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Title	Key Issues and Problems of Genetic Anti-Discrimination Laws
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Citation	Osaka University Law Review. 2006, 53, p. 199-242
Version Type	VoR
URL	https://hdl.handle.net/11094/9724
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Key Issues and Problems of Genetic Anti-Discrimination Laws*

*Koichi SETOYAMA***

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* This paper is a 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.

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I. Introduction

In another article in this Law Review,[1] I reviewed current patchwork legal protections against genetic discrimination in the U.S.A. and identified their limitations, including the first Genetic Information Nondiscrimination Act passed in the U.S. Senate. However, the key issues over genetic anti-discrimination laws were not examined. The mission of this paper is to address these issues and also point out the practical and theoretical flaws of the non-discrimination legislation which separate genetic information from non-genetic medical information.

As I reviewed in another paper mentioned above, many attempts to pass the federal bill failed in the U.S. Congress. Some of the reasons for these failures lie in the fact that there were strong political lobby by the health insurance industry and the fact that genetic discrimination was not yet perceived by the majority of the people. However, I believe that one of the main reasons comes from the following problems inherited in the legislation. Even though any genetic-specific anti-discrimination law may have good intentions to prohibit genetic discrimination and protect the genetic privacy of the people, such legislations have serious practical and normative flaws that cannot be easily eliminated by measures. Before addressing these issues, I will look into the key issues of genetic anti-discrimination laws: the scope of genetic information and its definitional problems (Section II-A). I will demonstrate the problems both in the narrow definition and the broad definition by giving several examples. I will also examine the affirmative use of "favorable" genetic information (Section II-B). This issue occurs as genetic tests become cheaper and more common, and people want to use their favorable genetic test results, sometimes called "clean genetic bills", to get insurance at a cheaper price and to take any advantage in career promotion and the like. Another issue that I will examine is "authorized" disclosure and different types of regulatory strategy, and I will explain the importance of prohibiting *access* to and *acquisition* of genetic information (Section II-C).

Then, in Section III, I will discuss the issues of practical and normative problems inherited in genetic-specific legislation. These problems are derived from the so called "genetic exceptionalism" which means genetic information is uniquely sensitive and fundamentally different from other medical information, and therefore it requires and deserves special legal protection. Virtually no genetic-specific

1) *Legal Protection Restricting Genetic Discrimination in U.S.A.*

legislation can be drafted without depending on some version of genetic exceptionalism because defining genetic information is unavoidable and such a practice more or less presupposes that a line can be drawn between genetic and non-genetic information. It will be shown why it is practically impossible to draw a line between genetic information and other medical information (Section III-A). I argue that this practical impossibility to distinguish between the two causes definitional problems in the genetic-specific anti-discrimination laws, and I address how these definitional difficulties of genetic information resulted in both under-inclusiveness (Section III-C) and over-inclusiveness (Section III-B) of the protection against genetic discrimination. However, a more important and fundamental problem inherent in the laws is the normative problem incurred by genetic exceptionalism.

In Section IV, I will demonstrate how genetic-specific anti-discrimination laws produce unequal and unintended consequences that occur between the people with genetically linked health problems and those with non-genetic health problems. I argue that it is not fair for the law to protect only genetic privacy and prohibit only genetic discrimination while leaving the people with non-genetic diseases unprotected. Moreover, this inequality leads to inequality between the classes. These normative problems raise the fairness issue that we all have to answer before we enact genetic anti-discrimination laws. One of the few arguments addressing these issues seriously is presented by Sonia M. Suter. By introducing her insightful arguments in detail, I will point out the fundamental problems of genetic-specific anti-discrimination laws. Here, we face a dilemma: on the one hand, there is a strong need to prevent genetic discrimination, but on the other hand, genetic-specific anti-discrimination laws have unavoidable practical problems and fundamental normative problems which result in unintended unfair consequences. In Section IV-D, I will consider alternative ways to protect all predictive medical information from discriminatory use in the insurance arena. A national single-payer / mandatory community-rating health insurance system will be addressed.

I conclude that the real issue that we face right here is not how to prevent "genetic" discrimination but the very issue that we have to debate seriously is whether or not the law should ban discrimination on the basis of all predictive medical information.

II. Key Issues of Genetic Anti-Discrimination Laws

In the subsequent sections I will address the key issues in drafting genetic-specific anti-discrimination laws and then identify the nature of genetic information as preliminary inquiries for the examination of practical and normative problems incurred by genetic exceptionalism.

A. Scope of Genetic Information: The Problem in Narrow and Broad Definition

One of the most difficult issues that all lawmakers face in drafting genetic anti-discrimination legislation is the scope and definition of "genetic information." Many commentators have already pointed out the serious problems both in the narrow definition and the broad definition. In this section, I will present some such examinations regarding definitional questions addressed by commentators, and demonstrate the difficulties in defining "genetic information."

a. Problems in Narrow Definition

Henry T. Greely gives an example of narrow definition by referring to the Wisconsin Statutes; "a test using deoxyribonucleic acid extracted from an individual's cells in order to determine the presence of genetic disease or disorder or the individual's predisposition for a particular genetic disease or disorder."[2] However, he argues that this narrow definition has "the disadvantage of being easy to circumvent, intentionally or not."[3]

> Genetic information can come from many sources other than DNA tests. Tests for carrier status of Tay-Sachs disease, sickle-cell anemia, and APOE status, for example, have all been routinely done, in the past or in the present, on proteins, not on DNA. Genetic variations involved in these conditions lead the body to produce slightly different proteins, which can be separated out and tested for without dealing with DNA. Those "genetic tests," and others, are routinely done without using any DNA.[4]

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2) Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. PA. L. REV. 1483, 1495 (2001) (quoting WIS. STAT. ANN. § 631.89(1) (West 1997)).

3) *Id.*

4) *Id.*

Greely also points out the problem of the broader version of the narrow definition represented by Michigan's statute which defines genetic information as "information about gene, gene product, or inherited characteristic derived from a genetic test" and a genetic test is defined as "the analysis of human DNA, RNA, chromosomes, and those proteins and metabolites used to detect heritable or somatic disease- related genotypes or karyotypes for clinical purpose."[5)]

> [S]ome genetic information" can be obtained without doing any tests for the purpose of identifying genetic variations. . . . A pediatrician can, with great accuracy, diagnose whether a child has the chromosomal disorder Down syndrome without doing any biochemical tests, through the child's appearance and, later, behavior. . . . similarly, the family history that is part of any good physician's examination reveals some probabilistic genetic information. A person with a parent who died of Huntington disease has a fifty percent chance of carrying the Huntington allele. A person with three or four close relatives, on the same side of her family, who had early-onset breast or ovarian cancer has a much higher than average chance of carrying a mutated BRCA 1 or BRCA 2 gene.[6)]

Suter also addresses a shortcoming in defining genetic information narrowly by limiting it to only the results of a genetic test or DNA analysis:

> [N]ot all genetic information comes from genetic test or DNA analysis. Indeed, of the over 10,000 catalogued genetic diseases, genetic tests exist for only a few hundred. Most genetic information . . . comes from clinical evaluations, nongenetic tests, and family and medical history. As a result, those narrow definitions are under-inclusiveness, leaving unprotected a great deal of relevant and significant genetic information. For example, a family history of Huntington disease (HD), which indicates a fifty percent risk of the condition and is precisely the kind of predictive information that people want to protect, would not fall within the legislatively protected class of information.[7)]

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5) *Id* (quoting MICH. COMP. LAWS ANN. § 550.1401 (West 2000)).

6) *Id.* at 1496.

7) Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 702 (2001).

b. Problems in Broad Definition

Greely points out the problem of the broad definition of genetic information. When he mentions broad definition, it means

> information about inherited genes or chromosomes, and of alterations thereof, whether obtained from an individual or family member, that is scientifically or medically believed to predispose an individual to disease, disorder or syndrome, or believed to be associated with a statistically significant increased risk of development of a disease, disorder or syndrome.[8)]

Greely illustrates "an unintended feedback effect" of the broad definition as follows:

> If a person has been diagnosed with sickle-cell anemia, that is conclusive evidence that she carries two copies of a gene with the particular sickle-cell mutations. If this medical information is treated as genetic information because it yields inferences about genes, the broad definition effectively outlaws all consideration of medical conditions that have some probabilistic association with inherited genetic variations.[9)]

Suter also points out the problem associated with the broad definitions of genetic information covering "information about genes, gene products, or inherited traits that may derive from an individual or family member," which is taken by some state legislatures in trying to avoid the shortcomings involved in the narrow definition. Suter notes that if we adopt the broad definition of genetic information, they also include "information about height, eye color, and sex, all of which are primarily genetic traits. . . . Moreover, they include information about conditions like heart disease, cancer, diabetes, and some mental illness, which have a genetic component."[10)] Therefore, as I will discuss the details later, she asserts that the broad definitions are "over-inclusive, protecting more information than was intended."[11)]

In sum, if genetic information is narrowly defined as limited only to DNA test

8) Henry T. Greely, *supra* note 2, at 1496-97 (citing DEL. CODE ANN. TIT 18, § 2317(a)(2) (2000)).
9) *Id.* at 1497.
10) Sonia M. Suter, *supra* note 7, at 703 (2001).
11) *Id.*

results excluding family history, genetic privacy is not sufficiently protected and genetic discrimination cannot be prevented adequately. If genetic information is defined broadly enough to encompass all of the information about genetic luck, it is impossible to distinguish between genetic information and other medical information. The more genetic technology advances, the more difficult it will become to distinguish between them and find where the line is to be drawn. Therefore, in order to protect genetic privacy appropriately, the law should also protect the privacy of all predictive medical information as well as the so-called genetic information. This definitional quandary inherent in any of the genetic-specific legislations will be discussed in detail in the next chapter. Before that, I will address below, some of the other key issues in drafting genetic anti-discrimination statutes.

B. Affirmative Use of Favorable Genetic Information

As the genetic tests become more advanced and the cost of tests becomes much less expensive, it is not hard to imagine that genetic tests will become common and some of the people who take genetic tests may find that s/he has *favorable* genetic information and a clean bill of genetic makeup while some may find abnormality or defects in her/his genes. Genetic tests may not only create "genetic under-class" but also create "genetic upper-class or genetic elite." Then, there seems to be one issue that has not been paid much attention to in drafting genetic anti-discrimination laws: whether or not we should also legally ban taking into account an individual's favorable genetic information disclosed voluntarily in the insurance and employment settings. In other words, this is an issue related with the authorized disclosure of genetic information and so-called affirmative medical defenses.

According to Colin S. Diver and Jane Maslow Cohen, "[v]irtually all of the extant regulatory measures speak only to the issue of using genetic information to discriminate against individuals. They are silent about the use of genetic information to discriminate in favor of an individual."[12] However, according to the survey conducted by William F. Mulholland II and Ami S. Jaeger on January 15, 1999, "some states explicitly authorize insurance companies to consider genetic information voluntarily submitted by an applicant indicating favorable results."[13]

12) Colin S. Diver & Jane Maslow Cohen, *Genophobia: What Is Wrong With Genetic Discrimination?* 149 U. PA. L. REV. 1439, 1453 (2001).

13) William F. Mulholland II & Ami S. Jaeger, Comment, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317, 319 (1999) (referring to state statutes such as

Mulholland and Jaeger note that "these statutes assume that insurers will respond to favorable test results by reducing premiums and increasing benefits, but they prohibit insurers from acting adversely in response to unfavorable results."[14)]

The issue here is well illustrated by the following questions raised by Diver and Cohen.

> Should a prohibition on the use of genetic information apply only to uses that disadvantage the subject? What if a person, perhaps previously thought to be at risk of a genetic disease, discovers, thanks to a genetic test, that she is not? Can an insurer use that information to place her in a more favorable risk classification? Should a key individual in a corporate hierarchy not be able to provide this kind of reassurance when she is being considered for a move to the top? . . . What, then, is to prevent insurers and employers from inferring that a failure to volunteer favorable information represents the existence of genetic bad news?[15)]

However, they do not present extensive discussion on these questions.

Suppose that the laws prohibit or regulate only the insurers' disadvantageous usage of genetic information of the insureds and employees, then the insurance companies would not be able to force genetic tests or submission of genetic information but may release plans where insurance companies would not use genetic information adversely, such as denying eligibility or limiting coverage or increasing premiums etc., but instead would decrease the premiums if applicants or insureds voluntarily submit their favorable genetic information, that is, clean bill of genetic makeup found by voluntary genetic tests. Likewise, employers would not be able to force job applicants or current employees to undergo genetic tests or to submit genetic information or family history and would not consider genetic abnormality in any adverse way but instead may offer some advantage for applicants in the hiring or placement process or for employees in the promotion decision. In other words, this is the issue of whether or not the individuals who underwent genetic tests and found they did not have any serious genetic abnormalities or genetic predisposition to serious diseases can use such genetic clean bills of their health to receive some advantage in the insurance setting such as

410 ILL. COMP. STAT. ANN. § 513/20 (West 1993); IND. CODE ANN. § 27-8-26-9 (Michie Supp.1998)). *Id.* n.14.

14) *Id.*

15) *Id.*

less expensive premiums, or in the employment setting to prove high possibility of their productivities and their ability for promotion.

Chetan Gulati addresses this question as affirmative medical defenses which "may lead to circumvention" of the genetic legislation.[16] According to Gulati, this "dilemma arises when insureds attempt to use a genetic clean bill of health to secure lower premiums."[17] Gulati states:

> [I]magine that an insurer is allowed to differentiate on the basis of family history and thus charges high insurance rates to a child whose parent died of Huntington's disease. If that individual obtains screening and can prove that he does not have the Huntington's gene, could he then bargain for a normal rate?[18]

Gulati notes that "[s]tate statutes based on the Unfair Trade Practices Act (UTPA) may allow, or even require, insurers to charge this insured a lower rate."[19] And Gulati adds, "[i]t seems that it would clearly be "unfair discrimination" to charge someone a rate based on an actuarial estimate when that individual had proof that they would not get the disease in anticipation of which his/her rates were being set at a higher level."[20]

However, Gulati well addresses the plausible consequences of allowing affirmative medical defenses as follows:

> If individuals are allowed to use affirmative medical defenses, the consequence will be that those who do not use these defenses will pay higher rates. If genetic screening becomes widespread, it is possible that the majority of people who do not use affirmative medical defenses will be those for whom the results of the screen would be no defense at all. Of course, those who do not get tested would also be differentiated against making the price of not being tested very high. As such, more and more people will be induced to forego their desire not to get tested

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16) Chetan Gulati, *Genetic Antidiscrimination Laws In Health Insurance: A Misguided Solution*, 4 QUINNIPIAC HEALTH L.J. 149, 193 (2001).

17) *Id.* at 193.

18) *Id.* at 193-94.

19) *Id.* at 194 (referring to Model Unfair Trade Practice Act § 4(g)(1) (Nat'l Ass'n Ins. Comm'rs 1993).

20) *Id.*

> and to undergo genetic screening in the hopes that they will have a clean bill of genetic health and thereby qualify for a lower premium. Taken to its logical conclusion, the scenario is one in which many of those with genetic predispositions to disease end up being price differentiated against.[21)]

Natalie E. Zindorf also addresses the problem of the issue. She argues that

> some state statutes provide that individuals may submit favorable genetic test results. Although a statute allowing insurers to consider such test results appears to benefit consumers on its face, it ultimately harms most consumers in the long run. ... As a result, the only way premiums can be decreased for individuals submitting favorable results is by raising rates for the entire applicant pool and lowering costs to the test takers. Consequently, the people that refrain from genetic testing or receive unfavorable test results will bear the burden of paying higher premiums.[22)]

Mark A. Hall also is one of the few commentators who address this issue. He articulates the issue here as follows:

> For instance, a person with a family history of Huntington's Disease has a fifty percent chance of having a debilitating degenerative neurological disease. This individual may have great difficulty obtaining both life and health insurance because of the clinical record of their first degree relatives. A genetic test that shows they in fact have the gene and so increases the probability to 100% would not make them much worse off, but a test that shows the opposite would reduce their risk to virtually nothing and so could greatly benefit their insurability. Would these laws bar such favorable use? If so, have they had that effect?[23)]

Based on the observation from the interviews to insurers conducted by Hall, he

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21) *Id.*

22) Natalie E. Zindorf, Comment, *Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance*, 36 TULSA L.J. 703, 720 (2001).

23) Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 JURIMETRICS J. 93, 118 (1999).

states that "[n]one of the few insurer subjects we asked had given these issues any thought, so it appears that favorable use of genetic test results has not arisen very often."[24] Hall also states that "the few insurer subjects and regulators who addressed this issue all agreed that, logically, if the law prohibits adverse use of genetic information, it should also prohibit favorable use." This is because "[u]nderwriters cannot look only at the positive side of a potential source of information. They must either consider both sides, or disregard it altogether. This is not only dictated by insurers' notions of what is fair, but by practical realities."[25]

Hall gives a simple but good example for this reasoning:

> Consider, for instance, allowing younger applicants to disclose their age but prohibiting insurers from inquiring about age. Insurers would simply assume that anyone who does not volunteer the information is not young. Therefore, to preclude age discrimination in rating, states must prohibit any consideration of age, both positive and negative.[26]

Hall also notes that "[t]his logic may not apply with the same force to risk factors that only a few applicants have, such as a single, rare gene defect."[27] This is because "[c]onsidering the Huntington's Disease example above, it may in fact be feasible for only those with favorable test results to reveal them to insurers since those with a family history who do not reveal their results are already regarded as being at greatly increased insurance risk based merely on family history."[28] He goes on to state that "[t]hus, a few states explicitly allow insurance applicants to voluntarily submit favorable genetic test results, or they ban only adverse use."[29]

However, he argues that "as more and more genetic conditions become identifiable, it is more likely that greater portions of the population will be able to demonstrate that they are genetically favored, and so allowing favorable use would undermine the goal of preventing wide scale genetic discrimination."[30]

Some might argue that banning the use of favorable genetic information deprives some people who have a family history of, for instance, Huntington's

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24) *Id.*
25) *Id.*
26) *Id.*
27) *Id.*
28) *Id.*
29) *Id.*
30) *Id.*

disease but are not actually positive, of an opportunity for affirmative medical defenses to show their clean bills of genetic markers and therefore, they are not allowed to buy an insurance policy at an affordable price. In other words, it exacerbates otherwise avoidable discrimination because the law which prohibits considering favorable genetic information also results in preventing such people with an adverse family history from having access to insurance or obtaining it at an affordable price. However, this argument seems to have a flaw because it has a fallacy in which it presupposes an unregulated insurance market. If the law bans any use of genetic information regardless of whether it is favorable or unfavorable, the person who has an adverse family history but actually has a clean bill of genetic markers can buy an insurance policy at the same price as others regardless of whether or not s/he shows favorable genetic information.

Consequently, if the purpose of the genetic legislation is to protect individuals against treating some individuals with gene defects adversely, to use favorable genetic information of some genetically lucky individuals in order to get advantage should also be banned because if the law allows the use of genetic information favorably, it eventually results in almost the same adverse effects for the individuals who do not submit their favorable genetic information. Non-submissions imply that there is a high possibility that they have unfavorable genetic information. Treating persons who prove to have clean genetic bills favorably means that the person who does not submit such a certificate would be treated comparatively disadvantageously. Accordingly, if the purpose to enact genetic anti-discrimination law is to prevent genetic discrimination and to ban treating some genetically unlucky individuals adversely, any law which does not regulate using favorable genetic information in a favorable way has a loophole in its protection. And this means that the problem in genetic discrimination is not only unauthorized or forced disclosure of genetic information but also some type of voluntary and authorized disclosure of genetic information with informed consent.

C. Authorized Disclosure and Regulatory Strategy: Front- / End-loading Approach

When we analyze and review the issues with regard to genetic-specific anti-discrimination statutes, as an analytical frame of reference, it seems very beneficial to examine the different approaches of the regulatory strategy presented by Lawrence O. Gostin and James G. Hodge. In this subsection I examine the "authorized disclosure" issue in the light of regulatory strategy of legislation.

According to them, these state legislations can be characterized as divided into three different approaches in their regulatory protections: Front-loading approach; Information Management approach; and End-loading or Harm Avoidance approach. Under the Front-loading approach, "legislation impedes the ability to generate genetic information by placing restrictions on testing (e.g., informed consent requirements)."[31] They refer to this approach as front-loading because "they provide individual protection up-front, before genetic information is produced."[32] Under the Information Management approach, "laws regulate the collection, use, storage, and disclosure of genetic information."[33] And under the third approach, Harm Avoidance or End-loading approach, "states permit use and disclosure of genetic data, but prohibits certain entities from discriminating based on a genetic status and prohibit certain disclosures to prevent individual discrimination."[34] While the Front-loading and Information Management approaches focus mainly on the generation and collection of the genetic information, the Harm Avoidance or End-loading approach regulates mainly the coverage or application such as whether it applies to group health insurance plans or individual plans. Accordingly, if the statute takes the former approach and defines genetic information as narrowly limited to only genetic test results and excludes family history, then there are many legal loopholes in discriminating against insureds in the underwriting process.

Here, I would like to consider the issue of "authorized disclosure" of genetic information as an example where the approach of regulatory strategy becomes crucial. Generally, genetic-specific anti-discrimination statutes ban only "unauthorized" disclosure and they do not prohibit "voluntary" and "authorized" disclosure of genetic information. Therefore, the issue of "authorized" disclosure has received little public and scholarly attention. However, what is "authorized/ unauthorized" itself and how to achieve the due process of getting authorization (how to eliminate economic and psychological pressures which force authorization, etc.) itself should be the debating issue. Moreover, as I have pointed out in the previous subsection, to disclose favorable genetic information voluntarily (that is, authorized disclosure) has adverse ripple effects on preventing genetic discrimination against other people who want to but cannot give favorable genetic information.

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31) Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End To Genetics Exceptionalism,* 40 Jurimetrics J. 21, 22, 47-48 (1999).

32) *Id.* at 22, 47.

33) *Id.* at 22, 48- 49.

34) *Id.* at 47, 49.

Charles J. Sykes observes that "most attempts by state legislatures to protect genetic privacy have proven to be week and inadequate."[35] This is so because although "many of the laws limit the ways in which employers can use the information, they do not actually restrict access to the information."[36] He notes:

> Most of the legislation seeks to prevent [only] unlawful, inadvertent, and unauthorized disclosure of genetic information . . . a much more significant problem is the *authorized* disclosure of genetic information. As a condition of employment or insurance, individuals can still be required to execute a release authorizing the disclosure of medical (including genetic) information.[37]

Thus, Sykes argues that "if the goal of such legislation is to ensure privacy, then the focus of legislation cannot be limited simply to how the information is *used*—it must be on restricting *access* to the information in the first place."[38]

Mark A. Rothstein is also one of the few commentators who addresses this issue seriously. He asserts that "the bigger problem is the authorized disclosure of genetic information."[39] This is so because

> under the American with Disability Act, as well as the laws in virtually all the states, after an employer makes a conditional offer of employment, it is lawful for the employer to require as a condition of employment that the individual sign a blanket release authorizing the disclosure to the employer of all the individual's medical records.[40]

The employer is "able to obtain genetic information" even if the law makes it "unlawful for an employer to perform a genetic test, and . . . use the results of a genetic test to discriminate in employment"[41] because ordinary medical records "would include the individual's genetic information."[42] Therefore, Rothstein

35) CHARLES J. SYKES, THE END OF PRIVACY 132 (St. Martin's Press 1999).
36) *Id.*
37) *Id.* at 132-33 (emphasis in original).
38) *Id.* at 132 (emphases added).
39) Mark A. Rothstein, *Why Treating Genetic Information Separately Is a Bad Idea,* 4 TEX. REV. L. & POL. 33, 35 (1999).
40) *Id.* at 35-36.
41) *Id.* at 35.
42) *Id.* at 36.

concludes that "[u]nless we prevent employers from getting access to the information, merely labeling the use of the [genetic] information as unlawful is of very little value indeed."[43] He points out one ultimate question which law makers sometimes lose sight of in drafting genetic anti-discrimination laws but which requires further discussion, that is, "under what circumstances is it appropriate for third parties, which would include employers, health insurance companies, disability insurance companies, long-term care insurance companies, etc., to consider medical information about individuals' current health status or that predicts their future health status?"[44]

As has been seen, the real issue is not whether the law adequately restricts unauthorized disclosure of genetic information of the applicants, insureds and employees, but the very content of the authorized and unauthorized disclosure. Therefore, even though the law sufficiently bans unauthorized disclosure, if the law makes a voluntary or authorized disclosure legal, insurers and employers easily can find a big loophole. Here again there is the same structure that I have pointed out in the discussion on the affirmative use of favorable genetic information in the previous subsection. Moreover, it should be noted that, as discussed before, in order to get legal protection, for example, under the ADA, it is the employee's burden of proof that s/he was discriminated against on the basis of genetic abnormality, however it is sometimes very hard to prove it, especially in the case where discriminatory use was made in the process of selecting job applicants at the pre-employment stage. Therefore, the Front-loading regulation which strictly bans access to (authorized disclosure of) genetic information is indispensable to sufficiently protect genetic privacy and prohibit genetic discrimination.

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43) *Id.* at 35.

44) *Id.* at 36.

III. Practical Flaws of Legislation: Practical Problems of Genetic Exceptionalism

— Can we draw a clear line between genetic and non-genetic information? —

As I mentioned before,[45] currently most of the states have enacted their own genetic-specific anti-discrimination statutes in employment and insurance in order to make up for the legal loopholes and limited sporadic protections provided by the existing federal laws, but their coverage and forms vary significantly state by state. And this inconsistency of protection for genetic information on the state level has urged a comprehensive federal level genetic-specific anti-discrimination law, and indeed many bills have been introduced in the U.S. Congress.

However, none of these attempts have succeeded so far. In my view, both of the reasons why state statutes vary widely and why many proposed bills failed to be passed are mainly resulted from the practical and normative problems of the so called "Genetic Exceptionalism." Genetic Exceptionalism is a principle which asserts that genetic information is substantially different from non-genetic information, and therefore, a line can be drawn somewhere in between genetic information and other medical information. Indeed, no genetic-specific anti-discrimination legislation can be drafted without defining the scope and meaning of "genetic information" and every such attempt more or less is based on the assumption of Genetic Exceptionalism. The inconsistency of the state statutes seems to reflect the fact that it is difficult to define genetic information and there are many different views on where to draw the line to fix the scope of genetic information.

Many failed attempts to enact a comprehensive genetic-specific anti-discrimination federal law are sometimes explained as owing to the strong political lobby by the health insurance industry such as the Health Insurance Association of America and large employer groups such as the U.S. Chamber of Commerce and the National Association of Manufacturers.[46] In my opinion, however, a more fundamental theoretical explanation can be obtained by examining the arguments

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45) *Legal Protection Restricting Genetic Discrimination in U.S.A.*, 53 OSAKA UNIV. LAW REV. (2006).

46) Louise M. Slaughter, *The Genetic Discrimination in Health Insurance and Employment Act: H.R. 602*, 18 N.Y.L. SCH. J. HUM. RTS. 1, 7-8 (2001) (Citing William Roberts, *Daschle Urges U.S. Senate Panel to Ban Genetic Discrimination*, BLOOMBERG NEWS, July 25, 2001; the statement of Harold P. Coxon, Shareholder in the National Labor and Employment Law Firm Ogletree, Deakins, Nash, Smoak & Stewart, P.C., Genetic Information in the Workplace Hearing Before Senate Health, Education, Labor & Pensions, 107th Cong. (2000)).

against genetic exceptionalism. In other words, failure to enact a comprehensive federal law is ultimately explained as a flaw derived from genetic exceptionalism inherent in any genetic-specific legislation. In this Section, I will review respectively the difficulty in defining genetic information (the practical problem of genetic exceptionalism) and inequality between the person who suffers from a genetic disease and the person who suffers from a non-genetic disease (normative problem of genetic exceptionalism).

It is stated in the Introduction of the model Genetic Privacy Act of 1995 that "[t]he Act is based on the premise that genetic information is different from other types of personal information in ways that require special protection."[47] Virtually all the genetic privacy laws or genetic anti-discrimination statutes and their proponent arguments which assert that genetic privacy requires special protection by law presuppose that genetic information has unique characteristics to a substantial degree, and therefore, it is different from other kinds of personal information. Accordingly, one important task to evaluate the genetic-specific anti-discrimination laws lies in exploring the question of "what is genetic information?" The answer to this question decisively affects the evaluation of the genetic-specific anti-discrimination laws.

In my previous article,[48] I identified the nature and character of genetic information by reviewing the arguments of "genetic exceptionalism."[49] The agenda I examine in this subsection are as follows: I examine whether genetic

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47) George J. Annas, Leonard H. Glantz, & Patricia A. Roche, *Genetic Privacy Act and Commentary* (1995) available at <http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html> (last visited Nov. 17, 2000); also available at <http:// www.ornl.gov/hgmis/resource/privacy/privacy1.html>(last visited June 17, 2002). Also see George J. Annas, Leonard H. Glantz & Patricia A. Roche, *Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations,* 23 n4 J. L. MED & ETHICS 360 (1995); Patricia Roche et al., *The Genetic Privacy Act: A Proposal for National Legislation,* 37 JURIMETRICS J. 1 (1996).

48) *Privacy of Genetic Information,* 52 OSAKA UNIV. LAW REV. pp. 75-105 (2005).

49) *See, e.g.*, Thomas H. Murray, *Genetic Exceptionalism and "Future Diary": Is Genetic Information Different from Other Medical Information?,* in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60 (Mark A. Rothstein ed., Yale Univ. Press 1997); Lawrence O. Gostin & James G. Hodge Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism,* 40 JURIMETRICS J. 21 (1999); Zita Lazzarini, *What Lessons Can We Learn From the Exceptionalism Debate (Finally)?,* 29 J.L. MED. & ETHICS 149 (2001); Glenn McGee, Foreward: *Genetic Exceptionalism,* 11 HARV. J.L. & TECH. 565 (1998); Lainie Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons From HIV*, 29 J.L. MED. & ETHICS 141 (2001); Natalie E. Zindorf, *supra* note 22; Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System,* 28 AM. J.L. & MED. 1 (2002).

information can be distinguished from other kinds of medical information in a feasible manner and demonstrate that it is very hard to draw a clear line between the two as a practical matter. And then, I consider how this creates definitional difficulties of genetic information and results in over- and under-inclusiveness of the genetic anti-discrimination statutes which intend to give special legal protection to genetic information.

A. Definitional Dilemma: Two-Bucket Quandary — Can We Distinguish Genetic Information from Other Medical Information? —

Mark A. Rothstein, observes two practical reasons why "treating genetic information separately is a bad idea."[50] One is impossibility to develop a working definition and another is economic unfeasibility.

The first reason comes from his actual experience when he was trying to define genetic information for enacting legislation in Texas that purports to prohibit discrimination in employment and insurance. He notes that "[i]f you define genetic information as the results of a DNA-based test, . . . you are leaving out a tremendous amount of information that is not derived from a genetic test."[51] If there is a notation in your medical record stating that one of your parents died of Huntington's disease, we can see that you "have a fifty-percent risk of developing this invariably fatal disorder" without having any genetic test. He asserts that "[i]f we protect people who have a positive test for the Huntington's disease mutation and don't protect" those "with only the medical record, that seems illogical."[52] Moreover, he also observes that in order to avoid this problem with a narrow definition of genetic information, if we adopt a definition broad enough to include all genetic information "derived from an individual or an individual's family members, in addition to the results of genetic tests,"[53] it poses another problem. He goes on to state that "[w]e are now discovering genetic components in the most common multi-factorial disorders: heart disease, cancer osteoporosis, epilepsy, diabetes,"[54] and "[i]f we included predisposition to any of those within the ambit of genetic information, and then took certain actions, such as prohibiting employers

50) Mark A. Rothstein, *supra* note 39, at 33.
51) *Id.* at 33.
52) *Id.*
53) *Id.*
54) *Id.* at 34.

from getting access to 'genetic information,' in many instances employers that have employees doing very dangerous jobs would not have the information necessary to select workers appropriately."[55] He states that "if we ever could separate genetic from non-genetic medical information, that day has long since passed, and everything that we discover in the future is going to make the distinction even more difficult."[56]

Murray calls these difficulties the dilemma of the "two-bucket theory" of disease. He states that "there are two buckets—one labeled 'genetic,' the other labeled "non-genetic'—and we should be able to toss every disease and risk factor into one of the two. So, Huntington disease goes into the 'genetic' bucket and getting run over by a truck goes into the 'non-genetic' one."[57] However, he asserts "many diseases and risks don't fit neatly into either bucket."[58] He takes up the cases of breast cancer, heart disease and cholesterol level. He observes:

> Some cases of breast cancer have strong genetic roots, but others have no clear genetic connection. For that matter, not every woman with a mutated BRCAI gene will develop breast cancer. And some apparent risk factors have little or no link to genetics. Similar complexity exists for heart disease: cholesterol is a risk factor, and one's cholesterol level can be modified by diet, exercise, and other factors; but our genes have much or more to do with the level of cholesterol circulation in our blood as our environment or behavior. Into which bucket, then should we toss breast cancer? Heart disease? Cholesterol level?[59]

Another difficulty with genetic exceptionalism, Murray observes, is that "it seemed practically infeasible to divide medical records into those portions that were genetic . . . from those portions that were nongenetic."[60] This is because we don't have a feasible measure "to identify and keep separate genetic information from nongenetic information in the medical record."[61]

Charles J. Sykes, a journalist and the author of THE END OF PRIVACY, also notes:

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55) *Id.*
56) *Id.*
57) Murray, *supra* note 49, at 68.
58) *Id.*
59) *Id.* at 67-68.
60) *Id.* at 68.
61) *Id.*

> The reality is that much of what we consider routine medical information has a genetic component, including our family histories. As the science advances, it seems likely that genetic testing and information will increasingly be integrated into everyone's medical records as a standard part of diagnostic tests and medical profiles. Genetic information is already so deeply embedded into the practice of medical underwriting that it seems both impractical and unlikely that any attempt to somehow screen it out or segregate the material could ever be adopted in the real world. As a practical matter, doctors would have to edit each and every medical record, chart and history, to delete any reference to family histories or other genetic information. This would not only be time-consuming, and expensive, it would likely prove to be impossible.[62)]

Another reason why Rothstein thinks it is impossible to regulate genetic information separately from other medical information is that it would be economically infeasible. He asserts that "[p]resumably, certain information from medical records would be disclosed, while other information would not. Those in the health care industry tell me that making such distinctions and separating information, when it is debatable whether numerous condition are subject to disclosure, would be a logical nightmare."[63)]

Sonia M. Suter also demonstrates how difficult it is to draw the line between genetic and nongenetic information:

> Genes play some role in all disease, but environment plays a role as well, even with genetic diseases. . . . AIDS is a classic nongenetic condition caused by infection with HIV. Yet genetics is crucial with respect to whether the infection will cause illness, how soon one becomes ill, and how quickly the disease progresses. Conversely, PKU [Phenylketonuria], a classic genetic condition, caused by two recessive non-functional genes, is highly influenced by environmental factors. If you eliminate phenylalanine from the diet, the symptoms of PKU will not develop.[64)]

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62) CHARLES J. SYKES, *supra* note 35, at 132.

63) Mark A. Rothstein, *supra* note 39, at 34.

64) Sonia M. Suter, *supra* note 7, at 703 (alteration added).

Suter observes that "no sharp line divides genetic from nongenetic information. Instead, there is a great deal of overlap between these categories, making line-drawing exceedingly difficult."[65)]

According to Suter, the rationale for genetics legislation can be divided into two categories: 1) concerns related to genetic discrimination; and 2) concerns related to privacy interests.[66)] At the heart of the former rationale—to prevent genetic discrimination, Suter states there is a fairness argument: "We cannot control the genes we inherit. Like race, our genetic information is an immutable trait, for which we should not be penalized."[67)] Also "certain characteristics of genetic information make it particularly vulnerable to insurance or employment discrimination."[68)] And "genetic information is prone to discrimination because it can be misunderstood."[69)] Additionally, "genetic discrimination can lead to forms of racial, ethnic, or gender bias when discrimination is based on a gene that predominantly affects discrete groups. For example, the breast cancer genes are most common in women of Askenazi Jewish descent."[70)] According to Suter, the latter rational, privacy interest, is based on public concern; "public fears of genetic discrimination may prevent people from undergoing valuable genetic testing or participating in genetics research."[71)]

Suter argues that with regards to these rationales for genetics legislation, the dichotomy between genetic and nongenetic information makes no difference.

> They [rationales] do not apply to all genetic information, but more importantly, they apply equally to other types of medical information. In short, there is a grossly imperfect fit between the justifications for carving out special protections for genetic information and the category of genetic information because genetic information is both over- and under-inclusive with respect to its legislative purposes. This imprecise fit, particularly the under-inclusiveness, suggests the line between genetic and nongenetic information is not morally compelling.[72)]

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65) *Id.* at 701.
66) *Id.* at 706.
67) *Id.*
68) *Id.* at 707.
69) *Id.*
70) *Id.*
71) *Id.*
72) *Id.* at 705.

Accordingly, any genetic legislation which gives special legal protections for genetic information is both over-inclusive and under-inclusive. In the subsequent subsections, I will respectively review the details of her arguments on over-inclusiveness and under-inclusiveness as a fundamental flaw of the genetic-specific legislation.

B. Over- Inclusiveness

Sonia M. Suter asserts that "it is virtually impossible fully to distinguish genetic information from other medical information."[73] This is because of the fact that "[g]enetic information and medical information are 'so intimately intertwined that they cannot be segregated legislatively or by regulation in any way that would prove operationally feasible.'"[74] And Suter argues that "the various attempts to define genetic information so as to distinguish it from other medical information are inevitably unsatisfactory, suffering from under- or over-inclusiveness [in the light of their intended scope of protections]."[75]

According to Suter, genetic legislation is over-inclusive in regards to its legislative purposes because of the following reasons; "[1] [c]oncerns about the lack of control over one's genes, [2] the high level of predictiveness of genetic information, and [3] its stigmatizing and hidden features do not apply equally to all genetic information."[76]

First of all, she asserts that "[a]lthough we cannot control the genes that we inherit, we can sometimes control factors that influence the degree to which genes affect our future health."[77] She gives several supporting examples for this: "[I]f one has two copies of the gene for PKU, and phenylalanine is removed from the diet, the symptoms of PKU will not develop. Similarly if one has the gene for colon cancer, one may reduce the risk of developing cancer by undergoing regular endoscopies, dietary regimes, or surgery."[78]

Moreover, second, she states that "[m]any genes are only predisposing and do

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73) Sonia M. Suter, *supra* note 7, at 701.

74) *Id.* at 702 (quoting David Korn, *Genetic Privacy, Medical Information Privacy, and the Use of Human Tissue Specimens in Research*, in GENETIC TESTING AND THE USE OF INFORMATION 40-41 (Clarisa Long ed., 1999)).

75) *Id.* (alteration added).

76) *Id.* at 709.

77) *Id.*

78) *Id.*

not guarantee that the condition will develop"[79] except for some limited genetic information such as Huntington disease (She asserts that Huntington disease should "be the exception, not the rule" because it represents a small number of all genetic link diseases).[80] She states that "most genetic information does not predict future health risk. For example, information that someone carries a single copy of a recessive gene may increase the chances of having an affected child, but it does not increase the risk of future disease in the carrier."[81]

Third, Suter asserts that genetics legislation is over-inclusive in regards to its stigmatizing and hidden features. For instance, "[g]enetics legislation is also over-inclusive with respect to concerns that it addresses race- or gender-based discrimination" because "[w]hile some genetic diseases are more prevalent in certain racial or ethnic groups or a particular sex, most are not."[82] Furthermore, she notes that "genetics legislation is over-inclusive to the extent that it is based on the 'uniqueness' argument" because "the vast majority of genetic information is not unique. We share more than 99.9% of our genetic information with others and even 99% with chimpanzees."[83] Suter further argues that "not all genetic information is highly sensitive and stigmatizing. Blood type is neither sensitive nor stigmatizing."[84] Also she goes on to state that "a great deal of information is not hidden from us and others. Whether we have two X chromosomes or an X and Y is readily apparent, as is eye color, a genetically inherited trait."[85] Moreover, "some genetic conditions, such as hemochromatosis and PKU, are treatable."[86]

Accordingly, "it is not genetic information per se that is necessarily susceptible to misuse. Rather certain kinds of genetic information—particularly predictive or predisposing genetic information, or information that increases genetic risks in family members— raise concerns of discrimination."[87] Hence, "it may be unnecessarily costly to restrict uses of genetic information that do not seem particularly susceptible to discriminatory uses."[88] However, according to Suter, the problem of over-inclusiveness "can easily be ameliorated with some definitional

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79) *Id.*
80) *Id.*
81) *Id.* 709-10.
82) *Id.* at 710.
83) *Id.*
84) *Id.*
85) *Id.*.
86) *Id.* at 710-11.
87) *Id.* at 711.
88) *Id.*

fine-tuning," for example, by "limit[ing] protections to the categories of genetic information that seem particularly susceptible to misuse, such as asymptomatic, predictive, or predisposing genetic information or carrier status."[89] Contrary to over-inclusiveness, Suter states that under-inclusiveness of legislation is more problematic and cannot be ameliorated by definitional fine-tuning. In the next subsection, let me present her arguments about under-inclusiveness.

C. Under Inclusiveness

Suter doubts the notion that genes are not in our control while nongenetic risk factors are.

> Although we cannot control the genes we inherit, we cannot control a great many other risk factors, such as in utero exposures, environmental conditions, or drunk drivers, which may have profound effects on our future health. Moreover, many risk factors, which seem very much in one's control, may be less so than we imagine. Addictive behavior is influenced by genetic elements, as well as many social elements outside of our control, such as family, socioeconomic status, and culture. Controlling one's weight, for example, is not solely a matter of willpower. Even addiction to smoking has genetic elements. Thus, genetics does not function satisfactorily as an exclusive category for risks outside our control.[90]

Accordingly, if we resort to the factor of "beyond our control" criteria as a basis of the legislation, to protect only genetic information is under-inclusive and protection for non-genetic medical information outside our control would be required as well.

Suter also points out that "genetic information is not alone in its predictive capacity." She notes that "[b]efore the advent of protease inhibitors, HIV infection virtually ensured the future development of AIDS. Similarly, significant asbestos exposure leads to a high risk of lung cancer. Worries that insurers or employers will discriminate based on genetic information apply equally to other medical information."[91] Moreover, she argues that "to the extent that people view genetic

89) *Id.*
90) *Id.* at 712.
91) *Id.*

discrimination as a proxy for race or gender discrimination, protecting genetic information is under-inclusive. Racial discrimination has occurred through the use of other proxies for race."[92] Furthermore, "concerns that fears of discrimination will prevent individuals from participating in medical research or treatment for conditions such as mental illness or cancer also justify the protection of other medical information."[93] Thus, if we regard the predictive capacity of genetic information as a ground for enacting new legislation, protecting only genetic information is under-inclusive and legal protection should be provided for some kinds of similarly highly predictive nongenetic medical information as well.

Suter further asserts that genetics legislation is under-inclusive because the privacy concerns "also extend well beyond genetics."

> Genetic information is not *uniquely personal and revealing*. Our *life histories* are as personal and revealing as our genetic code. One's culture, family, friends, education, career, beliefs, and dreams all reveal as much, if not more, about who we are and will become than our genes. Nor is genetic information uniquely unique. Other information is *personally identifying*. Old-fashioned fingerprints, dental analysis, iris scans, voice prints, handwritten signature measurements, and "esoteric biometrics" can identify individuals, as can other less high-tech information, such as social security numbers, addresses, phone numbers, and credit card numbers. Even more general information, such as neighborhood, age, occupation, marital status, and number and ages of children, can be identifying in the aggregate.[94]

Also she adds that "genetics is not the only mechanism to probe into past lives. Other techniques [such as bone analysis, infrared light and computer imaging software, etc. also] have been used to explore the personal history of the deceased."[95]

Furthermore, she asserts that not only genetic information has a sensitive or stigmatizing nature.

> [N]ongenetic information may be highly *sensitive* or *stigmatizing*,

92) *Id.* at 712-13.
93) *Id.* at 713.
94) *Id.* (emphases added).
95) *Id.*

> perhaps even more so than most genetic information. Information regarding sexually transmitted diseases, mental illness, reproductive history, addiction, marital status, or a history of abuse might influence how potential partners, insurers, employers, and society view and treat us. Indeed, because people view genes as *outside our control,* genetic information might be less stigmatizing than other information associated with behavior—such as a history of sexually transmitted diseases—and therefore less susceptible to moral judgment.[96)]

Moreover, Suter states, "[n]or is genetic information unique in its capacity to be hidden risks such as viral infections, prenatal exposures, abnormal biochemical levels, and even environmental risks. Cancers may grow within our bodies long before we exhibit symptoms."[97)]

Suter points out that "genetic information is not the only information that is relevant to family members," and notes that "[w]hether someone in the family has tuberculosis, scarlet fever, or a sexually transmitted disease may tell us something about certain family members' risks. So relevant is this information to family members that courts have imposed duties on physicians to warn families of the infectious nature of the patient's disease."[98)]

Accordingly, Suter concludes that "genetic information is a seriously under-inclusive category with respect to virtually all of the concerns motivating genetic legislation."[99)] As has been seen, Suter well demonstrates that the main reasons and nature which exclusively seem to belong to genetic information are also equally true of non-genetic information and therefore genetic legislation is inevitably and problematically under-inclusive with regard to its purposes. She regards this under-inclusiveness as resulting in morally unacceptable unintended inequities. This is the normative problem of genetic-specific anti-discrimination laws, that is, the fundamental problem of Genetic Exceptionalism that I will address in detail in the next subsection by referring to the arguments presented by Suter.

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96) *Id.* at 714 (emphases added).

97) *Id.*

98) *Id.* at 714-15 (2001) (referring to Skillings v. Allen, 173 N.W. 663, 664 (Minn. 1919)).

99) *Id.* at 715.

IV. Theoretical Flaws of Legislation: Normative Problems of Genetic Exceptionalism

—Is it fair to treat people with genetic diseases differently from people with non-genetic diseases? —

Murray states:

> [T]here was no good moral justification for treating genetic information, genetic diseases, or genetic risk factors as categorically different from other medical information, diseases, or risk factors. If someone genuinely needed health care, it did not matter whether one could find a genetic root for the disease or whether it was the product of nongenetic bad luck or accident. . . . Our need for health care in most cases will be the product of a complex mix of factors, genetic and nongenetic," [therefore] "[t]he distinction between genetic and nongenetic factors is not the crucial one.[100)]

Even though we assume that a line could be drawn somewhere between genetic and non-genetic medical information and somewhat solve the practical problems in defining genetic information by creating many exceptions in order to ameliorate over- and under-inclusiveness with regard to the scope of the protection, genetic-specific legislations still cannot escape from its normative problem discussed in this section. The most serious normative problem of genetic-specific legislation underlined by genetic exceptionalism is that its special protection only for "genetic information" leads to inequality and unfairness between the individuals with genetic abnormality and other predictive medical information, and also among the classes. Although this inequality has been mentioned by several commentators opposing the genetic anti-discrimination law,[101)] as far as I have surveyed more than one hundred articles published in the past ten years, it was not fully discussed until recently when Suter addressed this issue in her insightful article. Let us take a look at her arguments in detail.

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100) Murray, *supra* note 49, at 69.

101) *See, e.g.*, Mark A. Rothstein, *supra* note 39, at 33. Colin S. Diver & Jane Maslow Cohen, *supra* note 12, at 1460.

A. Inequality between People with Genetic and Non-genetic Health Problems

Suter gives an illustrative example which demonstrates how any legislation which prohibits discrimination based on only "genetic" information leads to inequities. She presents the following hypothetical situation.

> Imagine that two women face an increased risk for breast cancer. The first woman, Jeannie, has a positive test for BRCA1, a gene associated with an increased risk of breast cancer and other cancers. This test result puts her at anywhere from a thirty-six percent to eighty-seven percent lifetime risk of breast cancer. The second woman, Eve, faces a significant risk of cancer, not based on a genetic test or family history, but on other factors or tests that suggest she has a high predisposition. For example, she may have faced significant exposure to asbestos or she may have a precancerous condition that resulted from environmental exposures, which puts her at risks of cancer. Both women face a notable cancer risk, but one risk is perceived as genetic and the other as nongenetic.[102)]

Suter further assumes that in a state which has passed an anti-discrimination law banning insurance and employment discrimination based only on genetic information, if these two women are seeking coverage through individual insurance plans, they would be treated totally differently (unequally).

> Legislation prohibiting insurance discrimination based on genetic information would cover Jeannie's risk, even under the narrowest definition of genetic information, but it would not cover Eve's. Eve might be denied insurance, but more likely, she would pay higher premiums to reflect her increased risk. However, Jeannie's premiums would not be raised to reflect her risk because, like others with genetic risk, her genetic risks would be subsidized by everyone in the insurance pool. In other words, Eve would "cover" her known increased risk, even as she helps subsidize Jennie's. This result is unjust because some known risks are subsidized and others are not. Moreover, there is no coherent

102) Sonia M. Suter, *supra* note 7, at 715-16.

> reason for that difference, except that one risk is "genetic" and the other is not.[103)]

Rothstein also asserts that any laws or proposals which aim at regulating and protecting genetic information separately from other medical information are "illogical" and "ineffective."[104)] The first reason he asserts is that there is no logical reason to draw distinction between genetic disorders and other disorders. He gives a breast cancer case as an example:

> In a jurisdiction with a statute prohibiting discrimination in the insurance of an individual health insurance policy on the basis of a genetic test result, a woman who was asymptomatic, but had one of the breast cancer gene mutations, could not be denied access to health insurance, nor charged a higher rate. However, if that woman goes on to develop breast cancer, then the general health insurance laws in that state could apply. The woman could be assessed higher premiums, or, indeed, her health insurance could be cut off entirely.[105)]

He considers the plausible counter-argument which may assert that "[p]erhaps we could correct that situation by enacting another law that stated that women who develop genetic-based breast cancer also cannot be discriminated against."[106)] But, he argues that it makes no sense because "[w]e would be protecting about five percent of breast cancer cases—those who have a genetic alteration associated with their breast cancer—and not protecting from discrimination the ninety-five percent of breast cancer cases whose cause we have not yet determined."[107)]

Suter notes that under the genetic-specific legislation, a similar inequality would happen also in the employment context: "Jeannie's job and promotions would be protected, but Eve's might be at risk, particularly if the employer had access to all other health information."[108)] And "[o]nce again no coherent reason justifies this disparity" she states.[109)]

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103) *Id.* at 717.
104) Mark A. Rothstein, *supra* note 39, at 35-36.
105) *Id.* at 35.
106) *Id.*
107) *Id.*
108) *Id.* at 717.
109) *Id.* at 718.

Moreover, Suter points out inequalities and disparities with regards to "self-determination, autonomy, and dignity interests" between Jeannie and Eve.

> Both Jeannie and Eve have an interest in deciding for themselves whether to disclose their increased risk of cancer to others. In a state with only genetic privacy legislation, Jeannie would have greater, though not full, control over such disclosure than Eve. The fact that Jeannie's risk is "genetic" does not necessarily increase her interests in preventing disclosure. Indeed, Eve may feel more sensitive about her increased cancer risk, given that she has no protection against discrimination based on this information. Again, no principled reason exists for this disparity. Jeannie's and Eve's interest in controlling disclosure of personal health information is equally powerful and therefore deserving of equal forms of protection.[110)]

B. Inequality between the Classes

Furthermore, Suter argues that genetic-specific legislation leads to not only inequality between the individuals with genetic and non-genetic abnormality, it also results in social inequality between the classes. She asserts:

> The most disturbing aspect of the under-inclusiveness of genetic legislation . . . is that the unintended inequalities of genetics legislation exacerbate *social inequalities*. Although genetic risks transcend socioeconomic class, nongenetic risks frequently do not. Many nongenetic risks have sociological components related to poverty and environmental hazards, some of which are not in one's control. For example numerous studies demonstrate that people of color and low income communities face *disproportionate* environmental impacts in the United States. Some sources of such environmental risks include "hazardous waste sites, incinerators, chemical factories, and sewage treatment plants," which are placed *disproportionately* in these lower-income communities. . . . Continuous exposure to such environmental hazards poses increased risks of "cancer, asthma, chronic bronchitis, emphysema and other respiratory diseases, reproductive and birth

110) *Id.* at 719.

> defects, immunological problems, and neurological defects." In addition, low socioeconomic status is *disproportionately* associated with "virtually all of the chronic diseases that are the leading causes of mortality"; infectious diseases, such as HIV or tuberculosis; traumatic injuries and death; and developmental delay and other disabilities.[111)]
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> As a result, the poor, which includes many minorities, are more likely to face nongenetic risks than the middle or upper classes. . . . If insurers, for example, can make actuarial decision on the basis of evidence of nongenetic risks, but not genetic risks, we allow discrimination that will *disproportionately* disadvantage these vulnerable populations. Or to put it differently, we ask the least advantaged to bear their own nongenetic risks alone, even as we ask everyone, including them, to subsidize genetic risks.[112)]

Suter continues to assert that

> [g]iven that many environmental hazards, as well as other health risks, are linked to poverty and low socioeconomic status, there is reason to be concerned about the social impact of a policy that only protects genetic risks, but does not protect the risks that most profoundly affect the poor and minorities.[113)]

She concludes that genetic-specific legislation disproportionately treats the most vulnerable low socioeconomic class adversely.

> [G]enetic discrimination is principally a concern of the middle to upper classes, who have financial resources for testing and jobs and insurance they fear losing. This group of well-educated, well-off individuals has lobbied heavily for genetics legislation. In contrast, the groups most vulnerable to health risks associated with poverty and environmental hazards do not have the same political voice or cohesiveness. There is a danger that the strong political voice of the first group outshadows the

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111) *Id.* at 719-20 (emphases added).

112) *Id.* at 720 (emphasis added).

113) *Id.* at 720-21.

> interests of more vulnerable, but less politically powerful groups. In short, genetic-specific legislation becomes another middle-class entitlement.[114)]

C. Incrementalism: Plausible Defense for Genetic-Specific Legislation

In sum, Suter argues that "genetic information is a simultaneously under- and over-inclusive category with respect to the policy concerns motivating genetic legislation."[115)] This is because "[n]ot all genetic information requires protective legislation, which makes genetic legislation over-inclusive. More importantly, a great deal of other medical information shares many of the features of genetic information that have inspired this legislation, which makes it dramatically under-inclusive."[116)] And "[t]his under-inclusiveness . . . results in inequities between similarly situated individuals and . . . exacerbates class inequities. . . . Because genetics legislation only protects genetic information, those facing nongenetic risks will not be protected."[117)] "While genetic risks transcend socioeconomic class, nongenetic risks frequently do not. The poor and minorities face a disproportionate degree of nongenetic, environmental risks and, therefore, are disproportionately disadvantaged by laws that protect against discrimination based only on genetic risks."[118)]

As has been seen, Suter points out the problems of genetic exceptionalism and strongly criticizes genetic-specific legislation. However, it should be noted that, for Suter, recognizing the practical and normative problems inherent in genetic exceptionalism does not mean that legal protection against genetic discrimination is not needed but rather all sensitive and predictive medical information including some types of genetic information should be protected. Indeed, her intention is to point out that "the concerns motivating genetics legislation extend well beyond genetic information."[119)] Suter asserts:

> Currently, our system has a default rule that allows insurers to access and use most medical information for underwriting purposes, with a few

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114) *Id.* at 721.
115) *Id.* at, 672.
116) *Id.*
117) *Id.*
118) *Id.*
119) *Id.* at 724.

> exceptions for race, genetics, and, in some instances, gender. If policy makers understand that many risk factors are significantly outside of our control and predictive, the opposite default rule might be more appropriate. In other words, perhaps insurers should not be able to obtain or use most medical information for underwriting.[120)]

However, as the unsuccessful attempt of the Clinton administration's national large-scale health care reform in 1993-94 shows, in reality it is difficult to give legal protections for all predictive and sensitive medical information in the health insurance arena in the short run. Therefore, some "political realists" may argue as follows:

> By urging reform with respect to genetics, one can move toward the ultimate goal of protecting all medical information, without directly placing on the table the fact that similar concerns apply to other medical information. Extending genetic protections to other medical information too soon, for example, might be at best, very difficult, and at worst, politically unwise. The better approach, the pragmatist would argue, is to open the door to reform with genetics legislation, for which there is widespread political and public support. Once the door is ajar, we can incrementally open it wider over time.[121)]

Suter calls this strategy the incrementalism or the step-by-step political realists' approach and regards it as a plausible defense for the under-inclusiveness of genetics legislation. Under the incrementalism, it is argued that "the protections created by genetics legislation will eventually apply to all medical information because genetic analysis will be so integral to every aspect of future medical records."[122)] However, Suter "doubt[s] its ability to fulfill the promise of expanding the protections of genetic information to other medical information in light of the deeply entrenched perspective of genetics exceptionalism."[123)] While Suter admits exceptionalism could be an adequate strategy in some fields, she does not believe that genetic legislation could be one step toward larger reform. She believes that "[r]ather than being the first step toward broader reform with respect

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120) *Id.* at 744-45.
121) *Id.* at 722.
122) *Id.*
123) *Id.* at 672.

to insurance discrimination, employment discrimination, or privacy protections, genetics legislation might be the last step."[124] Since the motivation of genetics legislations is deeply entrenched by genetic exceptionalism, once such a law is enacted, legislators will have a false sense that they have solved the discrimination at issue. She argues:

> As long as genetics legislation is largely understood as grounded in genetics exceptionalism, legislatures will think they have addressed the real problems, and they will not want to go further. Similarly, the public, media, and even many scientists will likely feel satisfied that genetics legislation has resolved the important issues. . . . As a consequence, once genetics legislation is in place, public support is likely to be anemic with respect to further reform, and politicians may be reluctant to invest political capital in extending these protections beyond genetics.[125]

This scenario would likely happen when we take the following fact into account, she argues.

> The group most attentive to the genetics exceptionalism perspective will be the more politically active middle and upper classes, whose primary concern is genetic discrimination. Because the broader concerns of the poor and minorities do not affect these groups, they are even less likely to advocate widening the scope of protections; their needs have been met. Instead, the group who would have the greatest self-interest in expanding genetics legislation—the poor and minorities—is least likely to have the political force and clout to effect such change.[126]

Accordingly, she concludes that "when we consider both the social norms that reinforce genetics exceptionalism and the relative powerlessness of those who most benefit from broadening the reach of genetics legislation, it is easy to be pessimistic about the success of incrementalism."[127]

A similar argument is presented by Chetan Gulati. It is argued that

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124) *Id.* at 725.
125) *Id.* at 726.
126) *Id.* at 726-27.
127) *Id.* at 727.

> genetic antidiscrimination laws placate the higher socioeconomic classes and help prevent more radical reforms and that eventually, faced with the realization that genetic antidiscrimination laws will fail, Americans will have to either reevaluate the ways in which health care is financed or they will have to accept the implications of a system that distributes health care goods according to wealth and predisposition to disease.[128)]

As I have demonstrated by referring to the arguments presented by many commentators, genetic-specific anti-discrimination laws have serious and inescapable problems which stem from genetic exceptionalism. As you may notice, we face a serious dilemma over the genetic discrimination issues. On one hand, virtually all feel that we desperately need a law to protect genetic privacy and prevent genetic discrimination; on the other hand, however, such genetic-specific anti-discrimination laws result in unintended unfair consequences which produce inequality between people with genetic and non-genetic health problems, and also between the classes.

D. Alternative Ways Out of the Dilemma

Although we admit that it is practically impossible and morally unfair to treat genetic information differently from other medical information, we should not presuppose that we have only one option, namely, no legal protection should be provided for genetic information against genetic discrimination. Here, there is another normative question that we have to discuss before we reach this conclusion. Even though in practice it *is* impossible to treat genetic information differently from other medical information and, in theory it is unfair to do so, these observations do not necessarily mean that the law *ought not to* protect genetic privacy and prevent genetic discrimination. We should distinguish the issue between "is" and "ought to be." The latter is the normative issue. If we can not draw a line between genetic information and other medical information, and it is unfair for the law to protect only people with negative genetic profiles and leave people with negative non-genetic profiles unprotected, it might be possible to argue why it can not be the opposite way. In other words, if genetic privacy is of very important value to each of us and there is a strong need to prevent genetic discrimination, why do we not design the law so as to prohibit insurers and employers from having access and

128) Chetan Gulati, *supra* note 16, at 151.

using all types of predictive medical information in order to protect all people equally regardless of whether their information is genetic or non-genetic, against discrimination in the workplace and health insurance field?

Charles J. Sykes states that "[t]he answer is not to leave genetic information unprotected, but to create protection for *all* medical information, including genetic data."[129] Some of the commentators who point out the fundamental problems of the genetic-specific anti-discrimination laws also think in the same way including the author of this paper. However, this conclusion creates additional issues. Those commentators who reject the genetic-specific anti-discrimination laws should present an alternative policy to protect genetically unlucky people from genetic discrimination and find the way out of the dilemma. Without presenting such an alternative, the real problem can not be resolved. Accordingly, in this section, I consider such alternative policies.

a. DHHS Privacy Regulations of 2000

As has been seen before, Suter points out the problems of genetic exceptionalism and strongly rejects enacting genetic-specific anti-discrimination laws. However, she does not think that leaving genetic information unprotected is acceptable. Rather, she argues that all predictive medical information, including genetic information, should be protected against genetic discrimination. Then, what is an alternative which can replace genetic-specific anti-discrimination law? On December 22, 2000, the U.S. Department of Health and Human Services (HHS) issued the final rules designed to protect the privacy of personal health information. It was promulgated by the Department of Health and Human Services (DHHS) under the authority of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).[130] Suter regards the privacy regulations as an ideal alternative approach. She asserts that "HIPAA privacy regulations, in short, avoid the trap of genetic exceptionalism" since the "federal privacy regulations protect all individually identifiable health information used or disclosed electronically or orally by health plans, health clearinghouses, and health care providers . . . and the regulations protect the most sensitive medical information—identifiable medical

129) CHARLES J. SYKES, *supra* note 35, at 132.

130) *Standards for Privacy for Individually Identifiable Health Information*, 65 Fed. Reg. at 82, 464, 620, 804. 801 (Dec. 28, 2000). Both the proposed rule and the final rule are available at <http://aspe.hhs.gov/admnsimp/index.html>; <.html" http://www.hhs.gov/ocr/hipaa/finalmaster.html>; <http:// www.hhs.gov/news/press/2001pres/20010706a.html> (July 6, 2001).

information—and they include, but are not limited to, genetic information."[131]

According to the commentary made by Human Genome Project Information,

> [t]he new standards: limit the non-consensual use and release of private health information; give patients new rights to access their medical records and to know who else has accessed them; restrict most disclosure of health information to the minimum needed for the intended purpose; establish new criminal and civil sanctions for improper use or disclosure; and establish new requirements for access to records by researchers and others. They are not specific to genetics, rather they are sweeping regulations governing all personal health information.[132]

To be free from the trap of genetic exceptionalism, this kind of regulation which designs to protect all individually identifiable health information could be one plausible path out of the dilemma. However, this kind of strategy where genetic information is protected by incorporating it into the general privacy protection of all health information is promising only when it provides strong protection.

b. Universal Single-Payer / Community-Rating Health Care System

Jon Beckwith and Joseph S. Alper address the dilemma in regulating genetic discrimination. On the one hand, "genetic antidiscrimination laws are needed because genetic discrimination is a real problem that seems certain to expand dramatically as many new tests become available."[133] On the other hand, current genetic antidiscrimination laws which are "based on the misconception" of "the presumption that a clear distinction exists between genetic and nongenetic information, tests, and diseases" are flawed.[134]

One way that Beckwith and Alper suggest to solve this dilemma is to introduce a "single-payer universal health care system." In this system, they insist that "distinction between genetic and nongenetic diseases and tests become totally unnecessary. Because everyone would already be insured, problems such as adverse selection in health insurance would not exist."[135] They assert that "genetic discrimination legislation is required because it attempts to address a deeper and

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131) Sonia M. Suter, *supra* note 7, at 673.

132) Human Genome Project Information, Genetic Privacy and Legislation, available at <http://www.ornl.gov/TechResources/Human_Genome/elsi/legislat.html> (last visited July 10, 2002).

133) Jon Beckwith & Joseph S. Alper, *Reconsidering Genetic Antidiscrimination Legislation*, 26 J.L. MED. & ETHICS 205, 208 (1998).

134) *Id.*

135) *Id.*

more pervasive underlying problem than discrimination arising from the use of genetic information alone. The problem is not merely discrimination based on genetics, but also discrimination based on any type of predictive medical information."[136] They defined genetic information as information which includes not only genetic material itself but also family history and ethnicity.[137] Therefore, they emphasize "the importance of prohibiting discrimination based on *all types of predictive medical information* as opposed to prohibiting only that discrimination based on a person's genotype."[138]

Elaine Draper also states that "[a]nti-discrimination laws should be extended to cover genetic predispositions, to guard against individuals being labeled and penalized as high-risk."[139] However, Draper notes that "[a]lthough the ADA arguably covers individuals perceived to be susceptible to illness and not just those who are symptomatic, that coverage is by no means certain."[140] Under this circumstance, she mentions a national single-payer health-care system of government-financed services as a policy recommendation for a way out of the present problems. Draper notes that "[i]n addition to legal protections against genetic discrimination, universal access to health services is a crucial concern in addressing problems of genetic discrimination, privacy, and availability of health care."[141] In order to assure availability of health care, Draper finds a desirable policy for "[n]ational health coverage and a single-payer health-care system of government-financed services" and states that "[it] could mean that high-risk individuals and groups would no longer be denied health coverage or affordable medical care. They would thus have less to fear from screening under such a system."[142] She states that under this system, "[m]andated national health coverage would remedy problems within the workers' compensation system that now encourage people to seek compensation benefits simply to get medical coverage. It would also assist people who now decline health insurance coverage because of the high cost of premium co-payments that many companies require."[143] Moreover, Draper notes that "[w]ith national health care, investigators

136) *Id.* at 209.

137) *Id.*

138) *Id.* (emphasis added).

139) Elaine Draper, *The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information*, 20 BERKELEY J. EMPLOYMENT & LABOR L. 286, 315 (1999).

140) *Id.*

141) *Id. at* 318.

142) *Id.*

143) *Id.*

could use national data systems to track suspected employee hazards and disease patterns by workplace or region, which would facilitate mortality and morbidity studies."[144] Draper asserts that "[d]espite political obstacles to enacting a national single-payer system, political leaders could overcome opposition to reform by educating the public about the expense, the gaps in coverage, and the inequities of the current health care delivery system."[145]

According to Gulati, genetic antidiscrimination laws are misguided solutions as the title of his article "*Genetic Antidiscrimination Laws In Health Insurance: A Misguided Solution*" shows. However, contrary to Suter, Gulati states that the consequences of the insufficient protections against genetic discrimination provided by genetic antidiscrimination laws will ironically create a "policy window" for more radical changes to the health care financing system such as a universal single-payer health care system which Gulati believes to be the best solution to solve genetic discrimination.[146]

Another alternative may be found in the community-rating health insurance system. Under this system, contrary to individual risk-rating, underwriting is processed by depending on the experience of all the community.

Jennifer S. Geetter finds an alternative in this approach. She asserts a community-rating health insurance system which abolishes risk-rating and introduces a community-rating system as an alternative policy.[147] She states that "[c]ommunity-rating means a commitment to a social norm that as a society we will not allocate health benefits on the basis of health conditions that are largely beyond our control."[148] And also community-rating "would represent an explicit commitment to low-risk individuals subsidizing high-risk individuals— a sort of progressive insurance regime."[149]

In order to make community-rating workable and feasible, a certain size of community pool or certain mandatory or compulsory health care system is required. Therefore, it is debatable whether a community-rating health insurance system can be achieved in the private health insurance market with or without some governmental intervention. To examine the possibility of building a community-rating health insurance system in the market is beyond the scope of this paper.

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144) *Id.*

145) *Id.*

146) Chetan Gulati, *supra* note 16, at 151.

147) Jennifer S. Geetter, *supra* note 49, at 68.

148) *Id.* at 69.

149) *Id.*

However, we can put it on the list of alternative strategies for a way out of the dilemma over genetic privacy and the discrimination issues.

If the community-rating is achieved as a national scale, it becomes a system like the universal single-payer health care system.

V. Conclusion

In the former part of this paper, I examined several key issues in drafting such laws (Section II). First, I examined the scope of genetic information: I addressed the problem in narrow and broad definition (Section II-A). One of the most difficult issues in drafting a genetic-specific anti-discrimination law is the scope and definition of genetic information. If genetic information is narrowly defined as limited only to genetic test results or DNA analysis, a great deal of genetic information obtained through other sources such as clinical evaluations, non-genetic tests, and family and medical history, are left unprotected and therefore genetic privacy is not sufficiently protected and genetic discrimination cannot be prevented. On the other hand, if genetic information is defined broadly enough to encompass all of these genetic-linked information such as genes, gene products, or inherited traits that may derive from an individual or family member, it is almost impossible to distinguish between genetic information and other medical information because it inevitably includes heart disease, cancer, diabetes, etc. which have been traditionally regarded as non-genetic diseases but in fact caused by the combination of genetic traits and environmental factors.

Another issue that I examined is the affirmative use of favorable genetic information or clean bill of genetic makeup (Section II-B). This is a question of whether or not we should also legally ban taking an individual's favorable genetic information disclosed voluntarily into account in the underwriting process. I asserted that if the law allows favorable use of genetic information, it eventually results in almost the same adverse effects for the individuals who do not submit favorable genetic information because non-submissions imply that there is a high possibility that they have unfavorable genetic information. Therefore, I argued that if we aim to protect individuals against treating some individuals with gene defects adversely, using favorable genetic information of some genetically lucky individuals in order to get advantage should also be prohibited. The final issue that I addressed is authorized disclosure and different types of regulatory strategy (Section II-C). In general, genetic-specific anti-discrimination state statutes prohibit only "unauthorized" disclosure and not "authorized" or "voluntary"

disclosure of genetic information. However, I noted that especially in the employment settings, if the law makes an authorized disclosure legal, employers easily can find a big loophole because it is sometimes very hard to prove that discriminatory use was made in the process of selecting job applicants. Therefore, I argued that not only banning the use of genetic information (Harm Avoidance or End-loading approach) but also prohibiting access to and acquisition of genetic information by regulating authorized disclosure is indispensable (Front-loading approach).

Another agenda I explored in the latter part of this paper was why many federal attempts to enact a genetic nondiscrimination law have failed. I do not believe that these failures can be explained sufficiently only by the strong political pressures of the lobbying activities of the health insurance industry and large employer groups. I believe that good reasons why no federal level comprehensive law designed to prohibit genetic discrimination has been enacted so far and why state statutes vary so greatly, can be obtained by examining the problems genetic-specific anti-discrimination laws approach. Under this academic interest, in Section III and IV, I examined the problems of genetic-specific anti-discrimination laws.

The next question is whether we can distinguish genetic information from other medical information. To answer this question, I identified the nature and features of genetic information. In so doing, I examined "genetic exceptionalism" (Section III-A). Genetic exceptionalism is a principle which asserts that genetic information is substantially different from non-genetic information, and therefore, a line can be drawn somewhere in between genetic information and other medical information. The argument of genetic exceptionalism is based on the observations of the unique characters and specific features of genetic information. Such unique features are represented by the increased nature of vulnerability to genetic discrimination and stigmatization, the longevity of DNA (immutable nature), the highly identifiable feature of DNA, increased familial risks, and community impacts, and the like. Even though several specific features of genetic information could be identified, I demonstrated that it is practically impossible to draw a line between genetic information and other medical information (Section III-A). Thus, I noted that the more genetic technology advances, the more practically impossible it will become to distinguish between the two and find where the line is to be drawn. Therefore, in order to protect genetic privacy appropriately, the law should also protect the privacy of all of the predictive medical information as well as the so-called genetic information. I have also pointed out how these definitional difficulties of genetic information resulted in both over-inclusiveness (Section III-B) and under-

inclusiveness (Section III-C) of the protection against genetic discrimination. Since virtually no genetic-specific legislation can be drafted without more or less presupposing that a line can be drawn between genetic and non-genetic information, the legislation is not free from the practical problems of genetic exceptionalism. I believe these practical problems could offer a good explanation on the inconsistency of the coverage of the statutes among the states.

However, more serious and fundamental problems inherent in the genetic-specific anti-discrimination laws are normative problems stemming from genetic exceptionalism. This issue has been addressed in Section IV. By referring to the arguments presented by Sonia M. Suter, I pointed out that genetic-specific anti-discrimination laws are unfair and create an inequality in that the laws give protection of privacy only to genetic information and not to other medical information, and we cannot find any good moral reason for giving greater legal protection only to a person whose elevated risk, for instance, to develop breast cancer happens to be traceable to a gene mutation and not provide protection to another whose elevated risk is traceable to environmental exposure (Section IV-A). Moreover, this inequality leads to social inequality between the classes. Based on the arguments delivered by Suter, I have shown that genetic-specific legislation disproportionately treats the most vulnerable low socioeconomic class adversely (Section IV-B). And then, I considered incrementalism as one plausible defense for genetic-specific legislations but concluded that the arguments of incrementalism are not appropriate in justifying the normative problems of the laws (Section IV-C). Here, I identified a serious dilemma over the genetic discrimination issues: there is a strong need to protect genetic privacy and prevent genetic discrimination, but at the same time genetic-specific anti-discrimination laws have unavoidable practical problems which produce over- and under-inclusiveness and also serious inherent normative problems which result in unintended unfair consequences between people with genetic health problems and those with non-genetic health problems, and also between the socioeconomic classes. I believe that these normative problems — unfair protection and inequalities could offer one plausible explanation on the fact that it is hard to enact a comprehensive genetic-specific anti-discrimination bill in the U.S. Congress.

By observing the practical and normative flaws of genetic-specific anti-discrimination laws, I have reached the insight that if we aim to prevent genetic discrimination by law, it is inevitable that we also have to design the law to prohibit all discriminations on the basis of all predictive medical information in the health insurance and employment arena. Therefore, I considered a national single-payer /

mandatory community-rating health insurance system, and DHHS Privacy Regulations of 2000 as such alternative ways to protect all predictive medical information against discriminatory use in the insurance arena (Section IV-D).

The fundamental issue that I explored in this paper was regarding whether or not these fundamental problems inherent in the genetic-specific laws justify the argument asserting that the law should not prohibit insurers and employers from taking genetic information into account in their discriminatory decisions. Some commentators may emphasize these problems of the anti-discrimination laws to justify the discriminatory use of genetic information. However, we can reach the opposite conclusion as seen in the argument presented by Suter. That is, if we intend to prohibit genetic discrimination adequately, the law should be and, in fact, inevitably must be designed to protect all predictive medical information against discrimination. Why not protect all predictive medical information against all kinds of discrimination instead of limiting it to genetic discrimination? In other words, the real issue that we face right here is not how to prevent genetic discrimination but the very issue that we have to debate seriously is whether or not the law should ban discrimination on the basis of all predictive medical information. However, this is an open question that has not yet reached a consensus because American tradition has been legally admitted to take medical information (health status or condition) into account in the underwriting practice in insurance as "actuarial fairness." In other words, protecting all predictive medical information from discriminatory use means a paradigm shift in the long-standing practice in the private health insurance system in the U.S. In order to answer this question, both the reasons of the proponents and the opponents of the anti-discrimination laws and balance of interests between the merits of banning discrimination and the adverse consequences resulting from such prohibition must be fully addressed and examined.

Even though the federal genetic nondiscrimination bill should be enacted, 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, 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 and what the theoretical grounds are to justify such a policy in spite of its producing serious side-effects. This is the issue I will address in another paper to be published at another opportunity.