GENETIC TESTING: TOWARD A COMPREHENSIVE POLICY TO PREVENT GENETIC DISCRIMINATION IN THE WORKPLACE

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She was a 40-year-old mother of two young children when she agreed to participate in the genetic research study.¹ The research concerned BRCA1,² a gene that had been implicated in a small percentage of breast and ovarian cancer cases.³ Since many women in her family had suffered

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¹ This story is adapted from an article by Karen Rothenberg, the Marjorie Cook Professor of Law and Director of the Law and Health Care Program at the University of Maryland Law School. See Karen Rothenberg, Genetic Testing Raises Real Fears of Molecular Discrimination, TAMPA TRIB., Aug. 3, 1997, at 1, available in 1997 WL 10800415.

² BRCA1 was identified in 1994 as the first known gene mutation responsible for an increased susceptibility to inherited breast cancer. See Yoshio Miki et al., A Strong Candidate for the Breast and Ovarian Cancer Susceptibility Gene BRCA1, 266 SCI. 66-71 (1994). Mutations in this gene are estimated to lead to approximately five percent of all breast cancer cases, as well as a significant number of ovarian cancer cases. See Jonathan Lancaster et al., An Inevitable Dilemma: Prenatal Testing for Mutations in the BRCA1 Breast-Ovarian Cancer Susceptibility Gene, 87 OBSTETRICS & GYNECOLOGY 306-09 (1996). Women who inherit mutations in this gene have an estimated 80-90% risk of developing breast cancer over the course of their lifetimes. In contrast, the estimated lifetime risk of the general population for developing breast cancer is approximately 11%. See Jeffrey P. Struweving et al., The Carrier Frequency of BRCA1 185delAG Mutation is Approximately 1 Percent in Ashkenazi Jewish Individuals, 11 NATURE GENETICS 198-200 (1995). As with all susceptibility markers, the presence of a mutation in the BRCA1 gene indicates that the person has a substantially increased risk of developing cancer. However, it is important to note that not all carriers of BRCA1 mutations will develop cancer and that not all cases of breast or ovarian cancer are caused by mutations in BRCA1. See Lynda M. Fox & Sherman G. Finesilver, Genetics and the Workplace: ADA Applicability to Genetic Information, COLO. LAW., Apr. 1997, at 77.

³ Most cancers are initiated by genetic changes; that is, by changes in the DNA sequence of a cell. See Bruce Alberts et al., The Molecular Biology of the Cell 1190 (2d ed. 1989). However, not all cancers are hereditary; in fact, most forms of cancer likely arise by spontaneous changes in DNA structure brought on by combinations of environmental causes. See id. at 1197.
from these two diseases, she was a good candidate for studies on this mutation.\(^4\)

Through her participation in the research, it was determined that she was positive for mutations in the BRCA1 gene. Although she was not diagnosed with cancer, she decided to minimize her risk of developing malignancies by undergoing prophylactic surgery to remove her breasts and ovaries.

The specialist who performed the genetic test billed her employer-based health insurance. Before she was even aware of the results of her test, her insurance provider had doubled her premium. Merely by asking for this genetic test, she was elevated to a high-risk insurance category.

After her surgeries, her health insurance company became aware of her BRCA1 status and promptly terminated her coverage. Additionally, she lost her job, even though she had always received positive work evaluations before her employer learned the results of her genetic test.

When her daughter seeks to obtain her own health insurance a decade from now, she may be denied coverage because of her mother’s genetic history. The mother refused to participate further in the scientific studies because she was worried about discrimination against herself and her children. As a result, the enormous amount of medical information that could have been gained about familial breast and ovarian cancer from follow-up studies will now be lost.

In another example, a twenty-four-year-old woman was fired from her position as a social worker after she revealed that she had a family history of Huntington’s disease.\(^5\) While conducting an in-service training on admitting and caring for patients with Huntington’s disease, she confided to her employer that a family member suffered from the illness. Soon afterwards she was given a negative performance review, although her employers refused to cite examples of her poor performance. In the eight months prior to her firing, she had received three promotions and outstanding performance reviews. After she was terminated, a coworker informed her that the employer had expressed concern about her risk for

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4. A “mutation” refers to an error in the DNA sequence of a gene. See id. at 97.

5. Huntington’s disease is a hereditary condition caused by a defect in a single gene. A person who has a defect in the Huntington’s gene does not exhibit any symptoms until mid-life. Once symptoms develop, the patient suffers from memory loss and loss of muscular body control; the disease invariably leads to death. See Brian R. Gin, Note, Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act, 97 COLUM. L. REV. 1406, 1414 (1997).

The gene mutation responsible for Huntington’s disease has been mapped to the tip of human chromosome four. See J.F. Gusella et al., A Polymorphic DNA Marker Genetically Linked to Huntington's Disease, 306 NATURE 234, 234-38 (1983). The identification of this gene in 1983 was heralded as one of the early successes in human genetic mapping technology, and is viewed as a precursor to the explosion of genetic research that took place in the mid-1980s. See Gin, supra note 5, at 1409 n.11.
developing Huntington's disease.\(^6\)

By examining the sequence of an individual's genes, it is now possible to calculate the statistical probability that a particular person will develop any number of serious illnesses. As demonstrated by the examples above, the use of genetic markers to "predict" future illness in a currently asymptomatic\(^7\) person creates the opportunity for employment discrimination based on the misuse of this information. The implications for employment law arise in two contexts: access to health insurance (as part of an employee benefit plan) and employment discrimination (affecting hiring, firing, or other conditions of employment). Each of these contexts implicates privacy issues, raising questions about how much access to genetic information employers and insurers should be entitled to receive and to act upon.

The use of genetic information is part of a larger policy debate concerning the privacy of all types of medical records.\(^8\) The outcome of this debate will impact the privacy protections specifically afforded to genetic information. In turn, the federal and state laws intended to prevent disclosure of genetic information may inform the broader discussion over what statutory protections are necessary to maintain the confidentiality of all individually identifiable medical data.

This Comment will examine the legal and social policy implications of the use of genetic information in the workplace and evaluate the federal and state statutory schemes that are evolving to address this issue. Currently, a patchwork of state laws is in place or is being proposed, most of which regulate the use of genetic information by health insurers. A few

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7. A person who is "asymptomatic" has no symptoms of disease. See STEDMAN'S MED. DICTIONARY 160 (26th ed. 1995).

state laws also address the potential for employment discrimination based on the results of genetic tests. In addition, federal law offers some potential safeguards against discrimination. Nevertheless, under the current state and federal statutory schemes there are serious gaps in protection. Therefore, it will be necessary to continue to enact federal laws to protect such information in both the health insurance and general employment contexts. In designing these laws, it will be necessary to apply a broad definition of genetic information to protect fully the privacy of employees and to prevent the potential misuse of genetic information by employers and insurers.

Part I of this Comment provides background on the scientific advances in genetic testing that impact the workplace. Part II discusses the implications of the explosion of available genetic information for the social policy values of privacy and autonomy. Part III discusses state statutes that have been enact to address the use of genetic information by health insurers and employers, highlighting the inadequacy of the legal protection provided by these laws. Part IV examines the protections against genetic discrimination that may be afforded by current federal statutes. Part IV concludes that the current legal protections are inadequate and argues for the passage of greater federal protections similar to proposals currently being considered by Congress. This section also emphasizes that to ensure protection against various possible forms of genetic discrimination, the laws that are enacted should include a broad, comprehensive definition of "genetic information."

I. SCIENTIFIC BACKGROUND AND HISTORY

"Genetic testing" or "genetic screening" involves the use of diagnostic tests to provide information about possible "mutations" or errors in an individual's DNA that correlate with particular disorders or an increased risk of developing a disorder.9 Diagnostic tests include DNA-based tests,

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9. The genetic information that dictates the development of every organism is encoded by DNA (deoxyribonucleic acid). A DNA molecule is a long, unbranched linear polymer (a molecule made up of repeating chemical structures) composed of smaller chemical units known as "nucleotides" in an irregular but nonrandom sequence. The genetic information is contained in ("encoded by") the linear order of the nucleotides. See ALBERTS ET AL., supra note 3, at 483. In the cell, each DNA molecule is packaged into a separate "chromosome." Each region of a chromosome that directs production of a functional RNA molecule constitutes a "gene." See id. at 486. The linear DNA sequence of a gene is responsible for the structure of the RNA, and ultimately, the protein whose sequence it encodes. The totality of the genetic information of a given organism is termed its "genome." See id. at 483.

The portions of the DNA sequence that encode proteins are first copied by a chemical process known as "transcription" into a molecule of RNA (ribonucleic acid). See id. at 101. Molecules of RNA are made up of smaller chemical units ("nucleotides") arranged in a
also known as gene tests, which involve direct examination of the sequence of the DNA molecule itself. Other genetic tests include biochemical tests for gene products (proteins) such as enzymes and microscopic examinations of stained chromosomes. Genetic tests may be employed for several reasons, including: (1) carrier screening, which can identify an unaffected individual carrying a single copy of a defective gene for a disease that requires two defective copies for the disease to be expressed, (2) prenatal diagnostic testing, (3) newborn screening, (4) presymptomatic testing for predicting adult-onset disorders such as Huntington's disease, (5) presymptomatic testing for estimating the risk of developing certain disorders such as adult cancers and Alzheimer's disease, (6) confirmational diagnosis of a symptomatic individual, and (7) forensic/identity testing.

The tests for adult-onset disorders such as Huntington's disease, Alzheimer's disease, and certain cancers have been the subjects of many of the legal and policy debates over the proper use of genetic testing.

Until fairly recently, there have been few ways to discriminate on the basis of knowledge of an individual's genes. One exception was the screening program for sickle-cell anemia in the 1970's. Although neither prenatal diagnosis nor effective treatment was available at that time, many state legislatures mandated screening of African-Americans for carriers of sickle-cell disease. This practice continued until 1972, when a federal law required that federal funds could only be used for voluntary screening. Widespread mandatory screening, coupled with inadequate confidentiality, led to discrimination in both the employment and insurance contexts. Many people were unfairly subjected to stigmatization and discrimination because there was a lack of understanding by the general public about the manner that mirrors the sequence of the DNA molecule that directed their synthesis. By a process known as "translation," certain RNA molecules known as "messenger RNAs" or "mRNAs" are used to direct the synthesis of protein molecules. See id. at 103. Proteins are long linear polymers (made up of smaller molecular units known as "amino acids") that make up more than half of the dry weight of each cell. The linear amino acid sequence of each protein dictates its three-dimensional structure and functional properties. Proteins serve a variety of functions, including determining the shape and structure of the cell and serving as the primary effectors of molecular recognition and the catalysis of biochemical reactions. See id. at 107.

A "mistake" in the sequence of DNA is termed a "mutation." See id. at 97. A mutation in a gene may cause defects in the corresponding protein encoded by the gene, leading to a genetic disease.


11. Sickle-cell anemia is a hereditary disease caused by a single change ("point mutation") in the linear nucleotide sequence of the gene encoding the blood protein hemoglobin. See ALBERTS ET AL., supra note 3, at 191. It is inherited as a recessive trait, which means that the harmful effects of the mutation are manifested only when a person inherits a defective version of the gene from both parents. See id.
difference between carrying the sickle-cell trait and actually having the disease.  

In 1986, the federal government initiated studies to determine the viability of a large-scale project aimed at mapping and sequencing all of the genes in a human being. Based on these studies, Congress formally began the Human Genome Project under the auspices of the Department of Energy and the National Institutes of Health. This project is now an international undertaking that includes research being done in countries including the United States, the former Soviet Union, Japan, France, Italy, and the United Kingdom. As a result of this international effort, many markers for genetically inherited conditions have been identified, thereby leading to genetic tests for many diseases. As the research progresses, many more markers are expected to become available. Although this information will undoubtedly prove valuable for the prevention and treatment of many diseases, it also increases the potential for its discriminatory use by employers and insurers. The Working Group on Ethical, Legal and Social Implications ("ELSI"), a branch of the Human Genome Project, has identified a number of issues raised by the developing technology, including employment discrimination, access to health insurance, and the privacy of genetic records.

Individuals at risk for genetic discrimination include: people who carry a gene that predisposes them to developing a disease, but who are currently asymptomatic; those who are carriers for certain genetic conditions, but who will never develop symptoms; individuals with genetic

12. See Fox & Finesilver, supra note 2, at 75.
13. Through DNA "sequencing," scientists determine the order of all of the nucleotides in a purified DNA fragment, making it possible to delineate the precise boundaries of a gene on the DNA molecule and determine the protein sequence it encodes. See Alberts et al., supra note 3, at 181.
16. See Burnett, supra note 14, at 511.
17. See Gin, supra note 5 at 1409 n.11.
18. The term "marker" refers to an isolated DNA sequence or other genetic information that can be used to distinguish between the normal and defective versions of a gene. See Alberts et al., supra note 3, at 191.
19. See Casey, supra note 10 (listing currently available DNA-based genetic tests).
20. See Fox & Finesilver, supra note 2, at 75.
21. "Genetic discrimination" is defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual." Marvin R. Natowicz et al., Genetic Discrimination and the Law, 50 Am. J. Hum. Genetics 465, 466 (1992).
polymorphisms that are not known to be associated with a disease; and relatives of individuals about whom a genetic characteristic is known or presumed.

Testing positive for a mutation most often indicates an increased likelihood that the individual will develop a particular condition, not an absolute certainty that the individual will inevitably become ill. For example, the genetic tests currently available for BRCA1, breast and ovarian cancer, colon cancer, and Alzheimer’s disease are susceptibility tests that provide only information regarding an estimated risk for developing the disease. Unfortunately, the important distinction between a genetic test result indicating a predisposition to a disease, and medical data that indicates a present illness, is lost on many people. According to Dr. Francis S. Collins, Director of the National Human Genome Research Institute, “A ‘fundamental difference’ exists between an older person who has had a heart attack and is now at risk for congestive heart failure and a twenty-five year old whose genetic tests show he is at higher risk for cancer down the road.” In other words, “[p]redisposition does not equal certitude.”

Therefore, it is unfair to deny health coverage to healthy individuals or to discriminate against them in the workplace based on a test result that suggests that they might develop a disease at some unknown point in the future. Every individual has potential errors in the sequence of his DNA. “Each of us has an estimated five to thirty serious misspellings or alterations in our DNA. Thus we could all be targets for discrimination based on our genes.”

There are many ways in which employers and insurers could obtain information about a person’s genetic potential. Many laws focus narrowly on “genetic tests,” which tend to refer to techniques that provide information about the DNA sequence of a particular gene. However, to effectively protect against genetic discrimination, the scope of protected information must be expanded more broadly to include genetic information obtained by family history, physical examinations, or medical records. Employers or insurers are concerned about the probability of the individual

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22. A “polymorphism” refers to a naturally occurring difference in the sequence of the gene, such that two or more forms of the gene exist in the population, the least common occurring at a frequency of at least one percent. See Sherman Elias & George Annas, REPRODUCTIVE GENETICS AND THE LAW 97 (1987).


26. Id. (quoting Yank D. Coble, Jr., M.D., member of the AMA Board of Trustees).

27. Id. (quoting Dr. Francis Collins, M.D., Ph.D.).
developing the disease. Thus, the fact that a family member is diagnosed with a disorder that is known to be inherited often leads to the conclusion that the given individual is more likely than the general population to have inherited the defective gene, and therefore, is more likely to develop the disease. This information, although less conclusive than the knowledge that the person has inherited the mutation, may still cause employers and insurers to conclude that the individual is a poor financial risk. However, as noted above, everyone likely has some mistakes lurking in his or her DNA. It is by chance that we have identified the cause of a particular subset of genetic diseases; there are likely many more disease-causing mutations that we have yet to identify. Defining the concept of "genetic test" too narrowly will not protect an individual’s privacy regarding a great deal of meaningful information that is now available about genes, gene products (i.e. proteins), or inherited characteristics.  

Advances in the knowledge of human genetics hold great promise for improving health by vastly improving our ability to detect, and perhaps cure, many deadly diseases. However, many in our society fear that this technology could also "create an underclass of biologically unemployable and uninsurable" citizens. This fear of biological stigmatization is not without foundation. According to one study, as many as twenty-two percent of people who are considered at-risk for genetic disorders are denied insurance coverage based on this label.  

The potential for discrimination in the employment context is another concern. Many employers already screen job applicants for particular medical conditions, and some have started to require genetic tests. One scholar has recently observed that "American firms are engaging in ... a frenzy of inspecting, detecting, selecting, and rejecting. ... Employers’ use of genetic testing is likely to increase as tests become more widely available."  

It is quite conceivable that insurers and employers who wish to maximize profits will use genetic screening to identify and "weed out" individuals who have a higher probability of developing a serious disease.

29. Burnett supra note 14, at 507-08.
30. See Billings et al., supra note 6, at 75. This study, which was partially funded by the Department of Energy, used a total of 27,790 questionnaires mailed to individuals considered to be at-risk for genetic discrimination, based on having the genetic marker for or having a relative who was at-risk for the genetic disorders of hemochromatosis, phenylketonuria, mucopolysaccharidoses or Huntington’s disease. Of the 917 questionnaires returned, 206 individuals reported experiencing behavior that fit the definition of genetic discrimination. See id.
32. Id.
that may incur high medical expenses. For example, it may be economically feasible for employers to determine which genetic diseases are the most expensive, screen all applicants for genetic markers associated with these diseases, and then refuse to hire anyone who shows a higher than average predisposition for these conditions. Insurance companies may behave in a similar fashion, screening potential clients and refusing to insure those who are a higher risk based on genetic tests.

The opportunity for genetic discrimination is a cause for concern by many people. A recent study of individuals with one or more relatives with a genetic disorder found that thirteen percent believed that they were denied a job or fired because of their family genetic history, seventeen percent chose not to reveal genetic information to their employers, and ten percent chose not to undergo genetic testing because of fear of discrimination.

II. PRIVACY CONSIDERATIONS

The social policy concerns raised by the availability of genetic information include issues of privacy and autonomy. In the context of genetic testing, autonomy "refers to the right of persons to make an informed, independent judgment about whether they wish to be tested and then whether they wish to know the details of the outcome of the testing." Once a person has submitted to a genetic test, "privacy includes the right to make an informed, independent decision about whether—and which—others may know details of their genome." The concepts of privacy and personal autonomy are interrelated, each "reflecting the importance of a person's ability 'to make personal decisions without interference.'"

This widespread public expectation of privacy is well-founded. Both federal statutes and court decisions have protected the confidentiality of

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33. See Gin, supra note 5, at 1411.
34. The concerns of insurance companies are not completely without foundation. If individuals know that they have a greater risk of developing a disease, they will have an incentive to purchase more insurance. Consequently, insurers will have to pay more than they might otherwise without their clients' access to genetic tests. See Gin, supra note 5, at 1411 (citing Robert Cook-Deegan, Mapping the Human Genome, 65 S. CAL. L. REV. 579, 587 (1991)).
36. See Bornstein, supra note 23, at 571-72.
37. Bornstein, supra note 23, at 572 (quoting ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 248 (Lori B. Andrews et al. eds., 1994)).
39. Id. at 256.
information as commonplace as one’s Social Security number.\textsuperscript{40} In addition, a “medical privacy” jurisprudence has developed concerning the privacy values underlying such issues as reproductive rights\textsuperscript{41} and the right to refuse medical treatment.\textsuperscript{42}

The sequence of a person’s DNA may be likened to a future diary in that it can be a source of highly personal information concerning an individual’s current and future health.\textsuperscript{43} The information that may be obtained is powerful and uniquely personal since: (1) it contains information that the individual himself may not want to know but that others such as insurers or employers may wish to discover; (2) valuable information may be obtained about the individual’s family members; (3) future advances in genetic tests may allow a sample to be a continuing source of new information; and (4) those labeled genetically inferior have historically been subjected to discrimination.\textsuperscript{44}

The “explosion of information generated by the Human Genome Project”\textsuperscript{45} and other advances in biotechnology are being met with great concern by policymakers and citizens because of the potential for the abuse of private genetic information. Because genetic testing provides information that describes some of the most intimate, personal features of an individual’s identity,\textsuperscript{46} lawmakers and the public have begun to clamor for legislation designed to prohibit genetic discrimination.\textsuperscript{47}

The concern over the privacy of genetic information is part of a broader debate regarding the confidentiality of individually identifiable medical records. At present, there are serious gaps in the legal protection given to such records. The proposed federal legislation aimed at maintaining the privacy of genetic information may spur more general efforts toward protecting the privacy of medical records, as genetic data makes up an important component of such records. Protections for this

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\textsuperscript{40} See Greidinger v. Davis, 988 F.2d 1344, 1353 (4th Cir. 1993) (stating that the use of Social Security numbers is one of the most serious privacy concerns in the nation); Lombardo, supra note 8, at 589 n.6, (citing the Privacy Act of 1974, 5 U.S.C. § 552A (1994)).

\textsuperscript{41} See, e.g., Roe v. Wade, 410 U.S. 113 (1973) (holding that a woman’s right to privacy regarding reproduction is a fundamental right under the Fourteenth Amendment).


\textsuperscript{43} See Burnett, supra note 14, at 523 n.109 (citing George J. Annas et al., Genetic Privacy Act and Commentary (Jan. 1996) (unpublished proposal and commentary, on file with the Seton Hall Legislative Bureau)).

\textsuperscript{44} See id. at 523 n.109.

\textsuperscript{45} Lombardo, supra note 8, at 589.

\textsuperscript{46} See id.

\textsuperscript{47} See, e.g., Fate of Federal Privacy Legislation Far From Certain, HEALTH DATA MGMT., Sept. 19, 1997, available in 1997 WL 8747999 (calling for a federal law protecting the confidentiality of medical records information).
type of information are becoming increasingly necessary as computer databases become more advanced. The combination of the ability to obtain increasingly personal medical information—such as genetic information—with the ability to manipulate and transmit that data electronically increases the need for privacy.\footnote{48}

One concern that is unique to genetic information (as compared to general medical data) is the lack of understanding by the public and even many professionals of the difference between predisposition and illness. This problem is exacerbated by the rapid progress of the Human Genome Project (the "Project"). As the Project identifies more genetic markers, more and more individuals will be seen as having genetic "taints." A lack of understanding of the interaction between genetic and environmental causes of disease may lead to further unwarranted discrimination.\footnote{49}

Another policy concern is that fear of discrimination will create an incentive to avoid genetic testing, even when it may save lives by aiding medical diagnosis, treatment, and research. These concerns highlight the need for the protection of privacy and autonomy with regard to genetic information.

III. STATE LAW PROTECTIONS

A. Health Insurance

Prior to 1986, state laws enacted to protect against genetic discrimination were limited in scope. Many statutes addressed only the use of information regarding a specific genetic trait, such as sickle-cell anemia. For example, Maryland's insurance statute\footnote{50} prohibited health and life insurers from treating individuals differently with respect to ratings, premium payments, or dividends based on genetic traits, but only for the "sickle-cell trait, thalassemia-minor trait, \footnote{51} hemoglobin C trait, [or] Tay-Sachs \footnote{52} trait."\footnote{53}

\footnote{48. See Lombardo, \textit{supra} note 8 at 590; Goldstein, \textit{supra} note 8.}

\footnote{49. Many diseases having a genetic component, such as certain forms of cancer, are actually the product of multiple causes. Genetics play only a partial role in the development of such a disease; other factors, such as diet or exposure to environmental risk factors also contribute to the likelihood of disease development. \textit{See ALBERTS ET AL., supra} note 3, at 1197.}

\footnote{50. \textsc{MD. CODE ANN., INS.} § 223 (1997).}

\footnote{51. Thalassemia minor is a disorder of hemoglobin metabolism that is usually asymptomatic, which may lead to a slightly lowered hemoglobin level and a slightly elevated red blood cell count. \textit{See Bornstein, supra} note 23, at 590 n.173.}

\footnote{52. Tay-Sachs disease is a lysosomal storage disease. Lysosomes are membrane-bound vesicles within cells that contain enzymes. Babies born with this disease suffer blindness and seizures during the first year of life and usually die within a few years of birth. \textit{See id.}}
Since the inception of the Human Genome Project in 1990, a number of states have enacted statutes employing broader definitions of "genetic information." Some of the most recent statutes have comprehensive definitions of "genetic testing" or "genetic characteristics" that cover tests for any alterations in genes or gene products (i.e., proteins) that are associated with a disease or abnormality. For example, the Maryland statute described above has been amended to make it illegal for health insurers to:

(1) use a genetic test or the results of a genetic test to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms of or conditions of, or otherwise affect a health insurance policy or contract;

(2) request or require a genetic test for the purpose of determining whether or not to issue or renew health benefits coverage; or

(3) release the results of a genetic test without the prior written authorization of the individual from whom the test was obtained.

This statute now defines a "genetic test" as "a laboratory test of 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."

The expansion of the definitions of "genetic testing" in these statutes provides more protection for individual privacy. Thus, the trend of enacted and proposed state legislation has been to move toward more comprehensive language, thereby affording increased protection against genetic discrimination by health insurers.

State legislatures have been quite active in addressing the issue of genetic discrimination. As of September 1998, at least twenty-four states had passed laws prohibiting discrimination in certain types of health benefit plans based on genetic information. As of the start of the 1999 legislative session:

at 590 n.174.

54. See, e.g., Bornstein, supra note 23, at 584 (examining state legislation that restricts the use of genetic information in insurance underwriting); John V. Jacobi, The Ends of Health Insurance, 30 U.C. DAvis L. Rev. 311 (1997) (discussing the evolution of state statutes restricting the use of genetic information in insurance underwriting).
55. MD. CODE ANN., INS. § 27-909(b) (1997).
56. Id. § 27-909(a).
57. See, e.g., COLO. REV. STAT. § 10-3-1104.7 (1999) (prohibiting the use of genetic test information by certain insurance providers).
58. See Sue Goetinck, Courts Are Jumping Into the Gene Pool, DALLAS MORNING NEWS, Sept. 6, 1998, at 7B.
session, at least twelve states had introduced bills regulating the use of genetic information by insurers and/or employers.\(^5^9\)

The majority of current and proposed state laws address the use of genetic information in the context of health insurance, an industry which has long been regulated primarily at the state level. In practice, however, state laws do not reach many insurers, due to preemption by the federal Employee Retirement Income Security Act of 1974 ("ERISA").\(^6^0\) ERISA preempts state laws that regulate self-insured employee health plans.\(^6^1\)


60. See §§ 1-4401, 29 U.S.C. §§ 1001-1461 (1994). The section that embodies the scope of preemption states, “(a) Except as provided in subsection (b) of this section, the provisions of [ERISA] shall supersede any and all state laws insofar as they may now or hereafter relate to any employee benefit plan . . . .” 29 U.S.C. § 1144. Thus, the preemptive scope of ERISA is quite broad; any law that “relates to” a plan is preempted by this language.

61. ERISA contains a “savings clause” that explicitly saves state laws regulating insurance from preemption. See 29 U.S.C. § 1144(b)(2). However, it also contains a “deemer clause” which provides that state laws regulating insurance are not saved from preemption if they deem an employee benefit plan to be an insurance company with the purpose of regulating it. See id. § 1144(b)(2)(B). “Thus, a preempted law is saved from preemption if it regulates insurance, . . . but at bottom, state insurance regulation may not directly or indirectly regulate self-funded ERISA plans.” American Med. Sec., Inc. v.
Many employees obtain health insurance through self-insured employers who cannot be reached by state laws regulating insurance. Although ERISA imposes substantive regulation primarily on pension plans, its language provides inadequate protection for employees in the area of health insurance and fails to provide adequate federal regulation to replace the state regulation it preempts. Consequently, there is a need for a comprehensive scheme of federal regulation to protect employee rights against genetic discrimination by the health insurance industry.

B. Employment Discrimination

As discussed above, a number of states have passed legislation aimed at regulating the use of genetic test information by health insurers. A subset of these statutes, such as the one in effect in North Carolina, prohibits employment discrimination (in this case, termination of employment) in addition to the denial of health insurance based on genetic testing information. Currently, only fourteen states have legislation to prevent genetic discrimination in the workplace as a consequence of genetic tests. Although a number of states are currently proposing legislation aimed at curbing discrimination based on genetic information, most of these bills only address the use of genetic tests by insurers, not employers. For this reason, it is important for any federal legislation intended to prevent genetic discrimination to include language regulating the use of genetic information by employers.

IV. CURRENT FEDERAL LAW

A. Title VII of the Civil Rights Act of 1964

One limited source of protection against genetic discrimination under current federal law is Title VII of the Civil Rights Act of 1964 ("Title VII"), which prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. Employers subject to Title VII include all private employers having fifteen or more workers, labor organizations, employment agencies, and federal, state and municipal

Bartlett, 111 F.3d 358 (4th Cir. 1997).


64. See Goetinck, supra note 58.

65. See id.

government employers. Under Title VII, a member of a protected class may raise a claim under a theory of disparate treatment or disparate impact. To establish a claim of disparate treatment, an individual must show that, although qualified for the job, he was rejected by an employer who continued to seek applications from persons with the complainant’s qualifications. To avoid liability, an employer may articulate an objective nondiscriminatory reason for the decision, which the claimant may overcome by demonstrating that the reason given is only a pretext concealing discriminatory intent. A claimant may also assert that an employer engaged in a general pattern of systematic disparate treatment of members of a protected class, either on the basis of a formal policy or through a discriminatory pattern of past employment. Since some genetic traits are associated with particular ethnic groups, it is possible that an employer could discriminate by requiring that members of a particular protected group submit to genetic testing, or by refusing to hire members of the group based on the fact that members of that group are more likely to carry the gene for a particular genetic disorder.

Since employment classifications are facially neutral, Title VII claims of discrimination based on genetic testing are more likely to be brought under the theory of disparate impact. To make a disparate impact claim, the individual does not need to show that the employer intended to discriminate, only that the hiring decision was based upon a neutral factor that had a disproportionate adverse effect on a protected class. If the claimant demonstrates disparate impact, the burden shifts to the employer to show that the employment policies have a “manifest relationship to the employment in question.” In the recent case of Norman-Bloodsaw v. Lawrence Berkeley Laboratory, the Ninth Circuit found that employees

67. See id. § 2000(e).
69. See id.
70. See id. at 804.
72. Examples include sickle-cell anemia, which is predominantly found among African-Americans, Tay-Sachs and Gaucher’s diseases, which show a high incidence among Ashkenazi Jews, and glucose-6-phosphate dehydrogenase deficiency, which is primarily found in individuals of Central African, Mediterranean, Filipino, and East Indian ancestry. See Kristie A. Deyerle, Genetic Testing in the Workplace: Employer Dream, Employee Nightmare—Legislative Regulation in the United States and the Federal Republic of Germany, 18 COMP. LAB. L.J. 547, 567 n.157 (1997). The more recently discovered BRCA1 mutation, which is associated with an increased risk of breast and ovarian cancer, is found with greater frequency among Ashkenazi Jews.
74. Id. at 432.
75. 135 F.3d 1260 (9th Cir. 1998).
were able to state a cause of action under Title VII for being subjected to nonconsensual, pre-employment testing for particular sensitive medical information. The court found that the employer’s unauthorized acquisition of information regarding whether African-American employees carried the sickle-cell trait and whether female employees tested positive for pregnancy constituted an adverse effect under Title VII.\(^{76}\)

However, *Norman-Bloodsaw* represents the exception rather than the rule. Overall, only a fraction of genetic conditions are known to be associated with a particular protected class. In general, Title VII cannot adequately protect employees from genetic discrimination in the workplace.

**B. The Americans with Disabilities Act.**

The Americans with Disabilities Act of 1990 (“ADA”) provides another potential source of protection under federal law for individuals suffering from certain genetic conditions.\(^{77}\) To establish a prima facie case of discrimination under the ADA, a potential plaintiff must establish three elements: (1) that she has a disability; (2) that she is otherwise qualified for the employment or benefit in question; and (3) that she was excluded from the employment or benefit due to discrimination based solely on the basis of her disability.\(^{78}\) Most of the debate\(^{79}\) has centered around the issue of whether possessing an indicator of a genetic disease falls within the ADA’s definition of “disability.”\(^{80}\)

The Equal Employment Opportunity Commission (“EEOC”) is responsible for enforcing Title I of the ADA, which prohibits discrimination against persons with disabilities by employers in the private

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76. See id. at 1272.

77. See Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101-12213 (1994). The Act states that: “No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions and privileges of employment.” *Id.* § 12112(a). A “covered entity” includes employers, employment agencies, labor organizations, and joint labor-management committees, excluding the United States. *See id.* § 12111.

78. *See id.* § 12132.

79. See generally Fox & Finesilver, *supra* note 2, at 75 (discussing the applicability of the term “disability” to those individuals possessing certain genetic markers); Gin, Note, *supra* note 5 (discussing the applicability of the term “disability” to those who test positive for the genetic anomaly linked to Huntington’s Disease).

80. The statute 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 impairment; or (C) being regarded as having such impairment.” 42 U.S.C. § 12102(2).
sector and by state and local governments with fifteen or more employees. The current EEOC guidelines suggest that genetic test results may potentially be covered under the ADA as a "disability." The guidelines include the following:

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 major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability."\

However, to this date there is virtually no case law interpreting the ADA in this regard, so it is unclear how much protection against genetic discrimination may be afforded by the statute.

One proposal suggests that pre-symptomatic persons with Huntington's disease should be covered under the ADA's definition of "disability" by analogy to HIV-positive persons, who are currently protected under the ADA. Like the tests used to determine whether a person is infected by HIV, the predictive test for Huntington's disease is highly accurate. Patients with both conditions may remain asymptomatic for long periods of time before becoming ill. Once symptoms develop, however, the victims of both diseases have an extremely high probability, if not certainty, of dying from the disease. In addition, both those with HIV infection and those with Huntington's disease are extremely likely to transmit their condition to their offspring.

The Supreme Court has held that HIV-positive persons have a disability under the ADA because they are "substantially limit[ed]" from having children, which has been deemed a "major life activity" as defined by the statute. The Court's decision in this case is likely to influence the analysis of ADA applicability to Huntington's disease and other genetic

81. See Fox & Finesilver, supra note 2, at 76.
82. See EEOC COMPLIANCE MANUAL § 902 (March 1995) (defining disability as part of the guidelines prepared by the EEOC in response to a petition requesting clarification of the applicability of the ADA to genetic disorders and the results of genetic tests).
83. Id.
84. See Gin, supra note 5, at 1422-34; see also Fox & Finesilver, supra note 2, at 76-77.
85. See Bragdon v. Abbott, 524 U.S. 624, 118 S. Ct. 2196 (1998) (holding that being infected with asymptomatic HIV was a physical impairment that limited the patient's major life activity of reproduction, and thus constituted a disability within the meaning of the ADA).
86. See Gin, supra note 5, at 1423, 1427.
87. Bragdon, 118 S. Ct. at 2207.
conditions. Since Huntington's disease is caused by a dominant mutation, one who tests positive for the marker has a fifty percent probability of passing the defective gene on to his or her child. This could certainly impose psychological and social burdens on someone such that they are "substantially limited" from the "major life activity" of producing and raising children. Whether or not the reasoning of the Court in Bragdon will be extended to protect those who test positive for genetic disorders or predispositions remains to be seen.

Even if courts do not find genetic disorders such as Huntington's disease to constitute a mental or physical impairment, those who suffer from them may fall under the scope of the ADA by being "regarded as" as having an impairment. People with Huntington's disease may be particularly limited by the attitudes of employers. It is likely that many employers may be unwilling to hire Huntington's individuals because of fear of incurring high medical costs in the future. Employers may also fear that they will not fully realize the investment made in training the employee, since the disease is likely to cut short the length of the employee's working life.  

Even if the courts are willing to find Huntington's disease to be a "disability" under the ADA, it is far from certain that the same logic could be applied to other genetic conditions. Like HIV-positive status, the finding of the Huntington's mutation indicates that the person is pre-symptomatic. As such, there is a virtual certainty of developing active symptoms. This is not often the case for carriers of other genetic markers. Most genetic tests do not determine that a person has or will necessarily

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88. Under the ADA, an individual is "regarded as" having an impairment if she suffers from:

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

Gin, supra note 5, at 1430 (quoting 29 C.F.R. § 1630.2(1)).

89. See, e.g., Rothenberg, supra note 1 (describing the reaction of employers to the discovery that an employee has undergone genetic testing).

90. For each trait determined by a particular gene, one has two alleles of the gene, one contributed by each parent. The mutation causing Huntington's disease is genetically dominant, which means that having only one mutated allele is sufficient to lead to the disease. In contrast, many other genetic diseases are recessive, which means that two defective alleles are required to produce symptoms. If a person tests positive for the Huntington's mutation, he has at least one defective allele and will therefore develop symptoms at some point in his life. Huntington's disease is passed down to the offspring of its carriers because the onset of the disease does not occur until mid-life, most likely after the victim has already produced children. See Gin, supra note 5, at 1414 n.45.
ever develop a particular disease, but indicate that a person has a predisposition to a particular illness. Although this may be a basis for discrimination in the workplace, it is not likely to be considered a "disability" under the ADA. It is difficult to imagine that someone who merely has a higher probability of developing a particular illness could be considered "disabled" by such a condition. At present, the fact that a given individual is aware of their predisposition is an accident of fate. Many of us carry "ticking time bombs" in our genes, but most of us are not aware of it, either because we have not been tested or because the test does not yet exist that would reveal our particular imperfection. For these reasons, it is not likely that the ADA will provide much protection for employees facing discrimination based on the results of genetic tests.

C. Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act of 1996\(^9\)\(^2\) ("HIPAA") offers some protections against genetic discrimination.\(^9\)\(^3\) Under HIPAA, it is prohibited for a group health insurance plan to "establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on . . . health status-related factors in relation to the individual or a dependent of the individual [including] . . . [g]enetic information."\(^9\)\(^4\) The statute also prohibits using the results of genetic tests as evidence of a pre-existing condition if the disease itself has not been diagnosed.\(^9\)\(^5\) The language of HIPAA does not, however, prohibit insurers from requesting or requiring genetic tests. Also, those who are not covered under group plans are not protected under this statute. While only a small percentage of Americans currently buy individual health insurance, changes in the work force, such as the growth of home businesses and the increase in the percentage of self-employed workers, will likely lead to a larger percentage of people seeking insurance outside of the group market.\(^9\)\(^6\) These people will not be protected against insurance discrimination by HIPAA.

The language of HIPAA does not explicitly protect the privacy of genetic information. However, section 264 of the statute provides a mandate for the creation of standards for the protection of the

\(^9\)\(^1\) There is some possibility that they may be "regarded" as having an impairment, particularly since many people do not readily grasp the difference between predisposition and disease. See supra text accompanying notes 24-26.


\(^9\)\(^3\) See Rothenberg, supra note 1 (discussing some of the protections under HIPAA).

\(^9\)\(^4\) § 102(a), 110 Stat. at 1961.

\(^9\)\(^5\) See § 102(a), 110 Stat. at 1955.

\(^9\)\(^6\) See Kahn, supra note 28.
confidentiality of individually identifiable health data. On September 11, 1997, Secretary of the U.S. Department of Health and Human Services ("HHS") Donna E. Shalala testified before the Senate Committee on Labor and Human Resources, presenting a report containing recommendations for federal standards regarding the protection of confidential medical information. Her testimony discussed the gaps left by state laws regulating the confidentiality of medical data and the need for federal health care privacy standards. However, HHS's recommendations did not include specific provisions concerning genetic information in medical records. Acknowledging the "unique properties of genetic information," particularly its use in prediction and its close connection to personal identity, the Secretary recommended the consideration of recent proposals for federal legislation concerning genetic privacy. These proposals are discussed in the section below.

D. Recent Federal Proposals

Recent years have seen a push toward federal legislation aimed at protecting individuals from genetic discrimination. At least ten bills pertaining to this issue were introduced into the 105th session of Congress. Among these, one of the most influential and widely supported was the Genetic Information Nondiscrimination in Health

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97. See § 264, 110 Stat. at 2033.
Insurance Act of 1997, also known as the "Slaughter-Snowe Act."\textsuperscript{102} When President Clinton announced proposed federal legislation aimed at protecting against genetic discrimination by health insurers in July, 1997,\textsuperscript{103} his administration's proposal was based upon legislation previously introduced in the House of Representatives by Representative Louise Slaughter\textsuperscript{104} (D-N.Y.) and in the Senate by Senator Olympia Snowe\textsuperscript{105} (R-Me.). Each of these proposals sought to prevent group health insurers from charging higher premiums based on the results of genetic tests. The stated purpose of each of these bills was "[t]o prohibit discrimination against individuals and their family members on the basis of genetic information, or a request for genetic services."\textsuperscript{106} The Senate bill stated in pertinent part:

In General - In the case of benefits consisting of medical care provided under a group health plan or in the case of group health insurance coverage offered by a health insurance issuer in connection with a group health plan, the plan or issuer may not deny, cancel, or refuse to renew such benefits or such coverage, ... for any participant or beneficiary under the plan—

(1) on the basis of genetic information; or

(2) on the basis that the participant or beneficiary has requested or received genetic services.\textsuperscript{107}

The bills also prohibited discrimination based on genetic information in the context of individual health insurance:

The provisions of [above sections] shall apply to health insurance coverage offered by a health insurance issuer in the individual market in the same manner as it applies to health insurance coverage offered by a health insurance issuer in connection with a group health plan in the small or large group market.\textsuperscript{108}

By extending the same protections to those buying individual health insurance, these proposals addressed an important gap in the protection afforded under HIPAA, which applies only to group health insurance.\textsuperscript{109}

\textsuperscript{103} See President Clinton, President Remarks at Genetic Screening Event 07/14/97 (July 14, 1997), available in 1997 WL 394479 [hereinafter President Remarks].
\textsuperscript{105} See S. 89, 105th Cong. (1997).
\textsuperscript{106} Id.; see also H.R. 306, 105th Cong. (1997).
\textsuperscript{107} S. 89, 105th Cong. § 2(a) (1997); see also H.R. 306, 105th Cong. § 2(a) (1997).
\textsuperscript{108} S. 89, 105th Cong. § 3 (1997); see also H.R. 306, 105th Cong. § 3 (1997).
\textsuperscript{109} See Geri Aston, Preventing Genetic Discrimination: Legislation Proposed to Ban Denial of Health Insurance Based on Genetic Tests, AM. MED. NEWS, Aug. 4, 1997, at 3, available in 1997 WL 9149539 (discussing the Clinton and Stearns proposals); see also Fate of Federal Privacy Legislation, supra note 8; Lisa Seachrist, Genetic, Health Care Revolutions Leave Policymakers Uneasy, BIOWORLD TODAY, Oct. 1, 1997, available in
A similar measure proposed by Representative Clifford Stearns (R-Fla.) extended privacy protection for genetic information beyond the health insurance context to the area of employment discrimination. In addition to preventing discrimination by group and individual health insurers, his proposal would also have prevented employers from requiring genetic tests and from using genetic information to discriminate against employees or applicants in the contexts of hiring, firing, and employment benefits.

Both the Clinton administration and Stearns proposals had similarly broad definitions of "genetic information" that included not only information about nucleic acid sequences obtained from genetic tests, but also information about any gene products (proteins) or inherited characteristics that might be inferred from the condition of the individual or a member of the individual's family. In addition, both proposals prevented the unauthorized disclosure of genetic information by insurers. Both plans offered similarly broad protection for group health insurance, and extended federal protection to the individual health insurance market. Steams's plan had the advantage of extending protection explicitly to the arena of employment discrimination.

Over time, the Clinton administration seemed to agree with Representative Stearns on the issue of employment discrimination. On
January 20, 1998, Vice President Gore presented a speech calling for federal legislation that would prevent discrimination by employers on the basis of genetic information. The proposed legislation was designed to prohibit employers from requesting or requiring genetic information from applicants for purposes of hiring; prohibit discrimination against employees in the workplace; and prevent the disclosure of genetic information without the express authorization of the individual. This would create a law similar to the one Representative Steams proposed. Recognizing the danger of discrimination, it seemed that the federal government was moving toward granting greater protection for genetic information. In addition to protecting the privacy of employees, the administration was also driven by another policy incentive: ensuring that genetic data could be used for appropriate biomedical research. Given the potential of genetic testing for great progress and dangerous misuse, one of these proposals (either the Steams measure or the combined administration proposals) should have been enacted.

Unfortunately, none of the above-mentioned bills was enacted by Congress. At the end of 1999, there were four bills pending in Congress directly pertaining to genetic discrimination. However, by 1999 much of the debate in Congress had become focused upon the various broad-based attempts to regulate managed health care that were being hailed as the "Patients' Bill of Rights." Although two early versions of proposals

117. See Vice President Albert Gore, Address at the Third Annual James Watson Lecture at the National Academy of Sciences (Jan. 20, 1998), in VP Calls for Legislation on Genetic Discrimination 01/20/98 (Jan. 20, 1998), available in 1998 WL 19833. This event is held each year by the Genome Action Coalition, a voluntary association of 125 patient advocacy organizations, professional groups, and pharmaceutical companies. This group seeks to garner support for genetic research among policymakers and the public, and has focused on engendering support for the Human Genome Project. See id. at 2.
118. See id. at 1.
119. See President Remarks, supra note 103 (expressing President Clinton's support for the Human Genome Project in particular and for genetic research in general).
introduced by Republican senators included provisions prohibiting genetic discrimination by health insurers,122 most of the health care-related bills before Congress did not address the issue of genetic discrimination. In any event, 1999 ended without the passage of any of the above proposals. At this time, federal protection against the discriminatory use of genetic information by health insurers and employers has apparently become a casualty of the political process that has allowed the debate over managed health care reform to swallow up the issue of genetic discrimination.

V. CONCLUSION

Given the speed at which technology is advancing in the field of human molecular genetics, there is a grave danger that the results of genetic tests and other genetic information may be misused by employers and insurers. Protection against discrimination based on genetic information is inadequate under the current scheme of state and federal law. As discussed above, there is significant uncertainty in current federal protections against genetic discrimination. The language in HIPAA is limited, and the application of the ADA to genetic information is uncertain. There has been significant recent effort on the part of state legislatures to remedy this situation. However, this effort has been focused on insurance reform while less attention has been paid to the potential for employment discrimination. In addition, preemption by ERISA severely limits the reach of state legislative protections.

Congress should address this issue specifically by passing federal legislation protecting the privacy of genetic information and prohibiting the discriminatory use of such information in both the employment and health insurance contexts. Such legislation should include a comprehensive definition of the types of genetic information to be protected that encompasses not only information from genetic tests, but also knowledge about a person’s genome gleaned from other medical tests and from family histories. Any measure regulating the use of genetic information by health insurers should cover both group health plans and those with individual insurance. Although the regulation of managed health care is a vitally important issue, Congress should not allow the debate over managed health care reform to overshadow the need to provide comprehensive protection against genetic discrimination in the workplace.

122. See S. 300, 106th Cong. (1999); S. 326, 106th Cong. (1999). Title III of each of these bills was cited as the “Genetic Information Nondiscrimination in Health Insurance Act of 1999,” and essentially incorporated the earlier, similarly-named, proposal by Senator Snowe.