

# Genetic Screening and Disability Insurance: What Can We Learn From The Health Insurance Experience?

*Nancy Kass and Amy Medley*

The Human Genome Project has allowed researchers to gain new insights into the genetic causes of health and disease. With this knowledge comes the potential to develop new genetic tests that are capable of predicting the risk of disease or disability among presently healthy individuals. This information is potentially beneficial in that it may allow individuals to develop strategies to reduce their risk of illness and may allow health providers to recognize and treat the early stages of disease more effectively. As knowledge about genetic contributions to disease continues to grow and genetic testing technology becomes more widespread, there is a risk that personal genetic information could be used in ways potentially concerning to consumers. Genetic testing technology could potentially be used to discriminate against individuals in terms of their ability to obtain health, life, and disability insurance. Decreased access to insurance, in turn, significantly hinders access to health care and income for oneself and/or for one's dependent(s).

Such concerns highlight the ambiguous role of insurance companies in the United States. Individuals, particularly sick ones, desperately need access to insurance or the ability to maintain their private insurance. At the same time, however, insurers are private businesses with, under current arrangements, a responsibility to generate profits for their stock-

holders. Insurers have argued that it is no more their responsibility to assure access to care than it is the responsibility of any other private business.<sup>1</sup> This philosophy has led insurance companies to employ risk-rating strategies whereby individuals at high risk of disease or disability are charged higher premiums or denied coverage altogether. This trend, along with the rapid growth in the cost of health care for employers, creates a situation where insurance companies are under increased pressure to cut costs. One mechanism is to refine their screening procedures to weed out individuals who may generate high costs in terms of pay-outs. Specifically, it is possible that insurers may begin adding genetic testing and screening to existing risk-rating procedures. Whether or to what extent these procedures should be used by insurers is a matter of public policy. This paper discusses genetic testing and screening and health insurance to consider what lessons might be learned for the disability insurance context. Ultimately, this paper provides policy options and suggests that responses focusing narrowly on the use of new genetic technologies may seem strategic, but cannot be justified as fair.

## History of the Insurance Industry<sup>2</sup>

The first private health insurance plan in this country was established in 1929 to cover hospital expenses for 1,250 Texas schoolteachers. By the mid 1940s, such "Blue Cross" hospital plans existed in 43 states.<sup>3</sup> The first plans designed to reimburse for physician services were instituted in 1939, and by the 1950s had come to be known as "Blue Shield." From their inception until 1986, the "Blues" were nonprofit and tax-exempt enterprises. Initially, their premiums were based on "community rating" whereby all subscribers in a given geographic area were charged the same rates. Under

---

*Nancy Kass, Sc.D., is the Phoebe R. Berman Professor of Bioethics and Public Health, Department of Health and Policy Management, at Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins University Berman Institute of Bioethics. Amy Medley is a doctoral candidate in the Department of International Health at the Johns Hopkins Bloomberg School of Public Health.*

community rating, the only qualifying principle for health coverage was community membership.<sup>4</sup> An individual's health status or pre-existing risks were not considered part of eligibility.<sup>5</sup> Thus, insurance premiums from healthy persons subsidized the health care costs for the sick.

Commercial insurance companies emerged in the 1940s.<sup>6</sup> To compete for employer contracts, they offered premiums based on the new concept of "experience rating": Employers were charged based on the actual claims experiences of their own employees. Since employed persons tended to be healthier than the general population, experience-rated premiums were lower than community-rated ones. By the 1950s commercial insurance companies surpassed the "Blues" in the proportion of covered Americans. Non-profit companies, therefore, in order to compete and remain viable, had little choice but to alter their own rating practices, establishing a system in which those who were sicker, unemployed, or not part of a group were charged higher rates than lower-risk individuals, employees, or individuals who applied as a group. People with pre-existing conditions or with known higher risks were charged higher premiums or denied coverage altogether. Thus, insurance coverage has evolved from primarily a community-rated "system for all" to one that selects which persons will be covered based on knowledge about their health status.

### Insurance Coverage Today

In accordance with the onset of risk classification in the 1940s, unfair trade practices acts exist in each of the 50 states and the District of Columbia. These acts prohibit unfair discrimination "between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees, or rates charged for any policy or contract of health insurance."<sup>7</sup>

More germane to the genetic testing issue, unfair trade practices acts have been interpreted to justify treating individuals at *different* risk disparately. It is the insurance industry's perspective that an insurance company "has the responsibility to treat all its policy holders fairly by establishing premiums at a level consistent with the risk represented by each individual policy holder."<sup>8</sup> Such is the concept of insurance "equity": Premiums must correspond fairly to the differences in risk posed by individual policy holders.

Whereas applicants for group health insurance typically are not screened to determine their individual risks, individuals and small groups generally are. To obtain health insurance, individual applicants must complete a health history questionnaire. Depending on the company, sometimes responses to the initial insurance application precipitate a request by the insur-

ance company for the applicant's medical record or a statement from their physician. Applicants are then classified as standard, substandard, or denied. In the individual market today, 71 percent of applicants are rated standard, 20 percent are rated substandard, and 12 percent are denied coverage.<sup>9</sup> Those rated as substandard are offered a policy that comes with an exclusion waiver, a higher premium, or both. Currently, an estimated 86 percent of the American public has some form of health insurance.<sup>10</sup> Of these, 65 percent are covered in employment-based insurance programs, 14 percent have some type of public coverage, and seven percent have individually purchased coverage.<sup>11</sup>

A recent study by the Kaiser Family Foundation found that individual applicants who have at least one pre-existing condition often have a difficult time obtaining health insurance and are charged higher premiums than those in perfect health.<sup>12</sup> In the Kaiser study, seven hypothetical consumers who had a variety of health problems ranging from hay fever to HIV infection were presented to insurance companies. Insurers were then asked to underwrite each prototype for a policy. A total of 19 insurance companies from eight different states participated. The study found that 90 percent of the time, the hypothetical consumers were unable to obtain a standard rate for the coverage for which they had applied.<sup>13</sup> Furthermore, most who were accepted for coverage had benefit restrictions (28 percent), premium surcharges (13 percent), or both (12 percent).<sup>14</sup> Certain people, such as the applicant with HIV infection, were rejected by all companies. The one clear finding from the study was that those individuals with the most severe health problems were the least likely to be offered health insurance coverage.

A relevant trend in the health insurance industry in recent years is for employers to self-insure. A company who self-insures does not pay premiums to private insurance companies but instead accepts the risk itself. Employees file claims directly with their employer and are reimbursed out of the company's reserves. In many instances, insurance companies sell employers "stop-loss" coverage – essentially a catastrophic policy that protects employers from unexpectedly high individual or annual claims.<sup>15</sup> Many employers also contract with organizations that administer and process their claims.<sup>16</sup>

Employers have an incentive to self-insure both because of the savings achieved by avoiding state insurance regulations mandating that certain conditions be covered and because they are able to select whether and to what extent particular health services will be covered.<sup>17</sup> Cost savings also are achieved because self-insured plans are not subject to insurance premium

taxes that help subsidize state sponsored high-risk insurance pools.<sup>18</sup> Indeed, the Employee Retirement Insurance Security Act (ERISA) prohibits states from regulating self-funded employer insurance plans.<sup>19</sup> Thus, self-funded plans need not offer the minimum benefits mandated by a given state. Wisconsin, for example, became the first state to regulate the use of genetic tests by insurance companies in April 1992. Employers who self-insure are exempt from such regulation.<sup>20</sup> Thus, even if legislation were passed that forbade the use of genetic information in risk-rating, self-insured plans would be exempt. Currently, an estimated 49 percent of employees are in partly or completely self-insured plans.<sup>21</sup> The proportion of employees in self-funded plans increases as the size of the company increases.<sup>22</sup> For example, 70 percent of employees in firms with greater than five thousand employees are in self-funded plans, as compared to 15 percent of employees in firms with three to 199 employees.<sup>23</sup>

### **Genetic Testing and Its Potential Effect on Health Insurance**

#### *How Do Insurance Companies Obtain Information on Genetic Testing?*

Insurers could learn about an individual's genetic risks in several ways. The first requires applicants to undergo genetic testing. Currently, there is no evidence that insurance companies require genetic tests for underwriting.<sup>24</sup> This may be due to the uncertain predictive value of most tests, high costs, and the lack of genetic counseling facilities.<sup>25</sup> However, as genetic testing technology continues to improve and costs continue to decrease, there is reason to believe that in the future insurance companies may require individuals to undergo genetic testing as part of the risk-rating process.

While insurers may not require genetic testing currently, they do make decisions based on genetic information by routinely asking about family history. In addition, as described previously, companies ask applicants detailed questions about their own personal medical history and may ask for a release of an individual's medical record. While the company may have requested the record for reasons unrelated to genetic risks, the entire record typically is provided by physicians. The record may then reveal other family risks, past use of genetic tests, or discussions between providers and patients about whether to undergo genetic testing.

Information about an applicant's genetic risks may also be learned by an insurance company through the Medical Information Bureau (MIB). The MIB is a nonprofit cooperative agency formed by member

insurance companies to combat fraud. Made up of a large database of insurance applicants identified by name, birth date, and state, the MIB allows insurance companies to share information about potential applicants, including any medical impairments or previous insurance claims.<sup>26</sup> It is governed by a strict code of regulations and may be used only to underwrite new applications. Member companies can access an applicant's personal information only with the consent of the applicant, and insurers can only use the information to confirm that they have reviewed the same medical history of the applicant as was provided to their competitors.<sup>27</sup> The information cannot be used alone to rate or deny insurance to the applicant. Instead, it is meant to be a guide for further investigation.<sup>28</sup> However, if insurance companies learn through the MIB that an applicant has undergone genetic testing in the past, they could require applicants to release the results of those tests before making a decision about coverage and/or rates.

Insured persons run significant risks if they try to conceal information from companies. If an insured person files a claim for a condition within two years of submitting the insurance application, and insurers can prove that the individual had information related to the condition (e.g., a recently taken related genetic test) that was concealed from the company, the insurer can not only deny the claim but could potentially cancel the policy altogether.

#### *Why Should We Care about Genetic Screening in Health Insurance?*

Due to the high costs of health care in the United States, a lack of health insurance effectively limits an individual's access to health care in the same way that a lack of disability insurance effectively limits an individual's ability to sustain a meaningful income if severely disabled.<sup>29</sup> As genetic tests continue to improve and become better able to predict an individual's risk for disease, more individuals identified as "at risk" for certain diseases may see their insurance premiums rise or be denied health insurance altogether. Thus, the barriers to access to health care are likely to grow, especially for those most in need of care.

A normalization of genetic testing for insurance is of concern for other reasons as well. Individuals who might be interested in genetic testing due to a family history of a certain disease (e.g., breast cancer or Huntington's disease) may avoid being tested for fear that a positive result – or even just *seeking* the test – might have negative implications for insurance access. Insurance discrimination has been documented against currently healthy people who have a genetic predisposition for an illness.<sup>30</sup> A recent survey conducted

among individuals with a known genetic condition in their family found that 22 percent had been refused health insurance coverage because of their genetic status, regardless of their current health status.<sup>31</sup> In addition, individuals may have a disincentive to join new research on the genetic causes of disease for fear that the data collected may be used against them when applying for insurance coverage. Clearly, the societal and public health consequences of research avoidance could be substantial.<sup>32</sup>

Employers providing health insurance benefits to their employees may have an incentive to use genetic screening to eliminate job applicants, current employees, or coverage of certain diseases that could potentially increase the costs of employer-funded insurance programs.<sup>33</sup> Employers may also be reluctant to hire or promote individuals with known risks or employees with dependents with known risks.<sup>34</sup> Additionally, employees often avoid changing jobs for fear that they might lose needed benefits, especially health insurance.<sup>35</sup> In a recent national survey, three in ten people reported that a member of their household had experienced this type of “job lock.”<sup>36</sup>

Genetic screening also has implications for government programs. When private insurers or employers exclude or make coverage unaffordable for individuals with genetic risk factors, public programs often end up providing coverage.<sup>37</sup> Therefore, already cash-strapped states may find themselves with exploding health and/or welfare costs due to the increasing number of people being excluded from the private insurance system.

#### *Is Genetic Screening Different from Other Types of Screening?*

Public policies regarding insurance screening have focused more on genetic screening narrowly than they have on the appropriateness of risk screening more broadly. All but six states have now passed legislation prohibiting insurance companies from using genetic information for risk selection or risk classification purposes.<sup>38</sup> In addition, 26 states now prevent insurance companies from requiring applicants to obtain genetic tests as part of the underwriting process.<sup>39</sup> At the federal level, Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996. This Act specifically prohibits a group health insurance plan from using “genetic information” to establish rules for eligibility or continued eligibility.<sup>40</sup> It also prevents insurance companies from treating genetic information as a “preexisting condition in the absence of the diagnosis of the condition related to such information.”<sup>41</sup> This legislation has been passed in large part because of the growing belief that individuals shouldn’t be discriminated against based on

genetic tests. Similar advocacy has been less success related to discrimination based on other health risks or conditions, such as exclusions for risk of cancer or heart disease. Indeed, only a few states have passed “guaranteed issue” laws for health insurers that sell individual health plans. Guaranteed issue laws require insurers to accept an individual’s application for coverage regardless of his or her medical history or pre-existing conditions.<sup>42</sup> In some of these states, the legislation also requires rating bands, establishing that a maximum relative price (e.g., no more than three times the cost of a standard premium for an applicant of the same age and sex) can be charged. Thus, while several states have passed legislation to regulate genetic screening, few have attempted to regulate risk screening more broadly.

Creating legislation that focuses only on genetic risks, rather than risk screening *writ large*, is clearly strategic. There may be more sympathy among legislators and the public alike for genetic risks that are assumed to be “no one’s fault.” Further, it is always easier to introduce legislation that is piecemeal and targeted rather than legislation that fundamentally changes the way business has been done for half a century. A strategic approach, however, does not eliminate the moral question of whether this approach is right. To suggest that persons with genetic risks were owed societal protection for health care and income security while persons with other risks were not, would signify that genetic risks are different in morally relevant ways.

Arguments have been put forward to suggest that genetics *is* different.<sup>43</sup> Genetic diseases are the result of risks with which we are born; they are intrinsic and, at least theoretically, are not the result of one’s own behavior. People may choose to smoke or to drive without seatbelts, but people do not choose their genes. Such arguments suggest, of course, that disease causality, even for diseases with clear genetic components, is *simply* the result of genetics. Indeed, such diseases (examples would be Huntington’s or Tay-Sachs) seem to be the exception rather than the rule. It is not clear why some people who carry “susceptibility” genes get sick and others do not or, conversely, why some people who smoke get lung cancer and others do not. Very likely, most diseases are the result of varying interactions of genetics, environment, and behavior in ways we have yet to fully understand.<sup>44</sup> Even if one believed that genetic predisposition was itself a morally relevant characteristic for risk-screening purposes, the practical distinctions between conditions that have genetic roots and those that do not are nearly impossible to draw. We are in the midst of an explosion of scientific discoveries identifying genetic associations with

hundreds of chronic and even infectious conditions. To argue that we know which conditions are “genetic” and which are not clearly will be an empirically flawed distinction, even if the distinction could be defended on moral grounds.

From a practical perspective, others have argued for genetic “exceptionalism” in the insurance context because genetic risks can be detected from birth, whereas other risks may appear later in life.<sup>45</sup> Children, theoretically, could be denied insurance at early ages, during decades of good health. While this argument has intellectual appeal, insurance underwriting can be both informed and sophisticated. Insurers can calculate whether a child’s risk is for a disease of childhood, early adulthood, or late adult-onset and make coverage decisions accordingly. Children rarely maintain a policy from childhood through adulthood, and it is unlikely that an insurance company would deny a *child* coverage who, for example, had a gene increasing his or her risk for Alzheimer’s disease. Such exclusions for young adults, however, are more plausible. Finally, genetic exceptionalism in insurance has been supported by those who say that genetic discrimination in insurance may amount to systematic insurance denial for members of identifiable racial or ethnic groups (since certain conditions co-travel with race or ethnicity).

Genetic exceptionalism, however, is logically flawed.<sup>46</sup> As described above, even diseases assumed to be the result of environmental factors, such as cancer or heart disease, seem increasingly to involve complex interactions of genetics and behavior. Furthermore, arguments based on fairness cannot support policies that protect health care or income access for those with genetic risks but not for those with health problems of less clear etiology. A child with leukemia is no less deserving of health care than is a child with cystic fibrosis.

### **Policy Options for Addressing Genetic Testing and Screening in Insurance**

Genetic testing and screening by insurance companies have the potential to decrease access to health insurance and health care, and, for disability insurance, to limit access to responsible protection of income for oneself and one’s dependents. These concerns have prompted a variety of policy proposals for limiting the potential harmful effects of companies using genetic testing and screening in underwriting.

#### *Eliminate Genetic Screening but Maintain Other Types of Screening*

One option that would respond to concerns about insurers using genetic tests would be to leave the struc-

ture and practices of the current system intact, but to pass state-by-state legislation prohibiting insurance companies from using genetic testing and screening for insurance underwriting. This approach has been taken by several states resulting in legislation for genetic protections in certain states.<sup>47</sup> Indeed, genetic testing seems to be an area where insurers have shown some willingness to compromise. For example, insurance company spokespersons have suggested that while insurers must be able to perform HIV antibody tests, perhaps they could avoid conducting genetic screening.<sup>48</sup> Judging by the widespread legislation already passed by states to prevent insurance companies from using the results of genetic tests in their risk calculations, there seems to be widespread public support for this option.<sup>49</sup> However, such approaches are not themselves comprehensive in providing protection against genetic discrimination since self-insured employers are generally exempt from such legislation. In addition, while such approaches have been used as protections, to some degree in the health insurance context, they have not been extended to disability coverage.

#### *Eliminate Risk Screening Entirely*

Another option to address the issue of genetic screening would be to eliminate risk screening entirely. Under this option, insurance companies would be prevented from using any type of pre-existing risks, conditions, or medical history in eligibility or rate setting. Proponents of this option argue that it is morally unfair to charge sick or disabled persons or potentially disabled persons higher premiums or to deny them coverage altogether. They argue that a system that deliberately capitalizes on people’s misfortune is unjust.<sup>50</sup> They also point to inconsistencies in public policy allowing people with disabilities to be charged more for health or disability insurance, whereas other social institutions are available to all citizens equally, regardless of their needs.<sup>51</sup> Services such as national defense, fire protection, and education are financed equally by all citizens, regardless of who benefits. Society does not ask parents of a mentally retarded child to pay higher education taxes or individuals who have been the victims of crime to pay more for police protection. Nonetheless, it is standard policy to have the sick (or those who are at the most risk of becoming sick) pay considerably more for health protection than those who are healthy, if they are not excluded from the system altogether. To make the health care system more just, it is argued, risk screening must be eliminated altogether. The proposed mechanism to meet this goal is, thus, the return to a community-rated system.

Under a community-rating system, all subscribers in a given geographic area would be charged the same

rates for health insurance. Within such a system there would be no place for genetic testing because applicants would not be rated according to their individual health risks or conditions. Instead, the costs of health insurance would be spread throughout the community so that healthy individuals subsidize the costs for those who are ill. Options such as this one, while supported by many scholars, generally have been considered politically impractical and unlikely to be put forward in the near future either for health or for disability insurance.

#### *Overhaul of the Entire Health System*

Others argue that the current system of providing health care using a mixture of private and public programs has failed so completely that it is time to overhaul the entire health system. They point to the fact that an estimated 41 million people – mostly the poor, members of minority groups, young adults, children, and part-time workers – do not have health insurance coverage.<sup>52</sup> In addition, health costs have continued to soar in the past few years, and the United States now spends \$4,499 per capita on health care, as compared to \$2,058 per capita in Canada and \$1,747 per capita in the United Kingdom.<sup>53</sup> Both Canada and the United Kingdom provide different mechanisms of coverage to all their citizens and have lower prescription drug prices.<sup>54</sup> For this reason, some have advocated for the institution of a national health plan similar to the National Health Insurance plan in Canada or the National Health Service in the United Kingdom.<sup>55</sup> Under such systems, discrimination based on genetic screening would be a non-issue since everyone would be guaranteed access to health care regardless of pre-existing conditions or genetic risk factors. While an intuitive appeal for a national plan from the perspective of fairness exists, the American public has traditionally been resistant toward implementing a government-funded health care system.

#### **How Can We Apply the Health Insurance Debate to Disability Insurance?**

Disability-income insurance provides full or partial income protection to individuals who are unable to work due to an accident or illness. Many of the policies sold in the United States are issued to employer-based groups who are not subject to individually assessed risk ratings. However, applicants applying for individual disability-income policies, not unlike those applying for individual health insurance policies, are assigned to rating classes based on age, profession, health status, and avocation.<sup>56</sup> Individually acquired policies typically pay approximately 60 percent of the insured's income if they become disabled, although

individuals also can apply for more generous policies that will more closely replace lost income.<sup>57</sup> Furthermore, unlike publicly financed disability income, private policies will provide benefits when disability prevents the insured from performing his or her normal occupation even if the disability does not prevent the pursuit of other occupations.<sup>58</sup>

Like health insurance, disability-income insurance is necessary to continue to lead one's life after suffering an illness or injury. Because most people are dependent on their salaries for their livelihood, any injury or illness that keeps them from being able to work can lead to financial ruin. However, unlike health insurance, disability insurance seems to be viewed by most people as discretionary. That is, fewer people seek disability insurance compared to health insurance. At the same time, the consequences of being uninsured can be significant, as people with disabilities can be disabled for years or for life. Given these factors, the standards for underwriting disability insurance are much stricter than those for life or health insurance.<sup>59</sup> Moreover, since so few citizens choose to apply for disability insurance and because of the substantially greater incentive to make a disability claim, insurance companies are often more concerned about adverse selection in disability insurance than other types of insurance.<sup>60</sup>

Adverse selection results when individuals have more information about their risk of illness or disability than they provide to insurance companies, making it impossible for the companies to accurately assess the risk of extending coverage to the applicant. Because disability-income insurance is viewed as more discretionary, insurance companies are often concerned that individuals will wait to buy disability insurance until they have suffered from an injury or illness or learn that they are at greater risk of illness. Thus, insurance companies may have an even stronger incentive to conduct risk screening, including genetic testing, during the underwriting process for disability insurance.

Given the potentially devastating effects to a family's financial situation if the primary wage earner were to become disabled, it is important from a policy perspective to determine how vital it is to ensure some minimal access to disability insurance, regardless of pre-existing risks, such as one's genetics. Since insurers are justified in worrying about adverse selection under current arrangements, might we ever want to have a minimum amount of disability coverage required of all citizens? Currently, the federal government provides Social Security Disability Insurance (SSDI) to all workers with a minimum employment history who are unable to work due to disability. However, the money provided through SSDI may not be sufficient for indi-

viduals to support themselves and/or their families. Certainly the payments do not begin to match previous income levels. One response would be to increase both the “pay in” and “pay out” of SSDI by raising mandatory employee contributions and increasing disability income payouts. Private companies still could provide supplemental coverage for employees who want it, but arguably, risk screening would increase significantly with the size of the policy and smaller levels of coverage would be more widely available for the “average prudent” applicant. In this manner, society could insure that families will not face financial ruin if their primary wage earner becomes disabled, while still allowing insurance companies to offer competitively-priced extended coverage disability insurance plans.

While the most prudent, and the most fair, “solution” to the problem of inadequate disability insurance may be to require a basic package of disability insurance at somewhat higher levels of coverage than currently afforded by SSDI for all Americans, other approaches more specifically targeted to genetics may be successful in the short run. Legislative strategies described above from the health insurance context potentially could be used for disability insurance as well, such as limiting the ability of disability insurers to use genetic predispositions or information as the only means of limiting coverage and limiting the ability to use genetic information alone as a reason for charging higher rates. Advocates for genetic protections have had some success securing these targeted protections in the health insurance context, perhaps because genetic predispositions are often viewed by legislators as both pervasive and as “no one’s fault”; advocacy in the disability insurance context may prove to be effective on similar grounds.

## Conclusion

The genetic testing that will be made possible as we continue to map the human genome will bring many public health benefits. Yet these tests also have the potential to bring public health and societal harms. Technology may allow the exclusion of individuals from health and disability insurance whose risks – often not clearly interpretable – would previously have gone undetected. According to our present system, such exclusions are completely acceptable. Indeed, insurance companies accurately defend themselves by claiming that they would treat genetic conditions exactly as they presently treat other conditions. What is new as a result of genetic research is the vast number of people who would be affected by insurance company exclusions. Precedent exists for insurance companies to classify applicants by risk and to make exclusions accordingly. However, precedent also exists for insur-

ers and certainly for other businesses to be regulated when there are overriding social or public policy concerns. Insurance occupies an integral place in providing for the welfare of the majority of the population. As such, the Human Genome Project will challenge us to weigh the business goals of private insurance companies against the social need for health and income protection with the goal of a socially valuable and publicly endorsed outcome.

## References

1. N. Kass, “Insurance for the Insurers: The Use of Genetic Tests,” *Hastings Center Report* 22, no. 6 (1992): 6-11.
2. The first three sections of this paper are based extensively on a previous work by the author entitled, “Insurance for the Insurers: The Use of Genetic Tests.” See *id.*
3. O. Anderson, *The Uneasy Equilibrium: Private and Public Financing of Health Services in the United States, 1875-1965* (New Haven: Yale University Press, 1968).
4. T. Murray, “Genetics and the Moral Mission of Health Insurance,” *Hastings Center Report* 22, no. 6 (1992): 12-17.
5. *Id.*
6. See Kass, *supra* note 1.
7. *Id.*
8. K. A. Clifford and R. P. Iuculano, “AIDS and Insurance: The Rationale for AIDS-Related Testing,” *Harvard Law Review* 100 (1987): 1808.
9. T. Musco and T. Wildsmith, *Individual Health Insurance: Access and Affordability* (Washington, D.C.: Health Insurance Association of America, October 2002).
10. Employee Benefit Research Institute, *Employment-Based Health Care Benefits and Self-Funded Employment-Based Plans: An Overview* (Washington, D.C.: Employee Benefit Research Institute, April 2000).
11. *Id.*
12. K. Pollitz, R. Sorian, and K. Thomas, *How Accessible Is Individual Health Insurance for Consumers in Less Than Perfect Health?* (Washington D.C.: Henry J. Kaiser Family Foundation, June 2001).
13. *Id.*
14. *Id.*
15. See Kass, *supra* note 1.
16. *Id.*
17. *Id.*
18. The Ad Hoc Committee on Genetic Testing/Insurance Issues, “Background Statement: Genetic Testing and Insurance,” *American Journal of Human Genetics* 56 (1995): 327-331.
19. See Kass, *supra* note 1.
20. *Id.*
21. The Kaiser Family Foundation and the Health Research Educational Trust, *Survey of Employer-Sponsored Health Benefits, 2002 Annual Survey*, available at <[http://www.kaisernetwork.org/health\\_cast/uploaded\\_files/ACF4D93.pdf](http://www.kaisernetwork.org/health_cast/uploaded_files/ACF4D93.pdf)> (last visited March 19, 2007).
22. See Employment Benefit Research Institute, *supra* note 10; Kaiser Family Foundation, *supra* note 21.
23. See Kaiser Family Foundation, *supra* note 21.
24. See the Ad Hoc Committee on Genetic Testing/Insurance Issues, *supra* note 18; American Academy of Actuaries, *Genetic Information and Medical Expense Insurance*, June 2000.
25. NIH/DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, “Genetic Information and Health Insurance,” *Human Gene Therapy* 4 (1993): 789-808 [hereinafter cited as NIH/DOE Working Group].
26. See the Ad Hoc Committee on Genetic Testing/Insurance Issues, *supra* note 18.
27. *Id.*
28. *Id.*

- 
29. See NIH/DOE Working Group, *supra* note 25.
30. K. Hudson et al., "Genetic Discrimination and Health Insurance: An Urgent Need for Reform," *Science* 270 (1995): 391-393.
31. *Id.*
32. See Kass, *supra* note 1.
33. H. Ostrer et al., "Insurance and Genetic Testing: Where Are We Now?" *American Journal of Human Genetics* 52 (1993): 565-577.
34. K. Rothenberg et al., "Genetic Information and the Workplace: Legislative Approaches and Policy Challenges," *Science* 275 (1997): 1755-1757.
35. See NIH/DOE Working Group, *supra* note 25.
36. *Id.*
37. See Ostrer et al., *supra* note 33.
38. L. Gostin, J. Hodge, and C. Calvo, *Genetics, Policy, and Law: A Report for Policymakers* (Washington, D.C.: National Conference of State Legislatures, September 2001).
39. *Id.*
40. See Rothenberg et al., *supra* note 34.
41. *Id.*
42. C. Plaza, *The Health Insurance Portability and Accountability Act of 1996* (Washington, D.C.: National Conference of State Legislatures, September 2001).
43. L. Andrews, *Future Perfect: Confronting Decisions about Genetics* (New York: Columbia University Press, 2001): 5-7; P. A. Roche and G. J. Annas, "Protecting Genetic Privacy," *Nature Reviews Genetics* 2 (2001): 392-396; M. Watson and C. Greene, "Points to Consider in Preventing Unfair Discrimination Based on Genetic Disease Risk: A Position Statement of the American College of Medical Genetics," *Genetics in Medicine* 3 (2001): 436; G. Geller et al., "Genetic Testing for Susceptibility to Adult-Onset Cancer: The Process and Content of Informed Consent," *JAMA* 277 (1997): 1467-1474.
44. See the Ad Hoc Committee on Genetic Testing/Insurance Issues, *supra* note 18.
45. See Roche and Annas, *supra* note 43.
46. M. Green and J. Botkin, "'Genetic Exceptionalism' in Medicine: Clarifying the Differences between Genetic and Nongenetic Tests," *Annals of Internal Medicine* 138 (2003): 571-575.
47. See Gostin, Hodge, and Calvo, *supra* note 38.
48. See Kass, *supra* note 1.
49. See Gostin, Hodge, and Calvo, *supra* note 38.
50. See Murray, *supra* note 4.
51. See Kass, *supra* note 1.
52. National Center for Health Statistics, *Health Insurance Coverage in the United States*, available at <<http://www.cdc.gov/nchs/fastats/hinsure.htm>> (last visited March 19, 2007).
53. World Bank, *Data and Statistics for Health by Country*, available at <<http://www.worldbank.org/data/databytopic/health.html>> (last visited March 19, 2007).
54. *Id.*
55. D. Light, "The Practice and Ethics of Risk-Rated Health Insurance," *JAMA* 267 (1992): 2503-2508; D. U. Himmelstein, S. Woolhandler, and the Writing Committee of the Working Group on Program Design, "A National Health Program for the United States," *New England Journal of Medicine* 320 (1989): 102-108; D. Light, "Universal Health Care: Lessons from the British Experience," *American Journal of Public Health* 93 (2003): 25-30.
56. See Ostrer et al., *supra* note 33.
57. *Id.*
58. *Id.*
59. See Ad Hoc Committee on Genetic Testing/Insurance Issues, *supra* note 18.
60. See Ostrer et al., *supra* note 33.
-

Copyright of *Journal of Law, Medicine & Ethics* is the property of Blackwell Publishing Limited and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.