Arguments For and Against Genetic Privacy Protection Laws*
— Is It Fair to Prohibit the Use of Predictive Medical Information in the Health Insurance and Employment Context? —

Koichi SETOYAMA**

Content

I. Introduction

II. Arguments For and Against Genetic Privacy Protection Laws
   A. Marne E. Brom
      1. Insurers' Justifications for Using Genetic Tests to Classify Risks
      2. Arguments Opposing Use of Genetic Testing
   B. T. H. Cushing
      1. Insurers' Arguments in Favor of Using Genetic Testing
      2. Arguments Against Insurers' Use of Genetic Testing
   C. Eric Mills Holmes
      1. Supporting Arguments for Use of Genetic Information by Insurers
      2. Opposing Arguments for Use of Genetic Information by Insurers
   D. Richard A. Epstein (Libertarian Argument)
   E. Colin S. Diver and Jane Maslow Cohen (Economic Analysis Approach)

III. Adverse Selection
   A. Practical Problems of Adverse Selection
   B. Normative Problems of Adverse Selection

IV. Conclusion

* This paper is the final part of my LL.M. thesis submitted to the University of Wisconsin Law School U.S.A. in summer 2002, in partial fulfillment of the requirement for the degree of Master of Laws. Although the original thesis has been modified to some extent, in general the content is not revised at this time.

** Koichi SETOYAMA, Assistant Professor and Foreign Student Advisor at the Graduate School of Law and Politics, Osaka University, Japan. Ph.D. in Law 2005, Osaka University; M.L.I. 1999, LL.M. 2002, S.J.D. Dissertator at the University of Wisconsin Law School, U.S.A.
I. Introduction

In my previous article published in this Law Review, I concluded that the ultimate question over genetic discrimination is whether it is justifiable to protect the privacy of all predictive medical information, instead of limiting it to genetic discrimination, in the insurance and employment context. In order to answer this question, it seems requisite to examine what kind of unintended adverse consequences and side-effects would be produced if the law should prohibit the use of all predictive medical information including genetic information and, what the theoretical grounds are to justify such a policy in spite of its producing serious side-effects such as adverse selection. These are the agenda I explore in this paper. I will point out the pros and cons of using genetic information and predictive medical information in general by reviewing the arguments and debates for and against the legal prohibition on the use of genetic information, especially focusing on the health insurance setting.

In the following sections, I will look into arguments presented by several commentators. First, I begin by observing both sides of the argument in the early stage of discussion represented by Marne E. Brom (1990) in Section II-A, and by T. H. Cushing (1993) in Section II-B. Then, I look into the most comprehensive reviews of both sides of the argument by Eric Mills Holmes (1996) in Section II-C. And then, I introduce the strong libertarian argument against antidiscrimination laws presented by Richard A. Epstein (1994) which criticizes legal prohibition on the use of genetic information in Section II-D, and finally in Section II-E, I review the Economic approach arguments presented by Colin S. Diver and Jane Maslow Cohen (2001) against laws designed to prohibit genetic discrimination. Some parts of these commentators' arguments overlap each other but we may find different emphasis or persuasiveness in the same point of argument.

The alternatives to protect “all types of predictive medical information” against discrimination in the insurance arena are therefore free from the peril and trap of genetic exceptionalism as long as the information protected legally is not limited


2) “genetic exceptionalism” means genetic information is uniquely sensitive and fundamentally different from other medical information, and therefore it requires and deserves special legal protection. See, Koichi Setoyama, Privacy of Genetic Information, 52 Osaka Univ. Law Rev. pp. 94-100 (2005).
to only genetic information. However, a more fundamental issue arises. If we introduce such an alternative measure as to protect all predictive medical information in the employment and insurance setting, the next issue that we have to examine is what kind of adverse consequences and side-effects such alternatives produce. This is a question concerning the issue of what is the theoretical ground to justify a policy which prohibits insurers from using medical information, even though such prohibition produces serious effects. Without addressing and answering these ultimate issues and questions, no real problem can be resolved. Accordingly, after reviewing arguments for and against privacy protection laws, in Section III, I will address the practical and normative problems of so-called "adverse selection" issue as one of the most serious adverse consequences that may occur if the law prohibits insurers from taking predictive medical information into account.

It is important to note that in America, most health insurance is provided through employers. According to the Health Insurance Detailed Table 2000 presented by the U.S. Census Bureau, roughly 177,286 thousand people obtained health insurance through employment bases and it constitutes 64.1 percent of the total population including uninsureds in 2000.\textsuperscript{3) Therefore,} genetic discrimination in health insurance, if we do not use the word "discrimination," say "adverse treatment" in the health insurance setting due to the information of genetic defects, may increase the adverse treatment in the employment context at the same time. This is because employers try to not only avoid decreasing efficiency and productivity of the employee itself but also aim at cutting the group insurance premiums that the companies have to pay. The implication of this structure suggests that by using law, if we can clear the adverse treatment in the insurance setting, we can also decrease the employers’ incentive to exclude the employees with genetic abnormalities who become the factor for increasing the total amount of premiums that the companies have to pay to the health insurance company in the U.S.A.

\section*{II. Arguments For and Against Genetic Privacy Protection Laws}

\subsection*{A. Marne E. Brom}

More than fifteen years ago, soon after the Human Genome Project started,
Marne E. Brom had already presented arguments supporting and opposing the use of genetic test results. It was the beginning of the debate over the use of genetic tests or genetic information by insurers and employers, and also it was the time when the state statute designed to forbid genetic discrimination began to be enacted. Here, I look into these arguments.

1. Insurers’ Justifications for Using Genetic Tests to Classify Risks

The first and most compelling justification for using genetic tests described by Brom is the argument that legal prohibition on using genetic information results in “adverse selection.” Adverse selection is defined as “the tendency of persons with poorer than average health expectations to apply for or renew insurance to a greater extent than persons with average or better health expectation.”\(^4\) After mentioning adverse selection in the HIV antibody testing context, Brom explains the implication of adverse selection in the insurance setting as follows:

\[\text{An individual who undergoes genetic testing revealing a genetic disease or a propensity toward a genetic disease is more likely to apply for insurance or apply for a greater amount of insurance because the applicant knows a claim may be likely in the future. If the insurer is not permitted to perform genetic tests, or ask the applicant or his attending physician for the results of previous testing, adverse selection could occur and force the insurer to charge a premium unrelated to the actual risk.}\(^5\)

Another correlated justification for using genetic tests to classify risks provided by insurers is that any legislative restriction on genetic testing constitutes “unfair discrimination.” Brom states that the situation “[i]ncluding those who [HIV antibody] test positive with the rest of the insureds forces the healthy to subsidize the less healthy”\(^6\) is true of genetic testing as well and, therefore, “[f]ailure to separate individuals with different degrees of risk will allow the insurance principles of equity to give way to equality.”\(^7\) And then, “the healthy would realize

---


5) *Id.* at 134-35.

6) *Id.* at 135.

7) *Id.*
they were being overcharged or treated unfairly and, therefore, would choose not to buy new or further coverage.\(^8\)

Another argument which supports the insurance company is where some individuals “presently possessing no manifestations of a [genetic] disease, but having a family history of an inherited disease . . . would benefit from their use of genetic testing to classify risks” because “[w]ithout genetic testing, regardless of whether these individuals would actually develop to disease, they would be classified as substandard or declined, depending on the inherited disease” but “if a genetic test indicated they were not carrying the unfavorable gene, the insurance coverage could be offered at favorable rates.”\(^9\)

However, Brom points out the following self-defeating consequence of this argument:

If individuals were required to undergo extensive genetic tests and all results proved negative, the applicants would have heightened expectations of health and longevity. As a result, there would be little incentive to purchase large amounts of coverage, or to purchase insurance at all. . . . Therefore, extensive genetic testing by insurers may prevent significant numbers of applicants, both healthy and unhealthy, from obtaining insurance at affordable rates.\(^10\)

2. Arguments Opposing Use of Genetic Testing

The main arguments opposing use of genetic testing that Brom provides is decreasing insurance availability: “Insurers’ use of genetic testing or genetic test results identifying genetic disorders can potentially increase the number of uninsureds by preventing applicants from purchasing insurance, allowing applicants to purchase only limited coverage, or requiring applicants to pay increased premiums.”\(^11\) This argument alleges that people cannot afford escalating health care costs without health insurance, and therefore, “[f]or many, a denial of health insurance will leave them unable to finance the medical costs associated with diseases.”\(^12\)

Next, Brom points out a rationale and incentive by which employers

\(^8\) Id.
\(^9\) Id.
\(^10\) Id. at 136.
\(^11\) Id.
\(^12\) Id. at 137.
discriminate against prospective and present employees which would result in employment availability. According to Brom, there are three main motivations or incentives when employers use genetic testing; concern for employees’ job performance, safety in workplace, and concern for insurance cost.

He notes that “although employers’ use of genetic testing may begin with concern for safety and productivity, it extends to the general health of employees affecting the employer’s future cost of medical care.”13) He further explains the reason for this:

Insurance costs are the largest single component of employee benefits, constituting thirty-seven percent of total payroll costs. ... The amount an employer pays for worker’s compensation insurance is often determined by the past claim experience record of the employer. Therefore, employers may find genetic testing an attractive tool for effecting a strategy to avoid compensation claims and higher insurance costs by excluding individuals with adverse genetic predispositions.14)

Brom describes the employers’ economic incentives to perform genetic tests in the large group employer-sponsored insurance plans:

[I]ndividual underwriting is seldom performed by the insurer for a large group plan. Rather, the group as a whole is underwriting and priced according to past claims experience. Therefore, the group may contain individuals who would not individually qualify for coverage. The inclusion of such individuals increases the employer’s cost of insurance. This provides an incentive for the employer to perform genetic testing at the time of hiring.15)

It is maintained by Brom that in the self-insurer plan, employers also have economic incentives to perform genetic tests: “Because self-insuring employers avoid state insurance regulation, self-insurers have the advantage of using tests and testing information that some states deny to insurance companies.”16) He continues to insist that “[t]herefore, self-insurers’ access to test information, coupled with

13) Id. at 138.
14) Id. at 139.
15) Id.
16) Id.
economic incentives to deny employment to individuals with adverse genetic tests, exacerbates the problem of unavailable health insurance.\textsuperscript{17)}

Brom states that “[t]he threat of unemployment and the unavailability of health coverage, however, is not limited to individuals involved with large group employment-sponsored plans and self-insuring employers.”\textsuperscript{18)} This fear is also true of individuals applying for small group coverage because [s]mall companies may pay part of the cost of their employees’ individual insurance” and “[t]he employer will indirectly know of a prospective employee’s unfavorable genetic test results when the applicant does not qualify for insurance at a standard rate” and therefore, “[t]he increase in the employer’s cost of providing health insurance provides an incentive to deny employment to those who cannot qualify for insurance at standard rates”.\textsuperscript{19)}

Accordingly, Brom concludes that “regardless of whether the employer self-insures, and regardless of the size of the group plan offered by an employer, unfavorable genetic test results provide the employer a considerable economic incentive to refrain from hiring some prospective employees.”\textsuperscript{20)}

Another scenario on consequence and implication of using genetic test and its result is described by Brom as follows:

The money employers save by refusing to hire workers on the basis of genetic tests will increase societal costs. If all employers use tests to detect common genetic predispositions, prospective employees with unfavorable results will find themselves excluded from most jobs. Society will be forced to bear the increased burden of providing unemployment and health care benefits for these individuals.\textsuperscript{21)}

Brom also states the adverse implication of using genetic test results over the availability in family insurance. In a family insurance policy, normally “unborn as well as qualifying born children are automatically covered until at least each child’s eighteenth year.”\textsuperscript{22)} The medical cost for children who have genetic disorders is extremely high “because many of the conditions are not immediately fatal.”\textsuperscript{23)}  

\begin{itemize}
\item \textsuperscript{17)} \textit{Id.}
\item \textsuperscript{18)} \textit{Id.}
\item \textsuperscript{19)} \textit{Id.}
\item \textsuperscript{20)} \textit{Id.}
\item \textsuperscript{21)} \textit{Id.}
\item \textsuperscript{22)} \textit{Id.} at 140–41.
\item \textsuperscript{23)} \textit{Id.} at 141.
\end{itemize}
Therefore, Brom asserts that “[i]t is possible that companies will decide to grant family policies with a rider that only children born without identifiable genetic defects are eligible for coverage.”

Brom also mentions a concern for infringing on confidentiality raised by using genetic test and information: “If insurers are permitted to use genetic testing or acquire genetic information from an applicants’ attending physician, this information will be recorded in data bank.”

“Typically, insurers ask applicants to sign a blanket consent form allowing the insurers to examine the applicant’s medical history. ...once records are in the insurer’s hands, the records may be further disclosed to data centers such as the Medical Information Bureau (“MIB”).”

“The MIB serves as a detective agency and allows insurance companies to exchange applicants’ medical findings and test results.”

In sum, as we have seen in Brom’s review, in the early discussion stage, the main argument supporting the use of genetic information was adverse selection and its adverse implication in the market. The opposing argument was mainly based on the possibility of genetic discrimination. It is noteworthy that Brom emphasizes the incentives that employers discriminate employees when discussing the argument that opposes the use of genetic tests in insurance.

B. T. H. Cushing

1. Insurers’ Arguments in Favor of Using Genetic Testing
   a. Fair Discrimination Perspective

The first argument Cushing mentions is based on the traditional fair discrimination perspective theory of insurance. According to this perspective, the “[p]rimary goal of underwriting is the accurate prediction of the costs of death (how much an insured has paid in premiums before the insured dies versus the face value of the policy) and sickness (how much the insured has paid in premiums versus the cost of medical care for diseases the insured will contract.”

The former is called “future mortality costs” and the latter is called “morbidity costs.” And “[t]hrough

---

24) Id.
25) Id. at 141-2.
26) Id. at 142.
27) Id.
28) T. H. Cushing, Should There Be Genetic Testing In Insurance Risk Classification?: Arguments Both For and Against the Use of This New Technology May Be "Right," and Some Form of Universal Health Care May Be the Result, 60 DEF. COUNS. J. 249, 253 (1993).
underwriting, insurers classify applicants in accordance with factors such as age, sex, occupation, health history and the use of tobacco or alcohol.”29)

Cushing describes the importance of assessing risk properly:

> If an insurer under-assesses certain risks, it will not have sufficient funds to pay all the claims made in the future, unless it overcharges people who represent little or no risk. Without sufficient funds to meet contractual obligations, insurers will go bankrupt and leave many insureds without coverage. On the other hand, because of the free market nature of the insurance industry, if an insurer over-assesses the risks and sets premiums too high, prospective customers will purchase from other insurers.30)

With genetic testing, ... they [insurance companies] will be able to predict the future mortality and morbidity costs so accurately that they will be able to reduce premiums to the majority of people. Genetic testing, ... will increase the availability of insurance by eliminating some of the guesswork. People who smoke and drink but have “rock-solid” genes—for example, anti-lung cancer and anti-alcoholism—may qualify for lower premiums than would otherwise be the case.31)

Cushing points out the insurers’ fears behind this argument: “AIDS and genetic diseases are similar in that they can be predicted years before the appearance of symptoms. Legislative prohibitions on insurers’ use of genetic testing also raise insurers’ fears that applicants may select adversely against insurers.”32)

b. Genetic Testing Not Revolutionary

Another argument which justifies using genetic testing by insurers is epitomized by the following question: “Why should insurers be allowed access to most types of medical information but not to the genetic information that underlies the non-genetic medical history?”33) This argument asserts that “genetic testing, like AIDS testing, is no different from the many other sorts of tests performed by physicians to

29) Id. at 253.
30) Id.
31) Id.
32) Id. at 254.
33) Id.
which insurers routinely have access."\textsuperscript{34)} This is because "the present forms of medical testing routinely relied on by insurers also reveal conditions that existed prior to the issuance of the policy."\textsuperscript{35)} Thus, genetic testing is not revolutionary.

c. Consequence of Legislative Prohibitions

Another argument for using genetic information depends on the adverse consequences resulted from legislative prohibitions. One of these consequences is "adverse selection."

If you do not allow insurers the use of genetic testing, then insurers (1) will get out of the business on their own, (2) will spread the costs that they could not have anticipated to all of their customers..., or (3) may be driven out of business by unforeseeable claims, which insurers call "adverse selection."\textsuperscript{36)}

Adverse selection means "that people who have undergone testing and have tested positive for a genetic disorder will attempt to buy as much insurance as they can to cover the cost of future illness when the genetic disorder expresses itself."\textsuperscript{37)}

Also prohibition on using genetic testing is against "state unfair trade practices acts. This act compels insurers to discriminate between insureds on the basis of their risk factors. For example, unfair trade practices acts deem it inequitable to charge identical premiums for life insurance to a 60-year-old man in poor health and 20-year-old woman in good health."\textsuperscript{38)}

Cushing also describes the argument by insurers from even a societal point of view, banning insurers using genetic test information; in other words, forcing them to ignore relevant actuarial data leads to adverse consequences: "[A]llowing them [insurers] to use genetic testing and survive financially so that they can cover most people at affordable rates is preferable to driving them out of business and leaving their former customers uninsured or underinsured."\textsuperscript{39)}

Another unacceptable consequence of legal banning of the use of genetic tests is that it admits applicants' fraud and denies insurers' contestability for

\textsuperscript{34)} Id.
\textsuperscript{35)} Id.
\textsuperscript{36)} Id.
\textsuperscript{37)} Id.
\textsuperscript{38)} Id. at 255.
\textsuperscript{39)} Id.
misrepresentation of the insureds’ risks. This argument asserts that one consequence of legislative prohibition on the use of genetic tests by insurers is that it voids the exclusion clause which prevents insureds from engaging in fraud, that is, misrepresentations or concealment of pre-existing conditions. 40)

2. Arguments Against Insurers’ Use of Genetic Testing

The arguments against insurers’ use of genetic testing resorting to its adverse consequence for the prospective or present insureds are described as follows by Cushing.

[I]nsurers’ use of genetic testing as a classification tool...will produce unfair results. While a few “genetically healthy” people who do not need health insurance will be able to get it at a reduced premium rate, the vast majority who do need health insurance will not be offered the chance or will not be able to afford what’s offered. 41)

a. Uninsurability as Denial of Health Care

Another argument against insurers’ using genetic information is that it prevents genetically unlucky people from receiving health care service.

[G]enetic testing could create a class of people who cannot get health insurance coverage, and denial of health insurance today is the equivalent of a denial of health care for many Americans. Already the fairness of the health insurance system is questioned because it denies coverage to the individuals who need it most. 42)

Cushing points out an ironical consequence: “[t]he possible result would be that those able to obtain health insurance would be those who do not need it because they have ‘healthy gene.’” 43)

And also this uninsurability creates a chilling effect which leads people to refrain from undergoing genetic tests: “[n]ot being genetically tested for fear of losing insurance coverage could cost the individual and the health care system” 44)

40) Id. at 255-56.
41) Id. at 257.
42) Id. at 258.
43) Id. at 257.
44) Id. at 258.
Cushing notes how useless taking genetic tests would be, if its positive result means denial of health insurance:

The knowledge that one will develop a disease in the future is worthless without the ability to pay for the gene treatments that are certain to be expensive, if and when they are available. Applicants for insurance will not be inclined to investigate their potential for genetic diseases if they sense that the disheartening news of a positive result will be coupled with a total abandonment by all insurers.45)

b. Confidentiality

Another argument, Cushing notes, justifying legal prohibition on using genetic tests and their results is that genetic information is different from other types of medical information readily accessible to insurers because of its immutable characteristics.

The Medical Information Bureau is an unincorporated trade association whose several hundred members are the largest insurance companies in North America. The MIB has created a "list of impairment," which is intended to summarize information vital to insurers. ... whenever an application contains information about genetic testing or a claim for the cost of genetic testing filed with an insurer, that insurer files a coded report containing identifying data about the insured....46)

Therefore, if we accept insurers' using genetic tests and such data, the confidentiality of most personal genetic information will not be protected.

c. Infliction of Emotional Harm

The final argument supporting legal banning on using genetic tests for insurance underwriting, Cushing mentions, is that it inflicts emotional harm to the insured: "[T]he [genetic] information the testing reveals will have devastating psychological impacts on the persons tested, particularly when no treatment may be available or affordable for years to come."47)

45) Id.
46) Id. at 259.
47) Id.
After reviewing both sides of the argument, Cushing asserts that “[b]oth insurers and their critics are ‘right’ about this issue” because “[i]f insurers are not allowed to use genetic testing, private insurers will disappear—either by choice or by bankruptcy” and “[i]f insurers are allowed to use genetic testing, they will deny coverage to many people who will become uninsurable.” Therefore, Cushing concludes that some type of universal health care system may be the result.

C. Eric Mills Holmes

One of the most comprehensive and detailed descriptions concerning arguments both supporting and against the use of genetic information in the insurance setting is presented by Eric Mills Holmes. Let me summarize it.

1. Supporting Arguments for Use of Genetic Information by Insurers
   a. Fair Discrimination Is Efficient in Insurance Underwriting

   The first argument supporting the use of genetic information listed by Holmes is the assertion that fair discrimination is efficient insurance underwriting. This argument consists of three reasons: i) the law governing insurance underwriting has been the equitable, not equal, principle; ii) the history of insurance risk classification justifies fair discrimination in underwriting; iii) the use of genetic tests is efficient and equitably fair.

   i. Equitable, not Equal, Justification

   The prohibition of insurers’ access to and use of genetic information is against the principle of equity, that is the goal of insurance underwriting: “[T]he fundamental tenets of underwriting are selection of insureds based on sound actuarial standards, proper balance within each rate classification, and equity among policyholders.”

   Holmes states: “Risk transference and distribution are the keys to understanding the nature of insurance and insurance underwriting. Insurance is an arrangement for the transference of the risks of fortuitous losses to an insurer and the distribution of those risks among insureds who pay a premium to a common fund.” In these settings, “[t]he principle underwriting insurance is ‘fair discrimination’ predicated on efficient, actuarial analysis in establishing risk transference and risk

49) Id. at 531.
distribution.” For example, in life insurance, “failure to distinguish women, who present lower risks of early death, from men is unfairly discriminatory against women in favor of men.” On the other hand, “[r]egarding annuities which pay until death, it is unfairly discriminatory against men and in favor of women.” In other words, it means “the failure to differentiate between insureds results in unfair discriminatory rates because it forces policyholders with lower actuarially predicted risk to subsidize other policyholders with higher expected risk.”

It is well known that “[t]he very nature of insurance is discriminatory because individuals with a higher risk are routinely charged a higher premium.” For example, “a smoker is charged a higher premium than a non-smoker for a life insurance policy because, all other factors being equal, a smoker represents a higher mortality and morbidity risk than a non-smoker.” And “rates are established and premiums charged based on the principle of equity, not equality.” Equity means “[t]he lower the actuarially expected risk, the lower the premium. The higher the expected risk, the higher the premium.” Therefore, “equitable premiums vary according to the risk transferred.” Equitable treatment of applicants and policyholders means that “insureds with the same or similar actuarially predicted risk of loss are charged the same.”

ii. History of Insurance Risk Classification

Holmes states that the history of insurance risk classification in the United States provides further support for fair discrimination. He begins by explaining the importance of risk classification in insurance:

The pooling of risks with similar characteristics for the purpose of determining insurability and price is the bedrock principle of a workable, voluntary, private insurance system. This process, called risk classification, not only permits insurers to exercise their right to earn a reasonable profit but also creates an equitable insurance system for all policyholders. … Allowing insurers access to genetic testing, mapping,
and other relevant information regarding an individual’s genotype...will be necessary for proper risk classification. A system that does not classify risks will inevitably cease to be a private insurance system. If insurers are denied access to genetic information it would threaten insurers’ solvency by undercutting the use of actuarially sound risk classifications to properly and fairly price insurance policies.\(^{57}\)

Holmes states that the history of insurance risk classification in the United States supports these arguments. According to his explanation, in the U.S., the insurance risk classification to establish premium rates has shifted from “community rating” to “experience rating.” In community rating, “fair risk distribution” is emphasized and the premium rate is established based on “the average cost of all insured policyholders within a defined geographical region.”\(^{58}\) For example, “the early non-profit Blue Cross/Blue Shield plan used a community rating system”\(^{59}\) and “[a]ll premiums were the same for all policyholders regardless of the actual experience of the group.”\(^{60}\) On the other hand, in experience rating, “fair discrimination” is emphasized and it “bases premium rates on the current claims made by the particular group—the group’s experience.”\(^{61}\)

Holmes explains why community rating has been replaced by experience rating. In the history of the U.S., the advent of commercial insurers used an experience rating system to classify risks, and “because this system [experience rating] looks only at the group being insured, it allows these insurers to offer low rates by excluding from the calculation of premiums higher risk individuals.”\(^{62}\) And also “[t]his shift in pricing has the effect of reducing the forced subsidy of redistributing risk of loss from those with high expected medical costs to those with low expected medical costs.”\(^{63}\) Therefore, these profit insurers “lured away low-risk Blue Cross insureds by separately classifying them and giving them a lower premium.”\(^{64}\)

Holmes views this shift was inevitable because of the following reason:

\[T]\he health care system in the United States is financially

\(^{57}\) Id. at 534-35.
\(^{58}\) Id. at 536.
\(^{59}\) Id.
\(^{60}\) Id. at 537.
\(^{61}\) Id. at 536.
\(^{62}\) Id. at 536-37.
\(^{63}\) Id. at 537.
\(^{64}\) Id.
administered through a private insurance system. Therefore, . . . health insurance is a business. If this private system is to survive, it is necessary to allow the continued operation of the free market to the extent that it is equitable for all involved.65)

As the above U.S. History evidences, the shift from community rating system to experience rating shows, “properly utilized risk classification fuels an effective private system, enhances insurer solvency, encourages fair treatment of all policyholders, and provides an enormous public benefit through widely-available, low-cost health, life, and other health-related insurance.”66) Consequently, this argument asserts that it is indispensable to take genetic information into account for a sound insurance risk classification and therefore, this supports fair discrimination which avoids the situation where high-cost subscribers are subsidized by low-cost subscribers.

iii. Use of Genetic Tests Is Efficient and Equitably Fair

Another argument supporting the insurer’s use of genetic information based on the assertion of fair discrimination, alleges that use of genetic tests is efficient and equitably fair.

As we have seen before, “[t]he present health insurance industry has fundamentally abandoned an equitable community-wide rating system where the health costs for everyone in society are aggregated and premium charges are spread equally among all insureds. Health underwriting has been replaced by a system based on ‘experience rating’ by selective groupings.”67) In the present experience rating system, it is alleged that “[b]ecause the primary goal of insurance underwriting is the accurate prediction of mortality and morbidity costs, any medical tests which will be useful in assessing risks should be available to insurers.”68) For example, “[i]nsurers argue that women live longer than men, are safer drivers than men, and incur higher medical costs than men. Because the risks are different for men and women, the premiums should reflect these differences.”69)

Holmes explains the reasons why accurate risk assessment is so essential to the business of insurance by describing two scenarios which could potentially arise, if

65) Id.
66) Id. at 535.
67) Id. at 538-39.
68) Id. at 538.
69) Id.
risks are not properly assessed:

(1) If an insurer underassesses risks, it will have insufficient funds to pay claims submitted unless it overcharges people who represent low risk. If insurers have inadequate funds and are unable to meet their contractual obligations to pay claims, the insurers will go bankrupt, leaving people uninsured. (2) If an insurer overassesses risk and overcharges, the free market and competitive nature of business logically dictate that people will purchase insurance elsewhere.70

Holmes also explains the importance of accurate risk assessment in the light of fairness among insureds:

[T]he rate-setting philosophy of insurance companies is founded on the equitable treatment, not equal treatment, of all applicants for health insurance. Rates should be adequate, not excessive, and discriminate fairly between insureds. ... Rates should not be excessive, because excessive rates impose undue burden on insureds. To achieve adequate non-excessive rates, insurers must discriminate fairly so that each insured will pay in accordance with the quality of his/her life and health.

This argument asserts that genetic testing will provide a valuable tool for insurers to assess the risk more accurately to promote efficiency in the insurance market and achieve equitable fairness in premium rating.

A paternalistic ground is also alleged by this argument:

Because insurers try to correlate premiums with actuarial risk, genetic information could lower a person’s premiums or allow an individual previously considered uninsurable to obtain health insurance. For example, because Huntington’s disease is a monogenic disorder, a child of parents who are both carriers of the gene would have a fifty percent chance of inheriting this genetic disease. However, if the couple’s child tested negative for the disease-causing gene, the child would then be able to obtain more affordable insurance. Consequently, instead of all children whose parents are Huntington’s disease gene carriers being

70) Id.
rejected, half of them would qualify for insurance."71)

Moreover, it is alleged that using genetic tests makes it psychologically easier for the insured to accept high premiums:

Assuming that the risk was ascertainable but found to be high, the applicant, with this confirmed knowledge [accurate assessment of risk by using genetic test], would likely feel that it was fair to pay a higher premium for the correspondingly high risk. Applicant [for insurance] would probably not accept a policy with a very high premium charge unless the applicant had reason to believe that even though the premium was quite high, the insurer had nevertheless underestimated the risk. Thus, equal access by the insurer and insured to the insured’s genetic information would produce fair results: not only would previously uninsurable people find coverage, but relatively high premiums would be justifiable.72)

Furthermore, another efficient and paternalistic ground is alleged:

Another example where equal access to the insured’s genetic knowledge would produce favorable results to the insured is where an insured has a gene which in conjunction with external factors results in disease. That insured’s decision to take appropriate measures to reduce the risk of disease would include the economic benefit of a lower premium based on the insurer’s use of risk classifications. For instance, if an insured has a gene associated with cancer, then he or she would likely choose to periodically monitor the condition and follow a physician’s advice in reducing the risk through appropriate changes in lifestyle. . . . [I]mmediate economic and potentially long-lasting health benefits would be derived. . . . Therefore, equal access to genetic information for proper risk classification has the positive effect of creating loss prevention incentives in insureds."73)

As can be seen, many arguments alleging efficiency and fairness of using

71) Id. at 540.
72) Id.
73) Id. at 540-41.
genetic information as a fair discrimination for both the insurer and insured are presented to criticize genetic antidiscrimination laws. In the next subsection, I will review another argument focusing on asymmetries of information and its adverse effect on the insurance market according to Holmes’ analysis.

b. Equal Access to Genetic Information Fairly Rectifies the Unfairness of Imperfect Information in Underwriting

i. Applicant’s Good Faith Duty to Disclose Genetic Information

This argument alleges that equal access to genetic information by both the insurers and insureds is indispensable for actuarially fair risk classification because “the absence of genetic information will cause economically inefficient unfairness arising from imperfect information between insurer and applicant about applicant’s future health care needs. Imperfect information is an obstacle to an effectively functioning market.”74

This argument alleges that antidiscrimination laws create this asymmetry of information which imposes good faith duty to disclose genetic information on applicants for insurance:

If an applicant knows materially adverse genetic facts regarding the applicant’s foreseeable need for later medical treatment and care, and also knows that the insurer does not have equal access to these material genetic facts, then that applicant has a good faith obligation to disclose this information to protect the insurer’s solvency and to ensure equitable premiums.75

It is asserted that “[a]n applicant should not be allowed to take advantage of that undisclosed personal knowledge in purchasing insurance at an unreasonably low premium rate that subsequently will not adequately cover the applicant’s claims. An applicant’s bad faith non-disclosure is tantamount to fraud against the insurer and other policyholders.”76 Therefore, it is alleged that “[a]llowing insurers access to an applicant’s genetic tests and personal genomic information rectifies the problem of imperfect information regarding genetic risks.”77

74) Id. at 541 (emphasis added).
75) Id. (emphasis added).
76) Id. at 543 (emphasis added).
77) Id.
ii. Adverse Selection

Another strong and well known argument which consists of reasons that support equal access to genetic information is adverse selection.

It is alleged that because of the antidiscrimination laws which deny the use of genetic information in risk classification, "[i]f an insurer cannot distinguish and classify high-risk applicants from low-risk applicants, the insurer must offer all applicants the same premium for the same coverage. Low-risk applicants are then worse off and high-risk applicants are better off than in a properly functioning insurance risk classification system."\(^{78}\) And adverse selection occurs "when people with a greater probability of loss than reflected in their premiums buy and continue insurance coverage to a greater extent than other people. In an insurance market in which adverse selection is substantially present, low-risk people `actually subsidize the insurance purchases of high risks.'"\(^{79}\)

The general process where adverse selection would be triggered due to the inequality in information between applicants or insureds and insurers is explained as follows:

An applicant with knowledge of a high risk of loss will probably apply for insurance covering that high risk more than the average person. If insurers charge an equitably rated premium without knowledge of the high risk or charge an equal premium for all applicants, the high-risk person will select to apply and obtain insurance in greater proportion than low-risk people.\(^{80}\)

Likewise, the process of adverse selection in genetic information is explained as follows:

The potential for adverse selection increases as genetic information becomes available to insurance consumers. If an individual undergoes genetic testing and tests positive for a genetic disorder, that person may seek to buy as much insurance as is available to cover the costs of future illnesses which may later be expressed. If insurers are legislatively

\(^{78}\) Id.

\(^{79}\) Id. at 543-44 (quoting Mark J. Browne & Helen I. Doeringhaus, Information Asymmetries and Adverse Selection in the Market for Individual Medical Expense Insurance, 60 J. Risk & Ins. 300 (1993)).

\(^{80}\) Id. at 544.
prohibited from requiring genetic tests and from obtaining the results of genetic tests, they may insure individuals at rates that do not reflect the true risk.81)

Holmes describes the probable cycle of the adverse consequences of this adverse selection by stating that “the insurer must increase the premium price for insurance coverage because of unexpected claims”82) attributed to adverse selection; because of this, “low-risk insureds, noting the increase in premium, select to discontinue their insurance coverage”83) and thus “the remaining pool of insured-policyholders has a higher than average risk of lose”84) and “insurers then must again raise the premium price”85) and finally “either an equilibrium is reached with some of the low-risk insureds still buying the insurance, or the insurer’s risk pool entirely separates.”86)

Holmes mentions that in the future, if a biotechnology company creates at-home genetic tests and “if these tests are widely used, and the insurers are legislatively precluded from obtaining the same genetic information to which individuals have access, then there is a risk of widespread adverse selection.”87) And “if individuals test negative for a variety of genetic disorders, they may elect to purchase little or no insurance, while those who test positive, and who will submit the majority of claims, will be the primary people to purchase as much health insurance as possible.”88) Consequently, this “result[s] in catastrophic failures in the insurance industry, leaving many individuals uninsured altogether.”89)

iii. Incontestability Clauses

In general, in a situation where “an applicant [for insurance] has a good faith duty to disclose material facts about prior genetic testing or personally-known related genetic data, and conceals that genetic information in the application/contract formation process [or] ... affirmatively misrepresents or omits personal genetic information,” insurers have “contract-vitiating defenses for fraud, non-

81) Id. at 545.
82) Id. at 544.
83) Id.
84) Id.
85) Id.
86) Id.
87) Id. at 545.
88) Id.
89) Id.
disclosure, concealment, misrepresentation, and possibly mistake" and "seek rescission on the insurance contract."90)

However, Incontestability Clauses which are normally prescribed in the insurance policies by state insurance statutes or regulations, impose limits on the insurers' contestability for applicants' fraud and misrepresentation, and so on.

The implication of the existence of incontestability clauses is stated by Holmes as follows:

[Incontestability clauses] prevent insurers from asserting contract-vitiating defense and disputing the validity of a policy after it has been in effect for two years. Practically speaking, contractual incontestability provisions create a type of contractual two-year statute of limitations during which insurers must uncover an applicant’s fraud or bad faith in the contract formation process. ... Fraudulent insureds are rewarded for their misconduct by paying an unfairly low premium, while honest insureds pay an unfairly high premium. ... The untoward, unfair effects of uncontestability [sic] clauses can be avoided by granting insurers equal access to an applicant’s genetic information."91)

[M]any genetic disorders can be detected many years before their expression. Consequently, where an applicant had knowledge of personal genetic information regarding medical diseases and conditions which would affect insurability or premium rates and did not fairly share this information with the insurer at the time of application, these incontestability clauses may later prevent an insurer from claiming bad faith non-disclosure or even fraudulent misrepresentation.92)

Consequently, it is alleged that “[r]equired disclosure of genetic testing data thereby would eliminate problems associated with imperfect information and provide a fairly priced product of insurance for all applicants."93)

c. State's Unfair Trade Practices Statute

Another argument is based on the supremacy of state regulations on the

90) Id. at 546.
91) Id. at 547-48.
92) Id. at 548.
93) Id.
insurance industry. State insurance laws, modeled on the Unfair Trade Practices Act ("UTPA"), require insurers to use genetic information to achieve state-mandated fair discrimination and prohibit unfair discrimination. Under these state statutes "[u]nfairness in the insurance context occurs when equal risks are treated differently or unequal risks are treated equally."94) For example, "the Act deems it inequitable to charge the same premiums for life insurance to a fifty-year-old man in poor health and a twenty-year-old woman in good health."95) Under these state unfair trade practices, "grouping high-risk insureds with low-risk insureds and charging all an equal premium is unfair discrimination because the low-risks pay too much and subsidize the high-risks who pay too little."96) And these statutes "help assure that insurance companies are not rendered financially unsound due to an improper risk classification."97)

Accordingly, it is alleged that "insurers have a responsibility under the UTPA to treat all their policyholders fairly by setting premiums at a level consistent with the risk presented by each individual insured."98) Therefore, "insurers will be required to use this [genetic] information under the states’ versions of the UTPA to fulfill the statutory mandate of fair discrimination."99) In sum, "[s]ound and fair actuarial underwriting principles necessitate the consideration of genetic information in classifying and underwriting risk. Therefore, to avoid violating the states’ version of the UTPA, health insurers must require and use genetic testing of applicants in the insurance contract-formation process."100)

d. Insurers Will Fairly Use Genetic Information in Risk Rating

Another argument alleges that "[t]he foundation of private health insurance is risk rating. Through competition, risk rating should be fair and should give policyholders the best value for their money."101) However, antidiscrimination laws intending to ban the use of genetic information creates imperfect information "such as insurers not knowing the results of genetic testing of applicants when determining risk classifications." This imperfect information should be avoided in order to keep "insurance costs low and product availability high for the great

94) Id. at 551.
95) Id. at 550.
96) Id. at 552.
97) Id. at 551.
98) Id. at 552.
99) Id.
100) Id. at 553.
101) Id.
majority of insurance applicants." According to the, it is alleged that "genetic tests, along with more traditional medical questionnaires and tests, are essential in providing insurers with medical history for statistically fair evaluation of all applicants for health insurance." 

**e. Genetic Testing Conforms to Current Underwriting Practices and Will Not Affect an Applicant’s Ability to Obtain Insurance**

Another argument supporting the use of genetic testing alleges that genetic testing conforms to current underwriting practices and will not affect an applicant's ability to obtain insurance. This argument is based on the following reasons:

First, the cost of genetic testing and mapping may be too high for insurers to use these techniques routinely. Second, most health insurance and forty percent of the life insurance obtained in the United States is obtained by large groups of employees from their employers. Insurers do not customarily undertake individual underwriting or testing in connection with employer-provided large-group insurance. Third, for the smaller group of individuals applying for private health insurance policies, insurance companies will have little reason for generally requiring genetic tests. Of the individuals who are tested, some will have their eligibility adversely affected while others will be positively affected if, for instance, the test reveals no deleterious genetic conditions. Forth, a considerable amount of genetic information is presently obtained through means other than DNA-based genetic tests. These non-DNA genetic tests include biochemical tests, chromosome examinations, and physical examinations.

Consequently, it is asserted that "[i]nsurers do not expect that genetic information will affect many people’s access to private health, life, and disability insurance." This is also because of the fact that "[g]enetic testing is not radically different from the many other tests which are currently performed by physicians and to which insurers have access. Many current tests also predict

---

102) *Id.* at 554-55.
103) *Id.* at 555.
104) *Id.* at 555-56.
105) *Id.* at 555.
future disease and illnesses."  

f. Analogous Employment Discrimination Based on Genotype Is Fair

The final argument Holmes mentions is based on the assertion that analogous employment discrimination based on genotype is fair.

It is alleged that unless it is "invidious discrimination" such as "discrimination based on race, color, religion, sex, national origin, age, or disability," it is a well known fact that historically "[e]mployment discrimination has long been legally, ethically, and socially acceptable" and indeed presently "[e]mployers differentiate, or discriminate, routinely among job applicants with differing educational, intellectual, and experiential qualifications." Therefore, it is alleged that "employers may fairly discriminate based on other genetic characteristics. In other words, employers may hire and retain individuals predicated on occupationally-relevant physical and character traits which are largely dictated by genetics." For instance, "[w]hen an employer refuses to hire an individual because that person lacks certain relevant physical qualifications, or conversely, when an employer prefers one individual over another because of physical characteristics, the employer has discriminated based on factors which are, in part, genetically controlled."  

In the United States, most of the health insurance of the employees are obtained through employers and the "rising cost of health care has significantly increased employer health insurance costs." Therefore, "employers have . . . a strong financial incentive to reduce their health care expenditures by more accurately assessing health risks." Consequently, it is natural that "employers may control their premiums for large-group experience rated health insurance policies or the costs of self-insurance by discriminating against genetically high-risk individuals in the hiring process." Analogously, it is alleged that if employers are allowed to discriminate against employees who have genetic defects in this way, "it would be inequitable to not allow insurers to create fair risk ratings based on genetic information."  

106) Id. at 556.  
107) Id.  
108) Id.  
109) Id.  
110) Id. at 556-57.  
111) Id. at 557.  
112) Id.  
113) Id.
2. Opposing Arguments for Use of Genetic Information by Insurers

Many arguments against insurers’ use of genetic information are presented and now I will review these arguments in turn, according to Holmes’ description.

a. Use and Availability of Genetic Information Is Subject to Abuse

The first argument asserts that the use of genetic information by insurers “would produce essentially unfair discrimination and unfair results.” It is alleged that “[i]njecting genetic risk information into insurance underwriting will result in ever more refined classifications and ratings, thereby increasing the difficulty for many applicants in obtaining affordable health and health-related insurance coverages.” 114) This is because “the only individuals allowed to purchase reasonably priced health and health-related insurance coverages are those who are born with ‘healthy genes.’” Accordingly, “[a]llowing insurers either to mandate genetic testing of applicants or to have access to an applicant’s voluntary genetic tests can lead to abuses that will result in unfair discrimination.” 115)

Holmes refers to many cases where applicants who are asymptomatic or whose family member carries a defective gene were rejected health insurance or denied coverage including a shocking example in which a young, healthy, and productive attorney was denied insurance coverage totally because of the reason that her father may have Huntington’s disease. 116)

This argument is based on the observation that there is a “noteworthy difference” between ordinary medical tests “which reveal the existence of an extant disease or physical condition” and genetic tests “which indicate the presence of genes which may, at some future time and under specific conditions, cause a disease.” 117) For example “if an individual is ... found to have an elevated cholesterol level and a poor result on an exercise EKG [electrocardiogram] ... [and] indicate ... high risk for a heart attack. ... she may be denied coverage ... based on sound actuarial analysis.” However, it is alleged that “[i]f he [another individual] tests positive for this gene [heart disease], but he is a healthy individual, he should not be denied health insurance based solely on the fact that he possesses this gene.” 118) This is because of the reason that “[t]his individual may choose to alter his lifestyle, diet, exercise, and alcohol consumption with the knowledge that the

114) Id. at 558.
115) Id.
116) Id. at 560-61.
117) Id. at 562.
118) Id.
gene is present, and his actions may help prevent the onset of heart disease.\textsuperscript{119)}

Moreover, it is asserted that current genetic tests are still experimental and yield information of uncertain applicability and thus “[g]enetic tests, at this early stage, can offer insurers no more information than they could already obtain by requesting a detailed family history” and therefore, using genetic tests is likely to be subject to abuse by insurers.\textsuperscript{120)}

\textbf{b. Unfair Discrimination in Insurance Pricing and Availability}

\textbf{i. Insurance Requires Fair Redistribution, Not Fair Discrimination}

This argument is based on the concept of fairness which centers on the “freedom to choice” and “right of voluntary choice” and alleges as follows:

Unlike smoking, or other bad habits used in efficient risk classifications, a person’s genetic nature is entirely beyond that person’s voluntary choice. One has the capacity to improve bad habits and develop good habits, but one’s genetic circumstance cannot be improved or enhanced through willful effort in the same way that skills or talents can be improved. Since one cannot choose one’s genetic make-up, arguably there should be no duty to pay more for insurance because of a poor genetic make-up. The nature and purpose of insurance is risk transference and distribution, or fairly redistributing and equally sharing the fortuitous risks among all policyholders. Fair risk sharing is a fundamental insurance principle. Fair risk redistribution is a matter of equal fairness for all of us because all of us are genetically unequal.\textsuperscript{121)}

Consequently, it is asserted that “[b]ecause genetic differences are morally arbitrary, the notion of good or bad genetic luck ought not be the reason that one person receives better or worse insurance treatment than other people. Everyone deserves health care regardless of genetic luck.”\textsuperscript{122)} It is alleged that this argument is supported by the peoples’ belief that “they should not be burdened with bad luck in the genetic draw.”\textsuperscript{123)}

\textsuperscript{119)} Id.
\textsuperscript{120)} Id. at 562-63.
\textsuperscript{121)} Id. at 563-64 (emphases added).
\textsuperscript{122)} Id. at 564.
\textsuperscript{123)} Id.
ii. Misunderstanding and Misuse of Genetic Information

This argument emphasizes the uniqueness of genetic testing and its result and is based on the assumption of the difference between genetic tests and other traditional diagnostic tests such as X-ray or electrocardiograms, etc.

The nature of genetic information is different from other non-genetic information which has been used by insurance pricing and availability in the sense that “[o]nce a defective gene is detected within a family, all of the relatives are stigmatized as being ill or having the disease, even where no other relative ever manifests clinical signs of the disease.”124)

It is alleged that “[t]here are also many differences between genetic tests and the many diagnostic tests performed by physicians upon which insurers routinely rely to assess risks.”125) The diagnostic tests “reveal the presence or absence of specific chemicals, structures, or functions which indicate the presence or absence of a particular disorder”. However, genetic tests are different in the following senses:

Genetic tests can only indicate if an individual is either a carrier of a disease, or if she has a predisposition to developing a particular disorder. Even if a test reveals the presence of a single gene which causes a specific disorder, the test does not indicate when, if ever, the disease may actually be manifested, and genetic tests do not indicate how severe the disease might be if it ever does develop. ... [t]here is no certainty that she will ever become symptomatic and develop disease. In addition, many genetically controlled diseases are multigenic/multifactorial in origin, and an individual may not possess all the genes necessary for a disease to express itself.126)

Consequently, it is alleged that there is a high possibility to misunderstand and misuse genetic information.

iii. Availability of Insurance

Another argument insists that given the escalating costs of health care, using genetic information in the process of insurance underwriting deprives people who have bad genetic luck of the availability of insurance and health care itself.

124) Id. at 566.
125) Id.
126) Id. at 566-67.
This is allegedly because of the following reason:

Insurance has become an integral part of our health care system, and a denial of health insurance, for many, may be the equivalent of a denial of health care itself. Individuals who are denied health insurance based on their genetic make-up may refuse to seek medical care because of an inability to pay for it.127)

At the same time, this argument asserts that this consequence results in adverse effect on insurance companies as well: “Such inaction then shifts the burden of providing health care to the taxpayer, which is what the insurance industry has attempted to avoid in lobbying against a national health care system.”128)

c. Prohibiting the Use of Genetic Information Protects Individual Right to Privacy

The last category of the argument against the use of genetic information by insurers that Holmes describes is based on the concept of individual right of privacy. This argument consists of three assertions: 1) using genetic information can cause stigmatization and psychological trauma; 2) confidentiality must be protected; and 3) preferred social ignorance. This argument alleges that:

Genetic testing and the subsequent use of immutable, potentially stigmatizing genetic information may create a suspect genetic underclass, the ‘genetically inferior,’ in insurance rating classifications and thereby constitute unfair discrimination as a matter of law. Such discrimination based on an individual’s genome should be prohibited as a violation of the individual’s civil rights.129)

Consequently, it is asserted that “[p]rotecting privacy interests by restricting insurers’ unrestrained access to an individual’s genetic information is a matter of basic civil and legal rights. Therefore, any state or federal law authorizing mandatory genetic screening for insurance purposes would violate an applicant’s constitutional right to privacy.”130)

127) Id. at 567.
128) Id.
129) Id. at 569.
130) Id. at 570-71.
i. Genetic Information Can Cause Stigmatization and Psychological Trauma

It is alleged that since there is a genetic ignorance of the third parties, “[a]n inappropriate disclosure of genetic information may stigmatize an individual for life, causing serious emotional, financial, and perhaps physical harm.”\(^131\) Moreover, it is asserted that “genetic screening can cause psychological trauma. Genetic knowledge may have a devastating psychological impact on individuals who are told that they will develop a fatal, incurable disease.”\(^132\) A historical evidence is referred to where the screening program of mandating carrier status of African-Americans for sickle-cell anemia was administered in some states in the early 1970s.

Contrary to ordinary diagnostic tests, genetic tests are more likely to cause psychological trauma because of the reason that “when an individual is informed that she may develop an incurable illness at some indeterminate time in the future, this information may adversely impact her decisions about education, work, marriage, having children, aborting a pregnancy, and so forth.”\(^133\) It is alleged that this is supported by the statistical evidence that “the suicide rate is four times greater among patients diagnosed with Huntington’s disease than among the corresponding American Caucasian population.”\(^134\)

It is alleged that the “[f]ear of ‘stigmatization, job loss, becoming uninsurable, or a heightened personal anxiety’ are all valid reasons for asserting a ‘right not to know’.”\(^135\) Moreover, an adverse effect of this fear is asserted:

> Individuals who fear losing or being denied health insurance may refuse to seek testing. ... People may refuse to undergo genetic testing to determine compatibility with a relative who requires an organ transplant, for fear that the test results may be obtained by insurers and used to deny health care. This may, in turn, result in a decrease of potential donors who are willing to involve themselves in the screening process.\(^136\)

\(^131\) Id. at 572.
\(^132\) Id.
\(^133\) Id. at 573.
\(^134\) Id. (data is relying on Lindsay A. Farrer, Suicide and Attempted Suicide in Huntington Disease: Implications for Preclinical Testing of Persons at Risk, 24 AM. J. MED. GENETICS 305, 305-11 (1986)).
\(^135\) Id. at 574 (original quotation is Dennis Karjala, A Legal Research Agenda for the Human Genome Initiative, 32 JURIMETRICS J.121, 165 (1992)).
\(^136\) Id. at 574.
ii. Confidentiality Must Be Protected

Another argument based on the right of privacy alleges that the confidentiality of genetic information must be protected given "the immutable nature of genetic status" and computer-assisted data bank. It is alleged:

Insurers utilize systems of national data banks that allow them to keep track of those individuals who have tested positive for certain disease.... Insurers exchange information about people through the Medical Information Bureau ("MIB"), a data bank that contains medical information about insurance applicants. ...If genetic information makes its way into these files without the appropriate legislation in place to control the manner in which the information can be used, the results will be devastating.137)

iii. Preferred Social Ignorance

The final argument which supports the right to privacy is derived from "preferred social ignorance". It is stated that "[w]e can control our health to a certain extent through voluntary lifestyle choices: exercising, refraining from smoking, and developing healthier habits. On the other hand, we cannot control our genes."138) And this uncontrollable nature of genetic draw leads people to likely make the decision that "we may choose to live behind what the philosopher John Rawls refers to as the 'veil of ignorance'."139) Holmes states the implication of this Rawlsian theory of justice in the genetic discourse as follows:

Rawlsians posit a hypothetical state during which citizens do not know their race, their class, or their genetic make-up. Standing behind this veil of ignorance before the formation of the social contract, people would most likely not select rules that penalize individuals based on arbitrarily, or fortuitously, assigned characteristics such as genetic diseases. In this hypothetical initial position, all citizens have a common interest in obtaining health insurance. ... [E]ach citizen would perceive himself or herself as potentially in the "worse-off" insurance rating classification

137) Id. at 575.
138) Id. at 576-77.
139) Id. at 577 (referring to Marc A. Lappe, Justice and the Limitations of Genetic Knowledge, in JUSTICE AND THE HUMAN GENOME PROJECT 153 (Timothy F. Murphy & Marc A. Lappe eds., 1994)).
and prefer, in self-interest, to protect the interest of those insurance applicants most disadvantaged by risk classification.\(^{140}\)

Consequently, it is alleged that our preferred social ignorance is a ground to support the right to genetic privacy, and hence, the use of genetic information by insurers should be forbidden legally.

D. Richard A. Epstein

Libertarian Argument: Open Access to Genetic Information

—Anti-Discrimination Laws Create Fraud, Deception, and Concealment—

One of the strongest theoretical arguments criticizing the anti-discrimination laws protecting genetic information is presented by Richard A. Epstein. In this section, I review his libertarian arguments.

The first thing I should note is that in Epstein’s framework, the issue concerning genetic information is not a new problem since as his article’s subtitle *Old Responses to New Technology* shows, in his view, the genetic discrimination issue is nothing different from other types of traditional discrimination such as race or gender discrimination. Thus, Epstein applies his analytic framework that he addressed in basic discrimination to the issues concerning genetic discrimination.

According to his framework, to support anti-discrimination laws means to justify fraud and deception or concealment and therefore it is unfair. And also anti-discrimination laws result in situations where “positive rights destroys negative liberties.”\(^{141}\) Epstein asserts that “current anti-discrimination laws should be repealed insofar as they apply to private competitive employment market.”\(^{142}\) He relies on “libertarian bent” and explains “why a system of free entry and open markets can better cope with invidious forms of discrimination in employment markets than any system of government mandated and forced norms.”\(^{143}\) In the view of Epstein, government intervention is justified only if it has valid reasons: “(1) to counter the use of private aggression; (2) to limit the operation and influence of private monopolies; and (3) to provide for classical public goods that cannot be supplied by a network of contractual arrangements, given the risk of holdout and

---

140) *Id.*
142) *Id.* at 1.
143) *Id.*
However, antidiscrimination laws satisfy none of these criteria.

Here, let me review the details of his arguments. First of all, Epstein formulates the basic issue as "the question to be faced by society is whether the state, employers, and insurers ... should be allowed to take into account genetically derived information that reveals an individual's prospects for future disease and incapacity." Then, he states that "[a]t a theoretical level, the issue is what should be done to regulate the flow of information that indicates that persons have, or are susceptible to, certain kinds of genetic disease." The starting point of Epstein's argument rests on his understanding that genetic discrimination is "the inescapable issue and truth," and thus the key question at stake is "[w]hat kind of response is appropriate?" His following arguments are addressed in order to reject anti-discrimination laws as an appropriate response.

For Epstein, the implication of supporting antidiscrimination laws means nothing different from admitting fraud and misrepresentation legally.

Epstein asserts that antidiscrimination laws create asymmetrical information and adverse selection will be triggered, and insurance companies will behave to protect themselves in the following way:

A person who knows that he is at risk for Huntington's disease has a strong incentive to acquire life and health insurance for the condition. This is because the expected payoffs are far greater than the stated premiums, which are based on the life expectancy and health needs of ordinary persons. Once this asymmetry is known to insurance companies, they have a counterincentive to equalize the information so that they can either avoid the risk altogether or charge a premium commensurate with its severity.

On the other hand, Epstein points out a paternalistic merit of genetic tests on behalf of all at-risk individuals of the genetic disease:

144) Id. at 1-2.
145) Id. at 2-3.
146) Id. at 6.
147) Id. at 2-7.
148) Id. at 5.
149) Id. at 9-10.
Uncertainty places enormous burdens on all at-risk individuals, including those who are actually free of the [Huntington’s] disease. But with a perfect and costless test, fifty percent of the at-risk people will have a great weight lifted from their shoulders and will be able to lead normal lives from that point on. And what of the fifty percent who receive a death warrant? First note that the test does not cause the disease; it only delivers the bad message. Yet that message is not all bad. With the knowledge of the certain eventual onset of the disease in hand, extensive planning may be done—even absent information about exact date of onset.\(^{150}\)

Epstein asserts that “the plea for privacy is often a plea for the right to misrepresent one’s self to the rest of the world.”\(^{151}\) He asserts that:

> False statements about or deliberate concealment of genetic information is as much a fraud as false statements about or concealment of any other issue. The only possible justification for concealment, therefore, would be that it is unfair for the person with the pending disorder to deal alone with the suffering and financial loss. Yet, that loss is not sustained because of the wrong of another.\(^{152}\)

Epstein insists that “genetic discrimination raises problems no different from those associated with any other sort of misfortune, and calls for no different response. The greater knowledge that comes from testing increases the information asymmetries that are always the bane of insurance markets.”\(^{153}\) Therefore, he states that “[f]ull disclosure of material information in response to direct questions is an indispensable part of that [insurance] system.”\(^{154}\) He also asserts that “[t]he person who wants privacy need not apply for the position or the insurance coverage. But he should not be able to have it both ways, and at someone else’s expense.”\(^{155}\)

Moreover, Epstein asserts that “the prohibition against genetic discrimination

---

150) Id. at 10.
151) Id. at 12.
152) Id. at 13.
153) Id.
154) Id.
155) Id.
should be seen for what it is—an elaborate set of cross-subsidies that reduces the total level of social wealth as it transfers wealth between parties.”

Epstein notes that employers do not discriminate against employees without any good reason:

Employers have no incentive to discriminate against workers whose genetic conditions do not impose any cost, present or future, against them. Insurers have no incentive to discriminate against applicants whose genetic conditions pose no future risk. But both of these groups do have strong incentives to discriminate against parties who do pose greater risks. Efforts to keep genetic information secret do not make sense because employers and insurers are irrational.

Thus, Epstein asserts that “anti-discrimination principles have forced employers to behave irrationally by requiring them to ignore the known cost differentials of employing certain groups.” He notes that this is also true in the insurance setting, that is, “[i]f a person is a carrier of a deleterious gene, and the person’s offspring are covered under a proposed insurance contract, a decision by the insurer not to cover is not irrational, given the greater costs that are imposed.” Epstein also mentions that in the adoption context, it seems “wholly inappropriate to ignore genetic information.” And he asserts that “serious criminal sanctions should be imposed on anyone who misrepresents his health status on an issue [adoption] of this importance.”

Consequently, Epstein asserts that anti-discrimination laws force employers and insurers to behave irrationally and result in creating “implicit cross-subsidies.” He concludes, therefore, that anti-discrimination laws are not appropriate responses to genetic discrimination.

Then, what Epstein suggests as alternative proposals or responses which deal with the question of genetic discrimination are: 1) “do nothing collectively at all, at least through the government” and rest on “charitable efforts” made for handicapped; 2) expect “technical innovation” which “can produce new workplace
equipment that will assist disabled workers to assume more productive lives.”

As I have seen, Epstein points out the hidden costs and implicit cross-subsidies with which employers and insurers are forced to be burdened due to the structure of imperfect and asymmetrical information resulted from anti-discrimination laws. And he asserts that “[t]he subsidies must be made overt, and they must be in the form of direct charges against the public purse.” If the government interferes legally with employment or insurance contract by anti-discrimination laws, he continues to state that “the government should fund the additional costs associated with hiring or insuring individuals with genetic defects.” For example, “[i]f that cost [hiring or insuring people who have genetic defects] is $10,000 per year, and the cost of hiring or insuring ordinary workers is $1,000 per year, then government should fund the $9,000 difference from general revenues.”

Epstein describes three differences between tax route (subsidy tax) and anti-discrimination law: 1) “the anti-discrimination laws certainly cannot guarantee that social burdens will be distributed uniformly over society”; 2) “the use of the anti-discrimination law is likely to increase the total amount of expenditures for dealing with genetic discrimination beyond what they would be with a system of taxes and subsidies”; 3) “the anti-discrimination approach often leads to the adoption of general and neutral rules that are inefficient for the firm and society at large.”

As you may see, the bottom line in his argument is that anti-discrimination laws generate enormous costs that employers and insurers have to be burdened with. And it is not fair to impose such costs on them, and the burdens should be distributed uniformly over society. Epstein concludes by stating:

> [T]he economics literature points out the difficulties that arise when parties have to make joint decisions on the basis of imperfect and asymmetrical information. A sound system of law should allow parties to eliminate both forms of bias in making their decisions. The present attack on genetic discrimination only exacerbates these problems.

Regardless of whether or not we agree with libertarian arguments, what we have to take seriously from Epstein’s argument is the inescapable question of who would
compensate the costs given as a consequence of passing anti-discrimination laws. Next, I review one of the latest arguments which discuss this issue.

E. Colin S. Diver and Jane Maslow Cohen (Economic Analysis Approach)

One of the recent strong arguments criticizing legal prohibition on using genetic information is presented by Diver and Cohen. Here, I review their arguments addressed in their recent article rhetorically titled "Genophobia: What Is Wrong With Genetic Discrimination?"

First of all, their argument is the same as the arguments presented by law and economics theorists, that is, antidiscrimination laws diminish allocative efficiency which is one of the most important values in the open market. They begin by explaining the open market function:

Voluntary exchange between two willing and informed individuals is the paradigm of efficiency-enhancing transactions. ... according to most versions of utilitarian or social welfarist ethics, society should not only permit, but indeed encourage, its members to engage in voluntary transactions. Any form of government regulation, such as a prohibition on “genetic discrimination,” that interferes with the terms on which individuals may contract, is thus presumptively efficiency reducing. ... “Market failures” such as coercion, information asymmetries, or harmful externalities may cause individuals to enter into transactions that reduce their own welfare or that of third parties”. 167)

They argue that antidiscrimination laws create “information asymmetries” because these laws prohibit one contract party such as insurers and employers from accessing genetic information of another party who has the genetic information. On the other hand, another side of this argument, free access to genetic information enhances allocative efficiency in the market.

In the angle of open market, they assert “[i]nformation from genetic testing can improve the efficiency of health insurance markets by enabling insurers to classify risks more accurately and thus equate the price of coverage to its value.” 168)

168) Id. at 1465.
Persons who know that they are in an elevated risk category will thus have an even stronger incentive than at present to increase their insurance coverage, so long as insurers are unable to identify them in advance as high-risk and are therefore unable to place them in appropriate risk classifications.  

Diver and Cohen discuss that without using genetic information, “by using such techniques as medical underwriting, exclusion of preexisting conditions, and the structure of deductibles and coinsurance provisions,” insurance companies cannot “combat the allocative distortions caused by adverse selection” or “information asymmetry.” Consequently, they assert that “the asymmetrical treatment of genetic information by the incoming privacy regime [legal prohibition on insurers’ using genetic information] almost surely diminishes the allocative efficiency of individual health insurance markets.” They support “a market premised on full transparency of genetic information.”

Next, Diver and Cohen criticize the one common argument delivered by proponents of genetic antidiscrimination laws asserting that free access to the genetic information discourages genetic testing. They summarize the argument from privacy advocates.

[W]elfare losses caused by distortion of employment and insurance markets will be offset by welfare gain produced by removing an impediment to genetic testing. ...many people are likely to be discouraged from seeking genetic testing for fear that adverse results will be disclosed to, or demanded by, prospective employers and insurers. ... a legal prohibition on the use of genetic tests data in insurance and employment would thus unleash the therapeutic and ameliorative benefits that could flow from widespread use of predictive genetic testing.

Diver and Cohen object to this argument by stating:

---

169) Id. at 1466.
170) Id. at 1466-67.
171) Id. at 1467.
172) Id. at 1468.
173) Id. at 1468-69.
When a person decides not to undergo genetic testing, she is presumably deciding that her net utility would be reduced: that is, that the costs (including not only the direct cost of undergoing the testing, but also the expected adverse impact that the resulting knowledge would produce on both her economic prospects and her psychological state) outweigh the benefits (in terms of the improvement in her, and perhaps her offspring's, health that could result from ameliorative actions). 174)

Consequently, they conclude that "the encouragement of genetic testing does not provide a convincing welfare-based argument to prohibit the use of genetic test results in employment or insurance." 175)

Next, the argument which supports legal protection on genetic information by resorting to equality of opportunity is considered. This argument is based on distributive justice deriving from egalitarian ethics stating that "every human being deserves an equal opportunity to achieve her potential or her life goals and that a just society, therefore, has a moral obligation to redress barriers to equal opportunity." 176)

The argument based on equality of opportunity is as follows:

[I]ndividuals should not suffer social disadvantages as a result of factors beyond their control. A person's success in the "race of life" should be determined, not by the "brute luck" of the natural or social lottery, but only by the extent to which she uses her talents and opportunities. One deserves, by this account, only what one chooses. One does not morally deserve unchosen and uncontrollable attributes, nor the adverse consequences that flow from possessing such attributes. 177)

They call this argument "the brute luck version of egalitarianism" which "implies that the genetically unlucky should have a claim to some sort of compensatory treatment to offset their innate disadvantage." 178)

Their objection to this argument is addressed as follows:

174) Id. at 1469.
175) Id. at 1470.
176) Id. at 1471.
177) Id. (the phrase "brute luck" is labeled by Thomas Scanlon. See From Chance to Choice: Genetics & Justice 67 (Allen Buchanan et al., Cambridge Univ. Press 2000).
178) Id. at 1471-72.
[A] job applicant obtains a job despite knowing—and, indeed, concealing—information that would reveal limitations on productivity. The advantage gained by such a person comes at the expense of not only the employer, but also another disappointed job applicant who is presumably better qualified for the job. Indeed, if a ban on using genetic information makes it more difficult for employers to verify the accuracy of the health-related questions that they are permitted by law to ask, then the policy may have the consequence of benefiting the dishonest at the expense of the honest. Likewise, adverse selection in insurance penalizes not only the insurance company, but also other insured persons, a portion of whose premiums must contribute to the subsidy.  

Here, a rhetorical question is posed of "[h]ow, then, can a victim of genetic misfortune be considered morally entitled to demand employment or insurance, at the cost of corporations or individuals who have, by hypothesis, neither caused her genetic impairment nor consented to bear responsibility for its alleviation?"  

As Diver and Cohen point out, antidiscrimination laws force not only employers and insurance companies but also other honest or healthy insureds or job applicants or employees to take the burden of costs resulting from prohibition on using genetic information. Therefore, one implication of the antidiscrimination laws is to admit an unfairness between the parties. Who and which institution should have to be burdened with the cost resulting from antidiscrimination laws is an open question that needs to be answered. This issue will be discussed in the latter part of this paper.  

They also criticize the arguments resorting to necessity of health insurance and invidious discrimination resulting from free access to genetic information.

According to Diver and Cohen,

[t]he brute luck version of equal opportunity argues that a just society should readjust the point from which the genetically unlucky begin the race. One plausible way to accomplish this objective is to provide to every individual at least a minimal allotment of goods and services deemed indispensable to the pursuit of life’s goal. Among such goods and services, so it could be argued, are health insurance and

179) Id. at 1472.
180) Id.
employment. ...in the context of contemporary America, health insurance and employment should be considered as essential ingredients of a decent life. In a world of unpredictable health risks and highly specialized, expensive health care, health insurance should be understood as an essential means of protecting people against crippling financial losses....

Diver and Cohen give three objections to this argument. The first reason of objection is that necessity does not justify compelled altruism: they state that "[i]f a drowning man cannot demand that a passer-by save his life—the ultimate "necessity"—why can a genetically, disfavored person demand that a particular insurer offer him subsidized insurance or a particular employer offer him a subsidized job?"

The second reason they present is resorting to people's diversity of preferences. They state that "individuals...attach differing values to goods such as health insurance coverage or employment.... [For example,] [t]hose who are severely genetically disadvantaged...might place an especially high value on access to high-limit health, disability, or even life insurance [but] [t]hose who are mildly disadvantaged might place a higher value on access to a high-paying or particularly secure job. [Therefore, they assert that] the ethically superior means of providing even 'necessities' is a cash subsidy, not merit goods [blanket banning on using genetic information]."

Their third reason seems to be derived from the second reason and based on their belief that "even if one accepts that society has an obligation to provide employment and health insurance protection, the antidiscrimination strategy [laws] is particularly ill-suited to serving that goal."

In the context of health insurance, "egalitarians have argued that the state should provide every citizen protection against the consequences of the most common and devastating of health risks." They agree to what they called this minimum-benefit approach to equal opportunity. However, they do not agree to the argument asserting that to achieve this goal, antidiscrimination laws are appropriate means, and insist that "[a]ssuming that some minimal level of health insurance coverage is a necessity, the government should provide the benefit directly, as it does (albeit

181) Id. at 1473-74.
182) Id. at 1474.
183) Id.
184) Id. at 1475.
imperfectly) in the Medicare or Medicaid program, or indirectly through some form of subsidy or tax benefit.\textsuperscript{185}

The prohibitionist strategy [argument supporting antidiscrimination laws]...provides a (hidden) subsidy to any person who might be discriminated against for genetic reasons, regardless of financial or other need. More importantly, the antidiscrimination policy subsidizes the purchase of any level of insurance that the beneficiary might choose to obtain, not merely some basic minimum level of coverage. Because the value of the implicit subsidy surely increases as the level of coverage increases, such a policy gives beneficiaries an incentive to consume far more than the level of coverage that any plausible egalitarian theory would deem minimally necessary. It is as though the government sought to combat malnutrition by requiring all food-service establishments, from the neighborhood soup kitchen to the Michelin three-star restaurant, to give the malnourished a fifty percent discount on the price of every meal.\textsuperscript{186}

Diver and Cohen also raise an objection to the argument asserting that genetic information is closely akin to other forms of morally condemned invidious discrimination. According to this argument, “discrimination on genetic grounds...is morally indistinguishable from other forms of discrimination, such as racial or gender discrimination, that are widely condemned. These latter forms of discrimination are, after all, based on genetic attributes.”\textsuperscript{187}

However, Diver and Cohen present a counterargument by stating as follows:

Consider intelligence—a trait, or rather a congeries of cognitive information storage and processing abilities, with undeniable genetic roots. If genetic discrimination were per se immoral, how could we possibly condone the nearly universal use of intelligence measures in education, employment, and other settings? The same could be said for other attributes such as aggressiveness, stature, obesity, or physical beauty.\textsuperscript{188}

\textsuperscript{185} Id.
\textsuperscript{186} Id.
\textsuperscript{187} Id. at 1475-76.
\textsuperscript{188} Id. at 1477.
Indeed, the labeling of a condition as a “disease” often reduces social 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.  

In sum, as I have seen, Diver and Cohen assert the genetic privacy protecting regime is not an appropriate choice of means to provide redress for genetic inequalities. They suggest a regime of “genetic transparency,” a policy dissemination of information as a morally attractive alternative response to genetic inequality. They conclude that “only a regime of genetic transparency can enable our society to confront openly its phobias about genetic diversity and begin, at last, fully to appreciate its blessings.”

III. Adverse Selection

In this Section, I examine the so-called “adverse selection” issue because, as we have seen in the arguments of every commentator in the previous sections, it has been referred to as one of the most compelling justifications for using genetic information in the insurance arena and it would be one of the most persuasive grounds against anti-discrimination laws.

As discussed before, genetic-specific anti-discrimination laws have practical and normative problems which stem from genetic exceptionalism. I pointed out that if we intend to prohibit genetic discrimination, the law should be designed to forbid the use of all predictive medical information because in practice it is impossible to distinguish genetic information from other medical information, and moreover in theory it is not morally equal and fair to protect only individuals with genetic health problems and not protect individuals with non-genetic health problems against discrimination. Therefore, I argued that the real issue that we have to discuss seriously is whether or not we should prohibit legally the insurers and employers from obtaining and using all predictive medical information in their decisions in order to prevent discrimination. However, as I stated before, this is or should be an
open question because the present and the long-standing health insurance system in the U.S. has taken predictive medical information into consideration in the underwriting process, and it has been regarded as actuarial fairness to do so. Thus, banning the use of all predictive medical information means a paradigm shift of the entire present insurance system.191) The question here is whether this paradigm shift is justifiable or not. To answer this question, we have to examine the reasons of both sides of the argument for and against using all predictive medical information. One of the prudent approaches to explore this issue seems to be in examining the implication and consequences if the law prohibits the use of all predictive medical information. One of such consequences is caused by adverse selection.

A. Practical Problems of Adverse Selection

As we have seen in the arguments in the previous sections, adverse selection is referred to as "the greater tendency of those posing a comparatively high risk to seek insurance than those posing a comparatively low risk."192) Or it means "that people who have undergone testing and have tested positive for a genetic disorder will attempt to buy as much insurance as they can to cover the cost of future illness when the genetic disorder expresses itself."193) Adverse selection occurs when the law prohibits insurers from considering future risk—predictive medical information of policyholders.

Kirke D. Weaver addresses the scenario of adverse selection with a good example.

For instance, many individuals do not generally think about the possibility of catastrophic illnesses like Alzheimer’s disease. Therefore, they do not purchase long-term nursing home care insurance, that would provide for extended nursing home residency. However, if an individual discovers that they have a genetic abnormality which increases his or her chance to develop Alzheimer’s disease, that individual will be more likely to purchase long-term nursing home care insurance. A simple

---

example involves life insurance. Many individuals do not purchase life insurance or purchase very little, because death seems like such a remote possibility. However, individuals who discover that they have an increased risk of developing breast cancer or could develop Huntington’s disease have a greater incentive to purchase life insurance coverage in order to help provide for their family after their death. These individuals will purchase more insurance because of an increase in their perceived need for the coverage. Furthermore, the individuals will attempt to obtain the insurance without informing the insurance company or their self-insured employer of their condition, in order to obtain lower insurance rates. Because insurance companies determine the cost of their policies by calculating general risk patterns among large segments of the population, this increase in insurance coverage for high-risk individuals would force insurance companies to alter their rate structures for all insured individuals if the insuring companies were not permitted to inquire about genetic conditions. This over-insurance by genetically defective individuals causes lower risk individuals effectively to subsidize the health care of the higher risk, genetically defective individuals. If insurance companies cannot use genetic screening as part of their application processes, the companies will have no choice but to raise insurance rates for everyone. Therefore, employers could implement a policy of genetic monitoring or screening and potentially reduce the cost of insurance coverage. 194)

Chetan Gulati describes the scenario of detrimental adverse consequences of adverse selection on the insurance industry as follows:

[N]ot knowing what their individual risk of needing expensive medical treatments will be, rational, risk-averse actors assume the worst-case scenario and purchase insurance accordingly. Therefore, individuals who know that they are very likely to develop a disease that will require costly medical services will have an incentive to purchase a “gold-standard” insurance plan—or, will purchase “more insurance”—that will ensure that they will have first dollar coverage for the treatment of the

194) Kirke D. Weaver, Genetic Screening and the Right Not to Know, 13 ISSUES IN L. & MED. 243, 249-50 (1997).
diseases they are most likely to develop. Even though this plan may have higher premiums, individuals armed with information of their own riskiness will enroll in it because it represents a savings over what they would have to pay out-of-pocket if they purchased a different plan. Alternatively, individuals who know that they are unlikely to require expensive medical care, at least in the near future, may choose to purchase a cheaper, and less comprehensive plan. Therefore, individuals who get genetic screens and test negative for a variety of genetic disorders may elect to purchase less insurance. As high risks separate from low risks, the cyclical adverse consequences of that selection set in motion. The results of this cycle would be that premiums would rise and fewer people would be able to afford health insurance. Thus, adverse selection would likely result in catastrophic failures in the insurance industry. 195)

I summarize this scenario in the following way: Legal prohibition on the use of predictive medical information creates asymmetry of negative genetic information on future risks → high risk individuals buy more insurance disproportionately → increase premiums of all policyholders to maintain the solvency of the insurance companies → low-risk insureds leave the pool (plans) → death (downward) spiral of premium set in motion → result in collapse of the insurance market → ultimately create many uninsured people.

Jeremy A. Colby presents counterarguments against insurers’ adverse selection arguments:

First, the adverse selection argument assumes that low-risk insureds will discontinue their insurance coverage because of increased premiums, although there is no explanation of where low-risk insureds would get alternative risk management services. Second, insurers profitably insure the existing pool of insureds, a pool composed of the same low- and high-risk insureds whom they would ensure under a system not based on genetic information. Third, adverse selection would only affect the ten percent of the insurance market that is medically underwritten. Fourth, insurers may pool risk across the individual insurance market insureds

because "the actual financial losses for the pool will be close to the aggregate financial losses predicted for the pool by an insurance company." Finally, insurers may limit the effects of adverse selection by charging higher "unfair" premiums only for policies offering unusually rich benefits that most people would not opt for unless they knew of a genetic defect.196)

Gulati also presents five principal arguments asserting that adverse selection will not have a significant impact on the commercial health insurance system:

1. if all insurers are subjected to the laws, no single insurer will be disproportionately hurt and thus the cyclical consequences ... will be avoided;
2. low-risk insureds will not withdraw from the plans even if premiums increase;
3. because only a small percentage of the population would be affected by the laws, there would not be enough plan switching, or purchasing of more insurance to create adverse selection problems;
4. adverse selection problems will be limited to highly specialized plans that priced anticipating selection; and
5. the fact that states have passed genetic antidiscrimination laws without suffering the force of adverse selection is proof that its impact is limited.197)

However, Gulati asserts each of these propositions has flaws. According to Gulati, the first argument asserting that "adverse selection will not become problematic because all insurers will be equally affected, and thus no single insurer would be at a competitive disadvantage relative to other health insurers" is flawed for the following reasons.

Initially, it presupposes federal, uniform, regulation, including that of self-insured plans. If only insurance companies regulated by the states are not allowed to differentiate, they will end up with a larger proportion

of the highest risk population, putting them at a disadvantage vis-a-vis self-insurance. Also, companies that have healthier workforces and are enrolled in group plans will have an incentive to withdraw from those plans and to self-insure. In addition, any uneven distribution of high-risk individuals in a particular plan could start an irreversible adverse selection cycle. A particular insurance company, by chance or by having a plan that is attractive to those at high risk, could end up with a disproportionate pool of high-risk individuals. If this imbalance occurs, these plans will be unable to prevent the addition of more high-risk individuals using price differentiation. Thus, they would have to change their scope of coverage or raise the premiums for all of their enrollees. As a consequence, low-risk insureds will have an incentive to switch plans and the price of the plan will spiral upwards. Finally, there is still the problem that accompanies the purchase of more insurance by high risk individuals. Namely, if the law does not prevent high risk individuals from purchasing more insurance, the price of the insurance package goes up for all insureds and thus fewer people are able to afford to purchase insurance.198)

Gulati also notes that the second argument asserting that “adverse selection will be limited because low-risk insureds will not withdraw from their insurance plans when they are forced to pay increased premiums” is also dubious.

The immediate problem with this argument is that it ignores the fact that some people would not be able to pay higher premiums. Additionally, this argument implicitly assumes that low-risk insureds would not have any attractive alternatives and therefore will remain in their plans and continue to pay the higher costs. This ignores the fact that low-risk individuals could pool among themselves by way of purchasing plans that are cheaper and do not provide first-dollar coverage for expensive medical treatments. In other words, they could pool themselves into plans that have more limited coverage and charge higher co-payments. These plans would be unattractive to an individual who knows that they have a predisposition to disease and may require very expensive care. Thus, even if every insurer is not allowed to differentiate, there are other

198) Id. at 186-87.
ways in which the market can segregate individuals once those individuals are armed with the knowledge of their own genetic profile. In summation, the flaw in this argument is that it assumes that insureds have two choices, to be insured or uninsured, it ignores the myriad of options relating to the amount of insurance they purchase. 199)

According to Gulati, the third argument asserting that “[t]he threat of adverse selection is also not suppressed by the fact that only ten percent of the insurance market is medically underwritten” is not persuasive for the following two reasons.

First, . . . there is mounting evidence that because of the new economy and employers’ desire to switch their employees into fixed contribution schemes, more people may soon be purchasing health insurance as individuals. The impact of more individual purchasers, whether they be individuals purchasing insurance with their own dollars or with their employers’ dollars (vouchers), is that the market for health insurance will become more disaggregated thereby decreasing the mitigating impact of group purchasing on limiting adverse selection. In the case of fixed contribution systems, employees will have an opportunity to select from a variety of plans and options. Thus, those employees that are aware that their own genetic profile, or the profile of one of their family members, puts them into a high-risk category will want to use their voucher to purchase a plan that gives them more comprehensive coverage. They will be willing to pay some of the premium out of pocket in order to secure this insurance. On the other hand, an employee who has a clean bill of genetic health may be induced to purchase a less comprehensive plan. . . . The second . . . individuals may purchase supplemental or additional health insurance coverage if they know that they are particularly susceptible to illness. Thus, a person who finds out that they have a high probability of developing a disease for which their insurance plan does not cover will have an incentive to either purchase supplemental insurance or an entirely separate individual policy. For example, those who learn that they will likely develop Alzheimer’s disease will have a strong incentive to purchase long term care. 200)

199) Id. at 187-88.
200) Id. at 188-89.
Moreover, Gulati argues that the fourth argument asserting that "insurers may limit the effects of adverse selection by charging higher 'unfair' premiums only for policies offering unusually rich benefits that most people would not opt for unless they knew of a genetic defect" is also flawed.

Insurance rates are based, in large part, on the utilization of the average enrollee. Thus, if a policy that provided coverage for particular expensive treatments had the effect of only attracting those who knew that they were predisposed to need the treatments, the premiums for these policies would be so high that they would effectively price many of those who were genetically predisposed to disease out of the market. Therefore, the end result would be no different than up-front genetic differentiation. 201)

Furthermore, Gulati also argues that the fifth argument asserting "the fact that states have passed genetic antidiscrimination laws without suffering the force of adverse selection is proof that its impact is limited" is not persuasive "because of the limited empirical evidence that has been generated in states that have heretofore passed such laws." 202)

While it is true that the kinds of adverse selection cycles described in this subsection have not been set in motion in these states, adverse selection remains a threat. One of the prerequisites for the triggering of adverse selection cycles is reliable knowledge about one's own genetic risks. As noted earlier, this information is currently unreliable and very expensive. Therefore, few people are using genetic test data to make decisions about which health plans to enroll in and how much insurance to buy. In addition, it is possible that the adverse selection cycles are underway but evidence of them is yet to surface. 203)

Accordingly, Gulati concludes that "when the veil of ignorance is lowered on the side of the insureds and that same information is not available to insurers, adverse selection results." 204) And "this adverse selection will drive up the price of

201) Id. at 189.
202) Id.
203) Id. at 189-90.
204) Id. at 190.
the insurance product, making it harder for those in the lower socioeconomic classes to purchase insurance. At worst, the adverse selection will be so strong that it will destroy the commercial health insurance system.\(^{205}\)

However, Mark A. Hall notes that "this [adverse selection] concern has greater force for life insurance than health insurance, because life insurance typically covers a much longer subscription period, with guaranteed rights of renewal. Health insurance typically allows for annual changes in enrollment, price, and coverage."\(^{206}\)

Here, it is important to note that Kenneth S. Abraham points out three factors which distinguish health insurance from life and disability insurance. He regards each of these factors as the reason to support the justifications against health insurers' use of genetic information.

Abraham states that "adverse selection is much less likely to pose a problem in health than in life and disability insurance."\(^{207}\) He notes that "the magnitude of a health insurer's exposure to people who have in fact adversely selected is naturally limited because health insurance provides indemnity only—reimbursement for actual loss. The insurer's exposure is limited by a policyholder's policy limits."\(^{208}\) Contrary to this, "the threat of adverse selection in life insurance... is far greater" because "most life insurance is sold on an individual, rather than group, basis" and also "life insurance typically is automatically renewable annually at the option of the policyholder" and "life insurance has no principle of indemnity that automatically limits the amount of the insurer's exposure to a policyholder."\(^{209}\)

The second factor that Abraham notes is that "much health insurance is sold on a group basis through large employers without individual underwriting. There is virtually no selection by these applicants, and therefore no adverse selection."\(^{210}\)

The third factor Abraham points out is "the view that health insurance is substantially different in another important way from other voluntarily purchased private insurance" because "health insurance is a major vehicle through which the body politic is moving toward ensuring the universal availability of health care."\(^{211}\) In contrast, life and disability insurance "are much more discretionary, serving as

---

\(^{205}\) Id.


\(^{207}\) Kenneth S. Abraham, Understanding Prohibitions Against Genetic Discrimination in Insurance, 40 JURIMETRICS J. 123, 125 (1999).

\(^{208}\) Id.

\(^{209}\) Id.

\(^{210}\) Id. at 126.

\(^{211}\) Id.
consumption items that different individuals choose to purchase in different quantities. Prohibiting life and disability insurers from screening applicants who pose a serious threat of adverse selection could seriously undermine insurers' solvency and thereby threaten the availability of these forms of insurance to the rest of the population. 212)

As has been seen, in the health insurance setting, the scenario of adverse selection does not seem to be serious. Without increasing premiums, insurance companies also can mitigate the adverse effects of adverse selection by using such measures as increasing deductibles or copayment, capping the maximum benefits, coinsurance provisions.

Whether or not the perverse scenario of adverse selection — legal prohibition creates asymmetry of negative genetic information on future risks → increase premiums of all policyholders → low-risk insureds leave the pool (plans) → death (downward) spiral of premium set in motion → result in collapse of the insurance market → ultimately create many uninsured people —— will play out this way in reality is not certain at the present time because empirical data have not been accumulated to answer this. However, even though this scenario becomes true in reality, we can still assert why we have to protect the insurance industry if the present insurance system has a fundamental flaw in offering an opportunity to have access to minimum health care. To speak more boldly, why should we protect the health insurance industry at the expense of the many lives of the genetically unlucky people? The collapse of the private health insurance market is a big social problem and a serious policy concern as long as it results in creating many new uninsured people. However, if the Americans introduce a universal health insurance system as national social security, this concern would no longer exist. Some may still argue that, as the failure of the medical reform attempted by the Clinton administration proves, to establish a universal health insurance system in the short term can not be expected, and therefore, many new uninsured people would be created by the collapse of the private health insurance system. However, if the federal government could create some budget to rescue such uninsured people or could expand the eligibility of the covered entity under the Medicare and Medicaid program as temporal measures until a universal health insurance system is established, the concern for creating new uninsured people could be eliminated. To state it more ironically, it can be argued that it is even desirable if the present private health insurance system collapses because the Americans will be forced to

212) Id.
establish a universal health insurance system and stop depriving the present and all prospective future people with genetic abnormality of obtaining health insurance.213) However, even though adverse selection may not cause a downward spiral and the health insurance system should not be deemed to collapse, it raises a more serious normative problem concerning equality and distributive justice. Adverse selection creates cross-subsidization from low-risk (relatively having a clean bill of genetic health) people to high-risk (relatively having a worse genetic bill) people. Next I will discuss this issue.

B. Normative Problems of Adverse Selection

Eric Mills Holmes notes that “adverse selection is substantially present, low-risk people ‘actually subsidize the insurance purchases of high risks.’”214)

On the normative level, whether the death (downward) spiral scenario triggered by adverse selection is true or not is not a crucial issue. The more important normative issue that adverse selection presents is that it creates cross-subsidizing between low-risk insureds and high-risk insureds. Asymmetry of information is a problem not only between insurance companies and policyholders who know their negative genetic information but also between low-risk policyholders and high-risk policy holders. This is so because asymmetry of information (adverse selection) leads to, whether it is intentional or not, justified forced redistribution of wealth from low-risk policyholders to high-risk policyholders. Indeed, this is the very reason low-risk policyholders opt to flee from the insurance pool. This normative issue cannot be cleared even under the universal health insurance system, although the degree of subsidization or redistribution can somewhat be mitigated. Therefore, subsidization resulting from adverse selection is one of the key issues when we review the arguments for and against a legal legislation designed to prohibit discrimination on the basis of predictive medical information including genetic information. Adverse selection has been seen as the issue in the insurance settings, however, as long as most of the health insurance is provided through employers either in group health plans or self-insured plans in the U.S., it is closely relevant to

213) Such an argument can be found in Chetan Gulati, Genetic Antidiscrimination Laws In Health Insurance: A Misguided Solution, 4 QUINNIPAC HEALTH L.J. 149, 171 n.83 (2001).
the employment field. Moreover, the same structure of asymmetry of negative
genetic information between the employees and employers or among employees
exists, as has been seen in the arguments presented by Richard A. Epstein. He calls
it “fraud,” “deception or concealment,” and “implicit cross-subsidies.” This issue
involves the justice issue which has been illustrated by old and still ongoing
controversies between egalitarian liberal and libertarian or school of law and
economics over social justice and legal intervention with the market transactions.
To address this core issue behind the arguments over the genetic discrimination and
anti-discrimination laws is beyond the scope of this paper. However, here I would
like to confirm that without considering the justice and fairness issue, we cannot
make a persuasive argument and solve the fundamental issues over genetic
discrimination and anti-discrimination and find the way out of the dilemma that
these issues pose – a dilemma that we have to protect people with genetic
abnormality, but enacting genetic-specific antidiscrimination laws results in raising
serious and unavoidable normative problems such as creating inequality and unfair
treatment between the people who have a negative genetic profile and those who
have a negative nongenetic medical profile, and also exacerbating inequality
between the socio-economic classes as we have seen in the arguments presented by
Suter in Part IV-B. In this sense, I agree to Epstein’s understanding in which the
genetic discrimination issue is no different from other types of traditional
discrimination, although I do not agree to his substantial argument and conclusion
to the issue. Accordingly, one of the real issues that requires further discussion and
debate is the question of whether it would be fair to subsidize from genetically
healthy (lucky) people to unhealthy (unlucky) people through the health insurance
system.

III. Conclusion
— Reconstructing the Real Issues for Further Discussions —

My research began with the initial awareness that the Human Genome Project
has already opened the door of Pandora’s box and inside this box there is a book
In the twenty-first century, the advancement of genetic technology would seem to
pose one of the most serious civil rights issues. I believe that in this century genetic
discrimination will be the most serious and widespread class of discrimination in
the legal discourse. Under this understanding, I focused on genetic discrimination
in the health insurance and employment arena and addressed the underlying issues
and problems of genetic-specific anti-discrimination laws and noted that the real issue has not yet been solved and the ultimate question is whether it is justifiable to protect the privacy of all predictive medical information in the insurance and employment context.

In order to answer this question, in this paper I reviewed the arguments and debates for and against the legal prohibition on the use of all predictive medical information, especially focusing on the health insurance setting.

After looking into many arguments delivered by several commentators, I analyzed the so-called “adverse selection” problem because it seems to be one of the most serious unintended consequences on the health insurance industry in the case where the law prohibits insurers from using genetic information in their underwriting process. Indeed, adverse selection has been referred to as one of the most compelling justifications for using genetic information in the insurance arena and it would be one of the most persuasive grounds against anti-discrimination laws. I noted that whether or not the so-called “downward spiral” scenario of adverse selection — legal prohibition creates asymmetry of negative genetic information on future risks → high risk individuals buy more insurance disproportionately → increase premiums of all policyholders to maintain the solvency of the insurance companies → low-risk insureds leave the pool (plans) → death (downward) spiral of premium set in motion → result in collapse of the insurance market → ultimately create many uninsured people — would occur is not certain at the present time because empirical data have not been accumulated to answer this, and also it is not so serious in the health insurance market, contrary to life insurance. Therefore, I asserted that the argument resorting to adverse selection is not strong enough to deny legal prohibitions as a practical reason to preserve the insurance industry.

However, I noted that adverse selection poses a serious problem on the theoretical level. It creates inequality (disparity in information) not only between insurance companies and policyholders but also between low-risk policyholders and high-risk policyholders and this results in redistribution and subsidization from those (low-risk individuals) who have a clean bill of genetic profiles to those who do not. Accordingly, the legal policy which intends to protect all predictive medical information creates unintended unfairness between the policyholders. Historically, treating policyholders differently according to their future health risks (medical information and health condition) has been regarded as an “actuarially sound fair discrimination.” Therefore, prohibiting the use of genetic information is against the actuarial fairness principle in the underwriting and equal risk spreading
process in the health insurance system in the U.S.

Moreover, as has been seen in the arguments presented by Richard A. Epstein, anti-discrimination laws justify fraud, deception or concealment by people with genetic disorders and implicit cross-subsidies caused by adverse selection, and impose the hidden cost on insurance companies and employers because they have strong economic incentives to know the predictive medical information of their policyholders and employees. Accordingly, contrary to my initial expectation, I have reached the conclusion that the arguments opposing legislation banning genetic tests and discriminatory use of genetic information seem to be more persuasive theoretically as long as we presuppose the long-standing private health insurance system in the United States.

I asserted that regardless of whether we accept Epstein's argument or not, the inescapable question that we have to answer is who would compensate these hidden costs resulting from passing anti-discrimination laws. I concluded that a universal national health insurance system like the one in Japan should be introduced in the U.S. where health insurance is provided as a primary goods—social security, as many other countries do. This is simply because in order to receive sufficient health care, health insurance is indispensable to our lives. And also the right to genetic privacy and the right to know and not to know one's own genetic information should be regarded as a fundamental right and should be enlisted in the catalogue of the Bill of Rights of the 21st century. This is simply because genetic information is the most private information not only for the individual but also his/her family and is prone to be very sensitive to discrimination. By introducing some kind of universal national health insurance system, we can solve the problems which impose hidden costs on insurers and employers.

However, we still have to answer another question of what the theoretical grounds are to justify redistribution and subsidization from those (low-risk individuals) who have a clean bill of genetic profiles to those who do not, which would result from introducing a universal national health insurance system. This is not an easy question to answer because as I have mentioned in this paper, there is a fundamental philosophical quandary of distributive justice or fairness over the issue. To explore the question of what is fair in the genetic era, we have to examine the persistent and recurrent theoretical conflict between Libertarianism and Liberalism v.s. Communitarianism over justice and fairness.

Chetan Gulati mentioned this issue by referring to Deborah Hellman:
Drawing on Rawls's philosophy, she notes that from a normative perspective, because good health is generally a matter of luck, people are not entitled to benefit from their good health and thus they have no entitlement to actuarially fair pricing. Hellman then proposes a competing moral view that draws upon the philosophy of Robert Nozick that posits that even if good health is undeserved, people are entitled to the benefits of their good fortune and therefore they are entitled to actuarially fair pricing. Hellman concludes that those who take the Rawlsian position would "likely believe that risk rating is unjustified in most cases" and that "this rationale supports community rating and single-payer schemes." . . . Those who take Nozick's position are likely to believe that forcing healthy individuals to pay for the health insurance of unhealthy individuals is a denial of liberty because it does not allow the healthy individuals to fully exercise their liberty and thus, "this rationale supports the utilization of risk rating by private insurers." 215)

Examining this issue is beyond the scope of this paper. However, I would like to conclude this paper by confirming that without examining this issue carefully, the genetic discrimination issue can not be ultimately solved. Therefore, my research will continue to explore how to reconstruct the concept of fairness and equality in this genetic century.