




1997

Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project

Eric Mills Holmes
Appalachian School of Law

Follow this and additional works at: <https://uknowledge.uky.edu/klj>

 Part of the [Insurance Law Commons](#), and the [Science and Technology Law Commons](#)
Right click to open a feedback form in a new tab to let us know how this document benefits you.

Recommended Citation

Holmes, Eric Mills (1997) "Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project," *Kentucky Law Journal*: Vol. 85 : Iss. 3 , Article 2.
Available at: <https://uknowledge.uky.edu/klj/vol85/iss3/2>

This Article is brought to you for free and open access by the Law Journals at UKnowledge. It has been accepted for inclusion in Kentucky Law Journal by an authorized editor of UKnowledge. For more information, please contact UKnowledge@lsv.uky.edu.

KENTUCKY LAW JOURNAL

VOLUME 85

1996-97

NUMBER 3

ARTICLES

Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project

BY ERIC MILLS HOLMES*

TABLE OF CONTENTS

INTRODUCTION	506
I. THE HUMAN GENOME PROJECT	517

* Professor of Law, Appalachian School of Law, Grundy, Virginia 24614. J.S.D., LL.M., Columbia University; J.D., University of North Carolina; A.B., Duke University. National Insurance Expert/Consultant and Author/Editor of the multi-volume treatise, *Holmes's Appleman on Insurance, 2d*. Member, The American Law Institute. Grateful thanks to McGeorge law students Gustavo Matheus and Sarah Morgan for their initial research and to Joseph Lowe for the science lesson.

The basic dilemma thoroughly explored by this Article has been recognized for several years. See, e.g., T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification? Arguments Both for and Against the Use of this New Technology May Be "Right," and Some Form of Universal Health Care May Be the Result*, 60 DEF. COUNS. J. 249, 252 (1993). This Article represents an in-depth analysis of the insurance/genetics dilemma in light of recent state and federal legislation.

A.	<i>A Genetics Primer</i>	519
B.	<i>Scientific Issues for Insurance Underwriting</i>	523
1.	<i>Defining "Genetic Testing"</i>	523
2.	<i>Misunderstanding Genetic Data in Actuarial Analysis</i>	527
II.	ARGUMENTS SUPPORTING INSURERS' USE OF GENETIC INFORMATION	531
A.	<i>Fair Discrimination Is Efficient Insurance Underwriting</i>	531
1.	<i>The Equitable, Not Equal, Justification</i>	531
2.	<i>The History of Insurance Risk Classification</i>	534
3.	<i>Use of Genetic Tests Is Efficient and Equitably Fair</i>	537
B.	<i>Equal Access to Genetic Information Fairly Rectifies the Unfairness of Imperfect Information in Underwriting</i>	541
1.	<i>Applicant's Good Faith Duty to Disclose Genetic Information</i>	541
2.	<i>Adverse Selection</i>	543
3.	<i>Incontestability Clauses</i>	545
C.	<i>State Insurance Law Requires Insurers to Use Genetic Information to Achieve State-Mandated Fair Discrimination</i>	548
D.	<i>Insurers Will Fairly Use Genetic Information in Risk Rating</i>	553
E.	<i>Genetic Testing Conforms to Current Underwriting Practices and Will Not Affect an Applicant's Ability to Obtain Insurance</i>	555
F.	<i>Analogous Employment Discrimination Based on Genotype Is Fair</i>	556
III.	ARGUMENTS AGAINST INSURERS' USE OF GENETIC TESTING INFORMATION	557
A.	<i>Use and Availability of Genetic Information Is Subject to Abuse</i>	558
B.	<i>Unfair Discrimination in Insurance Pricing and Availability</i>	563
1.	<i>Insurance Requires Fair Redistribution, Not Fair Discrimination</i>	563
2.	<i>Misunderstanding and Misuse of Genetic Information</i>	564
3.	<i>The Availability of Insurance</i>	567

- C. *Prohibiting the Use of Genetic Information Protects Individual Right to Privacy* 568
 - 1. *Genetic Information Can Cause Stigmatization and Psychological Trauma* 571
 - 2. *Confidentiality Must Be Protected* 575
 - 3. *Preferred Social Ignorance* 576
- IV. STATE VS. FEDERAL LEGISLATIVE REGULATION OF GENETIC INFORMATION IN INSURANCE 578
 - A. *Preference for State Regulation of the "Business of Insurance"* 578
 - B. *Current Federal Law Is Inadequate and Problematically Defers to State Insurance Regulation* 585
 - 1. *ERISA: Employment Retirement Income Security Act of 1974* 585
 - a. *Section 514's Preemption, Saving, and Deemer Provisions* 588
 - (1) *Preemption Clause* 589
 - (2) *Saving Clause* 590
 - (3) *Deemer Clause* 594
 - b. *ERISA Permits Self-Insured Employers to Discriminate by Excluding and Limiting Employees' Health Insurance* 598
 - 2. *ADA: The Americans with Disabilities Act of 1990* 604
 - a. *Genetic Conditions and the ADA Definition of Disability* 607
 - b. *ADA Section 501(c) Exempts Insurance and Recognizes the Primacy of State Insurance Regulation* 613
 - C. *State Insurance/Genetic Legislation Is Inchoate But Promising* 623
 - 1. *Mandating Coverage Through Proscription and Prescription* 623
 - 2. *State Laws Concerning Genetic Testing and Insurers' Use of Genetic Information* 629
 - a. *Summary of State Insurance/Genetic Laws* . . . 629
 - b. *State Trend Toward Proscribing Insurance/Genetic Discrimination and Protecting Privacy of Genetic Testing Information* 644
 - D. *Reasons for State and Federal Legislative Solutions* . . 649
- CONCLUSION 657
- APPENDIX 664

INTRODUCTION

The advertisement boldly proclaims: "Get your personal genetic map today. Your destiny lies in your genes." Imagine a world with one all-purpose genetic test, like the diagnostic machine attached to your car, which yields a rich and accurate, albeit not conclusive, genetic profile of what you are and what you will be. Consider a child born in the year 2004. Routine blood tests reveal that the child will be five feet five and a half inches tall, right-handed, and red-headed, will develop early near-sightedness, is at high risk for heart disease and hypertension, is at moderate risk for developing lung cancer and alcoholism, is at total risk for cystic fibrosis, and, because the child is a genetic carrier, any future offspring will have a fifty percent chance of developing Tay-Sachs disease. This scenario soon will be closer to fact than to fiction.¹ It is predicted that, as a result of the Human Genome Project ("HGP"), by the year 2002, 99% of the human genome sequence will be mapped at an accuracy of 99.9%.² Consequently, the HGP

¹ In early March 1996, one multinational and one U.S. research team reported drawing guides (called "maps") to all 23 human chromosomes and all 20 mouse chromosomes. These maps are extraordinarily detailed; for example, the mouse map would require approximately 500 pages in a typical magazine. Consequently, both the mouse and human maps were published on the World Wide Web by the Whitehead Institute for Biomedical Research/MIT Center for Genome Research (visited Nov. 15, 1996 <<http://www.genome.wi.mit.edu>>). Resembling land surveys of the genes, the maps are thick with charted genetic bumps, streams, and valleys, allowing geneticists to find their way around the chromosomes. Publication of these maps ended the first phase of the Human Genome Project, the mammoth undertaking to describe every shred of genetic material in the human body.

² Patrick Young, *Funds are Key to Sequence Success*, 378 NATURE 655, 655 (1995) (quoting Francis S. Collins, director of the U.S. National Center for Human Genome Research, regarding the progress of the HGP).

Commencing in 1991, the HGP, also referred to as the Human Genome Initiative ("HGI"), is actually a number of separate projects. There is no single human genome project in the United States; instead, three major organizations (National Institutes of Health ("NIH"), Department of Energy ("DOE"), and Howard Hughes Medical Institute) finance discrete aspects of a comprehensive initiative for genetic mapping. Simultaneously, specific projects are also ongoing in other countries (including France, the United Kingdom, Japan, and Canada) and under the auspices of a private organization, the Human Genome Organization ("HUGO"). Francis Collins & David Galas, *A New Five-Year Plan for the U.S. Human Genome Project*, SCI., Oct. 1, 1993, at 43 (describing international aspects of the HGP).

has the potential to have a major impact on the ways insurers evaluate each applicant's health risks.

At this point, no one really knows what the future of genetics will do for, or to, insurance consumers or the insurance industry as we know it. Insurance consumers fear that genetic testing and genetic information will be used by insurers to separate out the "genetically inferior"³ and deny them insurance or charge them excessively high premiums. They fear that even applicants for insurance who simply have a chance of developing a genetic-based disease will not be able to obtain insurance. In contrast, a 1995 report by the Ohio Task Force on Genetic Testing provides a calming finding: "Insurers will not use genetic tests, if ever, until such tests are in common usage."⁴

On the other hand, insurers fear some consumers will use their knowledge about their own genetic predisposition for particular diseases or medical conditions to "adversely select" against insurance companies. They explain that adverse selection occurs when individuals with a high probability of loss apply for more insurance than do other "genetically normal" individuals.

Genetic mapping and testing have the salutary capacity to revolutionize medicine. But revolutions customarily have casualties and genetic discrimination foreseeably will be the civil-rights issue of the twenty-first century. So before genetic mapping and testing become routine in our twenty-first century society, it seems prudent to address the serious problems that will naturally arise regarding the potential use in private insurance⁵ of personal genetic information to create insurance risk

³ This Article primarily explores the adverse effects which might occur as a result of insurers having unrestrained access to genetic information. It is beyond the scope of this Article to address the history of and potential problems associated with the eugenics movement and similar areas of potential abuse of genetic information. Since the advent of the DNA era, there has been concern that genetic testing will create a biological underclass of people branded as poor risks for employment, marriage, and child-bearing, as well as insurance.

⁴ OHIO TASK FORCE ON GENETIC TESTING, FINAL REPORT iii-iv (Dec. 31, 1995). *But see* Geoffrey Cowley, *Flunk the Gene Test and Lose Your Insurance*, NEWSWEEK, Dec. 23, 1996, at 48, 49 (reporting mid-1990s studies at Georgetown and Harvard showing that several hundred healthy people lost or were denied health and life insurance because of genetic testing).

⁵ This Article concerns private commercial insurance except to the extent that public taxation or another public approach is deemed a preferable solution to the insurance/genetic dilemma. For instance, a distinguished law professor and economist suggests public taxation as a viable approach for resolving potential

classification, to control risk transference to insurers, and to achieve fair and non-discriminatory risk distribution.⁶ Addressing those concerns creates a dilemma over how to avoid unfair discrimination in insurance underwriting while accommodating: (1) each individual's civil rights to privacy and to protection of that individual's unique genetic property, and (2) the insured group's right to fairly priced insurance without a forced financial subsidy.

Two perspectives help to define "unfair" discrimination. First, does unfair discrimination occur when insurers use sound actuarial analysis of genetic data to differentiate among applicants and policyholders by risk

genetic discrimination in private insurance. Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 21 (1994). But a public taxation solution would not constitute "insurance" and issues of underwriting health risks using genetic information would be irrelevant for the following reasons. The business of private insurance has a significant but not exclusive role in American health care law. Private health and health-related insurance is only one approach for Americans to receive health care. Public insurance (e.g., Medicare, Medicaid, Social Security, Veterans' Administration programs, and Civilian Health and Medical Program of the Uniform Services ("CHAMPUS")) provides another avenue. Public health care, however, is not "insurance" because these programs are financed through Social Security and other mandatory taxes and not through premiums contractually made by volition and consent. More importantly, because current public health care programs do not apply risk selection and classification, the use of genetic testing and genetic information following the results of the HGP will foreseeably not occur.

As an aside, conventional private insurers occasionally attempt to relieve themselves of liability where one, or the other, of such governmental plans is operative. However, a private insurer is generally not exonerated of liability merely because the insured, for example, turned to a governmental plan to pay for a procedure after the insurer denied coverage. *See, e.g., Fagner v. American Community Mut. Ins. Co.*, 502 N.W.2d 350, 353 (Mich. App. 1993) (holding that an insurer could not avoid providing coverage for a liver transplant merely because the insured turned to Medicaid for help). Additionally, if health care is legislatively determined to be a universal right, private health insurance may be transformed from a voluntary bargained-for contract system to a public mechanism for universally providing the right to health care. In practical effect, that would be the death of private commercial health insurance. If the public insurance approach (discussed as one possible solution at *infra* Part IV.D (notes 548-69 and accompanying text)) becomes reality, then the private insurance solutions discussed in this Article will become mostly irrelevant.

⁶ For a general discussion of the risks transferred and distributed in personal insurance (life, annuities, health, medical, and disability), see ERIC MILLS HOLMES, 1 HOLMES'S APPLEMAN ON INSURANCE 122-53 (1996).

classifications and to price the insurance according to the risks each person represents? In other words, is it unfair to permit equitable, but not equal, treatment in insurance underwriting of genetically unequal individuals? As explained in Part III of this Article,⁷ some insurance consumers respond that it is unfair and discriminatory to price insurance based on genetic traits. Genetic information is the unique property of the person tested. In order to preserve individual autonomy regarding the individual's genotype and to protect the privacy of genetic information, it is appropriate to limit insurers' use of genetic information. All insureds should be treated equally in insurance risk rating classifications based on community risk sharing and redistribution of commonly shared losses. As explained in Part II of this Article,⁸ insurers respond that actuarially sound individual risk differentiation in rating and premiums constitutes fair discrimination. Adopting a policyholders' economic rights viewpoint, insurers assert a *duty* to treat all policyholders fairly by setting premiums actuarially based on the risk presented by each policyholder and a correlative *right* to fashion risk classifications for genetic and other statistical differences among all applicants.

Second, does unfair discrimination occur when insurers are prohibited or restricted in classifying risks and pricing insurance based on an individual's immutable, private, and potentially stigmatizing genome? In other words, is it unfair to require the equal treatment in insurance underwriting of genetically unequal individuals? Insurers obviously answer that it is unfair. As explained in Part III of this Article,⁹ consumers respond that prohibitions, or at least restrictions, on insurers requiring and using genetic testing and mapping constitute fair discrimination because they promote fair risk classification and fair risk distribution.

Insurance consumers offer various reasons for adopting the individual rights viewpoint: (1) to maintain the bedrock insurance principle of economic risk distribution, sometimes called redistribution, in pooling and sharing common fortuitous risks; (2) to avoid potential misuse and unfair genetic discrimination because, like gender and race, genetic information is involuntary, immutable, and potentially stigmatizing; (3) to maintain the confidentiality of the individual as well as family and relatives who may be adversely affected; (4) to preserve personal autonomy and the individual's singular genomic property rights; (5) to protect the civil right to privacy against intrusion and potential public disclosure through

⁷ See *infra* notes 140-216 and accompanying text.

⁸ See *infra* notes 68-139 and accompanying text.

⁹ See *infra* notes 140-216 and accompanying text.

computerized data banks; (6) to safeguard the individual's right not to know; (7) to rectify potential insurer misunderstanding of genetic data in creating risk classifications;¹⁰ and (8) to rectify unsound actuarial analysis due to the absence of reliable, definitive genetic information. Implicated here is the ongoing debate regarding health care as a universal right, the socialization of health risks, the demands of distributional justice, and the question of how the medically uninsured will acquire their right to health care.¹¹

Parts II and III strongly state the positions of, respectively, the insurance industry and insurance consumers. This author does not necessarily agree or disagree with those positions but asks whether middle-ground solutions can be fashioned in order to avoid, or at least fairly ameliorate, unfair genetic discrimination in insurance.¹² That may

¹⁰ The concern for misunderstanding genetic data is discussed at *infra* Part I.B.1 (notes 49-62 and accompanying text). For example, the presence of a genetic marker does not imply that a carrier will develop the disease but only that the individual is asymptotically ill with a higher predisposition to such disease.

¹¹ For an excellent discussion of this debate in its formative years, see CONGRESSIONAL RESEARCH SERVICE, HEALTH INSURANCE AND THE UNINSURED: BACKGROUND DATA AND ANALYSIS (1988). The debate continued during the first two years of President Clinton's administration, especially regarding the grave shortage of employer-sponsored health insurance for high-risk employees. The stated purpose of President Clinton's proposed, but unenacted, 1300-page plan was "to ensure individual and family security through health care coverage for all Americans in a manner that contains the rate of choice in health care, and to ensure and protect the health care of all Americans." H.R. 3600, 103d Cong., 1st Sess. (1993). The heart of the President's plan was the creation of health alliances, run by the states under federal scrutiny, offering consumers three types of medical plans: "an H.M.O., a fee-for-service plan, or a combination of the two." *Clinton's Health Plan: A New Framework for Health Care*, N.Y. TIMES, Sept. 23, 1993, at A22. Unlike many other countries, the United States does not have a universal health care system; therefore, the debate over universal health care continues. For a useful analysis, in the context of the universal health care debate, of insurance as a free market product versus a public good, see Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL., POL'Y, & L. 287 (1993).

¹² This Article's underlying assumption is that universal genetic mapping will occur following completion of the HGP. This Article then proceeds to examine significant issues that will arise in the next century. For example: Should insurers be permitted to require insurance applicants to undergo genetic testing and mapping? Should insurers have access to any future voluntary genetic

not be possible, because in the end "it is likely that the compromise between efficiency and broad distribution of risk that is inevitable in any insurance system will never fully satisfy the proponents of either value."¹³ Much depends on one's viewpoint in judging what is fair. The conflicting points of view will lead to a debate regarding insurers' use of information from genetic testing. Foreseeably, the positions in this debate will resemble the structure of the debates over insurance and gender, or insurance and AIDS.¹⁴ Some will advocate the group perspective for fair, economically efficient risk classification, while others will support the individual perspective for distributionally fair risk classification.

testing and mapping? Does an applicant have a civil right to privacy and protection from disclosure of the applicant's genetic information? Rather than stating and justifying simplistic yes/no answers, this Article seeks middle ground by stating and later evaluating arguments for insurers and then against insurers requiring and/or having access to genetic information in contract formation (i.e., in underwriting genetic risks) and in risk distribution (i.e., in socializing genetic risks).

¹³ KENNETH S. ABRAHAM, *DISTRIBUTING RISK* 100 (1986).

¹⁴ In the last few decades, insurance law has involved two significant issues of fair versus unfair insurance discrimination; first regarding gender, and then HIV and AIDS. This Article naturally draws upon, and is grateful for, the vein of scholarly ink in the legal literature devoted to those important topics. Appropriate citations are given throughout. For an excellent overview of the controversy regarding unisex and gender-based insurance ratings as well as the Supreme Court's Title VII cases forbidding gender discrimination in employer benefit plans, see ROBERT H. JERRY II, *UNDERSTANDING INSURANCE LAW* 102-09 (2d ed. 1996). Concerning the debate over prohibiting testing and health insurance coverage for HIV or AIDS, see Benjamin Schatz, *The AIDS Insurance Crises: Underwriting or Overreaching?*, 100 HARV. L. REV. 1782 (1987) (making a powerful argument for prohibiting insurers from pricing their policies or selecting insureds on the basis of either sexual orientation or HIV testing) and Karen A. Clifford & Russel P. Iuculano, *AIDS and Insurance: The Rationale for AIDS-Related Testing*, 100 HARV. L. REV. 1806 (1987) (strongly stating the insurance industry's position for using HIV antibody tests and against legislative and regulatory restrictions). For an extraordinarily fine critique of these two articles, see Deborah A. Stone, *The Rhetoric of Insurance Law: The Debate over AIDS Testing*, 15 L. & SOC. INQUIRY 385 (1990) (emphasizing broader risk sharing and risk redistribution in health insurance based on need and not on fair or unfair discrimination). For a more recent, equally outstanding summary and evaluation of the issues, see Alan I. Widiss, *To Insure or Not to Insure Persons Infected with the Virus that Causes AIDS*, 77 IOWA L. REV. 1617 (1992).

But new solutions may require new viewpoints, or at least a concoction of familiar ones. The classic posturing in debates over insurance between group and individual rights may shift in light of future advances in genetic screening and mapping which will evidence the universality of our human condition. For example, a geneticist explains that only two to ten million nucleotide bases, out of three billion, differ from individual to individual, and instructs us that “most of the information in [genetic maps] will pertain to everyone.”¹⁵ Each of us has a common interest in insuring that fortuity. That common interest may cause a shift to a more group-centered, societal perspective.

Since insurance is a social institution, the idea of the social contract may provide a different viewpoint from the classical debate over insurance. Assume insurance companies use medical testing to create risk classifications for the avowed purpose of selecting and excluding medical risks. Standing behind what the philosopher John Rawls describes as a “veil of ignorance”¹⁶ before the formation of the social contract, people would most likely not select rules that penalize people who incur medical and health-related costs from illness, disease, and other conditions. Each person would perceive herself/himself as potentially in the “worst-off” insurance risk classification and prefer, in self-interest, to protect the interest of the insurance applicants most disadvantaged by risk classification. That seems to make good economic, social, and moral sense.

In any event, if the HGP is successful, then everyone will have a personalized genetic map. Genetic maps may provide the quintessential predictive data for sound actuarial analysis in selecting and excluding risks. For example, scientists estimate that over 2000 diseases are genetic in origin.¹⁷ Carrying sound actuarial analysis to its logical extreme may

¹⁵ Marc A. Lappé, *Justice and the Limitations of Genetic Knowledge*, in JUSTICE AND THE HUMAN GENOME PROJECT 153, 155 (Timothy F. Murphy & Marc A. Lappé eds., 1994) (quoting CHARLES WILLS, EXONS, INTRONS, AND TALKING GENES: THE SCIENCE BEHIND THE HUMAN GENOME PROJECT 3 (1991)).

¹⁶ See *id.* at 160 (citing JOHNS RAWLS, A THEORY OF JUSTICE (1971)). The social contract concept is discussed in greater detail at *infra* Part III.C.3 (notes 215-16 and accompanying text).

¹⁷ Catherine M. Valerio Barrard, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1043 (1993) (examining an individual's property interest in the information encoded in that individual's genetic material). The point is that the potentially enormous amount of genetic data discovered by the HGP would provide insurers with a powerful sword for excluding or limiting insurance coverages of genetically caused diseases and medical conditions.

toll the bell for private insurance. Private insurance is defined as the transfer and distribution of the risk of fortuitous losses.¹⁸ The element of risk distribution of fortuitous losses would be eliminated if actuarial rating, using genetic mapping in risk transference, is accomplished perfectly.¹⁹ The end result of this scenario would, by definition, be the death of private insurance; certainly an unwelcome prospect for the multi-trillion dollar insurance industry. In re-establishing post mortem the requisite risk-distribution element, private health and health-related insurance would foreseeably be changed into a system of public insurance. Given the possibility of death to private insurance, insurers should rethink and reassess their policy of actuarially fair discrimination.

But, perfect actuarial rating may not be possible because the information obtained from mapping the human genome will not allow absolute predictability of all illnesses, diseases, and medical conditions.²⁰ When the HGP completes its development of detailed maps of the genome, determines the complete nucleotide sequence of human DNA, and creates new technology for genetic analysis, a new era of sequence-based biological investigation by twenty-first century scientists will begin. However, it is unclear whether perfect genetic data will ever be available for perfect actuarial rating. Consequently, solutions for rectifying perceived flaws in the current system of private health insurance will be explored and evaluated in this Article. Thus, the purpose of this Article is to analyze: (1) whether insurers can require or should have access to genetic tests and maps; (2) if so, how insurers should be allowed to use

¹⁸ Risk transfer is controlled by actuarial classification and rating. Risk distribution requires pooling, sharing, and redistributing potential fortuitous financial losses. For a more thorough discussion of the nature and definition of insurance, see *Risk, Classifications and Definitions*, in HOLMES, *supra* note 6, at 2-43.

¹⁹ Perfect actuarial risk rating of each individual would eliminate the fortuity element, resulting in either an exclusion, limitation, or higher premium charge for each individual's genetically-based future medical costs. Thus, there would be no group risk sharing of that individual's future medical costs. The basis for pooling and common risk sharing among a similarly situated group is the notion of fortuity. A simple example is the risk of being struck by a meteor. That risk is unpredictable, equally affects all people, and does not cause adverse selection; and issues of imperfect information are not applicable because nobody has more or less information regarding the probability of the fortuitous meteoric event occurring. Epstein, *supra* note 5, at 8-9.

²⁰ See *infra* Part I (notes 26-67 and accompanying text).

genetic information; and (3) what new state or federal legislative action, if any, should be implemented to prevent misuse of this new technology.

Historically, insurers used predictive diagnostic tests to select and exclude risks. As more predictive tests became available, more and broader risk classifications were established, and private insurance underwrote and protected fewer people. At that juncture, governmental regulation intervened, prohibiting some classifications and mandating some insurance coverages. Part IV of this Article²¹ probes federal and state statutes to ascertain if effective solutions already exist proscribing unfair genetic discrimination in insurance or whether further legislation is desirable and necessary. Part IV first considers relevant federal legislation. These statutes include the 1945 McCarran Act, which established the primacy of state insurance regulation; ERISA, which affords protection to employees under employer benefit and insurance plans; and the Americans with Disabilities Act, which may prevent some genetic discrimination in insurance. Finally, Part IV discusses and evaluates state legislation that both mandates coverages for genetic diseases and conditions, and specifically addresses genetic discrimination in insurance.

Ostensibly, an overriding issue is where fairly to place the responsibility for health loss — on the individual, or the insurer, or the public. In addition to risk transference and distribution, fortuity is a significant defining element of insurance. Each of us has a bundle of discrete, individualized risk factors affecting our health and longevity. Some factors are within our control and some are not.²² Arguably, only those health risks that can be classified as fortuitous should be the subject of private insurance. The issue of fortuity must be kept in mind in reading this Article.

²¹ See *infra* notes 217-569 and accompanying text.

²² Included are gender, race, genome, level of education, job, home, family, doctor, spirituality, socio-economic status, good habits (exercise, healthy eating), bad habits (smoking, drinking, lack of exercise), driving habits, etc. For an enlightening discussion, see Deborah A. Stone, *At Risk in the Welfare State*, 56 SOC. RES. 591 (1989) (Discussing the tension between the “lifestyle factor theory which holds that much disease and disability is caused by behavioral factors that are within an individual’s control,” *id.* at 591, and “the theory of ‘genetic predisposition’ or ‘susceptibility’ which holds that there is a specific gene or set of genes that controls whether an individual will develop a disease,” *id.* at 592. Stone analyzes this tension in “the conservative context of the American welfare state [that] emphasizes individualism, responsibility for oneself, and deterrence.” *Id.* at 593.).

Before turning to the broader philosophical and policy issues, this Article will first address the basic science of genetic mapping. What the HGP will discover accurately is the primary concern. Undoubtedly, upon completion of the HGP, our understanding of genomic information will be transformed. Often, however, laypersons ascribe too much definitive significance to what science discovers. Unfair genetic discrimination in insuring can occur simply because of insurer ignorance in granting statistical validity to genomic data that is not sufficiently precise for that purpose. In an attempt to address the potential for misconceptions about science, Part I of this Article²³ is intended as a genetics primer. This section provides a basic understanding of the goals of the HGP, the meaning and scope of genetic testing, and genetic terminology relevant to insurance. Participants in this debate need to understand what is meant by genotype, phenotype, and karyotype; monogenic, chromosomal, and multifactorial diseases and disorders; genetic predisposition to disease, genetic carrier, asymptomatic genetic condition, presymptomatic genetic condition, expression (the variability in severity of a genetic trait), and other genetic terminology relevant to insurance risk classification. This scientific information is critical for addressing and attempting to solve the foreseeable future insurance/genetic fair/unfair discrimination dilemma, especially in health insurance.²⁴

²³ See *infra* notes 26-27 and accompanying text.

²⁴ Obviously, the HGP's findings will affect many forms of insurance which extend beyond what we customarily perceive as health insurance (e.g., automobile liability insurance coverage of people with genetic conditions that affect their motoring risk). "Health" insurance is used as a shorthand in this Article to refer to the variety of personal insurances (e.g., medical including physician's services, hospitalization, health and accident, disability income, annuities, and life) as well as other forms of insurance for which personal genetic information may be pertinent in classifying, pricing, and underwriting "genetic risks." However, distinctions may be made between "health" insurance and other lines of health-related insurance such as life and disability income insurance. This Article recognizes that insurance underwriting differs among lines of insurance. Adverse selection, see *infra* Part II.B.2 (notes 99-102 and accompanying text), for example, is a significant factor in all lines of health-related insurance, but its statistical importance, operation, and avoidance differs among types of insurance. Moreover, medical (including genetic) screening using predictive diagnostic tests historically is used more in individual and small (fewer than 10-15 employees) employer-provided health insurance than in group health insurance. But with the advent of modern technological advances in genetic testing, group health insurers will increase their use of predictive genetic diagnostic testing. Historically, medical testing and screening of applicants were more frequently used and had

For instance, upon completion of the HGP, we will understand that some diseases and medical conditions are a complex fusion of genetic and non-genetic factors; others are not. Mapping the human genome sequence²⁵ may be 99.9% accurate, but whether a person will (one hundred percent), or may (fifty percent), or will not (zero percent) genetically express a physical or mental disease or other medical condition as well as the degree of that expression (as influenced by personal life-style habits and by the environment) may not be sufficiently accurate for customary actuarial analysis in underwriting health risks. Insurers may consider some health risks to be wholly genetic and, further, may believe that genetic mapping allows the statistically accurate prediction of illness. Reality is more complex, however. The gene for Huntington's disease, for example, accurately predicts the fatal expression of the disease, but environmental factors and personal habits of diet, exercise, smoking, drinking, and so on, may or may not affect the expression. Cancer and heart disease are currently known examples of an expression diversely affected by a combination of genetics, personal habits, and the environment. Cancer, as expressed by genetic alteration in an individual, may be caused by genetic inheritance, random mutation, viruses, radiation, toxic chemicals, or their combination, and may be affected by personal habits. An individual's serum cholesterol level and the risk of heart disease are based on a number of genes and not solely on personal habits in exercise and diet. In other words, insurers without sufficient genetic understanding may be unaware that their actuarial analysis based on genomic data is unfair and discriminatory. Given that, it may prove difficult to identify when unfair genetic discrimination occurs in insurance underwriting.

their greatest impact in life insurance rather than in health insurance; individual life insurance applicants were medically tested evidencing an opposite market structure from group health insurance. *See infra* Part II.A.2 (notes 76-82 and accompanying text). The trend, following completion of the HGP, however, will be toward more medical/genetic testing among all lines of insurance. Thus, this Article recognizes that the fundamental issues regarding genetic information and insurance must be initially addressed and solutions evaluated before drawing any resulting fine distinctions between lines of insurance.

²⁵ For a detailed explanation regarding the methodology of gene mapping, see Victor A. McKusick, *The Human Genome Project: Plans, Status, and Applications in Biology and Medicine*, in *GENE MAPPING: USING LAW AND ETHICS AS GUIDES* 18 (George Annas & Sherman Elias eds., 1992) (discussing aspects of social policy in the area of human genetics and the developing technologies).

I. THE HUMAN GENOME PROJECT

The HGP is not a single effort, but rather is comprised of a number of independent international research efforts with the common goal of analyzing the structure of human DNA and mapping and sequencing the estimated 100,000 human genes, the basic units of heredity.²⁶ The HGP's purpose is to generate information, material, and technology that will be readily available to the whole scientific community.²⁷ That scientific infrastructure will significantly improve the capacity of investigators from a variety of fields to apply molecular approaches to the study of wide-ranging biological problems in the twenty-first century. The HGP will develop efficient, cost-effective detailed genetic and physical maps of the human genome,²⁸ determine the complete nucleotide

²⁶ For discussion of the HGP's history, see Robert Mullon Cook-Degan, *Origins of the Human Genome Project*, 5 RISK: HEALTH, SAFETY & ENV'T 97 (1994); MAXINE SINGER & PAUL BERG, *GENES & GENOME: A CHANGING PERSPECTIVE* (1991) (examining the molecular structures and mechanisms that underlie the utilization of genetic information by complex organisms); George J. Annas, *Mapping the Human Genome and the Meaning of Monster Mythology*, 39 EMORY L.J. 629 (1990) (presenting a history of genetic fascination and analysis of the HGI); Jon Beckwith, *Foreword: The Human Genome Initiative: Genetics' Lighting Rod*, 17 AM. J.L. & MED. 1 (1991) (analyzing the most serious problems arising out of the HGI); John C. Fletcher, *Where in the World Are We Going with the New Genetics?*, 5 J. CONTEMP. HEALTH L. & POL'Y 33 (1989) (discussion of "old" and "new" genetic research and analysis of related ethical issues); James D. Watson, *The Human Genome Project: Past, Present and Future*, 248 SCI. 44 (1990) (discussing the development, current status, and future of the HGP in the U.S.).

²⁷ OFFICE OF TECHNOLOGY ASSESSMENT, *MAPPING OUR GENES — THE GENOME PROJECT: HOW BIG, HOW FAST?* 7 (1988) [hereinafter *MAPPING OUR GENES*].

²⁸ Simply put, the genome is the human genetic endowment. This information is stored in every cell. An individual's genome is essentially synonymous with that individual's genotype, or genetic makeup. More specifically, genes determine all inherited characteristics. Each gene governs a biochemical function, such as protein synthesis or cell division; individually or collectively genes determine a trait, such as hair color. Genes consist of molecules of DNA arranged on microscopic structures called chromosomes within each cell. Genetic mapping, broadly defined, is the process of locating genes on chromosomes. The gene locus is the position on the chromosome of a specific gene. The HGP's goal is to construct a finely detailed map of all human genes.

sequence of human DNA, and create the new technology required to fulfill its purpose. With the maps, DNA sequences, and improved technology for genomic analysis, a new era of biological and medical investigation will be initiated.

Federal funding for the project began in 1991 and the budget is estimated at three billion dollars over a projected fifteen-year completion time.²⁹ Many believe the HGP to be one of the most important research projects ever undertaken.³⁰ The ultimate objective of the HGP is to map and sequence the human genome,³¹ the inclusive database within every cell of an individual which stores the total genetic information. This research will yield information that will be a resource for the study of gene structure and function. Scientists working on this project are attempting to map the human genome by identifying and locating genes and the specific information they contain. Once the human genome has been deciphered, medical researchers intend to use the information to cure genetically-based diseases by designing interventions to prevent the manifestation of these diseases. The scope of intervention could include either gene therapy or gene design. Notwithstanding these worthy aspirations, the HGP presents many practical, ethical, social, and legal concerns.

Since the HGP will reveal vast information about individuals, the potential for abuse of genetic information in the underwriting and marketing of health and related personal insurance coverage is but one of many concerns raised by this new technology. The HGP initially engendered controversy concerning: its scientific merit relative to other projects, its use of resources that might be better employed for human health and research, and the diverse means and ends in which the newly discovered information might be used or misused. Those controversies prompted the allocation of five percent of the federal government's HGP

²⁹ U.S. DEP'T OF HEALTH AND HUMAN SERVS. & U.S. DEP'T OF ENERGY, UNDERSTANDING OUR GENETIC INHERITANCE, THE U.S. HUMAN GENOME PROJECT: THE FIRST FIVE YEARS, FY 1991-1995, at ix (1990) (estimating costs for the HGP at \$200 million per year for 15 years).

³⁰ Mark A. Rothstein, *The Human Genome Project As Public Policy*, 68 BULL. N.Y. ACAD. MED. 144, 146 (1992) (noting that the project is "expected to move [genetic] science beyond single gene disorders to a wide range of genetically predisposing conditions").

³¹ Dennis Karjala, *A Legal Research Agenda for the Human Genome Initiative*, 32 JURIMETRICS J. 121, 147 (Winter 1992) (presenting the results of a project to identify legal issues raised by the HGI and the work necessary to resolve them).

budget to study the ethical, legal, and social implications ("ELSI") of the project.³² The more disputed ELSI include: the patentability of DNA sequences identified by the HGP, privacy issues of both the person tested and that person's genetic family, the history of past misuses of genetic information, racial and genetic prejudices, the fear of a new eugenics movement, and, the subject of this Article, potential unfair genetic discrimination in insurance.³³ To fashion any solution and to prevent or rectify this potential insurance/genetic discrimination, one must have a basic understanding of genetics.

A. *A Genetics Primer*³⁴

The central unit of heredity is the gene. Genes determine the production of proteins which, in turn, determine the function of each cell and, ultimately, an individual's traits. Each cell in the human body (except for red blood cells and sperm or egg cells) contains the complete set of genes located on the twenty-three chromosomes inherited from each parent. What differentiates one human cell from another, say a heart cell from a liver cell, is not the genes, but which of the genes are turned on. Through reproduction, the total genetic code is transmitted. This total genetic code, stored within each cell, constitutes the genome. Conceptually speaking, the genome is the genetic blueprint for the species and it is the goal of the HGP to map this blueprint.

The science of human genetics evolved from traditional physical and biological sciences, and seeks to understand the transmission of biological information from one generation to the next.³⁵ The gene, the basic physical and functional unit of heredity, is comprised of DNA. In 1953, James Watson, Rosalind Franklin, and Francis Crick first postulated the double helix model of DNA to be the chemical basis of heredity.³⁶ In

³² See, e.g., James D. Watson & Eric T. Juengst, *Foreword: Doing Science in the Real World: The Role of Ethics, Law, and the Social Sciences in the Human Genome Project*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES xv, xviii (George J. Annas & Sherman Elias eds., 1992).

³³ *Id.* at xix.

³⁴ For more detailed information on genetics, see JOEL DAVIS, *MAPPING THE CODE* (1990).

³⁵ Louis J. Elsas II, *A Clinical Approach to Legal Education and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 811 (1990) (discussing legal, ethical, and moral responsibilities in genetic science).

³⁶ James Watson & Francis Crick, *Genetical Implications of the Structure of Deoxyribonucleic Acid*, 171 NATURE 964, 965-66 (1953); ANNE SAYRE,

1961, the genetic code of DNA was broken.³⁷ From this breakthrough, scientists recognized that the DNA's linear arrangement of paired bases in triplets provided the blueprint for protein synthesis. They also recognized the start and stop sequences of strings of amino acids on proteins which perform the cellular functions of genes. These relatively recent advances allowed scientists to develop recombinant DNA technology, which permits the search for the genetic basis of a disease to proceed directly at the gene level. Currently, two direct DNA-based techniques are used in this search: the linkage or direct marker technique, and direct gene probes.³⁸

A gene probe is a way of directly looking at the gene responsible for a particular disease. While it is a complex task to determine exactly which base pairs cause a particular disease, additional gene probes are developed virtually each month. Gene probes can be used in general screening.³⁹ The other method of conducting genetic tests is through genetic markers which indirectly link genes with known locations to genes with previously unknown locations.⁴⁰

A genome is the totality of the genetic information that is stored in cells and passed from one generation to the next. Genetic information is a type of chemical blueprint for any species of plant or animal. This information directs an organism's development from a seed or fertilized egg into an adult plant or animal. The genome is central because it largely determines how cells behave and how complex organ systems interact throughout life. Different genes carry the instructions not only for different inheritable characteristics, such as hair color, eye color, gender, musculature, and intelligence, but also for many inheritable mental and physical conditions and diseases. Of course, each individual has a

ROSALIND FRANKLIN AND DNA (1975).

³⁷ JAMES WATSON, *THE DOUBLE HELIX: A PERSONAL ACCOUNT OF THE DISCOVERY OF THE STRUCTURE OF DNA* (1968).

³⁸ DAVID T. SUZUKI & PETER KNUDTSON, *GENETHICS: THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES* 144 (1989).

³⁹ U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, *MEDICAL TESTING AND HEALTH INSURANCE* 135-39, OTA-H-384 (1988).

⁴⁰ Direct gene probes are biologically or artificially constructed pieces of DNA containing DNA sequences complementary to the human gene. The probe is labeled with a radioactive isotope and seeks out its matching DNA sequence. If the probe combines with a segment of human DNA, the human DNA fragments can be identified. Fragment lengths differing from those of unaffected individuals indicate that a genetic defect is present.

different genetic makeup and a crucial part of medical genetics is the study of variation in the genome.

In the 1940s, scientists discovered that genes consisted of DNA (deoxyribonucleic acid). The accepted model of DNA takes the form of an elegant double helix and looks much like a ladder that has been twisted. The rungs of the ladder are the base pairs: the union of two of the four molecules, known as nucleotides, each one from an opposing strand of DNA. The four nucleotides which make up the base pairs are adenine (A), cytosine (C), guanine (G), and thymine (T). Through consecutive base pairing, the double stranded structure of DNA is formed. The order of the nucleotides in the DNA chain is referred to as the DNA sequence.

The genetic code, or DNA sequence, provides these instructions in a language of three letter words composed from the four letters from the chemical bases or nucleotides: A, C, G, and T. The instructions passed on by DNA are spelled out in various sequences of the four chemical bases. These bases match up in predictable ways; for instance, A pairs with T, and G with C. Hence, this language yields sixty-four words, called codons. These three-letter codons encode for one of twenty amino acids, the chemical compounds which are the building blocks of proteins. Proteins are chemical compounds made from different combinations of the twenty amino acids. Proteins are responsible for determining cell structure and function in living organisms. Therefore, genes control the production of proteins and proteins control cell function; thus, ultimately, cellular function is dictated by an individual's genes.

DNA gets its characteristic "double-helix" structure from the bonding of the four chemical bases. Approximately three billion base pairs are contained in human DNA. The bonds between bases can be thought of as steps on the DNA spiral staircase. The sequence of these bases within DNA is fundamental to the cell's ability to perform the most basic activities of life. As explained, a gene is a series of instructions that tells cells how to behave. The segments of DNA that constitute a gene vary. Genes contain varying numbers of bases ranging from a few hundred to over a million. All the information stored in a complete strand of human DNA — the three billion base pairs comprising roughly 100,000 genes — constitutes the human genome.

Genes are grouped together in distinctive structures called chromosomes. In a nutshell, a chromosome is a very long strand of DNA. Each human cell contains forty-six individual chromosomes grouped into twenty-three pairs. One chromosome of each pair is inherited from each

parent.⁴¹ Along with the seemingly benign characteristics that determine one's physical appearance, one may also, unfortunately, inherit ostensibly undesirable family diseases and disorders, such as heart disease, arthritis, and breast cancer. Scientists have determined that there is a link between human genes and diseases such as cystic fibrosis, Tay-Sachs disease, sickle-cell anemia, Alzheimer's disease, and various forms of cancer.⁴² Some report that genes may even "predispose people to behavioral traits such as alcoholism, schizophrenia, depression and even 'aggression.'"⁴³ The presence of some hereditary diseases can be explained by a single gene, or monogenic, defect. But the majority of hereditary diseases are multifactorial, caused by the interaction of environmental factors and numerous abnormal genes presumably on different chromosomes. Many diseases have a molecular mechanism of pathology at the gene and protein levels. Some genetic disorders are understood at the molecular level, but the mechanisms underlying most genetic diseases remain unknown. The HGP will eventually provide insights into the treatment and prevention of both inherited disorders and diseases caused by our genetically influenced physiological reactions to pathogens, toxins, and mutagens of external origin. It will shed light on our evolution as a species and our development as individuals. The culmination of the HGP will be the starting point for scientific research exploring the biological elements in human behavior.⁴⁴

The combined efforts of government agencies, university researchers, and private supporters of biomedical research have produced rough, but extremely useful, maps of DNA markers covering most regions of the human chromosomes. As of 1990, chromosomal locations of over 1215 human genes were known, including those causing twenty of the most common genetic diseases.⁴⁵ As of March 1996, maps to all twenty-three

⁴¹ Each gene is located on a specific site on one of the 23 chromosomes. Each cell, therefore, has copies of all of that individual's genes. (Red blood cells and sperm and egg cells, however, have only one set of genes.)

⁴² See *infra* note 45.

⁴³ CARL F. CRANOR, ARE GENES US? THE SOCIAL CONSEQUENCES OF THE NEW GENETICS 1 (1991).

⁴⁴ *Id.* at 7.

⁴⁵ MAPPING OUR GENES, *supra* note 27, at 24. The following list shows the conditions and year a specific gene was recognized: 1986: retinoblastoma, Duchenne muscular dystrophy, and chronic granulomatous disease; 1990: Wilms tumor and neurofibromatosis type 1; 1989: cystic fibrosis; 1991: fragile X, familial polyposis coli, X-linked Kallmann syndrome, and aniridia; 1992: myotonic dystrophy, Norrie syndrome, and Lowe syndrome; 1993: Huntington's

human chromosomes and all twenty mouse chromosomes were drawn.⁴⁶ Although sequencing of human DNA has rapidly increased, fewer than one percent of the more than three billion base pairs comprising the human genome have been sequenced. It is expected that 99% of the human genome sequence will be completed at an accuracy of 99.9% by the year 2002, which is considerably earlier than the original completion date of 2009.⁴⁷ A 1995 NIH report states that the beginning phase of the HGP has been remarkably successful. The amount of genetic data describing human DNA and the DNA of other organisms that is available in public databases has increased enormously, and the information is being used at an increasing rate. The contributions that the HGP has already made to advance the study of inherited disease and other biological phenomena are, by now, widely recognized in the scientific community. The community is no longer arguing whether the HGP is a good idea, but instead is now debating the most effective ways to reap its rewards. We are rapidly approaching the time when we will have the initial products of the HGP, including maps, genomic DNA sequences, and the improved technology for genomic analysis, in hand. "That will represent the true point of initiation for the era of sequence-based biological investigation."⁴⁸

B. *Scientific Issues for Insurance Underwriting*

1. *Defining "Genetic Testing"*

Genetic testing or screening⁴⁹ is the process of scanning an individual's genetic composition to determine if the individual has genetic material

disease, neurofibromatosis type 2, adrenoleukodystrophy, amyotrophic lateral sclerosis, Menkes syndrome, and X-linked agammaglobulinemia. NIH-DOE WORKING GROUP ON ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH, NATIONAL CENTER FOR HUMAN GENOME RESEARCH, GENETIC INFORMATION AND HEALTH INSURANCE, REPORT OF THE TASK FORCE ON GENETIC INFORMATION AND INSURANCE 12 (1993) [hereinafter REPORT].

⁴⁶ See *supra* note 1.

⁴⁷ Young, *supra* note 2, at 655.

⁴⁸ Mark S. Guyer & Francis S. Collins, *How Is the Human Genome Project Doing, and What Have We Learned so Far?*, 92 PROC. NAT'L ACAD. SCI. USA 10,841, 10,847 (Nov. 1995).

⁴⁹ Genetic screening should not be confused with genetic monitoring, which refers to the periodic testing of an individual to check for changes in the individual's genome that may have been caused by toxic substance at the workplace. Genetic monitoring is of great interest to employers, and it raises a host of issues which are beyond the scope of this Article.

rendering him or her susceptible to developing or transmitting a genetic defect or disease.⁵⁰ Techniques that identify genetic variations are known as genetic tests.⁵¹ A blood sample is drawn, and DNA is then extracted from the blood cells to determine a base pair sequence of a section of the individual's DNA. The technician then maps that base sequence and compares it to other known sequences. In this manner, physicians can determine whether an individual's genome contains a specific gene or set of genes known to cause a disease or to render an individual more susceptible to a disease. Currently, for proven genetic disorders, genetic testing can identify individuals with three types of genetic conditions: (1) individuals who have, or are certain to develop, a specific genetic disease,⁵² (2) individuals who do not have a genetic disease, but are genetic carriers of a disease,⁵³ and (3) individuals with a genetic predisposition to developing a specific disease in the future.⁵⁴

The problem, then, is whether to limit insurers' use of genetic testing information in underwriting. One obvious solution is to do nothing; but other resolutions seem more likely. For instance, in any solution involving state or federal efforts to prescribe or proscribe insurers' use of genetic testing information, the first step is to define "genetic testing" with linguistic precision. In formulating this definition, legislators must decide whether to describe genetic testing broadly or narrowly. Quite

⁵⁰ SUZUKI & KNUDTSON, *supra* note 38, at 144.

⁵¹ DOROTHY NELKIN & LAURENCE TANCREDI, DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION 51-105 (1989) (discussing the potential uses and abuses of biological tests that are emerging from genetic and neuro-scientific research).

⁵² Robert Wachbroit, *Making the Grade: Testing for Human Genetic Disorders*, 16 HOFSTRA L. REV. 583, 586 (1988). Examples of disorders in the first category are individuals who inherit the gene for Huntington's disease, cystic fibrosis, and Duchenne muscular dystrophy. The presence of the defective gene is all that is required to cause the disease, and the individual with this defective gene will develop the disease regardless of extraneous factors such as lifestyle, diet, and environment. *Id.*

⁵³ Wachbroit, *supra* note 52, at 587. Examples in this category are carriers of sickle-cell anemia and Tay-Sachs disease. Carriers pass the genes to their children who will probably develop the disease if both parents are carriers. *Id.*

⁵⁴ *Id.* Examples include a predisposition to lung cancer, other cancers, heart disease, hypertension, diabetes mellitus, and epilepsy. Individuals with such a predisposition have the ability to affect the likelihood of developing a disease by controlling influences such as tobacco, toxic environments, diet, lifestyle, and alcohol. *Id.*

frankly, however, prior to the completion of the HGP, one cannot know all the possible forms of future genetic tests.

So why try now to divine a definition? The moratorium on genetic testing for insurance provides one good reason. As explained later in Part III.B.1 of this Article,⁵⁵ several states have recently enacted insurance/genetic legislation. Three of those states (California, Ohio, and Virginia)⁵⁶ have imposed a moratorium, suspending insurers' use of genetic tests and genetic information for a specified time. The moratorium approach requires defining what "genetic testing" is prohibited.

Genetic tests can include scientifically precise testing such as direct molecular manipulation of genetic material, or simply an individual's medical examination. As commonly understood, however, "genetic testing" can be defined in terms of one or more of the following current genetic tests: (1) direct and indirect determination of "altered" DNA composition using molecular genetic techniques to analyze a blood or skin sample (e.g., gene mutations evidencing cystic fibrosis or adult polycystic kidney disease), (2) microscopic examination of chromosomes from a blood or skin sample to detect an abnormal number of chromosomes or chromosomes with aberrant structures (e.g., Down's syndrome (extra copy of chromosome), Turner syndrome (females missing one X chromosome), Klinefelter syndrome (males with an extra X chromosome), and fragile X syndrome (a DNA test is also now available) (which sometimes causes mental retardation)), and (3) chemical, immunochemical, or biochemical analysis which detects genetic conditions by measuring chemicals or enzymes in blood or other body samples (e.g., Tay-Sachs disease, sickle-cell anemia, hypercholesterolemia, phenylketonuria, and galactosemia can be detected by this genetic test).

Although there is no uniformity among the states that currently have comprehensive insurance/genetic legislation, a number of states have adopted a narrow definition that results in only limited protection for genetically-tested individuals. For instance, the intent of Colorado's 1994 statute is to prevent the use of information derived from genetic testing

⁵⁵ See *infra* notes 159-62 and accompanying text.

⁵⁶ The California moratorium is from October 9, 1995 (when the governor signed Senate Bill No. 1020) until January 1, 2002. The bill amended CAL. INS. CODE §§ 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 10143, 10146-10149.1, 11512.96, 11512.65 (West 1994) and CAL. HEALTH & SAFETY CODE § 1374.7 (West 1995); and the bill added *id.* § 1374.9. The Ohio moratorium is from February 9, 1994, through February 9, 2004. OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50 (Page's Supp. 1994). The Virginia moratorium is for two years. VA. CODE ANN. §§ 38.2-508.4 (Michie Supp. 1996).

to deny access to health care insurance, group disability insurance, or long-term care insurance.⁵⁷ The statute, however, narrowly defines genetic testing as any direct laboratory test "of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness."⁵⁸ This definition does not include the two other diagnostic tests: microscopic examination of chromosomes or chemical, immunochemical, and biochemical tests measuring bodily enzymes or chemicals. Florida's 1995 act employs a similarly restricted definition in its efforts to protect the confidentiality of DNA tests — except for genetic information used in criminal prosecutions and for paternity suits.⁵⁹ Similarly, Georgia specifically excludes "routine physical measurements; chemical, blood and urine analysis; tests for abuse of drugs; and tests for the presence of [HIV]."⁶⁰

In contrast, Ohio, in its 1994 act, more broadly defines "genetic screening or testing" to mean:

a laboratory test of a person's genes or chromosomes for abnormalities, defects, deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.⁶¹

Currently, none of the states that has attempted to define genetic testing includes in its statutory definition two common and low-tech ways insurers obtain genetic information. One is the familiar medical or physical examination which can provide genetic information about an applicant for insurance. Some of the genetic conditions that can be diagnosed directly from a medical examination include: neurofibromatosis, von Hippel-Lindau syndrome, and tuberous sclerosis. The other is the taking of a family medical history, which is useful to insurers in assessing the risk of an applicant contracting a disease or in predicting a future genetic disorder or condition. Obviously, a family medical history is a primitive means of obtaining genetic information and it differs from a true genetic test in its lack of accuracy. One can predict, for instance, that

⁵⁷ COLO. REV. STAT. § 10-3-1104.7 (1994).

⁵⁸ *Id.* at (2)(b).

⁵⁹ FLA. STAT. ANN. § 760.40 (West 1995).

⁶⁰ GA. CODE ANN. § 33-54-2(1) (1996).

⁶¹ OHIO REV. CODE §§ 1742.42(A), 3901.49(A)(1), 3901.50(A)(1) (Anderson Supp. 1995).

on average one out of every two progeny of a person with Huntington's disease will have that disease, but one cannot predict which child will contract the disease and which will not.

Finally, whether insurance companies will use any of the foregoing tests following the HGP's completion will certainly depend on costs. Some current genetic tests for a specific disease or disorder cost only a few dollars, but others cost several thousand dollars.⁶² Obviously, the future cost for a genomic analysis of an individual applicant is unknown. Nonetheless, in drafting insurance/genetic legislation or regulation, one factor for consideration is the costs of genetic testing as it relates to the probability of use by insurance companies. That relationship might affect not only the definition of genetic testing used but also whether or not regulating insurers' use of certain testing techniques is deemed necessary.

2. *Misunderstanding Genetic Data in Actuarial Analysis*

Most critically, the HGP will reveal data concerning the genetic predisposition to diseases, illnesses, and disorders, and not merely to their occurrence. In advance of the onset of the actual disease/disorder, the HGP should unveil significant gene-based differentiation in human proclivities to environmental factors or infectious organisms. Those expected discoveries are important in determining how to fairly distribute health care costs and individual resources via the risk distribution nature of private insurance, or through a national- or state-mandated health insurance pool.

Also critical is an understanding by insurers and others of the genetic nature of disease. A significant part of the study of medical genetics is the variation in the genome. Geneticists can determine with accuracy in some cases that when a particular abnormality in a gene is present, an individual will be affected with a particular disease; but in many cases the relationship between genes and disease is significantly more complex. Genetic anomalies can cause diseases in four ways:⁶³

(1) *Monogenic or Single Gene Disorders*. Some diseases may be caused by one improperly functioning gene: these are termed single gene or monogenic disorders. This type of disorder is characterized by a pattern of transmission in a family. If an abnormality is evident when

⁶² A list of the costs of most current tests is included as an Appendix to this Article. See Appendix *infra* p. 664.

⁶³ The description of the four classifications of genetically-caused diseases is adapted from the OHIO TASK FORCE ON GENETIC TESTING, FINAL REPORT, *supra* note 4, at 3-4.

only one of the chromosomal pair contains the variant gene, the disorder is termed a dominant single gene disorder. Typically, a person affected by the dominant single gene disorder had a parent who was affected, who had a parent who was affected, and so on through the family line, back to the occurrence of the initial gene mutation. If the disease manifests itself only when both of the chromosomal pair possess the variant gene, it is termed a recessive single gene disorder. The recessive disorder occurs when an affected person inherits a mutant gene from each parent, often even though neither parent has the disease. Most recessive single gene disorders occur at a rate of one in 15,000 to 100,000 births. Common examples are sickle-cell anemia in one of every 600 African Americans, and cystic fibrosis in one of every 2500 births. These single gene disorders are rare, but there are about 3600 different identified disorders. Approximately three percent of the population will develop a single gene disease.

(2) *Chromosomal Disorders*. Other diseases result from visible aberrations in chromosome structure or number: these are termed chromosomal disorders. These disorders account for a significant percentage of birth defects, mental retardation, and miscarriages. Chromosomal disorders arise if the number or structure of any of an individual's forty-six chromosomes is abnormal. This type of disorder concerns a large number of genes typically on one or two chromosomes. Disease results because there is either a missing or an extra chromosome which results in physical or mental maldevelopment. People with Down's syndrome, for instance, have three rather than two copies of chromosome "twenty-one." Irregularities may also occur during the division of cells resulting in either too little or too much chromosomal material in the new cells. The material may also be rearranged in the new cells which disturbs the normal balance and may result in abnormal development.

(3) *Multifactorial Disorders*. Probably the largest genetic-disorder classification is termed multifactorial. This category has statistical, but potentially misleading, value in insurance underwriting. If a disorder is not within the foregoing two classifications and if it runs in families, it is usually classified as multifactorial in origin. Multifactorial means that these disorders result from the interaction of environmental factors and many abnormal genes presumably on different chromosomes. Examples include asthma, epilepsy, coronary heart disease, diabetes mellitus, multiple sclerosis, schizophrenia, and some forms of arthritis and emphysema.

(4) *Non-Inherited Disorders*. The fourth classification encompasses the disorders resulting from genetic changes occurring during one's life

that are not inherited disorders. During a person's life, the genetic structure of certain cells may be altered. Thus, people genetically "normal" at birth may develop disorders when the DNA in a cell mutates. This change can happen when genes are damaged or if external factors (such as chemicals, radiation, viruses, or cigarette smoking) alter the genetic structure of cells. Most cancers are examples.

Although the HGP has uncovered monogenic disorders, diseases caused by a single specific gene are, as explained, rare. Even if a disorder is monogenic, its expression may depend on other factors.

Once genes for monogenic disorders are sequenced, some may be found to be almost completely determinative of the particular disorder. To that extent, we must regard genetic testing as deterministic. However, in the vast majority of cases, the result of the genetic test will simply be an increased or decreased susceptibility to a particular disease or . . . to diseases associated with environmental influences (such as smoking or asbestos).⁶⁴

Although the presence of specific genes is all that is required to bring on a disorder, the degree of severity, timing of onset, or whether the disease will ever manifest itself at all, remain a matter of statistical probability. For these reasons, most genetic test information is largely a matter of probability theory and less conclusive than might be assumed from popular perception. This distinction of statistical probability from absolute conclusiveness is important when one explores the issues of economic and social policy in health insurance underwriting, which may, in turn, depend upon the accuracy of genetic testing. For instance, one goal of insurance underwriting is the accurate prediction of an insured's future medical needs, costs, mortality, and morbidity. With this information an insurer can establish a premium at a level consistent with the medical/health risk represented by each individual policyholder. In other words, an insurer must fairly differentiate and discriminate among insureds regarding health risks by setting "actuarially fair" rates.⁶⁵

⁶⁴ Karjala, *supra* note 31, at 146.

⁶⁵ Risk transference and risk distribution are the basis of underwriting. The Mother Mold of insurance is "risk" (i.e., statistically probable, future "fortuitous harm" of an applicant for insurance). That risk is transferred to an insurance company. The insurer then distributes the risk among a group, exposed to similar risks, who pay premiums to a common fund. Risk distribution refers to the process insurers use to decide if an insurance application by an individual, family, or group represents an actuarially acceptable risk.

Actuarial fairness then turns on accurate genetic information about each policyholder. Although the HGP seeks to find the genetic causes for diseases, it is imperative to keep in mind that there are many factors which affect disease. Excepting those rare monogenic diseases, it may be many years before genetic testing will be completely accurate in terms of its ability to predict with any accuracy the likelihood of an individual developing a genetic disorder solely on the basis of a positive genetic test result.

Risk determination through the identification of specific genes which either directly or indirectly cause a disease differs from the age-old reliance on an individual's written or verbal account of family history to determine risk of disease. The increased specificity of identifying the presence of so-called "problem genes" gives insurers a powerful tool which they may use to deny insurance coverage to individuals. In an effort to reduce their health care expenditures, insurers may wish to use genetic testing to identify individuals with an increased risk of developing costly medical conditions. An overall, primary concern is that insurers may misunderstand, misinterpret, and misuse genetic information in creating risk classifications and excluding or limiting insurance coverages.

Insurer decisions could be based on an applicant's or an insured's genetic testing information and not on their actual state of health. A common misunderstanding equates the presence of a genetic trait with an actual disease or medical condition. People most prone to genetic discrimination include unaffected carriers (heterozygotes), asymptomatic individuals, at risk presymptomatic people with a predisposition to disease, and people with a minor expression of a disease or medical condition.⁶⁶ Insurer decisions based on risk classifications may also fail to account for the early identification of a genetic disorder which may lead to early intervention, which may in turn prevent the disease from developing. Moreover, scientists anticipate the eventual development of routine cures for gene disorders through genetic replacement therapy.

In its recent 1995 report, the NIH's National Center for Human Genome provides wise, circumspect counsel. After extolling the current research findings regarding the causes of human disease and disability as

⁶⁶ High heritability must not be equated with inevitability because the environment can dramatically affect the expression of a disease. For example, the genetic disease phenylketonuria (which causes profound mental retardation) has a 100% heritability. But eliminating the amino acid phenylalanine from the diet of affected individuals prevents retardation from occurring. John Horgan, *Eugenics Revisited*, 268 *SCI. AM.* 122, 125 (June 1993).

well as discovery of genes and genetic markers associated with other human characteristics, the report strongly cautions:

Typically, such genetic studies provide only introductory and incomplete clues about the interplay of biological, psychological, and sociocultural factors that influence the development and expression of these complex human traits. However, the results of such research can be misinterpreted in two important ways. First, they can be interpreted to imply that such traits can be reduced to the expression of particular genes; this has the effect of de-emphasizing the important role of psychosocial and other environmental factors. Second, the results can also be interpreted in a way that narrows the range of variation considered to be 'normal' or 'healthy.' Such overly deterministic interpretations can, in turn, be misused to undercut the respect owed individuals as responsible moral agents or to inappropriately label individuals as sick or abnormal. Both forms of misinterpretation can have untoward consequences, such as devaluing human genetic diversity or fostering social discrimination on the basis of genotype. As it proceeds, the HGP will need to foster a better understanding of the meaning of human genetic variation among members of the public and the professions and expand its efforts to propose policy initiatives designed to prevent genetic stigmatization, discrimination, and other misinterpretation or misuses of genetic information.⁶⁷

II. ARGUMENTS SUPPORTING INSURERS' USE OF GENETIC INFORMATION

A. *Fair Discrimination Is Efficient Underwriting*

1. *The Equitable, Not Equal, Justification*

Risk transference and distribution are the keys to understanding the nature of insurance and insurance underwriting. Insurance is an arrangement for the transference of the risks of fortuitous losses to an insurer and the distribution of those risks among insureds who pay a premium to a common fund. The principle underlying insurance underwriting is "fair discrimination" predicated on efficient, actuarial analysis in establishing risk transference and risk distribution (also called redistribution). In underwriting risks, insurance companies seek "to measure as accurately

⁶⁷ Guyer & Collins, *supra* note 48, at 10,847.

as is practicable the burden shifted to the insurance fund by the policyholder and to charge exactly for it, no more and no less. To do so is 'fair' discrimination Not to do so is unfair discrimination."⁶⁸ Gender discrimination is illustrative. In life insurance, for instance, failure to distinguish women, who present lower risks of early death, from men is unfairly discriminatory against women and in favor of men.⁶⁹ Regarding annuities which pay until death, it is unfairly discriminatory against men and in favor of women. Hence, the failure to differentiate between insureds results in unfair discriminatory rates because it forces policyholders with lower actuarially predicted risk to subsidize other policyholders with higher expected risk.⁷⁰

Underwriting of insurance is the process which an insurer uses to determine whether, and on what basis, it will accept an application of insurance. Underwriting requires the application of risk classification principles to a particular insurance applicant, or block of business, to ascertain if insurance coverage will be provided and what premium rates are required. In every insurance arrangement, each insured contributes to a common fund from which amounts are paid to or on behalf of policyholders who suffer covered losses. To maintain equity among the policyholders, each must contribute according to the loss probabilities each individual transfers to the common fund. If one policyholder is permitted to pay less than that policyholder's share, it will necessitate an overcharge against the other policyholders which constitutes an unfair "forced subsidy." Thus, insurance companies must, by sound actuarial analysis, determine the loss expense presented by each applicant and

⁶⁸ Spencer L. Kimball, *Reverse Sex Discrimination*: Manhart, 1979 AM. B. FOUND. RES. J. 83, 105.

⁶⁹ See *infra* notes 88-91 and accompanying text.

⁷⁰ The HGP has the potential of providing insurers with a wealth of information about each health insurance applicant's genetic disposition to disease, illness, and other conditions. Denying insurers that genetic information would prevent insurers from accurately differentiating among insureds and actuarially predicting each applicant's future medical, mortality, and morbidity costs. To deny insurers the right to conduct genetic tests and to obtain genetic information will result in unfair discrimination and adverse selection. For an explanation of adverse selection, see *infra* Part II.B.2 (notes 99-102 and accompanying text). "It seems more than a little ironic that, in a society which generally has prized maximizing access to information for both consumers and investors, to suggest societal interests are now served by blocking an insurer's access to information which is clearly relevant to the risks to be undertaken." Widiss, *supra* note 14, at 1648 n.138.

charge a fair premium for each. Circumspect selection and classification of risks accomplishes that principle of pricing based on risk.

The very nature of insurance is discriminatory because individuals with a higher risk are routinely charged a higher premium. For example, a smoker is charged a higher premium than a non-smoker for a life insurance policy because, all other factors being equal, a smoker represents a higher mortality⁷¹ and morbidity⁷² risk than a non-smoker. Thus, rates are established and premiums charged based on the principle of equity, not equality, so that insureds with the same or similar actuarially predicted risk of loss are charged the same. The lower the actuarially expected risk, the lower the premium. The higher the expected risk, the higher the premium. Whereas equal premiums would simply mean that all insureds pay the same price, equitable premiums vary according to the risks transferred. Thus, the goal of insurance underwriting is equity; that is, equitable, but not equal, treatment of applicants and policyholders. To achieve that goal, insurers must differentiate among policyholders by risk classifications and discriminate fairly so that each insured will pay a premium at a level consistent with the risk represented by each individual insured. In sum, the fundamental tenets of underwriting are the selection of insureds based on sound actuarial standards, proper balance within each rate classification, and equity among policyholders.

An important final point must be made regarding the impact of fair discrimination by health insurers' use of genetic testing information in medical underwriting. The non-governmental, private health insurance industry offers two types of insurance: individual health policies and large employer group health policies.⁷³ Approximately eighty-five to ninety percent of all private health insurance policies are group policies.⁷⁴

⁷¹ "Mortality" is defined as the "death rate at each age as determined from prior experience." HEALTH INSURANCE ASSOCIATION OF AMERICA, A COURSE IN GROUP LIFE AND HEALTH INSURANCE, pt. A, at 379 (1985), *quoted in* Clifford & Iuculano, *supra* note 14, at 1808 n.9.

⁷² "Morbidity" is defined as the "incidence and severity of sickness and accidents in a well-defined class or classes of persons." *Id.* at 366.

⁷³ Rather than purchasing a traditional medical insurance policy, some large employers opt for self-funded plans or administrative services only ("ASO") contracts. Under an ASO contract, the insurer charges the group for only the actual cost of the claims made plus administrative expenses.

⁷⁴ Stone, *supra* note 14, at 389. Although the data is somewhat out of date, unquestionably the great majority of health insurance is acquired by employees through their employer. See Richard Kronick, *Health Insurance, 1979-1989: The*

Approximately ten to fifteen percent of private health insurance policies are individual policies, or small groups of less than ten to fifteen people, sold through private commercial insurers and Blue Cross/Blue Shield. The important point is that medical underwriting occurs for individual policies and small groups and, generally, not for group policies. Because of their ability to average utilization over a large number of employees, large employer groups customarily are not medically underwritten. New employees are eligible for coverage without medical underwriting by the insurer. In buying insurance, large groups are typically not denied health insurance due to the poor health of some employees or their dependents. Large groups are experience rated; in other words, their insurance premiums will vary at renewal based on the discrete group's total claims. Experience rating will vary based on the group's size. For instance, groups of fifty to one hundred employees could be thirty percent experience rated and seventy percent pool rated. That means thirty percent of the group's premium is based on the group's claims and seventy percent on the general experience of all similarly-sized groups using customary insurance industry classification. The larger the group, the greater the weight given to the particular group's claims experience. In sum, concern over discrimination is greatly diminished when medical premiums are based on experience rather than calculated through underwriting.⁷⁵

2. *The History of Insurance Risk Classification*

The pooling of risks with similar characteristics for the purpose of determining insurability and price is the bedrock principle of a workable, voluntary, private insurance system. This process, called risk classification, not only permits insurers to exercise their right to earn a reasonable profit but also creates an equitable insurance system for all policyholders. Through underwriting insurers create risk classifications,⁷⁶ based on the abundant differences among individuals, to put applicants into groups with comparable expectations of future loss. Risk classification necessari-

Frayed Connection Between Employment and Insurance, 28 INQUIRY 318, 320-22 & fig. 3 (1991).

⁷⁵ The statements in this paragraph are based on the findings of the OHIO TASK FORCE ON GENETIC TESTING, FINAL REPORT, *supra* note 4, at 17-18.

⁷⁶ For perhaps the best article on risk classification in the legal literature to date, see Leah Wortham, *Insurance Classification: Too Important to Be Left to the Actuaries*, 19 MICH. L. REV. 349, 349 (1986) ("War is much too important to be left to the generals.").

ly includes the use of data about an applicant's age, sex, occupation, health status, and medical history including genetic tests and genetic information. Allowing insurers access to genetic testing, mapping, and other relevant information regarding an individual's genotype based on techniques developed by the HGP will be necessary for proper risk classification. A system that does not classify risks will inevitably cease to be a private insurance system. If insurers are denied access to genetic information it would threaten insurers' solvency by undercutting the use of actuarially sound risk classifications to properly and fairly price insurance policies.

Risk classification is a process whereby an insurer develops a number of different categories, or classes, that accurately reflect the varying degrees of risk which members of the classes represent. While individual outcomes cannot be predicted, trends and averages for classes composed of people with similar characteristics can be predicted with an adequate degree of certainty. The present risk classification system permits private insurance companies to respond fairly to experience-related differences and the costs of policyholders' claims for loss. The standard for the practice of risk classification, developed for the actuarial profession by the Actuarial Standards Board, states three requirements for an appropriate risk classification system: (1) it must be fair, (2) it must permit economic incentives to operate thereby encouraging widespread availability of insurance coverages in the marketplace, and (3) it must assure that insurers will be solvent.⁷⁷ The great flywheel of a sound insurance risk classification system is efficient, fair discrimination.

The history of insurance risk classification provides further support for fair discrimination. A brief review of this history evidences that properly utilized risk classification fuels an efficient private system, enhances insurer solvency, encourages fair treatment of all policyholders, and provides an enormous public benefit through widely-available, low-cost health, life, and other health-related insurance.⁷⁸ The risk classifica-

⁷⁷ Robert J. Pokorski, *Use of Genetic Information by Private Insurers*, in JUSTICE AND THE HUMAN GENOME PROJECT 91, 95 (Timothy F. Murphy & Marc A. Lappé eds., 1994) (arguing that genetic information must be made available to insurers as a matter of equity).

⁷⁸ As of 1988, more than 143 million people nationwide had life insurance coverage. The overwhelming majority (approximately 96% of ordinary life insurance) were classified as "standard" risks for insurance purposes and were charged standard insurance rates. See AMERICAN COUNCIL OF LIFE INSURANCE, LIFE INSURANCE FACT BOOK UPDATE 1989, at 54 (1989). Similarly, most insurers accept 70-80% of applicants for individual health coverage at standard

tion system developed without specific regard to any individual risks. It evolved independent of the response to a discrete disease or medical condition and it established the framework within which underwriting for all medical/genetic conditions can be performed.

The contemporary system of employer-funded health insurance evolved because of the economic pressures on hospitals during the Great Depression. In response to their extraordinary financial burden, hospitals arranged to provide certain services to patients in exchange for a set annual fee.⁷⁹ These arrangements for "hospitalization insurance" were made with employers who offered the programs as a benefit to their employees. These early programs were the predecessors of Blue Cross. Although "medical insurance" which reimbursed for physicians' services was a known quantity with a longer history than hospital insurance arrangements, medical societies quickly followed suit and began to offer similar plans. This led to the creation of Blue Shield. The shortage of workers during World War II led employers to offer and expand these health plans as fringe benefits.⁸⁰

Community rating and experience rating are the two primary approaches that insurers historically used to establish premium rates. With an emphasis on fair discrimination, experience rating bases premium rates on the current claims made by the particular group — the group's experience. In contrast, with an emphasis on fair risk distribution, community rating bases the premium rate on the average cost of all insured policyholders within a defined geographical region. The early non-profit Blue Cross/Blue Shield plans used a community rating system to price their group health insurance. This method took into account the average expected health expenses of the population in a particular geographic community, not the expected health expenses of any particular employee or work force. This community rating system, which included those for whom insurance would otherwise have been expensive or unavailable — such as the elderly, infirm, and those unable to work —

rates. Most individual health insurers' declination rates are less than 10%. See HEALTH INSURANCE ASSOCIATION OF AMERICA, INDIVIDUAL HEALTH INSURANCE pt. A at 132 (1989). These statistics evidence that the risk classification system operates to afford the great majority of applicants with ready access to insurance coverage at a reasonable premium reflecting the risk accepted by their insurer.

⁷⁹ Bryan Ford, *The Uncertain Case for Market Pricing of Health Insurance*, 74 B.U. L. REV. 109, 113 (1994) (discussing the origin of health insurance in the United States).

⁸⁰ *Id.* at 114.

worked well with no competitive markets. But the advent of health maintenance organizations and other forms of competition revealed the weaknesses in this system. These more recent commercial insurers used an experience rating system to classify risks, and because this system looks only at the group being insured,⁸¹ it allows these insurers to offer lower rates by excluding from the calculation of premiums higher risk individuals. This shift in pricing has the effect of reducing the forced subsidy of redistributing risk of loss from those with high expected medical costs to those with low expected medical costs.

In 1933, Blue Cross used community rating. All premiums were the same for all policyholders regardless of the actual experience of the group. Then came stiff competition from for-profit insurers who lured away low-risk Blue Cross insureds by separately classifying them and giving them a lower premium.

The effect of community rating, or the failure to classify risks, is the creation of a situation in which high-cost subscribers are subsidized by low-cost subscribers. In a market where subscribers are not forced to purchase coverage and may choose among several competing sources for insurance, the failure to classify risks will be fatal.⁸²

This brief history teaches one lesson: private insurers must classify risks to remain in business.

In other words, the health care system in the United States is financially administered through a private insurance system. Therefore, any analysis of the system must keep in mind the idea that health insurance is a business. If this private system is to survive, it is necessary to allow the continued operation of the free market to the extent that it is equitable for all involved.

3. *Use of Genetic Tests Is Efficient and Equitably Fair*

Insurers use risk classification methods to establish premium rates commensurate with the level of risk an individual or group represents.

⁸¹ *Id.* at 113.

⁸² Maria O'Brien Hylton, *Insurance Risk Classification after McGann: Managing Risk Efficiently in the Shadow of the ADA*, 47 BAYLOR L. REV. 59, 71 (1995) (discussing the development of the market for small group insurance and the community rating system as a result of the competitive market's demand for an efficient risk classification system).

Insurers' use of such techniques has expanded the availability of health and medical insurance because premiums are fixed at levels representing the relative risk of insuring an individual or a given group. Because the primary goal of insurance underwriting is the accurate prediction of mortality and morbidity costs,⁸³ any medical tests which will be useful in assessing risks should be available to insurers. Insurance underwriting involves the classification of applicants based upon one's medical/health history, including static factors (such as age, sex, and genotype) and personally diverse factors (such as occupation, diet, and tobacco/alcohol/drug use).⁸⁴ Although these factors may affect individuals differently, they are statistically significant in affecting mortality and morbidity. Insurers uniformly use them in an effort to assess risk accurately before agreeing to insure an individual applicant.

If risks are not properly assessed and factored into the rates charged, then two scenarios could potentially arise: (1) If an insurer underassesses risks, it will have insufficient funds to pay claims submitted unless it overcharges people who represent low risk. If insurers have inadequate funds and are unable to meet their contractual obligations to pay claims, the insurers will go bankrupt, leaving people uninsured. (2) If an insurer overassesses risk and overcharges, the free market and competitive nature of business logically dictate that people will purchase insurance elsewhere. Thus, accurate risk assessment is essential to the business of insurance.⁸⁵ In addition to accurate risk assessment, the methods used to transfer and distribute costs have affected the insurance companies' need to remain competitive and to keep costs as low as possible for their insureds.

The present health insurance industry has fundamentally abandoned an equitable community-wide rating system where the health costs for everyone in society are aggregated and premium charges are spread

⁸³ Mortality costs are based on how much an insured has paid in premiums before he or she dies. Morbidity costs are based on how much the insured has paid in premiums versus the cost of medical care for diseases the insured will contract.

⁸⁴ According to the Health Insurance Association of America, medical underwriting may be based on some or all of these sources of information: the application, agent's statement, medical or paramedical examination, attending physician's statement ("APS"), hospital medical records, inspection reports, and the files of the Medical Information Bureau ("MIB"). HEALTH INSURANCE ASSOCIATION OF AMERICA, *supra* note 78, at 122-32. *See infra* notes 209-13 and accompanying text for a description of the MIB.

⁸⁵ Clifford & Iuculano, *supra* note 14, at 1810.

equally among all insureds. Health underwriting has been replaced by a system based on "experience rating" by selective groupings.⁸⁶ These changes in underwriting practices combined with the competitive nature of the insurance business provide a compelling argument that the use of genetic testing will provide a valuable tool for insurers. Insurers agree that the use of genetic testing is discriminatory, but they would argue that it is fair discrimination because it is based on sound actuarial analysis. Accordingly, the rate-setting philosophy of insurance companies is founded on the equitable treatment, not equal treatment, of all applicants for health insurance. Rates should be adequate, not excessive, and discriminate fairly between insureds. Adequate rates provide insurers with sufficient income to process and fairly pay claims at a reasonable profit and without fear of bankruptcy. Rates should not be excessive, because excessive rates impose undue burden on insureds. To achieve adequate non-excessive rates, insurers must discriminate fairly so that each insured will pay in accordance with the quality of his/her life and health.⁸⁷

An analogy can be made to the arguments of those in favor of using gender as an actuarially relevant criterion in assessment of risk. Insurers argue that charging an insured a premium that is proportional to the individual's actual risk of loss is fundamental to the principles of the insurance business. The insurers argue that women live longer than men,⁸⁸ are safer drivers than men,⁸⁹ and incur higher medical costs than men.⁹⁰ Because the risks are different for men and women, the premiums should reflect these differences.⁹¹

⁸⁶ Roger J. Bulger, *How the Genome Project Could Destroy Health Insurance*, WASH. POST, Aug. 4, 1991, at C4.

⁸⁷ Pokorski, *supra* note 77, at 93 (quoting Herman T. Bailey et al., *The Regulatory Challenge to Life Insurance Classification*, 25 DRAKE L. REV. (Insurance Annual) 23 (1976) (discussing federal and state regulatory approaches which threaten the current insurance risk classification system)).

⁸⁸ NATIONAL SAFETY COUNCIL, ACCIDENT FACTS 8 (1989) (containing statistical information regarding accidents causing injury or death in the United States).

⁸⁹ *Id.* at 54.

⁹⁰ JERRY, *supra* note 14, at 102 ("In health and disability insurance, because of maternity costs women as a group present more of a risk to insurers than do men as a group. Thus, women often pay more than men for the same health and disability insurance coverage.").

⁹¹ See generally George J. Benton, *The Economics of Gender Discrimination in Employee Fringe Benefits: Manhart Revisited*, 49 U. CHI. L. REV. 489 (1982).

The insurance industry's ability to fairly discriminate based on the actuarial knowledge derived from the HGP could have a positive impact on many insureds. Because insurers try to correlate premiums with actuarial risk, genetic information could lower a person's premiums or allow an individual previously considered uninsurable to obtain health insurance. For example, because Huntington's disease is a monogenic disorder, a child of parents who are both carriers of the gene would have a fifty percent chance of inheriting this genetic disease. However, if the couple's child tested negative for the disease-causing gene, the child would then be able to obtain more affordable insurance. Consequently, instead of all children whose parents are Huntington's disease gene carriers being rejected, half of them would qualify for insurance.

Currently, about three percent of individual insurance applications are rejected due to high risk — in fact, in these cases it is often impossible, currently, to make accurate predictions of risk.⁹² Through the use of genetic information in these cases, however, insurance companies could accurately assess risk. Assuming that the risk was ascertainable but found to be high, the applicant, with this confirmed knowledge, would likely feel that it was fair to pay a higher premium for the correspondingly high risk. An applicant would probably not accept a policy with a very high premium charge unless the applicant had reason to believe that even though the premium was quite high, the insurer had nevertheless underestimated the risk. Thus, equal access by the insurer and insured to the insured's genetic information would produce fair results: not only would previously uninsurable people find coverage, but relatively high premiums would be justifiable.

Another example where equal access to the insured's genetic knowledge would produce favorable results to the insured is where an insured has a gene which in conjunction with known external factors results in disease. That insured's decision to take appropriate measures to reduce the risk of disease would include the economic benefit of a lower premium based on the insurer's use of risk classifications. For instance, if an insured has a gene associated with cancer, then he or she would likely choose to periodically monitor the condition and follow a physician's advice in reducing the risk through appropriate changes in lifestyle. Not only would adverse selection be avoided, but immediate economic and potentially long-lasting health benefits would be derived. Risk classification positively promotes efficient, less risky behavior. Therefore, equal access to genetic information for proper risk classifica-

⁹² Pokorski, *supra* note 77, at 104.

tion has the positive effect of creating loss prevention incentives in insureds.⁹³ This incentive to avoid losses arises only if insurance premiums are a function of risk classifications and experience rating.

B. *Equal Access to Genetic Tests Fairly Rectifies the Unfairness of Imperfect Genetic Information in Underwriting*

1. *Applicant's Good Faith Duty to Disclose Genetic Information*

As a prerequisite to risk transference based on actuarially fair risk classification, insurers submit that they be allowed to require applicants to undergo genetic testing, or minimally, to disclose genetic information from prior tests. The rationale is that the absence of genetic information will cause economically inefficient unfairness arising from imperfect risk information between insurer and applicant about the applicant's future health care needs. Imperfect information is an obstacle to an effectively functioning market. Almost always there is a disparity in knowledge between the insurer and the prospective insured regarding the factors that affect the degree of risk presented by the applicant. If an applicant knows materially adverse genetic facts regarding the applicant's foreseeable need for later medical treatment and care, and also knows that the insurer does not have equal access to these material genetic facts, then that applicant has a good faith obligation to disclose this information to protect the insurer's solvency and to ensure equitable premiums.⁹⁴ If, however,

⁹³ For a discussion of behavioral activity and care level effects, see Steven Shavell, *Strict Liability versus Negligence*, 9 J. LEGAL STUD. 1 (1980) (comparing strict liability and negligence on the basis of how effectively money reduces accident loss based on incentives found under each scheme).

⁹⁴ For a discussion of the insured's duty of good faith (*uberrimae fidei*) to disclose material facts based on unequal knowledge in insurance contract formation, see Eric Mills Holmes, *A Contextual Study of Commercial Good Faith: Good-Faith Disclosure in Contract Formation*, 39 U. PITT. L. REV. 381, 409-35 (1978). The American rule recognizing an affirmative obligation to disclose material facts in insurance contract formation requires the following six elements: (1) when the insurance contract is formed, the insured knows fact X (i.e., material genetic information); (2) insured does not disclose fact X to insurer and insurer is not chargeable with its knowledge; (3) fact X is material; (4) insured knows fact X is material; (5) insurer does not know fact X when insurance contract is formed; and (6) insured knows that insurer does not know fact X. *Id.*

insurers are granted equal access to an applicant's genetic tests and genetic information, then the good faith obligation to disclose does not arise.

In the famous English marine insurance case of *Carter v. Boehm*,⁹⁵ Lord Mansfield, deftly mixing natural law, continental codes, and the *lex mercatoria* with English equity and law, established for the first time in our common-law a good faith duty to disclose material facts in contract formation. Mansfield assumed, as does classical contract theory, that parties are legal equals in contracting. This legal equality often leads to a violation of equitable principles as recognized in modern contract law.⁹⁶ Mansfield recognized the potential inequity to the contracting parties resulting from non-disclosure of material facts.

The special facts, upon which the contingent chance is to be computed, lie most commonly in the knowledge of the insured *only*: the underwriter trusts to his [applicant's] representation and proceeds upon confidence that he does not keep back any circumstances in his knowledge, to mislead the underwriter into a belief that the circumstance does not exist, and to induce him to estimate the risqué, as if it did not exist.⁹⁷

An applicant for insurance, with material genetic knowledge that the applicant knows the insurer does not know, has an obligation to disclose those material genetic facts to the insurer in the insurance contract formation process.⁹⁸ An applicant should not be allowed to take advan-

⁹⁵ *Carter v. Boehm*, 3 Burr. 1095, 97 Eng. Rep. 1162 (K.B. 1766). This case is thoroughly explained in Holmes, *supra* note 94, at 426-35.

⁹⁶ For example, the equitable principles of good faith and conscience, so important in insurance law, are recognized as contract policing principles in modern contract law. Under the heading "Considerations of Fairness and the Public Interest" in the RESTATEMENT (SECOND) OF CONTRACTS (1981) are section 205 "Duty of Good Faith and Fair Dealing" ("Every contract imposes on each party a duty of good faith and fair dealing in its performance and its enforcement.") and section 208 "Unconscionable Contract or Term" ("If a contract term is unconscionable at the time the contract is made a court may refuse to enforce the contract . . ."). See generally JOHN EDWARD MURRAY JR., MURRAY ON CONTRACTS 473-81 (3d ed. 1990) ("The fact situations requiring disclosure are myriad." *Id.* at 473).

⁹⁷ *Carter*, 3 Burr. at 1909, 97 Eng. Rep. at 1164 (emphasis added).

⁹⁸ The requirement of good faith disclosure in insurance contract formation is well-established. In his monumental insurance treatise, Professor Vance states:

tage of that undisclosed personal knowledge in purchasing insurance at an unreasonably low premium rate that subsequently will not adequately cover the applicant's claims. An applicant's bad faith non-disclosure is tantamount to fraud against the insurer and other policyholders. The result is that the equity rationale — the principle of fair discrimination — underlying risk classification is violated if an insurer raises premiums for all policyholders to cover losses, unexpected from the insurer's standpoint, but expected by the applicant.

In order to address the danger of relying on a duty to disclose genetic information, both the applicant and insurer should, instead, have equal access to all material genetic data. Allowing insurers access to an applicant's genetic tests and personal genomic information rectifies the problem of imperfect information regarding genetic risks. It renders the duty to disclose irrelevant and fairly avoids the unfairness to insurers associated with the issues addressed in the next two sections: adverse selection and incontestability clauses.

2. *Adverse Selection*

Whenever applicants for insurance are treated similarly, regardless of some risk factor or risk element that differentiates them as insurance risks, adverse selection takes place.⁹⁹ If an insurer cannot distinguish and classify high-risk from low-risk applicants, the insurer must offer all applicants the same premium for the same coverage. Low-risk applicants are then worse off and high-risk applicants are better off than in a properly functioning insurance risk classification system. If insurers are denied genetic information for purposes of risk classification, insurers will be forced to treat applicants equally rather than equitably. The result will be adverse selection because applicants will have more information about their risk of loss due to disease, illness, or medical condition than insurance companies. Adverse selection occurs when people with a greater probability of loss than reflected in their premiums buy and continue insurance coverage to a greater extent than other people. In an insurance market in which adverse selection is substantially present, low-

"If the applicant is aware of the existence of some circumstance which he knows would influence the insurer in acting upon his application, good faith requires him to disclose that circumstance, though unasked." WILLIAM R. VANCE, *HANDBOOK ON THE LAW OF INSURANCE* 372 (3d ed. 1951).

⁹⁹ For a more comprehensive discussion, see *Adverse Selection and Discriminatory Practices*, in HOLMES, *supra* note 6, § 3.5, at 361-69.

risk people “actually subsidize the insurance purchases of high risks.”¹⁰⁰

Applicants for health, disability, and life insurance are said to adversely select when they seek insurance coverage based on information in their possession which they conceal from the insurer. Consequently, an accurate assessment of risk cannot be calculated and an appropriate premium cannot be determined for those applicants. If the insurers cannot efficiently and accurately assess risks and apply rates based upon actual risks, insurers are “at risk” not only of violating state insurance laws, but also of becoming insolvent because they will not have sufficient resources to pay claims. If an insurance company does not fairly differentiate among the applicants for insurance, a disproportionately high percentage of applications will typically be submitted by people at higher risk because they will pay a lower premium. In turn, more claims for payment are submitted than would be made if there were no adverse selection. Thus, adverse selection can seriously threaten insurers’ financial stability.

The problem is inequality in knowledge between applicant-insureds and insurance companies. An applicant with knowledge of a high risk of loss will probably apply for insurance covering that high risk more than the average person. If insurers charge an equitably rated premium without knowledge of the high risk or charge an equal premium for all applicants, the high-risk person will select to apply and obtain insurance in greater proportion than low-risk people. Thereafter, the cyclical adverse consequences of that selection are set in motion.

In the first part of this cycle, the insurer must increase the premium price for insurance coverage because of unexpected claims. Second, low-risk insureds, noting the increase in premium, select to discontinue their insurance coverage. Third, the remaining pool of insured-policyholders has a higher than average risk of loss. Fourth, insurers then must again raise the premium price. Finally, either an equilibrium is reached with some of the low-risk insureds still buying the insurance, or the insurer’s risk pool entirely separates. In either situation, unless the insurer has the requisite information to distinguish, classify, and appropriately rate the high- and low-risks, low-risk people purchase less coverage and high-risk people purchase more insurance coverage.

¹⁰⁰ Hylton, *supra* note 82, at 72 n.41 (quoting Mark J. Browne & Helen I. Doerpinghaus, *Information Asymmetries and Adverse Selection in the Market for Individual Medical Expense Insurance*, 60 J. OF RISK & INS. 300, 300 (1993) (discussing empirical studies that concluded that low-risk subscribers subsidize medical insurance for high-risk subscribers)).

Avoiding adverse selection is one of the fundamental tenets on which a statistically sound, and hence fair, insurance classification system is founded. Specifically, four primary principles are recognized: (1) “[r]isk classification should reflect cost and experience differences;” (2) “[t]he system should be applied objectively and consistently;” (3) “[t]he system should be practical, cost effective, and responsive to change;” and (4) most importantly, “adverse selection should be minimized.”¹⁰¹ In order to minimize adverse selection, insurers must receive all material information including genetic information.

The potential for adverse selection increases as genetic information becomes available to insurance consumers. If an individual undergoes genetic testing and tests positive for a genetic disorder, that person may seek to buy as much insurance as is available to cover the costs of future illnesses which may later be expressed. If insurers are legislatively prohibited from requiring genetic tests and from obtaining the results of genetic tests, they may insure individuals at rates that do not reflect the true risk. Companies that specialize in biotechnology may market at-home tests which can disclose genetic disorders. If these tests are widely used, and the insurers are legislatively precluded from obtaining the same genetic information to which individuals have access, then there is a risk of widespread adverse selection based on genetic information. Carrying this scenario to its logical extreme, if individuals test negative for a variety of genetic disorders, they may elect to purchase little or no insurance, while those who test positive, and who will submit the majority of claims, will be the primary people to purchase as much health insurance as possible. This adverse selection would likely result in catastrophic failures in the insurance industry, leaving many individuals uninsured altogether.¹⁰²

3. *Incontestability Clauses*

Health, life, and disability insurance applications require applicants to answer sundry questions concerning their health, medical histories, and related

¹⁰¹ Pokorski, *supra* note 77, at 95-96.

¹⁰² The argument against adverse selection is that consumer choices depend dramatically upon insurance marketing and upon what people are told about rate increases. The importance of adverse selection is also diminished because the real issue is whether an individual can afford insurance at all. Those who can afford it can make choices. “[P]eople have enough discretionary income to buy a whole lot more health insurance or life insurance. You either have health insurance or you don’t. The difference in cost between the really good policy and the really [lousy] policy is not that much.” Reginald Rhein, *Federal Disability Law Bans Genetic Discrimination*, BIOTECHNOLOGY NEWSWATCH, May 1, 1995, at 6, available in 1995 WL 2196533 (quoting Paul R. Billings).

personal information in order to promote efficiency and fairness in risk classification as well as in rating and pricing.¹⁰³ Most insurers use this information to determine if further information should be provided by the applicant, by doctors and hospitals, or by medical tests (blood, urine, or complete physical), which foreseeably might include genetic testing. Assume an applicant has a good faith duty to disclose material facts about prior genetic testing or personally-known related genetic data, and conceals that genetic information in the application/contract formation process.¹⁰⁴ Or assume an applicant affirmatively misrepresents or omits personal genetic information. In those situations, insurers may have a garden-variety of familiar contract-vitiating defenses for fraud, non-disclosure, concealment, misrepresentation, and possibly mistake. Typically, insurers will seek rescission of the insurance contract.¹⁰⁵

¹⁰³ See *supra* Part II.B.1 (notes 94-98 and accompanying text). Applicants have an obligation to fully and fairly inform insurers of material facts affecting their risk.

¹⁰⁴ See *supra* note 96. See generally JOHN D. CALAMARI & JOSEPH M. PERILLO, *THE LAW OF CONTRACTS* 366-71 (3d ed. 1987) (discussing situations in a bargaining transaction where there is a duty, predicated on community expectations of good faith and fair dealing, to disclose information to the other party).

¹⁰⁵ See, e.g., *Slevin v. Amex Life Assur. Co.*, 695 F. Supp. 712 (E.D.N.Y. 1988) (granting summary judgment because the applicant's failure to disclose his history of venereal diseases was a material misrepresentation as a matter of law); *Zachary Trading Inc. v. Northwestern Mut. Life Ins. Co.*, 668 F. Supp. 343, 347 (S.D.N.Y. 1987) (holding that an applicant with AIDS who failed to disclose two prior visits to physicians had committed a material misrepresentation entitling the insurer to summary judgment on its rescission counterclaim). In some jurisdictions, if misrepresentations are material, it makes no difference whether the applicant acted fraudulently, negligently, or innocently. See, e.g., *William Penn Life Ins. Co. v. Sands*, 912 F.2d 1359, 1361-62 (11th Cir. 1990) (holding that, under Florida law, material misrepresentation in an insurance policy application provides the basis for rescinding an insurance contract even when the applicant could not have known the information was incorrect or inaccurate); *Elder v. SMA Life Assur. Co.*, 1990 U.S. Dist. Lexis 4030 (D. Or. Mar. 30, 1990) ("There is no requirement in O.R.S. § 742.013(1) that Elder's misrepresentations be 'intentional' in order to preclude recovery by Elder" under a disability income insurance policy. *Id.* at *5); *Guardian Life Ins. Co. v. Tillinghast*, 512 A.2d 855, 859 (R.I. 1986) (holding that a material misrepresentation, even if innocently made, may provide a basis for rescinding a contract); *Hendren v. Allstate Ins. Co.*, 672 P.2d 1137, 1140 (N.M. App. 1983) (holding that insurer's misrepresentation, whether fraudulent or negligent, may allow rescission). For further

In many cases, however, the insurer is contractually barred from seeking to vitiate the insurance contract. All life insurance, and many health and disability insurance policies, contain "incontestability clauses."¹⁰⁶ These clauses, which are typically prescribed by state insurance statutes or insurance regulations,¹⁰⁷ prevent insurers from asserting contract-vitiating defenses and disputing the validity of a policy after it has been in effect for two years. Practically speaking, contractual incontestability provisions¹⁰⁸ create a type of contractual two-year statute of limitations during which insurers must uncover an applicant's fraud or bad faith in the contract formation process. Insurance companies have a two-year period during which they must raise any potential contract-vitiating defenses. Thus, incontestability clauses not only foster

discussions regarding the legal effect of an applicant's undisclosed knowledge of the true state of his/her health or physician, see ROBERT E. KEETON & ALAN I. WIDISS, *INSURANCE LAW* § 5.7, at 570 (1988) (discussing whether the insurer must prove fraudulent intent of insured in order to obtain rescission).

¹⁰⁶ Incontestability means that the insurer is foreclosed from legally contesting the insurance policy's validity and that the policy stands as is. *Northwestern Mut. Life Ins. Co. v. Johnson*, 254 U.S. 96, 101-02 (1920) (Holmes, J.) (explaining the clause's object is "to create an absolute assurance of the benefit, as free as may be from any dispute of the fact except the fact of death, and as soon as it can reasonably be done."). As insurance law students well know, interpreting the effect of the clause, beyond its precluding contract formation defenses, can be an enigmatic and perplexing exercise. The best instruction in the legal literature for understanding what is incontestable is written by my insurance casebook co-author, William F. Young Jr., *Incontestable — As to What?*, 1964 ILL. L. F. 323 (1964) (comparing advantages and disadvantages of incontestability clauses). For an excellent explanation of the history, scope, purposes, and problems of incontestability clauses, see JERRY, *supra* note 14, at 701-12. "Incontestability clauses do not need to be as broad in health insurance policies because, unlike the situation in life insurance, the insured under a health policy usually survives and is able to testify and take other steps to protect his or her interests when the insurer denies coverage." *Id.* at 702.

¹⁰⁷ For citations to each state's legislation, see Eric K. Fosaaen, Note, *AIDS and the Incontestability Clause*, 66 N.D. L. REV. 267, 270 n.27 (1990).

¹⁰⁸ An excerpt from an incontestability clause is as follows: "The validity of this policy shall not be contested, except for the nonpayment of premiums, after it has been in force for two years from the date of issue." This language is from a policy litigated in *Crawford v. Equitable Life Assur. Soc.*, 305 N.E.2d 144, 147 (Ill. 1973) (insurer's defense based on insured's non-eligibility for employer-provided group insurance plan, due to her lack of status as an employee, was not foreclosed by incontestability clause even after two year period).

a moral hazard of fraud but also unfairly require insurers to pay claims that should not be paid. Fraudulent insureds are rewarded for their misconduct by paying an unfairly low premium, while honest insureds pay an unfairly high premium. The effect on underwriting and insurance pricing, therefore, is similar to adverse selection. The untoward, unfair effects of incontestability clauses can be avoided by granting insurers equal access to an applicant's genetic information.

In summary, many genetic disorders can be detected many years before their expression. Consequently, where an applicant had knowledge of personal genetic information regarding medical diseases and conditions which would affect insurability or premium rates and did not fairly share this information with the insurer at the time of application, these incontestability clauses may later prevent an insurer from claiming bad faith non-disclosure or even fraudulent misrepresentation.¹⁰⁹ In fairness to insurers and other policyholders, such an applicant should be required to disclose that information or provide insurers reasonable access to obtain it. Required disclosure of genetic testing data thereby would eliminate problems associated with imperfect information and provide a fairly priced product of insurance for all applicants.

C. *State Insurance Law Requires Insurers to Use Genetic Information to Achieve State-Mandated Fair Discrimination*

Prior to the McCarran-Ferguson Insurance Regulation Act of 1945 (the "McCarran Act"),¹¹⁰ competition was essentially the only method for assuring that rates were fair and nondiscriminatory. The McCarran Act was a compromise which, in effect, recognized the supremacy of states to regulate the business of insurance. A few years after the passage

¹⁰⁹ See, e.g., *Blue Cross & Blue Shield of Ga., Inc. v. Sheehan*, 450 S.E.2d 228 (Ga. App. 1994) (holding that, although insured lied on his application that he was not HIV-positive, incontestability clause barred insurer's rescission). Some states, however, provide that fraudulent misstatements in individual accident and health insurance applications are excepted from the application of the incontestability clause. See, e.g., N.Y. INS. LAW § 3216 (d)(B)(i) (1995) ("After two years from the date of issue of this policy no misstatements, except fraudulent misstatements, made by applicant in the application for such policy shall be used to void the policy . . .").

¹¹⁰ McCarran-Ferguson Insurance Regulation Act of 1945, Pub. L. No. 79-15, 59 Stat. 33 (1945) (codified as amended at 15 U.S.C. §§ 1011-1015 (1996)). The McCarran Act is discussed at *infra* Part IV.A (notes 218-38 and accompanying text).

of the McCarran Act, there was widespread state adoption of model regulatory legislation, prepared through the joint efforts of state insurance departments and insurance industry committees. The legislation contained strictures against deceptive practices, unfair methods of competition, and excessive, inadequate, and unfairly discriminatory rates. The acts are sometimes referred to as the "All Industry laws," and were avowedly designed as an "umbrella" against federal intervention. Congressional committees, federal agencies, and others have inveighed repeatedly against various shortcomings in state regulation. Nonetheless, the settlement achieved in the McCarran Act has proven to be surprisingly durable on the whole. In the insurance/genetic debate, insurers continue to support the McCarran compromise and the supremacy of state regulation of the business of insurance.

As a result of the All Industry laws, fairness and equity are now an integral and regulated aspect of insurance underwriting.¹¹¹ In addition to assuring insurer solvency and preventing contractual overreaching, one significant objective of state insurance regulation is to require fair, equitable, and nondiscriminatory rating classifications. This objective is achieved by regulation fashioned to produce premium rates which are equitable to all insureds while providing insurers with a fair return for the risks underwritten. Fair discrimination under states' unfair discrimination statutes is required, giving rise to insurance risk classifications that differentiate between individuals. The history of state unfair discrimination statutes is evidence of public support for the equitable treatment of applicants/insureds premised upon differentialization in statistical association with loss — in other words, actuarial fair discrimination.¹¹²

The central question of what is fair discrimination is answered by the Unfair Trade Practices Act ("UTPA" or the Act), which was developed by the National Association of Insurance Commissioners ("NAIC") and enacted by all states, in some form, by 1960.¹¹³ For life insurance

¹¹¹ However, there has historically been "relatively little regulation of life, health and accident insurance policy forms and even less regulation of life, health and accident insurance rates." R. KEETON, BASIC TEXT ON INSURANCE LAW 558 n.2 (1971). An untoward result is that it is extremely difficult for the ordinary consumer to make price comparisons. See, e.g., Spencer L. Kimball & Werner Pfennigstorf, *Administrative Control of the Terms of Insurance Contracts: A Comparative Study*, 40 IND. L.J. 143, 214-15 (1965).

¹¹² Stanford Research Institute Final Report 49, cited in U.S. GENERAL ACCOUNTING OFFICE, ISSUES AND NEEDED IMPROVEMENTS IN STATE REGULATION OF INSURANCE 117-19 (1979).

¹¹³ For a current version of the NAIC UTPA, see NAIC MODEL LAWS,

contracts, the UTPA prohibits any insurer from “making or permitting any unfair discrimination between individuals of the same class and equal expectation of life in the rates charged for any life insurance policy or annuity.”¹¹⁴ For health insurance, the UTPA has a similar provision that proscribes “unfair discrimination between individuals of the same class and of essentially the same hazard.”¹¹⁵ Since differentiation is the linchpin of underwriting, pricing, and selling insurance, the litmus test is to ascertain what types of differentiation are fair. The UTPA’s answer is to distinguish between fair and unfair discrimination, and then prescribe fair discrimination and proscribe unfair discrimination.

State insurance statutes, modeled on the UTPA, compel fair discrimination in certain areas and prohibit unfair discrimination in other areas. For example, the Act deems it inequitable to charge the same premiums for life insurance to a fifty-year-old man in poor health and a twenty-year-old woman in good health.¹¹⁶ To charge an *equal* premium would be *inequitable*. Therefore, insurers are required by the UTPA to discriminate fairly between the two people to determine an equitable premium. “[R]ates should be *adequate* but not excessive and should *discriminate* fairly between the insureds. . . . so that each insured will pay in accordance with the quality of his risk.”¹¹⁷ By requiring adherence

REGULATIONS AND GUIDELINES 880-1 (1996). For an extended description of the McCarran Act and the development of state unfair practices acts, see *infra* Part IV.A (notes 218-38 and accompanying text). Some states make HMOs subject to their TPA. See, e.g., COLO. REV. STAT. §§ 10-3-1102(2) and 10-3-1110(3) (1996) (including HMOs in the definition of “person” under the unfair competition deceptive practices statute).

¹¹⁴ NAIC, *supra* note 113, § 4.G(1).

¹¹⁵ *Id.* § 4.G(2).

¹¹⁶ See, e.g., *Langan v. U.S. Life Ins. Co.*, 130 S.W.2d 479, 483 (Mo. 1939) (Missouri’s unfair trade practices statute declares a “legislative policy that the older the applicant the more he shall pay for a given amount of insurance”).

¹¹⁷ Bailey et al., *supra* note 87, at 782 (quoting ANDREW MOWBRAY ET AL., INSURANCE 411 (6th ed. 1969)). All three authors are listed as counsel for Bankers’ Life Company as of the publication date. This influential article gave academic authenticity to the insurance industry’s rationale of fair discrimination, justifying differentiation and classification of risks so that each insured person will pay according to the quality of his/her risk. Of course, this rationale is valid only if one accepts that the notion that “each policyholder pays only for himself or herself” comports with the true nature of insurance. The rationale ignores the fundamental insurance characteristic of risk distribution — the idea that losses from fortuitous risk of loss are pooled and shared. For instance, if you pay for a one-year health insurance policy and make no claims under it, you will have

to actuarially sound classification systems, state unfair trade practices statutes help assure that insurance companies are not rendered financially unsound due to an improper risk classification.

State versions of the UTPA explicitly require discrimination, when fair, in the issuance of insurance policies. Indeed, the risk classification system is a frank expression of such discrimination. On the other hand, unfair discrimination is proscribed.¹¹⁸ Unfairness in the insurance context occurs when equal risks are treated differently or unequal risks are treated equally. As a New York court explained:

[D]ifferential premium rates on the basis of sound underwriting practices accurately assessing risks/future costs are not by nature misleading to the public or prejudicial to policyholders. Indeed, valid underwriting practices promote fairness to the policyholder in not requiring him or her to bear in the premiums the costs of insuring others in higher risk categories, and solvency of the insurer, another goal of insurance regulation.¹¹⁹

paid for the claims that other policyholders made during that year. In other words, pooling and sharing the risk of loss is also at the heart of insurance; and that is also fair.

¹¹⁸ It may be difficult, however, to set equitable rates under a UTPA regime that disallows “unfairly discriminatory” insurance premiums. *See, e.g.,* Spencer L. Kimball, *The Purpose of Insurance Regulation: A Preliminary Inquiry in the Theory of Insurance Law*, 45 MINN. L. REV. 471, 495-98 (1961).

¹¹⁹ *In re Health Ins. Ass’n v. Corcoran*, 551 N.Y.S.2d 615, 618-19 (N.Y. App. Div.) (The court unanimously struck down a New York regulation which prohibited insurers from testing applicants for individual, and small group, health and accident insurance policies to determine if they were infected with the HIV virus. The court held that the Insurance Superintendent exceeded his authority by substituting legislatively recognized insurance principles of fair risk classification with his own vision of societal policy choices. The New York Court of Appeals unanimously affirmed.), *aff’d*, 565 N.E.2d 1264 (N.Y. 1990); *see also* *Life Ins. Ass’n v. Comm’r of Ins.*, 530 N.E.2d 168, 171-72 (Mass. 1988) (The court struck a regulation similar to that struck in *Corcoran*. The court stated: “The basic principle underlying [Massachusetts’ unfair trade practices act] governing underwriting practices is that insurers have the right to classify risks and to elect not to insure risks if the discrimination is fair.”); *Physicians Mut. Ins. Co. v. Denenberg*, 327 A.2d 415, 420 (Pa. 1974) (holding that health insurance policy provisions providing an annual monthly premium of \$1, regardless of insurance coverage or risk of insured, were actuarially unsound and constituted unfair discrimination under Pennsylvania’s unfair trade practices statute).

In other words, unfair discrimination occurs, from the insurance industry's point of view, when there is no sound actuarial justification for the manner in which risks are classified. For example, charging blue-eyed insurance applicants a higher premium than brown-eyed applicants is unfair discrimination because there is no recognized actuarial, medical, or scientific basis for such differentiation and classification.

In addition to assuring insurers of adequate funds to pay losses and their administrative costs and eliminating excessive profits, one specific purpose of state rate regulation is to prevent discriminatory rates. "In other words, the regulation of premium rates is generally intended to assure that an insurer's income is adequate to cover the risks (with a reasonable margin) without being either excessively expensive for the purchasers or unfairly discriminatory among purchasers."¹²⁰ In that economic sense, unfair discriminatory rates occur when one insured pays too much and another pays too little. In other words, grouping high-risk insureds with low-risk insureds and charging all an equal premium is unfair discrimination because the low-risks pay too much and subsidize the high-risks who pay too little. The apparent solution is to equalize the difference by creating as many rating classifications of insureds as feasible, thereby achieving actuarial fairness. Providing insurers access to applicants' genetic information will accomplish that state-mandated goal. However, the more rating classifications an insurer creates, the higher the insurer's administrative and overhead costs, and the higher the premiums for all insureds to cover these costs. Another apparent solution is to fairly balance the difference by creating just enough rating classifications to minimize both the subsidy by low-risk insureds and the administrative costs.

In summary, insurers have a responsibility under the UTPA to treat all their policyholders fairly by setting premiums at a level consistent with the risk presented by each individual insured. Upon completion of the HGP, genetic information will become available and insurers will be required to use this information under the states' versions of the UTPA to fulfill the statutory mandate of fair discrimination. Those individuals who have a documented genetic disorder are not of the same class as those who do not have such a genetic disorder, and thus when the risks are not equal it would be unfair discrimination to the latter group to charge them the same insurance rates as those charged to the former

¹²⁰ KEETON & WIDISS, *supra* note 105, at 955. For an excellent discussion of the history, objectives, and methods of insurance rating and regulation, see *id.* at 954-67.

group. Sound and fair actuarial underwriting principles necessitate the consideration of genetic information in classifying and underwriting risk.¹²¹ Therefore, to avoid violating the states' versions of the UTPA, health insurers must require and use genetic testing of applicants in the insurance contract-formation process.

D. Insurers Will Fairly Use Genetic Tests in Risk Rating

The foundation of private health insurance is risk rating. Through competition, risk rating should be fair and should give policyholders the best value for their money. "However, with half of all expenses incurred by 5% of the population and 70% of all expenses incurred by 10% of the population, risk rating can be both highly profitable and highly injurious to its victims."¹²² Direct risk rating is a method used by health insurers to document the medical problems or risks people have, and to address those risks in one of several ways. First, an insurer can elect to charge a higher premium for certain medical conditions.¹²³ Alternatively, an insurer can write exclusion clauses within a policy so that any costs arising from pre-existing conditions are not covered.¹²⁴ Finally, the insurer can elect to deny coverage altogether.¹²⁵

¹²¹ For instance, OHIO REV. CODE § 3923.021 (1996) makes rate increases for non-group health and accident policies subject to review by the Superintendent of Insurance. Absent evidence that the rates were not calculated in accordance with sound actuarial principles, the Superintendent must find that the benefits are not unreasonable in relation to the premium charged and must approve the rate increase. *See Community Mut. Ins. Co. v. Fabe*, 556 N.E.2d 1155, 1160-61 (Ohio 1990) (holding that the Superintendent has no authority to object to a rate increase if it meets sound actuarial principles). Similarly, Washington requires insurers to practice "equity" in all insurance matters. WASH. REV. CODE § 48.01.030 (1994).

¹²² Donald W. Light, *The Practice and Ethics of Risk-Rated Health Insurance*, 267 JAMA 2503, 2503 (May 13, 1992).

¹²³ *Id.* at 2504. An insurer may charge a higher premium for: allergies, asthma, back strain, controlled hypertension, arthritis, gout, glaucoma, obesity, mild psychoneurosis, kidney stones, mild to moderate emphysema, alcoholism/drug use, heart murmur, peptic ulcer, and colitis. *Id.*

¹²⁴ *Id.* An insurer may write an exclusion waiver for: cataract, gallstones, a uterine fibroid tumor, a hiatal or inguinal hernia, migraine headaches, pelvic inflammatory disease, recent chronic otitis media, spine/back disorders, hemorrhoids, knee impairment, asthma, allergies, varicose veins, chronic or severe sinusitis, and fractures. *Id.*

¹²⁵ *Id.* An insurer may totally deny coverage for: AIDS, ulcerative colitis,

Insurers have specified at least eight conditions that must be met before they will consider using a medical test in risk classification:

(1) the test must supply information in addition to information otherwise available from other sources (e.g., from a medical questionnaire), (2) the disease of interest must have serious morbidity and/or mortality implications, (3) the disease must be common enough to ensure that the test is predictive and that the cost can be justified, (4) the test must be predictive of disease (or absence of disease) and reliable, (5) the test must be understood, accepted and used by the medical profession, (6) laboratories must be able to readily perform the test, (7) the test must be affordable and able to provide results quickly, (8) the test must be risk free.¹²⁶

The American Academy of Actuaries has indicated how these conditions are interpreted:

Insurers will want to know (1) whether the test improves the equity of the risk classification by more accurately assigning individuals to appropriate risk classes, and (2) whether the test enhances value to the consumer by keeping insurance costs low and product availability high for the great majority of insurance applicants.¹²⁷

The results of a survey conducted by the U.S. Office of Technology Assessment of fifty-one commercial health insurers, over twenty-seven Blue Cross/Blue Shield plans, and twenty-three HMOs provides evidence of the potential detrimental effect of "imperfect information," such as insurers not knowing the results of genetic testing of applicants when

cirrhosis of the liver, diabetes mellitus, leukemia, schizophrenia, uncontrolled hypertension, emphysema, stroke, severe obesity, severe angina, coronary artery disease, epilepsy, lupus, and alcoholism/drug abuse. *Id.*

¹²⁶ T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification? Arguments Both for and Against the Use of this New Technology May Be "Right," and Some Form of Universal Health Care May Be the Result*, 60 DEF. COUNS. J. 249, 252 (1993); see U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC TESTS AND HEALTH INSURANCE: RESULTS OF A SURVEY 141, OTA-BP-BA-98 (1992) [hereinafter GENETIC TESTS AND HEALTH INSURANCE].

¹²⁷ Cushing, *supra* note 126, at 252 (citing Robert Pokorski, *Genetic Testing in Private Insurance — Bridging the Gap Between New Knowledge and Its Application*, CONTINGENCIES, Sept./Oct. 1990, at 20).

determining risk classifications.¹²⁸ According to the survey, sixty-seven percent of the commercial insurers, seventy percent of the HMOs, and approximately sixty percent of the Blue Cross/Blue Shield plans stated that the widespread availability of genetic tests, with concurrent restraints on insurers' access to the results, would likely have a negative financial effect on their business.¹²⁹ In addition, seventy-four percent of the HMOs' responses asserted that carrier status for mono-genetic conditions, such as Huntington's disease or cystic fibrosis, are statistically considered to be pre-existing conditions and must be taken into consideration.¹³⁰ The bottom line of this survey suggests that personal and family medical histories are probably the most meaningful factors in ascertaining insurability.¹³¹ Thus, genetic tests, along with more traditional medical questionnaires and tests, are essential in providing insurers with medical history for statistically fair evaluation of all applicants for health insurance.

E. Genetic Testing Conforms to Current Underwriting Practices and Will Not Affect an Applicant's Ability to Obtain Insurance

Insurers do not expect that genetic information will affect many people's access to private health, life, and disability insurance.¹³² First, the cost of genetic testing and mapping may be too high for insurers to use these techniques routinely. Insurers are not likely to require genetic tests that cost several hundred dollars or more per applicant if the total cost of all tests for all applicants will exceed the loss from additional risks of a small number of applicants. Second, most health insurance and forty percent of the life insurance obtained in the United States is obtained by large groups of employees from their employers. Insurers do not customarily undertake individual underwriting or testing in connection with employer-provided large-group insurance. Thus, most insureds will be unaffected. Third, for the smaller group of individuals applying for private health insurance policies, insurance companies will have little reason for generally requiring genetic tests. Of the individuals who are

¹²⁸ GENETIC TESTS AND HEALTH INSURANCE, *supra* note 126, at 31.

¹²⁹ *Id.*

¹³⁰ *Id.* at 32.

¹³¹ *Id.* at 33.

¹³² R. Steven Brown, *The Impact of Advances in Genetics on Insurance Policy*, in COUNCIL OF STATE GOVERNMENTS, ADVANCES IN GENETIC INFORMATION: A GUIDE FOR STATE POLICY MAKERS 42, 57 (Steven R. Brown & Karen Marshall eds., 2d ed. 1993).

tested, some will have their eligibility adversely affected while others will be positively affected if, for instance, the test reveals no deleterious genetic conditions. Fourth, and finally, a considerable amount of genetic information is presently obtained through means other than DNA-based genetic tests. These non-DNA genetic tests include biochemical tests, chromosome examinations, and physical examinations.¹³³

Genetic testing is not radically different from the many other tests which are currently performed by physicians and to which insurers have access. The information these tests provide to health, life, and disability insurers is similar to that attributable to medical questionnaires currently in use and upon which coverage is limited or denied with actuarial justification. Many current tests also predict future diseases and illnesses. But, on balance, most applicants will be found to present an average risk, with a few at lower risk and a small number of applicants at a higher risk.

F. Analogous Employment Discrimination Based on Genotype Is Fair

Employment discrimination has long been legally, ethically, and socially acceptable. Employers differentiate, or discriminate, routinely among job applicants with differing educational, intellectual, and experiential qualifications. While invidious discrimination — discrimination based on race, color, religion, sex, national origin, age, or disability — is illegal, employers may fairly discriminate based on other genetic characteristics. In other words, employers may hire and retain individuals predicated on occupationally-relevant physical and character traits which are largely dictated by genetics. When an employer refuses to hire an individual because that person lacks certain relevant physical qualifications, or conversely, when an employer prefers one individual over another because of physical characteristics, the employer has discriminated based on factors which are, in part, genetically controlled.

Data suggest that many employers would use test results indicating employee propensities to certain diseases to limit, but not deny, the company's health care liability. These statistically fair limitations could be effected through exclusions from insurance coverage of pre-existing conditions, waivers of specific disease coverage, or caps on pay outs.¹³⁴ The rising cost of health care has significantly increased employer health

¹³³ *Id.*

¹³⁴ Paul R. Billings et al., *Discrimination as a Consequence of Genetic Screening*, 50 AM. J. HUM. GENETICS 476 (1992).

insurance costs,¹³⁵ and these costs have continued to increase at least ten to twenty percent per year.¹³⁶ This trend has pressured employers to reduce health care expenditures. In response, employers have attempted to limit the number of employees who are high-cost users of health care such as cigarette smokers, HIV positive individuals, and those with high cholesterol.¹³⁷ Employers have, in many cases, virtually assumed the role of the insurance companies and have a strong financial incentive to reduce their health care expenditures by more accurately assessing health risks.¹³⁸ The cost of providing medical care has drastically changed. More sophisticated forms of diagnostics and specialized treatments translate into high medical bills for some individuals, especially when compared with expected low medical expenses for a healthy individual.¹³⁹

In other words, employers may control their premiums for large-group experience rated health insurance policies or the costs of self-insurance by discriminating against genetically high-risk individuals in the hiring process. If employers are allowed to discriminate in this manner, it would be inequitable to not allow insurers to create fair risk ratings based on genetic information.

III. ARGUMENTS AGAINST INSURERS' USE OF GENETIC TESTING INFORMATION

Insurers compellingly argue that they should not be legislatively prohibited from including genetic test results in their actuarial assessment and classification of risk. Equally compelling, however, are the arguments against insurers' use of genetic information. Those who oppose the use of genetic testing data base their case on a variety of considerations, including: the need for fairness in risk distribution; the availability of insurance; the danger of discrimination, abuse, and stigmatization of individuals with genetic diseases and their relatives; concern over confidentiality of genetic information; the desire to protect an individual's right not to know his or her genetic profile; the preservation of individual

¹³⁵ MARK A. ROTHSTEIN, *MEDICAL SCREENING AND THE EMPLOYEE HEALTH COST CRISIS* 4 (1989) (discussing how medical screening procedures may be implemented by employers as health care costs control measures).

¹³⁶ A. Foster Higgins & Co., *Indemnity Plans: Cost, Design and Funding*, *MED. BENEFITS*, Feb. 28, 1991, at 3.

¹³⁷ See ROTHSTEIN, *supra* note 135, at 63, 84.

¹³⁸ See Ford, *supra* note 79, at 124.

¹³⁹ *Id.* at 125.

autonomy regarding genetic information; and the absence of absolute reliability, accuracy, and predictability based on genetic testing for sound actuarial risk classification.

A. Use and Availability of Genetic Testing Information Is Subject to Abuse

One compelling argument in opposition to insurers' use of genetic information is that it would produce essentially unfair discrimination and unfair results.¹⁴⁰ Injecting genetic risk information into insurance underwriting will result in ever more refined classifications and ratings, thereby increasing the difficulty for many applicants in obtaining affordable health and health-related insurance coverages. If insurers either have access to the results of genetic tests already performed, or are permitted to require genetic tests as a pre-condition to insurability, then those individuals who have the least need for health insurance will be eligible to obtain comprehensive coverages at reasonable rates. Those individuals who test positive for the presence of a defective gene will either be denied insurance; or they will be offered an exclusion or coverage limited by a low maximum financial limit, a cap, for treatment of the genetic defect; or they will be unable to afford the premiums. The critical issue, therefore, is whether society prefers a system where the only individuals allowed to purchase reasonably priced health and health-related insurance coverages are those who were born with "healthy genes." Allowing insurers either to mandate genetic testing of applicants or to have access to an applicant's voluntary genetic tests can lead to abuses that will result in unfair discrimination.¹⁴¹

Recently, state legislatures have acknowledged such abuses. In conjunction with its 1996 Genetic Privacy Act, the Virginia legislature made the following findings of fact:

¹⁴⁰ See, e.g., Cowley, *supra* note 4. One definition of genetic discrimination is "discrimination directed against an individual or family based solely on an apparent or perceived genetic variation from the 'normal' human genotype." Billings et al., *supra* note 134, at 476 (applying this definition to a survey on genetic discrimination).

¹⁴¹ Lori B. Andrews, *Public Choices and Private Choices: Legal Regulation of Genetic Testing*, in JUSTICE AND THE HUMAN GENOME PROJECT 46, 56 (Timothy F. Murphy & Marc A. Lappé eds., 1994); see also E. Brom Marne, Note, *Insurers and Genetic Testing: Shopping for that Perfect Pair of Genes*, 40 DRAKE L. REV. 121, 133 (1991) (describing insurer use of genetic test information).

[N]umerous accounts of anecdotal information from around the country have been provided to the committee to indicate that there is a great potential for misuse of genetic information, especially in the field of health insurance; . . . [T]he presence of a genetic marker does not imply that the carrier will ever develop the disease but only that the person has a higher predisposition to such malady, thereby giving rise to the term 'asymptomatic ill;' . . . [T]here are persons who have lost health care coverage because a member of their family developed a disease for which a genetic marker has been identified, thereby potentially increasing their risk of developing the disease, persons who have lost coverage because of an inherited condition that was declared to be a previously preexisting condition, and persons who were denied coverage for certain members of their family who were determined to have a genetic predisposition for a certain condition¹⁴²

The New Jersey 1996 Genetic Privacy Act made a similar finding: "The improper collection, retention or disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance."¹⁴³

Indeed, the popular press is replete with examples of such insurer abuse.¹⁴⁴ The National Institutes of Health task force on genetic infor-

¹⁴² Virginia Senate Joint Resolution Bill No. 50, Va. 1996 session, 1996 Va. S.J.R. 50 (adopted Mar. 4, 1996). The Virginia legislature established a "Joint Subcommittee to Study the Legal and Policy Ramifications of Genetic Research [and] review existing and new Virginia law on genetic information and privacy." *Id.* Concurrently, Virginia enacted a Genetic Privacy Act, VA. CODE ANN. § 38.2-508.4 (Michie 1996 Supp.), signed by the governor on March 6, 1996, which established a two-year moratorium on health insurers' use of genetic information.

¹⁴³ N.J. REV. STAT. § 178:30-12(2)(C) (1996).

¹⁴⁴ In Boston, a woman with a family history of Huntington's disease made 13 unsuccessful applications for health insurance before the test showed she hadn't inherited the gene "She couldn't even get insurance for her children" These are some of the "unbelievable things" confronting people at risk for serious diseases with genetic origins "I would think that people who have [genes predisposing them to breast or colon cancer] have a hell of a lot to worry about in terms of insurability and employability," said Dr. Ellen Clayton, a pediatrician and lawyer at Vanderbilt University in Nashville. "I think you'd have to be nuts to let anybody know about it."

mation and insurance reported cases of genetic discrimination and recommended: "Information about past, present or future health status, including genetic information, should not be used to deny health care coverage or service to anyone."¹⁴⁵ Studies have shown that applicants who are asymptomatic are being rejected by insurers when it is revealed that a genetic disorder is present.¹⁴⁶ In a survey of genetic information, Dr. Paul Billings found thirty-two cases of unfair genetic practices.¹⁴⁷ These anecdotes "do not necessarily show the prevalence of discriminatory practices by insurers, and insurers have challenged the research methodology used in such surveys."¹⁴⁸ However, proponents of these studies point out that the studies do not necessarily document the complete range of prejudices faced by those people considered as having defective or abnormal genes.¹⁴⁹ Research by the Office of Technology Assessment ("OTA") of the U.S. Congress uncovered examples of people being denied health insurance coverage based on their genotype.¹⁵⁰ Moreover, the OTA reported that approximately thirty percent of

Richard Saltus, *Fear of Insurers Leading to Gene Testing in Secret*, BOSTON GLOBE, Sept. 12, 1994, at 1-2 (discussing the trend of secret gene testing).

"Joshua is a healthy, normal two-year-old Joshua has been diagnosed as suffering from an inherited disorder called polycystic kidney disease The disease . . . usually doesn't cause health problems before adulthood Yet when Joshua's father changed jobs, the new employer's health insurer wouldn't cover the child Joshua's case illustrates an issue usually raised only by experts gazing darkly into crystal balls and foreseeing the classification of people by their genes. A number of similar cases have surfaced . . . [which may foretell] 'a big problem 10 years from now, when we have 100 tests for genetic diseases. Such tests could put millions of people into high-risk disease categories, branding them for insurance and employment purposes'"

David Shipp, *Health: Genetic Testing May Mark Some People as Undesirable to Employers, Insurers*, WALL ST. J., July 9, 1990, at B1 (quoting Philip Reilly, head of Boston's Shriver Center for Mental Retardation, who argues that people are being singled out based on genetic test results).

¹⁴⁵ REPORT, *supra* note 45, at 9.

¹⁴⁶ Billings et al., *supra* note 134, at 478.

¹⁴⁷ *Id.* at 476; *see also infra* note 158.

¹⁴⁸ Brown, *supra* note 132, at 52.

¹⁴⁹ *Id.*

¹⁵⁰ U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, CYSTIC FIBROSIS AND DNA TESTS, IMPLICATIONS OF CARRIER SCREENING 200, OTA-BA-532 (1992).

Americans indicated that someone in their immediate family has remained at a job because of concerns related to the preservation of their health care coverage.¹⁵¹ In another instance, soon after the development of a test for fragile X syndrome, a form of inherited mental retardation, there were at least twelve cases in which families carrying the fragile X gene were refused health insurance.¹⁵² They were denied coverage despite the fact that the individuals were asymptomatic and the fragile X mutation can result in normal children for many generations.¹⁵³

Perhaps this abuse is best summarized in the words of Theresa E. Morelli, an attorney, describing her experience with genetic discrimination:

I have had problems getting insurance although I am a young, healthy, and productive attorney. Because my then-employer did not provide disability income insurance coverage, I purchased my own policy in 1990. I completed an application, had a medical examination, signed an authorization for the release of my medical records, and paid my premium. More than one month later and without any prior notice, the insurer returned my premium without giving me a reason. I wrote the home office, and an underwriter informed me of the reason for the denial: my father may have Huntington's Disease (HD), a hereditary illness. I remember that the application did not ask if I had a genetic disorder or was at risk for one. The insurer got my father's diagnosis from my doctor. I was angry and upset. The insurer did not offer to exclude coverage for HD should I inherit it. The insurer did not even offer me coverage at a higher rate. Rather, the insurer denied me coverage absolutely.¹⁵⁴

The foregoing examples of insurers abusing genetic information in underwriting will suffice here; but there are many other examples of "eligibility denial" and other insurer misuses of genetic information.¹⁵⁵

¹⁵¹ *Id.* at 192.

¹⁵² *Fragile X Gene Sparks Hope for Mass Screening; Fear of Discrimination*, BIOTECHNOLOGY NEWSWATCH, Nov. 16, 1992, at 14, available in 1992 WL 2512940, at 2 (discussing a new test which would make mass screening for mental retardation possible).

¹⁵³ *Id.*

¹⁵⁴ Theresa E. Morelli, *Genetic Discrimination by Insurers: Legal Protections Needed From Abuse of Biotechnology*, HEALTH SPAN, Sept. 1992, at 8.

¹⁵⁵ See, e.g., Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L.

In sum, insurers should be legislatively prohibited from using genetic tests in the same ways that they use currently available diagnostic tests. There is a noteworthy difference between tests which indicate the presence of genes which may, at some future time and under specific conditions, cause a disease, and medical tests which reveal the existence of an extant disease or a physical condition. For example, if an individual is examined by a cardiologist and is found to have an elevated cholesterol level and a poor result on an exercise EKG, the medical report may indicate that she is at high risk for a heart attack. If she then applies for health insurance, she may be denied coverage based on this information. This decision would be based on sound actuarial analysis. Alternatively, assume that through the efforts of the HGP the familial gene for heart disease is located. Another individual might undergo a test for this gene because he has a family history of heart disease. If he tests positive for this gene, but he is a healthy individual, he should not be denied health insurance based solely on the fact that he possesses this gene. Insurers should not be permitted to deny this individual health insurance, especially in light of the fact that heart disease, like many diseases, is known to be multifactorial, and family history is but one of many factors associated with actual heart disease. This individual may choose to alter his lifestyle, diet, exercise, and alcohol consumption with the knowledge that the gene is present, and his actions may help prevent the onset of heart disease.

Finally, commercially available genetic tests do not meet the conditions customarily required by insurers to consider medical tests in the assessment and classification of risk.¹⁵⁶ Current genetic tests: "(1) are still experimental, (2) [are] expensive, (3) yield information of uncertain applicability and (4) do not provide any significant additional information beyond that which insurers can get from an applicant's medical history questionnaire."¹⁵⁷ Despite these limitations, some insurers are currently using genetic information to deny health and life insurance.¹⁵⁸ Genetic tests, at this early stage, can offer insurers no

& MED. 109, 115-19 (1991) (analyzing Office of Technology Assessment reports on genetic screening in the workplace). For additional examples, see also Brown, *supra* note 132, at 51-53.

¹⁵⁶ See *supra* notes 126-31 and accompanying text.

¹⁵⁷ Cushing, *supra* note 126, at 252; see GENETIC TESTING COMMITTEE TO THE MEDICAL SECTION OF THE AMERICAN COUNCIL OF LIFE INSURANCE, POTENTIAL ROLE OF GENETIC TESTING IN RISK CLASSIFICATION 21 (1989).

¹⁵⁸ See *supra* notes 140-44. See also Paul R. Billings, *The Context of Genetic Screening*, 64 YALE J. BIOLOGY & MED. 47, 50 (1991). While at the Clinic for

more information than they could already obtain by requesting a detailed family history. Until genetic testing can be shown to be significantly relevant from an actuarial standpoint, these tests cannot be said to be the equivalent of contemporary testing methods which are currently available to physicians.

B. Unfair Discrimination in Insurance Pricing and Availability

1. *Insurance Requires Fair Redistribution,
Not Fair Discrimination*

The American concept of fairness centers on our right of voluntary choice and our correlative responsibility for the freedom to choose. For better or for worse, a person's genetic endowment is received before birth and lasts a lifetime. Unlike smoking, or other bad habits used in efficient risk classifications,¹⁵⁹ a person's genetic nature is entirely beyond that person's voluntary choice. One has the capacity to improve bad habits and develop good habits, but one's genetic circumstance cannot be improved or enhanced through willful effort in the same way that skills or talents can be improved. Since one cannot choose one's genetic make-up, arguably there should be no duty to pay more for insurance because of a poor genetic make-up. The nature and purpose of insurance is risk

Inherited Diseases at Harvard Medical School, Dr. Billings conducted a study in which he concluded that discriminatory denial of insurance policies was already in practice. Dr. Billings placed an ad in the *American Journal of Human Genetics* soliciting responses from individuals who had experienced discrimination based on genetic information. Dr. Billings reported his findings: 29 respondents who reported 41 incidents, 32 of which involved insurance discrimination, 7 of which involved employment discrimination, and 2 of which involved adoption. Billings et al., *supra* note 134.

¹⁵⁹ Risk classification regarding smoking is customarily considered fair discrimination because sound actuarial principles in insurance underwriting can account for the health care costs attributable to cigarette smoking. See, e.g., Emmett W. Lee & Gilbert E. D'Alonzo, *Cigarette Smoking, Nicotine Addiction, and Its Pharmacologic Treatment*, 153 ARCH. INTERN. MED. 34, 35 (1993) (\$17 billion estimated annual medical care costs resulting from smoking); Kenneth E. Warner, *Health and Economic Implications of a Tobacco-Free Society*, 258 JAMA 2080, 2084 (1987) (stating that \$22 to \$23 billion estimated annual medical care costs and \$30 to \$43 billion estimated annual indirect costs of productivity losses are associated with premature smoker mortality and excess morbidity).

transference and distribution, or fairly redistributing and equally sharing the fortuitous risks among all policyholders. Fair risk sharing is a fundamental insurance principle. Fair risk redistribution is a matter of equal fairness for all of us because all of us are genetically unequal.

Because genetic differences are morally arbitrary, the notion of good or bad genetic luck ought not be the reason that one person receives better or worse insurance treatment than other people.¹⁶⁰ Everyone deserves health care regardless of genetic luck.

Many people do not believe that individuals own their own talents and abilities. Still more people believe that they should not be burdened with bad luck in the genetic draw. When differences in luck are attributable solely to external circumstances, this modern view holds that something ought to be done to rectify the situation. That is, we must equalize the positions of various individuals or groups, even if it means (as it always does) that property, wealth, and opportunities must be taken from one group of people and given to another. . . . This general view offers fertile ground to support some general prohibition against genetic discrimination.¹⁶¹

It is not genetic information per se which is unfair; it is the unfair treatment of genetically unequal people which is unfair. Each of us is genetically different and potentially unequal in insurance rating and classifications, but we attain equality through socializing and redistributing our immutable genetic risks. Each of us thereby receives value through insurance. Thus, the issue to resolve is when, if at all, should genetically unequal people be treated unequally in insurance underwriting.¹⁶²

2. *Misunderstanding and Misuse of Genetic Information*

The American component of the U.S. HGP's Working Group on Ethical, Legal, and Social Implications of Human Genome Research ("ELSI"), sponsored an independent Task Force on Genetic Information

¹⁶⁰ See Lappé, *supra* note 15, at 160 (discussing the basis of equality in systems of justice).

¹⁶¹ Epstein, *supra* note 5, at 4-5.

¹⁶² The converse — the equal treatment of genetically unequals in pricing health insurances constitutes unfair discrimination — was explained above as the insurers' justification for fair discrimination. See *supra* Part II.A (notes 68-93 and accompanying text).

and Insurance. The task force consisted of experts in the fields of health care, genetics, health policy, and insurance analysis, as well as representatives of national genetic disease organizations. The majority of the group issued a report entitled *Genetic Information and Health Insurance*, outlining issues and solutions to the genetic information problem.¹⁶³ Intended to be included as part of President Clinton's 1993 health care initiative, the report states: "the problems associated with increasing genetic information expose inequities and perversities in the current system, and would exacerbate them unless the system itself is altered in certain fundamental respects."¹⁶⁴ Because almost all diseases have environmental or other non-genetic components, the Task Force explains that it will become increasingly difficult to distinguish non-genetic from genetic diseases, and non-genetic information from genetic information.¹⁶⁵ However, because the contemporary American health care system erects barriers to health care coverage for citizens most likely to need it, the Task Force suggested that information regarding a person's present, past, or future health status should not be used to deny health care coverage. "In the past, medical histories and conventional genetic diagnostic techniques have resulted in limitation or denial of insurance coverage or claims for the relatively small percentage of the population burdened by debilitating conditions such as cystic fibrosis and Huntington's disease."¹⁶⁶

In order to ensure that those people who most need access to genetic information and its attendant medical benefits are able to do so free from fear of losing coverage or paying higher premiums, the receipt of basic health services should not be conditioned on the disclosure of this information, whether genetic or not. "[T]he sensitivity of genetic information and the importance Americans historically place on privacy and self-determination argue strongly for a policy that does not hold access to health care hostage to one's willingness to reveal or to discover intimate facts about oneself."¹⁶⁷ However, the prevailing attitude within

¹⁶³ REPORT, *supra* note 45. However, two insurance industry analysts withdrew from the report. The American Council of Life Insurance opposed the document, explaining that it "directly conflicts with ACLI policy in its overall thrust and specific recommendations." *Id.* at v. Meanwhile, the Health Insurance Association of America decided that it "should neither oppose or support the final report; that the association's position should be one of neutrality." *Id.*

¹⁶⁴ *Id.* at 3.

¹⁶⁵ *Id.* at 8.

¹⁶⁶ *Id.* at 5.

¹⁶⁷ *Id.* at 11.

the insurance industry is that genetic information should not be treated any differently than any other medical history information.¹⁶⁸ Consequently, genetic discrimination in obtaining insurance already exists.¹⁶⁹ Often, this discrimination takes place following an individual's decision to undergo genetic testing because of a family member's affliction with a genetic disorder. Once a defective gene is detected within a family, all of the relatives are stigmatized as being ill or having the disease, even where no other relative ever manifests clinical signs of the disease.¹⁷⁰ Having a particular trait is equated with the burden of predetermined and severe illness. "Decision making concerning these individuals is based solely on a diagnostic label, without regard to the variable decision making or testing procedures that occur and are worsened by this irrational and unfair simplification of genetic condition . . . the equating of trait with significant disability."¹⁷¹

This flawed decision making may well take place because of superficial similarities between genetic testing of applicants for insurance and other tests currently available. Both can be said to serve the same purpose, which is to assess more accurately the risk of disease or other conditions necessitating medical attention. But there are also many differences between genetic tests and the many diagnostic tests performed by physicians upon which insurers routinely rely to assess risks. One major concern in the area of genetic testing is the confusion between an individual who is merely a carrier of a defective gene, and an individual who has an inherited disease.

Tests currently available and in use by physicians identify the condition of an individual at the time the test is taken. Blood tests, X-rays, electrocardiograms, and other screening, scanning, and monitoring tests reveal the presence or absence of specific chemicals, structures, or functions which indicate the presence or absence of a particular disorder. Genetic tests can only indicate if an individual is either a carrier of a disease, or if she has a predisposition to developing a particular disorder. Even if a test reveals the presence of a single gene which causes a specific disorder, the test does not indicate when, if ever, the disease may actually be manifested, and genetic tests do not indicate how severe the disease might be if it ever does develop.¹⁷² There are many genetically

¹⁶⁸ Brown, *supra* note 132, at 53.

¹⁶⁹ Billings, *supra* note 158, at 50.

¹⁷⁰ *Id.* at 49-50.

¹⁷¹ Billings et al., *supra* note 134, at 481.

¹⁷² See *supra* note 17 and accompanying text.

controlled disorders for which an individual may possess a defective gene; yet there is no certainty that she will ever become symptomatic and develop the disease.¹⁷³ In addition, many genetically controlled diseases are multigenic/multifactorial in origin,¹⁷⁴ and an individual may not possess all the genes necessary for a disease to express itself.¹⁷⁵ Further, it may be that genetic research within the HGP will not discover all of the genes necessary for a particular multigenic/multifactorial disease to express itself. Lastly, a person who appears to have the requisite genetic make-up for a particular disease may live a pristine lifestyle, and be environmentally free from those extrinsic factors which can effect the expression of a genetic disease.¹⁷⁶

3. *The Availability of Insurance*

Individuals rely on health insurance to absorb a large percentage of their health costs.¹⁷⁷ This reliance is due, in large part, to the escalating costs of health care.¹⁷⁸ Insurance has become an integral part of our health care system, and a denial of health insurance, for many, may be the equivalent of a denial of health care itself. Individuals who are denied health insurance based on their genetic make-up may refuse to seek medical care because of an inability to pay for it. Such inaction then shifts the burden of providing health care to the taxpayer, which is what the insurance industry has attempted to avoid in lobbying against a national health care system.¹⁷⁹ Regulation of access to the results of genetic tests and the use of those results would encourage insurers to re-evaluate the methods by which they assess risk. If known genetic risks are not allowed to be calculated in rate setting, then insurers will, of necessity, be forced to spread the costs for these present and future diseases more evenly among their insureds.¹⁸⁰

¹⁷³ See *supra* note 66 and accompanying text.

¹⁷⁴ Karjala, *supra* note 31, at 146.

¹⁷⁵ *Id.*

¹⁷⁶ See *supra* note 19 and accompanying text.

¹⁷⁷ Wortham, *supra* note 76, at 397.

¹⁷⁸ *Id.*

¹⁷⁹ Schatz, *supra* note 14, at 1805 (stating that the insurance industry claims that it is better equipped to manage health care costs than the federal government).

¹⁸⁰ Insurers counter that they are already required by state law to cover certain high-risk individuals through insurance assigned risk pools. Clifford & Iuculano, *supra* note 14, at 1823. These legislatively created pools are comprised

C. *Prohibiting the Use of Genetic Information Protects the Right to Privacy*

One of the most cherished, basic, and vital human rights is the right to privacy, the long-standing American "right to be let alone."¹⁸¹ But no one can guarantee the privacy of genetic information. The HGP has radically transformed our perception of privacy rights,¹⁸² and genetic discrimination will thereby become the civil-rights issue of the twenty-first century. Each genotype defines the humanness of each individual; a person's genome is that person's unique property, like land. Society will have to decide whether to allow, require, or forbid the use of genetic testing in sundry contexts. As subsequently explained in Part IV.C of this Article,¹⁸³ a summary of several states' statutes evidences a small but

of people that insurers consider to be uninsurable. Insurers who do business in a state are then assigned a percentage of the pool based on the insurer's share of the business in the state. However, these risk pools do not adequately address the problems related to access to health insurance because employers continue to become self-insured. *Id.* at 1824. Risk pools are regulated by state law, and ERISA's preemption clause exempts self-insured employers, who make up a large share of the insurance market, from participation in the risk pools. *See infra* Part IV.B.1 (notes 239-314 and accompanying text). Because such a large percentage of people are covered by employer sponsored health plans, MEDICAL TESTING AND HEALTH INSURANCE, *supra* note 39, at 107, the employer exemption from participating in risk pools would place an additional burden on private insurers, who would then pass the additional costs to their customers. The result would be that people who were not covered by employer-sponsored health insurance plans would bear the entire burden for covering those higher risk, uninsurable individuals.

¹⁸¹ W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 117, at 849, 864 (5th ed. 1984) (quoting THOMAS M. COOLEY, LAW OF TORTS 29 (2d ed. 1888)). This quote is often attributed to Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 193 (1890).

¹⁸² *See, e.g.,* George P. Smith II & Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. OF CONTEMP. HEALTH L. & POL. 23, 43-50 (1994) (examining the extent to which discrimination against an individual by a state entity, based upon genetic material rather than a recognized suspect classification, is proscribed by traditional equal protection analysis). To the extent a genetic disease is confined to a specific race, genetic screening may involve a Fourteenth Amendment issue. *See* Janet A. Kobrin, *Medical Privacy Issue: Confidentiality of Genetic Information*, 30 UCLA L. REV. 1283, 1293 & n.62 (1983).

¹⁸³ *See infra* notes 391-547 and accompanying text.

evidently growing trend toward prohibiting genetic discrimination and protecting the privacy of genetic testing information. For example, on March 6, 1996, Virginia enacted a Genetic Privacy Act¹⁸⁴ which prohibited health insurers from using genetic information to deny, restrict, cancel, or impose other criteria on current or future policyholders. Moreover, model legislation for state and federal consideration has been prepared by the Ethical, Legal and Social Issues ("ELSI") Working Group under the auspices of the National Institutes of Health ("NIH") and Department of Energy ("DOE").¹⁸⁵

Genetic testing and the subsequent use of immutable, potentially stigmatizing genetic information may create a suspect genetic underclass, the "genetically inferior," in insurance rating classifications and thereby constitute unfair discrimination as a matter of law.¹⁸⁶ Such discrimination based on an individual's genome should be prohibited as a violation of the individual's civil rights.¹⁸⁷ On March 14, 1996, New Jersey did just that by enacting an insurance civil rights law, The Genetic Privacy Act.¹⁸⁸ In pertinent part, the New Jersey statute provides:

No person shall discriminate against any individual on the basis of genetic information or the refusal to submit to a genetic test or make available the results of a genetic test to the person in the issuance, withholding, extension or renewal of any hospital confinement or other supplemental limited benefit health or credit life or credit accident insurance coverage . . . or in the fixing of rates, terms or conditions thereof¹⁸⁹

In recently amending their insurance statutes, Colorado and Georgia provided their answers restricting insurers' use of genetic testing

¹⁸⁴ See *supra* note 142 and accompanying text.

¹⁸⁵ See NIH/DOE ELSI Working Group, *Genetic Privacy Act* (visited Feb. 25, 1997) <http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html>.

¹⁸⁶ Carol Lee, Comment, *Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry*, 13 PACE L. REV. 189, 213-17 (1993) (discussing how various states regulate genetic testing).

¹⁸⁷ See generally Richard C. Turkington, *Legacy of the Warren and Brandeis Article: The Emerging Unencumbered Constitutional Right to Informational Privacy*, 10 N. ILL. U. L. REV. 479 (1990) (arguing that personal information, including medical records, implicates the right to privacy).

¹⁸⁸ S.B. 695, 207th Leg. (N.J. 1996) (Oct. 24, 1996 amended substitute).

¹⁸⁹ *Id.*

information and protecting an individual's property right in genetic information. The two statutes are virtually identical, stating:

(1) The general assembly hereby finds and determines that recent advances in genetic science have led to improvements in the diagnosis, treatment, and understanding of a significant number of human diseases.

The general assembly further declares that:

(a) Genetic information is the unique property of the individual to whom the information pertains;

(b) Any information concerning an individual obtained through the use of genetic techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual to whom the information pertains;

(c) To protect individual privacy and to preserve individual autonomy with regard to the individual's genetic information, it is appropriate to limit the use and availability of genetic information;

(d) The intent of this statute is to prevent information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage.¹⁹⁰

This state statutory approach illustrates the contemporary inchoate trend toward recognizing and protecting the individual's personal property right and privacy in the unique property of each individual's genome.

With the proliferation of highly proficient computers, modern technology arms insurers with practical and, from the consumer's perspective, clandestine means of obtaining, organizing, storing, retrieving, releasing, and disseminating genetic and other actuarial data about applicants and policyholders. A justifiable fear arises that widespread delineation of genotypes and genetic profiles may, like credit information, culminate in centralized genetic information databases. Protecting privacy interests by restricting insurers' unrestrained access to an individual's genetic information is a matter of basic civil and legal rights.¹⁹¹ Therefore, any state or federal law authorizing mandatory

¹⁹⁰ COLO. REV. STAT. ANN. § 10-3-1104.7 (1)(a)-(d) (West 1994). The Georgia statute is identical except that in subsection (d), Georgia prohibits denial of accident and sickness insurance. GA. CODE ANN. § 33-54-1 (1)-(4) (Michie 1996).

¹⁹¹ See *Whalen v. Roe*, 429 U.S. 589, 605 (1977) (signaling the Court's concern regarding privacy implications of modern technology). An analogy may be drawn to the employment context. See, e.g., Frank J. Cavico, *Invasion of*

genetic screening for insurance purposes would violate an applicant's constitutional right to privacy.¹⁹²

1. *Genetic Information Can Cause Stigmatization and Psychological Trauma*

Genetic information represents a very sensitive category of medical information. If the HGP is successful and genetic mapping becomes routine, inaccurate testing and analysis could cause serious harm. For instance, the "comparison of an individual's genetic profile to an error-ridden prototype could have the same stigmatizing effect as do false positives on drug tests and tests for the HIV antibody."¹⁹³ Additionally,

Privacy in the Private Employment Sector: Tortious and Ethical Aspects, 30 HOUS. L. REV. 1263, 1319 (1993).

Operating within a modern, complex, heterogeneous, and litigious society compels a private sector employer to acquire and retain information regarding current employees and applicants for employment. The centralized collection and easy accessibility of computerized data, however, greatly increase the danger of abuse of information. This may increase tension between the employer's need to know the information and the employee's expectation of privacy.

Id. (citations omitted); see also George B. Trubow, *Protecting Informational Privacy in the Information Society*, 10 N. ILL. U. L. REV. 521, 523 (1989) (discussing federal studies documenting the impact of government computerized data banks on personal privacy and noting that courts recognize the threat to personal privacy posed by the accumulation of vast amounts of information in computerized data banks).

¹⁹² Any statute authorizing insurers to require applicants to undergo mandatory genetic screening would most likely not pass constitutional muster. In the reproductive context, for example, mandatory prenatal screening interferes with a couple's constitutional right to privacy regarding procreative decisions. See, e.g., *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1376-77 (N.D. Ill.) (holding that the right to privacy covers decisions regarding prenatal genetic testing), *aff'd*, 914 F.2d 260 (7th Cir. 1990), and *cert. denied sub nom. Scholberg v. Lifchez*, 498 U.S. 1069 (1991). If courts were to extend that reasoning to one's genetic information, mandatory genetic screening should be upheld only to further a compelling state interest. Ostensibly, requiring genetic testing to promote fair discrimination in insurance rates among all policyholders is not such a compelling state interest.

¹⁹³ Catherine M. Valerio Barrad, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1047 (1993) (arguing that stigmatizing effects could result from errors in centralized data banks of genetic profiles).

unlike a discrete transient illness or disease, a genetic disease, disorder, or condition is immutable. An inappropriate disclosure of genetic information may stigmatize an individual for life, causing serious emotional, financial, and perhaps physical harm.¹⁹⁴

One aspect of stigmatization arises from genetic ignorance of third parties, including insurance companies.¹⁹⁵ Although data gathered from genetic tests may appear to constitute sound actuarial information for insurance classification, ambiguity surrounds the accuracy of this genetic data in insurance underwriting. As discussed in Part I.B.2 of this Article,¹⁹⁶ some genetic tests will predict the statistical probability of developing a disease that may involve the interaction of: (1) multiple genes, or (2) the presence of specific environmental factors, or (3) both multiple genes and environmental factors.¹⁹⁷ Other genetic tests may indicate the presence of specific genes, and along with that presence, the certainty that an individual will develop a disease; but the extent of the disease's development and its influence on any insured's life is uncertain.¹⁹⁸

In addition to the social stigma, genetic screening can cause psychological trauma. Genetic knowledge may have a devastating psychological impact on individuals who are told that they will develop a fatal, incurable disease.¹⁹⁹ For instance, in the early 1970s, some states adopted laws mandating carrier status screening of African-Americans for sickle-cell anemia. The idea was that carriers of the disorder may wish to consider that information when making reproductive plans, since if two carriers conceived a child together, there would be a twenty-five percent chance that the child would be affected with sickle-cell anemia. This screening program had a disastrous consequence. Appropriate counseling was not provided, and people were psychologically harmed by the information. Societal institutions did not know how to use the test results, and consequently, carriers of sickle-cell anemia, who

¹⁹⁴ Lori B. Andrews, *The Future Confidentiality of Genetic Information*, in *MEDICAL GENETICS: A LEGAL FRONTIER* 187-88, 209 (1987).

¹⁹⁵ See, e.g., Billings et al., *supra* note 134, at 476-81 (affirming genetic discrimination by insurers against people who are totally asymptomatic — their only statistical "abnormality" lies in their genotypes).

¹⁹⁶ See *supra* notes 63-67 and accompanying text.

¹⁹⁷ Karjala, *supra* note 31, at 146-47.

¹⁹⁸ Joseph M. Miller, *Genetic Testing and Insurance Classification: National Action Can Prevent Discrimination Based on the "Luck of the Genetic Draw,"* 93 DICK. L. REV. 729, 737 (1989).

¹⁹⁹ See, e.g., *id.* at 742.

were themselves healthy, were nonetheless discriminated against in insurance and employment.²⁰⁰

Genetic information differs from other diagnostic tests that indicate the presence of fatal diseases. If an individual is informed that she has a life-threatening illness, she has choices. She can avail herself of any treatment that might be available, put her affairs in order, prepare for the inevitable, and attempt to enjoy to the fullest whatever lifetime remains. In contrast, when an individual is informed that she may develop an incurable illness at some indeterminate time in the future, this information may adversely impact her decisions about education, work, marriage, having children, aborting a pregnancy, and so forth. A thoughtful commentator explains that “[t]here is a risk of suicide, job loss, divorce, and substance abuse for those persons so ‘sentenced.’”²⁰¹ For instance, the suicide rate is four times greater among patients diagnosed with Huntington’s disease than among the corresponding American caucasian population.²⁰²

Genetic diseases do not have to be fatal to cause psychological harm. One study reported that an American adolescent in a Tay-Sachs screening program suffered a psychotic reaction when told she was a *carrier* of the disease.²⁰³ Similar traumatic reactions can happen when people learn that they are not carriers of a fatal disease following genetic screening. For example, when at risk individuals learn that they are not carriers of Huntington’s disease, they can “experience ‘survivor guilt,’ similar to that of soldiers whose buddies have died in war.”²⁰⁴

How people react to being labelled as diseased does vary, but such labels oftentimes have profound and far-reaching effects on the person’s self-conception. “[T]he understanding of ourselves as sick or diseased tends to correlate fairly closely with our own and others’ senses of us as

²⁰⁰ Andrews, *supra* note 141, at 53.

²⁰¹ Richard Shapiro, *New Frontiers in Genetic Medicine*, 104 ANNALS OF INTERNAL MED. 527, 536 (1986) (examining the ethical and legal issues of pre-symptomatic diagnosis of people with the Huntington’s disease gene).

²⁰² Lindsay A. Farrer, *Suicide and Attempted Suicide in Huntington Disease: Implications for Preclinical Testing of Persons at Risk*, 24 AM. J. MED. GENETICS 305, 305-11 (1986).

²⁰³ J.T.R. Clark, *Screening for Carriers of Tay-Sachs Disease: Two Approaches*, 119 CANADIAN MED. ASS’N J. 549, 550 (1978) (comparing large neighborhood screening programs to a more individualized case-finding approach to screening for Tay-Sachs disease).

²⁰⁴ Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 977 (1996).

having suffered some impairment of normal function.”²⁰⁵ Since the HGP will substantially enlarge the capacity to predict disease, genetic testing will have a greater effect on people who feel healthy and suffer no functional impairment; these people will increasingly be labelled as sick, diseased, or unhealthy.²⁰⁶

Because the foregoing psychological risks are inherent due to the nature of the information revealed, they will exist even if an individual chooses to be tested for a genetic disorder. Ethical issues arise, however, when we consider whether insurers should be permitted to require genetic testing given the potential dire consequences of such information. Fear of “stigmatization, job loss, becoming uninsurable, or a heightened personal anxiety” are all valid reasons for asserting a “right not to know.”²⁰⁷ During the course of writing this Article, the author made a very unscientific, informal survey of several hundred people, explaining the HGP and asking: “Assume the HGP is successful and everyone can have their genome mapped. Should health insurance companies be permitted to require genetic testing and genome mapping so that they can more fairly price health insurance for each person?” Without exception, everyone said no. Those instinctive, gut reactions evidence the American ideal of freedom — individual rights to privacy and to decide to know or not know.

There is a fundamental difference between genetic information and other types of information currently available to insurers. In addition to concerns about confidentiality and psychological effects, individuals who fear losing or being denied health insurance may refuse to seek testing. This result is in direct opposition to the stated purpose of the HGP.²⁰⁸ People may refuse to undergo genetic testing to determine compatibility with a relative who requires an organ transplant, for fear that the test results may be obtained by insurers and used to deny health care. This may, in turn, result in a decrease of potential donors who are willing to involve themselves in the screening process. People may be less willing

²⁰⁵ Dan W. Brock, *The Human Genome Project and Human Identity*, 29 HOUS. L. REV. 7, 19 (1992) (arguing that a person’s conception of self is often influenced by being labelled as sick or diseased).

²⁰⁶ See, e.g., Karjala, *supra* note 31, at 165.

²⁰⁷ *Id.* (discussing an extreme example of a French privacy statute that prevents geneticists from informing large numbers of individuals who have been identified to be at risk for treatable juvenile glaucoma); see also Alexander Dorozynaka, *Privacy Rules Blindside French Glaucoma Effort*, 252 SCI. 369 (Apr. 19, 1991).

²⁰⁸ See *supra* note 27 and accompanying text.

to donate a kidney to extend the life or improve the quality of life of a loved one if such a generous gesture comes at the risk of losing health insurance coverage, perhaps permanently.

2. Confidentiality Must Be Protected

Personal medical information has become less protected and private in the United States.²⁰⁹ Insurers utilize systems of national data banks that allow them to keep track of those individuals who have tested positive for certain diseases, and thereby reduce the risk of adverse selection. Insurers exchange information about people through the Medical Information Bureau ("MIB"), a data bank that contains medical information about insurance applicants.²¹⁰ The MIB is comprised of over seven hundred insurance companies,²¹¹ and contains information on over fifteen million people.²¹² If genetic information makes its way into these files without the appropriate legislation in place to control the manner in which the information can be used, the results will be devastating. Individuals who have credit problems or treatable medical conditions often have the opportunity to "clear up the record." However, the immutable nature of genetic status is similar to a birthmark; it is permanent and irreparable. We are what our genes say we are, and action needs to be taken to prevent unrestrained access to and use of such personal information.

Tort claims for invasion of privacy, or intrusion, may be raised against insurers based on the pervasive, computer-assisted collection and dissemination of stigmatizing genetic information.²¹³ This tort could be

²⁰⁹ For example, when Earvin "Magic" Johnson announced that he was infected with HIV, his physician released Magic's confidential medical information to the *New York Times*, which published it with no comment regarding confidentiality or violation of Magic's right of privacy. Richard W. Stevenson, *Magic Johnson Ends His Career, Saying He Has AIDS Infection*, N.Y. TIMES, Nov. 8, 1991, at A1.

²¹⁰ Schatz, *supra* note 14, at 1801. See *infra* note 539 for a description of efforts to regulate the MIB.

²¹¹ Lee, *supra* note 186, at 209.

²¹² Sandra Blakeslee, *Ethicists See Omens of an Era of Genetic Bias*, N.Y. TIMES, Dec. 27, 1990, at B9.

²¹³ However, the few extant cases hold otherwise. In an invasion of privacy action by an insurance applicant against an insurer that transferred medical information concerning the applicant to the MIB centralized data bank, the Kansas Supreme Court held that the insurer had an interest in the medical

triggered if insurers require genetic testing or collect genetic information without an applicant's fully informed and genuine consent.²¹⁴

3. *Preferred Social Ignorance*

It may be that our concept of health care is partly, but intrinsically, related to those aspects of our lives that we can or cannot change through voluntary effort. We can control our health to a certain extent through

information which it forwarded to MIB, that the insurer had a duty under its MIB membership to supply such information, and that the transmittal of information was a legitimate business procedure and vital to the life insurance industry. *Senogles v. Security Benefit Life Ins. Co.*, 536 P.2d 1358, 1363 (Kan. 1975) (holding that the information was qualifiedly privileged and, thus, its transmittal was not actionable as an invasion of right to privacy); *see also Mayer v. Northern Life Ins. Co.*, 119 F. Supp. 536, 536 (N.D. Cal. 1953) (holding that defendant insurer causing false information "to be recorded in the records of an agency subscribed to by life insurance companies" was a case of qualified privilege under California statutory law which is not actionable as defamation absent an allegation of malice); *Milsaps v. Bankers Life Ins. Co.*, 342 N.E.2d 329, 335 (Ill. App. Ct. 1976) ("Likewise the forwarding of a code number by Bankers Life to MIB all of whose members had a common business interest and access to information concerning insurability of applicants for insurance, comes within the privilege doctrine.").

²¹⁴ RESTATEMENT (SECOND) OF TORTS § 652B cmt. b, at 378-79 (1977). Analogous cases have arisen in the employment context. *Cf. Borse v. Piece Goods Shop, Inc.*, 963 F.2d 611, 620-21 (3d Cir. 1992) (suggesting that plaintiff, a sales clerk terminated for refusing to sign a consent form for drug-use urinalysis screening, had a valid privacy concern). With its potential for stigmatization, an individual's genome may be recognized as within the sphere of privacy protection. If so, an insurer's investigation intruding into that recognized privacy zone may be actionable in tort if it is highly offensive to a reasonable person. This has been recognized in the analogous employment context where the employer acquires confidential medical information from an employee's physician or psychologist without the employee's consent. *See, e.g., Neal v. Corning Glass Works Corp.*, 745 F. Supp. 1294, 1298-99 (S.D. Ohio 1989) (allowing employee's colorable claim for wrongful intrusion where employer induced emergency room doctor to disclose confidential results of employee's drug test); *Leggett v. First Interstate Bank, N.A.*, 739 P.2d 1083, 1086-87 (Or. Ct. App. 1987) (finding invasion of privacy when head of personnel and employee counselor met with employee's clinical psychologist and discussed plaintiff's condition without plaintiff's permission).

voluntary lifestyle choices: exercising, refraining from smoking, and developing healthier eating habits. On the other hand, we cannot control our genes. The "accident of birth" is the randomness by which a defective gene could be a part of the genetic makeup of anyone. Despite the risk associated with this uncontrollable component of our health, we may choose to live behind what the philosopher John Rawls refers to as the "veil of ignorance."²¹⁵

A Rawlsian theory of justice advocates social policies based on decisions that citizens would make in forming a social contract. Rawlsians posit a hypothetical state during which citizens do not know their race, their class, or their genetic make-up. Standing behind this veil of ignorance before the formation of the social contract, people would most likely not select rules that penalize individuals based on arbitrarily, or fortuitously, assigned characteristics such as genetic diseases. In this hypothetical initial position, all citizens have a common interest in obtaining health insurance. Assuming that insurance companies would use genetic testing information to create risk classifications for the avowed purpose of selecting and excluding medical risks, each citizen would perceive himself or herself as potentially in the "worst-off" insurance rating classification and prefer, in self-interest, to protect the interest of those insurance applicants most disadvantaged by risk classification. Therefore, a Rawlsian theory of justice dictates that society should regulate health insurance in order to protect the interests of those insureds who are the most disadvantaged.²¹⁶

In essence, our social mores have yet to catch up with the knowledge obtainable as a result of the HGP. For instance, will parents want knowledge that their children will have a strong propensity for traits now considered part of personality (such as rage, impatience, or difficulty with mathematics) that one day may be attributable to our genes? Responsible parents may desire such information because parental concern for the welfare of children invites parents to direct their children toward success and well-being. But the social consequences and stigmatization which may stem from this knowledge may be devastating in the hands of an uncaring society. Thus, only when we can accept that a genetic "brand of Cain" rests on each of us can we be comfortable in leaving the refuge of our genetic privacy. Meanwhile, the veil of ignorance may be our best ally in the world carved by the HGP.

²¹⁵ See Lappé, *supra* note 15, at 160.

²¹⁶ *Id.*

IV. STATE VS. FEDERAL LEGISLATIVE
REGULATION OF GENETIC INFORMATION IN INSURANCE

A solution to the insurance/genetic fair/unfair discrimination dilemma may include legislation — either a comprehensive uniform act or discrete statutes for discrete problems. In considering legislative solutions, there is an overriding political, economic, and jurisprudential issue that must be addressed: Should Congress or each state legislature enact insurance/genetic legislation? On the one hand, the history of American insurance suggests state regulation. On the other, a national concern that affects every citizen — each of us has four to ten genetic defects²¹⁷ — suggests a nationally uniform and comprehensive approach.

A. Preference for State Regulation of the "Business of Insurance"

Perhaps no other commercial business affects the public so intimately as does the business of insurance. As a consequence, the insurance business is held to be "affected with a public interest"²¹⁸ and thus is subject to stringent regulation. For instance, governmental regulation of the business of insurance commenced over six centuries ago in Europe.²¹⁹ In the United States, the business of insurance, like the banking business, is subjected to more continuous and thoroughgoing governmental control and regulation than other varieties of private business enterprise. Today, American insurance regulation commences and ends with the states.

Influenced by political, business, and consumer interests in protecting their respective turfs, insurance regulation has historically swung like a pendulum between state and federal control. Insurers favored and lobbied for that level of government, generally the states, which would regulate the least. Naturally, consumers reacted conversely. Although Congress could initially have exercised jurisdiction under the Commerce Clause,²²⁰ Congress sparingly exercised this power in the nineteenth

²¹⁷ See, e.g., Lori B. Andrews, *Genetics and the Law, Introduction*, 39 EMORY L.J. 619, 619 (1990).

²¹⁸ See, e.g., *O'Gorman & Young, Inc. v. Hartford Fire Ins. Co.*, 282 U.S. 251, 257 (1931) (upholding a New Jersey statute limiting commissions of fire insurance agents); *German Alliance Ins. Co. v. Lewis*, 233 U.S. 389, 406-07 (1914) (allowing legislative regulation of insurance rates).

²¹⁹ See EDWIN E. PATTERSON, *ESSENTIALS OF INSURANCE LAW* 2 (2d ed. 1957).

²²⁰ U.S. CONST. art. I, § 8, cl. 3 (granting Congress the power "[t]o regulate

century. Consequently, regulation began with the states from the 1820s to the 1850s when several states established insurance departments.²²¹ Perceiving this uneven, piecemeal state regulation as unduly burdensome, the insurance industry advocated that Congress enact uniform, national standards that would have recognized insurance companies as federal institutions analogous to banks. This nineteenth-century advocacy, which questioned the efficacy and fairness of unequal, patchwork state regulation and urged Congress to adopt a national approach, fittingly applies to the current debate over insurers' use of genetic information.²²²

The insurance industry organized and challenged, in 1868, the power of state government to regulate interstate insurance transactions. Several New York insurers, seeking to induce federal regulation and invalidate state regulation, divined a test case. These insurers appointed Paul, a Virginia resident, as their agent. The agent applied for a Virginia insurance agent's license, but refused to deposit the required bonds with the Virginia state treasurer and was denied a license. Thereafter, the agent sold insurance to a Virginia resident and was convicted of violating Virginia's licensing statute — a conviction the Virginia Supreme Court affirmed. Taking the case, *Paul v. Virginia*,²²³ to the United States Supreme Court, the agent argued that the Commerce Clause authorized regulation of insurance companies and that this regulatory power was exclusively a federal power. The Supreme Court, in rejecting the argument, held that “[i]ssuing a policy of insurance is not a transaction of commerce”²²⁴ and therefore is not within the purview of the Commerce Clause. That decision effectively put the insurance industry beyond the constitutional authority of Congress to regulate for the next seventy-six years.

One advantage of the Court's decision for the insurance industry was that insurers were allowed to continue their customary practice of sharing

Commerce with foreign Nations, and among the several States”).

²²¹ See generally EDWIN W. PATTERSON, *THE INSURANCE COMMISSIONER IN THE UNITED STATES* (1927).

²²² The same argument for federal regulation was made more recently. See UNITED STATES DEPARTMENT OF JUSTICE, *THE PRICING AND MARKETING OF INSURANCE* 359-72 (1977) (proposing a dual system of insurance regulation which would utilize the general scheme of the federal banking system).

²²³ *Paul v. Virginia*, 75 U.S. (8 Wall.) 168 (1868) (holding that insurance contracts are created by local transactions to be governed by local law and such contracts do not constitute interstate transactions).

²²⁴ *Id.* at 183.

“experience actuarial data,” used to predict the probability of losses associated with particular risks in setting premiums and were allowed to establish rating bureaus to assist in determining premiums. Fair discrimination among applicants and insureds based on experience rated classifications became the norm for our law of insurance. However, these voluntary rate-making and price-fixing activities among insurers would later cause the Supreme Court to reverse itself.

Until the 1940s, the states’ turf was protected by the decision in *Paul* that stood for the proposition that states had the sole power to regulate insurance business conducted within their borders. Nonetheless, the states came to recognize that the business of insurance was national in scope. Thus, to coordinate administration of regulating a national enterprise, the National Association of Insurance Commissioners (“NAIC”) was organized in 1871. Even though the NAIC is without power to enforce any of its decisions, it has considerable influence over state legislatures and has been a powerful force in solving insurance regulatory problems since its creation.

By the early twentieth century, the pendulum had already begun to swing toward federal regulation as state regulation of life insurers was exposed as wholly inadequate. A striking episode involved an investigation conducted in New York by a joint legislative committee in 1905-06: the Armstrong Committee investigation.²²⁵ It exposed various unsavory practices among life insurers, such as deferring dividends and creating slush funds, and led to extensive legislation in New York and a few other states. It also led, in 1905, to the introduction of a bill in the United States Senate to federalize regulation of insurance. Although insurers at this juncture differed in opinion, state regulation seemed preferable compared to the tendency of certain federal agencies to become potent proactive regulators, as reflected in the antitrust arena. Louis D. Brandeis, then counsel for the Protective Committee of Policyholders in the Equitable Life Assurance Society, scathingly protested federal insurance regulation in the Brandeis tradition. Regarding insurance overhead and stockholder dividends, he stated:

The sole effect of a Federal law would be . . . to free the companies from the careful scrutiny of the commissioners of some of the States.

²²⁵ For a detailed description of the work of the Armstrong Committee, see Mark J. Roe, *Foundations of Corporate Finance: The 1906 Pacification of the Insurance Industry*, 93 COLUM. L. REV. 639, 656-75 (1993).

It seeks to rob the State even of the right to protect its own citizens from the legalized robbery to which present insurance measures subject the citizens, for by the terms of the bill a Federal license would secure the right to do business within the borders of the State, regardless of the State prohibitions, free from the State's protective regulations.²²⁶

Brandeis's advocacy prevailed, the federal legislation was not enacted, and the primacy of state regulation continued for another forty years.

By the 1940s, however, another movement for federal regulation of the insurance business had arisen. This movement was adamantly opposed by the insurance industry which supported continued state regulation. One important concern was a perceived unfair discrimination by insurers' voluntary sharing of actuarial data based on experience and by insurers' fixing uniform risk classifications and premiums. The argument against this practice was that this collective action created discriminatory rates and unfairly limited the availability of insurance for some applicants — this same basic argument echoes in the current debate over genetic information. Fairness in rate-making continues to be the issue.

The ongoing state-versus-federal debate was temporarily settled by the famous decision in *United States v. South-Eastern Underwriters Association*.²²⁷ This case concerned a Sherman Anti-Trust Act indictment of an association of 198 stock fire insurance companies in six states for fixing non-competitive premium rates and for monopolization in boycotting nonmembers. The Court determined that Congress had not manifested a clear intention to exempt insurance companies from the federal antitrust laws and held the insurers in the association were subject to the Sherman Act.²²⁸ *South-Eastern Underwriters* threatened the continued supremacy of the states in insurance regulation. This decision caused confusion and created an uncertain void regarding the validity of state regulation because, after the decision, Congress could assume regulation of the business of insurance.

In response, NAIC, representing the turf interests of the states, as well as the insurance industry's position now favoring state regulation,

²²⁶ *United States v. South-Eastern Underwriters Ass'n*, 322 U.S. 533, 594 n.17 (Jackson, J., dissenting in part) (quoting Louis D. Brandeis, counsel for the Protective Committee of policy-holders in the Equitable Life Assurance Society, Address before the Commercial Club of Boston (Oct. 26, 1905)), *reh'g denied*, 323 U.S. 811 (1944).

²²⁷ *United States v. South-Eastern Underwriters Ass'n*, 322 U.S. 533, *reh'g denied*, 323 U.S. 811 (1944).

²²⁸ *Id.* at 938.

drafted a compromise proposal that Congress enacted as the McCarran-Ferguson Insurance Regulation Act of 1945²²⁹ (more popularly known as the McCarran Act). For our purposes of deciding whether a state or a federal statutory solution is the most practical, productive approach, three pertinent points regarding the McCarran Act are useful:

1. The Act states as a matter of public policy that "the continued regulation and taxation by the several States of the business of insurance is in the public interest,"²³⁰ and then concedes power to the states to regulate the business of insurance.²³¹ This public policy evidences a preference for a state-by-state legislative response to insurance/genetic discrimination issues. Yet that apparent public policy is undercut by other provisions of the Act.

2. The Act provides that federal law shall not preempt state regulation of insurance; however, it is unclear if the anti-preemption clause would apply to the use by insurers of genetic testing in classifying and rating risks or in the subsequent processing and paying or denying insureds' claims.²³² Assuming that new legislation is the appropriate approach to

²²⁹ McCarran-Ferguson Insurance Regulation Act of 1945, Pub. L. No. 79-15, 59 Stat. 33 (1945) (codified as amended at 15 U.S.C. §§ 1011-1015 (1994)).

It is beyond the scope of this Article to explain and analyze the substance, effect, and current status of the state-federal accommodation achieved by the McCarran Act. For a discussion of these concerns, see generally JERRY, *supra* note 14; KEETON & WIDISS, *supra* note 105, § 8.1, at 930-38 (discussing the allocation of regulatory power between state and federal institutions).

²³⁰ § 1, 59 Stat. at 33; 15 U.S.C. § 1011 (1994).

²³¹ "The business of insurance . . . shall be subject to the laws of the several States which relate to the regulation or taxation of such business." § 2(a), 59 Stat. at 34. 15 U.S.C. § 1012 (1994).

²³² "No Act of Congress shall be construed to invalidate, impair, or supersede any law enacted by any State for the purpose of regulating the business of insurance . . ." 15 U.S.C. § 1012(2)(b) (1958). This language, which was primarily intended to create an antitrust exemption for the business of insurance, has engendered the most litigation to date. The litigation has focused on what is meant by the "business of insurance," which is not defined in the Act. The Supreme Court adopted a three-prong test for determining when a particular activity, such as the use of genetic tests in underwriting, is the "business of insurance" as opposed to the "business of insurance companies." The three factors to be evaluated in determining if a practice constitutes the business of insurance are: "first, whether the practice has the effect of transferring or spreading a policyholder's risk; second, whether the practice is an integral part of the policy relationship between the insurer and the insured; and third, whether the practice is limited to entities within the insurance industry." Union Labor

Life Ins. Co. v. Pireno, 458 U.S. 119, 129 (1982) (re-adopting the three-step test articulated earlier in Group Life & Health Ins. Co. v. Royal Drug Co., 440 U.S. 205 (holding that a pharmacy agreement did not constitute the business of insurance), *reh'g denied*, 441 U.S. 917 (1979)); *cf.* Everson v. Blue Cross and Blue Shield, 898 F. Supp. 532 (N.D. Ohio 1994) (Under the four-part analysis applicable to the McCarran Act, "a federal statute is precluded if (1) the statute does not specifically relate to the business of insurance . . . ; (2) the complained of activities constitute 'business of insurance'; (3) the state has enacted laws for the purpose of regulating the complained of activity; and (4) the federal statute would invalidate, impair or supersede the state law."). What is unclear from these decisions is whether the use of genetic tests in either the underwriting process or in the claims presentation-processing-payment process, or both, would be the "business of insurance" controlled by state law, or the "business of insurance companies" to which federal law applies. Using the third *Pireno* factor, for example, ask: Is the genetic testing limited to entities within the insurance industry? Unless insurers have in-house genetic testing facilities, the answer is no, and federal law could preempt state law. Using the first *Pireno* factor, ask: Does denying payment of an insured's claim based on genetic testing involve the underwriting or spreading of risk? Based on *Pireno*, the answer is no, and federal law could again preempt. The transfer of risk is complete upon the issuance of the policy, which inexorably leads to the conclusion that no claim settlement activity can comply with the Court's first criterion — the transferring and spreading risk. *Pireno* held that the contract underwrites and spreads risk; thus, all insurer activities after insurance contract formation would be the "business of insurance companies," which is not exclusively regulated by the states under the McCarran Act. Arguably, no insurer activity can comply with all three factors. However, the Court indicated that none of the three parts of the test is always outcome-determinative, *Pireno*, 458 U.S. at 129, which evidently means that any insurer activity must be assessed against all three factors. Further uncertainty results if a court, for example, emphasizes only the "relationship" part of the three-pronged test. In 1993, the United States Supreme Court held that an Ohio law establishing the priority of claims against insolvent insurers governed despite a federal statute purporting to give United States' claims higher priority; that the federal statute did not preempt the state law; and, that the Ohio statute was one regulating the business of insurance within the McCarran Act to the extent, at least, of protecting policyholders. *U.S. Dep't of Treasury v. Fabe*, 508 U.S. 491, 508-09 (1993); *cf.* Colonial Life & Accident Ins. Co. v. American Family Life Assurance Co., 846 F. Supp. 454, 458-60 (D.S.C. 1994) (holding that a false advertising claim brought under the Lanham Act against insurer was preempted by the McCarran Act because state laws regulating advertising are encompassed within the McCarran Act because advertising clearly affects the relationship between the insurer and insured). As just explained, the decisions applying the three-pronged test have narrowed the scope of the "business of insurance" from

the insurance/genetic problem, this "jurisdictional" uncertainty is a convincing rationale for adopting a federal, rather than a state, legislative solution. For instance, if diverse federal laws can preempt state insurance/genetic statutes, then state legislation would provide neither the requisite assured guidance for insurers, courts, attorneys, and the public, nor an efficacious, comprehensive solution to the insurance/genetic dilemma.

3. In the Act, Congress explicitly reserved the power to enact legislation relating to the business of insurance.²³³ Thus, it would neither violate public policy nor usurp state regulatory power for Congress to enact exclusive, comprehensive or discrete, insurance/genetic legislation.

Immediately following the passage of the McCarran Act, state insurance commissioners and the insurance industry took joint action to satisfy the Act's requirement for the exemption of insurers from federal antitrust regulation.²³⁴ With the participation of an All-Industry Committee, NAIC prepared and recommended for each state's adoption model regulatory acts containing strictures against deceptive practices, unfair methods of competition, and "excessive, inadequate, and unfairly discriminatory" rates.²³⁵ The acts (sometimes called the "All-Industry laws") were avowedly designed as an "umbrella" against federal intervention. By 1950, all states had enacted versions of this legislation, thereby firmly establishing it as the sole province of the states.²³⁶

what probably was originally intended in 1945. But that observation may not be accurate. Although a comprehensive critical analysis of the three-part *Pireno* test could be written, the bottom line is that to avoid the uncertainty regarding the exclusivity and supremacy of any state statutory solution to the insurance problems that will arise upon completion of the HGP, a uniform, comprehensive federal insurance/genetics statute appears to be the most certain and preferable approach.

²³³ After stating in section 2(b) that "No Act of Congress" shall preempt state insurance regulatory laws, Congress reserved the power by stating "unless such Act specifically relates to the business of insurance . . ." 15 U.S.C. § 1012(2)(b) (1958).

²³⁴ The last part of section 2(b) states that the Sherman Act, the Clayton Act, and the Federal Trade Commission Act "shall be applicable to the business of insurance to the extent that such business is not regulated by State law." *Id.*

²³⁵ These acts primarily concerned rate regulation, a complex subject well beyond the scope of this Article. *See generally* 1 GEORGE RICHARDS, INSURANCE LAW 216-20 (5th ed. 1952) (explaining NAIC's recommendations to 1947 state legislatures and listing the states that adopted the recommendations).

²³⁶ *See, e.g.,* James B. Donovan, *State Regulation of Insurance*, 1956 INS.

Before attempting to resolve the underlying issue of federal versus state regulation of insurance/genetic concerns, current federal and state statutes addressing these concerns should be evaluated to ascertain which approach appears to be the most efficacious. The reasons for governmental regulation are primarily to prevent contractual overreaching and to assure the solvency and quality of insurers and their agents. More importantly for purposes of this Article, regulation also seeks to assure the availability of insurance coverages with premium rates and rating classifications that are fair and nondiscriminatory. At present, the use of genetic information by insurers is prohibited in a relatively small, but growing number of jurisdictions. Of the regulation that does exist, most fails specifically to address the use of genetic information in the underwriting process. Since the enactment of the McCarran Act, there have been some congressional efforts to regulate insurance classification, but these efforts to date have been unsuccessful.²³⁷ This lack of federal regulation allows insurers to exchange medical information through organizations such as the Medical Information Bureau.²³⁸ The use of this information is then at the discretion of the insurers, and other existing laws are inadequate to protect people from the arbitrary and unfair use of genetic information by insurers.

B. Current Federal Law Is Inadequate and Problematically Defers to State Insurance Regulation

1. ERISA: Employee Retirement Income Security Act of 1974

The issues surrounding health care in America cannot be adequately addressed without considering the extent to which Americans rely upon their employers for insurance coverage.²³⁹ Our employment-based

L.J. 11, 12-15 (discussing various regulatory provisions adopted by the states following NAIC's recommendations). For a full explanation of the NAIC Model Unfair Trade Practices Act and the state versions, *see infra* Part II.C (notes 110-21 and accompanying text).

²³⁷ *See, e.g.,* Wortham, *supra* note 76, at 364-66 (discussing proposed federal bills that would prohibit discrimination by insurers on the basis of race, color, religion, gender, or national origin).

²³⁸ *See, e.g.,* Schatz, *supra* note 14, at 1801. *See supra* notes 209-13 and accompanying text for a description of the Medical Information Bureau.

²³⁹ Tracy S. Guice, *AIDS Discrimination in Employee Health Benefits: Is There a Federal Remedy for Modification of a Plan Once an Employee Develops AIDS?*, 18 LAW & PSYCHOL. REV. 377, 377-78 (1990) ("[O]ur society has

health insurance arose from the desire of employers, confronting governmental controls of wage rates during WWII, to attract and retain scarce labor. One way to augment an employee's effective wage without violating the WWII wage controls was to provide employees with health insurance as a fringe benefit. Currently, most people under age sixty-five obtain health insurance through their employers.²⁴⁰ As of 1990, eighty-five percent of these Americans had some form of private health insurance, and seventy percent of these insureds had employer-sponsored health coverages.²⁴¹ In the late 1980s, it was estimated that over 146 million Americans had some form of employer-provided health insurance, either through an employer's self-insurance benefit plan or through a group-medical insurance plan commercially purchased through a third-party insurance company.²⁴²

Employer-based health insurance organizations are subject to federal legislation known as the Employee Retirement Income Security Act ("ERISA"),²⁴³ enacted in 1974 to protect the rights of employees and their beneficiaries in employee benefit plans. ERISA promotes continued coverage and assured benefits²⁴⁴ by providing civil remedies over which federal courts have exclusive jurisdiction. This exclusivity is mitigated only by a grant to state courts of concurrent jurisdiction over actions to recover benefits due, to enforce rights, or to clarify rights to future benefits.²⁴⁵ However, virtually all state and local regulation of employer-established plans is preempted and eliminated by ERISA. The problem is that this ERISA preemption of state remedies creates a regulation-free void where state regulation of employee health insurance and other benefits was and would be.²⁴⁶

placed the onus of health care funding on the employment relationship'" (quoting John F. Dudley, Comment, *The Medical Costs of AIDS: Abandoning the HIV-Infected Employee*, 30 DUQ. L. REV. 915, 915 (1992)).

²⁴⁰ See, e.g., Kronick, *supra* note 74.

²⁴¹ See CONGRESSIONAL BUDGET OFFICE, ECONOMIC IMPLICATIONS OF RISING HEALTH CARE COSTS 30-33 (1992).

²⁴² MEDICAL TESTING AND HEALTH INSURANCE, *supra* note 39, at 41; see also INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, CONFRONTING AIDS: DIRECTIONS FOR PUBLIC HEALTH, HEALTH CARE, AND RESEARCH 165 (1986) (noting that private insurance covers a significant proportion of the costs of AIDS care); INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, CONFRONTING AIDS: UPDATE 1988 (updating 1986 study).

²⁴³ Pub. L. No. 93-406, 88 Stat. 829 (1974).

²⁴⁴ 29 U.S.C. § 1001-1461 (1988 & Supp. I 1989).

²⁴⁵ *Id.* § 1132 (e)(1).

²⁴⁶ See Mary Anne Bobinski, *Unhealthy Federalism: Barriers to Increasing*

Congress designed ERISA to promote the interests of employees and their beneficiaries in employee welfare benefit plans that, through insurance, provide medical, surgical, or hospital care as well as benefits in the event of sickness, accident, disability, or death.²⁴⁷ The statute governs employee benefit plans, classifying them according to two sets of characteristics: the types of benefits provided, and the means of funding of the plan.²⁴⁸ The first distinction separates welfare plans²⁴⁹ from pension or retirement plans.²⁵⁰ Noteworthy for our purposes are the following: (1) "ERISA does not mandate that employers provide any particular benefits . . .";²⁵¹ (2) ERISA does not proscribe employer discrimination in providing employee benefits;²⁵² and (3) unlike pen-

Health Care Access for the Uninsured, 24 U.C. DAVIS L. REV. 255, 274-75 (1990) (criticizing ERISA's preemption given the absence of federal substantive regulation); Alan I. Widiss & Larry Gostin, *What's Wrong With the ERISA "Vacuum"?: The Case Against Unrestricted Freedom for Employers to Terminate Employee Health Care Plans and to Decide What Coverage Is to Be Provided When Risk Retention Plans Are Established for Health Care*, 41 DRAKE L. REV. 635, 655 (1992); Lizzette Palmer, Comment, *ERISA Preemption and Its Effects on Capping the Health Benefits of Individuals with AIDS: A Demonstration of Why the United States Health and Insurance Systems Require Substantial Reform*, 30 HOUS. L. REV. 1347, 1360 (1993) ("Ultimately, Congress, through ERISA preemption of state remedies, has left a void where state regulation of employee benefits was or would be.").

²⁴⁷ *Shaw v. Delta Airlines*, 463 U.S. 85, 90-91 (1983) (discussing ERISA's purpose and relevant definitions).

²⁴⁸ 29 U.S.C. § 1002 (1994).

²⁴⁹ *Id.* § 1002(1). An employee welfare benefit plan includes any program that provides benefits for contingencies such as illness/medical/hospitalization, disability, accident, death, or unemployment. Courts have broadly interpreted and construed ERISA: "[S]ingle employer purchases of insurance constitute ERISA governed plans." E. Thomas Bishop & Paula Denney, *Hello ERISA, Good-bye Bad Faith: Federal Pre-emption of DTPA, Insurance Code, and Common Law Bad Faith Claims*, 41 BAYLOR L. REV. 267, 269 (1989).

²⁵⁰ 29 U.S.C. § 1001(2)(A) (1994) (stating that an employee pension plan provides income deferral and a retirement income).

²⁵¹ *Shaw*, 463 U.S. at 91.

²⁵² *Id.* The absence of ERISA proscription or prescription regarding unfair insurance discrimination issues is considered throughout this section. Employer-sponsored self-insured plans are a primary concern. The principal problem is the ERISA vacuum created by excluding employer self-insured plans from state regulation while concomitantly providing no federal insurance regulation. *See, e.g.,* Widiss & Gostin, *supra* note 246, at 638-40; *see also* Palmer, *supra* note

sion-retirement benefits,²⁵³ ERISA's strict funding²⁵⁴ and vesting²⁵⁵ requirements do not apply to welfare benefits.

The second basic ERISA distinction relates to the source of a benefit plan.²⁵⁶ A plan is either self-funded by the employer or purchased from an insurance company. Because of ERISA's preemption, savings, and deemer clauses, the distinction between employer self-insured plans and employer plans purchased from commercial insurers is very significant to the issue of health insurance coverage for employees with genetically identified disorders.

*a. Section 514's Preemption,
Saving, and Deemer Provisions*

Understanding ERISA's section 514 preemption is difficult. Concentric circles of confusion surround this preemption clause which was intended to effect national uniformity in the regulation of employee benefit plans.²⁵⁷ Confusion arises because section 514 has three relevant clauses: a preemption clause, a saving clause, and a deemer clause. As an overview, ERISA first preempts and supersedes all state laws *relating to* an employee benefit plan. But the saving clause excepts from the preemption clause state laws that *regulate insurance*. Then the deemer

246, at 1361-62 (discussing ERISA's preemption as providing a method for employees to avoid state regulation by self-insuring).

²⁵³ See, e.g., Frances Figetakakis, *Retiree Welfare Benefits: ERISA, LMRA and the Federal Common Law*, 20 AKRON L. REV. 455, 456 (1987) (noting the stringent funding and vesting requirements based on age and length of service required of ERISA pension plans).

²⁵⁴ 29 U.S.C. §§ 1081-1086 (1994). For an examination of ERISA funding requirements, see MICHAEL J. CANAN, *QUALIFIED RETIREMENT AND OTHER EMPLOYEE BENEFIT PLANS* § 12.2 (1996) (offering a detailed examination of ERISA funding standards in relation to the Internal Revenue Code).

²⁵⁵ When a benefit vests, it becomes nonforfeitable. 29 U.S.C. § 1053(a) (1994); Joan Vogel, *Until Death Do Us Part: Vesting of Retiree Insurance*, 9 INDUS. REL. L.J. 183, 183-84 (1987) (noting that most cases have held that retiree insurance vests at retirement). In contrast, employers under self-insured plans may redraft a welfare plan to exclude or limit specific medical conditions after learning that a particular employee suffers from an extraordinary medical risk such as AIDS. This concern is considered in this Article in relation to both ERISA and the Americans with Disabilities Act ("ADA").

²⁵⁶ 29 U.S.C. § 1144(b) (1994).

²⁵⁷ *Id.* § 1001.

clause provides that a state law that *purports to regulate insurance* cannot deem an employee benefit plan to be an insurance company. In other words, if a state law relates to an employee benefit plan, ERISA preempts that state law unless the state law regulates insurance and does not inaptly deem an employer offering a benefit plan with health insurance coverages to be an insurer.

(1) *Preemption Clause*

Except as provided in subsection (b) of this section [the saving clause], the provisions of this subchapter and subchapter III of this chapter shall supersede any and all State laws insofar as they may now or hereafter relate to any employee benefit plan.²⁵⁸

The words “relate to” have been construed expansively by the Supreme Court,²⁵⁹ so that ERISA’s preemption has been applied to all forms of state action that might affect benefit plans.²⁶⁰ Since ERISA preempts state laws that conflict with its enforcement provisions,²⁶¹ the Court has interpreted ERISA’s civil enforcement scheme to be exclusive and controlling over state law, including state insurance common-law causes of action²⁶² as well as state statutes mandating health insurance coverages.²⁶³ In sum, ERISA

²⁵⁸ ERISA section 514(a), as set forth in 29 U.S.C. § 1144(a) (1994).

²⁵⁹ See, e.g., *Fort Halifax Packing Co. v. Coyne*, 482 U.S. 1, 8 (1987) (noting that “relates to” has been defined as “having a connection with or reference to”).

²⁶⁰ See, e.g., *Ingersoll-Rand Co. v. McClendon*, 498 U.S. 133, 137-42 (1990) (holding that a state claim for relief was preempted by ERISA since it related to an ERISA plan and because it directly conflicted with an ERISA claim for relief).

²⁶¹ ERISA’s civil enforcement clause is stated in section 502(a), as set forth in 29 U.S.C. § 1132(a) (1994).

²⁶² See, e.g., *Pilot Life Ins. Co. v. Dedeaux*, 481 U.S. 41, 48 (1987). Dedeaux, an employee, claimed permanent disability benefits under a group disability policy which the employer purchased from Pilot Life. Dedeaux had a disabling accident in 1975, which he alleged caused a permanent disability, but Pilot Life terminated his benefits after two years. Dedeaux sued under Mississippi insurance “bad faith” law regarding the failure to pay the disability benefits. The Court held that this common-law first-party-insurance “bad faith” cause of action did not “regulate insurance” and was preempted by ERISA. *Id.* at 51.

²⁶³ For instance, under the District of Columbia Workers’ Compensation Equity Amendment Act of 1990, the District of Columbia required employers who provide health insurance for their employees to provide equivalent health

preempts and eliminates virtually all state and local regulation of employer-established employee benefit plans.²⁶⁴

(2) *Saving Clause*

Except as provided in subparagraph (B) [the deemer clause], nothing in this subchapter shall be construed to exempt or relieve any person from any law of any State which regulates insurance, banking, or securities.²⁶⁵

Similar to the McCarran Act,²⁶⁶ ERISA's saving clause expresses a public policy preference for the continued regulation of the insurance industry by the states. Obviously, the saving clause saves state laws regulating insurance from ERISA preemption. In ascertaining if ERISA preempts a state law that purports to regulate insurance, the Supreme Court applied a common-sense construction to "insurance"²⁶⁷ as well as the three-prong test used to define "business of insurance" under the

insurance coverage for injured employees eligible for workers' compensation benefits. Assuring that federal regulation of covered employee benefit plans shall be exclusive, the Supreme Court held that the D.C. statutory requirement is preempted by ERISA. *District of Columbia v. Greater Wash. Bd. of Trade*, 506 U.S. 125, 130 (1992).

²⁶⁴ *Id.*; *Shaw v. Delta Airlines, Inc.*, 463 U.S. 85, 108-09 (1983) (holding ERISA preempted New York's Human Rights Law only to the extent it prohibited actions permitted under federal law, but ERISA did not preempt New York's Disability Benefits Law); *Metropolitan Life Ins. Co. v. Taylor*, 481 U.S. 58, 62-63 (1987) (holding that ERISA preempted common law contract and tort claims which were not laws regulating insurance); *Cathey v. Metropolitan Life Ins. Co.*, 805 S.W.2d 387, 389-90 (Tex.) (finding that state law includes all laws, decisions, rules, regulations, or other action having the effect of law and is preempted by ERISA if it relates to a covered plan), *cert. denied*, 509 U.S. 1232 (1991).

²⁶⁵ ERISA section 514(b)(2)(A), as set forth in 29 U.S.C. § 1144(b)(2)(A) (1994).

²⁶⁶ See *supra* Part IV.A (notes 218-38 and accompanying text) for a description of the McCarran Act.

²⁶⁷ The common-sense meaning of "regulates insurance" requires that the state law specifically be directed to the insurance industry. See *Pilot Life Ins. Co. v. Dedeaux*, 481 U.S. 41, 50 (1987) (stating that in order to regulate insurance, the state law cannot merely impact the insurance industry; it must be directed specifically toward the insurance industry).

McCarran Act.²⁶⁸ Under this dual test, ERISA has been found to preempt insurance common-law “bad faith” claims,²⁶⁹ state deceptive trade practices regulations,²⁷⁰ and claims under state unfair settlement practices acts.²⁷¹

²⁶⁸ In determining whether the state law regulates the business of insurance, the *Pilot Life* Court, quoting *Union Labor Life Ins. Co. v. Pireno*, 458 U.S. 119, 129 (1982), applied the three-part test: “[F]irst, whether the practice has the effect of transferring or spreading a policyholder’s risk; second, whether the practice is an integral part of the policy relationship between the insurer and the insured; and third, whether the practice is limited to entities within the insurance industry.” *Id.* at 48-49; see also *Metropolitan Life Ins. Co. v. Massachusetts*, 471 U.S. 724, 740 (1985) (considered to be the leading case applying the three-prong McCarran test in determining if a state law regulates insurance and falls within the saving clause).

The Court in *Pilot Life* concluded: “Considering the common-sense understanding of the saving clause, the McCarran-Ferguson Act factors defining the business of insurance, and, most importantly, the clear expression of congressional intent that ERISA’s civil enforcement scheme be exclusive, we conclude that Dedeaux’s state law suit asserting improper [“bad faith”] processing of a claim for benefits under an ERISA-regulated plan is not saved by § 514(b)(2)(A), and therefore is pre-empted by § 514(a).” *Pilot Life*, 481 U.S. at 57.

²⁶⁹ The Supreme Court held that Mississippi’s law of insurance “bad faith” does not regulate insurance directly because its roots are in contract and tort law. *Id.* at 50. *Pilot Life* has been followed regarding state common law causes of action for delay in processing insurance claims that are preempted by ERISA. See, e.g., *Belasco v. W.K.P. Wilson & Sons, Inc.*, 833 F.2d 277, 281 (11th Cir. 1987) (holding that the saving clause did not apply because Alabama law of bad faith had roots in contract and tort law).

²⁷⁰ Deceptive trade practices regulation, as well as the insurance bad faith tort, do not affect spreading of risk nor are they limited to insurance companies. See, e.g., *Bishop & Denney*, *supra* note 249, at 277.

²⁷¹ For instance, lower federal courts have held that claims of unfair settlement practices arising under CAL. INS. CODE § 790.03(h) (West 1993) are preempted under ERISA. See, e.g., *Lee v. Prudential Ins. Co. of Amer.*, 673 F. Supp. 998, 1002 (N.D. Cal. 1987) (holding that, while a California statute that prohibited fifteen unfair insurance claims settlement practices “regulated insurance” for purposes of ERISA’s saving clause, congressional intent that the ERISA civil enforcement scheme be the exclusive remedy for assertion of improper processing of benefit claims displaces claims under the California statute); *Roberson v. Equitable Life Assurance Soc’y of U.S.*, 661 F. Supp. 416, 424 (C.D. Cal. 1987) (holding that even if the California statute regulates insurance and is within the scope of the saving clause, it must be preempted for

In the 1970s and 1980s, ERISA preemption became a significant issue for health policy. ERISA preemption forbade states from requiring an employer to provide particular health benefits or to provide any benefits at all.²⁷² Hawaii mounted a concerted attack on ERISA's preemption in the Hawaii Prepaid Health Care Act²⁷³ which required Hawaiian employers to provide health care for almost all Hawaiian employees. But in the congressional debate that followed, other states did not come to Hawaii's aid. State insurance commissioners were more concerned with ERISA preempting their power to enforce state insurance laws to regulate multiple employer-trusts ("METS"), set up by independent agents that sold health insurance to small employers. The state insurance commissioners worriedly witnessed the proliferation of self-insured METS that had a propensity to become insolvent with millions of promised benefits unpaid.²⁷⁴ However, Congress's main worry was with Hawaii. In 1983, Congress amended section 514 to provide a partial exemption for Hawaii that specifically stated that the Hawaii exemption would not apply to any other state law.²⁷⁵

infringing on ERISA's same exclusive civil remedy provision), *aff'd*, 869 F.2d 1498 (9th Cir. 1989). Additionally, tort claims of federal employees insured under the Federal Employee Health Benefits Act ("FEHBA") for common-law "bad faith" or violation of CAL. INS. CODE § 790.03(h) have been held to be preempted by the federal FEHBA. *See* 5 U.S.C. § 8902(m); *Hayes v. Prudential Ins. Co.*, 819 F.2d 921, 925-26 (9th Cir. 1987) (drawing an analogy to ERISA preemption of state common law tort and contract claims), *cert. denied*, 484 U.S. 1060 (1988); *Hartenstine v. Superior Ct.*, 241 Cal. Rptr. 756, 764 (Cal. Ct. App. 1987) (holding that state law claims refer to plan and therefore fall under preemption clause of FEHBA), *cert. denied*, 488 U.S. 899 (1988).

²⁷² *Wadsworth v. Whaland*, 562 F.2d 70, 78 (1st Cir. 1977) (holding that state law regulating insurance that requires employers to provide coverage for treatment of mental illnesses and emotional disorders does not conflict with ERISA, which does not require coverage, and thus is not preempted), *cert. denied*, 435 U.S. 980 (1978).

²⁷³ HAW. REV. STAT. § 393 (1974).

²⁷⁴ For an account of multiple employer trusts, see Edward A. Scallet, *The Regulation of Multiple Employer Trusts: Past, Present and Future*, 61 WASH. U. L.Q. 359, 360-61 (1983) (discussing the ability of operators of METS to drain assets of the trusts as a result of ERISA regulation).

²⁷⁵ For a thorough discussion of Hawaii's challenge to ERISA's preemption and the special ERISA exemption compromise, see Daniel M. Fox & Daniel C. Schaffer, *Semi-Preemption in ERISA: Legislative Process and Health Policy*, 7 AM. J. TAX POL'Y 47, 52-60 (1988).

The 1983 exemption for Hawaii, which was coupled with permission to the states to regulate METS, was the last exemption but one to ERISA preemption that Congress granted. In 1986, Congress granted the state the power to mandate that employee health plans not include any provision which require the employee to use Medicaid before claiming benefits under the plan. Federal law required the states to make Medicaid a secondary payor when a beneficiary had private health insurance. This the states could do when the health insurance was issued by a carrier: they could forbid carriers [insurers] to insert in policies that the carrier would pay only after the insured had exhausted Medicaid benefits. But the states could make no similar law as to *self-insured employee health plans*: ERISA semi-preemption forbade it.²⁷⁶

The saving clause received further clarification when the Supreme Court, in a 1985 opinion, held that states could regulate only the health insurance in employee benefit plans that was written by insurance companies, including nonprofit companies.²⁷⁷ The saving clause allowed the states to require insurance companies to include mandated benefits in the insurance policies even though mandated benefits constituted "indirect regulation"²⁷⁸ of the employee benefit plans that Congress had forbidden the states to regulate. The Court held that a Massachusetts statute setting forth mandatory minimum health care benefits for inclusion in general insurance policies was saved and not preempted by ERISA.²⁷⁹ However, a state was forbidden from regulating an employer's self-insurance benefit plan by declaring it to be insurance or in the insurance business. It is noteworthy that the Court explained that if the distinction between insurer-insured and employer self-insured employee benefit plans is to be abolished, Congress, and not the courts, would have to make that change.²⁸⁰ The final section of this Article suggests that ERISA ought to be so amended or that a comprehensive federal insurance/genetics law should address the matter.²⁸¹

²⁷⁶ *Id.* at 59-60 (emphasis added) (citing 29 U.S.C. § 1144(b)(8) (1988)).

²⁷⁷ *Metropolitan Life Ins. Co. v. Massachusetts*, 471 U.S. 724, 747 (1985) (holding that insured plans were not preempted by ERISA).

²⁷⁸ *Id.*

²⁷⁹ Noting that the preemption and saving clauses seem to contradict one another, the Court nevertheless concluded that Congress did not intend to preempt areas of traditional state regulation such as mandated insurance benefits. *Id.* at 744.

²⁸⁰ *Id.* at 747.

²⁸¹ See *infra* Part IV.D (notes 548-69 and accompanying text).

For our purposes, then, the question is whether a state law concerning genetic testing and insurance underwriting would be saved from ERISA preemption? The answer seems to be “yes,” but only as to insurer-underwritten plans. Employers’ self-insured plans are deemed beyond the reach of state insurance commissioners. Therein lies the problem.

(3) *Deemer Clause*

Neither an employee benefit plan nor any trust established under such a plan, shall be deemed to be an insurance company or other insurer or to be engaged in the business of insurance for purposes of any law of any State purporting to regulate insurance companies, [or] insurance contracts ²⁸²

The deemer clause makes clear that a state law purporting to regulate insurance cannot deem an employee benefit plan to be an insurance company. The United States Supreme Court interpreted ERISA’s deemer clause to mean that employer self-insured plans are to be regulated only by ERISA and are exempt from state insurance regulation. Employee benefit plans funded by commercially purchased health insurance remain subject to state regulation of insurance law but are also subject to ERISA. The Supreme Court explained:

We read the deemer clause to exempt self-funded ERISA plans from state laws that “regulat[e] insurance” within the meaning of the saving clause. By forbidding States to deem employee benefit plans “to be an insurance company or other insurer or to be engaged in the business of insurance” the deemer clause relieves plans from state laws “purporting to regulate insurance.” As a result, self-funded ERISA plans are exempt from state regulation insofar as that regulation “relate[s] to” the plans. State laws directed toward the plans are pre-empted because they relate to an employee benefit plan but are not “saved” because they do not regulate insurance. State laws that directly regulate insurance are “saved”; but do not reach self-funded employee benefit plans because the plans may not be deemed to be insurance companies, other insurers, or engaged in the business of insurance for purposes of such state laws. On the other hand, employee benefit plans that are insured are subject to indirect state insurance regulation. An insurance company that insures

²⁸² ERISA section 514(b)(2)(B), as set forth in 29 U.S.C. § 1144(b)(2)(B) (1994).

a plan remains an insurer for purposes of state laws “purporting to regulate insurance” after application of the deemer clause. The insurance company is therefore not relieved from state insurance regulation. The ERISA plan is consequently bound by state insurance regulations insofar as they apply to the plan’s insurer.²⁸³

However, the deemer clause undercuts ERISA’s public-policy preference for state regulation of insurance by prohibiting states from regulating self-insured employee benefit plans.²⁸⁴ State insurance laws and regulations designed to assure adequate health insurance for employees of commercially insured employers do not give any protection to the millions of employees of self-insured employers.²⁸⁵ As a conse-

²⁸³ *FMC Corp. v. Holliday*, 498 U.S. 52, 61 (1990).

²⁸⁴ A “self-insurance” plan is also known as a “risk retention,” “self-funded,” or “employer-sponsored” plan. The Supreme Court recognizes the distinction between commercially-funded plans and self-insured plans. *Metropolitan Life Ins. Co.*, 471 U.S. at 747 (“We are aware that our decision results in a distinction between insured and uninsured plans . . .”). Risk retention is an attractive option for several reasons. Businesses that self-insure retain control over the funds they allocate for employee health financing. Rather than paying a premium to a commercial insurer, self-insured employers directly assume the risk of loss and pay some or all of their employees’ health care costs. Sometimes, they purchase catastrophic loss coverage from commercial insurers to diminish their financial exposure. Most avoid administrative costs of processing claims by contracting with commercial or non-profit, such as Blue Cross/Blue Shield, insurers or other third-party administrators. But, most importantly, employers with self-funded plans avoid the oversight of state insurance commissioners and state-mandated health insurance coverages.

²⁸⁵ For instance, well over half of all employees work for employers that are partially or fully self-insured. Robert Pear, *Court Approves Cuts in Benefits in Costly Illness*, N.Y. TIMES, Nov. 27, 1991, at 1 [hereinafter Pear, *Court Approves Cuts*]; Robert Pear, *Bush Faces Hard Choice on Limits on Insurance*, N.Y. TIMES, May 19, 1992, at A12 (noting that tens of millions of employees receive health insurance from employers serving as their own insurers); Robert Pear, *Justices Leave Intact Ruling That Lets Business Cut Health Benefits*, N.Y. TIMES, Nov. 10, 1992, at A18 (noting that a growing number of employers serve as their own insurers). By 1992, almost two-third of all employers were self-insured. Milt Freudenheim, *Employers Winning Right to Cut Back Medical Insurance*, N.Y. TIMES, Mar. 29, 1992, at A1. For discussions of the employer movement to self-insure, see L.H. Otis, *Self-Insureds Proliferate in Soft Market*, 95 NAT’L UNDERWRITER PROP. & CASUALTY, Nov. 25, 1991, at 1, 38 (“Self-insurance grew 19.4 percent (from \$32 to \$38.2 billion) while conventional market

quence, employer self-insured or risk retention plans are becoming the norm in employee health insurance.

Self-insurance is a very enticing option for employers. Self-funding frees employers from scrutiny by state insurance commissioners. It allows employers to escape state-mandated minimum health benefit requirements,²⁸⁶ and to evade insurance premium taxes that subsidize state-administered high-risk insurance pools. But self-insurance is not an attractive alternative for employees. Whereas ERISA was intended to effect national uniformity in regulating employee benefit plans, it fails to regulate self-insured plans, which the states cannot regulate. ERISA has no regulations either prescribing or proscribing self-insured plans with health care benefits.²⁸⁷ Notwithstanding that ERISA prohibits discrimination against an employee in exercising or attaining a right under a welfare benefit plan (i.e., the employer cannot fire the employee),²⁸⁸ ERISA does not prohibit a self-funded employer, after finding out about a particular genetic or other medical condition, from redrafting its employee health insurance benefits to limit or exclude specific medical conditions. The absence of federal ERISA regulation in the self-insured context has been critically described as creating a regulatory vacuum, that is, ERISA's regulation-free zone.²⁸⁹ It is said that ERISA's vacuum

premium volume rose just 3.8 percent (from \$115.6 to \$120 billion) between 1988 and 1990"); Sara Marley, *Alternative Risk Financing Continues to Gain Strength: Larger Employers Explore Options in Many Lines*, 27 BUS. INS., Jan. 25, 1993, at 3 (stating that self-insurance accounted for 27% of the commercial market in 1992 and by the end of 1993 will account for 30% of the market).

²⁸⁶ All states currently regulate the terms of group health insurance policies. See *infra* Part IV.C.1 (notes 391-422 and accompanying text). See, e.g., Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 80 (1992) (noting more than 1000 extant state insurance coverage mandates).

²⁸⁷ Henry T. Greely, *AIDS and the American Health Care Financing System*, 51 U. PITT. L. REV. 73, 104-11 (1989). But see *EEOC Issues Guidance on Relationship Between Insurance and ADA*, BNA News and Background Information (June 14, 1993), available in Westlaw, 143 LRR 193 d8 (discussing health-related insurance conditions based on disability as possible violations of the ADA).

²⁸⁸ ERISA section 510, as set forth in 29 U.S.C. § 1140 (1994).

²⁸⁹ See generally Fox & Schaffer, *supra* note 275, at 48-49 (commenting that ERISA's regulatory vacuum was not carefully considered but was hurriedly inserted in the conference committee just before Congress took final action on ERISA). See also Marci A. Firfer, *Direct Employer-Provider Contracting and*

exercising state regulation has seriously impeded the capability of state governments to create appropriate universal coverage solutions for millions of uninsureds.²⁹⁰ Others retort that ERISA's regulation-free zone protects employers from conflicting, inconsistent state regulatory laws and permits employers to operate uniform employee health care plans across many states.²⁹¹

One point is clear. The extent to which self-funded plans will cover employees is, with ERISA's blessing, at the absolute discretion of the employer. Moreover, an employer's power to limit or exclude employee health insurance benefits under conditions solely determined by the employer has been upheld in the context of medical coverage for AIDS under an employer's self-insured plan.²⁹² When considering this power

ERISA Preemption: A Regulatory Loophole?, 40 FED'N OF INS. & CORP. COUNS. Q. 195, 195-242 (1990) (concluding that ERISA's regulatory loophole creates significant policy issues yet to be resolved by the courts); Morelli, *supra* note 154, at 8 ("Even if there were some type of protective legislation [regarding genetic testing] in every state, persons working for self-insured employers would not be covered because of ERISA which exempts self-insured employers from state laws pertaining to health benefits."); Jeffrey A. Mello, *Limitations of the Americans with Disabilities Act in Protecting Individuals with HIV from Employment Discrimination*, 19 SETON HALL LEGIS. J. 73, 104-08 (1994) (discussing ERISA's vacuum as a loophole in insurance laws); Edward F. Shay, *Discrimination in Health Benefits: ERISA and Beyond*, 7 AIDS & PUB. POL'Y 92-95 (1992); Widiss & Gostin, *supra* note 252, at 654-55 (recognizing that ERISA allows employers to enter a regulation-free zone); Palmer, *supra* note 246, at 1360 (noting the void left by ERISA preemption); Steven L. Brown, Note, *ERISA's Preemption of Estoppel Claims Relating to Employee Benefit Plans*, 30 B.C. L. REV. 1391, 1416-22 (1989) (discussing the emergence of federal common law under ERISA to fill gaps created by state law preemption); Jonathan Goldstein, Comment, *ERISA's Deemer Clause and the Question of Self-Insureds: What's a State to Do?*, 67 WASH. U. L.Q. 291, 299-303 (1989) (discussing ERISA's deemer clause and preemption for self-insured plans). For an analysis approving ERISA's regulation-free zone, see Hylton, *supra* note 82, at 78 ("Thus, the creation of a risk retention plan enables an employer, regardless of what the otherwise applicable state [health insurance] mandates require, to regain the ability to fashion a health plan which meets the particular needs of her employees at an acceptable price.").

²⁹⁰ Bobinski, *supra* note 246, at 275.

²⁹¹ Kathlynn L. Butler, *Securing Employee Health Benefits Through ERISA and the ADA*, 42 EMORY L.J. 1197, 1239 (1993) (recognizing ERISA's broad preemption as successful in protecting employers' interests).

²⁹² *McGann v. H & H Music Co.*, 946 F.2d 401, 404-05 (5th Cir. 1991), *cert.*

to self-regulate together with the financial incentives employers have to reduce the cost of health care, it is reasonably foreseeable that employers will pragmatically use genetic information following completion of the HGP to make decisions about health insurance coverages.²⁹³

*b. ERISA Permits Self-Insured
Employers to Discriminate by Excluding
or Limiting Employees' Health Insurance*

The judge-made bottom line under ERISA is that self-insured employers can discriminate without impunity in the creation, alteration (e.g., by exclusions or by capping monetary benefits for medical risks or conditions), and termination of employees' insurance coverages in employee benefit plans. It is generally understood that if an employee can establish a causal connection between a medical risk, the loss of insurance benefits, and an adverse employment action, the employee may be entitled to relief under section 510 of ERISA, which provides:

It shall be unlawful for any person to discharge, fine, suspend, expel, discipline, or discriminate against a [plan] participant or beneficiary for exercising any right to which he is entitled under the provisions of an

denied sub nom. Greenberg v. H & H Music Co., 506 U.S. 981 (1992). In *McGann*, the Fifth Circuit held that an employer was within its rights when reducing the maximum amount of benefits available to employees with AIDS from \$1 million to \$5000. McGann was employed by H & H which provided insurance to its employees through a purchased plan. McGann had AIDS. After he filed a claim for benefits in March of 1988, H & H changed its plan, became self-funded, and reduced the total coverage available for AIDS claims. The district court found no discrimination because H & H was not required by ERISA to continue insurance benefits. In affirming, the Fifth Circuit held that to find discrimination would clearly conflict with congressional intent that employers remain free to create, modify, and terminate the terms and conditions of employee benefit plans. *Id.*; accord *Owens v. Storehouse, Inc.*, 984 F.2d 394, 399 (11th Cir. 1993) (holding that an employer, for economic reasons, could reduce lifetime AIDS-related benefits from \$1 million to \$25,000); see also *Custer v. Pan Am. Life Ins. Co.*, 12 F.3d 410, 421-22 (4th Cir. 1993). In *Custer*, the plaintiff's first claim was for maternity benefits which the insurance policy did not cover. Moreover, her pregnancy was a pre-existing condition. The court held that there was no basis for a discrimination claim when medical benefits for the newborn baby were denied.

²⁹³ For a description of possible hiring discrimination based on genetic information, see *supra* Part II.F (notes 134-39 and accompanying text).

employee benefit plan . . . or for the purpose of interfering with the attainment of any right to which such participant may become entitled under the plan.²⁹⁴

The significance of section 510 is that it could, although it generally does not, provide redress for employees who are discriminated against because they are considered insurance risks.²⁹⁵ For instance, self-insureds may deny, exclude, or limit coverage based on an employee's medical risks. Also importantly, section 510 is inapplicable to job applicants as well as to employees who do not receive insurance plan benefits. Therefore, an applicant who is refused employment because of his/her anticipated medical costs has no claim for relief under section 510. Any federal or state insurance/genetics discrimination law should address and rectify unfair discriminatory wrongs to such employees and job applicants.

In a decision with far-reaching implications for genetic testing of employees to actuarially ascertain medical risks, the Fifth Circuit, in *McGann v. H & H Music Co.*,²⁹⁶ ruled that a self-insured employer can change its insurance policy to reduce coverage for workers who develop costly illnesses.²⁹⁷ In December 1987, John W. McGann, an employee of H & H Music, discovered he had contracted HIV. McGann submitted his first claims for reimbursement under the employer's group medical plan and informed management he had AIDS. In July 1988, H & H Music informed its employees that changes would be made in their medical coverage. These changes included limiting benefits for AIDS-related claims to a lifetime maximum of \$5000. Before the change, the lifetime coverage was \$1 million for all diseases. Other changes included increased individual and family deductibles, elimination of coverage for chemical dependency treatment, adoption of a preferred provider plan, and increased contribution requests. No limitation was placed on any other catastrophic illness. H & H Music also became a self-insurer under

²⁹⁴ ERISA section 510, as set forth in 29 U.S.C. § 1140 (1988).

²⁹⁵ See, e.g., Joan Vogel, *Containing Medical and Disability Costs by Cutting Unhealthy Employees: Does Section 510 of ERISA Provide a Remedy?*, 62 NOTRE DAME L. REV. 1024, 1037 (1987) (discussing the elimination of "expensive" employees as an ERISA section 510 violation).

²⁹⁶ *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991) (holding that there was no discrimination by employer in limiting AIDS benefits to \$5000 because limitation applied to all present and future beneficiaries who might contract AIDS), *cert. denied sub nom. Greenberg v. H & H Music Co.*, 506 U.S. 981 (1992). For an excellent analysis of *McGann*, see Hylton, *supra* note 82.

²⁹⁷ *McGann*, 946 F.2d at 403-08.

the new plan. By January 1990, McGann had exhausted the \$5000 limit on coverage for his illness.²⁹⁸

In August 1989, McGann sued H & H Music, alleging that the company discriminated against him in violation of both prohibitions of ERISA section 510.²⁹⁹ He claimed the coverage limitation for AIDS-related expenses was directed specifically at him in retaliation for exercising his rights under the plan and for the purpose of interfering with the attainment of a right to which he was entitled as a beneficiary under the plan. The employer, conceding the factual allegations of McGann's complaint, moved for summary judgment. The district court granted summary judgment, reasoning management had an absolute right to alter the terms of the plan, regardless of intent.³⁰⁰ The district court also held that "even if the issue of discrimination motive were relevant, summary judgment would still be proper because the [employer's] motive was to ensure the future existence of the plan and not specifically to retaliate against McGann"³⁰¹

In sustaining the lower court, the Fifth Circuit noted that, at trial, McGann would bear the burden of proving the existence of the employer's discriminatory intent as an element of each of his claims. McGann conceded the reduction in AIDS benefits will apply equally to all employees filing AIDS-related claims and the effect of this reduction will not be felt only by him. McGann did not allege the company's reduction had any purpose other than to reduce costs.³⁰² Consequently, McGann could not make the showing necessary to establish that management had a specific intent to retaliate against him.³⁰³

²⁹⁸ *Id.* at 403.

²⁹⁹ *Id.*

³⁰⁰ *Id.* at 404.

³⁰¹ *Id.*

³⁰² *Id.* at 403-04.

³⁰³ The burden of proof may be insurmountable for an employee. In section 510 actions, courts put the burden on the employee to prove that the employer had a specific intent either: (1) to retaliate against the employee for exercising rights under an existing plan, *see, e.g.*, *Kimbro v. Atlantic Richfield Co.*, 889 F.2d 869, 880-81 (9th Cir. 1989), *cert. denied*, 498 U.S. 814 (1990); or (2) to interfere with the employee's attainment of any right to which he or she may have become entitled, *see, e.g.*, *Dister v. Continental Group, Inc.*, 859 F.2d 1108, 1111 (2d Cir. 1988). Arguably, section 510 should be amended to eliminate the requirement that the employee prove the employer's specific intent to single out the employee. If section 510 is amended, the focus could return to the issue of fair discrimination based on a sound actuarial basis and equal treatment of all

Because the reduction in AIDS coverage affected all employees and because there was no evidence that McGann was ever promised that the \$1 million policy limit was permanent, the Fifth Circuit concluded that McGann could not prove that he was entitled to a higher cap or that he was the victim of personal retaliation.³⁰⁴ The Fifth Circuit refused to hold that section 510 prohibits any discrimination in the alteration of an employee benefit plan that results in an identifiable employee or group of employees being treated differently than other employees. Instead, the court held that:

[S]ection [510] does not prohibit welfare plan discrimination between or among categories of diseases. Section 510 does not mandate that if some, or most, or virtually all catastrophic illnesses are covered, AIDS (or any other particular catastrophic illness) must be among them. It does not prohibit an employer from electing not to cover or continue to cover AIDS, while covering or continuing to cover other catastrophic illnesses, even though the employer's decision in this respect may stem from some "prejudice" against AIDS or its victims generally. The same, of course, is true of any other disease and its victims. That sort of "discrimination" is simply not addressed by section 510.³⁰⁵

Thus, *McGann* creates a safe haven with wide leeway for employers to limit exposure to claims by employees with high medical costs.³⁰⁶

Based on the *McGann* opinion and the foregoing discussion, the limitations of ERISA in addressing future issues arising from genetic testing and the use of genetic information in designing employee benefit plans can be summarized as follows. First, unlike the states' legislation,³⁰⁷ ERISA does not establish any requirements regarding insurance

employees. Regarding retaliation, see *Stiltner v. Beretta U.S.A. Corp.*, 74 F.3d 1473, 1482-84 (4th Cir.) (holding that ERISA section 510 does not preclude an employer from revoking gratuitous benefits unless it is substantially motivated by an improper intent to retaliate rather than by legitimate business considerations), *cert. denied*, 117 S. Ct. 54 (1996).

³⁰⁴ *McGann*, 946 F.2d at 404-05.

³⁰⁵ *Id.* at 408. The holding was based on earlier authority. See *Aronson v. Servus Rubber*, 730 F.2d 12, 16 (1st Cir.) ("A termination [of benefits] that cuts along independently established lines . . . and that has a readily apparent business justification, demonstrates no invidious intent."), *cert. denied*, 469 U.S. 1017 (1984).

³⁰⁶ *Freudenheim*, *supra* note 285, at A24.

³⁰⁷ See *infra* Part IV.C.1 (notes 391-422 and accompanying text).

underwriting or insurance coverages for employee health care plans. Second, only ERISA, and not state insurance regulation, applies to employer self-funded plans. This situation creates a regulation-free vacuum. Courts give self-funded employers a hands-off liberty of action in the creation, alteration, and termination of their employee benefit plans.³⁰⁸ Employers can either refuse to provide health insurance, lower the monetary limits for health insurance, or terminate some or all health coverages.³⁰⁹ As a consequence, all future state insurance/genetic legislation is of no consequence to employers who can self-insure. Since this ERISA "opt-out option" makes all state insurance regulation ineffective and irrelevant, a national rectifying law seems imperative. Third, ERISA does provide protection prohibiting the firing of employees to remove them from the insurance pool even if the firing is financially motivated to reduce health insurance costs.³¹⁰ Fourth, ERISA section

³⁰⁸ The Fifth Circuit explained: "If a federal court could prevent an employer from reducing an employee's coverage limits for AIDS treatment once the employee contracted AIDS, the boundaries of judicial involvement in the creation, alteration or termination of ERISA plans would be sorely tested." *McGann*, 946 F.2d at 408.

³⁰⁹ In addition to *McGann*, other courts have so held. *See, e.g., Owens v. Storehouse, Inc.* 773 F. Supp. 416, 419 (N.D. Ga. 1991) (holding that a unilateral modification of existing employee plan to provide a \$25,000 cap on AIDS coverage does not state a section 510 cause of action), *aff'd*, 984 F.2d 394 (1993).

³¹⁰ ERISA section 510 was held in the following cases to proscribe employers from discharging employees to avoid paying health insurance or to reduce health coverage costs. *Seaman v. Arvida Realty Sales*, 985 F.2d 543, 546-47 (11th Cir.) (holding that section 510 is violated when an employee is discharged for failing to accept an employer's requirement that she become an independent contractor with concurrent loss of health and other employee benefits), *cert. denied*, 510 U.S. 916 (1993); *Kloss v. Western Elec. Co.*, 701 F.2d 1238, 1243 (7th Cir. 1983) (holding that the employee "by alleging that he was discharged for the purpose of depriving him of continued participation in Western Electric's company-provided life and medical insurance plans . . . stated a claim cognizable under section 510 of ERISA"); *Zipf v. American Tel. & Tel. Co.*, 799 F.2d 889, 894 (3d Cir. 1986) (finding that an employee stated a section 510 claim by alleging that her employer fired her to prevent her from obtaining disability benefits as a result of her rheumatoid arthritis; the employee was fired one day before she would have been entitled to disability payments); *Zimmerman v. Sloss Equip., Inc.*, 835 F. Supp. 1283, 1288 (D. Kan. 1993) (holding that the firing of an employee on medical leave while her health insurance application was pending evidences the requisite discriminatory intent to establish a prima

510 requires only that an employer's plan treat all employees equally. That opens the door for genetic testing and the use of genetic information by employers. Since equal treatment is said to authorize fair discrimination in the interest of all employees, coverage caps and limitations for specific diseases, illnesses, or treatments are not permitted unless an employer could actuarially justify classifying the treatment of a disease or illness or medical condition differently from other diseases, illnesses, or medical conditions. Thus, employers could use genetic data to demonstrate a sound actuarial justification for the unequal treatment of employees regarding their health insurance benefits.³¹¹ Finally, perhaps some or all of these ERISA limitations may be addressed and solved by other federal laws, such as the Americans with Disabilities Act of 1990.³¹² Unfortunately, that is generally not the case. Although one might think the ADA's protection of handicapped employees might alter the effect of ERISA's preemption provisions on employer self-insured plans, the ADA's legislative history evidences otherwise.

Section 501(c)(3) [of the ADA] is designed to clarify that self-insured plans, which are currently governed by the preemption provision of [ERISA], are still governed by that preemption provision and are not

facie case under section 510 of ERISA), *aff'd*, 72 F.3d 822 (10th Cir. 1995); *Nemeth v. Clark Equip. Co.*, 677 F. Supp. 899, 904-05 (W.D. Mich. 1987) (holding that prima facie section 510 case established where a company chose to close one of its two plants; pension expenses were considerably more at the closed plant than the other plant); *Folz v. Marriott*, 594 F. Supp. 1007, 1010 (W.D. Mo. 1984) (holding that Marriott violated employee's ERISA rights by discharging the employee shortly after it was informed that the employee suffered from multiple sclerosis; plaintiff was fired "to avoid the economic consequences that would result due to his continued participation in [Marriott's self-insured medical plan]").

³¹¹ However, retaliation without actuarial justification is actionable. See *Stiltner v. Beretta U.S.A. Corp.*, 74 F.3d 1473, 1484 (4th Cir.) (holding that termination of existing benefits that the employer has no contractual obligation to continue providing can be actionable under section 510 if there is no actuarial justification and the employer was motivated by improper intent to retaliate), *cert. denied*, 117 S. Ct. 54 (1996). Discrimination under the anti-retaliation provision of section 510 is not limited to disparate treatment of similarly situated people but also includes any adverse action taken against a plan participant or beneficiary that is motivated by a specific intent to retaliate against that person for exercising ERISA rights. The retaliation in question need not substantially affect ongoing employment relations between the parties. *Id.*

³¹² 42 U.S.C. §§ 12101-12213 (Supp. II 1994). See *infra* Part IV.B.2 (notes 315-90 and accompanying text).

subject to state insurance laws. . . . Until the preemption provision of ERISA is modified, these self-insured plans are subject to state law only to the extent determined by the courts in their interpretation of ERISA's preemption provision. Of course, under the ADA, the provisions of these plans must conform with the requirements of ERISA, just as the provisions of other plans must be based on or not inconsistent with state [insurance] law.³¹³

One piecemeal solution is to amend ERISA to permit states to mandate health care benefits that employers must provide under both commercial group insurance plans and employer self-insured plans.³¹⁴

2. ADA: The Americans with Disabilities Act of 1990

Signed into law by President Bush on July 26, 1990, the ADA³¹⁵ requires equal opportunity in employment, public accommodations, public services, transportation, and telecommunications for the estimated forty-three million Americans with disabilities.³¹⁶ The ADA "will ensure

³¹³ H.R. REP. NO. 101-485(III), 101st Cong., 2d Sess., at 71 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 494. "Concerns had been raised that [ADA] Sections 501(c)(1) and (2) could be interpreted as affecting the preemption provision of ERISA. The Committee does not intend such an implication." *Id.*

³¹⁴ Since the federal government does not presently require minimum universal health care coverages, all employees and their families would be protected by an ERISA amendment expanding the saving clause and redefining the deemer clause to include all employee health insurance benefit plans.

In other words, in the absence of federal regulations establishing minimum requirements for employee health care plans, federal law [should] remove the obstacles which stand in the way of states that want to ensure decisions affecting health care for all workers are made with due concern for the public interest. Therefore, ERISA should be amended to allow states to mandate the health care benefits employers provide under group insurance plans *and* risk retention plans.

Widiss & Gostin, *supra* note 252, at 654.

³¹⁵ Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328, 42 U.S.C. §§ 12101-12213 (1994). According to the ADA, as the demographics of society change and the average age of a citizen increases, so too does the number of Americans with disabilities. 42 U.S.C. § 12101(a)(1) (1994).

³¹⁶ The ADA's purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." *Id.* § 12101(b)(1). The Act is divided into four titles: Title I, Employment; Title II, Public Services; Title III, Public Accommodations and Services Offered

. . . . [i]ndependence, freedom of choice, control of their lives, [and] the opportunity to blend fully and equally into the right mosaic of the American mainstream.³¹⁷ The ADA seeks to provide individuals with disabilities with protection similar to that provided by the Civil Rights Act of 1964,³¹⁸ which prohibits discrimination in employment based upon race, color, religion, and national origin.³¹⁹

The ADA, however, generally fails to prohibit genetic discrimination and specifically relegates authority to the states regarding insurance/genetic issues. Thus, the scope of this portion of the Article is limited to establishing to what extent, if any, the ADA regulates the use of genetic tests and genetic information in employment and in employee health insurance plans. In the spirit of the McCarran Act,³²⁰ the ADA's insurance exemption, section 501(c),³²¹ primarily leaves insurance regulation to the states. The ADA, surprisingly, avoids insurance discrimination issues by adopting the status quo of conventional risk underwriting based on legitimate actuarial support by commercial insurers and self-insured employers. These traditional, customary insurance practices in underwriting, classifying, and administering risks generally do not constitute prohibited discrimination under the

by Private Entities; Title IV, Miscellaneous Provisions. The ADA became effective on a staggered basis. It applied to employers with 25 or more employees as of July 26, 1992, and to employers with 15 or more employees as of July 26, 1994.

³¹⁷ President Bush: Let the Shameful Wall of Exclusion Finally Come Tumbling Down, in *WORKLIFE*, Fall 1990, 9, 10 (transcript of oral remarks at ceremony accompanying signing of ADA on July 26, 1990).

³¹⁸ Civil Rights Act of 1964, Pub. L. No. 88-350, 78 Stat. 241 (amended by 86 Stat. 103 (1972), 92 Stat. 2076 (1978)) (codified as amended in scattered sections of U.S.C.).

³¹⁹ The ADA extends the coverage of the Vocational Rehabilitation Act of 1973, Pub. L. No. 93-122, 87 Stat. 355 (amended by 92 Stat. 2984 (1978)) (codified as amended in scattered sections of the U.S.C.). The Vocational Rehabilitation Act covered only the federal government as an employer, federal contractors and subcontractors, and recipients of federal grants and funds. *See also* 29 U.S.C. § 706 (1994) (giving definitions that apply to Vocational Rehabilitation Act). As with most legislation that attempts to change long-standing societal norms, the Vocational Rehabilitation Act was somewhat limited in scope.

³²⁰ *See supra* Part IV.A (notes 218-38 and accompanying text).

³²¹ 42 U.S.C. § 12201(c) (1994).

ADA,³²² so long as the insurance benefit plan is not used as a “subterfuge” to evade the ADA.³²³ Moreover, because neither the ADA, nor its regulations, mention genetic discrimination, serious problems arise regarding whether the ADA’s definition of “disability” covers genetic conditions.³²⁴ In sum: “Of all the areas of the employment relationship in which individuals with disabilities face major obstacles, health insurance is the area in which the ADA offers the least protection.”³²⁵

³²² The term “discriminate” in the employment context includes several prohibited activities. Genetic discrimination may be covered by the prohibition against “using qualification standards, employment tests, or other selection criteria that screen out or tend to screen out an individual with a disability” unless they are shown to be job-related and consistent with business necessity. 42 U.S.C. § 12112(b)(6) (1994). There are six other prohibited activities. First is “limiting, segregating, or classifying a job applicant or employee in a way that adversely affects the opportunities or status of [the] applicant or employee because of [that person’s disability].” *Id.* § 12112(b)(1). Second is “participating in a contractual or other arrangement or relationship that has the effect of subjecting a . . . qualified applicant or employee with a disability” to discrimination prohibited by the ADA. *Id.* § 12112(b)(2) (“includes a relationship with an employment or referral agency, labor union, an organization providing fringe benefits to an employee of the covered entity, or an organization providing training and apprenticeship programs”). Third is using “standards, criteria, or methods of administration . . . that have the effect of discrimination on the basis of disability[] or . . . that perpetuate the discrimination of others who are subject to common administrative control.” *Id.* § 12112(b)(3). Fourth is “excluding or otherwise denying equal jobs or benefits to a qualified individual because of the known disability of an individual with whom the qualified person is known to have a relationship or association.” *Id.* § 12112(b)(4). Fifth is failing to make reasonable accommodation, unless the employer can show undue hardship or denying employment opportunities because of the need for reasonable accommodation. *Id.* § 12112(b)(5). The last is failing to conduct employment tests in the most effective manner to ensure that they test what they purport to test. *Id.* § 12112(b)(7).

³²³ See *infra* Part IV.B.2.b (notes 357-90 and accompanying text).

³²⁴ In reviewing the ADA (as well as other federal and state statutes), the Office of Technology Assessment concluded that the ADA and other statutes neither prohibit nor effectively address genetic discrimination. CONGRESS OF THE UNITED STATES, OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 15-17, OTA-BA-455 (1990).

³²⁵ Rothstein, *supra* note 286, at 79. The best scholarship on this topic is *id.*

*a. Genetic Conditions and
the ADA Definition of Disability*

In determining whether an insurance plan violates the ADA, the first step is to ascertain if the insurance plan makes a disability-based distinction.³²⁶ With regard to genetic discrimination, the question is whether the use of employees' genetic data for insurance risk classification and underwriting purposes constitutes a disability-based distinction. The two ADA titles that pertain to this question are Title I concerning "employment" and Title III regarding "public accommodations." Title I regulates employment relationships and prohibits employers from discriminating against any qualified individual with a disability.³²⁷ Specifically, section 102(a) provides: "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment."³²⁸ Since employee health care benefits are an employment term, condition, or privilege to which a person with a disability is entitled, an employer may not discriminate in offering health care benefits.³²⁹ Title I prohibits an employer from discriminating against an individual with a disability based on the employer's concern that its insurance does not cover injuries or accidents that may happen to the individual, or based on concern that the costs of insurance to the employer will increase because of the individual. Moreover, under Title III, concerning access to services, an insurer similarly "may not refuse to insure, or refuse to continue to insure, or limit the amount, extent, or kind of coverage available to an individual, or charge a different rate for the same coverage solely because of [an individual's] physical or mental impairment. . . ."³³⁰ For instance, the Equal Employment Opportunity

at 79-83 (discussing coverage of employees with a genetic condition, coverage of genetic conditions, and health insurance and discrimination).

³²⁶ *EEOC Issues Guidance on ADA and Insurance*, 1993 Daily Lab. Rep. 109 (BNA) § AA (June 9, 1993). These EEOC guidelines are more thoroughly considered at *infra* notes 347-53 and accompanying text.

³²⁷ 42 U.S.C. § 12112(a) (1994).

³²⁸ *Id.*

³²⁹ *See, e.g.*, 29 C.F.R. § 1630.4(f) (1996) (prohibiting discrimination on the basis of disability in regard to fringe benefits whether or not they are administered by the covered entity).

³³⁰ H.R. REP. NO. 101-485, pt. 2, at 136-37 (1989), *reprinted in* 1990

Commission ("EEOC") opines that the ADA would probably prohibit an employer from setting grossly unequal insurance policy limits, or financial caps, of \$5000 a year for treatment of AIDS and \$100,000 a year for other physical conditions.³³¹ In addition, because an insurance office is considered a public accommodation, a person with a disability is protected from discrimination even when seeking insurance without employer assistance.³³² Nonetheless, the bottom-line problem is that neither the ADA nor its regulations specifically mention genetic issues, such as genetic screening, genetic disease, or genetic discrimination. The "subterfuge" provision,³³³ considered in the next subsection, might provide relief for genetic-disability insurance discrimination.

In order to employ the ADA to fight genetic discrimination, one must first demonstrate that genetic conditions are disabilities under the ADA. Due to the uncertainty of the ADA's definition of "disability" as applied to "genetic conditions," the ADA neither directly prohibits nor effectively addresses genetic discrimination in insurance. For instance, because the ADA does not apply to discrimination based on an employee's genetic profile, employers apparently can discriminate without ADA restriction against an employee with a genetic disability so long as that disability has caused no "impairment." Under the ADA's definition, an individual has a "disability"³³⁴ if that individual: (1) "has a physical or mental impairment that substantially limits one or more of the major life activities of the individual;" (2) "has a record of such an impairment;"³³⁵ or (3) "is

U.S.C.C.A.N. 267, 420.

³³¹ This policy is a direct response to *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991) (holding that ERISA does not prohibit employers from modifying benefits and placing explicit coverage limits on certain conditions, such as AIDS). For a full description of *McGann*, see *supra* notes 296-306 and accompanying text.

³³² 42 U.S.C. §§ 12181(7)(F), 12182 (1994).

³³³ See *infra* Part IV.B.2.b (notes 357-90 and accompanying text).

³³⁴ *Id.* § 12102(2). The term "qualified individual with a disability" means a person "who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires." *Id.* § 12111(8). One of the important components of the ADA is the broad definition of a disabled person, which includes people who suffer discrimination because of past disabilities that no longer exist, *id.* § 12102(2)(B), or because of the perceptions and attitudes of others, *id.* § 12102(2)(C).

³³⁵ Record of impairment means that the person "has a history of, or has been misclassified as having, a mental or physical impairment that substantially limits one or more major life activities." 29 C.F.R. § 1630.2(k) (1996). This second

regarded as having such an impairment." The key word in this three-prong definition is "impairment." An impairment is a physiological disorder, whether physical or mental,³³⁶ including presently expressed genetic diseases.³³⁷ Beyond expressed genetic diseases, there is uncertainty as to ADA coverage of genetic conditions. For instance, the impairment definition appears to exclude genetic markers and traits.³³⁸ Moreover, the EEOC explains that the ADA impairment definition "does not include characteristic predisposition to illness or disease."³³⁹ Additionally, it is unclear whether a person would be considered to have a disability based on a genetic test that shows an increased risk of genetic disease, illness, or other condition, but not a definitive diagnosis that she or he will get the disease, illness, or condition. In the early 1990s, the EEOC took the position that the ADA did not cover an asymptomatic individual.³⁴⁰ In fact, the "EEOC also . . . specifically rejected efforts

definitional prong protects people with a history of heart disease, cancer, or mental illness, who often suffer discrimination many years after their recovery. However, genetic conditions or defects that fluctuate, such as acute intermittent porphyria, would probably not be covered.

³³⁶ The ADA regulations define physical or mental impairment as "[a]ny physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, specific sense organs, . . . and endocrine; or . . . [a]ny mental or psychological disorder . . ." 29 C.F.R. § 1630.2(h) (1996).

³³⁷ Muscular dystrophy, an X-linked genetic disorder, and multiple sclerosis, a disease with a genetic component, are cited as covered impairments in ADA legislative history. H.R. REP. NO. 101-485, pt. 2, at 51 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 333. However, "minor" currently expressed genetic conditions — eye color, weight, height, muscle tone, and so forth — may not be covered unless they substantially limit a "major life activity," which is defined as "functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 29 C.F.R. § 1630.2(h)(2)(i) (1996).

³³⁸ As an Office of Technology Assessment report notes: "Whether a genetic marker or a trait constitutes an 'impairment' under [the] ADA is unclear." GENETIC MONITORING AND SCREENING IN THE WORKPLACE, *supra* note 324, at 16.

³³⁹ 29 C.F.R. § 1630.2 app. (1992).

³⁴⁰ Neil A. Holtzman & Mark A. Rothstein, *Eugenics and Genetic Discrimination*, 50 AM. J. HUM. GENETICS 457, 458 (1992) (citing letter from R. Blumenthal, Acting Director of Communications and Legislative Affairs, EEOC, to Bob Wise, Chair, House Subcommittee on Government Information, Justice and Agriculture, Nov. 22, 1991).

by the National Institutes of Health-Department of Energy Joint Working Group on Ethical, Legal and Social Issues to interpret the ADA as prohibiting genetic discrimination and as proscribing mandatory genetic testing at employee's placement examinations."³⁴¹

In March 1995, however, the EEOC reversed its position and issued a new compliance manual that classified individuals with a genetic susceptibility to disease as individuals with an asymptomatic illness. In other words, the EEOC now classifies carriers of genetic defects as individuals with a disability under the ADA.³⁴²

Coverage under the ADA will, however, vary depending on the specific nature of the genetic condition. Only physical or mental impairments that substantially limit a major life activity are covered as disabilities under the ADA.³⁴³ If an individual has a genetic disorder that is already expressed, and the individual has a physical or mental impairment that substantially limits a major life activity, then the individual is covered under the first prong of the ADA's three-pronged definition. If an individual carries the gene for a disease that will definitely develop, such as Huntington's disease, but which has not yet expressed itself, ADA coverage is problematic. Even though the ADA does not directly address this issue and, thus, may not prohibit discrimination against carriers, such an individual might be covered under either of two theories. First, individuals might be considered to be "already impaired" because they are limited in their ability to freely procreate,³⁴⁴ which may be considered a major life activity.³⁴⁵ Second, the ADA arguably may cover carriers of late onset, unexpressed genetic conditions

³⁴¹ *Id.* (citing E. Juengst, *Priorities in Professional Ethics and Social Policy for Human Genetics*, 266 JAMA 1835 (1991)).

³⁴² See, e.g., Rick Weiss, *Gene Discrimination in Workplace; EEOC Says Job Can't Be Denied Based on Predisposition to Disease*, WASH. POST, Apr. 7, 1995, at A3.

³⁴³ 29 C.F.R. § 1630.2(g).

³⁴⁴ "Because there is no treatment or cure for Huntington's disease (HD), and there is a 50% chance a child of an infected individual will also get HD, individuals with HD are counseled to refrain from having children." MERCK MANUAL 1363 (Robert Berkow et al. eds., 15th ed. 1987).

³⁴⁵ EEOC regulations provide: "Other impairments, however, such as HIV infection, are inherently substantially limiting." 29 C.F.R. § 1630.2(j). Reproduction is considered to be a major life function. Because HIV-positive individuals should abstain from unprotected sexual contact due to the manner in which the AIDS virus is transmitted, their ability to procreate is circumscribed and, thus, they suffer from an impairment that is substantially limiting.

because individuals who are excluded from employment because of future health risks are "regarded as" having a disability. Thus, they may be protected under the ADA's third prong of the definition of "disability."³⁴⁶

The 1995 guidelines issued by the EEOC state that "the definition of the term 'disability,' therefore, is designed to protect against myths, fears, stereotypes, and other attitudinal barriers . . . but [is] not limited to 'concerns about productivity, safety, insurance, liability'"³⁴⁷ The directive declares that the "issue is whether the employer treats the individuals as having an impairment that substantially limits major life activities."³⁴⁸ Accordingly, "[t]he perception of the covered entity is a key element of this test."³⁴⁹ A victim of discrimination need not show that the employer's perception is inaccurate compared to how other individuals and organizations treat the employee.³⁵⁰

Importantly, the EEOC guidelines provide an example of genetic discrimination covered by the definition of disability:

CP's genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R learns about CP's increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP's productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of "disability."³⁵¹

Robert Silverstein, an assistant to Senator Tom Harkin (D-Iowa), who sponsored the ADA, explains that "[t]his interpretation doesn't get into the issue of discrimination, only whether you can make the claim. It can get you into court to make the claim."³⁵² According to Dr. Paul Billings, a prominent geneticist at Stanford University School of Medicine

³⁴⁶ 42 U.S.C. § 12102(2)(C) (1994).

³⁴⁷ 2 EEOC Compl. Man. § 902.8, at 5325 (CCH 1995) (quoting H.R. REP. NO. 101-485, pt. 3, at 30 (1990)).

³⁴⁸ *Id.*

³⁴⁹ *Id.* (quoting H.R. REP. NO. 101-485, pt. 3, at 30 (1990)).

³⁵⁰ *Id.* (citing H.R. REP. NO. 101-485, pt. 3, at 31 (1990)).

³⁵¹ *Id.* at 5326.

³⁵² Reginald Rhein, *Federal Disability Law Bans Genetic Discrimination*, BIOTECHNOLOGY NEWSWATCH, May 1, 1995, at 6, available in 1995 WL 2196533, at *1 (quoting Robert Silverstein).

and a strong opponent of genetic discrimination, the ADA does not adequately protect people. Characterizing the ADA's definition of disability as inherently flawed, Dr. Billings explains:

"The ADA was constructed for people with basically phenotypic [expressed] disabilities who had a long history of discrimination, and to redress that problem. . . . We are now diluting those people's interests with a large number of people who conceivably will argue that they are being perceived . . . as disabled even though they only have a gene for colon cancer, breast cancer, or Alzheimer's dementia, whatever the gene of the week is. . . . I don't think we should offer protections to people with [disease-prone] genes through disability [legislation]. . . . Most . . . people are normal with genes for colon cancer. . . . We should be fighting their perception as disabled, we shouldn't be codifying it in law. . . . I think that's a very substantial problem."³⁵³

Discrimination against those with disabilities in employment settings has often involved the use of questions aimed at discovering the existence of a disability. The presence of health-related questions, similar to those found on health questionnaires used by physicians on patients' first visits, exemplifies this discrimination. The employment applicant is asked to note whether she has experienced any of a laundry list of medical conditions, such as high blood pressure, heart disease, or diabetes. Despite the lack of a correlation between an individual's health and the individual's ability to perform a specific job, these methods have long been used to exclude individuals with disabilities from the workplace.³⁵⁴ Because the ADA prohibits medical examinations as part of the job application process,³⁵⁵ employers are now commonly requiring medical

³⁵³ *Id.* at *2-3 (quoting Dr. Paul Billings).

³⁵⁴ Mello, *supra* note 289, at 76 & n.20.

³⁵⁵ The ADA precludes the use of medical information in any initial hiring decision. 42 U.S.C. § 12112(d)(2) (1994). A job applicant cannot be asked if he or she suffers from a disability, *id.* § 12112(d)(2)(A), and no medical examination can be made before an offer is extended, *id.* § 12112(d)(3)(A). The job applicant can be asked if he or she can perform job-related functions. *Id.* § 12112(d)(2)(B). If the applicant answers, "No. I cannot perform those tasks," the ADA is unclear as to whether the employer can ask why. Anyone giving a reference faces the same dilemma. This dilemma, as well as problems arising from partial concealment, is explored by Professor Richard Epstein. Epstein, *supra* note 5, at 13-18 ("Currently, our policy . . . is a variation of the policy 'don't ask, don't tell,' or, more accurately for this case, 'can't ask, don't tell.'")

examinations after conditional job offers are made. According to the EEOC's assistant legal counsel, an employer's concerns about a particular condition found in a post-offer medical examination are insufficient reason to withdraw the offer. However, withdrawal of the offer may not be illegal if the employer can show another — legal — reason, for instance, that another person seeking the job is more qualified. The abuses of genetic testing presently outnumber its uses, according to Dr. Billings, who said, "I only wish the remedy for people who are being discriminated against now would be simpler. . . . They have to basically be able to have reasonable belief that discrimination that they suffered arose from genetic information, which is very difficult to prove at times, and the whole ADA-EEOC process is cumbersome." ³⁵⁶

b. ADA Section 501(c) Exempts Insurance and Recognizes the Primacy of State Insurance Regulation

Given that health insurance is a nationally divisive political issue,³⁵⁷ Congress, in enacting the ADA, decided via section 501(c) to continue the status quo of state regulation of health insurance and other insurance programs. Insurers and entities that administer employee-benefit plans are given the same traditional insurer rights to underwrite, classify, and administer risks that existed prior to the ADA. Specifically, section 501(c) exempts insurance companies and employers,³⁵⁸ and does not

This surely is the position with respect to disabilities that are now covered by the Americans with Disabilities Act (ADA)." *Id.* at 13).

³⁵⁶ Rhein, *supra* note 352, at *2 (quoting Dr. Paul Billings).

³⁵⁷ See generally Kenneth R. Wing, *American Health Policy in the 1980's*, 36 CASE W. RES. L. REV. 608, 608-18 (1986) (discussing the political context within which risking health care costs must be viewed). The ADA apparently would have lost political support if it had made sweeping changes regarding health insurance.

³⁵⁸ Subsection one of section 501(c) exempts insurers, subsection two exempts employers, and subsection three continues the ERISA preemption by recognizing the right of self-insured employers to be exempt from state insurance law. 42 U.S.C. § 12201(c) (1994) provides:

Subchapters I through III of this chapter and title IV of this Act shall not be construed to prohibit or restrict —

- (1) an insurer, hospital or medical service company, [HMO], or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State

limit their ability to underwrite, classify, or administer risks under health insurance plans provided the insurance benefit plans and insurance programs are based on or consistent with state insurance law and are not utilized as a subterfuge³⁵⁹ to circumvent the intent of the ADA.

Notwithstanding section 501(c), an insurance company is a public entity and, accordingly, should be covered under the full provisions of the ADA. Since an insurance office, for instance, is considered a public accommodation, a disabled person has ADA protection from discrimination even when applying for health insurance without employer assistance.³⁶⁰ Whereas employers are subject to Title I, Title III should govern insurers and self-insured employers involved in the creation, alteration, capping, and termination of health insurance plans.

In a recent decision, *Carparts Distribution Center, Inc. v. Automotive Wholesaler's Association*, the Court of Appeals for the First Circuit held that a self-funded medical reimbursement plan could be subject to Title III, which prohibits barring an individual, on the basis of disability, the opportunity to benefit from a service provider who operates a place of public accommodation.³⁶¹ In *Carparts*, a participating member and a covered employee brought an action against an association and its self-insured health plan challenging the plan's \$25,000 limitation on health

law; or

(2) a person or organization covered by this chapter from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that are based on underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or

(3) a person or organization covered by this chapter from establishing, sponsoring, observing or administering the terms of a bona fide benefit plan that is not subject to State laws that regulate insurance.

³⁵⁹ Section 501(c) concludes by providing that "[p]aragraphs (1), (2), and (3) [of subsection (c)] shall not be used as a subterfuge to evade the purposes of subchapter I and III of this chapter." *Id.*

³⁶⁰ 42 U.S.C. § 12181(7)(F) (defining "public accommodation" to include an insurance office); *id.* § 12182 (prohibiting discrimination on the basis of disability in the full and equal enjoyment of the services of a public accommodation).

³⁶¹ *Carparts Distrib. Ctr., Inc. v. Automotive Wholesaler's Ass'n*, 37 F.3d 12, 20 (1st Cir. 1994) (A self-funded medical plan limited benefits after a member suffering from AIDS submitted claims. "[P]lace or accommodation" was read to include the "substance of what is being offered," not merely physical structures for people to enter.).

coverage for AIDS in contrast to a \$1,000,000 lifetime cap for other conditions. Plaintiff claimed that this disparate AIDS cap constituted illegal disability discrimination under the ADA. The federal district court dismissed the claim because neither the association nor the plan was an "employer" or a "public accommodation" under the ADA. Taking guidance from Title VII opinions under the Civil Rights Act of 1964, the First Circuit reversed and held that the lower court had taken too narrow a view of the ADA. Discussing Title III of the ADA, the First Circuit noted that "public accommodations" are not necessarily limited to "actual physical structures."³⁶² Although acknowledging that a claim under Title III "may be a less promising vehicle" than a claim under Title I for AIDS-infected plaintiffs, the court held that "services" may properly be within the ambit of public accommodations.³⁶³

Discrimination, such as that in *Carparts*, against an insured by a self-funded medical reimbursement plan would presumably have an actuarial, and thus legal, basis under the ADA. By not addressing insurance issues relating to genetic testing and discrimination and by not otherwise restricting insurers and similar entities in underwriting, classifying, or administering risks, the ADA provides little, if any, assured guidance or solutions for future insurance/genetic problems. The critical points regarding section 501(c) include: (1) the ADA fails to provide a uniform approach to insurance/genetic discrimination issues by deferring to hundreds of non-uniform state health insurance laws and regulations;³⁶⁴ and (2) the ADA accepts and continues the traditional insurance concept of fair discrimination based on sound actuarial principles.³⁶⁵

Under the ADA, it is not illegal for a health insurer or an employer to alter, limit, or cap insurance coverage or to charge higher rates for genetically-based conditions, provided state law is not violated and such action is not a subterfuge to evade the ADA. Under section 501(c), an insurer or employer may fairly discriminate based on classification of

³⁶² *Id.* at 19.

³⁶³ *Id.* at 20.

³⁶⁴ For instance, a 1991 study reported that almost 1000 state laws mandate coverage of discrete health services or medical conditions. *Tally of Mandated Benefits Nears 1000*, MODERN HEALTHCARE, Nov. 25, 1991, at 8 (citing data compiled by the Health Benefits Letter based in Alexandria, Va.). Most of these mandates concern home health care, maternity, alcoholism, drug abuse, mental health, outpatient surgery, and nursing home benefits. For a more extensive catalogue of state mandates and insurance/genetic laws, see *infra* Part IV.C.1.-2.a (notes 391-533 and accompanying text).

³⁶⁵ See *supra* Part II.A (notes 68-93 and accompanying text).

risks by refusing to insure, limiting insurance coverage, or charging a rate differential, so long as such choices are justified by sound actuarial principles.³⁶⁶ A House Committee Report explained that if an insurance benefit plan is based on sound actuarial principles, the amount, extent, or kind of coverage available to an individual can be limited.³⁶⁷ The basic principle is that section 501(c) is intended to require that “[e]mployees with disabilities . . . be given equal access to whatever insurance or benefit plans the employer provides.”³⁶⁸ Across-the-board coverage

³⁶⁶ Employers may, for instance, create as well as change the terms of a bona fide benefit plan based on sound actuarial data. Thus, an employer may be able to charge a different premium to an individual with a disability for the identical coverage provided to other employees if the decision is based on customary actuarial principles or related to actual or reasonably anticipated experience. *See* S. REP. NO. 101-116, at 85 (1989) (discussing legal discrimination in the same language used by the House of Representatives (*see infra* note 367)).

³⁶⁷ The report states that a plan may limit coverage, but that:

[T]he plan [may] not refuse to insure, or refuse to continue to insure, or limit the amount, extent, or kind of coverage available to an individual, or charge a different rate for the same coverage solely because of a physical or mental impairment, except where the refusal, limitation, or rate differential is based on sound actuarial principles or is related to actual or reasonably anticipated experience.

For example, a blind person may not be denied coverage based on blindness independent of [f] actuarial risk classification.

H.R. REP. NO. 101-485, pt. 2, at 136-37 (1989), *reprinted in* 1990 U.S.C.C.A.N. 267, 420.

³⁶⁸ U.S. Equal Employment Opportunity Comm’n, *A Technical Assistance Manual on the Employment Provisions (Title I) of the Americans with Disabilities Act*, at VII-8 (1992) [hereinafter *Technical Assistance Manual on Employment Provisions of ADA*]. A House Committee on Education and Labor Report explains that “employers may not deny insurance coverage completely to a person based on that person’s diagnosis or disability [but] it is permissible for an employer to offer insurance policies that limit coverage for certain procedures or treatments” [e.g., a limit on the extent of kidney dialysis, whether dialysis will be covered at all, or a limit on the amount of blood transfusions or whether transfusions will be covered]. *Id.* It would not be permissible, however, to deny coverage to individuals, such as people with kidney disease or hemophilia, who are affected by such limits, for other procedures or treatments connected with their disability. It would also not be permissible to deny coverage to such individuals for other conditions not connected with such limitations on coverage, such as treatment for a broken leg or heart surgery. While “limitation may be placed on reimbursements for a procedure or the types of drugs or procedures covered, . . . that limitation must apply to persons with or without disabilities.

limitations, exceptions, and exclusions applicable to all plan participants are permissible even though they may adversely affect people with disabilities. Lifetime or yearly financial caps applying equally to all plan participants are legal. For instance, a plan that sets a maximum lifetime benefit of \$1,000,000 or a yearly limit of \$25,000 does not violate the ADA.

A second fundamental principle is that “[a]n employer cannot fire or refuse to hire an individual with a disability because [its] current health insurance plan does not cover the individual’s disability, or because the individual may increase the employer’s future health care costs.”³⁶⁹ A third and final principle is that “[a]n employer cannot deny insurance to an individual with a disability or subject [him] to different insurance terms or conditions of insurance based on disability alone, if the disability does not pose increased insurance risks.”³⁷⁰

In sum, section 501(c) is intended to afford to insurers and employers the same opportunities they would enjoy in the absence of this legislation to design and administer insurance products and benefit plans in a manner that is consistent with basic principles of insurance risk classification. This legislation assures that decisions concerning the insurance of persons with disabilities which are not based on bona fide risk classification be made in conformity with non-discrimination requirements. Without such a clarification, this legislation could arguably find violative of its provisions any action taken by an insurer or employer which treats disabled persons differently under an insurance

All people with disabilities must have equal access to the health insurance coverage that is provided by the employer to all employees.” H.R. REP. NO. 101-485, pt. 2, at 59, *reprinted in* 1990 U.S.C.C.A.N. 267, at 341.

³⁶⁹ *Technical Assistance Manual on Employment Provisions of ADA, supra* note 368, at VII-9. An example is *Finley v. Cowles Business Media*, No. 93 Civ. 5051 (PKL), 1994 WL 273336, at *1 (S.D.N.Y. June 20, 1994). An employee, Finley, one month on the job, was fired only a few weeks after he completed a life insurance application revealing his heart condition. *Id.* at *1. In an ADA action, that evidence was sufficient to withstand summary judgment because a reasonable jury could find that the employer learned of the heart disease and then fired Finley so it would not be liable for expensive treatment under its health insurance plan. *Id.* at *3.

³⁷⁰ *Technical Assistance Manual on Employment Provisions of ADA, supra* note 368, at VII-8. Also, an employer cannot execute a contract or agreement that would have the same effect. *Id.*

or benefit plan because they represent an increased hazard of death or illness.³⁷¹

Notwithstanding this permissible disability-based benefits discrimination, the ADA may provide relief for insurance-related genetic discrimination when the disability-based distinction resulting in disparate insurance benefits is being used as a subterfuge to circumvent the intent of the ADA. Even though the ADA permits insurers and employers to refuse insurance coverage, limit insurance coverages, or charge a different actuarially-sound premium based on a person's disability, they cannot engage in insurance practices as a subterfuge to evade the ADA's purposes. What conduct, practices, and policies will be held to constitute a subterfuge is an open question. Neither the ADA nor the EEOC regulations explain what actions constitute subterfuge.³⁷²

In 1993, however, the EEOC issued its first formal guidance regarding the relationship between the ADA and employer-provided insurance.³⁷³ The complex document, described as "interim enforcement guidance," took effect June 8, 1993, and generally declares that the ADA prohibits employers from discriminating on the basis of disability in employee health insurance plans.

In applying this EEOC policy to ascertain if an employer-provided insurance plan violates the ADA, one must address three issues. First is whether the plan makes a "disability-based distinction."³⁷⁴ On the one hand, the guidelines permit employers to make very broad distinctions. For example, an employer may elect reduced coverage for mental and

³⁷¹ H.R. REP. NO. 101-485, pt. 2, at 137-38 (1989), *reprinted in* 1990 U.S.C.C.A.N. 303, 420-21.

³⁷² See, e.g., *Health Insurance: ADA's Effect on Plans Remains Puzzle Attorney Says*, 19 PENS. & BEN. REP. (BNA) 824 (May 18, 1992) ("Pre-existing condition clauses and other restrictions may not be used as 'a subterfuge' to evade the purposes of the act In other words, employers and insurance companies may be liable under the ADA if policy exclusions are not in line with valid risk-assessment principles.") (description of District of Columbia Bar Seminar presentation by attorney Jonathan Mook on May 12, 1992); Kimberly A. Ackourey, Comment, *Insuring Americans with Disabilities: How Far Can Congress Go to Protect Traditional Practices?*, 40 EMORY L.J. 1183, 1189-99 (1991) (discussing definition of "subterfuge" and determination of to what employment practices it applies).

³⁷³ EEOC Issues Guidance on ADA and Insurance (June 9, 1993), *supra* note 326.

³⁷⁴ *Id.*

nervous conditions or for eye care. Such broad distinctions are not distinctions based on disability because they apply to all people, with or without disabilities, and to the treatment of a multitude of dissimilar conditions. Moreover, an employer does not violate the ADA by generally refusing to cover experimental drugs and treatments since such distinctions are not based on disability and may affect people with different diseases and conditions. On the other hand, a disability-based distinction occurs when a discrete disability is singled out. An employer may not, for instance, set a lower level of benefits for a specific disability, such as AIDS, or a discrete group of disabilities, such as cancer. The guidelines show that an employer makes a disability-based distinction by setting unequal policy limits of \$5000 a year for AIDS treatment and \$100,000 a year for other physical conditions.³⁷⁵

If a disability-based distinction exists, then two issues arise as the burden of proof shifts to the employer. The employer must prove that: (1) it has a bona fide plan³⁷⁶ and (2) the disability-based distinction at issue is not being used as a subterfuge to circumvent the ADA.³⁷⁷ The employer must prove that the disability-based disparate treatment is justified by the risks or costs associated with the disability. In other words, the ADA gives an employer a chance to demonstrate a legitimate business or insurance justification for the distinction. Although an employer can rely on costs and on legitimate actuarial data for making a disability-based distinction, the employer also may have to produce evidence to support its decision to show that other alternatives are not available.³⁷⁸ An employer who, for example, asserts that it restricted

³⁷⁵ *EEOC Interim Guidance on Application of ADA to Health Insurance*, 1993 Daily Lab. Rep. (BNA) 109 § E, E-2 (June 9, 1993). This policy is a direct response to *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991) (holding that ERISA does not prohibit employers from modifying benefits and placing explicit coverage limits on certain conditions, such as AIDS). For a full description of *McGann*, see *supra* notes 296-306 and accompanying text.

³⁷⁶ This burden of proof can be easily satisfied. An employer need only prove that the plan exists and pays benefits, and that the plan's terms were accurately communicated to the covered employees. *Id.* at E-3.

³⁷⁷ *Id.*

³⁷⁸ The EEOC has established a non-exclusive list of potential justifications. These justifications include assertions that the health insurance plan actually treats all similar catastrophic conditions in the same way, the disability-based disparate treatment is attributable to the application of customary risk classification and underwriting procedures to the increased risks of the disability, and the specific treatment has no medical value — it does not cure, slow deterioration,

coverage of certain disabilities to avoid a large increase in insurance premiums or to avoid insolvency of its plan is required to prove that its management evaluated alternative ways to save money without having to discriminate against disabled individuals. An employer may not use justifications based on myths, fears, or stereotypes. For instance, an employer cannot exclude epilepsy from its insurance plan based on unsupported testimony that people with epilepsy will have more accidents and file more claims.

The EEOC guidelines provide the following example of a disability-based distinction that violates the ADA unless the employer can carry the burden of proving the distinction is not a subterfuge:

R Company's new self-insured health insurance plan caps benefits for the treatment of all physical conditions, except AIDS, at \$100,000 per year. The treatment of AIDS is capped at \$5000 per year. CP, an employee with AIDS enrolled in the health insurance plan, files a charge alleging that the lower AIDS cap . . . is a disability-based distinction. Accordingly, if R is unable to demonstrate that its health insurance plan is bona fide and that the AIDS cap is not a subterfuge, a violation of the ADA will be found.³⁷⁹

Unlike the ERISA section 510 opinions, the EEOC guidelines shift the burden of proving a non-discriminatory purpose to employers. To prove the absence of subterfuge, an employer is required to present "a detailed explanation of the rationale" for its decision, which typically will be based on sound actuarial data showing legitimate insurance risk classification and underwriting.³⁸⁰ Even if an employer cannot produce such evidence of customary insurance risk classification, the guidelines permit an employer to prove "necessity" as evidence of no subterfuge.

Necessity can be proven by negative implication in one of two ways under the guidelines. First, an employer may prove that there was no non-disability-based change that could have been made without making an unacceptable change in the premiums for or coverage provided by the insurance.³⁸¹ An unacceptable change is a change that either makes the plan effectively unavailable to a significant number of other employees,

alleviate symptoms, or maintain the current health status of the disabled person.
Id. at E-3.

³⁷⁹ *Id.* at E-2.

³⁸⁰ *Id.* at E-3.

³⁸¹ *Id.*

makes the plan so unattractive as to cause significant adverse selection, or makes the plan so unattractive in comparison to other employer health insurance plans in the community as to harm the employer's ability to recruit and maintain qualified employees.³⁸² Second, an employer may demonstrate necessity by proving that there is no non-disability based health insurance plan that could be drafted without breaching the commonly accepted or legally required standards for a fiscally sound health insurance plan.³⁸³

The efficacy of the new EEOC guidelines is an open issue. The courts may give little weight to the guidelines in light of legislative history demonstrating that the ADA was not intended to disrupt current insurance practices and the primacy of state insurance laws and regulation.³⁸⁴ However, unlike the ERISA section 510 opinions as well as opinions by courts interpreting the subterfuge provision in the Age Discrimination in Employment Act ("ADEA"),³⁸⁵ the guidelines make a positive shift in discrimination law by shifting the burden of proving discrimination from employees to their employers, who must prove a non-discriminatory reason or a lack of subterfuge. The open question is how courts will treat cost justifications. All serious diseases and conditions are costly. As the guidelines suggest, courts should require employers to prove more than that a specific disease or condition will impose a financial burden on the plan. When a discrete disease, illness, or condition is excluded, limited, or financially capped in an insurance plan, courts should require employers to prove why the relative financial burden is greater for insuring that condition than for insuring other conditions. In other words, employers must introduce "legitimate cost or actuarial data" evidencing that expenses for treatment, or other costs, for the discrete disability are greater than treatment expenses and costs for other covered genetic or medical diseases, illnesses, and conditions. Also,

³⁸² *Id.*

³⁸³ *Id.*

³⁸⁴ See, e.g., *The Impact of the ADA on Medical Plans*, 1 ERISA Litig. Rep. (P-H) No. 11, at 31 (Dec. 1992) (predicting that the Supreme Court will give little weight to the EEOC regulations as it did in interpreting and construing the ADEA subterfuge provision).

³⁸⁵ For example, in *Public Employees Retirement Sys. v. Betts*, 492 U.S. 158, 159-60 (1989), the Supreme Court put the burden on the employee under the ADEA to prove the employer had a "subjective intent" to discriminate in relation to an employee benefit plan. Note, however, that Congress responded to the *Betts* decision by amending the ADEA in 1990 to require a cost-based justification to avoid a finding of subterfuge. 29 U.S.C. § 623(f)(2)(B)(i) (1994).

an employer must prove that it considered, but found unworkable, other insuring methods which might have saved costs and avoided the discriminating disability-based distinction.

*Mason Tenders District Council Welfare Fund v. Donaghey*³⁸⁶ appears to confirm the three-step approach of the EEOC guidelines. Donaghey was a construction worker and union member who was diagnosed with AIDS. Thereafter, Donaghey's self-insured union fund rewrote its medical insurance plan by adding an exclusion of all payments for AIDS and AIDS-related conditions. Donaghey brought an action against the self-insured, multi-employer labor management-sponsored medical plan. Because the express exclusion of AIDS is a disability-based distinction, the EEOC placed the burden on the union fund to prove that its AIDS exclusion was not a subterfuge to evade the ADA. Although the union fund produced no evidence of an actuarial justification for the AIDS exclusion or of necessity for the change, it vigorously explained that prudent management of the medical insurance fund necessitated eliminating insurance coverage for AIDS.³⁸⁷ But as the guidelines explain, expected substantial future medical cost alone is not a justification for a disability-based distinction. The EEOC, therefore, found that the union fund "ha[d] no viable defense to the charge of discrimination"³⁸⁸ and held that the union's action violated the ADA.³⁸⁹

³⁸⁶ *Mason Tenders Dist. Council Welfare Fund v. Donaghey*, 25 Daily Lab. Rep. (BNA) at D-1 (Feb. 9, 1993).

³⁸⁷ Certainly the costs of treating a person with AIDS or HIV is substantial. Experts estimate that the lifetime cost of treating an individual with HIV from the date of infection until death is approximately \$119,000; \$50,000 is the estimated health care cost from HIV infection until AIDS develops; and \$69,000 is the estimated cost from AIDS development until death. Fred J. Hellinger, *The Lifetime Cost of Treating a Person with HIV*, JAMA, July 28, 1993, at 474, 474; see also David J. Solomon et al., *Analysis of Michigan Medicaid Costs to Treat HIV Infection*, PUB. HEALTH REP. 416 (Sept.-Oct. 1989) (analyzing medical payment records of people who had indications of HIV infection).

³⁸⁸ *Mason Tenders*, 25 Daily Lab. Rep. (BNA) at D-1.

³⁸⁹ See also *Estate of Kadinger v. International Bhd. of Elec. Workers, Local 110*, No. 3-93-159, 1993 WL 597548, at *3 (D. Minn. Dec. 21, 1993) (A union health plan agreed to rescind its \$50,000 cap on AIDS in settlement of a claim that an AIDS cap violated the ADA. The plan provided a lifetime maximum benefit of \$500,000 for all other conditions.); cf. *Gonzales v. Garner Food Servs., Inc.*, 855 F. Supp. 371, 374 (N.D. Ga. 1994) (granting employer's motion to dismiss because terminated plaintiff was no longer an employee of the company when the AIDS cap amendment was adopted); *Carparts Distrib. Ctr., Inc. v. Automobile Wholesaler's Ass'n*, 826 F. Supp. 583, 585 (D.N.H. 1993) (holding

In conclusion, the ADA will probably have little effect on fair discrimination insurance practices. The ADA permits disability-based insurance practices provided the practices are based on customary risk management having legitimate, sound actuarial support.³⁹⁰ With actuarial justification or a showing of necessity, insurers and employers can then exclude disabilities from coverage or financially cap them. They can price discriminate by fixing price differentials for the same level of coverage to reflect the higher expected cost. Given the necessity defense and traditional cost/accounting/actuarial justifications for a disability-based distinction in a proffered health insurance contract, the EEOC guidelines may do little more than authoritatively approve and continue the insurance principle of fair discrimination based on actuarial soundness. If so, the ADA will probably be ineffective in restricting insurers from using genetic information to make actuarial predictions of disease and other health risks.

C. *State Insurance/Genetic Legislation Is Inchoate But Promising*

1. *Mandating Coverage Through Proscription and Prescription*

An insurance policy is aptly characterized as a mass-standardized contract,³⁹¹ often called a contract of adhesion, customarily sold on a mass marketing take-it-or-leave-it basis. Seldom does true bargaining over its terms occur. Consumers buy the insurance product like any other mass-produced good. Consequently, states intervene in the public interest to regulate standardized insurance policy coverage terms, conditions, exclusions, and exceptions. The standard insuring coverage language,

that Title I of the ADA does not apply to sponsor of health benefit plan that placed a cap on AIDS-related benefits because sponsor was not the plaintiff's employer).

³⁹⁰ ADA section 510(c) is "not intended to disrupt the current nature of insurance underwriting . . ." 29 C.F.R. § 1630.16(f) app. (1996); see also Ted Storer, Comment, *The Americans With Disabilities Act: Will the Insurance Field Change?*, 20 OHIO N.U. L. REV. 1031, 1031-32, 1033-40 (1994) (discussing the small impact of the ADA because both the ADA and state law protect insurers in their grouping of classes and risks provided they use "sound actuarial principles").

³⁹¹ How an insurance policy becomes a mass-standardized product is complicated and well beyond the scope of this Article. For a history, examination, and evaluation of the standardization process, see generally HOLMES, *supra* note 6, §§ 2.1-2.18, at 189-330.

historically speaking, is created in part through an ongoing process of state legislative and regulatory proscription and prescription of an insurance policy's coverage language.³⁹² State insurance law is best described as a vast wilderness of some discrete and some comprehensive legislative statutes and administrative regulations on a common subject. The sheer number and diversity among the states' regulatory schemes makes it difficult to chart and summarize them with certainty. All states, for instance, now regulate and proscribe/prescribe the terms of group health insurance contracts. By mandating certain coverages, these provisions indirectly address issues of genetic discrimination. One study reports that as of 1990, there were nearly one thousand state mandates for health insurance coverage.³⁹³

Another concern is finding all the relevant statutes and regulations. Placement of all the relevant statutes within a state's compilation of statutes varies. Typically, these statutes are placed somewhere within the state's insurance code, and often within a chapter prohibiting unfair trade practices. In some states, however, there are additional prohibitions found in other places. California's Insurance Code, for example, contains a comprehensive body of law pertaining to discriminatory practice in insurance, including an article specifically referring to the use of genetic characteristics in underwriting;³⁹⁴ yet further regulation, however, is

³⁹² See *id.* at 197-200, 203-18 (§ 2.2 A. *Legislative Proscription and Proscription of Policy Terms*, § 2.2 B. *Legislative Requirements for Administrative Approval of Policy Forms*, and § 2.3 *Effect of Legislation Standardizing Insurance Policy Language*). While all states have enacted legislation and promulgated regulatory schemes to proscribe/prescribe the terms of a variety of policies, there are numerous model acts and model regulations drafted by the National Association of Insurance Commissioners. These model acts and regulations, in whole or in part, form the basis of many of the schemes enacted by the states. One example pertinent to this Article is the 1989 Group Health Insurance Definition and Group Health Insurance Standard Provisions Model Act, which has been adopted in virtually all states. The state citations are compiled at *id.* at 243 n.24. In that model act, section 2. D. provides: "An insurer may exclude or limit the coverage on any person as to whom evidence of individual insurability is not satisfactory to the insurer." *Id.* at 244 (quoting the Act). Moreover, the Act does not address the issue of genetic testing of applicants or an insurer's use of genetic information to determine insurability.

³⁹³ Rothstein, *supra* note 286, at 80.

³⁹⁴ CAL. INS. CODE §§ 10123.3 (prohibiting discrimination by self-insured employee welfare benefit plans based on genetic disability traits), 10123.35 (assessing civil penalties for unauthorized disclosure of genetic test results), 10140 (prohibiting discrimination on basis of race, color, religion, national

found within the Health and Safety Code.³⁹⁵ State statutes also differ by lines of insurance, regulating providers of life, health, or disability insurance, and a variety of combinations thereof. Notwithstanding the maze of state statutes, statements of general trends and generalizations regarding specific mandated coverage are possible.

The 1980s and 1990s have witnessed an explosion in state statutes that mandate certain coverages in health and health-related insurance. From 1979 to 1989, the number of state statutes mandating coverage more than doubled.³⁹⁶ All fifty states now have some insurance coverage mandates. A 1986 survey found that insurance benefits had been mandated in the following areas (the number of states mandating coverage is shown in parentheses): alcoholism (thirty-eight states); psychologists (thirty-four states); mentally/physically handicapped (thirty-two states); chiropractors (twenty-six states); mental health (twenty-six states); divorced spouse (twenty-three states); nurse practitioners (eight states); nurse midwives (seventeen states); home health (fifteen states); hospice (five states); drug abuse (fifteen states); and breast reconstruction (eight states).³⁹⁷

origin, ancestry, sexual orientation, or genetic disability trait), 10143 (prohibiting discrimination "solely by reason of the fact that the person to be insured carries a gene which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects on the carrier"), 10146-10149.1 (collectively, article 2.6, establishing standards related to underwriting on the basis of tests of genetic characteristics) (West 1993 & Supp. 1996).

³⁹⁵ CAL. HEALTH & SAFETY CODE § 1374.7 (West 1996) (containing language very similar to CAL. INS. CODE § 10143 (*see supra* note 394)).

³⁹⁶ Gail A. Jensen & Jon R. Gabel, *State Mandated Benefits and the Small Firm's Decision to Offer Insurance*, 4 J. REG. ECON. 379, 380 (1992). This article takes a cautionary view toward more state mandates.

Mandates typically stipulate that certain benefits be included in a group plan, if one is offered. By making insurance more expensive, minimum coverage rules may price some firms out of the insurance market. Especially vulnerable are small firms, which face a much higher premium to begin with. ERISA grants employer self-insured benefit plans exemption from all state insurance laws and taxation. Small firms, however, cannot viably self-insure as a means of circumventing mandated benefits requirements. Ironically, it is these very firms where coverage needs to be encouraged if we are to reduce the number of employed uninsured.

Id. at 404, *quoted in* Hylton, *supra* note 82, at 75 n.53.

³⁹⁷ Linda E. Demkovich, *Covering Options Through Mandated Benefits*, BUS.

It is not feasible to cite all the statutes that mandate coverage. The following list demonstrates the breadth of state mandates: treatment of mental health conditions,³⁹⁸ alcohol and drug treatment,³⁹⁹ kidney disease treatment,⁴⁰⁰ coverage of diabetes,⁴⁰¹ special dietary treatment,⁴⁰² coverage of infertility procedures,⁴⁰³ maternity coverage,⁴⁰⁴ coverage of newborn infants from moment of birth,⁴⁰⁵ coverage for children's preventive health services such as immunizations and cytological screenings,⁴⁰⁶ coverage of newborns with cleft palate or cleft lip,⁴⁰⁷ extended hospital or medical expense coverage into adulthood for dependent handicapped children,⁴⁰⁸ coverage for pap

AND HEALTH, Jan./Feb. 1986, at 27, 28 (listing "selected mandated benefits by number of states" (source: Blue Cross and Blue Shield Association)).

³⁹⁸ D.C. CODE ANN. § 35-2302 (1995); HAW. REV. STAT. § 431M-2 (1993); KY. REV. STAT. ANN. § 304.17-3185 (Michie Supp. 1994); MISS. CODE ANN. § 83-9-39 (1991); MO. ANN. STAT. § 376.381 (West 1991 & Supp. 1996); MONT. CODE ANN. § 33-22-703 (1995); N.H. REV. STAT. ANN. § 415:18-a (1991 & Supp. 1995); TENN. CODE ANN. § 56-7-2601 (1994); TEX. INS. CODE ANN. art. 3.51-14 (West Supp. 1997).

³⁹⁹ D.C. CODE ANN. § 35-2302 (1993); HAW. REV. STAT. § 431M-2 (1993); KY. REV. STAT. ANN. §§ 304.18-130-.18-180 (Michie 1988); MINN. STAT. ANN. § 62A.149 (West 1996); MONT. CODE ANN. § 33-22-703 (1995).

⁴⁰⁰ WIS. STAT. ANN. § 632.895(4) (West 1995).

⁴⁰¹ IOWA CODE ANN. § 509.3-6 (West 1988) (coverage for diabetic outpatient and self-management education programs); WIS. STAT. ANN. § 40.52(1)(b) (West 1992).

⁴⁰² MINN. STAT. ANN. § 62A.26 (West 1996).

⁴⁰³ MASS. REGS. CODE tit. 211, § 37.05 (1994) (coverage of six infertility procedures); *cf.* CAL. INS. CODE §§ 10119.6, 11512.28 (West 1994 & Supp. 1996) (requires health and disability policies to offer coverage for infertility treatment except in vitro fertilization).

⁴⁰⁴ CAL. HEALTH & SAFETY CODE § 123180(6) (West 1996); MINN. STAT. ANN. § 62A.041 (West 1996); N.J. STAT. ANN. § 17B: 26-2.1b (West 1996); N.Y. INS. LAW § 3216(i)(10)(A) (McKinney 1985).

⁴⁰⁵ COLO. REV. STAT. § 10-16-104 (1994 & Supp. 1996); KY. REV. STAT. ANN. § 304.17-042 (Michie Supp. 1994) (coverage includes "medically diagnosed congenital defects and birth abnormalities"); WIS. STAT. ANN. § 632.895(5) (West 1995) (coverage includes "congenital defects and birth abnormalities" and "functional repair or restoration of any body part when necessary to achieve normal body functioning" but does not cover surgery "to improve appearance").

⁴⁰⁶ N.Y. INS. LAW § 3216(i)(17)(A) (McKinney Supp. 1996).

⁴⁰⁷ COLO. REV. STAT. § 10-16-104(1)(c)(II) (1994).

⁴⁰⁸ WIS. STAT. ANN. § 632.88 (West 1989).

smears,⁴⁰⁹ coverage for low-dose mammography screening,⁴¹⁰ coverage for reconstructive breast surgery resulting from a mastectomy,⁴¹¹ coverage for diagnostic prostate cancer screening for male insureds age fifty and over,⁴¹² coverage for treatment of temporomandibular joint disorders and craniomandibular disorders,⁴¹³ coverage for prosthetic devices⁴¹⁴ including “coverage for hair prostheses worn for hair loss suffered as a result of alopecia areata,”⁴¹⁵ and coverage of HIV and AIDS.⁴¹⁶

In addition to prescribing insurance coverage, another method of mandating coverage is for a state to supplement its definition of unfair

⁴⁰⁹ DEL. CODE ANN. tit. 18, § 3552 (1989 & Supp. 1994) (pap smears); KAN. STAT. ANN. § 40-2230 (1993) (pap smears and mammographies).

⁴¹⁰ KY. REV. STAT. ANN. § 304.17-316 (Michie Supp. 1994).

⁴¹¹ WASH. REV. CODE § 48.20.395 (1994).

⁴¹² W. VA. CODE ANN. § 5-16-9 (1994).

⁴¹³ KY. REV. STAT. ANN. § 304.17-319 (Michie Supp. 1994).

⁴¹⁴ ALASKA STAT. § 21.42.375 (Michie 1991); MD. ANN. CODE art. 48A § 354Q (1994).

⁴¹⁵ MINN. STAT. § 62A.28, subd. 2 (1996).

⁴¹⁶ When the AIDS epidemic arose in the 1980s, the initial reaction of some states was to prohibit insurers from using the HIV antibody test to ascertain insurability; others prohibited insurers from requiring applicants to undergo blood testing. Now, with the rise in medical and insurance costs, the trend is not to prohibit HIV testing information but rather to regulate insurers' use of HIV information and protect the applicant's confidentiality. *See, e.g.*, ARIZ. REV. STAT. ANN. § 20-448.01 (West Supp. 1996) (requiring confidentiality and required insurance procedures relating to HIV information); CAL. INS. CODE §§ 799-799.09 (West 1993 & Supp. 1996) (establishing standards for insurers); FLA. STAT. ANN. § 627.429 (West 1996); N.Y. PUB. HEALTH LAW §§ 2780-2787 (McKinney 1993). Statutes generally require that insurers first obtain an applicant's written, informed consent. *See, e.g.*, VT. STAT. ANN. tit. 8, § 4724(20)(B) (1993) (requiring informed consent be obtained before HIV-related tests are performed). Texas permits an HIV test only if the test is based on the applicant's “current medical condition or medical history or if underwriting guidelines for the coverage amounts require all persons within the risk class to be tested.” TEX. INS. CODE ANN. § 21.21-4(b) (West Supp. 1997). Kentucky, which has the same requirement as Texas, requires informed consent for HIV testing, protects confidentiality, and provides that the insurer “shall not exclude coverage for [HIV and] . . . [the] contract shall not be canceled or nonrenewed solely because [of an HIV diagnosis and] [s]exual orientation shall not be used in the underwriting process” KY. REV. STAT. ANN. § 304.12-013(5) (Michie Supp. 1994).

trade practices.⁴¹⁷ In other words, a state can prescribe coverage through specific prohibitions — these proscriptions are phrased as specific bars on unfair discrimination. Illustrative is blindness, a particular state concern. The proscribing statute states: “Unfair discrimination against individuals on the basis of blindness or partial blindness is prohibited.”⁴¹⁸ In addition to proscribing specific discrimination based on a specific disease, or mental or physical condition, states can generally proscribe unfair insurers’ customs and practices that constitute discrimination.

All fifty states have enacted statutes or ordinances prohibiting employer discrimination on the basis of race, color, gender, national origin, or religion.⁴¹⁹ At the federal level, comparable “insurance civil rights” legislation was considered in the 1980s but was not enacted.⁴²⁰ At the state level, unfair trade practices statutes proscribe such discrimination by insurance companies. This Kentucky statute is an example:

No person shall, whether acting for himself or another in connection with an insurance transaction, fail or refuse to issue or renew insurance to any person because of race, color, religion, national origin or sex except that rates determined through valid actuarial tables shall not be violative of KRS chapter 344.⁴²¹

⁴¹⁷ For a description of state regulation of unfair trade practices in insurance, see *supra* notes 113-21 and accompanying text.

⁴¹⁸ KY. REV. STAT. ANN. § 304.12-215(1) (Michie 1988). The statute defines unfair discrimination: “For the purposes of this section, unfair discrimination against individuals on the basis of blindness or partial blindness consists of refusing to insure, refusing to continue to insure, limiting the amount, extent, or kind of coverage available to an individual, or charging an individual a different rate for the same coverage solely because of blindness or partial blindness.” *Id.* § 304.12-215(2).

⁴¹⁹ For a compilation and discussion of these state statutes and pertinent case law, see MARVIN F. HILL, JR. & JAMES A. WRIGHT, *EMPLOYEE LIFESTYLE AND OFF-DUTY CONDUCT REGULATION* 105-15 (1993). These statutes are also important because Title VII of the 1964 Civil Rights Act requires the EEOC initially to defer processing employment discrimination charges to those states that have a comprehensive fair employment statute (defined as a “706 agency”). 42 U.S.C. § 2000e-5(d) (1996).

⁴²⁰ For a discussion of proposed federal insurance civil rights legislation, see Wortham, *supra* note 76, at 364-70.

⁴²¹ KY. REV. STAT. ANN. § 304.12-085 (Michie 1988). This statute, as written, may have limited impact on insurance risk classifications because its reference to actuarial tables appears to permit insurers to use fair discrimination

The issue is whether states will amend their civil rights or insurance statutes to add “genotype” or perhaps “genetic characteristics” to the list of traits that constitute unfair discrimination by insurers. On March 14, 1996, New Jersey did just that by adopting an insurance civil rights amendment similar to the Kentucky statute above, and adding:

No person shall discriminate against any individual on the basis of genetic information or the refusal to submit to a genetic test or make available the results of a genetic test to the person in the issuance, withholding, extension or renewal of any hospital confinement or other supplemental limited benefit health or credit life or credit accident insurance coverage . . . or in the fixing or rates, terms or conditions therefor⁴²²

The statutory amendment proscribes the defined insurers from requiring applicants to undergo genetic testing, conditioning insurance coverage on genetic testing information, inquiring or determining if an applicant has had a genetic test, and using genetic testing information to determine classifications, rates, or benefits. This type of statute could also protect genetic privacy and confidentiality, create a private cause of action for aggrieved parties, and empower the state attorney general to sue for violations that deny applicants and insureds rights created under the statute. As the next section explains, approximately eight states have specific genetic condition statutes while ten states have enacted more comprehensive, but non-uniform, insurance/genetic legislation.

2. State Laws Concerning Genetic Testing and Use of Genetic Information

As the summary below demonstrates, there is a significant trend at the state level to address issues concerning genetic testing and the use of genetic information by insurance companies and others.

a. Summary of State Insurance/Genetic Laws

The following list alphabetically summarizes current state laws, as of mid-1996, concerning genetic testing and the use of genetic information by insurance companies.

to justify differentiating applicants and charging different premiums based on actuarial principles.

⁴²² Genetic Privacy Act, S.B. 695, 207th Leg., 1st Sess. (N.J. 1996) (“An Act Concerning Genetic Testing and Privacy and Medical Underwriting”).

Alabama — Section 27-5-13 of the Alabama Code prohibits any health or disability insurance policy from denying coverage to applicants diagnosed as having sickle-cell anemia.⁴²³

Arizona — Section 20-448 of the Arizona Revised Statute Annotated prohibits any insurer from “refus[ing] to consider an application for life or disability insurance on the basis of a genetic condition,⁴²⁴ developmental delay or developmental disability.”⁴²⁵ However, an insurance company may reject such an applicant if “the applicant’s medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition, developmental delay or developmental disability.”⁴²⁶

In sum, Arizona requires that life and disability insurers use information regarding a genetic condition only if actuarial projections establish that the genetic condition will result in substantial differences in claims made. In effect, Arizona permits fair genetic discrimination based on sound actuarial analysis.

California — On October 9, 1995, the governor signed Senate Bill Number 1020, effective until January 1, 2002, which in practical effect puts a moratorium on the use of genetic testing information in insurance until the approximate completion⁴²⁷ of the HGP.⁴²⁸ The law amends: (1) the California Civil Code by adding Chapter 2.5,⁴²⁹ (2) section 1374.7 of the California Health and Safety Code⁴³⁰ by adding section 1374.9,⁴³¹ and (3) the California Insurance Code by adding sections 10123.31, 10123.35, 10140.1, 10140.5, 11512.96, and 11512.965 to existing sections 10123.3, 10140, 10147, and 11512.95.⁴³²

⁴²³ ALA. CODE § 27-5-13 (1982).

⁴²⁴ ARIZ. REV. STAT. ANN. § 20-448(H)(5) (Supp. 1996) (“Genetic condition means a specific chromosomal or single-gene genetic condition.”).

⁴²⁵ *Id.* § 20-448(D).

⁴²⁶ *Id.* § 20-448(E).

⁴²⁷ *See supra* note 1.

⁴²⁸ S.B. 1020 (Cal. 1995).

⁴²⁹ CAL. CIV. CODE § 56.17 (West Supp. 1996) (unlawful disclosure by health care service plan).

⁴³⁰ CAL. HEALTH & SAFETY CODE § 1374.7 (West Supp. 1996) (prohibiting genetic discrimination by health service plan).

⁴³¹ *Id.* § 1374.9 (administrative penalties for violations of § 1374.7).

⁴³² CAL. INS. CODE §§ 10123.31 (administrative penalties for violations of section 10123.3); 10123.35 (unlawful disclosure by self-insured welfare benefit

The general purpose of this legislation is to prevent insurance discrimination on the basis of a person's genetic characteristics. "Genetic characteristic" is defined as:

any scientifically or medically identifiable gene or chromosome, or alteration thereof, which is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder that is presently not associated with any symptoms of any disease or disorder.⁴³³

The law applies to the following entities: health care service plans,⁴³⁴ life and disability insurers,⁴³⁵ nonprofit hospital service plans,⁴³⁶ and self-insured employee welfare benefit plans.⁴³⁷ The statute prohibits those entities "on the basis of a person's genetic characteristics" from: (1) refusing to enroll or accept an applicant,⁴³⁸ (2) refusing to issue an insurance policy to any applicant,⁴³⁹ (3) cancelling the applicable insurance,⁴⁴⁰ (4) charging a higher rate or premium,⁴⁴¹ (5) offering or providing different terms, conditions, or benefits,⁴⁴² and (6) placing a limitation on coverage under the applicable insurance.⁴⁴³

Additionally, the law recognizes a person's right to privacy regarding genetic testing by proscribing the disclosure of genetic test results

plan); 10140.1 (unlawful disclosure by a life or disability insurer); 10140.5 (administrative penalties for violation of section 10140); 11512.96 (administrative penalties for violation of section 11512.95); 11512.965 (unlawful disclosure by a nonprofit hospital service plan); 10123.3 (prohibiting genetic discrimination by self-insured employee welfare benefits plans); 10140 (prohibiting genetic discrimination by insurer); 10147 (definitions); 11512.95 (prohibiting genetic discrimination by nonprofit hospital service plan) (West Supp. 1996).

⁴³³ *Id.* § 10147(b).

⁴³⁴ CAL. HEALTH & SAFETY CODE § 1374.7.

⁴³⁵ CAL. INS. CODE § 10140.

⁴³⁶ *Id.* § 11512.95.

⁴³⁷ *Id.* § 10123.3. This provision appears to fit under ERISA's saving clause.

See supra Part IV.B.1.a (notes 257-93 and accompanying text).

⁴³⁸ *Id.* §§ 10123.3(a), 10140(b), 11512.95(a); CAL. HEALTH & SAFETY CODE § 1374.7(a).

⁴³⁹ CAL. INS. CODE §§ 10123.3(a), 10140(b), 11512.95(a).

⁴⁴⁰ *Id.* § 10140(b).

⁴⁴¹ *Id.* §§ 10123.3(a), 10140(b), 11512.95(a); CAL. HEALTH & SAFETY CODE § 1374.7(a).

⁴⁴² *Id.*

⁴⁴³ CAL. INS. CODE § 10140(b).

contained in an applicant's or enrollee's medical records.⁴⁴⁴ The law penalizes any such disclosure by imposing civil penalties for negligent and willful violations, and by imposing criminal liability if "economic, bodily or emotional harm" results from the violation.⁴⁴⁵

Colorado — The Colorado statute regulating the use of genetic information is based on four premises:

(a) Genetic information is the unique property of the individual to whom the information pertains;

(b) [Genetic testing information] may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual to whom the information pertains;

(c) To protect individual privacy and to preserve individual autonomy with regard to the individual's genetic information, it is appropriate to limit the use and availability of genetic information;

(d) The intent of this statute is to prevent information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage.⁴⁴⁶

The covered entities "may not seek, use or keep" genetic testing information for any underwriting or nontherapeutic purpose.⁴⁴⁷ Genetic testing information is "confidential and privileged," except when used in diagnosis, treatment, or therapy; it can be released only with the "specific written consent of the person tested."⁴⁴⁸ Note, however, that there is no liability if a covered entity receives genetic testing information.

Additionally, the statute applies only to entities that provide health, group disability, and long-term care insurance that are within the Colorado Insurance Commission's jurisdiction.⁴⁴⁹ Significantly, the statute does not apply to employer self-insured employee welfare benefit plans.

⁴⁴⁴ CAL. CIVIL CODE § 56.17 (applying to disclosure by a health care service plan); CAL. INS. CODE §§ 10123.35 (applying to disclosure by a self-insured welfare benefit plan), 10140.1 (applying to disclosure by a life or disability insurer), 11512.965 (applying to disclosure by a nonprofit hospital service plan).

⁴⁴⁵ *Id.*

⁴⁴⁶ COLO. REV. STAT. § 10-3-1104.7 (1994) (effective July 1, 1994).

⁴⁴⁷ *Id.* § 10-3-1104.7(3)(b).

⁴⁴⁸ *Id.* § 10-3-1104.7(3)(a).

⁴⁴⁹ *Id.* § 10-3-1104.7(2)(a).

Genetic testing is defined as “any laboratory test of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness.”⁴⁵⁰ This very specific definition may be flawed in that it circumscribes the legal protection granted to personal genetic information. This definition does not, for instance, cover other tests used to diagnose genetic conditions, such as chemical, immunochemical, and biochemical tests measuring chemicals or enzymes in the body, or examination of chromosomes by microscopy. Nor does the definition cover medical or physical examinations, or written or anecdotal family medical histories of genetic disease, illness, or conditions. Moreover, new technological complexities following completion of the HGP may present formidable tasks in the interpretation and construction of this discrete statutory definition.

Violation of the statute is an unfair insurance practice subject to Insurance Commission sanctions.⁴⁵¹ In addition, the statute provides a private right of action for people injured by wrongful use of genetic information, with both legal and equitable remedies available.⁴⁵² The prevailing party may recover attorney fees.⁴⁵³

Florida — Effective October 1, 1994, Florida amended its civil rights statute to protect individuals from the misuse of DNA typing and genetic testing information.⁴⁵⁴ The statute defines “DNA analysis” as “the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person’s body includ[ing] DNA typing and genetic testing.”⁴⁵⁵ Except for criminal prosecutions and for determining paternity, DNA analysis and genetic testing information are “confidential” and “the exclusive property of the person tested.”⁴⁵⁶ The test cannot be performed or the results disclosed without the tested person’s informed consent. A violation constitutes a first degree misdemeanor.⁴⁵⁷

⁴⁵⁰ *Id.* § 10-3-1104.7(2)(b).

⁴⁵¹ *Id.* § 10-3-1104.7(11).

⁴⁵² *Id.* § 10-3-1104.7(12).

⁴⁵³ *Id.* § 10-3-1104.7(13).

⁴⁵⁴ FLA. STAT. ANN. § 760.40 (West Supp. 1996) (establishing the confidentiality of DNA typing and genetic testing information and limiting insurers’ use of this information by assuring its accuracy).

⁴⁵⁵ *Id.* § 760.40(1).

⁴⁵⁶ *Id.* § 760.40(2)(a).

⁴⁵⁷ *Id.*

The statute also provides that any person who conducts a DNA/genetic test must provide a notice to the person tested stating "whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity."⁴⁵⁸ In the event of a denial, the test "must be repeated to verify the accuracy."⁴⁵⁹

In 1978, Florida passed a series of laws proscribing sickle-cell testing and screening, and the use of sickle-cell trait information. Life and disability insurers may not deny insurance or "carry a higher premium rate or charge solely because the [applicant] has the sickle-cell trait."⁴⁶⁰ Other 1978 acts prohibited any condition requiring sickle-cell testing or screening in public and private employment, state higher education, and eligibility for adoption.⁴⁶¹ Moreover, private and public employers shall not "deny or refuse employment to any person or discharge any person from employment solely because such person has the sickle-cell trait."⁴⁶²

Georgia — Effective July 1, 1995, chapter 54, Genetic Testing, was added to title 33, Insurance, of the Georgia Code.⁴⁶³ Virtually identical to the Colorado and Virginia legislation,⁴⁶⁴ the legislative findings state that genetic information "is the unique property of the individual tested,"⁴⁶⁵ genetic testing is subject to abuse if disclosed to third parties,⁴⁶⁶ and, to protect privacy and personal autonomy, the use and availability of genetic information should be limited.⁴⁶⁷ The stated intent of the chapter "is to prevent [defined insurers] and other payors from using information derived from genetic testing to deny access to accident and sickness insurance."⁴⁶⁸ Section two defines "insurers" to

⁴⁵⁸ *Id.* § 760.40(3).

⁴⁵⁹ *Id.*

⁴⁶⁰ FLA. STAT. ANN. §§ 626.9706 (life insurance), 626.9707 (disability insurance) (West 1996).

⁴⁶¹ FLA. STAT. ANN. § 63.043 (West 1985); FLA. STAT. ANN. § 228.201 (West 1989); FLA. STAT. ANN. § 448.096 (West 1981).

⁴⁶² FLA. STAT. ANN. § 448.075 (West Supp. 1996).

⁴⁶³ GA. CODE ANN. § 33-54-1 to -8 (1996).

⁴⁶⁴ *See supra* note 446 and accompanying text and *infra* notes 524-29 and accompanying text.

⁴⁶⁵ GA. CODE ANN. § 33-54-1(1).

⁴⁶⁶ *Id.* § 33-54-1(2).

⁴⁶⁷ *Id.* § 33-54-1(3).

⁴⁶⁸ *Id.* § 33-54-1(4).

mean “an insurer, a fraternal benefit society, a nonprofit medical service corporation, a health care corporation, a health maintenance corporation, [or] a self-insured health plan not subject to the exclusive jurisdiction of [ERISA].”⁴⁶⁹

Similar to the Colorado statute, Georgia’s law also applies a restrictive definition of genetic testing.⁴⁷⁰ It limits “genetic testing” to include human DNA or chromosomal laboratory tests for “the purpose of identifying the presence or absence of inherited alterations in genetic material or genes which are associated with a disease or illness that is asymptomatic at the time of testing and that arises solely as a result of such abnormality in genes or genetic material.”⁴⁷¹ It further restricts the definition by excluding “routine physical measurements; chemical, blood and urine analysis; tests for abuse of drugs; and tests for the presence of [HIV].”⁴⁷²

Although genetic testing is narrowly defined, information derived therefrom is confidential and privileged.⁴⁷³ Furthermore, the statute prohibits an insurer from seeking such information.⁴⁷⁴ But if an insurer has genetic testing information, the insurer “may not use the information for any nontherapeutic purpose”⁴⁷⁵ and cannot release it to third parties without the tested individual’s written consent.⁴⁷⁶ Notwithstanding these protections, use of genetic testing information is authorized in criminal investigation and prosecution and for scientific research purposes.⁴⁷⁷ Any violation of the act constitutes an unfair trade practice and is punishable by a civil penalty plus court costs and attorney’s fees if applicable.⁴⁷⁸

Louisiana — Title 22, section 652.1 of the Louisiana Revised Statutes Annotated prohibits unfair discrimination in life insurance rates or coverage because of severe disability or the presence of the sickle-cell trait.⁴⁷⁹ Furthermore, title 23, Labor and Worker’s Compensation,

⁴⁶⁹ *Id.* § 33-54-2(2).

⁴⁷⁰ *See supra* note 450 and accompanying text.

⁴⁷¹ GA. CODE ANN. § 33-54-2(1).

⁴⁷² *Id.*

⁴⁷³ *Id.* § 33-54-3(b).

⁴⁷⁴ *Id.* § 33-54-3(a).

⁴⁷⁵ *Id.* § 33-54-4.

⁴⁷⁶ *Id.* § 33-54-3(b).

⁴⁷⁷ *Id.* § 33-54-5.

⁴⁷⁸ *Id.* § 33-54-8.

⁴⁷⁹ LA. REV. STAT. ANN. § 22:652.1 (West 1995). Discrimination in life

section 1002 of the Louisiana Revised Statutes Annotated, makes it unlawful for an employer “to fail or refuse to hire, or to discharge, any individual or otherwise discriminate” because such individual has the sickle-cell trait.⁴⁸⁰

Maryland — The Insurance Code of the Annotated Code of Maryland, section 223, prohibits unfair discrimination in rate, premium, or dividend differential in life and annuity contracts “solely because the applicant or policyholder has the sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or any genetic trait which is harmless within itself, unless there is actuarial justification for it.”⁴⁸¹

Minnesota — In Minnesota the Genetic Discrimination Act regulates the use of genetic tests by health, life, and fraternal benefit societies.⁴⁸² In subdivision 2(b), “genetic test” is defined as:

a presymptomatic test of a person’s genes, gene products, or chromosomes for the purpose of determining . . . [genetic] abnormalities, defects, or deficiencies, including carrier status, that are known to be the cause of a disease or disorder, or are determined to be associated with a statistically increased risk of development of a disease or disorder. . . . [But] “genetic test” does not include a cholesterol or other test not conducted for the purpose of determining the presence or absence of a person’s gene or genes.⁴⁸³

The statute prohibits health insurers from using genetic testing information to determine eligibility, “establish[] premiums, limit[] coverage, [or] renew[] coverage.”⁴⁸⁴ It also prohibits health insurers

insurance rates or coverage because of severe disability is permitted if the rate differential “is based on sound actuarial principles or is related to actual experience.” *Id.* § 22:652.1(A). Section (D) regarding sickle-cell trait was added in 1982 and does not allow for discrimination based on actuarial principles or actual experience. *Id.* § 652.1(D).

⁴⁸⁰ LA. REV. STAT. ANN. § 23:1002 (West 1985) (prohibiting sickle-cell trait discrimination by employers, employment agencies, and labor organizations).

⁴⁸¹ MD. CODE ANN., INS. § 223(a)(3) (Supp. 1996) (effective Oct. 1, 1996). Prior to this 1996 Amendment, unfair discrimination was prohibited regarding health insurance contracts as well. *Id.* § 223(b)(4) (repealed 1996). However, effective September 30, 2002, health insurance contracts will once again be prohibited from such discrimination, *id.* § 223(b)(4) (effective Sept. 30, 2002).

⁴⁸² MINN. STAT. ANN. § 72A.139 (West Supp. 1996) (effective Jan. 1, 1996).

⁴⁸³ *Id.* § 72A.139.2(b).

⁴⁸⁴ *Id.* § 72A.139.3.

from requiring or requesting a genetic test and from inquiring or determining whether or not an individual has had a genetic test.⁴⁸⁵ On the other hand, life insurers and fraternal benefit societies may request that an applicant undergo a genetic test to determine insurability provided the applicant gives "written informed consent,"⁴⁸⁶ the insurer pays the testing costs,⁴⁸⁷ and the applicant is told the genetic test result.⁴⁸⁸

Montana — Subsections (3), (4), and (5) to section 33-18-206 of the Montana Code Annotated prohibit unfair discrimination in life and disability insurance.⁴⁸⁹ The 1991 Montana Act is the same as section 20-448 of the Arizona Revised Statute Annotated.⁴⁹⁰ Both the Montana and Arizona acts prohibit insurers from refusing to consider an application for life or disability insurance on the basis of genetic condition, developmental delay, or developmental disability. Rejecting an application or determining rates, terms, or conditions of the policy based on these three factors constitutes unfair discrimination, "unless the applicant's medical condition and history, and either claims experience, or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition"⁴⁹¹

New Hampshire — On May 16, 1995, New Hampshire enacted a sweeping new Genetic Testing Act effective January 1, 1996.⁴⁹² Significantly, the law states that "no individual or member of the individual's family shall be required to undergo genetic testing as a condition of doing business with another person."⁴⁹³ The statute also specifies conditions for any genetic testing done in New Hampshire.⁴⁹⁴ "Genetic testing" is defined as:

⁴⁸⁵ *Id.* § 72A.139.3(2), (3).

⁴⁸⁶ *Id.* § 72A.139.5.

⁴⁸⁷ *Id.* § 72A.139.7.

⁴⁸⁸ *Id.* § 72A.139.6.

⁴⁸⁹ MONT. CODE ANN. § 33-18-206 (1995).

⁴⁹⁰ *See supra* notes 424-26 and accompanying text.

⁴⁹¹ MONT. CODE ANN. § 33-18-206(4).

⁴⁹² N.H. REV. STAT. ANN. §§ 141-H:1 to H:6 (1996) (describing the proper conditions and use of genetic testing).

⁴⁹³ *Id.* § 141-H:2(I).

⁴⁹⁴ *Id.* § 141-H:2 (prohibiting the genetic testing of individuals without written consent except in certain specified instances and for bidding disclosure of results without written and informed consent).

a test, examination or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence or alteration of any gene or chromosome, and any report, interpretation, or evaluation of such a test, examination, or analysis, but excludes [any lawful test to determine if a person] meets reasonable functional standards for a specific job or task.⁴⁹⁵

New Hampshire prohibits health insurers from requiring a genetic test, from inquiring or determining whether or not an individual has had a genetic test, from conditioning health insurance coverage on the results of genetic testing, and from considering genetic testing in the determination of rates or benefits.⁴⁹⁶ The genetic testing statute does not apply to life, disability income, and long-term care insurance.⁴⁹⁷

Regarding employment, the statute prohibits the use of genetic testing as a condition to employment, as affecting the terms of employment, or for termination purposes.⁴⁹⁸ However, the law "shall not prohibit or limit genetic testing for evidence of insurability with respect to life, disability income, or long-term care insurance under the terms of an employee benefit plan."⁴⁹⁹

The New Hampshire law provides for civil damages of at least \$1000 for each violation, plus costs and reasonable legal fees.⁵⁰⁰

New Jersey — New Jersey adopted, on October 24, 1996, the Genetic Privacy Act which concerns genetic testing, genetic privacy, and medical insurance underwriting.⁵⁰¹ The statute commences with eight legislative findings of fact, including:

b. Genetic information is personal information that should not be collected, retained or disclosed without the individual's authorization.

⁴⁹⁵ *Id.* § 141-H:1(IV).

⁴⁹⁶ *Id.* § 141-H:4 (listing prohibited uses of genetic testing by health insurance companies).

⁴⁹⁷ *Id.* § 141-H:5. However, the statute prohibits life, disability income, or long-term care insurers from using genetic "information in writing a type of insurance coverage other than life, disability income or long-term care insurance." *Id.* § 141-H:5(II).

⁴⁹⁸ *Id.* § 141-H:3.

⁴⁹⁹ *Id.* § 141-H:3(V).

⁵⁰⁰ *Id.* § 141-H:6.

⁵⁰¹ Genetic Privacy Act, S.B. 695, 207th Leg., 1st Sess. (N.J. 1996) (amending N.J. STAT. ANN. § 17B:30-12 (West 1996)).

c. The improper collection, retention or disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance.

d. An analysis of an individual's DNA provides information not only about an individual, but also about an individual's parents, siblings and children, thereby impacting family privacy, including reproductive decisions.

e. Current legal protections for medical information, tissue samples and DNA samples are inadequate to protect [individual] genetic privacy.

f. Laws . . . are needed both to protect individual privacy and to permit legitimate genetic research.

g. Progress in mapping the genes that cause breast cancer and other diseases has far outpaced the development of a legal and ethical context in which genetic information can be properly evaluated.⁵⁰²

“Genetic test” is defined as “a test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic.”⁵⁰³

The law generally proscribes discrimination “against any person or group of persons because of race, creed, color, national origin or ancestry” in rate classifications, acceptance of applications, and renewal of policies.⁵⁰⁴ This important civil rights provision, however, does not explicitly mention genetic discrimination.⁵⁰⁵ The statute, however, subsequently prohibits discrimination in underwriting, rates, acceptance, and renewals, and contract terms in “hospital confinement or other supplemental limited benefit health or credit life or credit accident insurance coverage” based on “genetic information or the refusal to submit to a genetic test . . .”⁵⁰⁶

Finally, New Jersey prohibits “any unfair discrimination against an individual in the application of the results of a genetic test or genetic

⁵⁰² *Id.* § 2b-g. Additionally, section h recognizes the “devastating potential for discrimination against carriers” of genes “that cause breast cancer and other diseases.” *Id.* § 2h.

⁵⁰³ *Id.* § 3e(2).

⁵⁰⁴ *Id.* § 3a.

⁵⁰⁵ Similarly, gender is not included as a class protected from insurance discrimination.

⁵⁰⁶ *Id.* § 3e.

information in the underwriting of or determining insurability" for a policy of life insurance, an annuity, or disability income insurance contract.⁵⁰⁷ The insurance commissioner is authorized to determine by hearing if an insurer's act or practice conflicts with this section and can seek a cease and desist order.

Note that the statute does not provide any civil liability, penalties,⁵⁰⁸ costs, or attorney's fees for a violation as some other recent state insurance/genetic legislation does.⁵⁰⁹

Additionally, the law empowers life, annuity, and disability income insurers (in the issuance, withholding, extension, or renewal of any policy) to notify the applicant or insured that the insurer requires a genetic test. The insurer must first obtain the individual's written informed consent prior to the required test.⁵¹⁰

In sum, and contrary to the law's title, the statute seems to be a watered-down compromise that neither specifically nor adequately responds to the eight legislative findings of fact stated at the outset, nor does the statute provide comprehensive privacy protection to genetic testing and personal genetic information.

North Carolina — Since July 1, 1975, a series of North Carolina statutes have, in effect, prohibited life and health insurers both from refusing to issue or deliver a policy and from charging a higher rate or premium for applicants having the sickle-cell trait or hemoglobin C trait.⁵¹¹

Ohio — Ohio enacted three statutory revisions, effective February 9, 1994, that prohibit the requirement and use of genetic testing information by HMOs, sickness and accident insurers, and governmental self-insurers.⁵¹² However, the three statutes are automatically repealed on

⁵⁰⁷ *Id.* § 3f.

⁵⁰⁸ However, the Act does give the commissioner the power to "order payment of a penalty consistent with the provisions of N.J.S. 17B:30-1 et seq." *Id.*

⁵⁰⁹ See, e.g., *supra* notes 445, 453, 478, & 500 and accompanying text.

⁵¹⁰ Genetic Privacy Act § 3f.

⁵¹¹ N.C. GEN. STAT. §§ 58-51-45, 58-58-25 (prohibiting insurance companies from refusing to issue policies or charging higher rates for individuals with the sickle-cell trait or hemoglobin C trait), 58-65-70 (prohibiting hospital, medical, dental, and other health service plans from refusing to issue or charging higher rates for individuals with the sickle-cell trait or hemoglobin C trait) (1995).

⁵¹² OHIO REV. CODE ANN. §§ 1742.42 (HMOs), 3901.49 (sickness and

February 9, 2004, the approximate completion date for the HGP.⁵¹³ The legislature provided back-up statutes, which foreseeably will be repealed or amended following the mandated 2004 repeal.⁵¹⁴ The legislation also established a Task Force on Genetic Testing in Health Insurance, which was to report back no later than December 31, 1995.⁵¹⁵ In other words, Ohio put a ten-year moratorium (1994-2004) on the use of genetic testing information by health insurers.

The extensive provisions under the three acts are identical. In summary, the statutes prohibit health insurers from refusing to issue policies, cancelling or renewing coverage, or limiting benefits based on genetic testing or screening. The statutes prohibit health insurers from requiring genetic tests or asking applicants about the results of genetic tests. A violation is considered an unfair trade practice. The statutes allow an insurer to consider genetic testing if the results are favorable to the applicant and the results are voluntarily submitted.⁵¹⁶ Each statute defines "genetic screening or testing" as:

a laboratory test of a person's genes or chromosomes for abnormalities, defects, deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.⁵¹⁷

On December 31, 1995, the Task Force reported the following recommendations:

The Task Force feels that the moratorium on the use of genetic information is an adequate safeguard to protect consumers' interests for the time being. The Task Force, however, has formulated several

accident insurers), 3901.50 (government self-insurers) (Anderson Supp. 1995).

⁵¹³ See *supra* note 1.

⁵¹⁴ OHIO REV. CODE ANN. §§ 1742.43 (HMOs), 3901.491 (sickness and accident insurers), 3901.501 (government self-insurers).

⁵¹⁵ *Id.* § 1742.42(G). "The Task Force shall conduct a comprehensive study of genetic screening and testing as they relate to the medical underwriting of health benefit plans. . . ." *Id.* § 1742.42(E).

⁵¹⁶ *Id.* §§ 1742.42, 3901.49, 3901.50.

⁵¹⁷ *Id.* §§ 1742.42(A), 3901.49(A)(1), 3901.50(A)(1).

recommendations in order to ensure that the consumers are protected even after the moratorium is repealed.⁵¹⁸

1. The Department of Insurance should conduct a yearly review of complaints regarding genetic testing. The Department's Division of Consumer Services has added a specific complaint code for genetic testing in their database. By conducting a yearly review, the Department will be able to gauge when or if the problem is manifesting itself.

2. Another Task Force on Genetic Testing, similar in size and composition, should be appointed near the expiration date of the moratorium. This will allow policymakers to assess the current definition and impact of genetic testing in health insurance. This recommendation is, of course, subject to legislative action.

3. The Department of Insurance should continue to monitor the National Association of Insurance Commissioners' Working Group on Genetic Testing in order to keep current with advances in genetic technology and to remain engaged in discussions regarding possible regulatory mechanisms.⁵¹⁹

Oregon — A straightforward, one-half page 1995 statute, provides: "An insurance provider may not use genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms and conditions of or otherwise affect any policy for hospital or medical expenses."⁵²⁰ Additionally, the law requires that the insurer reveal the use of the test to the applicant and obtain consent.⁵²¹ Finally, the statute prohibits an insurance provider from using "a favorable genetic test as an inducement to purchase insurance."⁵²²

Tennessee — In 1988, Tennessee passed a statute prohibiting any life insurer from refusing to issue or deliver a policy solely because the applicant possesses the sickle-cell trait or hemoglobin C trait.⁵²³

Virginia — Virginia enacted the Genetic Privacy Act in April 1996.⁵²⁴ For a period of two years, the law prohibits health insurance

⁵¹⁸ OHIO TASK FORCE ON GENETIC TESTING, FINAL REPORT, *supra* note 4, at 22-23.

⁵¹⁹ *Id.* at v.

⁵²⁰ OR. REV. STAT. § 746.135(3) (1995).

⁵²¹ *Id.* § 746.135(1).

⁵²² *Id.* § 746.135(2).

⁵²³ TENN. CODE ANN. § 56-7-207 (1994).

⁵²⁴ VA. CODE ANN. § 38.2-508.4 (Michie Supp. 1996).

companies from using genetic information for the purpose of denying, restricting, cancelling, or imposing other criteria on current or future policyholders on the basis of the results of genetic testing or the request for genetic testing services.⁵²⁵ Similar to Ohio's ten-year moratorium,⁵²⁶ this Act established a two-year moratorium on health insurers' use of genetic testing information.⁵²⁷

Concurrently with the law's passage, the legislature established a subcommittee to study genetic testing issues, including insurance. Adopted March 4, 1996, the Virginia Senate Joint Resolution Bill Number 50 created the Joint Subcommittee to Study the Legal and Policy Ramifications of Genetic Research to study and review "existing and new Virginia law on genetic information and privacy."⁵²⁸ The legislature made thirteen findings of fact to justify creating the subcommittee, including recognition of the HGP's accomplishments, accounts of health insurers' abuse and misuse of genetic information, insurer and societal misunderstanding ("the presence of a genetic marker does not imply that the carrier will ever develop the disease but only that the person has a higher predisposition to such malady, thereby giving rise to the term 'asymptomatic ill'"), and concerns about genetic discrimination and an individual right to privacy ("without adequate protection for persons to ensure privacy and prevent discrimination, future research will be greatly hindered").⁵²⁹

Wisconsin — Effective July 1, 1992, section 631.89 of the Wisconsin Statutes Annotated prohibits health insurers from using genetic testing information to determine rates, requiring a genetic test, or inquiring if a genetic test has or has not been performed.⁵³⁰ The statute also prohibits insurers from conditioning the provision of insurance coverage or benefits on genetic testing.⁵³¹ "Genetic test" is narrowly defined as "a test using deoxyribonucleic acid extracted from an individual's cells in order to determine the presence of a genetic disease or disorder or the individual's predisposition for a particular genetic disease or disorder."⁵³²

⁵²⁵ *Id.* § 38.2-508.4(B).

⁵²⁶ *See supra* notes 512-19 and accompanying text.

⁵²⁷ VA. CODE ANN. § 38-2-508.4 is effective until July 1, 1998.

⁵²⁸ VA. S.J. RES. 50 (Va. 1996).

⁵²⁹ *Id.*

⁵³⁰ WIS. STAT. ANN. § 631.89 (West 1995).

⁵³¹ *Id.*

⁵³² *Id.* § 631.89(1).

Additionally, Wisconsin's mandatory health insurance risk sharing plan provides that people "are not ineligible for coverage under the plan by reason of" payments or reimbursements for conditions such as hemophilia or cystic fibrosis.⁵³³

*b. State Trend Toward Proscribing
Insurance/Genetic Discrimination and
Protecting Privacy of Genetic Testing Information*

The statutes from the foregoing eighteen jurisdictions are neither sufficiently uniform nor plentiful to draw broad, assured conclusions. But the trend is there and additional state legislation is anticipated.⁵³⁴ The statutes may be grouped into two categories: (1) eight states have adopted a limited, genetic-specific, insurer-specific resolution, and (2) ten states have enacted a comprehensive insurance/genetics solution.

In the first category, the laws of Alabama, Arizona, Florida, Louisiana, Maryland, Montana, North Carolina, and Tennessee do not suggest a comprehensive solution due to the limited scope of the protection against potentially unfair insurer use of genetic information. With the exception of Florida,⁵³⁵ seven states do not address issues of

⁵³³ *Id.* § 619.12(3)(b).

⁵³⁴ OHIO TASK FORCE ON GENETIC TESTING, FINAL REPORT, *supra* note 4, at 22-23. The unpaginated appendix to the December 31, 1995, Final Report of the Ohio Task Force on Genetic Testing states that the following states are presently considering insurance/genetic legislation: Alaska, Hawaii, Illinois, Indiana, Massachusetts, Michigan, Mississippi, Nebraska, Nevada, New York, Pennsylvania, Rhode Island, Texas, and Vermont. Earlier, New York and Wyoming introduced insurance/genetic bills but failed to pass them. 1992 N.Y. LAWS A.11956 (1992) (bill prohibiting discrimination based on genetic predisposition), S.1432 (1992) (bill establishing a sickle-cell anemia screening program and prohibiting discrimination based on same); 1992 Wyo. Sess. Laws 0098 ("an act . . . relating to genetic testing"). The Wyoming bill stated: "No person who has undergone forensic DNA testing and whose test results indicate the person has a genetic characteristic determined to be associated with a statistically increased risk of development of a disease or disorder may apply for, or obtain, insurance coverage without first disclosing the results of the testing to the insurance carrier." *Id.*

⁵³⁵ Effective October 1, 1994, Florida amended its civil rights statute to require informed consent and privacy protection of DNA typing and genetic testing information as well as to restrict insurers' use of personal genetic information by requiring mandatory reanalysis if the use results in a denial of insurance. Amending a state's civil rights statute is an important consideration

individual privacy and of disclosure of personal genetic information to third parties. Five states' statutes very narrowly restrict insurance/genetic discrimination, prohibiting insurers from discriminating only against people who are carriers of specific genetic traits, such as sickle-cell or Tay-Sachs.⁵³⁶ Most of these states restrict only life and disability insurers.

These states appear to have continued the traditional approach epitomized by state-mandated coverages — the micro-management of insurance discrimination. To continue this approach state legislatures will have to evaluate each genetic trait, disorder, or condition and each type of insurance. Obviously, as the thousand or so state-mandated insurance coverages demonstrate, such genetic-specific, insurer-specific legislation is a possible solution following completion of the HGP. But a piecemeal approach in enacting hundreds of statutes seems politically impractical and ineffective when compared to a comprehensive genetic testing act protecting privacy and addressing the insurer's use of genetic testing information in insurance. However, a potential solution (especially if limited to life, annuity, disability income, and, possibly, supplemental or excess health care insurances) is to authorize fair insurance/genetic discrimination, as do Arizona and Montana with their identical statutes.⁵³⁷ Their approach is to proscribe life, annuity, and disability insurers from discriminating on the basis of genetic condition; however, that law has very minimal impact because: (1) it does not cover health insurers, and (2) the prohibited discrimination is permitted if the insurer can prove that substantial differences in claims are likely based on either the applicant's genetic condition and medical history, claims experience, or actuarial projections. Similarly, Louisiana and Maryland permit "actuarially justifiable"⁵³⁸ insurance/genetic discrimination. In other words, Arizona, Louisiana, Maryland, and Montana codify the insurance principle of fair discrimination based on sound actuarial analysis. These statutes indirectly make a useful distinction: certain types of insurance

in fashioning an appropriate solution to insurance/genetic discrimination. *See, e.g.,* FLA. STAT. ANN. § 760.40 (West 1995).

⁵³⁶ ALA. CODE § 27-5-13 (1975); FLA. STAT. ANN. §§ 626.9706, 626.9707 (West 1984); LA. REV. STAT. ANN. § 652.1 (West Supp. 1993); N.C. GEN. STAT. §§ 58-51-45, 58-58-25, 58-65-70 (1991); TENN. CODE ANN. § 56-7-207 (1989).

⁵³⁷ ARIZ. REV. STAT. ANN. § 20-448 (West 1990 & West Supp. 1992); MONT. CODE ANN. § 33-18-206 (1987 Supp. 1992).

⁵³⁸ LA. REV. STAT. ANN. § 652.1 (West Supp. 1993); MD. CODE ANN., INS. § 223 (1986).

such a life insurance, disability insurance, and annuities are purchased for financial protection and as investments. Therefore, the idea of fair discrimination based on economics seems appropriately fair. But that principle may be unfair if applied to health insurance, which has the dominant purpose of providing medical care. The bargained-for exchange is health care protection and not financial protection. Foreseeably, the insurance industry would favor the fair discrimination approach for all lines of insurance.

The statutes of California, Colorado, Georgia, Minnesota, New Hampshire, New Jersey, Ohio, Oregon, Virginia, and Wisconsin better portend the future of insurance/genetic legislation. Although precious little uniformity exists among these ten state statutes, they evidence the contemporary trend toward comprehensive genetic testing, anti-discrimination, and privacy legislation in insurance generally and health insurances in particular. Comprehensive legislation, rather than piecemeal sections scattered throughout state statutes, appears more appropriate for addressing the diverse genetic testing information issues, including privacy and disclosure issues.⁵³⁹ These ten statutes represent the point

⁵³⁹ When insurers make underwriting decisions, they rely on several sources for medical information, including individual medical and health reports from the Medical Information Bureau ("MIB"). The MIB is an association of about 750 health insurance companies who underwrite 90-95% of all health insurance. The MIB maintains a national computer network of approximately 11 million files on Americans and Canadians. See Russell S. Burnside, Note, *The Electronic Communications Privacy Act of 1986: The Challenge of Applying Ambiguous Statutory Language to Intricate Telecommunication Technologies*, 13 RUTGERS COMPUTER & TECH. L.J. 451 n.27 (1987). There is no statutory authority to discover the information contained in MIB records. However, in addition to the genetic state statutes cited in this section, other states have taken steps to protect people from inaccurate and unauthorized disclosures. For example, Rhode Island's Confidentiality of Health Care Information Act permits the release of medical information to insurers only if the patient has given written consent, and the release describes both the need for and the purpose of the disclosure and the extent of the information to be disclosed. R.I. GEN. LAWS §§ 5-37.3-1 to .3-11 (Supp. 1986).

For a description of privacy concerns related to "gene banks," see George J. Annas, *Rules for Gene Banks: Protecting Privacy in the Genetic Age*, in JUSTICE AND THE HUMAN GENOME PROJECT 75 (Timothy F. Murphy & Marc A. Lappé eds., 1994). Gene banks would ostensibly store genetic samples or profiles of individuals. Annas proposes that respected genetic libraries can only be maintained if legislatures pass rules governing the collection and storage of genetic materials. To accomplish that, Annas proposes rules that require public

of the compass toward more meaningful legislation, with a focus on the practice of genetic testing and the use of test results, rather than on the presence of specific genetic traits or conditions.⁵⁴⁰ Moreover, these state acts apply primarily to health insurance and reject the fair discrimination actuarial principle. Minnesota, New Hampshire, and New Jersey make that point clearer by drawing a bright line between health care insurance and the financial-protection insurance (e.g., life, annuities, disability income, fraternal benefit societies). These three states either include only health care with the proscriptions or they allow life, disability income, and other similar forms of insurance to practice fair discrimination.

But these assorted state statutes have flaws. The principal drawback is the lack of uniformity. There is no consistency regarding the types of insurance covered by the legislation.⁵⁴¹ Some define genetic testing broadly, some narrowly. Some provide explicit privacy protection, some do not. Some provide a private cause of action under the unfair trade practices law, civil penalties including attorney fees and costs, and criminal sanctions; others do not. Recognizing and understanding these flaws and choices in language and provisions will aid in drafting future legislation. For instance, even a statute mandating broad bans on insurers'

notice of the establishment of gene banks, informed consent in their policies, and restricted use of their samples.

⁵⁴⁰ GA. CODE ANN. §§ 33-54-1 to 33-54-8 (1995) (prohibits insurers from using information derived from genetic testing for any nontherapeutic purpose); MINN. STAT. ANN. § 72A.139 (West 1996) (prohibits health insurers from requiring, inquiring about, considering refusal to take, or considering results of genetic tests in determining or limiting eligibility or coverage, establishing premiums, or in any other underwriting decision).

⁵⁴¹ See, e.g., Regulating health insurers only: OR. REV. STAT. § 746.135 (1995); WIS. STAT. ANN. § 631.89 (West 1992). Regulating life insurers only: TENN. CODE ANN. § 56-7-207 (1989). Regulating health and disability insurers only: ALA. CODE § 27-5-13 (1975); OHIO REV. CODE ANN. § 1742.43 (Baldwin 1994) (repealed). Regulating life and disability insurers only: ARIZ. REV. STAT. ANN. § 20-448 (West 1990 & West Supp. 1992); CAL. INS. CODE § 10143 (West Supp. 1988); FLA. STAT. ANN. §§ 626.9706, 626.9707 (West 1984); LA. REV. STAT. ANN. § 652.1 (West Supp. 1993). Regulating life and health insurers only: MD. CODE ANN., INS. § 223 (1986); MINN. STAT. ANN. § 72A.139 (West 1996). Regulating "sickness and accident" insurers only: COLO. REV. STAT. ANN. § 10-3-1104 (West 1994); GA. CODE ANN. § 33-54-1 (1995). Regulating health, life, and disability insurers: MONT. CODE ANN. § 33-18-206, 33-22-507 (1987 Supp. 1992); N.H. REV. STAT. ANN. § 101:1-141-H (1995); N.C. GEN. STAT. §§ 58-51-45, 58-58-25, 58-65-70 (1991).

use of information obtained through genetic testing can be avoided by insurers.

A possible end-run by an insurer can be illustrated with reference to California's Senate Bill 1146, authored by state Senator Patrick Johnson and enacted into law in September 1994. "No [health care service, self-insured employee welfare benefit, or nonprofit hospital] plan shall require a higher rate or charge on the basis of a person's genetic characteristics."⁵⁴² Because the law merely prohibited insurers from charging higher premiums due to an insured's genetic profile, the insurers simply lowered the benefits under the terms of their policies. Consequently, the legislature amended the law the following year to close this loophole.⁵⁴³

Three observations are offered in conclusion. First, the deficiencies at the federal level in ERISA and the ADA, both of which defer to state insurance law,⁵⁴⁴ will be cured through comprehensive state insurance/genetic acts, with one exception. The exception is employer self-funded employee benefit plans which the Supreme Court has held, in interpreting ERISA, are to be regulated only by ERISA and are exempt from state insurance regulation.⁵⁴⁵ Thus, if all states pass comprehensive acts, millions of American employees under employer self-funded plans will not be affected. That is a critical consideration in determining the best solution.

Second, one reason that only a handful of states have enacted insurance/genetics laws may stem from the fact that some states, such as Kentucky,⁵⁴⁶ indirectly address the genetic information problem by mandating health coverages through health purchasing alliances. Health purchasing alliance legislation requires that rates be determined by community rates in which "the premium for each individual policy and

⁵⁴² SB 1146 (Johnston); 1994 Stat. Ch. 761 (referring to CAL. HEALTH & SAFETY CODE § 1374.7 (1995)).

⁵⁴³ For example, CAL. HEALTH & SAFETY CODE § 1374.7 now reads, "No plan shall require a higher rate or charge, or offer or provide different terms, conditions, or benefits, on the basis of a person's genetic characteristics . . ."

⁵⁴⁴ See *supra* Part IV.B (notes 239-390 and accompanying text).

⁵⁴⁵ *FMC v. Holiday*, 498 U.S. 52 (1990). See *supra* notes 282-83 and accompanying text.

⁵⁴⁶ Effective July 17, 1994, the Kentucky General Assembly created the Kentucky Health Purchasing Alliance to serve its state employees (mandatory alliance members) and voluntary alliance members (employers with 100 or fewer employees, affiliated groups with 100 or fewer members, and any citizen who chooses to join). KY. REV. STAT. ANN. §§ 304.17A-010-.17A-160 (Michie 1994).

group policy is determined solely on the basis of age, geography, family composition, benefit plan design, and cost containment provisions⁵⁴⁷ In practical effect, a health insurer under the alliance can ask only the applicant's age, address, and family composition. Thus, this type of state legislation indirectly eliminates any health insurer from seeking genetic testing of applicants and from using genetic information in fixing rates and premiums.

The third, and final, observation concerns the moratorium solution adopted by California, Virginia, and Ohio. Serious consideration should be given to the ten-year Ohio moratorium with its interim insurance genetics statutes and the establishment of a Task Force on Genetic Testing in Health Insurance.

D. Reasons for State and Federal Legislative Solutions

Several solid reasons support a state solution to the insurance/genetics dilemma.⁵⁴⁸ (1) *History favors state regulation of the insurance busi-*

⁵⁴⁷ *Id.* at 304.17A-120(1). No attempt was made to canvass all 50 states to catalogue which states had health insurance alliances. The core of the President's failed universal health care legislation was the creation of regional health purchasing alliances. *Clinton's Health Plan: A New Framework for Health Care*, *supra* note 11, at A22. One goal of health purchasing groups or alliances is to equally redistribute the good and bad health risks among all policyholders by using a modified community rating system controlled by a state board, such as the Kentucky Policy Health Board. In essence, the premium is levelled among the group. The good risks pay a higher price than a rating system using risk classifications; the bad risks pay less and are thus subsidized. The down side is that health insurers may decide to stop selling individual health insurance policies which they cannot rate based on personalized medical and other data from the individual applicant. That may be reflected in Kentucky's short-term experience with its alliance. Under the insurance reforms of 1994 and 1995, 15 of the 20 companies that sold individual health policies have stopped doing so. Another potential problem is that associations can sell insurance without using the community rating system that drives up rates for younger, healthier people under the law. That means healthy people might flock to association insurance policies, leaving other carriers — particularly the state-run insurance alliance — to pick up higher-risk people. Bill Estep, *Insurance Industry "Unstable" Commissioner Says Reform Changes Must Be Reconsidered*, *HERALD-LEADER* (Lexington, Ky.), Aug. 28, 1996, at B1 (discussing impacts of state insurance reform on availability and affordability).

⁵⁴⁸ For a more thorough discussion of the rationale supporting continued state regulation, see Spencer Kimball, *The Case for State Regulation of Insurance*, in

ness. "When the States speak in the field of 'insurance,' they speak with the authority of a long tradition."⁵⁴⁹ The vital centers of modern insurance regulation are the fifty departments of insurance in the fifty states. The charter for state authority over the insurance business is the McCarran Act of 1945 in which Congress struck a "hands off" attitude and expressed a strong public policy for the continued state regulation of the business of insurance.⁵⁵⁰ Thereafter, with extensive cooperation among the state insurance commissioners and their agencies, the states achieved a degree of national uniformity by enacting legislation promulgated by the NAIC.⁵⁵¹ In some states, this body of insurance law is sufficiently unified and codified to be characterized as an "insurance code," which leads to the second point. (2) *States can achieve a uniform, national approach.*⁵⁵² This point undercuts the notion that the requisite uniformity to this national issue can be done only at the federal level. (3) *States can better experiment with innovative approaches.* Unlike one national approach affecting everyone, any state legislation will have a smaller, discrete impact which encourages experimentation to achieve the most fair and nondiscriminatory method of regulating genetic testing, use of genetic information, and privacy. (4) *No federal insurance regulatory structure exists.* Instead of creating yet another level of expensive, untested bureaucracy, it is more economically efficient to utilize the extant, seasoned state system of insurance departments to effect and regulate any statutory reform. (5) *One federal insurance agency is more easily lobbied than fifty insurance departments* (oddly, a point often

INSURANCE, GOVERNMENT, AND SOCIAL POLICY: STUDIES IN INSURANCE REGULATION 411-34 (Spencer Kimball & Herbert Denenberg eds., 1969).

⁵⁴⁹ *Securities & Exch. Comm'n v. Variable Annuity Life Ins. Co.*, 359 U.S. 65, 68 (1959) (stating that while regulation of insurance is within the "ambit" of federal power, it has been traditionally controlled by the states).

⁵⁵⁰ See *supra* notes 229-34 and accompanying text.

⁵⁵¹ See *supra* notes 235-36 and accompanying text.

⁵⁵² To achieve more coherence and uniformity, many states have codified their insurance laws or re-codified their earlier codified statutes. The quintessential effort in this regard occurred in Wisconsin, commencing in 1965 and finishing in 1974. See Spencer L. Kimball & Herbert S. Denenberg, *Modern Insurance Code Revision: Reflections on the Art of Legislative Reform*, 21 C.L.U.J. 34 (No. 4 1967); Symposium, *Insurance Regulation*, 1969 WIS. L. REV. 1019-1170 (discussing generally the history of insurance regulation, purposes for regulation, and needs for reform). In many states, however, the insurance statutes are not sufficiently unified (in form or substance) to be called a "code" or even a body of insurance law.

boldly asserted by the insurance industry). Also, any federal insurance commissioner would be an insignificant, less effective official in the massive federal bureaucracy. In contrast, each state insurance commissioner is closer to the citizens and has considerable power to implement their preferred social and economic policies. (6) *Any supposed ineffective state regulation is restricted to a mere handful of states, in contrast to unknown and potentially ineffective federal regulation which would have national adverse consequences.* Most insurers are licensed in states (such as California, Massachusetts, North Carolina, New York, and Pennsylvania) which are effective, vigorous regulators. (7) *Prevailing current public opinion endorses state regulation.* Recent trends in national and state politics regarding health care⁵⁵³ as well as the American deregulation movement⁵⁵⁴ suggest that responsibility for regulation of health insurance and health benefits will remain with the states.

The foregoing points merit consideration, especially the fact that long-standing, experienced, and effective state insurance departments are in place to provide the regulatory enforcement vehicle for any federal insurance/genetics law(s). Such a sharing of enforcement duties would avoid costly administrative duplication as well as the traditional turf battle fought by the states to maintain their primacy in insurance regulation. For example, Congress could enact a comprehensive federal Insurance Act Regulating Genetic Testing Information and Privacy which by its terms would be uniformly administered and enforced by the fifty state departments of insurance. Alternatively, a federal insurance administrator or ombudsman position could be created for the limited purpose of supervising the states' implementation of the federal insurance/genetics law.

⁵⁵³ The failure of President Clinton's 1993 proposal for universal health insurance (a 1300-page statute titled Health Security Act) is well known. More recent but less far-reaching federal legislation has been introduced in Congress but none has been enacted.

⁵⁵⁴ Since the mid-1970s, there has been an expansive deregulation movement in America generally, including portions of the insurance industry. *See generally* INSURANCE DEREGULATION: ISSUES AND PERSPECTIVES (N. Weber ed., 1982); JERRY, *supra* note 14, at 78-80. Rate regulation has been the primary insurance concern for deregulation. *See, e.g.,* Stewart W. Kemp, *Insurance and Competition*, 17 IDAHO L. REV. 547 (1981) (evaluating proposed federal bills to promote competition; concluding that although more price competition would be beneficial, total regulation would not be).

The following are some of the reasons favoring a uniform, comprehensive federal approach — which, again, could be enforced by the existing state regulatory structures:

1. *Uncertainty under the McCarran Act, ERISA, and judicial decisions preempting state insurance/genetic legislation.* The McCarran Act concedes power to the states to regulate the “business of insurance.”⁵⁵⁵ However, given the vagaries of the judicial meaning given to “business of insurance” under the three-part *Pireno-Royal Drug* test,⁵⁵⁶ one must make an educated guess as to what activity will be held to be the business of insurance (to which state law applies) and the business of companies, including insurance companies (to which federal law applies by preemption). In *Royal Drug*, for example, an agreement between the health insurer (Blue Shield) and pharmacies to sell prescription drugs for \$2 each to Blue Shield policyholders was held not to be the “business of insurance” (not exempted from federal law), but rather, was the business of insurance companies.⁵⁵⁷ Moreover, in *Union Labor Life Ins. Co. v. Pireno*,⁵⁵⁸ the insurance policy limited the insurer’s liability to pay “the

⁵⁵⁵ See *supra* Part IV.A (notes 218-38 and accompanying text).

⁵⁵⁶ See *supra* notes 230-33 and accompanying text. For a discussion of this three-prong test, see, for example, *United States v. Title Ins. Rating Bureau*, 700 F.2d 1247 (9th Cir. 1983), *cert. denied*, 467 U.S. 1240 (1984); *Feinstein v. Nettleship Co.*, 714 F.2d 928, 931 (9th Cir. 1983), *cert. denied*, 466 U.S. 972 (1984); see also *Donovan*, *supra* note 236, at 11; Comment, *Definition of ‘Business of Insurance’ Under the McCarran-Ferguson Act After Royal Drug*, 80 COLUM. L. REV. 1475 (1980); Note, *Federal Regulation of Insurance Companies: The Disappearing McCarran Exemption*, 1973 DUKE L.J. 1340.

⁵⁵⁷ *Group Life & Health Ins. Co. v. Royal Drug Co.*, 440 U.S. 205, 210-11 (1979), *cert. denied*, 469 U.S. 1160 (1985).

⁵⁵⁸ *Union Labor Life Ins. Co. v. Pireno*, 458 U.S. 119 (1982). Consider this activity: When insurance rates and premium financing are regulated by state law, does the federal Truth in Lending Act, Pub. L. No. 90-321, 82 Stat. 146 (codified as amended at 15 U.S.C.A. §§ 1601-1667) apply to credit financing of auto insurance premiums? Under premium financing, an insurer or a third party advances the insured money to pay the premium, and thereafter the insured makes installment payments of the premium plus interest on the loan. Some decisions hold that the insurer is engaged in the business of insurance subject to state regulation, and thus (under McCarran) the Truth in Lending Act does not apply by preemption. See, e.g., *Ben v. General Motors Acceptance Corp.*, 374 F. Supp. 1199, 1203 (D. Colo. 1974) (holding that claims under the Truth in Lending Act were barred by the McCarran Act); *Gerlach v. Allstate Ins. Co.*, 338 F. Supp. 642, 651 (S.D. Fla. 1972) (holding that a Florida Statute and the McCarran Act precluded application of the Truth in Lending Act). However,

'reasonable' charges" for "'necessary' medical care and expenses."⁵⁵⁹ In determining if a chiropractor's treatments of an insured were medically "necessary" and the charges "reasonable," an insurance company's use of a professional Peer Review Committee (consisting of ten chiropractors) in processing, evaluating, and making decisions to deny or to pay claims was held not to be the business of insurance and, thus, exempt from federal antitrust laws. The point is that the uncertainty and ambiguity surrounding federal preemption make it difficult to predict the fate of state regulatory schemes that are passed. Moreover, under the ERISA saving clause,⁵⁶⁰ the Supreme Court has held that the same uncertain three-prong test determines whether ERISA preempts a state law that purports to regulate insurance.⁵⁶¹ The uncertainties thereby created by the McCarran Act, ERISA, and the Court can be clarified and resolved only by federal congressional action. If varied federal statutes can preempt state insurance laws in surprising and unforeseeable situations, then a state insurance/genetic discrimination statute will not provide the assured solution so necessary in definitely resolving the insurance/genetic dilemma.

2. *Deficiencies in federal laws necessitate federal rectification and other actions.* It would not entirely solve the insurance/genetics dilemma even if all states were to enact legislation that fairly addressed the issues

arguably these holdings would be reversed under the subsequent *Pireno-Royal Drug* test because a loan to pay a premium is "business" and not "insurance." In other words, financing insurance premiums does not transfer a policyholder's risk and is ancillary to and not an integral part of the policy relationship between insurer and insured. Accordingly, some decisions would allow the federal Truth in Lending Act to preempt state insurance regulatory law and apply to the insurer/creditor. *See, e.g., Cochran v. Paco, Inc.*, 606 F.2d 460, 467 (5th Cir. 1979) (holding that premium financing in connection with automobile insurance did not constitute the "business of insurance" under the McCarran Act, and that the Truth in Lending Act, therefore, applied); *Perry v. Fidelity Union Life Ins. Co.*, 606 F.2d 468, 471 (5th Cir. 1979) (holding that premium financing by an insurance company did not constitute the "business of insurance" and, thus, the Truth in Lending Act applied), *cert. denied*, 446 U.S. 987 (1980); *Cody v. Community Loan Corp.*, 606 F.2d 499, 508 (5th Cir. 1979) (holding that loan offices were not in the "business of insurance" for purposes of the McCarran Act and, as a result, the Truth in Lending Act applied), *cert. denied*, 446 U.S. 988 (1980).

⁵⁵⁹ *Pireno*, 458 U.S. at 119.

⁵⁶⁰ *See supra* Part IV.B.1.a.(2) (notes 265-81 and accompanying text).

⁵⁶¹ *See supra* notes 267-68 and accompanying text.

voiced by all parties. These laws would still have a limited effect on the insured population even if it were possible to reconcile the insurers' concerns for economical and actuarial fair discrimination, financial stability, potential for adverse selection, and the public policy concerns that large numbers of individuals may be unfairly denied access to health insurance. The great majority of health insurance is acquired by insureds through their employers.⁵⁶² Over half of all employees work for companies that are partially or fully self-insured,⁵⁶³ and ERISA exempts employer self-insured health plans from state laws which regulate insurance.⁵⁶⁴ Because so many Americans are being affected by the restrictions ERISA places on the states' ability to prohibit self-insurance plans from inappropriately using genetics tests, it is necessary for Congress to intercede with legislation directly addressing the issues which are peculiar to employers' use of genetic information.

Employer self-insured health plans should not be exempt from state laws which require insurers to contribute to states' uninsurable risk pools. A few states have such pools but do not require self-insured employers to contribute.⁵⁶⁵ If ERISA is revised to provide that these self-insured

⁵⁶² For a statistical analysis of the connections between employment and insurance, see Kronick, *supra* note 74.

⁵⁶³ Pear, *Court Approves Cuts*, *supra* note 285. From 1988-90, self-insurance grew 19.4% (from \$32 billion dollars to \$38.2 billion) while traditional insurance increased only 3.8% (from \$115.6 billion to \$120 billion). Otis, *supra* note 285, at 1, 38. In 1992, self-insurance constituted 27% of the commercial financing market and approximately 30% at the end of 1993. Marley, *supra* note 285, at 3.

⁵⁶⁴ The Supreme Court holds that ERISA's preemption of state laws, but not state insurance regulatory laws, means that employer self-insured benefit plans are to be regulated solely by ERISA. In other words, employer self-insured insurance plans are exempt from state insurance laws. *See, e.g.*, *FMC v. Holliday*, 498 U.S. 52, 57-58 (1990) (under ERISA's "deemer" clause, an employee benefit plan is not deemed an insurance company insurer). *See generally* Daniel M. Fox & Daniel C. Schaffer, *Health Policy and ERISA: Interest Groups and Semipreemption*, 14 J. HEALTH POL., POL'Y, & L. 239 (1989) (discussing unintended effects of ERISA on health policy). For an examination of the negotiated accommodation that authorizes states to regulate insurers of employers' benefit plans but not to regulate self-insured employers, see Fox & Schaffer, *supra* note 275, at 48-52.

⁵⁶⁵ For a discussion of fairly recent state efforts to regulate "risk pool" coverage and to finance health care for the uninsured, see GEORGE J. ANNAS ET AL., *AMERICAN HEALTH LAW* 159-62 (1990). For example, in January 1989, the Illinois General Assembly created a statewide insurance pool called the

plans pay their fair share, the costs of health care for high-risk individuals will be spread more evenly among all insured individuals. Another solution is to adopt a taxation approach. For example, federal legislation could offer tax incentives for states to form high-risk medical insurance pools and tax employers who do not voluntarily participate in the state high-risk pools.⁵⁶⁶

3. *Minimize foreseeable market disruptions.* Federal legislation is essential to minimize potential market disruptions following completion of the HGP which could result from piecemeal, state-by-state insurance/genetic legislation. Uniform action across the entire insurance market would eliminate any market disadvantages which might occur in those states choosing to proscribe insurers use of genetic tests and genetic information in insurance.

4. *Disparity in state regulation and inconsistency in state funding and staffing.* In 1859, New York created a superintendent of insurance. The New York example has been widely followed so that now all states have an official with the duty of seeing that insurance regulations are enforced. Customarily, this official is appointed by the governor, with the confirmation of the state senate. In a few states, the insurance commissioner is chosen by popular vote. While many able and distinguished people have held this state office, many second-rate politicians have also held it. The compensation is only fair, and the office has frequently been a stepping stone to more lucrative employment with insurance organizations.⁵⁶⁷

Comprehensive Health Insurance Plan ("CHIP"). This plan provides coverage for the "hard-to-insure" who have been denied health insurance or charged exorbitant premiums by private insurers. See Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J. L. & MED. 75, 103 n.190 (1991) (analyzing "existing legal protections for confidentiality of information collected through genetic screening or genetic monitoring in the workplace.").

⁵⁶⁶ See, e.g., Clifford & Iuculano, *supra* note 14, at 1822 (advocating federal legislation).

⁵⁶⁷ An additional rub is that given the high turnover of insurance commissioners who leave the post to work for the insurance industry, they are less likely to protect consumers and insureds. Commissioners who promote and protect insurance industry interests are more likely than consumer-oriented commissioners to be rewarded with an industry job. For the archetypal studies regarding these concerns, see Jon S. Hanson & Thomas E. Obenberger, *Mail Order Insurers: A Case Study in the Ability of the States to Regulate the Insurance Business*, 50 MARQ. L. REV. 175 (1966); Spencer L. Kimball, *Introduction:*

Governmental control of the insurance business is exercised almost exclusively by the states and the District of Columbia under acts of Congress. One cannot speak of a single, uniform set of insurance regulations, but only of fifty-one sets. Some insurance departments are massive, others are tiny annexes to another state agency; some do a commendable job, while others do precious little or nothing; and some appear to be captives of the powerful insurance industry, while others actively harass the insurance industry. This unevenness and inefficiency of fifty-one state regulators of a truly interstate business argues for a uniform federal law enforced, or at least overseen, at the federal level. The counterpoint is that the current state insurance regulatory system does operate with extensive cooperation among the several state departments, which helps diminish the disparity in funding, staffing, and enforcement among the states. The insurance commissioners act in concert through the National Association of Insurance Commissioners which might be an additional vehicle for implementation and enforcement of any comprehensive federal insurance/genetics law.

Finally, the potential for misuse of genetic information by insurers seems sufficiently compelling for Congress to act pursuant to its Commerce Clause power to enact legislation which addresses how genetic information may be used by insurers. The McCarran Act leaves open to Congress the option of taking specific action regarding insurance regulation.⁵⁶⁸ Enactment of a comprehensive federal Insurance Genetics Act addressing insurers' use of genetic information and privacy issues will avoid many of the problems which limit the effectiveness of leaving insurance regulation at the state level. A comprehensive federal insurance/genetics law would resolve the issues resulting from the lack of uniformity among state statutes and eliminate the problem of delay in state legislative action. As outlined, numerous obstacles accompany state insurance regulation, and federal legislation may be the remedy.⁵⁶⁹

Unfinished Business in Insurance Regulation, 1969 WIS. L. REV. 1019. Moreover, some state insurance agencies are so underfinanced and understaffed that insurance regulation is mostly an illusion. *See, e.g.*, Spencer L. Kimball & W. Eugene Hansen, *The Utah Insurance Commissioner: A Study of Administrative Regulation in Action*, 6 UTAH L. REV. 1, 19 (1958) (reporting that although the state collected about \$100,000 from the insurance industry in fees, only \$30,000 was available for Insurance Department services).

⁵⁶⁸ 15 U.S.C. §§ 1011-1015 (1988).

⁵⁶⁹ For additional reasons, see Wortham, *supra* note 76, at 416. Wortham proposes:

CONCLUSION

As society becomes more technologically advanced, the task of deciding how best to utilize new technology and information in the insurance industry becomes increasingly difficult. The economic aspects of health care in this country are driven by a system of private insurers, and technology is giving insurers an arsenal with which, unless regulated, they can justify excluding individuals from the insurance system. The HGP, in attempting to characterize the human genetic make-up and identify the causes of genetically transmitted disorders, is stocking that arsenal. Arguably, the federal government should not be permitted to subsidize the insurance industry by allocating three billion dollars for a scientific project, and then allowing the insurance industry to use the information obtained in that project to exclude from the health insurance system those very individuals who were the intended beneficiaries of the project. The overriding problem is how to assure that all citizens have affordable access to health and health-related insurance. Any solution ought to be a balanced one which has a societal consensus.

Rather than adopting comprehensive, uniform insurance/genetic legislation, Congress recently took a micro-management approach by addressing the discrete problem of "pre-existing conditions" and "employee job lock"⁵⁷⁰ by amending ERISA in its Health Insurance Portability and Accountability Act of 1996 (better known as the Kennedy-Kassenbaum Act).⁵⁷¹ One goal of the Act is to improve portability and

[a]n increased role in federal legislation for the following reasons: (1) reform efforts in individual states frequently have been frustrated by insurers' threats of withdrawal from doing business in the state; (2) it has proven difficult for state regulators to withstand the political pressure that can be exerted by insurers; (3) because so much insurance business is done across state lines, state regulators are often no match for large national and international insurers; (4) to divert competitive efforts in selection competition to more desirable forms of competition, all insurers must be required to play according to the same rules; (5) the proposed study of availability would require considerable resources and should look at availability concerns nationwide.

Id.

⁵⁷⁰ Employee "job lock" occurs when an employee decides not to change employment due to fear of losing health insurance coverage because the employee or family member has a present, or genetically potential, illness, disease, or medical condition. See Mark L. Glassman, Comment, *Can HMOs Wield Market Power? Assessing Antitrust Liability in the Imperfect Market for Health Care Financing*, 46 AM. U. L. REV. 91, 147 n.255 (1996).

⁵⁷¹ Pub. L. No. 104-191, 110 Stat. 1936 (1996), effective Aug. 21, 1996.

continuity of an employee's group health insurance coverage under ERISA when an employee, or an employee's family member, with a pre-existing condition changes employers. The Act not only circumscribes pre-existing condition exclusions but also prohibits discrimination in enrollment in the new employer's group health insurance against a new employee or family members based on health status, including genetic information.⁵⁷² Consequently, the Act assures continued health insurance coverage for employees and their families when employees leave one employer group-insurance plan for another.

The Act also guarantees that individual (non-group) health insurance shall be renewed or continued in force at the insured's option. A private health insurer can refuse to renew or continue individual health insurance coverage in only five instances: (1) for nonpayment of premiums, (2) fraud, (3) insurer ceasing to offer coverage in individual market, (4) individual moves outside service area, or (5) individual ceases membership with association that offered the insurance.⁵⁷³ Since genetic information is not listed, genetic information implicitly is not a legitimate ground for nonrenewal or discontinuance.

In sum, the Kennedy-Kassenbaum Act has two restrictions on health insurers' use of genetic information. First, regarding group health insurers under ERISA, the Act has two prohibitions. It prohibits insurers from treating genetic information as a pre-existing condition unless the genetic

⁵⁷² *Id.* §§ 701, 702(a)(1), 29 U.S.C.A. §§ 1181, 1182(a)(1) (1996). Section 702, entitled *Prohibiting Discrimination Against Individual Participants and Beneficiaries Based on Health Status*, provides that a group health plan or insurer may not establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on any of the following health status-related factors . . .

- (A) Health status.
- (B) Medical condition (including both physical and mental illness).
- (C) Claims experience.
- (D) Receipt of health care.
- (E) Medical history.
- (F) Genetic information.
- (G) Evidence of insurability (including conditions arising out of acts of domestic violence).
- (H) Disability.

⁵⁷³ 110 Stat. at 1892 § 2742(a), (b). By negative implication, section 2742 *Guaranteed Renewability of Individual Health Insurance* prohibits private health insurers from using genetic information to justify nonrenewal or discontinuance of individual health insurance policies.

information results in a medical diagnosis of an actual condition needing medical care or treatment. The Act bars genetic discrimination by excluding as pre-existing conditions: asymptomatic people; at risk presymptomatic people having a genetic predisposition to disease, illness, or medical condition; and unaffected genetic carriers (heterozygotes). The Act also assures continuity for employees changing jobs by prohibiting group plans and insurers from using genetic information in fashioning eligibility criteria for enrollment or continuation. Second, regarding individual health insurance policies, the Act implicitly prohibits the use of genetic information in decisions regarding renewal or continuance of coverage.

Notwithstanding the Kennedy-Kassenbaum Act's very real significance for a majority of employed workers as well as for individual insureds, it is only a patchwork solution to the insurance/genetic dilemma. The Act, for instance, does not address the problems of genetic privacy, or of ERISA's exemption of self-insured employers and others, such as HMOs,⁵⁷⁴ from regulation and liability under state insurance laws, or

⁵⁷⁴ Any legislative recasting of the ERISA preemption clauses should address all related health care issues including HMO liability, a subject beyond the scope of this Article. The popular press explains the effect of ERISA's preemption on over 30 million HMO members under ERISA plans:

ERISA was meant to protect us from corporate misdeeds, but it includes a special provision that health organizations have been throwing around themselves like a Teflon blanket whenever a lawsuit comes their way: employee-benefit plans are exempt from state law. For consumers, that's bad news. Why? Because under state law you can sue for damages (such as lost income and suffering) as well as for medical expenses. Under federal law, however, you can sue only for the costs of the medical benefit denied you. So if your loved one dies of leukemia because your HMO wouldn't authorized an early blood test, for instance, you can recover no more than the \$130 cost of the test.

Ellyn E. Spragins, *HMOs: To Sue or Not To Sue*, NEWSWEEK, Dec. 9, 1996, at 50. For scholarly discussions of the effects of ERISA's exemption of HMOs from state law liability, see, for example, Diana Joseph Bearden & Bryan J. Maedgen, *Emerging Theories of Liability in the Managed Health Care Industry*, 47 BAYLOR L. REV. 285 (1995) (exploring the issues, problems, and trends regarding liability in the managed health care industry); L. Frank Coan, Jr., Note, *You Can't Get There From Here — Questioning the Erosion of ERISA Preemption in Medical Malpractice Actions Against HMOs*, 30 GA. L. REV. 1023 (1996) (discussing whether HMOs that are part of employer provided benefit plans can use ERISA as a viable defense to state medical malpractice claims asserted by plan participants and beneficiaries); Laura H. Harshbarger, Note, *ERISA*

of insurers' use of genetic tests and genetic information in risk classification and in individual insurance underwriting. As this Article suggests, the insurance/genetic dilemma is simply too complex and too important for piece-meal solutions. Whether at the federal or state level, the dilemma demands assured, uniform, and comprehensive resolution in the public interest.

This Article has strongly stated the positions of the insurance industry and those who would restrict insurers' use of genetic testing information. No attempt was made to state the best or preferable solution. Rather, a variety of discrete as well as comprehensive solutions have been presented with an emphasis on a private law approach at either the state or federal level. Of course, a public law approach provides possible solutions. National health care insurance or state health care reforms⁵⁷⁵ are options.

Taxation is another option.⁵⁷⁶ A noted insurance expert, Professor Spencer Kimball, addresses the tax approach:

Preemption Meets the Age of Managed Care: Toward a Comprehensive Social Policy, 47 SYRACUSE L. REV. 191, 192 (1996) (exploring the issue of ERISA preemption of vicarious liability claims and noting: "[i]f ERISA is found to preempt claims for physician malpractice, millions of injured plaintiffs will find that their claims are limited or barred").

⁵⁷⁵ Universal health care must be addressed at the federal level. States could create a general health care reform package which addresses genetic testing issues such as community-based rating and small market reform. Community rating would eliminate most insurer incentives for using genetic testing information. Insurers would not be able to use genetic information in setting rates but could use it in denying coverage — an issue which should be addressed. Community rating would introduce other problems, such as defining "community" and concerns over payment equitability. Small market reform permits a range of insurance prices within a community. A cost limit could be established for applicants with adverse genetic testing results. Issues of test validity and accuracy would have to be addressed. For an example of limited state reform, see Kentucky's health insurance purchasing alliance, *supra* note 546.

⁵⁷⁶ For an explanation of public taxation as the preferable solution rather than a "forced subsidy" in private insurance, see Epstein, *supra* note 5, at 20, 21. Amending the 1986 Internal Revenue Code, the Kennedy-Kassenbaum Act of 1996, for instance, provides: (1) in section 301, an itemized deduction for individual medical savings account, (2) in section 311, an increase in self-employed persons' deduction for health insurance costs, and (3) in sections 341 and 342 an exemption from taxation for state insurance pools providing health coverage for high risk people and for state-sponsored worker's compensation reinsurance organizations. Health Insurance Portability and Accountability Act, 110 Stat. at 2036, 2070-71.

State legislatures have been quick to put burdens on health insurance companies by mandating coverage for particular illnesses. This raises public policy questions fundamental to the health care issue. How far should the private insurance industry be pressed into service as a vehicle for cross-subsidization within society, compelling the transfer of particular medical costs from one portion of society (the afflicted) to another portion (insureds)? Should not any humanitarian transfers of that kind be from the afflicted to the whole society, at least as represented by all those who are taxed to support the good works legislatures choose to engage in?⁵⁷⁷

An example is to encourage, through taxation, state high-risk health insurance pools. A federal act could establish tax incentives for the states to mandate pools that offer comprehensive health insurance to all citizens, thereby fairly apportioning the social responsibility of providing health insurance to the uninsurable citizens.⁵⁷⁸

⁵⁷⁷ SPENCER L. KIMBALL, *TEACHER'S MANUAL FOR CASES AND MATERIALS ON INSURANCE LAW* 70 (1982).

⁵⁷⁸ A thorough discussion of all the available options for assuring health insurance coverage for unwanted insureds is beyond the scope of this Article. The problem of unwanted and uninsurable applicants is a recurrent concern in insurance. There are many existing legislative and regulatory approaches in other lines of insurances which could be adapted to health insurance. Probably the most familiar is automobile liability insurance, which is a prerequisite to registering a car. Most states have an "assigned risk plan" which distributes the unwanted insureds among the auto liability insurers doing business in the state. These insurers must each insure a pro rata portion of the uninsurable applicants. *See, e.g., Virginia Farm Bureau Mut. Ins. Co. v. Saccio*, 133 S.E.2d 268, 272-74 (Va. 1963) (discussing how an assigned risk plan works). In property insurance, "FAIR" plans require insurers to accept (sharing them ratably) applications for insurance on inner-city properties that are exposed to exceptional hazards. *See WILLIAM F. YOUNG & ERIC M. HOLMES, CASES AND MATERIALS ON INSURANCE LAW* 505 n.5 (2d ed. 1985). For a discussion of five statutory approaches for assuring Workers' Compensation Insurance for employers, see KEETON & WIDISS, *supra* note 105, at 982-84. Another technique is governmental sponsorship of insurance either through governmental participation, subsidy, or prescription. *Id.* at 971-80. For example, public debate in the mid-1950s led to legislation that established the Federal Flood Insurance Program of 1956 which provided flood insurance and reinsurance as well as disaster relief. The 1956 act was repealed by the National Flood Insurance Act of 1968, 82 Stat. 572 (1968) (codified at 42 U.S.C. §§ 4001-4128 (1988)). The list of areas in which either federal or state government participates as an insurer or reinsurer would include:

Although the public approach provides viable solutions, this Article has focused on solving genetic testing issues within private insurance. In the private law context, varied solutions were explained. One is to continue the customary insurance practices of fair, equitable underwriting — fair discrimination — by allowing insurers to use genetic information in ways similar to other medical information in insurance risk classification based on sound actuarial principles.⁵⁷⁹ That approach should require that applicants give informed consent, allowing insurers to have access to genetic testing information.⁵⁸⁰ As a practical matter, however, insurers will refuse to consider an applicant if consent is not given. Under this approach, no state has authorized insurers to require an applicant to undergo genetic testing without the insured's consent. That prohibition seems preferable. Moreover, state incontestability statutes could be amended.⁵⁸¹ If an applicant has been tested for a genetic condition and it is revealed that the applicant will develop the condition, insurers should not be precluded from challenging the policy's validity after the two-year incontestability statute has expired.

However, the contemporary trend at the state level is to restrict or prohibit insurers' use of genetic testing information and to provide explicit privacy protection for personal genetic information. This state legislation evidences several considerations in fashioning a comprehensive statutory insurance genetics law. The following are illustrative but not exhaustive: (1) a distinction has been made between health insurance and other related insurance lines such as life, annuities, and disability income; (2) insurers are precluded from using genetic testing information in establishing eligibility for health and other health-related insurance, or alternatively, genetic information can be used if the insurer can demonstrate significant variances in the applicant's claims experience or in the applicant's actuarial projections; (3) insurers are prohibited from using genetic information in decisions to price, deny, limit, cancel, fail to renew, or impose other criteria on present or future policyholders; (4) the

social security (including old-age, survivors, supplemental security, disability, Medicare, and Medicaid), unemployment insurance, crop insurance, bank deposit insurance, bank guaranty funds, public property insurance, public official bonding funds, title insurance, housing mortgage insurance, veterans' life insurance, postal insurance, war risk insurance, and nuclear hazards insurance. Obviously, universal health insurance, a less universal medical savings account, or other governmental health insurance approaches could be added to this list.

⁵⁷⁹ See *supra* Part II.A. (notes 68-93 and accompanying text).

⁵⁸⁰ See *supra* Part II.B.1-2 (notes 94-102 and accompanying text).

⁵⁸¹ See *supra* Part II.B.3 (notes 103-09 and accompanying text).

term genetic tests can be broadly or narrowly defined; (5) privacy rights are given to genetic information as well as ownership attributes to one's unique genetic property; and (6) civil remedies, including attorney's fees, are statutorily provided. Finally, and most importantly, is the moratorium on the use of genetic testing for insurance. Serious consideration ought to be given to the California, Virginia, and especially the ten-year Ohio moratorium with its interim insurance genetics law and its Task Force on Genetic Testing in Health Insurance.⁵⁸²

The field of genetics presents a unique set of problems because of the nature of the information it can reveal. The information to be obtained from the HGP is neither intrinsically good nor intrinsically bad. Rather, what gives the HGP value is what our society chooses to do with the information. The choice in private insurance presents a dilemma. Insurance is a societal institution for risk-sharing through the transfer and distribution of fortuitous medical expenses among all the insureds. If an individual suffers from an immutable genetic condition, should that not be simply accepted as part of the human condition to be redistributed by the risk sharing pool? But, since insurers customarily make risk classifications based on medical data to minimize the economic risks of all policyholders, why should insurers not have equal access to accurate genetic testing information which evidences the presence of genetic conditions which may affect an individual's health or life expectancy? To address these and other issues and to protect the interests of both insurers and those seeking health and related insurance coverages, a comprehensive and uniform approach through federal legislation which is administered by state insurance departments ostensibly offers a middle ground solution to the insurance/genetic fair/unfair discrimination dilemma. Thus, on balance, a comprehensive federal "Insurance Genetics Act" implemented by the states in conjunction with a moratorium on insurers' use of genetic testing information merits serious consideration.

⁵⁸² For a description of the Ohio moratorium and Task Force, see *supra* notes 512-19 and accompanying text.

APPENDIX⁵⁸³

<u>Test for</u>	<u>Cost of Test</u>
Charcot-Marie-Tooth Disease	\$385
Cystic Fibrosis	\$125 — \$245
Duchene Muscular Dystrophy	\$250 — \$435
Fragile X	\$120 — \$250
Galactosemia	\$350
Glycogen Storage Disease	\$200
Huntington's Disease	\$205
Myotonic Dystrophy	\$250 — \$305
Prader Willi-Angelman Syndrome	\$250
Sickle-Cell	\$210 — \$500
Spinocerebellar Ataxia	\$250
Thalassemia	\$210 — \$300
Velocardiofacial Syndrome	\$135

⁵⁸³ The information in this Appendix is from the *Final Report* of the Ohio Task Force on Genetic Testing. See Ohio Task Force on Genetic Testing, *supra* note 4, at app. 5.