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GENETIC DISCRIMINATION IN THE WORKPLACE AND THE NEED FOR FEDERAL LEGISLATION

Heather Rae Watterson*

INTRODUCTION

In his State of the Union Address, President Clinton "urged Americans to prevent the misuse of genetic testing for discrimination against individuals." A week earlier, Vice President Al Gore announced his support for federal legislation to prohibit employers from discriminating against employees based on their genetic profile.

Genetic discrimination is on the rise and will become increasingly prevalent with the completion of the Human Genome Project (HGP). The HGP was initiated in 1990, with its purpose to identify and map the genes in the human body. Ultimately, the HGP, which is set to be completed by the year 2005, will lead to the treatment, curing and hopefully to the prevention of all genetic disorders.

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2Id.


Although geneticists believe that the ability to identify the genes offers tremendous medical benefits, it also poses severe legal and ethical dilemmas.\(^6\) State legislatures have identified the legal and ethical dilemmas associated with the HGP and have begun to initiate statutes to prevent against such discriminatory use.\(^7\) At present, states have begun to promulgate statutes that prohibit genetic discrimination in employment and insurance, that either regulates insurance companies from gaining access to confidential information or prohibits employers from using the private information to discriminate against the employees.\(^8\)

Despite the growing awareness from both state legislatures and federal officials, there is no federal law that adequately prevents an employer from gaining access to private medical information and using that information to discriminate against the employee or applicant.\(^9\) This paper analyzes the implications of genetic testing in the workplace and the need for greater federal intervention to protect against genetic discrimination. The first section provides an overview of genetics and genetic testing. The second section outlines the current federal protection under the Americans with Disabilities Act (ADA) and the Health Insurance and the Portability Accountability Act (HIPAA) and analyzes why both Acts fail to adequately prevent genetic discrimination in the workplace. The third section provides an overview of the federal legislation that was proposed by the 105th

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\(^6\) Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 AM. J.L. & MED. 109, 110 (1991). The HGP will have an immediate and major impact on medicine. The ability to map the genes and the diseases/disorders associated with the gene will enhance the ability to predict a person's future potential to develop the disability and lead the medical community to understanding the etiology of the disorder. Understanding the etiology of a disorder can help lead to disease prevention, through genetic counseling and treatment, and through genetic manipulation, which can eliminate genetic disorders altogether. See Dogramaci, supra note 5, at 180. In addition to the medical benefits of the HGP, scientists believe that the with the completion of the HGP, will have positive affects on anthropology, DNA forensics and identification, agriculture, livestock breeding, and bioprocessing. See also www.ornl.gov/hgmis/project/benefits.html.

\(^7\) Melinda Kaufmann, Genetic Discrimination in the Workplace: An Overview of Existing Protections, 30 LOY. U. CHI. L.J. 393 (1999).


\(^9\) See Kaufmann, supra note 7, at 436.
Congress and discusses why such federal legislation must be passed. The final section provides a brief discussion of the current strides that have been made to prevent genetic discrimination throughout this millennium.

AN OVERVIEW OF GENETICS, THE HUMAN GENOME PROJECT AND GENETIC TESTING

An Introduction Into Genetics

"Genetics is the study of how physical and mental features of an organism are passed down to their offspring."\(^{10}\) Due to the rapid developments in technology our understanding of genetics has increased.\(^ {11}\) Scientists have also increased their knowledge of how to change and edit the genetic code, allowing them to recreate or edit life.\(^ {12}\)

Deoxyribonucleic Acid

The "human genome", the complete set of instructions for making up an organism, contains the master blueprint for the cellular structure for the lifetime of the cell.\(^ {13}\) The human genome is made up of 23 pairs of chromosomes, each containing deoxyribonucleic acid (DNA).\(^ {14}\)

"[A] DNA molecule consists of two strands that wrap around each other."\(^ {15}\) These strands of DNA are termed chromatin and are "composed of four kinds of molecular sub-units called nucleotides...."\(^ {16}\) "Each nucleotide contains one sugar, one phosphate, one of four nitrogen bases, consisting of: adenine (A), thymine (T), cytosine (C), and guanine (G)."\(^ {17}\) The genetic code of any particular organism

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\(^{10}\) Available at www.geocities.com.

\(^{11}\) Id.

\(^{12}\) Id.

\(^{13}\) Available at www.om.gov/hgmislprojectlinfo.html.

\(^{14}\) See Colby, supra note 3, at 446. If unwound, the strands of DNA would stretch more than 5 feet. The components of each strand, contains the entire coding for all the information necessary for maintaining life.

\(^{15}\) Available at www.om.gov/hgmislprojectlinfo.html.

\(^{16}\) See David Suzuki & Peter Knudson, Genethics: The Clash Between Genetics and Human Values (rev. ed. 1990), cited in Colby, supra note 3, at 445 n.4.

\(^{17}\) Id at n.26
utilizes these four nucleotides, in addition to the sugar and phosphate, as the chemical instructions of hereditary information.\textsuperscript{18}

**Genes**

A gene, the physical and function units of heredity, is the specific sequence of the nucleotide bases.\textsuperscript{19} The ordering of the nucleotides are composed of three units call codons.\textsuperscript{20} Sixty-four codons make up the entire genetic code, which is responsible for making amino acids, the building blocks of all living organisms.\textsuperscript{21} The particular sequences also carry the information necessary for creating proteins.\textsuperscript{22} The genetic code, therefore, is a series of the codons that determine which grouping of amino acids are required to make up specific proteins.\textsuperscript{23}

These proteins are transmitted through the messenger ribonucleic acid (mRNA), where the RNA strand is produced from the DNA inside the nucleus.\textsuperscript{24} The mRNA can be isolated in a laboratory setting, and used as a "template to synthesize a complementary DNA strand"\textsuperscript{25} assisting scientists in mapping the corresponding gene on a chromosomal map.\textsuperscript{26}

**Chromosomes**

The 3,000,000,000 base pairs are organized into 24 sub-units called chromosomes.\textsuperscript{27} The nucleus of most cells contains two sets of chromosomes, one set from the mother and one from the father.\textsuperscript{28} Each

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\textsuperscript{19} Available at www.oml.gov/hgmis/project/info.html.

\textsuperscript{20} See Holmes, *supra* note 18, at 521.

\textsuperscript{21} Id.

\textsuperscript{22} Available at www.oml.gov/hgmis/project/info.html. Humans can synthesize about 80,000 different kinds of proteins. Each proteins are made up of amino acids. Id.

\textsuperscript{23} Id.

\textsuperscript{24} Id. RNA is an intermediary molecule similar to a single strand of DNA. The "mRNA is moved from the nucleus to the cellular cytoplasm, where it serves as the template for protein synthesis. The cells' proteins-synthesizing machinery then translates the codons into a string of amino acids that will constitute the protein molecule for which it codes." Id.

\textsuperscript{25} Id. The complimentary DNA is abbreviated cDNA.

\textsuperscript{26} Id.

\textsuperscript{27} Available at www.oml.gov/hgmis/project/info.html.

\textsuperscript{28} Id.
set of chromosomes has 23 single\textsuperscript{29} chromosomes, consisting of an ‘X’ or ‘Y’ sex chromosome. A normal female will have a pair of ‘X’ chromosomes and a normal male will have an ‘X’ and a ‘Y’ chromosome.\textsuperscript{30}

In some cases, abnormalities can occur. Some of these abnormalities are apparent through microscopic testing, whereby scientists can discover missing or extra chromosomes, such as Down’s Syndrome.\textsuperscript{31} Most DNA mutations, however, are too subtle to be seen by the eye and can only be discovered through molecular analysis.\textsuperscript{32} Being able to identify the mutation depends upon being able to identify the gene or group of genes associated with a particular disorder or disease. The HGP has begun to do just that.

**The Human Genome Project**

The HGP, a federally funded project, was initiated by scientists in 1990 and is set to meet its goal of sequencing the entire human genome in the year 2005.\textsuperscript{33} This project is now an international affair, including research being done in the United Kingdom, France, Italy, Japan, and Russia.\textsuperscript{34} The United States HGP initially began as a $3,000,000,000, fifteen-year program to locate the 100,000 human genes and sequence the nearly 3 billion DNA building blocks.\textsuperscript{35} In the early phases of the project, scientists focused their efforts on creating the biological, instrumentation, and computing resources necessary for efficient DNA sequencing.\textsuperscript{36} Because of the rapid technological progress, the plan was revised in 1993 and scientists began projecting its goals through 1998.\textsuperscript{37} Scientists believed that they would complete the project by 2003, two years earlier than originally planned.\textsuperscript{38}

\textsuperscript{29}Id.
\textsuperscript{30}Id.
\textsuperscript{31}Id.
\textsuperscript{32}Available at www.ornl.gov/hgmis/project/info.html. For example, cystic fibrosis can only be determined through genetic testing.
\textsuperscript{33}See Colby, supra note 3, at 445. The human genome is the 100,000 genes in the 23 pairs of chromosomes.
\textsuperscript{35}Available at www.ornl.gov/hgmis/project/info.html.
\textsuperscript{36}Id.
\textsuperscript{37}Id.
\textsuperscript{38}Id.
With the HGP, scientists have been able to map all forty-six chromosomes, but only one-percent of the 3 billion pairs have actually been sequenced. The research from the HGP continues to discover the particular gene(s) responsible for certain disorders. Although some of the genetic disorders are in fact focused on a single gene defect, most are caused by the interaction of environmental factors and numerous abnormal genes or chromosomes. By engaging in gene mapping, scientists have been able to discover how the interaction of factors lead to disorders and what gene or set of genes are responsible for the mutation.

This discovery has had tremendous impact within the medical and scientific communities. The results have affected (1) agriculture and livestock breeding, (2) microbial genomics, (3) risk assessment, (4) bioarchaeology, (5) anthropology, (6) DNA forensics, and (7) molecular medicine.

The HGP has focused on plants and animals, in addition to human cells. By studying plant and animal genomes, researchers have begun to create more disease-resistant plants, reducing the costs of agriculture and providing consumers with more pesticide-free foods. The benefits extend into the environment, leading researchers to utilize biomanufacturing, which uses nontoxic chemicals and enzymes that not only reduce the costs, but also provides a healthier alternative for the consumer.

By examining the human genome, scientists have begun to understand human evolution and the common biology that many organisms share, in addition to the relationships among the three kingdoms: archaebacteria, eukaryotes, and prokaryotes. Additionally, scientists have been able to compare breakpoints in evolution of mutations with ages of population and historical events.

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39 See Holmes, supra note 18, at 522-23. Gene mapping is the process where scientists associate certain diseases with a gene or group of genes. See also Colby, supra note 3, at 447.
40 Id. at 523.
41 Id. at 522.
42 See also Colby, supra note 3, at 448.
43 Id.
44 Available at www.oml.gov/html/project/benefits.html
45 Id.
46 Id.
47 Id.
Gene mapping has also led to the ability to identify individuals based on the gene structure. By examining DNA and the human genome, scientists can now identify paternity and other family relationships and identify potential suspects whose DNA may match evidence left at the scene of a crime.

Within molecular medicine, researchers have uncovered, and will continue to uncover, the genes associated with genetic conditions, including cystic fibrosis, fragile X syndrome, and Alzheimer's disease. By understanding the etiology of diseases, scientists can begin to utilize disease prevention, through genetic counseling, and disease treatment, through genetic manipulation, leading to the eventual elimination of all genetic disorders.\(^\text{48}\)

With the benefits and opportunities obtained from the HGP come the possibility of social detriment. The ability to determine the genetic makeup of an individual, can lead to a certain stigma, whereby the information could be used, for example, to determine custody in a custody battle, or determine whether potential adoptive parents are appropriate.\(^\text{49}\) Additional discrimination is likely to occur. An employer or insurance carrier can take a simple blood test and obtain the complete genetic profile of any individual.\(^\text{50}\) The employer will have the ability to identify any genetic disorders, such as sickle-cell anemia and cystic fibrosis, of the employee or applicant.\(^\text{51}\) Complicating the matter even more, the employer will be able to determine whether the employee or applicant has the potential to develop a wide range of physical conditions, such as heart disease, cancer, or schizophrenia.\(^\text{52}\) With this personal medical information, the employer can then refuse to hire the applicant because of his or her disorder or susceptibility to develop the disorder.

\(^{48}\text{See also Gostin, supra note 6, at 110.}\)

\(^{49}\text{Id. See also Kaufmann, supra note 7, at 393.}\)

\(^{50}\text{Id.}\)

\(^{51}\text{Id.}\)

\(^{52}\text{See Lance Liebman, Too Much Information: Predictions of Employee Disease and the Fringe Benefit System, 1988 U. CHI. LEGAL F. 57.}\)
Genetic Testing

Because the HGP has begun to identify the genetic disorders associated with genes, genetic testing is on the rise. Genetic testing involves analyzing an individual’s DNA or proteins, focusing on the sequence and the discovery of any mutated genes. There are three types of conditions that genetic testing can reveal.

First, genetic testing can reveal with an individual has a genetic disorder, such as cystic fibrosis or sickle cell anemia. Genetic testing can also identify whether the individual is carrier of the disease. A person who is a “carrier” of the disease does not actually have the disorder, but may pass that disorder onto his or her child. Finally, genetic testing can identify whether the individual has a predisposition to developing the disease, such as cancer, heart disease, or schizophrenia. An individual who has a predisposition or developing a disorder may have a gene mutation present, but is currently asymptomatic and other factors will determine whether the individual ever becomes ill.

Genetic monitoring can also be performed. Genetic monitoring is the process whereby an employer, for example, will perform periodic testing of employees for any chromosomal changes and DNA damage that might have occurred as a result of working with, or being exposed to, hazardous substances. This process (and practice) is extremely important and necessary, when used properly and not discriminatorily applied, because the periodic testing could prevent an employee from developing an illness associated with his or work.

With the completion of the HGP, employers will have the capability of obtaining the genetic blueprint of every applicant and employee. The U.S. Congress Office of Technology (OTA) provides

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51Genetic testing is also referred by many professionals as genetic screening. See Rachinsky, supra note 34, at 578.
52Id. Gene tests involve analyzing the individual’s DNA and looking for any gene mutations. Id.
53Id.
54See Gostin, supra note 6, at 110.
55See Kaufmann, supra note 7, at 411.
56Id.
57See Gostin, supra note 6, at 110.
58See Rachinsky supra note 34, at 581.
Currently, few companies have elected to partake in genetic screening of employees; however, a survey of Fortune 500 companies indicated that twice as many companies are using genetic information today than just a few years ago. Additionally, a survey conducted by the Northwestern National Life Insurance Company indicated that 15% of the companies stated that in the year 2000, they planned on initiating mandatory genetic testing as a pre-condition of employment.

Although some employers have legitimate interests in performing genetic testing and monitoring, others may use the information for discriminatory purposes. Allowing employers to gain access to the employees’ private medical information poses severe legal and ethical dilemmas. First, the medical examinations, to which employees are often subjected, are not adequately justified by scientific evidence, the results of which could lead to “false positives.” The Scientific community has also questioned the validity of the results, arguing that a correlation between the presence or absence of a genetic disorder, and increased risk of illness has not been found. Furthermore, even if a correlation was found to exist, evidence supporting a link between screening employees and a reduced chance of illness has not shown; rather, other factors, such as drinking, smoking, and marital status have been shown to have significant impact in development of the disorder.

Being susceptible to a disorder does not, in itself, determine the onset of the disorder; instead, a person’s lifestyle choices have serious implications in the overall mental and physical health of that individual.

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62 See OTA 171-188 (1990), cited in Gostin, supra note 6, at 115, n.29.
63 See Gostin, supra note 6, at 115.
65 See Sweltz, supra note 61; legitimate interest was discussed supra page 9.
66 Elaine Draper, The Screening of America, The Social and Legal Framework of Employees’ Use of Genetic Information, 20 BERKLEY J. EMPLOY. & LAB. L. 286 (1999). A false positive is where a person has tested positive for a particular disease, but, the person does not have the disease. Because results are not necessarily 100%, due to human failure, contamination, or other factors, false positives can occur.
67 See Sweltz, supra note 61.
68 Id.
69 Id.
The screening also evaluates people on future ability to perform and the probability that the disease will manifest itself, rather than on actual ability and symptoms of current disease.\textsuperscript{70} The information obtained from the genetic test can also lead to social stratification and discrimination.\textsuperscript{71} Because many genetic disorders are disproportionately found among specific racial classes, the screening of individuals for these disorders will mean singling out the races disproportionately.\textsuperscript{72} For example, companies have been found to screen employees for the sickle-cell trait, found almost exclusively among African Americans.\textsuperscript{73}

Once the employer elects to mandate genetic testing or monitoring, the employer can then, for example, refuse to hire the applicant or even fire the employee because of the disorder of predisposition to a disorder, which leaves the employee without much remedy.

\section*{THE AMERICANS WITH DISABILITIES ACT\textsuperscript{74}}

At present, the ADA is the most effective federal remedy available to an employee or applicant who is discriminated against because of his or her genetic makeup; however, the available remedies are limited.\textsuperscript{75} The ADA, promulgated in 1990, extends anti-discrimination protection of persons with a disability into the private sector arena;\textsuperscript{76} however, the ADA does not provide clear cut answers to questions regarding genetic discrimination. In fact, the ADA does not even mention genetics or genetic traits, leaving open the question whether individuals with a genetic disorder are protected.\textsuperscript{77}

\textsuperscript{70}See Draper, supra note 66, at 290.
\textsuperscript{71}Id. at 291.
\textsuperscript{72}Id.
\textsuperscript{73}See Sweltz, supra note 61. Two employment discrimination cases have recently brought suit under Title VII for screening African Americans for the sickle-cell trait. Under Title VII, it is illegal to discriminate against an individual based on race, religion, sex, or national origin. 42 U.S.C. §2000e-2.
\textsuperscript{74}42 U.S.C. §12112.
\textsuperscript{75}See Kaufmann, supra note 7, at 404.
\textsuperscript{76}42 U.S.C. §12112; See Gostin, supra, note 6, at 120.
\textsuperscript{77}See Gostin, supra note 6, at 121.
An Overview of the Protection Under the ADA

The ADA prevents an employer, with fifteen or more employees, from discriminating against qualified individuals with a disability in regards to “job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”

Under the ADA, an employer is prohibited from conducting pre-employment testing on applicants; instead, he must limit the inquiry to the applicant’s ability to perform the job in question. This inquiry usually involves current physician conditions and usually does not encompass a genetic disorder. A genetic disorder would, therefore, only present itself through the use of genetic testing.

Once he extends an offer of employment, the employer can, and often does, condition the offer on the outcome of a medical examination. In conducting these medical examinations, the employer is bound by three requirements. First, the employer must not act with discrimination in deciding whom he tests, and therefore, if the employer chooses to mandate medical testing, he must do so across the board. Second, the results of any medical test must be kept confidential and separate from the application. Finally, the results of the test may only be used “in accordance with [the] subchapter.”

The sub-chapter, however, does not restrict the employee from testing for any medical condition and the medical condition does not have to be job-related or related to a business necessity. In theory, the ADA restricts an employer from discriminating against an employee based on the results of the examination; however, the ADA’s unrealistic categories limit the individuals who are protected.

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78 42 U.S.C. § 12112 (a). Hereinafter, when “employer” is used, it is used in the context of an employer with 15 or more employees.

79 Id. at § 12112 (d)(2)(A). An employer does have the limited right to inquire into disabilities to correct past discrimination; however, the employer must notify the applicant that the information is voluntary, confidential, and will not be determinative of their employment with the company.

80 Kaufmann, supra note 7, at 407.

81 Id.

82 Id.

83 42 U.S.C. § 12112 (d) (3) (C), cited in Kaufmann, supra note 7, at 407.

84 See Kaufmann, supra note 7, at 408.

Once the applicant becomes an employee, the employer may conduct medical examinations or genetic testing if what is being tested for is "directly related for doing the task or if necessary for employee safety." Generally, at this stage, employers have the right to conduct medical and genetic testing for monitoring purposes.

The ADA does provide a small number of people with protection. Individuals with a disorder, as defined by the ADA, are protected, and employers may not discriminate against them because of that disability; however, a very limited number of individuals with a genetic disorder actually have a disability.

Establishing a Claim Under the ADA

Definitions
To establish a claim under the ADA, an individual must be able to show that he: (1) has a disability within the meaning of the Act, (2) was qualified for the position or promotion, and (3) was denied the position or promotion because of his disability. The ADA defines a disability as "(A) a physical or mental impairment that substantially limits one or more of the major life activities...; (B) a record of such impairment; or (C) being regarded as having such an impairment." A physical or mental impairment is "any psychological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following systems: neurological, musculoskeletal, special sense organs, respiratory,...cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine." A mental impairment, as defined by the Equal Employment Opportunity Commission (EEOC) includes "[a]ny mental or psychological disorder, such as mental retardation, organic brain syndrome, emotion[al] or mental illness, and specific learning disabilities."

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86 Charles Gurd, Whether a Genetic Defect is a Disability Under the Americans With Disabilities Act: Preventing Genetic Discrimination by Employers, 1 ANNALS HEALTH L. 107, 110 (1992), cited in Kaufmann, supra note 7, at 409.
87 42 U.S.C. § 12112 (a).
88 Id. at § 12102(2).
89 29 C.F.R. § 1630.2 (h)(1).
90 Id. at § 1630.2 (h)(2).
The EEOC defines a "major life activity" as anything that deals with "caring for oneself, performing manual tasks, seeing hearing, speaking, breathing, learning, working" and sexual relationships.

Problems with the ADA
Congress and Courts have recognized that certain disorders cause a certain amount of impairment in relation to one of the major life activities, thereby protected under the ADA; however not all, not even most, of the genetic disorders fall into the categories set by the ADA and EEOC.  

Mitigating Measure
In June, 1999, the Supreme Court of the United States decided two separate cases, detrimentally removing any individual who can mitigate his or disability through corrective measures, from having a disability, as defined by the ADA. In Sutton, two pilots, suffering from severe myopia, brought suit against respondent, for refusing to hire them as pilots. In dismissing the claim, the Court held that petitioner did not have a disability within the meaning of the Act because a disability must be determined with regard to all corrective measures available to the individual and whose physical or mental impairment is corrected by the measure. In Murphy, the Court similarly held that high blood pressure was not a disability, when medication caused petitioner to function normally.

91Id. at §1630.2(i).
92Gostin, supra note 6, at 123. Down Syndrome, muscular dystrophy, cystic fibrosis, heart disease, schizophrenia, epilepsy, diabetes, and arthritis have all been found to qualify as a disorder; however, the inquiry is fact specific and depends upon the severity and lack of available medications.
93A person with a disability can mitigate the disability through medication or any other device that limits the effects of the disability. For example, somebody who wears contacts, bringing their vision close to 20/20, would not have a disability within the meaning of the Act. Sutton v. United Air Lines, Inc., 527 U.S. 471 (1999).
95Myopia is a severe sight impairment. Sutton, 527 U.S. 471.
96Id. Respondent, airline, had a requirement that all pilots have uncorrected visual acuity of 20/100 or better. Petitioners had 20/200 or worse without corrected acuity, but with corrective measures, both functioned identically to individuals without similar impairment. Id.
97Id.
98527 U.S. 516.
In light of the two recent decisions, fewer individuals with a genetic disorder will receive the ADA’s protection. High blood pressure and asthma, for example, depending on the severity, can all be controlled by medication and, therefore, those suffering from these disorders could not turn to the ADA for protection against discrimination.

**Presence of Actual Disorder**

The second major problem with the definitions set by the ADA and EEOC is the requirement that the individual actually have a current disorder/disease. This requirement mandates that the employee (1) actually have a disorder, or (2) be regarded as having a disorder.\(^5\)

The problem with these categories is the creation of the “at risk” individuals. The “at risk” individuals who do not have a current genetic disorder, but whose tests indicate a susceptibility to a genetic disorder, such as breast cancer, are not individuals with a disability under the ADA, thereby not protected.\(^6\) These individuals will be forced to wait until they symptoms exacerbate before they will be eligible for ADA protection. The employer could refuse to hire, promote, or could even fire the employee, leaving him or her without any relief for the discriminatory treatment.

In addition to individuals with a genetic disorder or susceptibility to a disorder, carriers of genetic disorders, such as cystic fibrosis, are left without a federal remedy.\(^7\) Carriers of genetic disorders do not actually have the disorder, nor do they have any symptoms of the disorder, but their offspring may develop the genetic disorder. Because of the lack of information and stereotypical belief that these individuals could be discriminated against, yet cannot rely on the ADA for protection.

Although the ADA offers many individuals with a variety of disabilities protection, it fails to completely protect individuals with a genetic disorder. Because of the subjective and unrealistic categories set by the ADA and EEOC, many employees with genetic disorders are not protected, leaving them without much alternative legal assistance.

\(^{5}\)42 U.S.C. § 12102 (2).

\(^{6}\)See Kaufmann, *supra* note 7, at 411.

\(^{7}\)See Gostin, *supra* note 6, at 124.
OTHER EXISTING PROTECTION

At present, employees subjected to genetic discrimination in the workplace are left without federal assistance. Ostensibly, the federal government is aware of the growing need for intervention to protect individuals who are discriminated against based on their genetic makeup, due to both federal initiatives and statement addressing the issue. Last year, President Clinton and Vice President Al Gore offered their support for legislation to protect against workplace genetic testing.102

In his State of the Union Address, President Clinton, inter alia, asked the nation:

To support this initiative [referring to the 21st Century Research Fund], so that ours will be the generation that finally wins the war against cancer-and being a revolution against all disease....As important as rapid scientific progress is, science must continue to serve humanity-never the other way around. We must prevent the misuse of genetic tests to discriminate against any American.103

Al Gore, addressing the attendants at the Third Annual James Watson Lecture, presented proposals for new legislation to protect against genetic discrimination.104 In that address, Gore suggested that "we are vulnerable to prejudice" and urged Americans not to "succumb to it."105 He further stated that the goal of the millennium is to work "toward ensuring that our moral code and genetic code are forever intertwined."106

Although the privacy of medical records already has protection through the ADA, the Family Medical Leave Act, and the Occupational Safety and Health Act (OSHA), the President and his administration maintain that the current restrictions on employers using the

102 See Orthmann, supra note 1, at 17.
104 See Orthmann, supra note 1, at 18.
105 Id.
106 Id.
employees' medical files are insufficient. At the 3rd Annual James Watson Lecture, Gore presented the administration's recommendations for preventing genetic discrimination in the workplace.

The administration recommended three guidelines for future legislation. First, Gore recommended that employers be prohibited from requesting or requiring employees or applicants from taking genetic tests as a condition or benefit of employment. Second, he recommended that employers be prohibited from using any genetic information to discriminate, limit, classify, or segregate employees. Finally, the administration suggested that employers be denied the ability to obtain or disclose any genetic information from employees or applicants.

Despite the proposed regulations, the administration admitted that genetic screening in the workplace should be permitted under certain circumstances. Under the proposed regulations, employers could monitor employees for the effects of hazardous and/or toxic substances that might cause a genetic disorder. Additionally, the employers would be permitted to use the results of the tests to control the adverse work conditions and prevent future harm. Under these limited circumstances, the employer would still be restricted in the use of that information to work safety, would not be permitted to infringe upon the employee's right of privacy, and could not allow the results to affect job security.

In addition to the President and Vice President, prominent experts in the scientific, legal, and genetic fields have urged for the passage of federal legislation to protect against workplace genetic discrimination. The Director of the NIH's National Center for Human Genome Research (NCHGR) urged the government to increase funding for the research of the ethical, legal, and social implications

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107 Mary Pivek, *Mum's the Word on Health*, LEGAL TIMES, May 18, 1999, at 44.
108 Orthman, *supra* note 1, at 18.
109 Id. at 18-19.
110 Id. at 19.
111 Id.
112 Id.
113 Id.
114 Id.
115 Id.
surrounding genetic research. Furthermore, the Director stated that "genetic discrimination in the workplace must no and will not be tolerated."  

The Judicial Branch has also recognized the possibility of genetic discrimination and recently announced its position that genetic discrimination in the workplace will not be tolerated. In Norman-Bloodshaw v. Lawrence Berkeley Laboratory, employees of a research facility were tested, without their knowledge, for syphilis, pregnancy, and sickle-cell anemia. The Ninth Circuit held that the employees' right under Title VI were violated because the employer only tested women for pregnancy and African Americans for sickle-cell anemia. The Court concluded that although the employees did not suffer traditional harms related to employment discrimination, such as denial of promotion or raises, the employer's unauthorized testing of sensitive medical information based on race or sex, in itself, constituted harm under Title VII.  

Title VII

Establishing A Claim

Under Title VII, employers, with fifteen or more employees, are prohibited from discriminating against their employees on the basis of race, religion, sex, or national origin. Claims are generally brought under Title VII through either (1) disparate treatment, or (2) disparate impact.

Disparate Treatment Theory

In the case of Norman-Bloodshaw, the employees raised the claim of disparaging treatment, under Title VII. To establish a claim of disparate treatment, an individual must show the following:

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116 Id.
117 Id.
118 See Norman-Bloodshaw v. Lawrence Berkely Laboratory, 135 F.3d 1260 (9th Cir. 1998).
119 Id.
120 Id.
121 Id.
123 See Kaufmann, supra note 7, at 419.
1. He or she is qualified for the job,
2. That he was rejected by an employer who continued to seek applications from persons with the complainant's qualifications.
3. The employer intended to discriminate against the employee.\(^{124}\)

Because many genetic disorders, such as sickle cell anemia, are associated with particular ethnic groups, an employer could require that a particular class of individuals submit to genetic testing, as did the employer in *Norman-Bloodshaw*.\(^{125}\) Title VII disproportionately and discriminatorily prohibits this singling out of races. The employee must show that the employer "intended to discriminate against the individual because of a particular trait."\(^{126}\) However, because intent is extremely difficult to prove beyond a preponderance of the evidence, a claim under disparate treatment will most likely fail.\(^{127}\)

**Disparate Impact Theory**

Because of the likelihood of failure under the disparate treatment theory, an individual being discriminated against based on his or her genetic profile, will most likely bring an action based on the disparate impact theory.

To establish a claim under the disparate impact theory, the employee must show that the genetic testing or screening "had a discriminatory effect on groups protected by Title VII."\(^{128}\) The burden then shifts to the employer to prove that he had a legitimate business reason for the screening or testing of the individual(s).\(^{129}\) If he meets this burden, the employee must present sufficient evidence to establish that a less-restrictive viable alternative was available.\(^{130}\)

Establishing a claim under this theory is easier for the employee because he or she need only establish that he was a member of a

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\(^{124}\) See Rachinsky, *supra* note 34.

\(^{125}\) *Id.* Sickle cell anemia is predominately found among African Americans.

\(^{126}\) Kaufmann, *supra* note 7, at 420.

\(^{127}\) *Id.*

\(^{128}\) *Id.* at 421.

\(^{129}\) *Id.*

\(^{130}\) *Id.*
minority group (protected class) and was denied because of the results.  

**Legitimate Business Reason**

Under both the disparate treatment theory and the disparate impact theory, the employer can meet its burden by establishing that it had a legitimate business reason for testing and screening a small number of employees.

A 'legitimate business reason' denotes the legitimacy in testing employees, for example, who work with toxic or potential carcinogens. The employer would require periodic testing of its employees for safety and overall health. To determine whether the reasons are valid and justifiable, courts look to the nature of the business involved, the business practice at issue, and the degree of discriminatory impact.  

Under this standard, it would be difficult, if not impossible, for an employer to justify screening only women or only African Americans; however, only a small number of individuals can rely on Title VII. Title VII is only applicable to members of a protected class. If the individual is not in the protected class, he or she cannot rely on Title VII for protection.

**The Health Insurance Portability and Accountability Act of 1996**

The federal legislatures took a step in the right direction in 1996 when it passed the Health Insurance Portability and Accountability Act, which took effect in August of 1997. HIPAA was enacted to protect individuals, who might be reluctant to undergo genetic testing out of fear of reprisal by their health insurance company.  

HIPAA prohibits insurance companies from instituting rules or regulations on eligibility for enrollment based on genetic information. It also prohibits insurance companies from declaring any susceptibility to a genetic disorder as a pre-existing condition,

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131 See Kaufmann, supra note 7.
132 *Id*. at 421.
134 *Id*.
135 See Rachinsky, *supra* note 34, at 593.
unless "medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period before enrollment."\(^{136}\)

Any violations of HIPAA could result in public or private causes of action for damages, injunctive relief, and attorney's fees.\(^{137}\) Violators could also be subjected to criminal sanctions for the illegal acquisition of private medical information.

**LEGISLATION PROPOSED BY THE 105\(^{TH}\) CONGRESS**

Although the federal government has begun to initiate legislation, such as HIPAA, it fails to adequately protect against genetic discrimination in the workplace. Because the ADA, Title VII, and HIPAA fail to circumvent the problem of genetic discrimination, federal legislation must be instituted before the increased technology destroys our ethical and moral code.

The federal government has been aware of the possibility of the adverse affects of beneficial and needed medical technology for some time. Because of this awareness legislature have attempted to promulgate statues that prevent against such discriminatory use. Legislatures have proposed four important pieces of legislation that would have helped reduce the potentially disastrous effects of the HGP; however, none of them ever materialized.

**The Genetic Privacy and NonDiscrimination Act of 1997\(^{138}\)**

The Genetic Privacy and NonDiscrimination Act of 1997 (the Privacy Act) would prohibit insurers and employers from discriminating against individuals on the basis of their genetic tests.\(^{139}\) The Privacy Act states, inter alia,

> [g]enetic information is uniquely private and personal information that should not be disclosed without the authorization of the

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\(^{136}\)See Hurd, supra note 133, at 141.

\(^{137}\)Id.

\(^{138}\)See Hurd, supra note 133, at 143. The Act was introduced by Clifford B. Stearns (R. Fla.).

\(^{139}\)Id. The privacy act refers to both employers and insurance companies and when referring to any restriction on part of employer's access, or otherwise, insurance companies are given equal restrictions. Additionally, when referring to employees, the individuals covered under health insurance companies enjoy equal protection.
individual...[because] improper disclosure...[could] lead to significant harm...including stigmatization and discrimination in areas such as employment, education, health care, and insurance.\textsuperscript{140}

The Privacy Act of 1997 contains three vital provisions that could potentially alter the discrimination laws in existence today. First, an employer would be prohibited from attempting to acquire...or use the genetic information of an employee or applicant...or to require a genetic test...for the purposes of distinguishing among employees or applicants...or for the purpose of discriminating against or restricting any right or benefit otherwise due or available to an employee or applicant for employment, in connection with any matter relating to employment, or employment opportunities, including terms and conditions of employment, privileges and benefits for employees, and termination of employment.\textsuperscript{141}

The second restriction would prohibit access to genetic information, maintaining the privacy of the medical information and the individual.\textsuperscript{142} Finally, the Privacy Act of 1997 would require the National Bioethics Advisory Committee to submit to congressional reports recommending the implementation of standards to increase the protection of the use and storage of DNA and for the further protection of genetic information.

The Privacy Act of 1997 was sent to the Commerce Committee, the Committee of Government Reform and Oversight, the Committee on Education and the Workplace, and the Veterans' Affairs Committee for consideration.\textsuperscript{143} The passage of the Privacy Act would have important consequential benefits and allow technology to better our civilization without the negative repercussions that are currently intertwined with its existence. The Act would permit technology to advance itself, keeping up with the times, while maintaining the integrity of the medical field. The congressional reports, required by the third provision, would permit the legislators, while protecting

\textsuperscript{140} H.R. 341, cited in Colby, \textit{supra} note 3, at 472.
\textsuperscript{141} See Hurd, \textit{supra} note 133, at 145.
\textsuperscript{142} \textit{Id.}
\textsuperscript{143} \textit{Id.} at 145.
employees and regulating the behavior of employers, to adapt to the changes and advancements of our scientific world.

**Genetic NonDiscrimination in the Workplace Act**

Further along the same lines as the Privacy Act of 1997, Representative Joseph Kennedy introduced the Genetic Nondiscrimination in the Workplace Act. The Workplace Act of 1997 would prohibit an employer from obtaining genetic information about an employee or applicant without the written authorization from the individual. To obtain legal authorization, the employee would be required to place, in writing, their name, the employer requesting the information, and the predictive use of the genetic information. The Workplace Act further mandates that the employer act in accordance with the ADA, state law, or any other federal law prohibiting employment discrimination and/or genetic discrimination.

The Workplace Act adds an informed consent requirement to the Privacy Act that would theoretically limit the employer's access; however, the Workplace Act, alone, is not sufficient. The Workplace Act is an important piece of legislation in that it prohibits an employer from obtaining confidential genetic information from its applicants or employees; however, the act in itself does not prohibit the employer from requiring the information as a precondition of employment. Because of this, the employer could demand that his employees consent to authorization, just as many employers mandate medical examinations or drug testing. Under the Workplace act, the employer is only provided with guidelines on the testing and use of the genetic information.

Therefore, in order to provide a more comprehensive legislation and protection against genetic discrimination in the workplace, federal legislators need to institute a combination of multiple bills that would prevent an employer from requiring a genetic test and prohibit employer access. An exception would need to be instituted whereby an

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145 Id.
146 See Hurd, supra note 133, at 145.
147 Id. at 146.
employer whose company deals in toxic or potentially hazardous substances should have limited access to genetic monitoring, to screen for potential DNA abnormalities, and institute any necessary safety and health precautions. This information, however, should only be available to qualified medical personnel who could act as a liaison between the employer and the employee, thus ensuring the nondiscriminatory use of the information.

Genetic Confidentiality and Non-Discrimination Act
Adding the Genetic Confidentiality and Nondiscrimination to the Workplace Act and Privacy Act would ultimately complete the set of legislation, furnishing comprehensive protection to employees, while at the same time permitting employer access to monitor health and safety measures. The Genetic Confidentiality and Nondiscrimination Act, introduced by Sen. Pete V. Domenici, adds another piece to the important restrictions needed to prevent discrimination. The Nondiscrimination Act focuses its regulations on the manner in which the DNA samples and genetic information is collected, stored, and analyzed. The Nondiscrimination Act sets forth detailed obligations of the DNA collector. The collector of the genetic information would be required to present information stating that the individual being tested voluntarily consents to the procedure, provide an explanation of the possible uses of genetic testing, and explain what information will be given to the provider of the DNA material. The collector would further be required to inform the provider of his or her rights to: (1) invoke the consent at any time, (2) destroy the DNA at any time, and (3) genetic counseling.

The Nondiscrimination Act provides yet another aspect, lacking in other genetic discrimination acts. It prohibits an employer from requiring, using, or gaining access to the employee’s genetic

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148 Id. S. 422 [hereinafter the Nondiscrimination Act]. See also Hurd, supra note 133, at 146.

149 See Hurd, supra note 133, at 146.

150 Id. Hereinafter, the individual who is undergoing genetic testing will be referred to as the “provider,” and the medical professional eliciting the genetic information will be referred to as the “collector.”

151 Id.

152 Id.
information.\textsuperscript{153} The latter part of the act attempts to limit the possibility of misuse of the genetic material, while still allowing the employees to partake in genetic testing for their own benefit.\textsuperscript{154}

The Genetic Justice Act

The Genetic Justice Act, introduced in July 1997, would prohibit pre-employment genetic testing as a precondition of employment and require that employers restrict genetic testing to current employees with job offers.\textsuperscript{155} Although the Justice Act permits an employee to request a genetic test once an offer of employment is extended, the employer may only request such information as it relates to a business necessity.\textsuperscript{156} The Act would also prohibit an employer from segregating the employees based on the genetic information elicited.\textsuperscript{157}

Genetic discrimination, a serious and rapidly increasing problem, will continue until the government institutes federal legislation protecting the hard working citizens and non-citizens of this great country. The 105\textsuperscript{th} Congress attempted to circumvent this problem by instituting a variety of statutes that would reduce the possibility of misuse of genetic testing, while maintaining the integrity of the technological world. Despite this attempt, the 105\textsuperscript{th} Congress ultimately failed because no such federal law has been passed as of yet. The 106\textsuperscript{th} Congress has further addressed the issue and sent several more congressional reports and bills to committees for review.

CONCLUSION

With the turn of the century, our civilization began relying more on the medical and scientific communities to improve the quality of life and better our world. As we enter the new millennium, it is apparent that the world, as we know it today, will be forever changed. Scientists and

\textsuperscript{153}Id.

\textsuperscript{154}See Hurd, supra note 133, at 146. The Nondiscrimination Act would also prohibit insurance companies from discriminating against healthy individuals on the basis of genetic information or request genetic information. The Act would also prohibit insurance companies from requiring an applicant to take a genetic test before coverage is offered.

\textsuperscript{155}Id. S. 1045; see also Hurd, supra note 133, at 147. The Genetic Justice Act [hereinafter the Justice Act] was introduced by Sen. Thomas Daschle (D-SD).

\textsuperscript{156}Id.

\textsuperscript{157}Id.
Geneticists have begun to sequence the entire human genome, mapping specific genes with certain genetic disorders. By the year 2003, the HGP is set to be completed and its goal satisfied, where an individual will be able to undergo a simple blood test and from that test medical professionals will be able to determine three important pieces of information. First, results of any test will determine whether the individual has any genetic disorders or chromosomal abnormalities. Second, the results would indicate whether the individual is carrier of any genetic disorders. Finally, the results would determine whether the individual was susceptible to developing a disorder, such as heart disease or breast cancer. It is important to keep in mind, however, that being susceptible to a disorder is not a guarantee of development of that disorder, but rather multiple factors have serious implications on the actual development of that disorder.

The results of the genetic test have both beneficial and potentially disastrous results. With the testing, comes the ability to treat, prevent, and cure all genetic disorders through the use of genetic counseling and manipulation. Increased research is necessary to help cure individuals suffering from a potentially life-threatening illness, such as cystic fibrosis; however, the possibility of discrimination should not be over-looked. Specifically, genetic discrimination in the workplace has already begun and will continue to rise in numbers throughout this century. An employer, for example, could require all employees and applicants to undergo genetic testing to determine their current and future health and then refuse to hire (or fire) the individual based on the results.

If discrimination does occur, the employee is left with few remedies. The ADA limits protection to individuals with a current disorder that interferes with a major life activity. Most genetic disorder, however, are controlled by medication, and in light of Sutton and Murphy, are taken out of the category of protected individuals. Additionally, carriers and individuals with susceptibility are not

158 Hudson, supra note 5, at 395.
159 Gostin, supra note 6, at 109.
160 Id.
161 Id.
162 Id.
163 See Kaufmann, supra note 7, at 410.
individuals with a disability under the Act and not protected. The effect of the definition set by the ADA and EEOC ultimately gives the employer the right to discriminate against these individuals, and leaves most employees without a remedy to rectify the negative, prejudicial treatment.

Title VII can also be used to combat genetic discrimination, but it can only be applied to those individuals falling into a protected class. Unfortunately, very few individuals have disability or disorders that would render them protected. Even if the employee were a member of a protected class, the employer would rebut the testimony with a legitimate business reason for its actions.

Members of the 105th and the 106th Congress took a step in the right direction by sending several important pieces of legislation to Committees for review. Although legislators have begun to take some notice of the potentially disastrous affects of the HGP and have attempted to intervene, they have failed to pass any legislation that protected every working individual in this county.

The federal government must take the initiative and stop genetic discrimination before it becomes a common practice. Without such coverage our moral and ethical code will forever be superseded by the technological, scientific, and medical world.