States' first sterilization law, forcing the sterilization

53. SUSAN MALAMATE VAZAKAS, *GENETIC DISCRIMINATION AND THE AMERICANS WITH DISABILITIES ACT 24* (1993) (citing Billings et al., *supra* note 7, at 477).

54. See Robert N. Proctor, *Genomics and Eugenics: How Fair is the Comparison?*, in *GENE MAPPING 57, 59* (George J. Annas & Sherman Elias eds., 1992). At the root of the eugenics movement was the fear that "'racial poisons' (especially alcohol, tobacco, narcotics, and syphilis) were threatening the health of the race; that the criminal, mentally ill, and morally dissolute were outbreeding the more upstanding elements of society." *Id.* at 60. One of the basic tenets of the eugenics movement was "biological determinism--the idea that biology lies at the root of most human talents and disabilities." *Id.*

55. See *id.* This movement was especially strong in Germany where the Nazi government funded substantial research into the area of eugenics. See *id.* at 60.

56. See *GENETIC MONITORING SURVEY*, *supra* note 2, at 41 (noting Haldane's specific suggestion to screen out potters who had "constitutions" that predisposed them for bronchitis).

57. See *id.*

58. See *id.* (explaining that people with this trait or status are commonly found in malaria-ridden areas, and it is also prevalent among African Americans and those with a Mediterranean ancestry).

59. DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USE OF HUMAN HEREDITY 97* (1985) (citing KENNETH LUDMERER, *GENETICS AND AMERICAN SOCIETY 95-96* (1972)) (quoting Congressman Robert Allen of West Virginia). In addition to the states, the federal government also passed biological laws aimed at keeping America's blood "pure." See *id.* at 97. Specifically, in April 1924, President Calvin Coolidge signed the Immigration Act, which severely limited the entrance of Europeans into the United States through 1927. See *id.*

of people suffering from many identified genetic disorders.<sup>60</sup> Other states followed suit over the next thirty years, generally targeting poor, immigrant, and institutionalized individuals.<sup>61</sup> The Eugenics Records Office was established in 1910 to collect genetic data to advise people on what constituted a fit marriage.<sup>62</sup> In 1927, the Supreme Court upheld these state-sanctioned sterilizations, and while this practice today seems dubious, the Court has never specifically overruled this decision.<sup>63</sup>

Several decades later, genetic screening again gained widespread use. Specifically, in the 1970s, sickle cell anemia screening programs began.<sup>64</sup> These programs were aimed to expose poor health care systems by identifying carriers of sickle cell anemia, a disease common among African Americans.<sup>65</sup> These programs were designed to identify both healthy carriers<sup>66</sup> and diseased carriers of sickle cell anemia. The programs affected healthy carriers of the gene because scientists suggested that carriers of the gene might be hyper-susceptible to certain workplace toxins such as benzene, lead,

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60. See Proctor, *supra* note 54, at 61 (noting that Indiana's sterilization law was a product of both American Eugenics and German racial hygiene).

61. See *id.* (noting that state laws preventing interracial marriages can also be linked to genetic discrimination); see also Patricia A. King, *The Past as Prologue: Race, Class, and Gene Discrimination*, in *GENE MAPPING* 94, 98 (George J. Annas & Sherman Elias eds., 1992). The most comprehensive of these laws was passed in Iowa which allowed sterilization of inmates in public institutions for crimes and other reasons including "drug addition, sexual offenses, and epilepsy." KEVLES, *supra* note 59, at 100.

62. See KEVLES, *supra* note 59, at 53-55 (discussing a program designed to ensure that marriages were appropriate based on a host of genetic criteria).

63. See *Buck v. Bell*, 274 U.S. 200 (1927) (per curiam). The Court upheld Virginia's forced sterilization law for "mental defectives" and found that the law did not violate the Fourteenth Amendment's Due Process or Equal Protection Clauses. See *id.* at 207. The law purportedly provided sufficient procedural safeguards and only targeted those who need treatment, which is done for their benefit. See *id.* at 207-08.

64. See Fox & Finesilver, *supra* note 12, at 75 (noting that screening was "widespread" until 1972 when a federal law mandated that all such screening be voluntary); see also King, *supra* note 61, at 98 (asserting that sickle cell anemia is a genetic disorder that may occur with varying severity and occurs with greatest frequency in people of African American descent).

65. See King, *supra* note 61, at 99 (noting that these programs began with the best intentions, and were supported by African American leaders until they realized that such measures "would be used to stereotype and disadvantage the very people they sought to help.").

66. A healthy carrier refers to an individual who carries only one gene for the trait. That person is said to be a sickle cell carrier. A person with sickle cell disease, on the other hand, has two sickle cell genes. That person will manifest symptoms of the condition. See *GENETIC MONITORING SURVEY*, *supra* note 2, at 42 (discussing sickle cell traits and discrimination against carriers of sickle cell).

cadmium, carbon monoxide, and cyanide.<sup>67</sup> Based on these suggestions, employers began testing workers for the gene even though available evidence and studies did not support this theory.<sup>68</sup> Moreover, many state legislatures mandated sickle cell testing, leading to further fear and discrimination.<sup>69</sup> Inadequate measures to keep the test results confidential led to stigmatization and discrimination against sickle cell carriers in employment.<sup>70</sup> Further, lack of knowledge and understanding of the disease led to discrimination against many carriers of the trait even though they would never develop sickle cell disease.<sup>71</sup> To alleviate some of this stigma Congress passed the National Sickle Cell Anemia Control Act.<sup>72</sup> This Act withholds federal funding from states unless sickle cell testing is voluntary.<sup>73</sup>

Our country's experience with sickle cell anemia testing suggests the dangers inherent to genetic testing. Like the sickle cell tests of the 1970s, scientists today understand relatively little about the genetic

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67. See Brokaw, *supra* note 47, at 323 (discussing concerns leading to testing for sickle cell in the workplace).

68. See *id.* Du Pont pioneered one of the first testing programs for employees exposed to benzene. See *id.* Du Pont, however, did not terminate workers who carried the sickle cell gene. See *id.* Instead, it transferred these workers to comparable positions where they would not come into contact with potentially dangerous toxins. See *id.* Additionally, Dow Chemical piloted one of the first cytogenetic monitoring programs in 1964. See GENETIC MONITORING SURVEY, *supra* note 2, at 44. Dow conducted evaluations of employees exposed to epichlorohydrin and benzene. See *id.* These tests were discontinued in 1977 because of questions about validity and reliability of the results. See *id.* In the 1980s, Johnson and Johnson conducted cytogenetic monitoring on employees exposed to ethylene oxide. See *id.* After six months these tests were discontinued. See *id.*

69. See MARK A. ROTHSTEIN, MEDICAL SCREENING OF WORKERS 73 (1984). Thirty states enacted legislation requiring African Americans to be tested for the sickle cell trait. See *id.* Twenty-one of these states have not repealed their sickle cell screening laws. See *id.* Some states required children be tested upon entering school while others would only issue marriage licenses on a showing that the individuals had been tested. See *id.* at 73-74.

70. See King, *supra* note 61, at 99 (discussing how the mandatory testing of African Americans for sickle cell anemia negatively affected them because of the strong possibility for stereotyping, discrimination, and general misinformation).

71. See *id.* For example, for many years the United States Air Force Academy refused to allow African Americans with sickle cell trait to participate in pilot training based on the mistaken belief that the low-oxygen environment associated with flight would cause the carrier to undergo a sickling episode. See GENETIC MONITORING SURVEY, *supra* note 2, at 42-43. This policy was discontinued in 1981 even though it was determined in 1974 that there was insufficient evidence to link carrier status with sickling episodes in low-oxygen environments. See *id.*

72. See National Sickle Cell Control Act, Pub. L. No. 92-294, 86 Stat. 136 (1972) (codified as amended at 42 U.S.C. §300b (1976)).

73. See *id.* § 300b-2.

conditions they are now able to identify. Today, we have the ability to identify an increasing number of genes, and scientists are working to correlate those genes with diseases and other human traits. In using this knowledge, scientists must be cognizant of past discrimination and avoid attaching any stigma to individuals because of the public's lack of knowledge and understanding of genetic traits. Extending the coverage of the ADA to persons with certain "inferior" genetic traits may help combat potential abuses that accompany genetic testing.

### III. THE AMERICANS WITH DISABILITIES ACT

Generally, employment decisions are based on some type of discrimination or differentiation. Employment applicants often are discriminated against on the basis of their level of education, previous experience, dress, mannerisms, and a host of other details. Congress, however, has prohibited the use of certain factors to differentiate among applicants. Title VII, for example, prevents discrimination based on race, religion, nationality, color, and sex.<sup>74</sup> More recently, Congress passed the ADA to discourage discrimination against individuals based on their disabilities.<sup>75</sup> The ADA potentially provides employees the greatest protection against genetic discrimination.<sup>76</sup>

#### A. Covered Entities Under the ADA

Title I of the ADA prohibits employment discrimination on the basis of disability,<sup>77</sup> by employers with fifteen or more employees.<sup>78</sup> The

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74. See 42 U.S.C. § 2000e-2(a) (1964) ("It shall be an unlawful employment practice for an employer . . . to discriminate against any individual . . . because of such individual's race, color, religion, sex or national origin."); see also *infra* Part IV (analyzing Title VII and genetic discrimination).

75. The ADA was passed in 1990 and became effective in 1992. See 42 U.S.C. § 12111 (1990) ("No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to . . . employment.").

76. See Thomas H. Christopher & Charles M. Rice, *The Americans With Disabilities Act: An Overview of the Employment Provisions*, 33 S. TEX. L. REV. 759, 760 (1992) (quoting 136 CONG. REC. H2430 (daily ed. May 17, 1990) (statement of Rep. Conte)) (describing the ADA as the "declaration of independence" for millions of disabled Americans).

77. 42 U.S.C. § 12112(a). The ADA provides that "[n]o covered entity shall discriminate against a qualified individual with a disability because of the disability of such an individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment." *Id.*

78. See *id.* § 12111(5)(A); 29 C.F.R. § 1630.2(e)(1) (1998). Employer, as defined in the ADA excludes "(i) [t]he United States, a corporation wholly owned by the government of the United States, or an Indian Tribe; or (ii) [a] bona fide private

ADA also includes provisions that apply to public services performed by governmental entities;<sup>79</sup> public accommodations operated by private entities;<sup>80</sup> and telecommunications networks.<sup>81</sup>

### B. Medical Testing Under the ADA

The medical testing provisions within the ADA pose the first obstacle to employers who seek to perform genetic testing on job applicants.<sup>82</sup> While the ADA does not specifically define a medical test,<sup>83</sup> it was enacted to discourage the use of medical test results in the hiring process regardless of whether a revealed condition would have any impact on the applicant's ability to perform the job.<sup>84</sup> Further, while there is no precise meaning of a medical test it cannot seriously be argued that a genetic test is not a medical test under the ADA. The ADA addresses medical testing in three separate stages of the

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membership club . . . that is exempt from taxation under section 501(c) of the [Internal Revenue Code of 1986]." *Id.*

79. *See id.* §§ 12131-12165. "[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity." *Id.* § 12132.

80. *See id.* §§ 12181-12189. "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation . . ." *Id.* § 12182(a).

81. *See* 47 U.S.C. §§ 225, 611 (1994 & Supp. 1996). "[T]he Commission shall ensure that interstate and intrastate telecommunications relay services are available, to the extent possible and in the most efficient manner, to hearing-impaired and speech-impaired individuals . . ." *Id.* § 225(b)(1).

82. *See* 42 U.S.C. § 12112(d)(1) ("The prohibition against discrimination . . . shall include medical examinations and inquiries."). This section was enacted to discourage the prevalent practice of medically testing job applicants and making job offers based on the outcome of those tests regardless of whether the medical conditions revealed would have any impact on the applicant's ability to perform the job in question. *See* Christopher & Rice, *supra* note 76, at 790.

83. The definition of a medical exam has been found to encompass psychological tests. *See* Barnes v. Cochran, 944 F. Supp. 897 (S.D. Fla. 1966), *aff'd*, 130 F.3d 443 (11th Cir. 1997); *see also* Equal Employment Opportunity Commission, *ADA Enforcement Guidance: Pre-Employment Disability-Related Questions and Medical Examinations*, BNA-DLR, Oct. 10, 1995, at 8, available in WESTLAW, 1995 DLR 196 d46 ("A 'Medical Examination' is a procedure or test that seeks information about an individual's physical or mental impairments or health.").

84. *See* Christopher & Rice, *supra* note 76, at 790 (discussing actions permitted and prohibited by the employer under the ADA). A survey conducted by the Office of Technology Assessment in 1989 (before the ADA was enacted) reported that 49% of companies surveyed required pre-employment health examinations of *all* job applicants and an additional 10% required health examinations for *most* job applicants. *See* MEDICAL MONITORING SURVEY, *supra* note 6, at 4.

employment relationship: pre-employment,<sup>85</sup> after a job offer is made but before it is finalized,<sup>86</sup> and during employment.<sup>87</sup>

### 1. Pre-employment Testing

Under the ADA, an employer cannot conduct pre-offer medical examinations on an applicant.<sup>88</sup> In addition, the employer is prohibited from asking an applicant about the existence or severity of any disability.<sup>89</sup> The employer may, however, inquire into the ability of the applicant to perform job-related functions.<sup>90</sup> It is likely, however,

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85. See 42 U.S.C. § 12112(d)(2)(A) (1990) (“[A] covered entity shall not conduct a medical examination or make inquiries of a job applicant as to whether such applicant is an individual with a disability or as to the nature or severity of such disability.”); 29 C.F.R. § 1630.14 (a) (1998) (“A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions . . .”).

86. See 42 U.S.C. § 12112(d)(2)(B) (“A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions.”); 29 C.F.R. § 1630.14(b) (stating that an employer may condition an offer of employment on the results of a medical exam after the offer is made).

87. See 42 U.S.C. § 12112(d)(3)(A) (allowing medical testing upon acceptance of an offer if all employees are tested as such); 29 C.F.R. § 1630.14(c) (“A covered entity may require a medical examination . . . of an employee that is job-related and consistent with business necessity.”).

88. See 42 U.S.C. § 12112(d)(2)(A). This is particularly significant in light of a study indicating that, prior to the passage of the ADA, 87.8% of large plants (those with more than 500 workers) and 56.4% of medium plants (those with 100-499 workers) required medical examinations prior to employment. See Jennifer M. Ratcliffe et al., *The Prevalence of Screening in Industry: Report from the National Institute for Occupational Safety and Health, National Occupational Hazard Survey*, 28 J. OCCUPATIONAL MED. 906, 907-08 (1986); see also Rothstein, *supra* note 11, at 52-53 (stating that at the time of the article (1992), nearly 90% of workers at larger plants and over 50% of workers at smaller plants were subjected to pre-employment medical examinations).

89. See 42 U.S.C. § 12112(d)(2)(A). The ADA does recognize, however, the right of employers to ask questions about disabilities in limited situations. See Christopher & Rice, *supra* note 76, at 791-92 (discussing legitimate reasons for an employer to invite a job applicant to identify his disabilities). The ADA’s legislative history indicates that an employer may inquire as to disabilities and their extent if the employer is taking affirmative action to correct past discrimination or in order to overcome the effect of conditions that previously prevented the employer from hiring disabled individuals. See *id.* In requesting this information the employer must inform the applicant that it is for remedial or affirmative action purposes, it is entirely voluntary, and that the information will be kept confidential and will not be used to discriminate against the applicant. See *id.* at 792.

90. See 42 U.S.C. § 12112(d)(2)(B) (“A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions.”). In fact, EEOC guidelines suggest that an employer may list the essential job functions and ask an applicant whether he or she is capable of performing those functions. See 29 C.F.R. § 1630.14(a). The Code of Federal Regulations states that: “A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related

that most genetic disorders do not present symptoms that affect job-related functions.<sup>91</sup> Only testing reveals the existence of a genetic marker in the individual, therefore, the individual who is unaware of his or her genetic condition cannot answer questions about the unknown. Even if an individual had knowledge of a genetic disorder, an inquiry into whether an individual could perform basic job functions would be irrelevant in most cases of latent genetic disorders because the disorder would have no discernible effect on the employee's ability to perform the job at the present moment.

A second pre-employment issue arises after the offer of employment is extended. Such an offer is not always permanent. Typically, once the offer of employment is made, that offer may be conditioned on the outcome of a medical examination.<sup>92</sup> The ADA provides that "[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 examination."<sup>93</sup> These examinations must satisfy three requirements. First, an employer must test all entering employees regardless of disability.<sup>94</sup> Second, the information collected must be maintained on separate forms and in a separate medical file and treated as confidential.<sup>95</sup> Third, the results of the medical examination may be

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functions and/or may ask an applicant to describe or to demonstrate how, with or without reasonable accommodation, the applicant will be able to perform job-related functions." *Id.*

91. Often these genetic disorders will manifest no symptoms at all during the individual's entire life span. For example, the carrier of a single recessive gene for Tay Sachs Disease of Galactosemia will have no symptoms of the disease. *See* ORAM, *supra* note 45, at 161.

92. In some cases the law may even require employers to perform medical examinations before allowing a worker to begin employment. For example, OSHA requires medical examinations of employees who will be exposed to certain toxins. *See infra* note 199 (providing examples of circumstances when testing is required).

93. 42 U.S.C. § 12112(d)(3); *see also* 29 C.F.R. § 1630.14(b) ("A covered entity may require a medical examination . . . after making an offer of employment . . . and may condition an offer of employment on the results of such examination.").

94. *See* 42 U.S.C. § 12112(d)(3)(A); 29 C.F.R. § 1630.14(b) (conditioning medical examinations on the fact that "all entering employees in the same category are subjected to such an examination . . . regardless of disability").

95. *See* 42 U.S.C. § 12112(d)(3)(B); 29 C.F.R. § 1630.14(b)(1). There are exceptions to the confidentiality rule for: (1) supervisors and managers who need to be informed of any required restrictions on the work or duties of employees and any necessary accommodations; (2) first aid and safety personnel who may be informed when the disabled individual might require emergency medical treatment; and (3) government officials investigating compliance with the Act. *See* 29 C.F.R. § 1630.14(b)(1)(i-iii).



used only “in accordance with this sub-chapter.”<sup>96</sup> This section, however, does not restrict the purpose behind the test, so an employer may theoretically test for any medical condition. In fact, the relevant EEOC regulation states that “[m]edical examinations conducted in accordance with this section do not have to be job-related and consistent with business necessity.”<sup>97</sup> Yet, the third requirement under the ADA provides protection against discrimination,<sup>98</sup> which means that while the employer can test for anything, he cannot then use the test results to discriminate against the employee or applicant in violation of the ADA.<sup>99</sup>

## 2. Testing During Employment

An individual’s status as an employee restricts the type of medical examinations an employer can require throughout the duration of employment.<sup>100</sup> Medical examinations of employees must be “job-related and consistent with business necessity.”<sup>101</sup> In addition, an employer can conduct voluntary medical examinations, including those that accompany an employee health program.<sup>102</sup> The employer may

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96. 42 U.S.C. § 12112(d)(3)(C).

97. 29 C.F.R. § 1630.14(b)(3).

98. *See* 42 U.S.C. § 12112(d)(3)(C); *see also* 29 C.F.R. § 1630.14(b)(3) (stating that “if certain criteria are used to screen out an employee or employees with disabilities as a result of such an examination or inquiry, the exclusionary criteria must be job-related and consistent with business necessity, and performance of the essential job functions cannot be accomplished with reasonable accommodation”).

99. *See* 42 U.S.C. § 12112(b)(6) (providing that an employer cannot use “employment tests or other selection criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities unless the standard, test or other selection criteria, as used by the covered entity, is shown to be *job-related for the position in question and is consistent with business necessity*”) (emphasis added).

100. *See id.* § 12112(d)(4)(A) (“A covered entity shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability . . .”). However, the Code of Federal Regulations makes clear that “[a] covered entity may require a medical examination . . . of an employee that is job-related and consistent with business necessity.” 29 C.F.R. § 1630.14(c).

101. 42 U.S.C. § 12112(d)(4)(A); 29 C.F.R. § 1630.14(c). These sections may interact with other laws such as OSHA that require employers to perform medical tests on workers exposed to certain toxins.

102. *See* 42 U.S.C. § 12112(d)(4)(B). The statute states, “[a] covered entity may conduct voluntary medical examinations, including voluntary medical histories, which are part of an employee health program.” *Id.*; *see also* 29 C.F.R. § 1630.14(d) (stating “[a] covered entity may conduct voluntary medical examinations and activities, including voluntary medical histories, which are part of an employee health program”).

also make inquiries into "the ability of an employee to perform job-related functions."<sup>103</sup>

Genetic screening would theoretically be legal if it were "directly related to qualifications for doing the task or if necessary for employee safety."<sup>104</sup> Job-relatedness, however, generally applies only to the employee's present capability to perform the job.<sup>105</sup> It is doubtful that most genetic conditions, especially asymptomatic ones, would rise to the level of job-relatedness or business necessity so as to allow an employer to discriminate against applicants with the condition. An asymptomatic genetic disorder might have future ramifications, but would not affect the individual's present ability to perform his or her job. An employer could rarely justify genetic screening based on job-relatedness in order to overcome the ADA's protection.

Overall, with the exception of medical tests required by OSHA or other federal regulations, employers are most likely to use genetic testing after a conditional job offer is made, but before the offer is finalized.<sup>106</sup> Employers have a right to conduct medical or genetic tests at this stage in the hiring process. The issue becomes whether the employer can use the information gained from these tests to discriminate against workers with genetic defects.

### C. *Establishing an ADA Claim*

In order to establish a discrimination claim under the ADA, an applicant or employee must show that he (1) has a disability, (2) was otherwise qualified for the employment or benefit in question, and (3) was excluded from the employment or benefit because of the

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103. 42 U.S.C. § 12112(d)(4)(B); *see also* 29 C.F.R. § 1630.14(c).

104. Charles B. Gurd, *Whether a Genetic Defect is a Disability Under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers*, 1 ANNALS HEALTH L. 107, 110 (1992) (quoting Peter T. Rowley, *Genetic Discrimination: Rights and Responsibilities of Tester and Testee: Summary of a Workshop Sponsored by the Social Issues Committee, American Society for Human Genetics, November 2, 1986*, 43 AM. J. HUM. GENETICS 105 (1988)) (analyzing whether genetic defects qualify as disabilities under the ADA).

105. *See* 29 C.F.R. § 1630.10 (noting that tests must be related to the position in question); *see also* Gurd, *supra* note 104, at 110 (suggesting that refusal to employ a disabled applicant should only be allowed where the applicant is presently unable to perform the job).

106. *See* MEDICAL MONITORING SURVEY, *supra* note 6, at 4. While few employers are currently using genetic screening, an OTA survey found that approximately 50% of responding personnel officers said they would approve of health exams of applicants for workplace susceptibilities. *See id.*

disability.<sup>107</sup> Whether an individual is affected by a disability, as defined under the ADA, is generally the most controversial issue in a genetic discrimination claim. A plaintiff can establish a disability under the ADA three different ways. A disability is defined as “(A) a physical or mental impairment that substantially limits one or more of the major life activities . . . ; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”<sup>108</sup>

### 1. Physical or Mental Impairment Substantially Limiting One or More Major Life Activities

The EEOC has defined a physical impairment as “[a]ny physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin and endocrine.”<sup>109</sup> Mental impairments encompass “[a]ny mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.”<sup>110</sup> Not all impairments receive protection under the ADA. In order to receive protection, the impairment must substantially limit a major life function. Whether a disability is “substantially limiting” depends on the nature and severity of the impairment, the duration or expected duration of the impairment, and the permanent or long-term impact of the impairment.<sup>111</sup> Additionally, to invoke coverage under this prong, the impairment must affect “a major life activity.” The EEOC regulations provide that a “major life activity” includes things such as “caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and *working*.”<sup>112</sup>

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107. See 42 U.S.C. § 12112(a) (“No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual . . . [in] employment.”).

108. *Id.* § 12102(2).

109. 29 C.F.R. § 1630.2(h)(1).

110. *Id.* § 1630.2(h)(2).

111. See 29 C.F.R. § 1630.2(j)(2). A person with a short-term injury, such as a broken leg, would not qualify as having a substantially limiting impairment; nor would someone with a temporary illness such as influenza or pneumonia. See Christopher & Rice, *supra* note 76, at 769 (providing examples of substantially limiting impairments).

112. 29 C.F.R. § 1630.2(i) (emphasis added). The EEOC has added sitting, standing, lifting, reaching, reading, thinking, concentrating, and interacting with others as major life functions. See 29 C.F.R. pt. 1630 App. § 1630.2(i); EEOC Disability Guidance § 902.3(b); EEOC Technical Assistance § 2.2(a)(ii). The United States Supreme Court

Most genetic disorders do not exhibit present symptoms that would qualify as “substantially limiting a major life function.”<sup>113</sup> Specifically, subsection (A) of the ADA appears to omit three major categories of genetic disorders. First, this section would not apply to an individual whose genetic defect has not yet become a physical disorder, but may become one in the future.<sup>114</sup> Second, this section does not protect an individual who may be a carrier for a disease that will never manifest itself in the individual, but may appear in his or her offspring.<sup>115</sup> Finally, the section does not protect a person who may have a disabling disorder that is under treatment, but manifests no physical symptoms.<sup>116</sup> Employees in any of these three categories would not be protected under section (A) of the ADA because their “disability” does not currently affect “a major life function.”<sup>117</sup> If an

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recently added reproduction to the list of major life functions and hinted that sexual relations were a major life function as well. *See* *Bragdon v. Abbott*, 118 S. Ct. 2196, 2205 (1998).

113. For example, an individual with sickle cell trait will never develop symptoms. Additionally, a person who is identified as having a genetically higher risk of breast cancer, but without the disease, would not have a disability that presently substantially limits any major life function.

114. For example, the gene for Huntington’s disease is carried by a person for his or her entire life, but the disease may not cause physical symptoms for years. None of the listed major life activities, therefore, are presently limited. *See* *Gin, supra* note 3, at 1414-15 (providing a description of the physical manifestations of Huntington’s disease).

115. For example, Tay Sachs disease, a disease caused by a recessive gene, usually results in death by age three due to failure of the nervous system to properly develop. Whether a person is a carrier for Tay Sachs is detectable through a simple blood test. The carrier, however, will not manifest the disease. The only danger is to the individual’s offspring if he or she should have a child with another Tay Sachs carrier. *See* *ORAM, supra* note 45, at 161 (discussing the effects of Tay Sachs disease on both carriers and those who exhibit its symptoms).

116. *See id.* (noting that PKU, a disease caused by a recessive gene, if left untreated will result in severe mental retardation, can be successfully treated through diet). Note, however, that some courts have determined that these individuals would qualify as “disabled” under the ADA because they do not take into account mitigating measures, but rather look to the individual in an unmedicated state. *See, e.g.,* *Matczak v. Frankford Candy & Chocolate Co.*, 136 F.3d 933, 937 (3d Cir. 1997) (involving a former epileptic employee who brought a suit against his former employer for violating the ADA when the employee was dismissed due to his condition).

117. *See supra* note 112 and accompanying text (describing “a major life activity” under section (A) of the ADA). For a carrier of an inheritable disease such as Tay Sachs it can be argued that reproduction is a major life function that is substantially impaired. This argument, however, has generally been unsuccessful even in the context of AIDS where the risk of passing on the disease to one’s offspring is much greater than for carriers of Tay Sachs, and the risk is associated with all partners rather than other carriers of the trait. *See* *Runnebaum v. NationsBank of Md.*, 123 F.3d 156, 172 (4th Cir. 1997) (finding that AIDS does not substantially limit procreation, and intimate

employee did have a disability and exhibited symptoms that limited a major life function, he would be covered under this section whether the root of that disability was a genetic defect or another medical condition.

## 2. Record of Impairment

The ADA's second classification of disability involves an individual's record of a substantially limiting impairment.<sup>118</sup> Through this requirement, Congress sought to protect individuals who have recovered from a disabling condition,<sup>119</sup> and individuals who never had a disability, but were misclassified or misdiagnosed in the past.<sup>120</sup> This prong may have ramifications for individuals who incorrectly test positive for a genetic disorder, an outcome that is highly likely given the inaccuracies and inconsistencies of current genetic tests.

## 3. Regarded as Having an Impairment

The third prong, subsection (C), is the employee's greatest protection against genetic discrimination. This prong includes "being regarded as having such an [substantially limiting] impairment."<sup>121</sup> Subsection (C) recognizes that "society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment."<sup>122</sup> To determine

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sexual conduct does not interfere with a major life function under the ADA); *Cortes v. McDonald's Corp.*, 955 F. Supp. 541, 546 (E.D.N.C. 1996) (finding that procreation was not a major life function under the ADA); *Zatarain v. WDSU-Television, Inc.*, 881 F. Supp. 240, 243 (E.D. La 1995) (finding that reproduction was not a major life function), *aff'd*, 79 F.3d 1143 (5th Cir. 1996). *But see Doe v. District of Columbia*, 796 F. Supp. 559, 568 (D.C. Cir. 1992) (finding that an HIV-positive firefighter was substantially impaired in the major life functions of "procreation, sexual contact, and normal social relationships").

118. *See supra* note 108 and accompanying text (providing the definition of a disability under the ADA).

119. *See Christopher & Rice, supra* note 76, at 770 (citing S. REP. NO. 116, 101st Cong., 1st Sess. 23 (1989); H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 2, at 52 (1990)).

120. *See* 29 C.F.R. § 1630.2(k) (1998) ("*Has a record of such impairment* means has a history of, or has been misclassified as having, a mental or physical impairment.>").

121. *See* 42 U.S.C. § 12102(2) (1990).

122. *School Bd. of Nassau County v. Arline*, 480 U.S. 273, 284 (1987) (finding that the dismissal of a teacher based on her susceptibility to tuberculosis violated the Rehabilitation Act of 1983. Even though she was not impaired she was being discriminated against because of a perceived impairment). The category of perceived impairment has been used to protect individuals with severe burns, asymptomatic back abnormalities, and high blood pressure. *See Christopher & Rice, supra* note 76, at 771-72 (discussing examples of being "regarded as having an impairment" under the ADA).

whether an employee is regarded as having a disability the court must “examine the employer’s perception and treatment of the charging party.”<sup>123</sup> Unlike the other disability categories, this section is based on the employer’s perceptions, not the existence of a true disability or even the individual’s own perception of himself or herself as disabled. Individuals with asymptomatic genetic disorders, therefore, would most likely be covered by this section because employers would be discriminating based on the presence of a genetic anomaly, not on the employee’s inability to perform.<sup>124</sup>

#### D. EEOC Guidelines

The Equal Employment Opportunity Commission must develop standards and guidelines to implement federal laws that deal with equality in employment. The EEOC has failed to provide clear direction regarding genetic classification as a form of discrimination under the ADA. In its first statement on the subject, the EEOC refused to include genetic discrimination as a violation of the ADA.<sup>125</sup> In 1991, the Acting Director of Communications and Legislative Affairs for the EEOC wrote an opinion letter stating that the ADA does not prohibit genetic discrimination “until the condition ‘exists’ and the individual is symptomatic.”<sup>126</sup> This letter, however, was only an

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The Rehabilitation Act of 1983 was a precursor to the ADA that only applied to government employees. While the Rehabilitation Act has not been repealed, it is not dealt with in this paper because of its similarity to the ADA, which is discussed in-depth.

123. EEOC Compl. Man. (BNA) § 902.8(a) (1995).

124. *But see* OR. REV. STAT. § 659.705(e) (Supp. 1998) (stating the legislative finding that “[c]urrent legal protections for medical information, tissue samples and DNA samples are inadequate to protect genetic privacy”); Frank R. Emmerich, Jr., *Employee Terminated/Cause of Action Dismissed: The Americans with Disabilities Act Provides No Haven for Employees Hypersusceptible to Genetic Illness*, 4 J. INDIVIDUAL EMPL. RIGHTS 185 (1995-96) (suggesting that an employee will not be able to challenge genetic discrimination under the ADA because a genetically hyper-susceptible employee does not have a “disability” within the meaning of the ADA); Gostin, *supra* note 5, at 142-43 (suggesting that the ADA fails to adequately protect against genetic discrimination because of its silence about discrimination based on the potential for future disability); Rothstein, *supra* note 11, at 83-84 (concluding that the ADA does not provide sufficient protection to employees against genetic discrimination).

125. *See* Rothstein, *supra* note 11, at 45 (citing Letter from Ronnie Blumenthal, Acting Director of Communications and Legislative Affairs, EEOC, to Rep. Bob Wise, Chairman, House Subcommittee on Government Information, Justice and Agriculture (Nov. 22, 1991)); *see infra* note 126 (providing text of letter in which the Acting Director of Communications and Legislative Affairs for the EEOC stated that the ADA does not cover genetic discrimination).

126. Rothstein, *supra* note 11, at 45 (citing Letter from Ronnie Blumenthal, Acting Director of Communications and Legislative Affairs, EEOC, to Rep. Bob Wise,

informal statement given to the news media with little lasting authority.

In its first formally published statement on the subject, the EEOC reversed this position and included genetic discrimination under the auspices of the ADA. The EEOC compliance manual now includes a short statement that addresses the "being regarded as having a disability" prong of the ADA's disability test. This statement provides that the ADA:

[A]pplies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability."<sup>127</sup>

This more recent statement better illustrates the modern ADA interpretation. If the intent behind the law is to protect individuals from the myths and fears of society, it should apply to individuals with genetic disorders as well as other types of asymptomatic diseases.

#### *E. An Employer's Defense Under the ADA*

The ADA does not *per se* prevent discrimination against disabled individuals. The interests of the worker are balanced against the interests of the employer to determine whether the employer can discriminate against a specific worker or applicant. One way for an employer to circumvent the ADA protections is to establish that making

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Chairman, House Subcommittee on Government Information, Justice and Agriculture (Nov. 22, 1991)). The letter stated that:

Everyone has hereditary genetic characteristics that predispose them to the onset of particular illnesses or diseases that could become disabilities under the ADA. If your grandmother had heart disease, you may have a predisposition to heart disease . . . . However, the presence of these genetic characteristics does not indicate that an individual has an impairment or a record of an impairment, or necessarily that the individual may develop an impairment in the future. Consequently, the Commission determined that a characteristic predisposition to illness, like that revealed in a family history, is not an impairment covered by the ADA.

*Id.* at 46-47. The letter also stated that genetic issues "are unique and outside the Commission's expertise, [and therefore] they should be resolved by means of legislation, not by agency regulation." *Id.*; see also Emmerich, *supra* note 124, at 200 (explaining that the EEOC's interpretation of the ADA as described in the November 22, 1991 letter prevented individuals with genetic disorders from receiving ADA protection from genetic discrimination).

127. EEOC Compl. Man. (BNA) § 902.8(a) (1995).

accommodations for the disabled worker would create an “undue hardship” on the employer.<sup>128</sup>

### 1. Undue Hardship

The ADA defines an “undue hardship” as “an action requiring significant difficulty or expense.”<sup>129</sup> In order to determine whether the proposed accommodation would constitute an undue hardship, the employee’s interests are balanced against those of the employer.<sup>130</sup> In some instances an employer must expend substantial sums of money to accommodate a disabled employee if it cannot establish an undue hardship.<sup>131</sup>

It would be difficult for an employer to establish that it could not reasonably accommodate a hyper-susceptible worker without an undue hardship. Asymptomatic carriers of genetic diseases do not need workplace modifications and it is doubtful the employer can hide behind fears of the need for future modifications. Failure to reasonably accommodate based on the economic costs of future illness

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128. See 42 U.S.C. § 12112(b)(5)(A) (1990). The statute states that a reasonable accommodation must be provided to an otherwise qualified but disabled individual unless the employer “can demonstrate that the accommodation would impose an undue hardship on the operation of the business” of the employer. *Id.*

129. *Id.* § 12111(10)(A). The Code of Federal Regulations further defines undue hardship as referring to “any accommodation that would be unduly costly, extensive, substantial, or disruptive, or that would fundamentally alter the nature or operation of the business.” 29 C.F.R. § 1630.2(p) app. at 353-54 (1998).

130. Courts consider several factors in balancing an employee’s interest against the expense to an employer. The factors to be considered include: (1) the nature and cost of the modifications; (2) the overall financial resources of the facility; (3) the number of employees at the facility; (4) the overall financial resources of the entire company; (5) the type of operations of the company; and (6) the impact the accommodations would have on the operations at the facility. See 29 C.F.R. § 1630.2(p)(2). The EEOC has not given guidelines as to how each of these factors should be weighted in determining whether accommodating a disabled worker would be an undue hardship.

131. See 29 C.F.R. § 1630.2(p) app. at 353-54 (stating “[i]n other cases, consideration of the financial resources of the employer . . . may be inappropriate because it may not give an accurate picture of the financial resources available to the particular facility that will actually be required to provide the accommodation”). For example, a large company may be required to provide costly accommodations to a worker at a small facility based on its overall resources. If that accommodation, however, would result in the closing of the small plant due to unprofitability, then the modification might not be required even though the overall company could afford it. See Christopher & Rice, *supra* note 76, at 782-84 (citing H.R. REP. NO. 485, 101st Cong. 2d Sess., pt. 2, at 69-70 (1990)) (explaining that “the overall size of the employer may be decisive in some instances, but the local situation may be the determinative factor in others”).



has never successfully been raised by an employer.<sup>132</sup> The employer, however, may be able to reduce the effect of future costs by limiting the type of medical insurance available to the employees.<sup>133</sup> Employers have alleged that the rising insurance cost and other health care benefits create a sufficient "undue hardship," but this too is likely to fail.<sup>134</sup>

Because there is no case law<sup>135</sup> and few regulations address genetic disorders and discrimination under the ADA, observers must compare genetic discrimination with other types of medical discrimination. Genetic discrimination is best analogized to discrimination against asymptomatic individuals with Human Immunodeficiency Virus ("HIV").

#### *F. HIV as a Disability Under the ADA—A General Comparison*

Like many genetic disorders, HIV is a precursor to a more serious illness: Acquired Immune Deficiency Syndrome ("AIDS"). A simple blood test can identify HIV. Testing positive for HIV means that there is a high likelihood the individual will contract AIDS in the future.

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132. See *Shawn v. Legs Co. Ltd. Partnership*, No. 89-23216, 1989 WL 258819 (N.Y. Sup. Ct. Sept. 11, 1989) (refusing to allow employer to use speculation concerning future health problems to discriminate against an employee).

133. The limitation, however, would have to apply to all employees. Providing different insurance to different employees based on genetic make-up would run afoul of the ADA. See also JAMES G. FRIERSON, *EMPLOYER'S GUIDE TO THE AMERICANS WITH DISABILITIES ACT* 222 (2d ed.1995) (noting that the legality of insurance caps for AIDS under the ADA has not yet been decided).

134. See *id.* at 221 (discussing doubt that excessive insurance costs can be used by employers to justify discrimination against employees or applicants with AIDS or HIV). But see Emmerich, *supra* note 124, at 210 (arguing that when considering health care costs and the costs of training an employee who is not likely to provide long years of service, it would be possible that the employer, especially a smaller one, would be protected from the ADA provisions requiring accommodations).

In addition, employers who self-insure may be able to cut health costs by eliminating insurance coverage for specific genetic diseases. Because § 501 of ERISA protects the self-insured from broad ERISA legislation, the self-insuring employer may be able to side-step the ADA by eliminating coverage for specific illnesses. For example, in *McGann v. H & H Music Company*, 946 F.2d 401 (5th Cir. 1991), an employer who discovered an employee was diagnosed with HIV reduced the health benefits available for AIDS from \$1 million to \$5,000. This action was upheld by the Fifth Circuit, even though it had an adverse effect on the disabled worker. See *McGann*, 946 F.2d at 408; see also *Owens v. Storehouse, Inc.*, 984 F.2d 394 (11th Cir. 1993) (upholding an employer's right to modify its insurance plan to include a \$25,000 lifetime cap for AIDS-related claims).

135. See Fox, *supra* note 13 (discussing *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998), which is a currently pending case concerning an employer's use of genetic testing).

In *Bragdon v. Abbott*,<sup>136</sup> the Supreme Court recently held that an individual with asymptomatic HIV is disabled under the ADA.<sup>137</sup> The Court found that even asymptomatic HIV was a physical impairment because the virus is still thriving within the individual's lymph nodes although relatively few symptoms are exhibited during this stage.<sup>138</sup> The Court also pointed to the fact that an HIV infection "causes immediate abnormalities in a person's blood."<sup>139</sup> Like any other medical test, the employer could arguably include an HIV test as part of a post-offer medical exam, but would be limited on how it could use that information.<sup>140</sup> Like any other disability, the ADA only permits an employer to rescind a job offer based on a positive test result if the applicant is unable to perform the job<sup>141</sup> or is a threat to the safety or health of others.<sup>142</sup> A direct threat may arguably exist in those few jobs where the employee is likely to come in contact with bodily fluid from other individuals. Even here, however, the Center for Disease Control does not recommend mandatory HIV testing.<sup>143</sup> In addition, a

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136. *Bragdon v. Abbot*, 118 S. Ct. 2196 (1998).

137. *See id.* at 2204.

138. *See id.* ("The HIV infection must be regarded as a physiological disorder with a constant and detrimental effect on the infected person's hemic and lymphatic systems from the moment of infection.")

139. *Id.*

140. Its use as part of a post-offer medical exam is permitted if not prohibited by state law. *See*, ME. REV. STAT. ANN. tit. 5, § 19204-B (West Supp. 1998) (prohibiting an employer from requiring an HIV test for an employee or prospective employee as a condition of employment); VT. STAT. ANN. tit. 3, § 961 (1995), (stating it is an unfair employment practice for an employer to condition future or continuing employment on testing for HIV); WIS. STAT. ANN. § 103.15 (1997) (providing that no employer may, as a condition of employment, require any employee or prospective employee to submit to an HIV test).

141. *See* 42 U.S.C. § 12113(a) (1990) (explaining that standards which "tend to screen out or otherwise deny a job or benefit to an individual with a disability" may be a defense to discrimination if such standards "ha[ve] been shown to be job-related and consistent with business necessity, and such performance cannot be accomplished by reasonable accommodation"); *see also* 29 C.F.R. § 1630.14(b)(3) (1998) (stating that exclusionary criteria is permissible where such criteria is "job-related and consistent with business necessity, and performance of the essential job functions cannot be accomplished with reasonable accommodation").

142. *See* 42 U.S.C. § 12111(3) (defining a "direct threat" as "a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation").

143. *See* Stephen F. Befort, *Pre-Employment Screening and Investigation: Navigating Between a Rock and a Hard Place*, 14 HOFSTRA LAB. L.J. 365, 389 (1997) (citing *Recommendations for Prevention of HIV Transmission in Health-Care Settings*, 36 MORBIDITY & MORTALITY WKLY. REP., at 15S-17S) (noting the CDC's recommendations that "health care workers who perform exposure prone procedures voluntarily monitor their own HIV status and refrain from performing those procedures if they become HIV infected").

minority of states have promulgated statutes that restrict HIV testing.<sup>144</sup> Most of these states prohibit employers from performing HIV tests or requiring the employee to disclose the results of tests taken privately.<sup>145</sup>

When genetic testing is compared to HIV testing, it is clear that a genetic disorder (or hyper-susceptibility) should also be considered a disability under the ADA. Like HIV, most genetic disorders do not affect job performance. The only effect, if it ever manifests, will be in the future. Furthermore, an HIV blood test has a much higher accuracy rate than most genetic tests.<sup>146</sup> Like many tests for genetic disorders, no test can predict when an individual will contract AIDS or the individual's capability to continue a productive existence after contracting AIDS. Unlike most genetic diseases, however, AIDS is contagious.<sup>147</sup> Therefore, HIV is potentially more dangerous in the workplace than most genetic diseases.<sup>148</sup> If an infectious disease such as HIV is regulated, so should genetic testing, which poses no contagious risk.<sup>149</sup>

#### IV. GENETIC DISCRIMINATION AS A FORM OF RACIAL DISCRIMINATION UNDER TITLE VII

At first glance, racial or ethnic discrimination based on genetic testing seems far-fetched. After all, what could be more color-blind than a test that identifies anomalies at the cellular level of human biology? The lessons of history, however, teach us differently. From the eugenics projects of the early 1900s,<sup>150</sup> to the discrimination that

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144. See ME. REV. STAT. ANN. tit. 5, § 19204-B (West Supp. 1998) (providing that employers may not request prospective employees to submit to HIV tests); VT. STAT. ANN. tit. 3, § 961 (1995) (stating that employers may not discriminate against future or current employees on the basis of HIV tests); WIS. STAT. ANN. § 103.15 (1997) (prohibiting employers from requiring HIV tests prior to employment or discriminating against employees because of the HIV test).

145. See ME. REV. STAT. ANN. tit. 5, § 19204-B; VT. STAT. ANN. tit. 3, § 961; WIS. STAT. ANN. § 103.15.

146. See Joseph W. Moch & William Thompson, *Suing for Misdiagnosis and Improper Treatment of HIV*, MICH. L. WKLY, Summer 1992, at 6A (stating that the ELISA and Western Blot HIV tests are very accurate).

147. Although AIDS cannot be spread casually, it is considered an infectious disease.

148. Since there are few professions where employees are in contact with blood and other bodily fluids on a daily basis, it is arguable that fear of contagion is not legitimate at all because of the difficulty in spreading HIV and AIDS through casual contact.

149. The only exception is the potential danger to an individual's offspring if conceived after the individual has contracted HIV. The danger of HIV to an unborn fetus is outside the scope of this article.

150. See *supra* notes 54-63 (examining the turn of the century movement towards

arose out of the sickle cell anemia scare,<sup>151</sup> racial and ethnic discrimination has arisen in the most unlikely places.

Advances in genetic mapping may have a disproportionate effect on minority groups.<sup>152</sup> Because genetic information is complex and easily misunderstood, it may be manipulated to legitimize existing racial and ethnic stereotypes.<sup>153</sup> Some authors suggest that the potential for manipulation may result in the creation of a biological underclass composed mostly of minority groups.<sup>154</sup> For example, Patricia King posits that when a disease occurs more frequently among a particular minority group, two negative consequences can arise. First, members of the minority group without the trait may be stigmatized and discriminated against solely because they are part of a group associated with the trait.<sup>155</sup> Second, a disease associated with a minority group is less likely to be highly prioritized in the search for a treatment or cure.<sup>156</sup> Protection, however, against this discrimination may exist under Title VII of the Civil Rights Act of 1964 ("Title VII")<sup>157</sup> if genetic testing causes discrimination that has a disparate impact on a particular minority group.

#### A. Title VII

Title VII prevents discrimination in employment based upon race, religion, nationality, color, and sex.<sup>158</sup> Claims are brought under Title VII through one of two theories: (1) disparate treatment theory or (2) disparate impact theory.

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classifying workers, criminals, and prospective spouses according to gene type).

151. *See supra* notes 64-72 and accompanying text (discussing the historic discrimination in the United States against individuals who were carriers of the sickle cell anemia trait).

152. *See King, supra* note 61, at 99-102 (reasoning that lessons from the past suggest that current and future gene mapping efforts could potentially have a negative impact on minority groups).

153. *See id.* (citing D. NELKIN & L. TANCREDI, *DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION* (1989)).

154. *See id.*

155. *See id.* King uses the potent image of the existing discrimination against gay men who are not infected with HIV but are discriminated against because they are part of a group that is associated with HIV and the AIDS virus. *See id.* at 100.

156. *See id.* at 100 (stating "because of [the disease's] higher frequency among the members of an identifiable minority group, the disease might be given lower priority in terms of research for treatment or cure").

157. 42 U.S.C. §§ 2000e (1994).

158. 42 U.S.C. §2000e-2(a)(1) (providing "[i]t shall be an unlawful employment practice for an employer to fail or refuse to hire . . . any individual . . . because of such individual's race, color, religion, sex, or national origin").

### 1. Disparate Treatment Theory

Disparate treatment discrimination is the most identifiable type of discrimination under Title VII. "The employer simply treats some people less favorably than others because of their race, color, religion, sex, or national origin."<sup>159</sup> The most important element in disparate treatment discrimination is that the employer must have intended to discriminate against the individual because of a particular trait.<sup>160</sup>

Although many genetic traits are linked to racial and ethnic groups,<sup>161</sup> a genetic marker is a facially neutral criterion. An employer that refuses to hire all individuals who possess a specific genetic marker is not *per se* discriminating against members of a single race because many genetic diseases cross racial lines.<sup>162</sup> Therefore, under the disparate treatment test, a genetic discrimination claim would likely fail.<sup>163</sup> Failure is probable because it is difficult to prove an

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159. *Teamsters v. United States*, 431 U.S. 324, 335 n.15 (1977). The Court held that when a company engages in a pattern or practice of discrimination against minorities in its hiring practices, it will be held in violation of Title VII of the Civil Rights Act. *See id.* at 335-36.

160. In some situations a discriminatory motive may be inferred solely from the fact of different treatment. For example, in *Wroblewski v. Lexington Gardens, Inc.*, 448 A.2d 801 (Conn. Sup. Ct. 1982), a medical questionnaire that inquired into the urogenital health of women, but not men, was found to violate the state discrimination laws. Similarly, the United States Supreme Court in *City of Los Angeles v. Manhart*, 435 U.S. 702 (1978), held that an employer could not require women to contribute more to their pension plans than men based on the longer life expectancy of women as a class.

161. For example, sickle cell anemia has been linked to African Americans. *See Gostin, supra* note 5, at 111 (stating that the "potential for invidious discrimination" is increased because certain genetic diseases are intimately associated with particular racial or ethnic groups). Bloom's Syndrome, Gaucher's disease, and Tay Sachs have been linked to Ashkenazi Jews. *See id.* at 111 n.10. Familial Mediterranean fever has been linked to Armenians. *See id.* at 111 n.11. Cystic fibrosis is more prevalent in Caucasians. *See Brokaw, supra* note 47, at 324 n.33 (listing examples of certain genetic traits which can be linked to specific maladies and are "concentrated among identifiable ethnic groups"). Thalassemia has been linked to Greeks, Italians and Africans. *See id.* Wilson's disease and BRCA1 (a gene linked with breast cancer) are associated with Eastern European Jews. *See Rothenberg, supra* note 47, at 98-99 (discussing the link between a genetic mutation, breast cancer and the Jewish community).

162. For example, Thalassemia affects Greeks, Italians, and Africans. *See Brokaw, supra* note 47, at 324 n.33. Glucose-6-phosphate dehydrogenase deficiency affects Africans, Mediterranean Jews, Greeks and Filipinos. *See id.* (demonstrating that some genetic ailments affect people of different races and ethnicities).

163. There would likely be a different result if the employer were to target only members of a certain race or sex and perform the tests on members of those groups. For example, in *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1265-66 (9th Cir. 1998), where the employer is alleged to have tested only African Americans for sickle cell anemia and women for pregnancy, a claim for disparate treatment under Title

employer's intent to discriminate. Thus, any claim based on genetic testing would have to be brought using the disparate impact theory.

## 2. Disparate Impact Theory

In *Griggs v. Duke Power Co.*,<sup>164</sup> the Supreme Court held that Title VII applies not only to direct discrimination,<sup>165</sup> but to practices that appear neutral on their face and result in discrimination along racial lines. The Court stated that "good intent or absence of discriminatory intent does not redeem employment procedures or testing mechanisms that operate as 'built-in headwinds' for minority groups and are unrelated to measuring job capability."<sup>166</sup>

To establish a disparate impact claim, an individual must prove that the genetic screening had a discriminatory effect on groups protected by Title VII.<sup>167</sup> The burden then shifts to the employer to prove that the screening is "job-related" or a "business necessity."<sup>168</sup> If the employer meets this burden, the individual can only prevail if he or she can demonstrate that there is a less restrictive alternative to genetic screening.<sup>169</sup>

The prima facie case for disparate impact discrimination based on genetic testing would be relatively easy for a job applicant to satisfy. The plaintiff need only establish that he or she was a member of a minority group and was denied a job because of the results of a genetic test that tested for a condition more prevalent in that minority group.

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VII may exist. See *supra* note 13 (discussing the only case regarding an employer's use of genetic testing).

164. *Griggs v. Duke Power Co.*, 401 U.S. 424 (1971). The court found that the practice of screening employment applicants using a specific IQ test, and requiring applicants to have earned a high school diploma violated Title VII. See *id.* at 432-36. The court reasoned that the criteria operated to disqualify African American applicants at a substantially higher rate than white applicants and were unrelated to measuring job capability. See *id.*

165. Such as when an employer refuses to hire anyone of a certain race.

166. *Griggs*, 401 U.S. at 432.

167. See Brokaw, *supra* note 47, at 332 (citing *Griggs*, 401 U.S. at 432, which described the requirements for a disparate impact claim). For example, an individual must be able to show that sickle cell anemia affects African Americans disproportionately before he can claim racial discrimination based on the employer conducting pre-employment testing for the trait.

168. See *Griggs*, 401 U.S. at 432; see also 42 U.S.C. §2000e-2(k)(1)(A) (1990) (providing that an individual establishes a disparate impact claim where "a complaining party demonstrates that a respondent uses a particular employment practice that causes a disparate impact" and "the respondent fails to demonstrate that the challenged practice is job related for the position in question and consistent with business necessity").

169. See *Griggs*, 401 U.S. at 432.

### 3. Business Necessity and Job-Relatedness

Once the individual is able to establish a prima facie case, the burden shifts to the employer who may try to establish that the criteria was “job-related” or a “business necessity.” While some courts have used these terms interchangeably,<sup>170</sup> others have attempted to draw a distinction between them.<sup>171</sup> “Business necessity” denotes an employment practice whose purpose is to determine whether an applicant is capable of performing the necessary job functions.<sup>172</sup> “Job-relatedness” has a narrower scope and concerns only whether the employee selection criteria are reasonably related to the demands of the job.<sup>173</sup> A determination of whether the employer satisfied either standard depends on “a consideration of the nature of the business involved, the business practice at issue, and the degree of discriminatory impact.”<sup>174</sup> The court will then balance the “business necessity” against the impact of the discriminatory treatment to determine whether the genetic testing can continue.

Commentators suggest several reasons employers why may want to use genetic testing, however, these reasons are insufficient to establish a business necessity. For example, genetic testing may be used in an attempt to reduce the costs of absenteeism, decreased productivity, and increased training costs associated with training new employees who replace sick employees.<sup>175</sup> Employers may determine the most costly ailments and then screen for those diseases to limit the future costs of employee illness.<sup>176</sup> Employers who cannot afford or do not want to

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170. *See id.* at 431 (making no differentiation between the terms job-related or business necessity). The Court stated: “[t]he touchstone [for determining whether a practice has a discriminatory effect] is business necessity. If an employment practice which operates to exclude Negroes cannot be shown to be related to job performance, the practice is prohibited.” *Id.*

171. *See, e.g.,* ROTHSTEIN, *supra* note 69, at 134-35 (describing business necessity as “whether there exists an overriding legitimate business purpose such that the practice is necessary to the safe and efficient operation of business,” and job-relatedness as a comparison of legitimate “job requirements with the employer’s method for assessing fitness”).

172. *See id.* at 134 (explaining “[t]he standards used for determining the merits of the business necessity and job-relatedness defenses are similar”).

173. *See id.* at 134-35 (citing *Albemarle Paper Co. v. Moody*, 422 U.S. 405, 432 (1975), which stated that the employer’s methods must be predictive of or significantly correlated with important elements of the job).

174. *Id.* at 134.

175. *See Deyerle, supra* note 31, at 558 (reasoning that there may be a potential cost savings for employers who are able to identify employees susceptible to illness).

176. *See Gin, supra* note 3, at 1411 (suggesting employers and insurance companies may use genetic screening to “identify individuals who might impose ‘unnecessary’

incur the expense of extra safety measures in the workplace, may see genetic screening as a way to prevent employment-related illnesses and encourage worker health and safety.<sup>177</sup> Other commentators suggest that genetic screening can be used to alert susceptible workers to dangers that exist in the workplace in light of their genetic make-up.<sup>178</sup> Employers may argue that this allows them to position workers in the jobs most suited to both their talents and their susceptibilities.<sup>179</sup>

The “business necessity” prong does not justify genetic testing because the tests determine the potential of future illness, not the existence of a present condition. Many courts have held that the avoidance of future liability is insufficient to establish a business necessity.<sup>180</sup> One court held that avoiding expense alone, without a showing of a significant threat to the business, is insufficient to overcome a Title VII discrimination claim.<sup>181</sup> Thus, an employer would probably not be able to pass the business-necessity test when using a genetic screening device that has a disparate impact on minority applicants. Generally, present genetic tests only predict possibilities of disease or disorders. This futuristic and unspecified threat is insufficient to rise to the level of “business necessity.”

#### 4. Less Restrictive Means—The Plaintiff’s Last Resort

Even if the employer proved a sufficient “business necessity” for genetic testing, the plaintiff could still render the “necessity” moot by

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costs in the form of high medical expenses”).

177. See Deyerle, *supra* note 31, at 558 (stating that employers advocate such screening to allow employees to be placed in a position for which they are best suited).

178. See Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 76 (1991) (stating that a one-time genetic screening could determine whether an employee could safely work in a particular job).

179. For example, when Du Pont began testing employees for benzene susceptibility the company did not fire susceptible workers. Instead, the company moved them to more appropriate positions. See Brokaw, *supra* note 47, at 323. An employer using genetic screening to place workers in different jobs would still have to face Title VII’s hurdles if, as a result of the testing, minorities were consistently being placed in less desirable positions.

180. See *Los Angeles Dep’t of Water & Power v. Manhart*, 435 U.S. 702, 716-17 (1978) (finding that future liability is insufficient to establish a business necessity); *Wright v. Olin Corp.*, 697 F.2d 1172, 1190 n.26 (4th Cir. 1982) (stating that future liability alone will not create a business necessity); *Myers v. Gilman Paper Corp.*, 544 F.2d 837, 849 (5th Cir. 1977) (suggesting that financial necessity may be considered a business necessity only if it speaks to present financial concerns, not future ones).

181. See *Chrapliwy v. Uniroyal, Inc.*, 458 F. Supp. 252, 259-72 (N.D. Ind. 1977) (finding that an employer may be forced to incur large expenses in order to comply with Title VII).



showing less restrictive means that satisfy the same “business necessity.” If the employer sought to improve safety, this safety should apply to all employees, rather than eliminating hyper-susceptible workers.<sup>182</sup> In addition, if the workplace poses a specific hazard to an employee, that employee should make the informed decision whether to incur or avoid the risk.<sup>183</sup>

The high correlation between many genetic disorders and race or ethnicity, prohibits screening applicants for many diseases without violating Title VII.<sup>184</sup> For example, tests for sickle cell anemia would by their very nature discriminate against African Americans, a fact recognized by many states when they prohibited employment-related testing for the disease.<sup>185</sup> Further, in most situations the employer would not be able to point to a sufficient “business necessity” to justify the testing. Even if the employer were able to establish a business necessity, it is likely that a less-restrictive and less-invasive means would meet that same requirement. The existence of these less-restrictive and less-invasive means renders the discriminatory genetic test improper. The employer may, however, be able to point to other federal legislation such as the Occupational Safety and Health Act to attempt to establish the necessity of conducting genetic tests.

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182. *See infra* Part V (discussing the imposition of a general duty on employers to provide a hazard-free work environment pursuant to certain regulations promulgated under OSHA).

183. *See International Union v. Johnson Controls, Inc.*, 499 U.S. 187, 211 (1991) (finding that an employer did not have a right to exclude a woman who was of child-bearing age from a work environment where lead was present because the “choice [was] hers to make”).

184. Some courts have sided with the employee when dealing with regulations that have a disparate impact on minority groups. For example, in *EEOC v. Trailways, Inc.*, 530 F. Supp. 54 (D. Colo. 1981), the court struck down a regulation requiring bus drivers to be clean shaven. The regulation was struck because it had a discriminatory impact on African Americans who demonstrated a higher incidence of a skin disorder that made shaving painful. *See id.* at 59. *But see Woods v. Safeway Stores*, 420 F. Supp. 35 (E.D. Va. 1976) (upholding the dismissal of African American employees who grew beards as a result of a skin condition where customers found bearded workers in a grocery store distasteful). Similarly, most of the employers who pioneered sickle cell testing soon stopped, and some states have now prohibited the testing because of its disparate impact on African Americans.

185. *See generally* FLA. STAT. ANN. § 448.076 (West 1997) (prohibiting sickle cell trait screening as a condition of employment); LA. REV. STAT. ANN. § 23:352 (West 1998) (prohibiting employment discrimination on the basis of sickle cell trait).

## V. THE OCCUPATIONAL SAFETY AND HEALTH ACT: NO SAFE HARBOR FOR EMPLOYERS THAT USE GENETIC TESTING

The Occupational Safety and Health Act ("OSHA") was passed in 1970. By enacting OSHA, Congress intended "to assure so far as possible every working man and woman in the Nation safe and healthful working conditions and to preserve our human resources."<sup>186</sup> OSHA imposes two duties on employers. First, employers have a general duty to provide places of employment "free from recognized hazards that are causing or are likely to cause death or serious physical harm."<sup>187</sup> Recognized hazards are those known to the employer or recognized as a hazard by the industry.<sup>188</sup> To establish a recognized hazard a plaintiff must show that the employer had actual or constructive knowledge of the hazard, or that the employer's standards were below the general industry standards.<sup>189</sup> Second, each employer must comply with safety regulations promulgated under OSHA.<sup>190</sup>

### A. An Employer's General Duty

Under OSHA, an employer is not required to provide a perfectly safe working environment.<sup>191</sup> The employer is only required to eliminate significant risks of hazard as much as possible.<sup>192</sup> The general duty to provide a safe workplace arguably requires employers

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186. 29 U.S.C. § 651 (1994).

187. *Id.* § 654(a)(1).

188. See Jack F. Williams, *A Regulatory Model for Genetic Testing in Employment*, 40 OKLA. L. REV. 181, 190-91 (1987) (noting that a recognized hazard may be shown through actual or constructive knowledge on the employer's part or by reference to an industry practice. However, the fact that an industry has not previously addressed a certain hazard does not "foreclose a court's inquiry").

189. See *Magma Copper Co. v. Marshall*, 608 F.2d 373, 375-76 (9th Cir. 1979) (stating that an employer's actual knowledge of a hazard is sufficient proof that the hazard was recognized).

190. See Williams, *supra* note 188, at 190 n.61 (discussing the Secretary of Labor's authority to set standards requiring "conditions, or the adoption or use of one or more practices, means, methods, operations, or processes, reasonably necessary or appropriate to provide safe or healthful employment and places of employment").

191. See Judith Richter, *Taking the Worker as You Find Him*, 8 MD. J. CONTEMP. LEGAL ISSUES 189, 212-13 (1997); see also *Industrial Union Dep't v. American Petroleum Inst.*, 448 U.S. 607, 615 (1980) (holding that the Secretary's standard for Benzene was too low and not "reasonably necessary or appropriate to provide safe and healthful employment").

192. See Ellen R. Peirce, *The Regulation of Genetic Testing in the Workplace-A Legislative Proposal*, 46 OHIO ST. L.J. 771, 814 (1985) (discussing employers' concerns with genetic testing in the workplace in connection with an employer's common law duty to test and OSHA compliance).

to genetically test employees and applicants for hyper-susceptibility to known toxins. Specifically, if an employer knows, or should know, that a certain toxin can be excessively dangerous to hyper-susceptible individuals, then the employer places these individuals at increased risk by hiring and exposing them to a hazardous work environment. This argument is unpersuasive for several reasons.

### B. Safety Regulations Under OSHA

OSHA empowers the Secretary of Labor to create standards that require medical testing of employees exposed to certain toxins in the workplace.<sup>193</sup> The Secretary of Labor, however, is not required to draft regulations to eliminate all toxins in the workplace, or even to eliminate any toxin in its entirety.<sup>194</sup> Rather, regulations must be technologically and economically feasible.<sup>195</sup> Further, they should focus on the workplace, and not the individual workers.<sup>196</sup> Therefore, any safety standard designed to protect the hyper-susceptible worker would probably be successfully challenged as either unreasonable or infeasible.<sup>197</sup> Yet, the Secretary of Labor is allowed to "prescribe the type and frequency of medical examinations . . . which shall be made available, by the employer or at his cost . . . in order to most effectively determine whether the health of such employees is adversely affected by such exposure."<sup>198</sup>

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193. See 29 U.S.C. § 651(b)(3) (1994) (authorizing "the Secretary of Labor to set mandatory occupational safety and health standards applicable to businesses affecting interstate commerce").

194. See *Industrial Union Dep't*, 448 U.S. at 614.

195. While OSHA does not give a specific definition of what it means to be economically or technologically feasible, courts have interpreted the requirement to mean that an employer may have to expend significant amounts of money before successfully claiming that a standard is economically infeasible. For example, courts have held that a standard will not be considered economically infeasible merely because the cost is high. See *Asarco, Inc. v. OSHA*, 746 F.2d 483, 501 (9th Cir. 1984); *United Steelworkers of Am. v. Marshall*, 647 F.2d 1189, 1307 (D.C. Cir. 1980) (finding that high cost alone did not make a standard economically infeasible). The cost must be weighed against the expected benefit in determining whether the standard is appropriate. See *United Parcel Serv. v. OSHA*, 570 F.2d 806, 812 (8th Cir. 1978) (holding that the UPS need not require its employees to wear steel-toed shoes where the cost outweighed the potential safety benefit).

196. See 29 U.S.C. § 651(b)(1) (stating the first purpose of the act is "to reduce the number of occupational safety and health hazards at . . . places of employment").

197. See Peirce, *supra* note 191, at 814 (stating that the standard "might be challenged as not reasonably necessary or appropriate to provide safe and healthful employment or because it is technologically or economically infeasible").

198. 29 U.S.C. § 655(b)(7).

Currently, OSHA's medical surveillance regulations require pre-employment or pre-placement examinations. Following the examination, the treating physician must give the employer a statement that the employee is suitable for the desired position. Additionally, the employee is periodically tested during the term of employment.<sup>199</sup> These tests range in level of invasiveness from a simple physical examination to blood and urine analysis.<sup>200</sup> Currently, none of these regulations require disclosure of uncovered genetic information. Theoretically, however, under the auspices of the Act, the Secretary of Labor could create a rule that requires employers to genetically test employees and applicants for known susceptibilities to certain toxins.<sup>201</sup> The legitimacy of this rule would depend on the cost of the test, its accuracy, and the feasibility of requiring its widespread use in the industry.<sup>202</sup> At present, it is doubtful that any genetic test would meet these criteria because most genetic tests are currently expensive and unreliable.<sup>203</sup>

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199. See Mark A. Rothstein, *Employee Selection Based on Susceptibility to Occupational Illness*, 81 MICH. L. REV. 1379, 1414 (1983) ("[E]mployers must conduct preplacement examinations, the physician must furnish employers with the physician's statement of suitability for employment in the regulated areas, the employer must conduct periodic (usually annual) examinations.").

200. See 29 C.F.R. § 1910.1001 (1998) (requiring pulmonary function tests and chest x-rays for exposure to asbestos); 29 C.F.R. § 1910.1017 (requiring complete physical exam and liver studies for exposure to polyvinyl chloride); 29 C.F.R. § 1910.1025 (requiring a complete medical exam and detailed blood analysis for exposure to lead), 29 C.F.R. § 1910.1044 (requiring examination of genitourinary tract and serum specimen analysis by radioimmunoassay).

201. See Williams, *supra* note 188, at 192 (discussing genetic testing in light of feasibility standards).

202. Courts have found that when determining whether a standard is appropriate the cost of the measure must be balanced against the expected benefit. The benefit, however, must be given more weight than the cost in determining whether the standard should be passed. See *RMI Co. v. Secretary of Labor*, 594 F.2d 566, 572 (6th Cir. 1979) (suggesting that cost must be balanced against benefit, but that the benefit should be given greater weight than the cost); *United Parcel Serv. v. OSHA*, 570 F.2d 806, 812 (8th Cir. 1978) (ruling that foreseeable hazards must be eliminated even if costly); *American Petroleum Inst. v. OSHA*, 581 F.2d 493, 502-03 (5th Cir. 1978) (requiring a balancing test between cost and benefit of the proposed standard).

203. The expense of genetic tests outweighs their benefit since most genetic tests are still considered inaccurate predictors of hyper-susceptibility. See Brokaw, *supra* note 47, at 321; Deyerle, *supra* note 31, at 551-52. Without an accurate measure, it is unlikely that any genetic testing requirement would withstand a challenge.

The broad goal of OSHA is to limit workplace toxins.<sup>204</sup> OSHA focuses specifically on the workplace, not the individual worker.<sup>205</sup> Identifying and excluding hyper-susceptible workers from known toxins contradicts OSHA's goal to provide safe workplaces "free from recognized hazards that are causing or are likely to cause death or serious physical harm."<sup>206</sup> Rather than reducing workplace toxins, broad-scale genetic testing and exclusion of hyper-susceptible workers would encourage employers to continue operating hazardous work sites while at the same time creating a class of unemployable workers. The better approach, and the one supported by OSHA's general goals,<sup>207</sup> is to reduce or eliminate workplace toxins and implement safety procedures that would give all workers, hyper-susceptible or not, a safer work environment.<sup>208</sup>

OSHA would not prohibit genetic testing in the workplace, but it does not permit the actual use of information gained from the tests. The goal of OSHA is to improve the workplace, not exclude certain workers from certain jobs. Therefore, OSHA does require testing of employees where workplace includes known toxins. Given an accurate and fairly inexpensive test, OSHA could possibly require employers to conduct certain genetic tests on employees in the future. With current genetic technology, however, this requirement is unlikely because any genetic test would probably fail the economically and technologically feasible test that is applied to OSHA standards. In addition, it is doubtful that an employee could use the general duty

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204. See 29 U.S.C. § 651(b) (1994) (stating that the act's goal is to "provide safe and healthful working conditions").

205. See Peirce, *supra* note 192, at 817-18 (claiming that genetic testing does not create a safe working environment); Richter, *supra* note 191, at 217 (explaining that under OSHA, genetic testing is not a general duty of employers).

206. 29 U.S.C. § 654(a)(1).

207. OSHA's general duty clause provides that every employer "shall furnish to each of his employees employment and a place of employment which are free from recognized hazards that are causing or are likely to cause death or serious physical harm to his employees." 29 U.S.C. § 654(a)(i).

208. Genetic testing should not be permitted under OSHA because it should be up to the hyper-susceptible worker to determine whether he or she is willing to risk exposure to toxins at levels that are relatively safe for the "normal" person. See *International Union v. Johnson Controls, Inc.*, 499 U.S. 187, 220 (1991) (invalidating a regulation which prevented fertile women from working in conditions with high lead levels and reasoning that women have the right to decide where to work). Further, past OSHA administrators have given public statements disapproving of genetic testing of employees under OSHA. See Peirce, *supra* note 192, at 818 (claiming that genetic testing does not fit into the general duty clause) (citing Bingham, *Letter to the Editor*, N.Y. TIMES, Mar. 22, 1980, at A20).

clause to justify conducting genetic testing because the testing would only accomplish restricting access to jobs, not increasing the overall safety of the workplace.

Another area of protection against genetic testing may come from constitutionally protected privacy rights. These protections will be especially strong for public employees who are protected by the Fourth Amendment against unlawful searches and seizures.

## VI. THE RIGHT TO PRIVACY AND GENETIC INFORMATION

Although not specifically enumerated in the Constitution, the Supreme Court recognized a right to privacy in *Griswold v. Connecticut*<sup>209</sup> through a combination of the First, Third, Fourth and Fifth Amendments to the United States Constitution.<sup>210</sup> To fall within this zone of privacy, a right must be either "implicit in the concept of ordered liberty,"<sup>211</sup> or "deeply rooted in this Nation's history and tradition."<sup>212</sup> To date, however, no recognized constitutional right to privacy would prohibit employment testing.<sup>213</sup>

### A. Right to Privacy in Medical Information

In *Whalen v. Roe*,<sup>214</sup> the Supreme Court recognized a right to privacy in medical information.<sup>215</sup> The Court considered a New York statute that required the state to record prescription drug user names and addresses.<sup>216</sup> The Court held that the zone of privacy encompassed an individual's interest against disclosure of personal

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209. *Griswold v. Connecticut*, 381 U.S. 479 (1965) (establishing a married couple's right to privacy within their own bedroom).

210. See U.S. CONST. amends. I, III, IV, V. Plaintiffs in California may be provided an extra level of protection because the California Constitution includes within it a right to privacy. See CAL. CONST. art. I, § 1.

211. *Bowers v. Hardwick*, 478 U.S. 186, 191-92 (1986) (upholding a criminal sodomy law and declining to find a Constitutional right to engage in homosexual relations).

212. *Id.* (quoting *Moore v. East Cleveland*, 431 U.S. 494, 503 (1977)).

213. See *Deyerle*, *supra* note 31, at 563, (discussing the treatment of *Griswold v. Connecticut* by lower courts in the context of genetic testing); *Peirce*, *supra* note 192, at 801 (finding no Supreme Court decision concerning an employee's right to privacy in the workplace).

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

215. See *id.* at 598-600 (upholding a New York patient identification statute where the statute did not substantially invade an individual's right to privacy in medical information).

216. See *id.* at 591.

information such as prescription drug use.<sup>217</sup> The Court, however, found the statute was constitutional because the interest of the state in collecting the information outweighed the individual's interest in keeping it private.<sup>218</sup>

Arguably, because genetic information is uniquely personal, it deserves more protection than other forms of medical information.<sup>219</sup> The information available through our genes, including the potential to unlock secrets unknown even to the individual, highlights the unique nature of genetic information.<sup>220</sup> In addition, genetic information carries implications not only for the individual but also for his or her family.<sup>221</sup> History, therefore, should be a guide to determine the scope of privacy applicable to genetic information.<sup>222</sup> Specifically, the release of genetic information conjures up the specters of social stigma, employment and insurance discrimination, and ultimately creates a genetic underclass.<sup>223</sup>

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217. See *id.* at 598-600.

218. See *id.* at 600.

219. But see Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, in *GENETIC SECRETS PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA* 60, 62 (Mark A. Rothstein ed., 1997). Murray argues that "genetic information is neither unique nor distinctive" in offering a view of an individual's future health. *Id.* at 64. He further suggests that genetic information and risk factors are no different than other medical information and risk factors. See *id.* at 69. Murray analogizes an individual's genetic make-up to a diary, stating:

Our genes might be regarded metaphorically as the physical, but blank, volume in which we will create our diary. Some volumes have fewer pages in which to write, some more. Certain pages, often toward the back of the volume, may be more difficult to write on. And some leaves may require great skill and effort to open at all. But the physical volume is not the content of the diary. The content we must write ourselves.

*Id.* at 72.

220. See Lawrence O. Gostin, *Genetic Privacy*, 23 *J.L. MED. & ETHICS* 320, 324-26 (1995) (discussing the need for genetic privacy statutes, particularly in a health system with computerized medical records).

221. See *id.* at 324. This argument can be carried further to suggest that an individual's genetic information may have far-reaching implications for those in the same racial or ethnic group. See *supra* Parts II, IV (providing a further discussion of racial and ethnic implications for genetic testing).

222. See *supra* Part II (discussing past misuses of genetic information). Toward this end, many proposals for genetic privacy acts have been made, including a proposed "Genetic Privacy Act" and Congressional "genetic privacy" bills. See Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in *GENETIC SECRETS-PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA* 31 (Mark A. Rothstein ed., 1997) (defining and discussing the regulation of genetic privacy); see also Gurd, *supra* note 104, at 118 (discussing the relationship between genetic discrimination and the ADA).

223. See Allen, *supra* note 222, at 32 (warning against sacrificing privacy for

### B. Fourth Amendment Protections

Public employees gain another layer of protection against genetic testing through the Fourth Amendment of the United States Constitution. The Fourth Amendment provides protection against unreasonable searches and seizures.<sup>224</sup> The Supreme Court has stated that “the overriding function of the Fourth Amendment is to protect personal privacy and dignity against unwarranted intrusion by the State.”<sup>225</sup> Generally, the Fourth Amendment speaks to criminal searches. In certain situations, however, the Fourth Amendment protections have been applied to noncriminal searches as well.

#### 1. Genetic Tests as Unlawful Searches

In *O'Connor v. Ortega*,<sup>226</sup> the Supreme Court applied the Fourth Amendment to analyze the invasion of a government employee's privacy.<sup>227</sup> The Court found that a government employee had an expectation of privacy within his locked desk and office filing cabinet.<sup>228</sup> Two years later, the Supreme Court found that a drug test was a search within the meaning of the Fourth Amendment.<sup>229</sup> In so doing, the Court set up a balancing test for employee drug testing. Under this test, the government's interest is balanced against the employee's privacy interest.<sup>230</sup>

Where a government employer requires applicants or employees to submit to a genetic test, the government undertakes a search within the meaning of the Fourth Amendment.<sup>231</sup> Although a specific case has

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science); King, *supra* note 61, at 100 (discussing the correlation between current genetic testing and past racial stereotypes).

224. See U.S. CONST. amend. IV. The amendment provides, in pertinent part, “[t]he right of the people to be secure in their persons, papers, and effects, against unreasonable searches and seizures, shall not be violated.” *Id.*

225. *Schmerber v. California*, 384 U.S. 757, 767 (1966) (holding that withdrawal of blood to conduct a blood-alcohol test does not violate the Fourth Amendment).

226. *O'Connor v. Ortega*, 480 U.S. 709 (1987).

227. See *id.* at 714 (stating that the hospital conducted a search of one of its doctor's offices due to suspicion about the doctor's management of a residency program).

228. See *id.*

229. See *Skinner v. Ry. Labor Executives' Ass'n*, 489 U.S. 602, 633 (1989) (upholding random drug testing of railroad employees).

230. See *id.* at 619.

231. Currently, the largest government collector of genetic material is the United States Military. Through the Department of Defense DNA Registry and Repository, every American service member, and civilian employee located in a potential combat zone, is compelled to provide blood and tissue samples to the government. The samples are maintained in a large databank. Unlike other genetic material collection, however, this information is not being used to deny employees jobs or promotions. The stated



not addressed the Fourth Amendment's application to genetic testing,<sup>232</sup> it is likely that courts would borrow from drug testing jurisprudence and balance the individual's privacy interest against the government's interest in the test.<sup>233</sup>

An individual's interest in maintaining the privacy of genetic information is high due to the unique information contained within human genes. Unlike minimally intrusive tests, such as drug or

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purpose of the databank is to assist the government in identifying remains of service members if needed during a military conflict. See generally Robert Craig Scherer, Note, *Mandatory Genetic Dogtags and the Fourth Amendment: The Need for a Post-Skinner Test*, 85 GEO. L.J. 2007 (1997) (arguing that the current non-consensual, non-criminal testing of government employees is outmoded and should be replaced). In *Mayfield v. Dalton*, the district court of Hawaii upheld the constitutionality of the Registry. See *Mayfield v. Dalton*, 901 F. Supp. 300, 303-05 (D. Haw. 1995), vacated by *Mayfield v. Dalton*, 109 F.3d 1423 (9th Cir. 1997). The court found that the important interest of the government in identifying remains outweighed the individual's privacy interest. See *id.* The appeal of the case, however, was summarily dismissed as moot because the servicemen involved had since been honorably discharged from the military. See *Mayfield*, 109 F.3d 1423 (9th Cir. 1997), vacating as moot 901 F. Supp. 300, 303-05.

232. The Ninth Circuit has recognized the possibility of a privacy claim based on genetic testing in a state and federally owned laboratory. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998) (acknowledging a cause of action based on privacy interests under both the United States Constitution and the California Constitution, where the lab did testing for syphilis, sickle cell anemia, and pregnancy without an individual's knowledge).

233. This same balancing test has been applied by lower courts for mandatory AIDS testing in the workplace. In *Local 1812 v. United States Department of State*, the union challenged the government's mandatory HIV testing policy. See *Local 1812 v. United States Dep't of State*, 662 F. Supp. 50, 51 (D.D.C. 1987). The government argued that service by HIV-infected individuals at many foreign posts would pose a "serious hazard" to the infected individual because of the poor medical facilities and poor quality of other health and sanitary conditions. See *id.* at 52. The court upheld the test, finding it was minimally intrusive because blood testing for other conditions was already required. In addition, the court found that the tests were rationally related to fitness for duty. See *id.* at 54. The Fifth Circuit followed similar reasoning in upholding the discharge of a nurse from a hospital who refused to submit the results of an HIV-test he had voluntarily taken outside the course of his employment. See *Leckelt v. Board of Comm'rs*, 909 F.2d 820, 833 (5th Cir. 1990). The court applied a balancing test and determined that the hospital's interest "in maintaining a safe workplace through infection control outweighed the limited intrusion on any privacy interest of Leckelt in the results of his HIV antibody test." *Id.* at 833.

In contrast, the Eighth Circuit struck down a health service's mandatory HIV-testing policy. See *Glover v. Eastern Neb. Community Office of Retardation*, 867 F.2d 461, 464 (8th Cir. 1989). The agency argued that it was necessary to test employees for HIV because mentally retarded individuals often scratched and bit workers. See *id.* at 463. The court based its decision on the fact that there was no conclusive evidence that the disease could be spread through casual contact. See *id.* The court found that "from a medical viewpoint, this policy is not necessary to protect clients from any medical risks." *Id.* at 463.

alcohol tests, genetic tests reveal traits beyond an individual's control. The government's interest, however, in this genetic information about its employees is relatively low. Generally, this information does not reveal anything about an individual's *present ability* to perform job functions safely and successfully. Rather, the information may reveal risks to the individual, but not risks to fellow workers.<sup>234</sup> Admittedly, the government can express some interest in the protection of its workers against unnecessary risk of disease. A paternalistic reason, however, is not sufficient to overcome the individual's interest in privacy.<sup>235</sup>

## 2. Genetic Tests as Unlawful Seizures

Government employees also have some protection against genetic testing based on the privacy rights against illegal seizures inherent in the Constitution. Taking an individual's blood or tissue for the purposes of genetic testing is a type of seizure protected by the Fourth Amendment.<sup>236</sup> In order to make this seizure, the government would have to establish an overwhelming need for the test. Yet, this need may be difficult to establish. Unlike drug testing that only tests for the existence of a limited number of substances voluntarily ingested by the individual, genetic testing reveals the deepest secrets of an individual's past, present, and projected future including those of his or her family. This added level of invasiveness strengthens the individual's privacy interest thus raising the government's burden in showing a need to justify an intrusion. The government, therefore, would be hard-pressed to articulate a satisfactory need.

## VII. STATE LEGISLATION—AN ATTEMPT TO CLARIFY THE LAW OF GENETIC TESTING

In response to the confusion over whether federal laws protect against genetic discrimination, many states have stepped in and passed their own legislation.<sup>237</sup> The laws range from total protection against

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234. Risks to fellow workers include risks such as those inherent in drug use at dangerous work sites or AIDS testing in a medical facility. These risks could arguably support intrusive testing to secure the safety of co-workers. *See Leckelt*, 909 F.2d at 833.

235. *See International Union v. Johnson Controls, Inc.*, 499 U.S. 187, 206 (1991) (striking down a company's policy that disqualified fertile females from working near lead).

236. The Fourth Amendment guarantees an individual the right to be free from "unreasonable searches and seizures." U.S. CONST. amend IV.

237. Most of the state legislation refers only to discrimination in insurance, and not

genetic testing to limited restrictions on the use of such tests. Unlike the ADA, the protections in the state laws are not restricted to employers with fifteen or more employees.

In 1981, the state of New Jersey was the first to enact legislation addressing employment discrimination based on genetic testing. This law prohibited "employment discrimination based on an individual's 'atypical hereditary cellular or blood trait.'"<sup>238</sup> In 1996, New Jersey revised this law to ban discrimination based on "genetic information" including information "that may derive from an individual or family member."<sup>239</sup>

Other states in the years to follow, however, have provided the most comprehensive protection.<sup>240</sup> Wisconsin, Iowa and New Hampshire

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employment. See NEB. REV. STAT. ANN. § 689A.417 (Supp. 1997) (prohibiting health insurers from requiring the insured or any member of his family to take a genetic test, disclose whether he or any member of his family had previously taken a genetic test, or determine the rates or other aspects of coverage based on whether the individual or a family member had taken a genetic test, or any other genetic information). The prohibition, however, is not extended to an insurer "who issues a policy of health insurance that provides coverage for long-term care or disability income." *Id.*; see also COLO. REV. STAT. ANN. § 10-3-1104.7 (West Supp. 1997) (preventing genetic testing from being used to deny "health care insurance, group disability insurance, [and] long-term care insurance." The statute specifically exempts life insurance and individual disability insurance.); FLA. STAT. ANN. § 627.4301 (Supp. 1998) (preventing health insurers from canceling, limiting or denying coverage, or establishing differentials in premium rates, based on genetic information in the "absence of a diagnosis of a condition related to genetic information"); 410 ILL. COMP. STAT. 513/20 (West 1997) (providing that an insurer may not use genetic testing in connection with accident and health insurance. The law makes an exception when the genetic testing information is provided voluntarily by the individual and the results are favorable to that individual.); GA. CODE ANN. 33, ch. 54-1, -3, -7 (1996) (preventing "accident and sickness insurance companies, health maintenance organizations, managed care organizations, and other payors from using genetic information to deny accident and sickness coverage); N.H. REV. STAT. ANN. § 141-H:4-5 (1996) (providing that a health insurance company may not require or request an individual or his family to undergo genetic testing or reveal whether the individual or his family has previously taken a genetic test. An exception is provided, however, for "life insurance, disability income insurance, [and] long-term care insurance."). A complete discussion of the limitations on genetic discrimination in insurance is beyond the scope of this paper.

238. Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace*, in *GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA* 281, 291 (1997) (citing N.J. STAT. ANN. § 10:5-5(x) (West 1993), which states that "[a] typical hereditary cellular or blood trait" means sickle cell trait, hemoglobin C trait, thalassemia trait, Tay Sachs trait, or cystic fibrosis trait").

239. *Id.*

240. These states are Wisconsin, Iowa, and New Hampshire. See WIS. STAT. ANN. § 111.372 (West 1997) (Use of Genetic Testing in Employment Situations); N.H. REV. STAT. ANN. § 141.H:3 (1996) (Use of Genetic Testing in Employment Situations); IOWA CODE ANN. § 729.6 (West 1993) (Genetic Testing).

provide virtually identical statutory provisions:<sup>241</sup>

No employer, labor organization, employment agency, or licensing agency shall directly or indirectly: (a) [s]olicit, require or administer genetic testing relating to any individual as a condition of employment, labor organization membership, or licensure[;] (b) [a]ffect the terms, conditions, or privileges of employment, labor organization membership, or licensure or terminate the employment, labor organization membership, or licensure of any individual based on genetic testing.<sup>242</sup>

The statute goes on to provide that “[a]ny agreement between an employer, labor organization, employment agency, or licensing agency and an individual offering employment, labor organization membership, licensure, or any pay or benefit to that individual in return for taking a genetic test is prohibited.”<sup>243</sup> The statute, however, does provide an exception that permits employee testing under limited circumstances, but prohibits termination based on the results of these tests.<sup>244</sup> In effect, this eliminates virtually all chance of discrimination based on latent genetic defects. It is more restrictive than the ADA medical testing provisions because it does not allow genetic testing at any stage of the employment relationship. By allowing testing for susceptibility to workplace toxins, while still preventing negative employment decisions based on the results, the statute protects workers from harmful environments and discrimination.<sup>245</sup> It may, however, restrict paternalistic employment decisions that seek to transfer hyper-susceptible employees to a safer work environment. If the employee views the transfer as an adverse employment action, the transfer may be prevented even though the employer had good intentions.<sup>246</sup>

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241. The New Hampshire statute is cited by way of example. See N.H. REV. STAT. ANN. § 141-H:3.

242. *Id.* § 141-H:3(I)(a)-(b).

243. *Id.* § 141-H:3(III).

244. See *id.* § 141-H:3 (IV)(b) (allowing consensual genetic testing to determine an “employee’s susceptibility or level of exposure to potentially toxic chemicals or potentially toxic substances in the workplace, if the employer does not terminate the employee, or take any other action that adversely affects any term, condition, or privilege of the employee’s employment”) (emphasis added).

245. Note, however, that while the employers may test for susceptibility to workplace toxins, there is no requirement that the employer move the employee out of the hazardous workplace if susceptibility is found. There is also no requirement that the test results be revealed to the employee. Thus, the law may not provide as much protection against workplace toxins as it appears at first glance. See *id.* § 141-H:3.

246. North Carolina provides similar protection. See N.C. GEN. STAT. § 95-28.1A (Michie Supp. 1997). The statute, titled “Discrimination Against Persons Based on

Given the confusion over the protections provided in federal legislation such as the ADA, more states will likely follow suit in enacting statutes specifically aimed at protecting workers against genetic discrimination in the future.<sup>247</sup>

### VIII. CONCLUSION

Genetic research promises a wealth of medical benefits. When diseases can be identified and linked to genetic traits there is a promise of treatment and cure in the future. The Human Genome Project's goal of identifying all 100,000 human genes within the next ten years holds the promise of healthier, longer lives. With this promise, however, lies the specter of fear and discrimination.

Genetic testing may be applied in employment to discriminate against "genetically inferior" workers. Employers have an interest in healthy, productive workers who will remain with the company far into the future. Unhealthy workers cost a company money in lost time, insurance, and retraining to replace seriously ill workers. This vision includes a picture of employers who screen applicants and

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Genetic Testing or Genetic Information Prohibited," states that:

No person, firm, corporation, unincorporated association, State agency, unit of local government, or any public or private entity shall deny or refuse employment to any person or discharge any person from employment on account of the person's having requested genetic testing or counseling services, or on the basis of genetic information obtained concerning the person or a member of the person's family.

*Id.* Theoretically, this does not prevent employers from requiring genetic testing. There would be little purpose to the testing, however, because the employer is prevented from acting upon anything he or she discovers. *See id.*

247. For example, New York law statutes include the language "genetic predisposition or carrier status" in its existing discrimination laws. *See* N.Y. EXEC. LAWS § 296 (1)(a) (McKinney Supp. 1998) (Unlawful Discrimination Practices). Thus, under New York law, genetic "predisposition or carrier status" is raised to the level of "age, race, creed, color, national origin, sex, disability . . . [and] marital status" in terms of protection against employment discrimination. *Id.* Additionally, an Oregon statute makes it an "unlawful employment practice for an employer to seek to obtain, to obtain, or to use genetic information . . . of an employee or a prospective employee to distinguish between or discriminate against . . . an employee or prospective employee." OR. REV. STAT. § 659.036(1) (Lexis Supp. 1996). The law, however, includes an exception for the use of genetic information with the authorization of the employee to determine a "bona fide occupational qualification." *Id.* The law does not define a "bona fide occupational qualification," thus diminishing the strength of a law that without this caveat, could have protected virtually all employees from genetic discrimination. *Id.* Additionally, section 659.227 of the Oregon statute prohibits an employer from subjecting an employee or prospective employee to genetic testing, again with the exception that the genetic test be administered to determine a "bona fide occupational qualification." *Id.* § 659.227(1).

refuse employment based on genetic markers correlated with serious diseases. While this seems futuristic, research has shown that genetic testing in the employment arena is a reality.<sup>248</sup> As genetic tests get easier, cheaper, and more accurate, their use is likely to increase if proper guidelines are not established.

Workers currently have many protections in place against the abusive use of genetic testing. First, the ADA provides employees with their greatest protection. It dictates how and when medical testing—and by extension, genetic testing—may be performed. In addition, employees may gain added protection through Title VII when a specific genetic disorder is correlated along racial, ethnic, or gender lines.

OSHA may also add a layer of protection. Under OSHA, the Secretary of Labor may promulgate regulations that require genetic testing in certain work environments. These tests, however, would be government regulated and only administered in limited situations. Further, an employer cannot hide behind the dictates of OSHA's general duty clause to justify its own implementation of genetic testing because the clause requires employers to provide a safe environment for all employees, not just the genetically susceptible ones.

Finally, government employees gain an added layer of protection from privacy rights inherent in the Constitution. Like drug testing, genetic testing is a type of seizure protected by the Fourth Amendment. In order to use a genetic test, the government would have to establish an overwhelming need for the test. Unlike drug testing, which only tests for the existence of a few limited substances taken voluntarily by the individual, genetic testing reveals the deepest secrets of an individual. This invasiveness strengthens the individual's privacy interest and heightens the government's burden to establish "need" in order to overcome it.

Yet, despite all these protections, it remains unclear whether any of these laws actually apply to genetic discrimination. Many commentators suggest that these laws are insufficient to protect workers from unjustified genetic discrimination. Toward this end, many states have passed their own laws protecting individuals within their borders from genetic discrimination in employment. A simple statement from Congress including latent genetic disorders as a

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248. See GENETIC MONITORING SURVEY, *supra* note 2 (discussing the feasibility of genetic tests currently utilized in the employment setting); see also notes 4-9 and accompanying text (stating that at least 20 Fortune 500 companies have admitted to using genetic testing at one time or another).

disability under the ADA would resolve this issue and guarantee that employees are protected from genetic discrimination in the future.