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002. list	Genetic Discrimination meeting list of attendees [partial] (1 page)	01/19/2000	P3/b(3)
003. report	Issues discussed in Genetic Discrimination meeting (3 pages)	12/22/1999	P3/b(3)
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NOTES AND COMMENTS: An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress

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SUMMARY: ... The genetic age offers great potential, including a future where gene and germ-cell therapy may virtually eliminate genetic disease. ... Although genetic information will be used to develop revolutionary treatments, such as gene therapy and other molecular medicine, it will also bring genetic discrimination and heretofore unrealized invasions into the privacy of our genetic codes. ... Gene probes look for a base sequence associated with a disease or genetic predisposition. ... Concern about continued access to health insurance, and thus health care, is a major reason for many genetic discrimination bills. ... Genetic test results do not accurately indicate health risk because such testing fails to provide information about a person's "actual state of health." ... Two federal laws that fill some of the legislative gaps left by state genetic discrimination laws include the Americans with Disabilities Act of 1990 (ADA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA). ... Moreover, genetic discrimination bills introduced in both Congresses similarly define genetic information, genetic test, insurer and other terms necessary for effective prohibition of genetic discrimination. ... Many of the genetic discrimination bills introduced by the 104th Congress also prohibited employers from altering health benefits offered on the basis of genetic information. ...

TEXT: [*443]

It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness ... it was the spring of hope, it was the winter of despair ... we were all going direct to Heaven, we were all going direct the other way. n1

----------Footnotes----------

n1. Charles Dickens, A Tale of Two Cities 1 (Running Press 1986) (1859). This passage provides an apropos introduction into human genetics and the ramifications such knowledge will have. Although it is the genetic "age of wisdom" because of potentially life-saving scientific discoveries, it is also the "age of foolishness" because of our failure to safeguard ourselves from our own designs. Thus, "the double helix reflects the hopes and fears of an age." Richard Saltus, Sounding the Alarm Like Splitting the Atom, Boston Globe Mag., May 26, 1996, at 14.

----------End Footnotes----------

- Charles Dickens

I. INTRODUCTION

The Human Genome Project (HGP) n2 provides information about the human genome that will forever alter society and the way we view ourselves. n3 The genetic age offers great potential, including a future where gene and germ-cell therapy may virtually eliminate genetic disease. n4 However, genetic information may also result in [*444] a world

characterized by genetic discrimination and genetic determinism. n5 Although genetic information will be used to develop revolutionary treatments, such as gene therapy and other molecular medicine, it will also bring genetic discrimination and heretofore unrealized invasions into the privacy of our genetic codes. n6

----------Footnotes----------

n2. See Human Genome Project, About the Human Genome Project (last modified Sept. 2, 1998) <http://www.ornl.gov/TechResources/Human<uscore>Genome/home.ht ml> (describing the Human Genome Project (HGP) as "an international 15-year effort formally begun in October 1990 to discover all the 60,000 to 80,000 human genes (the human genome) and make them accessible for further biological study").

n3. See Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing on H.R. 2748 Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 9 (1996) (statement of Rep. Louise Slaughter) [hereinafter Slaughter Testimony] (stating that "our genes represent the most personal, private, and fundamental aspects of ourselves. They are inescapable; they cannot be concealed, disguised or avoided. They are the ultimate identification and definition of who we are .... Research efforts like the Human Genome Project are unlocking the secrets of our genes on an almost daily basis.").

n4. See Kathy L. Hudson et al., Genetic Discrimination and Health Insurance: An Urgent Need to Reform, 270 Science 391, 391 (1995); see also David Suzuki & Peter Knudtson, Genethics: The Clash Between the New Genetics and Human Values 165-66 (rev. ed. 1990) (predicting that gene therapy - the medical repair or replacement of defective genes in human living cells - will become a reality).

n5. The motion picture Gattaca provides an excellent glimpse into the future of genetic discrimination and subsequent genetic determinism - where people's lives are preordained by their genome. See Bob Kurson, Dabbling in DNA: "Gattaca' Director Exploring Ethics, Chi. Sun-Times, Nov. 16, 1997, at 7, available in *1997 WL 6379554.* Gattaca is "a journey into a world where humans are judged not by their characters but by their genes." Id. This journey describes a world where parents genetically engineer their children, selecting traits such as intelligence, attractiveness and near perfect health. See Kathi Wolfe, Genetic Engineering: Two Sides of the Coin, Las Vegas Rev.-J., Nov. 28, 1997, at 15B, available in *1997 WL 4558846.* Vincent, the genetically inferior protagonist, is doomed to remain a second-class citizen because of poor vision and heart disease resulting from his natural conception. See Roger Ebert, Future Tense: "Gattaca" Sees Flaws in a Perfect World, Chi. Sun- Times, Oct. 24, 1997, at 35, available in *1997 WL 6375250.* The antagonist, Hugo, is Vincent's genetically engineered, and thus superior, brother. See id. In a society predicated on "prejudice with a scientific basis," genetically inferior Vincent is an "in-valid" destined for menial jobs and low class status. See Rene Downing, "Gattaca' Premise: Future's Not in Stars, but in Our Genes, Ariz. Daily Star, Nov. 20, 1997, at 1C, available in *1997 WL 7934923.* Therefore, to avoid genetic stigmatization, Vincent undertakes an elaborate conspiracy to assume the identity of Jerome, a genetically superior "valid" left lame by a car accident. See id. Vincent pays Jerome for his skin cells, blood, urine, hair and other bodily products used for genetic identification through genetic testing. See id. Finally, against all odds, Vincent achieves his life-long dream of becoming an astronaut, a position reserved for the genetically superior because of the substantial investment involved. See id. Gattaca, whose title is comprised of the letters G, T, C, and A, which represent the four nitrogenous bases making up deoxyribonucleic acid (DNA), is a "vision of a possible high-tech-militarized-corporate future" with elements of Aldous Huxley's "social-control dystopia," Brave New World. See id.

n6. See Hudson et al., supra note 4, at 391; see also Privacy, Confidentiality and Discrimination in Genetics, 1997: Hearing on H.R. 272 before the Task Force on Health Records and Genetic Privacy of the House Comm. on Commerce, 105th Cong. 10 (1997) (statement of Francis Collins, Director, National Center for Human Genome Research) [hereinafter Collins 1997 Testimony] (stating that "as knowledge grows about the genetic basis of diseases, so too does the potential for discrimination and stigmatization based on genetic information"). Genetic discrimination has been defined as "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests." Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, *17 Am. J.L. & Med. 109, 110 (1991).*

----------End Footnotes----------

Congress and the state legislatures have proposed and enacted legislation to prevent potential abuses of genetic information. n7 However, genetic discrimination legislation n8 enacted thus far leaves several legislative loopholes permitting genetic discrimination. n9 Furthermore, many existing genetic discrimination laws leave unaddressed the issues of genetic privacy and autonomy. n10 Consequently, closing [*445] these gaps will require additional legislation.

----------Footnotes----------

n7. See Hudson et al., supra note 4, at 392; see also Collins 1997 Testimony, supra note 6, at 19 (reporting that 19 states enacted laws restricting the use of genetic information in health insurance and that at least 31 states have introduced laws prohibiting genetic discrimination in insurance). For a discussion of state and federal legislation targeting abuse of genetic information, see infra Part VI.

n8. Genetic discrimination legislation is being used to refer to legislation protecting genetic privacy and prohibiting discrimination. See Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 9 (1996) (statement of Alan Goldhammer, Director of Technical Affairs, Biotechnology Industry Organization) (noting that Congress intends to prevent unauthorized use or dissemination of genetic information and use of such information to discriminate against individuals seeking health insurance).

n9. See Hudson et al., supra note 4, at 392 (stating that existing state genetic discrimination laws leave some people unprotected because the Employee Retirement Income Security Act of 1974 (ERISA) preempts state regulation of self-funded plans, and because many state laws focus narrowly on mandatory genetic testing rather than more broadly on the use of genetic information); see also infra notes 196-203 and accompanying text (discussing shortcomings of current state genetic discrimination legislation).

n10. See, e.g., Eric Mills Holmes, Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project, *85 Ky. L.J. 503, 647* (1996-97).

----------End Footnotes----------

This Note focuses on genetic testing and discrimination legislation. Part II provides a brief description of the HGP and developments in genetic science. Parts III and IV respectively discuss arguments for and against legislation regulating the use of genetic information. Part V discusses the need for legislation to prevent abuse of genetic information, including a discussion of the various genetic discrimination bills proposed by the 105th Congress. Finally, Part VI concludes that legislation is necessary: to prohibit genetic discrimination by employers and health insurers; to protect individuals' genetic privacy from unauthorized disclosure of genetic information; to protect people from mandatory genetic testing; and to regulate the collection, use, storage and distribution of genetic information. Specifically, this Note argues that Congress should enact the Genetic Privacy and Nondiscrimination Act of 1997 n11 or the Genetic Confidentiality and Nondiscrimination Act of 1997. n12 These bills should be reintroduced and enacted by a subsequent session of Congress because the 105th Congress failed to enact either bill. n13

----------Footnotes----------

n11. H.R. 341, 105th Cong. (1997).

n12. S. 422, 105th Cong. (1997).

n13. Thus far, Congress has failed to enact either bill. Search of WESTLAW, Bill Tracking (Nov. 8, 1998).

----------End Footnotes----------

II. THE HGP AND ADVANCES IN GENOMIC RESEARCH FUEL CONCERN FOR GENETIC DISCRIMINATION

The HGP n14 is a federally funded project coordinated by the National Institutes of Health (NIH) and the U.S. Department of Energy. n15 Established in 1990, the HGP is scheduled to meet its goal of mapping the entire human genome by 2005. n16 Furthermore, the HGP produces genetic maps and the technology required to store [*446] systematically the vast amounts of information contained in the human genome. n17 However, deoxyribonucleic acid (DNA) structural information revealed by the HGP "is only the beginning of biological interpretation," as scientists must then determine what the "[instructions] encoded in human DNA mean." n18

----------Footnotes----------

n14. The HGP is a collaboration among many independent international research institutions with the common goal of analyzing the human DNA structure and mapping and sequencing the estimated 100,000 human genes. See Holmes, supra note 10, at 517. The Human Genome Organization (HUGO), a private organization, coordinates genomic research conducted in the United Kingdom, Canada, France and Japan. See id. at 506 n.2. For discussion about the history of the HGP, see id. at 517 n.26. Further information about the HGP is available online at Human Genome Project Information (visited Nov. 18, 1998) <http://www.ornl.gov/TechResources/ Human<uscore>Genome/home.html>.

n15. See Ari Patrinos & Daniel W. Drell, Introducing the Human Genome Project: Its Relevance, Triumphs and Challenges, Judges' J., Summer 1997, at 5, 6. The HGP will cost the federal government an estimated three billion dollars. See Holmes, supra note 10, at 518. This amounts to more than 20% of all biomedical research funding. See Catherine M. Valerio Barrad, Comment, Genetic Information and Property Theory, *87 Nw. U. L. Rev. 1037, 1042 n.19 (1993);* see also Susan O'Hara, The Use of Genetic Testing in the Health Insurance Industry: The Creation of a "Biologic Underclass," *22 Sw. U. L. Rev. 1211, 1215 (1993)* (discussing the HGP's $3 billion price tag).

n16. See Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 2 (1996) (statement of Francis Collins, Director, National Center for Human Genome Research) [hereinafter Collins 1996 Testimony]. However, some experts have predicted that the HGP may map 99% of the human genome with 99.9% accuracy by the year 2002. See Holmes, supra note 10, at 516; see also Patrinos & Drell, supra note 15, at 6. The human genome is defined as "all the information stored in a complete strand of human DNA ... [including] the three billion base pairs comprising roughly 100,000 genes." Holmes, supra note 10, at 521. The HGP's goal is to "develop efficient, cost-effective detailed genetic and physical maps of the human genome, determine the complete nucleotide sequence of human DNA, and create the new technology required to fulfill its purpose." Id.; see also Barrad, supra note 15, at 1042-43 (describing the HGP as a fifteen-year project with approximately five percent of the total three billion pairs of nucleotides identified in 1993).

n17. See Collins 1996 Testimony, supra note 16, at 1.

n18. See id. at 3.

----------End Footnotes----------

The human genome n19 is comprised of forty-six chromosomes n20 grouped into twenty-three pairs, n21 and is contained in "each somatic n22 human cell." n23 Chromosomes contain strands of DNA in the shape of a double helix. n24 These strands of DNA are called chromatin n25 and are "composed of four kinds of molecular sub-units called nucleotides." n26 Scientists estimate that the human genome contains three billion nucleotide base pairs, n27 and that these base pairs are divided into [*447] between 50,000 and 100,000 genes. n28 Genes n29 chemically encode hereditary information by "determining the production of proteins which, in turn, determine the function of each cell and, ultimately an individual's traits." n30 Consequently, genes are responsible for a person's genotype, which represents the "actual genes carried by an individual (as distinct from phenotype, the physical characteristics into which genes are translated)." n31

----------Footnotes----------

n19. See Holmes, supra note 10, at 520 (defining genome as "the totality of the genetic information that is stored in cells and passed from one generation to the next ... [which] determines how cells behave and how complex organ systems interact...."); see also Mahlon Hoagland & Bert Dodson, The Molecules of Life, Judges' J., Summer 1997, at 11, 11 (suggesting that if DNA is compared with language, then "there are four ... letters (nucleotides, or bases)

arranged in paragraphs of 1,000 to 2,000 letters (genes), thence books of a million letters each (chromosomes), thence a library (genome). Our human library contains 46 books."). See generally A Genetic Glossary for Judges, Judges' J., Summer 1997, at 65, 65 [hereinafter Judges' Glossary] (defining key terms used in genetics).

n20. See Judges' Glossary, supra note 19, at 65 (defining chromosomes as "structures found in the nucleus of a cell that contain the genes. Chromosomes come in pairs, and a normal human cell contains forty-six chromosomes, twenty-two pairs of autosomes, and two sex chromosomes."). Human chromosomes range in size from 50 to 250 million nucleotide base pairs. See Richard A. Bornstein, Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes, 4 J.L. & Pol'y 551, 556 (1996).

n21. See Holmes, supra note 10, at 521.

n22. For a good discussion of the difference between somatic and zygotic cells, see Barrad, supra note 15, at 1042 n.20.

n23. See id. at 1042.

n24. The double helix model of DNA was first proposed in 1953 by James Watson, Rosalind Franklin and Francis Crick. See Holmes, supra note 10, at 519. Watson's 1961 discovery of DNA's genetic code subsequently led to the recognition that "DNA's linear arrangement of paired bases in triplets provides the blueprint for protein synthesis." See id. at 519-20. The double helix model of DNA "looks much like a ladder that has been twisted." See id. at 521. The "rungs of the ladder" are the base pairs formed from the "bonding of the four chemical [nucleotide] bases." See id.

n25. See Suzuki & Knudtson, supra note 4, at 31.

n26. See id. at 32. Furthermore, "each nucleotide contains a sugar, a phosphate, and one of four kinds of nitrogen containing bases: adenine (A), guanine (G), cytosine (C), and thymine (T)." Id. The genetic code utilizes these four nucleotides as the chemical instructions for hereditary information. See Holmes, supra note 10, at 521. Nucleotides are complementary, so that pairs are either A-T or C-G base pairs. See id. Moreover, DNA sequences, or ordering of the nucleotides, are composed of three nucleotide units called codons. See id. Sixty-four codons comprise the entire genetic code responsible for making twenty different amino acids, which are the basic building blocks of living organisms. See id. Actually, only 61 codons are responsible for instructing the production of 20 amino acids, and the three remaining codons are "regulatory" or "stop" signals. See Hoagland & Dodson, supra note 19, at 13; see also Suzuki & Knudtson, supra note 4, at 43 tbl. 2.1 (listing the codons in the genetic code and resultant amino acids). Furthermore, "variations in the linear ordering of the [nucleotide] bases make up different genetic sequences." Bornstein, supra note 20, at 556. Consequently, the "body "reads' these [nucleotide] base pairs in groups of three [i.e. codons], and since every sequential triple identifies a specific amino acid, the body will string together amino acids to form the protein or other bodily chemical dictated by that particular sequence of triple base pairs." Barrad, supra note 15, at 1042.

n27. See Suzuki & Knudtson, supra note 4, at 305; see also Judges' Glossary, supra note 19, at 65 (defining base pairs as "two complementary, nitrogen rich molecules held together by weak chemical bonds. Two strands of DNA are held together in the shape of a double helix by the bonds between their base pairs."). Furthermore, each letter in each base pair "is the chemical complement of the letter opposite it.... [and the nucleotide bases], held together by weak bonds, can separate, have new chains laid down along them, and so be perfectly reproduced." Hoagland & Dodson, supra note 19, at 11.

n28. See T.H. Cushing, Should There be Genetic Testing in Insurance Risk Classification?, 60 Def. Couns. J. 249, 250 (1993). However, despite the existence of approximately three billion base pairs in the human genome, "most of the DNA in our chromosomes is not genes. We don't know what the function of the excess DNA is." See Hoagland & Dodson, supra note 19, at 11; see also Denise K. Casey, What Can the New Gene Tests Tell Us?, Judges' J., Summer 1997, at 14, 15 (noting that genes "are interspersed among millions of bases of DNA that do not code for proteins (noncoding DNA) and whose functions are largely unknown. In fact, genes constitute only a tiny fraction of the human genome, a mere 3 percent.").

n29. See Judges' Glossary, supra note 19, at 65 (defining genes as "units of inheritance; a working subunit of DNA ... [with each gene] containing the code for a specific product, typically a protein ....").

n30. Holmes, supra note 10, at 519. For a good description of the interaction between genes and proteins, see Hoagland & Dodson, supra note 19, at 11-13 (noting that "proteins are workers, machinery; they do life's jobs. Genes are information molecules; they carry life's ideas. This relationship between genes and proteins is recursive: the two are locked together in a single, interdependent system.")(emphasis in the original).

n31. See Judges' Glossary, supra note 19, at 66; see also Suzuki & Knudtson, supra note 4, at 344-46 (defining genotype and phenotype, respectively).

----------End Footnotes----------

Genomic research primarily focuses on mapping the human genome, or "the process of assigning genes to specific chromosomes." n32 Genetic mapping determines where genetic loci are relative to each other "on the basis of how often they are inherited together." n33 As of October 1998, maps to all forty-six human chromosomes have been drawn. n34 Nonetheless, despite the rapid sequencing of the human genome, "fewer than one percent of the more than three billion base pairs comprising the human genome have been sequenced." n35

----------Footnotes----------

n32. O'Hara, supra note 15, at 1213.

n33. Id. A genetic locus is an identifiable area or "marker" on a chromosome indicating that a specific trait will be expressed by the gene. See id.

n34. See Holmes, supra note 10, at 522-23. Detailed genetic maps of the 46 human chromosomes can be found at A Gene Map of the Human Genome (visited Nov. 18, 1998) <http://www.ncbi.nlm.nih.gov/genemap98>.

n35. Holmes, supra note 10, at 523.

----------End Footnotes----------

HGP research constantly leads to "the discovery of particularized genes responsible for certain diseases." n36 These diseases have "a molecular mechanism of pathology at the gene and protein levels" n37 and are caused by genetic mutation. n38 Although "some hereditary diseases can be explained by a single gene, or [*448] monogenic, n39 defect .... the majority of genetic diseases are multifactorial, [or are] caused by the interaction of environmental factors and numerous abnormal genes ... on different chromosomes." n40 Gene mapping associates diseases with genes. n41 Consequently, "high quality [genetic] maps have dramatically sped up the discovery of disease genes," n42 and hasten the day when such knowledge will be used systematically to eliminate genetic disease. n43

----------Footnotes----------

n36. O'Hara, supra note 15, at 1213. Genomic research "suggests that specific genes or groups of genes predispose individuals to some forms of cancer, emphysema, juvenile diabetes, Alzheimer's disease, ... heart disease and mental illness." Id. Moreover, "genes have been identified that are associated with breast cancer, cystic fibrosis, [and] skin cancer ...." Slaughter Testimony, supra note 3, at 7. Daily updates regarding genetic discoveries may be found on the Internet at The Institute for Genomic Research (visited Nov. 18, 1998) <http://www.tigr.org>.

n37. See Holmes, supra note 10, at 522. More than 5,000 diseases currently affect over half of the population of the United States. See Bornstein, supra note 20, at 557.

n38. See Judges' Glossary, supra note 19, at 66 (defining mutation as "[a] change in the number, arrangement, or molecular sequence of a gene"). Most genetic mutations are in-consequential. For example, "changes in an amino acid here and there in proteins whose key function is unaffected." Hoagland & Dodson, supra note 19, at 13. Yet, some genetic mutations "are detrimental [because] they alter an amino acid at a vulnerable location in a protein." Id.; see also Casey, supra note 28, at 16 (discussing the role genetic mutation plays in disease pathology).

n39. Monogenic disorders are relatively rare, comprising only three percent of all diseases. See Casey, supra note 28, at 16 (discussing monogenic disorders, including sickle cell anemia, cystic fibrosis (CF), Huntingtons disease (HD) and Tay-Sachs disease).

n40. Holmes, supra note 10, at 522. See Bornstein, supra note 20, at 557-59; see also O'Hara, supra note 15, at 1219 (stating that the "manifestation of genetic disease also depends upon specific genes acting in concert with other genes [because] neighboring genes have various effects upon one another ... creating yet another variable in the manifestation of disease").

n41. See Collins 1996 Testimony, supra note 16, at 28 (stating that "As a result of the Human Genome Project, new disease genes are discovered almost weekly. Once a disease gene is identified, it is often only a matter of months before a diagnostic test can be made available.").

n42. Casey, supra note 28, at 17.

n43. See Roberta M. Berry, The Human Genome Project and the End of Insurance, 7 U. Fla. J.L. & Pub. Pol'y 205, 206-07 (1996).

----------End Footnotes----------

Although the HGP's immediate goal is to "describe the human genome in molecular detail, its longer term goal and more profound impact will be to reveal critical mechanisms of human biology and supply the medical context within which investigations on the molecular pathology of human diseases can most efficiently take place." n44 Consequently, gene mapping technology "will lead to a future medicine in which prevention will be firmly rooted in mechanistic knowledge and potential interventions can be more targeted and effective." n45 Thus, mapping the human genome is only the HGP's penultimate goal. n46 The ability to take information about the human genome and to develop viable gene therapies for most, if not all disease, is the ultimate goal of the HGP. n47 Although gene therapy "technology itself still faces many obstacles before it can become a practical approach for treating disease," n48 DNA testing has "hastened the day when gene therapy - the medical replacement or repair of defective genes in living human cells - will become a reality." n49

----------Footnotes----------

n44. Patrinos & Drell, supra note 15, at 6.

n45. Id. In other words, medical diagnostics will vastly improve "by monitoring human DNA variability and correlating it with patients' therapeutic responsiveness, [creating] new methods for treating or curing diseases." Jim Graves, Should Evolution be Guided by Genetic Control?: University Lecture Wrestles with Ethics of Tomorrow's Biomedicine, B.U. Bridge, Oct. 24, 1997, at 3.

n46. The HGP's penultimate goal, by definition, must be realized before the ultimate goal. In other words, "once the human genome has been deciphered, medical researchers intend to use the information to cure genetically-based diseases by designing interventions to prevent the manifestation of these diseases." Holmes, supra note 10, at 518.

n47. The ultimate goal of the HGP has been described as "an attempt to erase the uncertainty of humankind regarding genetic illness." O'Hara, supra note 15, at 1214; see also Casey, supra note 28, at 19 (stating that gene therapy "holds great potential for treating or even curing genetic and acquired diseases, using normal genes to replace or supplement a defective gene or bolster immunity to disease"). Over 150 clinical gene therapy trials were in progress as of summer 1997, mostly involving different kinds of cancers. See id.; see also Patrinos & Drell, supra note 15, at 6-7 (discussing the future of medicinal applications of genomic research).

n48. Casey, supra note 28, at 82; see also Leslie Sowers, The Basics on Genes, Houst. Chron., Aug. 17, 1997, at 1, available in *1997 WL 13056793* (stating that a "genetic cure for a disease will take much more knowledge and experimentation" because scientists need to learn "how to send a correct version of the instructions into the body on a cellular level and get the corrected version to keep reproducing itself").

n49. Suzuki & Knudtson, supra note 4, at 166 (emphasis in the original); see also Barrad, supra note 15, at 1043 (noting that "identifying the genetic cause of disease could suggest new methods of treatment, aid early identification, or lead to eradication of the syndrome through gene therapy").

----------End Footnotes----------

[*449] Genetic testing bridges the gap between contemporary disease gene mapping and the future development of gene therapies, because once disease genes or their approximate chromosomal regions are identified, academic and commercial laboratories will develop gene tests to detect the mutations associated with a disease. n50 After accurate genetic tests are developed, "commercial efforts will shift away from diagnostics and toward developing a new generation of therapeutics based on genes." n51 Gene testing involves an analysis of bodily tissue or fluid, usually blood, for any genetic abnormalities. n52 Genetic technicians take extracted DNA and map the individual's base sequence in order to compare it with known sequences on HGP-created gene maps to determine whether the individual's DNA contains any differences in the base sequence. n53 There are two types of gene tests: n54 gene probes n55 and genetic marker or linkage tests. n56 Gene probes look for a base sequence associated with a disease or genetic predisposition. n57 Linkage tests involve analysis of chromosome segments containing a gene suspected to cause a disease. n58 Moreover, linkage tests require testing several generations of a family with a history of genetic disease to determine whether inheritance of the DNA segment correlates with inheritance of the disease. n59 Although direct gene probes are easier to perform and more accurate than linkage tests, the probes are available for fewer diseases because of their research intensive nature. n60 The price of genetic tests vary between several hundred and several thousand dollars, depending on the sizes of the genes and the number of mutations tested. n61 Genomic discoveries and improved methods [*450] for developing genetic tests decrease the cost of such tests. n62 Thus, reducing the cost of genetic testing will soon make widespread genetic testing feasible. n63 Consequently, the likelihood of universal genetic testing raises many ethical issues regarding such testing. n64

----------Footnotes----------

n50. See Casey, supra note 28, at 17-19; see also Berry, supra note 43, at 206-07 (stating that with the "knowledge gained from the HGP, diagnostic tests for genetic defects will soon be widely available, and cures for diseases caused by these genetic defects will follow").

n51. Casey, supra note 28, at 19.

n52. See Holmes, supra note 10, at 524; Cushing, supra note 28, at 250. Gene testing is defined as an examination of "a sample of blood or other body fluid or tissue for biochemical, chromosomal, or genetic markers that indicate the presence or absence of genetic disease." Judges' Glossary, supra note 19, at 66; see also Casey, supra note 28, at 18-19 (discussing gene tests for HD, CF, Alzheimer's disease and breast cancer). For a table listing diseases for which gene tests were available as of 1996 in New York State approved clinical laboratories, see Casey, supra note 28, at 15.

n53. See Cushing, supra note 28, at 250-51. Genetic technicians accomplish genetic screening by testing the DNA "in blood cells to determine the presence of certain genetic markers associated with various genetic diseases." Naomi Obinata, Comment, Genetic Screening and Insurance: Too Valuable an Underwriting Tool to be Banned from the System, 8 Santa Clara Computer & High Tech. L.J. 145, 148 (1992).

n54. See Suzuki & Knudtson, supra note 4, at 145-47.

n55. A gene probe is defined as a "specific sequence of single-stranded DNA, typically labeled with a radioactive atom, which is designed to bind to, and thereby single out, a particular segment of DNA." Judges' Glossary, supra note 19, at 67. Gene probes involve researchers designing "short pieces of DNA, called probes, whose sequences are complementary to the mutated sequences. These probes will seek their complement among the three billion base pairs of an individual's genome. If the mutated sequence is present in the patient's genome, the probe will bind to it and flag the mutation." Casey, supra note 28, at 17.

n56. A linkage test is defined as a "gene-hunting technique that traces patterns of heredity in large, high risk families, in an attempt to locate a disease-causing gene mutation by identifying traits that are co-inherited with it." Judges' Glossary, supra note 19, at 66.

n57. See Cushing, supra note 28, at 251.

n58. See id.

n59. See id. at 251-52.

n60. See id. at 252. Because of the complexity in determining which sequence of base pairs causes a particular disease, diseases must be studied extensively in order to develop gene probes. See id. at 251. Consequently, gene probes are fewer in number than less research intensive linkage tests. See id.

n61. See Casey, supra note 28, at 17.

n62. See Gostin, supra note 6, at 116.

n63. See id. at 116-17.

n64. See O'Hara, supra note 15, at 1215; Holmes, supra note 10, at 518-19.

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Genomic information produced by the HGP implicate myriad ethical, social and legal issues. n65 Concerns over the possible ramifications concerning HGP research and subsequent discoveries about the human genome led to the development of a program to address the ethical, legal and social implications (ELSI) of genomic research. n66 Congress allocates between three percent and five percent of the HGP's $3 billion budget for ELSI. n67 ELSI represents the first coordinated effort to address the ethical, legal and social implications of scientific research conducted prior to the conclusion of such research. n68 Although access to an individual's genetic defect may prove advantageous to the patient for diagnostic purposes, the risk of access by commercial entities, particularly insurance companies, n69 consternates researchers, academics and legislators alike. n70

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n65. See Patrinos & Drell, supra note 15, at 8 (discussing issues including: (1) fair use of genetic information; (2) impact on genetic counseling and medical practice; (3) effects on personal reproductive decisions; (4) past uses and abuses of genetic information; (5) privacy implications of personal genetic information; and (6) commercialization and intellectual property protection of genome results); see also Holmes, supra note 10, at 519-20 (discussing the patentability of DNA sequences identified by the HGP); James E. Bowman, The Road to Eugenics, 3 U. Chi. L. Sch. Roundtable 491, 491 (1996) (discussing the possibility of a new eugenics movement); Wendy McGoodwin, A Look at ... DNA Dilemmas, Wash. Post, May 5, 1996, at C3 (describing the situation where an health maintenance organization (HMO) told a pregnant woman whose fetus tested positive for CF that the HMO would not cover the infant under the family's medical policy if the expectant mother chose to carry the pregnancy to term).

n66. See Patrinos & Drell, supra note 15, at 8.

n67. See O'Hara, supra note 15, at 1215; Holmes, supra note 10, at 518-19.

n68. See id. (noting that "the ELSI program can contribute to the integration of HGP results in ways that are less disruptive, painful, or destructive than [the manner in which genetic information has been used] in the past").

n69. See O'Hara, supra note 15, at 1215.

n70. See Paul Recer, Group Warns Against Genetic Bias, Denv. Post, Mar. 21, 1997, at A14, available in *1996 WL 6067905* (noting concerns expressed by researchers); Slaughter Testimony, supra note 3, at 10 (discussing several cases of genetic discrimination by health insurers); Nancy E. Kass, The Implications of Genetic Testing for Health and Life Insurance, in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era 299, 299 (Mark A. Rothstein ed., 1997) (noting concerns expressed by academics).

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III. CONSEQUENCES OF THE HGP

Technological advances in genomic researchand electronic manipulation of information make access to genetic information potentially unlimited. n71 Furthermore, a "generally porous medical information system in which the traditional norm of confidentiality has all but deteriorated," inadequately protects privacy interests in medical records. n72 Concerns about maintaining the privacy, [*451] integrity and accuracy of genetic information are further exacerbated by the establishment of genomic databases such as the Genome Data Base (GDB), a global repository for genome mapping data. n73 For example, genetic databases containing identifiers linking individuals with their genetic traits would seriously jeopardize genetic privacy. n74 Consequently, as detailed genetic information becomes widely available, many "entities would have a financial stake in obtaining this information." n75

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n71. See Barrad, supra note 15, at 1047; Paul A. Lombardo, Genetic Confidentiality: What's the Big Secret?, 3 U. Chi. L. Sch. Roundtable 589, 589 (1996); see also Patrinos & Drell, supra note 15, at 7-8 (stating that electronic archives facilitate genetic data storage, provide increased access to research results and foster dissemination of information, leading to substantial increases in the number of individuals having access to medical information in electronic form).

n72. Lombardo, supra note 71, at 590; Mark Siegler, Confidentiality in Medicine - A Decrepit Concept, *307 New. Eng. J. Med. 1518, 1518-19 (1982).*

n73. See Patrinos & Drell, supra note 15, at 7. Genomic databases are "informantics tools" developed to manipulate genetic information concerning the human genome, which if printed out in its complete letter sequence would fill 200 major city phone books. See id. at 7-8; see also The Consumer Protection and Medical Record Confidentiality Act of 1998: Hearing before the Subcomm. on Gov't Management, Info., and Tech. of the House Comm. on Gov't Reform and Oversight, 105th Cong. (1998) (testimony of Janlori Goldman, Director, Health Privacy Project Institute) (discussing concerns regarding the integrity of genetic information); David Brown, Individual "Genetic Privacy' Seen as Threatened: Officials Say Explosion of Scientific Knowledge Could Lead to Misuse of Information, Wash. Post, Oct. 20, 1991, at A6 (discussing privacy concerns with respect to use of genetic information); Sally Lehrman, Genetic Privacy Debated Rapidly Developing New Technology Raises Questions, S.F. Examiner, Nov. 21, 1990, at B1, available in *1990 WL 7773740* (discussing concerns over the accuracy of genetic information).

n74. See George J. Annas, Privacy Rules for DNA Databanks: Protecting Coded "Future Diaries", *270 JAMA 2346, 2346 (1993).* But cf. Lisa L. Dahm, Using DNA Profile as the Unique Patient Identifier in the Community Health Information Network: Legal Implications, 15 J. Marshall J. Computer & Info. L. 227, 254-55 (1997) (arguing that the effect of electronic medical records and DNA fingerprints on individual privacy would be minimal).

n75. See Mark A. Rothstein, Discrimination Based on Genetic Information, *33 Jurimetrics J. 13, 13-14 (1992)* [hereinafter Jurimetrics] (listing entities interested in receiving genetic information, including insurers, employers, mortgage lenders, educational institutions, adoption agencies, potential business partners and courts involved in custodial disputes).

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Unveiling vast amounts of information about the human genome will invariably lead to various forms of genetic discrimination. n76 Specifically, "employers and insurers may believe that genetic discrimination is warranted for business profitability." n77 Therefore, people taking genetic tests may face a serious risk of genetic discrimination. n78 The risks of discrimination can adversely affect them as well because families share genomic information. n79 The potential abuse of genetic [*452] discrimination in the employment and insurance contexts concerns some scholars, n80 and may be "the civil rights battle of the next century." n81

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n76. Genetic discrimination has been defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal' genome in the genetic constitution of the individual." George P. Smith II, Accessing Genomic Information or Safeguarding Genetic Privacy, 9 J.L. & Health 121, 124 (1994-95) (quoting Marvin R. Natowicz et al., Genetic Discrimination and the Law, 50 Am. J. Hum. Genetics 465, 466 (1992)). Genetic discrimination is not based on any notion of the present function of the individual, because the discriminating party relies on that individual's genotype to assess the probability of future risks. See id. at 124 n.15. For examples of various forms of genetic discrimination, see Berry, supra note 43, at 209; Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 11-12 (1996) (statement of Rep. Jim McDermott) [hereinafter McDermott Testimony].

n77. Smith, supra note 76, at 124. Employers and insurers normally have access to detailed medical records of employees and customers. See id. at 124-25. Consequently, discrimination cases based on "the dissemination of genetic information to official or private entities" will shortly be heard in courts across the country. See Patrinos & Drell, supra note 15, at 5.

n78. See Casey, supra note 28, at 14; see also infra text accompanying notes 82-85 (noting how genetic discrimination may arise).

n79. See Casey, supra note 28, at 14; see also Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 79 (1996) (statement of Karen Rothenberg, Director, Law & Healthcare Program, University of Maryland School of Law) [hereinafter Rothenberg Testimony] (stating that the risk of misusing genetic information is significant and unique because of the information's intergenerational impact); Hudson et al., supra note 4, at 393 (discussing third parties' ability to "obtain sensitive genetic information about individuals, families and even populations").

n80. See Hudson et al., supra note 4, at 391 (describing the plight of a father unable to obtain insurance for his four-year-old son who was fatally diagnosed with a genetic predisposition for long QT syndrome); Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, *29 Hous. L. Rev. 23, 27 (1992)* (reporting on "considerable anecdotal evidence of genetic discrimination in employment"); see also Bornstein, supra note 20, at 564-68 (reporting various studies detailing genetic discrimination by health insurers, concluding that millions of Americans are at risk of losing health coverage as a result of carrying genes that make them vulnerable to diseases); Joyce Lain Kennedy, Genetic Testing in the Workplace Holds Potential for Discrimination, Buff. News, Aug. 23, 1997, at A13 (expressing concerns about the potential impact of employer-mandated testing).

n81. Technological Advances in Genetic Testing: Implications for the Future, 1996: Hearing on H.R. 2690 Before the Subcomm. on Tech. of the House Comm. on Science, 104th Cong. 4 (1996) (statement of Rep. Cliff Stearns) [hereinafter Stearns Testimony].

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Insurers have already genetically discriminated against consumers by declining coverage. n82 The extent and degree of such genetic discrimination by insurers will increase absent preventative legislation because HGP developments in predicting a person's health will greatly affect the pricing and availability of individual and group insurance. n83 Accordingly, several major insurers have made substantial investments in developing genetic tests for potential screening programs and will likely increase such investments as genetic testing of applicants becomes more feasible. n84 Therefore, the HGP and the knowledge that it reveals about the human genome have had, and will continue to have, serious implications for the health insurance industry. n85

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n82. For example, a young attorney from Ohio, Theresa Morelli, was denied disability insurance because her father suffers from HD. See Myk Cherskov, Fighting Genetic Discrimination, A.B.A. J., June 1992, at 38, 38. Although Morelli has not received genetic test results indicating that she has the Huntington's genotype, she has a 50% chance of inheriting the debilitating disorder. See id.; see also Theresa E. Morelli, Genetic Discrimination by Insurers: Legal Protections Needed from Abuse, HealthSpan, Sept. 1992, at 8 (describing Morelli's experience with genetic

discrimination); Bornstein, supra note 20, at 565-66 (describing example of an eight-year-old girl who tested positive for phenylketonuria at birth who was denied insurance, despite the fact that she is asymptomatic).

n83. See Cherskov, supra note 82, at 38; see also O'Hara, supra note 15, at 1220 (noting that genetic discrimination by insurers will likely increase because experts predict genetic screening will seep into insurance underwriting); Morelli, supra note 82, at 10 (stating that unless state and federal laws ban genetic discrimination, insurance companies will continue to insure only the genetically healthy in order to maximize profits).

n84. See Morelli, supra note 82, at 10.

n85. See Berry, supra note 43, at 209. Inevitable genetic discrimination litigation will likely affect insurance industry practices. See George J. Annas, Genetic Prophecy and Genetic Privacy, Trial, Jan. 1, 1996, at 19, 20. Furthermore, the genomic information age may bring other profound changes to the insurance industry. See Berry, supra note 43, at 209. For example, if insurance companies are not given access to genetic information, the consequence may be the end of insurance because insureds predisposed to cost-intensive afflictions will not be assessed a proportional premium and "an adverse selection spiral will result ... [that] may well conclude with the insurance company's insolvency." Id. at 218. However, even if insurance companies have access to the genetic information, the consequence may still be the end of insurance, because the insurance mechanism is premised on the insureds' guarding against financial loss associated with vulnerability and ignorance about diseases, which will inevitably be reduced with increased knowledge through genetic testing. See id. at 209.

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The specter of genetic discrimination by insurers extends beyond the problem of health care availability for genetic discrimination victims. First, people may refuse potentially life-saving genetic testing services because they fear repercussions to their health insurance coverage. n86 Second, cost-containment pressures may [*453] compel insurers to "refuse to pay medical costs if an individual elects not to undergo a certain treatment, or if a child with a prenatally identified genetic defect is born." n87 Fear of genetic discrimination may also chill voluntary participation in genomic research, ironically hampering the research providing insurers with the means to discriminate. n88 Finally, genetic discrimination by employers is a byproduct of genetic discrimination by health insurers. n89

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n86. See Rothstein, supra note 80, at 66-67. Alternatively, some people pay cash for their genetic testing so that no insurance claim is submitted, which keeps insurers and employers ignorant of the existence of any genetic test results that may be used for discriminatory purposes. See id.; see also O'Hara, supra note 15, at 1222 (stating that some people who believe that they may be carriers of disease-causing genes have declined new genetic testing for fear of putting "black marks" on their medical records and losing insurance coverage).

n87. Barrad, supra note 15, at 1046. For a discussion of cost-containment pressures on insurance providers, see Jurimetrics, supra note 75, at 15-16 (reporting the findings of a study indicating that "about 5% of health insurance claimants represent about 50% of healthcare expenditures, while the top 10% of health insurance claimants represent 75% of expenditures. Excluding even a few of these potential claimants could save substantial sums of money [for insurers and self- insured employers]."). See also infra notes 90-92 (discussing cost-containment pressures on employers).

n88. See Stearns Testimony, supra note 81, at 4.

n89. See Barrad, supra note 15, at 1046 (discussing the problem of genetic discrimination by insurers and employers).

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Genetic discrimination by employers "may be viewed as a subset of health based [genetic] discrimination ... [and] is already a significant problem and likely to get much worse because of the economic pressures placed on employers to reduce health care expenditures." n90 A 1990 report issued by the congressional Office of Technology Assessment found that although companies did not intend to screen applicants genetically in the near future, cost-containment

pressures would eventually lead employers to genetically discriminate. n91 Furthermore, employers may genetically discriminate against employees or job applicants for reasons indirectly related to job performance and health care cost containment. n92 Genetic discrimination by employers decreases the availability of health care and thus places [*454] greater strain on the public treasury. n93 Public reaction decrying genetic discrimination prompted state legislators to respond with various genetic discrimination laws and bills. n94

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n90. Rothstein, supra note 80, at 28. For example, from 1985 to 1991, employer health insurance costs per employee increased from $1,724 to $3,605 per year. See id. Moreover, insurance costs continue to increase at least 10% to 20% a year. See id. To streamline costs, "both large, self-insured companies and small-to-medium sized, experience rated companies are acting much like commercial health insurers who have financial incentives to screen out health risks." Id. at 29-30; see also Jurimetrics, supra note 75, at 15 (remarking that "if employers have been placed in the role of health insurance underwriters, then it is hardly surprising that some of them are behaving as an insurance company behaves - limiting costs by excluding those at high risk. Furthermore, if some employers are willing to screen out people based on [risk] factors ... then scientific genetic screening would have great appeal.").

n91. See Rothstein, supra note 80, at 26-28 (discussing the 1989 survey Office of Technology Assessment (OTA) conducted of Fortune 500 companies, large utilities and major unions). This study found that of the 330 companies that responded, only 12 reported using biochemical genetic screening and none anticipated using direct DNA screening over the next five years. See id. at 26. However, OTA's separately published survey data indicated that 42% of employers considered applicants' health risks in hiring decisions. See id. at 27. Additionally, 36% of employers took a proactive role in assessing applicants' health insurance risks. See id. These numbers are evidence of "the growing concern among employers over the rising costs of employee health insurance, and the increased efforts to reduce these costs to the employer, [which is] likely to increase the scope of health insurance screening in the workplace." Id. at 28. Thus, OTA concluded that employers may increase genetic testing to identify applicants with "atypical subsequent health care demands" as a means of health insurance cost-containment. See id. at 27-28.

n92. See Smith, supra note 76, at 125-26. Reasons for genetic discrimination by employers include "increased medical and insurance premiums, absenteeism, lowered productivity, increased risk in the line of duty and increased liability for workers compensation." See id.; see also Melanie Payne, Genetic Fears, Chi. Trib., Apr. 29, 1998, at 7 (quoting Mark Rothstein as stating that "employers have a tremendous economic incentive to discriminate based on perceived future health status ... [because the] key motivation for employers is to save money on health costs").

n93. See Jurimetrics, supra note 75, at 15. If the employment system is unable to create adequate levels of health care coverage, more people will become uninsured, underinsured, or placed on public health finance, leading to more cost-shifting to the remaining private payers underwriting uncompensated care. See id. Furthermore, genetic discrimination "seems to fly in the face of the letter and spirit of our antidiscrimination laws." Id.

n94. See O'Hara, supra note 15, at 1224. See infra Part VI for discussion of various legislative proposals targeting genetic discrimination.

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IV. ARGUMENTS FOR LEGISLATION PROHIBITING GENETIC DISCRIMINATION

Proponents of legislation prohibiting genetic discrimination make several persuasive arguments to support their position. First, they argue that genetic information creates too much potential abuse by insurers and employers. n95 Genetic discrimination by insurers would increase the number of uninsurable people, n96 and would unfairly limit affordable health care to people already genetically predisposed to remain healthy. n97 Likewise, employers may increasingly use genetic tests to screen applicants and employees. n98 Reports of genetic discrimination already abound in the popular press. n99 Consequently, those individuals born with "defective" genes may face denial of both health insurance and employment opportunities, creating a "biologic underclass." n100 Moreover, not only will genetic discrimination deny people employment and insurance, but it may also shift costs onto society. n101

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n95. See Holmes, supra note 10, at 558-63 (discussing abuses by insurers); Katherine Brokaw, Genetic Screening in the Workplace and Employer's Liability, *23 Colum. J.L. & Soc. Probs. 317, 317-18 (1990)* (discussing abuses by employers).

n96. See McDermott Testimony, supra note 76, 11 (stating that "since we all carry some genetic mutations, [the scenario of genetic discrimination by health insurers] carried to its conclusion would leave us all uninsurable").

n97. See Holmes, supra note 10, at 558. Individuals with the least need for health insurance will be able to obtain comprehensive coverage at reasonable rates, whereas those with genetic predispositions for illness may be unable to afford their insurance premiums or may be denied insurance altogether. See id.; see also Berry, supra note 43, at 254 (predicting that as "the HGP progresses and genetic testing advances in its wake, the class of those excluded from the benefits of insurance will grow").

n98. See Barrad, supra note 15, at 1046-47. Employers may attempt to use genetic information to ascertain whether a prospective employee is "predisposed to job- related disabilities, low productivity, or absenteeism." See id. Employers will be increasingly tempted to use genetic screening tests "in the face of pressure from insurers and top management to cut medical costs." See Brokaw, supra note 95, at 318.

n99. See, e.g., Dana Hawkins, Dangerous Legacies: New Gene Tests Provide Fresh Grounds for Discrimination, U.S. News & World Rep., Nov. 10, 1997, at 7; David Stipp, Health: Genetic Testing May Mark Some People as Undesirable to Employers, Insurers, Wall St. J., July 9, 1990, at B1; David Smith, Rite and Reason, Irish Times, June 4, 1996, at 12, available in WL 10575420.

n100. See O'Hara, supra note 15, at 1212. In essence, genetic discrimination by insurers and employers "penalizes those who do not conform to the institutional norm of "healthy' individuals." See id.; see also Brokaw, supra note 95, at 319 (stating that "genetic screening in the workplace has undeniable potential for ... the "leperizing' of hundreds of thousands of American workers ... [and that genetic information could] become a substantial barrier to employment with little basis other than the fears, prejudices and misunderstandings of people who know little about genetics").

n101. See Brokaw, supra note 95, at 320; see also Morelli, supra note 82, at 8 (stating that insurers "shift the risk to individuals and ultimately to the taxpayers when uninsurable and impoverished people are forced onto Medicaid").

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For many people, denial of health insurance may be the equivalent of denying [*455] them health care itself. n102 Denial of insurance based on genetic test results seriously threatens access to health care, n103 something greatly valued by Americans. n104 Concern about continued access to health insurance, and thus health care, is a major reason for many genetic discrimination bills. n105 Therefore, the public policy of maintaining health care access for most Americans represents an underlying rationale for genetic discrimination bills. n106

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n102. See Morelli, supra note 82, at 8.

n103. See id. Because private health insurance is the means by which many Americans pay for health care, genetic discrimination resulting in uninsurability leads to a denial of health care for a large number of people. See Bornstein, supra note 20, at 577; Kass, supra note 70, at 299, 305.

n104. See Alan I. Widiss & Larry Gostin, What's Wrong with the ERISA "Vacuum"?: The Case Against Unrestricted Freedom for Employers to Terminate Employee Health Care Plans and to Decide What Coverage is to be Provided When Risk Retention Plans are Established for Health Care, *41 Drake L. Rev. 635, 636 (1992).*

n105. See Lombardo, supra note 71, at 613. Genetic discrimination is one part of a much larger problem of competitive risk-rating, which puts many potential policyholders beyond the ambit of insurance coverage. See id. Until

this problem is fixed, "the attempt to carve out some portion of the public for unfavorable treatment because of medical condition - genetic or not - will remain endemic." See id.

n106. See Holmes, supra note 10, at 565. If insurers are not permitted to calculate known genetic risks of individuals seeking health insurance coverage in rate setting, then the insurers will be forced to distribute the costs for present and future diseases more evenly among their insureds. See id. at 567.

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The majority of genetic diseases are polygenic n107 and multi-factorial. n108 This complexity undermines the utility of genetic testing because test results may only indicate a predisposition for a disease, not a conclusive diagnosis. n109 Furthermore, genetic tests inaccurately predict "an illness' severity or age of onset," and do not reflect the role environmental factors play in the manifestation of diseases with a genetic component. n110 Therefore, because many people have genes for various diseases that may or may not develop into illnesses, insurers may incorrectly place unwarranted reliance on genetic tests. n111 Genetic tests only indicate a genetic predisposition for disease based on the presence or absence of a specified genotype. n112 The ambiguous nature of the test results, because of the multi-factorial nature of most genetic diseases, strongly supports legislation prohibiting genetic discrimination. n113

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n107. See Suzuki & Knudtson, supra note 4, at 347. Polygenic means "controlled by or associated with more than one gene." See id.

n108. See Holmes, supra note 10, at 527. There are basically four types of genetic anomalies. See id. at 527-29. First, monogenic disorders involve "one improperly functioning gene." See id. at 527-28. Although there are 3,600 monogenic disorders, only "three percent of the population will develop a single gene disease." See id. at 528. Second, chromosomal disorders result from an abnormal chromosomal number or structure (i.e., Down's Syndrome). See id. Third, there are noninherited disorders with "genetic changes occurring during one's [lifetime]," such as cell mutation leading to cancer. See id. at 528-29. Finally, multi-factorial disorders comprise the "largest genetic-disorder classification" and are diseases that "result from the interaction of environmental factors and many abnormal genes presumably on different chromosomes." See id. at 528. Heart disease is an example of a multi-factorial genetic disorder. See id.

n109. See id. at 529. In the majority of cases, the results of genetic tests simply reflect an increased or decreased susceptibility to a particular disease or to diseases associated with environmental influences. See id. Furthermore, despite links made between diseases and genes, "the degree of severity, timing of onset, or whether the disease will ever manifest itself at all, remain a matter of statistical probability." See id. Therefore, most genetic test results reflect probabilities and are less conclusive than one may assume. See id.

n110. See Bornstein, supra note 20, at 569-71.

n111. See O'Hara, supra note 15, at 1218-19.

n112. See Holmes, supra note 10, at 524; Frances H. Miller & Philip A. Huvos, Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act, *46 Admin. L. Rev. 369, 372 (1994).*

n113. See Graves, supra note 45, at 3. For example, gene tests "rarely provide definitive information about the function of particular genes" because they only indicate an abnormality in one gene, and are thus unable to predict the onset of a disease caused by the interaction of several genes. See id.

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[*456] Furthermore, the ambiguities inherent in genetic test results make them unreliable for use in insurance and employment decisions because "insurers may misunderstand, misinterpret, and misuse genetic information in creating risk classifications and excluding or limiting insurance coverages." n114 Genetic test results do not accurately indicate health risk because such testing fails to provide information about a person's "actual state of health." n115 Additionally,

genetic tests are often given greater weight than they deserve, and thus "what frightens many people is that given scientists' limited understanding of how genetic systems work, insurers will misuse genetic information." n116 Genetic tests differ from other medical tests in that they do not reveal existing health problems, only a likelihood of susceptibility. n117 Accordingly, a 1995 report issued by NIH's National Center for Human Genome Research cautioned against over-reliance on genetic test results. n118

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n114. See Holmes, supra note 10, at 530. Historically, misinterpretation and subsequent misuse of genetic information has caused unreasonable discrimination, most notably in the 1970s among the population carrying the sickle cell trait. See Cushing, supra note 28, at 258.

n115. See Holmes, supra note 10, at 530.

n116. Cushing, supra note 28, at 258. Despite their imperfections, genetic tests are accorded an illusion of precision. See O'Hara, supra note 15, at 1215-16. Thus, the danger in genetic testing lies not in the test's imperfect powers of prediction, but rather in the hasty adoption of unreliable test results by "institutions eager to minimize costs [in a health care system where] costs are rising at the rate of twenty percent per annum." See id. at 1216.

n117. See Bornstein, supra note 20, at 559; see also Casey, supra note 28, at 17 (explaining that genetic test results are difficult to interpret because they only provide a predictive guess).

n118. See Holmes, supra note 10, at 530-31. The report further warned against two major misinterpretations of genetic information: reductionism and determinism. See id. at 531. Reductionism occurs when genetic test results reduce particular traits to the "expression of particular genes" and neglect to consider fully the importance of external factors. See id. Determinism occurs when an individual is "inappropriately" labeled as "sick or abnormal." See id.

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Everyone has a few bad genes. n119 Given the universality of genetic defects, genetic discrimination by insurers "will threaten the viability of the insurance industry." n120 As "insurance companies force individuals to gain and reveal knowledge about their health futures," insurers will increasingly eliminate potential insurance consumers. n121 However, assuming that insurers have an interest in balancing genetic information with their financial self-interest, insurers will more likely attempt to use genetic information to eliminate claims rather than consumers. n122 Thus, because everyone has a few bad genes, insurers would not eliminate all insureds from the insurance pool, but would probably eliminate coverage for specific conditions for each insured. n123

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n119. See O'Hara, supra note 15, at 1224. It is estimated that every human being has between four to eight genetic defects. See id.

n120. See Berry, supra note 43, at 232.

n121. See id.

n122. See id. at 236.

n123. See id. at 235-36. For example, insurers may agree to insure an individual genetically predisposed to heart disease, but contractually exclude coverage for claims involving heart disease. See id. The strategy reflects the fact that insurers lack the economic motivation to eliminate every insured with genetic defects because that would completely eliminate the market for insurance, and that insurers have an economic incentive to write as many policies as possible. See id. at 232.

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Insurers contend that the threat of adverse selection makes necessary underwriters' use of genetic information. n124 However, this argument is unpersuasive. [*457] First, if all insurers were denied the use of genetic information, then insurers as a class would be equally subject to the additional costs associated with adverse selection. n125 Thus, if all insurers were proportionally affected by adverse selection, then no single insurer would be at a competitive disadvantage relative to the health insurance industry as a whole. n126 Furthermore, "insurance is a method of risk-sharing against the unknown, and the more the unknown becomes knowable in advance, the less the current system makes sense." n127 Accordingly, the insurance system should be restrucured to accommodate the ability to predict future risks. n128 Denying insurers the use of genetic information provides a powerful economic incentive to develop alternative insurance mechanisms accommodating both insurers' desire to avoid adverse selection and insureds' desire to protect genetic information. n129 The insurance industry must develop a system that spreads genetic risk across the entire pool of insureds to ensure the continued insurability of people with genetic predispositions. n130

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n124. See infra notes 157-62 and accompanying text (discussing the use of adverse selection by insurers).

n125. See Richard H. Underwood & Ronald G. Cadle, Genetics, Genetic Testing, and the Specter of Discrimination: A Discussion Using Hypothetical Cases, *85 Ky. L.J. 665, 686* (1996-97).

n126. See id.

n127. Bornstein, supra note 20, at 609.

n128. See id.

n129. Universal health care may alleviate the problem of adverse selection caused by genetic discrimination legislation. See Bornstein, supra note 20, at 609 n.299. Since medical underwriting is unnecessary in universal health care, it would eliminate the need for the disclosure of genetic information. See id. Insurers could also adopt "genetic community rating," a variant of "community rating." Cf. John V. Jacobi, The Ends of Health Insurance, *30 U.C. Davis L. Rev. 311, 316 (1997)* (discussing use of community rating by Blue Cross in the 1930s). Community rating involves charging all insureds a premium based on the average risk experienced by people living in a particular community. See id. Genetic community rating, however, would only be successful in a competitive insurance market if legislation prevents insurers from using genetic information to offer cheaper insurance to insureds. Cf. Jacobi, supra, at 316 (discussing commercial insurers' attempt to undermine Blue Cross's market by charging low-risk groups based on experience rating rather than community rating). Moreover, insurers could adopt insurance pooling arrangements to cover high-risk insureds. Cf. Robert Lowe, Genetic Testing and Insurance: Apocalypse Now?, *40 Drake L. Rev. 507, 515 (1991)* (discussing state plans pooling those who have been rejected by insurers and whose premiums are exorbitantly high, require insurers to pay into the pool and then charge the insurers a separate fee to make up for any shortfalls in the pool). State legislatures could require insurers to cover a percentage of high- risk insureds in proportion to each insurer's market share thereby eliminating adverse selection. See id. Pooling insurance for genetic risk assumes that genetic information would be available to insurers and would thus be a compromise between absolute genetic privacy and unrestricted access to genetic information. Cf. Holmes, supra note 10, at 543 (suggesting that insurers and insureds should have equal access to relevant genetic data to avoid unfairness to insurers and adverse selection by insureds). Alternatively, insurers could determine the average or median levels of insurance and charge a premium reflecting the increased costs of health insurance associated with adverse selection to all insureds purchasing insurance coverage who fall too far outside of a predetermined range. Cf. id. at 540 (suggesting that rates should discriminate fairly among insureds to reflect their health status).

n130. Otherwise, the people most in need of health insurance will be unable to acquire it. See Cushing, supra note 28, at 257.

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Genetic discrimination unfairly discriminates because of the involuntary and presently immutable nature of our genetic endowment. n131 Accordingly, this immutability provides an inequitable basis on which to make insurance and employment decisions. n132 Furthermore, insurance availability predicated on genetic defects exacerbates the present

inequality of health care distribution n133 by providing [*458] health care to those people least in need of it. n134 It is inherently unfair to require people to pay more for insurance because of poor genetic make-up because the "American concept of fairness centers on our right of voluntary choice and our correlative responsibility for the freedom to choose" and because the human genome is not a product of volition. n135

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n131. See Holmes, supra note 10, at 563-64. However, gene therapies may soon change this immutable nature. See supra notes 48-49 and accompanying text (noting the promise of gene therapy).

n132. See Holmes, supra note 10, at 516. Moreover, because "genetic differences are morally arbitrary, the notion of good or bad genetic luck ought not be the reason that one person receives better or worse insurance" coverage. Id. at 564.

n133. See Hudson et al., supra note 4, at 391. The high costs of health care in the United States make insurance coverage necessary in order to access health care. See id.

n134. See Cushing, supra note 28, at 258. Essentially, ""genetically healthy' people who do not need health insurance will be able to get it at a reduced premium rate, [while] the vast majority who do not need health insurance will not be offered the chance or will not be able to afford what's offered." Id. at 257.

n135. See Holmes, supra note 10, at 563.

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Americans have an expectation of privacy, or the "right to be let alone." n136 Genomic privacy is the right to make an informed determination regarding whether to release genomic information and to whom. n137 The HGP and contemporary technological abilities to store, retrieve and transmit data will seriously challenge our right to genetic privacy, and will likely lead to widespread dissemination of genetic information. n138 Therefore, "the sensitivity of genetic information and the importance Americans historically place on privacy and self-determination argue strongly for a policy that does not hold access to health care hostage to one's willingness to reveal or to discover intimate facts about oneself." n139 Consequently, insurers' access to genetic information threatens genetic privacy and people's right to determine whether they want to be genetically tested.

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n136. See Samuel D. Warren & Louis D. Brandeis, The Right to Privacy, *4 Harv. L. Rev. 193, 193 (1890).*

n137. See Bornstein, supra note 20, at 572; see also Cushing, supra note 28, at 258-59 (noting that "genetic information is fundamentally different from other types of medical information readily accessible to insurers [because] the immutable quality of genetic information sets it apart from other sorts of medical information, such as a person's blood pressure or cholesterol level").

n138. See Annas, supra note 74, at 2346; Holmes, supra note 10, at 570-71. Modern technology provides insurers with practical and possibly clandestine means of obtaining, storing, organizing, retrieving and disseminating genetic and other actuarial data about applicants and policyholders. See Holmes, supra note 10, at 570-71. A "justifiable fear arises that widespread delineation of genotypes and genetic profiles may, like credit information, culminate in centralized genetic information databases." Id.

n139. Holmes, supra note 10, at 565 (quoting NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, National Center for Human Genome Research, Genetic Information and Health Insurance, Report of the Task Force on Genetic Information and Insurance 12 (1993)).

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Autonomy represents an individual's "right not to know" their genetic information. n140 Some choose to avoid knowing their genetic make-up because serious consequences may accompany the acquisition of genomic information. n141 This desire is further exacerbated by the lack of effective treatment for diagnosed diseases and the inability to erase knowledge acquired from genetic test results. n142 Consequently, if insurers and/or employers could mandate genetic testing, individuals would "lose their freedom not to know" their genomic information. n143 Thus, mandated genetic testing threatens autonomy. Mandated testing also forces people to discover genomic knowledge regarding their future lives and deaths. n144 Such revelations may be [*459] damaging to people psychologically if they are unprepared for what they learn about their mortality. n145

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n140. See id. at 574. Genetic autonomy is defined as "the right of persons to make an informed, independent judgment about whether they wish to be tested," including whether they wish to know the results of the genetic test. See Bornstein, supra note 20, at 572.

n141. See Bornstein, supra note 20, at 573.

n142. See id.

n143. See id. at 575.

n144. See Annas, supra note 85, at 19.

n145. See Marilyn Chase, Genetic Testing Needs Clear Plans for How to Handle Treatment, Wall St. J., Feb. 26, 1996, at B1.

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Unregulated access by insurers and employers to genetic information, or their abilities to mandate genetic testing, creates potential psychological harm. n146 Potentially unlimited psychological harms resulting from genetic information abuses include: anxiety caused by inaccurate testing; a stigmatic effect; and the harm caused by revealing information about an individual's immutable genome and, in a sense, their mortality. n147 Unadvised revelation of such information can be devastating, affecting every facet of a person's life. n148

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n146. See Holmes, supra note 10, at 571-72.

n147. See id. at 571-73. Although genomic information is not dispositive of a person's future health, people place the same over-reliance on the value of genetic testing results that insurers and employers do, and may thus cause themselves unnecessary angst. See id. at 572-73. Having knowledge about one's own genetic make-up may have a devastating psychological impact when the individual is told that he or she will develop a fatal, incurable disease. See id. Historical experience with sickle cell anemia in the 1970s exemplifies the psychological damage that injudicious use of genetic information can cause. See id. at 572.

n148. See id. at 573. The genetic information may adversely affect an individual's decisions regarding education, work, marriage and reproduction. See id.

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V. ARGUMENTS AGAINST LEGISLATION PROHIBITING GENETIC DISCRIMINATION

Interest groups, primarily insurers and employers, n149 advocating against legislation prohibiting genetic discrimination "argue that they should not be legislatively prohibited from including genetic test results in their actuarial assessments" and employment decisions. n150 Insurance underwriters n151 attempt to "fairly discriminate" n152 between policyholders to ensure that policyholders presenting [*460] lower risks pay lower premiums. n153 Insurers

contend that genetic information is merely a more refined method of risk classification and therefore more equitable to those insureds posing lower risk. n154 Furthermore, insurers argue that prohibiting the use of genetic information to create accurate risk classifications will ultimately undermine the financial solvency of insurers. n155 Although insurers acknowledge the discriminatory nature of genetic testing in its application to insurance underwriting, they argue that it is a business necessity and that it is "fair discrimination because it is based on sound actuarial analysis." n156

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n149. Although arguments for the right to discriminate genetically against certain individuals are primarily made by insurers, they apply with equal force to employers inasmuch as employers provide health care to employees and are thus similarly interested in containing the cost of health care. See id. at 557. Furthermore, employers are also interested in genetically discriminating against individuals to increase job-related productivity. See Kimberley Nobles, Note, Birthright or Life Sentence: Controlling the Threat of Genetic Testing, *65 S. Cal. L. Rev. 2081, 2089 (1992).*

n150. See Holmes, supra note 10, at 557.

n151. For a general discussion of the mechanics of underwriting in the insurance industry, see Berry, supra note 43, at 216-18, and Roberta B. Meyer, Justification for Permitting Life Insurers to Continue to Underwrite on the Basis of Genetic Information and Genetic Test Results, *27 Suffolk U. L. Rev. 1271, 1279 (1993).* Underwriting is done in the individual insurance market when the "private health insurance industry offers two types of insurance: individual health policies and large employer group health policies." See Holmes, supra note 10, at 533-34. Approximately 90% of private health insurance policies are group policies, with the remaining 10% comprised of individual policies or policies for small groups of fewer than 10 to 15 people. See id. Medical underwriting generally only occurs for individual and small group policies and not for large group policies. See id. at 534. "Because of their ability to average utilization over a large number of employees, large employer groups customarily are not medically underwritten." Id. Moreover, "new employees [working for large employers] are eligible for coverage without medical underwriting by the insurer." Id. The group's insurance premiums will vary based on the group's size because large groups are experience rated, whereby the insureds' premiums change based on their total claims. See id. As such, these large groups are typically not denied health insurance due to the poor health of some employees or their dependents. See id. Hence, "concern over [genetic] discrimination is greatly diminished when medical premiums are based on experience rather than calculated through underwriting." Id.

n152. See Holmes, supra note 10, at 531-34. "Fair discrimination" requires efficient, actuarial analysis establishing risk transference and risk distribution, which are the keys to understanding insurance underwriting. See id. at 531. Insurance, by its nature, is discriminatory because individuals with a higher risk are routinely charged a higher premium. See id. at 533. Consequently, "the goal of insurance underwriting is equity; that is, equitable, but not equal, treatment of applicants and policyholders. To achieve that goal, insurers must differentiate among policyholders by risk classifications and discriminate fairly so that each insured will pay a premium at a level consistent with the risk represented by each individual insured." Id.; see also Obinata, supra note 53, at 146-47 (discussing the necessity of genetic discrimination in the underwriting process to achieve fairness).

n153. See Holmes, supra note 10, at 532.

n154. See id. at 538. However, inasmuch as everyone has a few bad genes, no insured poses an absolutely lower risk, because all insureds pose a greater risk for some disease. See O'Hara, supra note 15, at 1224. Therefore, insurers would refine the risk classification to such a degree either that no insured would be able to afford health insurance or, alternatively, that no insured would be able to get insurance that covers whatever condition an individual insured would be predisposed to suffer. See Holmes, supra note 10, at 558.

n155. See Holmes, supra note 10, at 534-35. Prohibiting insurers' use of genetic information yields two alternative scenarios:

(1) If an insurer under-assesses risks, it will have insufficient funds to pay claims submitted unless it overcharges people who represent low risk. If insurers have inadequate funds and are unable to meet their contractual obligations to

pay claims, the insurers will go bankrupt, leaving people uninsured. (2) If an insurer over-assesses risk and overcharges, the free market and competitive nature of business logically dictate that people will purchase insurance elsewhere. Thus, accurate risk assessment is essential to the business of insurance.

Id. at 538; see also Meyer, supra note 151, at 1279 (discussing the possibility that deficient risk classification systems will make insurers insolvent); Obinata, supra note 53, at 149 (stating that "premium rates must be high enough to assure permanent financial security for the company and, at the same time, low enough to enable the company to be competitive").

n156. See Holmes, supra note 10, at 539 (discussing insurers' arguments supporting the view that genetic tests are efficient and equitably fair). However, the argument for equitable treatment of insureds fails for two reasons. First, risk underwriting is only used for the individual insurance market, which comprises just 10% to 15% of the total insurance market. See id. at 534. This relatively small size undermines the argument that under-assessing insureds will result in financial insolvency for the insurance industry. See id. Rather, insurers may be attempting to hide a naked desire to eliminate expensive policyholders from coverage or at least to limit coverage by excepting an insured's expensive condition. See Jill Gaulding, Race, Sex and Genetic Discrimination in Insurance: What's Fair?, *80 Cornell L. Rev. 1646, 1651-52 (1995)*. Second, if all insurers were denied the ability to use genetic information in their risk classifications, then over-assessing premium rates would not result in a loss of business among insureds because all insurers would be similarly disadvantaged with respect to incorporating genetic information into actuarial analysis. See Jacobi, supra note 129, at 403. Preventing insurers from using genetic information will merely maintain the status quo because insurers have operated profitably for many years without the benefit of genetic information. See, e.g., Philip R. Reilly, Laws to Regulate the Use of Genetic Information, in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era 369, 374-79 (Mark A. Rothstein ed., 1997).

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Logical extension of the equitable treatment argument leads to the argument that prohibiting insurers from obtaining genetic information will encourage adverse selection, n157 which also evokes concerns of unfair subsidization and premonitions of [*461] widespread insurer insolvency. n158 Insurance industry advocates argue that genetic discrimination legislation will create a problem of information inequality between applicants/insureds and insurance companies. n159 Insurers suggest that the resulting imbalance in knowledge will cause them to increase premiums to cover expenses for high-risk insureds who disproportionately buy insurance, thus driving the low-risk insureds out of the market. n160 Consequently, insurers claim that they "would be left with a pool of increasingly unhealthy insureds, many of whom would not be paying appropriately high premiums." n161 Insurers believe that unchecked adverse selection based on an imperfect balance of genetic information will ruin the insurance industry. n162

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n157. Adverse selection is the tendency of insureds to apply for insurance based on the knowledge that the insured is in poor health, while concealing this fact from the insurer. See Cushing, supra note 28, at 254; Berry, supra note 43, at 217; see also Meyer, supra note 151, at 1289 (defining adverse selection as the "tendency of persons who are poorer risks to seek insurance to a greater extent than do persons who are better risks").

n158. See Cushing, supra note 28, at 254-55.

n159. Holmes, supra note 10, at 544.

n160. See Meyer, supra note 151, at 1290. Typically, applicants at a higher risk for a specific disease would be more likely to seek insurance covering that disease than the average person. See Holmes, supra note 10, at 544. "If insurers charge an equitably rated premium without knowledge of the high risk or charge an equal premium for all applicants, the high risk person will select to apply and obtain insurance in greater proportion than low risk people ... [leading to a cycle of] adverse consequences." Id. This cycle starts with increased premiums resulting from greater claims made by high-risk individuals, leading to a discontinuance of insurance by low-risk insureds, which in turn leads to a residual of extremely high-risk insureds, which finally leads to another premium increase that renews the cycle. See id. However, this argument assumes that there are low-risk insureds to drive out of the health insurance market. See O'Hara, supra note 15, at 1224.

n161. Meyer, supra note 151, at 1290.

n162. See Holmes, supra note 10, at 545; see also Berry, supra note 43, at 218 (stating that the genetically spurred "adverse selection price spiral may well conclude with ... [an] insurance company's insolvency").

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However, insurers' adverse selection argument has several problems. First, the adverse selection argument assumes that low-risk insureds will discontinue their insurance coverage because of increased premiums, although there is no explanation of where low-risk insureds would get alternative risk management services. n163 Second, insurers profitably insure the existing pool of insureds, a pool composed of the same low- and high- risk insureds whom they would ensure under a system not based on genetic information. n164 Third, adverse selection would only affect the ten percent of the insurance market that is medically underwritten. n165 Fourth, insurers may pool risk across the individual insurance market insureds because "the actual financial losses for the pool will be close to the aggregate financial losses predicted for the pool by an insurance company." n166 Finally, insurers may limit the effects of adverse selection by [*462] charging higher "unfair" premiums only for policies offering unusually rich benefits that most people would not opt for unless they knew of a genetic defect. n167

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n163. Cf. Jacobi, supra note 129, at 389 (suggesting that "even risk-averse, low-risk people will select the lower price offered by a risk-rated [health insurance policy]" rather than opting for no coverage at all).

n164. See Privacy of Individual Genetic Information, 1998: Hearings on S. 422 Before the Senate Comm. on Labor, 105th Cong. (1998) (statement of Senator Jim Jeffords) [hereinafter Jeffords 1998 Testimony].

n165. See Holmes, supra note 10, at 555; Kass, supra note 70, at 300. Moreover, only a fraction of this 10% slice of the market involves monogenic diseases, see Holmes, supra note 10, at 536, which in turn represent only 3% of diseases. See Casey, supra note 28, at 16. Accordingly, insurers will probably only face increased costs from adverse selection by an extremely small fraction of the insurance market, which would not not be enough to make the industry insolvent.

n166. Berry, supra note 43, at 221.

n167. See Alexandra K. Glazier, Genetic Predispositions, Prophylactic Treatments and Private Health Insurance: Nothing is Better Than a Good Pair of Genes, *23 Am. J.L. & Med. 45, 63-64 (1997);* cf. Kirke D. Weaver, Genetic Screening and the Right to Know, 13 Issues in L. & Med. 243, 249 (1997) (discussing the impact of adverse selection on the insurance industry and the industry's response to the problem).

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Insurers also argue that genetic testing is not significantly different from many types of medical testing already used in underwriting. n168 For example, underwriters presently incorporate medical history and tests as well as other risk factors making illness more or less likely. n169 Therefore, employers and insurers contend that they should be allowed continued access to genetic information that they already have. n170

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n168. See Cushing, supra note 28, at 254.

n169. See Hudson et al., supra note 4, at 391.

n170. See Cushing, supra note 28, at 254.

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In many instances, employers have "assumed the role of the insurance companies and [thus] have a strong financial incentive to reduce their health care expenditures by more accurately assessing health risks." n171 As such, the employers' arguments in favor of genetic discrimination mirror those of the insurance industry. n172 However, inasmuch as employers' interests diverge from those of insurers, they merit discussion. Employers argue that they have traditionally made hiring and promotional decisions "predicated on occupationally-relevant physical and character traits," and that employers should be able to incorporate genetic information in making such decisions. n173 Accordingly, employers contend that access to genetic information constitutes a business necessity in a competitive marketplace. n174 Specifically, employers want genetic information in order to reduce potential costs resulting from their employees' job-related illnesses, absenteeism, sick leave, employee turnover and expenses incurred for employee benefits and retirement programs. n175

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n171. Holmes, supra note 10, at 557.

n172. See Glazier, supra note 167, at 63.

n173. See Holmes, supra note 10, at 556.

n174. See Brokaw, supra note 95, at 326.

n175. See id.

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Employers and insurers make several other arguments in support of their access to genetic information. First, because most insurance is not medically underwritten, most health coverage would be unaffected by the insurers' access to genetic information. n176 Second, insurers and employers contend that they will not rely on genetic tests because the tests' great expense makes them cost ineffective. n177 However, this argument is weakened by the fact that private laboratories already sell genetic tests n178 and that improved technology and market forces will inevitably make genetic tests more affordable. n179 Finally, employers and insurers argue that proposed genetic [*463] discrimination bills define "genetic information" too broadly. n180 Thus, they contend that federal legislation that prevents insurers from using genetic information, as opposed to "genetic testing information" such as family medical history, gender and other factors, would have a devastating impact on insurers who use such information to underwrite individual policies. n181

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n176. See Holmes, supra note 10, at 555. However, the marginal effect genetic information will have on insurance availability also undermines the insurers' argument that such information is needed to maintain solvency.

n177. See Cushing, supra note 28, at 252. Furthermore, insurers contend that the average price for genetic tests, between $450 and $1,000 per test, would be prohibitively expensive if performed on insureds in the aggregate. See id.

n178. See generally Michael J. Malinowski & Robin J.R. Blatt, Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards, *71 Tul. L. Rev. 1211 (1997)* (discussing the growing market in commercial genetic tests and the need for regulating such tests); Casey, supra note 28, at 15 (listing available genetic tests).

n179. See Rothstein, supra note 80, at 28.

n180. See Jeffords Continues Push to Markup on Health Bills, Health Legis. & Reg. Wkly., May 27, 1998, available in *1998 WL 10395863* (stating that "insurers argue that, if a bill is passed at all, it must define gene information narrowly to include only knowledge gleaned from directly testing an individual's DNA and ribonucleic acid (RNA), and exclude information about inheritable traits gleaned from family histories or other medical tests.").

n181. See id.

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VI. LEGISLATION REQUIRED TO PROHIBIT GENETIC DISCRIMINATION

Genetic discrimination, already problematic, will worsen in the near future as the HGP and commercial researchers provide insurers, employers and other institutions with the means to read our genetic profiles. n182 The noble ends of genomic research will be accompanied by ignoble discrimination, and the consequent genetic determinism may outweigh the medical advances and positive aspects of genomic research. Well-drafted legislation can preempt, or at least mitigate, the perils of genetic discrimination on the horizon. n183 This legislation should address the needs of potential genetic discrimination victims, genomic researchers and the institutions likely to discriminate. n184

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n182. See Jeffords 1998 Testimony, supra note 164.

n183. See Holmes, supra note 10, at 578.

n184. See Smith, supra note 76, at 121. However, balancing these divergent interests is easier said than done.

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The McCarran-Ferguson Insurance Regulation Act of 1945 n185 (hereinafter "McCarran Act") gives the states regulatory power over insurance companies. n186 However, in enacting the McCarran Act, "Congress explicitly reserved the power to enact legislation relating to the business of insurance." n187 Consequently, congressional enactment of the Employee Retirement Income Security Act of 1974 (ERISA) n188 has exempted health insurers from many state regulations. n189 Although federal and state governments have proposed and or enacted genetic discrimination legislation, only federal genetic discrimination legislation will offer comprehensive coverage. n190

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n185. Ch. 20, 59 Stat. 33 (1945) (codified as amended at *15 U.S.C. 1011*-1015 (1998)).

n186. See Cushing, supra note 28, at 260. For a general background of the McCarran-Ferguson Insurance Regulation Act of 1945, see Holmes, supra note 10, at 582-84.

n187. Holmes, supra note 10, at 584.

n188. Pub. L. No. 93-406, 88 Stat. 829 (1974).

n189. Telephone Interview with Brian O'Connor, Communications Director, Office of U.S. Representative Joseph P. Kennedy II (Feb. 18, 1998) (stating that the insurance industry was able to secure freedom from state regulations by lobbying for the McCarran Act); see also Karen Rothenberg, Miracles of Genetics Can Bear Heavy Cost, Balt. Sun, July 20, 1997, at 6F (stating that "state insurance laws cannot apply to self-funded employer plans because of [ERISA]").

n190. See Rothenberg, supra note 189, at 6F.

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A.State Genetic Discrimination Laws and Bills

There is a trend toward state enactment of genetic discrimination legislation. n191 As of [*464] October 1, 1998, some form of genetic discrimination legislation existed in thirty- nine states, n192 and numerous other genetic discrimination bills have been introduced in various state legislatures between 1997 and 1998. n193 This bevy of state

genetic discrimination [*465] legislation represents a range of protection. n194 However, state genetic discrimination laws provide an inherently circumscribed solution. n195

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n191. See Bornstein, supra note 20, at 589; Holmes, supra note 10, at 644. One source noted that there are genetic discrimination laws in 24 states that restrict insurers' use of genetic information, and that as many as 250 genetic discrimination bills are currently pending in 44 state legislatures. See Laws to Forbid Gene- Test Penalties by Insurers Languish in Congress; Thousands Wanting to Know of Risk Fear Being Denied Coverage, Balt. Sun, Apr. 12, 1998, at 4A. Some states have begun to require insurers to use "community rates" whereby premiums for individual and group policies are based solely on the basis of age, geography and family composition, thus preventing "any health insurer from seeking genetic testing of applicants and from using genetic information in fixing rates and premiums." See Holmes, supra 10, at 648-69.

n192. See Ala. Code 27-53-1 to -4 (1998); Alaska Stat. 21.54.100-.54.110 (Michie Supp. 1998); Ariz. Rev. Stat. Ann. 20-448 to -448.02, 20-1379 (West 1997); Ark. Code Ann. 23-86-304 to -306 (Michie Supp. 1997); Cal. Civ. Code 56.17-.18 (West 1998); Cal. Health & Safety Code 1374.7 (West 1990); Cal. Ins. Code 742.405-.407, 10123.3-.35, 10123.9, 10140, 10140.1, 10143, 10146, 10148-10149.1, 10198.9, 10705, 11512.7-11517 (West 1993 & Supp. 1998); Colo. Rev. Stat. Ann. 10-3-1104.7, 25-1-122.5 (1997); Conn. Gen. Stat. 38a-816(19) (1998); Fla. Stat. Ann. 627.4301, 627.65625, 636.0201, 641.31073, 641.438, 760.40 (West 1997 & Supp. 1998); Ga. Code Ann. 33-54-1 to -8 (1996); Haw. Rev. Stat. 431:10A-118, 432:1607, 432D-26 (1998); Idaho Code 41-2221, -3940, -4708 (Michie 1997); 215 Ill. Comp. Stat. 5/356t, 97/20-97/25, 513/45 (West 1998); Ind. Code Ann. 16-39-5-2, 27-8-26-1 to -12 (West Supp. 1998); Iowa Code Ann. 729.6 (West 1993); Kan. Stat. Ann. 40-2259 (1998); La. Rev. Stat. Ann. 22:213.7, :250.3, :1214, 40:1299.6, :2210 (West 1998); Me. Rev. Stat. Ann. tit. 24-A, 2850 (West Supp. 1997); Md. Code Ann., Ins. 27-208, -909 (1997); Minn. Stat. Ann. 72A.139 (West Supp. 1998); Mont. Code Ann. 33-18-206, -22-514, -22-526 (1997); Neb. Rev. Stat. 44-5246.02, -916 (1997); Nev. Rev. Stat. 629.101-.201, 689A.417, .545, .585, 689B.069, .420, .550, 689C.193, .198, .207 (1997); N.H. Rev. Stat. Ann. 141-H:1 to -H:5, 420-G:6 to -G:7 (1996); N.J. Stat. Ann. 10:5-5, :5-12, :5-43 to -49, 17:48-6.18, 17:48A-6.11, 17.48E-15.2, 17B:26-3.2, :27-36.2, :27-57, :30-12, 26:2J-15.1 (West 1993 & Supp. 1998); N.M. Stat. Ann. 24-21-1 to -7, 59A-23E-11 (Michie Supp. 1998); N.Y. Civ. Rights Law 48-a, 48-b, 79-l (McKinney 1992 & Supp. 1998); N.Y. Exec. Law 296 (McKinney 1993 & Supp. 1997); N.Y. Ins. Law 2612, 3221, 3232, 4305, 4318 (McKinney 1985 & Supp. 1998); N.C. Gen. Stat. 58-68-30, -35, 95-28.1A (Supp. 1997); N.D. Cent. Code 26.1-08-12, -36.3-01, -36.3-06, -36.4-03.1 (1995 & Supp. 1997); Ohio Rev. Code Ann. 1751.18, 1751.65, 3901.21, 3901.49, 3901.491, 3901.50, 3901.501, 3924.031, 3924.27 (Anderson 1997 & Supp. 1997); Or. Rev. Stat. 659.036, 659.227, 659.324, 659.340, 659.700-.720, 746.135 (1997); R.I. Gen. Laws 28-6.7-1 to -4 (1995); S.C. Code Ann. 38-41-45, 38-71-670, -840, -860 (Law Co-op. Supp. 1997); S.D. Codified Laws 58-17-84, 58-18-45, 58-18B-27 (Michie Supp. 1998); Tenn. Code Ann. 56-7-2701-7-2708, 56-7-2802 (Supp. 1997); Tex. Lab. Code Ann. 21.401-.405 (West Supp. 1998); Tex. Rev. Civ. Stat. Ann. art. 9031 (West Supp. 1998); Va. Code Ann. 32.1-67.1 to -69.1, 38.2-508.4, 38.2-613 (Michie 1997 & Supp. 1998); W. Va. Code 33-15-2a, -16-1a, -16-3k (Supp. 1998); Wis. Stat. 111.372, 631.89, 632.746, 632.748 (1998); Wyo. Stat. Ann. 26-19-107, -306 (Michie 1998).

n193. See H.B. 10, 1st Spec. Sess. (Ala. 1997); H.B. 218, Reg. Sess. (Ala. 1997); S.B. 113, Reg. Sess. (Ala. 1997) (enacted); H.B. 415, 20th Leg., 2d Reg. Sess. (Alaska 1998); S.B. 104, 20th Leg., 1st Reg. Sess. (Alaska 1997) (enacted); H.B. 2600, 43d Leg., 2d Reg. Sess. (Ariz. 1998); H.B. 2144, 43rd Leg., 1st Reg. Sess. (Ariz. 1997) (enacted); H.B. 2011, 81st Leg., Reg. Sess. (Ark. 1997); A.B. 2688, 97-98 Reg. Sess. (Cal. 1997); A.B. 310, 97-98 Reg. Sess. (Cal. 1997); A.B. 34, 97-98 Reg. Sess. (Cal. 1997); S.B. 1654, 97-98 Reg. Sess. (Cal. 1997); H.B. 5471, 139th Leg., 2d Reg. Sess. (Conn. 1998); H.B. 6527, 139th Leg., 1st Reg. Sess. (Conn. 1997) (enacted); H.B. 5349, 139th Leg., 1st Reg. Sess. (Conn. 1997); H.B. 5134, 139th Leg., 1st Reg. Sess. (Conn. 1997); H.B. 5053, 139th Leg., 1st Reg. Sess. (Conn. 1997); S.B. 85th, 139th Leg., 2d Reg. Sess. (Conn. 1998); S.B. 80, 139th Leg., 2d Reg. Sess. (Conn. 1998) (enacted); S.B. 89, 139th Leg., 1st Reg. Sess. (Conn. 1997); S.B. 166, 139th Leg., 1st Reg. Sess. (Del. 1997) (enacted); S.B. 153, 139th Leg., 1st Reg. Sess. (Del. 1997) (enacted); S.B. 152, 139th Leg., 1st Reg. Sess. (Del. 1997); H.B. 127, 100th Leg., 1st Reg. Sess. (Fla. 1997); S.B. 1850, 100th Leg., 1st Reg. Sess. (Fla. 1997); S.B. 138, 100th Leg., 1st Reg. Sess. (Fla. 1997); H.B. 386, 144th Leg., Reg. Sess. (Ga. 1997); H.B. 1822, 19th Leg., Reg. Sess. (Haw. 1997); H.B. 1566, 19th Leg., Reg. Sess. (Haw. 1997); H.B. 476, 19th Leg., Reg. Sess. (Haw. 1997); S.B. 2160, 19th Leg., Reg. Sess. (Haw. 1997); S.B. 1565, 19th Leg., Reg. Sess. (Haw. 1997) (enacted); S.B. 112, 19th Leg., Reg. Sess. (Haw. 1997); H.B. 388, 90th Leg., 1st Reg. Sess. (Ill. 1997); H.B. 8, 90th Leg., 1st Reg. Sess. (Ill. 1997) (enacted); S.B. 802, 90th Leg., 1st Reg. Sess. (Ill. 1997) (enacted); S.B. 672, 90th Leg., 1st Reg. Sess. (Ill. 1997); S.B. 165, 110th Leg., 1st Reg. Sess. (Ind.

1997); H.F. 701, 77th Leg., 1st Reg. Sess. (Iowa 1997) (enacted); H.F. 171, 77th Leg., 1st Reg. Sess. (Iowa 1997); S.F. 100, 77th Leg., 1st Reg. Sess. (Iowa 1997); H.B. 2734, 77th Leg., 1st Reg. Sess. (Kan. 1997); H.B. 2417, 77th Leg., 1st Reg. Sess. (Kan. 1997); S.B. 463, 77th Leg., 1st Reg. Sess. (Kan. 1997); S.B. 204, 77th Leg., 1st Reg. Sess. (Kan. 1997) (enacted); S.B. 334, 97-98 Reg. Sess. (Ky. 1998); H.B. 2071, 97-98 Reg. Sess. (La. 1997); S.B. 771, 97-98 Reg. Sess. (La. 1997); S.B. 526, 97-98 Reg. Sess. (La. 1997); H.B. 893, 118th Leg., 1st Reg. Sess. (Me. 1997); H.B. 845, 118th Leg., 1st Reg. Sess. (Me. 1997); S.B. 384, 118th Leg., 1st Reg. Sess. (Me. 1997) (enacted); H.B. 297, 412th Leg., 1998 Reg. Sess. (Md. 1998); H.B. 920, 411th Leg., 1997 Reg. Sess. (Md. 1997); H.B. 776, 411th Leg., 1997 Reg. Sess. (Md. 1997); S.B. 324, 412th Leg., 1998 Reg. Sess. (Md. 1998); H.B. 4485, 180th Gen. Ct., Reg. Sess. (Mass. 1997); H.B. 4419, 180th Gen. Ct., Reg. Sess. (Mass. 1997); H.B. 4162, 180th Gen. Ct., Reg. Sess. (Mass. 1997); H.B. 2669, 180th Gen. Ct., Reg. Sess. (Mass. 1997); H.B. 2668, 180th Gen. Ct., Reg. Sess. (Mass. 1997); S.B. 2018, 180th Gen. Ct., Reg. Sess. (Mass. 1997); S.B. 1933, 180th Gen. Ct., Reg. Sess. (Mass. 1997); S.B. 659, 180th Gen. Ct., Reg. Sess. (Mass. 1997); H.B. 5963, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 5960, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 5462, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 5461, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 5460, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4991, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4990, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4882, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4881, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4880, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4836, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 4118, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 134, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 110, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 109, 89th Leg., Reg., Sess. (Mich. 1997); S.B. 108, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 107, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 70, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 69, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 68, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 67, 89th Leg., Reg. Sess. (Mich. 1997); S.B. 66, 89th Leg., Reg. Sess. (Mich. 1997); H.B. 1316, 89th Gen. Assembly, 2d Reg. Sess. (Mo. 1998); A.B. 549, 69th Leg., Reg. Sess. (Nev. 1997) (enacted); H.B. 241, 115th Leg., 1997 Reg. Sess. (N.H. 1997); A.B. 1716, 208th Leg., Reg. Sess. (N.J. 1998); A.B. 1641, 208th Leg., Reg. Sess. (N.J. 1998); A.B. 331, 208th Leg., Reg. Sess. (N.J. 1998); S.B. 565, 208th Leg., Reg. Sess. (N.J. 1998); H.B. 331, 43d Leg., 2d Reg. Sess. (N.M. 1998) (enacted); H.B. 395, 43d Leg., 1st Reg. Sess. (N.M. 1997); S.B. 176, 43d Leg., 2d Reg. Sess. (N.M. 1998) (enacted); A.B. 8412, 220th Leg., Reg. Sess. (N.Y. 1997); A.B. 5553, 220th Leg., Reg. Sess. (N.Y. 1997); A.B. 4512, 220th Leg., Reg. Sess. (N.Y. 1997); A.B. 4510, 220th Leg., Reg. Sess. (N.Y. 1997); S.B. 4009, 220th Leg., Reg. Sess. (N.Y. 1997); S.B. 3284, 220th Leg., Reg. Sess. (N.Y. 1997); S.B. 3283, 220th Leg., Reg. Sess. (N.Y. 1997); S.B. 3198, 220th Leg., Reg. Sess. (N.Y. 1997); S.B. 1497, 220th Leg., Reg. Sess. (N.Y. 1997); H.B. 1495, 141st Leg., 2d Reg. Sess. (N.C. 1998); H.B. 350, 141st Leg., 1st Reg. Sess. (N.C. 1997); S.B. 254, 141st Leg., 1st Reg. Sess. (N.C. 1997) (enacted); H.B. 698, 122d Leg., 2d Reg. Sess. (Ohio 1998); H.B. 3169, 46th Leg., 2d Sess. (Okla. 1998) (enacted); H.C.R. 2021, 46th Leg., 1st Reg. Sess. (Okla. 1997); H.B. 1012, 46th Leg., 1st Reg. Sess. (Okla. 1997); H.B. 2779, 182d Leg., 1997 Reg. Sess. (Pa. 1997); S.B. 100, 182d Leg., 1997 Reg. Sess. (Pa. 1997); H.B. 7590, 97-98 Reg. Sess. (R.I. 1997); H.B. 6349, 97-98 Reg. Sess. (R.I. 1997); H.B. 5157, 97-98 Reg. Sess. (R.I. 1997); S.B. 2805, 97-98 Reg. Sess. (R.I. 1997); S.B. 2202, 97-98 Reg. Sess. (R.I. 1997); S.B. 181, 112th Leg., Reg. Sess. (S.C. 1997); S.B. 56, 73d Leg., 1998 Reg. Sess. (S.D. 1998); S.B. 989, 100th Leg., 1st Reg. Sess. (Tenn. 1997); H.B. 413, 75th Leg., 1997 Reg Sess. (Tex. 1997); H.B. 263, 75th Leg., 1997 Reg. Sess. (Tex. 1997); H.B. 39, 75th Leg., 1997 Reg. Sess. (Tex. 1997) (enacted); S.B. 98, 75th Leg., 1997 Reg. Sess. (Tex. 1997); H.B. 271, 52d Leg., 1998 Gen. Sess. (Utah 1998); S.B. 78, 65th Leg., 97-98 Reg. Sess. (Vt. 1997); H.B. 1384, 1998 Reg. Sess. (Va. 1998); H.B. 854, 1998 Reg. Sess. (Va. 1998); H.B. 781, 1998 Reg. Sess. (Va. 1998); S.B. 652, 1998 Reg. Sess. (Va. 1998); S.B. 6663, 55th Leg., 1997 Reg. Sess. (Wash. 1997); S.B. 5298, 55th Leg., 1997 Reg. Sess. (Wash. 1997); A.B. 69, 93d Leg., Reg. Sess. (Wis. 1997); A.B. 157, 93d Leg., Reg. Sess. (Wis. 1997) (enacted). See generally Lisa Seachrist, A Plethora of Genetic Privacy Bills Floods State Legislatures, Bioworld Today, Apr. 10, 1997, available in *1997 WL 7473568* (discussing common provisions found in various state genetic privacy bills).

n194. See Bornstein, supra note 20, at 589-608; see also Holmes, supra note 10, at 629-47 (providing an extensive discussion and examination of state genetic discrimination laws).

n195. See O'Hara, supra note 15, at 1224; Sally Lehrman, Clinton Backs Laws Against Genetic Discrimination, Biotechnology Newswatch, July 21, 1997, at 1, available in *1996 WL 8791009.*

----------End Footnotes----------

State genetic discrimination laws have several shortcomings. First, state genetic discrimination laws fail to regulate self-insured employers exempted from state insurance laws by ERISA. n196 Consequently, "self-insured plans need not comply with any of the state laws that require health insurance contracts to ... comply with [*466] anti-discrimination restrictions." n197 Furthermore, ERISA's failure to prohibit discriminatory distribution of employee benefits in

conjunction with ERISA's preemption of state action creates a void where state regulation of employee health insurance would be. n198 Therefore, comprehensive protection from genetic discrimination requires federal legislation. n199 Second, many state genetic discrimination laws "focus narrowly on genetic tests rather than more broadly on genetic information generated by family history, physical examination, or the medical record." n200 Third, state genetic discrimination regulations provide only a patchwork of protections. n201 State genetic discrimination laws provide "no consistency regarding the types of insurance covered ... [because some state laws] define genetic testing broadly, some narrowly ... some provide explicit privacy protection, some do not." n202 Therefore, because state genetic discrimination laws only protect insureds not covered by self-insured employers and because the people who are protected by state laws only receive disjointed protection, federal legislation would fill these state legislative gaps. n203 Two federal laws that fill some of the legislative gaps left by state genetic discrimination laws include the Americans with Disabilities Act of 1990 (ADA) n204 and the Health Insurance Portability and Accountability Act of 1996 (HIPAA). n205

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n196. See Collins 1997 Testimony, supra note 6, at 19. Almost two-thirds of U.S. employers are self-insured. See Morelli, supra note 82 at 9. Therefore, even if every state passed comprehensive genetic discrimination laws, millions of American employees with employer self-funded plans would not be protected. See Holmes, supra note 10, at 648.

n197. O'Hara, supra note 15, at 1225.

n198. See Holmes, supra note 10, at 586.

n199. See O'Hara, supra note 15, at 1225.

n200. Collins 1997 Testimony, supra note 6, at 14. Thus, insurers may still be permitted to use phenotype indicators, pattern of inheriting genetic characteristics or a request for genetic testing as the basis for genetic discrimination. See id. Consequently, "meaningful protection against genetic discrimination requires that insurers be prohibited from using all information about genes, gene products, or inherited characteristics to deny or limit health insurance coverage." Id.

n201. See Holmes, supra note 10, at 645. When compared with a comprehensive approach to protecting genetic privacy, "piecemeal approach in enacting hundreds of statutes seems politically impractical and ineffective." See id.

n202. Id. at 647.

n203. See id. at 663.

n204. Pub. L. No. 101-336, 104 Stat. 327 (1990). See also Charles B. Gurd, Whether a Genetic Defect is a Disability Under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers, 1 Annals Health L. 107, 111 (1992) (stating that the ADA "prevents discrimination by private employers who hire more than 15 employees ... [and] prohibits discrimination based on a disability").

n205. Pub. L. No. 104-191, 110 Stat. 1936 (1996).

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B. Federal Laws Regulating and Prohibiting Genetic Discrimination

The ADA offers some limited protections from genetic discrimination by employers, n206 specifically preventing employers from discriminating against employees/applicants because of a disability. n207 In 1995, the Equal Employment Opportunity Commission issued a guideline incorporating "genetic information relating [*467] to illness, disease, or other disorders" into the ADA's definition of "disability." n208 However, discrimination victims may have difficulty invoking the ADA's protections because they must "both show that an employer regarded the individual as having a genetic defect, and "acted on that basis.'" n209 It is also presently unclear whether the ADA prevents genetic discrimination predicated on something other than an individual's disability. n210 For example, some employers may have substantial economic incentives to exclude from the workforce individuals with, or who are likely to have,

dependents who will incur major health expenses. n211 However, the ADA may not prohibit genetic discrimination based on an employer's desire to eliminate potentially expensive dependent health care. n212 Furthermore, the ADA may not protect asymptomatic carriers of recessive genetic mutations. n213 Finally, the ADA may not protect genetic privacy. n214 Therefore, the ADA offers little protection against genetic discrimination absent judicial delineation of the ADA's scope in this area. n215

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n206. See Bornstein, supra note 20, at 581-82. However, the ADA may not prohibit the underwriting and classification of risks by employers or insurers, thus permitting employers and insurers to treat employees differently for purposes of insurance coverage based on their disabilities. See Rothstein, supra note 80, at 79.

n207. See Dee Lord, Something in the Genes, A.B.A. J., Apr. 1996, at 86. The ADA provides a three-prong definition of "disability" as follows: (1) a physical or mental impairment that substantially limits one or more of a person's major life activities; (2) a record of such impairment; or (3) being regarded as having such an impairment. See id. For a discussion of how the ADA extends protection for people with the gene for HD, see generally Brian R. Gin, Note, Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act, *97 Colum. L. Rev. 1406 (1997).*

n208. See Bornstein, supra note 20, at 581; see also Lord, supra note 207, at 86 (explaining that the Equal Employment Opportunity Commission (EEOC) compliance manual "categorizes a genetic susceptibility to a disease ... as a "disability"'). But see Rothstein, supra note 80, at 39-43 (arguing that although the ADA protects "qualified individuals who have an already-expressed genetic disease" that substantially limits their major life activities, the ADA does not protect those with minor genetic conditions without such limitations).

n209. Bornstein, supra note 20, at 581-82. Nonetheless, despite the inadequacies of ADA protections from genetic discrimination, the EEOC compliance manual "codifies a principle that you are not to be held responsible for what's in our [sic] genes ...." See Richard Saltus, US Ruling Bars Discrimination Based on Genes, Boston Globe, Apr. 11, 1995, at A4 (quoting Francis Collins, Director, National Center for Human Genome Research).

n210. See Karen Rothenberg et al., Genetic Information and the Workplace: Legislative Approaches and Policy Changes, 275 Science 1755, 1756 (1997).

n211. See Rothstein, supra note 80, at 47.

n212. See Bornstein, supra note 20, at 582.

n213. See Rothenberg et al., supra note 210, at 1756.

n214. See *Norman-Bloodshaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1273 (9th Cir. 1998).* The court in Norman-Bloodshaw explained that the ADA does not impose restrictions on the scope of medical entrance exams of employees. See id. Thus, genetic make-up information may be disclosed in such examinations. See id.

n215. See Rothenberg et al., supra note 210, at 1756.

----------End Footnotes----------

HIPAA amended ERISA, offering several limited protections from genetic discrimination by insurers. n216 First, HIPAA prohibits insurers from treating a genetic predisposition "as a pre-existing condition unless the genetic information results in a medical diagnosis of an actual condition needing medical care or treatment." n217 Second, by prohibiting the use of genetic information by insurers when considering eligibility for enrollment or continuation of coverage, the Act ensures that employees changing jobs will be able to do so without losing their health insurance. n218 Finally, HIPAA implicitly prohibits the use of genetic information in decisions regarding renewal or continuance of coverage. n219 Despite the importance of the protections offered, HIPAA fails to prohibit several types of genetic discrimination. n220

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n216. See Patrinos & Drell, supra note 15, at 9.

n217. Holmes, supra note 10, at 658-59. The Act prohibits genetic discrimination against asymptomatic people, pre-symptomatic people with a genetic predisposition and unaffected genetic carriers. See id. at 659.

n218. See id.

n219. See id. at 658; see also Barbara A. Ryan, Health Law Promises Access, Portability Obstacles to Insurance Coverage Addressed, N.Y.L.J., Feb. 18, 1997, at S5 (stating that the Health Insurance Portability and Accountability Act of 1996 (HIPAA) may prevent insurers from denying health insurance coverage based on risk and claims history for a group of employees).

n220. See Holmes, supra note 10, at 659; see also Slaughter Testimony, supra note 3, at 8-10 (stating that HIPAA represents an important step toward ending genetic discrimination in health insurance, but fails to close loopholes that leave many people vulnerable to genetic discrimination).

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[*468] First, HIPAA was an amendment to ERISA, and thus fails to address ERISA's shortcomings in preventing genetic discrimination. n221 Specifically, it does not regulate the discriminatory conduct of self-insured employers and health maintenance organizations (HMOs) that ERISA exempts from state insurance laws. n222 Second, the Act does not address genetic privacy concerns such as the dissemination of genetic information. n223 Third, it fails either to prohibit or to regulate genetic testing requirements by insurers. n224 Fourth, it leaves unprotected the self-employed and consumers in the individual health insurance market. n225 Fifth, it does not prohibit the use of genetic information in risk classification and insurance underwriting. n226 Finally, HIPAA fails to prohibit employers from genetically discriminating against people seeking health insurance. n227

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n221. See Collins 1997 Testimony, supra note 6, at 19; see also Lisa Seachrist, Clinton Endorses Legislation to Protect Genetic Privacy, Bioworld Today, July 15, 1997, available in *1997 WL 11130570* (noting that HIPAA left loopholes that H.R. 306 would close).

n222. See Holmes, supra note 10, at 659.

n223. See id.; see also Rothenberg Testimony, supra note 79, at 85 (stating that HIPAA "does not require insurers to obtain authorization before disposing genetic information"); Collins 1997 Testimony, supra note 6, at 20 (stating that HIPAA does not protect "against unauthorized people or institutions having access to the genetic information contained in their medical records").

n224. See Rothenberg Testimony, supra note 79, at 83; Collins 1997 Testimony, supra note 6, at 20.

n225. See Slaughter Testimony, supra note 3, at 10; Collins 1997 Testimony, supra note 6, at 19; see also Rothenberg Testimony, supra note 79, at 84 (stating that HIPAA "provides even less protection for employees not in group plans and provides no coverage for the uninsured").

n226. See Slaughter Testimony, supra note 3, at 11; see also Rothenberg, supra note 189, at 6F (stating that HIPAA does not prohibit insurers from raising rates, excluding coverage for certain conditions, imposing lifetime caps on benefits, requesting or requiring genetic testing and protecting the privacy of genetic test results); Holmes, supra note 10, at 659-60 (stating that the HIPAA "is only a patchwork solution to the insurance/genetic dilemma").

n227. See Rothenberg Testimony, supra note 79, at 84; see also Collins 1997 Testimony, supra note 6, at 19 (stating that HIPAA "leaves open the possibility that all individuals within a group could be charged a higher premium based on the genetic information of one or more members of the group").

----------End Footnotes----------

C. Genetic Discrimination Bills Introduced by the 104th Congress

Despite the introduction of myriad bills since 1990, n228 Congress has thus far failed to pass genetic discrimination legislation. n229 The Human Genome Privacy Act of [*469] 1990, introduced during the HGP's infancy, was the first federal genetic discrimination bill. n230 However, this bill only prohibited the disclosure of genetic information by government agencies, and thus failed to address genetic discrimination in either the insurance or the employment contexts. n231 The 104th Congress later introduced bills addressing genetic discrimination in the employment and health insurance contexts. n232

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n228. Federal genetic discrimination bills introduced in past sessions of Congress include: The Genetic Confidentiality and Nondiscrimination Act of 1996, S. 1898, 104th Cong.; Genetic Information Nondiscrimination in Health Act of 1996, S. 1694, 104th Cong.; Genetic Fairness Act of 1996, S. 1600, 104th Cong.; Health Insurance Reform Act of 1996, H.R. 3185, 104th Cong.; Health Coverage and Availability and Affordability Act of 1996, H.R. 3160, 104th Cong.; Health Insurance Reform Act of 1996, H.R. 3103, 104th Cong.; Working Families Health Access Act of 1996, H.R. 3043, 104th Cong.; Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, 104th Cong.; The Genetic Privacy and Nondiscrimination Act of 1995, S. 1416, 104th Cong., also introduced in the House as H.R. 2690, 104th Cong. (1995); The Genetic Information Privacy Act of 1992, H.R. 5838, 102d Cong.; The Human Genome Privacy Act of 1990, H.R. 5612, 101st Cong. It should be noted that H.R. Res. 392, 104th Cong. (1996) amended H.R. 3103 by substituting and combining the bill with H.R. 3160, which did not contain any genetic information provisions. See Bornstein, supra note 20, at 585 n.149. For a general discussion of federal genetic discrimination legislation introduced between 1995 and 1996, see Reilly, supra note 156, at 379-86.

n229. Genetic discrimination legislation introduced prior to the 105th Congress failed to pass because of staunch opposition from a "very powerful insurance industry lobby." See Interview with O'Connor, supra note 189. Insurance companies have a strong economic incentive to use genetic discrimination to "cherry pick" the healthiest insureds, thereby eliminating health insurance for those people most in need of it. See id. Thus, insurers' opposition to the "fair and equal access to health care" offered by genetic discrimination legislation makes it necessary to include genetic discrimination protection provisions into unrelated bills that are more likely to pass of their own accord. See id. However, the strong insurance lobby and the "ponderous pace of politics [are] not the only reasons for the lag" in enacting genetic discrimination legislation. See Cindy Schreuder, Can Laws Protect Us From Our Genes?, Chi. Trib., July 20, 1997, at 1. Rather, the "complexity, uncertainty and the fast pace of genetic research" have hampered efforts to enact federal genetic discrimination legislation. See id.

n230. See Bornstein, supra note 20, at 579. This bill was introduced by Representative John Conyers (D-MI). See H.R. 5612, 101st Cong. (1990).

n231. See Bornstein, supra note 20, at 579-80.

n232. See id. at 579. For a list of genetic discrimination bills introduced in the 104th Congress, see supra note 228.

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An examination of the 104th Congress's genetic discrimination legislation is beneficial inasmuch as it provides the legislative context for the bills introduced in the 105th Congress. Indeed, many sections of the 105th Congress's genetic discrimination bills are similar, if not verbatim, with those of bills introduced in the 104th Congress. n233 Moreover, genetic discrimination bills introduced in both Congresses similarly define genetic information, n234 genetic test, n235 insurer n236 and other terms necessary for effective prohibition of genetic discrimination. n237 Consequently, because the genetic discrimination bills introduced by the 104th and 105th Congresses are quite [*470] similar, this Note discusses in detail the Genetic Privacy and Nondiscrimination Act of 1995 and the Genetic Privacy and Nondiscrimination Act of 1997, because they contain most major genetic discrimination provisions common to all bills. Additionally, this Note discusses other genetic discrimination bills inasmuch as they differ materially from either the Genetic Privacy and Nondiscrimination Act of 1995 or the Genetic Privacy and Nondiscrimination Act of 1997.

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n233. Several legislative findings made by the 104th Congress were expressly made by the 105th Congress. For example, in H.R. 341, the 105th Congress adopted the same legislative findings as those adopted by the 104th Congress in H.R. 2690 and S. 1416. Both Congresses found that:

(1) The DNA molecule contains information about an individual's probable medical future. (2) Genetic information is uniquely private and personal information that should not be disclosed without the authorization of the individual. (3) The improper 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. (4) An analysis of an individual's DNA provides information not only about an individual, but also about the individual's parents, siblings and children. (5) Current legal protections for genetic information, tissue samples and DNA samples are inadequate to protect genetic privacy, and require further attention. (6) Laws for the collection, storage and use of identifiable DNA samples and private genetic information obtained from those samples are needed both to protect individual privacy and to permit legitimate genetic research.

H.R. 341, 105th Cong. 2 (1997); H.R. 2690, 2; S. 1416, 2.

n234. Genetic information is defined as "the information about genes, gene products or inherited characteristics that may derive from an individual or a family member." H.R. 341, 3; S. 1600, 104th Cong. 2(2) (1996); H.R. 2690, 3; S. 1416, 3.

n235. Genetic test is defined as "a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic." H.R. 341, 3; H.R. 2690, 3; S. 1416, 3.

n236. An insurer is defined as "an insurance company, health care service contractor, fraternal benefit organization, insurance agent, third party administrator, insurance support organization or other person subject to regulation under State insurance laws. Such term includes self-funded health plans and health plans regulated under the Employee Retirement Income Security Act of 1974." H.R. 341, 3; H.R. 2690, 3; S. 1416, 3.

n237. For example, genetic services are defined as "health services to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling." H.R. 306, 105th Cong. 2(a) (1997); H.R. 2748, 104th Cong. 2(e) (1995). Employee health benefit plans are defined as "any employee welfare benefit plan, governmental plan, or church plan" by ERISA. See H.R. 2748, 2(e).

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The Genetic Privacy and Nondiscrimination Act of 1995 n238 would have protected genetic privacy by prohibiting employers, insurers, and government agencies from disclosing or redisclosing genetic information. n239 However, the bill also included several narrowly tailored exceptions to the disclosure prohibition. n240 Several other genetic discrimination bills also included provisions prohibiting unauthorized disclosure of genetic information. n241

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n238. H.R. 2690; S. 1416. Representative Clifford Stearns (R-FL) and Senator Mark Hatfield (R-OR) introduced the bill in their respective Houses during the 104th Congress. Representative Stearns re-introduced this bill during the 105th Congress as the Genetic Privacy and Nondiscrimination Act of 1997. See infra text accompanying notes 257-77 (discussing the scope of the proposed Genetic Privacy and Nondiscrimination Act of 1997). Whenever possible, discussion of the Genetic Privacy and Nondiscrimination Act of 1995 hereinafter will reference provisions in both H.R. 2690 and S. 1416.

n239. See H.R. 2690, 4(a)(1); S. 1416, 4(a)(1)-(2); see also S. 1898, 104th Cong. 201-205 (1996) (stating that entities may not disclose or be compelled to disclose an individual's genetic information unless disclosure is provided for by one of the enumerated exceptions).

n240. See H.R. 2690, 4(a)(2); S. 1416, 4(a)(2). Both bills specify that an individual's genetic information may be disclosed if authorized under federal or state criminal laws, required under a specific order of a federal or state court, authorized to establish paternity, used for medical diagnosis of a decedent's blood relatives or used to identify a body. See H.R. 2690, 4(a)(2); S. 1416, 4(a)(2). Furthermore, the Genetic Privacy and Nondiscrimination Act of 1995 would have allowed disclosure of genetic information if the individual specifically authorized such disclosure in a writing, indicating the information to be disclosed, the entity authorized to receive the information and the purpose of the disclosure. See H.R. 2690, 4(a)(1); S. 1416, 4(a)(1).

n241. See H.R. 2748, 2(b); S. 1694, 104th Cong. 2(b) (1996). Both bills prohibit disclosure of an individual's genetic information without the written authorization of the individual or the individual's legal representative, and require the authorization to identify to whom the disclosure is made. See H.R. 2748, 2(b); S. 1694, 2(b).

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Furthermore, the Genetic Privacy and Nondiscrimination Act of 1995 would have prohibited employers from seeking or using the genetic information, or requiring genetic testing, of current or prospective employees. n242 The bill would have prohibited employers from "obtaining, or using the genetic information of an employee or prospective employee ... to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to the employee or prospective employee." n243 Many of the genetic discrimination bills introduced by the 104th Congress also prohibited employers from altering health benefits offered on the basis of genetic information. n244 Likewise, genetic discrimination bills [*471] invariably extend these prohibitions to providers of health care coverage. n245 Accordingly, the Genetic Privacy and Nondiscrimination Act of 1995 would have prohibited health insurers from "using genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, or otherwise affect health insurance." n246 Genetic discrimination bills typically extend the prohibition to health insurers, self-insured employers and other ERISA plans such as HMOs. n247 These protections are also often extended to both the individual and group health insurance markets. n248

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n242. See H.R. 2690, 5(a); S. 1416, 5(a); see also S. 1898, 104th Cong. 301 (1996) (prohibiting employers or potential employers from using genetic information to discriminate against employees or applicants).

n243. H.R. 2690, 5(a); S. 1416, 5(a).

n244. See H.R. 3160, 104th Cong. 101(b) (1996) (prohibiting insurers from classifying genetic predispositions as preexisting conditions that are excluded from coverage); H.R. 3103, 104th Cong. 101 (1996) (prohibiting insurers from using genetic information as a preexisting condition so long as the patient has not sought treatment for the condition to which the genetic information is related during the six- month period before the effective date of the insurance coverage); H.R. 2748, 2(a) (prohibiting insurers from altering any terms of the insurance contract based on genetic information). The Working Families Health Access Act of 1996 would have imposed a tax on health plan providers who use genetic predisposition to establish or impose eligibility, continuation or contribution requirements. See H.R. 3043, 104th Cong. 4986(a) (1996). That bill regulated health insurers, self-insured employers and ERISA plans by imposing a tax of 25% on collected premiums, or, in the case of self- insured employers, a tax of 25% on health coverage expenditures. See id. 4986(a)-(b). In addition, the bill protected people in both individual and group health insurance markets. See H.R. 3043, 4987(a)-(b).

n245. See Bornstein, supra note 20, at 582-88.

n246. H.R. 2690, 6(a); S. 1416, 6(a). However, insurers other than those providing health care coverage would be able to require applicants to undergo genetic testing. See H.R. 2690, 6(c); S. 1416, 6(c).

n247. See S. 1694, 104th Cong. 2(c)(1)-(2) (1996); see also S. 1600, 104th Cong. 2(6)(a)-(c) (1996) (defining "insurer" to include insurance companies, managed care organizations and ERISA plans).

n248. See H.R. 3185, 104th Cong. 101, 110 (1996); see also supra note 151 (discussing differences between group and individual insurance policies).

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Additionally, the Genetic Privacy and Nondiscrimination Act of 1995 would have required the National Bioethics Advisory Commission (NBAC) to submit a report to Congress with recommendations. n249 Some genetic discrimination bills include provisions that contain, relative to the other bills, minor variations or additions. n250 For example, some bills create a private right of action for people who have suffered invasions of genetic privacy or genetic discrimination. n251 Although the genetic discrimination bills of the 104th Congress would have provided greater protection from genetic discrimination and invasions of genetic privacy, n252 none of them became law. However, they are important inasmuch as their provisions have been almost completely reincarnated by the 105th Congress.

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n249. See H.R. 2690, 7; S. 1416, 7. The National Bioethics Advisory Commission (NBAC) report would include recommendations on the development and implementation of standards "to provide increased protection for the collection, storage, and use of identifiable DNA samples and genetic information obtained from those samples" and "for the acquisition and retention of genetic information in all settings, including appropriate exceptions." H.R. 2690, 7; S. 1416, 7.

n250. The Working Families Health Access Act of 1996, for example, varied the provision prohibiting health insurers from genetically discriminating by imposing a substantial tax for noncompliance rather than by commanding an outright ban against genetic discrimination. See H.R. 3043, 104th Cong. 4986(a) (1996). This approach to addressing genetic discrimination by health insurers appears more effective because insurers may be more averse to confronting the Internal Revenue Service than they would individual insureds. However, the approach may also offer less protection from genetic discrimination if the tax imposed was less than the amount saved by genetically discriminating.

n251. See H.R. 2748, 104th Cong. 2(c)(3) (1995).

n252. See Bornstein, supra note 20, at 587.

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D. Genetic Discrimination Bills Introducted by the 105th Congress n253

The 105th Congress n254 introduced fifteen genetic discrimination bills in an [*472] attempt to close the legislative gaps between state and federal laws. n255 Many provisions included in the 105th Congress's genetic discrimination bills are similar or identical to those of the 104th Congress's genetic discrimination bills. n256 The Genetic Privacy and Nondiscrimination Act of 1997 will serve as the paradigm for discussion of genetic discrimination bills introduced by the 105th Congress.

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n253. Several other bills introduced during the 105th Congress indirectly address the issue of genetic discrimination, but are beyond the scope of this Note. For example, Congress introduced several bills prohibiting genetic discrimination in the issuance of Medicare supplemental policies. See H.R. 1738, 105th Cong. 1(a)(2) (1997); S. 386, 105th Cong. 103(a)(3) (1997); S. 302, 105th Cong. 2(a)(3) (1997); H.R. 625, 105th Cong. 2(a)(3) (1997); H.R. 598, 105th Cong. 1(b)(2) (1997); H.R. 451, 105th Cong. 1(b)(2) (1997). The 105th Congress also introduced two bills prohibiting genetic discrimination in state-based health care coverage programs for children and uninsured pregnant women. See H.R. 1229, 105th Cong. 2852(a)(5) (1997); S. 13, 105th Cong. 104(b)(1) (1997).

n254. President Bill Clinton "urged Congress to pass laws that would prevent health care companies from discriminating against consumers on the basis of genetic information." Lehrman, supra note 195, at 1. Furthermore, Senator Pete Domenici (R-NM) "hopes that the 105th Congress will reach conclusions about "what we are to set as

national standards regarding gene confidentiality and discrimination.'" M.B., Genetic Privacy, Discrimination Issues Could Cripple Biotech Industry, Biotechnology Newswatch, Oct. 7, 1996, at 13.

n255. See Patients' Bill of Rights Act, S. 2330, 105th Cong. (1998); Family Genetic Privacy and Protection Act, H.R. 3299, 105th Cong. (1998); Medical Information Privacy and Security Act, S. 1368, 105th Cong. (1997); Genetic Employment Protection Act of 1997, H.R. 2275, 105th Cong.; Genetic Justice Act, S. 1045, 105th Cong. (1997); Genetic Nondiscrimination in the Workplace Act, H.R. 2215, 105th Cong. (1997); Genetic Protection in Insurance Coverage Act, H.R. 2216, 105th Cong. (1997); Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong.; Medical Privacy in the Age of New Technologies Act of 1997, H.R. 1815, 105th Cong.; Children's National Security Act, H.R. 1726, 105th Cong. (1997); Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong.; Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105th Cong. (companion bill to H.R. 306, 105th Cong. (1997)); Genetic Information Health Insurance Nondiscrimination Act of 1997, H.R. 328, 105th Cong.; Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong.; Genetic Privacy and Nondiscrimination Act of 1997, H.R. 341, 105th Cong.

n256. For example, the Genetic Privacy and Nondiscrimination Act of 1995 was reintroduced in 1997 without change. Compare H.R. 2690, 104th Cong. (1995) (The Genetic Privacy and Nondiscrimination Act of 1995) with H.R. 341 (Genetic Privacy and Nondiscrimination Act of 1997). See also supra note 233 (discussing similar congressional findings motivating H.R. 2690 and H.R. 341).

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The Genetic Privacy and Nondiscrimination Act of 1997 n257 stated that "genetic information is uniquely private and personal information that should not be disclosed without the authorization of the individual ... [because] improper disclosure ... can lead to significant harm ... including stigmatization and discrimination in the areas such as employment, education, health care and insurance." n258 The threat to genetic privacy is exacerbated by the existence of the Internet and other electronic means of transmitting information. n259 Accordingly, [*473] H.R. 341 would prohibit entities from disclosing n260 or being compelled to disclose genetic information n261 within their possession unless "specifically authorized by the individual involved or the legal representative of the individual." n262 Authorization for disclosure must be in writing and describe "the information being disclosed, the name of the individual or entity to whom the disclosure is being made, and the purpose of the disclosure." n263 One bill prohibits disclosing genetic information by electronic means, n264

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n257. H.R. 341. Representative Cliff Stearns (R-FL) introduced H.R. 341. See id. Representative Stearns, however, subsequently introduced H.R. 2198 on July 17, 1997, which is also entitled the Genetic Privacy and Nondiscrimination Act of 1997. See H.R. 2198. Unless otherwise stated, the discussion herein involving the Genetic Privacy and Nondiscrimination Act of 1997 will be based on H.R. 341.

n258. H.R. 341, 2(a).

n259. See, e.g., The Medical Privacy in the Age of New Technologies Act of 1997, H.R. 1815, 2(a). This Act includes the following legislative findings:

(1) Health information plays a vital role in every aspect of an individual's life [and] ... includes some of the most sensitive information available about an individual.

(2) An individual's health information is currently accessible to many people who do not need the information to provide health care to the individual, often without the individual's knowledge or consent.

(3) Individuals will be deterred from using the health care system unless they are assured that the confidentiality of their health information will be respected.

(4) There exists little Federal protection of the confidentiality of an individual's health information.

(5) While health information often is transferred across State lines, protection of the confidentiality of health information varies greatly from State to State, with little protection in some States.

(6) New technologies increase the importance of addressing new threats to the confidentiality of health information. For example, technologies that permit an individual's health information to be computerized increase the possibility of unauthorized electronic access to the information. Technologies that provide genetic information provide information not just about an individual's current health but also about the individual's potential future health and the health of the individual's relatives. This creates potential new uses and abuses of genetic health information that need to be addressed by legislation.

(7) The potential benefits from new genetic technologies will not be realized if individuals cannot trust that their health information is safe from unauthorized uses.

Id.

n260. See H.R. 341, 4(a)(1); see also S. 422, 3(3) (defining disclose as "to convey, or provide access to, the genetic information" of an individual to someone other than that individual); H.R. 1815, 3(3) (defining disclose as "to release, transfer, provide access to, or otherwise divulge the [genetic] information to any person other than an individual who is the subject of the information"). As defined under H.R. 1815, "disclose" includes "the placement of protected health information into a computerized data base, networked computer system, or any other electronic or magnetic data system, that more than one person may access by any means." H.R. 1815, 3(3). The term, however, "does not include oral communication between an individual who is the subject of protected health information and a health care provider delivering health care to such individual." Id.

n261. See H.R. 341, 3(4) (defining genetic information as "information about genes, gene products or inherited characteristics that may derive from an individual or a family member"). Several other bills defined genetic information with the same or similar language. See S. 2330, 105th Cong. 302(b), 303(c), 304(c) (1998); H.R. 3299, 105th Cong. 2(a)(1)(C), 2(a)(2)(C), 3(d)(3) (1998); H.R. 2216, 105th Cong. 2(2) (1997); H.R. 2198, 2(a)(1)(C); H.R. 1726, 105th Cong. 105(a)(1) (1997); H.R. 328, 105th Cong. 2(a)(1)(C) (1997); H.R. 306, 105th Cong. 3(a)(1) (1997); see also S. 422, 3(10) (defining genetic information as "information from a human DNA sample about molecular genotype, information from mutation analysis, or information about nucleotide sequence of a gene"). However, the Genetic Employment Protection Act of 1997 and its companion bill, the Genetic Justice Act, defined genetic information more broadly to include "a physical medical examination, [and/or] a family history [in addition to] a direct analysis of genes or chromosomes." H.R. 2275, 105th Cong. 2(2) (1997) (Genetic Employment Protection Act of 1997); S. 1045, 105th Cong. 2(2) (1997) (Genetic Justice Act).

n262. H.R. 341, 105th Cong. 4(a)(1). This prohibition also applies to the redisclosure of genetic information by any entity properly possessing such information. See id.; S. 422, 201(b); see also H.R. 3299, 2(a)(1)(B) (detailing prohibitions against the use or disclosure of genetic information that might adversely affect health benefits). The prohibition on disclosure or redisclosure presumably refers to entities with authorized access to genetic information, such as health care professionals requiring genetic information for medical diagnoses and therapy. Several other bills also use the same or similar language as H.R. 341 in prohibiting unauthorized disclosure of genetic information. See S. 2330, 302(b), 303(c), 304(b); H.R. 3299 2(a)(1)(B), 2(a)(2)(B), 3(b); S. 1368, 105th Cong. 202(b) (1997); H.R. 2198, 2(a)(1)(B); H.R. 1726, 105; S. 422, 302; H.R. 328, 2(a)(1)(B); H.R. 306, 3(a)(1). H.R. 341, however, includes several exceptions where competing policy reasons outweigh a blanket prohibition against disclosure. See H.R. 341, 4(a)(2). This section permits disclosure of genetic information under five circumstances: (1) when disclosure is authorized under federal or state criminal laws; (2) when disclosure is required under the specific order of a federal or state court; (3) when disclosure is authorized to establish paternity; (4) when disclosure is needed for the medical diagnosis of a decedent's blood relatives; or (5) when disclosure is needed to identify bodies. See id. Other bills also include the same or similar exceptions. See H.R. 3299, 2(a)(1)(B), 2(a)(2)(B), 3(a)(2); H.R. 2198, 2; S. 1368, 211-215; H.R. 328, 2.

n263. H.R. 341, 4(a)(1). For other bills that use the same or similar language in discussing disclosure authorization requirements, see H.R. 3299, 2(a)(1)(B), 2(a)(2)(B); S. 1368, 202; H.R. 2215, 2; H.R. 2198, 2; H.R. 1726, 105; H.R. 306, 3.

n264. See H.R. 1815, 2(b). The Act had seven defined purposes. First, the Act intended to "recognize that there is a right to privacy with respect to health information, including genetic information, and that this right must be protected accordingly." Id. Second, the Act was designed to "ensure that an individual's interest in the privacy of [his] health information cannot be overridden without meaningful notice and informed consent, except in limited circumstances where there is a compelling public interest." Id. Third, the Act aimed to "provide individuals [with] access to health information of which they are the subject [and the] power to challenge the accuracy and completeness of, and amend or correct, records containing such information." Id. Fourth, the Act intended to "establish a minimum Federal standard for the protection of health information which will promote confidentiality while allowing efficient transfer of health information between States." Id. Fifth, the Act aimed to "help ensure the confidentiality of computerized or electronically transferred health information." Id. Sixth, the Act was designed to "restrict the gathering of aggregate health information for financial gain or other purposes without each subject's knowledge or consent." Id. Finally, the Act intended to "establish strong and effective remedies for [violators]." Id.

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[*474] but others prohibit unauthorized collection of such information. n265

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n265. See H.R. 328, 2 (stating that "health insurance issuers may not request or require an individual to whom the issuer provides health insurance coverage in connection with a group health plan ... to disclose any genetic information or to obtain any genetic test"); see also H.R. 2275, 3(2) (preventing employers from using genetic information in any way that would deprive an individual employment opportunities or that would affect that status of the individual as an employee); H.R. 1726, 105 (amending ERISA to include exceptions provided in H.R. 306); H.R. 306, 3 (stating that group health plans cannot request or require participants, beneficiaries, or potential participants or beneficiaries to disclose genetic information); S. 422, 101, 202, 203 (requiring written authorization and informed consent to collect an individual's DNA sample and giving individuals the right to inspect and copy the records containing their genetic information, in addition to the right to amend inaccurate records). Moreover, the Genetic Confidentiality and Nondiscrimination Act of 1997 would promulgate standards for scientists engaged in the collection of DNA samples for research purposes. See S. 422, 501.

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The Genetic Privacy and Nondiscrimination Act of 1997 would also prohibit employers from seeking or using the genetic information, or requiring genetic testing, of current or prospective employees. n266 The bill would prohibit employers from "obtaining, or using the genetic information of an employee or a prospective employee ... to distinguish between or discriminate against or restrict any right or benefit otherwise due or available to the employee or prospective employee." n267 To enforce this prohibition, the bill creates a private right of action for victims of genetic discrimination to seek compensatory, consequential and punitive damages. n268 Other genetic discrimination bills would permit employers to use genetic information when such information was "job related and consistent with business necessity." n269 For example, the Genetic Nondiscrimination in the [*475] Workplace Act, n270 introduced by Representative Joseph Kennedy II (D-MA) would permit employers to request genetic information. n271 Although the bill appears to give employers enough regulatory room to discriminate genetically, this provision may be predicated on the assumption that the ADA prohibits such genetic discrimination by employers. n272 Other bills also limit benign classifications drawn by employers based on genetic information n273

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n266. See H.R. 341, 5(a); see also Geri Aston, Preventing Genetic Discrimination, Am. Med. News, Aug. 4, 1997, at 3.

n267. H.R. 341, 5(a). Several bills also use similar language to prohibit genetic discrimination by employers. See H.R. 3299, 3; H.R. 2275, 3; S. 1045, 105th Cong. 3 (1997); H.R. 2215, 2; H.R. 2198, 3; S. 422, 401.

n268. See H.R. 341, 5(b) (incorporating private remedies provided under 705-709 of the Civil Rights Act of 1964). Several other genetic discrimination bills provide a private right of action. See H.R. 3299, 3(c) (incorporating private remedies provided under 705-709 of the Civil Rights Act of 1964); S. 1368, 323 (permitting an individual to recover compensatory, punitive and consequential damages); H.R. 2275, 8 (providing private right of action with equitable and legal relief); S. 1045, 8 (same); H.R. 2215, 2(d) (providing private right of action with remedies including actual damages and equitable relief); H.R. 1815, 302 (providing a private right of action with remedies including equitable relief, actual or liquidated damages, punitive damages and attorney's fees); H.R. 1726, 105 (permitting recovery for compensatory, consequential and punitive damages); S. 422, 701(d) (permitting recovery for: actual damages or a specified amount of money, whichever is greater; treble damages in cases of violations made for pecuniary gain; and/or reasonable attorney's fees and civil penalties).

n269. See H.R. 2198, 3(a)(2)(A). Three other bills also contain similar exceptions that permit genetic discrimination by employers in cases of "business necessity." See H.R. 3299, 3(a)(2)(A); H.R. 2275, 3(3)(B); S. 422, 401(a)(2); see also S. 1045, 3(3) (permitting employers to disclose employees' genetic information if the employer requests the information after an offer of employment, the information requested is a business necessity and the employee voluntarily consented in writing). However, the Genetic Employment Protection Act of 1997 and the Genetic Justice Act would expand protection by prohibiting employment agencies and labor organizations from genetically discriminating. H.R. 2275, 4-5; S. 1045, 4-5.

n270. H.R. 2215.

n271. See id. 2 (1997). An employer who wants genetic information about an employee or prospective employee "shall provide the employee or prospective employee with a written statement of the uses which the employer intends for such genetic information." Id. The bill also would allow individuals to sue employers who fail to use genetic information in accordance with their stated purpose. See id.

n272. See id. 2. The section states that "nothing in this section authorizes an employer to obtain, disclose, or use genetic information about an employee or prospective employee in violation of the Americans with Disabilities Act of 1990 or any other Federal or State law that restricts access to, disclosure of, or use of genetic information." Id.

n273. See H.R. 2275, 3(2); see also S. 1045, 3(2) (making it unlawful for employers to "limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual, including an inquiry by the individual regarding genetic services").

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Furthermore, the Genetic Privacy and Nondiscrimination Act of 1997 would prohibit health insurers from "using genetic information to reject, deny, limit, cancel, refuse to renew, increase the rates of, or otherwise affect health insurance." n274 The bill would also prohibit genetic discrimination by health insurers, self-insured employers and ERISA plans (i.e., HMOs), thus covering both the independent and group insurance markets. n275 Other genetic discrimination bills would protect consumers in both the individual and group health insurance markets. n276 Finally, the Genetic Privacy and Nondiscrimination Act of 1997 would require the NBAC to submit a report to Congress recommending appropriate [*476] regulations and standards governing the collection and use of genetic information. n277 This provision would thus provide adequate regulatory adaptability, enabling legislation to keep pace with a growing body of scientific knowledge and terminology.

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n274. H.R. 341, 105th Cong. 6(a) (1997). Similarly, other bills would prohibit health insurers and self-insured employers from "denying, cancelling, or refusing to renew such benefits or such coverage, or varying the premiums, terms, or conditions for such benefits or such coverage, for any participant or beneficiary ... on the basis of genetic information ... or on the basis that the participant or beneficiary has requested or received genetic services." H.R. 1726,

105th Cong. 105 (1997); see also S. 2330, 105th Cong. 302(a), 303(a)(1)(A), 304(a) (1998) (providing similar prohibitions as H.R. 1726); H.R. 3299, 2(a)(1)(A), (B) (same); S. 422, 402(a) (same); H.R. 306, 105th Cong. 3 (1997) (same). Genetic services is defined as "health services provided to obtain, assess, and interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling." H.R. 1726, 105; H.R. 306, 3. However, the Genetic Privacy and Nondiscrimination Act of 1997 would permit life insurers to require applicants to undergo genetic testing. See H.R. 341, 6(c). But see H.R. 2216, 105th Cong. 3 (1997) (proposing to prohibit life and disability insurers from genetically discriminating). Genetic test is defined as "a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic." H.R. 2216, 2(3); H.R. 2198, 2; H.R. 341, 3(5); see also H.R. 328, 105th Cong. 2(a)(1)(B) (1997) (defining genetic test with similar language).

n275. See H.R. 341, 3(6). The term insurer is defined as "insurance company, health care service contractor, fraternal benefit organization, insurance agent, third party administrator ... or other such person subject to regulation under State insurance laws [as well as] self-funded health plans and health plans regulated under [ERISA]." Id. Other bills impose similar proscriptions on health insurers and ERISA plans. See S. 2330, 302(a), 303(a)(1)(A), 304(a); H.R. 3299, 2(a)(1)-(2); H.R. 1726, 105(a)-(b); S. 422, 402(b).

n276. See S. 2330, 303(a)-(b); H.R. 3299, 2(b); H.R. 2198, 2; H.R. 1726, 105; H.R. 328, 2; H.R. 306, 3; see also Collins 1997 Testimony, supra note 6, at 15 (stating that H.R. 328 closed some of the loopholes left by HIPAA by "addressing discrimination in the individual health insurance market").

n277. See H.R. 341, 7(1)-(2). Under a similar bill, H.R. 2198, the NBAC would be required to make recommendations on

(1) the development and implantation of standards to provide increased protection for the collection, storage, and use of identifiable DNA samples and genetic information obtained from those samples; and

(2) the development and implementation of appropriate standards for the acquisition and retention of genetic information in all settings, including appropriate exceptions.

H.R. 2198, 4(1)-(2). This provision is also contained in H.R. 2690, 104th Cong. 7 (1995). In addition, H.R. 3299 proposed to establish elaborate procedures for the creation of the National Bipartisan Commission on the Use of Genetic Information. See H.R. 3299, 4.

----------End Footnotes----------

The Genetic Privacy and Nondiscrimination Act of 1997, however, does not contain provisions permitting people to inspect, copy and correct genetic information lawfully possessed by entities authorized under the Act. n278 Several other bills introduced in the 105th Congress would permit inspection and copying of protected genetic information by the person who furnished such information. n279

----------Footnotes----------

n278. See H.R. 341.

n279. See S. 1368, 105th Cong. 101-103 (1997); H.R. 1815, 105th Cong. 101-103 (1997); S. 422, 202-203.

----------End Footnotes----------

E. Genetic Discrimination Legislation Recommendations

Federal genetic discrimination legislation must address many issues affecting almost every aspect of society. n280 Revolutionary discoveries and their consequent technology will vastly improve our pharmaceutical and medical abilities to detect, cure, and prevent many, if not all, human afflictions. n281 However, with the influx of potentially life-saving

knowledge will come less noble applications as well. n282 Mapping the human genome will facilitate the collection, storage, use and dissemination of individuals' genetic information. n283 Consequently, the potential for abuse of such information, specifically genetic discrimination and invasions of genetic privacy, increases exponentially with scientific progress. n284 Furthermore, the [*477] rapidity of such genomic discoveries complicates the legislator's task of drafting laws that adequately anticipates subsequent developments. n285 Nevertheless, there are several basic provisions necessary to make genetic discrimination legislation effective.

----------Footnotes----------

n280. The HGP and the genomic information that it reveals implicate various ethical, legal, social, political and economic issues. See Patrinos & Drell, supra note 15, at 8.

n281. See Elizabeth Shogren, White House to Seek Genetic Test Safeguards, L.A. Times, Jan. 20, 1998, at A1, available in *1998 WL 2390404* (quoting Chris Jennings, President Clinton's senior health care advisor, as stating that genomic research "has extraordinary potential for diagnoses and treatment"); see also Philip R. Reilly, Public Policy and Legal Research Issues Raised by Advances in Genetic Screening and Testing, *27 Suffolk U. L. Rev. 1327, 1333 (1993)* (suggesting that genetic testing will revolutionize medicine).

n282. See Shogren, supra note 281 (quoting from a preliminary draft of a study, entitled Genetic Information and the Work Force stating that "while genetic technology increases the ability to detect and prevent health disorders, it can also be misused to discriminate against or stigmatize individuals"); see also Steve Ginsberg, The New Resume: Jobs, Schools, Genetic Makeup?, S.F. Bus. Times, Nov. 21, 1997, at 8A, available in *1997 WL 15945933* (discussing workers' fears of genetic discrimination in the workplace).

n283. See Annas, supra note 74, at 2346. The collection, storage and use of genetic information have already created litigation. See *Mayfield v. Dalton, 109 F.3d 1423, 1424 (9th Cir. 1997).* The plaintiffs, two U.S. Marines, challenged the constitutionality of the Department of Defense's DNA registry, fearing that "information obtained from the repository samples, regarding the donors' propensities for hereditary diseases and genetic disorders, might be used to discriminate against applicants for jobs, insurance or benefit programs." Id.

n284. See Rothenberg Testimony, supra note 79, at 85-86 (stating that "as the flow of genetic information increases, so too will the risk of its misuse"); see also *Norman-Bloodshaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1268-70 (9th Cir. 1998)* (holding unanimously that the "constitutionally protected privacy interest in avoiding disclosure of personal matters" and the Fourth Amendment's search and seizure clause prohibit employers from secretly collecting and using employees' genetic information).

n285. See, e.g., G. J. V. Nossal & Ross L. Coppel, Reshaping Life: Key Issues in Genetic Engineering 139 (2d ed. 1989).

----------End Footnotes----------

First, because everyone has a few bad genes, genetic discrimination legislation should offer protection to all Americans. n286 Consequently, genetic discrimination legislation must apply to insurers regulated under state insurance laws and entities regulated under ERISA, including HMOs and self-insured employers. n287 Moreover, genetic discrimination legislation should protect consumers in both group and individual health insurance markets. n288 Second, health insurers and employers must be prohibited from genetically discriminating against insureds or employees, especially by eliminating health coverage for individuals in the highest risk category. n289 Third, individuals should be free from mandatory genetic testing absent a compelling interest. n290 Fourth, genetic discrimination legislation must prohibit unauthorized disclosure of genetic information, n291 and should allow individuals to inspect and correct their genetic information records. n292 Fifth, such legislation should provide effective measures of enforcement, including, but not limited to, a private right of action for individuals harmed by abuses of genetic information. n293 [*478] Finally, genetic discrimination legislation should be adaptable to the changing corpus of scientific knowledge. n294

----------Footnotes----------

n286. See Collins 1997 Testimony, supra note 6, at 12; see also Stearns Testimony, supra note 81, at 3 (stating that "each and every one of us could be affected once the mapping and sequencing phase of [HGP] research has been completed").

n287. See H.R. 341, 105th Cong. 3(6) (1997) (defining insurer to include HMOs and self- insured employers); see also Hudson et al., supra note 4, at 393 (defining "insurance provider" broadly to include "an insurance company, employer, or any other entity providing a plan of health insurance or health benefits").

n288. See Hudson et al., supra note 4, at 393.

n289. See H.R. 341, 5-6; see also Hudson et al., supra note 4, at 393 (listing several legislative recommendations of the Working Group on Ethical, Legal, and Social Implications that would prohibit insurers from "using genetic information, or an individual's request for genetic services, to deny or limit any coverage or establish eligibility, continuation, enrollment, or contribution requirements ... [or from] establishing differential rates or premium payments based on genetic information or an individual's request for genetic services").

n290. See H.R. 341, 5(a); see also Hudson et al., supra note 4, at 393 (recommending that "insurance providers should be prohibited from requesting or requiring collection or disclosure of genetic information"). But see H.R. 341, 6(c) (permitting life insurers to request genetic tests). For some compelling reasons that would permit mandatory genetic testing, see Kristin M. Raffone, Note, The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy, *26 Hofstra L. Rev. 503, 534-44 (1997)* (citing preventative medicine, inheritable diseases, genetic diversity and societal interest in potential life as compelling reasons given by states for instituting genetic screening programs).

n291. See Lauran Neergaard, Doctor Lobbies for Genetic Privacy Legislation, Buff. News, Sept. 30, 1995, at A4; see also Hudson et al., supra note 4, at 393 (recommending that "insurance providers and other holders of genetic information should be prohibited from releasing genetic information without prior written authorization of the individual [and that written] authorization should be required for each disclosure and include to whom the disclosure would be made"); H.R. 341, 4(a)(1)-(2) (prohibiting disclosure or redisclosure of genetic information, subject to several narrowly tailored exceptions).

n292. See Lori B. Andrews & Ami S. Jaeger, Confidentiality of Genetic Information in the Workplace, *17 Am. J.L. & Med. 75, 108 (1991).*

n293. See bills discussed in supra note 268.

n294. See H.R. 341, 7 (requiring the NBAC to make recommendations to Congress in order to keep genetic legislation adaptable to subsequent scientific developments).

- - - - - - - - - - - - - - - - -End Footnotes- - - - - - - - - - - - - - - - -

Many protections are needed against the limitless potential abuse of genetic information. Federal legislation regulating genetic information must prohibit: genetic discrimination by health insurers and employers; unauthorized disclosure of genetic information; mandatory genetic testing; collection of genetic information without informed consent; and other genetic abuses. n295 Although several genetic discrimination bills of the 105th Congress would provide substantial protections, n296 the Genetic Privacy and Nondiscrimination Act of 1997 and the Genetic Confidentiality and Nondiscrimination Act of 1997 both offer comprehensive protection from abuses of genetic information, and should be enacted into law by Congress. Because the 105th Congress failed to enact genetic discrimination legislation, n297 the provisions contained in these bills should be the basis for future [*479] bills to be considered in the 106th Congress. n298

- - - - - - - - - - - - - - - - - -Footnotes- - - - - - - - - - - - - - - - - -

n295. See id. 4-7.

n296. Several genetic discrimination bills introduced in the 105th Congress offer adequate protections. Table 1 indicates the protections offered by each of the 105th Congress's genetic discrimination bills. Although different bills

may include provisions of the same general type (for example, provisions protecting genetic privacy), not all of the provisions were equally comprehensive. Table 1 does not reflect the superiority of some provisions relative to those in other bills.

[SEE TABLE IN ORIGINAL]

Table 1. 105th Congress's Genetic Discrimination Provisions. * S. 2330, entitled the Patients' Bill of Rights Act, is not strictly a genetic discrimination bill. Title III of S. 2330, cited as Genetic Information Nondiscrimination in Health Insurance Act of 1998, provides the relevant provisions relating to genetic discrimination. Similarly, H.R. 1726, entitled Children's National Security Act, is also not strictly a genetic discrimination bill.

n297. The odds that any of the 105th Congress's genetic discrimination bills would be enacted were low. See Search of WESTLAW, Billcast (Oct. 6, 1998). Table 2 represents the odds of passing for each of the 105th Congress's genetic discrimination bills.

[SEE TABLE IN ORIGINAL]

Table 2. Odds of Success for 105th Congress's Genetic Discrimination Bills.

n298. A staff member from Representative Kennedy's office indicated that, in light of heavy opposition from insurance lobbyists, genetic discrimination legislation might have to be inserted as a rider into bills supported by the Republican majority. See Interview with O'Connor, supra note 189.

----------End Footnotes----------

VII. CONCLUSION

Although federal and state legislatures are beginning to enact genetic discrimination laws, these laws offer inadequate protection. n299 Genomic research and discoveries of disease genes are rapidly producing commercially available genetic tests, ushering in an age of widespread genetic screening. n300 More comprehensive genetic discrimination legislation is needed to prevent an infinite train of abuses made possible by unlocking the human genome. n301 Scientific discoveries made by the HGP provide great potential. Genomic research may lead to a revolution in medicines' ability to heal people at the molecular level through gene therapy. n302 However, this research may concomitantly lead to genetic discrimination and invasions of genetic privacy and autonomy. n303 Therefore, this influx of genetic information should be accompanied by federal legislation designed to limit potential abuses of such information, especially abuses decreasing the availability of health care. Congress should enact legislation that prohibits genetic discrimination by health insurers and employers, and protects genetic privacy and autonomy. Several bills proposed during the 105th Congress would adequately regulate the uses of genetic information, n304 although the Genetic Privacy and Nondiscrimination Act of [*480] 1997 offers the most comprehensive protection. n305 Although the rapidity of genomic discoveries will likely make comprehensive genetic legislation impossible and will require subsequent legislation to respond to new developments, enactment of any of these bills would provide a necessary foundation for future genetic discrimination laws and jurisprudence.

----------Footnotes----------

n299. See Bornstein, supra note 20, at 609; O'Hara, supra note 15, at 1227.

n300. See O'Hara, supra note 15, at 1212.

n301. See Holmes, supra note 10, at 663.

n302. See Gostin, supra note 6, at 113.

n303. See supra note 5 (describing a fictional, though plausible, account of a society incorporating genetic discrimination).

n304. See, e.g., H.R. 2198, 105th Cong. (1997) (limiting "the disclosure and use of genetic information in connection with group health plans and health insurance coverage," and prohibiting "employment discrimination on the basis of genetic information and genetic testing, and for other purposes"); S. 422, 105th Cong. (1997) (defining "the circumstances under which DNA samples may be collected, stored, and analyzed"). Restrictions imposed by S. 422 would include genetic discrimination by employers and health insurers, as well as unauthorized disclosure of genetic information by any entity. See S. 422, 201. Moreover, comprehensive genetic discrimination protections would be enacted under two bills introduced by Representative Kennedy. See H.R. 2215, 105th Cong. (1997) (restricting "employers in obtaining, disclosing, and using genetic information"); H.R. 2216, 105th Cong. (1997) (limiting the "disclosure and use of genetic information by life and disability insurers").

n305. See H.R. 341, 105th Cong. (1997). The Genetic Privacy and Nondiscrimination Act of 1997 would prohibit genetic discrimination by employers and health insurers. See id. 5-6. The bill would also prohibit unauthorized disclosure of genetic information. See id. 4. Furthermore, genetic discrimination prohibitions would apply to HMOs and other ERISA- regulated entities. See id. 3(6). Finally, the bill would require the NBAC to prepare subsequent reports for Congress regarding new legislative needs in light of scientific advances. See id. 7.

----------End Footnotes----------

LEVEL 1 - 38 OF 1343 STORIES

Knight Ridder/Tribune News Service
Knight Ridder Washington Bureau

October 21, 1999, Thursday

SECTION: DOMESTIC NEWS

KR-ACC-NO: K4854

LENGTH: 860 words

HEADLINE: Two studies give conflicting views on privacy risks of genetic testing

BYLINE: By Usha Lee McFarling

BODY:

SAN FRANCISCO Although genetic tests are becoming more widely available, many people are avoiding them. They're afraid the results could make it harder for them, and their children, to get jobs or health insurance.

Although such tests can be the key to early treatment for some diseases, even many experts are afraid the results could be used to discriminate against people with a predisposition to certain ailments.

According to a study released here Thursday at the international meeting of the American Society of Human Genetics, one-quarter of the nation's genetic counselors would use aliases during testing and nearly 70 percent would pay for the expensive tests themselves to avoid alerting their insurance companies.

Nearly 90 percent of counselors would choose to be tested for the genetic defects that can help trigger breast and colon cancer, but more than 10 percent of those surveyed said they would not even tell their doctors about test results because doing so might affect their health insurance.

Those who would tell their doctors would "make a special request that it not be noted in their records," said Ellen T. Matloff, who founded the Yale Cancer Center's genetic counseling resource and led the survey of 163 counselors.

Such concerns also appear to be common among the general public. Another study presented at the meeting found that many people passed up genetic testing because they didn't want to bill their insurance or to fork over $ 300 to $ 2,400 themselves for the tests.

But such fears may be overblown.

In another study, Mark A. Hall, a professor of law and public health at the Wake Forest University School of Medicine in North Carolina, attempted to document the extent of insurance discrimination by interviewing genetic counselors, insurance agents and patient advocates and analyzing the application forms of 50 insurers.

"We heard frequently from genetic counselors that genetic discrimination was a serious problem and assumed to be widespread," he said. His investigation, though, turned up no insurance discrimination. "I was surprised," he said. "I

went in expecting to find a lot more of a problem."

While medical insurance companies and health maintenance organizations have earned a reputation for denying care to people with pre-existing conditions, Hall said his research shows they are not discriminating against people who are healthy but carry a genetic predisposition to some illness.

Insurance companies could even benefit financially by providing genetic testing, because early detection and treatment could save health care dollars in the long run. "It could be a win-win," Matloff noted.

Most insurance companies, Hall said, are not concerned with future health problems, only with current health conditions largely because consumers changei nsurance plans so frequently. The use of genetic information to determine health insurance coverage is also deterred by some state through laws outlawing genetic discrimination. Such laws are in effect in 28 states, Hall said, and Congress is considering a federal law.

Though they do not blanket the United States, "the laws have reinforced the attitude that it is inappropriate to use this (genetic) information to categorize people," said Hall.

One of America's leading genetic doctors agreed.

"I have yet to encounter a case where a woman said, 'I had trouble getting insurance after I found out my genotype,' " said Mary Claire King, a leading breast cancer geneticist from the University of Washington who has worked with thousands of women with genetic diseases.

But others who have genetic disorders or care for people who have them still say discrimination is widespread.

"I would disagree," said Kathy Hunter, who founded the International Rett Syndrome Association 17 years ago after her daughter was diagnosed with the disease, which robs little girls of the ability to speak and move properly. "We still have parents who change jobs and the insurer says, 'We'll insure you, but not your child.' "

(STORY CAN END HERE)

Hall said health insurance companies may well discriminate against those who already show symptoms, like Hunter's 25-year-old-daughter, but not against healthy people who simply carry disease genes. He also said it was possible that life and disability insurance providers might discriminate against those predisposed to genetic disorders.

The issue is becoming increasingly important as more genetic tests become available to the public, a byproduct of today's furious pace of genetic research. For example, the discovery of the Rett Syndrome gene was announced this month and a test for the disorder is already becoming available.

The most common genetic tests are for two breast cancer genes that are responsible for 5 to 10 percent of breast and ovarian cancers and for another gene responsible for some inherited forms of colon cancer. People who know they are carrying these genes can opt for increased preventative care, like

colonoscopies and mammograms, or even undergo removal of their breasts and ovaries.

03YBAHRANI

LANGUAGE: ENGLISH

JOURNAL-CODE: WA

LOAD-DATE: October 23, 1999

Devorah R. Adler
01/29/2000 05:54:59 PM

Record Type: Record

To: Eric P. Liu/OPD/EOP@EOP

cc: Anna Richter/OPD/EOP@EOP
Subject: Genetic Discrimination E.O. -- Comment regarding HHS privacy rules

Hello --

Wanted to let you know what we think of Peter's memo. In case you haven't had time to read it, his basic thrust (although he does not actually make any formal recommendations) is that we should use the opportunity offered by the genetic discrimination EO to extend the protections in the recently released privacy regulations to entities that are not currently covered by the rule.

I think that we are generally not supportive of this idea.

First, it is important to note that he has not determined whether there are actually any entities which are covered by the genetic discrimination EO that are not covered by the privacy regulation. This seems to be to be an extremely important question -- because if there aren't, then his whole issue is moot. I spoke to Peter Friday night. He is going to try to answer this question before pushing this issue further.

If there actually are entities which are covered by the EO that aren't covered by the regulation, we feel strongly that it would be inappropriate to use the EO to extend the reach of the privacy regulation for two reasons.

(1) In the development of the privacy regulation, we actually discussed whether we could use other regulations, such as the Medicare conditions of participation, to apply our new privacy protections entities which are not covered entities under the privacy regulation. We decided not to do that for fear of criticism that we were over-extending our bounds on privacy. The same criticism would apply to this situation, and I believe that it is still valid.

(2) This would place the genetic discrimination EO -- which is going to come under significant scrutiny as it is -- in the middle of the privacy debate, which is equally as contentious. We do not want to endanger the future of the EO, or prevent it being used as a model for legislation by unnecessarily loading it down with potentially controversial provisions.

Finally, in addition to the substantive concerns I have with Peter's idea, I think we are generally against anything that would slow this EO down. Chris has been working on it forever, and we are anxious to get it out. If possible, I would like to nip this issue in the bud.

Anyway, I hope this information is useful to you. Let us know what you think about all this -- I'm happy to answer questions if you have any.

Thanks, Devorah

---------- Forwarded by Devorah R. Adler/OPD/EOP on 01/29/2000 05:31 PM ----------

January 28, 2000

Genetic Discrimination E.O. and Health Privacy Rules
Disclosure to Researchers

Issue: Whether and how to incorporate the same standard for privacy protections for research included in the HHS privacy rule in the genetic discrimination E.O.

Background: Section 1-202(d) of the draft E.O. states that an employer "shall not disclose genetic information except . . . (3) to an occupational or health researcher if the research is conducted in compliance with the [Common Rule]."

The HHS proposed health privacy rule builds on Common Rule criteria and adds additional criteria specific to information practices. The proposed rule allows covered entities (i.e., health care providers, plans, and clearinghouses) to disclose protected health information without patient consent upon documentation by an Institutional Review Board ("IRB") or "Privacy Board" that the research meets criteria in the Common Rule, plus 4 additional privacy-related criteria. The proposed rule also extends the requirements mentioned above to researchers that are not currently subject to the Common Rule, but receive protected health information from covered entities.

While the HHS privacy rule applies to federal agencies that are "covered entities" under the rule, the E.O. would apply to all federal agencies. Therefore, *any decisions made on standards for disclosure for research under the E.O. would affect more agencies than are covered under the HHS privacy rules.*

During the development of the proposed health privacy rule, EOP and HHS staff noted the limitations of the statutory authority, notably that the HHS rule would only reach "covered entities" – health care providers, plans, and clearinghouses, but not employers, researchers, and others. The question is whether the statutory scope of the health privacy regulation should also be the scope of the E.O.

Options:

1. Do nothing.

Pro: Upon publication of the E.O., agencies will have certainty about the disclosure rules upon publication of the E.O. Nothing in the final privacy rules will be incorporated into the E.O. (though the standards in the HHS rule for disclosure for research would still apply to agencies that are covered entities).

Con: If the final HHS privacy rule is similar to the proposed rule, the result will be more lenient disclosure rules for genetic information under the E.O. than rules governing a broader set of information (usually less sensitive) under the HHS privacy rule. Issuance of an E.O. with a

lower standard for privacy protections could be viewed as inconsistent with previous statements and a weakening of the Administration's position on health privacy.

2. E.O. incorporates research standards of final privacy rule upon publication [or one year thereafter?]

This could be done through the following language, to 1-202(d) (above): " . . . and if in conformance with the standards for disclosure in Section 164.510(j) of the Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164, upon publication [or one year thereafter?]."

Pro: This would ensure the same standard for disclosure for research in the E.O. and the final HHS rules. As for timing, it would impose the stricter standards on the government one or two years earlier than the private sector, demonstrating government leadership in protecting privacy.

Con: It will be difficult for federal agencies to comply with the stricter disclosure-for-research standards earlier than the private sector, and particularly difficult to comply immediately upon publication of the final rule.

3. E.O. incorporates research standards of final privacy rule upon effective date

This could be done by adding the following language to 1-202(d) (above): " . . . and if in conformance with the standards for disclosure in Section 164.510(j) of the Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164, upon the effective date of such rules."

Pro: Like Option 2, this would ensure the same standard for disclosure for research in the E.O. and the final rules. It also gives agencies, like the private sector, two years to comply, which should be ample.

Con: This option is not as privacy protective because of the delay in implementation.

4. E.O. incorporates research standards currently in the *proposed* rule, noting that they may change in accordance with the final rule

This could be done by adding the following language to 1-202(d) (above): " . . . and if in conformance with the standards for disclosure in Section 164.510(j) of the Proposed Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160-164."

Pro: This would make a strong statement that the Administration wants to serve as a leader and extend the research standards in the health privacy NPRM to federal agencies. Even though the rule is not yet final, the standards included in the NPRM represent the Administration's current policy position based on thoughtful analysis.

Con: This option could be viewed as undercutting or pre-judging the rulemaking process. It could also be opposed by agencies that have been told they would have the comment period to comment on the research-related section of the NPRM.

Withdrawal/Redaction Marker
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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	Genetic Discrimination meeting list of attendees [partial] (1 page)	01/19/2000	P3/b(3)

COLLECTION:
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Health Care - Genetic Discrimination

2013-0717-S
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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

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P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

TO: [redacted] (b)(3)

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Eric Liu	6-2878
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Eddie Correia	6-5055
Peter Swire	5-3047
Neal Lane / Rachel Levinson	6-6021

FROM: Chris Jennings

RE: Genetic Discrimination

For your information, attached is the version of the EO that has been dropped into the formal OMB clearance process. Thanks once again for your hard work and all your effort on this issue.

Revisions from 1/11 Draft Incorporated in 1/18/00 Draft

1. Title; Delete "PREDICTIVE"

2. 1-201(b), 5th line: DELETE "or" after "evaluate,"; DELETE "," after "control".

3 1-201(e)(1)(C): INSERT "medical condition," after "disease" in order to be consistent with other places where "medical condition" has been inserted.

4. 1-202(a), (b) and (d) -- DELETE references to family members

5. 1-301(a)(3): INSERT "or employee" after "applicant" since this exception has been modified to apply to applicants and employees

6. 1-301(a)(2); 1-301(a)(3): INSERT "medical" before "condition" to be consistent with other provisions.

7. 1-301(a)(2) and (4): INSERT references to applicants who become employees to make clear that information that is obtained from applicants, which remains in the medical files, can later be used in the same way as information obtained from employees, provided that the requirements of 301(b) are met.

8. 1-301(a): ADD new subparagraph (4) to clarify that this information should remain within the medical department. The employer will receive a medical assessment in order to make a determination about qualifications for employment, but the assessment will not include this information.

9. 1-301(b)(1): REPLACE parenthetical with "(other than use pursuant to 1-301(a))" in order to be more precise.

10. 1-301(c): REPLACE subparagraph (2) and (3) with the a single paragraph to clarify how the employee obtains such information and to avoid forcing individuals to receive the results of monitoring.

11. Delete 1-402(d) to avoid suggesting that the order can be superseded by a more permissive disclosure rule.

12. Incorporate various technical and stylistic changes recommended by the Office of Legal Counsel of the Department of Justice.

Responses to State Department Comments

1. State suggests that there be a statement clarifying that the order applies to employees, not family members or others. Section 1-101 of the order refers states that the purpose is to protect employees. This purpose will be restated in the statement of the President when the order is issued.

2. State asks if an agency could use family history as a basis for "testing for the presence of disease, e.g., hemoglobinopathies such as sickle cell disease/trait or thalassemia, and acting on the basis of the results of those tests." My understanding is that sickle cell disease is manifested in the type of hemoglobin that is produced and that this disorder can be identified through blood tests. Consequently, this disorder is a present disorder, rather than simply a genetic marker indicating that a disease may manifest itself in the future. This disorder may result in disabling symptoms under some circumstances, e.g., high altitudes. Agencies could, therefore, take this disorder into account under some circumstances, provided that the requirements of the Rehabilitation Act are met.

Revisions 11/18

DRAFT 01/11/00

Draft, Revised 1/18/00, 5:00 P.M.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Section 1. Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in section 1-101 for all its employees covered by section 717 of Title VII of the Civil Rights Act of 1964, as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

Section 2. Requirements Applicable to Employing Departments and Agencies

1-201. Definitions.

(a) The term "employee" shall include an employee, applicant for employment, or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16).

(b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, respond to the effects of, or control adverse environmental exposures in the workplace.

(c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.

(d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites fall within the definition of "genetic tests" when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about the genetic tests of family members of the individual; or

(C) information about the occurrence of a disease, medical condition or disorder in family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. In discharging their responsibilities under this order, agencies shall implement the following nondiscrimination requirements.

(a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of

protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee.

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee except --

(1) to the employee who is the subject of the information, at his or her request;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; or

(4) to government officials investigating compliance with this order if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

Section 3. Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in section 1-202.

(a) The employing department or agency may request or require information defined in 1-201(e)(1)(C) with respect to an applicant who has been given a conditional offer of employment or an employee if:

(1) the request or requirement is consistent with the Rehabilitation Act and other applicable law;

(2) the information obtained is to be used exclusively to assess whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder, or in the case of applicants who become employees, under the terms of 1-301(b) of this order;

(3) such current disease, medical condition or disorder could prevent the applicant or employee from performing the essential functions of the position held or desired; and

(4) the information defined in 1-201(e)(1)(C) of this order will not be disclosed to persons other than medical personnel involved in or responsible for assessing whether further medical evaluation is needed to diagnose a current disease, medical condition or disorder or, in the case of applicants who become

employees, under the terms of 1-301(b) of this order.

(b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee if:

(1) the employee uses genetic or health care services provided by the employer (other than use pursuant to section 301(a) of this order);

(2) the employee who uses the genetic or health care services has provided prior knowing, voluntary, and written authorization to the employer to collect protected genetic information;

(3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except to the employee who uses the services; for purposes of treatment, payment, or health care operations; or pursuant to section 1-202(d) of this order; and

(4) such information is not used in violation of sections 1-202(a) or 1-202(b) of this order.

(c) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

(1) the employee has provided prior, knowing, voluntary, and written authorization;

(2) the employee is notified when the results of the monitoring are available and, at that time, the employer makes any protected genetic information that may have been acquired during the monitoring available to the employee and informs the employee how to obtain such information;

(3) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and

(4) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(d) This order does not limit the statutory authority of a Federal agency to:

(1) promulgate or enforce workplace safety and health laws and regulations;

(2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations; or

(3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Section 4. Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy and, to this end, shall designate a high level official responsible for carrying out its responsibilities under this order.

1-402. Nothing in this order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701, et seq.), the Privacy Act of 1974 (5 U.S.C. 552a), or other applicable law; or

(b) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program.

1-403. This order clarifies and makes uniform Administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE
[DATE]

Revisions from 1/11 Draft Incorporated in 1/18/00 Draft

1. Title; Delete "PREDICTIVE"

2. 1-201(b), 5th line: DELETE "or" after "evaluate,"; DELETE "," after "control".

3 1-201(e)(1)(C): INSERT "medical condition," after "disease" in order to be consistent with other places where "medical condition" has been inserted.

4. 1-202(a), (b) and (d) -- DELETE references to family members

5. 1-301(a)(3): INSERT "or employee" after "applicant" since this exception has been modified to apply to applicants and employees

6. 1-301(a)(2); 1-301(a)(3): INSERT "medical" before "condition" to be consistent with other provisions.

7. 1-301(a)(2) and (4): INSERT references to applicants who become employees to make clear that information that is obtained from applicants, which remains in the medical files, can later be used in the same way as information obtained from employees, provided that the requirements of 301(b) are met.

8. 1-301(a): ADD new subparagraph (4) to clarify that this information should remain within the medical department. The employer will receive a medical assessment in order to make a determination about qualifications for employment, but the assessment will not include this information.

9. 1-301(b)(1): REPLACE parenthetical with "(other than use pursuant to 1-301(a))" in order to be more precise.

10. 1-301(c): REPLACE subparagraph (2) and (3) with the a single paragraph to clarify how the employee obtains such information and to avoid forcing individuals to receive the results of monitoring.

11. Delete 1-402(d) to avoid suggesting that the order can be superseded by a more permissive disclosure rule.

12. Incorporate various technical and stylistic changes recommended by the Office of Legal Counsel of the Department of Justice.

Responses to State Department Comments

1. State suggests that there be a statement clarifying that the order applies to employees, not family members or others. Section 1-101 of the order refers states that the purpose is to protect employees. This purpose will be restated in the statement of the President when the order is issued.

2. State asks if an agency could use family history as a basis for "testing for the presence of disease, e.g., hemoglobinopathies such as sickle cell disease/trait or thalassemia, and acting on the basis of the results of those tests." My understanding is that sickle cell disease is manifested in the type of hemoglobin that is produced and that this disorder can be identified through blood tests. Consequently, this disorder is a present disorder, rather than simply a genetic marker indicating that a disease may manifest itself in the future. This disorder may result in disabling symptoms under some circumstances, e.g., high altitudes. Agencies could, therefore, take this disorder into account under some circumstances, provided that the requirements of the Rehabilitation Act are met.

Revisions 11/18

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. list	Genetic Discrimination meeting list of attendees [partial] (1 page)	01/19/2000	P3/b(3)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Eric Liu
OA/Box Number: 16241

FOLDER TITLE:
Health Care - Genetic Discrimination

2013-0717-S
sb19

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

TO: [redacted] (b)(3)

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Francis Collins / Kathy Hudson	301 402 0837
Gary Claxton / Steve Finan	202 401 7321
Jane Horvath	202 690 8425

DEPARTMENT OF JUSTICE

Rosemary Hart	202 514 0563
Robin Lendhardt	

DEPARTMENT OF LABOR

Stacy Grundman	202 219 9216
Dan Maguire	

DEPARTMENT OF STATE

Julie Herr	202 736 7028
Cedric Dumont	202 663 1613

EEOC

Paul Miller	202 663 7101
Peggy Masroiani	202 663 7276
Louis Lopez	

NASA

Edward Frankle	202 358 2741

PEACE CORPS

Paul Zimmerman	202 692 2151

WHITE HOUSE

Eric Liu	6-2878
David Beier	6-6231
Eddie Correia	6-5055
Peter Swire	5-3047
Neal Lane / Rachel Levinson	6-6021

FROM: Chris Jennings

Attached is the latest version of the executive order for your final review before it is placed into formal OMB clearance.

This version reflects the changes that were discussed at yesterday's meeting. The significant revisions are summarized as follows:

1. 1-202(d) and 1-301(b) have been revised to reflect the fact that the order covers collection of genetic information from employees, not from family members or others;

2. 1-301(a) has been revised to contain the exception for collection of family history from both applicants and employees and to require that collection in both cases be consistent with the Rehab. Act and other applicable law;

3. 1-301(b)(1) has been revised to make more explicit that this exception applies in cases where employees receive genetic or health care services from the employee in cases other than simply job evaluation;

4. 1-301(b)(3) has been revised to disclosure of information for purposes of treatment, payment or health care operations;

5. 1-402(b) has been revised to carry out our intent with regard to the relationship between the order and the Privacy Act; and

6. 1-403(d) has been deleted to avoid suggesting that the order can be superseded by a more permissive disclosure rule.

Comments on this version are due by 5 pm Friday, January 14. Please fax them to our office at 456 5557.

DRAFT 01/11/00

Draft, Revised 1/11/00 -- 5:00 P.M.

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON PREDICTIVE GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in Section 1-101 for all its employees covered by Section 717 of Title VII of the Civil Rights Act of 1964 as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

DRAFT 01/11/00

Requirements Applicable to Employing Departments and Agencies

1-201. Definitions.

(a) The term "employee" shall include an employee, applicant for employment, or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16).

(b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, or respond to the effects of, or control, adverse environmental exposures in the workplace.

(c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.

(d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites are covered when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. The agencies, in discharging their responsibilities under this order, shall implement the following nondiscrimination requirements.

(a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of protected genetic information with respect to the employee or because of information

about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee or by a family member of an employee except --

(1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; or

(4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

(a) The employing department or agency may request or require information defined in 1-201(e)(1)(C) with respect to an applicant who has been given a conditional offer of employment or an employee if:

(1) the request or requirement is consistent with the Rehabilitation Act and other applicable law;

(2) the information obtained is to be used exclusively to assess if further medical evaluation is needed to diagnose a current disease, condition or disorder; and

(3) such current disease, condition or disorder could prevent the applicant from performing the essential functions of the position held or desired.

(b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee if:

(1) the employee uses genetic or health care services provided by the employer (other than use solely connected with evaluation of fitness for employment);

(2) the employee who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;

(3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except: i) to the employee who uses the services; ii) for purposes of treatment, payment, or health care operations; or iii) pursuant to section 1-202(d) of this order; and

(4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

(c) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

(1) the employee has provided prior, knowing, voluntary, and written authorization;

(2) the employee is informed of the specific results of the monitoring;

(3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;

(4) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and

(5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(d) This Executive Order does not limit the statutory authority of a Federal agency to (1) promulgate or enforce workplace safety and health laws and regulations or (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, (3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-402. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

(b) limit the rights or protections of an individual under the Privacy Act of 1974 (5 U.S.C. 552a);

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) supersede any other statute, regulation, or rule that requires disclosure of information.

1-403. This order clarifies and makes uniform Administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE
[DATE]

TO:	Francis Collins / Kathy Hudson	301 402 2218
	Eddie Correia	(e-mailed)
	Eric Liu	62878
	Gary Claxton	401 7321
	Jane Horvath	690 8425
	Stacy Grundman	219 9216
	Paul Miller	663 7101
	Peter Swire / Lauren Steinfeld	(e-mailed)
	David Beier	(e-mailed)
FROM:	Devorah	
RE:	Genetic Discrimination	

Hello –

Attached is the most recent iteration of our modifications to the genetic discrimination EO as discussed in the last meeting.

If folks could take a QUICK look at this before 12 noon today and let me know if they concur with the changes, that would be great. I think that if we have a significant number of non-concurrences, we should have a conference call this afternoon to straighten things out.

Also, Chris may want to contact some of you this afternoon to talk about presentation at Tuesday's meeting.

Thanks very much for your help, and please call with questions.

December 7, 1999

1. NEW EXCEPTION:

THE FOLLOWING WOULD BE INSERTED UNDER SECTION 1-301

"The employing department or agency may request or require information defined in 1-201(3)(1)(C) with respect to an applicant who has been given a conditional offer of employment if:

(1) the information is to be used exclusively to assess if further medical evaluation is needed to diagnose whether an applicant has a current disease or disorder; and

(2) such current disease or disorder would prevent the applicant from performing the essential functions of the position for which the applicant has applied."

2. TECHNICAL CORRECTIONS

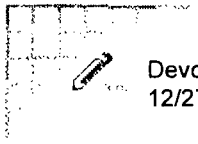
A) In 1-301(a) STRIKE "require". (Inclusion of the word is a drafting error; inconsistent with the voluntariness provision in subparagraph 2.)

B) In 1-301(a)(3) INSERT "and" at the end of the subparagraph (ie, after the word "order;");

3. ADDITIONAL CLARIFICATION

The need to redraft 1-103(a)(3) to allow disclosure, under certain circumstances, for treatment purposes has been raised numerous time. The following revision is based on a short conversation I had with Peter Swire last Tuesday. It also allows disclosure, under certain circumstances, for payment and health care operations. It is not clear that we had agreement on this approach.

(3) ~~the person who performs the genetic or health care services does not disclose~~ the results of the genetic services are not disclosed to anyone (i) except to the employee who uses the services or for the purposes of treatment, payment and health care operations, and (ii) pursuant to section 1-202(d) of this order; and



Devorah R. Adler
12/27/99 08:58:56 AM

Record Type: Record

To: Zoe E. Lanier/OPD/EOP@EOP

cc: Anna Richter/OPD/EOP@EOP
Subject: small group meeting on genetic discrimination

Hello --

Can you please set up a small group meeting on genetic discrimination sometime for Jan 3 or 4?

We would like to invite:

Paul Miller (EEOC)
Francis Collins (NIH)
Gary Claxton (ASPE)
Eddie Correia (WH Counsel)
Jane Horvath (ASL)
David Beier (OVP)
Stacey Grunman (DOL)
Eric Liu

The purpose of this meeting is to brainstorm about potential solutions re: the EO. Please ask them not to discuss this meeting with others -- we are not inviting everyone.

Also, can you please set up a large group meeting on genetic discrimination for Jan 6 or 7?

It should be everyone we had the last time around.

Thanks a lot.

Devorah

Original options

OPTION 1: ALLOWING FAMILY HISTORY (BUT NOT GENETIC TESTS) TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE

[1-201]

(e) Protected genetic information.

In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual **unless such information is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder.**

OPTION 2: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder.**

OPTION 3: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE AND PROHIBITING COLLECTION AS A CONDITION OF EMPLOYMENT

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder, provided that no individual may be required to furnish such information as a condition of employment.**

WORKING GROUP DRAFT 12/21/99

OUP & NIH edits on options

OPTION 3: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE AND PROHIBITING COLLECTION AS A CONDITION OF EMPLOYMENT

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used ~~exclusively~~ to determine if further medical evaluation is needed to diagnose a current disease or disorder, provided that no individual may be required to furnish such information as a condition of employment.**

OR as a condition for promotion or advancement

OR treat

Condition

"Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>
01/05/2000 04:45:15 PM

Record Type: Record

To: Devorah R. Adler/OPD/EOP

cc: "Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>, "Collins, Francis (NHGRI)" <francisc@exchange.nih.gov>

Subject: More Options

Devorah-

Thank you for sending the three options from Eddie Correia. NIH is concerned about making modifications to the definition of "protected genetic information" and would prefer a specific and narrow exception. The term "protected genetic information" and its definition in the E.O. are used in legislation regarding employment and health insurance and are almost becoming a term of art. Changing it now may create some problems and confusion. Specifically, in the health insurance context, the modifications to the definition would seem to be at odds with intent of those bills. Thus, we would like to propose the following.
Please share this note with the group that met yesterday. We look forward to meeting tomorrow. Thanks,

Exceptions:

Insert as a new 301(a):

The employing department or agency may request, but not require, information defined in 1-201 (e)(1)(C) with respect to an applicant or employee that is used exclusively to assess if further medical evaluation is needed to determine an individual's fitness for duty in accordance with applicable law.

discussion questions from Peter S.

Peter P. Swire
01/06/2000 12:18:27 PM

Record Type: Record

To: See the distribution list at the bottom of this message
cc:
bcc:
Subject: Re: draft e.o. on genetic discrimination

Because I won't be able to attend this afternoon's meeting, I thought it might be useful to list the issues that I think people should be sure to make sure are well answered:

(1) There is a spectrum from an employer (a) requiring a test; (b) requesting a test; and (c) not being allowed to ask for a test. Gary Claxton said he might try to define a new category for (c).

(2) Is the definition of "protected genetic information" going to change from the draft? Despite NIH's concerns, the inclusion of family history in that definition is a major concern.

(3) Do we ever distinguish between family history and other sorts of protected genetic information? Perhaps without touching the actual definition of protected genetic information?

(4) How do we implement Eddie's idea of allowing use of protected genetic information for treatment (and therefore payment and health care operations)? Should there be some reference to the "substantial and direct risk" test?

(5) Are there any exceptions for space, intelligence activities, etc.? It seems we want to minimize these.

(6) Be sure to include the "treatment, payment, and health care operations" change.

Thanks,

Peter

Edward W. Correia

Edward W. Correia

01/06/2000 10:16:23 AM

Record Type: Record

To: Peter P. Swire/OMB/EOP@EOP

EXCEPTIONS FOR COLLECTING AND DISCLOSING INFORMATION IF THE AGENCY PROVIDES HEALTH CARE SERVICES TO THE EMPLOYEE [1-301]

(a) The employing department or agency may request, require, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if:

(1) the employee or family member uses genetic or health care services provided by the employer;

(2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information; and

(3) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

(b) The employing department or agency may disclose protected information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if:

(1) the employee or family member uses genetic or health care services provided by the employer;

(2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer regarding the circumstances under which protected genetic information may be disclosed;

(3) disclosure of the results of genetic services is limited to:

i) the employee or family member who uses the genetic or health care services;

ii) disclosures described in Sections 1-202(d)(1) and 1-202(d)(2) of this order; or

iii) disclosures necessary for treatment, payment, or health care operations;

and

(4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

WORKING GROUP DRAFT 12/21/99

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON PREDICTIVE GENETIC INFORMATION

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in Section 1-101 for all its employees covered by Section 717 of Title VII of the Civil Rights Act of 1964 as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

Requirements Applicable to Employing Departments and Agencies

1-201. Definitions.

(a) The term "employee" shall include an employee, applicant for employment, or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16).

(b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, or respond to the effects of, or control, adverse environmental exposures in the workplace.

(c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.

(d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites are covered when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. The agencies, in discharging their responsibilities under this order, shall implement the following nondiscrimination requirements.

(a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

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(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee or by a family member of an employee except --

(1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; and

(4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

(a) The employing department or agency may request, require, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if:

(1) the employee or family member uses genetic or health care services provided by the employer;

(2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;

(3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except to the employee who uses the services, and pursuant to section 1-202(d) of this order; and

(4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

(b) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

(1) the employee has provided prior, knowing, voluntary, and written authorization;

(2) the employee is informed of the specific results of the monitoring;

(3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;

(4) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and

(5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(c) This Executive Order does not limit the statutory authority of a Federal agency to (1) promulgate or enforce workplace safety and health laws and regulations or (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, (3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-402. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

(b) supercede any provision of the Privacy Act of 1974 (5 U.S.C. 552a), and actions taken under this Executive Order shall be in compliance with the Privacy Act.

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) superceded any other statute, regulation, or rule that requires disclosure of information.

1-403. This order clarifies and makes uniform administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE
[DATE]

WORKING GROUP DRAFT 12/21/99

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
BASED ON PREDICTIVE GENETIC INFORMATION

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(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; and

(4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.

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THE WHITE HOUSE
[DATE]

OPTION 1: ALLOWING FAMILY HISTORY (BUT NOT GENETIC TESTS) TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE

[1-201]

(e) Protected genetic information.

In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual **unless such information is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder.**

OPTION 2: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE

[1-201]

(e) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder.**

WORKING GROUP DRAFT 12/21/99

OPTION 3: ALLOWING ALL FORMS OF GENETIC INFORMATION TO BE COLLECTED BUT RESTRICTING USE TO MEDICAL EVALUATION OF CURRENT DISEASE AND PROHIBITING COLLECTION AS A CONDITION OF EMPLOYMENT

[1-201]

(e) Protected genetic information.

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(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual

(2) **Protected genetic information does not include information, otherwise included in subparagraph (1), that is used exclusively to determine if further medical evaluation is needed to diagnose a current disease or disorder, provided that no individual may be required to furnish such information as a condition of employment.**

"Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>
01/05/2000 04:45:15 PM

Record Type: Record

To: Devorah R. Adler/OPD/EOP

cc: "Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>, "Collins, Francis (NHGRI)" <francisc@exchange.nih.gov>

Subject: More Options

Devorah-

Thank you for sending the three options from Eddie Correia. NIH is concerned about making modifications to the definition of "protected genetic information" and would prefer a specific and narrow exception. The term "protected genetic information" and its definition in the E.O. are used in legislation regarding employment and health insurance and are almost becoming a term of art. Changing it now may create some problems and confusion. Specifically, in the health insurance context, the modifications to the definition would seem to be at odds with intent of those bills. Thus, we would like to propose the following.
Please share this note with the group that met yesterday. We look forward to meeting tomorrow. Thanks,

Exceptions:

Insert as a new 301(a):

The employing department or agency may request, but not require, information defined in 1-201 (e)(1)(C) with respect to an applicant or employee that is used exclusively to assess if further medical evaluation is needed to determine an individual's fitness for duty in accordance with applicable law.

Edward W. Correia

01/06/2000 01:19:08 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: Genetic Discrimination

I have a few questions and comments about NIH's proposed new 301(a).

1. NIH says that the current definition of protected genetic information has become a widely used standard definition and it would be confusing to change it. However, I tend to think that it is confusing to describe a large category of information as "protected" on the grounds that it cannot be used, then specify in some other part of the order ways it can be used. If we are not going to change the definition, why not just call it "genetic information", then specify the narrow circumstances when it can be used.

2. David suggested that we allow the use of genetic information for treatment as well as medical evaluation. I agree.

3. The NIH language does not include the express statement that the medical evaluation is needed to determine fitness **based on a current condition.** That seems to me to be the major point that agencies (and private employers) have to understand. The concept of "fitness for duty" does not extend to the possibility that disease will develop later. That concept may be implied by the phrase "in accordance with applicable law." However, employers are not aware of the applicable law and they may not read this limitation into the phrase. Consequently, I believe we should retain some express reference to diagnosis or treatment of a current condition.

4. By providing that employers may not require the information, we are saying that employees should have a meaningful opportunity to refuse to provide it. That can only be done by requiring some disclosure to the employee that it need not be provided. Otherwise, when a question about family history pops up in the middle of a medical evaluation, which is otherwise required, the employee will have no one of knowing that he can say no. However, I do have some concerns about the whole idea of saying that the employer cannot require this information. We will be imposing a disclosure and waiver process on family history questions that are an established part of medical practice and are probably asked a thousand times a day in this country.

On another issue, here's a version of the provisions in 1-301(a) dealing with collecting and disclosing information, which Peter Swire has reviewed.

1-301(a) Collection, disclosure exceptio

Message Sent To:

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003. report	Issues discussed in Genetic Discrimination meeting (3 pages)	12/22/1999	P3/b(3)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Eric Liu
OA/Box Number: 16241

FOLDER TITLE:
Health Care - Genetic Discrimination

2013-0717-S
sb19

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
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b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
004. list	Genetic Discrimination meeting list of attendees [partial] (1 page)	12/221999	P3/b(3)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Eric Liu
OA/Box Number: 16241

FOLDER TITLE:
Health Care - Genetic Discrimination

2013-0717-S
sb19

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12/22 Genetic Discrimination Mtg

Jane Horvath - ASL
Kathy Hudson - NIH
Francis Collins - NIH
Stacy Grundman - DOL
Peggy Masroianni - EEOC
Nancy Segal -EEOC
Peter Gray - EEOC
Vicky Gonzalez-Rovira - EEOC
Paul Miller - EEOC
[redacted] (b)(3)
Cedric Dumont - State Dept.
Julie Herr - State Dept.
Robin Lenhardt - DOJ
Phil Breen - DOJ
Kevin Maroney - DOL
Daniel Maguire - DOL
Kaye Pespaina - DOL
Amy Turner - DOL
Edward Frankle - NASA
William Raub - ASPE

HEALTH —
GEN DISCRIM

- KK HIPA — ~~comp~~ min expected in emp but Built-in ... in HC
- in employment, slower
  - Third EO end of last yr.
  - Exemptions – [wanna use for placements that needs / [for health problems
  - HHS: fear undermine Cred
  - MWC's would make same arg.

WORKING GROUP DRAFT 12/21/99

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
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(a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee or a family member of the employee or information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee or by a family member of an employee except --

(1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality requirements; and

(4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records, and kept separate from personnel files.

Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

(a) The employing department or agency may request, require, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if:

(1) the employee or family member uses genetic or health care services provided by the employer;

(2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;

(3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except to the employee who uses the services, and pursuant to section 1-202(d) of this order;

(4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

(b) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

(1) the employee has provided prior, knowing, voluntary, and written authorization;

(2) the employee is informed of the specific results of the monitoring;

(3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;

(4) the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and

(5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(c) This Executive Order does not limit the statutory authority of a Federal agency to (1) promulgate or enforce workplace safety and health laws and regulations or (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, (3) collect protected genetic information as a part of a lawful program, the exclusive purpose of which is to carry out identification purposes.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-402. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

(b) supercede any provision of the Privacy Act of 1974 (5 U.S.C. 552a), and actions taken under this Executive Order shall be in compliance with the Privacy Act.

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) superceded any other statute, regulation, or rule that requires disclosure of information.

1-403. This order clarifies and makes uniform administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE
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ARTICLE: Genetic Discrimination in the Workplace: An Overview of Existing Protections

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SUMMARY:
... The sophistication of genetic technology has grown at an amazing rate. ... Next, this Article addresses the effect of the Occupational Health and Safety Act ("OSHA") on genetic testing. ... Finally, this Article concludes that current juris-prudence provides adequate protection against genetic discrimination based on genetic testing in the employment arena. ... Often a genetic test can only reveal the possibility that a person may develop a certain disease in the future, but cannot tell whether the individual will actually get the disease. ... The use of genetic testing is more frightening when considering the history of genetic discrimination in the United States. ... Whether an individual is affected by a disability, as defined under the ADA, is generally the most controversial issue in a genetic discrimination claim. ... When genetic testing is compared to HIV testing, it is clear that a genetic disorder (or hyper-susceptibility) should also be considered a disability under the ADA. ... The prima facie case for disparate impact discrimination based on genetic testing would be relatively easy for a job applicant to satisfy. ... "Business necessity" denotes an employment practice whose purpose is to determine whether an applicant is capable of performing the necessary job functions. ...

TEXT:
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I. Introduction

The sophistication of genetic technology has grown at an amazing rate. As this technology improves, scientists can predict more genetic markers and traits than ever before. n2 Genetic information can potentially benefit society because it is likely to lead to cures and treatments for currently incurable genetic disorders. This knowledge, however, also has the potential to create a biological underclass of people based on their latent genetic disorders. Some critics have gone so far as to suggest that knowledge of genetic fitness could be used to choose between parents in custody battles, or to determine whether potential adoptive parents are suitable. n3 More commonly, however, genetic technology can be used to screen applicants for both employment and health insurance.

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n2. For example, genetic tests currently available include identification of adult polycystic kidney disease, fragile X syndrome, sickle cell anemia, Duchenne muscular dystrophy, cystic fibrosis, Huntington's disease, hemophilia, phenylketonuria, and retinoblastoma. See Office of Tech. Assessment, U.S. Congress, Genetic Monitoring and Screening in the Workplace 15, tbls.1-2 (1990) [hereinafter Genetic Monitoring Survey].

n3. See Brian R. Gin, Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act, 97 Colum. L. Rev. 1406, 1411 (1997) (suggesting that in the future adoption agencies may choose suitable parents based on their genetic potential and that the same information may be used by courts in determining who should receive custody of children in divorce settlements).

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Several studies have noted a significant trend in the use of genetic testing in employment. For example, a 1989 study conducted by the United States Congress Office of Technology Assessment ("OTA") that surveyed Fortune 500 companies, n4 discovered that of the 330 [*394] companies responding, twelve companies admitted to currently conducting genetic tests on employees. n5 In a follow-up survey, the OTA reported that almost half of the health officers and personnel officers surveyed said their companies would approve of pre-employment exams to screen applicants for genetic susceptibility to workplace toxins. n6 These numbers are projected to increase as another survey revealed that fifteen percent of responding companies plan to use genetic testing as a condition to employment by the year 2000. n7 In addition, some companies indicated that their future use of genetic testing could depend upon its cost-effectiveness. n8 At the time of the survey, however, few of these surveyed companies felt that genetic testing was cost-effective. n9

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n4. See Genetic Monitoring Survey, supra note 2, at 21 tbls.1-5 (asking each company if it was conducting either "biochemical genetic screening" or "direct DNA screening" on its employees or potential employees).

n5. See Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 Am. J.L. & Med. 109, 115 (1991). Further, eight companies admitted to utilizing genetic testing in the past. See id.

n6. See Office of Tech. Assessment, U.S. Congress, Medical Monitoring and Screening in the Workplace: Results of a Survey-Background Paper 4 (1991) [hereinafter Medical Monitoring Survey]. Congress initially became interested in the issue of genetic monitoring and screening in the workplace in the late 1970s and early 1980s. See id. at 16. This interest led to hearings by the House Committee on Science and Technology and an OTA assessment formally labeled The Role of Genetic Testing in the Prevention of Occupational Diseases in 1983. See id.

n7. See Gostin, supra note 5, at 115 (discussing the Northwestern National Life Insurance Company survey conducted in 1989). Further studies have

uncovered anecdotal information about genetic discrimination in employment. See Paul R. Billings et al., Discrimination as a Consequence of Genetic Testing, 50 Am. J. Hum. Genetics 476 (1992). Billings reported 42 incidents of genetic discrimination, 39 of which involved insurance or employment. See id. at 478. For example, one insurance company denied an individual coverage due to his hereditary hemochromatosis, a condition resulting in excessive iron storage. See id. The insurance company refused coverage despite the fact that the individual never had even the slightest symptom and underwent preventative treatment. See id. Another case involved an individual whose brother was diagnosed with Gaucher Disease. See id. When the individual applied for a governmental job, the government agency denied him employment because he was a "carrier, like sickle cell." See id.

n8. See Medical Monitoring Survey, supra note 6, at 5.

n9. See id. at 38.

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Currently, some employers already use the results of medical tests as a hiring criterion before extending a final job offer. n10 While the practice of genetically testing employment applicants is not widespread, its expansion seems inevitable as the tests become cheaper and easier for employers to use. Support for this proposition comes [*395] from the Ethical, Legal and Social Implications research component of the Human Genome Project, n11 which has identified the possibility of employers using the new genetic information for discrimination as one of the major concerns of increased genetic knowledge. n12 Yet, thus far no court has directly addressed the issue of genetic testing. n13

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n10. See id. at 44. Specifically, 36% of the companies surveyed admitted to periodically engaging in health insurance risk assessments of prospective employees. See id.

n11. The Human Genome Project is a collection of related, independent research projects with the ultimate goal of analyzing the structure of human DNA, and mapping and sequencing the estimated 100,000 human genes. The project began in 1990 and its estimated completion date is 2005. See Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 24-25 (1992) (discussing the impact of the Human Genome Project on the operation of the ADA and the inadequacies of the ADA to protect against genetic based discrimination).

n12. See Lynda M. Fox & Sherman G. Finesilver, Genetics and the Workplace: ADA Applicability to Genetic Information, 26 Colo. Law. 75, 75 (1997) (citing Using Gene Tests to Deny Jobs is Ruled Illegal, N.Y. Times, Apr. 8, 1995, at A12) (reporting that the Equal Employment Opportunity Commission considers the use of genetic tests discriminatory if used to deny employment)).

n13. Recently, both current and former employees of a state and federally funded laboratory filed a claim in the Northern District of California. The claim alleged that the laboratory performed genetic and other medical tests (specifically for syphilis, sickle cell, and pregnancy) without informing the applicants of the tests. Further, the claims alleged violations of the

Americans with Disabilities Act ("ADA"), Title VII, and the right to privacy under both the United States and California Constitutions. See Norman-Bloodsaw v. Lawrence Berkeley Lab., No. 95-03220 (N.D. Cal. Sept. 3, 1995). The District Court dismissed all the employees' charges based on motions for dismissal, improper pleadings, and summary judgment. On appeal, the Ninth Circuit reversed all but the district court's dismissal of the ADA claims. See Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1275 (9th Cir. 1998). The Court of Appeals found that the plaintiffs stated a claim based on violations of Title VII (the plaintiffs' complaint alleged that the tests for sickle cell were only given to African Americans, and the pregnancy tests were only given to women), as well as privacy claims based on violations of both the United States Constitution and the California Constitution. See id. at 1269-73. Thus, while the merits of the claims are pending, at least one circuit has recognized that genetic testing implicates Title VII and privacy claims.

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This Article discusses the legal and ethical ramifications of using genetic screening to select job applicants and genetic monitoring of employees. This Article begins by explaining how genetic testing is used as a screening and monitoring tool. n14 In doing so, it also traces the history of discrimination based on genetic testing in the United States. n15 This Article then addresses an individual's potential protections under the Americans with Disabilities Act ("ADA") including individuals protected by the ADA, the impact of testing on job applicants, the requirements of an ADA action, and the Equal Employment Opportunity Commission's ("EEOC") interpretation of [*396] the ADA. n16 Further, this Article discusses potential claims based on Title VII of the Civil Rights Act. n17 Next, this Article addresses the effect of the Occupational Health and Safety Act ("OSHA") on genetic testing. n18 It follows with a discussion of the constitutional ramifications based on privacy rights that arise from genetic testing. n19 It then chronicles several state efforts to control genetic testing within their borders. n20 Finally, this Article concludes that current juris-prudence provides adequate protection against genetic discrimination based on genetic testing in the employment arena. n21 It suggests, however, that Congress needs to specifically include genetic testing within the protections of the ADA, in order to stem the present confusion that has spurred so many states to pass their own genetic protection laws.

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n14. See infra Part II.

n15. See infra Part II.B.

n16. See infra Part III.

n17. See infra Part IV.

n18. See infra Part V.

n19. See infra Part VI.

n20. See infra Part VII.

n21. See infra Part VIII.

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II. Genetic Testing-An Overview

Every person is genetically unique. An individual's genetic structure is the blueprint to his or her personal characteristics. A basic understanding of genetics begins with a discussion of deoxyribonucleic acid ("DNA"), which is the building block of an individual's genes. n22 These genes link together to make up chromosomes. Each individual has 23 pairs of chromosomes that ultimately determine the individual's genetic traits. Scientists estimate "that there are over 3 billion base pairs of DNA in the human genome." n23 The Human Genome Project began in 1990. n24 It is a collection of related, independent research projects with the ultimate goal of analyzing the structure of human DNA by mapping and sequencing the estimated 100,000 human genes. n25 Although its [*397] estimated completion date is 2005, n26 only a few thousand of the known genes have been mapped on particular chromosomes to date. n27

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n22. See Alton Biggs et al., Biology: The Dynamics of Life 312 (1995) (noting that organisms differ due to variations in the nucleotides of DNA).

n23. Id. at 386. The human genome is the approximately 100,000 genes in the 46 human chromosomes. See id.

n24. See Rothstein, supra note 11, at 24 (noting that the Human Genome Project is widely considered to be one of the most significant scientific projects ever conducted).

n25. See id. at 24 (citing Office of Tech. Assessment, U.S. Congress, Mapping Our Genes-The Genome Projects: How Big, How Fast? 4 (1988)).

n26. See id.

n27. See Biggs, supra note 22, at 386.

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Some genetic traits can be linked to a single, identifiable gene. Geneticists have been able to identify over 200 human traits that are coded by a single, dominant allele or contrasting gene. n28 About 250 other traits have been traced to homozygous recessive genes. n29 Other genetic traits, however, are controlled by multiple genes. n30 As scientists learn more about genetics, it will become possible to determine an individual's genetic susceptibility to different conditions based on an examination of the individual's genetic make-up. Genetic testing allows doctors to predict a person's potential for future health problems and behavior disorders. n31 Testing to identify genetic disorders can occur through two processes: genetic screening and genetic monitoring.

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n28. See Albert Towle, Modern Biology 171 (1993). Huntington's disease is an example of a trait linked to a single allele or dominant contrasting gene. See

id. This disease causes "loss of muscle control, uncontrollable physical spasms, severe mental illness, and eventual death." Id. at 172.

n29. See id. at 171. A homozygous recessive gene is a gene that is directly linked to a single genetic trait. For example, cystic fibrosis and phenylketonuria (PKU) are two genetic diseases linked to a single, recessive gene. See Biggs, supra note 22, at 358-59.

n30. See Towle supra note 28, at 173. Thus, in order for an individual to manifest such a trait, he or she would have to possess a certain combination of genes.

n31. See Kristie A. Deyerle, Comment, Genetic Testing in the Workplace: Employer Dream, Employee Nightmare - Legislative Regulation in the United States and the Federal Republic of Germany, 18 Comp. Lab. L.J. 547, 549 (1997) (noting the implications of genetic information for family members and its potential to stigmatize individuals).

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A. The Types of Testing-Tools For the Employer

Genetic screening is a one-time test performed on job applicants in order to determine their current genetic predisposition. n32 Employers may genetically screen applicants using two methods-each can be used to identify the presence of genetic traits that render a person hyper-susceptible to certain toxins n33 or detect general genetic conditions that are not necessarily associated with occupational diseases. n34 The first [*398] method, and the one most often used in the employment setting, is biochemical genetic screening. n35 This method consists of the analysis of mutant genes based on altered proteins or enzymes in the individual's bloodstream. n36 Biochemical genetic screening may be accomplished through either a simple blood test or the collection of a tissue sample. The second method is direct-DNA screening. n37 This method involves the direct examination of the individual's DNA.

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n32. See Genetic Monitoring Survey, supra note 2, at 5 (noting that the focus of genetic screening is the "preexisting genetic makeup" that workers bring to the job).

n33. See id. For example, an employer may screen applicants for susceptibility to benzene before beginning work when large amounts of benzene will be present in the workplace.

n34. See id. For example, an employee could be tested for sickle cell trait, or Huntington's disease, neither of which is triggered by workplace toxins.

n35. See id., at 21 tbls.1-5 (tracking Fortune 500 companies' use of genetic screening).

n36. See id. at 10 (noting that the strides in DNA technology have increased our capability to examine the genetic basis for disease and to protect and to diagnose such diseases in large population groups).

n37. See id. at 21 tbls.1-5. At the time of the survey, no employers reported current use of direct DNA-screening or monitoring of employees or applicants. See id.

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Several reasons may motivate employers to conduct these or similar medical tests. For example, some employers simply may be complying with OSHA guidelines that require medical testing. n38 Alternatively, employers may be paternalistically shielding susceptible workers from known toxins. The employer's rationale, however, may also be self-serving. For instance, as employers increasingly provide health benefits to workers, genetic and medical screening may be used to weed out job applicants or workers who are likely to have higher insurance costs. n39 In addition, employers may be interested in decreasing the costs associated with occupational illnesses by eliminating workers with a genetic predisposition to those diseases. n40

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n38. See infra Part V (discussing OSHA and genetic testing).

n39. See Rothstein, supra note 11, at 27 (pointing out that 42% of the companies questioned in an OTA survey used a job applicant's health insurance risk as a factor in deciding employability). This will unlikely serve as a successful argument for employers because of legislation, such as the Americans with Disabilities Act, that limit the type of medical testing employers are allowed to conduct on job applicants. See id. at 39-62 (discussing the ADA and its effect on genetic testing).

n40. See id. at 73 (noting that concern over this type of screening surfaced in the 1980s when it was documented that some employers were investigating genetic traits for a link to occupational exposure).

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The second type of genetic testing is genetic monitoring. These tests involve periodic testing of individuals to evaluate any modifications that may have occurred in their genetic material. n41 These tests help determine the effect of workplace toxins on an employee's [*399] genetic make-up. n42 Reasons given to conduct genetic monitoring include: identifying risks associated with certain toxins, targeting work areas for increased safety, and identifying previously unknown workplace toxins. n43

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n41. See Genetic Monitoring Survey, supra note 2, at 4 (listing "chromosomal damage" or "increased molecular mutations" during employment as examples of genetic material modifications).

n42. See id. It should also be noted that genetic monitoring can ascertain changes in genetic material due to factors outside the workplace such as habits, age, and lifestyle. See id.

n43. See id.

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Experts estimate that approximately three or four percent of all newborns, and approximately fifteen to twenty percent of adults, have congenital defects. n44 Additionally, each individual, regardless of any visible signs of a genetic defect, carries approximately five to seven lethal recessive genes. n45 Some of these defects will have immediate ramifications, while others only have future consequences or may have no impact on the individual's health. n46

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n44. See Deyerle, supra note 31, at 551 (noting that approximately one third of these adults have defects that involve either a major medical or major cosmetic impact).

n45. See id. The consequence of carrying a lethal recessive gene is that while the individual himself will show no evidence of the defect, it is potentially hazardous for the individual's offspring if he should mate with another person carrying the same recessive gene. See Raymond F. Oram, Biology Living Systems 144 (1983) (listing examples of diseases caused by gene defects such as sickle cell anemia, which blocks the normal transportation of oxygen to cells, and galactosemia, which may cause damage to the nervous system).

n46. See Oram, supra note 45, at 144. For example, carriers of one Tay Sachs gene will have no present symptoms. See Biggs, supra note 22, at 344. The disease could potentially manifest itself in the individual's offspring if he or she mated with another Tay Sachs carrier. Someone carrying the gene for Huntington's disease, however, will eventually develop the symptoms of this degenerative disease. It is not certain, however, when the symptoms will appear. See id. at 37, 161. Other diseases, such as phenylketonuria (PKU) and galactosemia can be treated successfully and will have little or no impact on an individual's ability to work productively. See Oram, supra note 45, at 145.

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Various illnesses, mental traits, and personality characteristics have been linked to genetics. n47 At present, however, most of the genetic [*400] tests available are unreliable and often inconclusive. n48 Often a genetic test can only reveal the possibility that a person may develop a certain disease in the future, but cannot tell whether the individual will actually get the disease. n49 This is true because genetic tests are limited to known genetic mutations associated with known diseases. n50 Even tests with high reliability cannot predict the time frame of disease onset and eventual prognosis. n51 The uncertainty associated with genetic tests makes their use in employment decisions risky. Specifically, even though individuals may never manifest symptoms during their lifetime, mere possibilities of disease or a future genetic condition may cause discrimination. The use of genetic testing is more frightening when considering the history of genetic discrimination in the United States. n52

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n47. See Rochelle Cooper Dreyfuss & Dorothy Nelkin, The Jurisprudence of Genetics, 45 Vand. L. Rev. 313, 320 (1992). Some personality traits thought to be linked to genetics include: mental illness, homosexuality, aggressive

personality, job and educational success, exhibitionism, stress, risk-taking behaviors, and shyness. See id. Some examples of diseases linked to genetics include: sickle cell anemia, Bloom's Syndrome, Tay-Sachs disease, breast cancer, cystic fibrosis, Huntington's disease, and thalassemia. See generally Gostin, supra note 5, at 111 nn.9-11 (pointing out the fact that specific genetic diseases are sometimes closely linked to particular ethnic or racial groups such as African Americans, Ashkenazi Jews and Armenians); Karen H. Rothenberg, Breast Cancer, The Genetic "Quick Fix" and the Jewish Community, 7 Health Matrix 97, 98 (1997) (noting that nearly one percent of sampled Eastern European Jews contain a gene mutation that predisposes them to breast and ovarian cancer); Katherine Brokaw, Comment, Genetic Screening in the Workplace and Employers' Liability, 23 Colum. J.L. & Soc. Probs., 317, 324 n.33 (1990) (charting genetic traits and the primary group of people affected).

n48. See Gostin, supra note 5, at 113 (explaining that medical technology does not always provide an accurate assessment); Brokaw, supra note 47, at 325-26 (discussing the inconclusive nature of scientific data linking traits to occupational disease).

n49. See Gostin, supra note 5, at 114. For example, new genetic studies have linked the gene BRCA1 to breast and ovarian cancer. See Rothenberg, supra note 47, at 98 (noting that this finding has prompted a clinical study to evaluate cancer risk in Eastern Europe). Only about 5 to 10% of breast cancer cases, however, are linked to this gene. See id. at 98-99. It is estimated that a woman from a high-risk family with the BRCA1 gene has an 85% chance of getting breast cancer. See id. at 99. This means that while many women with the BRCA1 gene will develop breast cancer, many others will not. An employer who does not wish to employ women who will contract breast cancer may screen employees for BRCA1, but only at the cost of excluding many workers who may never develop the disease.

n50. See Gostin, supra note 5, at 113 (noting that, at present, genetic screening can only detect 75% of cystic fibrosis chromosomes in the white population in the United States).

n51. See id. at 113-14. For example, the presence of Huntington's disease can be detected with 99% accuracy. See Gin, supra note 3, at 1415 (pointing out that a test to diagnose Huntington's disease may be administered at any time in a person's life and will have no bearing in the accuracy of the diagnosis). While a positive test result signals that an individual ultimately will get Huntington's disease, it is impossible to predict when the disease will manifest itself and how quickly the person will become debilitated. See Gostin, supra note 5, at 114 (attributing this inability to Huntington disease's "multi-factorial" nature and to the fact that it is caused by a specific gene mutation or marker). Thus, an individual with the genetic markers for Huntington's disease may lead a long, productive life before the onset of the debilitating symptoms. See Gin, supra note 3, at 1414-15 (estimating that the disease begins to surface at age 35).

n52. History has shown that we are apt to overreact to small steps in genetic under-standing, often with the result of discrimination against healthy, productive individuals.

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B. The History of Genetic Discrimination in America

Genetic discrimination is defined as "discrimination against an [*401] individual or a member of an individual's family solely on the basis of that individual's genotype." n53 The first known use of genetic discrimination occurred in the 1800s when Francis Galton published his theory of eugenics. n54 Eugenicists generally exaggerated the extent to which human behavior and other traits could be traced to biology, including the supposed connections between genetics and disease. n55 As early as 1938, J. B. S. Haldene introduced the idea of classifying workers based on their genetic susceptibilities to disease. n56 One of the first reported cases of genetic susceptibility to a chemical agent or drug was in the 1950s when some American soldiers in Korea experienced hemolysis, (the destruction of red blood cells), after receiving the anti-malaria drug primaquine. n57 The hemolysis was attributed to the soldiers' carrier status for glucose-6-phosphate dehydrogenase ("G-6-PD") deficiency. n58

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n53. Susan Malamate Vazakas, Genetic Discrimination and the Americans with Disabilities Act 24 (1993) (citing Billings et al., supra note 7, at 477).

n54. See Robert N. Proctor, Genomics and Eugenics: How Fair is the Comparison?, in Gene Mapping 57, 59 (George J. Annas & Sherman Elias eds., 1992). At the root of the eugenics movement was the fear that ""racial poisons' (especially alcohol, tobacco, narcotics, and syphilis) were threatening the health of the race; that the criminal, mentally ill, and morally dissolute were outbreeding the more upstanding elements of society." Id. at 60. One of the basic tenets of the eugenics movement was "biological determinism--the idea that biology lies at the root of most human talents and disabilities." Id.

n55. See id. This movement was especially strong in Germany where the Nazi government funded substantial research into the area of eugenics. See id. at 60.

n56. See Genetic Monitoring Survey, supra note 2, at 41 (noting Haldene's specific suggestion to screen out potters who had "constitutions" that predisposed them for bronchitis).

n57. See id.

n58. See id. (explaining that people with this trait or status are commonly found in malaria-ridden areas, and it is also prevalent among African Americans and those with a Mediterranean ancestry).

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History most vividly illustrates discrimination "based on genotype" through an examination of sterilization laws. During the early twentieth century many states enacted immigration laws aimed at "purifying and keeping pure blood in America." n59 In 1907, Indiana passed the United States' first sterilization law, forcing the sterilization [*402] of people suffering from many identified genetic disorders. n60 Other states followed suit over the next thirty years, generally targeting poor, immigrant, and institutionalized individuals. n61 The Eugenics Records Office was established in 1910 to collect genetic data to advise people on what constituted a fit marriage. n62 In 1927, the Supreme Court upheld these state-sanctioned sterilizations, and while this

practice today seems dubious, the Court has never specifically overruled this decision. n63

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n59. Daniel J. Kevles, In the Name of Eugenics: Genetics and the Use of Human Heredity 97 (1985) (citing Kenneth Ludmerer, Genetics and American Society 95-96 (1972)) (quoting Congressman Robert Allen of West Virginia). In addition to the states, the federal government also passed biological laws aimed at keeping America's blood "pure." See id. at 97. Specifically, in April 1924, President Calvin Coolidge signed the Immigration Act, which severely limited the entrance of Europeans into the United States through 1927. See id.

n60. See Proctor, supra note 54, at 61 (noting that Indiana's sterilization law was a product of both American Eugenics and German racial hygiene).

n61. See id. (noting that state laws preventing interracial marriages can also be linked to genetic discrimination); see also Patricia A. King, The Past as Prologue: Race, Class, and Gene Discrimination, in Gene Mapping 94, 98 (George J. Annas & Sherman Elias eds., 1992). The most comprehensive of these laws was passed in Iowa which allowed sterilization of inmates in public institutions for crimes and other reasons including "drug addition, sexual offenses, and epilepsy." Kevles, supra note 59, at 100.

n62. See Kevles, supra note 59, at 53-55 (discussing a program designed to ensure that marriages were appropriate based on a host of genetic criteria).

n63. See Buck v. Bell, 274 U.S. 200 (1927) (per curiam). The Court upheld Virginia's forced sterilization law for "mental defectives" and found that the law did not violate the Fourteenth Amendment's Due Process or Equal Protection Clauses. See id. at 207. The law purportedly provided sufficient procedural safeguards and only targeted those who need treatment, which is done for their benefit. See id. at 207-08.

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Several decades later, genetic screening again gained widespread use. Specifically, in the 1970s, sickle cell anemia screening programs began. n64 These programs were aimed to expose poor health care systems by identifying carriers of sickle cell anemia, a disease common among African Americans. n65 These programs were designed to identify both healthy carriers n66 and diseased carriers of sickle cell anemia. The programs affected healthy carriers of the gene because scientists suggested that carriers of the gene might be hyper-susceptible to certain workplace toxins such as benzene, lead, [*403] cadmium, carbon monoxide, and cyanide. n67 Based on these suggestions, employers began testing workers for the gene even though available evidence and studies did not support this theory. n68 Moreover, many state legislatures mandated sickle cell testing, leading to further fear and discrimination. n69 Inadequate measures to keep the test results confidential led to stigmatization and discrimination against sickle cell carriers in employment. n70 Further, lack of knowledge and understanding of the disease led to discrimination against many carriers of the trait even though they would never develop sickle cell disease. n71 To alleviate some of this stigma Congress passed the National Sickle Cell Anemia Control Act. n72 This Act withholds federal funding from states unless sickle cell testing is voluntary. n73

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n64. See Fox & Finesilver, supra note 12, at 75 (noting that screening was "widespread" until 1972 when a federal law mandated that all such screening be voluntary); see also King, supra note 61, at 98 (asserting that sickle cell anemia is a genetic disorder that may occur with varying severity and occurs with greatest frequency in people of African American descent).

n65. See King, supra note 61, at 99 (noting that these programs began with the best intentions, and were supported by African American leaders until they realized that such measures "would be used to stereotype and disadvantage the very people they sought to help.").

n66. A healthy carrier refers to an individual who carries only one gene for the trait. That person is said to be a sickle cell carrier. A person with sickle cell disease, on the other hand, has two sickle cell genes. That person will manifest symptoms of the condition. See Genetic Monitoring Survey, supra note 2, at 42 (discussing sickle cell traits and discrimination against carriers of sickle cell).

n67. See Brokaw, supra note 47, at 323 (discussing concerns leading to testing for sickle cell in the workplace).

n68. See id. Du Pont pioneered one of the first testing programs for employees exposed to benzene. See id. Du Pont, however, did not terminate workers who carried the sickle cell gene. See id. Instead, it transferred these workers to comparable positions where they would not come into contact with potentially dangerous toxins. See id. Additionally, Dow Chemical piloted one of the first cytogenetic monitoring programs in 1964. See Genetic Monitoring Survey, supra note 2, at 44. Dow conducted evaluations of employees exposed to epichlorohydrin and benzene. See id. These tests were discontinued in 1977 because of questions about validity and reliability of the results. See id. In the 1980s, Johnson and Johnson conducted cytogenetic monitoring on employees exposed to ethylene oxide. See id. After six months these tests were discontinued. See id.

n69. See Mark A. Rothstein, Medical Screening of Workers 73 (1984). Thirty states enacted legislation requiring African Americans to be tested for the sickle cell trait. See id. Twenty-one of these states have not repealed their sickle cell screening laws. See id. Some states required children be tested upon entering school while others would only issue marriage licenses on a showing that the individuals had been tested. See id. at 73-74.

n70. See King, supra note 61, at 99 (discussing how the mandatory testing of African Americans for sickle cell anemia negatively affected them because of the strong possibility for stereotyping, discrimination, and general misinformation).

n71. See id. For example, for many years the United States Air Force Academy refused to allow African Americans with sickle cell trait to participate in pilot training based on the mistaken belief that the low-oxygen environment associated with flight would cause the carrier to undergo a sickling episode. See Genetic Monitoring Survey, supra note 2, at 42-43. This policy was discontinued in 1981 even though it was determined in 1974 that there was

insufficient evidence to link carrier status with sickling episodes in low-oxygen environments. See id.

n72. See National Sickle Cell Control Act, Pub. L. No. 92-294, 86 Stat. 136 (1972) (codified as amended at 42 U.S.C. 300b (1976)).

n73. See id. 300b-2.

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Our country's experience with sickle cell anemia testing suggests the dangers inherent to genetic testing. Like the sickle cell tests of the 1970s, scientists today understand relatively little about the genetic [*404] conditions they are now able to identify. Today, we have the ability to identify an increasing number of genes, and scientists are working to correlate those genes with diseases and other human traits. In using this knowledge, scientists must be cognizant of past discrimination and avoid attaching any stigma to individuals because of the public's lack of knowledge and understanding of genetic traits. Extending the coverage of the ADA to persons with certain "inferior" genetic traits may help combat potential abuses that accompany genetic testing.

III. The Americans with Disabilities Act

Generally, employment decisions are based on some type of discrimination or differentiation. Employment applicants often are discriminated against on the basis of their level of education, previous experience, dress, mannerisms, and a host of other details. Congress, however, has prohibited the use of certain factors to differentiate among applicants. Title VII, for example, prevents discrimination based on race, religion, nationality, color, and sex. n74 More recently, Congress passed the ADA to discourage discrimination against individuals based on their disabilities. n75 The ADA potentially provides employees the greatest protection against genetic discrimination. n76

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n74. See 42 U.S.C. 2000e-2(a) (1964) ("It shall be an unlawful employment practice for an employer ... to discriminate against any individual ... because of such individual's race, color, religion, sex or national origin."); see also infra Part IV (analyzing Title VII and genetic discrimination).

n75. The ADA was passed in 1990 and became effective in 1992. See 42 U.S.C. 12111 (1990) ("No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to ... employment.").

n76. See Thomas H. Christopher & Charles M. Rice, The Americans With Disabilities Act: An Overview of the Employment Provisions, 33 S. Tex. L. Rev. 759, 760 (1992) (quoting 136 Cong. Rec. H2430 (daily ed. May 17, 1990) (statement of Rep. Conte)) (describing the ADA as the "declaration of independence" for millions of disabled Americans).

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A. Covered Entities Under the ADA

Title I of the ADA prohibits employment discrimination on the basis of disability, n77 by employers with fifteen or more employees. n78 The [*405] ADA also includes provisions that apply to public services performed by governmental entities; n79 public accommodations operated by private entities; n80 and telecommunications networks. n81

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n77. 42 U.S.C. 12112(a). The ADA provides that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such an individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment." Id.

n78. See id. 12111(5)(A); 29 C.F.R. 1630.2(e)(1) (1998). Employer, as defined in the ADA excludes "(i) the United States, a corporation wholly owned by the government of the United States, or an Indian Tribe; or (ii) [a] bona fide private membership club ... that is exempt from taxation under section 501(c) of the [Internal Revenue Code of 1986]." Id.

n79. See id. 12131-12165. "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity." Id. 12132.

n80. See id. 12181-12189. "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation ...." Id. 12182(a).

n81. See 47 U.S.C. 225, 611 (1994 & Supp. 1996). "The Commission shall ensure that interstate and intrastate telecommunications relay services are available, to the extent possible and in the most efficient manner, to hearing-impaired and speech-impaired individuals ...." Id. 225(b)(1).

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B. Medical Testing Under the ADA

The medical testing provisions within the ADA pose the first obstacle to employers who seek to perform genetic testing on job applicants. n82 While the ADA does not specifically define a medical test, n83 it was enacted to discourage the use of medical test results in the hiring process regardless of whether a revealed condition would have any impact on the applicant's ability to perform the job. n84 Further, while there is no precise meaning of a medical test it cannot seriously be argued that a genetic test is not a medical test under the ADA. The ADA addresses medical testing in three separate stages of the [*406] employment relationship: pre-employment, n85 after a job offer is made but before it is finalized, n86 and during employment. n87

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n82. See 42 U.S.C. 12112(d)(1) ("The prohibition against discrimination ... shall include medical examinations and inquiries."). This section was enacted to discourage the prevalent practice of medically testing job applicants and

making job offers based on the outcome of those tests regardless of whether the medical conditions revealed would have any impact on the applicant's ability to perform the job in question. See Christopher & Rice, supra note 76, at 790.

n83. The definition of a medical exam has been found to encompass psychological tests. See Barnes v. Cochran, 944 F. Supp. 897 (S.D. Fla. 1966), aff'd, 130 F.3d 443 (11th Cir. 1997); see also Equal Employment Opportunity Commision, ADA Enforcement Guidance: Pre-Employment Disability-Related Questions and Medical Examinations , BNA-DLR, Oct. 10, 1995, at 8, available in WESTLAW, 1995 DLR 196 d46 ("A "Medical Examination' is a procedure or test that seeks information about an individual's physical or mental impairments or health.").

n84. See Christopher & Rice, supra note 76, at 790 (discussing actions permitted and prohibited by the employer under the ADA). A survey conducted by the Office of Technology Assessment in 1989 (before the ADA was enacted) reported that 49% of companies surveyed required pre-employment health examinations of all job applicants and an additional 10% required health examinations for most job applicants. See Medical Monitoring Survey, supra note 6, at 4.

n85. See 42 U.S.C. 12112(d)(2)(A) (1990) ("[A] covered entity shall not conduct a medical examination or make inquiries of a job applicant as to whether such applicant is an individual with a disability or as to the nature or severity of such disability."); 29 C.F.R. 1630.14 (a) (1998) ("A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions ....").

n86. See 42 U.S.C. 12112(d)(2)(B) ("A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions.); 29 C.F.R. 1630.14(b) (stating that an employer may condition an offer of employment on the results of a medical exam after the offer is made).

n87. See 42 U.S.C. 12112(d)(3)(A) (allowing medical testing upon acceptance of an offer if all employees are tested as such); 29 C.F.R. 1630.14(c) ("A covered entity may require a medical examination ... of an employee that is job-related and consistent with business necessity.").

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1. Pre-employment Testing

Under the ADA, an employer cannot conduct pre-offer medical examinations on an applicant. n88 In addition, the employer is prohibited from asking an applicant about the existence or severity of any disability. n89 The employer may, however, inquire into the ability of the applicant to perform job-related functions. n90 It is likely, however, [*407] that most genetic disorders do not present symptoms that affect job-related functions. n91 Only testing reveals the existence of a genetic marker in the individual, therefore, the individual who is unaware of his or her genetic condition cannot answer questions about the unknown. Even if an individual had knowledge of a genetic disorder, an inquiry into whether an individual could perform basic job functions would be irrelevant in most cases of latent genetic disorders because the disorder would have no discernible effect on the employee's ability to perform the job at the present moment.

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n88. See 42 U.S.C. 12112(d)(2)(A). This is particularly significant in light of a study indicating that, prior to the passage of the ADA, 87.8% of large plants (those with more than 500 workers) and 56.4% of medium plants (those with 100-499 workers) required medical examinations prior to employment. See Jennifer M. Ratcliffe et al., The Prevalence of Screening in Industry: Report from the National Institute for Occupational Safety and Health, National Occupational Hazard Survey, 28 J. Occupational Med. 906, 907-08 (1986); see also Rothstein, supra note 11, at 52-53 (stating that at the time of the article (1992), nearly 90% of workers at larger plants and over 50% of workers at smaller plants were subjected to pre-employment medical examinations).

n89. See 42 U.S.C. 12112(d)(2)(A). The ADA does recognize, however, the right of employers to ask questions about disabilities in limited situations. See Christopher & Rice, supra note 76, at 791-92 (discussing legitimate reasons for an employer to invite a job applicant to identify his disabilities). The ADA's legislative history indicates that an employer may inquire as to disabilities and their extent if the employer is taking affirmative action to correct past discrimination or in order to overcome the effect of conditions that previously prevented the employer from hiring disabled individuals. See id. In requesting this information the employer must inform the applicant that it is for remedial or affirmative action purposes, it is entirely voluntary, and that the information will be kept confidential and will not be used to discriminate against the applicant. See id. at 792.

n90. See 42 U.S.C. 12112(d)(2)(B) ("A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions."). In fact, EEOC guidelines suggest that an employer may list the essential job functions and ask an applicant whether he or she is capable of performing those functions. See 29 C.F.R. 1630.14(a). The Code of Federal Regulations states that: "A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions and/or may ask an applicant to describe or to demonstrate how, with or without reasonable accommodation, the applicant will be able to perform job-related functions." Id.

n91. Often these genetic disorders will manifest no symptoms at all during the individual's entire life span. For example, the carrier of a single recessive gene for Tay Sachs Disease of Galaetosemia will have no symptoms of the disease. See Oram, supra note 45, at 161.

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A second pre-employment issue arises after the offer of employment is extended. Such an offer is not always permanent. Typically, once the offer of employment is made, that offer may be conditioned on the outcome of a medical examination. n92 The ADA provides that "[a] covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of such examination." n93 These examinations must satisfy three requirements. First, an employer must test all entering employees regardless of disability. n94 Second, the information collected must be maintained on separate forms and in a separate medical file and treated as confidential. n95 Third, the results of the medical examination may be [*408] used only "in accordance with this sub-chapter." n96 This

section, however, does not restrict the purpose behind the test, so an employer may theoretically test for any medical condition. In fact, the relevant EEOC regulation states that "medical examinations conducted in accordance with this section do not have to be job-related and consistent with business necessity." n97 Yet, the third requirement under the ADA provides protection against discrimination, n98 which means that while the employer can test for anything, he cannot then use the test results to discriminate against the employee or applicant in violation of the ADA. n99

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n92. In some cases the law may even require employers to perform medical examinations before allowing a worker to begin employment. For example, OSHA requires medical examinations of employees who will be exposed to certain toxins. See infra note 199 (providing examples of circumstances when testing is required).

n93. 42 U.S.C. 12112(d)(3); see also 29 C.F.R. 1630.14(b) ("A covered entity may require a medical examination ... after making an offer of employment ... and may condition an offer of employment on the results of such examination.").

n94. See 42 U.S.C. 12112(d)(3)A); 29 C.F.R. 1630.14(b) (conditioning medical examinations on the fact that "all entering employees in the same category are subjected to such an examination ... regardless of disability").

n95. See 42 U.S.C. 12112(d)(3)(B); 29 C.F.R. 1630.14(b)(1). There are exceptions to the confidentiality rule for: (1) supervisors and managers who need to be informed of any required restrictions on the work or duties of employees and any necessary accommodations; (2) first aid and safety personnel who may be informed when the disabled individual might require emergency medical treatment; and (3) government officials investigating compliance with the Act. See 29 C.F.R. 1630.14(b)(1)(i-iii).

n96. 42 U.S.C. 12112(d)(3)(C).

n97. 29 C.F.R. 1630.14(b)(3).

n98. See 42 U.S.C. 12112(d)(3)(C); see also 29 C.F.R. 1630.14(b)(3) (stating that "if certain criteria are used to screen out an employee or employees with disabilities as a result of such an examination or inquiry, the exclusionary criteria must be job-related and consistent with business necessity, and performance of the essential job functions cannot be accomplished with reasonable accommodation").

n99. See 42 U.S.C. 12112(b)(6) (providing that an employer cannot use "employment tests or other selection criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities unless the standard, test or other selection criteria, as used by the covered entity, is shown to be job-related for the position in question and is consistent with business necessity") (emphasis added).

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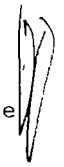
2. Testing During Employment

An individual's status as an employee restricts the type of medical examinations an employer can require throughout the duration of employment. n100 Medical examinations of employees must be "job-related and consistent with business necessity." n101 In addition, an employer can conduct voluntary medical examinations, including those that accompany an employee health program. n102 The employer may [*409] also make inquiries into "the ability of an employee to perform job-related functions." n103



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n100. See id. 12112(d)(4)(A) ("A covered entity shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability ...."). However, the Code of Federal Regulations makes clear that "[a] covered entity may require a medical examination ... of an employee that is job-related and consistent with business necessity." 29 C.F.R. 1630.14(c).

n101. 42 U.S.C. 12112(d)(4)(A); 29 C.F.R. 1630.14(c). These sections may interact with other laws such as OSHA that require employers to perform medical tests on workers exposed to certain toxins.

n102. See 42 U.S.C. 12112(d)(4)(B). The statute states, "[a] covered entity may conduct voluntary medical examinations, including voluntary medical histories, which are part of an employee health program." Id.; see also 29 C.F.R. 1630.14(d) (stating "[a] covered entity may conduct voluntary medical examinations and activities, including voluntary medical histories, which are part of an employee health program").

n103. 42 U.S.C. 12112(d)(4)(B); see also 29 C.F.R. 1630.14(c).

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Genetic screening would theoretically be legal if it were "directly related to qualifications for doing the task or if necessary for employee safety." n104 Job-relatedness, however, generally applies only to the employee's present capability to perform the job. n105 It is doubtful that most genetic conditions, especially asymptomatic ones, would rise to the level of job-relatedness or business necessity so as to allow an employer to discriminate against applicants with the condition. An asymptomatic genetic disorder might have future ramifications, but would not affect the individual's present ability to perform his or her job. An employer could rarely justify genetic screening based on job-relatedness in order to overcome the ADA's protection.

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n104. Charles B. Gurd, Whether a Genetic Defect is a Disability Under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers, 1 Annals Health L. 107, 110 (1992) (quoting Peter T. Rowley, Genetic Discrimination: Rights and Responsibilities of Tester and Testee: Summary of a Workshop Sponsored by the Social Issues Committee, American Society for Human Genetics, November 2, 1986, 43 Am. J. Hum. Genetics 105 (1988)) (analyzing whether genetic defects qualify as disabilities under the ADA).

n105. See 29 C.F.R. 1630.10 (noting that tests must be related to the position in question); see also Gurd, supra note 104, at 110 (suggesting that

refusal to employ a disabled applicant should only be allowed where the applicant is presently unable to perform the job).

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Overall, with the exception of medical tests required by OSHA or other federal regulations, employers are most likely to use genetic testing after a conditional job offer is made, but before the offer is finalized. n106 Employers have a right to conduct medical or genetic tests at this stage in the hiring process. The issue becomes whether the employer can use the information gained from these tests to discriminate against workers with genetic defects.

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n106. See Medical Monitoring Survey, supra note 6, at 4. While few employers are currently using genetic screening, an OTA survey found that approximately 50% of responding personnel officers said they would approve of health exams of applicants for workplace susceptibilities. See id.

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C. Establishing an ADA Claim

In order to establish a discrimination claim under the ADA, an applicant or employee must show that he (1) has a disability, (2) was otherwise qualified for the employment or benefit in question, and (3) was excluded from the employment or benefit because of the [*410] disability. n107 Whether an individual is affected by a disability, as defined under the ADA, is generally the most controversial issue in a genetic discrimination claim. A plaintiff can establish a disability under the ADA three different ways. A disability is defined as "(A) a physical or mental impairment that substantially limits one or more of the major life activities ... ; (B) a record of such an impairment; or (C) being regarded as having such an impairment." n108

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n107. See 42 U.S.C. 12112(a) ("No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual ... [in] employment.").

n108. Id. 12102(2).

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1. Physical or Mental Impairment Substantially Limiting One or More Major Life Activities

The EEOC has defined a physical impairment as "any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin and endocrine." n109 Mental impairments encompass "any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities." n110 Not all impairments receive protection under the

ADA. In order to receive protection, the impairment must substantially limit a major life function. Whether a disability is "substantially limiting" depends on the nature and severity of the impairment, the duration or expected duration of the impairment, and the permanent or long-term impact of the impairment. n111 Additionally, to invoke coverage under this prong, the impairment must affect "a major life activity." The EEOC regulations provide that a "major life activity" includes things such as "caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." n112

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n109. 29 C.F.R. 1630.2(h)(1).

n110. Id. 1630.2(h)(2).

n111. See 29 C.F.R. 1630.2(j)(2). A person with a short-term injury, such as a broken leg, would not qualify as having a substantially limiting impairment; nor would someone with a temporary illness such as influenza or pneumonia. See Christopher & Rice, supra note 76, at 769 (providing examples of substantially limiting impairments).

n112. 29 C.F.R. 1630.2(i) (emphasis added). The EEOC has added sitting, standing, lifting, reaching, reading, thinking, concentrating, and interacting with others as major life functions. See 29 C.F.R. pt. 1630 App. 1630.2(i); EEOC Disability Guidance 902.3(b); EEOC Technical Assistance 2.2(a)(ii). The United States Supreme Court recently added reproduction to the list of major life functions and hinted that sexual relations were a major life function as well. See Bragdon v. Abbott, 118 S. Ct. 2196, 2205 (1998).

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[*411] Most genetic disorders do not exhibit present symptoms that would qualify as "substantially limiting a ~~major life function~~." n113 Specifically, subsection (A) of the ADA appears to omit three major categories of genetic disorders. First, this section would not apply to an individual whose genetic defect has not yet become a physical disorder, but may become one in the future. n114 Second, this section does not protect an individual who may be a carrier for a disease that will never manifest itself in the individual, but may appear in his or her offspring. n115 Finally, the section does not protect a person who may have a disabling disorder that is under treatment, but manifests no physical symptoms. n116 Employees in any of these three categories would not be protected under section (A) of the ADA because their "disability" does not currently affect "a major life function." n117 If an [*412] employee did have a disability and exhibited symptoms that limited a major life function, he would be covered under this section whether the root of that disability was a genetic defect or another medical condition.

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n113. For example, an individual with sickle cell trait will never develop symptoms. Additionally, a person who is identified as having a genetically higher risk of breast cancer, but without the disease, would not have a disability that presently substantially limits any major life function.

n114. For example, the gene for Huntington's disease is carried by a person for his or her entire life, but the disease may not cause physical symptoms for years. None of the listed major life activities, therefore, are presently limited. See Gin, supra note 3, at 1414-15 (providing a description of the physical manifestations of Huntington's disease).

n115. For example, Tay Sachs disease, a disease caused by a recessive gene, usually results in death by age three due to failure of the nervous system to properly develop. Whether a person is a carrier for Tay Sachs is detectable through a simple blood test. The carrier, however, will not manifest the disease. The only danger is to the individual's offspring if he or she should have a child with another Tay Sachs carrier. See Oram, supra note 45, at 161 (discussing the effects of Tay Sachs disease on both carriers and those who exhibit its symptoms).

n116. See id. (noting that PKU, a disease caused by a recessive gene, if left untreated will result in severe mental retardation, can be successfully treated through diet). Note, however, that some courts have determined that these individuals would qualify as "disabled" under the ADA because they do not take into account mitigating measures, but rather look to the individual in an unmedicated state. See, e.g., Matczak v. Frankford Candy & Chocolate Co., 136 F.3d 933, 937 (3d Cir. 1997) (involving a former epileptic employee who brought a suit against his former employer for violating the ADA when the employee was dismissed due to his condition).

n117. See supra note 112 and accompanying text (describing "a major life activity" under section (A) of the ADA). For a carrier of an inheritable disease such as Tay Sachs it can be argued that reproduction is a major life function that is substantially impaired. This argument, however, has generally been unsuccessful even in the context of AIDS where the risk of passing on the disease to one's offspring is much greater than for carriers of Tay Sachs, and the risk is associated with all partners rather than other carriers of the trait. See Runnebaum v. NationsBank of Md., 123 F.3d 156, 172 (4th Cir. 1997) (finding that AIDS does not substantially limit procreation, and intimate sexual conduct does not interfere with a major life function under the ADA); Cortes v. McDonald's Corp., 955 F. Supp. 541, 546 (E.D.N.C. 1996) (finding that procreation was not a major life function under the ADA); Zatarain v. WDSU-Television, Inc., 881 F. Supp. 240, 243 (E.D. La 1995) (finding that reproduction was not a major life function), aff'd, 79 F.3d 1143 (5th Cir. 1996). But see Doe v. District of Columbia, 796 F. Supp. 559, 568 (D.C. Cir. 1992) (finding that an HIV-positive firefighter was substantially impaired in the major life functions of "procreation, sexual contact, and normal social relationships").

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2. Record of Impairment

The ADA's second classification of disability involves an individual's record of a substantially limiting impairment. n118 Through this requirement, Congress sought to protect individuals who have recovered from a disabling condition, n119 and individuals who never had a disability, but were misclassified or misdiagnosed in the past. n120 This prong may have ramifications for individuals who incorrectly test positive for a genetic disorder, an outcome that is highly likely given the inaccuracies and inconsistencies of current genetic tests.

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n118. See supra note 108 and accompanying text (providing the definition of a disability under the ADA).

n119. See Christopher & Rice, supra note 76, at 770 (citing S. Rep. No. 116, 101st Cong., 1st Sess. 23 (1989); H.R. Rep. No. 485, 101st Cong., 2d Sess., pt. 2, at 52 (1990)).

n120. See 29 C.F.R. 1630.2(k) (1998) ("Has a record of such impairment means has a history of, or has been misclassified as having, a mental or physical impairment.").

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3. Regarded as Having an Impairment

The third prong, subsection (C), is the employee's greatest protection against genetic discrimination. This prong includes "being regarded as having such an [substantially limiting] impairment." n121 Subsection (C) recognizes that "society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment." n122 To determine [*413] whether an employee is regarded as having a disability the court must "examine the employer's perception and treatment of the charging party." n123 Unlike the other disability categories, this section is based on the employer's perceptions, not the existence of a true disability or even the individual's own perception of himself or herself as disabled. Individuals with asymptomatic genetic disorders, therefore, would most likely be covered by this section because employers would be discriminating based on the presence of a genetic anomaly, not on the employee's inability to perform. n124

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n121. See 42 U.S.C. 12102(2) (1990).

n122. School Bd. of Nassau County v. Arline, 480 U.S. 273, 284 (1987) (finding that the dismissal of a teacher based on her susceptibility to tuberculosis violated the Rehabilitation Act of 1983. Even though she was not impaired she was being discriminated against because of a perceived impairment). The category of perceived impairment has been used to protect individuals with severe burns, asymptomatic back abnormalities, and high blood pressure. See Christopher & Rice, supra note 76, at 771-72 (discussing examples of being "regarded as having an impairment" under the ADA). The Rehabilitation Act of 1983 was a precursor to the ADA that only applied to government employees. While the Rehabilitation Act has not been repealed, it is not dealt with in this paper because of its similarity to the ADA, which is discussed in-depth.

n123. EEOC Compl. Man. (BNA) 902.8(a) (1995).

n124. But see Or. Rev. Stat. 659.705(e) (Supp. 1998) (stating the legislative finding that "current legal protections for medical information, tissue samples and DNA samples are inadequate to protect genetic privacy"); Frank R. Emmerich, Jr., Employee Terminated/Cause of Action Dismissed: The Americans with Disabilities Act Provides No Haven for Employees Hypersusceptible to Genetic

Illness, 4 J. Individual Empl. Rights 185 (1995-96) (suggesting that an employee will not be able to challenge genetic discrimination under the ADA because a genetically hyper-susceptible employee does not have a "disability" within the meaning of the ADA); Gostin, supra note 5, at 142-43 (suggesting that the ADA fails to adequately protect against genetic discrimination because of its silence about discrimination based on the potential for future disability); Rothstein, supra note 11, at 83-84 (concluding that the ADA does not provide sufficient protection to employees against genetic discrimination).

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D. EEOC Guidelines

The Equal Employment Opportunity Commission must develop standards and guidelines to implement federal laws that deal with equality in employment. The EEOC has failed to provide clear direction regarding genetic classification as a form of discrimination under the ADA. In its first statement on the subject, the EEOC refused to include genetic discrimination as a violation of the ADA. n125 In 1991, the Acting Director of Communications and Legislative Affairs for the EEOC wrote an opinion letter stating that the ADA does not prohibit genetic discrimination "until the condition "exists' and the individual is symptomatic." n126 This letter, however, was only an [*414] informal statement given to the news media with little lasting authority.

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n125. See Rothstein, supra note 11, at 45 (citing Letter from Ronnie Blumenthal, Acting Director of Communications and Legislative Affairs, EEOC, to Rep. Bob Wise, Chairman, House Subcommittee on Government Information, Justice and Agriculture (Nov. 22, 1991)); see infra note 126 (providing text of letter in which the Acting Director of Communications and Legislative Affairs for the EEOC stated that the ADA does not cover genetic discrimination).

n126. Rothstein, supra note 11, at 45 (citing Letter from Ronnie Blumenthal, Acting Director of Communications and Legislative Affairs, EEOC, to Rep. Bob Wise, Chairman, House Subcommittee on Government Information, Justice and Agriculture (Nov. 22, 1991)). The letter stated that:

Everyone has hereditary genetic characteristics that predispose them to the onset of particular illnesses or diseases that could become disabilities under the ADA. If your grandmother had heart disease, you may have a predisposition to heart disease .... However, the presence of these genetic characteristics does not indicate that an individual has an impairment or a record of an impairment, or necessarily that the individual may develop an impairment in the future. Consequently, the Commission determined that a characteristic predisposition to illness, like that revealed in a family history, is not an impairment covered by the ADA.

Id. at 46-47. The letter also stated that genetic issues "are unique and outside the Commission's expertise, [and therefore] they should be resolved by means of legislation, not by agency regulation." Id. ; see also Emmerich, supra note 124, at 200 (explaining that the EEOC's interpretation of the ADA as described in the November 22, 1991 letter prevented individuals with genetic disorders from receiving ADA protection from genetic discrimination).

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In its first formally published statement on the subject, the EEOC reversed this position and included genetic discrimination under the auspices of the ADA. The EEOC compliance manual now includes a short statement that addresses the "being regarded as having a disability" prong of the ADA's disability test. This statement provides that the ADA:

Applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability." n127

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n127. EEOC Compl. Man. (BNA) 902.8(a) (1995).

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This more recent statement better illustrates the modern ADA inter-pretation. If the intent behind the law is to protect individuals from the myths and fears of society, it should apply to individuals with genetic disorders as well as other types of asymptomatic diseases.

E. An Employer's Defense Under the ADA

The ADA does not per se prevent discrimination against disabled individuals. The interests of the worker are balanced against the interests of the employer to determine whether the employer can discriminate against a specific worker or applicant. One way for an employer to circumvent the ADA protections is to establish that making [*415] accommodations for the disabled worker would create an "undue hardship" on the employer. n128

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n128. See 42 U.S.C. 12112(b)(5)(A) (1990). The statute states that a reasonable accommodation must be provided to an otherwise qualified but disabled individual unless the employer "can demonstrate that the accommodation would impose an undue hardship on the operation of the business" of the employer. Id.

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1. Undue Hardship

The ADA defines an "undue hardship" as "an action requiring significant difficulty or expense." n129 In order to determine whether the proposed accommodation would constitute an undue hardship, the employee's interests are balanced against those of the employer. n130 In some instances an employer

must expend substantial sums of money to accommodate a disabled employee if it cannot establish an undue hardship. n131

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n129. Id. 12111(10)(A). The Code of Federal Regulations further defines undue hardship as referring to "any accommodation that would be unduly costly, extensive, substantial, or disruptive, or that would fundamentally alter the nature or operation of the business." 29 C.F.R. 1630.2(p) app. at 353-54 (1998).

n130. Courts consider several factors in balancing an employee's interest against the expense to an employer. The factors to be considered include: (1) the nature and cost of the modifications; (2) the overall financial resources of the facility; (3) the number of employees at the facility; (4) the overall financial resources of the entire company; (5) the type of operations of the company; and (6) the impact the accommodations would have on the operations at the facility. See 29 C.F.R. 1630.2(p)(2). The EEOC has not given guidelines as to how each of these factors should be weighted in determining whether accommodating a disabled worker would be an undue hardship.

n131. See 29 C.F.R. 1630.2(p) app. at 353-54 (stating "in other cases, consideration of the financial resources of the employer ... may be inappropriate because it may not give an accurate picture of the financial resources available to the particular facility that will actually be required to provide the accommodation"). For example, a large company may be required to provide costly accommodations to a worker at a small facility based on its overall resources. If that accommodation, however, would result in the closing of the small plant due to unprofitability, then the modification might not be required even though the overall company could afford it. See Christopher & Rice, supra note 76, at 782-84 (citing H.R. Rep. No. 485, 101st Cong. 2d Sess., pt. 2, at 69-70 (1990)) (explaining that "the overall size of the employer may be decisive in some instances, but the local situation may be the determinative factor in others").

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It would be difficult for an employer to establish that it could not reasonably accommodate a hyper-susceptible worker without an undue hardship. Asymptomatic carriers of genetic diseases do not need workplace modifications and it is doubtful the employer can hide behind fears of the need for future modifications. Failure to reasonably accommodate based on the economic costs of future illness [*416] has never successfully been raised by an employer. n132 The employer, however, may be able to reduce the effect of future costs by limiting the type of medical insurance available to the employees. n133 Employers have alleged that the rising insurance cost and other health care benefits create a sufficient "undue hardship," but this too is likely to fail. n134

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n132. See Shawn v. Legs Co. Ltd. Partnership, No. 89-23216, 1989 WL 258819 (N.Y. Sup. Ct. Sept. 11, 1989) (refusing to allow employer to use speculation concerning future health problems to discriminate against an employee).

n133. The limitation, however, would have to apply to all employees. Providing different insurance to different employees based on genetic make-up would run afoul of the ADA. See also James G. Frierson, Employer's Guide to the Americans with Disabilities Act 222 (2d ed.1995) (noting that the legality of insurance caps for AIDS under the ADA has not yet been decided).

n134. See id. at 221 (discussing doubt that excessive insurance costs can be used by employers to justify discrimination against employees or applicants with AIDS or HIV). But see Emmerich, supra note 124, at 210 (arguing that when considering health care costs and the costs of training an employee who is not likely to provide long years of service, it would be possible that the employer, especially a smaller one, would be protected from the ADA provisions requiring accommodations). In addition, employers who self-insure may be able to cut health costs by eliminating insurance coverage for specific genetic diseases. Because 501 of ERISA protects the self-insured from broad ERISA legislation, the self-insuring employer may be able to side-step the ADA by eliminating coverage for specific illnesses. For example, in McGann v. H & H Music Company, 946 F.2d 401 (5th Cir. 1991), an employer who discovered an employee was diagnosed with HIV reduced the health benefits available for AIDS from $ 1 million to $ 5,000. This action was upheld by the Fifth Circuit, even though it had an adverse effect on the disabled worker. See McGann, 946 F.2d at 408; see also Owens v. Storehouse, Inc., 984 F.2d 394 (11th Cir. 1993) (upholding an employer's right to modify its insurance plan to include a $ 25,000 lifetime cap for AIDS-related claims).

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Because there is no case law n135 and few regulations address genetic disorders and discrimination under the ADA, observers must compare genetic discrimination with other types of medical discrimination. Genetic discrimination is best analogized to discrimination against asymptomatic individuals with Human Immunodeficiency Virus ("HIV").

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n135. See Fox, supra note 13 (discussing Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998), which is a currently pending case concerning an employer's use of genetic testing).

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F. HIV as a Disability Under the ADA-A General Comparison

Like many genetic disorders, HIV is a precursor to a more serious illness: Acquired Immune Deficiency Syndrome ("AIDS"). A simple blood test can identify HIV. Testing positive for HIV means that there is a high likelihood the individual will contract AIDS in the future.

[*417] In Bragdon v. Abbott, n136 the Supreme Court recently held that an individual with asymptomatic HIV is disabled under the ADA. n137 The Court found that even asymptomatic HIV was a physical impairment because the virus is still thriving within the individual's lymph nodes although relatively few symptoms are exhibited during this stage. n138 The Court also pointed to the fact that an HIV infection "causes immediate abnormalities in a person's blood." n139 Like any other medical test, the employer could arguably include an HIV test as

part of a post-offer medical exam, but would be limited on how it could use that information. n140 Like any other disability, the ADA only permits an employer to rescind a job offer based on a positive test result if the applicant is unable to perform the job n141 or is a threat to the safety or health of others. n142 A direct threat may arguably exist in those few jobs where the employee is likely to come in contact with bodily fluid from other individuals. Even here, however, the Center for Disease Control does not recommend mandatory HIV testing. n143 In addition, a [*418] minority of states have promulgated statutes that restrict HIV testing. n144 Most of these states prohibit employers from performing HIV tests or requiring the employee to disclose the results of tests taken privately. n145

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n136. Bragdon v. Abbot, 118 S. Ct. 2196 (1998).

n137. See id. at 2204.

n138. See id. ("The HIV infection must be regarded as a physiological disorder with a constant and detrimental effect on the infected person's hemic and lymphatic systems from the moment of infection.").

n139. Id.

n140. Its use as part of a post-offer medical exam is permitted if not prohibited by state law. See, Me. Rev. Stat. Ann. tit. 5, 19204-B (West Supp. 1998) (prohibiting an employer from requiring an HIV test for an employee or prospective employee as a condition of employment); Vt. Stat. Ann. tit. 3, 961 (1995), (stating it is an unfair employment practice for an employer to condition future or continuing employment on testing for HIV); Wis. Stat. Ann. 103.15 (1997) (providing that no employer may, as a condition of employment, require any employee or prospective employee to submit to an HIV test).

n141. See 42 U.S.C. 12113(a) (1990) (explaining that standards which "tend to screen out or otherwise deny a job or benefit to an individual with a disability" may be a defense to discrimination if such standards "have been shown to be job-related and consistent with business necessity, and such performance cannot be accomplished by reasonable accommodation"); see also 29 C.F.R. 1630.14(b)(3) (1998) (stating that exclusionary criteria is permissible where such criteria is "job-related and consistent with business necessity, and performance of the essential job functions cannot be accomplished with reasonable accommodation").

n142. See 42 U.S.C. 12111(3) (defining a "direct threat" as "a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation").

n143. See Stephen F. Befort, Pre-Employment Screening and Investigation: Navigating Between a Rock and a Hard Place, 14 Hofstra Lab. L.J. 365, 389 (1997) (citing Recommendations for Prevention of HIV Transmission in Health-Care Settings, 36 Morbidity & Mortality Wkly. Rep., at 15S-17S) (noting the CDC's recommendations that "health care workers who perform exposure prone procedures voluntarily monitor their own HIV status and refrain from performing those procedures if they become HIV infected").

n144. See Me. Rev. Stat. Ann. tit. 5, 19204-B (West Supp. 1998) (providing that employers may not request prospective employees to submit to HIV tests); Vt. Stat. Ann. tit. 3, 961 (1995) (stating that employers may not discriminate against future or current employees on the basis of HIV tests); Wis. Stat. Ann. 103.15 (1997) (prohibiting employers from requiring HIV tests prior to employment or discriminating against employees because of the HIV test).

n145. See Me. Rev. Stat. Ann. tit. 5, 19204-B; Vt. Stat. Ann. tit. 3, 961; Wis. Stat. Ann. 103.15.

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When genetic testing is compared to HIV testing, it is clear that a genetic disorder (or hyper-susceptibility) should also be considered a disability under the ADA. Like HIV, most genetic disorders do not affect job performance. The only effect, if it ever manifests, will be in the future. Furthermore, an HIV blood test has a much higher accuracy rate than most genetic tests. n146 Like many tests for genetic disorders, no test can predict when an individual will contract AIDS or the individual's capability to continue a productive existence after contracting AIDS. Unlike most genetic diseases, however, AIDS is contagious. n147 Therefore, HIV is potentially more dangerous in the workplace than most genetic diseases. n148 If an infectious disease such as HIV is regulated, so should genetic testing, which poses no contagious risk. n149

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n146. See Joseph W. Moch & William Thompson, Suing for Misdiagnosis and Improper Treatment of HIV, Mich. L. Wkly, Summer 1992, at 6A (stating that the ELISA and Western Blot HIV tests are very accurate).

n147. Although AIDS cannot be spread casually, it is considered an infectious disease.

n148. Since there are few professions where employees are in contact with blood and other bodily fluids on a daily basis, it is arguable that fear of contagion is not legitimate at all because of the difficulty in spreading HIV and AIDS through casual contact.

n149. The only exception is the potential danger to an individual's offspring if conceived after the individual has contracted HIV. The danger of HIV to an unborn fetus is outside the scope of this article.

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IV. Genetic Discrimination as a Form of Racial Discrimination Under Title VII

At first glance, racial or ethnic discrimination based on genetic testing seems far-fetched. After all, what could be more color-blind than a test that identifies anomalies at the cellular level of human biology? The lessons of history, however, teach us differently. From the eugenics projects of the early 1900s, n150 to the discrimination that [*419] arose out of the sickle cell anemia scare, n151 racial and ethnic discrimination has arisen in the most unlikely places.

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n150. See supra notes 54-63 (examining the turn of the century movement towards classifying workers, criminals, and prospective spouses according to gene type).

n151. See supra notes 64-72 and accompanying text (discussing the historic discrimination in the United States against individuals who were carriers of the sickle cell anemia trait).

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Advances in genetic mapping may have a disproportionate effect on minority groups. n152 Because genetic information is complex and easily misunderstood, it may be manipulated to legitimize existing racial and ethnic stereotypes. n153 Some authors suggest that the potential for manipulation may result in the creation of a biological underclass composed mostly of minority groups. n154 For example, Patricia King posits that when a disease occurs more frequently among a particular minority group, two negative consequences can arise. First, members of the minority group without the trait may be stigmatized and discriminated against solely because they are part of a group associated with the trait. n155 Second, a disease associated with a minority group is less likely to be highly prioritized in the search for a treatment or cure. n156 Protection, however, against this discrimination may exist under Title VII of the Civil Rights Act of 1964 ("Title VII") n157 if genetic testing causes discrimination that has a disparate impact on a particular minority group.

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n152. See King, supra note 61, at 99-102 (reasoning that lessons from the past suggest that current and future gene mapping efforts could potentially have a negative impact on minority groups).

n153. See id. (citing D. Nelkin & L. Tancredi, Dangerous Diagnostics: The Social Power of Biological Information (1989)).

n154. See id.

n155. See id. King uses the potent image of the existing discrimination against gay men who are not infected with HIV but are discriminated against because they are part of a group that is associated with HIV and the AIDS virus. See id. at 100.

n156. See id. at 100 (stating "because of [the disease's] higher frequency among the members of an identifiable minority group, the disease might be given lower priority in terms of research for treatment or cure").

n157. 42 U.S.C. 2000e (1994).

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A. Title VII

Title VII prevents discrimination in employment based upon race, religion, nationality, color, and sex. n158 Claims are brought under Title VII through

one of two theories: (1) disparate treatment theory or (2) disparate impact theory.

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n158. 42 U.S.C. 2000e-2(a)(1) (providing "it shall be an unlawful employment practice for an employer to fail or refuse to hire ... any individual ... because of such individual's race, color, religion, sex, or national origin").

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1. Disparate Treatment Theory

Disparate treatment discrimination is the most identifiable type of discrimination under Title VII. "The employer simply treats some people less favorably than others because of their race, color, religion, sex, or national origin." n159 The most important element in disparate treatment discrimination is that the employer must have intended to discriminate against the individual because of a particular trait. n160

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n159. Teamsters v. United States, 431 U.S. 324, 335 n.15 (1977). The Court held that when a company engages in a pattern or practice of discrimination against minorities in its hiring practices, it will be held in violation of Title VII of the Civil Rights Act. See id. at 335-36.

n160. In some situations a discriminatory motive may be inferred solely from the fact of different treatment. For example, in Wroblewski v. Lexington Gardens, Inc., 448 A.2d 801 (Conn. Sup. Ct. 1982), a medical questionnaire that inquired into the urogenital health of women, but not men, was found to violate the state discrimination laws. Similarly, the United States Supreme Court in City of Los Angeles v. Manhart, 435 U.S. 702 (1978), held that an employer could not require women to contribute more to their pension plans than men based on the longer life expectancy of women as a class.

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Although many genetic traits are linked to racial and ethnic groups, n161 a genetic marker is a facially neutral criterion. An employer that refuses to hire all individuals who possess a specific genetic marker is not per se discriminating against members of a single race because many genetic diseases cross racial lines. n162 Therefore, under the disparate treatment test, a genetic discrimination claim would likely fail. n163 Failure is probable because it is difficult to prove an [*421] employer's intent to discriminate. Thus, any claim based on genetic testing would have to be brought using the disparate impact theory.

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n161. For example, sickle cell anemia has been linked to African Americans. See Gostin, supra note 5, at 111 (stating that the "potential for invidious discrimination" is increased because certain genetic diseases are intimately

associated with particular racial or ethnic groups). Bloom's Syndrome, Gaucher's disease, and Tay Sachs have been linked to Ashkenazi Jews. See id. at 111 n.10. Familial Mediterranean fever has been linked to Armenians. See id. at 111 n.11. Cystic fibrosis is more prevalent in Caucasians. See Brokaw, supra note 47, at 324 n.33 (listing examples of certain genetic traits which can be linked to specific maladies and are "concentrated among identifiable ethnic groups"). Thalassemia has been linked to Greeks, Italians and Africans. See id. Wilson's disease and BRCA1 (a gene linked with breast cancer) are associated with Eastern European Jews. See Rothenberg, supra note 47, at 98-99 (discussing the link between a genetic mutation, breast cancer and the Jewish community).

n162. For example, Thalassemia affects Greeks, Italians, and Africans. See Brokaw, supra note 47, at 324 n.33. Glucuse-6-phosphate dehydrogenase deficiency affects Africans, Mediterranean Jews, Greeks and Filipinos. See id. (demonstrating that some genetic ailments affect people of different races and ethnicities).

n163. There would likely be a different result if the employer were to target only members of a certain race or sex and perform the tests on members of those groups. For example, in Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1265-66 (9th Cir. 1998), where the employer is alleged to have tested only African Americans for sickle cell anemia and women for pregnancy, a claim for disparate treatment under Title VII may exist. See supra note 13 (discussing the only case regarding an employer's use of genetic testing).

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2. Disparate Impact Theory

In Griggs v. Duke Power Co., n164 the Supreme Court held that Title VII applies not only to direct discrimination, n165 but to practices that appear neutral on their face and result in discrimination along racial lines. The Court stated that "good intent or absence of discriminatory intent does not redeem employment procedures or testing mechanisms that operate as 'built-in headwinds' for minority groups and are unrelated to measuring job capability." n166

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n164. Griggs v. Duke Power Co., 401 U.S. 424 (1971). The court found that the practice of screening employment applicants using a specific IQ test, and requiring applicants to have earned a high school diploma violated Title VII. See id. at 432-36. The court reasoned that the criteria operated to disqualify African American applicants at a substantially higher rate than white applicants and were unrelated to measuring job capability. See id.

n165. Such as when an employer refuses to hire anyone of a certain race.

n166. Griggs, 401 U.S. at 432.

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To establish a disparate impact claim, an individual must prove that the genetic screening had a discriminatory effect on groups protected by Title VII. n167 The burden then shifts to the employer to prove that the screening is "job-related" or a "business necessity." n168 If the employer meets this

burden, the individual can only prevail if he or she can demonstrate that there is a less restrictive alternative to genetic screening. n169

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n167. See Brokaw, supra note 47, at 332 (citing Griggs, 401 U.S. at 432, which described the requirements for a disparate impact claim). For example, an individual must be able to show that sickle cell anemia affects African Americans disproportionately before he can claim racial discrimination based on the employer conducting pre-employment testing for the trait.

n168. See Griggs, 401 U.S. at 432; see also 42 U.S.C. 2000e-2(k)(1)(A) (1990) (providing that an individual establishes a disparate impact claim where "a complaining party demonstrates that a respondent uses a particular employment practice that causes a disparate impact" and "the respondent fails to demonstrate that the challenged practice is job related for the position in question and consistent with business necessity").

n169. See Griggs, 401 U.S. at 432.

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The prima facie case for disparate impact discrimination based on genetic testing would be relatively easy for a job applicant to satisfy. The plaintiff need only establish that he or she was a member of a minority group and was denied a job because of the results of a genetic test that tested for a condition more prevalent in that minority group.

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3. Business Necessity and Job-Relatedness

Once the individual is able to establish a prima facie case, the burden shifts to the employer who may try to establish that the criteria was "job-related" or a "business necessity." While some courts have used these terms interchangeably, n170 others have attempted to draw a distinction between them. n171 "Business necessity" denotes an employment practice whose purpose is to determine whether an applicant is capable of performing the necessary job functions. n172 "Job-relatedness" has a narrower scope and concerns only whether the employee selection criteria are reasonably related to the demands of the job. n173 A determination of whether the employer satisfied either standard depends on "a consideration of the nature of the business involved, the business practice at issue, and the degree of discriminatory impact." n174 The court will then balance the "business necessity" against the impact of the discriminatory treatment to determine whether the genetic testing can continue.

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n170. See id. at 431 (making no differentiation between the terms job-related or business necessity). The Court stated: "the touchstone [for determining whether a practice has a discriminatory effect] is business necessity. If an employment practice which operates to exclude Negroes cannot be shown to be related to job performance, the practice is prohibited." Id.

n171. See, e.g., Rothstein, supra note 69, at 134-35 (describing business necessity as "whether there exists an overriding legitimate business purpose such that the practice is necessary to the safe and efficient operation of business," and job-relatedness as a comparison of legitimate "job requirements with the employer's method for assessing fitness").

n172. See id. at 134 (explaining "the standards used for determining the merits of the business necessity and job-relatedness defenses are similar").

n173. See id. at 134-35 (citing Albemarle Paper Co. v. Moody, 422 U.S. 405, 432 (1975), which stated that the employer's methods must be predictive of or significantly correlated with important elements of the job).

n174. Id. at 134.

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Commentators suggest several reasons employers why may want to use genetic testing, however, these reasons are insufficient to establish a business necessity. For example, genetic testing may be used in an attempt to reduce the costs of absenteeism, decreased productivity, and increased training costs associated with training new employees who replace sick employees. n175 Employers may determine the most costly ailments and then screen for those diseases to limit the future costs of employee illness. n176 Employers who cannot afford or do not want to [*423] incur the expense of extra safety measures in the workplace, may see genetic screening as a way to prevent employment-related illnesses and encourage worker health and safety. n177 Other commentators suggest that genetic screening can be used to alert susceptible workers to dangers that exist in the workplace in light of their genetic make-up. n178 Employers may argue that this allows them to position workers in the jobs most suited to both their talents and their susceptibilities. n179

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n175. See Deyerle, supra note 31, at 558 (reasoning that there may be a potential cost savings for employers who are able to identify employees susceptible to illness).

n176. ,See Gin, supra note 3, at 1411 (suggesting employers and insurance companies may use genetic screening to "identify individuals who might impose "unnecessary' costs in the form of high medical expenses").

n177. See Deyerle, supra note 31, at 558 (stating that employers advocate such screening to allow employees to be placed in a position for which they are best suited).

n178. See Lori B. Andrews & Ami S. Jaeger, Confidentiality of Genetic Information in the Workplace, 17 Am. J.L. & Med. 75, 76 (1991) (stating that a one-time genetic screening could determine whether an employee could safely work in a particular job).

n179. For example, when Du Pont began testing employees for benzene susceptibility the company did not fire susceptible workers. Instead, the company moved them to more appropriate positions. See Brokaw, supra note 47, at 323. An employer using genetic screening to place workers in different jobs

would still have to face Title VII's hurdles if, as a result of the testing, minorities were consistently being placed in less desirable positions.

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The "business necessity" prong does not justify genetic testing because the tests determine the potential of future illness, not the existence of a present condition. Many courts have held that the avoidance of future liability is insufficient to establish a business necessity. n180 One court held that avoiding expense alone, without a showing of a significant threat to the business, is insufficient to overcome a Title VII discrimination claim. n181 Thus, an employer would probably not be able to pass the business-necessity test when using a genetic screening device that has a disparate impact on minority applicants. Generally, present genetic tests only predict possibilities of disease or disorders. This futuristic and unspecified threat is insufficient to rise to the level of "business necessity."

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n180. See Los Angeles Dep't of Water & Power v. Manhart, 435 U.S. 702, 716-17 (1978) (finding that future liability is insufficient to establish a business necessity); Wright v. Olin Corp., 697 F.2d 1172, 1190 n.26 (4th Cir. 1982) (stating that future liability alone will not create a business necessity); Myers v. Gilman Paper Corp., 544 F.2d 837, 849 (5th Cir. 1977) (suggesting that financial necessity may be considered a business necessity only if it speaks to present financial concerns, not future ones).

n181. See Chrapliwy v. Uniroyal, Inc., 458 F. Supp. 252, 259-72 (N.D. Ind. 1977) (finding that an employer may be forced to incur large expenses in order to comply with Title VII).

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4. Less Restrictive Means-The Plaintiff's Last Resort

Even if the employer proved a sufficient "business necessity" for genetic testing, the plaintiff could still render the "necessity" moot by [*424] showing less restrictive means that satisfy the same "business necessity." If the employer sought to improve safety, this safety should apply to all employees, rather than eliminating hyper- susceptible workers. n182 In addition, if the workplace poses a specific hazard to an employee, that employee should make the informed decision whether to incur or avoid the risk. n183

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n182. See infra Part V (discussing the imposition of a general duty on employers to provide a hazard-free work environment pursuant to certain regulations promulgated under OSHA).

n183. See International Union v. Johnson Controls, Inc., 499 U.S. 187, 211 (1991) (finding that an employer did not have a right to exclude a woman who was of child-bearing age from a work environment where lead was present because the "choice [was] hers to make").

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The high correlation between many genetic disorders and race or ethnicity, prohibits screening applicants for many diseases without violating Title VII. n184 For example, tests for sickle cell anemia would by their very nature discriminate against African Americans, a fact recognized by many states when they prohibited employment-related testing for the disease. n185 Further, in most situations the employer would not be able to point to a sufficient "business necessity" to justify the testing. Even if the employer were able to establish a business necessity, it is likely that a less-restrictive and less-invasive means would meet that same requirement. The existence of these less-restrictive and less-invasive means renders the discriminatory genetic test improper. The employer may, however, be able to point to other federal legislation such as the Occupational Safety and Health Act to attempt to establish the necessity of conducting genetic tests.

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n184. Some courts have sided with the employee when dealing with regulations that have a disparate impact on minority groups. For example, in EEOC v. Trailways, Inc., 530 F. Supp. 54 (D. Colo. 1981), the court struck down a regulation requiring bus drivers to be clean shaven. The regulation was struck because it had a discriminatory impact on African Americans who demonstrated a higher incidence of a skin disorder that made shaving painful. See id. at 59. But see Woods v. Safeway Stores, 420 F. Supp. 35 (E.D. Va. 1976) (upholding the dismissal of African American employees who grew beards as a result of a skin condition where customers found bearded workers in a grocery store distasteful). Similarly, most of the employers who pioneered sickle cell testing soon stopped, and some states have now prohibited the testing because of its disparate impact on African Americans.

n185. See generally Fla. Stat. Ann. 448.076 (West 1997) (prohibiting sickle cell trait screening as a condition of employment); La. Rev. Stat. Ann. 23:352 (West 1998) (prohibiting employment discrimination on the basis of sickle cell trait).

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V. The Occupational Safety and Health Act: No Safe Harbor for Employers that Use Genetic Testing

The Occupational Safety and Health Act ("OSHA") was passed in 1970. By enacting OSHA, Congress intended "to assure so far as possible every working man and woman in the Nation safe and healthful working conditions and to preserve our human resources." n186 OSHA imposes two duties on employers. First, employers have a general duty to provide places of employment "free from recognized hazards that are causing or are likely to cause death or serious physical harm." n187 Recognized hazards are those known to the employer or recognized as a hazard by the industry. n188 To establish a recognized hazard a plaintiff must show that the employer had actual or constructive knowledge of the hazard, or that the employer's standards were below the general industry standards. n189 Second, each employer must comply with safety regulations promulgated under OSHA. n190

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n186. 29 U.S.C. 651 (1994).

n187. Id. 654(a)(1).

n188. See Jack F. Williams, A Regulatory Model for Genetic Testing in Employment, 40 Okla. L. Rev. 181, 190-91 (1987) (noting that a recognized hazard may be shown through actual or constructive knowledge on the employer's part or by reference to an industry practice. However, the fact that an industry has not previously addressed a certain hazard does not "foreclose a court's inquiry").

n189. See Magma Copper Co. v. Marshall, 608 F.2d 373, 375-76 (9th Cir. 1979) (stating that an employer's actual knowledge of a hazard is sufficient proof that the hazard was recognized).

n190. See Williams, supra note 188, at 190 n.61 (discussing the Secretary of Labor's authority to set standards requiring "conditions, or the adoption or use of one or more practices, means, methods, operations, or processes, reasonably necessary or appropriate to provide safe or healthful employment and places of employment").

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A. An Employer's General Duty

Under OSHA, an employer is not required to provide a perfectly safe working environment. n191 The employer is only required to eliminate significant risks of hazard as much as possible. n192 The general duty to provide a safe workplace arguably requires employers [*426] to genetically test employees and applicants for hyper-susceptibility to known toxins. Specifically, if an employer knows, or should know, that a certain toxin can be excessively dangerous to hyper-susceptible individuals, then the employer places these individuals at increased risk by hiring and exposing them to a hazardous work environment. This argument is unpersuasive for several reasons.

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n191. See Judith Richter, Taking the Worker as You Find Him, 8 Md. J. Contemp. Legal Issues 189, 212-13 (1997); see also Industrial Union Dep't v. American Petroleum Inst., 448 U.S. 607, 615 (1980) (holding that the Secretary's standard for Benzene was too low and not "reasonably necessary or appropriate to provide safe and healthful employment").

n192. See Ellen R. Peirce, The Regulation of Genetic Testing in the Workplace-A Legislative Proposal, 46 Ohio St. L.J. 771, 814 (1985) (discussing employers' concerns with genetic testing in the workplace in connection with an employer's common law duty to test and OSHA compliance).

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B. Safety Regulations Under OSHA

OSHA empowers the Secretary of Labor to create standards that require medical

testing of employees exposed to certain toxins in the workplace. n193 The Secretary of Labor, however, is not required to draft regulations to eliminate all toxins in the workplace, or even to eliminate any toxin in its entirety. n194 Rather, regulations must be technologically and economically feasible. n195 Further, they should focus on the workplace, and not the individual workers. n196 Therefore, any safety standard designed to protect the hyper-susceptible worker would probably be successfully challenged as either unreasonable or infeasible. n197 Yet, the Secretary of Labor is allowed to "prescribe the type and frequency of medical examinations ... which shall be made available, by the employer or at his cost ... in order to most effectively determine whether the health of such employees is adversely affected by such exposure." n198

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n193. See 29 U.S.C. 651(b)(3) (1994) (authorizing "the Secretary of Labor to set mandatory occupational safety and health standards applicable to businesses affecting interstate commerce").

n194. See Industrial Union Dep't, 448 U.S. at 614.

n195. While OSHA does not give a specific definition of what it means to be economically or technologically feasible, courts have interpreted the requirement to mean that an employer may have to expend significant amounts of money before successfully claiming that a standard is economically infeasible. For example, courts have held that a standard will not be considered economically infeasible merely because the cost is high. See Asarco, Inc. v. OSHA, 746 F.2d 483, 501 (9th Cir. 1984); United Steelworkers of Am. v. Marshall, 647 F.2d 1189, 1307 (D.C. Cir. 1980) (finding that high cost alone did not make a standard economically infeasible). The cost must be weighed against the expected benefit in determining whether the standard is appropriate. See United Parcel Serv. v. OSHA, 570 F.2d 806, 812 (8th Cir. 1978) (holding that the UPS need not require its employees to wear steel-toed shoes where the cost outweighed the potential safety benefit).

n196. See 29 U.S.C. 651(b)(1) (stating the first purpose of the act is "to reduce the number of occupational safety and health hazards at ... places of employment").

n197. See Peirce, supra note 191, at 814 (stating that the standard "might be challenged as not reasonably necessary or appropriate to provide safe and healthful employment or because it is technologically or economically infeasible").

n198. 29 U.S.C. 655(b)(7).

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[*427] Currently, OSHA's medical surveillance regulations require pre-employment or pre-placement examinations. Following the examination, the treating physician must give the employer a statement that the employee is suitable for the desired position. Additionally, the employee is periodically tested during the term of employment. n199 These tests range in level of invasiveness from a simple physical examination to blood and urine analysis. n200 Currently, none of these regulations require disclosure of uncovered genetic information. Theoretically, however, under the auspices of the Act,

the Secretary of Labor could create a rule that requires employers to genetically test employees and applicants for known susceptibilities to certain toxins. n201 The legitimacy of this rule would depend on the cost of the test, its accuracy, and the feasibility of requiring its widespread use in the industry. n202 At present, it is doubtful that any genetic test would meet these criteria because most genetic tests are currently expensive and unreliable. n203

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n199. See Mark A. Rothstein, Employee Selection Based on Susceptibility to Occupational Illness, 81 Mich. L. Rev. 1379, 1414 (1983) ("Employers must conduct preplacement examinations, the physician must furnish employers with the physician's statement of suitability for employment in the regulated areas, the employer must conduct periodic (usually annual) examinations.").

n200. See 29 C.F.R. 1910.1001 (1998) (requiring pulmonary function tests and chest x-rays for exposure to asbestos); 29 C.F.R. 1910.1017 (requiring complete physical exam and liver studies for exposure to polyvinyl chloride); 29 C.F.R. 1910.1025 (requiring a complete medical exam and detailed blood analysis for exposure to lead), 29 C.F.R. 1910.1044 (requiring examination of genitourinary tract and serum specimen analysis by radioimmunioassay).

n201. See Williams, supra note 188, at 192 (discussing genetic testing in light of feasibility standards).

n202. Courts have found that when determining whether a standard is appropriate the cost of the measure must be balanced against the expected benefit. The benefit, however, must be given more weight than the cost in determining whether the standard should be passed. See RMI Co. v. Secretary of Labor, 594 F.2d 566, 572 (6th Cir. 1979) (suggesting that cost must be balanced against benefit, but that the benefit should be given greater weight than the cost); United Parcel Serv. v. OSHA, 570 F.2d 806, 812 (8th Cir. 1978) (ruling that foreseeable hazards must be eliminated even if costly); American Petroleum Inst. v. OSHA, 581 F.2d 493, 502-03 (5th Cir. 1978) (requiring a balancing test between cost and benefit of the proposed standard).

n203. The expense of genetic tests outweighs their benefit since most genetic tests are still considered inaccurate predictors of hyper-susceptibility. See Brokaw, supra note 47, at 321; Deyerle, supra note 31, at 551-52. Without an accurate measure, it is unlikely that any genetic testing requirement would withstand a challenge.

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[*428] The broad goal of OSHA is to limit workplace toxins. n204 OSHA focuses specifically on the workplace, not the individual worker. n205 Identifying and excluding hyper-susceptible workers from known toxins contradicts OSHA's goal to provide safe workplaces "free from recognized hazards that are causing or are likely to cause death or serious physical harm." n206 Rather than reducing workplace toxins, broad-scale genetic testing and exclusion of hyper-susceptible workers would encourage employers to continue operating hazardous work sites while at the same time creating a class of unemployable workers. The better approach, and the one supported by OSHA's general goals, n207 is to reduce or eliminate workplace toxins and implement safety procedures that would give all workers, hyper-susceptible or not, a safer work

environment. n208

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n204. See 29 U.S.C. 651(b) (1994) (stating that the act's goal is to "provide safe and healthful working conditions").

n205. See Peirce, supra note 192, at 817-18 (claiming that genetic testing does not create a safe working environment); Richter, supra note 191, at 217 (explaining that under OSHA, genetic testing is not a general duty of employers).

n206. 29 U.S.C. 654(a)(1).

n207. OSHA's general duty clause provides that every employer "shall furnish to each of his employees employment and a place of employment which are free from recognized hazards that are causing or are likely to cause death or serious physical harm to his employees." 29 U.S.C. 654(a)(i).

n208. Genetic testing should not be permitted under OSHA because it should be up to the hyper-susceptible worker to determine whether he or she is willing to risk exposure to toxins at levels that are relatively safe for the "normal" person. See International Union v. Johnson Controls, Inc., 499 U.S. 187, 220 (1991) (invalidating a regulation which prevented fertile women from working in conditions with high lead levels and reasoning that women have the right to decide where to work). Further, past OSHA administrators have given public statements disapproving of genetic testing of employees under OSHA. See Peirce, supra note 192, at 818 (claiming that genetic testing does not fit into the general duty clause) (citing Bingham, Letter to the Editor, N.Y. Times, Mar. 22, 1980, at A20).

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OSHA would not prohibit genetic testing in the workplace, but it does not permit the actual use of information gained from the tests. The goal of OSHA is to improve the workplace, not exclude certain workers from certain jobs. Therefore, OSHA does require testing of employees where workplace includes known toxins. Given an accurate and fairly inexpensive test, OSHA could possibly require employers to conduct certain genetic tests on employees in the future. With current genetic technology, however, this requirement is unlikely because any genetic test would probably fail the economically and technologically feasible test that is applied to OSHA standards. In addition, it is doubtful that an employee could use the general duty [*429] clause to justify conducting genetic testing because the testing would only accomplish restricting access to jobs, not increasing the overall safety of the workplace.

Another area of protection against genetic testing may come from constitutionally protected privacy rights. These protections will be especially strong for public employees who are protected by the Fourth Amendment against unlawful searches and seizures.

VI. The Right to Privacy and Genetic Information

Although not specifically enumerated in the Constitution, the Supreme Court recognized a right to privacy in Griswold v. Connecticut n209 through a

combination of the First, Third, Fourth and Fifth Amendments to the United States Constitution. n210 To fall within this zone of privacy, a right must be either "implicit in the concept of ordered liberty," n211 or "deeply rooted in this Nation's history and tradition." n212 To date, however, no recognized constitutional right to privacy would prohibit employment testing. n213

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n209. Griswold v. Connecticut, 381 U.S. 479 (1965) (establishing a married couple's right to privacy within their own bedroom).

n210. See U.S. Const. amends. I, III, IV, V. Plaintiffs in California may be provided an extra level of protection because the California Constitution includes within it a right to privacy. See Cal. Const. art. I, 1.

n211. Bowers v. Hardwick, 478 U.S. 186, 191-92 (1986) (upholding a criminal sodomy law and declining to find a Constitutional right to engage in homosexual relations).

n212. Id. (quoting Moore v. East Cleveland, 431 U.S. 494, 503 (1977)).

n213. See Deyerle, supra note 31, at 563, (discussing the treatment of Griswold v. Connecticut by lower courts in the context of genetic testing); Peirce, supra note 192, at 801 (finding no Supreme Court decision concerning an employee's right to privacy in the workplace).

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A. Right to Privacy in Medical Information

In Whalen v. Roe, n214 the Supreme Court recognized a right to privacy in medical information. n215 The Court considered a New York statute that required the state to record prescription drug user names and addresses. n216 The Court held that the zone of privacy encompassed an individual's interest against disclosure of personal [*430] information such as prescription drug use. n217 The Court, however, found the statute was constitutional because the interest of the state in collecting the information outweighed the individual's interest in keeping it private. n218

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n214. Whalen v. Roe, 429 U.S. 589 (1977).

n215. See id. at 598-600 (upholding a New York patient identification statute where the statute did not substantially invade an individual's right to privacy in medical information).

n216. See id. at 591.

n217. See id. at 598-600.

n218. See id. at 600.

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Arguably, because genetic information is uniquely personal, it deserves more protection than other forms of medical information. n219 The information available through our genes, including the potential to unlock secrets unknown even to the individual, highlights the unique nature of genetic information. n220 In addition, genetic information carries implications not only for the individual but also for his or her family. n221 History, therefore, should be a guide to determine the scope of privacy applicable to genetic information. n222 Specifically, the release of genetic information conjures up the specters of social stigma, employment and insurance discrimination, and ultimately creates a genetic underclass. n223

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n219. But see Thomas H. Murray, Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?, in Genetic Secrets Protecting Privacy and Confidentiality in the Genetic Era 60, 62 (Mark A. Rothstein ed., 1997). Murray argues that "genetic information is neither unique nor distinctive" in offering a view of an individual's future health. Id. at 64. He further suggests that genetic information and risk factors are no different than other medical information and risk factors. See id. at 69. Murray analogizes an individual's genetic make-up to a diary, stating:

Our genes might be regarded metaphorically as the physical, but blank, volume in which we will create our diary. Some volumes have fewer pages in which to write, some more. Certain pages, often toward the back of the volume, may be more difficult to write on. And some leaves may require great skill and effort to open at all. But the physical volume is not the content of the diary. The content we must write ourselves.

Id. at 72.

n220. See Lawrence O. Gostin, Genetic Privacy, 23 J.L. Med. & Ethics 320, 324-26 (1995) (discussing the need for genetic privacy statutes, particularly in a health system with computerized medical records).

n221. See id. at 324. This argument can be carried further to suggest that an individual's genetic information may have far-reaching implications for those in the same racial or ethnic group. See supra Parts II, IV (providing a further discussion of racial and ethnic implications for genetic testing).

n222. See supra Part II (discussing past misuses of genetic information). Toward this end, many proposals for genetic privacy acts have been made, including a proposed "Genetic Privacy Act" and Congressional "genetic privacy" bills. See Anita L. Allen, Genetic Privacy: Emerging Concepts and Values, in Genetic Secrets-Protecting Privacy and Confidentiality in the Genetic Era 31 (Mark A. Rothstein ed., 1997) (defining and discussing the regulation of genetic privacy); see also Gurd, supra note 104, at 118 (discussing the relationship between genetic discrimination and the ADA).

n223. See Allen, supra note 222, at 32 (warning against sacrificing privacy for science); King, supra note 61, at 100 (discussing the correlation between current genetic testing and past racial stereotypes).

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B. Fourth Amendment Protections

Public employees gain another layer of protection against genetic testing through the Fourth Amendment of the United States Constitution. The Fourth Amendment provides protection against unreasonable searches and seizures. n224 The Supreme Court has stated that "the overriding function of the Fourth Amendment is to protect personal privacy and dignity against unwarranted intrusion by the State." n225 Generally, the Fourth Amendment speaks to criminal searches. In certain situations, however, the Fourth Amendment protections have been applied to noncriminal searches as well.

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n224. See U.S. Const. amend. IV. The amendment provides, in pertinent part, "the right of the people to be secure in their persons, papers, and effects, against unreasonable searches and seizures, shall not be violated." Id.

n225. Schmerber v. California, 384 U.S. 757, 767 (1966) (holding that withdrawal of blood to conduct a blood-alcohol test does not violate the Fourth Amendment).

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1. Genetic Tests as Unlawful Searches

In O'Connor v. Ortega, n226 the Supreme Court applied the Fourth Amendment to analyze the invasion of a government employee's privacy. n227 The Court found that a government employee had an expectation of privacy within his locked desk and office filing cabinet. n228 Two years later, the Supreme Court found that a drug test was a search within the meaning of the Fourth Amendment. n229 In so doing, the Court set up a balancing test for employee drug testing. Under this test, the government's interest is balanced against the employee's privacy interest. n230

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n226. O'Connor v. Ortega, 480 U.S. 709 (1987).

n227. See id. at 714 (stating that the hospital conducted a search of one of its doctor's offices due to suspicion about the doctor's management of a residency program).

n228. See id.

n229. See Skinner v. Ry. Labor Executives' Ass'n, 489 U.S. 602, 633 (1989) (upholding random drug testing of railroad employees).

n230. See id. at 619.

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Where a government employer requires applicants or employees to submit to a genetic test, the government undertakes a search within the meaning of the

Fourth Amendment. n231 Although a specific case has [*432] not addressed the Fourth Amendment's application to genetic testing, n232 it is likely that courts would borrow from drug testing jurisprudence and balance the individual's privacy interest against the government's interest in the test. n233

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n231. Currently, the largest government collector of genetic material is the United States Military. Through the Department of Defense DNA Registry and Repository, every American service member, and civilian employee located in a potential combat zone, is compelled to provide blood and tissue samples to the government. The samples are maintained in a large databank. Unlike other genetic material collection, however, this information is not being used to deny employees jobs or promotions. The stated purpose of the databank is to assist the government in identifying remains of service members if needed during a military conflict. See generally Robert Craig Scherer, Note, Mandatory Genetic Dogtags and the Fourth Amendment: The Need for a Post-Skinner Test, 85 Geo. L.J. 2007 (1997) (arguing that the current non-consensual, non-criminal testing of government employees is outmoded and should be replaced). In Mayfield v. Dalton, the district court of Hawaii upheld the constitutionality of the Registry. See Mayfield v. Dalton, 901 F. Supp. 300, 303-05 (D. Haw. 1995), vacated by Mayfield v. Daulton, 109 F.3d 1423 (9th Cir. 1997). The court found that the important interest of the government in identifying remains outweighed the individual's privacy interest. See id. The appeal of the case, however, was summarily dismissed as moot because the servicemen involved had since been honorably discharged from the military. See Mayfield, 109 F.3d 1423 (9th Cir. 1997), vacating as moot 901 F. Supp. 300, 303-05.

n232. The Ninth Circuit has recognized the possibility of a privacy claim based on genetic testing in a state and federally owned laboratory. See Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1269 (9th Cir. 1998) (acknowledging a cause of action based on privacy interests under both the United States Constitution and the California Constitution, where the lab did testing for syphilis, sickle cell anemia, and pregnancy without an individual's knowledge).

n233. This same balancing test has been applied by lower courts for mandatory AIDS testing in the workplace. In Local 1812 v. United States Department of State, the union challenged the government's mandatory HIV testing policy. See Local 1812 v. United States Dep't of State, 662 F. Supp. 50, 51 (D.D.C. 1987). The government argued that service by HIV-infected individuals at many foreign posts would pose a "serious hazard" to the infected individual because of the poor medical facilities and poor quality of other health and sanitary conditions. See id. at 52. The court upheld the test, finding it was minimally intrusive because blood testing for other conditions was already required. In addition, the court found that the tests were rationally related to fitness for duty. See id. at 54. The Fifth Circuit followed similar reasoning in upholding the discharge of a nurse from a hospital who refused to submit the results of an HIV-test he had voluntarily taken outside the course of his employment. See Leckelt v. Board of Comm'rs, 909 F.2d 820, 833 (5th Cir. 1990). The court applied a balancing test and determined that the hospital's interest "in maintaining a safe workplace through infection control outweighed the limited intrusion on any privacy interest of Leckelt in the results of his HIV antibody test." Id. at 833. In contrast, the Eighth Circuit struck down a health service's mandatory HIV-testing policy. See Glover v. Eastern Neb. Community

Office of Retardation, 867 F.2d 461, 464 (8th Cir. 1989). The agency argued that it was necessary to test employees for HIV because mentally retarded individuals often scratched and bit workers. See id. at 463. The court based its decision on the fact that there was no conclusive evidence that the disease could be spread through casual contact. See id. The court found that "from a medical viewpoint, this policy is not necessary to protect clients from any medical risks." Id. at 463.

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An individual's interest in maintaining the privacy of genetic information is high due to the unique information contained within human genes. Unlike minimally intrusive tests, such as drug or [*433] alcohol tests, genetic tests reveal traits beyond an individual's control. The government's interest, however, in this genetic information about its employees is relatively low. Generally, this information does not reveal anything about an individual's present ability to perform job functions safely and successfully. Rather, the information may reveal risks to the individual, but not risks to fellow workers. n234 Admittedly, the government can express some interest in the protection of its workers against unnecessary risk of disease. A paternalistic reason, however, is not sufficient to overcome the individual's interest in privacy. n235

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n234. Risks to fellow workers include risks such as those inherent in drug use at dangerous work sites or AIDS testing in a medical facility. These risks could arguably support intrusive testing to secure the safety of co-workers. See Leckelt, 909 F.2d at 833.

n235. See International Union v. Johnson Controls, Inc., 499 U.S. 187, 206 (1991) (striking down a company's policy that disqualified fertile females from working near lead).

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2. Genetic Tests as Unlawful Seizures

Government employees also have some protection against genetic testing based on the privacy rights against illegal seizures inherent in the Constitution. Taking an individual's blood or tissue for the purposes of genetic testing is a type of seizure protected by the Fourth Amendment. n236 In order to make this seizure, the government would have to establish an overwhelming need for the test. Yet, this need may be difficult to establish. Unlike drug testing that only tests for the existence of a limited number of substances voluntarily ingested by the individual, genetic testing reveals the deepest secrets of an individual's past, present, and projected future including those of his or her family. This added level of invasiveness strengthens the individual's privacy interest thus raising the government's burden in showing a need to justify an intrusion. The government, therefore, would be hard-pressed to articulate a satisfactory need.

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n236. The Fourth Amendment guarantees an individual the right to be free from "unreasonable searches and seizures." U.S. Const. amend IV.

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VII. State Legislation-An Attempt to Clarify the Law of Genetic Testing

In response to the confusion over whether federal laws protect against genetic discrimination, many states have stepped in and passed their own legislation. n237 The laws range from total protection against [*434] genetic testing to limited restrictions on the use of such tests. Unlike the ADA, the protections in the state laws are not restricted to employers with fifteen or more employees.

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n237. Most of the state legislation refers only to discrimination in insurance, and not employment. See Neb. Rev. Stat. Ann. 689A.417 (Supp. 1997) (prohibiting health insurers from requiring the insured or any member of his family to take a genetic test, disclose whether he or any member of his family had previously taken a genetic test, or determine the rates or other aspects of coverage based on whether the individual or a family member had taken a genetic test, or any other genetic information). The prohibition, however, is not extended to an insurer "who issues a policy of health insurance that provides coverage for long-term care or disability income." Id.; see also Colo. Rev. Stat. Ann. 10-3-1104.7 (West Supp. 1997) (preventing genetic testing from being used to deny "health care insurance, group disability insurance, [and] long-term care insurance." The statute specifically exempts life insurance and individual disability insurance.); Fla. Stat. Ann. 627.4301 (Supp. 1998) (preventing health insurers from canceling, limiting or denying coverage, or establishing differentials in premium rates, based on genetic information in the "absence of a diagnosis of a condition related to genetic information"); 410 Ill. Comp. Stat. 513/20 (West 1997) (providing that an insurer may not use genetic testing in connection with accident and health insurance. The law makes an exception when the genetic testing information is provided voluntarily by the individual and the results are favorable to that individual.); Ga. Code Ann. 33, ch. 54-1, -3, -7 (1996) (preventing "accident and sickness insurance companies, health maintenance organizations, managed care organizations, and other payors from using genetic information to deny accident and sickness coverage); N.H. Rev. Stat. Ann. 141-H:4-5 (1996) (providing that a health insurance company may not require or request an individual or his family to undergo genetic testing or reveal whether the individual or his family has previously taken a genetic test. An exception is provided, however, for "life insurance, disability income insurance, [and] long-term care insurance."). A complete discussion of the limitations on genetic discrimination in insurance is beyond the scope of this paper.

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In 1981, the state of New Jersey was the first to enact legislation addressing employment discrimination based on genetic testing. This law prohibited "employment discrimination based on an individual's "atypical hereditary cellular or blood trait.'" n238 In 1996, New Jersey revised this law to ban discrimination based on "genetic information" including information "that may derive from an individual or family member." n239

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n238. Mark A. Rothstein, The Law of Medical and Genetic Privacy in the Workplace, in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era 281, 291 (1997) (citing N.J. Stat. Ann. 10:5-5(x) (West 1993), which states that "[a] typical hereditary cellular or blood trait" means sickle cell trait, hemoglobin C trait, thlassemia trait, Tay Sachs trait, or cystic fibrosis trait").

n239. Id.

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Other states in the years to follow, however, have provided the most comprehensive protection. n240 Wisconsin, Iowa and New Hampshire [*435] provide virtually identical statutory provisions: n241

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n240. These states are Wisconsin, Iowa, and New Hampshire. See Wis. Stat. Ann. 111.372 (West 1997) (Use of Genetic Testing in Employment Situations); N.H. Rev. Stat. Ann. 141.H:3 (1996) (Use of Genetic Testing in Employment Situations); Iowa Code Ann. 729.6 (West 1993) (Genetic Testing).

n241. The New Hampshire statute is cited by way of example. See N.H. Rev. Stat. Ann. 141-H:3.

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No employer, labor organization, employment agency, or licensing agency shall directly or indirectly: (a) solicit, require or administer genetic testing relating to any individual as a condition of employment, labor organization membership, or licensure[;] (b) affect the terms, conditions, or privileges of employment, labor organization membership, or licensure or terminate the employment, labor organization membership, or licensure of any individual based on genetic testing. n242

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n242. Id. 141-H:3(I)(a)-(b).

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The statute goes on to provide that "any agreement between an employer, labor organization, employment agency, or licensing agency and an individual offering employment, labor organization member-ship, licensure, or any pay or benefit to that individual in return for taking a genetic test is prohibited." n243 The statute, however, does provide an exception that permits employee testing under limited circumstances, but prohibits termination based on the results of these tests. n244 In effect, this eliminates virtually all chance of discrimination based on latent genetic defects. It is more restrictive than the ADA medical

testing provisions because it does not allow genetic testing at any stage of the employment relationship. By allowing testing for susceptibility to workplace toxins, while still preventing negative employment decisions based on the results, the statute protects workers from harmful environments and discrimination. n245 It may, however, restrict paternalistic employment decisions that seek to transfer hyper-susceptible employees to a safer work environment. If the employee views the transfer as an adverse employment action, the transfer may be prevented even though the employer had good intentions. n246

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n243. Id. 141-H:3(III).

n244. See id. 141-H:3 (IV)(b) (allowing consensual genetic testing to determine an "employee's susceptibility or level of exposure to potentially toxic chemicals or potentially toxic substances in the workplace, if the employer does not terminate the employee, or take any other action that adversely affects any term, condition, or privilege of the employee's employment") (emphasis added).

n245. Note, however, that while the employers may test for susceptibility to workplace toxins, there is no requirement that the employer move the employee out of the hazardous workplace if susceptibility is found. There is also no requirement that the test results be revealed to the employee. Thus, the law may not provide as much protection against workplace toxins as it appears at first glance. See id. 141-H:3.

n246. North Carolina provides similar protection. See N.C. Gen. Stat. 95-28.1A (Michie Supp. 1997). The statute, titled "Discrimination Against Persons Based on Genetic Testing or Genetic Information Prohibited," states that:

No person, firm, corporation, unincorporated association, State agency, unit of local government, or any public or private entity shall deny or refuse employment to any person or discharge any person from employment on account of the person's having requested genetic testing or counseling services, or on the basis of genetic information obtained concerning the person or a member of the person's family.

Id. Theoretically, this does not prevent employers from requiring genetic testing. There would be little purpose to the testing, however, because the employer is prevented from acting upon anything he or she discovers. See id.

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[*436] Given the confusion over the protections provided in federal legislation such as the ADA, more states will likely follow suit in enacting statutes specifically aimed at protecting workers against genetic discrimination in the future. n247

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n247. For example, New York law statutes include the language "genetic predis-position or carrier status" in its existing discrimination laws. See N.Y. Exec. Laws 296 (1)(a) (McKinney Supp. 1998) (Unlawful Discrimination

Practices). Thus, under New York law, genetic "predisposition or carrier status" is raised to the level of "age, race, creed, color, national origin, sex, disability ... [and] marital status" in terms of protection against employment discrimination. Id. Additionally, an Oregon statute makes it an "unlawful employment practice for an employer to seek to obtain, to obtain, or to use genetic information ... of an employee or a prospective employee to distinguish between or discriminate against ... an employee or prospective employee." Or. Rev. Stat. 659.036(1) (Lexis Supp. 1996). The law, however, includes an exception for the use of genetic information with the authorization of the employee to determine a "bona fide occupational qualification." Id. The law does not define a "bona fide occupational qualification," thus diminishing the strength of a law that without this caveat, could have protected virtually all employees from genetic discrimination. Id. Additionally, section 659.227 of the Oregon statute prohibits an employer from subjecting an employee or prospective employee to genetic testing, again with the exception that the genetic test be administered to determine a "bona fide occupational qualification." Id. 659.227(1).

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VIII. Conclusion

Genetic research promises a wealth of medical benefits. When diseases can be identified and linked to genetic traits there is a promise of treatment and cure in the future. The Human Genome Project's goal of identifying all 100,000 human genes within the next ten years holds the promise of healthier, longer lives. With this promise, however, lies the specter of fear and discrimination.

Genetic testing may be applied in employment to discriminate against "genetically inferior" workers. Employers have an interest in healthy, productive workers who will remain with the company far into the future. Unhealthy workers cost a company money in lost time, insurance, and retraining to replace seriously ill workers. This vision includes a picture of employers who screen applicants and [*437] refuse employment based on genetic markers correlated with serious diseases. While this seems futuristic, research has shown that genetic testing in the employment arena is a reality. n248 As genetic tests get easier, cheaper, and more accurate, their use is likely to increase if proper guidelines are not established.

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n248. See Genetic Monitoring Survey, supra note 2 (discussing the feasibility of genetic tests currently utilized in the employment setting); see also notes 4-9 and accompanying text (stating that at least 20 Fortune 500 companies have admitted to using genetic testing at one time or another).

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Workers currently have many protections in place against the abusive use of genetic testing. First, the ADA provides employees with their greatest protection. It dictates how and when medical testing - and by extension, genetic testing - may be performed. In addition, employees may gain added protection through Title VII when a specific genetic disorder is correlated along racial, ethnic, or gender lines.

Draft: 3/9/99
3:45 pm

HEALTH — Genetic Discrimination

EXECUTIVE ORDER

TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT
BASED ON PROTECTED GENETIC INFORMATION

By the authority vested in me as President by the Constitution and the laws of the United States of America, it is ordered as follows:

Nondiscrimination in Federal Employment on the Basis of

Protected Genetic Information

1-101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1-102. The head of each Executive department and agency shall extend the policy set forth in Section 1-101 for all its employees covered by Section 717 of Title VII of the Civil Rights Act of 1964 as amended.

1-103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information or information about a request for or the receipt of genetic services.

Requirements Applicable to Employing Departments and Agencies..

1-201. Definitions.

(a) The term "employee" shall include an employee, applicant for employment or former employee covered by Section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-

16).

(b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, or respond to the effects of, or control, adverse environmental exposures in the workplace.

(c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.

(d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites are covered when an excess or deficiency of the metabolite indicates the presence of a mutation or mutations.

(f) Protected genetic information.

(1) In general, protected genetic information means--

(A) information about an individual's genetic tests;

(B) information about genetic tests of family members of the individual; or

(C) information about the occurrence of a disease or disorder in family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses of the individual) is not protected genetic information unless it is described in subparagraph (1).

1-202. The agencies, in discharging their responsibilities under this order, shall implement the following nondiscrimination requirements.

(a) The employing department or agency shall not discharge, fail or refuse to hire, or

otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(c) The employing department or agency shall not request, require, collect or purchase protected genetic information with respect to an employee or a family member of the employee or information about a request for or the receipt of genetic services by such employee or by a family member of such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee or information about a request for or the receipt of genetic services by an employee or by a family member of an employee except --

(1) to the employee who is the subject of the information, at the request of that employee to whom disclosure is being made;

(2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;

(3) under legal compulsion of a Federal court order, except that if the court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the court order unless the court order also imposes confidentiality

requirements;

(4) to government officials investigating compliance with this Executive Order if the information is relevant to the investigation; and.

(5) to government officials in connection with a compelling national security or law enforcement matter.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be maintained separately from personnel files.

Exceptions

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in Section 1-202.

(a) The employing department or agency may request, require, collect, or purchase protected genetic information with respect to an employee or any information about a request for or receipt of genetic services by such employee or by a family member of such employee if :

(1) the employee or family member uses genetic or health care services provided by the employer;

(2) the employee or family member who uses the genetic or health care services has provided prior, knowing, voluntary, and written authorization to the employer to collect protected genetic information;

(3) the person who performs the genetic or health care services does not disclose the results of the genetic services to anyone except to the employee who uses the services, and pursuant to section 1-202(d) of this order; and

(4) such information is not used in violation of Sections 1-202(a) or 1-202(b) of this Executive Order.

(b) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

(1) the employee has provided prior, knowing, voluntary, and written authorization;

(2) the employee is informed of the specific results of the monitoring;

(3) the employee is informed of any other protected genetic information that may have been acquired, provided that the employee has given prior, knowing, voluntary, and written consent to such additional disclosure;

(4) the monitoring conforms to any genetic monitoring, regulations that may be promulgated by the Secretary of Labor; and

(5) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(c) This Executive Order does not limit the statutory authority of a Federal agency to (1) promulgate or enforce workplace safety and health laws and regulations or (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, Code of Federal Regulations, (3) collect protected genetic information as part of a lawful program, the exclusive purpose of which is to carry out identification of remains.

Miscellaneous

1-401. The head of each department and agency shall take appropriate action to disseminate this policy, and to this end shall designate a high level official responsible for carrying out its responsibilities under this Executive Order.

1-402. Nothing in this Executive Order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), including coverage afforded to individuals under section 102 of Americans with Disabilities Act of 1990 and any other Federal statute;

(b) supersede any provision of the Privacy Act of 1974 (5 U.S.C. 552a), and actions taken under this Executive Order shall be in compliance with the Privacy Act;

(c) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program; or

(d) supersede any other statute, regulation, or rule that requires disclosure of information.

1-403. After consultation with the Secretary of the Department of Health and Human Services and the Chair of the Equal Employment Opportunity Commission, an agency may:

(a) determine that the collection of protected genetic information is required from an individual, after a conditional offer of employment is made, when the collection of such protected genetic information is job-related and consistent with business necessity within the meaning of the Rehabilitation Act;

(b) determine that the use of such protected genetic information to make an employment decision is necessary to avoid a direct threat within the meaning of the Rehabilitation Act.

1-404. This order clarifies and makes uniform administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

THE WHITE HOUSE,