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GINA, What Could You Do for Me One Day?: The Potential of the Genetic Information Nondiscrimination Act to Protect the American Public

Lauren J. Sismondo*

INTRODUCTION

This Note addresses genetic privacy and proposed federal legislation that purports to afford all citizens the right to genetic privacy as applied to employment and insurance. Scholars debate whether genetic privacy and genetic discrimination are concerns that should be addressed by federal legislation. Many argue that the best way to further development in genetic research and to secure citizen cooperation in clinical genetic research trials is to legislate, thereby alleviating the public's concern about the possibility of genetic discrimination.

Part I of this Note discusses the theory of genetic exceptionalism, the theory that genetic information is somehow different from other medical data and therefore deserves a higher degree of protection. This section explores the idea of discrimination based on genetics, demonstrating that Americans fear discrimination based on genetic make-up, something over which they have no control. This fear of genetic discrimination pervades the employment and insurance realms, on which most people are deeply dependent.

Part II analyzes existing federal legislation as applied to genetic information in the context of maintaining privacy and preventing discrimination. Part III examines the Genetic Information Nondiscrimination Act of 2005 (GINA),¹ currently pending in the

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1. Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005).

United States House of Representatives, for its potential to prevent genetic discrimination in employment and insurance.²

Part IV addresses a 2001 case between the Equal Employment Opportunity Commission (EEOC) and Burlington Northern & Santa Fe Railway (BNSF).³ This case was the first lawsuit ever filed alleging genetic discrimination in employment.⁴ However, because the case settled out of court and did not go to trial, there is still no direct evidence as to how a court would rule on genetic discrimination.

Part V explores several questions left unanswered because of the lack of judicial resolution of the BNSF case. If a similar case of genetic discrimination were to occur, would GINA, the proposed federal legislation, be of any value? Would a defendant such as BNSF be able to allege that its testing is different and not used in a discriminatory manner? Finally, Part VI answers the questions of how protective GINA would really be and whether it should be enacted by Congress.

I. GENETIC INFORMATION, GENETIC TESTING, AND THE FEAR OF GENETIC DISCRIMINATION

Genetic information is seen as a unique entity that requires special attention. This view is based on the theory of genetic exceptionalism, which distinguishes genetic information from other types of medical information as more sensitive and subject to misuse.⁵ Because

2. The majority of this Note was written while the 2003 version of GINA was pending in the House of Representatives. *See* Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. (2003). The Senate Report corresponding to the 2003 version of the bill and other sources relating to it are used extensively throughout this Note for reference and support. Because the 2003 and 2005 versions of GINA are substantially the same, these sources are both informative and useful in analyzing both versions of the bill.

3. EEOC v. Burlington N. Santa Fe Ry. Co., Civ. No. 01-4013 MWB (N.D. Iowa Apr. 18, 2001) (granting preliminary settlement agreement).

4. *Id.*

5. *See* ASHLEY BISER, COUNCIL FOR RESPONSIBLE GENETICS, GENETIC INFORMATION AND EMPLOYMENT: A REPORT ON LAW IN THE UNITED STATES (2004), <http://www.genelaw.info/reports/employment.pdf>. The following factors, while not unique to genetic information, combine to make genetic information more vulnerable:

First, there is a long history of the abuse of hereditary information in the eugenics movements. Second, genetic information is considered uniquely intimate in that it

genetic tests, non-genetic medical tests, and family medical histories can all provide some type of genetic information, it is difficult to obtain a precise definition of genetic information.⁶ One useful summary of the characteristics of genetic information is as follows:

Genetic information relates to families and not just individuals; genetic information can offer a degree of certainty in determining which of those persons is likely to be affected by genetic disease; genetic information can provide a measure of predictability in the assessment of likelihood of ill health in particular individuals from an affected group; genetic information can reveal secrets about future ill health, even in those who are currently well; genetic information can help to determine future risks in future persons, i.e. one's progeny.⁷

Presently, genetic tests cover four main areas.⁸ First, genetic tests can identify a disease in individuals who exhibit few clinical symptoms.⁹ Second, testing can identify individuals who are presymptomatic, but will be affected with a late-onset disease.¹⁰

provides predictive information about an individual's future health status. Third . . . genetic information provides data about not only the individual in question, but their family members as well.

Id. at 4. For a discussion opposed to the theory of genetic exceptionalism, see Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669 (2001).

6. See Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653, 659 (1998). For example, "most clinical tests detect abnormal concentrations of biochemical entities, which can provide information about the genes that code for those entities, as well as the functioning of various organs. Thus, practically every clinical test may be considered a test for gene products." *Id.* at 661 (footnote omitted). Therefore, the determination of what is a genetic test "may depend on the context or purpose of the test: for example, whether cholesterol is tested in an individual with a family history of hypercholesterolemia or as part of a routine physical." *Id.*

7. GRAEME LAURIE, *GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS* 104 (1st ed. 2002). "However, other examples of information which functions in one or more of these fashions can also be derived from non-genetic data, or at least from data that have not traditionally been considered to be genetic." *Id.*

8. For more information on the scope and usefulness of genetic testing in general, see *id.* at 86-113.

9. See BISER, *supra* note 5, at 2.

10. *Id.* Huntington's disease is one type of late-onset disorder. *Id.* For more information on Huntington's disease, see Huntington's Disease Society of America, <http://www.hdsa.org> (last visited Aug. 16, 2006).

Third, genetic tests can indicate predisposition to a disease by locating associated gene sequences.¹¹ Finally, genetic tests can be used to identify individuals more susceptible to certain environmental hazards.¹²

While genetic testing seems promising to some, others have reservations about the widespread use of genetic testing and the amount of information that can be obtained. As one critic states, “[f]ear that genetic information will be misused to harm individuals . . . casts a shadow over [the] glowing portrait of the future of genomic medicine.”¹³ Part of the reason for this fear is the number of parties interested in genetic information—genetic information is important not only to the individual to whom it pertains, but also to relatives, employers, insurers, researchers, and the government.¹⁴

Scholars debate whether the fear of genetic discrimination is based in reality.¹⁵ Widespread genetic testing in the workplace has

11. See Biser, *supra* note 5, at 2. This type of genetic test is more controversial, due to the unreliability of the test. These tests are available for many diseases, such as cystic fibrosis, Alzheimer’s disease, breast cancer, colon cancer, and Parkinson’s disease. See NAT’L COUNCIL ON DISABILITY, POSITION PAPER ON GENETIC DISCRIMINATION LEGISLATION 2 (2002), http://www.ncd.gov/newsroom/publications/2002/pdf/geneticdiscrimination_positionpaper.pdf [hereinafter NCD POSITION PAPER]. A specific example is the BRCA1 or 2 gene associated with an increased risk of breast cancer. See Biser, *supra* note 5, at 2. For more information about the genes associated with an increased risk of breast cancer, see National Cancer Institute, Genetic Testing for BRCA1 and BRCA2, <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA> (last visited Aug. 16, 2006).

12. See Biser, *supra* note 5, at 2. “[I]t is assumed that genetic information may at some point in the future be able to both provide employers with predictive health data and warn employers about individual employees’ susceptibility to environmental hazards.” *Id.*

13. Patricia A. Roche, *The Genetic Revolution at Work: Legislative Efforts to Protect Employees*, 28 AM. J.L. & MED. 271, 271 (2002). “A job action based on a genetic predisposition is rooted in an employer’s fears, myths, and stereotypes, rather than in an employee’s ability to do the job, and therefore constitutes unlawful discrimination.” Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J.L. MED. & ETHICS 189, 194 (1998).

14. See Laurie, *supra* note 7, at 113. The level of interest varies, but is usually based on the perception that the genetic information will provide a personal, economic, societal, or paternalistic benefit. *Id.* at 114.

15. See William Nowlan, *A Rational View of Insurance and Genetic Discrimination*, 297 SCIENCE 195 (2002). Nowlan believes that it is an “erroneous belief that the threat of genetic discrimination by health insurers represents a clear and present danger.” *Id.* He also thinks it “is increasingly likely that the power of genetic testing to predict mortality in otherwise healthy adults will never be compelling enough to justify the expense of testing or the inevitable public furor.” *Id.* at 196 (footnotes omitted). *But see* Karen H. Rothenberg & Sharon F. Terry, *Before It’s Too Late—Addressing Fear of Genetic Information*, 297 SCIENCE 196 (2002). “Regardless

not yet occurred, therefore limiting possible instances of discrimination.¹⁶ Several factors contribute to this result. First, “[f]ew genetic sequences have been identified which could offer predictive information with the sort of accuracy needed for widespread genetic screening.”¹⁷ The cost and questionable reliability of genetic tests also limit their use by employers.¹⁸ In addition, it is doubtful that widespread genetic testing would be cost-effective for employers because of the short-term nature of many employment contracts.¹⁹ Nonetheless, employers’ interest in the genetic information of their employees is expected to increase in the future.²⁰

Regardless of whether the fear of genetic discrimination is justified,²¹ numerous studies show that the public is concerned.²²

of whether fear of genetic discrimination is based on perception or reality, we must find a way to ensure public confidence in genetics research and the use of genetic information.” *Id.* at 197.

16. See Biser, *supra* note 5, at 2. However, “[t]he concern is that employers could use [genetic] data to weed out those most likely to incur large medical expenses—either through increased health care costs or workers’ compensation claims.” *Id.*

17. *Id.*

18. *Id.*

19. *Id.* “In a 2001 survey of large U.S. firms, only 1.3% of firms used a genetic test to identify individuals with sickle-cell anemia, and less than 1% of firms tested either employees or new-hires for the gene associated with Huntington’s Disease.” *Id.* (footnote omitted).

20. *Id.* at 3. Biser described the cost-benefit calculation:

Whether predictive genetic information will eventually be of use to employers in assessing the future health characteristics of workers has yet to be determined; as the cost of testing decreases and the information to be gleaned from such tests becomes more accurate, it is predicted that the incentive for employers to gain access to genetic information will increase.

Id. at 1.

21. When asked in an interview about public fears of genetic discrimination, Francis Collins, M.D., Ph.D., and the director of the National Human Genome Research Institute, observed: “You could say they are overestimating the risk, but these are people who are given the facts and this is the decision they make. Remember, genetic test results follow you for life—they aren’t going to change.” Joel B. Finkelstein, *Protecting Genetic Privacy*, AM. MED. NEWS, Apr. 5, 2004, at 6.

22. See Rothenberg & Terry, *supra* note 15, at 196–97. “[W]orkers clearly fear that employers will use genetic information to lower their insurance and sick leave costs by weeding out individuals who have traits linked to inherited medical conditions.” Miller, *supra* note 13, at 189. One study, conducted at the National Institutes of Health, investigated the attitudes and intentions of patients about undergoing genetic testing for the most common form of hereditary colon cancer, hereditary nonpolyposis colorectal cancer. See Donald W. Hadley et al., *Genetic Counseling and Testing in Families with Hereditary Nonpolyposis Colorectal Cancer*, 163 ARCHIVES INTERNAL MED. 573 (2003). Thirty-nine percent of eligible participants chose not to undergo testing because of the potential effect on their health insurance coverage. *Id.*

Because most ordinary citizens do not understand the complexities of genetics, “[p]ublic education is needed so patients have a better understanding of both the power and limits of genetic testing.”²³ Fear of discrimination leaves many individuals wary of genetic testing, which hurts not only themselves,²⁴ but the scientific community as well.²⁵ For example, many institutional review boards, in response to public concerns, have added language to their informed consent documents that warns of the risk of genetic discrimination resulting from participation in genetic research.²⁶ However, scientists and

23. Finkelstein, *supra* note 21, at 6 (quoting Dr. Nancy L. Fisher, geneticist and clinical associate professor at the University of Washington). In addition, because most diseases are very complex, genetic information alone is insufficient for understanding the disease in its entirety. “[L]egislation will have to recognize these nuances [of diseases] in order to provide a balance between an employer’s interest in safety and an individual’s interest in protecting his or her genetic information.” BISER, *supra* note 5, at 5.

24. “These fears eliminate people’s opportunities to learn that they are not at increased risk for the genetic disorder in the family or to make lifestyle changes to reduce risks.” NCD POSITION PAPER, *supra* note 11, at 5.

25. See Miller, *supra* note 13, at 190. “[M]edical researchers have voiced concerns because individuals are refusing to participate in long-term medical studies to assess their risk of developing genetically linked diseases . . . because these individuals believe that involvement in such studies would be a red flag on their medical records that could subject them to genetic discrimination.” *Id.* Without protection from genetic discrimination, “individuals who do agree to participate [in genetic research] will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating, and preventing disease.” Francis Collins & James D. Watson, Editorial, *Genetic Discrimination: Time to Act*, 302 SCIENCE 745 (2003).

26. See Aaron Hamvas et al., *Informed Consent for Genetic Research*, 158 ARCHIVES PEDIATRIC ADOLESCENT MED. 551, 552 (2004). Washington University is one institution where this has occurred. *Id.* During a study on infants to determine the connection between a genetic variation in the surfactant protein B gene and a higher risk of respiratory distress syndrome, researchers also studied the reasons why parents refused to consent to their infant’s participation in the study. *Id.* at 551–52. The specific language Washington University used on the consent form was as follows:

- (1) An insurance company might consider participation in genetic research in a family study an indication that there is a family history of a genetic condition;
- (2) If your baby’s participation in a genetic study becomes known outside of the research (for example, if your baby’s participation were noted in her/his medical record), your baby (and family members) may be unable to obtain health, life, or disability insurance; and
- (3) You and/or your baby might also be refused employment or be terminated from your current employment.

Id. at 553 (internal quotations omitted). The study showed that ninety-seven percent of nonconsenting families feared language on the consent form that indicated the possibility of genetic discrimination. *Id.*

doctors predict that genetic information will soon be an inevitable part of most medical records and will be of great importance in maintaining good health; fear of genetic discrimination is thus a barrier to progress.²⁷

The best way to address this concern is with federal legislation aimed at preventing genetic discrimination.²⁸ Precluding any possibility of genetic discrimination would ensure fairness and equality for everyone.²⁹ As one author notes, “[i]f you have a circumstance where somebody can lose [the right to health care]

This study suggests that the possibility of losing employment and insurance defines the social context in which families determine whether to consent to a genetic study, even in the absence of any legal precedent or evidence showing that genetic discrimination is a reality. *Id.* at 554. It also concluded that “institutionally required alarmist statements tend to perpetuate misconceptions about the current state of genetic technology rather than promote deliberate discussion with families or patients.” *Id.* The researchers suggested that “information about federally and institutionally mandated protections for confidentiality of participants in genetic research should be included in the informed consent document to balance the description of hypothetical risks and more accurately inform subjects.” *Id.* The uniformity of responses suggests that the language required by the institutional review board “scar[ed] rather than inform[ed] families” of risks, especially since there are no known cases of genetic discrimination arising from participation in a genetic study. *Id.* The language of the informed consent document for participation in genetic research at Washington University was modified, as of March 15, 2004, to read as follows:

You and family members may be unable to get health, life, or disability insurance if the information in this study becomes known. Rarely, you may have problems getting or keeping a job. This could happen if you talk to your doctor about your participation without asking that the information be kept out of your medical record. Having genetic information in your medical record may allow insurance providers to get this information.

Id. at 554–55.

27. See Philip R. Reilly, *Genetic Discrimination*, in *GENETIC TESTING AND THE USE OF INFORMATION* 106, 129 (Clarisa Long ed., 1999). One prominent scientist noted that personalized medicine based on genetics is realistic: “Doctors will also begin tailoring prescribing practices to each patient’s unique genetic profile, choosing medications that are most likely to produce a positive response.” Francis S. Collins, *Personalized Medicine: A New Approach to Staying Well*, *BOSTON GLOBE*, July 17, 2005, at E12.

28. Some have argued that protecting privacy and preventing discrimination are not the best ways to deal with genetic information, and that a property rights approach may be a better option. For a discussion of this argument, see Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 *GEO. WASH. L. REV.* 737 (2004).

29. For example, the National Council on Disability supports federal genetic discrimination legislation, noting that “due to narrow judicial interpretations of ADA . . . these same interpretations also create the need for legislation to restore protections for individuals who have actually developed health conditions.” *NCD POSITION PAPER*, *supra* note 11, at 2.

based on something they have no control over—their DNA sequence—then you have a fundamentally unjust system.”³⁰

II. EXISTING FEDERAL LAWS THAT MAY PROTECT AGAINST GENETIC DISCRIMINATION

Currently, no federal legislation specifically protects against genetic discrimination in individual insurance coverage or in the workplace.³¹ Most legislation has occurred at the state level, where a complex assortment of genetic discrimination laws exists.³² However, there are several federal anti-discrimination laws, including the Americans with Disabilities Act of 1990 (ADA),³³ the Health Insurance Portability and Accountability Act of 1996 (HIPAA),³⁴ and Title VII of the Civil Rights Act of 1964 (Title VII),³⁵ whose provisions can be interpreted to prohibit genetic discrimination.³⁶ In

30. Finkelstein, *supra* note 21, at 6 (quoting Dr. Frances Collins). Dr. Collins also asserted that “it will be much easier to nip this in the bud before it has become widespread than to wait until there is already a sort of standard practice in the insurance industry or the human resources office to find out information about people’s genetics.” *Id.* But see Yesley, *supra* note 6, at 663. Yesley observes that “[l]aws barring genetic discrimination in health insurance do not respond to a substantial problem but to a perceived threat of loss of insurance that might hinder genetic researchers’ search for human subjects.” *Id.* Yesley points out that while legislation aimed at removing the fear of insurance loss “may seem a reasonable step,” the costs of such legislation must also be considered. *Id.* The “piecemeal approach of barring genetic discrimination” in health insurance may help some, but “it also removes a compelling argument for the ultimate goal of universal health coverage.” *Id.*

31. See Miller, *supra* note 13, at 190 (“No current federal statute explicitly addresses genetic discrimination by employers.”).

32. State laws have been described as “a patchwork of provisions which are incomplete, even inconsistent, and which fail to follow a coherent vision for genetic screening, counseling, treatment and prevention of discrimination.” NCD POSITION PAPER, *supra* note 11, at 9–10 (quoting Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 142 (1991)). For more detailed information regarding state genetic legislation, see Biser, *supra* note 5, at 12; William F. Mullholland II & Ami S. Jaeger, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317 (1999); Human Genome Project Information, Genetics Legislation, http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml (last visited Aug. 16, 2006) [hereinafter Genetics Legislation].

33. Americans with Disabilities Act, 42 U.S.C. §§ 12111–117 (2000).

34. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26 U.S.C., 29 U.S.C. and 42 U.S.C.).

35. Civil Rights Act of 1964, 42 U.S.C. § 2000e (2000).

36. See Miller, *supra* note 13, at 190–91. This is “because genetic discrimination may have a disparate impact based on race, color, religion, sex, or national origin.” *Id.* at 191.

addition, President Clinton signed an executive order that prohibits discrimination in employment based on genetic information; however, it applies only to federal employees.³⁷

The ADA generally protects private sector employees from discrimination on the basis of disability, but it uses broad language and does not explicitly mention genetic discrimination.³⁸ The ADA defines disability in three ways: “(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.”³⁹ The Equal Employment Opportunity Commission (EEOC) enforces the ADA,⁴⁰ and, in 1995, determined that the ADA “prohibits discrimination against workers based on their genetic make-up.”⁴¹ The EEOC guidelines are only persuasive authority, however, and have not yet been tested in court.⁴²

HIPAA is the only enacted federal law that directly addresses genetic discrimination.⁴³ However, HIPAA only applies to “employer-based and commercially issued group health insurance.”⁴⁴ HIPAA “[p]rohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or

37. Exec. Order No. 13,145, 3 C.F.R. 235 (2001), *reprinted in* 42 U.S.C.A. § 2000e-1b (West 2003).

38. *See* 42 U.S.C. § 12112(a) (2000).

39. *Id.* § 12102(2). “While one piece of EEOC guidance has suggested that those with presymptomatic or asymptomatic genetic abnormalities would be ‘regarded as’ having a disability and therefore eligible for the act’s protections, others have argued, and the EEOC would not foreclose, that asymptomatic genetic conditions constitute an ‘actual’ disability.” Biser, *supra* note 5, at 10.

40. 42 U.S.C. § 12206(c)(2)(A) (2000); *see also* Press Release, EEOC, EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act (Feb. 9, 2001), *available at* <http://www.eeoc.gov/press/2-9-01-c.html> [hereinafter EEOC Feb. Press Release]. The ADA also prohibits employers from seeking disability-related information that is unrelated to the employee’s ability to perform his or her job. *Id.*

41. Miller, *supra* note 13, at 190–91; *see* 2 EEOC Compl. Man. (CCH) § 902 (Mar. 14, 1995).

42. *See* Genetics Legislation, *supra* note 32. “And yet, courts have not yet determined whether the ADA should be understood to restrict discrimination on the basis of a diagnosed, but asymptomatic, genetic condition or trait.” Miller, *supra* note 13, at 190.

43. *See* HIPAA, Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26 U.S.C., 29 U.S.C. and 42 U.S.C.).

44. *See* Genetics Legislation, *supra* note 32.

limiting eligibility for coverage or for charging an individual more for coverage.”⁴⁵ However, HIPAA explicitly states that genetic information in the absence of a current diagnosis of illness is not a preexisting condition.⁴⁶ This provision is problematic, and affects both those with late-onset diseases and those predisposed to disease.⁴⁷

Both the ADA and HIPAA fail to address family medical histories.⁴⁸ Many employers require prospective employees to provide family medical histories because they are good predictors of the likelihood of developing disease.⁴⁹ Therefore, “family medical history constitutes a form of genetic information that goes largely unregulated.”⁵⁰

Title VII of the Civil Rights Act of 1964 could support an argument that genetic discrimination based on a racially or ethnically linked genetic disease constitutes unlawful discrimination.⁵¹ However, this protection would be available only for diseases linked to specific protected groups, such as sickle-cell⁵² or Tay-Sachs

45. *See id.*

46. *See* HIPAA, 110 Stat. 1936 § 701(b)(1)(B); *see also* BISER, *supra* note 5, at 8. “HIPAA states that a genetic condition . . . [if] it is not the basis of a clinical diagnosis, cannot be considered a preexisting condition for the purposes of health insurance exclusions and cannot be . . . the basis of a limitation or exclusion, unless such provisions are applied to all ‘similarly situated individuals.’” *Id.* (quoting 42 U.S.C. §§ 300gg(b)(1), 300gg-1 (2000)). In addition, HIPAA “does not address the larger problem of gathering or using genetic information in the workplace outside the health insurance context.” Miller, *supra* note 13, at 192. For a more extensive discussion of HIPAA and genetics, see Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 281 (Mark A. Rothstein ed., 1997).

47. *See supra* notes 9–10 and accompanying text.

48. *See* BISER, *supra* note 5, at 8.

49. *See id.* at 3, 8. “While few employers reported using genetic tests directly, 20% reported requesting family medical histories of employees or new-hires . . . [m]ore importantly, almost 5% of those surveyed reported using family medical histories in employment decision-making practices.” *Id.* at 3.

50. *Id.* at 8.

51. *See* 42 U.S.C. § 2000e-2(a) (2000). It is an unlawful employment practice for an employer “to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual . . . because of such individual’s race, color, religion, sex, or national origin,” or “to limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee, because of such individual’s race, color, religion, sex, or national origin.” *Id.*

52. Sickle cell disease is an autosomal recessive anemia, characterized by an unstable hemoglobin variant (Hb S). Homozygotes generally have severe anemia, while heterozygotes are sickle cell trait carriers with minimal clinical problems. Sickle cell disease occurs most

disease.⁵³ Therefore, because most genetic diseases do not disproportionately affect a Title VII protected group, Title VII's protection against genetic discrimination is not comprehensive.⁵⁴

President Clinton's executive order prohibits the use of genetic information⁵⁵ in any hiring or promotion action by all federal departments and agencies.⁵⁶ Specifically, the order prohibits the use of genetic tests and information as a condition of hiring or receiving benefits⁵⁷ or to classify employees in a way that deprives them of advancement opportunities.⁵⁸ However, this order is underinclusive

often in individuals of African descent. *See* STEDMAN'S MEDICAL DICTIONARY 80 (28th ed. 2006).

53. Tay-Sachs disease, a lysosomal storage disease, results from hexosaminidase A deficiency. Within three to six months, infants begin rapid neurological deterioration, and death occurs within a few years. *Id.* Tay-Sachs is an autosomal-recessive transmission, found primarily in Jewish populations. *Id.*

54. *See* Miller, *supra* note 13, at 191-92.

55. Exec. Order No. 13,145, 3 C.F.R. 235 (2001). Protected genetic information is defined in subparagraph (1) as: "(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." *Id.* at 236. The order further provides 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 unless it is described in subparagraph (1)." *Id.* This raises concern about the correctness of the definition of genetic information. *See supra* note 6 and accompanying text.

56. The order provides:

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. This policy of equal opportunity applies to every aspect of Federal employment.

Exec. Order No. 13,145, 3 C.F.R. 235.

57. *Id.* at 236.

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.

Id.

58. *Id.*

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

because it only protects federal employees;⁵⁹ in the private sector, employment discrimination based on genetics is not yet prohibited.⁶⁰

III. PENDING FEDERAL LEGISLATION: GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005

In October, 2003, the United States Senate passed the Genetic Information Nondiscrimination Act of 2003 (GINA).⁶¹ The bill is the first federal legislation to exclusively address the issue of genetic privacy.⁶² The bill's unanimous passage, with a vote of 95–0, ended six years of legislative gridlock.⁶³

The House of Representatives took no action with the 2003 version of GINA. As a result, the United States Senate, in February, 2005, passed the Genetic Information Nondiscrimination Act of 2005.⁶⁴ The text of this bill is substantially similar to the 2003 version. The Senate passed the 2005 version of GINA with a

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.

Id.

59. *Id.*; see also Genetics Legislation, *supra* note 32.

60. See Biser, *supra* note 5, at 9. “[T]he federal government has yet to enact legislation prohibiting private sector employment discrimination on the basis of genetic information.” *Id.* But see GINA of 2003, S. 1053, 108th cong. (2003).

61. GINA of 2003, S. 1053. The Senate report accompanying the bill provided:

The purpose of this legislation is to protect individuals from discrimination in health insurance and employment on the basis of genetic information. Establishing these protections will allay concerns about the potential for discrimination and encourage individuals to participate in genetic research and to take advantage of genetic testing, new technologies, and new therapies. The legislation will provide substantive protections to those individuals who may suffer from actual genetic discrimination now and in the future. These steps are essential to fulfilling the promise of the human genome project.

S. REP. NO. 108-122, at 1–2 (2003).

62. See Sheryl Gay Stolberg, *Senate Sends to House a Bill on Safeguarding Genetic Privacy*, N.Y. TIMES, Oct. 15, 2003, at A12.

63. See *id.* “Negotiators said the measure had been mired in disputes over details, including the precise definition of genetic testing. The disagreements took years to work out, they said, because the topics were so complex.” *Id.*

64. GINA of 2005, S. 306, 109th Cong. (2005). As noted, *supra* note 2, the majority of this Note was written while the 2003 version of the bill was pending. For that reason, sources referring to the 2003 version are used throughout.

unanimous 98-0 vote.⁶⁵ This bill is still on hold in the House of Representatives.

GINA, if passed by the House, will set new standards for safeguarding genetic privacy. GINA defines genetic information rather broadly as information about “an individual’s genetic tests; the genetic tests of family members of the individual; or the occurrence of a disease or disorder in family members of the individual.”⁶⁶ It will prevent insurance companies from using genetic information in deciding enrollment in health plans or in underwriting.⁶⁷ In addition, employers will be permitted to use information from genetic tests only to determine workplace exposures,⁶⁸ but never for hiring purposes.⁶⁹

GINA prohibits the use of genetic information in any type of employment decision, rather than prohibiting only unfair

65. See Collins, *supra* note 27. “The president has indicated strong support, but the bill remains before the House of Representatives, with no hearings scheduled. Given that more than 800 genetic tests are now available and hundreds more are on the horizon, we need this legislation.” *Id.*

66. GINA of 2005, S. 306 § 201(4)(A). “The inclusion of this last provision is particularly significant, because it protects against the use of family history information, as well as information gathered through DNA or RNA-based tests.” Biser, *supra* note 5, at 11. Genetic tests are further defined by the bill as “the analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.” S. 306 § 201(7)(A). An individual’s family member is defined as “(A) the spouse of the individual; (B) a dependent child of the individual, including a child who is born to or placed for adoption with the individual; and (C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).” *Id.* § 201(3).

67. See Stolberg, *supra* note 62, at A12; see also GINA of 2005, S. 306 §§ 101–06. The health insurance requirements will apply to employer-sponsored group health plans, health insurance issuers in both group and individual markets, Medigap insurance, and non-federal governmental plans at the state and local levels. See America’s Health Insurance Plans, Summary of S. 1053, <http://www.aahp.org/DocTemplate.cfm?Section=Genetics&template=/ContentManagement/ContentDisplay.cfm&ContentID=12753> (last visited Aug. 16, 2006).

68. GINA of 2005, S. 306 § 202(b)(5) (“It shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee . . . except . . . where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace.”). Restrictions on this exception include the following requirements: the employer’s written notice of the monitoring to the employee; the employee’s written informed consent; informing the employee of the individual monitoring results; employer compliance with any federal monitoring regulations; and the employer receiving the monitoring results in a manner that does not disclose the identity of specific employees. *Id.* § 202(b)(5)(A)–(E).

69. See Stolberg, *supra* note 62, at A12.

discrimination resulting from the use of genetic information.⁷⁰ This eliminates any exceptions to the use of genetic material for employers.⁷¹ If passed, a provision in GINA allows for a commission review of the Act and any relevant scientific discoveries in six years;⁷² this sunset provision makes a permanent ban on the use of genetic information uncertain.⁷³

Legal action under GINA is limited because it relies on the EEOC's enforcement mechanisms.⁷⁴ First, an individual must file a complaint against his or her employer with the EEOC, which will then determine if there is cause to believe that a GINA violation has occurred.⁷⁵ At that point, the individual can bring a discrimination claim in state or federal court.⁷⁶ In addition, GINA permits civil claims against employers but not against health insurers, and caps damages available against employers.⁷⁷

The bipartisan bill is described as "civil rights legislation,"⁷⁸ and is hoped to "encourage millions of Americans to have genetic testing

70. GINA of 2005, S. 306 § 202; *see also* Biser, *supra* note 5, at 12. "[T]he employer bears the burden of proving a legitimate, nondiscriminatory basis for the employment action." Harold P. Coxson, *Newest Discrimination Law Covers the Broadest Possible Category of Your Workers*, 1 No. 3 FED. EMP. L. INSIDER 1, 1 (Nov. 2003).

71. *See* Biser, *supra* note 5, at 12. "Instead of merely prohibiting 'unfair' discrimination, the act comprehensively prohibits the use of genetic information in employment decision-making; there are no exceptions that would allow employers to use genetic information even if a condition poses a significant risk of a disabling condition." *Id.*

72. GINA of 2005, S. 306 § 208(b); *see also* Biser, *supra* note 5, at 12 ("[I]t is possible that, as relevant tests are developed, [GINA] will be changed.").

73. *See* GINA of 2005, S. 306 § 208(b). Critics approve of this "sunset provision," believing that "there may come a day when Congress and the scientific community will want employers to collect and act on genetic information." Coxson, *supra* note 70, at 1.

74. *See* Biser, *supra* note 5, at 12. Earlier versions of GINA permitted employee lawsuits to be filed directly in federal court. *See* Coxson, *supra* note 70, at 1.

75. *See* Biser, *supra* note 5, at 12.

76. *See id.*

77. *See id.* Harold Coxson reported:

Although remedies would include full 'make-whole' relief, including reinstatement with back pay and front pay, damages would be capped at \$300,000 (the same as Title VII of the Civil Rights Act of 1964, the ADA, and other federal employment discrimination laws). Earlier versions of the legislation . . . provided for unlimited punitive and compensatory damages.

Coxson, *supra* note 70, at 1.

78. *See* Stolberg, *supra* note 62, at A12 (quoting Sen. Judd Gregg, Republican, N.H.). GINA is "for 'a world where the secrets of human life have been plotted out and sheep have been cloned.'" *Id.*

done without fear of discrimination” by their employers or insurance companies.⁷⁹ In addition, supporters anticipate that GINA will encourage participation in genetic research.⁸⁰ The Senate report accompanying GINA states that the steps proposed by this legislation are “essential to fulfilling the promise of the human genome project.”⁸¹ The chief sponsor of the bill, Senator Olympia J. Snowe,⁸² stated that “[t]he American people . . . cannot have access to the quality of care and the advancement of medical and scientific discoveries if they are subjected and held hostage to the fears of discrimination by their employers and by insurers.”⁸³

Opponents of GINA include health insurers and business groups, who deny the existence of discrimination and believe the legislation is unnecessary.⁸⁴ These critics argue that GINA poses many problems, including the possibility of frivolous lawsuits,⁸⁵ overbroad

79. *See id.* “With the genome mapping, researchers have developed tests for vulnerabilities to genetic disorders like cancer and diabetes . . . studies ha[ve] shown that up to one in three Americans eligible for the tests did not take them because they feared they could jeopardize their health coverage or jobs.” *Id.* (quoting Dr. Francis S. Collins).

80. *See* Aaron Zitner, *Senate Blocks Genetic Discrimination*, L.A. TIMES, Oct. 15, 2003, at A16. Dr. Francis Collins, director of the Genome Institute at the National Institutes of Health, said that participation in genetics research is hindered by fear of genetic discrimination. “In two studies of breast cancer and one of colon cancer, one-third of the individuals who were qualified to participate ultimately declined after hearing that there was no federal law against such discrimination . . .” *Id.* “‘If Congress fails to act, we may well squander the vast potential of this research to improve the nation’s health,’ Sen. Edward M. Kennedy of Massachusetts, the senior Democrat on the health committee, said in a written statement.” *Id.*

81. S. REP. NO. 108-122, at 2 (2003).

82. *See* Stolberg, *supra* note 62, at A12. Senator Snowe is a Republican from Maine. *Id.* Senator Snowe “said one patient’s problems prompted her to begin work on the bill in 1996. Breast cancer had struck nine women in the patient’s family. But, Ms. Snowe said, the patient’s daughter was afraid to have genetic screening for breast cancer.” *Id.*

83. *See id.*

84. One such group is the Genetic Information Nondiscrimination in Employment (GINE) Coalition, a business community group. *See* Coxson, *supra* note 70, at 1; *see also* Laura Meckler, *Bill Banning Genetic Discrimination Advances*, CONN. L. TRIB., June 2, 2003, at 4. “‘Federal nondiscrimination legislation has never been based on potential or theoretical discrimination, but, rather, on some appreciable history of actual discrimination,’ R. Bruce Josten of the U.S. Chamber of Commerce said in a letter to Gregg.” *Id.* Supporters respond with the question, “‘Why wait for the discrimination to advance that far, especially if it impedes scientific and medical breakthroughs?’” Coxson, *supra* note 70, at 1.

85. “[T]he legislation will serve as the basis for future unwarranted, frivolous lawsuits, which will be costly . . . to defend, challenging any adverse employment action as being based on . . . knowledge of the genetic information.” Coxson, *supra* note 70, at 1. Also, critics want GINA to preempt state genetic discrimination laws and other federal laws that might apply, “so

definitions,⁸⁶ and the lack of a statute of limitations.⁸⁷ The Bush administration has announced its support for GINA,⁸⁸ and President Bush, while governor of Texas, enacted similar state legislation.⁸⁹ The United States House of Representatives is now considering the Genetic Information Nondiscrimination Act of 2005.⁹⁰

IV. THE LAWSUIT BETWEEN THE EEOC AND BURLINGTON NORTHERN & SANTA FE RAILWAY

No case of genetic discrimination has been decided by a United States federal or state court.⁹¹ However, in 2001, the EEOC brought

that employers aren't faced with defending multiple charges and that the employee alleging genetic information discrimination should be required to make an 'election of remedies.'" *Id.*

86. Critics believe that GINA's scope should be limited to genetic testing only, and should not include things such as family history. *Id.* In addition, critics want a narrower definition of family member, which now includes anyone related by blood and adopted children, to include only the immediate family. *Id.*

87. "There's no statute of limitations or legal defense based on the time elapsed from when the employer first learns about the genetic information and the unfavorable employment action." *Id.*

88. See Stolberg, *supra* note 62, at A12.

89. See Coxson, *supra* note 70, at 1. President Bush views GINA as an extension of disability workplace protections such as the ADA, which was signed by his father, President George H.W. Bush. *Id.* In addition, the Bush Administration has stated that it:

wants to work with Congress to ensure that individuals can be certain that they are protected against the improper use of genetic information. Unwarranted use of genetic information, and the fear of potential discrimination, threatens both society's ability to use new genetic technologies to improve human health and the ability to conduct the very research needed to understand, treat, and prevent diseases.

Id.

90. See National Human Genome Research Institute, Summary of S. 1053, <http://www.genome.gov/11508845> (last visited Aug. 16, 2006). "Medical research advocates said the measure, if it became law, would speed the arrival of 'personalized medicine,' in which patients' genes are studied to learn what diseases they are most vulnerable to and which treatments best suit them." Zitner, *supra* note 80, at 30. However, Republican leadership has kept GINA and other genetic nondiscrimination bills introduced by House members tied up in committee. See Editorial, *Genetic Privacy: House Ought to Follow the Senate's Lead in Outlawing DNA Discrimination*, BUFFALO NEWS, Oct. 25, 2003, at B4.

91. See Roche, *supra* note 13, at 271-72. For insight into how courts may handle genetic discrimination cases, see *Chevron U.S.A., Inc. v. Echazabal*, 536 U.S. 73, 86 (2002) (concluding that an employer may refuse to employ a disabled person under the ADA if employment would endanger his or her health); *Bragdon v. Abbott*, 524 U.S. 624, 641 (1998) (holding that HIV is a disability under the ADA despite the infection not progressing to the symptomatic phase, because HIV substantially limits the ability to reproduce, which is a major life activity); *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269-70, 1274

the first lawsuit alleging genetic discrimination against Burlington Northern & Santa Fe Railway (BNSF).⁹²

In 2001, BNSF, a company employing about 36,000 workers,⁹³ received approximately 125 disability claims from its employees for work-related injuries leading to carpal tunnel syndrome.⁹⁴ BNSF requested certain employees alleging work-related carpal tunnel to submit to a medical examination, one part of which was a diagnostic blood test for a genetic marker believed to be associated with the development of the syndrome.⁹⁵ The genetic marker was specifically for Hereditary Neuropathy with Liability to Pressure Palsies (HNPP), which is believed to be often accompanied by carpal tunnel syndrome.⁹⁶

The EEOC filed a court action alleging genetic discrimination against BNSF in February, 2001, in the U.S. District Court for the Northern District of Iowa.⁹⁷ The EEOC sought a preliminary injunction against BNSF under the ADA to prohibit the genetic testing of the employees who filed disability claims for carpal tunnel syndrome.⁹⁸ In addition, the EEOC sought to prevent disciplinary

(9th Cir. 1998) (holding that blood tests did not violate the ADA, but that their secretive nature violated federal and state guarantees of privacy and unfairly discriminated against African-Americans and women under Title VII); *Laws v. Pact, Inc.*, 2000 WL 777926, at *3 (N.D. Ill. 2000) (holding that a woman in the early stages of Huntington's Disease was not discriminated against at the time of her termination because she was not substantially impaired in a major life activity).

92. EEOC v. Burlington N. Santa Fe Ry. Co., Civ. No. 01-4013 MWB (N.D. Iowa Apr. 18, 2001) (granting preliminary settlement of injunctive claims); *see also* EEOC v. Burlington & Santa Fe Ry. Co., No. 02-C-0456, 2002 WL 32155386 (E.D. Wis. 2002) (granting monetary settlement).

93. BNSF, BNSF Facts, <http://www.bnsf.com/media/bnsffacts.html> (last visited Aug. 16, 2006).

94. *See Roche, supra* note 13, at 276. Carpal tunnel syndrome, the entrapment of the nerve at the wrist, usually occurs with excessive use of the wrist. *See HARRISON'S PRINCIPLES OF INTERNAL MEDICINE* 2501-02 (Dennis L. Kasper et al. eds., 16th ed. 2005). The main symptoms are nocturnal itching and tingling of the thumb, index, and middle fingers. *Id.* With worsening, numbness occurs in the area. *Id.* Carpal tunnel syndrome is believed to be caused or worsened by repetitive hand or wrist motions, similar to those required to operate railway machinery or pound railway spikes. *See Roche, supra* note 13, at 276.

95. *See Burlington Northern*, 2002 WL 32155386.

96. *See* Stephen Fink, EEOC v. BNSF: *The Risks and Rewards of Genetic Exceptionalism*, 42 WASHBURN L.J. 525, 527 (2003).

97. *See* EEOC Feb. Press Release, *supra* note 40.

98. *See id.* BNSF had a policy that required any employee who filed a disability claim for carpal tunnel syndrome to submit blood samples for a genetic DNA test. *Id.* The genetic test

action against or termination of any employee who refused the genetic test.⁹⁹

The EEOC alleged that BNSF employees were neither informed of or asked to consent to the genetic test.¹⁰⁰ The EEOC also alleged that at least one individual refused to provide a blood sample for the test, and was “threatened with imminent discharge if he fail[ed] to submit the sample.”¹⁰¹

The EEOC and BNSF reached a settlement agreement out of court in April, 2001, in the form of an agreed order.¹⁰² BNSF admitted that it tested certain employees who alleged carpal tunnel syndrome for the genetic marker.¹⁰³ The order specified that BNSF shall not “directly or indirectly require its employees to submit blood for genetic tests”; “analyze any blood previously obtained”; “evaluate, analyze or consider any gene test analysis previously performed on any of its employees”; or “retaliate or threaten to take any adverse action against any person who opposed the genetic testing or who participated in EEOC’s proceedings.”¹⁰⁴ However, because the parties reached a settlement, the court had no occasion to rule on the parties’ arguments under the ADA,¹⁰⁵ giving no further guidance as to how genetic privacy and discrimination cases will be decided and

was designed to reveal a chromosome seventeen deletion, which some claim predicts forms of carpal tunnel syndrome. *Id.*

99. *See id.* The EEOC determined that “employees would suffer irreparable injury through the invasion of their most intimate privacy rights if the practice of testing is not ended.” *Id.* (quoting Chester V. Bailey, Director of the EEOC’s Milwaukee District Office).

100. *See id.*

101. *Id.* The employee suspected that the blood samples requested would be used for genetic testing. *Id.*

102. *See* Press Release, EEOC, EEOC Settles ADA Suit Against BNSF for Genetic Bias (Apr. 18, 2001), available at <http://www.eeoc.gov/press/4-18-01.html> [hereinafter EEOC Apr. Press Release].

103. *See id.*; *see also* Finkelstein, *supra* note 21, at 5. BNSF had “the clear intent of trying to figure out a way to let employees go if they might be at some risk of collecting workman’s comp.” *Id.* (quoting Dr. Francis Collins).

104. EEOC Apr. Press Release, *supra* note 102. In addition, the order provided that “BNSF shall preserve all evidence relevant to its genetic testing until several charges of discrimination filed with EEOC against the company are resolved,” and that “EEOC may seek compensatory and punitive damages up to \$300,000 per individual (the statutory cap) for a class of claimants ranging from 20 to 30 BNSF workers who were either subjected to genetic testing or retaliated against for failing to submit to such tests.” *Id.*

105. *See* LAURIE, *supra* note 7, at 160.

leaving unanswered “the question of the legality of genetic susceptibility monitoring programs.”¹⁰⁶

After agreeing to the order halting the genetic testing, BNSF and the EEOC mediated a monetary settlement of \$2.2 million in May, 2002.¹⁰⁷ BNSF denied engaging in unlawful testing or workplace discrimination in violation of the ADA,¹⁰⁸ but agreed to settle the charges with the EEOC through voluntary mediation.¹⁰⁹ BNSF agreed to “not use genetic tests in required medical examinations of its employees . . . provide enhanced ADA training to its medical and claims personnel . . . and . . . have senior management review of all significant medical policies and practices.”¹¹⁰

V. APPLYING GINA TO THE BURLINGTON NORTHERN & SANTA FE RAILWAY CASE

If another case of genetic discrimination similar to BNSF were to occur, would GINA be of any value? Would the employee have any additional protections, or would the employer be permitted to test? How is susceptibility testing protected under GINA? Would BNSF be able to allege that its testing is different and not used in a discriminatory manner? These are just a few of the many questions raised by GINA’s possible enactment.

Applying GINA’s provisions to the facts of the BNSF case, it is likely that the outcome would not be substantially different from the settlement terms. BNSF requested certain employees who alleged work-related carpal tunnel syndrome to submit to a medical examination, one part of which was a diagnostic blood test for a genetic marker believed to be associated with the development of the

106. Biser, *supra* note 5, at 9.

107. EEOC v. Burlington N. & Santa Fe Ry. Co., No. 02-C-0456, 2002 WL 32155386 (E.D. Wis. 2002); *see* Press Release, EEOC, EEOC and BNSF Settle Genetic Testing Case Under Americans with Disabilities Act (May 8, 2002), *available at* <http://www.eeoc.gov/press/5-8-02.html> [hereinafter EEOC May Press Release].

108. *See* EEOC May Press Release, *supra* note 107. EEOC Commissioner Paul Steven Miller noted that, “[w]hile the EEOC did not find that BNSF had used genetic tests to screen out employees, employers should be aware of the EEOC’s position that the mere gathering of an employee’s DNA may constitute a violation of the ADA.” *Id.*

109. *See id.*

110. *Id.*; *see also* Joanne L. Husted and Janlori Goldman, *Genetics and Privacy*, 28 AM. J.L. & MED. 285 n.55 (2002).

syndrome.¹¹¹ Under GINA, although there are several provisions that may allow such genetic testing, BNSF did not comply with the imposed requirements.

To require a genetic test in compliance with GINA, BNSF would have to offer the medical services as part of a bona fide wellness program,¹¹² with prior informed written consent by the employee,¹¹³ and it would have to disclose the results only to the employee and the physician.¹¹⁴ BNSF's actions did not conform to these standards. BNSF employees were neither informed of nor asked to consent to the genetic test, violating GINA.¹¹⁵ BNSF's threat to terminate an employee who refused to provide a blood sample for the genetic test is an additional GINA violation.¹¹⁶ Further, it would be difficult for BNSF to assert that the genetic test was part of a bona fide wellness program because only those employees who had previously submitted a disability claim for carpal tunnel were required to undergo the genetic test.¹¹⁷

Another possible route by which to allow the genetic test requires that BNSF show that the test was intended to monitor workplace conditions.¹¹⁸ However, the GINA provision under which this might

111. *See supra* notes 94–95 and accompanying text.

112. GINA of 2005, S. 306, 109th Cong. § 202(b)(2)(A) (2005) (allowing an exception for genetic testing “[w]here health or genetic services are offered by the employer, including such services offered as part of a bona fide wellness program”). The Senate Report on GINA describes this exception as necessary

to achieve the bill's stated goal of encouraging employees to take advantage of genetic technologies and opportunities to improve human health without fear of discrimination by their employer. . . . Participation in the program must be voluntary and confidential, and safeguards must be in place to ensure that the sponsoring employer . . . does not have access to individually identifiable health information. . . .

S. REP. NO. 108-122, at 27 (2003).

113. GINA of 2005, S. 306 § 202(b)(2)(B) (allowing an exception “where the employee provides prior, knowing, voluntary, and written authorization”).

114. *Id.* § 202(b)(2)(C) (allowing an exception “where only the employee (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services”).

115. *See supra* notes 99, 110 and accompanying text.

116. *See supra* notes 100, 110 and accompanying text.

117. *See supra* notes 94, 111 and accompanying text.

118. GINA of 2005, S. 306 § 202(b)(5)(B)(ii) (allowing an exception “where the information involved is to be used for genetic monitoring of the biological effects of toxic

occur specifically refers to toxic substances.¹¹⁹ It would be difficult, if not impossible, to connect a toxic substance with carpal tunnel syndrome,¹²⁰ especially when the condition is believed to result from operating railway machinery or pounding railway spikes.¹²¹

Based on the proposed GINA legislation, the BNSF employees would have a plausible case of genetic discrimination. Although BNSF admitted that it tested certain employees alleging carpal tunnel syndrome for a genetic marker,¹²² it denied any wrongdoing, unlawful testing, or workplace discrimination.¹²³ However, provided that the EEOC could prove its alleged facts, BNSF would nonetheless be liable to those employees under GINA for genetic discrimination in employment practices.

VI. WILL GINA REALLY PROTECT? SHOULD IT BE ENACTED?

Despite the limited known instances of genetic discrimination, the public is concerned. This fear of genetic discrimination affects participation in genetic research trials and willingness to undergo genetic tests, because of the risk of discriminatory action by an employer or insurer.

The 2003 Senate report on GINA provides many reasons why federal legislation prohibiting genetic discrimination is necessary. Legislators believe it is important to prevent “[e]nabling employers, health insurers and others to base decisions about individuals on the characteristics that are assumed to be their genetic destiny,” because it “would be an undesirable outcome of our national investment in genetic research, and may significantly diminish the benefits that this research offers.”¹²⁴

substances in the workplace, but only if . . . the genetic monitoring is required by Federal or State law”).

119. See *supra* notes 98, 108 and accompanying text.

120. See *supra* note 91 and accompanying text. For additional information on carpal tunnel syndrome, see National Institute of Neurological Disorders and Stroke, Carpal Tunnel Syndrome Information Page, http://www.ninds.nih.gov/disorders/carpal_tunnel/carpal_tunnel.htm (last visited Aug. 16, 2006).

121. See *supra* note 91 and accompanying text.

122. See *supra* note 100 and accompanying text.

123. See *supra* note 105 and accompanying text.

124. S. REP. NO. 108-122, at 6 (2003).

GINA should be enacted because it “provides the broadest employment discrimination coverage and workplace protections of any discrimination law in the nation’s history.”¹²⁵ The legislation would assure the public that employers and insurers cannot discriminate against individuals based on their genetic make-up. While some disagree with the need for federal legislation because of the few documented cases of genetic discrimination, the correct approach is a preemptive one. Although genetic testing is not currently widespread, it is much easier to address the problem now, rather than waiting until it is standard practice for insurance companies and employers to have access to genetic information.¹²⁶ By enacting GINA, Congress will protect individuals from genetic discrimination and make it more likely that they will participate in genetic research and benefit from genetic tests and technology.¹²⁷

CONCLUSION

The idea of genetic privacy is one of current concern for the American public. Proposed federal legislation, GINA, will afford all citizens the right to genetic privacy as applied to employment and insurance. Although scholars debate whether genetic privacy and genetic discrimination are pressing concerns requiring federal legislation, many argue that the best way to further development in genetic research and to secure citizen cooperation in clinical research trials is to legislate, thereby alleviating the public’s fear of genetic discrimination.

125. Coxson, *supra* note 70, at 1.

126. Wal-Mart recently circulated a memo discussing ways to cut the costs of employee benefits. Steven Greenhouse & Michael Barbaro, *Wal-Mart Memo Suggests Ways to Cut Employee Benefit Costs*, N.Y. TIMES, Oct. 26, 2005, at C1. The main tone of the memo, discouraging unhealthy workers and job applicants and focusing particularly on obesity, could be seen as an attempt at a form of genetic discrimination by the company. “The memo proposed incorporating physical activity in all jobs and promoting health savings accounts [which] are financed with pretax dollars and allow workers to divert their contributions into retirement savings if they are not all spent on health care . . . these accounts will be more attractive to younger, healthier workers.” *Id.*

127. “It is only fitting that in 2003, a year filled with historic DNA milestones, the U.S. Congress and the president move forward to give a present to the American people: enactment of a nondiscrimination law protecting all of us.” Francis Collins & James D. Watson, Editorial, *Genetic Discrimination: Time to Act*, 302 SCIENCE 745 (2003).

Federal legislation should be enacted as soon as possible, although it appears that GINA is on the back burner in the United States House of Representatives. The United States Senate, as demonstrated by its unanimous passage of both the 2003 and 2005 versions of GINA, is eager to enact federal legislation that protects American citizens from genetic discrimination in employment and insurance. The House of Representatives should follow the lead of the Senate and pass GINA as well. The quicker the House acts, the more protection the American public will have, and, as a result, the greater the chance that genetics research and technologies will advance to their fullest potential.