

1-1-2002

Genetic Technology as a Tool for Discrimination: It is Time for Federal Legislation to 'Catch Up' with Science and Medicine

Jeremy Fetty

Michigan State University College of Law

Follow this and additional works at: <http://digitalcommons.law.msu.edu/king>

Recommended Citation

Jeremy Fetty, *Genetic Technology as a Tool for Discrimination: It is Time for Federal Legislation to 'Catch Up' with Science and Medicine* (2002),

Available at: <http://digitalcommons.law.msu.edu/king/18>

This Article is brought to you for free and open access by Digital Commons at Michigan State University College of Law. It has been accepted for inclusion in Student Scholarship by an authorized administrator of Digital Commons at Michigan State University College of Law. For more information, please contact domannbr@law.msu.edu.

GENETIC TECHNOLOGY AS A TOOL FOR DISCRIMINATION: IT IS TIME FOR
FEDERAL LEGISLATION TO “CATCH UP” WITH SCIENCE AND MEDICINE

Jeremy L. Fetty

TABLE OF CONTENTS

INTRODUCTION.....	1
I. BACKGROUND.....	3
A. Description of the Problem	5
B. Employment Discrimination.....	8
C. Health Insurance Discrimination.....	10
II. OVERVIEW & ANALYSIS OF LEGISLATION PROTECTING AGAINST GENETIC DISCRIMINATION..	12
A. Current Federal Law: Employment Discrimination.....	12
1. <i>The Americans with Disabilities Act (ADA)</i>	13
2. <i>Title VII of the Civil Rights Act of 1964</i>	17
B. Executive Order 13145.....	17
C. Current State Law: Employment Discrimination.....	18
D. Current Federal Law: Health Insurance Discrimination.....	20
E. Current State Law: Health Insurance Discrimination.....	21
F. Pending Federal Legislation.....	23
III. ANALYSIS & PROPOSAL.....	29
A. Argument for Protections Against Employment Discrimination.....	29
B. Argument for Protections Against Health Insurance Discrimination.....	34
C. Current Legislation Provides Inadequate Protection.....	41
D. Simple Proposal: Legislation Protecting Individuals From Genetic Discrimination..	44
CONCLUSION.....	47

INTRODUCTION

“The challenge, and it is a formidable one, is to nurture scientific exploration, encourage, the translation of these new discoveries into life saving medicines, and put into place public policies reflective of our core American values that prevent the unjust, unfair, and discriminatory use of genetic information.”¹ In the area of genetic technologies, medicine and science have far surpassed the law. What can now be learned about a person’s genetic make-up is far beyond anything that was ever imagined.² Genetic testing can provide presymptomatic information

¹ *Hearings on the National Genome Research Institute*, 105th Cong. (1997) (statement of Francis S. Collins, Director of the National Human Genome Research Institute).

² See Kourtney L. Pickens, *Don’t Judge Me by My Genes: A Survey of Federal Genetic Discrimination Legislation*, 34 TULSA L.J. 161 (1998).

about an individual's predisposition to future disease, disability, or early death.³ The problem is that people are refusing to take these potentially lifesaving genetic tests out of fear of being discriminated against, particularly in employment and health care. Currently, there is no adequate federal legislation to protect individuals from this genetic discrimination.

Every individual has genetic predispositions to a variety of conditions.⁴ No individual should have to choose between the benefits of a genetic test and keeping a job or health insurance. Individuals should not be hesitant to undergo potentially lifesaving genetic tests or to participate in genetic research based on the fear that they will be discriminated against by employers and health insurers. Public perceptions and fears of genetic discrimination indicate that current legislation provides inadequate protection, and that more comprehensive federal legislation is warranted. It is time for Congress to act on this complex and extremely important issue of genetic discrimination by employers and health insurers. Comprehensive legislation needs to be passed that addresses and alleviates public fear of genetic discrimination.

Legislation that addresses and alleviates public fear will enable more individuals to seek genetic testing and treatment, thus contributing to research, public health, and the general welfare of society. With genetic discrimination as a growing concern, President George W. Bush, in a June 23, 2001 radio address urged Congress to work with the administration to pass a law that is "fair, reasonable, and consistent with existing discrimination statutes."⁵

³ See Paul S. Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 226 (2000).

⁴ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Debra L. Ness, National Partnership for Women & Families). Scientists estimate each person has somewhere between five and fifty predispositions to certain conditions, and that by knowing our genetic makeup will allow us to reduce our risks through preventive medicine or lifestyle changes. *See id.*

⁵ OLPA, *Genetic Discrimination*, (visited April 6, 2002) <<http://www.olpa.od.nih.gov/Legislation.December%202001/geneticdiscrim.htm>>.

This Article will give a brief explanation of genetics and the potential for genetic discrimination in employment and health insurance. Federal and state legislation will be addressed, as well as pending legislation potentially affecting genetic discrimination. The legislation will be analyzed to come to the conclusion that current legislation provides inadequate protection against genetic discrimination in the areas of employment and health insurance. Arguments will be presented in support of protection from employment and health insurance discrimination based on genetic information. Finally, a proposal will be made for federal legislation that protects individuals from denial or loss of employment or health insurance based on genetic information.

I. BACKGROUND

Genes contain the set of instructions for making proteins within cells.⁶ These proteins constitute the building blocks of cells, and ultimately, of entire organisms, including complex organisms such as human beings.⁷ Genes represent the blueprint for each individual's biological make-up.⁸ Each gene is a large molecule of deoxyribonucleic acid, or DNA.⁹ Inheritance of individual traits such as certain diseases or disorders and predisposition to diseases or disorders are passed from generation to generation by one's genes.¹⁰ Genetic mutations can potentially alter the protein and result in a disease or disorder.¹¹ These genetic mutations can be inherited from a parent, can develop from an error during cell division, or can merely be acquired from the

⁶ See Jeremy A. Colby, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443, 446-47 (1998).

⁷ See Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 KY. L.J. 503, 519 (1997).

⁸ See *id.*

⁹ See Miller, *supra* note 3, at 228.

¹⁰ See *id.* at 227-28.

¹¹ See *id.* at 229.

environment.¹² Therefore, by identifying certain genetic information, one can determine a person's probability of manifesting certain traits, including diseases and other disorders.¹³

Genetic testing involves examining a person's DNA for something that flags a disease or disorder.¹⁴ Through this process "[s]uspected mutations and predisposition to disease can be confirmed by genetic testing before symptoms appear."¹⁵ There are three different types of genetic tests: (1) carrier; (2) prenatal or postnatal; and (3) adult presymptomatic.¹⁶ Genetic testing can identify carriers of certain diseases and disorders.¹⁷ Carriers do not have the disease or disorder and may never develop it, but possess the recessive genes and pass them to their children.¹⁸ Adult presymptomatic testing is conducted to analyze an individual's susceptibility to disease or disorder before the individual shows any symptoms.¹⁹ The predictive ability of genetic testing is somewhat limited because a genetic test will only reveal a possibility that the individual may develop the trait, disease, or disorder sometime in the future and are not absolute indicators that symptoms will develop.²⁰

It was not until recently that scientists and medical experts conducted adult presymptomatic genetic testing on single genes that predispose a person to a genetic disease.²¹

¹² *See id.*

¹³ *See id.* at 228.

¹⁴ *See* Denise K. Casey, *What Can the New Gene Tests Tell Us?*, 36 JUDGES' J. 14, 16 (1997).

¹⁵ Miller, *supra* note 3, at 229.

¹⁶ *See* Nathalie Smith, Note, *The Right to Genetic Privacy? Are we Unlocking the Secrets of the Human Genome Only to Risk Insurance and Employment Discrimination*, 2000 UTAH L. REV. 705, 709 (2000).

¹⁷ *See* Miller, *supra* note 3, at 229.

¹⁸ *See* NATIONAL CANCER INST., U.S. DEP'T OF HEALTH AND HUMAN SERVS., UNDERSTANDING GENE TESTING 5, 9 (1995).

¹⁹ *See* Smith *supra* note 16, at 709.

²⁰ *See* Colby, *supra* note 6, at 449. The probability that one of these genetic mutations will manifest into a particular disease or disorder is based on a variety of factors such as environment. *See* National Cancer Inst., *supra* note 18, at 7. A genetic mutation for Huntington's disease will develop with an almost certainty. *See* Casey, *supra* note 14, at 18. The likelihood of the breast cancer BRCA1 mutation manifesting is around eighty percent, but only if there is a family history of breast cancer. *See* National Cancer Inst., *supra* note 18, at 14. Without a history the individual's risk remains uncertain. *See id.* at 19. Mutations for diseases such as cystic fibrosis and Alzheimers Disease have an uncertain predictive ability. *See* Miller, *supra* note 3, at 231.

²¹ *See* Smith, *supra* note 16, at 709.

Faster ways of discovering new genes through genomics has significantly increased the number of genes that can be tested for certain diseases and disorders.²² Currently, there are over five hundred genetic tests available and this number is increasing rapidly.²³ The increase in genetic research and technology has been directly related to the Human Genome Project (HGP).²⁴

The HGP is an international research effort designed to locate and map out all human genes, collectively known as the human genome.²⁵ Information that is gained from these biological studies will be made available to scientists, physicians, and others in order that the results may be rapidly used for the improvement of human health and the public good.²⁶ In February of 2001 the HGP scientists published the working draft DNA of the human genome, “the three billion-letter genetic instruction book for a human being.”²⁷ With the human genome sequence in hand scientists are working to develop new diagnostic tests and therapeutics.²⁸ This genetic information can potentially lead to early detection, intervention, and prevention of many common diseases.²⁹

From the beginning of the HGP, “it was clearly recognized that acquisition and use of such genetic knowledge would have momentous implications for both individuals and society

²² *See id.*

²³ *See Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Bobby P. Jindal, U.S. Department of Health and Human Services).

²⁴ *See Miller, supra* note 3, at 226.

²⁵ *See Hearings on the National Genome Research Institute*, 105th Cong. (1997) (statement of Francis S. Collins, Director of the National Human Genome Research Institute). The HGP is jointly managed by the U.S. Department of Energy and the National Institutes of Health, with the goal of analyzing and sequencing the estimated 50,000-100,000 human genes. *See National Human Genome Research Inst., The Human Genome Project* (visited Nov. 6, 2001) <<http://www.nhgri.gov/HGP/>>.

²⁶ *See id.*

²⁷ *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Bobby P. Jindal, U.S. Department of Health and Human Services).

²⁸ *See id.*

²⁹ *See id.*

and would pose a number of policy choices for public and professional deliberation.”³⁰

Therefore, “[a]nalysis of the ethical, legal, and social implications of the genetic knowledge, and the development of policy options for public consideration” is another major component of the HGP, which has devoted a portion of its funding to ethical, legal, and social implications (ELSI).³¹ While these HGP developments will aid society in countless ways, even with ELSI there remains the fear of genetic discrimination.

A. Description of the Problem

The benefits of these advances in genetic technologies are clear because as genetic causes of disease are found, effective treatments and cures may be developed.³² Furthermore, an individual with a genetic predisposition towards a disease will have an opportunity to plan for the future, and a chance to prevent adverse effects or onset of the disease.³³ However, with the benefits of genetic testing also comes risks to the individual, “many of which are evident given America’s history of genetic discrimination.”³⁴ In the broadest sense, genetic discrimination occurs when genetic information is used to treat people differently.³⁵

Genetic testing inevitably causes conflicts between an employers and insurers right to access information and the individuals right to privacy.³⁶ For employers, access to genetic information reduces employment costs relating to potential time-off for illness or replacement, as well as reduce costs for those employers who either self-insure or provide for group health

³⁰ National Human Genome Research Inst., *supra* note 25.

³¹ *Id.*

³² See Robert Mullan Cook-Deegan, *Mapping the Human Genome*, 65 CAL. L. REV. 579, 580 (1991).

³³ See Deborah Gridley, Note, *Genetic Testing Under the ADA: A Case for Protection From Employment Discrimination*, 89 GEO. L.J. 973, 977 (2001).

³⁴ *Id.*

³⁵ See *Genetic Information in the Workplace: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 106th Cong. (July 20, 2000) (testimony of Susannah Baruch, National Partnership for Women & Families).

³⁶ See Smith, *supra* note 16, at 711.

insurance.³⁷ Similarly, for health insurers, access to genetic information provides a more cost effective means of implementing its industry-wide practice of classifying individuals based on their future risks.³⁸ “Access to, and the use of, genetic information, the potential threats posed by insurers or employers mandating genetic testing, and whether policy makers should treat genetic information separately from an individual’s medical records, are continuous topics in today’s state and federal legislatures.”³⁹ The reason is that there are policy concerns, including autonomy, privacy, and justice because a person’s genetic information can be considered highly personal information about an individual’s current and future health.⁴⁰ Privacy is of the utmost importance because DNA contains information that the individual may not want to know, but others such as employers and insurers wish to discover.⁴¹

One major problem with giving employers and health insurers access to genetic information is the misperception that “genetic tests can predict completely and accurately whether a person will develop a genetic disease.”⁴² The concern is that employers and health insurers may misinterpret and misuse genetic information to exclude an individual based on the misconception that having a genetic trait is the same as having the actual disease or disorder.⁴³ Discriminating against people based on their genes is unfair, considering that it cannot be accurately predicted that an individual will actually develop the disease or disorder.

³⁷ *See id.*

³⁸ *See id.*

³⁹ *Id.*

⁴⁰ See Burk Burnett, Note, *Genetic Discrimination: Legislation Required to Keep Genetic Secrets*, 21 SETON HALL LEGIS. J. 502, 533 (1997).

⁴¹ See Tara L. Rachinsky, Comment, *Genetic Testing: Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace*, 2 U. PA. J. LAB. & EMP. L. 575, 584 (2000).

⁴² Miller, *supra* note 3, at 232.

⁴³ *See id.*

A second major problem is that people fearing discrimination from employer and health insurers will refuse to take genetic tests.⁴⁴ This is alarming considering that in some situations genetic testing may be a potentially lifesaving measure.⁴⁵ The fact that the people who seriously need genetic testing are avoiding it, to avoid discrimination seems to suggest that current legislation provides inadequate protection to these individuals.

Another major problem is that the potential for genetic discrimination may have an adverse effect on research. Scientists fear that this problem of individuals avoiding genetic tests will halt research. The concern is that misuse of genetic information by employers and health insurers will cause serious problems, and impede the ability of scientists to continue important genetic research.⁴⁶ Therefore, the advancement of genetic research is another reason laws should provide protection from discrimination based on genetic information.

B. Employment Discrimination

Currently, estimates show that genetic testing by employers is relatively uncommon.⁴⁷ American Management Association reports show that in 2000 approximately three percent of employers conducted genetic screenings on employees.⁴⁸ Although this count is low, the numbers will most likely increase as genetic technology of human genetics improves and genetic testing becomes more cost efficient.⁴⁹ It is anticipated that an employer's economic incentives for genetic testing will increase as the number disease causing genes or genes that indicate a

⁴⁴ See Colby, *supra* note 6, at 452.

⁴⁵ See *id.*

⁴⁶ See *Genetic Information in the Workplace: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 106th Cong. (July 20, 2000) (statement of Francis S. Collins, Director of the National Human Genome Research Institute), 2000 WL 1115522, at *3.

⁴⁷ See Smith, *supra* note 16, at 716.

⁴⁸ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Ronald L. Adler, Laurdan Associates, Inc.) (only 7 of the 2,133 companies responding to the survey admitted performing genetic tests).

⁴⁹ See National Conference of State Legislatures, *Mapping Public Policy for Genetic Technologies: A Legislator's Resource Guide* 8-3 (Brenda A Trolin ed., 1998).

predisposition to disease or disorder grows, and as health care cost continue to increase.⁵⁰

Employers will likely attempt to gain this information by conducting genetic testing, gaining access to employee's medical records, or "simply by learning about the individual's family history."⁵¹

Various reasons exist as to why an employer would want to use genetic information to screen employees. There is a growing public concern over the use of genetic information for discriminatory purposes by employers to "lower their insurance and sick leave costs by screening out individuals who have traits linked to inherited medical conditions."⁵² This is an increasing concern as more employers self-insure their employees rather than use group health insurance policies.⁵³ Many genetic diseases and predispositions to diseases are serious and require costly and comprehensive medical care.⁵⁴ This is an incentive for employers to refrain from hiring, promoting, or firing individuals who are predisposed to genetic diseases or disorders.⁵⁵

According to a Georgetown University study, fears of workplace discrimination have prevented one out of ten respondents from "getting tested for genetic traits linked to breast cancer, cystic fibrosis, Huntington's Disease, colon cancer, or other conditions, even though early detection and treatment could possibly improve their lives."⁵⁶ These fears are not baseless.⁵⁷ Thirteen percent of the respondents to the Georgetown University survey reported that they or a family member had been denied a job or terminated from a job because of a genetic

⁵⁰ *See id.*

⁵¹ *Id.*

⁵² Miller, *supra* note 3, at 232.

⁵³ *See* Smith, *supra* note 16, at 717. It is estimated that fifty-eight percent of employers self-insure employees. *See id.*

⁵⁴ *See* National Conference of State Legislatures, *supra* note 49, at 8-2.

⁵⁵ *See id.*

⁵⁶ Miller, *supra* note 3, at 234.

⁵⁷ *See id.*

condition in the family.⁵⁸ In a well-publicized case settled by the Equal Employment Opportunity Commission (EEOC), Burlington Northern Santa Fe Railroad required any employee who suffered from carpal tunnel syndrome to undergo genetic testing, and employees who refused to be tested were threatened with discipline or even the loss of their jobs.⁵⁹ In another case, not as well known, a woman in her early thirties found out through a genetic test that she had the BRCA 1 and BRCA 2 genetic predisposition to breast cancer, and decided to undergo preventive surgery.⁶⁰ Everyone in her small office knew about this test and her decision to undergo preventive surgery.⁶¹ A few weeks later the woman was fired, despite excellent reviews and recent promises of promotions and raises.⁶² Genetic discrimination does exist in the workplace, and it is likely that employers will increasingly use genetic information in the future for hiring and for continued employment. This likely impact on an individual's privacy and employment possibilities needs to be addressed by the legislature.

C. Health Insurance Discrimination

As genetic technologies advance, and as the ability to anticipate disease or disorder becomes more refined, the question of who should pay and how much will pose a great dilemma for insurance companies and policy makers.⁶³ Individually purchased health insurance is based on medical underwriting, which takes into account an individual's health when an application for

⁵⁸ *See id.* at 237.

⁵⁹ *See infra* note 90 and accompanying text.

⁶⁰ *See Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Debra L. Ness, National Partnership for Women & Families). The woman in early thirties decided to get tested because of an extensive family history of early deaths from breast cancer. *See id.* The extensive family history combined with the BRCA 1 and BRCA 2 genetic predisposition indicate a very high risk of developing breast cancer. *See id.* The woman decided to undergo a prophylactic mastectomy as a form of preventive treatment. *See id.*

⁶¹ *See id.*

⁶² *See id.*

⁶³ *See* Chetan Gulati, *Genetic Antidiscrimination in Health Insurance: A Misguided Solution*, 4 QUINNIPIAC HEALTH L.J. 149, 162 (2001).

insurance is reviewed.⁶⁴ Therefore, advancements in genetic technology and predicting an individual's future health will affect health insurance, and potentially lead to discrimination.⁶⁵

The group of individuals at risk for genetic discrimination are people who are carriers of a genetic predisposition and relatives of people with a disease or disorder that has been linked with a gene.⁶⁶ Once a disease or disorder has been linked with a gene an insurance company will look for a family history, for an unknown preexisting condition.⁶⁷ These actions by health insurance companies have negative implications for otherwise healthy individuals. In a recent survey of individuals with a known genetic condition in the family, twenty percent indicated that they had been refused health insurance coverage because of their genetic information, regardless of whether they were sick or not.⁶⁸ Further studies have documented cases of genetic discrimination against individuals who are healthy themselves, but who have a gene that predisposes them or their children to a later illness such as Huntington's disease.⁶⁹

The threat of genetic discrimination is real, and "millions of Americans risk losing health coverage because they carry genes making them vulnerable to disease."⁷⁰ Health insurance companies have used results of genetic tests "to justify canceling coverage, saying that a genetic abnormality is a preexisting condition; to deny coverage to unaffected relatives of a person with

⁶⁴ See Richard A. Bornstein, Note, *Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes*, 4 J.L. & POL'Y 551, 563-64 (1996). Medical underwriting is used to evaluate different risk factors, and the higher the risk, the higher the premium; the lower the risk, the lower the premium. See Robert J. Pokorski, Principles of Insurance and Risk Classification, in THE POTENTIAL ROLE OF GENETIC TESTING IN RISK CLASSIFICATION 45 (Genetic Testing Committee to the Medical Section of the American Council of Life Insurance ed., 1989).

⁶⁵ See Bornstein, *supra* note 64, at 564-65.

⁶⁶ See *id.* at 568.

⁶⁷ See *id.*

⁶⁸ See H.R. 602, *The Genetic Nondiscrimination in Health Insurance and Employment Act*, (visited Feb. 8, 2002) <<http://www.house.gov/slaughter/leg-record/leg602.htm>>.

⁶⁹ See *id.*

⁷⁰ Medical Ethics: Experts Recommend Genetic Privacy Laws: AM. HEALTH LINE, Oct. 23, 1995, at 12 (citing top U.S. health officials who appealed to insurance companies to end discriminatory insurance practices).

a genetic disorder; and to refuse to issue a policy unless an applicant submits to a genetic test.”⁷¹ It is clear that health insurance companies will deny insurance based on genetic information even though an individual may never have the disease or disorder, or even have the genetic predisposition to the disease or disorder. Health insurance is a necessity, and excessive premiums or denial of health insurance should not burden individuals who might have an increased risk of suffering from a particular disease.⁷² Information such as this favors the idea that state and federal legislation protecting privacy and prohibiting genetic discrimination is necessary, and is currently inadequate.

II. OVERVIEW & ANALYSIS OF LEGISLATION PROTECTING AGAINST GENETIC DISCRIMINATION

Congress and state legislatures have proposed and enacted some legislation to prevent potential abuses of genetic information. However, genetic discrimination legislation enacted so far leaves several legislative loopholes permitting genetic discrimination.⁷³ Currently, no federal statute explicitly addresses genetic discrimination in the workplace or by health insurance companies.⁷⁴ Many states have implemented a variety of nondiscrimination laws, but the approaches are incomplete, vary significantly and are often too narrowly worded.⁷⁵

A. Current Federal Law: Employment Discrimination

No current federal statute explicitly addresses genetic discrimination in the workplace.⁷⁶ However, there are existing federal laws in place that prohibit disability discrimination in employment, which may provide some protection against genetic discrimination.⁷⁷

⁷¹ See Susan Ince, *Predictive Testing: A Bite of the Apple*, HARV. HEALTH LETTER (Harvard Medical School Health Publications Group, Boston, MA), June 1995, at 4.

⁷² See Bornstein, *supra* note 64, at 577-78.

⁷³ See Colby, *supra* note 6, at 452.

⁷⁴ See Miller, *supra* note 3, at 237.

⁷⁵ See Pickens, *supra* note 2, at 172.

⁷⁶ See Miller, *supra* note 3, at 237.

⁷⁷ See *id.* at 237-38.

1. *The Americans with Disabilities Act (ADA)*⁷⁸

The ADA prohibits employers from denying employment on the basis of an individual's disability.⁷⁹ The ADA makes no explicit mention of genetic discrimination, but Congress intended a broad reading.⁸⁰ In fact, the ADA does not specifically identify any single medical condition for protection.⁸¹ The ADA defines an individual with a disability as a person with one or more physical or mental impairments that substantially limits him or her in performing a major life activity, a person with a record of such an impairment, or a person regarded as having such an impairment.⁸² The ADA also requires that an employer make reasonable accommodations in the workplace, if these accommodations do not impose an undue hardship on the employer.⁸³

There is little question that the ADA covers an individual who has a genetically related disease or disability that has manifested, and substantially limits a major life activity.⁸⁴ The ADA likewise protects individuals who have a prior record of genetically related disability, such as someone who has recovered from cancer.⁸⁵ However, the critical question is whether a predisposition to disease, or the diagnosis of a condition without accompanying symptoms, constitutes a disability under the ADA.⁸⁶

⁷⁸ 42 U.S.C. §§ 12101-12213 (1994).

⁷⁹ See 42 U.S.C. § 12112(a) (1994) (“No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application processes, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms”).

⁸⁰ See *id.* §§ 12111-12117.

⁸¹ See *id.*

⁸² See 42 U.S.C. § 12112(a) (1994).

⁸³ See *id.* § 12112(b) (5) (A).

⁸⁴ See Miller, *supra* note 3, at 238-39. See also *Bragdon v. Abbot*, 524 U.S. 624, 637, 642 (1998); *Harris v. H&W Contracting Co.*, 102 F.3d 516, 524 (11th Cir. 1997) (holding that an individual with Graves disease is covered by the ADA, although the court also held that the disease should be considered in its unmitigated state); *Gilday v. Mecosta County*, 124 F.3d 760, 766 (6th Cir. 1997) (finding that an individual with diabetes is covered by the ADA, and that the disease should be considered in its mitigated state).

⁸⁵ See Miller, *supra* note 3, at 239.

⁸⁶ See Alissa Brownrigg, Note, *Mother Still Knows Best: Cancer-Related Gene Mutations, Familial Privacy, and a Physician's Duty to Warn*, 26 *FORDHAM URB. L.J.* 247, 262 (1999).

The U.S. Equal Employment Opportunity Commission (EEOC) adopted policy guidance, stating that the ADA prohibits discrimination against individuals based on their genetic makeup.⁸⁷ The policy guidance states the third prong of the definition of disability, the “regarded as” prong covers individuals who are subjected to discrimination on the basis of a genetic predisposition to illness, disease, or other disorder, even if the disability has not yet manifested.⁸⁸ It is the position of the EEOC that discrimination in the workplace based on genetic information is exactly the kind of behavior Congress intended to prohibit when it passed the ADA.⁸⁹ The EEOC’s position is clear that the ADA protects individuals with asymptomatic genetic conditions from discrimination in the employment arena.⁹⁰ These EEOC guidelines can be used as persuasive authority, but do not have the same force as a federal statute or regulation.⁹¹ Various concerns and questions are raised following the U.S. Supreme Court’s decision in *Bragdon v. Abbott*,⁹² interpreting the ADA.

⁸⁷ See 2 U.S. EEOC, COMPLIANCE MANUAL, Order 915.002, at 902-45 (1995).

⁸⁸ See *id.*

⁸⁹ See *id.*

⁹⁰ See *id.* On February 9, 2001, the EEOC filed its first lawsuit challenging genetic testing. See The U.S. Equal Employment Opportunity Commission, *EEOC PETITIONS COURT TO BAN GENETIC TESTING OF RAILROAD WORKERS IN FIRST EEOC CASE CHALLENGING GENETIC TESTING UNDER AMERICANS WITH DISABILITIES ACT*, (visited Nov. 16 2001) <<http://www.eeoc.gov/press/2-9-01-c.html>>. The EEOC petitioned in federal district court to enjoin Burlington Northern Santa Fe Railroad, a Texas based railroad, from engaging in genetic testing of its employees who had submitted claims of work related carpal tunnel syndrome. See *id.* The EEOC alleged that workers were not told of the genetic tests, nor did they consent to such testing. See *id.* At least one worker refused to provide a blood sample based on his suspicions of genetic testing and was threatened with immediate discharge. See *id.* The EEOC took the position that the railroads actions violated the ADA and that “employers may only require employees to submit to any medical examination if those examinations are job related and consistent with business necessity. Any test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee’s present ability to perform his or her job.” *Id.* On April 19, 2001, the EEOC announced that it had settled its case against the railroad. See The U.S. Equal Employment Opportunity Commission, *EEOC PETITIONS COURT TO BAN GENETIC TESTING OF RAILROAD WORKERS IN FIRST EEOC CASE CHALLENGING GENETIC TESTING UNDER AMERICANS WITH DISABILITIES ACT*, (visited Nov. 16 2001) <<http://www.eeoc.gov/press/2-9-01-c.html>>. As a part of the settlement the railroad will not: directly or indirectly require its employees to submit blood for genetic tests; analyze any blood previously obtained; evaluate, analyze or consider any gene test analysis previously performed on any of its employees; or retaliate or threaten to take any adverse action against any person who opposed the genetic testing or who participated in EEOC proceedings.

⁹¹ See Miller, *supra* note 3, at 241.

⁹² 524 U.S. 624 (1998).

In *Bragdon*, the majority of the U.S. Supreme Court ruled that a person with asymptomatic HIV is an “individual with a disability” under the ADA.⁹³ Although *Bragdon* was not an employment discrimination case, its analysis of the ADA covers the employment context.⁹⁴ The Court found that HIV infection is a “physical impairment” that substantially limits the major life activity of reproduction, even in the absence of any manifest visible symptoms of the illness.⁹⁵ The Court recognized that a disability may be based solely upon the cellular and molecular changes in the body.⁹⁶ This reasoning suggests that individuals with asymptomatic genetic disorders and genetic predispositions are protected by the ADA, both when their condition is viewed as an actual and a perceived impairment.⁹⁷ Whether or not the reasoning in *Bragdon* will be extended to protect those who test positive for genetic disorders or predispositions remains to be seen. Without judicial decisions, the amount of protection provided by the ADA remains unclear.

Chief Justice Rehnquist dissenting in *Bragdon* wrote, “[r]espondent’s argument taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease ‘disabled’ here because of some future effects.”⁹⁸ The concern is that since, according to scientists, every person has a genetic alteration of some form, which would classify every person as disabled.⁹⁹

Three later Supreme Court decisions have significantly narrowed the scope of the ADA, and in so doing, may have seriously limited the ADA’s coverage of genetic predisposition

⁹³ *Bragdon v. Abbott*, 524 U.S. 624, 641-42 (1998).

⁹⁴ See Miller, *supra* note 3, at 242.

⁹⁵ *Bragdon*, 524 U.S. at 639.

⁹⁶ See *id.*

⁹⁷ See Miller, *supra* note 3, at 244.

⁹⁸ *Bragdon*, 524 U.S. at 661 (Rehnquist, C.J., dissenting).

⁹⁹ See *id.*

discrimination.¹⁰⁰ None of these decisions concerned the issue of asymptomatic genetic disabilities, but significantly restricted the definition of who is considered a qualified individual with a disability.¹⁰¹

There is also a channel of thought that ADA coverage depends on the genetic predisposition a person has. Some commentators argue that the ADA would extend to a person possessing a predisposition to Huntington's disease, but that a person possessing the BRCA 1 or 2 mutation for breast cancer would have a much harder argument to make under the ADA.¹⁰² Both with Huntington's disease and HIV there is nearly a hundred percent chance of manifestation, while with BRCA 1 or 2 gene alteration there is only a fifty-six percent chance of developing the disease.¹⁰³

Another reason there is question as to the ADA's coverage of genetic predispositions is that legislation has been introduced in Congress that would make it unlawful to discriminate in terms or conditions of employment because of an individual's genetic information.¹⁰⁴ This suggests that at least some members of Congress do not believe that the ADA provides adequate coverage. Furthermore, President Clinton signed an executive order that prohibits the federal government from discriminating against employees based on disease related genotypes or

¹⁰⁰ See *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999), *Albertsons, Inc. v. Kirkinburg*, 527 U.S. 555 (1999), *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516 (1999). The Court held in these cases that actual impairments must be considered in their corrected or mitigated state when determining whether they are disabilities under Title I of the ADA. See *Sutton*, 527 U.S. at 487; *Albertsons*, 527 U.S. at 565; *Murphy*, 527 U.S. at 520.

¹⁰¹ See Miller, *supra* note 3, at 245.

¹⁰² See Eugenia Liu, *Bragdon v. Abbott: Extending the Americans with Disabilities Act to Asymptomatic Individuals*, 3 J. HEALTH CARE L. & POL'Y 382, 393 (2000).

¹⁰³ See *id.* at 396 (the BRCA 1 and BRCA 2 genetic predisposition combined with a family history of breast cancer significantly increases the chance of developing the disease).

¹⁰⁴ See Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, S. 1322, 106th Cong. (1999); H.R. 2457, 106th Cong. (1999).

genetic mutations.¹⁰⁵ It seems that these would be largely redundant and unnecessary if the ADA provided adequate protection.

2. *Title VII of the Civil Rights Act of 1964*

One limited source of protection against genetic discrimination under current federal law is Title VII of the Civil Rights Act of 1964 (“Title VII”), which prohibits employment discrimination on the basis of race, color, religion, sex, or national origin.¹⁰⁶ Therefore, Title VII will likely provide protection against certain forms of genetic discrimination that have a significant correlation to race, national origin, religion, or gender.¹⁰⁷ Since genetic screening is a facially neutral policy, claims under Title VII would have to be brought under the theory of disparate impact.¹⁰⁸ That means the employee would have to show that the hiring decision was based upon a neutral factor that had a disproportionate adverse effect on a protected class.¹⁰⁹ Only a fraction of genetic conditions and mutations are known to be associated with a particular class, therefore Title VII does not provide adequate protection against genetic discrimination in the workplace.¹¹⁰

B. Executive Order 13145

On February 8, 2000, President Clinton issued Executive Order 13145, “To Prohibit Discrimination in Federal Employment Based on Genetic Information.”¹¹¹ The executive order precludes federal employers from requesting, requiring, collecting, or purchasing genetic

¹⁰⁵ See Exec. Order No. 13,145, 65 Fed. Reg. 6877 (2000).

¹⁰⁶ See 42 U.S.C. § 2000e (1994)

¹⁰⁷ See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1271 (9th Cir. 1998).

¹⁰⁸ See *Rachinsky*, *supra* note 41, at 589.

¹⁰⁹ See *id.*

¹¹⁰ See *id.* at 590. Some examples of genetic conditions associated with certain classes sickle-cell (individuals of African American descent) or Tay-Sachs (Ashkenazi Jews). See *Miller*, *supra* note 3, at 247-48.

¹¹¹ Genetic Exec. Order, 6,875, 6,877.

information from applicants and employees.¹¹² The order also prohibits federal employers from using protected genetic information in a manner that deprives employees of advancement opportunities.¹¹³ An exception allows for the genetic testing of applicants if the obtained information is to be used exclusively to determine whether further evaluation is needed to diagnose a current medical condition that could prevent the applicant from performing the essential job functions.¹¹⁴ The weakness of Executive Order 13145 is obvious in that it is only applicable to federal employers. This is due to a lack of executive power, thus leaving further protections in the hands of the federal and state legislatures.

C. Current State Law: Employment Discrimination

Currently, nearly half of the states have legislation prohibiting genetic discrimination in the workplace.¹¹⁵ The form and coverage, protections afforded, and enforcement schemes of these statutes vary considerably. The earliest state legislation addressing genetic discrimination in the workplace prohibited employers from “discriminating against individuals possessing particular genetic traits or disorders.”¹¹⁶

In the 1990’s, a number of states passed more comprehensive statutes, which either prohibit employers from requiring genetic testing as a condition of employment or which

¹¹² See *id.* at 6,878-79. Section 501 of the Rehabilitation Act prohibits disability discrimination by federal employers in the same manner as the ADA applies to private employers. See 29 U.S.C. § 791 (g) (1994). Thus, the Rehabilitation Act prohibits discrimination by the federal government on the basis of genetic information to the same extent as the ADA. See *id.*

¹¹³ See Genetic Exec. Order, 6,875, 6,877.

¹¹⁴ See Genetic Exec. Order, 6,875, 6,879.

¹¹⁵ As of August 2001, twenty-two states have statutes that prohibit genetic discrimination in employment: Arizona, California, Connecticut, Delaware, Illinois, Iowa, Kansas, Maine, Massachusetts, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Oklahoma, Oregon, Rhode Island, Texas, Vermont, and Wisconsin. See Joseph J. Wang, Health Law and Policy Inst., *Genetic Nondiscrimination Laws in Employment* (visited Nov. 6, 2001) <<http://www.law.uh.edu/healthlawperspectives/Genetics/010830Genetic.html>>.

¹¹⁶ See Miller, *supra* note 3, at 259. For example, Florida prohibits entities from denying or refusing employment to any person or discharging any person from employment based on the sickle-cell trait. See FLA. STAT. ANN. § 448.076 (West 2000). A North Carolina statute has nearly identical provisions and also covers individuals with the hemoglobin C trait. See N.C. GEN. STAT. § 95-28.1 (2001). New Jersey prohibits employment discrimination based on the sickle-cell trait, the hemoglobin C trait, the thalassemia trait, the Tay-Sachs trait, or the cystic fibrosis trait. See N.J. STAT. ANN. §§ 10:5-5, 10:5-12 (West 2001).

prohibit the use of genetic information in employment decisions, or work as combination of the two.¹¹⁷ Seventeen states prohibit employers from requiring genetic testing.¹¹⁸ Michigan is one of these states.¹¹⁹ In March of 2000, the Michigan Legislature passed a series of bills dealing with genetic issues.¹²⁰ The Governor's Commission on Genetic Privacy and Progress, which completed a two-year study in February 1999, shaped the content of Michigan bills addressing genetic discrimination.¹²¹ The applicable Michigan statute provides that except as otherwise provided by federal law, an employer shall not require an individual to submit to a genetic test or to provide genetic information as a condition of employment or promotion.¹²²

Twelve states go further by prohibiting requiring genetic testing in employment, and prohibiting employers from even requesting genetic testing or information.¹²³ Some states additionally prohibit employment discrimination based on genetic information obtained from sources other than genetic tests.¹²⁴ New Jersey's law, the most comprehensive, prohibits genetic discrimination based on categories including "genetic information," "atypical hereditary cellular or blood trait," or "because of the refusal to submit to a genetic test or make available the results of a genetic test to an employer."¹²⁵ The current patchwork of state laws has begun to address the issue of genetic discrimination, but often provides either inadequate protection or no

¹¹⁷ See Miller, *supra* note 3, at 260.

¹¹⁸ These states are: California, Connecticut, Iowa, Kansas, Maine, Massachusetts, Michigan, Nevada, New Hampshire, New Jersey, New York, Oklahoma, Oregon, Rhode Island, Texas, Vermont, and Wisconsin. See Wang, *supra* note 115.

¹¹⁹ See MICH. COMP. LAWS ANN. § 37.1202 (West 2001).

¹²⁰ See Wesley Hsu, Communities of Color & Genetics Policy Project, *A Review of Genetics State Laws in Alabama and Michigan* (visited Nov. 6, 2001)

<http://www.sph.umich.edu/genpolicy/current/newsletter/jun2000/state_laws.html>.

¹²¹ See *id.*

¹²² See MICH. COMP. LAWS ANN. § 37.1202 (West 2001).

¹²³ See Wang, *supra* note 115. These states are: California, Connecticut, Iowa, Kansas, Massachusetts, Nevada, New Hampshire, New York, Oklahoma, Oregon, Rhode Island, and Wisconsin. See *id.*

¹²⁴ See N.C. GEN. STAT. § 95-28.1A (1999).

¹²⁵ N.J. STAT. ANN. § 10:5-12 (West Supp. 2001).

enforcement mechanisms. Federal legislation is necessary to address these inadequacies of state law protections for employees and to provide employers with a uniform law.

D. Current Federal Law: Health Insurance Discrimination

The Health Insurance Portability and Accountability Act (“HIPAA”),¹²⁶ is the only federal law that directly addresses the issue of genetic discrimination and provides some limited protections from discrimination on the basis of genetic information in health insurance. The law only applies to employer based and group health insurance plans that are commercially issued.¹²⁷ Under HIPAA, it is prohibited for a group health insurance plan to “establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on ... health status-related factors in relation to the individual or a dependant of the individual [including] ... [g]enetic information.”¹²⁸ The statute further prohibits the using of the results of genetic tests as evidence of a preexisting condition, if the actual disease has not been diagnosed.¹²⁹ The statute protects individuals changing from one health insurance plan to another and also protects uninsured individuals applying for group coverage.¹³⁰ In general, HIPAA makes it possible for individuals to get insurance coverage when they have past or present medical problems, and to maintain coverage when they change jobs or insurance.¹³¹ Specifically, the Act provides important protections for individuals who have preexisting conditions such as a genetic predisposition, and therefore, are afraid to change jobs or insurance for fear of losing their coverage.¹³²

¹²⁶ 29 U.S.C. § 1181 (1999).

¹²⁷ *See id.*

¹²⁸ *See* Rachinsky, *supra* note 41, at 593.

¹²⁹ *See id.*

¹³⁰ *See* Pickens, *supra* note 2, at 174.

¹³¹ *See* Miller, *supra* note 3, at 255.

¹³² *See id.*

However, due to the fact that the provisions of HIPAA apply only to group health insurers, it does not ban insurers from using genetic information in the individual insurance market.¹³³ Furthermore, the statute does not “prevent plans from charging more to all members of a group plan, such as an entire office, because of the genetic makeup of a specific member of the group.”¹³⁴ Moreover, HIPAA does not prohibit health insurers from requesting or requiring genetic tests.¹³⁵ Additionally, a high burden is placed on the plaintiff to prove that insurance coverage was denied because of genetic information.¹³⁶ At first glance, HIPAA seems to provide adequate protection for individuals, but “it retains sufficient loopholes for health insurers to discriminate against individuals with a ‘negative’ genetic makeup.”¹³⁷ While HIPAA is a good start, it still remains deficient in protecting individuals from genetic discrimination in the health insurance context. Additional legislation will be needed to address the loopholes that remain for health insurers to discriminate based on genetic information.

E. Current State Law: Health Insurance Discrimination

Early states laws enacted to protect against genetic discrimination for health insurance like employment was limited in scope.¹³⁸ Since the inception of the Human Genome Project (HGP) in 1990, a number of states have enacted statutes employing broader definitions of genetic information.¹³⁹ Some of the recent statutes have more comprehensive definitions of “genetic testing” or “genetic characteristics” that cover tests for genes or mutations in genes that

¹³³ See Natalie E. Zindorf, Comment, *Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance*, 36 TULSA L.J. 703, 719 (2001).

¹³⁴ Miller, *supra* note 3, at 255-56.

¹³⁵ See Rachinsky, *supra* note 41, at 593-94.

¹³⁶ See Pickens, *supra* note 2, at 174-75.

¹³⁷ Smith, *supra* note 14, at 716.

¹³⁸ For example, Maryland’s insurance statute prohibited health and life insurers from treating individuals differently with respect to ratings, premium payments, or dividends based on genetic traits, but only for “sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, [or] Tay-Sachs trait.” MD. CODE ANN., INS. § 223(a)(3), (b)(4) (1997). This statute has been amended to be more comprehensive. See MD. CODE ANN., INS. § 27-909(b) (2000).

¹³⁹ See Rachinsky, *supra* note 41, at 585.

are associated with diseases or disorders.¹⁴⁰ The expansion of the term “genetic testing” in various statutes provides more protection for individual privacy.¹⁴¹ Currently, forty-six states have enacted laws prohibiting insurers from using genetic information to discriminate against individuals.¹⁴² These statutes typically fall into one of two categories. The first group prohibits health insurers from using genetic information about an individual except for research or investigative purposes.¹⁴³ The second group specifically names prohibited uses of genetic information.¹⁴⁴

State legislation varies significantly in scope, and some states explicitly prohibit information “ranging from family medical history to DNA testing, while others ban discrimination based on chromosomal test results alone.”¹⁴⁵ In almost every state that has laws prohibiting genetic discrimination, the laws apply to both the group and individual health insurance providers.¹⁴⁶ The scope of protection in each state is dependant on the definition of “genetic information” in the statutory language. If the definition is broader, the scope of protection is broader.¹⁴⁷ This is most important in determining whether family history will be considered a part of genetic information.¹⁴⁸

In Michigan, new legislation forbids Blue Cross and Blue Shield of Michigan, health insurers, and health maintenance organizations (HMOs) from: 1) requiring insured persons or applicants to submit to genetic testing before issuing, reviewing, or continuing a policy; and 2)

¹⁴⁰ *See id.* at 586.

¹⁴¹ *See id.*

¹⁴² Only Mississippi, Pennsylvania, Utah, and Washington have no general genetic nondiscrimination laws in health insurance. *See* Joseph J. Wang, Health Law and Policy Inst., *Genetic Nondiscrimination Laws in Health Insurance* (visited Nov. 6, 2001) <<http://www.law.uh.edu/healthlawperspectives/Genetics/010831HealthIns..html>>.

¹⁴³ *See* William F. Mullholland II & Ami S. Jaeger, *Genetic Privacy and Legislation: A Survey of State Legislation*, 39 JURIMETRICS J. 317, 318 (1999).

¹⁴⁴ *See id.*

¹⁴⁵ *See* Zindorf, *supra* note 133, at 719-20.

¹⁴⁶ *See* Wang, *supra* note 142 (Alaska, Texas, and Wyoming genetic discrimination laws only apply in the group health insurance context, not the individual market).

¹⁴⁷ *Id.*

¹⁴⁸ *See id.*

sharing whether genetic testing has been conducted and/or the results of the genetic testing or genetic information that has been collected.¹⁴⁹ The statute does not prohibit an insurer or an HMO from requiring an applicant to answer questions concerning family history as a precursor to coverage.¹⁵⁰

The majority of current laws address the use of genetic information in the context of health insurance, which has primarily been regulated at the state level. However, in practice, state laws do not reach many insurers, due to preemption by the federal Employee Retirement Income Security Act of 1974 (“ERISA”),¹⁵¹ which preempts state laws that regulate self-insured employee health plans.¹⁵² Consequently, there is a need for more comprehensive federal legislation to protect against discrimination by the health care industry based on genetic information.

F. Pending Federal Legislation

For the fourth straight year,¹⁵³ the United States Congress is attempting to pass comprehensive legislation banning genetic discrimination in employment and health insurance. Currently, there are several pieces of recently introduced legislation that deal with the issue of discrimination in either employment, insurance, or both, based on genetic information. On February 16, 2001, the Genetic Nondiscrimination in Health Insurance and Employment Act (Senate Bill 318 & House Bill 602) was introduced in the Senate by Senator Tom Daschle (D-SD) and in the House of Representatives by Representative Louise Slaughter (D-NY).¹⁵⁴

¹⁴⁹ See MICH. COMP. LAWS ANN. § 500.3407(b) (West 2001).

¹⁵⁰ See *id.*

¹⁵¹ 29 U.S.C. §§ 1001-1461 (1999).

¹⁵² See Rachinsky, *supra* note 41, at 587-88.

¹⁵³ Legislation was proposed by both the 105th and 106th Congress to combat genetic discrimination. See H.R. 306, 105th Cong. (1997); S. 89, 105th Cong. (1997); H.R. 2457, 106th Cong. (1999); S. 1322, 106th Cong. (1999).

¹⁵⁴ See S. 318, 107th Cong. (2001); H.R. 602, 107th Cong. (2001). The House bill had 152 bipartisan co-sponsors, including Connie Morella (R-MD) who joined Slaughter in introducing the bill. See American Medical Association,

In the area of employment discrimination this pending legislation would make it illegal for an employer to fire, refuse to hire, or otherwise discriminate against an individual based on genetic information.¹⁵⁵ With a few exceptions, the proposed legislation would also make it illegal for an employer to request, require, collect or purchase protected genetic information with respect to an individual or a family member of the individual.¹⁵⁶ The exception allows for an employer to request, require, collect or purchase such information where needed to monitor the adverse effects of hazardous workplace exposures or with the consent of the employee.¹⁵⁷ The same or similar provisions apply to employment agencies, labor organizations, and training programs.¹⁵⁸

Three major provisions of the proposed legislation address genetic discrimination in health insurance. First, it would prohibit use of genetic information in determining eligibility or in adjusting premium rates.¹⁵⁹ Second, it would prohibit health insurers from requesting or requiring individuals or their family members to undergo genetic testing.¹⁶⁰ Third, it would prohibit health insurers from requesting or requiring an individual or their family members to provide genetic information.¹⁶¹ The proposed legislation would apply to both group and individual health insurance programs, including state regulated plans and those regulated by the federal government under the Employee Retirement Income Security Act of 1974 (ERISA).¹⁶²

Genetic Discrimination Legislative Update (visited Nov. 16, 2001) <<http://www.ama-assn.org/ama/pub/category/3999..html>>.

¹⁵⁵ See Watson Wyatt Insider, *Bill Pending in Congress on Genetic Discrimination* (visited Nov. 6, 2001) <http://www.watsonwyatt.com/homepage/us/new/Insider/new/2001/2001_10_04.asp>.

¹⁵⁶ See *id.*

¹⁵⁷ See *id.*

¹⁵⁸ See S. 318, 107th Cong. (2001); H.R. 602, 107th Cong. (2001).

¹⁵⁹ See Watson Wyatt, *supra* note 155.

¹⁶⁰ See *id.*

¹⁶¹ See *id.*

¹⁶² See *id.*

Thus, addressing a significant loophole from HIPAA by including individual health insurance programs.

A significant part of S. 318/H.R. 602 is that it provides individuals the right to bring unlimited action in federal or state courts for violations by insurance plans or employers.¹⁶³ This allows claimants to bypass the Equal Employment Opportunity Commission (EEOC) and file immediately in federal or state court.¹⁶⁴ Once in court S. 318/H.R. 602 allows for unlimited compensatory and punitive damages.¹⁶⁵

Congressional committee meetings are currently being held to determine the best way to keep genetic information out of employment and health care decisions.¹⁶⁶ Senate 318 has been referred to the Senate Health Education, Labor, and Pensions Committee, which held hearings on the bill July 25, 2001 and February 13, 2002.¹⁶⁷ House Bill 602 has been referred to the House Energy and Commerce Subcommittee on Health, the Ways and Means Subcommittee on Health, and the Education and the Workforce Subcommittee on Employer-Employee Relations.¹⁶⁸ Both bills would be effective October 1, 2002.¹⁶⁹ As of April 5, S. 318 has been supported 26 cosponsors, all Democrat, and H.R. 602 has been supported 259 cosponsors (more than a majority), bipartisan.¹⁷⁰ A key issue that hearings have focused on is whether current laws, such as the ADA and HIPAA provide adequate protection, and whether proposed legislation is consistent with existing discrimination statutes.¹⁷¹

¹⁶³ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Ronald L. Adler, Laurdan Associates, Inc.)

¹⁶⁴ See *id.*

¹⁶⁵ See *id.*

¹⁶⁶ See S. 318, 107th Cong. (2001); information available at (visited April 5, 2001) <<http://thomas.loc.gov/>>.

¹⁶⁷ See *id.*

¹⁶⁸ See H.R. 602, 107th Cong. (2001); information available at (visited April 5, 2001) <<http://thomas.loc.gov/>>.

¹⁶⁹ See *id.*

¹⁷⁰ See *id.*

¹⁷¹ See Watson Wyatt, *supra* note 155.

Another pending bill, the Genetic Information Nondiscrimination in Health Insurance Act of 2001 (Senate Bill 382), was introduced by Senator Olympia Snow on February 15, 2001.¹⁷² The bill currently has six cosponsors.¹⁷³ This bill though similar to S. 318/ H.R. 602, only contemplates discrimination in health insurance and its coverage of health insurance discrimination is not as comprehensive as S.318/H.R.602.¹⁷⁴ Senate Bill 382 similar to S. 318 and H.R. 602 applies to both individual and group health insurance programs.¹⁷⁵

A significant difference is that S. 382 stipulates that an insurance company may “request, but not require” genetic information from clients.¹⁷⁶ This is in contrast to S. 318 and H.R. 602, which prohibit even the request for information without the authorization of the individual.¹⁷⁷ The potential problem is that insurance companies could potentially pass off requests as requirements. Another significant difference is that S. 382 does not have an enforcement clause like the one provided in S. 318/H.R. 602, which allows for unlimited action in federal or state courts.¹⁷⁸ Without significant penalties it is unlikely legislation will deter employers and health insurers from discriminating based on an individuals genetic information.

The measures in S. 382 would prevent individual health insurers and group health plans from discriminating against individuals on the basis of “predictive” genetic information.¹⁷⁹ The bill would also prohibit health insurers from adjusting premiums from groups based on “predictive” genetic information.¹⁸⁰ A health insurer under this bill cannot require an individual

¹⁷² See S. 382, 107th Cong. (2001); information available at (visited April 5, 2002) <<http://thomas.loc.gov/>>.

¹⁷³ See *id.*

¹⁷⁴ See *id.*

¹⁷⁵ See *id.*

¹⁷⁶ See OLPA, *supra* note 5.

¹⁷⁷ See *id.*

¹⁷⁸ See *id.*

¹⁷⁹ *Id.*

¹⁸⁰ *Id.*

to give “predictive” genetic information, but can request it.¹⁸¹ The word “predictive” also highlights another difference between S. 382 and S. 318/H.R. 602, which use the word “potential.”¹⁸² The National Association of Health Underwriters (NAHU) favors S. 382 for fear that the S. 318/ H.R.602 “potential” language is so broad that it will disrupt and prevent the normal underwriting process.¹⁸³

Senate Bill 382 exempts genetic information from protection if it is “derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests.”¹⁸⁴ Since the majority of genetic information is collected in this manner, this definition excluding nearly all genetic information from protection renders the bill inadequate to protect against genetic discrimination. Furthermore, S. 382 does not provide protection for information that is discovered through tests not intended to reveal genetic information.¹⁸⁵ A close study of the definitions and exceptions provided by the proposed bill indicates that the bill would provide very minimal protections from genetic discrimination by health insurers and no protections from genetic discrimination in the employment arena. On February 13, 2002 the Committee on Health Education, Labor, and Pensions held hearings for S. 318 and S. 382 addressing some of these concerns.¹⁸⁶

On March 6, 2002 Senator Snowe introduced a new bill backed by Republicans, the Genetic Information Non-Discrimination in Health Insurance and Employment Act of 2002 (Senate Bill 1995).¹⁸⁷ The bill was referred to the Committee on Health, Education, Labor, and

¹⁸¹ *Id.*

¹⁸² See NAHU, *Issues: Genetic Discrimination*, (visited April 6, 2002) <http://www.nahu.org/governmnet/issues/genetic_discrimination/>.

¹⁸³ See *id.* The intent of the Daschle/Slaughter bill is to keep the definition sufficiently broad to close any loophole that might in some way lead to genetic discrimination. See *id.*

¹⁸⁴ S. 382, 107th Cong. (2001); information available at (visited April 5, 2002) <<http://thomas.loc.gov/>>.

¹⁸⁵ See *id.*

¹⁸⁶ See *id.*

¹⁸⁷ See S. 1995, 107th Cong. (2002); information available at (visited April 5, 2002) <<http://thomas.loc.gov/>>.

Pensions, and currently has eight cosponsors.¹⁸⁸ The proposed legislation was an effort to find some common ground with S. 318/ H.R. 602.¹⁸⁹ However, significant differences still remain.

The employment part of the bill is drafted to prohibit the use of genetic information in employment decisions, including in hiring, firing , and promotions.¹⁹⁰ Employers would only be able to collect genetic information in limited circumstances, such as monitoring the effect of workplace hazards.¹⁹¹ Genetic information that is obtained by employers would be confidentially protected.¹⁹² The health insurance portion of the bill prohibits health insurers, issuers and group health plans from using genetic information ,including family history, to deny coverage or to set premiums and rates.¹⁹³ Health plans that hold genetic information would have to treat it in compliance with existing privacy rules.¹⁹⁴

The EEOC would enforce all provisions of the bill, which is different from S. 318/H.R. 602 which provide for direct access to the courts.¹⁹⁵ This is significant in that under S. 318/ H.R. 602 a claimant can make the decision of filing suit through the EEOC or can directly bring an action in federal or state court. Under the provisions of S. 1995 a claimant is forced to file its suit through the EEOC. Furthermore, S. 1995 does not provide for the unlimited compensatory and punitive damages that are available under S. 318/H.R. 602. As a point of compromise, S. 1995 by providing the EEOC enforcement clause makes it a more meaningful deterrent than S. 382.

¹⁸⁸ *See id.*

¹⁸⁹ *See* Genetic Alliance March 2002 Alert, *Genetic Nondiscrimination: Is a deal in sight?*, (visited April 6, 2002) <<http://www.geneticalliance.org/alert.html>>.

¹⁹⁰ *See* CCH Federal Law Changes, *Summary of Federal Law Changes – March 2002*, (visited April 6, 2002) <<http://www.hr.cch.com/federal-law-changes/march02.asp?home>>.

¹⁹¹ *See id.*

¹⁹² *See id.*

¹⁹³ *See* Towers Perrin, *Health and Welfare Legislative Tracking Chart*, (visited March 29, 2002) <http://www.towers.com/TOWERS/services_products/TowersRerrin/hw.html>.

¹⁹⁴ *See id.*

¹⁹⁵ *See id.*

A significant weakness of S. 1995 is that it exempts from protection the exact same forms of genetic information that are excluded under S. 382.¹⁹⁶ By excluding genetic information that is obtained from blood tests, urine tests, and information discovered through a test not intended to reveal genetic information, the proposed legislation does not adequately protect individuals from genetic discrimination in the workplace or by health insurers. The definition, when examined, indicates that only a minimal amount of genetic information will be protected. Senate Bill 1995 with the employment discrimination and enforcement provisions represents an effort in coming to a compromise on some form of genetic discrimination legislation. However, as drafted S. 1995 provides inadequate protections to address public fears of discrimination. More comprehensive legislation such as S. 318/ H.R. 602 will be needed to address and alleviate public fears of genetic discrimination. Thus, contributing to research, public health, and the general welfare of society. President Bush in a March 2002 statement indicated support for legislation such as S. 1995, and characterized the bills protections as “fair, reasonable and consistent with existing laws.”¹⁹⁷

III. ANALYSIS & PROPOSAL

A. Argument for Protections Against Employment Discrimination

Employers can learn employees or potential employees genetic information through genetic testing, company medical exams, family history, or medical records.¹⁹⁸ Employers have the authority to monitor employees and want employees who are physically and mentally fit.¹⁹⁹

¹⁹⁶ See S. 1995, 107th Cong. (2002); information available at (visited April 5, 2002) <<http://thomas.loc.gov/>>. The bill does not protect genetic information that is “derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests.” See *id.* The bill does not protect information that is discovered through a test not intended to reveal genetic information.

¹⁹⁷ CCH Federal Changes, *supra* note 190.

¹⁹⁸ See Paul Miller: Human Genome News, *Analyzing Genetic Discrimination in the Workplace*, (visited March 28, 2002) <<http://www.ornl.gov/hgmis/publicat/hgn/v12n1/09workplace.html>>.

¹⁹⁹ See Tobi T. Bromfield, *Your DNA is your Resume: How Inadequate Protection of Genetic Information Perpetuates Employment Discrimination*, 7 WASH. & LEE RACE & ETHNICITY ANCESTRY L.J. 117, 125(2001).

Employers also have a valid interest in an individuals' health that may pose a hazard to the applicant, to others or to the business.²⁰⁰ However, beyond this valid interest (,) employment decisions should be based on merit, not on speculative information about potential diseases or disorders that may never develop.

A genetic test may inform the employer of an individual's potential future medical condition, but not the individual's present ability to perform the specific job.²⁰¹ Requiring of genetic testing is becoming a wide spread practice.²⁰² The problem that arises is that employers are using these tests to protect from future problems that may arise from a potential medical condition, rather than looking at the individual's present ability to do the job.

Concerns about discrimination arise when employers begin to express interest in genetic information that is not related to the job. Employers are increasingly finding this as a way of assessing risk and avoiding possible increased operating expenses down the road.²⁰³ Plain and simple employers do not want to hire someone who may develop a disease, and have to cover the costs such as absences from work, extra costs of recruitment and training a replacement, early retirement, worker's compensation, or excessive use of healthcare benefits.

One problem associated with potential genetic discrimination in the workplace is that individuals will not undergo a genetic screening for fear that it may result in future discrimination by an employer.²⁰⁴ Genetic testing at times can be a lifesaving measure, and individuals should not have to fear adverse consequences in the employment arena based on the result of a genetic test.²⁰⁵ A study by the National Center for Genome Research (NCGR)

²⁰⁰ *See id.*

²⁰¹ *See id.*

²⁰² *See id.*

²⁰³ *See id.* at 129.

²⁰⁴ *See Smith, supra* note 16, at 718.

²⁰⁵ *See Miller, supra* note 3, at 232.

indicates that thirty-six percent of people surveyed would not take genetic tests for fear that their employer could get access to the results.²⁰⁶ This behavior results in negative consequences both for the individual who does not get tested and for the advancement of scientific research in this area.²⁰⁷ This fear is clearly not unwarranted. In the Burlington Northern Railroad case examined earlier, Burlington North admitted to using genetic testing to determine if employees who had developed carpal tunnel syndrome had a predisposition to the disease.²⁰⁸ Furthermore, employees who refused to be tested were threatened with discipline or even termination.²⁰⁹ The concern is also illustrated in the case of the woman who was terminated from her job after finding out she had a BRCA 1 and BRCA 2 genetic predisposition to breast cancer.²¹⁰ Comprehensive legislation needs to be enacted that will prevent employers from abusing genetic information in this manner.

Another problem associated with genetic information being used in the workplace is that employers are likely to misuse and misinterpret health risks based on a common misconception that having a genetic trait is the same as having the disease or disorder.²¹¹ A genetic trait may mean an increased risk of a certain disease, but does not mean the individual is afflicted with the disease or disorder. In some cases there is only a slight risk of being afflicted with the disease or disorder, and with other traits the probability is much higher.²¹² Employers may discriminate against a carrier because of this fundamental misconception that genetic trait might affect a persons health or capabilities.²¹³ Being susceptible to a disease or disorder, does not always

²⁰⁶ *See id.* at 233.

²⁰⁷ *See id.* at 234.

²⁰⁸ *See supra* notes 59, 90 and accompanying text.

²⁰⁹ *See supra* notes 59, 90 and accompanying text.

²¹⁰ *See supra* notes 60-62 and accompanying text.

²¹¹ Holmes, *supra* note 7, at 529.

²¹² *See* Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 126 (1991).

²¹³ *See id.*

determine the onset of a disease or disorder, often times a persons lifestyle choices and the environment have a serious effect on the overall health and the potential of the onset of a disease or disorder on a certain individual.²¹⁴ It is unjustified for an employer to discriminate based on a mere medical speculation, when decisions should be based on merit.

Information pertaining to an individual's body and state of health is a matter, which an individual is ordinarily entitled to privacy.²¹⁵ Allowing employers access to genetic information poses several legal and ethical dilemmas that could better addressed with legislation directed at employment discrimination based on genetic information. Genetic information should only be used by individuals in consultation with their doctors, to make the best diagnostic and treatments decision possible.²¹⁶

Laws should be enacted which prevent employers from requiring employees to undergo genetic testing or using results of genetic tests as a basis for adverse discriminatory employment decisions.²¹⁷ Under certain limited circumstances employers should be able to use genetic testing and the use of genetic information in the workplace to ensure workplace safety and health and to preserve research opportunities.²¹⁸ However, in all cases where genetic information is obtained it should be maintained as confidential medical records separate from personnel files.²¹⁹ An employer should be permitted to monitor employees for the effects of a particular substance found in the workplace to which continued exposure could cause genetic damage under certain

²¹⁴ See Heather Rae Watterson, *Genetic Discrimination in the Workplace and the Need for Federal Legislation*, 4 DEPAUL J. OF HEALTH CARE 423, 431 (2001).

²¹⁵ See U.S. v. Westinghouse Elec. Corp., 638 F.2d 570, 577 (3d Cir. 1980).

²¹⁶ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (statement of Senator Edward M. Kennedy).

²¹⁷ See Human Genome Project Information, *Genetics Privacy and Legislation*, (visited Nov. 16 2001) <<http://www.ornl.gov/hgmis/elsi/legislat.html>>.

²¹⁸ See *id.*

²¹⁹ See *id.*

circumstances.²²⁰ Second, an employer may use the results only to identify and control adverse conditions in the workplace and to take action necessary to prevent significant risk of substantial harm to the employee or others.²²¹ Once again it is important that informed consent and confidentiality are required.²²²

Legislation addressing all of these points “should apply to public and private-sector employees, unions and labor management groups that conduct joint apprenticeship and other training programs. Employment agencies and licensing agencies that issue licenses, certificates, and other credentials required to engage in various professions and occupations also should be covered.”²²³ Courts should be given the authority to halt violations and order relief, including but not limited to order to halt violations and order of relief, such as hiring, promotion, back pay, and compensatory and punitive damages to the individual.²²⁴

Antidiscrimination law “is built upon the premise that applicants and employees must be selected based on their ability to do the job and not on myths, fears, stereotypes regarding race, gender, age, religion, or disability.”²²⁵ Just as it is illegal to refuse to hire an individual based on their race or gender, it should be illegal to make employment decisions based upon genetic information rather than an individual’s ability to do the work.²²⁶ “It is simply bad science to use the presence of a predictive genetic trait or marker to make workplace decisions because those traits cannot predict how well that person will succeed in the workplace Society should not

²²⁰ *See id.*

²²¹ *See id.*

²²² *See id.*

²²³ Human Genome Project Information, *supra* note 217.

²²⁴ *See id.*

²²⁵ *See Miller supra* note 198.

²²⁶ *See Miller supra* note 3, at 264.

allow employers to assign a negative value to genetic markers that have no effect on one's ability to perform in their job.”²²⁷

Comprehensive legislation needs to be enacted that will protect individuals from not being hired or being fired based on genetic information. Such discrimination is particularly unfair because it is based on characteristics that an individual is powerless to change. An individual's genetic makeup should not be substituted for qualifications, and no employer should ever review as such when the ability of an individual to perform the essential job functions is unaffected. Legislation needs to be enacted that will alleviate public fears of employers using genetic information in a discriminatory manner. While the ADA and some state legislation may offer some protections in the employment context, further legislation is needed to combat discrimination in the workplace based on genetic information.

B. Argument for Insurance Protection

The historic purpose of insurance has typically been to “protect the insured against the economic consequences of fortuitous events.”²²⁸ A “‘fortuitous’ event is one that occurs by chance, without obvious causation, unexpectedly, or not according to the usual course of things.”²²⁹ Of course, a profit for the insurance company is also figured into the system.²³⁰ In the individual market, where risk is high compared to the group market, family medical history has traditionally played a role in the underwriting process.²³¹ Underwriting “involves evaluating a person's risk of accident, disease, or death, and based on the relevant risk, applicants are classified into groups and charged premiums accordingly.”²³² The underlying principle of

²²⁷ *Id.* at 264-65.

²²⁸ Jerry Elmer, *Human Genomics: Toward a New Paradigm for Equal-Protection Jurisprudence*, 50 APR. R.I. B.J. 5, 27 (2002).

²²⁹ *Id.*

²³⁰ *See id.*

²³¹ *See* Zindorf, *supra* note 133, at 717.

²³² *Id.*

insurance underwriting is “fair discrimination” based on efficient, actuarial analysis in establishing risk transference and risk distribution.²³³ In underwriting risks, insurance companies attempt “to measure as accurately as is practicable the burden shifted to the insurance fund by the policyholder and to charge exactly for it, no more and no less. To do so is ‘fair’ discrimination Not to do so is unfair discrimination.”²³⁴

There is an argument that if health insurers were restricted from certain genetic information, normal underwriting procedures would be disrupted, which would result in increased premiums throughout the market.²³⁵ Supporters of underwriting further argue that use of genetic testing is fair discrimination because it is based on “sound actuarial analysis.”²³⁶ However, this section will show that discrimination based on genetic testing is neither fair nor sound.

Health insurance companies could potentially save millions of dollars if they could use predictive genetics to identify in advance, and then reject, policy applicants who are predisposed to certain diseases and disorders.²³⁷ With regard to genetic information, insurance companies continue assert that this information that can be used to predict symptoms or susceptibility are imperative to risk assessment.²³⁸ Regardless, of whether the disclosure is necessary for efficient continuation of insurance policies, experience shows that this information can expose people to increased premiums, cancellation of policies, loss of employment, and other negative effects.²³⁹

²³³ See Holmes, *supra* note 7, at 531.

²³⁴ *Id.* at 531-32.

²³⁵ See *id.*

²³⁶ *Id.* at 540.

²³⁷ See The Associated Press, *Gene Map Creates New Frontier for Discrimination, Experts say* (visited March 10, 2002) <http://www.//theskanner.com/special01/blk2001/gene_map_creates_new_frontier_fo.htm>.

²³⁸ See David Shore et. al., *Legal and Ethical Issues in Psychiatric Research*, 48 AM. J. OF MED. GENETICS, 17, 17 (1993).

²³⁹ See *id.*

The problem is that the unfamiliarity with particulars in gene theory may result in unwarranted negative judgments, such as discrimination based on the finding of one bad gene, which does not mean the person has a genetic disease. Even if genetic science were completely accurate, which it is not, predictions based on genetic test results are not conclusive.²⁴⁰ The genetic test may reveal that an individual is more susceptible to developing a particular disease or disorder in comparison with the rest of the population, but environmental and behavioral factors play key roles in determining whether the individual is actually afflicted.²⁴¹ Furthermore, genetic flaws can also be affected by behavioral changes and medical intervention.²⁴² The problem is that when medical underwriters rely on genetic tests these other factors are overlooked. Special protection of genetic information is justified by how unique it is, and by how likely it is that insurers will misuse and misinterpret this information. Without special protection health insurance companies without sufficient genetic understanding will make decisions that are unfair and discriminatory.

Many advocates of legislation protecting against genetic discrimination do not believe that family medical history should be included in the definition of genetic discrimination.²⁴³ They argue that family medical history has long been a part of patient information.²⁴⁴ The National Association of Health Underwriters (NAHU) “supports the prohibition of the use of genetic information in the health insurance underwriting process as long as the definition of genetic information is limited to DNA, RNA and related gene testing.”²⁴⁵ It is the position of the NAHU that the expanding of the definition of genetic information to include an individual’s

²⁴⁰ See Zindorf, *supra* note 133, at 722.

²⁴¹ See *id.*

²⁴² See *id.*

²⁴³ See National Association of Health Underwriters, *Issues: Genetic Discrimination* (visited February 12, 2002) <http://www.nahu.org/government/issues/genetic_discrimination/>.

²⁴⁴ See Zindorf, *supra* note 133, at 724.

²⁴⁵ National Association of Health Underwriters, *supra* note 243.

personal and family medical history will interfere with the normal health insurance underwriting process.²⁴⁶ The NAHU favor S. 382 over S. 318 and H.R. 602 because the definition of genetic information is not as broad in S. 382.²⁴⁷ The problem with this argument is that when personal and family medical history are not included in the definition of genetic information, health insurance companies are permitted genetic tests by other means. What this means is that health insurance companies will be permitted to “use crude, old-fashioned, relatively less reliable, twenty-first-century means of collecting the data from the same people.”²⁴⁸ The health insurance companies would just use personal medical history and family history to learn what they could about a person’s genetic makeup for the purposes of underwriting. It would make no sense for the law to allow a health insurance company to do by a less reliable means what it is barred from doing by more reliable means.²⁴⁹

Other health insurers fear that consumers will use their knowledge about their own genetic predisposition for particular diseases or medical conditions to “adversely select” against insurance companies.²⁵⁰ The argument is that this will force the insurer to increase the premium price for insurance coverage to cover all of these unexpected claims.²⁵¹ The fear is that adverse selection will increase as genetic information becomes available to individuals.²⁵² However, this argument is unpersuasive. If insurers were denied the use of genetic information, then insurers as a class would be equally subject to additional costs associated with adverse selection.²⁵³ Therefore, if all insurers were proportionally affected by adverse selection, then no single insurer

²⁴⁶ *See id.*

²⁴⁷ *See id.*

²⁴⁸ *See Elmer, supra* note 228, at 27.

²⁴⁹ *See id.*

²⁵⁰ *See Holmes, supra* note 7, at 507. Adverse selection occurs when individuals with a high probability of loss apply for more insurance than do other “genetically normal” individuals. *See id.*

²⁵¹ *See id.* at 544.

²⁵² *See id.* at 545.

²⁵³ *See Colby supra* note 6, at 457.

would be at a competitive disadvantage.²⁵⁴ This is certainly a problem, but is outweighed by the potential for unfair discrimination and unfair results that could result in a violation of an individual's civil rights when genetic information is used.

If insurance companies are permitted to use genetic information the result will be those who least need coverage will obtain it at reasonable rates, while those who need it most will either be denied coverage or unable to afford coverage.²⁵⁵ If not denied coverage completely individuals who are a genetic risk will be offered an exclusion or coverage limited by a low maximum financial limit, or a cap for treatment of the genetic defect.²⁵⁶ This is not good policy for those most in need of health insurance to be the individuals least likely to be the ones to get the coverage needed. This will be the result if insurance companies are allowed to abuse genetic information.

An individual's genetic makeup is entirely beyond voluntary choice.²⁵⁷ Arguably because of this there should be no duty to pay more for insurance because of genetic makeup.²⁵⁸ The "nature and purpose of insurance is risk transference and distribution, or fairly redistributing and equally sharing the fortuitous risks among all policy holders Fair risk redistribution is a matter of equal fairness for all of us because all of us are genetically unequal."²⁵⁹ Basically because genetic makeup is morally arbitrary it should not be the basis for one's treatment by health insurance companies. The argument then goes on that "[e]ach of us is genetically different and potentially unequal in insurance classifications, but we attain equality through

²⁵⁴ *See id.* Under this theory each insurer can pass the additional expenses on equally to their customers, without one insurance company having an advantage over another. *See id.*

²⁵⁵ *See Holmes, supra* note 7, at 558.

²⁵⁶ *See id.*

²⁵⁷ *See id.* at 563.

²⁵⁸ *See id.*

²⁵⁹ *Id.* at 563-64.

socializing and redistributing our immutable genetic risks.”²⁶⁰ This way everyone receives value through insurance.²⁶¹

The majority of individuals rely on health insurance to absorb most of their health care costs.²⁶² Denial of health insurance may result in a denial of health care period, and this inaction then leads the burden of health care being shifted to the taxpayer.²⁶³ This is a cost that should be spread among the insured. The insurance companies should not be allowed to include genetic information in its rate setting, and should spread these costs evenly among the insured.

Another argument against allowing insurance companies to use genetic information is that individuals may decide not to have genetic testing done for fear of the potential consequences. There is the potential that an individual would rather not know about a genetic defect, rather than be penalized when trying to obtain health insurance.²⁶⁴ This a serious problem considering the value an individual may receive from a genetic test, yet individuals have to weigh the risks as to whether they are better off not knowing for fearing of adverse effects in health insurance. The primary concern of individuals who choose not to participate in a genetic test is fear of losing health insurance.²⁶⁵ The statistic indicates there is a need for legislation that addresses individual’s fear of being denied or losing health insurance based on a genetic testing, which can potentially be a lifesaving measure.

Legal measures should be pursued at the federal and state levels to protect individuals from such discrimination. Health insurers should be prohibited from declining to cover or

²⁶⁰ *Id.* at 564.

²⁶¹ See Holmes, *supra* note 7, at 564.

²⁶² See Leah Wortham, *Insurance Classification: Too Important to Be Left to the Actuaries*, 19 MICH. L. REV. 349, 397 (1986).

²⁶³ See Holmes, *supra* note 7, at 567.

²⁶⁴ See *id.* at 577.

²⁶⁵ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Bobby P. Jindal, U.S. Department of Health and Human Services) (39% of individuals who refused to participate in genetic testing stated that fear of losing health insurance was their reason for refusal).

overcharging individuals known to carry genetic predispositions. They should also be prohibited from mandating genetic testing. Health insurers should have minimal use for genetic information because the focus is on short-term problems.²⁶⁶ Genetic testing reveals information with regard to an individual's long-term health risks, which is insignificant considering most individuals stay with insurance companies for a short period of time.²⁶⁷

Until medical underwriting is no longer performed, legislation is needed to protect individuals from genetic discrimination. According to one lead expert in the field “[i]nsurance is a method of risk-sharing against the unknown, and the more the unknown becomes knowable in advance, the less the current system makes sense. We need to think of ways of restructuring our insurance system ... to accommodate this ability to predict future risks.”²⁶⁸ Legislation preventing the use of genetic information by medical underwriters is the way to take into account the increased ability to predict future risk, and keep genetic information, which is of minimal significance private from the insurers. Insurance companies should be forbidden to use individual's genetic information to deny them coverage or to raise their premiums. In addition, insurance companies should not be allowed to use genetic information or family history of disease to deny anyone coverage or to raise their premiums.

Federal legislation is needed to protect individuals from genetic discrimination, a form of discrimination needing protection just as racial, ethnic, age and sexual discrimination. This type of legislation will force insurers to make decisions based on an individual's actual state of health

²⁶⁶ See Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 JURIMETRICS J. 93, 96-97. The author's information comes from research conducted in the insurance industry of seven different states. *See id.*

²⁶⁷ *See id.* at 109. The reason for the high turnover of insurance coverage in group policies is job shifting. *See id.* In the individual market, the majority of policy holders are recently out of school or work and seek only temporary coverage. *See id.*

²⁶⁸ Rick Weiss, *Gene Discrimination Barred in Workplace; EEOC Says Jobs Can't Be Denied Based on Predisposition to Disease*, WASH. POST, APR. 7, 1995, AT A3 (quoting Professor Mark Rothstein, Director of the University of Houston Health Law and Policy Institute).

rather than genetic information that is affected by many factors, which cannot be reduced to a risk determination. Genetic testing is extremely uncertain in its predictions, and it is unfair to use this data to determine insurance coverage or costs. The insurance industry should be forced to spread genetic risks across the entire pool of insureds to ensure those with genetic predispositions are not discriminated against.

C. Current Legislation Is Inadequate

Currently, the law fails to sufficiently address genetic discrimination. There are respective arguments, both for and against, further legislation regulating the use of genetic information. Critics of further legislation concerning genetic discrimination argue that it is unnecessary because of existing statutes such as the ADA and HIPAA, and that any further legislation would be inconsistent with existing discrimination statutes.²⁶⁹

The ADA is clearly lacking in its protection against genetic discrimination in the workplace. First, it is possible and highly likely that the ADA does not protect genetic predispositions that have not manifested.²⁷⁰ The law is unclear as to whether these genetic predispositions are considered disabilities. Another major disadvantage of the ADA is that it only applies to employers with fifteen or more employees, thereby excluding a large number of small employers from complying with the ADA.²⁷¹ Furthermore, the public fear of genetic discrimination indicates that the ADA currently provides inadequate protection.

Although a great start, HIPAA also fails to provide adequate protections against genetic discrimination. First, HIPAA does not require an employer to provide a health plan, and if an employer does provide such a plan, HIPAA does not require the inclusion of certain benefits.²⁷²

²⁶⁹ See Pickens, *supra* note 2, 173.

²⁷⁰ See *id.*

²⁷¹ See 42 U.S.C. § 12111(5)(A) (1994).

²⁷² See Pickens, *supra* note 2, 174.

Plans may exclude certain coverage of a particular condition or place a lifetime cap on certain benefits, provided it is not directed at certain individuals. A second, major disadvantage of HIPAA is that it does not help uninsured individuals who apply for individual coverage.²⁷³ A third weakness of HIPAA is that it leaves open the possibility that all members of an insured group may be charged at a higher premium based upon the genetic information of one person.²⁷⁴ Additionally, premiums are not controlled by HIPAA as long as similarly situated individuals in the plan are charged the same amount.²⁷⁵ Furthermore, HIPAA does not prohibit insurers from requiring genetic tests as a condition for coverage, nor does it restrict the releasing of that information to other sources.²⁷⁶ Finally, HIPAA does not prevent insurers from raising rates or excluding coverage for a particular condition, and places a high burden on the plaintiff to prove that coverage was denied because of genetic information.²⁷⁷

Current state law also offers inadequate genetic discrimination protection in employment and health insurance. Existing state laws differ in coverage, protections afforded, and enforcement schemes. The majority of state genetic nondiscrimination laws are incomplete and often too narrowly worded.²⁷⁸ For example the problems with state genetic nondiscrimination laws can easily be understood by looking at the Michigan statutes. Michigan's genetic nondiscrimination statute for health insurers forbids insurers from requiring genetic testing or requiring disclosure of prior genetic testing, but does not prohibit an insurer from requiring an applicant to answer questions concerning medical history and does not include family history in

²⁷³ *See id.*

²⁷⁴ *See id.*

²⁷⁵ *See Privacy of Individual Genetic Information: Hearings On Discrimination in Health Insurance Underwriters and Privacy of Individual Genetic Information Before the Senate Comm. On Labor and Human Resources*, 105th Cong. (1998) (statement of Chairman James Jeffords and statement of Christine Brunswick, Vice President, National Breast Cancer Coalition).

²⁷⁶ *See id.*

²⁷⁷ *See Pickens, supra* note 2 at 172.

²⁷⁸ *See id.*

the definition of genetic information.²⁷⁹ Therefore, in Michigan the banning of genetic testing while allowing the use of medical and family history provides an opportunity for insurers to use a less reliable means of collecting genetic information. What this means is that insurers have an opportunity to come to conclusions about an individual through medical or family history that could be potentially eliminated by a genetic test showing a person does not have a certain genetic trait. There needs to be legislation that forbids health insurers and employers from inquiring into genetic information. More importantly there is a need for uniformity that can only be provided by federal legislation.

Uniform genetic discrimination legislation would be beneficial to individuals as well as insurers and employers. Insurers and employer would be able to base standards on a uniform federal law, rather than a patchwork of state laws. This is especially significant for insurers and employers who have operations in more than one state. Uniform genetic discrimination legislation will only be helpful to individuals if it alleviates the fear of discrimination. With comprehensive federal legislation addressing these concerns individuals would be able to participate in genetic testing without fear of being discriminated against based on the results.

Another reason why current legislation is inadequate is that people are making major life decisions to avoid the risk of discrimination. Perceived risk of discrimination is leading people to refuse genetic testing to safeguard employment and health insurance, and sometimes this occurs with significant health consequences. If this is not policy enough for further legislation, fears of discrimination also results in a significant decline in research participation. Thus, affecting the continued ability to undertake important genetic research.

Additional federal legislation will be required to adequately prohibit genetic discrimination by employers and health insurers; to protect individuals' genetic privacy from

²⁷⁹ See MICH. COMP. LAWS ANN. § 500.3407(b) (West 2001).

unauthorized disclosure of genetic information; to protect people from mandatory genetic testing; and to regulate the use, storage, and distribution of genetic information. Congress and the state legislatures have proposed and enacted legislation to prevent potential abuses of genetic information. However, genetic discrimination enacted thus far leaves several legislative loopholes permitting genetic discrimination. Furthermore, many existing genetic discrimination laws left the issues of genetic privacy and autonomy unaddressed. Consequently, closing these gaps will require additional legislation.

B. Simple Proposal: Legislation Protecting Individuals From Genetic Discrimination

There are several approaches that may be taken to prevent genetic discrimination. First, we may rely on current state and federal laws to provide genetic discrimination protection. This, however, is an inadequate solution. A second option is to leave the decision to the courts to decide. Again, this solution is inadequate and poses serious problems. A uniform law is necessary to ensure fairness and eliminate genetic discrimination.²⁸⁰ Specific federal legislation should be passed which prohibits genetic discrimination by employers and health insurers.

The most important parts of any legislation that will protect against genetic discrimination are simple: 1) coverage and definitions, 2) scope, 3) strong enforcement, and 4) privacy and disclosure.²⁸¹ First, in coverage and definitions the legislation must cover all genetic information, including personal medical history and family history, which predicts future health risks in healthy individuals. The coverage must include blood tests, urine tests, chemical, and cholesterol tests. Predictive genetic information should be protected regardless of how it is discovered. Information that is discovered through a test not intended to reveal genetic

²⁸⁰ See Gridley *supra* note 33, at 998.

²⁸¹ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Debra L. Ness, National Partnership for Women & Families).

information should be covered. The broad definition of genetic information would have to include information of family history to provide adequate protection. The “protected” genetic information definition should be used rather than the “predictive.” The “protected” definition provides much broader protections. This essentially will protect information from use even if it is used to confirm a diagnosis or symptoms to an illness.

Second, the scope of the legislation must prohibit both employers and health insurers (all health insurers, individual and group) from collecting protected genetic information and using it to discriminate in the health care system and in the workplace. Employers and health insurers should not be able to collect, require, or request any genetic information including personal medical history or family medical history. An exception should be placed in the area of employment law in that the use of genetic information should be permitted in certain situations to ensure workplace safety and health. An example of this would be when employees are monitored for the effects of a particular substance, found in the workplace, to which continued exposure could cause genetic damage under certain circumstances.²⁸² However, when genetic information about an employee is obtained, the information should be maintained in a confidential medical file, rather than a personnel file.²⁸³

Third, legislation must provide individuals who experience genetic discrimination the right to seek redress through legal action, with access to meaningful remedies. A meaningful penalty or sanction to encourage employers and health insurers to comply is needed. Individuals who are discriminated against should be able to choose whether to file suit with Equal Employment Opportunity Commission (EEOC) or bring a claim in federal or state court. Individuals should have the right to bring unlimited claims for compensatory and punitive

²⁸² See Human Genome Project Information, *Genetics Privacy and Legislation*, (visited Nov. 16 2001) <<http://www.ornl.gov/hgmis/elsi/legislat.html>>.

²⁸³ See *id.*

damages. The reason for the harsh penalties is to act as a deterrent. Genetic discrimination is very hard to prove, and without harsh penalties employers and health insurers will have no incentive not to discriminate.

Finally, legislation must ensure that those entities or people holding genetic information about individuals will not disclose it to third parties without the permission of the individual. All genetic information that is obtained should be kept as confidential medical records, not as personnel records. Genetic information is the most personal form of private information, and should not be shared by employers and insurers.

Currently, there is no federal legislation that provides the protection of the simple provisions outlined above. Although, Senate Bill 318 and House Bill 602 would provide similar protection, and fill some of the loopholes left by the ADA and HIPAA, they still have some potential shortcomings. One potential problem with these proposed bills is that they may increase employment litigation. Critics of these bills argue that the EEOC dispute resolution procedures provide adequate protection, and there is no reason for these claims to clog the court docket.²⁸⁴ However, it very unlikely that EEOC dispute resolution procedures would provide the same incentive not to discriminate, as would the ability to bring unlimited claims in federal and state courts. The right to bring unlimited claims in federal and state courts will provide a meaningful incentive for employer and health insurers to avoid discriminating based on genetic information. If employers and insurers are provided with this incentive, there will be less genetic discrimination, thus less claims will be brought in the future.

²⁸⁴ See *Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the Committee on Health, Education, Labor, and Pensions*, 107th Cong. (Feb. 13, 2002) (testimony of Ronald L. Adler, Laurdan Associates, Inc.)

Both Senate Bill 382 and Senate Bill 1995 do not provide enough coverage of genetic information, and fail to provide meaningful remedies. Both of these bills exclusions from what is considered genetic information render them inadequate in protecting against genetic discrimination by employers and health insurers. Senate Bill 382 lacks an enforcement provision and Senate Bill 1995 only provides for enforcement by the Equal Employment Opportunity Commission (EEOC), which could lack the authority of a court and the right to bring an unlimited action. Current legislation is inadequate in protecting individuals from genetic discrimination. Federal legislation needs to be passed which provides protections similar to the those provided by the simple provisions outlined above.

CONCLUSION

While genetic information and genetic technology show great promise for improving human health and preventing future health problems, they can also be used in ways that are fundamentally unjust. Genetic information can be used as a basis for “insidious discrimination.”²⁸⁵ This will be important to all of us because with advances in genetic technology, we will soon realize that everyone has genetic predispositions for one condition or another.

Protection against discrimination based on genetic information is inadequate under the current scheme of state and federal law. There is a lot of uncertainty as to protections against genetic discrimination, in particular the ADA and HIPAA. What remains clear from the public apprehension of genetic testing is that current state and federal legislation is not offering adequate protections.

²⁸⁵ See *Hearings on the National Genome Research Institute*, 105th Cong. (1997) (statement of Francis S. Collins, Director of the National Human Genome Research Institute).

It is time that Congress takes steps to catch up with the world of medicine and science. There are signs of progress in the fact that there is extensive bipartisan support for legislation protecting against genetic discrimination. While the tragic events of September 11 may have slowed genetic discrimination legislation for a time, it appears both parties are ready to support some sort of legislation addressing genetic discrimination. With the recent introduction of Senate Bill 1995, while not identical to Senate Bill 318 or House Bill 602, there appears to be enough common ground that there is room to compromise and potentially adopt part of these bills. Although a quick enactment of legislation is unlikely due to the complexity of genetic discrimination, it is time for Congress to take the necessary steps. Federal legislation is needed to adequately and uniformly address the serious problem of genetic discrimination by employers and health insurers. If left unregulated fear of genetic discrimination has the potential to prevent individuals from participating in research studies or taking advantage of new genetic technologies to improve their health. Advances in genetic technology should be used as a tool to address the health needs of the nation, not as tool for discrimination by employers and health insurers. President Bush when outlining his health care agenda in a speech to the Medical College of Wisconsin February 11, 2002 remarked: "Genetic information should be an opportunity to prevent and treat disease, not an excuse for discrimination. Just as we addressed discrimination based on race, we must now prevent discrimination based on genetic information."²⁸⁶

²⁸⁶ See Whitehouse, *President Bush Outlines Health Care Agenda*, (visited April 5, 2002) <<http://www.whitehouse.gov/news/releases/2002/02/20020211-4.html>>.