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Articles

IS THERE A PINK SLIP IN MY GENES? GENETIC DISCRIMINATION IN THE WORKPLACE

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"The challenge, and it is a formidable one, is to nurture scientific exploration, encourage the translation of these new discoveries into life saving medicines, and to put in place public policies reflective of our core American values that prevent the unjust, unfair, and discriminatory use of genetic information."¹

* Commissioner, United States Equal Employment Opportunity Commission; J.D., Harvard Law School; B.A., University of Pennsylvania. This Article was written by Mr. Miller in his private capacity. No official support or endorsement by the EEOC or any other agency of the U.S. government is intended or should be inferred. The author would like to thank Laura Pho for her research assistance, and Nancy Segal, Lisa Cottle, R. Paul Richard, Antoinette Eates, Peggy Mastrianni, Peter Gray, Kathy Hudson, and Barbara Fuller for their invaluable input and guidance in reading earlier drafts of this Article.

The author dedicates this Article to Dr. Victor McKusick and the entire team of doctors, geneticists, social workers, and nurses at the Johns Hopkins Hospital who, for nearly 35 years, have enriched me with much more than simply a better understanding of my own genetic code.

1. National Human Genome Research Inst., *Dr. Francis Collins, Director of NHGRI, Applauds President Clinton's Action to Protect Federal Workers From Genetic Discrimination* (visited Mar. 7, 2000) <http://www.nhgri.nih.gov/NEWS/Executive_order/index.html> (Remarks of Dr. Francis Collins, Director of the National Human Genome Research Institute (NHGRI) delivered on February 8, 2000 on the occasion of the President signing an executive order prohibiting employment discrimination by the federal government on the basis of genetic information).

INTRODUCTION

The surge in genetic research and technology, fueled in large part by the Human Genome Project (HGP),² has resulted in the continuing expansion of the range of genetic tests and other genetic information available to physicians, insurance companies, employers, and the general public.³

Genetic tests can provide presymptomatic medical information about an individual, including information about an individual's increased risk of future disease, disability, or early death.⁴ These tests can reveal information about an individual's carrier status and provide clues about the health of the individual's family members.⁵ Although genetic information provides the prospect of early detection and treatment of illness and medical disorders, it is not without ethical and legal implications.⁶ As a result of the increase in genetic testing and the availability of genetic information, legal issues regarding employment discrimination on the basis of genetic information are emerging. These issues are important to all workers as genetic testing becomes more prevalent. If employers are permitted to base personnel decisions on genetic information, people will be unfairly barred or removed from working for reasons unrelated to their ability to perform their jobs. In addition, people will be reluctant to take advantage of the growing array of genetic testing that can identify their vulnerability to specific diseases and may permit early treatment because of a fear that employers will misuse the genetic information or

2. The Human Genome Project is a coordinated, international research effort, jointly managed by the U.S. Department of Energy and the National Institutes of Health, to analyze the structure of human DNA and to map and sequence the estimated 50,000-100,000 human genes. See National Human Genome Research Inst., *The Human Genome Project* (visited Feb. 29, 2000) <<http://www.nhgri.nih.gov/HGP/>>.

3. The HGP will improve technology for biomedical research and influence medicine, including reproductive planning, prenatal diagnosis and treatment, and preventive and therapeutic health treatment for a range of genetically-related illnesses. See *id.* Recognizing that the acquisition and use of genetic information has enormous individual and societal implications, analysis of the ethical, legal, and societal implications of genetic knowledge has been an important component of the HGP research effort. See *id.* For a discussion of the HGP, see generally, Ari Patrinos & Daniel W. Drell, *Introducing the Human Genome Project: Its Relevance, Triumphs, and Challenges*, 36 JUDGES' J. 3 (1997); Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 Hous. L. Rev. 23 (1992).

4. See Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 Ky. L.J. 503, 523-24 (1997).

5. See *id.* at 524; see also The National Human Genome Research Inst., *Ethical, Legal and Social Implications (ELSI) High Priority Areas* (visited Feb. 22, 2000) <http://www.nhgri.nih.gov:80/About_NHGRI/Der/Elsi/high_priority.html>.

6. See Rothstein, *supra* note 3, at 24.

draw inappropriate inferences from an individual's request for testing.

This Article outlines the growing concerns about genetic discrimination in the workplace and suggests possible methods for addressing such discrimination. The first section provides the reader with background information on genetics and genetic testing.⁷ The second section outlines workers' fears and the reality of genetic discrimination in employment;⁸ the third section discusses the application of existing federal statutes, particularly the Americans with Disabilities Act (ADA), to genetic discrimination.⁹ The fourth section discusses the Presidential Executive Order on genetic discrimination.¹⁰ The fifth section discusses issues of genetic privacy,¹¹ and the sixth section provides an overview of current state laws enacted to protect workers from genetic discrimination, as well as proposed federal legislation to address the current gaps in protection from genetic discrimination in the workplace.¹²

I. GENETICS PRIMER

A meaningful discussion of genetic discrimination necessarily involves a rudimentary understanding of the science of genetics.¹³ Quite simply, genes contain the set of instructions for making proteins within cells.¹⁴ Proteins constitute the building blocks of cells, and ultimately, of entire organisms, including complex organisms such as human beings.¹⁵ Genes represent the blueprint for each individual's biological make-up.¹⁶

The inheritance of individual human traits is determined by genes.¹⁷ The gene transmits biological information from generation

7. See *infra* text accompanying notes 13-66.

8. See *infra* text accompanying notes 67-100.

9. See *infra* text accompanying notes 101-178.

10. See *infra* text accompanying notes 179-197.

11. See *infra* text accompanying notes 198-253.

12. See *infra* text accompanying notes 254-284.

13. See generally Jeremy A. Colby, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443 (1998) (discussing the implications of the Human Genome Project and gene testing); see also Holmes, *supra* note 4, at 519 (discussing a gene's function as the basic physical unit of heredity comprised of DNA). The University of Kansas' Genetics Education Center website provides links to basic materials and resources concerning human genetic issues. See University of Kansas Medical Center, *Genetics Education Center* (visited Feb. 29, 2000) <<http://www.kumc.edu/gec/>>.

14. See Colby, *supra* note 13, at 446-47.

15. See Holmes, *supra* note 4, at 519.

16. See *id.*

17. See American Bar Ass'n, *A Genetics Glossary for Judges*, 36 JUDGES' J. 65, 66 (1997).

to generation.¹⁸ Characteristics such as gender, hair color, and height are passed from parent to child through genes.¹⁹ In addition, certain diseases and the predisposition to such diseases, are also passed on from generation to generation by one's genes.²⁰ Many diseases are thought to stem from mutated genes inherited from a parent or which may develop throughout a person's life.²¹ Moreover, common disorders, such as heart disease and most cancers, arise from the complex interplay among multiple genes and factors within the environment.²² Thus, by identifying certain genes, one can determine an individual's likelihood of manifesting certain traits, including disease and other disorders, or of passing along those traits to offspring.

A. *The Biology Behind Genetic Testing*

Each gene is a part of a large molecule of deoxyribonucleic acid, or DNA.²³ Four chemical bases—adenine, thymine, cytosine, and guanine—connect to form long strands of DNA.²⁴ In doing so, the bases, which are often represented by their initial letters (A, T, C, and G, respectively) create a sequence that ultimately will determine how a particular cell operates.²⁵ Single strands of DNA become chemically bonded to each other in such a manner that they resemble a ladder, with each strand representing one of the ladder's vertical rails and the chemical bonds representing the horizontal rungs.²⁶ Finally, the ladder twists, forming the familiar "double helix" and a complete molecule of DNA.²⁷

Genes are the "working subunits" of complete DNA molecules.²⁸ In a gene, the sequence of chemical bases is a coded instruction for a specific cell product or function.²⁹ There are an estimated 50,000 to 100,000 genes in a human being, only a fraction of which have been identified or "mapped" according to the sequence of chemical bases

18. See Colby, *supra* note 13, at 447.

19. See Holmes, *supra* note 4, at 520.

20. See Colby, *supra* note 13, at 447-48.

21. See NATIONAL CANCER INST., U.S. DEP'T OF HEALTH AND HUMAN SERVS., UNDERSTANDING GENE TESTING 5 (1995) [hereinafter UNDERSTANDING GENE TESTING].

22. See *id.* at 4.

23. See *id.* at 1.

24. See *id.*

25. See *id.*; see also Holmes, *supra* note 4, at 521.

26. See Denise K. Casey, *What Can the New Gene Tests Tell Us?*, 36 JUDGES' J. 14, 14-15 (1997).

27. See UNDERSTANDING GENE TESTING, *supra* note 21, at 1.

28. See *id.*

29. See Holmes, *supra* note 4, at 521.

of which they are made.³⁰ Science has yet to discover the purpose for, or function of, the vast majority of human genes.³¹

Genetic mutations occur when the chemical bases become rearranged, lost, or changed, resulting in a "misspelling" of the gene.³² Some mutations are silent and do not affect the structure of the encoded protein or its function.³³ Other mutations, however, can alter the protein and result in a disease or disorder.³⁴ Genetic mutations can be inherited from a parent, develop as a result of errors that occur during cell division, or be acquired from the environment.³⁵ For example, one particular gene instructs the cell to produce hemoglobin, an oxygen-carrying protein in the blood.³⁶ If that gene mutates, the result may be flawed hemoglobin, a condition associated with sickle-cell anemia.³⁷

B. Genetic Testing and What It Can Reveal

Genetic testing involves examining a person's DNA for some anomaly that flags a disease or disorder.³⁸ Suspected mutations and predisposition to disease can be confirmed by genetic testing before symptoms appear.³⁹ In addition, these tests can be used to identify carriers of certain diseases or disorders. Carriers do not themselves have a particular disease or disorder and may never develop the disease or disorder, but they nevertheless possess recessive genes and pass them along to their children in whom the disease or disorder might occur.⁴⁰ Possessing a faulty gene without more does not necessarily lead to the realization of the disease or disorder.⁴¹ A variety of factors influence the gene's penetrance and the chances one will actually develop symptoms.

Genetic testing can be accomplished through a variety of methods, yet all of these methods require cells from the individual being tested. The cells used for testing most often come from a drop of blood,⁴² but can also be taken from the individual's saliva, the inside

30. See UNDERSTANDING GENE TESTING, *supra* note 21, at 10.

31. See Colby, *supra* note 13, at 447.

32. See UNDERSTANDING GENE TESTING, *supra* note 21, at 4.

33. See *id.*

34. See *id.*

35. See *id.* at 5.

36. See *id.* at 4.

37. See *id.*

38. See Casey, *supra* note 26, at 16.

39. See UNDERSTANDING GENE TESTING, *supra* note 21, at 9.

40. See *id.*

41. See *id.*

42. See Casey, *supra* note 26, at 17; see also Colby, *supra* note 13, at 449.

of the cheek, or any other tissue.⁴³ Once the cells have been collected, a variety of tests can be applied. For example, in a "probe test," a disease gene has been identified, copied, and a DNA probe constructed.⁴⁴ The constructed, single-stranded probe then chemically binds to and "highlights" a particular mutation in the cell's DNA.⁴⁵ Probe tests are fairly accurate but are only available for a limited number of genetic diseases because of their research-intensive nature.⁴⁶ Another type of DNA genetic test involves comparing the patient's gene and its DNA sequence to a "normal" version of the gene.⁴⁷ Linkage tests involve the analysis of chromosome segments of a "disease family" which contain a gene suspected of causing an inherited disease.⁴⁸ They are difficult to administer because researchers must screen several generations of a family with a history of genetic disease to learn if the DNA segment is linked to inheriting the genetic disease.⁴⁹ Regardless of which genetic test is used, the goal of such tests is to identify the presence of a genetic mutation that predisposes the tested individuals or their offspring to a particular disease or condition.⁵⁰

While genetic tests can diagnose symptomatic disease, they are relevant to issues of genetic discrimination because of the ability to reveal whether an asymptomatic person is predisposed to, or has a genetic marker for, a particular trait. The predictive ability of genetic tests is somewhat limited though because they reveal only the *mere possibility* that the person may develop the trait, disease, or disorder in the future and are not absolute indicators that symptoms will develop.⁵¹

The probability that a genetic mutation will manifest in a particular disease or disorder in the future is based on a variety of factors.⁵² For example, persons who have the Huntington's Disease⁵³ gene do

43. See generally Colby, *supra* note 13, at 449.

44. See UNDERSTANDING GENE TESTING, *supra* note 21, at 15.

45. See *id.*

46. See Colby, *supra* note 13, at 449.

47. See Casey, *supra* note 26, at 17.

48. See UNDERSTANDING GENE TESTING, *supra* note 21, at 28.

49. See Colby, *supra* note 13, at 449.

50. See UNDERSTANDING GENE TESTING, *supra* note 21, at 9.

51. See Colby, *supra* note 13, at 449. The question of whether an individual at risk for a particular genetic condition should be tested is fraught with complex emotional, psychological, and ethical considerations. See generally ALICE WEXLER, *MAPPING FATE* (1995) (describing a personal account of issues confronting an individual with a family history of Huntington's Disease).

52. See UNDERSTANDING GENE TESTING, *supra* note 21, at 7.

53. Huntington's Disease is an untreatable, hereditary autosomal disorder which is characterized by involuntary movements and progressive dementia. See HARRISON'S PRINCIPLES

develop, with a “chilling certainty,” the fatal neurological condition sometime during middle age.⁵⁴ The implications of the presence of the “breast cancer gene,” on the other hand, are far less certain. A woman who has the gene, known as the *BRCA1* mutation, has an eighty percent chance of developing breast cancer but *only if* there is a clear history of breast cancer in her family.⁵⁵ If there is no such history, that person’s risk remains unknown.⁵⁶ In fact, the uncertainty surrounding genetic testing for the breast cancer gene is such that the National Breast Cancer Coalition and the American Society for Human Genetics have discouraged its use outside the research laboratory.⁵⁷ Other genetic tests with uncertain predictive ability are used to determine the presence of genetic mutations linked to diseases such as cystic fibrosis⁵⁸ and Alzheimer’s Disease.⁵⁹

It is important to note that an individual’s genetic information, including information about one’s carrier status or likelihood for developing genetic diseases, can also be revealed without the use of genetic tests. For example, one may learn such information through inferences gleaned from a detailed written medical history. That an employer, or other third party, may have access to such information without even having to conduct an invasive test of any kind, raises the same discrimination and privacy concerns for workers as do genetic tests.⁶⁰

C. *The Accuracy of Genetic Testing and Popular Perception*

The majority of genetic tests can indicate only an increased or decreased susceptibility to a particular disease and are “less conclusive than might be assumed from popular perception.”⁶¹ There are a variety of factors, other than mere possession of a particular gene, that influence the severity of the disease, timing of its onset, and whether

PLES OF INTERNAL MEDICINE 2014-15 (E. Braunwald et al. eds., 11th ed. 1987) [hereinafter PRINCIPLES OF INTERNAL MEDICINE].

54. See Casey, *supra* note 26, at 18.

55. See UNDERSTANDING GENE TESTING, *supra* note 21, at 14; Casey, *supra* note 26, at 19.

56. See Casey, *supra* note 26, at 19.

57. See *id.*

58. Cystic fibrosis is an inherited multi-system disorder which is characterized by an abnormal functioning of the endocrine gland and results in chronic progressive disease of the respiratory system for nearly all patients. See PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1085-86.

59. See *id.* at 18.

60. However, the ADA restricts an employer’s ability to conduct medical examinations and inquiries of applicants and employees. See 42 U.S.C. §§ 12111-12117 (1994).

61. Holmes, *supra* note 4, at 529.

the disease will ever manifest itself at all.⁶² In other words, a positive test result is not a guarantee of disease; to the contrary, a positive result often is of limited value in predicting whether the individual will actually develop the disease or pass it along to offspring.

The common misperception that genetic tests can predict completely and accurately whether a person will develop a genetic disease is problematic for many reasons.⁶³ First, employers and insurers may misinterpret and misuse genetic test results to weed out persons according to their perceived health risks based on a common misunderstanding that having a genetic trait is the same as having the actual disease or condition.⁶⁴ Second, people may refuse to take genetic tests, a potentially life-saving measure, for fear that employers, insurers, or others may discriminate against them.⁶⁵ Individuals most susceptible to genetic discrimination include asymptomatic individuals, unaffected carriers of a genetic trait, and at-risk presymptomatic persons with a predisposition to a disease or disorder.⁶⁶

II. WORKERS' FEARS AND THE REALITY OF GENETIC DISCRIMINATION

A number of surveys document the growing public concern over the use of genetic information for discriminatory purposes and show that some employers may use information obtained from genetic testing to try to lower their insurance and sick leave costs by screening out individuals who have traits linked to inherited medical conditions.⁶⁷ The federally-funded National Center for Genome Resources (NCGR) commissioned a national survey in 1998 to gauge the public's attitude toward genetic issues.⁶⁸ The NCGR polled one thousand people and found that an overwhelming eighty-five percent of those surveyed think employers should be prohibited from obtaining

62. *See id.*

63. *See id.*

64. *See id.*; *see also* Casey, *supra* note 26, at 14.

65. *See* Colby, *supra* note 13, at 452.

66. *See* Holmes, *supra* note 4, at 529.

67. *See, e.g.*, National Ctr. for Genome Resources, *Employers Should be Barred from Accessing Genetic Information, Americans Say in NCGR Survey* (visited Feb. 29, 2000) <<http://www.ncgr.org/about/news/1998/0304.html>> [hereinafter Nat'l Center for Genome Resources News]; Stephanie Armour, *Workers Fear Genetic Discrimination*, USA TODAY, Feb. 25, 1998, at 4B.

68. The National Center for Genome Resources is a nonprofit organization that develops educational programs on biotechnology and genetic issues. *See* Nat'l Center for Genome Resources, *supra* note 67. The 1998 survey was conducted in collaboration with the New York Academy of Sciences. *See id.* Among the groups surveyed were primary care physicians, leaders of health care organizations, scientists, religious leaders, and the media. *See id.*

information about an individual's genetic conditions, risks, and predispositions.⁶⁹ Data from the study also indicates that thirty-six percent of those surveyed would probably not take genetic tests, and twenty-seven percent would definitely not take such tests if health insurers or employers could get access to the test results.⁷⁰ Dr. Susan Root, Director of Human Genetics at NCGR, accurately expresses the dilemma the public faces regarding genetic testing: "People desire the information these tests can provide, allowing them to improve their own preventive measures, but also fear the impact the information may have on their own insurability, employability, and confidentiality."⁷¹

Researchers at Georgetown University conducted a similar study in 1995 and found that over eighty-five percent of the 332 people surveyed were very concerned or somewhat concerned about insurers and employers gaining access to, and using, genetic information in a discriminatory manner.⁷² The individuals polled for the Georgetown study had one or more family members with genetic disorders who were affiliated with genetic support groups.⁷³ A vast majority of those surveyed, eighty-seven percent, responded that they would not want employers to know if they were tested and found to be at high risk for a genetic disorder with serious complications.⁷⁴ Seventeen percent

69. *See id.* Results from the study also showed that 69% of respondents think health and life insurers should be prohibited from accessing genetic information due to the fear that the information will be misused and would lead to discrimination. *See id.* Public concern about genetic discrimination and genetic privacy is also indicated by the finding that 65% of those surveyed feel that only their spouses or adult children should have access to such information while others, including other relatives, should no have access. *See id.*

70. *See id.*

71. *Id.*

72. *See* E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621, 621-24 (1996); *see also*, Department of Labor, Department of Health and Human Serv., Equal Employment Opportunity Comm'n, and Department of Justice, *Genetic Information and the Workplace*, (visited Feb. 29, 2000) <http://www.dol.gov/dol/_sec/public/media/reports/genetics.htm> (citing Harris Poll, 1995, #34) [hereinafter *Genetic Information and the Workplace*].

73. *See* Lapham et al., *supra* note 72, at 621-24 (stating that because volunteers for this study were recruited through genetic support groups and did not constitute a statistically-representative sample, survey findings are applicable only to the group studied). The Health Insurance Association of America (HIAA), which represents approximately 200 health insurers and managed care corporations, contends that fears of genetic discrimination are "overblown" because existing surveys of discrimination are usually self-selected, based on individuals' perceptions of discrimination, and not statistically-representative samples. *See* K.C. Swanson, *New Tests, New Concerns*, NAT'L J., Jan. 4, 1996, at 29; Health Insurance Association of America, *Testimony of the HIAA on Genetic Testing: Submitted to the Senate Committee on Labor and Human Resources May 21, 1998*, (visited Mar. 6, 2000) <<http://www.hiaa.org/news/news-state/genetic-testing.html>>.

74. *See* Lapham et al., *supra* note 72, at 622.

also reported that they have not revealed known genetic information to their employers for fear of losing their jobs or insurance coverage.⁷⁵

Workers' fears of workplace discrimination, according to the Georgetown study, have prevented one out of ten respondents from getting tested for genetic traits linked to breast cancer, cystic fibrosis, Huntington's Disease, colon cancer, or other conditions, even though early detection and treatment could possibly improve their lives. Fear of stigmatization has also been documented by the Department of Labor, which found that many women did not take advantage of genetic screening to determine the likelihood of breast cancer because they feared the information might be made available to employers or insurers.⁷⁶

Refusal to submit to genetic tests due to fear of discrimination results in negative consequences both for the individuals who do not get tested and for the advancement of scientific research in this area.⁷⁷ Medical researchers have voiced concern about the refusal of potential subjects to participate in long-term medical studies that would help assess the risk of developing genetically-linked diseases, such as various forms of cancer, because they believe that such involvement may be a "red flag" on their medical records and would result in discrimination.⁷⁸

Workers' fears of genetic discrimination are not baseless. There is limited data gauging the extent of actual discrimination due to the fairly recent development of genetic screening and the inherent problem that exists in documenting such discrimination.⁷⁹ However, cases

75. See *id.*

76. See *Genetic Information in the Workplace*, *supra* note 72, at 2.

77. See Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 *SCIENCE* 1755, 1755-57 (1997); Lapham et al., *supra* note 72, at 621 (noting that fears of genetic discrimination may affect the number of individuals willing to participate in scientific research); Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 *AM. J.L. & MED.*, 109, 113 (1991) (noting that benefits of genetic data collection will not be achieved if fear of discrimination deters people from genetic diagnoses).

78. See Gina Kolata, *Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination*, *N.Y. TIMES*, Feb. 4, 1997, at C1.

79. As Professor Karen Rothenberg has noted, this lack of data should not be surprising since there is an inherent problem in documenting actual genetic discrimination. Because individuals must reveal that they have, or are at risk for, genetic abnormalities in order to register a discrimination complaint, many people will not make such a complaint because they fear that they have too much to lose in revealing this confidential information. See Sarina M. Kopinsky, *Genetic Discrimination Is Less Widespread Than Feared*, *HEALTH CARE NEWS SERVER*, Nov. 20, 1997, available at <<http://www.healthcarenewserver.com/sto>

of actual and anecdotal evidence of genetic discrimination in the workplace have been compiled.⁸⁰

As new biotechnology is emerging, so are cases of genetic discrimination as a result of the information obtained from genetic testing. As of August 1997, the Council for Responsible Genetics (CRG),⁸¹ a national bioethics advocacy organization, had documented over two hundred cases of genetic discrimination.⁸² The cases document a range of genetic-based discriminatory actions by insurance companies, employers, and others against asymptomatic individuals with genetic predispositions to certain diseases.⁸³ The CRG predicts that as the utility of genetic testing expands, and tests become easier and less expensive to administer, such testing may increase.⁸⁴ This increase in genetic screening may ultimately result in the stigmatization of individuals based on their genetic makeup. According to the CRG, "[n]ot only is this discrimination unjust, it is scientifically inaccurate. Genes can tell us only part of the story about why some people get sick and others do not."⁸⁵

Additionally, mandatory testing in the workplace is already prevalent in the form of medical and drug testing. The American Management Association (AMA) polled its membership of major U.S. companies and organizations in 1997 and found that an overwhelming three-fourths of the 906 survey respondents conduct mandatory medical and drug tests.⁸⁶ According to the study's findings, six per-

ries/ HCN1997112000021.shtml> (reporting Rothenberg's comments at an October 29, 1997 panel on Genetic Testing in the Marketplace).

80. See, e.g., P.R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 476-82 (1992) (describing anecdotal evidence of discrimination against individuals based on "apparent or perceived" genetic abnormalities); Armour, *supra* note 67 (citing statements by director of NCGR that people have lost jobs because of genetic discrimination).

81. The Council for Responsible Genetics is a national nonprofit bioethics organization that was founded in 1983 and is based in Cambridge, Massachusetts. See The Council for Responsible Genetics, Position Statement on Genetic Information (visited Feb. 29, 2000) <<http://www.gene-watch.org/org.html>> [hereinafter CRG, *Position Statement*]. Its membership includes scientists, public health advocates, and others interested in the use of new genetic technologies in a socially responsible manner. See *id.* The CRG's main mission is to educate and raise the public's awareness about the ethical implications of emerging genetic issues and to document cases of genetic discrimination. See *id.*

82. See *id.*

83. See Billings et al., *supra* note 80, at 476.

84. See CRG, *Position Statement*, *supra* note 81.

85. *Id.*

86. See Rosemary Orthmann, 1997 American Management Association Survey: Workplace Testing and Monitoring (on file with the *Journal of Health Care Law & Policy*). AMA membership consists of 10,000 major U.S. companies and organizations, which employ one-fourth of U.S. workers. See *id.* The AMA survey found that of the respondents who

cent of the companies surveyed reported conducting tests for genetic disease or susceptibilities, HIV infection, or sexually transmitted diseases.⁸⁷ Although genetic screening comprises only a fraction of workplace testing in comparison to mandatory drug testing, this proportion is still relatively high when viewed in light of the legal and ethical controversy surrounding such testing. Although the AMA study did not ask the companies surveyed why they conducted genetic monitoring, or what the companies do with the information, the study's findings may lead one to surmise that some companies use such tests to screen out applicants who have particular genetic conditions or traits that are associated with potential health-care costs.⁸⁸

A subsequent 1999 AMA survey of 1054 employers reflected that approximately twenty percent of the employers surveyed obtained family medical history information of applicants, and twelve percent obtained family medical history information of employees.⁸⁹ In addition, five percent of the employers acknowledged using family history information in hiring decisions and two percent admitted using family history information in assigning or reassigning current employees.⁹⁰ Genetic information about an individual is often reflected in family medical history information.⁹¹

Similarly, in a study conducted in 1989 to gauge the extent of genetic monitoring, the Congressional Office of Technology Assessment (OTA) found that twelve out of the 330 companies surveyed use some sort of biochemical genetic screening.⁹² Although none of the companies that responded anticipated using direct DNA screening over the next five years, OTA's survey data indicated that forty-two percent of employers considered an applicant's health insurance risks in making employment-related decisions.⁹³ These findings evidence

mandated genetic testing, a majority (33 out of 52) were manufacturers. *See id.* According to the survey, eight percent of the manufacturers tested for genetic diseases or for susceptibilities. *See id.* The study also found that four percent of manufacturers surveyed required applicants and new hires to submit to genetic tests, and one percent conducted unscheduled tests on employees. *See id.* The AMA study also found that seven percent of employers in the non-profit sector conducted some form of genetic testing. *See id.*

87. *See id.*

88. *See id.*

89. *See* 1999 American Mgmt. Ass'n, *AMA Workplace Testing Survey*, 36-37 (March 24, 1999).

90. *Id.* at 47.

91. *See* discussion *supra*, text accompanying notes 38-60.

92. The Congressional Office of Technology Assessment surveyed the company health officers of Fortune 500 companies, large utilities, and major unions for a study conducted in 1989. The purpose of the study was to determine how many of those surveyed conducted genetic testing. *See Genetic Information in the Workplace*, *supra* note 72.

93. *See id.*

"[t]he growing concern among employers over the rising costs of employee health insurance, and the increased efforts to reduce these costs to the employer, [which is] likely to increase the scope of health insurance screening in the workplace."⁹⁴ The OTA concluded that employers' interest in containing health-care costs may lead to an increase in genetic testing to identify applicants with "atypical subsequent health care demands."⁹⁵

Survey data appears to support the OTA's conclusion that genetic screening may increase in the workplace. In 1989, a survey of four hundred employers by Northwest Life Insurance found that by the year 2000, fifteen percent of employers expected to check the genetic status of prospective employees and their dependents before making job offers.⁹⁶ Similarly, the researchers at Georgetown found that fifteen percent of respondents reported that they or affected family members were asked questions about genetic diseases or disabilities on job applications (although it is not clear how often this information was used to subsequently deny jobs to applicants).⁹⁷ Thirteen percent of respondents reported that they or another family member had been denied a job or terminated from a job because of a genetic condition in the family.⁹⁸ In another recent survey attempting to assess the extent of discrimination against individuals with genetic abnormalities who were otherwise healthy, genetic services providers and primary care physicians reported knowing of 582 people who were refused employment or insurance based on their genetic predisposition.⁹⁹ The study's authors note that although this number is modest in relation to the total number of patients seen by the surveyed professionals, genetic discrimination does in fact exist.¹⁰⁰

III. PROTECTION AGAINST GENETIC DISCRIMINATION UNDER EXISTING FEDERAL LEGISLATION

No current federal statute explicitly addresses genetic discrimination in the workplace. However, existing federal laws designed to prohibit disability discrimination in employment may provide protection

94. *Id.*

95. *Id.*

96. See Susan Page, *White House: Ban Gene Bias in Workplace*, USA TODAY, Jan. 20, 1998, at A1.

97. See Lapham et al., *supra* note 72, at 622.

98. See *id.*

99. See Kopinsky, *supra* note 79, (citing results of survey by Dr. Dorothy C. Wertz and colleagues at the Shriver Center in Massachusetts).

100. See *id.*

against genetic discrimination. The ADA¹⁰¹ can and should be interpreted to prohibit employment discrimination based on asymptomatic genetic characteristics and genetic predisposition. As there has been virtually no case law regarding genetic discrimination in the workplace, coverage must be inferred from a statutory interpretation of the ADA.¹⁰²

A. *The Americans with Disabilities Act and Genetic Discrimination*

Title I of the ADA,¹⁰³ the federal law that protects individuals seeking work or employed in the private sector from discrimination on the basis of disability, makes no explicit mention of genetic discrimination.¹⁰⁴ In fact, the ADA does not specifically identify any single medical condition for protection. Rather, the ADA contains broad language prohibiting discrimination against a "qualified individual with a disability" in hiring, promotion, discharge, compensation, and other terms and conditions of employment.¹⁰⁵ The ADA defines an individual with a disability as a person with one or more physical or mental impairments that substantially limits him or her in performing a major life activity, a person with a record of such an impairment, or a person who is regarded as having such an impairment.¹⁰⁶ The ADA requires that an employer make reasonable accommodations for qualified individuals with disabilities if such accommodations are needed and do not impose an undue hardship on the employer.¹⁰⁷

There is little question that the ADA covers an individual who has a genetically-related illness or disability once it becomes manifest and

101. See 42 U.S.C. §§ 12101-12213 (1994).

102. In addition, an employer's use of genetic information may violate Title VII of the Civil Rights Act, where discrimination is based on race, national origin, religion, or gender. See *infra* notes 171-78 and accompanying text.

103. 42 U.S.C. §§ 12111-12117 (1994).

104. See *id.* Section 501 of the Rehabilitation Act, on which the ADA is based, prohibits disability discrimination against federal workers in the same manner as the ADA applies to private employers. See 29 U.S.C. § 791(g) (1999).

105. 42 U.S.C. § 12112(a) (1994).

106. See *id.*

107. See *id.* § 12112(b)(5)(A). Title I of the ADA requires an employer to provide reasonable accommodation to qualified individuals with disabilities who are employees or applicants for employment. See *id.* In general, an accommodation is any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities. See 29 C.F.R. app. § 1630.2(o) (1999); see generally 29 C.F.R. § 1630.9 (1995). An employer's duty to provide a reasonable accommodation is limited only by whether it creates an undue hardship for the employer, that is, whether it causes significant difficulty or expense. Undue hardship analysis focuses on the resources and circumstances of the particular employer in relationship to the cost or difficulty of providing a specific accommodation. See 42 U.S.C. §§ 12112(b)(5)(A), 12111(10).

substantially limits a major life activity.¹⁰⁸ Moreover, there is little debate that the ADA covers individuals who have a prior record of a genetically-related disability, for example, someone who has recovered from cancer.¹⁰⁹ And yet, courts have still not determined whether the ADA should be understood to restrict discrimination on the basis of a diagnosed, but asymptomatic, genetic condition or trait.¹¹⁰

In 1995, the U.S. Equal Employment Opportunity Commission (EEOC) adopted policy guidance stating that the ADA prohibits discrimination against workers based on their genetic makeup.¹¹¹ This policy guidance explicitly states that the third part of the definition of disability, the "regarded as" prong, covers individuals who are subjected to discrimination on the basis of a genetic predisposition to illness, disease, or other disorder, even if the disability has not yet manifested.¹¹² In other words, employers who discriminate against individuals on such a basis are regarding the individuals as having impairments that substantially limit a major life activity and therefore are violating the ADA.¹¹³ In the hypothetical example described in the EEOC guidance, an employer makes a conditional offer of employment and then learns that the candidate harbors a gene that increases

108. See *Bragdon v. Abbott*, 524 U.S. 624, 637, 642 (1998); see also, e.g., *Harris v. H & W Contracting Co.*, 102 F.3d 516, 524 (11th Cir. 1997) (holding that an individual with Graves disease is covered by the ADA, although the court also held that the disease should be considered in its unmitigated state); *Gilday v. Mecosta County*, 124 F.3d 760, 766 (6th Cir. 1997) (finding that an individual with diabetes is covered by the ADA and that the disease should be considered in its mitigated state); *Matczak v. Frankford Candy & Chocolate Co.*, 136 F.3d 933, 937 (3d Cir. 1997) (holding that an individual with epilepsy is covered by the ADA and that mitigating factors should not be considered). *Harris* and *Matczak* were decided prior to the Supreme Court's 1999 decisions narrowing the scope of the ADA. See discussion *infra*, accompanying notes 155-170. Although *Harris* and *Matczak* held that mitigating factors should not be considered in determining whether an individual is disabled under the ADA, Grave's disease and epilepsy could still be within the scope of the ADA if they substantially limited a plaintiff's major life activities in their mitigated state.

109. A "record of disability" is defined as a record of a physical or mental impairment that substantially limits one or more of the major life activities of an individual. See 42 U.S.C. § 12102(2); R. S. Olick, *Genes in the Workplace: An Ethical and Legal Analysis of Genetic Discrimination Under the Employment Provisions of the Americans with Disabilities Act*, in *Employment, Disability and the Americans with Disabilities Act*, (Peter David Blanck ed., 2000); Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans With Disabilities Act?*, 42 VILL. L. REV. 613, 613-33 (1997).

110. See Olick, *supra* note 109.

111. See 2 U.S. EEOC, COMPLIANCE MANUAL, Order 915.002, at 902-45 (1995) [hereinafter EEOC COMPLIANCE MANUAL].

112. See *id.*

113. See *id.*

her risk of colon cancer.¹¹⁴ Although the woman is healthy and may never get cancer, the job offer is withdrawn because of concerns about the possibility that she may contract the disease, which might negatively impact her future productivity and insurance costs.¹¹⁵ That woman, in the eyes of the EEOC, would be covered under the anti-discrimination protections of the ADA.¹¹⁶ A person who has a genetic predisposition to a disease, disorder, or disability is exactly the kind of person that Congress must have intended to be covered by the "regarded as" prong.¹¹⁷

To be protected under the ADA, people who have an asymptomatic genetic trait must show not only that they were "regarded as disabled" by an employer but also that the employer discriminated against them based on that perception.¹¹⁸ Some have argued that the ADA may not cover individuals with genetic conditions that have not yet manifested, because to fall within the Act's definition, an employer who regards an employee as having an impairment that substantially limits a major life activity must regard that individual as *presently* disabled.¹¹⁹ However, the EEOC's Interpretive Guidance as well as several court decisions support the view that an employer's concerns for an employee's *future* productivity, health insurance costs, and attendance fall within the "regarded as" prong of the ADA.¹²⁰ For example, at least one court has held that an employer regarded an employee as disabled where the employer was concerned about the employee's future performance because of sickle-cell disease.¹²¹ Other courts have held that an employee has standing to sue under the "regarded as" prong of the ADA based on employer concerns about future health insurance costs.¹²²

114. *See id.*

115. *See id.*

116. *See id.*

117. *See* H.R. REP. NO. 101-485, at 64-70 (1990).

118. *See id.* at 68.

119. *See* Dichter & Sutor, *supra* note 109, at 631.

120. *See id.* at 630-31; EEOC COMPLIANCE MANUAL, *supra* note 111, at 902-45.

121. *See* Jones v. Inter-County Imaging Ctrs., 889 F. Supp. 741, 744 (S.D.N.Y. 1995) (denying defendant employer's summary judgment motion to plaintiff's ADA claim alleging that he was terminated because defendant believed that his sickle-cell condition would adversely affect future work attendance). The sickle-cell trait originates through inheritance of an unstable hemoglobin variant (Hb S). *See* PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1518. The abnormality occurs almost exclusively in persons of color. About eight percent of African-Americans are heterozygous for Hb S. *See id.* Although the genetic abnormality may give rise to congenital hemolytic anemia, Hb S carriers generally have minimal clinical problems. *See id.*

122. *See* Anderson v. Gus Mayer Boston Store, 924 F. Supp. 763, 769 (E.D. Tex. 1996); Sawinski v. Bill Currie Ford, Inc., 866 F. Supp. 1383, 1387 (M.D. Fla. 1994).

In addition to providing protection to individuals who are regarded as disabled, the ADA prohibits discrimination against individuals who associate with people with disabilities.¹²³ Thus, a parent or spouse of an individual with a "genetic predisposition" would be protected by the ADA from adverse employment actions. For example, under an associational theory, an employer would be prohibited from taking an adverse employment action against a worker who has no genetic anomaly, but who has a spouse or child with a genetic predisposition to a disease or condition.

The EEOC's position is clear that the ADA protects individuals with asymptomatic genetic conditions from discrimination in employment, and the EEOC's Interpretative Guidance can be used as persuasive authority.¹²⁴ However, the guidance does not have the same force of law as a federal statute or regulation. The EEOC's position regarding discrimination based on genetic information has yet to be tested in the courts, and not all observers agree that the ADA applies to people who may not presently have a disease such as breast cancer, cystic fibrosis, and certain types of colon cancer, but who have "unexpressed genetic conditions" that predispose them to those diseases.¹²⁵ Some observers argue that the ADA can be read to cover genetic carriers,¹²⁶

123. See 42 U.S.C. § 12112(b)(4) (1994); see also *Morgenthal v. American Tel. & Tel. Co, Inc.*, No. 97 Civ. 6443 DAB, 1999 WL 187055 (S.D.N.Y. 1999); *Saladin v. Turner*, 936 F. Supp. 1571 (N.D. Okla. 1996).

124. But see *Sutton v. United Air Lines, Inc.*, 119 S. Ct. 2139, 2145-46 (1999) (calling into question the persuasive authority of EEOC Interpretative Guidance on the ADA). In *Sutton*, the Court stated

No agency, however, has been given authority to issue regulations implementing the generally applicable provisions of the ADA, see §§ 12101-12102, which fall outside Titles I-V. Most notably, no agency has been delegated authority to interpret the term 'disability.' § 12102(2). Justice Breyer's contrary, imaginative interpretation of the Act's delegation provisions, see post at 2161-2162 (dissenting opinion), is belied by the terms and structure of the ADA The agencies have also issued interpretative guidelines to aid in the implementation of their regulations Although the parties dispute the persuasive force of these interpretative guidelines, *we have no need in this case to decide what deference is due.*

Id. at 2145-46 (emphasis added).

125. Compare *Dichter & Sutor*, *supra* note 109 (arguing that courts should refrain from interpreting the ADA to provide protection to individuals with genetic disorders that are currently asymptomatic), with *Frances H. Miller & Philip A. Huvos, Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act*, 46 ADMIN. L. REV. 369, 375-77 (1994) (arguing that the ADA can be read to cover asymptomatic individuals who possess genetic disorders) and *Gostin*, *supra* note 77, at 109 (stating that the ADA may not sufficiently protect employees from genetic discrimination and that the advent of new genetic technologies requires new statutes regulating employer use of such technologies to close coverage gaps).

126. See *Miller & Huvos*, *supra* note 125, at 375-77 (arguing that the ADA can be read to cover asymptomatic individuals who possess genetic disorders).

while others state that the ADA may not sufficiently protect all employees from genetic discrimination and that the advent of new genetic technologies requires new legislation regulating employer use of such technologies to close the coverage gaps.¹²⁷ The need for additional, specific legislation to make explicit the prohibition against discrimination based upon genetic predisposition may be more imperative following the U.S. Supreme Court's recent decisions interpreting the ADA.

Since the passage of the ADA, the Supreme Court has addressed the issue of who is a covered individual with a disability in four cases.¹²⁸ In *Bragdon v. Abbott*, a person with asymptomatic HIV infection was held to be a covered "individual with a disability" under the ADA as having a physical impairment that substantially limits a major life activity.¹²⁹ Although *Bragdon* was not an employment discrimination case, its analysis of who the ADA covers applies in the employment context. In *Bragdon*, the plaintiff, Sidney Abbott, was denied dental services because she was HIV-positive.¹³⁰ Abbott disclosed to her dentist, Randon Bragdon, the fact of her HIV infection.¹³¹ After completing a dental examination of Abbott, Bragdon discovered a cavity, and informed her of his policy against filling cavities of HIV-infected patients.¹³² Although Abbott had been infected with HIV for eight years at the time of her dentist's refusal of service, her infection had "not yet progressed to the so-called symptomatic phase."¹³³

The Court concluded that HIV infection in which the individual is not exhibiting any visible symptoms of illness is a "physical impairment" that substantially limits the major life activity of reproduction.¹³⁴ It found that asymptomatic HIV is a physical impairment from the moment of infection due to "the immediacy with which the virus begins to damage the infected person's blood cells and the severity of the disease."¹³⁵ The Court described in great detail the cellular

127. See Gostin, *supra* note 77, at 109.

128. See *Bragdon v. Abbott*, 524 U.S. 624 (1998); *Sutton v. United Air Lines, Inc.*, 119 S. Ct. 2139 (1999); *Albertsons, Inc. v. Kirkingburg*, 119 S. Ct. 2162 (1999); *Murphy v. United Parcel Serv., Inc.*, 119 S. Ct. 2133 (1999). As the "regarded as" prong of the definition was not at issue in *Albertsons*, the case does not bear on the question of coverage of individuals with genetic predispositions.

129. See *Bragdon*, 524 U.S. at 641-42.

130. See *id.* at 628-29.

131. See *id.*

132. See *id.* at 629.

133. *Id.* at 624.

134. See *id.* at 639, 641.

135. *Id.* at 637.

impact of HIV infection on blood and other body tissues.¹³⁶ The Court noted that, "after the symptoms associated with the initial stage subside, the disease enters what is referred to sometimes as its asymptomatic phase. The term is a misnomer, in some respects, for clinical features persist throughout, including lymphadenopathy, dermatological disorders, oral lesions, and bacterial infections."¹³⁷ Thus, the Court looked beyond any visible symptoms or easily detectable manifestations of the disease and found a physical impairment based upon the cellular and molecular changes that take place in the body due to the infection.¹³⁸ The individual may be clinically asymptomatic despite the fact that these cellular abnormalities are occurring. With HIV infection, an individual can be asymptomatic for seven to eleven years,¹³⁹ and the Court concluded such an individual has a physical impairment for purposes of the ADA.¹⁴⁰

In order to be covered by the ADA, the physical impairment must substantially limit a major life activity.¹⁴¹ The Court found that asymptomatic HIV substantially limits the major life activity of reproduction because reproduction in these circumstances imposes significant risks of infection on the sexual partner and on the child created.¹⁴² The Court acknowledged that while reproduction is not impossible for a person with HIV, it is dangerous to the public health.¹⁴³ As stated by the Court, "[w]hen significant limitations result from the impairment, the definition [of disability] is met even if the difficulties are not insurmountable."¹⁴⁴

The reasoning underlying the *Bragdon* decision supports the application of the ADA to individuals with asymptomatic genetic disorders and genetic predispositions. As the Court found asymptomatic HIV to constitute a physical impairment because it causes abnormalities in an infected person's hemic and lymphatic systems from the moment of infection,¹⁴⁵ the reasoning of the case directly extends to many asymptomatic genetic conditions. Science may be able to demonstrate that many asymptomatic genetic disorders, while not resulting in any visible symptoms or characteristics, may create abnor-

136. *See id.* at 633-37.

137. *Id.* at 635.

138. *See id.* at 637.

139. *See id.* at 635.

140. *See id.* at 637.

141. *See id.*

142. *See id.* at 639-40.

143. *See id.* at 641.

144. *Id.*

145. *See id.* at 635.

malities in an individual's body systems or changes on a cellular level as was shown with asymptomatic HIV. Expert medical evidence such as testimony, treatises, and articles may be relevant, as such evidence was relied upon in *Bragdon* to demonstrate the physical impact of HIV on body systems and cells. Should a plaintiff be able to demonstrate that the genetic condition causes some abnormality in the person's body, even on a molecular level, the condition would constitute a physical impairment for ADA purposes.

Similarly, *Bragdon* supports the argument that an asymptomatic genetic predisposition limits a major life activity. For example, if the genetic disorder is inheritable, the impairment would limit reproduction in the same manner as in *Bragdon*. While reproduction is not impossible for the person with an asymptomatic genetic predisposition, the risk of transmitting that genetic disorder to her child may be "dangerous to the public health" as the Court found with asymptomatic HIV.¹⁴⁶ The Court concluded that,

It cannot be said as a matter of law that an 8% risk of transmitting a dread and fatal disease to one's child does not represent a substantial limitation on reproduction. . . . The decision to reproduce carries economic and legal consequences as well. There are added costs for antiretroviral therapy, supplemental insurance, and long term healthcare for the child who must be examined and, tragic to think, treated for the infection.¹⁴⁷

These same factors lead to the conclusion that a genetic predisposition substantially limits the major life activity of reproduction.¹⁴⁸ Thus, like asymptomatic HIV, many genetic predispositions are covered by the ADA as actual disabilities.

Chief Justice Rehnquist directly raised the issue of ADA coverage for individuals with genetic markers for debilitating diseases in his dissent in *Bragdon*, which was joined by Justices Scalia and Thomas.¹⁴⁹ Justice Rehnquist disagreed with the majority's holding that asymptomatic HIV infection substantially limits reproduction. He argued that while an HIV-infected individual is able to engage in sexual intercourse and, if she becomes pregnant, give birth to a child, and per-

146. *Id.* at 640.

147. *Id.* at 641.

148. *See id.* Moreover, a substantial limitation of the major life activity of reproduction occurs even if the difficulties do not make reproduction impossible. Thus, the disability definition does not turn on the personal choice to engage in reproduction, and is met even if the difficulties are not insurmountable. *See id.*

149. *See id.* at 661 (Rehnquist, C.J., dissenting).

form the manual tasks necessary to rear a child, such an individual may choose not to engage in these activities.¹⁵⁰ He found, "no support in language, logic, or our case law for the proposition that such voluntary choices constitute a 'limit' on one's own life activities."¹⁵¹ He similarly rejected the argument that a person's ability to reproduce is limited because the fatal nature of HIV infection decreases the likelihood that the parent could survive to raise and nurture the child to adulthood.¹⁵² He continues, "[a]symptomatic HIV does not presently limit respondent's ability to perform any of the tasks necessary to bear or raise a child. Respondent's argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease 'disabled' here and now because of some future effects."¹⁵³ Justice Rehnquist's comments raise the question whether he would reject outright the ADA's protection of individuals with asymptomatic genetic conditions, or whether he would accept coverage under a major life activity theory other than reproduction, such as working.¹⁵⁴

On June 22, 1999, the Supreme Court handed down a trilogy of decisions that significantly narrowed the scope of coverage of the ADA.¹⁵⁵ Although none of these decisions concerned the issue of asymptomatic genetic disabilities, these cases restrict the definition of who is a qualified individual with a disability, and thus, they may ultimately have an impact on the issue. To the extent that the theory of ADA coverage relies on the "regarded as" prong of the definition, these cases may be relevant due to the narrow approach the Court took in defining the major life activity of working.

In *Sutton*, the Court found that myopic applicants for airline pilot positions were not regarded as disabled by their employer, as they were not substantially limited in the major life activity of working.¹⁵⁶ Their poor vision only precluded them from the single job of global airline pilot.¹⁵⁷ The inability to perform a single, particular job was

150. See *id.* at 660-61 (Rehnquist, C.J., dissenting).

151. *Id.* at 661 (Rehnquist, C.J., dissenting).

152. See *id.* (Rehnquist, C.J., dissenting).

153. *Id.* (Rehnquist, C.J., dissenting).

154. See *infra* text accompanying notes 156-170.

155. See *Sutton v. United Air Lines, Inc.*, 119 S. Ct. 2139 (1999), *Albertsons, Inc. v. Kirkingburg*, 119 S. Ct. 2162 (1999), *Murphy v. United Parcel Serv., Inc.*, 119 S. Ct. 2133 (1999). The Court held in these cases that actual impairments must be considered in their corrected or mitigated state when determining whether they are disabilities under Title I of the ADA. See *Sutton*, 119 S. Ct. at 2149; *Albertsons*, 119 S. Ct. at 2169; *Murphy*, 119 S. Ct. at 2137.

156. See *Sutton*, 119 S. Ct. at 2151.

157. See *id.*

held not to constitute a substantial limitation of the major life activity of working, and their claim failed.¹⁵⁸ To be substantially limited in the major life activity of working, one must be precluded from more than one type of job, a specialized job, or a particular job of choice.¹⁵⁹

A person is "regarded as" disabled within the meaning of the ADA, if a covered entity mistakenly believes an individual has a substantially limiting impairment that one does not have, or that an individual has a substantially limiting impairment, when in fact, the impairment is not so limiting.¹⁶⁰ Under such a theory, coverage for individuals with a genetic predisposition would generally rely on demonstrating a mistaken belief concerning the major life activity of working.¹⁶¹

A person with a genetic predisposition may demonstrate that they are substantially limited in the major life activity of working if the individual can prove that their employer mistakenly believes that, due to the genetic anomaly, they are unable to work in either a class of jobs or a broad range of jobs in various classes as compared to the average person.¹⁶² Evidence of such a belief could include, for example, the employer's fear that health insurance costs would rise, the fear that the employee would have increased absences from work as a result of developing the genetic condition, or some concern over the employee's future productivity.¹⁶³ Thus, for example, such an individual

158. *See id.*

159. *See id.*

160. *See id.* at 2150.

161. Because reproduction is an intensely private and personal major life activity, it is typically of no concern to employers, and therefore, unlikely to form the basis of the employer's mistaken belief concerning the employee. Moreover, as the employee's condition is asymptomatic, other major life activities such as hearing, walking, or breathing, would also not be factors under a "regarded as" theory. Thus, the argument would likely hinge on the major life activity of working.

162. *See Sutton*, 119 S. Ct. at 2151.

163. *See Heyman v. Queens Village Comm.*, 198 F.3d 68, 73 (2d Cir. 1999) (stating that a reasonable jury could find defendants believed that plaintiff's lymphoma would significantly reduce his ability to do work); *Riemer v. Illinois Dep't of Transp.*, 148 F.3d 800, 807 (7th Cir. 1998) (affirming jury's finding that defendants perceived the plaintiff to be substantially limited in the major life activity of breathing as evidenced by the defendants' testimony over fear of a possible workmen's compensation liability); *EEOC v. Williams Elec. Games, Inc.*, No. 94C5384 1997 WL 201584, *1-2 (N.D. Ill. 1997) (finding on motion to reconsider that the defendant's affidavit revealed that employer refused to hire plaintiff based on the belief plaintiff was disabled); *Olson v. General Elec. Aerospace*, 101 F.3d 947, 954 (3d Cir. 1996) (finding that a reasonable factfinder could infer defendant perceived plaintiff as disabled based on the knowledge of previous frequent hospitalizations causing plaintiff to miss significant amounts of work); *Haiman v. Village of Fox Lake*, 79 F. Supp. 2d 949, 956 (N.D. Ill. 2000) (finding that a genuine issue of fact exists as to whether defendant regarded plaintiff as disabled based on defendant's statement about plaintiff's condition causing entire office's insurance rates to rise).

may be substantially limited from working in all jobs with health insurance.¹⁶⁴ Moreover, a fear about one's increased absences or future productivity also impacts a broad range of jobs.¹⁶⁵ In fact, the more generalized and inchoate the employer's fear that the individual with a genetic predisposition will not be productive, the greater the limitation that individual faces in working.

Similarly, the Court's discussion of ADA coverage issues in *Murphy* may be relevant to determining whether individuals with genetic predispositions are "regarded as" disabled. The Court concluded that the plaintiff, who had high blood pressure, was not "regarded as" disabled for purposes of ADA coverage.¹⁶⁶ The Court found that the plaintiff's employer did not regard him as substantially limited in the major life activity of working in a broad class of jobs but rather regarded him as unqualified to work in the particular job of a mechanic who was required to drive a commercial motor vehicle.¹⁶⁷ As plaintiff was unable to obtain a Department of Transportation health certification due to his high blood pressure, his employer simply regarded him as unqualified to work in the particular job requiring such a certification.¹⁶⁸ As such, no issue of material fact was created as to whether plaintiff was regarded as unable to perform in a class of jobs utilizing his skills.¹⁶⁹ Since the Court found the plaintiff was not precluded from more than one particular job, he was not covered by the ADA.¹⁷⁰

B. Title VII of the Civil Rights Act

Title VII of the Civil Rights Act of 1964¹⁷¹ may provide protection against forms of genetic discrimination that have a significant correlation to race, national origin, religion, or gender.¹⁷² For example, an employer may violate Title VII by engaging in discrimination based on a genetic trait that disproportionately impacts a particular protected group of people, such as those with sickle-cell (individuals of African

164. See *Murphy*, 119 S. Ct. at 2137.

165. See *id.* at 2139.

166. See *id.*

167. See *id.* at 2137.

168. See *id.*

169. See *id.* at 2139.

170. See *id.* at 2138-39.

171. See 42 U.S.C. § 2000e (1994).

172. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1271 (9th Cir. 1998); Rothstein, *supra* note 3, at 32. One commentator has even suggested that discrimination in employment based on late-onset genetic conditions could constitute disparate impact age discrimination in violation of the Age Discrimination in Employment Act, 29 U.S.C. §§ 621-634 (1999). See Rothstein, *supra* note 3, at 32 n.44.

descent)¹⁷³ or Tay-Sachs (Ashkenazi Jews).¹⁷⁴ Since genetic screening is a facially neutral policy, claims under Title VII would most likely be brought on a disparate impact theory.¹⁷⁵ Although some courts have implied that employment decisions based on genetic profiles associated with a particular protected class would violate Title VII,¹⁷⁶ thus far there have been no successful lawsuits brought under this theory.¹⁷⁷ Because many, if not most, genetically-related diseases and disorders do not disproportionately affect one of Title VII's protected classes, Title VII would not provide comprehensive protection against genetic discrimination in employment.¹⁷⁸

IV. PRESIDENTIAL EXECUTIVE ORDER ON GENETIC DISCRIMINATION

Recognizing that workers face potential discrimination and privacy problems raised by the genetics revolution, on February 8, 2000, President Clinton issued Executive Order 13,145, To Prohibit Discrimination in Federal Employment Based on Genetic Information (the Genetic Executive Order).¹⁷⁹ This Executive Order explicitly

173. See, e.g., *Smith v. Olin Chem. Corp.*, 555 F.2d 1283, 1284-85 (5th Cir. 1977) (claiming that plaintiff's dismissal was due to suspected sickle-cell disease and alleging disparate impact race discrimination in violation of Title VII); *Peoples v. Salina*, No. Civ. A. No. 88-4280-S, 1990 WL 47436 at *1 (D. Kan. Mar. 20, 1990) (claiming dismissal based on employer's fears of sickle-cell trait).

174. "Tay-Sachs disease is a relatively common inborn error of metabolism with thousands of documented cases." PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1667. The trait is associated with a deficiency of hexosaminidase A, a protein activator. The features are similar in all carriers, beginning in the third to sixth month of infancy with rapid neurological deterioration. Ashkenazi Jews are about 100 times more likely than other ethnic groups to carry the Tay-Sachs trait. See *id.* at 1668.

175. See Gostin, *supra* note 77, at 138.

176. See cases cited *supra* note 173.

177. See Gostin, *supra* note 77, at 138; see also Kristie A. Deyerle, *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, 568 (1997) (citing *Smith v. Olin Chem. Corp.*, 555 F.2d 1283 (5th Cir. 1977)); see generally Rothstein, *supra* note 3, at 32.

178. See Deyerle, *supra* note 177, at 567-68.

179. See Exec. Order No. 13,145, 65 Fed. Reg. 6,875 (2000) [hereinafter Genetic Exec. Order]. On July 1, 1999, President Clinton had endorsed the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, introduced by Senator Thomas A. Daschle (D-S.D.) as S. 1322 and by Congresswoman Louise McIntosh Slaughter (D-N.Y.) as H.R. 2457. See Office of the Press Sec., The White House, *Press Briefing by Joe Lockhart* (visited Mar. 13, 2000) <<http://www.pub.whitehouse.gov/uri-res/12R?urn:pdi://oma.eop.gov.us/2000/2/8/6.text.1>>. These bills would extend the protections for genetic information included in the President's Genetic Executive Order to the private sector and to individuals purchasing health insurance. See generally Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, S. 1322, 106th Cong. (1999); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, 106th Cong. (1999). In addition, this legislation would provide an enforcement mechanism that the Genetic Executive Order does not.

prohibits discrimination on the basis of protected genetic information in all aspects of civilian federal government employment and limits federal departments' and agencies' access to, and use of, genetic information.¹⁸⁰ As the President stated at the time, "[b]y signing this executive order, my goal is to set an example and pose a challenge for every employer in America, because I believe no employer should ever review your genetic records along with your resume."¹⁸¹

Under the Genetic Executive Order, federal departments and agencies may not refuse or fail to hire, promote, discharge, or otherwise discriminate against any employee, applicant for employment, or former employee with respect to the compensation, terms, conditions, or privileges of employment, because of protected genetic information.¹⁸² Similarly, federal departments and agencies may not limit, segregate, or classify an employee or otherwise adversely affect the employee's status because of protected genetic information.¹⁸³ The Genetic Executive Order defines "protected genetic information" as, (1) information about an individual's genetic tests or genetic tests of that individual's family members;¹⁸⁴ (2) information about the occurrence of a disease, medical condition, or disorder in family members of the individual; and (3) information that an individual requested or received genetic services, such as genetic education and counseling.¹⁸⁵ While using medical information to determine whether someone can perform the essential functions of the job may be appropriate, the Genetic Executive Order makes clear that it is inappropriate to use genetic information to make employment decisions based upon one's predisposition to disease, medical condition, or disorder which have no bearing on his or her present ability to do the job.

The Genetic Executive Order also prohibits federal employers from requiring or requesting genetic tests as a condition of being

180. See Genetic Exec. Order, 6,875, 6,878-79. Section 501 of the Rehabilitation Act prohibits disability discrimination against federal workers in the same manner as the ADA applies to private employers. See 29 U.S.C. § 791(g) (1999). Thus, the Rehabilitation Act prohibits discrimination by the federal government on the basis of genetic predisposition to the same extent as the ADA. See *id.* While the Rehabilitation Act provides an enforcement framework that is absent in the Genetic Executive Order, the Genetic Executive Order specifically addresses the issue of genetic information. See Genetic Exec. Order, 6,875, 6,878-79.

181. Office of the Press Sec., The White House, *Remarks by the President on Genetic Discrimination* (visited Mar. 7, 2000) <<http://www.pub.whitehouse.gov/uri-res/12R?urn:pdi://oma.eop.gov.us/2000/2/8/7.text.2>>. President Clinton gave this speech at the American Association for the Advancement of Science on February 8, 2000. See *id.*

182. See Genetic Exec. Order, 6,875, 6,878.

183. See *id.*

184. See *id.*

185. See *id.* at 6,878.

hired or receiving benefits.¹⁸⁶ In addition, federal departments and agencies are precluded from requesting or requiring employees to undergo genetic tests to evaluate their ability to perform a job.¹⁸⁷ The Genetic Executive Order prohibits federal employers from using protected genetic information to classify employees in a manner that deprives them of advancement opportunities.¹⁸⁸ For example, federal employers may not deny employees promotions or overseas posts based solely on their genetic predisposition to certain illnesses.

The Genetic Executive Order generally prohibits the disclosure of protected genetic information and mandates that such information be kept confidential and separate from personnel files.¹⁸⁹ However, disclosure of the information is permitted to be made in the following very limited circumstances: (1) to the individual who is the subject of the information;¹⁹⁰ (2) to an occupational or other health researcher under certain circumstances;¹⁹¹ (3) where required by law, congressional subpoena, or order from a court of competent jurisdiction;¹⁹² or (4) to executive branch officials investigating compliance with the Genetic Executive Order where the information is relevant to the investigation.¹⁹³

A limited exception to the Genetic Executive Order allows federal employers to request or require family medical information, but only of an applicant who has received a conditional offer of employment or of an employee.¹⁹⁴ The request must comply with the requirements of the Rehabilitation Act,¹⁹⁵ and the information obtained must be used exclusively to assess whether further medical evaluation is needed to diagnose a current disease, medical condition, or disorder that could prevent the applicant or employee from performing the essential functions of the position held or desired.¹⁹⁶ Information obtained under this exception may be disclosed only to medical per-

186. *See id.*

187. *See id.*

188. *See id.*

189. *See id.* at 6,879.

190. *See id.* at 6,878.

191. *See id.* Disclosure of protected genetic information may be made to an occupational or other health researcher if the research is coordinated pursuant to Part 46 of Title 45 of the Code of Federal Regulations which states that research subjects must be informed about the confidentiality of records identifying the subject. *See* Protection of Human Subjects, 45 C.F.R. § 46.11 (a)(5) (1999).

192. *See* Genetic Exec. Order, 6,875, 6,878.

193. *See id.*

194. *See id.* at 6,879.

195. *See id.*

196. *See id.*

sonnel involved in or responsible for determining whether further tests are needed.¹⁹⁷

V. GENETIC PRIVACY

Genetic discrimination arguably would be diminished in the face of laws that provide extensive protection against the disclosure and use of an individual's genetic information. Employers would be greatly limited in their ability to engage in genetic discrimination if such laws prevented them from either requiring employees to undergo genetic testing or using the results of genetic tests as the basis for adverse employment decisions.

A. Federal Privacy Rights

There is "no question that an employee's medical records, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection."¹⁹⁸ Information about one's body and state of health is a matter which the individual is ordinarily entitled to privacy.¹⁹⁹ Genetic information should thus be protected pursuant to the right to privacy under the United States Constitution. This right to privacy is limited in that it applies only to government action, and does not reach private employers. In *Whalen v. Roe*,²⁰⁰ the Supreme Court found that "in some circumstances" the government has a duty to avoid disclosing private information based on the liberty interests guaranteed by the Fourteenth Amendment of the Constitution.²⁰¹

Federal and state constitutional privacy interests are not absolute in that they must be balanced against the government employer's legitimate interests in collecting the information.²⁰² Provided the government has a valid societal purpose and employs reasonable security measures, courts will not interfere with traditional governmental activities of health information collection and distribution.²⁰³

197. *See id.* Family medical history information collected in accordance with § 1-301(a) may also be disclosed under the provisions of § 1-301(b). *See id.*

198. *U.S. v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980).

199. *See id.*

200. 429 U.S. 589 (1977).

201. *See id.* at 605-06.

202. *See Westinghouse*, 638 F.2d at 577.

203. *See Planned Parenthood v. Danforth*, 428 U.S. 52, 80-81 (1976); *see also Mayfield v. Dalton*, 109 F.3d 1423 (9th Cir. 1997). Two active duty Marines filed a class action lawsuit challenging the requirement that they provide DNA samples to the armed forces. The suit did not invoke the ADA, but instead was based on the Fourth Amendment right against unreasonable search and seizure. The District Court held that DNA sampling did not con-

Although the Supreme Court has not specifically addressed privacy rights in genetic information, the Ninth Circuit did so in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* and held that an individual's constitutional right to privacy "clearly encompasses medical information."²⁰⁴ Moreover, the court stated, "[o]ne can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health and genetic make-up."²⁰⁵ In *Norman-Bloodsaw*, the Ninth Circuit permitted plaintiffs' federal and state constitutional privacy claims to survive summary judgment.²⁰⁶

Norman-Bloodsaw also provides an interesting example of how existing federal and state law can be used to challenge genetic and other medical testing by an employer. In this case, the plaintiffs brought suit against their employer, the Lawrence Berkeley Laboratory, a government-funded research institution, challenging the lab's practice of testing for syphilis, pregnancy, and the sickle-cell trait.²⁰⁷ Plaintiffs alleged that the genetic testing was conducted during routine mandatory medical exams without the employees' knowledge or consent, and the conditions for which testing was performed bore no relationship to the clerical and administrative jobs the employees had been hired to perform.²⁰⁸

These practices were challenged under the ADA and Title VII, on the grounds that the practice constituted discrimination on the basis of sex (pregnancy), race, and disability, as well as under the U.S. and California constitutions on due process and privacy grounds.²⁰⁹ It is important to note that in this case, plaintiffs did not allege that the defendants took any subsequent employment-related action on the basis of the test results or that the results had been disclosed to third parties.

The Ninth Circuit reversed the district court's dismissal of these claims and allowed the case to go to trial on the following grounds.²¹⁰ The court found that there was sufficient evidence in the record to conclude that the testing for syphilis, sickle cell trait, and pregnancy is not an appropriate part of an occupational medical examination, and

stitute an unreasonable search and seizure because the repository served the legitimate function of identifying the remains of soldiers killed during combat. On appeal the claim became moot when plaintiffs were discharged from the Marines. *Id.*

204. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998).

205. *Id.*

206. *See id.* at 1275.

207. *See id.* at 1264-65.

208. *See id.*

209. *See id.*

210. *See id.* at 1275.

that the employer lacked any reasonable basis for performing these tests on clerical and administrative employees such as the plaintiffs.²¹¹ In addition, the court found that the performance of these tests, without explicit notice and informed consent, violates prevailing medical standards.²¹² The court also found that the constitutional right to privacy clearly encompasses confidentiality of medical information, and that the performance of unauthorized tests constitute the most basic violation possible.²¹³ Plaintiffs' Title VII claims that the employer selectively invaded the privacy of women and African-Americans were permitted to go forward.²¹⁴

However, the court upheld the dismissal of the ADA claims on the following grounds: (1) that no job related action was taken against the plaintiffs as a result of the testing; (2) the lack of evidence of inadequate safeguards to protect the confidentiality of the information; and (3) the scope of the exams did not violate the statute.²¹⁵ It is important to note that the *Norman-Bloodsaw* case was decided before the Supreme Court's decision in *Burlington Industries v. Ellerth*, which found that a plaintiff did not have to show a tangible harm in order to maintain a Title VII action.²¹⁶ Arguably, *Ellerth* might have had an impact on *Norman-Bloodsaw*.

The Privacy Act of 1974²¹⁷ provides individuals with another source of privacy protection under federal law. Like the federal Constitution, however, it applies to only government action, particularly, the disclosure of information obtained by a government agency. Generally, the Privacy Act requires federal agencies to use fair information practices in the collection, use, and dissemination of systematized records. It limits the federal government's right to maintain information to that which is "relevant and necessary" to an agency purpose,²¹⁸ allows access to one's records upon request,²¹⁹ grants the right to re-

211. *See id.* at 1267.

212. *See id.*

213. *See id.* at 1269.

214. *See id.* at 1271-72.

215. *See id.* at 1273.

216. *See Burlington Indus. v. Ellerth*, 524 U.S. 742, 765-65 (1998). In *Burlington*, the District Court granted summary judgment for the defendant employer. *See id.* at 749. The District Court reasoned that, although the plaintiff was subjected to sexual harassment, the employer took no detrimental job action and therefore the plaintiff had no Title VII claim. *See id.* The Supreme Court held that the sexual harassment itself may be sufficient to bring a Title VII claim, even if the employer did not take detrimental job action. *See id.* at 764-65.

217. 5 U.S.C. § 552(a) (1996 & Supp. 1999).

218. *Id.* § 552(e)(1).

219. *See id.* § 552(d)(1).

quest that the date be corrected or amended if inaccurate, irrelevant, untimely, or incomplete,²²⁰ and limits disclosure of personal data to third persons.²²¹

There are also some privacy rights under the ADA. An employer must keep any medical information about applicants or employees, including genetic information, confidential.²²² There are very limited exceptions to this confidentiality mandate.²²³ However, it is highly unlikely that genetic information would ever fall within any of these narrow exceptions. The Rehabilitation Act provides similar confidentiality restrictions of medical information for applicants and employees of the federal government. As discussed earlier, the Genetic Executive Order also provides privacy protections for genetic information in certain circumstances.²²⁴

While the Constitution, the Privacy Act, the ADA, the Rehabilitation Act, and the Genetic Executive Order provide some proscriptions against the unwarranted collection or disclosure of medical information by federal departments and agencies and private employers, albeit in very different ways, many believe that such protections are insufficient, and additional federal legislation is necessary. Several bills were introduced in the 105th Congress on this issue.²²⁵ For example, one bill would prohibit disclosure of genetic information without informed consent in most cases, strictly limit insurers' use of genetic information in their coverage decisions, and give individuals property rights over their DNA.²²⁶

220. *See id.* § 552(d)(2)(B)(i).

221. *See id.* § 552(b).

222. *See* 29 C.F.R. § 1630.14(b)(1)(i-iii) (1995).

223. Medical information may be given to, and used by, appropriate decision makers involved in the hiring process so that they can make employment decisions consistent with the ADA. *See* EEOC, ADA PREEMPLOYMENT ENFORCEMENT GUIDANCE 21-23 (1995) available at <<http://www.eeoc.gov/docs/preemp.txt>>. In addition, supervisors and managers may be told about the necessary restrictions on the work or duties of the employee and about necessary accommodations. *See id.* First aid and safety personnel may be told medical information if the disability might require emergency treatment. *See id.* Government officials investigating compliance with the ADA must be given relevant information upon request. *See id.* Employers may give information to state workers' compensation offices, state second injury funds or workers' compensation insurance carriers in accordance with state workers' compensation laws. *See id.* Lastly, employers may use the information for insurance purposes. *See id.*

224. *See supra* text accompanying notes 189-197.

225. *See infra* notes 278-80 and accompanying text.

226. *See* Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997).

B. *The Health Insurance Portability and Accountability Act*

The Health Insurance Portability and Accountability Act (HIPAA),²²⁷ provides some limited protections from discrimination on the basis of genetic condition in health insurance. This is important because the relationship between health insurance and employment is intertwined, for most American workers receive their health insurance from their job.²²⁸ The law prohibits a group health insurance plan from using "genetic information" to establish rules for eligibility or continued eligibility. In general, HIPAA makes it possible for individuals to get insurance coverage when they have past or present medical problems, and to maintain coverage when they change jobs or insurance. Specifically, the Act provides important protections for persons who have preexisting conditions, and therefore, are afraid to change jobs or insurance for fear of losing their coverage.²²⁹ The law primarily helps people who have access to group insurance coverage through their employers or unions.

Under HIPAA, genetic information or susceptibility to genetic disorders alone may not be treated as a preexisting condition in the absence of a diagnosis and may not be used to limit access to health insurance by group health insurance providers.²³⁰ For example, if an individual is a member of a group plan covered by HIPAA and tests positive for a gene that may predispose him or her to a certain condition, that individual cannot be denied insurance coverage or treated as though they have a preexisting condition solely due to their genetic profile. In addition, coverage cannot be denied for a newborn or newly adopted child's medical condition, as long as the child is enrolled within thirty days of birth or adoption, and benefits for the medical condition are otherwise available under the plan.²³¹ Thus, genetic information by itself cannot constitute a preexisting condition, and a covered employee cannot be denied coverage on that basis.

Although HIPAA protects against the use of genetic information to restrict or deny coverage, these protections are limited in that they do not apply to persons who buy insurance in the individual market, and do not prevent plans from charging more to all members of a group plan, such as an entire office, because of the genetic makeup of

227. 29 U.S.C. § 1181 (1999).

228. See Rothenberg et al., *supra* note 77, at 1755.

229. See 28 U.S.C. § 1181(a) (1999).

230. See *id.* § 1181(b)(1)(B).

231. See *id.* § 1181(d)(1).

a specific member of the group. Moreover, HIPAA does not prohibit insurers from requesting or requiring genetic tests.²³²

The language of HIPAA does not explicitly protect the privacy of genetic information. However, the statute provides a mandate for the creation of standards for the protection of the confidentiality of individually identifiable health data.²³³

C. *State Privacy Rights Involving Private Employers and Insurers*

At the state level, a flurry of legislation seems to signal legislators' intent to provide more protections for genetic information than other types of information. Colorado, Florida, and Georgia, for example, have even given individuals property rights over their DNA.²³⁴ In addition, at least twenty-four states have enacted legislation prohibiting genetic discrimination in the workplace.²³⁵ That legislation is discussed in detail in Section VI of this Article. Finally, individuals may be able to find some privacy protection in the state common law duty of confidentiality, which limits the situations in which physicians may disclose to employers their patients' medical records. However, most state legislation involving genetic information addresses its use in the insurance arena.

1. *Anti-Discrimination in the Provision of Insurance*

There is a difference between statutes protecting privacy and those preventing discrimination. Privacy protections regulate genetic information before it is produced. Anti-discrimination statutes regulate information after it is produced, prohibiting disclosure and procurement, and will more often apply to private employers or insurance companies. Anti-discrimination measures can protect individuals from unauthorized disclosure of their genetic information by insurance companies. Thirty-five states now prohibit genetic discrimi-

232. Tara Rachinsky, *Genetic Testing: Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace*, 2 U. PA. J. LAB. & EMPLOYMENT L. 575, 593 (2000).

233. *See id.* at 593-94.

234. *See* COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West, WESTLAW through 1999 Reg. Sess.); FLA. STAT. ANN. § 760.40(2)(a) (West, WESTLAW through 1999 Reg. Sess.); GA. CODE ANN. § 33-54-1(1) (WESTLAW through 1999 Gen. Ass.).

235. *See infra* note 255 and accompanying text.

nation by health insurers,²³⁶ and the method by which they do so varies widely.²³⁷

There has yet to emerge a consensus among the states on the extent to which genetic information should be protected in the insurance field. What is clear is that genetic discrimination in insurance has received greater attention from state legislatures than has discrimination in employment, as evidenced by the number of statutes addressing the issue.²³⁸

2. State Common-Law Protections

The common law duty of confidentiality, or a breach of confidentiality tort, acknowledges that a patient has a right, derived from the moral principle of personal autonomy, to give informed consent for medical treatment and surgical procedures.²³⁹ The physician-patient privilege is a form of this duty that imposes an obligation on a physician to maintain the confidentiality of patient communications, including patient records.²⁴⁰ This privilege applies to physicians as well as hospitals, and most often arises when a physician is forced to testify about a patient's condition pursuant to litigation.

But some states also recognize a common law duty of confidentiality that applies to other health care professionals.²⁴¹ The professional may be liable for disclosure without the patient's consent if the

236. Alabama, Arizona, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Kentucky, Maine, Maryland, Michigan, Minnesota, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Texas, Vermont, Virginia, Washington, and Wisconsin. See National Human Genome Res. Inst., *Genetic Information and Health Insurance Enacted Legislation*, (visited Mar. 13, 2000) <http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm>.

237. See Meredith A. Jagutis, *Insurer's Access to Genetic Information: The Call for Comprehensive Federal Legislation*, 82 MARQ. L. REV. 429, 438 (1999). Depending on the jurisdiction, insurers may be prohibited from using genetic information as a basis for denying coverage, for establishing rates and premiums, or for canceling or refusing to renew policies. See *id.* at 439. Several states have made it illegal for insurers to require or request genetic testing. See *id.* Still others prohibit insurers from considering the fact that a policyholder (or prospective policyholder) may have requested a genetic test or refused to take one. See *id.* at 440.

238. As this Article discusses in Section VI, state legislatures increasingly are beginning to add genetic predisposition to their employment discrimination statutes as an improper basis for making an adverse employment decision. See *infra* notes 254-277 and accompanying text.

239. See Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 511 (1995).

240. See *Estate of Behringer v. Medical Ctr. at Princeton*, 592 A.2d 1251, 1268 (N.J. Super. Ct. Law Div. 1991).

241. See Gostin, *supra* note 239, at 508.

patient demonstrates a clear expectation of privacy.²⁴² States also have recognized an exception to the duty for the private interests of the patient.²⁴³ A physician may be required to reveal confidences in order to “protect the welfare of the individual or of the community,” for example, when a clinical record is provided to another health care professional responsible for the patient’s care.²⁴⁴

There are problems with applying this duty to employee-employer relationships. The breach of confidentiality tort usually requires a special kind of relationship, one in which the patient is able to demonstrate a clear expectation of privacy.²⁴⁵ Consequently, it must be “reasonable” for employees to expect that the person to whom they are divulging their medical information will keep it in confidence. Because of this requirement, courts may limit the confidential duty to physicians. Discussions with a doctor acting for an insurance company pursuant to litigation, for example, may make the nature of the relationship ambiguous, and a duty of confidentiality may not exist.²⁴⁶ There are other problems with application of the duty of confidentiality. A tort action can only be brought against the person who holds the information in confidence.²⁴⁷ The “holder” is often unclear because modern health information systems are electronic, and the information can be passed from one place to another.²⁴⁸ A duty in tort may not be very useful if the foregoing problems cannot be resolved.²⁴⁹

Regardless of whether employees have an expectation of privacy when meeting with their employer’s physician, employers still may

242. *See id.*

243. *See id.* at 509.

244. *Id.* (citing *McIntosh v. Milano*, 403 A.2d 500 (N.J. Super. Ct. Law Div. 1979)).

245. *See, e.g.*, *Bratt v. International Bus. Machs. Corp.*, 785 F.2d 352, 362 (1st Cir. 1986) (finding that a physician-patient relationship existed where the physician was retained by patient’s employer and patient reasonably believed physician-patient relationship existed). *But see, e.g.*, *Mares v. Conagra Poultry Co., Inc.*, 971 F.2d 492, 496 (10th Cir. 1992) (holding that an employer’s request for medication information did not constitute an invasion of privacy); *Childs v. Williams*, 825 S.W.2d 4, 9 (Mo. Ct. App. 1992) (holding that letter from psychologist to plaintiff’s supervisor did not constitute public disclosure of private facts).

246. *See Gostin, supra* note 239, at 510; *see also Hague v. Williams*, 181 A.2d 345, 349 (N.J. 1962) (concluding that an exception to the patient’s right to confidentiality exists where the public or private interest of the patient so demands, for example disclosure may be made to a person with a legitimate interest in patient’s health). *But see, e.g., Bratt*, 785 F.2d at 362; *Alberts v. Devine*, 479 N.E.2d 113, 121 (Mass. 1985) (holding that “one who, induces a physician wrongfully to disclose information about a patient, may be held liable to the patient for the damages that flow from that disclosure.”).

247. *See Gostin, supra* note 239, at 511.

248. *See id.*

249. *See id.*

lawfully obtain personal health data in many instances²⁵⁰ by using a "balancing approach."²⁵¹ For example, a legitimate business interest in obtaining and publishing the information should be weighed against the substantiality of the intrusion on the employee's privacy resulting from the disclosure.²⁵² It is not an invasion of privacy for a physician to disclose medical information to an employer that is reasonably necessary to serve a substantive and valid interest.²⁵³

VI. GENETIC DISCRIMINATION LEGISLATION

While there are some existing state and federal laws explicitly prohibiting genetic discrimination under certain circumstances, they do not provide comprehensive coverage for workers. For example, although the ADA prohibits genetic testing of current employees unless job-related and consistent with business necessity, employers in most jurisdictions are not prohibited from requiring prospective employees to undergo genetic testing once a conditional offer of employment has been extended. In addition, ADA protection does not extend to private employers of less than fifteen employees.²⁵⁴

A. State Legislation

Twenty-four states have enacted laws providing additional protections against discrimination in the workplace on the basis of genetic information.²⁵⁵ The form and coverage of these statutes vary considerably. The earliest state legislation addressing genetic discrimination in the workplace prohibited employers from discriminating against individuals possessing particular genetic traits or disorders. For example, Florida prohibits entities from denying or refusing employment to any person or discharging any person from employment based on the sickle-cell trait.²⁵⁶ A North Carolina statute has nearly identical prohibitions and also covers individuals with the hemoglobin C

250. See *id.* at 510-11 n.305.

251. *Bratt*, 785 F.2d at 358 (affirming a "balancing test" articulated by the Massachusetts Supreme Judicial Court in *Bratt v. International Bus. Machs. Corp.*, 467 N.E.2d 126 (Mass. 1984)).

252. See *Bratt*, 467 N.E.2d at 135-36.

253. See *id.* at 137.

254. See 42 U.S.C. § 12111(5)(A) (1994).

255. Arizona, California, Connecticut, Delaware, Florida, Illinois, Iowa, Kansas, Louisiana, Maine, Michigan, Missouri, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, Oklahoma, Oregon, Rhode Island, Texas, Vermont, and Wisconsin. See National Human Genome Research Inst., *Genetic Information and the Workplace Enacted Legislation* (visited Mar. 7, 2000) <http://www.nhgri.gov/Policy_and_public_affairs/Legislation/workplace.htm>.

256. See FLA. STAT. ANN. § 448.076 (West, WESTLAW through 1999 Reg. Sess.).

trait.²⁵⁷ Louisiana prohibits employers from refusing to hire, discharging, classifying, segregating, or discriminating with respect to terms, conditions, and privileges of employment against individuals with the sickle-cell trait.²⁵⁸ New Jersey prohibits employment discrimination based on the sickle-cell trait, the hemoglobin C trait, the thalassemia trait, the Tay-Sachs trait, or the cystic fibrosis trait.²⁵⁹ New York prohibits discrimination based on the sickle-cell trait, the Tay-Sachs trait, or the beta-thalassemia trait.²⁶⁰

In the 1990s, a number of states passed more comprehensive statutes which either prohibit employers from requiring genetic testing as a condition of employment or which prohibit the use of genetic information in employment decisions. Arizona, Iowa, New Hampshire, North Carolina, Oregon, Rhode Island, Texas, and Wisconsin prohibit employers and, in some cases, labor organizations, employment agencies, and licensing agencies, from discriminating against any individual in hiring or discharge or in terms and conditions of employment based on the results of a genetic test.²⁶¹ Some states additionally prohibit employment discrimination based on genetic information

257. See N.C. GEN. STAT. § 95-28.1 (1999). The hemoglobin C trait (Hb C) is related to sickle-cell disorders. See PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1522. Although the gene frequency for Hb C is only one-fourth that for Hb S, the prevalence of sickle-cell related symptoms and illnesses is far greater. See *id.* "The increased tendency of S[ickle] C[ell] red cells to sickle, compared with sickle trait cells, can be explained by two phenomena: increased intercellular hemoglobin concentration and significantly higher percent Hb S." *Id.* at 1523.

258. See LA. REV. STAT. ANN. § 23:352 (West, WESTLAW through 1999 Reg. Sess. Acts).

259. See N.J. STAT. ANN. §§ 10:5-5, 10:5-12 (West, WESTLAW through L. 1999, C. 198). "The thalassemias are a diverse group of congenital disorders in which there is a defect in the synthesis of one (or more) of the subunits of hemoglobin. As a result of the decreased production of hemoglobin, the red blood cells are microcytic and hypochromic." PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1525. Thalassemias can lead to a variety of conditions, from subtle abnormalities to life-threatening diseases. See *id.* The two types of thalassemias are classified as α -chain and β -chain. See *id.* A normal individual inherits two α -chain genes from each parent. See *id.* The great majority of cases of α -chain thalassemia result from deletion or impaired production of α -chain genes. See *id.*

260. See N.Y. CIV. RIGHTS LAW § 48-a (McKinney 1999). Generally, individuals inherit only a *single* β -chain gene from each parent. See PRINCIPLES OF INTERNAL MEDICINE, *supra* note 53, at 1525. In persons who inherit genetic beta-thalassemia trait, the β -chains have normal structure, but are produced at greatly reduced rates. See *id.* The "gene frequency for β thalassemia approaches 0.1 in southern Italy and certain Mediterranean islands." *Id.* Beta-thalassemia is also "encountered quite commonly in central Africa, Asia, the south Pacific, and certain parts of India." *Id.*

261. See ARIZ. REV. STAT. ANN. § 41-1463(B) (West, WESTLAW through 1999 1st Reg. Sess. and 2nd Spec. Sess.); IOWA CODE ANN. § 729.6 (West, WESTLAW through 1999 Reg. Sess.); N.H. REV. STAT. ANN. § 141-H:3 (West, WESTLAW through 1999 Reg. Sess.); N.C. GEN. STAT. § 95-28.1 (1999); OR. REV. STAT. § 659.036(1) (1998); R.I. GEN. LAWS § 28-6.7-1 (1999); TEX. LAB. CODE ANN. § 21.402 (West 2000); WIS. STAT. ANN. § 111.372 (West 1999).

obtained from sources other than genetic tests.²⁶² Iowa, New Hampshire, New York, Oregon, Rhode Island, Texas, and Wisconsin prohibit employers from soliciting, requiring, or administering a genetic test to individuals as a condition of employment or as part of the job application process.²⁶³ Iowa, New Hampshire, and Wisconsin prohibit offering inducements such as employment, membership, licensure, pay, or benefits in return for taking a genetic test,²⁶⁴ and Iowa, Rhode Island, and Wisconsin further prohibit discriminating with regard to hiring and to terms and conditions of employment against people because they have obtained genetic tests on their own.²⁶⁵ Some state statutes carve out exceptions to permit genetic testing if there is employee consent for the purposes of investigating workers' compensation claims, or determining and monitoring the worker's susceptibility to potentially toxic substances in the workplace.²⁶⁶

These statutes cover anyone who may be subjected to genetic testing by his or her employer. Because coverage under most of these statutes revolves around who is or may be subjected to genetic testing,²⁶⁷ coverage is both over- and under-inclusive. Individuals who do not have any genetic abnormalities are protected from being subjected to testing while, at the same time, most of the statutes do not prohibit employers from genetic discrimination based on information obtained from sources other than testing.

New Jersey's law, the most comprehensive of state statutes regarding workplace genetic discrimination, avoids this problem by prohibiting employment discrimination based on categories including

262. See N.C. GEN. STAT. § 95-28.1A (1999).

263. See IOWA CODE ANN. § 729.6.2 (West, WESTLAW through 1999 Reg. Sess.); N.H. REV. STAT. ANN. § 141-H:3I(a) (WESTLAW through 1999 Reg. Sess.); N.Y. CIV. RIGHTS LAW § 48-a (McKinney 1999); OR. REV. STAT. § 659.036(1) (1998); R.I. GEN. LAWS § 28-6.7-1(a)(1) (1999); TEX. LAB. CODE ANN. § 21.402(a)(2) (West 2000); WIS. STAT. ANN. § 111.372(1)(a) (West 1999).

264. See IOWA CODE ANN. § 729.6.4 (West, WESTLAW through 1999 Reg. Sess.); N.H. REV. STAT. ANN. § 141-H:3III (WESTLAW through 1999 Reg. Sess.); WIS. STAT. ANN. § 111.372(3) (West 1999).

265. See IOWA CODE ANN. § 729.6.2.b (West, WESTLAW through 1999 Reg. Sess.); R.I. GEN. LAWS § 28-6.7-1(a)(2) (1999); WIS. STAT. ANN. § 111.372(1)(b) (West 1999).

266. See IOWA CODE ANN. § 729.6.7 (West, WESTLAW through end of 1999 Reg. Sess.); N.H. REV. STAT. ANN. § 141-H:3IV (WESTLAW through 1999 Reg. Sess.); N.Y. EXEC. LAW § 296.19(c) (Consol. 1999); WIS. STAT. ANN. § 111.372(4) (West 1999).

267. The following statutory definition of "genetic testing" for Iowa is representative of other state statutes: "a test of a person's genes, gene products, or chromosomes, for abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, impairment, or other disorders, whether physical or mental, or that demonstrate genetic or chromosomal damage due to environmental factors." IOWA CODE ANN. § 729.6.1.c (West, WESTLAW through 1999 Reg. Sess.).

“genetic information,” “atypical hereditary cellular or blood trait,” or “because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer.”²⁶⁸ Rather than focusing on results of genetic testing, “genetic information” is defined broadly to include “information about genes, gene products or inherited characteristics that may derive from an individual or family member.”²⁶⁹ New York and North Carolina also prohibit employment discrimination based on genetic information, regardless of the source from which such information is obtained.²⁷⁰ Although most state statutes do not distinguish between genetic disorders which have become manifest and those which are as yet unexpressed, New York and North Carolina statutes, prohibiting discrimination by employers based on genetic characteristics or genetic predisposition, define these terms generally as those identifiable chromosomal traits associated with an increased statistical risk of developing a disease or disorder which currently are asymptomatic of any disease or disorder.²⁷¹

California has a statute which prohibits health care service plans from discriminating in enrollment, terms, conditions, benefits, rates, or charges “on the basis of a person’s genetic characteristics that may, under some circumstances, be associated with disability in that person or that person’s offspring.”²⁷² This statute defines “genetic characteristics” as “[a]ny scientifically or medically identifiable gene or chromosome, or combination or alteration thereof, that is known to be a cause of a disease or disorder, . . . [or] . . . [i]nherited characteristics that may derive from the individual or family member, . . . [and] *that are presently not associated with any symptoms of any disease or disorder.*”²⁷³

Beyond these laws specifically aimed at workplace discrimination, other states have enacted statutes that more generally limit genetic testing, require consent by the individual prior to testing, and require confidentiality with regard to results.²⁷⁴ These general statutes place

268. N.J. STAT. ANN. § 10:5-12 (West Supp. 1999).

269. *Id.* § 10:5-500.

270. See N.Y. CIV. RIGHTS LAW § 48-a (McKinney 1999); N.C. GEN. STAT. § 95-28.1A (1999).

271. See N.Y. EXEC. LAW § 292.21-b (Consol. 1999) (“‘Genetic predisposition’ shall mean the presence of a variation in the composition of the genes of an individual which is scientifically or medically identifiable and which is determined to be associated with an increased statistical risk of being expressed as a physical or mental disease or disability in the individual *but which has not resulted in any symptoms of such disease or disorder.*” [emphasis added]); N.C. GEN. STAT. § 95-28.1A(b) (1999).

272. CAL. HEALTH & SAFETY CODE § 1374.7(a) (West 2000).

273. *Id.* (emphasis added).

274. For example, Florida regulates genetic testing and prohibits genetic testing except with the informed consent of the individual to be tested and provides that the results of

some limits on an employer's ability to require employees to take genetic tests or to get access to genetic test results of current or potential employees.

These statutes potentially cover anyone who may be subjected to genetic testing by his or her employer. The statutory definition for "genetic testing" for Iowa is representative of other state statutes:

a test of a person's genes, gene products, or chromosomes, for abnormalities or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, impairment, or other disorders, whether physical or mental, or that demonstrate genetic or chromosomal damage due to environmental factors.²⁷⁵

New York and New Jersey have incorporated prohibitions on genetic discrimination into their general statutes prohibiting employment discrimination in hiring, discharge, or terms and conditions of employment.²⁷⁶ New York prohibits employment discrimination based on "genetic predisposition or carrier status."²⁷⁷ Unlike New York, New Jersey's statute does not limit coverage to asymptomatic genetic characteristics.

To date, there have been no cases reported based on these state statutes prohibiting genetic discrimination in the workplace.

B. *Federal Initiatives*

Given the uncertainties and gaps in federal and state protections against genetic discrimination in employment decisions, comprehensive federal legislation to establish minimum protections may be needed to ensure that advances in genetic technology and research, while being used to address the health needs of Americans, are not used to deny individuals employment opportunities and benefits. There have been proposals for federal legislation in this area. Senator

such tests may not be disclosed without the consent of the tested individual. See FLA. STAT. ANN. § 760.40(2)(a) (West, WESTLAW through 1999 Reg. Sess.); see also 410 ILL. COMP. STAT. ANN. 513/15, 513/30 (West 1999) (regulating confidentiality and disclosure of genetic information); TEX. LAB. CODE ANN. § 21.403 (West 2000) (prohibiting disclosure of genetic information unless specifically authorized by the individual); WIS. STAT. ANN. § 942.07(3) (West 1999) (prohibiting employers, labor organizations, employment agencies, and licensing agencies from disclosing results of an individual's genetic test without the individual's written informed consent).

275. IOWA CODE ANN. § 729.6.1.c (West, WESTLAW through 1999 Reg. Sess.).

276. See N.J. STAT. ANN. § 10:5-12 (West Supp. 1999); N.Y. EXEC. LAW § 296 (Consol. 1999).

277. N.Y. EXEC. LAW § 296 (Consol. 1999).

Tom Daschle (D-S.D.) and Representatives Joe Kennedy (D-Mass) and Nita Lowey (D-N.Y.) have each introduced bills that would amend civil rights or labor laws to prohibit employment discrimination based on genetic information.²⁷⁸ In addition, Senator Pete Domenici (R-N.M.) and Representative Cliff Stearns (R-Fla.) have sponsored bills that include protection from genetic discrimination in the workplace along with other proposals regulating the use of genetic information more broadly.²⁷⁹

In January 1998, the Clinton Administration called for legislation banning genetic discrimination in the workplace.²⁸⁰ The guiding principles for the proposed legislation would generally prohibit employers from (1) requiring workers to take a genetic test or provide genetic information as a condition of employment or benefits; (2) using genetic information to discriminate against, limit, segregate, or classify workers; and (3) disclosing genetic information.²⁸¹ It would allow employers to monitor employees for the effects of a particular substance found in the workplace, exposure to which could cause genetic damage, but only with the employee's informed consent and assurance of confidentiality.²⁸² Results could be used only to identify and control adverse conditions in the workplace and to prevent risk of harm.²⁸³ Genetic information maintained under these circumstances also would have to be kept in medical files separate from personnel files.²⁸⁴

CONCLUSION

Employment civil rights laws are rooted in the principle that certain characteristics such as race, national origin, gender, religion, age, or disability may not be considered in making employment decisions because they are ultimately irrelevant to the person's ability to perform the job in question. Discrimination based upon genetic information is no different. Just as it is illegal to refuse to hire an individual because of their race or gender, it should be illegal to make job decisions based solely upon genetic information without considering that person's ability to do the work. It is simply bad science for an

278. See JOINT MEMORANDUM OF DEPARTMENT OF LABOR, *supra* note 73; see generally S. 1045, 105th Cong. (1997); H.R. 2275, 105th Cong. (1997).

279. See JOINT MEMORANDUM OF DEPARTMENT OF LABOR, *supra* note 73; see also S. 422, 105th Cong. (1997); H.R. 2198, 105th Cong. (1997).

280. See JOINT MEMORANDUM OF DEPARTMENT OF LABOR, *supra* note 73.

281. See *id.*

282. See *id.*

283. See *id.*

284. See *id.*

employer to use the presence of a predictive genetic trait or marker to make workplace decisions because those traits cannot predict how well that person will succeed in the workplace.

With advances in genetic technology, we will soon realize that everyone has genetic predispositions for one condition or another. Mapping the human genome will change the way we view and understand who is "normal" and who is "disabled." If we all have genetic misspellings, how do we *now* define who is healthy and who is not? If we all have genetic diseases that are just waiting to express themselves in the future, aren't we all truly disabled? As we will all have knowledge of the potential genetic disorders that we each harbor, disabled people can no longer remain stigmatized as "the other" in society.

It is important to note that genetic mutations and misspellings are not themselves all bad—even those that cause a disorder. For example, a genetic misspelling caused this author to be a dwarf, yet having dwarfism and the gene that caused it is not bad or something that needs to be cured. Many people with non-life threatening genetic disabilities, such as mental retardation or deafness, feel the same way. Society imparts value to one's mutation, and until now, society has always imparted a negative value on those mutations which are expressed. As non-disabled people discover their unexpressed genetic mutations and genetic predispositions for disabilities, values may change. Employers, insurance companies, and even society may try to assign a negative value to genetic mutations which are known but not expressed in an illness or disease. Society should not allow employers to assign a negative value to genetic markers that have no effect on one's ability to perform in their job.

While advances in genetic research and technology portend tremendous benefits for humankind in medicine and science, adequate protections must be in place to insure that such technology will not be used for the wrong reasons. The use of genetic testing or genetic information to exclude qualified individuals from the workplace should be illegal. Genotype should not be used as a blanket substitute for qualifications. An otherwise qualified individual should not be precluded from getting or holding a job based upon having a genetic marker or a genetic predisposition for a disease, disorder, or disability. While the ADA protects against the misuse of genetic information in the employment context, no court has ruled on this issue. Thus, additional legislation may be needed to protect workers from genetic discrimination, as we enter this brave new world.