The Thin Edge of the Wedge: Prohibiting Underwriting on the Basis of Genetics in Health Insurance

by

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INTRODUCTION

"Today every invention is received with a cry of triumph which soon turns into a cry of fear."¹ The German playwright Bertolt Brecht’s frequently quoted observation echoes the anxiety that accompanies the new technologies encompassing the field of human genetics, most notably the completion of the Human Genome Project in 2003.² While such technologies may ultimately prove to be the “defining scientific advancement of the 21st century”³, promising to revolutionize medical practice and greatly improve public health, they have been met with ethical concerns and often misguided fears of adverse social impact.

In response to public concern that insurance companies and employers would rely on genetic information obtained by means of genetic technologies and otherwise, and unfairly discriminate against individuals who are deemed to present greater health-related risk, legislators drafted the Genetic Information Nondiscrimination Act, which was passed by the Senate and is currently pending passage by the House of Representatives. This thesis suggests that an overly broad restriction on the use of genetic information in health insurance underwriting, as set forth in this currently pending federal legislation, as a reflection of a misguided fear of genetic discrimination, fails to recognize both the infancy of genetic information and genetic testing and the nature of the U.S. health

insurance industry. This thesis proposes that any future genetic antidiscrimination legislation be more narrowly tailored to take into account the limits and benefits of technological advances in the field of genetics, and the adverse implications that restricting the use of genetic information might have on the private insurance industry in the U.S. The thesis further suggests other possible policy alternatives to a comprehensive ban on the use of genetic information.

Discussion

Advances in genetics over the past two decades have spawned a myriad of genetic technologies, among them the ability to conduct genetic testing. Genetic testing has, in turn, made it possible to identify individuals at risk for certain disorders and conditions. The resulting information obtained from genetic testing has and will continue to assist in the detection and treatment of diseases or disorders that, until today, have eluded therapeutic intervention. Sometimes, however, this information, which can be used to prevent disease, can also have a socially undesirable result; it can be used to exclude an individual from insurance coverage or limit the coverage that is available.

Concerns about this particular type of potential abuse since far earlier than the launching of the Human Genome Project in 1996, have stimulated a countercurrent of public pressure for state legislation restricting the use of genetic information in insurance.\(^4\),\(^5\)

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\(^4\) The McCarran-Ferguson Act, 15 U.S.C. §§ 1011-1012, signed into law on March 9, 1945, after extended controversy over the jurisdiction of state and federal governments in regulating the business of insurance and in response to the 1944 Supreme Court decision in United States v. South-Eastern Underwriters Ass’n, 322 U.S. 533 (1944), holding that insurance is interstate commerce and subject to federal regulation under
Genetic discrimination in health insurance,\(^6\) as opposed to other lines of insurance, has been the focus of particular attention.\(^7\)

Subsequent criticism of state genetic anti-discrimination laws\(^8\) has led to the contemplation of a federal initiative\(^9\) intended to provide a uniform comprehensive remedy to the alleged inadequacy of the disparate protections afforded under the existing

the Commerce Clause, stated that regulation of insurance by the states was in the public's interest. Under the Act, therefore, state insurance regulation supersedes federal law, but only to the extent that federal law does not "specifically relate[s] to the business of insurance" (section 1012(b)), thus explicitly reserving Congress's power to enact legislation that specifically relates to the business of insurance.

Genetic anti-discrimination legislation has been enacted in 47 states since 1992, restricting the use of genetic information in health insurance. The various states differ in their treatment of different lines of insurance as well as in the restrictions imposed for the use of genetic information in health insurance. Some states require actuarial evidence in order to use genetic information, while others ban the use completely. Alissa Johnson, Genetics and Health Insurance, Genetics Brief, August 2004, Vol. 3, Issue No: 4, available at: http://www.ncsl.org/programs/health/genetics/geneticsbrief2004.pdf. For a complete list of states and the specific restrictions, see Genetics Policy Report, supra note 3, Appendix A.

The term health insurance has often been defined to include long-term health and disability insurance in addition to medical expense insurance. For purposes of this paper, the term health insurance will primarily refer to medical expense insurance—insurance that provides benefits for expenses incurred for medical care such as physician fees, hospital fees, nursing costs, related health services and supplies.

It is unclear why legislators consider health insurance, as opposed to other lines of insurance, more worthy of protection. Despite the public's increased awareness of healthcare as an important social benefit, healthcare in the U.S. has never been elevated to the status of a fundamental right, possibly as a result of health-care lobbies and Americans' fear of anything that sounds like "socialized medicine". For a recent article discussing America's healthcare crisis, see Desperate Measures, Special Report, America's Healthcare Crisis, THE ECONOMIST, January 28, 2006. The right to healthcare is not expressly protected by the U.S. Constitution. While the preamble to the Constitution does recognize a duty to promote the public good, the method by which such a duty is realized is left to the discretion of the states. See Amanda Littell, Can a Constitutional Right to Health Guarantee Universal Health Care Coverage or Improved Health Outcomes?: A Survey of Selected States, 35 Conn. L. Rev. 289 (2002). Soaring healthcare spending, with subsequent increases in health insurance premiums, leaving many previously insured individuals either uninsured or underinsured, seem to have prompted significant interest in the problem of health insurance and healthcare financing in the U.S. in recent years. Carmen DeNavas-Walt, Bernadette D. Proctor and Robert J. Mills, U.S. CENSUS BUREAU, Current Population Reports, P60-226, Income, Poverty, and Health Insurance Coverage in the United States, 2003, U.S. Gov't Printing Office, Washington D.C. 2004, available at: http://www.census.gov/prod/2004pubs/p60-226.pdf. KAISER FAMILY FOUNDATION HEALTH RESEARCH AND EDUCATIONAL TRUST 2004 Annual Employer Health Benefits Survey (Kaiser/HERET), http://www.kff.org/insurance/chem090904ar.cfm. See also, Morton Mintz, Single-Payer: Good for Business, THE NATION, November 15, 2004.


The federal government did attempt to regulate this area indirectly with the passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996. HIPAA applies to government-funded insurance plans as well as group health plans but does not apply to the individual health insurance.
regulatory scheme.\textsuperscript{10} Entrusted with the representation of its constituents as well as with the protection of the nation as a whole, the legislature was then faced with the daunting and inherently difficult task of creating a balance between the interests of consumer, industry and public. The result was the Genetic Information Non-Discrimination Act. On October 14, 2003, six months after completion of the Human Genome Project and following seven years of negotiation, the US Senate, in a vote of 95-0 in favor, passed the Genetic Information Non-Discrimination Act of 2003.\textsuperscript{11} This measure, however, stalled in the House. Almost identical legislation has been introduced in the 109\textsuperscript{th} Congress as Senate Bill 306, the Genetic Information Non-Discrimination Act of 2005. On February 17, 2005, this bill was passed in the Senate by a vote of 98 to 0.\textsuperscript{12} Should this Act becomes law, companies offering health insurance will be prohibited from using any genetic information about an applicant, whether the person applies individually for insurance coverage or as part of a group scheme, nor will insurers be permitted to ask whether a person has requested or received genetic services. Moreover, it would be illegal for health insurers to charge individuals higher premiums based on the results of genetic testing.

While genetic advances, particularly genetic testing, have made it possible to identify a variety of genes and genetic mutations that have been linked with the manifestation of various conditions affecting human morbidity, a direct correlation between the existence

\textsuperscript{10} For a general discussion of the background of genetic antidiscrimination legislation, including state law, and the need for comprehensive federal legislation specifically addressing genetic discrimination in health law and employment, see S. Rpt. 108-122, Genetic Information Non-Discrimination Act of 2003 Report, 108\textsuperscript{th} Congress, 1\textsuperscript{st} Session (2003)(to accompany S. 1053).
\textsuperscript{11} S. 1053, 108\textsuperscript{th} Cong. (2003).
\textsuperscript{12} S. 306 is almost identical to S. 1053, the only difference being the deletion of one tax-related provision from § 103 of the legislation. See GovTrack: S. 306 at \texttt{WWW.GOVTRACK.US}. 

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of a given genetic mutation and the actual manifestation of a disorder has not been established in most instances. Given that health insurance companies are not inclined to use information that is not actuarially justified and which fails to accurately predict future risk in their underwriting practices, the use of genetic information with little predictive value is highly unlikely. Those conditions for which a direct correlation between the presence of a genetic mutation and the manifestation of disease has been clearly established are so few in number and so severe in their expressivity that the use of genetic testing for their identification and any potential discrimination based on positive genetic test results is no cause for real concern at this time. Furthermore, the U.S. health insurance industry is a primarily for-profit venture forged by America’s historical rejection of governmental interference and strong belief in free enterprise. As such, it must be permitted to protect and increase its profitability by utilizing all available tools, including underwriting, that enable it to properly classify risks, provided such tools are used in a responsible manner. The proper use of such tools will, in turn, enable U.S. health insurance companies to offer affordable health insurance products to the majority of applicants.

Although controversy surrounding the use of genetic information and testing in insurance is not exclusive to the United States and has been the subject of much examination in Europe\textsuperscript{13} and in other countries\textsuperscript{14}, it poses a unique dilemma in the United States due to

\textsuperscript{13} For an examination of the professional and scientific views on the social, ethical and legal issues that impact on the use of genetic information and testing in insurance in Europe, see Beatrice Godard et al., \textit{Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical Issues}, 11 EUR. J. HUMAN GENETICS, Suppl. 2, S123-S142 (2003), available at \url{www.nature.com/qjgh}.

\textsuperscript{14} Natasha Stott Despoja, \textit{The Human Genome Project: how do we protect Australians?}, 173 MED. J. AUSTL. 596, (2000), available at \url{www.mja.com.au}. See also, Natasha Stott Despoja, \textit{Law is Slow to Catch
the primarily private and selective nature of health insurance in this country. Beyond the concern that the health insurance industry might be interested in the use of genetic information and testing in the underwriting process is a further concern that genetic discrimination will lead to a further increase in the number of uninsured in this country. Consequently, the controversy surrounding genetic testing goes beyond whether genetic information is proper for determining insurance underwriting into the realm of whether we, as a country, should continue to adhere to a health financing system that poses such a dilemma in the first place.

This paper will discuss and analyze the Genetic Information Nondiscrimination Act of 2005 (GINA) in the context of the seemingly unrelated fields of genetics and insurance which shaped its emergence. Part I will present the limited case for using genetic information in health insurance underwriting. It will provide an overview of health insurance underwriting as a tool to control adverse selection and its utilization in context of the U.S. health insurance market, followed by a brief introduction to the science of genetics that has made genetic testing possible, and the genetic information resulting from such testing, together with arguments favoring the utilization of genetic information in connection with individual insurance underwriting. This will provide the foundation for Part II, which will be devoted to a discussion of GINA and its shortcomings in addressing the issues involved in the use of genetic information in health insurance underwriting and to possible policy alternatives to all-inclusive federal legislation as well.

_up with Genetics, web article available at www.ieasg.com.au (discussing preliminary findings of the Genetic Discrimination Project initiated in 2002 in Australia)._
as a suggestion for less restrictive and more narrowly tailored legislation as an alternative to GINA.

This paper confines itself to examining the ramifications of the regulation of the use of genetic information and testing in the field of health insurance and will therefore avoid any discussion of how such regulation may impact other lines of insurance as well as employment practices, issues that have certainly been the target of recent legislation.
PART I: THE LIMITED CASE FOR USING GENETIC INFORMATION IN HEALTH INSURANCE UNDERWRITING

A. MEDICAL UNDERWRITING: A TOOL TO CONTROL ADVERSE SELECTION

Insurer as Underwriter

Among other things, insurance functions as a “mechanism for contractually shifting burdens of a number of pure risks (uncertainty of financial loss) by pooling them”.15 Hence, insurance is a risk transfer and distribution device where many people pay a relatively small sum, as protection against uncertain losses, that is pooled for payment of costs incurred by the relatively few who actually suffer a loss.16 The business of insurance17 depends on being able to properly and accurately assess the probability of a variety of risks and calculate the premiums needed to create a fund large enough to cover any likely loss payment, while maintaining a healthy profit margin. Prudent individuals or companies, in an attempt to manage their risks of serious economic losses under conditions of uncertainty,18 would purchase health insurance and pay modest, predictable losses on a regular basis in the form of premiums rather than face catastrophic losses at

15 Harvey W. Rubin, DICTIONARY OF INSURANCE TERMS (Barrons 2nd ed. 1991).
17 The definition of “business of insurance” varies according to state statute and as interpreted by the courts. It typically includes activities related to the writing of insurance and all acts necessary or incidental to such writing.
18 Uncertainty about an individual’s risks allows the members of the group or pool to share the sense that “we are all in this together”.

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unpredictable times. The 'solidarity' that is achieved as a result of this prudence is one of the principles underlying the concept of insurance. There is however, another concept that is generally perceived to go hand in hand with 'solidarity'—equity. Equity demands that each member of the group make contributions that are roughly in line with the individual member's level of risk. This equity is achieved by insurers assuming the position of underwriter, i.e. examining, selecting and classifying insurance risks for the purpose of spreading and distributing the risk in a manner that is equitable for their insureds. At the end of the day, therefore, insurers, who are profit-driven, must consider not only solidarity and equity, but also profitability when carrying on the business of insurance.

The Utilization of Genetic Information in Health Insurance Underwriting

Health insurance, like other lines of insurance, is a business that depends on predicting risks and setting premiums to account for them, and so insurers are very likely to be interested in any information that can make the risks insured against more predictable. Genetic information, particularly genetic testing for individuals and the results of such testing, provides the health insurer with a tool for more properly and accurately predicting health risks and setting appropriately reflective premiums. Questions arise, of course, as to whether and to what extent, insurers may access an individual's genetic information.

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20 This is, of course, simplifying the role of the insurer/insurance institution, which does more than simply assessing and classifying risks. As clarified by Tom Baker in his book, Insurance Law and Policy, supra note 17, at 8-12, other functions of insurance institutions include harm prevention, by means of developing and promoting harm reducing technologies and practices, gate keeping, social stratification, capital accumulation and allocation as well as knowledge production.
information and genetic test results, whether insurers should be permitted to require applicants to undergo genetic testing as a prerequisite of insurability and more specifically, should insurers be permitted to classify their applicants based on their genetic makeup.21

The goal of the insurance company, at least in the United States, is to maximize its profits.22 In order to achieve this goal, it is not only imperative that the insurer issue policies to as many individuals as possible, but that it obtain the kind of information necessary for setting the premium level according to the individual applicant's risk, thereby ensuring that overall payout of claims does not exceed the total premiums paid, and avoiding the possibility of adverse selection.23

Underwriting is the method by which insurers classify individuals according to the risk they present. Underwriting is actually a two-step process of risk selection — the process by which insurers decide whether or not to accept an application and issue a policy — and risk classification — the process of assigning an individual or group to a particular class or pool of insureds based on specific characteristics.24 Underwriting requires access to

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21 Christopher M. Keefer, Bridging the Gap Between Life Insurer and Consumer in the Genetic Test Era: the RF proposal, 74 IND. L.J. 1375 (1999), available at
22 Literature abounds with criticism of this "profit" aspect of health insurance in the U.S., pointing out that the profitability of health insurance contradicts the purpose of health care and that such contradiction is exacerbated by the opportunity to discrimination by using genetic testing to deny applicants health insurance. See Ruth Hubbard & Elijah Wald, EXPLODING THE GENE MYTH (Beacon Press 1997). What many critics fail to realize is that American society has rejected complete socialized medicine and has rejected universal health coverage; that we, as a society, have supported insurance as a profitable business — one that is in the business of discrimination. Such discrimination is fair, however, so long as there is actuarial data supporting such discrimination. It is only unfair when no such actuarial justification exists.23 Adverse selection is the process by which an individual applying for insurance, who is either uninsurable or at greater than average risk, seeks to obtain coverage at a standard premium rate.24 Genetics Policy Report, supra note 3, at ix.
information about the individual. In health insurance, such information has traditionally included answers to questions about an individual’s medical and family history. The ultimate purpose of the underwriting process is to place applicants into distinct groups that have similar health risks, wherein each insured pays a premium or price that closely reflects his or her expected loss. Distinguishing between risks with regard to expected losses and grouping individuals accordingly makes it possible to reduce the amount of financial cross-subsidization between various groups of insured in an insurance pool. Underwriting, therefore, distinguishes insured that present a high risk from those who present a lower risk in a pool and these higher-risk individuals are charged a higher premium than the lower risk insured.

Underwriting in health insurance is properly performed when the potential insured’s expected morbidity, or likelihood to manifest a disease or suffer from a condition for which medical costs will be incurred, has been properly estimated based on all pertinent information known to the insured and made available to the insurer at the time of underwriting or when the policy is renewed. Therefore, in order to accomplish this classification of risks, it is vital that the insurer, as underwriter, have access to

27 Brockett et al., supra note 27, at 5.
28 Ibid.
information that will make it possible to properly, and as accurately as possible, assess health risk.\textsuperscript{29}

In cases where an applicant or insured obtains information about his or her health risks and fails to disclose such information to the insurer, a situation of ‘asymmetry of information’ is created. Such suppression of information on the part of the insured disrupts the “equilibrium of the relationship”\textsuperscript{30} between insured and insurer and allows the insured to take advantage of the private knowledge of the risks he or she is submitting for coverage. This is where the possibility of adverse selection arises. In order to combat this possibility, contracts of insurance contain a duty of disclosure, imposing upon an applicant the obligation to declare anything and everything that bears relevance to his or her risk and classification.

This duty of disclosure has raised particular concern in recent years with availability of information with regard to the risk of disease and the move of genetic testing from the laboratory into the clinical setting. With the availability of genetic information and test results to the public, questions have arisen with respect to whether such information and results are to be considered relevant information that must be disclosed to insurers and to what extent such information should be used by insurers in determining insurability, classifying risks and establishing premiums. If the results of genetic tests are indeed considered relevant information, the suppression of such information, either by excluding such information from the information to which the duty of disclosure applies or by

\textsuperscript{29} Robert K. Gleeson, \textit{Medical Underwriting} in \textit{GENETICS AND LIFE INSURANCE: MEDICAL UNDERWRITING AND SOCIAL POLICY} 74 (Mark A. Rothstein ed. 2004).

\textsuperscript{30} Godard et al., \textit{supra} note 26, at S124.
forcing insurers, by law, to ignore genetic information in the classification process, would have a significant impact on how health insurance in the United States operates, forcing insurers to charge the same rate to insureds who are known to have different expected loss costs\textsuperscript{31}, ultimately driving rates upwards and possibly threatening the solvency of insurers.\textsuperscript{32}

To date, health insurers do not routinely, if at all, use genetic test results for underwriting purposes or require applicants to undergo genetic testing. Beyond the legal restrictions placed on such use, lack of information on the positive predictive value of such tests and on the cost of a given disease as well as the prohibitive costs of the testing itself are cited as reasons that health insurers do not currently use genetic information.

In order to evaluate the basis of public concern about the use of genetic information and genetic test results by health insurers and to understand the potential impact that genetic antidiscrimination legislation might have on the individual health insurance market, it is necessary to understand how medical information and possibly genetic information is and can be used in the underwriting process.

\textsuperscript{31} Brockett et al., supra note 27, at 5.

\textsuperscript{32} If there is asymmetry of information between insured and insurer regarding a particular insured's higher health risk, the insured will be incorrectly placed in a pool with individuals having lower expected costs and consequently lower premiums. In such a case, the insurance company's losses for this subclass of insureds will be higher than expected. Premiums to everyone in the group will increase to cover the loss. The resulting higher cost of insurance will then encourage healthy people to drop out of the pool. When the pool is smaller, the expenses of the pool will be spread among fewer, higher-risk people, and the premiums will once more increase and the cycle will repeat itself. If more individuals are inappropriately matched into a pool, the combination of adverse selection process, greater losses and smaller pools threatens the solvency of the book of business of the insurance company.” See Brockett et al., supra note 27, at 11.
When we think about insurance, genetics is not the first thing that comes to mind. In fact, the effect of genetics on insurance was of no great concern until the launching of the Human Genome Project, which essentially “propelled the biological sciences into rapidly growing endeavors in genetic technologies”. These new technologies, including the ability to clinically test individuals for the presence of certain genetic mutations that have been positively linked to the presence or risk of disease, while offering hope for future advances in gene therapy, have also given rise to the fear that such genetic knowledge will be used by insurance companies to discriminate against insurance applicants by setting higher premiums, limiting coverage or denying coverage altogether. Thus the optimism embodied in these new technologies quickly turned to fear and genetics and insurance became inextricably linked in a battle between scientific progress and the preservation of ethics and social justice.

Spanning a period of 13 years, the Human Genome Project (HGP), an international collaborative research program coordinated and funded jointly by the National Institute of Health and the U.S. Department of Energy, has succeeded in sequencing the human genome and thus identifying the location of the approximately 30,000 genes in our DNA. Although scientists still lack a great deal of knowledge about the function of many of these genes and the manner in which they interact with each other, daily innovations and breakthroughs regarding the function and estimation of risk factors involved in the

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34 The U.K. became a major partner during HGP’s early years, followed by additional contributions from Japan, France, German and China. See Human Genome Project website, at http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml
presence, absence or malfunction of specific genes or gene products, have lead us much closer to making genetics an ‘accurate’ science in terms of predicting an individual’s future risk of disease.

B. PROHIBITING INSURER ACCESS TO ACCURATE GENETIC INFORMATION GENERATES ADVERSE SELECTION

While information obtained from genetic testing may be currently irrelevant to insurers, it is likely to become increasingly relevant in the future, when genetic testing becomes more accurate at predicting risk and when the cost of such testing is no longer prohibitive. GINA is a culmination of a long line of legislative initiatives geared to prohibit the use of this information by insurers. While once can argue against a positive correlation between risk and coverage in the current health insurance market, a prohibition on the current and future use of genetic test results can generate ‘regulatory adverse selection’.

Asymmetry of Accurate Genetic Information Results in Adverse Selection

Michael Rothschild and Joseph Stiglitz\textsuperscript{36} observed that insurance applicants who know more about their health than do insurers and know their risk is greater than average, will tend to purchase more insurance when premiums are based on average risk, while those who know their risks are less than average will purchase less insurance. The empirical

prediction from this model is that there should be a positive correlation between coverage and \textit{ex post} risk in the presence of asymmetric information, in the form of adverse selection.\textsuperscript{37} Adverse selection may, over time, set off a spiral whereby insurers realize greater than expected costs and respond by increasing premiums, leading the lower-risk consumers to quit the market, causing a further round of premium increases and market contraction, until, in the worst case scenario, the overall health insurance market collapses.\textsuperscript{38}

Although Rothschild and Stiglitz appear not to have intended their theoretical speculations to be interpreted as a reflection of the real world,\textsuperscript{39} the theory of ‘adverse selection’ seems to have nevertheless been adopted as a dominant reality. A key condition to the presence of adverse selection is asymmetry of information – where one party possesses information that the other party does not. For purposes of this paper, the asymmetry of information occurs where the consumer (or health insurance applicant) possesses private genetic information about his or her health risk and that such information is not known by the insurer. If the insurer is unable to distinguish between high-risk consumers and low-risk consumers, it will charge both ‘groups’ a premium that reflects an ‘average’ risk. This will create a situation where the low-risk consumer actually subsidizes the ‘high-risk’ consumer. Assuming the low-risk consumer knows he or she is low-risk, he or she might be reluctant to pay a premium that does not actuarially

\textsuperscript{37} Hamming Fang, Michael Keane and Dan Silverman, \textit{Sources of Advantageous Selection: Evidence from the Medigap Insurance Market} (February 21, 2006)(unpublished manuscript available on file at Yale University Department of Economics), available online at http://www.econ.yale.edu/seminars/nppmicro/nm06/fang-keane-060223.pdf

\textsuperscript{38} Often referred to as a ‘death spiral’.

reflect his or her actual risk and might decide to forego insurance. High-risk consumers, on the other hand, who would be paying less than they should, will be more likely to purchase more generous insurance. The insurer ends up losing money because, theoretically, only the high-risk consumers will wish to insure themselves and ultimately incur higher health costs than the costs contemplated by the insurer when calculating the premium. Even when ‘actual’ asymmetry of information does not exist and the insurer is able to discern high-risk and low-risk consumers, as would occur if insurers could easily access genetic information, regulatory restrictions on the use of such information, as provided in legislation like GINA, creates a ‘virtual’ asymmetry of information which can result in ‘regulatory’ adverse selection.  

Testing the validity of the ‘adverse selection’ model proposed by Rothschild and Stiglitz, several papers have examined the empirical evidence for adverse selection and asymmetry of information in various insurance markets in the United States and abroad.  

It is worth noting that recent studies have failed to find either informational asymmetry, adverse selection, or both, in insurance and have not established any positive correlation between risk levels and insurance coverage predicted by Rothschild and

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43 David Cutler & Richard Zeckhauser, *The Anatomy of Health Insurance*, in *The Handbook of Economics* (A.J. Culyer and J.P. Newhouse, eds. 2000). While the study does offer evidence for death spirals involving adverse selection, the death spiral documented was caused by adverse selection against a particular health plan rather than against the insurance market as a whole.

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Stiglitz’s adverse selection model. In fact, several empirical studies have found a negative correlation between risk level and insurance purchase rather than the positive correlation predicted by the standard model.

David Hemenway offered an explanation for this negative correlation. His theory, which he calls ‘propitious selection’ implies that insurance is actually most attractive to low-risk individuals, assuming, however, that individuals have different tastes for risk and that risk-averse individuals are those who attempt to reduce their risk and thus also more inclined to purchase insurance. While this theory explains a negative correlation between risk and insurance purchase in some instances, it has been challenged by a recent study by De Donder and Hindriks that shows that the negative correlation between risk and coverage is not guaranteed even when the conditions that are implicit in the propitious selection theory are satisfied.

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41 Robin Hanson, *Adverse Selection in Group Insurance: The Virtues of Failing to Represent Voters*, 6 ECON. GOVERNANCE 139,142 (2005).
43 Gawley and Philipson used four data sources, including Health and Retirement Study (HRS) and the Asset and Health Dynamics Among the Oldest Old (AHEAD) to examine whether there is a positive correlation between self perceived or actual mortality risk and the probability of purchasing life insurance. They found that individuals who purchase life insurance have a lower death rate than those who do not, even after controlling for factors such as smoking status and income.
44 David de Meza & David Webb, *Advantageous Selection in Insurance Markets*, 32 RAND J. ECON. 249 (2001). The study revealed that individuals who have credit card insurance are less likely to lose their cards than those not having insurance. De Meza and Webb postulate that this negative correlations results from what they term ‘advantageous selection’ – selection that is based on risk aversion rather than risk (when individuals have private information about both their risk and their risk aversion). See Siegelman, supra note 40, at 1271.
45 Hamming Fang et al., *supra* note 38.
48 The properties implicit in the propitious selection theory are that risk-averse individuals exert more care, that they have stronger preference for insurance and that they actually purchase more insurance.
Peter Siegelman\textsuperscript{52} suggests other failings of the adverse selection model. He argues that any private information that insureds possess and is made unavailable to the insurer, while sometimes offering a greater prediction of risk\textsuperscript{53}, is nevertheless irrelevant due to either the insureds inability to correctly utilize the information to accurately assess and forecast their own risk\textsuperscript{54} or to the questionable significance of the information for predicting actual risk (particularly owing to other unknown factors that may undermine the predictive value of the information). Consequently, the asymmetry of such information does not place the insurer at a predictive disadvantage and does not support adverse selection.

While this may be true in the existing insurance market, where actual risk is influenced by a variety of factors as well as by information that is unknown to both insurer and insured, certain genetic information, unlike any other private information currently known by the insured, creates a certainty, or near-certainty, of risk that if denied to the insurer, does in fact put him at a predictive disadvantage.

Seigelman refers to several studies, including those conducted by Mark Pauly\textsuperscript{55} and Cawley & Philipson\textsuperscript{56} that reveal that individuals do not use informational advantages to

\begin{itemize}
\item \textsuperscript{52} Siegelman, \textit{supra note} 40.
\item \textsuperscript{53} Referring to a survey conducted by William Grove and Paul Meehl, Siegelman suggests that insurers, using statistical predictions to assess risk, may actually have an informational advantage over insureds even in the absence of private information. See Siegelman, \textit{supra note} 40, at 1246, 1247.
\item \textsuperscript{54} Siegelman refers to a study conducted by Ola Svenson, which revealed the inaccuracy of the subjects’ prediction of their own level of risk and to several experiments conducted by Thomas Gilovich, Daniel Kahnemann and Amos Tversky, as well as others, the results of which support the proposition that individual insureds possessing private information about factors that contribute to their level of risk are not capable of properly and accurately assessing their level of risk. See Siegelman, \textit{supra note} 40, at 1244, 1245.
\end{itemize}
select against insurers. While most studies do not explain the reason for this failure, some
do suggest that either the insurance demand is not sensitive to self-perceived risk level or
that higher-risk insured are also those who take the most precautions against loss and
thereby mitigate against adverse selection. If genetic information is made available, while
it is likely that high risk individuals will use the informational advantage to purchase
more health insurance at lower price, it is unlikely that they could counteract the risk by
engaging in preventive activities, at least with respect to conditions that are highly
penetrant and monogenic.

Adverse Selection in the US Health Insurance Market

The American health care system is predominantly a “privately financed, privately
organized system of multiple payers.” 57 68.1% of the United States population is covered
under private health insurance. Of this number, roughly 59.8% secure health insurance
coverage under employer-sponsored or employer-arranged group plans. 27.2% of the
population is insured under government health programs, primarily Medicare, and 12.9%
are insured through Medicaid, a joint federal and state run program. Only 9.3% of
Americans secure health insurance through direct purchase of private individual
coverage. 58

54 Cawley & Philipson, supra note 46.
57 HEALTHCARE DELIVERY IN THE UNITED STATES 125 (Anthony R. Kovner & Steven Jonas, eds. 7th ed.
2002).
58 Carmen DeNavas-Walt, Bernadette D. Proctor and Cheryl Hill Lee, Income Poverty and Health
Insurance Coverage in the United States: 2004 (issued August 8, 2005), U.S. CENSUS BUREAU, Current
http://www.census.gov/prod/2005pubs/p60-229.pdf. Note that estimates by type of coverage are not
mutually exclusive; individuals may be covered by more than one type of insurance during the year.
Employer-based coverage retains its popularity primarily due to the tax favored status to both employer and employee. Employer contributions are considered a tax-deductible business expense to the employer and are tax-exempt for the employee, while employee contributions may often be payable on a pre-tax basis. Individual coverage, on the other hand, the primary source of health insurance coverage for approximately 17 million Americans, offers no favorable tax treatment, and often forces individuals to interact with insurers on a one-to-one basis, weakening their bargaining power and often out-pricing them for insurance.

While some issues posed by genetic advances and technologies, are common to both private and public health insurance systems, private, individually purchased insurance, in particular, raises unique issues. While the number of Americans covered through individually purchased insurance is relatively small, as noted, the market still comprises 17 million persons and remains an important residual source of coverage for those who do not have access to an employer-sponsored or government-sponsored program.

The private health insurance market in the United States, often referred to as a "voluntary" health insurance market, consisting of several different types of health plan providers, including commercial insurance companies, Blue-Cross/Blue-Shield, self-

60 Geetter, supra note 36, at 44.
63 Unlike health insurance in numerous European countries, which is mandatory, health insurance in the United States is predominantly voluntary; hence "voluntary" is often used to refer to the American private health insurance system.
insured employers, and managed care organizations (MCOs), offers, as noted, two distinct types of health insurance: group plans and individual plans. The two types of health insurance differ greatly in nature, government regulation and underwriting practices.

While American society is a society with complementing principles of market justice and social justice, the two principles often conflict. This "conflict" of principles is particularly apparent in the field of health insurance where "the American interest in individual responsibility...coexists uncomfortably with the underlying goal in insurance law to pool risk". The advances in genetics, enabling individuals to be tested for the risk of future illness, brings this conflict to the surface, particularly in the field of private individual health insurance, pitting the social commitment to providing affordable healthcare to all citizens against the market forces that demand a differentiation between risks.

Employer Based Group Insurance

Employer-sponsored or employer-arranged insurance is the primary source of insurance coverage for the under-65 population in America, and, as mentioned, are usually structured with a significant subsidy by the employer, making such plans attractive to

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both healthy and less than healthy plan participants. Consequently, “disproportionate enrollment of relatively unhealthy individuals remains less likely in group plans than in individually purchased health insurance policies”, 68 and adverse selection seems less of an issue in this market segment. 69

**Individually Purchased Health Insurance**

For those Americans who are not covered through employer-sponsored health plans or government programs, individually purchased private health insurance remains their only source of coverage. In individual health insurance, premiums are set based on the risk indicated by each individual’s health status. Consequently, high risk individuals are often unable to obtain such health insurance due to the high premiums charged. 70 Moreover, coverage in individual health insurance is not automatic and can be denied by the insurer based on its determination that the individual is uninsurable.

Subject to certain state restrictions, individual health insurers are permitted to use medical underwriting when making coverage and premium decisions. Depending on the results of the underwriting process, the insurer may either deny coverage altogether or charge higher premiums to those individuals who present with costly medical conditions or who present with the risk of high future health-related costs. 71 Medical underwriting, therefore, includes the consideration of each individual applicant’s “personal health

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69 When underwriting and pricing group insurance, insurers tend to consider the overall makeup of the eligible group, rather than the health of any particular individual in the group. Ibid.
70 Singh & Shi, supra note 65, at 192.
71 Geetter, supra note 36, at 45.
characteristics which indicate the likely need for present and future medical care. Data used for establishing insurance premiums and eligibility include age, sex, smoking behavior, medical history and current physical condition."\textsuperscript{72}

Historically, medical history has included "recent medical expenses, current medical conditions that require medical treatment and any physical condition that increases the possibility of future illness. When analyzing the current physical condition, insurers evaluate treatment costs, the likelihood of recurrence and the normal progression of the condition."\textsuperscript{73} This information can be obtained from questionnaire responses, the results of medical examinations performed at the request of the insurer, physician statements and reports as well as previous claim experience.

Traditionally, the individual health insurance market has served individuals with short-term coverage needs – often as a result of movement between jobs – and its turnover rates therefore tended to be quite high. Consequently, most policies remained in force for only a brief period\textsuperscript{74} and insurance underwriters tended to focus on health care costs likely to arise during the first few years after a policy is sold. Thus, the insurance industry has stated that family medical history is not typically used in calculating costs for individual policies.\textsuperscript{75} In fact, to date, family medical history is almost never used in assessing risk for individuals applying for individual health insurance because it has not proven to be a

\textsuperscript{72} See AMERICAN ACADEMY OF ACTUARIES, Risk Classification in Individually Purchased Voluntary Medical Expense Insurance (February 1999) [hereinafter: "AAA"]
\textsuperscript{73} CRG, supra note 66, based on AAA, supra note 72.
\textsuperscript{74} Genetics Policy Report, supra note 3, at 15.
\textsuperscript{75} AAA, supra note 72.
good predictor of short-term medical costs.\textsuperscript{76} Nevertheless, there are individual policies that are available for longer periods of time and it is with regard to these long term individual policies that medical underwriting and the possibility of adverse selection becomes an issue. Medical history, including genetic information, is a better predictor of future long-term health-related costs. The greater the predictive value of such information, the more relevant it becomes to the insurer.

In the individual market, consumers make voluntary, individual choices and have an incentive to purchase insurance only when they expect to incur health-related costs in the future. Since the individual market is small and costs cannot be spread broadly, insurers in the individual market use underwriting to either deny coverage for very high risks or to charge different premiums for different risks. While the possible result of underwriting is the denial of coverage for those who are at greatest risk,\textsuperscript{77} the individual market is still comprised of both high-risk and low-risk insureds. Underwriting enables the insurer to consider the individual’s risk type when calculating premiums and to offer both the high-risk and low-risk individuals actuarially fair premiums. In a situation where informational asymmetry exists, the standard ‘adverse selection’ theory holds that individuals who know that they are high-risk will wish to purchase the insurance offered at a lower than actuarially fair premium, while those who know they are low-risk will prefer to forego insurance rather than pay the higher than actuarially fair premium.

\textsuperscript{76} Ibid.

\textsuperscript{77} Estimates of denials range from 8 to 18 percent of applicants. See Melinda Beeuwkes Buntin, Susan Marquis and Jill M. Yegian, \textit{The Role Of The Individual Health Insurance Market And Prospects For Change}, 23 \textit{Health Affairs} 79 (2004).
While, as described, most recent empirical studies do not provide support for the widespread concern surrounding the existence and implications of adverse selection in the current health insurance market, the evolution of genetics, by introducing a different kind of information, raises the informational asymmetry that potentially leads to adverse selection and subsequent “death spiral” to a new level.

In the current health insurance market, private information only in the possession of an insured is, in most instances, of little relevance to insurers, primarily because of its low predictive value, consisting of little more than mere speculation about future health status based on an amalgamation of variable factors that contribute to overall health status. Most genetic information currently suffers from the same inadequacy. Because of the multi-factorial nature of most genetic conditions and disorders, private genetic information held by an insured and not disclosed to an insurer will not place the insurer at a predictive disadvantage and will have no affect on adverse selection. Even informational asymmetry related to certain highly predictive genetic disorders, which may, in fact, result in adverse selection, should be no cause of immediate concern for the solvency of the individual insurance market, primarily because of the rarity of such conditions.

Nevertheless, genetic advances will inevitably result in a much greater number of genetic tests that are capable of accurately predicting future health status. Once such genetic tests become available, the information they reveal will certainly be ‘relevant’ to the insurer. At such time, withholding of such information by a genetically determined high-risk
insured, will result in a predictive advantage to the insured and a predictive disadvantage to the insurer, resulting in adverse selection and a possible ‘death spiral’. A recent study\textsuperscript{78} examined the insurance purchasing behavior of individuals who tested positive for presence of a specific allele of the Apolipoprotein E gene, a risk factor for the onset of Alzheimer’s disease. The study tested for the potential for adverse selection consistent with a positive correlation between risk and the purchase of insurance coverage among those testing positive for the gene. The results found evidence of such correlation in relation to long-term care insurance. No positive correlation was found in relation to health insurance, but this may be because, as stated, Alzheimer’s like many other conditions for which genetic tests exist, are multi-factorial and APOE testing provides only incomplete predictive information.\textsuperscript{79} As genetic tests increasingly provide more complete, predictive information about diseases, the potential for adverse selection, assuming informational asymmetry, will invariably grow.

Moreover, while empirical studies appear to negate the proposition that individual insureds use their informational advantage to select against the insurer, such studies are based on a market in which the informational advantage may not be perceived by the insured as being highly predictive. Risk aversion among low-risk individuals is a phenomenon that exists only when actual risk is not conducive to accurate prediction. When a risk-averse individual is incapable of knowing, with accuracy, that he will incur significant health expenses in the future due to a variety of health related factors of which

\textsuperscript{78} Cathleen D. Zick et al., Genetic Testing for Alzheimer’s Disease and Its Impact on Insurance Purchasing Behavior, 24 Health Affairs 483 (2005).

\textsuperscript{79} The e-4 allele of the APOE gene confers increased susceptibility to the development of Alzheimer’s, but is neither necessary nor sufficient to cause the disease. Other factors are increasing age and a family history of the disease. See Zick et al., supra note 80, at n. 13 and accompanying text.
he has knowledge but which have low predictive value, he will be more inclined to pay even non-actuarially justified premiums to avoid the possibility that the said factors will indeed result in poor future health status. However, should this same risk-averse individual know with certainty, or near certainty, that he will not be inflicted with a particular disorder that will increase his risk of incurring substantial health-related costs, his risk-averse behavior might theoretically alter and he may decide to forego insurance altogether.

In the current health insurance market, a risk-averse individual might face a 50-50 situation in which he may or may not suffer from a particular disorder that will result in significant future health costs, despite any knowledge that he might have regarding his actual health status. This is because of the multi-factorial nature of most health-related information. Genetic technologies, however, may result in a situation where this same individual possesses information pursuant to which he has only a 5 percent chance of ever getting sick. Will the risk-averse individual still be willing to be pooled with higher-risk individuals? Will he still value insurance so highly that it will still be worthwhile for him to purchase coverage at rates substantially too high in a purely actuarial sense? Referring to the anecdote80 of the low risk insured who purchases optional collision insurance and who is more likely to wear a seatbelt, what would happen if that same individual knew with certainty, or near certainty, that he would never be involved in a collision? Would he still wear a seatbelt and would he still purchase collision insurance? With genetic information, actual risk will become closer to a certainty (at least with respect to certain conditions) and for those particular diseases, no amount of risk

80 Siegelman, supra note 40, at 1270.
reduction (taking precautions or refusing to engage in risky activities) will make any difference.

Asymmetry of information in a market, whether occurring naturally or as a result of regulatory restrictions on its use, where the information is certainly relevant to the insurer and is sufficiently accurate so as to eliminate the effect of risk aversion on the individual’s purchasing decisions may indeed lead to adverse selection and, in the worst case scenario, to a death spiral for the individual health insurance market.

C. THE CASE FOR PERMITTING LIMITED USE OF GENETIC INFORMATION IN MEDICAL UNDERWRITING IN THE US HEALTH INSURANCE MARKET

Introduction to Genetic Information and Testing

Genetics is the field of science that examines heredity, or the passing of traits from one generation to the next.\(^{81}\) The term genetics is derived from the gene, a working subunit of deoxyribose nucleic acid (DNA) that occupies a specific position (or locus) within a chromosome.\(^{82}\) The human genetic structure, or genome, consists of 23 pairs of chromosomes\(^{83}\). A gene has two primary functions. The first is to provide a mechanism

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\(^{81}\) Stedman’s Medical Dictionary (Williams & Wilkins 26th ed. 1995).
\(^{83}\) One pair of chromosomes are the sex chromosomes (X and Y) that determine genetic sex, while the other 22 pairs are autosomes, which guide the expression of most other human traits. See Elaine N. Marieb, Human Anatomy & Physiology 1150 (Benjamin Cummings 5th ed. 2001).
for inheritance between generations and the second is to provide a mechanism for the
development of the biological individual. Every cell of the human body’s trillions of cells
contains, among other things, its DNA. Every human cell contains the same DNA
contained in tightly coiled chromosomes that are located in the nucleus of each cell. DNA is a long molecule whose function is to carry a complete set of instructions for
making all the proteins that a cell will ever need. DNA is made up of three components:
deoxyribose sugars, phosphates and nitrogenous building blocks called bases. The three
components form a nucleotide. Thousands of these nucleotides come together in pairs,
spiraled into the famous double helix structure. The nitrogenous bases are Adenine (A),
Guanine (G), Thymine (T) and Cytosine (C). These four bases are of two kinds, either
purines (Adenine and Guanine) or pyrimidines (Thymine and Cytosine). The bases attach
as pairs – a purine with a pyrimidine. The gene is, in essence, a ‘sentence’ made up of
sets of nitrogenous bases as its ‘words’, a section of the DNA that, in the appropriate
chemical environment, via RNA (ribonucleic acid), creates a protein – that is, this part of
the DNA interacts chemically with its environment and the product of this interaction is a
protein. Thus a gene is a unit of DNA that codes for one specific protein. Proteins are
necessary for the structure, function, and regulation of the body’s cells, tissues, and
organs.

Each gene consists of two parts, or alleles, one inherited from the mother and one
inherited from the father. Therefore, the likelihood of receiving any given allele is 50%.

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84 Ibid.
85 Each individual is unique owing to the fact that the sequence of the nitrogenous bases is different in each individual, with the exception of genetic twins, which have an identical genetic sequence.
87 Alleles are, in essence, different variations of the same gene.
The two received alleles\textsuperscript{89} interact to dictate a particular trait. They may code for the same form of a trait or for alternative forms of a trait.\textsuperscript{90} Any given genetic trait can be either dominant or recessive. A dominant trait is one that is expressed (or manifested) in anyone who inherits the gene (allele) for the trait. This means you need to inherit it from only one parent. If the allele is recessive, you have to inherit it from both parents in order to express the trait. Recessive traits are expressed only when an individual inherits two identical copies of the gene that determines the trait. While the alleles and the genes they comprise determine who we and how we look, they also determine what diseases or disorders we have or have a risk of developing. The disease or disorder, therefore, is but another inheritable trait.

Sometimes genes undergo random change. This means that change occurs in the sequence of nucleotides in the DNA strand. Such change is called a ‘mutation’. Many mutations are silent, affecting neither the structure of the encoded protein nor its function. Harmful mutations, however, sometimes do occur. Such genetic changes can result in malfunctioning or disabled proteins. When the mutated gene creates a normal protein, the mutation is considered neutral. When the mutated gene creates a new protein, the function of the gene changes. These changes in function can either create a new trait or cause the existing gene to stop functioning or alter its normal function.

Functional changes may lead to disease or disorder. Genetic disorders may be classified as either "multifactorial" or "single-gene" (monogenic) disorders. Multifactorial disorders

\textsuperscript{89} GAI, supra note 86, at 14.
\textsuperscript{90} While we inherit only two alleles for each gene, some genes exhibit more than two alternate forms. This phenomenon, an example of which is the ABO blood type, is rare. Marieb, supra note 83, at 1156.
\textsuperscript{90} Marieb, supra note 83, at 1151.
are ones that may never manifest themselves in the absence of certain other factors, both genetic\textsuperscript{91} and environmental. Often, the elimination of the environmental factors in disorders or diseases the manifestation of which depends on the presence of such factors, will keep the disorder or disease from manifesting itself. In the case of single-gene disorders, however, the disease will manifest itself regardless of environmental factors. For the health insurer, monogenic disorders are of greater predictive value than multifactorial disorders. Since multifactorial disorders rely on extrinsic factors that may not be genetically or otherwise verifiable, their manifestation is far from certain. While the presence of a gene that contributes to their possible manifestation does increase the risk of manifestation (relative to an individual who does not carry that gene), it by no means indicates certain manifestation. Monogenic disorders, on the other hand, do predict manifestation and while the future health cost implications of such manifestation also depend on other factors, penetrance and expressivity, these factors, unlike the extrinsic factors for multifactorial disorders, are verifiable.

Here it is worth mentioning the terms ‘presymptomatic’ and ‘predisposition’ as these relate to the types of disorders discussed above. An individual with a presymptomatic genetic condition would mean that this individual, while currently not displaying symptoms of the disease (i.e. asymptomatic) will, with certainty, develop the disease given time, regardless of outside factors.\textsuperscript{92} An individual with a predisposition to a genetic disease, on the other hand, means that an individual has an increased likelihood of

\textsuperscript{91} Those disorders that occur as a result of several genetic mutations (different genes) are called polygenic, as differentiated from single-gene (or monogenic) disorders that occur due to a mutation in a single gene. Multifactorial will be used here to refer to both polygenic disorders and those disorders that are due to both genetic and environmental factors combined.

\textsuperscript{92} Although outside factors may play a role in the severity of the symptoms.
developing a particular disease owing to the presence of a genetic mutation, but may nevertheless never present with the disease.\textsuperscript{93}

An important aspect of genetic disease is, as discussed above, the gene’s penetrance and expressivity. Penetrance refers to a gene’s ability to express itself, while expressivity refers to the degree and manner in which the gene manifests itself once it has penetrated. Genetic disorders differ with regard to penetrance and expressivity. Genes with complete penetrance and high expressivity will mean that every individual with the gene will present with the disease and the manifestation will be severe. Genes with incomplete penetrance and low expressivity may often be undetectable.\textsuperscript{94} Genetic diseases or disorders, like genetic traits, are classified into either dominant or recessive, as discussed, and further classified into either autosomal or sex-linked. Many autosomal dominant disorders have complete penetrance\textsuperscript{95}, meaning that every person inheriting the gene shows the trait.

Knowing that an individual has a family history of an autosomal monogenic disorder with high penetrance and expressivity or suffers from such a disorder is therefore ‘relevant’ to the insurer. Such information, which predicts that the individual will certainly manifest the disease, places the individual at a high risk of incurring significant

\textsuperscript{93} Absent to this discussion are what are termed “acquired” genetic diseases, which arise from mutations that may form spontaneously from environmental or age-related factors. They are, therefore, not heritable. Spontaneous cancers are acquired genetic disorders. The inherited BRCA1 gene is responsible for approximately 5-10% of breast cancers, while 90-95% of breast cancers are spontaneous genetic disorders. See Keefer, supra note 22.

\textsuperscript{94} GA1, supra note 86, at 14.

\textsuperscript{95} Phenotype is the total of all observable features of an individual, including anatomic, physiologic and biochemical makeup as well as that individual’s potential or actual disease reactions.
health costs and should be taken into consideration when issuing a policy or setting
premiums for such individual.

Arguments for Allowing the Use of Genetic Information in Individual Health
Insurance Underwriting

1. Restricted Scope of Use

Insurers have traditionally relied on medical information in underwriting and have
essentially used genetic information, broadly defined, in the underwriting process as
well. Information gleaned from an individual applicant’s family history as well as from
traditional chemical tests that reveal cholesterol level, hypertension, diabetes and other
disorders not traditionally considered genetic in nature, although currently perceived as
being genetically-based, have been used to deny coverage or increase premiums without
raising any public outcry for many years. The emergence of new genetic technologies
over the past several decades has caused many to re-evaluate and attempt to re-classify
the information that has been available to insurers in an effort to increase individual
protections against discrimination and invasion of privacy, partly in response to perceived
and often exaggerated suggestions of potential abuse by insurers should such information
be made available to them. Despite the threats of potential abuse, the insurance industry

96 Roberta B. Meyer, The Insurer Perspective in Genetics and Life Insurance: Medical
Underwriting and Social Policy 35 (Mark A. Rothstein ed. 2004).
does not appear to have "rushed to embrace" genetic testing as a tool for predicting future health costs, preferring to take a cautious approach. Even absent present state and federal legislation that imposes certain restrictions on access to and use of genetic information and testing, it appears that health insurers will opt to refrain from using genetic information, whether inferred from an individual applicant's family history or obtained from genetic test results, unless such information is deemed accurate and reliable.\(^9\)

2. Genetic Advancement vis-à-vis Scope of Use

Genetic technology is still in its infancy. At present, the genetic information that can be gathered either from an individual's history or from the results of genetic testing is relatively limited in value for insurers. While many tests for a variety of genetic mutations are available, few of these tests provide information that is relevant to the insurer when making underwriting decisions. Assuming that insurers are wary of using information that has little or no actuarial value, it is highly unlikely that insurers will use genetic information unless an established link exists between the genetic information and the manifestation of a given disease, which, in turn, gives risk to increase health-related costs. So far, such correlation exists only for a handful of diseases, all of which are life-altering in their severity. While future breakthroughs may lead to greater accuracy in the ability to predict future health risks using genetic tools, such advancements would only serve to diminish the fear of unfair discrimination on the part of health insurers.

\(^9\) Ibid at 36
\(^9\) Ibid.
3. **Scope of Privacy Associated with Genetic Information**

If genetic information is treated like any other personal information, current protections against the improper disclosure of such information should be deemed sufficient.\(^9\) The public’s informational gap when it comes to genetics, coupled with questionable studies and media reports regarding genetic discrimination have resulted in an irrational fear of genetic information. Such fear, in turn, has led to the perception that more extensive privacy protections are necessary for genetic information, as opposed to other personal information. Greater restrictions on the collection and disclosure of genetic information will merely fuel the fire of misguided concern rather than dampen it. It may potentially cause more individuals to forego genetic testing and withhold genetic-related information from physicians and other healthcare workers, thereby hindering beneficial therapy. Greater privacy protections may unintentionally hinder genetic advances by effectively denying scientists the use of genetic information for research purposes. Stalled research, will subsequently deny individuals the benefit of potentially life-saving or life-extending technologies.

4. **Commercial Rationale**

\(^9\) HIPAA does not specifically address genetic information, but provides protection against non-consensual disclosure of any personal medical information (including genetic information) provided such information meets the definition of ‘protected health information’. The HIPAA protections are meant to set a “**federal floor of policy protection**” and are not meant to preempt state laws if the laws offer more comprehensive protections. Joanne L. Husted et al., *Genetics and Privacy: A Patchwork of Protections*, Health Privacy Project, Institute for Healthcare Research and Policy, April 2002. Available at http://www.chicf.org/documents/health/GeneticsAndPrivacy.pdf at 13.
As previously mentioned, any prohibition or limitation of underwriting for health insurance on the basis of genetic information or the results of genetic tests, could have profound implications for risk classification and consequently for the continued vitality of the health insurance system.\textsuperscript{100} The preservation of insurers' freedom to access relevant information and use such information in the underwriting process is essential to ensure the continued availability of health insurance and fair premium rate setting.

D. COUNTERVAILING CONCERNS

Privacy

Beyond public concern that individuals applying for insurance will be required to undergo genetic testing as a prerequisite for obtaining health insurance coverage or that the results of such testing or genetic information in general will be disclosed or disseminated without their consent, there is concern that genetic information obtained from testing or revealed to a physician as part of a treatment plan will be divulged to third parties. To what extent is an individual's genetic information protected so that it does not get into the hands of others? To what extent should a physician or other health professional who requests that a patient undergo genetic testing or who requests genetic information for the purpose of treating the patient be permitted to reveal test results or other genetic information to third parties, including health insurance companies without the patient's consent?

\textsuperscript{100} Meyer, \textit{supra} note 96, at 46.
Proponents of comprehensive genetic protections argue that genetic information, unlike most sources of medical information, is highly invasive in that it provides an overly broad picture of the individual\(^\text{101}\) and is not limited to the individual insurance applicant, but involves members of his or her family as well.

Final standards for the protection of individuals' personal medical records and information were issued by the Department of Health and Human Services in December 2002, in compliance with the Health Insurance Portability and Accountability Act (HIPAA)\(^\text{102}\). While these standards restrict the nonconsensual use and release of private health information and establish requirements for access to records by third parties, the standards do not specifically address genetics, but rather apply to all personal health information.\(^\text{103}\) Some state laws that have successfully addressed privacy issues as they relate to genetic information\(^\text{104}\) nevertheless do not apply to employer self-insured health


\(^{104}\) While state laws protect the privacy of medical information to a certain extent, genetic-specific privacy protection has been provided by state laws in 29 states. The extent of such protection varies widely among states. Laws in 16 states require informed consent to perform or require a genetic test or obtain genetic information, and 26 states require informed consent or written authorization to disclose genetic information. Michigan, Nebraska and South Dakota place higher standards on the performance of genetic testing, but treat the information like other health data once it is created. See National Conference of State Legislatures website at [http://www.ncsl.org/programs/health/genetics/geneticprivacy2004.htm](http://www.ncsl.org/programs/health/genetics/geneticprivacy2004.htm), last visited on March 13, 2006.
plans, which are exempt from state regulation under the Employee Retirement and
Income Security Act (ERISA).105

While privacy concerns should not be discarded as unimportant, they cannot really be
met in the context of the existing U.S. health insurance market, whose primary objective
is to maximize profits. Any restriction on disclosure of relevant information in the name
of privacy protection would deprive insurers of information needed for risk management
as well as for underwriting.

Solidarity

It has been argued that individuals who are genetically disadvantaged should be able to
obtain insurance coverage on the same terms as the genetically advantaged.106 The moral
foundation for this argument is that it would be wrong to use genetic information to deny
insurance coverage since it is unfair to hold people accountable for inherited genetic
conditions over which they have no control.107 Discrimination on the basis of genetic
information would arguably counter the principle of solidarity that underlies the concept
of insurance.

In the private individual insurance context, however, the principle of solidarity is often
incompatible with the second goal of insurance – equity. Accurate risk classification and

(codified as 29 USC § 1001 et seq.)
106 See Jorgen Husted, Insurance, Genetics and Solidarity in GENETICS AND INSURANCE 9 (Tony
differentiation is inherent to the nature of private insurance and is necessary for the setting of premiums to reflect estimated risk level. While insurance promotes solidarity by spreading risk among a large population, or pool, it must also aspire to ensure equity, meaning that the contribution to the pool by any given individual should reflect his or her known level of risk, or be 'actuarially fair'. Denying an insurer's ability to differentiate insurance applicants in the name of solidarity would therefore undermine the basic idea of private health insurance. Finally, one must recall that profitability guides the U.S. individual health insurance market, and is as or more important than either solidarity or equity. Underwriting is therefore necessary to ensure that the insurer's payouts do not exceed its income. In the individual health insurance market, differentiation (underwriting) based on genetically determined characteristics has been common practice for a long time.\textsuperscript{108} Therefore, the inheritance of many genetic disorders that affect risk is already considered in the underwriting process and is taken into account in determining coverage to individuals. The fact that this genetically-based information is currently available through genetic testing should not alter the insurer's legitimate right to use it.

PART II: TOWARDS A LIMITED FEDERAL LEGISLATION

A. HISTORY

It has been said that legislation “has always lagged behind the pace” at which technology is advancing. This may be the reason why lawmakers have sought to ‘jump the gun’ in this instance and draft legislation in an effort to pre-empt abuse of genetic information by enacting legislation barring the use of genetic information even before the use of such information becomes economically useful. While many state laws had been enacted, and HIPAA was the first federal law that addressed the use of genetic information, it is the proposed Genetic Information Nondiscrimination Act, also fondly known as GINA, which marks the culmination of lawmakers’ efforts to grapple with the complexity of genetic policy.

Efforts at finding appropriate federal legislation to specifically address genetic discrimination began in 2001 with Senator Daschle’s introduction of Senate Bill 318, the Genetic Nondiscrimination in Health Insurance and Employment Act. The bill sought to amend ERISA, the Public Health Service Act and the Internal Revenue Code, and incorporate provisions that would prohibit, with respect to genetic information, discrimination in individual enrollment as well as in group eligibility or group premium

109 Deborah L. McLochlin, Whose Genetic Information is it Anyway? A Legal Analysis of the Effects that Mapping the Human will have on Privacy Rights and Genetic Discrimination, 19 J. MARSHALL J. COMP. & INFO. L. 609, 610 (2001)(citing Mark Terry, Human Genome Map Is No Cause for Alarm, DET. NEWS (August 16, 2000)).

110 See supra note 5 and accompanying text.


or contribution rates, any request or requirement to undergo genetic testing as a condition of insurance, and any request, requirement, collection, purchasing or disclosure of genetic information without the explicit consent of the individual.\textsuperscript{113} The bill prohibited medical underwriting on the basis of genetic information or genetic testing, defining ‘genetic information’ so broadly as to make up for its otherwise ‘narrow’ definition of ‘genetic test’. Genetic information included any information about an individual’s genetic tests as well as information about genetic tests of family members and other family history of genetic diseases or disorders,\textsuperscript{114} effectively prohibiting insurers from using any family history in their medical underwriting process. Since insurers were nevertheless permitted to obtain information that indicated the individual applicant’s current health status, including the results of chemical, blood and urine analyses, they could still make coverage decisions based on genetic diseases that had already manifested themselves.\textsuperscript{115}

Senator Snowe introduced a competing bill, Senate Bill1995, the Genetic Information Nondiscrimination Act of 2002. This bill, like the one previously introduced by Senator Daschle, also sought to amend ERISA, the Public Health Service Act and the Internal Revenue Code, and prohibit a health insurance plan from requesting or requiring genetic information concerning an individual or a family member or using genetic information as a condition of eligibility or in setting premiums. This bill, however, defined protected ‘genetic information’ as including information “that is used to predict risk of disease in

\textsuperscript{113} S.318, supra note 19, §§ 714, 2707, 2753, 2754, 9813.
\textsuperscript{114} S.318, supra note 19, §201(5), (6).
\textsuperscript{115} Geetzer, supra note 36, at 55.
asymptomatic or undiagnosed individuals"¹¹⁶ thereby protecting the use of predictive genetic information.¹¹⁷

Almost one year later, in May 2003, Senators Snowe and Daschle joined forces and introduced Senate Bill 1053, the Genetic Information Nondiscrimination Act of 2003. The bill also prohibited group and individual health insurers from basing eligibility and premium decisions on genetic information and genetic services.¹¹⁸ This bill was passed by a 93-0 vote in the Senate, but stalled in the House. Almost identical legislation has been introduced in the 109th Congress as Senate Bill 306, the Genetic Information Nondiscrimination Act of 2005 (hereinafter: "GINA").¹¹⁹ On February 17, 2005, this bill, too, was passed in the Senate, this time by a vote of 98 to 0.¹²⁰

B. THE GENETIC INFORMATION NONDISCRIMINATION ACT (GINA)
AND HEALTH INSURANCE

GINA, like its predecessor, applies to all health insurance markets, including employersponsored group health plans, group and individual health insurance issuers. It prohibits employer-sponsored group health plans and health insurance issuers offering health insurance in connection with a group health plan from imposing enrollment restrictions based on genetic information (which includes the request for or receipt of genetic

¹¹⁷ Geeter, supra note 36, at 54.
¹¹⁸ CRG, supra note 66, at 12.
¹²⁰ S. 306 is almost identical to S. 1053, the only difference being the deletion of one tax-related provision from Section 103 of the legislation. See GovTrack: S. 306 accessed at www.govtrack.us.
services by an individual or a family member of such individual), adjusting premiums or contribution amounts for a group on the basis of genetic information of an individual in the group or a family member of such an individual, and requesting or requiring an individual to undergo a genetic test. In the first provision, which appears to be an expansion of the protection afforded by HIPAA, GINA clarifies that all genetic information, including a request for or receipt of genetic services by an individual, which might hint at a predisposition, is prohibited from serving as a basis for the application of enrollment restrictions. In the second provision, GINA further expands HIPAA by prohibiting discrimination that might result from allowing insurers to adjust premiums for the group as a whole and to consider genetic factors of individuals within the group for the establishment of group rates, a practice permitted under HIPAA. GINA further addresses the individual health insurance market by prohibiting insurers in this market from requiring an individual to undergo a genetic test, to establish rules for the eligibility or continued eligibility to enroll based on genetic information, and to adjust premium or contribution amounts based on genetic information.

GINA defines ‘genetic information’ as all information about “(i) an individual’s genetic tests; (ii) the genetic tests of family members of the individual; or (iii) the occurrence of a disease or disorder in family members of the individual,” excluding only information

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123 S.306, supra note 26, §§ 101(b), 102(a)(2), 103(b).
124 Rich & Zeigler, supra note 2, at 33.
125 Rich & Zeigler, supra note 2, at 34.
126 S.306, supra note 26, §§ 102(b)(1)(B) and 104(a)(1)(b)(1).
127 S. 306, supra note 26, §101, 102, 103.
“about the sex and age of an individual.”\textsuperscript{128} This definition of ‘genetic information’ provides the foundations of GINA. The term is used consistently throughout Title I of the Act, which addresses discrimination in insurance.\textsuperscript{129} By including “the occurrence of a disease or disorder in family members of the individual”, in the definition of ‘genetic information’, GINA effectively bans the use of any ‘family history’, genetic, quasi-genetic, or non-genetic in nature. The reason for this addition was, according to the Committee on Health Education, Labor and Pensions (HELP), that an individual’s family history “could be used as a surrogate for a genetic trait”\textsuperscript{130} by a health insurer. While family history could reveal a heritable disease that might “open the door” for an insurer to infer that the individual is at higher risk for inheriting the disease, such inference would be highly unlikely unless the disease is a monogenic disorder with very high prevalence, in which case ignoring the family history of such a disease or failing to have access to such a disease would certainly encourage adverse selection. Moreover, knowledge of occurrences and diseases in an individual’s family may provide insurers with information that might actually be beneficial to the applicant. A consistent history of heritable disease in a patient’s family may indeed place the applicant at an increased risk for that disease, but for many diseases, that risk can be reduced or eliminated by early intervention and possibly, in the future, gene therapy. It should be noted that the statutory definition of ‘genetic information’, in GINA also specifically includes the “genetic tests of family members” Together with the previously mentioned inclusion of “the occurrence of disease or disorder in family members...” an insurer cannot even obtain information regarding diagnosed conditions in family members, even if such

\textsuperscript{128} S. 306, supra note 26, §101,102, 103.
\textsuperscript{130} Ibid.
conditions are symptomatic, in which case such conditions would be barred by the “occurrence of disease...” inclusion. This does not mean that an insurer is barred from obtaining information about the claims experience of relatives (whether such claims relate to a genetic disorder or a physical injury), but it is questionable how much information could be gleaned from this. The broad definition of ‘genetic information’ in GINA, while providing almost absolute protection to the consumer, does almost nothing to protect the interests of the insurer. By effectively including all family history under the protection of ‘genetic information’, GINA denies the insurer the ability to continue to use important information about family history.  

An important, and inseparable, element in the definition of ‘genetic information’ in GINA is the definition of ‘genetic test’. GINA defines ‘genetic test’ as “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations or chromosomal changes.”  

but excludes from the definition “an analysis of proteins and metabolites that does not detect genotypes, mutations or chromosomal changes” and “an analysis of proteins or metabolites that is directly related to a manifested disease, disorder or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved”. The second exclusion reflects an awareness of the fact that many metabolite and protein-based tests are used to diagnose existing diseases, and it was

131 Genetics Policy Report, supra note 3, at 9
132 S.306, supra note 26, §101-103.
133 S. 306, supra note 26, §101-103
134 S. 306, supra note 26, §101-103.
135 Genetic testing can be ‘direct testing’, involving an examination of DNA and RNA only, and can also entail looking at the markers that are co-inherited with the disease-causing gene (linkage, or indirect testing), assaying certain metabolites, or products of a gene (biochemical testing), or examining the
not the intent of the drafters to include in the definition of genetic information, any tests that indicate the presence of a manifested disease, disorder or pathological condition. The HELP Committee states that by including the ‘manifested disease’ exception, it “sought to draw a bright line between genetic information and information about a manifested disease.” Despite the Committee’s awareness that the distinction between genetic information and other health information “may not be possible or even desirable” they nevertheless choose to adopt ‘genetic exceptionalism’ for purposes of this legislation. What the Committee fails to address, however, is the distinction between predictive disorders and pre-symptomatic disorders. While both these disorders may be asymptomatic at the time of testing, the pre-symptomatic disorder, as opposed to the predictive disorder, will inevitably present with symptoms, although the onset or severity of such symptoms is not certain.

While the statute does not define the word ‘manifested’, it does specify that the testing for such manifested disease would not be protected if such disease “could reasonably be detected by a health professional with appropriate training in the field of medicine involved.” What kind of genetic tests are therefore excluded, i.e. are directly related to a manifested disease? The adjective manifested is defined as “clearly apparent to the

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136 Supra note 131, at 12.
137 Ibid.
138 Ibid.
139 ‘Genetic Exceptionalism’ is a term apparently coined by T.H. Murray in Genetic Exceptionalism and ‘Future Diaries’: Is Genetic Information Different from Other Medical Information? in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (M.A. Rothstein ed. Yale University Press 1997). The theory underlying ‘genetic exceptionalism’ holds that genetic information is sufficiently different from other types of medical information to justify the establishment of specific rules and regulations that govern its collection and dissemination.
140 S.306, supra note 26, §102.
sight or understanding; obvious"141 The medical term "manifestation" as it pertains to disease is defined as "the display or disclosure of characteristic signs or symptoms of an illness"142 While pre-symptomatic diseases are not a "manifested disease" in the sense that they are not "apparent" or "evident" and do not display characteristic signs or symptoms of an illness, the disorders will inevitably display symptoms and such symptoms will progressively get worse143. While it appears that the intent of the drafters was to exclude from protection only those diseases or disorders that are symptomatic, as opposed to pre-symptomatic, it is not clear whether such a distinction should be made, particularly in light of the certainty of a 'symptomatic' stage in conditions that may be "pre-symptomatic" at the time of testing.

It is important, if not essential, that an insurer be aware of 'relevant' or 'actuarially justified' genetic information in order to accurately assess risk of future health costs. It is also important that an insurer be aware of the same information available to the individual insured in order to avoid an asymmetry of information resulting in adverse selection. GINA, in an effort to protect the public from real or imagined fears of discrimination, seems to ignore the importance of genetic information in insurance and leaves no loopholes for future advances in genetic testing that will make current testing even more accurate in predicting disease.

142 STEIDMAN'S MEDICAL DICTIONARY, supra note 83.
143 Genetic testing for Huntington's allows individuals with an affected parent to determine whether they have inherited the mutation. If the mutation is present, the individual’s risk of developing the disease is virtually 100 percent, yet there is no effective intervention or preventive treatment currently available. See Wylie Burke, Genetic Testing, 347 N. ENG. J. MED. 1867 (2002).
In conclusion, GINA, the latest legislative effort to embrace ‘genetic exceptionalism’ on a federal level, appears to protect the individual and the public at the expense of the insurer, thereby failing to balance the seemingly conflicting but intertwined interests involved. Broad statutory definitions of ‘genetic information’ and ‘genetic testing’ leave no wiggle room for using almost any information pertaining to an individual applicant’s health in predicting future risk.

C. WHY IS GINA OVERLY BROAD?

1. Disassociation between Scope of Restriction and Technological Reality

GINA makes no distinction between sub-categories of genetic information (i.e. pre-symptomatic, predictive, carrier) and makes no mention of the differences between monogenic and multifactorial disorders. Its definition of genetic information is all-encompassing, leaving no room for maneuver, even when the use of genetic information can be beneficial to the health insurance applicant.

2. The Nature of the Health Insurance Industry

In essence, the U.S. health insurance market, historically restrained by state and federal legislation, has been molded to contend with the conflict between the public’s need for accessibility and affordability of health insurance, the individuals’ need for protection against discrimination and invasion of privacy and the insurers’ need to protect their
freedom to underwrite and guarantee the continued existence of the market. Strict
regulation of health insurer activity has aspired to protect the public against fraud and
abuse yet permit insurers to remain profitable so as to guarantee the continued
availability and affordability of health insurance products. As described, the U.S. health
insurance market is essentially divided into two segments the employer-based group
insurance segment and the individually purchased insurance segment. 144 While concerns
about the potential abuse of genetic information is far more prevalent in the latter, it is
particularly in this market that underwriting on the basis of genetic information holds the
greatest promise in guaranteeing availability and affordability of coverage. GINA appears
to ignore the issue of the continued solvency of this segment of the private health
insurance market. By wholly denying the use of any genetic information for underwriting
purposes, GINA will potentially cause the collapse of this market segment and ironically
negate its own purpose.

3. Existence of State and Federal Legislation Addressing Genetic
   Discrimination in Health Insurance

Regulation of insurance, including health insurance has traditionally been left to the
states.145 It has therefore been left to the states to govern all aspects of insurance. The
states have done this by enacting laws that regulate insurance operations, contracts, rate

144 Which in itself is subdivided into short-term individual insurance and long-term individual insurance
145 The signing into law of the McCarran-Ferguson Act in 1945 further strengthened the federal
government’s deferral to the states in the regulation of the business of insurance. The Act reads as follows:
“(a) State regulation. The business of insurance, and every person engaged therein, shall be subject to the
laws of the several States which relate to the regulation or taxation of such business. (b) Federal regulation.
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, cited in Baker, supra note 17, at
143.
setting and financial reserves that must be maintained to guarantee insurer solvency.\footnote{Genetics Policy Report, \textit{supra} note 3. at 13.} In an effort to facilitate access to health insurance coverage, states have, over the past two decades, enacted regulation targeted at guaranteeing the availability of insurance as well as access to "both the insurance and to the goods and services for which insurance is required."\footnote{Baker, \textit{supra} note 17, at 126.}

Health insurance policies, whether offered to groups or individuals, are insurance contracts that are subject to state regulation. States usually give insurers a great deal of flexibility in accepting or rejecting applicants and in establishing or raising premiums.\footnote{Genetics Policy Report, \textit{supra} note 3, at 15.} Most states permit medical underwriting in individual health insurance and allow and insurer to deny, limit or charge higher premiums for coverage because such individual presents with higher than average risk. Access and availability legislation was enacted in an effort to provide coverage options for otherwise 'uninsurable' individuals under the existing health insurance system, which provided few restrictions on the insurer-insured relationship.

States have established guaranteed issue requirements in the individual health insurance market, which demand that insurers provide some form of coverage to all applicants regardless of individual health status. Certain state laws limit the extent to which insurers are permitted to vary premium rates between individuals or the risk characteristics that they are allowed to consider, and the majority of states have created high-risk health
insurance pools that guarantee health care access to the otherwise medically uninsurable.  

While risk classification based on medical underwriting is perceived as a practice that is capable of increasing ‘uninsurable’ individuals and thus establishing the need for regulatory solutions to offset its effects, it remains at the core of the existing voluntary private health insurance business. Risk classification enables insurers to group individuals into classes where all members of the class present the same or comparable level of risk and pay the same premium. This process guarantees that the premium that is set is appropriate to the level of risk presented and that individuals who present the same or similar risks pay the same premium. The risk classification process, which “assure[s] that the premiums are financially prudent or adequate to enable the insurer to meet the contractual obligation to its policyholders” is therefore essential for protecting the insurer’s solvency.

Medical underwriting in the era of genetics has become an issue with which legislators have grappled over the past several decades. Many states have enacted legislation that prohibits insurers from using genetic information to determine eligibility in individual health plans. Some states place additional restrictions, such as prohibiting insurers from

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149 Genetics Policy Report, supra note 3 at 15. Participation in such plans, however, usually involves a higher than standard premium as well as high deductibles, creating an economic barrier to access for many individuals. In some states, certain medical conditions and diseases are not eligible under the risk-pool. Also, inmates of public institutions are not eligible. In addition, some states limit the number of people they will allow in the risk-pool, so if that limit is met new enrollees will be denied until there is an available opening. See National Association of Health Underwriters website at http://www.nahu.org/consumer/HRPGuide.htm.

150 Meyer, supra note 96, at 27.

151 Ibid., at 29.

152 Ibid.
requiring individual applicants to undergo genetic testing. Restrictions vary from state to state, depending, in large part, on the specific statute's definition of 'genetic information'.

On the federal level, one of the most significant steps toward the regulation of private health insurance was the enactment in 1974 of ERISA. While the primary purpose of the proponents of the Act was to correct abuses in employer-sponsored retirement benefit plans, ERISA had a significant impact on health insurance. ERISA preempted state authority over all employer-sponsored employee benefit programs, which included any health insurance benefits. Consequently, any self-insured plan, regardless of who administered it, would no longer be subject to state insurance laws. Since most large employers were either already self-insured or could afford to become self-insured, ERISA's provisions removed the health benefit plans offered by most large employers from the scope of state regulation. ERISA's preemption of state regulation of health insurance for self-insured health plans exempts such plans from compliance with state insurance laws and regulations that restrict underwriting practices, including risk classification. Self-insured plans are also not subject to laws that restrict the use of genetic information, however defined. Nevertheless, the size of the self-insured plans would likely obviate the need for individual underwriting based on genetic information or

156 Haker, supra note 17, at 202.
any other medical information, for that matter, or premium adjustments based on experience rating.\textsuperscript{158}

For those nevertheless fearful of abuses within the self-insured health plan system as a result of such plans' exemption from state insurance regulation, federal legislation seemed the only option. HIPAA,\textsuperscript{159} which took effect in April 2003\textsuperscript{160}, delivered that option.

One of HIPAA's principal objectives was to provide portability of health insurance, namely guaranteed access to health insurance for employees when they change jobs or when they lose employer-sponsored health insurance coverage. HIPAA also guaranteed renewability of coverage, although no such guarantee was made with respect to premium rates. Additionally, HIPAA prohibits "a group health plan" or "health insurance issuer offering group health insurance coverage" from basing eligibility or continued eligibility on an individual's health status, including genetic information.\textsuperscript{161} The inclusion of genetic information in this prohibition is the only explicit mention of genetic information in federal law.\textsuperscript{162} Accordingly, an employee who has a genetic condition and who receives health insurance coverage under a plan offered by a current employer, is entitled to receive health insurance when he or she changes jobs under their new employer's plan.

\textsuperscript{158} Geetter, \textit{supra} note 36, at 46, 47.
\textsuperscript{160} CRG, \textit{supra} note 66, at 10.
\textsuperscript{161} HIPAA §702(a) – In Eligibility to Enroll – (1) In general – Subject to paragraph (2), a group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, may not establish rules of 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 in relation to the individual or a dependent of the individual (A) Health status…(F) Genetic information…
and cannot be denied health insurance because his or her genetic conditions would be deemed a pre-existing condition.\textsuperscript{163}

Although HIPAA does not require that group insurance plans provide particular benefits for genetic disorders or prevent such plans from limiting or restricting the “amount, level or nature of the benefits or coverage for similarly situated individuals enrolled in the plan or coverage”,\textsuperscript{164} it does prevent an insurance plan from applying premiums on the basis of a health-status related factor, which explicitly includes genetic information.\textsuperscript{165}

While HIPAA’s provisions protect individuals participating in group health insurance plans, they do not protect individuals purchasing individual health insurance. Subject to any binding state regulations, issuers of individual health insurance are permitted to continue to use genetic information in determining eligibility and setting premiums for individuals seeking health insurance in the individual insurance market.\textsuperscript{166} Critics therefore argue that additional federal legislation is needed to provide further protections against genetic discrimination in health insurance. Beyond the argument that HIPAA fails to address individuals purchasing insurance in the individual market\textsuperscript{167}, critics cite insurers’ ability to “pass down” discriminatory practice and thus indirectly obviate

\textsuperscript{163} Geetter, supra note 36, at 47.
\textsuperscript{164} HIPAA §702(a)(2)(A) and (B).
\textsuperscript{165} HIPAA §702 (b)(1).
\textsuperscript{166} Geeter, supra note 36, at 47
HIPAA's protective mandate" by offering incentives to employers to cover individuals without any genetic risk factors. \(^{168}\)

Despite their alleged shortcomings, existing state and federal legislation seems to address most of the problems posed by the genetic technology revolution. It can be argued that the regulation of insurance should remain with the states, as envisioned by the McCarran-Ferguson Act, and that constantly evolving state legislation is keeping apprised of genetic advances and the specific problems that such advances pose to the public. While HIPAA fails to address individuals purchasing health insurance individually, the states are well-equipped to address the problems in this market segment, which is, as discussed, significantly smaller than the group insurance market. Therefore, federal legislation like GINA is not necessary.

4. Fear of Discrimination is Unfounded

A large majority of the American people believes that health insurers should not have access to genetic information, particularly the results of genetic testing, even if the insurer has paid for such testing. \(^{169}\) In large part, this belief is based on public perceptions that genetic information will be used by health insurers to deny health coverage or to charge higher premiums based on such information or on the results of

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\(^{169}\) CRG, supra note 66, at 6, citing Karen H. Rothberg and Sharon F. Terry, Before It's Too Late—Addressing Fear of Genetic Information, 297 SCIENCE 196 (2002) and E. Virginia Lapham et al., Genetic Discrimination: Perspectives of Consumers, 25 SCIENCE 621, Table 2 (1996).
Potential applicants also fear that they may be forced to take genetic tests, perhaps receive unwanted information about their health status, and perhaps be denied access to coverage now and in the future. The greatest concern seems to be among those who undergo predictive genetic testing. These asymptomatic individuals, who appear healthy for all intents and purposes, fear that their test results may have negative consequences on their insurability.

These fears, however, are unfounded. In many instances, insurers avoid using genetic information not only because of its present inaccuracy or unreliability in predicting future risks, but because of its inherent inability to predict near-term future medical costs. At this point in time, health insurance is primarily concerned with short-term future costs and most genetic information and test results project long-term, rather than short-term, health costs. Therefore, the likelihood that genetic information and testing would be used by health insurers, who are primarily concerned with short-term risks, in making coverage-denial decisions, is small and does not justify the applicants' fears or the enactment of broad genetic antidiscrimination legislation.

5. Laws against Genetic Discrimination Mislead the Public

Passing legislation against genetic discrimination might actually convince the public that the potential for genetic discrimination is high, even though it certainly is not. This

170 Johnson, supra note 167.
misguided notion may actually be responsible for deterring certain individuals from taking part in clinical trials and genetic research. Despite widespread concern about genetic discrimination in health insurance, there are few examples of it and almost no evidence.\textsuperscript{173} The American Academy of Actuaries notes that private insurers do not require applicants for insurance to undergo genetic tests or use genetic tests to limit coverage for pre-existing conditions.\textsuperscript{174} The unlikelihood of genetic discrimination in health coverage probably results from a combination of current state and federal regulations protecting genetic information, the current status of genetic science, and the cost of genetic testing. The absence of genetic discrimination would seem to be supported by an often quoted empiric study conducted by Prof. Mark Hall who found that actual cases of genetic discrimination are, at present, very infrequent.\textsuperscript{175} Another study found no well documented cases of health insurers either requesting or using genetic test results in their underwriting decisions.\textsuperscript{176}

While fear of discrimination may indeed deter participation in genetic research to a certain degree, the enactment of broad legislation may actually exacerbate rather than allay public concern. The broader the restrictions placed on the use of genetic information, the greater the public perception that such information is potentially 'dangerous'. A more limited, less restrictive approach, coupled with public education

\textsuperscript{174} Genetic Information and Medical Expenses Insurance, supra note 171.
\textsuperscript{175} Mark A. Hall, Legal Rules and Industry Norms: the Impact of Laws Restricting Health Insurers' Use of Genetic Information, 40 JURIMETRICS J. 93, 98 (1999). Prof. Hall conducted a study in several states to assess the effect of genetic discrimination laws. The results of questionnaires and interviews with a variety of sources, including representatives from major health insurers, revealed that genetic discrimination by insurers was virtually non-existent in states with and without the laws, both before the laws were enacted as well as afterwards. See also Levy & Lawler, supra note 168.
about the benefits of genetic research and its implications for beneficial gene therapy in the future, might do more to convince the public that genetic information exists and should not be ignored and that the use of such information holds little or no threat to the availability of health insurance.

6. Misguided Notion that Utilization of Genetic Information by Insurers will fundamentally affect the Insurable Population

There is the concern that insurers will use genetic tests to select only low-risk individuals, excluding many other individuals from coverage, with the result that more individuals will become uninsured and that most of these uninsured will be those high-risk individuals who need healthcare the most.\(^\text{177}\) It is believed that access to genetic information may enable health insurers to gauge the future medical costs of applicants in the individual market and insure only those who will prove profitable\(^\text{178}\), while denying coverage to everyone else. Estimates for 2004 show that about 46 million Americans, or some 18% of the population under the age of 65, are uninsured.\(^\text{179}\) Assuming a desire to guarantee at least some form of health insurance coverage to the greatest number of people, any policy that would increase the number of uninsured is, therefore, undesirable.

As mentioned, barring insurers from obtaining genetic information and test results already known to the applicant or insured would result in asymmetry of information that would leave insurers at a disadvantage, result in adverse selection and have a direct

\(^{177}\) Genetic Information and Medical Expenses Insurance, supra note 171.

\(^{178}\) Genetics Policy Report, supra note 3, at 17.

\(^{179}\) Health Coverage Issues, supra note 60, at 3.
adverse impact on premium rates. Absent the ability to access or acquire actuarially significant genetic information, insurers will be unable to classify insurance applicants into actuarially sound risk categories. Insurers will respond by increasing premiums or restricting coverage for everyone, a result that will, in essence, 'discriminate' against all applicants. Higher premiums will begin to drive many low-income, high-risk insureds and many low-risk insureds of all income groups from the market. There appears, therefore, to be no justification for individual interests in protecting existing genetic information to completely outweigh the interests of the insurance industry in obtaining actuarially relevant information.

7. Complete Ban Unnecessary Due to Prohibitively High Costs Associated with Genetic Testing

A complete ban on the use of genetic testing in health insurance is unnecessary since the cost of genetic testing is still prohibitive. Whether insurers use genetic information depends not only on whether or not such information is actuarially significant, but on whether accessing such information is cost-effective - either the financial benefit to the risk selection process is greater than the cost of obtaining the information and administering the tests, or the insurers can impose the cost of obtaining the information

on applicants without reducing the sales of the insurance product.\textsuperscript{183} Obtaining genetic information obviously has its cost, as does genetic testing. Collecting specimens, conducting the test, interpreting results and relating that interpretation to a relative risk all have their cost.\textsuperscript{184} Today, cost is a considerable factor when determining whether to access, request and/or use genetic information. While traditional methods of obtaining medical information costs very little per applicant, the cost of genetic testing is still very high, usually in the hundreds to thousands of dollars per individual applicant.\textsuperscript{185} Certainly, testing methodology changes almost daily, and cost consideration today may be meaningless tomorrow. The cost of genetic testing is expected to decrease over the next few years so that it matches the cost of common clinical chemistry tests currently conducted,\textsuperscript{186} but it is hoped that by that time, the advances in genetics will make genetic testing sufficiently reliable as an underwriting tool to allay fears of genetic discrimination.

In an effort to speed up advances in genetic research, those who oppose broad antidiscrimination legislation look to projects like the one funded by the Genome Research Institute, a federal agency in Maryland, which is financing a campaign to cut the cost of sequencing a genome to ten thousand dollars by 2009 and down to one thousand dollars by 2014.\textsuperscript{187} George Church, a leading genome expert at Harvard Medical School and the brainchild of the project, plans to place individual genomes,

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\textsuperscript{183} Jacobi, \textit{supra} note 66, at 328.
\textsuperscript{185} \textit{Ibid.}
\textsuperscript{186} \textit{Ibid.}
\textsuperscript{187} Robert S. Boyd, \textit{Name, Birthdate and Personal Genome, Please}, Last visited at www.theolympian.com/apps/pbcs.dll/article on 1/8/06.
\end{flushright}
along with the names and photos of the donors, in a public government database, where anyone can see them. "Our purpose is to make all this genomic and trait information broadly accessible so that anyone can mine it to test their own hypotheses and algorithms – and be inspired to come up with new ones." While cognizant of the risks involved in such openness, Church believes that the advantages outweigh the drawbacks.

Lack of any true evidence of abuse, however, coupled with the reality of genetic testing, the restrictions currently imposed on the use of genetic information and testing by state and federal law, and the true nature of the U.S. health insurance market, should convince policymakers to approach the matter of further comprehensive restrictions in this field with caution. With GINA, as proposed, policymakers appear to have treaded too firmly in their efforts to mollify the public’s often unfounded fears at the expense of the health insurance industry. Given an opportunity to step back and evaluate their position, would they proceed otherwise?

D. SUGGESTED ALTERNATIVES TO A COMPLETE BAN

It has been argued that a complete ban on the use of genetic information in health insurance would elevate genetic information to the status of other prohibited health insurance criteria, such as race, religion and national origin, a position supported by those who believe that a complete ban is the correct step for promoting ethics and social justice. Such a ban would reflect the belief that individuals should not be discriminated
against for something beyond their control, making our genetic make-up an inappropriate factor for consideration in insurance underwriting, and the understanding that the use of genetic information in underwriting undermines the social objective of providing access to healthcare, which is necessary for the well-being of society, to all those who need it, and particularly to those who require it the most.\textsuperscript{190} Advocates of a complete ban believe that broad restrictions help spread risk and “prevents the creation of a permanent class of genetically uninsurable, and creates an environment that will foster the use of genetic services to advance health care and encourage participation in genetic research.”\textsuperscript{191} As explained, however, the use of genetic information is necessary for the continued existence of health insurance, particularly the individual health insurance market. A complete ban on the use of genetic information, therefore, will not only result in increased premiums, hence less available and affordable coverage, but will also threaten insurer solvency.\textsuperscript{192}

A complete rejection of any federal move attempting to restrict the use of genetic information is probably unwise at this time. Even if we suggest that ‘genetic exceptionalism’ should not be encouraged by passing federal legislation that furthers this principle, we already have federal legislation, in the form of HIPAA, as well as numerous state statutes, which treat genetic information as requiring separate treatment and protection. Unrestricted use by insurers of genetic information would, many believe, allow the use of information in underwriting that is inaccurate and/or inappropriate. It would threaten individuals’ privacy by allowing insurers to freely access information that

\textsuperscript{190} Ibid.
\textsuperscript{191} Ibid.
\textsuperscript{192} Ibid.
individuals may not want to know or share and would do nothing to solve the public fears about the misuse of genetic information.193

There are several options available to policymakers, short of a complete ban on the use of genetic information, as embodied in GINA, and more appropriate than a rejection of all regulation addressing the use of genetic information in health insurance. These include the passing of a moratorium on the use of genetics in health insurance, as implemented in the United Kingdom with much success; permitting the use of genetic information by health insurers conditioned on applicants’ informed consent, allowing the use of genetic information that is actuarially justified only; and finally, narrowly tailoring restrictions on the use of genetic information and genetic testing so that a better balance is achieved between consumer and insurer interests.

A moratorium prohibiting the use of genetic information by health insurers is a worthy solution to the genetic information dilemma. First and foremost, a moratorium, unlike legislation, would be voluntary agreement between the government and the health insurance industry. Being a voluntary agreement would evidence the health insurance industry’s commitment to the principles set forth therein, rather than have such principles mandated by law. Unlike GINA, which appears to favor consumer protection over protection of commercialization of the health insurance industry, a moratorium would seek to balance the interests of both consumer and insurer. It would recognize the need of health insurers to access relevant information so that they can properly and accurately assess and price risk in the interest of both the consumer and insurer. It would understand

193 Ibid., at 22.
and seek to avoid the problem of adverse selection that results from the asymmetry of information. A moratorium, setting a restriction for a defined period of time would also acknowledge the constantly changing science of genetics and understand that the accuracy of genetic testing will change and evolve over time.\(^{194}\)

Those who oppose a moratorium would argue that deferring the issue could leave individuals without legal protection when the moratorium expires, unless the safeguards embodied in such a moratorium are reauthorized.\(^{195}\) They would insist that a moratorium equates with indecision. Nevertheless, the United Kingdom has responded to the problem of genetic information and insurance by calling for a moratorium and said it would extend the existing moratorium, which had been due to expire in November 2006, until November 2011. In addition to this extension, the parties to the moratorium also agreed to a new Concordat, a policy agreement on the use of genetic results by insurers in underwriting, designed to relieve public fears about the possible abuse of genetic test results.\(^{196}\)


\(^{195}\) *Ibid.*

\(^{196}\) The parties have agreed that genetic test results will not be used to deny people insurance cover. No one will be required to disclose the results of a predictive genetic test unless approved by GAIC and is for insurance cover of over £500,000 or critical illness and income protection insurance of over £300,000. See Department of Health website, Concordat and Moratorium on Genetics and Insurance (2005), available at [http://www.dh.gsi.gov.uk](http://www.dh.gsi.gov.uk). A recent statement on the GIAC's website states: "The Committee expects that the ABI will submit in late 2006-2007 four revised and updated applications for the use of adverse results from predictive genetic tests of the BRCA1 and BRCA2 genes, in helping to determine insurance premiums for life and critical illness insurance". These applications, if approved, will allow insurers to ask those applying for health insurance policies whether they have been tested for the two above mentioned gene mutations, which place them at a higher risk of developing cancer. The applications illustrate the flexibility of a moratorium, which makes changes possible as the reliability of genetic tests, as well as public and governmental acceptance of genetic tests in underwriting increase. See Nic Fleming, *Women Taking Breast Cancer Test May Face Insurance Ban*, *Daily Telegraph*, 2/14/06, available at [www.telegraph.co.uk](http://www.telegraph.co.uk).
Policymakers also have the option of permitting the use genetic information by insurers and possibly allowing insurers to request that individuals undergo genetic testing only after obtaining the individual applicant's informed consent. Any informed request requirements can be mandated by statute. Any applicant undergoing a genetic test would have to be informed of the purpose and nature of the test, confidentiality protections, their right to have access to medical records and policies regarding any storage or destruction of tested genetic material\textsuperscript{197} and the possible implications of a positive result.\textsuperscript{198} Any genetic information from personal medical records or genetic test results that might be required from either dead or living relatives of the applicant, would require consent, even if tissue is already available for testing.\textsuperscript{199} Although this option ensures confidentiality of genetic information, consent requirements alone do not guarantee that insurers will not discriminate on the basis of inaccurate or unreliable genetic information. Also, if an applicant does not consent to the release of genetic information or to genetic testing, would the insurer then be permitted to deny coverage simply because of the applicant's withholding of consent? A possible solution, which would preserve confidentiality as well as avoid a situation where an individual does not wish to undergo testing for psychological reasons, would be to permit insurers to place those individuals who refuse testing in higher-risk pools, charging them higher premiums. The rationale behind this would be that such individuals, by denying the insurer the opportunity to properly assess the risk that such individual presents, as demonstrated most accurately by a genetic test, should not be penalized by coverage denial but rather should be willing, in exchange for

\textsuperscript{197} Genetics Policy Report, supra note 3, at 22, 23.
\textsuperscript{199} Ibid.
the option to keep all genetic information to himself/herself (or at least away from the insurer) to pay a higher premium. Those consenting to testing and testing negative for high risk conditions would benefit from a negative test result and be appropriately placed in a low-risk, low-premium pool.

Another often suggested option is to permit the use of only that information that is actuarially justified. Actuarial justification demands that underwriting decisions, whether coverage determinations or premium increases, reflect the actual risk presented by the individual applying for health insurer. Such actuarial justification would require a showing, by the insurer, of a credible statistical link between a particular test result and increased health care costs, which would then warrant higher premiums or justify denial of coverage because of unacceptable risk. Currently, there appear to be very few test results that can be statistically linked to increased health care costs, because most are not sufficiently predictive. When such tests do emerge, they are only likely to have an impact in terms of adverse selection if traditional underwriting practices are disrupted, a possibility that this particular policy option does not envision.

Recognizing that the only conditions for which genetic test results are today truly predictive are those monogenic diseases with high penetrance and expressivity, it is arguable whether the whole controversy surrounding the use of genetic information in health insurance underwriting is much ado about nothing. There is little doubt, that the real concerns that motivate the public's insistence on allegedly 'premature' legislation is

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the creation, in the future, of a genetic ‘underclass’ that will remain uninsurable based on factors beyond its control, and that the real concerns that motivate the insurance industry’s response to a proposed ban on the use of genetic information for underwriting purposes is that such ban is merely ‘the thin edge of the wedge’, ultimately resulting in “the erosion of their ability to underwrite freely.”

A solution that recognizes these concerns yet is cognizant of the fact that such concerns do not reflect present reality is suggested as a final viable policy option. This solution, which combines elements suggested above as alternative solutions, does not reject the possibility of federal legislation targeted to address the potential for genetic discrimination in health insurance, yet calls for a reevaluation of current efforts to wholly and broadly restrict the use of genetic information in health insurance, as embodied in GINA, with a view to more properly balance the concerns of the individual insurance applicant, the public at large and the private health insurance industry. Such a balance could be achieved by drafting legislation that would restrict insurer access to genetic information and insurer-mandated testing by establishing guidelines that nevertheless fall short of an absolute ban (or at least conceivably absolute, given the proposed inclusive definitions of genetic information and genetic testing) and ones that are more narrowly tailored to reflect the current status of genetic testing. Such legislation would have to incorporate statutory definitions of ‘genetic information’ that would differentiate between genetic information that is highly predictive, whether the source is medical, quasi-genetic or a genetic test, and information that is of low-predictive value. Genetic information on

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multifactorial disorders that are not actuarially justified would be banned in light of its low predictive value. Since all multifactorial diseases contain elements that are non-genetic, many of which can be controlled, it is unjust, both socially and actuarially, to rely on such information to make decisions about insurability and premium rates.\textsuperscript{202}

Genetic information on monogenic disorders,\textsuperscript{203} particularly those with high penetrance, however, would not be protected despite arguments that persons testing positive for these disorders are discriminated against simply for the fact that tests exists for these disorders as opposed to others. While there is certainty regarding the onset of the disease in the future,\textsuperscript{204} actual time of onset and severity of symptoms is still uncertain and thus insurable. Insurers would be permitted to request genetic testing for monogenic disorders for which therapy/cure exists with early intervention. A list of such disorders should be made available and frequently updated to reflect new breakthroughs in testing and therapy. This might also work to encourage individuals to undergo testing even before applying for health insurance. Those testing positive for a disorder for which therapy is available will benefit from early intervention and a possible cure, while those testing negative would benefit from lower premiums and peace of mind. In order to address the problems of stigmatization and psychological impact, testing for all other monogenic

\textsuperscript{202} Actuarial justification would have to be determined according to mandated standards. Should a credible statistical link be shown between any given test for a multifactorial disease and actual future health costs, that particular multifactorial disease could theoretically be added to the list of those conditions that can be used by the insurer to determine premiums. The availability of statistical data and lists to all insurers would ensure uniformity of decision making.

\textsuperscript{203} Monogenic disorders such as Huntington's, Duchenne's Muscular Dystrophy and Adult Polycystic Kidney Disease (APKD) have very high penetrance, around 100%, meaning that virtually all individuals with the mutation will develop the disease. Others, like inherited colorectal cancer syndrome, about 75% are likely to be affected. See Burke, supra note 145. See also Barbara A. Bullock & Reet L. Henze, Focus on Pathophysiology 61 (Lippincott 1999).

\textsuperscript{204} A fact that would seem to make the individual ' uninsurable', since insurance is meant to protect against a risk, not a certainty.
conditions (i.e. those for which no therapy is currently available and which are currently incurable) should be consensual.\textsuperscript{205} Obviously, a list of these conditions should be updated as well, to account for changes and new treatments. Nevertheless, insurers should be permitted to charge those individuals with high familial risk of adult-onset autosomal dominant disorders with high penetrance who do not consent (i.e. refuse) to testing higher premiums to reflect the higher risk. This would maintain the insurability of such individuals, enabling them to obtain coverage despite their ‘unknown’ risk,\textsuperscript{206} yet combat the asymmetry of information and consequent adverse selection.

Federal legislation that would incorporate the above elements would succeed in balancing individual, public and industry interests. It would provide sufficient protections to individuals by disallowing the use in underwriting decisions of genetic information offering no actuarially justified predictive value, thus eliminating the fear of ‘unfair’ genetic discrimination and ensure availability of health insurance by providing an opportunity to refuse testing yet remain insurable, albeit with higher premiums to reflect possible higher risk. It would address public concerns about un-insurability and unaffordability of health insurance by continuing risk classification practices which, pursuant to guidelines ensuring the proper use of genetic information, would guarantee affordability of health insurance for the large majority of applicants. For the health insurer, such legislation would allow for more accurate risk assessment, risk

\textsuperscript{205} Burke, supra note 143 – test results have the potential to be stigmatizing or psychologically harmful.

\textsuperscript{206} It would appear justified placing such individuals in higher-risk pools due to the fact that, although not tested for the mutation, 50% of offspring of those affected with such disorder carry the mutated gene. Such individuals therefore, have a 50% chance of developing the disorder. It is important to note that among the general public, a positive genetic test (yielding unfavorable results) is often erroneously equated with non-insurability. In cases like these, individuals fearing that a positive result will automatically cause denial of coverage can opt to forego testing and remain insurable, although at a higher premium.
classification and appropriate rate setting and combat asymmetry of information and adverse selection. Frequent updating of relevant information regarding genetic testing advances would allow us, as a society, comprised of socially conscious individuals, cost-saving insurance applicants and profit-motivated insurers, to continue to recognize and benefit from genetic advances without being fearful that they will be used to our detriment.