Insurer's Access to Genetic Information: The Call for Comprehensive Federal Legislation

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INSURER’S ACCESS TO GENETIC INFORMATION: THE CALL FOR COMPREHENSIVE FEDERAL LEGISLATION

I. INTRODUCTION

Rapid developments in science and medicine are constantly creating new methods of determining an individual’s genetic composition, including any predisposition to certain diseases. Genetic screening includes tests that can be used to find sickle-cell trait, a risk of emphysema, a predisposition for chronic bronchitis, an increased risk of lung cancer, and a tendency towards anemia, among other things. However, as scientists discover these traits, individuals are becoming more concerned about the privacy of their genetic information. In response to the fears of the public, lawmakers are reacting by creating laws to prevent discrimination based on genetic information. Even Vice-President Gore has been quoted as saying, “Genetic progress should not become a new excuse for discrimination.”

One of the many debates surrounding genetic information is that insurance companies are charging certain applicants or insureds increased premiums or denying them benefits because these individuals are at a higher risk of developing a certain disease. In response to attacks on insurance companies, the president of the California Health Care Institute framed the concern of insurers throughout the United States: “Our fears . . . are producing a spate of ill-advised laws that will have serious unintended consequences in the private insurance industry.” The Health Insurance Association of America (HIAA) is also troubled by

state restrictions on insurers’ ability to collect information for risk assessment and selection. Essentially, concern is surfacing about the lack of uniformity in “patchwork” state legislation designed to prevent genetic discrimination in health insurance. The hasty laws being created across the country are also causing concern in the scientific community. One industry representative has stated:

The sponsors of these bills are well intentioned, but often they don’t understand the science or the potential consequences of their bills. Some of the legislation would virtually stop genetic research or severely limit our ability to conduct clinical trials. There should be Federal standards on medical and genetic privacy.

However, as concern about genetic information increases, more states are developing laws to protect individuals.

This Comment examines the various methods of regulating genetic information in order to protect individual privacy. The inherently slow nature of the federal legislative process has spawned legislation by several states, and this Comment will expose the pitfalls of such hasty decision making. Part II provides a brief history of genetic research and a basic foundation of insurance principles. It then establishes a framework for state and federal legislation by evaluating the collision of the individual’s demand for privacy and the insurer’s demand for information. Part III examines the differences in numerous state law definitions and prohibitions. Part IV discusses the failed attempts by the federal government to introduce a genetic privacy law. Finally, Part V addresses the need for a comprehensive federal law and proposes a solution that is both favorable to insurers and individual privacy interests. Even though individuals should not be denied the right to privacy in genetic information, total privacy will eventually drive the business of insurance out of states without the ability to distinguish among applicants.

9. Pear, supra note 7, quoting Carl B. Feldbaum, the president of the Biotechnology Industry Organization, which represents 730 genetic testing companies.
II. RELATIONSHIP BETWEEN GENETIC INFORMATION AND INSURANCE

A. Understanding Genetic Information

The recent surge of concern related to genetic information may be a result of the Human Genome Project. This project is a federally funded biotechnology research program expected to last fifteen years and cost three billion dollars.\(^\text{10}\) The project is designed to map out the human genome in hopes of creating widely available diagnostic tests and cures for diseases that are caused by genetic defects.\(^\text{11}\) Overall, the project is expected to map three billion pairs of genome.\(^\text{12}\) Francis Collins, director of the Human Genome Project ("HGP") believes that, "[i]n the next five to ten years, there will be tens if not hundreds of genetic-predisposition tests available."\(^\text{13}\)

Interestingly, concern over genetic privacy is not always well-founded because the tests used are not completely accurate.\(^\text{14}\) However, over time, the HGP promises a decrease "in vulnerability to disease, disability, and premature death."\(^\text{15}\) Along with early diagnosis, the HGP brings hope for a new ability to diagnose and treat diseases.\(^\text{16}\) However, the tests are not yet able to predict the date that the actual disease will manifest itself, the severity of the symptoms after manifestation, or the efficacy of treatment.\(^\text{17}\) For example, the uncertainty of genetic tests is displayed by the fact that scientists are still unable to determine the probability of developing breast or ovarian cancer in a woman with the altered BRCA1 gene, a well researched and documented gene.\(^\text{18}\)

Genetic discrimination is based on an apparent genetic variation

\(^{10}\) See Berry, supra note 1, at 206.

\(^{11}\) See id.


\(^{14}\) See Draper, supra note 2, for a more complete explanation of genetic testing and genetics in general beginning with the use of genetic screening for employment purposes concerning hazardous substances.

\(^{15}\) Berry, supra note 1, at 233.

\(^{16}\) See id. at 207.

\(^{17}\) See Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 AM. J.L. & MED. 109, 114 (1991). Future advances will further define the impact of discrimination. Eventually, genetic diagnosis and prognosis will be more accurate and less expensive. See id. at 113.

\(^{18}\) See Rothenberg, supra note 8.
from normal.\textsuperscript{19} Amidst all the controversy regarding genetic discrimina-
tion lies a debate within the scientific community about the exploration
of genetic information.\textsuperscript{20} For example, individuals may lose the desire to
take care of their bodies and live a healthy life if their future is geneti-
cally inescapable.\textsuperscript{21} However, even if the scientific community claims to
be concerned about discovering too much, the federal government has
expended three billion dollars, and it is unlikely that research will be
halted.\textsuperscript{22}

B. Genetic Information Within the Insurance Industry

The foundational premise of insurance is that of distributing risk;
that is, to distribute the cost of injury or loss among individuals or en-
terprises.\textsuperscript{23} Therefore, classifying risk is a fundamental step in the opera-
tion of insurance.\textsuperscript{24} When entry into and operations within the market
are restricted by regulations, insurance prices may not adequately reflect
risk costs, resulting in low-risk people being charged increased premi-
ums.\textsuperscript{25} For example, when the government prohibits insurers from using
 genetic information in underwriting, the insurance company must in-
crease premiums across the board to compensate for those individuals
who are predisposed to certain catastrophic diseases.\textsuperscript{26}

Genetic information will change the face of insurance with or with-
out laws to guard it. Too much information may destroy the central
function of insurance—spreading risk—because there is no risk if an in-
dividual knows his or her future to some degree of reasonable cer-

\textsuperscript{19} See Paul R. Billings et al., Discrimination as a Consequence of Genetic Testing, 50
AM. J. HUM. GENET. 476 (1992). Within the broad category of genetic discrimination lie
three distinct types of discrimination: (1) against healthy individuals who merely carry the
gene; (2) against individuals carrying a certain gene that is misunderstood; or (3) against indi-
viduals who are healthy and at risk, but not yet tested. See id.

\textsuperscript{20} See THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW (Ruth Chadwick et al.
eds., 1997).

\textsuperscript{21} See Rothenberg, supra note 8, at 103.

\textsuperscript{22} See Berry, supra note 1, at 206. The HGP is expected to last fifteen years. See id.

\textsuperscript{23} See KENNETH S. ABRAHAM, DISTRIBUTING RISK 1 (1986). Insurance is not the
only mechanism of managing risk. Individuals may distribute risk by diversifying investments
or spending money on safety, among other things. See id. at 2.

\textsuperscript{24} See id. at 64. Abraham provides a thorough explanation of how insurance works and
how it works best. See id. at 64-100.

\textsuperscript{25} See id. at 13.

\textsuperscript{26} See Berry, supra note 1, at 218-22 for a thorough description of insurance operations
including underwriting and actuarial determinations. However, be aware that Berry proposes
that genetic testing will provide the “proper end of insurance.” Id. at 256.
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tainty. Rationally, it is logical for insurers to discriminate based on genetic information just as they discriminate based on other personal information, such as age, sex, and smoking.

The fear of unfair discrimination by insurers, however, arises with genetic testing. While as a profit-making business, an insurance company has an interest in genetic information when charging premiums or developing coverage, that interest in the information is only relative to an individual's interest in confidentiality. Professor Richard Epstein contends that "full benefits of . . . predictive power of genetic data will be reaped only if unrestricted access is provided."

Furthermore, Judge Richard Posner emphasizes the necessity for open disclosure of personal information because "data privacy primarily serves to allow individuals to carry out dishonest manipulations."

The scientific community is also concerned that "setting legal restrictions on access to genetic information will . . . permit the advances of science to be 'frittered away.'" One method being pursued by the medical and scientific community is anonymous testing, similar to HIV testing, for specific diseases that are largely untreatable. The problem, however, is that anonymity cannot coincide with third-party payment. For example, even the cost of a test for determining a genetic alteration

27. See Berry, supra note 1, at 209.
28. See Jensen, supra note 5, at 368.

People at risk for genetic discrimination include individuals who carry a gene that increases the probability that they will develop a disease but who are currently asymptomatic; individuals who are carriers for certain genetic conditions but who will remain asymptomatic; individuals who have genetic polymorphisms that are not known to cause disease; and relatives of individuals with known or presumed genetic characteristics.

Id.

30. See THE RIGHT TO KNOW AND THE RIGHT NOT TO KNOW, supra note 20, at 16-17.
32. Id. at 4.
33. Id. at 10. Schwartz's article generally discusses privacy and the harms of open information.
35. See id. at 396.
concerning colon cancer (two hundred dollars) is reimbursable.

While insurers do have an interest in promoting genetic screening, they generally do not seek genetic information. Typically, insurers offer group policies that are not determined on individual underwriting standards. In addition, the tests are rarely determinative of what will happen in the future. Arguably, several conditions should be met before insurers consider using genetic tests to classify risk or discriminate among insureds: (1) The test should yield additional information not available elsewhere; (2) the disease should have serious morbidity/mortality rates; (3) the disease should be a common one; (4) the test must be reliable and predictive; (5) the test must be understood, accepted, and used; (6) the test should be readily performable; (7) the test must be affordable and quick; and (8) the test should be risk-free. Regardless of whether insurers follow practical guidelines concerning genetic information, several states have decided to regulate the use of genetic information by the insurance industry in order to protect the privacy of individuals.

III. STATE REGULATION OF GENETIC INFORMATION

A. Concerns of State Legislatures

Scholars have identified three periods of laws regarding genetic testing. First, laws emerged that prohibited underwriting or rating based on specifically identified genetic traits. Next, states began barring genetic testing altogether from underwriting or rating. Finally, laws barring insurance industry use of genetic information broadened beyond information collected in laboratory tests. This third phase began with the passage of a Wisconsin law shortly after the Human Genome Project

37. See Billings, supra note 19, at 476.
38. See Berry, supra note 1, at 217. For group underwriting, the insurance company uses previous claims information. See id.
39. See id. at 234.
42. See id.
43. See id.
began. Other states have continued to pass their own laws preventing genetic discrimination by insurers out of concern that the federal government is acting too slowly. Last year alone, legislators saw 153 bills in various states. Even states that currently have laws prohibiting insurers from discriminating based on genetic information are considering new laws. Ohio, for example, is now concerned that its law does not address family histories. Other states are trying to be proactive and establish safeguards. Apparently, the underlying goal in most states is to encourage the use of genetic tests by individuals by protecting the privacy of the results.

The change in laws exhibited in the past five years illustrates the rapid developments in research. Unfortunately, hasty decision making by state legislatures creates laws that will long outlive their usefulness, as some already have. For example, a bill in Florida sought to prohibit insurers from soliciting information from any other source if that information could be obtained through genetic tests. Without knowing even what genetic tests can reveal, this law could have been potentially dangerous. Even Wisconsin, the state that passed one of the first genetic testing laws, has considered a new bill in order to keep pace with scientific progress.

The driving force behind these laws is the fear of unfair discrimination. However, the term “discrimination” misconstrues the method and use of genetic information by insurers. Insurance is essentially a system based on fair “discrimination” and selection. Many of these new laws restrict an insurer’s ability to evaluate risk. The spokesman from HIAA articulated this concern by stating that insurance companies do not want to require tests, but they need to be able to evaluate medical

44. See Rothenberg, supra note 8, at 108.
45. See Pear, supra note 7.
46. See Gollaher, supra note 6.
47. See Kevin Lamb, Ohio's Genetic Privacy Law, DAYTON DAILY NEWS, Feb. 3, 1998, at 3C.
49. See Shogren, supra note 36. Three other approaches are available for protecting genetic information and encouraging testing. In addition to prohibiting the use of information by insurers and thereby creating genetic privacy, states could (1) use laws that allow use of information when it is actuarially justified; (2) set fair limits in order to evenly distribute risk between insurer and insured; or (3) establish laws for community rating. See Berry, supra note 1, at 237.
52. See Jacobi, supra note 41, at 335.
history. Not only are state laws limiting the function of insurance, they may be limiting future coverage if a genetic test reveals methods of possible treatment. The difficulty presented with prohibiting discrimination lies in the way that these laws define genetic information or genetic testing, coupled with the specific activities prohibited or restricted.

B. Variance in Definitions Among States

Most state laws concerning genetic information include definitions for the various genetic terms. However, several states use unnecessarily restrictive or unreasonably broad definitions that may lead to problems when researchers are discovering future uses for genetic testing. There are several basic terms and methods of definition that states use when defining significant terms in their legislation, and these methods directly impact insurers.

1. Scattered Definitions

Several states have adopted a simple definition of "genetic characteristics" that means "a scientifically or medically identifiable gene or chromosome, or alteration thereof, that is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder." Although this definition provides a clear idea of what a genetic characteristic is, it may not be narrow enough. Definitions similar to this should be restricted to apply to genes that are only scientifically or medically identifiable. Several states use the term "genetic condition." The normal definition is "a specific chromosomal or single-gene genetic condition." The problem


54. Along with the discrepancies among definitions and prohibitions, each state applies its laws to a different class of insurer. I will not address the issues surrounding type of insurance. For purposes of this Comment, I am assuming the broad definition of insurer, regardless of type of insurance.

55. This Comment will not address those states that have failed to include a definition of genetic information or genetic characteristic because the implications of this failure stretch far beyond the scope of this piece. Leaving the decision up to the courts, and therefore subject to multiple interpretations, is in some aspects much more deficient than beginning with a poor definition.


57. ARIZ. REV. STAT. ANN. § 20-448 (West 1998); MONT. CODE ANN. § 33-18-206(5)
with this definition is that it is circular—it includes the term defined within the definition.

2. Simple Definition

States have created two different ways of defining "genetic information" that are fairly straightforward, yet still problematic. One method is defining "genetic information" as "information derived from the results of a genetic test." While this definition appears concrete, it opens the door to various definitions of "genetic test" that could end up including routine blood work.

The other simple approach is to define genetic information as "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member." This definition is overwhelmingly broad. Technically, the term "inherited characteristics" could preclude insurers from asking the applicant's eye color or any other basic feature inherited from a parent. An even more prevalent display of this flaw is Louisiana's law that provides as follows: "'Genetic information' means all information about genes, gene products, inherited characteristics, or family history/pedigree that is expressed in common language." By including family history, the legislature slammed the door on any questioning by insurers of applicants about family medical history or other inherited traits.

3. Exclusions

A few states have taken an extra step to exclude routine tests and other procedures that may be interpreted to yield genetic information. Florida and Tennessee have nearly identical statutory provisions that provide as follows:

"Genetic information" means information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder, or syndrome, or are associated with a statisti-

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(c) (1997).


cally increased risk of developing a disease, disorder, or syndrome, which is asymptomatic at the time of testing. Such testing does not include routine physical examinations or chemical, blood, or urine analysis, unless conducted purposefully to obtain genetic information, or questions regarding family history.\textsuperscript{61}

This definition is probably the most accurate, safe, and comprehensive of all the states. A similar effort was made by North Carolina by tagging on to the end of its simple statute a clause that eliminates the "results of routine physical measurements, blood chemistries, blood counts, urine analyses, tests for abuse of drugs, and tests for [HIV]."\textsuperscript{62}

While it is admirable that these states are concerned about the inclusion of routine tests, other fears have arisen that should now be included in any exemptions. Legislatures have addressed the need to exclude newborn screenings and confidential research information.\textsuperscript{63} As new categories emerge, a laundry list of exemptions will become difficult and excessive to create. Therefore, lawmakers need to consider a catch phrase for new developments.

\section*{C. Variance in Activities Prohibited}

Aside from the diversity of definitions, states have passed a wide variety of laws to safeguard an individual's genetic information. These safeguards are likewise diverse. The assumption is that insurers will use genetic information for discriminatory purposes in underwriting. In order to prevent this, states have enacted several different types of laws. The prohibitions fall into three distinct categories, with the exception of a handful of states enacting seemingly arbitrary laws. The three categories are those that (1) restrict the actual use of genetic information; (2) prohibit insurers from requiring a genetic test; and (3) prohibit insurers from making certain considerations.

\subsection*{1. Laws Restricting the Use of Genetic Information}

The major concern in using genetic information is that insurers will use test results to deny an applicant's request for insurance. Twenty


states have determined that an insurer may not deny coverage because of genetic information. However, several states then go further and prohibit insurers from limiting coverage or determining rates or premiums based on genetic information. Prohibiting coverage limits and premium increases based on increased risk undermines the theory of insurance. Several states expand even further and prohibit insurers from canceling or refusing to renew policies. For most individuals this is a moot point because federal law requires guaranteed renewability. Arguably, the only reasonable public policy restriction on the use of genetic information by insurers is the prohibition on denial of applicants.

2. Laws Prohibiting Requiring a Genetic Test

Many states also prohibit insurers from requiring or requesting a genetic test. The purpose behind these laws is to prohibit insurers from requiring a genetic test when the results would be used for eligibility


purposes. However, many of these states also have laws prohibiting certain activities, such as canceling, limiting, denying, or determining rates. After the scientific community has discovered more about certain genetic traits, it will probably develop methods of treatment. If insurers are going to be responsible for payment of any treatment, the insurer should have the right to require a genetic test. Typically, the earlier a disease is caught or manifests itself, the more effective the treatment. Insurers should be able to evaluate their customers and assist in treatment by requiring genetic tests.

3. Laws Prohibiting Certain Considerations

Six states also have laws that restrict insurers from considering actions by the insured or applicant. Florida, Louisiana, and Tennessee prohibit an insurer from considering whether the applicant made a request for a genetic test. Several other states prohibit the insurer from considering whether the applicant refused or obtained a genetic test. For example, Kansas law provides that an insurance company may “not consider in the determination of rates or any other aspect of [coverage or benefits] whether an individual or a [family member] has obtained a genetic test or the results of the test....” These laws are premised on the idea that people would be afraid to get tested if insurers will use the test results.

4. Irregular Laws

The hasty decision making in state legislatures becomes apparent when other individual and unique laws are examined. Oregon and Texas have laws that prohibit an insurer from using favorable genetic tests as an inducement for coverage. This type of law is counterintuitive in terms of the fear of discrimination. Up until now, states have been concerned with the inevitability of increased premiums and limited benefits. However, a favorable test result could reduce rates. Indiana seemingly embraced this idea because its law allows an insurer to consider the results of a genetic test if the results are voluntarily submitted

68. See, e.g., CAL. INS. CODE § 10149 (West Supp. 1998).
69. See supra Part III (C)(1).
70. See FLA. STAT. ANN. § 627.4301(2) (West Supp. 1998); LA. REV. STAT. ANN. § 213.7 (West 1998); TENN. CODE ANN. § 56-7-2703 (Supp. 1997).
71. E.g., KAN. STAT. ANN. § 40-2259 (Supp. 1997).
and favorable to the applicant or insured. Indiana's law promotes the interest of the individual in both privacy and business. One might argue, however, that the insurance company already has one foot in the door.

A few states have recognized the idea that genetic information could potentially be useful for treatment and diagnosis purposes. Georgia recently enacted a law which provides that "any insurer that receives information derived from genetic testing may not use the information for any nontherapeutic purpose." Montana also has a more relaxed law in that it allows an insurer to deny an application or fix rates and terms if the "applicant's medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition. . . ." 

Two other states have laws that are unique—as well as perplexing. Alabama prohibits insurers from requiring, "as a condition of insurability[,] that a person take a genetic test to determine if the person has a predisposition for cancer" and from using the "results of a genetic test which may show the predisposition for cancer to determine insurability or to otherwise discriminate. . . ." Therefore, an insurer in Alabama seemingly could use genetic information related to any other disease. Colorado, on the other hand, is extremely strict on insurers. Colorado's law provides that an insurer that "receives information derived from genetic testing may not seek, use, or keep the information for any non-therapeutic purpose or for any underwriting purpose. . . ." This type of law poses a serious threat to insurers. If an insurer incidentally receives medical records from an applicant's doctor for underwriting purposes, the insurer may not even legally keep those records on file. This vast array of state regulation illustrates the need for federal guidance on the issue of genetic information.

IV. FEDERAL ATTEMPTS AT REGULATION

The impetus for federal legislation is the Human Genome Project and concern about how the information will be used once it is collected. However, the data is not even close to being fully collected yet.

74. GA. CODE ANN. § 33-54-4 (1996); see also COLO. REV. STAT. ANN. § 10-3-1104.7(3) (West Supp. 1998).
77. COLO. REV. STAT. ANN. § 10-3-1104.7 (West Supp. 1998) (emphasis added).
This may be part of the reason that federal legislative proposals have not been heavily pursued. Another reason may be that the government is also still pursuing laws dealing with genetic discrimination in employment. The Healthcare Leadership Council believes that even federal proposals concerning employment are “too far-reaching” because the application of genetic information is still largely unknown.\textsuperscript{79} A third reason for the delay is that the government is still evaluating whether the Americans with Disabilities Act ("ADA") carries possible significance for genetic discrimination.\textsuperscript{80}

The federal bills that have been introduced generally have strong support and stronger motivations. A core of five organizations typically supports the bills, including the American Cancer Society, the National Breast Cancer Coalition, the Council for Responsible Genetics, the National Action Plan on Breast Cancer, and the National Advisory Council for Human Genome Research.\textsuperscript{81} When introducing the Genetic Privacy Act of 1995, Senator Hatfield claimed that the purpose was to “establish some initial limitations..."\textsuperscript{82} The Senator urged that insurer discrimination is “problematic because we are only in the first stages of understanding the human genome.”\textsuperscript{83} The converse of this idea is also true. It is extremely problematic to begin legislating against an idea that is in its mere infancy. We have not even begun to scrape the surface of the potential use of genetic information.

The bills proposed by the federal legislature have consistently tried the same approach to limiting discrimination. Typically, they attempt to prohibit a group health plan from denying, limiting, or canceling a plan based on genetic information, or the request or receipt of genetic information.\textsuperscript{84} One particular bill introduced in Congress contained four distinct protections: (1) it prohibited denial or cancellation; (2) it prohibited changing premiums, terms, or conditions of policies; (3) it prohibited the request or requirement of a genetic test; and (4) it provided for confidentiality.\textsuperscript{85} Another bill, a year later, prohibited insurers from requiring an applicant or insured to be subjected to questions re-

\textsuperscript{80} See Gostin, supra, note 17.
\textsuperscript{83} Id.
\textsuperscript{85} See McAfee, supra note 78, at 563.
lating to genetic information. A bill proposed last year provided that a health insurer could not impose a rider or establish different premiums "on the basis of any molecular genetic information about a healthy individual." Overall, the life span of a bill restricting limitations to healthy individuals has not been very long.

One of the most recent House bills appeared to follow the trend of a couple of states. The bill prohibited an insurer from rejecting, denying, limiting, canceling, refusing to renew, increasing the rates, or otherwise affecting a policy of insurance. This bill also prohibited the use of favorable genetic tests as an inducement. Other bills have been overly broad by prohibiting insurers from seeking, receiving, or maintaining genetic information. This poses the same problem as Colorado's law by potentially restricting information that insurers have no control over receiving. Senator Hatfield emphasized that the strongest point of his 1995 Genetic Privacy Act related to protecting individuals against the cancellation of coverage. However, other insurance laws provide for guaranteed renewability of coverage, and it should not be a concern related to genetic privacy.

V. PROPOSAL FOR A FEDERAL LAW

Insurance is primarily a state-regulated industry; however, this multi-state approach has often left the insurance industry to wrestle with weak and inconsistent regulations. Because genetic privacy is such a universal concern, federal regulation is entirely appropriate to strengthen the force of legislation. Scholars and legal activists alike have been urging strong federal protection of confidentiality. The Health and Human Services' report on genetic research was accurate in

86. See S. 1898, 104th Cong. § 302 (1996).
89. See id.
90. See id.
91. See, e.g., H.R. 2216, 105th Cong. § 3 (1997).
92. See COLO. REV. STAT. ANN. § 10-3-1104.7 (West Supp. 1998).
93. See supra note 82.
94. See supra notes 65-67.
95. See ABRAHAM, supra note 23, at 37 (brief history of federal and state insurance law).
96. See id.
97. Even without federal legislation, states should refrain from passing laws without a sound basis and laws that are in conflict with other state provisions.
recommend[ing] a federal approach, [because] laws in place in [nineteen] states present a 'patchwork' approach that is often narrow in scope.199

However, recommending strong federal guidance does not mean that insurers should be totally barred from using genetic information, as some have argued. A Science magazine writer stated, for example, that "[m]eaningful protection against genetic discrimination requires that insurers be prohibited from using all information about genes, gene products, or inherited characteristics to deny or limit health insurance coverage." Genetic screening can just as easily be used for self-serving as well as discriminatory reasons by individuals.100 An individual may discover his predisposition for cancer and decide to purchase health or life insurance to pay for his medical expenses and provide for his family in case of death. The American Council of Life Insurance believes that if the patient has the information, the insurer should also have access.101 "The plea for privacy," Professor Richard Epstein has commented, "is often a plea for the right to misrepresent one's self to the rest of the world."102

We need to strike the proper balance in order to prevent the onset of disease, encourage research, and not threaten people with the loss of insurance. The scientific community believes that as "at-risk populations are identified, research can be done to determine effective prevention and treatment strategies that will lower the personal, social, and perhaps the financial costs of disease in the future."104 The trend in insurance is toward a total health management perspective and improving the quality of life. Insurers would potentially use genetic information for preventative measures in treatment. The other factor to consider is the vast amount of uncertainty and confusion that still surrounds genetic information. Genetic information merely shows a predisposition towards the disease; there is no guarantee that the individual will manifest symptoms. Another item to consider is that insurers will be reluctant to

99. President Clinton Endorses Expansion of Federal Ban on Genetic Underwriting, 1 No. 20 MEALEY'S INS. L. WKLY 7 (July 21, 1997).
101. See Gollaher, supra note 6.
102. See David Ballingrud, Gene Testing Raises Fears of Insurance Discrimination, ST. PETERSBURG TIMES, June 4, 1995, at 14A.
104. Hudson, supra note 100.
pay for the tests if the information is unavailable to them. Until all this uncertainty begins to clear, genetic privacy should be the norm without concerns for discrimination. The proper approach is to take the target off of the private insurance industry and establish baseline federal protections for privacy. The federal government is funding the Human Genome Project, and is therefore in the best position to make any determinations about what legislation is proper. Until then, the government can learn from the states' mistakes and rash judgment.

VI. CONCLUSION

The public is constantly bombarded with the idea that "[u]nless state and federal laws make genetic discrimination unlawful, insurance companies will continue to abuse biotechnology to insure only the 'genetically healthy' and accordingly maximize their profits."\(^{105}\) However, this is far from the truth. Recently, Missouri considered a bill concerning genetic discrimination and the news reported: "At a recent hearing before the House Insurance Committee, no one testified claiming to have been dropped from coverage because of results of genetic tests. The bill's backers know of no case in Missouri where someone has been denied coverage."\(^{106}\) The fact remains that there is a much broader spectrum of potential users of genetic information including the following: mortgage lenders, medical colleges, scholarship donors, business partners, adoption agencies, and politicians.\(^{107}\)

Genetic composition is beyond our control, but it is potentially treatable. What if the fear behind insurance discrimination laws is misguided? The fear of discrimination may not be the primary deterrent for avoiding genetic tests. There are other factors such as cost and fear of knowing the unknown. For insurance companies, evaluating risk is a part of the business and genetic predisposition is just another piece of the puzzle.

MEREDITH A. JAGUTIS

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