

# The Genetic Information Nondiscrimination Act of 2008: History, Successes, and Future Considerations

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## Recommended Citation

Christine F. Norris, *The Genetic Information Nondiscrimination Act of 2008: History, Successes, and Future Considerations*, 7 U. Md. L.J. Race Relig. Gender & Class 192 (2007).

Available at: <http://digitalcommons.law.umaryland.edu/rrgc/vol7/iss1/11>

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# THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008: HISTORY, SUCCESSES, AND FUTURE CONSIDERATIONS

CHRISTINE FORMAS NORRIS\*

The mapping of the human genetic code is one of the greatest scientific achievements of the Twentieth Century.<sup>1</sup> To date, Congress has committed \$3.5 billion in the Human Genome Project with the hope that genetic research will lead to great medical advances.<sup>2</sup> Many considered genetic discrimination to be a major threat to these advances.<sup>3</sup> Genetic information can be used to deny individuals affordable health insurance or employment benefits.<sup>4</sup> Genetic discrimination can also manifest itself indirectly through genetic research and testing that reinforces racial, ethnic, or gender stereotypes.<sup>5</sup> Fear of genetic discrimination may prevent individuals from seeking genetic testing or from enrolling in genetic research.<sup>6</sup> In a hearing before the Senate Committee on Health, Education, Labor and Pensions, the President of The National Partnership for Women and Families aptly stated:

No individual should have to choose between the benefits of genetic testing and keeping a job or health insurance. In some cases, fear of genetic discrimination can be as destructive as traditional discrimination. Unless Congress acts quickly and decisively, people's fears may prevent them from getting the health care they need. The more individuals fear discrimination, the less willing they will be to participate in clinical trials and studies that may require genetic testing – the very kind

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1. NATIONAL PARTNERSHIP FOR WOMEN AND FAMILIES, *FACES OF GENETIC DISCRIMINATION* (2004), available at <http://www.nationalpartnership.org/portals/p3/library/GeneticDiscrimination/FacesofGeneticDiscrimination.pdf> [hereinafter *FACES*].

2. Michael Hill, *All in the DNA*, *BALT. SUN*, Feb. 4, 2007, § 6, at 16 (interview with Karen Rothenberg).

3. *Id.*

4. See discussion *infra* Part III.A.

5. See discussion *infra* Part III.D.

6. See discussion *infra* Part III.B and Part III.C.

of research that could help us all live longer, healthier lives.<sup>7</sup>

Congress found that federal health insurance, employment and other anti-discrimination laws do not sufficiently protect individuals from genetic discrimination.<sup>8</sup> While many states have passed genetic nondiscrimination laws, their protections and approaches vary extensively.<sup>9</sup> In response, Congress recently passed the Genetic Information Nondiscrimination Act, which would prohibit a broad range of discriminatory actions on the part of group health plans, health insurers and employers.<sup>10</sup>

While passage of the Genetic Information Nondiscrimination Act of 2008 is a major accomplishment for policymakers, the medical profession, researchers, and American citizens alike, several unresolved issues still remain.<sup>11</sup> Most importantly, no serious steps have been taken to regulate genetics research that can reinforce racial, ethnic and other group stereotypes.<sup>12</sup> In the future, policymakers should consider whether regulatory standards or other forms of intervention in group-identity based genetics research are necessary.<sup>13</sup>

## I. INTRODUCTION

It is best to start with a basic introduction to genetics and the Human Genome Project. Each of us inherits a set of genes from our parents.<sup>14</sup> These genes are like blueprints for our body. From birth, they predispose us to certain physical and even psychological characteristics.<sup>15</sup> These characteristics may be as simple and stable as the

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7. *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing on H.R. 1227 Before the S. Comm. on Health, Educ., Labor and Pensions, 107th Cong.* (2002) (testimony of Debra L. Ness), *quoted in* *FACES, supra* note 1, at 1.

8. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 2 (2008).

9. *See* discussion *infra* Part IV.F.

10. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. (2008) (enacted). The President signed the bill into law on May 21, 2008. *See* President Bush Signs H.R. 493, the Genetic Information Nondiscrimination Act of 2008 (May 21, 2008), *available at* <http://www.whitehouse.gov/news/releases/2008/05/20080521-7.html>. A broad range of parties, including business, professional, and community sponsors endorsed this bill. Janet Brewer, "Diseases of Place": *Legal and Ethical Implications of Surname and Ethnicity as Predictors of Disease Risk*, 9 *QUINNIPIAC HEALTH L.J.* 155, 173 (2006).

11. *See* discussion *infra* Part V.C.

12. *Id.*

13. *Id.*

14. SRB ET AL., *General Genetics* (Freeman & Company, 1965).

15. *Id.*

color of one's eyes. At the same time, they may be complex and less predictable, creating predispositions to diseases like heart disease and cancer.<sup>16</sup>

The Human Genome Project is an international research program coordinated by the National Institutes of Health. This organization mapped the entire human genetic code in hopes of locating an estimated 50,000-100,000 genes and to understand how they affect our bodies.<sup>17</sup> The potential for medical advances arising from our knowledge of the human genome is dramatic. Medical advances could range from new methods of medical diagnosis and treatment to a new practice of personalized medicine and individualized drugs, genetically engineered organs for transplants, and preventative care based on individual's genes.<sup>18</sup> However, the scope and significance of genomic innovation as well as the ability of genetics to directly touch everyone's lives raises serious moral and ethical concerns.<sup>19</sup>

The National Human Genome Research Institute has identified genetic discrimination as one of the ethical dilemmas and greatest obstacles to realizing the benefits of the Human Genome Project.<sup>20</sup> Genetic discrimination is generally defined as prejudice against persons who have a genetic predisposition towards an inherited disease.<sup>21</sup> Al-

16. H. Eiberg & J. Mohr, *Major genes of eye color and hair color linked to LU and SE*, 31 CLINICAL GENETICS 186, 186 (1987); H. Eiberg & J. Mohr, *Assignment of genes coding for brown eye colour (BEY2) and brown hair colour (HCL3) on chromosome 15q*, 4 EUR. J HUM. GENETICS 237, 237 (1996); R. A. Sturm & T. N. Frudakis, *Eye colour: portals into pigmentation genes and ancestry*, 20 TRENDS GENETICS 327, 327 (2004); see Presidential Radio Address to the Nation, (June 23, 2001), available at [www.whitehouse.gov/news/releases/2001/06/20010623.html](http://www.whitehouse.gov/news/releases/2001/06/20010623.html), quoted in NATIONAL PARTNERSHIP FOR WOMEN AND FAMILIES, *FACES OF GENETIC DISCRIMINATION* (July 2004), available at <http://www.nationalpartnership.org/portals/p3/library/GeneticDiscrimination/FacesofGeneticDiscrimination.pdf> ("A genetic predisposition to cancer or heart disease does not mean that the condition will develop.").

17. Nat'l Human Genome Research Inst., *An Overview of the Human Genome Project*, available at <http://www.genome.gov/12011238> (last visited Jan. 2007).

18. The Chattanooga.com, *Frist Applauds Senate Passage of Genetic Discrimination Protections Bill*, available at [http://www.chattanooga.com/articles/article\\_42097.asp](http://www.chattanooga.com/articles/article_42097.asp) (Oct 14, 2003); see also STATEMENT OF ADMINISTRATIVE POLICY, S.306, GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005, (Feb. 16, 2005).

19. See Nat'l Human Genome Research Inst., *Policy and Program Analysis Branch*, available at <http://www.genome.gov/10001087> (last visited Jan. 2007); see generally Nat'l Human Genome Research Inst., *Policy and Ethics*, available at <http://www.genome.gov/PolicyEthics> (last visited Jan. 2007) (see for a list of genomics ethics and policy issues).

20. Nat'l Human Genome Research Inst., *Genetic Discrimination*, available at <http://www.genome.gov/10002077> (last updated Feb. 2007).

21. U.S. Dept. of Energy Office of Sci., Human Genome Program, *Genome Glossary*, available at [http://www.ornl.gov/sci/techresources/Human\\_Genome/glossary/glossary\\_g.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/glossary/glossary_g.shtml) (last modified Oct. 29, 2003) (definition also includes discrimination against those who have actually developed a disorder).

though genetic discrimination is a relatively new concept, it is analogous to other forms of discrimination. First, our genetic profiles are immutable characteristics, because much like race and gender, our genes are inherited and unalterable.<sup>22</sup> Second, genetic discrimination is based on status or category rather than actual conditions.<sup>23</sup> Having a genetic predisposition to a disorder does not mean the disorder is certain to develop.<sup>24</sup> For instance, complex genetic disorders such as heart disease and cancer are influenced by a myriad of genes and environmental factors, each having an ability to predispose or prevent a person from developing the disease.<sup>25</sup> In such cases, genetic predisposition may be little more than medical speculation.<sup>26</sup> Therefore, an individual testing positive for a genetic susceptibility, such as to cancer, could be discriminated against for a condition that will never manifest. However, unlike other forms of discrimination, genetic discrimination has the potential to affect every human being because every human carries approximately five to seven fatal recessive genes<sup>27</sup> and up to thirty predispositions to various disorders.<sup>28</sup> For this reason, a wide variety of groups have expressed concern over genetic discrimination.<sup>29</sup>

## II. THE AFFECTED CLASS: A PATIENT'S PERSPECTIVE

Imagine that your physician just diagnosed you with Polycystic Kidney Disease (PKD), the world's most common life threatening genetic disease.<sup>30</sup> Painful kidney cysts, kidney stones, urinary tract infections, and high blood pressure, as well as problems in other organs

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22. *Cf.* *Frontiero v. Richardson*, 411 U.S. 677 (1973) ("Since sex, like race and national origin, is an immutable characteristic determined solely by the accident of birth, the imposition of special disabilities upon the members of a particular sex because of their sex would seem to violate the basic concept of our system that legal burdens should bear some relationship to individual responsibility.").

23. *Genetic Discrimination and Polycystic Kidney Disease: News Conference on H.R. 1227 Before House*, 109th Cong. (2006) [hereinafter *PKD News Conference*].

24. Presidential Radio Address to the Nation, *supra* note 16.

25. *Id.*

26. *Id.*

27. Alexander M. Capron, *Which Ills to Bear?: Reevaluating the "Threat" of Modern Genetics*, 39 EMORY L. J. 665, 690 (1990).

28. Louis M. Slaughter, *Genetic Information Must Remain Private to Prevent Discrimination*, *Spur Research*, 2 GENETIC TESTING 17, 19 (1998).

29. See generally *FACES*, *supra* note 1.

30. See *Polycystic Kidney Disease*, NAT'L KIDNEY AND UROLOGIC DISEASES CLEARINGHOUSE (Nat'l Kidney and Urologic Diseases Clearinghouse, Bethesda, MD), 1996, at 1, available at <http://kidney.niddk.nih.gov/kudiseases/pubs/polycystic/> (describes three types of polycystic kidney disease and its genetic origins, symptoms, diagnosis, and treatment, as well as ongoing research) [hereinafter *PKD*].

such as brain aneurysms, abnormal heart valves, and cysts in other organs characterize PKD.<sup>31</sup> To make matters worse, you now know that you have a fifty/fifty chance of developing kidney failure.<sup>32</sup>

Your physician informs you that a genetic test is available for PKD.<sup>33</sup> You urge your much younger sister to get tested because the condition may otherwise be undiagnosable for decades and, as a young woman, she may be able to forestall the disease through diet and blood pressure control.<sup>34</sup> Sadly, she tested positive for mutations in the PKD1 and PKD2 genes that cause PKD.<sup>35</sup> After receiving her results, she is repeatedly turned down for life insurance and health care insurance<sup>36</sup> even though her condition may not develop for another twenty years and the severity of the disease may be mild enough to be controlled by over-the-counter pain and blood pressure medications.<sup>37</sup> Perplexingly, insurers singled her out as a high risk, when PKD is not even the leading cause of kidney failure in this country.<sup>38</sup> Your sister fears the impact that her test results may have on her career if her employer finds out.<sup>39</sup>

After your sister's ordeal, you choose not to pursue genetic testing for your child because you fear for your son's job opportunities and health or life insurance coverage in the future.<sup>40</sup> But your own genetic test results are a part of your son's family history, so insurers may already take into consideration the fact that your son has a fifty percent chance of inheriting the disease from you.<sup>41</sup> You avoid testing although he may be able to safely donate a kidney to you one day should he test negative for PKD.<sup>42</sup> When your physician asks your family to participate in PKD genetic research, you decline because you are afraid that your genetic information may be disclosed.<sup>43</sup>

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31. *Id.*

32. *See id.*

33. *See id.*

34. *See id.*

35. *See PKD, supra* note 30.

36. *See PKD News Conference, supra* note 23.

37. *See PKD, supra* note 30.

38. *See id.* PKD is only the fourth leading cause of kidney failure. *Id.*; *see also* Diabetes and Blood Pressure, Two Leading Causes of Kidney Disease, NAT'L KIDNEY DISEASE EDUC. PROGRAM (Nat'l Kidney Disease Educ. Program), May 2006, at 1, *available at* [http://nkdep.nih.gov/resources/NKDEP\\_GenPopBrochure\\_508.pdf](http://nkdep.nih.gov/resources/NKDEP_GenPopBrochure_508.pdf).

39. *See PKD News Conference, supra* note 23.

40. *See id.*

41. *See PKD, supra* note 30.

42. *Id.*

43. *Id.*; *see also PKD News Conference, supra* note 23.

One can put the concept of genetic discrimination in context by reflecting back on the personal struggles of members of the Polycystic Kidney Disease Association.<sup>44</sup> Like PKD, genetic diseases can range from mild to serious. While a correct diagnosis can aid in treatment and perhaps even preventative treatments for the sufferer and their family, it can also subject them to genetic discrimination. Congress passed the Genetic Information Nondiscrimination Act to precisely address such concerns.<sup>45</sup>

### III. THE ISSUES: HOW DOES GENETIC DISCRIMINATION MANIFEST ITSELF?

#### *A. Employment and Insurance Discrimination*

Although genetic discrimination can be manifested in a number of different ways, genetic discrimination in health insurance and employment is most disconcerting and has been most frequently reported.<sup>46</sup> Issuers of health insurance have denied healthy individuals (much like our PKD sister) health insurance, increased the cost of coverage, or limited insurance benefits because of that individual's genetic information.<sup>47</sup> Similarly, employers have denied healthy individuals employment, fired current employees, or denied workers compensation benefits on the basis of genetic information.<sup>48</sup> According to the American Management Association, employers are accessing genetic information in a number of ways:<sup>49</sup>

- [O]ne percent was conducting genetic tests for Sickle Cell Anemia, 0.4 percent was testing for Huntington's disease

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44. See *PKD News Conference*, *supra* note 23.

45. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 101-102 (2008).

46. *FACES*, *supra* note 1, at 3.

47. *Id.*

48. *Id.*; see also Nat'l Human Genome Research Inst., *Cases of Genetic Discrimination*, available at <http://www.genome.gov/12513976> (last visited Dec. 2006) ("Despite claims of hundreds of genetic-discrimination incidents, an article from the January 2003 issue of the European Journal of Human Genetics reports a real need for a comprehensive investigation of these claims. The article warns that many studies rely on unverified, subjective accounts from individuals who believe employers or insurance companies have unfairly subjected them to genetic discrimination.").

49. *Privacy Concerns Raised by the Collection and Use of Genetic Information by Employers and Insurers: Hearing before the Subcommittee on the Constitution of the H.R. Comm. on the Judiciary*, 107th Cong. (Sept. 12, 2002), cited in *FACES*, *supra* note 1, at 3.

- Fourteen percent were conducting workplace susceptibility testing which surveyors acknowledged might include genetic testing
- Twenty percent were requesting family medical histories.<sup>50</sup>

In addition, twenty-two percent of individuals surveyed that are at risk, pre-symptomatic, or asymptomatic for a number of genetic diseases, identified a number of institutions that discriminated against them, including health and life insurers, employers, clinical professionals, blood banks, and public institutions.<sup>51</sup>

### *B. Avoidance of Genetic Testing*

Although there have been a number of well-documented cases of discrimination, no case directly claiming genetic discrimination has been brought before a United States federal or state court.<sup>52</sup> Experts speculate that many individuals and their family members are forgoing genetic testing in order to avoid discrimination in the first place.<sup>53</sup> Unlike race, ethnicity, religion, or gender, genetic predispositions are not readily apparent without laboratory genetic testing, physical medical examinations, or the disclosure of family medical histories.<sup>54</sup> Therefore, a fear of genetic discrimination may keep individuals, like the above hypothetical PKD family, from undergoing tests that could provide them with valuable information concerning their health, including predispositions to diseases they may be able to take preventative action against, possible adverse drug reactions, or hereditary diseases.<sup>55</sup>

50. *Id.*

51. M. Adya & B. Bornstein, Genetic Discrimination and Discrimination in Employment: A Psycho-legal Perspective, 32 Wm. Mitchell L. Rev. 265, at 275-276 (2005) (citing Lisa Geller et al., *Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis in The Double-Edged Helix*, Social Implications of Genetics in a Diverse Society 247 (2002)).

52. *FACES*, *supra* note 1, at 3.

53. *PKD*, *supra* note 30 (Patients with polycystic kidney disease would not genetically test their children to see if they had a predisposition to the disease because they feared for their child's ability to obtain health insurance or employment when they got older.).

54. *Id.*

55. OFFICE OF MANAGEMENT AND BUDGET, STATEMENT OF ADMINISTRATIVE POLICY, S. 306 – GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005 (Feb. 16, 2005), available at <http://www.whitehouse.gov/omb/legislative/sap/109-1/s306sap-s.pdf>; OFFICE OF MANAGEMENT AND BUDGET, STATEMENT OF ADMINISTRATIVE POLICY, S. 1053 – GENETIC INFORMATION NONDISCRIMINATION ACT OF 2003 (Oct. 14, 2003), available at <http://www.whitehouse.gov/omb/legislative/sap/108-1/s1053sap-s.pdf>.



The fear of genetic discrimination has adversely impacted genetic testing for breast cancer susceptibility in exactly this way.<sup>56</sup> Women with BRCA1 or BRCA2<sup>57</sup> genetic mutations have an extremely high lifetime risk of breast cancer (50-85%) and increased risks of ovarian cancer (10-40%).<sup>58</sup> Some women who test positive obtain preventative mastectomies, oophorectomies, and hysterectomies to reduce their risk of breast and ovarian cancer.<sup>59</sup> While BRAC1/2 testing is widely available and women are highly interested in such screening, only about half of all eligible women choose to be tested.<sup>60</sup> Research shows that:

Individuals considering BRAC1/2 testing consistently identify health insurance discrimination among their major concerns about testing . . . In one testing program, 34% of individuals reported that the possibility of losing health insurance was a major risk of having BRCA1 testing . . . In order to avoid discrimination, many of the respondents . . . obtained insurance prior to any genetic testing, received testing that could not be linked back to them personally, only partially disclosed relevant information, and personally paid for testing that would ordinarily be paid for by insurers.<sup>61</sup>

### *C. Reluctance to Participate in Genetics Research*

Genetic discrimination also has the effect of reducing the number of willing participants in clinical research because individuals are afraid their genetic information could be disclosed and used for ille-

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56. See generally Katherine A. Schneider, *Adverse Impact of Predisposition Testing on Major Life Activities: Lessons from BRAC1/2 Testing*, 3 J. HEALTH CARE L. & POL'Y 365 (2000) (discussion on impact of the perception of genetic discrimination on BRAC1/2 testing).

57. NATIONAL CANCER INSTITUTE, available at <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA> (last visited Feb 6, 2002) ("Inherited alterations in the genes called BRCA1 and BRCA2 (short for breast cancer 1 and breast cancer 2) are involved in many cases of hereditary breast and ovarian cancer. Researchers are searching for other genes that may also increase a woman's cancer risk.")

58. Katherine A. Schneider, *Adverse Impact of Predisposition Testing on Major Life Activities: Lessons from BRAC1/2 Testing*, 3 J. HEALTH CARE L. & POL'Y 365, 367 (2000) (discussion on impact of the perception of genetic discrimination on BRAC1/2 testing).

59. *Id.*

60. *Id.* at 378 (for a multitude of reasons, including genetic discrimination, perceptions of testing and psychological impact); see also Adya, *supra* note 51, at 278-79.

61. See also Schneider, *supra* note 56, at 377.

gitimate purposes.<sup>62</sup> Ironically, this is precisely the type of research that is necessary to find new treatments and to improve our understanding of genetic diseases.<sup>63</sup> This may also affect the development of new genetic tests.<sup>64</sup> In the late 1990s, investors were warned that genetic discrimination may affect investment in biotechnology.<sup>65</sup> Consequently, the biotechnology industry is generally supportive of genetic nondiscrimination legislation because of their increasing reliance upon genetic testing, pharmacogenomics, population-based genetic research, and innovative genetic technologies.<sup>66</sup>

#### *D. Reinforcement of Ethnic/Racial/Group Stereotypes*

Much like other physical characteristics, genes define one's race, ethnic background, sex, and possibly sexual orientation.<sup>67</sup> Therefore, genetic research associated with such groups has the potential to reinforce group stereotypes.<sup>68</sup> Historically, ethnic and racial discrimination have even been "justified" by genetic research.<sup>69</sup> For example, Nazi atrocities, sterilization policies, and Eastern European immigration restrictions in the 1920s were justified by genetic findings during the eugenics movement.<sup>70</sup> Today, Ashkenazi Jewish, African-

62. OFFICE OF MANAGEMENT AND BUDGET, STATEMENT OF ADMINISTRATIVE POLICY, S. 306 – GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005 (Feb. 16, 2005), available at <http://www.whitehouse.gov/omb/legislative/sap/109-1/s306sap-s.pdf>.

63. *Id.*

64. Janet Brewer, "Diseases of Place": Legal and Ethical Implications of Surname and Ethnicity as Predictors of Disease Risk, 9 QUINNIPIAC HEALTH L. J. 155, 170-171 (2006).

65. *Id.* at 170-71.

66. *Id.* at 171 ("Laboratory Corporation of America (LabCorp), one of the largest providers of genetic testing services in the United States, has recognized the potential for genetic discrimination and has endorsed appropriate policies to protect individuals. To that end, LabCorp was a cosignatory of a letter supporting genetic nondiscrimination legislation in the United States House of Representatives posted by the Genetic Alliance in 2005.").

67. THE COUNCIL FOR RESPONSIBLE GENETICS, DO GENES DETERMINE WHETHER WE ARE LESBIAN, GAY, BISEXUAL, OR STRAIGHT?, available at <http://www.gene-watch.org/programs/privacy/gene-sexuality.html> (position paper) (last visited Feb. 15, 2007).

68. *The Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing before the Subcomm. on Commerce, Trade and Consumer Prot. of the H. Comm. on Energy and Commerce*, 106th Cong. (July 11, 2001) (testimony of KAREN H. ROTHENBERG), available at <http://energycommerce.house.gov/107/Hearings/07112001/hearings322/Rothenberg521.htm>, cited in *FACES*, *supra* note 1, at 14.

69. *Id.*

70. *Id.*, ELOF CARLSON, SCIENTIFIC ORIGINS OF EUGENICS, available at <http://www.eugenicsarchive.org/html/eugenics/essay2text.html> (last visited Aug. 30, 2007) ("The eugenics movement arose in the 20th century as two wings of a common philosophy of human worth. Francis Galton, who coined the term eugenics in 1883, perceived it as a moral philosophy to improve humanity by encouraging the ablest and healthiest people to have more

American, and Native-American communities have all raised concerns over research implying genetic tendencies towards violence, alcoholism, or genetic abnormalities suggesting racial or ethnic inferiority.<sup>71</sup>

In one prime example of genetic discrimination, states instituted mandatory sickle cell anemia screening programs for African-Americans in the 1970s, even though other races and ethnicities were at risk for the disease.<sup>72</sup> A seemingly innocent screening program designed to protect anemics was used for racially discriminatory ends.<sup>73</sup> Screening programs identified both individuals with sickle cell anemia and healthy carriers of one sickle cell gene that could not develop the disease.<sup>74</sup> Test results were not confidential.<sup>75</sup> Healthy carriers were subsequently stigmatized and discriminated against in employment and health insurance.<sup>76</sup> As a result, Congress passed the National Sickle Cell Anemia Control Act in 1972, barring states from receiving federal funds unless their sickle cell screening programs are voluntary.<sup>77</sup> Similar discriminatory programs could be implemented today with respect to other genetic conditions.

#### IV. THE FINDINGS/MOTIVATION: INADEQUATE LEGAL PROTECTIONS

Sufficient legal protections against genetic discrimination did not exist at law prior to the Genetic Information Nondiscrimination Act.<sup>78</sup> Although certain federal statutory schemes may apply to genetic

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children. The Galtonian ideal of eugenics is usually termed positive eugenics. Negative eugenics, on the other hand, advocated culling the least able from the breeding population to preserve humanity's fitness. The eugenics movements in the United States, Germany, and Scandinavia favored the negative approach.”)

71. *The Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing before the Subcomm. on Commerce, Trade and Consumer Prot. of the H. Comm. on Energy and Commerce*, 106th Cong. (July 11, 2001) (testimony of KAREN H. ROTHENBERG), available at <http://energycommerce.house.gov/107/Hearings/07112001hearings322/rothenberg521.htm>, cited in *FACES*, *supra* note 1, at 14.

72. *FACES*, *supra* note 1, at 14 (“At that time, scientists had raised concerns that individuals with sickle cell anemia carried a heightened risk from some workplace toxins.”) available at <http://www.genome.gov/10002401>.

73. *Id.*

74. *Id.*

75. *Id.*

76. *Id.*

77. 42 USCS § 300(b)(1) (omitted in the general revision of Title XI of the 1944 Act by Act April 22, 1976).

78. See generally Robert B. Lanman, *An Analysis of the Adequacy of Current Law in Protecting Against Genetic Discrimination in Health Insurance and Employment* (May 2005), available at [http://www4.od.nih.gov/oba/SACGHS/reports/legal\\_analysis\\_May2005.pdf](http://www4.od.nih.gov/oba/SACGHS/reports/legal_analysis_May2005.pdf) (In 2005, the Health and Human Services Secretary's Advisory Committee on Genetic, Health

discrimination, the protections are limited and it is uncertain how courts will interpret these laws in the context of genetic information.<sup>79</sup> In addition, state genetic nondiscrimination laws vary widely in their approach, application, and level of protection.<sup>80</sup> The federal government assessed how the following laws could protect individuals from genetic discrimination and found that each law was inadequate.

### *A. Constitutional Right to Privacy*

In *Norman-Bloodsaw v. Lawrence Berkeley Lab*, the Ninth Circuit Court of Appeals found a constitutional right to privacy of genetic information. In this case, employees at a research facility underwent genetic testing for sickle cell anemia without their knowledge.<sup>81</sup> The court held that the employee's right to privacy of their genetic information is protected under the Fourth Amendment searches and seizures and under the Fifth and Fourteenth Amendment Due Process Clauses.<sup>82</sup> The court held that the analysis of a bodily sample to obtain physiological data involves a search and seizure of information over which a person has a legitimate expectation of privacy.<sup>83</sup> The court specifically stated that there are "few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up."<sup>84</sup>

However, the Ninth Circuit remanded the case to determine whether the defendant company had any interest in obtaining the genetic information.<sup>85</sup> While it is uncertain what level of constitutional scrutiny this issue will encounter (rational basis, intermediate, or strict scrutiny), the court's decision suggests that a state's interests may

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and Society commissioned a paper to study the adequacy of current law in protecting against genetic discrimination in health insurance and employment. The Department of Justice, Department of Labor, Equal Opportunity Commission, Centers for Medicare & Medicaid Services and Office for Civil Rights assisted in the development of this report. Findings from this paper were used to support and develop the Genetic Information Nondiscrimination Act. The paper contains much background material on anti-discrimination laws as they may apply to genetic discrimination.)

79. See generally Lanman, *supra* note 78, at 20.

80. See, e.g., Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. (2008).

81. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998) at 1265; Lanman, *supra* note 78, at 20.

82. *Norman-Bloodsaw*, 135 F.3d at 1268-1270; Lanman, *supra* note 78, at 21.

83. *Norman-Bloodsaw*, 135 F.3d at 1270 n.13, cited in Lanman, *supra* note 78, at 21.

84. *Norman-Bloodsaw*, 135 F.3d at 1268-1270; Lanman, *supra* note 78, at 20.

85. *Id.*

outweigh a claim of privacy of genetic information.<sup>86</sup> In addition, such constitutional protections only apply to government action, and therefore private employers and insurance companies are immune from suit under constitutional privacy claims.<sup>87</sup>

*B. The Americans with Disabilities Act and The Rehabilitation Act*

Federal laws that prohibit disability discrimination, such as the American's With Disabilities Act (ADA)<sup>88</sup> and the Rehabilitation Act (RA),<sup>89</sup> provide partial protections to genetic discrimination. These statutes prohibit discrimination based on the existence or perception of a disability. The ADA is applicable to private employers having fifteen or more workers, labor organizations, employment agencies, and state and municipal government agencies,<sup>90</sup> while the RA applies to federal employers only.<sup>91</sup>

In 2001, the U.S. Equal Employment Opportunity Commission (EEOC) settled the first lawsuit directly alleging genetic discrimination in employment under the ADA.<sup>92</sup> In *Burlington Northern Santa Fe (BNSF) v. EEOC*, BNSF Railroad tested its employees without their knowledge for a genetic condition that causes carpal tunnel syndrome.<sup>93</sup> BNSF additionally threatened one employee with termination when they refused to comply.<sup>94</sup> According to the EEOC, the genetic tests were unlawful under the ADA because they were not job-related,

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86. *Norman-Bloodsaw*, 135 F.3d at 1275, cited in Lanman, *supra* note 78, at 21. In *Whalen v. Roe*, a case cited extensively by *Norman-Bloodsaw* the Supreme Court found that a constitutional right to privacy of medical information exists, but a state's interest in access to such information outweighs that right. *Whalen v. Roe*, 429 U.S. 589 (1977), cited in Lanman, *supra* note 78, at 21. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1265 (9th Cir. 1998); Lanman, *supra* note 78, at 20.

87. See *Norman-Bloodsaw*, 135 F.3d at 1269, cited in Lanman, *supra* note 78, at 21; U.S. CONST. AMEND IV.

88. 42 U.S.C. § 12102.

89. 29 U.S.C. § 79.

90. 42 U.S.C. § 12102.

91. 29 U.S.C. § 791.

92. *EEOC v. Burlington Northern Santa Fe Railroad*, Civ. No. 01-4013 MWB (N.D.L.A. April 23, 2001) (Agreed Order); see also JEAN P. KAMP, EEOC PETITIONS COURT TO BAN GENETIC TESTING OF RAILROAD WORKERS IN FIRST EEOC CASE CHALLENGING GENETIC TESTING UNDER AMERICANS WITH DISABILITIES ACT (Feb. 9, 2001), <http://www.eeoc.gov/press/2-9-01-c.html>; see also JEAN P. KAMP, EEOC AND BNSF SETTLE GENETIC TESTING CASE UNDER AMERICANS WITH DISABILITIES ACT (MAY 8, 2002), <http://www.eeoc.gov/press/5-8-02.html>.

93. *EEOC*, Civ. No. 01-4013 MWB; Lanman, *supra* note 78, at 17.

94. *Id.*

and conditioning employment on genetic test results constituted disability discrimination.<sup>95</sup>

While the ADA and RA may be applied in genetic discrimination cases, the scope of their protections is limited. First, the statutes define a disability as a substantially limiting impairment.<sup>96</sup> To be substantially limiting, a disability would have to be expressed in the past or present.<sup>97</sup> Therefore, neither statute would protect currently healthy individuals with genes that increase their susceptibility to certain disorders.<sup>98</sup> Second, these statutes only limit how an employer uses genetic information. They do not prevent employers from generally inquiring about genetic information.<sup>99</sup> An employer could potentially require genetic tests as a condition of employment and not extend offers to those with genetic traits that the employer deems undesirable.<sup>100</sup>

The affect of the ADA on genetic discrimination in health insurance is more tenuous. While the ADA regulates insurance offices as places of public accommodation, the Supreme Court has not spoken as to whether the ADA regulates the content of insurance policies, such as cost or coverage limitations.<sup>101</sup> Therefore, the ADA may not prevent issuers of health insurance from using genetic information to alter enrollment policies or the terms and conditions of a health insurance policy.

### *C. Health Insurance Portability and Accountability Act of 1996*

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is the only statute that directly prohibits certain uses of genetic information.<sup>102</sup> It directly prohibits group health plans from using genetic information to increase the cost of health insurance, or lim-

95. *Id.*

96. Lanman, *supra* note 78, at 13; see also Nat'l Human Genome Research Inst., *Existing Federal Anti-Discrimination Laws and How They Apply to Genetics*, available at <http://www.genome.gov/12513979> (last visited Jan. 5, 2007) [hereinafter *Existing Fed. Anti-Discrim. Laws*].

97. 42 U.S.C. § 12102.

98. Lanman, *supra* note 78, at 13; see also *Existing Fed. Anti-Discrim. Laws*, *supra* note 96.

99. Lanman, *supra* note 78, at 13.

100. Lanman, *supra* note 78, at 12-13; see also *Existing Fed. Anti-Discrim. Laws*, *supra* note 96.

101. 42 U.S.C. 12181(7)(F); Lanman, *supra* note 78, at 5.

102. 29 U.S.C. § 1181; 42 U.S.C. § 300; 26 U.S.C. § 9801.

it or deny individuals coverage.<sup>103</sup> HIPAA also prohibits group health plans and health insurers from treating genetic information as preexisting conditions, unless an individual is diagnosed with a medical condition that is related to the genetic information.<sup>104</sup>

Unfortunately, HIPAA protections against genetic discrimination in health insurance fail in several ways. First, while prohibiting individual cost increases, HIPAA does not prevent insurance providers from charging entire groups of individuals more or increasing an employer's overall premium based on genetic information.<sup>105</sup> Second, while HIPAA prevents an issuer of insurance from denying a policy to a small employer because of an enrollee's genetic information, this prohibition does not apply to large employers.<sup>106</sup> Third, HIPAA does not apply to insurance policies for individuals, which includes 10-15% of people with health insurance.<sup>107</sup> Finally, HIPAA does not prohibit employers from denying insurance coverage to any individuals.<sup>108</sup>

#### *D. Employee Retirement Income Security Act/Social Security Act*

The ability of the Social Security Act (SSA) to protect against genetic discrimination is especially tenuous. The Employee Retirement Income Security Act sets national standards for Medicare supplemental health insurance policies (Medigap) offered by states and private issuers of health insurance.<sup>109</sup> Medigap issuers may not condition or price Medigap policies based on "health status, claims experience, or receipt of medical care or medical condition" of the applicant.<sup>110</sup> In addition, Medigap may not exclude benefits because of a pre-existing condition.<sup>111</sup> Besides the limited applicability of these policies to Medigap, the statute does not describe and no court has determined

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103. 29 U.S.C. § 1181, 42 U.S.C. § 300, 26 U.S.C. § 9801 (defining preexisting condition, permit preexisting condition exclusions under limited circumstances and allow for the portability of health insurance plans); *see also Existing Fed. Anti-Discrim. Laws, supra* note 96; *see also Lanman, supra* note 78, at 2.

104. 29 U.S.C. § 1181(b)(1)(B); 42 U.S.C. § 300(b)(1)(B); 26 U.S.C. § 9801(b)(1)(b); *see also Existing Fed. Anti-Discrim. Laws, supra* note 96; *see also Lanman, supra* note 78, at 2.

105. Lanman, *supra* note 78, at 3.

106. 45 C.F.R. 146.150; *see also Lanman, supra* note 78, at 3.

107. Lanman, *supra* note 78, at 4.

108. *Existing Fed. Anti-Discrim. Laws, supra* note 96; *see also Lanman, supra* note 78, at 4.

109. *See Lanman, supra* note 78, at 5.

110. 42 U.S.C. § 1395ss(s)(2)(A); 42 U.S.C. § 1395ss(s)(3)(A); *see also Lanman, supra* note 78, at 5.

111. 42 U.S.C. § 1395(s)(3)(A)(iii); Lanman, *supra* note 78, at 5.

how, if at all, these restrictions apply to genetic information.<sup>112</sup> Therefore, even Medigap may not protect its own policyholders from genetic discrimination.

### *E. Title VII of the Civil Rights Act of 1964*

Title VII of the Civil Rights Act of 1964 prohibits discrimination on the basis of race, color, religion, sex, and national origin in employment.<sup>113</sup> Title VII protects against genetic discrimination where group identities<sup>114</sup> are used as a proxy to discriminate against individuals with genetic predispositions.<sup>115</sup> In *Norman-Bloodsaw v. Lawrence Berkeley Lab*, the court found that testing African-American's exclusively for sickle cell disease violated Title VII because the research facility singled out African-Americans on the basis of race.<sup>116</sup> However, Title VII protections are limited because most genetic disorders do not disproportionately affect a protected class such as African-Americans.<sup>117</sup> Therefore, Title VII offers little protection from employment discrimination for many individuals.

### *F. State Statutory Protections*

Thirty-four states have passed some form of legislation that prohibits genetic discrimination by employers.<sup>118</sup> However, the form and function of these laws vary extensively.<sup>119</sup> While many states bar discrimination based on genetic testing, not all states bar discrimination based on other sources of genetic information such as family history.<sup>120</sup> Even fewer states restrict employer access to genetic information in the first place.<sup>121</sup> Only fourteen states prescribe specific penalties for genetic discrimination by employers.<sup>122</sup>

112. Lanman, *supra* note 78, at 5.

113. 42 U.S.C. § 2000; Lanman, *supra* note 78, at 19.

114. Such as race, color, religion, sex, and national origin.

115. Lanman, *supra* note 78, at 19.

116. *Norman-Bloodsaw*, 135 F.3d (similarly holding that pregnancy testing discriminated against women and pregnant women); Lanman, *supra* note 78, at 19.

117. *See comment supra* 34.

118. ALISSA JOHNSON, STATE GENETICS EMPLOYMENT LAWS, NATIONAL CONFERENCE OF STATE LEGISLATURES, (November 2006), available at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>.

119. *Id.*

120. *Id.*

121. *Id.*

122. *Id.*



Similarly, while a majority of states enacted laws that restrict genetic discrimination by health insurers, their form, function and applicability vary extensively.<sup>123</sup> Some anti-insurance discrimination statutes may govern individual insurance policies, and not group insurance, or vice versa.<sup>124</sup> These statutes can never apply to employer-sponsored health benefit plans because these plans are governed solely by the federal government.<sup>125</sup> These statutes also vary in the types of activities they restrict, such as conditioning insurance coverage and cost on genetic information or requiring genetic testing.<sup>126</sup> Few states have statutes that restrict genetic discrimination in life, disability and long-term care insurance.<sup>127</sup> In addition, variations in individual state laws give insufficient warning to insurers and employers operating across state lines, creating high transaction costs associated with determining the scope of individual state statutes.<sup>128</sup>

## V. THE SOLUTIONS

### *A. What Kind of Response Was Necessary?*

Some critics continue to argue that genetic discrimination is an acceptable insurance and employment practice.<sup>129</sup> Their reasoning is that genetic risk is no different from other risks that employers and insurers have a right to know about, and therefore, patients should fully disclose their genetic information to employers and insurers.<sup>130</sup> It must be stressed that the science of genomics is still evolving as is our understanding of genetic predisposition to certain disease. Therefore, genetic markers are not always accurate predictors of disease.<sup>131</sup> Once again, genetic background is an unacceptable form of classification because a person has a right not to be classified for insurance or employment purposes unless the classification corresponds to an accurate

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123. ALISSA JOHNSON, GENETICS AND HEALTH INSURANCE STATE ANTI-DISCRIMINATION LAWS, NATIONAL CONFERENCE OF STATE LEGISLATURES (June 2005), <http://www.ncsl.org/programs/health/genetics/ndishlth.htm>.

124. *Id.*

125. *Id.*

126. *Id.*

127. *Id.*

128. See JOHNSON, *supra* note 118.

129. See Epstein *supra* note 139; see Kathleen Taradash, *Preventing a Market for "Lemons": A Voluntary Disclosure Model as an Alternative to the Prohibition of Genetic Discrimination and the Distortion of Allocative Efficiency*, 34 CONN. L. REV. 1353, 1353 (2002).

130. *Id.*

131. *Id.*

and predictable risk.<sup>132</sup> Given the seriousness of genetic discrimination<sup>133</sup> and the incomplete protections of federal and state laws,<sup>134</sup> the federal government passed the Genetic Information Nondiscrimination Act.

### *B. Genetic Information Nondiscrimination Act*

The Genetic Information Nondiscrimination Act (GINA) is a comprehensive bill that prohibits employment and insurance discrimination based on genetic information.<sup>135</sup> In general, the act bars group health plans and health insurers from conditioning the health insurance of healthy individuals based solely on genetic information.<sup>136</sup> The legislation would also bar employers from hiring, firing, placing, or making promotional decisions based solely on an individual's genetic information.<sup>137</sup> The Act fills in many of the missing gaps in the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act and Title XVIII of the Social Security Act relating to Medigap.<sup>138</sup>

#### *1. Prohibitions Against Health Insurance Discrimination*

GINA amends several of the previously mentioned statutes<sup>139</sup> to protect against genetic discrimination in health insurance. Most importantly, the statute amends ERISA, the Public Health Service Act, the Internal Revenue Code, and portions of the Social Security Act relating to Medigap.<sup>140</sup> First, it bars group health plans and issuers of health insurance from restricting health insurance enrollment because of the receipt or requests for genetic testing either by an individual or their family member.<sup>141</sup> Second, group health plans and issuers of health insurance may not use genetic information to adjust premiums

132. Jill Gualding, *Race, Sex, and Genetic Discrimination in Insurance: What's Fair?*, 80 CORNELL L. REV. 1646, 1648 (1995) (noting that efficient discrimination is the idea that accurate indicators of risk should be used in businesses founded on risk assessment).

133. See discussion *supra* Part III.

134. See discussion *supra* Part IV.

135. H.R. 493, 110th Cong. (2008).

136. *Id.* § 101-105.

137. *Id.* § 201-205 (2008).

138. H.R. 493, 110th Cong. (2008).

139. See discussion *supra* Part IV.

140. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 101-104 (2008).

141. *Id.*

or health insurance pricing.<sup>142</sup> Third, these entities may not request or require genetic testing for participants or beneficiaries.<sup>143</sup> ERISA applies these prohibitions to small group plans, while the PHSA is applicable to individual insurance plans and non-federal governmental plans.<sup>144</sup> GINA outlines several enforcement mechanisms.<sup>145</sup> The Act also gives federal agency secretaries the power to impose monetary penalties for not complying with this Act.<sup>146</sup> GINA also applies similar prohibitions to issuers of Medigap policies.<sup>147</sup>

First, group health plans, health insurance issuers, or issuers of Medigap may not use or disclose genetic information to underwrite, determine enrollment eligibility and rate premiums, or to create, renew, or replace a plan, contract, or coverage for health insurance or health benefits.<sup>148</sup> These entities also may not request, require, or purchase genetic information for such purposes.<sup>149</sup> They may not request, require, or purchase genetic information prior to the enrollment of an individual under their respective plan, coverage, or policy.<sup>150</sup> The Act provides for an enforcement mechanism of the above provisions.<sup>151</sup>

## 2. Prohibitions Against Employment Discrimination

GINA includes several provisions that prohibit employers as well as employment agencies, labor organizations, and joint labor-management committees<sup>152</sup> from discriminating against employees or members because of their genetic information.<sup>153</sup> GINA prohibits a wide range of discriminatory practices, including failing to hire an individual, discharging an employee, binding employees to discriminatory terms of employment, failing or refusing to refer an individual for employment, expelling a member, causing or attempting to cause an

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142. *Id.*

143. *Id.*

144. *Id.*

145. *Id.*

146. *Id.*

147. *Id.* § 104.

148. Genetic Information Nondiscrimination Act, H.R. 493, 110th Cong. § 104 (2008).

149. *Id.*

150. *Id.*

151. *Id.* § 105.

152. *Id.* § 202 (“(2) EMPLOYEE; EMPLOYER; EMPLOYMENT AGENCY; LABOR ORGANIZATION; AND MEMBER- The terms-- (A) ‘employee,’ ‘employer,’ ‘employment agency,’ and ‘labor organization’ have the meanings given such terms in section 701 of the Civil Rights Act of 1964 (42 U.S.C. 2000e); and (B) ‘employee’ and ‘member,’ as used with respect to a labor organization, include an applicant for employment and an applicant for membership in a labor organization, respectively.”).

153. *Id.* § 202-205.

employer to discriminate, or refusing admission to or employment in an apprenticeship or other training program on the basis of genetic information.<sup>154</sup> These employment agencies, labor organizations, or joint labor-management committees may not use genetic information to limit, segregate, or classify individuals in any way that would deprive them of employment opportunities or adversely encroach upon their employment status.<sup>155</sup> In addition, these entities may not request, require, or purchase an employee's genetic information, except to comply with other statutory requirements or to monitor the biological effects of toxic substances in the workplace.<sup>156</sup>

Should an employer, employment agency, labor organization, or joint labor-management committee possess the genetic information of an individual, they must treat the information as a confidential medical record and keep it in separate files.<sup>157</sup> These entities may only disclose such information "(1) to the employee or member upon request; (2) to an occupational or other health researcher; (3) in response to a court order; (4) to a government official investigating compliance with the Genetic Nondiscrimination Act if the information is relevant to the investigation; or (5) to comply with other statutory requirements."<sup>158</sup> Provisions for enforcement are included.<sup>159</sup>

Under this Act, disparate impact<sup>160</sup> does not establish a cause of action.<sup>161</sup> However, the Act establishes the Genetic Nondiscrimination Study Commission to review developments in genetics and to make recommendations to Congress on whether to provide a disparate impact cause of action.<sup>162</sup>

154. *Id.*

155. *Id.*

156. *Id.* (may be requested or required to comply with the certification provisions of the Family and Medical Leave Act of 1993 or such requirements under State family and medical leave laws).

157. *Id.* § 206.

158. *Id.*

159. *Id.* § 207.

160. *Caron v. Scott Paper Co.*, 834 F. Supp. 33, 36 (1993) ("The disparate impact mode of analysis permits a plaintiff to recover for employment practices that are facially neutral in their treatment of different groups but that in fact fall more harshly on one group than another and cannot be justified by business necessity. Disparate impact claims assess the effects, rather than the intent, of the practices, procedures, or tests neutral on their face.").

161. H.R. 493, 110th Cong. § 208 (2008).

162. *Id.*

*C. The Next Step: Regulating Group-Identity Genetics Research*

Genetics has the ability to improve the public health, but it can also affect our understanding of ethnicity and race. While members of a race or ethnic group may have certain genetic similarities, these groups are impossible to distinguish from each other on the genetic level.<sup>163</sup> However, many scientists and clinicians continue to isolate races and ethnic groups in their genetic studies for a number of reasons.<sup>164</sup> First, a researcher may study a particular group if its members exhibit high levels of a particular disease.<sup>165</sup> Second, restricting research to a particulate population can improve the results of certain studies, especially those involving the identification of a gene.<sup>166</sup> Finally, researchers have isolated racial and ethnic groups for non-medical reasons, such as to study evolution.<sup>167</sup>

Such studies may not only improve our understanding of genes, race and ethnicity, but they may lead to stereotyping and affect relations between these groups.<sup>168</sup> This holds especially true if the results of such studies are “tainted by racialization, historical attempts at eugenics, and the potential abuse of genetics targeting groups partially defined by superficial genetic characteristics.”<sup>169</sup> For such reasons, research shows that African-Americans are more likely to oppose group-identity based genetics research.<sup>170</sup> In addition, negative attitudes towards group-identity based genetics research reduces the willingness to undergo genetic testing, which are the precise results that legislation like GINA was trying to prevent.<sup>171</sup>

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163. GENETIC RESEARCH: RACE, ETHNICITY & DISEASE: HANDBOOK FOR COMMUNITY ORGANIZATIONS 13, available at [http://www.societyandmedicine.columbia.edu/genetics\\_cobook\\_3.shtml](http://www.societyandmedicine.columbia.edu/genetics_cobook_3.shtml) (last visited May 18, 2008).

164. *Id.*

165. *Id.* (“For instance, many studies investigating the genetic basis of diabetes are conducted in Native-American and Alaska Native tribes where the incidence of the disease is high. In such cases researchers may target the group in order to best address a pressing health need. They may also target the group to increase the chance that a disease gene will be identified.”).

166. *Id.*

167. *Id.*

168. L. Allen Furr, *Perceptions of Genetics Research As Harmful to Society: Differences among Samples of African-Americans and European-Americans*, 6(1) *Genetic Testing* 25, 25 (2002).

169. *Id.*

170. *Id.*

171. *Id.*

While Congress and policymakers are directly addressing employment and insurance discrimination,<sup>172</sup> less drastic measures have been undertaken to address the reinforcement of ethnic, racial, and other group stereotypes. The use of racial, ethnic, and gender categories in genetics research, when combined with environmental, behavioral, and psychological studies, may provide a better understanding of common diseases and health disparities between such groups.<sup>173</sup> In addition, regulation may have the effect of stunting research, much of which is funded and conducted by the National Institutes of Health (NIH), the agency that envisioned and was the primary supporter of GINA.<sup>174</sup>

At this moment in time, the scientific community is taking small steps to self-regulate. NIH has developed the Guidance for Genetic Research.<sup>175</sup> NIH opposes genetic research that may reinforce harmful stereotypes about particular populations or communities.<sup>176</sup> However, NIH guidance only regulates NIH-funded research.<sup>177</sup> In addition, these guidelines do not delineate what types of group-identity based research<sup>178</sup> would reinforce harmful stereotypes, most likely because the answer would differ on a case-by-case basis.<sup>179</sup>

Several scientific journals have issued their own genetics research guidelines maintaining that researchers should carefully define their descriptions of populations to avoid reinforcing stereotypes, and reduce the use of group identities as proxies to describe certain popula-

172. See discussion *supra* Part V.B.

173. See Race, Ethnicity and Genetics Working Group, *The Use of Racial, Ethnic, and Ancestral Categories in Human Genetics Research*, 17 American J. of Human Genetics 519, 519 (2005).

174. Genetic Discrimination, <http://www.genome.gov/10002077> (last visited May 19, 2008) (“In the mid 1990s, the National Institutes of Health-Department of Energy (NIH-DOE) Ethical, Legal and Social Implications (ELSI) Working Group and the National Action Plan on Breast Cancer (NAPBC) cosponsored workshops on genetic discrimination in health insurance and the workplace. The findings and recommendations of the workshops were published in *Science*. They are the foundation for policy-making in the Executive branch, and for legislation at both the state and federal level.”).

175. NIH COMMITTEE ON SCIENTIFIC CONDUCT AND ETHICS, NIH GUIDELINES FOR RESEARCH, CHAPTER 24: GUIDANCE FOR GENETIC RESEARCH 12 (2007) (source on file with author).

176. *Id.*

177. See Nat’l Human Genome Research Inst., *Policy and Program Analysis Branch*, available at <http://www.genome.gov/10001087> (last visited Jan. 2007).

178. Group-identity based research being defined as any research based on racial, ethnic, and gender categories.

179. See NIH COMMITTEE ON SCIENTIFIC CONDUCT AND ETHICS, NIH GUIDELINES FOR RESEARCH, CHAPTER 24: GUIDANCE FOR GENETIC RESEARCH 12 (2007) (source on file with author).

tions unless it is deemed necessary.<sup>180</sup> Some scientific journals have asked researchers to justify their use of racial or ethnic groups in research.<sup>181</sup> However, scientific journals have not consistently enforced these guidelines.<sup>182</sup> Nor do such journals provide any real regulatory oversight that can stop or redirect research efforts.

The National Bioethics Advisory Commission recommends an extension of human subject research protections to social groups, not just individuals.<sup>183</sup> The commission proposes that investigators and ethics review boards “a) work directly with community representatives to develop study methods that minimize potential group harms, b) discuss group implications as part of the informed consent process, and c) consider group harms in reporting research results.”<sup>184</sup> Again, at this stage, these recommendations are only recommendations.

Federal and state legislators have infrequently stepped in to regulate the actual content of biomedical research, but it is not unheard of in the genomic era.<sup>185</sup> These instances have been limited to extremely controversial types of genetic research, like cloning and stem cell research. It remains to be seen to what extent group-identity based research will reinforce stereotypes and how, if at all, such research could be regulated without destroying the rewards it reaps. As our understanding of the human genome improves, as well as its impact on medical research, these issues must be addressed.

## VI. CONCLUSION

Genetic discrimination is a serious issue, not only to individuals with genetic predispositions to disease, but also to their families, their communities, the scientific community, and the biotechnology and pharmaceutical industries.<sup>186</sup> Because of the negative implications of genetic discrimination resulting from a lack of adequate legal protections, Congress passed the Genetic Information Nondiscrimination

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180. See Race, Ethnicity and Genetics Working Group, *supra* note 178, at 527.

181. *Id.*

182. *Id.*

183. Richard R. Sharp and Morris W. Foster, *Community involvement in the ethical review of genetic research: lessons from American Indian and Alaska Native populations*, 110(2) *Environmental Health Perspect* 145, 145 (2002).

184. *Id.*

185. See generally Nat'l Human Genome Research Institute, Welcome to the NHGRI Policy and Legislation Database, available at <http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm> (database contains genetics legislation from all fifty states, the federal government, as well as other sources).

186. See discussion *supra* Part III.

Act.<sup>187</sup> Only with such protections will people be willing to undergo genetic testing to inform themselves about their genetic predispositions to certain disease so they may take a more proactive role in their health care.<sup>188</sup> While the Genetic Information Nondiscrimination Act is a major success for individuals, families, and the public health community alike, additional steps should be taken to assure that genetic research does not lead to population-wide racial, ethnic or sexual discrimination.<sup>189</sup> This would bring genetic nondiscrimination efforts full circle and protect individuals from misconceptions with eugenic roots.<sup>190</sup>

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187. See discussion *supra* Part IV; see discussion *supra* Part V.A; see discussion *supra* Part V.B.

188. See discussion *supra* Part III.

189. See discussion *supra* Part V.C.

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