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LEGISLATION AND GENETIC DISCRIMINATION

SHARONA HOFFMAN¹

I will be talking about the laws that address genetic discrimination, and there is quite a variety of them. Let me begin with state laws.

I. STATE LEGISLATION

State legislation addresses genetic discrimination in both employment and health insurance. Thirty-one states have passed laws that address genetic discrimination in employment. Approximately thirteen states prohibit employers from requiring applicants to undergo genetic testing as a condition of employment. Some states have more limited restrictions. Florida prohibits only the screening of applicants for the sickle-cell trait. Wisconsin requires employers to obtain written and informed consent from applicants prior to administering genetic tests, but does not preclude their utilization altogether. Some states establish exceptions that permit genetic testing that is job-related or that is conducted, with the employee's written and informed consent, for the purpose of investigating Workers' Compensation claims or to protect the employee's health by testing for potential work-related medical problems.

Some employees actually wish to undergo genetic testing to determine if they have genetic conditions such as chronic beryllium disease, which is triggered by exposure to toxins in the workplace. I have read that a few employees have filed claims against their employers for not conducting this kind of genetic testing. The issue of genetic testing can therefore be a "catch 22" for employers. Many employees will be upset if the employer subjects them to genetic tests because they believe the tests constitute an invasion of privacy. Others, however, will accuse the employer of misconduct if the employer does not offer genetic testing that will detect susceptibility to a condition that is triggered by a known substance in the workplace.

Let us turn to health insurance. As of 1999, over half the states had enacted laws prohibiting health insurance companies from requiring genetic testing as a condition of coverage or from denying insurance or charging higher rates based upon the results of genetic tests. Again, the statutes vary in their breadth and scope. The Texas statute, for example, applies only to group health benefits plans and not to individual health insurance policies. The Alabama statute pertains only to genetic tests for cancer.

Even the statutes that address the discriminatory use of all genetic test results may leave many individuals unprotected. One problem that drafting legislation presents is the challenge of crafting language that is precise enough to be sufficiently inclusive. This is particularly difficult when it comes to discussing new technology, such as genetic testing. "Genetic test" is typically defined as "A laboratory test of

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human chromosomes or DNA that is used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness.” Under this definition, an insurer would violate the law if it discriminated against an individual based on a physical DNA test, but not if it discriminated based on a family history of genetic abnormalities, such as a parent’s death from Huntington’s disease. A better, more inclusive approach is to prohibit discrimination based on any “genetic information,” which would include information derived from family histories. A few states have adopted this approach, and in the employment arena, several states specifically prohibit employers from attaining genetic data concerning the applicant’s family members.

The state laws are largely inconsistent in their scope, and therefore, the degree of protection one enjoys may depend on the state of one’s residence. Another limitation of the state statutes is that they do not apply to self-funded employer plans. Under the Employee Retirement Security Act of 1974 (ERISA),² state laws regulating health insurance, including those that prohibit discrimination, are preempted by ERISA insofar as they apply to self-funded employee benefit plans. An increasing number of employers, especially large employers, are self-insured. Employees who obtain insurance through these self-insured employers are not protected by the state laws that prohibit genetic discrimination. Consequently, the regulation of insurers’ use of genetic information cannot be left to the states alone.

II. HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

Significant protection is provided by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).³ HIPAA mandates that group health plans may not establish rules for enrollment eligibility based on “genetic information.” So, for example, if there is a group seeking health insurance, the insurer cannot refuse to insure particular members of the group because of genetic information.

HIPAA also requires that all group health plans limit to no more than twelve months their period of excluded coverage for pre-existing conditions; that is, conditions for which medical advice, diagnosis, care, or treatment was recommended or received in the prior six months. HIPAA provides, however, that genetic information may not be considered a preexisting condition “in the absence of a diagnosis of the condition relating to such information.” Thus, a woman who undergoes genetic testing and tests positive for BRCA1,⁴ which indicates that she is at an increased risk of breast cancer, may not be excluded from coverage for breast cancer for any period of time unless she has actually been diagnosed with the disease. These mandates, however, apply only to group health plans and therefore do not protect the 10 to 15 percent of the insured who have individual policies.

²29 U.S.C. § 1001, *et seq.* (2003).

³Pub. L. No. 104-191, 100 Stat. 1936 (codified in various sections of Titles 26, 29 and 42 U.S.C.)

⁴BRCA1 mutations are linked to breast and ovarian cancer. BRCA1 is a tumor suppressor gene, which plays a role in regulating cell growth. When a woman inherits a defective form of BRCA1, she is predisposed to breast or ovarian cancer. Available at <http://bioinformatics.weizmann.ac.il> (last visited, April 15, 2003).

III. AMERICANS WITH DISABILITIES ACT (ADA)

The second federal law that is relevant to the issue of genetic discrimination is the Americans with Disabilities Act (ADA).⁵ The ADA prohibits employers from discriminating against qualified individuals with disabilities with respect to a variety of employment activities, such as hiring, promotion, firing, *and* benefits of employment, including insurance. Employers cannot refuse to hire or fire someone because of her disability, and they cannot provide inferior insurance benefits or no benefits to an individual because she has a disability. So, the question is: Does the ADA protect people who don't have a disability but who have a genetic abnormality that might lead to a disability in the future?

The ADA covers individuals who have a "physical or mental impairment that substantially limits one or more of [their] major life activities."⁶ This provision does not apply to discrimination based solely on the results of a genetic test. Someone who is asymptomatic but tests positive for the BRCA1 abnormality and therefore has over a 50 percent chance of developing breast cancer in the future is not currently an individual with an actual disability. The ADA also protects those who have a "record of" a disability.⁷ This is also inapplicable to an asymptomatic person who tests positive for the BRCA1 abnormality, because she has not developed the disease and therefore has no record of suffering from a disability. Finally, the ADA protects individuals who don't have a disability but who are incorrectly "regarded as" having a disability, and this is the most relevant category for our purposes.⁸

In March of 1995, the Equal Employment Opportunity Commission (EEOC) issued interpretive guidance regarding the ADA that addressed the issue of genetic discrimination.⁹ According to the EEOC, employers that discriminate against individuals based upon genetic information are "regarding" the employees as having a disability, and their acts of discrimination constitute violations of the ADA.¹⁰ Thus, according to the EEOC, employers who provide health insurance benefits to their employees may not deny such benefits to individuals or charge them higher premiums based upon genetic data.

Unfortunately, I think this might be a bit of a stretch, and the guidance has not yet been tested in court. If an employer refuses to hire someone who tests positive for BRCA1 or refuses to provide her with health insurance, the employer isn't regarding her as having a disability. Rather, the employer is regarding her only as having a high likelihood of developing an illness at some time in the future. It should also be noted that breast cancer is not necessarily a disability, according to the courts. Some courts have ruled that it is a serious illness but not a "disability," especially if it goes into remission quickly after treatment with surgery or surgery

⁵42 U.S.C. § 12101, *et seq.* (2003).

⁶42 U.S.C. § 12102(2)(B) (2003).

⁷42 U.S.C. § 12102(2)(c) (2003).

⁸42 U.S.C. § 12101 (2003).

⁹EEOC, Definition of the Term "Disability," Compliance Manual, §§ 902-902.8 (March, 1995).

¹⁰*Id.* at § 902.8.

and a short course of radiation therapy. Some genetic tests, therefore, will identify susceptibilities to illness that are not necessarily disabilities covered by the ADA. It is difficult to argue that an individual should benefit from statutory protection stemming from a genetically-based prediction that she is likely to develop a disease, even though she would not be covered by the ADA if she actually had the illness in question. Consequently, I do not think that the EEOC's interpretation of the ADA will withstand judicial scrutiny.

There has been one case filed by the EEOC involving a challenge to genetic testing under the ADA. On February 9, 2001, the EEOC sued Burlington North Santa Fe Railroad, charging that the railroad violated the ADA by requiring employees who filed claims for work-related carpal tunnel syndrome to provide blood samples in order to determine whether they had a genetic susceptibility to the condition. Presumably, if they were genetically susceptible to the disease, it would not be a work-related injury, and the railroad would not have to pay the claim. On February 12, 2001, the defendant announced that it would voluntarily stop conducting the genetic tests, and the matter settled in April of 2001, so no court opinion was issued in the case.

IV. EXECUTIVE ORDER

Federal employees enjoy stronger protection against genetic discrimination than do most other Americans. On February 8, 2000, President Clinton issued Executive Order No. 13145, "To Prohibit Discrimination in Federal Employment Based on Genetic Information." The executive order precludes federal employers from requesting, requiring, collecting or purchasing genetic information from applicants and employees. An exception to the general rule allows for the genetic testing of applicants if the obtained information is to be used exclusively to determine whether further evaluation is needed to diagnose a current medical condition that could prevent the applicant from performing essential job functions. Only federal employees are covered by the executive order.¹¹

V. PROPOSED FEDERAL LEGISLATION

I have tried to show that neither state legislation nor existing federal law provides comprehensive protection to the American public against genetic discrimination. Consequently, if we are serious about addressing the issue, we will need new federal legislation that will create a national mandate concerning genetic discrimination. Numerous bills have in fact been introduced in Congress during the past few years, though none has yet become law.

The first bill that Senator Thomas Daschle promoted after he became Minority Leader in June of 2001 was his "Genetic Non-discrimination in Health Insurance and Employment Act."¹² The bill would prohibit employers from using genetic information in hiring new employees or in determining promotions, salary and

¹¹Exec. Order No. 13145, 65 Fed. Reg. 6877 (Feb. 8, 2000).

¹²S. 318, 107th CONG. (2001).

benefits.¹³ It would also bar all insurers from raising premiums or denying coverage because of genetic test results.¹⁴

The Patient's Bill of Rights that was passed by the Senate on June 29, 2001, contained a last-minute amendment that would prohibit health insurers from restricting enrollment or raising premium rates based on an individual's genetic information.¹⁵ In addition, President Bush pledged his support for banning genetic discrimination by employers and insurers during a radio address in June, 2001.¹⁶

In light of the accomplishments of the Human Genome Project, the issue of genetic discrimination has raised significant concern in academic and legislative circles and has generated considerable media attention. Given the public's repeated and vocal cries for action, I think it is quite likely that Congress will pass an anti-discrimination mandate in the not too distant future.

¹³*Id.* at § 202(a)(1).

¹⁴*Id.* at § 104(a)(1)(E)(i).

¹⁵S. 1052, 107th CONG. § 122(b)(2).

¹⁶Remarks by the President in meeting with House Leaders on Patients' Bill of Rights (White House Radio Address, June 27, 2001).

