2002

Genetic Testing & Discrimination in Employment: Recommending a Uniform Statutory Approach

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GENETIC TESTING & DISCRIMINATION IN EMPLOYMENT: RECOMMENDING A UNIFORM STATUTORY APPROACH

I. INTRODUCTION

Advances in science and technology have made it possible for the medical community to diagnose and detect genetic abnormalities before the people who have these abnormalities become symptomatic. These advances will give doctors the ability to prevent and treat life-threatening conditions with early and aggressive treatment. As a result of this ability to detect diseases and debilitating medical conditions before they arise, employers now have the ability, and are utilizing this new medical advance, to screen potential employees. This screening takes place before employees have been hired and the result can affect employers' hiring decisions. With the possibility of putting their current or future employment at jeopardy, people who might benefit from the use of genetic tests may not undergo these tests if the results are made available to their employers.

While the use of genetic testing and screening is not currently widespread, its expansion is inevitable with the advent of newer genetic technologies and the rapidly decreasing cost to conduct these genetic tests. One motivation "for an employer to use an employee's genetic

3. Santiago, supra note 1, at 703. Contra Melinda B. Kaufmann, Genetic Discrimination in the Workplace: An Overview of Existing Protections, 30 LOY. U. CHI. L.J. 393, 399-400 (1999) ("[H]owever, most of the genetic tests available are unreliable and often inconclusive. Often a genetic test can only reveal the possibility that a person may develop a certain disease in the future, but cannot tell whether the individual will actually get the disease." (footnote omitted)).
5. Wukitsch, supra note 2, at 40. "One study conducted by Harvard and Stanford University found that '[a]bout half of the respondents surveyed experienced genetic discrimination [even though they] did not exhibit symptoms of a disease, and may never exhibit them in the future.'" Santiago, supra note 1, at 705 (footnote omitted).
6. Kaufmann, supra note 3, at 394. "A 1989 survey of 400 employers by Northwest Life Insurance found that, by the year 2000, 15 percent of employers plan to check the genetic status of
results would be to assess the increased costs associated with various types of illnesses (i.e., increased medical costs, early retirements, or the extra costs of new staff). 7 The rationale behind this assessment is that a majority of an employer's expenses can be derived from health and welfare costs. 8 Thus, employers would be tempted to use the results of genetic tests to determine which employees would increase productivity, and at the same time, minimize health and welfare expenses. 9

In response to the potential for employers to discriminate against employees using the results of genetic tests, at least twenty-six states have enacted statutory laws addressing genetic discrimination. 10 The issue of genetic discrimination has also been raised on the federal level, but currently there is no uniform federal law regulating the use of genetic information in the workplace. 11 With the lack of federal guidance, and the numerous and varied state approaches to the issue, it is time to enact a uniform statutory approach. A uniform approach would serve as a guide at both the federal and state level. This note recommends a model statute that addresses the employment discrimination facilitated by genetic testing.

This note first outlines a background on genetic science. After a basic understanding of the fundamentals of genetic research is presented, the note illustrates how the advent of scientific technology and breakthroughs in genetic research are making it possible for employers to use this technology to the detriment of their employees. This note presents the various types of genetic testing employers have at their disposal and how employers can use these tests to discriminate against employees in the hiring/firing process. Next, the note analyzes the current federal legislation regulating workplace discrimination, illustrates its various shortcomings, and examines its failure to protect employees from genetic discrimination in the workplace. A detailed examination of numerous state laws is presented next. The state statutes were developed to regulate genetic discrimination in the workplace in the absence of federal guidance. The analysis of current state laws.

7. Wukitsch, supra note 2, at 40.
9. Id. at 111.
10. Medical Breakthrough Revives Debate on Genetic Information Employment Issues, 1120 Lab. L. Rep.: Empl. Prac. (CCH) 1, 6 (July 20, 2000) [hereinafter Medical Breakthrough].
11. Wukitsch, supra note 2, at 43.

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addressing the issue shows a lack of comprehensive protection offered to employees suffering from genetic disorders. Finally, a model statute is constructed, drawing on current federal and state law in the area. This model statute melds existing federal and state laws into a cohesive unit that offers employees protection from genetic discrimination in the workplace.

II. BACKGROUND

This section provides a brief introduction to the science and history behind genetic discrimination. The use of genetic testing in the employment setting has potential benefits, as well as numerous drawbacks and shortcomings. Employers have access to different methods of genetic screening and monitoring and offer certain justifications for their use.

A. Genetics: Understanding the Science of Discrimination

Genes are the true building blocks of life. Genes are pieces of deoxyribonucleic acid, better known as DNA, which link together to make chromosomes with every individual cell consisting of twenty-three pairs of chromosomes. Every cell that makes up the human body contains genetic information. This genetic information is encoded in DNA and organized in genes. Each gene contains information that determines specific human traits, such as eye color and hair color. Every person's genes are unique and, as such, contain a map of each individual's biological past and future. Additionally, it is through our genes that familial characteristics are inherited and ultimately passed on to our children.

In 1986, the United States initiated a series of studies to determine whether a large-scale effort aimed at mapping and sequencing all genes

12. Santiago, supra note 1, at 704.
13. Id.
16. Id.
17. Santiago, supra note 1, at 704.
19. Id. at 360.
within the human body was a feasible project. As a result of the study, the Human Genome Project (HGP) was born. The sheer size of the project is illustrated by the fact that scientists estimate “that there are over 3 billion base pairs of DNA in the human genome.” What began as a study in the United States has mushroomed into an international effort that now includes France, Italy, Japan, Russia, and the United Kingdom, with all countries focused on the goal of mapping and sequencing every gene within the human body. The ultimate goal of the HGP was the treatment, cure, and prevention of diseases of genetic origin. As a result of the knowledge and new information gained from the HGP, the use of genetic testing will become more available and widespread.

The use of genetic testing allows scientists and doctors to detect the presence of genes that are the cause of future human diseases. Genetic testing is the laboratory analysis of DNA’s genetic make-up and determines the presence or absence of defective genes. Genetic information is important because a large number of health disorders contain a genetic component. The use of genetic testing has many benefits, such as finding cures for numerous diseases and alerting people about a genetic predisposition they have toward a disease, allowing them

21. “The Human Genome Project (HGP) is... jointly managed by the U.S. Department of Energy and the National Institutes of Health, to analyze the structure of human DNA and to map and sequence the estimated 50,000 to 100,000 human genes.” Miller, supra note 6, at 194 n.1.
22. Rachinsky, supra note 20, at 580. “Amidst euphoria generated by the Human Genome Initiative, the National Institutes of Health and the Congress have expressed concern that genomic information may result in stigmatization and discrimination.” Gostin, supra note 8, at 112 (footnotes omitted).
23. Kaufmann, supra note 3, at 396 (footnote omitted).
24. See Rachinsky, supra note 20, at 580.
25. Santiago, supra note 1, at 704. 
27. Santiago, supra note 1, at 704. 

Genetic tests may be employed for several reasons, including: (1) carrier screening, which can identify an unaffected individual carrying a single copy of a defective gene for a disease that requires two defective copies for the disease to be expressed, (2) prenatal diagnostic testing, (3) newborn screening, (4) presymptomatic testing for predicting adult-onset disorders such as Huntington’s disease, (5) presymptomatic testing for estimating the risk of developing certain disorders such as adult cancers and Alzheimer’s disease, (6) confirmational diagnosis of a symptomatic individual, and (7) forensic/identity testing.

Rachinsky, supra note 20, at 579.
29. Id. at 360.
to take preventive measures to reduce their chances of contracting the disease. Unfortunately, while the use of genetic testing may provide invaluable information about the detection of numerous human diseases, a potentially disastrous side effect is that employers can gain access to the genetic information and discriminate in the hiring of employees on the basis of their genetic test results.

Genetic testing can reveal three different categories of human conditions. The first condition is a "disease or defect that is directly attributable to a genetic defect." This condition means that a person tested either has the disease or will develop the disease in the future. The second condition reveals whether a person is a carrier of a particular disease or genetic defect. It is important to note that someone who is a carrier will never develop the disease. Finally, the third condition is a predisposition to developing a disease. Under the third condition, the individual is "asymptomatic" and may never develop the disease, but the person is susceptible to developing the disease. As a result of the three conditions revealed by genetic research, scientists are able to determine which individuals are at risk of falling prey to genetic discrimination.

Those likely to be victims of genetic discrimination are individuals who "carry a gene that predisposes them to developing the disease, but who are currently asymptomatic," individuals who are carriers of certain genetic diseases, but who will never develop the diseases or symptoms of the diseases in their lifetimes, and, individuals with genetic defects, but whose genetic defects are not associated with any type of disease. The last category of people with the possibility of being discriminated against, because of genetic testing, are those guilty by association—relatives of the individuals about whom a genetic defect is known.

30. Santiago, supra note 1, at 704-05.
31. Rachinsky, supra note 20, at 580.
32. Santiago, supra note 1, at 704; see also Rachinsky, supra note 20, at 580-81.
33. Santiago, supra note 1, at 704.
34. Id.
35. Id.
36. Id. at 705.
37. Id.
38. Santiago, supra note 1, at 705.
40. Id.
41. Id.
42. Id. at 581.
43. Id.
While genetic testing can alert an individual to an increased likelihood of developing a particular disease or physical condition, it is important to note that this predisposition is not an absolute indication that the individual will definitely become ill.\textsuperscript{44} "In other words, \textquoteleft[p]redisposition does not equal certitude.'\textsuperscript{45} Thus, the issue is that everyone has the potential to be discriminated against because anyone can have errors in their DNA.\textsuperscript{46} This point is supported by the fact that genetic testing is unable to determine with 100\% accuracy that an individual will develop a disease or condition, which is an important reason why a uniform genetic discrimination law is needed.

B. The Use of Genetic Testing in Employment

Over the years, employers have used various tests and other means to obtain information about their job applicants.\textsuperscript{47} These methods have included written tests used to measure an applicant’s ability to perform the job, questionnaires about family history, drug tests, and the administration of polygraph tests.\textsuperscript{48} But with each new test employers have used to determine an applicant’s qualifications, legislation has usually followed to regulate the administration of these tests and to protect applicants from employment discrimination.\textsuperscript{49} Today, with the advent of genetic testing, employers have a new avenue open to them through which they can test and screen their applicants.\textsuperscript{50} The difference between genetic testing and the earlier forms of testing available to employers is that there has been no federal legislation enacted directly addressing genetic discrimination.\textsuperscript{51} The result has been a lack of protection for employees facing genetic discrimination.\textsuperscript{52}

While the increased use of genetic testing has the potential to generate many positive benefits for society, there is also the risk that the information provided by the tests will be used by employers to

\begin{footnotes}
\footnotetext[44]{Rachinsky, supra, note 20, at 581.}
\footnotetext[45]{Id. (footnote omitted).}
\footnotetext[46]{Id. ("Each of us has an estimated five to thirty serious misspellings or alterations in our DNA. Thus we could all be targets for discrimination based on our genes.") (footnote omitted).}
\footnotetext[47]{Wukitsch, supra note 2, at 42.}
\footnotetext[48]{Id.}
\footnotetext[49]{Id. at 42-43.}
\footnotetext[50]{Kaufmann, supra note 3, at 397.}
\footnotetext[51]{Wukitsch, supra note 2, at 43 (identifying prior legislation prohibiting discrimination on the basis of sickle cell, Tay-Sachs, or Cooley’s anemia traits).}
\footnotetext[52]{Id.}
\end{footnotes}
discriminate against their employees. With the use of genetic testing, employers now have the ability to discriminate in hiring, and weed out employees with the potential to develop serious diseases that may affect their ability to carry out the jobs for which they were hired. "American firms are engaging in . . . a frenzy of inspecting, detecting, selecting, and rejecting. . . . Employers' use of genetic testing is likely to increase as tests become more widely available." In response to the possibility of employers gaining access to their genetic information, some employees are refusing to take genetic tests out of fear that the results will be used against them in their pursuit of employment opportunities.

C. Genetic Screening and Genetic Monitoring

Employers have two methods available to test their employees for genetic disorders: genetic screening and genetic monitoring. Genetic screening can be used as a one-time test to determine the genetic predisposition of an applicant or current employee. There are two methods of genetic screening available to employers; one method is biochemical genetic screening and the other is direct-DNA screening. Both methods provide employers with the ability to "identify the presence of genetic traits that render a person hypersusceptible to certain toxins or detect general genetic conditions that are not necessarily associated with occupational diseases." When employers screen for employees' hypersusceptibilities to certain toxins, they are trying to

53. Id. at 40.
54. Santiago, supra note 1, at 705. "[T]he use of genetic markers to 'predict' future illness in a currently asymptomatic person creates the opportunity for employment discrimination based on the misuse of this information." Rachinsky, supra note 20, at 577 (footnote omitted).
56. Santiago, supra note 1, at 705 & n.20 (noting that technology could create a "biological underclass of unemployable and uninsurable people").
57. Kaufmann, supra note 3, at 397.
58. Id.
59. Id. at 397-98.
60. Id. at 397 (footnote omitted). "Employees designated as hypersensitive more readily become targets of discrimination because they are singled out from other workers." Kirke D. Weaver, Genetic Screening and the Right Not to Know, 13 Issues L. & Med. 243, 246 (1997).
locate pre-existing genetic defects the employees may have that would react negatively with certain workplace conditions.\textsuperscript{61}

Biochemical genetic screening “consists of the analysis of mutant genes based on altered proteins or enzymes in the individual’s bloodstream.”\textsuperscript{62} It is the most commonly used genetic screening method in the employment setting, and is performed by conducting a blood test or collecting tissue samples.\textsuperscript{63} Direct-DNA screening, an alternative process, is performed through the direct examination of an individual’s DNA.\textsuperscript{64}

In addition to the genetic screening methods described above, employers also have the ability to perform genetic testing through the use of genetic monitoring.\textsuperscript{65} Unlike genetic screening, which involves employers singling out employees, genetic monitoring looks to, and focuses on, the workplace itself as a potential breeding ground for genetic defects. Genetic monitoring is also used by employers to improve the workplace environment, and, thus protect their employees.\textsuperscript{66} Employers can perform genetic monitoring on employees by periodically evaluating them to see if there has been any change in their genetic material.\textsuperscript{67} The purpose of these tests is to help employers determine if the employees are being affected by any toxins that they come into contact with through various daily tasks.\textsuperscript{68} Genetic monitoring increases the safety of the workplace by allowing employers to determine if there are dangerous toxins to which employees are being exposed.\textsuperscript{69}

Employers use genetic testing on their employees for several reasons.\textsuperscript{70} One reason is to comply with the Occupational Safety and Health Act (OSHA)\textsuperscript{71} guidelines that require medical testing.\textsuperscript{72} Congress

\textsuperscript{61}. Weaver, \textit{supra} note 60, at 246 (“[A]n example of genetic screening would be a test to locate individuals affected by thalassemia, a deficiency that results in smaller red blood cells, which are possibly adversely affected by exposure to lead or benzene.”).

\textsuperscript{62}. Kaufmann, \textit{supra} note 3, at 398.

\textsuperscript{63}. \textit{Id.}

\textsuperscript{64}. \textit{Id.}

\textsuperscript{65}. \textit{Id.}

\textsuperscript{66}. Weaver, \textit{supra} note 60, at 246.

\textsuperscript{67}. Kaufmann, \textit{supra} note 3, at 398.

\textsuperscript{68}. \textit{Id.} at 398-99. “Chemicals such as lead, asbestos, arsenic, and nickel have also been known to cause chromosome changes.” Weaver, \textit{supra} note 60, at 245.

\textsuperscript{69}. Kaufmann, \textit{supra} note 3, at 399. \textit{Contra} Weaver, \textit{supra} note 60, at 245 (“The technique does have problems with narrowing the causes of the genetic changes because genetic monitoring detects not only genetic changes that are a result of workplace exposure, but also changes resulting from outside exposures such as smoking.”).

\textsuperscript{70}. Kaufmann, \textit{supra} note 3, at 398.

enacted OSHA "to assure so far as possible every working man and woman in the nation safe and healthful working conditions and to preserve our human resources." Under this congressionally imposed duty to provide safe and healthful working conditions, employers are allowed to genetically test employees and applicants to ensure that they do not have a hypersusceptibility to certain toxins. A second reason why employers use genetic testing, which furthers the purpose of OSHA, is to shield susceptible workers from known toxins and to determine if applicants have a genetic predisposition to illnesses caused by toxins commonly used in the workplace.

Not only would the screening improve the health of employees, but also the safety of the workplace could improve as well. Certain genetic conditions could pose serious risks to the safety of the individual worker and other co-workers. For instance, prohibiting individuals prone to heart attacks from becoming airline pilots would improve the safety of the industry. Workers operating heavy machinery or other dangerous equipment could be screened for certain forms of Alzheimer's disease in order to prevent future accidents based on neurological deterioration. Thus genetic screening or monitoring techniques could help to improve worker health and workplace safety.

While the justifications for the use of genetic testing by employers appear legitimate and valid, another purpose behind the use of genetic tests may be to further the employers' own interests. By determining the susceptibility of potential employees to certain diseases, employers may use the results of genetic testing and screening to discriminate against applicants in an effort to maximize profits. Employers are able to use an applicant's genetic information to maximize profits by first determining which diseases are the most expensive to treat and then discriminating against any potential applicant who might show a genetic susceptibility toward developing those diseases. The knowledge gained from genetic testing maximizes employers' profits because employees

72. Kaufmann, supra note 3, at 398.
73. 29 U.S.C. § 651(b); see also Kaufmann, supra note 3, at 425.
75. Id. at 398.
76. Weaver, supra note 60, at 248 (footnote omitted).
77. Kaufmann, supra note 3, at 398.
78. Rachinsky, supra note 20, at 582-83.
79. Id. at 583.
who suffer long illnesses incur large health insurance disbursements.  

As a result, employers incur higher insurance costs from the companies underwriting the employers' health insurance policies.

Employers claim that over the past few years their costs for health care and other disability benefits have increased substantially. In addition to the possibility of incurring higher insurance costs, employers are also concerned about hiring applicants who are genetically susceptible to certain diseases because they have the potential to miss a large amount of work if they become sick and have to tend to their ailments. The final financial effect of hiring genetically susceptible workers is that their productivity suffers as a result of a disease or condition that might develop.

III. FEDERAL STATUTORY ANALYSIS

The increasing use of genetic testing raises important questions regarding the regulation and control of employers' use of their employees' genetic information. Unfortunately, current federal legislation regulating the workplace does not properly address genetic testing and discrimination in that context, and proposed legislation to appropriately address the issue has yet to be enacted. There is no legislation at the federal level specifically drafted to address genetic discrimination in employment.

80. Kaufmann, supra note 3, at 398.
     [In a study conducted in 1989 to gauge the extent of genetic monitoring, the Congressional Office of Technology Assessment (OTA) found that twelve out of the 330 companies surveyed use some sort of biochemical genetic screening. Although none of the companies that responded anticipated using direct DNA screening over the next five years, OTA's survey data indicated that forty-two percent of employers considered an applicant's health insurance risks in making employment-related decisions.


81. Kaufmann, supra note 3, at 398.
82. Gostin, supra note 8, at 133.
84. Id.
85. Id. at 361. "[U]ntil we can prevent as well as predict genetic disorders, we must use legal or economic tools to guard against potential misuse of genetic information." Michael S. Yesley, Protecting Genetic Difference, 13 BERKLEY TECH. L.J. 653, 655 (1998).
86. See Jensen, supra note 15, at 361.
87. Wukitsch, supra note 2, at 43. ("As a result, in a state lacking a comprehensive statute, an aggrieved individual must search existing anti-discrimination legislation for a potential remedy.").

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While it is clear that no federal statutes regulating the workplace were written with genetic discrimination in mind, analyzing current federal statutes addressing the workplace, and the protection of employees or potential employees from discrimination, is beneficial. An analysis highlights the shortcomings of the current federal statutes in dealing with genetic discrimination, and explains why it is necessary to have a uniform statute specifically drafted to address the issue of genetic discrimination in the workplace. Current federal statutes serve as a foundation on which future legislation addressing genetic discrimination in the workplace should be based. More specifically, current federal statutes serve as the building blocks for the model statute presented by this note.

Federal statutes that currently protect employees in the workplace include the Americans with Disabilities Act of 1990, Title VII of the Civil Rights Act of 1964, and the Health Insurance Portability and Accountability Act of 1996. In addition to the current federal legislation regulating the workplace, proposed federal legislation addressing the issue of genetic testing and discrimination is analyzed in this note.

A. The Americans with Disabilities Act of 1990

With the current lack of federal laws specifically addressing the issue of genetic discrimination in the workplace, the Americans with Disabilities Act (ADA) offers the greatest possible protection to individuals with genetic abnormalities. However, the ADA is limited and has numerous shortfalls. The ADA protects employees who either display a disability trait or are regarded as having that trait, and provides those employees with protection from genetic discrimination. There is no clear congressional intent, and courts have yet to construe the ADA

88. Id.
94. Kaufmann, supra note 3, at 404.
95. Miller, supra note 6, at 190.
as offering employment discrimination protection to people with asymptomatic genetic conditions.\textsuperscript{96}

Title I of the ADA prohibits employment discrimination on the basis of a disability.\textsuperscript{97} It is important to note that nowhere in Title I of the ADA, or in any other part of the ADA, is any reference made to genetic discrimination.\textsuperscript{98} What the ADA does contain is comprehensive language prohibiting employers from discriminating against a "qualified individual with a disability in hiring, promotion, discharge, compensation, and other terms and conditions of employment."\textsuperscript{99} The ADA indirectly addresses genetic testing in the workplace by establishing "three-stages" outlining what type of access employers have to employees' medical information.\textsuperscript{100} The three stages of the employment relationship the ADA addresses are pre-employment, job offer pendency, and employment.\textsuperscript{101}

First, at the pre-employment stage, before an offer of employment, the employer is not permitted to make any medical inquiries or to require that the individual undergo a medical examination. Second, the employer may condition an offer of employment on the individual's undergoing and receiving a satisfactory recommendation on a medical examination. . . . Third, once an individual commences employment, all medical examinations and inquiries must be either voluntary or job-related.\textsuperscript{102}

At the pre-offer stage, while employers are not able to conduct medical examinations on prospective employees, they can inquire into the ability to perform job-related functions.\textsuperscript{103} Once an offer of employment has been made, but before it has been accepted, the ADA

\textsuperscript{96} Id.; see also Kaufmann, supra note 3, at 395 ("Yet, thus far no court has directly addressed the issue of genetic testing."); Weaver, supra note 60, at 263 ("No cases have determined whether or not a genetic defect is considered a disability under the ADA.").

\textsuperscript{97} 42 U.S.C. § 12111(5) (1994); see also Kaufmann, supra note 3, at 404 & nn.78-80 (explaining inclusion of state and local governments); Rachinsky, supra note 20, at 590-91 (same).

\textsuperscript{98} Miller, supra note 80, at 238.

\textsuperscript{99} Id.; see also 42 U.S.C. §12112(a) (1994).

\textsuperscript{100} Mark A. Rothstein, Genetics and the Work Force of the Next Hundred Years, 2000 COLUM. BUS. L. REV., 371, 385 (2000).

\textsuperscript{101} Kaufmann, supra note 3, at 405-06.

\textsuperscript{102} Rothstein, supra note 100, at 385-86 (citing 42 U.S.C. § 12112(d)(2)(A), (3), (4)(B) (1994)).

\textsuperscript{103} Kaufmann, supra note 3, at 406-07. ("It is likely, however, that most genetic disorders do not present symptoms that affect job-related functions. Only testing reveals the existence of a genetic marker in the individual, therefore, the individual who is unaware of his or her genetic condition cannot answer questions about the unknown." (footnote omitted)).
provides that "a covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of such examination." Thus, it appears that at the pre-offer stage employers cannot obtain medical tests, thereby protecting potential employees from genetic discrimination. However, once a conditional offer has been made, employers probably can obtain genetic information.

After a conditional offer has been accepted, the medical testing that employers can require is limited once again. Subsequent to employees being hired, employers cannot force the employees to undergo medical testing to determine if the employees are disabled unless the employers can show that the tests are job-related and consistent with business necessity. Because an asymptomatic condition does not affect an employee's ability to carry out his job, employers would be hard pressed to justify using job-relatedness as the reason for conducting genetic screening. For these reasons, employers would most likely engage in genetic testing or screening once a conditional offer is made, but before it is accepted. Therefore, while the ADA does an adequate job limiting medical/genetic testing in the pre-offer and employment stages, the Act fails to completely protect a prospective employee from genetic discrimination in the hiring process.

104. 42 U.S.C. § 12112(d)(3); see also Kaufmann, supra note 3, at 407.
These examinations must satisfy three requirements. First, an employer must test all entering employees regardless of disability. Second, the information collected must be maintained on separate forms and in a separate medical file and treated as confidential. Third, the results of the medical examination may be used only "in accordance with this sub-chapter."

105. Wukitsch, supra note 2, at 44.
106. Kaufmann, supra note 3, at 408.
107. Gostin, supra note 8, at 132 (reporting that Congress recognized that a non-job-related medical inquiry has no legitimate employer purpose and simply stigmatizes the disabled person).
108. Kaufmann, supra note 3, at 409 ("An asymptomatic genetic disorder might have future ramifications, but would not affect the individual's present ability to perform his or her job.").
109. Id.
1. Establishing a Claim Under the ADA

“The ADA prohibits an employer from discriminating against a qualified individual because of that individual’s disability.”110 To establish a prima facie case of discrimination and to make a showing of a disability under the ADA, an employee must prove three elements: “(1) that [he] has a disability; (2) that [he] is otherwise qualified for the employment or benefit in question; and (3) that [he] was excluded from the employment or benefit due to discrimination based solely on the basis of [his] disability.”111 The predisposition for a genetic disease should be within the purview of the ADA because the affected employee falls within the definition of a disability under the “regarded as” prong of the Act.112 An individual with a disability is defined by the ADA “as a person with one or more physical or mental impairments that substantially limits him or her in performing a major life activity, a person with a record of such impairment, or a person who is regarded as having such an impairment.”113

To receive protection under the ADA, an employee must comply with the ADA’s definition of a disability and show that the disability substantially limits a major life function.114 Whether or not a disability substantially limits a major life function—such as major life activity—depends on the disability’s nature and severity, expected duration, and possible permanence.115 For a genetically caused illness to be considered a physical or mental impairment, the underlying genetic defect must manifest itself.116 Most genetic disorders will present symptoms in the future.117 Therefore, the ADA’s requirement that “a physical or mental impairment limit a major life activity” does not offer sufficient

110. Wukitsch, supra note 2, at 45.
111. Rachinsky, supra note 20, at 590; see also Wukitsch, supra note 2, at 45.
114. Kaufmann, supra note 3, at 410.
115. Id. (“The EEOC regulations provide that a ‘major life activity’ includes things such as ‘caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.’ ” (quoting 29 C.F.R. § 1630.2(i)).
116. Weaver, supra note 60, at 261.
117. See Kaufmann, supra note 3, at 411.

A number of genetically-based illnesses have already been classified as disabilities under the ADA. These diseases which include muscular dystrophy, an X-linked genetic disorder, and multiple sclerosis were all mentioned as covered diseases in the legislative history of the Act. However, this factor is not entirely convincing. These diseases have been classified as disabilities once an individual has manifested symptoms of the diseases.

Weaver, supra note 60, at 262 (footnote omitted).
protection to individuals with genetic disorders because the disorders would be classified as impairments. Thus, genetic disorders are considered disabilities only if the defects have already manifested themselves.118

Under the ADA’s second definition of a disability, an employee is considered disabled if the individual has a record of a substantially limiting impairment.119 The purpose of this requirement is to protect employees who recover from a disabling condition, and those individuals who never had a disability but were improperly diagnosed.120 This second definition of disability has the potential to protect employees from genetic discrimination because there is a high probability that individuals may incorrectly test positive for a genetic defect, and without the benefit of the second definition, they could be discriminated against.121

The third part of the ADA’s definition of what constitutes a disability offers the most protection to individuals who have asymptomatic genetic disorders.122 Protection is extended to an individual who is “regarded as” having an impairment.123 This definition of a disability suggests that an employee could receive protection from discrimination based on an impairment, even if that individual does not currently have an impairment.124 As opposed to the other classifications of disability, the “regarded as having an impairment” definition is based on employers’ perceptions of the employees and not the existence of true disabilities.125 In contrast to the other definitions of a disability, employees with asymptomatic genetic disorders would most likely benefit from this definition because discrimination by employers would be based on a genetic anomaly, not inability.126

118. Weaver, supra note 60, at 262.
119. Kaufmann, supra note 3, at 412.
120. Id.
121. Id.
122. Weaver, supra note 60, at 262.
123. Id.
124. Id.; see also Kaufmann, supra note 3, at 412 (recognizing that the third prong provides an employee with the “greatest protection against genetic discrimination”).
125. Kaufmann, supra note 3, at 413.
126. Id.
2. The EEOC’s Interpretation of the ADA

The Equal Employment Opportunity Commission (EEOC) is the federal agency charged with enforcing Title I of the ADA.\textsuperscript{127} The EEOC’s current guidelines suggest that genetic test results obtained by employers may be covered under the ADA as a disability.\textsuperscript{128} Currently there is no case law upholding the EEOC’s interpretation of the ADA.\textsuperscript{129}

The EEOC’s past actions have failed to provide clear instruction as to whether genetic discrimination is covered under the ADA.\textsuperscript{130} The EEOC’s position is unclear because in 1991, in its first statement on the issue, the Commission refused to define genetic discrimination as a violation of the ADA.\textsuperscript{131} Then, in 1995, the EEOC reversed itself and clarified that the ADA’s definition of disability includes individuals with genetic impairments.\textsuperscript{132} The EEOC’s policy states that the “regarded as” prong protects individuals from discrimination for an unmanifested genetic predisposition.\textsuperscript{133}

Although the EEOC’s position is clear that the ADA protects individuals with asymptomatic genetic conditions from discrimination in employment, the Commission’s interpretations do not have the force of law. Until the EEOC guidelines are tested and upheld in a court of law, or codified in a federal or state statute, the guidelines remain only persuasive authority.\textsuperscript{134}

B. Title VII of the Civil Rights Act of 1964

Title VII of the Civil Rights Act of 1964 (Title VII)\textsuperscript{135} may provide some form of protection from genetic discrimination in the workplace.\textsuperscript{136} Individuals with genetic disorders may be protected by Title VII if they are also members of a protected class as defined by the Act.\textsuperscript{137} Unfortunately, as with the ADA, while it has been implied that certain

\textsuperscript{127}  Rachinsky, supra note 20, at 590.
\textsuperscript{128}  Id. at 591.
\textsuperscript{129}  Yesley, supra note 85, at 655.
\textsuperscript{130}  Kaufmann, supra note 3, at 413.
\textsuperscript{131}  Id. (reporting that an EEOC opinion letter stated that the ADA does not prohibit genetic discrimination until the defect manifests itself).
\textsuperscript{132}  Santiago, supra note 1, at 707.
\textsuperscript{133}  Miller, supra note 80, at 239.
\textsuperscript{134}  Id. at 241.
\textsuperscript{136}  Miller, supra note 6, at 191.
\textsuperscript{137}  Rachinsky, supra note 20, at 588.
people may fall under the purview of Title VII and be granted protection, there have been no successful lawsuits based on genetic discrimination brought under this statute. Another potential, and perhaps fatal, drawback to bringing genetic discrimination claims under Title VII is that only a fraction of genetic disorders can be associated with a protected class under Title VII. The following analyzes Title VII and the ways employees can bring claims under the statute.

Title VII prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. Employers subject to Title VII include all private employers having fifteen or more workers, labor organizations, employment agencies, and federal, state, and municipal government employers. Employers may violate Title VII by discriminating on a genetic basis that disproportionately impacts a protected group. Under Title VII, claims may be brought through one of two theories: disparate treatment or disparate impact.

Under Title VII, disparate treatment is the most identifiable type of discrimination. In bringing a disparate treatment case, the employee will use direct and circumstantial evidence to prove that he was subject to an adverse employment action as a result of intentional discrimination. To prove disparate treatment, it is essential to show that the employer intended to discriminate against the employee because of a particular trait associated with a protected class. Although many genetic traits are linked to racial and ethnic groups, an asymptomatic genetic condition is a facially neutral criterion. Genetic testing is a facially neutral policy; therefore, an employee would bring his Title VII claim under a theory of disparate impact.

138. Miller, supra note 6, at 191.
139. Rachinsky, supra note 20, at 590.
141. Id. § 2000e(b).
142. Miller, supra note 6, at 191 (providing examples of sickle cell anemia, affecting individuals of African descent; and Tay-Sachs disease, affecting Ashkenazi Jews).
143. Kaufmann, supra note 3, at 419.
144. Id. at 420.
145. Wukitsch, supra note 2, at 41.
146. Kaufmann, supra note 3, at 420.
147. Id. "An employer that refuses to hire all individuals who possess a specific genetic marker is not per se discriminating against members of a single race because many genetic diseases cross racial lines." Id.
148. Gostin, supra note 8, at 138.

The prima facie case for disparate impact discrimination based on genetic testing would be relatively easy for a job applicant to satisfy. The plaintiff need only establish that he or she was a member of a minority group and was denied a job because of the results of a genetic test that tested for a condition more prevalent in that minority group.
To succeed on a disparate impact claim under Title VII, the individual must prove that the genetic screening had a discriminatory effect on him as a member of a protected class. If the individual establishes a prima facie case under disparate impact theory, the burden shifts to the employer to prove that the genetic criterion was either a “business necessity” or “job-related.” “Business necessity” refers to an employment practice, the purpose of which is to ascertain the applicant’s ability to perform the necessary job functions. The “job-relatedness” exception applies where the employer proves that the selection criteria fit the demands of the job. The court balances the employer’s claim against the impact of the discriminatory treatment to determine whether the genetic testing is permissible under Title VII.

As stated, genetic testing may be unlawful under Title VII only if the test results are used to discriminate on the basis of race, color, religion, sex, or national origin. Because most genetic disorders do not disproportionately impact a protected class, Title VII does not sufficiently protect employees from genetic discrimination.

C. The Health Insurance Portability and Accountability Act of 1996

While currently there is no federal legislation regulating genetic discrimination in the workplace, Congress enacted the Health Insurance Portability and Accountability Act of 1996 (HIPAA), prohibiting genetic discrimination by group health plans and health insurance issuers. The main purpose of the statute is to prevent individuals who are in the process of transferring jobs from losing health insurance.
coverage because of a genetic defect. The major drawback of HIPAA is that insurers are permitted to request or require genetic testing. Two additional deficiencies of HIPAA are that it does not protect individuals who are not covered under group plans, and it does allow insurance companies to access group plan members’ genetic information.

HIPAA bars a group health insurance plan from using genetic information in establishing criteria for eligibility. Unless a disease has been diagnosed, genetic test results cannot be used as evidence of a pre-existing condition, thereby offering protection to asymptomatic individuals. HIPAA allows individuals with medical problems, past or present, to obtain insurance coverage and carry that coverage with them when they change jobs.

D. Proposed and Pending Federal Legislation

Currently there is no federal statute addressing or preventing discriminatory employment practices involving the use of genetic information. Recent sessions of Congress have proposed bills regulating the use of genetic testing and information in the workplace. At the time of this writing, three bills were pending.

Unwilling to wait for Congress to act, former President Clinton issued an Executive Order mandating that there be no genetic

159. Id.
160. Rachinsky, supra note 20, at 593.
161. Id.
While only a small percentage of Americans currently buy individual health insurance, changes in the work force, such as the growth of home businesses and the increase in the percentage of self-employed workers, will likely lead to a larger percentage of people seeking insurance outside of the group market. These people will not be protected against insurance discrimination by HIPAA.

162. Santiago, supra note 1, at 708.
163. Miller, supra note 80, at 254 (noting the intertwined relationship between health insurance and employment).
164. Rachinsky, supra note 20, at 593.
For example, if an individual is a member of a group plan covered by HIPAA and tests positive for a gene that may predispose him or her to a certain condition, that individual cannot be denied insurance coverage or treated as though they have a preexisting condition solely due to their genetic profile.

165. Miller, supra note 80, at 255.
166. See Medical Breakthrough, supra note 10, at 6.
167. See Medical Breakthrough, supra note 10, at 6.
discrimination in federal employment.\textsuperscript{168} It is now the express policy of the United States to prohibit discrimination in federal hiring based on genetic information.\textsuperscript{169} Executive departments and agencies are responsible for carrying out the policy,\textsuperscript{170} and the EEOC is responsible for coordinating the effort.\textsuperscript{171} The policy is unambiguous in its goal to end employment discrimination related to genetic information. The policy covers genetic testing,\textsuperscript{172} genetic services,\textsuperscript{173} and genetic monitoring.\textsuperscript{174} This broad incorporation of all sources of genetic information assures protection to employees at all stages of employment.

A federal department may not discriminate based on genetic information in the hiring or firing of employees.\textsuperscript{175} The department or agency is further restricted from segregating or classifying employees “in any way that would deprive or tend to deprive” the employees of opportunities.\textsuperscript{176} The department or agency is also prohibited from disclosing the protected genetic information of employees, or even from disclosing whether the employees received genetic services.\textsuperscript{177} To ensure that confidentiality of genetic information is maintained, the department or agency must store the records separately from personnel records.\textsuperscript{178}

The federal department or agency employing a particular individual may be able to request or require information about that individual’s family medical history, but only for disclosure to medical personnel “responsible for assessing whether further medical evaluation” of the employee is needed.\textsuperscript{179} The department or agency is permitted to monitor

\textsuperscript{168} See Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 8, 2000). President Clinton announced: “By signing this Executive order, my goal is to set an example and pose a challenge for every employer in America, because I believe no employer should ever review your genetic records along with your resume.” Remarks on Signing an Executive Order To Prohibit Discrimination in Federal Employment Based on Genetic Information, 36 WEEKLY COMP. PRES. DOC. 241 (Feb. 8, 2000).


\textsuperscript{170} Id.

\textsuperscript{171} Id. at 6,878 (stating that tests “not intended to reveal . . . a mutation shall not be a violation,” but if a mutation is revealed the results are protected).

\textsuperscript{172} Id. at 6,177 (allowing genetic testing for “diagnostic or therapeutic purposes”).

\textsuperscript{173} Exec. Order 13,145, 65 Fed. Reg. at 6,877 (stating that the purpose of the continued monitoring of employees is to ascertain if any genetic harm has occurred from workplace exposure).

\textsuperscript{174} Id. at 6,878.

\textsuperscript{175} Id.

\textsuperscript{176} Id. at 6,879. (allowing disclosure at the employee’s request to a statutorily authorized researcher, or pursuant to a court order).

\textsuperscript{177} Id. at 6,879.

\textsuperscript{178} Exec. Order 13,145, 65 Fed. Reg. at 6,879. The Order authorizes the request or requirement if consistent with law and the information is to be used for evaluation of the employee
the genetic effects that might be caused by toxic substances in the workplace. Such monitoring is permitted if the department or agency adheres to several conditions: (1) the employee provides prior written consent; (2) the employee is notified when the results are available and informed about how to obtain them; (3) the monitoring conforms to regulations which may exist; and (4) data is supplied to the employer in a means that maintains confidentiality of a specific employee and his or her results.

The Executive Order implemented a policy that addresses many issues involved in genetic testing in the workplace and gives broad protection to applicants and employees. Federal departments or agencies are prohibited from discriminatory practices in hiring and firing decisions. This policy is similar to the protection offered by the various state statutes. However, the Executive Order goes further by implementing a policy that allows for safeguarding information gathered through genetic monitoring. Not only are individuals protected from employment discrimination by this scheme, but they can participate in monitoring programs aimed at safeguarding their health while being assured confidentiality.

The President has power over federal departments and agencies. Through the exercise of that power, the President can effectuate protection from genetic discrimination in those workplaces. For non-federal employees and applicants there is still no national policy addressing the issue of genetic discrimination in the private sector workplace. However, Congress has not been idle in this area. Since the 104th Congress, the House and Senate introduced over twenty bills related to genetic discrimination in employment, but none came out of committee. At the time of this writing, there were three bills pending in Congress, and former President Clinton supported H.R. 2457. The House Bill would extend the protection scheme implemented under Executive Order No. 13,145 to the private sector.

for further medical diagnosis; or if the disease could prevent performance of “the essential functions of the position.”

180. Id. at 6,879-80.
181. Id.
182. Id. at 6,878.
183. See discussion infra Part IV.B.
184. See Medical Breakthrough, supra note 10, at 6.
185. Id.
186. Id.
187. Id.
IV. STATE STATUTORY ANALYSIS

Legislatures of various states have protected employees and prospective employees from genetically-based discrimination by enacting statutes that focus on key issues involving genetic testing and the use of genetic information by employers. Legislatures found that the public was wary of seeking genetic tests for fear the results would be used in a discriminatory manner. To prevent individuals from becoming members of a “genetic underclass,” states developed policies prohibiting employment discrimination based on genetic information. At least twenty-six states have enacted laws specifically prohibiting genetic discrimination in employment decisions. There appear to be no reported decisions regarding actions brought under these state statutes against employers for genetic discrimination. The extent of these state prohibitions, and their exceptions, are the subject of this section.

A. State Attempts to Contain Workplace Genetic Discrimination

State statutes regulating genetic discrimination almost universally prohibit employers from making hiring, firing, or other employment

188. The language used in genetic sciences does not have a uniformly accepted meaning. Brenda A. Trolin, The Emergence of Biopolitics in State Legislatures, 6 NCSL LEGISBRIEFS 17 (Mar. 1, 1998). Compare MASS. GEN. LAWS ch. 151B, § 1.23 (2001) (“The term ‘genetic test’ shall mean any tests of human DNA, RNA, mitochondrial DNA, chromosomes or proteins for the purpose of identifying genes or genetic abnormalities, or the presence or absence of inherited or acquired characteristics in genetic material.”) with N.C. GEN. STAT. § 95-28.1A(a) (2000) (“[T]he term ‘genetic test’ means a test for determining the presence or absence of genetic characteristics in an individual . . . in order to diagnose a genetic condition . . . or ascertain susceptibility to a genetic condition.”).

189. The term “genetic information” is also the subject of statutory definition having varying scope and breadth. See Trolin, supra note 188.

190. The term “employer” is used throughout this section with no mention of other parties or entities that may have authority to make employment decisions. “Employer” is used so that the reader may focus on how the various and varied state provisions impact employees and prospective employees. Certain states do have statutory provisions directed toward employers’ agents, labor organizations, joint labor-management committees, or employment agencies. See generally ARIZ. REV. STAT. § 41-1463 (1999); CONN. GEN. STAT. § 46a-60 (1999); DEL. CODE ANN. tit. 19, § 711 (2000); MASS. GEN. LAWS ch. 151B, § 4 (2001). But see MICH. COMP. LAWS § 37.1202 (2001) (prohibiting conduct by an employer and not mentioning other entities); see also ME. REV. STAT. ANN. tit. 5, § 19302 (West Supp. 2000); MO. REV. STAT. § 375.1306 (1999); OR. REV. STAT. § 659.705(2)(d) (1999) (same).


193. Medical Breakthrough, supra note 10, at 6.

194. Miller, supra note 6, at 193.
decisions based on genetic information. Many states prohibit employers from requiring, or even requesting, that a genetic test be given. Several states also prohibit gathering information on employees’ or prospective employees’ families. The rationale for this prohibition is that family medical history may contain a wealth of genetic information. Certain state statutes explicitly ban employers from requesting or obtaining such family information. Where there is no outright ban on genetic testing, employers may not condition employment, or continued employment, on the refusal or acquiescence of employees to submit to a genetic test or to supply genetic information to the employers.

Employers may be permitted to perform genetic testing of employees and prospective employees if their informed consent is obtained. Genetic testing is sometimes allowed for reasons of business necessity, determining a bona fide occupational qualification (BFOQ), or to investigate a worker’s compensation claim. Some states allow employers to discharge employees if there is a showing that they may be at risk because of a particular occupational environment and there is a likelihood of injury because of the employee’s genetic makeup. Other states specifically prohibit such actions by employers.

B. A Survey of State Statutory Prohibitions Against Employers’ Discriminatory Use of Genetic Information

New Jersey is among the states that make it unlawful discrimination for employers to base hiring and firing decisions on genetic information. The protection is made even more comprehensive

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195. See infra Part IV.B.
196. See infra Part IV.D.
197. See Yesley, supra note 85, at 659-60.
198. See infra Part IV.B.
199. See infra Part IV.C.
200. See infra Part IV.C.
201. See infra Part IV.C.
202. See infra Part IV.C.

It shall be an unlawful employment practice, or, as the case may be, an unlawful discrimination: a. For an employer, because of the . . . genetic information, . . . or atypical hereditary cellular or blood trait of any individual, . . . or because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer, 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.

Id.
by prohibiting discrimination on "atypical hereditary cellular or blood traits."\(^{204}\) Thus, protection is purposefully extended to cover chronic hereditary diseases.\(^{205}\) As a result, the New Jersey statute prohibiting workplace genetic discrimination is described as "the most comprehensive" state statute.\(^{206}\)

Other state legislatures are more sparing in their statutory language. Arizona prohibits discrimination only if it is "based on the results of a genetic test received by the employer."\(^{207}\) Connecticut bars employers from requesting or requiring genetic information from either employees or individuals seeking employment.\(^{208}\) In Delaware, it is an unlawful employment practice for employers to consider genetic information in making employment decisions.\(^{209}\) Delaware employers are also prohibited from "[l]imit[ing], segregat[ing], or classif[y]ing employees" in a manner that may deprive them of "employment opportunities or otherwise adversely affect . . . [their] status."\(^{210}\) A different approach is taken in Florida, where statutory protection is extended to prospective employees denied employment predicated on genetic information.\(^{211}\) The statute requires the applicant to be informed that genetic information was used in the decision, and requires a mandatory second genetic analysis; "the denial must be reviewed" if the result is not repeated.\(^{212}\)

Iowa prohibits employers from asking, demanding, or giving a genetic test to an individual as a condition precedent to employment.\(^{213}\) Similarly, employers are prohibited from changing "the terms, conditions, or privileges of employment" of anyone who undergoes a genetic test.\(^{214}\) Iowa's law does not have plain language prohibiting employers from using genetic information in their employment decisions.\(^{215}\)

\(^{204}\) Id.; see also id. § 10:5-5(x) (1993) (defining sickle cell, Tay-Sachs, and cystic fibrosis to be among these traits).

\(^{205}\) N.J. STAT. ANN. §§ 10:5-5(aa)-(cc).

\(^{206}\) Miller, supra note 6, at 193.


\(^{208}\) CONN. GEN. STAT. § 46a-60(a)(II) (Supp. 2001). Employers are also prohibited from discharging employees because of their genetic information. Id.

\(^{209}\) DEL. CODE ANN. tit. 19, § 711(a)(1) (Supp. 2000). The term "employment decisions" encompasses hiring, discharging, compensation, terms, conditions, and privileges. Id.

\(^{210}\) Id. § 711(a)(2).

\(^{211}\) FLA. STAT. ch. 760.40(3) (1997).

\(^{212}\) Id.

\(^{213}\) IOWA CODE § 729.6(2)(a) (1993).

\(^{214}\) Id. § 729.6(2)(b).

\(^{215}\) Id. § 729.6(3) (restricting a third party from selling or interpreting genetic tests of employees or prospective employees). However, employers can obtain genetic test results through other means and interpret the information themselves.
The Kansas Act Against Discrimination prohibits employer discrimination based on "race, religion, color, sex, disability, national origin or ancestry . . . without a valid business necessity." Although the statute does not specify what a valid necessity may be, it makes it an unlawful employment practice for employers to seek, obtain, or use employees' or prospective employees' genetic makeup as a basis to "distinguish between or discriminate against" that individual.

Maine prohibits employment discrimination on the basis of genetic information or genetic testing. Additionally, employees who refuse to submit to a genetic test or make test results available are protected from discrimination. To meet the public policy goal of protecting results of genetic tests, Massachusetts prohibits employers from requiring genetic test results as a condition of employment. It is an unlawful practice for employers to refuse to hire, or to discharge, individuals because of genetic information. Furthermore, employers may not "collect, solicit or require" an individual to disclose genetic information or to submit to a genetic test as a condition of employment.

Michigan and Missouri allow employers to use genetic information in employment decisions, but through differently worded statutes. Employers in Michigan may not discriminate against individuals because of "genetic information that is unrelated to the individual's ability to perform the duties of a particular job or position." Missouri allows employers to "distinguish between [or] discriminate against" an individual based on genetic information when the information is "directly related to" his or her ability to perform a job.

Nevada proscribes employers from "ask[ing] or encouraging" persons to submit to a genetic test or to make the test a condition of

217. Id. § 44-1009(a)(9)(A). Employers may not use information from genetic screening or testing. See id. Genetically screening or testing individuals is also an unlawful employment practice. See id. § 4-1009 (a)(9)(B).
219. Id. Basing discrimination on the fact that individuals have undergone genetic tests or received genetic counseling is also prohibited. Id.
222. Id. § 4.19(a)(2). Employers may also not ask questions regarding previous genetic tests or genetic information about family members. Id. § 4.19(a)(5).
employment. New Hampshire similarly prohibits employers from conditioning employment on the administration of a genetic test.

New York's legislature chose wording that clearly places a "genetic predisposition" under the protection of the state's anti-discrimination laws. In New York, a genetic test is defined as a test performed to diagnose or predict a genetic anomaly "linked to a physical or mental disease or a disability." An anomaly is any genetic variation that either confers or predisposes an individual to a genetically influenced disease. New York's law regulates the actions of a broad spectrum of employers. The legislature's intent is to prohibit the discriminatory practices of employers seeking to maintain low health insurance premiums by testing a potential employee's genetic makeup. However, the legislature recognized a legitimate employer interest exists where a work environment might increase a prospective employee's risk of disease when the prospective employee has a particular genetic anomaly. The New York statute is comprehensive, restricting employers' access to genetic information, and establishing genetic predisposition to a disease as a protected category.

North Carolina prohibits employment discrimination based on genetic test results. But the statute does not prohibit employers from obtaining the genetic information of employees or members of their families. There is no clear intent to protect a person who refuses to submit to a genetic test from hiring discrimination. Additionally, the statute is not to be construed to prevent employees from being

226. N.H. REV. STAT. ANN. § 141-H:3(I)(a) (1996). However, there is explicit allowance for genetic testing to determine insurability for life, disability, and long-term care insurance under an employer benefit plan. Id. § 141-H:3(V).
227. N.Y. EXEC. LAW § 296(1)(a) (McKinney 2000). Employers cannot discriminate in hiring and discharging nor in compensation or conditions of employment based on the genetic predisposition of individuals. Id.
228. Id. § 292(21-d).
229. Id. § 292(21-a).
230. Wukitsch, supra note 2, at 47 ("[T]he New York statute applies to very small companies... as well as large regional and national businesses.").
231. N.Y. EXEC. LAW § 292 note (McKinney 2000). The legislature wanted to protect individuals from unregulated genetic testing "not subject to quality control... [with] the danger of error or misinterpretation." Id. The declared policy of New York is that "employers have no legitimate interest in requiring or requesting a genetic test or test results from an employee." Id.; see also Wukitsch, supra note 2, at 48 (stating that public policy is to "prevent the creation of a genetic underclass—branded by the employer").
233. Wukitsch, supra note 2, at 50.
235. Id. § 95-28.1A(a).
discharged for just cause.\textsuperscript{236} Therefore, in North Carolina, employers may be able to discharge employees at risk from a particular work environment due to a genetic predisposition—the exact activity an employee is protected from under the New York statute.

Oklahoma prevents employers from seeking genetic test information or requiring genetic testing as a condition of employment or continued employment.\textsuperscript{237} However, Oklahoma permits employers to use genetic tests and genetic information for “distinguishing between or discriminating against” individuals in connection with insurance coverage or benefits.\textsuperscript{238} Therefore, employers wanting to make a determination of benefits for prospective employees could possibly request, or even require, genetic testing or the submission of genetic information.

The Oregon legislature purposefully enacted a series of statutes relating to genetic characteristics, information, and testing.\textsuperscript{239} The legislature’s goal was to balance a need to permit legitimate research and protect individuals from employers’ discrimination based on genetic characteristics.\textsuperscript{240} To accomplish this end, the legislature made it unlawful “for any employer to subject, directly or indirectly, any employee or prospective employee to . . . [a] genetic test.”\textsuperscript{241}

Rhode Island’s statute prohibits genetic testing as a condition precedent of employment.\textsuperscript{242} Interestingly, employers are not prohibited from using genetic information to discriminate against or distinguish between employees. Employers’ requests for genetic information from employees, as a condition of continued employment, may be an action not covered by the statute. Texas, however, unequivocally makes employer discrimination “on the basis of genetic information” an unlawful employment practice.\textsuperscript{243} The Texas Labor Code also protects individuals who refuse to submit to a genetic test.\textsuperscript{244} Wisconsin’s statutory language is just as clear in prohibiting employers from making

\textsuperscript{236} Id.
\textsuperscript{237} OKLA. STAT. tit. 36, § 3614.2(C) (1999).
\textsuperscript{238} Id.
\textsuperscript{239} OR. REV. STAT. § 659.705(2) (1999).
\textsuperscript{240} Id. § 659.705(1)(f), (2)(d).
\textsuperscript{241} Id. § 659.227(1).
\textsuperscript{242} R.I. GEN. LAWS § 28-6.7-1(a) (2000) (prohibiting affecting the “terms, conditions, or privileges . . . of any person who obtains a genetic test”).
\textsuperscript{244} Id. § 21.402(a)(2).
genetic testing a requirement of employment, or affecting the employment arrangements of an individual who obtains a genetic test.\textsuperscript{245}

The above survey shows the many different approaches taken by states that have enacted legislation. These approaches include: making it unlawful to base hiring or firing decisions on genetic information, prohibiting employers from requesting or requiring genetic information, allowing the use of genetic information but mandating a retest and review, and preventing the use of genetic information to change employment conditions. Other states allow genetic testing when the results can determine an individual’s ability to perform a job. There is a clear need for comprehensive, uniform national legislation outlining the use of genetic testing and information in employment decisions. The legislation’s language should be unambiguous in accomplishing its purpose.

C. Exceptions to Prohibitions on Employer Use of Genetic Information and Genetic Testing

A legitimate employer interest in requiring genetic testing or obtaining genetic information of employees is recognized to exist under special circumstances.\textsuperscript{246} Employers may require or request a genetic test "where such a test is shown to be directly related to the occupational environment" and an individual with a "particular genetic anomaly" is at an increased risk of disease as a result of working in that environment.\textsuperscript{247} Genetic testing of employees may be needed to investigate worker’s compensation claims.\textsuperscript{248} Those states that make discrimination on genetic information an unlawful employment practice allow genetic testing of employees if their employers can show business necessity or a BFOQ.\textsuperscript{249} Typically, business necessity or BFOQ exceptions are applied to the employees’ current physical conditions. Genetic traits might develop

\begin{itemize}
\item \textsuperscript{245} Wis. Stat. § 111.372 (1997).
\item \textsuperscript{246} See, e.g., N.Y. Exec. Law § 296(19)(b) (McKinney 2000).
\item \textsuperscript{247} Id.; see also Yesley supra note 85, at 663 (noting that discrimination may be appropriate where a genetic anomaly indicates a “susceptibility to an occupational exposure”).
\item \textsuperscript{248} Joanne Seltzer, The Cassandra Complex: An Employer's Dilemma in the Genetic Workplace, 27 Hofstra L. Rev. 411, 451 (1998). Genetic screening may help determine if the work environment triggered the disease. Id. Furthermore, successive screening may assist in apportioning liability among all the different jobs that could have contributed to the condition. Id.
\end{itemize}
into future problems, but it is possible that the traits do not affect the employees' current capabilities.250

Delaware makes two exceptions to its ban on employer access to genetic information of employees or applicants.251 An exception exists if the information is "job related and consistent with business necessity" or if the information is sought to aid in administering employee retirement or benefit plans.252 Iowa does not prohibit genetic testing of employees who give informed consent if done for the purposes of either investigating worker's compensation claims or determining the employees' susceptibility to workplace toxins.253 Iowa's exceptions are coupled with the condition that employers "[do] not terminate the employee, or take any other action that adversely affects... the employee's employment."254

Michigan employers may use genetic information voluntarily provided by employees if it "is related to the employee's health or safety in the workplace."255 Employers are not prohibited from using the information "to protect the employee's health or safety."256 Missouri's proscription against employers using genetic information does not prohibit its use in underwriting insurance benefits, in actions taken with written permission of the employees, when the information is "directly related to [the] ability to perform[,]" or in any "action required or permissible by law."257

New York's Civil Rights Law provides that a person who is otherwise qualified will not be denied equal opportunities in employment "[u]nless it can be clearly shown that [the] person's unique genetic disorder would prevent [the] person from performing [a] particular job."258 New York allows employers to require a genetic test under limited circumstances. A specific genetic test may be required when it is proven that exposure to the work environment can increase the

250. Kaufmann, supra note 3, at 409 ("It is doubtful that most genetic conditions, especially asymptomatic ones, would rise to the level of... business necessity so as to allow an employer to discriminate... ").
251. DEL. CODE ANN. tit. 19, § 711(e) (Supp. 2000).
252. Id.; see also id. § 710(6) (Supp. 2000) (defining the phrase "job-related and consistent with business necessity" to mean a condition that "renders the individual unable to perform the essential functions of the position").
254. Id.; see also N.H. REV. STAT. ANN. § 141-H:3(IV) (1996) (allowing employer's use of genetic tests provided that the employer does not terminate the employee).
255. MICH. COMP. LAWS § 37.1202(2) (2001).
256. Id.
risks to employees who may have particular genetic anomalies. With the employees' written consent, genetic testing can be performed; but there is a statutory protection preventing adverse actions by employers based on the test results.

Oregon employers may not subject employees or prospective employees to a genetic test without informed consent. The test may only be given "to determine a bona fide occupational qualification." If employers successfully argue that non-susceptibility to a hazardous occupational environment constitutes a BFOQ, the employers may request a genetic test. In Oregon, there is no explicit protection against being discharged if test results indicate a potential risk through exposure. Therefore, an employee is only protected if he or she does not give informed consent. Similarly, Wisconsin allows genetic testing to determine employees' susceptibility to workplace toxins; however, the state extends to employees protection from employer actions based on the results.

Under certain circumstances, a legitimate employer interest justifies requiring genetic testing or obtaining genetic information. Employees would almost certainly want to be tested to determine if, because of a genetic anomaly, they are at an increased disease risk of contracting a disease through exposure to the occupational environment. While some states protect employees from genetic discrimination, those states also create exceptions if the need to utilize genetic test results is job-related, a business necessity, or involves a workers' compensation claim. Clarification is needed in defining the criteria for the first two exceptions. The job-related and business necessity exceptions should be permitted only when necessary to protect employees' health or safety. Some states prohibit employers from taking any actions adverse to their employees on the basis of genetic test results. However, a few states protect employees only from being discharged based on genetic information. Legislation allowing exceptions should require that employers first prove that exposure to the work environment increases risks to those employees with a genetic anomaly. The legislation should also protect genetically tested employees from being discharged or adversely affected.

259. N.Y. EXEC. LAW § 296(19)(b) (McKinney 2000).
260. Id. § 296(19)(c).
262. Id.
263. Id.
D. Statutory Protection of Employees’ Genetic Privacy

The Constitutional right to privacy has not been extended to prohibit employment testing.265 If the Constitutional right to privacy were to protect genetic information, the protection would not impact private sector employers.266 However, several state statutes provide protection to employees’ privacy interests in their genetic information.267 Protection mechanisms enacted by different states include: requiring informed consent before testing, vesting in the individual a property right in the genetic information, prohibiting third parties from providing or interpreting an individual’s genetic test results, recognizing the privacy interest of the individual’s family, and requiring strict confidentiality of the results.

Florida mandates that genetic testing may be performed only with the informed consent of the individual.268 The results of the test “are the exclusive property of the person tested, are confidential, and may not be disclosed without . . . consent.”269 The Georgia legislature declared genetic information to be the “unique property of the individual tested” and that it is “appropriate to limit the use and availability of genetic information” so as “[t]o protect individual privacy and . . . preserve individual autonomy.”270 Iowa prohibits a person from selling to—or interpreting for—employers, the genetic test of employees or applicants unless done with informed consent, and for the purpose of investigating workers’ compensation claims or determining employees’ susceptibility to a workplace toxin.271

Kansas does not explicitly extend protection to the genetic privacy of employees, but the Acts Against Discrimination272 make it an unlawful employment practice for a person to “aid [or] abet” employers in any of the actions proscribed by the statute.273 Proscribed activities include seeking or obtaining genetic information of employees or

265. Kaufmann, supra note 3, at 429-33 (applying the First, Third, Fourth, and Fifth Amendments to develop protections for employees’ genetic privacy because “genetic information is uniquely personal” and more deserving of protection).
266. Miller, supra note 80, at 251. (“Th[e] right to privacy is limited in that it applies only to government action, and does not reach private employers.”).
267. Id. at 256.
269. Id.
271. IOWA CODE § 729.6(2)(b), (3) (1993); see also R.I. GEN. LAWS § 28-6.7-1(b) (2000); WIS. STAT. § 111.372 (1997).
273. Id.
applicants. This protection may prevent an individual from selling genetic information to employers or interpreting the results of a genetic test for employers. Massachusetts restricts the genetic testing of individuals by first requiring written consent prior to testing and then prohibiting release of the results to a third party without a separate written consent. Employers are prohibited from “question[ing] a person about their genetic information or the genetic information concerning their family” or prior genetic tests. Similarly, Michigan bars employers from acquiring or accessing genetic information concerning employees or applicants, and their families.

New Jersey requires that a person who “receives records, results, or findings of genetic testing” notify the subject of the test that they are in receipt of these materials. Disclosure is prohibited without the subject’s written consent. Disclosure of the genetic information is a violation punishable by fines up to $5000, and a prison term of one year. Similarly, New York also seeks to prevent employers from acquiring employees’, or prospective employees’, genetic test results or an interpretation of those results. Although Oklahoma prohibits employers from using “information derived from ... a genetic test,” employers can use family history in making employment decisions.

Oregon’s legislature found that genetic analysis of an individual could lead to stigmatization and possible employment discrimination. The legislature also found that providing information about blood relatives could have a potential impact on family privacy. The legislature stated that existing laws were “inadequate to protect genetic privacy” and there was a need for legislation that would “protect individual privacy and ... permit legitimate ... research.” To achieve

274. Id. § 44-1009(a)(9).
276. MASS. GEN. LAWS ch. 151B, § 4.19 (Supp. 2001) (prohibiting employers from “seek[ing], receiv[ing], or maintain[ing] genetic information for non-medical purposes”).
279. Id.
282. OKLA. STAT. tit. 36, § 3614.2(B)(3) (1999) (excluding family history from the definition of genetic information).
284. Id.
these goals, Oregon made genetic information the property of the individual subject, except if used in anonymous research.\textsuperscript{285} Texas provides that “genetic information is confidential and privileged” and cannot be disclosed without the consent of the individual.\textsuperscript{286} The sample genetic material must be destroyed promptly after use.\textsuperscript{287} The individual subject to the genetic test is given a “right to know the results” but must make a written request to obtain the test results.\textsuperscript{288} Under this framework, a genetic sample can be analyzed and the results used without the consent of the subject. The only control individuals have over their genetic test results is the right to limit dissemination.

Constitutional rights to privacy do not prohibit employers from requiring genetic information from their employees, but a few states provide employees protection from certain adverse employment actions based on that information. These states mandate informed consent before testing, grant property rights to employees, prevent employers from using family data, and prohibit third-party access to genetic test results. Some states also prohibit the selling or interpreting of employees’ genetic test results by third-parties on behalf of employers. Employers may be required to notify test subjects when the employers are in receipt of genetic test results. States concerned with inadvertently restricting genetic research allow anonymous use of test results.

Privacy rights should be highly respected in the context of genetic testing. Genetic information, like other medically-related data, is highly personal and sensitive information. Legislation should require that, prior to testing, informed consent is obtained from employees, and that family data may be used only with the consent of all family members.

\textbf{E. Remedies Available to Employees and Penalties Imposed on Violators}

At least ten states have incorporated provisions for remedies and penalties into statutes prohibiting employment discrimination based on genetic information. The remedies include injunctive relief, traditional tort causes of action with compensatory damages, awards for backpay, and administrative agency awards. The penalties range from civil fines

\textsuperscript{285} Id. § 659.715. Genetic test samples from an individual used for employment purposes are to “be destroyed promptly after the purpose . . . has been accomplished.” Id. § 659.715(6).
\textsuperscript{286} TEX. LAB. CODE ANN. § 21.403(a) (Vernon Supp. 2001).
\textsuperscript{287} Id. § 21.405.
\textsuperscript{288} Id. § 21.404.
of nominal amounts to a maximum of $25,000 and criminal penalties of up to one year in prison.

The Delaware Department of Labor (Department) is empowered by statute to prevent employers from discriminating on the basis of genetic information.\(^{289}\) A proceeding may be initiated by either a "person claiming to be aggrieved" or an appropriate member of the Department.\(^{290}\) The investigation and charges are not to be made public.\(^{291}\) If it is determined "that there is reasonable cause to believe" the allegations, the Department enters into "informal methods of conference, conciliation and persuasion" to end the alleged practice.\(^{292}\) If an agreement cannot be reached, a review board examines the case.\(^{293}\) The review board has authority to award the reinstatement of employees or to order the hiring of applicants, along with an award of backpay.\(^{294}\)

Wisconsin has a procedural framework similar to that implemented by Delaware.\(^{295}\) The key differences between the states are that the Wisconsin Department of Labor can make its findings public,\(^{296}\) and an examiner, not a review board, holds hearings.\(^{297}\) The examiner is empowered to "order such action ... as will effectuate the purpose" of the statute including ordering an award instead of reinstatement.\(^{298}\) The award is not to be "less than 500 times nor more than 1,000 times the hourly" rate of the employee.\(^{299}\)

Iowa gives individuals whose rights have been violated the ability to bring civil actions against their employers for genetic discrimination.\(^{300}\) Employers violating the Iowa statute may be liable for "affirmative relief including reinstatement or hiring, with or without back pay, ... or any other equitable relief [deemed appropriate by the court,] including attorney fees and court costs."\(^{301}\) Prospective injunctive relief is also available to enjoin employers from committing a violation.\(^{302}\)

\(^{290}\) Id. § 712(b).
\(^{291}\) Id.
\(^{292}\) Id. § 712(c).
\(^{293}\) Id. § 712(e).
\(^{296}\) Id. § 111.39(1).
\(^{297}\) Id. § 111.39(4)(b).
\(^{298}\) Id. § 111.39(4)(c).
\(^{299}\) Id.
\(^{300}\) Iowa Code § 729.6(6) (1993).
\(^{301}\) Id.
\(^{302}\) Id.
The Maine Human Rights Commission enforces that state’s law prohibiting genetic discrimination. Remedies for violations are the same as for other discriminatory practices. Oregon authorizes the Commissioner of the Bureau of Labor and Industries to enforce its unlawful employment practice statutes. Employers violating the prohibition on genetic discrimination are subject to the same civil and criminal remedies of other employment practice violations.

New Jersey punishes a person who willfully discloses another’s genetic information to a third party with “a fine of $5,000, a prison term of one year, or both.” Furthermore, the violator is liable to the injured party for actual damages, including emotional harm. Massachusetts gives a victim of genetic discrimination the right to bring private action against a violator and seek “injunctive and other equitable relief.” The Attorney General may also bring action on behalf of Massachusetts. Employers violating Missouri’s prohibition on genetic discrimination are fined only to a maximum of $500 for each violation. Conversely, Oklahoma deters violations of its statute by imposing a maximum penalty of a $25,000 fine and imprisonment of up to one year.

In civil actions brought by employees or applicants alleging genetic discrimination, a Rhode Island court may award actual damages, reasonable attorneys’ fees, and punitive damages. The legislature allows courts to issue an injunction enjoining employers who “propose[] to commit a violation.

A minority of states with statutes prohibiting genetic discrimination incorporate provisions for remedies. Remedies include injunctive relief, traditional tort causes of action with compensatory damages, awards for backpay, and penalties ranging from nominal civil fines to criminal imprisonment. One state authorizes administrative agency hearings, but prevents the charges and investigation from being made public; another allows public hearings. Prospective relief through judicial injunction is

304. Id.
306. Id.
308. Id.
309. MASS. GEN. LAWS ch. 111, § 70G(d) (Supp. 2001).
310. Id.
312. OKLA. STAT. tit. 36, § 3614.2(D) (1999).
314. Id.
available to prevent employers from committing violations. In just a few
states, successful plaintiffs may be awarded attorneys’ fees and court
costs.

Without remedies and penalties, legislation lacks substantive
enforcement mechanisms. Legislation with clear pronouncement of
remedies will discourage employers from violating statutes and
encourage employees to assert the protections available to them. Remedies
should provide for both private action and administrative
agency oversight. Awards should permit lost wages, reinstatement, and
attorneys’ fees and court costs. Civil penalties and criminal penalties,
such as imprisonment, act as necessary deterrents in keeping employers
from using cost analysis data as a justification for genetic information
discrimination.

V. A PROPOSED MODEL STATUTE

Having found no federal law regulating discrimination in the
workplace to be adequate to protect employees from genetic
discrimination, and finding state attempts to address this lack of federal
guidance to be inconsistent, this note suggests a model statute. The
proposed model statute is a compilation of the most effective approaches
used by various states to address the issue of genetic discrimination in
the workplace.315

The model statute protects employees from being coerced by
employers into undergoing genetic tests, which the employers could use
to screen employees for various genetic disorders. The recommended
legislation is designed to protect employees’ rights to keep genetic
information private and beyond their employers’ reach. Employers
would be prohibited from using employee genetic information, whether
obtained through a genetic test or from other medical records, in making
hiring and firing decisions and setting the terms and conditions of
employment. Finally, the proposed statute acknowledges the benefits of
genetic testing by factoring in the employers’ interests in maintaining a
safe workplace and their right to condition tests based on business
necessity against the employees’ rights to privacy.

315. See discussion supra Part IV. The model statute was compiled from the various state
statutes analyzed in Part IV. See generally FLA. STAT. ch. 760.40 (1997); IOWA CODE § 729.6
(1993); MASS. GEN. LAWS ch. 151B, § 1 (2001); MICH. COMP. LAWS § 37.1202 (2001); N.J. STAT.
ANN. § 10:5-5, 12, 47, 49 (Supp. 2001); N.Y. CIV. RIGHTS LAW § 48-a (McKinney 2000); N.Y.
EXEC. LAW § 296 (McKinney 2000).
GENETIC DISCRIMINATION IN EMPLOYMENT ACT

(1) Definitions.
As used in this Act:

a. “Person” includes one or more individuals, partnerships, associations, organizations, labor organizations, or corporations.

b. “Employer” includes any person engaging in any enterprise, or business employing at least four individuals.

c. “Employment agency” includes any person undertaking to procure employees or opportunities for others to work.

d. “Labor organization” includes any organization which exists and is constituted for the purpose, in whole or in part, of collective bargaining, or of dealing with employers concerning grievances, terms or conditions of employment, or of other mutual aid or protection in connection with employment.

e. “Atypical hereditary cellular or blood trait” means sickle cell trait, hemoglobin C trait, thalassemia trait, Tay-Sachs trait, or cystic fibrosis trait.

f. “Genetic characteristic” means any inherited gene or chromosome, or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder, or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder, or syndrome.

g. “Genetic information” means any written, recorded, or individually identifiable result of a genetic test as defined by this section, or explanation of such a result, or family history pertaining to the presence, absence, variation, alteration, or modification of a human gene or genes.

h. “Genetic test” means any test of human DNA, RNA, mitochondrial DNA, chromosomes, or proteins for the purpose of identifying genes or genetic abnormalities, or the presence or absence of inherited or acquired characteristics in genetic material, including tests to identify a predisposing genetic characteristic.

(2) Unlawful employment practices, discrimination.
It shall be an unlawful employment practice, or, unlawful discrimination:

a. For an employer, because of the genetic information or atypical hereditary cellular or blood trait of any individual, or because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer, to refuse to hire or employ, or to bar, discharge, or require to retire from employment such individual, or to
discriminate against such individual in compensation or in terms, conditions, or privileges of employment.

No person who is otherwise qualified shall be denied equal opportunities to obtain and/or maintain employment, and/or to advance in position, in his or her job solely because said person has a unique genetic disorder, unless it can be clearly shown that a person’s unique genetic disorder would prevent such person from performing the particular job.

b. For a labor organization, because of the genetic information or atypical hereditary cellular or blood trait of any individual, or because of the refusal to submit to a genetic test, or make available the results of a genetic test, to exclude or to expel from its membership such individual or to discriminate in any way against any of its members, against any applicant for, or individual included in, any apprentice or other training program or against any employer or any individual employed by an employer.

c. For any employer or employment agency to print or circulate or cause to be printed or circulated any statement, advertisement, or publication, or to use any form of application for employment, or to make an inquiry in connection with prospective employment, which expresses, directly or indirectly, any limitation, specification or discrimination as to genetic information or atypical hereditary cellular or blood trait of any applicant for employment, or any intent to make any such limitation, specification or discrimination, unless based upon a bona fide occupational qualification.

d. For any employer, labor organization, or employment agency to discharge, expel or otherwise discriminate against any person because he or she has opposed any practices forbidden under this Act or because he or she has filed a complaint, testified or assisted in any proceeding under this Act.

e. For any person, whether an employer or an employee, to aid, abet, induce, compel or coerce the doing of any of the acts forbidden under this Act, or to attempt to do so.

(3) Conditions for disclosure of genetic information.

a. Genetic testing may be performed only with the informed consent of the person to be tested, and the results of such genetic testing, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.

b. Except as otherwise provided in subsection (2), no employer may directly or indirectly acquire or have access to any genetic information
concerning an employee or applicant for employment, or a member of the employee’s or applicant’s family.

c. The provisions of this section apply to any subsequent disclosure by any person after another person has disclosed genetic information or the identity of an individual upon whom a genetic test has been performed.

d. This section does not prohibit the genetic testing of an employee who requests a genetic test and who provides written and informed consent to taking a genetic test for any of the following purposes:

   i. investigating a worker’s compensation claim; or

   ii. determining the employee’s susceptibility or level of exposure to potentially toxic chemicals or potentially toxic substances in the workplace, provided the employer does not terminate the employee, or take any other action that adversely affects any term, condition, or privilege of the employee’s employment as a result of the genetic test.

(4) Violations, penalties for unlawful disclosure of genetic information.

a. Any person violating the provisions of section (2) or (3), shall be punished by a fine of $25,000, a prison term of up to one year, or both, for each violation.

b. Any person who willfully discloses an individual’s genetic information to any third party in violation of section (3) shall be punished by a fine of $5000, a prison term of up to one year, or both.

c. Any person who discloses an individual’s genetic information in violation of section (3) shall be liable to the individual for affirmative relief including reinstatement or hiring, with or without backpay; all actual damages, including damages for economic, bodily, or emotional harm proximately caused by the disclosure; or any other equitable relief as the court deems appropriate including attorneys’ fees and court costs.

d. If a person commits, is committing, or proposes to commit, an act in violation of section (2) or section (3), an injunction may be granted through an action in court to prohibit the person from continuing such acts. The action for injunctive relief may be brought by an aggrieved employee, labor organization member, aggrieved prospective employee, or the appropriate federal agency authorized to enforce this Act.

VI. CONCLUSION

Various types of genetic testing make it possible for employers to use the technology to the detriment of employees. Current federal
legislation regulating workplace discrimination fails to protect employees from genetic discrimination. A detailed examination of the numerous state laws regulating genetic discrimination in the workplace reveals a broad and inconsistent range of protections. Therefore, there is a need for a uniform statute regulating genetic information in employment relationships. The proposed model statute offers a comprehensive solution by achieving the goal of extending genetic discrimination protection to employees.

\textit{Jared A. Feldman* and Richard J. Katz**}

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  \item I would first like to thank Rich, whose collaboration, insight, and good humor made the note writing and editing process such a success. I would like to express special thanks to Vincent R. FitzPatrick III for the countless hours he spent with us editing and re-editing this Note. I would also like to thank JoAnn Nelson for her advice and for her tireless efforts on our behalf. Most importantly, I would like to thank my wife, Ronit, for her love, support, and inspiration not only during the writing of this Note but also throughout my entire law school tenure.
  
  ** First, I would like to thank Jared, whose cooperative nature made this collaboration a pleasant experience. Vincent R. FitzPatrick III certainly deserves thanks and recognition for the hours of effort he expended in contributing to the editing of this Note. Special thanks to JoAnn Nelson for her suggestions, which were both valuable and instructive. Foremost, I want to thank my wife, Gail. Without her love, support, and generosity, nothing I do would be possible or meaningful.
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