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Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes

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GENETIC DISCRIMINATION, INSURABILITY AND LEGISLATION: A CLOSING OF THE LEGAL LOOPHOLES

Richard A. Bornstein[*]

Why does this magnificent applied science, which saves work and makes life easier, bring us so little happiness? The simple answer runs: Because we have not yet learned to make sensible use of it.

—Albert Einstein[1]

INTRODUCTION

Genetic testing is one of the newest methods for predicting a person's health.[2] While genetic tests can be extremely helpful in preventing disease,[3] they can also prevent many people from

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[1] Address at the California Institute of Technology, *in* GEORGE SELDES, GREAT QUOTATIONS 854-55 (1967).

[2] "Genetic testing" involves "the use of specific assays [analyses] to determine the genetic status of individuals already suspected to be at high risk for a particular inherited condition because of family history or clinical symptoms," while "genetic screening" denotes "the use of various genetic tests to evaluate populations or groups of individuals independent of a family history of a disorder." However, these terms are used interchangeably. ASSESSING GENETIC RISKS 4 (Lori B. Andrews et al. eds., 1994). *See* notes and accompanying text *infra* p. 607 (analyzing the definitions of genetic testing for enacted state legislation).

[3] According to Mark Ferguson, professor of molecular biology at Manchester University, advances in the mapping of human genes will eventually mean that people could obtain a "genetic passport" which would tell them what diseases

obtaining medical insurance because coverage may be denied if genetic test results reveal a propensity for illness.[4] Researchers have found that a number of institutions, including health and life insurers, have discriminated on a genetic basis.[5] People at risk for genetic discrimination[6] include individuals who carry a gene that increases the probability that they will develop a disease but who are currently asymptomatic;[7] individuals who are carriers for certain genetic conditions but who will remain asymptomatic;[8] individuals who have genetic polymorphisms[9] that are not known

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they would likely suffer from in the future. Chris Mihill, *Gene Maps of Illness Risk*, GUARDIAN, Sept. 2, 1993, at 6 ("This information would allow a profound shift towards preventive medicine . . . because people could be treated for or take precautions against the diseases they were at risk of contracting.").

[4] *Genetic Tests Could Help Insurance Firms Discriminate* (All Things Considered-National Public Radio broadcast, June 29, 1995) (transcript No. 1893-15).

[5] *See* Susan Ince, *Predictive Testing; A Bite of the Apple*, HARV. HEALTH LETTER (Harvard Medical School Health Publications Group, Boston, MA), June 1995, at 3, 4 (discussing predictive testing and problems with discrimination); *see also* Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENET. 476 (1992) (describing the results of a case history study showing that genetic discrimination exists); Marvin R. Natowicz et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENET. 465 (1992) (discussing genetic discrimination and the applicability and limitations of federal and state laws in insurance discrimination); Richard Saltus, *Fear of Insurers Leading to Gene Testing in Secret*, BOSTON GLOBE, Sept. 12, 1994, at 1 (discussing the denial of health insurance as a result of genetic information).

[6] "Genetic discrimination" is defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual." Natowicz, *supra* note 5, at 466. "Genome" refers to all of an organism's genetic material in its chromosomes. *Glossary*, *in* THE CODE OF CODES 375, 380 (Daniel J. Kevles & Leroy Hood eds., 1992) [hereinafter *Glossary*]. *See infra* note 19 (defining chromosome).

[7] Natowicz, *supra* note 5, at 466. An individual who is asymptomatic has no disease symptoms. STEDMAN'S MEDICAL DICTIONARY 160 (26th ed. 1995) [hereinafter MEDICAL DICTIONARY].

[8] Natowicz, *supra* note 5, at 466.

[9] A "polymorphism" is "the occurrence in a population of two or more forms of a gene, the least common having a frequence of at least 1%." SHERMAN ELIAS & GEORGE ANNAS, REPRODUCTIVE GENETICS AND THE LAW 97 (1987). An example of a human genetic polymorphism is the ABO blood groups. *Id.*

to cause disease; and relatives of individuals with known or presumed genetic characteristics.[10]

Currently, twelve states have enacted general legislation restricting genetic testing or the use of genetic information in the context of insurance practice,[11] and five of these states have pending legislation to update their genetic testing laws.[12] In addition, at least fifteen more states have some type of genetic discrimination legislation proposed.[13]

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[10] Natowicz, *supra* note 5, at 466.

[11] ARIZ. REV. STAT. ANN. § 20-448 (1990 & Supp. 1995); CAL. CIV. CODE § 56.17 (West Supp. 1996); CAL. INS. CODE § 11512.95 (West 1988 & Supp. 1996); CAL. INS. CODE § 10143 (West 1993); CAL. INS. CODE §§ 10123.3, 10140 (West 1993 & Supp. 1996); CAL. INS. CODE §§ 10123.31, 10123.35, 10140.1, 10140.5, 10146, 10147, 10148, 10149, 10149.1, 11512.96, 11512.965 (West Supp. 1996); CAL. HEALTH & SAFETY CODE § 1374.7 (West 1990 & Supp. 1996); CAL. HEALTH & SAFETY CODE § 1374.9 (West Supp. 1996); COLO. REV. STAT. ANN. § 10-3-1104.7 (1994); FLA. STAT. ANN. § 760.40 (West Supp. 1996); GA. CODE ANN. §§ 33-54-1 to 8 (Supp. 1995); MD. CODE ANN., INS. § 223 (1994); MINN. STAT. ANN. § 72A.139 (West Supp. 1996); MONT. CODE ANN. § 33-18-206 (1995); N.H. REV. STAT. ANN. §§ 141-H:1 to 6 (Supp. 1995); OHIO REV. CODE ANN. §§ 1742.42, 1742.43, 3901.49, 3901.491, 3901.50, 3901.501 (Anderson Supp. 1995); OR. REV. STAT. §§ 659.700, 659.705, 659.710, 659.715, 659.720, 746.135 (1995); WIS. STAT. ANN. § 631.89 (West 1995).

[12] Legislation to update genetic testing laws is pending in California, Florida, Georgia, Maryland and Wisconsin. *See* S.B. 1740, 1995-96 Reg. Sess. (Cal. 1995); S.B. 748, 1996 Reg. Sess. (Fla. 1996); H.B. 923, 1996 Reg. Sess. (Fla. 1996) (identical bills); S.B. 233, 143d Gen. Assembly, 1995-96 Reg. Sess. (Ga. 1995); S.B. 276, 1996 Leg. Sess. (Md. 1996); A.B. 227, 92d Leg. Sess., 1995-96 Reg. Sess. (Wis. 1995).

[13] Genetic testing legislation is pending in fifteen states including Alaska (H.B. 407, 19th Leg., 2d Sess. (Ala. 1995)), Connecticut (H.B. 5705, 1996 Reg. Sess. (Conn. 1996)), Hawaii (S.B. 299, 18th Leg., 1995 Reg. Sess. (Haw. 1995); S.B. 576, 18th Leg., 1995 Reg. Sess. (Haw. 1995); S.B. 2141, 18th Leg., 1995 Reg. Sess. (Haw. 1995); S.B. 2526, 18th Leg., 1995 Reg. Sess. (Haw. 1995); H.B. 1556, 18th Leg., 1995 Reg. Sess. (Haw. 1995)), Illinois (S.B. 1384, 89th Gen. Assembly, 1995-96 Reg. Sess. (Ill. 1995); H.B. 2943, 89th Gen. Assembly, 1995-96 Reg. Sess. (Ill. 1995)), Indiana (H.B. 1200, 109th Gen. Assembly, 2d Reg. Sess. (Ind. 1996)), Kansas (S.B. 444, 76th Leg., 1996 Reg. Sess. (Kan. 1996); H.B. 2251, 76th Leg., 1st Reg. Sess. (Kan. 1995)), Massachusetts (H.B. 4485, 179th Gen. Court, 1st Annual Sess. (Mass. 1995)), Michigan (H.B. 5237, 88th Leg., 1995 Reg. Sess. (Mich. 1995)), Nebraska (L.B. 1216, 94th Leg., 2d Sess. (Neb. 1995)), New Jersey (S.B. 695, 207th Leg., 1st Annual Sess. (N.J.

This Note focuses on the genetic testing legislation. Part I introduces genetic disorders and new gene discoveries. Parts II and III discuss genetic discrimination and the weaknesses of using genetic information for insurance underwriting, respectively. Part IV examines policy issues of privacy and autonomy, and part V analyzes the current legislation, including the scope of protection provided by each law.[14] This Note concludes that there is a trend in the newest enacted laws[15] and in the pending changes to older

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1996); S.B. 854, 207th Leg., 1st Annual Sess. (N.J. 1996); A.B. 1411, 207th Leg., 1st Annual Sess. (N.J. 1996); A.B. 1499, 207th Leg., 1st Annual Sess. (N.J. 1996)), New York (S.B. 15, 218th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); S.B. 869, 218th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); S.B. 4293, 219th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); S.B. 6599, 219th Gen. Assembly, 2d Reg. Sess. (N.Y. 1996); A.B. 161, 218th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); A.B. 5796, 219th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); A.B. 5892, 218th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); A.B. 8963, 219th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995); A.B. 9457, 219th Gen. Assembly, 2d Reg. Sess. (N.Y. 1996)), Oklahoma (H.B. 2478, 45th Leg., 2d Reg. Sess. (Okla. 1995)), Pennsylvania (S.R. 6, 179th Gen. Assembly, 1995-96 Reg. Sess. (Pa. 1995); S.B. 394, 179th Gen. Assembly, 1995-96 Reg. Sess. (Pa. 1995); S.B. 1386, 180th Gen. Assembly, 1995-96 Reg. Sess. (Pa. 1995); H.B. 1026, 179th Gen. Assembly, 1995-96 Reg. Sess. (Pa. 1995); H.B. 1662, 179th Gen. Assembly, 1995-96 Reg. Sess. (Pa. 1995)), Texas (H.B. 343, 74th Reg. Sess. (Tex. 1995)) and Virginia (S.J.R. 50, 1996 Sess. (Va. 1996); S.B. 335, 1996 Sess. (Va. 1996)).

[14] For instance, Maryland's statute prohibits health and life insurers from permitting any differential in ratings, premium payments or dividends because of a genetic trait, but allows consideration if "there is actuarial justification for it." MD. CODE ANN., INS. § 223(a)(3), (b)(4). *See infra* part V.B.1 (discussing Maryland's unfair discrimination statute).

[15] *See, e.g.*, CAL. INS. CODE §§ 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 10143, 10146, 10147, 10148, 10149, 10149.1, 11512.95, 11512.96, 11512.965; CAL. HEALTH & SAFETY CODE §§ 1374.7, 1374.9; GA. CODE ANN. §§ 33-54-1 to 8; MINN. STAT. ANN. § 72A.139. *See infra* part V.C. (discussing trends in the enacted state laws).

laws[16] that is moving in a more comprehensive and consumer protective direction in the area of health insurance.

The enactment of legislation which regulates genetic testing is necessary and overdue. With the discovery of new genes, the causes of genetic disorders are now ascertainable.[17] The majority of states must recognize that legislation is needed to protect individuals from denial or loss of insurance due to this information.

I. GENES AND GENETIC DISORDERS[18]

Humans have twenty-three pairs of chromosomes[19] made of the hereditary material deoxyribonucleic acid ("DNA"),[20] which

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[16] *See, e.g.*, S.B. 748, 1996 Reg. Sess. (Fla. 1996); H.B. 923, 1996 Reg. Sess. (Fla. 1996). Legislation enacted between 1986 and 1992 focused primarily on life insurance, and gave little protection to individuals in the area of health insurance. However, the trend in the law is shifting—between 1993 and 1995, less emphasis was given to life insurance, and greater protections were established for health insurance. *See infra* part V.C. (discussing trends in the enacted state laws).

[17] *See infra* notes 37-41 (discussing new gene discoveries and causes of genetic disease).

[18] Information on genes and the human genome project is available on the Internet from the Uniform Resource Locator: http://www.ornl.gov/TechResources/Human_Genome/home.html. "Begun in 1990 by the National Institutes of Health and the U.S. Department of Energy, the Human Genome Initiative (HGI) is a 15-year coordinated research endeavor. The goal is to locate and identify the functions of the 50,000 [to] 100,000 genes that determine human hereditary characteristics . . . ." Bill Allen & Ray Moseley, *Predictive Genetic Testing: Ethical, Legal, and Social Implications*, USA TODAY, Nov. 1994, at 66, 67. *See Scientists Finish First Phase in Mapping of Human Genes*, N.Y. TIMES, Mar. 19, 1996, at C7 (discussing two "maps" of DNA recently published); *see also* Tim Beardsley, *Trends in Human Genetics; Vital Data*, 274 SCI. AM. 100 (1996) (discussing the "genetic revolution" and implications of the Human Genome Project).

[19] A "chromosome" is defined as "[o]ne of the bodies (normally 46 in humans) in the cell nucleus that is the bearer of genes." MEDICAL DICTIONARY, *supra* note 7, at 338. A "gene" is the "fundamental physical and functional unit of heredity." *Glossary*, *supra* note 6, at 379.

[20] Marne E. Brom, Note, *Insurers and Genetic Testing: Shopping for that Perfect Pair of Genes*, 40 DRAKE L. REV. 121, 123 (1990/1991) (citing JAMES J. NORA & F. CLARKE FRASER, MEDICAL GENETICS: PRINCIPLES AND PRACTICE

is composed of four bases that are paired.[21] Human chromosomes range in size from 50 million to 250 million of these base pairs.[22] The four bases form the "alphabet of the genetic code," and variations in the linear ordering of the bases make up different genetic sequences.[23] Certain segments of these sequences are genes,[24] and it is estimated that up to 100,000 genes exist per

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9 (1989)). Deoxyribonucleic acid ("DNA") is "[t]he type of nucleic acid . . . considered to be the autoreproducing component of chromosomes and of many viruses, and the repository of hereditary characteristics." MEDICAL DICTIONARY, *supra* note 7, at 459.

Although the significance of DNA cannot be overstated in the context of genetic testing and disease predictability, DNA is also becoming extremely important in criminal proceedings. For example, the Florida District Court of Appeals in Andrews v. State, 533 So. 2d 841 (Fla. Dist. Ct. App. 1988), affirmed a defendant's rape conviction on the basis of DNA tests "resulting in the first criminal conviction based on DNA evidence in the United States." Denise A. Filocoma, Comment, *Unravelling the DNA Controversy:* People v. Wesley, *A Step in the Right Direction*, 3 J.L. & POL'Y 537, 542 (1995). Currently, state courts are "grappling" with the issues of DNA reliability and admissibility. *See, e.g.*, James Morgan, *DNA Profiling in North Carolina*, 21 N.C. CENT. L.J. 300 (1995) (discussing "the reliability and the credence the North Carolina courts have given DNA analysis"); Scott D. Sherwood, *The Pennsylvania Supreme Court Defines the Standard of Admissibility for DNA Evidence at Trial*—Commonwealth v. Crews, *640 A.2d 395 (Pa. 1994)*, 68 TEMPLE L. REV. 953 (1995) (discussing the Pennsylvania Supreme Court's admission of testimony concerning DNA matching); Michael J. Short, *Forensic DNA Analysis: An Examination of Common Objections Raised to the Admission of DNA Fingerprinting as Illustrated by* State v. Pierce, 19 DAYTON L. REV. 133 (1993) (discussing the admissibility of DNA testing in criminal trials); Filocoma, *supra* (analyzing the New York Court of Appeals decision which found "DNA evidence was . . . generally accepted as reliable"); Sarah E. Snyder, Note, *Experimental or Demonstrable: Has DNA Testing Truly Emerged from the Twilight Zone? An Assessment of Washington's Response to DNA Identification*, 31 WILLAMETTE L. REV. 201 (1995) (discussing Washington state's handling of the introduction of DNA evidence in criminal trials).

[21] Daniel J. Kevles, *Out of Eugenics: The Historical Politics of the Human Genome*, *in* THE CODE OF CODES, *supra* note 6, at 3, 15. The bases are bonded together in pairs of either adenine and thymine or cytosine and guanine. Kevles, *supra*, at 15.

[22] Kevles, *supra* note 21, at 17.

[23] Kevles, *supra* note 21, at 15.

[24] Kevles, *supra* note 21, at 15.

person.[25] Genes are responsible for the structures and properties of proteins which make up a large portion of the body.[26] A mutation in a gene may lead to defects in the corresponding protein, resulting in a genetic disease.[27]

More than 5,000 human disorders have a genetic component,[28] and affect over half the population of the United States.[29] Certain disorders can be caused directly by gene defects,[30] while others,

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[25] William H. Alexander, *Overview of Genetics*, *in* THE POTENTIAL ROLE OF GENETIC TESTING IN RISK CLASSIFICATION 31, 33 (Genetic Testing Committee to the Medical Section of the American Council of Life Insurance ed., 1989) (noting that 100,000 genes make up only six percent of the total chromosomal DNA while the rest is repetitive, involved in regulatory function or has no known function). Only 8,000 human genes have been identified to date. James Schultz, *Average Americans Will Gain from Gene Study, Expert Says; Researchers Believe Cures Are Embedded in Genetics*, VIRGINIAN-PILOT, Oct. 11, 1995, at B1. However, identification has rapidly accelerated since the late 1980s, and today, four to five new genes are discovered each week. *Id.*

[26] Sue Goetinck, *A New Body of Knowledge; Gene Project Unravels Mysteries, Changes Future Course of Biology*, DALLAS MORNING NEWS, Oct. 15, 1995, at 1J. Proteins make up skin, hair and organs. Other proteins "integrate the different parts of the body, process information in the brain, send and receive hormone signals, and activate other genes." *Id.*

[27] Brom, *supra* note 20, at 123.

[28] Steve Gushee, *Tempest in a Test Tube*, PALM BEACH POST, May 29, 1995, at 1D (noting that 150 new genetic diseases are discovered each year). More than 15 million Americans suffer from inherited diseases which also account for one-third of all childhood hospitalizations, and almost half of all infant deaths. Chris Petrakos, *Theory of Relativity; A Family Medical Tree Can Get to the Root of Health Concerns*, CHI. TRIB., Sept. 25, 1995, at 1 (according to statistics of the Hereditary Disease Foundation in Santa Monica, California).

[29] Alexander, *supra* note 25, at 31. More than 125 million Americans are affected by a human disorder with a genetic component. Henry T. Greely, *Health Insurance, Employment Discrimination, and the Genetics Revolution*, *in* THE CODE OF CODES, *supra* note 6, at 264, 265.

[30] An example of a disease caused directly by a gene defect is cystic fibrosis. Alexander, *supra* note 25, at 31. Cystic fibrosis "is the most common simple genetic disease, occurring once in every 2,300 births." Daniel Green, *Testing Ground for Gene Therapy—Cystic Fibrosis Is Heavily Researched but Progress Has Been Faltering*, FIN. TIMES, Feb. 27, 1996, at 12. The cystic fibrosis gene is responsible for a protein which regulates the movement of salt across body membranes. *Id.*

like heart disease and some cancers, may result from a genetic predisposition.[31] Genetic disorders can be classified into three categories: large chromosomal abnormalities,[32] single gene molecular mutations[33] and multi-factorial disorders.[34] While some individuals may not suffer from genetic disease, they may carry an aberrant gene which can pass to their offspring.[35]

Genetic disorders are discoverable through genetic testing.[36] The availability of genetic testing is increasing as a result of recent

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> [T]he movement of salt in solution across the surface of the lung is slowed. That leaves the mucus that coats the lung much stickier than in healthy people. It becomes both an obstacle for breathing and a hospitable place for bacteria to multiply. Most cystic fibrosis sufferers die from lung disease before the age of 30.

Id.

[31] Alexander, *supra* note 25, at 31. An individual has the propensity to develop a genetic disorder when environmental factors "[tip] the balance of the genetically primed individual towards disease." Alexander, *supra* note 25, at 35.

[32] Chromosomal abnormalities result from changes in the structure or number of chromosomes. OFFICE OF TECHNOLOGY ASSESSMENT, MAPPING OUR GENES; GENOME PROJECTS: HOW BIG, HOW FAST? 25-26 (1988) [hereinafter MAPPING OUR GENES]. An example is Down's syndrome which results from three copies of chromosome 21 instead of the normal two. Alexander, *supra* note 25, at 31.

[33] Molecular mutations result from changes in the sequence or number of bases that make up DNA. MAPPING OUR GENES, *supra* note 32, at 25. An example of a disease caused by molecular mutations is sickle cell anemia. Alexander, *supra* note 25, at 31. Sickle cell anemia results from a substitution in the DNA of an adenine by a thymine. ELIAS & ANNAS, *supra* note 9, at 101. The disease is characterized by crescent-shaped red blood cells. MEDICAL DICTIONARY, *supra* note 7, at 78.

[34] A disorder is multi-factorial when its expression depends both on one or more pairs of genes, each having a small additive effect, and factors in the environment. Alexander, *supra* note 25, at 35. The bulk of adult diseases are multi-factorial, and "display variable patterns of inheritance." Alexander, *supra* note 25, at 31. Examples are diabetes mellitus, heart disease and mental disorders, such as manic depression. Alexander, *supra* note 25, at 31.

[35] Alexander, *supra* note 25, at 31-32. "The thousands of genes that we inherit from our parents at the moment of conception not only determine our physical characteristics, such as the color of our hair and eyes, but they exert a strong influence over our health." Petrakos, *supra* note 28, at 1.

[36] Natowicz, *supra* note 5, at 465.

advances in genetics that have improved the understanding and diagnosis of many disorders.[37] Currently, hundreds of tests that identify an individual's genetic predisposition to rare inherited disorders are available.[38] Moreover, many tests will soon predict

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[37] Natowicz, *supra* note 5, at 465. For example, scientists recently discovered a protein (HAP1) that may interact with the defective protein of a mutated Huntington's disease gene, causing a "cascade of events that kill cells in Huntington patients' brains." Sandra Blakeslee, *Newfound Brain Protein May Be 'Smoking Gun' in Huntington's Disease*, N.Y. TIMES, Nov. 14, 1995, at C3. *See* Sandra Blakeslee, *Protein Culprit Acts to Cause Huntington's*, N.Y. TIMES, Mar. 5, 1996, at C8 (discussing "new insight into the underlying mechanisms in Huntington's disease"). Huntington's is a rare disease which affects one person in 10,000. Richard Saltus, *Genetic Clairvoyance*, BOSTON GLOBE, Jan. 8, 1995, (Magazine), at 14, 26. "About 150,000 relatives of [Huntington's disease] patients in the United States are at risk." *Id.* Huntington's disease usually does not manifest until the thirties, forties, or later, and is known as an "adult-onset" disorder. *Id.* at 32. An afflicted person loses body movement control as "vital parts of the brain atrophy." Personality changes and depression are also common. *Id.* After 15 to 20 years, the "disability and dementia worsen" and much of the patient's memory and speech is destroyed. Death often results from infection. *Id. See generally* Simeon Margolis, *Diagnosing, Predicting Huntington's Disease*, BALTIMORE SUN, Dec. 19, 1995, at 5E.

In addition, researchers have discovered a gene which causes malignant melanoma, an aggressive form of skin cancer, Lawrence Fisher, *Second Gene is Linked to a Deadly Skin Cancer*, N.Y. TIMES, Jan. 2, 1996, at B18, and a gene linked to pancreatic cancer. *Gene Discovery; Another Gene Linked to Pancreatic Cancer*, Feb. 12, 1996, *available in* LEXIS, Nexis Library, CURNWS File. Scientists also claim there may even be possible genetic links with homosexuality, shyness, grammar, aggression and alcoholism. Joe Donnelly, *Joe Donnelly Reports on the Benefits of a Genetic Breakthrough and Warns of the Ethical Dangers*, HERALD (GLASGOW), Oct. 19, 1995, at 16; *see also* Nigel Hawkes, *Bad-tempered and Extravagant? Blame it on the Genes*, Jan. 2, 1996, *available in* LEXIS, Nexis Library, CURNWS File (discussing a gene independently identified by two groups of scientists "that makes some people extrovert[ed] and eager for new experiences and others stolid and introverted").

[38] About 500 laboratories in the United States provide some type of genetic testing. *Genetic Screening: An Idea Whose Time is Coming, Slowly*, Sept. 1994, *available in* LEXIS, Nexis Library, CURNWS File. "The genetic diagnostic market in the United States currently consists of tests for the prenatal detection of chromosomal abnormalities, identification of genetic defects in infants, testing for both the disease and carriers of single-gene defects, and detection of genetic cancer markers." *Id.* Genetic tests for the following diseases are now available: some forms of leukemia, some forms of cancer, cystic fibrosis, fragile X (type

more common illnesses, such as heart disease.[39] Gene discoveries concerning Alzheimer's disease[40] and, more recently, breast

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of mental retardation), myotonic dystrophy (progressive muscle weakness, MEDICAL DICTIONARY, *supra* note 7, at 537), some forms of ataxia (inability to coordinate muscle activity, MEDICAL DICTIONARY, *supra* note 7, at 161), hemophilia, Huntington's disease, sickle cell anemia and Tay-Sachs disease. Gordon Slovut, *Genetics and Medicine; Genetic Testing Makes an Ounce of Prediction Worth Pound of Fear; Patients, Insurers, Doctors Question Who Should Be Told*, STAR TRIB., Oct. 25, 1995, at 1A. *See* Heather McClure, *The Insurance Industry's Use of Genetic Information: Legal and Ethical Concerns*, 28 J. HEALTH & HOSP. L. 231, 232-33 (1995) (listing genetic tests available and their costs); *see also Genetic Disease is Targeted; Testing Offered for Those at Risk of Developing Huntington's Disease*, MILWAUKEE J. SENTINEL, Oct. 2, 1995, at 5 (highlighting two physicians that offer presymptomatic testing for people at risk of developing Huntington's disease); *New Test to Detect Cancer Proves Cheaper and More Precise*, Feb. 2, 1996, *available in* LEXIS, Nexis Library, CURNWS File (discussing a new test to detect bladder cancer which is "twice as precise and much less expensive than tests currently used"); Denise Grady, *Tracing a Genetic Disease to Bits of Traveling DNA*, N.Y. TIMES, Mar. 5, 1996, at C1, C5 (discussing a discovery concerning Charcot-Marie-Tooth syndrome, a nerve deterioration disorder, that can "lead to simpler diagnostic tests").

[39] Seth Shulman, *Legislation Aims to Prevent Genetic Discrimination by Insurers*, TIMES UNION, July 16, 1995, at E2. Genetic tests will soon be available for the following diseases: heart disease, prostate, colon, melanoma and lung cancers, autoimmune diseases, diabetes and Alzheimer's disease. Slovut, *supra* note 38, at 1A. *See* Ulysses Torassa, *Family Ties*, PLAIN DEALER, Dec. 17, 1995, at 5 (discussing the process of one scientist's discovery of a colon cancer gene); *see also* Michael Lasalandra, *Hub Researchers Help ID Alzheimer's Gene*, BOSTON HERALD, Aug. 18, 1995, at 5; Paul Recer, *Gene Discovery May Be a Key to Puzzles of Cancer*, SAN DIEGO UNION & TRIB., June 23, 1995, at A1; *Discovery of Breast Cancer Gene Opens New Research Door*, CHI. TRIB., Feb. 15, 1995, at 7.

[40] *See* Gina Kolata, *If Tests Hint Alzheimer's, Should a Patient Be Told?*, N.Y. TIMES, Oct. 24, 1995, at A1, C6. Researchers have confirmed a link between Alzheimer's disease and the apoE gene. *Id.* at C6. There are four variations of the apoE gene (E1, E2, E3 and E4), and according to studies, individuals who inherit two copies of apoE4 have approximately six times the normal risk of developing the disease. *Id.* Inheriting only one copy of apoE4 confers a threefold increased risk. *Id.* In contrast, inheriting two copies of apoE2 may protect a person from developing Alzheimer's. *Id.* "From half to two-thirds of all Alzheimer's patients have at least one copy of an apoE4 gene. But just 15[%] of the general population has an E4 gene." *Id.*

cancer[41] now elucidate the causes of these diseases. Thus, the

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[41] *See* Gina Kolata, *Breast Cancer Gene in 1% of U.S. Jews*, N.Y. TIMES, Sept. 29, 1995, at A24. Biologists have discovered that a particular genetic defect in the gene BRCA1, which was found to be associated with familial breast cancer, is found with unusual frequency in American Ashkenazi Jews (whose ancestors lived in Eastern and Central Europe). *Id.* The mutation is a small deletion of genetic material which causes a defective protein, destroying the gene's function of suppressing malignant changes. *Id.* Women with both a BRCA1 mutation and a family history of breast cancer are at a considerably increased risk to develop breast cancer. *Id.* "[T]he mutation confers an 80[%] to 90[%] chance of getting breast cancer and a 40[%] to 50[%] chance of developing ovarian cancer. There are also hints that it might lead to colon cancer and, in men, prostate cancer." *Id.* As many as 1% of Ashkenazi Jews have this mutation, which in effect amounts to 1% of all American Jews since 90% to 95% are of Ashkenazi descent. *Id.* It is estimated that the mutation could account for as much as 16% of the breast cancer and 39% of the ovarian cancer in Jewish women under age 50. Robert Cooke & Earl Lane, *Cancer-Enhancing Mutation Found in Certain Jews; Genetic Aberration in Eastern European Women Could Bring Widespread Screening,* AUSTIN AM. STATESMAN, Sept. 29, 1995, at A4. Only one in 800 non-Jews are expected to have this genetic defect. Kolata, *supra*, at A24. According to Dr. Francis S. Collins, director of the National Center for Human Genome Research in Bethesda, Maryland, this mutation is the most common genetic disorder for the Jewish population. Kolata, *supra*, at A24; *see also* Richard Saltus, *Gene in Some Jewish Women Tied to Cancer Risk,* BOSTON GLOBE, Sept. 29, 1995, at 1 (describing the genetic mutation and its implications).

Furthermore, researchers have recently discovered that women with breast cancer who do not have a family history of the disease have certain abnormalities related to the BRCA1 gene. Gina Kolata, *Research Links Single Gene to Almost All Breast Cancers*, N.Y. TIMES, Nov. 3, 1995, at A1, D19. In addition, new studies have shown that the BRCA1 gene is often the cause of breast cancer in women in their twenties and thirties, even when there is no familial history. *Breast Cancer in Young Tied to Faulty Gene*, N.Y. TIMES, Jan. 18, 1996, at A19. According to Dr. Richard Klausner, director of the National Cancer Institute, "[i]t takes genetic susceptibility the next step—from individuals who are members of pre-selected families with a history of cancer—and now looks at all young women." *Id.* at A19. Therefore, the BRCA1 gene plays even more of a pivotal role in breast cancer than previously suspected. Kolata, *supra*, at D19. *See* Natalie Angier, *Surprising Role Found for Breast Cancer Gene*, N.Y. TIMES, Mar. 5, 1996, C1, C3 (discussing the discovery of essential properties of the BRCA1 gene that could lead to new treatments). Moreover, on December 21, 1995, another breast cancer gene, BRCA2, was disclosed. Gina Kolata, *Scientists Speedily Locate a Gene that Causes Breast Cancer; Better Screening Is Seen*,

medical community must immediately confront ethical issues,[42] such as whether to deliver genetic services to the general population, because researchers are ready to execute genetic screenings.[43]

N.Y. TIMES, Dec. 21, 1995, at B18. Mutations in this gene may "account for an additional third of hereditary breast cancer and possibly all of it that is not caused by BRCA1 mutations." *Id.*

[42] According to one commentator, "[a] technology-driven culture says let's introduce the technology first and the ethics questions second." John A. Nagy, *Scientists Dig for Diseases' Roots*, GREENSBORO NEWS & REC., Nov. 13, 1995, at A1 (quoting Nancy King, a specialist in medical ethics at the University of North Carolina-Chapel Hill). Doctors face ethical issues of confidentiality and disclosure if patients with genetic diseases refuse to share the information with family members. Marilyn Moysa, *Disclosure of 'Bad Genes' Urged in Study; MD-Patient Confidentiality at Issue*, EDMONTON J., Dec. 23, 1995, at A3. In addition, doctors may diagnose genetic disorders, but may not be able to offer cures or preventive measures. *See* Laurie Smith Anderson, *Scientists Explore Implications of New Knowledge About Genes*, ADVOCATE, Feb. 15, 1996, at 18A; Fletcher Stack, *Ethics: Lines Graying in Medicine*, SALT LAKE TRIB., Dec. 25, 1994, at A1. Other ethical issues involving widespread genetic testing include "labeling and discrimination," and the fact that people will "give too much weight to the genetic component of behavior and neglect social elements." Stack, *supra*, at A1. The ultimate ethics questions deal with "breeding a 'superior' human being based on the parents' desirable genetic traits," and sterilizing or even killing "people with 'undesirable' traits." Stack, *supra*, at A1; *see also* Sandra Blakeslee, *Advances in Genetics Give Biology Curriculums a Thought-Provoking New Dimension*, N.Y. TIMES, Mar. 6, 1996, at B9 (discussing a new biology curriculum that contains exercises exploring the "ethical questions raised by [genetic] research"); John F. Haught, *Ethical Views of Humans and Genetic Engineering*, WASH. TIMES, Mar. 31, 1996, at B8 (commenting on the ethical issues raised by Philip Kitcher's recent book THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES (1996)).

[43] General population screenings can now be achieved. For instance, biologists have discovered a genetic defect in the gene BRCA1 which causes breast cancer, and the defect is the most common genetic disorder for the Jewish population. Kolata, *supra* note 41, at A24. Because there are six million Ashkenazi Jews in the United States, testing would be easy because it involves looking for a single gene alteration at a known position. Kolata, *supra* note 41, at A24. Thus, as of September 1995, large scale genetic screening can be easily done to test millions of healthy people for breast cancer. *See Cancer Gene Analysis Announced Available to High Risk Patients*, Jan. 22, 1996, *available in* LEXIS, Nexis Library, CURNWS File (discussing a Maryland company's offering of BRCA1 genetic testing "to any person in the United States who is

II. DISCRIMINATION BY INSURERS USING GENETIC TESTING

A large majority of the United States population is covered through a variety of health care mechanisms,[44] which include private group insurance, individually purchased insurance, Medicare and Medicaid.[45] Individually purchased health insurance is based on medical underwriting,[46] which takes an individual's health

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considered to be at high risk for inherited breast-ovarian cancer . . ."); Gina Kolata, *Breaking Ranks, Lab Offers Test to Assess Risk of Breast Cancer*, N.Y. TIMES, Apr. 1, 1996, at A1 (discussing a Virginia company's decision to offer BRCA1 genetic tests to the general public). Moreover, recent mutations found in the BRCA2 gene may "account for an additional third of hereditary breast cancer and possibly all of it that is not caused by BRCA1 mutations." Kolata, *supra* note 41, at B18. As a result of this discovery, scientists "will be able to offer greatly improved genetic screening to women in so-called breast cancer families." Kolata, *supra* note 41, at B18. For a discussion of the negative social and psychological consequences of widespread genetic screening, see Angus Clarke, *Populations Screening for Genetic Susceptibility to Disease*, 310 BRITISH MED. J. 35 (1995); *see also* Catherine Clabby, *Scientist Discovers 2nd Breast Cancer Gene; Duke Researcher's Concern About Bias in Insurance Mutes Medical Triumph*, NEWS & OBSERVER, Dec. 21, 1995, at A1 (discussing the offering of BRCA1 and BRCA2 genetic tests at Duke University, and the negative implications of such tests); Warren E. Leary, *Doctors' Group Recommends Reducing Cholesterol Checks*, N.Y. TIMES, Mar. 1, 1996, at A18 (discussing guidelines which recommend restricting routine cholesterol testing to 35 to 65-year-old men and 45 to 65-year-old-women).

[44] Approximately 84% of the United States population, or 210 million people, was covered by health insurance in 1994, *Pulse; Uninsured*, N.Y. TIMES, Oct. 28, 1995, at 23, while approximately 40 million people were uninsured. Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need For Reform*, 270 SCIENCE 391, 391 (1995).

[45] Greely, *supra* note 29, at 265. Ten to fifteen million people rely on individually purchased health insurance while approximately 150 million have private group insurance, usually as an employee, employee's spouse or dependent. Greely, *supra* note 29, at 265. In addition, approximately 55 million Americans rely on public insurance like Medicare and Medicaid. Greely, *supra* note 29, at 265.

[46] Greely, *supra* note 29, at 265. "Medical underwriting" is the process used by an insurance company to evaluate different risk factors including age, gender, health history, general physical condition, occupation, alcohol or tobacco use, family history and serum cholesterol, in order to determine an applicant's

status into account when an application for insurance is reviewed.[47] Therefore, improvements in predicting a person's

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contribution to the common "pool" of all policy holders. Robert J. Pokorski, *Principles of Insurance and Risk Classification, in* THE POTENTIAL ROLE OF GENETIC TESTING IN RISK CLASSIFICATION, *supra* note 25, at 45, 45. "The higher the risk, the higher the premium; the lower the risk, the lower the premium." Pokorski, *supra*, at 45. The goal of underwriting is to treat policyholders with "similar expected risk of loss" the same. Pokorski, *supra*, at 45. Insurance rates and premiums are computed on the basis of actuarial tables consisting of statistical data which indicates life expectancy and mortality. BLACK'S LAW DICTIONARY 36 (6th ed. 1990).

A current debate exists over whether insurers should be allowed to use an individual's genetic information for underwriting. Insurers argue that if genetic information is available, "they have an undisputed right to it." Damian Reece, *A Premium on Your Genes; Insurers Want Access to Genetic Test Results but a Row is Brewing Over the Ethics of Their Demands*, SUN. TELEGRAPH, Feb. 11, 1996, at 10. They claim that by withholding the information "the principle of life assurance would collapse." *Id; see also* Roberta B. Meyer, *Justification for Permitting Life Insurers to Continue to Underwrite on the Basis of Genetic Information and Genetic Test Results*, 27 SUFFOLK U. L. REV. 1271 (maintaing that life insurers should be allowed to use genetic information in underwriting). *See* notes and accompanying text *infra* part III (discussing the weaknesses of using genetic testing to underwrite), and notes and accompanying text *infra* p. 608 (comparing health and life insurance).

[47] Greely, *supra* note 29, at 265. Individuals participating in a public insurance plan, such as Medicare, Medicaid and Social Security, are automatically insured, including those deemed poor risks and those with terminal illnesses. Robert J. Pokorski, *Public and Government Relations Issues, in* THE POTENTIAL ROLE OF GENETIC TESTING IN RISK CLASSIFICATION, *supra* note 25, at 9, 11. Additionally, in private group health insurance, insurers consider relevant characteristics of the group, and not characteristics of each individual member. T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification?*, 60 DEF. COUNS. J. 249, 257 (1993). In fact, evidence of the insurability of each individual is usually not required. *Id.* However, an employer may discriminate and reject an applicant based on genetic information due to the possibility of increased medical and insurance premiums. Kimberly Nobles, Note, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081, 2089 (1992). *See generally* Mark Rothstein, *Discrimination Based on Genetic Information,* 33 JURIMETRICS J. 13 (1992) (illustrating the use of genetic information by employers); *see also* discussion of the Americans with Disabilities Act ("ADA") *infra* pp. 581-82 (discussing recent Equal Employment Opportunity Commission guidelines that extend coverage of the ADA to individuals regarded as having genetic impairments).

health will greatly affect individually purchased insurance,[48] and unfortunately also lead to discrimination based on genetic information.

Insurance companies have used the results of genetic tests "to justify canceling coverage, saying that a genetic abnormality is a preexisting condition; to deny coverage to unaffected relatives of a person with a genetic disorder; and to refuse to issue a policy unless an applicant submits to a genetic test."[49] In one study, researchers found that one hundred people were denied insurance benefits because of genetic risks.[50] According to one commentator, twenty-two percent of families that were diagnosed with a genetic flaw have been denied health insurance,[51] while a survey of families with inherited diseases found that thirty-one percent were denied coverage although there was no actual illness.[52]

Individuals at risk for genetic discrimination include those who carry a gene for a disease that may develop, but are currently asymptomatic.[53] One example of this involved an eight-year-old girl who was diagnosed as having phenylketonuria ("PKU")[54] when she was fourteen-days-old.[55] At that time a low phenylalanine diet was instituted.[56] According to her clinical geneticist,[57]

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[48] Greely, *supra* note 29, at 265.

[49] Ince, *supra* note 5, at 4.

[50] Richard Liefer, *Congress Told to Protect Privacy of Americans Who Get Gene Tests*, CHI. TRIB., Sept. 30, 1995, at 10.

[51] *Genetic Knowledge Brings Ethical Dilemmas*, MILWAUKEE J. SENTINEL, Oct. 6, 1995, at 2.

[52] Liefer, *supra* note 50, at 10. Many people ask their health care providers if they can pay for genetic tests in cash in order to keep the results from their insurance companies. Paul Cotton, *Prognosis, Diagnosis, or Who Knows? Time to Learn What Gene Tests Mean*, 273 JAMA 93, 93 (1995).

[53] Natowicz, *supra* note 5, at 466.

[54] Phenylketonuria ("PKU") is an inherited disease in which the amino acid phenylalanine cannot be metabolized. If special diets are not instituted, mental retardation, seizures and psychotic disorders will develop. Laurie Smith Anderson, *Should Newborns Undergo Routine Genetic Tests as They Become Available?*, BATON ROUGE ADVOC., Nov. 4, 1994, at 1C, S.

[55] Billings, *supra* note 5, at 478.

[56] Billings, *supra* note 5, at 478.

[57] A "clinical geneticist" is "[a]n individual who holds an M.D., D.D.S., D.M.D., or D.O. degree and can demonstrate competence to provide

> [g]rowth and development have been completely normal. . . . Routine developmental assessments done at 26 weeks, 53 weeks, and 54 months revealed skills solidly appropriate for age, and in many instances skills were above age expected levels. The child continues to be developmentally normal and be healthy. The circumstances of the discrimination that this child has experienced involve rejection for medical insurance. . . . [W]hen [her father] changed jobs recently, he was told that his daughter was considered to be a high risk patient because of her diagnosis, and therefore ineligible for insurance coverage under their group plan. She is currently being covered at the expense of her family, but this is a temporary solution at best.[58]

Thus, insurers will deny insurance based on genetic information even though an individual may never manifest the genetic disorder.

Another group of individuals at risk for genetic discrimination includes relatives of people with known or presumed genetic characteristics.[59] An example is discrimination against a person with a familial history of Huntington's disease, a rare disease which affects one person in 10,000.[60] "About 150,000 relatives of [Huntington's disease] patients in the United States are at risk."[61] For instance, "[i]n Boston, a woman with a family history of Huntington's made [thirteen] unsuccessful applications for health insurance before the test showed she hadn't inherited the gene. . . . 'She couldn't even get insurance for her children.'"[62]

Genetic discrimination also occurs with otherwise healthy individuals. One example of this discrimination involved a man

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comprehensive diagnostic, management, and counseling services." ELIAS & ANNAS, *supra* note 9, at 36. *See generally* Kathy Katella, *Connecticut Q&A: Ellen Matloff; The Secrets of Your Genes and What to Do*, N.Y. TIMES, Mar. 24, 1996, at 3 (containing excerpts from a conversation about genetic testing with genetic counselor Ellen Matloff); A.B. 7840, 219th Gen. Assembly, 1995-96 Reg. Sess. (N.Y. 1995) (proposing regulations on the licensure of genetic counselors).

[58] Billings, *supra* note 5, at 478.

[59] Natowicz, *supra* note 5, at 466.

[60] Saltus, *supra* note 37, at 26.

[61] Saltus, *supra* note 37, at 26.

[62] Saltus, *supra* note 5, at 1 (quoting Richard Myers, a geneticist at Boston University Medical Center).

who suffered a heart attack.[63] His insurer "refused to pay the hospital bills or cover future treatment for cardiovascular disease" after a genetic test revealed he had a hereditary type of high cholesterol.[64] The insurer argued that since he had the "faulty gene" at birth, it "counted as a preexisting condition."[65] Such

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[63] Ince, *supra* note 5, at 3-4.

[64] Ince, *supra* note 5, at 4.

[65] Ince, *supra* note 5, at 4. A "preexisting condition" is a "condition which either existed at the inception of the [insurance] contract or that occurs during a prescribed period after the insurance goes into effect." Alan I. Widiss, *To Insure or Not to Insure Persons Infected with the Virus that Causes AIDS*, 77 IOWA L. REV. 1617, 1714 (1992). Preexisting condition clauses exclude, restrict or postpone insurance coverage. *Id.* In general, insurers refuse to issue insurance to individuals when the risk of developing the disease is too great. Pokorski, *supra* note 46, at 46.

> There is a point where yearly premiums for certain risks become so high that they appear to be unaffordable to most people. At this point, only a very small percent of those who are offered such insurance will accept. And these tend to be people who know more about their health problems than the underwriter was able to learn. So even if the premium were set quite high, it would probably be inadequate to cover claims.

Pokorski, *supra* note 46, at 46.

On July 13, 1995, Senators Nancy Kassebaum (R-KS) and Edward Kennedy (D-MA) introduced the Health Insurance Reform Act of 1995, which would prohibit insurers from denying individuals insurance coverage based on preexisting conditions. S. 1028, 104th Cong., 1st Sess. (1995). President Bill Clinton endorsed the bill during his State of the Union Address on January 23, 1996. Christina Kent, *Bipartisan Push for Insurance Reform Bill*, AM. MED. NEWS, Feb. 12, 1996, at 3. *See* Helen Dewar, *Key GOP Senators Agree to Consider Limited Health Insurance Bill in Spring*, WASH. POST, Feb. 7, 1996, at A5 (discussing the legislation). Representative Marge Roukema (R-NJ) introduced an almost identical bill in the House of Representatives on January 25, 1996. H.R. 2893, 104th Cong., 2d Sess. (1996). However, Representative Dennis Hastert (R-IL), leader of the House Republican task force on health care reform, advocates a different "multi-pronged approach aimed at providing affordable coverage. . . ." Bob Estill, *Democrats Alter Diagnosis of Republican Health Plan*, STATE J. REGISTER, Mar. 15, 1996, at 9. Representative Bill Archer (R-TX) utilized this approach when he introduced the Health Coverage Availability Act of 1996 on March 18, 1996. H.R. 3103, 104th Cong., 2d Sess. (1996). The bill was amended by H.R. Res. 392, 104th Cong., 2d Sess. (1996), which substituted and combined H.R. 3103 with H.R. 3160, 104th Cong., 2d

actions by insurance companies have negative implications for many healthy and insured individuals. Once a gene is linked with a particular disease, sufferers of the disease could lose their insurance and security because of an unknown "preexisting condition."[66] The threat of genetic discrimination is real, and "millions of Americans risk losing health coverage because they carry genes making them vulnerable to disease."[67]

III. WEAKNESSES OF USING GENETIC TESTING FOR INSURABILITY

Insurers currently use family history in medical underwriting, which acts as a surrogate for genetic information.[68] According to

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Sess. (1996). The House passed this substituted version on March 28, 1996, with all Republicans except Marge Roukema voting for the bill. Robert Pear, *House Approves a Bill to Broaden Health Insurance*, N.Y. TIMES, Mar. 29, 1996, at A1. *See* notes and accompanying text *infra* pp. 585-87 (discussing the genetic information provisions of H.R. 3103/3160). In response to the Republican approach, House Minority Leader Richard Gephardt (D-MO) stated that:

> the Republicans want to turn a straightforward health insurance reform bill into a special interest smorgasbord. According to Congressman Dennis Hastert, they plan to load up the bill with controversial, divisive provisions that would doom its chance of becoming law. At the same time, it is still unclear whether their bill would even contain the insurance reforms people need and demand.

Statement by House Democratic Leader Richard A. Gephardt on Republican Plan to Load Up Health Insurance Reform Bill with Controversial Provisions, PR Newswire, Mar. 8, 1996, *available in* LEXIS, Nexis Library, WIRES File.

[66] "[E]very single person has between 10 and 20 genes that are abnormal or mutated." Katella, *supra* note 57, at 3. In addition, "[s]cientists believe that each person carries five genes that are capable of causing disease or disability or even death." *The Age of Genes*, INDIANAPOLIS STAR, Oct. 23, 1995, at A6. For instance, one person out of every 20 carries the recessive gene for cystic fibrosis. Paul Daugherty, *Esiason Finds Life Lacks Warnings; Son of Jets Quarterback Diagnosed with Cystic Fibrosis*, SAN FRAN. EXAMINER, June 27, 1993, at C2. A child may suffer from cystic fibrosis if both parents are carriers. *Id.*

[67] *Medical Ethics: Experts Recommend Genetic Privacy Laws*, AM. HEALTH LINE, Oct. 23, 1995, at 12 (citing top U.S. health officials who appealed to insurance companies to end "discriminatory insurance practices").

[68] *A Little Knowledge*, ECONOMIST, Feb. 25, 1995, at 13, 15. The purpose of using familial history is to achieve actuarial fairness. *Id.* "If people can be

a 1992 survey by the United States Office of Technology Assessment, a majority of insurers believe that it is fair for them to have access to genetic test results for medical underwriting.[69] Although insurers regard genetic testing as "an extension of diagnostic tests that describe people's current condition,"[70] they should acknowledge the difference between tests that reveal existing health problems, and those that only predict disease susceptibility.[71] Moreover, genetic tests do not predict an illness' severity or the age of onset.[72]

Another problem with relying on genetic tests for medical underwriting is that reliance on genetic tests may cause insurers to overlook environmental factors that affect a person's health.[73] As one commentator pointed out, "in our excitement we forget that there's still the nurture part of the equation. It hasn't gone away just because we have the opportunity to understand the nature part

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sorted into different classes of risk, those in the lower risk categories should pay lower premiums for the same cover." *Id.* Knowing an individual's genetic information from testing could make medical insurance actuarially fairer because people with unknown predispositions are currently treated the same as other applicants. *Id.* However, "[i]t might be actuarially unfair on the utterly healthy; but one of the implications of genetic testing is that no one is utterly healthy. At some level, there is something in everyone's genome that could get them into trouble eventually." *Id.*

[69] ASSESSING GENETIC RISKS, *supra* note 2, at 269-70.

[70] *Genetic Testing; Protecting the Rights of the Insured*, STAR TRIB., Feb. 14, 1995, at 12A [hereinafter *Protecting the Rights of the Insured*].

[71] *Id.* The accuracy of a particular genetic test in predicting susceptibility depends on the disease. *Id.* For most illnesses, the accuracy is less than 100%. *Id.* Genetic tests for illness, such as a predisposition for cancer, only yield a probability and not a specific prediction because some people who carry the gene may not develop the disease. Saltus, *supra* note 37, at 33-34.

[72] *Protecting the Rights of the Insured*, *supra* note 70, at 12A. For example, although the genetic test for the gene that causes Huntington's disease is completely accurate, a positive result does not predict when the disease will appear. Saltus, *supra* note 37, at 33. Thus, an individual may be denied insurance based on genetic information while completely healthy. *See* Susan O'Hara, Comment, *The Use of Genetic Testing in the Health Insurance Industry: The Creation of a "Biologic Underclass,"* 22 SW. U. L. REV. 1211 (1993) (explaining the limited powers of genetic testing in predicting disease).

[73] *Protecting the Rights of the Insured*, *supra* note 70, at 12A.

more quantitatively."[74] For instance, one study suggests that a woman's environment or diet may influence her risk of breast cancer.[75] Likewise, studies on the risk factors associated with prostate cancer have implicated a diet high in animal fat.[76] Furthermore, while some gene variations[77] may increase the chance of developing cancer,[78] these variations "raise the specter

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[74] Charles Siebert, *The DNA We've Been Dealt*, N.Y. TIMES, Sept. 17, 1995, § 6 (Magazine), at 50, 94 (quoting Dr. Francis Collins, director of the National Center for Human Genome Research). *See* Jane E. Brody, *Good Habits Outweigh Genes as Key to a Healthy Old Age*, N.Y. TIMES, Feb. 28, 1996, at C9 (discussing studies that show people can successfully "foster a healthy and productive old age" by remaining physically and socially active).

[75] *New Study Suggests a Woman's Breast Cancer Risk May Be Influenced by Environment or Diet Instead of Just Genetics* (CBS Evening News, Aug. 2, 1995) (available in WESTLAW, CBSEVNEWS database). The study found that women who move to a new country eventually have the same breast cancer risk as native-born women, suggesting that the risk of breast cancer does not completely depend on genetic makeup. *Id.*

A recent controversy in Long Island, New York, over the causes of a high incidence of breast cancer resulted in study mandated by Congress. Ford Fessenden, *Meeting of Minds on Cancer Study*, NEWSDAY, Mar. 15, 1995, at A27. The Long Island Breast Cancer Study Project will conduct a four-year study that "will focus on environmental causes of breast cancer." *Id.* Breast cancer activists claim that "something endemic to Long Island—water contamination, pesticide use, landfills near homes—may be causing higher levels of breast cancer." Michelle Slatalla, *Cancer Cluster? A Look at 1 Neighborhood That Seemed to Be a Classic Example*, NEWSDAY, Dec. 5, 1993, at 4.

[76] Dean Edell, *Gene Testing Could Result in Discrimination: Study*, HOUSTON POST, Aug. 28, 1994, at E10 (finding that there is a lower rate of prostate cancer death in countries like Japan, Singapore and Greece, where people eat little animal fat, than in the United States, where animal fat from meat and dairy products are consumed in larger quantities). According to a report released by a panel of the National Research Council of the National Academy of Sciences, "Americans trying to avoid cancer-causing substances in foods would benefit most from eating fewer calories and fats and more fruits and vegetables." Jane Brody, *Chemicals in Food? A Panel of Experts Finds Little Danger*, N.Y. TIMES, Feb. 16, 1996, at A1, A20.

[77] Gene variations are called "polymorphisms." Kathleen Fackelmann, *Variations on a Theme: Interplay of Genes and Environment Elevates Cancer Risk*, SCIENCE NEWS, May 6, 1995, at 280, 280. *See supra* note 9 (defining polymorphism).

[78] For example, smokers with one type of polymorphism run a high risk of

of cancer only in the presence of specific environmental hazards."[79] Thus, genetic testing alone does not reveal the affects of environmental factors on health, and should not be used to determine insurability.

IV. POLICY CONSIDERATIONS — DO WE REALLY WANT TO KNOW?[80]

Despite the issues of accuracy in genetic testing, society must also address social policy issues raised by the testing.[81] Should people be required to take genetic tests? What if those tested do not want to know their genetic makeup? How much control can individuals have over another's access to their test results?[82] The

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breast cancer, while another variant may increase a person's chance of developing a deadly brain cancer. Fackelmann, *supra* note 77, at 280.

[79] Fackelmann, *supra* note 77, at 280.

[80] For information on the ethical, legal and social implications of the Human Genome Project, see generally the Internet Uniform Resource Locator: http://www.ornl.gov/TechResources/Human_Genome/resource/elsi.html.

[81] "In the absence of state legislation, private parties may conduct across-the-board genetic testing without the constitutional implications faced by federally funded programs." Nobles, *supra* note 47, at 2104. Nonetheless, an individual may find some safeguards under the Equal Protection Clause of the Fourteenth Amendment and the right to privacy derived from the Due Process Clause of the Fourteenth Amendment. For a comprehensive essay that explores constitutional protections for individuals subject to genetic discrimination, see George P. Smith, II & Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. CONTEMP. HEALTH L. & POL'Y 23 (1994).

[82] On May 18, 1995, two marines were court-martialed for failing to give blood and saliva samples to the Department of Defense for a registry maintained by the Armed Forces Institute of Pathology in Gaithersburg, Maryland. Arthur Caplan, *The Military and DNA*, TIMES UNION, Dec. 12, 1995, at A18. The military has collected and stored samples from active duty and reserve troops since June 1992. It intends to use biological records to identify bodily remains too damaged for dental record or fingerprint identification. *Id.* The two marines fear that employers and insurers could discover and use their genetic information to deny them jobs or insurance. *Id.* Their fears are justified because "Congress or the president could order that the specimens in the DNA bank be made available to the FBI, the CIA, health insurance companies, private businesses, local police departments or the Medicaid program." *Id.*

answers to these questions coupled with the implementation and use of genetic tests and genetic test results greatly impact the areas of privacy and autonomy.

Autonomy, in the context of genetic testing and screening, "refers to the right of persons to make an informed, independent judgment about whether they wish to be tested and then whether they wish to know the details of the outcome of the testing."[83] Once a person takes a genetic test, "privacy includes the right to make an informed, independent decision about whether—and which—others may know details of their genome."[84] The principles of privacy and personal autonomy overlap, reflecting the importance of a person's ability "to make personal decisions without interference."[85]

The marines filed suit in the U.S. District Court of Hawaii, but Judge Samuel King dismissed the case in September 1995. Stephen Goode, *Marines Stand Ground Against DNA Testing*, WASH. TIMES, Feb. 19, 1996, at 38. The case is now before the Ninth U.S. Circuit Court of Appeals. *Id.* "The case could go all the way to the Supreme Court should the appeals court deny the Marines the right to refuse the tests." *Id. See GIs Concerned About Confidentiality of DNA Dog Tags* (All Things Considered-National Public Radio broadcast, March 8, 1996) (transcript No. 2146-16) (discussing the lawsuit with the two marines); *see also* H.R. 2873, 104th Cong., 2d Sess. (1996) (proposing "to limit the collection and use by the Department of Defense of individual genetic identifying information for the purpose of identification of remains. . .").

[83] ASSESSING GENETIC RISKS, *supra* note 2, at 248. In a recent survey to members of the New York City Chapter of the Alzheimer's Association, 63% of the respondents said that they would take a genetic test for Alzheimer's disease. Susan Gilbert, *Alzheimer's Group Finds Many Members Want Test for Risk*, N.Y. TIMES, Dec. 13, 1995, at C13. Of the people who did not want the test, 68% said that the reason was because there was no treatment or cure. *Id.* In addition, 54% did not want to know, and 18% were concerned about job, health insurance and other discrimination. *Id.*

[84] ASSESSING GENETIC RISKS, *supra* note 2, at 249. *See supra* note 6 (defining genome).

[85] ASSESSING GENETIC RISKS, *supra* note 2, at 256. Although genetic tests are "invaluable for tailoring each patient's treatment to the precise molecular cause of his or her disease. . . . handled wrongly they could destroy employment prospects, insurance eligibility and much more besides." Clive Cookson, *Leaders for a News Millennium: Cartographer of Life—Eric Lander*, FIN. TIMES, Dec. 22, 1995, at 16.

Some individuals do not want to know their genetic makeup.[86] The lack of effective treatment, anxiety over the testing itself and the "inability to 'undo' the knowledge" are some reasons people refuse to take genetic tests.[87] For example, one woman who tested positive for Huntington's disease, indicating that she would suffer from the disorder, found it difficult to accept that her dreams for the future would not be fulfilled.[88] Therefore, as a result of testing, the hope that a person will not suffer from genetic disease is irrevocably lost.

One woman, concerned about her children being afflicted with hypertrophic cardiomyopathy ("HCM"),[89] decided not to genetically test them. Her concern over the possibility of affliction was based on familial history:

> Their father died six years ago, at 43, after a heart transplant that didn't take. Their uncle had a transplant five

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[86] Results of a 1994 *Time* magazine survey indicated 49% of those surveyed did not want to know if they carried certain genes that were indicators of disease. Michael Landau, *Use of Genetic Testing by Employers and Insurance Companies*, 3 DICK. J. ENVTL. L. & POL'Y 105, 118 n.72 (1994) (citing survey, TIME, Jan. 17, 1994, at 50). *See generally* Charles Siebert, *At the Mercy of Our Genes*, N.Y. TIMES, Jan. 5, 1996, at A13 (explaining the impact of new technology and information on the "luxury of not knowing").

[87] *Testing for Cancer Genes: Do You Want to Know?*, HEALTH NEWS, Aug. 1995, at 1, 3 [hereinafter *Do You Want to Know?*].

[88] *Profile: Ability to Predict Genetic Future Requires Consideration* (NBC Nightly News, July 6, 1995) (transcript available in WESTLAW, NBCNN database). According to the woman, "[t]he inevitability that you're not going to necessarily be able to do everything that you wanted to do, that's really hard. That was hard to accept. And also giving up, you know, a whole life-long set of dreams. That was hard. That was really hard." *Id.*

In fact, the brother of this woman decided not to know his genetic future. According to the brother, "[w]hy take the test and dwell on what the test results are and waste more time? Because now, I have four children. And my focus right now is the importance of all those children and my wife." *Id.*

[89] "Hypertrophic cardiomyopathy" ("HCM") is an incurable form of heart disease characterized by a thickening of the heart muscle. Siebert, *supra* note 74, at 50. "Victims commonly suffer from chest pain, shortness of breath, dizziness and fainting spells. Over time, HCM often leads to congestive heart failure. It can also cause sudden death, most commonly in the young. Death, in fact, is often HCM's first symptom." Siebert, *supra* note 74, at 50.

> years ago; two of their four cousins have HCM. . . . Fortunately, neither of my children has HCM, but each may carry the defective gene. When they are adults they will have to decide whether to undergo genetic testing to avoid passing HCM on to their children. As . . . I did, they will make this choice themselves.[90]

Additionally, genetic testing may cause adverse psychological consequences. As genetic diseases are generally immutable,[91]

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[90] Thea L. Volpe, *Letters*, N.Y. TIMES, Oct. 15, 1995, § 6 (Magazine), at 16. According to a March of Dimes poll, out of 1,000 people questioned:

- 64[%] said they'd have a test during pregnancy to determine if the fetus has a genetic disease; 32[%] said they wouldn't test.
- 79[%] said they'd have genetic tests before conceiving to discover if offspring might inherit a fatal genetic disease; 72[%] said they'd test their children for genetic risks.
- 38[%] would ban new genetic tests until privacy-of-information laws exist.

Parent Poll, CHILD, Mar. 1995, at 59, 59. In addition, when one survey posed the question of whether to test a five-year-old for Huntington's disease at the parents' request, only two out of 49 geneticists (4%) said they would comply, while 100 out of 189 pediatricians (53%) said they would do the test. George J. Annas, *Genetic Prophecy & Genetic Privacy*, TRIAL, Jan. 1996, at 18, 20. If a doctor recommends a genetic test, an individual should ask the following questions about the testing:

- Why are you suggesting the test?
- What does the test detect?
- How will having the results, either positive or negative, change your advice to me about treatment or overall medical care?
- How could my being tested affect my children or other family members? Should I disclose the results to them?
- Has the test been approved by the Food and Drug Administration? (The best use of experimental tests may be uncertain).
- How much does the test cost?
- Will my insurance pay for the test? (You may or may not choose to submit a claim).
- Who will have access to my test results now and in the future?

Ince, *supra* note 5, at 4.

[91] "Generally immutable" refers to the fact that an individual's genetic blueprint cannot be altered. However, environmental factors may prevent the manifestation of a genetic disorder. *See* notes and accompanying text *supra* pp. 569-71 (discussing environmental factors that affect a person's health).

people carrying defective genes may view themselves as defective.[92] Many people with defective genes feel stigmatized despite the fact that they may never develop a disease.[93] In addition, carriers of abnormal genes often experience confusion, alienation and depression after being tested.[94] Mandatory genetic testing compounds psychological harm because an individual would be forced to learn about the information.[95] Thus, if insurance companies mandate genetic testing, individuals will learn about their defective genes and will lose their freedom not to know.[96]

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[92] ASSESSING GENETIC RISKS, *supra* note 2, at 257.

[93] *Do You Want to Know?*, *supra* note 87, at 3. In addition, forcing people to learn their genetic makeup can lead to stigma. This was found on the island of Orchemonos in Greece where there was a high incidence of sickle cell anemia, an automsomal recessive genetic disorder. Lori B. Andrews, *Genetic Fallout: New Technologies Are Changing the Legal Landscape*, TRIAL, Dec. 1995, at 20, 23 (citing George Stamatoyannapoulous, *Problems with Screening and Counseling in the Hemoglobinopathies*, *in* BIRTH DEFECTS: PROCEEDINGS OF THE FOURTH INTERNATIONAL CONFERENCE 268, 274 (A.G. Motulski & F.J.G. Ebling eds., 1974)). Health care workers tested the island population so that carriers would not marry other carriers. *Id.* This was done because a child could only get the disease if both parents carried the sickle cell gene. *Id.* "When the workers later returned to the island, they found that the carriers had been so stigmatized that no noncarriers would marry them. Instead, carriers lied about their status or married other carriers, thus increasing the number of affected children." *Id.*

[94] *Do You Want to Know?*, *supra* note 87, at 3. For example, a woman in her forties who tested positive for Alzheimers's disease "reacted 'with anxiety, sorrow, depressive feelings and, for a period of a month, suicidal thoughts.'" Robin McKie, *New Genetic Forecast Led Woman to Suicide Brink*, OBSERVER, Feb. 5, 1995, at 2. Another individual in Minnesota committed suicide after obtaining negative genetic test results about Huntington's disease over the phone. Saltus, *supra* note 37, at 28.

[95] ASSESSING GENETIC RISKS, *supra* note 2, at 257.

[96] *See* David Ballingrud, *Gene Testing Raises Fears of Insurance Discrimination*, ST. PETERSBURG TIMES, June 4, 1995, at 14A. However, insurers argue that serious errors in risk classification would result if insurance companies were unaware of important and unfavorable information known to applicants. Pokorski, *supra* note 46, at 47. "Some people would get their insurance at unreasonably low cost. More claims would be filed than were expected by the insurer. And if the insurer made a significant number of risk classification errors, the financial status of the entire insurance pool would be significantly affected." Pokorski, *supra* note 46, at 47.

V. LEGISLATION

New times demand new measures and new men;
The world advances, and in time outgrows
The laws which in our fathers' times were best;
And doubtless, after us, some purer scheme
Will be shaped out by wiser men than we,
Made wiser by the steady growth of truth.

—James R. Lowell[97]

Health insurance is a necessity,[98] and excessive premiums or

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[97] *A Glance Behind the Curtain, reprinted in* SELDES, *supra* note 1, at 568-69.

[98] *See* Daniel Callahan, *Symbols, Rationality, and Justice: Rationing Health Care,* 18 AM. J.L. & MED. 1 (1992) (proposing an ideal American health care system whereby every American is guaranteed an adequate and affordable level of health care); Ivette Mendez, *Legislators Go to Bat for Privatized Workers*, STAR-LEDGER, June 7, 1995, at 17 (quoting New Jersey State Senator Wayne Bryant for the proposition that New Jersey, under the guise of privatization, should not deprive direct service employees of the basic necessity of health insurance).

Universal health care was one of the preeminent issues of President Clinton's election campaign. He originally defined universal health care as "functional full coverage [that would cover] 96, 97, 98 percent" of Americans. Mark Z. Barabak, *President Bends on Health Care*, SAN DIEGO UNION-TRIB., July 20, 1994, at A1. Following the President's lead, both the United States Senate and the House of Representatives introduced the Health Security Act on November 20, 1993. S. 1757, 103d Cong., 1st Sess. (1993); H.R. 3600, 103d Cong., 1st Sess. (1993). The purpose of the legislation was:

> to ensure individual and family security through health care coverage for all Americans in a manner that contains the rate of growth in health care costs and promotes responsible health insurance practices, to promote choice in health care, and to ensure and protect the health care of all Americans.

Id. The bill contained over 1300 pages, and "[t]he drafting effort took approximately eleven months and involved about ten attorneys." Sara Rosenbaum, *Symposium: Setting a Place for Ed Sparer at the National Health Reform Table*, 60 BROOK. L. REV. 71, 72 (1994). However, "[a]fter months of heated discussion, the latest round of the national health care debate ended in Congress . . . without passage of any reform legislation." Note, *Universal Access*

the denial of health insurance altogether should not burden individuals because they might have an increased risk of suffering from a particular disease.[99] A large portion of the United States population could become uninsurable if insurers are allowed to use genetic testing.[100] "Since private health insurance is the means by which this country pays for health care, uninsurability means a denial of health care for a large number of people."[101] According to a report of the multidisciplinary Committee on Assessing Genetic Risks,[102]

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to Health Care, 108 HARV. L. REV. 1323, 1323 (1995) [hereinafter Note]. *See supra* note 65 (discussing current health care proposals). *See generally* Cathie Jo Martin, *Stuck in Neutral: Big Business and the Politics of National Health Reform*, 20 J. HEALTH POL. POL'Y & L. 431 (1995) (discussing the lack of "big business" participation in health care reform); Arnold J. Rosoff, *The Role of Clinical Practice Guidelines in Health Care Reform*, 5 HEALTH MATRIX 369 (1995) (reviewing the development of the clinical practice guideline movement and its "implications for health care reform at all levels. . ."); Sven Steinmo & Jon Watts, *It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America*, 20 J. HEALTH POL. POL'Y & L. 329 (1995) (discussing American political institution bias against comprehensive national health insurance); Note, *supra* (discussing "the prospects for and the problems with justifying universal access to health care in late twentieth-century America").

[99] Leo Uzych, *Is Big Brother Closing in? Genetic Testing Could Demolish Broad Access to Health Care*, PENN. L.J., Aug. 23, 1993, at 2.

[100] Cushing, *supra* note 47, at 262.

[101] Cushing, *supra* note 47, at 262. According to Mary-Claire King, professor of genetics and epidemiology at the Universtiy of California at Berkely, everyone is predisposed to some type of disease and "as we become better at [testing], we would have to remove everyone from the insurance pool." Daniel J. Lehman, *Genetic Tests Called a Threat to Privacy,* CHIC. SUN-TIMES, Oct. 10, 1995, at 8.

[102] The Committee on Assessing Genetic Risks, jointly supported by the Institute of Medicine of the National Academy of Sciences, the National Center for Human Genome Research at the National Institutes of Health ("NIH") and the Department of Energy, Health Effects Program of the Life Science Research Office ("DOE"), held a series of workshops and meetings on the many phases and impacts of genetic testing. ASSESSING GENETIC RISKS, *supra* note 2, at v-vi. A report was written that was based on information from experts, the public, scientific and policy literature and discussions at committee meetings. ASSESSING GENETIC RISKS, *supra* note 2, at v-vi.

> [b]ecause health insurance differs significantly from other types of insurance in that it regulates access to health care, an important social good, risk-based health insurance should be eliminated. A means of access to health care should be available to every American without regard to the individual's present health status or condition, including genetic makeup. Any health insurance reform proposals need to be evaluated to determine their effect on genetic testing and the use of genetic information in health insurance.[103]

Until medical underwriting is no longer performed, legislation is necessary to protect people from genetic discrimination and to ensure privacy.[104] The following sections will discuss enacted and proposed legislation concerning genetic testing and insurance. Part A will review federal legislation, and part B will survey state legislation.

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[103] ASSESSING GENETIC RISKS, *supra* note 2, at 281.

[104] In July 1995, the National Action Plan on Breast Cancer and the NIH-DOE Ethical, Legal, and Social Implication of Human Genome Research Working Group ("ELSI") cosponsored a workshop on genetic discrimination and health insurance. Hudson, *supra* note 44, at 393 (citing *Genetic Discrimination and Health Insurance: A Case Study on Breast Cancer* (Workshop, Bethesda, MD, July, 11, 1995)). The workshop developed the following recommendations for state and federal lawmakers to protect against genetic discrimination:

1) Insurance providers should be prohibited from using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment, or contribution requirements.
2) Insurance providers should be prohibited from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.
3) Insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information.
4) Insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior written authorization of the individual. Written authorization should be required for each disclosure and include to whom the disclosure would be made.

Hudson, *supra* note 44, at 393.

A. Federal Legislation

Federal legislation prohibiting insurers from using genetic information for insurance coverage has yet to be enacted. The first legislation introduced on the federal level to protect genetic information was the Human Genome Privacy Act of 1990.[105] No other federal bills were proposed until the end of 1995. Then, within a five month period, six different bills regulating genetic information were introduced.[106] Three bills, the Genetic Privacy and Nondiscrimination Act of 1995,[107] the Genetic Information Nondiscrimination in Health Insurance Act of 1995[108] and the Genetic Fairness Act of 1996,[109] were proposed to protect individuals against genetic discrimination. In addition, three bills introduced to improve the "portability and continuity of health insurance coverage" include restrictions on the use of genetic information for health insurance.[110]

Representative John Conyers (D-MI) introduced the Human Genome Privacy Act on September 13, 1990.[111] According to Representative Conyers, "[p]ublic release of people's genetic information is a Pandora's Box that is best left unopened."[112] The purpose of the bill was to "safeguard individual privacy of genetic

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[105] H.R. 5612, 101st Cong., 2d Sess. (1990). The Human Genome Privacy Act was not enacted because "[i]n October, 1992, Congress adjourned sine di[e]. Thus, all unpassed bills pending at that time died." Smith & Burns, *supra* note 81, at 53 n.160. This bill was not reintroduced.

[106] S. 1416, 104th Cong., 1st Sess. (1995); H.R. 2690, 104th Cong., 1st Sess. (1995) (identical to S. 1416); H.R. 2748, 104th Cong., 1st Sess. (1995); S. 1600, 104th Cong., 2d Sess. (1996); H.R. 3043, 104th Cong., 2d Sess. (1996); 3103, 104th Cong., 2d Sess. (1996); H.R. 3160, 104th Cong., 2d Sess. (1996) (combined with H.R. 3103); H.R. 3185, 104th Cong., 2d Sess. (1996).

[107] S. 1416; H.R. 2690 (identical bills).

[108] H.R. 2748.

[109] S. 1600.

[110] Working Families Health Access Act of 1996 or H.R. 3043; Health Coverage Availability and Affordability Act of 1996 or H.R. 3103/3160; Health Insurance Reform Act of 1996 or H.R. 3185.

[111] H.R. 5612.

[112] Douglas A. Levy, *Experts Call for Genetic Privacy Legislation*, UPI, Oct. 18, 1991, *available in* LEXIS, Nexis Library, ARCNWS File.

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 . . . ."[113]

Although the Human Genome Privacy Act protected genetic privacy, it contained many weaknesses. The greatest weakness was that it only prohibited disclosure from government agencies, and did not prohibit disclosure from other sources.[114] The bill, if passed, also would have given insurance companies the ability to discover genetic information.[115] One provision permitted disclosure of genetic information without authorization to medical professionals if the information was used for treatment of a specific individual.[116] Doctors working for an employer's Health Maintenance Organization ("HMO")[117] carrier would record this disclosed information on the individual's medical file, where it could be subject to discovery[118] because "both the current system of health care financing and the multitude of people with direct access to patients' records, especially in institutional settings, seriously compromise the traditional notion of medical confidentiality."[119] Moreover, many policyholders are required to

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[113] H.R. 5612. According to the congressional findings:

> the opportunities for an individual to secure education, employment, health care, insurance, and credit, and his or her right to due process and other legal protections are endangered by the misuse of genetic information systems [and] in order to protect the genetic privacy of individuals in informational systems maintained by agencies, it is necessary and proper for the Congress to regulate the collection, maintenance, use and dissemination of information by such agencies.

Id. § 2(a)(4), (5).

[114] *Id.* §§ 101(1); 114. *See* O'Hara, *supra* note 72, at 1227.

[115] O'Hara, *supra* note 72, at 1226.

[116] H.R. 5612 § 123(a). *See* O'Hara, *supra* note 72, at 1226.

[117] A Health Maintenance Organization ("HMO") is defined as "a type of managed care health plan that requires members to seek care from a limited network of hospitals and doctors. . . . In return for giving up freedom of doctor choice, HMOs offer significant financial benefits." Tim Bonfield, *Seniors Face HMO Blitz; Big Changes in Medicare May Save Money, but Will They Maintain Quality?*, CINCINNATI ENQ., Nov. 19, 1995, at A1.

[118] O'Hara, *supra* note 72, at 1226-27.

[119] Allen & Moseley, *supra* note 18, at 68. On November 14, 1995, Senators Robert F. Bennett (R-UT) and Patrick Leahy (D-VT) held hearings on the

sign releases that permit insurance companies to access "any and all records," so information placed in a medical file would be discoverable.[120]

Over four years passed before genetic information issues once again reached the federal level. In March 1995, the Equal Employment Opportunity Commission ("EEOC") extended the coverage under the Americans with Disabilities Act ("ADA")[121] to include individuals who are regarded as having genetic impairments.[122] The EEOC released guidelines which clarified the definition of "disability" under the ADA to include "individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders."[123] However, in

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Medical Records Confidentiality Act, a bill "intended to establish uniform Federal rules for the use and disclosure of health information . . . ." Gina Kolata, *When Patients' Records Are Commodities for Sale*, N.Y. TIMES, Nov. 15, 1995, at A1, C14. According to Senator Bennett, "the bill would give Americans 'greater confidentiality and greater access to see their own records.'" *Id.* at A1. However, critics of the bill argue that it "would supersede state laws, making it easier to set up national medical databases, and would set a dangerously loose standard of accessibility to patients' records." *Id.* at C14. The bill does not cover the use of genetic information. *See* S. 1360, 104th Cong., 1st Sess. (1995); Beverly Woodward, *Patients' Privacy at Risk*, N.Y. TIMES, Nov. 15, 1995, at A23 (criticizing the proposed bill); *see also* Lawrence O. Gostin et al., *Privacy and Security of Health Information in the Emerging Health Care System*, 5 HEALTH MATRIX 1 (1995) (discussing "the objectives for the collection, storage, and use of information in the health care system and the means to attain those objectives").

[120] Cotton, *supra* note 52, at 93-95.

[121] Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213 (1990)).

[122] Executive Summary: Compliance Manual Section 902, Definition of the Term "Disability," EEOC Order 915.002, Mar. 14, 1995, at 902-45 [hereinafter Compliance Manual]. *See* Abbey S. Meyers, *EEOC Genetic Ruling Protects Society*, 4 EMPL. TESTING L. & POL'Y REP., 103, 103 (1995); Rick Weiss, *Gene Discrimination Barred in Workplace; EEOC Says Jobs Can't Be Denied Based on Predisposition to Disease*, WASH. POST, Apr. 7, 1995, at A3.

[123] Compliance Manual, *supra* note 122, at 902-45. The ADA definition of "disability" includes "with respect to an individual—(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." 42 U.S.C. § 12102(2). The third part of the

order to qualify, an individual must both show that an employer regarded the individual as having a genetic defect, and "acted on that basis."[124] Although federal legal protection now exists for employment discrimination based on perceived genetic impairments, the EEOC has not specifically determined whether a potential employer can deny an applicant a job because the individual, although completely healthy, carries a defective gene which can pass to the applicant's offspring, and the employer does not want to pay future health care costs associated with the children.[125]

The first legislation since the Human Genome Privacy Act was introduced on November 15, 1995, by Senator Mark Hatfield (R-OR).[126] Senator Hatfield proposed the Genetic Privacy and Nondiscrimination Act of 1995,[127] which would establish limitations "with respect to the disclosure and use of genetic information."[128] Two weeks later, Representative Clifford Stearns (R-FL)

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definition applies to individuals subjected to discrimination based on a genetic impairment. Compliance Manual, *supra* note 122, at 902-45. Thus, employers who make adverse employment decisions based solely on genetic predisposition violate the ADA because they regard an applicant as having an impairment. *New EEOC Guidelines Clarify Disability*, HUMAN GENOME NEWS, July-Aug. 1995, at 4. *See* Dee Lord, *Something in the Genes*, A.B.A. J., Apr. 1996, at 86 (discussing the recent EEOC "steps to forestall discrimination for predisposition to illness").

[124] Compliance Manual, *supra* note 122, at 902-46.

[125] Andrews, *supra* note 93, at 25.

[126] S. 1416.

[127] Senator Mark Hatfield (R-OR) based the legislation on Oregon's genetic privacy act. *See* Liefer, *supra* note 50, at 10; discussion of Oregon law *infra* pp. 602-03; *see also* The Genetic Privacy Act (Feb. 28, 1995) (Available on the Internet from the Universal Resource Locator: http://www-busph.bu.edu/Depts/HealthLaw/). The Genetic Privacy Act is a proposal for federal legislation that governs the collection, analysis, storage and use of DNA samples, and the genetic information that results from this DNA. *Id.* The proposal was authored by George Annas, Leonard Glantz and Patricia Roche of the Health Law Department, Boston University School of Public Health, with funding provided by NIH-DOE ELSI. *See* Annas, *supra* note 90, at 22-24 (highlighting the Genetic Privacy Act).

[128] S. 1416. The purpose of the Genetic Privacy and Nondiscrimination Act is to "(1) define the rights of individuals whose genetic information is disclosed; (2) define the circumstances under which an individual's genetic information may

sponsored the identical bill in the House of Representatives.[129] The legislation would protect individual privacy, and prohibit discrimination by insurers and employers based on an individual's genetic information.[130] The bill states that "[a]n insurer offering health insurance may not use genetic information[131] to reject, deny, limit, cancel, refuse to renew, increase the rates of, or otherwise affect health insurance."[132] Insurers, other than those issuing health insurance, would be permitted to request an applicant to take a genetic test.[133] However, an insurer would need specific written consent from an applicant in order to use the test results.[134] In addition, an insurer could not induce the purchase of insurance based on a genetic test.[135]

On December 7, 1995, Representative Louise Slaughter (D-NY) proposed a similar bill[136] which would "prohibit insurance providers from denying or canceling health insurance coverage, or varying the premiums, terms, or conditions for health insurance

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be disclosed; and (3) protect against discrimination by an insurer or employer based upon an individual's genetic information." *Id.* § 2(B). According to Senator Connie Mack (R-FL), cosponsor of the Senate bill, "[t]he science of genetic testing is moving at a rate that far outpaces our understanding of how to apply the discoveries once they're made. . . . Regardless of the tremendous advances in the science, we must ensure that genetic tests remain voluntary and completely private." Connie Mack, *Genetic-Test Balance*, ORLANDO SENTINEL, Feb. 4, 1996, at G2.

[129] H.R. 2690. This bill was introduced on Nov. 29, 1995. *Id.*

[130] S. 1416 § 2(B); H.R. 2690 § 2(B).

[131] "Genetic information" is defined as "the information about genes, gene products or inherited characteristics that may derive from an individual or a family member." S. 1416 § 3(4); H.R. 2690 § 3(4).

[132] S. 1416 § 6(a); H.R. 2690 § 6(a).

[133] S. 1416 § 6(C); H.R. 2690 § 6(C). "Genetic test" is defined as "a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic." S. 1416 § 3(5); H.R. 2690 § 3(5).

[134] S. 1416 § 6(C); H.R. 2690 § 6(C).

[135] S. 1416 § 6(B); H.R. 2690 § 6(B).

[136] Representative Louise Slaughter introduced the Genetic Information Nondiscrimination in Health Insurance Act of 1995 or H.R. 2748. The scope of the legislation is limited to discrimination by health insurers. *Id.*

coverage on the basis of genetic information[137] or a request for genetic services."[138] Representative Slaughter found that insurance carriers refuse health insurance coverage to people if a genetic condition runs in their family, and that the problem could worsen with the "rapid advances in gene mapping."[139] Representative Slaughter announced the legislation at a news conference which focused on breast cancer.[140] The bill follows recommendations from a recent meeting of scientists, health officials and insurance industry representatives.[141] However, a spokesman for the Health Insurance Association of America indicated that insurers are not sure if they can support the bill, and that they are "wary of proposals that would limit their ability to assess an applicant's medical history as a way of spreading the risk on individual policies."[142]

Three months later, on March 7, 1996, Senator Dianne Feinstein (D-CA) introduced the Genetic Fairness Act of 1996[143] on behalf of herself and Senator Connie Mack (R-FL).[144] The bill would prohibit an insurer offering health care coverage from terminating, restricting, limiting, canceling, refusing to renew, varying rates, denying coverage or "otherwise" discriminating against an individual or member of the individual's family on the

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[137] "Genetic information" is defined as "information about genes, gene products, or inherited characteristics." *Id.* § 2(e)(3).

[138] H.R. 2748. "Genetic services" are "health services to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and couselling." *Id.* § 2(e)(4). Currently, New York does not have laws against genetic discrimination in health insurance. John Machacek, *Slaughter Bill Protects People with Genes Linked to Serious Illness*, GANNETT NEWS SERVICE, Dec. 7, 1995, *available in* LEXIS, Nexis Library, CURNWS File. *See supra* note 13 (listing pending legislation in New York).

[139] Machacek, *supra* note 138. According to Representative Slaughter, "[t]his is an issue not unknown to a number of people here, who have lost a spouse [to cancer]. They would like very much to see something happen." Machacek, *supra* note 138.

[140] Machacek, *supra* note 138.

[141] Machacek, *supra* note 138. *See supra* note 104 (discussing the workshop on genetic discrimination and health insurance).

[142] Machacek, *supra* note 138.

[143] S. 1600.

[144] *Id.*

basis of genetic information[145] or a "request for or receipt of genetic services."[146] In addition, an insurer offering health care coverage could not require an applicant or member already covered "to be the subject of a genetic test or to be subjected to questions relating to genetic information."[147]

In March 1996, several House bills introduced to provide greater access to health care also contained genetic information provisions.[148] The provisions are similar to those contained in the Health Coverage Availability and Affordability Act of 1996, which the House of Representatives passed on March 28, 1996.[149] A striking section in this legislation states that "genetic information shall not be considered to be a preexisting condition . . . ."[150] In addition, the bill prohibits a group health plan[151] and "an insurer or HMO offering health insurance coverage in connection with a group health plan" from denying coverage or varying rates on the

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[145] *Id.* § 3(a). "Genetic information" is defined as "information about genes, gene products or inherited characteristics that may be derived from an individual or a family member." *Id.* § 2(2).

[146] *Id.* § 3(a). "Genetic services" are defined as "health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling." *Id.* § 2(3).

[147] *Id.* § 3(b).

[148] H.R. 3043; H.R. 3103 (substituted and combined with H.R. 3160); H.R. 3185.

[149] H.R. 3103. The Health Coverage Availability and Affordability Act was amended by H.R. Res. 392, 104th Cong., 2d Sess. (1996), which substituted and combined the bill with H.R. 3160. When introduced, H.R. 3103 did not contain any genetic information provisions.

[150] H.R. 3103/3160 § 101(B)(1)(B). According to Martha Volner, the Alliance of Genetic Support Groups' director of health policy, "[i]t's a piece of legislation whose time has come." Elizabeth Neus, *Bill Ensures Your Genes Won't Cost You Insurance*, SALT LAKE TRIB., Mar. 30, 1996, at A1.

The Working Families Health Access Act of 1996 or H.R. 3043 also limits the use of genetic information as a preexisting condition. According to the bill, "information relating to one's genetic predisposition alone shall not be considered to be a preexisting condition. . . ." *Id.* § 4988(C)(2).

[151] A "group health plan" is defined as "an employee welfare benefit plan to the extent that the plan provides medical care . . . to employees or their dependents . . . directly or through insurance, reimbursement, or otherwise. . . ." H.R. 3103/3160 § 191(a)(1).

basis of health status, which includes genetic information.[152] Companies that offer health insurance coverage in the "small or large group market,"[153] would also be prohibited from discontinuing or refusing to renew coverage on the basis of health status.[154] Moreover, individual health insurance coverage[155] would be guaranteed "to certain individuals with prior group

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[152] *Id.* § 103(a), (b). "Health status" refers to an individual's "medical condition, claims experience, receipt of health care, medical history, genetic information, evidence of insurability (including conditions arising out of acts of domestic violence), or disability." *Id.* § 191(C)(6). "Genetic information" is not defined in the legislation.

The Health Insurance Reform Act of 1996 or H.R. 3185 has the identical definition of "health status." H.R. 3185 § 100(9). In addition, this bill prohibits a health plan issuer offering a group health plan or an individual health plan from refusing or discontinuing coverage based on the health status of an individual. *Id.* §§ 101(1), 110(a), 111(b)(C).

The Working Families Health Access Act of 1996 or H.R. 3043 also contains a provision limiting discrimination based on health status. According to the legislation:

> a group health plan and a carrier offering health insurance coverage in connection with such a plan may not establish or impose eligibility, continuation, enrollment, or contribution requirements for an individual based on factors directly related to health status, genetic predisposition, medical condition, claims experience, receipt of health care, medical history, disability, or evidence of insurability of the individual.

Id. § 4987(a). A similar provision applies to health insurers offering individual health care coverage. *Id.* § 4987(B).

[153] A "large group market" is "the market for health insurance coverage offered to employers (other than small employers) on behalf of their employees (and their dependents) . . . ." H.R. 3103/3160 § 191(e)(2). A "small group market" is "the health insurance market under which individuals obtain health insurance coverage (directly or through any arrangement) on behalf of themselves (and their dependents) on the basis of employment or other relationship with respect to a small employer . . . ." *Id.* § 191(e)(4).

[154] *Id.* § 132(B)(5).

[155] "Individual health insurance coverage" is defined as "health insurance coverage offered to individuals if the coverage is not offered in connection with a group health plan (other than such a plan that has fewer than two participants as current employees on the first day of the plan year)." *Id.* § 191(C)(7).

coverage."[156] However, nonqualifying individuals would not be covered under the Act.[157]

The federal bills specifically introduced to protect individuals against genetic discrimination are comprehensive, and the passage of any of the bills would effectively prevent genetic discrimination by health insurers.[158] In fact, the bills' prohibitions against using "genetic information" would prevent health insurers from relying on information they currently use in medical underwriting.[159] The definitions of genetic information include "inherited characteristics," which could not be used by insurers when making health coverage decisions.[160] Thus, insurers could not take into account hereditary information obtained through medical questionnaires based on family history of disease.[161] Enactment of this type of

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[156] *Id.* § 141.

[157] A "qualifying individual" is defined as an individual:

> (A) (I) for whom, as of the date on which the individual seeks coverage under this section, the aggregate of the qualified coverage periods [aggregate health insurance coverage without a lapse of 60 days] is 18 or more months and (II) whose most recent prior coverage was under a group health plan, governmental plan, or church plan (or health insurance coverage offered in connection with any such plan);
>
> (B) Who is not eligible for coverage under (I) a group health plan, (II) part A or part B of Title XVIII of the Social Security Act, or (III) a state plan under Title XIX of such Act (or any successor program), and does not have individual health insurance coverage;
>
> (C) With respect to whom the most recent coverage within the coverage period described in subparagraph (A)(I) was not terminated based on [nonpayment of premiums or fraud];
>
> (D) If the individual had been offered the option of continuation coverage under a COBRA continuation provision or under a similar state program, who elected such coverage; and
>
> (E) Who, if the individual elected such continuation coverage, has exhausted such continuation coverage.

Id. § 141(b)(1).

[158] *See* S. 1416, H.R. 2690, H.R. 2748, S. 1600.

[159] *See supra* note 68 (discussing family history in medical underwriting).

[160] *See, e.g.*, S. 1416 § 3(4); H.R. 2748 § 2(e)(3); S. 1600 § 2(2).

[161] Passage of a federal bill specifically proposed to combat genetic discrimination would prevent insurers from taking into account any hereditary information of any individual or individual's family. This interpretation is

legislation is exactly what is needed to prevent genetic discrimination. Although the bill passed by the House of Representatives offers some protection,[162] many individuals are not covered under the legislation, and they would still suffer from genetic discrimination.

B. State Legislation[163]

Before 1986, state laws prohibiting genetic discrimination were extremely limited in scope, and did not cover a large range of genetic conditions.[164] The first state laws only addressed specific genetic traits such as hemoglobin C[165] or sickle cell traits.[166]

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supported by the language of Oregon's genetic privacy act, which was the basis of the Genetic Privacy and Nondiscrimination Act of 1995. *See* Liefer, *supra* note 50, at 10. The Oregon law defines "genetic information" as "information about an individual or family obtained from: (a) A genetic test; or (b) An individual's DNA sample." OR. REV. STAT. § 659.700(4). However, the proposed federal laws do not limit genetic information to genetic tests or DNA samples. *See* S. 1416; H.R. 2690; H.R. 2748; S. 1600. The definition of "genetic information" is broad and includes any information on inherited characteristics. S. 1416; H.R. 2690; H.R. 2748; S. 1600.

[162] *See* H.R. 3103/3160.

[163] The McCarran-Ferguson Act permits states to regulate insurance. *See* Act Mar. 9, 1945, ch. 10, 59 Stat. 33 (codified as amended at 15 U.S.C. §§ 1011-1015 (1956)). However, states cannot directly regulate self-insured employee benefit plans under the Employee Retirement Income Security Act ("ERISA"), *see* Pub. L. No. 93-406, 88 Stat. 832 (codified as amended at 29 U.S.C. § 1144 (1993)), and "about half of all employer-provided policies are exempt from state regulations because the companies are self-insured. . . ." Ince, *supra* note 5, at 5. *See* McClure, *supra* note 38, at 233 (discussing insurance law and authority); *see also* Devon P. Groves, *ERISA Waivers and State Health Care Reform*, 28 COLUM. J.L. & SOC. PROB. 609, 620-26 (1995) (examining ERISA preemption with respect to health insurance); Jerry L. Mashaw & Theodore R. Marmor, *Federalism and Health Care: A Reply*, 28 CONN. L. REV. 161 (1995) (supporting a proposal to eliminate the preemption of state regulation of employer-funded insurance under ERISA).

[164] *See, e.g.*, MD. CODE ANN., INS. § 223. This law, enacted in 1986, only covers genetic "traits." *Id.* § 223(b)(4). A "trait" is defined as "a qualitative characteristic; a discrete attribute as contrasted with metrical [of or relating to measurement] character." MEDICAL DICTIONARY, *supra* note 7, at 1835.

[165] Hemoglobin C is caused by an abnormal hemoglobin which reduces the

However, since 1990, with the start of the Human Genome Project,[167] ten states have enacted laws that protect against genetic discrimination for most genetic conditions.[168] Moreover, since 1986, the trend of enacted and proposed legislation has moved, and is moving, in a more comprehensive direction, giving greater protection against genetic discrimination to individuals in the area of health insurance.[169] At the same time, state legislatures opted to focus only on health and not life insurance. Less emphasis is given to life insurance protection, and the trend is moving away from restrictions (albeit limited in the first place) on the use of genetic information in life insurance policies.[170] The following section surveys statute proposals, and state laws in order of enactment to show the trend in the state legislation.

1. Maryland

As early as 1986, Maryland's unfair discrimination statute covered genetic traits.[171] The statute prohibits life and health insurers from making any differential in ratings, premium payments or dividends solely because an applicant or policyholder has a

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normal plasticity of red blood cells. MEDICAL DICTIONARY, *supra* note 7, at 778.

[166] *See* Hudson, *supra* note 44, at 393 n.8 (citing single genetic trait discrimination laws); *see, e.g.*, ALA. CODE § 27-5-13 (1986); FLA. STAT. ANN. § 626.9707 (West 1984); N.C. GEN. STAT. § 58-65-70 (1994).

[167] *See supra* note 18 (discussing the Human Genome Project).

[168] *See* Hudson, *supra* note 44, at 392. *See* CAL. CIV. CODE § 56.17; CAL. INS. CODE §§ 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 10143, 10146, 10147, 10148, 10149, 10149.1, 11512.95, 11512.96, 11512.965; CAL. HEALTH & SAFETY CODE §§ 1374.7, 1374.9; COLO. REV. STAT. § 10-3-1104.7; FLA. STAT. ANN. § 760.40; GA. CODE ANN. §§ 33-54-1 to 8; MINN. STAT. ANN. § 72A.139; MONT. CODE ANN. § 33-18-206; N.H. REV. STAT. ANN. §§ 141-H:1 to 6; OHIO REV. CODE ANN. §§ 1742.42, 1742.43, 3901.49, 3901.491, 3901.50, 3901.501; OR. REV. STAT. §§ 659.700, 659.705, 659.710, 659.715, 659.720, 746.135; WIS. STAT. ANN. § 631.89.

[169] *See* Table 1 and discussion *infra* pp. 603-08 (comparing state restrictions on the use of genetic information by health insurers).

[170] *See* Table 1 and discussion *infra* pp. 603-08 (comparing state restrictions on the use of genetic information by life insurers).

[171] MD. CODE ANN., INS. § 223.

particular genetic trait.[172] These traits include "sickle-cell trait, thalassemia-minor trait,[173] hemoglobin C trait, Tay-Sachs trait,[174] or any genetic trait which is harmless within itself, unless there is actuarial justification."[175] However, the statute does not protect information disclosure, and only covers these limited genetic conditions.

Pending legislation introduced on January 25, 1996[176] would establish greater protections against genetic discrimination to individuals in Maryland for health insurance.[177] The bill states that an insurer, nonprofit health service plan, or HMO could not "use genetic information[178] to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect a health insurance policy or contract."[179] In addition, the statute would prohibit all of the above insurers from requesting or collecting genetic information,[180] or releasing genetic information without prior written consent.[181] An

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[172] *Id.* § 223(a)(3), (b)(4).

[173] Thalassemia-minor is a hemogloblin metabolism disorder which is usually asymptomatic, and often has a "slightly reduced hemoglobin level with slightly increased [red blood cell] count." MEDICAL DICTIONARY, *supra* note 7, at 1792-93.

[174] Tay-Sachs disease is a lysosomal ("membrane-bound vesicle" which contains enzymes) storage disease. Blindness and seizures occur during the first year of birth and death results "within a few years." MEDICAL DICTIONARY, *supra* note 7, at 504, 1012.

[175] MD. CODE ANN., INS. § 223(a)(3), (b)(4). *See supra* note 46 (discussing the determination of rates and premiums by insurance companies).

[176] S.B. 276, 1996 Leg. Sess. (Md. 1996). Maryland State Senators Jennie Forehand, Perry Sfikas, Delores Kelley, Leonard Teitelbaum, Ulysses Currie and Donald Munson introduced the legislation. *Id.*

[177] *Id.* § 223.1(B).

[178] "Genetic information" is defined as "information about the genes, gene products, or inherited characteristics of an individual." *Id.* § 223.1(A). *See* notes and accompanying text *supra* pp. 587-88 (discussing the significance of the term "genetic information" in pending federal legislation).

[179] S.B. 276 § 223.1(B)(1).

[180] *Id.* § 223.1(B)(2).

[181] *Id.* § 223.1(B)(3).

individual harmed by a violation would be able to recover equitable relief[182] and actual damages.[183]

2. *Arizona*

In 1989, the Arizona legislature amended the state's unfair discrimination statute to include genetic conditions.[184] The law prohibits life or disability insurers[185] from refusing to consider applications for insurance on the basis of a genetic condition.[186] The rejection or the determination of rates, terms or conditions of life or disability insurance on the basis of a genetic test 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 . . . ."[187] Health insurance is not covered under this statute, and in any event, discrimination can occur if there is actuarial justification.

3. *Montana*

In 1991, the Montana legislature amended the state's unfair discrimination statute concerning life and disability insurers by restricting the use of information based on genetic conditions.[188]

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[182] Equitable relief includes "a retroactive order directing the insurer, nonprofit health service plan, or health maintenance organization to provide health insurance to the individual under the same terms and conditions that would have applied had the violation not occurred." *Id.* § 223.1(C)(1).

[183] *Id.* § 223.1(C)(1), (2).

[184] ARIZ. REV. STAT. ANN. § 20-448.

[185] Life insurers protect against "the economic loss resulting from the unexpected death of the insured," while disability insurers pay benefits to an insured individual because of "an impairment or handicap resulting from accident or ill health, that prevents an individual from earning a living." MICHAEL THOMSETT, INSURANCE DICTIONARY 115 (1989).

[186] "Genetic condition" is defined as a "specific chromosomal or single-gene genetic condition." ARIZ. REV. STAT. ANN. § 20-448(F). *See supra* notes 32-33 (discussing chromosomal and single-gene abnormalities).

[187] ARIZ. REV. STAT. ANN. § 20-448(E).

[188] MONT. CODE ANN. § 33-18-206. "Genetic condition" is defined as a

However, the restrictions are limited, and only prohibit an insurer from refusing to consider an application for life or disability insurance.[189] In addition, the rejection of an application or the determination of rates based on a genetic condition do not constitute unfair discrimination if "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."[190] There are no restrictions on the use of genetic information for health insurance coverage.

4. Wisconsin

In 1991, the Wisconsin legislature passed a statute restricting the use of genetic test results.[191] According to Representative Marlin Schneider, the author of the bill, the issue of genetic testing is "the most important privacy issue ever."[192] He argued that individuals "ought not to be compelled to give up their genetic code information for insurance purposes."[193] Representative Schneider's sentiment was codified in the statute, which prohibits "an insurer, county, city, village or school board that provides health care services for individuals on a self-insured basis" from requesting or requiring an individual or family member to obtain

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"specific chromosomal or single-gene genetic condition." *Id.* § 33-18-206(5)(c). *See supra* notes 32-33 (discussing chromosomal and single-gene abnormalities).

[189] MONT. CODE ANN. § 33-18-206(3). In addition, the law does not restrict any disclosure of genetic information by insurers.

[190] *Id.* § 33-18-206(4).

[191] WIS. STAT. ANN. § 631.89. "Genetic test" is defined as "a test using [DNA] extracted from an individual's cells in order to determine the presence of a genetic disease or disorder or the individual's predisposition for a particular genetic disease or disorder." *Id.* § 631.89(1). However, people who are discriminated against on the basis of gene protein tests are not protected. Andrews, *supra* note 93, at 25. Proteins are products of DNA, thus a protein test is not covered under the definition of "genetic test." *See* notes and accompanying text *supra* p. 557 (discussing proteins and their functions), and notes and accompanying text *infra* p. 607 (comparing the different state law definitions of "genetic testing").

[192] Joe Manning, *Gene Tests Bare What Ailments Lurk*, MILWAUKEE J. & SENTINEL, June 6, 1992, at 1A.

[193] *Id.*

a genetic test, reveal if a genetic test was taken or any results of such a test.[194] In addition, insurance coverage and health care benefits cannot be conditioned on the above, or considered in the determination of rates or any other aspect of coverage.[195] These prohibitions do not apply to life or income continuation insurers,[196] however, life and income continuation insurers are prohibited from using obtained information when writing any other type of insurance coverage.[197]

On March 17, 1995, a bill was proposed to repeal and amend certain sections of the Wisconsin statute in order to expand the definition of "genetic test."[198] Genetic tests would include the physical examination of an individual or an examination of the individual's family history to determine if there is a genetic disorder or predisposition to a genetic disease.[199] "Individual" would include an unborn child.[200] In addition, the proposal specifies that the prohibitions restricting the use of genetic testing by insurers would apply only to an insurer "that offers health care coverage."[201] The restrictions on requesting or requiring a genetic test would be repealed, but insurers could not condition coverage or determine rates on the results of genetic tests in their underwriting process.[202]

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[194] WIS. STAT. ANN. § 631.89(2).

[195] *Id.*

[196] Income continuation insurance provides "full or partial payment of the financial loss of earnings incurred as a result of injury or illness. . . ." WIS. STAT. ANN. § 40.62(1) (West 1992).

[197] WIS. STAT. ANN. § 631.89(3). Thus, a life insurer who obtains genetic information in order to issue a life insurance policy cannot use this information for health insurance coverage.

[198] A.B. 227, 92d Leg. Sess., 1995-96 Reg. Sess. (Wis. 1995). *See supra* note 191 (defining "genetic test" as currently used in the Wisconsin statute).

[199] A.B. 227 § 631.89(1)(A).

[200] A.B. 227 § 631.89(1)(b).

[201] A.B. 227 § 631.89(2)(bm).

[202] The bill would limit the restrictions to the underwriting process, which is defined as "the process of risk evaluation and selection conducted by an insurer." *See* WIS. STAT. ANN. § 631.89(1)(d).

5. *Florida*

The only legislation in Florida concerning genetic testing and insurance was enacted in 1992.[203] The law states that any person who perfoms a DNA analysis or receives any information regarding an analysis must give notice of the analysis or results to the individual tested.[204] The only mention of insurance is in the statute's last section:

> The notice must also state whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. If the information was used in any decision that resulted in a denial, the analysis must be repeated . . . and if the first analysis is found to be inaccurate, the denial must be reviewed.[205]

Thus, the statute only provides for information disclosure. Insurers can use genetic information in insurance underwriting, so Floridians are not afforded substantive protection.

However, proposed legislation introduced in January and February 1996[206] would prevent insurers from requiring or soliciting genetic tests,[207] using or reviewing genetic test results, or considering an individual's decisions or actions relating to genetic testing in any manner for any insurance purpose.[208] These provisions would not apply to life or disability income insurance policies.[209]

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[203] FLA. STAT. ANN. § 760.40(3).

[204] *Id.*

[205] *Id.*

[206] S.B. 748, 1996 Reg. Sess. (Fla. 1996); H.B. 923, 1996 Reg. Sess. (Fla. 1996) (identical bills).

[207] "Genetic test" is defined as "a test to determine the presence of mutations or variations in an individual's DNA associated with clinically recognized diseases or disorders by the analysis of: 1. Any portion of the individual's DNA; or 2. Any gene product of the individual's DNA." S.B. 748 §§ 627.4301(1)(a), 760.40(1); H.B. 923 §§ 627.4301(1)(a), 760.40(1).

[208] S.B. 748 § 627.4301(2)(a); H.B. 923 § 627.4301(2)(a).

[209] S.B. 748 § 627.4301(2)(a); H.B. 923 § 627.4301(2)(a). According to Florida Senator Howard Forman, sponsor of S.B. 748, "[i]t's a real-world [bill]

6. Ohio

In 1993, the Ohio legislature enacted temporary genetic screening and testing prohibition statutes.[210] According to Representative Wayne Jones, the sponsor of the legislation, "[g]enetic makeup is not something anybody can control. If insurers have access to this information, they'll abuse it."[211] The statutes cover health maintenance organizations, sickness and accident insurers[212] and self-insurers,[213] and they prohibit these insurers from requiring an individual to submit to a genetic screening or testing,[214] or taking into consideration or making inquires about

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with common sense." Jay Weaver, *Bill Forbids Gene Screening by Health Insurance Groups*, SUN-SENTINEL, Mar. 7, 1996, at 17A. According to Florida Representative Tracy Staff, sponsor of H.B. 923, "[w]e have this burgeoning technology that can be used to determine the predisposition of people's medical status, but we don't have any guidelines for how this information should be used." *Id.* However, an attorney representing the Health Insurance Association of America stated that the bill "allows for an applicant to consider the results of his genetic testing when he applies for health insurance, but it prevents us from considering the same information." *Id.*

[210] OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50. These three laws will remain in effect until February 9, 2004. As of that date they will be repealed and replaced by OHIO REV. CODE ANN. §§ 1742.43, 3901.491 and 3901.501, respectively, which would allow insurers to use genetic information obtained after February 9, 2004. *Id.*

[211] Christine B. O'Malley, *Insurance Gene Tests Face Restrictions*, BUS. FIRST, Sept. 27, 1993, at 17.

[212] Sickness and accident insurance is "any policy, contract, or certificate of insurance against loss or expense resulting from the sickness of the insured, or from the bodily injury or death of the insured by accident, or both. . . ." OHIO REV. CODE ANN. § 3923.01 (Anderson 1989).

[213] "Self-insurer" is defined as a "government entity providing coverage for health care services on a self-insurance basis." OHIO REV. CODE ANN. §3901.50.

[214] "Genetic screening or testing" is defined as:

> a laboratory test of a person's genes or chromosomes for abnormalities, defects, or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.

any genetic screening or testing.[215] Insurers can only use genetic information if the results are voluntarily submitted by an applicant, and the results are favorable to the applicant.[216] Disability income insurers and life insurers are not covered under the statutes.

7. *California*

On September 23, 1994, the California legislature enacted Senate Bill 1146, Insurance Discrimination: Genetic Characteristics,[217] which amended the state's Health and Safety and Insurance Codes.[218] When passed, the California statute was one of the strongest genetic testing laws in the United States due to its coverage and the "breadth" of its definition of genetic characteristics.[219] According to Senator Patrick Johnston, who sponsored the legislation for three years,[220] "[t]he issue of discrimination

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Id. §§ 1742.42(A), 3901.49(A)(1), 3901.50(A)(1).

[215] *Id.* §§ 1742.42(B), 3901.49(B), 3901.50(B).

[216] *Id.* §§ 1742.42(F), 3901.49(F), 3901.50(F).

[217] S.B. 1146, 1993-94 Reg. Sess. (Cal. 1994) (enacted). Most of the amendments will remain in effect until January 1, 2002, and, as of that date, will be repealed unless a later enacted statute deletes or extends the January 1, 2002 date. *Id.*

[218] For example, the bill deleted the limitation that "those reasons for refusal or discrimination be the sole reasons for that refusal or discrimination." *See* S.B. 1146, 1993-94 Reg. Sess., 1993 Cal. Stat 10123.3, 11512.95 (enacted).

[219] The California statute was one of the strongest according to Dr. Paul Billings, advocate for genetic privacy protections and San Francisco-based physician who helped author the law. *See* Sally Lehrman, *New California Law Prohibits Genetic Discrimination by Health Insurers*, BIOTECH. NEWSWATCH, Oct. 17, 1994, at 1; Shulman, *supra* note 39, at E2. The statute was the first to cover protein tests. *See* notes and accompanying text *infra* p. 607 (comparing the different state law definitions of "genetic testing").

Under the California law, "genetic characteristics" are defined as "any scientifically or medically identifiable gene or chromosome, or alteration thereof, which is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder, and which is asymptomatic of any disease or disorder." CAL. HEALTH & SAFETY CODE § 1374.7(c); CAL. INS. CODE § 10147(b).

[220] Lehrman, *supra* note 219, at 1.

based on one's genetic traits is becoming an increasing problem."[221] He warned that "many individuals will choose not to be tested for the simple reason the test results may be held against them by potential insurers."[222]

The California law prohibits those forms of refusal and discrimination of insurance by health care service plans, self-insured employee welfare benefit plans and nonprofit hospital service plans on the basis of an individual's genetic characteristics which in certain situations may be associated with disability in that person or that person's offspring.[223] The law also prohibits an insurer licensed to issue disability policies for hospital, medical and surgical expenses from failing or refusing to accept an application for that insurance, issuing or cancelling that insurance, charging a higher rate or premium, or placing a limitation on coverage based on an individual's genetic characteristics.[224] Further protections both specify penalties for willful or negligent disclosure of genetic characteristic test results,[225] and prevent insurers from requiring genetic tests in order to determine insurability.[226] The law does not apply to life and disability policies that are "contingent on review or testing" for illness.[227]

Recent legislation enacted on October 10, 1995,[228] imposes

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[221] *Lawmaker to Present Bill Extending Bar on Gene-Based Discrimination*, BNA'S HEALTH CARE POL'Y REP., Dec. 5, 1994, at 2007, 2007.

[222] *Id.*

[223] CAL. HEALTH & SAFETY CODE § 1374.7(a); CAL. INS. CODE §§ 10123.3(a), 11512.95(a). A "self-insured employee welfare benefit plan" is "any plan or program of benefits provided by an employer or an employee organization, or both for the purposes of providing hospital, medical, surgical, nursing, or dental services . . . ." *See* CAL. INS. CODE § 10121(f) (West 1993). A "nonprofit hospital service plan" may include "maintenance and care in the hospital" and reimbursement for medical services. CAL. INS. CODE § 11493 (West 1988).

[224] CAL. INS. CODE § 10140(b).

[225] *Id.* § 10149.1.

[226] *Id.* § 10148.

[227] *Id.* § 10140(b).

[228] CAL. INS. CODE §§ 10123.31, 10123.35, 10140.1, 10140.5, 11512.96, 11512.965; CAL. HEALTH & SAFETY CODE § 1374.9 The Insurance Discrimination: Genetic Characteristics law took effect on January 1, 1996. This legislation was proposed by Senator Patrick Johnston, sponsor of Senate Bill

increased penalties for a violation of provisions relating to discrimination based on an individual's genetic characteristics by insurers.[229] In addition, the law prohibits insurers from offering separate health care policies to people genetically predisposed to illness.[230] This was done to "close a potential loophole," because there were cases in which applicants were offered bare-minimum policies with different terms and benefits as a result of their genetic characteristics.[231] According to Senator Johnston, this bill responded to a situation where "science has outstripped the law and ethics, and public policy has to come along and account for new technology."[232]

Moreover, on February 22, 1996, Senator Johnston introduced legislation designed to further strengthen existing California law.[233] The bill would prohibit discrimination in renewal policies,[234] prohibit health care service plans, self-insured employee welfare benefit plans, some life and disability insurers and nonprofit hospital service plans from seeking, using or maintaining "any genetic information for underwriting purposes or for any nontherapeutic purpose,"[235] and would replace the term "genetic characteristics" with "genetic information."[236]

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[229] Violations by health care service plans, self-insured employee welfare benefit plans, life or disability insurers and nonprofit hospital service plans can now result in administrative penalties of up to $100,000 depending on the number of violations. CAL. HEALTH & SAFETY CODE § 1374.9(a); CAL. INS. CODE §§ 10123.31(a)-(c), 10140.5(a)-(c), 11512.96(a)-(c).

[230] CAL. HEALTH & SAFETY CODE § 1374.7(a); CAL. INS. CODE §§ 10123.3(a), 10140(b), 11512.95(a).

[231] *Cal. Bars Use of Genetic Tendency Data*, NAT'L UNDERWRITER, Oct. 23, 1995, at 3.

[232] *Id.*

[233] S.B. 1740, 1995-96 Reg. Sess. (Cal. 1995).

[234] *Id.* §§ 1374.7(a), 10123.3(a), 11512.95(a).

[235] *Id.* §§ 56.17(h), 10123.35(h), 10140.1(h), 11512.965(h).

[236] *See* S.B. 1740. "Genetic information" is defined as "information about genes, gene products, or inherited characteristics, that may derive from the individual or family member." *Id.* §§ 1374.7(c), 10123.3(c), 10140(f), 11512.95(c). *See* notes and accompanying text *supra* pp. 587-88 (discussing the significance of the term "genetic information" in pending federal legislation).

8. *Colorado*

In 1994, the Colorado legislature enacted a legislative declaration limiting the uses of genetic testing.[237] The purpose of the statute is to protect individual privacy and autonomy with regard to a person's genetic information.[238] The statute intends to "prevent information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage."[239] The statute prohibits "entities"[240] from seeking, using, or keeping information derived from genetic testing for any underwriting purpose connected with the covered insurance.[241] In addition, "information derived from genetic testing shall be confidential and privileged."[242] Thus, to release any genetic testing information, the statute requires entities to obtain "specific written consent" by the person tested.[243] These prohibitions do not apply to life insurance or individual disability insurance.[244]

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[237] COLO. REV. STAT. § 10-3-1104.7. "Genetic testing" is defined as "any laboratory test of human DNA, RNA [product of DNA], or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness" and only includes tests that directly measure the alterations. *Id.* § 10-3-1104.7(2)(b).

[238] *Id.* § 10-3-1104.7(1)(c).

[239] *Id.* § 10-3-1104.7(1)(d).

[240] "Entities" are defined as "any sickness and accident insurance company, health maintenance organization, nonprofit hospital, medical-surgical and health service corporation, or other entity that provides health care insurance, group disability insurance, or long-term care insurance coverage . . . ." *Id.* § 10-3-1104.7(2)(a).

[241] *Id.* § 10-3-1104.7(3)(b).

[242] *Id.* § 10-3-1104.7(3)(a).

[243] *Id.* § 10-3-1104.7(3)(a), (5).

[244] *Id.* § 10-3-1104.7(10).

9. Georgia

On April 21, 1995, the Georgia legislature added a new chapter on genetic testing to the state's insurance code.[245] The legislature found that it was appropriate to limit the use and availability of genetic information in order to protect individual privacy and autonomy, and thus, prohibited insurance companies from seeking information derived from genetic testing,[246] or using information derived from genetic testing to deny access to accident and sickness insurance.[247] However, the current prohibitions do not apply to life, disability or health insurance.[248] Pending legislation introduced on January 30, 1995, would extend these prohibitions, providing that information derived from genetic testing could not be sought or used to deny access to health or disability insurance by entities engaged in health or disability insurance underwriting.[249]

10. New Hampshire

On May 16, 1995, the New Hampshire legislature enacted a new act which limits genetic testing.[250] The law prohibits health insurance providers from requiring or requesting an individual or family member to undergo genetic testing,[251] revealing if testing

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[245] GA. CODE ANN. §§ 33-54-1 to 8.

[246] *Id.* § 33-54-1. "Genetic testing" is defined as:

> laboratory tests of human DNA or chromosomes for the purpose of identifying the presence or absence of inherited alterations in genetic material or genes which are associated with a disease or illness that is asymptomatic at the time of testing and that arises solely as a result of such abnormality in genes or genetic material.

Id. § 33-54-2.

[247] *Id.* § 33-54-1.

[248] *Id.* § 33-54-7.

[249] S.B. 233, 143d Gen. Assembly, 1995-96 Reg. Sess. (Ga. 1995).

[250] N.H. REV. STAT. ANN. §§ 141-H:1 to 6. The Genetic Testing law took effect on January 1, 1996. *Id.*

[251] "Genetic testing" is defined as:

occurred or any results of a test, conditioning insurance on any genetic test information or considering genetic testing in the determination of rates or other aspects of coverage.[252] These provisions do not apply to life, disability income or long-term care insurance.[253] Disclosure of the results or fact that an individual underwent genetic testing is prohibited without prior written and informed consent of the individual.[254]

11. Minnesota

On June 1, 1995, the Minnesota legislature passed the Genetic Discrimination Act,[255] which regulates the use of genetic testing by insurers. According to Representative Charlie Weaver, sponsor of the legislation, the bill was introduced to prevent the danger of creating an uninsurable "genetic underclass."[256] The Act prohibits a health plan company[257] from requiring or requesting an individual or blood relative to take a genetic test,[258] inquiring if

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> a test, examination or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence or alteration of any gene or chromosome, and any report, interpretation or evaluation of such a test, examination or analysis, but excludes any otherwise lawful test, examination or analysis that is undertaken for the purpose of determining whether an individual meets reasonable functional standards for a specific job or task.

N.H. REV. STAT. ANN. § 141-H:1.

[252] *Id.* § 141-H:4.

[253] *Id.* § 141-H:5.

[254] *Id.* § 141-H:2.

[255] MINN. STAT. ANN. § 72A.139. The Genetic Discrimination Act took effect on January 1, 1996. *Id.*

[256] *Bill Would Prevent Insurers from Using Genetic Tests to Make Coverage Decisions*, STAR TRIB., Jan. 26, 1995, at 2B.

[257] A "health plan company" is a health care carrier (insurance company, nonprofit health service plan, HMO, fraternal benefit society or self-insurance employee health plan) or an integrated service network (which provides health services "to enrollees for a fixed payment per time period"). MINN. STAT. ANN. §§ 62Q.01(4), 62A.011(2), 62N.02(8) (West Supp. 1996).

[258] "Genetic test" is defined as:

a genetic test was taken or refused, taking into consideration the fact of whether a genetic test was taken or refused or taking into consideration any results of a genetic test, when making any underwriting decision in connection with the offer, sale or renewal of a health plan.[259] A life insurance company or fraternal benefit society[260] is permitted to require genetic testing for the purpose of determining insurability.[261] However, the insurer must obtain written informed consent for the test and must notify the applicant of any test result.[262] In addition, an insurance company must pay for any testing before an individual has to submit to a genetic test.[263]

12. Oregon

On July 19, 1995, the Oregon legislature approved an act relating to genetics.[264] The Legislative Assembly found that

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> a presymptomatic test of a person's genes, gene products, or chromosomes for the purpose of determining the presence or absence of a gene or genes that exhibit abnormalities, defects, or deficiencies, including carrier status, that are known to be the cause of a disease or disorder, or are determined to be associated with a statistically increased risk of development of a disease or disorder. "Genetic test" does not include a cholesterol test or other test not conducted for the purpose of determining the presence or absence of a person's gene or genes.

MINN. STAT. ANN. § 72A.139(2)(b).

[259] *Id.* § 72A.139(3).

[260] A "fraternal benefit society" is:

> [a]ny incorporated society, order, or supreme lodge, without capital stock . . . conducted solely for the benefit of its members and their beneficiaries and not for profit, operated on a lodge system with ritualistic form of work or branch system that confines its membership to any one religious denomination, having a representative form of government, and which provides benefits. . . .

MINN. STAT. ANN. § 64B.01 (West 1986).

[261] MINN. STAT. ANN. § 72A.139(4).

[262] *Id.* § 72A.139(5), (6).

[263] *Id.* § 72A.139(7).

[264] OR. REV. STAT. §§ 659.700, 659.705, 659.710, 659.715, 659.720, 746.135.

"[g]enetic information is uniquely private and personal information that should not be collected, retained or disclosed without the individual's authorization."[265] Thus, providers "may not use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy for hospital or medical expenses."[266] The statute also prohibits insurance providers from using favorable tests to induce the purchase of insurance.[267] However, the law allows an insurance provider to ask an applicant to take a genetic test[268] in connection with an application for insurance, although specific authorization from the individual is required.[269] In addition, the DNA sample must promptly be destroyed after the testing.[270]

C. *Analysis of State Legislation*

Table 1 reflects the trend of enacted legislation which restricts health and life insurers from using an individual's genetic characteristics in the underwriting process. The states are listed according to the date that their laws were enacted. Restrictions on the use of genetic information or genetic testing are marked ("X"), and statutes without restrictions on health and life insurance are blank. Pending legislation that would restrict the use of genetic information by health insurers is also marked.

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[265] *Id.* § 659.705(b). According to Senator Bob Shoemaker, who helped author the law, "[t]he fundamental premise is . . . that my genetic characteristics are my private property and others are not entitled to access [this information]." *It's All in the Genes*, INDIANAPOLIS NEWS, Sept. 30, 1995, at A6.

[266] OR. REV. STAT. § 746.135(3).

[267] *Id.* § 746.135(2).

[268] *Id.* § 746.135(1). "Genetic test" is defined as "a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic." *Id.* § 659.700(5). "Genetic characteristic" is defined as "any gene or chromosome, or alteration thereof, that is scientifically or medically believed to cause a disease, disorder or syndrome, or to be associated with statistically increased risk of development of a disease, disorder or syndrome." *Id.* § 659.700(3).

[269] *Id.* § 746.135(1).

[270] *Id.* § 659.715(5).

Table 1. *Restrictions on the Use of Genetic Information by Insurers*

State	Date of Law	Health Insurance	Life Insurance	Health Insurance Proposals
Maryland	1986	X	X	X
Arizona	1989		X	
Montana	1991		X	
Wisconsin	1991	X		X
Florida	1992	X	X	X
Ohio	1993	X		
California	1994	X	X	X
Colorado	1994	X		
Georgia	1995			X
New Hampshire	1995	X		
Minnesota	1995	X	X	
Oregon	1995	X		

Source: ARIZ. REV. STAT. ANN. § 20-448; CAL. CIV. CODE § 56.17; CAL. INS. CODE §§ 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 10143, 10146, 10147, 10148, 10149, 10149.1, 11512.95, 11512.96, 11512.965; CAL. HEALTH & SAFETY CODE §§ 1374.7, 1374.9; COLO. REV. STAT. ANN. § 10-3-1104.7; FLA. STAT. ANN. § 760.40; GA. CODE ANN. §§ 33-54-1 to 8; MD. CODE ANN.,

INS. § 223; MINN. STAT. ANN. § 72A.139; MONT. CODE ANN. § 33-18-206; N.H. REV. STAT. ANN. §§ 141-H:1 to 6; OHIO REV. CODE ANN. §§ 1742.42, 1742.43, 3901.49, 3901.491, 3901.50, 3901.501; OR. REV. STAT. §§ 659.700, 659.705, 659.710, 659.715, 659.720, 746.135; WIS. STAT. ANN. § 631.89; S.B. 1740, 1995-96 Reg. Sess. (Cal. 1995); S.B. 748, 1996 Reg. Sess. (Fla. 1996); H.B. 923, 1996 Reg. Sess. (Fla. 1996) (identical bills); S.B. 233, 143d Gen. Assembly, 1995-96 Reg. Sess. (Ga. 1995); S.B. 276, 1996 Leg. Sess. (Md. 1996); A.B. 227, 92d Leg. Sess., 1995-96 Reg. Sess. (Wis. 1995).

The state statutes reflect a trend giving greater protection to individuals in the area of health insurance. While three out of the five states that enacted legislation before 1993 restrict the use of genetic information for health insurance,[271] only Wisconsin has a comprehensive policy with effective protections.[272] The Wisconsin legislation prohibits any consideration of genetic information for medical underwriting.[273] Moreover, Wisconsin's pending legislation, if passed, would give the most expansive definition yet of "genetic testing."[274] In contrast to these states, six out of the seven states that enacted legislation after 1992 (most at the end of 1994 through 1995), give comprehensive protection to individuals for health insurance.[275] The laws prohibit the

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[271] Florida, Maryland and Wisconsin do not have effective restrictions on the use of genetic information for health insurance. *See* FLA. STAT. ANN. § 760.40; MD. CODE ANN., INS. § 223; WIS. STAT. ANN. § 631.89.

[272] WIS. STAT. ANN. § 631.89. *See supra* pp. 592-93 (analyzing Wisconsin's enacted legislation). However, pending legislation in Florida and Maryland would extend protections against genetic discrimination to individuals for health insurance. *See* S.B. 748, 1996 Reg. Sess. (Fla. 1996); H.B. 923, 1996 Reg. Sess. (Fla. 1996) (identical bills); S.B. 276, 1996 Leg. Sess. (Md. 1996).

[273] WIS. STAT. ANN. § 631.89(2).

[274] A.B. 227, 92d Leg. Sess., 1995-96 Reg. Sess. (Wis. 1995). *See supra* p. 593 (analyzing Wisconsin's pending legislation).

[275] California, Colorado, Minnesota, New Hampshire, Ohio and Oregon give comprehensive protection to individuals for health insurance. *See* CAL. INS. CODE §§ 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 10143, 10146, 10147, 10148, 10149, 10149.1, 11512.95, 11512.96, 11512.965; CAL. HEALTH & SAFETY CODE §§ 1374.7, 1374.9; COLO. REV. STAT. ANN. § 10-3-1104.7; MINN. STAT. ANN. § 72A.139; N.H. REV. STAT. ANN. §§ 141-H:1 to 6; OHIO REV. CODE ANN. §§ 1742.42, 1742.43, 3901.49, 3901.491, 3901.50, 3901.501; OR. REV. STAT. §§ 659.700, 659.705, 659.710, 659.715, 659.720, 746.135.

requirement, use or consideration of genetic information for health insurance coverage.[276]

The trend in the law also gives less protection, from the already limited restrictions in place, to individuals in the area of life insurance. Out of the five states that enacted legislation before 1993, four contain provisions limiting the use of genetic information for life insurance.[277] However, three allow use if there is "actuarial justification."[278] This effectively eliminates protection because insurance companies would not use genetic information unless they had an actuarial reason. The fourth, Florida, only provides for the testing to be repeated if genetic information was used to deny insurance.[279] If the test results are accurate, any decision based on the information is permitted. In contrast to these laws, most of the legislation enacted after 1992 does not even attempt to restrict the use of genetic information for life insurance.[280] California has a provision for life insurance, but the restrictions are limited to small and group life insurance policies that are not contingent upon medical testing.[281] In addition, Minnesota's provision only requires that life insurers obtain a

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[276] *See* CAL. INS. CODE §§ 10123.3(a), 10140(b), 10148, 11512.95(a); CAL. HEALTH & SAFETY CODE § 1374.7(a); COLO. REV. STAT. ANN. § 10-3-1104.7(3)(b); MINN. STAT. ANN. § 72A.139(3); N.H. REV. STAT. ANN. § 141-H:4; OHIO REV. CODE ANN. §§ 1742.42(B), 3901.49(B), 3901.50(B); OR. REV. STAT. § 746.135(3). Although Georgia does not have any restrictions concerning health insurance, a pending bill, S.B. 233, 143d Gen. Assembly, 1995-96 Reg. Sess. (Ga. 1995), would extend protection.

[277] Arizona, Florida, Maryland and Montana have laws restricting the use of genetic information for life insurance. *See* ARIZ. REV. STAT. ANN. § 20-448; FLA. STAT. ANN. § 760.40; MD. CODE ANN., INS. § 223; MONT. CODE ANN. § 33-18-206.

[278] Arizona, Maryland and Montana allow the use of genetic information for life insurance if there is an actuarial reason. *See* ARIZ. REV. STAT. ANN. § 20-448; MD. CODE ANN., INS. § 223; MONT. CODE ANN. § 33-18-206. *See supra* pp. 589-92 (analyzing these laws).

[279] FLA. STAT. ANN. § 760.40(3).

[280] *See* notes and accompanying text *supra* pp. 595-603 (discussing the scope of genetic discrimination laws enacted after 1992).

[281] CAL. INS. CODE § 10140(b). *See* Lehrman, *supra* note 219, at 1.

written informed consent for the genetic test and that they notify the applicant of the test results.[282]

The definitions of "genetic testing" for the state laws have also become more comprehensive over time. Three out of the five genetic discrimination statutes enacted before 1993 do not even contain the term "genetic testing."[283] Although Florida's statute includes the term, "genetic testing" is not specifically defined.[284] In addition, four states, which did enact laws defining "genetic testing,"[285] do not prohibit discrimination based on gene protein tests because "proteins" are not covered under the definitions.[286] However, four more states have enacted statutes with comprehensive definitions of "genetic testing" or "genetic characteristics,"[287] and three of these states were the latest to enact genetic discrimination laws.[288] These laws cover tests performed using genes or gene products.[289]

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[282] MINN. STAT. ANN. § 72A.139(5), (6).

[283] Arizona, Maryland and Montana's statutes do not contain the term "genetic testing." *See* ARIZ. REV. STAT. ANN. § 20-448; MD. CODE ANN., INS. § 223; MONT. CODE ANN. § 33-18-206.

[284] *See* FLA. STAT. ANN. § 760.40(1).

[285] Colorado, Georgia, Ohio and Wisconsin define the term "genetic testing" in their statutes. *See* COLO. REV. STAT. § 10-3-1104.7; GA. CODE ANN. § 33-54-2; OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50; WIS. STAT. ANN. § 631.89.

[286] *See* COLO. REV. STAT. § 10-3-1104.7; GA. CODE ANN. § 33-54-2; OHIO REV. CODE ANN. §§ 1742.42(A), 3901.49(A), 3901.50(A); WIS. STAT. ANN. § 631.89. *See supra* notes 237, 246, 214, 191 (providing the definition of "genetic testing" for the respective statutes).

[287] These states include California, Minnesota, New Hampshire and Oregon. *See* CAL. HEALTH & SAFETY CODE § 1374.7(c); CAL. INS. CODE § 10147(b); MINN. STAT. ANN. § 72A.139(2)(b); N.H. REV. STAT. ANN. § 141-H:1; OR. REV. STAT. § 659.700(5). *See supra* notes 219, 258, 251, 268 (providing the definition of "genetic testing" or "genetic characteristics" for the respective statutes).

[288] These states include Minnesota, New Hampshire and Oregon, each enacting their genetic discrimination statutes in 1995.

[289] *See* CAL. HEALTH & SAFETY CODE § 1374.7(c); CAL. INS. CODE § 10147(b); MINN. STAT. ANN. § 72A.139(2)(b); 1995 N.H. Laws 101 § 141-H:1; OR. REV. STAT. § 659.700(5). *See supra* notes 219, 258, 251, 268 (providing the definition of "genetic testing" or "genetic characteristics" for the respective statutes).

The trend of the law, affording greater protections to individuals for health insurance and lesser protections for life insurance, is consistent with social policy considerations. Historically, more life insurance policies have been medically underwritten than health insurance policies, and fewer Americans believe life insurance is a basic right.[290] In addition, adverse selection plays an important role when considering life insurance and genetic information.[291] If an individual learns of the likelihood or certainty of getting a genetic disease, and then purchases large amounts of life insurance, there is a potential for "significant economic losses by insurers."[292] However, it is unlikely that a person will purchase health insurance solely on the basis of their genetic makeup.[293] Many people who purchase health insurance will not suffer from genetic disease, but they obtain health insurance because it covers a wide variety of ailments.[294] Factors including environmentally-caused diseases, accidents, injuries and maternity costs, all give incentives for purchasing health insurance long before the discovery of any genetic disease.[295] Health insurance is a necessary protection against these ailments. Thus, preventing insurers from considering genetic information in health insurance underwriting is both fair and appropriate.

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[290] ASSESSING GENETIC RISKS, *supra* note 2, at 280. For a discussion of the distinctions between health and life insurance, see Meyer, *supra* note 46, at 1293-94; *see also* Thomas H. Murray, *Genetics and the Moral Mission of Health Insurance*, HASTINGS CTR. REP., Nov.-Dec. 1992, at 12, 14-15 (discussing the right to health insurance and life insurance).

[291] "Adverse selection" occurs when people believe themselves to be at a high risk. Thus, they are inclined "to seek insurance or to keep insurance in force . . . ." THOMSETT, *supra* note 185, at 8. *See* Kenneth S. Abraham & Lance Liebman, *Private Insurance, Social Insurance, and Tort Reform: Toward a New Vision of Compensation for Illness and Injury*, 93 COLUM. L. REV. 75, 102-03 (1993) (discussing adverse selection in the context of disability insurance); Alexander M. Capron, *Hedging Their Bets; Genetic Testing and Life Insurance*, HASTINGS CTR. REP., May 1993, at 30 (discussing genetic testing, life insurance and adverse selection).

[292] Joseph M. Miller, Comment, *Prevent Discrimination Based on the "Luck of the Genetic Draw,"* 93 DICK. L. REV. 729, 753 (1989).

[293] *Id.*

[294] *Id.*

[295] *Id.*

CONCLUSION

Federal and state legislatures are beginning to address the problem of genetic discrimination. Although many states have recently enacted comprehensive laws, the vast majority must now recognize that, since September 1995, general population screenings for genetic disorders are possible.[296] Thus, the enactment of legislation regulating genetic information can no longer wait. New genes are constantly being discovered,[297] and genetic tests can now pinpoint those of us predisposed to disease. Insurance companies will use this information to our detriment. According to one commentator, "[i]nsurance is a method of risk-sharing against the unknown, and the more the unknown becomes knowable in advance, the less the current system makes sense. We need to think of ways of restructuring our insurance system . . . to accommodate this ability to predict future risks."[298] Legislation preventing the use of genetic information in medical underwriting is the way to accommodate this ability to predict future risks. Although there are other insurance mechanisms whereby genetic information would not be needed,[299] until they are implemented, state and federal

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[296] In September 1995, researchers discovered a genetic defect in a gene associated with familial breast cancer that had an unusual frequency in American Ashkenazi Jews. Kolata, *supra* note 41, at A24. Moreover, in December 1995, another breast cancer gene was disclosed. Kolata, *supra* note 41, at B18. Greatly improved genetic screening can now be offered to women. Kolata, *supra* note 41, at B18. *See supra* note 41 (discussing general population screenings).

[297] *See supra* notes 37-41 and accompanying text (discussing new gene discoveries and causes of genetic disease).

[298] Weiss, *supra* note 122, at A3 (quoting Professor Mark Rothstein, Director of the University of Houston Health Law and Policy Institute).

[299] One alternative system in which medical underwriting would not be necessary, and thus genetic information would not be needed, is universal health care. *See supra* note 98 (discussing universal health care). Another mechanism is for states to individually organize health care for all of its citizens. *See* Martin Gottlieb, *A Managed Care Cure-All with Flaws and Potential*, N.Y. TIMES, Oct. 1, 1995, at 1 (explaining Tennessee's approval of health care measures which give health insurance to every uninsured person who wants it); *see also* Jerry L. Mashaw & Theodore R. Marmor, *The Case for Federalism and Health Care Reform*, 28 CONN. L. REV. 115 (1995) (discussing state-led health care reform).

legislation is needed to keep an individual's genetic information strictly private, and out of the hands of health insurers.