

GENETIC DISCRIMINATION IN THE WORKPLACE: LESSONS FROM THE PAST AND CONCERNS FOR THE FUTURE

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What happened to me should not happen to anyone, especially in the United States. It is a direct infringement on our fundamental rights to be who we are. No one can help how we are put together. Only God knows that. The employer, the insurance company or anyone else has no business of that knowledge. That information . . . should not be used against you and your family for hiring and firing practices or acceptance and/or denial into insurance programs.

Gary Avary on Burlington Northern Santa Fe's efforts to secretly genetically test him¹

Today, the Senate is considering the first major new civil rights bill of the new century We know there are numerous barriers to new discoveries that Congress can do little about—the complexities of disease, the uncertainties of science, the rarity of true inspiration. But this is one major problem that is entirely within our power to solve. We can make a difference, and we can do it today.

Senator Edward Kennedy on the Genetic Information Nondiscrimination Act²

The law against genetic discrimination has entered a new era. In April 2008, after more than a decade of failed efforts,³ Congress passed the

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1. *Genetic Nondiscrimination: Implications for Employers and Employees: Hearing Before the Subcomm. On Employer-Employee Rel. of the Comm. on Educ. and the Workforce*, 107th Cong. 7-9 (2001) (statement of Gary Avary, Member of the Brotherhood of Maintenance of Way Employees union).

2. Press Release, Senator Edward Kennedy, Kennedy in Support of Genetic Information Nondiscrimination Bill (Apr. 24, 2008), http://www.allamericanpatriots.com/48746785_senator-ted-kennedy-support-genetic-information-no.

Genetic Information Nondiscrimination Act (GINA), which President George W. Bush signed into law on May 21, 2008.⁴ GINA's employment provisions became effective on November 21, 2009.⁵ This new legislation, especially when combined with the recent amendments to the Americans with Disabilities Act (ADA),⁶ has great potential to prevent genetic discrimination against persons in employment. Two questions persist, however. First, is the legislation even necessary? Second, if so, is the legislation enough?

I. GENETIC DISCRIMINATION: HORROR OR HYPERBOLE

As efforts to pass legislation in Congress stalled year after year, one constant argument of opponents to the bill was that it was unnecessary. So, is there genetic discrimination in the workplace, or is GINA a law looking for a fictitious problem?

The answer depends on who is asked. Some studies seemed to indicate the potential for broad discrimination based upon genetic information. According to a 2004 study by the American Management Society,

companies were genetically testing employees for risk of breast and colon cancer, Huntington's disease, and susceptibility to workplace hazards. One in six of the companies surveyed collected family medical histories of their employees. At least one-half of the companies testing for breast and colon cancer risk and Huntington's disease considered the results in their hiring, re-assigning and firing decisions. One-fifth of the companies use the information gleaned from family medical histories, and more than one-half use the information from tests regarding susceptibility to workplace hazards in their employee decision-making.⁷

3. Legislation was first introduced in 1995, and one of its principal proponents has been U.S. Representative Louise Slaughter (D-NY). Rep. Slaughter: Real Action Still Needed on Genetics Legislation, US Fed News, July 22, 2004. For more about Representative Slaughter's efforts, see *Politics and Perseverance, An Interview with U.S. Rep. Louise Slaughter, D-NY*, GENEWATCH, Apr.-May 2009, at 7.

4. Genetic Information Nondiscrimination Act of 2008 (GINA), Pub. L. No. 110-233, 122 Stat. 881(2008) (to be codified in scattered sections of 26 U.S.C., 29 U.S.C., and 42 U.S.C.); see U.S. Dept. of Energy, Office of Science, Breaking News: GINA Becomes Law (May 2008), http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml.

5. GINA § 213.

6. ADA Amendments Act of 2008 (ADAAA), Pub. L. No. 110-325, 122 Stat. 3553 (2008) (codified as amended in scattered sections of 42 U.S.C.).

7. Susannah Carr, *Invisible Actors: Genetic Testing and Genetic Discrimination in the Workplace*, 30 U. ARK. LITTLE ROCK L. REV. 1, 2-3 (2007); see American Management Association, *AMA 2004 Workplace Testing Survey: Medical Testing 2 (2004)*, available at http://www.amanet.org/research/pdfs/Medical_testing_04.pdf; see also NAT'L P'SHIP FOR WOMEN & FAMILIES ON BEHALF OF THE COAL. FOR GENETIC FAIRNESS, *FACES OF GENETIC DISCRIMINATION: HOW GENETIC DISCRIMINATION AFFECTS REAL PEOPLE* 7 (2004) [hereinafter

Another study, from 1996, wherein nearly forty-eight percent of respondents who were at risk, presymptomatic, or asymptomatic for a genetic disorder, reported that they had experienced some form of discrimination based on their risk status.⁸ Beyond such studies, proponents of legislation barring genetic discrimination also pointed to two federal lawsuits—*Norman-Bloodsaw v. Lawrence Berkeley Laboratory*⁹ and *EEOC v. Burlington Northern Santa Fe Railway*¹⁰—which both confirmed the existence of secret genetic testing by employers on unsuspecting employees.

Opponents of the legislation, however, asserted that there was no evidence, anecdotally or in studies, indicating that genetic discrimination in employment was a widespread problem.¹¹ They argued that other laws, including Title VII of the Civil Rights Act of 1964, the ADA, and state laws already provided protection against genetic discrimination.¹² They also pointed to the fact that in more than a decade and a half since the ADA was adopted, only two genetic testing cases have ever been confirmed, and in both cases the employees had legal remedies.¹³

There are counters to these arguments, of course. In the end, GINA passed because of a belief that, whatever the extent of current genetic discrimination in the workplace, the potential for abuse existed.¹⁴ For

FACES OF GENETIC DISCRIMINATION] (describing a 2001 American Management Association survey), available at <http://www.nationalpartnership.org/site/DocServer/FacesofGeneticDiscrimination.pdf?docID=971>.

8. Lisa N. Geller et al., *Individual, Family, and Social Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 SCI. & ENGINEERING ETHICS 71, 74-75 (1996).

9. See *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1264 (9th Cir. 1998) (reversing the district court's grant of summary judgment for the defendants on Title VII and state and federal privacy claims after employees were subjected to non-consensual testing for sensitive medical information).

10. *EEOC v. Burlington N. & Santa Fe Ry. Co.*, No. C 01-4013-MWB (N.D. Iowa Apr. 18, 2001). Although there were no reported decisions in the case, the underlying facts and arguments of the parties were discussed extensively in court filings, public statements, and in congressional testimony.

11. *Employer Advocates Remain Wary of New Bias Law's Potential Effects*, [2008] Daily Lab. Rep. (BNA) No. 99 (May 22, 2008) (noting that "management representatives said they did not know of any employers that were conducting genetic testing of their workforce or were interested in obtaining employees' genetic data"), <http://emlawcenter.bna.com/pic2/em.nsf/id/BNAP-7KMKU9?OpenDocument>; see also Mark A. Hall et al., *Genetic Screening for Iron Overload: No Evidence of Discrimination at One Year*, 56 J. FAM. PRAC. 829, 831-33 (2007).

12. See *infra* text accompanying notes 39-40.

13. See *infra* section II A-C.

14. See GINA, Pub. L. No. 110-233, § 2(5), 122 Stat. 881, 882-83 (2008) (noting that the legislation was passed to assuage the public's fear of genetic discrimination); see also Jeremy Gruber, *GINA: How It Came to Pass and What It Does*, GENEWATCH, Apr.-May 2009, at 4, 4-6 (describing the legislative efforts that culminated in the passage of GINA); Henry T. Greely, *Banning Genetic Discrimination*, 353 NEW ENG. J. MED. 865, 865 (2005).

example, advancements in genetic testing are increasing rapidly,¹⁵ and tests are becoming increasingly easier to obtain.¹⁶ Concern about potential abuse has led to a marked reluctance by persons to undergo genetic tests.¹⁷ A massive majority of the American public is scared of getting a genetic test because people fear that the test results will impact their health insurance or their employment.¹⁸ As a result, the reluctance of persons to get genetic tests interferes with the ability of scientists to conduct research.¹⁹

There's no doubt the public wanted legislation prohibiting genetic discrimination.²⁰ A 2004 study found that ninety-two percent of individuals opposed allowing employers access to their genetic information, and eighty percent opposed allowing access by insurance companies.²¹ With scientific advancements in the area of human genome research and with the increased availability of commercial sources that offer genetic testing

15. Kathy L. Hudson et al., *Perspective: Keeping Pace with the Times — The Genetic Information Nondiscrimination Act of 2008*, 358 NEW ENG. J. MED. 2661, 2661-62 (2008) (indicating that, in 1995, when genetic discrimination legislation was first introduced, there were 300 genetic tests available, and in 2008, at the time of GINA's passage, there were more than 1500).

16. See GINA § 2(5) (finding that developments in science and law justified adoption of GINA); see also Mark A. Rothstein, *GINA's Beauty Is Only Skin Deep: The Law's Passage May Have Been a Step Forward, But It Has Significant Flaws*, GENEWATCH, Apr.-May 2009, at 9 ("To some degree, GINA was enacted to prevent genetic discrimination in the future when health records will routinely contain genetic information and genetic testing will be so inexpensive that it's cost-effective to perform it on a widespread basis.").

17. Kathy L. Hudson, *Prohibiting Genetic Discrimination*, 356 NEW ENG. J. MED. 2021, 2022 (2007) ("To keep genetic information out of their medical records and out of the hands of insurers and employers, patients sometimes pass up genetic testing that could benefit their health."); Amy Harmon, *Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests*, N.Y. TIMES, Feb. 24, 2008, § 1, at 1; see also Greely, *supra* note 14, at 867.

18. GENETICS & PUB. POLICY CTR., SURVEY: PUBLIC AWARENESS AND ATTITUDES ABOUT REPRODUCTIVE GENETIC TECHNOLOGY (2002) (finding that more than nine out of ten persons oppose allowing employers access to genetic information, and eight out of ten oppose such access by insurers), available at <http://www.dnapolicy.org/images/reportpdfs/PublicAwarenessAndAttitudes.pdf>; FACES OF GENETIC DISCRIMINATION *supra* note 7, at 7.

19. See Perry W. Payne, Jr., *Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination*, 5 J. HEALTH & BIOMED. L. 33, 38-40 (2009) (discussing studies indicating fear of discrimination prevents the use of genetic testing); see also FACES OF GENETIC DISCRIMINATION, *supra* note 7, at 1 (noting that fear of discrimination prevents individuals from participating in research, thereby slowing the pace of scientific progress).

20. See GINA, Pub. L. No. 110-233, § 2(5), 122 Stat. 881, 882-83 (2008) (noting that the legislation was passed to protect the public's fear of genetic discrimination).

21. FACES OF GENETIC DISCRIMINATION, *supra* note 7, at 7. See Carr, *supra* note 7, at 3 (noting that in a 1997 study, eighty-five percent of the respondents "felt that employers should be prohibited from obtaining information about an individual's genetic conditions and predispositions").

services, the concern over possible misuse of genetic information has become heightened.²² With GINA, the public got what they wanted—at least as far as it pertains to employment and health insurance.

II. THE LAWS AS THEY EXIST REGARDING GENETIC TESTING IN EMPLOYMENT

GINA does not supplant other state and federal laws that provide more protection to employees.²³ GINA, therefore, must be read in light of the backdrop of the other state and federal laws that prohibit employment discrimination.

A. Title VII

Title VII of the Civil Rights Act of 1964 prohibits employment discrimination based upon race, sex, color, national origin and religion.²⁴ Title VII is invoked in genetic testing cases when the employer singles out a protected group for testing, or uses tests that have a disparate impact upon one protected group.²⁵

The classic case of Title VII coming into play in a genetic testing case arose in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*.²⁶ Lawrence Berkeley Laboratory was a research facility operated by state and federal agencies.²⁷ Employees contended that, in the course of their mandatory entrance exams, Lawrence Berkeley Laboratories secretly tested the employees' blood and urine for syphilis, the sickle cell trait, and pregnancy, without the employees' knowledge or consent.²⁸ The employees brought suit under the ADA and Title VII, and asserted violations of their constitutional rights to privacy under the federal and state constitutions.²⁹ The employees' claim under the ADA, which is the only statute upon which they relied that contained provisions restricting an employer's ability to conduct medical tests on employees,³⁰ failed in the district court and in the Ninth Circuit Court of Appeals because the medical exams were conducted after offers of employment were made but before the employees started

22. See FACES OF GENETIC DISCRIMINATION, *supra* note 7, at 1.

23. GINA § 209(a).

24. Civil Rights Act of 1964, 42 U.S.C. § 2000e-2 (2006).

25. See *Griggs v. Duke Power Co.*, 401 U.S. 424, 424 (1971) (finding in favor of African-American employees that it was in violation of Title VII of the Civil Rights Act of 1964 to require them to submit a high school diploma or pass intelligence tests in order to transfer positions as such information did not provide a reasonable measure of job performance).

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

27. *Id.* at 1264.

28. *Id.*

29. *Id.*

30. Americans with Disabilities Act, 42 U.S.C. §12112(d) (2006).

work.³¹ While the ADA restricts employers from conducting medical examinations before an offer of employment³² and confines tests upon current employees to those situations where the test is job-related and consistent with business necessity,³³ there are few restrictions on the scope of examinations conducted after a contingent offer of employment has been made and before the employee starts work.³⁴ As long as an employer tests everyone in the incoming job categories, maintains the confidentiality of the information, and complies with the ADA's other provisions—including its prohibition against discrimination based upon disability—an employer's tests do not need to be job-related under the ADA at that stage.³⁵

In *Norman-Bloodsaw*, the plaintiffs were allowed to proceed with their constitutional claims, which were of a unique basis because the employer was operated by state and federal agencies.³⁶ The Title VII claim was able to proceed because Lawrence Berkeley conducted the genetic test for sickle cell trait only on African Americans.³⁷ The Title VII claim was also allowed to proceed on sex discrimination grounds because the pregnancy test was only performed on women.³⁸

Thus, Title VII is a possible check to genetic tests and discrimination, but it is limited in its impact. Title VII will apply where the employer is selecting persons to screen based upon their protected status, such as race or sex, or screening for a genetic condition that is disproportionately linked to a specific population or sex. A Title VII claim would arise, for example, if an employer was screening only women for mutations on the BRCA1 or BRCA2 genes,³⁹ which indicate an increased risk for developing breast cancer.⁴⁰ Similarly, a Title VII disparate impact claim could be asserted based on race

31. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1273-74 (9th Cir. 1998).

32. 42 U.S.C. § 12112(d)(2).

33. 42 U.S.C. § 12112(d)(4)(A).

34. 42 U.S.C. § 12112(d)(3).

35. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1273 (9th Cir. 1998); see also EEOC, ADA ENFORCEMENT GUIDANCE: PREEMPLOYMENT DISABILITY-RELATED QUESTIONS AND MEDICAL EXAMINATIONS (1995), available at <http://www.eeoc.gov/policy/docs/preemp.html>. GINA changes this result. See *infra* section III.

36. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1268-71 (9th Cir. 1998) (discussing federal and state constitutional claims).

37. *Id.* at 1272.

38. *Id.*

39. See *Wroblewski v. Lexington Gardens, Inc.*, 448 A.2d 801, 806-07 (1982) (holding that inquiring into urogenital health of women, but not men, violated state employment discrimination law).

40. NAT'L CANCER INST., FACT SHEET: BRCA1 AND BRCA2: CANCER RISK AND GENETIC TESTING 1 (2009), http://www.cancer.gov/images/documents/abcb7812-a132-4e78-a532-f002c92fa9b9/fs3_62.pdf.

if the employer was screening out applicants whose tests showed the sickle cell trait, because this would disproportionately exclude African Americans.⁴¹ A claim could also be based on national origin if the employer was screening out carriers for Tay-Sachs because it would disproportionately exclude Ashkenazi Jews (those of Eastern European descent).⁴² Most other genetically based conditions will not trigger a disparate impact claim because such conditions may not be disproportionately linked to a protected class.

B. State Laws

In addition to Title VII, there are also state laws that protect employees. Most states have laws against genetic discrimination in one form or another.⁴³ However, these laws vary widely in their protection. Some do not cover employment and are limited to insurance.⁴⁴ Others prohibit employers from firing employees because of genetic conditions, but do not bar or restrict employers from requesting the information.⁴⁵ Only a minority of the state laws provide for a private cause of action.⁴⁶ Thus, this patchwork of state laws, with its limited ability to allow for private enforcement, does not provide for an effective barrier against unwarranted genetic testing and discrimination in employment.

41. See EEOC Dec. No. 81-8, 2 EPL. PRAC. GUIDE (CCH) 6764 (1980) (finding that rejecting all applicants based on sickle cell anemia violated Title VII).

42. Victor Ctr. for Jewish Genetic Disease, Ashkenazi Jewish Genetic Diseases, <http://www.jewishvirtuallibrary.org/jsourc/Health/genetics.html> (last visited Feb. 11, 2010); see also Mark A. Rothstein, *Employee Selection Based on Susceptibility to Occupational Illness*, 81 MICH. L. REV. 1379, 1453-54 (1983) (discussing occurrence of G-6-PD deficient individuals in different populations and concluding that G-6-PD screening would have a disparate impact based on race, sex and national origin).

43. Hudson, *supra* note 17, at 2021-22 (“[Thirty-five] states have laws against genetic discrimination in employment, and [forty-seven] have laws against genetic discrimination in health insurance.”); Nat’l Conference of State Legislatures, *Genetic Employment Laws* (identifying thirty-five states with laws prohibiting genetic discrimination in hiring, firing, and/or terms, conditions or privileges of employment, but only fourteen with specific penalties against employers), <http://www.ncsl.org/IssuesResearch/Health/GeneticEmployment/Laws/tabid/14280/Default.aspx> (last visited Feb. 11, 2010).

44. See Hudson, *supra* note 17, at 2021 (noting that no law directly protects the use of genetic information by employers and that “additional clarification is needed to ensure that genetic information cannot be used to discriminate in employment decisions such as hiring, firing, job assignments, and promotions . . .”).

45. U.S. Dep’t of Energy, *Human Genome Project Information: Genetics Privacy and Legislation*, http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml (last visited Feb. 11, 2010).

46. See National Conference of State Legislatures, *Genetic Nondiscrimination in Health Insurance Laws Enforcement Provisions* (2008), <http://www.ncsl.org/default.aspx?tabid=14279>.

C. *Americans with Disabilities Act*

In the employment context, there also is the Americans with Disabilities Act. As mentioned earlier, the ADA restricts medical examinations of applicants and employees.⁴⁷ In short, the employer (1) *cannot* conduct medical examinations prior to a conditional offer of employment; (2) *can* conduct a medical examination after a conditional offer of employment has been made, even if it is not job-related; and (3) *can* conduct such exams of current employees only when the examination is job-related and consistent with business necessity.⁴⁸ Even if the employer is permitted to require the medical examination, the employer cannot use the information obtained to discriminate against a qualified individual with a disability.⁴⁹

As noted, the ADA's restrictions on employers conducting genetic tests on incoming employees are limited, as shown in *Lawrence Berkeley Laboratory*.⁵⁰ More protection exists during the employment relationship because the tests must be job-related and consistent with business necessity. To date, the only suit to challenge a genetic test performed on current employees on the basis that it was an unlawful medical exam and constituted discrimination based on disability was the EEOC lawsuit against Burlington Northern Santa Fe Railway (BNSF).⁵¹

In *EEOC v. Burlington Northern Santa Fe Railway*, BNSF performed genetic tests on employees who had made internal claims of work-related carpal tunnel syndrome.⁵² The BNSF employees were not told that they were being genetically tested. Instead, BNSF merely told them that, "to ascertain whether the . . . carpal tunnel syndrome [was] 'work-related,' the employee must undergo medical testing 'to ensure that all possible contributing causes of [the] condition have been evaluated.'"⁵³ Although

47. 42 U.S.C. §12112(d) (2006).

48. 42 U.S.C. § 12112(d)(2)(A)-(4)(A) (2006); 29 C.F.R. § 1630.14(a)-(c) (2009).

49. 29 C.F.R. § 1630.14(b)(3) (2009) ("If certain criteria are used to screen out an employee or employees with disabilities as a result of such an examination or inquiry, the exclusionary criteria must be job-related and consistent with business necessity, and performance of the essential job functions cannot be accomplished with reasonable accommodation"); see also 42 U.S.C. §12112(d)(3)(C) (2006) (noting the only three instances when the information may be used).

50. *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1273 (9th Cir. 1998) (stating that the ADA places no restriction on the scope of employment entrance examinations).

51. *EEOC v. Burlington N. & Santa Fe Ry. Co.*, No. C 01-4013-MWB (N.D. Iowa Apr. 18, 2001).

52. Sam Anderson, *When Science Fiction Becomes Fact*, GENEWATCH, Apr.-May 2009, at 11.

53. EEOC's Memorandum in Support of Petition for a Preliminary Injunction at 2, *EEOC v. Burlington N. & Santa Fe R.R.*, No. C 01-4013-MWB (N.D. Iowa Apr. 18, 2001) [hereinafter EEOC's Memorandum in Support of Preliminary Injunction].

the employees were told that there would be "laboratory testing," they were not told that BNSF's doctor would be drawing a number of vials of blood that would be shipped to a genetic testing facility in Massachusetts, where it would be tested to determine whether there was a "submicroscopic 1.5 million base pair DNA deletion on the short arm of chromosome 17."⁵⁴ According to information from the genetic testing facility, "this deletion is 'suggestive' of a rare genetic condition called Hereditary Neuropathy with liability Pressure Palsies ('HNPP')."⁵⁵

HNPP is not a common condition, occurring only in 1 out of 20,000 persons.⁵⁶ "[It] is a slowly progressive, hereditary, neuromuscular disorder which makes an individual susceptible to nerve injury from pressure, stretch or repetitive use."⁵⁷ The typical onset for HNPP is adolescence or early adulthood, and the problem areas include the wrists, elbows, and knees.⁵⁸ It usually does not present with carpal tunnel alone,⁵⁹ it is accompanied by other conditions, like drop foot.⁶⁰ The mutation is very unlikely to be found in work-related cases of carpal tunnel syndrome.⁶¹ Francis Collins, who led the Human Genome Project, called the test as used by BNSF "junk science."⁶² The scientist who developed the test said that he wished that BNSF had called him, because he would have told BNSF to save its money.⁶³

The fact that BNSF was genetically testing its employees was discovered by accident.⁶⁴ One of the employees slated to be tested, Gary Avary, was talking to another employee who had been tested.⁶⁵ The employee told

54. *Id.*

55. *Id.* at 3.

56. *A Newshour with Jim Lehrer: Genetic Testing* (Online Focus broadcast June 7, 2001) [hereinafter *Newshour*], available at http://www.pbs.org/newshour/bb/health/jan-june01/genetest_06-07.html.

57. The University of Chicago Jack Miller Center for Peripheral Neuropathy, Hereditary Neuropathy with Liability to Pressure Palsies (HNPP), <http://millercenter.uchicago.edu/learn/aboutpn/typesofpn/hereditary/hnpp.shtml> (last visited Feb. 11, 2010). Welcome to the Hereditary Neuropathy with Liability to Pressure Palsies or HNPP Website, <http://www.hnpp.org/> (last visited Feb. 11, 2010).

58. See Maureen Horton, *More About HNPP*, http://www.charcot-marie-tooth.org/about_cmt/hnpp.php (last visited Feb. 6, 2010).

59. *Newshour*, *supra* note 56.

60. *Id.*

61. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 3.

62. *Newshour*, *supra* note 56.

63. Lisa Girion, *Nurse Derails Genetic Testing: Wife of Railroad Worker Sparks Probe that May Have Wide Implications*, L.A. TIMES, Feb. 25, 2001 at W1 ("If they had just bothered to call me I could have saved them a lot of money and a lawsuit they richly deserve.")

64. Anderson, *supra* note 52, at 11.

65. *Id.*

Avary that seven vials of blood were taken during his examination.⁶⁶ Avary informed his wife, Janice, who was a nurse and who could not understand why so many vials of blood were being drawn.⁶⁷ She pursued her concerns, first calling BNSF's medical liaison, who after being pressed, told her that the tests included "genetic tests."⁶⁸ Janice then spoke to BNSF's chief medical officer, who wanted to know who had revealed the tests.⁶⁹ He ultimately conceded that a genetic test for HNPP was going to be performed.⁷⁰ Avary objected and refused to take the test.⁷¹ BNSF accused him of insubordination and of violating BNSF's safety rules.⁷² BNSF scheduled him to appear before an "investigation" panel for a hearing with the possible result of termination.⁷³ Avary and other employees went to both their union and the EEOC, which consequently sought an injunction to stop the testing within the same week.⁷⁴

The case captured the public's attention. It was in *People Magazine*, on *Good Morning America*, *The Lehrer Report*, and it was featured in a PBS documentary called "Bloodlines: Technology Hits Home."⁷⁵ It became the virtual poster child for the need for a federal law that could protect against genetic testing. Part of the attention arose by virtue of its timing: the same week in which the EEOC moved for a preliminary injunction against BNSF, the Human Genome Project announced the draft sequence and initial analysis of the human genome.⁷⁶ Some of the interest stemmed from the secretive nature of the testing; and in legal fields, some of the interest arose from the problems that the case revealed about the reach of the ADA with regard to genetic testing and discrimination.

66. *Id.*

67. *Id.*

68. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 4.

69. *Id.*

70. *Id.*

71. *Id.* at 5; Anderson, *supra* note 52, at 11, 13.

72. Anderson, *supra* note 52, at 11, 13.

73. *See id.*

74. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 2 ("During the past week, the EEOC learned that BNSF recently instituted a policy whereby any employee who claims to have developed carpal tunnel syndrome as a result of BNSF's working conditions is forced to undergo genetic testing.").

75. Nick Charles, *Telling Them No*, PEOPLE, July 9, 2001, at 81; *Good Morning America: Interview with Diane Sawyer* (ABC television broadcast April 18, 2001); *Newshour*, *supra* note 56; BLOODLINES: TECHNOLOGY HITS HOME (Backbone Media, 2003).

76. *See* EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53. *See* Press Release, Nat'l Human Genome Research Inst., International Human Genome Sequencing Consortium Publishes Sequence and Analysis of the Human Genome (Feb. 12, 2001), <http://www.genome.gov/10002192>.

In the case itself, the EEOC argued first that the test violated the ADA provisions on medical examinations of current employees.⁷⁷ The EEOC contended that before a test could be conducted, it had to be job-related and consistent with business necessity.⁷⁸ It further asserted, consistent with EEOC guidance,⁷⁹ that an employer could conduct such a test only if it was testing to see whether a condition interfered with the employee's ability to perform the essential functions of the job, or whether he posed a direct threat to the safety of himself or others.⁸⁰ The EEOC asserted that BNSF was looking for the cause of the carpal tunnel, and not whether the condition posed a threat to the employee.⁸¹ Consequently, the EEOC argued the test was not job-related or backed by business necessity.⁸²

BNSF, however, asserted that the genetic test was permissible under the ADA. BNSF contended that there was no evidence it intended to take adverse action against the workers as a result of the test.⁸³ "Burlington Northern said it was merely 'trying to determine whether the injuries were work-related so that we could fix it.'"⁸⁴ BNSF asserted that the company was obligated by federal law to determine whether the injuries were work-related.⁸⁵

BNSF's defenses raised a host of unresolved issues under the ADA, such as—even assuming that an employer could argue that its medical tests were

77. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 9. See 42 U.S.C. § 12112(d)(4)(A) (2006); 29 C.F.R. § 1630.13(b) (2008); see also U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, ENFORCEMENT GUIDANCE: DISABILITY-RELATED INQUIRIES AND MEDICAL EXAMINATIONS OF EMPLOYEES UNDER THE AMERICANS WITH DISABILITIES ACT (ADA) 4 (2000) [hereinafter EEOC ADA ENFORCEMENT GUIDANCE] (noting that medical examinations include "blood, urine, saliva, and hair analyses to detect disease or genetic markers"), <http://www.eeoc.gov/policy/docs/guidance-inquiries.html>.

78. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 9-10. See 42 U.S.C. § 12112(d)(4)(A) (2006); see also 29 C.F.R. § 1630.14(c) (2008).

79. EEOC ADA ENFORCEMENT GUIDANCE, *supra* note 77 at 6; U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, EEOC ENFORCEMENT GUIDANCE ON THE AMERICANS WITH DISABILITIES ACT AND PSYCHIATRIC DISABILITIES: NOTICE CONCERNING THE AMERICANS WITH DISABILITIES ACT AMENDMENTS ACT OF 2008, U.S. Equal Employment Opportunity Commission, available at <http://www.eeoc.gov/policy/docs/psych.html> (last visited Feb. 11, 2010).

80. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 9-10.

81. *Id.* at 10.

82. *Id.* at 9-10.

83. Indeed, the EEOC did not contend otherwise except for its assertions that BNSF intended to retaliate against Gary Avary based upon his good faith refusal to take the genetic test. See EEOC Memorandum in Support of its Preliminary Injunction, *supra* note 53, at 15-16.

84. Art LeClair, *Railworkers Win Against Genetic Testing*, SOCIALIST VIEWPOINT, May 2001, http://www.socialistviewpoint.org/may_01/may_01_9.html.

85. Stephen Fink, *EEOC v. BNSF: The Risks and Rewards of Genetic Exceptionalism*, 42 WASHBURN L.J. 525, 527-28 (2003).

job-related and consistent with business necessity—whether it could keep the tests secret from the employee. There is nothing in the ADA that explicitly requires notice to and consent by the employees to the specific tests that the employer conducts.⁸⁶ However, notice and consent arguably are assumed in the ADA's provisions on prohibited medical testing. An employee would be permitted to protest taking tests that he or she believed in good faith violated the ADA, and would be protected from retaliation for those protests.⁸⁷

The *Burlington Northern* case ultimately settled for \$2.2 million and broad equitable relief, including an end to genetic testing by BNSF and the development of a protocol for handling the genetic samples and test results.⁸⁸ The early settlement left unknown whether the courts would have adopted the EEOC's position that BNSF's genetic testing violated the ADA's restrictions on medical examinations of current employees. In even more doubt is the ultimate resolution of the EEOC's additional claim⁸⁹ that BNSF "regarded" the tested employees as having disabilities, and by subjecting them to special genetic testing, BNSF imposed upon them different terms and conditions of employment because of their disabilities. The EEOC asserted that, by singling out those employees with claims of carpal tunnel syndrome, BNSF presumed that these employees had or potentially had a chromosomal defect leading to carpal tunnel.⁹⁰ The EEOC argued that BNSF therefore regarded the employees as having conditions that would substantially limit them in the major life activities of performing manual tasks and working, as would carpal tunnel syndrome.⁹¹

The EEOC has long taken the position that employers who discriminate against individuals based upon genetic information are regarding the individuals as having impairments that substantially limit a major life activity.⁹² Considerable doubt has been expressed as to whether courts

86. See 42 U.S.C. § 12112 (2006).

87. See 42 U.S.C. § 12203 (2006); see also Rothstein, *supra* note 42, at 1466-67 (discussing that an employer is barred from retaliating against an employee based upon the employee's refusal to take tests believed in good faith by the employee to be discriminatory).

88. Press Release, U.S. Equal Employment Opportunity Comm'n, EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act (May 8, 2002), <http://www.eeoc.gov/press/5-8-02.html>.

89. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 13-15; See 42 U.S.C. § 12102(2) (2006).

90. EEOC's Memorandum in Support of Preliminary Injunction, *supra* note 53, at 12.

91. *Id.* at 14.

92. See 136 Cong. Rec. H4623 (daily ed. July 12, 1990) (statement of Rep. Owens). This part of the definition of "disability" 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

would accept the EEOC's position, however.⁹³ Under the federal law against disability discrimination—as it existed prior to ADA amendments effective in January 2009—employers could argue that they were not regarding the employee as currently restricted in major life activities, such as lifting, walking, and performing manual tasks,⁹⁴ and therefore, the person was not regarded as having a disability.⁹⁵ Prior to the recent ADA Amendments Act (ADAAA), courts concluded that individuals who manifested HIV,⁹⁶ breast cancer,⁹⁷ heart disease,⁹⁸ diabetes,⁹⁹ and epilepsy,¹⁰⁰ for example, were not disabled because the limitations imposed by the conditions were not severe enough nor did they affect the persons' abilities to perform major life functions for the requisite period of time. It is possible, therefore, that an employer that based its decision exclusively upon genetic information could escape liability under the ADA.

major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability." *Id.* at H4624-25 (statement of Rep. Edwards); *id.* at H4627 (statement of Rep. Waxman). U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, SECTION 902 DEFINITION OF THE TERM DISABILITY: NOTICE CONCERNING THE AMERICANS WITH DISABILITIES ACT AMENDMENTS ACT OF 2008 § 902.8(a), <http://www.eeoc.gov/policy/docs/902cm.html> (last visited Feb. 6, 2009).

93. See, e.g., William J. McDevitt, *I Dream of GINA: Understanding the Employment Provisions of the Genetic Information Nondiscrimination Act of 2008*, 54 VILL. L. REV. 91, 104 (2009) ("[T]he applicability of the 'regarded as' prong of the ADA's definition of 'disability' to individuals who are predisposed to genetically related diseases is tenuous."); Mark A. Rothstein, *Currents in Contemporary Ethics: GINA, the ADA, and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 838 (2008) (noting that "individuals with a genetic predisposition to future illness are probably not covered by the ADA").

94. 29 C.F.R. § 1630.2(i) (2008).

95. 29 C.F.R. § 1630.2(l) (2008).

96. *St. John v. NCI Bldg. Sys., Inc.*, 537 F. Supp. 2d 848, 861-62 (S.D. Tex. 2008).

97. See, e.g., *Garrett v. Univ. of Ala. at Birmingham Bd. of Trs.*, 507 F.3d 1306, 1309, 1315 (11th Cir. 2007). This case ultimately reached the Supreme Court, which held against the employee on Eleventh Amendment grounds.

98. *Taylor v. Nimock's Oil Co.*, 214 F.3d 957, 960-61 (8th Cir. 2000) (noting that employee's heart disease recovery period did not qualify as substantial limitation on a major life activity).

99. *Diaz Rivera v. Browning-Ferris Indus. of P.R., Inc.*, 626 F. Supp. 2d 244, 257 (D. P.R. 2009).

100. *Fred Mancini v. Union Pacific R.R. Co.*, No. 02-36151, 2004 U.S. App. LEXIS 8213, at *4-5 (9th Cir. Apr. 23, 2004) (noting that epilepsy is not a disability for ADA purposes where its "manifestations . . . are 'totally controlled' through the consistent use of medication").

D. Amendments to the ADA

The ADA was amended, however, effective as of January 1, 2009, by the ADA Amendments Act of 2008 (ADAAA).¹⁰¹ The ADAAA allows for a better argument that someone who is subjected to differential treatment because he or she has a genetic condition—even though not currently or completely manifested—is regarded as having a disability.¹⁰² The amendments to the ADA are sweeping and beyond the scope of this discussion. However, as a brief overview, the amendments reversed several Supreme Court opinions, which contracted the ADA's protections, and are intended to make it easier for an individual to show that he or she has a disability under the ADA.¹⁰³ For example, the definition of "major life activities" was expanded to include "major bodily functions" such as "functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions."¹⁰⁴ Further, under the amended Act, persons are to be considered in their unmitigated state, without regard to whether their condition is controlled by treatments such as medications or prosthetics.¹⁰⁵ Persons who have a condition that is episodic or in remission are to be considered as though the condition is active as long as it substantially limits a major life activity while active.¹⁰⁶ Therefore, the standard for whether someone is substantially limited is to be lower than previously asserted.¹⁰⁷

In September 2009, the EEOC issued a Notice of Proposed Rulemaking (NPRM), setting forth proposed regulations interpreting the new ADA amendments.¹⁰⁸ The proposed regulations accompanying the NPRM,

101. ADA Amendments Act of 2008, Pub. L. No. 110-325, § 1, § 8, 122 Stat. 3553 (2008) (amending scattered sections of 42 U.S.C.).

102. ADA Amendments Act of 2008 § 4(a), 122 Stat. at 3555 (to be codified at 42 U.S.C. § 12102(3)(A)).

103. ADA Amendments Act of 2008 § 2(a)(2)-(5), 122 Stat. at 3554 (declaring that the ADAAA overturns *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 534 U.S. 184, 197-98 (2002) and *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 488 (1999)); see also *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516, 521 (1999); *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555, 564 (1999).

104. ADA Amendments Act of 2008 § 4(a), 122 Stat. at 3553, 3555 (to be codified at 42 U.S.C. § 12102(2)(B)).

105. ADA Amendments Act of 2008 § 4(a), 122 Stat. at 3556 (to be codified at 42 U.S.C. § 12102(4)(E)(i)(I)).

106. ADA Amendments Act of 2008, Pub. L. No. 110-325, § 4(a), 122 Stat. 3556 (2008) (to be codified at 42 U.S.C. § 12102(4)(D)).

107. ADA Amendments Act of 2008 § 4(a), 122 Stat. at 3555 (to be codified at 42 U.S.C. § 12102(4)(A)).

108. Regulations to Implement the Equal Employment Provisions of the Americans With Disabilities Act, as Amended, 74 Fed. Reg. 48,431, 48,431 (proposed Sept. 23, 2009) (to be codified at 29 C.F.R. pt. 1630).

although not final, suggest that individuals whose genetic conditions have manifested will be able to argue that their conditions have affected a major life activity. For example, the proposed regulations published in the Federal Register and subject to a comment period,¹⁰⁹ provide that “sickle cell disease affects functions of the hemic system” and therefore is a major life activity because it involves the operation of a bodily function.¹¹⁰

For discrimination based solely upon genetic makeup where there is no and may never be any manifested condition, the most important change comes in the definition of whether an employer regards the individual as having a disability. Prior to the ADAAA, the individual had to establish that the employer regarded the individual as having an impairment that substantially limited a major life activity.¹¹¹ Now, it is only necessary for the employee to show that the employer regarded the employee as having an actual or perceived mental or physical impairment, and that the employee was subjected to discrimination as a result. Consequently, the employee does not have to show that the employer perceived him or her as substantially limited in a major life activity.

An employee fired for a genetic condition, whether it never manifested or became only slightly symptomatic, could argue that the employer perceived him or her as having an impairment. The regulations define impairment to mean:

- (1) Any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine; or
- (2) Any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.¹¹²

109. *Id.* The deadline for written comments on the rulemaking was on or before Nov. 23, 2009. *Id.*

110. *Id.* at 48,440.

111. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 490 (1999) (“Under subsection (C), individuals who are ‘regarded as’ having a disability are disabled within the meaning of the ADA. Subsection (C) provides that having a disability includes “being regarded as having,” “a physical or mental impairment that substantially limits one or more of the major life activities of such individual.” There are two apparent ways in which individuals may fall within this statutory definition: (1) a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or (2) a covered entity mistakenly believes that an actual, nonlimiting [sic] impairment substantially limits one or more major life activities.”) (internal citations omitted).

112. 29 C.F.R. § 1630.2(h) (2009). The regulations proposed in the EEOC’s recent NPRM would leave this regulation unchanged except for substituting “intellectual disability” for

An applicant or employee today could argue that if he or she were discriminated against based on a genetic condition that the employer perceived the person as having an impairment. For example, a woman discharged for having a mutation on the BRCA1 or BRCA2 gene could argue that the employer perceived her as having a disorder that substantially affects a body system, and therefore, the employer regarded her as having a disability.

It is unlikely that courts will be called to decide the issue of the asymptomatic victim, however, because November 2009 began the brave new world of GINA. Under GINA, there is a much clearer and simpler answer.

III. THE BRAVE NEW WORLD OF GINA

GINA prohibits genetic discrimination in both health insurance and employment. Title II specifically applies to employment and bars the intentional acquisition of genetic information about applicants or employees, prohibits employment decisions based on genetic information, and imposes strict confidentiality requirements on the handling of genetic information.¹¹³

The EEOC is the federal agency tasked with enforcement of Title II.¹¹⁴ On March 2, 2009 the EEOC published a Notice of Proposed Rulemaking (NPRM), setting out a summary and text of the EEOC's proposed implementing regulations.¹¹⁵ It received numerous comments on the proposed regulations.¹¹⁶ Subsequently, on August 6, 2009, the Commissioners approved proposed GINA regulations, whereupon the EEOC submitted them to the White House Office of Management and Budget (OMB) for review.¹¹⁷ The content of the regulations submitted to

"mental retardation." Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended, 74 Fed. Reg. at 48,432.

113. GINA, Pub. L. No. 110-233, §§ 201-13, 122 Stat. 905 (2008) (to be codified at 42 U.S.C. §§ 2000ff-2000ff-11); Pub. L. No. 110-233, §§ 202-06 (to be codified at 42 U.S.C. §§2000ff-1 – 2000ff-5).

114. GINA, § 207(g) (to be codified at 42 U.S.C. § 2000ff-6) (incorporating enforcement provisions of Title VII).

115. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9056 (proposed March 2, 2009) (to be codified at 29 C.F.R. pt. 1635).

116. *Genetic Discrimination: EEOC Receives Varying Advice on Tweaking Its Proposed Rules Under Genetic Bias Law*, [2009] Daily Lab. Rep. (BNA) No. 90, at C-1 (May 13, 2009) (summarizing comments). The comments are posted without change at <http://www.regulations.gov>, and can be accessed through the Regulatory Information Number (RIN) for the rulemaking, RIN 3046-AA84.

117. *Genetic Discrimination: EEOC Clears GINA Rule for OMB Review*, [2009] Daily Lab. Rep. (BNA) No.151, at A-18 (Aug. 10, 2009).

OMB, including the extent to which changes were made in response to the submitted comments, has not yet been made public.

The employment provisions in Title II are modeled after those in Title VII of the Civil Rights Act of 1964. The enforcement and remedies section in GINA incorporates those of Title VII.¹¹⁸ Unlike Title VII, it does not permit disparate impact claims,¹¹⁹ although it does provide that a committee be formed within six years to consider whether such a cause of action should be included in the statute.¹²⁰

GINA hinges on the definition of genetic information. Genetic information is broadly defined by GINA and the proposed regulations accompanying the EEOC's NPRM and does not include information about the age or sex of the individual:¹²¹

Genetic information means information about (i) [a]n individual's genetic tests; (ii) [t]he genetic tests of that individual's family members; (iii) [t]he manifestation of disease or disorder in family members of the individual (family medical history); (iv) [a]n individual's request for, or receipt of, genetic services, or participation in a clinical research that includes genetic services by the individual or a family member of the individual; or (v) [t]he genetic information of a fetus [including information obtained from assisted reproductive services].¹²²

This definition also lends itself to a number of sub-definitions, such as, for example, what is a "genetic test." Genetic test is "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes."¹²³ "An analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes is not a genetic test."¹²⁴ "A medical examination that tests for the presence of a virus that is not composed of *human* DNA, RNA, chromosomes, proteins, or metabolites is not a genetic test."¹²⁵

118. GINA, § 207, 122 Stat. at 914 (to be codified at 42 U.S.C. § 2000ff-6).

119. *Id.* § 207, 122 Stat. at 917 (to be codified at 42 U.S.C. §2000ff-7).

120. *Id.*

121. GINA, Pub. L. No. 110-233, §201(3)(c), 122 Stat. 905, 906 (2008) (to be codified at 42 U.S.C. §2000ff(4)(C); Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9067 (to be codified at 29 C.F.R. pt. 1635.3(c)(2)).

122. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9067 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.3(c)(1)).

123. GINA § 201(7)(A), 122 Stat. at 907 (to be codified at 42 U.S.C. §2000ff); Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9068 (to be codified at 29 C.F.R. pt. 1635.3(f)(1)).

124. GINA § 201(7)(B), 122 Stat. at 907 (to be codified at 42 U.S.C. §2000ff); Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9068 (to be codified at 29 C.F.R. pt. 1635.3(f)(1)(i)).

125. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9068 (to be codified at 29 C.F.R. pt. 1635.3(f)(1)(ii)).

Thus, as the proposed regulations set out, a “test for the presence of drug or alcohol is not a genetic test; [although a] test to determine whether an individual has a genetic predisposition for alcohol or drug use is a genetic test.”¹²⁶ According to information from the Genetics & Public Policy Center, an HIV test would not be considered a genetic test under GINA. “Although it is a retrovirus that inserts itself into human DNA, HIV is not itself human DNA and measuring its presence does not constitute a genetic test under the law’s definition.”¹²⁷

Tests that would be covered by this definition would include the test for the sickle cell trait in *Lawrence Berkeley Laboratory*, and the test for the deletion on Chromosome 17, which is indicative of HNPP and was at issue in *Burlington Northern*.¹²⁸ GINA would include tests for BRCA 1/BRCA 2, indicating an increased risk of breast cancer, as well as tests for the Huntington’s disease mutation; and carrier screening for conditions such as cystic fibrosis, spinal muscular atrophy, and fragile X syndrome, as genetic tests.¹²⁹

Medical history and genetic tests of family members are considered genetic information under GINA.¹³⁰ “Family member” is similarly broadly defined as extending to fourth degree relatives, which would include great-great grandparents and children of cousins.¹³¹ Interestingly, by reference to another statute, it also includes genetic information of dependents, including those who become related through marriage or adoption.¹³² Consequently, the reach of this statute does not restrict its coverage to genetic information about the individual but also will reach that of certain family members who are not of the same bloodline.

126. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9068 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.3(f)(2)) (emphasis added).

127. GENETICS & PUB. POLICY CTR., JOHNS HOPKINS UNIV., INFORMATION ON THE GENETIC INFORMATION NONDISCRIMINATION ACT (GINA) 2, <http://www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf> (last visited Feb. 11, 2010).

128. *Id.* See *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1264-65 (9th Cir. 1998); *EEOC v. Burlington N. & Santa Fe Ry. Co.*, No. C 01-4013-MWB (N.D. Iowa Apr. 18, 2001); *EEOC v. Burlington N. & Santa Fe Ry. Co.*, No. 02-C-0456, slip op. at *1 (E.D. Wis. May 8, 1990).

129. See GENETICS & PUB. POLICY CTR., *supra* note 127.

130. GINA, Pub. L. No. 110-233, §201(4)(A)(iii), 122 Stat. 905, 906 (2008) (to be codified at 42 U.S.C. 2000ff).

131. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9067 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.3(a)(2)). See GINA § 201(4)(A)(iii), 122 Stat. at 906 (to be codified at 42 U.S.C. 2000ff).

132. GINA § 201(3)(A), 122 Stat. at 906 (incorporating the definition of “dependent” in section 701(f)(2) of ERISA); see Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9067 (to be codified at 29 C.F.R. pt. 1635.3(a)(1)).

Employers, unions, training programs, and employment agencies (“covered entities”) are barred from requesting, requiring, or purchasing genetic information of an individual, except for a few exceptions.¹³³ Thus, the hole in the ADA that was pointed out by the *Lawrence Berkeley Laboratory* case, where an employer is not constrained from obtaining genetic information in the post-offer/pre-placement stage has been plugged by GINA.¹³⁴ Under GINA, a covered entity will not be permitted to take a family history at this stage or at any point in the employment relationship unless the genetic information falls into one of the few exceptions.¹³⁵

A covered entity does not violate GINA’s restrictions regarding obtaining genetic information if the entity inadvertently obtained the information.¹³⁶ The NPRM addresses supposed “water cooler” talk. For example, the NPRM’s section-by-section analysis and the proposed regulations conclude that an employer does not violate GINA when it learns genetic information by overhearing a conversation that contains information about someone’s family history.¹³⁷ The proposed regulations also address where an employer receives genetic information in response to a question such as, “How is your family?”¹³⁸

Also, the proposed NPRM regulations recognize that genetic information may be inadvertently obtained by a covered entity who seeks other information relating to a request for a reasonable accommodation under the ADA.¹³⁹ This recognition by the NPRM responds to concerns that covered entities might receive more than they asked for from employees or their physicians during the ADA’s interactive process. The NPRM cautions, however, that the covered entities’ requests for medical information should

133. GINA §§ 202(b), 203(b), 204(b), 122 Stat. at 907-10 (to be codified at 42 U.S.C. §2000ff-1(b), §2000ff-2(b), §2000ff-3(b), §2000ff-4(b)); Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9068 (to be codified at 29 C.F.R. pt. 1635.3(7)).

134. See *supra* text accompanying notes 30-35.

135. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9061.

136. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9068 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.8(b)(1)); GINA, Pub. L. No. 110-233, §§ 201, 203-05, 122 Stat. 905, 905-12 (2008) (to be codified at 42 U.S.C. §2000ff-1(b)(1), §2000ff-2(b)(1), §2000ff-3(b)(1), §2000ff-4(b)(1)).

137. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9061, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(1)(i)).

138. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9061, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(1)(ii)).

139. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9061-62, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(1)(iii)).

not be overbroad, and if they are, genetic information obtained in response might not be considered inadvertently obtained.¹⁴⁰

Similarly, GINA exempts information received from employees to support a request for leave under the Family Medical Leave Act (FMLA).¹⁴¹ Employees covered by the FMLA¹⁴² can obtain leave to care for a family member who has a serious health condition.¹⁴³ An employer can request verification of the need, even though the information obtained may fall within the definition of "family medical history."¹⁴⁴

GINA recognizes that an employer may obtain information from commercial or public sources.¹⁴⁵ The EEOC's proposed GINA regulations and its section-by-section analysis in its NPRM discuss employers who gain genetic information from sources like newspapers and the Internet.¹⁴⁶ Importantly, the regulations prohibit employers from surfing medical websites or court records with the intention of obtaining medical information.¹⁴⁷

Whether and the extent to which employers are restricted from obtaining information from things such as personal web pages and social networking sites, remains an open question.¹⁴⁸ The EEOC's NPRM explicitly solicited

140. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9061-62.

141. GINA, Pub. L. No. 110-233, §202(b)(3), 122 Stat. 905, 907-08 (2008) (to be codified at 42 U.S.C. 2000ff-1).

142. 29 U.S.C. §2611(2)(A) (2006).

143. 29 C.F.R. § 825.112 (a)(3) (2006).

144. Even if the genetic information was inadvertently or not inappropriately obtained, GINA requires that the information be held in confidence. GINA § 205(b)(3), 122 Stat. at 912 (to be codified at 42 U.S.C. 2000ff-4). For example, in litigation, the covered entity cannot release the information without a court order. A discovery request or a stipulation of confidentiality will not suffice. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9063-64, 9069 (proposed Mar. 2, 2009). Regardless of how the information was obtained and regardless of whether the genetic information is regarded as "confidential" genetic information, covered entities are absolutely prohibited from using the genetic information in making employment decisions. See Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9063-64, 9069. See *supra* text accompanying notes 130-31.

145. GINA § 203(b)(4), 122 Stat. at 909 (to be codified at 42 U.S.C. 2000ff-2). Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9063.

146. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9063, 9069 (to be codified at 29 C.F.R. pt. 1635.8(b)(4)).

147. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9063, 9069 (to be codified at 29 C.F.R. pt. 1635.8(b)(4)).

148. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. at 9063.

comment on the issue of personal web pages and social networking sites.¹⁴⁹ Commentators were divided on whether the exception for commercially or publicly available material would extend to such information, with business groups taking the position that employers should not be penalized for material found on the Internet when searching for other purposes, and privacy rights groups and employee advocates asserting that the exception should not include sites likely to contain such information.¹⁵⁰ It is unknown whether the proposed regulations submitted to OMB after the comments were received address this issue.

GINA also does not punish an employer who learns about genetic information through a voluntary wellness program if certain prerequisites are met.¹⁵¹ Wellness programs are those where an employer takes steps to encourage employees to engage in activities that will decrease their health risks.¹⁵² More than sixty percent of companies with 10,000 or more employees maintain wellness programs.¹⁵³ Most wellness programs include a health risk assessment and a significant number solicit information relating to family history.¹⁵⁴ For example, when assessing whether someone is at risk for Type II diabetes, the assessment may ask about height, weight, and whether there is a family history of Type II diabetes.

The proposed regulations for GINA impose prerequisites to the acquisition of genetic information in connection with a voluntary wellness program.¹⁵⁵ The employee participating in the wellness program must provide knowing, voluntary, and written authorization which must be understandable.¹⁵⁶ The authorization must describe the genetic information that will be obtained, and describe the restrictions on disclosure of the

149. Regulations Under the Genetic Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9063 (proposed Mar. 2, 2009).

150. *Genetic Discrimination: EEOC Receives Varying Advice on Tweaking Its Proposed Rules Under Genetic Bias Law*, *supra* note 116.

151. GINA, Pub. L. No. 110-233, §§ 202-05, 122 Stat. 881, 907, 909-10, 912 (2008) (to be codified at 42 U.S.C. §§ 2000ff-1(b)(2), 2000ff-2(b)(2), 2000ff-3(b)(2), 2000ff-4(b)(2)).

152. See Lisa Phillips, *Wellness in the Workplace: How and Why to Take Advantage of Preventive Care Coverage*, NEUROLOGY NOW, July-Aug. 2009, at 32, 33.

153. Laura Petrecca, *Companies Re-Evaluate Wellness Programs*, USA TODAY, June 19, 2009, at 3B, available at http://www.usatoday.com/money/workplace/2009-06-16-wellness-programs-companies_N.htm.

154. See Phillips, *supra* note 152, at 32.

155. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9062, 9068-69 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.8(b)(2)).

156. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9062, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(2)(i)(A)).

information.¹⁵⁷ The results of this analysis can be disclosed to the employer only in aggregate terms.¹⁵⁸

Before the exception for genetic information obtained in connection with a wellness program applies, participation in the program must be *voluntary*.¹⁵⁹ Wellness programs may even be hinged on incentives.¹⁶⁰ Some incentives, though, arguably can operate like penalties, such as when an employer makes availability of health insurance contingent on participation in a wellness program.¹⁶¹ The EEOC Guidance on the ADA, which also considers the receipt of medical information in connection with voluntary wellness programs, says that programs are voluntary “as long as an employer neither requires participation nor penalizes employees who do not participate.”¹⁶² The EEOC has not yet answered the question of when an “incentive” might become such a “penalty” as to make the wellness program involuntary. In its NPRM, the EEOC noted that this is an area in which it has not yet spoken and therefore invited comment.¹⁶³ It received a number of comments on this issue, with employer representatives and benefits groups asserting that the EEOC should incorporate the Health

157. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9062, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(2)(i)(B)-(C)).

158. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9062, 9069 (to be codified at 29 C.F.R. pt. 1635.8(b)(2)(iii)).

159. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9062, 9068 (to be codified at 29 C.F.R. pt. 1635.8(b)(2)(i)).

160. See Petrecca, *supra* note 153.

161. See e.g., U.S. Equal Employment Opportunity Comm’n, EEOC Informal Discussion Letter: ADA: Disability-Related Inquiries and Medical Examinations; Health Risk Assessment (March 6, 2009), http://www.eeoc.gov/eeoc/foia/letters/2009/ada_disability_medexam_healthrisk.html.

162. EEOC ADA ENFORCEMENT GUIDANCE, *supra* note 77, at 14; see also U.S. Equal Employment Opportunity Comm’n, *supra* note 161 (an informal opinion letter concluding that the requirement that employee participate in health risk assessment as a condition to qualify for participation in the employer health plan was not “voluntary” under the ADA.) “Thus, even if the health risk assessment could be considered part of a wellness program, the program would not be voluntary, because individuals who do not participate in the assessment are denied a benefit (i.e., penalized for non-participation) as compared to employees who participate in the assessment.” *Id.*

163. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9062 (proposed Mar. 2, 2009); see also EEOC, Questions for the EEOC Staff for the 2006 Joint Committee of Employee Benefits Technical Session (May 4, 2006) <http://www.abanet.org/jceb/2006/EEOC2006final.pdf> (providing nonbinding responses concerning Wellness Programs “if the [wellness] program requires employees to answer disability-related inquiries or submit to medical examinations, participation in the program must be voluntary”). “[A] wellness program is ‘voluntary’ (thus disability-related questions and medical examinations are permitted) if the employer neither requires participation nor penalizes employees for non-participation in the program.” EEOC, *Id.*

Insurance Portability and Accountability Act (HIPAA)¹⁶⁴ non-discrimination standard.¹⁶⁵ Under this standard, a group health plan does not violate the non-discrimination provisions of HIPAA if it maintains a wellness program under which, among other things, the rewards offered for participation in the program are not greater than twenty percent of the cost of employee-only coverage under the group health plan, or, if dependants can also participate in the wellness program, twenty percent of the cost of coverage in which the employee and dependants are enrolled.¹⁶⁶ On the other hand, employee and privacy organizations, as well as the Genetics and Public Policy Center, contend that any financial inducement offered to the employee to participate in the wellness program should not be considered “voluntary.”¹⁶⁷ The resolution of this dispute could have an impact on the structure of wellness programs generally, because the ADA contains a similar requirement that wellness programs be “voluntary.”¹⁶⁸

Finally, in addition to GINA provisions relating to the acquisition of genetic information, the statute provides that a covered entity cannot discriminate based upon genetic information that it has acquired.¹⁶⁹ GINA

164. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified at 42 U.S.C. § 1320d (2000)).

165. See *Genetic Discrimination: EEOC Receives Varying Advice on Tweaking Its Proposed Rules Under Genetic Bias Law*, *supra* note 116.

166. 29 C.F.R. § 2590.702(f)(2) (2008).

167. *Genetic Discrimination: EEOC Receives Varying Advice on Tweaking Its Proposed Rules Under Genetic Bias Law*, *supra* note 116.

168. On October 7, 2009, the Labor Department, Centers for Medicare and Medicaid, and Internal Revenue Service published interim final rules to Title I of GINA, which covers health plans. Sean Forbes, *Health Care: IRS, Labor, CMS Issue Interim Rules Implementing GINA, Request Comments*, [2009] Daily Lab. Rep. (BNA) No. 189, at A-18 (Oct. 2, 2009). The interim final rules will, if adopted, prohibit covered entities from obtaining genetic information in any wellness program that uses rewards in health benefit premiums:

GINA prohibits collecting genetic information for underwriting purposes. As described earlier, underwriting purposes is defined broadly to include rules for eligibility for benefits and the computation of premium or contributions amounts, and not merely activities relating to rating and pricing a group policy. Moreover, GINA defines genetic information as including family medical history. Consequently, wellness programs that provide rewards for completing [Health Risk Assessments] that request genetic information, including family medical history, violate the prohibition against requesting genetic information for underwriting purposes. This is the result even if rewards are not based on the outcome of the assessment, which otherwise would not violate the 2006 final HIPAA nondiscrimination rules regarding wellness programs.

Interim Final Rules Prohibiting Discrimination Based on Genetic Information in Health Insurance Coverage and Group Health Plans, 74 Fed. Reg. 51,664, 51,668 (proposed Oct. 7, 2009) (to be codified at 45 C.F.R. pts. 144, 146, and 148).

169. GINA, Pub. L. No. 110-233, §§ 202-05, 122 Stat. 881, 907, 908, 910, 911 (2008) (to be codified at 42 U.S.C. §§ 2000ff-1(a), 2000ff-2(a), 2000ff-3(a), 2000ff-4(a)).

provides no defenses for an entity that discriminates against an employee based upon genetic information, regardless of how the information was obtained. There is, for example, no “bona fide occupational qualification” or BFOQ defense. In a statement issued concurrently with its NPRM, the EEOC wrote:

Q: Are there any exceptions to the prohibition on the use of genetic information?

A: No. This prohibition is absolute. Covered entities may not use genetic information in making employment decisions under any circumstances.¹⁷⁰

GINA does not extend to manifested conditions.¹⁷¹ Under the NPRM, someone has a “manifested” condition when “that . . . individual has or could reasonably be diagnosed with the disease, disorder, or pathological condition by a health care professional with appropriate training and expertise in the field of medicine involved.”¹⁷² A disease is not manifested “if the diagnosis is based principally on genetic information or on the results of one or more genetic tests.”¹⁷³ So, a person who has no manifestation of the condition is protected against discrimination by GINA. One whose condition is fully developed may be covered by the ADA as amended. The problem is whether people might fall through a gap between unmanifested and fully manifested conditions.

IV. PROBLEMS REMAINING AFTER GINA

GINA does not resolve all concerns over genetic testing or discrimination. The potential gap is a problem that is raised by many commentators.¹⁷⁴ Are there people who would be covered by GINA when the condition was nascent, and who would be covered by the ADA when it is

170. U.S. Equal Employment Opportunity Comm’n, Background Information for EEOC Notice of Proposed Rulemaking on Title II of the Genetic Information Nondiscrimination Act of 2008, http://www.eeoc.gov/policy/docs/qanda_geneticinfo.html (last visited Feb. 11, 2010).

171. GINA §210, 122 Stat. at 920 (to be codified at 42 U.S.C. § 2000ff-9) (“An employer, employment agency, labor organization, or joint labor-management committee shall not be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.”).

172. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9059-60, 9068 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635.3(g)).

173. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. at 9059-60, 9068 (to be codified at 29 C.F.R. pt. 1635.3(g)).

174. See, e.g., Rothstein, *supra* note 93, at 838-39 (noting that “individuals with a genetic predisposition to future illness are probably not covered by the ADA” even after the ADAAA).

full-blown, but who fall through a gap when their condition falls somewhere in the middle?

Whether there is, in fact, a gap will largely depend on how the courts interpret the amendments to the ADA. With the ADAAA, there is a colorable argument if someone is discriminated against because of the presence of a genetic condition, even if that condition is presenting only slightly, that the employer regarded the individual as having an impairment, thereby invoking ADA's coverage.¹⁷⁵

However, the coverage of GINA is not all-encompassing, and may not have the benefit of encouraging people to engage in genetic counseling and testing as is hoped. Life and disability insurance are not covered, for example.¹⁷⁶ Discrimination in such areas occurs.¹⁷⁷ A study from Australia in early 2009 surveyed cases of persons who had undergone genetic testing and who were subsequently denied life insurance.¹⁷⁸ A five year study through the Genetic Discrimination Project found that ten percent of more than 1,000 people who received a genetic test subsequently experienced some sort of discrimination.¹⁷⁹

GINA also does not have the scope of some other antidiscrimination laws, such as the Civil Rights Act of 1964 and the ADA, which reach public accommodations and programs. Nothing in GINA, for example, would stop a private intramural athletic program from adopting a screening process aimed at identifying young athletes carrying genes that potentially

175. See *supra* text accompanying notes 102-12.

176. Rothstein, *supra* note 16, at 9 ("GINA does nothing to prohibit discrimination in life insurance, disability insurance, long-term care insurance, mortgages, commercial transactions, or any of the other possible uses of genetic information.").

177. See, e.g., Myk Cherskov, *Fighting Genetic Discrimination*, A.B.A. J., June 1992, at 38, 38 (noting how an individual was denied disability insurance because her father suffered from Huntington's disease); Kristine Barlow-Stewart et al., *Verification of Consumers' Experiences and Perceptions of Genetic Discrimination and Its Impact on Utilization of Genetic Testing*, 11 GENETICS MED. 193, 200 (2009) (analyzing genetic discrimination in life insurance coverage).

178. Barlow-Stewart, *supra* note 177, at 195, 200.

179. ABC News, *Research Finds Evidence of Genetic Discrimination*, ABC NEWS, Mar. 10, 2009, <http://www.abc.net.au/news/stories/2009/03/10/2511689.htm?section=justi>; see also Genetic Discrimination Project, Reports & Papers (listing papers and reports of the Genetic Discrimination Project), <http://www.gdproject.org/reports/index.php> (last visited Feb. 11, 2010). Australia has been on the forefront of examining whether genetic testing leads to differential treatment in insurance and employment. Kristine Barlow-Stewart, *Genetic Discrimination: Australian Experiences and Policies*, GENEWATCH, Apr.-May 2009, at 15, 15-17. On the employment front, it found little evidence that genetic information was systemically being used to discriminate. An important distinction between employment in Australia and the United States, however, is that health insurance is not tied to employment in Australia. Instead, Australia has a national health plan and private insurance is not risk-rated. *Id.*

put them at higher risk for sudden heart attacks,¹⁸⁰ or alternatively, to identify those candidates whose genetic profile indicates that they might make better athletes.¹⁸¹ Although other checks may exist, they are not found in GINA.

The military is not included, even though it has been accused of genetic discrimination.¹⁸² Elected officials are also not covered. There is nothing that stops an intrepid reporter from picking up some discarded gum and sending it off to a facility like 23andme¹⁸³ to obtain information about a presidential candidate's genetics.¹⁸⁴

180. Cf. Kathleen Fackelmann, *Flaws of the Heart: Sudden Death in Athletes Is Often Caused by Cardiac Defects*, 150 SCI. NEWS, 76, 77 (1996) (discussing the need for screening of athletes for heart conditions), available at <http://www.sciencenews.org/pages/pdfs/data/1996/150-05/15005-16.pdf>; Heart Hospital of N.M. Found., Heart of a Champion Teen Athlete Screening Program (offering free ECG to test for hypertrophic cardiomyopathy for student athletes), http://www.hhnmfoundation.org/programs_heart.php. In 2005, the Chicago Bulls demanded center Eddy Curry, who was a restricted free agent, take a genetic test for susceptibility to hypertrophic cardiomyopathy (HCM) as a condition for extending his contract. Associated Press, *Bulls Ship Curry to Knicks*, N.Y. TIMES.COM, Oct. 3, 2005, http://www.nytimes.com/2005/10/03/sports/basketball/04curry-wire.html?_r=1. Curry refused, and ultimately, after a lengthy standoff, the Bulls traded Curry to the Knicks. *Id.*

181. Juliet Macur, *Born to Run? Little Ones Get Test for Sports Gene*, N.Y. TIMES, Nov. 30, 2008 at A1 (discussing genetic tests that aim to predict children's athletic strengths). See generally Sports Law Blog, Update on MLB's Use of Genetic Testing (July 24, 2009) (discussing DNA testing in sports), <http://sports-law.blogspot.com/2009/07/update-on-mlbs-use-of-genetic-testing.html>. An interesting issue has recently arisen with regard to Major League Baseball conducting genetic tests of potential Latin American players to determine paternity/maternity of the player. See Michael S. Schmidt & Alan Schwarz, *Baseball's Use of DNA Tests on Prospects Finds Controversy, Too*, N.Y. TIMES, July 22, 2009, at A1. The results are part of an effort to verify the players' age and identity, and prevent older players from passing themselves off as younger. *Id.* The possibility of the genetic information being used to screen persons out because of perceived risk of future disease is evident. As the scouting director for one team stated, "It's a tough area to figure morally and in all kinds of directions," he said. "Can they test susceptibility to cancer? I don't know if they're doing any of that. But I know they're looking into trying to figure out susceptibility to injuries, things like that. If they come up with a test that shows someone's connective tissue is at a high risk of not holding up, can that be used? I don't know. I do think that's where this is headed." *Id.* See also Dan Vorhaus, *MLB Meets GINA*, GENOMICS L. REP. (July 22, 2009) (further discussing genetic testing in Major League Baseball), <http://www.genomicslawreport.com/index.php/2009/07/22/mlb-meets-gina/>.

182. See Karen Kaplan, *U.S. Military Practices Genetic Discrimination in Denying Benefits*, L.A. TIMES, Aug. 18, 2007, at A1 (discussing how the U.S. military has denied disability benefits for servicemen and woman who have congenital or hereditary conditions).

183. 23andMe, Inc., Home Page (an online service that provides direct-to-consumer genetic testing), <https://www.23andme.com/> (last visited Feb. 11, 2010).

184. See Teneille R. Brown, *Double Helix, Double Standards: Private Matters and Public People*, 11 J. HEALTH CARE L. & POL'Y 295, 299 (2008).

State entities are currently covered by the employment provisions of GINA,¹⁸⁵ and Congress did include findings regarding state conduct, such as sterilization for presumed “genetic” defects.¹⁸⁶ It seems likely, though, that eventually there will be an Eleventh Amendment challenge to private causes of action against state entities for monetary relief. Prior challenges under the Age Discrimination in Employment Act and the ADA were successful, although the EEOC, as the federal enforcement agency, retains its authority to bring suit even if the private cause of action was limited.¹⁸⁷

So GINA should not stop the discussion. We have to consider, as members of a society, what we are going to permit. And even if we are going to permit it, what safeguards do we need? Right now, the safeguards on genetic testing, which are becoming increasingly available through online commercial sources, are not heavily regulated, and some would say such tests are not effectively regulated at all.¹⁸⁸

CONCLUSION

The hope for GINA is that it cuts down, if not outright eliminates, genetic discrimination in employment, before it takes root. This will be different from any other federal anti-discrimination statute. Race discrimination, religious discrimination, sex discrimination, age discrimination, national origin discrimination, disability discrimination—all were well established before the laws prohibiting them were passed.

It is not the same with genetic discrimination. GINA is getting in on the ground floor. There remain numerous areas in which discrimination based on genetics can occur, however, and as a society, we need to continue to balance the needs of discovery against the needs for protection of individual privacy and protection against unwarranted discrimination. The public debate about the role of genetics in our lives will continue.

185. GINA, Pub. L. No. 110-233, § 201, 122 Stat. 881, 906 (2008) (to be codified at 42 U.S.C. § 2000ff(2)(B)(ii)).

186. GINA § 2, 122 Stat. at 882 (to be codified at 42 U.S.C. § 2000ff note).

187. *Bd. of Trs. of Univ. of Ala. v. Garrett*, 531 U.S. 356, 363 (2001); *Kimel v. Fla. Bd. of Regents*, 528 U.S. 62, 91-92 (2000).

188. Bruce Patsner, *New “Home Brew” Predictive Genetic Tests Present Significant Regulatory Problems*, 9 *HOUS. J. HEALTH L. & POL’Y* 237, 240-41 (2009) (discussing the lack of and need for oversight of predictive genetic testing kits and on-line commercial genome testing companies).

