GENETIC TESTING IN INSURANCE UNDERWRITING: A BLESSING OR A CURSE? AN EXAMINATION OF THE TENSION BETWEEN ECONOMICS AND EQUITY IN USING GENETIC TESTING IN RISK CLASSIFICATION

INTRODUCTION

The Human Genome Project ("HGP") is a federally funded program established for the purpose of mapping and sequencing all human genes. The dramatic genetic advances resulting from the HGP have given rise to hope of finding additional approaches to the prevention and cure of diseases. However, these same advances also lead to ethical problems relating to right to privacy and discrimination. Some of the deepest fears of society relate to the confidentiality of genetic test results and to the discriminatory effect of genetic testing on the issuance of insurance. Moreover, physicians also fear that stigmatization, which would undoubtedly accompany denial of insurance coverage, would prevent individuals from seeking early diagnosis and treatment, thereby aggravating the existing problem of escalating health care costs and uninsurability in the United States.

1. H.R. 2045, 102d Cong., 1st Sess. § 2(6-7)(1991) [hereinafter H.R. 2045]; Rossiter & Caskey, Molecular Studies of Human Genetic Disease, 5 FED'N. AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. 21, 24-25 (1991). The authors state that the ultimate goal of the Human Genome Project is to enable clinical geneticists to study the mechanism of genetic diseases and to provide molecular diagnoses of genetic disorders. This goal could be achieved by locating an individual's entire complement of genes and deciphering the message encoded in each gene. Id.


3. OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 15 (1990). The report states that if the method used in genetic testing as well as the use of information resulting from such testing are in accord with ethical principles, then genetic testing is ethically justifiable. The report also notes that job applicants and employees believe in the confidentiality of all genetic information to prevent the use of such information to deprive them of opportunities and benefits such as job and health insurance. Id.

4. ACLI-HIAA, supra note 2, at 2.

5. Meyer, Battle Brews Over Genetic Screening, Am. Med. News, Nov. 25, 1991, at 3, col. 3, at 24, col 2. See Friedman, The Uninsured: From Dilemma to Crisis, 265 J. AM. MED. ASS'N 2191, 2494 (1991). Friedman notes that because of delays in diagnosis and treatment, the savings obtained from cost-effective prevention and treatment of the disease conditions are lost when the diseases progress to severe illnesses. These illnesses are associated with higher morbidity and they require high-cost emergency and specialty treatments. Id. For example, the simple careful review of foot care for a diabetic may avoid life threatening gangrene and potential amputations. Id.
These concerns prompted the introduction of the Human Genome Privacy Act ("HGPA") to limit access of insurers to an applicant's genetic information. The remarkable advancement in genetic technology and an increase in our understanding of the relation between genetics and diseases raise questions on the proper use of such information. The acquisition and disclosure of an individual's personal genetic information by agencies such as the Department of Energy ("DOE") and the National Institutes of Health ("NIH") can infringe on the individual's right to privacy and right to due process and other legal protections. In addition, misuse of such information can hinder the individual's opportunities in the areas of education, employment, health care, insurance, and credit. To prevent the misuse of an individual's genetic data, the HGPA proposes that Congress regulate the "collection, maintenance, use, and dissemination" of an individual's genetic data by such agencies.

In response to the proposed legislation and because of fear that legislation such as the HGPA will lead to unfair discrimination and adverse selection, the American Council of Life Insurance ("ACLI") and the Health Insurance Association of America ("HIAA") have formed the ACLI-HIAA Task Force on Genetic Testing. The purpose of the Task Force is to examine societal concerns and to determine the effect of genetic testing on the insurance industry. The report reiterates the importance of insurance companies being involved in the formulation of legislative policies relating to the insurance industry.

These issues fuel the debate on the validity of using genetic test results as a variable in risk classification. To better understand the debate, this Comment will provide overviews on genetics and insurance. This Comment will then evaluate the opposing positions on the use of genetic testing in insurance underwriting based on the goals of risk classification. The Comment concludes that genetic testing results should not be used as a variable in risk classification.

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7. H.R. 2045, supra note 1, at § 2(a)(3).
8. Id. at § 2(a)(4, 6-7).
9. Id.
10. Id. at § 2(a)(5).
11. ACLI-HIAA, supra note 2, at 2, 8.
12. Id.
13. Id.
14. Id. at 10.
15. See infra notes 18-70, 123-87 and accompanying text.
16. See infra notes 204-392 and accompanying text.
17. See infra notes 300-03 and accompanying text.
Hereditary traits are transmitted through genes from one generation to the next in a predictable manner. The primary material of genes is deoxyribonucleic acid ("DNA"). An individual's entire complement of genes is known as the genome. The human genome has forty-six chromosomes, which are linear collections of approximately 50,000 to 100,000 genes. The genes of all humans are very similar throughout the human genome. However, small variations known as genetic polymorphisms exist between individuals.

Genetic diseases are important examples of polymorphisms. The study of genetic diseases has focused on locating genes that fail to function properly. Molecular biologists estimate that four thousand known inheritable diseases are caused by a defect in a single gene, an interaction between genes, or an interaction between genes and environmental factors. Diseases caused by a single gene defect — such as Huntington's disease, cystic fibrosis, Duchenne muscular dystrophy, and chronic granulomatous disease — are easy to explain. To understand how these defective genes are different from the normal genes, as well as to develop different approaches for early detection and treatment, the defective genes have to be mapped and sequenced. Diseases that involve multiple genes rather than a single gene are poorly understood. Multiple gene diseases — such as cancer, Alzheimer's disease, cardiovascular disease, stroke, arthritis, some psychiatric disorders, and autoimmune disorders — require

19. Id. at 37. See Annas, Mapping the Human Genome and the Meaning of Monster Mythology, 39 Emory L.J. 629, 638 (1990). Annas states that the DNA is composed of two linear strands in double helix form. Each strand is made of four different nucleotides; adenyl acid (A), guanylic acid (G), cytidylic acid (C), and thymidylic acid (T). The nucleotides are bound together as base pairs to form the double helix. Id.
20. Annas, 39 Emory L.J. at 638. Annas notes that the human genome has approximately three billion base pairs. Id. at 635.
25. Id.
complex interactions among genetic and environmental factors.\textsuperscript{30} Recently, researchers discovered that the flawed gene associated with myotonic dystrophy grows in size as the gene is transmitted from one generation to another.\textsuperscript{31} This finding challenges the traditional belief that genes are transmitted unchanged.\textsuperscript{32} Although not everything will be explained by genetics, having access to the genetic material is essential to the detailed understanding of any of these diseases.\textsuperscript{33} Mapping and sequencing are fundamental steps in deciphering these genetic diseases.\textsuperscript{34}

Genetic mapping is the method of determining the location of genes in specific chromosomes.\textsuperscript{35} Developing a human genome map means isolating a large number of identifiable fragments of a chromosome called genetic markers.\textsuperscript{36} Each genetic marker defines the position occupied on the chromosome by the gene representing a particular trait.\textsuperscript{37} Over 1000 genetic markers now exist, and more markers are being found and isolated each week.\textsuperscript{38} The chromosomal locations of genes responsible for more than 500 genetic diseases have been identified.\textsuperscript{39} Marker analysis is presently used to detect about twenty-five single-gene diseases, providing information with great ramifications.\textsuperscript{40} As genetic mapping advances, the number of chromosomal markers will greatly increase, and the time required to locate a gene will be dramatically reduced.\textsuperscript{41} These genetic technological developments will lead to greater use of genetic testing in the diagnosis...

\textsuperscript{30} Watson & Cook-Deegan, Human Genome Project and International Health, 263 J. AM. MED. ASS'N 3322 (1990).
\textsuperscript{31} Harley, Brook, Rundle, Crow, Reardon, Buckler, Harper, & Housman, Expansion of an Unstable DNA Region and Phenotypic Variation in Myotonic Dystrophy, 355 NATURE 545 (1992). The authors define myotonic dystrophy as the most common "adult form of muscular dystrophy." The disease is characterized by progressive muscle weakness and sustained muscle contraction. The age at onset and severity of the disease vary widely even within the same families. Id.
\textsuperscript{32} Gene Flaw Gets Worse With Time, Omaha World-Herald, Feb. 6, 1992, at 6, col. 1.
\textsuperscript{33} Watson & Cook-Deegan, 263 J. AM. MED. ASS'N at 3322. See Beckwith, Foreword: The Human Genome Initiative: Genetics' Lightning Rod, 17 AM. J.L. & MED. at 7. Beckwith states that manic-depressive illness (MDI) is a heterogeneous disease. Although good evidence exists that some cases of MDI have a genetic component, the evidence also suggests that other cases of MDI have a major environmental component. Id.
\textsuperscript{34} Watson & Cook-Deegan, 263 J. AM. MED. ASS'N at 3322.
\textsuperscript{35} Annas, 39 EMORY L.J. at 636.
\textsuperscript{36} Beckwith, 17 AM. J.L. & MED. at 4.
\textsuperscript{37} Annas, 39 EMORY L.J. at 636.
\textsuperscript{38} M. ROTHSTEIN, MEDICAL SCREENING AND THE EMPLOYEE HEALTH COST CRISIS 74 (1989).
\textsuperscript{39} McKusick, 5 Fed'n AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. at 17-18.
\textsuperscript{40} Johnson, Genetic Screening, CRS ISSUE BRIEF, June 19, 1991, at 3 [hereinafter CRS ISSUE BRIEF].
\textsuperscript{41} Beckwith, 17 AM. J.L. & MED. at 5.
and treatment of diseases. Genetic testing allows the detection of genetic aberrations that may be linked to inheritable diseases, susceptibilities to diseases, and traits in asymptomatic, healthy individuals who are genetic carriers. The use of genetic markers and familial linkage analyses makes possible the presymptomatic diagnosis of single-gene disorders, such as Huntington's disease. Genetic testing permits the detection of the defective gene before the disease actually manifests. Advances in molecular biology have made possible the determination of an individual's predisposition to disease by directly detecting the mutant gene associated with the disease. Thus, the detection of disease-related genes is possible even in persons without any family history of the disease or in those persons whose families are not available for genetic linkage analyses. Genetic testing also detects susceptibility genes, which require additional factors such as other genes or environment for the disease to be manifested. In most of these cases, the environment serves as the controlling factor. The presence of the predisposition gene alone may not be sufficient to cause disease.

**Implications of Genetic Testing**

Continued progress in the mapping of the human genome will result in a dramatic increase in the number of genetic tests available to predict an individual's personal risk of developing certain diseases and disabilities. This technology, however, may result in discrimina-

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42. M. Rothstein, *supra* note 38, at 76.
43. Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace I* (1990). See Genetic Testing Comm., American Council of Life Ins., The Potential Role of Genetic Testing in Risk Classification 4 (1989) [hereinafter Genetic Testing Comm.]. The Committee reports that in inheritable genetic diseases, "the genetic component is so overwhelming that its results are predictable and needs no environmental interaction." These diseases are rare but collectively are an "important cause of morbidity and mortality." Diseases caused by susceptibility genes are manifested only when other genetic or environmental factors are present. Although the diseases may or may not develop, these diseases are common and significantly affect the "morbidity and mortality of an insurance pool." *Id.* See also CRS Issue Brief, *supra* note 40, at 3. The report states that genetic carriers are individuals who have one normal gene and one abnormal gene for a disease which requires two abnormal genes to be manifested. *Id.*
47. CRS Issue Brief, *supra* note 40, at 5.
49. *Id.*
50. *Id.*
tion of insurance applicants and in the stratification of society on the basis of an individual's genetic makeup. Over fifteen million individuals in the United States are afflicted with disorders caused by single-gene defects, and several millions more have diseases that are either caused by multiple gene defects or are environmentally induced. More than one-third of the American population has indicated that some immediate family members are afflicted or have been afflicted with a genetic disorder. Molecular biologists believe that each person carries between "five to seven lethal recessive genes." In addition, each one has an "undetermined number of genes" that render each individual predisposed to developing diseases that become manifest when the genes interact with the environment. Thus, the tools are available to use genetic testing to diagnose latent inherited conditions as well as diseases with a genetic predisposition that probably will affect a larger number of individuals. The scope of the new technology raises public policy concerns about the appropriate use of genetic testing.

Although genetic markers may be useful in diagnosing and treating diseases, their use has limitations. For example, for a result to be conclusive, samples from a number of the affected individual's relatives need to be obtained. Differentiating the DNA variations present in the samples is expensive and labor-intensive. Moreover, the interpretation of data pertaining to genetic markers may be limited because the presence of a certain gene does not infallibly indicate the severity of the disease in the affected individual. For example, the expression of the signs of Fragile X-syndrome varies widely; some affected individuals are extremely retarded while others are normal. In some cases, if the defect results from spontaneous mutation during fetal development, then individuals who did not inherit a particular

52. CRS ISSUE BRIEF, supra note 40, at 2.
53. Id.
54. Id.
55. Capron, 39 EMORY L.J. at 690.
56. Id.
57. OFFICE OF TECHNOLOGY ASSESSMENT, supra note 43, at 1.
58. Id.
59. CRS ISSUE BRIEF, supra note 40, at 4.
60. Id.
61. Id.
62. Id. See Rossiter & Caskey, 5 FED'N AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. at 21. The authors note that some disease-causing genes, particularly diseases linked to genes located on the "X" chromosome, are susceptible to mutations resulting in different genetic alterations in every affected family member. Id. See also Green, Discrimination by DNA: Possible Consequences of Genetic Testing, 22 HEALTH 86 (1990).
63. CRS ISSUE BRIEF, supra note 40, at 4. The report indicates that Fragile X-syndrome is the most common inheritable form of mental retardation. Id. at 3.
genetic defect may still develop the same disease.64 In addition, abnormalities can occur at different locations in the gene.65 Testing for only some of these aberrations may result in failure to identify a particular individual's defect.66

Inaccurate interpretations of genetic testing may also arise when the genetic marker is associated with the abnormal gene.67 If the particular gene and the marker are separated because of a chromosomal break, then the marker will lose its capability to predict the inheritance of the defective gene.68 When researchers determine exactly the disease-causing gene and its precise location, the development of a widely applicable and more conclusive diagnostic test will be feasible.69 Experience shows that no test is perfect, and that the errors of the test can be minimized, but cannot be completely eliminated.70

HUMAN GENOME PROJECT

The Human Genome Project ("HGP") is a federally funded program formed to assist biomedical scientists in fighting genetic diseases by helping to find the specific genes responsible for specific diseases.71 The primary goal of the HGP is to collect data on DNA structure in human and nonhuman chromosomes.72 A secondary goal is to expand mapping and sequencing technologies.73 Supporters of the program have suggested that achieving the goals of the program is synonymous to providing the "Rosetta Stone or the Holy Grail of

64. Id. at 4.
65. Id. at 5.
66. Id.
67. Id.
68. Id.
69. Id. The report notes that this information will facilitate the identification of the typically abnormal portions of the gene in an affected individual. Id.
70. Id. at 6.
71. H.R. 2045, 102d Cong., 1st Sess. § 2(a)(6-7) (1991) [hereinafter H.R. 2045]; Watson & Cook-Deegan, 283 J. AM. MED. ASS'N at 3322. See DeLisi, 76 AM. SCIENTIST at 489; Watson & Cook-Deegan, Origins of the Human Genome Project, 5 FED’N AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. 8, 9 (1991); Dulbecco, A Turning Point in Cancer Research: Sequencing the Human Genome, 231 SCIENCE 1055 (1986). The authors state that three major events provided impetus for the formation of the project. The first event involved a June 1985, meeting in Santa Cruz, California, where the idea of a large scale project of sequencing the human genome was proposed. A second event was a Department of Energy-sponsored international workshop in Santa Fe, New Mexico, in March 1986 where the proposal for the DOE to shift the focus of research from assessing the effects of radiation on genetic mutation to sequencing the human genome was made. A third impetus to the formation of the HGP was a 1986 editorial in Science journal arguing for human genome sequencing as an effective means to facilitate cancer research. Id.
72. Watson & Cook-Deegan, 5 FED’N AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. at 8.
73. Id.
life," because deciphering the message encoded in each individual's genes will reveal what makes each individual human.\textsuperscript{74}

The challenge of deciphering the human genome was first undertaken by the Department of Energy ("DOE") in early 1986.\textsuperscript{75} Because of concern about the appropriateness of the DOE spearheading the HGP, the National Institutes of Health ("NIH") was urged to participate in the HGP.\textsuperscript{76} The NIH agreed to participate in the HGP and established the National Center for Human Genome Research.\textsuperscript{77} Initially, much uncertainty existed over the extent of coordination between the NIH and DOE programs.\textsuperscript{78} The NIH must concentrate on human diseases and on genomes of other organisms to fulfill the needs of the biologists.\textsuperscript{79} The DOE must carry out its congressional mandate by monitoring the inherited effects of exposure to low-level radiation and other environmental hazards.\textsuperscript{80} Currently, Congress is funding both the NIH and DOE genome initiatives.\textsuperscript{81}

Interest in human genome research is not confined to the United States.\textsuperscript{82} The events leading to the formation of the United States Human Genome Project were also instrumental in initiating human genome research projects in other countries.\textsuperscript{83} This concerted international interest in genome research prompted the establishment of the Human Genome Organization ("HUGO") in 1988.\textsuperscript{84}

\textbf{SCIENTIFIC IMPACT OF THE HUMAN GENOME PROJECT}

The Human Genome Project is by far the largest coordinated effort ever undertaken in the biological sciences.\textsuperscript{85} The project will un-

\textsuperscript{74} Beckwith, 17 AM. J.L. & MED. at 1.
\textsuperscript{76} Id. Watson stated that the grantees of NIH would be primary users of the generated data and that most of the human genetics research leading to the HGP had been NIH-supported. \textit{Id}.
\textsuperscript{77} Beckwith, 17 AM. J.L. & MED. at 3.
\textsuperscript{78} Watson, 248 SCIENCE at 47.
\textsuperscript{79} Cantor, Orchestrating the Human Genome Project, 248 SCIENCE 49, 50 (1990).
\textsuperscript{80} Id.
\textsuperscript{81} Id. See H.R. 2045, supra note 71. The Act indicates that Congress appropriated to the NIH $28,230,000 in 1989, $59,530,000 in 1990, and proposed $109,029,000 in 1991. Congress also appropriated to the DOE $17,500,000 in 1989, $26,000,000 in 1990, and proposed $45,000,000 in 1991. \textit{Id.} See also Beckwith, 17 AM. J.L. & MED. at 2. Beckwith states that the proposed appropriation for the Project in 1992 is approximately $160 million. \textit{Id}.
\textsuperscript{82} Watson & Cook-Deegan, 5 FED'N AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. at 9-10.
\textsuperscript{83} Id.
\textsuperscript{84} Id. at 10; Bodmer, HUGO: The Human Genome Organization, 5 FED'N AM. SOCIETIES FOR EXPERIMENTAL BIOLOGY J. 73 (1990) (stating that presently, HUGO has 239 members representing twenty-three countries).
\textsuperscript{85} Cantor, 248 SCIENCE at 49.
doubtedly have a powerful effect on medicine, biology, and health.\textsuperscript{86} Advances in molecular biology and human genetics have already provided understanding of the causes of some diseases.\textsuperscript{87} For example, genes that play a role in DNA repair and, thus, may be associated with known human diseases, have been discussed.\textsuperscript{88} In addition, genes believed to be essential for successful pregnancy have been isolated.\textsuperscript{89} A number of immune receptor genes, which are associated with inherited autoimmune diseases such as rheumatoid arthritis and multiple sclerosis, also have been found.\textsuperscript{90} Scientists predict that all major immune receptor genes that play a role in autoimmune disease will be found by the year 2000.\textsuperscript{91} Thus, medical science will gain powerful new abilities to diagnose, cure, and eventually prevent many genetic diseases.\textsuperscript{92}

The development of new technologies arising from the HGP will aid in the determination of public health needs.\textsuperscript{93} For example, techniques for the rapid sequencing of DNA may improve the detection of mutations caused by exposure to radiation or environmental factors.\textsuperscript{94} As detailed genetic maps are developed, susceptibilities to workplace and other environmental toxins may be identified.\textsuperscript{95} DNA-based tests may also replace many of the conventional tests currently used in clinical medicine.\textsuperscript{96} Improvement in the speed, cost, and accuracy of the genetic tests should result in the routine use of these tests.\textsuperscript{97}

THE ETHICAL IMPLICATIONS OF THE HUMAN GENOME PROJECT

The greater availability, affordability, and accuracy of such tests may have significant ethical ramifications.\textsuperscript{98} The prospect of routine genetic testing has raised concerns about the use of an individual's genetic information by third parties, such as insurers, for nonmedical purposes.\textsuperscript{99} Many individuals in society fear that the use of genetic

\textsuperscript{86} OFFICE OF TECHNOLOGY ASSESSMENT, supra note 43, at 6.
\textsuperscript{87} Id.
\textsuperscript{89} Id.
\textsuperscript{90} Id. The author states that immune receptor genes mediate the inheritance of autoimmune diseases — such as multiple sclerosis and rheumatoid arthritis — predisposing an individual to such diseases. Id.
\textsuperscript{91} Id.
\textsuperscript{92} See supra notes 87-91 and accompanying text.
\textsuperscript{93} OFFICE OF TECHNOLOGY ASSESSMENT, supra note 43, at 6.
\textsuperscript{94} Id.
\textsuperscript{95} Id.
\textsuperscript{96} Watson & Cook-Deegan, 263 J. AM. MED. ASS’N at 3323.
\textsuperscript{97} Id.
\textsuperscript{98} Id. at 3324.
\textsuperscript{99} Id.
testing results to identify high-risk individuals will lead to the use of the genetic information by insurers to determine an applicant's insurability.\textsuperscript{100} This practice would inevitably result in unequal access to medical care—a human need.\textsuperscript{101} Moreover, such use would create a new genetic underclass of people who would be denied access to health insurance coverage and, consequently, also denied access to health care.\textsuperscript{102} Such denial would highlight and exacerbate the existing problem of uninsurability in the United States.\textsuperscript{103} As genetic mapping and sequencing advance, these issues will increase in complexity and urgency.\textsuperscript{104}

To address these issues, the Working Group on Ethical, Legal, and Social Implication of the Human Genome Project was formed.\textsuperscript{105} The purpose of the Working Group is to analyze the broader social, ethical, and legal implications of genome research to make certain that society uses the genetic information only to benefit humanity.\textsuperscript{106} If necessary, the Working Group will draft legislation at both federal and state levels to prevent third parties from infringing on the privacy of a person's genetic information and also to prevent discrimination on the basis of genetics.\textsuperscript{107}

HUMAN GENOME PRIVACY ACT

The knowledge derived from the Human Genome Project regarding the role of genes in controlling diseases could lead to greater possibilities for discrimination based on the genetic make-up of individuals.\textsuperscript{108} The growing fear is that discrimination will occur against persons identified to be at risk of developing genetic disorders or of

\textsuperscript{100} AMERICAN COUNCIL OF LIFE INS. & HEALTH INS. ASS'N. OF AM., REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING 4 (1991) [hereinafter ACLI-HIAA].

\textsuperscript{101} Friedman, The Uninsured: From Dilemma to Crisis, 265 J. AM. MED. ASS'N 2491, 2494 (1991).

\textsuperscript{102} CRS ISSUE BRIEF, supra note 40, at 14.

\textsuperscript{103} See infra notes 333-41 and accompanying text. See also Meyer, Report: Number of Uninsured Up to 34.7 Million, Am. Med. News, Jan. 20, 1992, at 5, col. 1. The author reports that the figure of 34.7 million uninsured Americans is the highest figure ever released by the Census Bureau in decades. The author also notes that “[i]n all, 13.9% of Americans were uninsured in 1990, up from 13.6% the year before.” The author also states that according to Dr. Wolfe, “[i]ncreasingly, Americans who have families, jobs and steady incomes are unable to get health insurance. A bad situation is getting worse.” Id.

\textsuperscript{104} OFFICE OF TECHNOLOGY ASSESSMENT, supra note 43, at 6.

\textsuperscript{105} Beckwith, 17 AM. J.L. & MED. at 11. Beckwith notes that “the group consists of individuals with backgrounds in civil rights law, ethics, medicine, and science, most of whom have a history of examining the implications and social effects of genetic screening programs.” Id.

\textsuperscript{106} Watson, 248 SCIENCE at 46.

\textsuperscript{107} Id.

\textsuperscript{108} Davies & Gershon, Law to Keep Labels Off Genes, 347 NATURE 221 (1990).
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having offspring likely to develop genetic diseases.\textsuperscript{109} This fear has prompted the introduction of a legislative bill in the United States Congress to address the ethical dilemmas raised by the Human Genome Project.\textsuperscript{110} On April 24, 1991, John Conyers, the Democratic Representative from Michigan and Chairman of the House Committee on Government Operations, introduced the Human Genome Privacy Act ("HGPA").\textsuperscript{111} The purposes of the Human Genome Privacy Act are:

[t]o safeguard individual privacy of genetic information from the misuse of records maintained by agencies or their contractors or grantees for the purpose of research, diagnosis, treatment, or identification of genetic disorders, and to provide to individuals access to records concerning their genome which are maintained by agencies for any purpose.\textsuperscript{112}

The HGPA attempts to safeguard an individual's right to privacy which "is a personal and basic right protected by the Constitution of the United States."\textsuperscript{113} The HGPA also provides that any federal agency or government grantee that maintains personal genetic information is required by the HGPA to protect individuals from invasion of personal genetic privacy.\textsuperscript{114}

The HGPA requires six major actions by the agencies.\textsuperscript{115} First, agencies must allow an individual to decide what information pertaining to him or her is "collected, maintained, used, or disseminated."\textsuperscript{116} Second, an agency must allow a person to prevent his or her records from being used or disclosed for a different purpose without the person's consent.\textsuperscript{117} Third, to ensure individuals access to their genetic records, the HGPA requires agencies to allow a person to obtain the records, to have copies of the records, and to amend any records.\textsuperscript{118} Fourth, the agencies must gather, maintain, utilize, or disseminate personal genetic information in a fashion that guarantees the information is current and accurate.\textsuperscript{119} The agencies must provide safeguards to prevent misuse of the identifiable genetic information.\textsuperscript{120} The fifth portion of the HGPA requires agencies to allow exemptions from these requirements for personal genetic records

\textsuperscript{109} Id.
\textsuperscript{110} Id.
\textsuperscript{111} H.R. 2045, supra note 71.
\textsuperscript{112} Id.
\textsuperscript{113} Id. § 2(a)(1).
\textsuperscript{114} Id. §§ 101(1), 2(a)(2).
\textsuperscript{115} Id. § 2(b)(1-6).
\textsuperscript{116} Id. § 2(b)(1).
\textsuperscript{117} Id. § 2(b)(2).
\textsuperscript{118} Id. § 2(b)(3).
\textsuperscript{119} Id. § 2(b)(4).
\textsuperscript{120} Id.
kept anonymously only for research purposes. Finally, the agencies will be subject to legal action and penalties for any damages that might result from violations of any person’s rights under this HGPA.

Insurance

The essence of an insurance system is embodied in the risk classification of the system, which is a method of developing different risk classes based on the different degrees of risk of loss represented by each applicant to the insurer. Insurers apply actuarial principles to reasonably estimate the expected loss of a class of persons and to determine which specific risks the insurers will assume and what rate to charge for protection against the assumed risks. Thus, the insurer’s goal is to accurately assess risk and to set a fair price for the risk assumed.

Insurance is based on unknown contingencies. If neither the insurer nor the insured have information as to the occurrence of a loss, then people will share a common interest in risk pooling. However, in the health insurance industry, underwriters traditionally use an applicant’s personal and family health and occupational history to predict an applicant’s possible disease and time of death. Acquisition of any relevant information by the insurer will result in the stratification of risk pools and differential pricing for protection based on the principle of fair discrimination. The insurer’s goal is equitable treatment and not equal treatment of the insureds. Fair discrimination eliminates subsidization of high-risk insureds by low-risk insureds, thereby encouraging low-risk insureds to remain in the risk pool through offers of lower rates. When equal risks are ac-

121. Id. § 2(b)(5).
122. Id. § 2(b)(6).
125. K. Abraham, supra note 123, at 68.
128. Clifford & Iuculano, 100 Harv. L. Rev. at 1808.
129. Id. at 1810-11; Daniels, 68 Milbank Q. at 501.
131. Clifford & Iuculano, 100 Harv. L. Rev. at 1811; R. Pokorski, supra note 130, at 10.
corded different treatment or unequal risks are treated the same, un-
fair discrimination results.\textsuperscript{132} This practice is prohibited.\textsuperscript{133}

If the applicant, but not the insurer, possesses the relevant infor-
mation indicating high risk of loss, then fair discrimination is vi-
olated, and adverse selection results.\textsuperscript{134} The advantaged applicant may
be grouped inappropriately with low-risk insureds, resulting in the
equal treatment of unequal risks.\textsuperscript{135} This treatment will encourage
greater insurance coverage purchases by high-risk individuals, result-
ing in the insurer incurring pay-out claims which are higher than an-
ticipated.\textsuperscript{136} To make up for the loss, the insurers will be forced to
increase premium rates across the board.\textsuperscript{137} This measure will en-
courage low-risk insureds to withdraw from the pool while leaving
the high-risk individuals to remain in the pool because they cannot
afford to withdraw.\textsuperscript{138} Consequently, the size of the risk pool shrinks
to include only those insureds with huge medical costs, which further
escalates insurance rates.\textsuperscript{139} Such an upward spiral would inevitably
render insurance coverage either unavailable or unaffordable, and
eventually cause the insolvency of some insurance companies.\textsuperscript{140}

To protect themselves from insolvency resulting from misrepre-
sentation of health conditions, insurers incorporate incontestability
and preexisting conditions clauses in their insurance contracts.\textsuperscript{141} An
incontestability clause provides that the insurer cannot void a policy
or coverage on the basis of misrepresentation by the insured if such
policy or coverage has been in force for a specified period of time,
usually two years from the date of issue.\textsuperscript{142} Thus, if misrepresen-
tation is found to exist within this specified time period, the insurer
could void the policy.\textsuperscript{143} A preexisting condition clause provides that
the insurer will not pay benefits for any disease or illness acquired

\begin{itemize}
  \item \textsuperscript{132} R. Pokorski, supra note 130 at 7. See Bad Luck Insurance, 374 Nature 214 (1990).
  \item \textsuperscript{133} Id.
  \item \textsuperscript{134} Id. at 8-9.
  \item \textsuperscript{135} Id. at 8.
  \item \textsuperscript{136} Id.
  \item \textsuperscript{137} Id. at 8-9.
  \item \textsuperscript{138} Id. at 9.
  \item \textsuperscript{139} Id.
  \item \textsuperscript{140} Id.
  \item \textsuperscript{141} Hoffman & Kinsaid, AIDS: The Challenge to Life and Health Insurers' Free-
dom of Contract, 33 Drake L. Rev. 709, 735-36 (1986-87); See Cotton, Preexisting Con-
ditions 'Hold Americans Hostage' to Employers and Insurance, 285 J. Am. Med. Ass'n
  \item \textsuperscript{142} Clifford & Iculano, 100 Harv. L. Rev. at 1818.
  \item \textsuperscript{143} Id. The authors state that "the clause protects an insured from excessive liti-
gation several years after the initial enforcement of the policy, thus enabling the in-
sured to plan financially for his family while affording an insurer an opportunity to
reasonably investigate." Id.
\end{itemize}
during a certain period of time, usually between three and six months, before the effective date of the policy. However, for an insurer to rely on the preexisting condition protection, the insured must have known of the presence of the disease or illness during the application time.

ECONOMIC EFFICIENCY

In analyzing the nature of risk classification, the role of expected loss in separation, reliability, and incentive value of the risk classes must be examined. These features of risk classification reflect the various aspects of economic efficiency, which is the extent by which resources are allocated to maximize the value of these resources. The first feature of economic efficiency is the separation between risk groups. For risk classification to be economically efficient, significant separation should exist between the various risk classes. The difference in the mean expected losses between different risk groups should be statistically significant. If the degree of separation between risk groups is great, then a lower risk of misclassification of members exists. In this situation, charging members of different risk groups variable premium rates is more justifiable.

A second feature of efficient risk assessment is the reliability of the risk variables on which the classes are based. The variables should be verifiable and not highly susceptible to administrative error or fraud. Verification should not be so difficult or expensive that economic efficiency is compromised.

The economic efficiency value of risk classification is also measured by the degree to which the risk classification scheme is able to provide loss prevention incentives to the insureds. This goal can be achieved by creating risk classes based on variables that are within

144. Id. at 1819.
145. Hoffman & Kincaid, 35 Drake L. Rev. at 736.
146. K. Abraham, supra note 123, at 69.
147. Id. at 10.
148. Id. at 69.
150. Id.
151. Id. Abraham defines separation as "a measure of the degree to which insureds in different risk classes have different expected losses." The greater the difference in expected loss between risk groups, the more distinct is the separation between groups and the less is the probability of misclassification. Id.
152. Id.
153. Id. at 71.
154. Id.
155. Id. Abraham notes that the difficulty in verifying information provided by the applicant is the primary cause of unreliability. Id.
156. Id.
the control of the insured. Additionally, the risk classification scheme should allow the insured to be periodically reclassified based on the insured’s effort to reduce actual loss.

**FAIR RISK DISTRIBUTION**

Although refined and accurate risk classification promotes economic efficiency, such classification may violate fair risk distribution, which stipulates that fairness and justice should not be sacrificed for economic efficiency. To assess the fairness of risk distribution, the homogeneity and admissibility of the risk classes must be evaluated.

Homogeneity, the first feature, is a relative term because complete homogeneity is never attained. Each insured within a group has a set of variables that is different from those possessed by the other insureds in the group. For this reason, only the relevant, available, and reliable variables common to the group members are taken into account in the classification, resulting in incomplete homogeneity. Homogeneity is also a comparative term because the homogeneity of risk classes can be compared with other risk groups. If the different risk groups vary in homogeneity, then greater risk-sharing will be imposed on the risk groups that are less homogeneous, resulting in uneven distribution of the burden of misclassification.

The second feature of fair risk distribution is the admissibility of the variable. In classifying individuals according to risk, some variables may not be ethically, socially, or legally admissible, even though these variables are highly predictive of expected losses. Race, sex, and genetic traits may be good predictors of medical costs, but because these variables have a disparate effect on specific groups, these variables are highly suspect. Because genetic testing fails to

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158. *Id.*
159. *Id.* at 76.
160. *Id.* at 69.
161. *Id.* at 74-75.
162. *Id.* at 75.
163. Clifford & Iuculano, 100 Harv. L. Rev. at 1809.
164. K. Abraham, supra note 123, at 75.
165. *Id.*
166. *Id.* at 76.
167. *Id.*
168. *Id.* See M. Rothstein, Legal and Ethical Issues in the Laboratory Assessment of Genetic Susceptibility to Cancer, in Detection of Cancer Predisposition: Laboratory Approaches 187 (L. Spatz, A. Bloom, & N. Paul eds. 1990); M. Rothstein, Genetic Screening in Employment: Some Legal, Ethical, and Societal Issues 10 (unpublished manuscript).
bring about complete homogeneity in risk classification and because genetic traits are highly suspect variables, most of the concerns focus on the issues of accuracy-equity, control-causality, suspect variables, and public policy.\textsuperscript{169}

Accuracy-equity concerns require classification and pricing to closely reflect predicted cost to prevent subsidization of high-risk insureds by low-risk insureds and to equitably distribute the burdens of inaccuracy in classification.\textsuperscript{170} However, because complete homogeneity in risk classification is never attained without sacrificing economic efficiency, fair risk distribution, or both, some subsidization is inevitable.\textsuperscript{171} If all risk groups are equally heterogeneous, then subsidization runs from the lucky to the unlucky in the same risk group but not from one group to another.\textsuperscript{172} But if the degree of heterogeneity between the groups is different, then the burden of inaccuracy is unevenly distributed.\textsuperscript{173} The core of the accuracy-equity concern in a classification scheme is the comparative homogeneity among the risk groups.\textsuperscript{174} Thus, for an even distribution of the burden of inaccurate risk classification, the degree of heterogeneity between risk groups must be similar.\textsuperscript{175}

A second concern in fair risk distribution relates to the issue of control-causality, which examines whether variables that are not within the insured's control should be used as risk classifiers.\textsuperscript{176} Use of variables that cause a loss gives credibility to the risk classification because it avoids arbitrariness.\textsuperscript{177} However, when these causal variables are beyond the insured's control, the scheme removes individual responsibility as a factor in price setting.\textsuperscript{178} This scheme denies the insured the opportunity to be reclassified based on the individual's responsible behavior.\textsuperscript{179}

A third concern in fair risk distribution relates to suspect variables.\textsuperscript{180} Whenever a variable that is socially, legally, and ethically suspect is used as a risk classifier, such classification is unacceptable

\textsuperscript{169} K. Abraham, supra note 123, at 83.
\textsuperscript{170} Id.
\textsuperscript{171} Id. at 84.
\textsuperscript{172} Id. at 88. Abraham states that "[i]f risk classes are relatively heterogeneous, but equally so . . . , then the members of one class do not benefit at the expense of the members of a different class. Instead, low-risk insureds in each class bear a similar burden of inaccuracy." Id.
\textsuperscript{173} Id.
\textsuperscript{174} Id.
\textsuperscript{175} Id.
\textsuperscript{176} Id. at 89.
\textsuperscript{177} Id.
\textsuperscript{178} Id.
\textsuperscript{179} Id.
\textsuperscript{180} Id. at 92.
even though the classification is economically efficient.\textsuperscript{181} Thus, the low-risk insureds, as identified by the inadmissible variable end up subsidizing the high-risk insureds.\textsuperscript{182}

A fourth concern in fair risk distribution concerns public policy.\textsuperscript{183} From the standpoint of public policy, risk classification may be used to benefit a certain group of people by imposing burdens on others.\textsuperscript{184} Insurers accomplish risk redistribution goals by two methods.\textsuperscript{185} First, insurers can disregard variables that are associated with expected losses.\textsuperscript{186} Second, insurers can construct classes with set premiums that result in cross-subsidization from overcharged groups to the undercharged groups.\textsuperscript{187}

\textbf{REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING}

The insurance industry is acutely aware of the growing societal dissatisfaction with the insurance industry.\textsuperscript{188} Reports of discriminatory practices by insurance companies regarding denial of health care coverage on the basis of individual genetic data have fueled these negative sentiments.\textsuperscript{189} The greatest fear of the industry, however, relates to the legislative initiatives, such as the HGPA, aimed at restricting insurance companies from gaining access to an individual’s genetic information.\textsuperscript{190}

To examine the issues regarding genetic testing and insurance, the American Council of Life Insurance ("ACLI") and the Health Insurance Association of America ("HIAA") have formed a Task Force on Genetic Testing.\textsuperscript{191} This joint Task Force has issued a report addressing public concerns about insurance and the concerns of insurers about adverse selection, and the task force has offered some recommendations to insurance companies.\textsuperscript{192}

The report reaffirms the position of the insurance industry on

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\begin{footnotesize}
\textsuperscript{181} Id. at 93.  \\
\textsuperscript{182} Id.  \\
\textsuperscript{183} Id. at 83.  \\
\textsuperscript{184} Id. at 95-96.  \\
\textsuperscript{185} Id. at 95.  \\
\textsuperscript{186} Id.  \\
\textsuperscript{187} Id.  \\
\textsuperscript{189} Zoler, \textit{Can We Afford the Answers? Genetic Tests}, Med. World News, Jan. 1991, at 33. Zoler reports that Dr. Paul Billings had collected reports about people being denied insurance coverage based on their genetic information even though these individuals may not develop the suspected disease. Id.  \\
\textsuperscript{190} AMERICAN COUNCIL OF LIFE INS. & HEALTH INS. ASS’N OF AM., REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING 8 (1991) [hereinafter ACLI-HIAA].  \\
\textsuperscript{191} Id. at 2.  \\
\textsuperscript{192} Id. at 2-11.  \\
\end{footnotesize}
\end{flushleft}
the importance of having a balance of information between the insurer and the insured in risk classification. Any informational advantage on the part of the insured will lead to adverse selection resulting in substantial increases in the premiums of most insureds. Thus, the Task Force asserts that the introduction of legislation, such as the HGPA, will not protect consumers but will instead harm the insureds. The report also notes that currently, because of the prohibitive cost and inaccuracy of genetic testing, no insurer requires genetic testing in determining the insurability of an individual. The insurance industry also recognizes the fact that because each person is believed to possess several genes that can result in diseases, denying coverage to an individual diagnosed to be genetically predisposed to a disease would mean the demise of the insurance industry. Moreover, because health care providers are not routinely using genetic testing in clinical care and because insurers can obtain information on an individual’s genetic profile through relevant medical information other than from genetic testing, the insurance industry does not foresee a need for genetic testing.

The report also sets forth confidentiality recommendations that would apply after the insurers obtain the applicant’s genetic information. Although the ACLI-HIAA guidelines on confidentiality mirror the provisions of the HGPA, the two sets of guidelines differ on the time of application. The report concludes by recommending that insurance companies inform the public of their position on risk classification. The report also recommends that insurance companies vigilantly monitor and evaluate developments in genetic technology and inform other member companies of these advances. The report also urges insurers to present their policies and their need for access to any relevant medical information, including genetic testing.
ANALYSIS

Risk classification is governed by insurance law, which attempts to promote justice through the dual purposes of economic efficiency and fair risk distribution. Because these purposes are intricately intertwined and are not easily separated, these purposes may overlap or even collide in some instances. When this happens, tension results. This tension is evident in the ongoing debate as to whether an applicant's genetic information should be used in insurance underwriting. The American Council of Life Insurance ("ACLI") and the Health Insurance Association of America ("HIAA") Task Force Report illustrates the economic efficiency perspective of risk classification while the Human Genome Privacy Act ("HGPA") focuses on the goal of fair risk distribution through public policy. Thus, the reasonableness of exempting genetic information in insurance underwriting depends on whether the insurance industry is viewed as a business or as an instrument of public policy.

Viewing the insurance industry as a business would normally necessitate the use of an applicant's genetic information as a risk classifier to ensure the financial viability of insurance companies. Such practice would ideally foster the economic efficiency of risk classification by providing separation between risk groups, assuring the reliability of the genetic information, and providing the insurance applicant an incentive to limit the expected loss through the applicant's behavior. On the other hand, viewing the insurance industry as a public policy tool would require the exemption of genetic information in insurance underwriting. To justify the use of genetic information, the features of fair risk distribution have to be satisfied. Genetic testing must facilitate the homogeneous grouping of applicants and must not have a disparate, negative impact on those indi-
individuals found to possess genetic abnormalities.\textsuperscript{214}

At the present time, genetic testing is not accurately informative to render the use of the applicant's genetic profile either economically efficient or risk distributionally fair.\textsuperscript{215} If genetic testing improves to a point that would allow accurate prediction of the development and severity of a disease, then the use of an applicant's genetic information may be economically efficient and therefore justifiable from a business perspective.\textsuperscript{216} However, because the ultimate goal of insurance law is to serve justice, fair risk distribution takes precedence over economic efficiency.\textsuperscript{217} Although economically efficient, using genetic information in underwriting would be tantamount to sentencing people with genetic defects to assume the burden of potentially catastrophic medical costs.\textsuperscript{218} This result amounts to punishing these unfortunate individuals for a condition over which they have no control.\textsuperscript{219} This result is unjust and is contrary to the ultimate goal of insurance law.\textsuperscript{220}

**GENETIC TESTING AND ECONOMIC EFFICIENCY**

From a business perspective, the use of genetic testing to classify risk is not economically efficient at the present time, based on the economic efficiency features of separation, reliability, and incentive value.\textsuperscript{221} If genetic testing improves to a point where the occurrence and severity of a disease becomes accurately predictable, then genetic testing may be economically efficient but inequitable.\textsuperscript{222}

The ACLI-HIAA Task Force Report focuses on the business aspect of insurance and emphasizes the importance of informational balance between the insurer and the applicant in risk classification.\textsuperscript{223} The report emphasizes the necessity of having complete access to an applicant's medical information, including genetic testing results, in order to prevent adverse selection and consequently, to

\textsuperscript{214} See supra notes 161-68 and accompanying text.
\textsuperscript{215} See supra notes 59-68 and accompanying text.
\textsuperscript{216} See supra notes 146-58 and accompanying text.
\textsuperscript{217} K. Abraham, supra note 204, at 18. Abraham states that “[i]n the broadest sense the goal of any legal system is to achieve justice and few would consider the single-minded pursuit of efficiency a sufficient prescription for reaching that goal.” Abraham adds that “[a] national consideration, therefore, is whether the distribution of risk produced by insurance and regulated or altered by insurance law is fair, regardless of whether the allocation involved is efficient. \textit{Id.}
\textsuperscript{218} M. Rothstein, Medical Screening and the Employee Health Care Crisis 79 (1989).
\textsuperscript{219} \textit{Id.}
\textsuperscript{220} See supra note 217 and accompanying text.
\textsuperscript{221} See infra notes 257-91 and accompanying text.
\textsuperscript{222} See infra notes 257-91, 307-57 and accompanying text.
\textsuperscript{223} ACLI-HIAA, supra note 208, at 8.
preserve the financial viability of the industry.\textsuperscript{224} The ACLI-HIAA report contends that the introduction of legislation, such as the HGPA, will lead to adverse selection forcing the insurers to raise premiums.\textsuperscript{225} The ACLI-HIAA report states that consequently, the HGPA will not protect the consumer but will instead harm the average insured.\textsuperscript{226}

The industry also justifies the insurance practice of discriminating based on reliable actuarial data.\textsuperscript{227} The very nature of underwriting requires the classification of applicants according to the risk they present to the insurer and the different treatment of different risk groups.\textsuperscript{228} Thus, the insurance industry maintains that no distinction should be made between a prognosis based on genetic test results and a prognosis based on an applicant's personal and family health history.\textsuperscript{229} The presence of a genetic defect must not be treated differently from smoking, elevated serum cholesterol levels, and hypertension, because, in each case, the medical information serves as a powerful predictor of future health and longevity.\textsuperscript{230} An editorial in a leading scientific journal notes that fair discrimination cannot be prohibited in situations in which genetic information is involved, yet permitted with comparatively relevant nongenetic information without being inequitable.\textsuperscript{231} Charging individuals who carry defective and potentially damaging genes higher premiums than those free of specified genetic defects is not any different from the practice of charging smokers higher rates than nonsmokers.\textsuperscript{232}

Dr. Billings notes from several anecdotal reports that some insurance companies use an applicant's genetic information to determine the applicant's insurability.\textsuperscript{233} Dr. Billings contends that this practice constitutes genetic discrimination.\textsuperscript{234} Insurers, on the other hand, assert that for such a claim to be valid, proof that insurance companies treat genetic and nongenetic diseases differently is
needed.\textsuperscript{235} Prohibiting access to an applicant's genetic information, as contemplated by the HGPA, would result in reverse discrimination against persons who are free from genetic impairments.\textsuperscript{236} In other words, prohibiting fair discrimination in insurance based on an individual's genetic profile would result in preferential treatment of persons with adverse genetic traits, resulting in unfair discrimination.\textsuperscript{237} Such prohibition would prevent insurers from underwriting based on any medical information having a genetic component.\textsuperscript{238} An insurer will issue coverage at a standard rate to an individual with a significant genetic abnormality, yet will deny coverage to an individual afflicted with a nongenetic disease that carries basically the same risk of mortality or morbidity.\textsuperscript{239} Applicants with genetic defects would be afforded preferential treatment over applicants with diseases not considered to be genetically based and over applicants who are healthy.\textsuperscript{240}

If the health insurance industry is viewed as a business, then prohibiting the use of genetic information in underwriting is problematic because the practice violates fair discrimination and encourages adverse selection.\textsuperscript{241} Because no one presently knows how many individuals with defective genes will eventually develop disease, the mere purchase of greater insurance coverage by individuals does not necessarily translate to higher pay-out expenses.\textsuperscript{242} On the contrary, if individuals with genetic defects buy increased coverage and do not develop disease, then the insurer would profit.\textsuperscript{243} Moreover, because of the uncertainty in disease development and severity, classifying an individual with a genetic defect with high-risk individuals would be unfair discrimination.\textsuperscript{244} However, if genetic technology ever advances to a point in which genetic testing will accurately identify individuals who will develop diseases, and will accurately predict how diseases will be manifested and averted, then the use of genetic test results by insurers as risk classifiers may prove to be economically efficient.\textsuperscript{245}

\begin{itemize}
\item \textsuperscript{235} Id.
\item \textsuperscript{236} R. Pokorski, supra note 228, at 10.
\item \textsuperscript{237} Id.
\item \textsuperscript{238} Id.
\item \textsuperscript{239} Id. at 11.
\item \textsuperscript{240} Id.
\item \textsuperscript{241} Id. at 6-9.
\item \textsuperscript{242} But see M. Rothstein, Legal & Ethical Issues in the Laboratory Assessment of Genetic Susceptibility to Cancer, in DETECTION OF CANCER PREDISPOSITION: LABORATORY APPROACHES \textsuperscript{186} (L. Spatz, A. Blum, & N. Paul eds. 1990).
\item \textsuperscript{243} Id.
\item \textsuperscript{244} Stipp, Genetic Testing May Mark Some People as Undesirable to Employers, Insurers, Wall St. J., July 9, 1990, at B1, col. 2.
\item \textsuperscript{245} K. Abraham, supra note 204, at 69-74.
\end{itemize}
The possibility that genetic testing may one day become an economically efficient means of risk classification raises concerns about how insurers will use an applicant's genetic information in risk classification.\footnote{Johnson, Genetic Screening, CRS Issue Brief, June 19, 1991, at 2 [hereinafter CRS Issue Brief].} Although the ACLI-HIAA Task Force has attempted to address public concerns about insurance, the report fails to allay societal fears for several reasons. First, although insurers presently do not require genetic testing in determining the insurability of an applicant, this position is likely to change as genetic testing becomes cheaper, more predictive of the occurrence of genetic diseases, and more routinely used by health care providers.\footnote{Id. n.4.} Second, because insurers insist on the need for informational balance, insurers will likely require access in the future to the genetic information of those individuals who have been tested.\footnote{Id.} Third, the Task Force guidelines on confidentiality, although comprehensive, are not fail-safe.\footnote{Schatz, The AIDS Insurance Crisis: Underwriting or Overreaching?, 100 Harv. L. Rev. 1782, 1800-01 (1987).} Fourth, the guidelines on confidentiality apply only after the insurer has obtained an applicant's genetic information.\footnote{Id. supra note 208, at 6-7.} Thus, the report fails to address the primary concern of society about the propriety of using an applicant's genetic information as a risk classifier in determining the insurability of the applicant.\footnote{See supra notes 246-50 and accompanying text.}

As the accuracy of genetic testing improves and the cost of such test becomes reasonable, a secondary concern would be the propriety of requiring genetic testing before issuing a health insurance policy.\footnote{See Bad Luck Insurance, 347 Nature at 214. The reporter states that if the HGP makes diagnosis of diseases certain, insurance applicants may be required to undergo the appropriate diagnostic test, a practice not different from the present requirement of medical examination before the issuance of a policy. Id.} Because insurance is founded on the concept of risk sharing against unknown contingencies, risk classification based on genetic test results that conclusively predict the occurrence and severity of a disease would violate this traditional concept of insurance.\footnote{M. Rothstein, supra note 218, at 78.} The use of genetic testing would drastically reduce the number of unknown contingencies, thereby limiting the issuance of health insurance policy primarily to cover accidents and nongenetically-based diseases.\footnote{Id.}

Claims by the insurance industry that legislation such as the HGPA will lead to unfair discrimination and adverse selection must be evaluated on the basis of whether the use of genetic testing en-
hances the economic efficiency of risk classification. To determine the validity of such claims, the use of genetic testing as a risk classifier will be analyzed on the basis of the three features of economic efficiency, namely, separation, reliability, and incentive value.

SEPARATION FEATURE OF ECONOMIC EFFICIENCY

The first feature of economic efficiency to be analyzed is separation. In classifying risk based on genetic testing, two approaches could be employed to achieve the separation of risk classes. With the first approach, individuals with any genetic trait for a disease could be classified as one group and their expected loss could be compared with the expected loss of the insureds who do not possess the genetic trait for a disease. This method of classification would not result in an acceptable separation of risk classes because, presently, genetic testing fails to identify all individuals who have or will have genetic diseases and does not provide an absolute answer about whether a disorder will occur.

In addition, great variability is present in the different genetic conditions. Depending on the disease, great variability exists in the age of onset, severity of the disease, length of time between disease stages, and in the degree to which the individual is affected physically as the disease progresses through its various stages. The expression of the same genes varies widely even within the family and even with nearly identical environmental factors. When one considers the presence of susceptibility genes, the occurrence of the dis-

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255. K. ABRAHAM, supra note 204, at 69-74.
256. Id. at 69.
257. Id.
258. See infra notes 259-69 and accompanying text.
259. Cf. Berman, AIDS Antibody Testing and Health Insurance Underwriting: A Paradigmatic Inquiry, 49 OHIO ST. L.J. 1059, 1063-64 (1989). Berman states that [t]he industry asserts that persons who have been infected by the AIDS virus are not of the same class and risk as those who have not been infected. To include them in the group of nonexposed would violate the underlying concept that each insured pay according to what he or she receives rather than being subsidized by others.
260. Id.
262. Id. at B1, col 2.
263. Green, Discrimination by DNA: Possible Consequences of Genetic Testing, 22 HEALTH 86 (1990); Berlfein, supra note 260 at 2, col. 1. Berlfein reports that the same gene defect can be manifested disparately. Berlfein adds that according to Dr. Billings, some individuals suffer grotesque disfigurement from neurofibromatosis—the elephant man’s disease—while others, even within the family, may have a few, unnoticeable "pigmented spots on their body." Id.
ease is not known with certainty due to the need of the susceptibility
genes to interact with specific contributing factors.264 Because of
these variations, classifying individuals on the basis of the mere pres-
ence of a genetic defect is problematic.265

With the second approach, multiple classifications could be estab-
lished to achieve acceptable separation of risk classes, which would
justify imposing different premium rates.266 Because of the belief
that all individuals have between “five and seven lethal recessive
genes” and an “undetermined number of genes” that may predispose
them to certain diseases, multiple classifications could be justified.267
Individuals could be grouped according to the specific genetic condi-
tion present and to the likelihood that an individual will develop the
genetic disease.268 These further classifications may facilitate the
comparing of costs among various groups with genetic traits for dif-
ferent diseases as well as between genetic-related diseases and
nongenetic-related medical costs.269

When the entire genome is completely mapped and sequenced
and the occurrence and severity of genetic diseases can be accurately
predicted by the individual’s genetic profile, a strong possibility exists
that everyone would be classified as having a genetic abnormality.270
However, these genetic abnormalities may vary in terms of expected
loss.271 The certainty in predicting expected loss based on genetic
testing will result in a more refined risk classification and greater
stratification of the insureds.272

RELIABILITY FEATURE OF ECONOMIC EFFICIENCY

A second relevant feature of economic efficiency is the reliability
of genetic testing.273 At present, the presence or absence of a marker
for a particular disease does not conclusively indicate the presence or
absence of the disease.274 Moreover, the prediction of a person’s risk
can vary depending on the availability of family samples, age of onset

264. GENETIC TESTING COMM., AM. COUNCIL OF LIFE INS., THE POTENTIAL ROLES
265. See supra notes 261-64 and accompanying text.
266. K. ABRAHAM, supra note 204, at 69.
267. Capron, Which Ills to Bear: Reevaluating the “Threat” of Modern Genetics, 39
268. See supra note 43 and accompanying text.
269. K. ABRAHAM, supra note 204, at 70.
270. See Capron, 39 EMORY L.J. at 690. Capron states that “because everyone has
several genes that predispose him or her to genetic diseases, the impact of genetic dis-
eease or uninsurability will be lessened.” Id.
271. Id.
272. See supra note 43 and accompanying text.
273. K. ABRAHAM, supra note 204 at 71.
274. CRS ISSUE BRIEF, supra note 246, at 5.
in the parent, and the affected parent's sex.275 The location of the gene itself does not necessarily make genetic test results more informative in most genetic conditions.276

Because the cost of genetic testing is also prohibitive, verifying the genetic data furnished by the applicant would be difficult and would affect the reliability of the genetic information supplied by the applicant.277 The ACLI-HIAA report reassures the public that presently, no insurer requires genetic testing in determining the insurability of the applicant.278 Moreover, insurers do not anticipate the need for such testing in the future because the cost of administering genetic testing broadly would be prohibitive.279 In addition, genetic testing results would not provide information such as the applicant's age, habits, and family and personal health history.280 For these reasons, genetic testing results are not currently a reliable variable in classifying risks.281 But as the procedures become more accurate and affordable, genetic testing may be a reliable variable to use as a risk classifier.282 Insurers may be more inclined to use genetic test results in risk classification.283

INCENTIVE VALUE FEATURE OF ECONOMIC EFFICIENCY

A third feature of economic efficiency is the incentive value of genetic testing.284 The crucial question is whether acquiring the genetic condition is within the individual's control.285 This may be rele-
vant only to those individuals who have inherited the predisposition genes, because the development of the disease could be either triggered or suppressed by the behavior of the individual. 286 Factors such as diet, exercise, and smoking may be under a person's control. 287 Thus, individuals who adhere to their prescribed dietary and exercise regimens or who refrain from smoking may be offered lower rates as an incentive to limit the actual loss. 288 However, not all behaviors would be under the control of the individual. 289 When the triggering factors, such as chemical pollutants, are found in the atmosphere, this situation would be beyond the individual's control and no incentive value to the risk classification exists. 290 This may also be true when the triggering factors are inherently present in the individual's job situation, avoidance of which would result in the individual's loss of job. 291

Risk classification based on genetic testing also increases transaction costs rather than reduces losses. 292 If insurers deny health care coverage to individuals with a defective genetic condition, then this group of individuals may avoid seeking early or preventive health care, resulting in greater medical costs as the disease is triggered or

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286. CRS ISSUE BRIEF, supra note 246, at 4.
287. K. ABRAHAM, supra note 204, at 90.
288. Cf. Berman, 49 OHIO ST. L. J. at 1070-71. Berman states that "the variable on which the classification is based should be one over which the insured can exercise control." Berman also notes that "the ability of the classifier to influence insured behavior in a positive way is an indicator of the classifier's efficiency." Id.
289. Cf. M. LAPPE, GENETIC POLITICS 198 (1979). Lappe notes that [it] is one thing to advise a man with the gene for an enzyme known as glucose-6-phosphate dehydrogenase (G6PD) not to eat fava beans because they may poison him; it is quite another to ask someone with one Z gene to avoid fumes that are widely dispersed in the air we breathe, or that may occur in sublethal concentrations in particular job settings or sections of a city or town. Where beans are a necessary staple of life for the at-risk black population with the highest levels of G6PD, and employment in the cement factory the only job in town, it is somewhat beside the point to issue discretionary warnings.

290. Id. Lappe states that "[t]he basic question is the individual's capacity to respond to the educational approach common to the health promotional activities so widely encouraged by health planners and so poorly subscribed to by lay citizens." Id.
291. Id.
292. Cf. Berman, 49 OHIO ST. L.J. at 1072. Berman states that transaction costs "are created when the costs of one's activities accrue to someone else and are not compensated." Thus, when this uninsured individual becomes sick, he or she will receive free medical services. The uninsured's medical costs will accrue to society without compensation. Id. See K. ABRAHAM, supra note 204, at 15. Abraham states that the unavailability or unaffordability of insurance premiums will force the applicant to allocate his or her resources to prevention rather than to insurance. Id.
made worse by the lack of health care. Moreover, without insurance, the costs for health care arising from accidental injuries or nongenetic illnesses will not be covered. When these individuals become seriously ill, whether from genetically-related diseases or from other nongenetically-related maladies, these uninsureds will seek and obtain health care services. These expenses will be covered by taxes or reallocated, through higher premiums, to other insured patients who are able to pay. Furthermore, individuals who suspect they have genetic defects would also avoid seeking medical care for fear of the stigmatization that accompanies the finding of such a genetic condition. These same individuals, who would benefit from early diagnosis and treatment, will avoid seeking medical care until the disease becomes manifest. Avoidance and delay will result in higher transaction costs.

Because of the failure of genetic testing to conclusively and accurately predict the occurrence and severity of genetic disease, expected loss based on an insured's genetic profile cannot be accurately estimated. Thus, genetic test results cannot be used to separate insureds into distinct risk categories. Other features that do not maximize the value of the resources allocated in insurance protection include the exorbitant cost of genetic testing, the absence of incentive value, and the increased transaction costs. For these reasons, the use of genetic test results is not economically efficient.

**GENETIC TESTING AND FAIR RISK DISTRIBUTION**

Insurance law stipulates that even if the use of genetic testing as

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293. *Cf.* Berman, 49 OHIO ST. L.J. at 1072. Berman states that "[b]ecause insurers are proposing denial of health care coverage to AIDS antibody positive individuals, this group may be deterred from seeking early or preventive health care. See Friedman, *The Uninsured: From Dilemma to Crisis*, 265 J. Am. Med. Ass'n 2491, 2494 (1991). Friedman notes that "[g]iven their compromised and nonexistent access to primary and preventive care, however, their point of entry into the system is too often a hospital emergency department. The timing of their seeking care is also often a case of too little, too late." Friedman also states that "[i]t is hardly a cost-effective use of health care resources." Id.

294. Id.
295. Id.
296. Id.
299. Id.
301. *See supra* notes 59-70 and accompanying text.
302. *See supra* notes 278, 284-99 and accompanying text.
303. *See supra* notes 300-02 and accompanying text.
If the health insurance industry is treated as an instrument of public policy, then exempting genetic information in underwriting is necessary. However, such an action would not only violate the economic efficiency of risk classification but would also raise concerns about four major issues. These issues include accuracy-equity, control-causality, suspect variables, and public policy. The first concern centers on accuracy-equity. Given the inability of genetic testing to accurately predict actual losses, allocating resources based on genetic testing alone may be inequitable. A classification based on the mere presence of a defective gene, will result in a classification with great heterogeneity. The insureds who are highly likely to develop the disease will have the rare autosomal dominant or two autosomal recessive genes for the disorder. They will be grouped with individuals who have the susceptibility genes, but may or may not develop the disease. The insureds with the disease also will be grouped with carriers of an autosomal recessive gene who are highly unlikely to develop the disease. A whole class of insureds may be forced to bear all the economic burdens of genetic-related health care costs simply because a small percentage of insureds in the group may experience high losses. Moreover, the discoveries of different ge-

304. Cf. Schatz, 100 HARV. L. REV. at 1791. Schatz notes that “the courts have rejected the argument that financial concerns alone justify discriminating behavior.” Id.
305. Gostin, 17 AM. J.L. & MED. at 137.
306. K. ABRAHAM, supra note 304, at 83.
307. Id.
308. Id.
309. See supra notes 60-70 and accompanying text. See infra notes 310-54 and accompanying text.
310. See supra note 43, see infra note 311 and accompanying text.
311. J. WATSON, MOLECULAR BIOLOGY OF THE GENE 692, 700, 715 (1976). Watson states that an autosomal dominant gene is an alternative form of a gene which manifests its effect when present either in homozygous or heterozygous form. An autosomal recessive gene is an alternative form of a gene which manifests its effect only when present in homozygous form. If the gene is present in heterozygous form, its effect will be masked by the dominant form of the gene. Id.
312. See supra note 43 and accompanying text.
313. See supra notes 43, 311 and accompanying text. See also Capron, 39 EMORY L.J. at 686-87. Capron states that if both parents are carriers of an autosomal recessive condition, “they have a one-in-four chance of producing a child who inherits the deviant gene from both of them and manifests the disease.” Id.
314. Cf. Berman, 49 OHIO ST. L.J. at 1064-65. Berman notes that the use of enzyme-linked immunosorbent assay (“ELISA”) test in risk classification will result in the uninsurability of a large portion of the population due to a “positive AIDS antibody test.” The ELISA test is used to “identify the antibody produced in response to the AIDS virus.” Denial of insurance to this large group of “seropositive individuals” because of the possibility of some members of the group developing AIDS is inequitable. Id.
No guarantee exists that the most common genetic conditions will be identified first. Thus, the potential benefits and risks associated with genetic testing will accrue unevenly throughout the whole population. This differential inaccuracy is objectionable.

A second concern relates to the issue of control-causality. The fundamental intuition is that variations in risks of disability and disease among individuals arise from natural lottery. If people expose themselves to excessive risks of disease or cause their own illness, then society may conclude that the responsibility lies on these individuals themselves. Thus, assessing individuals based on variables considered to be personally controllable is considered justifiable. However, possessing a genetic condition is not within the control of the individual. Therefore, to allow insurers to classify individuals based on genetic risks and to impose economic burden on them is considered unjust from the perspective of fair risk distribution.

A third concern pertains to the use of suspect variables. Because genetic diseases are often related to ethnicity, race, or gender, questions arise on the equitability of using genetic information in risk classification. For example, Gaucher's disease and Tay-Sachs are associated with Ashkenazi Jews, sickle cell anemia is associated with Africans, and Familial Mediterranean Fever with Armenians. Risks of congenital abnormalities to the fetus are often centered on women, thus establishing a class on the basis of gender. Exclusion of these groups from insurance based on genetic testing would raise issues of discrimination based on an immutable trait. Because genetic traits are the ultimate form of immutable characteristic, discrimination based on genetic traits would be unfair and would be strictly scrutinized judicially and legislatively because such discrimi-

315. Capron, 39 EMORY L.J. at 690.
316. Id.
317. Id.
318. K. ABRAHAM, supra note 204, at 85.
319. Id. at 89.
321. Id.
322. Id.
323. CRS ISSUE BRIEF, supra note 246, at 14.
324. Id.
325. K. ABRAHAM, supra note 204, at 92.
326. Gostin, 17 AM J.L. & MED. at 137.
327. Id.
328. Id.
nation would not be confined to a single generation.  

A fourth concern relates to public policy.  The social goal of insurance is to spread risk among various groups and to provide the greatest access to health care services to the greatest number of people.  Allowing an insurer to use genetic test results to screen applicants will result in the unavailability or unaffordability of health insurance.  This lack of insurance would frustrate the social goal of insurance because those people most likely to become sick, and thus those in the greatest need of health care coverage, are precisely the people who would be denied access to affordable health care coverage and services.  

Public interest in the use of genetic testing as an insurance classifier warrants particularly strict scrutiny in the field of health care protection.  The use of these genetic tests by insurers to ensure financial viability may exacerbate the well acknowledged limitations in the American health care system.  From 1980 through 1989, health care spending increased 128 per cent and insurance premiums increased eighteen per cent.  In our society, without access to health insurance, the corresponding access to an individual's choice of health care is denied.  In 1990, 34.7 million Americans were without health insurance, an increase of more than a million in one year.  Approximately one out of four Americans is either uninsured or underinsured.  This steady increase in the number of uninsureds and underinsureds in the United States indicates a failure in the current insurance system.  Because use of genetic information as a risk classifier fails to produce accuracy-equity, fails to influence control-causality, involves a suspect variable, and violates public policy, genetic testing does not satisfy the principle of fair risk distribution.  Thus, genetic testing should not be used in risk classification. To use genetic testing would aggravate the current problem

330. Id.
331. K. ABRAHAM, supra note 204, at 83.
333. Id. at 135.
334. Id. at 137.
335. Berman, 49 OHIO ST. L.J. at 1075.
336. Id. at 1067.
337. Friedman, 265 J. AM. MED. ASS'N at 2493.
338. M. ROTHSTEIN, supra note 218, at 79.
340. Friedman, 265 J. AM. MED. ASS'N at 2492.
342. See supra notes 308-34 and accompanying text.
343. See supra note 217 and accompanying text.
of uninsurability and frustrate the social goal of insurance.\textsuperscript{344}

The need for insurance and the national intent to assure adequate insurance protection to all citizens has created an obligation on behalf of society to be concerned about the legitimacy of using genetic testing to determine an individual's uninsurability.\textsuperscript{345} Considering the fact that all individuals carry several genes that render them predisposed to developing genetic disorders, each person could be identified as having an unfavorable genetic condition.\textsuperscript{346} A direct effect, therefore, of genetic testing could be the greater stratification of insureds which could, in turn, result in either the unavailability or unaffordability of insurance.\textsuperscript{347} These consequences would be financially devastating to both the insurance industry and the public at large.\textsuperscript{348} If insurers deny coverage only to those whose genetic profiles portend a high probability of acquiring the disease, this denial of coverage may be economically efficient, but it does not comport with public policy.\textsuperscript{349} Those individuals with a higher probability of acquiring a disease are precisely the individuals who need to be protected by society from the burden of catastrophic medical costs.\textsuperscript{350}

In the present health system, uninsured individuals requiring medical services tend to seek health care in public hospitals and emergency rooms, which in turn must redistribute the costs incurred among patients with insurance.\textsuperscript{351} Thus, without health insurance, the burden of additional health care needs would be imposed on the government, charitable organizations, and other uncompensated care providers.\textsuperscript{352} In 1988, hospitals provided $8.3 billion in uncompensated care, which is about five per cent of hospital costs.\textsuperscript{353} Allowing insurers to use genetic test results in insurance underwriting may aggravate the dilemma of health care costs.\textsuperscript{354} Moreover, although eco-

\begin{itemize}
\item \textsuperscript{344} Gostin, 17 AM. J.L. & MED. at 137.
\item \textsuperscript{345} See Berman, 49 OHIO ST. L.J. at 1075. Berman states that the crucial role of private insurers in our national scheme of protection is evidenced by the tax advantages provided to employment related health insurance. In addition, the taxpayer funded insurance plans of Medicare, Medicaid, and Social Security Disability insurance demonstrate a national intent to assure adequate insurance protection to all citizens.
\item Id.
\item \textsuperscript{346} ACLI-HIAA, supra note 208, at 6.
\item \textsuperscript{347} CRS ISSUE BRIEF, supra note 246, at 2, 13.
\item \textsuperscript{348} ACLI-HIAA, supra note 208, at 8.
\item \textsuperscript{349} See supra notes 257-348.
\item \textsuperscript{350} See supra notes 331-34 and accompanying text.
\item \textsuperscript{351} CRS ISSUE BRIEF, supra note 246, at 14.
\item \textsuperscript{352} M. Rothstein, Legal and Ethical Issues in the Laboratory Assessment of Genetic Susceptibility to Cancer, in DETECTION OF CANCER PREDISPOSITION: LABORATORY APPROACHES 186 (L. Spatz, A. Bloom, and N. Paul eds. 1990).
\item \textsuperscript{353} CRS ISSUE BRIEF, supra note 246, at 14.
\item \textsuperscript{354} Id.
\end{itemize}
nomic efficiency is based on the premise that insurance is only one of
the many methods of protecting oneself from risk, in the area of
health, the purchase of insurance is the only practical way of risk
protection.\textsuperscript{355} With the rising cost of medical care, a health insurance
policy assures access to health care.\textsuperscript{356} Because health care is a basic
necessity, the economic efficiency feature of risk classification be-
comes secondary to the risk distributional fairness.\textsuperscript{357}

The HGPA attempts to solve the problem of genetic uninsurables by refusing insurance companies access to an applicant’s ge-
netic data without the consent of the applicant.\textsuperscript{358} The HGPA aims to
protect the confidentiality of an individual’s genetic information by
regulating the “collection, maintenance, use, and dissemination” of
such information by the agencies in possession of such informa-
tion.\textsuperscript{359} The HGPA also provides that individuals may select the
records pertaining to themselves that the agency may maintain, use,
or disseminate.\textsuperscript{360} If an applicant requests the agency not to maintain,
use, or disseminate any record pertaining to him or her, then the in-
surers could offer discounts to those who voluntarily disclose their
genetic data.\textsuperscript{361}

If individuals with favorable genetic data who voluntarily dis-
close their genetic profile were charged reduced premium rates, then
those individuals with more questionable genes, who would tend not
to disclose their genetic data, would be forced to pay higher premi-
ums.\textsuperscript{362} Insurers could also ask, through the use of a questionnaire,
whether the applicant has had genetic testing done.\textsuperscript{363} If the appli-
cant responds in the affirmative but fails to provide the genetic test-
ing results or refuses to authorize the dissemination of the
information, then the insurer would be suspicious and might consider
this uncertainty in determining the insurability of the applicant.\textsuperscript{364} If
the applicant has had genetic testing and the results indicate the
presence of a genetic defect, then the applicant could deny ever hav-
ing genetic testing done, and the insurer would have no way of veri-

\begin{footnotesize}
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\textsuperscript{355} Berman, 49 OHIO ST. L.J. at 1068.
\textsuperscript{356} Id.
\textsuperscript{357} See supra note 217 and accompanying text. See also Schatz, 100 HARV. L. REV. at 1803; Friedman, 265 J. AM. MED. ASS’N at 2494.
\textsuperscript{358} H.R. 2045, supra note 208, at § 114.
\textsuperscript{359} Id. § 2(a)(5).
\textsuperscript{360} Id. § 2(b)(1).
\textsuperscript{361} Brownlee \& Silberner, supra note 283, at 59.
\textsuperscript{362} Id.
\textsuperscript{363} Cf. Hoffman \& Kincaid, 35 DRAKE L. REV. at 728. The authors state that “[i]nsurers should be allowed to seek information directly from proposed insured con-
cerning the results of prior antibody test, no matter where performed.” Id.
\textsuperscript{364} Id. at 729.
\end{footnotesize}
In this situation, the value of having the information provided by the applicant would be tantamount to not having the information at all.366

The HGPA also provides that the agency will provide an individual's record to a “licensed or certified health professional” chosen by the individual.367 This provision creates some concern because the HGPA applies only to government agencies and their affiliates.368 If an individual authorizes the agency to disseminate the individual’s record to his or her personal physician, then this information could become part of the individual’s medical record, which is traditionally available to insurers.369 However, HGPA also provides that an individual’s genetic information, which is disclosed by the agency to a medical professional for the purpose of the individual’s medical care and treatment, “shall not be further disclosed” unless required by law or necessitated to fulfill the purpose for the initial disclosure.370

The HGPA also provides that the disclosure by the agency will be limited to the information authorized by the individual to be disclosed.371 Thus, an applicant may authorize the selective disclosure of information deemed to be beneficial to the individual while prohibiting the disclosure of information that could negatively affect the individual's insurability.372 If the authorization is directly communicated to the agency, then the insurer would have no way of verifying the completeness of the disclosed report.373 However, if the insurer requires verification of the applicant’s authorization letter, then selective disclosure would cause suspicion on the part of the insurer.374

In situations in which the insurer doubts the honesty of the applicant, insurers may rely on the incontestability and preexisting conditions clauses.375 In genetic testing, the unusual nature of genetic characteristics weakens the effectiveness of these clauses and makes the insurer vulnerable to adverse selection.376 The most significant

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365. Id. See K. ABRAHAM, supra note 204, at 71.
366. K. ABRAHAM, supra note 204, at 71; Hoffman & Kincaid, 35 Drake L. Rev. at 729.
368. Id. § 101(1).
369. Hoffman & Kincaid, 35 Drake L. Rev. at 728.
370. H.R. 2045, supra note 208, at § 123.
371. Id. § 2(6)(1-3).
372. Id.
373. Id.
374. Id. See K. ABRAHAM, supra note 204, at 71. Abraham states that “the classes should be susceptible to as little administrative error and fraud as possible.” Id.
375. See supra notes 141-45 and accompanying text. See also Hoffman & Kincaid, 35 Drake L. Rev. 735-36.
376. Cf. Clifford & Iuculano, 100 Harv. L. Rev. at 1817. The authors state that the nature of AIDS undermines the protection afforded by several insurance mechanisms established to protect the insurer from adverse selection. Id.
problem in applying the incontestability clause to genetic testing results is the latency period.\textsuperscript{377} Because the mere presence of a genetic defect does not necessarily result in the manifestation of the disease, the onset of symptoms may not occur until after the expiration of the incontestability period.\textsuperscript{378} Unless the applicant experiences symptoms of the disease, no treatment will be sought and no claims will be made that would make the insurer suspicious of misrepresentation.\textsuperscript{379} Because insurers request information only on conditions for which the applicant has sought medical treatment, insurers relying on the incontestability provision for protection against adverse selection will find it difficult to avoid policies and coverages based on misrepresentations.\textsuperscript{380}

Insurers' reliances on the protection of preexisting conditions clause in genetic disease cases necessitate the resolution of the question about the time at which the condition initially occurs.\textsuperscript{381} Generally, a court will determine that a disease or illness has its inception at the time the disease first becomes manifest, or when a distinct condition or sign enables one to diagnose the disease with reasonable accuracy.\textsuperscript{382} In applying the general rule to genetic testing results, the question arises as to whether the mere presence of the defective gene constitutes a condition that is tantamount to presence of the disease, even though no manifestations of the disease are present.\textsuperscript{383} Thus, although the incontestability and preexisting conditions clauses generally provide protection against adverse selection in most clinical conditions, these clauses fail to provide the insurer with adequate protection against misrepresentation in the context of genetic testing.\textsuperscript{384} These concerns may encourage the insurers to err on the side of safety for the insurance industry and to presume the presence of genetic disease-related risk.\textsuperscript{385}

To prevent the use of genetic characteristics as a risk classifier, the HGPA could be amended to prevent government agencies that

\begin{itemize}
\item \textsuperscript{377} Cf. Hoffman & Kincaid, 35 Drake L. Rev. at 737. The authors state that when applied to AIDS risk, the latency period following exposure to the virus is problematic. Due to the lengthy incubation period, symptoms are unlikely to be manifested until after the incontestability period expires. \textit{Id.}
\item \textsuperscript{378} \textit{Id.}
\item \textsuperscript{379} \textit{Id.}
\item \textsuperscript{380} \textit{Id.} at 737-38.
\item \textsuperscript{381} \textit{Id.} at 739.
\item \textsuperscript{382} \textit{Id.}
\item \textsuperscript{383} \textit{Id.} The authors note that it is unlikely that a court will deem the mere virus infection sufficient to invoke the preexisting conditions clause. \textit{Id.} at 740.
\item \textsuperscript{384} \textit{Id.} at 740.
\item \textsuperscript{385} \textit{Id.} The authors state that an assumption can be made that a misrepresentation concerning a prior positive test is made to obtain coverage for the eventual development of the disease. \textit{Id.}
\end{itemize}
have custody of an individual’s genetic profile from disclosing the information to insurance companies or for insurance purposes. However, insurers can again circumvent such restrictions by asking the applicant to personally supply the information. Relying totally on the information provided by an applicant without having any way of verifying the accuracy of the information provided by the applicant would have the same degree of uncertainty as not having the information at all. Thus, from an insurer's standpoint, using an applicant's genetic data as provided by the applicant is not economically efficient. The HGPA could also be amended to prevent insurers from using genetic test results in insurance underwriting. Although such an amendment may be justified based on the fair risk distributional purpose of insurance law, such prohibition will enhance inaccurate classification and, therefore, compromise the economic efficiency of the risk classification system. Again, the tension is between economics and equity.

CONCLUSION

As genetic technology advances, the danger of discrimination based on an individual’s genetic blueprint also increases. The capability of genetic testing to accurately predict the occurrence and severity of a disease in each individual could have a negative impact on both the insurance industry and the public-at-large. This capability could result in the unacceptable choice between adverse selection and the creation of an underclass of genetic uninsurables making the formulation of public policies addressing this problem imperative.

Although insurers have the obligation to policyholders to protect the financial viability of the insurance industry and to treat the insureds equitably through proper risk classification, society also has an obligation to safeguard the right of each individual to health care by ensuring health care protection to everyone. If genetic test results are used to classify risks, then the rights of a great number of indi-

386. Brownlee & Silberner, supra note 283, at 57, 59.
387. Cf. Hoffman & Kincaid, 35 Drake L. Rev. at 728. The authors state that traditionally, insurers had been permitted to base the issuance of a policy on the acceptability of medical test results. Id. at 729.
388. Id. See K. Abraham, supra note 204, at 71. Abraham states that “the main cause of unreliability is the difficulty of verifying data furnished by the applicant herself or himself.” Id.
389. See supra notes 153-55 and accompanying text.
390. Contra Hoffman & Kincaid, 35 Drake L. Rev. at 728. The authors state that “[t]he right of a life and health insurer to request or have access to medical tests in the underwriting process previously has not been seriously questioned or impaired by regulators or the courts.” Id.
391. K. Abraham, supra note 204, at 82-83.
392. See supra notes 123-87, 204-357 and accompanying text.
individuals to health care protection will be abrogated. Health care is a basic necessity and should not be allowed to become a luxury in a democratic free-enterprise society like the United States. After all, "[c]ultures can be judged in many ways, but eventually every nation in every age must be judged by this test: how did it treat people?"\footnote{Letter from Andrew R. Barnosky to the editor of the Journal of the American Medical Ass'n, 265 J. AM. MED. ASS'N 2483, 2484 (1991) (citing KOOP & SCHAUFER, WHATEVER HAPPENED TO THE HUMAN RACE).}

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