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Genetic Disability: A Modest Proposal to Modify the ADA to Protect against Some Forms of Genetic Discrimination

Jennifer Chorpeneing

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Genetic Disability: A Modest Proposal To Modify the ADA To Protect Against Some Forms of Genetic Discrimination

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INTRODUCTION

Fifty years ago, Francis Crick and James D. Watson deduced the structure of DNA's¹ double helix, founding the new science of molecular biology.² In the spring of 2003, scientists announced a completed map of the human genome, a final goal of the Human Genome Project ("HGP"), which began in 1986 with the seemingly impossible dream of mapping and sequencing all the genes of the human body.³ In a mere half century, DNA technology has joined the

1. "DNA" is the acronym for deoxyribonucleic acid.

2. Nicholas Wade, *Watson and Crick, Both Aligned and Apart, Reinvented Biology*, N.Y. TIMES, Feb. 25, 2003, at F3.

3. Nicholas Wade, *Once Again, Scientists Say the Human Genome Is Complete*, N.Y. TIMES, Apr. 15, 2003, at F1. In 1986, the Human Genome Project began in the United States when scientists embarked on a series of studies to determine whether a large-scale effort to map and sequence the genes of the human body was possible. See Jared A. Feldman & Richard J. Katz, *Genetic Testing and Discrimination in Employment: Recommending a Uniform Statutory Approach*, 19 HOFSTRA LAB. & EMP. L.J. 389, 392 (2002); NAT'L CTR. FOR BIOTECHNOLOGY INFO., JUST THE FACTS: A BASIC INTRODUCTION TO THE SCIENCE UNDERLYING NCBI RESOURCES: BIOINFORMATICS, at <http://www.ncbi.nlm.nih.gov/About/primer/bioinformatics.html> (last revised Mar. 29, 2004) [hereinafter NCBI, JUST THE FACTS] (on file with the North Carolina Law Review).

tools in the physician's medical bag,⁴ allowing sophisticated testing for the diagnosis of, and the predisposition to, numerous diseases.⁵ Scientists continue to use their new mastery of genetics to discover causes of disease by combining information from the completed map of all human genes with extensive studies of symptomatic patients.⁶ While this process is more advanced for some diseases than others,⁷ more than 4,000 diseases are believed to have some genetic component.⁸

Genetic screening for specific diseases cannot perfectly predict all instances of disease, nor is it a panacea to eradicate all human disease.⁹ Because a disease may be caused by a single genetic mutation, several genetic mutations, or several genetic mutations working in concert with an individual's environment,¹⁰ genetic

The project became multinational, with France, Italy, Japan, Russia, and the United Kingdom all taking part. Feldman & Katz, *supra*, at 392. In 2000, scientists announced completion of a majority of the project, which initially was not supposed to be finished until years later. See Wade, *supra*. While scientists had sequenced the genome at that time, it could be described as a "working draft"—much work remained to determine which parts of the sequence were genes and which parts were "junk DNA," to which scientists could not ascribe a purpose. See *id.*

4. For a list of current tests available, see Human Genome Project Information, Gene Testing, at http://www.ornl.gov/TechResources/Human_Genome/medicine/genetest.html#testsavailable (last modified Dec. 9, 2003) (on file with the North Carolina Law Review).

5. Andrew Pollack, *How the Arms of the Helixes Are Poised to Serve*, N.Y. TIMES, Feb. 25, 2003, at F5.

6. NCBI, JUST THE FACTS, *supra* note 3. Symptomatic patients are those whose disease is currently being expressed by symptoms. See DORLAND'S ILLUSTRATED MEDICAL DICTIONARY 1805 (30th ed. 2003) [hereinafter DORLAND'S DICTIONARY]. Genetic testing can help symptomatic patients by determining the exact cause of symptoms—the first step to combating illness. See EDWIN H. MCCONKEY, HUMAN GENETICS: THE MOLECULAR REVOLUTION 189–92 (1993) (discussing treatment of Phenylketonuria after genetic screening of infants).

7. For example, genetic tests are currently available for about 930 diseases, including breast cancer, Huntington's disease, and Tay-Sachs disease. Pollack, *supra* note 5. Scientists expect tests for other diseases, such as Alzheimer's, to be available in the next five years. Lee Bowman, *Genetics May Show Risk for Disease*, HERALD-SUN (Durham, N.C.), Feb. 15, 2003, at A6.

8. See Access Excellence Resource Center, *Understanding Gene Testing: How Are Genes Linked to Disease?*, at <http://www.accessexcellence.org/AE/AEPC/NIH/gene05.html> (last visited Apr. 9, 2004) (on file with the North Carolina Law Review); see also DAVID L. RIMOIN ET AL., PRINCIPLES AND PRACTICE OF MEDICAL GENETICS 37 (4th ed. 2002) ("Perhaps we should require a disease to be shown *not* to be associated with any genetic variation, before saying it has no genetic basis.").

9. See GRAEME LAURIE, GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS 94–97 (2002).

10. For example, Phenylketonuria ("PKU") is a genetic disorder affecting one child in 10,000 that is caused by the inability to metabolize the amino acid phenylalanine. See Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative*

screening can ascertain only the probability of developing a disorder, not its certainty.¹¹ Not everyone with a particular genetic defect will develop the corresponding disease.¹² Therefore, the most that genetic screening can usually discover is that one person has an increased likelihood over another of developing a particular disease at some point in his or her life.¹³

Advances in genetics have led many to postulate that rampant genetic discrimination is inevitable.¹⁴ For example, employers may be interested in knowing whether one of their potential employees has an increased disease risk over another potential employee. Fears of genetic discrimination have led to a number of law review articles suggesting various forms of non-discrimination legislation.¹⁵ This Comment joins that group, but in so doing, seeks a middle ground between a “don’t ask, don’t tell” genetics gag order—the privacy model that could deny the benefits of the genetic revolution to make workplaces safer¹⁶—and the open-hand, economic efficiency model that would seem to reward all discrimination and turn society into genetic “haves” and “have-nots.”¹⁷ Further, it seeks to avoid accusations of “genetics exceptionalism”¹⁸ created by genetics anti-discrimination legislation that may inadvertently elevate genetic illness over environmental illness and other forms of disease.

Part I of this Comment will explore the precision of genetic

Protection, 149 U. PA. L. REV. 1483, 1485 (2001). Failure to metabolize this amino acid results in mental retardation. *Id.* But if a child can be screened at birth for this disorder, then a diet low in phenylalanine will prevent it. *Id.*

11. *Id.*; see Human Genome Project Information, Gene Testing, at http://www.ornl.gov/TechResources/Human_Genome/medicine/genetest.html#procon (last modified Dec. 9, 2003) [hereinafter HGPI, Pros and Cons] (on file with the North Carolina Law Review).

12. HGPI, Pros and Cons, *supra* note 11.

13. *Id.*

14. See Feldman & Katz, *supra* note 3, at 395; Brian Holt, *Genetically Defective: The Judicial Interpretation of the Americans with Disabilities Act Fails to Protect Against Genetic Discrimination in the Workplace*, 35 J. MARSHALL L. REV. 457, 460 (2002) (stating that “employers have embraced tests that detect genetic predispositions”); Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 NW. U. L. REV. 1497, 1498 (2002).

15. See generally Feldman & Katz, *supra* note 3 (suggesting a model statute); Holt, *supra* note 14 (advocating for changes to Title VII); Kim, *supra* note 14 (advocating for privacy rights legislation).

16. See, e.g., Kim, *supra* note 14, at 1532 (advocating for a privacy rights model).

17. See, e.g., Kathleen Taradash, *Preventing a Market for “Lemons”: A Voluntary Disclosure Model as an Alternative to the Prohibition of Genetic Discrimination and the Distortion of Allocative Efficiency*, 34 CONN. L. REV. 1353, 1382 (2002) (advocating a job market free of anti-genetic discrimination laws).

18. See *infra* Part III.C.

testing in predicting the onset of diseases that may directly threaten productivity and safety in the workplace.¹⁹ Part II will examine how current law could impact potential claimants of genetic discrimination,²⁰ focusing on the Americans with Disabilities Act (“ADA”),²¹ Executive Order 13,145,²² the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”),²³ Title VII,²⁴ state laws,²⁵ and pending legislation.²⁶ Part III will examine several proposed remedies and will craft a practical and effective remedy of its own.²⁷ Specifically, this Comment will argue that the ADA should be modified to provide limited protection for the most genetically at-risk, but allow the market to protect the larger mass of society with a less risky genome.²⁸ In so doing, this proposed remedy will combine the strengths of other proposed remedies, while minimizing their weaknesses, particularly their reliance on future government subsidies to the genetically unfortunate.²⁹

19. See *infra* notes 36–77 and accompanying text.

20. See *infra* notes 78–199 and accompanying text.

21. Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2000)).

22. Exec. Order No. 13,145, 65 F.R. § 6877 (2000), *reprinted as amended in* 42 U.S.C.A. § 2000e-16 (West Supp. 2003).

23. Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of 26, 29, and 42 U.S.C.).

24. 42 U.S.C. §§ 2000e to 2000e-17 (2000).

25. At least thirty-two states have enacted some form of legislation preventing the use of genetic discrimination in employment. See National Conference of State Legislatures, State Genetics Employment Laws, at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last visited Apr. 9, 2004) [hereinafter National Conference on State Legislatures] (on file with the North Carolina Law Review).

26. Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. § 202 (2003), *available at* <http://thomas.loc.gov>.

27. See *infra* notes 200–70 and accompanying text.

28. See, e.g., GARY S. BECKER, *THE ECONOMICS OF DISCRIMINATION* 22 (2d ed. 1971) (concluding that race discrimination in labor markets has costs both for the victim and the perpetrator); Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 1 (1994) (“Prejudice in markets is always costly to the parties who practice it.”).

29. To date, universal health care has not been passed, although it is often supported by various politicians. See Dean for America, Promoting American Health, at http://www.deanforamerica.com/site/PageServer?pagename=policy_statement_health (last visited Nov. 1, 2003) (advocating for universal health care) (on file with the North Carolina Law Review); Dick Gephardt for President, Matt’s Plan: Health Care for All, at <http://www.dickgephardt2004.com/plugin/template/gephardt/33> (last visited Nov. 1, 2003) (advocating for universal health care) (on file with the North Carolina Law Review); Kucinich on the Issues, Universal Health Care, at http://www.kucinich.us/issues/issue_universalhealth.htm (last visited Nov. 1, 2003) (advocating for universal health care) (on file with the North Carolina Law Review); see also Michael Rothschild, *Why Health Care Reform Died*, WALL ST. J., Sept. 22, 1994, at A10 (discussing the failure of President Clinton’s health care plan).

Despite the uncertainties, genetic information is valuable. Beyond the value to an individual of knowledge of future risk,³⁰ employers and insurers may value information about an individual's propensity for disease.³¹ Such knowledge could help employers make decisions between two equally qualified potential employees. It could potentially lessen that employer's future worker's compensation or insurance costs, as well as costs associated with employee absence. It could also help the employer provide a safer workplace by eliminating applicants whose genetic makeup increases their risk of adverse reaction to materials present in the particular work environment or who could face danger due to the unexpected onset of disease.³²

Some of these uses imply a dangerous form of discrimination that could divide the nation into two classes—the genetically superior and the genetically inferior who could be condemned to second-class treatment.³³ Theoretically, employers could decide that it is too risky or expensive to employ or train people with genetic predispositions for certain diseases or other conditions. Those with the predisposition for terminal diseases could find themselves passed over for management or promotions, leading to a spiral of unemployment, poverty, and homelessness. But some uses, applying to those with the less risky genomes, while perhaps seemingly unfair to the individual, may be better for both individuals and society as a whole.

To illustrate this concept, this Comment uses three

Many writers on this topic see universal health care—or subsidies for those genetically predisposed to the worst illnesses—as a potential solution. See Robert A. Bohrer, *A Rawlsian Approach to Solving the Problem of Genetic Discrimination in Toxic Workplaces*, 39 SAN DIEGO L. REV. 747, 763 (2002); Colin S. Diver & Jane Maslow Cohen, *Genophobia: What is Wrong with Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1482 (2001); Taradash, *supra* note 17, at 1388. These comments reflect an economic efficiency argument, which is discussed *infra* at Part III.B.

30. See, e.g., LAURIE, *supra* note 9, at 114 (“It is axiomatic that a person who has been tested for one or more genetic conditions has a significant interest in knowing, and determining what happens to, the resulting information.”).

31. See, e.g., Kim, *supra* note 14, at 1502 (stating that genetic privacy in the workplace is often discussed).

32. For example, a growing body of evidence suggests that some people have a predisposition to an elevated risk from exposure to benzene, a workplace chemical, which can cause cancer. See Bohrer, *supra* note 29, at 754–55 n.25. If employees were screened for benzene sensitivity, the workplace could become safer for them. *Id.*

33. But, since everyone's genome contains some disease risk, it will be likely that those with a predisposition for developing more costly, incurable diseases will be the genetically unfortunate, and those with the less costly or more curable diseases the genetically fortunate. See Taradash, *supra* note 17, at 1360–61. This, of course, is not to imply there is something morally wrong with a person who has a riskier genome, just that it has economic considerations.

hypothetical scenarios:

1. Employee Adam is trying to find a job as an airline pilot. During his employment pre-screening test, Adam is found to carry a genetic predisposition for epilepsy. Should the employer refuse to hire him?
2. Employee Barbara is seeking a job as an accountant. During her employment pre-screening test, Barbara is found to carry a genetic predisposition for epilepsy. Should the employer refuse to hire her?
3. Employee Charles is trying to find a job at an oil refinery. During his employment pre-screening test, Charles is found to carry a genetic predisposition for epilepsy that scientists believe would be made worse by exposure to oil. Should the employer refuse to hire him?³⁴

The first and second scenarios illustrate a predisposition for a disease that is primarily dangerous to others, depending on the profession; an epileptic seizure is unlikely to harm anyone at an accounting firm, but could potentially cause an accident if it occurred during an airplane flight. The third scenario illustrates a predisposition for a disease that is dangerous only to the individual³⁵ due to the profession's environment.

I. THE SCIENCE AFFECTING GENETICS AND EMPLOYMENT

On June 26, 2000, scientists announced that they had completed a "working draft" of the human genome³⁶ consisting of roughly three billion nucleotides.³⁷ Scientists refined that significant completion in April 2003 by further filtering out "junk DNA" to isolate actual

34. Epilepsy is likely caused, in some cases, by a person's genetics. NAT'L CTR. FOR BIOTECHNOLOGY INFO., GENES AND DISEASE: EPILEPSY, at <http://www.ncbi.nlm.nih.gov/disease/Epilepsy.html> (last visited Apr. 9, 2004) [hereinafter NCBI, GENES AND DISEASE] (on file with the North Carolina Law Review). This scenario draws on the case of *Chevron v. Echazabal*, 536 U.S. 73 (2002), in which an oil refinery worker was denied a job because of his increased risk of liver disease when exposed to refinery conditions. *Id.* at 76.

35. Theoretically, Charles's illness could be dangerous to others, for example if it were to occur at the wrong time, such as while using hazardous chemicals or moving heavy machinery. The point, however, is that it is primarily dangerous only to the individual.

36. See Feldman & Katz, *supra* note 3, at 392. A genome contains all the biological information needed to build and maintain a living example of that organism. NCBI, JUST THE FACTS, *supra* note 3.

37. See Wade, *supra* note 3.

genes.³⁸ What scientists have decoded can be used to discover individual genes, which are comprised of sequences of four nucleotide bases.³⁹ Genes code for proteins, and proteins—long chains of amino acids—in turn control body function.⁴⁰

Most genetic variation occurs when DNA is duplicated; duplication is a natural and continuous process occurring each time a new cell is formed.⁴¹ Mutations can occur in the new DNA strand such as base substitutions (when a single base gets replaced with another), deletions (where a base is left out), and insertions (where a base is added).⁴² These mutations may have an ultimate effect on what protein is created, and in turn, may be the source of genetic disease.⁴³

Most employer genetic testing will likely focus on an individual's inherited genes, rather than on current gene mutations.⁴⁴ Current gene mutation may be a very real worry in workplaces containing hazardous chemicals, such as in the example of Charles. However, few workplaces will likely be in this situation; therefore, an individual's inherited genome will provide a greater source of disease information for the majority of employers.

An individual's inherited genome consists of twenty-three pairs of chromosomes, half inherited from the mother and half from the father.⁴⁵ Each chromosome carries a number of specified genes, some of which have been linked to particular diseases.⁴⁶ Just how direct that link is may be determined by whether the genetic disease is monogenic or polygenic, a distinction that could play into employment decisions based on the risk of future disease. Monogenic diseases, such as Huntington's, are the direct result of a particular mutation to a specific gene.⁴⁷ Some monogenic diseases are recessive, which means they are inherited only if both parents passed on the

38. Wade, *supra* note 2.

39. NAT'L CTR. FOR BIOTECHNOLOGY INFO., A BASIC INTRODUCTION TO THE SCIENCE UNDERLYING NCBI RESOURCES: WHAT IS A GENOME?, at http://www.ncbi.nlm.nih.gov/About/primer/genetics_genome.html (revised Mar. 31, 2004) [hereinafter NCBI, BASIC INTRODUCTION] (on file with the North Carolina Law Review).

40. *See id.* Proteins include enzymes, structural components, hormones, antibodies, and transport molecules. *Id.*

41. *Id.*

42. *Id.*

43. *Id.*

44. *See* Feldman & Katz, *supra* note 3, at 395–98.

45. NCBI, BASIC INTRODUCTION, *supra* note 39.

46. *Id.*

47. LAURIE, *supra* note 9, at 94–97.

gene.⁴⁸ Recessive monogenic disorders include sickle cell anemia⁴⁹ and cystic fibrosis.⁵⁰ Some monogenic diseases are dominant, which means they are inherited with only one copy of the gene.⁵¹ About 50% of dominant disorders, such as Huntington's disease,⁵² do not manifest until late in life.⁵³ While the parents of a child with a recessive disease may or may not exhibit symptoms themselves, at least one parent of a child with a dominant disease will also exhibit that disease.⁵⁴ If both parents are carriers of a recessive disorder, any child they have has a 25% chance of actually having the disease, a 50% chance that the child will also carry the gene but will not suffer from the disease, and a 25% chance of neither having nor carrying the disease.⁵⁵ In terms of a dominant disorder, a child will have a 50% chance of having the disease if one parent carries the gene, and a 75% chance if both carry it.⁵⁶

Most genetic diseases are not monogenic, but polygenic, involving an interaction of two or more defective genes.⁵⁷ This decreases the likelihood of an individual being affected by the disease, and makes it more difficult to determine which genetic combination caused the disease.⁵⁸ Additionally, external factors influence many polygenic disorders, such as cancer, heart disease, and

48. For more information about recessive genes, see ALAN E. H. EMERY & DAVID L. RIMOIN, 1 PRINCIPLES AND PRACTICE OF MEDIAL GENETICS 99-105 (2d ed. 1992) (detailing autosomal recessive inheritance); *see also* Tiscali Reference: Recessive Gene, at <http://www.tiscali.co.uk/reference/encyclopaedia/hutchinson/m0008099.html> (last visited Apr. 9, 2003) (detailing recessive gene characteristics) (on file with the North Carolina Law Review).

49. In healthy individuals, a gene instructs cells to produce hemoglobin, an oxygen-carrying protein in the blood. Mayo Clinic Staff, Sickle Cell Anemia, at <http://www.mayoclinic.com/invoke.cfm?id=DS00324> (July 8, 2003) (on file with the North Carolina Law Review). In those with sickle cell anemia, the gene creates flawed hemoglobin. *Id.*

50. Cystic Fibrosis is an inherited multi-system disorder that produces abnormal functioning of the endocrine gland, resulting in chronic progressive disease of the respiratory system for nearly all patients. Mayo Clinic Staff, Cystic Fibrosis (Apr. 8, 2004), at <http://www.mayoclinic.com/invoke.cfm?id=DS00287> (on file with the North Carolina Law Review).

51. LAURIE, *supra* note 9, at 95.

52. Huntington's Disease is an untreatable, hereditary disorder that produces involuntary movements and progressive dementia. Mayo Clinic Staff, Huntington's Disease (Aug. 14, 2003), at <http://www.mayoclinic.com/invoke.cfm?id=DS00401> (on file with the North Carolina Law Review).

53. LAURIE, *supra* note 9, at 94-97.

54. *Id.*

55. *Id.*

56. *Id.*

57. *Id.*

58. *Id.*

diseases of the immune system,⁵⁹ by impacting both the appearance and the progression of the disease. Some factors may include the diet and exercise habits of the individual, her level of stress, whether she used alcohol or drugs, and whether she has been exposed to toxic chemicals or radiation.⁶⁰

Testing labs today provide more than 900 genetic tests, and screening newborns for a number of diseases is common.⁶¹ To perform this genetic testing, scientists and doctors take a sample of cells,⁶² such as a drop of blood, saliva, a cheek cell or any other tissue.⁶³ These cells are cultured and isolated to purify the DNA, then analyzed using a genetic test or studied by separating genes with gel electrophoresis.⁶⁴

Two common genetic tests are the "probe test" and the "linkage test."⁶⁵ A "probe test" involves using short pieces of DNA, or "probes," the sequences of which are complementary to mutated sequences.⁶⁶ When they are mixed with an individual's DNA, these probes will "seek their complement among the three billion base pairs of an individual's genome."⁶⁷ If the probe finds its complement, the

59. Wrong Diagnosis, Introduction to Polygenic Disease, at <http://www.wrongdiagnosis.com/genetics/polygenic.htm> (last updated Mar. 30, 2004) (on file with the North Carolina Law Review).

60. LAURIE, *supra* note 9, at 94-97. Alzheimer's disease is an example of a polygenic disease that may be influenced by factors external to an individual's genetic make-up. See Bowman, *supra* note 7. For example, scientists recently discovered that three genes may cause early-onset Alzheimer's disease, with a fourth gene that regulates cholesterol metabolism putting individuals at higher risk for the disease as they grow older. *Id.* Other research indicates that diets high in saturated fat increase the risk of developing Alzheimer's. See ALZHEIMER'S ASS'N, WAVE OF ALZHEIMER RESEARCH SPOTLIGHTS SCIENTIFIC MOMENTUM (Feb. 17, 2003), at <http://http://www.alz.org/Media/newsreleases/2003/021703research.asp> (on file with the North Carolina Law Review). Thus, Alzheimer's is likely a polygenic disorder with environmental variance.

61. Human Genome Project Information, Gene Testing, at http://www.ornl.gov/TechResources/Human_Genome/medicine/genetest.html#whatis (last modified Oct. 29, 2003) [hereinafter HGPI, Gene Testing] (on file with the North Carolina Law Review). For example, most states screen newborns for about eight disorders requiring early detection and treatment, including phenylketonuria, galactosmia, and sickle cell disease. See U.S. General Accounting Office, Newborn Screening: Characteristics of State Programs, March 2003, available at <http://www.gao.gov/new.items/d03449.pdf> (last visited Oct. 13, 2003) (on file with the North Carolina Law Review).

62. HGPI, Gene Testing, *supra* note 61.

63. *Id.*

64. See NCBI, BASIC INTRODUCTION, *supra* note 39. Gel electrophoresis separates genes by using an electric current to move dyed DNA fragments through a gel. *Id.* Smaller fragments of DNA move faster and further than longer fragments. *Id.* Scientists then study the patterns the DNA creates. *Id.*

65. HGPI, Gene Testing, *supra* note 61.

66. *Id.*

67. *Id.*

two will bind together, thereby flagging the mutation and demonstrating whether the individual also carries that gene.⁶⁸

A “linkage” test involves comparing the patient’s gene and its DNA sequence to a “normal” version of the gene.⁶⁹ Linkage tests can be difficult to administer because researchers must examine chromosome segments from several generations of a family to determine if the disease is genetic.⁷⁰ An example of a linkage test involves BRAC 1 and BRAC 2, the breast cancer genes. To determine if a woman carries either gene, doctors need to compare DNA samples from her immediate relatives who had breast cancer with the identified gene to search for a particular mutation.⁷¹ That mutation is then matched with the woman’s genes.⁷² If the woman’s genes match, and if her family has a history of breast and ovarian cancer, she has an 80% chance of developing breast cancer.⁷³ If the woman’s genes do not match, she may still develop breast cancer—because these genes account for only 5 to 10% of all breast cancer diagnoses.⁷⁴

Genetic testing can also be accomplished by a much more rudimentary—if not quite so accurate—method. By studying family histories, scientists can make predictions about a person’s genetic code.⁷⁵ The easiest cases are those of monogenetic disorders, such as Huntington’s or sickle-cell anemia.⁷⁶ Much more difficult to discern from genetic histories are polygenic disorders such as cancer or heart disease, since the link from genetic code to symptomatic disease is not as strong and more affected by environmental factors.⁷⁷

68. *Id.*

69. *Id.*

70. Lawrence Berkeley National Laboratory, What is Genetic Testing?, at <http://www.lbl.gov/Education/ELSI/Frames/genetic-testing-f.html> (last visited Apr. 9, 2004) (on file with the North Carolina Law Review).

71. The Cleveland Clinic, Genetics and Breast Cancer, 2003, at <http://www.clevelandclinic.org/health/health-info/docs/0300/0392.asp?index=4208> (last reviewed Dec. 21, 2001) (on file with the North Carolina Law Review).

72. *Id.*

73. *Id.*

74. *Id.*

75. Greely, *supra* note 10, at 1496.

76. *Id.*

77. See Denise Casey, *What Can the New Gene Tests Tell Us*, at http://www.ornl.gov/TechResources/Human_Genome/publicat/judges/judge.html (last visited Apr. 9, 2004) (on file with the North Carolina Law Review).

II. LAWS AND LEGISLATION THAT MAY IMPACT GENETICS AND EMPLOYMENT

As genetic testing for disease becomes more common, it remains important to consider how the tests are performed and what they can disclose. Monogenic disorders, though less common, are more likely to present themselves through actual symptoms.⁷⁸ Polygenic disorders are both more common than monogenic disorders but and less likely to be caused by genetic variance alone.⁷⁹ Employers may be interested in both forms of disorders as a means to distinguish among future employees. Various legislative possibilities for limiting discrimination against employees with potentially unfortunate genetic futures have been suggested. This Part of the Comment will examine current laws that may impact an employer's first decision in all three of the hypothetical scenarios set out above. As the law is today, can the employer refuse to hire these employees?

A. *Americans with Disabilities Act*

The Americans with Disabilities Act of 1990 was passed to ensure equal opportunity for people with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation.⁸⁰ Under the ADA, an employer may not ask for medical information prior to extending an offer to hire.⁸¹ Subsequently, an employer may conduct a medical examination and condition the commencement of work on satisfactory test results showing that the employee can perform the essential functions of the job.⁸² This exam, if required, must be given to all entering employees, regardless of disability, and the information collected must be treated as a confidential medical record.⁸³ The employer must demonstrate that the medical exam and inquiries related to disability are job-related and consistent with business necessity.⁸⁴ With test results in hand, the employer may screen out employees with disabilities if a reasonable accommodation⁸⁵ cannot

78. See Michael J. Smith, *Population-Based Genetic Studies: Informed Consent and Confidentiality*, 18 SANTA CLARA COMPUTER & HIGH TECH. L.J. 57, 64 (2001).

79. See LAURIE, *supra* note 9, at 94-97.

80. See Statement of President George Bush upon Signing S.933, 26 WEEKLY COMP. PRES. DOC. 1165 (July 30, 1990).

81. 42 U.S.C. § 12112(d)(2)(A) (2000).

82. See *id.* § 12112(d)(3).

83. *Id.*

84. *Id.* § 12112(d)(4)(A).

85. Under the ADA, making "reasonable accommodations" to the known physical or mental limitations of an otherwise qualified individual with a disability includes making

be created, or if the individual would pose a "direct threat" to the health or safety of other individuals in the workplace.⁸⁶ The ADA defines a "direct threat" as a "significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation."⁸⁷

To come under the protection of the ADA, a person must be disabled. The Act defines the term "disability" in three ways:

- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment.⁸⁸

The ADA is enforced and regulated in the workplace by the Equal Employment Opportunity Commission ("EEOC").⁸⁹ EEOC regulations and their interpretations, however, do not have the force of law absent a court ruling.⁹⁰ To bring a *prima facie* case of employment discrimination under the ADA, the plaintiff bears the burden of showing: "(1) he is a disabled person under the ADA; (2) he is otherwise qualified to perform his job; and (3) he suffered adverse employment action because of his disability."⁹¹ If a person is found to have a medical condition that does not rise to the level of a "disability," he would have no recourse under this Act if an employer refuses to hire him due to his medical condition.⁹² The ADA is "not a general protection of medically afflicted persons"; rather it protects those who are discriminated against because of a disability or "because their employer mistakenly believes them to be disabled."⁹³

changes in "ordinary work rules, facilities, terms, and conditions . . . to enable the disabled individual to work." *Vande Zande v. Wis. Dep't of Admin.*, 44 F.3d 538, 542 (7th Cir. 1995).

86. 42 U.S.C. § 12113(b).

87. *Id.* § 12111(3).

88. *Id.* § 12102(2).

89. *Id.* §§ 12116–12117.

90. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 479 (1999).

91. *Simms v. City of New York*, 160 F. Supp. 2d 398, 402 (E.D.N.Y. 2001).

92. *See, e.g., Sutton*, 527 U.S. at 494 (holding that petitioner's myopia did not rise to the level of a disability and refusing to apply the ADA).

93. *Christian v. St. Anthony Med. Ctr., Inc.*, 117 F.3d 1051, 1053 (7th Cir. 1997). In *Christian*, Judge Posner ruled that a woman's claim that she was fired either (1) because of the stigma of having hypercholesterolemia (an excessive amount of cholesterol) or (2) because her treatment for hypercholesterolemia was expensive, was deemed insufficient to support a claim under the ADA. *Id.* at 1052. The court held that a medical condition, in and of itself, does not bring a person within the ADA. *Id.* at 1053. For example:

Suppose that the plaintiff had a skin disease that was unsightly and also very expensive to treat, but neither the disease itself nor the treatment for it

EEOC regulations have interpreted genetic discrimination to come under the third definition of disability, being regarded as having such an impairment.⁹⁴ Clearly, the first two definitions would not apply.⁹⁵ An asymptomatic employee, an employee afflicted with a predisposition to disease but who is not currently suffering from any symptoms, is not, by definition, currently suffering from a physical or mental impairment. Additionally, the employee has no record of suffering from an actual physical or mental impairment. The EEOC claims, however, that employers may mistakenly see the employee as suffering from a genetic disease and, as such, discriminate against the employee.

The problem with the EEOC's position—besides the fact that no court has yet to affirm this judgment⁹⁶—is that employers are not actually misperceiving a current impairment, but rather they are

would interfere with her work. And suppose her employer fired her nevertheless, either because he was revolted by her disfigured appearance or because the welfare plan that he had set up for his employees was unfunded and he didn't want to incur the expense of the treatment that she required. Either way he would not be guilty of disability discrimination.

Id.

94. U.S. EEOC, Notice No. 915.002, Policy Guidance on Executive Order 13,145: To Prohibit Discrimination in Federal Employment Based on Genetic Information (July 26, 2000), available at 2000 WL 33407180.

95. However, the EEOC also asserts that someone with an altered gene associated with a severe disorder would be covered under the "actual disability" prong of the ADA, because an alteration in a gene causes "cellular and molecular changes leading to disturbances in cell function." *Id.* Under the rule of *Bragdon v. Abbott*, 524 U.S. 624, 641–43 (1998), the EEOC asserts that such an individual could transmit that altered gene to an offspring, and so may have a disability. *Id.* This construction is even more tenuous than the EEOC's interpretation of the "regarded as" prong, considering the recent rulings of the Supreme Court in *Toyota Motor Manufacturing* and *Sutton v. United Air Lines, Inc.* that narrowly defined a "major life activity" to an activity that causes a "substantial" limitation. See *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184, 195 (2002); *Sutton*, 527 U.S. at 489; see also Katherine R. Annas, *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams: Part of an Emerging Trend of Supreme Court Cases Narrowing the Scope of the ADA*, 81 N.C. L. REV. 835, 848 (2003) (noting that *Toyota* has overruled *Bragdon's* interpretation of a "major life activity" because the *Toyota* Court requires that such activities occur daily).

96. The EEOC has settled a case against Burlington Industries under this argument. See Press Release, EEOC, EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act (Feb. 9, 2001), at www.eeoc.gov/press/2-9-01-c.html (on file with the North Carolina Law Review); Press Release, EEOC, EEOC Settles ADA Suit Against BNSF for Genetic Bias (Apr. 18, 2001), at www.eeoc.gov/press/4-18-01.html (on file with the North Carolina Law Review). In that case, the company, without the consent or knowledge of the affected employees, tested employees for a gene for carpal tunnel syndrome. *Id.* After a complaint by those employees to the EEOC, the company settled for \$2.2 million. *Id.*

eliminating individuals who might develop a future impairment.⁹⁷ They understand quite well that the employee is not currently disabled but might become so in the future.⁹⁸ That statement is also true of any employee hired without a genetic test. For this reason and others to be discussed below, the predisposed but asymptomatic employee is probably not a covered individual for the purposes of the ADA.⁹⁹

At least one court has accepted that tests for predisposition for disease do not indicate that an employer is misperceiving a current impairment. In *EEOC v. Rockwell International Corp.*,¹⁰⁰ Rockwell required applicants to undergo a nerve conduction test prior to employment in order to discover which applicants were more likely to develop carpal tunnel syndrome.¹⁰¹ The prospective employees sought positions requiring constant repetitive motion.¹⁰² Applicants with abnormal test results were rejected.¹⁰³ In response, the EEOC filed suit on behalf of seventy-two job applicants rejected by Rockwell on the basis of abnormal nerve tests, alleging the company's policy violated the ADA.¹⁰⁴ Rockwell argued that it did not misperceive the applicants as disabled, and the district court agreed.¹⁰⁵ The Seventh Circuit affirmed the case on another basis—that the EEOC did not show any evidence that the claimants faced significant restrictions in their ability to meet the requirements of other jobs in the area.¹⁰⁶ Most significantly, the court did not challenge Rockwell's assertion that it did not misperceive the applicants as disabled.¹⁰⁷

In *Sutton v. United Air Lines, Inc.*,¹⁰⁸ the Supreme Court

97. Holt, *supra* note 14, at 473–75.

98. *Id.*

99. In dicta in *Bragdon*, Chief Justice Rehnquist discussed the “regarded as” prong in relation to an asymptomatic HIV patient:

[T]he “regarded as” prong requires a plaintiff to demonstrate that the defendant regarded him as having “such an impairment” (*i.e.*, one that substantially limits a major life activity). Respondent has offered no evidence to support the assertion that petitioner regarded her as having an impairment that substantially limited her ability to reproduce, as opposed to viewing her as simply impaired.

Bragdon, 524 U.S. at 658 n.1 (Rehnquist, C.J., concurring in part and dissenting in part) (citations omitted).

100. 243 F.3d 1012 (7th Cir. 2001).

101. *Id.* at 1014.

102. *Id.*

103. *Id.*

104. *Id.*

105. *Id.* at 1015.

106. *Id.* at 1018.

107. *Id.*

108. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 489 (1999).

explained exactly what it interprets the “regarded as” prong to entail: “(1) a covered entity mistakenly believes that a person *has* a physical impairment that substantially limits one or more major life activities, or (2) a covered entity mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities.”¹⁰⁹ The Supreme Court’s use of the word “has” suggests that the employer must believe that an employee is currently suffering from the genetic disease. If the employer does not have this belief, then the employee is not covered by the “regarded as” prong of the ADA.¹¹⁰

Under the hypothetical scenarios presented above, the potential employees were not afflicted with epilepsy at the time of the hiring decision. Rather, they carried genes predicting that they might develop epilepsy at some point in the future.¹¹¹ If an employer believed that an employee carrying an epilepsy gene was presently suffering from the disease, then that employee would likely be covered by the ADA. But in most cases, an employer should know that unless the employee is currently diagnosed with the disease, a genetic predisposition amounts to an increased likelihood of developing the disease at some time in the future, and nothing more.

If the Supreme Court finds that genetic predispositions fall under the “regarded as” prong, claimants may have difficulty proving that their genetic predispositions substantially limit one or more major life activities—or, in this case, that the employer misperceives that the employee is substantially limited in one or more major life activities. The Court has yet to rule on whether “working” is a significant daily activity and in fact has appeared hostile to this notion.¹¹² The Court

109. *Id.* at 489 (emphasis added).

110. *Id.*; see also *Giordano v. City of New York*, 274 F.3d 740, 749 (2d Cir. 2001) (holding that the decisive issue under the “regarded as” prong is the employer’s perception of the employee’s alleged impairment).

111. An employer looking at this situation may know that epilepsy affects about “[one] percent of the population[,] making it one of the most common neurological diseases.” See NCBI, GENES AND DISEASE, *supra* note 34. While epilepsy will vary in severity, all forms are marked by “recurring seizures resulting from abnormal cell firing in the brain.” *Id.* Mounting evidence also suggests that repeated seizures can harm the brain, causing changes that make future seizures more likely, or even causing death. See Linda Carroll, *Mounting Data on Epilepsy Point to Dangers of Repeated Seizures*, N.Y. TIMES, Feb. 18, 2003, at F5. “[T]o date, at least twelve forms of epilepsy have been found to possess some genetic basis.” NCBI, GENES AND DISEASE, *supra* note 34.

112. See *Sutton*, 527 U.S. at 492 (“Assuming without deciding that working is a major life activity.”); see also *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184, 200 (2002) (“Because of the conceptual difficulties inherent in the argument that working could be a major life activity, we have been hesitant to hold as much, and we need not decide this difficult question today.”). In *Toyota*, the Court declared that evidence that a plaintiff is

has ruled that a claimant must show more than inability to perform a particular job for a particular employer, as this is insufficient to render one disabled under the ADA.¹¹³

In *Sutton*, the Supreme Court considered whether twin sisters with myopia were disabled under the ADA after a potential employer refused to hire them as pilots because they did not meet sight standards without corrective lenses.¹¹⁴ The Court held they were not disabled (while assuming, but not deciding, that “working” is a major life activity) because the plaintiffs failed to prove that their vision condition precluded them from more than a position as a “global airline pilot.”¹¹⁵ “Because the position of [a] global airline pilot is a single job, this allegation does not support the claim that respondent regards petitioners as having a *substantially limiting* impairment.”¹¹⁶

Genetic predispositions may or may not limit an employee from practicing a particular class of jobs, assuming external presentment of the disease is likely. Epilepsy, as in the hypothetical scenarios, is one disease that would likely preclude a greater variation of positions than other diseases because of the risk of a seizure at an inconvenient time (for example, while driving a commuter bus). Other genetic diseases, such as myopia,¹¹⁷ are not generally seen as limiting, particularly where corrective lenses improve much of the disability.¹¹⁸ Depending on whether the Court takes a narrow or expansive view, however, epilepsy may not be considered limiting, particularly if it is correctable with medication. Employee Adam, with a predisposition

unable to perform repetitive work with hands and arms extended at or above shoulder levels is insufficient proof that the plaintiff is substantially limited in a major life activity. 534 U.S. at 201. Instead, the Court was concerned with whether the plaintiff's health problem “substantially limits” a “major life activity” which includes “those activities that are of central importance to daily life . . . a category that includes such basic abilities as walking, seeing, and hearing.” *Id.* at 197. This impairment must “prevent[] or severely restrict[] the individual from doing activities that are of central importance to most people's daily lives. The impairment's impact must also be permanent or long-term.” *Id.* at 198 (citing Regulations to Implement the Equal Employment Provision of the Americans with Disabilities Act, 29 C.F.R. § 1630.2(j)(2)(ii)-(iii) (2001)).

113. As the U.S. Supreme Court held in *Sutton*, “[t]he inability to perform a single, particular job does not constitute a substantial limitation in the major life activity of working.” *Sutton*, 527 U.S. at 493 (quoting 29 C.F.R. § 1630.2(j)(3)(i) (1998)).

114. *Id.* at 471.

115. *Id.* at 493.

116. *Id.*

117. “Myopia” is commonly known as nearsightedness. DORLAND'S DICTIONARY, *supra* note 6, at 1215.

118. In *Sutton*, the Court ruled that correctable conditions are not disabilities. *Sutton*, 527 U.S. at 488–89. The pilots' argument failed because the airline carrier had an uncorrected vision requirement, presumably for safety purposes. *Id.*

toward epilepsy, may be considered dangerous as an airline pilot. But as Employee Barbara demonstrates, Adam would not be considered so dangerous if he were an accountant, since an epileptic seizure in that position would be unlikely to put others in danger. Thus, the class of jobs from which Employee Adam may be excluded may not be so great that the Supreme Court would consider him disabled as that term is defined by the ADA.¹¹⁹

In his dissent in *Bragdon v. Abbott*,¹²⁰ Chief Justice Rehnquist stated that to find an asymptomatic HIV patient disabled because of a limited ability to reproduce and raise a child would, "taken to its logical extreme . . . render every individual with a genetic marker for some debilitating disease 'disabled' here and now because of some possible future effects."¹²¹ While that argument was made in dissent, in recent years, the majority of the Supreme Court has been extremely hostile to broadening the definition of disability.¹²²

When Congress passed the ADA, it expected the Act to apply to more than 43 million Americans with one or more physical or mental disabilities.¹²³ Congress did not intend for the Act to apply to everyone. In *Sutton*, the Court stated:

Because it is included in the ADA's text, the finding that 43 million individuals are disabled gives content to the ADA's terms, specifically the term "disability." Had Congress intended to include all persons with corrected physical limitations among those covered by the Act, it undoubtedly would have cited a much higher number of disabled persons in the findings.¹²⁴

The Court reaffirmed this position in *Toyota Motor*

119. However, the courts have often found epilepsy to be a disability. See, e.g., *Otting v. J.C. Penney Co.*, 223 F.3d 704, 711 (8th Cir. 2000) (finding epileptic plaintiff to be disabled); *Rowles v. Automated Prod. Sys., Inc.*, 92 F. Supp. 2d 424, 429 (M.D. Pa. 2000) (finding epileptic plaintiff to be disabled, despite being on medication for the illness). But see *Runkle v. Potter*, 271 F. Supp. 2d 951, 963 (E.D. Mich. 2003) (refusing a motion for summary judgment where a jury could find the plaintiff disabled).

120. 524 U.S. 624 (1998). In *Bragdon*, the Court found that having children was a major life activity; thus, an asymptomatic HIV patient was "disabled" and covered by the ADA. *Id.* at 640-41.

121. *Id.* at 661 (Rehnquist, C.J., concurring in part and dissenting in part) (arguing that reproduction is not substantially limited by an asymptomatic HIV infection and, even if it were, that it is not a "major life activity").

122. See, e.g., *Toyota Motor Mfg., Ky., Inc., v. Williams*, 534 U.S. 184, 197 (2002) (holding that the term "disability" needs to be interpreted strictly because of the legislative purposes of the ADA); *Sutton*, 527 U.S. at 487 (finding that Congress did not intend for all people with correctable conditions to come under the ADA).

123. 42 U.S.C. § 12101(a)(1) (2000).

124. *Sutton*, 527 U.S. at 487.

Manufacturing, Kentucky, Inc., v. Williams,¹²⁵ when it stated: “[T]hese terms need to be interpreted strictly to create a demanding standard for qualifying as disabled . . .”¹²⁶ In *Toyota*, the Court considered whether an employee with carpal tunnel syndrome was disabled when during her employment she could not do repetitive work requiring her to extend her arms at or above shoulder level for long periods of time.¹²⁷ The Court held that the employee’s problem did not rise to the level of a disability; instead, to be disabled, an individual must have a permanent or long term “impairment that prevents or severely restricts the individual from doing activity that are of central importance to most people’s daily lives.”¹²⁸

Every living person has some form of genetic predisposition for a disease.¹²⁹ If society begins regarding all genetic defects as disabilities, the ADA would have to be expanded, and this is something the Supreme Court does not seem prepared to do.¹³⁰ Allowing all genetic predisposition for disease to come under the ADA would weaken the Act and make it less meaningful for the 43 million Americans it was designed to help.

The dissent in the Seventh Circuit’s *Rockwell* decision raised the issue of employer perception of disability and condemned the idea that an employer could refuse to hire an employee currently not disabled, but who may become disabled in the future.¹³¹ As discussed earlier, in *Rockwell* the EEOC brought suit for applicants who failed nerve conductive tests designed to test for a predisposition to carpal tunnel syndrome.¹³² The court held that there was no evidence as to whether the prospective employees were foreclosed from an entire class of jobs or just those requiring frequent repetition or the use of vibrating power tools.¹³³ In her dissent, Judge Wood stated:

I note that this assumption [that nerve testing predicts carpal tunnel syndrome] was at best highly dubious, and certainly a contested point of fact. And it is not at all clear to me that as a matter of law the ADA permits an employer to refuse to hire a person who is fully qualified to perform certain work, simply

125. *Toyota*, 534 U.S. 184.

126. *Id.* at 197.

127. *Id.* at 184.

128. *Id.* at 185.

129. Holt, *supra* note 14, at 485.

130. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 487 (1999).

131. *EEOC v. Rockwell Int’l Corp.*, 243 F.3d 1012, 1018–19 (Wood, J., dissenting) (7th Cir. 2001).

132. *Id.* at 1014.

133. *Id.* at 1017–18 (Wood, J., dissenting).

because that individual might at some unspecified time in the future develop a physical or other disability that would render her unable at that later date to meet the employer's reasonable expectations. This smacks of exactly the kind of speculation and stereotyping that the statute was designed to combat.¹³⁴

Judge Wood's criticism applies directly to genetic discrimination. Yet, an employer might respond to Judge Wood's dissent by arguing that hiring someone who is predisposed to develop carpal tunnel syndrome from working with vibrating machines would be both negligent and would allow a defense under the ADA: the direct threat.¹³⁵ While the ADA defines "direct threat" as a threat to others, recent EEOC regulations have redefined it as a "threat to self or others."¹³⁶ This definition was ruled consistent with the ADA by the Supreme Court in *Chevron U.S.A. Inc. v. Echazabal*.¹³⁷ There, the Court considered whether an oil refinery could refuse to hire a man with a liver condition that might become worse in such an environment.¹³⁸ The Court held that the EEOC regulation was consistent with the language and purpose of the ADA.¹³⁹ Additionally, the Court held that given an individual fact-finding by the company on this employee's disability, it could refuse to hire him.¹⁴⁰ The Court in *Chevron* decided this was not an impermissible use of paternalism as decried by the framers of the ADA.¹⁴¹ Further, the Court noted that Chevron was right to worry about the risk of violating the Occupational Safety and Health Act of 1970,¹⁴² and to have been concerned about time lost to sickness, excessive turnover, litigation under state tort law, and moral concerns.¹⁴³

The question for genetic predisposition is just how "direct" a "direct threat" must be to qualify for the exception. Under at least one court's interpretation, a "slightly increased risk" is not enough to constitute a "direct threat" for purposes of ADA employment

134. *Id.* at 1018–19 (Wood, J., dissenting).

135. 42 U.S.C. § 12113(b) (2000).

136. 29 C.F.R. § 1630.15(b)(2) (2002) ("The term 'qualification standard' may include a requirement that an individual shall not pose a direct threat to the health or safety of *the individual* or others in the workplace." (emphasis added)).

137. 536 U.S. 73, 86–87 (2002).

138. *Id.* at 76–77.

139. *Id.* at 87.

140. *Id.*

141. *Id.* at 85–86.

142. Occupational Safety and Health Act of 1970, Pub. L. No. 91-596, 84 Stat. 1590 (codified as amended at 29 U.S.C. § 651 (2000)).

143. *Chevron*, 536 U.S. at 84–85.

discrimination action.¹⁴⁴ Instead, the court found “there must be a high probability of substantial harm.”¹⁴⁵ Such a finding is unlikely to occur with a predisposition for a genetic disease, except for monogenic, dominant disorders such as Huntington’s disease that are nearly guaranteed to someday occur.¹⁴⁶ Therefore, if the present ADA applied to genetic predispositions, employers would have a difficult time determining such things as what percentage of risk would qualify as a “high probability.” When an employee with a predisposition for epilepsy applies to be an airline pilot, the employer may have to choose between being subject to an employment lawsuit by the pilot or a negligent hiring lawsuit after some form of accident.¹⁴⁷

Privacy advocates usually suggest that an employee with a genetic predisposition could be tested repeatedly, thus catching in time the newly-symptomatic epileptic prior to any bad results.¹⁴⁸ But employers and the public should not have to take that risk. Even if most diseases would not appear suddenly, an employer would always have to wonder how often testing is necessary—an expensive and dangerous proposition. This raises other questions, such as whether an employee who knows he is becoming symptomatic would be liable for fraud to the employer or negligence to anyone injured. Otherwise, an employee would have little reason other than his own safety to self report because of the risk of job loss after the reporting.¹⁴⁹ Clearly, a better model is needed if the ADA is to apply to genetic predispositions.

Other current laws may be useful against genetic discrimination, but they are as flawed as the ADA. The following Part will discuss some of these laws.

B. Executive Order 13,145

As a stopgap measure to prevent genetic discrimination, President Bill Clinton issued Executive Order 13,145 on February 8,

144. *Simms v. City of New York*, 160 F. Supp. 2d 398, 407 (E.D.N.Y. 2001).

145. *Id.*

146. See *supra* notes 48–56 and accompanying text.

147. See Samantha French, *Genetic Testing in the Workplace: The Employer’s Coin Toss*, 2002 DUKE L. & TECH. REV. 0015, ¶¶18–23 (Sept. 5, 2002), at <http://www.law.duke.edu/journals/dltr/articles/2002dltr0015.html> (on file with the North Carolina Law Review).

148. See Kim, *supra* note 14, at 1540 (explaining that airline pilots undergo routine medical screenings).

149. Clearly, someone who was both a symptomatic epileptic and an airline pilot would be a direct threat to the health of the public and to him or herself.

2000.¹⁵⁰ Executive Order 13,145 prohibits the use of “protected genetic information,” including information from genetic tests, information about genetic tests of the individual’s family, and information about the occurrence of disease within that family.¹⁵¹ Federal employers may not use such information to:

[D]ischarge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges or employment of that employee, because of protected genetic information with respect to the employee, or because of information about a request for or the receipt of genetic services by such employee.¹⁵²

Additionally, the employing department may not use such information to deprive the employee of employment opportunities, request or require such information, or disclose protected genetic information with respect to the employee.¹⁵³ The Executive Order provides for very limited exceptions to these general rules.¹⁵⁴ An employer may request or require protected genetic information if the request is consistent with the Rehabilitation Act¹⁵⁵ and if it is used only to diagnose a current disease that could prevent the employee from performing the essential functions of the position.¹⁵⁶ Genetic monitoring of the biological effects of toxic substances in the workplace is permitted if an employee has given knowing and voluntary consent and if the employer learns of test results only in aggregate terms that “do not disclose the identity of specific employees.”¹⁵⁷ The Order also purports to place no limitations on the “statutory authority of a Federal department or agency to . . . promulgate or enforce workplace safety and health laws and regulations.”¹⁵⁸

150. Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000), *reprinted as amended in* 42 U.S.C.A. § 2000e-16 (West Supp. 2003).

151. *Id.*

152. *Id.*

153. *Id.* The Executive Order does allow the employing department to release such information to the employee who is the subject of the information, at his request, or to an occupational or health researcher in certain conditions, or if required by a court order. *Id.*

154. *Id.*

155. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355, §§ 501, 505. The Rehabilitation Act prohibits employment discrimination against people with disabilities by federal employers. *Id.*

156. Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000), *reprinted as amended in* 42 U.S.C.A. § 2000e-16 (West Supp. 2003).

157. *Id.*

158. *Id.*

This last statement appears, however, to be false. As discussed in *Chevron*, the company was worried about violating OSHA regulations¹⁵⁹ by employing persons who had predispositions to health damage when exposed to certain chemicals.¹⁶⁰ Under this Executive Order, if the company was a federal employer, the company would have been able to test employees in the aggregate for genetic changes, but could not, even given poor results, learn the test results of individual employees. Further, this Order appears to contradict the EEOC's interpretation of the "direct threat" defense. It would appear that this Order would prevent an employer from learning whether an employee has a predisposition to a disease, such as epilepsy, that could cause a direct threat. Therefore, the Order is over-inclusive because it ties employers' hands in their efforts to create a safe workplace. But it is also under-inclusive: executive orders apply only to federal government employers, so they have little effect on the majority of employers. In other words, Adam and Barbara may or may not be covered by the Executive Order—depending on whether they are federal employees—and Charles could choose to run the risk of epileptic seizures and be paid for it.

C. Title VII

Under Title VII of the Civil Rights Act of 1964,¹⁶¹ it is unlawful for an employer to base employment decisions, such as hiring or firing, on an individual's race, color, religion, sex, or national origin.¹⁶² Prior to its passage, employment was seen as a private contract between the employer and employee.¹⁶³ The Act was enacted, *inter alia*, to help raise the status of African-Americans, whose economic inferiority had become a pressing public policy issue.¹⁶⁴ Today, an anti-discrimination norm has broad acceptance, including the belief that an employer should not discriminate on the basis of race or sex because those characteristics reveal little about how an employee will perform a job.¹⁶⁵

Title VII, as currently written, appears to be an ineffective tool

159. The Occupational Safety and Health Administration is a division of the U.S. Department of Labor. The Occupational Safety and Health Act of 1970, 29 U.S.C. § 651 (2000), requires employers to provide a safe and healthful workplace, free of recognized hazards. *Id.*

160. *Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73, 84–85 (2002).

161. 42 U.S.C. §§ 2000e to 2000e-17 (2000).

162. 42 U.S.C. § 2000e-2(a) (2000).

163. Kim, *supra* note 14, at 1515–16.

164. *Id.*

165. *Id.*

to deter genetic discrimination. Few diseases have been found to correspond closely with race, sex or national origin.¹⁶⁶ The case may be made that if an employer discriminates based on a predisposition to sickle cell anemia, a disease closely associated with African-Americans, or with Tay-Sach's disease, a disease closely associated with Ashkenazi Jews,¹⁶⁷ then that employer is actually discriminating based on race or religion. But not all carriers of sickle cell anemia are African-American, nor are all carriers of Tay-Sach's Jewish. Thus, it would seem that, on its face, Title VII, as currently written, has little utility for combating genetic discrimination.

Some commentators support amending Title VII to include genetic discrimination.¹⁶⁸ One commentator argues that Title VII is a more appropriate legal remedy for genetic discrimination than the ADA, because the ADA allows employers to discriminate based on a disability if the employer can show some degree of danger to the applicant.¹⁶⁹ Further, defining genetic predispositions as a disability creates misperceptions and stereotypes surrounding individuals with impairments, thus creating fear about genetic information.¹⁷⁰ For employers, amending Title VII would afford them the opportunity to avoid the ADA's reasonable accommodations requirement, so an applicant with a genetic predisposition would be free to make employment decisions regardless of potential health risks, and an employer would be free to disregard necessary accommodations for the applicant as a result of those risks.¹⁷¹

However, these arguments in favor of amending Title VII illustrate why amending Title VII is not appropriate. Employers should be able to consider whether a job poses a health risk to an applicant. Defining some genetic predispositions as disabilities does not necessarily stigmatize those who have predispositions that may become disabling. Employers should have to make reasonable accommodations for those who have disabilities as defined by the

166. Feldman & Katz, *supra* note 3, at 406.

167. Gina Kolata, *Using Genetic Tests, Ashkenazi Jews Vanquish a Disease*, N.Y. TIMES, Feb. 18, 2003, at F6.

168. See Holt, *supra* note 14, at 481-84 (supporting amending Title VII by adding genetics to the statute).

169. *Id.* at 481.

170. See *id.* at 482.

171. *Id.* at 483; see also *Int'l Union, United Auto, Aerospace and Agr. Implement Workers of Am. v. Johnson Controls*, 499 U.S. 187, 198-99, 206-07 (1991) (holding that it was illegal under Title VII for a company to refuse to hire women based on the fact that the risk of the female employees' infertility was too great, particularly where male infertility was also at risk due to exposure to lead).

ADA, unless such accommodations are unreasonable or the job poses a direct threat to the applicant, other employees, or the public.

Furthermore, a genetic predisposition is not quite like race, color, or national origin.¹⁷² A genetic predisposition, while determined before birth and beyond an individual's control, may supply some useful information that employers need to know in order to help workers and ensure the general public safety.¹⁷³ Furthermore, anti-discrimination legislation protecting against genetic discrimination does not redress systematic historical injuries, as is the case with legislation prohibiting race discrimination.¹⁷⁴ Enactment of Title VII punishes those who discriminated in the past for an irrational reason, and theoretically it imposes no more costs on an employer than making any employment decision would.¹⁷⁵ Title VII makes an employer hire an employee who, but for the past systematic discrimination, would be the same as any other employee.¹⁷⁶ Genetic discrimination, however, is more like the ADA in that it makes an employer hire an employee who is not the same as any other employee and, in fact, may need a costly accommodation to perform the required tasks.¹⁷⁷ Thus, legislation such as the ADA that would ban genetic discrimination may create allocation difficulties: employers who had nothing to do with causing or creating an individual's genetic code must hire those who are more likely to become disabled in the future, and by so doing, increase the cost for these employers relative to their competition.¹⁷⁸ Title VII, unlike the ADA, does not contain any exceptions for direct threat or compelling business necessity. Employers would fare worse under a modified Title VII that simply banned the use of genetic information in hiring decisions. The potential benefits of controlled genetic discrimination of employees, such as for safety reasons, would be eliminated if genetic discrimination is added to Title VII. As Title VII currently stands, it does not apply to, or help, Adam, Barbara, or Charles.

172. See Kim, *supra* note 14, at 1520–23 (explaining that genetic predispositioning does not arouse the same kind of concerns as racial hatred of disfavored groups). But see Holt, *supra* note 14, at 477–83 (advocating for a Title VII amendment because “[a] genetic predisposition is similar to race, color and national origin”).

173. See Kim, *supra* note 14, at 1521 (noting that “variations in an individual's genetic material may provide information that is highly relevant to job performance”).

174. *Id.* at 1522.

175. *Id.* at 1518–19.

176. *Id.*

177. See Justin Nelson & Samuel Issacharoff, *Discrimination with a Difference: Can Employment Discrimination Law Accommodate the Americans With Disabilities Act?*, 79 N.C. L. REV. 307, 353–57 (2001).

178. *Id.*

D. State Law

At least thirty-two states have enacted statutes against using genetics in employment decisions.¹⁷⁹ For example, Massachusetts enacted chapter 151B,¹⁸⁰ which prohibits: refusals to hire based on genetics; soliciting of genetic information; administering genetic tests as a condition of employment; questioning about family histories; or terminating an employment relationship based on genetic information.¹⁸¹ Massachusetts does not allow exemptions to the act for worker and public safety or a direct threat defense.¹⁸²

Other states have legislation that is as wide ranging, although state laws “almost universally prohibit employers from making hiring, firing, or other employment decisions based on genetic information.”¹⁸³ Some states only prevent decisions based on DNA

179. See National Conference of State Legislatures, *supra* note 25; see also Feldman & Katz, *supra* note 3, at 390 (noting that twenty-six states have enacted anti-genetic discrimination employment laws); see, e.g., N.J. STAT. ANN. § 10:5-12(a) (West 2002) (making it unlawful to discriminate because of genetic information or atypical hereditary cellular or blood trait); N.Y. EXEC. LAW § 296.1(a) (McKinney 2003) (making it unlawful to discriminate based on genetic predisposition or carrier status); TEX. LAB. CODE ANN. § 21.402 (Vernon Supp. 2003) (making it unlawful to discriminate on the basis of genetic information or because an individual refused to take a genetic test).

180. The text of the Massachusetts statute is as follows:

SECTION 23A. Said section 4 of said chapter 151B, as so appearing, is hereby further amended by adding the following subsection:

19. (a) It shall be unlawful discrimination for any employer, employment agency, labor organization, or licensing agency to

(1) refuse to hire or employ, represent, grant membership to, or license a person on the basis of that person's genetic information;

(2) collect, solicit or require disclosure of genetic information from any person as a condition of employment, or membership, or of obtaining a license;

(3) solicit submission to, require, or administer a genetic test to any person as a condition of employment, membership, or obtaining a license;

(4) offer a person an inducement to undergo a genetic test or otherwise disclose genetic information;

(5) question a person about their genetic information or genetic information concerning their family members, or inquire about previous genetic testing;

(6) use the results of a genetic test or other genetic information to affect the terms, conditions, compensation or privileges of a person's employment, representation, membership, or the ability to obtain a license;

(7) terminate or refuse to renew a person's employment, representation, membership, or license on the basis of a genetic test or other genetic information; or

(8) otherwise seek, receive, or maintain genetic information for non-medical purposes.

MASS. GEN. LAWS ANN. ch. 151B, § 4 (West 2000).

181. See *id.*

182. *Id.*

183. See Feldman & Katz, *supra* note 3, at 411; see, e.g., ARIZ. REV. STAT. § 41-1463,

tests; other states prohibit gathering information on employees' families.¹⁸⁴ Where states do not completely ban the use of genetic information, employers may not condition employment on consent to submit to a genetic test or to supply genetic information.¹⁸⁵ Some states allow genetic testing for reasons of business necessity, to determine a bona fide occupational qualification, or to investigate a worker's compensation claim.¹⁸⁶ Other states allow employers to discharge employees if the employer can show that the employee's genetic makeup may put them at greater risk for illness because of the particular occupational environment.¹⁸⁷ Some states refuse to allow employers to take adverse employment action based on test results, no matter what the results mean to worker safety.¹⁸⁸

Inconsistent state law has led some commentators to propose both model state legislation¹⁸⁹ and model federal legislation.¹⁹⁰ Current state law approaches are flawed because they are inconsistent in their definitions of what is protected and in their remedies for employers.¹⁹¹ A federal approach is needed to provide employers, particularly employers with multi-state operations, with certainty, and to provide the critical controls and exceptions for safety. While states serving as laboratories may be useful in other contexts, a federal approach to regulating the use of genetic information in employment is necessary to protect all workers

B.3 (2004) (prohibiting discrimination based on genetic tests received by the employer); NEV. REV. STAT. 613.345 (2000) (prohibiting employers from requiring genetic tests as a condition of employment).

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

185. See OKLA. STAT. tit. 36 § 3614.2(C) (1999).

186. See IOWA CODE § 729.6(7) (1993).

187. See OR. REV. STAT. § 654.227(6) (1999).

188. See IOWA CODE § 729.6(7) (1993); see also Feldman & Katz, *supra* note 3, at 412–16. For example, section 296 of the New York Executive Law provides “statutory protection preventing adverse actions by employers based on the test results.” *Id.* at 418 (citing N.Y. EXEC. LAW § 296(19)(c)).

189. Feldman & Katz, *supra* note 3, at 424–27 (proposing a model statute “designed to protect employees’ rights to keep genetic information private and beyond their employers’ reach”).

190. See generally Kathryn E. Cox et al., *Model Act for Genetic Privacy and Control*, 88 IOWA L. REV. 121 (2002) (developing a model act on use of genetic information).

191. See ARIZ. REV. STAT. § 41-1463, B.3 (barring only employer genetic testing); ME. REV. STAT. ANN. tit. 5 § 19302 (West, Supp. 2000) (barring both employer testing and employer use of genetic information); MO. REV. STAT. § 375.1306 (Supp. 2001) (allowing an employer to use genetic information when it is directly related to ability to do a job); OKLA. STAT. tit. 36 § 3614.2(C) (prohibiting use of genetic testing on information as a condition of employment or continuual employment); see also Feldman & Katz, *supra* note 3, at 412–16 (noting variations in state laws and the need for a comprehensive federal approach).

equally. Furthermore, the field of genetics and the scientific concepts surrounding it are complicated. Therefore, a uniform federal approach would allow employers, employees, and other interested parties involved in the discussion to speak the same language. Because state law is so varied, it is unclear whether it applies to Adam, Barbara, or Charles.

E. Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act of 1996 ("HIPAA")¹⁹² is designed primarily to protect the privacy of health information, but it also prohibits insurance carriers from engaging in genetic discrimination.¹⁹³ The statute helps to prevent individuals who transfer from one job to another from losing health insurance because of a genetic defect.¹⁹⁴ HIPAA, however, does not apply to employment discrimination, and thus, as enacted, would not help an employer decide whether to hire an individual with a genetic predisposition. HIPAA could make an employer who provides its own group health plan think twice about hiring an employee with a serious genetic predisposition, because the employer could not hire the employee and fail to provide health insurance for such an employee. Additionally, HIPAA provides incentives for fewer employers to offer health insurance to workers because of the inability to discriminate based on genetic predispositions.¹⁹⁵ Clearly, HIPAA does not help Adam, Barbara, or Charles because HIPAA does not apply to employment discrimination.

F. Pending Legislation

The Genetic Information Nondiscrimination Act of 2003¹⁹⁶ ("Act") purports to prohibit employers from refusing to hire or discharging any individual because of protected genetic information or to classify such employees in a way that limits employment opportunities.¹⁹⁷ Further, the Act prevents employers from requesting or collecting protected genetic information except to

192. Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of 26, 29, and 42 U.S.C.).

193. 29 U.S.C. §§ 1001-1461 (2000); see Feldman & Katz, *supra* note 3, at 406-07.

194. 29 U.S.C. §§ 1001-1461.

195. See Taradash, *supra* note 17, at 1381-82 (noting that "HIPAA does not prohibit employers from refusing to offer health coverage as part of their benefits package").

196. Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. § 202 (2003), available at <http://thomas.loc.gov>.

197. *Id.*

monitor biological effects of toxic workplaces, and then only if the employees have provided informed consent and the employer receives the results only in aggregate terms that do not disclose the identity of specific employees.¹⁹⁸ Thus, this legislation suffers from some of the same problems plaguing the Executive Order and some state statutes: it does not provide the employer a “direct threat” defense, nor does it allow an employer to focus on individual employees who have a predisposition for a genetic abnormality aggravated by the occupational environment, a standard that may be required for the employer to remain in compliance with its OSHA obligations.¹⁹⁹ Furthermore, the pending legislation falls into the trap of genetics exceptionalism, where genetic information is treated as superior to ordinary health information. Thus, the Act may be wide-reaching, but it is not the best solution for employers or employees.

Under the Act, Adam could end up dying of a seizure while flying a plane and Charles could someday learn of the increased likelihood of epilepsy. Barbara is probably helped by the legislation, because an employer could not ask her about her disability, but this legislation is clearly inadequate, particularly as to public safety.

III. PROPOSED REMEDIES AND THEIR IMPACT

Commentators proposing remedies to potential genetic discrimination fall into several clearly divided philosophical camps. Most commentators believe that the ADA as written does not provide protection for genetic predispositions.²⁰⁰ They often agree that other legislation presently enacted is also inadequate, such as inconsistent state laws and the limited usefulness of Title VII to the few genetic diseases most commonly associated with race or sex. Some commentators advocate a model statute that would preclude the use of genetics in hiring, firing, and other employment decisions as an appropriate mechanism to eradicate genetic discrimination.²⁰¹

198. *Id.*

199. Occupational Safety and Health Standards § 1910, U.S. Dept. of Labor, available at http://www.osha.gov/pls/oshaweb/owastand.display-standardgroup?p_toc_level=1+p_part_number=1910.

200. See Kim, *supra* note 14, at 1515; Taradash, *supra* note 17, at 1368–69. But see Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL’Y 225, 265 (2000) (arguing that the ADA does protect against the misuse of genetic information by employers).

201. See Cox et al., *supra* note 190, at 121; Feldman & Katz, *supra* note 3, at 425–27. Another problem with a model statute is its future interpretation. The ADA has a decade of legal interpretation—albeit controversial—to lend credence to its potential applicability to prohibit genetic discrimination. New statutes, by definition, have none, and are even

Many others subscribe to either a privacy model or an economic efficiency model, and argue for particular solutions based on their ideological positions.

A. *The Privacy Model*

At least one commentator has argued for a privacy model which would forbid employers from asking for or using an employee's genetic information.²⁰² The commentator argues that the risk of misuse by employers is too great because employers will equate predispositions with actual diseases.²⁰³ Employers will avoid hiring people with predispositions for diseases with more severe symptoms.²⁰⁴ More particularly, use of any genetic information threatens individual autonomy because it takes employment choices away from the individual, while absolute privacy would help safeguard that autonomy.²⁰⁵ As a more practical matter, genetic predispositions are not always as obvious as race or sex. Thus, if employers have access to any genetic information, proving unlawful use of that information will be very difficult. A privacy model alleviates this concern because discrimination on the basis of genetic traits "becomes impossible."²⁰⁶

Despite these arguments, a pure privacy model is not the best solution for employers *or* employees. Employees may wish to tell an employer about their favorable genetic condition, as a way to sell themselves to their employer.²⁰⁷ If we deny the relatively genetically healthy employee the ability to tell an employer about his genetic condition, we disadvantage that employee.²⁰⁸ Hypothetically, if this practice became common, employees who remain silent about their genetic condition (because the law allows them to do so) may be presumed by their employers to have a poor genetic predisposition. Additionally, this solution ignores the benefits of the genomics revolution, such as allowing an employer to protect worker safety through advance knowledge of future illness. It also ignores the fact that inefficient allocation of information, where the employee knows of a poor prognosis but the employer does not, could harm both the

more likely to be attacked under the theory of "genetics exceptionalism," discussed *infra* Part III.C.

202. See Kim, *supra* note 14, at 1543.

203. *Id.* at 1534.

204. See *id.* at 1534–35.

205. *Id.* at 1537.

206. *Id.*

207. See Taradash, *supra* note 17, at 1378.

208. *Id.*

employment and insurance markets.²⁰⁹ The privacy model does not allow for progressive policies to protect fellow workers, the public or the employee himself from situations in which the employee's health could be at risk. Failing to provide such protections, even though the science is readily available, could further open the employer up to accusations of negligent hiring, violations of OSHA, and increased worker's compensation problems, in addition to the loss of productivity.²¹⁰ As for the difficulties in claims of genetic discrimination, just because something is hard to prove does not necessarily make it a bad law.²¹¹ Congress could modify the ADA or Title VII if it believes that plaintiffs are facing too much difficulty in proving their cases; however, Congress has yet to do this.

B. *The Economic Model*

Some commentators argue that genetic discrimination legislation should not be enacted because it destroys market efficiency.²¹² Under the economic model, anti-discrimination legislation interferes with the freedom to contract and prohibits both the employer and the employee from making the most efficient decisions possible.²¹³ Further, anti-discrimination legislation such as the ADA creates negative allocation effects by putting too much strain on some employers but not others.²¹⁴ The use of anti-discrimination law would increase the total amount of expenditures for dealing with genetic discrimination beyond what it would cost to provide subsidies to the

209. See *id.* at 1383–86 (arguing that just as an asymmetry of information reduces the quality and quantity of goods available in the open market, a similar result will occur with an asymmetry of information in health insurance). But see Greely, *supra* note 10, at 1489 (discounting the notion that asymmetrical information may limit health coverage to many people or that use of genetic information is likely in employment decisions).

210. See generally French, *supra* note 147 (discussing the possibilities of negligent hiring, negligent retention, negligent entrustment and OSHA responsibilities). For example, it may be negligent hiring for a trucking company to hire an epileptic employee because a trucking company must determine the risk that its employees pose to third parties. *Id.* ¶18. Similarly, it may be negligent retention to continue employing such an employee as a truck driver if he has suddenly developed epilepsy. *Id.* ¶19. Negligent retention claims are based on the employer's duty to retain "fit and competent" employees. *Id.*

211. For example, medical causation is often hard to prove, but unless the United States moves to a no fault system, it remains important in assigning liability in medical negligence cases.

212. See Diver & Cohen, *supra* note 29, at 1462 (arguing for the efficiency gains of a "transparency regime"); Epstein, *supra* note 28, at 9 (referring to asymmetrical information as a "fraud" on the employer); Taradash, *supra* note 17, at 1382 (arguing for economic efficiency).

213. Epstein, *supra* note 28, at 21.

214. See *id.*

genetically unfortunate and tax breaks to the employers who hire them.²¹⁵ Moreover, an anti-discrimination approach may also lead “to the adoption of general and neutral rules that are inefficient for the employer and society at large.”²¹⁶ For example, instead of spending money to make workplaces safe for all employees, it is more efficient if the workers who would be particularly affected by the work environment are simply not hired.

However, these commentators admit that the most genetically unfortunate would likely be penalized under this model.²¹⁷ Therefore, in exchange for facing this discrimination, these commentators argue that these individuals should receive subsidies from the “public purse.”²¹⁸ More specifically, “the government should fund the additional costs associated with hiring or insuring individuals with genetic defects,”²¹⁹ and perhaps even provide a public job so that individuals can do useful work for society.²²⁰

Like the privacy model, the economic model also has its problems. Allocation efficiency is not always the most worthy goal. On its face, this model seems to most disadvantage those with the poorest genetic predispositions because those who want to work may not be able to find an employer who is willing to hire them. Proponents of this position often argue that we should transform health and insurance systems to provide universal health care because, without employment, it is likely that those with the poorest predisposition will also lack health insurance.²²¹ Providing universal health insurance has not happened yet, and it is unlikely to ever happen considering both the historic budget deficit²²² and the history of health care reform in the United States.²²³ Unlike Canada and Great Britain, the United States has never had a nationally-subsidized

215. *See id.*

216. *Id.* at 21–22. For example, making factory improvements to reduce the exposure of benzene for every worker would likely cost a great deal more than removing the one worker with a special sensitivity to it.

217. *Id.* at 20.

218. *Id.* at 21.

219. *Id.* at 21; *see also* Taradash, *supra* note 17, at 1354 (arguing that the “voluntary submission of genetic information” by employees would be “exchanged in consideration for certain benefits”).

220. *See* Diver & Cohen, *supra* note 29, at 1482 (arguing that subsidies must be provided for genetic justice, perhaps taking the form of direct cash payments on public jobs).

221. Taradash, *supra* note 17, at 1382 n.164.

222. Edmund L. Andrews, *Congressional Deficit Estimate May Exceed a Half-Trillion*, N.Y. TIMES, Aug. 26, 2003, at A17 (discussing the United States economic projections).

223. Rothschild, *supra* note 29 (discussing the failure of President Clinton’s health care plan).

health care system and movements to start such a system have not been successful.²²⁴ While universal health care might be the best solution, it is not something upon which this Comment depends in constructing a possible solution to genetic discrimination today.

C. *The ADA Model*

A few commentators would agree with this Comment's position that the ADA can be modified to supply the answer to the problem of how to deal with the use of genetic information in employment, but these commentators do not usually specify who should be covered under the ADA.²²⁵ This failure gives rise to criticism known as "genetics exceptionalism."²²⁶ Genetics exceptionalism refers to making an irrational decision that if a person has a genetically-based disease they should be protected by the ADA or other legislation, but not if their disease is environmentally based.²²⁷ Genetics exceptionalism is an argument also lodged against stand-alone genetics discrimination legislation such as the Genetic Information Nondiscrimination Act.²²⁸ Recall that ordinary illness is not a disability and, as such, is not protected by the ADA. The solution offered in this Comment takes this problem into account by treating a genetic illness the same as an environmentally-based illness. Additionally, opponents of modifying the ADA argue that the Act is unfair because it places burdens on private employers with disabled employees applying for jobs.²²⁹ Thus, opponents contend that the risk spreading of the ADA is inconsistent and unfair to private employers.²³⁰

Furthermore, some commentators oppose modifying the ADA

224. *Id.*

225. See Diver & Cohen, *supra* note 29, at 1481.

226. See generally Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 671 (2001) (arguing for more comprehensive, genetic-specific legislation to avoid the "spiral of genetics exceptionalism").

227. See Deborah Hellman, *What Makes Genetic Discrimination Exceptional?* 29 AM. J. L. & MED. 77, 80–81 (2003).

228. See *id.* (revealing that critics argue that laws that "define genetic discrimination as discrimination on the basis of the results of a test of a person's genetic material, such as an examination of DNA . . . [,] will fail to capture many instances of discrimination on the basis of genetic predisposition to disease").

229. See *supra* notes 212–20 and accompanying text.

230. For example, the minimum wage is also an unfunded mandate on employers, but since it applies to all employers, the risk is spread. Whereas, under the ADA, one employer may be put at a disadvantage as to other employers because of the need to make accommodations for a disabled employee. See Nelson & Issacharoff, *supra* note 177, at 348–51.

because the Act, with its direct threat defense, is open to claims of “paternalism.”²³¹ Paternalism essentially means making choices for others in order to help them, without considering whether the individual involved desires that help.²³² The concept is generally used to defend policies such as requiring seatbelt or helmet use, the contract doctrine of unconscionability, and any other court decisions that suggest the State is making decisions for an individual’s own good, without considering whether the individual would agree.²³³ In *Chevron*, the plaintiff alleged that application of the “direct threat” standard to the facts of his case would inappropriately engage in paternalism of the sort forbidden by the ADA.²³⁴ But as the Supreme Court in *Chevron* noted, allowing an interpretation of direct threat that did not include the individual employee is not the sort of paternalism that Congress attempted to curtail.²³⁵ Instead, it is only rational—and consistent with OSHA—to allow employers to take into consideration, after an individual determination, whether a specific job might be harmful because of that employee’s health condition.²³⁶ Just as an innocent bystander does not want a high-rise worker with vertigo²³⁷ working above him, so should a rational employee with vertigo show concern for his own health by refusing such a job.

However, without paternalistic legal intervention in the case of genetic predispositions, employees may be willing to take increased

231. See Holt, *supra* note 14, at 481.

232. See JOHN KLEINIG, PATERNALISM 13 (1984). Paternalism can be defined as “X acts paternalistically in regard to Y to the extent that X, in order to secure Y’s good, as an end, imposes upon Y.” *Id.*

233. See generally Paul Burrows, *Analyzing Legal Paternalism*, 15 INT’L REV. L. & ECON. 489 (1995) (looking at areas of the law that appear to have paternalistic intent and measuring them against a law and economics model). Burrows defines paternalist legal interventions as those that “deliberately interfere with people’s freedom of choice, for example, the freedom to choose to consent to an injury inflicted by another person, or the freedom to sell a right.” *Id.* at 491.

234. See *Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73, 85 (2002). The ADA was designed to root out irrational, paternalistic decisions by employers that certain disabled employees could not perform a specific job, rather than to require an employer to ignore specific and documented risks to the employee himself, even if that employee would be willing to take such risks. *Id.* at 86.

235. *Id.* at 85–86.

236. See Occupational Safety and Health Act of 1970, Pub. L. No. 91-596, 84 Stat. 1590 (codified as amended at 29 U.S.C. § 651 (2000)); Feldman & Katz, *supra* note 3, at 396–97 (noting that employers may test employees for hypersensitivity to certain toxins).

237. “Vertigo” is defined as dizziness characterized by a spinning sensation. Mayo Clinic Staff, *Dizziness*, at <http://www.mayoclinic.com/invoke.cfm?id=DS00435> (Oct. 10, 2002) (on file with the North Carolina Law Review).

risks with their health.²³⁸ Thus, where employment is on the line, employees may be more likely to take unreasonable risks if allowed to do so.²³⁹ It is hard to predict an accident or the magnitude of injury from an accident.²⁴⁰ When such an underestimation occurs, “people will take risks that they would have been unwilling to take if they had had full information and had been able to process the information efficiently.”²⁴¹ Therefore, even though the occupational environment may be harmful, an employee may still be willing to take a job if he believes that any accidents that may occur will not involve him. Further, for at least two accident risk scenarios it has been well established that people fail to understand their own risk: where people feel they are in control of the risk and imagine that owing to exceptional skill in risk avoidance they will not suffer; or where cognitive dissonance induces a pretense that one is not facing a serious risk because of other characteristics of that activity, including a high income or excitement.²⁴²

But even the anti-discrimination statutes, as written, practice a form of paternalism by making employees learn whether they carry a genetic predisposition that would be a direct threat. As one commentator has noted, some individuals may prefer not to know their genetic predisposition:

The situation might be seen as analogous to the problem of the incapax. The individual who is incapax cannot choose for herself and so choices must be made for her. In the same way, the individual who is ignorant of genetic information might be seen as a pseudo-incapax, and therefore it might be assumed that it is legitimate to make choices about the genetic information on her behalf. . . . It is far from clear, however, how one would determine an individual's best

238. Bohrer, *supra* note 29, at 760; see Burrows, *supra* note 233, at 500.

239. See Bohrer, *supra* note 29, at 761. Bohrer has an interesting discussion on the application of John Rawls's philosophy to this question, noting that “risk ostriches”—those who refuse to learn their genetic predispositions—and “non-risk adverse” individuals will, by taking these risks, cause harm both to themselves and their loved ones. *Id.* According to Bohrer, “[b]argaining for freedom under such circumstances is bargaining for the acceptability of such avoidable losses and the costs that they impose on others. . . . I think the rational bargainers would determine that their self-interest actually provides a sufficient incentive to limit their future freedom to inflict avoidable losses on others.” *Id.*

240. See Paul Slovic, *Rational Actors and Rational Fools: The Influence of Affect on Judgment and Decision-Making*, 6 ROGER WILLIAMS U. L. REV. 163, 180–85 (2000); see also Burrows, *supra* note 233, at 500 (noting instances where paternalistic laws deal with safety measures because risk is hard for an individual to determine).

241. Burrows, *supra* note 233, at 500.

242. *Id.*

interests concerning genetic information.²⁴³

Therefore, if we do not want the government determining an individual's best interests with respect to genetic information, perhaps the employer should be able to learn the result of genetic tests without informing the employee of the result. This would necessarily happen with the employee's consent—plus a release of liability—assuming the employer uses good faith in determining whether the employee has a condition that would be impacted by the work environment. Legislation or laws, including some state statutes and Executive Order 13,145, that require employers to make available to employees their test results may be seen as a reverse violation of privacy, and paternalistic in their own way by reducing autonomy in learning health care information.²⁴⁴ Despite claims to the contrary, paternalism is not only unavoidable, but also is not necessarily the evil it is often made out to be.

D. A Modest Proposal

A possible solution to all these problems exists that would both avoid genetics exceptionalism and protect individuals with poor genetic futures. Congress should modify the ADA to stop discrimination against individuals predisposed to a disease that, if symptomatic, would be covered by the ADA in most symptomatic individuals.²⁴⁵ The EEOC could promulgate regulations designating which diseases are most likely to be found disabling based on a scientific risk analysis of an individual's predisposition becoming symptomatic. These regulations would require an individualized genetic assessment be conducted to analyze the nature of the risk of symptomatic genetic disease, the likelihood that symptoms cannot be controlled or corrected by medication, and the likelihood of actual disability percentage associated with a symptomatic form of the

243. LAURIE, *supra* note 9, at 204.

244. See, e.g., Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. § 202 (2003), available at <http://thomas.loc.gov> (stating that if employers are allowed to request or collect genetic information to use for biological effects of toxic substances, employers are required to inform the employee of individual monitoring results). There is also an argument that any consent to receive such information should be greeted skeptically because "in many contexts and especially in those of employment and insurance, the individual from whom consent is to be obtained is in a substantially weaker position than the party seeking consent." LAURIE, *supra* note 9, at 205.

245. See Mark A. Rothstein et al., *Using Established Medical Criteria to Define Disability: A Proposal to Amend the Americans With Disabilities Act*, 80 WASH. U. L.Q. 243, 282–96 (2002) (developing a list of diseases that typically fall under the ADA).

disease.²⁴⁶ For instance, an individual with epilepsy is covered by the ADA in most cases, even if the epilepsy can be mostly controlled by medication, because epilepsy usually affects major life activities.²⁴⁷

In addition to this modification, the Act should unambiguously allow employers to refuse to hire an applicant if the applicant's disease is such that if symptomatic the applicant would be barred from that particular job because of a direct threat to the applicant or to others. This modification would allow sensible results for Adam, Barbara, and Charles. In the cases of Adam, the airline pilot predisposed to epilepsy, or Charles, the oil refinery worker whose epilepsy could be made more likely by exposure to oil, both would be covered under the ADA—but, for both, the employer would be allowed a refusal to hire because of a direct threat. In the case of Barbara, the accountant predisposed to epilepsy, the ADA would also apply but, unlike the situation with Adam or Charles, the employer would not be allowed a refusal to hire on the basis of Barbara's genetic predisposition because she would be considered "genetically disabled."

For those with genetic predispositions that would not normally come under the ADA when symptomatic, the employer would be allowed to choose whether to employ the individual without implicating the ADA. This result may seem harsh at first, because of the narrow conditions the Supreme Court has placed on the definition of disability.²⁴⁸ In fact, the great majority of people with predisposed genetic diseases probably would not be able to argue that their case came under the protection of the ADA. This result, however, provides a quid pro quo for the employer: in exchange for taking on those employees with the most potentially dangerous genomes (assuming no direct threat), the employer is assured that the government will not interfere with other employment decisions as would be the case under the other models.

Where an employee is predisposed to a disease that would not generally be considered a disability when symptomatic, such as a condition that can be corrected with medical treatments, the ADA

246. For example, Congress could set a predisposition risk percentage above which the law applies, such as ten percent risk or perhaps a two-fold increase in risk over the general population. For a discussion regarding general principles of genetic risk assessment, see RIMOIN ET AL., *supra* note 8, at 654–74. Until genetic information becomes more certain, the percentage should be low so as to make the Act apply to a greater number of employees with potential unfortunate genetic futures.

247. Rothstein et al., *supra* note 245, at 289.

248. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 487–89 (1999).

would not apply. These conditions, by definition, are likely to be of lesser scope, insurance cost, and hardship to both the employer and the employee. Therefore, the employer would have less reason to discriminate against them in the first place. Because most employees (and their employers) have some form of genetic abnormality, the employer would likely find negligible the differences between employees with readily fixable or inconsequential illnesses. The costs of hiring (from advertising the position to medical testing) would become too great if employers fixated on finding the "perfect" genetic employee.

Results under this statutory construction are also less likely to be as harsh as one may initially suspect. Theories of cognitive behavioralism suggest that when an employer has full information about the genetic predispositions of more than one employee, the employer would be less likely to discriminate against the majority of less than severe genetic predispositions.²⁴⁹ One researcher looked at the "notion of evaluability" to explain the interplay between the precision of an emotional impression and its meaning for decision-making.²⁵⁰ The researcher asked people to assume they were music majors looking at a used music dictionary.²⁵¹ One dictionary had 20,000 definitions, but a tattered cover.²⁵² A second dictionary had 10,000 definitions, but was like-new.²⁵³ When subjects evaluated both dictionaries simultaneously, subjects were willing to pay more for the larger, tattered dictionary.²⁵⁴ But when the dictionaries were evaluated separately, subjects were willing to pay more for the smaller, like-new dictionary.²⁵⁵ This scientist argues that:

[W]ithout a direct comparison, the number of entries is hard to evaluate, because the evaluator does not have a precise notion of how good or how bad 10,000 (or 20,000) entries are. . . . Evaluability can thus be seen as an extension of the general relationship between the variance of an impression and its weight in an impression—formation task.²⁵⁶

This theory suggests that if an employer knows only one thing

249. See Slovic, *supra* note 240, at 175–77 (discussing an experiment concerning the notion of evaluability).

250. *Id.*

251. *Id.* at 175.

252. *Id.*

253. *Id.*

254. *Id.*

255. *Id.*

256. *Id.* at 175–76.

about an employee, i.e., his genetic predisposition, the employer will have difficulty evaluating the significance of that attribute. Further, cognitive behavioralism theory suggests that if a specific concept has a negative feeling associated with it, then that feeling may overcome logic suggesting that the possibility of the negative event is unlikely.²⁵⁷ For instance, other research in the field finds that the perception of risk and society's response to risk is strongly linked with "the degree to which a hazard evoked feelings of dread."²⁵⁸ Scientists have discovered that activities associated with cancer are seen as riskier and in more need of regulation than activities associated with less dreaded causes of ill health, such as accidents.²⁵⁹ Thus, to counteract the feelings of dread an employer may feel upon learning that a potential employee has a genetic predisposition to lung cancer, the employer must also know that other prospective employees have a genetic predisposition to diabetes, heart disease, epilepsy, or other diseases.²⁶⁰

The perceived risk of employing a particular person is likely to lessen as an employer's belief of benefit associated with that employment increases.²⁶¹ Under cognitive theory, when a person likes an activity, he or she is likely to judge the risks as low and the benefits as high, but when the person dislikes it, to judge the risk as high and the benefits as low.²⁶² This suggests that any risks of real genetic discrimination may be more likely to fall on lower-skilled workers than on higher-skilled workers.²⁶³ Employers of higher-skilled workers will likely have fewer potential applicants to choose from, and will likely view choosing the most-highly skilled applicant as more important than worrying about a potentially poor genetic predisposition.²⁶⁴ And, if the real risks lie with lower-skilled workers, then, until genetic testing is as simple as getting one's genome microarrayed on a chip, employers are less likely to make an investment in investigating a lower-skilled worker's genetic identity—except for

257. *Id.* at 179–80.

258. *Id.* at 180.

259. *Id.*

260. *Id.*

261. *Id.* at 182.

262. *Id.* at 181.

263. Indeed, one case concerning genetic discrimination involved low-skilled workers at Burlington Industries suing for unconsented genetic tests as to carpal tunnel syndrome. *See supra* note 96.

264. Of course, this would not be true for the most dangerous predispositions because that would likely overcome the employer's positive feeling for the benefits of the employee, and greatly increase the employer's worry about risk.

specific occupational diseases such as in the case of *Chevron*²⁶⁵ or *Rockwell Industries*.²⁶⁶ In those cases, this model would find such employees not to be covered because of the direct threat to themselves. Additionally, employers of lower-skilled workers may be less worried about genetic diseases because of a belief that most workers change jobs regularly, and thus the onus of any genetic disease will fall on some other employer.

Rationally, an employer should be unlikely to discriminate based on genetics because everyone has some potential genetic disease in their background. For an employer to differentiate between an employee with potential heart disease and an employee with potential diabetes would not make much sense because both are potentially chronic illnesses. Each employee that is screened and rejected costs the company money. And, if the employer acts irrationally, the potential employee can look for another position. It is not illegal for employers to act irrationally when making employment decisions, and it should not become so.²⁶⁷

As for genetics exceptionalism, consider the case of two workers, one with a genetic predisposition to a disease, and one without. Once the disease becomes symptomatic, both workers will have mild illnesses along with weakness and loss of sensation in their extremities—one the result of a genetic disease and the other due to environmental causes.²⁶⁸ By banning discrimination based on genetic diseases, without anything more, one worker is seemingly more protected than the other, unless the non-genetically diseased worker can show that her condition constitutes a “disability” under the ADA. But because the courts interpret that term narrowly, workers with mild physical ailments are not considered “disabled.”

Under this Comment’s proposed restructuring of the ADA, this apparently unfair result would not occur. If the genetic disease was generally known to cause a “disability” under the ADA, the worker with the genetic predisposition would be protected up until the time the disease becomes symptomatic. The worker without the genetic predisposition would not have to worry about genetic discrimination prior to the manifestation of the disease. After the manifestation of the disease, traditional ADA interpretation would apply to both: if the disease has mild physical symptoms, then there would be no

265. *Chevron v. Echazabal*, 536 U.S. 73 (2002).

266. *EEOC v. Rockwell Int’l Corp.*, 243 F.3d 1012 (7th Cir. 2001).

267. See Hellman, *supra* note 227, at 85 (“In employment law, by contrast, there is no general requirement of rational behavior.”).

268. See Kim, *supra* note 14, at 1510.

protection for either. If the disease has severe physical symptoms that limit a major life activity, then there would be protection for both. This modification to the ADA serves to put a worker in as good a position as he or she would have been in—but for the genetic predisposition—unless such a predisposition is not generally known to cause disability. In those cases, an employer is less likely to discriminate in the first place, or be able to argue a business necessity for such discrimination.

The primary problem with this model is that under current law, the Supreme Court has emphasized that an ADA inquiry is based on an individual assessment of the disease and its impact on a major life activity.²⁶⁹ By applying the ADA to presymptomatic genetic diseases, that inquiry is obviously not possible—no one knows how debilitating the disease will be once it becomes symptomatic. It is possible that someday science will have a better idea of how a disease will manifest itself, based on genetics alone, but until then, the ADA will have to be modified to provide for the results detailed above.

Therefore, based on the benefits of allowing employers some access to specific genetic information, but in order to deter genetic discrimination against those affected the most by unfortunate genetic predispositions, this Comment proposes the following changes to the ADA:

Section 12102 Definitions of disability:

Additions in italics: *(D) A genetic predisposition for a disease that if symptomatic would likely be covered by this Act, provided the likelihood of future illness is greater than ten percent.*

Section 12111 Definitions:

Additions in italics: The term “direct threat” means a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation. *In the case of a genetic predisposition, a “direct threat” may include any disease that if symptomatic would likely pose a direct threat to the employee or to others, provided the likelihood of future illness is greater than ten percent.*

The change to section 12102 makes clear that genetic predispositions for diseases that normally are disabling would be covered by the ADA. The change to section 12111 makes clear that

269. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 483–84 (1999).

employers can use the “direct threat” defense against these same genetic predispositions, but only for diseases that could cause harm to the individual or others within the occupational environment. Including a threshold of ten percent—or some other scientifically significant number—would both limit claims of disability for predispositions that are extremely unlikely to ever occur and provide a form of individualized inquiry as previously required by United States Supreme Court precedent.²⁷⁰

CONCLUSION

As written, the ADA most likely does not cover genetic discrimination, nor are other current laws useful in preventing this form of discrimination. State laws are extremely varied, providing inconsistent results. Proposed federal legislation would not allow employers to make workplaces safer by both screening individuals for genetic predispositions that may be harmful to that individual or to others and letting the employer know which employees are most affected. Many commentators have proposed various models for dealing with these problems, but each model has its own limitations. The privacy model would ignore the benefits provided by the genomic revolution, and the economic efficiency model would harm the most genetically unfortunate. Other anti-discrimination statutes fail because they elevate genetic information above all else, thus potentially treating two workers with the same disease differently.

By modifying the ADA to forbid genetic discrimination of employees who would likely be considered disabled if symptomatic, this Comment provides a workable middle ground. Additionally, this model allows employers to retain use of information that may make workplaces safer. Genetics should not be looked at as exceptional when compared to other employee illnesses, and this model provides that answer.

JENNIFER CHORPENING

270. *See id.*