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INVISIBLE ACTORS: GENETIC TESTING AND GENETIC DISCRIMINATION IN THE WORKPLACE

*Susannah Carr**

I. INTRODUCTION

In the fall of 2005, Wal-Mart executives, attempting simultaneously to respond to criticism about stingy health coverage for employees and to contain costs, recommended that the company recruit a “healthier, more productive work force.”¹ As people’s deoxyribonucleic acid (DNA) becomes more closely linked with health and the ability to predict health, Wal-Mart’s broad recommendation could be the harbinger of a clash between employers and employees because these groups have diverging interests when it comes to managing health information, particularly genetic information. Genetic information is knowledge of a person’s genome that indicates a predisposition towards an illness, disease, or medical condition, where symptoms of the condition have yet to manifest themselves.² As genetic testing enters the mainstream, employees increasingly fear genetic discrimination—the use of employees’ genetic information to influence employment decisions.

Current federal and state law is inadequate to protect employees from employers’ misuse of their genetic information. Federal law protections are insufficient, and relevant state laws vary in their scope and application. Not only are employees unevenly protected across the United States, but varying standards also make complying with the law difficult for interstate employers. To give employees sufficient protection and to facilitate employer compliance, Congress should pass a law specifically addressing genetic discrimination in the workplace. The law should have broad applicability, prohibit employers from using workers’ genetic information in employment decisions, have limited exceptions for employers’ requests for genetic information, enhance employee privacy protections, and create a private right of action. Congress is taking steps in the right direction. This year both the House and the Senate reintroduced identical Genetic Information Nondi-

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1. Reed Abelson, *Everyday High Health Cost; One Giant’s Struggle Is Corporate America’s, Too*, N.Y. TIMES, Oct. 29, 2005, at C1.

2. The breadth of information offered by genetic analysis could change and expand as scientific study progresses.

scrimination Acts (hereinafter, the "Bill").³ This law provides employees with more protection than many similar state laws, while sufficiently protecting employers from being penalized for collecting genetic information in well-defined circumstances. To be complete, however, the Bill should extend its coverage to both licensing organizations and employers acting as self-insurers.

II. EMPLOYEES NEED UNIFORM PROTECTIONS AGAINST GENETIC DISCRIMINATION

To many managers, owners, and executives, obtaining genetic information about their employees appears to be sensible business policy. Because of their financial role in providing healthcare, employers have "a strong economic incentive to screen out perceived future high cost" healthcare users.⁴ They want to maximize employees' fitness and productivity while minimizing employee absenteeism and turnover.⁵ Hazardous workplaces, in which employers have obligations to monitor the health of their workers and may want to protect the health of those with a genetic predisposition for disease by excluding them from the hazardous environment, heighten these concerns.⁶ Finally, some employers have a seemingly insatiable desire for tests, submitting their employees to personality tests and handwriting analyses in an effort to predict employee performance.⁷

Employers have already started using genetic information in the workplace. In 2004, the American Management Association found that companies were genetically testing employees for risk of breast and colon cancer, Huntington's disease, and susceptibility to workplace hazards.⁸ One in six of the companies surveyed collected family medical histories of their employees.⁹ At least one-half of the companies testing for breast and colon cancer risk and Huntington's disease considered the results in their hiring,

3. Genetic Information Nondiscrimination Act, S. 358, 110th Cong. (2007); Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. (2007).

4. Mark A. Rothstein, *Genetics and the Work Force of the Next Hundred Years*, 2000 COLUM. BUS. L. REV. 371, 390 (2000).

5. Mark A. Rothstein, Betsy D. Gelb, & Steven G. Craig, *Protecting Genetic Privacy by Permitting Employer Access Only to Job-Related Employee Medical Information: Analysis of a Unique Minnesota Law*, 24 AM. J. L. & MED. 399, 401 (1998).

6. Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J. L. & MED. 109, 111 (1991).

7. Rothstein, *supra* note 4, at 382-83.

8. AMERICAN MANAGEMENT ASSOCIATION, AMA 2004 WORKPLACE TESTING SURVEY: MEDICAL TESTING 2 (2004), http://www.amanet.org/research/pdfs/Medical_testing_04.pdf.

9. *Id.* Out of 503 responses, 3% of employers test for breast or colon cancer, 0.8% test for Huntington's disease, 14.7% collect family medical history, and 15.1% test for susceptibility to workplace hazards. *Id.*

re-assigning, and firing decisions.¹⁰ 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.¹¹ As the quantity of available tests increases and their costs decline, employers will become even more likely to use them.

But as genetic testing for asymptomatic health conditions and predispositions has become more common, broad consensus is emerging that employees need safeguards against employers accessing and using workers' genetic information.¹² In 1997, eighty-five percent of respondents in a national survey "felt that employers should be prohibited from obtaining information about an individual's genetic conditions and predispositions."¹³ In 2000, President Clinton signed an executive order to "prohibit discrimination in federal employment based on genetic information."¹⁴ As of August 2004, thirty-two states had passed statutes that limited employers' ability to require or request genetic information from their employees and prohibited employers from using such information in making employment decisions.¹⁵ The United States Senate passed the Genetic Information Nondiscrimination Act in 2003 and 2005, and for the second time an identical bill has been introduced in the United States House of Representatives.¹⁶

The reasons for limiting employers' access to and use of genetic information are numerous. At the most basic level, employees want their privacy protected. In addition, genetic tests contain inherent uncertainty. In some cases, such as Huntington's disease, the time and rate at which the disease

10. *Id.* at 2.

11. *Id.*

12. See Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 13 (1994). Epstein argues that employees should be obliged to disclose at least some genetic predispositions in order to distribute complete information across markets. *Id.*

13. See Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J.L. Med. & Ethics 189, 189 (Fall 1998) (citing S. Armour, *Workers Fear Genetic Discrimination*, USA TODAY, Feb. 25, 1998 at 4B). The survey, conducted by the National Center for Genome Resources, polled 1000 people.

14. Exec. Order No. 13145, 3 C.F.R. 13145 (2000).

15. ROBERT B. LANMAN, OFFICE OF BIOTECHNOLOGY ACTIVITIES, NATIONAL INSTITUTES OF HEALTH, AN ANALYSIS OF THE ADEQUACY OF CURRENT LAW PROTECTING AGAINST GENETIC DISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT; A REPORT COMMISSIONED BY THE SECRETARY'S ADVISORY COMMITTEE ON GENETICS, HEALTH, AND SOCIETY ii (2005).

16. The Library of Congress, Thomas, <http://thomas.loc.gov>. The Senate passed S.1053 on October 14, 2003 with a 95 – 0 vote, and S. 306 on February 17, 2005 by a 98 – 0 vote. The two bills are identical. H.R. 1227, a bill exactly the same as S. 306, was introduced in the House and referred to the House Subcommittee on Employer-Employee Relations on April 18, 2005.

will manifest itself are uncertain, though its eventual appearance is definite.¹⁷ In other instances, such as breast cancer, the information simply represents an increased risk of developing a condition;¹⁸ whether the condition appears at all may depend on multiple factors, such as family history,¹⁹ the age at which the woman had her first full term pregnancy,²⁰ lifestyle,²¹ and other still unknown factors.²² Genetic tests can never predict what contributions, advancements, and innovations an employee will make to a company before any type of condition manifests itself. Workers fear being consigned to a limited, unproductive professional life, when in fact they could have many good years ahead of them. As genetics becomes more closely linked with behavioral traits, employers may confuse “heritability”—the ability of a trait to be passed from one person to his or her offspring—with “immutability”—the ability of the trait to be altered through the environment, personal effort, or other factors—and make unjustified judgments regarding employees. Fear of discrimination may keep employees from being tested even though early detection and treatment could improve and extend their lives.²³ Allowing employers to make decisions based on characteristics they assume to be an individual’s genetic “destiny” would be an undesirable outcome of the United States’ investment in genetic research and could diminish the benefits that the research offers.²⁴ Scientists also foresee difficulty in collecting research data as people become unwilling to submit to genetic tests.²⁵

III. CURRENT FEDERAL AND STATE PROTECTIONS FOR EMPLOYEES ARE INADEQUATE

No federal law squarely protecting employees from genetic discrimination exists. Initially, legal scholars and the Equal Employment Opportunity

17. Sky Dawson et al., *Living with Huntington’s Disease: Need for Supportive Care*, NURSING & HEALTH SCI., June 2004, at 123–30.

18. Thomas C. Rosenthal & Stirling M. Puck, *Screening for Genetic Risk of Breast Cancer*, AM. FAM. PHYSICIAN, Jan. 1, 1999, at 100.

19. Mary-Claire King et al., *Breast and Ovarian Cancer Risks Due to Inherited Mutations in BRCA1 and BRCA2*, SCI., Oct. 24, 2003, at 645.

20. A. Antoniou et al., *Parity and Breast Cancer Risk among BRCA 1 and BRCA 2 Mutation*, Breast Cancer Research 2006:8(6) at 72.

21. King, *supra* note 19, at 644.

22. A. Antoniou et al., *Average Risk of Breast Cancer Associated with BRCA 1 or BRCA 2 Mutations Detected in Case Series Unselected for Family History: A Combined Analysis of Studies*, AMER. J. HUM. GENETICS, May 2003 72(5), at 1117–30.

23. Miller, *supra* note 13, at 190.

24. S. Rep. No. 108-122, at 6 (2003). This report was created with the Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. (2003). Nevertheless, it applies to S. 306 because the bills are identical.

25. Miller, *supra* note 13, at 190.

Commission (EEOC) contended that courts should interpret the Americans with Disabilities Act (ADA) to prohibit genetic discrimination.²⁶ Employers who made decisions based on asymptomatic genetic conditions arguably “regarded” their employees as disabled.²⁷ The United States Supreme Court’s holding in *Bragdon v. Abbott*,²⁸ that a woman with asymptomatic human immunodeficiency virus (HIV) was disabled under the ADA because the virus altered her cellular composition and limited her in the major life activity of reproduction, supported their interpretation.²⁹ The case suggested that ADA coverage extended at least to people whose genetic compositions affected their reproductive decisions.³⁰

The Supreme Court’s subsequent decision in *Sutton v. United Airlines, Inc.*,³¹ however, narrowed the definition of disability and eliminated the possibility that the ADA applies to people with genetic predispositions.³² The *Sutton* court held that a person must be “presently—not potentially or hypothetically—substantially limited” in a major life activity in order to demonstrate a disability.³³ In order to claim that an employer “regarded” them as disabled, employees had show that the employer believed an employee was substantially limited in a major life activity *at the time the discrimination occurred*.³⁴ An employer’s perception that an employee was unsuited for a particular position was insufficient to show that the employer regarded the employee as substantially limited in a major life activity.³⁵

In the case of genetic discrimination, employers are unlikely to regard their employees as currently unable to perform a job or as substantially limited in their ability to do anything. Rather, employers view their employees as a future medical risk. In addition, under *Sutton*, carriers of recessive genes could never receive ADA protection, although they might be victims of genetic discrimination.

26. E.g., Miller, *supra* note 13, at 191; UNITED STATES EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, 2 EEOC COMPLIANCE MANUAL § 902.8(a) (2000).

27. See, e.g., Paul Steven Miller, *Is There a Pink Slip in My Genes?*, 3 J. HEALTH CARE L. & POL’Y 225, 239–40 (2000).

28. 524 U.S. 624 (1998).

29. *Id.* at 637–41.

30. *Id.* at 638.

31. 527 U.S. 471 (1999).

32. *Id.* at 482.

33. *Id.* The ADA defines “disability” as “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.” 42 U.S.C. § 12102 (2)(A)–(C) (1999).

34. *Sutton*, 527 U.S. at 489.

35. *Id.* at 490.

Any protections provided by Title VII of the Civil Rights Act of 1964³⁶ are also incomplete. Title VII only applies if genetic testing is used as a pretext to discriminate intentionally on the basis of race, color, religion, sex, or national origin, or if genetic testing had a disparate impact on one or more of those groups.³⁷ The Statute would only provide limited protection: "Many, if not most, genetically related diseases and disorders do not disproportionately affect one of Title VII's protected classes."³⁸ For example, the Ninth Circuit Court of Appeals found a Title VII violation in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*³⁹ in which a research center singled out African-American employees for sickle cell anemia testing and female employees for pregnancy testing.⁴⁰ Absent such obvious overlap, Title VII is unlikely to protect employees.

The patchwork of state laws is also inadequate. Current state laws addressing genetic discrimination create heightened protection for genetic information compared to other health data in the workplace and prohibit employers from using genetic information in making workplace decisions.⁴¹ States, however, define genetic information differently, address different methods of gathering genetic information, and do not provide employees with equal remedies. Wisconsin, for example, only extends its protections to information obtained from "tests of a person's genes, gene products or chromosomes,"⁴² and limits enforcement to the administrative remedies provided by the Department of Industry, Labor and Human Relations, the state's equivalent of the EEOC.⁴³ Utah similarly limits its definition of genetic information to information derived from tests, but the state expressly grants employees a private right of action and the ability to collect punitive damages if the act is "willful" and "malicious."⁴⁴ In contrast, Oklahoma fails to give employees a private right of action.⁴⁵ Washington includes information derived from family medical histories in its definition of genetic infor-

36. Title VII, 42 U.S.C. § 2000e (2006).

37. Miller, *supra* note 13, at 191.

38. *Id.*

39. 135 F.3d 1260 (9th Cir. 1998).

40. *Id.* at 1265, 1272.

41. LANMAN, *supra* note 15, at 11.

42. WIS. STAT. § 111.32 (7m) (2006).

43. See *Nawrocki v. Milwaukee Fire & Police Comm'n*, 478 N.W.2d 67 (Wis. Ct. App. 1991) (concluding that the Department of Industry, Labor and Human Relations has exclusive power to enforce the Wisconsin Fair Employment Act).

44. UTAH CODE ANN. §§ 26-45-102, 26-45-105 (2006).

45. OKLA. STAT. tit. 36, § 3614.2 (2006) (prohibiting genetic discrimination); see *Walker v. Chouteau Lime Co.*, 849 P.2d 685 (Okla. 1993) (explaining Oklahoma's narrow rule for finding an implied right of action in a statute).

mation and probably has an implied right of action.⁴⁶ As these examples demonstrate, state laws “vary widely with respect to their approach, application, and level of protection.”⁴⁷ Many people, both within the American public and medical community, find state laws inadequate as a result.⁴⁸

Due to incomplete federal coverage and a patchwork of state laws, private sector employees have limited protection from genetic discrimination. Companies operating across state lines face the burden of complying with a variety of laws. A federal law specifically addressing genetic discrimination in the workplace would establish a national uniform standard.⁴⁹ Employees would have comprehensive protections no matter where they lived, and employers would have consistent standards to follow no matter where they operated.

IV. OPTIMAL CHARACTERISTICS OF A FEDERAL LAW

Once the need for a federal law has been established, the next question is what protections the law should provide. In order to accomplish its goal of preventing genetic information from being used in employment decisions, the law should (1) recognize that scientific knowledge of the human genome is rapidly changing, (2) apply broadly to the employment sector, (3) give genetic information heightened privacy protections, and (4) consider its interaction with other federal and state laws. Current state laws prohibiting genetic discrimination, federal employment laws such as the ADA and Title VII, and the unique nature of genetic information suggests a number of characteristics that are necessary for a federal law to succeed.

A. The Law Cannot Be Disease Specific

Early state laws forbidding employers from genetic testing and discrimination applied to specific diseases. New Jersey, for example, until it changed its law in 1996, prohibited discrimination against people with sickle cell, hemoglobin C, thalassemia, Tay-Sachs, or cystic fibrosis traits.⁵⁰ As all the states with genetic discrimination statutes have recognized, knowledge about genetic links to disease is changing rapidly, and current laws cannot be limited to genetic markers for specific diseases. Otherwise, the law would need amending frequently and be too narrow in its scope.

46. WASH. REV. CODE § 49.44.180 (2006); *see Bennett v. Hardy*, 784 P.2d 1258, 1261–62 (Wash. 1990) (explaining test for finding implied right of action in state statutes).

47. Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Cong. § 2(5) (2005).

48. *Id.*

49. LANMAN, *supra* note 15, at ii.

50. Rothstein, *supra* note 5, at 402 (citing N.J. STAT. ANN. § 10:5–5(y)-(cc) (1995)).

B. The Law Must Cover Current Employees and Applicants, Including People that Have Received a Job Offer but Have Not Yet Started Working

The purpose of any legislation must be to prohibit employers from using genetic information to make employment decisions. To effectuate that purpose, legislation must extend not only to employees, but also to job applicants and employees who have received an offer but have not started working. If the law does not provide this coverage, employees who have already been victims of genetic discrimination and lost their job will have an increased danger of receiving discriminatory treatment again. In addition, not extending protection to job applicants could speed up the creation of a "genetic underclass" by preventing people with genetic predispositions from entering the workforce. Other anti-discrimination statutes, such as Title VII, recognize that protecting current employees is insufficient and apply to job applicants as well.⁵¹ State legislation prohibiting genetic discrimination also extends to job applicants or people who have received job offers but have not started working.⁵² Any federal law must be as comprehensive as possible and cover applicants in all stages of the hiring process, as well as current employees.

C. The Law Should Apply to Labor Organizations, Employment Agencies, and Licensing Agencies

Utah and Virginia are two states that prohibit genetic discrimination by employers but do not make the same requirements of labor organizations and licensing agencies.⁵³ As with excluding job applicants, this gap undermines the purpose of those states' statutes. For many professions, membership in a labor organization, placement through an agency, or a professional license is essential to obtaining employment. In these cases, the organization or agency is acting as the *de facto* hiring person by standing in the employer's shoes. With this loophole, employers could manufacture a "recommendation process" and essentially outsource hiring, allowing these organizations to screen out the genetically undesirable before they ever reach the employer's doorstep. Even if employers are not premeditating a screening-out process, labor organizations and employment agencies have an economic interest in offering employers physically fit workers. Taken to the extreme, these entities could offer "Genetically tested and fit employees, guar-

51. Title VII, 42 U.S.C. § 2000e (2006).

52. *E.g.*, TEX. LABOR CODE ANN. § 21.402 (Vernon 2006).

53. UTAH CODE ANN. §§ 26-45-103, 34A-2-103 (2006); VA. CODE ANN. §§ 40.1-28.7:1, 40.1-2 (2006).

anteed!" Licensing organizations, such as state bar associations, present a similar risk. A federal law must broadly define the term "employer" in order to create adequate protections for workers.

D. The Law Should Apply to Employers Acting as Self-insurers

Employers who do not purchase health insurance from a provider, but instead self-insure, present another potential loophole. A self-insured employer could circumvent anti-discrimination principles by claiming that they were underwriting risks, rather than making employment decisions, if they took adverse action against employees based on genetic information.⁵⁴ Although most states have laws providing some protection against genetic discrimination by health insurers, these laws do not always extend to self-insured employers. The Employee Retirement Income Security Act of 1974 (ERISA) preempts state laws that "relate to any employee benefit plans," except state laws regulating insurance.⁵⁵ State insurance laws do not always cover employers who self-insure.⁵⁶ They must comply with the Health Insurance Portability and Accountability Act (HIPAA), which prohibits insurance plans from using genetic information to determine insurance eligibility, rates, continuing coverage, and pre-existing health conditions, but HIPAA does not provide any heightened privacy protections for genetic information.⁵⁷

Because state laws prohibiting genetic discrimination in insurance are even more of a patchwork than the current state laws prohibiting genetic discrimination in employment, and because protections provided by HIPAA and ERISA are insufficient, employment anti-discrimination legislation should apply to employers in their underwriting capacities. For these employers, hiring and firing decisions are closely linked with insurance coverage.

E. The Definition of "Genetic Information" Should Include Information Obtained from Family Medical Histories

Only a limited number of states include data obtained from family medical histories in their definition of "genetic information."⁵⁸ Again, the

54. Gostin, *supra* note 6, at 134.

55. 29 U.S.C. § 1144(a), (b)(A)(2) (2006); *see* Gostin, *supra* note 6, at n.146, n.159.

56. Gostin, *supra* note 6, at n.159.

57. Karen Rothenburg, et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 SCI. 1755, 1756 (1997).

58. *See, e.g.*, WASH. REV. CODE § 49.44.180 (2006) (providing that genetic information includes information stemming from family history); UTAH CODE ANN. § 26-45-102 (7)(a)(ii)

purpose of any genetic discrimination statute is to prevent employers from making decisions based on the genetic predispositions of employees. The source of the information is irrelevant to the nature of the information and the ways in which employers use it. A family medical history can be just as revealing as a DNA test. An employer does not need a laboratory test to realize that a person with a parent who suffers from Huntington's disease or with siblings who have sickle cell anemia is at risk for those diseases. By excluding knowledge obtained from family medical histories in its definition of "genetic information," a statute would significantly weaken its ability to protect employees.

F. The Law Should Prohibit Employers From Requesting and Collecting Genetic Information, Except in Limited Circumstances

The best way to prevent adverse employment actions stemming from genetic information is to prevent employers from obtaining genetic information about their employees. Also, prohibiting employers from requesting genetic information will allay employees' fears that employers are using such information against them. Such a blanket prohibition in a federal law, however, would reach too broadly.

To avoid unduly burdening employers, the rule should have a few well-circumscribed exceptions. For example, employers should be able to offer genetic services as part of a bona fide wellness program, and they may need to request genetic information in order to comply with other laws, such as the Family and Medical Leave Act.⁵⁹ Nor should employers be penalized for the inadvertent collection of genetic information through casual conversation.

The most important exception should be for genetic monitoring. Employees' and employers' interests in genetic information shift in hazardous workplaces. Genetic monitoring occurs when employers periodically examine employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace.⁶⁰ Genetic monitoring seeks to control or to identify, evaluate, and respond to the effects of adverse environmental exposures in the workplace.⁶¹ Employees have an increased interest in obtaining information about their genetic composition in hazardous workplaces in order to monitor their health closely and make an informed

(2006) (providing that genetic information does include information derived from family medical history).

59. 29 U.S.C. § 2613 (2006).

60. H.R. 1227, 109th Cong. § 201 (2005).

61. *Id.*

decision about remaining at their job. For example, genetic information can provide information to workers regarding chromosomal damage caused by exposure to asbestos, chromium, nickel, and vinyl chloride. Workers who have the genes for alpha-1-antitrypsin deficiency have an increased risk of developing emphysema if they work in dust-producing jobs.⁶² Employers in hazardous workplaces have more stringent regulations governing occupational safety than those running non-hazardous workplaces, and they have a right to require employees to undertake medical examinations to fulfill their duty to maintain a safe workplace.⁶³ The information obtained from genetic monitoring is also important for furthering occupational disease research.

In a survey of eleven states, only one had a clear exception for requesting or requiring genetic information in the case of genetic monitoring; two states had an implied exception; and eight states prohibited all requests for genetic tests.⁶⁴ Because the use of genetic monitoring in hazardous workplaces can give employees important health information, assist research in occupational diseases, and potentially help employers meet their safety obligations, a genetic discrimination law should provide an exception for employers who are using the information to monitor the biological effects of toxic substances in the workplace. The exception should contain protections for workers, including a requirement that employees provide voluntary, written, and informed consent or that the testing be required by state or federal law. Monitoring must also comply with federal and state regulations.

G. The Law Should Provide Heightened Privacy Protections for Genetic Information, Especially in the Case of Genetic Monitoring

Like an HIV diagnosis, genetic information is very sensitive: it reveals that an asymptomatic worker will later suffer from a serious illness or has a greater likelihood than others of developing certain diseases; the information usually affects the person throughout her life, unlike a transient illness; and once such information is disclosed, it can stigmatize the individual and lead to adverse decisions throughout a lifetime in many different contexts.⁶⁵ For

62. Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 76 (1991).

63. *Id.* (citing OFFICE OF TECH. ASSESSMENT, UNITED STATES CONG., GENETIC MONITORING AND SCREENING IN THE WORKPLACE 130 (1990)).

64. Wisconsin has an express genetic monitoring exception. WIS. STAT. § 111.372 (2006). Texas and Utah have an implied genetic monitoring exception. TEX. LAB. § 21.401 (2006); UTAH CODE ANN. § 26-45-102 (2006). The states prohibiting all requests for genetic information are Nevada, Oklahoma, Oregon, Rhode Island, South Dakota, Vermont, and Washington. NEV. REV. STAT. 613.345 (2006); OKLA. STAT. tit. 36, § 14.2 (2006); OR. REV. STAT. § 659A.303 (2006); R.I. GEN. LAWS § 28-6.7-1 (2006); S.D. CODIFIED LAWS § 60-2-20 (2006); VT. STAT. ANN. tit. 18, § 9332 (2006); WASH. REV. CODE § 49.44.180 (2006).

65. Andrews & Jaeger, *supra* note 62, at 77.

these reasons, genetic information in medical records should receive heightened protection.

To help avoid both deliberate and inadvertent disclosure, genetic information should be maintained separately and disclosed only with independent authorization. Employers often ask for blanket access to medical records. These requests should not include access to genetic information. Instead, the law should require a separate request for genetic information. Employers subpoenaing medical records should also have to include a special request for genetic information before it will be released.

If employees do consent to the release of genetic information, their consent should be construed narrowly. Some states have already passed legislation following this precept. Texas, for example, prohibits disclosure of genetic information, by subpoena or otherwise, except in a few circumstances such as to establish paternity and identify remains, unless the individual specifically authorizes the disclosure.⁶⁶ The individual maintains his or her privacy interest even after disclosure to one party because the statute expressly prohibits "a redisclosure of genetic information by a secondary recipient of the information after disclosure of the information by an initial recipient."⁶⁷

Additional safeguards are necessary in workplaces conducting genetic monitoring. In these circumstances, the physicians conducting the testing should release the results to individual employees upon their request, and employers should receive only aggregate, anonymous results. Traditionally, occupational physicians hired by employers or employers' workers' compensation insurers were not in a physician-patient relationship with employees. Their clients were the employers, not the workers.⁶⁸ Consequently, the physicians' duty to disclose to the worker was lessened, and their ability to disclose information to the employer was heightened. Recently, that rigid rule has been relaxed, especially when the physician is providing care and treatment beyond testing.⁶⁹ The rule should be expressly overturned in the situation of genetic monitoring. This change would comport with the Occupational Safety and Health Act (OSHA), which gives employees in hazardous workplaces the right to see the medical records that their employer maintains.⁷⁰ Also, because genetic test results are difficult for lay people to interpret, results should include a referral to a genetic counselor. OSHA already contains a similar provision in its benzene standard, which requires

66. TEX. LAB. CODE ANN. § 21.403(b) (Vernon 2006).

67. TEX. LAB. CODE ANN. §§ 21.403, 21.4031 (Vernon 2006).

68. Andrews & Jaeger, *supra* note 62, at 88.

69. *Id.* at 89.

70. *Id.* at 91 (citing 29 C.F.R. § 1910.20 (1990)).

referral to a hematologist for further evaluation if the employee's test contains certain results.⁷¹

Employers engaging in genetic monitoring also need to take precautions to protect employee confidentiality. For example, employees should be able to request the means of delivery, whether by mail, in person, or in a confidential memorandum, and all employees should undergo tests with the same frequency. These practices are particularly important in small businesses, where other employees can easily spot an employee singled out for additional testing or receiving additional information.⁷²

Finally, an employee's consent to release results should be narrowly construed in genetic monitoring situations. The default rule should be that employers receive only aggregate, anonymous information rather than individually identified test results. An employee's consent to take the test should not imply consent to release the results to the employer. In addition, the law should establish a wall between scientific researchers, who may need individually identified results, and employers.

Of eleven states surveyed, none provide protection for genetic information beyond that given to ordinary medical records.⁷³ Supplying additional safeguards will reduce the risk that employers will misuse genetic information while still allowing its collection for important purposes, such as genetic monitoring and Family and Medical Leave Act compliance. Requiring specific consent from employees before releasing genetic information will make employees more aware that their genetic information is available and help them protect the confidentiality of their medical records.

H. The Law Should Have a Dual Enforcement Mechanism, Including a Private Right of Action that Applies to the Illegal Collection of Genetic Information, Not Just Adverse Employment Actions

One of the greatest challenges facing genetic discrimination laws is enforcement. For employees, proving an employer acted against them on the basis of genetic information will be exceedingly difficult. Although numerous states allow for a private right of action in instances of genetic discrimination, no employee has brought an action alleging genetic discrimination under state law. One case filed by the EEOC against Burlington Northern Santa Fe Railroad settled before reaching trial.⁷⁴ According to former EEOC Commissioner Paul Miller, disclosure of the alleged unauthorized genetic

71. *Id.* at 92 (citing 29 C.F.R. § 1910.1028 & Appendix C (1990)).

72. *Id.* at 92.

73. The states studied are Nevada, Oklahoma, Oregon, Rhode Island, South Dakota, Texas, Utah, Vermont, Virginia, Washington, and Wisconsin.

74. *Equal Employment Opportunity Comm'n v. Burlington N. & Santa Fe Ry. Co.*, No. 02-C-0456, 2002 WL 32155386 (E.D. Wis. 2002).

testing was happenstance.⁷⁵ The absence of complaints suggests either that genetic discrimination is not occurring or that evidence of it is too sparse to enable employees to gather sufficient knowledge and evidence of its occurrence. Employers' willingness to test employees for sickle cell anemia beginning in the 1970s⁷⁶ and the rapidly growing availability of genetic tests suggest that the latter possibility—that evidence of genetic discrimination is too sparse—is more likely. The difficulty in establishing the link between the knowledge and the action creates two issues. First, employers do not want their possession of genetic information to create a presumption of discrimination in the case of an employee experiencing an adverse employment action. Second, employees are afraid that they will be left fruitlessly trying to string together circumstantial evidence and will never be able to overcome their burden of proof.

The law should have a dual enforcement mechanism. Employers should be subject to civil penalties for unauthorized collection, disclosure, and use of genetic information. The EEOC would be well-suited to enforce these penalties because it has comprehensive experience in interpreting and enforcing employment laws.

The most important enforcement step is to create a private right of action. As in other anti-discrimination statutes such as Title IX and Title VII, private rights of action empower the people closest to the facts and most familiar with the circumstances to take action.⁷⁷ The private right of action must include the ability to be awarded attorneys' fees to enable potential plaintiffs to hire professional assistance. It must extend to violations of the provisions prohibiting collection of genetic information and requests for genetic tests, not just adverse employment actions. Not only will proof be easier in these situations, the most effective way to prevent adverse employment actions on the basis of genetic information is to deter and prevent employers from obtaining genetic information at the outset.

V. CURRENT PROPOSED FEDERAL LEGISLATION HAS MANY DESIRABLE CHARACTERISTICS BUT NEEDS SOME CHANGES

In 2007, the Senate introduced Senate Bill 358, The Genetic Nondiscrimination Act of 2007.⁷⁸ This bill is identical to the 2005 version, which passed by a vote of ninety-eight to zero. An identical version is pending for

75. Interview with Paul Steven Miller, Professor, Univ. of Wash. School of Law, in Seattle, Wash. (Feb. 22, 2006).

76. *See, e.g.,* Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998).

77. Title IX, 20 U.S.C. § 1681 (2006); Title VII, 42 U.S.C. § 2000e (2006).

78. Genetic Information Nondiscrimination Act of 2007, S. 358, 110th Cong. (2007).

the second time in the House.⁷⁹ The Bill outlaws discrimination based on genetic information in both insurance and employment.

Title II, the section of the Bill covering employment, has many of the characteristics described above for the model federal statute. It covers private sector employers with more than fifteen employees, some federal government employees, employment agencies, labor organizations and their members, job applicants, and workers in job training programs.⁸⁰ The Bill does not, however, apply to licensing organizations. Ideally, a federal law should apply to all private sector employers; nevertheless, civil rights statutes in the United States have traditionally been limited to employers with more than fifteen employees because including all small businesses is politically unfeasible.⁸¹ At the very least, the Bill should extend to licensing organizations.

The proposed legislation does contain many important protections for employees. Employers are not allowed to make employment decisions based on an employee's genetic information, an employee's request for genetic services, or an employee's receipt of "genetic services,"⁸² which include "genetic tests," "genetic counseling," and "genetic education."⁸³ Importantly, the definition of "genetic information" includes information obtained from family medical histories.⁸⁴ Employers also may not use their employees' genetic information, request for genetic tests, or receipt of genetic services to classify employees in any way that would deprive or tend to deprive employees of employment opportunities or adversely affect their employment status.⁸⁵

Significantly, the proposed Bill also forbids employers to request, require, or purchase genetic information about an employee or employee's family members.⁸⁶ This prohibition has a few limited exceptions. Employers do not engage in an unlawful employment practice if they inadvertently request or require family medical history of an employee; offer genetic services as part of a "bona fide wellness program" and never receive individually identifiable genetic information about their employees; request family medical history information to comply with the Family Medical Leave Act; purchase commercially and publicly available documents that include family

79. Because they are all identical, the bills will hereinafter be referred to as the "Bill."

80. Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. § 201 (2005).

81. *See, e.g.*, Section 701(b) of the Civil Rights Act of 1964, 42 U.S.C. § 2000e(b) (2006).

82. S. 306, § 202.

83. *Id.* § 201.

84. *Id.* ("genetic information" means information about "the occurrence of a disease or disorder in family members of the individual").

85. *Id.* § 202.

86. *Id.*

medical history; or engage in genetic monitoring and never receive individually identifiable information.⁸⁷ The exception for inadvertent requests of family medical history is meant to address the “water cooler” problem, in which an employer unintentionally learns about the medical condition of an employee’s family members through casual conversation.⁸⁸ The exception for publicly available documents exists to protect employers who self-insure and inadvertently acquire genetic information.⁸⁹ Nonetheless, these employers are still prevented from using the information in their employment decisions.

The Bill also addresses genetic monitoring. It defines genetic monitoring as the “periodic examination of employees to evaluate acquired modifications to their genetic material . . . that may have developed . . . due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.”⁹⁰ Employers who engage in genetic monitoring must give employees written notice of the practice and receive the employees’ informed consent to conduct the test, unless the law requires testing, in which case the employee’s consent is not necessary, although written notice is still required.⁹¹ Employers must inform employees of their individual monitoring results, and monitoring must comply with federal and state regulations.⁹² Finally, the employer can only receive the results of the monitoring in aggregate terms that do not disclose the identities of specific employees.⁹³ An employer can never use any of the information acquired through genetic monitoring to make an adverse employment decision regarding an individual employee.⁹⁴ These provisions serve to enable genetic monitoring while providing important protections for employees.

The Bill gives heightened protection to genetic information. It requires employers who have genetic information, or information about requests for and receipt of genetic services, to maintain the information “on separate forms and in separate medical files and be treated as a confidential medical record of the employee.”⁹⁵ The Bill also strictly prohibits disclosing the information except to the employee at the employee’s request to a researcher if the research is conducted according to federal regulations, to government officials investigating compliance with the Bill, for Family and Medical

87. *Id.*

88. S. Rep. 108-122, *supra* note 24.

89. Interview with Paul Steven Miller, *supra* note 75.

90. S. 306, *supra* note 67, § 201.

91. *Id.* § 202.

92. *Id.*

93. *Id.*

94. *Id.*

95. *Id.* § 206; 42 U.S.C. § 1981a (2006).

Leave Act purposes, or in response to a court order. In the case of court orders, the Bill carefully limits the disclosure to the information expressly authorized in the order, and employers must tell the relevant employee in enough time to give the employee adequate notice to challenge the order if it was secured without the employee's knowledge.⁹⁶

Finally, the Bill allows enforcement by the EEOC and creates a private right of enforcement. It provides private plaintiffs with the same remedies offered in Title VII, defined in 42 U.S.C § 1981a. If employees prove a violation, they can receive attorneys' fees and costs, plus punitive and compensatory damages up to \$300,000.⁹⁷

VI. CONCLUSION

Genetic discrimination is a real possibility and a real fear in American workplaces. A federal law must provide comprehensive and uniform protections for workers and include necessary exceptions currently ignored by many state laws. The current proposed federal legislation incorporates many of the protections and exceptions necessary to create a thorough, fair, and effective genetic nondiscrimination law. Nevertheless, the Bill fails to include certain necessary protections and may not sufficiently anticipate future developments in genetic testing. Because the Bill is relatively close to passing, lawmakers should keep the Bill in its current form and eliminate its weaknesses by amending it in subsequent Congressional sessions. This approach offers the greatest likelihood of giving American workers the protections they need as soon as possible.

96. S. 306, *supra* note 67, § 206.

97. However, there is no cause of action for disparate impact. *Id.* § 208.

