# THE USE OF GENETIC INFORMATION IN HEALTH INSURANCE: WHO WILL BE HELPED, WHO WILL BE HARMED AND POSSIBLE LONG-TERM EFFECTS

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#### I. INTRODUCTION

Recent polls on genetic discrimination show that many people fear the use of their genetic information by employers or insurance companies. This apprehension is closely linked to fears of a new form of genetic eugenics, or concerns that genetics will be used as a proxy for race in discriminatory practices. A 1995 Harris Poll survey indicated that while eighty-four percent of those polled believe the overall impact of genetic research is positive, "almost half listed misuse of genetic information as their biggest concern." Further, recent NIH studies indicate that one-third of individuals who could be tested for colon cancer, breast cancer or ovarian cancer choose not to be tested or participate in studies because they fear that the resulting information might be used to deny them access to health insurance or employment.<sup>4</sup>

Genetic testing has been making big headlines recently, as in the case of Eddy Curry, a twenty-four year old center for the New York Knicks,

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<sup>&</sup>lt;sup>1</sup> Poll Highlights Fear of Genetic Discrimination, HEALTH & MED. WK., Oct. 13, 2003, at 327.

<sup>&</sup>lt;sup>2</sup> See generally Erik Lillquist & Charles A. Sullivan, *The Law and Genetics of Racial Profiling in Medicine*, 39 HARV. C.R.-C.L. L. REV. 391 (2004).

<sup>&</sup>lt;sup>3</sup> Democratic Policy Committee, Democrats Fight for Comprehensive and Enforceable Genetic Nondiscrimination Legislation, http://democrats.senate.gov/~dpc/pubs/107-1-240.html (last visited Mar. 29, 2007).

<sup>&</sup>lt;sup>4</sup> *Id*.

who has the kind of talent that "comes around every 15-20 years." This promising young basketball player may have lost out on millions of dollars due to his genetic heart condition: "You just can't pass up a guy like Eddy Curry,' Stephon Marbury said yesterday. Actually, 28 other teams did. The Bulls couldn't get insurance on a contract for Curry after doctors informed them that he could run into big heart trouble down the line" and therefore the team refused to re-sign him.<sup>6</sup> Curry's situation demonstrates that although most genetic discrimination issues are theoretical dilemmas of the future, problems are already arising for those diagnosed with genetic disorders. Although this note primarily addresses issues of access to healthcare, employment discrimination (as in Curry's case) is another major area of concern.

Genetic testing raises many moral, ethical and legal problems.<sup>7</sup> To begin with, technology is advancing far more rapidly than our ability to legislate or otherwise deal with the moral ramifications of our newfound expertise.<sup>8</sup> Further, the utility of testing for serious illnesses for which no treatments are available is questionable; the only possible purposes are to inform the affected person of his or her potential future illness or to provide information to an insurance company, employer or other third party.

Part II of this note discusses the science of genetic testing, what the tests can tell us, and what can be done with that information. Part III explains the way that health insurance (and insurance generally) is currently priced in this country. Part IV summarizes the current state of the law regarding genetic information and healthcare. Part V discusses the arguments for and against the use of genetic information in healthcare pricing

<sup>&</sup>lt;sup>5</sup> Mitch Lawrence, Curry Is a Heightened Risk: Knicks Gambling on Center, N.Y. DAILY NEWS, Oct. 5, 2005, at 89.

<sup>6</sup> Id.

<sup>&</sup>lt;sup>7</sup> See Deborah L. McLochlin, Whose Genetic Information Is It Anyway? A Legal Analysis of the Effects that Mapping the Human Genome Will Have on Privacy Rights and Genetic Discrimination, 19 J. MARSHALL J. COMPUTER & INFO. L. 609, 620 (2001) ("There are ethical, moral, and legal implications of the mapping of the human genome.").

<sup>&</sup>lt;sup>8</sup> *Id.* at 615.

<sup>&</sup>lt;sup>9</sup> As two scholars put it:

At the same time, the prospect of genetic screening has engendered widespread popular apprehension. One source of this apprehension may be the fear, attributed to some particularly risk-averse individuals, that the new genetics will somehow force upon them unwanted selfawareness. Persons exhibiting this psychological aversion, sometimes called the "nocebo" effect, prefer to remain in a state of medical or genetic ignorance for fear that knowledge will reveal the presence of a predisposition for a condition that is incurable or preventable only by resort to costly and difficult measures.

Colin S. Diver & Jane Maslow Cohen, Genophobia: What Is Wrong with Genetic Discrimination?, 149 U. PA. L. REV. 1439, 1442 (2001).

and access. Finally, Part VI suggests solutions to the potential problems raised by the widespread availability of genetic information.

# II. BRIEF HISTORY OF GENETIC TESTING AND THE HUMAN GENOME PROJECT

The prospect of widespread genetic testing became a real possibility with the advent of the Human Genome Project, an international project launched in 1990. The project's goal, mapping the sequence of the entire human genome, was achieved in 2003. However, one significant problem persists: while scientists now know the sequence of the human genome, "[t]he functions are unknown for over 50% of the discovered genes." Furthermore, most of the genes that have been specifically identified do not necessarily correlate to human illness, or if they do, the illness is not treatable. Nonetheless, well over five thousand genes that code for genetic illnesses have been identified and this number is constantly growing.

## According to David C. Bonnin:

[D]espite . . . quantum leaps in technical proficiency, in most cases current understanding of the association of genetic mutations and disease is fledgling at best. Furthermore, a test might not always detect all the mutations of a gene, not all mutations have the same effects, and diseases can be caused by complex interactions between genetic and environmental factors that are not always clearly understood. <sup>16</sup>

While Bonnin is ostensibly correct, it is still useful to look at the different ways in which genetic tests are used.

Genetic testing is currently used in six different ways: diagnostic testing, predictive testing, carrier testing, prenatal testing, preimplantation testing and newborn screening.<sup>17</sup> First, diagnostic testing is used to test sick

<sup>12</sup> Id.

<sup>&</sup>lt;sup>10</sup> Press Release, Nat'l Human Genome Research Inst., International Consortium Completes Human Genome Project (Apr. 14, 2003), available at http://www.genome.gov/11006929.

<sup>11</sup> Id.

<sup>13</sup> Human Genome Project Info., The Science Behind the Human Genome Project, http://www.ornl.gov/sci/techresources/Human\_Genome/project/info.shtml (last visited Mar. 29, 2007).

<sup>14</sup> See Jennifer S. Geetter, Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System, 28 AM. J.L. & MED. 1, 6 (2002).

<sup>15</sup> Id. at 4.

<sup>&</sup>lt;sup>16</sup> David C. Bonnin, *The Need for Increased Oversight of Genetic Testing: A Detailed Look at the Genetic Testing Process*, 4 Hous. J. Health L. & Pol'y 149, 152 (2003).

<sup>17</sup> GeneTest.org, About Genetic Services, http://www.genetests.org/servlet/acess?id=8888891&key=w3SjmFtecqgab&fcn=y&fw=6XMY&filena me=/concepts/primer/primerusesof.html (last visited Mar. 29, 2007).

individuals to determine whether the cause of illness is genetic.<sup>18</sup> Second, there are two types of predictive testing performed on asymptomatic individuals: presymptomatic and predispositional. Presymptomatic predictive testing determines whether an individual, who appears healthy, is certain to develop a particular genetic illness at some point in the future.<sup>20</sup> Predispositional predictive testing attempts to determine predispositions to a particular illness, which may or may not develop at a later date.<sup>21</sup> Third, carrier testing identifies (mostly) asymptomatic individuals possessing genetic mutations inherited in an autosomal<sup>22</sup> or X-linked<sup>23</sup> recessive manner.<sup>24</sup> Carrier testing is often performed on one whose family members have a genetic condition or are carriers, as well as on members of ethnic or racial groups known to have high carrier rates for a particular condition.<sup>25</sup> Fourth, prenatal testing occurs during pregnancy to assess fetal health.<sup>26</sup> Prenatal diagnostic tests are generally performed when an increased risk of a genetic disorder exists due to maternal age, family history, ethnicity, suggestive multiple marker screen or fetal ultrasound examination.<sup>27</sup> Fifth. preimplantation testing is performed on in vitro fertilization embryos in order to detect the probability that genetic disorders might be present in the fetus if implantation were to occur.<sup>28</sup> Preimplantation testing gives couples a viable alternative to prenatal diagnosis of genetic disorders and the subsequent potential termination of affected pregnancies.<sup>29</sup> Sixth, newborn screening identifies infants with increased chances of having genetic disorders, thereby allowing treatment to start early in the child's life.<sup>30</sup> These tests are routinely performed at birth, unless refused by the parents in writ-

<sup>18</sup> See id. ("Diagnostic testing is used to confirm or rule out a known or suspected genetic disorder in a symptomatic individual.").

<sup>&</sup>lt;sup>19</sup> Id.

<sup>&</sup>lt;sup>20</sup> Id.

<sup>&</sup>lt;sup>21</sup> Id.

<sup>&</sup>lt;sup>22</sup> "Autosomal" is defined as "[p]ertaining to a chromosome that is not a sex chromosome; relating to any one of the chromosomes save the sex chromosomes." MedTerms Medical Dictionary, http://www.medterms.com/script/main/art.asp?articlekey=15358 (last visited Mar. 29, 2007).

<sup>&</sup>lt;sup>23</sup> "X-linked" is defined as "[o]n the X chromosome. 'Linked' in genetics does not mean merely associated. An X-linked gene travels with the X chromosome and therefore is part of the X chromosome." MedTerms Medical Dictionary, http://www.medterms.com/script/main/art.asp?articlekey=6031 (last visited Mar. 29, 2007).

<sup>&</sup>lt;sup>24</sup> GeneTest.org, *supra* note 17.

<sup>&</sup>lt;sup>25</sup> Id.

<sup>&</sup>lt;sup>26</sup> *Id*.

<sup>&</sup>lt;sup>27</sup> Id.

<sup>&</sup>lt;sup>28</sup> Id.

<sup>&</sup>lt;sup>29</sup> Id.

<sup>&</sup>lt;sup>30</sup> Id.

ing.<sup>31</sup> Newborn screening programs are often legally required, but vary greatly among different states.<sup>32</sup>

While some genetic tests can indicate with absolute certainty that an individual will develop a particular illness, most are only able to provide the statistical likelihood of an individual developing a particular illness.<sup>33</sup> Further, genetic illnesses are complicated and cannot be lumped into one category.<sup>34</sup> Indeed, there are four classes of genetic disorders: chromosomal disorders, single-gene disorders, multifactorial disorders and mitochondrial disorders.<sup>35</sup>

First, chromosomal genetic disorders can occur when an individual possesses the wrong number of chromosomes. One well-known chromosomal disorder is Down Syndrome, for many years now a disease for which physicians have screened. Other chromosomal disorders include Klinefelter Syndrome, which results in XXY males, and Turner Syndrome, which results in females with only one X chromosome (both disorders are due to nondisjunction of the sex chromosomes). Treatments for chromosomal genetic disorders are usually drastic due to their severity, often requiring surgery immediately after birth or even pre-natally. The chances of survival with chromosomal disorders are often slim, and a lifetime with an obvious severe disorder (such as mental retardation or physical deformation) is common.

Single-gene disorders, the second class of genetic disorders, are caused by a mutation in a single gene, which causes the gene product (the

<sup>&</sup>lt;sup>31</sup> Id.

<sup>&</sup>lt;sup>32</sup> Id.

<sup>&</sup>lt;sup>33</sup> Geetter, supra note 14, at 5-6.

<sup>&</sup>lt;sup>34</sup> See Genetic Sci. Learning Ctr., Univ. of Utah, What are Genetic Disorders?, http://gslc.genetics.utah.edu/units/disorders/whataregd (last visited Mar. 30, 2007).

Human Genome Project Info., Genetic Disease Information, http://www.ornl.gov/sci/techresources/Human\_Genome/medicine/assist.shtml (last visited Mar. 30, 2007).

<sup>&</sup>lt;sup>36</sup> Genetic Sci. Learning Ctr., Univ. of Utah, Chromosome Abnormalities, http://gslc.genetics.utah.edu/units/disorders/whataregd/chrom.cfm (last visited Mar. 30, 2007).
<sup>37</sup> Id.

<sup>38</sup> Nat'l Inst. of Child Health & Human Dev., Klinefelter Syndrome, http://www.nichd.nih.gov/health/topics/klinefelter\_syndrome.cfm (last visited Mar. 30, 2007); Nat'l Inst. of Child Health & Human Dev., Turner Syndrome, http://www.nichd.nih.gov/health/topics/Turner\_Syndrome.cfm (last visited Mar. 30, 2007).

<sup>&</sup>lt;sup>39</sup> Genetic Sci. Learning Ctr., Univ. of Utah, Diagnosis and Treatment Options for Birth Defects, http://learn.genetics.utah.edu/units/disorders/whataregd/treatment.cfm (last visited Mar. 30, 2007).

<sup>&</sup>lt;sup>40</sup> See id.; Chromosome Abnormalities, supra note 36.

protein that the gene codes for) to be damaged or missing altogether.<sup>41</sup> Common single-gene disorders are generally severe (though not as severe as chromosomal disorders) and include sickle-cell anemia, muscular dystrophy and cystic fibrosis.<sup>42</sup>

Third, multifactorial genetic disorders are caused by a combination of factors including, but not limited to, mutations in multiple genes, where one defect in each will generally not cause illness; environmental factors; and recessive alleles that may become dominant based on naturally occurring mutations in the "healthy" dominant allele. Common multifactorial genetic disorders include heart disease, diabetes and cancer. Predispositions for multifactorial genetic disorders are already considered in the family history questions of insurance policies; however, genetic testing could more accurately predict a person's risk for developing these disorders. Most multifactorial disorders fall into the category in which testing indicates only that a person will have a higher-than-average probability of developing a disease, but is not certain to do so (as is the case with many single-gene disorders).

Finally, mitochondrial genetic disorders are relatively rare genetic disorders caused by mutations in non-chromosomal DNA located within the mitochondria.<sup>47</sup> Mitochondria are small intracellular organelles found in each cell's cytoplasm.<sup>48</sup> Their presence in the ovum allows passage of disorders to the next generation, but only by the mother.<sup>49</sup>

<sup>&</sup>lt;sup>41</sup> Genetic Sci. Learning Ctr., Univ. of Utah, Single-Gene Disorders, http://gslc.genetics.utah.edu/units/disorders/whataregd/single.cfm (last visited Mar. 30, 2007).

<sup>42</sup> Id

<sup>&</sup>lt;sup>43</sup> Genetic Sci. Learning Ctr., Univ. of Utah, Multifactorial Disorders, http://gslc.genetics.utah.edu/units/disorders/whataregd/multi.cfm (last visited Mar. 30, 2007); Thomas G. Gregg, Latent Neomorphs and the Evolution of Dominance, 21 EVOLUTION 850, 850-52 (1967).

<sup>&</sup>lt;sup>44</sup> Multifactorial Disorders, *supra* note 43.

<sup>&</sup>lt;sup>45</sup> Id.

<sup>46</sup> Id.; Answers.com, Birth Defect, http://www.answers.com/topic/congenital-disorder (last visited Mar. 30, 2007). Multifactorial disorders are triggered by something more than a faulty gene. Therefore, an individual who has a multifactorial disorder may not develop the illness if he or she is never exposed to the triggering environmental stimulus. In contrast, a single-mutation disorder is caused by the mutation itself (that is, no outside factor is necessary to trigger it).

<sup>&</sup>lt;sup>47</sup> Human Genome Project Info., *supra* note 35.

<sup>&</sup>lt;sup>48</sup> Id. "Each mitochondrion may contain 5 to 10 circular pieces of DNA." Id.

<sup>&</sup>lt;sup>49</sup> Neuropathology, Inherited Metabolic Disorders: Mitochondrial Disorders, http://www.neuropathologyweb.org/chapter10/chapter10dMitochondria.html (last visited Mar. 30, 2007) ("Abnormalities of mitochondrial genes are transmitted from mother to offspring (material inheritance) because only the ovum has mitochondria.").

As of 2003, well over five thousand diseases with genetic correlations had been identified, and the number continues to rise rapidly.<sup>50</sup> This allows scientists to test for an increasing number of genetic disorders, and predictive genetic testing is already possible for a variety of genetic illnesses such as cystic fibrosis.<sup>51</sup> While these tests are currently prohibitively expensive for most people, scientists expect a significant reduction in cost due to the development of "Gene-Chips" or DNA-Microarrays, which will concurrently analyze a large number of genes.<sup>52</sup> It is likely that genetic tests will soon be affordable and widely available.<sup>53</sup> Thus, situations like Eddy Curry's are likely to arise more often in the near future.

# III. ECONOMIC MODELING OF HEALTH INSURANCE STRUCTURES: HOW HEALTH INSURANCE IS PRICED

According to the United States Census Bureau, approximately eighty-five percent of the U.S. population had health insurance in 2002.<sup>54</sup> Of that group, about one-quarter was covered through a government-sponsored health insurance program, such as Medicare or Medicaid, and over two-thirds had private health insurance that was either purchased or obtained through their employer.<sup>55</sup> Government-issued health insurance, unlike private insurance, does not rely upon a physical screening or the applicant's health status, and it therefore is unlikely to be affected by genetic discrimination.<sup>56</sup>

#### A. RISK-CLASSIFICATION: IS IT "FAIR"?

Unlike employment-based group health plans, insurers structure small group health plans and individual insurance plans "in order to calculate appropriate, i.e. actuarially fair, premium rates." Risk-classification, a

<sup>&</sup>lt;sup>50</sup> Robert F. Rich & Julian Ziegler, *Genetic Discrimination in Health Insurance—Comprehensive Legal Solutions for a (Not So) Special Problem?*, 2 IND. HEALTH L. REV. 5, 5 (2005) (citing Geetter, *supra* note 14, at 4).

<sup>&</sup>lt;sup>51</sup> Id.

<sup>52</sup> Id. (citing SENATE COMM'N ON GENETIC RESEARCH, PREDICTIVE GENETIC DIAGNOSIS: SCIENTIFIC BACKGROUND, PRACTICAL AND SOCIAL IMPLEMENTATION (Mar. 2003), available at http://www.dfg.de/aktuelles\_presse/reden\_stellungnahmen/2003/download/predictive\_genetic\_diagnosis.pdf).

<sup>53</sup> See id. at 5-6; McLochlin, supra note 7, at 624-25.

<sup>&</sup>lt;sup>54</sup> ROBERT J. MILLS & SHAILESH BHANDARI, U.S. CENSUS BUREAU, U.S. DEP'T OF COMMERCE, HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2002, at 20 (2003), available at http://www.census.gov/prod/2003pubs/p60-223.pdf.

<sup>&</sup>lt;sup>55</sup> Id.

<sup>&</sup>lt;sup>56</sup> Rich & Ziegler, supra note 50, at 10.

<sup>&</sup>lt;sup>57</sup> *Id.* at 11.

method utilized to determine rates, gives insurers a means to categorize individuals with similar projected claims.<sup>58</sup> This allows health insurance companies to employ "reasonable discrimination" and base premium rates on a particular individual's projected costs.<sup>59</sup> Thus, "insurers differentiate among individuals seeking health insurance coverage. The purpose of this practice is maintaining a system in which each insured person's premium is rated according to the amount of his or her risk."60 If this did not occur, average insurance coverage rates would be higher, and healthy people would be far less likely to purchase health insurance because their treatment costs would likely be less than their insurance costs. Only high-risk individuals or those with predispositions to illness would purchase insur-If health insurance companies were not allowed to pricedifferentiate according to risk-classification, the entire industry could collapse because too few policies would be purchased and rates would increase so dramatically that most high-risk individuals would be priced out of the market.<sup>62</sup>

As mentioned above, health insurance companies already employ probabilistic modeling to determine their rate structures.<sup>63</sup> Thus, certain types of discrimination are clearly permissible in determining rate structures.<sup>64</sup> Health insurance companies gather information that they use to compute rates based on statistical risk. Some of the factors used include age, gender (women often pay more for health insurance than men),<sup>65</sup> health status, personal medical history, financial status and occupation.<sup>66</sup> Some of these characteristics are immutable and intrinsic—e.g., one's age or family and personal medical history. These price models are arguably more equitable than a flat rate because they do not force those in lower-risk groups to subsidize the costs of those in higher-risk groups.<sup>67</sup> Two com-

<sup>59</sup> *Id.* at 11-12.

<sup>&</sup>lt;sup>58</sup> Id.

<sup>&</sup>lt;sup>60</sup> Id. at 12.

<sup>&</sup>lt;sup>61</sup> See id.

<sup>62</sup> See id.

<sup>63</sup> Id. at 10-12.

<sup>64</sup> See id. at 12.

<sup>&</sup>lt;sup>65</sup> Chetan Gulati, Genetic Antidiscrimination Laws in Health Insurance: A Misguided Solution, 4 QUINNIPIAC HEALTH L.J. 149, 170 (2001). Insurers can also limit coverage by setting the terms of the insurance contract in a way that sets caps or excludes certain benefits; these contractual decisions are made on the basis of the risk profile of the applicant. See Jill Gaulding, Note, Race, Sex, and Genetic Discrimination in Insurance: What's Fair?, 80 CORNELL L. REV. 1646, 1651-52 (1995).

<sup>&</sup>lt;sup>66</sup> Gulati, supra note 65, at 170 n.80 (citing Carol Lee, Comment, Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry, 13 PACE L. REV. 189, 208 (1993)).

<sup>&</sup>lt;sup>67</sup> See Rich & Ziegler, supra note 50, at 12 ("[I]nsurers differentiate among individuals . . . [so that] each insured person's premium is rated according to the amount of his or her risk. Implementation

mentators on genetic discrimination in health insurance, Robert Rich and Julian Ziegler, gloss over the fact that although health insurance companies are allowed to "discriminate" in certain ways, they are not allowed a blanket ability to discriminate and cannot offer different rates based on racial classifications (regardless of any scientific or actuarial basis). Thus, at least some classifications, even if based on factual data, are impermissible.

However, insurance companies are, in fact, "discriminating" in some way, whether based on genetic tests or family history. As Chetan Gulati points out, "[n]arrow interpretations of 'genetic tests' and 'genetic information' are problematic because they prohibit insurers from price differentiating on the basis of more actuarially sound genetic tests, while allowing them to differentiate on the basis of more *indirect and inaccurate* methods." Some argue that if insurance companies are allowed to discriminate based on genetic tests, at least those bearing the weight of increased pricing will indeed be those with higher risks. This argument is persuasive, but slightly flawed in that many people without genetic markers will develop diseases that have a genetic component. This is particularly true for multifactorial genetic disorders, such as heart disease or cancer. Thus, many people who develop an illness will *not* have paid the higher medical insurance costs associated with the illness.

It is also important to note that other types of insurance companies (i.e., non-health insurance) also employ discounts and rate hikes based on probabilistic modeling. For example, automobile insurance companies of-

of this notion of actuarial fairness requires that insurers are allowed to create classifications that represent real differences between individuals."). As two other scholars point out:

[I]f individuals were willing or able to reveal their information, everybody could be made better off. By their very being, high-risk individuals cause an externality: the low risk individuals are worse off than they would be in the absence of the high risk individuals. However, the high-risk individuals are no better off than they would be in the absence of the low-risk individuals.

Michael Rothschild & Joseph Stiglitz, Equilibrium in Competitive Insurance Markets: An Essay on the Economics of Imperfect Information, 90 Q.J. ECON. 629, 629 (1976).

68 See, e.g., CAL. HEALTH & SAFETY CODE § 1365.5(b) (West 2006) (stating that a health insurance plan contract cannot be modified and that the "benefits or coverage of any contract shall not be subject to any limitations, exceptions, exclusions, reductions, copayments, coinsurance, deductibles, reservations, or premium, price, or charge differentials, or other modifications because of the race, color, national origin, ancestry, religion, sex, marital status, sexual orientation, or age of any contracting party").

<sup>69</sup> Gulati, *supra* note 65, at 177.

As this discussion suggests, there is nothing unique about genetic information that warrants special protection or legislation. Perhaps the greatest irony of genetic antidiscrimination laws is that they allow insurers to use *less* actuarially sound principles (such as gender and family history) to price differentiate and prohibit insurers from using principles that are *more* actuarially sound (genetic tests).

Id. at 173 (citing Roberta M. Berry, The Human Genome Project and the End of Insurance, 7 U. FLA. J.L. & PUB. POL'Y 205, 244 (1996)).

ten provide good student discounts but have high rates for young males.<sup>70</sup> Good student discounts are not based on an intrinsic characteristic, unless one considers intelligence—clearly part of being a good student—an intrinsic genetic characteristic. And rate hikes for young males are clearly based on probability rather than any intrinsic genetic characteristic shared by this group. Obviously, one major difference exists between these two risk factors and genetic risk factors: the former (e.g., young-male status) is temporary, whereas the latter is "permanent." Regardless of whether a genetic illness ever develops, the person will always be branded as predisposed to that illness. Other characteristics used in risk classification that are certainly not intrinsic include smoking, drinking and exercise. Differential rate structures based on these criteria seem "fairer" to many because those who choose to put themselves into higher-risk categories bear the expense that accompanies that risk.

One can argue that genetic testing might actually increase overall fairness by allowing those with a family history of genetically transmitted illnesses to demonstrate that they do not, in fact, possess the relevant "bad genes." Their health insurance rates might actually decrease. Thus, the burden will actually be borne by those with actual, and not estimated, risk.

## B. ADVERSE SELECTION: COULD IT LEAD TO MARKET FAILURE?

Risk classification allows health insurance companies to counterbalance the effects of a phenomenon called adverse selection. 71 When choosing which plan to buy, health insurance purchasers weigh the rates of different insurance plans against the value they expect to receive from their coverage. 72 Problems of asymmetry arise when the purchaser has access to critical information about his or her health status that the health insurance company does not.<sup>73</sup> This informational asymmetry could ultimately lead to increases in the price of health insurance or market breakdown due to adverse selection.<sup>74</sup> Individuals who know they are high-risk (for example, due to genetic abnormalities) are far more likely to purchase health insurance than they would have been without access to that information.<sup>75</sup> Over time, health insurance companies increase the cost of plan premium rates to

<sup>70</sup> See, e.g., Car-Insurance-Rates-Info.com, Car Insurance Rates Guide, http://car-insurance-ratesinfo.com/tag/car-insurance-rates-male-teenager/ (last visited Apr. 23, 2007).

<sup>&</sup>lt;sup>71</sup> Rich & Ziegler, supra note 47, at 12.

<sup>&</sup>lt;sup>72</sup> Id.

<sup>&</sup>lt;sup>73</sup> Id.

<sup>&</sup>lt;sup>74</sup> Id.

<sup>&</sup>lt;sup>75</sup> Id.

cover their losses stemming from the increase in claims.<sup>76</sup> When plan premiums rise to a sufficiently high level, individuals who know they are lowrisk would be far more likely to discontinue their insurance plans, causing even more increases in plan premium rates in order to allow the companies to keep the plans balanced.<sup>77</sup> This process of adverse selection due to asymmetric information "is not likely to occur if applicants disclose all relevant information to insurers. Thus, the possibility of adverse selection could be offset and premium rates could be stabilized through fair risk classification."<sup>78</sup>

Michael Rothschild and Joseph Stiglitz (the latter of whom won a Nobel Prize for, at least in part, the duo's co-authored 1976 paper)<sup>79</sup> argue that in the case of insurance, more information is a good thing.<sup>80</sup> According to their hypothesis, if less information is available, more cross-subsidization will occur across the market, leading to a possible market breakdown or, potentially, total market failure.<sup>81</sup> They assert that "[i]f only individuals would admit to their having high accident probabilities, all individuals would be made better off without anyone being worse off."<sup>82</sup> Nonetheless, they acknowledge that the information supplied has to be "perfect" for this situation to be true.<sup>83</sup>

Obtaining perfect information, however, is hard to do and may have adverse consequences. In analyzing competitive insurance markets, Michael Smart notes that "[w]hen differences in risk aversion are sufficiently large, firms cannot use policy deductibles to screen high-risk customers. Types [of risk] may be pooled in equilibrium or are separated by raising premiums above actuarially fair levels."<sup>84</sup> An inability to screen high-risk

<sup>&</sup>lt;sup>76</sup> Id.

<sup>&</sup>lt;sup>77</sup> Id.

<sup>78</sup> I.I

<sup>&</sup>lt;sup>79</sup> The Prize in Economics 2001, http://nobelprize.org/economics/laureates/2001/public.html (last visited Mar. 30, 2007).

<sup>&</sup>lt;sup>80</sup> See Rothschild & Stiglitz, supra note 67, at 629.

<sup>&</sup>lt;sup>81</sup> Id.

<sup>82</sup> Id. at 638.

<sup>83</sup> According to Rothschild and Stiglitz,

<sup>[</sup>o]ur pathological conclusions do not require that people have particularly good information about their accident probabilities. They will occur under a wide variety of circumstances, including the appealing case of unbiasedness. Neither insurance firms nor their customers have to be perfectly informed about the differences in risk properties that exist among individuals: What is required is that individuals with different risk properties differ in some characteristic that can be linked with the purchase of insurance and that, somehow, insurance firms discover this link.

Id. at 640.

<sup>84</sup> Michael Smart, Competitive Insurance Markets with Two Unobservables, 41 INT'L. ECON. REV. 153, 153 (2000).

customers can put a great strain on insurers, and risk-averse purchasers may further skew their numbers. According to Rich and Ziegler,

[i]n order to stay in business, insurers must be allowed to risk-classify, which means, that they must be allowed to discriminate or distinguish among individual health insurance applicants. Because the private health insurance system covers nearly seventy percent of the American public without discrimination through risk-classification, the cornerstone of health insurance in the United States [is] endangered.<sup>85</sup>

An inability by insurers to risk-classify would hurt both the healthy patient, who would be required to pay more for insurance, as well as the unhealthy patient, who no longer could afford or access insurance.

The severe ramifications discussed by Stiglitz and Rothschild become much more likely if patients have access to their genetic information, but insurance companies do not. In such a scenario, low-risk people would begin to view insurance as optional and would stop participating in the insurance pool. This would lead to a disruption in the market, as the pricing systems used by insurance companies would start to break down. Due to this adverse selection, insurers would begin to assume that only high-risk people remained in their pool and would price policies accordingly, effectively pricing most people out of the market.

#### IV. CURRENT LAWS RELATED TO GENETIC TESTING PRIVACY

To date, forty-seven states have enacted legislation relating to genetic testing privacy and the restriction of access to genetic information. 86 Additionally, one major federal bill has been enacted and another may soon be: the Health Insurance Portability and Accountability Act of 1996 (HIPAA)<sup>87</sup> is currently codified in the United States Code and the Genetic Information Nondiscrimination Act (GINA)<sup>88</sup> is, at the time of this writing, working its way through the House of Representatives. Although HIPAA and GINA (and the various state statutes) differ enormously in scope, they contain the same two principal regulatory instruments to protect against feared abuses

Council for Responsible Genetics, Genetics http://www.genelaw.info/pages/health.html (last visited Mar. 30, 2007).

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<sup>85</sup> Rich & Ziegler, supra note 50, at 12.

<sup>&</sup>lt;sup>87</sup> Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered statutes of 29 and 42 U.S.C.).

<sup>&</sup>lt;sup>88</sup> Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong. (2007); see also Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Cong. (2005); 151 CONG. REC. S1595-02 (daily ed. Feb. 17, 2005) (passing S. 306, 109th Cong. (2005), the companion bill to H.R. 1227, by a Yea-Nay vote of 98-0).

of genetic information: restrictions on disclosure and restrictions on use."<sup>89</sup> Disclosure restrictions prohibit the release of an individual's genetic information to a third party without that individual's prior informed consent. <sup>90</sup> Use restrictions forbid certain uses of genetic information. <sup>91</sup> These restrictions were enacted mainly in response to public perception about genetic determinism rather than to actual practice or science, as genetic discrimination has mostly been an academic idea thus far. <sup>92</sup>

Nonetheless, HIPAA prohibits insurers from excluding individuals from coverage due to their genetic predispositions. Moreover, under HIPAA regulations, the existence of "bad" genetic information must be coupled with a corresponding diagnosis of illness to be considered a preexisting condition; HIPAA thus prevents insurers from denying coverage to those who are predisposed to, but have yet to develop, an illness. On the other hand, HIPAA does not prohibit insurers from collecting genetic information, requiring applicants to undergo genetic testing, or charging a higher rate to individuals based on their genetic predispositions. Further, HIPAA does not forbid the disclosure of an individual's genetic information to insurers.

GINA, which would be the second major federal regulation of genetic information, differs markedly from HIPAA. It would prevent health insurance companies from using genetic information as a factor in determining eligibility. Further, GINA section 2753 would prohibit health insurance discrimination based on genetic information. 98

Finally, although forty-seven states have enacted laws regarding genetic privacy, state laws vary immensely as compared to the federal regulations and each other. Under California law, for example, health insurance

<sup>&</sup>lt;sup>89</sup> Diver & Cohen, *supra* note 9, at 1443-44.

<sup>90</sup> Id. at 1444. "These measures often include ancillary requirements concerning the handling, segregation, updating, or the destruction of genetic information, the counseling of research subjects prior to genetic testing, methods for securing substituted consent for persons unable to give informed consent, and the like." Id.

<sup>91</sup> Id. By far the most common form of use restriction is a prohibition on so-called "genetic discrimination." The antidiscrimination norm seeks to prevent persons from using information about a subject's genetic profile as a basis for withholding certain privileges or benefits or granting such benefits only on conditions less favorable than would otherwise be imposed. See id.

<sup>92</sup> Rich & Ziegler, supra note 50, at 8.

<sup>93</sup> National Human Genome Research Institute, Genetic Discrimination in Health Insurance, http://www.genome.gov/10002328 (last visited Mar. 30, 2007).

<sup>&</sup>lt;sup>94</sup> Id.

<sup>&</sup>lt;sup>95</sup> Id.

<sup>&</sup>lt;sup>96</sup> Id.

<sup>97</sup> Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong. (2007).

<sup>&</sup>lt;sup>98</sup> Id.

companies cannot refuse to enroll applicants or renew already insured individuals based on their genetic characteristics and cannot request an individual's genetic information for any nontherapeutic purpose. Georgia goes one step further, requiring prior written consent before genetic testing occurs and mandating that genetic testing only be conducted for therapeutic or diagnostic purposes. Many states, including Iowa, Kansas and Idaho, prohibit health insurance companies from using genetic information as a pre-existing condition to determine eligibility. While such state legislation was enacted in order to protect the insured, the effect has been a rise in insurance costs and more uninsured individuals. Accordingly, states with more legislation have a larger number of uninsured individuals due to the increased cost attributed to those regulations.

A few courts have addressed the issues of genetic testing and access to healthcare. Notably, in *Katskee v. Blue Cross/Blue Shield* the Supreme Court of Nebraska held that a woman's genetic condition predisposing her to ovarian cancer—despite the fact that she had no symptoms and her condition was undetectable by physical examination—constituted an "illness" under her policy, and her insurer must cover "prophylactic" surgery. This decision seems contrary to the general protection of genetic information and, at the very least, unfair to insurance companies. On the one hand, the federal government and numerous states want to prevent insurance companies from using genetic information to price or provide healthcare; on the other, genetic information is being considered an "illness" and insurance companies are being forced to cover preventative care. This runs counter to what seems to be a more logical approach: if insurance companies are required to cover treatments, they should be able to price their policies accordingly. Instead, by forcing companies to cover treatments

<sup>&</sup>lt;sup>99</sup> CAL. HEALTH & SAFETY CODE §§ 1374.7(a), (b) (West 2006).

<sup>100</sup> GA. CODE ANN. §§ 33-54-3, -4 (2005).

 $<sup>^{101}</sup>$  See, e.g., Idaho Code Ann. \$ 41-3940 (2003); Iowa Code Ann. \$ 513B.10(3)(a) (West 1998); Kan. Stat. Ann. \$ 40-2209 (2000).

<sup>&</sup>lt;sup>102</sup> Gulati, *supra* note 65, at 159.

<sup>103</sup> Melinda L. Schriver & Grace-Marie Arnett, *Uninsured Rates Rise Dramatically in States with Strictest Health Insurance Regulations*, HERITAGE FOUND. BACKGROUNDER, Aug. 14, 1998, at 10.

<sup>104</sup> Katskee v. Blue Cross/Blue Shield, 515 N.W.2d 645, 653 (Neb. 1994). The court addressed the following definition of "disease":

A disease, condition, or illness exists within the meaning of a health insurance policy excluding preexisting conditions only at such time as the disease, condition, or illness is manifest or active or when there is a distinct symptom or condition from which one learned in medicine can with reasonable accuracy diagnose the disease.

*Id.* (quoting Fuglsang v. Blue Cross, 456 N.W.2d 281 (Neb. 1990)). The court noted that "[t]his statement concerns *when* an illness exists, not whether the condition itself is an illness. If the condition is not a disease or illness, it would be unnecessary to apply the above rule to determine whether the condition was a preexisting illness." *Id.* 

without pricing them, insurance companies will be forced to increase their general rates, thereby pricing many people out of the market and possibly causing the market to collapse altogether.<sup>105</sup>

# V. ARGUMENTS FOR AND AGAINST THE USE OF GENETIC INFORMATION IN ACCESS TO HEALTHCARE

Many ethical and moral issues arise in the area of genetic testing and over who should have access to an individual's genetic information. For instance, if health insurance companies have access to genetic information, why not grant access to spouses or employers? These issues are particularly important in the context of testing for incurable diseases, as there is questionable utility in such information. In this area, there is a particularly high disparity between what we know and what we can do for the affected individual. Accordingly, the utility of diagnosing incurable illnesses is limited to advancing the individual's personal knowledge, using the information to price health care, and contributing to scientific research. It seems unfair to test individuals who have no desire to know their own status simply for the purpose of pricing health care—especially when one considers that the benefit to scientific research is unclear due to the voluntary nature of genetic testing (i.e. individuals cannot be compelled to participate in medical research).

In addition to testing for incurable illnesses, another controversial area is genetic screening prior to or during pregnancy. This use of genetic testing fuels the widespread fear of eugenics, as test results could influence the parents' choice to abort a pregnancy or forego pregnancy altogether. And if insurance companies' access to genetic information adversely affects the cost of health insurance, the increased price might further impact decisions regarding pregnancy. Clearly, incentives or disincentives that impact one's ability to procreate could have a substantial and persistent effect on society.

## A. EFFECTS ON LOW-INCOME PEOPLE WITH PREDISPOSITIONS TO GENETIC ILLNESSES

Generally, individuals most harmed by having "bad" genetic information are also least helped by having access to their genetic information, as they cannot afford preventative or palliative treatment. Before exploring this issue in depth, it is important to note that many (if not most) low-income individuals have already been "priced" out of the health insurance

<sup>105</sup> Rothschild & Stiglitz, supra note 67, at 629.

market due to the rising costs of healthcare. Thus, differential pricing based on genetic testing is more likely to affect middle- and upper-class individuals. However, one can examine the potential impact on those low-income individuals who have not yet been priced out of the system, both to better understand how it will affect this group and to determine how it might affect future low-income individuals in a position to obtain health insurance.

In the short-term, genetic testing is likely to have a negative impact on low-income individuals because insurers would price individuals at risk of developing genetic disorders out of the healthcare system; however, potentially positive long-term effects exist. For some illnesses, inexpensive preventative treatments may become available, causing insurance companies to shift their coverage to include those illnesses that can be prevented. There is currently little coverage of such preventative treatments because insurance companies do not want to "waste" money on treating healthy individuals. But if insurance companies could accurately pinpoint the individuals who would benefit from these treatments, covering these preventative treatments could be cost-effective: the insurers would avoid more expensive palliative treatments down the line. If this were to occur, not only would poor people get treatments for their illnesses, but insurance eligibility issues might become moot (as preventive treatments are almost certain to cost insurance companies less in the long term than palliative treatments). Unfortunately, even if this change does occur, it will almost certainly apply only to specific illnesses and not across the board.

## B. WHAT LEVEL OF SCRUTINY DOES GENETIC INFORMATION DESERVE?

Undoubtedly, genetic discrimination is a highly controversial issue in modern American society. Accordingly, it is useful to consider what type of Constitutional scrutiny is appropriate in cases with purported genetic discrimination. One view, championed by Colin Diver and Jane Maslow Cohen, is that genetic discrimination does not deserve the same level of scrutiny as other types of discrimination such as racial and gender discrimination. Diver and Cohen claim that people with genetic predispositions are not a "discrete and insular minority," as defined in the oft-cited fourth footnote of *United States v. Carolene Products*, because race and

<sup>106</sup> ROBERT J. MILLS, U.S. CENSUS BUREAU, U.S. DEP'T OF COMMERCE, HEALTH INSURANCE COVERAGE: 2001 (2002), available at http://www.census.gov/prod/2002pubs/p60-220.pdf.

<sup>&</sup>lt;sup>107</sup> Diver & Cohen, supra note 9, at 1480.

gender are "conventionally understood, and employed, as discontinuous social constructs." Further, Diver and Cohen state:

[W]hether viewed as a biological reality or a social construct, the possession of an allele associated with the expression of a particular disease does not, by itself, define the person as belonging to a discrete category. Rather, it associates the person with a heightened probability, on a scale that varies continuously from zero to one, of contracting that particular disease. Risk of contracting a particular disease is, in turn, only one aspect of a multidimensional health profile. [109]

According to Diver and Cohen, genetic predispositions are merely probabilistic and do not "define the person as belonging to a discrete category." Therefore, this view assumes that every individual fits into some genetic classification: "Who, then, is the object of protection in a regime that outlaws genetic discrimination? Anyone with a genetic predisposition for a disabling or life-threatening disease? That description encompasses the entire human race." <sup>111</sup>

However, Diver and Cohen admit that genetic diseases (and diseases in general) might "elicit fear and ostracism." Accordingly, they point to the AIDS epidemic as the most significant current example of an illness that prompts such an emotional public reaction. Nonetheless, Diver and Cohen assert that any prejudice experienced by HIV positive individuals is unrelated to the disease's biology and instead "derives from an incendiary combination of widespread phobias relating to sex, homosexuality, licentiousness, and illicit drug use, coupled with, at least in the early years of the AIDS epidemic, exaggerated fears of communicability and, unfortunately, more accurate perceptions of incurability."

<sup>108</sup> Id. (citing United States v. Carolene Prods. Co., 304 U.S. 144, 152 n.4 (1938)).

<sup>109</sup> Id. at 1481.

<sup>&</sup>lt;sup>110</sup> Id.

<sup>&</sup>lt;sup>111</sup> Id.

<sup>112</sup> Id. at 1478.

 $<sup>^{113}</sup>$  See id.

<sup>114</sup> Id. Diver and Cohen further note:

By no means can one say that all genetic conditions, or even all diseases of genetic origin, generate social stigma remotely comparable to that visited on carriers of the AIDS virus. The most common genetically influenced diseases, such as heart disease or cancer, elicit reactions of sympathy and solicitude far more than fear and aversion. Indeed, the labeling of a condition as a "disease" often reduces the stigma attached to a condition or pattern of behavior. Consider the characterization of alcoholism as a disease, the relabeling of "senility" as Alzheimer's disease, or the emerging consensus that obesity has a strong genetic component. While surely there are genetic conditions that do produce the reactions one might fairly describe as "stigmatization," one can hardly justify a blanket prohibition on genetic discrimination on that ground.

While many of the arguments put forth by Diver and Cohen have merit, several of their presumptions are debatable. Certainly, the argument that individuals with genetic predispositions are not a discrete and insular minority makes sense for illnesses where a genetic predisposition gives an individual only a ten percent higher likelihood than a "normal" person of contracting that condition. In the case of such unlikely genetic predispositions, the affected group of individuals is not readily distinguishable from the general populace. However, the impending widespread availability of genetic tests may lead to the creation of a new discrete and insular minority, particularly for incurable illnesses and diseases that can be predicted with a high degree of certainty. That is, while individuals who are slightly more likely than the general populace to develop, for example, breast cancer, are not likely to become a "discrete and insular minority," those who are one hundred percent certain to develop Parkinson's disease might fit into that classification. The Parkinson-affected individuals could potentially constitute a discrete group that is excluded from the healthcare system.

Moreover, simply because a discrete and insular minority of genetically predisposed individuals has not existed historically, this does not preclude the development of such a group. Clearly, Diver and Cohen are not suggesting that racial and gender discrimination have not evolved over time or that new minorities are unlikely to develop in the future. Even though certain groups have not been discriminated against historically, they might be at some point. This includes groups sharing a genetic predisposition and is supported by Thomas H. Murray's assertion:

[T]he concern does not stop at the family's door but extends to those larger groupings of people who share a genetic heritage. . . . A focus on genetics emphasizes racial and ethnic differences . . . . Stressing the genetics of race has the potential to intensify those divisions, while reinforcing the view that perceived differences are not mere accidents of culture and circumstance but are grounded in biology, which is itself seen as somehow fundamental and unalterable. 115

In addition, the notion that genetic abnormalities "encompass" the entire human race is no more compelling than saying that race and gender also encompass the entire human race, which they both certainly do.

Diver and Cohen's purpose in rejecting individuals with genetic predispositions from the discrete and insular category seems clear—to avoid a

<sup>115</sup> Thomas H. Murray, Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60, 63 (Mark A. Rothstein, ed., 1997).

collapse of the healthcare system due to asymmetric information. While this is certainly an important, even critical, concern, their arguments as to why genetic minorities are not discrete and insular still fall flat.

In enacting GINA, Congress addressed an issue related to the one addressed by Diver and Cohen but came to the opposite conclusion. Congress fears, as many Americans do, that genetic discrimination could be used as a proxy for racial discrimination. The 109th Congress enacting GINA addressed this concern accordingly:

Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans.<sup>117</sup>

Congress enacted GINA, at least in part, to address the popular fear that a new form of "genetic" eugenics will develop.

# VI. HOW CAN WE GUARD AGAINST GENETIC DISCRIMINATION WITHIN THE HEALTHCARE SYSTEM?

The impending widespread availability of genetic testing has raised various moral and ethical issues, creating extensive debate about what the "right" thing to do is. The prevalent fears of eugenics and discrimination often create "knee-jerk" responses that have little, if anything, to do with legal or scientific reality. Nonetheless, these fears are legitimate, and we must be careful not to exacerbate the potential problems by creating laws that may create chaos in our already beleaguered healthcare system. According to one prominent scholar:

So stated, the question of genetic discrimination is a blend between the old and the new. The technology creates new situations to which principled answers must be provided. Yet, as is so often the case, the ultimate questions of value and choice depend less on the dramatic innovations in technology and more on the familiar inquiries into the relationship of individual to individual, and of the state to its citizens. Novelty in circumstance does not always require novelty in solution. Genetic discrimina-

<sup>116</sup> See generally Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005).

tion provides an ideal laboratory experiment in which old principles, rightly conceived, supply the best answers to modern problems. 118

Attempting to find novel solutions is unnecessary and only serves to muddy the waters, further complicating an already complex situation. What is needed is less regulation or perhaps a newer, more cohesive healthcare system.

Problems faced by people with genetic abnormalities are very serious under the current healthcare regime in the United States; however, the real problem might not be genetic testing or the potential for genetic discrimination, but rather the lack of a universal healthcare system. Universal healthcare, various forms of which have been enacted in numerous other countries, <sup>119</sup> would provide basic healthcare services to all American citizens. Further, it would spread the costs of healthcare through taxes and would not affect individual insureds by increasing their insurance premiums. Health insurance, or any other type of insurance for that matter, is a costspreading mechanism intended to promote "fairness" by providing health coverage and emergency services for those otherwise unable to afford them. The current healthcare system heavily favors the middle- and upperclass, as well as those employed full time because employers, who generally provide coverage only for full-time workers, subsidize the system. 120 Universal healthcare would solve many of the problems faced by the poor, under-employed or unemployed, in addition to the problems faced by those with genetic disorders. Universal healthcare would make it difficult, if not impossible, to discriminate against those with genetic illnesses or predispositions because everyone would be covered regardless of their health profile.

<sup>&</sup>lt;sup>118</sup> Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 4 (1994).

 $<sup>^{119}</sup>$  See European Observatory on Health Care Sys., Health Care Systems in Eight Countries: Trends and Challenges (2000).

<sup>&</sup>lt;sup>120</sup> See Rich & Ziegler, supra note 50, at 10-11.

Usually health insurance is obtained as an employment benefit. In 2002, roughly 85% of the privately insured American population (175,296,000 of 198,973,000 people) received health insurance coverage through employment in policies written for large groups. This means that most medical insurance coverage is provided on a group basis and financed jointly (in some "shared arrangement") by employers and employees. The insurance industry classifies the risk of such groups based on a group's size, on its past claims experience or on data of the claims experience of similar groups in the same industry or region. The group's premium rates are also set according to these factors. Since the risk incurred in employment-based health insurance plans is spread among the whole group, premium rates can be maintained at a relatively low price level. Furthermore, employer sponsored group health plans are usually subsidized by the employer.

Another possible solution to the problems posed by the availability of genetic information is an "efficiency model"; it would allow health insurance companies to maximize wealth by setting up the most economically efficient system, as suggested by Stiglitz and Rothschild, and then allocate funds for those in need. This model requires that insurance companies have access to as much information as possible in order to accurately structure their rates. In this model, the law could play a role in ensuring equality by mandating guidelines for insurance companies, subsidizing their coverage of high-risk individuals, or setting up a separate tax-funded healthcare system for those deemed "uninsurable." If this were done, there would be no need for anti-discrimination laws with regard to genetic information, at least in the health care industry.

## **CONCLUSION**

In recent years the topic of genetic testing and access to healthcare has received a great deal of attention. Genetic testing and genetic privacy have both been the subject of national debate, leading to the enactment of numerous state and federal statutes. This new legislation attempts to preemptively prevent discrimination based on an individual's genetic information.

While the goals of these new laws are noble, the laws may do more harm than good, potentially leading to a breakdown in the current health insurance paradigm. This prospective breakdown would result from the problems surrounding the asymmetry in access to an individual's genetic information. In order to ensure optimal healthcare for everyone—those with genetic abnormalities and those without such abnormalities—a better solution would be instituting a universal healthcare system or adopting an efficiency model of healthcare.