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## Don't Judge Me by My Genes: A Survey of Federal Genetic Discrimination Legislation

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# DON'T JUDGE ME BY MY GENES: A SURVEY OF FEDERAL GENETIC DISCRIMINATION LEGISLATION

## I. INTRODUCTION

Individuals do not get to choose their genes. Until recently, individuals knew very little about their genes. As genetic research has progressed, however, more information is known about a person's genetic make-up than anyone could have ever imagined. Scientists can now predict with some certainty whether an individual is predisposed to certain diseases.<sup>1</sup> However, people are refusing to take the tests to learn their genetic predispositions. As ridiculous as it sounds, people are passing up the chance to determine what conditions they may possess and are foregoing treatment to help these ailments for fear the genetic information will be used for discriminatory purposes.<sup>2</sup>

In a university lecture, United States Secretary of Health and Human Services Donna Shalala stated:

[e]very day, our private health information is being shared, collected, analyzed, and stored with fewer federal safeguards than our video store records. That is important. We have federal laws that protect the privacy of our video records, our motor vehicles records, and our credit records. But, the way we protect the privacy of our medical records right now is erratic at best—dangerous at worst.<sup>3</sup>

Many proposals to specifically regulate the use of genetic information have been entertained in both the House of Representatives and the Senate; however, Congress has yet to enact comprehensive legislation specifically targeting genetic discrimination. Genetic information has been defined as "information about genes, gene products, and inherited characteristics that may derive from the individual or a family member . . . includ[ing] information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical examinations, family histories, and direct analysis

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1. See BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 151 (3d ed. 1997).

2. For example, four North Carolina sisters, two of whom had been diagnosed and treated for breast cancer, and whose mother died from ovarian cancer, have mixed feelings about genetic testing. See Chris O'Brien, *Daughters and the Deadly Gene*, THE NEWS & OBSERVER, Sept. 3, 1996, at A1. One of the sisters with the disease is in the process of changing jobs and fears with a genetic test showing her positive for the breast cancer gene, she would be unable to get insurance coverage. See *id.* Another sister, who has never been diagnosed with breast cancer, works for a firm in the process of switching insurance carriers and fears the new insurance company will charge her and her co-workers higher premiums if she tests positive for the breast cancer gene. See *id.*

3. Donna E. Shalala, *Health Care Information and Privacy*, 8 HEALTH MATRIX—JOURNAL OF LAW & MEDICINE 223 (1998).

of genes or chromosomes.”<sup>4</sup>

Federal legislation is needed in order to protect an individual's genetic information from misuse by employers, insurance companies, and in all other areas of daily life.<sup>5</sup> Given the vast amount of genetic information now available, a comprehensive law is needed to combat genetic discrimination. Some states have passed limited anti-discriminatory legislation, but most of these laws target only the tested individual and do not extend protection to implicated family members.<sup>6</sup> The inability of individual state laws to protect family members undergoing testing creates a real risk that these family members may be harmed by the disclosure of the genetic information.<sup>7</sup> Federal laws are needed to extend protection across state boundaries and to provide for some uniformity among the states. Many people believe that “the interstate way medical care is delivered in today's society, the cost implications of fifty separate sets of standards, and the potential confusion for providers and payers, especially those which operate on or near state lines, call for a more uniform system nationwide.”<sup>8</sup> Genetic information impacts critical societal issues. It has already become an issue in child custody cases, personal injury actions, and medical malpractice litigation.<sup>9</sup> Because of the legal, ethical, and social concerns involved with genetic testing, current legislative proposals must be analyzed and integrated to give rise to the clear, explicit guidelines required to fully protect the rights of any individual undergoing genetic testing and his or her family members.

This comment addresses reasons why federal legislation is needed in order to provide adequate protection against genetic discrimination and surveys proposed federal legislation intended to combat such discrimination. Section II is devoted to providing necessary background information to illustrate why federal legislation is

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4. 26 C.F.R. § 54.9801-2T (1998) (Internal Revenue Serv.); 29 C.F.R. § 2590.701-2 (1997) (Pension and Welfare Benefits Admin.); 45 C.F.R. § 144.103 (1997) (Dep't. of Health and Human Serv.).

5. An example of such misuse is illustrated by a Kansas resident who had prenatal genetic testing performed on her fetus and learned her son would have spinal bifida. See *Don't Permit Abuses of Genetic Testing*, USA TODAY, July 19, 1990, at 10A. The health insurance at her husband's new job rejected the couple's application for health insurance because of the anticipated health care that would be needed for their son. See *id.* A medical school has denied admission to an applicant because a genetic disease ran in his family and the school believed the applicant was at risk of developing the genetic disease. See Cindy Schreuder, *Can Laws Protect Us From Our Genes?*, CHI. TRIB., July 20, 1997, at A1. One employee's child was diagnosed with a genetic kidney disease and the employer switched insurance companies, resulting in the new insurance company denying the child coverage based on a pre-existing condition. See Lori B. Andrews, *Genetic Fallout: New Technologies Are Changing the Legal Landscape*, TRIAL MAG., Dec. 1, 1995.

6. See H.B. 3169, 46th Leg., 2d Sess., (Okla. 1997) (to be codified at OKLA. STAT. tit. 36, § 3614.1); COLO. REV. STATE ANN. § 10-3-1104.7 (1997). See also Bryce A. Lenox, *Genetic Discrimination in Insurance and Employment: Spoiled Fruits of the Human Genome Project*, 23 U. DAYTON L. REV. 189, 193-4 (1997).

7. Singer Arlo Guthrie's father died from Huntington's Disease and the singer faces a 50% chance of inheriting the disease; however, he has stated he would rather not be tested. See *Don't Permit Abuses of Genetic Testing*, *supra* note 5.

8. *Privacy of Individual Genetic Information: Hearings On Discrimination in Health Insurance Underwriters and Privacy of Individual Genetic Information Before the Senate Comm. on Labor and Human Resources*, 105th Cong. (1998) [hereinafter *Labor and Human Resources Hearings*] (statement of Joanne Denise, National Association of Health Underwriters).

9. See Sue Goetinck, *Gene Science Adding Twists to Variety of Legal Disputes*, DALLAS MORNING NEWS, July 20, 1998, at 1A. For example, a South Carolina man asked a court to order his ex-wife to undergo a genetic test to determine if she had a genetic disease in order to increase his chance of gaining custody of their children. See Schreuder, *supra* note 5.

so important. This section provides information of the status of projects initiated to map all of the genes in the human body and to study their interactions with other genes and with the environment. Section II also addresses the importance of genetic testing and the effects these tests will have on many people, including the detection and possible treatment of certain genetic diseases. Finally, Section II outlines some of the moral, legal, and ethical concerns which are arising as a result of increased genetic knowledge.

Section III identifies the reasons why federal legislation is a necessity in combating genetic discrimination. In so doing, Section III presents an overview of various state approaches, focusing on Oklahoma and New Jersey. This overview demonstrates the general inadequacy of the states' attempts at genetic protection and illustrates the need for a federally comprehensive and uniform law to address this issue. Additionally, the Americans with Disabilities Act<sup>10</sup> ("ADA") and the Health Insurance Portability and Accountability Act<sup>11</sup> ("HIPAA") are critiqued to expose the loopholes present in existing federal legislation and to illustrate how most individuals are not fully protected against genetic discrimination. Last, Section III analyzes two recent cases addressing genetic discrimination to illustrate how courts are confronting genetic issues.

Section IV surveys federal legislation proposed in the 105<sup>th</sup> Congress involving genetic information and discrimination; strengths as well as weaknesses of the legislation are addressed. Federal legislation involving prohibition of insurance discrimination, employment discrimination, and more general legislation are discussed in connection with genetic testing and genetic information. Since such a large number of people will be affected by genetic discrimination, a comprehensive, uniform law is essential.

## II. BACKGROUND INFORMATION

### A. *Projects to Sequence The Human Genome*

In 1947, an article in the *Journal of the American Medical Association* predicted that "[o]ne of the most important tasks of medical genetics in the future will be to investigate further the significance of mutation as a cause of disease."<sup>12</sup> At that time, however, the prediction was viewed as unduly pessimistic since it was thought that the demonstration of mutated genes causing hereditary human diseases could never be anticipated with any degree of accuracy.<sup>13</sup> However, the prediction became a reality with the initiation of a global research project combining the efforts of

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10. 42 U.S.C. §§ 12101-12213 (1994).

11. Pub. L. No. 104-191, 110 Stat. 1936 (1995) (codified in scattered sections of 29 U.S.C., 42 U.S.C., 26 U.S.C., and 18 U.S.C.).

12. *Mutation as a Disease*, 278 JAMA 1216, 1216 (1997) (Brian P. Pace & Micaela Sullivan-Fowler eds.).

13. *See id.*

sixteen countries including the United States, Japan, and some European countries.<sup>14</sup> The Human Genome Project's ("HGP") purpose is to identify and localize every gene within the appropriate chromosome and to understand the genes and the part they play as they interact in human pathology and human development.<sup>15</sup> "Its [the Human Genome Project] mission is to identify the full set of genetic instructions contained inside our cells and to read the complete text written in the language of the hereditary chemical DNA (deoxyribonucleic acid)."<sup>16</sup> In finding the location of the gene, scientists can determine which protein the gene makes and what the protein's function is in contributing to the furtherance of the genetic disease.<sup>17</sup>

A major goal of the HGP is to compare a normal gene profile with that of a mutated one.<sup>18</sup> Of the 100,000 genes found in each human cell, only one-tenth are active, and with tests, scientists can ascertain which of the genes are indeed active, thereby determining the activity rate of those genes in different stages of gene development.<sup>19</sup> With the HGP rapidly approaching its goal of deciphering nearly all of the 100,000 genes in the human body, it is estimated that by the year 2002, 99% of the human genome sequence will be mapped at an accuracy of nearly 100%.<sup>20</sup>

Every cell in the human body (with the exception of the ovum and sperm) contains the full genome consisting of twenty three pairs of chromosomes.<sup>21</sup> Each of these chromosomes contains approximately 4,000 genes.<sup>22</sup> Genes contain the DNA which control the transmission of hereditary characteristics telling cells what to do by producing different proteins. DNA is made up of four bases: Adenine, Thymine, Cytosine, and Guanine.<sup>23</sup> "The code for the actual DNA instructions is the order of the bases as they are lined up."<sup>24</sup> Before each cell divides to produce a new cell, the "DNA must . . . replicate itself" thus giving "each new cell . . . a . . . copy" of the DNA instructions.<sup>25</sup> Each chromosome contains a very long strand of DNA with hundreds of genes.<sup>26</sup> Until recently, it was impossible to decode these genetic

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14. See FURROW, *supra* note 1, at 150. See also Lisa Seachrist, *Genetic, Health Care Revolutions Make Policymakers Uneasy*, BOWORLD TODAY, Oct. 1, 1997, v. 8 no. 190. ("When the Human Genome Project was formally started in 1991, no one expected it would achieve such early and dramatic success . . . and, in stark contrast to other publicly funded research projects, it manages the feat well under budget" and well ahead of schedule.)

15. See Genetech, Inc., *The Cancer Genome Anatomy Project Overview* (visited Oct. 28, 1997) <[http://outcast.gene.com/ae/AB/IE/Intro\\_The\\_Human\\_Genome.html](http://outcast.gene.com/ae/AB/IE/Intro_The_Human_Genome.html)>.

16. *Id.*

17. *See id.*

18. *See id.*

19. See Joan Stephenson, *Scientists Revel in New Research Tool: An Online Index of Cancer Genes*, 278 JAMA 1221, 1221 (1997).

20. See Eric Mills Holmes, *Solving the Insurance/ Genetic Fair/ Unfair Discrimination Dilemma in Light of The Human Genome Project*, 85 KY. L.J. 503, 563 (1997). ("The HGP is not a single effort, but rather is comprised of a number of independent international research efforts with the common goal of analyzing the structure of human DNA and mapping and sequencing the estimated 100,000 human genes, the basic units of heredity.")

21. See BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE AND ETHICS* 167 (2d ed. 1991).

22. *See id.*

23. See Healthtouch: Online for Better Health, *Decoding Genes: A Primer on Genetics & Molecular Biology* (visited Sept. 30, 1997) <<http://www.healthtouch.com/level1/leaflets/hhitr003.htm>>.

24. *Id.*

25. *Id.*

26. *See id.* These bases always work in pairs with the Adenine base always pairing with the Thymine base on the other side of the pair, and a Guanine base always pairing with a Cytosine base. *See id.*

messages; however, the research yielded by the HGP now allows researchers to decode genetic messages.

Other private efforts are being made to decode the human genome. J. Craig Venter and a large manufacturer of laboratory research equipment are together planning to attempt this feat for 90% less than the government's proposed budget and the private project could be completed four years ahead of the government's target completion date.<sup>27</sup> A new, more powerful sequencing machine will be used to sequence genes at a much faster rate.<sup>28</sup> However, Venter's proposal is less thorough than the HGP, omitting important steps such as mapping of reference points along the DNA and failing to fill in gaps to correct errors and ambiguities in the DNA sequence.<sup>29</sup> This increases the potential for mistakes.<sup>30</sup> Incyte Pharmaceuticals, Inc. has also communicated its intention of decoding the entire human genome in just one or two years; however, it realizes that its research will possess large gaps.<sup>31</sup> Even if some of the information is inaccurate, the genetic information will be available to the public at a much earlier date, therefore making genetic discrimination a much more urgent concern.

### B. Importance of Genetic Testing

"[S]cientists have identified more than 4,000 diseases caused by gene abnormalities."<sup>32</sup> Identifying and localizing these genes will play an important role in the prevention, diagnoses, and treatment of certain human diseases.<sup>33</sup> A non-exhaustive list of diseases identifiable thus far as resulting from a genetic mutation include: "phenlketonuria, cystic fibrosis, . . . cardiovascular disease, diabetes, some forms of cancer, mental and neurological disorders, and infectious diseases (including TB and AIDS)."<sup>34</sup> Scientists believe that these diseases result from interactions between the genes along with certain environmental factors.<sup>35</sup>

Medical advances are currently being developed to identify genetic abnormalities and investigate treatment options as a result of the information learned from the HGP research.<sup>36</sup> "Rapid advances, such as those related to the Human Genome Project, have dramatically increased the number of available molecular

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27. See Lisa Belkin, *Splice Einstein and Sammy Glick. Add a Little Magellan*, (visited Sept. 1, 1998) <<http://archives.nytimes.com/archive>>. See generally Celera Genomics Corp., *CELERA: The Definitive Source for Biological and Medical Knowledge* (visited Sept. 3, 1998) <<http://www.celera.com>>.

28. See Belkin, *supra* note 27.

29. See *id.*

30. See *id.*

31. See *Scientists Ignoring Naysayers Researcher Works on Genes Project*, OMAHA WORLD-HERALD, Aug. 30, 1998, at 27A. See generally Incyte Pharmaceuticals Inc., *IncyteGenetics* (visited Sept. 3, 1998) <<http://www.incyte.com>>.

32. Earl Ubell, *Should You Consider Gene Testing?*, HOUS. CHRON. PARADE MAG., Jan. 12, 1997, at 9.

33. See World Health Organization, *The International Human Genome Project: Future Perspectives for Health for All* (visited Oct. 28, 1997) <<http://www.who.int/ncd/hgn/humgen.htm>>.

34. *Id.*

35. See Genetech, Inc., *supra* note 15.

36. See Genetech, Inc., *What Can We Expect from the Human Genome Project* (visited Oct. 28, 1997) <[http://www.gene.com/ae/AB/IE/What\\_Can\\_We\\_Expect.html](http://www.gene.com/ae/AB/IE/What_Can_We_Expect.html)>.

genetic tests, and this number will only increase with future genetic research."<sup>37</sup> Tests are becoming available to identify both childhood disorders and conditions in healthy persons at risk of later disease development.<sup>38</sup> The development of tests to predict and determine the existence of certain conditions in fetuses is also becoming more prevalent.<sup>39</sup> Currently, commercial tests are available for the detection of mutations in about fifteen genes and approximately 450 disorders including: breast and colon cancer, Alzheimer's disease, Parkinson's disease, glaucoma, fragile x syndrome, and cystic fibrosis.<sup>40</sup> Tests for more common disorders such as heart disease, diabetes, and anxiety disorders will be available in the near future.<sup>41</sup>

It is important to note that testing positive for a gene does not absolutely guarantee the development of the disease.<sup>42</sup> Limitations exist with regard to genetic testing since the tests that do exist are new, and information is changing as more and more people undergo testing. One example can be seen in the breast cancer context. A test yielding positive results for the BRCA1 gene mutation means that a person carries the gene; however, an estimated 20 to 40% of patients carrying this mutated gene never actually develop the disease.<sup>43</sup> Conversely, a "negative test *does not* mean no [breast] cancer risk."<sup>44</sup> A negative genetic test actually gives little information. It may mean the test missed "certain true mutations in an uncertain but estimated to be 10-30% of cases."<sup>45</sup> False results can occur because of technical mistakes and human errors.<sup>46</sup> Another gene contributing to the onset of the disease may exist, but may have not yet been discovered.<sup>47</sup>

Most human diseases appear to result from the activity of multiple genes and their interaction with the environment.<sup>48</sup> For example, one of the genes identified as increasing the susceptibility of developing breast cancer is the BRCA1 gene.<sup>49</sup> People who inherit this gene mutation have an 80 to 90 % lifetime risk of developing breast

37. Wendy C. McKinnon et al., *Predisposition Genetic Testing for Late-Onset Disorders in Adults: A Position Paper of the National Society of Genetic Counselors*, 278 JAMA 1217, 1217 (1997).

38. *See id.* *See also Labor and Human Resources*, *supra* note 8 (statement of Francis S. Collins, Director, National Human Genome Research Institute).

39. *See* Christine M. Eng et al., *Prenatal Genetic Carrier Testing Using Triple Disease Screening*, 278 JAMA 1268, 1268 (1997).

40. *See* Joan Stephenson, *As Discoveries Unfold, A New Urgency to Bring Genetic Literacy to Physicians*, 278 JAMA 1225, 1225 (1997). *See also Labor and Human Resources Hearings*, *supra* note 8 (statement of Sen. Olympia Snowe).

41. *See* Stephenson, *supra* note 40.

42. *See* Letter from Louise C. Strong, M.D., Professor of Genetics, Ad-Interim Co-Director, Human Clinical Cancer Genetics Program, University of Texas M.D. Anderson Cancer Center, to Linda Pickens 2 (July 18, 1997) (on file with author).

43. *See id.* Different genes possess different penetrance probabilities. *See id.*

44. *Id.*

45. *Id.*

46. *See* Genetech, Inc., *supra* note 36.

47. *See* Letter from Louise C. Strong, M.D., *supra* note 42.

48. *See National Human Genome Research Institute FY 1998: Hearings Before the Senate Appropriations Subcomm. for Senate Appropriations Comm. on Labor, Health and Human Services, and Educ.*, 105th Cong. (1997) [hereinafter *National Human Genome Hearings*] (statement of Dr. Francis S. Collins, Director, National Human Genome Research Institute).

49. *See* Lynda M. Fox & Sherman G. Finesilver, *Genetics and the Workplace: ADA Applicability to Genetic Information*, 26 COLO. LAW. 75, 77 (1997).

cancer as compared to those without it.<sup>50</sup> The general population without this gene mutation possess only an 11% chance of developing the disease.<sup>51</sup> Not all cases of breast cancer result from the BRCA1 mutation.<sup>52</sup> In fact another gene, the BRCA2 gene, has also been linked to the development of breast cancer.<sup>53</sup> These two genes are thought to account for only a small percentage of all breast cancers.<sup>54</sup> Furthermore, these mutated genes “may be inherited from the father, mother” or from both parents.<sup>55</sup> The area of genetic research is far from complete and will continue to expand into the next century.

### C. Moral, Legal, and Ethical Concerns

The increasing knowledge the HGP is providing about a person’s genetic makeup is estimated to be approximately ten million times greater than that which is available at the chromosome level.<sup>56</sup> There is still a gap between diagnosing these genetic diseases and treatment or prevention of the diseases.<sup>57</sup> Obtaining such a great amount of genetic information raises new ethical, legal, and social concerns.<sup>58</sup> Some of the legal concerns include employment discrimination, privacy of genetic records, and health or life insurance discrimination.<sup>59</sup> Ethical issues raised include access to technological advances, presymptomatic diagnosis, and access to genetic information.<sup>60</sup> “Until legislation is in place to protect persons from discrimination based on genetic information, some [genetic testing] centers [have chosen] to safeguard genetic information by using identifiers instead of names on laboratory reports, restricting access to computer or paper files, and keeping . . . [any genetic] information separate from the general medical record.”<sup>61</sup> Many people other than doctors have access to an individual’s medical files such as secretaries, consultants, insurance coders, billing clerks, many types of therapists, nurses, and other health

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50. *See id.*

51. *See id.* *See also* Donna Shattuck-Eidens, et al., *BRCA1 Sequence Analysis in Women at High Risk for Susceptibility Mutations*, 278 JAMA 1242, 1242 (1997) (“These inherited mutations put women at greater risk for pre-menopausal breast cancer, with a 59% chance of breast cancer before the age of 50 years . . . BRCA1 is associated with a 44% risk of ovarian cancer by the age of 70 years.”).

52. *See* Fox & Finesilver, *supra* note 49.

53. *See* Diane Gingold, *Celebrating Survivorship: The Fight Against Breast Cancer*, NEWSWEEK, Oct. 13, 1997 (Special Advertising Section), at 2.

54. *See id.* (“According to the American Cancer Society (ACS), the identification of two breast cancer genes (BRCA1 and BRCA2) was the first step in developing a test to determine if these two genes, which account for only 5 to 10 percent of all breast cancers, are present in women whose family history shows a high risk of breast cancer.”)

55. Shattuck-Eidens, *supra* note 51, at 1243.

56. *See* Genetech, Inc., *supra* note 36.

57. *See* World Health Organization, *supra* note 33.

58. *See* 143 CONG. REC. S2129 (daily ed. Mar. 11, 1997) (statement of Sen. Domenici) (“[T]he implications of genetic information warrant allocating funds specifically for exploring the ethical, legal, and social implications of . . . new genetic technologies.”).

59. *See* Fox & Finesilver, *supra* note 49, at 75. *See also* Holmes, *supra* note 20, at 519. Other issues identified include the history of past misuses and genetic prejudices and privacy issues involving both the person tested and the person’s genetic family. *See id.*

60. *See* World Health Organization, *supra* note 33.

61. McKinnon, *supra* note 37, at 1218 (citing M. J. Mehlman, et al., *The Need for Anonymous Genetic Counseling and Testing*, 58 AM. J. HUM. GENET. 393, 393-97 (1996)).



care workers which contribute to the discrimination.<sup>62</sup>

In testimony before the Subcommittee on Government and Management, Information and Technology, Congressman Cliff Stearns stated:

I believe that genetic testing may become the Civil Rights issue of the 21<sup>st</sup> century. Should an insurance company be able to deny children medical coverage because their mother dies of an inherited heart defect that her children may or may not carry? That is the dilemma faced by a father in California who could not get family medical coverage under his group plan as a result of his wife's death.

In another instance, a man lost his auto insurance coverage because he had a genetic condition which affects the muscles. Although he had a clean driving record stretching back 20 years, genetic information was used to cancel his policy.

One young woman was hired as a social worker and for eight months she received promotions and positive performance reviews. However, while conducting a training program on caring for patients with Huntington's disease she mentioned that she had family members with that condition. She was soon fired and informed by another colleague that it was due to concern that she might develop Huntington's.<sup>63</sup>

Discriminating against people based on their genes is unfair, especially since it cannot be accurately predicted whether a person will ever actually develop the disease.<sup>64</sup> Genetic testing does more than give a genetic map of the human body. It can provide a person with choices in dealing with the possibility of getting a disease, and testing can aid in the furtherance of medical research. Also, depending on the disease, testing can assist in reproductive decision making.<sup>65</sup> "For a couple considering pregnancy, fears of passing on genetic diseases may either cloud the pregnancy with anxiety, or dissuade the couple from taking the risk altogether."<sup>66</sup> If the disease is one that is treatable, consideration can be given to surgery or other treatment options.<sup>67</sup> Gene therapy may be available in the near future.<sup>68</sup> The benefits of gene testing make these

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62. See *Medical Records Privacy: Hearings Before the Gov't Reform Subcomm. on Gov't Management, Info., and Tech.*, 105th Cong. (1997) [hereinafter *Medical Records Privacy Hearings*] (statement of Rep. Louise Slaughter).

63. *Id.* (statement of Rep. Cliff Stearns).

64. See 143 CONG. REC. S7863-01 (daily ed. July 22, 1997) (statement of Sen. Daschle). According to Senator Daschle, "many employers may not hire individuals whom they believe will require time off" because of a genetic disease, even though genetic testing only indicates a predisposition to the disease and not the actual development of the disease itself. *Id.*

65. See FURROW ET AL., *supra* note 21, at 175.

66. *Id.*

67. See *id.*

68. Gene therapy involves the insertion of genes containing "correct information into the DNA of the cells that contain" mutations to help those damaged cells function properly and possibly alleviate some symptoms of the disease. See FURROW ET AL., *supra* note 21, at 172 (citing *Department of Health and Human Services, Gene Therapy for Human Patients: Information for the General Public* (1990)); See also Ubell, *supra* note 32. Using technology, scientists can isolate the "culprit" gene and create a synthesized version of it. *Id.* "The synthesized gene is placed in a harmless virus, which is injected into the body. Ideally, it will infect the targeted cells, which will then replicate with the healthy gene in place." *Id.*

alternatives available for people who have discovered their genetic makeup. However, many individuals fail to take advantage of the genetic resources because of the fear of future discrimination against both the individual undergoing testing and their families.<sup>69</sup> To ease some of these concerns, states have begun to address fears by enacting laws to protect an individual's genetic information. One such state, Oklahoma, recently enacted legislation in this area.

### III. WHY FEDERAL LEGISLATION IS NEEDED

#### A. *The States' Approach*

##### 1. Oklahoma Law

In its attempt to combat discrimination based on genetic information, Oklahoma passed the Genetic Nondiscrimination in Insurance Act<sup>70</sup> which became effective in July 1998. The Insurance Act applies to both insurance and employment practices and places limitations on disclosure.<sup>71</sup> The Insurance Act prohibits health and accident insurers from using genetic information or requiring genetic tests in enrolling, covering, charging premiums, or applying other limitations in providing insurance.<sup>72</sup> The Oklahoma House defeated a provision, however, to apply these anti-discrimination measures to life insurance companies.<sup>73</sup> The law also fails to take into account discrimination involving insurers which occurs "in the ordinary course of business of life, disability income or long-term care insurance."<sup>74</sup>

The Genetic Nondiscrimination in Employment Act<sup>75</sup> prohibits employers from requiring genetic testing or otherwise obtaining genetic information of any employee or prospective employee. Violations of the Employment Act are punishable by fines of less than \$25,000, prison time of less than one year, or both.<sup>76</sup> Both the Employment Act and the Insurance Act define genetic information as "information derived from the results of a genetic test . . . [and] shall not include family history, the results of a routine physical examination or test . . . or the results of any other test commonly accepted in clinical practice at the time it is ordered by the insurer."<sup>77</sup> Finally, the law puts limitations on compulsory disclosure of genetic information.<sup>78</sup>

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69. See Fox & Finesilver, *supra* note 49, at 76 (discussing how the fear of genetic-based discrimination is discouraging at-risk family members to screen for genetic changes associated with certain conditions, including cancer).

70. H.B. 3169, 46th Leg., 2d Sess. (Okla. 1997) (to be codified at OKLA. STAT. tit. 36, § 3614.1).

71. See *id.*

72. See *id.*

73. See *Statelines Oklahoma: Passes Genetic Discrimination Bill*, AMERICAN POLITICAL NETWORK, May 28, 1998, at 8.

74. Marie Price, *House Passes Genetic Discrimination Bill*, THE JOURNAL RECORD, May 27, 1998.

75. H.B. 3169, 46th Leg., 2d Sess. (Okla. 1997) (to be codified at OKLA. STAT. tit. 36, § 3614.2).

76. See *id.*

77. *Id.* (to be codified at OKLA. STAT. tit. 36, §§ 3614.2, 3614.3).

78. See *id.*

## 2. Other States' Laws

"Concern that Congress is 'acting too slowly to protect the confidentiality of genetic information' has prompted at least 26 states to pass laws that 'regulate the use of genetic information results to prevent discrimination by insurers and employers.'"<sup>79</sup> At least fourteen states have laws prohibiting genetic discrimination in employment practices, including California whose law became effective July 1998.<sup>80</sup> The California law prohibits employers from using any genetic information including information obtained from genetic tests, family medical histories, or genetic information obtained from other sources in making any employment decisions.<sup>81</sup> Although other states possess non-discrimination laws in employment areas, many of the laws contain loopholes such as allowing discrimination if a belief exists that a particular genetic trait would produce an occupational hazard.<sup>82</sup> Similar to the Oklahoma law, Texas prohibits the use of genetic test results in employment and some insurance plans; however, genetic information derived from family histories is not addressed.<sup>83</sup>

Some states have passed laws forbidding insurance companies from dropping an individual's coverage based upon the results of a genetic test.<sup>84</sup> A New Mexico law enacted on May 9, 1998, prohibits such discrimination.<sup>85</sup> Other states have enacted laws criminalizing genetic discrimination.<sup>86</sup> "Seven states have even gone so far as to give people property rights to their genetic information."<sup>87</sup> Still other states have dealt with this issue by passing laws requiring confidentiality of medical

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79. *Genetic Testing: States Pass Legislation Regulating Uses*, AMERICAN POLITICAL NETWORK, Oct. 20, 1997, at 13. This year, Oklahoma and New Mexico have enacted genetic nondiscrimination legislation. *See 1998 State Wrap Up: Health Care*, BUS. INS., June 29, 1998, at 11. Alabama, Arizona, Connecticut, Florida, Hawaii, Illinois, Indiana, Kansas, Louisiana, Nevada, North Carolina, Tennessee, and Texas enacted legislation prohibiting genetic discrimination in 1997. *See* Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653, 665 n.9 (1998). Other states proposing legislation prohibiting genetic discrimination are California, Colorado, Georgia, Iowa, Maryland, Minnesota, Montana, New Hampshire, New Jersey, New York, Ohio, Oregon, Rhode Island, Virginia, and Wisconsin. *See id.* at n.10.

80. *See* Goetinck, *supra* note 9. *See also* S.B. 654, Chap. 99 1998 STATS. (amending CAL. GOV'T. CODE § 12926 (West 1998)). *See also* IOWA CODE ANN. § 729.6 (West 1997); N.J. STAT. ANN. § 10:5-12 (West 1998); N.Y. EXEC. LAW § 296 (McKinney 1993 & Supp. 1997); OR. REV. STAT. § 659.036 (1996).

81. *See* S.B. 654, Chap. 99 1998 STATS. (amending CAL. GOV'T. CODE § 12926 (West 1998)); Sally Lehrman, *California Law Protects Workers with Predisposition to Disease*, BIOTECHNOLOGY NEWSWATCH, July 20, 1998, at 1.

82. *See id.*

83. *See* TEX. CIV. STAT. ANN. §9031 (West 1998). *See also* Goetinck, *supra* note 9.

84. *See* CAL. INS. CODE §§ 742.405, 10123.3 (West 1998); COLO. REV. STAT. ANN. § 10-3-1104.7 (1997); OR. REV. STAT. § 746.135 (1997).

85. *See* H.B. 331, 43d Leg., 2d Reg. Sess. (N.M. 1998).

86. *See* N.Y. CIV. RIGHTS LAW § 79-1 (McKinney Supp. 1997) (where willful violations are punishable by not more than \$5,000 or by imprisonment for not more than ninety days or both); FLA. STAT. ANN. § 760.40(2)(a)(b) (West 1997) (where misuse of genetic information constitutes a first degree misdemeanor). *See* Courtenay Edelhart, *Advances Multiply Opportunities for the Genetic Testing Industry*, THE INDIANAPOLIS STAR, Aug. 8, 1997, at C1.

87. Katharine Beile, *New State Laws Target Genetic Discrimination*, CHRISTIAN SCI. MONITOR, July 27, 1998, at 3. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7 (1997); LA. REV. STAT. ANN. §22:213.7 (West 1998).

records.<sup>88</sup> One survey, according to the Electronic Privacy and Information Center, reported: thirty-seven states create a duty to physicians to maintain confidential medical records; twenty-six states place this duty on other health care providers; four states impose this duty on insurers; nine states impose the duty on employers; twelve states impose criminal penalties as a result of discrimination; nineteen states allow for civil penalties; and three states can impose both criminal and civil penalties.<sup>89</sup> With so many different state regulations, the scope of protection is inconsistent. Uniform federal legislation will provide security to those individuals with genetic conditions who relocate to other states with no genetic discrimination protection. Additionally, federal legislation will protect those family members who are without the genetic condition but whose state laws do not provide reciprocal protection.

One of the most comprehensive state laws is the Genetic Privacy Act enacted by New Jersey.<sup>90</sup> New Jersey's law not only applies to insurance companies and employers but expands its scope by amending New Jersey's anti-discrimination laws to apply to other societal discrimination.<sup>91</sup> The Genetic Privacy Act explicitly states "[t]he improper collection retention or disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance."<sup>92</sup> The Act requires informed consent before obtaining genetic information and requires consent for retention of genetic information.<sup>93</sup> The New Jersey law also restricts the disclosure of genetic information prohibiting the disclosure of the identity of the person upon whom the genetic test was performed, including disclosure of any genetic information gained from the actual individual.<sup>94</sup> Penalties for violations of this Act include: (1) a fine of \$1,000, six-month imprisonment, or both; (2) for willful violations, a \$5,000 fine, a one-year imprisonment term, or both; and (3) all actual damages suffered by the individual as a proximate result of the genetic disclosure.<sup>95</sup>

The Genetic Privacy Act also supplements other areas of the New Jersey statutes.<sup>96</sup> With relation to insurance coverage, the statute prohibits insurance companies from discriminating on the basis of "genetic information" or the refusal to submit or make available the results of genetic testing.<sup>97</sup> Genetic information is defined as "information about genes, gene products or inherited characteristics that may derive from an individual or family member."<sup>98</sup> Unlike Oklahoma, New Jersey

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88. See Yesley, *supra* note 79, at n.23 (citing N.Y. CIV. RIGHTS LAW § 79-1.3 (McKinney Supp. 1997)).

89. See *Medical Records Privacy Hearings*, *supra* note 62 (statement of Rep. Louise Slaughter).

90. See N.J. STAT. ANN. § 10:5-43 (West 1998).

91. See N.J. STAT. ANN. § 10:5-12 (West 1998); Natalie Anne Stepanuk, *Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U. L. REV. 1105, 1124 (1998).

92. N.J. STAT. ANN. § 10:5-44(c) (West 1998).

93. See *id.* § 10:5-46(a) (West 1998).

94. See *id.* § 10:5-47(a) (West 1998).

95. See *id.* § 10:5-49(a)(b) (West 1998).

96. See *id.* § 10:5-43 (West 1996).

97. See N.J. STAT. ANN. § 17B:30-12(e)(1) (West 1998).

98. *Id.* § 17B:30-12(e)(2) (West 1998).

does not limit its prohibition of genetic discrimination to the results of genetic tests.<sup>99</sup> Furthermore, genetic test is broadly defined as “a test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to identify a predisposing genetic characteristic.”<sup>100</sup> The Genetic Privacy Act supplements this provision to provide more comprehensive coverage of genetic information. This broad definition captures individuals linked to genetic conditions through personal diagnoses and through familial associations, resulting in greater protection against genetic discrimination.

### B. Current Federal Law

Although many states have implemented a vast number of genetic nondiscrimination laws, the approaches are incomplete and often too narrowly worded. Many of the state laws focus on the protection of genetic test results rather than the more inclusive genetic information.<sup>101</sup> Information gained from medical history, family histories, physical examinations, and other sources of information must also be protected.<sup>102</sup> More importantly, private self-funded employer-sponsored health insurance plans are usually exempt from state insurance laws pursuant to the Employee Retirement Income Security Act (“ERISA”).<sup>103</sup> Most people who are not on Medicare or Medicaid receive their health insurance benefits through these “self-funded” plans set up under ERISA.<sup>104</sup> Because state insurance regulations do not apply to these self-insured groups, nearly one-half of all Americans (approximately 125 million people) may be subjected to genetic discrimination.<sup>105</sup> To that end, federal legislation is needed to protect Americans not covered by state laws.

#### 1. Current Federal Laws Do Not Sufficiently Address the Issue of Genetic-Based Discrimination

Critics of state non-discrimination laws argue they are not necessary because

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99. *See id.* § 17B:30-12(e) (West 1998).

100. *Id.* § 17B:30-12(e)(1) (West 1998).

101. *See* H.B. 3169, 46th Leg., 2d Sess. (Okla. 1997) (to be codified at OKLA. STAT. tit. 36, § 3614.1).

102. *See Labor and Human Resources Hearings, supra* note 8 (statement of Francis S. Collins, Director, National Human Genome Research Institute).

103. *See id.* *See generally* Employee Retirement Income Security Act of 1974, Pub. L. No. 93-406, 88 Stat. 829 (1974).

104. *See* Lynn E. Egan, *Genetic Discrimination in Health Insurance*, 24 J. LEGIS. 237, 243 (1998) (quoting Prepared Testimony of Karen H. Rothenburg J.D., M.P.A., Marjorie Cook Professor of Law, Director Law & Health Care Program, University of Maryland School of Law, *Before the Senate Comm. on Labor and Human Resources*, 104th Cong. (1996)).

105. *See Labor and Human Resources Hearings, supra* note 8 (statement of Francis S. Collins, Director, National Human Genome Research Institute).

of existing federal statutes such as the ADA<sup>106</sup> and HIPAA.<sup>107</sup> The ADA ostensibly covers people with genetic mutations, but courts have yet to hold for those discriminated against based upon these conditions.<sup>108</sup> “The Equal Employment Opportunity Commission said in an opinion last year that people with potentially harmful genetic variations should be protected from employment discrimination under the Americans with Disabilities Act.”<sup>109</sup> However, this issue has not been litigated.<sup>110</sup> The Commission stated that “[t]he ADA does not specifically mention genetics but clearly covers expressed genetic disorders to the same extent as impairments without a genetic component;” however, it is not clear whether unexpressed genetic predispositions are covered.<sup>111</sup> The applicable portion of the ADA for analyzing genetic conditions and whether they are covered begins with the definition of “disability.”<sup>112</sup> Disability is defined in the ADA as: “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such impairment; or (C) being regarded as having such an impairment.”<sup>113</sup> The Equal Employment Opportunity Commission (“EEOC”) clarified when genetic information may be regarded as having substantial limiting impairment in the following example:

CP’s genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R learns about CP’s increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP’s productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of ‘disability.’<sup>114</sup>

A major disadvantage is that the ADA applies only to employers with fifteen or more employees thereby excluding a large number of small employers from complying with ADA standards.<sup>115</sup>

Clearly the ADA is lacking in its protection against genetic discrimination. However, even federal statutes created specifically to deal with genetic discrimination fall short of providing adequate coverage for individuals. HIPAA, passed in 1996, explicitly prohibits the use of genetic information to determine eligibility in group

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106. 42 U.S.C. § 12101-12213 (1994).

107. Pub. L. No. 104-191, 110 Stat. 1936 (1995) (codified in scattered sections of 29 U.S.C., 42 U.S.C., 26 U.S.C., and 18 U.S.C.).

108. See Joyce Lain Kennedy, *Genetic Testing in the Workplace Holds Potential for Discrimination*, THE BUFF. NEWS, Aug. 23, 1997, at 13A.

109. Richard Saltus, *Who Wants to Know*, BOSTON GLOBE MAGAZINE, Oct. 12, 1997, at 8.

110. See 143 CONG. REC. S.8619, 8620 (daily ed. July 31, 1997) (statement by Sen. Frist).

111. Yesley, *supra* note 79, at 655.

112. See Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act*, 46 ADMIN. L. REV. 369, 373 (1994).

113. 42 U.S.C. § 12102(2) (1994).

114. EEOC Compl. Man. § 902.8 (CCH) ¶ 6888 (1995).

115. See 42 U.S.C. § 12111(5)(A) (1994). See also Egan, *supra* note 104, at 244.

health insurance plans,<sup>116</sup> including both self-insured plans and plans purchased from an insurer.<sup>117</sup> For people with individual or group insurance coverage, this law prevents insurers from refusing to renew or continue coverage based upon genetic information.<sup>118</sup> HIPAA also prevents the use of genetic information as a pre-existing condition unless the individual has been diagnosed with actual symptoms of that condition.<sup>119</sup> The statute does not expressly define "genetic information"; however, the interim regulations attempt to fill in this gap.<sup>120</sup> Genetic information is broadly defined in the regulations and includes "information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical explanations, family histories, and direct analysis of genes or chromosomes."<sup>121</sup> The law protects individuals changing from one health insurance plan to another and also protects uninsured individuals applying for group coverage.<sup>122</sup>

Although a great beginning point, HIPAA falls short in many areas. HIPAA does not require an employer to provide a health plan, and if the employer does provide such a plan, HIPAA does not require the inclusion of particular benefits. Plans may exclude coverage of a particular condition or place a lifetime cap on certain benefits, provided it is not directed at certain individuals. HIPAA does not help uninsured individuals who apply for individual coverage, nor does it cover individuals who leave their employer and the group insurance market but do not continue their coverage under the Consolidated Omnibus Budget Reconciliation Act of 1985<sup>123</sup> ("COBRA").<sup>124</sup> HIPAA also leaves open the possibility that all members of an insured group may be charged a higher premium based upon the genetic information of one person. Additionally, premiums are not controlled by HIPAA as long as all similarly-situated individuals in the plan are charged the same amount.<sup>125</sup> Finally, HIPAA does not prohibit insurers from requiring genetic tests as a condition for coverage, nor does it restrict the releasing of that information to other sources.<sup>126</sup> HIPAA "doesn't stop the insurer from raising rates or excluding coverage for a particular condition."<sup>127</sup> Additionally, a high burden is placed on the plaintiff to

116. See Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936, 1939, § 701(b)(1)(B) (1996).

117. See *id.* §§ 2711, 2712, 110 Stat. at 1962-66.

118. See *id.* See also *Highlights of the Health Insurance Portability and Accountability Act (HIPAA)* [hereinafter *Highlights of HIPAA*] (based on the Women's Legal Defense Fund Health Insurance Reform Fact Sheet (1997)).

119. See Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, § 701, 110 Stat. 1939, 1939-44 and § 2701, 110 Stat. at 1954-60. See also *Implementation of the Health Insurance Portability and Accountability Act: Hearings Before the Subcomm. on Health of the House Comm. on Ways and Means*, 105th Cong. (1997) [hereinafter *HIPAA Implementation Hearings*] (statement by Judith L. Lichtman, President, Women's Legal Defense Fund).

120. See 26 C.F.R. § 54.9801-2T (1998); 29 C.F.R. § 2590.701-2 (1997); 45 C.F.R. § 144.103 (1997).

121. *Labor and Human Resources*, *supra* note 8 (statement by Jack Ehnes, Colorado Commissioner of Insurance).

122. See *Highlights of HIPAA*, *supra* note 118.

123. 29 U.S.C. § 1161 (1986).

124. See *Highlights of HIPAA*, *supra* note 118.

125. See *Labor and Human Resources Hearings*, *supra* note 8 (statement of Chairman Jim Jeffords and statement of Christine Brunswick, Vice President, National Breast Cancer Coalition).

126. See *id.* (statement of Christine Brunswick, Vice President, National Breast Cancer Coalition).

127. Kennedy, *supra* note 108.

prove that coverage was denied because of genetic information.<sup>128</sup>

### C. Case Law Litigating the Issue of Genetic-Based Discrimination

In *Katskee v. Blue Cross/Blue Shield*,<sup>129</sup> the Supreme Court of Nebraska broadly defined the terms “bodily disorder” and “disease” as an:

illness, encompass[ing] any abnormal condition of the body or its components of such a degree that in its natural progression would be expected to be problematic; a deviation from the healthy or normal state affecting the functions or tissues of the body; an inherent defect of the body; or a morbid physical or mental state which deviates from or interrupts the normal structure or function of any part, organ, or system of the body and which is manifested by a characteristic set of symptoms and signs.<sup>130</sup>

*Katskee* raised the issue of whether the condition from which the appellant suffered constituted an illness under the terms of her health insurance policy.<sup>131</sup> The appellant possessed a genetic condition putting her at substantial risk of developing breast and ovarian cancer; however, she showed no symptoms of either disease.<sup>132</sup> Appellant’s insurance carrier refused to cover a preventative surgery to decrease her risk of cancer because it did not consider her condition an illness under the terms of the policy.<sup>133</sup> The court held that appellant’s condition did constitute a bodily disorder or disease, thereby concluding she suffered from an illness within the meaning of the terms of the insurance policy.<sup>134</sup> In so doing, the court reasoned that the “[a]ppellant’s condition [was] a deviation from what is considered a normal, healthy physical state or structure . . . aris[ing], in part, from the genetic make-up of the woman,” therefore, increasing her chance of later cancer development.<sup>135</sup> This case illustrates one way to protect individuals from the results of genetic discrimination.

In a more recent case, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*,<sup>136</sup> the Ninth Circuit became the first court “to propose constitutional limits on how employers may use genetic information” and became the first court “to address the controversial issue of genetic privacy generally.”<sup>137</sup> The court addressed the issue of whether an employee undergoing a general health examination could be tested for sensitive medical or genetic information without the employee’s consent.<sup>138</sup> The court

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128. *See id.*

129. 515 N.W. 2d 645 (Neb. 1994).

130. *Id.* at 651.

131. *See id.* at 653.

132. *See id.* at 652.

133. *See id.* at 653.

134. *See id.*

135. *Id.* at 652.

136. 135 F.3d 1260 (9th Cir. 1998).

137. Rick Weiss, *Genetic Tests In Workplace Can Be Privacy Breach*, WASH. POST, Feb. 5, 1998, at A8.

138. *See Norman-Bloodsaw*, 135 F.3d at 1264.



viewed these intrusive examinations as implicating rights “protected under both the Fourth Amendment and the Due Process Clause of the Fifth or Fourteenth Amendments.”<sup>139</sup> To that end, the court applied a balancing test weighing “the government’s interest in conducting these particular tests against the plaintiff’s expectations of privacy.”<sup>140</sup> The court held that because of the personal nature of an individual’s health and genetic make-up and because the testing was unauthorized, “the testing constituted a significant invasion of a right that is of great importance”—the right to privacy.<sup>141</sup> Although these cases provide hope for people undergoing genetic testing, genetic information deserves the protection of federal law in order to maintain uniformity among the fifty states. It is well stated that “[a] judicial solution, resolving issues such as insurance and employment discrimination on a case-by case basis, could never parallel the rate of scientific research . . . . The legislature can address the most major issues, leaving the courts to refine the subtleties of these issues through case law.”<sup>142</sup>

#### IV. FEDERAL LEGISLATION PROPOSED IN THE 105TH CONGRESS

##### A. Insurance Legislation

Many bills have been introduced into the 105th Congress to combat discrimination, particularly in insurance practices. The Genetic Information Nondiscrimination in Health Insurance Act,<sup>143</sup> introduced in 1997, attempts to prevent discrimination against individuals and their family members on the basis of genetic information. This bill, if enacted, would amend ERISA,<sup>144</sup> the Public Health Service Act (“PHSA”),<sup>145</sup> Title XVIII of the Social Security Act,<sup>146</sup> and the Internal Revenue Code.<sup>147</sup> The changes made to ERISA would prohibit a group health plan or a group health insurance issuer from discrimination based upon genetic information.<sup>148</sup> The PHSA would be amended to require group health plans, group health issuers, and individual health issuers to demand written authorization from the participant prior to releasing any genetic information.<sup>149</sup> Under this bill, both the Social Security Act and the Internal Revenue Code would prohibit group health plans and group insurance issuers from genetic discrimination.<sup>150</sup> Finally, this Act would allow individuals covered by the policy to sue in civil court for compensatory,

139. *Id.* at 1269 (citing *Yin v. California*, 95 F.3d 864, 870 (9<sup>th</sup> Cir. 1996)).

140. *Id.*

141. *Id.* at 1270.

142. Stepanuk, *supra* note 91, at 1141.

143. H.R. 306, 105th Cong. (1997); S. 89, 105th Cong. (1997).

144. Pub. L. No. 93-406, 88 Stat. 829 (codified as amended in scattered titles of U.S.C.).

145. 42 U.S.C. § 201 (1994).

146. 42 U.S.C. § 1395 (1994).

147. Pub. L. No. 83-591, 68A Stat. 3 (1954) (as cited by Pub. L. No. 99-514).

148. *See* H.R. 306, 105th Cong. § 2 (1997); S. 89, 105th Cong. § 2 (1997).

149. *See* H.R. 306, 105th Cong. § 3 (1997); S. 89, 105th Cong. § 3 (1997).

150. *See* H.R. 306, 105th Cong. §§ 4, 5 (1997); S. 89, 105th Cong. §§ 4, 5 (1997).

consequential, and punitive damages.<sup>151</sup>

A similar bill is the Genetic Health Insurance Nondiscrimination Act of 1997.<sup>152</sup> This Act would also amend PHSA<sup>153</sup> and ERISA<sup>154</sup> to prohibit group health plans and group health issuers from discriminating on the basis of genetic information or genetic test results, but it would also apply the discrimination prohibitions to insurers offering individual coverage to participants.<sup>155</sup> The Genetic Health Insurance Nondiscrimination Act of 1997 would apply limits on the collection of genetic information and would restrict the disclosure of genetic information that had already been obtained.<sup>156</sup> A salient feature of this Act is the requirement of authorization each time a disclosure of any genetic information is to be made, including the name of the individual to whom the disclosure is to be made and the purpose of the disclosure.<sup>157</sup> The importance of this feature is that it ensures the participant's awareness each time a disclosure is made and the purposes for each disclosure.

A more general bill is the Genetic Protection in Insurance Coverage Act.<sup>158</sup> This Act would extend beyond health insurance to all life and disability insurers.<sup>159</sup> This Act would prohibit requiring or requesting genetic tests by refusing to enroll any individual or any individual's family members based upon genetic information; offering different rates, terms, conditions, or benefits based on genetic test results; or seeking, maintaining, or receiving any genetic information.<sup>160</sup> A drawback of this Act is its failure to define any penalties for violations.

### *B. Employment Legislation*

Genetic discrimination is also a concern in employment and labor-related practices. Recently, Congress has made attempts to address this issue with the Genetic Nondiscrimination in the Workplace Act.<sup>161</sup> This short bill would amend the Fair Labor Standards Act of 1938 ("FLSA")<sup>162</sup> to prohibit employers from "obtaining, disclosing, or using genetic information" about their employees or prospective employees unless they receive written authorization from such individuals, and provide such individuals with a written statement of the uses which the employer intends for such information.<sup>163</sup> Finally, an individual may sue for violations of this Act.<sup>164</sup>

A more complete piece of legislation addressing employment practices is the

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151. See H.R. 306, 105th Cong. § 4 (1997); S. 89, 105th Cong. § 4 (1997).

152. H.R. 328, 105th Cong. (1997).

153. 42 U.S.C. § 201 (1994).

154. Pub. L. No. 93-406, 88 Stat. 829 (codified as amended in scattered titles of U.S.C.).

155. See H.R. 328, 105th Cong. § 2 (1997).

156. See *id.*

157. See *id.*

158. H.R. 2216, 105th Cong. (1997).

159. See *id.* § 3.

160. See *id.*

161. H.R. 2215, 105th Cong. (1997).

162. 29 U.S.C. §§ 201-219 (1938).

163. H.R. 2215, 105th Cong. § 2 (1997).

164. See *id.*

Genetic Justice Act<sup>165</sup> introduced in the Senate and the Genetic Employment Protection Act of 1997<sup>166</sup> introduced in the House of Representatives. Both Acts intend to prohibit discrimination by employer practices,<sup>167</sup> employment agency practices,<sup>168</sup> labor organization practices,<sup>169</sup> and employee training programs.<sup>170</sup> The Acts would require employers, employment agencies, and labor organizations to maintain genetic information in separate medical files, and to treat the information as confidential.<sup>171</sup> Civil actions could be maintained in federal or state court for violations of these requirements.<sup>172</sup>

### *C. General Legislation Combating Both Employment and Insurance-Based Genetic Discrimination*

The Genetic Privacy and Nondiscrimination Act of 1997<sup>173</sup> addresses discrimination within both employment and insurance contexts. This bill would prohibit the disclosure of genetic information "regardless of the manner in which genetic information was recovered, or the source of such information."<sup>174</sup> This legislation would allow a legal representative to give consent to disclose genetic information if the individual has provided written authorization, including a description of the genetic information being disclosed, the name to whom the disclosure is made, and the purpose of the disclosure.<sup>175</sup> This is important since disclosure by an agent would ensure proper understanding of the information being disclosed.

A second Genetic Privacy and Nondiscrimination Act has been introduced into the House of Representatives and is more specific than the original bill.<sup>176</sup> With respect to insurance coverage, this bill would amend the PHSAA<sup>177</sup> and ERISA<sup>178</sup> to prohibit group health plans and group insurance carriers from discriminating in

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165. S. 1045, 105th Cong. (1997).

166. H.R. 2275, 105th Cong. (1997).

167. *See* S. 1045, 105th Cong. § 3 (1997); H.R. 2275, 105th Cong. § 3 (1997). Employers may not refuse to hire, limit, segregate, or classify any employee based on genetic information. *See id.* An employer may not require genetic testing unless it is requested after the offer for employment is made, the information is job-related, and voluntary consent is given by the individual on which the test is to be performed. *See id.*

168. *See* S. 1045, 105th Cong. § 4 (1997); H.R. 2275, 105th Cong. § 4 (1997) (preventing employment agencies from refusing to refer an individual for employment based on genetic information or otherwise genetically discriminating against an individual).

169. *See* S. 1045, 105th Cong. § 5 (1997); H.R. 2275, 105th Cong. § 5 (1997). Under these Acts, Labor Organizations may not exclude, expel, limit, segregate, classify, or attempt to cause an employer to discriminate based on genetic test results. *See id.*

170. *See* S. 1045, 105th Cong. § 6 (1997); H.R. 2275, 105th Cong. § 6 (1997). Anyone controlling training programs, including on the job training, may not discriminate based on genetic information. *See id.*

171. *See* S. 1045, 105th Cong. § 7 (1997); H.R. 2275, 105th Cong. § 7 (1997).

172. *See* S. 1045, 105th Cong. § 8 (1997); H.R. 2275, 105th Cong. § 8 (1997).

173. H.R. 341, 105th Cong. (1997).

174. H.R. 341, 105th Cong. §§ 5, 6 (1997).

175. *See id.* § 4.

176. *See* H.R. 341, 105th Cong. (1997).

177. 42 U.S.C. § 201 (1994).

178. Pub. L. No. 93-406, 88 Stat. 829 (codified as amended in scattered titles of U.S.C.).

issuing, renewing, establishing premiums, or otherwise affecting benefits based upon genetic information.<sup>179</sup> These prohibitions would also apply to the use of genetic information in individual insurance markets and in medical care relating to veteran benefits.<sup>180</sup> With respect to employment practices, this Act would prevent employers from acquiring, requiring, or using genetic information for any employment purposes.<sup>181</sup> Finally, this Act would make it unlawful for any employer to release genetic information to anyone other than those whose position requires access and to retain any information obtained from insurers without prior written consent of the employee.<sup>182</sup>

Another bill aimed at both labor and insurance practices is the Family Genetic Privacy and Protection Act.<sup>183</sup> This Act would prohibit discrimination in insurance practices and would amend federal law regarding veterans' benefits to comply with this Act when utilizing genetic information.<sup>184</sup> Furthermore, this Act would regulate employer access to, use of, and disclosure of genetic information.<sup>185</sup> Additionally, a National Bipartisan Commission on the use of genetic information would be established in order to implement the standards of this Act and would terminate thirty days after submitting its findings, recommendations, and conclusions to the President and Congress.<sup>186</sup>

Most of the proposed federal legislation fails to address genetic discrimination practices and the use of genetic information. The Genetic Confidentiality and Nondiscrimination Act of 1997<sup>187</sup> addresses not only unfair and prejudicial practices in the insurance and employment setting but also addresses the actual use of genetic information. The Act is divided into eight titles, each with a unique purpose. Title I discusses the collection, storage, and analysis of DNA samples. Collection would require written authorization containing specific information, and collection must be performed in accordance with appropriate authorization.<sup>188</sup> Title II would allow for third-party disclosure of genetic information only with written consent containing certain specifications and an expiration date. Written permission would also allow the individual to inspect and receive a copy of any record containing genetic information within twenty days.<sup>189</sup>

The other sections of this Act pertain to actual uses of genetic information. Title IV prohibits discrimination by both employers (or potential employers) and health insurers.<sup>190</sup> Title V sets the parameters and conditions for conducting research

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179. See H.R. 2198, 105th Cong. § 2 (1997).

180. See *id.*

181. See *id.* § 3.

182. See *id.*

183. H.R. 3299, 105th Cong. (1998).

184. See *id.* § 2.

185. See *id.*

186. See *id.* § 4.

187. S. 422, 105th Cong. (1997).

188. See *id.* §§ 101, 102.

189. See *id.* §§ 201, 204.

190. See *id.* §§ 401, 402.

activities.<sup>191</sup> Title VI contains miscellaneous provisions establishing annual notification of individuals in collecting, storing, or analyzing genetic information and the responsibilities and penalties for violations.<sup>192</sup> Title VII allows individuals whose rights have been violated to bring a civil suit in a U.S. District or state court.<sup>193</sup> Penalties differ for negligent violations, willful violations, and liability for employment discrimination with a six-year statute of limitations from the date of discovery.<sup>194</sup> In the interest of the public, the Attorney General would also be able to bring an action against a person in violation of this Act.<sup>195</sup> Finally, Title VIII is important because this Act would not preempt applicable state law if the state law “(1) more completely protects the confidentiality or privacy of an individual with respect to genetic information about the individual than does this Act; or (2) provides a greater right of access to genetic information.”<sup>196</sup> This Act is the most comprehensive because it seeks to remedy discriminatory employment and insurance practices and seeks to regulate the use of genetic information.

## VI. CONCLUSION

Genetic discrimination is an area of great concern for many individuals and their families. As more genes in the human body are identified and their interactions with other genes become known, an increased number of tests will be able to identify the likelihood of developing a genetic disorder. This kind of testing has the potential to impact literally thousands of people; broad federal laws must be in place to protect the individuals being tested and their families.

Discrimination must be prevented in employment practices, as well as insurance practices extending to life, health, automobile, disability, and other forms of insurance. Loan, mortgage, and credit card agencies must also be prohibited from discriminating against individuals with genetic predispositions. Additionally, reproduction practices, adoption practices, and schools should be included in legislation aimed at prohibiting genetic discrimination. While many bills have been introduced on this topic, they fail to provide a comprehensive solution. Federal legislation enacted must be broad enough to encompass genetic discrimination in every area of daily life.

In order for the future of genetics to yield promising results in treatment of disease and prevention, protection must be in place to make people comfortable with the way in which genetic information will be used. As more people take genetic tests, more knowledge can be obtained and learned about the genetic process. This will aid in the development of prevention and cures of diseases allowing people to live longer

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191. *See id.* §§ 501, 503.

192. *See id.* §§ 601, 602.

193. *See S. 422*, 105th Cong. §§ 701, 702 (1997).

194. *See id.* § 702.

195. *See id.*

196. *Id.* § 803.

and healthier lives. Until legislation is in place to protect people from the discrimination they fear, the possibility of developing treatments and finding cures to genetic diseases greatly diminishes. This lack of comprehensive federal legislation has the potential to bestow a great misfortune on our society.

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