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## Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance

Natalie E. Zindorf

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# **DISCRIMINATION IN THE 21ST CENTURY: PROTECTING THE PRIVACY OF GENETIC INFORMATION IN EMPLOYMENT AND INSURANCE**

## **INTRODUCTION**

Genetic science is gaining power every day. After ten years of research, geneticists are close to holding the key that unlocks the mysteries of the human body. As technology advances and revolutionary scientific endeavors like the Human Genome Project progress rapidly, the ability to predict a person's health destiny is no longer a mere guessing game. Upon completion of the Human Genome Project, scientists should be able to predict human susceptibility to disease with a high level of accuracy. While scientific developments in genomics will aid society in countless ways, many fear the possibility of discrimination at the hands of employers and insurers.

At this point, discrimination based on genetic information is highly speculative because the technology is new and still developing. However, as science continues to advance, genetic testing will become cheaper, more reliable, and more popular. With genetic science progressing at such a rapid pace, many people fear that the law will be slow to catch up. In order to address worries that genetic testing may subject people to abuse and discrimination, federal and state governments have enacted legislation banning certain uses of genetic information. This Comment will examine the existing law addressing genetic discrimination, noting specific problems caused by inadequate laws, and propose amendments to legislation.

Part II of this Comment begins by explaining the basics of the Human Genome Project and the project's implications on society, including definitions of key terms used in federal and state regulations. Following the scientific information in Part II, Part III will examine the existing laws designed to protect discrimination in employment. Federal employment discrimination based on genetic information may be covered by the Americans with Disabilities Act of 1990 and is specifically addressed in Federal Executive Order 13145. Additionally, this section examines existing state legislation addressing genetic discrimination.

Part IV evaluates federal and state legislation dealing with genetic discrimination in insurance. Also, this section discusses the distinctions between the various definitions of genetic information and the effect linguistic differences

make to insurers and consumers. Finally, Part V addresses the question of whether it is appropriate for an employer or insurer to use genetic information to discriminate against an individual in the workplace or in providing insurance coverage. This section will conclude with a proposal for reformation of state laws and suggestions for drafting uniform federal laws specifically addressing genetic discrimination in the sphere of health care confidentiality. Not only are the suggested changes aimed at protecting the confidentiality of genetic information, but also, by including genetic information within the definition of medical information, they are aimed at maintaining the privacy of medical information as a whole.

## II. BIOLOGY BACKGROUND

### A. *The Human Genome Project*

Scientific minds predict that the 21st Century will be the “biology century.”<sup>1</sup> At the forefront of the biology movement is the Human Genome Project, a federally funded mission to determine the sequence of human DNA.<sup>2</sup> The genome is dubbed the master blueprint for a person’s lifetime; it contains the complete list of instructions for making an organism.<sup>3</sup> Since 1990, researchers from the United States, the United Kingdom, Germany, Japan and France have been reconstructing DNA sequencing to produce detailed physical maps of the human genome.<sup>4</sup>

Initially, researchers set 2005 as the target date for completion of the human genome map, however, rapid progression in genetic research prompted scientists to revise the original plan.<sup>5</sup> In 1998, *Science* magazine published the updated plan and publicly released the predicted completion date of 2003.<sup>6</sup> On June 26, 2000, President Clinton announced the completion of a “working draft” of the human genome, a collection representing approximately 90% of the genetic composition of chromosomes.<sup>7</sup> Rapid scientific progress led to the February 12, 2001

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1. See HUMAN GENOME PROJECT INFORMATION, The Science Behind the Human Genome Project, at <http://www.ornl.gov/hgmis/project/info.html> (last visited Aug. 24, 2000) [hereinafter The Science Behind the Human Genome Project].

2. See *id.*

3. See *id.*; see also BRUCE ALBERTS, THE MOLECULAR BIOLOGY OF THE CELL 483 (2d ed. 1989). The human genome, consisting of DNA and chromosomes, is found in every nucleus of a person’s cells. See *id.* A DNA molecule is comprised of repeating chemical structures made up of nucleotides, which are chemical forms that reveal genetic information by their sequencing order. See *id.* The entire chemical arrangement making up DNA is contained in a chromosome, and the chromosomes involved in RNA functioning form a gene. See *id.* A genome consists of the entire chemical composition and represents all genetic information in an organism. See *id.*

4. See DIVISION OF EXTRAMURAL RESEARCH (DER): HGP, The Human Genome Project: Human Genome Project Goals: 1998-2003, at <http://www.nhgri.nih.gov/HGP> (last visited Aug. 20, 2000) [hereinafter DIVISION OF EXTRAMURAL RESEARCH].

5. See *id.*

6. See The Science Behind the Human Genome Project, *supra* note 1.

7. See *id.*

declaration of the first readable draft of the "Book of Life."<sup>8</sup>

Currently, completion of the human genetic roadmap awaits additional research, however, the February 2001 text contains a wealth of revolutionary information about the human species.<sup>9</sup> Genetic scientists can use this information to identify DNA sequence variation, which predicts the way humans respond to disease, bacteria, viruses, toxins, chemicals, drugs and therapies.<sup>10</sup> Different types of variation may hold the key to diseases such as cancer, deafness, kidney disease, diabetes, vascular diseases, and some mental illness.<sup>11</sup> Genetic disorders may occur as a result of "mutated genes," DNA structures that may be missing segments, multiplied or transposed.<sup>12</sup>

Although genetic mutations cause all genetic conditions, the disorders vary widely in their nature and effect. Genetic mutations can be either inherited or acquired, and can be classified as either multi-factorial or single-gene disorders.<sup>13</sup> A person with a multi-factorial genetic condition will not develop the disorder unless certain behavioral or environmental factors come into play.<sup>14</sup> For instance, a non-smoker with a multi-factorial genetic marker for lung cancer might never develop the disease due to the absence of environmental toxins created by smoking.<sup>15</sup> While multi-factorial disorders only make a carrier susceptible to developing a disease, single-gene conditions virtually guarantee that a person will develop the genetic disorder.<sup>16</sup> With single-gene mutations, environmental aspects are insignificant; if the person lives long enough, the disease will manifest itself.<sup>17</sup> Some examples of single-gene disorders include Huntington's disease and cystic fibrosis.<sup>18</sup>

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8. See HUMAN GENOME PROJECT INFORMATION: Announcements on the First Analysis of Genome Sequence, Feb. 12, 2000, at [http://www.ornl.gov/hgmis/project/feb\\_pr/initial\\_sequencePR.html](http://www.ornl.gov/hgmis/project/feb_pr/initial_sequencePR.html) (last visited February 24, 2001) [hereinafter Announcements on the First Analysis].

9. See *id.*

10. See The Science Behind the Human Genome Project, *supra* note 1.

11. See *id.* Detection methods for sequence variation are being developed. Currently, the most common type of sequence variation is single-nucleotide polymorphisms ("SNPs"). *Id.* Scientists use SNP maps to identify genes associated with common disorders. See *id.* See also *Genetic Information in the Workplace: Hearing Before the Committee on Health, Education, Labor and Pensions*, 106th Cong. (July 20, 2000) (statement of Francis S. Collins, Director, National Human Genome Research Institute, National Institutes of Health), 2000 WL 1115522, at \*2 [hereinafter Statement of Francis Collins]. Dr. Collins stated that scientists sequencing the human genome at the Department of Energy have identified more than a dozen genes responsible for diseases from deafness to kidney disease and cancer. See *id.*

12. See Christopher M. Keefer, *Bridging the Gap Between Life Insurer and Consumer in the Genetic Testing Era: The RF Proposal*, 74 IND. L.J. 1375, 1378 (Fall 1999). Forty-six molecules of DNA contain between 50,000 and 100,000 genes, each of which is responsible for different functions. See *id.* at 1377. Variations in sequencing can result in problems with an organism functioning normally. See *id.* at 1378.

13. See *id.* Inherited genetic conditions occur when a parent passes on genetic mutations to a child through a set of chromosomes that may result in a genetic disorder. See *id.* This set of chromosomes may continue to pass on to successive generations. See *id.* Acquired genetic mutations are formed as a result of exposure to certain age-related or environmental factors. See *id.*

14. See *id.*

15. See *id.*

16. See *id.* at 1378-79.

17. See *id.* at 1379.

18. See Keefer, *supra* note 12, at 1378.

Not only are genetic conditions classified as single-celled or multi-factorial, but people with genetic disorders can be distinguished as either predisposed or pre-symptomatic.<sup>19</sup> The primary difference between the two conditions lies in the issue of certainty. Although a person with a genetic predisposition has a greater chance of developing a certain disorder than someone without the genetic susceptibility, the predisposed person is not certain to become ill.<sup>20</sup> Additionally, the possibility of developing a genetic condition depends on the particular disorder. For instance, BRCA1, a gene that predisposes an individual to breast cancer, actually results in cancer for 85% of patients.<sup>21</sup> Unlike a predisposed carrier, a pre-symptomatic individual is certain to develop the genetic condition in a matter of time.<sup>22</sup> Another aspect effecting the nature of genetic conditions deals with "expressivity," the severity and manner in which the gene manifests into a disorder.<sup>23</sup> For instance, two women with the BRCA1 gene may develop breast cancer at different ages and in varying degrees of severity.<sup>24</sup>

### B. *Implications of Advances in Genetic Science*

Presently, the potential benefits of effective interpretation of the human genome are vast and impossible to fully understand. When the project began, scientific discoveries were limited to rare diseases such as sickle cell anemia and Huntington's Disease.<sup>25</sup> As hereditary factors of more common disorders are revealed, genetic testing will reveal a person's susceptibility to disease, allowing individuals to increase the likelihood of avoiding health problems by utilizing preventive measures.<sup>26</sup> Couples will be able to make reproductive decisions, such as whether to conceive or adopt, based on genetic information.<sup>27</sup> Further, scientists will be able to predict how an individual will respond to a particular drug, enabling physicians to create treatment programs designed to promote a cure rather than create problems for the patient.<sup>28</sup> However, large-scale genetic testing must be implemented to achieve complete, accurate readings of human genes and to provide solutions to the vast array of health problems prompted by

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19. *See id.* at 1379.

20. *See id.* at 1380.

21. *See id.* The BRCA1 gene results in breast cancer about 85% of the time. *See id.* The ability of a gene to cause a condition is known as "penetrance." *See id.* While the BRCA1 gene is eighty-five percent penetrant, the Huntington's disease gene is nearly 100% penetrant. *See id.*

22. *See id.*

23. *See id.*

24. *See Keefer, supra* note 12, at 1380.

25. *See id.*

26. *See* NATIONAL PARTNERSHIP: What Every Woman Should Know About Genetic Discrimination, at <http://www.nationalpartnership.org/healthcare/genetic/discrimination.htm> (last visited Aug. 20, 2000).

27. *See* Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 JURIMETRICS J. 21, 37 (1999).

28. *See* Statement of Francis Collins, *supra* note 11. New genetic discoveries enable scientists to predict how a person will react to a particular drug. *See id.* If a physician knows a patient will suffer a side effect, the physician can avoid prescribing that medication. *See id.*

genetic mutations.<sup>29</sup>

Large-scale genetic screening, which involves studying the DNA sequencing and medical histories of many people, opens the door to the possibility of future discrimination.<sup>30</sup> In order to conduct large-scale genetic testing, DNA samples from a large segment of the population must be collected and analyzed, allowing scientists to understand human cellular functions and reactions to environmental toxins.<sup>31</sup> Consequently, personal medical information and DNA structures contained in genetic databanks must be compared throughout the population.<sup>32</sup> Therefore, major advances in genomics largely depend upon the ability of researchers to access existing DNA banks and medical records.<sup>33</sup> To facilitate effective research, laws must be in place protecting the privacy of research subjects. Scientists fear that without anti-discrimination legislation in place protecting the privacy of research subjects, people will refuse to participate in testing and genomic progress will come to a halt.<sup>34</sup>

Public fear of genetic testing is not unfounded. While genetic science holds great potential to benefit the public, it also invites the possibility that people in powerful positions may use genetic information to society's detriment. Since most diseases have genetic factors, genetic illnesses include commonly occurring diseases, such as cancer and heart disease, that affect a large portion of the population.<sup>35</sup> The misuse of genetic information would cause serious problems in the workplace and the health insurance industry, impeding the ability of scientists to continue important genetic research.<sup>36</sup>

Since genetic screening is relatively new and many people avoid it for fear of discrimination, most cases involving discrimination based on genetic information are anecdotal.<sup>37</sup> Studies have revealed that genetic discrimination does exist and will become more widespread as access to genetic information increases.<sup>38</sup> One reported case involves Terri Seargant, who joined U.S. Representative Louise M.

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29. See DIVISION OF EXTRAMURAL RESEARCH, *supra* note 4.

30. See John A. Robertson, *Privacy Issues in Second Stage Genomics*, 40 JURIMETRICS J. 59, 66 (1999).

31. See *id.* at 60.

32. See *id.* (stating that successful genetic correlation also requires advances in bioinformatics, cell biology, and molecular medicine).

33. See *id.*

34. See *id.* at 61.

35. See Gostin & Hodge, *supra* note 27, at 32.

36. See Statement of Francis Collins, *supra* note 11, at \*3.

37. See *Genetic Information in the Workplace: Hearing Before the Committee on Health, Education, Labor and Pensions*, 106th Cong. (July 20, 2000) (statement of Commissioner Paul Steven Miller, U.S. Equal Employment Opportunity Commission), 2000 WL 1115566, at \*3 (discussing the reality of genetic discrimination) [hereinafter Statement of Paul Miller].

38. See *id.* The Council for Responsible Genetics had documented over two hundred cases of genetic discrimination as of August 1997. See *id.* The Congressional Office of Technology Assessment found that twelve out of 330 companies surveyed in 1989 used some type of biochemical genetic screening, and forty-two percent of employers considered an individual's health status when making employment decisions. See *id.* Researchers at Georgetown University found that fifteen percent of participants had been asked questions regarding genetic diseases on job applications. See *id.*

Slaughter at a press conference on genetic discrimination.<sup>39</sup> Terri's career boasted a record of success that included years of excellent job evaluations, raises and promotions.<sup>40</sup> Nevertheless, after her employer discovered Terri was receiving preventive treatment for a genetic condition, she was suddenly dismissed.<sup>41</sup> Unfortunately, along with her job, Terri lost her income and the insurance coverage providing for her preventive care.<sup>42</sup> Among other incidents of genetic discrimination, a woman lost her job the day after telling her boss about test results diagnosing a genetic skeletal disorder.<sup>43</sup> Another case deals with a man that was denied a job after a pre-employment medical examination revealed a sex-chromosome disorder.<sup>44</sup>

### C. Genetic Discrimination

In order to address the issue of genetic discrimination, some key terms must be defined, including genetic discrimination, genetic information and genetic testing. Genetic discrimination has been described as using genetic information to judge an individual with a predisposition to a certain disease or condition based on the possibility that he or she might one day develop that disease or condition.<sup>45</sup> In the context of this Comment, genetic discrimination involves making employment or insurance decisions about an individual on the basis of genetic information.<sup>46</sup> Attempting to pinpoint a precise definition of genetic information has prompted heated debate, with some groups narrowly defining genetic information as the results of DNA and related gene testing and other groups broadly interpreting it to include family medical history.<sup>47</sup>

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39. See generally Statement of Francis Collins, *supra* note 11, at \*3.

40. See *id.*

41. See *id.*

42. See *id.*

43. See *id.*

44. See *id.* In the case of the pre-employment physical, the employer explained the genetic test results prompted the job offer revocation. See *id.* If questioned, the employer claimed he would deny the incident occurred. See *id.*

45. See THE U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION: Policy Guidance on Executive Order 13145 Prohibiting Discrimination in Federal Employment Based on Genetic Information, at <http://www.eeoc.gov/docs/qanda-genetic.html> (last visited Aug. 20, 2000) [hereinafter *Policy Guidance*].

46. See GENETIC INFORMATION AND HEALTH INSURANCE: Genetic Information and the Workplace, Enacted Legislation, at [http://www.nhgri.nih.gov/Policy\\_and\\_public\\_affairs/Legislation/insure.htm](http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm) (last visited Aug. 20, 2000) [hereinafter *Enacted Legislation*]. Employment decisions include discharging and failing to hire or to promote an individual based on genetic information. See *id.* Insurance decisions include using the results of a genetic test to determine insurability, rates or benefits. See *id.*

47. See *id.* (defining a genetic condition as a specific chromosomal disorder and a genetic test as a DNA or chromosomal examination). See also NATIONAL ASSOCIATION OF HEALTH UNDERWRITERS: Legislative Resources, NAHU Position on Genetic Testing, at <http://www.nahu.org/Legislative/LegislativeGeneticTesting.htm> (last visited Aug. 20, 2000) [hereinafter *NAHU Position on Genetic Testing*]. The NAHU supports the narrow interpretation of genetic information for reasons this Comment later addresses. See *id.* See also *Policy Guidance*, *supra* note 45. Federal employees are protected from discrimination based on individual genetic tests, genetic testing of family members and family medical history. See NAHU Position on Genetic Testing, *supra*. Genetic testing includes analysis of DNA, RNA and other materials that provide information about an individual's genetic composition. See *id.*

Genetic testing or genetic screening involves detecting alterations or errors in an individual's genetic composition that indicate a person's susceptibility to developing a particular disorder.<sup>48</sup> Through DNA analysis, it is possible to determine whether an individual carries a genetic marker for a particular disorder, the nature and severity of that disorder, and the chances the condition will be passed on to the next generation.<sup>49</sup> The primary forms of genetic testing are prenatal, newborn, carrier and clinical screening.<sup>50</sup> Prenatal screening identifies possible disease in the fetus and newborn screening aims for early detection and disease prevention.<sup>51</sup> Carrier testing identifies individuals with genetic markers for specific hereditary diseases, and clinical testing is research-based, focusing on obtaining information to assist health care providers in understanding and treating patients.<sup>52</sup>

Genetic research yields test results that are collected and stored in genetic databases.<sup>53</sup> By compiling information from all stages of life, genetic databases retain all of an individual's past health information and hold the key to revealing future health conditions.<sup>54</sup> Genetic databases of various sizes are used for reasons including research, public health matters and identifying bodily remains.<sup>55</sup> Often, genetic information is part of a larger health database, where detailed records concerning medical treatment are available.<sup>56</sup> Not only do health databases contain detailed records of sensitive health matters, but technology allows users to access information about individuals and populations as well as to transfer information among databases.<sup>57</sup>

The vast amount of information contained in genetic databases is of a highly personal nature, and the thought that an employer or insurer could access such private health details is threatening to genetic test subjects as well as their family members.<sup>58</sup> For instance, if genetic testing reveals that a parent has the genetic marker for a serious disease or disorder, this information may be stored in a database and may be linked to the child's medical record indefinitely.<sup>59</sup>

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48. See Tara L. Rachinsky, *Genetic Testing: Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace*, 2 U. PA. L. REV. 575, 578 (Winter 2000) (discussing the need for laws to protect genetic privacy in employment and insurance). Diagnostic tests include DNA analysis, which involves examining gene sequencing, and biochemical testing for proteins revealing genetic composition. See *id*

49. See Keefer, *supra* note 12, at 1380.

50. See Gostin & Hodge, *supra* note 27, at 26.

51. See *id*.

52. See *id*.

53. See *id*. at 28.

54. See *id*. at 30.

55. See *id*. at 29. Genetic databases are used in the public and private sector and range in size from less than a hundred to thousands of samples. See *id*. The National Institute of Health holds a cancer research database; universities across the country maintain genetic data banks and commercial companies offer genetic data banking to individuals and researchers. See *id*.

56. See Gostin and Hodge, *supra* note 27, at 30. Health databases hold information including medical cost reimbursements, hospital discharges, health status, research, and disease details. See *id*

57. See *id*. at 29-30.

58. See *id*. at 40-41.

59. See *id*.



Furthermore, the danger of genetic information falling into the wrong hands may prevent a mother from undergoing prenatal or fetal screening that would be beneficial to both mother and child.<sup>60</sup> Whether or not the information would be misused is purely speculative. However, in the eyes of society, the threat is real, so laws must be in place to safeguard confidentiality if genetic science is to continue advancing and accomplishing goals to benefit the public.

### III. LAWS PROTECTING INDIVIDUALS FROM GENETIC DISCRIMINATION IN THE WORKPLACE

If an employer could access information about an individual's susceptibility to disease, that employer might misuse the data to avoid expenses associated with absenteeism, health benefits and eliminating risky occupational exposures.<sup>61</sup> Under existing law, Title VII of the Civil Rights Act of 1964 ("Title VII"), the Americans with Disabilities Act of 1990 ("ADA"), the Rehabilitation Act of 1973, Federal Executive Order 13145 and various state laws may protect victims of genetic discrimination.<sup>62</sup>

#### A. Title VII

Under Title VII, employers are prohibited from discriminating on the basis of sex, race, national origin, religion or color.<sup>63</sup> A few genetic diseases are tied strongly to race or ethnicity, so an employer that discriminates against an employee based on racially or ethnically linked disorders may violate Title VII.<sup>64</sup> In *Norman Bloodsaw v. Berkeley Laboratory*, plaintiffs were subjected to pre-employment screening.<sup>65</sup> Without obtaining consent from the plaintiffs, the defendant-company screened not only for standard health concerns, but included pregnancy testing for females and sickle-cell testing for African Americans.<sup>66</sup> In this case, since sickle-cell anemia has a strong link to people of African American descent, the plaintiffs Title VII claim was successful.<sup>67</sup> However, since most genetic conditions are not predominantly linked to a certain race or ethnicity, the majority of individuals falling victim to genetic discrimination will not be protected under Title VII.<sup>68</sup>

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60. *See id.*

61. *See* Michael S. Yesley, *Genetic Difference in the Workplace*, 40 JURIMETRICS J. 129, 130 (1999). Employment discrimination based on genetic disorders would probably not reduce costs for the employer because predictions based on genetic screening are not completely accurate. *See id.* Although the test may reveal that a person is more likely to develop a particular disorder than someone without the genetic alteration, there is no certainty in the outcome. *See id.* at 138.

62. *See* The U.S. Equal Employment Opportunity Commission: Federal Laws Prohibiting Job Discrimination, Questions and Answers, at <http://www.eeoc.gov/facts/qanda.html> (last visited Aug. 20, 2000) [hereinafter *Questions and Answers*].

63. 42 U.S.C. §§ 1971, 1975(a), 2000(a)-(h)(6) (1994).

64. *See Questions and Answers*, *supra* note 62.

65. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1264 (9th Cir. 1998).

66. *See id.* at 1265.

67. *See id.* at 1272.

68. *See Questions and Answers*, *supra* note 62.

### B. The ADA

The ADA may prohibit genetic discrimination in the workplace. However, whether discrimination based on a healthy employee's genetic disposition and susceptibility to disease is protected by the ADA is a source of debate.<sup>69</sup> The ADA prohibits discrimination on the basis of disability.<sup>70</sup> In creating the ADA, Congress found that millions of Americans suffer from disabilities of some kind and that discrimination against disabled individuals is a critical problem in today's society.<sup>71</sup> To combat discrimination against disabled individuals, Congress intended to provide a broad basis for individuals to sue under the ADA.<sup>72</sup>

Under the ADA, disability is defined as "[ (1) ] a physical or mental impairment that substantially limits . . . [a] major life activity; [ (2) ] a record of such impairment; or [ (3) ] being regarded as having such an impairment."<sup>73</sup> According to the Equal Employment Opportunity Commission ("EEOC"), the agency responsible for issuing guidelines for following the ADA, a major life activity includes basic "functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."<sup>74</sup> A person is regarded as substantially limited in performing the major life activity of working when, compared to the average person of similar training, skills and abilities, the individual is significantly restricted in the ability to perform either a class of jobs or a broad range of jobs in various classes.<sup>75</sup>

Although the ADA does not mention genetic discrimination, Congress intended a broad reading of the ADA. Genetic discrimination may have limited protection under the third prong of the ADA's definition of disability.<sup>76</sup> Under the third prong, or the "regarded as" provision, an individual may qualify for protection if an employer regards the individual as unable to perform a major life activity due to a genetic predisposition to certain diseases.<sup>77</sup> However, the Supreme Court has not been forced to answer the question of whether or not the ADA applies to genetic discrimination, and absent specific legislation addressing the issue, genetic discrimination remains a hazy area in federal law.

Some recent Supreme Court cases suggest that discrimination based on genetic information may not be covered under the ADA.<sup>78</sup> In *Bragdon v. Abbott*,

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69. See Statement of Paul Miller, *supra* note 37, at \*4.

70. 42 U.S.C. § 12102(2) (1994).

71. *Id.* § 12101(a)(1), (a)(3).

72. *Id.* § 12101(b).

73. *Id.* § 12101.

74. 29 C.F.R. § 1630.2(2)(i) (1996).

75. *Id.* § 1630.2(3)(c)(i).

76. 42 U.S.C. § 12112(a).

77. See Statement of Francis Collins, *supra* note 11. In its guidelines for interpreting the ADA, the EEOC stated that individuals with genetic markers are protected from discrimination. See *id.* However, the ADA does not mention genetic discrimination, and the EEOC's policy guidance, while helpful in interpreting the ADA, does not have the force of federal or state law. See *id.* Furthermore, while it has been assumed that the ADA would protect individuals from genetic discrimination in the workplace, some recent Supreme Court cases cast a shadow of doubt on this assumption. See *id.*

78. See *id.*

Chief Justice Rehnquist's dissenting opinion suggests that the Supreme Court justices might be reluctant to define individuals with genetic alterations as disabled under the meaning of the ADA.<sup>79</sup> According to the reasoning of the dissent, the possible effect of finding such individuals disabled would be that all individuals with genetic alterations would be considered disabled and, consequently, protected under the ADA.<sup>80</sup> Following this analysis could create problems since, according to scientists, every person has a genetic alteration of some form.<sup>81</sup> Consequently, the line must be drawn somewhere short of classifying every person with genetic misspellings as disabled.

If the third prong of the ADA is interpreted as protecting genetic discrimination, an individual with genetic alterations could be classified as a qualified individual with a disability. The ADA specifically bans discrimination against qualified individuals with disabilities.<sup>82</sup> Discrimination in the workplace includes: (1) limiting, segregating or classifying individuals in a way that denies equal opportunity to employees; (2) denying equal opportunity to an individual that has a relationship with a disabled person; (3) not making reasonable accommodations when feasible; and (4) using testing measures that tend to screen out disabled individuals.<sup>83</sup>

Tests that tend to screen out individuals with disabilities are allowed if the test is shown to be both job related and consistent with business necessity.<sup>84</sup> If the test meets the necessary requirements, an employer may ban a disabled individual from holding a certain job if that person's impairment would threaten the safety or welfare of others.<sup>85</sup> The EEOC guidelines state that an employer can refuse to employ a disabled person if the impairment would threaten the individual's health and safety or the safety and welfare of others.<sup>86</sup> While the EEOC's task is to interpret the ADA, EEOC policy guidelines are not law, and any disparity between the ADA provisions and the EEOC guidelines will result in application of ADA terms.<sup>87</sup>

While the ADA does not specifically address genetic testing, it does discuss medical examinations and inquiries.<sup>88</sup> Employers are prohibited from asking prospective employees if they are disabled, and employers cannot force current employees to undergo medical examinations unless the examination is job-related and consistent with business necessity.<sup>89</sup> However, employers are allowed to

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79. See *Bragdon v. Abbott*, 524 U.S. 624, 657-62 (1998).

80. See *id.*

81. See Gostin & Hodge, *supra* note 27, at 32.

82. 42 U.S.C. § 12112(a) (1994).

83. *Id.* § 12112(b)(1), (b)(4), (b)(5)(A), (b)(6).

84. *Id.* § 12112(b)(6).

85. *Id.*

86. *Id.* § 12113(a)(3).

87. See HUMAN GENOME PROJECT INFORMATION: Genetics Privacy and Legislation, at <http://www.ornl.gov/hgmis/elsi/legislat.html> (last visited Aug. 24, 2000) [hereinafter Genetics Privacy and Legislation].

88. 42 U.S.C. § 12112(d).

89. *Id.* § 12112(d)(4)(B).

administer pre-employment medical examinations if the test is conducted after the job offer and prior to commencement of employment.<sup>90</sup> Pre-employment medical screening is not required to be job-related or consistent with business necessity as long as all entering employees are tested and the information is kept confidential.<sup>91</sup>

### C. Executive Order 13145

On February 8, 2000, President Clinton signed an executive order prohibiting federal employers from using genetic information to discriminate against employees.<sup>92</sup> The Executive Order covers “[a]pplicants, employees and former employees of the Executive branch departments and agencies.”<sup>93</sup> Under the Executive Order, genetic information is defined as: (1) information concerning results of genetic tests undergone by an individual or that individual’s family members and (2) information about an individual’s family medical history, with one exception. That exception is that information about an individual’s current health status is not protected genetic information, and an employer is permitted to investigate a person’s family medical history to decide whether further testing is needed to diagnose a current medical condition.<sup>94</sup>

According to the Executive Order, federal employers are prohibited from requiring genetic testing as a condition to employment or promotion, and the employer may not use genetic information to classify current employees in a manner that deprives employees of equal promotion opportunities.<sup>95</sup> Employees cannot be denied overseas posts or promotion opportunities based on information regarding genetic susceptibility to certain disease.<sup>96</sup> Two exceptions to the general rule against collecting genetic information from employees are: (1) department or agency health offices may collect genetic information about employees that use the department or agency health services and (2) genetic monitoring of employees is allowed.<sup>97</sup> Unlike genetic screening, which tests the potential of an individual developing a future disorder, genetic monitoring determines to what degree a person has been exposed to or harmed by toxins.<sup>98</sup> “While genetic screening

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90. *Id.* § 12112(d)(3).

91. *Id.* § 12112(d)(3)(A)-(B).

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

93. *Questions and Answers, supra* note 62.

94. *See id.* Family medical history is defined as information about the occurrence of disease, medical conditions or disorders of a person’s family members. *See id.* If family medical history is considered genetic information, genetic data can be obtained fairly easily in ways many people never considered. *See id.* For instance, providing genetic information regarding family medical history is as simple as completing a traditional patient intake form at a physician’s office. *See id.*

95. *See Genetics Privacy and Legislation, supra* note 87.

96. *See id.*

97. *See Questions and Answers, supra* note 62. *See* Lillian Trettin et al., *Genetic Monitoring in the Workplace: A Tool Not a Solution*, 10 RISK 31, 33 (1999) [hereinafter Trettin]. Genetic monitoring involves screening employees to ascertain the effects of toxic substances in the workplace. *See id.* Employers use genetic monitoring to evaluate the workplace environment and make necessary adjustments in order to eliminate risk of harm to individuals from hazardous toxins. *See id.*

98. *See* Frank C. Morris, *Privacy, Defamation and the Intentional Infliction of Emotional Distress in*

focuses on the individual, genetic monitoring . . . focuses on the environment” and attempts to identify hazards to employees.<sup>99</sup>

Unlike the ADA, the Executive Order does not permit employers to prescreen individuals if the test is job-related and consistent with business necessity.<sup>100</sup> Additionally, the Executive Order protects individuals that undergo genetic testing by ensuring that the results remain private.<sup>101</sup> However, certain exceptions permit disclosure to select individuals, including: the employee, officials investigating compliance with the order, health researchers involved in researching human subjects, the court and as required by law.<sup>102</sup>

#### D. Section 501 of the Rehabilitation Act

In the event that a federal employer violates the Executive Order prohibiting discrimination based on genetic information, an applicant or employee may be protected under section 501 of the Rehabilitation Act.<sup>103</sup> The Rehabilitation Act was designed to maximize employment opportunities for disabled individuals and to ensure the federal government actively leads the way as a model for state governments.<sup>104</sup>

Under the Rehabilitation Act, an impairment is defined as a mental or physiological disorder that substantially limits a major life activity.<sup>105</sup> A genetic alteration should meet this requirement because misspelled genes cause disturbances in cellular functions and prohibit the body from operating properly.<sup>106</sup> Therefore, if a federal employer bases an employment decision on protected genetic information about a currently able-bodied person, that employer may be regarding an individual with no known disabilities as having an impairment that substantially limits a major life activity.<sup>107</sup> However, when an individual's genetic disorder relates to a severe or fatal disease, the serious nature of the disorder would cause the person to be regarded as substantially limited in performing a major life activity.<sup>108</sup> Consequently, an individual carrying a genetic marker for a severe disease would have an actual disability and would be protected under the Rehabilitation Act.<sup>109</sup>

#### E. State Law

Currently, nearly half of the states have legislation prohibiting genetic

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*Employment*, in AMERICAN LAW INSTITUTE-AMERICAN BAR ASSOCIATION CONTINUING LEGAL EDUCATION: ALI-ABA COURSE OF STUDY 727, 748 (Feb. 3, 2000).

99. Trettin, *supra* note 97.

100. 42 U.S.C. § 12112(d)(4)(B) (1994).

101. *Id.*

102. *Id.* § 12112(d)(3)(B). *Id.* § 12112(d)(3)(B).

103. 29 U.S.C. § 701(b)(1)-(2).

104. *Id.*

105. *Id.*

106. *See Questions and Answers*, *supra* note 62.

107. *See id.*

108. *See id.*

109. *See id.*

discrimination in the workplace.<sup>110</sup> Most states prohibit employers from requiring genetic testing as a condition of employment unless the employer is conducting genetic monitoring.<sup>111</sup> However, existing state laws vary widely in coverage, with some of the earlier laws only protecting individuals with specific genetic characteristics or particular genetic disorders.<sup>112</sup> For instance, Louisiana has not adopted legislation addressing genetic discrimination since the 1982 statute prohibiting employers and labor organizations from discriminating against individuals due to sickle cell trait, which is only one of a yet unknown number of genetic disorders.<sup>113</sup>

Other states vary widely in genetic discrimination legislation. Some states have broad bans on discrimination while others specify particular types of discrimination that are prohibited. Connecticut, Iowa, Kansas, North Carolina and Oklahoma are among the states that prohibit discrimination based on genetic discrimination and provide for no exceptions or qualifying circumstances.<sup>114</sup> In contrast, some states, including Delaware, Maine, Michigan, New Jersey and New York, allow employers to collect genetic information if it can be proved to be job related and consistent with business necessity.<sup>115</sup>

Approaching genetic discrimination by broadly banning the use of genetic information in employment as a general rule closes the door to the possibility that genetic information may be helpful, if not necessary, in certain situations. While genomics is not a perfect science today, the accuracy will increase as researchers come closer to completion of the Human Genome Project.<sup>116</sup> Genetic science may become routine in the future, and banning the use of testing that could potentially aid society, while alleviating fears for the moment, does not further public policy. If genetic testing could reveal threatening health characteristics about a worker that is responsible for public safety, it may be in society's best interest to allow the information to be used.<sup>117</sup> For instance, if a test could reveal that an airline pilot was susceptible to a genetic disorder causing sudden death, failure to take every possible precaution to prevent the possibility of harm to the public would be disastrous.

Until this year, California was among the states that broadly banned use of genetic information in the workplace. Previously, California distinguished

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110. See *Genetic Information in the Workplace: Hearing Before the Committee on Health, Education, Labor and Pensions*, 106th Cong. (2000) (statement of Harold P. Coxson), 2000 WL 23831631, at \*2. The following states have laws prohibiting workplace discrimination based on genetic information: (1) Arizona, (2) California, (3) Colorado, (4) Connecticut, (5) Delaware, (6) Florida, (7) Georgia, (8) Illinois, (9) Iowa, (10) Kansas, (11) Louisiana, (12) Michigan, (13) Missouri, (14) Nevada, (15) New Hampshire, (16) New Jersey, (17) New Mexico, (18) New York, (19) Oregon, (20) South Carolina, (21) Texas, (22) Vermont and (23) Virginia. See *id.*

111. See *id.*

112. See *The Science Behind the Human Genome Project*, *supra* note 1.

113. 12 LA. REV. STAT. ANN. § 301 (West 2000).

114. See *Enacted Legislation*, *supra* note 46.

115. See *id.* While some statutes use job related and consistent with business necessity, the terms used in the ADA, the actual language in each statute varies. See *id.*

116. See *Announcements on the First Analysis*, *supra* note 8.

117. See *Yesley*, *supra* note 61, at 139-41.

discrimination based on genetic characteristics from other types of discrimination.<sup>118</sup> However, new state legislation prohibits employers from discriminating against individuals based on physical or mental conditions or medical conditions.<sup>119</sup> Under the new law, the definition of a medical condition includes genetic characteristics.<sup>120</sup> By banning discrimination based on medical information generally, rather than genetic information specifically, California offers its citizens a higher level of protection. Changing the language of the statute signifies that law makers recognize the need for confidentiality of health records in their entirety.

Similarly, Arizona's statute provides broad protection to genetic information by establishing legislation based on confidentiality rather than specifying situations in which genetic discrimination is prohibited.<sup>121</sup> As a result, an individual that undergoes genetic testing will be protected against discrimination from any source, including employers and insurers. Consequently, no separate legislation is needed to distinguish between genetic discrimination in the workplace and the insurance industry.

Illinois takes a unique perspective by stating that "an employer shall treat genetic testing information in such a matter that is consistent with the requirements of federal law."<sup>122</sup> If federal law adequately addressed genetic discrimination, this statute would be ideal. Unfortunately, since the status of federal law with regard to genetic discrimination remains unclear, so does the Illinois statute.

#### F. Recommendations for Future Legislation

The Clinton Administration's recommendations for future legislation follow the Federal Executive Order closely, prohibiting the use of genetic information to deny equal opportunity to employees and banning employers from disclosing genetic information in most circumstances.<sup>123</sup> Additionally, the recommendations propose that employers should not request or require that an employee take a genetic test or provide genetic information as a condition of employment or benefits.<sup>124</sup> Additionally, the recommendations state that genetic monitoring should be used only to monitor employees for the effects of a hazardous substance

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118. See Enacted Legislation, *supra* note 46.

119. 2000 Cal. Legis. Serv. 1049 (West).

120. *Id.*

121. ARIZ. REV. STAT. ANN. § 20-448.02 (West 2000). Arizona's genetic information anti-discrimination legislation states that "genetic testing and information derived from genetic testing are confidential and considered privileged to the person tested and shall be released only to" the following individuals: (1) the person tested; (2) a "person specifically authorized in writing by the person tested" or that person's representative; (3) the authorized representative for the person tested; (4) a researcher for medical research or health purposes; (5) a third person (subject to approval by a special committee); (6) a health care provider's agent or employee, if certain qualifications are met; (7) certain particular types of health care providers; (8) authorized governmental agents, and (9) certain types of health care providers that must take possession of the medical records. *Id.* § 12-2802.

122. 410 ILL. COMP. STAT. ANN. § 513/25 (West 2000).

123. See Genetics Privacy and Legislation, *supra* note 87.

124. See *id.*

found in the workplace environment.<sup>125</sup> In order to obtain the test results, the employer must obtain the employee's informed consent and guarantee confidentiality.<sup>126</sup> Further, the employee must be given the opportunity to review the test results and personnel files relating to all health matters.<sup>127</sup> If the employee wishes to correct any misinformation in the file, the employer must comply.<sup>128</sup>

#### IV. LAWS PROHIBITING GENETIC DISCRIMINATION IN HEALTH INSURANCE

In the insurance industry, laws protecting individuals from discrimination based on genetic information focus mainly on health insurance.<sup>129</sup> Other types of insurance, such as life and disability insurance, only protect individuals from genetic discrimination in a few states.<sup>130</sup> Since life insurance focuses on long-term risk, the interest in obtaining genetic information is much higher than in the health insurance industry.<sup>131</sup> Unlike health insurance, life insurance has not been the subject of current legislation, so this Comment focuses on genetic discrimination in health insurance only.

##### A. *Definition of Genetic Information*

In the health insurance industry, statutory language is crucial, so the critical question is whether the broad or narrow definition of genetic information is used.<sup>132</sup> In the individual market, where risk is high compared to the group market, questions concerning family medical history have traditionally played a role in the underwriting process.<sup>133</sup> High rates in the individual market are due to adverse selection, which occurs when a high-risk individual purchases a disproportionate amount of insurance.<sup>134</sup> In response to adverse selection, insurers raise rates for all consumers to allocate the increased risk.<sup>135</sup> If insurers are restricted from asking individuals about their family medical history, normal underwriting procedures would be disrupted, resulting in increased premiums throughout the market.<sup>136</sup>

One proposed solution to problems associated with distinguishing diseases with genetic characteristics from diseases without genetic markers would be to

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125. *See id.*

126. *See id.*

127. *See id.*

128. *See id.*

129. *See* Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 JURIMETRICS J. 93, 95 (1999).

130. *See id.*

131. *See id.* at 110.

132. *See* NAHU Position on Genetic Testing, *supra* note 47.

133. *See id.*

134. *See* Hall, *supra* note 129, at 116. A disproportionate amount of insurance is more coverage than the individual would purchase if all health conditions were known. *See id.* By concealing health problems, individuals are able to afford more coverage at lower rates. *See id.*

135. *See id.*

136. *See id.*



eliminate all medical underwriting.<sup>137</sup> Medical underwriting involves evaluating a person's risk of accident, disease, or death, and based on the relative risk, applicants are classified into groups and charged premiums accordingly.<sup>138</sup> Thus, a person in the high-risk category will be charged high premiums while someone in the low-risk category will pay lower rates.<sup>139</sup> Since health insurance is voluntary, underwriting cannot be removed from the insurance industry without the financial implications associated with increased rates.<sup>140</sup>

According to a study conducted by Mark A. Hall, Professor of Law and Public Health at Wake Forest University, genetic discrimination by health insurers is very low or nonexistent, both before legislation was enacted and afterwards, in states with the laws and without.<sup>141</sup> One reason for the absence of genetic discrimination is that health insurers have little use for genetic information because medical underwriters focus on short-term problems.<sup>142</sup> Genetic testing reveals information concerning an individual's degree of risk for long-term health status, which is insignificant when most people stay with insurance companies for short time spans.<sup>143</sup> By not writing a risk based on genetic information, insurance companies would end up losing money.<sup>144</sup> Instead of focusing on long-term health problems, insurance companies tend to look for medical expenses that can be predicted with more certainty and in the near future.<sup>145</sup> In the survey of state legislation, Professor Hall concluded that genetic discrimination legislation has had no appreciable impact on actual genetic discrimination.<sup>146</sup> However, the laws have influenced insurers by discouraging them from considering the possibility of using genetic information to increase premiums or limit or deny coverage.<sup>147</sup> However, according to an interview conducted with an insurance agent in Professor Hall's study, insurance companies are set up to make a profit, and if the

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137. *See id.* Another possible solution would be limiting access to information, allowing health insurers to target only specific sources. *See id.*

138. *See Keefer, supra* note 12, at 1383.

139. *See id.*

140. *See Hall, supra* note 129, at 116.

141. *See id.* at 95.

142. *See id.* at 96-97. The author's information comes from research conducted in the insurance industry of seven different states. *See id.* In each state, in-depth interviews were conducted with representatives from the Department of Insurance, major health insurers, major medical centers that do clinical genetics work and three to six insurance agents specializing in health insurance. *See id.* In total, interviews were conducted with twelve regulators, thirty-five people with twenty-three insurers, thirty insurance agents, five patient advocates and one medical director from a genetic testing firm. *See id.* at 97. The insurers interviewed account for the majority of individual and small group health insurance companies in the participating states. *See id.* Additionally, several types of insurers were interviewed, including seven Blue Cross plans, six local and two national HMOs and seven national commercial indemnity insurers. *See id.*

143. *See id.* at 109. The reason for high turnover in insurance coverage is due to job shifting in the group market. *See id.* In the individual market, the majority of policy holders are recently out of school or work and seek only temporary coverage. *See id.*

144. *See id.* at 108. During an interview with an insurance agent from New Mexico, the agent stated that insurance companies cannot afford to spend two months worth of premium trying to decide whether to write a risk or not. *See id.*

145. *See id.* at 119-22.

146. *See Hall, supra* note 129, at 119-22.

147. *See id.* at 99.

law allows them to, the companies would use any information available to reduce costs.<sup>148</sup>

### B. Federal Law

According to the McCarran-Ferguson Act, state insurance laws supercede federal insurance laws unless Congress provides otherwise.<sup>149</sup> The federal law prohibiting genetic discrimination in health insurance is the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), which only applies to employer-based and commercially issued group health insurance.<sup>150</sup> HIPAA is the only federal law that directly addresses the issue of genetic discrimination, and no similar law applies to private consumers seeking health insurance in the individual market.<sup>151</sup>

To prevent genetic discrimination, HIPAA prohibits insurers from denying coverage or increasing premiums to members of group health plans based on health conditions, including genetic health conditions.<sup>152</sup> Furthermore, HIPAA prohibits group health insurers from considering an individual's genetic information in the underwriting process.<sup>153</sup> However, since the provisions specifically mentioning treatment of genetic information in HIPAA apply only to group health insurers, it does not ban insurers from using genetic information in the individual insurance industry.<sup>154</sup>

### C. State Law

As of October 2000, twenty-four states had enacted laws prohibiting insurers from using genetic information to discriminate against individuals.<sup>155</sup> A few states allow insurance applicants to submit favorable genetic test results, but most states ban use of genetic information all together.<sup>156</sup> State legislation varies significantly, with some states explicitly prohibiting the use of information ranging from family medical history to DNA testing, while others ban discrimination based on

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148. *See id.* at 112.

149. 15 U.S.C. §§ 1011-12 (1994).

150. 15 U.S.C. §§ 1011-12 (1994).

151. *See id.*

152. 29 U.S.C. § 1182(a)(1).

153. *Id.* § 1182(b)(1).

154. *Id.* § 1182.

155. *See* Enacted Legislation, *supra* note 46. The following states have enacted insurance genetic discrimination legislation: (1) Arizona, enacted legislation in 1997; (2) California, enacted legislation in 1998; (3) Connecticut, enacted legislation in 1998; (4) Delaware, enacted legislation in 1998; (5) Florida, enacted legislation in 1978; (6) Illinois, enacted legislation in 1997; (7) Iowa, enacted legislation in 1992; (8) Kansas, enacted legislation in 1999; (9) Louisiana, enacted legislation in 1982; (10) Maine, enacted legislation in 1998; (11) Michigan, enacted legislation in 1997; (12) Missouri, enacted legislation in 1998; (13) Nebraska, enacted legislation in 1997; (14) Nevada, enacted legislation in 1999; (15) New Hampshire, enacted legislation in 1995; (16) New Jersey, enacted legislation in 1981; (17) New York, enacted legislation in 1990; (18) North Carolina, enacted legislation in 1975; (19) Oklahoma, enacted legislation in 1996; (20) Oregon, enacted legislation in 1989; (21) Rhode Island, enacted legislation in 1992; (22) Texas, enacted legislation in 1997; (23) Vermont, enacted legislation in 1998 and (24) Wisconsin, enacted legislation in 1991. *See id.*

156. *See* Hall, *supra* note 129, at 118-19.

chromosomal test results alone.<sup>157</sup>

Statutes typically fall into one of two categories. The first group prohibits insurers from using genetic information about an individual except for research or investigative purposes.<sup>158</sup> The second group specifically names permitted uses of genetic information.<sup>159</sup> Since statutes in the second group provide certain limitations on the use of genetic test results, many discriminatory measures are left out.<sup>160</sup> For instance, by including a ban on limiting coverage or adjusting benefits based on genetic information, a statute fails to address topics such as factoring genetic information into calculating premiums.<sup>161</sup> This leaves the door open for insurers to misuse genetic information to harm individuals seeking coverage by charging exorbitant premiums to people with genetic susceptibility to disease.<sup>162</sup>

On the other hand, some state statutes provide that individuals may submit favorable genetic test results.<sup>163</sup> Although a statute allowing insurers to consider such test results appears to benefit consumers on its face, it ultimately harms most consumers in the long run.<sup>164</sup> The statutes allow insurers to consider laudatory genetic information, but prohibit insurers from reacting adversely to negative genetic test results. As a result, the only way premiums can be decreased for individuals submitting favorable results is by raising rates for the entire applicant pool and lowering costs to the test takers.<sup>165</sup> Consequently, the people that refrain from genetic testing or receive unfavorable test results will bear the burden of paying higher premiums.<sup>166</sup>

The difference between genetic discrimination legislation in the employment and insurance context is most notable in the state of Louisiana. Although Louisiana's employment discrimination laws lacked mention of disorders other than sickle cell anemia, the statute is quite specific in addressing genetic discrimination in insurance.<sup>167</sup> In Louisiana, genetic information will only be revealed if an individual gives written authorization specifying the person disclosing the information, the person to whom the information will be disclosed, the contents of the information to be disclosed and the purpose for disclosure.<sup>168</sup> Additionally, the form must be signed, dated and must specify the date the authorization expires.<sup>169</sup>

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157. *See id.*

158. *See* William F. Mullholland, II & Ami S. Jaeger, *Genetic Privacy and Legislation: A Survey of State Legislation*, 39 JURIMETRICS J. 317, 318 (Spring 1999).

159. *See id.*

160. *See id.*

161. *See id.*

162. *See id.*

163. *See id.*

164. *See* Mullholland & Jaeger, *supra* note 158, at 319.

165. *See id.*

166. *See id.*

167. LA. REV. STAT. ANN. §213(7) (West 2000)

168. *See id.*

169. *See id.*

#### D. *Suggestions for Reform*

Under HIPAA, the Department of Health and Human Services ("DHHS") is required to implement administrative regulations if Congress fails to enact adequate privacy legislation regarding health information.<sup>170</sup> Accordingly, DHHS produced recommendations designed to protect consumers in the wake of electronic health databases.<sup>171</sup> The proposed measures address five separate issues: (1) whether medical information should be distributed only for health purposes, with limited exceptions; (2) whether medical information should only be distributed if the patient authorizes it or if there is a valid reason for the release or whether anyone with access to released medical records has to ensure that the information remains confidential; (3) whether consumers are entitled to know the details pertaining to their medical information release and whether they may correct errors in their health records; (4) whether a person improperly handling confidential medical records should be criminally punished and whether the patient should be eligible to pursue civil recourse; and (5) whether national public policy issues concerning health, research, health care fraud and abuse, and general law enforcement override individual privacy interests.<sup>172</sup>

Where federal law falls short of protecting genetic information, some states have introduced their own legislation in an attempt to afford increased levels of safety.<sup>173</sup> However, several weaknesses confound the efforts to secure confidentiality in medical records.<sup>174</sup> First, while most states have enacted legislation designed to protect individual health privacy interests, many statutes only address governmental collection of genetic information.<sup>175</sup> Consequently, the majority of state laws fail to adequately safeguard confidential medical records for the private sector.<sup>176</sup> Another problem is that current legislation fails to recognize that health records are increasingly becoming automated; therefore, medical information is capable of being electronically transmitted.<sup>177</sup> Further, state laws vary widely in their coverage, with some giving genetic information superior confidentiality and others neglecting to mention genetic information altogether.<sup>178</sup>

### V. PROBLEMS WITH CURRENT LEGISLATION

#### A. *Genetics Exceptionalism*

A recurring problem with much of the legislation addressing genetic discrimination is captured in the term genetics exceptionalism. Genetics

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170. See Gostin & Hodge, *supra* note 27, at 44.

171. See *id.* at 44-45.

172. See *id.* at 45.

173. See *id.* at 47.

174. See *id.* at 45.

175. See *id.*

176. See Gostin & Hodge, *supra* note 27, at 45.

177. See *id.* at 46.

178. See *id.*

exceptionalism occurs when legislators emphasize the differences between genetic information and other health information when creating laws, giving genetic information priority and special status.<sup>179</sup> Deeming discrimination based on genetic information more deserving of legal protection than other types of medical information is fundamentally unfair. Even if genetic science were completely accurate, a stage genomics has yet to reach, predictions based on genetic test results are not conclusive.<sup>180</sup> While genetic screening may correctly reveal a person is more susceptible to developing a particular disease or disorder in comparison with the average population, environmental and behavioral factors play key roles in determining whether or not that individual actually becomes afflicted.<sup>181</sup> Additionally, genetic flaws can often be altered through behavioral changes and medical intervention.<sup>182</sup>

Another problem with ranking genetic disorders above other medical conditions is that health-care providers cannot always distinguish genetic information from other medical details in a patient's record.<sup>183</sup> Consequently, it may be difficult for a clinician or physician to know when certain types of information require a higher level of protection than others.<sup>184</sup> This leads to a question of fairness and equality in the privacy of medical records. Protecting individuals afflicted with genetic conditions by strict laws while ignoring others suffering from non-genetic conditions unfairly discriminates against the latter group.<sup>185</sup> Furthermore, people with non-genetic health problems may be the people most in need of statutory protection against the invasion of privacy and discrimination.<sup>186</sup>

When it comes to health matters, the medical conditions regarded as personal vary from one individual to the next.<sup>187</sup> For instance, a person infected with a sexually transmitted disease may consider such an affliction to be highly

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179. *See generally id.* (describing the problems associated with genetics exceptionalism). In this article, Gostin and Hodge counter the argument that genetic information deserves more protection than other health information based on differences in the nature of the data by emphasizing similarities between the two. *See generally id.* For instance, the three factors defeat the claim that genetic information is deserving of superior legal protection due to its distinguishing characteristics. The first factor is the distinct physical nature of genetic conditions. *See generally id.* Contrary to popular belief, genetic diseases generally involve not only physical attributes such as chromosomal structure, but often involve behavioral aspects as well, making genetic predisposition just another risk factor. *See generally id.* The second factor is that genetic information is uniquely identifiable. *See generally id.* While genetic information is considered unique in its ability to distinctly identify individuals, a person's genetic code is just one of several unique identifiers including fingerprints, voice, face geometry, birthmarks, moles, dental analysis and handwriting sample. *See generally id.* The third factor is the ability for genetic information to harm future generations. *See generally id.* While genetic testing may reveal potentially harmful information about an individual's family members that should be protected, family medical information has been recorded for years through routine medical forms and insurance applications. *See generally id.*

180. *See id.* at 34-35.

181. *See id.*

182. *See Gostin & Hodge, supra note 27, at 34-35.*

183. *See id.*

184. *See id.*

185. *See id.*

186. *See id.*

187. *See id.*

private whereas someone genetically susceptible to high blood pressure may not have even considered the issue of confidentiality.<sup>188</sup> However, by giving genetic conditions superior ranking in privacy and anti-discrimination legislation, law makers are favoring the person with susceptibility to future high blood pressure over the person suffering from a sexually transmitted disease.<sup>189</sup>

### *B. Use of Genetic Information in Employment*

While no person capable of working should be subjected to discrimination based on an actual or perceived disability, there are certain instances where discrimination should be allowed. The ADA allows employers to exclude qualified individuals with disabilities only if the disability is job-related and consistent with business necessity.<sup>190</sup> Genetic legislation should follow similar guidelines.

While the possibility that new technology may reveal susceptibility to a particular disorder frightens people, it may be helpful in certain limited situations. For instance, if a person is genetically predisposed to an illness that is characterized by sudden reactions leading to death, it would be unsafe for that person to be responsible for public safety. As previously mentioned, genetic information may have its place in certain fields, such as the airline industry, where many lives would be lost if a pilot had a sudden attack.<sup>191</sup>

As genetic testing becomes more common and reliable, it should be implemented in occupations where the employee's health status impacts the lives of others. In establishing standards for allowing employers to consider genetic information, law-makers should take into account the different characteristics of genetic disorders. One aspect that should be taken into account is the difference between multi-factorial disorders, which only make an individual susceptible to developing a disease, and single-gene conditions, which insure that a person will eventually develop the genetic disorder.<sup>192</sup> Similarly, the distinction between an individual classified as predisposed and more likely to develop the condition, as opposed to pre-symptomatic and certain to develop the disorder, should be noted.<sup>193</sup> Also, since scientists can detect expressivity, the severity and manner in which the gene manifests into a disorder, it is possible to predict certain types and degrees of genetic conditions with nearly complete certainty.<sup>194</sup> Consequently, scientists may be able to accurately assess the risk an individual may pose to himself or to the public as a result of his genetic condition. In limited cases where an individual clearly poses a substantial threat to public safety, genetic testing has its place as an extremely helpful tool.

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188. See Gostin & Hodge, *supra* note 27, at 34-35.

189. See *id.* at 23.

190. 42 U.S.C. § 12112(a) (1994).

191. See Yesley, *supra* note 61, at 140-41.

192. See Keefer, *supra* note 12, at 1379.

193. See *id.* at 1380.

194. See *id.*

### C. *Use of Genetic Information in Health Insurance*

The issue of genetic discrimination in health insurance depends largely on the definition used. Although the public fears discrimination will result from genetic screening, proposed and enacted legislation may go too far by including family medical history in the definition of genetic discrimination. Family medical history was a basic part of patient information forms long before genetic testing came into being. Furthermore, proposals to maintain medical records by separating files containing confidential genetic information from other health files may complicate medical record-keeping to a point where it is impossible to ascertain what person has a right to each type of information.<sup>195</sup>

### D. *Proposal for New Legislation*

Currently, federal law fails to sufficiently address genetic discrimination. The ADA does not mention genetic information in any of its provisions and HIPAA leaves insurers wondering which definition of genetic information will be applied. The federal government, through Executive Order 13145, attempted to lead the way in reforming federal employment law by banning genetic discrimination against its employees.<sup>196</sup> Similarly, the federal government expressed the view that insurers should be banned from using genetic information in the individual market as well as the group market, which has serious financial consequences to consumers.<sup>197</sup>

Although many states have enacted legislation addressing discrimination based on genetic information, the laws vary considerably, especially between states with recent laws and states relying on laws dating back decades, when genetic science had barely surfaced.<sup>198</sup> As a result of the disparity between federal and state law, federal law should be reformed, establishing a clear set of standards that allows states to follow suit in creating uniform provisions. Individuals should be afforded the same rights and protection regardless of the state they reside in.

When it comes to legislation, whether addressing genetic discrimination in employment or insurance, the real issue is one of privacy.<sup>199</sup> The two areas of genetic discrimination discussed in this Comment should fall under the broad category of confidentiality in medical records. As the term "genetics exceptionalism" connotes, genetic information should not be given superior levels of protection to other health information.<sup>200</sup> The real dilemma lies in attempting to give individuals privacy while simultaneously promoting the public interest by facilitating research.<sup>201</sup>

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195. See Gostin & Hodge, *supra* note 27, at 46.

196. See discussion *supra* Part III.C.

197. See discussion *supra* Part IV.B.

198. See discussion *supra* Parts III.E, IV.C.

199. See Gostin & Hodge, *supra* note 27, at 44.

200. See *id.* at 54.

201. A balance must be achieved between individual and public interest, and public interest is furthered by scientists pursuing genetic discoveries. See *id.* at 56. Genetic science cannot make

The starting point for successful privacy legislation involves insuring that legal and ethical principles prevail in protecting health information.<sup>202</sup> Such principles, known as fair information practices, should be implemented in the collection, use and disclosure of identifiable health information.<sup>203</sup> Fair information practices include implementing substantive review, in which collectors of genetic information provide the purpose for obtaining the sample and the way the sample will further that purpose.<sup>204</sup> Not only should health information collection have a substantive purpose, it should also meet procedural requirements by maintaining the privacy of each individual.<sup>205</sup> Additionally, individuals should have control over personal health data; they should be informed about the reasons for collection and allowed the opportunity to review and correct errors.<sup>206</sup> Finally, anyone who collects personal health information should only be allowed to use the information for the purpose agreed upon.<sup>207</sup>

The fair information principles guided law-makers and researchers in designing a model health information privacy act for the Centers for Disease Control and Prevention.<sup>208</sup> In applying this model more generally to health information, including genetic information, the authors suggested that individuals should be allowed to do the following: (1) obtain, review and correct their health information; (2) learn how the information is used; (3) obtain a disclosure record and (4) seek criminal or civil sanctions for anyone violating these provisions.<sup>209</sup> Safeguards for protecting health information would involve requiring a higher level of scrutiny for outside use as opposed to inside use of the information.<sup>210</sup>

#### CONCLUSION

In conclusion, the area of science known as genomics is still young and not

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significant progress without the communal sharing of genetic information, which is facilitated through electronic health databases containing a vast amount of personal information about individuals and their family members. *See id.* at 32.

202. *See id.* at 53-54.

203. *See id.* at 54.

204. Secretive systems of health information collection should not exist, and the information collector bears the burden of proving a substantial purpose exists for examining the sample. *See id.*

205. *See Gostin & Hodge, supra* note 27, at 54-55.

206. *See id.* at 55. In controlling personal data, individuals should have the right to the following types of information: (1) maintenance of health information privacy, (2) ability to access and review records, (3) length of time information will be stored, (4) under what circumstances and to whom it will be disclosed, and (5) future secondary uses. *See id.*

207. *See id.* at 56.

208. *See id.* at 57-58.

209. In order for these provisions and other safeguards to succeed, data and collection storage facilities must be completely secure. *See id.* To achieve such security, technical and legal standards must be implemented in new legislation. *See id.*

210. *See id.* at 57. Internal use of health information would be permitted on a need to know basis. *See id.* For instance, if the government had already obtained the information by showing a valid purpose and secure procedures, other governmental departments would not be required to prove substantive and procedural purpose again. *See id.* Instead, the data can be used internally if another department has a reason to use it. *See id.* On the other hand, given the same example, if someone outside the government wanted to use the information, such a disclosure or "secondary use," would require the individual's informed consent. *See id.*



yet complete. Many people fear the worst when the future is unknown, and genetic science is no exception. Through scientific breakthroughs such as the Human Genome Project, researchers are constantly discovering secrets to the encryption of the human body. While genomics promises to unleash a new world in which health care can cater to individual needs like never before, it also threatens to harm individuals by maintaining records of highly personal medical information that may be accessed by the wrong people. However, in certain instances, genetic testing could be used to the benefit of society. If genetic testing proves to be accurate and more readily accessible, circumstances should dictate whether or not genetic information can be used in an employment context. Since it is impossible to know exactly what the future will hold for genetic science and human kind, legislation strictly banning all use of genetic information for any purpose should be abolished and replaced by laws allowing for limited exceptions.

Whether or not genetic discrimination is afforded adequate protection in legislation is a matter in which viewpoints diverge. In the employment realm, it is not clear whether federal law protects victims of genetic discrimination; and in the insurance field, it is nearly impossible to ascertain what constitutes genetic discrimination. In addition, genetic discrimination in one state may be perfectly permissible in another state. As a result, as a nation, the existing legislation regarding genetic discrimination is haphazard. Since genetic information is just one of the many attributes of an individual's medical record and since genetic data should be given high levels of protection in the law, it follows that all health information should be protected. Because of this, to maintain uniformity federal law should be reformed to include genetic information in an individual's medical record and to mandate the privacy of that record.

*Natalie E. Zindorf*