The Human Genome Project: The Road to Our Improved Health or the New Civil Rights Movement

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Companies want to weed out the vulnerable and hire the 'superworker,' and whoever isn't, whether it be Italians, blacks, Sephardic Jews, or people with some genetic trait — whoever isn't superhardy could be excluded.¹

I. INTRODUCTION

With the help of scientific advancements and new technology, people may no longer have to wonder what the future holds. We may no longer have to speculate about how harmful a few extra minutes in the sun actually are² or about consuming that tempting cheeseburger.³ A quick and painless visit to the doctor could provide the answers to many of our questions. Taking a genetic test may someday be like looking into a crystal ball. We will be able to find out what our future holds in terms of what diseases or illnesses we may one day develop as a result of certain genes or gene mutations found in our genetic map.⁴

Because of this, the future of medicine anticipates turning from a "treatment-based to a prevention-based discipline."⁵ Today, a person commonly seeks medical attention only when they feel sick or when they discover a problem. Doctors presently treat diseases or illnesses after their effect on the human body has already begun

² See generally Leon Jaroff, Keys to the Kingdom, TIME, Sept. 18, 1996, at 25 (discussing the possibility that one day a test can reveal genes that will predict our susceptibility to cancers, heart disease, and other diseases); see also Philip Kitcher, The Lives to Come: The Genetic Revolution and Human Possibilities 73 (1996) (discussing how genetic tests, which reveal susceptibility to cancers, are beneficial when recommendations could be made to reduce one's risk of developing the cancer).
³ See Jaroff, supra note 2.
⁴ See Jaroff, supra note 2.
⁵ See Jaroff, supra note 2.
taking its toll. As the Human Genome Project works to uncover every gene in the human cell, it is anticipated that medical treatment will change. Doctors will soon be able to treat patients before a problem manifests itself, that is, before the person even becomes ill. Genetic information will reveal future disease, disease susceptibility or disease risks before the genetic mutation begins to manifest itself within the person in the form of the disease or illness.

Soon, you will be able to go to a doctor and by giving them a small blood sample, you may undergo a genetic test. This genetic test will enable doctors to discover and uncover a list of all your genes. By undergoing a genetic test, it is possible to find out whether or not you have the specific gene that places you at risk of being susceptible to skin cancer or even at risk of suffering from cardiovascular disease. As a result, a doctor will be able to recommend precautionary measures to lessen your risk of actually developing the illness you may be genetically susceptible to acquiring.

For example, if you have a gene that puts you at risk of developing skin cancer, the doctor will advise you to wear sunblock and to avoid getting sunburn. If you have the gene that predisposes you to cardiovascular disease, the doctor may recommend a low-fat, high fiber diet and exercise. This type of preventive treatment can substantially reduce the probability of developing the skin cancer or heart disease that the genes you are born with may predispose you to acquire.

Access to this newly obtainable information could be quite beneficial. A person can use their genetic information as a guide

6. See Jaroff, supra note 2.
7. See THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE 8 (Thomas H. Murray et al. eds., 1996) ("It now is possible for someone to say, 'I have Huntington's disease,' long before any manifestations of that dread disease will cripple the body. As the genome map becomes more specific, similar statements will be validated for a variety of other serious conditions.").
8. See Jaroff, supra note 2, at 25.
9. See Jaroff, supra note 2, at 25.
10. See KITCHER, supra note 2, at 73-74.
11. See Jaroff, supra note 2, at 24. See generally THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE, supra note 7, at 11 (discussing how the future of medical treatment will begin "treating" patients long before any illness sets in by providing advice about lifestyles and choices to reduce one's susceptibility).
12. See id.; see also KITCHER, supra note 2, at 73 (discussing how recommendations to those who are genetically at high risk for certain diseases are beneficial).
13. See Jaroff, supra note 2, at 25.
towards a healthier life. Unfortunately, this information is not private and has great potential for misuse.

The following hypothetical scenario is likely to occur unless proper legislative protections are applied and enforced. Imagine applying for a job at a law firm. Throughout the interview process, it is obvious that the firm is impressed with your exceptional qualifications and an offer of employment is informally extended to you. At the last minute, as the employment contract is drafted and about to be signed, the firm rescinds its offer. Obviously extremely disappointed and bewildered, you want to investigate the matter. After much inquiry, it is determined that the firm acquired the results of a genetic test that was previously performed on you. As a result, you were determined to be within the “high risk” category for insureds because of certain genetic defects detected by the test. Therefore, the firm decided to hire the applicant who was considered to be more economically beneficial, the applicant who wouldn’t be as expensive to insure, the one who was tested and found to be “genetically healthy.” The more “affordable” employee was not genetically predisposed to illnesses that require expensive medical treatment. Perhaps you were hired, but along with your offer of employment came a skimpy insurance plan with high premiums and several provisions exempting you from coverage for specific treatments that your genetic information proved might one day be necessary. As scientific advancements continue to discover gene mutations and create genetic tests, this type of discrimination is likely to occur and worsen because presently no all-inclusive federal legislation exists to protect against this type of abuse and to prevent the development of a “genetic underclass.”

14. See Kitcher, supra note 2, at 73.
16. See generally THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE, supra note 7, at 162 (discussing how “individuals whose offers are withdrawn after a medical examination have few avenues for getting sufficient information about the employment situation to successfully challenge the employer’s change of mind.”).
II. THE HUMAN GENOME PROJECT

A. Description, Explanation, Development and Goals

The Human Genome Project is a worldwide effort to map and isolate all of the genes in a human cell, and analyze these genes to determine how they influence our physical traits and our susceptibility to various inherited diseases. The project's ultimate goal is to identify the full sequence of the human genome. The human genome is the totality of the genetic material in a human cell. The project was launched in 1988 by the United States Congress. The project intends to produce a "physical map showing the location of individual genes within the genome, and a genetic linkage map showing the relationships between different genes in the genome." Medical researchers are comparing the mapping of the human genome to the systematic arrangement of chemicals and categorization of the elements into the periodic table.

The human body has about ten trillion cells. Each of these cells, with the exception of red blood cells, contain all of the genetic information necessary to create a human being. Twenty-three pairs of chromosomes are found within the nucleus of every cell. Each human chromosome contains a molecule of the chemical comp-

17. See Carl F. Cranor, Are Genes Us?: The Social Consequences of the New Genetics 12 (1994) ("The current scope of the project includes work in seven areas: (1) mapping and sequencing the human genome; (2) mapping and sequencing the DNA of model organisms; (3) informatics: data collection, analysis, and distribution; (4) ethical, legal and social considerations; (5) research training; (6) technology development; and (7) technology transfer.").
19. See Kitcher, supra note 2, at 88.
21. See Cranor, supra note 17.
22. Iles, supra note 18, at 30.
23. The Human Genome Project aims to produce biology's periodic table of not 100 elements, but of 100,000 genes. See Jaroff, supra note 2, at 25-26; Eric S. Lander, The New Genomics: Global Views of Biology, SCIENCE, October 25, 1996, at 536. ("[T]he Human Genome Project is best understood as the 20th century's version of the discovery and consolidation of the periodic table.").
24. See Mapping and Sequencing the Human Genome 4 (Committee on Mapping and Sequencing the Human Genome, 1988).
25. See id. at 12.
pound that carries genetic information known as, deoxyribonucleic acid (DNA). DNA usually exists as two linear strands that twist together forming a spiral structure known as the double helix. Each DNA strand is composed of four different units, called nucleotides, that are linked to form a long chain. These four nucleotides are made up of the bases adenine, guanine, cytosine and thymine. The nucleotides pair up into strands that twist together to form the double helix. Nucleotides are the smallest genetic unit and are paired in specific combinations within the double helix of DNA. The DNA for humans has approximately three billion of these base pairs within which there is a variation in the ordering of the four bases. The sequence of bases acts as a code that determines what proteins will be made in the cell. The forty-six chromosomes contain about 100,000 genes. A gene contains approximately 1,000 of the nucleotide pairs and has enough information to code for the production of a particular protein. The proteins determine the nature and activities of the cell. Most genes code for protein molecules, either enzymes or structural elements, which determine the characteristics of a cell. Genetic information is contained in a code based on the sequences of nucleotides.

Every person has a unique set of DNA molecules which determine what we look like, our eye color, how tall we are, the shape of our body parts and our behavior. "[V]ariations within the genotype - the collection of genes you inherit - can lead to very obvious

27. See MAPPING AND SEQUENCING THE HUMAN GENOME 16 (Committee on Mapping and Sequencing the Human Genome, 1988).
28. See id. at 17.
29. See id. at 13.
30. See id. at 13.
31. See id. at 17.
32. See id. at 13.
33. See MAPPING AND SEQUENCING THE HUMAN GENOME 16 (Committee on Mapping and Sequencing the Human Genome, 1988).
34. See id. at 13.
35. See id. at 18.
36. See id. at 13.
37. See id.
38. See id.
39. See id.
40. See ALDRIDGE, supra note 26, at 137.
differences in characteristics such as facial features, eye color and height."\(^{42}\) A mutation occurs when there is a change in the normal sequence of nucleotides in a gene.\(^{43}\) A mutation can be the deletion of a nucleotide or the change of one nucleotide to another.\(^{44}\) When a gene is mutated, it no longer produces the protein it was designed to produce.\(^{45}\) Since a cell has two copies of each gene, it can often remain unaffected by the mutation, without causing any medical consequences.\(^{46}\) Sometimes, differences as small as a single base can result in devastating disease.\(^{47}\) It has now been discovered that even without mutation, more subtle variations occurring within many genes can cause "susceptibility to heart disease, cancer and other common illnesses."\(^{48}\)

Intensive progress continues to be made as new genes are discovered almost every day.\(^{49}\) As of mid-1996, more than 6,000 genes had been identified, many of which are "those with defects or mutations that can cause or predispose [a person] to illness."\(^{50}\) Once a gene has been identified, a diagnostic test can be developed which would allow the person undergoing the test to know whether or not they are carriers of that gene.\(^{51}\)

**B. What is Genetic Testing?**

The Director of the Human Genome Project, Dr. Francis Collins, recently reported that approximately 800 to 900 genes have been identified as being linked to human diseases.\(^{52}\) Approximately seventy-two genes have been discovered that contribute to human disease.\(^{53}\) Examples of such diseases and disorders now discovered to

\(^{42}\) ALDRIDGE, supra note 26, at 138.


\(^{44}\) See id.

\(^{45}\) See id.

\(^{46}\) See id.

\(^{47}\) See ALDRIDGE, supra note 26, at 137, 140.

\(^{48}\) ALDRIDGE, supra note 26, at 138.


\(^{50}\) See id. at 26.


\(^{53}\) See NBC Nightly News (NBC television broadcast, Jan. 1, 1997) (interviewing the Director of the Human Genome Project).
be linked to genes are Tay-Sachs disease, Huntington's disease, muscular dystrophy, breast and ovarian cancer, cystic fibrosis, fragile X syndrome, Alzheimer's disease,\(^\text{54}\) colon cancer, Parkinson's disease as well as many others.\(^\text{55}\) Genetic tests are being created which can locate specific genes.\(^\text{56}\) Genetic tests can detect a genetic deficiency that is expressed from the time of birth.\(^\text{57}\) It can also reveal a person's potential to develop a disease in the future.\(^\text{58}\) Genetic tests are capable of providing carrier and presymptomatic information,\(^\text{59}\) including risk of future disease, disability and early death.\(^\text{60}\) These tests can reveal genetic information about both the individual and his or her family members.\(^\text{61}\)

The first test has already been put on the market and has been sold for $2,400.\(^\text{62}\) It indicates mutations linked to both breast cancer and ovarian cancer.\(^\text{63}\) It detects every known mutation on the two genes BRCA1 and BRCA2, which are the genes that can cause inherited breast or ovarian cancer.\(^\text{64}\) "It is the first in a new generation of tests that detect not the presence of a genetically inherited disease but rather the genetic susceptibility to illness."\(^\text{65}\)

Developing a genetic test can be extremely complicated because a gene may have many different mutations or variations.\(^\text{66}\) This

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\(^{54}\) Four different genes for Alzheimer's disease have been discovered. See id.

\(^{55}\) See Saturday Today (NBC television broadcast, Sept. 21, 1998); NBC Nightly News (NBC television broadcast, July 6, 1995); NBC Nightly News (NBC television broadcast, Jan. 1, 1997).

\(^{56}\) See id.


\(^{58}\) See id.

\(^{59}\) Presymptomatic information is a term used to describe that information which reveals one's predisposition or susceptibility to genetic disease in the future. For an explanation of this term, see Assessing Genetic Risks: Implications for Health and Social Policy 8-10 (Lori B. Andrews et al. eds., 1994).


\(^{61}\) See id.


\(^{63}\) See id.


\(^{66}\) The BRCA1 breast cancer gene has 50 or 60 mutations; the cystic fibrosis gene has several hundred. See Technological Advances in Genetics Testing: Implications for the Future: Hearings Before the Subcomm. on Technology of the House Comm. on Science, 104th Cong. 103 (1996) (statement of Alan Goldhammer, Ph.D.).
information is significant because different mutations may lead to an increased or decreased susceptibility to disease, different symptoms or different morbidity rates.67

Presently, three different types of conditions can be detected through genetic testing.68 The first is directly attributable to specific genetic defects.69 These individuals either currently have a genetic disease or are certain to develop a genetic disease, which is directly caused by a specific defect within one’s genetic material.70 Huntington’s disease, cystic fibrosis, and Duchenne muscular dystrophy are examples of this type of genetic condition.71 For these diseases, “the presence of the defective gene is all that is required to cause the disease.”72 If you have the gene, you will inevitably develop the disease.

A second condition arises in individuals who do not possess a genetic disease, but rather are carriers of a gene that causes a disease.73 People who are carriers will never develop the particular impairment that the gene can cause, but may transmit them to their children.74 Although that person will never suffer from any symptoms or consequences of that disease, that individual runs the risk of passing that gene onto their children, who run the risk of suffering from the consequences of that gene.75

The third type of genetic condition that can be identified through genetic testing is an individual’s genetic predisposition to future disease.76 These individuals are genetically susceptible to developing a disease,77 but have not yet developed the disease. With such individuals, the possibility of developing that particular disease is not guaranteed.78 Whether or not the person is likely to develop a dis-

67. See id.
69. See id.
70. See id.
71. See id.
72. Id. This individual “will develop the disease regardless of environmental factors or preventive health measures.” Id.
73. See id.
74. See id.
75. See Brom, supra note 68, at 123-24 (“When both parents are carriers there is a significant probability that their children will develop the disease.”).
76. See Brom, supra note 68, at 123.
77. See Brom, supra note 68, at 123.
78. See Brom, supra note 68, at 123.
ease can depend on a number of factors.\textsuperscript{79} For example, an individual’s environment and lifestyle can significantly impact the development and manifestation of a disease.\textsuperscript{80}

C. Benefits of Taking a Genetic Test

The potential for improvement in medical care is great because of the significant achievements being made in the study of genetics. However, the benefits that genetic testing can offer will be insignificant if people refuse to use the new technology because of other concerns they may have.\textsuperscript{81} Knowledge of the presence of a specific gene that can place an individual in a high risk category for developing a specific disease is extremely beneficial because it can substantially reduce the risk of dying of that disease.\textsuperscript{82} If such options are available, the disease can be curable.\textsuperscript{83} More importantly, however, individuals can reduce their risk of getting the disease.\textsuperscript{84} Because doctors can make a pre-clinical diagnosis, this can be done through a myriad of ways.\textsuperscript{85} Doctors can prescribe medicine and can recommend lifestyle changes.\textsuperscript{86} For example, with the new breast cancer test now available, a person can undergo preventive treatment, such as having a prophylactic mastectomy.\textsuperscript{87} Alternatively, one can follow a low-fat diet and exercise regime as a means

\textsuperscript{79}. See Brom, supra note 68, at 123.
\textsuperscript{80}. See Brom, supra note 68, at 123.
\textsuperscript{82}. See Kitcher, supra note 81, at 124-36.
\textsuperscript{84}. See id.
\textsuperscript{85}. Now we know that cardiomyopathy, primary heart disease, is a genetic condition which can be passed down from parent to child through generations. When a doctor finds out that a patient has a family member who died of cardiomyopathy the doctor could prescribe drugs, implant pacemakers, or give advice on a lifestyle to help reduce the risk of suffering from a fatal heart attack. See Jay Rayner, The Genetic Underclass, The Observer (England), Sept. 15, 1996, (Magazine), at 4.
\textsuperscript{86}. See Cowley, supra note 83, at 49.
\textsuperscript{87}. See Jaroff, supra note 83; see also Clive Cookson & Daniel Green, Gene is Out of the Bottle, Fin. Times, Oct. 30 1997, at 15 (discussing how a woman can undergo a mastectomy, which is the removal of her breasts before the cancer appears, as a preventative measure). Cf. The Human Genome Project and the Future of Health Care 15, 200 (Thomas H. Murray et al. eds., 1996) (discussing how a prophylactic mastectomy is an extreme measure
of decreasing one's chances of developing breast cancer or simply just be on alert that a tumor can be quickly detected and promptly removed.\(^8^8\) Having the predisposing BRCA1 gene increases a person's chances of developing breast cancer, but it does not make its development inevitable.\(^8^9\) Because the typical treatment for such cancers does not start until after the cancer has taken effect in the person's body, the person with the gene can substantially reduce their risk of developing breast or ovarian cancer.\(^9^0\)

With all of these new findings, pharmaceutical companies are rushing to develop drugs that will either neutralize the effects of dangerous genes or replace the needed proteins that are missing from the individual as a result of a gene mutation or defect.\(^9^1\) In addition, researchers are working on a new technique known as gene therapy. Simply explained, gene therapy is similar to a transplant but instead of transplanting an organ, microscopic genetic material is transplanted.\(^9^2\) This technique intends to successfully introduce genetic material into existing cells to prevent or cure diseases.\(^9^3\)

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88. See generally Cowley, supra note 83 (discussing how with knowledge of a special risk for cancer a person will be alerted to the need for extensive monitoring); see also Jaroff, supra note 83.

89. It predisposes a person to a certain illness, however, it does not make obtaining the illness inevitable or definite. See supra notes 76-80 and accompanying text. See supra note 83 (discussing how having the BRCA1 gene gives that person an 85% risk of developing breast cancer and a 40-60% risk of developing ovarian cancer).


91. See supra notes 33-45 and accompanying text (discussing how because of a gene mutation certain proteins or enzymes that should be made are not made or atypical proteins are made instead).


93. See Reforming the System: Containing Health Care Costs in an Era of Universal Coverage 245 (Robert J. Blendon & Tracey Stelzer Hyams eds., 1992); supra note 92.
III. GENETIC TESTING IN EMPLOYMENT

A. Usefulness of Genetic Information to Employers and Employees

Employers have legitimate, nondiscriminatory reasons for seeking medical information about prospective and current workers. Just as many jobs have educational prerequisites and skill requirements, so, too, many jobs require that people demonstrate physiologic, sensory, and perhaps neurologic abilities that are discerned most efficiently by a medical examination. In addition, as more and more evidence accumulates about the toxic effects of certain work environments, employers may wish to monitor the health of those continually exposed to known hazards.\(^9\)

Genetic information enables an employer to anticipate an employee's future job performance and how this will affect the safety of others.\(^9\) Genetic tests can disclose whether or not an applicant will develop a disease that will affect their productivity; whether or not they can work in the particular environment the employer provides; and whether or not a person is susceptible to diseases that might be triggered by substances emitted in the workplace.\(^9\) All of this can have a direct effect on an employee's well-being, as well as the well-being of others.\(^9\) If employees are aware that they are genetically at risk for a specific illness caused by substances in the workplace, then this awareness would enable the employees to choose a different job where they can maintain their health. This information is also important to employers because they can hire only those applicants who will not be harmfully affected by the toxic substances. This will lead to greater productivity and it could save the employers money.\(^9\)

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96. See Philip Kitcher, THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES 145 (1996). This author refers to the last two as "general health" risks and "work-place specific" risks. See also THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 183 (Daniel J. Kevles & Leroy Hood, eds. 1992) (justifying the use of genetic tests identifying the susceptibility of particular workers to harm from toxic exposures when it is used as a means of protecting workers' health).
97. See Kitcher, supra note 96.
98. It could prevent potential lawsuits brought by employees against employers because of the detrimental effect of substances released in the workplace. See Kitcher, supra note
1. Legitimate Use of One’s Genetic Information

Although this Note predominantly discusses an employer’s potential abusive use of genetic information, circumstances do exist where employers can legitimately use genetic information about applicants or employees. These situations are usually those that deal with the well-being of the employee and the general public.99

One type of situation involves “workplace-specific” risks, i.e., those risks that can cause illnesses that directly result from the work environment.100 Obviously, it would be beneficial for an employee or applicant to know whether or not they are genetically susceptible to diseases triggered by particular substances that exist in a workplace.101 If one’s genetic information reveals that a particular work environment would be harmful to their health, then applicants can have the opportunity to decline employment or employees can have the choice to stop working.102 Rather than just firing these individuals or precluding them from these jobs, the employer can clean up the workplace environment so that these substances are not harming the employees.

Unfortunately, this cleanup option is not always available to employers because of the economic costs involved.103 In addition, if employees do have other options available to them where they will not be exposed to dangerous substances that could detrimentally affect their well-being, it is a logical conclusion that they will take these opportunities instead.

96, at 143 (discussing how genetic screening could lead to a future where a person will have to produce a clean bill of health in order to get certain jobs).

99. See Kitcher, supra note 96, at 144.

100. See Kitcher, supra note 96, at 143, 145; see also Carl F. Cranor, Are Genes Us?: The Social Consequences of the New Genetics 176 (1995) (discussing employers’ preference in hiring those who do not have a genetic predisposition or susceptibility to “work-environment-related illnesses”).

101. See Kitcher, supra note 96, at 146.

102. Although it seems as if employers are looking out for the best interests of the employee, it may not always work out that way. Even though a specific work environment may be unhealthy, a person may still want and/or need to work there because they do not have any other option. They might not be able to find any other job suitable for them or what they are qualified to do. See Kitcher, supra note 96, at 146 (“Use of genetic information may not simply debar them from a particular job, albeit a job that would imperil their health, but render them effectively unemployable.”).

103. Although we are discussing legitimate uses of genetic information by employers, we must keep in mind the situations when employers can not bear the costs of cleanup or when they are simply irresponsible, ignorant or apathetic, and when applicants are misinformed or have no other choice.
It is also important for employers to look at "general health" risks in order to determine an applicant's qualifications for certain jobs. A genetic defect which predisposes a person to certain ailments or diseases, could have a direct impact on that person's productivity. An employer has an obvious incentive to choose a more productive applicant. A construction company, for example, would probably benefit from knowing which applicants seeking work in construction are not genetically susceptible to developing back problems. Also, certain jobs require extensive training. It would be beneficial for the employer to know if an applicant will develop an illness or ailment that could render them unproductive because it would be extremely costly for the employer to train replacements during these periods of unproductivity.

In some situations, a gene causing an illness that will manifest suddenly may be discovered and this information can be important where grave consequences could result affecting not only that person but the public at large. For example, it would be important for an airline to know whether or not a pilot is genetically at risk to develop heart disease. If a pilot is found to be at risk for heart disease, his/her employment could be detrimental to the public's safety because that pilot is more likely to suffer a heart attack in flight than is the pilot who is not predisposed to heart disease.

104. See supra note 96 and accompanying text.
105. See Kitcher, supra note 96 ("Genetic tests might show, for example, that a potential employee is at high risk for a neurological disorder that would inevitably curtail the person's career.").
106. See Herman Schuchman et al., Confidentiality of Health Records 147 (1982).
108. See id. at 144.
110. See Kitcher, supra note 96, at 144. (stating that "[a]t least one person working as an air traffic controller in the United States carries the long repeat for Huntington's disease. Should the flying public be protected by forcing him to retire before the symptoms of nervous degeneration begin?"). But see 67 The Reference Shelf: Genetics and Society 83-84 (Penelope Barker ed., 1995) which discusses how

[g]enetic tests are not only generally inaccurate when used for public safety purposes, but also unnecessary. A more effective approach to protecting the public's safety would be routine testing of a worker's actual capacity to function in a job that is safety-sensitive. Airline pilots, for example, currently undergo physical examinations every 6 months.

Id.
The negative consequences of allowing employers access to such information far outweigh the benefits. In the limited circumstances where access protects the individual or the public, genetic testing may be justified. However, in most situations the employer is allowed to benefit monetarily, while applicants and employees may be denied employment and may lose their jobs or insurance. Individuals with a heightened risk for certain illnesses are less attractive as employees. On average they may be able to spend fewer years in the workforce and they may impose greater health care costs on the employer. Therefore, there are some justifications for an employer's use of genetic information. However, some of these justifications only reveal the financial benefit received by the employer. Unfortunately, the government cannot simply trust that employers will only use one's genetic information when it will benefit the person and the public. Just as an employer has the right to run their business and to maximize their profits, the employees and job applicants have the right not to be discriminated against and not to have their genetic information used unjustly. Before discussing the abusive use of the information by the employer, it must also be understood that employers might not intentionally be using an employee's genetic information unjustly. The potential for mistake and misinformation is also highly probable.

2. The Potential for Misuse

Employers will not be able to justify their use of an employee's genetic information when the information is misinterpreted, when the employers are misinformed or when a mistake has been made. Many employers are not aware of the biological relevance of a gene defect. Often the presence of a gene or a gene mutation only predicts a "higher probability of disease, not the certainty of future illness."
An employer must understand the genetic information and its implications. It is important to realize that genetic testing is a relatively new phenomenon and is continually being perfected.\textsuperscript{116} Having a gene does not mean a person will inevitably have the illness nor does it mean that that person's children will also have the gene.

An employer might obtain an employee's genetic information and find that they have a gene that predisposes them to a specific illness. This information does not always give a definitive prediction. Often, genes are characterized by incomplete penetrance, meaning that "many individuals who carry the gene will never show manifestations of the gene."\textsuperscript{117} The specific gene or gene mutation may be a "necessary but not a sufficient condition for the disease to become manifest; other conditions must be present as well."\textsuperscript{118} Sometimes mutations on other genes are necessary, and, at other times, environmental factors are needed to trigger the symptoms.\textsuperscript{119} "As a result, genetic test information on predispositions to a disorder has a potential for falsely labeling persons as being at risk for the disorder."\textsuperscript{120}

Sometimes, when a gene manifests itself into developing the disease or disorder, "the extent of the gene's effects may differ widely from person to person."\textsuperscript{121} The resulting severity a disease will have upon a given person cannot always be predicted by a genetic test.\textsuperscript{122}

In addition, it is unlikely that employers will take into consideration the fact that individuals can modify their behavior so as to limit gene expression, thereby reducing the probability of developing the

\textsuperscript{116} See Brokaw, \textit{supra} note 114.

\textsuperscript{117} The Reference Shelf, \textit{supra} note 112, at 81; see Assessing Genetic Risks: Implications for Health and Social Policy 38 (Lori B. Andrews et al. eds., 1994).

\textsuperscript{118} Assessing Genetic Risks, \textit{supra} note 117 (emphasis omitted).

\textsuperscript{119} See Assessing Genetic Risks, \textit{supra} note 117 (emphasizing that although these factors do exist, they are often unknown).

\textsuperscript{120} Assessing Genetic Risks, \textit{supra} note 117.

\textsuperscript{121} The Reference Shelf, \textit{supra} note 112, at 81 ("Among individuals with sickle cell anemia, some die within the first years of life, while others survive into their 50s.").

\textsuperscript{122} See Assessing Genetic Risks, \textit{supra} note 117 ("Problems of penetrance and expressivity become even greater in testing for complex disorders in which multiple factors, of which the gene being tested is only one, contribute to the causation of the disease.").
An employer might react hastily to the employee who has a gene that will ultimately trigger a disabling disease, when the effects of the gene may not appear for some time. Because of the varying consequences that result from having a "disease gene," and the potential for employers to act without being fully aware of the significance of that gene, many individuals will unfairly be denied employment. The person may never develop the disease, and even if they do, it may have a mild effect or it may take years to affect the individual.

Even if employers are made aware of the fact that genetic information can be misinterpreted, no law exists protecting those at risk from an employer's ability to use such information when deciding whom to hire, whom to place in certain job categories, whom to promote to various positions, and whom to fire.

IV. GENETIC DISCRIMINATION

A. Definition

Genetic discrimination is the "denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests." A person is denied equal opportunity when they are discriminated against because of a particular genetic characteristic or on the perception of the existence of a genetic characteristic. This discrimination is as equally unjust as is discrimination based on race, gender or disability, because it too is based on a status over which an individual has no control.

123. See THE REFERENCE SHELF, supra note 112, at 81 ("Patients at risk for diabetes can modify their diet, as can patients at risk for coronary artery disease.").
124. See ASSESSING GENETIC RISKS, supra note 117, at 39 ("Because of the imperfect nature of genetic tests and the implications of both true positive and false positive test results, as well as false negative results, the understanding of those who offer tests and of the recipients themselves is crucial to appropriate use of genetic testing.").
125. See THE REFERENCE SHELF, supra note 112, at 81 ("For example, the onset of Huntington's disease does not occur until the patient is between the ages of 30 and 50 years.").
126. See THE REFERENCE SHELF, supra note 112, at 81.
129. See id. at 112.
130. See id.
B. Examples of Genetic Discrimination

Americans are losing jobs and health coverage because of the discovery of damaging genetic information. A recently conducted survey by Harvard and Stanford University examined people who might one day develop an inherited disease. About half of the respondents surveyed experienced genetic discrimination. Although these respondents did not exhibit symptoms of a disease, and may never exhibit them in the future, they admitted suffering from some form of discrimination.

One respondent, a twenty-four year old woman, was fired from her job as a social worker shortly after her employers learned that she was at risk of developing Huntington's disease. Prior to her termination she had received promotions and outstanding performance reviews. Obviously without any inclination that her job security would in any way be threatened, she had revealed to her employer during an in-service training session held on caring for Huntington disease patients, that she was at risk of developing Huntington's disease. Shortly thereafter, she was given a poor performance review, yet her employers were unable to justify the negative review and could not offer any examples that would deem her performance poor. After she was fired, a co-worker revealed

132. This study is entitled “Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis.”
133. See Swanson, supra note 131.
134. See Swanson, supra note 131.
135. See Swanson, supra note 131.
136. See Technological Advances in Genetics Testing: Implications for the Future: Hearings Before the Subcomm. on Technology of the House Comm. on Science, 104th Cong. (1996) (statement of Joseph P. Kennedy II); see also Swanson, supra note 131 (mentioning another respondent from this study who had a strong family history of Huntington’s disease and was told by her life insurance company that she could not get coverage unless she tested negative for the disease). For an explanation of this disease, see The Code of Codes: Scientific and Social Issues in the Human Genome Project 212 (Daniel J. Kevles & Leroy Hood eds., 1992) which explains that Huntington’s disease, a debilitating, fatal neurological disorder, causes “uncontrollable jerking and writhing movements of all parts of the body” and is “accompanied by . . . profound intellectual deterioration and . . . emotional disturbances,” lasting about 15-25 years and always resulting in death.
138. See id.
139. See id.
the employer's concern about her risk of developing Huntington's disease.\textsuperscript{140}

In another case, a fifty-three year old man, during his first job interview with an insurance company, had revealed that he had hemochromatosis, but was asymptomatic.\textsuperscript{141} At the second interview for the job with the insurance company, the company representative expressed the company's interest in hiring him, but disclosed that the company would withhold from offering him health insurance because of his hemochromatosis.\textsuperscript{142} He agreed to the condition and accepted the job offer without the added health insurance benefits.\textsuperscript{143} Finally, at the third and last interview, the offer of employment was rescinded, and the company representative expressed their interest in hiring him but stated that they were unable to do so because of his hemochromatosis.\textsuperscript{144} These are simply two examples of genetic discrimination in employment.

Researchers from Georgetown University and the Alliance of Genetic Support Group conducted another survey involving 332 people who have genetic disorders or who have family members with such disorders, and found that 43% of respondents were denied health insurance, life insurance or employment based on their disclosure.\textsuperscript{145} The study also found that “9% of respondents had refused a genetic test for fear that their insurance would be dropped if the result was positive.”\textsuperscript{146}

\textsuperscript{140} See id.

\textsuperscript{141} Since he was asymptomatic, he had not yet had any manifestations of the illness. See supra notes 117-120 and accompanying text; Technological Advances in Genetics Testing: Implications for the Future: Hearings Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. (1996) (statement of Joseph P. Kennedy II).


\textsuperscript{143} See id.

\textsuperscript{144} See id.


\textsuperscript{146} Id. This fear exists because people are not protected from this type of discrimination and because this information is not yet completely private. If people are afraid to take advantage of genetic testing, they are precluding themselves from possibly prolonging their own lives. It can also be detrimental to society as a whole because studies on improvements in medical treatments will be curtailed. See id. (referring to this study as the first major study to document serious genetic discrimination).
C. History of Genetic Discrimination in Employment

Genetic discrimination is not a new phenomenon. In the 1970's, a number of states initiated screening for sickle-cell anemia for African-Americans after the highly publicized events concerning four African-American Army recruits with sickle cell anemia caused distress amongst many American communities.\footnote{147} The four recruits had died during a pilot training exercise while at a moderately high altitude.\footnote{148} The National Academy of Sciences committee recommended that all African-American "recruits be screened and carriers [of the gene] be barred from duty as pilots."\footnote{149} For six years, the U.S. Air Force Academy barred carriers of the sickle cell gene regardless of whether they showed symptoms of the disease.\footnote{150} The Department of Defense initiated a policy of excluding carriers from aviation and flight crew training.\footnote{151} Several corporations began introducing sickle-cell screening amongst their workers because of fears that carriers might perform poorly or absorb medical resources.\footnote{152}

D. Why and How Genetic Testing Leads to Discrimination in Employment

Since genetic testing reveals an individual's predisposition for illness, it causes potential for employment discrimination.\footnote{153} People must be made aware that although genetic tests are presently available, the results of these tests are not private.\footnote{154} Employers, insur-
ance companies, adoption agencies or the federal government can obtain the results of these tests, increasing the chances for their adverse uses.\textsuperscript{155} Employers can decide not to hire a potential employee if that person will not be capable of working in the future because they possess a gene for a certain disease.\textsuperscript{156} "Employers may not want to hire individuals with a predisposition for cancer, Alzheimer's disease, or other illnesses since these individuals might impose higher health care costs on the employer."\textsuperscript{157} It can be argued that it is in the employer's best interest to hire individuals who are not predisposed to illnesses.\textsuperscript{158} Doing so "reduces replacement and retraining costs, interruptions in production, and insurance costs."\textsuperscript{159} As discussed in the previous section, having the gene for a disease or illness is not the same as having the disease or illness.\textsuperscript{160} Physical symptoms may either never manifest or may manifest far into the individual's future, which will cause an individual to be denied employment for no legitimate or fair reason.\textsuperscript{161}

Employers have many concerns when it comes to running a successful business. There are many factors that need to be taken into consideration to ensure profit maximization, the main goal of any business.\textsuperscript{162}

They may hope that [genetic] screening will avoid or reduce their civil liability in the case of a worker's job-related illness. They also may wish to avoid hiring susceptible workers and thus reduce expenses under worker's compensation, health benefits, retirement plans or other benefit programs, and to reduce the costs associated with absenteeism, sick leave, turnover, and the loss of business goodwill. Many prefer not to expose vulnerable

\textsuperscript{155} See id. (By "adverse use," the author is referring to a use contrary to the interests of the person submitting to genetic testing.).
\textsuperscript{156} See Miller & Huvos, supra note 153, at 371.
\textsuperscript{157} 67 THE REFERENCE SHELF: GENETICS AND SOCIETY 82 (Penelope Barker ed., 1995).
\textsuperscript{159} Id.
\textsuperscript{160} See Miller & Huvos, supra note 153, at 371.
\textsuperscript{161} See Miller & Huvos, supra note 153, at 371 (discussing how individuals can be refused work when they are completely able to work and their future ability to work is grounded in erroneous assumptions).
\textsuperscript{162} See generally George P. Smith & Thaddeus J. Burns, Genetic Determinism or Genetic Discrimination, 11 J. CONTEMP. HEALTH L. & POL'Y 23, 26 (1994) (discussing how employers and insurance companies might believe that discrimination based on genetic information is needed in order to run a profitable business).
workers to hazardous conditions for reasons of altruism, benevolence and medical ethics.163

Employers have an incentive to find out illnesses or diseases a person may be predisposed to have.164 Employers take into consideration an employee's performance at the job, the safety of co-workers and the public's safety165 and its overall effect on the company.

The greatest concern regarding employers' use of genetic information is its adverse effects on health insurance.166 In addition to the risk of not being hired or being fired, people's main concern is having health insurance for themselves and for their family. With the high costs of medicine and health care, people must have some type of health insurance in order to receive the benefits of medicine in the United States.167 Approximately 240 million Americans have some form of health insurance coverage.168 The majority of Americans obtain their health coverage through employment.169 “Many employers provide health insurance coverage through self-funded

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164. See generally Marne E. Brom, Note, Insurers and Genetic Testing: Shopping for that Perfect Pair of Genes, 40 Drake L. Rev. 121, 138 (1991) (stating that genetic testing can identify and predict genetic disorders, which would in turn, enhance workplace safety).
165. See id. at 136-39.
168. See id. (stating that “[g]roup insurance, individual insurance, self-insurance, and publicly financed insurance (for example, Medicare and Medicaid) are the principal forms of health insurance in the United States” for all of the approximately 240 million Americans that have coverage).

The United States is the only developed country that relies on the voluntary choices of employers to provide health coverage for most of its population. The source of this reliance lies both in the historically smaller role of government in American life and in a set of fortuitous, fifty-year-old legal decisions. During World War II, the War Labor Board ruled that medical benefits were not wages for purposes of binding wage controls. At the same time, the federal government, confronted for the first time with applying the vastly expanded income tax to ordinary workers, decided that health benefits were not taxable 'income.' Finally, the labor laws were interpreted to mean that employers had to bargain with their unions about health benefits.

THE CODE OF CODES, supra note 166, at 267; see also THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE 158 (Thomas H. Murray et al. eds., 1996) (“[Sixty-four] per-
plans in which the employer, either directly or through a third party, provides health insurance coverage."\textsuperscript{170} Employers are extremely interested in obtaining genetic information since they will bear the financial burden of their employees' medical costs.\textsuperscript{171} It has been shown that over the last ten years, employers lost a sizable part of their profits to health care costs.\textsuperscript{172}

There are three different methods by which employers pay for the health coverage that they buy for their employees. The first is known as "community-rating."\textsuperscript{173} With this type of coverage, the insurer charges each employer an amount per employee that corresponds to the insurer's average costs in that region.\textsuperscript{174} These premiums pay for the claims. The second method is "experience-rating" insurers.\textsuperscript{175} Here, different premiums are offered to different employers based on each employer's claims experience of the previous year or on a rolling average of the claims of past years.\textsuperscript{176} The third method is "self-insurance."\textsuperscript{177} When an employer is self-insured, "employers (and occasionally unions) agree to pay for the specified health benefits directly."\textsuperscript{178} Self-insured employers take the risk that the covered employees will have unusually high medical costs. If a company has healthy employees then it would be economical to use the "experience rating" method. This leaves the community-rating insurers with the more expensive groups which will lead to an increase in their rates.\textsuperscript{179}

Although many insurance companies are not yet administering genetic tests, the industry admitted that they do intend to use genetic information in the same manner that they utilize other pre-
dictive medical information. Because [insurance companies] bear the financial risk for the contingencies they insure, insurers need to predict how much money to collect in order to cover their expected payouts .... [I]nsurers need to remain solvent in order to make good on the claims or liabilities represented by their policy holders." In addition, commercial insurance companies have the right to make a profit. Since insurers are in the business of assessing risks, they can defend their right to use such predictive information as genetic information, as a simple exercise of "their right to earn a reasonable profit, and [to provide] an equitable insurance system to policy holders."  

E. How Employers Gain Access to Genetic Information

There are several ways in which insurers can acquire medical information including, information provided by the applicants themselves through application forms and questionnaires, through physician medical records and through the Medical Information Bureau.

Through a process known as underwriting, insurers select policy holders by examining the applicants through their medical history and other individual risk factors. Employers claim to lose a substantial amount of their profits to health care costs, and underwriting is one way of reducing financial risks. As a result, employers who are also insurance providers, have access to vast quantities of information concerning an employee or a potential employee's health, medical and family medical history and their use of medical services. Nothing is precluding their ability to gain access to a person's genetic information or genetic test results.  

180. See The Human Genome Project, supra note 169, at 133, 136.
181. See The Human Genome Project, supra note 169, at 135.
182. See The Human Genome Project, supra note 169, at 135.
183. See Kathy L. Hudson et. al., Genetic Discrimination and Health Insurance: An Urgent Need for Reform, SCIENCE, Oct. 20, 1995, at 391-92; see also The Human Genome Project, supra note 169, at 138 (defining the term underwriting to mean "the selection of risks") (emphasis omitted).
184. See Draper, supra note 169, at 206-07.
185. Small employers have a large incentive to weed out high risk employees as well because high medical costs cause a heavy burden to them. See id. at 207 ("While a large company can support high-risk employees, an employer with 20 employees is less able to sustain several employees with large health costs.").
186. "[T]here are whole companies that are dedicated to looking at people's medical record, abstracting the useful information for employers and insurers and other people who
access to individuals’ medical histories is so extensive that as soon as genetic tests enter into medical practice . . . the results will be available to underwriters.187

The following list exemplifies the extensive amount of information an employer can get from an employee’s medical record:

(1) a preemployment questionnaire and/or medical history, with or without a physical examination; (2) laboratory tests; (3) a chronology of episodic visits; (4) scheduled periodic examinations; (5) notes or letters from the employee’s private physician; (6) summaries of hospital records and other outside treatment records or consultations; (7) substance abuse problems; (8) psychiatric problems; (9) nonoccupational medical problems; and (10) family records.188

Self-insured companies have access to vast amounts of information concerning a person’s health history and use of medical services. Although self-insured companies obtain access to one’s medical records, other companies who are not self-insured can gain access to it as well.189 Once an employee goes to their own private doctor, they have to file a claim form administered by an insurance company.190 The insurance company then sends the employer a report on the employee’s medical treatment.191

Another problem exists when an employer hires their own in-house physicians as a means of screening employees.192 Employers will perform “genetic screening” tests on “job applicants and employees [to test] for certain inherited traits that may predispose them to disease.”193 These in-house doctors complain that the employers are constantly making requests to find out detailed medical information and test results.194 Employers make these requests

are interested in them, storing it, and selling it to them.” 60 Minutes (CBS television broadcast, Apr. 21, 1996) (quoting Dr. Paul Billings, from Stanford University and Veterans Administration Hospital, who was discussing how one’s medical record is similar to one’s credit record because anyone has access to the information).

187. The Human Genome Project, supra note 169, at 139.
188. Herman Schuchman et al., Confidentiality of Health Records 143 (1982).
189. See Draper, supra note 169, at 207.
190. See Draper, supra note 169, at 207.
191. See Draper, supra note 169, at 207.
192. See Draper, supra note 169, at 202.
so that they can use the information when making hiring and placement decisions. After employers make a “conditional offer of employment” to a job applicant, employers are allowed to require that person to undergo a series of tests. Employers can test for drugs, HIV and now with genetic tests available, they can test for certain genetic defects. Once the person is hired, the employer can modify the person’s health insurance coverage or can change their decisions regarding future employment and future job positions. Employers can exclude a person from medical coverage, charge extremely high rates, withdraw all coverage at any time or decide not to offer full family health coverage.

Employers also contract with outside doctors to conduct tests and provide screening data. As a result, “[m]ajor breaches of confidential medical records occur.” Contractors will breach the client-patient confidentiality because they do not want to lose the employer's business. “Many contractors send the entire employee medical record to management.” Often times, the contractors are not aware of the regulations regarding medical records and they just “assume that since the company pays for the medical information, they are entitled to all of it.”

In addition to these techniques utilized to obtain genetic information, “employers and insurers can obtain employee medical information from data bases such as the national Medical Information Bureau (MIB).” The MIB is an insurance industry-run data bank, accessible to nearly 800 member companies in the U.S. and Canada. This bureau contains medical records of about fifteen

195. See DRAPER, supra note 193.
197. See id.
198. See id.
199. See id.
200. See id. at 203.
201. Id.
202. They will submit the medical records for fear that if they don't, the employer will find another contractor who will. Id.
203. Id.
204. Id.
205. Id. at 204.
million people in the United States. These records contain information about genetics and family diseases of the individuals. Member companies send information acquired through underwriting to the MIB daily. In many circumstances, people sign a waiver authorizing the MIB to have the medical information when applying for insurance. This enables an insurance provider the ability to obtain whatever records the MIB has. Unfortunately, these records could be inaccurate and can contain negative information about the person which can be used against the person in employment or in receiving health insurance and little restriction is placed on insurance companies to limit their use of information obtained from the MIB in underwriting decisions.

V. THE NEED FOR FEDERAL LEGISLATION

A. State Legislature's Role in Preventing Genetic Discrimination

Several states have already recognized that this is a tremendous problem and have taken action to protect against these discriminatory situations. Fifteen states have enacted laws that offer varying levels of protection against different abuses that could result when an employer/insurer has access to a person’s genetic information. As significant a step as this may be, people in thirty-seven states are still left unprotected, and in those where laws have been enacted, the laws are not all adequate in completely protecting people against genetic discrimination. The state laws offer various levels of protection against genetic discrimination with some geared only to

207. See Draper, supra note 194, at 204.
208. See Draper, supra note 194, at 204.
209. See The Human Genome Project, supra note 206.
210. See The Human Genome Project, supra note 209; Draper, supra note 194, at 204.
211. See Draper, supra note 194, at 204.
212. See Draper, supra note 194, at 204-5.
213. See The Human Genome Project, supra note 206.
discrimination in employment\textsuperscript{215} and others limited to only insurance.\textsuperscript{216} Six states have laws prohibiting employers from discriminating based on one’s genetic information.\textsuperscript{217} Eleven states have laws that restrict the use of genetic testing by insurance companies.\textsuperscript{218} Of these states, some of the laws prohibit insurers from requiring a person to undergo a genetic test\textsuperscript{219} and some prohibit insurers from using the information obtained through genetic testing to deny coverage or to limit the terms and conditions of insurance,\textsuperscript{220} and some do both.\textsuperscript{221} As demonstrated, several states are deficient in certain areas. Only five of the fifteen states have recognized the need to protect individuals in both the employment and insurance realms.\textsuperscript{222} Although these statutes are extremely differ-

\textsuperscript{215} See IOWA CODE ANN. § 729.6 (West 1997); N.J. STAT. ANN. § 10:5-12 (West 1997); N.Y. EXEC. LAW § 296 (McKinney 1997); R.I. GEN. LAWS § 28-6.7-1 (1995).
\textsuperscript{216} See CAL. INS. CODE § § 10140, 10146 & 10148 (West 1997); COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1997); FLA. STAT. ANN. § 760.40 (West 1997); GA. CODE ANN. § 33-54 (Michie 1996); MD. CODE ANN., INS. § 27-909 (1997); MNE. STAT. ANN. § 72A.139 (West 1997); OHIO REV. CODE ANN. § § 1742.42 & 3901.49 (Anderson 1996); VA. CODE ANN. § 38.2-508.4 (Michie 1997).
\textsuperscript{217} See IOWA CODE ANN. § 729.6 (West 1997); N.H. REV. STAT. ANN. § 141-H (1996); N.J. STAT. ANN. § 10:5-12 (West 1997); N.Y. EXEC. LAW § 296 (McKinney 1997); R.I. GEN. LAWS § 28-6.7-1 (1995); WIS. STAT. ANN. § 111.372 (West 1996).
\textsuperscript{218} See CAL. INS. CODE § § 10140, 10146 & 10148 (West 1997); COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1997); FLA. STAT. ANN. § 760.40 (West 1997); GA. CODE ANN. § 33-54 (Michie 1996); MD. CODE ANN., INS. § 27-909 (1997); MNE. STAT. ANN. § 72A.139 (West 1997); N.H. REV. STAT. ANN. § 141-H (1996); OHIO REV. CODE ANN. § § 1742.42 & 3901.491 (Anderson 1996); OR. REV. STAT. § 746.135 (1995); VA. CODE ANN. § 38.2-508.4 (Michie 1997); WIS. STAT. ANN. § 631.89 (West 1997).
\textsuperscript{220} See CAL. INS. CODE § § 10140, 10146 & 10148 (West 1997); COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1997); FLA. STAT. ANN. § 760.40 (West 1997); GA. CODE ANN. § 33-54 (Michie 1996); MD. CODE ANN., INS. § 27-909 (1997); MNE. STAT. ANN. § 72A.139 (West 1997); N.H. REV. STAT. ANN. § 141-H (1996); OHIO REV. CODE ANN. § § 1742.42 & 3901.491 (Anderson 1996); OR. REV. STAT. § 746.135 (1995); VA. CODE ANN. § 38.2-508.4 (Michie 1997); WIS. STAT. ANN. § 631.89 (West 1997).
\textsuperscript{221} See CAL. INS. CODE § § 10140, 10146 & 10148 (West 1997); GA. CODE ANN. § 33-54 (Michie 1996); MD. CODE ANN., INS. § 27-909 (1997); MNE. STAT. ANN. § 72A.139 (West 1997); N.H. REV. STAT. ANN. § 141-H (1996); OHIO REV. CODE ANN. § § 1742.42 & 3901.491 (Anderson 1996); WIS. STAT. ANN. § 631.89 (West 1997).
ent, ranging from extremely broad protection to almost no protection at all; they are the only states that have acknowledged that the potential for genetic discrimination can occur in both insurance and employment. California, Colorado, Georgia and Ohio have statutes that only prohibit health insurance companies from using genetic information to deny coverage or set higher rates based on genetic tests. Rhode Island, Iowa, Wisconsin and New York state statutes regarding genetic discrimination prohibit employers from using genetic information to the detriment of the employee or job applicant. In addition, Florida’s Civil Rights Law acknowledges the existence of a right to privacy with regard to results of genetic tests and genetic information.

Other states have begun to examine this issue as at least four bills are pending in California, Massachusetts, Michigan and Pennsylvania. Although it would appear as if progress has been made, ten states voted down genetic discrimination laws in the 1995-96 legislative session.

1. Limitations in State Laws

The incomplete patchwork of state laws that leave some less protected and some persons completely unprotected, stresses the need for an all-inclusive, comprehensive federal statute. This would mandate all states to offer protection and it would provide state legislators with guidance when creating such laws. Several issues need to be considered when enacting a statute that will protect peo-
ple from being discriminated against because of their genetic information. These issues include assuring that this private information that we are born with is kept confidential. Individuals should have complete control over who has access to their genetic information and individuals should have control over how this information is being used. Another issue deals with the use of a person's genetic information by employers and insurance companies and whether these entities should be permitted to require an employee, applicant or insured to undergo a genetic test. This issue is important because genetic testing during a routine medical examination could soon become as commonplace as a blood test is today. Nothing prohibits an employer or insurer from compelling applicants or employees to undergo a medical examination. If a genetic test is administered, it is important to decide whether or not an employer/insurer should have access to this information. If they do have access, the individual needs to be protected from the negative consequences that can result when employers/insurers use this information to their benefit. As previously discussed, employers can refuse to hire or can fire an individual when they have knowledge of certain genetic defects. Employers could also withhold certain medical benefits that come with employment. Insurers could use one's genetic information as a means of assessing risks in such a way that they will deny coverage to individuals or limit the terms and conditions of insurance. It is also important to define exactly what constitutes "genetic information." Most of the laws focus only on genetic tests. This is not enough because broader protection is needed for all genetic information, not simply the results of a genetic test. Genetic information can also be deciphered through family history, physical examinations or medical records.230

2. An Evaluation of State Statutes

a. New Hampshire

New Hampshire has one of the most comprehensive statutes regarding genetic discrimination in all of the United States.231 To date, it offers the best protection against genetic discrimination.


Firstly, "genetic testing" is defined more broadly than the definition provided for in most other state statutes. Most other statutes focus only on genetic testing material being only specific biological tests of a person's chromosomes. A person's genetic information could also be generated by family history, physical examinations and medical records. New Hampshire's definition includes, in addition to an actual genetic test, any examination or analysis generally accepted in the scientific and medical communities. One important aspect of the law is that an individual is assured that they have complete control over what genetic information is generated about them. The New Hampshire law on genetic testing sets out guidelines for the performance of genetic tests on individuals. In order for an individual to undergo a genetic test, that individual must give their written and informed consent. In addition, the results of the test can only be disclosed if the individual undergoing the test approves of the disclosure in writing. No one can disclose the results of one's genetic test or even disclose that a given individual underwent a genetic test "without the prior written and informed consent" of that individual. Furthermore, no person can refuse to do business with an individual solely because the individual to be tested refuses to consent to providing the test results to some or all persons.

232. Section 141-H:1(IV) defines "genetic testing" as follows:

a test, examination, or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence, or alteration of any gene or chromosome, and any report, interpretation, or evaluation of such a test, examination, or analysis, but excludes any otherwise lawful test, examination, or analysis that is undertaken for the purpose of determining whether an individual meets reasonable functional standards for a specific job or task.

§ 141-H:1(IV).

233. One example of the limited scope of the protection offered for genetic testing comes from Colorado's statute where genetic testing is defined as "any laboratory test of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness." COLO. REV. STAT. ANN. § 10-3-1104.7(2)(b) (West 1997). Another example is from Iowa's statute. Genetic testing is defined as "a test of a person's genes, gene products, or chromosomes, for abnormalities or deficiencies . . . ." IOWA CODE ANN. § 729.6 (1)(e) (West 1997).


235. Section 141-H:2(II) states that, except with respect to paternity testing, newborn screening and forensic testing, "no genetic testing shall be done . . . without the prior written and informed consent of the individual to be tested." § 141-H:2(II).

236. See id.

237. Id.

238. See id.
New Hampshire’s law also describes the use of genetic testing in employment situations as well as its use in health insurance.\(^\text{239}\) It prohibits employers, labor organizations, employment agencies and licensing agencies from requiring an individual to take a genetic test as a condition of employment, labor organization membership or licensure, nor can they affect the terms, conditions or privileges of employment.\(^\text{240}\) The law even accounts for specific situations when genetic testing may be needed to determine “the employee’s susceptibility or level of exposure to potentially toxic chemicals or . . . substances in the workplace” by giving employees the opportunity to take such tests without fearing termination and without allowing the employer to take any adverse action against the employee.\(^\text{241}\)

This law covers most areas where problems may arise and it protects an individual from the harms that could result if an employer or insurer obtains the results of their genetic test. The law, however, does lack in some respects because its provisions do not apply to life, disability income or long-term care insurance.\(^\text{242}\) In addition, although New Hampshire’s law provides a broader definition of genetic testing it may not be broad enough. “[A] test, examination, or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence, or alteration of any gene or chromosome”\(^\text{243}\) has not yet been tested in the courts. Therefore, it may be construed narrowly to only include the results of an actual genetic test.\(^\text{244}\) Another deficiency in New Hampshire’s statute is that although it provides control over what information is generated, individuals are not given control over who has access to the information that is obtained. Colorado’s statute, for instance, gives individual’s exclusive control of their genetic information by ensuring its confidentiality.\(^\text{245}\)

\(^{239}\) See § 141-H:3.

\(^{240}\) See § 141-H:3(I).


\(^{242}\) See § 141-H:5(I).


\(^{244}\) Protection is needed for even that information simply obtained by analyzing a person’s family history.

\(^{245}\) Colorado’s §§ 10-3-1104.7(1)(a) & (3)(a) state: "genetic information is the unique property of the individual to whom the information pertains . . . . Information derived from genetic testing shall be confidential and privileged. Any release, for purposes other than diagnosis, treatment, or therapy, of genetic testing information that identifies the person
b. New York

New York recently amended its Executive Law, which deals with unlawful discriminatory practices, to add genetic predisposition to the list of factors upon which discrimination is prohibited. Under the new amended law, it shall be an unlawful discriminatory practice:

- for an employer or licensing agency, because of the age, race, creed, color, national origin, sex, disability, genetic predisposition or carrier status, or marital status of any individual, to refuse to hire or employ or to bar or to discharge from employment such individual or to discriminate against such individual in compensation or in terms, conditions or privileges of employment.\(^{246}\)

New York’s law now offers protection from almost all forms of genetic discrimination committed by an employer. Rather than only prohibiting the unlawful use of a person’s genetic test information, New York’s Executive Law provides protections for one’s genetic predispositions. The term “genetic predisposition” is defined as:

- the presence of a variation in the composition of the genes of an individual which is scientifically or medically identifiable and which is determined to be associated with an increased statistical risk of being expressed as a physical or mental disease or disability in the individual but which has not resulted in any symptoms of such disease or disorder.\(^{247}\)

New York’s law discusses genetic testing separately, making it unlawful for an employer to directly and indirectly solicit, require or administer a genetic test to a person as a condition of employment.\(^{248}\) The employer is prohibited from acquiring the results of a genetic test through any means.\(^{249}\) An employer, however, does have permission to require an employee or applicant to undergo a genetic test if the test results released requires specific written consent by the person tested.

\(^{246}\) N.Y. Exec. Law § 296(1)(a) (McKinney 1997).

\(^{247}\) § 292(21)(b).

\(^{248}\) See § 296(19)(a)(1).

\(^{249}\) It shall be an unlawful discriminatory practice for an employer “to buy or otherwise acquire the results or interpretation of an individual’s genetic test results or to make an agreement with an individual to take a genetic test or provide genetic test results.” § 296(19)(a)(2).
specific genetic test as a condition of employment. This test must be "directly related to the occupational environment, such that the employee or applicant with a particular genetic anomaly might be at an increased risk of disease as a result of working in said environment."

**c. Florida**

Florida’s genetic testing statute offers the least amount of protection. It only discusses genetic testing with regard to an extremely narrow definition. It deals only with the “medical and biological examination and analysis of a person to identify the presence and composition of genes in that person’s body.” The only protection offered is that the results of this DNA analysis may not be disclosed without consent of the person tested, making it the person’s “exclusive property.” However, it almost seems as though genetic discrimination in employment and insurance is permissible in Florida. Under Florida’s law, the only “protection” offered to people is that they must be given notice of its use and if it was used to deny employment or insurance, the results of the tests must be analyzed to determine its accuracy. If it is accurate, the statute seems to imply that the denial would be upheld.

**B. The Americans with Disabilities Act: One Small Step**

The first step to forestall discrimination in employment based on a person’s genetic predisposition for an illness or disease was taken by the Equal Employment Opportunity Commission (“EEOC”) for the Americans with Disabilities Act. In March 1995, the Equal

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250. § 296(19)(b).
253. The author comes to this conclusion because of the following words in the statute: [a] person who performs DNA analysis . . . must provide the person tested with notice . . . stat[ing] whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. If the information was used in any decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed. § 760.40(3). Therefore the only real protection offered to people in Florida is the opportunity to have an unjust action subject to review.
254. The EEOC is the administrative federal agency responsible for enforcing the ADA. See The Human Genome Project and the Future of Health Care 162 (Thomas H. Murray et al. eds., 1996).
Employment Opportunity Commission ("EEOC") extended the coverage under the Americans with Disabilities Act ("ADA") to include individuals who are regarded as having genetic impairments. The EEOC issued an amended compliance manual that released guidelines which clarified the definition of "disability" under the ADA to include people who experience "discrimination on the basis of genetic information relating to illness, disease, or other disorders." The EEOC refers to an asymptomatic illness and categorizes it as a 'disability' for ADA purposes. The ADA definition of "disability" includes "with respect to an individual (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." The third part of the definition applies to individuals subjected to discrimination based on genetic impairment. Therefore, employers who make adverse employment decisions based solely on genetic predisposition violate the ADA because they regard an applicant as having an impairment. However, in order to qualify, an individual must both show that an employer regarded the individual as having a genetic defect, and 'acted on that basis.' There have been several documented situations where a person is discriminated against as merely being a carrier of a genetic defect. It does not appear as though the ADA takes this type of genetic discrimination into account. Therefore, individuals who are merely carriers of a gene, but who will never manifest the disease can suffer from discrimination because this doesn't seem to fit into any of the definitions of disability.

Although the EEOC defines a disability broadly to include genetic mutations that predispose an individual to an illness, it still does nothing to prohibit employers from obtaining a person's medi-

256. Id.
257. An asymptomatic illness refers to an individual’s susceptibility to develop a disease due to a genetic predisposition. See Dee Lord, Something in the Genes, A.B.A. J., Apr. 1996, at 86.
259. See id.
The EEOC does not limit what type of medical information an employer could ask for. Genetic screening is permitted under the ADA after a conditional offer of employment is extended only if all new employees in the same job category are subjected to such screening. It is unclear how properly obtained genetic information may be used. Also "the EEOC has not specifically determined whether a potential employer can deny an applicant a job because the individual, although completely healthy, carries a defective gene which can pass to the applicant's offspring, and the employer does not want to pay future health care costs associated with the children." After an offer of employment is made, physicians are not limited in what medical information they collect. The employers' ability to make these unlimited and questionable inquiries and examinations leaves any individual skeptical about how this information is being used. As long as employers have access to genetic information, they will have the ability to use it, which most likely will be to the detriment of the employee. The EEOC should limit what type of medical examinations and inquiries an employer could make so that employers are not able to obtain whatever information they want. Presently, employers have access to many types of non-job-related information about their workers and their workers' families. Furthermore, the EEOC and the ADA do not set any restrictions on the information acquired through genetic testing and little protection is offered to people on the insurance level. Under the ADA, employers are permitted to retain and devise health benefit plans that vary in the type of coverage offered to employees. Health insurance provided by the employer can exempt an entire class of disabilities from cover-
age or can refuse to provide reimbursement to an entire class of medical services or treatments without being in violation of the ADA. "The EEOC does not view the creation of a benefit plan as discriminatory if its decisions can be justified on valid risk classification and underwriting principles, or if the employer can show that it can financially sustain its plan only by excluding certain classes of disorders."  

C. The Next Step: The Health Insurance Portability and Accountability Act

The recently enacted health insurance reform law, the Health Insurance Portability and Accountability Act of 1996, prohibits insurance companies from refusing health insurance coverage to individuals on the basis of their medical history, including "genetic information." The main purpose of this insurance act was to guarantee coverage to anyone leaving one group health insurance plan for another and to allow employees to take health insurance with them to new jobs. However, the 104th Congress did recognize the newly debated issue concerning genetic information and its detrimental use by insurance companies by not including genetic information within the "preexisting condition exclusion." Under this Act, "a group health plan, and a health insurance issuer offering group health insurance coverage, may, with respect to a participant or beneficiary, impose a preexisting condition exclusion" if the exclusion "relates to a condition ... for which medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period ending on the enrollment date ...." Under this Act, group health insurance plans are prohibited from considering genetic information to be a preexisting condition when the manifestations of the gene defect have yet to be diagnosed. This is a

271. See id.
272. See id.
The Human Genome Project

significant first step in the evaluation of federal legislation. According to the Act:

a group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, may not establish rules for eligibility . . . of any individual to enroll under the terms of the plan based on any of the following health status-related factors in relation to the individual[']s . . . genetic information . . . .

There are several drawbacks to this provision which reinforces the fact that an all-inclusive federal law is still needed. The biggest drawback to this provision is that it does not define what constitutes “genetic information.” As previously discussed, there is an ongoing debate about what constitutes “genetic information,” whether it should be confined solely to the results of genetic tests or whether it should include other details, such as a person’s family history and previous medical treatment. For example, even without a genetic test, insurance companies can draw conclusions about one’s genetic information based on the medical histories of their parents.

Another major deficiency with this Act is that it only applies to group health insurance plans. The Act does not protect the rights of those who purchase independent insurance plans or individual plans or those who are self-employed, and the uninsured. Those individuals who need individual plans, like the self-employed, may be denied individual coverage based on their genetic information. If a person is unemployed and does not have access to group insurance from a previous employer, they could be denied coverage if their genetic information reveals that they are at risk for developing a genetic illness. Those with individual plans still suffer the risk that their premiums will be raised or their coverage will be dropped if a gene defect is discovered. Many Americans who need individual plans have to satisfy numerous conditions

278. This is extremely important because there are approximately 40 million people who are uninsured in the U.S. today. See Ken Cottrill, US Reforms Leave Many in the Cold, THE GUARDIAN (England), Oct. 3, 1996, (Magazine), at 2; see also Technological Advances in Genetics Testing: Implications for the Future: Hearings Before the Subcomm. on Technology of the House Comm. on Science, 104th Cong. 81 (1996) (testimony of Karen Rothenberg).
before obtaining coverage. Even if an individual could jump all the hurdles by satisfying the "litany of conditions," insurers are still allowed to charge exorbitant rates. Insurance companies are not prohibited from raising rates for entire groups, excluding all coverage for a particular group or from imposing lifetime caps on all benefits or on specific benefits.

To name yet another drawback, the group health insurers are still permitted to obtain the results of a genetic test. The Act does nothing to secure the privacy and confidentiality protections that every individual has a right to in their own genetic material. Insurers are still allowed to require or request that an individual undergo genetic testing and they do not need to obtain the consent of the individual or authorization from the individual before obtaining the results of the genetic test.

VI. CONCLUSION

Genetic information is like race, gender, national origin and disability. We are born with it and it represents who we are. We cannot choose what types of genes we will inherit just like we cannot choose our race or gender. It should not be used against us. As minorities were once treated as a "lower class," genetic testing, if not protected, could create a new "biological underclass." What is important to realize is that unlike other pieces of civil rights legislation, this will eventually affect each and every one of us. Dr. Collins, the Director of the Human Genome Project, says that "[w]e all have four or five glitches, misspellings in our DNA somewhere.

280. Id.
281. See id. At some point this ability to charge high rates could have the same effect as the denial of coverage.
282. For example, "it appears that this form of discrimination against women with breast cancer and/or genetic predisposition to breast cancer . . . would be permitted as long as plan characteristics are not directed at individual sick employees or dependents." See Technological Advances in Genetics Testing: Implications for the Future: Hearings Before the Subcomm. on Technology of the House Comm. on Science, 104th Cong. 83 (1996) (testimony of Karen Rothenberg).
283. See id.
284. See id.
We're all going to have the opportunity to learn those bits of information if we decide we want to. If a person gets an unlucky genetic inheritance they should not have to suffer discrimination as well.

Something must be done quickly. New genes are constantly being discovered each week and once a gene related to a disease is identified, a diagnostic test detecting that gene is made available in just a matter of months. In order for this research to benefit society, people cannot be afraid to take advantage of the new medical technology that has developed and continues to develop. Congress must pass federal law now, before decisions against each and every one of us are made by self-interested parties. Congress has proscribed discrimination against certain classes based on inherent characteristics like race, gender, religion, national origin, age and disability. Genetic predisposition must be added to the list.

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286. Saturday Today (NBC television broadcast, Sept. 21, 1996); see also MAPPING AND SEQUENCING THE HUMAN GENOME 26 (Committee on Mapping and Sequencing the Human Genome, 1988).
