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Whose Genetic Information Is It Anyway? A Legal Analysis of the Effects That Mapping the Human Genome Will Have on Privacy Rights and Genetic Discrimination, 19 J. Marshall J. Computer & Info. L. 609 (2001)

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COMMENT

WHOSE GENETIC INFORMATION IS IT ANYWAY? A LEGAL ANALYSIS OF THE EFFECTS THAT MAPPING THE HUMAN GENOME WILL HAVE ON PRIVACY RIGHTS AND GENETIC DISCRIMINATION

I. INTRODUCTION

> Privacy is the right to control your own body, as in the right to have an abortion or the right to whatever sexual activities you choose. Privacy is the right to control your own living space, as in the right to be free from unreasonable searches and seizures. Privacy is the right to control your own identity, as in the right to be known by a name of your choice and not by a number, the right to choose your own hair and dress styles, the right to personality. Privacy is the right to control information about yourself, . . . as in the right to prevent disclosure of private facts or the right to know which information is kept on you and how it is used.[1]

There is no information more personal and private, than an individual's genetic information.[2] Deoxyribonucleic acid ("DNA") is the information that defines who we are as individuals both physically and mentally; it is the building block of life.[3]

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1. Robert Ellis Smith, *Privacy* 323 (Archer/Doubleday 1979) (quoted in Deckle McLean, *Privacy and Its Invasion* 49 (Praeger1995)).

2. Ruth Macklin, *Privacy & Control of Genetic Information*, Gene Mapping: Using Law & Ethics as Guides 157, 158 (George J. Annas & Sherman Elias eds., Oxford U. Press 1992). Genetic information is personal information. *Id.* An individual's hair color, skin color, eye color, height, and other observable characteristics are personal. *Id.* An individual's genetic information is what defines what an individual's personal observable characteristic are. *Id.* at 158-59. "Genetic information is private as well as personal." *Id.* at 159. Genetic information is personal in that it is what makes us who we are, as it determines our physical characteristics, our intellectual potential and our psychological being. *Id.*

3. Arthur Caplan, *Cracking the Human Genome: Just the Beginning,* Phila. Bus. J. ¶ 2 (July 14, 2000) (available in 2000 WL 17145183); *see also* William S. Klug & Michael R.

The Human Genome Project is an international scientific collaboration to map the genes on the twenty-three human chromosomes that are made up of DNA.[4] This map of the genetic code of human DNA, which should be completed by 2003,[5] will have a tremendous impact on life as we know it. Since scientists believe the human genetic code varies only slightly from one human being to another,[6] science will soon be able to take a blood or tissue sample and determine what our individual genetic codes are.[7] From an individual's genetic code and the map of the human

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Cummings, *Essentials of Genetics* ch.1 & 2 (2d ed., Prentice Hall 1996). Cells are the fundamental units of living organisms. *Id.* at 4. Within cells are nuclei, which serve as the "life force" of the cells. *Id.* The nucleus contains the genetic material in eukaryotic organisms, organisms which have true nuclei and membranous organelles. *Id.* at 7. In prokaryotes and viruses, organisms which lack true nuclei, their genetic information is stored in a nucleoid region or in their protein coat of their cell membrane. *Id.* DNA and RNA are the nucleic acids found in an organism's cells. *Id.* at 8. DNA serves as the molecule, which stores genetic material. *Id.* A molecule of DNA is organized into units called genes. *Id.* at 19. Genes are the functional units of heredity, composed of a linear array of nucleotides, which are the building blocks of DNA and RNA. *Id.* at 8. Genes are organized into chromosomes, and the chromosomes serve as the vehicle through which genetic information is transmitted. *Id.* Within a person's cell is a nucleus, the nucleus houses the DNA molecule, DNA is the building block of genes, the genes make up chromosomes, and the chromosomes serve as the transmitter of genetic information. *Id.* Therefore, DNA serves as the structural building blocks, which define an organism's life. Genetic information "directs cellular function, determines an organisms external appearance, and serves as the link between generations in every species." *Id.* at 3.

4. Encarta Encyclopedia, *Human Genome Project* § II <http://encarta.msn.com/index/consieindex/AC/0AC83000.htm?z=/&pg=2&br=1> (accessed Sept. 5, 2000). The Human Genome Project is an international collaboration in which eighteen countries, including Japan, United States, Germany, France, the United Kingdom and China, are involved. *Id.*

5. U.S. Dept. of Energy Off. of Science, Off. of Biological & Envtl. Research & Human Genome Project, *U. S. Human Genome Project 5-Year Research Goals 1998-2003: Time Table Accelerates on U.S. Human Genome Project* ¶ 2 <http://www.ornl.gov/TechResources/Human_Genome/hg5yp/> (accessed Sept. 5, 2000) [hereinafter U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals*]. The original date of scheduled completion of the Human Genome project was 2005, however with the June 2000 completion of the "working draft" that mapped ninety percent of the human genome, the projected completion date has been moved up to 2003. *Id.* Researchers believe that the human genome map will be 100 percent complete on or before the projected 2003 completion date. *Id.*

6. Encarta Encyclopedia, *supra* n. 4, § II. Although each person's genetic code is composed of unique genetic sequences, "the average variation in the genomes of two different people is estimated to be less than [one] percent." *Id.* *See* Klug, *supra* n. 3, at 8 (describing how genetic variation and mutations occur in an individual's genetic code). Genetic variations usually occur through gene mutations and chromosomal mutations, where there is a deletion, duplication, or rearrangement in a chromosome segment. *Id.* This usually occurs during mitosis or meiosis when the chromosomes are replicating themselves. These mutations are often caused by environmental factors. *Id.*

7. *See* Greg Fowler, *Genetic Privacy Issues Call for Public Discussion*, Portland Oregonian ¶ 6 (Sept. 14, 2000) (available in 2000 WL 5432346) (explaining that genetic information can be obtained through a relatively small sample of anything containing cells such as blood, saliva, fingernail clipping, or a strand of hair).

genome, scientists and medical personnel will then be able to determine if an individual possesses the genes that will predispose them to a genetic disease or condition linked with our genes.[8] Our genetic code can show if we are predisposed to develop diabetes, breast cancer, cystic fibrosis or numerous other genetically linked diseases.[9]

Once this genetic information becomes available to the mass public, there is a great likelihood that employers, the government and insurance companies will be able to gain access to an individual's genetic code.[10] With access to an individual's genetic information, companies may begin to discriminate against individuals predisposed to develop cancer or other disease.[11] Insurance companies may be able to deny individuals

8. Dept. of Labor, Dept. of Health & Human Serv., Equal Employment Opportunity Commn. & Dept. of Justice, *Genetic Information & the Workplace* ¶ 1 <http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html> (Jan. 20, 1998) [hereinafter Dept. of Labor]. Scientist have found an estimated 3,000 to 4,000 diseases that are genetically linked, including Huntington's disease, cystic fibrosis and breast cancer. *Id.* at ¶ 2. Errors in an individual's genetic code have also been determined to "increase an individual's risk of developing common disorders such as cancer, heart disease, and diabetes." *Id.* However it should be noted that just because an individual possesses the gene that is associated with a certain genetic disease, it does not mean that that individual will definitely develop that condition or disease. *See id.* Scientist believe that environmental factors, lifestyle and other variables influence the chances of developing the genetically predisposed disease or condition. Just because an individual possesses the gene associated with breast cancer, it does not mean that that individual will develop cancer during her lifetime. *Id.*

9. Ctr. for Disease Control & Prevention, *Translating Advances in Human Genetics into Public Health Action: A Strategic Plan* ¶ 1 <http://www.cdc.gov/genetics/publications/strategic.htm# Issue 2> (accessed Sept. 21, 2000) [hereinafter Ctr. for Disease Control, *Translating Advances*]. Scientists have found that the $BRCA_1$ gene is associated with a high risk of developing breast cancer and the CCR_5 gene is associated with conferring a protection against the HIV infection and development of AIDS. *Id.*; *see e.g.* Health Tech. Advisory Comm., *Genetic Testing for Susceptibility to Breast Cancer* ¶ 6 <http://www.health.state.mn.us/htac/gt.htm> (June 1998). The genes $BRCA_1$ and $BRCA_2$ were identified as playing a role in the development of breast cancer in 1994. *Id.* When these genes are performing regularly in the human body, they help the body to suppress cancer. *Id.* However, when a mutation in either of these genes occurs, the body can "no longer protect itself as effectively from certain kinds of cancer, most notably breast and ovarian cancer." *Id.* According to studies which have been done, the average risk of breast cancer for women with either the $BRCA_1$ and $BRCA_2$ gene mutation have an approximate 50 percent chance of developing breast cancer by age 50 and a 85 percent chance of developing breast cancer over their lifetime. *Id.* at ¶ 14. Therefore, if an individual has a mutated $BRCA_1$ or $BRCA_2$ gene, it does not mean that this individual will definitely develop breast cancer during her lifetime. *Id.* at ¶ 40. It simply means that this individual has a higher probability of developing breast or ovarian cancer, than another individual that does not have a mutated $BRCA_1$ or $BRCA_2$ gene. *Id.*

10. U.S. Dept. of Energy Off. of Science, Off. of Biological & Envtl. Research, & Human Genome Project, *Human Genome Project Information: Genetics, Privacy & Legislation* § I <http://www.ornl.gov/hgmis/elsi/legislat.html> (accessed Sept. 5, 2000) [hereinafter U.S. Dept. of Energy, *Genetics, Privacy & Legislation*].

11. *Id.* § V.

coverage simply because they know that a certain individual has the possibility of developing a genetic disease.[12] With the completion date of the Human Genome Project quickly approaching,[13] there is no federal legislation directly covering the privacy of an individual's genetic code.[14] There is also no federal legislation directly covering the genetic discrimination issues that are likely to arise in the employment and insurance industries.[15]

Technological advancements have increased the speed and complexity of our world, and these advancements will inevitably reduce our ability to control it.[16] Our society's traditional views of family, customs and practices are being pitted against the increasing speed and complexities created as our technologies advance.[17]

There are two types of problems that arise from our technological advancements: problems that can be managed and problems that cannot.[18] The loss of privacy created by technological advances is a problem that can and should be managed before privacy rights are eroded.[19] The Human Genome Project, which is close to completing the map of the human genome,[20] has social, ethical and legal implications, such as the impact of new gene-finding technologies on an individual's privacy rights.[21]

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12. *Id.*

13. *See* U.S. Dept. of Energy Off. of Science, Off. of Biological & Envtl. Research, & Human Genome Project, *Genetics in the News*, Wkly. Research Digest ¶ 4 <http://www.ornl.gov/hgmis/archive/news.html> (June 2000) [hereinafter U.S. Dept. of Energy, *Genetics in the News*] (explaining that the Human Genome Project is expected to complete the entire map of the human genome on or before 2003).

14. Ray Henry, *Boston U.: DNA Privacy a Priority*, U-WIRE ¶ 12 (Sept. 29, 1999) (available in 1999 WL 18816041) (explaining that the United States federal government has not yet established any genetic privacy legislation that would protect an individual's privacy rights concerning their genetic codes); *see also* U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § I.

15. *See id.* (noting that no specific federal genetic non-discrimination legislation has been enacted, but that some individuals believe that some current non-discrimination laws could be interpreted to include genetic discrimination into their protections).

16. Robert Kalinoski, *The Role of Law in Our Technological World*, 33 Aug. Md. B.J. 2, 3 (2000).

17. *Id.*

18. *Id.* at 4.

19. *Id.* at 5.

20. *See* Cong. Test., H.R. Subcomm. on Tech. Comm. on Science, Francis Collins, *Implications of Genetic Testing* ¶ 5 (Apr. 21, 1999) (available in 1999 WL 16946489) [hereinafter Collins] (explaining that the Human Genome Project will be completed by 2003, or sooner); *see also* Cong. Test., Joint Economic Comm., J. Craig Venter, *New Economy Barrier* (June 7, 2000) (available in 2000 WL 19304599) (explaining that with a new sequencer the complete map of the human genome may be complete by 2001).

21. *See generally* Collins, *supra* n. 20 (explaining that the map of the human genome will raise questions of right to privacy, cloning, and genetic discrimination).

The privacy concerns at issue today are manageable, if we identify and reconcile the competing public policy issues raised by the new technological developments and advancements posed by the map of the human genome[22] with the privacy rights that are protected in the U.S. today.[23] While the map of the human genome will provide scientists

22. *See* Kalinoski, *supra* n. 16, at 4-5 (explaining that the privacy issues that arise with technological advancements are the manageable problems that technology brings with it).

23. *See generally* Irwin R. Kramer, *The Birth of Privacy Law: A Century Since Warren & Brandeis*, 39 Cath. U. L. Rev. 703 (1990) (describing how privacy rights have developed in the United States). There is no constitutional right to privacy expressly contained in the United States Constitution. *Id.* at 703. Instead, privacy law was "invented" by Louis Brandeis and Samuel Warren in a 1890 law review article. *Id.* Before the Warren and Brandeis article, the law provided some protection for privacy, but it only provided limited legal theories, which were rather useless. *Id.* at 705. These laws were designed to safeguard an individual's privacy interests, and the courts then provided remedies for only a limited number of intrusions, most of which were inadequate and incomplete. *Id.* Warren and Brandeis were concerned about by the lack of legal remedies available to individual's whose privacy was invaded, specifically the individuals who had their privacy violated by the press. *Id.* at 709. Warren and Brandeis argued that the gossip columns and abusive press tactics, were the result of nineteenth century technological advancements, which were "foster[ing] more intrusive press tactics at the expense of individual privacy." *Id.* at 710. In response, Brandeis and Warren proposed that the common law, which had English precedent that had protected privacy under remote legal theories of intellectual property and contract law, be expanded to meet the needs of society and to afford individuals the right "to be let alone," the essence of the right of privacy. *Id.* Warren and Brandeis examined a number of English cases and reasoned that the English courts had extended copyright laws and implied contracts to protect privacy, and theorized that each decision rested on privacy grounds. *Id.* They believed that "[t]he principle which protects personal writings and nay other productions of the intellect or of the emotions, is the right to privacy, and the law has no new principle to formulate when it extends this protection to the personal appearance, sayings, acts, and to personal relation, domestic or otherwise." *Id.* at 714 (quoting Warren & Brandeis, *The Right to Privacy*, 4 Harv. L. Rev. 193, 213 (1980)). And they maintained that the courts need only apply the same privacy principles that they had long been using under the guise of alternative legal theories and legal fictions, to afford individual's a right to privacy. *Id.* Warren and Brandeis' ideas about the right to privacy were not adopted quickly by the courts. *Id.* at 715. It was not until three years after their article's publication that the Supreme Court of Georgia recognized a common law right of privacy, in *Pavesich v. New England Life Ins. Co. Id.* at 717. With the popularity of the *Pavesich* decision, the American Law Institute codified the right to privacy in the *Restatement of Torts*, which provides that "[a] person who unreasonably and seriously interferes with another's interest in not having his affairs known to others or his likeness exhibited to the public is liable to the other." *Id.* at 718 (quoting *Restatement of Torts* § 867 (1939)). That later evolved into the four separate torts of right to privacy, found in the *Restatement (Second) of Torts*, which exists today. *Id.* at 719. The four privacy torts are (1) "unreasonable intrusion upon the seclusion of another"; (2) "appropriation of the other's name or likeness"; (3) "unreasonable publicity given to the other's private life"; and (4) "publicity that unreasonably places the other in the false light before the public." *Id.* (quoting *Restatement (Second) of Torts* § 652A (1977)). As technology has increased in our society, privacy law has had a difficult time keeping up with the speed of technology. *Id.* at 719. *See also* Warren & Brandeis, *The Right to Privacy*, 4 Harv. L. Rev. 193, 213 (1980); *see also* Kristin M. Raffone,

with insights into the biochemical processes that control human traits, inheritance of diseases and conditions, and the factors that effect whether an individual will develop a disease or not,[24] it will also provide mechanisms by which individuals may discriminate against others based on their genetic code and the resulting "future diary" formed by the nucleotide sequence of an individual's DNA.[25]

The solution, which may balance these competing public interests of medical and biological advancements and the infringement on privacy rights, is held within the legal field.[26] It is up to the legislative branch of our federal government to place controls on the technological advancements that have allowed scientists to sequence the genetic code and disburse genetic information to the public.[27] The federal government has yet to enact legislation that would protect the privacy of genetic information and prohibit genetic discrimination in the employment and insurance industries.[28] The federal government is running out of time though. The Human Genome Project is scheduled for completion by 2003, if not earlier.[29]

The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy, 26 Hofstra L. Rev. 503, 530 (1997). The Fourth Amendment of the Constitution protects an individual from the unreasonable searches and seizures. *Id.* The Fourteenth Amendment has also been recognized as providing a fundamental right to due process, which the Supreme Court extended to create a zone of privacy, which was extended to create a right of privacy in a married couples marital relations, in *Griswold v. Connecticut*. *Id.* at 534. The right to privacy created by the court developed into "the right to selective disclosure" and "the right of autonomy in personal decision-making." *Id.* (citing *Skinner v. Railway Labor Executives' Assn.*, 489 U.S. 602, 617; *Whalen v. Roe*, 429 U.S. 589, 599-600).

24. *See generally* William Porter, *Genes That Fit: Revealing DNA Blueprint as a Matter of Courtship Has Ethical Implications*, Denver Post (Sept. 17, 2000) (available on LEXIS, News, News Group File) (explaining that a genetic predisposition does not mean that a person will definitely develop the genetic condition or disease); *see also* Ctr. for Disease Control, *Translating Advances*, *supra* n. 9, at ¶ 4 (explaining that scientists believe that the risk for disease increase when genes interact with environmental factors, including chemical, physical, infectious agents, and behavioral and nutritional factors).

25. Patricia A. Roche, *Genetic Privacy Must Be Guarded*, 22 Natl. L.J. 50, ¶ 3 (Aug. 7, 2000) (explaining that genetic information is different from any other medical information, as it is more sensitive, and that a DNA sample can be seen as a sort of diary that is a 'future diary' which reflects our probabilities of developing diseases or conditions later in our lifetime). The reason I only propose that the federal government must enact legislation is that one uniform and consistently enforceable law is what is needed to protect every citizen's privacy right to their individual genetic information.

26. *See* Kalinoski, *supra* n. 16, at 11 (explaining that the legal system must be involved on all fronts of technological development, and play the role of regulating the advancements so to control its effects on society).

27. *See id.* (explaining that it is up to the legislature to keep up with technological advancements and regulate it accordingly).

28. *See generally* Mark Terry, *Human Genome Map Is No Cause for Alarm*, Det. News (Aug. 16, 2000) (available in 2000 WL 3488060).

29. U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals*, *supra* n. 5, at ¶ 2.

Legislation "has always lagged behind the pace" at which technology is advancing.[30] However, it is time for the legislature to catch up with the technological advancements that have lead to the mapping of the human genome, and take action to protect an individual's privacy rights and prevent genetic discrimination. DNA and our genetic information are what defines each of us and makes us unique.[31]

Our genetic code determines what we look like, what diseases we are likely to develop, and what traits, conditions and diseases we pass to our children.[32] Our genetic code is the most personal and private information that we will ever possess in our life,[33] and as such, we must set forth federal legislation that will protect our genetic information as our own, and gives us, as individuals, the right to control that information.

This comment presents an analysis of current federal legislation,[34] the possible interpretations that could apply to the genetic discrimination in the workplace and insurance field,[35] why there is a need for new legislation addressing genetic discrimination and the right to privacy concerning an individual's DNA and their genetic information and proposes possible new legislation for protecting a person's right to privacy concerning their DNA.

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30. Terry, *supra* n. 28, at ¶ 6.

31. Macklin, *supra* n. 2, at 158-59.

32. *Id.*

33. *See id.* at 159 (describing that an individual's genetic code is the most private and personal information that an individual will ever possess, as it holds the information that determines what we look like, that shows our predispositions to develop disease and the information that we will pass on to our biological children).

34. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § III. Current legislation that may apply to genetic discrimination and right to privacy are the *Americans with Disabilities Act of 1990*, the *Health Insurance Portability & Accountability Act of 1996* ("HIPAA"), and Title VII of the *Civil Rights Act of 1964*. *Id.* There are individuals who believe that current non-discrimination laws can be interpreted to include genetic discrimination. *Id.* Individuals believe that under the *Americans with Disabilities Act of 1990*, individuals who have an expressed genetic disease or genetic condition, could be found to be "disabled" under the legislation. *Id.* As a disabled person, these individuals would then be protected from discrimination in the workplace based on their genetic disease/condition. *Id.* The *Health Insurance Portability & Accountability Act of 1996*, covers individuals who are insured by employer-based and commercially issued group insurance plans. *Id.* Under HIPAA, group insurance plans are prohibited from using any health-status related factor, including genetic information, in denying or limiting eligibility for coverage or charging an individual for more coverage. *Id.* The last of the current non-discrimination legislation that is thought to possibly be interpretable to include genetic discrimination is Title VII of the *Civil Rights Act of 1964*. *Id.* Under Title VII, genetic discrimination would be prohibited if discrimination was based on racially or ethnically linked genetic disorder that is substantially related to a particular race or ethnic group. *Id.*

35. *Id.*

II. BACKGROUND

A. WHAT IS DNA AND THE GENETIC CODE?

DNA is the bio-molecule that holds all the answers to life.[36] DNA contains the information that make up the "basic set of inherited instructions for the development and functioning of the human being."[37] DNA is a double-helix molecule found within a cell's nucleus.[38] DNA molecules are nucleic acids and are composed of nucleotides.[39] Nucleotides consist of three structural units, a nitrogenous base, a pentose sugar and a phosphate group.[40] There are four different nitrogenous bases found in the DNA structure.[41] The combination of these four nucleotides found in the DNA structure, make up the genetic code.[42] Almost every triplet combination of these codes specifies one of the twenty amino acids.[43] A human being has twenty-three pairs of chromosomes that consist of three billion nucleotide base pairs.[44] Genes are the linear array of nucle-

36. Klug, *supra* n. 3, at 4.

37. Natl. Human Genome Research Inst., *The Human Genome Project: What Is the Human Genome Project* ¶ 1 <http://www.nhgri.nih.gov/HGP/> (accessed Sept. 5, 2000). The genetic code contained in DNA both "construct[s] and operate[s] [the] human body." Museum Innovation, *The Tech* ¶ 2 <http://www.thetech.org/exhibits_events/online/genome/overview.html> (accessed Oct. 28, 2000).

38. Klug, *supra* n. 3, at 8.

39. *Id.* at 9.

40. *Id.* at 198.

41. *Id.* The four nitrogenous bases in DNA are adenine, guanine, cytosine and thymine. *Id.* These nitrogenous bases are what is read by researchers to determine what an individual's genetic code is. *Id.* There are also four nitrogenous bases when DNA is converted into RNA, however the thymine is replaced by uracil. *Id.* So, RNA contains the nitrogenous bases of uracil and adenine, and guanine and cytosine. *Id.* The nitrogenous base pairing still occurs as it does in DNA, except that adenine pairs with uracil, instead of thymine. *Id.* The four base nucleic acids for RNA are adenine, uracil, cytosine and guanine. *Id.* RNA, ribonucleic acid, is a single stranded nucleic acid that differs from DNA molecule structure in that RNA has a ribose sugar instead of a deoxyribose sugar nucleoside. *Id.* In some organisms, such as most viruses, the genetic information is stored in an RNA molecule instead of a DNA molecule. *Id.* at 197. RNA is also found in organisms that have DNA too. *Id.* at 204. Ribosomal RNA (rRNA), messenger RNA (mRNA) and transfer RNA (tRNA) are complementary copies of one of the two strands of DNA during the process of transcription. *Id.* Transcription is the transfer of genetic information from DNA by the synthesis of an RNA molecule copied from a DNA template. *Id.* at 553. RNA can either serve as the mechanism by which DNA can be taken out of the cell nucleus and replicated within other cellular structures or as the primary genetic information holder, depending on the organism in which it is found. *Id.*

42. *Id.* at 9. The triplet combination of nucleotides is called a codon. *Id.* Each individual codon, then specifies or encodes the information for a single amino acid. *Id.* at 521. Amino acids are the building blocks for proteins. *Id.*

43. *Id.* at 9. Amino acids are the subunits that are covalently linked to form proteins. *Id.* at 519.

44. *See generally* Georgetown University, *The Human Genome Project* <http://www.georgetown.edu/research/nrcbl/scopenotes/sn17.htm#elsi> (accessed Sept. 20, 2000).

otides and are the functional unit of heredity.[45] The sequence of the nucleotides, an individual's genes, found in an individual's chromosomes, determine human traits,[46] such as whether an individual has brown, blue, green or hazel eyes. These nucleotide sequences can also be used to determine whether an individual is predisposed to or has a genetically linked disease, such as sickle cell anemia, Huntington's disease, and cystic fibrosis, or if the individual possesses a gene that has been associated with a common disease or condition, such as anemia, arthritis, or myocardial infarction.[47]

B. WHAT IS THE HUMAN GENOME PROJECT?

The Human Genome Project is an international collaboration funded by the National Institutes of Health and the Department of Energy.[48] The goal of the project is to identify all the genes and map their locations on the twenty-three pairs of chromosomes found within the human cell.[49] The twenty-three pairs of chromosomes in the human cell contain

45. Klug, *supra* n. 3, at 8. Genes are located on chromosomes. *Id.* Chromosomes, in eukaryotes, are composed of linear DNA molecule and are intimately associated with proteins. *Id.* Viruses and bacteria have a single chromosome, which is usually a circular DNA molecule organized into genes. *Id.* In all organisms chromosomes serve as the vehicle for transmission of genetic information. *Id.*

46. *Id.* at 9.

47. *See* Ctr. for Disease Control, *Translating Advances*, *supra* n. 9, at ¶ 20 (explaining that there are a number of genes associated with common disease, not just the rare metabolic disorders and malformation syndromes that are genetically linked). A few of the common diseases that have been found to have a genetic link, that makes an individual at a higher risk for these diseases are listed below (with the number of genetic mutations which have been found to increase an individual's risk of developing these common diseases):

Number of Genes Reported To Be Associated with Selected Conditions	
Condition	Number of Entries
Mental Retardation	802
Cancer	367
Anemia	288
Infection	258
Diabetes	242
Arthritis	96
Myocardial Infraction	44

Id. (quoting statistics from the *Online Mendelian Inheritance in Man*, 1997).

48. U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals*, *supra* n. 5, at ¶ 5.

49. Encarta Encyclopedia, *supra* n. 4, § I. The map of the human genome by HGP, will locate where the genes are found on the human chromosomes, by sequencing the DNA nucleotide sequence. *Id.* The determination of where the genes are located on the chromosomes and the particular sequence of those genes will allow scientists to determine the precise location of a gene that is associated with a specific human trait and specific inherited diseases. *Id.* The completion of the genome map will revolutionize the therapeutic and preventive medicine available to treat genetic disorders and diseases, as well as allowing

50,000 to 100,000 genes.[50] To accomplish the mapping of the genes on the human chromosomes, scientists must sequence the DNA's nucleotide bases.[51] The project will map the specific locations on the chromosomes of genes that determine specific human traits and inherited diseases.[52]

The Human Genome Project began in the United States in 1990 and is scheduled for completion in 2003.[53] President Clinton announced in June 2000, the completion of the first survey of the human genome by the Human Genome Project.[54] The survey is a "working draft" of a reference of the DNA sequence of the human genome, and the draft represents a map of approximately ninety percent of the genes on every chromosome.[55] After the Human Genome Project maps the human genes, the genome sequence are recorded into GenBank,[56] a public

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scientists an insight into the biochemical processes that underlie human diseases. *Id. See also* DNA Sciences, *The Human Genome Project*, DNA Basics ¶ 10 <http://www.dna.com> (accessed Nov. 3, 2000) (describing the goals of the Human Genome Project). The first goal of the HGP is to is to list all of the base pair nucleotides found on the DNA molecule. *Id.* at ¶ 3. The second goal is to take this nucleotide sequence and determine what constitutes the individual genes (find where the gene starts and ends in this nucleotide sequence) and then determine where these genes are on the chromosomes. *Id.* at ¶¶ 4-6. A gene is simply a group of nucleotides which tell the body to make a protein molecule, which is composed of amino acids. *Id.* at ¶ 4. Once the individual genes are found and identified, scientists will be able to identify the functions of the individual genes and then determine the results of variations in the nucleotide sequence. *Id.* at ¶ 10. Once these variations are found, scientist can then figure out why these variations increase an individual's susceptibility to different diseases and conditions. *Id.* at ¶ 10. The map of the human genome will provide a better understanding of diseases, provide mechanisms for early detection of diseases, provide tests to determine an individuals predisposition to a genetic condition or disease, as well as providing gene therapy and the development of new treatments and drugs for these diseases. *Id.* at ¶ 11.

50. *See* Encarta Encyclopedia, *supra* n. 4, § I.; *see generally* Natl. Ctr. for Biotechnology Info., *A Gene Map of the Human Genome* <http://www.ncbi.nlm.nih.gov/SCIENCE96/> (accessed Sept 21, 2000) (describing that scientists believe that there are an estimated three billion base pair nucleotides on the DNA molecule, which make approximately 50,000 to 100,000 genes, which are located on the twenty-three pairs of human chromosomes).

51. *See* Encarta Encyclopedia, *supra* n. 4, § I (describing that the genetic information is encoded by DNA in base pairs of nucleotides, and to map the human genome, scientists must determine the nucleotide sequence, through a process known as sequencing). *See also* DNA Science, *supra* n. 49, at ¶¶ 1-3.

52. *See* Encarta Encyclopedia, *supra* n. 4, § I.

53. U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals, supra* n. 5, at ¶¶ 5-6.

54. U. S. Dept. of Energy, *Genetics in the News, supra* n. 13, at ¶ 4.

55. *Id.*

56. Natl. Ctr. for Biotechnology Info., *GenBank Overview* ¶ 1 <http://www.ncbi.nih.gov/Genbank/GenbankOverview> (last updated Mar. 12, 2002). "GenBank is the NIH genetic sequence database, an annotated collection of all publicly available DNA sequences." *Id.* As of February 2002, the database contains some 17,089,000,000 bases in 15,465,000 sequence records. *Id.*

database that is available to anyone who has access to the Internet.[57] Publication of the human genome project on the Web will allow anyone access to the genome map, so that if someone gains access to an individual's genetic code, that someone will be able to decipher what mutations and possible predispositions the individual has to genetically linked diseases and conditions, by which an entity may then discriminate against an individual.[58]

C. Legal Overview of Genetics

The working draft of the human genome is a monumental achievement in scientific history,[59] because it will provide the medical community with great opportunities and information that will aid in the

57. *See id.; see also* U.S. Dept. of Energy Off. of Science, Off. of Biological & Envtl. Research, & Human Genome Project, *Human Genome Project Information: Genetics & Patenting* ¶ 27 <http://www.ornl.gov/hgmis/elsi/patents.html> (accessed Sept. 5, 2000). The reasoning for disseminating the human genome information on the Internet, was to "encourage[ ] widespread use of [the] information, minimize transaction costs, and make[ ] the R&D cheaper and faster." *Id.* at ¶ 28. Placing the human genome information on the Web, allows individuals to gain access to the information, which might have otherwise been "priced out of by the market." *Id.*

58. Natl. Ctr. for Biotechnology Info., *supra* n. 56, at ¶ 6. The GenBank database is searchable by anyone with Internet access. *Id.* And despite the open access to this genetic database, the National Center of Biotechnology Information "places no restrictions on the use or distribution of the GenBank data." *Id.* Because of the lack of control over the use of the genetic information on this Web site, once I was able to collect a DNA sample from an employee, I could then use the resulting genetic code of that employee, log on the GenBank Web site, look up the genetic sequence associated with breast cancer associated with $BRCA_1$, and then compare the known genetic variation associated with that disease, with that employee's genetic code, I could determine if that person in fact had that variation. This information would tell me that this specific individual has the pre-disposition to develop breast cancer.

59. DNA Sciences, *supra* n. 49, at ¶ 10. The mapping of the human genome is expected to benefit molecular medicine by providing a better understanding of genetic diseases, providing for earlier detection and improved diagnosis of diseases, providing information about an individual's genetic susceptibility to a genetic disease or condition, providing information that may aid in the new treatments and drugs for genetic diseases and conditions and providing gene therapy. *Id.* at ¶ 11. The mapping of the human genome will also benefit science by increasing our knowledge of microbial (bacteria and viruses) genomics. *Id.* at ¶ 12. With increased knowledge of human genetics, scientists will be able to increase their knowledge about other organisms genetic information, including the genetics of bacteria and viruses. *Id.* With increased microbial genetic knowledge, scientists will be able to create new energy sources, provide environmental monitoring to detect pollution levels in the environment, come up with toxic waste cleanup mechanisms and also create protections from biological and chemical warfare. *Id.* The human genome will also provide scientists with more information about the history of humans, their evolution, migration and lineage. *Id.* at ¶ 14. The Human Genome Project will help law enforcement agencies and provide for identification mechanisms. *Id.* at ¶ 15. Genome information will also benefit agriculture, livestock breeding and bioprocessing. *Id.* at ¶ 17. Genetists will be able to develop crops and farm animals that are more disease, insect and drought resistant. *Id.*

development of treatments for genetic diseases and detection methods that could provide earlier possible detection and even prevention of genetic diseases.[60] The implications of this project are profound for the global community.[61] There are ethical, moral, and legal implications of the mapping of the human genome.[62] There will be legal issues revolving around privacy rights because of the availability of the human genome map and individual's genetic code,[63] issues of genetic discrimination in insurance coverage,[64] discrimination in the workplace,[65] and issues of human cloning rights.[66] There are no federal laws currently in place to deal with the genetic discrimination that will likely explode in the insurance field,[67] and no federal laws currently dealing with possible genetic discrimination in the workplace.[68]

While Congress has tried to pass several bills involving genetic information and its usage, none have become law.[69] In February 2000, President Clinton signed an executive order "prohibiting federal departments and agencies from using genetic information in any hiring or promotion action,"[70] but this order does nothing for the vast number of

60. *Id.* at ¶ 11.

61. *See* Ctr. for Disease Control, *Translating Advances*, *supra* n. 9, at ¶¶ 1-3 (describing that because of the advances in genetic research and genetic tests, and the increasing public availability of these advances, there are increasing questions about ethical ramifications, variations in personal and cultural views on what constitutes disease and disability, concerns about accumulations of genetic information on individuals, and questions about confidentiality of genetic information that is obtained).

62. Natl. Human Genome Research Inst., *supra* n. 37, ¶ 1. With the Human Genome Project nearing its completion, individuals and society will have to face policy issues concerning the disbursement of genetic information into the world. *Id.* There will likely be issues of who should have access to our genetic information and how that information may be used. Legal issues involving issues of right to privacy, patent and genetic discrimination and moral issues include rights to clone, abortion, prenatal selection and genetic testing. *Id.*

63. U.S. Dept. of Energy Off. of Science, Off. of Biological and Envtl. Research, Human Genome Project, *DOE ELSI Program Emphasizes Education, Privacy: A Retrospective (1990-1999)* ¶ 3 <http://www.ornl.gov/resource/elsiprog.html> (last updated Aug. 2, 2000).

64. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

65. *See* Dept. of Labor, *supra* n. 8, at ¶ 6 (explaining that as genetic technology increases, so will the ability to detect and prevent health disorders, but that the genetic information that is obtained may also be misused to discriminate against or stigmatize individuals).

66. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

67. *Id.* § III.

68. *Id.* § I; *see* Dept. of Labor, *supra* n. 8, at ¶ 17 (explaining that there is a need for federal legislation addressing genetic discrimination in the workplace, because there are no federal laws that directly and comprehensively protect against abuses in the gathering and using of genetic information in the employment industry).

69. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

70. *Id.* § I. President Clinton's executive order prohibits federal employers from requiring or even requesting genetic testing for the basis of hiring procedures. *Id.* It also

working individuals in the United States who do not work for a federal agency or department.[71]

Only a handful of states have passed laws that prohibit genetic discrimination in the workplace,[72] but none of these state laws are comprehensive.[73] There is no commonality or uniformity in the coverage given by these state laws, the protection allotted to those whom are covered, or the enforcement schemes available under the state laws.[74] And only a few states have passed legislation that prohibits the unauthorized access

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prohibits federal employers from requiring genetic testing to evaluate an individual's ability to perform his/her job. *Id.* The order also prohibits federal employers from classifying employees based on their genetic information that would result in depriving an individual from advancement within their office. *Id.* The executive order also provides a basic privacy protection for genetic information to be used by medical personnel for medical treatment and research, and only allows federal employers to disclose the genetic information of the employees when medical treatment is needed to ensure workplace health and safety. *Id. See also* Exec. Or. 13145, 65 Fed. Reg. 6877 (Feb. 8, 2000) (prohibiting genetic discrimination by federal government employers).

71. *See* U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

72. Dept. of Labor, *supra* n. 8, at ¶ 25. As of October 1997, only fourteen states had enacted legislation to deal with genetic discrimination in the workplace. *Id.* The states' legislation are not uniform and only afford individuals limited rights against discrimination. *Id.* at ¶ 30. Florida's genetic discrimination law only prohibits genetic discrimination against individuals with a specific genetic disorder, such as sickle cell anemia, while New York law prohibits employers from denying equal employment opportunities based on "unique genetic disorders." *Id.* at ¶ 26. Oregon law prohibits employers from using genetic information to discriminate or even distinguish between applicants and employees. *Id.* at ¶ 27. Oregon also prohibits employers from subjecting employees or job applicants to genetic testing. *Id.* And Texas law prohibits employers from discriminating against an individual on the basis of genetic testing or because the individual refuses to submit to genetic testing. *Id.* On the other hand, some states have statutes that specifically allow employers to genetically test employees, in order to investigate a worker's compensation claim or to determine susceptibility to toxic chemicals in the workplace. *Id.* at ¶ 28. *See also* Sen. Comm. on Health, Education, Labor & Pensions, *Genetic Information Discrimination in the Workplace*, Cong. Testimony of Harold Coxson (July 20, 2000) ¶ 9-10 (available in LEXIS, Federal News Service). As of 2000, there are twenty-one states that prohibit employment discrimination based on genetic information. *Id.* at ¶ 9. These states and there dates of enactment are: Arizona (1997), California (1998), Connecticut (1997), Delaware (1998), Illinois (1997), Iowa (1997), Kansas (1999), Maine (1998), Missouri (1998), Michigan (2000), Nevada (1999), New Hampshire (1995), New Jersey (1996), New York (1996), North Carolina (1997), Oklahoma (1998), Oregon (1995), Rhode Island (1992), Texas (1997), Vermont (1997), and Wisconsin (1991). *Id.* There are only nineteen states that have enacted genetic privacy laws. *Id.* at ¶ 10. These states are: Arizona, California, Colorado, Delaware, Florida, Georgia, Illinois, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, South Carolina, Texas, Vermont, and Virginia. *Id.* The major problem with the majority of the individual state's legislation is that the state laws are narrow in scope and deal specifically with genetic information and side-step genetic testing. *Id.*

73. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § II.

74. *Id.*

and release of genetic information.[75] There are many legislators that believe that the existing *Americans with Disabilities Act of 1990*, the *Health Insurance Portability & Accountability Act of 1996*, and Title VII of the *Civil Rights Act of 1964* can be interpreted to include genetic discrimination in the workplace and by the insurance industry,[76] but none of these possible interpretations have been tested in the courts.[77]

In fact, the government began using genetic information in a law enforcement program that has come under much scrutiny as to whether the use of genetic information deprives individuals of their privacy rights. In 1998, the Federal Bureau of Investigation ("FBI") revealed a database system that allows state and local criminal investigators to share and use genetic information to help the police solve crimes.[78] The FBI's National DNA Index System ("NDIS") integrated the existing DNA databases used by state and local law enforcement agencies into a federal database.[79] The NDIS allows criminal investigators to take DNA found at a crime scene and match that DNA with the DNA of known criminals in other states.[80]

Observers of the system have questioned if the database compromises the right to privacy of individual whose DNA are found on the

75. Paul Hardwick, *What To Do with DNA data?* ¶ 3 <http://www.privacydigest.com/1999/11/18> (accessed Sept. 5, 2000). According to Hardwick, only three states have enacted legislation that prevents unauthorized access and release of genetic information. *Id.* These three states are Connecticut, Rhode Island, and Virginia. *Id. See also* Conn. Gen. Stat. § 38a-816 (10) (2000). Connecticut law prohibits the use of genetic information by the insurance industry for the determination of coverage. *Id.* The state also prohibits access to genetic information by unauthorized individuals. *Id.* Rhode Island's laws are more comprehensive. *See also* R.I. Gen. Law §§ 27-20-39, 27-18-52, & 27-19-44 (1999). The Rhode Island law prohibits human cloning, prohibits unauthorized release of genetic information, prohibits insurance companies from discriminating against individuals based on their genetic information and prohibits genetic discrimination in the workplace. *Id. See also* Va. Code Ann. § 32.1-67.1 (2000). Virginia has also passed legislation that prohibits the release of genetic information obtained through genetic testing without the express permission of the person who has been tested, unless under the age of eighteen and then only if a parent or guardian consents to the release of the genetic information. *Id.* Otherwise the statute provides that the genetic information of an individual will remain confidential and only accessible by certain medical personnel. *Id.*

76. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § III (explaining why some individuals believe that these three pieces of federal legislation may be interpreted to include genetic discrimination as a prohibited practice in the workplace and insurance field).

77. *See id.*

78. L. Scott Tillett, *DNA Database Initiative Raises Privacy Fears* ¶ 1<http://www.fcw.com/fcw/articles/1998/FCW 101998 1203.asp> (Oct. 19, 1998).

79. *Id.* at ¶ 2.

80. *Id.*

database.[81] The FBI has stated that individuals who have access to the database will undergo background checks, but that the DNA profiles that are entered into the NDIS will depend on the laws and procedures of the individual states.[82] Therefore, it is up to individual states to determine those who will have their DNA samples taken.[83] Some states have laws that only allow convicted felons to be tested, while other states allow DNA samples to be taken from anyone who is arrested for any crime.[84] Some critics of the NDIS fear that the system may eventually become "a store-house for DNA information on innocent people as well as known criminals."[85] Critics of the NDIS also believe that it will be easy for the FBI to eventually expand the DNA database use beyond criminal investigations.[86]

D. Discrimination Based on Genetic Conditions

In 1996, a survey of 917 individuals, who were determined by genetic testing to be at risk of developing a genetic condition and the parents of children with specific genetic conditions, found more than 200 cases of genetic discrimination.[87] These instances of discrimination included discrimination by insurance companies, employers, and other organizations that use genetic information.[88]

In 1983, the United States Office of Technology Assessment ("OTA") found that of 366 firms that responded to the survey, eight large firms were using genetic screening in their hiring process, seventeen firms reported having used genetic testing in the past, and fifty-nine firms

81. Geraldine Sealey, *Debating DNA: The Ultimate Crime-fighting Tool, or the Ultimate Invasion of Privacy* ¶ 8 <http://www.abcnews.go.com/sections/us/DailyNews/dnadebate990804.html> (accessed Sept. 20, 2000).

82. Tillett, *supra*. n. 78, at ¶¶ 8-9.

83. *Id.* at ¶ 9.

84. *Id.* Louisiana allows the law enforcement to take DNA samples from anyone who is arrested for any crime. *Id.* All states collect DNA from people convicted of serious sexual offenses. *Id.*

85. *Id.* at ¶ 10.

86. *Id.* at ¶ 11.

87. Dept. of Labor, *supra* n. 8, at ¶ 6 (citing Lisa Geller, *Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 Science & Engineering Ethics, 71-88 (1996)).

88. *Id.*; *see e.g.* Geri Aston, *Ban Genetic Discrimination?*, Am. Med. News ¶ 34 <http://www.ama-assn.org/sci-pubs/amnews/pick_97/pick0505.htm> (May 5, 1997) (describing a American Medical Association sponsored survey of 917 members of genetic disease support groups in February 1997, which found 455 of them reported that they were subject to genetic discrimination by life insurers, employers, health care providers, military and schools).

planned to use genetic screening in the future.[89] Six years later, in 1989, OTA conducted a follow-up survey and found that thirteen percent of the health officers responding from Fortune 500 companies reported using genetic screening in the hiring process.[90] A 1989 survey by Northwestern National Life Insurance Company found that fifteen percent of some four hundred firms planned on using genetic testing by the year 2000 to determine the genetic status of potential employees before deciding whom to hire.[91]

The private sector is not the only one to have used or have considered using genetic testing in their hiring processes. In the 1970s, for a six-year period, the U.S. Air Force screened all of its African-American recruits for sickle cell anemia and rejected the application of any individual that possessed the gene for sickle cell anemia, even if they were only carriers for the genetic disease.[92] Since there is only a limited number of states in the United States that have laws in effect that address genetic privacy and genetic discrimination in the workplace and insurance field,[93] and because there is no overarching federal genetic privacy or genetic discrimination law in existence, there is no protection of genetic information that will prevent unauthorized disclosure to the insurance field, employers or government.[94]

Genetic tests are becoming more widely available.[95] Within this

89. Priscilla M. Regan, *Genetic Testing & Workplace Surveillance: Implications for Privacy* in *Computers, Surveillance, & Privacy* 21, 28 (David Lyon & Elia Zureik eds., U. of Minn. Press 1996).

90. *Id.*

91. *Id.*

92. *See* Andy Ho, *Body Bountiful*, 55 The Straits Times ¶¶ 17-18 (Sept. 3, 2000) (available in 2000 WL 2985019) (explaining that many insurers and employers do not grasp the difference between an individual having a mutated gene that predisposes them to a genetic disease, or which makes them only a carrier of the gene, which they might pass to their progeny).

93. *Id.* at ¶ 26; *see also* Ann Scott Tyson, *Lawmakers Play Catch-up to Genetic Science*, Christian Science Monitor ¶ 13 (Aug. 10, 2000) (available on LEXIS, News, News Group File) (describing that there is only very limited federal legislation concerning genetic discrimination, and is silent concerning genetic privacy and that only nineteen states have passed genetic privacy laws, twenty-one that bar genetic discrimination and thirty-two states that prohibit insurers from underwriting or rate-making decisions based on genetic information).

94. *See* Ho, *supra* n. 92, at ¶¶ 20-26 (explaining that intimate genetic information is collected in electronic databases and is therefore vulnerable to prying eyes and is data which may be manipulated and abused and that without federal legislation directly addressing the privacy of genetic information, that there may be unauthorized disclosure of genetic information).

95. Ctr. for Disease Control, *Translating Advances*, *supra* n. 9, at ¶ 2. There are currently genetic tests available for more than 400 genes associated with genetic diseases and conditions. *Id.* at ¶ 4. *See e.g.* Darryl R. J. Macer, *Shaping Genes: Ethics, Law and Science of Using New Genetic Technology in Medicine and Agriculture* ¶¶ 1-6 <http://

decade, it is believed that science will come up with more inexpensive genetic tests that will make genetic screening more readily available.[96] Doctors are performing genetic testing every day. Yet there is no federal legislation controlling the privacy of an individual's genetic information and there are no federal laws controlling dissemination of genetic information and the resulting likelihood of genetic discrimination.[97]

III. ANALYSIS

A. Current Anti-Discrimination Legislation and Its Implications on DNA

Although no federal legislation has been passed to prevent genetic discrimination,[98] there are some individuals who believe that certain parts of existing federal anti-discrimination laws can be used to protect individuals against genetic discrimination.[99] The laws thought by some to be possible sources of protections for an individual's genetic code[100] and that would prevent employers and insurance companies from discriminating against persons possessing a certain genetic code that predisposes them to a genetic condition or disease are the *Americans with Disabilities Act of 1990* ("ADA"),[101] the *Rehabilitation Act of 1973* ("RA"),[102] the *Health Insurance Portability & Accountability Act of 1996*

Zobell.boil.tsukuba.ac.jp/~macer/SG13.html> (accessed Oct. 18, 2000) (describing that genetic testing is becoming more widely available and listing a few of the genetic diseases/conditions that there are genetic tests for, including hypercholesterolemia, polycystic kidney disease, Huntington's disease, neurofibromatosis, myotonic dystrophy, polyposis, cystic fibrosis, phenylketonuria, sickle cell anemia, Duchenne muscular dystrophy and haemophilia). Genetic testing allows for detection of genetic disorders before physical symptoms emerge. *Id.* at ¶ 1. There are many advantages with the increased availability of genetic screening/testing. *Id.* at ¶ 105. Many individuals may now be identified as carrying a genetic disease, through genetic screening, and these individuals and their progeny can receive the appropriate therapy to treat their genetic disorder/disease. *Id.* However, genetic testing also bring with it questions regarding the rights of individual privacy, regarding what of genetic information is accessible by other individuals. *Id.*

96. Tyson, *supra* n. 93, at ¶ 6.

97. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra*. n. 10, § III; *see also* Macer, *supra* n. 95, at ¶ 108 (describing the implications of genetic testing and the availability of genetic information causing privacy infringement and genetic discrimination by employers and insurance companies).

98. U.S. Dept. of Energy, *Genetic Privacy & Legislation*, *supra* n. 10, § III.

99. *Id.*

100. *Id.*

101. 42 U.S.C. §§ 12101-12117 (1994) (prohibiting an employer from discriminating against an individual because of a protected disability).

102. 29 U.S.C.A. §§ 701-796 (West 2000) (prohibiting disability-based discrimination in the employment field).

("HIPAA"),[103] and Title VII of the *Civil Rights Act of 1964*.[104]

The *Americans with Disabilities Act of 1990* may provide the best protection against genetic discrimination in the workplace of all existing law.[105] Although the ADA does not mention genetic information,[106] it does give limited protection against disability-related genetic discrimination in the workplace.[107] The ADA does protect individuals, who are regarded as having a disability, from being discriminated against for that disability or the perceived disability.[108] The *Rehabilitation Act of 1973* protects individuals with symptomatic genetic conditions, the same as any other disabled individual.[109] So, if an individual has a genetic code that predisposes him or her to a disease at a later time but the condition is unexpressed at the present point in time, then this individual is not a protected class of persons who may not be discriminated against under the ADA or RA.

Further, neither the ADA nor the RA protect against discrimination of individuals with unexpressed genetic conditions.[110] These statutes also fail to limit employers from requesting or even requiring potential employees or current employees from providing them with genetic information or submitting to genetic testing.[111] The ADA and the RA also do not protect employees from employers who require medical information to be provided by their employees if it is related to their jobs or if it is a business necessity.[112]

In March 1995, the Equal Employment Opportunity Commission ("EEOC") issued an interpretation of the ADA with respect to genetic conditions.[113] According to the EEOC, the ADA does not allow entities

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103. 29 U.S.C.A. §§ 1181-1187 (West 2000) (prohibiting employer-based and commercially issued group health insurance from using health status factors, including genetic information, to deny, limit, or exclude pre-existing conditions for more than one year).

104. 42 U.S.C.A. § 2000e-16 (West 2000) (prohibiting discrimination that are racially or ethnically linked).

105. U.S. Dept. of Energy, *Genetic, Privacy & Legislation*, *supra* n. 10, § III.

106. *Id.*

107. *Id.*

108. 29 C.F.R. § 1630.4 (stating that it is unlawful for a covered entity to discriminate against a "qualified individual" with a disability in the recruitment, advertising, job application procedures, hiring, promotion, demotion, transfer, layoff, termination, rehiring, rates of pay, job assignment, classification, seniority, leaves of absence, sick leave, fringe benefits, or any other term, condition, or privilege of employment).

109. 29 U.S.C.A. §§ 701-796 (prohibiting discrimination against an individual who has symptoms of a genetic disease or condition present, by making these symptomatic individuals classified as "disabled," therefore making them protected under the *Americans with Disabilities Act of 1990*).

110. U.S. Dept. of Energy, *Genetic Privacy & Legislation*, *supra* n. 10, § III.

111. *Id.*

112. *Id.*

113. *Id.*

to discriminate on the basis of genetic predisposition, because these individuals are regarded as having impairments covered under by the ADA.[114] However, the EEOC said that the ADA does not cover persons who are unaffected[115] carriers of recessive or X-linked disorders,[116] or

114. *Id.*

115. *Id.* Unaffected individuals would be those individuals whom have been genetically tested and whose genetic code shows that they carry the genetic code for a certain genetic condition or disease. *Id.* An example of an unaffected individual would be an individual found to have the mutated form of the breast cancer gene $BRCA_1$. *See also* Thomas 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, 66 (Mark Rothstein ed.Yale U. Press 1997). An individual with the mutated $BRCA_1$ gene has an approximately 85 percent lifetime risk of breast cancer. *Id.*

116. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § III; *see also* Klug, *supra* n. 3, at 46 & 478 (describing what a recessive gene is and its implications on genetic expression of that trait in a recessive gene carriers' children). An individual can have recessive genes, which remain unexpressed because individual possess pairs of chromosomes. *Id.* at 46. When an individual has a recessive gene but does not express the trait, the individual's second chromosome of the pair has a dominant gene on it, and the dominant gene trait is expressed. *Id.* However, when this individual has a child, this parent may pass either the dominant or recessive gene onto their progeny, because the parent's chromosomes divide during meiosis, where there is one replication of the chromosomes and then two nuclear divisions to form gametogenesis or sporogenesis (egg or sperm). *Id.* During these nuclear divisions, the recessive gene and dominant gene chromosomes are separated. So, the parent's progeny could receive either a recessive or dominant allele. *Id.* So, if a child receives a recessive allele from each parent, that person will express the recessive trait. Cystic fibrosis is an example of a recessive genetic disease. Both parents must be a carrier the cystic fibrosis disease gene. While the cystic fibrosis disease gene is recessive and not expressed in either parent, the child who receives both recessive genes will express the genetic disease. X-linked recessive alleles/genes are carried on the X chromosome. *Id.* at 478. In the human species, the female carries two X chromosomes, while the male carries an X and Y chromosome. *Id.* Women can possess a recessive X-linked gene on one of their X chromosomes and a dominant gene on the other chromosome. *Id.* When the woman has a child, she could pass a X chromosome with either a recessive gene or a dominant gene. *Id.* If she passes the recessive gene on the X-chromosome to a son, who receives the Y chromosome from the father, then the person will express the recessive gene's trait. *Id.* If the woman with the X-linked recessive trait has a daughter, then she will receive the second X chromosome from her father. Unless her father expresses the X-linked genetic trait, then she will receive a dominant X-linked gene from him. *Id.* So, a woman may have an X-linked recessive trait and not express the genetic trait. *Id.* Genetic testing shows whether an individual has a recessive gene or X-linked genetic condition or disease. *Id.* at 178-79. Both of these classes of individuals, who carry the X-linked gene whether only a carrier or a person who expresses the X-linked genetic condition, have a chance of passing the recessive gene on to their progeny. *Id.* at 478. *See generally e.g.* Jacob Bhatt, Cristi Coburn, Traci Barbosa, & Scott Trevino, *Duchenne's Muscular Dystrophy* <http://www.rlc.dcccd.edu/MATHSCI/reynolds/MD/dmd2.HTM> (accessed Oct. 18, 2000) (describing the characteristics of the X-linked genetic disorder.) Duchenne's Muscular Dystrophy is a X-linked genetic disease. *Id.* at ¶ 1. A mutation in the Xp21 locus on the X chromosome has been found to cause the disease. *Id.* As an X-linked genetic disease, with only rare exceptions, the disease only affects males. *Id.* at ¶ 2. The mutation in the Xp21 gene causes the absence of the gene product dystrophin, the protein which is

individuals who are at high-risk of developing a late-onset genetic diseases or conditions that are identified through genetic testing or by a person's family history.[117] Therefore, individuals who are merely carriers of a recessive or X-linked genetic trait or disease and those who have a family history of a genetic disease are not covered under the ADA or RA, and there are lingering questions about how the court will regard the EEOC's policy guidance interpreting the ADA as protecting individuals, who are predisposed to a genetic disease. Until the courts address a specific case of an individual who has a predisposition to a genetic condition/disease who has been subjected to genetic discrimination in the workplace, it is unclear if the EEOC's interpretation of the ADA will apply.

The third piece of current law that may be interpreted to cover genetic discrimination is the *Health Insurance Portability & Accountability Act of 1996*.[118] HIPAA is the only federal law that explicitly deals with the issue of genetic discrimination.[119] However, HIPAA only applies to employer-based and commercially issued group health insurance.[120]

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normally localized to the sarcolemma of muscle cells. *Id.* at ¶ 1. The absence of this protein causes muscle weakness and causes muscle degeneration and the patient will eventually die. *Id.* There are no cures for Duchenne's Muscular Dystrophy. *Id.* To best describe how any genetic condition or disease is passed to the child of a parent with a mutated or recessive gene, a punnett square is used:

		Mother	
		X	X'
Father	X	XX	X'X
	Y	XY	X'Y

[The gene with the apostrophe represents the defective X chromosome.]

The possible individual formed by the X'Y pairing would have the genetic disease, and be male. *See id.* The individual with the X'X pairing would be a female, and only a carrier of the genetic disease. *Id.* at ¶ 4. However, she would have the same odds that her mother had in passing the defective X chromosome on to her children. *Id.* The other two possible individuals would not have the genetic disease and would not possess the defective gene in their genome. *Id.* So, in an X-linked genetic disease, the mother who carried the defective gene would have a fifty percent chance of producing a child who would inherit her defective gene. *Id.* However, she would only have a twenty five percent chance of having a son, who would actually have the genetic disease. *Id.*

117. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § III. The policy guidance given by the EEOC is limited in its scope and legal effect that it has though. *Id.* The policy guidance does not have the same effect on the courts as a statute or regulation does and therefore must be tested in courts before one can be sure if the policy guidance given by the EEOC will stick in the real world when it comes to genetic discrimination. *Id.*

118. 29 U.S.C.A. §§ 1181-1187 (prohibiting employer-based and commercially issued group insurance from discriminating against an individual because of a person's genetic information, which reflects that an individual has or is predisposed to develop a genetic condition or disease).

119. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § III.

120. *Id.*

There is no federal legislation that protects individuals who are seeking private health insurance.[121] HIPAA prohibits group insurance health plans from denying or limiting an individual's eligibility for coverage or from changing an individual's coverage based on any health status related factor,[122] which includes genetic information.[123]

HIPAA also limits the pre-existing condition exclusions to one year and prohibits insurance companies from using pre-existing exclusions if the individual has been covered by other insurance and the condition was covered for more than one year under prior insurance.[124] HIPAA explicitly states that genetic information that predisposes an individual to a genetic condition or disease is not to be deemed a pre-existing condition for insurance purposes, unless there was a current diagnosis of actual illness for the genetic condition.[125] However, HIPAA does not "prohibit employers from refusing to offer health coverage as part of their company's benefit packages."[126]

Title VII of the *Civil Rights Act of 1964* is the last of the current federal anti-discrimination laws that could be applied to genetic discrimination.[127] If genetic discrimination is linked with a racially or ethnically linked genetic disorder,[128] it might be found to constitute an unlawful race or ethnic discrimination.[129] However, that protection would only be available if an employer's discrimination is based on a genetic trait that is substantially related to a specific race or ethnic group.[130] However, there are currently only a few genetic diseases and conditions that have been scientifically linked with a particular race or ethnicity.[131] So, the chances of genetic discrimination falling under the

121. *Id.*; *see also* Tyson, *supra* n. 93, at ¶ 13 (stating that thirty-two of the fifty states in the United States have passed laws prohibiting insurers from basing underwriting or rate-making decisions on genetic information).

122. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § III.

123. *See id.*; *see also Health Insurance Portability & Accountability Act*, 26 U.S.C.A. § 9801. The HIPAA provides that pre-existing conditions are allowed to be used, for purposes of pre-existing conditions, for which insurance may exclude coverage for a period of time, if the condition is expressed. *Id.* The act provides that "[f]or purposes of this section, genetic information shall not be treated as a condition . . . in the absence of a diagnosis of the condition related to such information." *Id.*

124. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § III.

125. *Id.*; *see Health Insurance Portability & Accountability Act*, 26 U.S.C.A. § 9801.

126. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § III.

127. 42 U.S.C.A. § 2000e-16.

128. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § III.

129. *Id.*

130. *Id.*

131. *Id.*; *see also* Klug, *supra* n. 3, at 319-21 (describing Sickle-cell anemia and its correlation with black community). Sickle-cell Anemia is a genetic disorder found almost exclusively in the individual who are of African descent. *Id.* at 421. In individuals with sickle-cell anemia, their erythrocytes, red blood cells, become elongated and curved in shape,

Civil Rights Act of 1964 are very small, unless that specific disorder is strongly linked to a specific race or ethnic group, or Title VII includes genetic pre-disposition.

B. WHY GENETIC DISCRIMINATION LEGISLATION IS NEEDED

Federal legislation explicitly addressing genetic discrimination is currently needed for several reasons. First, the only federal law concerning genetic discrimination is President Clinton's executive order,[132] which prohibits federal employers from requiring or even requesting ge-

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under low oxygen tension. *Id.* at 319. The "sickle" shaped blood cells can aggregate in the veins of the capillary system. *Id.* at 320. The result of the build-up the tissues supplied with oxygen from the veins in which the build-up occurs, can become deprived of oxygen and the tissues can be severely damaged. *Id.* The kidneys, muscles, joints, brain, gastrointestinal tract, and lungs can be affected during episodes of sickle-cell crisis. *Id.* The crisis can be fatal if not treated. *Id.* Sickle-cell anemia affects about one in every 625 black infants born in the United States. *Id.* at 321. One in every 145 black married couples, both partners who are heterozygous carriers, and their children have a 25 percent chance of having sickle-cell anemia. *Id. See e.g.* Gene Levinson, Carolyn Coulam, W. Christine Spence, Richard Sherins & Joseph Schulman, *Genetics & IVF Institute: Recent Advances in Reproductive Genetic Technologies* Table 1 <http://www. givf.com/argtv.html> (accessed Oct. 18, 2000) (listing disease incidence with ethnic predilection in Table 1). Cystic fibrosis is highly linked with Caucasians, Tay Sachs with Ashkenazi Jewish, sickle-cell anemia with Africans, just to name a few. *Id.*

132. Exec. Or. 13145, 65 Fed. Reg. 6877 (Feb. 8, 2000). Executive Order 13145 will remain in effect until rescinded or superceded. *Id.*; E.E.O.C., *Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information* ¶ 4 <http://www.eeoc.gov/docs/guidance-genetic.html> (July 26, 2000). The question then becomes, will President George W. Bush recind or replace Executive Order 13145. In his remarks given at the Medical College in Wisconsin, on February 11, 2002, President Bush praised the strides science is making in determining the sources of diseases and illnesses. ProQuest Information & Learning, *Remarks at the Medical College of Wisconsin in Milwaukee, Wisconsin George W. Bush*, 38 Wkly. Compilation of Presidential Documents 211 (Feb. 18, 2002) (available in 2002 WL 14547023). President Bush stated that one of the most important advances sciences is making, is the mapping of the human genome. *Id.* President Bush believes that within the next couple of decades, there will be gene therapies and specific drugs that will be in existence to target many of the genetic diseases and conditions. *Id.* However, President Bush warned that although the benefits from the mapping of the human genome are immense and promising, that the genetic information that may be obtained and used to show genetic predisposition, should not be used by individuals as "an excuse for discrimination." *Id.* President Bush went on to say "just as we addressed discrimination based on race, we must now prevent discrimination based on genetic information." *Id.* However, President Bush said that

> [t]here is another danger to guard against, the use of genetic research to threaten the dignity of life itself. The powers of science are morally neutral, as easily used for bad purposes as good ones. In the excitement of discovery, we must never forget that mankind is developed-is defined not by intelligence alone but by conscience. Even the most noble ends do not justify every means. Life itself is always to be valued and protected. In biomedical research, we're dealing with the very makings of life, and the law must be firm and clear in restraining the reckless and protecting the voiceless.

netic testing for the basis of hiring procedures.[133] President Clinton's executive order prohibits federal departments and agencies from requiring genetic testing as a condition of receiving employment benefits.[134] The executive order also prohibits federal employers from requiring genetic testing to evaluate an individual's ability to perform his/her job.[135] The order prohibits federal employers from classifying employees based on their genetic information that would result in depriving an individual from advancement within their office.[136] The executive order provides a

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Id. Yet only a few minutes earlier in his remarks to the medical college, he stated that the role of the federal government is "to fix the system where it's failing, while preserving the quality and innovation of private, patient-centered medical system." *Id.* The reforms he mentions during his speech are only to provide medical insurance to everyone, that every person should be able to choose a health care plan that meets his specific needs, to improve quality and ability of patients to get the best care possible from whom they choose, and to make the interests of the patients come before those of lawyers. *Id.* And he believes that the federal government should not take control or centralize medicine. *Id.* President Bush then went on to say that this health care reform can only be achieved through "the right reforms, the right philosophy, a philosophy of trust—trust- in the people." *Id.* However, two breaths earlier, he said that genetic information and science itself can be used just as easily for bad as good; and that the law as to use of such information should be firm and clear. *Id.* However, there is no federal legislation, other than Clinton's Executive Order 13145. And from what President Bush said in his speech to the Medical College of Wisconsin it really does not sound as if he will propose new federal legislation to protect genetic information. And in fact, on March 21, 2002, the Bush administration proposed altering the privacy rights that individuals currently had in relation to their medical records. Amy Goldstein, *Proposal Alters Medical Privacy Safeguard*, The Fort Worth Star-Telegram (Mar. 22, 2002) (available in 2002 WL 15685597). President Bush's proposal will change the current federal law that requires that a patient give his express written consent for his medical records to be released to anyone, including doctors, hospitals, insurance companies, and pharmacies, and will remove the current written consent requirement and only require that the patients be informed of their privacy rights to their records. *Id.* Opponents believe that "[t]here is more opportunity for patient privacy to be violated now." *Id.*

133. *Id.* at 6878. "The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee, . . . because of protected genetic information with respect to that employee, or because of information about a request for the receipt of genetic services by such employee." *Id.* Protected genetic information is defined by the executive order as being "information about an individual's genetic tests; information about the genetic tests of an individual's family members; or information about the occurrence of a disease, or medical condition or disorder in family members of the individual." *Id.* The act defines that "[i]nformation about an individual's current health status (including information about sex, age, physical exams, chemical, blood, or urine analyses) is not protected genetic information." *Id.*

134. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I; *see also* Exec. Or. 13145, 65 Fed. Reg. at 6878 ("[e]mploying department or agency shall not . . . discriminate against any employee with respect to . . . privileges of employment of that employee, . . . because of protected genetic information").

135. *Id.*

136. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I; *see also* Exec. Or. 13145, 65 Fed. Reg. at 6878 (stating that "[t]he employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to

basic privacy protection for genetic information that is used by medical personnel for the medical treatment and research,[137] and only allows federal employers to disclose genetic information of their employees when medical treatment is needed to ensure workplace health and safety.[138]

While the Clinton executive order is a good start for genetic discrimination law, it is limited in its scope[139] because it only applies to federal employers and employees.[140] The executive order is silent as to the private sector of employment.[141] Unless an individual state has a law prohibiting private employers from using genetic information in its hiring or promotion processes, private employers may avoid hiring or promoting employees based on genetic information that predisposes an individual to a genetic condition or disease.[142] Employers are allowed to use genetic information in their hiring procedures simply because of concerns that the individual will require sick leave, resign or retire early for health reasons, file for worker's compensation, or use health care benefits excessively, if that individual does develop a genetic condition or disease during their employment.[143] Private employers may still request or require genetic testing or genetic information from potential employees

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deprive . . . employment opportunities or otherwise adversely affect that employee's status, because of protected genetic information").

137. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I; *see also* Exec. Or. 13145, 65 Fed. Reg. at 6878-79.

138. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I; *see also* Exec. Or. 13145, 65 Fed. Reg. at 6879-80 (stating that "[t]he employing department or agency may collect protected genetic information with respect to an employee if . . . . Genetic monitoring of biological effects of toxic substances in the workplace . . . [if] conditions are met").

139. *See* U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

140. *See id.*; *see also* Exec. Or. 13145, 65 Fed. Reg.at 6877 (referring to the federal employment practices and applies only to federal departments and agencies).

141. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

142. *Id.* § V.

143. *Id.*; *see also* Regan, *supra* n. 89, at 21-23 (explaining why employers have used surveillance mechanisms to test their employees and potential employees in order to determine an individual's productivity, honesty, and to ensure the employees meet the employers expectations once hired). In the past, employers have used pre-employment and workplace monitoring/screening, such as drug testing, video surveillance, polygraph testing, integrity testing and genetic testing, to ensure that a potential worker or current employee is doing or will do a good job while employed with them. *Id.* at 21. Regan gives three reasons why genetic testing is different from the other surveillance mechanisms. *Id.* First, genetic information that is obtained through genetic screening, yields information about a person's physical and psychological development. *Id.* at 23. She also feels that genetic testing is a "greater invasion of the individual's privacy than other forms of surveillance because of the biological, and inherently personal, nature of the information revealed." *Id.* A second reason for concern about genetic testing, is that while one can change his/her work habit, or drug usage, a person can not change their genetic code. *Id.* And the third reason that genetic testing is different from other surveillance mechanisms

in the hiring process and may request or require genetic information from their current employees.[144] Health insurers still may have broad discretion to use genetic information in their coverage, enrollment and premium determinations,[145] unless a state has laws which expressly prohibit it. Currently, insurers can still require genetic testing of insured individuals, and individuals are not protected from disclosure of genetic information to insurers,[146] unless state law prohibits such disclosure.

Federal anti-discrimination legislation is needed to fill in "the substantial gaps" in the current state and federal protections against employment and insurance discrimination,[147] to guarantee that "genetic technology and research are used only to [further] the health needs of the nation and not to deny individuals employment opportunities or insurance coverage."[148]

C. Genetic Privacy Law

Currently, there are no federal privacy laws expressly regarding genetic information.[149] Oregon was the first state to adopt genetic privacy

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is that genetic information is not just plain information, it reveals predispositions and probabilities. *Id.* at 23-24.

144. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § V.

145. *Id.* § I.

146. *Id.* § V.

147. *Id.*

148. *Id.*

149. Henry, *supra* n. 14, at ¶¶ 11-12. Congress has attempted to pass several different bills concerning genetic privacy, but each has failed. *Id.* at ¶ 11; *see generally Genetic Information Nondiscrimination Health Insurance Act of 1995*, H.R. 2748, 104th Cong. (1995). The *Genetic Information Nondiscrimination Health Insurance Act of 1995* would have prevented discrimination by insurance providers based on a person's genetic profile. *Id.* § 2. The bill would have prevented insurance providers from denying, canceling, varying premiums, terms or conditions for health insurance coverage for an individual on the basis of genetic information or an individual's request for genetic services. *Id.* § 2 (a)(1)-(2). *See also* George Annas, Leonard Glantz, & Patricia Roche, *The Genetic Privacy Act & Commentary* (Feb. 28, 1995) § 1 <http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html> (accessed Oct. 6, 2000). Congress tried to pass the *Genetic Privacy and Nondiscrimination Act of 1995*, but the bill failed. *Id.* Genetic information would have been information would have been protected and the bill would have not prevented the disclosure of genetic information without express consent of the individual. *Id.* This bill was the first attempt to create an inviolable right of genetic privacy. *Id.* This bill would have given the individual complete control over how his genetic record would be disclosed. *Id.* Neither the *Genetic Information Nondiscrimination Health Insurance Act of 1995* nor the *Genetic Privacy & Nondiscrimination Act of 1995*, which sought to privacy right in an individual's genetic information made it into law. *Id.* So, the only genetic privacy law that exists in the United States are ones passed by individual states. *See* Henry, *supra* n. 14, at ¶ 12; *Genetic Privacy & Non-discrimination Act of 1995*, S 1416 IS 104th Cong. 1st Session, (Nov. 15, 1995) <http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/pri-

law,[150] which protects an individual's genetic information as personal property.[151] Oregon's *Genetic Privacy Act* is one of the most comprehensive genetic privacy legislation in the nation.[152] However, in the summer of 1999, the *Genetic Privacy Act* came under attack by the Oregon legislature.[153] The legislature proposed changes in the law that would take away the individual's property rights to his/her DNA.[154] An advisory committee named the Genetics Research Advisory Committee ("GRAC"), formed by the 1999 Oregon Legislature,[155] offered recommendations to the Oregon Legislature and governor in 2000.[156] A year after the GRAC formation, the GRAC reported to the governor and legislature that the property right given to the residents of Oregon with respect to their DNA and genetic information was not essential.[157] The GRAC then proposed a change in the *Genetic Privacy Act* that would remove the property interest in DNA that provides the utmost guarantee of privacy and allows only civil and criminal penalties to be assessed if the individual's DNA is misappropriated.[158] This proposed change in Oregon's *Genetic Privacy Act*, Senate Bill 114, was passed by the House 52-3 and Governor Kitzhaber in June 2001.[159] The new law removed barriers to medical and pharmaceutical research in Oregon.[160] Under the old law only medical researchers could use DNA for informational purposes if

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vacy1.html> (accessed Oct. 18, 2000) (actual text of original bill introduced into Senate in 1995, which did not pass).

150. Fowler, *supra* n. 7, at ¶ 7; *see also Genetic Privacy Act*, Or. Rev. Stat. Ann. § 659.715 (1999).

151. Elizabeth Neus, *DNA-rights Defenders: Get off my genetic property Money creates conflict of research vs. privacy*, Life ¶ 6 (Sept. 25, 2000) (available in 2000 WL 5790622).

152. *Id.* at ¶¶ 6-7.

153. *Id.*; *see also The Politics of DNA Research*, Portland Oregonian ¶ 3 (May 31, 1999) (available in 1999 WL 5347667). Oregon's Genetic Privacy Act came under fire in the Oregon legislature in 1999. *Id.* Legislatures have been asked to "strike a balance, protecting the privacy of a person's genetic information while removing the barriers to medical and pharmaceutical research in Oregon." *Id.* at ¶ 5.

154. Neus, *supra* n. 151, at ¶ 6.

155. Geneforum, Inc., *Genetic Privacy—What's Going On Now? Oregon Genetic Privacy Act* ¶ 7 <http://www.geneforum.org/learnmore/gp/or_gpa.cfm> (accessed Feb. 26, 2002). The GRAC is composed of health care professionals, business leaders and policy makers. *Id.*

156. *Id.*

157. *Id.* at ¶ 8.

158. *The Politics of DNA Research*, *supra* n. 153, at ¶ 8; Steve Mayes, *Legislators Strengthen State's Genetic Privacy Law The Governor Now Will Consider A Bill That Would Give Patients Greater Say About How Their Genetic Material is Used*, Portland Oregonian B04 (June 12, 2001) (available at 2001 WL 3603522) [hereinafter Mayes, *Bill That Give Greater Say*].

159. Mark Bonanno, *In My Opinion Ownership of Your Own DNA Is Now Wide Open*, Portland Oregonian D13 (Aug. 3, 2001) (available at 2001 WL 3610037); Mayes, *Bill That Give Greater Say*, *supra* n. 158, at B04.

160. *Id.* at ¶ 5.

the donors were anonymous.[161] Critics of the new law fear that the changes to the law will result in an individual's privacy right getting overrun and allow huge multinational corporations to win the privacy/research balance.[162] Proponents of the law feel that the new provisions[163] only strengthen the privacy rights of individuals concerning their genetic information.[164] However, I disagree. By removing the property interest that had been given to individuals with regard to their genetic information, Oregon has decreased the strength of privacy associated with their genes. While the law provides criminal and civil damages that may be assessed for misuse of an individual's genetic information, after the genetic information is released into the stream of information, the ramifications of that are huge. No amount of money, even if it were the maximum $250,000 available under the Oregon law, would be enough to amply compensate that person for the employment, insurance and societal implications of that release of the most personal and private information that his/her body contains. The release of genetic information could cause employment discrimination in hiring, promotion, and firing; the genetic information could be used to determine eligibility for insurance policies, or determine the insurance premium the person must pay; and the release of genetic information may also cause society to isolate or shun individuals who may carry the gene for disease or condition. At least when a person had property rights in their DNA, the person had the ultimate right to control his or her genetic information. This is no longer the case.

Our genetic information is the most personal and private information that we as individuals will ever possess, and Oregon's original law was the first to create a guarantee of privacy over that information. The revision of Oregon's genetic privacy law has definitely taken away some of the personal autonomy that the law initially gave Oregon residents, diminishing an individual's rights to keep that information confidential,

161. Beth Silver, *Washington State Lawmakers Work to Preserve DNA-Privacy Rights*, Knight-Ridder Trib. Bus. News ¶ 11 (Jan. 26, 2000) (available in 2000 WL 10328336).

162. *The Politics of DNA Research*, *supra* n. 153, at ¶ 9.

163. Steve Mayes, *Legislators Consider DNA Privacy Bill; Genetic Information Would No Longer Be Personal Property, So Researchers Could Gain Easier Access*, The Oregonian D07 (Feb. 1, 2001) (available in LEXIS, News, News Group File, Most Recent Two Years) [hereinafter Mayes, *Legislators Consider*]. Senate Bill 114 added provisions that require researchers to tell patients of the intended use of their genetic information; allow civil and criminal penalties for those who violate the privacy guarantees provided; and provide legal protection against discrimination of blood relatives of people who undergo genetic testing. *Id.*

164. Mayes, *Bill That Give Greater Say*, *supra* n. 158, at B04. The proponents of the law argue that the new law provides stronger privacy rights because it provides civil and criminal penalties, as well as giving individuals the right to know what is being done with their DNA and genetic information derived from their DNA. *Id.*

and has taken away an individual's control of how that information is disclosed and to whom it is disclosed.[165]

D. Why There Is a Need for Federal Privacy Legislation Concerning DNA

There are some individuals that believe that an individual's genetic code is no different from any other medical record,[166] and others who believe that genetic information must be distinguished from other medical information.[167] Opponents of genetic exceptionalism[168] argue that federal legislation that covers health-related information and regulates the physical and informational privacy of such health-related information will cover genetic information as well.[169] On the opposite side from those who believe that genetic information is the same as other medical information are individuals that believe that genetic information is distinguishable from other medical information and must be regulated specifically.[170] These proponents of genetic exceptionalism offer three reasons why genetic information must be distinguished from other medical information.[171] The first reason is that genetic information predicts an individual's likely medical future.[172] These individuals argue that DNA is like a "diary of future" medical conditions.[173] The second reason is that genetic information divulges personal information about ourselves, and our parents, children and siblings.[174] And the third reason is

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165. *Id.*

166. Murray, *supra* n. 115, at 61.

167. *Id.* at 61-71; *see also* Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values* in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* 451, 457 (Mark Rothstein ed. Yale U. Press 1997); *see also* Roche, *supra* n. 25, at ¶ 3.

168. Murray, *supra* n. 115, at 61. Genetic exceptionalism is the claim that genetic information is sufficiently different from other kinds of health-related information that it needs special protection. *Id.*

169. *Id.*

170. *Id.* at 61-62.

171. *Id.* at 62.

172. *Id.*

173. *See* Roche, *supra* n. 25, at ¶¶ 2-3; *see also* Murray, *supra* n. 115, at 62. The proponents of genetic exceptionalism argue that DNA is a future diary in that the information contained in one's DNA in code is largely unknown to the individual. *Id.* Diaries invocate a concept of privacy as they contain the author's intimate thoughts and dreams. *Id.* The difference between an individual's diary and their genetic code that is a future diary, is that the code of their DNA is largely unknown to themselves and holds the possible answers as to genetic conditions and diseases that they either carry and may pass on to their progeny or conditions and diseases which may one day express themselves. *Id.*

174. *Id.* The reason for the claim that genetic information divulges personal information about ourselves, and our parents, children and siblings, is simple. *Id.* Each individual receives half of their genes from each parent. *Id.* And when we have children, we will pass half of ours to each of our children. *Id.* Our genetic information is to some extent the ge-

the history of genetics being used to stigmatize and victimize people.[175]

Proponents of DNA privacy rights believe that genetic exceptionalism must be supported to protect the privacy of genetic information.[176] One proponent of genetic exceptionalism argues that genetic information is distinguishable from other medical information because of:

> the sheer breadth of information discoverable; the potential to unlock secrets that are currently unknown about person; the unique quality of the information enabling certain identification of the individual; the stability of DNA rendering distant future applications possible; and the generalizability of the data to families, genetically related communities, and ethnic and racial populations.[177]

Another proponent of genetic exceptionalism believes that "genetic information is generally the most private information of all,"[178] and argues that there is a need for federal legislation in the United States to ensure genetic privacy immediately.[179] The fact is that it is now possible

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netic information of our biological children, our siblings, our parents, their parents and our ancestors and descendents. *Id.*

175. *Id.* The concept of genetics being used to stigmatize and victimize people is the concern, of proponents to genetic exceptionalism, who worry that eugenic programs, ill-conceived genetic screening, or the use of genetic information by employers, insurers and others will result in our genetic information being the basis of discrimination. *Id.*

176. *Id.* Lawrence Gostin is the author of an article on genetic privacy cited in the Murray article. *Id.* at 61. Gostin is a proponent of genetic exceptionalism. *Id.* He believes that the genetic code is such a highly sensitive piece of information about an individual, that without legislation insurance companies, employers, government, military, and private individuals may be able to obtain an individual's genetic information and use it for purposes of discrimination. *Id.*

177. *Id.* Lawrence Gostin argues that a person's DNA is so unique that even if a DNA database, such as a database similar to the FBI's DNA database, contains only a person's genetic code, without the person's name, DNA is so unique that the genetic fingerprint could be easily traceable back to the owner. *Id.* at 63. Genetic fingerprinting works by identifying differences in a person's genetic code in regions of the genome that are highly variable. *Id.*

178. Henry, *supra* n. 14, at ¶ 3. Dr. Graeme Laurie is a proponent of genetic exceptionalism and is from the Health Law Department and is a legal analyst from Scotland. *Id.* at ¶ 2. Laurie is an advocate of Great Britain's European Union's Data Protection Act of 1998, which took affect in Europe in March 2000. *Id.* at ¶ 9. The act governs the collection, storage and disclosure of genetic information. *Id.* The law gives data subjects the right to access and correct their genetic record and requires the express consent of the individual before the genetic information may be disclosed to anyone and the law mandates information security measures. *Id.* The European law also provides a compensation system if an individual's genetic privacy rights are violated. *Id.* at ¶ 10.

179. *Id.* at ¶¶ 11-12. Dr. Graeme Laurie said that the United States federal government has failed to establish genetic privacy legislation, and states are the only ones that are taking any action on this issue. *Id.* at ¶ 11. However, state action thus far concerning genetic privacy, is not uniform and the states have remained silent as to the accumulation of DNA samples by non-genetic research. *Id.* at ¶ 16. There are an estimated 176 million Americans' DNA samples are being held by the military, government, universities and hospital laboratories alone. *Id.* at ¶ 1.

to take a cigarette butt, a drop of blood, saliva, a strand of hair or a skin sample and determine our genetic code.[180] Proponents of genetic privacy laws simply believe that your DNA and genetic information belongs to you.[181] In order to protect that idea, federal legislation must be passed.[182]

E. Proposed Genetic Discrimination Legislation

Both genetic privacy rights and genetic discrimination in the employment and insurance industry are needed.[183] First, genetic discrimination legislation needs to define as clearly as possible the definition of genes, genetic information, genetic testing and any other essential terms.[184] Genetic discrimination legislation needs to prohibit employers from requiring or even requesting that employees or potential employees submit to genetic testing or provide the employer with genetic information.[185]

Employers should also be prohibited from using "genetic information to discriminate against, limit, segregate, . . . classify employees" or exclude individuals from any employment opportunities.[186] Legislation should also prohibit employers from releasing genetic information about an employee,[187] should they have knowledge of such information. Em-

180. *Id.* at ¶ 15; *see generally DNA, Crime Fighting and the Right to Privacy*, Roanoke Times & World News (July 12, 1999) (available in 1999 WL 8138762); *see* Fowler, *supra* n. 7, at ¶ 6. DNA can be found in any human tissue or substance that contains cells. *Id.* These sources include blood, body tissue, saliva, hair and fingernail parings. *Id.*

181. Neus, *supra* n. 151, at ¶ 5.

182. *See* Henry, *supra* n. 14, at ¶ 14.

183. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § IV.

184. Mark A. Rothstein, *Genetic Secrets: A Policy Framework* in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* 451, 457 (Mark Rothstein ed., Yale U. Press 1997). New genetic discrimination legislation must have satisfactory definitions of genetic terminology in any future genetic legislation is critical. *Id.* For example, the term genetic testing, it must be clear that a non-DNA-based test, such as a sweat chloride test used to determine if an individual has cystic fibrosis, must be either excluded expressly from genetic legislation, or should be explicitly included. *Id.* Another term that could create problems if not carefully defined is genetic information. *Id.* at 478. If genetic information is defined as DNA-based test results, since employers can currently access non-genetic medical information through post-offer medical examinations or a general release of medical information. *Id.* If genetic information is defined too narrowly, e.g. DNA-based test results, by future genetic legislation, then employers could still gain access to much of an individual's genetic information. If genetic information is defined too broadly, to include health information from relatives of any illnesses with genetic component, then employers would be restricted from access to essentially all medical information. *Id.* If employers are prohibited from gaining access to an individual's medical information, then it will be impossible for employers to gain information that could endanger workplace safety. *Id.*

185. U.S. Dept. of Energy, *Genetics, Privacy & Legislation, supra* n. 10, § IV.

186. *Id.*

187. *Id.*

ployers should only be allowed to use genetic testing or obtain genetic information where such information is necessary to "ensure workplace safety and health."[188] And in cases where genetic information is obtained to ensure workplace safety and health, the legislation should require that genetic information be kept in a separate medical file,[189] separate from the employee's personnel files,[190] and these medical records should be treated as confidential and should be protected by current state and federal laws.[191] Employers should be prohibited by this anti-discrimination legislation from disclosing an employee's genetic information for research purposes without receiving a written, informed consent from the individual employee.[192]

This legislation should be applicable to both the private and public sectors of business, to unions and also labor-management groups.[193] It should also prescribe relief available to employees or potential employees who suffer genetic discrimination.[194] This anti-discrimination legisla-

188. *Id.*

189. *See id.* (describing that genetic information obtained by employers should be filed separately from that employees personnel files, because genetic information should be maintained as confidential medical information and to prevent unauthorized disclosure, that might occur if the genetic information was simply stored in personnel files).

190. *Id.*

191. *See id.* (explaining that genetic information should be stored as medical records by employers so that the individual's genetic information is protected under existing state and federal laws prohibiting unauthorized disclosure of medical records); *see also* Amitai Etzioni, *The Limits of Privacy Medical Records*, 139, 140 (Basic Bks. 1999) (explaining that medical records that are stored in databases have been breached and unauthorized disclosure of patient's medical records have been released). In 1993, medical records from Medicare recipients were illegally sold to sales representatives of a health maintenance organizations "HMO." *Id.* In Massachusetts, a convicted child rapist acquired nearly one thousand patient files through a hospital in which he worked, and then used the files to make obscene phone calls. *Id.* And in Florida, a state health department worker used state computers to compile a list of nearly four thousand individuals who tested positive for HIV and disclosed the list to the local health department and newspapers. *Id.* at 140-41. *See generally* PR Newswire, *First Genetic Trust to Address Individual Privacy & Security Requirements for Genetic Research & Personal Care*, Financial News (Oct. 9, 2000) (describing the company Genetic Trust that will serve as a third party intermediary among researchers, health care providers and patients, and store genetic information in an electronic database). Since electronic databases that hold medical information have been breached by numerous individuals, as described by the preceding examples, there is a possibility that the Genetic Trust DNA database may be breached and genetic information disclosed without authorization. *Id.* at ¶ 2.

192. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § IV.

193. *See id.* (explaining that federal legislation must be uniform and apply to private and public sector employment, as well as unions and labor management groups to ensure that everyone is protected against genetic discrimination in the workplace).

194. *See id.* (noting that federal legislation must provide individuals, whom have been subjected to workplace discrimination based on their genetic information, with ways to file a charge, bring lawsuits and receive compensation for the discrimination).

tion should provide limits on use of genetic information by insurance companies as well.[195] The legislation should prohibit insurance providers from using genetic information to limit any coverage or establish one's eligibility, continuation or enrollment requirements.[196]

Insurance providers should also be prohibited from establishing different rates or coverage based on an individual's genetic information.[197] The insurance providers should be prohibited from denying coverage or prohibiting genetic services for an individual who requests genetic services.[198] Legislation should prohibit insurance providers from disclosing genetic discrimination to third parties,[199] either through sale or re-disclosure, without the express written informed consent of the insured individual.[200] Insurance companies should also be prohibited from using genetic information to sell any insurance coverage at below standard rates.[201] Legislation should also address coverage of individual whose genetic conditions are either symptomatic or asymptomatic.[202] And genetic discrimination legislation must address cancellation of insurance policies or raising the rates on a policy once an individual, whose genetic condition at the initial time of coverage was asymptomatic, but later becomes symptomatic.[203]

F. Proposed Genetic Privacy Legislation

While there are those that feel genetic privacy legislation is not nec-

195. *See id.* (noting recommendations made by the NIH-DOE Joint Working Group on the Ethical, Legal, & Social Implications of Human Genome Project).

196. *Id.*

197. *Id.*

198. *Id.*

199. Rothstein, *supra* n. 184, at 469; *see also* Silver, *supra* n. 161, at ¶ 6. Some third party individuals who would be interested in obtaining an individual's genetic information include pharmaceutical and biotechnology companies, research centers, researchers and universities. *Id.* at ¶ 8.

200. Rothstein, *supra* n. 184, at 469.

201. *Id.* at 470. Some insurers currently permit at-risk individuals, such as individuals who are at risk of developing Huntington disease because a family member has this genetic disease, to obtain insurance coverage by submitting to genetic test results that show that the individual did not inherit the gene mutation associated with Huntington disease. *Id.*

202. *Id.* at 471.

203. *Id.* Currently under the typical state statutes that address genetic discrimination in insurance coverage, an individual, who possesses the mutated $BRCA_1$ gene, the gene that is associated with the high risk of developing breast cancer, cannot be denied insurance coverage until the individual develops symptoms of breast cancer. *Id.* However, once the insured individual develops symptoms, the insurer may either cancel coverage or may increase the rates of the insured policy to such that the individual may not be able to afford to continue on the policy. *Id.* at 472-73. The individual is thereby denied the health insurance "at the precise time and for the precise condition that she needs it the most." *Id.* at 473.

essary,[204] the vast majority of critics contend that the federal legislature must pass genetic privacy laws in order to protect an individual's DNA.[205] As with genetic discrimination legislation, genetic privacy legislation must start with solid and satisfactory definitions of genetic terms.[206] Critics believe that genetic privacy legislation must prohibit the secret collection and analysis of DNA,[207] require an individual's voluntary consent for collection and analysis of DNA,[208] and give the individual the right to access their genetic information.[209] The legislation should also require that the DNA collectors obtain a written, informed consent before dispersing any genetic information to anyone else.[210] The legislation should prohibit anyone from requiring that genetic information be submitted,[211] unless done so voluntarily.[212] The Legislation could place exceptions into the privacy law that DNA samples and genetic information could be legally obtained in criminal investigations and for missing persons,[213] so as not to compromise the FBI DNA-database and other genetic databases which are currently used by states and the federal government to link criminals with crimes.[214] An example of legislation that encompasses protection of genetic privacy and prohibits genetic discrimination might look something like this:

1-101 Definitions

(1) "DNA" means deoxyribonucleic acid,[215] which is a genetic material composed of nucleotides, that encode genetic information.[216]

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204. Murray, *supra* n. 115, at 61.

205. *Id.*

206. Rothstein, *supra* n. 184, at 457.

207. Henry, *supra* n. 14, at 1.

208. *Id.* at ¶¶ 18-19; *see also* Caplan, *supra* n. 3, at ¶ 15.

209. Henry, *supra* n. 14, at ¶ 18.

210. *Id.* at ¶¶ 18-19.

211. Rothstein, *supra* n. 184, at 458. Individuals should not be required to submit genetic information to employers, insurance companies, government or anyone else. *Id.* at 458-79.

212. Caplan, *supra* n. 3, at ¶ 15.

213. *Id.*

214. *See generally* Tillett, *supra* n. 78. The FBI's National DNA Index System ("NDIS") is a database of genetic information of criminals though-out the United States that allows local, state and federal law enforcement to match DNA samples found at crime scenes with criminals across the nation. *Id.* at ¶ 2. By placing exclusions on privacy rights of criminals, so to allow the FBI database to continue, the genetic privacy legislation will not overturn the current trend to allow law enforcement from taking DNA samples from criminals.

215. *See* Or. Rev. Stat. Ann. § 659.700 (defining DNA); *see also* Tex. Civ. Stat. Art. 9031 (defining DNA).

216. *See* The Parliament of the Commonwealth of Australia, *Genetic Privacy and Non-discrimination Bill 1998, No., 1998* <http://www.search.aph.gov.au/search/ParlInfo.ASP?

(2) "RNA" means ribonucleic acid.[217]

(3) "DNA sample" means any human biological specimen from which DNA can be extracted, or any human biological specimen that is obtained or retained for the purpose of extracting and analyzing DNA to determine a genetic characteristic.[218] "DNA sample" includes DNA extracted from the specimen.[219]

(4) "Gene" means the unit of hereditary that has a fixed location on a chromosome.[220]

(5) "Genetic characteristic" means any gene or chromosome, or alteration thereof, that is scientifically or medically believed to cause a disease, disorder or syndrome, or to be associated with statistically increased risk of development of a disease, disorder or syndrome.[221]

(5) "Genetic information" means information about genes, gene products, or inherited characteristics that is derived from:[222]

(a) a genetic test; or

(b) an individual's DNA sample[223]

(6) "Genetic testing" means a test of an individual's DNA, RNA, chromosomes, proteins or certain metabolites for inherited abnormalities or deficiencies, including carrier status, that are linked with physical and/or mental disorders, impairments, genetic characteristics, or that indicate that an individual is predisposed to an illness, disease, impairment, or other disorders.[224]

(7) "Insurer" means an insurance company, healthcare service contractor, benefit center, insurance agent, third party, administrator, insurance support organization or other person subject to regulation under federal or state law.[225]

1-102 Privacy of Genetic Information

(1) Genetic information is uniquely private and personal information that should not be collected, retained or disclosed without the ex-

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WCI=. . /Text+of™he£ill&action=view&WC> (accessed Oct. 18, 2000) (text of Australia's *Genetic Privacy and Non-discrimination Bill 1998*, defining "DNA").

217. Tex. Civ. Stat. Art. 9031 (defining "RNA").

218. Or. Rev. Stat. Ann. § 659.700 (1999) (defining a DNA sample).

219. *Id.* (explaining that a DNA sample includes DNA extracted from a biological specimen).

220. *See* Natl. Human Genome Research Inst., *Glossary of Genetic Terms: Gene* ¶ 1 <http://www.nhgri.nih.gov/DIR/VIP/Glossary/pub_glossary.cgi?key=gene&view_value_pair=on> (accessed Mar. 30, 2002) (defining "gene").

221. Or. Rev. Stat. Ann. § 659.700 (1999) (defining genetic characteristic).

222. Va. Code Ann. § 38.2-508.4 (2000) (defining genetic information).

223. Or. Rev. Stat. Ann. § 659.700 (1999) (providing that genetic information is obtainable through a genetic test or an individual's DNA sample).

224. R.I. Gen. Laws § 27-30-39 (2000); *see also* Exec. Order 13145 at 6877; *see also* Or. Rev. Stat. Ann. § 659.700 (defining genetic testing).

225. Sen. 1416 § 3(6), 104th Cong. (1995) (defining insurer).

press, written informed consent of the individual.[226]

(2) No person or entity shall obtain a DNA sample from any individual without the express, written informed consent of that individual.[227]

(3) Protected genetic information will include:[228]

(a) information about an individual's genetic test;[229]

(b) information about the genetic tests of an individual's family members; or[230]

(c) information about the occurrence of a genetically linked disease, or medical condition or disorder in family members.[231]

1-103 Genetic Discrimination Prohibited

(1) No person or entity shall discriminate against an individual based on his/her genetic information.[232]

(2) No employer may seek to obtain, obtain, require genetic testing or use an employee or potential employee's genetic information, to distinguish between or discriminate against or restrict the benefits available to the employee or potential employee.[233]

(3) No employer may require, request, or use genetic information obtained to terminate, limit, restrict, apply conditions to, cancel, refuse to renew, exclude, impose a waiting limit on, or establish different premium rates on health care benefits provided by the employer to any employee.[234]

(4) No insurer may request or require or use genetic information of an individual if the genetic information has already been taken or if the genetic record already exists, to discriminate against a person

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226. Or. Rev. Stat. Ann. § 659.705(b) (1999) (legislative finding that genetic information is "uniquely private and personal information," which "should not be collected, retained, or disclosed without the individual's authorization").

227. Or. Rev. Stat. Ann. § 659.710(1) (1999) (explaining that informed consent is required for obtaining genetic information from an individual under Oregon Law).

228. *See* Exec. Order 13145, 65 Fed. Reg. at 6878 (defining the types of genetic information that are protected by the Executive Order on Genetic Discrimination).

229. *Id.* (providing that genetic information obtained through a genetic test are "protected" genetic information).

230. *Id.* (providing that protected genetic information under the Executive Order includes genetic information obtained through genetic testing of family members).

231. *Id.* (providing that information obtained about a family member's medical condition or genetic disorder or disease is a "protected" class of genetic information).

232. Or. Rev. Stat. Ann. § 746.015 (1999) (prohibiting any person or entity from discrimination against an individual based on their genetic information).

233. Sen. 1416 § 5(a), 104th Cong. (1995) (stating that no employer may require or request that an individual submit to genetic testing for hiring, promotion, or benefit determination).

234. Va. Code Ann. § 38.2-508.4(b) (2000) (prohibiting employers from using genetic information for the purpose of restricting, denying or altering benefits offered to an employee).

for the determination of insurance coverage.[235]

(5) No insurer may use or require any genetic information for the purpose of terminating, restricting, limiting, refusing to renew, increasing the rates of, or otherwise restrict conditions of coverage of an individual under a insurance policy or plan.[236]

1-104 Genetic Information Confidential, Exceptions

(A) Genetic information, except as provided by this section, is confidential and privileged regardless of the source of the information. No person or entity, which holds the information may disclose or be compelled to disclose the information, by subpoena or otherwise, unless by express, written informed consent of that individual for the disclosure or release of their genetic information unless provided under this section.[237]

(B) Genetic information of an individual may be disclosed, without authorization for the disclosure, if:

(1) Federal or state criminal law authorizes the use of genetic information for:

(a) the identification of individuals or a decedent; or

(b) a criminal or juvenile proceeding, inquest or child fatality review by a child abuse claim;

(2) required under a specific court order by a state or federal court;

(3) authorized by state or federal law to establish paternity;[238] or

(4) for identification purposes by law enforcement purposes relating to forensic work, or for DNA samples obtained from convicted offenders under state law.[239]

1-105 Method of Relief for Individuals Subjected to Genetic Discrimination

(A) Individuals, who believe that they have been subjected to genetic discrimination in the employment or insurance industries, should file a claim with the Equal Employment Opportunity Commission, Department of Labor, State insurance commissioner, or other appropriate federal agencies or officials for investigation and

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235. The Parliament of the Commonwealth of Australia, *supra* n. 216, at Part 4 § 19 (prohibiting insurers from discrimination of individuals based on their genetic information).

236. *Id.* at pt. 4 § 19(a); *see also* Or. Rev. Stat. Ann. § 746.135 (3) (1999) (prohibiting insurers from using genetic information for the purposes of changing the terms of an insurance policy, terminating a policy or failing to renew a policy).

237. Tex. Civ. Stat. Art. 9031 § 3 (2000) (defining genetic information as confidential information that may only be disclosed with express consent of the individual).

238. *Id.* (explaining that genetic information may be disclosed without the express consent of the individual under certain conditions).

239. R.I. Gen. Laws § 12.1-5.2 (2000) (providing that genetic information may be used without the express consent of the individual for the purpose of identification by law enforcement officers).

resolution.[240]

(B) If the federal agency, committee or commissioner is not able to resolve the dispute, a private individual may bring a civil action to:
(1) enjoin the practice or act which violates this act;
(2) obtain equitable relief to redress the violation; or
(3) obtain legal relief, including monetary damages, for the discrimination or unauthorized release of an individual's genetic information.[241]

IV. CONCLUSION

DNA was discovered in 1953, yet only fifty years later, the world is nearing the completion of the map of the human genome by the Human Genome Project.[242] With the scientific and technological advancements being made in the field of genetics everyday, there are bound to be legal issues that will arise.[243] The legal questions will include genetic discrimination, rights to clone, rights of disclosure of genetic information, and rights to privacy of genetic information.[244] With the federal legislature remaining silent concerning genetic privacy rights of individuals,[245] the presence of only a few federal laws in existence that may be applicable to genetic discrimination,[246] and only President Clinton's executive order,[247] which only limits genetic discrimination by federal employers,[248] there will likely be conflict as to who can obtain, request, or require one to produce genetic information.[249] It is also likely that individuals will increasingly face genetic discrimination in employment and by the insurance industry as our understanding of the human genome increases,[250] unless Congress enacts an overarching federal law that prohibits genetic discrimination and preserves an individual's privacy rights associated with our genetic information. As of today, the only substantive law concerning genetic information exists in the individual

240. U.S. Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § IV (stating that genetic discrimination legislation must contain methods of relief for individuals whom are the victims of genetic discrimination).

241. H.R. 2748 § 2 (c)(3), 104th Cong. (1995) (explaining enforcement mechanisms available to individuals who have been subjected to genetic discrimination).

242. U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals*, *supra* n. 5, at ¶ 2 (explaining that the Human Genome Project is slated to be 100 percent completed by 2003, if not earlier).

243. Natl. Human Genome Research Inst., *The Human Genome Project* ¶ 1 <http://www.nhgri.nhi.gov/HGP/> (accessed Sept. 5, 2000).

244. *Id.*

245. Henry, *supra* n. 14, at ¶ 11.

246. U.S Dept. of Energy *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

247. Exec. Or. 13145, 65 Fed. Reg. at 6877.

248. U.S Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § I.

249. *Id.* § IV.

250. *Id.* § V.

states,[251] but none of these statutes are uniform in their protection or application.[252] The federal government must propose new genetic legislation now, before the Human Genome Project is completed,[253] and before genetic information becomes more available than it already is today.[254]

DNA encodes the most personal and private information that defines who and what we are as individuals and a family. The federal government must provide the general public with protection mechanisms by which individuals may maintain personal discretion over their genetic information and prohibit discrimination in employment and by the insurance industry that may arise from our genetic information. It is time for Congress to catch up with science and the technological advancements that are providing the world with knowledge of our genome, and to strike a balance between technology and our right to privacy, by statutory means.

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251. Henry, *supra* n. 14, at ¶ 12.

252. U.S Dept. of Energy, *Genetics, Privacy & Legislation*, *supra* n. 10, § II.

253. U.S Dept. of Energy, *U.S. Human Genome Project 5-Year Goals*, *supra* n. 5, at ¶ 2. The Human Genome Project will be completed in 2003. *Id.*

254. Ctr. for Disease Control, *Translating Advances*, *supra* n. 9, at ¶ 1.

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