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

*Koichi SETOYAMA***

Content

- I. Introduction**
- II. Existing Federal Legal Protections and Limitations**
 - A. Federal Legal Protections in Health Insurance**
 - a. Health Insurance Portability and Accountability Act of 1996
 - b. Americans with Disabilities Act of 1990 (ADA)
 - B. Federal Legal Protections in Employment**
 - a. Title VII of the Civil Rights Act of 1964
 - b. Executive Order
 - c. Americans with Disabilities Act of 1990 (ADA) and EEOC
- III. State Legislations Banning Genetic Discrimination**
 - A. State Legal Protections in Insurance**
 - B. State Legal Protections in Employment**
- IV. Federal Bills in the U.S. Congress**
 - A. Proposed Federal Bills in the U.S. Congress (1995-2002)**
 - B. Genetic Information Nondiscrimination Act of 2003 and 2005**
- V. Conclusion**

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I. Introduction

In my previous article published in this Law Review,¹⁾ I addressed the pressing reasons why genetic discrimination, if any, should be legally banned, and examined the nature and character of genetic information by reviewing the arguments of “genetic exceptionalism.” However, I did not address the present legal responses to this matter nor examine the underlying issues and problems of genetic anti-discrimination laws.

In this Paper, I will review current “patchwork” legal protections against genetic discrimination in the health insurance and employment settings at the federal level and state level in the United States respectively.

The present legal protection regime in the U.S. over the issue of genetic discrimination is called “patchwork” or “piecemeal” protections because, as of fall in 2005, no comprehensive genetic-specific anti-discrimination law at the federal level has been enacted although the Genetic Information Nondiscrimination Act was passed in the U.S. Senate on February 17, 2005.²⁾ Therefore, on the federal level, legal protection against genetic discrimination so far is provided partly by each of various different legal sources. In the following sections, I will look into the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Americans with Disabilities Act of 1990 (ADA), Title VII of the Civil Rights Act of 1964, Executive Order, Regulations (policy guidelines) of the Equal Employment Opportunity Commission (EEOC), and several judicial decisions related to the interpretation of these laws and regulations. The primary objective of these reviews is to examine to what extent the currently existing laws give legal protection in prohibiting genetic discrimination in employment and insurance, and also to identify the limitations and shortcomings of such patchwork legal protections. I confirm, as many commentators have pointed out, that the present patchwork protections provided at the federal level are insufficient in banning

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- 1) *Privacy of Genetic Information*, 52 OSAKA UNIV. LAW REV. pp. 75-105 (2005). I asserted that legal protections against genetic discrimination are indispensable in order to prevent creating a “genetic underclass,” to preserve the “right to know” and “right not to know” of our own genetic information, to eliminate fear which discourages people from undergoing genetic tests or participating in genetic research, and as a result, to develop medicine and biology, and ultimately enhance public health by curing and preventing genetic diseases which will lead to cutting overall health care costs.
 - 2) S.306. Official Title of the bill is “A bill to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.”

genetic discrimination. Indeed, the limitations of the existing federal laws prompted state legislatures to enact their own genetic-specific anti-discrimination statutes which provide more comprehensive protection against genetic discrimination. In section III, by briefly surveying such state statutes, I confirm, as many scholars have asserted, that state statutes vary widely state by state and therefore, cannot provide consistent legal protection and also some statutes give inadequate protection attributed to their mal-defined genetic information. This understanding is proved by the fact that many attempts have been made to enact a genetic-specific nondiscrimination legislation at the federal level. However, although many federal bills have been introduced in each session of the U.S. Congress since 1995, none of these bills were passed until 2003 nor enacted to date.

II. Existing Federal Legal Protections and Limitations

A. Federal Legal Protections in Health Insurance

As of fall in 2005, there is no uniform, comprehensive federal legal legislation against genetic discrimination that has been passed in the House of Representatives in the U.S. Congress, although a couple of such bills were passed in the Senate³⁾. However, genetic privacy of the people is protected partly by existing federal legal protections and each state's anti-discrimination legislation. These present legal protections are sometimes called "patch-work protection"⁴⁾ or "piece-meal solution."⁵⁾ In this section, I review these legal protections against genetic discrimination and protection for genetic privacy. And then I describe several shortcomings that have been pointed out by commentators and assert that a comprehensive, uniform federal genetic legislation is needed to cap the legal loopholes of the present patch-work legal protections.

a. Health Insurance Portability and Accountability Act of 1996

To date, the only federal legislation which explicitly addresses restrictions on insurers' using genetic information discriminatorily is the Health Insurance Portability and Accountability Act of 1996 (also known as "Kennedy-Kassebaum

3) In Section IV, these bills will be reviewed.

4) See, e.g., Wendy Lovejoy, *Ending the Genetic Discrimination Barrier: Regaining Confidence in Preconception, Prenatal, and Neonatal Genetic Testing*, 74 S. CAL. L. REV. 873, 907 (2001).

5) See, e.g., Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 KY. L.J. 503, 533 (1996-97).

Act”) (hereinafter “HIPAA”).⁶⁾

i. Protections

HIPAA prescribes several legal protections for the insured and prospective policyholders in terms of eligibility for enrollment, coverage, renewal and the like.

Wendy Lovejoy well describes several legal protections for genetic information under HIPAA.

- 1) “HIPAA does not allow group health plan or health insurers offering group coverage to treat genetic information as a *preexisting condition*, which would enable the insurer to exclude that condition from coverage.”⁷⁾
- 2) “group health plans cannot deem an applicant *ineligible* for enrollment in the group plan based on genetic information or health status.”⁸⁾
- 3) “HIPAA prevents group health plans from *charging higher premiums* based on genetic information than the plan charges other ‘similarly situated individual[s] enrolled in the plan.’”⁹⁾
- 4) “HIPAA provides special protections for *newborns and pregnancies*.”¹⁰⁾ “Group health plans may not enforce preexisting condition exclusions against pregnancy-related conditions during the month following birth.”¹¹⁾
- 5) HIPAA “requires health insurers to *renew individual coverage* at the option of the insured, except in cases of fraud, nonpayment of premiums, or other terminating events.”¹²⁾ “There are no limitations, however, on the premiums that may be charged under the renewed policy.”¹³⁾

Lovejoy explains several actual implications of these provisions under HIPAA:

[F]or individuals who undergo genetic carrier screening and find they are the carrier of Tay Sachs, this part of their medical record cannot be used to deny them eligibility to enroll on a group health plan. Additionally, a pregnant woman who learns through prenatal genetic testing that her baby has spina bifida cannot be excluded from her group health plan for

6) 104 Public Law No. 104-191, 701, 110, STAT, 1936 (1996) (codified in scattered section of 18 U.S.C., 26 U.S.C., and 42 U.S.C.).

7) 29 U.S.C. § 1181(b)(1)(B), 1182(a)(1)(F), 1182 (b)(1) (Supp.II 1996) (emphasis added).

8) 29 U.S.C. § 1182 (a)(1)(A), (F) (emphasis added).

9) 29 U.S.C. § 1182 (b)(1) (emphasis added).

10) 29 U.S.C. § 1181(d)(1), (3) (emphasis added).

11) 29 U.S.C. § 1181(d)(1), (3).

12) 42 U.S.C. § 300gg-42 (Supp. II 1996) (emphasis added).

13) Wendy Lovejoy, *supra* note 4, at 904 (2001).

having a preexisting condition. Furthermore, a newborn covered under a group health plan and testing positive for PKU can undergo treatment for PKU without the parents being worried about the treatment being excluded as a preexisting condition.¹⁴⁾

ii. Limitations

Chetan Gulati addresses the limitations of HIPAA in preventing genetic discrimination.

- 1) HIPAA “does not prohibit insurers from requiring genetic tests as a condition of enrollment in a health plan. Therefore, an applicant may be denied coverage or charged a higher rate for refusing to comply with a testing requirement.”
- 2) “HIPAA does not apply to those who are individual policy holders and who are the most susceptible to genetic differentiation.”
- 3) “HIPAA does not prohibit the use of genetic information in risk classification and insurance underwriting. Therefore, HIPAA does not deny insurers the ability to raise rates, exclude coverage for certain conditions and impose lifetime caps on certain benefits, provided they are applied to the group.”
- 4) “the new regulations do not control the price of insurance because the Act does not prevent insurance companies from raising rates for entire groups, which can have the same effect as denying coverage.”
- 5) “the provision does not define what constitutes genetic information, making it difficult to know whether or not the provision has been violated.”
- 6) “under HIPAA, the remedies available to an individual are very limited and the penalties that could be imposed on an employer amount to no more than \$100 per day.”¹⁵⁾

Lovejoy also points out the limitations of HIPAA in preventing genetic discrimination:

The largest population that HIPAA leaves unprotected is insureds in the individual market. For the 14.5 million Americans who acquire health insurance through nongroup plans, their genetic information can be used by insurers to raise premiums and cut benefits. For example, if a woman in the individual market undergoes genetic testing and finds that she is a carrier of sickle cell disease, her individual market insurer can access her

14) *Id.*

15) Chetan Gulati, *Genetic Antidiscrimination Laws In Health Insurance: A Misguided Solution*, 4 QUINNIPIAC HEALTH L.J. 149, 200 (2001).

genetic testing results and place a low cap on pregnancy related claims or exclude pregnancy health care altogether. If this woman is in the middle class, she will not be eligible for Medicaid as a safety net and could find herself with no coverage for prenatal care.¹⁶⁾

Furthermore, for uninsured individuals applying for health insurance in the individual market, insurers can access their genetic information and deny eligibility to enroll based on that information. For a pregnant couple who learns through prenatal genetic testing that their baby will be born with a genetic birth defect, the individual market insurer can refuse to insure the baby.¹⁷⁾

HIPAA allows group health insurance plans to respond to the genetic information of one group member by raising premiums for the entire group. Similarly group health plans can exclude coverage for certain conditions or place claim limits on particular conditions, 'provided it is not directed at certain individuals.' Thus ... some parents may find that their attempt to prevent genetic birth defects through genetic testing is used against them to raise premiums or to deny certain benefits.¹⁸⁾

Diver and Cohen also describe the shortcomings of HIPAA and state that it "applies only to employment-based group health insurance, its provisions do not reach the roughly one-third of American workers unprotected by such plans nor, of course, the unemployed."¹⁹⁾

Lovejoy points out that "[i]f the genetic condition associated with the genetic information has been diagnosed, however, then insurers can consider it to be a preexisting condition and exclude it from coverage."²⁰⁾

b. Americans with Disabilities Act of 1990 (ADA)

Some may try to seek federal legal protection against genetic discrimination concerning health insurance coverage by interpreting the Americans with

16) Wendy Lovejoy, *supra* note 4, at 905.

17) *Id.*

18) *Id.*

19) Colin S. Diver & Jane Maslow Cohen, *Genophobia: What Is Wrong With Genetic Discrimination?* 149 U. PA. L. REV. 1439, 1450 (2001)

20) Wendy Lovejoy, *supra* note 4, at 903 (29 U.S.C. § 1181(b)(1)(B)).

Disabilities Act of 1990 (ADA). This is because Title III of the ADA provides that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, lease (or leases to), or operates a place of *public accommodation*.”²¹⁾ And the insurance office is included in the illustrative list of places of “public accommodation.”²²⁾

Wendy Lovejoy examines this possibility. According to her, the court decision also suggests that “the ADA was intended to apply to access to insurance coverage.”²³⁾

In *Winslow v. IDS Life Insurance Co.*, the district court followed the First Circuit in determining that a place of public accommodation is not limited to actual physical structures. The court found that the defendant’s policy of denying access to disability insurance based on the plaintiff’s mental health condition “is founded on a disability-based discrimination violative of the ADA.”²⁴⁾

However, Lovejoy does not believe that the ADA provides sufficient protection for health insurance coverage. She states:

[T]he ADA allows plans to “refuse to insurer, or refuse to continue to insure, or limit the amount, extent, or kind of coverage available to an individual, or charge a different rate for the same coverage’ if the disparate treatment is ‘based on sound actuarial principles or is related to actual or reasonably anticipated experience.”²⁵⁾

She notes that, for example, “prospective parents learning that they are carriers of a genetic condition will likely be protected from discrimination since carrier status is not likely actuarially to create anticipated expense because carriers will never achieve symptoms. The ADA, however, cannot stop the insurer from refusing to insure the couple’s baby.” Moreover, she states that “the insurer may be able to

21) 42 U.S.C. §12182 (a) (1994) (emphasis added).

22) 42 U.S.C. §12181 (7).

23) Wendy Lovejoy, *supra* note 4, at 902.

24) *Id.* (citing *Winslow v. IDS Life Insurance Co.*, 29 F. Supp. 2d 557, 563 (D. Minn. 1998)).

25) *Id.* (quoting *Winslow*, 29 F. Supp.2d at 566).

deny coverage for the woman's pregnancy since it is likely to be associated with expensive complications."²⁶⁾ Furthermore, "employers with fewer than fifteen employees are exempted from ADA compliance. This exemption leaves insureds in employee group-benefit plans unprotected when the group is small."²⁷⁾ Furthermore, "the ADA provides no protection for those insured in the individual market."²⁸⁾

Lynn E. Egan also gives a negative comment on this issue.

[C]omplaints under the ADA against limitations of fringe benefits like health insurance, are also similar to those of state legislation combating health insurance discrimination when suits were brought against companies using self-insured plans. As was seen in McGann, ERISA would once again be used to protect an employer's right to limit coverage based on inordinate medical expenses incurred by a few individuals who would endanger the fiscal solvency of the company, if they were to be included in that company's self-funded insurance plan.²⁹⁾

Eric Mills Holmes also presents a negative opinion on the possibility that the ADA effectively regulates genetic discrimination in the employee health insurance plan. He notes:

In the spirit of the McCarran Act, the ADA's insurance exemption, section 501(c), primarily leaves insurance regulation to the states. The ADA, surprisingly, avoids insurance discrimination issues by adopting the status quo of conventional risk underwriting based on legitimate actuarial support by commercial insurers and self-insured employers. These traditional, customary insurance practices in underwriting, classifying, and administering risks generally do not constitute prohibited discrimination under the ADA, so long as the insurance benefit plan is not used as a "subterfuge" to evade the ADA.³⁰⁾

26) *Id* at 903.

27) *Id*.

28) *Id*.

29) Lynn E. Egan, Note, *Genetic Discrimination in Health Insurance*, 24 J. LEGIS. 237, 244 (1998).

30) Eric Mills Holmes, *supra* note 5, at 605-06.

Mark A. Rothstein addresses the great limitation and inadequacies of the ADA with regard to the protection for employer-sponsored health insurance for genetic conditions. Indeed, provisions under section 501 of the ADA permit a wide range of discriminatory discretion for the employers with regard to coverage, underwriting risks, classifying risks, etc. First of all, he points out that “[s]ection 501(c) of the ADA makes it clear that the law does not prohibit or restrict employers or insurers from underwriting risks, classifying risks, or administering risks. Thus, employers and insurers are not prohibited from treating employees differently with regard to health insurance on the basis of their disabilities.”³¹⁾ In other words, “[e]mployers are free to discriminate against certain disabilities [such as ‘kidney dialysis’]”³²⁾ as long as “other conditions [are] made available to employees without disabilities.”³³⁾ Second, in regards to risk he notes that “[u]nder section 501(c)(1) of the ADA, it is not illegal for an insurer to charge higher rates for certain conditions, to exclude certain conditions, or to limit the coverage of certain conditions, so long as such action does not violate state law.”³⁴⁾ And “[s]ection 501(c)(2) permits employers to do the same thing, so long as there is no violation of state law.”³⁵⁾ He quotes the statement in the House report: “In sum, section 501(c) is intended to afford to insurers and employers the same opportunities they would enjoy in the absence of this legislation to design and administer insurance products and benefits plans in a manner that is consistent with basic principles of insurance risk classification.”³⁶⁾

Rothstein observes:

The legislative history of section 501(c) indicates that arbitrary, invidious discrimination in health insurance against individuals with disabilities is unlawful but that *actuarially-based* discrimination is permissible. Unfortunately, a wide range of employer and insurer practices are actuarially-based and therefore legal, including the following: exclusion of preexisting conditions, exclusion of coverage for

31) Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans Disabilities Act*, 29 HOUSTON L. REV. 23, 79 (1992) (referring to 42 U.S.C.A. § 12201(c)(1) (West Supp.1992)).

32) *Id.*

33) *Id.* at 80.

34) *Id.* (referring to 42 U.S.C.A. § 12201(c)(1) (West Supp.1992)).

35) *Id.* (referring to 42 U.S.C.A. § 12201(c)(2) (West Supp.1992)).

36) *Id.* at 81. (quoting House Educ. and Labor Comm., H.R.Rep. No. 485, 101st Cong., 2d Sess., pt. 2, at 137, (1990), reprinted in 1990 U.S.C.C.A.N. 303, at 420).

certain conditions, charging higher premiums for high risk individuals, imposing low maximum lifetime caps on payments for certain conditions, and the exclusion of dependents.³⁷⁾

Lynn E. Egan also states that “if the discrimination falls within actuarial fairness as defined under state law, it is not actionable under the ADA, whether ethical or not.”³⁸⁾

Rothstein notes the real implications of these provisions by giving the following examples.

[A]n individual with hemophilia may not be denied employment based on hemophilia, but an employer could establish a \$100 lifetime maximum for blood transfusions and clotting factor treatment. An individual who carried the gene for APKD legally could be offered a job where dialysis treatment is not covered by the employer’s health insurance. An individual who carried the gene for Huntington’s disease (HD) might be told that no treatment for HD is covered under the employer’s health insurance policy. An employee for a self-insured company who had a child with Duchenne muscular dystrophy or cystic fibrosis could suddenly lose all dependent coverage.³⁹⁾

Accordingly, Rothstein concludes that “[o]f all the areas of the employment relationship in which individuals with disabilities face major obstacles, health insurance is the area in which the ADA offers the least protection.”⁴⁰⁾

Given the fact that when the ADA was enacted in 1990, it was neither designed to address genetic discrimination nor health insurance, it is not surprising that the Act offers no protection against genetic discrimination in the employer-sponsored health insurance settings.

Accordingly, the possibility of the ADA providing legal protection against genetic discrimination cannot be found in the health insurance and therefore federal protection in the insurance arena rests on HIPPA’s limited protection. As discussed in the next subsection, the ADA is referred to as the main federal protection against genetic discrimination in the employment arena.

37) *Id* at 81-82 (emphasis added).

38) Lynn E. Egan, *supra* note 29, at 244.

39) *Id* at 82.

40) *Id* at 79.

B. Federal Laws and Regulations in Employment

In this section, I review the existing federal laws and regulations which have been regarded as providing patch-work protections against genetic discrimination in the employment arena: Title VII of the Civil Rights Act of 1964, Executive Order, Americans with Disabilities Act of 1990 (ADA) and EEOC Compliance Manual (policy guideline). Especially I will focus on the ADA provisions and examine to what extent the ADA can give legal protection to job applicants and employees against genetic discrimination.

a. Title VII of the Civil Rights Act of 1964

Paul Steven Miller states that Title VII “also may incidentally provide protection against some forms of genetic discrimination, because genetic discrimination may have a disparate impact based on race, color, religion, sex, or national origin.” This is because “an employer may violate Title VII by engaging in discrimination based on a genetic trait that disproportionately impacts a particular protected group, such as sickle cell disease (individuals of African descent) or Tay-Sachs disease (Ashkenazi Jews).”⁴¹⁾

According to his book titled “YOUR GENETIC DESTINY”, Milunsky, a medical geneticist and Professor of Human Genetics and Director of the Center for Human Genetics notes the correlation between inherited genetic disorders and particular ethnic groups.⁴²⁾ It is reported that “[o]ne in 27 to 1 in 30 Ashkenazic Jews carries a Tay-Sachs disease gene mutation. Without testing, about 1 birth in 3,600 would be that of an affected infant—100 times the number of such births in the non-Ashkenazic population.”⁴³⁾ And it is reported that “about 1 in 600 blacks in the United States are affected by Sickle Cell disease.”⁴⁴⁾ And also it is found that Cystic Fibrosis “is most frequently encountered among whites, 1 in 25 of whom are carriers. ... The frequency of various cystic fibrosis gene mutations varies among ethnic groups within the white population.”⁴⁵⁾

Chetan Gulati also notes that “[i]t is possible that an employer could refuse to hire employees who are members of a protected group based on the fact that

41) Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J. L. MED. & ETHICS 189, 191 (1998).

42) AUBREY MILUNSKY, *YOUR GENETIC DESTINY* 85-97 (PERSEUS PUBLISHING 2001).

43) *Id.* at 86.

44) *Id.* at 93.

45) *Id.* at 92.

members of that group are more likely to carry the gene for a particular genetic disorder.”⁴⁶⁾ And Gulati states that “a disparate impact claim under Title VII [of the Civil Right Act of 1964] would probably be the most effective way to combat this form of discriminatory hiring.”⁴⁷⁾

However, Miller notes that “many, if not most, genetically related diseases and disorders do not disproportionately affect one of Title VII’s protected classes; thus, Title VII does not provide comprehensive protection against genetic discrimination in employment.”⁴⁸⁾

Elaine Draper also mentions Title VII of the Civil Rights Act of 1964 as one of the potential federal level legal protections against employment discrimination. She notes that

[Title VII] provides limited protection against genetic discrimination by making it illegal for employers to limit, segregate, or classify employees in any way that would tend to deprive individuals of employment opportunities or otherwise adversely affect their status as employees, where screening programs disproportionately affect a class protected under Title VII (such as race, sex, or ethnicity) or treat a protected class differently.⁴⁹⁾

Elaine Draper gives “prime examples of disorders that could give rise to disparate impact claims” and notes that “G-6-PD deficiency, sickle-cell trait, and hypertension ... are found among blacks at a higher rate than the rest of the population.”⁵⁰⁾ However, Draper asserts that “Title VII reaches genetic testing and discrimination only if the genetic trait at issue traces gender, race, or ethnic line. A limited number of genetic traits meet this qualification.”⁵¹⁾

Draper addresses the employers’ defense:

An employer can avoid liability for a policy that discriminates according to protected status only upon presenting a *valid business justification*. If

46) Chetan Gulati, *Genetic Antidiscrimination Laws In Health Insurance: A Misguided Solution*, 4 QUINNIPIAC HEALTH L.J. 149, 201 (2001).

47) *Id.*

48) Paul Steven Miller, *supra* note 41, at 191-92.

49) Elaine Draper, *The Screening of America: The Social and Legal Framework of Employers’ Use of Genetic Information*, 20 BERKELEY J. EMPLOYMENT & LABOR L. 286, 308-09 (1999).

50) *Id.* at 309.

51) *Id.* at 310.

an employer discriminates intentionally, the employer must show that the exclusion based on genetic predisposition is a *bona fide occupational qualification*. If an employer is found to have a policy that unintentionally discriminates on the basis of protected status, the employer can escape liability by showing the classification is related to the position in question and *consistent with a business necessity*.⁵²⁾

She states that “even if an employer’s genetic policy discriminates on an impermissible basis, it is unlikely the discrimination would be intentional. If so, an employer would have to satisfy only the less-rigorous business necessity defense, making it more likely the policy would survive judicial scrutiny.”⁵³⁾ Accordingly, we can say that Title VII has a limited protection against genetic discrimination in the workplace.

b. Executive Order

On February 8, 2000, former President William J. Clinton signed an executive order, titled “To Prohibit Discrimination in Federal Employment Based on Genetic Information.”⁵⁴⁾ The Order prohibits federal employers from using genetic information to discriminate against employees. Section I of the Order states: “It is the policy of the Government of the United States to provide *equal employment opportunity* in Federal employment for all qualified persons and to prohibit discrimination against employees based on *protected genetic information*, or information about a request for or the receipt of genetic services.”⁵⁵⁾ [emphasis added]

Under the Executive Order, “protected genetic information” is defined broadly: it means “(A) information about an individual’s genetic tests; (B) information about the genetic tests of an individual’s family members; or (C) information about the occurrence of a disease, or medical condition or disorder in family members of the individual.”⁵⁶⁾ However, it adds that “[i]nformation about an individual’s current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses) is not protected genetic information.”⁵⁷⁾

52) *Id.* at 309 (emphases added).

53) *Id.* at 310.

54) Exec. Order No. 13145, 65 Fed. Reg. 6877, 2000 WL 142053 (Pres.) (Feb. 8, 2000).

55) *Id.* § 1-101.

56) *Id.* 6878 § 1-201 (e)(1)(A)-(C).

57) *Id.* 6878 § 1-101 (2).

Section 1-202 states:

- (a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of that employee, because of protected genetic information with respect to the employee, or because of information about a request for or the receipt of genetic services by such employee.
- (b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect that employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee.
- (c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by such employee.
- (d) The employing department or agency shall not disclose protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by an employee except: (1) to the employee who is the subject of the information, at his or her request; (2) to an occupational or other health researcher, if the research conducted complies with the regulations and protections provided for under part 46 of title 45, of the Code of Federal Regulations; (3) if required by a Federal statute, congressional subpoena, or an order issued by a court of competent jurisdiction, except that if the subpoena or court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the subpoena or court order, unless the subpoena or court order also imposes confidentiality requirements; or (4) to executive branch officials investigating compliance with this order, if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records and kept separate from personnel files.⁵⁸⁾

Natalie E. Zindorf notes that “[a]ccording to the Executive Order, federal employers are prohibited from requiring genetic testing as a condition to employment or promotion, and the employer may not use genetic information to classify current employees in a manner that deprives employees of equal promotion opportunities.”⁵⁹⁾ And also under the Order, “[e]mployees cannot be denied overseas posts or promotion opportunities based on information regarding genetic susceptibility to certain disease.”⁶⁰⁾

However, there are many exceptions to the above proscriptions: “(1) department or agency health offices may collect genetic information about employees that use the department or agency health services and (2) genetic monitoring of employees is allowed.”⁶¹⁾ Zindorf explains that “[u]nlike genetic screening, which tests the potential of an individual developing a future disorder, genetic monitoring determines to what degree a person has been exposed to or harmed by toxins.”⁶²⁾ Moreover, Zindorf states that “[u]nlike the ADA, the Executive Order does not permit employers to prescreen individuals if the test is job-related and consistent with business necessity. Additionally, ‘certain exceptions permit disclosure to select individuals, including: the employee, officials investigating compliance with the order, health researchers involved in researching human subjects, the court and as required by law.’”⁶³⁾

Diver and Cohen also note that “[l]ike the ADA, the Order contains several exceptions, including the use of genetic information at the pre-placement stage.” For example, “[t]he Order permits federal employers to consider genetic information ‘to assess whether further medical evaluation is needed to diagnose a current disease, or medical condition or disorder’.”⁶⁴⁾ They also note that

58) *Id.* 6878-79 § 1-202 (a)-(e).

59) Natalie E. Zindorf, Comment, *Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance*, 36 *TULSA L.J.* 703, 713 (2001).

60) *Id.*

61) *Id.*

62) *Id.*

63) *Id.* at 714.

64) Colin S. Diver & Jane Maslow Cohen, *supra* note 19, at 1451 n44 (quoting Exec. Order No.

“significantly, moreover, it permits employees considerable latitude with respect to information they wish to voluntarily disclose.”⁶⁵⁾ For instance, “[t]he Order permits federal employees to authorize their employers to use genetic information obtained in connection with genetic or health care services provided by the employing agency.”⁶⁶⁾

As has been seen, the Executive Order proscription has many exceptions and also it bans genetic discrimination only in the federal employment context and leaves employees on the state level or in private sectors unprotected.

c. Americans with Disabilities Act of 1990

As mentioned before, so far there has been no federal genetic-specific antidiscrimination law enacted in the employment arena nor in the insurance field. And also there is currently no case law precisely addressed over the issue of whether the individuals with asymptomatic genetic disorders would be protected against genetic discrimination in the workplace. Under this circumstance, the federal Americans with Disabilities Act (ADA) has been regarded by many commentators as the most promising federal level legal legislation which potentially provides legal protection against genetic discrimination in the workplace.⁶⁷⁾ In this subsection, I review the ADA provisions and consider to what extent the ADA can give legal protection to job applicants and employees against genetic discrimination. At the same time, I address several insufficiencies of the ADA in regards to protecting job applicants and workers from genetic discrimination by referring to several arguments presented by commentators who have examined this issue seriously. Moreover, I introduce a proposed amendment presented by a scholar. And then, I review the state-level genetic-specific statutes which try to make up for the insufficiencies and fill the legal loopholes of the federal level legal protections in employment.

i. Applicability (Establishing an ADA Claim): Qualified Individual with a Disability

The ADA was enacted in 1990 and became effective on July 26, 1992, aiming to

13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000) § 1-301 (a)(2), at 6879)).

65) *Id.* at 1451.

66) *Id.* n44 (quoting Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000) § 1-301 (b)(2), at 6877)).

67) *E.g.* Kaufmann states that “[t]he ADA potentially provides employees the greatest protection against genetic discrimination.” Melinda B. Kaufmann, *infra* note 74, at 404.

prohibit employers from discriminating against job applicants and employees with disabilities (without the intention of banning genetic discrimination). It applies to all employers with fifteen or more employees regardless of whether the employer is the federal government or private sectors which do not receive federal funding.

(1) Scholarly Interpretation: Three Prongs of the Definition of Disability

Title I of the ADA states that “[n]o covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”⁶⁸⁾

The ADA does not specifically address genetic discrimination. Therefore, the first controversial issue that needs to be discussed is whether an individual with an unexpressed genetic condition (presymptomatic or predisposed to diseases or illnesses) is a “disability” under the definition of the ADA. The answer rests on the interpretation of the provisions of the ADA. Indeed, by interpreting the provision of the ADA as to include people with genetic abnormality in the definition of an individual with “a disability”, the ADA has been regarded the most prospective legal protection presently offered on the federal level against genetic discrimination in the workplace.

To establish a discrimination claim under the ADA, an applicant or employee must show that s/he is within at least one prong of the following three parts of the definition of an individual with a disability. Under the ADA, “disability” is defined as “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”⁶⁹⁾

The individuals with presymptomatic genetic illness or those genetically predisposed to disease might be seen as falling within (A) or at least within (C) the third “perception” prong of the definition of disability.⁷⁰⁾ “Physical or mental impairment” means “any physiological disorder or condition, disfigurement, or anatomical loss affecting any of the major body systems or any mental or

68) 42 U.S.C. §12112(a) (Supp. III 1991).

69) 42 U.S.C. §12102(2)(A)-(C).

70) Amanda J. Wong, Comment, *Distinguishing Speculative and Substantial Risk In the Presymptomatic Job Applicant: Interpreting the Interpretation of the Americans with Disabilities Act Direct Threat Defense*, 47 UCLA L. REV. 1135, 1141 (2000).

psychological disorder.”⁷¹⁾ Whether a disability is “substantially limiting” depends on “the nature and severity of the impairment, the duration or expected duration of the impairment, and the permanent or long-term impact of the impairment.”⁷²⁾ According to the regulations issued by the Equal Employment Opportunity Commission (EEOC), “major life activity” includes activities such as “caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.”⁷³⁾

(1-a) First Prong of the Definition of “Disability”— Impairment Substantially Limiting a Major Life Activity

According to Melinda B. Kaufmann, “[m]ost genetic disorders do not exhibit present symptoms that would qualify as ‘substantially limiting a major life function.’”⁷⁴⁾ She notes:

First, this section would not apply to an individual whose genetic defect has not yet become a physical disorder, but may become one in the future. Second, this section does not protect an individual who may be a carrier for a disease that will never manifest itself in the individual, but may appear in his or her offspring. Finally, the section does not protect a person who may have a disabling disorder that is under treatment, but manifests no physical symptoms.⁷⁵⁾

Hence, she concludes that “[e]mployees in any of these three categories would not be protected under section (A) of the ADA because their ‘disability’ does not currently affect ‘a major life function.’”⁷⁶⁾

However, Deborah Gridley analyzes the provisions of the ADA and demonstrates that a genetic marker for disease qualifies as a disability under either the first or third prong of the disability definition. She asserts that the first prong also can be interpreted as to include genetic predispositions for disease in the scope of the disability defined under the ADA. She notes that “[a] genetic disorder that

71) Deborah Gridley, *Genetic Testing Under the ADA: A Case for Protection From Employment Discrimination*, 89 GEO. L. J. 973, 983-84 (2001) (referring to 29 C.F.R. § 1630.2(h)(1) (2000)).

72) 42 U.S.C. § 12102(2) (2000).

73) 29 C.F.R. § 1630.2(i) (2000).

74) Melinda B. Kaufmann, *Genetic Discrimination in the Workplace: An Overview of Existing Protections*, 30 LOY. U. CHI. L. J. 393, 411 (1999).

75) *Id.*

76) *Id.*

does not exhibit present symptoms would not seem to qualify as an impairment that 'substantially limits' any 'major life function.'"⁷⁷⁾ However, by referring to the majority opinion in *Bragdon v. Abbott* discussed later, she argues that "by using an analogy to persons with HIV, it seems that in some cases a genetic marker for disease should be considered a disability under this prong of the ADA's definition."⁷⁸⁾

A person with HIV may live for years with no symptoms at all, yet she is still impaired; likewise, a person with a genetic condition may be asymptomatic for some time, but still possess the impairment of the genetic marker. Thus, a person with a genetic marker for disease should be considered "impaired" for ADA purposes.⁷⁹⁾

As Gridley admits, "a person who is a mere carrier and will never develop the genetic disease could not be considered impaired in this context [first prong]."⁸⁰⁾ She states that "such a defect would not actually be the 'beginning of a genetic disease process,' but rather a genetic flaw that does no real harm to the individual and will never manifest itself in any way."⁸¹⁾ She concludes that

to the extent that a person is not a mere carrier but is someone who will at some point develop the disease in the future, she may be considered impaired under the first prong of the Act because she possesses a defect which is the "beginning of a genetic disease process."⁸²⁾

Brian R. Gin also draws "an analogy between individuals infected with HIV and individuals affected by Huntington's disease,"⁸³⁾ and argues that "Huntington's individuals are protected by the Act [ADA] as persons with a disability, either as individuals with an *impairment that substantially limits a major life activity*, or as individuals *regarded as having such an impairment*."⁸⁴⁾

77) Deborah Gridley, *supra* note 71, at 983.

78) *Id.*

79) *Id.* at 984.

80) *Id.* at 984-85.

81) *Id.* at 985.

82) *Id.*

83) Brian R. Gin, Note: *Genetic Discrimination: Huntington's Disease and the American with Disabilities Act*, 97 COLUM. L. REV. 1406, 1408 (1997).

84) *Id.* (emphasis added).

(1-b) Second Prong of the Definition of “Disability”—Record of Impairment

Gridley notes that “[t]his provision is designed to protect individuals who have recovered from a disability as well as those who were misdiagnosed in the past as having a disability.”⁸⁵⁾ She notes that “[i]t may be argued that a ‘record’ of an impairment may include a ‘record’ of a future, rather than past, impairment as indicated by a genetic test showing a likelihood of developing a certain disease.”⁸⁶⁾ However, she argues that “this view finds little support in either scholarly views or legislative history”⁸⁷⁾ and also “the EEOC regulations do not mention future impairment as included under this prong of the ADA’s definition,”⁸⁸⁾ and therefore “this definition of disability does not include any kind of record of future impairment.”⁸⁹⁾

However, Kaufmann notes that “[t]his prong may have ramifications for individuals who incorrectly test positive for a genetic disorder, an outcome that is highly likely given the inaccuracies and inconsistencies of current genetic tests.”⁹⁰⁾

Accordingly, the second prong—“Record of Impairment” is relevant to genetic disorder as long as individuals have recovered from a genetic disease, such as Phenylketonuria⁹¹⁾ or mistakenly regarded as having a genetic disease, for example, due to inaccurate genetic tests. In general, virtually all commentators who try to find legal protection for individuals with genetic abnormalities under the ADA rest on the third prong.

1-c) Third Prong of the Definition of “Disability”—Regarded as Having Impairment

Gridley states that “[i]ndividuals who do not fit within the actual disability prong [first and second definitions] of the ADA but who are nevertheless discriminated against on the basis of a genetic defect can find protection as individuals ‘regarded as’ having an impairment.”⁹²⁾ Gridley addresses the purpose of enacting the ADA; “the ADA was intended to protect disabled individuals, who

85) Deborah Gridley, *supra* note 71, at 988.

86) *Id.*

87) *Id.*

88) *Id.*

89) *Id.*

90) Melinda B. Kaufmann, *supra* note 74, at 412.

91) Phenylketonuria is treatable genetic disease. It is “a genetic disorder that can cause mental retardation [only] if the infant is not treated soon after birth.” Lori Andrews, *Genetics, reproduction, and the Law*, 35-JUL TRIAL 24 (1999).

92) Deborah Gridley, *supra* note 71, at 988.

had historically been victims of purposeful unequal treatment because they possess characteristics that are beyond their control and that are not truly indicative of each individual's ability to participate in, and contribute to, society."⁹³⁾ She quotes a statement of Congress; "unnecessary discrimination denies people with disabilities the *opportunity* to compete on an equal basis and to pursue those *opportunities* for which our free society is justifiably famous."⁹⁴⁾ And she argues that "[f]or purposes of the Act [ADA], an employee is disabled when her employer regards her as having a substantially limiting impairment, whether or not she is actually limited."⁹⁵⁾

The ADA defines "Regarded as having an impairment" as having:

(1) . . . a physical or mental impairment that does not substantially limit major life activities but is *treated by* [an employer] as constituting such limitation; (2) . . . a physical or mental impairment that substantially limits major life activities only as a result of the attitudes of others toward such impairment; or (3) . . . none of the impairments [specifically stated by the EEOC] but [[being] *treated by* [an employer] as having a substantially limiting impairment.⁹⁶⁾

Therefore, for example, Gridley argues that

an employee who is discriminated against on the basis of a genetic marker that does exist but that has not manifested itself in any disease will also find coverage under the Act as a person regarded as disabled by the employer, even though the employee does not yet have an actual disability.⁹⁷⁾

Accordingly, she concludes that "an employee who is denied employment on the basis of a genetic marker falls under the 'regarded as' prong of the Act and may be protected from such discrimination, even if the defect is not severe enough to place her within the protection of the 'actual disability' prong."⁹⁸⁾

93) *Id.* at 981.

94) *Id.* at 981 (quoting 42 U.S.C. §12101(a)(9) (2000)).

95) *Id.* at 988-89.

96) Brian R. Gin, *supra* note 83, at 1430 (alteration in original, emphases added, quoting 29 C.F.R. § 1630.2(l)).

97) Deborah Gridley, *supra* note 71, at 989.

98) *Id.* at 992.

Kaufmann also argues that “[t]he third prong, subsection (C), is the employee’s greatest protection against genetic discrimination.”⁹⁹⁾ She notes that “[u]nlike the other disability categories [prongs], this section is based on the employer’s perceptions, not the existence of a true disability or even the individual’s own perception of himself or herself as disabled.”¹⁰⁰⁾ Kaufmann concludes that “[i]ndividuals with asymptomatic genetic disorders, therefore, would most likely be covered by this section because employers would be discriminating based on the presence of a genetic anomaly, not on the employee’s inability to perform [the job].”¹⁰¹⁾

Jennifer S. Geetter states that this third “prong provides protection to an individual if she can show that (1) while she had a physical or mental impairment, it did not substantially limit her ability to perform major life activities, or alternatively, that (2) she did not suffer at all from a statutorily prescribed physical or mental impairment.”¹⁰²⁾ However, Geetter notes “the applicability of the third prong may vary widely depending on the nature of the genetic abnormality, the likelihood of expression and the victim of expression (the individual or his/her child).”¹⁰³⁾

Brian R. Gin also notes that although Huntington’s disease, a typical monogenetic disorder which will be manifested with almost certainty, is covered by the third prong, other genetic disorders may not be regarded as having an impairment because of the uncertainty of the time and severity of manifesting diseases.¹⁰⁴⁾

(2) Equal Employment Opportunity Commission Compliance Manual (policy guideline)

In 1995, the Equal Employment Opportunity Commission (EEOC), the federal agency charged with enforcing federal workplace anti-discrimination laws, issued a Compliance Manual (policy guideline).¹⁰⁵⁾ In this Manual, the issue of whether

99) Melinda B. Kaufmann, *supra* note 74, at 412.

100) *Id.* at 413.

101) *Id.* at 413.

102) 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, 43 (2002).

103) *Id.*

104) Brian R. Gin, *supra* note 83, at 1431-32.

105) According to Paul Steven Miller, Commissioner U.S. Equal Opportunity Commission, EEOC was created by Title VII of the Civil Rights Act of 1964. And in 1972, title VII was amended to give the EEOC broad authority to file lawsuits against private employers, labor unions and

individuals with unexpressed, late on-set genetic disorders are in the scope of the term “qualified individual with a disability” under the provision of the ADA is addressed.¹⁰⁶⁾ It is stated that the ADA

applies to individuals who are subjected to discrimination on the basis of *genetic information* relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such *genetic information* are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of “disability”.¹⁰⁷⁾

The manual gives a hypothetical example to clarify the above statement:

CP[charging party]’s genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R[one particular employer] learns about CP’s increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP’s productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of “disability”.¹⁰⁸⁾

Melinda B. Kaufmann asserts that this “statement better illustrates the modern ADA interpretation. If the intent behind the law [ADA] is to protect individuals from the myths and fears of society, it should apply to individuals with genetic

employment agencies. Paul Steven Miller, *The EEOC’s Enforcement of the ADA in the Second Circuit*, 48 SYRACUSE L. REV. 1577, 1587 (1998). Miller explains the role of the EEOC and states that “[t]he EEOC’s mission is to eliminate discrimination in the workplace based upon an individual’s disability, race, color, religion, sex, national origin, or age. The EEOC fulfills this mandate by investigating charges of discrimination, initiating litigation on behalf of individuals, and interviewing in private litigation.” *Id.* at 1587-88.

106) *EEOC Compliance Manual*, vol. 2, EEOC Order 915.002, reprinted in *Daily Labor Report*, Mar. 16, 1995, at E-1, E-23, 2 EEOC Compliance Manual (CCH), § 902.8(a) ¶ 6880, at 5303 (Mar. 14, 1995); Paul Steven Miller, *EEOC Compliance Manual, Executive Summary: Compliance Manual Section 902, Definition of the Term “Disability”*, 562 PLI/LIT 249, 301 (1997).

107) *Id.* (emphases added).

108) *Id.* Also see, Paul Steven Miller, *supra* note 106, at 301.

disorders as well as other types of asymptomatic diseases.”¹⁰⁹⁾

Paul Steven Miller, Commissioner of U.S. Equal Opportunity Commission, notes that the EEOC “adopted policy guidance stating that the ADA prohibits discrimination against workers based on their genetic make-up.”¹¹⁰⁾ And “[t]his policy guidance explicitly states that the third part of the definition of disability, the ‘regarded as’ prong, covers individuals who are subjected to discrimination on the basis of genetic preposition to illness, disease, or other disorder, even if the disability has not yet manifested.”¹¹¹⁾ Accordingly, “employers who discriminate against individuals on such a basis are regarding the individuals as having impairments that substantially limit a major life activity and therefore are violating the ADA.”¹¹²⁾ Miller emphasizes that “EEOC’s position is clear that the ADA protects individuals with asymptomatic genetic conditions from discrimination in employment, and the EEOC’s Interpretive Guidance is used to interpret the law and can be used as persuasive authority.”¹¹³⁾

(3) Judicial Responses: *Bragdon v. Abbott* (1998)

Although EEOC is a federal agency which was given the task to interpret and implement federal workplace anti-discrimination laws and is given deference, EEOC policy guidelines do not have the force of law. To this date, the Court has not been forced to answer the very issue of whether individuals with asymptomatic genetic disease or predisposed to genetic illness are included in the term “qualified individual with disability” under the ADA. Thus, it is not clear whether the court will adopt the interpretation set forth by EEOC guidelines. However, several case decisions have been seen as providing guidance on the issue at question.

In *Bragdon v. Abbott*, the Supreme Court held that asymptomatic HIV was a disability that substantially limited a major life activity.¹¹⁴⁾ This case addressed asymptomatic HIV, not genetic predisposition. However, this five-to-four-decision has been read by some commentators as suggesting that a genetic predisposition could be seen as a disability. It might be argued that “having a genetic predisposition to certain disorders could adversely affect an individual’s decision to

109) Melinda B. Kaufmann, *supra* note 74, at 414.

110) Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL’Y 225, 239 (2000).

111) *Id.*

112) *Id.*

113) *Id.* at 241.

114) *Bragdon v. Abbot*, 524 U.S. 624, 188 S.Ct. 2196 (1998).

reproduce for fear of passing on the gene mutation to the individual's offspring. Thus, the Bragdon Court's reasoning would protect individuals from discrimination on the basis of those genetic markers."¹¹⁵⁾

Indeed, before Bragdon, some commentators had already argued that the ADA could be interpreted as protecting qualified individuals with disability. For instance, Frances H. Miller and Philip A. Huvos argued that the ADA could be read to cover asymptomatic individuals who possess genetic disorders.¹¹⁶⁾ Brian R. Gin also pointed out the shared similarity between presymptomatic Huntington's individuals (a typical genetic disease caused by a single dominant gene defect) and HIV-positive status and argued that Huntington's individuals should be afforded the protection of the ADA for the same reasons that HIV-positive persons are protected.¹¹⁷⁾

Bragdon gave hope to the commentators trying to interpret the ADA as to encompass the asymptomatic genetic condition in its phrase "disability." However, there are scholarly opinions which raise serious doubts as to whether the Court would include presymptomatic or asymptomatic genetic information under the ADA. One of such analyses is presented by Laura E. Rothstein. By quoting the long reasoning in the Court opinion, L. Rothstein analyzes that "Bragdon provides little assurance that the ADA adequately protects individuals with genetic predispositions against discrimination."¹¹⁸⁾ Furthermore, after detailed analyses of Bragdon and several subsequent court decisions, she states that "[b]ased on Sutton,¹¹⁹⁾ Murphy,¹²⁰⁾ and Albertsons,¹²¹⁾ combined with Bragdon, any attempt to assert that a particular genetic predisposition is per se a disability entitled to statutory protection as interpreted by the Supreme Court is highly questionable."¹²²⁾ Accordingly, L. Rothstein concludes that "the belief that Bragdon resolves the issue of genetic discrimination is not well founded" and therefore, she argues that "it would be much better to provide additional statutory protection to ensure consistent

115) Laura E. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 HEALTH CARE L. & POL'Y 330, 338 (2000).

116) Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the American with Disabilities Act*, 46 ADMIN. L. REV. 369, 375-77 (1994).

117) Brian R. Gin, *supra* note 83, at 1406.

118) Laura E. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 HEALTH CARE L. & POL'Y 330, 344 (2000).

119) Sutton v. United Air Lines Inc., 527 U.S. 471, 119 S. Ct. 2139 (1999).

120) Murphy v. United Parcel Serv., Inc., 527 U.S. 516, 119 S. Ct. 2133 (1999).

121) Albertson's, Inc. v. Kirkingburg, 527 U.S. 555, 119 S. Ct. 2162 (1999).

122) *Id.* at 350.

application of the ADA to genetic discrimination.”¹²³⁾

Moreover, in *Bragdon v. Abbott*, Chief Justice Rehnquist’s dissenting opinion which was joined by Justice Scalia and Thomas suggests that asymptomatic genetic disease and predisposed to genetic illness are not covered under the ADA.¹²⁴⁾ Justice Rehnquist disagreed with the majority opinion which held that asymptomatic HIV is a disability under the ADA, and argued that

the ADA’s definition of a disability is met only if the alleged impairment substantially “limits” (present tense) a major life activity. Asymptomatic HIV does not *presently* limit respondent’s ability to perform any of the tasks necessary to bear or raise a child. Respondent’s argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease “disabled” here and now because of some possible future effects.¹²⁵⁾

Zindorf notes that “in *Bragdon v. Abbott*, Chief Justice Rehnquist’s dissenting opinion suggests that the Supreme Court justices might be reluctant to define individuals with genetic alterations as disabled under the meaning of the ADA.”¹²⁶⁾ Gulati also cites Paul Steven Miller’s statement, in footnote 202; “three of the justices, Chief Justice Rehnquist, Justice Scalia and Justice Thomas, have already voiced their opinion that genetic predispositions to disease would not be covered under the ADA.”¹²⁷⁾ P. Miller states that “Justice Rehnquist’s comments raise the question whether he would reject outright the ADA’s protection of individuals with asymptomatic genetic conditions, or whether he would accept coverage under a major life activity theory other than reproduction, such as working.”¹²⁸⁾ L. Rothstein also notes that in *Bragdon*, in his dissenting opinion “Chief Justice Rehnquist took the position that while asymptomatic HIV-positive status is a physical impairment, it is questionable whether reproduction is a major life activity. Even if reproduction is a major life activity, Justice Rehnquist would hold that HIV

123) *Id.* at 331.

124) *Bragdon v. Abbot*, 524 U.S. 624, 188 S.Ct. 2196 (1998).

125) *Bragdon v. Abbot*, 524 U.S. 624, 661, 188 S.Ct. 2196, 2216 (1998) (citation omitted) (emphasis added).

126) Natalie E. Zindorf, Comment, *Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance*, 36 TULSA L.J. 703, 711-12 (2001).

127) Chetan Gulati, *supra* note 46, at 203 n202 (citing Paul Steven Miller, Commissioner U.S. Equal Opportunity Commission, Federal News Service, July 20, 2000)).

128) Paul Steven Miller, *supra* note 110, at 245.

infection does not substantially limit that activity.”¹²⁹⁾

As has been seen, at present the court position is not clear with regard to the issue of whether or not asymptomatic genetic disease and predisposed to genetic illness can be covered by the phrase “qualified individual with disability” under the ADA.

ii. Obtaining Genetic Information Under the ADA: Genetic Tests

In this subsection, I will review the restrictions under the ADA on employers’ obtaining genetic information of the job applicants and current employees.

(1) Genetic Tests: Genetic Screening and Genetic Monitoring

In general, genetic tests are categorized into two types: genetic screening and genetic monitoring. According to Melinda B. Kaufmann, genetic screening is “a one-time test performed on job applicants in order to determine their current genetic predisposition.”¹³⁰⁾ And there are two methods in genetic screening: Biomedical genetic screening and direct-DNA screening. The former method “consists of the analysis of mutant genes based on altered proteins or enzymes in the individual’s bloodstream” and the latter method “involves the direct examination of the individual’s DNA.”¹³¹⁾ Genetic monitoring tests “involve periodic testing of individuals to evaluate any modifications that may have occurred in their genetic material. ... Reasons given to conduct genetic monitoring include: identifying risks associated with certain toxins, targeting work areas for increased safety, and identifying previously unknown workplace toxins.”¹³²⁾

Kaufmann notes the employers’ rationale to perform genetic testing and have access to the genetic information of job applicants and workers:

[A]s employers increasingly provide health benefits to workers, genetic and medical screening may be used to weed out job applicants or workers who are likely to have higher insurance costs. In addition, employers may be interested in decreasing the costs associated with occupational illnesses by eliminating workers with a genetic predisposition to those diseases.¹³³⁾

129) Laura E. Rothstein, *supra* note 118, at 347.

130) Melinda B. Kaufmann, *supra* note 74, at 397.

131) *Id.* at 398.

132) *Id.* at 398-99.

133) *Id.* at 398.

Sharona Hoffman notes that “[g]enetic testing has been described as a ‘fast-moving gold rush’ into which employers, among others, are ‘trying to sink in stakes.’ The rapid development of genetic testing capabilities is raising profound concern about genetic privacy and discrimination.”¹³⁴⁾ According to one source, “[g]enetic tests are currently available for more than 400 diseases, and tests for over 300 others are being developed. ‘More than 175,000 genetic tests were performed in 1996,’ and it is estimated that throughout the mid-1990s there was an annual thirty percent increase in the use of genetic testing.”¹³⁵⁾

Hoffman notes that “in 1994, DNA testing cost between \$50 and \$900 per test. It was estimated that with automation and the proliferation of genetic testing, costs could significantly diminish to a price of \$50 to \$150 for a panel of six or more DNA tests.”¹³⁶⁾ However, she also notes that “commentators have noted that the patenting and licensing of genetic tests may increase the costs of genetic testing and that the need for interpretation, education, and genetic counseling relating to such tests may further raise their overall cost.”¹³⁷⁾ Hoffman also notes that “[i]n the future, multiplex testing will also be available. Multiplex screening will allow for multiple genetic tests on a single blood or tissue sample to identify disease, carrier status, and susceptibility all at the same time. In some cases, DNA chips will be utilized to analyze thousands of genes simultaneously.”¹³⁸⁾

However, it should be noted that “[g]enetic testing often predicts nothing about a person’s ability to perform a job at the time he or she is hired. In many cases, it can at most predict the likelihood that a person will develop a disease in the future or will have a child with a particular disease.”¹³⁹⁾

At any rate, given the fact that as the cost of performing genetic tests decreases and tests become more accurate and automated and that employers have strong economic incentives to have access to the genetic information of job applicants and employers to screen out the individuals who may incur future insurance costs and compensation damage, employers will have stronger incentives to utilize genetic

134) Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, 49 U. KAN. L. REV. 517, 532 (2001).

135) *Id.* at 534 (numbers are cited from Rick Weiss, *Ignorance Undercuts Gene Tests’ Potential*, WASH. POST, Dec. 2, 2000, at A01.).

136) *Id.* at 535 (data are based on ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 235 (Lori B. Andrews et al. eds., 1994)).

137) *Id.* (data are based on ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 235 (Lori B. Andrews et al. eds., 1994)).

138) *Id.*

139) *Id.*

tests.

Generally, the ADA bans or restricts employers' obtaining or having access to the genetic information of job applicants or current employees through medical examinations performed in the following three different stages of the employment process: pre-employment medical examination of the job applicants; post-offer medical examination of conditional offerees; and periodic medical examination of the current employees.

(2) Pre-employment Testing (Medical Examination) of Job Applicants

At this stage, all medical examinations and medical inquiries are illegal under the ADA unless inquiries are relevant to the ability of a job applicant to *perform job-related functions*.¹⁴⁰⁾ It is prescribed that "[a] covered entity shall not conduct a medical examination or make inquiries of a job applicant as to whether such applicant is an individual with a disability or as to the nature or severity of such disability."¹⁴¹⁾

Frances H. Miller & Philip A. Huvos note that "the ADA makes it unlawful for an employer to require a job applicant to submit to a pre-employment medical examination. Nor may an employer ask an applicant whether he has a disability or about the nature or severity of an apparent one."¹⁴²⁾

According to the commentary made by Rothstein,

This provision is significant because preemployment medical examinations have been used since the turn of the century and remain in widespread use today throughout the country. Nearly ninety percent of applicants for jobs at large plants—more than 500 workers— and over fifty percent of applicants for jobs at smaller plants—fewer than 500 workers— are subject to preemployment examinations. It is no longer lawful for employers to immediately exclude "generally unhealthy" applicants from all possible jobs in the application process.¹⁴³⁾

140) 42 U.S.C.A. § 12112(d)(2) (A)-(B) (West Supp. 1992).

141) 42 U.S.C.A. § 12112(d)(2)(A) (West Supp. 1992).

142) Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the American with Disabilities Act*, 46 ADMIN. L. REV. 369, 378 (1994) (referring to 42 U.S.C. §12112(d)(2)(A) (Supp. III 1991)).

143) Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans Disabilities Act*, 29 HOUSTON L. REV. 23, 52-53 (1992).

Rothstein goes on to comment that “[w]ith regard to genetic-related inquiries, a wide range of employer queries will no longer be lawful. For example, job applicants may not be asked about their past, current, or future genetic conditions, the health histories of family members, or the genetic health conditions of associates.”¹⁴⁴⁾

Melinda B. Kaufmann also comments on the reason why genetic tests at this stage are prohibited under the ADA:

Only testing reveals the existence of a genetic marker in the individual, therefore, the individual who is unaware of his or her genetic condition cannot answer questions about the unknown. Even if an individual had knowledge of a genetic disorder, an inquiry into whether an individual could perform basic job functions would be irrelevant in most cases of latent genetic disorders because the disorder would have no discernible effect on the employee’s ability to perform the job at the present moment.¹⁴⁵⁾

However, even though genetic testing and inquiry about genetic information are prohibited at the pre-employment stage, employers can obtain virtually all of the genetic information in the next stage discussed below.

(3) Pre-placement Testing (Entrance Examination) after Conditional Job Offer

Contrary to the pre-employment and before job offer stage discussed above, at the pre-placement stage in which a conditional offer is made but employment has not yet started, the ADA allows employers to perform genetic testing and obtain the genetic information of the job applicants.

The ADA provides that “[a] covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of such examination.”¹⁴⁶⁾

According to the commentary made by Miller and Huvos, under the ADA, as

144) *Id.* at 53.

145) Melinda B. Kaufmann, *supra* note 74, at 407.

146) 42 U.S.C. § 12112(d)(3); see also 29 C.F.R. § 1630.14(b) (“A covered entity may require a medical examination . . . after making an offer of employment . . . and may condition an offer of employment on the results of such examination.”).

has been seen above, "an employer discovering a prospective employee's disability upon medical examination is barred from withdrawing a job offer for that reason alone; unless the disability *impairs job fitness* and reasonable accommodation would create *undue hardship* for the business, an employer cannot withdraw the offer."¹⁴⁷⁾

Kaufmann points out that "[t]his section [] does not restrict the purpose behind the test, so an employer may theoretically test for any medical condition."¹⁴⁸⁾

However, these examinations must satisfy three requirements. First, an employer must test all entering employees regardless of disability.¹⁴⁹⁾ Second, the information collected must be maintained on separate forms and in a separate medical file and treated as confidential.¹⁵⁰⁾ Third, the results of the medical examination may be used only in accordance with this subchapter.¹⁵¹⁾

According to the commentary made by Rothstein, the first requirement means that "an employer can require examinations only of loading dock employees, but cannot require examinations of only those applicants who have, or who are regarded as having, disabilities."¹⁵²⁾

According to Rothstein, the second requirement means:

This information must be treated as confidential, except that supervisors and managers may be informed regarding necessary restrictions on the work or duties of the employee and necessary accommodations;¹⁵³⁾ first aid and safety personnel may be informed if the disability might require emergency treatment;¹⁵⁴⁾ and government officials investigating compliance with the ADA must be provided with relevant information on request.¹⁵⁵⁾

With regard to the third requirement, Rothstein comments:

147) Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the American with Disabilities Act*, 46 ADMIN. L. REV. 369, 379 (1994) (emphases added).

148) Melinda B. Kaufmann, *supra* note 74, at 408.

149) 42 U.S.C. § 12112(d)(3)(A); 29 C.F.R. § 1630.14(b).

150) 42 U.S.C. § 12112(d)(3)(B); 29 C.F.R. § 1630.14(b)(1).

151) 42 U.S.C. § 12112(d)(3)(C).

152) 56 Fed.Reg. 8601.

153) 42 U.S.C.A. § 12112(d)(3)(B)(i) (West Supp. 1992).

154) 42 U.S.C.A. § 12112(d)(3)(B)(ii) (West Supp. 1992).

155) 42 U.S.C.A. § 12112(d)(3)(B) (iii) (West Supp. 1992).

Of particular relevance is section 102(b)(6), which prohibits employers from using "selection criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities unless the . . . criteria are shown to be job-related for the position in question and consistent with business necessity."¹⁵⁶⁾ In other words, if a conditional offer of employment is withdrawn based on an employment entrance examination, the only permissible reason for doing so is the individual's inability, even with reasonable accommodation, to perform the essential requirements of the job.¹⁵⁷⁾

Kaufmann also notes "[y]et, the third requirement under the ADA provides protection against discrimination,¹⁵⁸⁾ which means that while the employer can test for anything, he cannot then use the test results to discriminate against the employee or applicant in violation of the ADA."¹⁵⁹⁾

Rothstein observes that "[t]he only issue left unclear in the language of the ADA is whether the actual examinations given to conditional offerees must be job-related."¹⁶⁰⁾

At this pre-placement stage, that is, after conditional job offer is made, the EEOC regulations state that "post-offer employment entrance examinations 'do not have to be job-related and consistent with business necessity.'"¹⁶¹⁾

Rothstein examines the implication of the EEOC regulations and states:

The preceding regulation has grave implications for genetic discrimination and deserves careful review. Pursuant to the regulation, employers may require, as a condition of employment, that individuals accede to medical examinations, including genetic testing, but these results may not be used for screening purposes.¹⁶²⁾ Under these

156) 42 U.S.C.A. § 12112(d)(6) (West Supp. 1992).

157) Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans Disabilities Act*, 29 HOUSTON L. REV. 23, 55 (1992) (referring to Equal Employment Opportunity for Individuals with Disabilities 56 Fed.Reg. 35,726 app. at 35,751 (1991)).

158) Melinda B. Kaufmann, *supra* note 74, at 408(1999) (referring to 42 U.S.C. § 12112(d)(3)(C); see also 29 C.F.R. § 1630.14(b)(3)).

159) *Id.* (referring to 42 U.S.C. § 12112(b)(6)).

160) Mark A. Rothstein, *supra* note 157, at 55.

161) *Equal Employment Opportunity for Individuals with Disabilities* 56 Fed.Reg. 35,726 app. at 35,751 (1991).

162) *Id.*

circumstances, permitting non-job-related genetic testing may lead to discrimination and other harms.¹⁶³⁾

Rothstein criticizes the EEOC regulations and argues:

In theory, the regulation prohibits discrimination by proscribing the use of non-job-related medical examinations for screening purposes.¹⁶⁴⁾ Even if the test results are never used, however, serious problems arise from allowing non-job-related medical examinations. The ADA has other objectives besides prohibiting discrimination, including promoting autonomy and protecting the privacy and dignity of individuals with disabilities.¹⁶⁵⁾ Specifically, one of the ADA's statutory goals is to prevent the compelled disclosure of non-job-related medical information.¹⁶⁶⁾ As the Senate Committee Report noted with regard to cancer: "The individual with cancer may object merely to being identified, independent of the consequences because . . . being identified as disabled often carries both blatant and subtle stigma."¹⁶⁷⁾ Throughout the statute, Congress adopted the policy of prohibiting employer access to nonessential medical information.¹⁶⁸⁾ Only in section 102(d)(3), as interpreted by the EEOC, has Congress permitted unrestricted employer access to wide-ranging medical information, with the ADA merely proscribing the discriminatory use of the information.¹⁶⁹⁾

Rothstein further argues:

[M]edical inquiries and examinations for workers' compensation and health insurance purposes are performed for reasons other than determining fitness to work or job placement. These examinations need not and should not, however, be performed on conditional offerees. They

163) Mark A. Rothstein, *supra* note 157, at 56.

164) *Id.* (referring to 56 Fed.Reg. 35,737).

165) *Id.* (referring to 42 U.S.C.A. § 12101(a)(2) (West Supp. 1992)).

166) *Id.* § 12112(d)(4).

167) Senate Committee on Labor and Human Resources, The Americans with Disabilities Act of 1989, S.Rep. No. 116, 101st Cong., 1st Sess. 21 (1989).

168) *Id.* 42 U.S.C.A. § 12112(d)(1) (West Supp. 1992).

169) *Id.* at 56-57 (Equal Employment Opportunity for Individuals with Disabilities, 56 Fed.Reg. 35,726).

should be permitted only as post-employment procedures. At best, these examinations should act as exceptions to section 102(d)(4) governing inquiries and examinations of current employees.¹⁷⁰⁾ With the current wording and interpretation of section 102(d)(3), however, employers may require any non-job-related medical examination without first showing that it is required for baseline data collection, workers' compensation, health insurance, or another legitimate purpose.¹⁷¹⁾ Granting employers the right to obtain non-job-related medical information is, by itself, harmful and incongruous with the spirit of the ADA. Permitting these inquiries at a time when a conditional offer of employment may be withdrawn creates a real risk of health-based discrimination.¹⁷²⁾

In sum, as has been seen, at the pre-placement stage, employers are allowed to perform genetic testing and obtain genetic information of the job applicants regardless of whether it is job-related and consistent with business necessity.

(4) Periodic Testing of Current Employees (During Employment)

At this stage, "[a]n employer cannot require an employee already on the job to submit to a medical examination or inquiry unless it 'is shown to be *job-related* and *consistent with business necessity*.'"¹⁷³⁾ However, "[a]n employer can acquire non-job-related medical information, including the results of genetic testing, when workers offer it voluntarily."¹⁷⁴⁾

Section 102(d)(4) of the ADA mandates medical examinations of current employees. It provides that employers

shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability or as to the nature or severity of the disability, unless such examination or inquiry is shown to be *job-related* and *consistent with business necessity*.¹⁷⁵⁾

170) 42 U.S.C.A. § 12112(d)(4) (West Supp. 1992).

171) 42 U.S.C.A. § 12112(d)(3) (West Supp. 1992).

172) Mark A. Rothstein, *supra* note 157, at 61.

173) Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the American with Disabilities Act*, 46 ADMIN. L. REV. 369, 380 (1994) (emphases added).

174) *Id.*

175) 42 U.S.C.A. § 12112(d)(4)(A) (West Supp. 1992) (emphases added).

Kaufmann notes that “[g]enetic screening would theoretically be legal if it were ‘directly related to qualifications for doing the task or if necessary for employee safety.’ Job-relatedness, however, generally applies only to the employee’s present capability to perform the job.”¹⁷⁶⁾

According to the commentary made by Rothstein, “[m]ore comprehensive medical examinations are permissible only if they are voluntary. All medical information obtained about current employees must be treated as confidential. Thus, the information is subject to the same protections as medical information obtained during an employment entrance examination.”¹⁷⁷⁾

Rothstein goes on to comment:

Under the ADA, periodic medical examinations of current employees must be job-related or voluntary. This requirement is another major change from the way in which occupational medicine is currently practiced in the United States. Nearly half of all employees and three-quarters of all employees working in large plants—more than 500 employees—are now subject to mandatory periodic medical examinations.¹⁷⁸⁾

Kaufmann asserts:

It is doubtful that most genetic conditions, especially asymptomatic ones, would rise to the level of job-relatedness or business necessity so as to allow an employer to discriminate against applicants with the condition. An asymptomatic genetic disorder might have future ramifications, but would not affect the individual’s present ability to perform his or her job. An employer could rarely justify genetic screening based on job-relatedness in order to overcome the ADA’s protection.¹⁷⁹⁾

176) Melinda B. Kaufmann, *supra* note 74, at 409 (Quoting Charles B. Gurd, *Whether a Genetic Defect is a Disability Under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers*, 1 ANNALS HEALTH L. 107, 110 (1992); referring to 29 C.F.R. § 1630.10)).

177) Mark A. Rothstein, *supra* note 157, at 61-62 (referring to 42 U.S.C.A. § 12112(d)(4)(B)-(C) (West Supp. 1992)).

178) *Id.* at 62.

179) Melinda B. Kaufmann, *supra* note 74, at 409.

Kaufmann observes that “[o]verall . . . employers are most likely to use genetic testing after a conditional job offer is made, but before the offer is finalized. Employers have a right to conduct medical or genetic tests at this stage in the hiring process.”¹⁸⁰⁾ Therefore, she states that “[t]he issue becomes whether the employer can use the information gained from these tests to discriminate against workers with genetic defects.”¹⁸¹⁾

In sum, Hoffman notes:

While the statute requires that any testing administered to existing employees be “job-related and consistent with business necessity,” it does not similarly restrict the scope of preplacement tests and inquiries that are administered to job applicants. Consequently, medical examinations required of individuals who have received job offers but have not yet commenced their employment need not be job-related or justified by business necessity.¹⁸²⁾

Hoffman argues that

employers should be prohibited from conducting genetic testing that is not job-related and justified by business necessity. Under this standard, tests designed only to determine the likelihood that an individual will develop an illness at some point in the future would be prohibited. Genetic testing would be permitted only if it aims to identify present disease that could affect job performance.¹⁸³⁾

Hoffman further argues that

the difference between preplacement and postplacement examinations should be eliminated. Employers should be prohibited from conducting any testing that is not designed to reveal whether the potential employee

180) *Id.*

181) *Id.*

182) Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, 49 U. KAN. L. REV. 517, 519 (2001) (referring to § 102(d)(4)(A), 42 U.S.C. § 12112(d)(4)(A); § 102(d)(3), 42 U.S.C. § 12112(d)(3); 29 C.F.R. § 1630.14(b)(3) (2000)).

183) *Id.* at 559.

can perform assigned job duties at the time of hiring. Moreover, medical data that is not relevant to job performance should never be accessible to employers.¹⁸⁴⁾

According to Hoffman, “[r]estricting preplacement medical testing would benefit both employees and employers.”¹⁸⁵⁾ Hoffman states:

Medical testing that is not job-related constitutes an unjustifiable invasion of the examinee’s privacy and creates temptations and opportunities for discrimination on the part of employers. Furthermore, individuals who undergo genetic testing and learn genetic information of which they were previously unaware may suffer significant psychological trauma if they do not receive appropriate counseling. For employers, medical examinations that are not job-related constitute an unnecessary financial expenditure and create a risk of litigation based on invasion of privacy, discrimination, and other theories. In addition, invasive medical testing can erode morale and productivity in the workplace.¹⁸⁶⁾

Moreover, as Miller and Huvos, and Rothstein point out, it also should be noted that to regulate the employers’ acquisition of genetic information or gaining *access* to it during the three stages of medical examinations discussed above, is not sufficient enough to protect employees from genetic discrimination by employers. It should be noted that “[e]mployers can legitimately obtain genetic information through employee release of medical information necessary to process health insurance claims when the company self-insures, and through other voluntary examinations and wellness programs.”¹⁸⁷⁾ Therefore, it is necessary to provide adequate legal regulations on the discriminatory use of genetic information of the employees.

As has been seen, under the ADA, employers can obtain genetic information of the job applicants and current employees legally under certain circumstances. Therefore, even if the ADA covers individuals with genetic abnormalities or predisposition to genetic illnesses as qualified individuals with disability, the ADA

184) *Id.*

185) *Id.* at 520.

186) *Id.*

187) Frances H. Miller & Philip A. Huvos, *supra* note 173, at 381.

safeguard against genetic discrimination is limited, given the fact that there is a loophole in blocking the employers' gaining access to the genetic information of the applicants or employees. This limited protection under the ADA is weakened more by the employer's defenses under the ADA that I will discuss later.

(5) Judicial Response: Norman-Bloodsaw v. Lawrence Berkeley Laboratory (1998)

As has been seen, commentators have criticized the EEOC's regulations which interpret the provisions of the ADA as allowing employers to perform a wide range of medical tests at the pre-placement stage. In this subsection, I will review the judicial response to this issue.

The leading case where genetic testing in employment was addressed is the Ninth Circuit decision in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*.¹⁸⁸⁾ The plaintiffs sued the Lawrence Berkeley Laboratory, a government-funded research institution,¹⁸⁹⁾ challenging the employer's pre-placement medical tests conducted to some conditional offerees for syphilis, pregnancy, and sickle cell trait. Paul Steven Miller, a Commissioner of U.S. Equal Opportunity Commission, notes that "[t]he plaintiffs alleged that the genetic testing was conducted during routine mandatory medical exams without the employees' knowledge or consent, and that the conditions for which testing was performed bore no relationship to the clerical and administrative jobs the employees had been hired to perform."¹⁹⁰⁾

The U.S. Court of Appeals for the Ninth Circuit reversed the district court's dismissal of these claims and held that "the employees alleged a valid constitutional claim for invasion of privacy at this governmental facility, as well as a valid Title VII claim for sex (pregnancy testing) and race (sickle cell testing) discrimination."¹⁹¹⁾ Miller notes:

The appellate court . . . found sufficient evidence in the record to

188) *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F. 3 1260 (9th Cir. 1998).

189) Lawrence Berkeley Laboratory is a research institution jointly operated by state and federal agencies. Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J. L. MED. & ETHICS 189, 192 (1998). The state, through the Regents of the University of California, operates Lawrence Berkeley Laboratory under a contract with the Department of Energy (DOE). Becky Risse, *Privacy: Nonconsensual Testing of Employees for Medical and Genetic Information*, 24 AM. J.L. & MED. 131, 131 (1998).

190) Paul Steven Miller, *supra* note 189, at 192.

191) Mark A. Rothstein, *Genetics and the Work Force of the Next Hundred Years*, COLUM. BUS. L. REV. 371, 386 (2000).

conclude that testing for syphilis, sickle cell trait, and pregnancy is not an appropriate part of an occupational medical examination, that the employer lacked any reasonable basis for performing these tests on clerical and administrative employees such as the plaintiffs, and that the performance of these tests, without explicit notice and informed consent, violates prevailing medical standards.¹⁹²⁾ . . . The plaintiffs' Title VII claim [] was permitted to go forward, based on their claim that different medical examinations were administered to African Americans (sickle cell trait) and women (pregnancy test), finding that such differential examinations constituted an "adverse effect" sufficient to support a Title VII claim.¹⁹³⁾

However, the Ninth Circuit court dismissed the ADA claims. Miller notes that

the court upheld the dismissal of the ADA claims on the following grounds: (1) that no job related action was taken against the plaintiffs as a result of the testing; (2) the lack of evidence of inadequate safeguards to protect the confidentiality of the information; and (3) the scope of the exams did not violate the statute.¹⁹⁴⁾

The Court states that "an employment entrance examination need *not* be concerned solely with the individual's 'ability to perform job-related functions,' nor must it be 'job-related or consistent with business necessity.' Thus, the ADA imposes no restriction on the *scope* of entrance examinations."¹⁹⁵⁾

Although the Supreme Court has not yet specifically addressed the issue, the Circuit court decision affirms that medical examinations during the pre-placement stage under the ADA may be of unlimited scope. Consequently, the ADA gives employers an opportunity to have access to genetic information and therefore the ADA has a big loophole in regards to limiting the employers' access to genetic information. The limitation of the ADA is not only found in *obtaining* genetic information but also found in *using* it. The review in the next subsection will prove

192) Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 135 F. 3 1260, 1267-68 (9th Cir. 1998).

193) Paul Steven Miller, *supra* note 189, at 192 (referring to Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 135 F. 3 1260, 1272-73 (9th Cir. 1998)).

194) Paul Steven Miller, *supra* note 110, at 253.

195) Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 135 F. 3 1260, 1273 (9th Cir. 1998) (citations omitted) (emphases in original).

the significant limitation of the ADA with regard to banning discriminatory use of genetic information in the workplace.

iii. Employer's Defense Under the ADA: Undue Hardship and Direct Threat

(1) Undue Hardship Defense

Even if a job applicant or current employee with any genetic disorder should be covered by the term "disability" under the ADA, it does not per se mean that discrimination on the basis of genetic information always constitutes a violation of the ADA. Employers have two defenses to a claim of discrimination under the ADA: Undue Hardship and Direct Threat defenses. Gridley notes that "[d]iscrimination by an employer against an employee with a disability is not always a violation of the ADA. The interests of the employee are balanced against those of the employer to determine whether such discrimination will be allowed."¹⁹⁶⁾

Under the ADA, "a reasonable accommodation must be provided to an otherwise qualified but disabled individual unless the employer 'can demonstrate that the accommodation would impose an *undue hardship* on the operation of business' of the employer."¹⁹⁷⁾ Undue hardship is defined under the ADA as "an action requiring significant difficulty or expense."¹⁹⁸⁾ And also the Code of Federal Regulations defines undue hardship as "any accommodation that would be unduly costly, expensive, substantial, or disruptive, or that would fundamentally alter the nature or operation of the business."¹⁹⁹⁾ It means that "[e]mployers need not provide accommodations that would fundamentally alter the nature of the business. For example, a company need not stop producing batteries to eliminate levels of lead."²⁰⁰⁾ According to the Code of Federal Regulations, "[t]he factors to be considered include (1) the nature and cost of the modification; (2) the overall financial resources of the facility; (3) the number of employees at the facility; (4) the overall financial resources of the entire company; (5) the type of operations of the company; and (6) the impact the accommodations would have on the operations

196) Deborah Gridley, *supra* note 71, at 993.

197) Melinda B. Kaufmann, *supra* note 74, at 415 n.128 (quoting 42 U.S.C. §12112 (b)(5)(A) (1995)(emphasis added).

198) 42 U.S.C. §12111 (10)(A).

199) 29 C.F.R. § 1630.2(p) app. At 353-54 (1998).

200) Deborah Gridley, *supra* note 71, at 993 n152 (referring to Lawrence O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J. L. & MED. 109, 131 (1991)).

at the facility.”²⁰¹⁾ Therefore, “[t]he needs of the employee are compared with details such as the nature and the cost of the accommodation and the resources of the business.”²⁰²⁾ Accordingly, “if the employer can demonstrate that accommodating the employee’s disability would create an ‘undue hardship’ on the employer, then the employer’s interests outweigh those of the employee, and the discriminatory action is not prohibited.”²⁰³⁾

Gridley states that “an employer may argue that the increased insurance cost associated with hiring individuals at heightened risk for disease constitutes a significant expense, one that outweighs an employee’s interest and allows an employer to refuse to hire her without violating the ADA.”²⁰⁴⁾ Also it may be argued by employers that “the need to provide insurance for the employee should be considered an accommodation and that the possible future high expense of that accommodation is an undue hardship.”²⁰⁵⁾ However, Gridley argues that “the employer could reduce the effect of future costs by limiting the type of medical insurance available to employees, thus eliminating the hardship without any unwarranted discrimination.”²⁰⁶⁾ So far, “the failure of an employer to accommodate a worker based on the potential economic costs of future illness has never been successfully raised by an employer as a defense to an ADA violation.”²⁰⁷⁾ Hence, it seems to be difficult to make an argument that potential health insurance costs in the future incurred by employees with genetic predisposition to disease can constitute an undue hardship that justifies an employer in discriminating against them. Accordingly, the employers’ defense is more likely claimed, based on the direct threat defense.

(2) Direct Threat Defense

Gridley states that “[t]he ADA’s ‘direct threat’ standard refers to the health or safety of other individuals in the workplace. An employer may discriminate against an individual with a disability if that person poses such a threat.”²⁰⁸⁾ And the decision made concerning direct threat “must be based upon scientific evidence;

201) Melinda B. Kaufmann, *supra* note 74, at 415 n130 (citing 29 C.F.R. § 1630.2(p)(2)).

202) Deborah Gridley, *supra* note 71, at 993.

203) *Id.*

204) *Id.* at 994.

205) *Id.* at 994-95.

206) *Id.* at 955.

207) *Id.*

208) Deborah Gridley, *supra* note 71, at 995.

irrational fears, speculation or stereotypes will not suffice.”²⁰⁹⁾ It means that “[a] specific determination must be made that a person with genetic predisposition will develop symptoms in the immediate future that represent a real threat to health or safety in the workplace.”²¹⁰⁾ And also “[t]he determination must be made on a case by case basis through a fact-specific, individualized inquiry.”²¹¹⁾ In other words, “the evaluation of a direct threat must be done on a case-by-case basis, with real evidence and a fact-specific inquiry.”²¹²⁾ Therefore, “[w]ithout a determination that the person will develop symptoms in the immediate future that present a threat to others, discrimination is not allowed.” However, Gridley notes that “[m]ost people with genetic markers for disease are not likely to pose a direct threat to the health or safety of others.”²¹³⁾ This is because “[s]uch individuals have no current symptoms, and usually both the time of the disease’s onset (or whether it will manifest itself at all) and its severity are impossible to predict.”²¹⁴⁾ Thus, Gridley argues that “[g]eneral exclusion of large groups of people with genetic markers for disease on the basis of a direct threat is simply too speculative,” and therefore, “use of this defense must be limited to those cases where it is clear that the individual does in fact pose a threat to the health or safety of others because of the manner in which the person’s genetic disease has begun to manifest itself.”²¹⁵⁾

Consequently, with regard to the people with genetic markers, the defense of direct threat to health or safety of others seems applicable only to limited types of genetic disorder such as genetic-link hypertension which may trigger sudden heart attack or death, and specific situations where the workplace at issue is a safety-sensitive position such as public transportation drivers, airline pilots, police officers, and the like.

(3) EEOC’s Regulations: Direct Threat to Self-Risk (Paternalistic Employment Practice)

In July 1991, one year after the U.S. Congress passed the ADA, the EEOC, federal agency authorized to enforce and issue regulations implementing Title I of the ADA, issued its final rules in compliance with the ADA.²¹⁶⁾ The EEOC’s rule

209) *Id.*

210) *Id.* (quoting Lawrence O. Gostin, *supra* note 200, at 129-30).

211) *Id.* (referring to Lawrence O. Gostin, *Id.*)

212) *Id.*

213) Deborah Gridley, *supra* note 71, at 995.

214) *Id.*

215) *Id.* at 996.

216) Equal Employment Opportunity for Individuals with Disabilities, 56 Fed. Reg. 35,726 (July 26,

interpreted direct threat defense paternalistically to include direct threat to the health and safety of the employee him/herself in addition to others.²¹⁷⁾

As I mentioned before, the term “direct threat” is defined originally under the ADA as a “significant risk to the health or safety of *others* that cannot be eliminated by reasonable accommodation.”²¹⁸⁾ However, EEOC’s rule expanded the meaning of the term “direct threat” to those that pose “a significant risk of substantial harm to the health or safety of *the individual* or others that cannot be eliminated or reduced by reasonable accommodation.”²¹⁹⁾

After reviewing in detail the legislative history and congressional intent of the ADA including House Judiciary Committee Report and House Labor Committee Report and also relevant case laws, Amanda J. Wong argues that the EEOC’s interpretation of extending direct threat to self (in addition to “threat to others”) is not only against the plain language of the direct threat provision of the ADA but also undermines the spirit and purpose behind the ADA. Wong states that “if direct threat is interpreted to encompass risk to self and others, . . . then, a loophole is created that allows employers to avoid potential liability by simply not hiring those who are at potential risk of injury or disease.”²²⁰⁾ She argues that EEOC’s paternalistic interpretation “goes against the very spirit of the ADA, which sought from its inception to open opportunities for the disabled and allow them to compete on an equal, not favored, basis with the rest of society.”²²¹⁾ Furthermore, she asserts that by allowing employers to take “direct threat to self” into consideration, EEOC’s expanded interpretation results in the situation where “placing the decision in the hands of employers provides them with a means of avoiding compliance with the ADA, reducing the incentive to work to accommodate the disabled and to reduce environmental hazards overall in the workplace.”²²²⁾

1991) (to be codified at 29 C.F.R. Part 1630).

217) 29 C.F.R. § 1630.2(r).

218) 42 U.S.C. § 12111 (3) (emphasis added).

219) 29 C.F.R. § 1630.2(r) (emphasis added).

220) Amanda J. Wong, Comment, *Distinguishing Speculative and Substantial Risk In the Presymptomatic Job Applicant: Interpreting the Interpretation of the Americans with Disabilities Act Direct Threat Defense*, 47 UCLA L. REV. 1135, 1145 (2000).

221) *Id.* at 1146.

222) *Id.*

(4) Judicial Responses: Deference to EEOC (Paternalism) v. Employee's Right to Decide

— *Chevron U.S.A. Inc. v. Echazabal* (2002) —

In regards to this issue, several court decisions have supported the EEOC's paternalistic interpretation and "permits employers to exclude otherwise qualified disabled individuals from positions solely because placement in the job would pose a risk to their own health and safety."²²³⁾ For instances, in *EEOC v. Exxon Corp.*, the Fifth Circuit Court held that employer might use either direct threat defense or business necessity argument to prove defendant is unqualified because he poses a risk to his own safety or to the safety of others."²²⁴⁾ In *Rizzo v. Children's World Learning Centers, Inc.*, the Fifth Circuit Court relied on the EEOC guideline in defining a qualified individual as one who poses no threat to self or others.²²⁵⁾ In *Daugherty v. City of El Paso*, the Fifth Circuit Court held that an insulin-dependent bus driver was not qualified as matter of law because he could injure himself or others.²²⁶⁾ In *LaChance v. Duffy's Draft House, Inc.*, the First Circuit Court took self-risk into consideration in the direct threat decision.²²⁷⁾ In *EEOC v. Amego, Inc.*, the First Circuit Court admitted health and safety concern for the individual.²²⁸⁾ In *Moses v. Am. Nonwovens, Inc.*, the Eleventh Circuit Court held that an employer might fire a disabled employee who cannot prove his disability does not create a direct threat to his own health or safety.²²⁹⁾

However, after Wong published her article, her argument was legally endorsed by the Court in 2000. In *Echazabal v. Chevron USA, Inc.*,²³⁰⁾ the Ninth Circuit Court of Appeals did not follow these precedents and rejected the EEOC's paternalistic interpretation of the direct threat and held that an employer may not "shut disabled individuals out of jobs on the ground that, by working in the job at issue, they may put their own health or safety at risk."²³¹⁾

223) Scott E. Schaffer, *Echazabal v. Chevron USA, Inc.: Conquering the Final Frontier of Paternalistic Employment Practices*, 33 CONN. L. REV. 1441, 1441 (2001).

224) *EEOC v. Exxon Corp.*, 203 F.3d 871, 873-75 (5th Cir. 2000).

225) *Rizzo v. Children's World Learning Centers, Inc.*, 213 F.3d 209 (5th Cir. 2000) (en banc).

226) *Daugherty v. City of El Paso*, 56 F.3d 695, 698 (5th Cir. 1995).

227) *LaChance v. Duffy's Draft House, Inc.*, 146 F.3d 832, 835-36 (11th Cir. 1998).

228) *EEOC v. Amego, Inc.*, 110 F.3d 135, 142-44 (1st Cir. 1997).

229) *Moses v. Am. Nonwovens, Inc.*, 97 F.3d 446, 447 (11th Cir. 1996).

230) *Echazabal v. Chevron USA, Inc.*, 213 F.3d 1098 (9th Cir. 2000), reprinted as amended at 226 F.3d 1063 (9th Cir. 2000) and amended by 2000 Cal. Daily Op. Service 7915 (9th Cir. 2000).

231) *Id.* at 1072. Also see, Julie Brienza, *Ninth Circuit Upbraid Chevron for 'Paternalistic' Decision in Worker's ADA Case*, 36-AUG TRIAL 80 (2000).

This case is praised by commentators who discussed this issue in their articles. For example, Adam B. Kaplan notes that “[t]he Ninth Circuit adopted the proper approach to applying the ‘direct threat’ provision of the ADA.”²³²⁾ Based on his textual analyses of the ADA, Kaplan criticizes the EEOC’s paternalistic interpretation of direct threat defense and argues that “an employer’s ‘direct threat’ defense to claims under the ADA should retain its black letter interpretation and extend only to employees who cause a direct threat to ‘other individuals in the workplace.’”²³³⁾ Scott E. Schaffer also notes that in *Echazabal v. Chevron*, “[t]he court appropriately held that denial of employment to ‘otherwise qualified’ disabled individuals is only permissible when their presence would pose a significant risk to the health or safety of others in the workplace.”²³⁴⁾ Schaffer concludes that “[t]he text of the ADA, its legislative history, particularly Congress’ clearly articulated intent to graft the Arline concept of ‘risk-to-others’ into the defense section of the Act, and important policy considerations all support the Echazabal decision.”²³⁵⁾ Schaffer further argues that “[w]hile deference is due to an oversight agency, it should be limited to those instances where the agency is filling in gaps created by ambiguous language. No such ambiguity exists in the affirmative defense section of the ADA.”²³⁶⁾ Schaffer also argues that

[s]afety can only serve as a justifiable rationale for rejection when an employer, in defending his actions, can show that an “otherwise qualified” individual who can perform all the essential functions of the job would pose a threat to the well-being of others that cannot be eliminated through reasonable accommodation.”²³⁷⁾

Schaffer asserts that “[w]e do not tell the soldier, police officer, or miner, who all face higher risks of injury or death, to stay home because they may get injury.” Therefore, she argues that “[t]he disabled should be treated no differently when they make decisions to take some elevated level of risk to secure a job that best

232) Adam B. Kaplan, *Father Doesn’t Know Best: Rejecting Paternalistic Expansion of the ‘Direct Threat’ Defense to Claims Under the Americans with Disabilities Act*, 106 DICK. L. REV. 389, 413 (2001).

233) *Id.* at 391.

234) Scott E. Schaffer, *Echazabal v. Chevron USA, Inc.: Conquering the Final Frontier of Paternalistic Employment Practices*, 33 CONN. L. REV. 1441, 1485 (2001).

235) *Id.* at 1484-85.

236) *Id.* at 1485.

237) *Id.*

meets their overall needs.”²³⁸⁾

However, the Ninth Circuit decision which rejected paternalistic interpretation was reversed by the U.S. Supreme Court in June 2002. In *Chevron U.S.A. Inc. v. Echazabal*, the Supreme Court held that the EEOC regulation authorizing refusal to hire an individual because his performance on the job would endanger his own health owing to a disability did not exceed the scope of permissible rulemaking under the ADA.²³⁹⁾ In other words, the Supreme Court authorized EEOC’s interpretation and the employer can make an affirmative direct threat defense if job-applicants and employees pose direct threat to themselves. Here, I will not further examine this new judicial decision but rather confirm the following matters. Although in *Chevron*, the employee at issue is not an individual with genetic disorder, it is not hard to presume that the Supreme Court decision will have a great implication on genetic discrimination in the workplace. As mentioned before, if employers are able to resort to direct threat defense as including the situation of “threat to self,” it should be noted that the ADA protection against genetic discrimination also has a big legal loophole. This understanding leads us to believe that we cannot expect the ADA to prevent genetic discrimination in the workplace and need to enact genetic-specific anti-discrimination laws. In the next section, I will review the state antidiscrimination statutes which intend to fill the legal loophole and provide sufficient protection for individuals with genetic disorder and discuss their shortcomings and shared issues that require to be examined.

iv. Inadequateness and Limitations of the ADA.

Chetan Gulati also addresses several limitations of the ADA and EEOC’s interpretations of its provisions. First of all, Gulati states that “the ADA does not prohibit employers from genetic testing job candidates who have been given conditional offers of employment and current employees if they can demonstrate that the testing is job-related and that there is a demonstrated business necessity.”²⁴⁰⁾ Secondly, “EEOC guidelines are not binding upon the courts. ... [I]t is not clear whether the courts will accept the EEOC’s interpretation of the term disability.”²⁴¹⁾ Thirdly, “the EEOC’s interpretation applies only to differentiation

238) *Id.*

239) *Chevron U.S.A. Inc. v. Echazabal*, 122 S.Ct. 2045, in 2002 WL 1270586, 13 A.D. Cases 97 (U.S. Jun 10, 2002) (NO. 00-1406).

240) Chetan Gulati, *supra* note 46, at 202-03.

241) *Id.* at 203-04. Gulati refers to Paul Steven Miller’s remark stating that “three of the justices, Chief Justice Rehnquist, Justice Scalia and Justice Thomas, have already voiced their opinion

against employees because of their own genetic predisposition. Therefore, it does not protect individuals who are unaffected carriers of recessive or X-linked disorders who may be differentiated against by employers who fear that the children of these individuals may be at risk of genetic disorders.” Moreover, “self-interested employers may violate the law, knowing that enforcement will be difficult. This would be especially true for self-insured employers who directly bear the health care costs of their employees and who therefore have direct access to the medical records of their employees.”²⁴²⁾ And finally, “medical caps on medical coverage can be used to nullify its ultimate goal.”²⁴³⁾

Although little attention has been paid to it, the fourth limitation presented by Gulati seems to be worth addressing seriously, given the fact that lately more and more companies have become self-insured in which the companies legally gain access to employees’ genetic information.

Rothstein discusses this issue carefully and notes that genetic information “may be obtained by employers in the course of paying health insurance claims.”²⁴⁴⁾ Given the fact that “[b]y 1993, 85% of employers with 5,000-40,000 employees and 93% of employers with more than 40,000, and 37% of employers with 50-199 were self-insured, ...”²⁴⁵⁾

Rothstein explains several advantages of the employers if they are self-insured.

They [companies] save the profits of the commercial insurers, they can retain and use the earnings on amounts paid to insurers and held as claims reserves, and they pay no tax on premiums. Most important, in an era of increasing state regulation of health insurance, self-insured plans are exempt from state insurance laws and regulations, including state laws limiting policy cancellations and rate increases, and mandating high-risk insurance pools and the coverage of specified services and conditions. This exemption from state insurance law is pursuant to the preemptive effect of the federal Employee Retirement Income Security

that genetic predispositions to disease would not be covered under the ADA.” *Id.* at 203 n202 (2001) (citing Paul Steven Miller, Commissioner U.S. Equal Opportunity Commission, *Federal News Service*, July 20, 2000)).

242) *Id.* at 204 (2001).

243) *Id.*

244) Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace* in *GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN GENETIC ERA* 281, 293 (Mark A. Rothstein ed., Yale Univ. Press 1997).

245) *Id.* at 294.

Act of 1974 (ERISA).²⁴⁶⁾

Self-insured employers are free to amend or even terminate their plans at any time so long as the notice provisions of the plan are satisfied. Discrimination in health benefits is permissible under the ADA so long as it is based on valid actuarial principles and is not a subterfuge for disability discrimination.²⁴⁷⁾

[S]elf-insured employers may be self-administered or they may use a third-party administrator to handle claims. Under the former arrangement, claims by health care providers are submitted for payment to the benefits department of the company. Typically, claims contain the employee's name as well as a code or description of the specific diagnosis or procedure. Thus, at least the employer's benefits department inevitably learns of the specific medical conditions of the employee or the employee's covered dependents.²⁴⁸⁾

Rothstein also notes that "[i]t is not necessary for the result of particular diagnostic tests to be known by the employer for adverse treatment to result."²⁴⁹⁾ He gives good examples for this.

[I]f an individual undergoes genetic testing for Huntington disease, even if the result of the test is not disclosed, the employer knows that the individual is at a 50% risk of the disease. Similarly, reimbursement for an annual colonoscopy for an employee under age 40 may not be approved in the absence of a notation that the individual was at risk of inherited susceptibility to colon cancer.²⁵⁰⁾

These observations show several loopholes of ADA's regulations in order to prevent genetic discrimination in the workplace. These limitations of the ADA prompted many states to enact its own antidiscrimination laws in the employment arena. In the next subsection I will review the state level legal protections against

246) *Id.*

247) *Id.* at 295.

248) *Id.* at 294.

249) *Id.*

250) *Id.*

genetic discrimination and examine the problems involved.

v. Proposed Amendments to the Text of the ADA

In order to avoid the definitional problems concerning “genetic” tests or information in the present genetic specific state statutes and to overcome the inadequacy of the ADA in protecting genetic privacy in the employment arena, Rothstein presents two proposed amendments which do not use the term “genetic.”

Rothstein adds the following new subsection (D) after the ADA, section 3(2)(C). “(D) having a risk of a future physical or mental impairment that would substantially limit one or more of the major life activities of such individual, having a record of such a risk, or being regarded as having such a risk.”²⁵¹⁾

And he asserts that “the ADA also should include within the definition of ‘disability’ the carrier state for recessive and X-linked disorders that, if manifested, would substantially limit one or more of the major life activities of an individual.

The second proposed amendment that Rothstein presented is designed to prohibit employers from *gaining access to* an employee’s medical records containing non-job-related genetic information. He inserts the following provision after the ADA section 102 (d)(3)(C), which prescribes the conditions under which medical examinations may be performed after a conditional offer of employment.

(D) [A] covered entity shall not require a medical examination, shall not undertake a review of medical records, and shall not make inquiries of an applicant as to whether such applicant is an individual with a disability or as to the nature or severity of the disability, unless such examination, medical records review, or inquiry is shown to be job-related and consistent with business necessity.²⁵²⁾

As we have seen, several existing patchwork federal laws provide insufficient protection against genetic discrimination in the insurance and employment arena. In order to prohibit genetic discrimination, many believe additional legal protections for genetic privacy is necessary. This belief prompts many state legislatures to enact their own genetic-specific statutes. In the next subsection, I will review genetic anti-discrimination legislation at the state level.

251) Mark A. Rothstein, *Recommendations: Genetic Secrets: A Policy Framework*, in *GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN GENETIC ERA* 451, 477 (Mark A. Rothstein ed., Yale Univ. Press 1997).

252) *Id.* at 478.

III. State Legislations Banning Genetic Discrimination

A. State Legal Protections in Insurance

a. Existing State Anti-Discrimination Laws

According to the Table presented by Richard A. Bornstein, before the end of 1994, only six states had enacted statutes which restrict health insurers from using genetic information in the underwriting process.²⁵³⁾ According to Eric Mills Holmes, as of mid-1996, eighteen jurisdictions had enacted legislation concerning genetic testing and the use of genetic information by insurance companies and others.²⁵⁴⁾ However, most of these jurisdictions restrict only life and disability insurers.²⁵⁵⁾ Among these jurisdictions, only ten states enacted a comprehensive legislation covering any genetic testing and the use of test results in insurance which Holmes categorized as “the contemporary trend” rather than “the traditional approach” which focused only on specific genetic traits or conditions.²⁵⁶⁾

After 1996, the year HIPAA was passed, in order to fill in the gaps left by HIPAA and to provide expanded protection for genetic information in the insurance settings, many states rushed to have enacted their own statutes. As a results, as of April 3, 2002, the Chart presented by the National Conference of State Legislatures (NCSL)²⁵⁷⁾ shows forty-eight states have enacted some form of genetic nondiscrimination laws which regulate health insurers’ use of genetic information with the exception of Mississippi and Pennsylvania. However, the range and coverage differ widely by state. According to the NCSL Chart, with regard to the form, forty-three state statutes prohibit insurers from establishing rules for eligibility on the basis of genetic information, twenty-six states ban requiring genetic tests, forty-one state statutes prohibit the use of genetic information for risk selection and risk classification purposes. In regards to the type of insurance, three

253) Richard A. Bornstein, Notes & Comments, *Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes*, 4 J. L. & POL’Y 551, 604 (1996).

254) Eric Mills Holmes, *supra* note 5, at 629-49.

255) *Id.* at 645.

256) *Id.* at 645-47.

257) NCSL is the pre-eminent bipartisan organization founded in 1975. In its website, it is stated that “It is the only organization that provides an open, bipartisan, national forum for lawmakers to communicate with one another and share ideas. NCSL is an effective and respected voice for the states in Washington, D.C., representing their interests—their “ideas”—before Congress, the administration and federal agencies.” <<http://www.ncsl.org/public/guide.htm>> (last visited June 8, 2002).

state statutes apply only to individual health plans, seven state statutes apply only to group health plans, and thirty-seven state statutes apply to both individual and group health plans. With regard to the components of definition for protected genetic information, besides individual genetic test results, thirty-one state statutes cover the test results of family members, only three state statutes also cover family history, nine state statutes also include inherited characteristics, but some state statutes explicitly exclude routine physical measurement or standard chemical, blood, and urine analysis or indirect manifestations of genetic disorders from their coverage.²⁵⁸⁾

At present, according to NCSL's survey of the 2002 State Legislative Activity, twenty-two bills concerning genetics and health insurance have been introduced in twelve states in 2002, and among these, two bills have been enacted as of April 26, 2002.²⁵⁹⁾

Here, I will not describe the details of each statute.²⁶⁰⁾ Instead, I will examine the practical and normative problems of these state legislations in the next subsection.

b. Shortcomings and Limitation

Many attempts to enact federal legislation designed to prohibit genetic discrimination in the health insurance arena have been inspired because of the lack of uniformity and consistency regarding the scope of genetic information and insufficient restriction on the use of genetic information in the state statutes. Wendy Lovejoy notes that the diversity of state-level legislation "fails to offer insureds any consistent form of protection upon which they can rely."²⁶¹⁾ However, besides these inconsistent and insufficient protections under the state legislations, they have one serious technical limitation.

258) NCSL, *State Genetic Nondiscrimination in Health Insurance Laws*,
<<http://www.ncsl.org/programs/health/Genetics/ndishlth.htm>> (last updated June, 2005).

259) NCSL, *Genetics and Health Insurance 2002 Legislative Activity*,
<<http://www.ncsl.org/programs/health/genetics/chhealthins.htm>> (last updated April 26, 2002).

260) For the survey and review of these state statutes, see, Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 692-95 (2001); Jennifer R. Taylor, *Mixing the Gene Pool and the Labor Pool: Protecting Workers from Genetic Discrimination in Employment*, 20 TEM. ENVTL. L. & TECH. J. 51, 66-70 (2001); Marisa Anne Pagnattaro, *Genetic Discrimination and the Workplace: Employee's Right to Privacy V. Employer's Need to Know*, 39 AM. BUS. L. J. 139, 172-75 (2001); William F. Mulholland, II & Ami S. Jaeger, Comment, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317 (1999).

261) Wendy Lovejoy, *supra* note 4, at 899.

Chetan Gulati addresses practical shortcomings of the present state legislations which limit price differentiation on the basis of an individual's genetic makeup.

Although states have the authority to pass genetic antidiscrimination laws targeting health insurers, their reach, and therefore their effectiveness, is significantly reduced because they are preempted by the federal Employee Retirement Income Security Act of 1974 (ERISA), which exempts self-insured employers from state regulation. While 98% of employers with over 100 employees offer some form of health insurance, the majority of them are self-insured, and therefore, millions of Americans are enrolled in plans that would be exempt from state genetic antidiscrimination laws.²⁶²⁾

Holmes also notes that since "the Supreme Court has held that, in interpreting ERISA [Employee Retirement Income Security Act of 1974], [employer with self-funded employee benefit plans] are to be regulated only by ERISA and are exempt from state insurance regulation," even "if all states pass comprehensive [anti-discrimination] acts [in health insurance], millions of American employees under employer self-funded plans will not be affected."²⁶³⁾

Because of the recognition of these limitations and shortcomings of state level statutes banning genetic discrimination in health insurance, many commentators assert to enact a comprehensive federal genetic anti-discrimination law in this arena.

B. State Legal Protections in Employment

a. Existing State Anti-Discrimination Laws

On the state level, before the Human Genome Project started, several anti-discrimination laws in the workplace already existed in the 1970s and 80s.²⁶⁴⁾

262) Chetan Gulati, *supra* note 46, at 166-67.

263) Eric Mills Holmes, *supra* note 5, at 648.

264) For example, Louisiana, North Carolina, and Florida enacted the first laws banning employment discrimination on the basis of Sickle Cell trait. FLA. STAT. ANN. § 448.075 (1999); N.C. GEN. STAT. § 95-28.1 (1999-2000); LA. REV. STAT. ANN. § 23:353 (West 2000). New Jersey's statute of 1981 bans discrimination in employment on the basis of genetic trait such as Sickle Cell trait, Hemoglobin C trait, Thalassemia trait, Tay-Sachs Trait, or Cystic Fibrosis trait. N.J. STAT. ANN. §§ 10:5-5(x), 10:5-12 (West 2000).

However, these statutes protected only specific genetic disorders such as sickle cell trait.

It was not until the 1990s that states began to enact statutes prohibiting genetic discrimination generally beyond specific genetic traits. Wisconsin became the first state which banned genetic testing and discrimination in the workplace in 1991.²⁶⁵⁾

Today, compared to the number of state statutes banning genetic discrimination in health insurance, the number of state level anti-discrimination statutes in the workplace is fewer. However, as of April 29, 2002, thirty states have enacted some form of anti-discrimination law which prohibits the employer from discriminating against job applicants or employees in hiring, firing, and/or terms, conditions or privileges of employment. The main difference between these state legislations and the ADA is that "the ADA applies only to employers with fifteen or more employees whereas approximately half the state laws also cover employers with one to fifteen employees."²⁶⁶⁾ Contrary to the insurance field, because there is no preemption in the employment field, "[t]he ADA operates as a minimum standard and does not preempt state laws that afford equal or greater protection than federal law."²⁶⁷⁾ However, state statutes vary greatly by state in its scope of protection and form. With regard to the coverage, although all of these statutes ban discrimination based on, at least, the results of genetic tests, some states extend its coverage of protection. According to the Chart presented by the National Conference of State Legislatures (NCSL), besides genetic test results, among these thirty states, only nine states cover predictive genetic information, only nine states cover also information about genetic testing such as the receipt of genetic services, only eleven states include also family history, and only half of the statutes also cover inherited characteristic.²⁶⁸⁾ With regard to form, eighteen states prohibit the employer from requesting genetic information or test, twenty-three states ban requiring genetic information or test, sixteen states prohibit performing genetic test and only ten states ban obtaining genetic information or genetic test results but only twelve statutes prescribe specific penalties.²⁶⁹⁾ According to the survey conducted

265) WIS. STAT. § 111.372 (West Supp. 1994). See, <<http://www.ncsl.org/programs/health/Genetics/ndiscrim.htm>> (last visited June 8, 2002).

266) Mark A. Rothstein, Besty D. Gelb, & Steven G. Craig, *Protecting Genetic Privacy by Permitting Employer Access Only To Job-related Employee Medical Information: Analysis of a Unique Minnesota Law*, 24 AM. J.L. MED. & MED. 399, 404 (1998).

267) *Id.*

268) NCSL, *State Genetic Employment Laws*, <<http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>> (last updated June, 2005).

269) *Id.*

by the NCSL on State Legislative Activity in Employment in 2002, thirteen bills were introduced in eight states and two of those were enacted (these two new laws are already included in the number of thirty) and two bills are awaiting Governor signature or veto.²⁷⁰⁾

Here, I will not describe the details of each statute.²⁷¹⁾ Instead, I will examine the general problems of these state legislations in the next subsection.

b. Shortcomings and Limitations

Rothstein addresses “two serious problems” entailed in the state antidiscrimination laws. The first problem is with regard to the definition of “genetic” test or “genetic” information. He states that

[n]ew developments in genetics have identified a genetic component of some forms of common disorders, such as asthma, hypertension, osteoporosis, diabetes, hypercholesterolemia, rheumatoid arthritis. Are routine tests that identify an individual as having such a condition ‘genetic’ tests? Is a pedigree that reveals a family history of a genetic or multifactorial disorder ‘genetic’ information?²⁷²⁾

The second problem Rothstein points out is that state laws do not prohibit authorized access to genetic information. He states that “they [state laws] do not prohibit an employer from making the execution of a general medical release a valid condition of employment. Consequently, if the employer has a right of access to all the individual’s medical files..., then genetic information within the files will be revealed.”²⁷³⁾

Rothstein referred to Minnesota Human Rights Act (MHRA) as a state statute

270) NCSL, *Genetics and Employment 2002 Legislative Activity*,

<<http://www.ncsl.org/programs/health/genetics/chemploy.htm>> (last updated June 3, 2002).

271) For the survey and review of these state statutes, see, Sonia M. Suter, *supra* note 260, at 692-95; Jennifer R. Taylor, *Mixing the Gene Pool and the Labor Pool: Protecting Workers from Genetic Discrimination in Employment*, 20 TEM. ENVTL. L. & TECH. J. 51, 66-70 (2001); Marisa Anne Pagnattaro, *Genetic Discrimination and the Workplace: Employee’s Right to Privacy V. Employer’s Need to Know*, 39 AM. BUS. L. J. 139, 172-75 (2001); William F. Mulholland, II & Ami S. Jaeger, Comment, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317 (1999).

272) Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace* in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN GENETIC ERA 281, 293 (Mark A. Rothstein ed., Yale Univ. Press 1997).

273) *Id.*

which can escape from these problems because it “prohibits all non-job-related medical examinations at any stage of the employment process and limits employers’ access to applicant and employee medical records.”²⁷⁴⁾

IV. Federal Bills in the U.S. Congress

A. Proposed Federal Bills in the U.S. Congress (1995-2002)

As we have seen, state statutes vary widely, state by state, in its coverage and form. Moreover, in some states, legal protection against genetic discrimination is not sufficient. Under these circumstances, many commentators assert enacting federal level genetic-specific anti-discrimination laws to protect genetic privacy and confidentiality of genetic information of the individuals in order to secure a consistent and uniform minimum safeguard among the fifty states.

Since 1995, many federal bills have been proposed both in the Senate and House of Representatives.²⁷⁵⁾ Seven bills were introduced to the 104th U.S. Congress through 1995 to 1996,²⁷⁶⁾ and in the 105th Congress in 1997, nine bills were proposed,²⁷⁷⁾ and in the 106th Congress through 1999 to 2000, eight bills were

274) *Id.* (MINN. STAT. ANN. § 363.02, subd. 1(b)(9)(i)(b), 363.03 subd. 4(b) (West Supp. 1995).

275) For a review of the content of the proposed bills introduced in the 104th Congress, see, Joanne Seltzer, Note, *The Cassandra Complex: An Employer's Dilemma in the Genetic Workplace*, 27 HOFSTRA L. REV. 411-441-45 (1998). For a survey of the genetic antidiscrimination bills introduced in the 105th Congress, see, Jeremy A. Colby, Note & Comment, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443, 468-476 (1998); Lynn E. Egan, Note, *Genetic Discrimination in Health Insurance*, 24 J. LEGIS. 237, 244-46 (1998); Kourtney L. Pickens, Comments, *Don't Judge Me by My Genes: A Survey of Federal Genetic Discrimination Legislation*, 34 TULSA. L.J. 161, 176-80 (1998); Bryce A. Lenox, Comment, *Genetic Discrimination in Insurance and Employment: Spoiled Fruits of the Human Genome Project*, 23 U. DAYTON L. REV. 189, 209-11 (1997). For the note on the bill introduced in the 106th Congress, see, Wendy Lovejoy, *supra* note 4, at 905-06.

276) The Genetic Information Nondiscrimination in Health Insurance Act of 1996, S. 1694, 104th Cong. (1996) (sponsored by Olympia Snowe); H.R. 3477, 104th Cong. (1996) (sponsored by Joseph Kennedy) (amendment to the Fair Labor Standards Act of 1938); Genetic Confidentiality and Nondiscrimination Act of 1996, S. 1898, 104th Cong. (1996) (Pete Domenici); The Genetic Fairness Act of 1996, S. 1600, 104th Cong. (1996) (Dianne Feinstein); The Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, 104th Cong. (1995) (Louis Slaughter); The Genetic Privacy and Nondiscrimination Act of 1995, S. 1416, 104th Cong. (1995) (Mark Hatfield); The Genetic Privacy and Nondiscrimination Act of 1995, H.R. 2690, 104th Cong. (1995) (Cliff Stearns).

277) Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997) (Pete

proposed.²⁷⁸⁾ And in the 107th Congress through 2001 to 2002, four genetics-specific bills have been introduced.²⁷⁹⁾ However, all of these bills have failed to be passed.

The parallel bills entitled The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001 were introduced on February 13, 2001 in the Senate by Tom Daschle and in the House by Louis M. Slaughter. The bills amend existing federal laws such as ERISA, the Public Health Service Act, and the Internal Revenue Code to provide comprehensive and sufficient legal protection against genetic discrimination.²⁸⁰⁾ The bills define genetic information broadly as to cover "(i) information about an individual's genetic tests; (ii) information about genetic tests of family members of the individual; or (iii) information about the occurrence

Domenici); Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong. (1997) (Cliff Stearns); The Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997) (Louis Slaughter); The Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105th Cong. (1997) (Olympia Snowe); Genetic Information Health Insurance Discrimination Act of 1997, H.R. 328, 105th Cong. (1997) (Gerald Solomon); The Genetic Privacy and Nondiscrimination Act of 1997, H.R. 341, 105th Cong. (1997) (Cliff Stearns); Genetic Protection in Insurance Coverage Act, H.R. 2216, 105th Cong. (1997) (Joseph Kennedy); The Genetic Justice Act, S. 1045, 105th Cong. (1997) (Tom Daschle); Genetic Nondiscrimination in the Workplace Act, H.R. 2215, 105th Cong. (1997) (Joseph Kennedy) (amendment to the Fair Labor Standards Act of 1938).

278) Genetic Information Health Insurance Nondiscrimination Act of 1999, H.R. 293, 106th Cong. (1999) (amendment to the Public Health Service Act and the Employee Retirement Income Security Act of 1974) (John Sweeney); Genetic Information Nondiscrimination in Health Insurance Act of 1999, H.R. 306, 106th Cong. (1999) (Louis Slaughter); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, 106th Cong. (1999) (Louis Slaughter); Genetic Privacy and Nondiscrimination Act of 1999, H.R. 2555, 106th Cong. (1999) (Cliff Stearns); Genetic Information Nondiscrimination in Health Insurance Act of 1999, S. 543, 106th Cong. (1999) (Olympia Snowe); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, S. 1322, 106th Cong. (1999) (Tom Daschle); Genetic Information Nondiscrimination in Health Insurance Act of 1999, 146 Cong. Rec. S6152 (daily ed. June 29, 2000) (Senate Amendment 3691 to H.R. 4577) (James Jeffords).

279) Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, S. 318, 107th Cong. (2001) (Tom Daschle); Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, H.R. 602, 107th Cong. (2001) (Louis Slaughter); Genetic Information Nondiscrimination in Health Insurance Act of 2001, S. 382, 107th Cong. (2001) (Olympia Snowe); Genetic Information Nondiscrimination Act of 2002, S. 1995, 107th Cong. (2002) (Olympia Snowe). For a survey of the genetic antidiscrimination bills introduced in the 107th Congress, see Sonia M. Suter, *supra* note 260, at 696-68; Jennifer S. Geetter, *supra* note 102, at 53-55; Louise M. Slaughter, *The Genetic Discrimination in Health Insurance and Employment Act: H.R. 602*, 18 N.Y.L. SCH. J. HUM. RTS. 1 (2001).

280) Jennifer S. Geetter, *supra* note 102, at 54.

of a disease or disorder in family members.”²⁸¹⁾

In the insurance settings, the bills regulate the insurers’ access and use of the broadly defined genetic information. Under the bills, it is prohibited, based on “protected genetic information concerning an individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual),” for insurers to establish rules for eligibility to enroll in health insurance coverage and adjust premium rates in the individual market and also to deny eligibility or adjust premium or contribution rates in the group health plans.²⁸²⁾ Moreover, the bills limit insurers’ access to genetic information. The bills ban “insurers from requesting, requiring, collecting, or purchasing such genetic information from an individual or a family member; from disclosing such genetic information without authorization; or from requesting or requiring individuals or family members to undergo genetic testing.”²⁸³⁾

However, Jennifer S. Geetter notes a loophole in the insurance setting under the bill.

[T]he bill still permits underwriting on the basis of “information about physical exams of the individual, and other information that indicates the current health status of the individual” and “information about chemical, blood, or urine analyses of the individual, unless these analyses are genetic tests.” Thus, insurers could still base coverage determinations on genetic information that was gathered incidentally, and could still make coverage decisions based on a genetic disorder once the individual was symptomatic and these symptoms manifested themselves during a physical examination of the individual.²⁸⁴⁾

In the employment settings, under the bills,

[it is prohibited for employers] to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to compensation, terms, conditions, or privileges of employment of the individual [or otherwise deprive an individual of employment opportunities], because of protected genetic information with respect to the individual . . . or information about a request for or the receipt of genetic services by such individual or family member of such

281) S. 318, 107th Cong. § 201 (6) (2001).

282) S. 318, 107th Cong. § 101 (a)(2)(A), § 102 (b)(2) (2001).

283) Sonia M. Suter, *supra* note 260, at 697-98.

284) Jennifer S. Geetter, *supra* note 102, at 55.

individual.²⁸⁵⁾

Moreover, the bills prohibit “employers from requesting, requiring, collecting, or purchasing such genetic information from an individual or a family member.”²⁸⁶⁾ Additionally, “the bills emphasize that the federal law would not supersede any provision of state law that ‘provides equal or greater protection to an individual than the rights under this Act.’”²⁸⁷⁾

On March 6, 2002, another bill entitled Genetic Information Nondiscrimination Act of 2002 was introduced by Senator Snow.²⁸⁸⁾ However, the odds that any of these bills introduced in the 107th Congress would be enacted were very low. According to the WESTLAW Billcast (accessed June 9th 2002), the odds that these bills pass the Senate Committee and Floor, and House Committee and Floor ranged from only seven percent to zero percent and did not become a law.

B. Genetic Information Nondiscrimination Act of 2003 and 2005

In May 2003, just after the completion of the Human Genome Project, Senator Olympia J. Snowe (R-Maine) reintroduced a bipartisan bill called the Genetic Information Non-Discrimination Act (S.1053). The bill prohibits discrimination on the basis of genetic information in health insurance and the workplace. On October 14, 2003, the U.S. Senate passed the bill by a vote of 95-0. This is the first time the Senate has passed a genetic nondiscrimination bill. However, the US House of Representatives did not pass the bill.

In February, 2005, by a vote of 98 to 0, the US Senate passed the Genetic Information Nondiscrimination Act, introduced by U.S. Senator Olympia J. Snowe (R-Maine).²⁸⁹⁾ According to the Bill Tracking by the Office of Legislative Policy and Analysis (OLPA):²⁹⁰⁾

285) *Id.* at 698 (alteration in original) (quoting S. 318 § 202; H.R. 602 § 202).

286) *Id.* S. 318 § 203; H.R. 602 § 202.

287) *Id.* S. 318 § 209(3); H.R. 602 § 208(3).

288) Genetic Information Nondiscrimination Act of 2002, S. 1995, 107th Cong. (2002) (Olympia Snowe).

289) S.306. Official Title of the bill is “A bill to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.” The full text of the bill can be downloaded at <<http://www.govtrack.us/congress/bill.xpd?bill=s109-306>>

290) The website of the Office of Legislative Policy and Analysis (OLPA) states that their mission “serves as the principal office within the Office of the Director (OD), National Institutes of Health (NIH), for providing legislative analysis, policy development, and liaison with the

The bill would prohibit health insurers in both the group and individual markets from (1) using genetic information to impose enrollment restrictions or to adjust premium or contribution amounts, (2) requesting genetic testing or results except as necessary for treatment, payment, or health care operations, or (3) requesting or requiring the use of genetic information for the purposes of underwriting. It defines a genetic test as an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes. S. 306 specifically would exclude an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes, or an analysis of proteins or metabolites directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved. The bill defines genetic information as information about the genetic tests of an individual or family member, or the occurrence of a disease or disorder in family members of an individual. It also specifically would exclude information about the age or sex of an individual.²⁹¹⁾

According to the URL of ASCO (American Society of Clinical Oncology)²⁹²⁾, as of February 17, 2005, the date the U.S. Senate passed the bill, there is a total of 26 cosponsors for this bill (14 Democrats, 11 Republicans, 1 Independent). Since its passage, the bill has been waiting to be brought to a floor vote in the House of Representatives.

On March 10, 2005 a bipartisan group of over 100 members of Congress introduced the "Genetic Information Non-Discrimination Act of 2005 in the 109th Congress,"²⁹³⁾ The bill was introduced by Representatives Judy Biggert (R-IL), Louise Slaughter (D-NY), Bob Ney (R-OH), and Anna Eshoo (D-CA) and includes

Congress. OLPA facilitates and enhances the relationship between NIH and the Congress; advances NIH legislative priorities; and ensures that the NIH community receives essential information, advice, and guidance regarding developments in the Congress that affect NIH." <<http://olpa.od.nih.gov/about/>> (last visited December 1, 2005)

291) <http://olpa.od.nih.gov/tracking/109/senate_bills/session1/s-306.asp> (last visited December 6, 2005)

292) <<http://capwiz.com/asco/home/#>> (last visited December 6, 2005).

293) HR 1227. Official Title of the bill is "To prohibit discrimination on the basis of genetic information with respect to health insurance and employment." The full text of the bill can be downloaded at <<http://www.govtrack.us/congress/bill.xpd?bill=h109-1227>>

a group of bipartisan cosponsors.²⁹⁴⁾ The main provisions of the bill are identical to S. 306. According to the URL of ASCO (American Society of Clinical Oncology),²⁹⁵⁾ as of November 8, 2005, there is a total of 159 cosponsors for this bill (93 Democrats, 65 Republicans, 1 Independent).²⁹⁶⁾ ASCO gives a brief summary of the bill:

[the bill amends] [e]mployee Retirement Income Security Act of 1974 (ERISA) and the Public Health Service Act to expand the prohibition against discrimination by group health plans and health insurance issuers in the group and individual markets on the basis of genetic information or services to prohibit: (1) enrollment and premium discrimination based on information about a request for or receipt of genetic services; and (2) requiring genetic testing. Sets forth penalties for violations. Amends title XVIII (Medicare) of the Social Security Act to prohibit issuers of Medicare supplemental policies from discriminating on the basis of genetic information. Extends medical privacy and confidentiality rules to the disclosure of genetic information. Makes it an unlawful employment practice for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive such individual of employment opportunities because of genetic information. Prohibits the collection and disclosure of genetic information, with certain exceptions. Establishes a Genetic Nondiscrimination Study Commission to review the developing science of genetics and advise Congress on the advisability of providing for a disparate impact cause of action under this Act.²⁹⁷⁾

Since President Bush has expressed his support for the bill in a Statement of Administrative Policy,²⁹⁸⁾ if the bill should be passed, the U.S. President would sign the bill and the first stand alone federal legislation which prohibits potential genetic discrimination in the insurance and employment settings would be enacted.

294) <<http://www.genome.gov/pfv.cfm?pageid=11510230>> (last updated August 2005) (last visited December 1, 2005).

295) <<http://capwiz.com/asco/home/#>> (last visited December 6, 2005).

296) <<http://capwiz.com/asco/issues/bills/?bill=7410196>> (last visited December 6, 2005)

297) *Id.*

298) <<http://www.whitehouse.gov/omb/legislative/sap/109-1/s306sap-s.pdf>>

V. Conclusion

In this paper, I examined the scope and appropriateness of current patchwork legal protections against genetic discrimination and identified their limitations (Section II). First, I reviewed the existing federal laws and regulations in which legal professionals have tried to find legal protection against genetic discrimination. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Americans with Disabilities Act of 1990 (ADA), Title VII of the Civil Rights Act of 1964, Executive Order, Regulations (policy guidelines) of the Equal Employment Opportunity Commission (EEOC), and several judicial decisions related to the issue have been reviewed. Then I demonstrated that there were many loopholes in prohibiting the use of genetic information in discriminatory ways and confirmed that none of these federal laws and regulations provides sufficient legal protection against genetic discrimination, if any, in the workplace and insurance fields respectively (Section II). Next, I examined whether state genetic-specific anti-discrimination statutes could fill the gaps of insufficient protection left by patchwork and sporadic federal laws (Section III). By surveying state statutes briefly, I confirmed that the coverage and form of the state statutes vary greatly state by state, and therefore, could not provide consistent legal protection. Accordingly, I have reached the tentative opinion, as many commentators have, that a comprehensive federal level legislation which specifically and uniformly intends to prohibit genetic discrimination is needed in order to eliminate the fear of genetic discrimination. In the last section I review many attempts to enact a comprehensive federal law since the mid 90s and the recently passed genetic nondiscrimination bill in the U.S. senate (Section IV).

