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Comment

Creating A Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry

I. Introduction

Imagine the following: you are a healthy individual, married to a healthy spouse, with healthy children. You attempt to purchase health insurance coverage for yourself and your family. As a prerequisite to eligibility, the insurance company requires both you and your spouse to submit to a variety of genetic tests.¹ Because you are both in good health and have never suffered from serious illness, you feel confident that there is no reason for concern. Therefore, you both freely consent to the simple blood tests.² Neither you nor your spouse are aware of any history of

1. According to the American Council of Life Insurance Medical Section Committee on Genetic Testing, "[g]enetic tests are laboratory tests used to determine the presence or absence of abnormal or defective genes and/or chromosomes. Such tests are direct measures of such defects or abnormalities, as opposed to indirect manifestations of genetic disorders." AMERICAN COUNCIL OF LIFE INSURANCE AND HEALTH INSURANCE ASSOCIATION OF AMERICA, REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING 1991 2 (1991) [hereinafter ACLI-HIAA TASK FORCE]. Genetic tests employ various technologies to detect pre-existing genetic traits, changes in chromosomes, or changes in deoxyribonucleic acid (DNA), the chemical bearer of genetic information. OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 3 (1990) [hereinafter GENETIC MONITORING]. See *infra* Part II for a further discussion of DNA; and *infra* note 2 for a discussion of the various tests. Genetic testing by insurers involves screening individuals to identify particular inherited traits or disorders. See NEIL HOLTZMAN, PROCEED WITH CAUTION 193-200 (1989).

2. Today, DNA tests are administered through a variety of diagnostic techniques. OFFICE OF TECHNOLOGY ASSESSMENT, MEDICAL TESTING AND HEALTH INSURANCE 18 (1988) [hereinafter MEDICAL TESTING]. Because DNA is present in all body cells, it can be easily extracted from blood and stored for an indefinite period. GENETIC MONITORING, *supra* note 1, at 78. In prenatal genetic tests, fetal cells are obtained through amniocentesis.

illness within your families. Unfortunately, the test results show that you are a carrier of the DNA marker³ that indicates a predisposition to lung cancer.⁴ Faced with the prospect that you may develop lung cancer and become an economic drain through huge medical costs, the insurance company denies coverage to you and even to your family because of the possibility that your children may carry the gene. Your family is left without health insurance, despite the fact that you have not manifested any symptoms of the disease and your children have not been tested to determine if they even possess this risk-laden genetic make-up.

In November, 1991, Earvin "Magic" Johnson announced his early retirement from professional basketball because he had tested positive for the human immunodeficiency virus (HIV).⁵ The announcement provoked disbelief at Johnson's tragedy and controversy at Johnson's disclosure that he became infected from "messing around with too many women."⁶ Amidst the uproar, one fact seemed forgotten; a fact that underlies this trag-

DAVID SUZUKI & PATRICK KNUDTSON, *GENETHICS: THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES* 148 (1990). Because most DNA-based tests for genetic disorders are technically difficult, costly to perform, and are sometimes unreliable, widespread use of genetic testing is limited. *MEDICAL TESTING*, *supra*, at 19. Most blood tests are limited to biochemical profiles that are derived from analyzing a battery of twelve or more tests per blood sample. *Id.* at 122. *See generally id.* at 121-41 (explaining technical background of HIV screening). *See also* *GENETIC MONITORING*, *supra* note 1, at 77-95 (discussing the technical molecular background behind genetic testing). Diagnostic tests offered by biotechnology firms range in price anywhere from \$200 to \$980 per test, and can rise as high as \$3000. *Id.* at 95; Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 *AM. J.L. & MED.* 109, 116 (1991) [hereinafter *Genetic Discrimination*]. For example, the test for Huntington's disease costs \$450 per sample. *GENETIC MONITORING*, *supra* note 1, at 95. *See infra* Part II for a further discussion of diagnostic tests administered by biotechnology firms.

3. Genetic tests identify diseases by isolating a "marker," an "unusual DNA sequence that is believed to be inherited with a disease causing gene." DOROTHY NELKIN & LAURENCE TANCREDI, *DANGEROUS DIAGNOSTICS* 27 (1989). Markers are detected through techniques that fragment DNA drawn from blood cells so that the region on a chromosome where a defective gene is located can be identified. *Id.*

4. Lung cancer is the leading cause of cancer death among Americans. *GENETIC MONITORING*, *supra* note 1, at 91. There is evidence of various genetic defects that contribute to the development of cancer. Environmental exposures such as smoking may exacerbate this condition. *Id.*

5. Richard W. Stevenson, *Magic Johnson Ends His Career, Saying He Has AIDS Infection*, *N.Y. TIMES*, Nov. 18, 1991, at A1.

6. Harvey Araton, *Players, Temptation and AIDS*, *N.Y. TIMES*, Nov. 10, 1991, § 8, at 11.

edy and is telling of the direction technology is leading our society. Johnson did not decide to submit to an acquired immune deficiency syndrome (AIDS) test because of his personal concern of infection, rather he consented to an AIDS test along with several other tests as part of a routine annual procedure mandated by his insurance company.⁷ Johnson's experience reflects the growing use of diagnostic testing by insurance companies to screen applicants for eligibility and rate-setting purposes.⁸ Johnson is fortunate that his public figure status sets him apart from the rest of society, and he probably does not have to worry that this discovery may threaten his insurance coverage. The majority of society does not enjoy the same economic status as Johnson, and the potential for abuse by insurance companies that use diagnostic testing as a tool for profit is greater than ever before.

Genetic researchers are continuously unearthing secrets of the human body that seem to indicate that the course of life does not lie with fate, but rather with inherited human qualities that are determined long before birth.⁹ New diagnostic tests that probe DNA sequences for the genetic markers of diseases that are inherited through families can predict illnesses long before they are clinically manifested.¹⁰ Hundreds of genetic markers have been identified that indicate an inherited predisposition not only to physical and mental illness, but to physical and personality traits.¹¹ Diagnostic genetic tests can provide enormous

7. Stevenson, *supra* note 5, at B12.

8. See Nancy E. Kass, *The Ethical, Legal and Social Issues Concerning the Use of Genetic Tests by Insurers: Toward the Development of Appropriate Public Policy* (January 1992) (manuscript available from National Institutes of Health, National Center for Human Genome Research).

9. See Rick Weiss, *Bio-Menace: Genetic Discrimination*, WASH. POST, Feb. 19, 1989, at D3.

10. NELKIN & TANCREDI, *supra* note 3, at 4.

11. To date, thousands of hereditary genes have been discovered. These include: the gene associated with Huntington's chorea, a fatal, degenerative disease that affects the brain; the gene associated with neurofibromatosis, or "Elephant Man's Disease;" and the gene associated with cystic fibrosis, a debilitating lung disease that was first discovered through "mapping" of family history. OFFICE OF TECHNOLOGY ASSESSMENT, *MAPPING OUR GENES; GENOME PROJECTS: HOW BIG, HOW FAST?* 134-35 (1988) [hereinafter *MAPPING OUR GENES*]; Natalie Angier, *Scientists Discover the Gene in a Nervous System*, N.Y. TIMES, July 30, 1990, at A1, col. 2; Sandra Blakeslee, *Scientists Find Hope for Victims of Cystic Fibrosis by Discovering its Gene*, N.Y. TIMES, Aug. 24, 1989, at B13, col. 1. See *infra* Part II notes and accompanying text for a more expansive discussion of genetic mapping. Genetic structures associated with common illnesses such as heart disease, various forms

benefits, including early detection of predisposition to illness that creates an opportunity for preventive care.¹² Identifying and understanding the DNA sequences of disease-causing genes will also lead to discoveries of cures and new preventive treatments. Prenatal screening for genetic disorders provides parents with a choice of whether to raise a child with an untreatable disease.¹³ In nonclinical settings, genetic tests can provide legal evidence of an individual's criminality¹⁴ or provide early detection of learning disabled children.¹⁵

Despite all the apparent benefits associated with genetic information, it also carries "potential for social detriment."¹⁶ Genetic testing raises serious concerns that the identification of an individual's predisposition to illness may be used in ways that harm the individual. The insurance industry, employers, and the government all have an "immediate or potential interest in promoting large-scale genetic screening to identify" those individuals who carry genetic disorders.¹⁷ This is particularly true in the clinical setting, where genetic information may reduce or prevent access to health care through the loss of insurance. In this setting, testing becomes a means of identifying those individuals who are potentially at risk for future illness, and therefore present a potential insurance risk. Critics charge that insurance

of cancer, and emphysema have also been located. See John Carey, *The Genetic Age*, Bus. Wk., May 28, 1990, at 68; see generally Benjamin S. Wilfond, *The Cystic Fibrosis Gene: Medical and Social Implications for Heterozygote Detection*, 263 JAMA 2777 (1990) (discussing the background and regulation of screening for cystic fibrosis); Gina Kolata, *Scientists Pinpoint Genetic Changes That Predict Cancer*, N.Y. TIMES, May 16, 1989, at C1 (reviewing genetic research into particular kinds of cancer); Shannon Brownlee & Joanne Silberner, *The Assurances of Genes*, U.S. NEWS AND WORLD REP., July 23, 1990, at 57 (describing Huntington's chorea).

12. NELKIN & TANCREDI, *supra* note 3, at 7. Among the benefits are "disease prevention through genetic counseling, and treatment of the disorders through genetic manipulation." *Genetic Discrimination*, *supra* note 2, at 110.

13. NELKIN & TANCREDI, *supra* note 3, at 7.

14. *Id.* at 151. DNA tests are currently used in the courts to establish the identity of suspects in criminal cases when the key evidence is biological material such as blood or semen. Diagnostic tests are also used to provide evidence that correlates violent behavior with brain abnormalities. *Id.* See also Andrea De Gorgey, *The Advent of DNA Databanks: Implications for Information Privacy*, 16 AM. J.L. & MED. 381 (1990).

15. Carey, *supra* note 11, at 78.

16. *Genetic Discrimination*, *supra* note 2, at 110.

17. Paul S. Billings, *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 476 (1992).

companies may abuse genetic tests to legitimate arbitrary exclusionary practices that "enhance institutional power with little regard for the rights . . . of individuals."¹⁸ Thus, insurance companies may rely on genetic tests to deny access to health insurance, shifting the burden to the government to take care of the health care bill for the uninsured.¹⁹

In this age of genetic wizardry, genetic testing is a double-edged sword. It allows for early diagnosis and treatment of diseases and disorders, and possibly even their elimination. However, the social, medical, and legal issues surrounding the use of genetic tests are of a dimension not yet realized. In the field of health insurance, genetic testing threatens to infringe upon individual rights because it can be used to separate individuals into "insurable" and "uninsurable" groups.²⁰ Insurers may use genetic markers as a basis for denying coverage or determining rates and eligibility unfairly. "The fact that genetic diseases are sometimes closely associated with discrete ethnic or racial groups such as African Americans,²¹ Ashkenazi Jews²² or Armenians²³ compounds the potential for discrimination."²⁴ In addition, if insurance eligibility is tied to the results of genetic testing, individuals will seek confidentiality for the results of these tests. Genetic testing raises serious concerns about discrimination,²⁵ the right to privacy, and whether the legal world is prepared to confront these issues before their impact is widely felt.

This Comment will examine genetic research and its poten-

18. NELKIN & TANCREDI, *supra* note 3, at 8.

19. Kass, *supra* note 8, at 1.

20. The terms "insurable" and "uninsurable" connote separate insurance pools which are distinguished according to insurance risk classifications. See *infra* Part III for a discussion of insurance risk classification.

21. Sickle cell disease. *Genetic Discrimination*, *supra* note 2, at 111 n.9.

22. Bloom's Syndrome, Gaucher's disease, or Tay-Sachs disease. *Id.* at 111 n.10.

23. Family Mediterranean Fever. *Id.* at 111 n.11.

24. *Id.* at 111.

25. It is important to distinguish between insurers mandating genetic testing and insurers having access to genetic information. ACLI-HIAA TASK FORCE, *supra* note 1, at 8. The use of mandatory genetic tests by insurers for determining eligibility is remote, however, genetic testing is increasingly performed by clinicians. It is this information that insurers currently have an incentive to know about. *Id.* See *infra* Part IV.B. discussing adverse selection.

tial impact on health insurance.²⁶ Part II profiles the historical background behind this issue and the technologies used. Part III outlines the basic principles underlying insurance risk classification. Part IV addresses the potential for abuse of genetic testing by both insurers and private citizens. Part V examines current legislation to determine whether the law recognizes a right to confidentiality in genetic testing and whether existing legislation invites discrimination against genetically tested individuals. Current legislation is also evaluated to determine whether genetic testing by third parties violates existing statutes and whether analogies can be drawn to statutes that protect other groups at risk. Part VI proposes possible reforms to confront the implications of genetic testing. Part VII concludes that a ban on the use of genetic information for health insurance underwriting is needed to protect individuals from genetic discrimination.²⁷

II. Background

Before the profound legal and social effects of genetic testing can be appreciated, it is necessary to understand the basic principles of the technology and its application. The Human Genome Project²⁸ is a massive²⁹ international research initiative

26. Genetic testing also has a potential impact on life insurance. However, some of the strongest concerns about genetic testing focus on the accessibility and availability of health insurance. See ACLI-HIAA TASK FORCE, *supra* note 1, at 4. The ACLI-HIAA Task Force report presumes such fervor arises over health insurance because "life insurance is not perceived as an entitlement to the same extent as health insurance." *Id.* Although many of the issues raised in this Comment apply to both health and life insurance, this Comment will focus on health insurance. See generally MEDICAL TESTING, *supra* note 2.

27. Genetic discrimination is defined as "discrimination directed against an individual or family based solely on an apparent or perceived genetic variation from the 'normal' human genotype." Billings, *supra* note 17, at 476.

In a recent study, Dr. Paul Billings of the California Pacific Medical Center compiled information regarding actual cases of genetic discrimination. *Id.* Forty-one separate incidents of discrimination were reported; thirty-two involved insurance discrimination and seven involved employment discrimination. *Id.* at 478. Many of the individuals in the study possessed a hereditary condition but were asymptomatic and healthy. *Id.*

28. The agencies involved with the research efforts on the human genome use different terminology to refer to these efforts. At the National Institutes of Health, the term is the "Human Genome Project." At the Department of Energy, it is the "Human Genome Program." Other references also include the "Human Genome Initiative." H.R. REP. NO. 478, 102nd Cong., 2d Sess. 7, n.9 (1992).

29. "[T]he scope of . . . [the Human Genome Project] would be unparalleled in the

to study and detail the genetic structure of human DNA.³⁰ The long-term goal of the project is to map and sequence the molecular structure of all human genes, including disease-causing genes hidden within the DNA structure.³¹ The research project, primarily funded by the United States, is scheduled to last at least fifteen years and cost an estimated three billion dollars.³² The two major United States government institutions sponsoring the genome project are the National Institutes of Health and the United States Department of Energy.³³ The genome project includes an unprecedented study of the social, legal, and ethical issues raised by genetic testing.³⁴

The structure of DNA was discovered in 1953 by Dr. James Watson, who won a Nobel Prize for his achievement.³⁵ DNA is a double helix structure,³⁶ partially composed of four nucleotide³⁷

history of the life sciences This [project is] among the ranks of such ambitious, goal-oriented Big Science projects of the past as the building of the first atomic bomb or sending astronauts to the moon." SUZUKI, *supra* note 2, at 316-17.

30. Elke Jordan, *Invited Editorial: The Human Genome Project: Where Did it Come From, Where is it Going?*, 51 AM. J. HUM. GENETICS 1 (1992). Although the United States was the first country to initiate research efforts, other programs are under way in the United Kingdom, France, the European Community, and Japan. *Id.*

31. A gene is a unit of hereditary information. MAPPING OUR GENES, *supra* note 11, at 21. The genome is the total genetic endowment packaged in the chromosomes. MEDICAL TESTING, *supra* note 2, at viii. The genome has also been defined as "[a]ll the genetic material in the chromosome of a particular organism; its size is generally given as the total number of base pairs." Jon Beckwith, *The Human Genome Initiative: Genetics' Lightning Rod*, 17 AM. J.L. & MED. 1, 2 n.8 (1991) (quoting United States Dep't of Health & Human Services and Dep't of Energy, *Understanding Our Genetic Inheritance, The U.S. Human Genome Project, The First Five Years, FY 1991-1995* 86 (1990)).

32. Jordan, *supra* note 30, at 1.

33. The United States Department of Energy began a genome research program in 1987. James D. Watson, *The Human Genome Project and International Health*, 253 JAMA 3322, 3323 (1990). Within the National Institutes of Health, the project is administered by the National Center for Human Genome Research. Smaller genome research projects are also under way at the United States Department of Agriculture and the National Science Foundation. Combined federal funding for these programs exceeded \$85 million in 1990. *Id.*

34. Jordan, *supra* note 30, at 4. Three areas earmarked for ethical study are: "privacy of genetic information, protection from discrimination based on genetics, and safe introduction of genetic tests into mainstream medical practice." *Id.*

35. Dr. Watson headed the National Institutes of Health's Genome Project until April 10, 1992, when he resigned over concerns regarding his investments in biotechnology firms. *Head of Federal Gene Research Agency Resigns*, L.A. TIMES, Apr. 11, 1992, at A18.

36. Each molecule of DNA is composed of two separate DNA strands that are held together by weak hydrogen bonds. SUZUKI, *supra* note 2, at 32. The two strands coil

bases: guanine (G), cytosine (C), adenine (A), and thymine (T).³⁸ The bases occur in pairs, and the arrangement of these pairs is defined as the sequence.³⁹ The sequence of the base pairs in the DNA encodes the genetic information.⁴⁰ Thus, the encoded genetic information can be described by sequences of base pairs such as GCATGTATCCTGTA.⁴¹

The base pair sequences that make up DNA are used by the body to manufacture proteins.⁴² In its simplest form, a sequence is "read" by the body, which generates messenger ribonucleic acid (RNA).⁴³ Messenger RNA is then decoded by the cell to form proteins.⁴⁴ Proteins, such as enzymes and hormones, control body activities and functions.⁴⁵ Thus, the genetic code establishes traits that are passed from one generation to the next.⁴⁶

The human body carries fifty to one hundred thousand genes.⁴⁷ A human gene can vary in size from less than ten thousand base pairs to more than two million.⁴⁸ The human genome consists of approximately three billion base pairs strung along the forty-six human chromosomes.⁴⁹ The Human Genome Project aims to ultimately map the sequence of all three billion base pairs that make up the human genome.⁵⁰

The first step to mapping a gene is charting the location of

together like a spiral staircase to form the double helix. *Id.*

37. A nucleotide is a molecular subunit. *Id.*

38. OFFICE OF TECHNOLOGY ASSESSMENT, *ROLE OF GENETIC TESTING IN PREVENTION OF OCCUPATIONAL DISEASE* 48 (1983) [hereinafter *ROLE OF GENETIC TESTING*]; SUZUKI, *supra* note 2, at 32. For a more detailed discussion, see generally HOLTZMAN, *supra* note 1, at 9-20. The bases are projected from each strand and act as "steps" that bridge the two strands. SUZUKI, *supra* note 2, at 32.

39. *MAPPING OUR GENES*, *supra* note 11, at 21.

40. Robert A. Weinberg, *The Dark Side of the Genome*, *TECH. REV.*, Apr. 1991, at 44.

41. *ROLE OF GENETIC TESTING*, *supra* note 38.

42. SUZUKI, *supra* note 2, at 34.

43. See generally *id.* at 34-95.

44. *ROLE OF GENETIC TESTING*, *supra* note 38, at 49.

45. *Id.*

46. *MAPPING OUR GENES*, *supra* note 11, at 3.

47. *Id.*

48. *Id.*

49. *Id.*

50. Jordan, *supra* note 30, at 1.

the gene on the chromosome.⁵¹ Genes are located by finding minor genetic variations, called polymorphisms, that occur throughout human DNA and act as markers.⁵² These markers are easily detected, and act as identifiable regions on a chromosome that are useful for locating nearby genes.⁵³ Creation of genetic linkage maps within families is accomplished by tracking variations in these genetic markers.⁵⁴ When parents have different forms of a marker, the linkage of the marker to a particular gene can be followed in the child.⁵⁵ Using family linkage studies, scientists can now locate a particular gene associated with a specific disease.⁵⁶

Genetic discoveries are not limited to disease-causing genes, but also include genes that belie a predisposition or susceptibility to a particular disease.⁵⁷ "Some common disease susceptibilities, such as heart disease or cancer, are correlated with an altered gene."⁵⁸ However, this correlation does not mean that all heart disease and cancer is related to such susceptibility genes.⁵⁹ The actual development of the disease is a result of a combination of factors, such as other genes and the environment.⁶⁰ The discovery of a genetic mutation associated with heart disease has made early detection a matter of life and death for carriers, who

51. SUZUKI, *supra* note 2, at 305.

52. MAPPING OUR GENES, *supra* note 11, at 27.

53. *Id.* A specific polymorphism may be associated with a gene variant that causes a disease. *Id.* at 28-30. These "linked polymorphisms" can then be used as indicators in predictive genetic tests. See Jason Brandt et al., *Presymptomatic Diagnosis of Delayed Onset Disease with Linked DNA Markers: The Experience in Huntington's Disease*, 261 JAMA 3108 (1989).

54. MAPPING OUR GENES, *supra* note 11, at 27.

55. *Id.* For a more complete description of genetic linkage mapping, see *id.* at 26-30. See generally Brandt, *supra* note 53.

56. NELKIN & TANCREDI, *supra* note 3, at 28. One of the oldest methods for studying human gene linkages is through the study of family histories. SUZUKI, *supra* note 2, at 307. By tracing a particular trait through a family tree, patterns of inheritance are detectable. *Id.* Single gene hereditary illnesses such as cystic fibrosis are the simplest to detect because they only require the location of one gene or its associated marker. ROLE OF GENETIC TESTING, *supra* note 38, at 51. There are currently over four thousand known single gene hereditary illnesses. E. Donald Shapiro, *Dangers of DNA: It Ain't Just Fingerprints*, N.Y.L.J., Jan. 23, 1990, at 1.

57. Beckwith, *supra* note 31, at 5.

58. *Id.*

59. *Id.*

60. *Id.*

can reduce the risk of developing the disease by changes in diet and exercise.⁶¹ Ultimately, genetic discoveries may unearth genetic susceptibilities to mental illnesses such as manic depression and schizophrenia, and to addictive behaviors such as alcoholism.⁶²

Genetic isolation of several diseases has resulted in easy identification of the associated genetic flaw through simple tests.⁶³ Current tests use blood or urine samples to test for chemical properties of certain genes.⁶⁴ The market for the tests is huge.⁶⁵ Within days of the discovery of the cystic fibrosis gene, two companies, Integrated Genetics and Collaborative Research, offered a diagnostic test priced at up to two hundred dollars per test.⁶⁶ This potential for large profits fuels genome research.⁶⁷ As genetic discoveries accelerate, tests proliferate, and prices drop, insurers will be increasingly tempted to use them.⁶⁸

Genetic tests, however, are not always correct. Genetic tests unaccompanied by a detailed family history leave room for error.⁶⁹ Also, "[t]he sensitivity of genetic testing is limited by the known mutations in a target population."⁷⁰ "Moreover, genetic

61. Carey, *supra* note 11, at 70.

62. *Id.* at 71, 78.

63. MEDICAL TESTING, *supra* note 2, at 15-16.

64. *Id.*

65. Recent reports predict that genetic tests will generate a two hundred million dollar to one billion dollar per year market for biotechnology companies. Carey, *supra* note 11, at 69; NELKIN & TANCREDI, *supra* note 3, at 33. Screening tests are currently available for several common cancers such as colon, breast, and uterine/cervical cancers. MEDICAL TESTING, *supra* note 2, at 16. Tests are also available for heart disease, diabetes, and other rare diseases. NELKIN & TANCREDI, *supra* note 3, at 33, 28-29.

66. Carey, *supra* note 11, at 71.

67. See generally *id.*

68. See generally Kass, *supra* note 8. The ACLI-HIAA Task Force reports that cost is a practical reason that has prohibited widespread use of genetic testing by insurers. ACLI-HIAA TASK FORCE, *supra* note 1, at 5. The Task Force further points out that it will be "years and perhaps decades before insurers could realistically afford genetic testing on any wide-scale basis." *Id.*

69. MEDICAL TESTING, *supra* note 2, at 135-40. Genetic test results may be inaccurate due to the possibility of multiple mutations that cause the same condition. "Linkage tests," tests that identify a marker associated with a causative gene rather than the gene itself, are generally reliable only to the extent that the marker is very close to the disease causing gene. *Id.*

70. Genetic Discrimination, *supra* note 2, at 113; HOLTZMAN, *supra* note 1, at 198-99. For example, because the cystic fibrosis (CF) chromosome is detectable in only 75% of the United States Caucasian population, false identification of the disease is inevita-

testing is not based on causality, but on correlation."⁷¹ The underlying premise of most genetic tests is not that the identified gene will always give way to illness, but that certain genetic markers are present in the chromosomes of people suffering from inherited illnesses.⁷² These genetic markers are then used to single out high-risk groups and sub-groups.⁷³ However, "the onset date, severity of symptoms, and efficacy of treatment and management are highly variable."⁷⁴ Thus, the results of genetic tests are far from scientific certainty.⁷⁵

III. Health Insurance and Risk Classification

The concept of insuring against loss by distributing risk dates back five thousand years.⁷⁶ Modern American health insurance effectively began in 1929 with the Baylor University Hospital Plan.⁷⁷ This plan served as the model for the nonprofit Blue Cross and Blue Shield (BC/BS) organizations that still exist today.⁷⁸ Private commercial health insurance blossomed in the 1940s, and by 1953 it covered more Americans than the BC/BS organizations.⁷⁹ Before considering the insurance industry's need to employ genetic tests as a basis for risk classification, a basic understanding of the American health insurance industry and the principles of insurance classification is compulsory.

ble. Wilfond, *supra* note 11, at 2779. Based on statistical analysis, it is further estimated that "one out of every two couples from the general population identified by CF population screening as 'at risk' will be falsely labeled, and therefore, may experience increased anxiety or discrimination, or needlessly alter their reproductive plans." *Genetic Discrimination*, *supra* note 2, at 114.

71. Katherine Brokaw, *Genetic Screening in the Workplace and Employers' Liability*, 23 COLUM. J.L. & SOC. PROBS. 317, 321 (1990).

72. MEDICAL TESTING, *supra* note 2, at 132-39.

73. Panel Discussion, *Role of the Knowledge of High Risk Groups in Occupational Health Policies and Practices*, 29 ENVTL. HEALTH PERSPS. 143, 145 (1979).

74. *Genetic Discrimination*, *supra* note 2, at 114.

75. *Id.*

76. EMMET J. VAUGHAN, *FUNDAMENTALS OF RISK AND INSURANCE* 67 (5th ed. 1989). For instance, as early as 3000 B.C. Chinese merchants distributed the risk of loss during shipment by shipping some of their goods on each other's boats. *Id.* The cost of losing any particular boat was thus split among the merchants. *Id.* at 68.

77. *Id.* at 75. See Kass, *supra* note 8, at 2.

78. VAUGHAN, *supra* note 76, at 75.

79. Kass, *supra* note 8, at 3.

A. *Health Care Financing Systems*

Today Americans may be covered under a variety of commercial and nonprofit health care financing systems.⁸⁰ The four major systems are nonprofit BC/BS organizations, commercial health insurers, self-insured health benefit plans, and health maintenance organizations (HMOs).⁸¹ Each system will be briefly discussed and their common reliance on risk classification will be explained.

BC/BS organizations are nonprofit health insurers that generally serve a limited geographic region.⁸² Most BC/BS organizations operate like commercial insurers, except that some states require them to have an annual open enrollment period.⁸³ There are approximately seventy-seven BC/BS organizations nationwide,⁸⁴ providing coverage for about seventy-nine million people.⁸⁵

Commercial health insurance providers are for-profit companies.⁸⁶ Commercial health insurers are not generally required to provide open enrollment periods, and are usually not restricted to a specific geographic area.⁸⁷ There are roughly one thousand commercial health insurers⁸⁸ that provide health insurance to approximately 111 million people.⁸⁹

Self-insured health benefit plans have become a major provider of health insurance over the last fifteen years.⁹⁰ Self-insurance is typically used by large employers, who can directly pro-

80. VAUGHAN, *supra* note 76, at 285. Not all of these health care financing systems are technically insurance. For example, health maintenance organizations (HMOs) are not considered insurance, but they provide similar benefits to members and are generally not distinguished by consumers. *Id.* at 76.

81. Henry T. Greely, *AIDS and the American Health Care Financing System*, 51 U. PITT. L. REV. 73, 77 (1989).

82. VAUGHAN, *supra* note 76, at 285.

83. MEDICAL TESTING, *supra* note 2, at 57. An open enrollment period is a limited period of time where the organization must provide a policy to any applicant regardless of his/her health status. Kass, *supra* note 8, at 4. Roughly thirty-one percent of BC/BS organizations have open enrollment periods. MEDICAL TESTING, *supra* note 2, at 57.

84. MEDICAL TESTING, *supra* note 2, at 57.

85. Kass, *supra* note 8, at 7.

86. *Id.* at 3.

87. MEDICAL TESTING, *supra* note 2, at 57.

88. VAUGHAN, *supra* note 76, at 267.

89. Kass, *supra* note 8, at 7.

90. MEDICAL TESTING, *supra* note 2, at 54.

vide insurance for their employees, rather than hire an outside insurance company or other provider.⁹¹ Companies began self-insuring in the 1970s in an effort to cut the cost of employee benefits.⁹² Self-insurance offers several other advantages to large employers; most importantly, the federal Employee Retirement Income Security Act (ERISA)⁹³ exempts self-insurance plans from most state insurance regulations.⁹⁴

Technically, HMOs are not health insurers. HMOs are health care providers, but they operate on the same basic principles as insurers. HMOs provide comprehensive medical services to members in return for a fixed monthly fee.⁹⁵ HMOs grew at an annual rate of twenty percent from 1981 to 1986, and as of 1987 over twenty-seven million people were enrolled in HMOs.⁹⁶

B. Risk Classification

Health insurance coverage is provided under either group or individual policies.⁹⁷ Group policies are generally issued to employers, unions, or other large affiliations of people.⁹⁸ Most commercial insurers and BC/BS organizations provide both group and individual policies.⁹⁹ HMOs rarely allow individual enrollment.¹⁰⁰ Self-insured health benefits plans are not easily classified as group or individual, but may have characteristics of both types of policies.

The critical differences between group and individual policies are the use of risk classification and the method of underwriting.¹⁰¹ The American insurance market is a private, volun-

91. *Id.*

92. *Id.*

93. 29 U.S.C. §§ 1001-1461 (1988).

94. Under ERISA, self-insured plans are not required to comply with state laws requiring minimum insurance benefits, anti-discrimination standards, payment of insurance premium taxes, or participation in insurance risk pools. *MEDICAL TESTING*, *supra* note 2, at 55.

95. VAUGHAN, *supra* note 76, at 275.

96. *MEDICAL TESTING*, *supra* note 2, at 58.

97. *Id.* at 41.

98. *Id.* at 42.

99. *Id.* at 56-58.

100. According to the Group Health Association, no more than four percent of HMO members are enrolled as individuals. *Id.* at 59.

101. *Id.* at 42. Underwriting is "[t]he process of selecting risks and classifying them according to their degrees of insurability so that the appropriate rates may be assigned."

tary market;¹⁰² thus, risk classification is a fundamental part of the insurance system.¹⁰³ Underwriting is used by insurers to determine whether, and on what basis, they will accept an application for insurance.¹⁰⁴ The premise of underwriting is that the insured should pay a premium according to the risk presented.¹⁰⁵ An insurer's goal is to accurately assess the quality of risk of the applicant and establish premiums that reflect that risk.¹⁰⁶ Thus, risk classification is used to set rates directly related to the anticipated cost of assuming the risk of a particular individual.¹⁰⁷ Insurance companies base underwriting decisions on medical information from various sources, including the insurance application, attending physician's statements, medical examinations, and information services such as the Medical Information Bureau.¹⁰⁸

A basic tenet espoused by insurance companies is their responsibility to treat all policyholders fairly and equitably.¹⁰⁹ Therefore, premiums charged should correlate to the risk an individual policyholder presents to the insurer.¹¹⁰ "Basic to the concept of providing insurance to persons of different ages, sexes, . . . occupations and health histories . . . has been the right of the insurer to create classifications to recognize the many differences which exist among individuals."¹¹¹ Characteristics that impact risk assessment, such as age, health, gender, occupation, and frequency of alcohol or tobacco use, are analyzed to deter-

MERRITT CO., GLOSSARY OF INSURANCE TERMS 210 (Thomas E. Green ed., 1987).

102. MEDICAL TESTING, *supra* note 2, at 41.

103. JUDITH K. MINTEL, INSURANCE RATE LITIGATION 113 (1983).

104. ALBERT H. MOWBRAY, ET AL., INSURANCE: ITS THEORY AND PRACTICE IN THE UNITED STATES 459 (6th ed. 1969).

105. *See id.* at 411.

106. Karen A. Clifford & Russel P. Incalano, *AIDS and Insurance: The Rationale for AIDS-Related Testing*, 100 HARV. L. REV. 1806, 1810 (1987).

107. Herman T. Bailey, et al., *The Regulatory Challenge to Life Insurance Classification*, 25 DRAKE L. REV. 779, 780 (1976).

108. John C. Angle & John J. McCuiston, *Risk Selection and Substandard Risks, in LIFE AND HEALTH INSURANCE HANDBOOK* (Davis W. Gregg & Vane B. Lucas eds., 3d ed. 1973); HOLTZMAN, *supra* note 1, at 196. *See infra* text accompanying note 169 for a description of the Medical Information Bureau.

109. Bailey, *supra* note 107, at 781-82.

110. *Id.* at 782.

111. *Id.* at 780.

mine their effects on an individual's mortality.¹¹² The influence these characteristics have on mortality forms a basis for insurance companies to classify individuals into groups with comparable mortality risks and charge appropriate premiums.¹¹³ Thus, risk classification allows insurers to maximize profits and efficiency by charging different rates based upon risk, and compete for customers by offering lower prices to lower risk individuals.¹¹⁴

The value of any risk classification is increased by its ability to create prevention incentives on the part of insureds.¹¹⁵ Ideally, the variable on which the classification is based should be one in which the insured exercises control.¹¹⁶ One way to measure prevention incentives is the degree to which risk classifications are based on variables within the insured's control.¹¹⁷ For example, smoking is a controllable addiction that is used by insurers in risk classification. Charging lower premiums for non-smokers is an incentive for smokers to quit smoking, which in turn, lowers the expected loss to insurers.¹¹⁸ Because the ability of the classification to influence an individual's behavior is an indicator of the classification's efficiency, controllable variables are more efficient risk classification tools.

Some variables, even if extremely accurate and efficient, cannot be used for other reasons and are considered suspect classification variables.¹¹⁹ Examples of suspect variables are those based on racial or ethnic groups.¹²⁰ Use of race or ethnic heritage as a classification variable is considered unacceptably discriminatory and is generally not allowed.¹²¹

112. ROBERT I. MEHR ET AL., *PRINCIPLES OF INSURANCE* 657-59 (8th ed. 1985). Individuals and family members are required to complete forms detailing their medical histories. HOLTZMAN, *supra* note 1, at 194. If applicants are at increased risk for a disease, the insurance company may seek additional information from other sources. *Id.*

113. *See generally id.*

114. *See* Bailey, *supra* note 107, at 782; *see generally* KENNETH ABRAHAM, *DISTRIBUTING RISK: INSURANCE, LEGAL THEORY, AND PUBLIC POLICY* (1986).

115. ABRAHAM, *supra* note 114, at 71.

116. *Id.*

117. *Id.* at 72-74.

118. Leah Wortham, *Insurance Classification: Too Important to Be Left to the Actuaries*, 19 U. MICH. J.L. REF. 349, 413 (1986).

119. ABRAHAM, *supra* note 114, at 92-93.

120. *Id.* at 93.

121. *Id.*

The use of risk classification is in natural tension with the basic insurance function of risk distribution.¹²² Risk classification seeks to sort the insured population into relatively homogeneous groups.¹²³ In a competitive market, effective risk classification gives an insurer a competitive edge.¹²⁴ If an insurer's system is extensively classified, that insurer will skim the low-risk population "away from insurers whose classifications are less refined."¹²⁵ This can leave a high-risk group faced with premiums so high that they are essentially uninsurable. Such extensive segregation of risks works against the basic concept of risk distribution that is the foundation of insurance.¹²⁶

IV. Potential Abuses

The availability of predictive and diagnostic genetic tests, and their potential use for health insurance risk classification, highlights the conflicting interests of the health insurance industry and the individual's right to privacy.¹²⁷ Access to genetic information is a means of planning long-term health costs for both individuals and insurers.¹²⁸ For insurers, the information may be used to deny coverage or increase insurance rates based on an individual's genetic risk.¹²⁹ For the individual, genetic information often carries profound benefits, affording an individual a chance to begin preventive care.¹³⁰ The potential for abuse of genetic information must be considered from both the individual's and the insurer's perspective.

A. Public Concerns

For individuals, the use of genetic testing by insurers presents several problems, but the most significant is the fear

122. *Id.* at 65.

123. *See id.* at 74.

124. *Id.* at 68. *See also* NELKIN & TANCREDI, *supra* note 3, at 58.

125. ABRAHAM, *supra* note 114, at 68.

126. *Id.* at 65.

127. *See* ACLI-HIAA TASK FORCE, *supra* note 1, at 4. Right to privacy involves issues of confidentiality not only in preventing insurers from acquiring genetic information, but also in keeping information obtained by insurers confidential. *Id.*

128. NELKIN & TANCREDI, *supra* note 3, at 70-73.

129. ACLI-HIAA TASK FORCE, *supra* note 1, at 4.

130. NELKIN & TANCREDI, *supra* note 3, at 72-74.

that insurers will use genetic information in the classification of risks.¹³¹ Opponents believe that such use threatens to create a "genetic underclass."¹³² Fear exists that the use of genetic tests will serve as a tool for denying access to health care either through higher premium rates, or by outright denial of insurance coverage for high-risk individuals.¹³³ On more basic moral grounds, individuals should be respected as "autonomous beings who hold views, make choices and take actions based on their personal values and beliefs."¹³⁴ Individuals should have the right to voluntarily determine whether they want to know if they are at risk for genetic illness and who should have access to their genetic information. In addition, because genetic testing cannot always provide conclusive results, its use should be approached with caution.¹³⁵ False positive test results sometimes occur, and even individuals with true positive results may never become ill.¹³⁶ The questionable reliability of genetic tests undermines their use as an efficient risk classifier.¹³⁷

A 1986 survey by the Health Insurance Association of America (HIAA) estimated that 158 million Americans under the age of sixty-five were covered by some form of group health insurance and nine million more were covered by individual health insurance.¹³⁸ Group policy insurance is "essentially low-cost, mass protection."¹³⁹ The basic premise of group policies is

131. See generally *id.* One slightly related ethical concern is the loss of the individual's right not to know his/her genetic makeup. If genetic tests are required by insurers, individuals will be forced to look at their future health prospects, something not everyone wants to do. Furthermore, those who do want to know "may be dissuaded from seeking early diagnostic tests because they may lose the insurance coverage needed to prevent the disease." H.R. REP., *supra* note 28, at 17.

132. ACLI-HIAA TASK FORCE, *supra* note 1, at 4.

133. Eric T. Juengst, *Priorities in Professional Ethics and Social Policy for Human Genetics*, 266 JAMA 1835, 1836 (Oct. 2, 1991).

134. Kass, *supra* note 8, at 24.

135. MEDICAL TESTING, *supra* note 2, at 136-40.

136. Brokaw, *supra* note 71, at 327.

137. MEDICAL TESTING, *supra* note 2, at 20.

138. Clifford & Iucalano, *supra* note 106, at 1808. In addition, "most people in the United States acquire health insurance (and often disability and life insurance) as subscribers to group plans through their employment." O. W. J. Quarrell, et al., *Insurance and Presymptomatic Diagnosis of Delayed-Onset Disease*, 262 JAMA 2385, 2385 (1989) (replying to O. W. J. Quarrell from Jason Brandt, et al.); see *supra* Part III for a discussion of various insurance plans.

139. MEDICAL TESTING, *supra* note 2, at 43.

that in a large group, although some individuals may require more expensive care than others, the overall risk and costs are balanced over a wide pool. Group insurance underwriting evaluates the risk of an insurable group to determine premium rates and coverage terms.¹⁴⁰ Because of the nature of group insurance, individuals are not generally classified into separate risk categories, and are therefore at less risk of discrimination based on the use of genetic testing.¹⁴¹

In contrast, insurers underwriting individual health insurance consider the characteristics of each individual applicant.¹⁴² Self-insurers also often consider the health status of individual job applicants because future medical costs are incurred directly by the company.¹⁴³ As a result, those seeking coverage under individual policies or self-insured plans face greater potential for discrimination than those who have access to group insurance.

In the absence of genetic testing for risk classification, the risk associated with genetic diseases or susceptibilities is distributed over the entire insured pool.¹⁴⁴ Currently, insurance companies must pay for treatment of a genetic disorder when it is manifested unless the policy specifically excludes coverage for such an illness.¹⁴⁵ Thus, the costs associated with genetic disorders are spread across the insurance pool just as the costs of other diseases are distributed.

Another potential concern for all policyholders relates to pre-existing condition clauses in both group and individual policies. Health insurance coverage is usually limited to current illnesses and does not cover pre-existing conditions.¹⁴⁶ If genetic defects qualify as pre-existing conditions, potential savings could be significant enough that insurers will seek the use of genetic tests even in the group insurance setting. Further, such pre-existing condition clauses could permit insurers to use genetic tests

140. MOWBRAY, *supra* note 104, at 350.

141. MEDICAL TESTING, *supra* note 2, at 42-45.

142. VAUGHAN, *supra* note 76.

143. MEDICAL TESTING, *supra* note 2, at 45.

144. See generally ABRAHAM, *supra* note 114, at 67-68.

145. Joseph M. Miller, *Genetic Testing and Insurance Classification: National Action Can Prevent Discrimination Based on the 'Luck of the Genetic Draw,'* 93 DICK. L. REV. 729, 741 (1989).

146. Wortham, *supra* note 118, at 398 n.292.

as a basis for avoiding liability on a policy long after it is written.¹⁴⁷

B. Insurance Industry

Currently, neither insurers nor employers require genetic testing to obtain coverage, but insurers use other tests to gather medical information that is "strongly influenced by genetic factors."¹⁴⁸ Insurers have powerful economic incentives for using genetic testing. Genetic testing can defray costs and guard against potentially unprofitable patients.¹⁴⁹ Insurers argue that access to diagnostic tests, including genetic tests, is necessary to keep the industry intact.¹⁵⁰ Insurers also argue that individuals possessing a genetic predisposition to disease will burden the rest of the insurance pool through high medical costs once they become ill.¹⁵¹

The insurance industry is based on the principle of shared risk.¹⁵² Appropriate levels of contribution are spread across the insurance pool based on a risk assessment of each individual.¹⁵³ Individual risk classification enables insurers to set rate schedules according to individual risk. Genetic testing would enhance risk classification by providing predictive information of an individual's chances of future illness. Not only can insurers benefit from distinguishing high-risk individuals, but employers who provide self-insured health benefit plans also stand to benefit by

147. See *Genetic Discrimination*, *supra* note 2, at 135.

148. Phillip Reilly, *ASHG Statement on Genetics and Privacy: Testimony to United States Congress*, 50 AM. J. HUM. GENETICS 640, 641 (1992). For example, individuals who purchase large life insurance policies must usually consent to cholesterol tests. *Id.* Diabetes and high blood pressure tests are also used in qualifying for life and health insurance. *Id.* Applicants are often required to reveal detailed family histories. *Id.*

149. "Unprofitable" patients within this context are individuals whose genetic profiles place them in high-risk categories. High-risk categories include those individuals whose genetic make-up is possibly degenerative or fatal, or both. See NELKIN & TANCREDI, *supra* note 3, at 58-59.

150. See Suzanne M. Russell, *Prohibiting AIDS Testing in the Health Insurance Context: Patching Up a Patchwork System*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 131, 134 (1990).

151. *Id.*

152. See generally Kass, *supra* note 8. See *supra* Part III for further explanation of risk classification.

153. Kass, *supra* note 8, at 5.

minimizing potential employee medical costs.¹⁵⁴ "The economic integrity of insurance companies is premised on the concept that an equitable 'risk selection and classification' is necessary in order for insurance companies to remain viable."¹⁵⁵ Insurers are businesses that must protect themselves from unprofitable investments.

Insurers argue that they should have access to all information that bears significantly on risk classification.¹⁵⁶ Failure to use this information will result in the "subsidization of high-risk persons by low-risk groups."¹⁵⁷ If this information remains undisclosed, it unfairly burdens the low-risk group. In addition, customers may be lost if low-risk individuals believe that the benefits of coverage are not worth the cost of high premiums.¹⁵⁸

Insurers also argue that genetic testing to determine eligibility is analogous to current insurance classification techniques.¹⁵⁹ Classification factors currently used include age, sex, health status, health history, financial status, and occupation.¹⁶⁰ Just as individuals who have poor driving records pay higher premiums for automobile insurance, individuals who smoke pay higher health insurance premiums than nonsmokers.¹⁶¹ Moreover, premiums for women are generally cheaper than for men because women live longer.¹⁶²

Perhaps the industry's gravest fear lies in the possibility that applicants "could use genetic testing to foresee coverage

154. Ray Moseley, et al., *Ethical Implications of a Complete Human Gene Map for Insurance*, 10 BUS. AND PROF. ETHICS J. 75 (1991).

155. *Id.* at 74.

156. MEDICAL TESTING, *supra* note 2, at 47.

157. *Id.*

158. *Id.*

159. Insurers currently use information available from other sources such as personal medical histories — to trace past illnesses and conditions; family medical histories — to identify concerns regarding parents, children, and spouses; and various tests to determine current physical conditions. See Moseley, *supra* note 154, at 77. See also MEDICAL TESTING, *supra* note 2, at 45.

160. MEDICAL TESTING, *supra* note 2, at 45.

161. See Leah Wortham, *The Economics of Insurance Classification; The Sound of One Invisible Hand Clapping*, 47 OHIO ST. L.J. 835, 837 (1986); Robert Wright, *The End of Insurance; Human Genome Project Could Remove Uncertainty from Actuarial Tables*, NEW REPUB., July 9, 1990, at 26.

162. Wright, *supra* note 161, at 26.

needs and exploit the insurance system.”¹⁶³ “Adverse selection” is the abusive purchase of insurance by individuals who are higher risks than their insurers are aware.¹⁶⁴ Adverse selection drives up the costs of the insurance pool. The result is an unfair distribution of these costs due to increased premiums for all policyholders, including healthy individuals with few medical costs.¹⁶⁵

Currently, insurance companies protect themselves against adverse selection in three ways.¹⁶⁶ First, insurers protect themselves by including pre-existing condition clauses in both group and individual policies. These clauses provide that if a pre-existing condition is discovered “within two years after the policy is sold, the policy can be canceled or rewritten.”¹⁶⁷ A pre-existing condition is one that existed prior to the applicant’s policy and has “impaired the applicant’s health to some degree.”¹⁶⁸ Second, some protection is afforded by the Medical Information Bureau (MIB).¹⁶⁹ Over seven hundred insurance companies belong to the MIB, which acts as an insurance databank carrying medical findings and test results on health and life insurance applicants. The MIB currently does not carry genetic information.¹⁷⁰ Finally, insurance companies may require the applicant to submit to a physical exam before providing coverage.

In 1990, the American Council of Life Insurance (ACLI) and the HIAA formed a task force to study the issues surrounding the industry’s use of genetic testing. The Task Force found that “[n]o insurer — life or health — currently requires genetic tests.”¹⁷¹ However, the ACLI and the HIAA consider genetic information as “potentially relevant to risk classification as any other medical information.”¹⁷² The Task Force has stated that “the ACLI and the HIAA should continue to aggressively defend

163. ACLI-HIAA TASK FORCE, *supra* note 1, at 8. See also H.R. REP., *supra* note 28, at 18.

164. ACLI-HIAA TASK FORCE, *supra* note 1, at 8.

165. Wright, *supra* note 161, at 27.

166. HOLTZMAN, *supra* note 1, at 195.

167. *Id.*

168. *Id.*

169. *Id.* at 196.

170. *Id.*

171. ACLI-HIAA TASK FORCE, *supra* note 1, at 5.

172. *Id.* at 10.

their member companies' need to have access to and to consider any relevant health information for underwriting purposes, including genetic test information."¹⁷³

V. Current Legislation

Since 1868, the federal government has not significantly regulated the insurance industry.¹⁷⁴ Initially, insurance was not considered interstate commerce, and regulation was left completely to the domain of the states.¹⁷⁵ Insurance companies were free to develop and set rates and policies pursuant to each state's regulatory law.¹⁷⁶ However, by 1944 the insurance industry "had grown to such an extent that its operation no longer could be regarded as anything less than 'commerce'. . . ."¹⁷⁷ In *United States v. South-Eastern Underwriters Association*,¹⁷⁸ the Supreme Court overruled earlier case law and held that the insurance industry was subject to congressional regulation under the Commerce Clause.¹⁷⁹ Industry fear of federal regulation prompted the National Association of Insurance Commissioners (NAIC)¹⁸⁰ to propose legislation that would maintain state regulatory authority.¹⁸¹

The NAIC proposal became the McCarran-Ferguson Act,¹⁸² which mandated that regulation of the insurance industry remain in the hands of the states.¹⁸³ Shortly after the enactment

173. *Id.*

174. Kass, *supra* note 8, at 6.

175. See *Paul v. Virginia*, 75 U.S. 168 (1869) (holding that "[i]ssuing a policy of insurance is not a transaction of interstate commerce," and thus, is regulated by the states), *overruled by United States v. South-Eastern Underwriters Ass'n*, 323 U.S. 811 (1944).

176. See ROBERT H. JERRY, *UNDERSTANDING INSURANCE LAW* 52-68 (1987).

177. Bailey, *supra* note 107, at 781.

178. 322 U.S. 533 (1944).

179. *Id.* See Bailey, *supra* note 107, at 781.

180. The insurance industry formed the National Association of Insurance Commissioners in 1871 to promote uniformity in insurance regulation and to protect insurance policyholders. JERRY, *supra* note 176, at 81.

181. *Id.* at 53.

182. 15 U.S.C. §§ 1011-1015 (Supp. II 1988).

183. Section 1011 of the McCarran-Ferguson Act states that, "the continued regulation and taxation by the several States of the business of insurance is in the public interest, and that silence on the part of the Congress shall not be construed to impose any barrier to the regulation or taxation of such business by the several States." 15 U.S.C. § 1011 (Supp. II 1988). Section 1012(a) further declares that "[t]he business of insurance,

of the McCarran-Ferguson Act, the insurance industry recognized the need for uniform legislation to allow insurers to transact business across state lines.¹⁸⁴ The NAIC began to formulate model statutes to guide insurance regulation, and today continues to develop model codes and act as a clearinghouse for insurance industry regulatory information.¹⁸⁵

Despite the efforts of the NAIC, state insurance statutes are still fragmented.¹⁸⁶ However, state regulations generally provide for the control of rates to prevent inadequate, excessive, or discriminatory practices; the prevention of unfair trade practices by insurers; and the prevention of insolvency of insurers to protect the interests of insureds.¹⁸⁷ Rate-setting regulations seek to ensure that rates are sufficient to prevent insolvency without being excessive, and are at the same time fairly and equitably distributed among individuals.¹⁸⁸ Generally insurers are free to cooperate in devising rate schedules.¹⁸⁹ These rate schedules are submitted for approval to the state administrative agency that regulates insurance.¹⁹⁰

The greatest area of difficulty lies in achieving the proper balance in rates to prevent discrimination among insureds.¹⁹¹ Generally, risks are classified to closely match individual premiums with the risk they present. However, errors in risk classification or the use of many classifications can increase administrative costs and, in turn, increase premiums beyond the savings achieved by classification.¹⁹²

and every person engaged therein, shall be subject to the law of the several States which relate to the regulation or taxation of such business." *Id.* § 1012(a). Section 1012(b) states that "[n]o Act of Congress shall be construed to invalidate, impair, or supersede any law enacted by any State for the purpose of regulating the business of insurance, . . . unless such Act specifically relates to the business of insurance . . ." *Id.* § 1012(b).

184. See S.S. HUEBNER & KENNETH BLACK JR., *LIFE INSURANCE* 655 (10th ed. 1982).

185. JERRY, *supra* note 176, at 81.

186. *Id.* at 68-69.

187. See *id.* at 69. See, e.g., CAL. INS. CODE §§ 780-790.10 (West 1972 & Supp. 1992), LA. REV. STAT. ANN. §§ 22:1211-22:1217 (West 1978 & Supp. 1992), MASS. GEN. LAWS ANN. ch. 176D § 1-14 (West 1987 & Supp. 1992), N.Y. INS. LAW §§ 2401-2409, 2602-2610 (McKinney 1985 & Supp. 1992).

188. JERRY, *supra* note 176, at 72.

189. *Id.* at 71.

190. *Id.*

191. *Id.* at 72.

192. See ABRAHAM, *supra* note 114, at 64-68.

All fifty states have enacted legislation requiring fair and equitable treatment of insured parties in the insurance underwriting process.¹⁹³ These state insurance laws are largely based on the Unfair Trade Practices Act (UTPA),¹⁹⁴ a model code developed by the NAIC.¹⁹⁵ The UTPA permits, and to a degree even requires, discrimination but distinguishes between fair and unfair discrimination.¹⁹⁶ For example, under the UTPA unfair discrimination results when identical premiums are charged to a sixty year old man in poor health and a twenty year old woman in good health.¹⁹⁷ Insurers must determine an equitable premium for both parties, and the "rates should be *adequate* but not *excessive* and should *discriminate* fairly between insureds . . . so that each insured will pay in accordance with the quality of his risk."¹⁹⁸

The UTPA proscribes "unfair discrimination between individuals of the same class and of essentially the same hazard."¹⁹⁹ The UTPA is generally interpreted to permit any classification variable as long as a "statistical difference between groups can be known, while ignoring other issues."²⁰⁰ Fair discrimination generally means that insurers must establish rates based on a measurement of the burden shifted to the insurance fund by each policyholder.²⁰¹ Anything less is unfair discrimination.²⁰²

In most of the state insurance discrimination statutes, interpretation of recurring phrases such as "unfair discrimination"

193. Bailey, *supra* note 107, at 782. Similar provisions prohibiting unfair discrimination are common to almost all state insurance statutes. *Id.* By October 1991, only Alabama, Illinois, Oregon, and Wisconsin had not adopted the provisions of the NAIC Unfair Trade Practices Act or similar legislation. NAIC MODEL LAWS, REGULATIONS AND GUIDELINES, VOL. IV, page 880-11-14 (Nat'l Ass'n of Ins. Comm'rs Oct. 1991).

194. NAIC MODEL LAWS, REGULATIONS AND GUIDELINES, VOL. IV, page 880-1 (Nat'l Ass'n of Ins. Comm'rs Jan. 1991).

195. See Bailey, *supra* note 107, at 782.

196. NAIC MODEL LAWS, REGULATIONS AND GUIDELINES, VOL. IV, page 880-1 (Nat'l Ass'n of Ins. Comm'rs Jan. 1991). Bailey, *supra* note 107, at 782-83. Rates should discriminate fairly between insureds and reflect each insured's risk classification; rates should not be unreasonable or excessive. *Id.*

197. *Id.*

198. MOWBRAY, *supra* note 104, at 411 (emphasis in original).

199. NAIC MODEL LAWS, REGULATIONS AND GUIDELINES, VOL. IV, page 880-4, UTPA § 4(g)(2) (Nat'l Ass'n of Ins. Comm'rs).

200. Wortham, *supra* note 118, at 370.

201. See *id.* at 361.

202. *Id.*

and "same class involving essentially the same hazard" is left to the judiciary.²⁰³ Cases have interpreted such terms in the same way that the UTPA has been interpreted.²⁰⁴ Thus, underwriting within the spirit of state anti-discrimination laws binds an insurer to accord similar treatment to those with similar health risks.²⁰⁵

The cases illustrate that risk classification is recognized as a fair means of establishing premiums. Generally, insurance companies have free reign to conduct health-related non-discriminatory screening in order to classify the risk of an applicant.²⁰⁶ The only significant exceptions are found in statutes that forbid insurers from denying insurance to individuals carrying the sickle cell trait, Tay-Sachs trait, or HIV-infected or AIDS-diagnosed individuals.²⁰⁷

A. *State Regulation of the Use of Genetic Testing*

In April 1992, Wisconsin became the first state to ban the use of genetic testing in health insurance underwriting.²⁰⁸ The

203. Miller, *supra* note 145, at 747-48.

204. See *Physicians Mutual Ins. Co. v. Denenberg*, 327 A.2d 415, 418 (1974) (defining "unfair discrimination" in the underwriting process to prohibit premiums unrelated to actuarial risk); *Hilson v. Sun Life Assurance Co. of Canada*, 132 F.2d 989 (5th Cir. 1943) (holding that risk classification to determine rates is not discrimination); *Reeves v. New York Life Ins. Co.*, 421 S.W.2d 686 (Tex. Civ. App. 1967) (interpreting insurance risk classification as a non-discriminatory means for rate-settings).

205. Clifford & Incalano, *supra* note 106, at 1811.

206. Kass, *supra* note 8, at 12.

207. See *infra* Sections IV.B., C. for a discussion of these statutes.

208. 1991 Wis. Act 269 (enacted Apr. 29, 1992). This Act created § 631.89 of the Wisconsin Statutes. WIS. STAT. ANN. § 631.89 (West 1992). Section 631.89(2) states that: [a]n insurer . . . may not do any of the following: (a) Require or request directly or indirectly any individual or a member of the individual's family to obtain a genetic test. (b) Require or request directly or indirectly any individual to reveal whether the individual or a member of the individual's family has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual's family, were. (c) Condition the provision of insurance coverage or health care benefits on whether an individual or a member of the individual's family has obtained a genetic test or what the results of the test, if obtained by the individual or a member of the individual's family, were. (d) Consider in the determination of rates or any other aspect of insurance coverage or health care benefits provided to an individual whether an individual or a member of the individual's family has obtained a genetic test or what the results or the test, if obtained by the individual or a member of the individual's family, were.

Id.

Wisconsin law amended the state's existing insurance code to prohibit health insurers from requiring any individual to obtain a genetic test, to reveal that he or she has undergone genetic tests in the past, or to disclose the results of such tests.²⁰⁹ In addition, health insurers are prohibited from denying insurance or setting premiums based on whether an individual has obtained a genetic test or on the results of such a test.²¹⁰

No other state has banned the use of genetic tests by health insurers, but some states restrict the use of genetic information or are considering a prohibition like that of Wisconsin. California statutorily prohibits an insurance company from classifying applicants or choosing premiums for life or disability insurance, but not health insurance, on the basis of an individual's genetic make-up.²¹¹ The California Insurance Code section 10143 provides that:

[n]o insurance company . . . shall refuse to issue or sell or renew any policy of life or disability insurance after appropriate application solely by reason of the fact that the person to be insured carries a gene which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects on the carrier. Such genes shall include, but not be limited to, Tay-Sachs trait, sickle cell trait, . . . and X-linked hemophilia A.²¹²

Further, the code provides that "[n]o such policy issued . . . shall demand or require a higher premium rate or charge by reason of the fact that the person to be insured carries such traits" ²¹³

In 1991, the California legislature passed a bill that would have prohibited most health care plans from refusing to enroll or charge different premiums to any person because that person "carries a gene which may, under some circumstances, be associated with disability in that person or that person's offspring."²¹⁴ The legislation, however, was vetoed by Governor Pete Wilson.²¹⁵ A similar bill is again pending before the California

209. WIS. STAT. ANN. § 631.89(2)(a), (b) (West 1992).

210. *Id.* at § 631.89(2)(c), (d) (West 1992).

211. CAL. INS. CODE § 10143 (West & Supp. 1992).

212. *Id.*

213. *Id.*

214. Cal. Assembly Bill 1888 Sec. 8 (1991).

215. Gov. Wilson Vetoes Measure to Ban Use of Genetic Testing to Deny Insur-

legislature.²¹⁶

A proposal to amend Michigan's insurance code to prohibit the use of genetic testing was also recently introduced.²¹⁷ The Michigan proposal defines "[u]nfair methods of competition and unfair or deceptive acts or practices in the business of insurance" to include a refusal to insure "because the insured or applicant for insurance declined to submit to genetic testing or because of the results of genetic testing."²¹⁸

Other states have enacted legislation that addresses the use of genetic testing or test results, but does not prohibit their use as a basis for denial of coverage or calculation of premiums. The Maryland Insurance Code provides that "[a]n insurer may not refuse to insure or make or permit any differential in ratings, [or] premium payments, . . . solely because the applicant or policyholder has the sickle cell trait, . . . or any genetic trait which is harmless within itself, unless there is actuarial justification for it."²¹⁹

Arizona statutorily provides that "[n]o insurer shall refuse to consider an application for life or disability insurance on the basis of a genetic condition" ²²⁰ Further, Arizona law provides that:

[t]he rejection of an application or the determining of rates, terms or conditions of a life or disability insurance contract on the basis of a genetic condition . . . constitutes unfair discrimination, unless the applicant's medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition.²²¹

Thus, an individual possessing a gene for a life-threatening disease or disorder is unprotected in Arizona and Maryland if the insurer can provide actuarial justification for use of the genetic trait in underwriting.

The issues relating to HIV status and certain genetic dis-

ance, Pens. Rep. (BNA) No. 42, at 1907 (Oct. 21, 1991).

216. 1991 Cal. Assembly Bill 3152 (introduced Feb. 20, 1992).

217. 1991 Michigan House Bill No. 5991 (introduced June 30, 1992).

218. *Id.*

219. MD. CODE ANN., INS. § 223(3) (1988).

220. ARIZ. INS. CODE § 20-448(D) (West 1990).

221. *Id.* at § 20-448(E) (West 1990).

eases that are distinctive to specific racial groups are closely related to genetic testing and concerns about confidentiality. Many states have enacted legislation to prohibit unfair discrimination against carriers of sickle cell anemia.²²² In the 1970s insurance companies charged higher premiums or denied coverage to African-Americans who carried the sickle cell trait.²²³ Workplace discrimination also occurred against such individuals. In the early 1970s laws requiring sickle cell screening were passed in twenty states, only exacerbating the discrimination.²²⁴ However, Florida, Louisiana, and North Carolina enacted laws prohibiting such discrimination and by the mid-1970s most state laws requiring sickle cell testing had been repealed.²²⁵ With the enactment of state legislation, such unfair discrimination appears to have ended. Under the Florida statute, no insurer "shall refuse to issue and deliver any policy of life insurance solely because the person to be insured has the sickle cell trait."²²⁶ Similarly, the Louisiana Insurance Code prohibits unfair discriminatory premiums, or insurance coverage denial to a person solely because the applicant has the sickle cell trait.²²⁷ Genetic traits for other diseases are no different from genetic traits for sickle cell anemia.

Tay-Sachs disease (TSD)²²⁸ screening programs were also implemented in the early 1970s.²²⁹ TSD screening can identify whether parents are carriers of the disease.²³⁰ If both parents are

222. See, e.g., ALA. CODE § 27-5-13 (1986); FLA. STAT. ANN. § 626.9706 (West 1984); LA. REV. STAT. ANN. § 22:652.1 (West Supp. 1992); TENN. CODE ANN. § 56-7-207 (1989).

Sickle cell anemia is a single gene "hereditary blood disorder found almost exclusively in black populations." SUZUKI, *supra* note 2, at 144. Individuals who inherit the sickle cell gene from both parents suffer from painful, often life-threatening symptoms of sickle cell anemia. Individuals who inherit one sickle cell gene and one normal gene are considered to have sickle cell trait. Individuals with the sickle cell trait show no clinical symptoms of sickle cell anemia. *Id.*

223. GENETIC MONITORING, *supra* note 1, at 41-42.

224. *Id.*

225. *Id.* at 42. See FLA. STAT. ANN. §§ 626.9706-626.9707 (West 1984); LA. REV. STAT. ANN. §22:652.1 (West Supp. 1992); N.C. GEN. STAT. § 58-195.5 (1982).

226. FLA. STAT. ANN. § 626.9706 (West 1984).

227. LA. INS. CODE § 22.652.1 (1992).

228. "TSD is a rare inherited, incurable, neurological disease most prevalent in Jews of Ashkenazi [northern European] origin." GENETIC MONITORING, *supra* note 1, at 43.

229. *Id.*

230. *Id.*

carriers they have a twenty-five percent chance of having a child with TSD.²³¹ As a result of screening in the United States, the incidence of TSD in the Jewish population has been reduced by at least seventy percent.²³² Similar to sickle cell anti-discrimination statutes, some states have enacted anti-discrimination statutes to prevent discrimination against individuals who carry TSD.

B. HIV/AIDS Testing

Like individuals who carry "abnormal" genetic traits, HIV-infected individuals have an interest in protecting the confidentiality of their health status.²³³ No statute affords HIV-positive individuals absolute confidentiality.²³⁴ All states require the reporting of AIDS cases and HIV-positive test results, but vary regarding identification of the infected individual.²³⁵ Those states that provide confidential testing also vary as to the degree of confidentiality.²³⁶ Some states support confidentiality but still require reporting of the subject's name to state health officials.²³⁷ Nevertheless, "there is little state legislation that specifically treats discrimination on the basis of HIV [status]."²³⁸

Several states have enacted legislation to forbid access to

231. *Id.*

232. *Id.*

233. Larry Gostin, *A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy*, 16 AM. J.L. & MED. 1, 17 (1990). Disclosure of an individual's HIV status can lead to employment and/or insurance discrimination. *Id.*

234. Harold Edgar & Hazel Sandomire, *Medical Privacy Issues in the Age of AIDS: Legislative Options*, 16 AM. J.L. & MED. 155, 163 (1991).

235. *Id.* at 166.

236. Illinois prohibits revealing names except to approved researchers with the subject's consent. ILL. ANN. STAT. ch. 111, para. 7354 (Smith-Hurd 1988). Nebraska and Maryland prohibit any reporting of HIV testing data except in statistical summaries. NEB. REV. STAT. § 71-502.04 (1990); MD. CODE ANN., HEALTH-GEN. § 18-207 (1991).

237. See, e.g., COLO. REV. STAT. § 25-4-1402 (West 1989); KAN. STAT. ANN. § 65-6002 (Supp. 1991).

238. Edgar & Sandomire, *supra* note 234, at 211. Some states specifically address the issue of discrimination based on HIV status as it relates to insurance. West Virginia prohibits cancellation or refusal to renew insurance policies based on HIV status. W. VA. CODE §§ 33-15-13, 33-16-9 (1992). Illinois and Iowa permit insurance testing for HIV but only with the applicant's prior informed consent. ILL. ANN. STAT. ch. 111, para. 5403(c) (Smith-Hurd 1988 & Supp 1992); IOWA CODE ANN. § 505.16 (West Supp. 1992). However, Illinois and Iowa fail to protect those individuals who do not consent to testing. *Id.*

HIV tests results by insurers.²³⁹ Such bans recognize the potential for discrimination if test results are made available to insurers. In New York, an individual's interest in privacy extends to his or her HIV status,²⁴⁰ and the disclosure of an individual's HIV status without consent is prohibited.²⁴¹ New York's legislative intent is expressed as the hope that this protection will stimulate "voluntary confidential testing for the human immunodeficiency virus (HIV) so that individuals may come forward, learn their health status, make decisions regarding the appropriate treatment, and change the behavior that puts them and others at risk of infection."²⁴²

However, Connecticut protects the insurer's right to know.²⁴³ Connecticut provides that "[n]o person who obtains confidential HIV-related information may disclose or be compelled to disclose such information, except to . . . (11) [l]ife and health insurers . . . in connection with underwriting and claim activity for life, health, and disability benefits"²⁴⁴

Genetic testing raises similar concerns regarding confidentiality of test results. "Discrimination based on an infectious condition can be as inequitable as discrimination based on other morally irrelevant grounds such as race, gender, or handicap."²⁴⁵ Confidentiality of HIV-related records and protection from discrimination based on HIV status have been addressed by state legislation in an effort to encourage voluntary HIV testing.²⁴⁶ Similar protection and legislation could be applied to genetic testing.

C. Federal Legislation on Genetic Testing

At the federal level, the House of Representatives is considering legislation introduced by Rep. John Conyers, Jr., (D-

239. See, e.g., N.Y. PUB. HEALTH LAW § 2782 (McKinney Supp. 1992); WIS. STAT. ANN. § 631.90 (West 1988 & Supp. 1989).

240. N.Y. PUB. HEALTH LAW § 2782 (McKinney Supp. 1992).

241. *Id.*

242. N.Y. PUB. HEALTH LAW § 2780 (McKinney Supp. 1992) (Hist. & Statutory Notes).

243. CONN. GEN. STAT. § 19a-583(a) (Supp. 1992).

244. *Id.*

245. Gostin, *supra* note 233, at 19-20.

246. Edgar & Sandomire, *supra* note 234, at 155.

Mich.), to safeguard the privacy of individuals who submit to genetic testing.²⁴⁷ The Human Genome Privacy Act is a response to the ethical questions²⁴⁸ raised by the Human Genome Project. The Human Genome Privacy Act proposes to

safeguard individual privacy of genetic information from the misuse of records maintained by agencies or their contractors or grantees for the purpose of research, diagnosis, treatment, or identification of genetic disorders, and to provide to individuals access to records concerning their genome which are maintained by agencies for any purpose.²⁴⁹

Congress held hearings on the bill on October 17, 1991,²⁵⁰ and it is currently pending before the House Government Operations Committee. While this bill would protect an individual's privacy interest in genetic information collected by the federal government, it does not address the use of genetic information provided by other sources. Thus, the bill would have no effect on a health insurer's ability to require genetic testing as a condition of coverage or to deny coverage based on genetic information otherwise obtained.

The bill has found support from the American Society of Human Genetics (ASHG).²⁵¹ The ASHG views the bill as the foundation of a comprehensive plan to protect individual privacy.²⁵² The ASHG has delineated several guidelines that they believe are critical to any successful plan. Any plan must be based on the premise that unauthorized disclosure of genetic information to third parties "may seriously harm the individual who has been tested."²⁵³ Such a plan must also determine "who should be authorized to collect genetic information, how it should be stored, how it may be linked to other data, [and] who

247. H.R. 2045, 102nd Cong., 1st Sess. (1991).

248. Possible ethical questions include the potential consequences of the use of genetic testing by nonclinical third parties such as insurers. NELKIN & TANCREDI, *supra* note 3, at 6.

249. H.R. 2045, 102nd Cong., 1st Sess. (1991).

250. *Domestic and International Data Protection Issues: Hearings Before the Government Information, Justice, and Agriculture Subcomm. of the House of Representatives Comm. on Government Operations*, 102nd Cong., 1st Sess. (1991).

251. Reilly, *supra* note 148.

252. *Id.*

253. *Id.*

should control access to it.”²⁵⁴ Furthermore, the ASHG believes that the plan must delineate rules “that clearly define the permissible and impermissible uses of such data by third parties such as insurers, employers, and school systems.”²⁵⁵

D. *The Americans with Disabilities Act*

Federal and state legislation prohibit discrimination based upon characteristics including race, gender, religion, national origin, age, and disability.²⁵⁶ However, there are no statutory safeguards that directly protect against discrimination based on the immutable characteristic of one's genetic make-up. If a genetic condition is recognized as a disability, significant protection from abuse may lie in disability law. The Americans with Disabilities Act (ADA) of 1990²⁵⁷ extended the Civil Rights Act of 1964 to protect individuals with disabilities. A disability is defined as “(A) a physical or mental impairment that substantially limits one or more of the major life activities . . . ; (B) a record of such impairment, or (C) being regarded as having such an impairment.”²⁵⁸ Physical or mental impairment includes any physical disorders, disfigurements, or any mental or psychological handicap, such as retardation or illness.²⁵⁹

Regulations interpreting the ADA do not discuss discrimination based on genetic predisposition to disease.²⁶⁰ Persons who suffer a current genetic disability, such as cystic fibrosis, are clearly protected.²⁶¹ In addition, the ADA protects not only the actually disabled but also those who are “regarded” as dis-

254. *Id.*

255. *Id.*

256. *Genetic Discrimination*, *supra* note 2, at 119.

257. The Americans with Disabilities Act of 1990, 42 U.S.C.A. § 12101 et. seq. (West Supp. II 1990). The Rehabilitation Act of 1973, Pub. L. No. 93-112 (codified as amended at 29 U.S.C. § 701-796 (1988)) survives the enactment of the Americans with Disabilities Act, and continues to be the principal legislation affecting persons with disabilities who work for the federal government. 42 U.S.C.A. § 12209(a)(2) (West Supp. II 1990). See *Genetic Discrimination*, *supra* note 2, at 120 n.58.

258. 42 U.S.C.A. § 12102(2) (West Supp. II 1990).

259. *Id.*; see *Genetic Discrimination*, *supra* note 2, at 122.

260. 29 C.F.R. § 1630 (1992); see Rorie Sherman, *Employer Use of Genetic Tests to Be Restricted?*, NAT'L L.J., Nov. 25, 1991, at 15.

261. *Genetic Discrimination*, *supra* note 2, at 120.

abled.²⁶² Whether the interpreting regulations take a restrictive or expansive construction of this provision will determine whether genetic predisposition to disease is covered by the ADA.²⁶³ Even if persons with genetic predispositions are included, the protection provided by the ADA does not extend to risk classification for purposes of insurance underwriting.²⁶⁴ The impact of the ADA on the field of health insurance is limited to those individuals who obtain health insurance through their employer.²⁶⁵ The ADA allows employers to require pre-employment medical examinations only after a job offer has been made.²⁶⁶ In addition, any medical exams and inquiries about disabilities must be "job-related and consistent with business necessity."²⁶⁷ Finally, the ADA prohibits an employer from "participating in a contractual or other arrangement or relationship that has the effect of subjecting a . . . qualified applicant or employee with a disability to discrimination," including relationships to provide fringe benefits.²⁶⁸

Considered together, these provisions appear to effectively prevent an employer from denying health insurance based on genetic testing, but do not restrict the premiums charged for such coverage. Since many employers have established self-insured health benefit plans, they have a significant incentive to discriminate in hiring based on genetic predispositions. If the ADA does prohibit employment discrimination against individuals with genetic predispositions, it will close this potentially major area of discrimination, but will have a limited effect on commercial health insurance.

262. 42 U.S.C.A. § 12102(2)(c) (West Supp. II 1990); see *Genetic Discrimination*, *supra* note 2, at 122-23.

263. *Id.* Representative John Conyers, Jr. (D-Mich.), is pushing for an expansive interpretation of who is regarded as disabled. Sherman, *supra* note 260, at 15.

264. 42 U.S.C.A. § 12201 (West Supp. II 1990). See *Genetic Discrimination*, *supra* note 2, at 135-37.

265. See Marvin R. Natowicz, et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS 465, 471 (1992).

266. 42 U.S.C.A. § 12112(c)(3) (West Supp. II 1990).

267. *Id.* at § 12112(c)(4) (West Supp. II 1990).

268. *Id.* at § 12112(b)(2) (West Supp. II 1990).

VI. Proposals to Prevent Genetic Discrimination

The existing health care financing system is facing major problems, even without the use of genetic testing to screen health insurance applications. In 1989, there were over thirty-three million Americans without health insurance coverage.²⁶⁹ Some segments of the population are disproportionately left without coverage, such as Hispanic-Americans, of whom forty-one percent have no health insurance.²⁷⁰ In addition, health care costs have skyrocketed, increasing the importance of adequate health insurance. Spending on health care in the United States increased 128% from 1980 through 1989.²⁷¹ Use of genetic testing by insurers would certainly increase the number of uninsured because people at risk for genetic disease would be faced with higher premiums or would become uninsurable. Many of the people who would be impacted in this way are currently insured because their genetic predispositions have not been detected.

There are several options for addressing the potential impact of genetic testing on the availability of health insurance. Many of the options would also address the broader problems of the health care financing system. The options include: 1) prohibiting genetic testing by insurers; 2) allowing testing, but limiting how insurers can use the information; 3) establishing a national health insurance program; 4) establishing high-risk insurance pools; 5) promoting private reinsurance; 6) mandating employer-funded health insurance; and 7) eliminating the ERISA exemption for self-insured plans.²⁷² Each of these options will be considered.

A. *Prohibit Genetic Testing by Insurers*

Legislation prohibiting genetic testing or the use of genetic test results by insurers is the simplest way to prevent discrimination in the availability of coverage or rate-setting. Such a ban

269. Carl J. Schramm, *Health Care Financing for All Americans*, 265 JAMA 3296, 3296 (1991).

270. Emily Friedman, *The Uninsured; From Dilemma to Crisis*, 265 JAMA 2491, 2491 (1991).

271. *Id.* at 2493.

272. For a discussion of several of these options, see Kass, *supra* note 8, at 30.

would be most effective at the national level. However, states could pass comparable restrictions, such as the Wisconsin statute, in the absence of federal legislation.²⁷³ Such a prohibition would prevent insurers from requiring genetic testing during the application process, and from acquiring and using the results of genetic tests performed for other purposes. This would eliminate the incentive for individuals to avoid genetic tests recommended by physicians or conducted for research purposes, out of the fear that they would not be able to acquire health insurance.²⁷⁴

The major objective of this proposal is to maintain the status quo, and prevent additional people from losing their health insurance. Although this option is vigorously opposed by the insurance industry,²⁷⁵ the actual impact on the industry would likely be limited. Unlike AIDS, which insurers believe creates a substantial incentive for adverse selection, most genetic predispositions do not present the individual with unequivocal knowledge of near-term life threatening illness. Many genetic traits only indicate a susceptibility to future illness. Thus, even if there is adverse selection based on genetic test results, the potential cost to insurers may not be as great as with AIDS, or may not occur at all.

Under this proposal, the risks that would have been detected by genetic testing would continue to be distributed across the insurance pool. As long as no insurer had access to genetic information, no company could gain a competitive advantage.²⁷⁶ Such a prohibition would be a very effective and relatively painless way to prevent abuse of genetic information by insurers.

B. *Regulate the Use of Genetic Testing by Insurers*

This option includes two possibilities for regulating the use of genetic information acquired by insurers. The first possibility is to allow insurers to conduct genetic testing, but not allow them to ask applicants for the results of unrelated genetic tests

273. Under the doctrine of preemption, federal law takes precedence over any inconsistent state law. JOHN E. NOWAK, ET AL., CONSTITUTIONAL LAW § 9.1, at 295 (3d ed. 1986).

274. Kass, *supra* note 8, at 30.

275. See ACLI-HIAA TASK FORCE, *supra* note 1. The industry has also vehemently opposed restrictions on the use of AIDS testing for risk classification. See generally Clifford & Incalano, *supra* note 106, at 1815-17.

276. Kass, *supra* note 8, at 29.

conducted by other parties or for other purposes. Similar to the ban on the use of genetic information, this would prevent individuals from avoiding unrelated beneficial genetic tests for fear of insurance implications.²⁷⁷

The second alternative is to prohibit insurers from completely denying insurance based on an applicant's genetic predisposition. Insurers would be allowed to attach a rider²⁷⁸ denying coverage for the disease the applicant is at risk of developing. This would allow the applicant to obtain coverage for all other health care needs.

Under either proposal, the use of genetic testing must be subject to certain standards.²⁷⁹ Applicants must give informed consent to the genetic tests required by the insurer. Applicants should also be made aware that coverage may be denied or limited based on the test results.²⁸⁰ Finally, specific tests should be evaluated and approved by the regulatory authority to assure test reliability.

C. *Establish National Health Insurance*

National health insurance has been a major topic of debate in recent years. Insurers vehemently oppose national health insurance because it would essentially put them out of business.²⁸¹ There is also increasing political debate on the subject as the number of people without health insurance rises.²⁸²

Although there are an unlimited number of ways to structure national health insurance, one likely scheme would be to establish a single insurer in each state.²⁸³ Under such a proposal, hospitals would receive an annual budget to cover all services.²⁸⁴

277. *Id.* at 30.

278. A rider is a restrictive condition on a policy that contains special provisions that are not contained in the policy contract. LEWIS E. DAVIDS, *DICTIONARY OF INSURANCE* 226 (1977).

279. Kass, *supra* note 8, at 32.

280. *Id.*

281. See, e.g., EDWARD NEUSCHLER, *CANADIAN HEALTH CARE: THE IMPLICATIONS OF PUBLIC HEALTH INSURANCE* (1990) (evaluating the Canadian national health care system).

282. For example, Senator Bob Kerrey (D-Neb.) is a strong supporter of a national health care system and has introduced legislation to create such a system. S. 1446, 102d Cong., 1st Sess. (1991). See generally, Friedman, *supra* note 270.

283. *Id.*

284. *Id.*

Patients would not be billed for services and the hospitals would consider it a budget expenditure.²⁸⁵ Fee-for-service physicians would submit claims directly to the insuring agency.²⁸⁶

National health insurance would not only address potential concerns regarding genetic testing, but would address the larger problem of the uninsured.²⁸⁷ The need for genetic testing would be eliminated under a system of national health insurance, because it would operate like a very large group policy. National health care, however, is certain to be vigorously opposed and is unlikely to be enacted in the near future. Thus, it does not offer short-term protection against genetic discrimination.

D. *Establish Risk Pools*

Risk pools are a method of providing subsidized health insurance to high-risk people.²⁸⁸ Risk pools would generally be established at the state level, and have already been created in some states.²⁸⁹ A risk pool is an insurance fund that makes coverage available to the medically uninsurable and to those applicants who cannot afford insurance elsewhere.²⁹⁰ Typically, policyholders pay premiums up to a legislatively imposed ceiling.²⁹¹ The remaining funds may be supplied by a market-share-based tax on insurance companies, a premium tax on individuals with health insurance, or from general tax revenues.²⁹² Although risk

285. *Id.*

286. *Id.*

287. See Kevin Grumbach, et al., *Liberal Benefits, Conservative Spending; The Physicians for a National Health Program Proposal*, 265 JAMA 2549 (1991).

288. Schramm, *supra* note 269, at 3297.

289. Kass, *supra* note 8, at 34. See CONN. GEN. STAT. ANN. § 692 (West Supp. 1986); ILL. ANN. STAT. ch. 73, paras. 1301-1314 (Smith-Hurd 1992); IND. CODE ANN. §§ 27-8-10-1 to 8 (Burns 1992); IOWA CODE ANN. §§ 514E.1-.13 (West 1988 & Supp. 1992); MINN. STAT. ANN. §§ 62E.01-.17 (West 1986); MONT. CODE ANN. §§ 33-22-1501 to 1521 (1991); NEB. REV. STAT. §§ 44-4201 to 4235 (1988 & Supp. 1991); N.D. CENT. CODE § 26.1-08 (Michie 1989 & Supp. 1991); TENN. CODE ANN. §§ 56-39-101 to 122 (West 1989 & Supp. 1992); WIS. STAT. ANN. §§ 619.01-.16 (West 1980 & Supp. 1991).

290. James S. Todd, et al., *Health Access America-Strengthening the U.S. Health-care System*, 265 JAMA 2503, 2505 (1991).

291. *Id.*

292. See MODEL HEALTH PLAN FOR UNINSURABLE INDIVIDUALS ACT § 7 (Nat'l Ass'n of Ins. Comm'rs 1992). This model code has been adopted by thirteen states as a response to the rise in the number of uninsurable individuals. NAIC Model Regulation Service (July 1992). See also Todd, *supra* note 290.

pools would not directly prevent abuse of genetic testing, they provide a secondary source of insurance for those rejected coverage based on the results of genetic tests.

E. *Promote Private Reinsurance*

Favored by the insurance industry, private reinsurance is a program for reducing the number of uninsurable people.²⁹³ Reinsurance is simply double insurance. The direct-insurer issues policies to individuals or groups, and purchases insurance from a second insurer to cover unexpected losses.²⁹⁴ This limits the direct-insurer's exposure to loss from high-risk policyholders, theoretically encouraging direct-insurers to take on high-risk applicants.²⁹⁵ Reinsurance is not a complete solution because the medically uninsurable would still be unable to buy coverage, but it would relieve some of the burden that might otherwise fall on the risk pools.²⁹⁶ As with risk pools, reinsurance would not directly prevent abuse of genetic information, but would increase the availability of insurance for those with a genetic predisposition to illness.

F. *Mandate Employer-Funded Health Insurance*

State mandated coverage could consist of a state regulatory requirement that all employers provide health insurance to all their employees.²⁹⁷ However, to provide complete coverage of the population, a pool similar to a risk pool must be established to provide coverage to the unemployed.²⁹⁸ The mandate to provide coverage would include high-risk and medically uninsurable individuals. Proponents estimate that two-thirds of those currently uninsured would become insured under such a proposal.²⁹⁹

293. Schramm, *supra* note 269.

294. *Id.*

295. *Id.*

296. *Id.*

297. Kass, *supra* note 8, at 35. Hawaii has implemented such a system, requiring coverage for all employees who work more than 19 hours a week. Rogers Worthington, *Hawaii Tries Health Coverage For All*, CHICAGO TRIB., Sept. 6, 1992 at C23.

298. *Id.*

299. Ronald S. Bronow, et al., *The Physicians Who Care Plan; Preserving Quality and Equitability in American Medicine* 265 JAMA 2511, 2512 (1991).

Since coverage would be mandated, this proposal would directly address the potential for abuse of genetic testing. However, such legislation would probably be opposed by the business community due to the cost it would impose on employers. Similar to national health insurance, mandatory employer-funded health insurance is not a likely short-term protection against genetic discrimination.

G. *Eliminate the ERISA Exemption for Self-Insureds*

Under ERISA,³⁰⁰ self-insured employee health benefit plans are not subject to state insurance regulations.³⁰¹ This exemption may blunt the effectiveness of state bans on the use of genetic information. The exemption also impacts the viability of risk pools because self-insureds may not be subject to premium or market share taxes. Thus, repeal of the exemption is necessary for effective regulation of the use of genetic information under any of the other proposals.

These proposals are just a few of the many possible health insurance reforms that would protect against genetic discrimination. Each would provide some measure of protection to individuals with a genetic predisposition to disease. Some of the proposals would also address the crisis facing the uninsured in today's health care system.

VII. Conclusion

This Comment has analyzed the potential use and abuse of genetic testing by the health insurance industry, and has presented several options for preventing such abuse. The single most effective way to prevent abuse is a ban on the use of genetic information in health insurance underwriting. A federal ban would provide comprehensive protection, but is unlikely considering the history of congressional deference to state insurance regulation. State bans modeled after the Wisconsin legislation offer a simple, effective means of protection for those with a genetic predisposition to disease. A ban would maintain the status quo, allowing policy-makers, citizens, and the insurance in-

300. 29 U.S.C. §§ 1001-1461 (1988).

301. Kass, *supra* note 8, at 33.

dustry time to evaluate the usefulness and consequences of genetic testing. Such a ban could easily be reconsidered if there is evidence of significant adverse selection or if necessary to adapt to developing genetic technology. Most importantly, a ban would allow individuals with genetic predispositions to remain covered until health care reforms reduce or eliminate the huge numbers of uninsured. Insurers can effectively classify risks without genetic testing. A ban on the requirement or use of genetic testing properly balances the insurers' right to fair and equitable risk classification with the public's interest in access to affordable health insurance.

*Carol Lee**

* To my parents, John and Wol Sue, my brother, Chris, and Jon.